

University of Tampere
School of Health Sciences

Nuno Ribeiro Nobre

WHY? HOW? And WHO?

A study on life dynamics and experiences of 50 + people living with HIV/AIDS in Finland

Master of Public Health Thesis
University of Tampere
School of Health Sciences

September 2011

University of Tampere

School of Health Sciences

Nuno Ribeiro Nobre: WHY? HOW? and WHO?- A study on life dynamics and experiences of 50 + people living with HIV/AIDS in Finland

Master's Thesis, 93 pages, 3 appendices

Supervisors: Senior Assistant Professor Tapio Kirsi, PhD & Adjunct Professor Jari Kylmä, PhD

Health Sciences (Public health)

September 2011

ABSTRACT

Purpose: Ageing of population is a worldwide phenomenon. Adults ageing with HIV/AIDS and older adults newly infected, represent a growing group in Finland. Successful ageing with HIV/AIDS is heavily dependent in how older people living with HIV/AIDS deal daily with the disease in the society where they live. So far, there is no information available in how older people experience and live with HIV/AIDS in Finland. Some qualitative studies have been conducted in North America and one in United Kingdom on older people living with HIV/AIDS experiences.

Objective: The aim of this study is to describe lived experiences of older people living with HIV/AIDS as it relates with their overall well-being and quality of life as HIV positive.

Methods and data: Semi-structured in-depth interviews were conducted with 9 participants, 50 years old and older living with HIV/AIDS. The transcript interviews were analysed using inductive content analysis methodology.

Results: The majority of the participants experienced negative emotional reactions towards a HIV positive diagnosis. In spite of these negative initial emotions all of the participants identified positive aspects related with living with HIV/AIDS which was translated into a good balanced life. From the qualitative analysis four themes emerged: experiences in living with HIV/AIDS disease, HIV/AIDS related stigma, disclosure patterns and types and kind of social network support.

Conclusions and implications: This study described the lived experiences of 50 + adults living with HIV/AIDS. Stigma, disclosure and social networks support played an important role in individuals' lives in dealing with the HIV/AIDS disease. Moreover, stigma, disclosure and social networks support was identified to be involved in a symbiotic relationship influencing each other. Further research is needed to explore the impact of these dimensions on other populations, especially among those not involved in any kind of support group. Health professionals and governmental institutions should start to include older people living with HIV/AIDS in their projects to secure equal opportunity to care and quality of life.

TABLE OF CONTENTS

List of abbreviations	iv
List of figures, graphics and tables	v
1. INTRODUCTION	1
2. LITERATURE REVIEW	3
3. HIV/AIDS IN AN AGEING SOCIETY	4
3.1 Gerontological perspectives on ageing	4
3.2 HIV/AIDS: a brief introduction to the disease	5
3.3 Ageing and HIV/AIDS	6
3.3.1 International and national HIV/AIDS epidemiological data on old people aged 50 years old and older	8
4. PSYCHOSOCIAL ASPECTS OF LIVING WITH HIV/AIDS	11
4.1 Getting the diagnosis	11
4.2 Living with HIV/AIDS	12
4.3 Stigma	15
4.3.1 HIV/AIDS related stigma dimensions	16
4.4 Social networks and support	19
4.5 Concealment and disclosure	22
5. AIMS OF THE STUDY	24
5.1 Justification	24
5.2 Research questions	24
6. DATA AND METHODS	25
6.1 Approach	25
6.2 Study subjects	26
6.3 Data collection	26
6.4 Data analysis	27
7. RESULTS	29
7.1 Profile of the participants	29
7.2 Experiences in living with HIV/AIDS	30
7.2.1 Individual reactions to HIV diagnosis	30
7.2.2 Impact of HIV/AIDS in daily life	33
7.2.3 Good balanced life as a 50+ HIV positive	37

7.3	<i>HIV/AIDS related stigma</i>	39
7.3.1	<i>Others' fear of contagion</i>	40
7.3.2	<i>Negative HIV related self-image</i>	40
7.3.3	<i>Free from self-stigma</i>	41
7.3.4	<i>Self protective behaviours against stigma</i>	41
7.4	<i>Disclosure issues</i>	42
7.4.1	<i>Motivations to disclose HIV diagnosis to others</i>	43
7.4.2	<i>Reasons for concealing HIV diagnosis from others</i>	44
7.4.3	<i>Regulating personal information</i>	46
7.4.4	<i>Others' reactions to HIV diagnosis disclosure</i>	47
7.4.5	<i>Unintended disclosure</i>	48
7.5	<i>Human relationships and social networks</i>	49
7.5.1	<i>Multifaceted social networks</i>	50
7.5.2	<i>The importance of support</i>	51
7.5.3	<i>Downsizing of social networks</i>	53
8.	DISCUSSION	55
8.1	<i>Credibility of the study</i>	55
8.1.1	<i>Strengths of the study</i>	57
8.1.2	<i>Limitations of the study</i>	57
8.2	<i>Interpretation of the findings</i>	58
8.3	<i>Ethical considerations</i>	67
8.4	<i>Public health implications and further research proposals</i>	68
9.	CONCLUSIONS AND RECOMMENDATIONS	69
10.	ACKNOWLEDGEMENTS	71
	REFERENCES	72

APPENDIX 1: World medical association declaration- Ethical principles for medical research involving human subjects.

APPENDIX 2: Table 3: Number of new HIV infection diagnosis by year in people aged 50 years old and older, in selected countries.

APPENDIX 3: Inductive content analysis process example used in the present study.

List of abbreviations

AIDS- Acquired Immune Deficiency Syndrome

CDC- Centers for Disease Control and prevention

EU- European Union

HAART- Highly Active AntiRetroviral Treatment

HIV- Human Immunodeficiency Virus

M- Men

PLWHA- People Living with HIV/AIDS

RNA- Ribonucleic Acid

STDs- Sexually Transmitted Diseases

SOC- Selection, Optimization and Compensation

THL- National Institute for Health and Welfare

QoL- Quality of Life

UK- United Kingdom

USA- United States of America

WHO- World Health Organization

W- Women

List of figures, graphics and tables

Fig. 1: HIV and ageing.....	3
Fig. 2: Five phases of HIV infection.....	6
Fig. 3: Model of factors influencing QOL of HIV-infected individuals.....	14
Fig. 4: Model of the HIV/AIDS identity incorporation process.....	14
Fig. 5: Study design.....	25
Graphic 1: Number of new cases of HIV diagnosis in people aged 50 years old and older by year of diagnosis.....	8
Graphic 2: The proportion of people aged 50 years and older living with HIV infection in selected countries.....	9
Graphic 3: Total cumulate of reported cases of people aged 50 years and older living with HIV infection in Finland by the end of 2009 by gender.....	10
Table 1: Stages of AIDS antibody-positive status congruency in homosexual men.....	12
Table 2: Demographic characteristics of the study participants.....	29
Table 3: Number of new HIV diagnosis by year in people aged 50 years old and older, in selected countries.....	92

1. INTRODUCTION

The unprecedented growth of the elderly population in the world is accompanied with a concern about increasing of incidence of HIV/AIDS among this fragile age group.

The elderly are the age group with the greatest growth of HIV infection in recent years in developed countries (Casau 2005). As a result, our societies face a double global public health problem: ageing of population and its increased incidence of HIV/AIDS problems that were inexistent few a decades ago. Old PLWHA must deal not only with pathologies associated with the process of ageing but also with the toxicity drug combination associated with antiretroviral therapy. This comorbidity poses a huge challenge to the medical community all over the world (Martin, Fain & Klotz 2008, Fisher 2010).

HIV infection in the elderly is often detected late (Knodel, VanLandingham 2002). This misdiagnosis results from the wrong believe that older adults are not sexuality active and from the unawareness of health professionals for the potential risk of becoming infected with HIV virus at older age (Lieberman 2000). Moreover, recent studies have shown exactly the opposite: sexual route is the main form of infection in the elderly (Cloud et al. 2003). The emergence of new drugs has prolonged active sex life, which may play an important role on infection patterns in older age (Alpert 2005).

An important key factor of HIV infection in the elderly is related to chronic diseases of the natural process of senescence (Mallon 2010) that often masks the symptoms of AIDS and may induce to inconclusive misdiagnoses (Lieberman 2000, Stoff et al. 2004). In a US study Karpiak, Shippy & Cantor (2006) reported that, among 60–79 old people who died in a health care facility, 5 percent were tested positive for HIV antibodies. Furthermore, those individuals were unaware of their serostatus during their life.

Old people belong to an age group that poses reduced information about the dangers of HIV infection contagion due to lack of awareness campaigns directed to their needs. This could be seen as one plausible explanation for the weak condoms use among the elderly (Bodley-Tickell et al. 2008, Reece et al. 2010a, Lovejoy et al. 2008). Also, other aspects such as the decline of partner's sexual activity and sex tourism should not be ignored (Stoff et al. 2004).

Besides of the importance of biomedical advantages in managing HIV/AIDS disease, it is important to consider the magnitude of psychosocial issues in QoL of older PLWHA. The biomedicalization of HIV/AIDS has overshadowed the social dimensions of the disease. Stigma and discrimination are big barriers in PLWHA's lives. These social dimensions might have a higher impact on older PLWHA, who already may suffer from other forms of discrimination including ageism. The way these dimensions affect individuals differs culturally. Yet, fear of stigma is still one of the main factors influencing disclosure patterns and potential social support. Without adequate support older PLWHA may sink in social isolation and fail to have medical assistance, which in turn will impact their QoL.

Finland is one of the European countries with lowest reported cases of HIV/AIDS. For all age groups heterosexual sex is the main route of transmission (THL 2010).

The classification used in this study for characterising old people as those aged 50 years and older is based on the CDC's age categorization system. This age categorization is widely used in the scientific literature whenever the study focus is on people aged 50 years and older living with HIV/AIDS (Emlet, Tozay & Raveis 2011).

Some international studies have been conducted on psychosocial aspects among older PLWHA; so far the topic has not been yet explored in Finland. Successful ageing with HIV/AIDS depends on how older PLWHA are accepted by the society and how they accept themselves as HIV positive citizens. Self-acceptance and social integration are important factors in promoting successful ageing with HIV/AIDS disease. Thus, it is a mandate of social gerontologists to increase academic knowledge about older PLWHA' lives. The aim of this pioneer study is to describe life experiences of older PLWHA's in Finland.

2. LITERATURE REVIEW

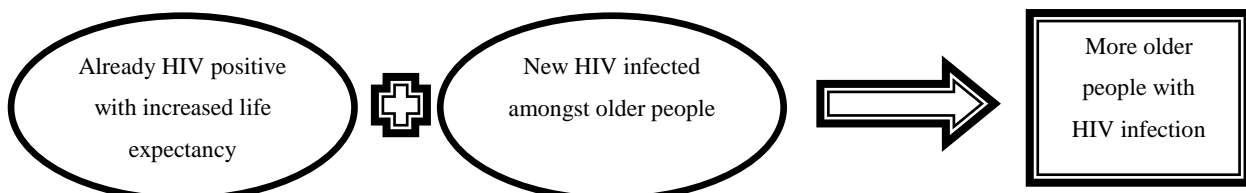
Due to advantages of biomedical technology, HIV/AIDS has become a manageable chronic disease (Capeau 2010). Although the new cases of infection are increasing at a high rate worldwide, the numbers of deaths attributed to HIV/AIDS have decreased, especially in countries where HAART treatment is fully accessible by the infected individuals. Yet, once considered a disease of the young, HIV/AIDS is also to be found amongst older populations. HIV/AIDS among older populations is characterised by two distinct groups: the veterans, who got infected with HIV/AIDS in their adulthood and have grown older and those newly infected (Emlet, Tozay & Raveis 2011) (Fig.1).

The background information considered in this literature review regarding social aspects of older PLWHA is mainly drawn from studies conducted in North America and one study recently done in UK. Therefore, the scarce present knowledge in literature highlights the urgent need for more research on the subject in years to come.

