

Lived Experiences of Immigrants with Chronic Illnesses in Denmark-

A Case of HIV Patients

Key Words; Lived experiences, Immigrants, Chronic illnesses, HIV and AIDS

BY

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D. O. B - 11.09.1986

**A Thesis Submitted For the Partial Fulfillment for the Award of Master of Science
in Public Health, To the Institute Of Public Health, Faculty of Health Sciences,
University of Southern Denmark**

July 2011

Declaration

I, Rogers Twesigye, do hereby solemnly declare to the best of my knowledge that this thesis is my original work except where otherwise acknowledged.

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Prof. Morten Sodemann(Supervisor)

Signed:

Date:

Dedication

I dedicate this work to all the patients that accepted to share their experiences with me.

Acknowledgements

I take this opportunity to thank the administration of the Immigrants health clinic under the department of infectious diseases, Odense University hospital, and the centre of migration and global health- University of Southern Denmark, for accepting and allowing me to carry out my study at their premises.

My sincere thanks go to my supervisor, and head of the immigrant's health clinic, Prof. Morten Sodemann. Your guidance and positive criticism was very helpful and made my study better; working with you was a learning experience I will treasure all my life.

Dlama and Mette, my colleagues, I appreciate all the different forms of assistance that you offered me throughout my project. Finally. I am very grateful for all the staff (Doctors, Nurses, secretaries) at the clinic and hospital at large, for the help and comfort extended to me throughout my research period, you made my work and stay with you comfortable and very rewarding. Thank you all.

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Definition of Key Concepts

Migration*¹ - The movement of a person or a group of persons, either across an international border, or within a State. It is a population movement, encompassing any kind of movement of people, whatever its length, composition and causes; it includes migration of refugees, displaced persons, economic migrants, and persons moving for other purposes, including family reunification.

Immigration* - A process by which non-nationals move into a country for the purpose of settlement.

Immigrant*- A person who migrates to another country, for either temporary or permanent residence.

Migrant*- The United Nations defines migrant as an individual who has resided in a foreign country for more than one year irrespective of the causes, voluntary or involuntary, and the means, regular or irregular, used to migrate

Asylum seeker* - A person who seeks safety from persecution or serious harm in a country other than his or her own and awaits a decision on the application for refugee status under relevant international and national instruments. In case of a negative decision, the person must leave the country and may be expelled, as may any non-national in an irregular or unlawful situation, unless permission to stay is provided on humanitarian or other related grounds.

Refugee* - A person who, "owing to a well-founded fear of persecution for reasons of race, religion, nationality, membership of a particular social group or political opinions, is outside the country of his nationality and is unable or, owing to such fear, is unwilling to avail himself of the protection of that country.

Ethnic minority- A group that has different national or cultural traditions from the main population

Culturally and linguistically Diverse (CALD) groups- Term used to describe non-Anglo migrant groups are exempted from meeting certain health requirements that govern migration

Chronic illness- An illness which lasts over an extended period of time and is treated by management rather than with the expectation of a cure

Lived experiences- Everyday experience, not as it is conceptualized, but as it is lived (i.e., how it feels).

¹ *Definitions courtesy of the International Organization of Migration (IOM) <http://www.iom.int/jahia/Jahia/about-migration/key-migration-terms/lang/en#Migrant>

Phenomenology- A philosophical doctrine proposed by Edmund Husserl based on the study of human experience in which considerations of objective reality are not taken into account

Social factors- Influences on individual behavior attributable to the social values and/or behavior of the groups to which an individual belongs or aspires to belong.

Psychological factors- Factors which refer to the mind or mental processes.

Psycho-social issues- Refers to the interaction between social and psychological factors.

Economic factors- Factors concerned with the influence of a person's income and other economic resources on purchasing behavior.

Socio-economic issues- Social and economic experiences and realities that help mold one's personality, attitudes, and lifestyle.

Socialwelfare system- Consists of actions or procedures — especially on the part of governments and institutions — striving to promote the basic well-being of individuals in need.

List of Acronyms

AIDS	Acquired Immune Deficiency Syndrome
BMI	Body Mass Index
CALD	Culturally and linguistically Diverse groups
CVD	Cardiovascular Diseases
ECDC	European Center of Disease Control
EE	Eastern Europe
EU	European Union
HAART	Highly Active Antiretroviral Treatment
HIV	Human Immune Virus
IDU	Injecting/Intravenous Drug Users
IHC	Immigrants Health Clinic
LA	Latin America
MSM	Men who have Sex with Men
MTCT	Mother-To-Child Transmission
OUH	Odense University Hospital
PTSD	Post Traumatic Stress Disorder
SSA	Sub- Saharan Africa
T2DM	Type 2 Diabetes Mellitus
TB	Tuberculosis
UK	United Kingdom
US	United States of America
WE	Western European

Abstract

The study aimed at exploring and understanding the life of an immigrant with a chronic illness, in this case HIV/AIDS, in Denmark; and implications for public health. It was based on the background that in addition to having poor health status compared to native populations, majority of immigrants continuously face challenges (Political, socio-cultural and economic) in their new countries of residence. Therefore, being a sick immigrant with a chronic illness yields another dimension in the already challenged life of an immigrant. Further, the gap in information and knowledge about the immigrants as a patient group in Denmark motivated the researcher to carry out this study. It focused on HIV/AIDS patients of African origin and was phenomenological in nature. Qualitative methods of data collection, analysis and reporting were used. Using purposive sampling methods, qualifying patients were selected with whom the researcher conducted in-depth interviews. Consequently, 9 interviews were conducted with 9 patients, 5 female and 4 male.

Overall, lived experience of the immigrant patients that took part in the study was a two sided story. For some, life was okay and for the other, life was not okay at all. The study discovered that African HIV patients face a number of issues in their daily life, that directly or indirectly affect their health as HIV patients. Some of the issues were as a result of being HIV infected, most of which their Danish counterparts may not come across.

Most of patients lived a double secret life. They do not want or fear, to disclose their HIV status to people that know them, except selected family members, friends and Health workers. The patients perceived HIV as a personal disease that should be kept to self, family and the Doctors and nurses. The fear of stigma and discrimination especially from fellow Africans was why patients view it better not to disclose or talk about their HIV status. This was the key reason that most of the patients also chose not to participate in support groups with other HIV patients. However, the patients identify the Doctors and nurses as the people they are most comfortable to share with their life.

Being HIV positive affected the social life of each of the participating patients in one way or the other. For some, being diagnosed with HIV had brought the family and friends closer, but for

others the opposite was true. The families of some of the patients had not been the same again, characterized with divorce and family break down, and being distanced by friends. Some patients continued with their lives as usual, responded well to treatment and continued with work to provide for their family. On the other hand, some of them had been weakened by the illness that they had to stop working. They had not responded well to treatment, faced a number of side effects from the medication and often got sick.

The patients highlighted a number of psycho-social issues which they faced, that directly or indirectly affected their lives as HIV immigrant patients. Emotions of depression as a result of coming to terms with the illness; being lonely and being frustrated, for those that couldn't live a normal working life, characterized lives of some of the patients. Stress due to pressure from the social system was the other key psycho-social issue that patients who were dependant on social assistance voiced in their lived experiences. Depression and stress had left the affected patients feeling more sick and subsequently affected their adherence to treatment. The affected patients questioned the use of taking medication if it would not solve their other major problems.

In terms of treatment and care, generally, the patients were satisfied, especially in comparison with the care back home in Africa. However, they felt the Doctors' visit should be more than just routine medical talk. The patients voiced the need for Doctors to address their overall life. This based on the fact that the patients view their Doctors as most trustworthy, comforting and like their 'family'. This relationship should be used as an opportunity to understand the unique issues that such a unique patient group faces in their life that somehow affects their health, adherence and compliance to treatment. The patients that faced pressure from the social system also identified the need for their Doctors to explain to the social workers the state of their health, which will help in reducing the pressure they face.

In conclusion, the study findings showed that African immigrant HIV patients face a number of unique issues that their Danish counter parts may not otherwise face. Therefore, there is need for unique or specialized programmes for this patient group so as to achieve treatment success and ensure social justice, health equality and equity in Denmark.

Chapter One: Background and Introduction to the Study

This chapter introduces the study. It includes the background of the study, problem statement, objective and research questions, scope and significance of the study.

1.1 Background:

The increasing number of immigrants world over has attracted concern over their integration in the hosting countries, not to mention their alarming socio- economic and poor health status. It has been documented that immigrants score poorly across all health indicators compared to the citizens in the countries they have moved to. The story is no different in Denmark. The definition of ethnicity and the terminology- ethnic minorities is not generally agreed on nationally in Denmark or internationally [1]. According to Statistics Denmark, immigrants are defined as “persons born abroad, whose parents are either foreign citizens or born abroad themselves. If information on parenthood is not available and the person is born abroad, he or she is also defined as an immigrant” [2].

According to a recent Danish report on Ethnic minority health, 23-40% immigrants from Ex-Yugoslavia, Lebanon/Palestine and Iraq, suffer from complex psychiatric illnesses such as anxiety or depression, PTSD, compared to 10% among those native to Denmark [3]. The report adds that among all ethnic minorities diabetes is 7 times more frequent compares to Danes. It further notes that 25-48% of immigrants have three or more diseases. Regarding health habits, immigrants have a higher intake of sugar and are less physically active compared to ethnic Danes. Hospital and immigration data also shows that immigrants and refugees have less access to disease, prevention and screening, more risk behavior, high BMI, higher blood pressure and have more travel related infections. It is also reported that 22-48% of all immigrants have poorer self-rated health compared with 10% among ethnic Danes. In all immigrant groups, a greater proportion has Long-term illnesses compared to ethnic Danes [4]. Data also shows that immigrants stay longer on waiting list for surgery and die more frequently after hospitalization[5]. In addition, in most countries, migrants often have poorer socio-economic conditions than the majority population[6]. In Denmark, Non-western immigrants have a marked higher unemployment rate (approximately 13 %) compared to ethnic Danes (3 %) [3].

Despite worldwide, regional and national recognition that immigrants live and face appalling conditions, there is limited detailed research and information on this patient group. Since the early '80s, Denmark has implemented studies of population health at national, regional and local levels. However, it is preferably ethnic Danes who have participated. While there are national, regional and local targets to reduce social inequality in health, the few Danish studies show that ethnic minorities face large and specific health problems. Publications about ethnic minorities and health are primarily research studies with the majority being quantitative studies, there is therefore a great need for more knowledge [4]. Municipalities and patient-organizations, however represent a considerable source of knowledge. There is also need of more knowledge about different sub-categories of ethnic minorities' illness and health as well as of general knowledge [3].

Knowledge about the effectiveness of health care services and programmes (targeting ethnic minority) as well as the reasons behind the statistics (poor health status) is nearly in non-existence [7]. This poses a challenge for now and the future as the number of immigrants, over the past years, has been increasing steadily in Denmark, Scandinavia and Europe at large. Immigrants have formed an increasing part of the population in Denmark throughout the past 30 years. By 1st January 1980, immigrants numbered only 99,796 among the population in Denmark. This number had more than doubled to 258,629 by 1st January 2001, amounting to about 5% of the total population [8]. As of January 2007, of the entire population in Denmark (5,447,084 people), the proportion of immigrants and descendants from Western countries and non-Western countries totaled 8.5 per cent [9]. In 2009, it is reported that immigrants constituted 9.1 % of the Danish population [3].

In a public health context this is interesting because for many years the Scandinavian countries have consisted of, overall, homogenous populations and national healthcare services that are "free" to all residents. However, since the 1970s the population in the Scandinavian countries has become more heterogeneous as a result of the rising number of immigrants. This represents a challenge, because the demands on the healthcare services have consequently changed. The way the Danish healthcare system is organized is different from most of the

countries immigrants come from. While it is described as free access, some services and medication have to be paid for; in addition, the system is completely based on the Danish language. In this context both language problems and insufficient knowledge about the structure of the Danish healthcare system may present access barriers for immigrants. Other access challenges may include different perceptions of illness and health, different expectations of the role of the patient and health personnel and communication problems in the meeting with Danish health personnel. Furthermore, lack of interpreters at times is often a challenge. There is no national strategy targeting ethnic minorities in the area of health. Most initiatives targeting ethnic minorities' health are individual projects led by municipalities, organizations or societies with a special interest in the field [3].

In addition to the poor socio-economic and health status compared to the majority population, immigrants face several political, legal/legislative and socio-cultural challenges on a daily basis in their host countries. They face issues to do with legal requirements and integration in the new country, and adjusting to socio-cultural changes. In Denmark, issues surrounding immigrants have been on the political agenda in the past years and drawn a lot of media attention and political discussions, such as passing a law on interpreters' fees [10] and reducing the duration of the government integration process. This has serious implications as the language barrier is associated with worse outcomes such as poor access to health care.

Since 2002, a number of policy measures have restricted the ability to get asylum and residence permit in Denmark. As a result, financial support to asylum seekers has dropped markedly and the number of people getting residence permits through family reunification was halved between 2000 and 2007. The general climate for ethnic minorities, especially with Muslim background, has deteriorated in the last decade and cases of discrimination appear to be more frequent in Denmark compared to other European Union (EU) countries [3].

My internship project at Immigrants Health Clinic (IHC) revealed that immigrants encounter and are daily faced with several obstacles in an effort to access health care services and other related social services. These are political, economic and socio-cultural in nature. The alarming fact is that it is not just one set of obstacles, but a combination of all. The challenges and

barriers, among others, included language barrier, lack of sufficient information and knowledge about the structure health care system, negative attitude and beliefs of perceived discrimination, low health literacy, socio-economic and political issues [7].

According to the head of the clinic, 'Everything is a problem' for an immigrant. In addition to some having diseases like HIV and Diabetes, they also suffer from either higher blood pressure, high BMI, low physical activity, complex psychiatric illnesses, and many are torture survivors. This is because many of the immigrants in Denmark are refugees that come or came from war or violence stricken countries in Africa, Eastern Europe, Asia and Middle East.

"...opening and reading their mail is a problem, (they) can't get their bills paid, have difficulty in handling family matters in Denmark because they have to be both African and Danish at the same time....they have to learn Danish, get integrated, get a job, so many things, and for a small group of these immigrants it is too much...." Head of the IHC [7]

With this at the back of my mind, it showed me that being an immigrant poses several challenges, and being a sick immigrant yields another challenge all together. Consequently, it bestowed on me that being an immigrant with a chronic illness yields another dimension in the already challenged life of an immigrant, hence this study on the lived experiences of immigrants with chronic illnesses. On this background therefore, I embarked on to explore, describe and document how it is for an immigrant to live with a chronic illness in Denmark amidst the other socio-cultural, political and economic dilemmas. The focus of this study was immigrants of African origin living with HIV in Denmark. Because of the advancement in HIV treatment that has been achieved over the years, many conceive HIV as a 'treatable', chronic disease.

