Living with HIV and without a residence permit:

dealing with life and health in illegalised exile

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‘…life can change every two hours, or in a second’ (Hana)

Living with HIV and without a residence permit: dealing with life and health in illegalised exile

A qualitative study with people living with HIV and without a residence permit in the greater Oslo area
Abstract
People living with HIV and without a residence permit have to deal with a serious chronic condition on one hand, and their lack of legal residence status on the other, including the ever-present risk of being deported to their country of origin.

Objectives: The objectives of the study were to generate new insight into the daily lives of people living with HIV and without a residence permit, and to generate understanding of how they perceive, experience and relate to their HIV infection and conceive of health and a healthy life in the context of irregular exile in Norway.

Methods: This study was carried out in the greater Oslo area in 2011-2012. Six persons who were living with HIV and without a residence permit participated in the study. They had backgrounds from different Sub-Saharan countries and had lived in Norway from 3-4 to 9-10 years. Data was produced through a combination of three qualitative research methods: dialogical interviews, participant observation and review of relevant documents and media reporting.

Findings: A combination of several types of external power, constraints and control mechanisms was palpably present in the lives of the study participants. This ‘web of power’ shaped their everyday lives to a considerable degree, and was also what the men and women in this study understood as most challenging to their own health. While they perceived of HIV as a significant life disruption, having had their application for protection rejected in Norway was portrayed as considerably more disruptive, and of greater significance for their own health. A double homelessness could be said to exist in the lives of the study participants: the sense of losing ground and grounding due to a serious illness, and the loss of home and a place in the world due to illegalised exile.

Conclusion: For people living with HIV, health is considerably more than HIV and HIV treatment, and illegalised exile in Norway shapes the everyday lives of people living with HIV in ways that generate a range of negative predictors of health. How the consequences of this influence the overall health of individuals and the course of the HIV-infection, should be explored further.
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The responsibility for what has emerged is, of course, my own.
Acronyms

AIDS - Acquired immune deficiency syndrome
ART - Antiretroviral treatment
CD4 – or T-helper cells, white blood cells that play a major role in the immune system / protecting the body from infection
CESCR - Committee on Economic, Social and Cultural Rights
DPS - District psychiatric centre
FHI - Norwegian Institute of Public Health
HIV - Human immunodeficiency virus
ICESCR - United Nations International Covenant on Economic, Social and Cultural Rights
IOM - International Organization of Migration
MSM - Men who have sex with men
NAV - The Norwegian Labour and Welfare Administration
NGO - Non-Governmental Organization
NOAS - Norwegian Organisation for Asylum Seekers
NRK - Norwegian Broadcasting Corporation
PU - The National Police Immigration Service
SEIF - Selvhjelp for innvandrere og flyktninger (NGO working with immigrants and refugees)
UDI - Directorate of Immigration
UNAIDS - United Nations Programme on HIV/AIDS
UNE - The Immigration Appeals Board
UNHCR - United Nations High Commissioner for Refugees
WHO – World Health Organization
Everyday terms

A stay - A residence permit for a permanent or longer period of time
Camp – the English word used in everyday language to refer to ‘asylum reception centre’
*Mottak* - A short form for UDI’s term *Asylmottak* (Asylum reception centre)
Negative - A rejection of the application for protection
*Nemnda* - The Immigration Appeals Board
Positive – To be granted a residence permit for a longer period of time
Paper, papers - A residence permit for a permanent or longer period of time
Residency, to have residence - A residence permit for a permanent or longer period of time
Reception centre - a short form of UDI’s term ‘asylum reception centre’
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Chapter one: Introduction

Background
When I was working as a nurse at a health clinic for asylum seekers in Oslo, I came into close contact with people who were diagnosed with HIV before, or soon after, arrival in Norway. This allowed me to see some of the dilemmas and difficulties faced by people living with HIV while at the same time experiencing uncertainties regarding their asylum status. Ways of perceiving HIV and of dealing with social relations, responsibilities and physical symptoms, together with worries about the future, were all part of their lived experiences. In addition came stories of deportations. A patient I had cared for at the clinic called me after she had been deported to another country in Europe, explaining that she was now detained and had only a small supply of HIV medicine and therefore took tablets only every other day. In 2010 a small family where the mother and father were HIV positive was picked up at the Support Centre of the Church City Mission (Aksept) and deported, after hours of a ‘stand-off’ between police officers and the leader of Aksept, who initially denied the police access to the building. Experiences and stories like these made me curious about what happens to people living with HIV after their time in the ‘asylum system’ has passed; when they no longer have legal authorisation to stay in Norway. How do they manage, and how do they lead their lives? Anecdotal knowledge and personal experience motivated an interest in the broader research question of health equity and of the life circumstances of people who are HIV positive but live in Norway without a legal residence permit. The motivation was also guided by the increasing proportion and significance of irregular migration into Norway/Europe and other parts of the world, and the ongoing debate on the rights of people in this group1.

Rationale for the study
For various reasons related to an unsafe situation in the country of origin, globalisation, economic factors and nation states’ stricter immigration policies, the number of people who enter or stay within a state’s territory without rights of residence is increasing globally. The exact number is difficult to estimate due to its very nature, but Jandl estimates that there are

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1Terms and labels used on this non-homogenous group are many. Platform for International Cooperation on Undocumented Migrants (PICUM) defines undocumented migrants as ‘...migrants without a residence permit authorising them to regularly stay in the country of destination’ (PICUM, 2007). The International Organisation of Migration (IOM) uses the term irregular
between 2.6 and 6.4 million irregular migrants in Europe (Jandl, 2003) and a combination of estimates published by the World Bank gives a figure of more than three million undocumented migrants in the EU (Mansoor & Quillin, 2006). In the same region it is suggested that several thousand migrants with uncertain residence status are living with HIV (AIDS & Mobility Europe, 2006). The HIV pattern in Europe is changing, with an increasing proportion of people living with HIV having a migrant background (de Carvalho, Haour-Knipe, & Dehne, 2010; Del Amo et al., 2010; Hamers & Downs, 2004). A review of epidemiological studies on HIV and migration in several countries in Europe has revealed a complex pattern of HIV prevalence and transmission modes among such persons (Hamers & Downs, 2004).

Factors linked to the different phases of the migration process may increase vulnerability to HIV infection and to HIV-related disease, and to health inequalities, i.e. that individuals in some parts of the population have fewer possibilities to secure a healthy life and have a higher chance of experiencing ill health than others (Carballo & Siem, 1996; Del Amo, Bröring, & Fenton, 2003; Dray-Spira & Lert, 2003; Grove & Zwi, 2006). Structural and societal factors including international and national legal frameworks and the public discourse play important roles in shaping living conditions and life circumstances of people in the group (Del Amo et al., 2003; Dray-Spira & Lert, 2003; Grove & Zwi, 2006). Such societal and legislative structures have an effect on the lives of migrants in general and in particular migrants without legal rights of residence in a country. The individual’s perceptions, experience and possibility of living a healthy life is likely to be shaped by the same relations.

UNAIDS, in cooperation with IOM International Organisation of Migration, have called for increased attention to all migrant groups as essential for governments to reach the goals of ‘zero discrimination, zero new HIV infections, and zero AIDS-related deaths’ (UNAIDS, 2011). Migrants constitute one of the main target groups for the official Norwegian HIV-response, but efforts are so far reportedly too weak (UNAIDS, 2012, 2014a).

The UN International Covenant on Economic, Social and Cultural Rights, Rights on the highest attainable standard of health, emphasises that health cannot be seen isolated from living conditions (UNHCHR, 2000). In Norway, politicians and others in the public arena often present polarising views on the rights of people without a residence permit. Marginal housing, poor financial and nutritional circumstances are found to be part of the everyday lives of many (Brunowski & Bjerkan, 2008; Hjelde, 2010; Ottesen, 2008; Sønsterudbråten & Øien, 2011).
People living with HIV and without a residence permit in Norway are entitled to what is regarded as necessary health care in relation to the HIV infection. However, the right to health care for people without a residence permit is disputed, the knowledge and application of human rights is questioned and access to health care is thus found to be arbitrary as health workers are left as gatekeepers with vague guidelines (Hjelde, 2010). The always-present risk for people without a residence permit of being sent out of the country may influence the way health care is perceived, used and also how it is given. For people who are deported, either to their home country\(^2\) or to the country of first-entry within the Schengen area\(^3\)\(^4\), policies to secure follow-up of health needs are lacking (Human Rights Watch, 2009). With a deportation, any achieved quality and predictability of life situation, HIV care or treatment is threatened, including continuity of treatment, with potential serious harm to the person in question, to their near ones, and in a public health perspective, to society. Lack of continuity of treatment may lead to illness, premature death or the development of drug resistance.

Little attention has been paid to the lives and health of those living in Norway with HIV and without legal residency, neither as a research topic nor in other contexts. The number of people living with HIV and without a residence permit in Norway is not known, however, whether it is high or low does not make allocation of attention and resources to the group any less important. With an increasing proportion of migration made by people without a travel or residence permit, and with the vulnerability of their particular circumstances, the life situation of people in this group needs to be included in planning an official HIV response. Qualitative research has been suggested as a way to generate knowledge of the processes behind the trends in HIV patterns related to migration (de Carvalho et al., 2010).

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\(^2\) The term home country is used throughout this thesis as a term for the participants’ country of origin, although Norway can be thought of as a second country of many in the group.

\(^3\) The Dublin II Convention of 2003 states that a person entering any of the European countries that has signed to this agreement - EU, Iceland and Norway-, will have to apply for protection in the first country he/she entered within that area and will be returned back to that first entry country if arriving in another signatory country. The decision can be appealed. The sovereignty clause or the humanitarian clause in article 3 (2) in the Dublin II agreement do give member states flexibility and UNHCR recommends that states should be encouraged to use this article in cases where asylum seekers’ transfer would result in hardship or potential harm, for instance for medical or other humanitarian reasons (UNHCR).

\(^4\) From January 1, 2014 the Dublin III replaced the Dublin II-regulation.
In the last few years several qualitative research projects on undocumented migrants have been conducted in Norway, and in one of these studies (Sønsterudbråten & Øien, 2011) the researchers met people who were living with HIV among the larger group of recruited participants. However, the life situation and experiences of people living with HIV in this group has not been explored in research.

Aims and objectives of the study

The study sought to generate new knowledge and understanding of the life worlds of people living with HIV and without a residence permit, and to increase insight into how they relate to and manage to live a healthy life.

The objectives of the study were:

1. To generate new insight into how people living with HIV and without a residence permit think about, feel about, and perform their daily lives.

2. To generate understanding of how people living with HIV and without a residence permit perceive, experience and relate to their HIV infection and conceive of health and a healthy life.

The study chose to use qualitative methods and an emerging research design to allow for flexibility and adjustments of methods in this little known area of research.

Thematic research fields

Life worlds of people living with HIV in irregular exile

HIV is the name of a virus and a diagnostic label, but also signifies a series of experiences and performances that contribute to shape peoples’ lives. Similarly, ‘undocumented migration’ and ‘irregular’, or ‘illegal exile’ are politico-legal concepts, but at their core they refer to a series of experiences and performances; to people’s lived realities. Such lived experience, ‘(…)…an individual’s perception of his or hers presence in the world at the moment when things, truths, or values are constituted’ (Morse & Richards., 2002, p. 44) are among basic structures of the life world. The concept ‘life world’ has its origin in Husserl’s phenomenology and involves the perceived reality, this being different from the physical world. It is through their life worlds that humans relate to their surroundings in life (Dahlberg & Dahlberg, 2003). With a life world perspective follows that humans’ lived realities and perceived health and suffering are taken into consideration. Focus lies not only on the individual nor only on the surrounding world, but on the interaction and interplay between these (Dahlberg & Dahlberg, 2003).
This study aimed to get insight into the life worlds of people living with HIV but without a Norwegian residence permit. By attempting to ‘get into the shoes’ of a few people it sought to build a picture of the everyday life and social worlds in irregular exile as perceived, experienced and performed by people living with HIV; to learn more about how they think about, feel about, act and deal with life and health. What meaning daily activities and chores, relations with others, special events, joys and satisfaction, challenges and problems have for people in the group, how they deal with these experiences and emotions was explored. People attach meaning to things, events and interactions in a process that is contextual, i.e. depends on the overall situation, including social and societal, legislative and financial structures. Knowledge of the meaning people give to their surroundings and interactions is essential in understanding their life worlds. In exploring the daily life, the study sought to understand the formation of meanings, and the meanings given to events, interaction and physical surroundings.

*Perceptions, experiences and performances of a healthy life* were explored, with a focus on how a healthy life is understood by people in irregular exile living with HIV. The context and ‘culture’ of people in this category may shape their perception of what a healthy life is like. The following were some of the questions that I wanted to explore in relation to the objectives of the study: How is the phenomenon ‘health’ perceived and created, experienced and performed in daily life? In the overall context, what is the meaning of health and how is this interpretation formed? Does the right to HIV treatment and care while staying in Norway assure a healthy life, as understood by the participants? The study wanted to explore participants’ understanding of health and a healthy life, what they perceive as risks and vulnerabilities to ill health, how they meet and experience life in a healthy way and how they perform a healthy life. What is it in their life worlds that make them able to live their lives in a way that they are content with, and in a way that they understand as healthy?

*Living with HIV: perception, experience and meaning formation in the context of irregular exile*: Insight into people’s actions and experiences, their knowledge, underlying beliefs and understandings of the phenomenon of living with HIV – while living in ‘irregularity’ - was explored. People’s lived experiences in this present context may shape and change the meaning they give to HIV infection and living with HIV. How daily activities and interaction with others shape the perception of HIV while living in irregular exile was explored;
questions relating to this was: How do they feel they are treated by others, how does this feel and how is it explained? What role and importance does HIV infection have to people – in what way is ‘living with HIV’ a part of life? What are the feelings, experiences and activities related to protection of self and others? How does a decline of an application for political asylum influence the way a person conceives of living with HIV? What is the perception, experience or expectations of ‘living with HIV’ in the light of a deportation?

Organisation of the thesis
This thesis is divided into nine chapters. This first chapter presents the background and rationale for the study, the aim and objectives, as well as the thematic fields ‘entered’ as part of exploring the life worlds of people living with HIV and without a residence permit. This chapter continues with a description of the Norwegian context in which the research was conducted, including the laws and regulations relating to the lives of people in the target group. Chapter two presents the theoretical underpinnings of concepts found relevant for the study and continues with a review of relevant literature. Chapter three presents the research methods and discusses the methodological challenges met in the study as well as the ethical considerations. The following chapters present and discuss the findings of the study, beginning with chapter four which presents some of the daily activities and social lives of the participants. Chapter five deals with the relationship the study participants have to the immigration services and the Norwegian authorities and how this relationship affects their lives. Chapters six and seven present and discuss the perceptions and experiences of living with HIV, and chapter eight how a healthy life is managed and understood by people living with HIV and without a legal residence authorisation. Finally, in chapter nine, the findings of the study are summarised.

The Norwegian context

Introduction
Norway is a country with a population of five (5,165) million people, and has been at the top of the UN’s development index (UNDP, 2014) for several years. People who reside within Norway’s borders but for different reasons are not recognised as doing so, are not part of such statistics. In 2008 it was estimated that 18,000 (10,000 – 30,000) people lived in Norway without a residence permit (Zhang, 2008), most of them in the Oslo area. Two thirds of the irregular migrants were found to be former asylum seekers who had their application for
protection rejected. Over the years Norway has been acclaimed for holding human rights high, and often claims to give protection to a relatively high proportion of refugees compared to the population size and GDP. Essential in the Norwegian society is the national welfare and health care system which is meant to ensure that all inhabitants gets the social support, care and treatment they need, regardless of income or status. A major principle in Norwegian politics is also summarized in the term *Arbeidslinja* – a term reflecting a situation where employment is viewed as the very fundament for both the health of individuals and of the society as a whole.

**HIV situation and statistics**

With therapeutic breakthroughs, HIV infection has changed from a disease with a guaranteed deadly outcome to a manageable, chronic illness with which one potentially can live a long life. Together with other factors (that will be returned to later) the prospect of living a long life without symptoms depends on the availability of and a dependable life long access to treatment. UNAIDS (UNAIDS, 2015) reports that in 2014, 36.9 million (34.3 million–41.4 million) people globally live with HIV, among them 15 million people are accessing antiretroviral (ART) treatment. In sub-Saharan Africa, 41 % of all people living with HIV were accessing such treatment. The number of people that die from AIDS-related diseases is reduced each year, yet 1,2 million (980 000–1.6 million) people lost their lives in 2014. In contrast, treatment coverage for HIV is reported to be 100 % in Norway, and people living with HIV are reaching a high age.

The Norwegian Institute of Public Health (FHI) (Folkehelseinstituttet, 2015) reports that (since 1984) a total of 5622 people have been diagnosed with HIV in Norway, and UNAIDS (UNAIDS, 2014b) estimated in 2014 that 5,800 (4,400 – 8,500) people are living with HIV in Norway. Among those living with HIV, 1,500 – 1,700 people have a background from other countries. FHI reports that half of the people who were newly diagnosed in 2014 belong to this group. However there is a slight reduction of the numbers of immigrants from countries with high HIV incidence, and FHI relates this to fewer asylum seekers or family reunited from these countries. Special attention, and appropriate and acceptable follow-up, for people in this (non-homogenous) group, as well as early diagnosis, is seen as an important part of the overall HIV response. The number of men who have sex with men (MSM) who get diagnosed with HIV is increasing, and around half of these men have an immigrant background. These men seem to be particularly vulnerable in relation to being at risk of HIV infection.
Furthermore, migrant women are seen to be particularly at risk (Folkehelseinstituttet, 2015). The majority of people who are HIV positive were living in the Oslo area at the time of the diagnosis.

**Immigration policies and procedures**

*Unauthorised residence*

Immigration authorities in Norway distinguish between four categories of people staying in the country without authorised residence (Hjelde, 2010). These are 1) people with a final rejection in their application for protection 2) people who had residence authorisation based on false information 3) people who have exceeded the validity of their visa (tourist, student, au pair, work) and 4) people who have entered the country by passing any border or arriving by boat without registering with Norwegian authorities.

The participants in this study have all applied for protection in Norway at some point in time and had their applications rejected. Considering the important role the Norwegian asylum system has in the life worlds of participants in this study I find it appropriate to try to describe the process of applying for protection or for appealing a decision. The following is meant to give an idea of the paths and sometimes labyrinths that are part of the (rather exhausting) present and recent past of the lives of the participants in this study. It may also show how people can have their residence status changed back and forth and not be quite sure of their present residence status. Moreover, opportunities for appeals and submission of new information, and guidelines for processing them have been revised during the years the participants in this study have stayed in Norway, thus adding to the complexity.

*The asylum process*

Norway has ratified the UN Convention relating to the Status of Refugees (1951 Refugee Convention), and people who arrive in Norway and apply for protection shall, according to the Immigration Act § 28 (Utlendingsloven, 2008a), be granted a residence permit as a refugee in Norway if he or she:

‘(…)has a well-founded fear of persecution because of his/her ethnicity, origin, skin colour, religion, nationality, membership of a particular social group or political views, or faces a real risk of being subjected to the death penalty, torture or other inhuman or degrading treatment or punishment if he or she has to return to his/her home country.’
If the applicant, according to the Directorate of Immigration (UDI), is found not to need protection as a refugee, UDI shall consider if he or she instead meets the requirements for being granted a residence permit on humanitarian grounds. The Immigration Act § 38 states that this can be granted where there are strong humanitarian concerns or the applicant has a strong connection to Norway (Utlendingsloven, 2008b). Compelling health reasons that require a person to stay in the country, situations where there are social and humanitarian aspects of the return situation that gives grounds for granting a residence permit, and in matters where a child’s best interest is at stake, are some aspects of UDI’s total assessment of whether an applicant meets the requirements. These factors may be seen by UDI in tandem with regards to immigration control, and UDI points out on their web page that only in special cases will residence permit on humanitarian grounds be granted (UDI, 2015; UNE, 2015a).

If a person’s application for protection is rejected by UDI, he or she can appeal the decision to the same organ, with the assistance of a lawyer assigned by UDI. A report from Oxford research requested by UDI pointed to a need to strengthen qualifications and motivation amongst these lawyers (Mohn, D. Ellingsen, Ø. B. Solheim, & Torgersen, 2014). Independent quality control of the legal assistance was also recommended. Non-governmental organisations such as the Norwegian organisation for asylum seekers (NOAS) also offer free legal advice. However, their capacity is limited compared with the high number of cases in which they are asked to assist. The appellant will need new information and documentation for the decision to be considered for reversal, or otherwise is likely to get the same negative decision.

If the first decision is not reversed by UDI, the case will be transferred to the Immigration Appeals Board (UNE). UNE was established in 2001 for the purpose of having an independent appeal body for people who had their applications for protection rejected by the UDI and was intended to secure the rule of law. One goal was for more appellants to be given the opportunity to meet with and give their explanation to the officials that are considering his or her appeal. However, according to UNE’s web page, the appeals board hearings can be held without the appellant present if the appellant’s explanation already has been taken into consideration (UNE, 2015b).

UNE’s practice regarding the processing of cases where the person seeking protection is HIV positive gives insight to the background and practice of granting or not granting residency on
humanitarian grounds for people living with HIV (UNE, 2015a). UNE states that appeals and petitions for commutation in cases where there are submissions regarding HIV/AIDS are processed in line with precedential effects of decisions in Stornemnda (The Immigration Tribunal). UNE states on their web page that they do a thorough investigation of access to antiretroviral therapy (ART) in the appellant’s home country and states that in most countries treatment is affordable and available to ‘people who are in a normal situation’. Lack of dependable information about health services and ART, however, has in some cases been an important argument in favour of the person seeking protection. An overall assessment of the applicant’s situation, together with vulnerability or specific circumstances pertaining to the individual, has led to UNE reversing their decision and thus granting protection to several people.

Being gay and having a well-founded fear of persecution in their home country has previously not been considered a reason for being granted protection in Norway by UDI. Applicants were instead advised to show discretion and not live openly as gays in their country. However, a Supreme Court ruling in March of 2012 in a case against UNE states that people cannot be required to hide their sexual orientation in their home country out of fear of reactions, and that people who need to do that should get protection in Norway (Høyesterett, 2012).

If UNE receives new information and documentation supporting the applicant’s case while processing the appeal, UNE can return the application to UDI for new processing and consideration. It is also possible for applicants to submit a petition for commutation at a later time, with new information they believe meets the requirements, or to apply for residency on other grounds (UDI, 2014). Such submissions to the case can be made up to one year after a final negative decision in UDI or UNE, and documents and applications can be delivered to the police, to UDI or UNE.

In cases where UDI have made the final decision, they can, also at a later time, according to the Public Administration Act § 35 (Forvaltningsloven, 1967) evaluate whether they should process an incoming petition for reversal of the decision. UDI circular 9/2-2010 states that this may be done where there are special reasons for doing so, for example if there are issues of special importance for the appellant which are not seen in most other cases, or with regards to the consequences of a rejection. UDI circular 9/10-2014 chapter 3.2.2 states, with reference to the Immigration Act § 73: UDI has ‘an obligation to consider applications for reversal of a
decision to ensure that nobody is sent to an area where he or she can be exposed to persecution or inhumane or degrading treatment’ (UDI, 2014)(my translation). A petition for reversal seen as important with regards to precedence effects is also more likely to be processed (UDI, 2010).

Final negative decisions by UDI, and appeals not accepted for consideration in UDI, may be appealed in the regular judicial system - if the appellant has the finances and can find a lawyer who will represent his or her case. There exists, however, an uncovered need for judicial assistance to foreigners without means to try their case in the judicial system, and few cases have been tried in court (according to UNE in 2006, 83 out of a total of 11000 asylum decisions) (Humlen & Myhre, 2014). To strengthen individuals’ rights, an association of lawyers, Advokatforenings aksjons- og prosedyregruppe i utlendingsrett (A&F) established a low-threshold service in 2007 to give people with limited resources ‘access to court’. Between 2007 and 2014 a number of people with cases that were a matter of principle received free judicial assistance through A&F. A report on their work, findings, criticisms of the grounds on which decisions are made in UNE, and recommendations for changes has been published (Humlen & Myhre, 2014). Among the criticisms was that UNE’s evaluation of asylum seekers’ trustworthiness is deficient, with failures and shortcomings, and based on wrong and unjustifiable methods. The applicant is rarely present and able to give an explanation in UNE (despite that being one of the motives for establishing the board), and the grounds for a negative decision are often too general, without enough details relevant for the case.

Only if the appellant has applied for and been granted deferred implementation is he or she allowed to stay in Norway awaiting the decision of UNE. If the decision in UNE confirms the previous rejection by UDI, a deadline will be issued for the asylum seeker to leave the country.

People who do not, or no longer have a permit to stay in Norway, can be deported, i.e. be escorted out of Norway by the police. Not leaving the country after having been given a deadline for leaving, for example after a final decision in UDI, is considered a breach of the Immigration Act and a criminal offence. The strictest sanction that can be imposed under the Immigration Act, is expulsion, where a person who is expelled, is in addition to the deportation/obligation to leave the country prohibited from re-entry to Norway and other countries in the Schengen area for a period of one or more years. UDI is to consider the
seriousness of the person’s offence, together with the consequences an expulsion will have for
the person and his or her family before such final expulsion decision is made. The National
Police Immigration Service (PU) is responsible for carrying through the deportation and do
this in co-operation with the local police. In the past decade the media has covered several
such deportations, particularly stories where the police wake families with children at night in
order to deport them.

**Laws and regulations**

The lives of the participants in this study are in many ways immersed in immigration policy
and procedure within the bureaucracy of immigration described above, even though (and also
because) they have received their ‘final negative’. Legislation pertaining to people without a
legal authorisation to reside in Norway has a knock-on effect in their lives, as their
unauthorised residence status turns into an array of other ‘unauthorised’ or ‘not allowed’ signs
they meet in the Norwegian society.

**The right to health care**

Norway’s Constitution §110 determines that the state is responsible for respecting and
ensuring human rights. Norway has ratified the UN’s International covenant on economic,
social and cultural rights (ICESCR) and made it part of Norwegian legislation in the Human
Rights Act of May 21, 1999 (Menneskerettsloven, 1999). Article 12.1 in ICESCR and Article
21.1 in Menneskerettsloven says that the parties recognise the right of any person to the
highest achievable standard of health, both physically and psychologically. It also
acknowledges that to ensure this, the state has to take an active role (ICESCR Article 12.2).

The Committee on Economic, Social and Cultural Rights (CESCR) in General Comment no.
14 (UNHCHR, 2000) refers to Article 25, paragraph 1, of the Universal Declaration of Human
Rights which affirms: ‘Everyone has the right to a standard of living adequate for the health
of himself and of his family, including food, clothing, housing and medical care and necessary
social services.’

The General Comment no. 14 point 34 determines that the state parties have specific legal
obligations

‘to respect the right to health by, inter alia, refraining from denying or limiting equal access for all
persons, including prisoners or detainees, minorities, asylum seekers and illegal immigrants, to
preventive, curative and palliative health services; abstaining from enforcing discriminatory practices as a State policy; and abstaining from imposing discriminatory practices relating to women’s health status and needs. (UNHCHR, 2000)

A joint publication by WHO, IOM and UNHCHR (2013) emphasises the Principle of non-discrimination:

‘(…) International Human Rights law provides that all persons, without discrimination, must have access to all fundamental human rights provided in the international bill of human rights. Therefore, migrants, regardless of their status, are protected by international human rights law. The provision of the ICESCR (..) clearly expresses that the right to health obligates governments to ensure that ‘health facilities, goods and services are accessible to all, especially the most vulnerable or marginalized sections of the population, in law and in fact, without discrimination on any of the prohibited grounds’ (IOM et al., 2013).

They further emphasise that following International Human Rights Law, states cannot use ‘nationality or legal status as a basis to draw a distinction between persons who may or may not enjoy access to health care facilities, goods and services’ (IOM et al., 2013).

In accordance with international standards, the Norwegian Patient Rights Act § 2-1 (Pasient- og brukerrettighetetsloven, 1999) entitles any person who stays in Norway, regardless of residence status, access to emergency medical assistance. The Health Personnel Act § 7 (Helsepersonelloven, 1999) states that health personnel have a corresponding obligation to give emergency health care. Such emergency medical assistance may be urgently required to ‘restore or maintain vital functions or to hinder or limit serious reduction of function caused by an injury or disease’. Both primary and specialist health services may be involved in examination and treatment of the patient. Examinations will typically have the purpose of identifying whether there is a need for urgent intervention. However, people without a residence permit do have to pay the full cost of health care. Other/ extended rights regulated in Norwegian Patient Rights Act are reserved for people who are members of the National Insurance Scheme (Folketrygden), are residents of a EU member country or have their own insurance.

The Health and Care Services Act § 3-5 (Helse- og omsorgstjenesteloven, 2011) states that any person who stays in the municipality is entitled to the necessary health care. A definition
of necessary health care is not given, and health personnel have to make decisions based on discretion. However, it is generally understood as more than emergency medical assistance as described above, but other than that left to the individual health worker to make a professional, reasonable judgment (Hjelde, 2010). Regardless of how it is defined, the health care is not covered by the state and, again, is supposed to be paid by the immigrant him/herself.

People without a residence permit, because they are not formal residents in the municipality, are not entitled to a GP (fastlege), despite living in the municipality, sometimes for years.

The Law on Protection against communicable diseases (Smittevernloven, 1994) states that ‘health care and preventive measures related to a communicable disease is regarded as part of the rights to necessary health care services’ described in the Norwegian Patients Rights Act § 2-1 (1999). Regardless of legal status, the law applies to all people residing in Norway. A person who is infected with a serious communicable disease, such as the HIV-infection, is ‘classified’ as having the right to medical assessment and diagnosis, treatment, care and other infection prevention measures. Both primary health care in the local municipality and specialist care can be involved in this.

For people with or without a residence permit in Norway, treatment for HIV infection is free of charge, as is HIV-related medical follow-up. People with a residence permit in Norway are also entitled to dental care for HIV-related problems and prevention of infection. In practice then, if undocumented migrants approach health services, they have access to HIV treatment and regular appointments at an infection clinic. However, they are ineligible for the fully-covered comprehensive care and treatment available to ‘legal’ residents living with HIV.

The Health Personnel Act § 21 (Helsepersonelloven, 1999) prohibits health personnel from making information about peoples medical and health conditions known to others (Hjelde, 2010). A patient without a residence permit is not a reason for health personnel to breach their confidentiality, and health personnel have no obligation to inform the police about a person residing in Norway ‘illegally’. Routine notification to health authorities of people diagnosed with a serious communicable disease is made anonymously for patients with HIV. Only if a person is perceived as being a danger to his/herself or others are health personnel obliged to contact emergency services (such as the police). However, people in this group may fear that
at any time the police or immigration authorities will be notified and thus avoid seeking health care, as has been found in other studies in a Norwegian context (Brunowski & Bjerkås, 2008; Hjelde, 2010).

It follows from the Social Services Act § 1-2 (Sosialtjenesteloven, 2009) that neither asylum seekers living in camps or undocumented migrants have the right to financial support from social services. They do, however, have the right to ‘acute emergency assistance’ to ensure that they survive a precarious situation.

**Legislation - children**

Two of the participants in this study live with their children at reception centres. The Child Welfare Act (Barnevernloven, 1992) covers all children in Norway, regardless of their legal status, and the state has a special obligation to safeguard children’s special needs as long as they stay in Norway. UN’s Convention on the Rights of the Child is incorporated in Norwegian law in the Human Rights Act § 2 (Menneskerettenloven, 1999). Parents have the main responsibility (also according to CRC) for their children. Irregular migrants lack of rights, however, may lead to problems providing a home with a ‘living standard sufficient for their child’s ‘physical, mental, spiritual, moral and social development’ as described in the law.

**Protection against discrimination**

People living with HIV have a legal protection against discrimination through the Anti-Discrimination and Accessibility Act (Diskriminerings- og tilgjengelighetsloven, 2013) . For example, the law protects against discrimination based on the presumption of present or future impaired functioning, e.g. regarding employment. After a decision in the Equality and Discrimination Committee (Likestillings- og diskrimineringsnemnda) in January 2012 it is clear that they also have legal protection against discrimination based on an unfounded fear of transmission. However, discrimination against and stigmatisation is a major problem for people living with HIV in Norway today. Some important goals of the 2009-2014 national HIV strategy , ‘Acceptance and Coping’ (Aksept og mestring) (Departementene, 2009) was to reduce stigmatisation and discrimination, with focus on attitudes, openness, and knowledge about HIV in the general population. The strategy has been extended for one year.

**Legislation – punitive law**

Despite the above objectives, people who are HIV-positive in Norway live their lives under the Penal Code § 155 (Straffeloven, 1902). Norwegian legislation with the Penal Code § 155
from 1902, criminalises transmission of serious communicable diseases. Often referred to as ‘the HIV-paragraph’, it means that a person living with HIV could be indicted for exposing others to a risk of being infected or for transmission of HIV, either negligently or wilfully. At the time when the fieldwork was taking place a government appointed committee (Syse-utvalget) was working on evaluating Penal Code § 155, and a public hearing took place in January 2012. Recommendations were given in their report in October 2012 (NOU, 2012); the proposed changes have been described as ‘toning down’ criminalisation, but still place the responsibility on the HIV-positive person, with the risk of him or her being prosecuted and punished. The people in this study receive advice in relation to § 155 (since 2015 replaced by § 237 and § 238) from different quarters, including advice that short- or long-term partner’s consent to sex does not exempt a person living with HIV from being punished if he or she is prosecuted. Informing a partner of the diagnosis is not a legal obligation, but this seems to be a matter of debate and a cause of confusion. According to the present Penal Code, only the use of proper barrier protection, i.e. a condom, can give a person exemption from punishment.

In contrast, UNAIDS states that ‘the application of criminal law should be rejected by legislators, prosecutors and judges’ (UNAIDS, 2008, p. 1) and works to remove criminalisation of HIV transmission and reduce the number of countries with punitive laws.

**Legislation – practice - housing, work**

In Norway, regulations regarding undocumented migrants’ housing have changed during the period the participants have stayed in the country. This is also the case concerning permission to work. In 2000 all asylum seekers were granted a temporary work permit. The work permit was not withdrawn automatically, so people who stayed in the country after the final negative decision from immigration authorities were able to work and pay tax. In 2004, the opportunity for rejected asylum seekers to live in reception centres was withdrawn, with the exception of (most) families with children and people with a medical condition. Work permits were withdrawn, as well as financial support for the very basic subsistence. After the change in government in 2005, people without residence permits were again allowed to live in reception centres, but now in so-called Ventemottak. The ‘waiting camps’ at Lier and Fagerli were established in 2006 and 2007 as a place to stay before leaving the country. The standard and the services provided were kept at a bare minimum. The camps were closed in 2010 after a series of complaints and frustrations voiced by the residents, culminating in a fire where one
of the buildings at Lier ventemottak burnt down. Rejected asylum seekers were again allowed into ordinary reception centres. However, many chose not to live there.

People who give ‘humanitarian aid’ to a person who is living in Norway without legal residency can according to the Immigration Act § 108 be subject to punishment for being accessory to illegal residency i.e. a criminal act, if he or she had the intention to assist the person in not leaving the country and has hindered or made difficult a deportation of that person. The same law applies to employers of people without a residence permit (Utlendingsloven, 2008c).
Chapter two: Literature review

I begin this chapter by taking a closer look at concepts related to the study and the theoretical foundations of these, before I go on to present available literature in the area of research.

Concepts relevant for the study

Illegalisation of migrants

The representation of people who enter or stay in a country without legal authorisation to do so can be problematic. All terminology has discursive power and thus consequences for how ‘ordinary people’ - and people such as journalists, bureaucrats and politicians, regard people in the group. The term illegal migrants, and also terms such as undocumented or irregular migrants, should be used with consideration of the origin of the terms and the context in which they evolved and exist. I will briefly present some views on the phenomenon of irregular migration, not in the legislative and more technical terms as in the previous chapter, but as seen in a broader context and as understood by writers and scholars in different disciplines. I rely here on Khosravi (2010), who in his work ‘Illegal’ traveller relates the story of his own and others’, ‘illegal’ crossing of borders. In this ‘auto-ethnography of borders’ the meaning and function of borders ‘in the era of globalisation and transnationalism’ is analysed and related to a state’s need to exclude some people in order to secure the freedom of mobility for others. Khosravi notes that ‘the national order of things usually passes as the normal or natural order of things’ (Khosravi, 2010, p. 2). Crossing borders becomes pathological in a reality where borders and border control is naturalised (Khosravi, 2010; L. Malkki, 1992), and displaced people are considered unnatural. People trespassing over the border challenge and weaken the nation-state system. In a sovereign-state system unauthorised border crossers and unidentified migrants within a country become ‘a disquieting element’; they break up the ‘identity between man and citizen’, the natural link between nationality and birth, and thereby threaten the state’s sovereignty (Agamben, 1995; 1998, p. 131). People who are ‘trespassing’, either at the border, or by remaining in a country without a residence permit, are construed as anti-citizens - a threat to society, which gives the state justification for governing by criminalisation and exclusion (Inda, 2006; Khosravi, 2010; Simon, 2007).

By violating the border; the natural and right order of things, the aesthetics and ethical norms are also violated (Khosravi, 2010). Douglas (1966) explored how, in a society, distinguishing
purity from impurity is imperative for preserving social structure, and that differentiating morality from immorality is based on the same fundament. Douglas views the concept of pollution to be ‘a reaction to protect cherished principles and categories from contradiction’. What is unclear and contradictory from the perspective of social definition tends to be regarded as unclean. In a system of nation-states people such as irregular migrants are unclassifiable and therefore seen as polluted and polluting (L. Malkki, 1995a, 1995b). In his article on liminality, Turner (1967) describes how ‘transitional beings’ - who are ‘neither one thing nor another; or maybe both; or neither here nor there’ - are ‘betwixt and between all recognised fixed points in the space-time of cultural classification’ (Turner, 1967, p. 97). As people without legal travel or residence documents, they are viewed as being in an intermediate, indeterminate or transitional state – and therefore as particularly polluting. Furthermore, ‘transitional beings’ have nothing. They are without status, position or rank and have no property; they are ‘structurally invisible’. Without a clear definition of their role in relation to others, they have no rights. To return to Agamben, he sees irregular migrants as the Roman *Hominis Sacri*, bare lives of today, being naked, depoliticised by the state; stripped of membership in society and stripped of all rights (Agamben, 1998). Someone deemed a *Homo Sacer* would remain ‘under the spell’ of law, in an illegalised state, although classified as not being relevant or no longer worthy to the state’s law. And yet ‘he is in a continuous relationship with the power that banished him...(..).’ (Agamben, 1998, p. 183). According to Agamben this sovereign power is based on inclusive exclusion, where the state includes such people under the law, by excluding them from political life; however, the law cannot subsume all life. Within the ‘state of exception’ there exists also the only means of seeking a way out of ‘bare life’ -seeking justice. The state of exception also becomes a ‘space of agency’ - and as is also shown in this study, irregular migrants do have agency. They act, speak, have family, form new relations, work, try to be heard and acknowledged. Action takes place in what Coutin (2006) calls ‘illegal time’, and illegality is confined by this illegal time.

**The health concept**

Whether it is possible or desirable to transform individual, subjective life experiences of health into a theoretical concept is, in itself, debated (Fugelli & Ingstad, 2009). Heath (2002) cited in Fugelli and Ingstad (2009) proposes that one needs to be critical and humble if attempting to conceptualise lived experiences. ‘A concept is fixed, but life is in flux, a concept often has an either-or notion while life is a mixture, and a concept radiates clarity
while life is characterised by ambiguity’ (Heath, 2002, cited in Fugelli & Ingstad, 2009, p. 422) (my translation). Fugelli and Ingstad found the same discrepancies between a concept and the lived experiences in their study of how people in Norway view ‘good health’. Qualities that characterise the health experiences of people in their study are the same as Heath’s – flux, mixture and ambiguity (Fugelli & Ingstad, 2009).

This study explores the meaning that people living with HIV and without a residence permit give to health and being healthy. Fundamental for the study is that participant’ voices and original perceptions, experiences and actions with regards to health were not overshadowed. Various definitions and understanding of health and the health concept were not focused on, neither in the planning stage of the study nor during data production. Also, I do not rely on one particular theory or understanding of health in the analysis. However, this study takes as a starting point that health and healthiness are socially constructed and dynamic concepts, and influenced by interactions between people. The social psychologist Radley (1994) draws on work from various disciplines when approaching the field of health and illness. Health is not merely the absence of illness; asking somebody if they feel healthy opens for a variety of thoughts and associations to what a healthy life is - associations other than to feeling ill. People have a variety of conceptions about health depending on their changing life settings and perceptions and ideas about health are also often born and shaped by people’s episodes of illness, and the consequences the illness has for social life (Radley, 1994).

Taking a closer look at ‘being ill’, Radley, with reference to Eisenberg (1977, cited in Radley, 1994), makes the distinction between disease, illness and sickness, and relates each to its conceptual focus – the body, individual experience and society, respectively. Disease here refers to pathological changes in the body, with or without a person feeling ill, and as something physicians can diagnose and treat. Illness is related to the individual concerned and his or her feelings and experience of bodily symptoms, and the consequences of bearing these. Lastly, sickness can be defined as ‘a social condition that applies to people who are deemed by others to be ill or diseased’ (Radley, 1994, p. 3). Sickness is related to ‘a particular status or role in society and is justified by reference either to the presence of disease or to the experience of illness’ (Radley, 1994, p. 3). People may chose to avoid the status of ‘being sick’ even if they feel ill, or if diagnosed with a disease. ‘…to occupy this social role, whether or not one suffers from the symptoms of disease, is to be subject to social categorisations that
have their origin in society.’ (Radley, 1994, p. 4). Becoming ill is thus socially and psychologically defined.

The phenomenon of HIV
‘What am I ‘living’ with?’ (Bernays, J. Seeley, T. Rhodes, & Mupambireyi, 2015, p. 270) was a question asked by the children in a study set in Uganda and Zimbabwe aiming to explore children’s experiences of living with HIV on treatment. The authors point to how a language of sickness that surrounded these children constructed their experience of HIV; medicalised talk and illness stories reduced attention to their healthiness and narrowed the framework in which the children could interpret and experience HIV. Furthermore, it undermined their wish and strives for ordinariness. The study was conducted with children who had lived with HIV since their birth, however the broader issue of how living with HIV is perceived and experienced, and what influences such experiences, is relevant also for other groups and settings.

From a more conventional point of view, being diagnosed with a chronic illness or condition is a critical incident in a person’s life - feeling ill or not. Uncertainty is one reaction that has been found to be important in all chronic illness, both with regards to what has happened and to the future course of the disease and life (Radley, 1994). The sense of one’s individual life course being undermined by chronic illness is essential in the concept biographical disruption first proposed by Bury (1982). Learning that one has a chronic illness then can be thought of as ‘…a tear in the fabric of one’s life that can suddenly bring into question all of the assumptions upon which it was based’ (Radley, 1994, p. 145). A chronic illness may also influence his or her role as a social individual and thus how he or she conceives of him or herself. When re-establishing oneself in life, the individual will need to construct a new timeline with the new understanding of him or herself incorporated (Charmaz, 1983, cited in Radley, 1994, p. 146).