The literature review was compiled out unsystematically, using Pub Med and Google scholar as searching engines. The used keywords were: old people, HIV/AIDS, stigma, disclosure, social networks, social support and elderly.

Due to scarce literature on the topic, the next step taken to expand the literature was using the articles cited by the most relevant found articles. Older and recent published articles and books in Portuguese, English and Finnish language were also reviewed.

Fig. 1- HIV and ageing



3. HIV/AIDS IN AN AGEING SOCIETY

3.1 Gerontological perspectives on ageing

Progresses at social, scientific, technological, educational and social level, along with a set of demographic transitions, have allowed individuals to live longer than before. There are several explanatory theories that try to enlarge our understandings about ageing. Ageing has been conceptualized from the biological, sociological and psychological point of view. Hence, it has become a multidisciplinary subject. However, no theory alone can fully explain the complex changes that time brings to individuals.

Within the framework of social gerontological theories, three important foundations are to be considerate: structural functionalism, symbolic interactionism and critical theory (Bengtson, Burgess & Parrott 1997).

For the critical theory point of view, individuals, by growing old, tend to disengage progressively from the society as a way to achieve what Tornstam (1989) has conceptualised as a Gerotranscendence. With this gradual process individuals try continually to ascend a high spiritual level by introversion. This self-disengagement represents a very selective decline of social relations affecting, in general, the more superficial relations, while the more intimate relationships remain basically unchanged. The need to be alone and reflect or meditate about life assumes higher level in old age. This positive life event represents the last level of Erik Erikson's individual development named as wisdom, represented by ego integrity versus despair (Newman, Newman 2008). During this period, individuals reflect on past events and accomplishments, resulting in life satisfaction or despair

The structural functionalism, in turn, argues that social disengagement may occur at different stages of life and for different reasons. Loss is the most frequent feeling that the elderly face by growing old. Death of the spouse and old friends as well as the loss of kinship bonds, professional links and own health, they all represent a social break down. This social break down, regardless if it happens at a micro or at a macro level, requires processes of adaptation (SOC) and coping strategies (assimilation, accommodation and immunization) to overcome losses (Dittmann-Koli, F., Jopp, D. 2007). For Baltes & Baltes (1993) it represents a continual optimization of human development, which is mediated by adaptive strategies. Consequently, the way older PLWHA adapt to these new

situations is related with their social skills and level of support. (Baltes, Baltes 1993, Fonseca A. M. 2006, Dittmann-Koli, F., Jopp, D. 2007).

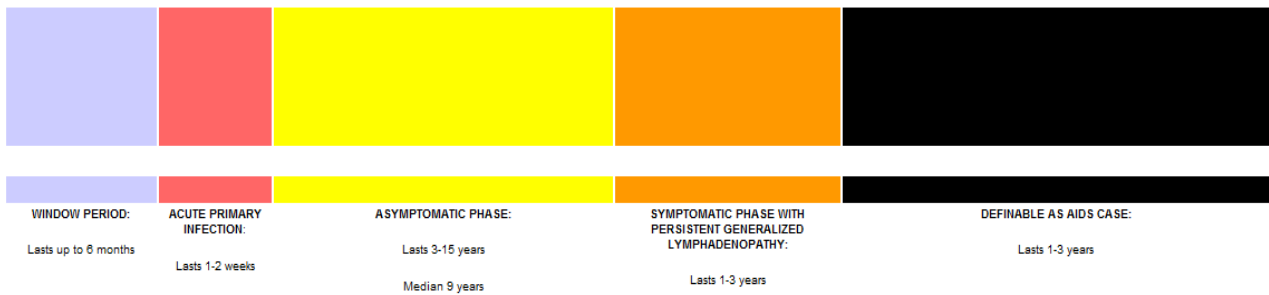
In line with the thoughts above, comes the symbolic interactionism which combines the elements of two sociological perspectives in the analysis of ageing- continuity and activity theory. On one hand, ageing is viewed as an integral and functional aspect that makes part of the individual's life circle. The elderly have the ability to keep all their lifestyles, preferences, experiences and commitments built throughout life. The pressures exerted by life events, whether social or health related life change events, lead to the adoption of new behaviours that give sense and continuity to life. On the other hand, the continuity of social relationships in older age is determinate by the level of activity individuals are ready to engage with as well as with their social environment. By growing older, individual should be able, within their own resources, to organize and discover actively new roles that could improve one's self-esteem and life satisfaction which could be achieved by trying to keep previous activities and social ties or substituting new roles for those lost previously, conducting therefore to successful ageing with HIV infection. (Ebersole et al. 2005, Bond et al. 2007)

3.2 HIV/AIDS- A brief introduction to the disease

The Human Immunodeficiency Virus (HIV) has been recognised to be the etiologic agent of Acquired immunodeficiency syndrome (AIDS) (Gallo, Montagnier 2003). Once infected, the immune system is threatened by opportunistic diseases. The primary sources of contagion are unprotected sexual intercourse, unprotected contact with the infected person's body fluids (blood and semen) (Stolley, Glass 2009) and, less often nowadays, child transmission and blood transfusions (UNAIDS 2010).

HIV is a retrovirus with a RNA genome, belonging to the Lentivirus family. Infections caused by Lentivirus are characterised for their long incubation period and disease chronicity. Once infected, the host remains infected until death. HIV infection is known by its five distinct phases (Fig. 2). Essentially there are two types of aetiological agents of HIV virus, HIV-1 and HIV-2. HIV-1 type, more virulent and infectious, is considered to be the most normal worldwide infection type and the HIV-2 is reported to be confined to West Africa region. (Gilbert et al. 2003)

Fig. 2 - Five phases of HIV infection



Source: (www.avsf.bm/HIVphases.html)

3.3 Ageing and HIV/AIDS

Since the HIV epidemic began in the 80's, governments and health institutions all around the world started to develop strategies for tackling with the new mortal disease. The main message developed by the governments was directed to safe sex practices, especially among those apparently more vulnerable. Therefore gays, prostitutes and injecting drug users were the main target groups. Later on the disease started to spread and to take higher incidence among heterosexual couples, as well. Nowadays the disease progress over a portion of the population physically, and in certain extent emotionally and socially fragile, demanding a more complex and integrated approach: the elderly.

UNAIDS and WHO estimated that approximately 40 million people live with HIV/AIDS in the world. Out of these people, about 2.8 million are 50 years old and older (Nguyen, Holodniy 2008). The number of confirmed cases of HIV and AIDS over the age of 50 grows every year (Ibid.). The reason for this fact lies behind two important features. On one hand, the development of new medical therapies has increased the life expectancy of people living with HIV (Villamil-Cajoto et al. 2006). On the other hand, the advantages of impotence treatment has made possible to men to continue their sexual life longer.

Regardless the increased incidence of HIV infection among ageing population, most of the prevention campaigns are still mostly directed to teenagers and young adults' population (Lovejoy et al. 2008). This misunderstanding is rooted in societal ideas about sexual activities as the prerogative of youth.

Many studies have strongly pointed out many important risk factors for HIV infection in older adults such as medical advances on male impotence treatment (Alpert 2005); sexual contacts through net (Strombeck 2003); low education levels, lack of specialized health care staff in the ageing and HIV thematic and lack of health promotion programs directed to older people (Levy-Dweck 2005) ; unsafe sexual behaviour among men and women (after their fifties, women tend not to use condoms because they do not get pregnant), cultural attitudes towards ageing and sexual behaviour (Nguyen, Holodniy 2008, Linsk, Fowler & Klein 2003, Orchi et al. 2008); sex tourism (Wright 2003), the death of one of the spouses and divorce.

The elderly who face the disease tend to isolate themselves and hide their diagnosis from family, neighbours and friends (Emlet, Gerkin & Orel 2009). Few of them have persons with whom to share insecurities and fear to be discriminated against. In some cases prejudice flows from the inside preventing old persons from sharing their HIV status with others which leads to loneliness and high risk of developing depression symptoms (Nguyen, Holodniy 2008).

Studies have shown that depression is the most common health disorder among older PLWHA. Sources of depression have been documented to be linked with coping cognitive strategies (Teri T. B. et al. 2004), stigma, discrimination and loneliness (Groves et al. 2010) changes in the social network and its support, and decreased social engagement (Tsasis 2000, Shippy, Karpiak 2005).

Emotional well-being is threatened by HIV/AIDS related stigma. This threat to the emotional well-being may be specifically present in older age groups who may experience age related stigma behaviours- ageism (Emlet 2006). This double negative stereotyping may lead to various negative outcomes e.g. reduced QoL, the increased feelings of depression, the loss of social support and increased loneliness. (Shippy, Karpiak 2005, Santos, França & Lopes 2007)

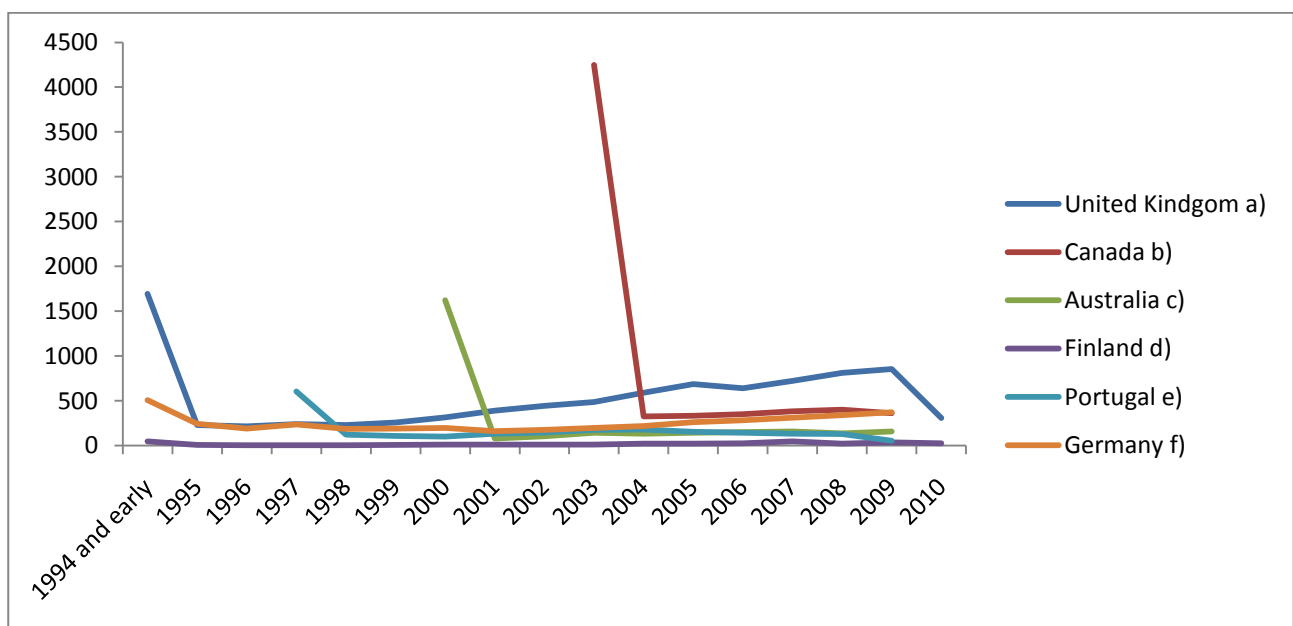
3.3.1 HIV/AIDS epidemiological data on people aged 50 years and older

Epidemiological data on older PLWHA is still deficient in developed countries and non-existence in the developing countries. In some developed countries the registration is still in its earlier stages due to the fact that more attention is given to the younger age groups. This inattention has lately raised critics to UNAIDS organization, for its latest report of HIV/AIDS worldwide epidemiological data where 49 years old was the limit age group. (UNAIDS and WHO 2009, Knodel, Watkins & VanLandingham 2003)

However, some countries have successfully included people aged 50 years and older in their HIV epidemiological reports. The total number of people living with HIV/AIDS differs substantially from country to country. Nevertheless, all countries share a common feature: the number of people living with HIV/AIDS and the new cases of HIV infection amongst people aged 50 years and older, is increasing.