The HIV epidemic is a major public health problem in the EU; the number of HIV infections has not ceased to increase since HIV reporting mechanisms came in place around 1999[11]. Migration and social exclusion make migrants highly vulnerable to HIV/AIDS and their related complications. Migrants are frequently affected by strong barriers to HIV/AIDS prevention and care, including cultural, socioeconomic and language barriers. In 2006, 6746 AIDS cases were reported in the EU27 countries plus Norway and Iceland. The largest number of migrants with HIV was observed among heterosexually transmitted cases; of those with known geographical origin, 50% were from a country different to that reporting the case, 77%

from Sub-Saharan Africa (SSA). Immigrants also tend to have a more progressed stage of HIV at diagnosis and hence higher risk of developing AIDS. Higher HIV mortality has also been registered among the immigrants compared the majority population [11].

In Denmark slightly over 5,000 persons are living with HIV, and every year an average of 250 – 300 newly diagnosed HIV cases are reported. Almost one third of the newly diagnosed persons have another ethnic background than Danish. Taking into consideration that immigrants in Denmark represent approximately 8-9% of the total Danish population, the prevalence among people with a minority ethnic background is fairly high [12].

1.2 Statement of the Problem

Majority of immigrants continuously face challenges (Political, socio-cultural and economic) in their new countries of residence. They have to, on a daily basis, adjust to changes in the countries they have moved to for a greater part of their lives as immigrants. Therefore, being a sick immigrant with a chronic illness yields another dimension in the already challenged life of an immigrant.

Very few studies, if any, have looked at the lived experience of immigrants with a given illness in Europe, later on in Denmark. From my internship research project at IHC, at Odense University Hospital (OUH); one of the key emerging issues was the limited information and research on immigrants as a patient group in Denmark [7]. While there are statistics and data about immigrants showing the occurrence, prevalence and incidence of diseases, the patients' experience of living with a given disease or diseases has not been documented extensively. Therefore, the gap in information and knowledge about the immigrants as a patient group in Denmark motivated the researcher to explore and describe, understand and document the lived experiences of immigrants with chronic diseases in Denmark by using HIV patients as a case.

It is the scope of this study to contribute to the greater goal of understanding issues surrounding the health and use of health care services of immigrants in Denmark. Letting

them (immigrant patients) tell their stories yielded important information and understanding of this 'problematic' patient group across the world.

1.3 Overall Objective of the study

The overall objective of the study was to describe and document what it is like for an immigrant living with a chronic illness (HIV/AIDS) in Denmark and highlight what this implies for public health.

1.4 Research Questions

- 1) How do the patients describe their lived experiences? What metaphors are used to describe their lived experiences?
- 2) What is the patients understanding of disease and treatment?
- 3) How and what has been the effect/impact of illness on; a) Patient (self), b) Immediate family, c) friends, d) Work?
- 4) How has the illness impacted on the psychological and socio-economic life of the patient?
- 5) What are the key issues expressed and highlighted by the patients?

1.5 Scope of the study

The field of focus of the study is global health, specifically looking at immigrants and health care systems. It is a phenomenological study both explorative and descriptive in nature. It was purely qualitative and therefore qualitative methods of sampling, data collection, analysis and reporting were employed. It was carried out at the Immigrants Health clinic (IHC) under the infectious diseases department at Odense University Hospital (OUH) in Odense, Denmark.

1.6 Significance of the study

- Documenting and understanding in-depth the patient view of their illness, as part of their overall life, provides a closer understanding for health workers of the patient they are treating. This consequently provides knowledge and information for improved health care service provision for such a group of special patients, by understanding why

things are the way they are (such as adherence and compliance) and how best and effectively they can be improved.

- Understanding patients' point of view and perception of their illness will reduce the gap between patients and the health workers, both in-terms of understanding and information wise.
- The study findings will add on the limited information, knowledge and understanding of immigrants as a patient group in Denmark.
- Consequently the study findings can be used to inform policy and practice of health care and other related services for special groups of people in the society.
- The study is a final thesis, a requirement to obtain a Msc. Public Health at the University of Southern Denmark.

Chapter Two: Literature Review

2.0 Introduction

This chapter reviews literature on immigrants in the world, Europe and in Denmark. It highlights the state of art and health of immigrants and their risk to chronic illnesses compared to the majority population in the hosting countries. The methodological challenges for research on migrants are assessed and the chapter ends with an analysis of HIV and immigrants in Europe and Denmark, which is the focus of this particular study.

2.1 Migrants in the developed world

Migration to European countries has increased since 2000 [13]. Estimates suggest that in 2005, 8.5% of the EU population consisted of migrants, with an additional 5.6 million arriving between 2005 and 2009. Migrants and ethnic minorities constitute approximately 64.1 million, equivalent to 9% of the total population in the EU [14]. Rising levels of immigration have been shaped by changing government policies, allowing for a diverse flow of immigrants from varied origins to traditional countries of immigration. In countries such as the US, UK, Canada, Australia and New Zealand, the numbers of foreign-born individuals has approximately doubled over the past 40 years, with the largest proportion originating from developing countries [15].

Immigrants have formed an increasing part of the population in Denmark throughout the past 30 years. By 1st January 1980, immigrants numbered 99,796 among the population in Denmark. This number had more than doubled to 258,629 by 1st January 2001, which amounted to about 5% of the total population [8]. As of January 2007, the population in Denmark comprised 5,447,084 people [9]. Of the entire population the proportion of immigrants and descendants from Western countries totaled 147,175 people, or 2.7 per cent, and the proportion constituted by immigrants and descendants from non-Western countries totaled 330,525 people, or 6.1 per cent. It is estimated that immigrants in Denmark constituted 10% of the total population in 2010². The three largest immigrant groups are from Turkey, Iraq and Germany. Asylum seekers are primarily from Iraq, Serbia, Montenegro, Afghanistan and Iran [3].

²Statistics Denmark (2010) Statistical yearbook 2010

A large proportion of migrants to traditional immigration countries have been born in countries recently affected by war and political unrest. Many of them have been subject to traumatic events such as prolonged periods of deprivation, the loss of family and friends in violent circumstances, or a perilous escape from their homeland [15,16,17]. Under such circumstances, many of these culturally and linguistically diverse (CALD) groups, a common term used to describe non-Anglo migrant groups, are exempted from meeting certain health requirements that govern migration [18,19]. As a result, many migrants arrive in the host countries with suboptimal or poor health, posing a public health challenge [20].

A central challenge for Europe, with its increased proportion of migrants, is the provision of accessible, equitable, and good quality health services for all [21]. In Denmark everyone registered under the National Register is entitled to services under the Danish National Health Insurance. Family reunification migrants and quota refugees undergo a quarantine period of six weeks. Asylum seekers and illegal and rejected immigrants, who are not registered under the National Register, are entitled to health services in acute cases. The Red Cross can apply for support to other health services through the Immigration Service. A number of informal barriers, however, influence immigrants' access to and usage of the health system. For example lack of knowledge about the health system and entitlements, different perceptions of illness and health, different expectations of the role of the patient and health personnel and communication problems in the meeting with Danish health personnel. Lack of interpreters is often a challenge as well. The lack of a national strategy targeting ethnic minorities in the area of health, doesn't make things any better in Denmark [3].

Understanding the health status and needs of migrants and ethnic minorities in the EU is crucial for several reasons [22]. First, the right to the highest attainable health is a fundamental human right [23] which constitutes one of the underlying values in the EU together with the principle of equity in health [24]. Second, EU has highlighted the importance of equity, social cohesion, and growth which has put migrant and ethnic minority health on the agenda [24]. Third, migrants and ethnic minorities constitute approximately 64.1 million equivalent to 9% of the

total population in the EU [25]; thus, contributing significantly to the health status of the European countries.

2.2 Migration, Migrants and Health (chronic illnesses)

Immigrants are reported to have a lower self-rated health [26], more mental health problems [27], higher risk of cardiovascular diseases [28], diabetes [29], and premature mortality 1997 [30], than the general native population. However, immigrants are also reported to have a lower prevalence of obesity [31], reduced risk of myocardial infarction [32], less alcohol intake and lower risk of premature mortality than the native population [28]. A strong association between socioeconomic status and health exists [33]. Since immigrants generally have a low socioeconomic status, some ethnic inequalities may therefore be related to socioeconomic differences 2009 [34]. The observed contradictory findings regarding immigrant health may therefore be caused by varied control for socioeconomic status [35].

2.3 Migration and Risk of chronic illnesses

Migration from developing countries to affluent, Westernized countries is associated with an increased risk of chronic disease, especially obesity, diabetes and chronic heart diseases, but with varying effect depending on ethnicity [36,37,38]. Findings indicate that migration to Western societies has a detrimental effect on the health status and health behaviours of CALD groups as they assimilate to their new surroundings, explore different cultures and customs, and embrace a new way of life. In particular, there is evidence that physical inactivity is common in migrant CALD groups, and is a key contributing risk factor to chronic disease for these individuals [39].

For example, the Ghanaian Health and Nutrition Analysis in Sydney found an increase in self reported BMI (23.8 (SD 2.2) kg/m² for men and 23.4 (SD 4.5) kg/m² for women pre-migration v. 27.2 (SD 2.8) kg/m² and 27.4 (SD 4.7) kg/m², respectively, post-migration) among Ghanaian migrants [40]. The study also found a high prevalence of both type 2 diabetes mellitus (T2DM) and impaired fasting glucose. The prevalence of T2DM was 20% in men and 11% in women, and impaired fasting glucose was 22% and 20 %, respectively. Only 23% of study participants were

aware of their T2DM status, indicating the lack of awareness and the increased risk of medical conditions related to uncontrolled diabetes. These findings were consistent with those reported in studies of the African Diaspora of West African origin [41,42] and Ethiopian migrants to Israel [43,44].

The pattern observed among African migrants has also been reported for other migrant sub-populations. For example, data reported by the Australian Institute of Health and Welfare [36] found that, overall, migrants born in Southern and Eastern Europe, North Africa and the Middle East experience rapid weight gain following migration and have a prevalence of overweight that is significantly higher than the Australian-born population. People whose main language spoken at home is a Middle Eastern, Northern African, Southern Asian, other South-West Asian or East Asian language were found to have higher rates of T2DM than Australian-born people [36].

Andre et al [45] write that in the USA, Hispanic (Mexican, Cuban and Puerto Rican) Americans have higher levels of overweight and obesity than do white Americans [46]. Similarly, in The Netherlands, the prevalence of overweight/obesity among Turkish and Moroccan immigrants is very high at 57–89% [47]. The risk of the escalation of obesity and T2DM has been found to follow a gradient as migrants become more affluent and urbanized, and as nutrition and lifestyle behaviours change [48].

In the UK, Asian men appear to be more prone to coronary heart disease than others, and both men and women of South Asian origin have 30–40% higher coronary disease mortality rates than UK-born individuals [49,50]. Similar findings have been reported in New Zealand, where there is a high prevalence of risk factors for lifestyle diseases including Cardiovascular Diseases (CVD) and diabetes in older Asian Indians[51] and older Tongan adults[52] living in urban settings compared with individuals born in New Zealand.

In Denmark, according to a study on the health status of ethnic minorities, immigrants are more vulnerable to a number of health problems, while disease patterns vary among ethnic groups [3]. Overall, immigrants judge their own state of health as being worse than ethnic Danes and experience stress more frequent. Several chronic diseases are more frequent, such as diabetes,

while cancer is less frequent. Mental health is also worse with more immigrants experiencing chronic anxiety and depression than ethnic Danes. Asylum-seeker children are especially vulnerable in relation to mental health disorders. Regarding health habits, immigrants have a higher intake of sugar and are less physically active than ethnic Danes. Men from some immigrant groups smoke more while immigrant women in general smoke less than ethnic Danes. Most immigrant groups consume less alcohol compared to Danes.

2.4 Reasons for Poor health behavior and health seeking behavior of Immigrants

Despite the increased risk of hypertension, diabetes, overweight/obesity and CVD, individuals from CALD groups are less likely to be proactive in accessing health care or undertaking preventative measures to ensure optimal health outcomes [53,54]. Although it has been well documented that engaging in preventive measures such as regular physical activity is associated with reduced risk of CVD and other chronic diseases,[55] it is evident that individuals from CALD backgrounds are less likely than others to participate in such activities [56,57,58]. For many CALD individuals there are several constraints on activity participation beyond personal motivation. Language barriers, socioeconomic factors, psychological trauma relating to migration and alternative health-seeking behaviours are just a few of the constraints that are likely to have a detrimental impact on health in these populations [59,60,61].

Challenges and barriers that limit physical activity participation in CALD groups include: cultural and religious beliefs, issues with social relationships, socioeconomic challenges, environmental barriers, and perceptions of health and injury [62].

2.5 Way forward

According to Gallant et al. [63] to reduce these disparities in chronic illness outcomes, there is need to better understand how members of these groups live with and manage chronic illnesses, in order to design effective intervention strategies that will enhance chronic illness outcomes [64]. However, the limited studies suggest racial/ethnic differences in the underlying determinants of self-care behaviors, including knowledge [65], attitudes regarding

responsibility for health and illness management [65], philosophy of illness [64], cultural influences [66], and spiritual practices and beliefs [67].

2.6 Methodological challenges

Nielsen and Krasnik [22] note that it is important to bear in mind, that migrants and ethnic minorities constitute heterogeneous groups with respect to their ethnic features, historical roots, culture, and practices concerning health. Also, several factors may influence the health of the minority population such as factors in the country of origin, including cultural background (e.g. early life risk factors, diet); factors related to the act of migration (forced or voluntary); factors during the migration process; socioeconomic factors in the host country (e.g. poor socioeconomic conditions, loss of social status); and selection effects such as the 'healthy migrant effect' [68].

Racial/ethnic disparities in the prevalence, awareness, and control of several chronic conditions have been well described. Several studies have hypothesized that racial disparities in chronic disease management may be related, in part, to differences in patient attitudes and/or behaviors,[69,70] though the status of such factors is not yet well-understood. Increasingly, investigators have used qualitative methods, including focus groups and in-depth interviews, to gain insight into modifiable patient-level behaviors and challenges in chronic disease management [71]. This particular study tries to do this using a phenomenological research design. It focuses on the lived experiences of migrants of African origin living with HIV in Denmark.

2.7 HIV and immigrants in the EU [11]

The HIV epidemic is a major public health problem in the EU; the number of HIV infections has not ceased to increase since HIV reporting mechanisms came in place around 1999. Migration and social exclusion make migrants highly vulnerable to HIV/AIDS and their related complications. Migrants are frequently affected by strong barriers to HIV/AIDS prevention and care, including cultural, socioeconomic and language barriers. According to the 2010 European Center of Disease Control (ECDC) report [11], the predominant transmission route is

heterosexual (53% of new HIV reports in 2006), followed by men who have sex with men (MSM) (37%) and by injecting drug users (IDU) (9%). It is worth highlighting 204 cases of HIV infection through mother-to-child transmission (MTCT) reported in 2006.