In addition to disruption, the concepts of transition and transformation were developed from research where the narratives of people diagnosed with a chronic illness were analysed (Kralik, 2002), and the concepts have continued to inform research in the field, including that of living with HIV as a chronic condition. Russell and Seeley(Russell & Seeley, 2010) refers to the term transition as ‘ a person’s movement towards incorporating a long-term illness, treatment regimen, and its various ramifications into his or her life’ (Russell & Seeley, 2010,
and further, with reference to Kralik (Kralik, 2002) as ‘a person’s adjustment towards incorporating the illness into their lives, within themselves (self), in their identity and interaction with others, in their daily routines and their future outlook’ (Russell & Seeley, 2010, p. 375). Disruption involves distress, uncertainty and fear, and affects not only a person’s identity and role as a social individual but also other essential parts in life, such as daily routines, work and leisure. Transition happens when people take action and are able to make changes in the various aspects of their lives, and does not just happen as time passes. Such actions, or self-management strategies are ‘the work people do to gain a sense of order following disruption, to regain control over decisions, to build independence and rebuild meaningful relationships’ (Russell & Seeley, 2010, p. 376). To move into a transitional phase is not necessarily a linear process, and new and complicating events or challenges may cause a change back again to disruption (Kralik, 2002). Lack of support from others and economic hardships are some of the factors that can cause difficulties making an initial move from disruption to transition. In their research with people living with HIV and on ART in rural Uganda, Russell and Seeley (Russell & Seeley, 2010) found that the processes underlying a transition to living with HIV as a chronic condition were complex; those who struggled more did so for several reasons, among them were reasons related to psychosocial factors, life circumstances of poverty and vulnerability, as well as emotional well-being. Having survived an got life ‘back again’ with ART had given renewed hope for the future – this hope itself was both important for, and evidence of transition. However, this hope would alternate with uncertainty and fear of death, mainly due to treatment insecurity. Getting back to work would improve the economic situation. Moreover, the importance the hard work had on transition was emphasised in the study. Work could be a way to restore order and get back a sense of control. Moreover, work would make on able to take decisions, decrease dependency on others, and make plans. Being very busy also underlined having control, in addition having routines gave back a sense of order and stability. Engaging in a constant planning was interpreted as a type of work done to integrate HIV as a chronic condition into their lives, in taking back control over important decisions in life.

According to Delbene (Delbene, 2011), Bury and others have later pointed to a need of re-examining the idea of illness as biographical disruption. In Delbene’s study with people living with HIV or with renal failure in South America, it was found through analysis of patients’
narratives that the onset of a chronic illness was in some cases not the complicating action\textsuperscript{5} they oriented to. Rather, it was earlier experiences such as poverty or drug addiction, instead of the onset of their illness that was seen as the complicating event in their lives (Delbene, 2011).

Stories of HIV have to do with issues that bring vulnerabilities upon people. At the same time HIV has to do with near and loving relationships between people, like the nearness between mother and child, or two lovers who engage in sex - actions that are considered normal and wanted in any society. Yet, since HIV was first identified, health strategies, policies and interventions both in high-, middle and low-income settings have focused on (unwanted) sexual behaviour and on behavioural change in response to HIV and the HIV epidemic, to such a degree that it is now called ‘The behavioural paradigm’ - and to such a degree that it has contributed to increased stigma and prejudices against people vulnerable to or living with HIV. The above approach has in recent years been criticized for neglect of other dimensions playing important roles in shaping the HIV-epidemic. To understand an HIV epidemic in a specific context it is necessary to understand the different issues that bring vulnerabilities upon people. That the course and outcome of HIV infection are shaped by social forces like poverty, racism, stigma or violence are now increasingly recognised. A move away from the biological model of HIV that addresses the proximate causes of HIV has been taken, to a model reflecting the biosocial nature of illness and considers the many different factors determining cause and outcome of HIV\textsuperscript{6}. Furthermore, Parker and Aggleton (2003) have pointed to how HIV related stigma has its origin in, strengthens and reproduces existing inequalities in a society and view HIV stigma as having ‘a key role in the producing and reproducing relations of power and control’ (Parker & Aggleton, 2003, p. 16).

\textbf{Review of relevant literature}

Available literature in the area of research is limited. Internationally, research with migrants and HIV has mostly been epidemiological, pointing to the need for prevention and accessibility of treatment. However, several qualitative studies have been conducted, with a focus on illness perception and on cultural relevance of health services. I have not been able

\textsuperscript{5} Complicating action is a core element in narrative analysis and is understood as the event that ‘breaks stasis and initiates the plot of the story’.

\textsuperscript{6} Moen, K. New priorities for HIV and AIDS in the developing world context. Lecture at UiO. 2011, March 17.
to find research made with people living with HIV and without a residence permit in Norway, or in Scandinavia, as a target population. Although this study recognize and has in focus the unique experience living with HIV brings to people’s lives, people in the group are also likely to share many of the same experiences as other people without a residence permit, or with other persons, in particular migrants, living with HIV. Studies with irregular migrants in general are therefore included in this literature review, as are studies with ‘regular’ migrants living with HIV in Norway, as well as in other contexts. People living with HIV and without a residence permit have participated in some of these studies. Research-based knowledge I have chosen to include here relates to the main areas of: the experiences of living without legal residency; the experiences of people living with HIV and with uncertain residence status; and in a Norwegian context, the experiences and living conditions of people living without a legal residency, some of whom are living with HIV.

**Life without legal residency**

A London-based study tells about the impact of living with an uncertain residence status over time can have on a person in the form of alienation, continued fear of being caught even after a residence authorisation is secure and of the imaginary world including delusions, and ties to home country (Jackson, 2010). ‘The Shock of The New: On Migrant Imaginaries and Critical Transitions’ by Jackson is an essay based on fieldwork with both (what he calls) legal and illegal Sierra Leone migrants living in southeast London. The essay focuses on the life world of a young man from Sierra Leone, where the priority of the researcher has been to ‘flesh out the empirical details of a particular person at a particular moment in time’, using ethnographic fieldwork methods – participant observation, informal talk and taking notes. The paper describes life with uncertain immigration status and gives a rich description of the participant’s thought world as well as interaction with others. Sharing daily life in the form of participant observation and through the actions of the participant, insights into inner thoughts such as hopes and fears, imaginations, connection with and disconnection from others was made possible. Connectedness to home country, alienation in the host country – how this makes him think, feel, see and act in his daily life, as a state of continued insecurity even after legal asylum status is secured, are among the findings generated. ‘The breaking point of a person – when hope is abandoned’, the author says, ‘is determined by the unresponsiveness of the environment to one’s presence or one’s voice, to one’s needs and one’s aspirations. It is
also determined by the individual’s frustrations and how he or she manage not to let these dominate his or her thoughts’’ (Jackson, 2010, p. 71). The author emphasises that the essay does not intend to contribute to the general knowledge about Sierra Leone or West African migrants, or to relate to comparative research on these groups. The essay is meant to tell the story of one person’s life world.

Living with HIV and with uncertain immigration status

There are a number of studies of migrants living with HIV, often with people of a particular descent, in different countries and cities in Europe, Canada and U.S., and where many of the participants (also termed immigrants) in the studies were without a residence permit. These studies have often had a focus on accessibility, availability or acceptability of health services and through use of qualitative methods have generated knowledge that is relevant for the target group in the present research, and beyond health care settings.

Pivnick et al. (Pivnick, Jacobson, Blank, & Villegas, 2010) combined quantitative and qualitative methods in order to do a multi-site evaluation of peer services in the use of HIV primary care among HIV positive Caribbean immigrants in the Bronx (Pivnick et al., 2010). The study used mixed methods and included ethnographic interviews, focus groups and progress notes, in addition to quantitative methods. 41.8% of the participants were reported to be without immigration documentation. During the exploratory interviews lack of residency permit was participants’ explanation for difficulties getting a job, health care, permanent housing, transportation, problems with dealing with immigration formalities, being without money, and also separation from family. The need for domestic violence services was also related to lack of immigration documentation. The extent of the influence of immigration status on the lives of the participants and on the outcome of peer services became increasingly apparent as the study went along. Using grounded theory, immigration status was included as one of the important influences in the ‘ecology of primary care’. Among the conclusions of the study is that the broader context of people’s lives needs to be addressed in a comprehensive way to reach any solution regarding health and illness. People’s long-term and daily stressors, competing needs, shifting priorities and unpredictable life circumstances make peer interventions in HIV primary care alone of limited use (Pivnick et al., 2010) .

Shedlin and Schulman’s (2004) qualitative needs assessment of HIV services is a study among Dominican, Mexican and Central American immigrant populations living in the New York
City area, where many of these migrants were believed to be undocumented. They used focus groups to explore the perceptions, beliefs, experience and knowledge of HIV care issues, in addition to interviews with key informants. This study generated ‘…detailed information on cultural meaning of HIV/AIDS, experience of stigma and rejection, gendered health-seeking behaviour, testing issues and satisfaction with services’ (Shedlin & Schulman, 2004, p. 434). Since there were different groups with different national backgrounds, the study allowed for cross-group comparison to see if one group’s perceptions were shared by other groups. It also gave the opportunity to compare and explore norms in the different groups. The study concludes with supporting the view that for services to be effective in reaching these immigrant groups, it is necessary to understand people’s backgrounds including environment in the home country and the impact of migration experiences.

Doyal’s (2009) research on life with HIV/AIDS among ‘Black African migrants’ in London was conducted in order to ‘map the ways in which this group of individuals shaped and (re)shaped themselves as their circumstances changed’ (Doyal, 2009, p. 177). Several of the individuals in the study were reported to have uncertain legal status or uncertain immigration status. The project used an intersectional approach to differentiate between and compare the experiences of heterosexual women, heterosexual men and gay/and or bisexual, and findings are based on three separate qualitative studies. The intersectional analysis was chosen after an initial study with only African women raised questions relating to how gender and sexual identity have an effect on experiences of HIV. Many in the group of heterosexual women had left their children behind in their native country; this caused suffering, as they both longed for the children and were not able to perform their perceived maternal responsibilities. A majority of the women lived with children in the UK, and most were living as single parents. Not being in a relationship, coupled with being HIV positive was seen by the women as a potential threat to their identity as mothers – which is noted by the author to traditionally mean being ‘the moral guardians in society’. Avoiding disclosure of their HIV status to others, including their children, was a challenge in their daily lives and for the same reason many chose to live without sexual relationships. Their lives revolved around their children, who caused practical challenges, but also gave happiness and the strength to persevere. The study with heterosexual men showed that they rather were concerned with the feeling of weakness and lack of worth, brought on them by lack of work and money, and consequently a dependency on others. Their inability to live up to what was perceived as being a real man, being financially capable and
physically strong led many men to remain single. They still had hopes; these were usually linked to getting an income. Their immigration status, however, was challenging any aspirations they had for the future. In the study with gay men, the focus was on fear of disclosure and fear of the potentially double stigma of being gay and HIV positive. Experiences of homophobia from growing up in their African home country also contributed to a fear that the HIV diagnosis would create more hostile and discriminatory attitudes towards gay men in the community. Being blamed for having the infection was a theme brought up with relation to family. Moreover, being gay had already caused detachment from their parents and loss of contact with their home community. There were few arenas for meeting people both of the same origin and same sexual identity. A life lived in secrecy, and the tensions between being an African man and a gay man, forced them to manoeuvre and negotiate the different and fundamental aspects of life. Depression and fear of death were themes that were brought up, however so was positivity, a focus on doing the right things to stay healthy – and hoping to establish a family in the future. Uncertainties regarding legal immigration status, together with poverty, made it more difficult to meet the needs related to the HIV diagnosis and made life with HIV harder (Doyal, 2009).

The three groups in the project also had common experiences and challenges. When first diagnosed, individuals in all three groups associated HIV infection with a rapid death, as experienced in their home countries. The stigma of HIV both in their home countries and in their native communities in UK was a main theme, together with the secrecy and fear of disclosure. Loss of contact with family in the home country was a heavy burden. However, life in exile also gave the opportunity to hide ones problems from the family, and thus protect them from suffering. Many perceived that HIV limited their ability to use their potential; this was found to be related both to the psychological, physical and social impacts of HIV. Access to antiretroviral drugs was seen as the reason for being alive, and many brought up the quality of specialist care that they received in UK. Due to uncertainty in their legal status they feared being deported, the fear being related both to a risk of persecution and the threat to their lives the cut-off from antiretroviral drugs would mean. The study also found that at the same time they felt imprisoned in the UK, as they would lose the right and access to treatment if they left the country for a short while (Doyal, 2009).
An ethnographic study among black and other minority groups in the UK in 2008-2009 aimed to explore the experiences of people who are both living with HIV and seeking asylum (Orton, J. Griffiths, M. Green, & Waterman, 2012). In this study, most of the participants had applied for asylum 5-6 years prior to the study and been diagnosed with HIV from 0-12 years earlier. The research focused on the stressors in the participants’ lives both linked to the HIV diagnosis and to the struggles of going through the asylum system; and to the ways participants respond to these stressors. Three major stressors were identified in the lives of the participants: lack of resources including social support left behind in their home country; HIV stigma and isolation; and a feeling of being trapped in the asylum system. The way they were treated in the asylum system had a deep impact on how they perceived their health and wellbeing, and isolation related to living with HIV made them unable to deal with and manoeuvre within the asylum system. However, the participants did show strength and resilience and found ways of dealing with the stressors in their lives through their personal faith, seeking support from HIV care workers and voluntary organisations, and by staying busy.

Internationally, some qualitative studies have looked at different aspects of the lives and experiences of migrants living with HIV, where a few have people with HIV and without a residence permit as the target group for the research. As I have not been able to find much research aimed at studying the life situation of people living with HIV in irregular exile, I include in this literature review a report published in 2006 by the organisation AIDS and Mobility (2006). The report gives the testimonies of migrants living with HIV and with uncertain residence status in different countries in Europe, and is based on interviews with migrant people themselves, and with physicians, social workers and others who are in contact with them.

The eight countries have different legislation regarding health care for undocumented migrants. The main problem reported in most countries is access to treatment systems. Also, lack of continuity in health care is reported in countries where undocumented migrants do have access to health care. One reason for this is the high mobility within the group, but legal and bureaucratic demands were also reported to constrain continuity of diagnosis and care. In addition, both administrative personnel and health care workers did not always implement laws that are supposed to secure undocumented migrants health care. A link between access to
health care and social exclusion was seen. Where migrants without a residence permit have a ‘right to health care’, they have to pay in full the cost of visits to a physician or hospital, which is near impossible. In addition they fear that administrative staff will contact migration services for payment. A physician providing free health services in Sweden stated that he was afraid to admit patients to a hospital’s psychiatric department, as immigration authorities on several occasions had picked people up from the hospital and deported them. Fear of such links between health services and immigration authorities is seen to be a reason for undocumented migrants not accessing health care facilities. Communication difficulties and fear of breach of confidentiality, as many translators are untrained, was another concern of both health care workers and migrants. On the other hand, those who use health services find psychosocial support through their meetings with health personnel. Sometimes, health personnel are in fact the only group with whom they interact. Health care workers often look for solutions to go around the limitations set by law, (in contrast to the above) and NGOs are in the forefront in this work. Open houses for people living with HIV, run by the municipality or NGOs, were also important sources for social contact; for support, friendliness, care and love.

In addition to the stigma and discrimination that migrants in general experience – for example in getting a job, or a place to live – people living with HIV experience another layer of stigmatisation. The testimonies of the migrants in the report showed that lack of privacy and worries about where to keep medicines so that the HIV diagnosis will not be revealed were reasons to want to move away from reception centres. The experiences and perceptions of being rejected were more profound in relation to people from the same community, and one told the story of how his near family, living in the same country in Europe, abandoned him - left him living on the street when he told them about being HIV positive, and of how this nearly destroyed him – because of rejection, not because of disease. What brought him back to life was the meeting with an HIV/AIDS activist. This happened in a context where people living with HIV do have access to health care and treatment.

Without a work permit, the informal work people can get is for short periods or just single days, and often for long hours. Lack of control over income, where to live, and what to occupy their days with caused much frustration. One woman from South Africa who had lived in Ireland for several years and felt it was her home, felt that the barriers to work made her
feel like a child. A different story was that of a man in Madrid who worked without a permit
did not worry much about it; he had got his well-paid job and other support through the Latin-
American community and through catholic NGO’s. He had a ‘public healthcare pass’, at least
for the time being, and regular appointments in a medical centre. However, to show friends
grateitude for finding him a job, and since he felt healthy, he sometimes prioritises work
obligations before hospital appointments.

Fear of deportation is always a concern, and more so because they foresee lack of treatment
and intense stigmatisation if they return home. As one of the men interviewed expressed it, he
now had the knowledge and experience of being HIV positive in France, but in his home
country HIV still means death, and as HIV positive you are already dead. A lack of
transparency in the Immigration Service, without openness about practice and criteria for
making decision in asylum applications, is also brought up in the testimonies (AIDS &
Mobility Europe, 2006, p. 26).

Pourrette’s (2008) research with African migrant women in France looks at the women’s
different reasons for leaving their home country and how this affected perceptions of living
with HIV/AIDS and choices on most arenas of social life in France, and on the possibility for
return or further migration. It was found that socialisation was generally based on ‘being a
person with HIV’. Living with HIV influenced migrants’ choices of social participation,
choice of life partner, family planning, work, education and also continued migration.

Enriques et al. (2010) conducted a qualitative study to better understand health needs and
concerns of immigrant HIV-positive Latinas living in the Midwest United States. The study
does not state whether any of the participants were ‘illegal’ immigrants in the U.S., but I still
find it relevant for both the area of research and the methodology of the present research.
Narrative descriptions were used in the study, repeated interviews were conducted and trust
building was given time. The authors inform that the emerging themes from the interviews
with these women were not at all expected beforehand. The over-arching theme that emerged
was living in silence. Many women had never shared their diagnosis with anyone except God;
those who were married had told their husbands. A constant and profound stigma surrounding
HIV meant that to disclose the diagnosis to others would mean rejection or social ostracism,
as people believe that a person becomes HIV positive only as a result of extremely negative
behaviour. The women’s feelings of shame, depression and thoughts about suicide were
revealed. God was the main emotional support for more than half of the women in the study, and only a few had received professional mental health services. Language barriers increased the sense of isolation. The need for and use of an interpreter also made it hard to share their true feelings with health personnel, in health care services otherwise appreciated and perceived as accessible by the women. A life in silence and in isolation and loneliness had become the norm for these Latina women living with HIV. Many longed to return to their native country, but losing the ART treatment they get in the U.S. and the fear of disclosing their HIV diagnosis to their family prevent them from leaving (Enriquez et al., 2010).

A study by Körner (2007) brings up themes such as social isolation, loneliness, stigma and fear of HIV testing as HIV infection was ground for not being granted residency in Australia. The author points to the importance of increased understanding of the lived experiences of people to increase appropriateness of health and social care. The objective of his study was „to describe the interrelationship between migration and resettlement, the Australian immigration system and living with HIV’ (Körner, 2007, p. 205). The method used was semi-structured in-depth interviews; participants were recruited from two different HIV support and health care facilities. The study was conducted over a period of 18 months. Three main themes were identified through the data collection process: HIV diagnosis, access to care and support, and forming social relations. Social isolation, loneliness, stigma and fear of HIV testing are some of the issues that emerged in the interviews. How the immigration system contributed to a feeling of uncertainty in the participants, fear of deportation if health services are sought or if the HIV test is taken and proves positive, are important parts of the result of the study. In addition, migrants’ new experiences are interpreted in the light of past experiences in home- or other countries, where HIV stigma is profound, access to treatment is limited and HIV is perceived to be a terminal illness. People living with HIV experience uncertainties in most areas of life – health, treatment, the future - in addition to questions on the very meaning of HIV. People who migrate may face uncertainties with residence status, fear of deportation, financial insecurity as well as barriers to health care or uncertainty about health care entitlements. Negotiating the two major life disruptions – living with HIV and migration – is fundamental in their lives (Körner, 2007).

The societal, and not the least the legal context of the study, is different to the Norwegian, since in Australia testing HIV positive was at the time of the research grounds for having an
application for protection rejected. However, the study participants in the two different contexts share the experiences of negotiating the two major dimensions in life – living with HIV and living without a residence permit, including the risk of being deported. Furthermore, people who migrate may not know, or have misconceptions, about legislation regarding HIV in the country they enter into and live.

Rosenthal’s (2007) study from Tel Aviv is based on ethnographic fieldwork between 2001 and 2003 and explores the life worlds and motivations of undocumented female migrants living with HIV, as well as motivations and lived experiences of a physician, and of an activist and volunteer counsellor. The study reveals how a legal and moral ‘gray zone’ – ‘….a zone of competing values, claims and interests…’ (Rosenthal, 2007, p. 142) is part of the structural framework where participants’ actions and interaction are played out. During fieldwork it became clear that the women’s lives were interwoven with the lives of other social actors, such as health officials and NGO activists. The impact the Israeli ‘contradicting policies of inclusion and exclusion’ have on the day-to-day lives of these different social actors is discussed. The nature of the relationships between the actors, the moral ambiguities they find themselves in, and the illness experiences of undocumented migrants are created in a social ‘gray area’ with links to the ambiguity of national policies. In Israel, undocumented migrants living with HIV are not entitled to ART, with the exception of children and of pregnant women throughout their pregnancy and six months after delivery. On the national level, contradicting policies were seen where people were employed illegally, but paying tax, and therefore covered by the National Health Law which gave entitlement to hospitalisation for childbirth and treatment for work accidents. On the municipal level, and supported by the ministry of health, a clinic provides care for pregnant female workers and their babies, regardless of legal status. The municipal welfare department had also opened a counselling centre for migrant communities, where both ‘documented and undocumented’ people can go.

NGO-run clinics are, however, where most of those go who seek help, also for HIV treatment. The Open Clinic in Rosenthal’s research co-operates with a local hospital for some services. Some of the volunteer doctors also work at public hospitals, and hospital clinics have been known to donate medicine to the NGO clinics. The different social actors /stakeholders must continually search for possibilities and solutions, at the same time trying to meet their own sometimes contradicting interests and demands from different quarters. Within this gray area
they have to negotiate with the law, health policies and also with one another. Breaking the law may be an option, with the rationale and justification that it’s morally right. They struggle to increase the migrants’ chance of survival, but also over ‘the rationality and the morality underlying the state’s – and their own – decisions and choices’ (Rosenthal, 2007, p. 143). Rosenthal explored the various social actors’ ‘local moral worlds’ to better understand their social positioning, beliefs, ideas and stakes – and thence their experiences and choices - with the aim of understanding the nature of the ‘grey area’. Hjelde’s research in Oslo revealed that ambiguity regarding the term ‘necessary/required health care’ left it to the individual health care worker to decide whether an undocumented migrant should get medical help or not (Hjelde, 2010).

**Studies in a Norwegian context**

*Migrants living with HIV*  
Aasland, Hellevik and Aasen’s (2012) report on targeting immigrants in HIV-related work in Norway is based on interviews with the most important actors working in this field as well as reviews of relevant documents. Among findings are that psychosocial support is not sufficiently catered for. HIV is surrounded by stigma and many immigrants with HIV, especially women, will not use organised services where they risk meeting people from the same native community. Flexibility, patience and individual meetings over time are emphasised as important for the psychosocial support to be relevant. People in the group often have high trust in health services, and the authors suggest that this could be used to a greater extent. With regards to HIV treatment and follow-up the medical care is good, but immigrants are diagnosed later than Norwegians, and the risk of advanced disease before contact is made with health services is higher (Aasland et al., 2012).

Some experiences of living with HIV in a Norwegian context are presented in a Norwegian study on living conditions among people living with HIV (Grønningaeter, Mandal, Nuland, & Haug, 2009). The study found a polarising pattern in the responses from the informants, where some people tend to lead their lives without giving the HIV diagnosis much thought and attention, while for others living with HIV becomes a part of one’s identity and is in many ways decisive both for daily activities and overall life. The authors relates this to the
availability of treatment, the safety net of the welfare system and the prospects of living long lives on the one hand; on the other hand the continued HIV stigma and prejudice in the society. With regards to social life, many people who are HIV positive feel okay and lead good lives, and some experienced a gain in social capital. However, there were also many who experience that the HIV status causes difficulties in social relations and loss of social capital. These difficulties were experienced within various groups of informants. People with migrant background were taking part in the study (but among them no gay men); openness in the various ethnic communities is rare, and migrants with HIV find it easier to tell Norwegian friends and colleagues about the diagnosis –if they are open at all. One in five migrants in the study had not told anyone about their HIV diagnosis. Worries for family members wellbeing if they came to know about the HIV diagnosis, was one reason not to tell friends in the ethnic community. The report also says that migrants living with HIV find that ethnic Norwegians living with HIV are not very understanding of their situation. Misconceptions about HIV are common in the general population, and likely to cause stigma and discrimination. People also hesitate to be open, because this leads others to always associate him or her as ‘being HIV positive’, however keeping it secret is also stressful and complicated. The authors note that although people say that they are okay, they leave an impression (on the researchers) of not being so, and that people who are HIV positive might perceive that it’s expected of them to be fine and content in a context where HIV treatment is available. In the Norwegian population few improvements are made when it comes to openness and knowledge about HIV, and restrictive attitudes towards people living with HIV prevail. People living with HIV in Norway still meet stigma and delusions regarding HIV transmission, and they meet general practitioners with limited knowledge of HIV, or health care workers performing exaggerated and offensive infection control measures. In addition, Penal Code § 155 was a reason for great concern and an experienced reduction of life quality among respondents in the study.

Problems with one’s partner on several levels, including the sexual relationship, was linked to this (Grønningsæter et al., 2009).

**Life without legal residency in Norway**

Research with people without a legal residence permit and living with HIV in Norway is limited. However, a handful of studies have been conducted in Norway during the last few years and resulted in increased understanding of living conditions and common health problems, and has revealed the difficulties in access to health care for this group. Brunovski
and Bjerkan’s (2008) study focused on methodological and ethical challenges with research with undocumented migrants.

Øien and Sønsterudbråten’s (2011) report on the living conditions of irregular migrants in Norway; ‘No way in, no way out?’ is based on a qualitative study. The researchers conducted one in-depth interview with each of 29 respondents, with some informal talk with a few people afterwards. Among the respondents were two people living with HIV, and the report gives important openings into and impressions of their life situation including perception of limitations of choice and being trapped. The objective of the study was to explore different aspects of the living conditions of irregular migrants in Norway, with a focus on the experience of living without legal residence status. A key aim was also ‘…to understand what entitlements irregular migrants have within the Norwegian welfare state and whether they are able to make use of their rights’ (Sønsterudbråten & Øien, 2011, p. 17). The target group was irregular migrants – in the study understood as any foreigner who stays in Norway without legal residence. Because of recruitment difficulties, no one who had never registered with the authorities is included in the study, and all respondents in the study were rejected asylum seekers. Motivation for participating in the study was for several a perceived responsibility of sharing the reality of living without legal residence, also on behalf of others. As the authors recognise, this could have caused respondents to feel obliged to share the suffering and hardships more than sharing other sides of life, but in the interviews they did also share their roles as active agents, as in finding strategies to survive. Interviews were also made with representatives from organisations that have knowledge related to undocumented migrants’ living conditions, which helped the researchers to contextualise the data that was produced.

The study covers many different areas and factors influencing the living conditions – legal framework, social network, family, housing, health, employment, education, and tries to see this from the perspective of the respondents’ subjective experiences. In addition, the study looks closer at how people perceive their own choices of staying in Norway where they do not have legal residence – which is found most often to be related to factors out of the control of the individual - how they reached that situation seemed confusing and sometimes incomprehensible to the respondents. In line with the aim of the study to increase knowledge of entitlements, rights and the ability of irregular migrants to make use of these, the study
found that even if irregular migrants do have the right to emergency health care, specialist health care and municipal health care, without consideration of the marginal financial situations people live under, access to the same health care becomes arbitrary and dependent on the health worker they meet and whether he/she is willing to omit the payment. On the individual level, fear of medical personnel reporting them to the police was a common reason that people hesitated to access health services. It was found that living conditions varied across the respondent group. The researchers conclude that the living conditions would improve if the access to health care and shelter was more organised, but also recognise that the respondents themselves emphasise that to get legal residency is the one determinant that could make their life and living conditions better. Living without a residence permit was the one factor that influenced and guided all other aspects of life. A recurring theme brought up by participants in the interviews was how living without legal residence created and worsened health problems. Different degrees of mental health problems and symptoms of psychological stress were common and added to this.

Referrals to interviews with two persons living with HIV are included in the report, where participants describe a profound feeling of having no choice but to stay in Norway. In the health area, participants brought up ‘how irregularity created and exacerbated health problems’. Psychological stress was seen to add to this. One man experienced complications and worsening of health condition after acquiring irregular status, which he described as being the factor that eventually made him fall completely down. A woman who had lived five years in Norway, and been diagnosed with HIV after arrival, saw no other solution than to stay. The state of health was the central reason for doing this. A feeling of being trapped was often described, both among the persons living with HIV and not, people seeing no way of getting a legal status, but also no way of getting out of life as ‘irregular’. The inability to foresee the end of the situation in which they find themselves is a theme that is brought up by participants. By looking at policies, practices and the participants lived experiences the authors find that ending up with irregular status is not only caused by migrants' unwillingness or inability to return to their countries of origin, but the result of complex causal relationships in migratory and asylum processes.

With the combination of the legal framework as a background, interviews with people with special competencies and experiences working with the group in addition to the interviews
with respondents to get their perspectives and views, the study captures the discrepancies between laws and perceived reality, and also the inconsistencies in policies and the consequences this has for people in the group. The study gives descriptions of the living conditions among people in the group. Even though the sample is small – when it comes to generalising, the authors propose that the variation in living condition between the respondents suggests that the study group is quite representative for the situation people in the group face. The study does show patterns of how irregular migrants are limited in their ability to make use of any rights or entitlements they have, and form a general picture of how irregular migrants view all aspects of their life in light of living without a residence permit. A re-analysis of the data from this study was conducted in 2012 in order to understand why rejected asylum seekers move out of reception centres (Øien, 2012). It was found that the motivation for people to move out of the centres are varied, but the most common were to avoid deportation, to find work and escape the passivity of the reception centre, to get freedom to chose whom to live with and not, to try to get control of one’s own situation, in addition to the placement of the centre. People who chose to live in the centres did so because a life outside without any financial support was viewed as too hard, and staying would at least secure the very basic needs. Most of those who had children or responsibility for other relatives remained in the centres. Living in the centre was also seen as giving a sign of being law-abiding and wanting to have a good relation with the authorities, as well as an expression of hope of eventually getting legal residency (Sønsterudbråten & Øien, 2011).

Health and health care
Hjelde’s study ‘I am always worried’ (Hjelde, 2010) was one of the first to address the health and welfare situation of undocumented migrants in Norway. Interviews with two groups, undocumented migrants and health personnel, was conducted with the aim of casting light on undocumented migrants’ welfare, health problems and health behaviour, and to demonstrate the ethical dilemmas among health personnel. The study is described as a qualitative adaption of the quantitative study done by the International Centre for Migration and Health. A structured interview guide was used in Hjelde’s study, but facility was made for the 30 informants - 15 migrants and 15 health workers, to talk more freely. The majority of the migrants were former asylum seekers who had their application refused. The study was conducted at a time when most people in this group were not allowed to stay in reception centres, and found that most of the informants were homeless and unemployed without
income, and therefore completely dependent on others. The migrants reported they had to rely on people from the same country or other acquaintances for housing, meals and other help, but were constantly on the move and one person slept outdoors. All who had a job, now or previously, felt they were exploited. Most of the undocumented migrants had lost contact with their families in the home country; only one had contact with his child.

The study showed that undocumented migrants suffer from several concurrent health problems and delay seeking care and treatment. All but one said that their health had deteriorated since they left their home country, and all the informants reported having mental health problems. Sleep disturbances, depression and suicidal thoughts were reported. Some had been going to therapy at a district psychiatric centre (DPS) over time and were suddenly told that they could not continue. Stress-related illnesses were also frequently reported, such as ulcers, severe headaches and chest and back pain, in addition to eye problems and serious dental problems. As the group, according to Norwegian law, has the right to emergency care only, and they have to cover the full cost themselves, the migrants often refrained from seeking help due to this cost, and also because of the fear of being caught by police. Most had experienced being refused access to health care because of the lack of ID number, both at a general practitioner’s office and in the emergency department, and even when they felt acutely sick, but many migrants had also received health care from general practitioners or emergency departments without questions. By combining and comparing the two target groups the study shows the problems faced by both and gives an impression of how they interact, and in particular how the lack of clarity in health care entitlements results in an arbitrary health system for the group, where personal attitudes of health workers become important. Recruiting informants to the study was difficult, the snowball method was not fruitful, and the 15 migrants were recruited through organisations working with the group and at a centre for migration health. Also health workers initially positive to participating withdrew before starting. Hjelde notes that both groups can therefore not be said to be representative of the population of undocumented migrants and health personnel, respectively (Hjelde, 2010). None of the informants in the study were HIV positive. Moreover, the policy shift back to letting rejected asylum seekers have the alternative of staying in reception centres, makes the context for Hjelde’s study different from this study. The findings from the study are nevertheless highly relevant for the group of undocumented migrants living with HIV, not least with regards to access to health care (Hjelde, 2010).
Chapter three: Study design

Epistemology
This study and its research design rests on certain philosophical assumptions on what we see as the nature of reality, and on whether and how we can get knowledge of this reality. The ontological assumption is that reality is not external to us or fixed, but is changing and subjective, as perceived by the participants in this study, and as perceived by me as a researcher. The epistemological assumption the study is based on is that knowledge of such realities can be generated by nearness to the phenomena studied. The influence of the researcher on what is studied is acknowledged, and so is that knowledge generation is intersubjective (Creswell, 2007).

The study also rests on a social constructivist view – that all knowledge is to some extent socially constructed. Individuals create subjective meaning to their experiences and situation through interaction with others, and those meanings are shaped by their individually experienced historical, cultural or societal norms (Creswell, 2007). In research, again the participants’ view on the situation becomes important.

With these assumptions as the basis for what constitutes reality and knowledge, the study aimed at generating understanding of the research topic by using explorative, participatory methods.

Methods
As already mentioned, very little is known from a research point of view about the lives of people living with HIV and without residence permit in Norway. This study’s purpose is to increase understanding of this thematic area, to generate insight into a complex situation, and to learn from the participants in a context how they experience and interpret it. Qualitative research methods were chosen for this study because they allow for in-depth exploration of that which is little known and the complex life processes that participants in this study are likely to experience (Creswell, 2007).

The study is inspired by Edmund Husserl’s phenomenology (Creswell, 2007) and sought to build rich descriptions of participants’ life worlds; their perceptions, experiences and performances, in order to understand how life is like for a certain group of people from their own perspective. Meaning is in phenomenology seen as constructed in the meeting between a
person and the outside world. To understand the lived experiences of people, and how they act, it is necessary to understand the meaning people give to those actions - this includes the thoughts, beliefs, values, feelings and assumptions the participants have. Internalized norms, roles, expectations from others as well as the physical and structural environment will influence human actions and how people perceive and experience them. Qualitative methodology may open for richer perspectives on these issues. Use of qualitative methodology is also seen suitable to increase insight in more informal and unstructured links that are important in people’s lives and their networks, highly relevant for the target group of this study (Sønsterudbråten & Øien, 2011).

Qualitative research methods in addition allows for building flexibility into the study design. This possibility of making modifications underway seemed appropriate in this study for several reasons. As the aim of the study was to generate insights into the lives and health of people seen from their perspective, the design should give room for bringing insight gained during data production back into the study design, like for adjusting focus areas, changing approaches to the participants, modifying the dialogue guide to facilitate further exploration of an issue. After I had talked with several participants in this study what they said led me to include review of relevant documents as a research method. Recognizing the target group’s vulnerability in research also called for focusing on the life circumstances the participants themselves were more occupied with or concerned about (Tangwa, 2009). Flexibility was also thought to be important in methods used for recruiting participants, as the people intended for participation in this study has not before been a sole target group of any study in Norway. Ways of meeting and inviting people to take part in the study was hoped to be further known after the recruitment process had started.

Two questions I have been met with when I told others about this master project were 1. How do you find them [participants]? 2. What are your findings? Both questions have left me puzzled and, when seen isolated, seem to be expressions of what I believe has not been the case, a research where the participant had to be lured out of somewhere in order to be the object of a study solely ‘performed’ by me. I hope the below will show the nuances in recruiting participants and how this, as well as creating data and ‘findings’, are processes where, indirectly or directly, and along with the participant, many ‘co-producers’ – people, places, work, time, unexpected and expected events - are involved. Knowledge about the
social world is not something to be ‘found’ by a researcher, but to be co-produced by two (or several) individuals, in a continuous fashion, ceaselessly. Despite the sometimes-long time lapses between meetings, the participants in this study were part of such continuous and changing co-construction of knowledge. Relevant to this is also that the theme itself can be seen as taking part in the process of meaning formation. Moen and Middelthon (Moen & Middelthon, 2015) refers to the philosophers Charles S. Peirce and Hans Skjervheim, and propose that the theme in an interview, not just the participant and the interviewer, should be seen as part of a triangular or triadic relationship. The theme is here seen ‘not a passive but a meaning-making process of the interview’ (Moen & Middelthon, 2015, p. 340), which can be understood as if the theme or topic of a research engages independently the two other parts of meaning-making.

Furthermore, the study participants’ life worlds are immediate - but also situated in ‘the social, cultural, political, historical, and contemporary context in which they live their lives….’ (Colapietro, 1989, cited in Moen & Middelthon, 2015, p. 332). It is a difficult task, and perhaps more so for this small study, to try to see and grasp the ‘situating’ and complexities of people's life worlds, but awareness of it gives another dimension to the meetings with participants and to the phenomena explored.

In the following I will present the process of getting into fieldwork and explain my choice of methods for generating data. I will try to concretize and make transparent what I have done during the course of the fieldwork, and why I made the choices I did. Ethical considerations has been a priority throughout this master project, from the planning stage, throughout the fieldwork and when writing up the thesis. Choice of methods, and reflections underway on how to use them, often originated from ethical dilemmas. Even though ethical considerations have been an integral part of the research, it will be presented more in depth in a separate chapter.

Three complementary qualitative research methods were planned used in the data production process: Dialogical interviews, participant observation, and review of relevant media reporting. The combination of research methods were chosen because of the combined wish to gain insight into the life worlds of participants from their perspective, both in word and in acts (interviews and participant observation) and to gain insight into broader societal perspectives (review of media reporting). As the fieldwork went on I found that the
participants life worlds in many ways stretched into the ‘inner’ reasoning, procedures and policies within immigration services; I therefore included review of relevant documents as part of the methods. More details about the methods and how they worked out in practice will be described further below.

First I will present the target group, the recruitment process and the people that were invited to participate in this study.

**Target group**

To know more about the life worlds of people living with HIV and without a residence permit in Norway was the main motivation for choosing the research topic, the site and place of study followed from this. The fieldwork was conducted from October 2011 to June 2012, which reflects of the slow progress of recruitment, of time lapses between interviews and in general long periods of waiting, as well as of time- or other- constraints on the behalf of the participants, and later, on my own.

People living with HIV and without a residence permit in the greater Oslo area were the main target group of the study. Many of the undocumented migrants in Norway are thought to live in the Oslo area (Ottesen, 2008), and the greater Oslo area was therefore considered a natural choice when deciding the place of the study. Since the number of people living with HIV and without residence permit in Norway is unknown, the choice of Oslo as the study setting was assumed to ensure a larger population to recruit from. The greater size of the population in Oslo was also thought to add to the goal of protecting the anonymity of study participants (along with other measures to ensure confidentiality described in ethical considerations). In addition, I knew of some of the environments in Oslo that potential participants might be part of, and I believed it to be possible to form trusting relationships with participants in this setting. The greater Oslo area was therefore considered a realistic site in that entry into the environments was considered feasible. In addition, this context may be termed rich with a number of processes, interactions and structures of interest to the study.

*Who was invited to participate*

Eligible to take part in this study were persons above 18 years living with an HIV infection and who:
• could be classified as an undocumented migrant

• had an uncertain residence status or could be expected to lose a residence authorization in near future, (like asylum seekers who have received notice of Dublin-status or decline of appeals to a negative asylum decision.)

• had received a final decline of application for protection but could not be returned to country of origin.

To clarify: people who had received a final rejection of their asylum application and appeal, or who expected to lose their residence permit, or who did not know (or doubted) if they still had a residence permit, were eligible to be included in the study. (ref. NB many/some don’t know)

Note: Persons below 18 years of age, young people unsure about their age, persons presenting with symptoms of severe mental illness and other persons in need of immediate medical attention would not be considered eligible to participate in the study. There was normally no doubt about these criteria. However, one of the participants had recently been hospitalized (after he was diagnosed with HIV), but had recovered and been discharged from the hospital at the time (some time before) I met him.

The recruitment process. Invitation to participate and establishing contact

To discuss the feasibility of the study, contact with personnel working in organizations and institutions for people with HIV, for migrants in general, and for migrants without legal residency in particular, was established in the planning stage of this study, in the spring of 2011. Most of those I contacted indicated that they thought the intended study would be feasible - that it would be possible for me to get in contact with people living with HIV and without a residence permit, and that to recruit them to the kind of study I planned, would most likely be feasible. I was also reassured of the relevance of the theme for the master thesis.

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7 Immigration authorities in Norway operate with four categories of persons without legal residence (Hjelde 2010), persons with: 1. Final decline of asylum application 2. A residence based on false information 3. Stay after a visa is expired (tourist, student, work, au pair). 4. Arrived via the border or with boat without registering to Norwegian authorities.
In this study, the recruitment process was based on convenience. I was not able to get in contact with potential participants as frequent / smoothly as I hoped for, and in the end whoever I met who fulfilled the inclusion criteria and agreed to take part in the study, were included (Corbin & Strauss, 2008). A recruitment process based on purposive sampling (Corbin & Strauss, 2008), where the idea would be to maximize the diversity of the sample with regards to the life situation the study was to explore, was considered, however was not found feasible. The recruitment by convenience did not however differ much from my initial idea of how to reach and include participants. Some qualitative research aims to continue data collection until saturation of the data occurs. Data saturation is a concept from grounded theory, and refers to a situation where no additional conceptual insight is provided when more participants are included in the study, or ‘when no new data are emerging’ (Corbin & Strauss, 2008, p. 143). While I could not claim that saturation of the data occurred in this study, it generated enough data to describe and analyse a variety of perceptions and experiences. Moreover, while the data material can in no way be considered representative for the population group it focuses on, I consider it highly informative about the circumstances that pertain to persons living with HIV but without a residence permit in Oslo.

In the research design chosen, it is more important that participants can give a certain type and amount of information than that they are many. In the planning stage, recruitment of 6-10 persons for participation in the study was thought to be sufficient for the study, and by key informants viewed as a realistic goal. It was anticipated that recruitment of people who did not spend time in the (for me) known arenas, would take time. Previous studies among people without a residence permit had shown little success with methods like ‘snowballing‘ (Brunowski & Bjerkan, 2008; Hjelde, 2010; Sønsterudbråten & Øien, 2011). When living with HIV is an inclusion criterion, this method of chain referral could prove even more unsuitable – if starting with people without a legal residence document. Snowball method has however been used successfully in research in different settings with people with migrant background who are living with HIV, where health services and care has been the focus of the studies. Snowballing with a starting point where potential participants already may know about each other’s HIV status was therefore thought of as an option also in this study. However, after I met with people who agreed to take part in the study I understood that expecting them to tell others about the study, and refer me to others, was not realistic. Those
of the participants who visited the same HIV support centre, did so not on a regular basis, or only sporadically. They met the same staff, and may have been present on the same events, and the same outpatient infection clinic, but were not necessarily sharing with others that they didn’t have residence permit. In fact, potential participants for the study were not necessarily having any communication at all with each other, or any common ‘sites’. I learned during fieldwork that they all lived their separate and very different lives, in different locations in the Greater Oslo area - and that any ideas of ‘grouping together’ people living with HIV and without residence permit was problematic.

A range of places were contacted for inviting people to take part in the study: a health care facility for undocumented migrants, a support center for people living with HIV, a health clinic for migrants in general, a few sexual health clinics, a few different hospitals’ outpatient clinics for infectious medicine, the PRO center, an interest organization for people living with HIV, some interest organization for asylum seekers, and some NGOs working with different groups of people: migrants, people who are homeless, people who inject drugs, and people who sell sex. Attempting to recruit participants from a broad spectrum of places would increase possibilities to meet people with differing perspectives and experiences. On the other hand, recruitment from the above places leave out persons who live without residence permit but do not seek assistance or health care from organizations or institutions like the above. People who use services and organizations for help, like the persons who agreed to participate in this study, are likely to have other experiences and perceptions about life than people who do not use health or social services. Nevertheless, they may still differ – and they did - in the extent they use these services and I anticipated in many other areas as well.