The following graphic shows the number of new cases of HIV diagnosis in some selected countries, by years of diagnosis among people aged 50 years old and older (graphic 1) and the proportion of people aged 50 years and older living with HIV infection (graphic 2).

Graphic 1: Number of new cases of HIV diagnosis in people aged 50 years old and older by year of diagnosis.

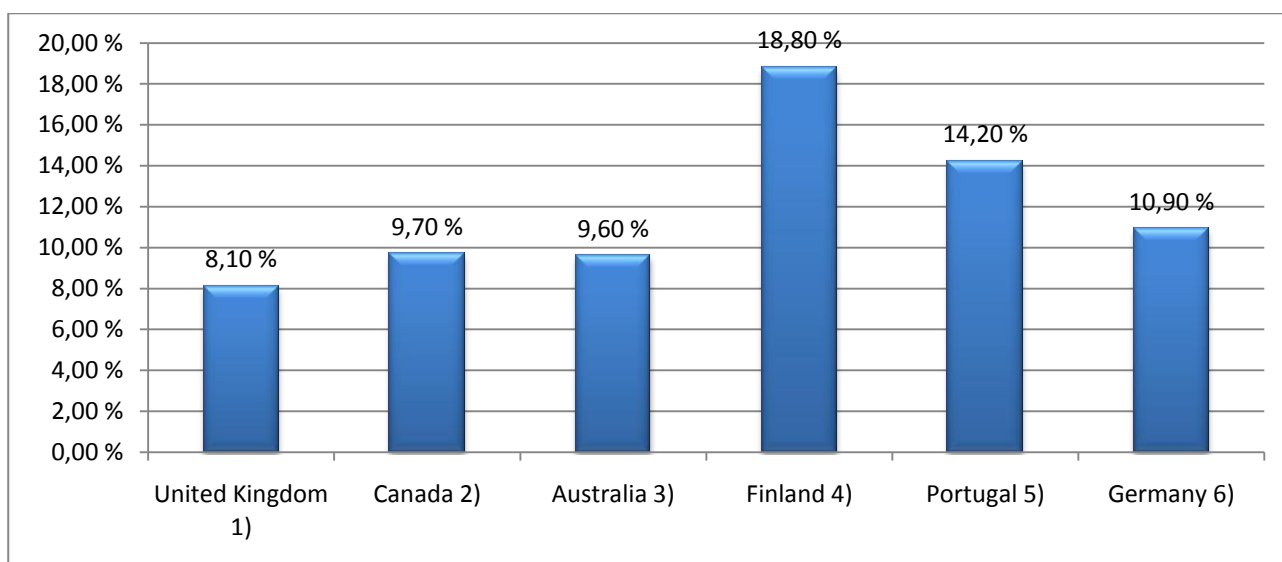


- a) Available data starts from 1994 and earlier, from 1995 to 2010 yearly new cases of HIV diagnosis.
- b) Available data starts from 1985-2003, from 2004 to 2009 yearly new cases of HIV diagnosis.
- c) Available data starts from < and year 2000, from 2001 to 2009 yearly new cases of HIV diagnosis.
- d) Reported data represents the total accumulated cases from 1983-1994, from 1995-2010 yearly new cases of HIV diagnosis.
- e) Available data starts from 1983/97, from 1998 to 2009 yearly new cases of HIV diagnosis.
- f) Available data starts from 1994 and earlier, from 1995 to 2009 yearly new cases of HIV diagnosis.

Source: (National Centre in HIV Epidemiology and Clinical Research 2010, Health Protection Agency Centre for Infections, Health Protection Scotland & UCL Institute of Child Health. 2010, Instituto Nacional de Saúde Dr. Ricardo Jorge 2009, Public Health Agency of Canada 2010, Das informationssystem der Gesundheitsberichterstattung des Bundes).

It is worth to note that the higher peaks presented in UK, Portugal, Canada and Australia on the graphic 1, refer to total cumulated new cases of HIV diagnosis during a certain period of time. Detailed information is to be found on appendix 2.

Graphic 2: The proportion of people aged 50 years and older living with HIV infection in selected countries



1), 2), 3), 5) and 6) same epidemiological data referred under the graphic 1.
 4) Epidemiological data by end of the year 2009.

Source: Ibid.

The graphic 2 shows that in some countries HIV infection is more prominent among younger populations, it also informs that in some countries like in Finland there is the tendency to age with HIV infection.

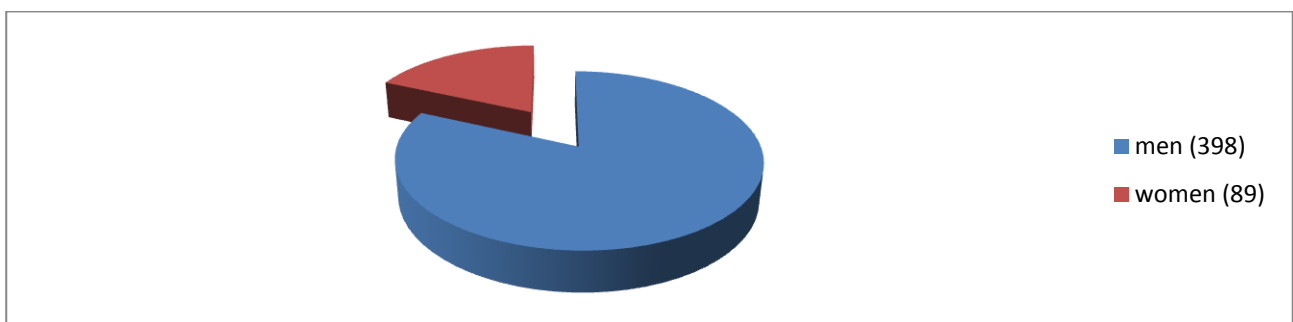
Africa is the foremost continent with incidences of HIV infection. Sub-Saharan Africa is still the most affected African region. In 2009, Sub-Saharan Africa alone, accounted with an estimated of 22.5 million people living with HIV (UNAIDS 2010, 26). In this region by the year 2007, it was

estimated that a total of 3 million people aged 50 years and older were living with HIV, corresponding to a total of 14.3 percent of all HIV cases among people aged 15 years and older (Negin, Cumming 2010). In turn, South Africa alone, counted with a total of 5.6 million people living with HIV infection, representing the country with the most cases in the world. In 2008 the prevalence of HIV infection in South- African in people aged 50 years and older was 20.1% for men and 19.7 for women respectively (Shisana et al. 2009)

Lazarus & Nielson (2010) have collected data from different European countries, regarding newly reported cases of HIV infection among people aged over 50 years registered by the end of 2008. According to their report 12.9 percent of new HIV infection cases in Western Europe were among people aged over 50 years. In Eastern Europe this proportion was of 3.7 percent. In countries of Central Europe, almost one in every ten newly reported cases of HIV infection was among older people. The trend of new cases of HIV infections among people aged over 50 years is therefore alarming.

In Finland, the first cases of HIV among people aged 50 years and older were reported in 1985 (three men). By the year 2009, Finland counted with a total accumulated of reported cases of HIV infection among people aged 50 years and older of 487. Among people born in Finland the total accumulated numbers of reported cases of individuals aged 50 and over by the year 2009 were 440 respectively. Men are the main infected group (Graphic 3). Sources of transmission are not included¹.

Graphic 3- Total cumulate of reported cases of people aged 50 years and older living with HIV infection in Finland by the end of 2009 by gender



1- Information not available on online, obtained directly from Kirsi Liitsola, researcher at THL. For further information please contact kirsi.liitsola@thl.fi

4. PSYCHOSOCIAL ASPECTS OF LIVING WITH HIV/AIDS

4.1 Getting the diagnosis

Receiving an HIV diagnosis is a life changing event (Bury 1982, Stevens, Hildebrandt 2006). The way individuals react and deal with life stressors vary widely from being negative to a neutral reaction. Yet, the most important feature in receiving a positive HIV diagnosis goes around two crucial questions: how the news are delivered? and how supportive or judgmental the health professionals are? (Hult, Maurer & Moskowitz 2009). These two factors may play an important role in how individuals react and cope with the disease. Cultural and social values around health and disease and the ways diseases are transmitted play an important role in how health professionals' deal with the new infected individuals.

Reactions to an HIV diagnosis vary. Shock has been reported in several studies of PLWHA, as the most felt immediate emotional reaction (Stevens, Tighe Doerr 1997, Malone 1998, Stevens, Hildebrandt 2006, Hult, Maurer & Moskowitz 2009). Length of shock which is directly bonded with self-acceptance to HIV infection, is a feature rarely found in existing literature.

In her the unique study regarding coping strategies in five HIV positive woman aged 50 years and older, Malone (1998) noted that that shock was the most emotional reaction shared by the participants. Despite the initial shock, most of the participants had recovered rather quickly and shared hope feelings regarding life and future. Social interaction and group support played an important role in the overall well-being construction.

Reactions to HIV diagnosis could be characterized as emotional and behavioural. Emotional reactions refer to those emotional-based states as shock, mental distress, translated into suicidal thoughts, fear, shame and depression (Stevens, Tighe Doerr 1997, Stevens, Hildebrandt 2006, Anderson et al. 2009, Hult, Maurer & Moskowitz 2009). Behavioural, in turn, are those related to individual actions which HIV diagnosis which may exacerbate or trigger the use of alcohol consumption and illicit drugs (Reeves, Merriam & Courtenay 1999). Both emotional and behavioural reactions conduct to life changes.

Changes in identity (Roth, Nelson 1997), in location, in social support network and in regarding the future (Kralik, Brown & Koch 2001), are some of the psychosocial changes that individuals go

through, after being diagnosed with HIV infection. Some of these changes were conceptualized by Ross and colleagues (1989, cited by Ross 1990) as psychological reactions to HIV diagnosis stages model. In this model, an individual passes throughout a series of self adjustments and reflections about self and disease and tries to conciliate both in a harmonic way (table 1). As any self-evaluation process, the individual might regress to previous stages whenever he or she is not ready to accept the challenge posed by the following adaptation stage.

Table 1: Stages of AIDS antibody-positive status congruency in homosexual men

Reaction	Psychological processes	Common presenting issues
Stages 1 and 2: Shock, denial, anger	Guilt, powerlessness, anger	Anxiety, frustration, distress, acting out
Stage 3: Withdrawal	Recognition of stigma, isolation	Fear of infecting others, depression
Stage 4: Bargaining		
Substage 4a: "Coming out" to significant others	Testing of other's reactions and bargaining, stress displacement, need to be loved	Rejection, stress, confrontation
Substage 4b: Looking for other antibody-positives	Sharing, recognition, trust positive reinforcement, social support	Dependency, overinvolvement, loss of anonymity
Substage 4c: Special status	Turning alienation into a unique advantage, difference becomes special, needed by others	Dependency, "us and them" dichotomy overidentification
Substage 4d: Altruistic behavior	Group commitment and cohesiveness, desire to give and share, feeling of community	Burnout, overreaction, over compensation
Stage 5: Acceptance	Integrated antibody positive status with self-identity; balance between altruism and self; coming to terms with one's condition.	Apathy, resistance to change

Source: (Ross 1990, 34)

However, this model does not reflect universal developmental stages after being diagnosed with HIV infection, but rather it provides a clear insight about individual psychological management process. Society and culture play an important role in these stages, particularly in the ways individuals are supported and viewed by others.

4.2 Living with HIV/AIDS

Individuals are unique in their way of thinking and behaving (Skaggs, Barron 2006). Reactions to negative life events are rather subjective and person bonded. After being diagnosed with HIV disease a set of individual internal resources are activated for successful adaptation to HIV disease. This introspection regarding self and life is a vehicle mechanism for searching meaning in life as a HIV positive (Barroso, Powell-Cope 2000). Searching meaning in life is considered as an adaption mechanism to HIV/AIDS which may raise hope feelings.