The absolute and relative contribution of migrants to national HIV epidemics is heterogeneous across the EU and depends on migration patterns, colonial history, state of HIV epidemics in countries of origin and destination, and on health and social responses.

There is an enormous diversity in the proportion of migrants with HIV infection in the different countries. For countries in Eastern Europe (EE) and for some from Central Europe, this proportion is below 10% while for most Northern countries it is over 40%. For most countries in Western Europe, the proportion of migrants among those infected by HIV is between 20% and 40%. This pattern is consistent with migratory trends as the countries where the proportion of migrants among HIV cases is higher are also the countries where the proportion of migrants in the general population is also higher, largely driven by past colonial history and recent socio-economic and demographic imbalances. There is also a substantial and worrying proportion of cases whose geographical origin is unknown, particularly in the UK, France, Belgium and Germany.

Late HIV diagnosis is a big problem in the EU and USA and the data suggest that this problem is even greater for the HIV-positive migrant population of non-Western origin. The number of AIDS cases reported in most EU countries has experienced a marked decline from the mid-1990s onwards, which has been largely attributed to the population impact of including having access to highly active antiretroviral treatment (HAART). However, for most migrants this decline is not observed, reflecting late diagnosis of HIV infection and poorer access and uptake of HAART, and may have a negative impact on the mortality of HIV positive migrant people in the EU. Furthermore, adequate treatment of HIV is also a strategy to prevent HIV transmission, given that people on HAART are less infectious. The approach treatment and prevention is also applicable to TB as prompt HIV testing would certainly decrease HIV-associated TB. As it has been well established, treatment of TB is equivalent to prevention of TB transmission and thus, of secondary cases.

The expansion of the HIV/AIDS pandemic and its uneven distribution worldwide may be associated with a higher HIV prevalence in migrants originating from countries with established HIV epidemics compared to those of the countries of destination. This is yet another consequence of the overlap between health inequity and poverty that acts as one of the major push factors for emigration. This phenomenon has been reported worldwide. In the USA, blacks accounted for 49% of persons diagnosed with HIV/AIDS in 2006, Hispanic/Latinos accounted for 18% and whites for 30% [72]. In the EU an increase in the absolute and relative number of migrants originating from SSA among heterosexually acquired HIV infections has been reported over the last years. EuroHIV surveillance data also show slower reductions in AIDS incidence in SSA migrants [73]. In Norway, Sweden, Ireland and Belgium, over 50% of the newly reported HIV cases in heterosexuals in 2006 were of migrants [74].

In 2006 6,746 AIDS cases were reported in the EU27 countries plus Norway and Iceland. The largest number of migrants was observed among heterosexually transmitted cases; of those with known geographical origin, 1,373 (50%) were from a country different to that reporting the case, 77% from SSA. Of 57 AIDS cases due to MTCT with known geographical origin, 23% were from SSA. Also, close to 20% of AIDS cases in MSM were migrants; the commonest origins were Latin America (LA) (106) and other Western European (WE) countries (52). Among 1 545 cases in IDU, 7% were migrants, largely from WE and North Africa & Middle East. The number of AIDS cases in the region has experienced a 42% decline from 1999–2006 in natives and migrants from WE. Rising numbers of AIDS cases in 1999–2006 are observed in migrants from EE (by 200%), SSA (by 89%) and LA (by 50%). AIDS cases are much more common in men than in women in the EU, though the male/female ratio is decreasing. Therefore, although the absolute numbers of men and women from SSA among AIDS cases reported in 2006 were 602 and 623 respectively, their proportions within the number of AIDS cases in males and females were 12% and 33%, respectively.

Prost et al, in a thorough review, summarized available data in Europe and identified that the most common features affecting SSA migrants living with HIV/AIDS are as follows: more advanced disease at the time of HIV diagnosis, higher rates of TB, major difficulties related to

their immigration status, social discrimination and stigma (which difficult access to HIV prevention and care), and high levels of poverty and unemployment [75].

Data on HIV/AIDS in migrants from the UK suggest that migrants from SSA are likely to be already infected by HIV when arriving to Europe [76]. This conclusion can be drawn from analyses that have measured lymphocyte CD4 counts at the time of HIV diagnosis and have related those values to the time since arrival to the country. This is, again, no surprise for those working in the field given the extent of the pandemic in SSA. There is also evidence that migrants from SSA are also becoming infected in EU countries [77], or when they travel to their countries of origin. Fenton et al, in the Mayisha study, have documented the very high proportion of men and women who have engaged in unprotected sex when travelling to their home countries [78].

In some communities, and in generations following the migration, relationships with people originating from the country of their ancestors may also be close, either travelling to the country of origin or in the country of destination. Given that the majority of people tend to choose sexual partners within their own communities, sexual mixing may take place between migrants and members of the same ethnic minority, as described by Grass et al, among others [79].

The estimates for number or proportion of HIV cases among undocumented immigrants are not unknown and not clear across most of the European nations. According to estimates from 2008[80], there are about 3.8 million undocumented migrants in Europe whom largely remain invisible in the eyes of policy makers [81].

2.8 HIV and immigrants in Denmark

In 2005, it was estimated that well over 5,000 people are living with HIV in Denmark; about 550 of these have been diagnosed with AIDS [82]. During the period 1 August 1990-31 December 2004, HIV infection was reported in 4,254 persons, 3,076 men (72%) and 1,178 women (28%). MSM accounted for 39% of the cases (50% of the Danes and 14% of the immigrants). Heterosexual transmission accounted for 45% (32% of the Danes and 73% of the immigrants).

Intravenous drug users (IDU) accounted for 9%. In 2004, 124 out of 190 Danes reported with HIV were MSM (65%). A total of 2,530 people were reported with AIDS. From the mid-1990s, the number of cases reported annually dropped. In 2004, 51 cases and 31 AIDS deaths were reported.

In Denmark about 5,300 persons are living with HIV, and every year an average of 250 – 300 newly diagnosed HIV cases are reported. Almost one third of the newly diagnosed persons have another ethnic background than Danish. Taking into consideration that immigrants in Denmark represent approximately 8% of the total Danish population, the prevalence among people with a minority ethnic background is fairly high [12].

In 2005, 300 newly diagnosed HIV cases were reported in Denmark. Of these people, 96 persons had an immigrant background. The two largest groups of immigrants represented in the statistics are people originating from Africa and from Asia, which reflects the epidemic in these countries and regions. Most of the HIV-positive immigrants living in Denmark contracted HIV in their countries of origin. In total, 1,339 immigrants (630 men and 709 women) have been reported to be living with HIV in Denmark. Near 73% of the HIV-positive immigrants contracted HIV through heterosexual contact. By contrast, the percentage for ethnic Danes is 31 [12].

Similar to overall number of undocumented immigrants in Denmark, the HIV cases among this group of immigrants is unknown in the country.

Chapter Three: Methodology

3.0 Introduction

This chapter describes how the study was organized. It includes the research design, study population and area, sample size and selection, methods of data collection and analysis, and ethical considerations.

3.1 Research Design

The study was a phenomenological one, both explorative and descriptive as well as interpretive in nature. Phenomenology is concerned with the study of experience from the perspective of the individual, 'bracketing' taken-for-granted assumptions and usual ways of perceiving [83]. Epistemologically, phenomenological approaches are based in a paradigm of personal knowledge and subjectivity, and emphasize the importance of personal perspective and interpretation. As such they are powerful for understanding subjective experience, gaining insights into people's motivations and actions, and cutting through the clutter of taken-for-granted assumptions and conventional wisdom [84, 85].

Pure phenomenological research seeks essentially to describe rather than explain, and to start from a perspective free from hypotheses or preconceptions [83]. Adding an interpretive dimension to phenomenological research, enables it to be used as the basis for practical theory, allows it to inform, support or challenge policy and action. Phenomenological approach can bring in terms of cutting through taken-for-granted assumptions, prompting action or challenging complacency [86].

3.2 Study area and population

The study participants were mainly selected from the patients registered with the Immigrants health clinic (IHC), department of infectious diseases, Odense University Hospital (OUH). According to the clinic's webpage, the Clinic was established in May 2008 after a growing awareness of infectious diseases under the auspices of the existence of a significant group of patients with different ethnic backgrounds who have no access to prevention and treatment at the same high level as other Danish patients. The clinic receives only patients of different ethnic

background residing in Funen. The clinic is the only of its kind in Denmark. The tasks at the Clinic are performed by a doctor, three nurses and a social worker. In 2008, the clinic had carried out around 200 consultations. In 2011 the clinic had 530 registered patients.

The patient population from which the sample or study participants was selected, was immigrants with HIV/AIDS as a chronic disease, that had been clinically diagnosed, had been in Denmark at least for 2 years and were of African origin.

3.3 Sample size and selection

The sample size was 9 patients. The sample size was chosen based on the nature of the study as well as limitations of time and other logistical constraints. The participants were purposively selected with help and guidance from the doctors due to the nature of the study, and not randomly selected. The inclusion criteria as mentioned before, immigrants with a clinically diagnosed HIV, spoke English or Danish, had been in Denmark at least for two years and of African origin.

3.4 Methods of data collection and Analysis

Data collection and analysis was qualitative in nature. With help of an interview guide, the research carried out in-depth interviews with the selected study participants. The Interview guide comprised of open ended question/s and captured;

a) background information about the participant- age, sex, period in Denmark, marital status, education, employment status, family size,

b) Illness- when and where diagnosed,

c) Description of lived experience by asking an open question- how has it been living with this illness since diagnosis. 'tell me more' and 'anything else' phrases will be used to encourage participant to describe their experience.

The interviews were carried out either at the clinic, at the patients' home or over the phone. Consequently, of the 9 patients that took part in the study, 5 interviews were carried at the

clinic, 2 at the patients' home, 1 in an office just away from the clinic and 1 over the phone. In total the researcher contacted 30 patients that qualified to participate in the study, only 10 agreed to take part in the study. The major reason of non-participation was; didn't want to talk about, the other reasons were; being busy and language barrier. One of the interviews was excluded from this report because the patient had not been diagnosed with HIV but Hepatitis. Of the 9 patients, 5 were female and 4 male, all of them were of African origin and resided in Fyn region and 2 in Copenhagen. Seven of the participants were from SSA, one from West Africa and one from North Africa. A translator was used for two of the interviews for patients that were not very fluent in English but Danish.

The interviews were audio taped, transcribed and printed out for analysis. The researcher used thematic content analysis. A descriptive and Narrative form of reporting is used, supplemented with direct quotations from the interviews.

According to Linda [85] when it comes to analysis, phenomenological researchers engage in active and sustained reflection as they 'dwell' with the data and interrogate it, for example asking: 'If a person has said this, what does this suggest of their experience of the world?' Beyond this reflection process, different methodological variants privilege either the use of systematic procedures or the spontaneous emergence of creative intuition. For instance, using the analytical method suggested by Wertz [87] and Giorgi [88], systematic readings of the transcript are undertaken by first dwelling on the phenomenon (through empathetic immersion and reflection), then describing emergent psychological structures (i.e., constituents and recurrent themes). The researchers are involved in "an extreme form of care that savors the situations described in a slow, meditative way and attends to, even magnifies, all the details" [89].

The precise form an analysis of research findings takes varies considerably. Often researchers will aim to identify significant themes or narratives emerging from the data. Each type of analysis and way of presenting the data simultaneously reveals and conceals. Different analyses highlight particular nuances and indicate various immanent possibilities of meaning as figural against a ground of other possible meanings.

3.5 Ethical considerations

The researcher had to take an oath of confidentiality about the patients' information that was availed to him by the clinic and doctors. Consent was sought from the patients before taking part in the study. This was first done by either the doctor or the nurse by contacting and informing the patient about the study, either on the phone or when the patient comes for a consultation visit. Confidentiality, anonymity, voluntary participation, the purpose and importance of the study to the researcher, clinic and patient were clearly explained and emphasized to each of the patients contacted for participation in the study.

Chapter Four: Presentation and Discussion of Findings

4.0 Introduction

This chapter presents the findings of the study as an attempt to answer the research questions that were set and the overall objective; to describe and document what it is like for an immigrant living with a chronic illness (HIV/AIDS) in Denmark and highlight what this implies for public health. Findings are presented along themes that resulted from the in-depth interviews conducted with the study participants. Quotations have been used to emphasize and bring out the actual voices of the participants that took part in the study. The chapter starts with a description of social demographic data of the participants aimed at providing a background to the results presented. It ends with a discussion of the findings by the research aimed at interpreting the findings in relation to other studies with a related focus, and implications for public health.

4.1 Social Demographic Description of Participants

Total No. of participants = 9 (4=Males, 5=Females)								
ID	Gender	Age	Years in DK	Family	Marital Status	Employ't	Reason to move to DK	Year of disease diagnosis
Patient 1	Female	50	4yrs	4 kids	Married	not working	Join Husband	2007 in Africa
Patient 2	Female	39	10yrs	2 kids	Divorced	working	Study and work	2004 in DK
Patient 3	Female	38	15	3 kids	Divorced	Not working	work	1998 in DK
Patient 4	Male	42	8	6 Kids	Married	Not working	Political refugee	2003 in DK
Patient 5	Male	64	30	5 kids	Married 3 times	Not working	Study and work	1996 in DK
Patient 6	Female	47	30	1 Child	Widow	Not working	Start over	1989 in Africa
Patient 7	Male	45	11	2 kids	Married	Working	Political refugee	1998 in Africa
Patient 8	Female	42	10	4 kids	Separated	Working	Asylum	2002 in DK
Patient 9	Male	26	5	2 Kids	Married	Working	Work and study	2003 in Africa

As noted earlier, the total number of participants was 9. They included 5 females and 4 males, all of African origin and had been clinically diagnosed with HIV. Four had found out about the illness while still in Africa and 5 got to know about it while here Denmark. The youngest

participant was 26yrs and the oldest was 64yrs. All the participants had been living in Denmark atleast for 4 years. Two had been living in Denmark for over 30 years. The reasons for coming to Denmark varied from joining partner, studying, working and others came as refugees. Below is a detailed description of each of the participants that took part in the study;

Patient 1: Tina (*The names used in this report are not the patients real names*)

She was 50yrs old and had been living in Denmark for over 4 years. She moved to Denmark to join her Danish husband (married at the time of the study) after being diagnosed with HIV in Africa. She was diagnosed with HIV in early 2007 while in Africa, and had therefore been living with HIV for 4 known years at the time of the study. Her husband is also infected and she has 4 children that live in Africa. She was studying and now working at the time of the study.