I contacted physicians at different infection clinics in the region, via mail and by phone, explaining the purpose of the study and requesting them to let patients know about the study, for example by allowing an invitation to participate in the study to be posted in the waiting area in the clinics. At one such clinic they were positive to the request and would look into it and get back to me. A representative for another clinic informed me that they didn’t ask their patients if they had any issues with their residency in Norway and preferred that I didn’t post an invitation in the clinic waiting area. I understood that the reason for this was to prevent patients from associating the clinic with UDI in any way. Other organizations were interested in the study and said they would get back to me. I made attempts to reach them again, but
was, because of the sensitivity of the topic, not wanting to impose the study on anybody, and perhaps out of politeness, not as persistent in this as I could have been. At the health clinic for undocumented migrants, there was an ongoing three months project for voluntary HIV testing during my fieldwork period, and I had an informal meeting with the project manager. However, to try to recruit people only a short time after they had learnt about the HIV diagnosis did not seem as an appropriate timing. Yet, I did post an invitation (see appendix 1) in the same health clinic, without getting a response.

In three of the organizations I was able to get in contact with potential participants through persons working there. One of these places was the first I contacted to learn about the perceived relevance and feasibility of the study, and the person I met with there provided much information about relevant issues for this study based on his experience with HIV among illegalised immigrants. For this reason, I consider him a ‘key informant’ in this study. He was also one of several ‘key persons’ for the recruitment process. All key persons were experienced employees in their respective organizations, and persons the participants had known and trusted over a period of time.

Attempts were made to reach people in different environments. To get a variation of people in the participant group (e.g., from different regions and countries, of different sex and age, and with different gender identity and sexual orientation) is generally considered valuable in qualitative studies (Moen & Middelthon, 2015), and was an aim also in this. However, as recruitment of participants turned out to be slow, I could not afford to let considerations about the variation in the sample take priority in the recruitment work. In the end, every potential participant I got in contact with and who met the inclusion criteria, had been invited to take part in the study, and all had agreed to participate. However, although I could not steer the selection, the six persons with whom I have done this research did have a wide variety of backgrounds, both with respect to country of origin, culture, language, religion, norms, education, profession, age, gender and family life. Among them were people who were single and in a relationship, were straight and gay, had children and not – and they differed with regards to the number of years they had been living with HIV and without residence permit in Norway.
The participants also had some things in common, including that they had all grown up in different countries in Sub-Saharan Africa. Besides this, living with HIV and living in irregular exile in Norway are the two major life circumstances they all had in common.

Information about the research participants is not given in detail in this thesis. The information that is given avoids specifying information that could be either directly or indirectly person identifying. Names are pseudonyms and portions of contextual information have been changed (and have been so since the first scratch notes and interview notes were made).

**Key informants and key persons**

The key informants were people who through their position or work have relatively close contact with people in the target group or had special competence relevant for the study. They had long experience working with people living with HIV, and with migrants living with HIV and/or had special knowledge about the life circumstances of people living without a residence permit in Norway, including the processes within the asylum/legal system. I knew some environments and potential key informants before the research started; and others were revealed during the process. I talked with employees in key roles in different organizations both with the purpose of getting help with recruitment of participants, and in order to learn; to gather information and hear their thoughts about the research topic.

Two of the study participants wanted the person who had helped me get in touch with them to be present during interviews with me. This opened for the influence of that person on the participant as well as on the emphasis put on different themes. Attention was given to this particular social context during the interview, as well as in data analysis. Considerations of and measures to ensure confidentiality were made both with regards to participants and the other person present, the latter because they were also having the role of key persons to the different participants (and to identify them could in some cases potentially have contributed to identify the participants themselves).

**Dialogical interviews**

The six persons above participated in dialogical interviews in this study. After the key persons in the different settings had informed potential participants individually about the study, I would called up those who had agreed to let me contact them (all preferred this rather than
them contacting me). The two of us would meet in a place of his or her choice. I never met with more than one participant at a time, but I did interviews with a key person or a family member present when a participant preferred so. This was the case with three of the interviews.

I informed about the study and we read through the invitation letter I had written, where information about confidentiality and anonymity also was specified (see appendix 2). If the person agreed to participate, they gave their consent either written or orally. They were also informed that they at any time, and without giving any reason, could withdraw from participation. Contact information to me, and the name of my advisor, was provided.

In the planning stage of the study I had been aiming for between 6 and 10 persons taking part in repeated dialogical interviews. I assumed that this would be a realistic, sufficient and suitable number for the research aim and within the study’s framework. How many participants that is ideal to recruit for a study of this kind may be seen in relation to how many interviews each of the participants will participate in. A lower number of participants might miss out on breadth of experiences, but fewer participants may at the same time allow more time for repeated/serial interviews - which could open up for additional depth of understanding (Crang & Cook, 2007). In this study, a total of six persons were recruited, and they were invited to take part in repeated dialogical interviews (but people who did not wish to set aside time for more than one conversation were also welcome to take part). For those who agreed to, it was attempted to have at least three interviews with each participant. In the end, I interviewed two persons (Alma and Hana) five times, one person (Miriam) four times, one person (Lucy) three times, and two persons (Adil and Shan) one time each.

Repeated interviews provide opportunities – time, space - for a researcher and participant to get to know each other better and could thus facilitate the development of trust between the two (Crang & Cook, 2007). In addition, several interviews may contribute to change the power relations in the interaction, giving more opportunities to break down any understanding of a ‘knowledge hierarchy’ where the researcher is understood to possess more knowledge than the participant, and to hopefully replace it with a perception that the two together, and on equal terms, are producing knowledge jointly (Crang & Cook, 2007). Repeated interviews also make it possible to return to further explore and clarify themes or issues from previous interviews. Meeting the same person again also allows (both the researcher and the
participant) opportunities to go back to the same themes after some reflection, see phenomena in new ways and describe them with other words. This can contribute to bring out fuller and more comprehensive stories, and give a deeper understanding of the thoughts, reasoning and concepts brought up in earlier conversations. Crang and Cook (2007) suggest that serial interviews facilitate a ‘potential move from rehearsed and/or quick explanations to thoughtful introspections and sensitive and intersubjective explorations of interviewee’s taken-for-granted lives. (…)’ (Crang & Cook, 2007, p. p. 77).

Repeat interviews also permits issues talked about with one participant to be brought up in interviews with others. This was the case also in this study, sometimes after having reflected on it, but probably just as often not as a conscious choice.

The possibility for follow-up over time is also seen as an increased chance of getting to know about and respond to the possible emotional reactions the participants might have to topics being discussed during interviews. In this study, for those who participated in only one interview, a telephone call was made to hear how the participant was doing a few days after the interview, either to the participant, or if this was not possible, to the key person involved.

Having my mind set on the advantages of repeated interviews did however, in retrospective judgment, have the disadvantage that I did not always fully ‘seize the moment’ and focus on further depth of exploration of a theme or thought the participant brought up, right at that time. Instead, on some occasions, I put much focus on efforts aiming at building trust while talking about the different themes, and expected to explore issues further when we next met - but in the end we only had that one interview. One of the male participants, Shan, I met and had an interview with only on one occasion. We did the dialogical interview in the support center for people living with HIV, where we talked for approximately two hours, with the key person present. Adil, the other male participant in the study, I talked with first on the phone, and we decided to meet in a cafeteria, where we had a first informal talk. Here I explained more about the study, and he already at that time told me much about his life situation and some of the problems he was facing – and we agreed to meet again and had a longer interview in his home one evening, with his partner present. Also in this case, my anticipation of meeting the participant for serial interviews did not materialise, as it turned out we had only this one dialogical interview after he had consented to participate. A positive side of this was that the atmosphere in the one interview we did have became relaxed, because I felt and
probably signalled that we had plenty of time to talk and we thus both seemed to allow the dialogue to run freely. Each of the four women in the study I met with several times.

A dialogical form of in-depth interview was chosen to open for emic perspectives to emerge and take a foreground position, with the perceptions and realities of the participant as a point of departure - and as a priority throughout the interview process. Open questions were chosen to give room for participants to talk about what was most important to them in their lives. An interview guide was not made before the meeting with the first participant, the rationale being that I wanted to avoid the ‘direct’ influence of my preconceptions, and especially so early on in fieldwork. Later I brought a thematic interview guide with me (see appendix 3), this was loosely followed in the sense that I used it as a checklist to remind myself to bring up the main thematic fields for the research if the participants had not already talked about these issues – and they had already had time to elaborate on other themes. The thematic interview guide was again modified after the subsequent interviews and in accordance with themes and issues brought up by the study participants (see appendix 4).

Participants being given room for more freely to express themselves may easier lead to emergence of new and unanticipated knowledge (Kvale, 2009). Open-ended questions could make participants respond in ways that are unexpected by the researcher, in rich ways, and in addition be explanatory in the sense that participants share their perceptions of relationships between different events as well as the meaning they assign to these relationships. Through in-depth interviews people are able to share their perceptions and perspectives. These are expressions of the participants’ subjective experience of what has happened, and they expressions of the part of their life that they select to share (Kvale, 2009). Probes - unprepared questions to follow up information that is unknown or unclear to the researcher, or to get a richer understanding of what is being said, was important.

The plan was for all the interviews to be between me and an individual participant, with a translator present only if needed and accepted by participants. However, as already mentioned, one of the participants chose to have his partner present during the interview (he took only little part in the dialogue). Another of the participants expressed that he wanted the key person (who had helped in recruiting him) to be present. The issue was not a language barrier (he spoke English), but rather that he felt more comfortable talking with me if she was there. He did confirm that he consented to participate in the study after we had talked for a
while. One participant wanted the key person to be present and translate, since she didn’t feel confident in English – and did not want an interpreter from a bureau. Both the participant’s native language, English, and Norwegian, was used during the dialogue. The key person took on a more active role than a professional interpreter; filling in on what the study participant was saying, explaining, and sometimes sharing his own experiences and stories. This may very well have distorted some of her meanings and expression. At the same time he brought a different perspective, based on his own perceptions and experiences as well as experiences from years of close contact with persons living in similar situation as the study participant. I did also meet with the same participant when she was alone; we spoke in English and were able to understand each other quite well in a more social setting. One participant spoke both English and Norwegian, and alternated between the two languages. The rest of the interviews were done in English. Following the participants’ wish, both to feel comfortable and to secure confidentiality and anonymity, none of the interviews were done with a professional interpreter.

Audio recording was not used, as I feared this might have caused participants to doubt and feel unsure whether their anonymity and confidentiality was secured. Notes were instead hand-written during the interviews. This did have the disadvantage of me not being able to write out in text much of my own part of the dialogue and rather had to put a mark or short note where I was responding or probing to explore further what the participant just said. This absence of my direct voice in the interview notes is revealed in the sections where quotations are used in this thesis, however it does not mean that my presence and influence on what was said is unrecognized.

The handwritten notes were later transcribed. Pseudonyms have been used since the first handwritten notes were made. Information like age, civil status, children, years lived in Norway, which could make the participants easier recognizable was never kept together with the interview notes.

I was also writing up notes after the interviews, as well as after spending time with the participants in social or other settings. Often participants would start talking when we were out walking, or before we sat down for an interview, and they would continue elaborating on issues or bring up new ones after we had ended that day’s interview. These moments had a different atmosphere, and especially after the interviews, a more relaxed one. I tried to capture
the content of the conversations we had in such situations, in writing, shortly after. In these notes I tried to pay attention to the setting and context of each meeting, and also to reflect more on the participants’ expressions and emotions. The informal talk here has some similarities to informal talk during participant observation. Impressions from participant observation were written down in the similar way as above.

In addition to the conversations, participants were showing me documents, such as letters from the police, from UDI and from UNE. Some were also during interviews, and informal talks, showing pictures of their children back home, and giving vivid descriptions of their lives there.

**Participant observation**

In this part of the fieldwork, I planned to ask permission to take part in everyday life contexts together with some participants for a period of shorter or longer duration. Participant observation is often seen as important for the emic perspective of the study as it affords possibilities of seeing people, and being part of people’s life, in natural settings, like people’s everyday places and their movements between them, the daily activities of people – what people do and what they take initiative to – and how they interact with others and in different settings, as well as reactions and emotions showed (Fangen, 2004).

Participant observation is expected to give insights into what is happening in a given context in a limited time period - ‘real life’ details of a particular person at a particular moment or period in time. Joint experiences and informal talk during these times hold the potential to give an insight into the lived lives of people in a different way than interviews can (Moen & Middelthon, 2015). Access to information that the participant may not share in an interview is made possible, and the method may also give opportunity to ‘discover’ new issues and factors that were not thought of beforehand, and this information can be used to add to the data produced in interviews.

Being part of the processes that are explored in research may be seen as a prerequisite to making meaningful interpretations of what is going on between people. Observing and taking part in the daily life of people gives the opportunity to get closer on people’s reality and more personal knowledge of the participants – and the method provides chances to learn through one’s own experiences (Fangen, 2004; Moen & Middelthon, 2015). Spending time with people
over time may also help build a fuller picture of the participants’ life world. Participant observation has for these reasons the potential of giving a broader and more complex basis for the research.

I assumed that the best way to recruit participants for this part of the study was to invite the persons that I was doing or had done interviews with. This way people would know me better and hopefully trust me as a person. The number of participants, and the time spent with me, had to depend on the participants’ available time, their acceptance, and their willingness to share parts of their everyday life and time. As it turned out, I did participant observation with four of the participants. The amount of time I spent with the participants varied a lot, as did the settings we spent time in together. Sometimes it was difficult to differentiate whether the data from these meetings are from ‘informal talk’, ‘warming up’ before, or part of dialogical interviews, ‘participant observation’, ‘observation’ or just me being a ‘visitor’ welcomed into a social setting. At least, in neither of these settings, dialogical interview was the main reason for meeting.

The main purpose for doing participant observation in this study was to gain insight into the everyday life of the participants. Sharing time and space with them, even on a limited basis, gave a different understanding of how their days went by- tasks, schedules, and social life - than what was learned from the interviews. My aim was to explore in a different way how it is ‘being in the world’ when living with HIV and without a residence permit. In none of the social settings I participated in were there other people with these same two life circumstances combined – at least that I know of. However, one of the settings was at the HIV support center. Moreover, friends of the participants all had different experiences with their, or their family member’s, residence status in Norway.

Apart from Adil who involved his boyfriend, all participants who agreed to, or invited me to, spend time in their home or with their friends, would like it not to be known to the others why I was there. Since other people present in the social setting were thus not aware of the ongoing research, they treated me like I was a friend of the participant, which in many ways had come to be the truth. Confidentiality was naturally a priority also here. This ‘secret’ between the participant and me did perhaps cause an extra tension in the social interaction, but then again, so did probably my presence in the first place. In addition, the distinctions between my roles of being a researcher and a friend could be vague sometimes. The secret
between the study participants and me also brought up a question of ethical relevance. Ethical guidelines related to third parties in research require that researchers evaluate the potential risks and are able to anticipate and prevent any injury to third parties (Hadjistavropoulos & Smyth, 2001). Was it ok for me as a researcher to be present in these social contexts when only the study participant knew, and not the people around him or her in the given social situation? Ideally, I would have wanted everyone present to be aware of my research, but this was obviously not possible if there was going to be any research done in this way at all. All of these encounters occurred in public spaces, where anyone could in principle be present. Yet, the boundaries between public and private are not always straightforward. Even in public spaces, people may engage in what they perceive to be private conversations, for example. In order to respect and protect third parties, I decided that I would not record information about them, and always make sure that information recorded about the study participants would in no way contain directly or indirectly person identifying information about others.

The settings in which I did participant observation varied. I spent time with Hana and Lucy in the camps where they lived, with their children playing inside or popping in and out. At Hana’s, friends or neighbors were coming by. We also had a meal and spent time together in the cafeteria in the support center on two occasions as well as sitting down and conversing /chatting with others at the support center after we had finished the interviews. We also met and walked in town. I met Alma several times in ‘her’ cafeteria, and in other cafes or restaurants, with her friends or her boyfriend, and also where she had a job one day. Miriam and I used to meet, walk and talk in town, or sit and talk in cafeterias. She was having an active role in events staged/arranged to make known the situation of people living without residence permit in Norway, and I attended two such events. I visited Lucy in her home three times, with her children and sometimes other tenants present, we also met in town, went to a cafe and had a long walk once. Meeting Adil in his home with his boyfriend set the dialogical interview very much in context.

Total length of the period for participant observation had to depend on participants’ wishes, as well as practical issues on both parts. With some, the contact ended because the fieldwork was over, with others because they had other needs and priorities.

A thorough evaluation of whether the data generated through participant observation was sufficient or not, was not so easy. The participant observation component of this study was
limited, and a longer period of participant observation together with more persons would clearly have provided me with more possibilities for learning. On the other hand, I was certainly exposed to a number of settings and social interactions that were important part of the study participants’ lives. As the Sage handbook points out,

‘But even when it is used on a limited basis, there is no denying the power of this technique to produce penetrating insights and highly contextual understanding.’ (Guest, E. E. Namey, & Mitchell, 2013, p. 76)

Following relevant public discourse and policy development in mass media

To follow the media and political debates, and to follow the rhetoric or terminology used when talking or writing about HIV-infection, about people living with HIV, and about migrants without a residence permit was useful and exposed me to an important aspect of the social and structural context in which the participants lived and which affected them directly or indirectly. It was also important for a broader and contextual analysis of the data gathered through other methods (ref). Mainly articles and news items in Aftenposten and Klassekampen (newspapers with differing political platforms), and news and debates on NRK’s TV channels (national public TV) were reviewed, but different web news channels and web forums were also visited. Migrants living without residence permit in Norway have been the focus of numerous debates and articles in newspapers. Policies are changing, and immigration issues in general are constantly debated; the sources are almost unlimited. People living with HIV are to a much lesser degree focused on in media, (and if they are it’s most often medical news about research, vaccines etc) but during the fieldwork, proposed changes in ‘HIV-paragrafen’ was on public hearing and this was to some extent covered by the media.

In addition to mass media used by the general population in Norway, it was interesting to talk with participants and key informant about the news they read or hear about, and what channels or newspapers they used.

Readings

In order to contextualize the data I have during and after the fieldwork searched for and reviewed literature I found interesting and relevant for the research area and research design. The group of people participating in this study –living both with HIV and without residence permit – has as already mentioned not been given much attention in research, while separated
from each other, these two life circumstances have been researched much more extensively. Therefore, it has been difficult to find any literature at all on the specific area of research. Literature with only one of the life circumstances as a theme has of course also been relevant for the study. However, to filter/extract out literature of specific relevance for this project from the rather large amount of literature on HIV/living with HIV and irregular migration/being a migrant, respectively, has been a challenge.

I used databases/search engines like PubMed, Cinahl, Web Of Science, PsycInfo. and Google Scholar, as well as different websites on international health or migration issues. The University library’s local database(?) BibSys has been useful, as have the traditional method of (physical and) purposeful browsing through the library’s bookshelves. References made by other authors in relevant journal articles, research papers and books have been important in the search, as one reference has led to another. Websites as well as novels have brought a different kind of understanding. Class notes from the M. Phil. program in International Community Health was revisited. I was not so familiar with social science theorists and therefore attended some classes in history of social anthropology. Visiting UDI’s homepage gave me an impression of the terminology used in the bureaucracy, as well as insight into the procedures and regulations relevant for this study. Some documents turned out to be of particular relevance to parts of the data analysis, and review of these were included as a method, but I will emphasize that the study did not include an in-depth analysis of these or any other documents.

The literature review has proved to be an on-going project, where I have continuously tried to grasp new concepts and frameworks for analysis and understanding, and I have often found myself in unfamiliar disciplines. I have tried to bear in mind that certain theories might attract me for reasons that has little to do with the data in this study, that I must use theories with caution, having little or no previous knowledge of them - and that theories must come second to the data generated. However, this on-going reading of literature (on theories, or critical perspectives) has influenced my choices, contributed to my reflections and helped shape analyses throughout the research project. When reading, I normally wrote notes on associations to the themes the study was about to explore, or to the participants and what we had talked about. I made memos on issues to check out or explore further, and I wrote short notes on reflections made between meetings with participants or between periods of writing.
In addition to the readings I attended meetings and conferences related to the research area. Through a key person I was invited to the conference ‘Religious leadership in response to HIV’ held in Oslo in October 2011 and also to participate in a working group arranged by ‘Snöball Film’, in connection with an educational film about HIV they were producing. I also attended the European Migration Network (EMN) Conference ‘Pathways out of irregularity’ in October 2011 and NSH/NAKMI’s conference on minority health including health care to irregular migrants. And, as mentioned earlier I attended debates and cultural events involving people living without a residence permit.

**Data recording, management and analysis**

In this study, I considered analysis an ongoing process, from the planning stage, to the initiation of data production and throughout the qualitative research process. The analysis was thus part of the different steps and levels of handling, and viewing, the data, from the practical and more ‘technical’ parts to building meaning and relating the data to theory.

As described earlier in chapter (the making of the data), attention to content, context and emotions expressed during the interview was attempted, and short scratch notes I made during and immediately after interviews and events enabled me to better recall the context and emotions involved. The handwritten notes from dialogical interviews, as well as the scratch notes taken during or immediately after events, participant observation and informal talks, were expanded short time after. As the data was produced and notes and interview transcripts/notes typed up, time was spent reading and re-reading the content, and by doing so, also remembering the setting and atmosphere.

Reading through the interview notes with comments also enabled reflection on the trajectory the interview took and the reasons for this. I strove to analyze data in light of the overall context, as well as in light of the interaction between researcher and participant. How I in different ways was having a role, also normative, in the data production was part of the analysis, as I will get back to below in the section on positioning and reflexivity.

Coding of the data has largely been done manually. Themes identified when first working through the text and coding manually were however broad and (I felt) too closely tied to the research objective and the thematic fields defined when planning the study. In an attempt to challenge a possible influence of my pre-understandings and facilitate that the themes
emerged more independently from the data itself, I later attempted to use software
(Hyperresearch) for coding and categorizing data – creating numerous key words and groups
with what I thought was closer attention to the participants’ perception. The categorization
here did however not differ much from the initial ones, but the method did help ‘spotting’
nuances and details in the data, like similarities and differences. It also helped in confirming
the relations between different groups of data that was found earlier.

Data from the different notes and transcripts was from early on sorted in mind maps, or code
maps, with a preliminary sorting of the data into categories or themes. These drawings and
rough grouping together of data was helpful in suggesting patterns, to see branches of themes
and sub-themes, relations and connections between different parts of the data, surprises and
disparities. Throughout the analysis the mind map was changed and re-drawn.

Data was also pulled together manually in an attempt to write the chronological story of each
of the participants’ lives, in order to understand fuller the lives they have lived, the
experiences, relations and events, from the past to the present. Present perceptions,
experiences and acts could in this way easier be seen, and again analysed, in relation to past
experiences.

Discussions with my advisor started early on, with reflections on how to approach the topic
both methodologically and analytically, on dilemmas and difficulties met, recurrent talks and
attempts to do analysis and present the findings in a way that is true to the participants’ view,
through the different periods of this project. Talks with fellow students (some of whom are
now my colleagues) were also useful.

Key themes were eventually identified - and again reflected upon, challenged and developed
further during the continued analysis when writing up of the thesis. Thick descriptions are
attempted used to build up and communicate the generated understandings.

Theory
Theories were included when perceived as having the potential to increase understanding, and
facilitating formation of meaning. The analysis has until the end of the writing process been a
process of abduction, where empirical data and theories were ‘tried’ against each other
throughout the research. Crang and Cook describes the process of abduction as ‘ a process
where researchers/writers pick up ideas from the world and develop them not so much to
prove them right or wrong but to see where they can lead and what they can do’ (Crang & Cook, 2007, p. 184).

In the analysis I wanted to follow up the participant perspective of the study and bear in mind emic categories - ‘parts’ of the life worlds of the participants. The concept of life world is derived from phenomenology as described earlier, and for the data analysis the four existentials that guide phenomenological reflection has been helpful (van Manen (1990), cited in Morse & Richards., 2002). Here, all phenomena in life, with the individual’s related perceptions, experiences and performances, is seen as lying along the following different and interrelated ‘axis’ of our very existence, and our life world: Temporality – lived time; spatiality – lived space; relationality – lived human relation; and corpororeality – lived body.

Reflections done with these existentials in mind have given another dimension and understanding of the themes emerged through the interviews. Below are other sets of ideas that have been inspiring to the analysis; allowing inspiration from different approaches has helped seeing the data along different ‘axes’.

My advisor led my attention to ideas of ‘ways in which to look’, inspired by Blumer’s ‘sensitizing concepts’ (Blumer, 1954, cited in Moen, 2015). Such sensitizing concepts, rather than more definitive concepts on what to see, was in this study an inspiration to see the data in new ways. It was also helpful in distancing myself from any pre-understandings of the relevance of political theories or framework and its concepts, and to stay in contact with the participants’ perspectives.

Among the above theorists is the French philosopher Gilles Deleuze, who sees life as lived along lines (Ingold, 2011), and with every living being having its own line, or bundle of lines. Their starting and end point cannot define these lines, nor can all the points the lines consist of. The lines are on the contrary characterized by existing between; they are ‘lines of becoming’. They run not in a straight line from one place or situation to another, but find new routes and openings in the landscape (Deleuze and Guattari, 2004, cited in Ingold, 2011). The geographer Torsten Hägerstrand saw every part of the environment ‘including humans, plants, animals and things all at once’ as having ‘continuous trajectories of becoming’ and continuously being forced to move on by the surroundings. These continuously extending trajectories are entwined and make up the texture of the world, the way Hägerstrand imagines it, the ‘big tapestry of Nature which history is weaving’ (Hägerstrand, 1976, cited in Ingold,
Ingold notes that ‘in this tapestry there are no insides and outsides, no enclosures or disclosures, only openings and ways through’ (Ingold, 2011, p. 84). These ‘metaphorical’ frameworks resonate with people’s lives - including the participants’ in this study - as well as with the meeting between people, including me, that this study entails. I believe the exploratory nature of this study – and the emic perspective – may also have been better preserved by these concepts of ways in which to look.

I found it also interesting to read Tim Ingold’s thoughts about what causes a person to act, and his skepticism of a theory of meaning holding that all actions are in accordance with a person’s ‘intention conceived in thought’. He argues that human relations with the environment are not necessarily mediated by culture (where ‘systems of significant symbols’ are seen as a defining part of culture) (Ingold, 2011, p. 76). He refers to the philosopher Alfred North Whitehead ‘from the moment of birth we are immersed in action, and can only fitfully guide it by taking thought’ (Whitehead, 1938, cited in Ingold, 2011, p. 76). This understanding has also been relevant for the analysis - in a time where, contrary to the above, a common perception is that all human actions have a purpose, are a result of a conscious, rational choice, and that the actions of rejected asylum seekers – i.e. remaining in Norway - are always calculated and based on an actual choice. It is possible to view people’s actions (and lifelines) from a different perspective, from ‘within the line’, to see how they act and react, look for and follow openings and ways through. That chain with moments of actions creates the life worlds of people.

Appadurai’s (Appadurai, 1996) idea of different (land)-scapes as dimensions where people’s imagined realities are shaped, has been helpful for bringing the reality of people’s lives in a more globalized world into the ongoing analysis of data. His idea stems from the notion that the overall context in peoples’ lives is less defined than in the past and than the assumptions in most social science research held. Phenomena are according to Appadurai shaped by peoples’ social imaginaries, and the dimensions that together form social imaginaries are not confined to a physical, social or cultural space around us here and now. For each of the participant, the data was by hand attempted sorted in accordance with different dimensions (-scapes), like ethnoscape (the people in each participant’s life), ideoscape, technoscape, financescape, mediascape as well as politiscape added from Shahani (Shahani, 2008), where the two first got most attention. The process may have helped me to see the data in a more
modern globalised context. The analysis has however not been bound to this or any of the other frameworks.

It would (however) be ignorant to assume that the lives and actions of people living with HIV and without residence permit are not inhibited by societal structures and their ‘symbolic systems’ and power, whatever way the context is viewed (and it would be arrogant to say ‘so what’). This study has not taken an explicit interpretive position, I have however associated to and found interpretive theories and related concepts relevant to the ongoing analyses, like Agamben’s as well as Hannah Arendt’s writings on statelessness, othering and stigma (Bauman, Goffmann), Bourdieu’s understanding of the social worlds in terms of capital and lastly the concepts of liminality (Turner) and purity (Douglas). Not being trained in social science research kept me from attempting to analyze the overall data in the light of one such theory or conceptual framework, at the same time the content of the data is, I believe, not served well by leaving such theories out completely. Another aspect is that meeting the participants’ agency despite structural barriers, made me seek alternative ways of viewing the data in a contextual way. To increase conceptual understanding of health and ill-health as well as HIV, I have looked to Svenaeus (Svenaeus, 2005, 2007), Kleinman (A. Kleinman, 1980) and Farmer (Farmer, 2009; Farmer & Kleinman, 1989) in addition to Fugelli and Ingstad (2009), Radley (Radley, 1994) and Bury (Bury, 1982).

The researcher role. Positioning, pre-understandings and reflexivity

In any research, the researcher cannot stand outside the situation, but is part of what is being studied. To conduct research is in this way also a normative affair. As a researcher I cannot avoid – because of my presence – to express a judgment of ‘what ought to be’. My personal biography could result in subjectivity in how I interpret, analyze data and formulate both the research objectives and findings in this study. An essential part of the research process therefore needs to be reflexivity.

‘Reflexivity requires an awareness of the researcher’s contribution to the construction of meanings throughout the research process, and an acknowledgement of the impossibility of remaining outside of one’s subject matter while conducting research. Reflexivity then, urges us ‘to explore the ways in which a researcher’s involvement with a particular study influences, acts upon and informs such research’ (Nightingale & Cromby, 1999, p. 228).
‘Personal reflexivity involves reflecting upon the ways in which our own values, experiences, interests, beliefs, political commitments, wider aims in life and social identities have shaped the research. It also involves thinking about how the research may have affected and possibly changed us, as people and as researchers’ (Willig, 2001, p. 10).

By some reflexivity is criticized for having developed into a tiresome, self-indulgent practice, like in this statement: ‘At present, in my view, we are spending too much time wading in the morass of our own positioning’ (Patai, 1994, cited in Pillow, 2003, p. 175). I have throughout the research process tried to make visible and reflect on my position, perspectives and possibly partial nature – and tried to do this with a focus not on me, but on the effect on research and knowledge production. I have chosen to write in the first-person with an active voice, which makes visible the role I have had as a researcher (but with the risk of drawing attention to me). It has been a constant reminder of my part in the data generation and analysis – and brought an extra urge to question my assumptions, conclusions, findings, and what I write.

Interpretations will occur during all stages of research, but could be easier to apply reflexive practice upon when looking at the research with a distance in time and space. Methods of meta-positioning myself as a researcher therefore lay the ground for enhancing reflexivity during research. Creation of time, space (distance) and context (detachment) during the study are important elements in increasing the possibility of me seeing, and understanding, what shapes research at the time of conducting it (Mauthner & Doucet, 2003). During this study there were days and sometimes weeks passing between meeting with the individual participants, and the time for reflections on the last meetings was sometimes too long. I went home or to work after having met with participants, and my everyday life and context was very different from theirs. Everyday connection to these other parts of life and who I am may have contributed to being too detached and a tendency to see myself as an ‘the elephant in the room’ when being with participants. This feeling does however also reflect the limited time practicing participant observation as well as consequences of the slow progress in both the fieldwork and writing up the thesis.

This qualitative research project did nevertheless allow for interaction between some of the participants and me over time, and of close relationships to develop. Awareness of the very likely possibility of me as a researcher to identify too closely with participants was therefore important. At the same time, this very identification, and my perception of participant’s views
or situation, was dependent on my own understanding of life, and my ‘bag of tools’. The same will be true of the opposite – any identification would depend on the participants’ perception of me and my view and position, and of their own situation and needs. (I did feel that) friendships developed with two of the participants, and that my role together with a third participant was at times more like a big sister. I did in the beginning inform about my background and my role in the research and did encourage their initiatives and independent responses. I could later have regularly included questions to participants on how they saw me as influencing their responses during the interviews and other settings, but did not ask these questions explicitly. I did however pay particular attention to their reactions to behaviour or expressions from my side, when I was unsure if they had interpreted me in such a way that they thought certain responses was expected from them. I had for instance to one of the participants brought up the issue of openness about HIV several times, when one day she told about when she had decided to have a friend that she could be open with about everything. Power relations are likely to have influenced the data produced in this study. The participants have both in ‘real’ sense very little power – they have little money, little control over their lives, no rights – to mention some aspects- while I have all the rights and power they are missing. In addition, it is likely that the participants saw me, even if a student researcher, as a scholar having some sort of expertise - they may have believed that I had power to help or even radically change their situation. My professional role as a nurse in a health clinic for asylum seekers may cause the same power gap. As discussed previously and in the chapter on ethical considerations, a participatory approach with open dialogical interviews and nearness between the researcher and participants was thought to have the potential to reduce the sense of power imbalance and the influence of this.

Being part of discourse belonging to an academic public health, international health or medical anthropology environment will influence the research. Research happens in an institutional context – discussions and feedback from advisor as well as other contacts in the institutional environment were important in attempts to identify how the public health or international community health context influences the interpretations, from the very beginning and throughout the research process. In a research I planned to approach with an open mind to increase participants’ chance of shaping, and directing the research, there are perhaps areas that would be considered more important with regards to public health than those identified
by the participants. This notion might be influencing the research also underway, either by me wanting knowledge useful for, and to please, the institution, or by me having been socialized into a public health discourse and acting and interpreting situations according to it. At the same time, intellectual development of the research is dependent on the same discussion with the people in the institutional environment.

Language used was another important point that was discussed with my advisor. The choice of words - how it influences the way we, and listeners, perceive phenomena, how we analyze them, and how words chosen can either open for evolvement of new meaning, or shut it down – and be including or excluding - have been reflected upon. I have aimed to keep language simple and to use value-laden words with caution only.

Thinking of undocumented migrants, where a majority is assumed to be rejected asylum-seekers, as ‘my patients’ who I somehow need to protect, fight or find solutions for, is a way I may have colored the research project. Work experience from psychiatric nursing may also have influenced both the interaction with the participants and the interpretations of the data. Impatience and political standpoint could further influence the approach to and the information produced during the research process. My pre-understanding of the Norwegian ‘asylum system’ and skepticism to the processes within it have been attempted challenged by reading more about their procedures. A focus on similarities rather than cultural differences between people may have limited my perception of cultural context and background, and therefore on meaning formation. Awareness of such pre-understandings has had the potential of reducing the influence of them in this study.

Open dialogues and the focus on relevance for the participants was important both for ethical reasons and for the objective of this study, but may on the other hand blur the lines between an interview and a therapeutic session (Smith, 1995). My background as a nurse in the psychiatric field may have reinforced this, even if my role in the research was clearly stated. Attempts to reduce the tendency were done during the interviews, but regards of and follow up of participants’ sometimes strong emotions was nevertheless an integral part of the dialogues. In this and other aspects I have been personally involved in both the means of data production and what data is produced in this study.
Reflexivity should be a way of assessing quality in the knowledge produced, as it is produced. This again demands an understanding of what constitutes quality in qualitative research. I will return to this after the chapter on ethical considerations, which also relies on reflexivity.

**Ethical considerations**

An application for ethical clearance was submitted to the Regional Ethical Committee in Norway June 2011 and approved in August 2011. The same committee was in a new application informed of the extended time needed for analysing and writing up the thesis, and a renewal of the ethical clearance was given in May 2015 (see appendix 5).

Throughout the research, I have assumed that the study population must be considered a group with many potential vulnerabilities. As persons without legal residence, they live in the society with almost no rights. Both as immigrants and HIV positive persons they could be subject to stigma, and they are economically disadvantaged, to mention some aspects. Ethical considerations were highly prioritized and were integrated in all steps in the research process.

The primary risks of participation in this study was likely to be related to a potential loss of confidentiality - both loss of confidentiality with regards to living with an HIV-infection, and with regard to living in the country without authorization to do so. There was also a risk of potential discomfort related to talking about HIV and about sexuality, and also to talk about possible traumatic experiences and memories. Participants might experience discomfort and dilemmas regarding attracting attention during the study or sharing their whereabouts, and fear that information could reach the foreign police or the immigration authorities. Ways of ensuring confidentiality and minimizing discomfort will be explained below, as well as potential benefits to the participants.

First I will present some ethical considerations regarding choice of research area.

**Vulnerabilities**

The CIOMS International Guidelines for Biomedical Research Involving Human Beings, Guideline 13, states that ‘Vulnerable persons are those who are relatively (or absolutely) incapable of protecting their own interests…they may have insufficient power, intelligence, education, resources, strength or other needed attribution to protect their own interests.’
The Helsinki Declaration paragraph 8 and CIOMS Guidelines 10 also states that members of economically disadvantaged group are vulnerable in relation to medical research (CIOMS, 1991; World Medical Association, 2000). Undocumented migrants are of course much more than people without the right documents to stay in a country, and people living with HIV live not only with HIV. Categorizing and grouping people as a unit of research- undocumented migrants living with HIV- could in itself contribute to reinforcement of marginalization, social rejection and stigmatization. In view of CIOMS Guidelines 13: ‘Special justification is required for inviting vulnerable individuals to serve as research subjects and, if they are selected, the means of protecting their right and welfare must be strictly applied’ (CIOMS, 1991), it could perhaps be tempting to leave the research area altogether. However, with that comes a confirmation of an ‘imaginary invisibility’ of the group, and ignorance of the people in the group will continue. Avoiding research with the group might also add to a somewhat condescending attitude towards people in vulnerable situation as people without strengths. A citation from the sociologist Mary Haour-Knipe can perhaps shed light on this dilemma:

‘Many of those working in the field of migration, although they feel they should be doing something, may hesitate to use the words ‘migration’ and ‘AIDS’ in the same paragraph (Decosas et al., 1995), fearing unfair finger-pointing at those who are all too easy to single out since they are, by definition, not of ‘us’. The result is that, in relation to HIV and to AIDS, and until recently, migrants have either been ignored, or they have been overprotected.’ (Haour-Knipe, 1996, p.2)

The critique that some (anthropologists) have raised against their own profession’s role in many projects ‘to better other peoples’ lives’ could be wise to remember also in public health research including mine. To me, next to the risk of revealing participants’ identities and means of surviving while living ‘illegally’ in the country, is the risk of conducting research that has no benefit for the group and at the same time bereaves participants of some of their strength. Moving in close to a landscape of participants as ‘worthy needy’, with researchers as gate openers for an ‘industry’ of public health interventions is a scenario that should be taken seriously and should not be omitted from reflexive practice. These our spoken and unspoken, conscious and unconscious, and sometimes not well-informed goals were attempted brought up, shared and discussed particularly during the first part of this master project.
‘Research in itself is a powerful intervention…which has traditionally benefited the researcher, and the knowledge base of the dominant group in society.’ (Tuhiwai Smith 1999 in Glesne 2006 s. 129)

Public health research must be regarded as normative, with an aim to better a situation. To whom the research will gain, if they view it as gain, and the long-term consequences of an immediate gain are all elements that needed to be addressed until the end of this project. Basic ethical principles for health research were followed in the research process. In reflecting on the ethical issues and dilemmas in this study has also literature on research with irregular migrants been helpful (Black, 2003; Brunowski & Bjerkan, 2008; Duvell, Triandafyllidou, & Vollmer, 2010; Tangwa, 2009). Also relevant for the ethical issues concerning this study - from the planning stage, via invitation to and asking for consent to participate, interaction with participants during data production process, analysis of the material, to dissemination of the end result - are factors related to the vulnerability of people in the actual context the study will be conducted in. To conduct research with vulnerable populations, a precondition is that the research should be of relevance and interest to the participants (Tangwa, 2009).

Participatory approaches and facilitating target groups’ ownership to the research as well as optimize relevance of the study to the people involved, like described above, are in my view the basis of ethically sound research. A close relationship between researcher and participant could contribute to this. The chosen qualitative methods were enabling such personal relevance, as close, collaborative and participatory approaches were made feasible. Research that remains close to participants’ true interests may be facilitated if an open dialogue and room for participants’ viewpoints are made throughout the research, and that this is consistent (Tangwa, 2009). This was a focus in my meetings with the participants, and also in the reflections and analysis of the data. However, as there were often time lapses before I met with participants again (and with one I met only once), in practice this focus was not consistent. I did bring up themes from earlier dialogues to better understand their views, or to check if I understood them right. In between these dialogues I was on my own analysing. In addition, I was not able to share with the participants a draft of the findings/thesis and get their responses, comments or corrections. Three of the participants, who all stayed in the Oslo area, had indicated that they wanted to contact me rather than me contacting them. Two women left Norway, and although we have kept some contact, it has not been possible to share the content of the thesis with them. One participant ceased the contact with staff at the
support center, and therefore with me. We don’t know if he is still in Norway and how he is doing.

The participants in this study were in different ways in a vulnerable position with regards to having an income, getting food and a place to stay. Participating in the study involved a potential risk of exposing their means of getting by and could thus leave them in an even more vulnerable position. Sensitivity to this matter was employed and is dealt with more in detail in the sections ‘Informed consent’ and of ‘Risks and benefits’ on this thesis.

To the study participants I specified that the intention of the study was not to find out exactly where and exactly how they manage to get by. The study participants themselves were also attentive to this matter and didn’t reveal to me concrete information about work places, with one exception.

Representation of the group of people in this study is problematic and has been reflected on in this study. The working title for this research project included the term ‘illegal exile,’ however, the study does recognize that the term may be perceived as both provocative and hurtful. A human being cannot be illegal, and a person living in illegal exile does so as a result of a process linked to national immigration categories, immigration law and the many various backgrounds and personal stories of those involved. The word ‘illegal’ was meant to underline the actual conditions these persons live under, despite human rights and despite, or because of, international conventions. Undocumented migrants, irregular migrants, Sans Papiers or ‘Papirløse’ refugees are all terms that are in use today, and they seem to be found more tolerable by people in the group. However, in different ways these terms do perhaps not reflect their situation. They don’t have a residence permit, but they certainly have papers, including ID papers from home. They have handed over many documents, and authorities seem to in most instances to know that they stay here. ‘Irregular’ (in my view) suggests that there exists an option for all people to migrate to Norway in something called a regular fashion, so if people wanted, they could. Persons in the study who feel that they have done what they could to be honest, cooperative and available do not feel that they have done something irregular, outside the rules and regulations. ‘Illegalised’ is a term that I find better reflecting that their life circumstance is a result of external circumstances. However, the word irregular is used in this thesis as it is by organizations representing people in the group.
Included in the ethical considerations, and prioritized throughout the study, was and is attention to participants’ own words used about their life and situation.

In the dissemination of the research results it is vital to consider how participants are portrayed. Language and terminology used have the potential of reflecting existing power structures and reinforce exclusion and stigma. In addition, when working in a politicized field like I find mine to be, findings may be appalling and provoking, and researchers may contribute to a polarization of opinions. I have tried to present the results in a balanced way, although this task may have shown to be difficult.

**Informed consent**

The autonomy of the potential participant and his/her freedom of choice are central to ensure that the process of obtaining informed consent is ethically sound. Degree of vulnerability could affect a person’s freedom of choice, as in deciding to participate in this study or not. Attentiveness to potential deception or inducement is important particularly in the case of a target group considered vulnerable (Tangwa, 2009). An example of deception is ‘therapeutic illusion’, where in spite of explanations to the contrary research participants themselves firmly believe procedures to be therapeutic; to better their lives in one way or another. People without a residence permit have in a Norwegian study shown to try to create hope where there probably are none (Brunowski & Bjerkås, 2008), and it is possible that this could occur here. When inviting people to participate and asking for informed consent to this study, I did reflect on participants’ motives to participate. People without a residence permit can be thought as being on the very lower end of a hierarchical system of immigrants, based on their legal status. They might be especially vulnerable in research because they are denied access on many arenas, whereas being asked to participate in research - being interviewed and somehow given ‘value’ - might seem as a meaningful thing to agree to. Poverty and sickness can further increase interest in participating in research, with hope to get a small income, or to get help with health problems. And, hopes that participation in the study will somehow give a greater chance to get a residence authorization or get their application for asylum re-considered, could influence the decision of participating in the study.