Hope is a continuous dynamic process that provides meaning to life and empowers individuals to overcome with difficulties. In turn despair, the opposite of hope, leads to a negative adaptation to live circumstances (Kylmä 2005) . Religion (Barroso, Powell-Cope 2000) and social support (friends and family) has been reported in some studies to be the most central sources of hope constructs and maintenance, which conducts to improved QoL and successful ageing with HIV/AIDS (Vance, Woodley 2005).

Research focusing in older adults experiences in living with HIV/AIDS is rather scarce. Siegel, Raveis & Karus (1998) were the first academics to study the advantages and disadvantages brought along with age among 12 older adults living with HIV/AIDS. In that study, increased respect for health and life, increased wisdom and having more time to themselves were found to be the major advantages related to growing older with HIV/AIDS. Similarly, their study of 25 older adults living with HIV/AIDS Emler, Tozay & Raveis's (2011) found sources of resilience. In this study sources of resilience and strengths were associated with self-acceptance, optimism regarding the future, will to live, generativity, self-management and social engagement. The authors concluded that those factors represented the pillars for a good successful ageing with HIV/AIDS. In the same vein Vance & Woodley (2005) noted in their pilot study on 12 older adults living with HIV/AIDS that strength sources were linked with spirituality, community participation and openness to ageing. Social support was identified in that study as one of the most crucial source of strengths.

These unique studies have shown that life satisfaction is essential to QoL and successful ageing with HIV/AIDS. Heckman (2003) found in a study of 27 people aged from 19 to 64 years living with HIV/AIDS that life satisfaction and QoL are related with internal and external individual factors. These factors were conceptualized in a logic model (figure 3).

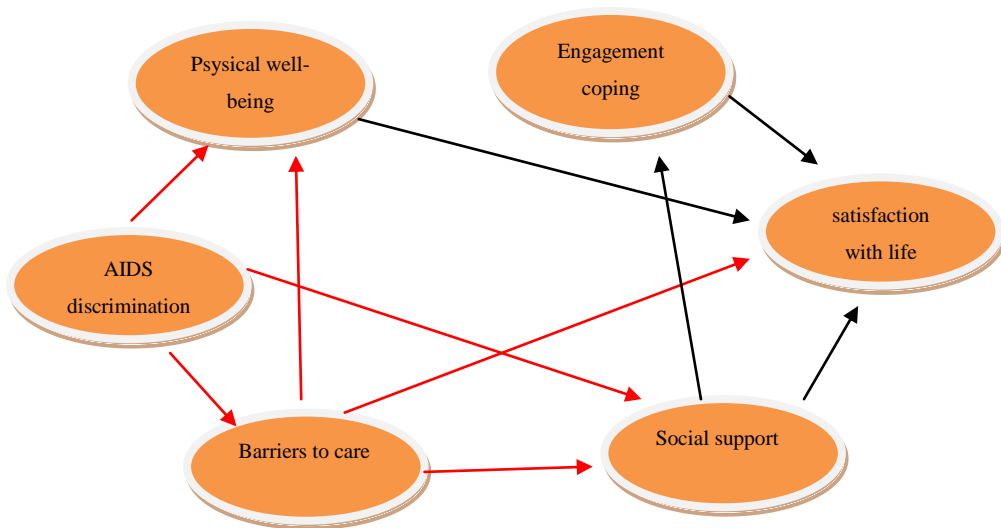


Figure 3- Model of factors influencing QOL of HIV-infected individuals (red arrows= negative association; black arrows= positive association)

This model shows that a harmonious balance between internal and external factors is therefore essential for individuals' identity construction as HIV positive. The studies of Baumgartner (2007) and Baumgartner & David (2009) on incorporation of HIV disease into self overtime, showed that good or life satisfaction is a continuous psychosocial process which is mediated by a healthy self-integration of HIV disease into identity (figure 4).

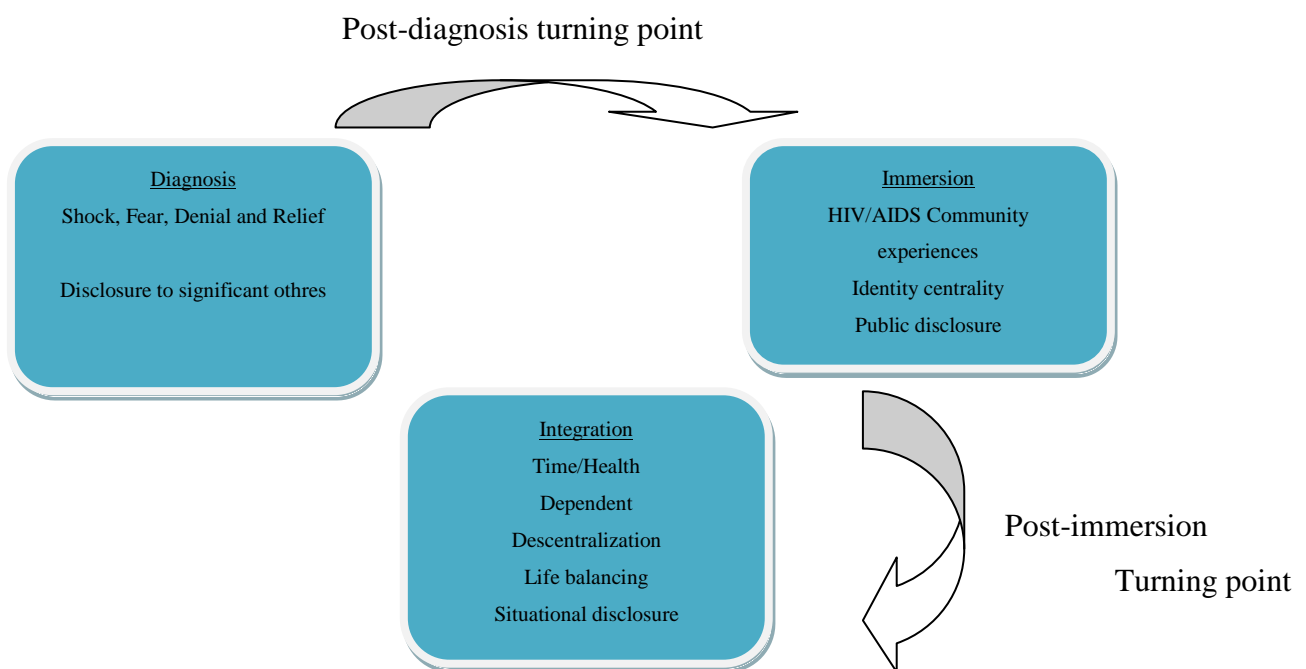


Figure 4: Model of the HIV/AIDS identity incorporation process

Both models provide an in deep understating about life satisfaction and its components. Time and social support are the foremost factors in the all processes of QoL and self-acceptance as HIV positive.

4.3 Stigma

The emergence of disease related stigmas and discriminations are dated much before the HIV/AIDS epidemic. The work on stigma made by Goffman (1986) offers a good body of knowledge around social stigma issues in homosexuality, mental diseases and physical deformations.

Thirty decades since the emergence of HIV/AIDS fear and discrimination towards those infected, still persists. Once considered as a biomedical concern, HIV/AIDS has become a social problem affecting in some cultures more than in others, individuals who must deal with a chronic disease in their daily basis (Mckinlay et al. 1989, Steward et al. 2008). HIV/AIDS related stigma has become an important societal hindrance in public health programs development and its goals achievement (Malcolm et al. 1998). The question around stigma is therefore the focus of global fight against the HIV/AIDS pandemic.

Clearly some victories have been achieved, particularly the development of new treatments and more effective therapies (HAART) fully accessible in developed countries and also in some developing countries. However much less has been obtained in an attempt to overcome the impact of stigma and discrimination acts towards infected individuals (Colbert et al. 2010). Not only infected individuals but also their families and communities suffer an association stigma or courtesy stigma (Goffman 1986).

The biological aspect of HIV/AIDS vanishes whenever compared with its social complexity. Its social complexity is associated with social forces involved in the production and spread of HIV/AIDS disease related stigma, as a social marker. Social marks become from the social need to attribute the HIV infection as an act of “irresponsibility” which is often linked with sexual behaviour, sexual orientation (homosexuality and bisexuality), intravenous drug use (Herek 1999) and elderly sexuality. Moreover, feelings of shame and guilt are deposited in individuals who do not “follow” the so called social norms or do not respect the social values, jeopardizing societal well-being (Malcolm et al. 1998), and representing thus a threat to social stability.

Weiner (1995) described responsibility and control as a key feature to negative cognitive outcomes. In the HIV/AIDS related stigma, this view is accepted assuming that society blame infected individuals for their lack of responsibility and uncontrolled behaviours. Thus, negative emotions are the root for the creation of stigma and discrimination acts, towards those who are “irresponsible”. Accordingly, stigma works as a societal protection shield by putting infected individuals in the societal layer periphery. This strategic defensive behaviour is responsible for the creation of sub-cultures, categorizing infected individuals as “others” (Devine, Plant & Harrison 1999). This so called categorization represents the social power exercised within groups, also known as Social Darwinism (Hawkins 1997). Thus, it characterizes the social vulnerability of the stigmatized groups (Malcolm et al. 1998, Lieberman 2000).

In his classic work on stigma Goffman (1986) used the terms of “social deviants” and “spoiled identity” for groups who has a kind of “undesired difference”. Consequently, stigma is seen as “an attribute that is significantly discrediting” in the eyes of the society.

Stigma has been often used as synonymous of discrimination and vice versa. UNAIDS defines stigma as a “*process of devaluation of people either living with or associated with HIV/AIDS*” and discrimination as something that “*follow stigma and is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status*”. The complexity of this non-linear relationship raises frequently confusion in academic discourses. (UNAIDS 2003)

4.3.1 HIV/AIDS related stigma dimensions

Stigma as a social construct has its roots on society owns’ values, norms and beliefs, consequently on society’s own culture (Goffman 1986). For that reason, international comparisons must take into account anthropological and sociological views. The core issue here is: why are some countries more stigmatization driven and towards what and whom stigmatization is targeted.

Goffman (1986, 4) distinguished three dimensions of stigma: abominations of the body, blemishes of individual’s moral conduct and tribal stigma (race, age, nationality). Based on these dimensions, individuals are characterized into two broad categories: discredited and discreditable individuals. In the first situation the individual is discredited by others due to the visibility of the stigma or due to

his past and/or present discredited social behaviour. On the other hand, an individual is categorized as discreditable whenever the stigma is hidden from others. (Goffman 1986)

Jones and colleagues (1984, cited by Dovidio, Major & Crocker 2003, Quinn 2006) identified six dimensions of stigma: visibility/concealability, origin/responsibility, aesthetics, peril, disruptiveness and course of the mark. In the context of HIV/AIDS related stigma, the most important dimensions are related with the visibility of the disease (e.g. lipodystrophy, Kaposi's sarcoma), the origin of the transmission and the perceived threat that HIV/AIDS poses to others in the society (peril).

Accordingly, stigma can be viewed from two different perspectives: HIV/AIDS related stigma from the uninfected and infected individuals' perspective (Earnshaw, Chaudoir 2009). From the uninfected perspective, three distinct dimensions can be considered: discrimination, prejudice and stereotyping features towards infected individuals. Discrimination is experienced by PLWHA and expressed by uninfected individuals as behaviour. Stereotypes are closely linked with beliefs and values as cognitive constructions (Biernat, Dovidio 2003). Prejudice as negative attitudes and emotions experienced by PLWHA, are closely related to power issues within society (Dovidio, Major & Crocker 2003, Biernat, Dovidio 2003).

The ultimate impact of above behaviours, attitudes and cognitive constructions towards PLWHA can be translated into three different kinds of reactions: enacted stigma (external), anticipated stigma and perceived or internalized or self-stigma (internal).