Patient 2: Tracy

She was 39yrs old and had been living in Denmark for 10 years. She moved to Denmark to study and work. She was diagnosed with HIV in 2004, and therefore had been living with HIV for 7 known years at the time of the study. She was divorced, had 2 children and was pregnant during the study. Her children were HIV negative. She was working at the time of the study.

Patient 3: Kate

She was 38yrs old and had been living in Denmark for 15 years. She moved to Denmark to study and work. She was diagnosed with HIV in 1998, and therefore had been living with HIV for 12 known years at the time of the study. She was divorced with 3 children and her children are HIV negative. She was not working at the time of the study.

Patient 4: Peter

He was 42yrs old and had been living in Denmark for 8 years. He came to Denmark as political refugee. He was diagnosed with HIV in 2003, and therefore had been living with HIV for 8 known years at the time of the study. He is married with 6 children, his wife and the last born (11yrs old at the time) are also infected with HIV. He was not working at the time of the study.

Patient 5: Amir

He was 64yrs old and had been living in Denmark for over 30 years. He moved to Denmark to study and work. He was diagnosed with HIV in 1996, and therefore had been living with HIV for 15 known years at the time of the study. Hewas married with 6 children with 3 different mothers, all of them HIV negative. He was not working at the time of the study.

Patient 6: Rita

She was 47yrs old and had been living in Denmark for over 30 years. She moved to Denmark after the loss her Danish husband while in Africa. She was diagnosed with HIV around 1989/1990 while in Africa, and therefore had been living with HIV for over 20 known years at the time of the study. She is a widow with 1 adopted child. She had stopped working at the time of the study.

Patient 7: John

He had been living in Denmark for 11 years. He moved to Denmark as a political refugee. He was diagnosed with HIV in 1998, and therefore had been living with HIV for 12 known years at the time of the study. He was married with 2 children at the time of the study. His wife and children were HIV negative. He was working at the time of the study.

Patient 8: Mary

She was 42yrs old and had been living in Denmark for 10 years. She moved to Denmark to start a new life. She was diagnosed with HIV in 2001/2, and therefore had been living with HIV for 10 known years at the time of the study.

She was separated with 4 children (one of them HIV positive (20yrs old at the time of the study)). She was working at the time of the study.

Patient 9: Sam

He was 26yrs old and had been living in Denmark for 5 years. He moved to Denmark to study and work. He was diagnosed with HIV in 2003, and therefore had been living with HIV for 8 known years at the time of the study. He was married with 2 children (wife and last born were HIV negative but not sure of the first born at the time of the study). He was working and studying at the time of the study.

4.2 Results:

This section entails a description of lived experience of the immigrants living with HIV that took part in the study. The researcher asked each of the patients to describe how it had been for them to live with HIV from the time they found out about it. Even though a lived experience is subjective, and in some way everyone has a unique story, making sense of each of the stories in a bigger picture in relation to the topic of focus yielded a common point or points of departure. From the lengthy and detailed stories of the participating patients, a number of themes were generated after a thorough analysis of all the transcripts from the interviews. Patients described their overall life right from when they found out, where they are now and what they planned or hoped for the future.

The themes highlighted include: finding out and reaction, acceptance/moving on; forms and source of support; perception of HIV and living with it; the impact of the illness on self and significant others; treatment and medication experience; psychological issues; and overall life as an immigrant in Denmark in relation to illness. Below is a detailed description of the experiences along the afore mentioned themes of the patients that took part in the study;

4.2.1 Finding out and reaction:

Some of the patients got to know that they had HIV while in Africa, while some of them found out about it from Denmark. What seems to be common to all the patients, is that they got to find out after getting very sick but not out of routine checkup as illustrated by some of them below,

“We didn’t know that we were sick until once we had a skin condition, and then he (husband) went to a Doctor. And they told him that he wasn’t well, I also went to doctor as well at home (Africa)... I think they did 3 or 4 times test and then they said that I was HIV positive”.... Tina

"I found out about it here in Denmark. I went for holiday in Africa and I was sick while there.... they suggested that I need blood transfusion.....when I came back (to DK) I was sick and I was admittedthey took blood tests, after 3 or 4 days, they break the news".....Kate

"I was sick and I was weak, and then I started having fever and then they found out that I had TB which was also very common where I was in Africa....but when they did more tests that's when I found out that I was HIV+"Mary

"I got sick form Gonorrhoea and I went to a nurse friend of mine in Africa, I said just give me a pill and I will be okay. She said no, you have to take this test to find out if you are HIV+ or not. So she encouraged me to do it and I did it"Sam

▪ **First reaction- 'Dead man walking'**

Nearly all the participants expressed their first reaction as that of shock on being told that they had HIV. To most of them, it was news they never expected and didn't want to believe. Out of experience and little knowledge they knew about the disease in an African perspective, the feeling of shock was worsened. Thoughts of neared death filled their mind and to most of them, the end of their life had arrived.

"At the start, it was very hard. Because, you know the way people die home (Africa), I just gave up..... I couldn't move, I couldn't do anything, because even to go to work I was afraid. I was thinking that everybody is going to say that she is sick, she cannot be with us."... Tracy

"I was shocked, I could not even talk and I didn't believe it. But I didn't cry at all, I was just stoned, because I was wondering how can this happen. So I began to realize may be while I was there (Africa) in the hospital, all this blood transfusion they were doing on me, maybe that's how I got it".....Kate

"I was shocked, I lived all my life in safety, doing my best to be protected and only be with my wife...it was like a bomb had exploded in my head. It was very difficult to accept the situation".....Peter

"I thought I was going to die, you don't think of anything else but death".....John

Emotions of uncertainty of the future, non-acceptance of the diagnosis and depression followed in the aftermath of the immediate reaction upon receiving the news about their HIV status.

"The first time you don't believe that you are sick, you are seeking many things, medicine, this and that.... The first time it was hard, I was sad all the time, crying".....Rita

"...because I knew about it from home.....and going through the things I went through...It was depressing....I had come to Denmark because of the things I had gone through back in Africa. So everything turned up-side down yet I thought that when I came here everything is going to be okay. So knowing that I was HIV+, I thought this is it now, and so I went through that period of being depressed".....Mary

"It was really heavy, so many things were going on in my head, I hadn't even finished my high school. I was like what am I going to do, am going to die, it was really hard....my friend said there is nothing that shows that you are sick, so we shouldn't think about that. So for the first one year, we were like its wrong, unless my grandmother 'sent' it to me, that's what we thought, that is a spiritual disease. But at that time we didn't know much about HIV,".....Sam

▪ **Self blame and asking questions- Why me?**

Some of the participants felt a sense of self blame for acquiring the virus. They blamed themselves for whatever they were going through and what had happened in the past in their life. Mary noted,

"I was only left with a blaming feeling, I was blaming myself for some of the things I went through my life, like how did I let this happen to me, maybe I should or would have been out of this (past) relationship long ago things like that".....Mary

For some of the participants, they went through a phase of questioning, why it was them that had been diagnosed with HIV. To some of them, asking questions is something that has continued up to today, as noted below by two of the participants,

"I was asking myself all the time, why me? What have I done to deserve this? And I keep on asking this to myself up to today"..... Kate

"All the children were tested and they were negative, but this one born in 2001 was positive....So we began to think, will this child die and how will we explain this, what is it that he ever done? This is a question that we have to face every single day. Our son is energetic, he likes running around and playing football, and the same question comes up, how will we tell him?.....what have I ever done to deserve this illness, I think about my son and I say he has not done anything to deserve this"....Peter

4.2.2 Acceptance/Moving on:

Having gone through the first phase of immediate reaction (shock, thoughts of death, non-acceptance, depression, among others), at a later time all the participants expressed feelings

and thoughts of acceptance of the situation they were in. This followed finding out that the illness has no cure but is 'treatable' or manageable for a long period of time. Therefore, understanding the illness and treatment available enabled most of them to accept what had got into their lives, and was going to be part of the rest of their lives. In this case, the health workers (Doctors and counselors) played a significant role in helping the participants face the illness they had been diagnosed with. The participants expressed that they took on to move on with their life and face the illness head on.

"We were not married then. We discussed, and said well, nothing will change, because neither of us knew how and when we got it. Neither of us could say it was you or it was that one. So we went ahead with our plans, we got married and I moved here"Tina

"I started treatment, talked to doctors, took medicine and everything was fine. I was feeling normal and okay, up to now, am just fine. I don't feel am sick anymore, because I get medicine, get people to talk with about this. My kids are fine and am pregnant now, so another one is on the way. So I take medicine to protect also my kid"Tracy

"Sometimes you feel lazy and even at times feel like killing yourself, but when you take the medicine you get okay, you are not getting sick so you don't think about it. Like now, I just take the medicine and I don't think a lot, I got used, as long as am okay, I can manage to make my food, clean my house, go shopping, it's okay. Because this disease is not going away tomorrow or next day"Rita

"It has been okay now, because I have medicine that helps m. I don't think about it a lot ever since I started treatment".....John

"At first it was hard, am a human being and sometimes, I wish it didn't happen to me. Sometimes I do it myself (blood test), because we also do the rapid tests at our work place, so I do it to see, even now, I do it, I know it's ridiculous, but I do it, I say may be it will come out negative, but it's not going to happen until they get the cure. So I will live with it and I have to accept it".....Sam

For some of the participants, the thoughts of the responsibilities they had further enabled them to accept and take on a decision to face the illness that had become part of their life.

"What changed my mind actually it's my kids, I have to live for them, I have to fight to the end. My first born is 20yrs, I came with him from Africa, the 2nd one is 15yrs, the last born is going to be 9yrs. My Doctor told me one day, "be who you are because you are not the only person in the whole world who is sick. So if people want to talk, let them talk, yah. Move on with your life, think about your life and you kids". So when am walking or in the supermarket, I don't look

down, I walk straight with my head up, because I am a human being like everyone else, I might be sick now and you are not sick, but you can die before me”Kate

4.2.3 Forms and sources of Support:

Facing a life time illness like HIV may be too much for the patient alone. The support from significant others in the life of the patient is very important. Some of the participants expressed the fact that they received and continue to be supported by close family members, friends and the overall health and social system in the country.

- **Family support**

Participants that were married or had partners at the time they were diagnosed with HIV, identified their spouses as being very supportive, even when they were not as well diagnosed with the illness. For some of the participants it was other family members like a sister or their own children, especially those that had children that were grown up.

“My husband, he is (was) not sick actually, but he is the one who supported me, we did everything together just like normal people. He never became different until I get divorced” ...Tracy

“He was here with me in the hospital when they told me. There was no problem, we were still the same, nothing changed. He accepted me for who I am. Because when he met me I was not like that, so we had deal with it both of us. He was supporting me, because at the start I could not accept that I could take medicine for the rest of my life. So he was supporting me”Kate

“First I told my sister, she is a nurse, she lives in the US, maybe she had seen it before, I don’t know. I called her, I was all in tears and she was like, I understand but don’t expect me to take care of your children, you have to live for them, and you are going to...she started telling me how advanced things were and how people are no longer dying, if take care of myself, follow the doctors’ instructions, she was really of great help”Mary

“They (children) have been there for me, because it was a hard time like I said before my so called friends left me when they heard about my first illness (TB). I think my girls did a pretty good job where the system couldn’t, We worked together through it”Mary

- **Friends support**

As noted by Kate below, an understanding friend can be very supportive in helping an HIV patient move on with life.

"I have one friend, she is also sick like me so we have something in common. I do visit her and sometimes she visits me. That's the only person I say, she is close to me, we can share everything"...Kate

- **System support**

Some of the participants mentioned the system as being very supportive in efforts to live and cope with HIV, right from the time of diagnosis. By system, they referred to the health care and social welfare services. Particularly, Mary noted,

"The system and the people here were very supportive, they helped me a lot to get through that time, with everything moral, financial, information. The entire system was very close to me, the municipality, social workers, the hospital, everything, everybody was there for me. They made me realize that it was not the end of it all. When they found out that I was struggling with that (self-blame), they found me somebody to talk to, to take me through that process of stopping blaming myself, that it could have happened anyhow. The system was willing to go up to giving me home care, people coming home and taking care of the children, but I refused because I wanted to be strong".....Mary

4.2.4 Impact on self, family, work and significant others:

Being diagnosed with a life time illness like HIV can have significant effect both the patient and those surrounding him or her, ranging from close family, friends to significant others. All the patients noted that being diagnosed and living with HIV has had an impact on their life or on how they view life.

- **Effect on family**

Family is the closest social group to the patient and therefore most impacted on by a life time illness if diagnosed in any of the family members. For some of the participants, the illness has not had any significant negative effect on the family, but they have stayed and faced the illness together. On no significant negative effect by the illness on family, two of the participants noted,

"You cannot see what is in the heart of the other person, but my wife hasn't changed, we are still husband and wife".....John

“For the children, I waited to tell them until I was able to cope with what was happening to me because eventually I had to take them for the blood test and they had to know why. I told them and the whole team was there to support them and me. When we found out that one of them was sick she had all of us be her side to support her. Actually, we have never been closer, like we are now, we are very open with it. We sit and talk about it, what is new, what we have read about the disease on the internet, how is it being treated nowadays, we are open about it and talk about it every time we are together”.....Mary

However, for some of the patients, the family has never been the same from the time they were diagnosed with HIV. A number of participants mentioned Divorce in the couple of years that followed was after being diagnosed with HIV, even though they insisted it was not because of the illness. Kate noted the following on this matter,

“We divorced 10yrs ago. He was not faithful, I can say and so we decided to end it. But we are still good friends, we can sit down together, still as a family, eat together for the sake of the children. I stay alone, because think it’s the best. I was a single mother (three kids) for all these years (15yrs) so they (the fathers) decided it’s time for me to relax. I don’t have the energy; you know with kids, you have to do this and that. In this situation and I have been doing all this for 15 years, so I think their fathers are right, I need time for myself and I need energy”.....Kate

She emotionally added,

“Every day I wish and I could wake up in the morning, send my children to school, I go to work, I come back home. I want to live on my sweat, I don’t want to sit there like a hand-cap waiting for assistance, but I can’t anymore. I don’t want my kids to see me every day sitting there, stressed, hopeless. I just want them to see me like a normal mother”.....Kate

Peter as well described how his family has faced difficulties ever since they were diagnosed with HIV. He noted,

“Our relationship has split, I have to live with the same problem all these 8 years in Denmark, because when my wife is angry, she says this is your problem, if you had not been politically active, I would never have been raped. My relationship with my wife has been a hard one, several times the issue of separating or divorce has come up, she has told me that she wants a divorce...but I always try to calm her down and try to explain that we need to be together, we care about each other, we have our children to take care of. When I approach her for sex, she refuses. So we are living just as adults of 42 and 41yrs, this is not old age, we are together taking care of the children but not together in that sense (sexually)”.....Peter

He also expressed emotional distress of living with a secret in a family because they had not yet told their children about the illness. He noted,

"This is a problem in the family, we are one family but we have a secret. It is very hard to live everyday with this secret. Our daughter always asks, why is that it is only my little brother and you, mummy and daddy that have to take medicine all the time?".....Peter

▪ **Effect on friends**

Some of the patients expressed that being diagnosed with HIV affected their relationship with close friends. Kate illustrates below how her friends deserted her and looked at her in a different way on finding out that she was HIV positive.