These factors together must be considered in the process when participants are to give consent. Even though the potential participants in this study were adults and capable of not
allowing him/herself to be induced rather than rationally convinced, the researcher in this particular setting was viewed to have a special responsibility, by being likely to have more knowledge and experience with the societal and legal structures than the participant, perhaps including what are realistic and unrealistic expectations. Participants’ possible expectations of benefits were attempted clarified, as well as making clear what the study and the researcher can and cannot do. We also talked about ways of avoiding any potential disadvantages for them in participating in the study, like to ensure meeting with me didn’t hinder their other daily activities, like going to work, and that they didn’t have to spend money in order to meet me – in addition to ways of ensuring confidentiality that is described below.

A strong motivation for participating in the study could make the potential participant less attentive to the information given prior to consent (Tangwa, 2009). Adequate and thorough information was given in a clear and simple way, ample time to read was given, or the participant was read the information to. Those who were invited to participate in the study were given information on the whole research process they were asked to be part of. The participants’ roles in the different phases of the process were explained, as was the purpose of the different methods.

Time was assured for the participants to reflect on the invitation, to discuss with someone and have opportunity to ask questions. Adil was first given brief information from the key person (who had read the invitation letter), then from me during our first meeting. He was encouraged to think about it and talk it over with somebody if he wanted to. His partner called me a couple of nights after this, asking me questions that Adil had, particularly on confidentiality issues. However, Lucy, a single mother with two small children and few or no other adults to lean on, did perhaps to a lesser degree feel that she could take the risk of saying no to the invitation, as participating would perhaps in her eyes be an only hope of getting help in one way or another – even if I did inform of my role and what I could not do.

When I met Shan the key person had already explained some about the study, and I went through the invitation letter again with him. After a few questions he stated that he was willing to participate in the study, but I did sense an obligation from his side towards the key person. I therefore made an extra effort to explain/share with him that choosing not to participate would be equally acknowledged, and understood by me.

In the invitation letter, information was specifically given that a participant may withdraw from the study at any time he/she wants to, or chose not to answer questions he/she for any
reason is not comfortable with, without further explanation and without any adverse consequences.

Who will see or are likely to see the study findings important, who will use it and how, how it will be shared with others are all matters that was shared with the participants as part of the process of obtaining voluntary consent. They were informed of how they can see the end result of the study – and I have attempted to contact them again with this in mind.

Some potential participants might, even if they would like to participate in the study, hesitate to sign a document as they considered that to be a major legal binding. In addition, they might be reluctant to give a written consent because of fear that the document will get into wrong hands and make authorities able to trace them. The study did for these reasons open for the alternative of obtaining consent orally.

Participants were compensated for transport, drinks/food and, for one of the participants, use of time in a reasonable manner, balancing avoidance of both exploitation and inducement of people in a vulnerable financial situation. That most participants do not have legal right to work cannot hinder a compensation for their use of time and effort. If compensation is not given, people who otherwise would consent to participate could be excluded because they cannot afford to loose income.

Confidentiality
Interview location was decided together with each participant, depending on where the participant felt comfortable and safe. Both considerations about confidentiality and discomfort about talking about some issues were met this way.

Interpreter was not used in the dialogical interviews or other settings since the majority of participants spoke English, and one also some Norwegian. None of them preferred to use a professional interpreter speaking their native language. One of the participants spoke some English, but wanted the key person to be present in the conversation and to interpret. The confidentiality matter was emphasized in that setting, with the participant present during information.

Personally identifying information was not collected from the participants. However, to be able to conduct repeated interviews and repeated appointments for participant observation, it
was necessary to have a method of getting in contact with them underway. A list with pseudonyms and participants’ phone numbers was kept in a locked file cabinet. My contact information was provided to participants to facilitate communication and continuity in the research process.

Notes were written by hand during interviews, and field notes were written in connection with participant observation, including notes on the environment, setting etc., were done so without names, names of buildings, addresses, names of places or any information that could directly or indirectly identify the person written about. Distortion of personal information was further used to help enhance confidentiality. Pseudonyms that cannot be associated with the participant were used. Notes were kept in a locked cabinet. Electronic material was password protected and restricted to the main researcher (who were conducting the fieldwork). Voice recording was not used as a method.

Dissemination of research results is a sensitive phase regarding confidentiality. The text will be guided by the principle of confidentiality and anonymity, and be attentive to the at all times possibility of recognition by readers. Of special concern in this regard could be citations in the text and information about events. Material that is obviously recognizable and associated with particular persons, and could not be made anonymous, was omitted. Moreover, I have constantly returned to a dilemma I found between the aim of sharing the lived experiences of whole persons who often preferred to share their stories in longer narratives, and the risk of unfolding too much of their personal lives and thoughts, even though the data were made anonymous. The discussion made by Hadjistavropoulos and Smythe (2001) has been of help when making decisions with regards to these dilemmas.
Risks and benefits

Potential risks of participating in the study

Sharing daily activities together with me, or having conversations in cafeterias where one person is taking notes, could cause reinforcement of fear in the participant. In the worst case, the risk of the research situation would draw attention in such a way that police or immigration authorities identified the person, or acquaintances might get to know about a participant’s HIV infection. To avoid exposure of participants to this risk was a major ethical priority. I asked for the participants’ advice and encouraged openness about any comfort or discomfort participants felt about spending time with me. In planning participant observation, as well as interviews, the participants decided the time and place. Confidentiality regarding places, settings, people that could identify the participant was employed. Problems that might arise, situations the participants thought would be difficult or awkward, was as far as this could be foreseen, discussed. Participants were informed that they at any time during the participant observation may chose to end it without that decision having any consequences to them.

I did become aware of participants’ strategies that are lying outside strictly defined legal limits, information that authorities could, if it was made visible, use to control ‘illegal migration’, either on individual or group level. (These strategies were however not deviant from what most Norwegians are accepting of and utilize in their daily lives). Sensitivity was employed to preserve confidentiality, both during data production, writing and dissemination phase. To leave research on the group out because of potentially illegal activities done for surviving would be to leave out the possibility to get to know about the vulnerabilities related to these strategies, like exploitation on the illegal job market. It might be viewed as a dilemma whether participants’ potentially illegal actions and strategies ought to be reported to the police or not. For this study, I find that some aspects of ‘illegality’ and strategies deriving from it must necessarily be considered as inseparable from the study itself, as the very being in the country is by the state considered an illegal act. Reporting such strategies to the police I view as unethical, as it would cause direct harm to the participant in question. The primary obligation of the researcher is towards the participants.
When one of the participants had to leave Norway, I had little means to be other than a passive bystander. Attempts to develop a trusting and respectful relationship with the participants from the beginning, to give clear information about my role beforehand and an open dialogue about the possible scenario was planned in order to prevent that participants were feeling personally left down in a situation that was already potentially traumatic. I could by keeping in contact and showing continued interest, give the participant opportunity to voice his/her experiences and feelings about the deportation. I hope that this contact might, without being therapeutic, have had the potential of bringing some relief of psychological distress in an otherwise difficult situation.

The interviews could cause reopening of wounds in the participant. If there was something the participant beforehand was sure he/she will not talk about, this was respected. I attempted to be personally prepared of emotional distress in the participant, and own reactions to this, as well as preparing for possibly having a personal impact on participants who otherwise may have none to confide in. Interviews with four of the participants were repeated, and participant’s emotional needs and reactions could be followed. Awareness of mixing of the two roles – researcher and nurse- and avoiding to enter into a therapeutic relationship was important to secure that professional help was offered – and to secure the research process - which was a ‘joint venture’. The study prepared for referral of participants to the health services also assisting in recruitment of participants - if this was needed and accepted by, or wanted by participants. Health care that people without legal right of residence can utilize is limited, but the NGO run health center for this group offer consultations with psychologists, among others.

_Potential benefits of the study_

A possible benefit from participating in the study was that participants that were in need of medical attention but had not dared to seek it, could be informed how to, or helped to get in contact with the right places and persons. One of the participants was referred to the clinic for undocumented migrants. Some participants were in need of other assistance. Information about organizations that work with these issues was given as far as I had the information. One of the participants had made an appointment with a lawyer and asked me to go with her the following day, something I could not manage. Instead she asked if I could write a letter with the information she had told me, and I did, viewing the information that came from her as her
property, and the combined interview notes were given to her. She was encouraged to discuss it with the key person that had connected us, or other she trusted, before handing it to the lawyer. Another participant would like to send the stories and thoughts she had shared with me, to UNE. Again, I considered her words, the data, as her property and pulled together the interview notes to a chronological narrative that would be readable. She did present the letter to a person she trusted before she sent it to UNE.

Being shown genuine interest, talking about one’s life, putting words on feelings and thoughts and having a partner to talk about one’s good and bad parts of everyday life with, or have somebody to share time and experiences with, could be perceived as a good experience and to some degree relieve psychological pressure.

By using a non-authoritarian approach where individuals participating in the research are encouraged to take free and active roles, the role of the researcher as one with possibly more power in the research setting will be toned down. Experiences of being treated as an equal could be of special value for the individuals in this study, who otherwise are likely to have met or meet people who both have more power and who use it. Being taken seriously, shown respect and being an equal partner in the interviews in this study could contribute to a minute part of a process of empowerment.

On a group level, by showing life as people living with HIV and without a residence permit see it, information about their lives, possible hardships and their health situation will be known to policy makers and health programmers who could work with the target group to better their living conditions including the health care provided. Learning of and hearing the stories of people in this study could inform migration policy makers and influence to a process of necessary changes.

The society as a whole has the potential of benefit from the study by the increased insights into vulnerabilities and risks related to HIV and being able to live a healthy life. To be able to lay a foundation for a positive public health development with regards to HIV, knowledge and understanding of the health of subgroups in the society, like the target group of this study, is needed.
Weaknesses and strengths

The quality of qualitative research like this study must be judged by other standards than quantitative research. The underlying assumptions of what constitutes knowledge are different, as qualitative research does not assume that there is a fixed truth or a ‘reality that is external to our perception of it’ (Trochim) that can be revealed or discovered, but instead see understandings of phenomena as being constructed by us in a context.

Lincoln and Guba (1985) referred to in Trochim (2006) have suggested the use of alternative terms – credibility, (authenticity), transferability, dependability and confirmability - to establish the quality, or soundness, of qualitative research.

A situation where participants’ true voices are heard can contribute to the credibility of a qualitative research. Nearness to and involvement of the participants, reflections on own positionality, participation, ample time for data generation, attention to context, and to triangulate the methods are all strategies that could increase credibility of the study. To establish the credibility of a qualitative research means also to discuss to what degree the methods chosen were able to meet the research objectives, in this study, to generate understanding of the life worlds of people living with HIV and without a residence permit. I have tried to make the research process transparent, including the dilemmas met and reflections made along the way. Showing explicitly the changes in the setting or context and how it has affected the research is according to Lincoln and Guba a way of increasing dependability of the research. Transferability of the study is attempted ensured by making clear the assumptions the study is based on; give a rich account of the context it is conducted in, and by conceptualizing the data. Transparency is also important with regards to confirmability of qualitative research, where one seeks to establish if others can confirm a study (Trochim, 2006).

I have when describing the different research methods also brought up limitations of the methods and dilemmas met. Discussion on reflexivity and ethical considerations has included the same. In this chapter I will add some other aspects.

A combination of different research methods/strategies is often used in order to draw on the strength of all of them and limit the weaknesses in each of them. In this study, interviewing, participant observation, reading documents and follow relevant news in media gave me
different ways and angles from where to engage with the topic under exploration. Exploring areas of interest with the help of different methods can make more nuances visible, produce new information, bring up other ideas and give a new or deeper understanding.

However, to use different methods, or, if it was chosen, to interview different groups, does not simply mean to view the themes from different angles or standpoints. Situations and contexts are not static, and this was taken into consideration during the data production and analysis. The situation where progression of this study for different reasons was delayed made this consideration obviously highly relevant, but it was also important to have in mind the subtler changes in the participants’ situation and environment from day to day. Rather than with a ‘traditional’ triangulation of the data in mind, the combination of methods was chosen to compliment each other in the process of data generation.

What I in the beginning perceived as the ‘backbone’ and major strength of this research with its participatory method and open approach has in many ways turned out to be a major weakness. Insisting on having each of the participants steer the data generation and bring their areas of emphasis in focus, and my reluctance to leave out some of the lived experiences they shared, may have instead caused each of their voices to drown. Being overwhelmed by the data, together with the nature of the contact with the participants (open approach, the meetings over time, trust) may have made me identify too close with the participants and lowered my ability to analyse and categorize the data. Furthermore, I find that I didn’t give enough room for reflections over what the participants did not say.

The delays in fieldwork and in writing up the thesis are other limitations of the research. In October 2011 I met the first participant, then there was a month’s delay between the next three, and the last two in April and June 2012, respectively. The delays have naturally had consequences for the way the data has been analysed. Meetings with the participants, occasions, and context had to again and again be brought back to ‘life’ from the various notes and the writings already started, and from memory. All that had happened between the many writing sessions of course added to those memories, and some of the first impressions may have become less vivid – even if I do not perceive it that way. The longer time period has thus given a broader context to the data. Another aspect is the amount of time passing without any changes in their residence situation, months and years passing without any major progress.
Detachment from the participants’ immediate context has nevertheless most likely made me miss out on issues and influences of importance to the process of meaning formation. With detachment I mean both in time, space and in situation/position, being an ethnic Norwegian, seemingly well-off with a full time job, conducting a master’s study perhaps seen by some merely in order to maximize meaning in life.

Another weakness of the study was not having repeated interviews with all the participants. With two persons I had only one interview, and the conversations were influenced by a belief that I would meet with them again. I know in the interview with Shan that I wanted to go deeper into some issues that came up, but postponed it to what I thought would be a second interview.

The two persons that didn’t have more than one interview were the two men in the study, so that in the end all those I met with repeated times and developed a more trusting relationship with, were women. The men in the study, particularly Adil did seem to speak openly and freely, the interview went on for a longer time in his home– and we had also met and talked in a cafeteria before. As mentioned before, expecting to have a second interview may create a more relaxed atmosphere in the first one, something that could have compensated some for the one only interview. Nevertheless, the larger part of the data has been produced in the meeting with women in the study.

In addition, since fieldwork extended over eight months, it would perhaps have benefited the study, in that changing context, to have several more interviews with the participants. Not the least it would have increased the quality of the study to meet up in order for them to review and comment on the ongoing analyses, so that the final part of the analysis, and the research, would be done in a joint fashion. This was not possible for several reasons. The approval for ethical clearance was at that time about to expire. And, the participants were busy living, finding strategies in their everyday lives; I didn’t want to impose anything on them if they already had said they would take contact but didn’t; with some I kept contact, but they left the country. My delay in the continued analysis and writing up the thesis made the before mentioned aim of including participants in all the stages of the study not feasible.
Chapter four: Daily life and social relations

Introduction

This and the following chapters will present the research findings together with a discussion of the findings. In the study, I wanted to get a greater understanding of how everyday life manifests itself for people living with HIV and without a residence permit in Norway - how they perceive, experience and act in the situations they find themselves in; that is, how they actually live their lives. Stories circulating in the public might give impressions of people without legal residency as just passive, waiting, and living in hiding, or that they all participate in criminal activity, or are victims of crime. Stories about life with HIV are rare or nearly non-existent (to most people) in the Norwegian society. Through informal talks with participants in the study, and from sharing in small parts of some of the participants’ everyday lives, I have tried to get an insight into 'how their days go' and it has revealed a picture of life as varied and different as perhaps rather should be expected. Their situations are also gradually changing in some aspects, although may be at a stalemate when it comes to their situations in regards to the Norwegian immigration authorities.

The study participants

I start with a short presentation of the six study participants. Individual biographical information is for confidentiality reasons not given, and the men and women in the study are instead here presented as a group. This means that the individual background and particular context of the lived experiences of each of the study participants will be somewhat compromised.

The six persons – in the study named Alma, Adil, Miriam, Hana, Lucy and Shan – who participated in this study are in the age group 25-45 and come from five different Sub-Saharan African countries. They have different backgrounds, including religion, social status, and financial status, educational level, and marital and family status. They also have different background history from their time spent in Norway. Their living situations at the time of the fieldwork also vary.

All four women in this study have children who live with relatives in their home country. Two of the women also have a child or children with them in Norway. One woman is cohabitant
and one is in a long-term relationship with a Norwegian man. One man is gay and in a long-term relationship with a Norwegian man, and one of the participants is a single man with no family in Norway. The women with children live in two separate UDI’s reception centres, and both are without partners. The four other study participants live in private accommodations of varying kind.

All came to Norway several (3-4 to 9-10) years ago as asylum seekers. Their reasons for applying for political asylum are varied and complex. They all got their application for protection denied, and, all of the study participants have appealed UDI’s decision once or twice, and some several times.

The individual study participants had lived with HIV for a different length of time. Most had lived with HIV for 3-6 years, while one man was diagnosed with HIV some months prior to the fieldwork. Four of the participants in the study were diagnosed with HIV while living in Norway; one woman, some months after she arrived, and the three others after they had been several years in Norway. Two of the women came to know about the HIV diagnosis before they left their home countries; one of these women fled her home country a short time after she learnt that she was HIV positive.

Throughout this chapter I will present the research findings through the experiences and perceptions of the individual participants in the study. As pointed out earlier, in order to protect the anonymity of the persons participating in the study, portions of contextualized information have been changed and names used are pseudonyms.

Presenting findings of the study through the voices of the individual participants does not mean that other participants had no attention to the same theme. The study participants have however given different weight to the themes that emerged and are presented in this thesis.
'I run and run’ or ‘Sit and see the medicines expire’

Alma

Alma had at first sounded enthusiastic when I asked her if she thought it ok if I spend some

time with her where she stayed now, she suggested I come to her friend’s place where she

lived at the moment; but let me know about the precautions we would have to make:

We can meet there also, you can come [at my friend’s house]…yes, you just come as a friend, we don’t

say anything, she doesn’t know about my situation, so you just come as a visitor you know and we

spend time together. (Alma)

It didn’t happen that I went to her friend’s house after all; I included this passage here to

illustrate the way things were sometimes going when trying to make appointments for

meeting up with a participant. The precautions she mentioned about being careful not to

reveal the HIV diagnosis were taken in all other settings, but may have caused extra anxiety

regarding a visit to her friend’s apartment. Furthermore, her days were quite busy, and the

best place for her to meet was in town in the cafeteria she used to go to. She also wished to

have activities outside the house, both to keep busy and not ‘be in the way’ where she lived.

Another reason why we didn’t meet as planned seemed to be that she was not staying at that

friend’s house all week; she was starting to spend more time with her boyfriend. During her

years in Norway she had moved from place to place.

She describes the constant search for

somewhere to live:

It is so much stress to not have your place. I have friends and ask them and stay with them, but I can’t

stay for long, they will get tired of me. I stay some time at a friend’s place and then I have to move. It is

going like that all the time. (Alma)

She is constantly thinking of how to stop those she lives with getting fed up with her and of

how she can manage to preserve a friendship where she is seen as an equal, and not just as

someone that needs help. When she is staying with friends, even though they are nice, she

must get used to never being alone. Taking medicines is also difficult when she has no

privacy. Meanwhile, it is hard for her to accept that she is dependent on others when for

several years she worked, paid taxes and rented her own place to live in Norway. For short

periods, she can stay at the HIV support centre where it is neutral; she can relax a little, and be

by herself. She keeps documents relating to her health at the support centre regardless of

where she spends the night; she won’t risk friends or others finding the papers or losing them.
Other possessions also generate logistical problems when not having your own place. When I met Alma the second time, she was staying in a room at the support centre, talking about the suitcase that was standing on the middle of the floor:

I left the (...) box at a friend’s place and I have my winter clothes in that. I leave the box sometimes here and sometimes I ask a friend but it is not so easy to ask all the time. And summer clothes I also keep because one time I cast them and when the summer came I don’t have clothes, and then you have to take care of… I have to support my two children in Africa, I have to pay the school fees and their clothes, and food. (Alma)

Her life in Norway and the daily lives of the children where they live with Alma's family in their home country are entwined, she talks of the children’s road to school and the details of their whereabouts. In many ways Alma spends her time not just in the Oslo area, but also in her home country where the children live. Her thoughts, choices and actions in everyday life in Norway are closely linked to the lives of her children at home, and their future. She guides them over phone, resolves arguments between them and laugh of things they all know well. Problems she encounters here will quickly have consequences for her children – whether it is minor consequences, to more significant ones, such as difficulty in paying school fees. Managing to look after her children in a good way, providing them with a decent education and thus a better chance in life than she had – this is her highest priority. Managing her own life here and having responsibilities in her home country, there are many things she should have liked to attend to, and she feels really busy one day I meet her:

‘I run and run, I don’t know what I’m running to or from, it’s not that I have so many appointments, don’t know to what I’m running really!’ (Alma)

Although she doesn’t have many appointments, she - and other participants - are busy with a multitude of things that need to be taken care of. The busyness is linked to having to get by here and now – for some trying to find a safe place to stay for a while, move again, find ways to get money, a job and how to get to work - spend time with a partner, or with friends or new acquaintances - all important things if they want to eat, use the bus or metro without concern, replace clothes as needed, pay for the doctor and for medicine. Alma and others who have children in their home country expect of themselves, and are expected especially by those looking after their children in their home country, to send money back regularly, which naturally increases the pressure and extra stress of everyday life. In
addition, there is the worry and the need for extra income and the means to be able to take action against UNE. Collection of arguments and evidence in a possible future case against immigration services is a job in itself.

Even without being responsible for children, the participants daily feel considerable pressure in terms of being able to support themselves. Having a roof over ones head, but not being able to contribute to this and being at the mercy and dependent on ones partner for most things also increases the wish for and felt pressure to look for a job.

Those who live with their friends or with acquaintances, like Alma, constantly makes precautions to prevent them finding out about their HIV status, in addition to making sure that whoever they are living with doesn’t get tired of them.

Furthermore, Alma sometimes stays with an acquaintance and helps with child care, but often feels she is being treated less favourably than she would be if she had not been in the situation that she’s in, without a work permit and her own place to stay. She looks after the child even when she does not live with them, and Alma talks upset about a recent incident when she got up at six o'clock, travelled across the city, waited outside until eight o'clock before she rang the doorbell at just the right time - all in vain. Why doesn’t this woman take the trouble to tell Alma in advance the days that she doesn’t have to come? It feels harsh and a waste of her time. She does not know if she will get paid for child minding as they had agreed. She is unable to get respect for her time being important, too. She does not have that job anymore – she will try to get a private cleaning job and has made a notice that she will hang up in different places. She needs extra money for expenses for her children in her home country. She does have one cleaning job already; she is smiling, telling that this guy has given her the key to the apartment so she can do the cleaning job they have agreed to whenever it’s convenient for her. Even though it’s just a few hours of a cleaning job, to Alma the arrangement, or rather the form of it, means more than income and a job to go to, it also means that she’s respected and valued.

For the same reasons that they are busy, participants also think and worry a lot, and they do wait a lot. While much of the worrying for some is part of the running and trying to find the next step towards a solution, other times the worrying and waiting takes place indoors, and for some alone. Miriam says she can’t do anything but ‘sit and see the medicines expire’,
referring to the one thing she is entitled to in Norway and the time that passes, as well as the
meaninglessness the situation entails. Despite her days of feeling busy, Alma too says that the
days without content and meaning makes her tired of being:

To be bored, is like confusion, depressed. The whole day you don’t have anything to do, keep thinking
about that you are tired of being. Just staying, just sitting, doing nothing. I start looking then… I try to
meet my friends, we meet here and there, here and there. The more you are doing nothing, the more you
lose. You need more to do so you can keep your life on…(.) With my friends I am not bored.
Sometimes I forget all my problems. (Alma)

Alma and I usually met and spent time in a cafeteria, sometimes with her other friends,
instead of meeting at the friend’s mentioned above – and in some ways this cafeteria was
more like a home to her than any other place; a place she felt comfortable. She spends a lot of
time there, she likes the crowd, but also because she feels lonely and restless when she’s by
herself. Usually she agrees to meet friends at this what has become her regular café, but she
can also sit there alone and wait for someone familiar to turn up. Having people around helps,
especially friends, but to be in the midst of the crowd of strangers hasting back and is also
comforting.

To have a partner and cohabitant in Norway has made it easier for some, especially when it
comes to having a more stable place to live – however again they think a lot about being
dependent on the other person and not being able to contribute to rent, food and other
expenses on an equal basis as the partner. Almas search for a job and income is both focused
on supporting her children, and on being independent here in Norway. She express that she is
busier and has more obligations now that she has a boyfriend - she wants to help him and
spend time with him, but also wants to keep working to earn money. She started to do
housecleaning at different places, earning 100 kroners per hours. She might clean for about
four hours at one place in the morning and four hours in the afternoon; other times just a
bathroom. She also works preparing food for various events – jobs she has gotten through her
social network. At her boyfriend’s place she keeps tidying up and cleaning the house,
something he generally protests about and says she does too much of, tells her that she is not
his servant. Some participants had besides health care and social workers had no contact with
Norwegians before entering into a relationship with one, and some still didn’t have much
contact with one. A boyfriend or girlfriend brings other people, activities and places into the
lives of the study participants. With a Norwegian boyfriend Alma’s life has gradually grown into being part of the lives of her boyfriend’s family, and she is getting familiar with and developing a sense of belonging to the same places as he does. They travel by train in Norway, meet old friends of his or cook dinner with his parents. She takes part in his hobbies, and he visits her when she cooks for an event, when he has to go away, they talk every night on the phone.

Both Alma and Miriam are surprised that they could even travel abroad by the ferry – and treasures the bankcard they once got – an ID.

I was lucky and got that a long time ago…(…).it’s so precious to me, like my friend. I’m so afraid to lose it, it helps me so much, I haven’t any problems with the bank. (Alma)

Miriam also tells how she got lucky and accidentally was offered the opportunity to open a bank account once. She lived in a reception centre and regularly went to the bank to withdraw the money she received for subsistence from UDI, one day she was asked if she wanted to save some of the money, and that’s how she got an account and a bankcard.

The doors that are closing… You know, it takes time to find good things. Bad things, they are here, there, everywhere! Then suddenly, like with the bank card, something so good happened, I thanked God. Now I’m afraid to show the bank ID card, I look at the person, I have to be careful, before I show it. They might take it. With the asylum ID card you cannot do anything, only to show the police. And now if I show it they will take it and find out. (Miriam)

She says actually you must have legal residency to get a bankcards - that was the information they were given at the reception centre, but she is not quite sure, maybe you can get it in savings banks - or perhaps you can only open an account, but not get a bankcard. It all seems a bit uncertain and arbitrary. ‘I don’t know, I’m lucky sometimes’ is Miriam’s comment to this and other ‘privileges’ she says she’s not supposed to have, but that nevertheless were given to her, by a mistake or by coincidence or because people, gate keepers choose to interpret the rules in their own way.

‘Always I have to stay here’

Adil
Adil’s experience from his home country is that he cannot move around freely there - he can definitely not walk along the street. In Norway he also experiences having limited mobility, freedom.

One thing is the letter he received from UNE that says: ‘The decision is sent to the National Police Immigration Service for monitoring. Reference is made to the previously determined deadline for leaving. Permission is not given to stay in the country while the request for commutation is evaluated. The complainant is thus residing illegally in the country. Previous decisions can be effected without further warning’ (my translation), which in itself is a clear message that he does not have permission to stay in the country - cannot be anywhere in the country - as is also the case in his home country. It means that he cannot do anything in this country without there always being an imminent danger of being discovered and thus sent out of the country. Daily activities are naturally affected by this limited freedom.

He says: ‘Always I have to stay here, I cannot go anywhere’. To live a good life, participate in life - he longs for it. However, he can’t go anywhere, not even within Norway. Planes, trains, buses, everywhere they can ask to see his ID. Again, he can’t do anything, just be in the apartment. Social activities, go out on the town, to a nightclub? They ask him about the ID that he doesn’t have, he is denied entry, and he knows they will threaten to call the police if he doesn’t leave the place. In addition to the fear, such incidents make him embarrassed in addition to stressing all that’s missing and all the barriers in his life.

What he has, he says, is to wake up in the morning and go to work five days a week. He has no chance to do anything else, so what he can do, and what he does, is to show others that he can work. And, make money and share the rent. He says the only thing he needs help with is getting papers - he needs an ID card so that he can get some rest and not be so stressed and nervous.

Also Adil has spent a lot of time thinking about needing help from others and finding ways to get away from a situation where he is dependent on such help. After a long time he got that job; now he has colleagues who talk about things they have bought and places they’ve been: the inadequacy persists even though he can now contribute to expenses that he and his partner have.
...all your friends have things, you cannot get respect you know if you always need help. I do what I can to survive. Before I did not have anything. So I found a job. But always you are scared, I’m so scared you know, even on the bus early in the morning, and I’m so afraid of control. (Adil)

Although he now has a job, he has a constant fear of losing the job he’s managed to get. He is aware that other employers have sacked people for fear of themselves being penalized and for that reason he is constantly unsure whether he will keep his job. In addition comes the fear of being discovered by the police either when they are looking for 'people like him' at workplaces or, for example, through a ticket inspection on the bus. He is certain that because he doesn’t have identification to show on the bus, the police will be warned. Moving about, taking the bus or being at work might mean a greater risk of being caught. Alma was terrified by the ticket inspectors on the subway recently, she had no ticket, and says she couldn’t find her wallet, they agreed to give her a fine without seeing her ID, she had cried, it was her birthday, she felt devastated, but ends the story by saying ‘let them see the realities the way they are’ and that after all the ticket inspector had been ‘nice’ to her.

Some try to take precautions to avoid being caught by the police to the extent that they can, but it is the idea of it and the imminent possibility of it that creates stress in their day-to-day lives. The constant worry that characterizes the lives of irregular migrants has been described in Hjelde’s study [1]. Adil does worry all the time, of being caught, about the process in UNE, of the future uncertainties and about his health, and death, after he learned that he has HIV. He and his partner tell about how they spend time finding places to get medical care for Adil; he had for example recently had dental problems that needed urgent treatment, they contacted many different dentists, but none of them would give him an appointment. He no longer has a D-number; this is presumably the reason why. This time it ended with help from his boyfriend’s dentist. This dentist knows Adil’s partner well and decided to treat Adil although she will not be refunded any of the costs of the treatment from NAV. The arbitrariness related to whether people living with HIV receive health care beyond that covered by the Infectious Diseases Act, caused Adil and his boyfriend to in vain search the city for a dentist for Adil. In addition to the pain and the worry for his teeth, another fear is that the dentist will contact authorities if a bill is not paid. Adil shows an old letter with a D-number and says ‘It's not working anymore’.

No one to rely on
Lucy

Lucy lives in a reception centre where she shares an apartment with two other women and one older child. They do not speak the same language as Lucy, and she seems to have little contact with them. She has a small room of 6-7 m² for herself and the children, and a shared kitchen, living room and bathroom. We sit on her bed in the small room one day while her children take a daytime nap. She shows the medicines she is taking and the papers from UDI. For Lucy, apart from her worries about her health and for her and her children’s future, most of her daily life revolves around the two small children. They are under school age and spend most of their time with her; Lucy says they exhaust her. Especially the younger is quite active, wanting things to happen or Lucy’s attention most of the time (probably not less when Lucy has company). Like most kids they get cranky when little happens the whole day, they also often wake up at night. Sometimes she takes the children to an open kindergarten when she feels able to - and the oldest child occasionally go to a friend’s from kindergarten. When the weather is good, and when she feels up to it, she loves to take a walk along the river. We take this walk when we go to town one day, the kids sitting in a stroller. She meets an acquaintance in town, exchanges a few words, and tells me she knows a few people from her stay at another camp. She has no close friends that she sees on a regular basis now. Staff at the HIV support centre has been an important source of support for her, and still is in a way, however now it’s difficult to go there. She also had to change to another infection clinic so she has only a superficial relation to the new doctor and staff at the clinic. Lucy worries a lot about what would happen if she became ill. She is tired much of the time and often feels unwell, has a headache and describes herself as depressed. Several times she has needed medical attention - how she will get the help she considers random and it makes her feel unsafe. The camp office is a distance away, and even if she contacts the office staff, how they will respond to her needs, she finds unpredictable. She worries about the situation today and in the future, especially for the children's sake, meanwhile it’s the children who give her pleasure in life. How to find ways so she can get send a new petition for reversal to UNE is also a major concern for her - and she has previously tried unsuccessfully to get help from various organisations, says not speaking Norwegian is the reason why she was turned down at one such office. She now has very few contacts and little time to herself, and no money to pay a lawyer. She also has little extra energy for a process that requires much effort. After we
have met a few times, she mentions that the children’s father lived in Norway previously and is now back, but lives 'underground', he comes and sees the children only occasionally. He seems to take very little part of her life, and thoughts, now. She doesn’t talk much about him, says she no longer sees a future for them together, the way things are. She feels alone here - with no one to rely on - and knows it will be the same if she deported. She waits and is always scared that the police will come. Living in a camp means it’s easier for the police to forcibly deport someone, being alone with children she sees no means of managing a life outside a camp - like having to move from place to place, and being without financial support from UDI.

Being without acute illness could also mean a heightened risk of being deported. The fact that time passes after the deportation deadline does give her a sliver of hope for something else.

They pick up people, you know, when they’ve been okay. (…) they knock on my door and say here you go, you have to leave now. Weeks are passing, though. (Lucy)

Building a home
Hana

Hana also lives at a reception centre, where I go to meet her. Here she and her daughter have a small room with space for a bed along each wall, a small fridge and a kettle. She has decorated the room with posters and carpets and has plenty of ornaments from thrift shops and flea markets around- some things were gifts from ‘local people’ she got to know - so it's an expressive and personal room, where each thing has its own place even though there are many things in a little room. When I’m there, people keep knocking at her door; some to say hi, one friend comes in for coffee. Hana bakes traditional bread from home and sells it - someone comes and knocks on the door to see if she has baked something. Others call her up or knock to see if she got a hold of things they are short of when she was in town. She works voluntarily as a ‘warden’ at the reception centre, cleans at the centre as everybody who lives there must - and also does other’s cleaning duty for payment. She travels to the city; the journey is costly for her, so to manage it she plans several activities, such as being with
friends after church, maybe visit the HIV support centre, and sometimes runs errands for others since she’s in town anyway.

In the camp there are others with a ‘final negative’ as well; they are usually open with each other about their case’ standing in UDI/UNE, but don’t go into details about the reasons for the decline or the appeal. However, even if among asylum seekers having ‘a negative’ is not directly shameful, it does divide people, as some are moving on, get a work permit, start introduction programme, school, or even settle in a ‘commune’, while Hana and others are constantly being reminded of lost opportunities and being different than others.

She works to overturn the case, obtain documents, writes letters to the UNE. She has no money to pay a lawyer, but asks for and receives help in writing letters from a contact person at the reception centre and from the support centre for people who are HIV-positive, collects documentation e.g. for access in her home country to the HIV medicines she uses, as well as from the kinder garden regarding her daughter. She keeps an eye on her daughter, has for long periods sat and waited the whole day in the kinder garden in case she needed her, at other times has been at home with her when she wouldn’t go there, and she goes to various meetings; everything she does is for her daughter.

Anyway she sometimes sleeps all day; after she has brought her daughter to kinder garden she just goes back to bed and stays there until her daughter comes home. She thinks that generally UDI takes too much time - it provides too many years to think, so that people can go crazy from it, just eat sleep eat for many years, she wonders how you can be able to benefit from a positive answer in the end, how you can manage to work? She says she is just waiting now. Her deportation deadline was two years ago, but she has appealed. They asked for documentation on appeal, but at the same time took money from her because she had not left before the deadline. Now she has 1,800 for herself and 2,200 for her daughter, it has to cover food, transportation, clothing, doctor, and medicines -everything except Hana’s HIV medication. She says her daughter needs a lot, and Hana herself was feeling unwell in other ways. Nowadays her daughter is watching TV where the ‘asylum children’ are in the news, she watches it time and time again, and it worries Hana. However, she says she would rather not worry; she will live in the present and be grateful for the things that are going well.

If you eat your lunch, don’t think about dinner…I like to be happy. Because life can change every two hours, or in a second. I say thank you…because I can sleep.
She feels she is able to have a proper job and do a lot - if she had the chance. She had a job for just a short time in Norway until she could no longer have a tax card.

She also has a child in her home country, living with her mother. The responsibility for children in her home country she has in common with the other women in this study. The family’ expectations of being supported by those who have left is considerable; as are the mothers’ expectations of themselves. Hana says nobody in her home country can understand what life is like in Norway and that it can be difficult financially. The key person suggests that if you’re HIV-positive then you’re extra careful to buy things or to send money to the family, as if to show that you’re strong - and that you’re not dead. You sacrifice even more, often living miserably yourself, to fulfil their expectations and not expose yourself to criticism or disapproval. Some of the mothers participating in this study have nevertheless resigned and no longer see any possibilities of fulfilling such expectations.

‘I have two families now’

_Miriam_

While Miriam and I were talking in a cafeteria, she got a text message from her partner’s mother - can Miriam buy something for grandmother that she’s visiting later today? Miriam laughs a little and says all the Norwegians are busy with Christmas now, and it’s good for her to do stuff like that. She often goes and visit her partner’s grandmother in the nursing home. She feels close to her and likes to be with her. However, she has just found out that she is not safe there, either:

> Yesterday I met in the nursing home this woman. She was asking ‘where do you know this woman? How long did you know her? Does she live with you? Where do you live? Do you have work? How long did you stay in Norway?’ I must answer her, I must do this. I was full of fear. Did I do something…will she call the police… (Miriam)

Miriam was scared by all these questions, and still feels scared - the woman who asked her behaved like the police. At the same time she feels that it is disrespectful that a stranger meddles like that, both because her grandmother would have said something if she didn’t
know Miriam, and because - what right does this woman have to interrogate Miriam in that way?

She, or rather her partner’s family, is active, working to overturn the decision in UNE. They have written to UNE about how much Miriam means to them, that she is part of the family. She has a lawyer who said that as long as she has a case being handled by UNE she can stay in the country, but she’s not sure, she has a deportation order – and later received an expulsion order. Now she is just waiting and waiting, 'killing time' and says it causes problems, both physical and mental, and between her and her partner, too. She is engaged in a campaign for people without legal residency, however her cohabitant wants her to be at home, doesn’t want her to go out much, wonders where she's going and who she’s going to be with. She cooks for him before she goes out, explains that she has work that must be done. Lately she has taken him along - to events for undocumented migrants, or as she’s looking for work or doing political work, and he is starting to understand more about her situation and who she is as the months are passing. It is not easy for him, either, she says, to always be there, to help and show that he appreciates her as he does when so much in her life is uncertain. He wants them to do things together, wants to take walks, travel, take trips abroad. Norwegian culture, says Miriam with a smile and continues to say that he waits for her, as she watches TV, reads the internet or the newspaper.

I’m watching TV. I’m thinking again, and again and again the same thing, the same circles. I can’t solve it, there is no solution. I have no plans. He is waiting for me. And I watch TV. (Miriam)

I have no plan for something. I don’t know about the morning. Maybe I will have to go, maybe police come. My life is like a car without steering. I go, but I don’t know where. Maybe I crash (…) Die. Nine years without nothing. Just waiting for something. Waiting, waiting…to decide something, you need something. (Miriam)

She explains that she and other women who come here alone, lose everything, they just sit and cry, miss out on everything, even their children growing up. But, she is glad that at least she has a family. She has children, and now also a partner, and a new family. Even so, her life is at the mercy of others:

Still your life is with the others, you’re just waiting for the other hand to decide. Like in Africa. Sitting and thinking. They can say you, yes you, you can live here. Or no, you must go. (Miriam)
She sees that life in Norway has both its good and bad sides. There is freedom here, she can see that others have freedom - and that she does too, to a certain extent. You are free to fulfil your needs, like making sure you don’t go hungry by working harder, in one way or another. However, you can’t get your rights, you are prevented and stopped. If you want to express your feelings and convictions, then you have to write, or meet a group but you are still without rights.

Maybe the world don’t need me. Maybe I’ve no place here. I don’t have control over anything in life. …(…)..No..I just try to find solutions. Human beings try to find solutions. He does everything what he can. But it’s beyond him. (Miriam)

To change my life, I have no chance. I tried everything. In (home country), here. School. I don’t want to sit and wait for something, like an animal. I didn’t take anything from social welfare or anything else for free. Just I worked myself. (Miriam)

She says it hurts any human not to be able to follow their own natural decisions. She would have wanted to live a full life in her home country, but was denied one - and says the same is happening to her in Norway–she has no control over anything in her life here. She says, ‘home is home, you know everything’, and you don’t just leave it. In the cities there are many opportunities. She once had a good job in her home country, a job she was good at. That was before she got married, before her husband was killed and before she had to escape. Lack of work was not why she left her home country; it is when the problems become so big that they are more important than whether your needs are covered that you have no choice but to leave. UDI says she is not alone and has help there - they do not understand that she’s the one who must help her family, and that it is impossible in the situation she’s in now.

Miriam has several things she's involved in. She lives with a Norwegian man, has good contact with his family and they often spend time together. She keeps contact with her children and other family members in her home country. She is engaged in politics and takes part in events for and with irregular migrants, and joins seminars for people living with HIV. The activities do not seem to change her feeling of not having anything meaningful to do, and that life and opportunity are passing her by. She keeps cooking dinner for herself and her cohabitant –says smilingly that he’s ‘just like an African man!’ When it comes to helping economically, she seems resigned, she recognises that she 'eats from his hand', but can’t do
anything about it. She has lived in Norway for many years and knows the limitations imposed on her. She worked for five years before they stopped issuing her a tax card. If she were to have money now, then she would have to think about the children at home.

After living two years at the reception centre in a small community - where it wasn’t possible to find work, she decided to move to Oslo - lived at a boarding house - she had a work permit and got a job as a cleaner. She did a course in cleaning work but lost her work permit and was scared to register and take the practical exam - scared because it would surely be registered with the authorities so that UDI and the police could find out, both where she was and that she was working without a work permit. Even so, she studied a lot by herself. Her boss liked her well, and even wrote to UDI for her. Regardless, she lost the job; she didn’t have a tax card and the employer became aware of her situation. The work permit was valid ‘until the case has been processed’ and expired when she got the second deadline for departure. All the years she worked in Norway, she never delivered a doctor’s note even when she had one. Now she spends most of her time at home, browses the Internet, watches YouTube, reads news from her home country - and the news on NRK. She thinks she should get to know the country she lives in, wants to be a 'good citizen', doesn’t want to ask for help, be a 'burden', but wants to work and help herself. She also doesn’t like to ask her partner for money. Previously she earned 15,000 kroners per month, so she had enough, now since she lost her job, it’s been quite normal that she can’t afford to eat anything. She finds it strange, paradoxical - almost unnatural - to stay in Norway and have to go hungry?

She has to walk a lot because she can’t travel by bus and metro, at least can’t afford to buy a ticket. When she got caught in a ticket inspection and was fined, she truthfully explained that she didn’t have money, the inspector said 'you can’t say that, you have to pay'. She repeated that she didn’t have any money. When he insisted that she had to take the fine, she said that she could take it, but that the money didn’t exist. She wasn’t anxious that the inspector would contact the police, like Adil and others in this study. Miriam acts in many ways like a person who is resigned to defeat or can’t bear to fight any more and only observes, records, examples of ‘being outside’. She says she has tried so much.