Enacted stigma refers to acts of discrimination or prejudice towards PLWHA, whether individually or collectively (Scambler, Hopkins 1986, Scambler 1998, Emlet 2005, Emlet 2006). Anticipated stigma refers to the degree that PLWHA expect they will be treated by others if full disclosure of their HIV serostatus is known (Markowitz 1998). Felt stigma refers to internalization of negatives feelings by PLWHA, resulting in self-stigma constructions.

Self-stigma constructions have been found to be associated with lower QoL (Holzemer et al. 2009), low self-esteem, shame, guilt, blame (Deacon, Stephney & Prosalendis 2005); less likely to disclose own HIV status and poor health self-assessment (Wolitski et al. 2009) and fear of enacted stigma (Scambler, Hopkins 1986, Emlet 2005, Emlet 2006) which interferes with HIV disclosure patterns (Poindexter, Linsk 1999, Steward et al. 2008).

Enacted stigma have been reported to generate psychological distress and lower health well being (Bogart et al. 2008, Root 2010), refusal of health care and physical distancing (Rahmati-Najarkolaei et al. 2010), rejection, stereotyping and violations of confidentiality (Emlet 2006). In this sense, stigma is a major barrier to social integration.

All at all, studies that look at HIV/AIDS related stigma, have shown that stigma have several psychological, societal, interpersonal and intrapersonal upshots. However, most of the psychological and sociological studies still fail to include 50 years old and older PLWHA on their studies or age has not been a statistical variable used to report the findings (Emlet 2006). Therefore, stigma's dimension and its impact on older population are still roughly understood. Nevertheless, some studies have analyzed the HIV/AIDS related stigma among older populations. His study of 25 participants over the age of 50 years living with HIV/AIDS Elmet (2006) found that felt and enacted stigma and discrimination were related to both ageism and HIV issues in the majority of the participants (68 percent). From the analysis of his interviews rejection, stereotyping, fear of contagion, violations to confidentiality and internalized ageism were the found sources of stigma. In his later study on 25 American and African American participants aged 50+ living with HIV/AIDS, Elmet (2007) found that stigma was related with depression among African American. Moreover, disclosure distress and protective silence were positively associated with stigma. This study once more confirmed that minority groups are those who experience and feel more stigma (Karpiak, Shippy & Cantor 2006).

Lee, Kochman and Sikkema (2002) studied internalized stigma in 268 participants living with HIV infection, aged from 21 to 60 years. They found no significant statistical difference in internalized stigma linked to age between those with high and low internalized stigma. Note that, in this study, old people were also included in the analysis. Similarly to Lee, Kochman and Sikkema (2002), neither Emlet (2006a), found any significant statistical difference regarding stigma between old people and their young counterparts living with HIV/AIDS. However, Emlet's (2005) earlier study on young adults reported more discrimination feelings than older people and more internalized stigma expressed by fear of losing their jobs due to their HIV serostatus. Thus, stigma may plays a minor role on age. On the other hand, it might play a role in gender and sexual orientation. Females tend to report higher stigma than males and heterosexuals tend to have higher internalized stigma than homosexuals (Colbert et al. 2010). Others studies have reported that older people have a higher vulnerability to stigma than their younger counterparts living with HIV/AIDS (Emlet 2006a).

Studies on the topic have reported different findings. In this sense, more research is needed for acquiring better knowledge on the issue.

Particular attention should be given to HIV/AIDS in an ageing society. Older PLWHA, in contrast with their younger counterparts, may suffer from double or even triple or more stigmatization. Stigma related to age, sexual orientation (Gorman, Nelson 2003), gender (Tangenberg 2004), race and ethnicity (Emlet 2007), all come together to affect older PLWHA's lives. The ways different stigmas influence older PLWHA, varies across cultures and time. Unfortunately, health care services are not yet ready to address these individuals in a holistic way.

4.4 Social networks and support

"It is not good for the man to be alone. I will make a helper suitable for him." Genesis 2:18 (Bible gateway.com)

Social support is normally defined as *"the existence or availability of people on whom we can rely, people who let us know that they care about, value and love us"* (Sarason et al. 1983, 127). The importance of social networks and the support it provides has been widely reported in the literature. Social network is a complex web of structures and relationships that surround individuals. The relationships between different structures occur at several levels: micro- (individual), meso- (immediate environment), exo- (interrelation between immediate environments) and macrosystems (social context). Changes between different levels or systems are influenced by the chronosystem (time) (Bronfenbrenner 1979). Thus, is from symbiotic relationships between different systems that individuals obtain the needed support to carry on their daily lives. Whenever an imbalance between different levels occurs, psychological distress may be the main outcome (Lawton 1973, cited by Knipscheer et al. 2000, Van der Meer, Fortuijn & Thissen 2008)

Ecological transitions in individual's social positions can occur due to ageing process, disease status, urbanization and globalization. The impact of such ecological transition on older PLWHA results in increased risk of social isolation (Schrimshaw, Siegel 2003, Kroenke et al. 2006, Emlet 2006b), psychological (Heckman et al. 2002 cited by Emlet 2006, Heinrich, Gullone 2006, Sun, Zhang & Fu 2007, Pettigrew, Roberts 2008, Reblin, Uchino 2008) and physiological (Heinrich, Gullone 2006, Tomaka, Thompson & Palacios 2006) disturbances due to deficient networks connections (Peplau, Perlman 1979). Moreover, AIDS related treatment adherence has been found

to be associated with social network support (Singh et al. 1999, Tucker et al. 2004, Battaglioli-DeNero 2007). Contrary, in their cross-sectional descriptive study, Ncama and colleagues (2008) found no relationship between social network support and AIDS medication adherence. Instead, alcohol abuse, lack of resources and food and HIV stigma were the main barriers to medication adherence in the studied population.

Malfunctioning social networks has been seen as one of the features that increase individual vulnerability to increased loneliness affecting individual's psychologically and physiologically (Karpiak, Shippy & Cantor 2006). Consequently depression can be exacerbated by the HIV infection. The distress caused by the infection and its treatment might boost depression in individuals whose social networks are somehow fragmented and difficult to access.

Studies on older people found that older women tend to report more depression than men (Zunzunegui et al. 2007, Seedat et al. 2009). However no significance difference was found regarding gender and depression (Karpiak, Shippy & Cantor 2006) and between age and depression (Heckman, Kochman and Sikkema 2002, cited by Emlet 2006) in studies with older PLWHA. How HIV infection does correlates with depression? Or, do HIV positive older adults have better social networks support compared with non-infected older adults? These questions need more research on the area of older PLWHA to obtain a valid answer.

The findings from studies based on associations between age, depression and loneliness among PLWHA point at different directions. While some studies have shown that older PLWHA are more depressed than their younger counterparts, other studies have reported that older PLWHA present less depression levels than their younger counterparts. Once more these studies imply the complexity of how social networks function. This complexity was explored by Jylhä & Jokela (1990) in their European study regarding loneliness and social networks among older adults. The authors found that besides of having larger social networks, the Southern older people expressed more feelings of loneliness than Northern counterparts. The reason for this finding was discussed in terms of cultural differences and personal expectations and actual support offered among South and North European populations. Thus, social networks are a multifaceted phenomenon varying across cultures, time, circumstances and intensity (Jylhä, Saarenheimo 2010).

The process of ageing involves undoubtedly changes in people's social networks. Retirement, loss of one's spouse and friends and co-morbidities ageing associated (Shippy, Karpiak 2005) all strain

the size of social networks. Moreover, the decreased social interactions can be jeopardized by the HIV/AIDS infection. Gerontological literature has shown that in old age it is not the quantity but rather the quality of social interactions that accounts for people's well-being (Askam, Ferring & Lamura 2007). Old people tend to keep those relations that are emotionally most rewarding for them. One study on HIV/AIDS infection among younger and older adults showed that older adults despite living with more co-morbidities felt less depressed compared with their younger counterparts (Mavandadi et al. 2009). The reason behind this difference was that older people reported higher subjective support than younger people, which was mediated by the quality of their close relationships.

Chesney and colleagues (2003) found that increased social support was associated with decreased distress in older men compared with younger adults. Additionally, Emlet (2006b) found that age and race had an impact on social isolation. In his study, 38 percent of older white adults and 54 percent of older colored adults were in risk of suffering social isolation. For younger adults the risk was smaller (25 percent), mainly because younger people were less likely to live alone. In both age groups, family was the main source of social support.

Gender has also been found to have repercussion in social networks composition. Older men living with HIV infection have less social support than women and younger adults with HIV infection (Chesney et al. 2003, Edwards 2006). As a result, older men with HIV are more likely to suffer from social isolation and psychological distress. In his study on younger and older women living with HIV infection, Peterson (2010) found that the main barriers to get support were related to stigma and lack of resources. Women considered social support as an important feature to cope with HIV infection, but such support was difficult to find.

Regardless of impact of gender or race Karpiak, Shippy & Cantor (2006) reported in their study that more than 40 percent of older PLWHA identified their social support network as insufficient to their needs. In an earlier study, Shippy & Karpiak (2005) had found that instrumental (79 percent) and emotional support (57 percent) were amongst the unmet social support due to non-disclosure. Similarly Schrimshaw & Siegel (2003) found unmet emotional (42 percent) and instrumental support (27 percent) among their study population of older PLWHA. Lack of family support and death of friends were the main barriers found to unmet support. Moreover, others studies have reported that older PLWHA are more isolated from other groups (Schrimshaw, Siegel 2003) due to ageism and HIV-related stigma issues (Shippy, Karpiak 2005, Emlet 2006).

4.5 Concealment and disclosure

Facing the fact of living with a chronic disease, PLWHA must deal with the question of disclosing their serostatus to others. The question of disclosure is one of the central scenarios in the HIV/AIDS epidemic. When and to whom to disclose and the consequences of such act, are the questions that puzzle PLWHA's life. As a consequence, PLWHA must balance the risks and the benefits before sharing such personal information. Some choose not to disclose. This "protective silence" (Emlet 2008) enables the individual to manage and control information avoiding therefore potential negative reactions from others. The fear of stigma, discrimination and breakdown of social networks are the main barriers to disclosure. On the other hand, disclosure may result in more social support, HIV/AIDS related stigma reduction, improved medical treatment access and sexual behaviour changes. (Parsons et al. 2004, Ko et al. 2007, Ssali et al. 2010).

The act of disclosing HIV infection to others might uncover hidden secrets such as infidelity, sexual orientation or sexual practices. Thus, disclosure embraces high levels of vulnerability and risks towards one's identity, involving therefore carefully rational thinking.

In their study on patterns to disclose or not among 5 adult women living with HIV infection Kimberly, Serovich & Greene (1995) found six dimensions: 1) adjustment to the diagnosis, 2) evaluating personal disclosure skills, 3) taking inventory, 4) evaluating the circumstances of the recipient, 5) anticipating reactions of the recipient and 6) motivation for disclosure. Similarly on their literature review from 1999–2009 on the concept of HIV disclosure, Eustace and Ilagan (2010) found similar dimensions. In this review, six themes emerge: 1) experiencing and event, 2) communicating something, 3) timing and contextual environment, 4) protecting someone, 5) relationship status, and 6) improving something or being therapeutic. However, due to the multidimensional aspect of HIV/AIDS and its inherent contextual and cultural meanings, these dimensions should be viewed as guidelines for researchers and health professionals to understand the pathways of HIV infection disclosure among their communities and to alleviate and support PLWHA in all the disclosure process. One of the major obstacles to understand pathways of disclosure amongst older PLWHA revolves around the lack of research on the topic (Emlet 2006a).

Emlet (2006a) studied stigma and disclosure issues among 44 individuals aged 20–39 and 50 years and older living with HIV/AIDS in USA. He found that old adults were less likely to disclose their serostatus to relatives, partners, health professionals, neighbours, HIV negative friends and church

members, than their younger counterparts. However, they disclosed it more frequently to their children than did younger adults. Nokes and colleagues (2000) found in their study that older participants disclosed their HIV diagnosis to a fewer people than younger participants.