"The person I thought was my best friend, that I could share this with, betrayed me, she started telling everybody about me. I thought I could trust the person, but I was wrong, I could have kept this to myself then my life could have been a little bit much better. I also blame myself for telling her... it was one friend, very good friend, this very friend phone called there, this one there, the other there" ...Kate

However, some of the participants noted no change in their relationship with friends, on finding out that they had or have HIV. Sam noted,

"My best friend we have grown up together, he didn't reject me. Here in Denmark, I have two African friends but we don't even talk about. When I cook and they come here and we eat, am like, be careful, am HIV+, they are like come on, stop that, we are your friends"Sam

▪ **Effect on ability to work**

HIV can lead to a weakening of the immunesystem leading to general discomfort and other symptoms e.g. fever, shortness of breath and diarrhea, consequently affecting the patient's ability to work normally. However, a number of participants in the study mentioned no significant effect of the illness on their ability to continue with work. They reported being able to continue with their life and work normally.

"No effect at all".....John

"Not at all, I work very well"....Mary

On the contrary, some participants had been severely affected in their ability to work and had to quit their Job. Three of the participants, who had to stop working because of the illness, noted as below,

"I Worked as a care taker for the elderly for 8 months and could not carry on because of the sickness. I was getting tired all the time, I was weak, I couldn't do anything so I decided to quit. Because that kind of work with my energy I cannot, because its hard work, you have to lift people, that situation I couldn't, so I stopped it".....Kate

"Am not currently working because of this illness, I have always had an open mind, very motivated; taking part in things, getting an education and a job, doing a contribution to society, but my body stops me because i get tired easily because of my illness.I completed the language course within 8 months and passed everything and learnt the language and then I went to a technical school where they teach different crafts, and then I started working. But then i realized that my body was limited in terms of how much I could push it".....Peter

"I stopped working because of illness. I was working but not full time job, part time job, sometimes it was 4hrs, there is also a time I was working 6hrs, then when I go home I could get fever and feel very tired the whole night, and then they put me on 4hrs. Then I worked for about 2 years for 4hrs a day until they stopped me".....Rita

4.2.5 Perception of HIV as a Disease:

Nearly all the participants perceive HIV as a personal illness that should be kept to the patient, family and people in the system, and therefore they prefer not to tell or talk about it with everyone else. While the participants expressed feelings and thoughts of stigma and discrimination towards people living with HIV, some of the patients feel that at times having HIV is 'better off' than having some cancers. They believe they can live longer compared to people with certain cancers, and may not even die of HIV. In line with the above, John noted,

"If you compare (HIV) to cancer and other natural disasters, few of us (HIV patients) think and feel that we are going to die, but if it wasn't for the treatment, things would be different".....John

▪ Disclosure issues- Living a double life

Patients that took part in the study perceive HIV as a personal or private illness. They feel there is no need to talk about it if it is not going to help them in any way to take away the disease. The most important thing, according to them is taking the medication. The participants that thought there is need to tell or talk about it mentioned, close family and the people in the system especially their Doctor. But anything away from that, they wouldn't consider telling or talking about it. Therefore most of the patients have kept it to themselves, a few family members and the health staff, as highlighted below,

"First of all, nobody knows apart from the doctor and ourselves".....Tina

"Only my Boss (knows).If want you can tell by myself, but if I don't want, I don't tell. All my family knows, because they have to know".....Tracy

"I can't tell anyone I find or even my workmates even if they asked me. It does not help me in any way, they would just tell everybody they find about me. And it's not only this health condition, but even certain personal things that are supposed to be a secret, such as financial issues. There is no need to tell anybody, if am not doing well financially, if it is not going to help me in anyway. If there was an advantage for it (disclosing my HIV status), I will do it, but I don't see any".....John

For some, previous experience of the negative reaction and response of close friends on finding out about a related health condition but not HIV, amplifies on their decision to keep their illness to themselves and family.

"In the beginning I would have told may be my colleagues and friends, but I had a very bad experience when I had TB. When I had TB, the type I had was not contagious and I tried to explain to my fellow Africans that were close to me, what I had, that it was not contagious, but they gave me a cold shoulder and I was shunned just about that. So after I found out that I was HIV+, I said if they could not take TB, how could they take this. So I kept it to myself and my family and the people in the system that work with me. I think this is a personal thing that you have to go through, may be with your family".....Mary

For some of the participants, even though they were and have been open about their illness to close friends and workmates, they have been selective when it comes to family members, depending on how close they are. Sam noted,

"I didn't tell anyone. And I was sure that my father will be really mad, kick me from the house, so I didn't tell them. Right now, it's only my mother who knows, am not too close to my father, so we agreed with my mum that let it be as it is. My closest friends in my home country, they also know. At school we only talk when we are doing group work, that's all, we don't talk about private matters. My friends who are close to me know, and also my work mates. Some of them I told them at work, but I don't know if they tell others"....Sam

▪ **Participation/non-participation in support groups**

Further still concerning disclosure and sharing about living with HIV, 7 of the 9 participants in the study were not, didn't and don't want to participant in support groups with other HIV patients. Again, they don't feel neither the need nor usefulness of sharing with other HIV

patients. In addition to terming the HIV a personal illness, participants noted that they don't trust other HIV patients in the groups, since most of them are Africans. Rita and Mary noted,

"Sometimes they have a meeting here where they call HIV patients to come and meet in a group, but we are scared to come. Because when we know each other, then they will start to talk around saying she is sick and then everybody will not want to be with you. Me I don't come, I don't want. Because when we know each other, people will just talk when they go outside"....Rita

"Again because of the stigma, no, because I don't want to be pointed at, I think the most important thing is to take care of yourself and look for more information as much as you can get to get over this, but with people, I don't know how, because very few people are understanding, even when you meet in (women) groups they still talk about each other and I didn't want to be like that. That is why every time there those meetings I am not interested in meeting with them".....Mary

John also added,

"There is a group here (at the clinic) for HIV patients where they meet, but I don't come, i don't see any advantage of meeting with others. These people, especially Africans talk a lot, anyways I already have my family and it's enough".....John

▪ **Issues of stigma and discrimination**

All participants expressed being stigmatized and/or discriminated against, felt stigmatized at one time or knew of a colleague or friend that was stigmatized and discriminated against because of having HIV. Most of the participants attributed stigma and discrimination to ignorance and lack of information regarding HIV in the general population.

"The way other people look down on us, this is something, we didn't ask for it, it's a thing you cannot call and say I need you today, or send a letter, or email, it just gets you just like that".....Kate

"Some people here have had problems, this one African lady worked in a place and she said, she had to open up, so she told the people she worked with. Immediately she told them, people changed and distanced themselves from her. She worked with taking care of old people and so once the boss found out, they said with her condition she couldn't take care of old people, it was really sad. There some people here who are also not well informed about the disease".....Tina

For some of the participants, the experience of being stigmatized and discriminated because of their HIV status had been very extreme as Kate emotionally expressed her experience,

“Who wants to sit next to me? Who wants to share a toilet with me? Who wants to share the same plate with me? No body. And that was really hard”.....Kate

As highlighted earlier, about participation in support groups, a number of the participants felt that they faced more stigma from fellow Africans compared to other groups in the society. Mary noted,

“What I have realized is that we the people from Africa we have stigma more than anybody. We used to meet on forums on the internet. We don't know each other but you could see someone laughing out at the other person, they have never met, but they could start saying that you have HIV, we heard this and that, you are going to die and all these people are living abroad”.....Mary

In trying to understand why there is more stigma from fellow African, the participant believes that probably it's because Africa or other countries in Asia have experienced HIV illness in a different way in terms of mortality and impact compared to for instance the Danes. But she also added the lack of information a major contributor to stigma from fellow Africans even when they have been living in Europe for some time.

4.2.6 Treatment and Medication:

Treatment is a pivotal point in living with HIV or any chronic illness. Starting treatment, ones response to it, adherence and over all care received determines how well a patient will live with a chronic illness like HIV. Health literacy, knowledge about disease and treatment are crucial. For immigrant patients, cultural beliefs and customs play a big role because significantly affect the patients' health literacy and knowledge about an illness. One of the participants stated the following on this subject matter,

“I was thinking in my head, if I start taking medication, it will be like a death sentence, I will have a lot of symptoms and so many things because they say that when you take medicine that you will die, that it will kill you even faster, I heard about it, in Africa, we used to think and say that if u take the medication, they are getting rid of you, that they give you medication so for you to die early or something like that. So I was still having it in my head, even if I went for counseling”.....Sam

As a result many may post pone or delay starting medication which in turn significantly affects the success of managing the illness. The same patient noted how this made him delay starting medication,

"No, I did not (start medication). I just pushed it, I said I am not going to take medication. I started medication when I came to Denmark. Before that, I just talked to my nurse friend, she said that since there are no symptoms, I could just take some pills- antibiotics, and I will be okay. So I took those and I got better. By the time I came here I was okay, very fine. I have a Danish mother, she is like a mother to me, and she said I have to do it, I have to start medication. So she took me to the hospital to start the medication because my CD4 count was really low. They were even surprised because the number of virus in the body was high in my blood but I wasn't sick"Sam

It should be noted however, that not all patients diagnosed with HIV start treatment immediately. Nevertheless, even when some of them have been on treatment for a number years, they don't seem to comprehend how exactly the medication and treatment is helping them. One of the male participants noted,

"It is doctor's story, they say I am HIV+, I have virus in my body, and I have to treat it the rest of my life, but that this virus will not be killed or go out of the body. I have to listen to the doctors, I don't know if it real story or not, what can I do?"....Amir

▪ **Effect on the body's immunity**

Like for most HIV patients generally, the effect of HIV on the immunity of the body and over all body health was mixed among the participants that took part in the study as well. For some, they have been healthy and normal ever since being diagnosed.

"Like you see I feel normal, I can say am more healthy"Amir

"I have never been admitted/internalized in the hospital".....John

"I think it has been wonderful, if I can say it like that, the only illness I have had was that which led me to find out that I was infected, I have never had even flu and the same applies to my daughter. We only go for check-ups, actually we don't even have anything to talk about when we go to see the doctor we don't have complaints... am grateful that I don't have or get the opportunistic infections, am surviving winter after winter".....Mary

However, the story was the opposite for some of the other participants. They noted that their immunity had weakened severely and that they got sick often. Kate noted,

"It's not something am just saying that am okay or am feeling better, I will be lying, there is a period where am nearly down, totally down. I can talk to you like today, tomorrow am down. Sometimes you lay there, you are hopeless, you cannot even manage to go to the bathroom" ...Kate

Peter also noted,

“We face challenges and difficulties during the winter, our immune system is not so strong so we face a lot of infections during this time like flu for a long period of time. In 2004, our son had an episode where half of his body was paralyzed, he couldn’t move his arms or legs, his face was all weak on one side, he was internalized in the hospital for almost 6 months. At that time we thought his whole life was over. One time, my wife was walking down the steps and she broke her leg without even falling.”.....Peter

▪ **Response to medication**

Like the effect of the illness on the body, the response and effect of medication was mixed among the participants. For some, they had responded well to the medication and had not had severe side effects from taking the medication, except for a few in the beginning or when they change the line of medication.

“No, no, only in the beginning when you start, because they change, they change medicine like every one or two years, new medicine comes. So when you start with new medicine, the first months you may vomit, may be head ache, but they will disappear when your body accepts the medicine”.....Amir

“Sometimes the body cannot tolerate the medicine (for some people), but for me I have not had any side effects, luckily. The doctors tell me that the virus has decreased so much because of the medicine and it’s even hard to see it”.....John

“I can say, my regimen was very successful, I never had any problem, I didn’t have to switch to another one, I have not had any side-effects. And last year when I found out that I was pregnant then we had to switch again. Though I was concerned what was going to happen but luckily nothing happened, I didn’t feel anything, so I changed from the one I was taking, to the new one then back on the old one but nothing has really happened with me. I think am lucky”.....Mary

“No serious problems, I think my first time was having some kind of fear, like image in my head that u get sick, so I remember when I took it, I just laid down here (on the couch) and I was like let it come now, let me see what it is going to do to me, am ready for it. So I laid down and I got a little bit dizzy, and when I stood up to go to the toilet I was weak, but I didn’t get any pain, no side effects, no nothing”.....Sam

On the other hand however, a number of participants noted difficulties in responding to medication. Kate who had come for a Doctor’s visit the same day she was interviewed informed the researcher of the news she had got from the Doctor,

"Today I had come for blood checkup but (Doctor) has told me that after today, they have to change to a new a medicine, because the other one is not working, the virus is very strong, the medicine cannot fight the virus, so we have to change"Kate

The other participants that had faced difficulties from the treatment and medication noted side effects such as general body weakness, body pains, head ache, sleepless nights, over sleeping, reduced sexual urge, among others. Peter noted,

"I could feel weak, head ache, body pains, sleepless nights, and started to get night mares. I experience these warm spells 2 times a week, where I feel as if my body has been put in a furnace and its burning. It deteriorates the bones and you have bone pains every day. These side effects are a problem, I discuss it with my doctor often, I ask him, how can I get medicine with less side effects because the medicine makes it hard for you to sleep, how can you wake up in the morning and go to work when you have hardly had a any sleep and your eyes are completely red."Peter

He added,

"I cannot stand for 3 hours without getting bone pains...when I take this medicine I get stomach pains, and for the last 2 years, I have not had sex with my wife, because it affects me. I also have pains in the evening when I take the medicine so I cannot perform. It's the same thing with my wife, when I approach her for sex, she refuses"Peter

Rita also noted,

"Every time you get new medicine, you get side effects .I get problems (pain) in my head I would feel I want to sleep all the time, and deep sleep. And I could fight in my sleep (night mares) and I could hear many other people in my head, things talking to me all the time. So they said that they think it was the medicine, so they gave another medicine for my head"Rita

▪ **Health Care Services and Staff**

When it comes to health care services and support, all the participants expressed overall satisfaction with the care and support received by the health care system. This was generally mainly in comparison with health care and support services for HIV patients back in their African home countries. All the participants noted poor, back-wardness, stigma, inadequate or lack of required treatment and care services in Africa compared to what they were receiving here in Denmark. Some of them believed, they would not be alive by now if they had been living back home in Africa.