No, this is not my life. I had hope when I came here, I thought I can continue education, get a job, build a good life. But everything close. This way and this way, every way close…so dark, so I decided to end
my life, everything so darker. Only thinking of my children…who will they have in the world? I have that responsibility. (Miriam)

The days go by, the years go by and so much has happened; she never thought she would be away from the children for that long. Sometimes she doubts herself, whether she is a bad mother, asking herself how she could leave them. She knows why she left and that she saw no other way, but at the same time thinks that she’s the one who’s responsible, it was her who actually left them, 'abandoned them'. She also says that 'we sit in Africa and think that this [Europe, Norway] is heaven and we don’t have any choice but to go. But for a woman to leave her children, you don’t do that just to get a better life. She and the children lived with her mother-in-law who ran a business, and they had no financial problems. There are other problems that make women flee, both political and in the family, she says. Now it’s rape that is everywhere in the news in Norway, Miriam met other women living ‘without documents’ recently - and it dawned on her that if she as an illegal resident in this country, was raped in Slottsparken, then she couldn’t go to the police. If she reported it, it would mean that she had to say where she lives, show some ID, so that then she’d also be exposed as a criminal, illegal - and deported. ‘You just have to go home and shut up. Even if you managed to catch the attacker, you can’t call the police if you’re illegal’, she says and compares it to her home country where security guards do what they want and authorities don’t believe the women that are raped. Often a guard came to her, she was powerless, had to do it, only then would he leave her alone, that was the important thing at the time: to be left alone again.

So it’s just like in (district in home country). We have no rights. This is a problem. Specially for women, they always have to be afraid of this, the violence and the power. (Miriam)

She keeps on going because of the children, even though she doesn’t live with them. She talks to them on the phone occasionally. Thinks of ways of meeting them, in a third country, perhaps - but she has no travel documents - and has received a decision that she is expelled, not only from Norway but from Europe, from the Schengen - because, as she says, she worked without a permit and stayed in Norway after her deportation date, that is, illegally. She gives the impression that it doesn’t entirely concern her. It's been so many years, and by now, she is past the time when disappointment, no matter how significant, really affected her? She gives the impression that she has no choice, and if she had, it wouldn’t be possible to decide.
Now I have a family here as well. It’s not easy. (Miriam)

From advertisements boards and taxi roofs around town the question ‘Do you need a ride home, or is somebody picking you up?’ is addressed to people without a residence authorization in Norway. IOM’s return campaign, commissioned by UDI, is meant to increase the motivation of people to return to their home country. In Miriam’s case, the text seems paradoxical as she in fact already has been ‘picked up’ and has a home in Norway too. The campaign also mirrors the importance and meaning of social relations in Norway for both wanting to and being able to stay rather than leave. People who are in a relationship with a Norwegian or are close to somebody who can give assistance may have a greater chance of trying their case again as well as managing their daily life at home in Norway, however the result of these approaches towards UNE had for none of the study participants so far been positive.

Where to go from here

Shan

I met Shan only once, when we were at the HIV support centre, and the key person, was present. From the talk we had together I understood that he had withdrawn to himself after he was diagnosed with HIV some months ago. At first, he didn’t think of meeting anybody again, ever. The key person was one of the few persons he after some time had allowed into his life, at least occasionally; weeks could pass without any contact. Shan is somehow hesitant about many of the issues we talk about, as he is hesitant and unsure of the larger question of what direction his life will take. Shan felt already before the diagnosis that life was extremely hard:

If you meet people, one without residence, and some with a different problem… he without residence? He will understand all the others. (Shan)

Living with HIV makes life in irregular exile even harder. He has been in Norway for several years and has worked, says he is still strong and could probably now do the same kind of heavy work he used to, but again seems hesitant about it. He’s been away from that work for some time, since he got the HIV diagnosis. During his years in Norway there has often been times between jobs when he didn’t have any money. To have a safe place to live was already a concern; living with HIV and taking HIV medicines gives him more reason for worry. He
has moved several times before, usually living together with other people. A major concern now is how to share a place with someone without them finding out about the HIV infection - if they come to know, he will have to leave. At the moment he shares with only one other person, they exchange some words, but Shan tries to avoid much contact, he is constantly thinking of the risk of being ‘caught’ as an HIV-positive person. He feels a pressing need for security and stability in his life now that he is living with HIV and sees life as a ‘regular’ irregular migrant as no longer possible. He wonders if he after all should return to his home country, but cannot think of any way that he would be able to afford medicines and stay healthy. He sees no future, neither in Norway nor in his home country. As he tries to find out which way to turn he wonders if life is possible at all.

**Discussion**

Let me first point out that, since the men and women who took part in this research are often referred to as *ulovlige innvandrere* (illegal immigrants), there is very little illegality or criminality that characterizes their lived lives in the Oslo area. I do not have any information to suggest that any of them engage in anything that would be considered serious illegal or criminal behaviour by most Norwegians. The illegal label is thus linked only to their residence status.

How and why they became ‘illegal immigrants’ was moreover not always very clear or easy to pinpoint. They all came to Norway as part of a completely legitimate and celebrated asylum mechanism intended to protect people who has reason to fear persecution or who face a risk of inhumane or degrading treatment if returning to their home country (as described earlier in this thesis). Their status as welcome had later been revoked by a letter, words on paper, but although it was in some way clear what it meant, that clarity had been lost in other bureaucratic processes. They had had the right to stay in the country while waiting for their appeals to be decided, they had continued to receive financial support for their children despite the letter that had told that they were not in Norway legally, and they had continued to receive letters from the authorities despite having been told they should leave.

At the core, they had come to Norway after life experiences that had made it clear to them that they would have to try life in another place. In most of the instances, it is easy to see that a person like me would have done the same, and my guess is that most Norwegians would also have done the same. While there was often a dramatic experience at the core of the decision to
leave, this had been mixed with several other kinds of motivations. All the study participants are whole human beings, and in real life there is seldom one single reason that shapes our decisions and actions. Experiencing that your husband is killed and yourself threatened does not exclude the wish and need to earn some money to support children to go to school, or the longing for new opportunities. In these respects, these men and women are very much alike the mainstream citizens of the Oslo area that I know.

As will be the case for most men and women who are categorised as illegal immigrants, they had been in Norway for an extended period. It lies in the nature of the asylum process that it takes time, often many years when going through appeals and trying to overturn the first decision. In this study, the participants had stayed for between 3 and 10 years; which amounts to a significant share of their adult lives for people in their twenties and thirties. Some had stayed away for most of their children’s lives.

A striking characteristic of the social lives of the people in this study is the stark contrasts in the way time and pace is experienced. On the one hand, time is slow because there are so many limitations. The waiting for a response from UNE is experienced as endless, and the limits people experience in terms of what they can do and where they can move can render days long and eventless, rendering the experience of time as very slow. They cannot travel freely or without worries, or go out at to a nightclub without risk. On the other hand, the pace is at the same time often high due to all the things these men and women must organise and take care of. They may move houses at short intervals, have to struggle to make ends meet and contribute to the financial situation at home, and they have to collect arguments and documents that are needed in their on-going dealing with the authorities. Moreover, there is also no opportunity to really rest. There are always a large number of worries to deal with: can I be detected if I take the bus, can a person I meet when visiting someone in a nursing home lead to problems with the police, could the dentist inadvertently bring me into trouble through the documentation that follows in connection with payment and registration, and moreover, can I be revealed as a person living with HIV. The instability of living in a suitcase, not having a place to call home, removes some common ways in which other people seek rest and reassurance in daily life. Nonetheless, those who were cohabiting and had a ‘regular Norwegian home’ to go to, felt that this home could not protect them and that they were in danger of being caught, and rather went out of the house to feel safer. Kjærre (H. A.
Kjærre, 2010) uses the concept of illegalised landscapes to describe the areas of town that illegalised migrants in his study considered high-risk of running into police, being exposed to authorities – and to the fear and shame they associated with living here without authorisation. To sum up, the participants did have a constant feeling of leading an erratic, disrupted life - regardless of any relative stability of having a job or a cohabitant over time. Most also had much time for themselves, with worries, fear, waiting and restlessness.

In the context of Norwegian expenses and costs all of the study participants have very little economic resources, or in Bourdieu’s terms, very little economic capital. The foundations of social life are according to Bourdieu formed by different forms of capital, where the capital possessed is decisive for what position a person holds within the social order. Capital exists in Bourdieu’s view in three basic forms – economic, cultural and social capital (Bourdieu, 1986). Economic capital encompasses all forms of economic resources that is’ immediately and directly convertible into money and may be institutionalized in the forms of property rights’ (Bourdieu, 1986, p. 243), i.e. capital that can give economic gain in the form of money, property etc. Some of the study participants are receiving support from UDI, some are doing low-paid jobs, and some are receiving support from their lovers and partners. The cost of housing and food normally more than exhausts the income level, but some of the study participants nonetheless were making contributions to their family in the home country as well, although they didn’t manage to do this regularly, and the size of the contribution varied. They had responsibilities for children there, their schooling, and for the needs of family members.

They had limited cultural capital as well in the context of Norwegian society, often wanting in language skills, knowledge of Norwegian culture, and education. The study participants were not brought up in Norway and had not acquired the habits and the cultural codes of the Norwegian, i.e. the dominating culture. Bourdieu’s concept of cultural capital implies that accumulated cultural knowledge will give an advantage in form of power and status within the system of exchange that all social relations entails (Harker, 1990). In this study, one of the participants with a higher education from her home country takes part in political and cultural events in Norway. However, she expresses exactly that living away from home where one knows everything, is not something one chooses willingly; everything becomes harder when you live in exile and don’t know the codes and ‘language’ of how to behave and interpret what is going on around you. The participants had no entry into formal arenas where one
could think that cultural capital over the years could be gained. Some had done work-related training and coursework, but fear of exposing their ‘illegality’ and reminding the authorities of their existence caused them not to take exam or get certificates.

Bourdieu defines social capital as ‘the aggregate of the resources, actual or virtual, that accrue to an individual or a group by virtue of possessing a durable network of more or less institutionalized relationships of mutual acquaintance and recognition’ (Bourdieu, 1986, p. 248) social capital is created and accumulated by the social obligations within the networks one belongs to, and the networks - family, friends, school, work, organisations - can be mobilised when one wishes to achieve something.

The social capital that study participants possessed varied. All had started in a situation where they had no social networks to lean on. Some were mostly dependent on networks existing between immigrants, such as Hana who lived in the reception centre still after many years and made an extra income through selling home-baked traditional bread from the home country. Others had grown into social networks associated with politics and HIV-related grassroots activism, but the latter was felt as unavailable arenas for most of the study participants because they were worried exposing their HIV positivity might bring troubles. Some had stories of having to move from friend to friend so as to not exhaust the relationship. Three of the study participants had Norwegian partners through whom they had entered into networks that were of significant purpose. It provided a sense of social belonging and support in connection with the immigration process, and also access to basic material values.

Bourdieu’s concept of symbolic capital entails that any of the three basic forms of capital are, when given a symbolic value, transformed into symbolic capital. What creates symbolic capital is that the agents involved perceive and ascribe an added value to the capital, and that it is ‘unrecognised as capital and recognized as legitimate competence’ (Bourdieu, 1986, p. 245). The study participants had limited amounts of symbolic capital, but the ways in which some of the study participants were symbolically valued in the Norwegian context was often as partners and lovers. In various ways, they were appreciated and loved as partners, perhaps romantically and erotically, as a good or devoted wife, as a person taking care of household chores, or as a cherished member of the extended family. Being a hard worker or a good employee could also give recognition, honour or prestige and increase symbolic capital for the study participants. In this way they could accumulate symbolic capital in some social spaces,
while on other arenas they had no position or function that appeared to be valued. Capital recognized in one social field is not valued symbolically in the same way by other agents in other fields, and in a context of illegality the symbolic capital accumulated could often not be converted into other resources. Having a recognised position in a social or cultural event would not increase possibilities of getting a job where the same qualifications or personal qualities was sought after, or of getting a paid job at all. Perceptions and experiences of illegality in everyday life are however changing as people move through various social spaces. Agents in different contexts have different views on irregularity and understanding of the law, and in some settings the study participants experienced that their formal legal status in Norway was a minor issue. As seen above they were much active in the areas they had a chance to participate in, whether it was taking care of and dressing the children with much thought, writing for one’s right, or waking up at 5 to go to work every morning.

The analysis of study participants’ capital takes into consideration the value of their ‘assets’ in the locally prevailing currencies. While this analysis indicates they were severely capital strapped, this does not mean that they had no strengths or personal resources. On the contrary, it is clear that the men and women in this study had many capabilities, capacities and strengths that they were able to mobilise and utilise. They managed to get up and get going day after day (often to a new day of uncertainty); look after and raise their children; look for and involve themselves in meaningful activities, and generate ways that could help them make ends meet. Except the mother who had small children and was staying at home with them, most kept looking for a job, and some women made efforts of entrepreneurial sort, like taking on extra work in the camp to make ends meet, or sell homemade bread or cook at events. The study participants persevered in looking for ways to try to convince UNE to reverse the negative decision, although the resources they had to get through to UDI/UNE varied. They gave of themselves and had the ability and energy to build new relationships, they made new friends, and they were dedicated partners in romantic relationships, while at the same time dedicated to stand on equal footing; to meet their own expectations of being independent in that relationship. They managed the HIV infection and the medicines, and dealt with and educated their near ones about what living with HIV means. They had the wish and need for maintaining social relations and were able to manoeuvre and reduce what they perceived as risks of being exposed to HIV stigma, although the fear of stigma also caused withdrawal from or hesitance to get into romantic relationships. When they felt down they
actively tried to find solutions to get or feel better again, it varied how the study participants had the possibility to do this, however within the available time they had they made attempts to have activities; finding ways to be with friends for a while, go to the HIV support centre to relax, or just be outside amongst people. They had hope, although they doubted at times, that life would take on a new direction. To live in freedom was brought up several times.

Being complete human beings, with dreams and with agency, does not fit into a one-dimensional image of forced migrants as being completely without agency, and it doesn’t fit into a public discourse of ‘true’ asylum seekers and refugees as non-agents. Khosravi notes that they represent themselves as victims and nothing more, adopting victimcy, they might be perceived as and deemed worthy of protection (Khosravi, 2010). Such victimcy, and performing refugeeness, also entails suitable behaviour and the visual representation of oneself. Khosravi describes how he was told by a refugee caseworker in Sweden that people who were well-dressed and went to town couldn’t be real refugees. On the other hand, refugees who are visibly poor, hungry, ill, or disabled are often instantly perceived as ‘merely’ in need of basic needs, therefore as economic refugees. Although their need and wish for seeking a safer life is (at best) ‘understood’, they are often portrayed in terms of costs to a welfare system and as if it’s self-evident that they do not qualify for protection (as in the many debates in Norway in 2015). The meaning of ‘a real refugee’ or ‘a true asylum seeker’ is constructed in such a way that few meets authorities’ and public’s expectations of who ‘real’ refugees should be and how they should behave.

Another fundamental part of the lives of the study participants was a feeling of loss. This sense of loss was linked to different parts, and places, of their life. All the women had left children behind in their home country and even if they had varying degree of contact with them, they had lost the nearness to them and the opportunity to be a mother the way they would want to. Being diagnosed with HIV had for them meant that they again had to give up any thoughts of living with their children in their home country. The men in the study were also detached from their home communities and saw no way of leading a life, or surviving there. All experienced a loss of home, the place ‘where you know everything’, as Miriam expressed it. They were longing for their children, mother or other family members. Khosravi describes his experiences of exile life as ‘the constant presence of the absent’ (Khosravi, 2010, p. 74) with unexpected images from home, from the past, disrupting the present. ‘One does not
stand on firm ground’, and one has a feeling of estrangement and alienation ‘from the world in general’ (Khosravi, 2010, p. 73). Exile life, whether legal or illegalised, is a ‘condition of transience’ (Khosravi, 2010, p. 74).

Their lack of rights in the Norwegian society was interfering with everyday activities and chain of thoughts, again limiting personal freedom. Lack of choices both in minor questions and with regards to the larger issues as where to live and with whom, to be with your children, plan the future and follow the direction you think best; depend on yourself as a whole person capable of making the right decisions were all examples of loss of personal freedom. Even if they knew what they wanted and still in some ways aimed for it, some experienced that they had lost control and had no direction in life. Brekke (Brekke, 2004) draws on the concept directionless time when describing the experiences of waiting among asylum seekers in Sweden. A person between a past and a future will have a subjective and characteristic experience of temporal space, ‘where the present does not point in a specific direction’ (Brekke, 2001, cited in Brekke, 2004, p. 28). The participants of this study did in many ways struggle to make sense of the world and to build a coherent picture of their life situation and the many influences on it. However, they did reason and think rationally over their situation time and again, in vain, as there was no solution to be found.

The study participants were struggling with a loss of function and status, both with regards to the community in their home country and in the Norwegian society. The loss was related both to being a person living with HIV and that of living without a residence permit, without the right to work and contribute. Having to depend on others was a burden both with regards to role and power in a relationship, but the men and women both emphasised how it also caused a loss of personal freedom.

They had different thoughts and experiences of losing themselves. This would manifest itself as perceptions of being invisible, not noticing where one had been for many hours or episodes of losing control over body -hearing others but not being able to utter words back. In addition there was the experiences over time of surroundings never responding to their needs, their capacities, opinions or dreams. Such experiences of non-existence is also mentioned in other studies with irregular migrants (Brunowski & Bjerkan, 2008; Jackson, 2010; Khosravi, 2010; H. A. Kjærre, 2010). The lack of direction also reduces the value of the present, according to Brekke (Brekke, 2004). Living ‘without direction’, together with the none-responsiveness of the
environment, threatens the personhood of the illegalised migrants, as described in Kjærres’s study Norway (H. A. Kjærre, 2010). In many ways, the participants in this study suffered a loss of what Hannah Arendt termed ‘a place in the world’, where they could belong, be heard and could express their opinions.

The study participants experienced loss of protection from the government. This was related to the rejection of their asylum application and appeal. In addition, they were unable to seek authorities for protection, like call for police’ help if they were to be victim of a crime. They feared the authorities; it was a constant fear of being caught and sent back to home country and also a fear of the shame and humiliation when and if the police come and pick you up.

None of the study participants had been imprisoned or experienced any degree of brute police force. Yet, it seems very clear that they were kept in a power grip by the authorities. Studies with irregular migrants like rejected asylum seekers have compared the lived experiences of people in this group to being in a condition of statelessness (Blitz & Otero-Iglesias, 2011). The concept of statelessness as explained by Hannah Arendt involved three distinct losses: the loss ‘of a home, as a result of being thrust into exile; of government protection, as a result of denaturalisation or the severing of the bond between the state and the individual; and the loss of ‘a place in the world’ where the individual could belong, be heard and express his or her opinions’ (Blitz & Otero-Iglesias, 2011, p. 3). Statelessness was by Arendt seen as a situation of rightlessness, ‘a loss of the right to have rights’ ((Blitz & Otero-Iglesias, 2011, p. 3) and where people living under such conditions are subject to total domination. Fundamental in the lived experiences of the participants in this study were the losses described above. With the arguments of Arendt, people living without a residence permit in Norway thus live under conditions that have an element of totalitarianism, in the midst of a democratic society. Hannah Arendt meant that since universal human rights are based on states and citizenship they can never secure the rights of those who already are deprived of them, like people living under stateless conditions (Krause, 2008). The influence of the authorities, or state power, on the actions of the participants of this study will be returned to below.

Chapter five: Relation to UDI
Introduction
Initially my thought before meeting the study participants was not to go in depth into how the participants have ended up in their respective situations. Neither had I expected that the interviews should be filled with their thoughts and opinions about the relationship that each one has with the immigration authorities - even though their legal residency status in Norway is clearly fundamental to how they live their lives. My idea was, rather, to get insight into their lives in the context of their present situation, or rather, the way I perceived that context to be. However, it became apparent during the interview process that their daily lives, and also the participants’ perceptions and experiences of their own health and living with HIV, is shaped not just by being without legal residency status, but also by the participants experience of and relationship with the immigration services and authorities in Norway. The nature of the contact they have with the authorities can in many ways resemble or magnify negative experiences in other relations.

Form of communication
Several of the participants who have received a deadline for leaving Norway from the police and thus reside illegally in the country are still either unsure if they have an ongoing case with the Immigration Appeals Board (UNE), or hope to assemble enough documentation to appeal for a reversal of the decision. In the period that the fieldwork was performed, there was thus still an expectation among the participants of some kind of communication with UDI or UNE.

Miriam came to Norway nine years before I met her in connection with this study. After the first application to UDI was rejected she had appealed the decision twice and petitioned for commutation three times; twice to marry her partner and once on health grounds. She is about to send the petition of commutation again. In all these years, Miriam has never met someone in UDI or UNE apart from the initial interview when she arrived in the country. She receives letters from them and they have her address. The same is true of other participants in the study; nobody has met representatives from UDI or UNE apart from at the initial interview with UDI.

The participants showed me letters from UDI, UNE and the National Police Immigration Service (PU), and all were written in Norwegian. For those who had Norwegian-speaking near relations it was possible to get help to understand the words, but grasping the full meaning and implications of the information was difficult without the advice of an
experienced person or an attorney. Lucy, who speaks English, explains that she doesn’t understand what’s written in the letters from UDI and UNE, everything is in Norwegian and she has to find someone herself who can translate. This person needs to be someone who understands Norwegian well, but also who you can trust, which she says can be difficult. She understands the main points in the letters, such as the rejection and departure deadline last year, and that UDI believes that the authorities in her native country give the inhabitants protection and that it’s thus safe for her and the children there. Her experiences tell her otherwise, and she thinks that UDI has made a mistake. Her own difficult experiences in her native country, from when she was a child to what she has experienced recently to what she hears about her country now, all this is taken into her consideration of whether or not it is safe there. She is struggling to try to find a way to communicate these facts to immigration services.

A struggle to show the truth
Those I spoke to expressed a deep conviction that UDI had treated them badly, or that UDI had misunderstood or misinterpreted something in their applications; that UDI couldn’t have correct or sufficient information about the situation in their country to understand. Since UDI doesn’t know the truth, it’s up to the individual to motivate UDI to look for and find the real picture; the truth, i.e. the same picture that the person him/herself sees. The hope is that UDI will eventually get the knowledge and finally believe him or her.

People’s subjective assessment of being at risk of persecution in their home country stems from their bodily experiences and perceptions in that context – which are still part of their social imaginary - and can seem to be far from the individual part of the application procedure in UDI. The country information that UDI emphasises for information on conditions in each country does not tell about the individual experience of being discriminated against. The key person stated that UDI does not think there is discrimination against a particular group although people with an HIV diagnosis in practice are removed from most areas of society without the authorities trying to avoid it and rather choose to maintain the systems that permit it.

Some participants felt they couldn’t trust the lawyer they have been assigned after a rejection, as this lawyer is appointed and paid by UDI. Lucy says for example that a ‘UDI lawyer’ cannot be 100% neutral, but presumably will be influenced in the direction of UDI's decision.
People who are used to corruption in their home country see it as obvious that a lawyer who has been given a status in and is paid by UDI, wants to preserve this relationship and thus will not challenge UDI. Some manage afterwards to acquire a private attorney to petition for commutation. Continued legal assistance requires money. This made it difficult for her and others without an income to seek reversal of a negative decision, even though there may be new information to the case that UNE might see relevant. Lucy says it is useless anyway to go to a lawyer by yourself, and that you need to have someone with you, preferably someone who speaks Norwegian. She says she knows that they are not going to listen to her. At a free counselling office for women, she felt that because she spoke English she received no consultation or help. Networks and contacts for access to financial and practical help becomes crucial for a case to be taken up by UNE.

Some participants said that it seems as though UDI are merely looking for points with exactly the goal of giving a negative response to their applications, see only the good side of the situation in their native country, and list possibilities for the person to manage even if it is totally unrealistic and far removed from reality according to the persons themselves. Immigration services choose to use more generalized information about the circumstances in the country in question, the information comes from commonly accepted sources, but the accuracy of this information is often debated (Human Rights Watch, 2009; Humlen & Myhre, 2014; NOAS, 2013). Meanwhile, those who have had a negative response collect points to make known the bad sides of the situation in their country.

The infallibility of UNE/UDI is challenged by Gerd Fleischer in SEIF, who in 2015 criticized the government for its plan of following ‘Tvangsretursporet’ where a focus is to increase the rate and number of deportation of persons, without the possibility to appeal after the final negative, regardless of new information or changes in their case. Fleischer states this plan is based on infallible immigration authorities, while in fact they very often make misjudgments. Of persons who are allowed to meet personally in Stornemnda after they have petitioned for commutation, 63 % were successful in the appeal (Fleischer, 2015).

Waiting and expectations
Alma was waiting the whole time to hear something from UNE, says she’s been calling their switchboard time and again. Moreover, she regards the lack of response – the silence - from UNE as a personal rejection.

(... because I don’t know how my case stands. They don’t want to give you the feedback. I don’t know anything. I wish they say ‘we take your case, we will look at it’ (Alma)

I got my second negative appealed again one year ago. I do ask them so many times. They tell me to wait. At the end of the day you are the one who suffer. You feel so hated and not appreciated. (...) So unwanted. (Alma)

Alms refers to UDI and UNE as a person or people having a personal opinion about her. When UNE doesn’t respond she construes this as UNE having a negative opinion of her and not acknowledging her, she feels disliked and she suffers. Furthermore, she interprets UNE’s lack of response as them being difficult, and that they will show or punish her, or that UNE thinks she isn’t worth responding to. She feels that she is meaningless or worthless to them. There is somebody who regards her as unwanted, and this discomfort is in addition to the waiting, uncertainty and fear of deportation - and the unsatisfactory life that she must live because of her irregular residency status. She isn’t able to function in the way that she would wish, and that which would give her value the ways she sees it.

**Ambiguity and distrust**

The participants have received letters saying that they can be forcibly repatriated/deported if they don’t leave the country by a certain deadline. However, when they receive letters from UDI or UNE about obtaining documentation anyway, this is perceived as, or hoped by some to be, a sort of acceptance that they are still in the country after the deadline. Other participants find it unclear and therefore undependable, and also suspicious. Although such communications can come from different agencies (the police, UNE and UDI) it is regarded by participants as ambiguous or inconsistent, and in any case as impossible to deal with because travelling back to the country of origin is not considered an actual possibility to them.

Some study participants refer to UNE as though it is a living thing in itself. As they have never seen it, it’s talked of as a matter with unclear form and indistinct boundaries. They perceive it as unpredictable, with justifications perceived as strange, incorrect, in some cases almost defiant, and perhaps something or someone who eventually can give in? Hana got the date of departure a couple of years back. Now Hana wonders if perhaps she will get a positive
response from her last petition for commutation because she had to wait so long. She is also unsure whether they actually have opened her case again. She says they are so reticent, and wonders why UDI don’t get in touch. (What she is basing these statements on is that she gets money from UDI for her daughter, so UDI knows that she is still here). The key person who is at the interview together with Hana agrees that it is impossible to know what to expect. Adil also experiences that correspondence from UNE is unintelligible and contradictory:

‘living like this is hard…I never know what will happen with me. (...) I don’t know really. I got a date long time ago. Still after that they send me letters to ask for documentation. They wanted proof of nationality. It took a long time to get. I finally got birth certificate and then they wrote they are easy to manufacture. Then after long time [they said] I could go to embassy in a country outside Norway to pick up my passport, but I would need travel documents to do that. Then UDI said I don’t have to, they now believed me when I said that I was from (country). And then I got negative again. (Adil)

The way Adil expresses it, the mixed and changing messages from UDI and UNE/immigration services’ leaves him feeling confused, unsure and trapped. Such contradicting and impossible options would in addition to confusion increase feelings of impotence or ineptness. It also demonstrates a lack of bargaining power and limited ability to play an active participant in own life. Where it appears that UDI meet him, they make demands that are impossible to attain because of restrictions from the same official body. And when after much effort he is able to satisfy their demands, such as obtaining a birth certificate, this is on general grounds dismissed as useless, as a possible counterfeit. This kind of behavior from UNE and UDI is an example to Adil of everything he does being held suspect by them – it isn’t technical or formal criteria that causes the documents to be rejected, it is he himself that is the problem – he is regarded as untrustworthy. Like Alma feels hated and not appreciated, Adil feels that Nesnda, and immigration authorities, consider him morally inferior, a bad person. He explains that he had to lie to UDI when he first came to Norway, that he didn’t have any choice; he had to do it so he wouldn’t be sent back to his home country. UNE wrote in the response to the appeal that they find many good arguments for letting Adil remain in Norway and that they agree that it’s hazardous for him to be in his home country. Nevertheless, his appeal was rejected. The reason was due simply to immigration policy and because he ‘lied about his identity’ five years ago.

The word Nesnda for Adil is like a symbol of an authority that will not be moved, and of the anxiety related to this. He expresses the opinion that the refusal is like a judicial ruling, where
the verdict is that he is not worthy as a human being. Thoughts and images related to this keep coming back to him all the time.

But I see this text and it’s *NEMNDA NEMNDA NEMNDA*, maybe they want to kill the mind…for so many years? An asylum seekers is a human being, he needs a life! He can make mistake, and wrong, and he can give excuse for mistakes? He is a human being! Everybody lies. Politicians lie, that is not a lie? It’s a lie! They lie to the people. I lied to the police. I was scared, I was afraid to say that I was from (...) They would send me back right away. I did not do harm to anybody. It is not that I am criminal. (Adil)

His view is that it’s the Minister of Justice and the government who give the negative response to the application for asylum, i.e. who pronounce the verdict, and that it’s they who find him not worthy of remaining here and thus brand him a criminal. Meanwhile, he feels that he hasn’t done anything worse than what politicians do when they say a lie. He reasons: it’s human to lie, and people should be allowed to repent and be excused or forgiven. He doesn’t get that chance and must be punished for what he sees as a harmless mistake that he made many years ago. He is not treated as a decent and equal human being, is without his rights and is not even worth apologising to or forgiving.

Seen together with UDI’s guidelines for assessing credibility, it becomes clearer that it may come to a ‘standstill’ between the asylum seeker who has been rejected and UDI/UNE. An evaluation report commissioned by UDI refers to UNHCR’s Handbook and guidelines on procedures and criteria for determining refugee status (UNHCR, 2003), and to Kagan (2003):

‘When the evidence in the case is laid out, the caseworker will find in favour of the applicant if there is any doubt about the actual facts when he or she generally considers the applicant to be trustworthy (UNHCR 2003: 204). The assessment of credibility is then often an important part of an application for protection(Kagan, 2003)’ (Bollingmo, M. Skilbrei, & Wessel, 2014, p. 19) (my translation).

And from the same report:

‘Even if credibility and the truth are not the same it is a part of the evaluation of credibility to differentiate the false stories from the genuine, and knowledge of detection of falsehoods is thus very relevant’. (Kagan 2003) [my transation]

Adil’s impression is that politicians themselves aren’t always truthful. Different questions to UDI and the authorities arise many times in interviews and informal talks with the participants, often the questions are bemused, confrontational or challenging. The participants
express doubt that the authorities can make, or will make, the right assessments. An example is Miriam who distrusts the Norwegian authorities credibility, their understanding of the truth and interpretation of who is doing right or wrong when they trust a corrupt regime in her native country and send millions (in aid) to it, but choose not to believe that she needs protection, she who had to leave her children after her husband was killed by the same regime that receives these millions. For Miriam it is a mad and absurd, incomprehensible evaluation that the authorities make. She also suggests that they know this themselves:

UDI…they see my name again…and they say no, again and again. Maybe they think I lie. They decided something and they don’t want to change it. I think sometimes they just see my name, and that’s it. As if they don’t want to admit it if they do a mistake. (Miriam)

She perceives that UDI consider her troublesome, not just because she has appealed and sent petition of commutation many times, and not necessarily because they think that she doesn’t have a case, but because she challenges and indicates that they have made a misjudgment. Her lack of confidence in the authorities and their knowledge about the real world is exemplified by Miriam’s view of the justice minister:

…if he has something to decide, he just decides on the spot, not looking back or to future…he is like a child…I think he is ‘snill’ and…but he just decides on the spot. (Miriam)

**Power of definition**

Nevertheless, it is the authorities that have the power to define what is and who are credible – and by definition are truthful and law-abiding. Miriam has a story that she considers perplexing and almost funny, and which exemplifies the above point. Her partner was scared that the police would come and fetch her:

Think of it, my *samboer* is also like an asylum seeker! And he is Norwegian. What he did…at 4 o’clock at night, he wanted us to hide in the bike shed! Hiding in the dark between the bikes…hiding from the police in Norway! Like criminals! And he is Norwegian!

This episode illustrates how the government holds the power to define, and how people may almost accidentally find themselves in a group that the authorities see as offenders, and thereafter act or feel they must act accordingly. Cohabitants are in many ways very engaged in what has become like a case against the immigration authorities, a struggle to be believed, about right and wrong. Miriam’s partner is meticulously taking care of and locking all the
documentation in a safe; she finds it somewhat exaggerated, like when he got them to hide in the basement.

People are nudged in the direction that the general public has assigned them and which UDI has imposed upon them; suspicious, not obedient or truthful, and their near relations becomes part of this in their shared everyday lives. Miriam in addition expresses worries that when someone sees no other option but to stay in the country, yet they don’t have a work permit, the situation can actually lead them into crime, causing immigration authorities to get their ‘proof’.

Another example that at the moment is more relevant for Miriam is the negative role that UDI assigns her in the family she has in Norway:

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\text{\ldots my mother-in-law has written to UDI too: ‘we got this woman sent to us from heaven’, she writes over two pages. (\ldots )\ldots they wrote something like ‘she is not a caregiver’. But he doesn’t need any help from me! UDI\ldots they pick out, they look for the negative. It’s so easy to find the negative things, hard to get anything good…’}
\]

Miriam says she doubts herself sometimes; after all she left her children and is thus responsible. Even though she feels that she had no choice, she blames herself. UDI’s rejection of the application for asylum is like an assertion that she didn’t need to leave them, that she didn’t travel to get to safety, but left the children just to get a better life or to be more financially secure. As with Adil, to persevere and continue to work to get a positive outcome from UDI implies a parallel and personal battle to clear (his) her name – for Miriam from accusations that she is not a responsible mother.

**Discussion**

Immigration authorities occupy a large part of the lived experiences of the participants of this study. Expectations, hopes, disappointments and rare letters from immigration services cause a relationship with ‘Immigration’ to be alive (although barely), even though they earlier had received warnings that they are staying illegally in the country. People who stay in Norway without legal residency, ‘irregular’, ‘undocumented’ or ‘illegal’ migrants are usually portrayed as if there is no doubt about their illegality, and that it’s an either-or situation. This
dichotomy is not reflected in this study. Also the migrants in a study by Kjærre (2010) sometimes found it hard to know whether they were ‘legal’ or ‘illegal’. Thomsen (2010) criticizes ‘the tendency to divide migrants into dichotic categories’, and argues that the empirical reality is more nuanced, and one where the legal status of migrants often change over time (Thomsen, 2010, p. 30).

The continued relationship that each of the study participants has with UDI or UNE is complicated. It’s also nuanced and not merely a question of ‘rejection or not rejection’. A major issue is, as might be expected, the perception and understanding of risk involved with returning to their home country. The study participants have their other individual reasons to fear deportation, but the fear is in this study expressed together with the fear of the everyday realities they expect to meet as an HIV positive person in their home country. Stigma, together with uncertainties of access to treatment and care made them see a future in their home country as one with illness, being bed-ridden, isolated but in need of help, and perhaps not possible to survive. In addition to their own life, the mothers in the study feared their children would be ostracized and lose any opportunity in life, so ultimately also their lives would be destroyed. Returning home would be to punish the children. When UDI argues that HIV is a disease like any other, the persons living with HIV argues that HIV means lost life, and when UDI claims that life in your home country is ok, the study participants argue that it’s unbearable. Subjective bodily experiences of what life with HIV is like in your home country is tried against a colossal apparatus that collects what is termed dependable information from respective countries and presents an image of the reality different than what the men and women in this study have experienced. At the same time, a relationship to that institution is the only means and chance the study participants have to ‘naturalize’ their lives; they are ‘in a continuous relationship with the power that abandoned’ them (Agamben, 1998).

Communication with UDI/UNE is longed for, feared and the source of rare relief for a while (as in the case of getting a receipt from UDI), but most of the time it is the source of much pain. The waiting time for response from UDI, just to know that UDI have received a letter, is regarded too long. At the same time they see no other way than to stay, and to try to reverse the decision through a time-consuming bureaucratic process. Some had partners and a family-in-law who were involved in the work to reverse the decision. Those who had other contacts would get some help in maneuvering in the process of appealing, however it seemed that at a
point this support was exhausted. In any case, the heaviest burden was upon the men and women in the study. They persevered; it did however cause much psychological distress, as will be returned to later in this thesis. As voiced in the AIDS & Mobility Europe report (2006) it is a paradox that people with a serious chronic illness have to go through lengthy administrative and legal procedures to enforce their basic rights – when they are already ‘suffering from the consequences of not having them’ (AIDS & Mobility Europe, 2006, p. 26).

Letters in Norwegian, the lack of personal contact with immigration caseworkers and the contradictory or ambiguous messages received contributed to the study participants having an unclear image of the immigration services and authorities. Most of them doubted that immigration authorities would even want to do a proper evaluation of their application or appeal. Some understood a rejection as them being unwanted, while others had a perception that UNE would just never admit a mistake; UNE was seen as a power that could not be moved. Yet, it was the only power they could turn to. The non-responsiveness from UDI/UNE not only to their request for protection, but to their voices and physical presence leaves people in this study in a state of non-existence. This feeling of being nothing at all and that others can walk right through you, has been described in other research with irregular migrants (Jackson, 2010; Khosravi, 2010).

The study participants in many ways also perceive the rejection of their application for protection as a personal rejection of their worthiness as human beings. The form of communication with UDI/UNE reinforces their otherness and that they’re unworthy, together with the grounds for the refusal, and not necessarily only the refusal itself. Immigration authorities and politicians emphasize trustworthiness in their demagoguery, and UDI/UNE emphasizes the same in their judgment of asylum seekers or appellants. Participants bring up years of experience of or with a real fear of degrading treatment - being considered and treated as less worthy or unclean because of the HIV-diagnosis (or homosexuality), and their past experiences are brought into the continuing struggle with UNE to be recognized as a morally decent human. Parallel to the resistance against deportation to a setting with uncertain chances of surviving, such arguments by UNE seem to motivate to a continued attempt to be extenuated, declared innocent, by getting overturned the decision of UDI/UNE after rejection.

People in this study have no clear position, no clear direction, they are ‘between all recognized fixed points’ in the Norwegian society, between countries and between homes;
they are in many ways what Turner called ‘transitional beings’ (Turner, 1967). They are ‘neither one thing nor another; or maybe both; or neither here nor there’ (Turner, 1967, p. 97). In Douglas’ (Douglas, 1966) terms, what is unclear is unclean, and unclassifiable people like irregular migrants would be regarded as polluted. They would also enable the differentiation of purity from impurity, and moral from immorality, and thus according to Douglas serve a purpose of preserving structure in a society, by defining and clarifying a society’s principles and norms as opposed to those of the ‘unclean’ (L. Malkki, 1995a, 1995b). In differentiating legal from illegal, the trustworthy from the liar, and the moral from the morally inferior, not only the men and women in this study but also their Norwegian family might find themselves classified as people with criminal inclinations.

How asylum seekers are presented in the public room is crucial for such definitions and shaping of opinions. Politicians and the media’s terminology have a large influence on asylum seekers generally and especially on those that have not been granted protection and remain in Norway without a residency permit. Simply ubegrunnede – groundless, unsubstantiated - is one of the designations often used about people that haven’t met UDI’s criteria for the right to protection, but is usually used more arbitrarily about those who people consider, for different reasons, don’t have a legitimate reason to be granted such protection. Kjærre (2011) describes how naming and everyday accusation of them being ‘asylum abusers’ and exploiters of the system caused illegalised migrants to think of themselves in the same way, even though they knew they were not. This, together with the dehumanizing conditions the waiting camps in so many ways entailed, caused self-criticism and shame to be ‘terrorizing their heads every single day’, as one informant in the study expressed it (H.A. Kjærre, 2011, p. 37).

In media, in debates and in interviews with politicians words are used that effectively group a variety of people together and make the audience lose sight of the nuances and the realities of the people concerned. Asylum seekers in general are seen as a group, not as individuals, and they are portrayed as some who may or may not get a gift – residency – from the Norwegian state and tax-payers, though it is their individual right to apply for protection, and according to international conventions adopted into Norwegian law they shall be granted protection if the criteria are met. However, how migrants are represented and portrayed by authorities can lead to little understanding and room in the society for individuals to protest against immigration authorities’ decision that they are groundless/unsubstantiated, and make it
unlikely that a petition to overturn a decision is upheld. Judicial interpretation, UDI caseworkers’ evaluation and decisions in UNE are not isolated from the society in which it takes place, as is also noted in the before mentioned report on UDI’s practice regarding trustworthiness (Bollingmo et al., 2014).

In the terminology of Agamben illegalised migrants are the *Hominis Sacri*, the bare lives of today, they are construed as anti-citizens and stripped of all rights (Agamben, 1998). Yet the relationship to the power that rejected them continues. The participants in this study felt and were indeed classified and treated as irrelevant by authorities, and at the same time they were ‘under the spell of law’. The process involved in excluding people is inseparable from inclusion of the same people. While participants in this study had the rights to treatment and care related to their HIV infection and thus were not ‘stripped of all rights’, this entitlement was based on *Smittevernloven*, i.e. protection of society. According to the Roman law depoliticized ‘bare lives’ were alive only because the state let them. One could say that people living with HIV and without a residence permit are with the access to HIV treatment similarly allowed to live, or not allowed to die, while they are staying on Norwegian soil. In addition, the National Police Directorate (Politidirektoratet, 2011) uses the term ‘tolerated stay’ (*tålt opphold*), and imply that some people without legal residency will not be deported for an unpredictable length of time. The combined message to people living with HIV - if they should belong to this group- is ‘we let you live, for now’. Although the alternative is worse, for Miriam in this study the present life means to ‘sit and see the medicines expire’, she is surviving, but is stripped of most that gives life meaning.

Rhetoric and terminology takes part in a process where people who have sought protection, been rejected and are residing in Norway without authorization are transformed into somebody considered fundamentally ‘different’, belonging to others and clearly detached from those that naturally should be here and have rights here. Such ‘othering’ and the mechanisms it entails reinforce stigma. It confirms a view that they shall not have the same rights and justifies, for example, that they are not entitled to health care that is considered natural and necessary for other people with the same condition (Grove & Zwi, 2006). Such a practice from the side of the authorities of failing to uphold people’s rights will again make negative attitudes more acceptable in society, more mundane and visible, and consequently reinforce stigmatization.
Chapter six: Perceptions and experiences of life with HIV in home country

Introduction

The participants in this study have since we first met brought up experiences and memories from their life in their home countries. Connection with the same set of thoughts is held through memories and through close ties to family members and their lives back home. The experiences are clearly of importance for how they perceive different phenomena today, as discussed earlier. Their own understanding of what it means to be HIV positive seems in many ways to have changed as they in the present environment have experienced to be healthy with HIV and gradually have started to conceive of HIV in another way. Still, the past experiences and understanding of HIV is decisive of how they understand other people to perceive of people living with HIV – also in the current context. Therefore, such culturally or socially integrated perceptions of HIV do influence how the study participants live with HIV in Norway today.

This understanding of what HIV means has also been decisive for their reaction when they first learnt that they were HIV positive, whether the test was taken in their home country or in Norway.