The three main conclusions, regarding disclose patterns drawn from these two studies are: firstly, in gerontological literature it is often mentioned that older individuals' social network size tends to decrease due to a series of losses (retirement, death of friends and spouse). Thus, compared with their younger counterparts, older people might have fewer people to whom to disclose. Secondly, older people are more likely to have adult children than younger counterparts. Studies have shown that HIV-infected parents avoid discussing their HIV-infection with young children, because they fear that their children unconsciously disclose their parent's serostatus to others (Greene et al. 2003a). Thirdly, since older people have less people in their social network, they may opt for concealment of their health status in order to avoid stigma, discrimination and further social network breakdown.

Emlet (2008) described the patterns of HIV disclosure and non-disclosure among of 25 older adults with HIV infection. On one hand, sources of concealment were related with protective silence and anticipatory disclosure, which reflected the fear felt by the individuals regarding stigma and discrimination. On the other hand, disclosure was mediated by self-disclosure to others and unintentional disclosure by others. Some participants mentioned intentional disclosure to others as to be interrelated with processes of selectivity and protective disclosure; others used open intentional disclosure for educational proposes. Therefore, the dilemma behind disclosure reflects a continuous process of risk and benefits analysis. Loss of control over private information is one of the greatest concerns on PLWHA lives (Greene et al. 2003b).

A recent study in United Kingdom revealed high levels of disclosure among the study participants living with HIV/AIDS aged 50 years and older. Moreover, the qualitative analysis of interviews revealed that the majority of participants described the outcomes of disclosure as neutral or positive (Power, Bell & Freemantle 2010). On the contrary, Karpiak, Skippy & Cantor (2006) found in their study of 914 older PLWHA in USA that disclosing to others was often accompanied with negative reactions. Once again studies on the issue point at different directions in different cultural settings.

5. AIMS OF THE STUDY

5.1 Justification

Due to HAART treatments people with HIV live longer and the infection has turned to be a manageable chronic disease. People aged over 50 years maintain their sexual activity exposing themselves to be at risk of contracting HIV virus. As discussed before, the number of people living with HIV/AIDS aged over 50 years has been increasing in the past few decades.

At the present, little is known about older PWLHA's life dynamics and experiences. Most of the studies have been carried out in North America and recently only one in UK. Until now, there is no research in Finland on stigma, disclosure patterns and social networks among people aged over 50 years living with HIV/AIDS. This descriptive exploratory qualitative study provides an insight to this overlooked infected population. Moreover, there are no studies which have researched Finnish older PLWHA life assessment, one aspect that this study intent to assess.

5.2 Research questions

The overall objective of the study is to describe how 50 years old and older people living with HIV/AIDS experience their lives.

The specific objectives are:

- 1- How do people aged over 50 years living with HIV/AIDS assess their life at the moment.
- 2- How do people aged over 50 years living with HIV/AIDS describe stigma.
- 3- How do people aged over 50 years living with HIV/AIDS talk about the issues of concealment and disclosure.
- 4- How do people aged over 50 years living with HIV/AIDS describe their social networks and social support.

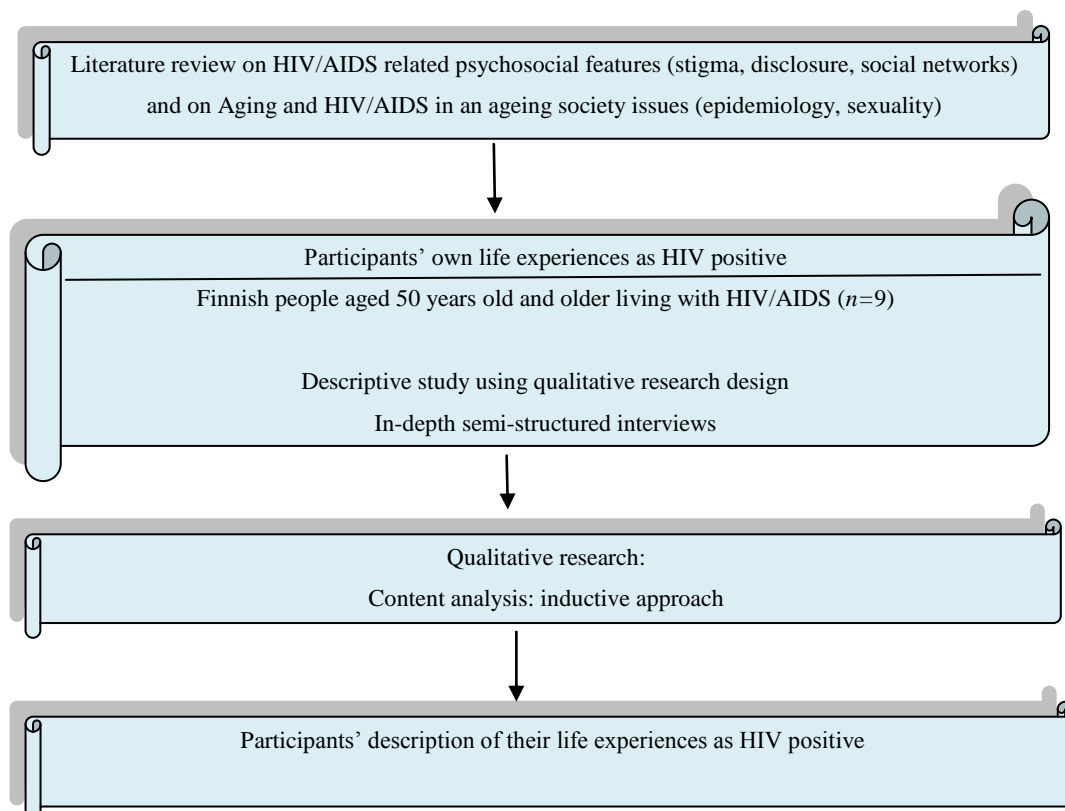
6. DATA AND METHODS

6.1 Approach

Research methods used in health sciences are diverse. The selection of the right method depends on the research question(s), the nature of the data and intention of the study. This study is based on qualitative approach. Phenomenological inquiry seeks to develop an understanding on human behaviour, experiences and attitudes (Bowling 2002), in naturalistic circumstances (Kylmä et al. 2007). This method enables people to express themselves through their own words, providing a rich insight in how people experience certain phenomenon (Kylmä et al. 2008). In present study phenomenological inquiry was used to understand and interpret the life dynamics and experiences of people living with HIV/AIDS aged over 50. The data was collected by in-depth semi-structured interviews. The interviewees were encouraged to talk freely about their life events.

Life dynamics and experiences of aged people living with HIV /AIDS in different life situations is a very sensitive and private topic which has not been earlier studied in Finland. Therefore, the use of inductive content analysis as a method for analyzing the interviews was considered an appropriated one (Elo, Kyngäs 2008) . With this method it is possible both to figure out commonalities and to extract and understand particularities communicated by the participants.

Figure 5: Study design





HIV/AIDS related psychosocial aspects of people aged 50 years and older living with HIV/AIDS in Finland

The data of the study was collected in the capital area of Finland. Finland is one of the European countries with the lowest reported cases of HIV/AIDS. By the end of 2009 Finland counted with a total of 2590 reported cases (THL 2010). About every fifth of the cases were observed among people aged over 50 years (excluding individuals who were not born in Finland).

6.2 Study subjects

The participants of the study were recruited by the Positiiviset association.

Seven participants agreed to participate by phone call and two were obtained by snow-ball technique. The only inclusion criteria used was being HIV positive and aged over 50 years.

Seven participants were interviewed on the Positiiviset facilities, one at library and one at the researcher's home. No monetary compensations and whatsoever were given to the participants.

The registered association named Positiiviset was founded in 1989 for offering social support for people with HIV/AIDS and their families in Finland. The association has international and national co-operations with other organizations. Its funding comes mainly from the Finnish slot machine association and from the Ministry of Social and Health Affairs.

6.3 Data collection

The data was collected by means of open-ended interviews. Before each interview, background information regarding education, year of diagnosis, HIV serostatus, mode of transmission, gender, age and relationship status, was collected.

The interviewees were asked to respond freely to four open-ended questions. The first question was: "Could you describe your life experience since you have been diagnosed HIV-positive until today?". The second question was: "Could you tell me about HIV related stigma in your life and possible factors related to it?". The third question was: "Could you tell me about concealment or

disclosure of your HIV status and possible factors related to it?”. The fourth question was: “Could you tell me about your social networks and possible social support you have got until now (possible factors related to it?)”. Additional questions were made to respondents depending upon the course and the content of each the interview.

All the interviews occurred between June 2010 and July 2010. The duration of interviews ranged from thirty minutes to one and half hours.

6.4 Data analysis

Each interview was *verbatim* transcribed into Finnish language. The written transcripts were reviewed by the researcher and the research assistant by replaying the recorded interviews at the same time as reading the written documents, in order to correct possible inaccuracies. This procedure revealed to be necessary because all the interviews were conducted in Finnish, which is not the interviewer’s mother language.

The interviews were analysed in Finnish language and only the extracts referred in the study, were translated into English. Once more the translation of such sections was made by the researcher and the research assistant for accuracy and consistence. At this point it is important to mention that the research assistant was unaware at all times of the participants’ identities. Therefore anonymity remains a constant during the entire of the study.

The interview transcripts were analysed qualitatively, by using inductive content analysis method. Initially, the transcripts were read and reread and replayed in order to familiarize with the interviews’ contents. After the first stage, a detailed analysis of the interviews’ content was performed. This detailed analysis included data reduction (coding), grouping (categorization) and finally abstraction of ideas and concepts raised from the data (Kylmä et al. 2008). During a carefully reading of the transcripts all the statements (words, sentences) that were related to each other were marked with different colours. Some side comments were written. Reduced expressions were derived from the original statements, which in turn were grouped as different sub-categories. Subsequently, sub-categories were organized in broader categories under the following themes: experiences in living with HIV infection, HIV/AIDS related stigma, disclosure issues and human relationships social networks. The outcomes of this inductive content analysis are presented in the results section and discussed later on with findings of previous studies.

An example of how the original data was converted to an analyzable form is shown on appendix 3.

7. RESULTS

7.1 Profile of the participants

The study participants consisted of nine individuals aged over 50 years living with HIV/AIDS. The data comprised two women and seven men. Table 2 provides a description of the participants' demographic characteristics.

Table 2- Demographic characteristics of the study participants

Background information	<i>n</i>
Gender	
Male	7
Female	2
Age	
50-55	1
55-60	5
60-65	1
65-70	0
70-75	2
Marital status	
Married	0
Divorced	5
Single	2
Widow(er)	2
Education	
Elementary school	2
Middle school	1
Higher school examination/ degree	2
College degree	2
Polytechnic or university degree	2
Mode of transmission	
Homosexual	5
Heterosexual	4

The interviewees' age ranged from 51 to 73 years with mean age of 60.6 years. Three participants were infected with HIV virus after completed 50 years. The number of years living with HIV/AIDS ranged from 4 to 24 years, with mean years of 11.1. Eight participants were in the asymptomatic HIV phase and one in AIDS phase. Most of the participants had an educational background equivalent or higher to higher school degree. In this small sample, homosexual contact was the major mode of infection transmission ($n = 5$). Most of the participants were divorced ($n = 5$), for all of them the divorce had occurred due to other personal reasons than HIV infection.

7.2 Experiences of living with HIV/AIDS

7.2.1 Individual reactions to HIV diagnosis

Receiving a HIV positive diagnosis had triggered several emotional reactions. Shock was the most often mentioned reaction felt by the participants. Thoughts about death, fear of HIV's visibility, use of alcohol and no shock, were other reactions shared by the participants.

Reactions to HIV positive diagnosis	Shock
	Thoughts about death
	Fear of HIV's visibility by others
	Use of alcohol
	No shock

Shock. Receiving a HIV positive diagnosis was for the majority of the participants a source of shock. Shock was described and felt differently. One got physical symptoms; others simply reported shock essentially as an emotional reaction.