"We (Africa) are back ward in these regards because for instance to take a blood test at a clinic they have to take blood, they put on gloves, it's as if you are what. In Africa I wouldn't think they would even touch your skin..... sometimes there is no medicine".....Tina

"It's like at home people die every time, and the way doctors and nurses treat the people. It's like when u sick there (Africa), you are nothing. It's like you are going to die anyway, who wants to help you? I will tell you that if I was in Africa, I wouldn't live for a long time".....Tracy

"Sometimes I go to Africa and visit my friends and come back again, I have seen people with this sickness in there and they are suffering a lot. Some don't have money for medicine, some have medicine but food is a problem. It's very difficult, so its better here may be by 100 times".....Rita

"It is really harsh (in Africa), I have one friend who came here and discovered he was HIV+ and he didn't know, so we called home, because where I work we do the counseling, we called home at told them that I have a friend, he is Ghanaian we need you to treat him like this and this, but it is now 2 years and he is still not getting the medication. So it's not easy, people even have to pay. I remember when I used to go to the clinic, I used to just got there to see what is going on there, I used to just stand there and look because I didn't want to get so much involved, I was young, scared of rejection from people. I used to see people come and line up around 4 in the morning, they (HIV patients) come all the way from their villages to come and try to get the medication and it's not enough".....Sam

The participants predominantly praised the health care and support received as HIV patients in Denmark. They praised the professionalism, empathy and confidence among the health workers and the quality of care received.

"I think it is easy here because the number of people is very few, so it is easy for them to make follow ups and they are doing investigations all the time and improving all the time. Here it's just one of those things, they look at u as a normal person, you are just another patient. It's a much more relaxed thing. So they are more educated about it. There isn't this stigma, that's the difference. Though they do get problems some times when people don't take the medicine,".....Tina

"Here it's different, you just feel you are just sick, they take you like other patient. That's the very good thing here. Here I live a normal life, I get good medicine, good advise, support, etc".....Tracy

"I think its ok, the treatment is fine and if say for instance I can't go to the hospital, they will send the medication here, at home (Africa) that is impossible. We give blood 2 weeks before, so that the doctor looks at it, if there is anything she should be worried about and so on, and by the time we go there to see her she knows everything. And if there is anything else, she refers to other clinics, so the system is quite good". ... Tina

"It is nice, they are good, it cannot get any better, Denmark is a developed country in Europe and very modern, but in Africa you hear that people die of AIDS because they don't have money for medicine, they have so many economic problems. But Danish economy is very strong, they have modern medicine, good treatment not like poor countries".....Amir

"They (health staff) are okay and very kind, I have no problem with them. Any time you want them, they are there for you".....Rita

"It is very okay, the nurses and doctors are gentle, friendly, and very caring"....John

Content and Quality of Doctor Consultation-not enough:

While all the patients praised the treatment and care received as HIV patients from the health care system, some of them expressed inadequacy in the content and quality of Doctor's consultation visits. They noted that the Doctors were so fixed in routines and seemed not bothered of the other aspects of the patients' life other than medication and status of the body.

"...But the only problem we have, and we used to say it in our group of Youths living with HIV, the doctor doesn't have time to talk with you and ask you things like, how is life? How is your sex life? Do u have a boyfriend or girlfriend? They don't talk about that. The only thing they do they say, you are welcome, are you taking the medicine? Okay, how is the CD4 count? okay...see u next 3 or 4 months, that's all. May be they think it's not their problem, but I think since this disease mainly come from sexual intercourse, they should talk about it find out how you patient is living. But they don't do that, and we have been talking about it so many times, not only me but the rest of the group, we are saying that they should do something about it, they should talk to us and ask us, how is your sex life? your partner? I have known my doctor for 4 years now, and will continue being my doctor for long, so he is somehow involved or part of my life, so why don't you talk about my life, but they don't do that".....Sam

The participant also noted that the consultations visits were usually cut shorter than the required time.

"It's only recently that I got to find out that my time is usually only 12 minutes, and it is supposed to be 20 minutes for every patient with the doctor. But my Doctor only uses 12 minutes. Sometimes it may even be less, he just looks and says, okay it looks good, alright, I will see you next 3 months, go to lab for testing 2 weeks before you come, okay see you....that's all"

The participant also added that the information passed on by the Doctor in this short time is most of the time too much to comprehend and make sense of it all.

"I even have someone I go with because sometimes, the information I get within those 12 minutes is really so much and am not sure what is going on. He (Doctor) will say, your CD4 count is this and this, your immune system is okay, the hepatitis as well, okay. I even told him to stop, I don't need the numbers, because every time I go there it's the same...I know that the numbers at times are up, sometimes it's down!"

Some of the participants also noted preference for the hospital doctors than the general practitioners. Tina noted,

"Though we do have our own family doctor, but I think those in that department of infectious diseases are much more learned about the whole thing. So we rather call them, if there is something we don't understand"....Tina

Peter also noted,

"Every time I want information and I go to my doctor he sends me to the (immigrants health) clinic, and to Doctors at the Hospital and I am even wondering what my own doctor is doing?".....Peter

The issue of undocumented immigrants with HIV living in Denmark also came to light in one of the interviews. One of the patient's who had come into contact with a number of immigrants with HIV but cannot access treatment because they are not documented, wondered how this can be dealt with. He believes the government needs to work out something because it is a fact that these people are there and may contribute to new cases if not handled well, and this will prove to be costly to the government in the long run.

4.2.7 Psychological issues (depression, loneliness, better alone) and illness:

Participants expressed a number of psychological issues that were either as a result of being HIV positive, had an effect on their health as HIV patients or being immigrants. Emotions of loneliness, depression, stress and distress, frustrations among others, were felt by most of the participants at a given time in their life. A number of participants felt that feelings such as that of stress affected their health, adherence to treatment and over all well being of their life.

- **Loneliness**

Some of the participants expressed loneliness and boring life here in Denmark. Tina noted,

"It is kind of a bit lonely compared to home"....Tina

For Kate, she prefers being alone than being among people ever since her diagnosis with HIV. She noted,

"I like being alone very much. Am a type of person that does not like to sit where there are a lot of people because that is the only time I enjoy myself, just sit there, listening to music, reading my books, so I really enjoy being alone".....Kate

On the other hand, Rita hated the feeling of being alone, having no one to talk to because she has no family here in Denmark. Her efforts to have children had failed and being HIV positive, didn't make it any easier. She noted,

"My life is okay, I get my medication, though some times its boring because I am alone, I don't have people to talk with. It's okay, I take my medicine, I don't feel sick, I can manage to do everything in my house. But like I said, sometimes it is so boring and you don't have people to talk to, no family. I am alone and when I get that sickness I didn't have any kid and here it's not easy to get someone to give sperms to have a kid, if you tell them the truth, they just laugh and run away from you.".....Rita

She added,

"It's better to work for a few hrs because it forces you to wake up early in the morning and go to the job, there you find and see people, you can talk to them, and when you get back home, you will be tired and feel like sleeping. Right now, I stay alone, I wake in the morning and then do what? So I sleep as long as I can. And I have that medicine for my head, it make me sleep a lot and I don't think it's good for me. so I think it's good and better to work for a few hours, but they said that this medicine I take for my head, it makes people sleep, so that is why I sleep many hours"....Rita

▪ **Stress and illness**

Some of the patients felt that their health deteriorates whenever they are stressed and felt better when they had nothing stressing them. Kate noted,

"This sickness doesn't need stress, because if you stress yourself you get more sick. if you are being pushed, you get more sick. The more you get stressed, the more you get sick"....Kate

In a similar view, Sam also noted,

"The only time I got sick was because of stress. When I get stressed, I get cold and some fever, and when I go to see t my doctor, there is nothing. And then I insist, u have to see very well, maybe there is something going on you can't see"....Sam

To illustrate how life and having HIV can be stressing, Kate noted,

“I went for holiday so I wasn’t around, but house rent they (Kommune) have to pay, which they didn’t. So I don’t know if am going to lose my house, I don’t know if am going to live on the street, I don’t know. Such things make me sick every day, things like that plus this news from (Doctor) you don’t know whether you should live or let go, its too much”.....Kate

She concluded noting,

“When I have no stress, I can feel like am re-born again, I feel life, I feel like am not even sick. I feel like I can sit and eat and look healthy. But when something small like this happens, then am down again”

- **Stress and adherence to treatment**

Some of the participants also noted psychological issues such as stress and depression affecting their adherence to treatment. A number of them noted having stopped taking medication at one time mainly because of stress or distress or depression. Tracy noted,

“It was once when I stopped medicine, i just stopped taking medicine because of some family reasons, I was so bad, I started feeling weak, I didn’t have energy. But I started medicine again, and I was okay”.....Tracy

Kate also described her experience on stress from dealing with social workers and taking medication,

“Sometimes I don’t want to even take my medicine because I feel like, why should I take my medicine? To live? With stress? No. So it’s better I go and they (social workers) get someone else to stress, if I go, may be they will move to someone else to stress up. I had decided that if I die, then I would have peace from them. Sometimes I feel like they are killing me slowly by slowly. All I ask is just peace. So that I can enjoy taking my medicine, because when am stressed, I don’t enjoy taking my medicine. There was a time I was happy when am taking medicine, I don’t feel like am taking HIV medicine, It is like am taking normal vitamin, but when am not stressed I don’t enjoy taking it”.....Kate

- **Causes of stress/psychological issues**

The participants that had experienced stress identified the social system as the major cause. They felt that the social workers, from the municipality, push them a lot, pressure them and they did not understand the health and bodies as HIV patients. A very stressed Kate noted,

“The only thing that is stressing me most is social workers. They don’t understand my body, if they could just borrow my body, just for a second, not even for a minute or hours or days, then they will never really like this body. They don’t understand me or what am going through. If you tell them that you are sick, you don’t feel well, they don’t believe you, they keep on pushing and pushing. Even if you call and say you are sick, they still want you to take the bus and go there. What about if you die on the way?”.....Kate

She further added,

“With my situation, it’s very hard to work and that’s what they cannot understand, why am sick today, tomorrow am well, next month am sick the other am well. They don’t understand HIV victims because they don’t live in our bodies. It is us to tell them or our doctors, how we feel, but it is not easy for them to understand, even when they are told. They want to see you every three months or may be after a month, they ask, when do you think you will be better again so that we can send you there or there? How can I know when I will be well again?”

Peter also thatat time he feels that being an immigrant seems to make things worse. He narrated,

““I have always been ready to fight, do everything it takes to get integrated, to get a job to survive...but the difficult thing here in Denmark is that it has a system that pressures people and this is not only for us immigrants but also Danes. The system pressures you into trying to get a job, get activated even though you may have health problems or issues. Sometimes you think it would be better if they had more access to understanding about my condition and illness. If only they could understand my condition, that am sick. They just see me as an immigrant and don’t see a reason why i shouldn’t work. As time goes, you feel more pressured and stressed, it reaches a point in time and you feel discriminated, and it’s not that in the real sense you are being discriminated, you just begin to ask yourself questions like, is it because i am an immigrant? That i am always being pressured into doing this”.....Peter

Kate further added,

“Sometimes you lay there, you are hopeless, you cannot even manage to go to the bathroom and someone keeps sending you letters saying we have to see you or else we are going to stop your money, when you hear that, how would you feel? You are going to lose your home, you are going to lose everything, how would you feel? They want you to go there yet your sick and hopeless”.....Kate

Because of the extreme stress she faced due to being pushed and pressured by the social workers, Kate hinted on the fact that committing suicide has crossed her mind. She noted,

"You feel like if I had a gun under my bed I would just shoot myself and go (die) because they know already that you are sick, hopeless, and am talking to them through the phone telling them, am sick, am laying down, if you don't believe me, send somebody, they still don't get it, how can you go there? If you cannot even walk around in your house, how can you walk all the way to the bus stop? If you cannot even wash a plate"

Kate concluded highlighting how stressful it is for her to deal with HIV as an illness at the same time deal with socio-economic pressures,

"(Doctor) has told me that after today, they have to change to a new a medicine, because the other one is not working, the virus is very strong, the medicine cannot fight the virus. So when your hear something like that, that the virus is up, and then someone calling and telling you something which you do not want to hear, will you not be stressed up?"....Kate

In describing and explaining how stressful and depressing it is being an immigrant, Peter narrated his situation,

"I have been facing challenges with this residence thing, every time i apply, they give me an extension of 2 years. The last time I applied for permanent residence i was rejected, i felt depressed. I have been here for 8 years now, my wife have permanent residence, my children have permanent residence, but i do not have permanent residence because i they owe me only 50,000 kr. from the government. I feel that I have a country that i cannot go to, and am living in a country and i don't know what am doing here. I often think about leaving this place and going to another country, so i cannot go back to my country in Africa, but i think of going to France for example, where i speak the language fluently, where my education is appreciated, where i don't have to work as a cleaning assistant but where am qualified. But am stuck, in Africa i am caught up in this politics, in Denmark i am pressured and stressed by the Danish laws".....Peter

He summarized his struggles of both being an HIV patient and an immigrant noting,

"I feel like am at war with many fronts without knowing exactly my enemy, one day it may be the municipality coming up with something, the other time it's a new law, the other time it's my illness. I have so many problems, yes my first problem is this illness but the second are the political (social) problems".....Peter

Related to stress factors for HIV immigrant patients, a number of participants also identified pressure from relatives back home that need help from them, as being stressing as times. Sam noted,

"You get more stress because your family is always calling you like send me money, buy me money, do this and that for me, so it's a big problem. They think that you have money but you don't want to support them, so I get so much stress"Sam

▪ **Stress reduction**

Some of the participants that had experienced pressure from the social system proposed a better way of how they can be dealt with as HIV patients. They believe that the Doctors have a big role to play reducing the pressure from the social workers at the municipality. They noted that, Doctors should explain thoroughly to the social workers about the effect of HIV on the body so as to make them understand some of the HIV patients that cannot function normally, in relation to work.

"Doctors know so much about illnesses, they are better at explaining to the municipality that this is the reason that he cannot work when they pressure people to go back to work again when they have been ill? They should just write these challenges down and explain to the municipality so that they stop pressuring people to go back to work. As it is right now, the municipality says, you have HIV, you receive medicine, then you can go and work"Peter

Kate also highlighted how only the Doctor could 'save' her from the pressure from the social workers in the social system. She emotionally noted,

"Am just hoping or praying if they can just give me peace because I don't know how much long I have, so if they could just give me that peace that moment to enjoy with my kids without no problem and no stress, then I will be very happy, until that day my Doctor will end it. The only person that can end this is My Doctor by asking for my retirement."Kate

Participants also suggested using patients with some sort of chronic illness cautiously when it came to work. They suggest flexible and short working hours so as to enable them contribute to the working group longer than when they are worked out a lot and have to retire early.