Meeting the HIV diagnosis

The men and women in the study all have clear memories of the moment they came to know about the positive HIV test and about the feelings and thoughts they had at the time, whether it’s recent or more distant in time. Regardless of where and when they found out about it, all were thinking the positive test means death. Miriam and Alma were both diagnosed with HIV while living in Norway:

Because I got a shock, they told me I have TB, I have HIV – but I was never sick. First when I heard this I felt that, tomorrow I am dead. I got very frightened, what will happen to my children, and who shall look after me? (Miriam) (my translation)

When I first knew it I thought I would die after a few years, or months – I think that I don’t have to live a life anymore. I’ve seen so many people in Africa, they just die. They get some medicine, but it does not help them. ‘It is finished, I have nothing, it’s a few months and then I’m gone. It was sad for my
kids, only for my kids. I was even asking God questions. I never had a good life with my kids. Didn’t I have a choice for something better? I hated myself. (Alma)

Hana is telling that she had to escape her home country after she had tested HIV positive. She had given birth to a child, and others started understanding that she was HIV positive:

In (..) when I was pregnant and I went to a pregnancy check-up they found that I had HIV. I was very sick, too, and my CD4 was 164. I started medicine almost at once. When he was born I did not give milk. They, my family, people, they asked, they wondered. Why I don’t give milk. I had to go. The baby was only three months when I had to go. I left him with my mother. You don’t breastfeed, everybody knows you have HIV. (Hana)

All the mothers participating in the study perceived it as impossible to combine taking care of their children in a good way and living as an HIV positive person in their home country. In addition to the difficulties imposed on them with regards to getting employment, they feared the consequences for their near ones, particularly their children. All talked about how children whose parents are living with HIV are excluded, outcast: other children will not play with them or visit, school will be difficult, their future probably destroyed. Leaving and staying away from her child is by Hana seen as a way of helping her child and preventing the above to happen.

You can die there easily

HIV where I come from... They die so fast. (Lucy)

The study participants bring up how living with HIV in their home country means a life in isolation. Nobody wants to share that they have HIV; people diagnosed with HIV sit in their houses, call the disease something else. Visiting a clinic at the hospital is conceived of as risky; somebody might see you going to the ‘wrong’ entrance to the hospital. Lucy tells about a huge sign telling ‘HIV clinic’ on the outer wall:

This section in the hospital, where it is boldly written… people see you there they will think you are ‘one of them’. This kind of demarcation is not good. If somebody sees you, a friend or something, they will tell. You’re afraid to meet anybody you know. They will talk about you. They will not even drink water in your house. Or let you have water. They will not associate at all with you, at all. Only a few know that for example a hug is ok. The government I think… I think they try to talk about it. But people don’t understand. The majority is blank. Especially in the villages. My God. (Lucy)
Job…to get a job in (home country) is difficult. Most people live of farming. If people get a government job or something, they make 100-400 per month. (...) No blood tests are required. If they know about the diagnosis they will be scared of course and you will probably lose your job. If somebody sees you there, at the hospital demarcation section, they spread your name. Only people working in the hospital are safe. Because they know they don’t have to be scared.(Lucy)

Lucy implies that the government are perhaps doing something to try increase knowledge among people in general, however their focus is not on how to live together with people who are HIV positive, but rather on how to prevent transmission.

To be more relaxed, and to be safe…it is not possible if you grow up with that kind of reasoning. NOAS, the organization, they confirmed after an investigation… You can die there easily even if you get treatment. (Lucy)

Two of the study participants had told about the HIV diagnosis to their sisters who were taking caring of their children at home, or made it understood to them. All the women in the study wanted to protect their children from knowing. They also didn’t tell their elderly mothers, as they feared they would not cope or even survive the shock and pain of knowing that their daughter had HIV; for the grandmothers it meant they are dying. Thoughts of and a wish to tell her mother is something that keeps coming back to Miriam, but each time she lands on not doing it. In addition, children who lived with their grandmothers or with other family members who were unaware of the diagnosis would not be able to follow up the children regarding this, and it was not something talked about. Miriam worried about her children:

I don’t know about my children, whether they are healthy or if they are infected. Youngest children, they don't know about it. They think that it’s hell, this disease. (Miriam) (my translation)

Alma has hopes and has decided she will tell her children when she meets them. She sometimes has long talks with her children on the phone and has brought up the issue of HIV without telling about herself. The children seem to associate HIV to death, too. Their conversation also gives a glimpse of the bond between them despite the distance in space and gives prospects of belonging and love regardless of them knowing about HIV:

When I meet them face to face I will tell them…Now I have asked my daughter on the phone a few questions… I asked what if we all got infected with hiv, and then my daughter said ‘then we shall kill ourselves all of us!’…and then I asked what if you get the infection, he said ‘I’m too small to be sick…. I hope mom you can’t cast me away if I get sick’ and I said no I can’t, I won’t…then I asked what if mommy gets sick. And he said ‘I love her so much and will not hate her’. (Alma)
Medical treatment

Lucy doesn’t agree with Norwegian immigration authorities that claim that she can get HIV treatment in her home country. She describes a situation where medicines are scarce and that people without money, or local people where she’s from, in effect do not have access to treatment. Corruption favours people who can pay for it – she says those who have the means make sure they have enough and stock it up.

They say they know that in my country I can get treatment. In this I don’t agree. In the area I live it is not true. Local people don’t have this treatment. And since they don’t have enough medicines, they skip it. The rich people who have the money they go and get it. And get more of it and keeps it for themselves. The poor people are neglected. It’s not right what they say that the government is protecting me. (Lucy)

You get vulnerable to other infections, you know. You see, that in the end of the week they can give you a date and they say sorry, we don’t have any left. You can imagine Africa, if you can pay everything extra, you get what you need of medicines. Bribing and corruption, that is what it is all about. The government - it’s the highest rate of corruption even at the top of the system. They say that the government can protect you, but they cannot. (Lucy)

Shan has not lived in his home country after he was diagnosed with HIV; he has thought a lot about it, but is sure that he would not be able afford HIV medicines if he returned. The financial situation is as described by study participants essential for managing a life with HIV, partly for having access to and a safe supply of medicines. Hana experienced that she didn’t get better even though she had been on treatment for some months in her home country, and relates this to medicines of poor quality. Now she is getting help to get a letter from her home country with information about what medicines, and if the kind she uses, is available there. Availability of ART drugs in a home country is an issue both for immigration authorities and for people living with HIV and without a residence permit. Some has had to change drugs because of side effect, and the question may be whether the particular type of ART drug is available in the home country or not. On some occasions, physicians in Norway have made a ‘transitional arrangement’ so that patients who expect to be deported or chose to return to their home country, do get supply of ART drugs for a longer period of time; one or two years. There are no formal guidelines for this arrangement (that I know of) and it is thus dependent on the relationship and the dialogue between the person in risk of being deported and the physician.
They say I have family there who can help me. How can they help me?

I’ve had many cases. Three times the asylum application. Two times applying for marriage permit. One time because of my health. I got a rejection on all of them. They [UDI] say for your health (home country) is good. (Miriam)

Miriam too cannot see a way of life if she was sent back to her home country. She is challenging UNE’s arguments in its letter of rejection – it says that she has nothing that can give her political asylum, and that she has family who can help her back home. To her, this is not true – her mother is old and it would be she who needs Miriam’s help, and so do the children, so how can they help her? Participants in the study express a deep pessimism about getting or keeping a job in their home country when being HIV positive, at the same time they imply that the HIV infection makes a safe income even more important. Hana explains how it is common that employers want you to take an HIV test and will not hire you if you are HIV positive, and if you have started working somewhere, you will lose your job. The key person present in the interview sees losing one’s job as part of an overall discriminatory context that HIV positive persons live within in their home country, where people living with HIV don’t have access to the only means of making a living, and were being poor or being of a particular ethnic origin reduces your chances in most areas of society, including access to ART.

Any thoughts the participants had about returning to home country were quickly banished partly because of the unbearable situation a lack of safe income would create. Alma says:

I was many times so fed up I wanted to go back to home, but how can I survive without a job, without anything, with my sickness. That would be like punishing my children. Back home, there you cannot do anything if you have the sickness. (Alma)

Lucy expresses loneliness and that she is alone with the children, both here and if she is sent back, and has no one to lean on. She has no experience of being protected by the government, neither when it comes to getting food on the table, getting medical care and treatment or get protection for herself or her child when they have been in danger. Other women in the study have stories of abuse, and Miriam after a long time talked about the sexual violence she was victim of.

Often one guard came. Many times. He had the power, I had to do it, then he left me alone again. He left me alone again, that was the important. (Miriam)
Discussion

Based on memories and stories like the ones above, the study participants have a constant worry and fear of returning to their home countries. They have seen or experienced what it means to be a person living with HIV in their home country: that you easily can die, cannot be sure if you get a safe and stable access to medication or trust the quality of the medicines, that the effects of stigma meet you both in your everyday life in you local community and when trying to have a role or claim your rights in the larger society. The prejudices, discrimination and exclusion both on a personal and societal level and the effects on their lives and bodies was what they brought up in the interviews in this study, both in ‘imaginary’ talks to the immigration services and as an expressed deep fear of destroying ones own, or ones children’s, lives. The children will be ostracized. The chances of getting and keeping a job, and have an income, are described as bleak or non-existent. Lack of medicines, lack of caring others, isolation, ailment and death – these are all parts of a scenario they see as realistic, and fear.

This study deals with the participants’ own perspectives of life with HIV in their home countries and doesn’t aim to give an objective image of the situation in the various countries. A commentary paper by Russell et al. (2007) in many ways mirror some of the worries of the study participants. The authors state that ‘the foundation upon which a return to normalcy depends – the assurance of an uninterrupted, affordable and accessible supply of medication and care – remains absent in many countries’ (Russell et al., 2007, p. 346). Moreover, with ART resistance, toxic side effects or treatment failure, the limited treatment alternatives increase the uncertainty of living with HIV. A main message in the paper is however how social and economic difficulties make it hard for people living with HIV to manage their HIV infection, despite getting treatment that initially cause renewed hope for a life. For people to survive with HIV as a chronic illness, they need support that address the social and economic hardship that otherwise may undermine their ability to come back to economic ‘normalcy’ as well as threaten their ability to adhere to treatment regimens. The paper describes a rural sub-
Saharan setting; however the principles can be relevant also in other contexts. Furthermore, in the study mentioned earlier in this thesis, Russell and Seeley (2010) explored the process of transition to living with HIV as a chronic illness in rural Uganda, a setting where ART was available, but not guaranteed over time. The study had a focus on how, among other factors, productive work and mobilisation of resources was part of creating order and get control in life. In the perspective of HIV as a chronic illness, leaving one’s home country after learning that one is HIV positive may ultimately be interpreted as a way of taking action, working, to restore and create order in life - a movement from disruption to transition. Similarly, the fear of returning to one’s home country as HIV- positive contains more than a fear of economic hardship or social exclusion in itself, it contains an underlying fear of the unstable and the barriers to the order-making that is necessary to get out of the disruption that a serious chronic illness entails.

Although the study participants’ reasons for seeking protection in another country and fear of returning home are varied and complex, the HIV diagnosis comes into focus and causes additional fear of being forcibly ‘repatriated’ to their home country. Moreover, HIV becomes a part of the negotiations the study participants attempt to have with immigration authorities, in form of appeals to try to reverse their decision. The images they have of ‘a life deported’ involves – apart from the question of how long they will be able to survive - the daily life with daily chores and activities, the relation they have to their near ones as well as the involvement they will need to have in that community in order to cope. In all these areas of everyday life, they fear the consequences of stigma, the discrimination and exclusion, and how otherness will be fundamental in their lives. As brought up in the chapter on UDI relation, faced with the rejection from UDI and UNE the men and women in this study try to grasp how immigration authorities can argue like they do and to find ways to make authorities understand reality the way they perceive and have experienced it.

Living with HIV can, in the interaction with immigration authorities, be interpreted as an advantage or as capital the study participants possessed. In their approaches towards the authorities, the study participants had the possibility of emphasising the HIV diagnosis and the uncertain future it entailed as an argument in their appeal; the HIV infection was thus transformed to capital in the meeting with immigration authorities. How this was received and responded to by the individual caseworkers in UDI/UNE, if at all, is not explored in this
study. Furthermore, to communicate to immigration authorities how work and order making can be crucial to a transition to living with HIV as a chronic illness is likely to be a difficult task. However, the fact that the study participants tried to collect information about availability of particular types of ART or other documentation about HIV in their home country, together with the arguments made by UNE in their rejection letters, or the rare receipts given, suggested to the study participants that the question of staying or leaving with HIV was a matter not completely closed.
Chapter seven: Living with HIV: perceptions, experiences and meaning formation in illegalised exile

Introduction
In the interviews with the participants I wanted to explore the meaning they give to HIV and living with HIV - when living without a residence permit. The participants’ lived experiences in the present and conceivably marginal context of irregular, illegalised exile may change and shape the meaning they give to HIV infection and living with HIV. However, as already brought up, not only the context or the environment they are part of at the moment influences people. Or, said differently, the context is not confined to the physical and social environment around us here and now. Phenomena are shaped by/within peoples’ social imaginaries – memories, thoughts, dreams, plans, pictures, the people they love – or fear, or just met once – all of which form a context just as real as ‘here and now’. Relations, actions and choices in different times and places shape each person– and a person’s perception on a phenomenon has a complex background. Alongside the participants’ present actions, experiences and their more recent perceptions about HIV are their former experiences, knowledge, underlying beliefs and understandings of what a life with HIV looks like; how a person can - or cannot - live with HIV. The context in which these views were formed, and still are being formed, is part of the life world of the participants, and influential on meaning formation, alongside the environment surrounding the participants today.

As an introduction, here is what Alma answered when I asked her what living with HIV means to her:

What I think about with the infection is that…to live a good life, we have to…I’m a Christian, I always ask God, to help so that I can be living with my children, living with my family, to see that I can support them. Because my parents wished to give me education, but I was not able to…so I just need that, that my kids get education and jobs and can live the life I couldn’t. If I could see that, then I would not think about sickness and medication. (Alma)
Dealing with HIV in illegalised exile

‘And then I have this disease’.

*HIV is not the biggest problem but exacerbates the difficulties*

When I asked the study participants if they could tell a little about what their life is like now, none of them did at that point bring up HIV as a main issue in their life. As described in the chapter on daily life, the study participants talked in various ways about their difficulties of everyday life in illegalised exile; the barriers they meet trying to manage in Norway without the formal authorization to stay here – together with the agony over the locked situation they are in, when not having any option but to stay, the way they see it. They described HIV rather as an additional concern to the overall hard situation of living without residence permit. HIV makes life in illegalised exile harder and brings in extra worry and uncertainty about the future.

The study participants’ perception of HIV is influenced by and seen in relation to, and relative to, other parts of their lives. Shan’s comparison of HIV and of not having residence permit - two major dimensions in his life right now - illustrates this. He had tested positive on an HIV test only some months ago, and he had started on medicines shortly after:

*The first time you know…when I was first diagnosed, I was very down. I don’t know much about it. I thought you just go…* (Shan)

When Shan and I talked about HIV he expressed that he of course still saw it as something he can die from. Despite this perception of HIV he was emphasizing how living without a residence permit (‘residence’), is the absolute worst problem a person can have:

*If you meet people, one without residence, and some with a different problem…he without residence? He will understand all the others.* (Shan)

Shan had thought HIV can cause death, but still: living without residence is worse for a person. Having recently gained some knowledge about HIV, about treatment, and experiencing getting treatment now, his acute fear of HIV is reduced some- while the unsafe and uncertain situation regarding money, job, food, shelter, future - everything else - is unchanged, or worsened.
‘The body needs support’

A need for structure and predictability

In the interviews, participants in this study did not right away associate issues of HIV to their health and idea of a healthy life. HIV nevertheless gives them an increased sense of need for paying attention to their body and health – when their insecure and inhibitory life situation makes this difficult. Shan’s perception of HIV as something a person can survive and live with in his view depends on stability and predictability in life. When I asked Shan if he now thinks HIV is something he can live with he is not sure. He says this depends on whether he is able to take care of himself, which depends on an ability to plan his days and his life – and this again depends on having a residence permit, a right to stay. So, Shan is hesitating whether HIV is something he can live with:

Naah [taking some time before he continues]…especially when you don’t have residence, you cannot plan. If I have a stay – then all you can think is to take care of yourself. If not- (Shan)

He still thinks of HIV as something he of course can die from, and something he doubts if he will be able to live with. He says his situation here in Norway, when sometimes not having money at all, makes it impossible for him to take care of himself and his body as he should.

Sometimes you don’t have any income. You need house, you need food, everything. You have to pay. The body needs support…both economically and psychologically. (Shan)

He, and other participants in the study, perceives that in order to live with HIV they need to be able to plan and structure their life. It has to do with a need to take medicines on a set time daily as well as to minimize side effects of the medications, to have regular meals, opportunity to take rests and get enough sleep, as well as have access to toilet and bathroom. Finally, it has to do with the need to have money to pay for the costs of living conditions like that.

Staying with HIV

To choose is not possible

Participants in this study did not talk about HIV when first telling me a little about their life. When the topic of HIV later was brought up they soon expressed, in various ways, that living with HIV controls their living space; decides where they can ‘be’- stay, rest, sleep, work, have
a family, bring up children. HIV is a controlling ‘factor’ with regards to where and how they can create a life and where they can - and cannot – go from here; in this sense HIV limits their freedom of choice, and freedom. They feel forced to move away if their HIV status is revealed.

But, living with HIV also makes it harder to move on, to change the ‘status quo’. Some participants talk about HIV as being in their way or something that ties them down, or slow them down, preventing them from taking necessary steps, if there were any to be found, to change their situation. Like other participants in this study, Miriam spends hours thinking, trying to find solutions to her life situation, from the very basic - and over-arching - need to be acknowledged as an able and equal human being, to the consequences the lack of this acknowledgment has for her future, and in the end, for her near relations. She talks about different options for living a life where she is independent and in control of her life, and thinks of possibilities that are out there – like moving back in to a reception centre in Norway, flee to another country or return to her home country – but sees none of them as a real choice for her because of the demands the infection puts on her, and her need to avoid new risks.

Here is what she said in two different interviews:

They [UDI] say you can come back to mottak [camps], everybody can come back to mottak, but for me it’s difficult. For me now it is difficult to live 4-5 people together in a room. I need rest sometimes. Then it’s the medicines. Sometimes I feel I would go to [home country] before that. It’s like animals. You sit and eat and sleep. Sitte, spise, sove. I get sick also from that. Psychologically. (Miriam)

I live a life now. It's boring, like a prison, you know…but sometimes I think, I’m like the children – sit and eat from his table, he takes care of me how long? I’m not a child, I know life. But then, I can not see any hope there, in the mottak. Sometimes then I think, should I go back to (home country)? Then it’s my sickness…it stops again. Then I think I need perhaps to go to another country in Europe…but then I’m afraid, what about the medicines. To choose is not possible. Everything is difficult. Look this way, that way, it is closed. Somebody I know they went to Iceland and there they took their case. Some of the people they go to Canada they pay somebody. But I cannot do that, I’m afraid…the infection. (Miriam)

Like Miriam, the other study participants in this study were negotiating the two life circumstances – living with HIV, and living without a residence permit. Shan too searches for solutions on how to find a way to live a life where he can take care of himself ‘even if he is on medication’. He is thinking, would it despite everything be better to return to his home country – but seems to decide it would not, because he is certain he would not be able to get
the medicines as he should if he lived there. A fear of the unknown, and with regards to HIV, a relatively more secure feeling of staying where they are makes participants stay for the sake of dealing with the HIV infection in the best possible way.

Social relations. The fear, the need and joy of others

Really, I’m ok with it. It’s the others

It is clear that living with HIV is in one way or another, a major theme in the participants’ relation to other people, as it is in their relation to UDI/UNE. Their perception of how they need to act in relation to others, and how they think other people perceive them, is built over time, and are constantly being formed. Memories of their own view of people living with HIV in their home country, minute changes in others’ behaviour today, gossip in the camp in Norway, UDI’s rejection, the fear of death, increasing knowledge or an accepting mother-in-law – are all factors and experiences that take part in the process of meaning formation and perception of HIV.

Even if the perception of HIV not as such a big problem is constantly being challenged by the threat of deportation, and the awareness of it is for some constant, most study participants seem to feel in control of HIV right now. HIV in itself they can manage - given the right conditions. Now, the biggest problem about HIV is not HIV; it’s what other people think and do about it:

Now I understand that HIV is not so dangerous, but now we have other things, like the stigma and all the problems with that. (Hana)

You learn you cannot tell everybody [about HIV], I myself I would like to, I don’t have a problem with it, that’s how it is for me and if they don’t like it they’re not for me, they can go their way. But then again it gets back to me and it just don’t work. So you learn you can not share it. (Alma)

Living with HIV means for many of the participants, as discussed above, that they are less mobile; have less opportunity to move about, move away – or move back. They relate this to fear of disrupting treatment or losing medical care – as well as fear of being more exposed to stigma where they move. While a recurrent theme among the participants is that living with HIV means a sense of being chained down, with a fear of an unknown situation, so is the
association they make between HIV and a need to disappear – because of others’ fear and prejudice. All of the participants in this study express that HIV to them has meant or means that they have to just leave, wherever they are. They perceive or experience this to be the case in their home country as well as in situations in Norway. How it’s communicated to them varies, at any rate they regard it indisputable.

In this way, the difficulties many in irregular exile face in having a permanent place to stay, or to have a place at all, are exacerbated by HIV stigma. Not to have your own place means there is always a higher risk of others finding out that you use HIV-medicines. Shan says if his roommates find out, he will have to leave:

You have to try to stay alone. You have to stay alone because of the medicines. (...) They will ask you to leave, just go. They may not show it directly, but you understand. (Shan)

He will get more worries again - the practical problems, as he will have the trouble again of trying to find a new place to stay - in addition to the fear of not finding it. A rumour about him can make it even more difficult to find a new shelter. Others finding out about the HIV medicines mean they will ‘know about him’ and treat him different.

I must have the choice to hide when I want. (...) It’s what I feel is the best. To hide and not to share it with others. You get more hot when you share it. (...) Stressed and depressed. They don’t wanna come to you, talk to you. I moved once. (Shan)

Shan makes precautions to prevent others from finding out about the infection – like hiding the medicines – but feels unsafe about it. All participants who are using ART drugs have strategies to hide this from others – from their roommates, from their children, and in their home country from other family members. Alma is using the HIV support centre:

I don’t like to keep any papers like that. I don’t keep any medical file or anything in the box or with me. They keep my medical file here [in the support centre] for me. I even keep the medicines here and go and get it when I need more. You don’t want anybody to find things, you don’t want people to know. (Alma)

Hana removes the labels on the medicine bottles, and tell her very curious daughter that the medicines are for other problems. The need to shield her daughter from her diagnosis also makes it hard for her to stay for a longer time in the HIV support centre and take use of the environment there like she would want to. While some are sure their parents (in their home country) and other relatives will throw them out if they knew about the HIV diagnosis, others
saying the reasons why they hide their HIV status from their children or older family members is to protect them.

**The need of others**

Being around, meeting and developing relations with people has the potential to make life easier with regards to money, food, work, house, health - as well as access to health care. Stigma caused the limitation and barriers met in illegalised exile to be reinforced. Revealing one’s HIV status can create new problems, as life in illegalised exile makes a social network essential for managing and getting along: if the HIV diagnosis is revealed, you will be excluded from the social network you are dependent on - to survive in a society you are excluded from. These worries appeared to be the case also for those who live in a reception centre.

Living with HIV can also make participants hesitant to develop near relations that could otherwise be important in a difficult life situation, for improving living conditions and quality of life. Shan thought not of meeting any other person at all after he got to know that he was HIV positive. Alma has had different experiences of how near relations can be of help, and that they can be destroying. Hana and the key person talks about how people living with HIV in general want to show their surroundings that they not only are healthy and alive, but also are doing great and therefore may keep people at a certain distance and be more reluctant to accept help. On the other hand, but for the same reason of wanting to ‘do’ good, to send money back home may feel as an even stronger obligation to people living with HIV in exile than others.

If you don’t buy things or send money to your family…many…we send 50% of our money, even we that are HIV positive, we send even more, to prove that we are strong, to prove that we are not dead! [laughing] If you don’t do that you are a bit odd(…) (the key person, key person)

Nobody at home understands how life here is like. Nobody believes you have problems with money. If you don’t send you are self-centred, egoistic…nobody can understand you. (Hana)

Financial responsibility for children in the home country and the expectations from the family back home is putting extra pressure on the participants with regards to having an income. For people back home, there is no difference between legal or illegalised exile.
Participants themselves express that they are quite accepting of their diagnosis. When we talked in the interviews, some were quite upset, though, defending themselves, thinking of near family members who have been unsupportive and judgmental, or condemned them. The steps they see necessary to take, like not revealing their HIV status or moving away to avoid hurtful reactions from others, are not because they feel ashamed, or feel they have a ‘mark’ on their body or are ‘dirty’. They seem to do those things more out of resignation, and from a (sadly) very realistic point of view. They have learnt that others put such mark on them and will treat them different. However, some do seem quite angry and tired of having to behave as if they have reason to be ashamed.

The fear of others. My secret and my weakness.

At the end of the day they will treat you different. HIV stigma.

I have seen from my interview notes that I had been quite eager to hear whether the participants were all alone ‘with’ their diagnosis, or if they had somebody to be open with and get some support from. But, the issue of openness was also something the participants brought up; their experience telling them to be very careful about whom they are open with.

I think about if ‘it is necessary’ or ‘it is not necessary’ to be open. Sometimes I feel I have to be open, for practical reasons. But not to everybody, even for practical reasons. Like now I regret that I told my [relative], she take advantage of it and uses it against me. I regret to tell her my secret and my weakness. (Alma)

I can’t tell many. I can tell some, but not everybody. At the end of the day they will treat you different. You can’t be open to everybody. (Alma)

I saw my friends’ reaction when they talk about other people with HIV and I decided I cannot tell them. They showed no respect. (Adil)

Hana is telling about her experiences of other people’s behaviour and their talking about persons who have HIV. She sees that people in the camp have no knowledge about HIV, but her position makes her unable to try to inform them about HIV and adjust their beliefs. She, and others in the study, do associate HIV stigma to a lack of knowledge.

In the camp… when women talk about others it is so bad. How they talk about others if they have HIV. I want to say something, but I can’t. And I think, they will look at me the same way, and talk about me. I feel bad. They don’t know better. (Hana)
Sometimes I cry. No one can feel my problem. HIV is also a big problem. Europeans mostly understand. Some think you get HIV from somebody if you share glass, cup, spoon. But people from other places like Africa or Asia people will not be with you. They will not visit you. They don’t have good information, I know. They think they get it just to see you even. (Adil)

If somebody is sick, I like to help. (…) I help her, it means I am better than her. She has pain, not sleeping twenty-four hours. I have power then. But now that I’m there, I help others, but why they talk about people with HIV. It does not hurt anybody else. If you don’t go to anybody, if you keep for yourself. And if you protect (yourself and others).(Hana)

Both in their home country and here in Norway in the reception centre or among friends, they have seen and heard comments about others with HIV and understand that people living with HIV are seen as weaker than and inferior to people without. Hana explains what she means by having power, saying that others get power over a person with HIV, and this power they use in such ways that the person becomes ‘ready to die’:

If it was in [home country] they will say all that… the bad. She is so sick, she will die… The power give you the person. They make you ready to die. It’s power for yourself if you talk about others. You don’t get freedom to be with yourself. (Hana)

‘It’s power for yourself if you talk about others’; Hana notes that pointing to the difference in others, what sets yourself apart from the diseased or ‘other’, strengthens the bond between other people in a group. It also produces an image of the ‘healthy’ person as a symbol for the normal and natural, strong and powerful; as opposed to the supposedly weak person with HIV diagnosis.

The way Hana explains it: if others come to know about the diagnosis they will behave as if you are about to die, and that you bring misery and death upon others. If you keep living, you are viewed as somebody who might as well die

Close relations. Blame or support
The participants in this study are like other people living without residence permit dependent on others to make life a little easier. The life situation makes them more vulnerable in cases of conflicts with their friends or close family, or brake ups with partners – where the consequence might be that they don’t have a place to stay, lose opportunities to make some
money on informal work, have less or nobody to exchange favours with when excluded from relationships where one help each other, in addition to the psychological strain.

Living with HIV can also make people more vulnerable as their near relations may have or misconceptions about or prejudices against HIV, act suspicious, or use the fact that they are HIV-positive against them. Participants in this study have different reactions to behaviour like this from their near ones. Alma told the one person she thought she could trust in Norway, her close relative, about the HIV diagnosis, but that this person spread the information to a lot of people.

When I was diagnosed with the HIV… I have my [relative] in [town in Norway]. I was getting sick by day by day, I wanted to tell her so that she could understand why and would know about me. I talked to her …and she was so negative to me. She told everybody, all people we know and close friends. And it was so uncomfortable. And so they all know who I am and what I am so I could not walk on the street. I had to leave that place. Then my [relative] called to Africa and told all my family. (Alma)

Later, the same relative has on several occasions made it clear that she thinks of Alma as promiscuous, saying, ‘that’s why you’re in your situation’. If she got attention from men the relative had called tell them up and warned them about Alma’s HIV-diagnosis. Alma explains that she was told, ‘you want to destroy everybody’. She had stayed in her relative’s house for some time, cleaning, cooking, and helping out in the house, when the relative in one of her outbursts gave Alma three days to leave the house. They didn’t talk for a long time, but now, slowly, they have had contact, mostly when the relative needs Alma’s help since she lives closer to the city. Alma is careful, though:

(…).and she told the boyfriend about me. Now I’m thinking, if you stay, or you leave, is ok for me. I don’t need her near to me. Distance is better for getting respect… for keeping the respect. (Alma)

To maintain dignity and fight for respect and recognition seem to be just as consuming as the other struggles. They are not accepting other people’s view that they are superior to them, but in the end they have little choice but to ‘let it go’.

(…)Today now I have many friends. If I tell them I have HIV I will not have a friend anymore. They think all the bad. They don’t see the person anymore. They will tell to another person and another. They will…
Really, I am so free to tell that I’m HIV positive. But I know I can’t, not to everybody, you can’t. They take advantage of you. (Alma)

I have told only (samboer). And I told my boss. I think, one day I will tell my other friends,…I will tell them, and if they don’t like it, then they don’t.(Adil)

‘It’s good that I got HIV since I am like that’. HIV as punishment.
It’s a short way from thinking of HIV as (a result of your own bad choices, to) deserved, to thinking of it as punishment for some sinful behaviour. Adil is thinking about his family, about people back home, and what he is certain are their thoughts on HIV and being a man attracted to men.

And with HIV… HIV is not possible, how can you be a man. You cannot be a man (they think). You are girl, you are… anything, but not a man. And they will be happy, say, it’s good that I got HIV since I am like that, you can call it, gay. ‘It’s good for him, he’s gay’. (Adil)

If others knew about him, they would not think of him even as a human belonging to the same classification system as them, wouldn’t have a word for him, he would be ‘anything, but not a man. Being gay, he will be perceived by others to lead a life so bad it’s beyond naming, and he will be a nobody, a non-existent to them except that he will be considered both ‘well suited’ to be HIV positive and deserving of the ‘punishment’ of an HIV infection.

Being free
Three of the participants are in long-term relationships. Adil has a life partner who has been with him since before he was diagnosed with HIV, and they have gone through the process of learning about it, and among other things trying to find health services for Adil - together (and the experience of living with HIV is of course only one of the things they share in life). The scolding Alma got from her relative was on one occasion witnessed by a friend who reacted to what he saw as punishment, and stood up for her. Now they are close friends, he comes to the HIV support centre with her and helps her in many ways. The expression ‘being free’ is used by several participants; like Alma says:

…and I thought, I have to be open to him so I can be free…free with everything, and he can understand me.(Alma)
By sharing the HIV diagnosis with the ‘right’ persons they create a space where they can relax and be themselves, as opposed to ‘not getting freedom to be with yourself’. Miriam says, she doesn’t tell many people about the HIV diagnosis, but says she is free with her Norwegian mother-in-law – her partner’s mother. Her mother-in-law was involved from the day Miriam got the letter with the test result – when Miriam couldn’t understand it – and her mother-in-law also went to the doctor together with Miriam:

She supported me, she said it’s ok, it’s like diabetes, or cancer. Now we are free. I’m not afraid, she knows everything. Her mother too she knows it. (Miriam)

Alma is many times mentioning her sister back home who has protected her for many years, knew about her diagnosis but kept it secret for Alma so not to

My sister in (home country), for eight years she did not talk to anybody, just kept it as secret. Ok she did tell my sister in (other country), but did not tell it open, more like ‘our sister is in a bad situation’. Later she said ‘I have to keep it secret so not to finish you’. (Alma)

Those who have a life partner are open about the diagnosis and the medicines, and partners may be involved in the ‘illness’ in various ways – going to doctor, reminding their partner to take the medicines, engaging in the worries about their partner’s health if sent back to home country. Of the participants in this study, two of them live with their partners and one is staying partly at her boyfriend’s, and partly at other friends’ houses, and sometimes in the support centre. She and her boyfriend are now planning to move in together.

You didn’t go look for it, did you? Acceptance

Alma has explained how she took the chance to get into a new relationship, how scared she was when telling her boyfriend about the HIV diagnosis, and how certain she was that she would never see him again. I include here what she shared about the time when she told him she is HIV positive, and his reaction:

And now after I met my boyfriend and we were together you know, for a while, and then I felt I must be open with him I said ‘I have something that I want to share with you, and I told him, and I said, that’s why I’ve been using protection… and he keeps… he kept quiet and…he didn’t react anything…he just went hmm, …ok...mmm… mm..ok…And I thought he wants to forget me. I told him it’s ok. It’s only me, it was secure.(?) He drove me home, he kissed me and said I love you. And I thought Oh my God what did I do to tell him so fast – this man will just hate me because of that. So I deleted his phone
number. And after two days… he didn’t call me I didn’t think I will ever hear from him again… then he calls me and asks if we should go for dinner, and invited me to his apartment again. And he said [about her having HIV] yes, so what? Did you get it by your own will? And what can I do about it…this is nothing to talk about. You didn’t go look for it, did not want it. You didn’t go ask for it, you can’t change, what can you do. He asked later about treatment and if I was getting good care from doctors. And he never discussed it again, it’s not so important when we’re together… we don’t talk about it. And it makes me love him more and more. (Alma)

In all settings and under all kinds of conditions where people meet people, some fall in love. Here, Alma was dreading the consequences of telling her boyfriend about what she has experienced in so many ways is regarded by others as a major flaw: being HIV positive. She is relieved and astonished that he still loves, accepts and stands by her. They are planning to move in together.

How to live together, you know, I don’t have anything now to hide from him. It’s ok for him, whatever. (Alma)

There is an emphasis on HIV not being something she actively had sought, that she instead is an innocent victim of it, in contrast to the earlier blame and charges she was met with- ‘that’s why you are in your situation’. There is nothing to be done about it now, apart from getting medical follow-up. HIV is not so important in their lives. Lately the boyfriend has become more interested to find information about ‘it’ on the web – he goes to the internet to find out more, for example HIV Norway’s home page. He also comes to the doctor appointment.

Problems with partner – Protection, respect
The same partners’ knowledge of, or lack of understanding about HIV infection can cause conflicts and sometimes distance. Some have experienced that partners shows little regards for them; putting the women in a difficult situation by refusing to protect themselves from HIV transmission, i.e. don’t want to use condoms. They worry about their near ones and if they could get the infection, and they fear becoming the reason for this. The participants express a sense of having the sole responsibility. They have to keep telling and reminding their boyfriend how he should protect himself from HIV transmission. This concern springs out of love and care for their loved ones. It also comes from the fact that they suddenly can be seen as criminals, law-offenders; if the other person turns against them and brings up charges about exposing them to HIV virus. These worries influence the relationship that involves sex, as well as behaviour on other aspects of life. Her Norwegian partner gets upset when Miriam brings up condom use and may bring the HIV diagnosis into a quarrel and use it against her.
They have this kind of conversation now and then, she laughs a little about it, but also seems sad. She doesn’t want to leave him, but even if she wanted to, she couldn’t.

At home I have a problem with protection because he don’t need it. I tell him that he needs it. I took him to the doctor at the infection clinic and made them tell him. It’s painful you know, if he gets this from me. I will blame myself yes. But before, when we met and I didn’t know, that is different. If I say no he will be angry. He argues. I ordered condoms free from Internet, it came in the mail, he said NO I don’t need it. (Miriam)

Maybe that is the knowledge. He doesn’t know, he doesn’t have enough knowledge about the seriousness of the disease. He thinks it is OK, we lived together for 2-3 years. Sometimes he says I can find another ‘dame’ if you talk to me like this. I say OK you can find another ‘dame’. He says he can find somebody not sick, I say yes you can live with her and I can go… It hurts. It hurts, sometimes I feel… but I can’t avoid it. He can find…, and I can go out. It’s better to leave it. Let him do what he wants, forget about these things. Sometimes when I sit and talk with him, I tell him that I feel bad when he says this. But I must hold it. I can hold it. I get angry. But where shall I go. (Miriam)

Hana thinks she is obliged by law to inform a boyfriend or potential sexual partner about the HIV-infection, and other women on the study are not sure. Some feel more responsible also for following up this, insist on the use of protection in form of condoms, and worries a lot when his or her partner doesn’t agree, like Miriam has expressed. Alma has another point of view and gets quite upset when we start talking about the laws concerning HIV, paragraph 155, and turns instead the focus to two people loving each other, asking why should there be any talk of responsibility for HIV transmission in a relationship like that?

I will tell you this… Who’s responsible then? My friend’s boyfriend don’t use, he don’t want to use protection. Because they are so in love… they love each other. And my old boyfriend, I always insisted on using protection and he didn’t want to. (Alma)

While Miriam wanted to stay despite conflicts or quarrels, Alma has seen no choice but to leave her earlier boyfriends, for reasons she relates to the HIV infection. She shares that she has had difficult relationships in Norway. She has the same experiences; her boyfriend refused to use protection. I addition, one partner didn’t tell her that he was HIV positive when she knew for certain he was, and even if she had told him about herself. This, she explained, was not possible for her to accept in the long run. Him not telling about his HIV status caused an imbalance in the relation - as if he wanted to feel better, stronger than her, and wanted the power this gave him. In other relations she has felt humiliated in different ways, and gets back to one particular story during our interviews - she needed sanitary towels, had no job and no money and asked him for a few kroners, but didn’t get it, whereas he spent a lot of money on himself. She felt humiliated and saw it as a symbol of an utter disrespect for her, and for her
body, and that she no longer could trust him with anything. After living with this man she sometimes thought that having a negative from UDI was in fact better than being HIV positive; that HIV causes more problems than lack of residency because of others’ perception of it, and of her. She relates her boyfriend’s lack of respect to the fact that she has HIV. She also relates experiences of disrespect to men from Africa. At the same time, she cannot quite distinguish between her and HIV, or don’t know if the boyfriend was not comfortable with her or with HIV.

.. I’ll tell you what, I have this experience with… I call it African men. With this other boyfriend, when it grew into something… I used to think I cannot tell somebody…like…it is even better to have a negative [thinking]. I cannot know if he was not comfortable with me or with it [HIV]. He did not have at all the support that usually is in a relation between girlfriend and boyfriend…(…) (Alma)

(...) I felt this is a person I cannot trust with ANYthing. There was no togetherness. Even now if he comes…for help of any kind, I help him. But I could not come to him with such small things. (Alma)

Meeting anybody? I don’t think it’s for me any longer

Shan was, after he knew he was HIV positive, not thinking of meeting anybody, not other people in the same situation, not anybody at all. The key person is eager and encouraging to make him want to meet others who are living with HIV, at the same time very much supportive of hiding the diagnosis from other people, outsiders.

I didn’t think about it. I have not even seen anyone. I thought not of meeting anyone. I thought not of meeting anyone, no one, just die and go. But she [nods towards the key person] encouraged me.(Shan)

You are not so free like others. For many it’s like a broken bridge. You cannot say I have ‘this’ – so you run and hide even if you need it. Like me…it’s not easy to find a boyfriend, either, in this situation…It’s nature, I need, and we all need it. (Miriam) (my translation)

You’re a woman and a person. It’s no… Because I’m ok, it’s no problem.(Hana)

The women in the study are clear on the fact that they have needs and longings, and view a life with romantic or sexual relations as the most natural. They do express that they nevertheless hesitate or all in all avoid getting involved in a romantic relationship, because of fear of the consequences if they are open about their HIV diagnosis. A belief or a feeling of having an obligation to inform potential sexual partners of the diagnosis seem to be the basis for a decision for not looking for, and not being receptive to any advances from others. This fear is a fear of being rejected – and of rumours, of being talked about, treated different, avoided. Being excluded from a social network will in addition make life and living
conditions harsher, as most of the ways people manage and get along, are through friends and acquaintances.

There are not many asking...now. Men here [in the camp], they have psychological problems, it’s difficult. They have final negative. The biggest problem is that men insist. Now I say I am married, that’s the only thing they understand, then they leave me alone. I know I have a duty to tell them, it makes it...I know I have this duty, and it makes it...I rather keep them away.(Hana) (my translation)

May be he tell another person. When I think about that… it’s better not to involve with a man. They push…but I’d rather not. I don’t think it’s for me any longer.(Hana)

I try to stop it with me. I don’t want to share it with somebody

As mentioned above, participants feel responsible for informing and trying to teach their male partners about condom use. One gets into repeated arguments with her partner about this, one see it more as a sign of true love between two people, and also that not using protection in these situations is a conscious choice by the man. The talk of responsibility upsets Alma; she expresses that nobody else can make judgments on what’s going on in a couple’s most private and cherished moments – and dislikes that somebody wants to question and control even the most intimate parts of her, or others’, life. The talk of duties, obligations and responsibility, as well as new suggestions on how to keep a register of people living with HIV, seems to be offending or hurtful to several of the participants in this study. A doctor came once to [interest organization] to talk about an anonymous HIV registration they were planning, telling that the register could be useful for people living with HIV – they can look up their CD4 numbers for example by using a code. The audience didn’t want to be a part of this, though. Miriam is saying, she felt that somebody wants to keep track of and control her and others because they are HIV positive.

In addition now, Miriam had heard on NRK that somebody suggested that a person who apply to get married should be obligated to inform (the authorities (?) about their Hiv status. Again, people protested, didn’t want this. Miriam wonders: is it because she is HIV positive that she is not allowed to marry? She has applied to UDI to marry her partner for many years, but the application was rejected. She has hard times understanding it since some women she knows, who also live irregularly in Norway, did get permission to get married here.
Is it because of HIV I don’t get permission to get married..? I don’t know… sometimes I believe it is. Others I know who were in my same situation, like with a negative, they were allowed to marry, so why can’t I? (Miriam)

The only way she can explain it is because she has HIV infection, and that it’s authorities attempt to control HIV transmission, protecting inhabitants, controlling people like her.

Miriam is telling about how she is taking precautions, one time she felt she had to interfere and tell a nurse so she could be more careful with needles. Also in other situations participants are acting very careful, thinking about how it transmits. Miriam visits her partner’s grandmother in the nursing home and helps her with a lot of things – exercises, clothing, buying and bringing things from town (as we have seen). She stays away from anything she thinks can cause HIV transmission and she is in many ways exaggerating the caution. She says:

I try to stop it with me, I don’t want to share it with somebody. (Miriam)

**HIV and social opportunities**

To not have a residence permit may limit the chances of meeting people and grow a sense of belonging to a group or local community. The natural arenas for getting to know people might not be available to them, or are there only on a temporary basis - as some has to move around. In addition, lack of money, or lack of valid ID, makes it difficult to take use of the arenas that otherwise would be open to them. Some have their own family – the Norwegian partner they live with and his family, or their own children they live with here in Norway. This does give opportunities for interaction with others – the extended family in law, parents of other children in school, teachers. Lucy, who has small children, takes one of her children to ‘open kinder garden’ sometimes, but spends most days alone with her children. One of the participants is active in a political group, and one is working in public settings for the rights of people without residency as well as having some friends in this group.