"... then I got to know that I was HIV positive I went into shock...In the beginning it was horrible, I was in the hospital for one week, I was in a deep shock, I got fever up to 40 degrees". (W 2)

"...in the beginning a huge shock, crisis which I needed to deal with...." (M 2)

"...was a quite high level shock..." (M 4)

Yet, regardless the type of experienced shock reaction, the participants needed some time to deal with the shocking news. The length of such state ranged few from weeks to years. The length of shock and mental adjustment to one's new health status were positively correlated. Moreover, having someone with whom to talk with and getting support played an important role on the shock length as well as disclosing one's status to others. One participant described this as follows:

"...in the beginning it was such a shock, a kind of shock phase...however it went pretty quickly over...Well of course, it's the first shock, such a shock that put me to think about life and it felt that, all came in a huge single dose and I needed to release the stress over me...as soon I got to know about the results [HIV diagnosis] I told to a close friend. He was my huge spiritual support in the begging. I think if I won't have anybody to rely on, the shock phase would be longer". (M 7)

“... I had a bit over a year a kind of shock...” (M 6)

“... It didn't last for long time [shock], I don't think so. Well I think it lasted about half a year, not longer for sure.” (M 5)

Thoughts about death. Three participants expressed thoughts about death. Death thoughts were related with lack of information regarding HIV/AIDS disease and media propaganda by means of pictures of infected African individuals in early years of the disease. Moreover, the participants who expressed such thoughts were infected in the early and mid 90's, when there was huge social misinformation about disease progression and transmission and lack of good medications.

“... in the beginning information was rather fragmented in a way, and and it was pretty, pretty like, well I thought that I will die straight away...” (M 6)

“...at the beginning it was a shock, a shock that I will die rapidly...I saw when Rock Hudson kissed Linda in Dynasty series and then I saw pictures of him when he got thinner just like a skeleton and moved to Paris and died there. Then I saw those pictures of African men like skeletons...that's all I knew, I didn't know more [information]” (M 2)

However, emotional and informational support played an important role in overcoming some stigmas associated with the disease shrinking the length of shock:

“...and then when I came to the hospital, they told me that with these medicines I can live up to 25 years. The before death thoughts that I had, vanished away with this information. It was a kind of a new shock when I realised that life is not getting shorter, I organised my life again” (M 4)

Fear of HIV's visibility by others. Closely connected with thoughts of death comes fear of HIV's visibility. As described above, some participants' thoughts of death were associated with media propaganda linked pictures of with physical deterioration of patients with advanced AIDS, mostly on face and upper-body fat distribution, also known as lipodystrophy. In this context, two participants manifested worries about disease's visibility to others. These mental constructions affected negatively their daily lives in terms of fear. This fear influenced social contact with others. Participants avoided public settings where close contact with others could trigger some self-uncomfortable feelings. Public transportation and restaurants were the public places that participants were most afraid of.

“...in the beginning it felt that I couldn't even seat near another person in a bus, for sure as soon I seat it can be seen that I'm an HIV positive....like crazy thoughts came up to mo my mind...so absolutely I...I couldn't go to restaurants, even though when I tried it was really horrible and

difficult, I had always the feeling that I can't be here. However over the years this situation has normalised, I don't have those feelings anymore" (W 2)

"...in a way it was in the beginning, I thought in a way that it could be seen on me somehow...in the beginning it was such a horrible feeling, it felt that somehow people could see it, however I get over it." (M 6)

Use of alcohol. Emotional reactions may trigger some behavioural reactions. Increased use of alcohol was associated with the unknown future as HIV positive and its inherent initial shock in the narration of two male interviewees:

"...well, my shock it lasts for more than one year during that time I drunk a lot, but now is somehow normalised, it's much more normal now..." (M 6)

The other interviewee interpreted his increased drinking as a coping mechanism overcoming some negative events in general:

"...at the moment I can say that alcohol has been a problem to me, I admitted it. I can say you that I drink everyday and it starts to have an impact on my memory, I forget things...well I started to drink after my good friend's death; it was a bad moment in my life...Honestly I must say that my drinking increased after I was infected...At the moment I'm drinking much again because I'm quite worried about my brother-in-law's health...He needs daily support and I'm the one who takes care of him..." (M 5)

No shock. Getting an HIV positive diagnosis had had no impact on three participants. One participant was having a cancer treatment, therefore we was more worried about this issue than his HIV infection:

"...then it came this HIV, I thought that is one more [disease], however is this cancer that will solve what will happen in my life. In my mind, I really thought about these things, I thought that I won't survive to this hard treatment [cancer], because I had several metastases, including liver metastases and I knew that was pretty bad." (M 1)

Past life experiences influenced the way one participant reacted to her HIV diagnosis. Factors such as being natural sciences teacher, having worked in Africa with HIV infected people and her parents' medical background, were the main reasons for her having no shock reaction.

“...I’m a biologist, diseases were a well know principle, accepting death as one part of life is as normal and natural process as birth. Moreover, I grew up in a hospital environment, my parents worked in a tuberculosis hospital, and so long-term diseases were familiar to me. ...therefore I adapted well to this picture [HIV diagnosis], I didn’t get any kind of shock. I lived in Africa, Zimbabwe, for some years. I went there for teaching duties...I saw many people dying every day. It was familiar thing to me. I saw there [HIV] before I got infected therefore it was really familiar situation to me. A couple of friends got infected there also. I didn’t make [HIV] a complex thing. It [HIV] didn’t affect my life in any way.” (W 1)

The fact of neither feeling sick nor having any kind of HIV/AIDS related symptoms or belonging to a risk group was expressed as others factors for no shock.

“...it didn’t affect me at all back then, not at all, mainly because I didn’t feel that I’m a sick person.” (M 4)

“...well it was not nice but I was prepared for it...I went without any referral to take a test [HIV test] because I heard about the disease and it was clear that I belonged to a risk group...” (M 3)

7.2.2 Impact of HIV/AIDS in daily life

The findings on talk of daily life were grouped into two main categories: personal meaning of HIV/AIDS and individual life changes after HIV diagnosis.

a) Personal meaning of HIV/AIDS

Personal meaning of HIV/AIDS is composed of four sub-categories: HIV is not the main purpose in life; HIV is not guilty of anything; blaming HIV for felt loneliness and HIV as a normal chronic disease. The category of individual life changes after HIV diagnosis is divided into six sub-categories: braver, life enrichment, sexual behaviours readjustments, getting religious, retirement and not big changes.

Impact of HIV/AIDS in daily life	Personal meaning of HIV/AIDS	HIV is not the main purpose in life
		HIV is not guilty of anything
		Blaming HIV for felt loneliness
		HIV as a normal chronic disease
	Individual life changes after HIV diagnosis	Braver
		Life enrichment
		Sexual behaviour readjustment
		Getting religious
		Retirement
		No big changes

HIV is not the main purpose in life. Being HIV positive does not mean that one's life should move around the disease. After the time of shock, individuals develop a sense purpose and meaning of living. This was described by participants as follows:

"...I don't live in a way that, like that that HIV should be the main purpose in life" (W 2)

"...HIV is not all me, it is only a small part of me. Inside of me there is much more than HIV" (M 2)

"...regarding my future, well, I take into account ageing issues rather than HIV issues" (M 6)

HIV is not guilty of anything. Those interviewees, who had mentioned not having any kind of shock reaction to their HIV positive diagnosis, saw HIV infection as not guilty of anything. This was described as follows:

"...I don't have any reason to blame [HIV]...the world is full of all kind of diseases..." (W 1)

Instead of seeing HIV infection as responsible for his situation, another participant who was infected in the 80's, faced it as a matter of faith.

"...well how I could say it. HIV is not guilty of anything. It's a faith, illness is a faith...is faith against it one can't do nothing about it...is a faith...it didn't fall from the heaven, I have acquired it. Of course before it was not enough knowledge [about HIV] so I can't even say that it was stupidity from me...before being infected I didn't have any source of knowledge about the disease's existence." (M 3)

Blaming HIV for felt loneliness. Loneliness as one of the potential social "side effects" felt by infected individuals. Loneliness may be self-induced or socially inflicted. Blaming others or situations, such as HIV, seems to be easier to be accepted by the individuals. One participant associated the felt loneliness with HIV disease as a main cause:

"...loneliness [blaming HIV], of course I would feel much better..." (M 2)

Following the above cited interviewee's argumentation further suggests the conclusion that, in this case that the felt loneliness has its roots on the self rather than on the HIV infection. HIV infection may yet be a source of low self-esteem that leads the person into his own world:

"...I don't dare to create close bonds with others...[what limits the social interactions] myself, laziness, undesired need, of course a certain anxiety about my disease [HIV]. Then we arrive at the ageing issues. When a person live long time alone and is over 50 years old, certain selfishness comes along..." (M 2)

HIV as a normal chronic disease. Being infected with HIV virus is nowadays quite different than being infected a few decades ago. Due to medical advantages and new therapies (HAART), HIV infection has assumed a manageable chronic disease character. This aspect of HIV disease was described by the participants as follows:

"...it is one among others diseases..." (W 1)

"... it is a treatable disease, same as others diseases... does it really matter if you have diabetes or HIV... it is the same, do I have HIV or other disease, I had cancer before the same way I face HIV..." (M 3)

b) Individual life changes after HIV diagnosis

Braver. After experiencing all kind of downwards in life after being diagnosed with HIV, one participant viewed her past as a positive self-grown experience:

"...I'm braver than before, I always have been brave but I feel now even braver than before..."
(W 2)

Life enrichment. Besides of all pitfalls associated with HIV, some participants perceived HIV infection as something that had enriched their life in many different ways:

"...it is a funny thing, it has been a very positive thing for me. People should believe on it, it has given many positive things..." (W 1)

"... it feels that it has enriched my life..." (M 4)

"... after being infected I had to change my working patterns...I ended the company...If I hadn't got HIV for sure I would die from a heart attack, I had a company and it was very stressful, I would drive my life into an end..." (M 3)

Sexual behaviour readjustments. For some interviewees sexual activity did not reach an end by being HIV positive. However, most of the participants told that since the time of learning of the diagnosis there has been a decline in their sexual activity. Decline in sexual activity was seen to be due to the fear of approaching others sexually and fear of getting other STDs which led to more careful and selective sexual encounters.