"If they found out that somebody has a chronic illness such as HIV, instead of pressuring or going on fast on them (persistently), they should go slow on them. Maybe offer flexible jobs, less hours, instead of giving them a full time job and wearing them down very fast so that they work only for a few years and then they completely break and can't work at all, yet they would have worked for a long period of time"Peter

4.2.8 Socio-Economic Challenges- life as an immigrant in Denmark

As illustrated in some of the previous sections, psycho-social, economic and other issues in the sphere of one's life have an effect on person's health. It was highlighted how stress and depression are related to the health of an HIV patient as well as adherence to treatment. In most cases, being an immigrant poses a number of socio-economic challenges that in turn affect the overall health of the individual. Like the effect of the illness and response to medication, participant's experiences as HIV migrant patients were mixed. For some, life was okay and felt they integrated in the Danish system, while others, they were facing a number of socio-economic difficulties and therefore felt excluded from the Danish system. All patients however, seemed to agree on one thing; 'life in Denmark, good or bad, was much better than back home in Africa'. John who had been in Denmark for over 10yrs noted how life was okay for him and his family,

"I work 37hrs per week and I earn sufficient money for my family. I have not had any social difficulties, I have had the support of my family from the time I came to Denmark. I feel integrated, life is good, I have a car, a job and a house".....John

Similarly, Rita who had been in Denmark for over 20yrs also stated,

"It [life] is better here because they look after me, they give money for food, house rent and everything basic. It's better for me because I didn't have a job in Africa, no income, no anything, my parents were just farmers, so I think to stay here its better, I don't think I have any problem. The money I get for pension is okay, I pay a few bills, they give me the medicine that I need. It is better than in Africa, there no one cares for you unless you have your money. Poor people have problems back there, they can't get what we are getting here. I see some of my cousins that have HIV back there, they stay in the village and I went to see them. They get cassava [local food] and tea and then take the medicine, no juice, no what, i just look and say oh my God! This is tough.".....Rita

Some participants that expressed facing a socially and economically challenging life, believed that it would be better for them to go back home. However, the thought of real life back in Africa, both economically and HIV health care wise, influenced their decision to stay in Denmark. In this line, Kate noted,

"sometimes I just feel like, I should just pack and go, because back there at home, they will understand that I am sick, they will understand my situation, there will be no this stress from

social workers, it will just be me relaxing, doing what I want to do, walking around the compound, planting some flowers , it makes me happy. But I cannot do that because of my kids. They belong here, I cannot take my kids there (Africa), because I cannot work there to support them. It's like am taking their life away from them. And my sickness, I don't know how the system works there, I don't know if I have to pay something to get medicine. But here I pay tax every month and I know how things work, whether I have money or not, they will treat me and get medicine at the right time. But back there, maybe there is not enough medicine to everybody"....Kate

Some of the participants however expressed a very challenging and frustrating life in Denmark as an immigrant. Peter hinted on the fact that, if he had a choice, he would not stay in Denmark for a day. The fact that he was highly educated and regarded back in Africa, didn't make his situation any better. He narrated his ordeals saying,

"I find it very frustrating here, there was a time i almost wanted to kill my boss, she was telling me that i am an immigrant and i have to do what she says, that i have to accept being in Denmark and all these things. It was very challenging and very difficult for me because a person who is less educated than me trying to teach me some things that were completely unnecessary, I actually got so angry that i grabbed her by the neck. I was and am highly educated in Africa and i had a very good life with all the good things that come along with being educated and then i come to Denmark because of necessity, being unable to go back to Africa because am a political refugee. So am trapped here and that's why i had to work as a cleaning assistant here, if it wasn't that i am a political refugee, i wouldn't spend more 2 weeks here in Denmark. I didn't choose to come here, had i known the consequences the way the Danish system works, i wouldn't have come if i had a choice.".....Peter

To further explain his frustrations, he noted,

"Every year there is a new law, every time you have to apply to extend your residence, you have to pay 2000 kr., I am not working how am I supposed to get this money to apply every time. My wife has pension already, I don't, I have too applied for pension because I need time to be able to take care of my children. I don't feel at all integrated into the Danish system, I feel frustrated, every time i turn on the TV, i see something about integration, about immigrants".....Peter

To describe how challenging it can be for an HIV migrant patient with responsibilities and pressure back home, Mary narrated a story of an African HIV patient friend,

"There was a certain lady, she was my friend also from Africa, she was HIV+ but she died and I think she died because she was careless. She was drinking a lot, she was not taking her medication and she was sharing her medication with her family in Africa. In the end I saw she was putting her life in a line, she should have known better. But I also understand because she

had some family members that were dying in Africa, so for her she just passed the medicine over”

Having some sort of social network proved to be very helpful for an immigrant in Denmark. Sam that had a fairly well established social network noted,

“Being a person from Africa being here, it is kind of really hard. And as you know, Danish society is not so much open to people. For me I can say it’s okay, just okay, not very okay. but if I need money, I just go to my Danish mother, when I tell her that am going to borrow money from the bank, she just says borrow from me. That’s like the good point I have from here”.....Sam

Mary pointed out that the attitude of the immigrants is very key on how well or bad their life will be in Denmark. She believes that a positive attitude can do wonders while the reverse is true.

“I think Denmark is complicated, it’s what you make it to be. If you come with an attitude that everything is hard, you can’t get this and that because you are a foreigner, actually there is nothing you cannot do. But if you listen to people who have been here for long and many years and are not integrated, then you will have this negative attitude that there things that they cannot do for you because you are foreigner but according to me, I have not been denied anything neither my children, you just have to make it happen. So I think it’s the attitude that we have that makes it feel that stigma”.....Mary

4.2.9 Future plans

While some of the participants, didn’t picture themselves going back home to Africa in the short run, a number of them felt the urge or had thoughts of contributing to the fight of HIV back in Africa. Some of them noted that they would love to go back a take part in the sensitizing and improving the treatment and care services for HIV patients, but also in prevention especially for the young people. They felt a sense of responsibility to fight ignorance and lack of information about HIV and its treatment, especially of what they had experienced and been able to learn in a developed country like Denmark.

“Right now am planning on doing an NGO project, where my aim is to tell about HIV and my experience of living with HIV, things i have been through so that i can help a lot of people in acquiring this type of knowledge which is not always accessible. So i have this vision to go out and educate people about HIV even though it means going and knocking Door to Door, so as to make a positive influence or contribution in Africa. I have talked to MY Doctor as well, if he is

going to do a project in Africa about educating people about illnesses i would be a volunteer and the first to talk about my illness and experience”.....Peter

“I plan to go home in 2015, now I know a lot about HIV/AIDS, and am doing nursing. I prefer to go back home and help people over there, that’s my dream, take this education, learn more and more, and go back and do something, talk to the government, if possible set an example. I can say I am the real model, I have been with this, I have a daughter and a son (1 and half years) who is negative. So that’s what I want to do, break the ice, I want to teach and tell people that it is no longer a deadly disease as our fore fathers used to say, maybe that time there was no medicine so people used to just die quickly, but now there is medication, if you take it, it will sustain your life, there are so many things I want to do”.....Sam

4.3 Discussion

The overall objective of the study was to discover and understand how life is for an immigrant with a chronic illness in Denmark. The thesis specifically focused on HIV patients in Denmark of African origin. The purpose was to try to understand the life of being both an immigrant and also burdened with a chronic illness at the same time, in this case HIV. Very few studies had looked at the experiences of immigrants as a patient group. The findings in the thesis are based on interviews with 9 HIV patients.

Uncertainty among African immigrant HIV patients

Four of the 9 patients had discovered that they were infected with HIV while still in Africa whereas the rest had come to know about it while living in Denmark or slightly after their arrival from Africa. This is in line with the fact that has been highlighted by immigration data and the ECDC [11], showing that a number of new HIV cases reported in Europe are as a result of immigrants coming from Africa, especially SSA. The majority of immigrants, especially of African origin, move to Denmark in pursuit of a better life or to start life all over again in the case for those forced to leave Africa due to political and/or other social issues. Therefore, being diagnosed with an incurable illness like HIV hits them hard, and many wonder if the new better life they had in mind when moving to Denmark, will ever commence.

The feeling of better life being crashed is also mentioned by Mogensen, who documented the lived experiences of African women with HIV in Denmark [90]. She cites Lotte Meinert who contributed a chapter on mobility among young Ugandans in the book "Local life Far relations"

(Gilliam, 2005³). Meinert notes, that moving physically is a sign of change in one's social position, and it is a crucial part of the process towards adulthood in Uganda. Some young Ugandans just move to their own hut built on a piece of his father's land, but even this is an important step in the movement from childhood to adulthood. For others, these are moves that take them to boarding schools in distant parts of the country and later perhaps even to a job in town. But the ultimate move, the one everybody dreams about, is the trip to Europe. If successful, it is believed that not only your own but also your family's life will be noticeably better and the expectations of those who come to Europe are extremely high. Eight of the 12 women Mogensen interviewed came to Denmark as the wife of a Danish man who had worked in Africa, and they all had great expectations for this ultimate movement to Europe and that their new life would be significantly better than the one they had previously lived. However, they all got divorced upon discovering that they were HIV positive.

Uncertainty of the future among African immigrants has also been highlighted by Haram and Yamba[91]. They note that migration involves not only a physical displacement but a mental displacement as well, and this aggravates already existing distress and uncertainty in the life of the migrant. For most Africans 'development' has remained an elusive and imaginary concept, even for many of those who experienced the better times of the 1970s and 1980s. People's expectations of economic 'development' have never quite materialized, where modest gains have been reversed and hopes for a better future dashed, exist in many parts of contemporary Africa. According to Haram and Yamba, the majority of African people believe that life has become more precarious and more uncertain. Uncertainty of life is a trait that was voiced by some of the participants of this particular study.

Social support and social networks

Accepting and facing a life long illness like HIV usually takes time and not easy for most of the patients. The majority of the patients interviewed noted a sense of acceptance and moving on with life and facing the illness head on. Getting well informed and starting medication played a

³ Gilliam, Laura; Karen Fog Olwigog Karen Valentin (2005) Lokate liv, fjerneforbindelser, studier af born, unge or migration, kobehavn; Hans reitzelsforlag

big part. In addition, the support of close family and friends was crucial for some of the patients. Unfortunately, many of the immigrants did not enjoy the comfort of having family and friends with them here in Denmark or Europe at large, and many had to face the illness on their own. Therefore, the health care system, especially health workers, played a crucial role in supporting the immigrant patient manage their illness. Nevertheless, any form of emotional support, however small in quality and quantity, was of great value to the immigrant HIV patients.

While some of the patients in the study were lucky to have support especially of their spouses and friends, the majority of the patients noted being deserted by their friends on finding out that they had been diagnosed with HIV. Even for those that had their partners support at the start, the partners turned their back at a later period, especially in cases where the partner was HIV negative. Family break down and divorce are issues that are described by HIV patients while voicing their lived experiences. Mogensen also mentions this trend of HIV African patients being deserted by their Danish spouses after being diagnosed with HIV [90]. The limited support from friends and family subsequently leaves patients in a difficult emotional state that affects their ability and efforts to face the illness and other social related issues.

In line with the above, a number of patients interviewed noted life being lonely, boring and having no one to talk to in Denmark. The feeling of loneliness and being depressed is also mentioned by Mogensen [90] among African women with HIV in Denmark and Rodkjaer et al. [92] among majority of HIV patients generally in Denmark, especially in the aftermath of finding out their HIV status. The complex sociability, as noted by Mogensen, in the Danish society in terms of distance and closeness does not make it any easier for people from outside Denmark to socialize with the natives [90]. Women in Mogensen's study highlighted differences in African and Danish ways of social support and socialization. In instances where one has lost a loved one, in Africa, relatives show their support by being their physically for a number of days, whereas in Denmark, instead of subsequent visits, they send you flowers. More so, there are no spontaneous casual visits to friend's homes or meetings in public places, in Denmark like it is in Africa. In Denmark, one has to make an appointment or inform the other in advance for such

social meetings. The amount and nature of social support is therefore significant in the way Africans respond and manage life events such as Death and life threatening illnesses. Inadequacy in social support or lack of it for most of the African HIV patients in Denmark, as highlighted by some of the participants of the current study, makes it therefore challenging for them to face HIV as a life long illness.

According Mogensen, the encounter of non- Danes with the Danes, is what Anderson (2006⁴) calls the 'arm's length relationship', "it means the civilian relations, one can have with others for years without ever invited inside privacy closed sphere. He believes that although these are found everywhere in the world, it is particularly pronounced in the Danish society. The Danes make significant divide between the civilian sphere of 'arm's length relationship' and the private sphere and that it is very difficult for newcomers ever allowed to enter the private sphere, which largely are based on long-lasting and continuous relationships. What the women in Mogensen's study experienced, is how difficult it is to get the arms-length relationships in Denmark converted to private relationships. They lack the proximity they know from families and networks in their African homelands, yet they are also excluded because of their HIV status. Consequently, one of the women interviewed by Mogensen noted that they are 'double lonely' in Denmark. This view is similar to some of the participants of this particular study.

Living a double secret life

On a differing view, a number of patients noted a preference of being alone rather than with other people and talking about their illness. Nearly all the patients that took part in the study perceive HIV as a personal/private illness that needs to be kept to the patient, family (at times) and the people within the system. This builds on to a related issue where nearly all the participants do not want to participant in support groups even if it means sharing with other HIV patients. The patients that were interviewed also exhibited traits of being very selective when it came to disclosure of HIV status to family, friends or workmates.

⁴Andersen, Sally (2006) at villenoget, at gore noget, at till nogetsammen- en vellejetperformativegenere. in: begrebet immaterial kulturarv, kobenhavn: kulturministrietsforskningsudvalg, s. 20-26

Living secretly with HIV among immigrant patients has come to light in other studies carried out in Denmark. Not yet published data from 2008 by Rodkjaer et al⁵, shows that while a significant percentage (nearly 50%) of people living with HIV in Denmark are secretive about it, the percentage is even more significant among HIV patients from ethnic minorities. There data shows that 45% of ethnic minority HIV patients live with HIV secretly compared to 19% among Caucasians in Denmark. In the present study, the researcher contacted in total 30 qualifying patients to share their experiences, only 10 agreed to participate, with majority of the other patients opting out, noting that they didn't want to talk about their illness.