Living with HIV doesn’t in itself limit the possibilities of participants in this study to be part of of various kinds of social environments –as long as their HIV status is not revealed. Nevertheless, their belonging in these different groups or environments mentioned above is not unconditional, and would not exist if others knew about their diagnosis, the way they see it. Living with HIV can thus lead to a feeling of being on your own and only partly being
accepted. Shan said he didn’t think of meeting anybody at all after he was diagnosed with HIV. Others in this study say that relationships of any romantic kind now belong to the past.

HIV is experienced to cause problems and barriers in social life, however irregular migrants living with HIV may also have some advantages as to where to turn to get in contact with people. One of the intentions of the HIV support centre is to counteract the loneliness that people living with HIV may experience. Like Hana says, coming to the HIV support centre was the very first time she talked with another person with HIV. When we talked about health, she also expressed that to her, hope means good health. Meeting others living with HIV made her feel happy and relaxed, not having to worry about what they think of her.

The best is to have hope. To continue to fight and to forget what people say about that diagnosis. Especially in [home country] it was difficult. It is perhaps better here. For the first time I could talk with somebody in the same situation. (Hana)

(…)For example here [at the HIV support centre] I like it, I’m very happy to meet other people. I don’t know anybody at the camp- I don’t see them. (Hana)

Only two of the participants go to the support centre relatively often or have contact with staff there, some have only had a few individual appointments with personnel at the centre, one other have attended parties they arrange, or they have attended seminars about HIV. Alma has rented a room there for short periods, and the centre has been a secure spot she returned to many times for the last years, and a place she can keep medical records and medicines safe from disclosure. Some don’t visit the support centre; Adil lives with his boyfriend and express that he is not very interested to be part of the environment at the support centre, others fear meeting people from their home country. Alma have experienced that she met an acquaintance there who immediately informed that she is ‘just visiting and is not HIV positive’, putting Alma in an awkward position. She doesn’t want to think much about it, though, says she cannot change it.

But I see it, that it makes me down and down. So that is what it is. If she wants to talk about it, she does it. If she talks to others…I don’t think about how she says it, or if she…Because it hurts too much. (Alma)

She does have a lot more good experiences than bad at the centre, and met the person who is now one of her best friends there. Contacts gotten at or through the centre seems to be important with regards to many things, like access to health care, practical support, guidance or help with paperwork to UDI. The staff at the centre has known over time some of the
persons who live with HIV in irregular exile, and had one day I met Alma encouraged her, she says, by putting today’s situation in perspective – before she had nothing at all, no place to live, no job, nobody really - today she has a boyfriend; and a place to live.

Time is a constraint to use the support centre. Like Miriam explains, she got advise from them, but didn’t go there - being too busy, and before, when she had a job, too tired after long days’ work. In addition came the fear of meeting ‘own’ people. She feels more comfortable going to the HIV interest organisation that she found on the internet, and tells that there are not many people from her home country. Saying she knows the other members well now, and express a sense of togetherness. She is also content with having actively looked for, found and made her own choice of what she wants to spend time on. Through the interest organisation she also gets in contact with other people and organizations that at times have become closer or been of help.

For Alma, to discover the ‘world’ of an HIV social network on the Internet was a great relief, and she met one of her very good friends there.

I went into dating site for HIV positive. Oh my God I met so many people! It was so good to meet so many people in your same situation. I thought I was on my own.(Alma)

The social arenas reserved for people living with HIV may invite to a deeper sense of loyalty and togetherness with those met there – like the HIV support centre and the HIV interest organization, and is experienced as such by the study participants who use the places on a regular basis. Being part of social / political movements like ‘Nobody is illegal’ also give experiences of belonging in a group, not fighting alone, but people may fear the publicity this kind of engagement may give. Some participants go to church regularly, and meet their friends there.

Discussion
In this study, Miriam’s expression ‘HIV is like a broken bridge’ is representative of the study participants’ perception of HIV as a major life disruption. To find out that one has tested HIV positive has been described as a major disruption in that person’s life (Körner, 2007; Svenaeus, 2007). The Swedish philosopher Fredrik Svenaeus (Svenaeus, 2005, 2007) has studied, within a phenomenological framework, people’s lived experience of illness. He describes sickness as an underlying form of homelessness in life, and becoming ill as a process of alienation. This feeling of homelessness will according to Svenaeus always have a link to the body, and the
illness will guide the person’s attention to his or her body. In this lie also opportunities for increased focus and actions in order to get well or stay strong. The alienation is however not confined to the body, but stretches to life itself, the life world. The challenge will be to find a homely sphere in ‘world and time’.

With the above perspectives, living with HIV is in its essence instability, insecurity; it means to lose ground. The life context of the participants of this study resemble that of stateless conditions involves ‘a loss of a place in the world’ (Blitz & Otero-Iglesias, 2011, p. 3) and ‘a loss of home’, as discussed earlier. In their lives, therefore, there exist a double homelessness: the loss of home and a ‘place in the world’ due to the illegalised exile, and the homelessness that comes with sickness. In a situation when HIV in itself feels destabilizing, the study participants feel a need for structure and stability also because of an underlying fear of the unstable; the uncertainty and insecurity. In irregular, illegalised exile, to find ways to live more sheltered and secured is a challenge. Participants in the study find that living with HIV brings a greater need for a safe and predictable life situation; however, to find such ‘homely sphere in world and time’ while living in illegalised exile may seem impossible. Irregular migrants in general often have difficulties finding it, and the study participants’ stories tell that HIV in many ways limits the possibilities of maintaining such stable situation; they know that if a roommate, acquaintance or family member finds out that he/she is HIV positive, he/she will have to leave the place – which means a new disruption. In addition, words about their HIV positive status may shut doors and add to a feeling of alienation.

Furthermore, the concept of biographical disruption proposed by Bury (1982) involves that learning that one has a chronic illness causes a sense of one’s individual life course being undermined. It entails a sudden uncertainty about the narrative of one’s past life, uncertainty about what will happen next and how one can live with others. Attempts to reconstruct a new time-line and with that ‘reconfigure his or her old self’ is seen by Charmaz (1983, cited in Radley, 1994) to be inhibited by four social psychological conditions – ‘living a restricted life, existing in social isolation, experiencing discredited definitions of self, and becoming a burden’ (1994, p. 146). The context of illegalised exile and the lived experiences of the men and women in this study tell stories of all the above. The men and women in this study have to work on such ‘reconfiguring’ of themselves under life circumstances that are fundamentally unstable.
The time lines in their lives are complex. Association to death, the end of their time, is there. On the other hand, HIV infection is ‘moving slow’ and years pass without the need of treatment, and at the same time you don’t know when the change will come. Appointments for medical check-ups come at regular time intervals, the numbers, the viral load or CD4, will rise or fall with time, and as soon as an appointment is over comes the anticipation of the next one, after three months, two months. Time is ‘on your side’: like one participant thanked God that she is healthy and not even now on medication. However time also works against you; the day you need to start life-long treatment will probably come, and the day you are deported, removed from the line of people waiting for the next appointment at the infection clinic, can arrive at any time. The years are passing being away from your children growing up, and the years without a centre in your life, where time is directionless is adding up. They are in many ways trapped in a vacuum. Time spent waiting for answer from UNE feels too long, but time passing gives certain hopes of a permission to prolong and extend their time in Norway. And, all the while time passes there are two looming disruptions that threaten to be greater than the disruptions they are experiencing today – the HIV infection can end in AIDS, and the illegal stay can end in a deportation.

In this study, a theme that recurs throughout the study participants’ experiences of living with HIV is that power and of being controlled. The power exerted against them materialised in various ways, from the very subtle in their everyday activities, to the restraints put on their social lives because of the HIV diagnosis, to the checkpoints embedded in the health care system as well as the barriers imposed on their wish to make major changes in their lives. In addition, their perception or experiences of life with HIV in their home country was that of control and expected submissiveness, exerted by their social network and community in the form of isolation and exclusion, and by authorities in form of repeated disciplining behaviour change campaigns, mandatory HIV tests at work places, structural barriers to secure access to treatment, and ‘demarcation zones’ and lack of discretion in health care settings. To do something to relief the difficulties of living with HIV in their home country were beyond their control or means.

Living with HIV in irregular exile in Norway meant that any thoughts of trying to change their situation, like escaping this life as ‘illegal’ and move to another country, was impossible. The demands of the HIV infection tied them down, and the stigma of HIV limited the
possibilities and choices they felt they had. For the mothers in this study, forces outside their reach caused barriers to leading a life together with their children. The lived experiences of the study participants are structured by powers beyond their control. The stories of Paul farmer’s patients living with HIV/AIDS in Haiti showed that their life choices, and their individual experiences of illness and suffering, were structured by political violence, racism, sexism and ‘grinding poverty’ (Farmer, 2009, p. 13). Although the historical and larger socioeconomic lines have not been part of the analysis in this present study, the narratives of the study participants do point to how social forces become embodied as individual experiences, to use Farmer’s expression.

Although several now had a more stable place to live, all had experiences or an understanding that the reactions or potential reactions from others were decisive of where, with whom and for how long they could live at a place. Disclosure of HIV status would further decrease the range and freedom of movement - the space wherein they could perform their daily lives at ease. There will be no room to relax and just be who you are. All had stories of how other knowing about your HIV diagnosis would mean that the others would feel in power, be in control and take advantage of them, and some had experienced this in their relationship with their loved ones, like their partner or family.

As for others living with HIV in Norway, the right to HIV treatment and care also implied some control from authorities, and some of the study participants were reacting to parts of the duties and control it implied. They cherished the treatment and follow-up that this right secured, but the law also entailed a duty to commit and adhere to the treatment and check-ups; information about these duties is part of the overall information people being diagnosed with HIV infection receives. A person who is diagnosed with a communicable disease is obliged to name/give information about the person he or she contracted the infection from and people who may have contracted the infection from him/her. Moreover, if a person does not cooperate or adhere to a treatment regimen, in theory, sanctions may be used against him or her. In the camps the study participants had to show receipt from the infection clinic when they got back if they wished to get expenses covered. The penal code (Straffeloven, 1902) was further adding to disciplining and gave a sense of being ‘punishable’ and controlled even in the very private sphere of a loving and caring relationship. Miriam was also questioning the purpose of a HIV register (although anonymous) suggested by doctors and health
programmers; she and others saw it as control. She wondered at the same time, was it because of HIV that she was not allowed to marry in Norway? The disciplining and order-making gives associations to Douglas (Douglas, 1966) concept of purity, where she explains dirt, uncleanliness, as essentially disorder, and argues that such ‘matter out of place’ is attempted avoided by approaching it through order (Douglas, cited in Bauman, 1997, p. 7).

The participants in this study had experienced that they were blamed and viewed by others as immoral persons because of HIV, and as having themselves to thank for the infection. In addition they understood that they were seen as a bad influence on others, and as somebody who need to be controlled. Their freedom is limited by HIV stigma: people around you ‘own’ you and control where you can and cannot be, and with whom, by excluding you. The way Hana explains it in this study, if others come to know about the diagnosis they will behave as if you are about to die, and that you bring misery and death upon others. If you keep living, you are viewed as somebody who might as well die. The word stigma is according to Goffman (1963) applied more to the disgrace itself (than to the original Greek meaning of the bodily evidence of it), and one type of stigma is ‘the blemishes of individual character’ perceived as deviant from a stereotype, and therefore leaves the person discredited, or discreditable. The effect of stigma is that a person is ‘reduced in our minds from a whole and usual person to a tainted, discounted one’ (Goffman, 1963, p. 3). Stigma thus exists between people; it involves the societal reactions to a person. Expecting and anticipating degrading reactions from their surroundings, the stigma may be internalised in ‘a deep sense of shame’, and ‘a spoiled identity’, in Goffman’s terminology. The person may ‘accept’ this stigmatised identity, or resist it, ‘either way, his or her world will be radically altered’ (A. Kleinman, 1988, p. 160). The study participants were exactly anticipating such reactions, and they acted, and planned and worried in line with it. Their lack of legal residency, and their ‘status’ as transitional beings ‘betwixt and between,’ in many ways confirmed their otherness. As Miriam expressed it, ‘I am not supposed to be’.

Perhaps in opposition to the above, this study suggest that there is a contrast between the way the study participants perceive HIV in relation to home community and how they perceive and experience living with HIV in Norway. Life in Norway was clearly perceived to mean a better chance to be shielded from the everyday discrimination and exclusion they knew,
through their own or others’ experiences, that living with HIV in their home country entailed. Life in their home country was seen as an impossibility, and if they survived there, as ‘life without life’, both for themselves and, for the women in the study, their children. For Adil, being gay meant he would be under control and unsafe everywhere in his home country; being HIV positive he was certain would justify disciplining, harassment, and ostracism, he would be ‘at the same time invisible and too visible’.

Although the study participants were indeed burdened by the reactions they experienced or expected from others and the considerations they needed to take in their everyday lives in Norway because of HIV, they seemed in many ways not to regard HIV as a main characteristic of their lives here. This seemed to be related to the relative security with regards to medical follow up of the infection -as long as they are here - together with the understanding they now had of HIV and the relative higher chance to maintain some privacy – and the supportive relationships some had. Living in exile could give hope of living a complete life, to be more than ‘a person living with HIV’ or ‘a disease’. Some had through their Norwegian partner and family developed relationships where their HIV diagnosis was not much of an issue, and where their personality, the role they took, their very existence were acknowledged - and needed. Such spaces of recognition gave freedom and some shelter from the stigma that otherwise could be experienced as dominating in the lives of people living with HIV. Arenas with a focus on trust, openness and assertiveness, whether it was in a new family or arenas reserved for people affected by HIV, increased social capital. This increase in social capital had the potential to increase resistance to stigma.

Living with HIV gave, through organisations and websites reserved for HIV positive persons, opportunities for developing a social life that others living without a residence permit might not have. Some women in the study were, or had been, visiting organisations like Aksept or HIV Norway several times, and found (exactly) ‘spaces of acceptance’ there. The possibility to relax, to be with others ‘in the same situation’, to be an equal and be met with respect and friendliness was cherished. In addition, to get help in connection with the appeal to UNE was sought after. Others had heard of these places, but found no time to go there because of work hours and unpredictability in daily life. Others stayed away or kept in contact with social workers without visiting the organisations because of worries of meeting people from their home country, as mentioned earlier. One was not so interested or didn’t feel a need for it. One
was sceptical, wondering if in such place you become ‘all disease’ and loose yourself as a whole person, while others said the good thing about Aksept was they could get a chance to relax and just be themselves. The study participants who had the least support and network in Norway associated HIV to more of their daily whereabouts and concerns and seemed to perceive HIV as more dominating in their lives than those who had more stable social relations – although for the last group this was dependent on the space they occupied at any moment. However, all saw the difficulties related to living without legal residency as a more over-arching and all-consuming circumstance in life here in Norway.

There is also a contrast between how most of the study participants themselves conceive of HIV and the way they understand others to generally perceive of HIV. Participants in this study have different reactions to demeaning and condescending behaviour from their near ones, and they were upset by the unfair treatment they were, or knew they would be subject to if their HIV status was revealed. They were in this way protesting and resisting HIV stigma, and at the same time ‘accepting’ it as a mere reality of life, not being in a position or having the power to change it. The protest is in many ways echoed in the relation they have to the immigration system, where they try to challenge the blame, suspicion and unjust treatment they felt they were met with, as well as the harsh living conditions and the many types of loss the condition of statelessness’ entailed.

Paul Farmer tells that during his work in Haiti, one person with AIDS stated:

‘I don’t know what my life expectancy is going to be, but I certainly know the quality is improved. I know that not accepting the shame or the guilt or the stigma that people would throw on me has certainly extended my life expectancy.’ (Farmer & Kleinman, 1989, p. 136)
Chapter eight: Perspectives on health

Perceptions of health in illegalised exile

Introduction
In the interviews, I asked the study participants what they associate with health and ‘being healthy’. They had many associations, about what it means to have a healthy life, about what can help maintain good health, and about what in their life situation that is challenging health. A range of reflections on these topics are presented below. Having the application for asylum rejected, and being without a residence permit, was what they saw as the over-arching reason for all the barriers to good health.

To get the negative is bad for my health

‘If I get paper…But when they told me I did not get the paper, I…To get the negative is bad for my health (…)’. (Hana)

Hana expresses clearly that having her application for protection rejected is bad for her health, and that to a large extent sums up the issues that the men and women in this study experience as challenges to good health – and what the main barrier to all that can give a healthy life is. Hana says this in connection with being allowed to have a job, as will be returned to below; having a ‘negative’ increase the everyday hardships as well as time available to worry, and leaves her without means to plan anything. Getting the negative is also bad because it challenges her hope, and hope itself she sees as important for health. She cannot give up; resign with regards appealing to UNE, as it would mean to give up any hope that’s left.

Work is health
When I asked the participants what their thoughts were about health, the issue they brought up was that in order to be healthy and have a healthy life, they need first and foremost to have a job and to work (and they did not express a need to feel healthy in order to work). During interviews they talk about how having a job makes, or would make, life healthier for different reasons. In response to a direct question from me about her perceptions of a healthy life, Alma stated:
If you have a job and you are working some days, not even all, but at least several in a week, and you’re earning your money and can support yourself, have your shelter, support your children … I think if you have that you can avoid the stress and disappointment. I think it is as simple as that… part of it is that. (Alma)

Having a job will give an income, an income she herself has generated, it will make her able to support herself and not be dependent on others. Aside from it being important for feeling of self-value to be able to support oneself and not be dependent, or less dependent on others, it would give a greater sense of security and predictability in life, even in the situation of living here without a residence permit. To have a job and make money would give increased control and less vulnerability when it comes to having a shelter - where to stay, with whom (if anybody), and for how long. Regardless whether the study participant was living in a reception centre, with a partner or temporary with friends; to be allowed to and in fact have a job is considered fundamental for their health, and obstacles to work is seen as reason for ill-health. Being able to have ‘real’ work and a place of one’s own depend on getting a positive answer to the asylum application.

Furthermore, to have a predictable income secures the felt need and obligation to support the children back in the home country. Alma and the other mothers viewed this as an important part of feeling content, and with that, healthier.

The need for work and income that the participants emphasize is fundamental to their perception of health. Spending time at work also gives less time alone, and to feel down, or worry. The satisfaction of having a job, and time spent at work, leads other concerns, like HIV, to fade. Hana says, when she is working she doesn’t think about the HIV-diagnosis:

To work, and come back to home. I don’t remember about the diagnosis when I work. I don’t think about it. I’m healthy, I think, I’m not sick. (Hana)

I thank God for being healthy. I was not under control. Now I am well, I don’t need any care from others so I’m ok. If I had a chance to have a real job and a place to live, then I had…I have capacity, I can work, I can do plenty of things. (Hana) (translated to Norwegian by key person present during interview, then translated to English by me)

Being dependent on others when you earlier could depend on yourself is in itself hard, a ‘fall’ of status, in addition to the financial and practical implications. Adil brings up the implications it has for him in a relationship, too:
I have friends, they know my situation, about the people I have no problem. 80% of people are ok, if they can help, they help you. No one can help you every day. Even your mother or father cannot help you always? …..but [you feel] no one wants you or like you [the cohabitant mentions that there might be some paranoia here, too?]. (Adil)

If anybody asks for an ID -and I don’t have it- police will come. Or ID control. Or at work, if they come and look for people like me. My boyfriend is here [looking at him]. He cannot give me food, clothes, pay for where I live? You want to share, you need to take part. [There is a saying]’the hand who pays is better than the hand that takes’. So what it makes me feel. I always owe him. It’s not equal. [we talk about the power of a gift] That’s what happens. It is no balance. (Adil)

Adil had been without a job for more than a year and told about a constant feeling of stress and anger with himself. This was also tied to the relationship with his partner, where the fact that he was without any income and therefore (completely) dependent on his partner for housing, food and other expenses always made him feel less worthy, frustrated and down (although his cohabitant didn’t think he should feel so bad about it).

To be financially equal in the relationship to his partner was important for him to feel good about himself. He got a job again after trying for a long time. Having a job fills the days and contributes to a feeling of value, reduces feeling of failure and of shortcoming in relation to partner and with regards to the role as a man, or as a mother, for the women in the study. Having a job does not, however, remove the everyday fear and insecurity arising from having a ‘negative’ from UNE and to know or fear one can be picked up by the police any time. The worries therefore continue, but as Adil expresses, so does his hopes, even though he seems quite resigned when sharing this:

Now, I wake up in the morning and I go to work five days a week. I can share the rent. And every night I think maybe tomorrow it will all be better, maybe tomorrow something good will happen. (Adil)

**HIV and health**

Among participants’ more immediate explanations about what it means to be healthy, perceptions of ill-health related to living with HIV was not brought up. Feeling safe and in control with regards to the HIV diagnosis at the moment, with regular appointments in the hospital and access to treatment, seemed to contribute to this. Hana stated that she is now under control and healthy, referring to the treatment she received in Norway, and also that she
doesn’t think that she is sick (with HIV) if she works. Another study participant used the Norwegian word for health and stated that for the ‘helse’, medicines can help.

However, they had worries about what the HIV infection would bring in the near or far future, for some there was the waiting for the time they would need to start medicines, others had experienced side effects from HIV medicines and had to change medication, in addition they were uncertain if they would get help if they were having pains of felt ill, and they had uncertainties about whether these symptoms were related to HIV or not. How the study participants responded to these uncertainties varied. For Adil, knowing that he has the HIV infection makes him always worry about his health:

I’m not feeling good about my health after I knew I had HIV. And I think always about it and that I might die. Even if I know about the medication. Last time my CD4 was good. It is up and down all the time. I’m supposed to start going for controls every two months now. (Adil)

And, as described earlier, living with HIV increased the overall fear for the future in the case of a deportation. Furthermore, side effects of HIV medicines could be a cause for some of the physical health problems they had experienced and add to sleep disturbances.

Feeling ill or not. Getting health care when sick

Most of the study participants did not talk much about feeling physically ill during the time (or at the time) I met them, but they did recall such episodes of feeling ill, both recent and further back in time. When they did, it was always linked to the difficulties they had in getting medical attention the times they felt ill. Knowing that apart from the HIV treatment and care, health care were not available to you before you are acutely ill, or without going through much trouble and embarrassment, was in itself a cause for worry and added to the general feeling of distress. How to get help when you get sick was perceived to be unpredictable. In addition there was the fear of a large bill after a visit to a health care facility, or that immigration authorities will find out about you. Feeling ill was in this way always seen in relation to the how to find help to get better. Lucy told about several visits to the emergency room, she has had bronchitis or pneumonia; she is not quite sure, and she has had other episodes with chest pain and breathing problems. She says, the doctors checked her heart, finding nothing wrong:

But the problem is the way I feel. As if…I just seize breathing and if someone talks to me I can’t respond to them. (Lucy)
The headaches… I have a depression. I went to a doctor, the camp office made the appointment. I got an antidepressant. (Lucy)

Side effects of HIV medicines were seen by the study participants to be the reason for some of the more physical health problems, such as stomach problems, diarrhea, dizziness, heart palpitations and feeling exhausted. All who use ART have been through different types of medicines to find types they tolerate better. Nightmares are well known side effects of some ART drugs; like Miriam says, she can tolerate the medicines she uses now, but they cause ‘strange things in my head at night’ – thoughts and nightmares – adding to the sleep problems and worries she already has at night. Both she and several others in the study are using antidepressants.

Part of staying healthy is a person’s opportunity to stay home from work when he or she is sick; Miriam told about how she was sick and exhausted, sitting in the toilet to rest when doing her cleaning job at a school. She was afraid to hand in the sick note the physician had written, expecting that UDI or the police then would get information about her from NAV. She says, in fact, that she did not take any sick leave for five years. To keep a job becomes crucial when you are lucky to have found one. When she felt fine and hadn’t started medicines, she wanted to do her best to keep the job. Having started treatment did not make this less important. Without a work permit, without labour rights, and with fear of losing their job in addition to the fear of being caught by the police or immigration authorities, it is difficult to follow advice from the infection clinic aiming to help you to overcome side effects of medications and other measures to save strength and improve general health, like stay home from work when sick, or seek help when needed.

When I started with these medicines I was supposed to stay at home and take it easy. But I was afraid, and I couldn’t give the [doctor’s] letter to my employer or to NAV since then UDI might send me out of the country. I had a sick note, but I couldn’t give it. (Miriam)

I was very tired during the day [at work], I almost couldn’t make it. I had to go to the toilet and sit there, perhaps for fifteen minutes to get some rest, I was dizzy and had heart palpitations. I couldn’t bear it, but I couldn’t stay at home. So I had to rest. Sometimes my stomach gets upset, the medicines can give diarrhoea, but I had to go to work, there were frequent visits to the toilet. (Miriam) (my translation)
Mental health problems. Fear and worries

All the men and women in the study were making reference to experiences of psychological distress in one form or another. Feelings of depression, and more optimistic emotions when they can enjoy the moment, alternate or change as they were moving between different parts of their daily life. Even if the participants in this study had times with more optimistic thoughts, and many of their actions in everyday life reflected these thoughts and feelings, they also had, or recalled recent periods or episodes of health problems, feeling sick, because of worries. For all of them, constant worries, fear, and – with time – a feeling of lack of meaning in life, stayed with them over the years after they received the final negative on their applications for asylum.

Not having daily obligations or meaningful routines contributed to a feeling of ill-health. Alma explains what she means by the word ‘bored’ that she uses to describe her feeling:

To be bored, is like confusion, depressed. The whole day you don’t have anything to do, keep thinking about that you are tired of being. Just staying, just sitting, doing nothing. (Alma)

Last time I was so tired in my head I can’t understand. And I was so tired in my body. I have no jobs now. (Alma)

To be without anything to do underlined a lack of belonging and meaning in life. Alma also describes an episode that frightened her – she was sitting alone at home:

(…) I felt all of a sudden so very sad yesterday. The hours were passing, and I didn’t notice, couldn’t do anything, not read, not watch TV or YouTube, nothing felt near, many hours passed without me knowing it, I was scared. (Alma)

Sleep disturbances were common. Some had problems falling asleep, while some woke up from nightmares. They relate their problems with sleep to their worries and many conflicting thoughts and contradicting ideas arising from the rejection of their asylum application and their staying here illegally. Adil tells about how he feels almost haunted by ‘Nemnda’ and has nightmares. Miriam describes how she lies awake at night, trying to find a solution to her situation, and how this always turns into a ‘thought chaos’ and more confusion:

Sleep is not so good. It’s always confusion. I think this way and then this way, again on another solution, but nothing is possible. All is closed. And my family is also here now! (Miriam)
Some talked about periods were they had lost hope. The distress could develop into thoughts about not wanting to live, to ideas about and plans to commit suicide. The psychological distress was, the way the study participants expressed it, related to the constant fear of the police and of being deported; the continued worries about the future, concerns for their children, also if they return to them, the loss of nearness to their children and to the more existential issues of lack of meaning and loss of a place in the world. A deeper depression that she relates to the pressure of living in an impossible situation with no means of getting out of it, led Miriam at one point to want to end her own life. She now suggests that the easiest way for her would be to do that, but she chooses the difficult way, which is to stay in this life, for her children’s sake.

Problems drive you to take your life from yourself. Maybe the shortest way is not to live. To live longer with the problem is the longest way. But the children are the reason why I live. Even if I don’t live with them.

(...)…I am a bad mother, perhaps. Sometimes I think how could I leave them.

I think we cannot hold the problems like a man, we, women, cannot hold it. No one is with me, no one needs me, I have cried a lot. I did not want to live anymore, I said to myself… (Miriam)

**Children**

The parents in the study, all mothers, often during our talks referred to their children as being the most important in their lives; they are the main reason for both deep worries about future and small everyday joys. Some they describe their children as the sole meaning in life the way life has turned out, also if they have a partner and family in Norway.

Alma also talks about HIV as something not directly linked to her feeling healthy or not, and that she has been through a process of learning about it and now knows how to live with it. Her first thoughts however was that she will die, without ever having had a good life with her children. She stills expresses (like above) that the most important for her to have a healthy life, is job and income to secure, and be near, her children.

I’m a Christian, I always ask God, to help so that I can be living with my children, living with my family, to see that I can support them. (Alma)

So I just need that, that my kids get education and jobs and can live the life I couldn’t. If I could see that, then I would not think about sickness and medication. (Alma)
Lucy’s family in Norway is herself and her two pre-school children – the father of the children lives ‘underground’ in Norway and they don’t see him very often. Having very few people to help her, both for taking care of the children and for continuing a case with UNE, and little time and resources herself, Lucy is telling that she is in a bad state, both mentally and physically. She expresses a sense of loneliness and that she is alone with the children, both here and if she is sent back, and that she has no one to lean on. She is telling that she is still making attempts to find a lawyer that can help her, but is not getting anywhere. Her experience from her home country tells her that she – living with HIV and with two small children - will not be able to manage a life there.

As we talk the children sleeping next to us start waking up, and Lucy says:

Only thing is, I get happy when I think about the children. But they tire me out, I ‘m not well and I don’t have any energy.

**Strengths**

Some are talking more about how they are coping life to live in a constant suspense. Hana is telling that she likes to and tries to live in the moment and be happy about what she has right now. She tries to have a routine and organizes her days and works to make ends meet and make a safe as possible home for her and her child in the camp.

If you eat your lunch, don’t think about dinner… I like to be happy. Because, life can change every two hours, or in a second. I say thank you…because I can sleep! (Hana)

Alma was telling about the struggles she has had in her life, with getting enough money for food, repeated disappointments and worries - and about how she despite all the difficulties is coping. She reflects on this when she’s been alone in the city, without anything to do.

The one thing I have in my life - I have courage. I don’t have the pessimism, when people think about the future and have fear. I would fall down like that if I had the fear. They can’t change it in any way. (Alma)

If I disturb myself…I will die very soon. So I try to live my life as good as possible. It was not my fault. Yes I got this (...) disease God has given me… I’m telling you the things I’ve gone through I would die if I’m not as strong. I never had a day to celebrate. If you don’t have anything …work, house, education…it’s not easy. And then the infection… It is not easy. (Alma)
What would you do if you… if you lost one hand, the left or the right, would you stop doing things?
No. And, my other sister in [other country] she supports me always.

Some of the study participants brought up how staying alone, for some in addition to being on your own in life, could cause a feeling of meaninglessness and depression to be intensified, and that just being with somebody would help. Not all of the participants had near friends they could spend time with, and Shan for example had tried to withdraw from all social life when he learnt about the HIV diagnosis. Alma, on the other hand, had many friends and actively tried to reach them when she felt down, to spend time with them so to avoid the sad feelings, get her mind on other things. After her episode of ‘falling out of time’ described earlier, meeting people would bring her back in ‘place and time’. During the times I have spent in the cafeteria with Alma and her friends, she has seemed to be relaxed and enjoying herself in their company.

(…)With my friends I am not bored. Sometimes I forget all my problems’. (Alma)

Talks on the phone with their loved ones gave comfort and was a source of strength, whether it was a sister in their home country or in other parts of the world, their mother or children. Having a family here in Norway also meant joy, support and a sense of belonging, and of leading a less isolated life. However it also made the situation even more complex, and choices, if there were any, might be even more difficult. A solution, if one could be seen, to problems in one part of life is likely to create new problems for another part, as discussed earlier. Most of the study participants mentioned several times how they were turning to God both with questions of why their life has to be so hard, and with thankfulness for the things that do work out.

**Freedom / lack of freedom**

Miriam is making a more direct connection between freedom and health, but also makes a distinction between the more medical needs necessary to be healthy, and other more existential needs. With freedom, she could for example be allowed to work, which would bring her money and (therefore more freedom to do things/act, buy, secure health), or, if there was freedom she could be in her home country, with her children – and not feel depressed being away from them.
The biggest problem I have is a home sickness. With the ‘helse’...medicines can help. If I get freedom here or there, get free to do what I need, I can meet the health problems. But now I cannot go wherever I want. I cannot work. I am not sick. (Miriam)

One of the best things to happen for Miriam in a long time, apparently, was that she got a receipt from UNE that they had received her last letter. ‘It gives a little peace’. It is also a confirmation that she did, could do something for herself and that it was noted. Miriam has talked about how important she thinks it is for a person to be able to and allowed to make individual choices and follow his or her own natural decisions, whether rational or intuitive. Instead she experiences - when living without residence permit over many years - that she is stopped in all directions, decided over and denied what she feels is a natural right. She comments on the whole situation rather cynically, and with resignation:

….I have no plan for something. I don’t know about the morning. Maybe I will have to go, maybe police come. My life is like a car without steering. I go, but I don’t know where. Maybe I crash. Die.(Miriam)

You’re without anything to do. Sit and see the medicines expire. The body sit still and thoughts fill the body. (Miriam)

Several of the participants, both men and women, have aspirations for a life characterized by individuality, individual freedom, independency, work, and to live with their family – like most others in the Norwegian society.

To be worthy of human rights

The study participants are very aware of the separate set of standard of health care that is allotted them. Some talk about how the government has constructed this separate standard for certain persons, and they reflect on whether it’s intentionally because the group is looked upon as unwanted, criminals; or if the state doesn’t know better and doesn’t see the consequences of their politics and practice. Miriam finds it strange, unreal, to live in Norway and not always be able to eat when she is hungry, it’s just like in her home country. It reinforces an impression of being classified as inherently different from other people here. Because of HIV she says she rather has a greater need for access to enough and right food to stay healthy. She gets HIV-medicines for free, but feels tired from them and the side effects- the dizziness, dryness in her mouth- and knows of the importance of not going hungry.
I am a human, first of all? You think you are hopeless. You feel it when you are sick, when you are hungry, like a big sickness, you feel why you live in this world? You have no place here. I don’t live with my children. (Miriam)

Everybody has a right to live, you know, and you need something to live, not only breathe. Norway also is cold. You need clothes. Only the air... only the air is free, yes, but breathing... needs more also to live. Politicians think you can live only by breathing. But no, it is not enough. (Miriam)

Health care

Access to health care

Here I will present some topics on health care that emerged during the interviews. Most of the study participants brought up the problems they had met regarding access to health services. They had learnt that the infection clinic they go to can only help with what is directly related to the HIV infection. When other health problems occur, people in the study have different ways of dealing with it. They do not have rights to health care other than for the infection – and to acute health care, but this is not free. One participant who live in a camp do seem to get health care appointments at a general practitioner’s office (fastlege) as before, also treatment at dentist’, however it costs a lot of money. The other participant who lives in a camp get help from the staff to go to a doctor, or to the emergency room when needed, but perceive it as confusing and unpredictable, and in addition unsatisfactory. Not having your own fastlege, you are left with someone who has little reason to show care and responsibility beyond the immediate acute condition. Whether they get specialist care or not is felt as arbitrary or just plain luck; one of the participants who go regularly to a psychologist at a district psychiatric centre says, ‘I don’t know, I get lucky sometimes’ (Miriam). Some of those who have partners had been seeing their partner’s fastlege, but because of the cost for the physician it is not easy to ask. Miriam is describing how she is trying to manage – and when she cannot:

I cannot go to the doctor very often, so I have to hold it. (year) ago I learned that I no longer have a right to health care except for emergencies. It’s like that after the second negative. Except for the infection. (Miriam) (my translation)

She is voicing what also other participants have expressed, problems and barriers met in situations where they need health care for other problems than HIV ‘directly’. In addition participants do not see other health problems necessarily as separable from the HIV infection.
On the contrary they express that taking good care of the body in all possible ways is necessary to be able to handle the HIV infection, along with predictability and structure in daily life as described earlier.

I try myself, to treat myself when I feel ill. For HIV I can go to the infection clinic. But for other problem, like… stomach, teeth, bronchitis… Even if it could be related to HIV. For HIV it’s control only every three months. Once I went directly there, my doctor said you cannot just come here like this, you have to go to your ‘fastlege’ or to the emergency room. Which costs money I don’t have. (Miriam) (my translation)

Hana who is living in a reception centre says she is till going to her old fastlege if she needs to. She receives some money when living in a camp, but it is not enough to cover these expenses. One time she had to pay 1200 kroner for ulcer medicines – she says it is not possible for a person with finale negative to pay this. Several of the participants describe an unpredictable and unclear practice when it comes to getting health care, regarding access to it, the content of it and the payment for it.

After I got negative, sometimes mottaket they pay that, I don’t know, they refund that, and sometimes not. Perhaps it’s a new system for those who have final negative. But they cannot pay for doctors themselves. (Hana)

And I just heard about somebody in Norway, he got two negatives and is waiting, but he still gets health care free from the same doctors. I knew before that it was after the first negative you lost the health care? So maybe it changed. (Miriam)

I got a final rejection in UNE in (.). I no longer have the right to ‘fastlege’, you don’t have a fastlege after you get your final rejection. It depends, sometimes they apply for appointment at a doctor’s office, sometimes they don’t send you to the emergency room. (Lucy)

Lucy talks about the experience of going to the emergency room once she was sick with high fever, the doctor found she had pneumonia, but wouldn’t give her a journal. She understands this as it was presented to her – ‘if you go to the E.R. they have to attend to you, but they can’t write a journal’. It’s a problem for her because the camp office covers the medical expenses for her – but only if she shows them this paper, the journal, from E.R. so in this other reception centre the practice is more predictable, but it can be hard to meet the criteria/get the documentation needed to get expenses covered. For pharmacy expenses her experience is that she just needs to show the receipt to the camp office in order to get a refund.
People in the study have different experiences with trying to get help for dental problems. Hana who lives in a reception centre says she has no problems getting a dentist appointment; she is also referring to living with HIV, telling that she was open and that the dentist was nice and helped her. The difficulties that Adil had in finding a dentist have already been mentioned. His boyfriend’s dentist helped him out this time. He doesn’t have a GP, unlike the two other study participants with a boyfriend who see the same GP as their partner, although they express that they cannot go very often.

**HIV test and ‘follow-up’**

Those of the participants that came to know that they ‘were HIV-positive’ after they came to Norway had stayed here for some time (from one to several years) before they had the HIV test. One of the women had a routine test done when she lived in an ‘ordinary’ reception centre in the countryside. In fact, she had a bad experience with a physician there, who basically told her – the way she heard it - that she is sick and that Africans spread this disease to white people. She talks about the episode with strong emotions, recalls saying to the doctor that she didn’t ask for the sickness and slapping him with the journal. It was a longer dispute, but eventually she changed to another doctor, who became a good support, and still is. However, she says that she did not see, and doesn’t think she was referred to, a specialist before she arrived in Oslo after a long time – there she got in contact with the HIV-support centre who arranged with an appointment for her at the hospital.

For others in the study, the test was taken either quite arbitrary or because partner had tested positive. Shan is telling that he tested negative when he stayed in Norway some years ago and never thought that he could have the infection now, but since a voluntary test was offered at the Health centre for undocumented migrants, he decided to take it again. The positive test was ‘a big surprise’ and as he said, he thought immediately that he would die. He is expressing, though, that the staff in the hospital he stayed were knowledgeable and that this made him feel safer – even though staying in the hospital was difficult. He is, by the way, the only one of the study participants who so far have used the health centre for undocumented migrants, only a couple of them have in fact heard of it. The health center had relatively recently opened, while the participants had stayed in Norway for several years.

Miriam was preparing for some elective treatment in the hospital when she after some weeks received a letter from them stating that they could not treat her because she has HIV-infection
– and that they had tried to reach her by telephone. It was a shock to her – she says she still remember the exact words in that letter. Later the doctor she used (her partner’s fastlege) did call her because of the same test results, and he referred her to a specialist.

A few have gone together with their partner to appointments, like Adil when he got the test result he had his boyfriend with him – so he says he was not alone, but it was bad, he didn’t know about it. They are still sharing the experiences of living with HIV, and his partner is involved in trying to find ways to get health care for Adil when the infection clinic doesn’t provide it.

Apart from the waiting time one of the study participants had experienced, getting to an infection specialist or clinic had not been a problem once he or she has tested HIV positive. ART drugs are free to all people living with HIV regardless of legal status. Hana had started medicines in her home country almost at once since her CD4 count was low – however it was still low when she arrived in Norway some months after, and she relates it to poor quality of drugs back home. She has now experienced to get medicines that give better results for her, and when she couldn’t tolerate one type of medicines she’s been able to change from one type to another she tolerates better. The talks about the controls in the hospital involves the blood tests and the counts; waiting for the numbers are for some cause for anxiousness, good numbers are like light posts and give a sense of control, and relief for a while.

December, yes, that was the last control, this month. Virus number was zero and CD4 was 605. I’m glad, something is good. (Miriam)

**Mental health care / psychosocial support**

The six participants in the study have as described above all felt, and feel, depressed and worried, to various degrees. The camp office had arranged for a doctor appointment for Lucy, who is now using antidepressants, as others in the study are as well (which doctors they get prescriptions from I don’t know) None except Miriam is seeing a therapist; she started after she had been to the hospital several times –she explains that everything was dark to her, and she wanted to kill herself. The doctor gave her some medicines she is still using, and said she needed a psychologist. She started going to a district psychiatric centre (DPS) and ascribe this to plain luck, as she is not supposed to get this kind of help.
To counteract isolation and to offer an environment of psychosocial support are some of the intentions of the support centre for people living with HIV. At the centre people can just have a meal, sit and talk, use the computers, watch a film with others, have individual talks with social workers – or stay for a period of time – to mention some. Some of the study participants visit, or used to visit the centre and some have over the years gotten a near relationship to the staff there and, as described earlier, two of the study participants wanted the person they knew at the centre to be present in the interviews.

HIV Norway is another organisation that, at the time of this study, one of the participants was using actively and regularly. When Miriam was afraid to start on HIV medicines she took the drugs to HIV Norway to talk to others who used those medicines. Much of the knowledge she has of HIV today she relates to what she has learnt through this organisation. She says she also feels at ease there, since there is little risk of meeting people from her home country.

For those who have a longer way to travel, a limitation to the use of the HIV support centre is the cost of getting there. Those who stay in reception centres get the travel cost covered when they have appointments at the infection clinic (after showing documentation to the staff at the camp that they have been there). According to a key person at the HIV support centre, it seems that camps have no routine practice or standard for covering or not covering the travel costs to visit the HIV support centre, it varies from camp to camp, and from person to person. Hana at least tries to get it covered by taking a letter confirming that she has been to the support centre.

(... to come to [the HIV support centre] is very good, but it’s expensive to get here. For them to cover the transport to the infection clinic I have to ‘confirm with attestation’ that I’ve been there for control. They demand to get documentation that I have been there. (Hana)

People working in the camp have different approaches, which can seem arbitrary, or dependent on the person. Sometimes the camp will cover the expenses of going to the support center, sometimes not. This is in fact also the case for travels to appointments at the infection clinic. In order to get the travel cost covered, as explained by Hana, she has to show the camp staff an attestation from the infection clinic as proof that she has been there.
People living with HIV and without a residence permit are in many ways at the mercy of the staff he or she meets in different institutions and settings. Furthermore, it seems that they sometimes do get assistance they are not clearly entitled to, because the staff has chosen to.

**Relevance and continuity of health care**

The men and women in this study live with a constant threat of being deported. This study doesn’t tell whether infection specialists in general don’t know about their patients’ life situation, however, (as mentioned in the methodology chapter) when I contacted an infection clinic about this project, a physician was telling me that they don’t really need to know about their patients’ residence status and never ask about it. I got the impression that this practice was made out of consideration for the patients, a way of protecting the patients; they don’t want to ask their patients about this in order to communicate that all their patients are equal to them, and all receive the same care and treatment. Another crucial aspect is that patients may fear to visit the infection clinic if they hear that staff is inquiring about residence permit.

Several of the study participants are expressing that the staff at the clinic they go to are nice and friendly, and one of the study participants think of her former doctor as a friend now. Although some of them are seeing the same doctor over a longer period of time and express that they feel secure and have a good relation with their doctor (or nurse), others don’t. Lucy moved to a new place and has a doctor who doesn’t know much about her, and she says when I ask, that he is not aware that she might suddenly have to leave the country. She says she gets medicines for three months at a time, that’s it.

> He’s a new doctor to me. I still wait for the next appointment, by March. I get medicines for three months. He does not know much about me. (Lucy)

A key person in this study informs that, depending on the individual physician, an arrangement is sometimes done to secure that their patient, in the case of a deportation, have a better chance to continue the treatment without disruptions. The patient is able to take with them for example a year’s supply of their prescribed ART drugs, and may get another supply shipped after a year. There are no system or official guidelines for this practice that I know of, and is of course dependent on the physician knowing about their patients’ situation. The practice facilitates a person’s chance to follow the treatment regimen and may in theory relieve one of the immediate fears of going back to their home country, however does not seem to give Hana a more secure feeling with regards to a life in her home country.
Furthermore, the practice is done in spite of UDI’s ‘Land Info’ mentioned earlier in this thesis – where no country is reported to not have sufficient and available HIV care and treatment for it’s inhabitants.

Miriam has a new doctor as well. She didn’t talk to this new doctor about a possible return or deportation to her home country. I understand that she also needed documentation to UNE, but didn’t feel she could ask the doctor. She had however told that she doesn’t have residency or job implying she doesn’t have any money – she felt weak and wanted to buy some vitamins, but the doctor couldn’t help with that, and neither with dentist when she needed that. She was told that healthy food is just as good.

I can get cheap or half price vitamins, the date have expired or will expire soon, but I have used them, I think they will not harm anyway. I don’t know if they do any good. But the healthy food is very expensive. Also other expired medicines you can get. (Miriam) (my translation)

**Lack of rights to health care**

Miriam, and others, is reflecting on the lack of rights to health care and limited possibilities of both leading a healthy life and getting the help and support needed to do so. She is going further as well, arguing that other people might become sick because of her and others in same situation. She also saw the limitations in health care access in relation to public health, protection against infectious diseases - and human rights.

So, Norway has to think not only on the ‘papirløse’, but also on everybody in Norway. We infect others if we don’t have enough health services, we get infections easier when we have a low immune defence. Authorities have to think about this, too! I get the infection, I get it, ok, finished. But I don’t want to give it to others. But, now, when I get a disease, I can infect others, like if I have, like TB. When I feel something I must go to the doctor. I think this is the best thing for the health institutions, that you don’t need the papers. As a human being you should if you stay one hour in a country you should get medical help. This is a humanitarian country. I have heard. Maybe only on paper… (Miriam) (my translation)

In a way Miriam’s arguments resemble the rhetoric used by those with prejudices against and fear of people with HIV, as well as against irregular migrants, seeing such ‘groups’ as a public health problem. Still, as Miriam sees it, it’s just facts and a way of making people and authorities understand that securing health care for all is for everybody’s best. Participants express that they are grateful for the health care received from the infection clinic, getting
medicines, but it is not sufficient for leading a healthy life. Miriam compares the situation here with the lack of support in her home country, while shaking her head and laughing a little:

Here in Norway, it’s the same. I get help in that I get the medicines, of course. It’s a little strange, to live in Norway, and you cannot always eat. It’s the same. (…) I cannot just eat bread and jam, it’s not good enough for those medicines. I have to eat healthy. Because of medicines and side effects. I get tired, too, dizzy and dry in my mouth. (Miriam)

Others have similar experience – appreciate the help from the infection clinic, but do not feel they have adequate health care, to meet their needs.

The clinic help me so much, I have a nurse I have a good relationship with her and they are very nice and support me, I get the medication. It is all the other things that make me depressed, things the clinic can’t help with. (Alma)

The Communicable diseases control act is the only legislation that secures the participants in this study some absolute rights in Norway. It’s a paradox that the only absolute right the participants have, is developed from a law with the aim of protecting the population against communicable diseases like theirs. This 'fear' of disease and a need to protect from, with the duties of health personnel to perform necessary actions to protect the population, is what people living with HIV and without a residence permit experience as one of the few acknowledgements in this country.

According to Miriam, a true generalized health care system, for all people that actually live their lives in this country, will keep people around her or him from getting sick and lead to a healthier overall population. But, in addition to the obvious importance of getting the health care you need when you need it, what is also meaningful to her and others the way they have expressed it during the interviews is on an existential level, to get a basic recognition of being an equal human being, just like any other person in this country and to be treated as such regardless of a residence permit or not.

Discussion
What does it mean to be healthy? What is striking in the answers the men and women in this study provide to this question is that HIV seems to play less of a role for their perception of health than what UDI does. Indeed, in the context of illegalised exile, the study participants do not perceive of HIV as the most significant determinant of their health. Both in their home countries and in Norway, HIV has for a long time been understood as a serious threat to people’s lives and health, and the study participants were well acquainted with this understanding of HIV from their own lived lives. In spite of this, when they were asked questions about their own health, HIV was seldom brought to the fore in the discussion. Rather, in their perception of what affects health, the study participants clearly seemed to be of the opinion that illegalisation and its consequences was much more salient than a chronic, life-long and potentially deadly viral disease.

Within the context of illegalised exile, what threatened their health most was the web of power and control mechanisms in which they were trapped due to their ‘illegal’ residence status. This web constrained them and shaped their everyday lives in ways that generated a range of negative predictors of health: disturbed sleep patterns, irregular eating habits, limited opportunities for activities, a deficient sense of safety, missing chances to and ability to relax, and limited means of getting help if they got sick. The lack of a work permit and very little income led to a general feeling of insecurity, and to poverty, and dependency on others. Their lack of legal residency was a barrier to fulfilling their own and others’ expectations, to prospects of being near their children, and led to a sense of not having meaning in life. To be allowed to have a job and daily obligations was seen as a way to escape thoughts and worries, which were often described as an almost all-consuming experience, however the barriers to employment made such escape hard to find. In addition, they perceived the very constraints and control they were subsumed to as a questioning of their worthiness as human beings. To get moral recognition, to be acknowledged as an equal human being and to have individual freedom were all themes that the men and women in the study returned to and related to their health.

When I asked the study participants more directly about what HIV means for their health, they did talk about this in terms of health as well as in more medical terms, in addition they associated to the worries the HIV infection entailed with regards to becoming ill. These and other comments make it obvious that HIV is important for their conception of health.
However, in our talks, all returned to the situation and conditions of illegalised exile and the ubiquitous constraints to a healthy life it meant. Radley (Radley, 1994, p. 37) notes that ‘ideas about health are likely to be fashioned, if not change, in the context of people’s experiences of illness’ (1994). Illness, and the consequences illness have for social life, shape people’s understanding of health, whether it is our own or others’ illness. How the HIV-infection has been and is shaping the study participants’ understanding of health has no definite answer and will also relate to the different images and understandings of HIV, dependent on the context in which you live with it. However, the study participants have in the interviews all turned to a broader understanding of health, and to a perception of health that does not have HIV at its centre, with other life conditions as necessities to be able to feel healthy with HIV. On the other hand, a recurrent theme in this study was issues related to HIV stigma, which caused much worry and exacerbated difficulties. As discussed earlier in this thesis, the study participants were also often returning to how having a residence permit would lead to less worries with regards to the HIV-infection.

Sønsterudbråten and Øien (2011) state in their report on living conditions of irregular migrants in Norway that ‘Just as irregularity can worsen the state of health of an irregular migrant, health problems can make the life of irregularity more challenging’ (Sønsterudbråten & Øien, 2011, p. 69). Health problems would for example cause difficulties securing decent living standards as they would have problems doing the type of manual, often heavy work often offered to irregular migrants. However, that irregularity caused health problems was a still more recurring theme in the responses of the irregular migrants in that study, as it is by the participants in this study. An informant in the above study was living with HIV and described how getting the rejection on his asylum application caused a worsening of his mental and physical health including an exacerbation of his pre-existing health problems.

In the present study the participants had the similar perception of how life without a residence permit made them both more vulnerable to, and to experience different forms of ill health. Symptoms of psychological distress or mental health problems were common, and over several years they experienced difficulties falling asleep, having nightmares, and a constant fear and apprehensiveness. In addition, the constraints inherent in the illegalised exile made it hard to deal with side effects of HIV medicines, like in the example where a study participant forced herself through days at work even though she was sick and couldn’t stand up at times;
once an ambulance picked her up. Moreover, whether symptoms they experienced were related to the HIV infection or side effects of medicines, so that they could contact the HIV clinic, or if the symptoms were caused by other illness, could be hard to differentiate. The worries about where to get help if they got sick were profound despite the access they had to HIV related health care. For some of the study participants, being able to visit or have contacts through organisations relieved some of the consequences of the exclusions from the general public health care, and one participant had visited the health centre for undocumented migrants. How to get health care when they got sick was anyhow seen as unpredictable and something they had to wait out, or portion out, because of the cost and also as to not exhaust the ‘goodwill’ that people gave them. Their perceptions and experiences indicated that the health services they could get to, depended on the choice of reception centre staff, or that in addition to the problems with the cost, both the access and relevance of health care depended on the individual health care worker’s position and interpretation of what ‘necessary health care that cannot wait’ means, similar to what Hjelde found in her study (Hjelde, 2010). The fact that the standards for what was considered ‘good enough health’ in reality was lower than that for the general population was in itself adding to the feeling of ill-health, by causing deep insecurity, and by giving a sense of being devalued. This restriction to health care and other structural barriers is what the study participants most often returned to as reducing their chance to attain a healthy life.

That health is more than the absence of a disease or the control of symptoms has since long been acknowledged, as in the current WHO definition of health from 1948, ‘Health is state of optimal physical, mental and social well-being, and not merely the absence of disease and infirmity’ (WHO, 2006). This expanded health concept and the ‘completeness’ of it has over the last decades and for several reasons been criticized, however the core of it, that reasons for healthiness are complex, seems not to be disputed. Health has to do with different parts of peoples’ lives – physical, social, mental and also spiritual - and it has to do with personal resources and characteristics of what it means to be a human being – like capacities for coping, adaptation, or self-preservation. A proposal for a new conceptual framework (rather than a definition) has been made by Huber and colleagues with the concept ‘Health, as the ability to adapt and to self manage’ (Huber et al., 2011), where the ‘capacity to cope and maintain and restore one’s integrity, equilibrium, and sense of well-being’ (2011, p. 2) are some of the fundaments of the concept.
Antonovsky’s concept of salutogenesis with the term ‘sense of coherence’ (Antonovsky, 1996) can be useful when looking at such ‘capacity to cope and maintain and restore’. Antonovsky looked at health and disease as the different ends of a continuum, and asked how we can understand movement of people in the direction of the health end of such continuum. He proposed that an answer to that question must relate to all aspects of the person. Of factors that can promote such movement are ‘general resistance resources’ the ‘biological, material and psychosocial factors that make it easier for people to perceive their lives as consistent, structured and understandable’ (Lindström & Eriksson, 2006, p. 241), such as money, knowledge, cultural capital, experience, self-esteem, commitment, social support, traditions, intelligence, and view of life. The ability to use these resources is what constitutes the sense of coherence – ‘a way of perceiving life and the ability to successfully manage the infinite number of complex stressors encountered in the discourse of life’ (2006, p. 241). The participants in this study were clearly experiencing that their existence was disrupted both by larger life circumstances and by smaller events that was stressful, at the same time they were short of several of the resources mentioned above – like economic and cultural capital, while some also had very limited social network. They did suffer because of these undesirable living conditions and the sense of being without control and direction, which led to constant worry, recurrent fear, questions of meaning in life and not seeing any way out of limbo, all some of the themes they voiced in the interviews. However, they seemed to have hope, although there were times when it was fading. In their everyday lives they showed capacities and strengths: they persevered, and they adjusted their approach to life and were capable of focusing on daily chores, at the same time plan for their children’s future. They enjoyed time with their near ones, or established new social relations. They focused on their healthiness, strength and capability to work; they worked to make ends meet and strived to be independent, and they resisted and protested – at least at home- against prejudices against people living with HIV and of the treatment in the immigration system; one took part in grass root campaigns for the rights of irregular migrants, others hoped one time in the future to help better the conditions for people living with HIV and in poverty. They were reflecting persons; thinking over the situations they were in, and how they managed, one woman referred to the courage she always had, stating, ‘I would die if I’m not as strong’, another that she knew hope meant everything and therefore deliberately hung on to it, as she also did with the wish to feel happy and with being thankful for the day right now and for the things that is not a problem. This,
the knowledge and experience that ‘life can change every two hours, or in a second’, like Hana in this study stated, may be interpreted as signs of the transformation that living with a serious chronic disease can lead to, where a person reconfigures her- or himself, perhaps with a different view on life. Also faith appears to be an important part of several of the study participants’ lives. Antonovsky’s idea was that ‘people have to understand their lives and they have to be understood by others, perceive that they are able to manage the situation and deepest and most important perceive it as meaningful enough to find motivation to continue’ (Lindström & Eriksson, 2006, p. 241). Parallel to being entangled in an ambiguous sort of communication with UDI/UNE, being mistrusted or not heard, and not having a voice or a recognised place in the larger society, it seems that the study participants had a strong sense of coherence and were able to utilise the resources they did have, like: experience, self-esteem, commitment, social support, intelligence, and view of life. The capability to do that may have contributed to keeping their health from deteriorating much under the varying, but nonetheless harsh living conditions; however, access to other general resistance resources – like work - is what they saw as most important for their health.

The men and women in this study were in their responses to what a healthy life entails, referring to the very basic things in life, like: to work and come back to home, to belong, to be with their loved ones, to give their children a secure life, to be safe, to have meaning and not be redundant, needless, but to be of use and be recognized - much in line with responses from informants in study on Norwegian health perceptions conducted by Fugelli and Ingstad (2009). One of their main findings was also that people’s perception of health is not a matter of adding up healthy and unhealthy ‘bits’, piece-by-piece, but is of that of health as a whole. Health is much larger than the single pieces, including the medical bits (Fugelli & Ingstad, 2009, pp. p. 438-439). The same is the case also in the present study: health is considerably more than HIV treatment. This does however not mean that they see any absence of wellbeing as ill health, or that they could only feel healthy if having an optimal and complete sense of wellbeing. They were on the contrary pointing to some very basic needs they saw as fundamental for being healthy, needs they were excluded from trying to meet.

Chapter nine: Conclusion
This chapter includes a brief final discussion with a summary of the findings, notes on the limitations of the study and some ending remarks.

This study has attempted to explore the life worlds of people living with HIV and without a residence permit with the objectives 1) to generate new insight into how people living with HIV and without a residence permit think about, feel about, and perform their daily lives, and 2) to generate understanding of how people living with HIV and without a residence permit perceive, experience and relate to their HIV infection and conceive of health and a healthy life.

The men and women who participated in this study had come to Norway after life experiences had made it clear to them that they had to leave their home country. They had lived their life on the margins of the Norwegian society for up to nine - ten years, while striving to deal with their rejected asylum applications, their relations, losses, poverty, health, and HIV infections. To make it clear: illegality or criminality did not characterize their lived lives in the Oslo area; the often-heard illegal label is thus linked only to their residence status. Moreover, although they had overstayed the deadline for leaving Norway, over time their legal residence status was not always clear, which suggests – like other studies – that the idea of a clear-cut dichotomy between legal and illegal residency is not echoed in the empirical reality (H. A. Kjærre, 2010; Thomsen, 2010).

The daily lives of the men and women in this study could sometimes resemble that of any other person in the Oslo area: meeting friends in a cafeteria, sharing everyday joys and worries with a co-habitant, running errands, attending to children, going to church or visiting significant others in a nursing home. The study participants’ lives were at the same time also significantly different from most others’ in Norway. A weekend of visiting in-laws in the countryside, for example, would in many cases be followed by a Monday morning characterized by fears of being caught on the bus and turned over to the police. Moreover, many study participants were at one and the same time experiencing both embrace and rejection; they might feel included in a private social sphere but excluded from the larger society. Although immigration authorities did not acknowledge their existence in Norway, their lives were tightly knit with the Norwegian state, much like in ‘a state of exception’
where a state includes under the law the very people it excludes (Agamben, 1998). Their everyday lives were entangled in webs of state power, laws and regulations, and they encountered considerable constraints in most areas in the Norwegian society – apart from the HIV treatment they had a right and access to - based on an Act relating to control of communicable diseases. To get out of what they saw as an unbearable situation, they tried to negotiate with the same state power; their everyday thoughts, and for some, activities, revolved around the struggle to appeal a negative asylum decision and to try to make immigration authorities understand.

**Power and constraints**
The lives of the persons in this study are to a considerable extent structured by a combination of medical power (aiming to achieve adherence to treatment and control of disease), the power of the national state (immigration authorities putting in place a wide range of constraints), the power of the extended family (monetary contributions), moral power (through stigma and discrimination arising from a devaluation of both illegality and hivseropositivity).

Medical power they were exposed to as persons living with HIV included moral and legal duties and practical responsibilities, and it meant being punishable both by law (the penal code) and, as a consequence, also by near and other relations. The sense of control that access to ART and regular appointments with an infection specialist gave was appreciated and needed by the persons in this study; it also involved a fear of losing it. It is however also a surface where medical power is apparent: their adherence to appointments and treatment is monitored, and their ill- or wellbeing is converted to manageable data and incorporated into a larger system of disease surveillance. Moreover, both in this and other health care settings the study participants experienced that restrictions to health care were enforced because of their lack of a residence permit. They did experience that physicians and others negotiated these restrictions and thus provided health care. Such conditional access to general health care nevertheless led to situations of embarrassment, also because of the lack of money, and underlined a need for them to be submissive and to have no further demands, as to not exhaust the generosity of the physician/health care worker in question.

The nation state exerted power on persons in this study through an array of constraints and barriers. In their everyday lives, it was the barriers to create an income through regular work,
to learn through education, and the limitations to care and treatment for their general health. Constraints with regards to banking, ID card, travel, or just to go out on town one evening, felt suffocating. Structural conditions had led them to leave their home country, for the mothers in the study the Norwegian state forced a separation from their children to continue, a scenario they had never foreseen. Their lack of legal residence status was a powerful argument for the authorities and an effective way of silencing persons in the group, who had a constant fear of getting the wrong attention from immigration authorities and be picked up by the police and deported. Although they kept trying or thinking of appealing the negative decisions in UNE, they expressed a deep sense of powerlessness, seeing immigration authorities/UNE as a power that cannot be moved, no matter how good arguments a person has. The effects of power were following them into their relationships and could include their near ones, who could end up in bizarre situations as ‘suspects’ when trying to have a normal life with their spouse. (What was seen as) a breach of the Immigration Act meant that a separate set of rules for defining right and wrong was applied to them. Furthermore, what the persons in the study perceived as ambiguous messages from immigration authorities contributed to uncertainty, confusion and underlined their lack of control. With the lack of control and without firm ground, and without power to change the situation, they saw no direction to turn to.

The moral power that the persons in the study were subjected to was linked both to living with HIV and to living in Norway without legal residency. Stigma caused the limitation and barriers met by living in illegalised exile to be reinforced. If the HIV diagnosis is revealed, they expect to be excluded from their social network - a network they were dependent on to survive in a society they were to a significant degree excluded from. One woman had experienced, and most of the study participants were convinced and feared, that through HIV stigma near relatives would reject them. All had clear perceptions about how living with HIV and not being able to hide it would cause friends and acquaintances, whether in their home country or in Norway, to mark a distance to them, to feel superior to them and be in power. Some experienced that others used this power to take advantage of them. What they saw as a reason for the prejudices and stigma, was other people seeing HIV infection as a result of immoral behaviour and of HIV infection ‘as deserved’. They also associated it to people’s lack of knowledge of mode of transmission. Fear of disclosing HIV status, and with that exposing themselves to HIV stigma, worsened problems and worries, first regarding housing
in Norway, as a lack of privacy would lead to a greater risk of revealing the HIV status. HIV disclosure meant to them that they had to leave the place, also to get a distance from the disrespect and power imbalance that being subject to stigma meant. Words about them meant ultimately that they could be excluded from networks that could make life easier with regards to work and thus give some relief from poverty. Living in the country without a residence permit meant to be included in a political and public discourse of illegality and be exposed to a constant devaluation and emphasis on their lack of deservedness, and to what they saw as a judgment of their worthiness as human beings. Immigration authorities emphasising trustworthiness in the assessment of application for protection, and the arguments and procedures involved in it, further underlined the state’s moral power over the persons in question. Ultimately, the combination of powers set into motion by authorities - entitlements to HIV treatment but exclusion from most other formal areas, like general health care and that of having an income – lead to a situation where people living with HIV and without a residence permit are allowed to survive, or not allowed to die, as long as they are staying on Norwegian soil, while they are prohibited from taking part in the formal parts of society they live. They are in this way, in Agamben’s terminology (Agamben, 1998), like the bare lives, Homo Sacer, in society.

For some, their family and children’s caregivers in their home country had expectations of receiving economic support. The obligation laid on the study participants to contribute from abroad appears to take part in structuring their lives and choices. The mothers felt it as a duty to provide for their children, however some found no means to do it and had given up. A continued pressure to support family at home, or the hopes of one day to be able to meet the expectations, added to the impossibilities of choices in life. The mothers in the study in various ways tell about how returning back home would be like punishing their children, because they would, as children of somebody with HIV infection, be ostracised and lose many opportunities in life. On a different hold, the men and the women in the study felt that their own economic dependency in Norway gave power to those who gave them support, whether it was their co-habitant, friends or acquaintances, as one male participant stated, ‘I always owe him’. This was a major part of the worries and frustrations of those in the study who lived in private housing. Some had a new family in Norway, their help and dedication was appreciated, but could cause feelings of being indebted. A relationship was a positive thing in
their lives; however having a family both in their home country and in Norway also made choices harder.

**Life disruptions and homelessness**

In the lives of the men and women in this study there existed a double homelessness: the loss of a home and a ‘place in the world’ due to the illegalised exile, and the homelessness and alienation that has been described to come with sickness (Svenaeus, 2007).

Not knowing what direction life will take and having little power and means to control it, they remained on infirm ground. Their lives without a residence permit were marked by losses: the loss of their home, where they had grown up, ‘knew everything’, and where their children and near family lived, the loss of a place in the world where they could belong, have a function, a meaning and being heard and responded to - and a loss of protection from a government. Having new relations or family in Norway meant they were valued as persons, and it gave more security and stability, however it could not remove their feeling of loss and alienation. The life context of the participants of this study as ‘illegal aliens’ thus resembles what Hannah Arendt described as conditions of statelessness, as brought up by Blitz and Otero-Iglesias (Blitz & Otero-Iglesias, 2011) in their study with rejected asylum seekers in England.

Living with HIV is in its essence instability, insecurity; to lose ground, or, as one woman in the study described life after being diagnosed with HIV, ‘Life is like a broken bridge’. In a situation when HIV exerts destabilizing effects, the study participants would be expected to seek structure and stability because of an underlying fear of the unstable, the uncertainty and insecurity. But, in irregular, illegalised exile, to find ways to live more sheltered and secured is a challenge. Participants in the study find that living with HIV brings a greater need for a safe and predictable life situation; however, all had experienced that to find such ‘homely sphere in world and time’ while living in illegalised exile is difficult, and can be fragile if found.

**Time**

Within the constraining context of illegalised exile, and with the losses that existed in their lives, the men and women in this study experienced time both as moving slow and fast, and as being too long and too short. The many limitations rendered days long and eventless, and the experience of time as very slow, as did the waiting time for a response from UNE. At the same time the pace was experienced as high due to all the things they needed to take care of
and organise in order to try to manage their daily lives or to change their situation. The experience of being at all times ‘deportable’ resembled that of being on the run and gave no opportunity to really rest. Everyday life was experienced as disrupted and erratic, as expressed by Hana: ‘...because life can change every two hours, or in a second’, which was the reason why she wants try to live in the moment, and be happy. Time is also experienced as too long as the years away from their children growing up, or the years of wasted opportunities, in limbo, is adding up. Time passing without a response from UNE or being picked up by the police could at times create a small hope that their staying in Norway would be accepted – but also the perception that they are approaching the ‘final date’. HIV-infection had caused a disruption in the time line of their life. Years passing without getting sick was a good sign, however uncertainty regarding living with HIV in the future was always present. As time passes there were, and are, two looming disruptions that threaten to be greater than the disruptions they were experiencing today – the HIV infection can end in AIDS, and the unauthorised stay can end in a deportation.

Value and strengths
The men and women in the study had little economic, cultural and social capital in the Norwegian society, where they were not allowed into the arenas where such capital could be accumulated. However, in their near relationships they were symbolically valued, for example as a devoted partner in a loving relationship, as a member of the extended family (new or old), as a good mother or as someone taking care of household chores. For those who at times had a job, being a hard worker and a dependable employee were also ways of being symbolically valued. Moreover, any money earned would go to get out of dependency of others, share the rent and other expenses, or be someone their children and family back home could depend on, by sending them money if they had the chance. Being a person to share a financial burden with gave value. Living with HIV had in some ways an advantage in the context of irregular exile as it gave access to social arenas where belonging and solidarity stood high, and where they could get much needed support as well as develop new social relations. However, not all visited these arenas. Their close relations – their children or their life partner - were important sources of joy and meaning in the lives of the men and women of this study. Despite the challenges they had in everyday life, they persevered. They had capabilities, capacities and strengths and were able to use these resources in focusing on their physical strength, ability to work and manage daily chores, to try to make a case towards immigration authorities, be a
good parent and to plan for their children both in Norway and in their home country. They gave of themselves in their relationship with their life partner, and had an important role in their new extended family. Despite the constant weight of the constraints and power of illegalisation and the consequences it had to their health, the study participants appeared to have considerable mental strength, or a sense of coherence (Antonovsky, 1996), with a will to keep trying to make their life situation meaningful and manageable, and with a will to maintain both hope and protest. Their attempts to take action, look for work, be busy can also be seen in the light of HIV as a chronic illness as a life disruption, where a movement from disruption to transition involves a need to restore and create order in life, as found in other studies (Russell & Seeley, 2010).

**The meaning of HIV**
The perceptions the men and the women in this study had of living with HIV appeared to be floating, or shifting, depending on the scenario most intruding or influencing at the moment, or on the situation there were in at the time. Such shifting perceptions of HIV mirrors in many ways the uncertainties, instability entailed in irregular, illegalised exile, the living ‘in between’. Their perception of HIV also appeared to depend on having support from near relations or not, and of having a sense of stability and structure in everyday life, like work, or not. There were occasions when study participants appeared to embrace an understanding of HIV infection as a ‘disease like any other’, free of any particular hardships, especially when this meant that in their lives with others HIV wasn’t important. In contrast, their perception of living with HIV in their home countries was that of open exposure to stigma, discrimination, limited means of subsistence, in addition to having serious doubts about treatment security and seeing chances of surviving for a longer time as bleak. HIV appeared to be more of a dominating part of their imagination of a life there and more directly linked to their health. Most often the perceptions they had in the present context was however of HIV as a potentially deadly disease that is possible to live with, but needs to be tended to and puts much responsibility and many constraints in their lives, including a need to have order and stability in life and not disclosing their HIV status. Living with HIV in irregular exile in Norway meant that any thoughts of trying to change their situation, like escaping this life as ‘illegal’ and move to another country, was impossible. The demands of the HIV infection tied them down, and the stigma of HIV limited the possibilities and choices they felt they had.
Yet, HIV did not appear to be seen as large a life disruption as that caused by a rejection of an asylum application in Norway, and HIV was laid out as less of a threat to overall health than living without legal residency. In spite of having grown up with and lived many years with an understanding of HIV a serious and potentially deadly viral disease, they perceived illegalisation and its consequences to affect their health more.

**Health problems and perceptions of health**
The men and women in the study did not perceive of HIV as the most significant determinant of their health: HIV seemed to play less of a role for their perception of health than what UDI did. When one participant stated, ‘to get the negative is bad for my health’, it did not merely mean that a positive answer to the application for protection would solve all her problems and give her good health, it was an expression of the embodied experiences of being subject to a range of constraints and control mechanisms over years. What threatened the health of the men and women in this study most was the web of power in which they were trapped due to their ‘illegal’ residence status. This web constrained them and shaped their everyday lives in ways that generated a range of negative predictors of health. Life without a residence permit made them both more vulnerable to, and to experience different forms of ill health. The constraints inherent in the illegalised exile could make it harder to deal with side effects of HIV medicines, they experienced having psychological distress and over several years they had difficulties falling asleep, had nightmares, and a recurrent feeling of fear and apprehensiveness. The lack of a work permit, and poverty, added to a general feeling of insecurity, and worries were often described as an almost all-consuming experience. Dependency on others, the lack of any possible direction in life, loss of nearness to children and eventually questioning meaning in life were themes that the study participants returned to. Moreover, the worries about where to get help if they got sick were profound despite the access they had to HIV related health care. Their everyday lived experiences of constraints, and the ways that power was exerted was perceived as a questioning of their worthiness as human beings. Moral recognition, to be acknowledged as an equal and to have individual freedom were themes that the men and women in the study returned to and related to their health.
The persons who participated in this study have in the interviews all turned to such broader understanding of health, and to a perception of health that does not have HIV at its centre. With their understanding of health –which is in line with both the understandings of other ‘ordinary people’ for example as some of those presented in the study by Fugelli and Ingstad (2009) and all formally recognized understandings of the concept health, as WHO’s definition (WHO, 2006) as well as other (Antonovsky, 1996) and newer concepts focusing on individuals’ participation and agency (Huber et al., 2011), the participants in this study were falling between most chairs when it comes to having a healthy life. Although they were relieved that they had access to treatment and care for the HIV infection, and they felt that HIV was ‘under control’ at the moment, this alone could not bring them to have a healthy life.

**Limitations of the study and ending remarks**

This study has several limitations; some of which are already discussed in the section on weaknesses of the study design. With its qualitative methodology and limited scope and size - with six study participants – it is obvious that generalisations cannot be made from the findings, however that was not the intention of the study. That the results can relate and be transferable to other studies with a similar aim is. As very little research had been done in this area before, an open approach, with qualitative methods and an emerging research design was chosen. Since the study participants had a lot to share, often in a narrative form, and I avoided steering the interviews in a certain direction, it became a challenge to deal with the large amount of different variables involved, to find ways of showing the complexity and at the same time maintain clarity in the presentation of findings. This may limit the way the study can relate and compare to other studies.

The analysis is limited because of the small number of participants and for the same reason may have been biased. All the participants were recruited through various grass root organisations; people who were not in contact with any support network, and would have been likely to have other experiences, were not reached. The immediate living conditions varied among the persons participating in the study: two of the women were single mothers and lived with their children in reception centres. The other four study participants lived in private households, where two of them were in long-time relationships and co-habiting with a Norwegian. At the time of the fieldwork, only one of the participants was without any near relations in Norway (known to me), however, others too felt they had no one to lean on, and several had recent experiences of being completely on their own. Whether the individual
study participants were typical or atypical for people living with HIV and without a residence permit in the greater Oslo area is not easy to say, however to include people who do not find their way to, or cease contact with grass root organisations, would have strengthen the study.

The different cultural background of the study participants and its impact on conceptions and meaning formation was not part of the analysis of the data, however the continued connection and associations to experiences in the various home countries was. The study also does not systematically take into account the differences between the lived experiences of being a straight woman, a straight man or gay man, all who are represented in this study. Gender and sexual identity have in other studies with rejected asylum seekers been found to be two factors of particular importance in shaping differences in challenges, and in responses to these challenges (Doyal, 2009). Aspects of gender and sexuality have nevertheless been noted throughout the study, although not in a systematic way. Furthermore, two of the study participants live with their children in Norway; how the life circumstances affect the children has not been given significant attention and is another limitation of the study. Finally, the Norwegian context means that the study participants had a right to and access to HIV treatment, which may be different than other settings.

In illegalised exile, the formation of meaning with regards to the phenomenon of living with HIV and with regards to the understanding of health happen in a complex set of ways. This study has attempted to bring forward the many different aspects of life that influences the way the study participants perceive, experience and act with regards to the HIV infection, their health and a healthy life, and chose an open and emerging approach into the area of research. However, the meanings they assign to these phenomena may be more heterogeneous than what has been presented in this thesis, and the process of meaning formation may have facets not recognised in this study. New studies aiming to contribute to conceptualizing the phenomena of HIV and health and their interrelation may choose to employ methods of more rigour and with that specific aim.

The narratives of the participants in this study have pointed to how social forces become embodied as individual experiences. Approaches using social theory as a framework, like that of social suffering, might better analyse the lived experiences of people in light of the larger historical, political, economic and societal matrix, also across borders, and may give more
detailed understanding of how the lives and health of people with HIV are structured by different forms of power in the context of irregular exile.

Moreover, to follow persons over time in the directions their lives take, has the potential of increasing knowledge of how continued life disruptions affect them and their health.

This study does not claim to have evaluated the health care available to the target group. Nevertheless, findings from the study suggests that health care available to people living with HIV and without a residence permit is not adequate and sufficient despite getting treatment related to the HIV infection. HIV treatment and care is also in some ways given in a form that is not relevant to their needs, since health personnel involved do not always know the life situation of their patients. The barriers to health care that this group of people living with HIV meet, raise ethical questions similar to that of Paul Farmer addressing the lower medical ethical standards for the ‘world’s poor’: ‘If access to health care is considered a human right, who is considered human enough to have that right?’(Farmer, 2010) Moreover, their entitlements deviated sharply from those normally found to be essential to secure in the lives of people living with HIV in Norway, as part of preventing discrimination, exclusion and securing overall health. Health care policies applying to people without a residence permit are based on temporary and short stays, when in reality people living with HIV may spend a large part of their life in Norway.

With the increased number of people seeking refuge in other countries including Norway, the study is believed not to be less relevant for the target group, whose voices are seldom heard. A political will to take a closer look at the present situation and the consequences it has for people in the group may be far-off, instead there is a tendency to shift the focus over to people’s responsibility for own choices. This study has pointed to how a complex set of influences and structures beyond the control of individuals shape their lives and limits their choices. The context of illegalised exile shape the lived experiences of people living with HIV in ways that generate a range of negative predictors of health. Whether the consequences are unintended or intended by policies, the manifestations of them is that people living with HIV in Norway over years live under conditions not only resembling those in resource-poor settings with limited possibilities to reconfigure oneself after the life disruption of a serious chronic illness, but may cause ill health as the even larger life disruption of being denied protection, and of living a life in irregularity, makes its impact. Health for people living with
HIV, also in this study, is considerably more than HIV treatment. Policies should ensure adequate and relevant attention to the lives and overall health of persons in this group.

For people living with HIV, health is considerably more than HIV and HIV treatment, and illegalised exile in Norway shapes the everyday lives of people living with HIV in ways that generate a range of negative predictors of health. How the consequences of this influence the overall health of individuals and the course of the HIV-infection, should be explored further.
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Lov om forbud mot diskriminering på grunn av nedsatt funksjonsevne (Diskriminerings- og tilgjengelighetsloven)/Act relating to a prohibition against discrimination on the basis of disability (Anti-Discrimination and Accessibility Act) (2013).


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INVITATION TO PARTICIPATE IN STUDY

I AM DOING A RESEARCH PROJECT WHERE I'M TRYING TO LEARN ABOUT HOW IT IS TO LIVE WITH HIV FOR PERSONS WITHOUT A RESIDENCE PERMIT IN NORWAY. WHAT ARE THE CHALLENGES YOU MEET, WHAT ARE OF HELP, WHAT IS DIFFICULT? WHAT IS THE MEANING OF GOOD HEALTH AND OF HIV IN YOUR SITUATION?

TO PARTICIPATE IN THE STUDY MEANS THAT YOU WILL MEET ME FOR ONE OR SEVERAL TALKS. IF YOU AGREE TO IT, I WOULD ALSO LIKE TO SPEND SOME TIME WITH YOU TO LEARN ABOUT YOUR EVERYDAY LIFE.

IF YOU SAY YES TO PARTICIPATE, YOU CAN BE ANONYMOUS. ALL INFORMATION ABOUT YOU WILL BE KEPT CONFIDENTIAL. TO PARTICIPATE IN THE STUDY IS COMPLETELY VOLUNTARY, AND YOU CAN WITHDRAW FROM IT ANY TIME YOU WANT TO.

THIS IS A RESEARCH PROJECT THAT I AM DOING AT THE UNIVERSITY OF OSLO. IF YOU WANT TO KNOW MORE ABOUT THE PROJECT PLEASE CONTACT ME ON PHONE NO. 92 60 39 41. I HOPE TO HEAR FROM YOU!

Synnøve Sømod
M Phil Programme in International Community Health
University of Oslo
Phone no. 92 60 39 41
Appendix 2: Invitation letter and consent form

Invitation to participate in a research project

“Living with HIV and without a residence permit: dealing with life and health in illegal exile”

Background and purpose
This is an invitation for you to participate in a research study that intends to increase the understanding of how life is like for people who are living with HIV in the Oslo region and at the same time do not have a residence permit. The research study also intends to increase knowledge of what a healthy life means to them and how they manage to live healthy. The University of Oslo is responsible for this research study.

You are being invited to participate in the study because we believe you have important insight into this situation.

What does the study entail?
Participating in the study means that you will be talking with the researcher in in-depth interviews. The interviews may be done with an interpreter present and at a place you feel comfortable. We plan to do three different interviews, but if you prefer one, you are still welcome to participate. Participating also means that the researcher spends time with you in your everyday life. This part of the research will be planned together with you. The time period and place for this will be done in a way that you feel safe and will be decided together with you.

The study will at all times try to understand how the world looks like from your perspective, it means that you will be asked to share many of your inner and more private thoughts, but you may at any time chose not to talk about a topic.

If interpreter is used, he/she will get particular information about confidentiality and you will meet with the interpreter before the first interview.

Potential advantages and disadvantages
By participating in the study you can help us understand the needs and challenges of people living with HIV and without residence permit. This could help to make health services or other care for the group better. It could also have an impact on policy makers to make changes that are positive. If you are in need of assistance, we will try to help you to get in contact with the right places.

In the interviews we might talk about sensitive things which could make you uncomfortable. In sharing time with the researcher there could be situations you find difficult. You do not have to answer questions, and you can withdraw from the study at any time, without this having any consequences to you.

What will happen to the information about you
All the information about you and what we together find out in the study will be used without name, ID number, name of place or other directly recognisable type of information. Information that indirectly could identify you will be changed so that they can not be associated with you. In every way, attempts will be made to publish the result in such a manner that your identity is not disclosed. You will be shown the result before publication and will be able to give comments on this matter.
Voluntary participation
Participation in the study is voluntary. You can withdraw your consent to participate in the study at any time and without stating any particular reason. This will not have any consequences for your further treatment. If you wish to participate, sign the declaration of consent on the final page. If you agree to participate at this time, you may later on withdraw your consent without your treatment being affected in any way. If you later on wish to withdraw your consent or have questions concerning the study, you may contact Synnøve Sømod, phone no 92603941

Consent for participation in the study

I am willing to participate in the study.

(Signed by the project participant, date)

Proxy consent when this is warranted, either in addition to or in place of the participant’s consent.

(Signed by representative, date)

I confirm that I have given information about the study.

(Signed, role in the study, date)
Appendix 3: Thematic interview guide

Thematic interview guide

Life worlds

- Personal history of migration
- The meaning of place, sense of belonging
- How do participants see themselves in the world
- What is daily life in the Oslo region like?
- Family and social life, role and relation to society

HIV

- Personal history of getting the HIV diagnosis and subsequently living with HIV
- How living without a residence permit and living with HIV have influenced each other

A healthy life

- What is understood by health
- How does experiences of migration and life in ‘irregularity’ affect healthy living
- What is perceived as risks and vulnerabilities to ill health?
- What inhibits a healthy life? What enables a healthy life?
- How does mobility/irregularity affect sense of self and how does this affect sexuality?
- How does inter-personal and family relations affect health?
- Self-worth and mental health, how important is physical health perceived?
- How important is health services in their lives?
Appendix 4: Modified interview guide

INTERVIEW GUIDE – modified

Can I ask you how old you are?
Your civil status?
Children?
Country of origin?

Can you tell about how your life is like right now?
Housing
Work
Education
Family
Friends
Romantic relationship
Church
Existential issues

What do you do when you get sick?
Camp
Infection clinic
Emergency room
Health center for undocumented migrants
Dentist
How do you feel about your right to health care?
Do you get sick sometimes/often? What kind of sickness?
What is good health for you? What do you think of with being healthy?

Negotiations between fear of being deported and other needs and good health
Can or could you be home from work if you were sick? (what if sick child?)

Are you using medicines for HIV

Can I ask how you came to know that you were HIV positive

What do you think about HIV, what is your understanding of living with HIV

(Did this change before or after getting the diagnosis,
did it change from before and after leaving home country,
did it change before and after getting a rejection from UDI)

How has the infection developed, information from the infection specialist and understanding of this

Partners and protection

Own sexuality

How do you communicate with UDI?

Can you think of what choices you have right now? Is it possible to go to other countries, or?

How do you see your situation compared to other people living with HIV in Norway?

How do you see your situation compared to other people without a residence permit in Norway?

Special events, news.
Det er ikke et prosjekt som skal gjennomføres i utlandet i samarbeid med utenlandske myndigheter. Komiteen har likevel valgt å behandle søknaden.


Rekrutteringen vil foregå via støtteenter for HIV eller spesielle helsentera for personer som oppholder seg i landet illegalt. Studien åpner for muntlig samtykke av hensyn til de HIV-smittedes spesielle situasjon.

Komiteen har ingen innvendinger til prosjektopplegget slik det er beskrevet i søknaden.

I informasjonsskriptet brukes ordet ”request”. Dette ordet kan virke for sterkt i denne sammenhengen. Det anbefales å vurdere å finne et annet ord som er mindre påtrengende som for eksempel” enquiry” eller ”invitation”.

Vedtak
Komiteen godkjenner at prosjektet gjennomføres i samsvar med det som framgår av søknaden.


Kåre Moen
Institutt for helse og samfunn
Universitetet i Oslo
Forskningsprosjektets data skal oppbevares forsvarlig, se personopplysningsforskriften kapittel 2, og Helsedirektoratets veiledet for «Personvern og informasjonssikkerhet i forskningsprosjekter innenfor helse- og omsorgssektoren». Opplysningene skal ikke oppbevares lenger enn det som er nødvendig for å gjennomføre prosjektet, deretter skal opplysningene anonymiseres eller slettes.

Dersom det skal gjøres endringer i prosjektet i forhold til de opplysninger som er gitt i søknaden, må prosjektleder sende endringsmelding til REK.

Prosjektet skal sende sluttmelding på eget skjema, se helseforskningsloven § 12, senest et halvt år etter prosjektslutt.

Med vennlig hilsen,

Gunnar Nicolaysen (sign.)
Professor
Leder

Jørgen Hardang
Komitésekretær
Anne Schiøtz Kavli
Førstekonsulent

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Kåre Moen
Universitetet i Oslo

2011/1391 Living with HIV and without a residence permit: dealing with life and health in illegal exile

Forskningsansvarlig: Universitetet i Oslo

Prosjektleder: Kåre Moen

Vi viser til søknad om prosjekttending innendt den 18.05.2015 av Synneolve Skjøje Sømmed.

Søknaden er behandlet av leder for REK sør-øst A på fullmakt. Vurderingen er gjort med hjemmel i helseforskningsloven § 11.

Vurdering

REK sør-øst A har vurdert følgende endringer i prosjektet:

- Forlengelse av prosjektpериode til 01.09.2015: Søker viser til at prosjektopplegget for hennes masteroppgave "Living with HIV and without residence permit: dealing with life and health in illegal exile", ble godkjent av REK i 2011 med gyldighet fram til 30.06.2012. Av personlige og økonomiske årsaker er søker forsikret med inlevering av oppgaven. All datamåling som involverte deltakere i studien var avsluttet før godkjenningen fra REK gikk ut, og prosjektopplegget er ikke endret fra det som var beskrevet i REK-søknaden.


Vedtak

Søknad om prosjekttending godkjennes med hjemmel i helseforskningsloven § 11.

Ny sluttdato for prosjektet er 01.09.2015.

Godkjenningen er gitt under forutsetning av at prosjektet gjennomføres slik det er beskrevet i søknaden og protokoll, med etterfølgende endringer, og de bestemmelser som følger av helseforskningsloven med forskrifter.