But why live in secrecy? Stigma is the main reason that HIV patients always mention for not wanting to disclose their status. This reason was given by most of the patients interviewed in this study. Patients were afraid of being stigmatized by people close to them. As African immigrants in Denmark, they had experienced or have seen other HIV patients being stigmatized especially by fellow Africans. This was further the reason the patients attributed to non- participation in support groups which are constituted of many African members. They note the lack of trust in African colleagues even though they were all HIV patients as well. Mogensen also notes a similar issue. Similar to findings from participants in this particular study, African women interviewed by Mogensen also noted 'Gossip' as a reason they prefer not take part in support groups and distance themselves from African colleagues. The women noted stigma and fear of exclusion and expulsion from African networks here in Denmark, as the other reason why they do not disclose their HIV status [90].

Being stigmatized or deserted by those that should ideally support you is an issue the Danish HIV patients may not have to face, unlike the immigrant HIV patients. Culture and lack of knowledge about HIV as a chronic illness is one of the reasons noted by researchers and patients themselves on the attitude and response of Africans to patients with HIV or AIDS. Patients attributed the reaction of most Africans and other ethnic minority to patients with HIV to the fact that this group of people (Africans) has experienced HIV as disease in a different way back home. In her chapter in a recently published book on HIV in Africa, Mogensen highlights a

⁵study among 304 hiv-positives at Skejby and Odense in 2008

similar issue. She notes that to Africans, HIV and AIDS is viewed as a death sentence and a burden to those around you, the farther away they distance from you, the better for them. This is because of the believed high cost of looking after an HIV patient. This perspective of HIV is very different for their Danish counter parts who view HIV as a manageable chronic illness [91].

So, do immigrant HIV patients don't really want to talk about their illness? The answer is no. They do want to talk about, and in some instances quiet a lot, but only to a person they deem trustworthy and knowledgeable about their illness. This is where the health workers (Doctors, nurses, counselors, etc) come into play in the lives of immigrant patients. At times with no family at all to tell or share, or having a family or friends but not willing to share with them due to reasons highlighted above, the Doctor and other health staff are viewed as confidants for most of the immigrant HIV patients. All the patients in the study identified the Doctor as the person they are most comfortable with and further provide unconstrained possibility to share personal issues. Mogensen also found out a similar issue. In reference to health workers in her life, one lady in her study noted, "all my friends are Danish" which really meant that her social life was limited to meetings with health workers and counselors [90]. Therefore for many HIV-positive Africans, who feel excluded or have allowed themselves to be expelled from the African networks, health workers are the only people in Denmark, they feel comfortable with.

Meeting with Danish Health care system for HIV patients

According to some patients, the time with the Doctor and other health workers is limited, and some feel the quality of the visit is not maximized at all. As noted in the previous chapter, one of the patients felt that what entails the Doctor's visit is not enough. Apart from the routine medical talk they felt the Doctors should ask and talk about HIV patient's life more. Women in Mogensen's 2007 study also noted a similar issue. One of the ladies disappointedly described the care (visit) as short intense periods. She describes being delighted about the Doctor's visit and preparing for it for days, but lamented being disappointed when it is suddenly over. The lady in the study expressed emotions of depression due to the thought that she has to sit just alone at home again now that the visit was over [90]. This illustrates how important health workers are in the lives of immigrants as a patient group in Denmark.

The immigrant patients view health workers as their key care provider. This is where the immigrant's health clinic, under the department of Odense, Odense University hospital has become very useful. Having staff with experience in dealing with immigrants has proved to be very helpful. The use of a multi-disciplinary approach and closely working in collaboration with a social worker at the clinic, has yielded a positive impact in the life of the immigrant's patient involved [7]. Unfortunately, a number of health care providers perceive immigrant patients as problematic. Nurses particularly have in a number of publications especially in the media, complained about the immigrants as a patient group. Mogensen [90] cited a survey of nurses that showed that nine out of ten nurses believe that patients with immigrant background are a burden on caregivers due to reasons such as language barriers and culture [93]. Seeberg [94] notes that the image that health workers have of Africa (and other immigrants), AIDS (and other illnesses) and African (ethnic minority) culture is closely linked with the way the media presents them. Therefore, it's important that health worker realize the significant role they play in the life of immigrants as a patient group.

Whereas it may be difficult to achieve, there is need to strike a balance between the needs and expectation of the immigrants, as a patient group, and the professionalism of the health workers. We need to understand that the great expectations among immigrant patients (especially African), for the meeting with health workers, is closely related to the problems they have with negotiating closeness and distance in their daily lives. Further, the perception of health workers that immigrants are a bigger challenge than other patients may have more to do with this than with clashes between different cultural requirements. Nevertheless, the patients are generally very satisfied with the treatment and care received as HIV patients in Denmark.

Psycho-social issues and HIV- Life as an immigrant and HIV patient at the same time

Another key issue worth highlighting is living a stressful life as an HIV patient. A number of studies have discussed the relationship between psychological issues, such as stress and depression, and the health of HIV patients and adherence to treatment. Individuals living with HIV have a two-fold greater risk of major depression compared to HIV-negative controls [95]. The diagnosis of HIV infection is typically a traumatic event [96], and depression compounds

the physical and emotional stress associated with HIV. Studies examining the impact of stressful events on changes in disease markers have suggested that psychological factors may affect HIV disease progression. Depression, depressive symptoms and psychological stress have also been associated with poor adherence to highlyactive antiretroviral treatment (HAART) [97,98].

Furthermore, several studies that examined depression at the initiation of HAART found that, compared with non-depressed patients, patients with depression exhibited over five times the risk of clinical progression to AIDS [99,100], slower viral suppression [101] and shorter survival [102]. Thus, depression has been associated with deterioration in psychosocial functioning, reduced immune response, more rapid progression of HIV and higher mortality rates [103, 104] Studies have found that depression was also associated with unsafe sex (unsafe sex is defined as unprotected intercourse (including anal intercourse) with a partner of opposite or unknown HIV status) and thus, increased the risk of transmitting or contracting HIV [105,106].

Experience of stress and depression was also commonly mentioned by the patients interviewed in this study. While for some it was a question of facing the illness and the impact on their life, a number of patients identified the fact of being immigrants and dealing with issues to do with immigrants in Denmark as being very stressful for them. Those that had been weakened by the illness and could not work anymore, and had to depend on social assistance and financial aid, expressed their frustrations with the social workers (at the municipality) in the system. Issues to do with failure to gain retirement or permanent residency in Denmark have left affected patients frustrated and disappointed. They felt this made them more sick most of the time and had opted not to take the medication at a number of occasions since it would not solve the other pressing socio-economic issues. Some patients had considered the option of leaving the country if they had a choice, but the thought of the conditions back home in Africa and the fact that some are political refugees, gave up on this possibility. Again in this case, the patients called upon the health workers especially their Doctors, to help them explain to the social workers about their illness and its effects. This, they hope will play a big part in making the social workers understand them as HIV patients. It should be noted, that the Danish

counterparts may not have to deal with most of these issues in the same way an immigrant will face them.

The patients that had dependants back home in Africa noted getting stressed up by the pressure from relatives living in Africa who believe that they have money because they are Europe. For some, the relatives did not even know their HIV status and do not understand the fact that they (immigrant) too have to struggle to make ends meet while here in Denmark. Therefore, they were facing or as one of the patients termed, 'fighting different wars on different fronts'....there is HIV as a life time illness; the stigma from fellow Africans here in Denmark; the system and its laws; uncertainty of fulfillment of self goals and also relatives back home, all for one person to deal with. Again, a Danish counterpart does not have face such life issues. Addressing these specific issues regarding immigrant patients could lead to better treatment success in terms of, for instance, adherence and decreased hospitalizations.

Chapter Five: Conclusions and Recommendations

5.0 Introduction

In this final chapter of the thesis, the researcher makes conclusions based on the key findings and what it implies for public health. The researcher also cites the limitations of the study and ends by suggesting areas for further research concerning the topic covered in the thesis.

5.1 Conclusions and Recommendations

Overall, the thesis shows that it is a two sided story when it comes to lived experiences of immigrants living with a chronic illness such as HIV in Denmark. Partly, for some, life is okay and for the other life is not okay at all. The severity and effect of HIV as an incurable illness on the patient seems to influence a lot how well the life of the immigrant patient will be.

For patients that have not been severely affected by the illness and have responded well to medication, they have gone on to live a 'normal' life where they do everything by themselves without depending on any one necessary. However, patients, where HIV has weakened their physical and mental health, voiced a challenging life filled with a number of difficulties. They have not responded well to medicine and experienced a number of side effects that have left them unable to perform daily life activities normally. This has necessitated seeking and depending on social assistance, which according to the affected immigrant patients has led to a very stressful and frustrating life. The pressure from the social workers and depression from being frustrated due to the fact that they cannot do things on their own, as they used to, has affected their overall health and adherence to treatment. Furthermore, pressure from dependants back in Africa has also left some of the immigrant patients living a stressed life.

Stigma from mainly fellow Africans, family problems and lack of a strong social support and social network has left a number of African HIV patients lonely and living a boring life in Denmark. For many of them, the health workers are looked at their family, people they can trust and share everything with. Perception of HIV as personal disease is an issue all the patients in the study agreed upon.

Generally, the immigrant patients are happy and satisfied with the treatment and care services they receive in Denmark as HIV patients. However, they cite inadequacy in the quality of the time they spend on the Doctors' visit. Patients feel and would like their Doctors should ask and talk about their overall life, other than the routine medical check-ups. More so, patients that feel that they are being pressured by the social welfare system would like their Doctors to be their ambassadors. They believe that the Doctors are more authoritative in explaining to social workers about their physical and mental state as HIV patients and this would contribute to reduction on the pressure from social workers at the municipality.

Overall therefore, while to some extent the effects of HIV on immigrant patients are similar to those of any other HIV patient, they face a number of unique issues that leaves them with what has come to be termed as the double burden. Living a life of secrecy, the lack of a strong social network, pressure from back home, and for some dealing with social workers in the social welfare system, are among the unique issues that immigrant HIV patients have to face unlike their Danish counterparts. This has left many of the immigrant patients living a life with HIV that is at the same time depressing, stressful, uncertain and at times very frustrating. In light with the fore mentioned psycho-social issues, a multidisciplinary approach to immigrant patients with HIV is imperative to ensure treatment success.

The trust the patients have in the health workers should be used as an opportunity and maximized to the fullest in order to understand immigrant patients more. The patients are willing to share everything about their life to their Doctors that they do not share with the rest of the people. This can be used as a starting point for helping the HIV patients overcome living a double/secret lives. Like mentioned earlier health workers especially the Doctors also have a crucial part to play in helping immigrant patients to have less pressure and stress from the social system. There is need to building a mutual working relationship between the social workers in the system and Doctors so as to come up with effective and efficient ways of handling patients with long term illnesses. Explaining the illness, and its effect on the patient to the social workers in the municipality, is one of the roles the Doctors should do on behalf of their patients more persistently.

In relation to public health, there is need to accept the fact that immigrant patients are in a way unique and different but not necessarily problematic. Health care providers in Denmark need to come up with programmes tailored for immigrant patients. It is a fact that due to differences in culture and other life experiences, immigrant patients on a daily basis face issues that their Danish counterparts do not come across due to the fact they are living in their home country. Therefore to reduce on the high costs incurred due to failure to understand this patient group, health policy makers and practitioners must specifically aim at specializing treatment and solve challenges faced by immigrant patients in order to insure social justice, equality and equity in health.

5.2 Limitations of the study

The study was purely qualitative which could make the findings hard to generalize. In addition, lived experiences tend to be very subjective depending on the participant's background. The sample may have been not very big, again which may cause a challenge of generalization of findings.

Because mainly English speaking immigrant HIV patients were interviewed, interesting stories concerning the topic at hand may have been missed.

Nevertheless, this study provides insight to an unexplored topic important to address when investigating health among immigrants. I believe that the sample size in relation to the research design was enough to fulfill the study objective and answer the research questions set at the start of the activity. And I strongly believe that the findings of the study are relevant and significant to the concerned field of public health.

5.3 Suggestions of areas for further study

- The overall objective of the study was to understand lived experiences of immigrants with chronic illness. This study only focused on HIV as an infectious chronic illness. Because of the limited research on this particular patient group, more studies are required focusing on the other non communicable chronic illnesses.

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- Studies focusing on other groups of ethnic minorities other than those of African yield may be required.
- Studies on undocumented immigrants with HIV and AIDS may prove to be useful in this field of public health.
- There is need for a more comprehensive study on immigrants with chronic illnesses living already in Denmark in comparison with those with similar illnesses back in their home countries.

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Appendix

Introduction and Consent Form

My names are Rogers Twesigye, a Msc. Public Health Student at the University of Southern Denmark from Uganda. You have been purposively selected to participate in this study because of your health condition, residency status and fluency in English. . The purpose of this study is to understand and document what it is like for an immigrant living with a chronic illness in a foreign country like Denmark. The focus is on how the patient views and describes his/her experience with seeking treatment, relationship with health care providers and other social issues at large.

The significance of the study is to add to the inadequate information available in Denmark on health care service experience of immigrants. The study findings will also enable understanding specific health issues about immigrants in Denmark and provide a reference for improved and effective health care provision. The study is also a thesis project for the researcher, a key requirement for attainment of his Masters of Science degree in Public Health.

Your participation is completely voluntary; you can choose to or not to participate. I will however be grateful if you accepted to participate in the study. All the information you give will be treated with a high degree of confidentiality and will be used only for academic purposes, if otherwise, you will be informed and your consent sought first.

Participant's Consent: **Yes**..... **No**.....

If Yes, Signature..... **Date**.....

Feel free to answer or not answer any of the questions. Thanks

Researcher:

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Interview Guide

Background of the participant/Patient:

Age, Sex, Nationality (country of origin), Period/time in Denmark, Education level, Employment status, Marital status, Family size in Denmark (number of children or siblings)

About Illness/disease:

Name or type of illness with (Details), Period with illness (since time of diagnosis), Where it was diagnosed (Denmark or elsewhere)

Lived experiences:

Description of living with illness in Denmark:

How has your life been in Denmark since diagnosis of the illness?

If patient had illness before coming to Denmark, (How is it for you here in Denmark with the illness compared to before Denmark?)

Use: 'anything else' as much as possible

Health care services:

How has it been with the health care and treatment?

How has it been with the health workers, GP, Doctors, nurses?

How do you find them in comparison with home country or country before Denmark?

Support:

Do you receive or have u received special care from anybody or any organization because of your health condition here in Denmark? Which ones if any? (family, friends, municipality, neighbours, NGOs, employers, etc) What type of support?

How do you find the support in comparison with home country or country before Denmark?

Has your health condition changed your daily life in anyway? (Jobs, goals, daily and future plans, etc.)

If yes, how has it changed? What changes have you had to make? How do you feel about this?

Have you had a serious incident/s due to your health condition? Tell me about it (if any) How about minor incidents? How do you respond? What do you do in such cases?

Do you have anything you would like to talk about or tell me, related to your health condition? Expectations, disappointments, etc

*******Thank you very much for your time*******