“...of course it [HIV] has changed my way to address others sexually. Nowadays I’m very careful, selective and reserved, above all I take into account others but at the same time myself also, those those crossed infections are not good. I must be extremely careful...” (M 7)

“...I always have been wanted by women... whenever I went to dance I needed to get away from the dancing floor if I wanted to rest. I had a kind of sexual way to approach and dance...lately I haven’t been dancing...About women...I haven’t really approach...” (M 4)

“...with this age sexual desire is in some way downwarding, and then this this HIV infection is in certain way a barrier that stops me from swinging around...” (M 6)

For satisfying one’s sexual needs, masturbation is a safety usually used. This was described by one participant as follows:

“...there is a certain border in any sexual encounter. For example I won’t come inside of anybody, even though knowing that my virus counting is very low...At the same time I fear crossed infections. Well nowadays it is more just like self masturbation.” (M 2)

Getting religious. Having faith in God, regardless of type of religion practiced, is a source of hope for some people. When facing hard times people tend to turn to God in search for spiritual guidance. Reading religious books, being in contact with religious groups and speaking with one’s God was described as a source of dealing with HIV infection as follows:

“... God? Yes I’ve [getting religious]...I prayed all the time to God and in certain way, searched, wanted to know or confront myself, I wanted to be with my own God face to face, this is based in Ghandi’s book...” (M 4)

Retirement. In the early and mid 90’s, becoming infected with HIV was a reason for possible early retirement. HIV positive individuals were guided to decide whether to go on with their working life or not. Two participants described their situation in the following ways:

“...then when I got sick [HIV] I stayed on sick leaf, at the same time my work was stopped...” (M1)

“...I have done my own resolutions, among other things I wanted to stop working, to stay away...”
(M 2)

For one interviewee earlier retirement was faced as something beneficial, in terms of having more time for himself and family:

“...I decided to end with my working life...I’m retired now...I have lived 10-12 years with HIV infection a very good life, I have time for myself and for my family...” (M 2)

No big changes. Being diagnosed with HIV does not necessary have big impact on life. One participant said that:

“...I didn’t let HIV to have impact my daily life...I have had my own hobbies for a long time and I still have them...no friendship has been broken down neither any kind of friendship has been formed due to HIV...the circle of friends that I have at the moment it has been before HIV...” (M 7)

7.2.3 Good balanced life as a 50+ HIV positive

Most of the participants perceived their life at the present moment as a good balanced life. The ways how life was described reflected hope and good relation with themselves and also with their HIV infection. Five interlinked aspects of the talk about participants’ current lives were extracted from the data:

Good balanced life as 50+ HIV positive	Good normal life
	Optimistic regarding future
	Advantages of being HIV positive in later adulthood
	Mentor
	Good relationship with HIV infection

Good normal life. All participants said that they enjoy(ed) of good normal life. They described their life as normal as it used to be before getting infected with HIV virus:

“...quite normal. As normal as before.” (W 1)

“...very good life at the moment.” (M 3)

“I live quite good balanced life” (M 2)

Optimistic regarding future. Looking forward for the future optimistically revealed an orientation based on hope towards life. Finding a new partner and searching for new working challenges were described as follows:

“Well I face the future with hope, I really want...studying is perhaps at the moment the most important thing, but if I could get work in some kind of organization that would be great. Regarding love matters, I hope one day to find a man; it doesn't matter if he is positive or negative.” (W 2)

Advantages of being HIV positive in later adulthood. Being HIV positive in later adulthood was regarded to be a positive thing then getting infected at younger age. Most of the participants said that they had time to enjoy their life before being infected with HIV virus. An additional positive aspect of being infected in later adulthood was the capacity to deal with the life change situation with maturity:

“I was over forty when I got to know that was HIV positive...somehow I had time to mature as a person in that time...it was somehow easier to deal with the information...However I think it could be difficult to deal with [HIV] if I was infected in my twenties or thirties...I had experienced almost everything, travelling a lot, well everything...” (W 2)

“... let's say if I was twenty years old and still living in country side perhaps... for sure...I would have hanged myself...” (M 5)

Being retired was also a positive aspect of the current situation. There was no more the need to inform working mates or bosses of one's health status:

“...it was a big relief that I wasn't anymore working. Thanks God I was retired and thanks God I have seen the world...I wasn't afraid of anything, especially in the way how I should live. Back then I thought lucky me for been twenty years old when I got to know.” (M 5)

Mentor. Caring about and feeling responsible for others were expressed by the participants by speech of acting as an instructor or as a support person to others:

“...I teach biology...HIV has influenced me in a way that every Fall I reserve two hours of my teaching schedule to HIV, because HIV belongs to human biology...” (W 1)

“...I have been asked to give conferences on HIV as an infected individual and as a person who has passed from different phases of disease...I really like it, it is very rewarding act, giving others information about prevention and care...in my audiences are also health professional students, I think it is important to show them what HIV is about...I'm also a support person...” (M 3)

“...I’m a support person, a kind of coordinator for heterosexuals; people can call me 24/7 I have also a web-site.” (M 4)

Good relationship with HIV/AIDS infection. Throughout years participants had had the opportunity to adapt themselves to and develop good healthy bonds with their HIV infection. Most of the participants described their relationship as good for example by comparing the daily HIV medication to taking vitamins pills.

“...why should I make HIV as a special problem, I have lived 13 years with it and so far I haven’t had problems with it, why should I start now, no point on it... I have a good theoretical relationship with my HIV positivity. More theoretical than practical, in practice I don’t have nothing else than HIV medication. Is not even a big thing, I take those [medicines] as multi-vitamin tablets.” (W 1)

“...it is a good thing that I have three pills. In the morning I take them as they were vitamin pills.” (M 5)

7.3 HIV/AIDS related stigma

The participants described HIV related stigma as something negative in their lives. The way stigma was experienced influenced not only the participants’ self-esteem but also their disclosure patterns. Creation of self protective measures was adopted by some participants as a way to avoid being stigmatized by others. The findings linked to stigma were organised into four main categories: fear of contagion, negative HIV related self-stigma reactions, free from self-stigma and self-protective behaviours against stigma. These categories were in turn divided into sub-categories, represented bellow.

HIV/AIDS related stigma	Others’ fear of contagion	
	Negative HIV related self-image	Dirty
		Self-blame
		A risk to others
		Self-constructed stigma
	Free from self stigma	No self-stigma
	Self-protective behaviours against stigma	Protective walls
		No disclosure

7.3.1 Others' fear of contagion

The talk of HIV related stigma is most often the talk of fear and discrimination actions towards those who are HIV positive (see chapter 2.3.2 above). Four participants had experienced discrimination acts and fear of contagion after disclosing their HIV status to friends and medical staff. Others' reactions expressed as fear of contagion, had led to deprivation of friendship "*the other [friend]...was so hysterically afraid that I infect her child...they left me...*" (W 2) and different nursing treatment "*I went for a flu shot with my boyfriend [HIV negative]...the nurse put gloves while giving me the shot...my boyfriend said she didn't use any gloves...*" (M 2).

7.3.2 Negative HIV related self-image

People with HIV are not only stigmatised by others, also they themselves. Self-stigma reactions are created by social images about the disease. Four participants mentioned different kind of self-stigma reactions or behaviours that had guided or influenced their social interactions with others and consequently had impacted their daily lives. Changes in one's identity as dirty and as a risk person, are some examples of self-constructed stigma given by the participants.

Dirty. Feeling somehow dirty was expressed by one female participant after learning of her seropositivity:

"...I had a sort of feeling....that I was somehow dirty..." (W 2)

Self-blame. One participant self-blamed herself for the infection. In her case, unprotected sex was the transmission route:

"...it was self-blaming and everything like that...well crazy thoughts..." (W 2)

A risk to others. Two participants had restricted their sexual contacts with others because they saw themselves as a potential risk person to others:

"...I'm sure that he doesn't want go further with the relation or doesn't want to be in a relationship where he would be constantly thinking how big risk I'm for him..." (M 2)

"...I left it to her...don't approach me because I have this disease [HIV]..." (M 4)

Self-constructed stigma. One participant referred to self-stigma as something that he had constructed by himself, based on fear that others will not accepted him as HIV positive:

“...for me self-stigma is something endogenous, I stigmatise myself...I would like to believe that somebody would care about me, that will make me feel necessary, accepted, that I’m important for somebody....but sometimes comes out the fear that nobody wants me or that nobody really dares to be with me...” (M 2)

7.3.3 Free from self-stigma

The category free from self stigma has two dimensions: those participants who never had any kind of self-stigma and those who over years had overcome the issue. These two dimensions were fused into a subcategory named no self-stigma.

No self-stigma. Those who never experienced self-stigma are those who did not had any kind of emotional reactions after receiving a HIV diagnosis. This was expressed as follows:

“...no, for God sake. The world is full of diseases...I don’t have any reason to blame myself...”
(W 1)

“...I never felt any kind of shame...” (M 5)

“...not at all. I never thought about it...the feeling of shame or feeling inferior to others due to my disease, I never had...I don’t even approve that kind of things, it doesn’t make part of my world...”
(M 4)

One participant said that she had stigmatised herself but at the present moment she is free from self-stigma reflecting the role played by time and self-reflection on living with HIV infection:

“...yes, yes it is completely out from me.” (W 2)

7.3.4 Self-protective behaviours against stigma

Individuals are prone to develop certain protective behaviours to avoid experiencing unpleasant stigmatising assessments from others. These behaviours were used by the participants as a protective shield against possible exterior harassments. Protective walls and non-disclosure were two common behaviours expressed in the interviews.

Protective walls. Two participants used symbolic expressions of protective walls and jail to describe how they protect themselves from potential stigma harms:

“...I think it is a kind of protective wall...I have consciously built a protective wall, I don't tell them [relatives] because I don't want their behaviour to change. It belongs to HIV this kind of strong wall. I really don't know to what extent is the issue of age that have made me to build this protective wall, when one wants to protect him/herself from potential HIV comments...” (M 1)

“...I have built my own jail and thrown the keys away...I have quite much built this jail by myself, I have closed the windows and doors and thrown the keys away...” (M 2)

Non-disclosure. By concealing their disease from others some participants were playing secure for avoiding any kind of stigma reactions. Non-disclosure was considered above as a means of stigma avoidance. Yet, it can be viewed also as selective disclosure, which will be discussed further on.

“...so far I haven't experienced any kind of stigma, not at all, in my life so far mainly because only a few know it [HIV infection]... however I don't have any doubts that it could happen if I were open [disclose]...” (M 7)

7.4 Disclosure issues

All of the participants had disclosed their HIV diagnosis to their significant others and found it to be a deed accompanied by both risks and benefits, therefore for most the decision to disclose was a source of stress. To whom to disclose, when and how to regulate private information and how others may react to the information disclosed, were aspects discussed by the participants. Three participants had disclosed to their friends and family, five only to friends and one only to family members. From the interviewee's speech it was possible to create five categories and respective sub-categories shown below.

Disclosure issues	Motivations to disclose HIV diagnosis to others	Trustful good relationship with others
		Difficult to handle alone
		Difficult to keep a secret
		Positive anticipated self-perceived others' reactions
	Reasons for concealing HIV diagnosis from others	Negative past experiences
		Sparing others from suffering
		Intimate concern
		Negative self-perceived others' reactions
	Regulating personal information	Disclosure since the time of diagnosis
		Getting to know others first
		Selective disclosure
	Others' reactions to disclosure of HIV diagnosis	Positive reactions after disclosure
		Rejection
	Unintended disclosure	Information welled-up
HIV medications inadvertent exposure to others		

7.4.1 Motivations to disclose HIV diagnosis to others

Participants described their reasons for disclosing HIV diagnosis to others as trustful good relationship with others, difficult to handle one's problems alone, difficult to keep a secret and with positive anticipated self-perceived others' reactions as a source of getting support.

Trustful good relationship with others. The pillars of good relationship with others are based on trust and mutual sharing of information. Most of participants told that good relationships with their friends led them to disclose their HIV diagnosis:

"...if it is a good relationship and a good friend, I don't want to hide from him/her anything...I want them to know me as a whole..." (W 2)

"...it would be horrible to meet friends and hide this information from them..." (W 1)

Maintaining good relation bonds with family members were driven forces for some participants for disclosing. Two of them described the issue by saying *"...my siblings are so dear to me"* (M 5) and *"...to my daughter I have told, I have three cousins, I have really a close relation with them, and to them I also told..."* (M 2)

By sharing private information with their good friends, participants trusted that they will not spread the information to outsiders:

“...I have a couple of good friends and I know that they won't tell to others...” (M 6)

Difficult to handle alone. For some participants HIV diagnosis was a too hard burden to carry alone *“...is so difficult to carry alone...for this reason I told”* (W 2). Disclosing one's diagnosis to significant others was seen as a source of getting support and acquiring a sense of emotional release:

“...the initial shock [getting an HIV diagnosis] made me to wonder: and what about now, everything came so quickly and I needed to ease myself...” (M 7)

Difficult to keep a secret. Closely linked with trustful relationships, participants found it difficult to keep a secret because they did not like to lie *“...I'm very bad liar, I don't like to lie...”* (M 2) or because it represented a big burden for them *“...keeping a secret...it's a burdensome...”* (W 2)

Positive anticipated self-perceived others' reactions. One additional reason for disclosing one's HIV diagnosis to others was based on anticipated self-perceived others' reactions. This self-perceived intuition was articulated as a signal of belonging to a group of well educated people *“...I know my friends very well...rational well educated people, and yes they can understand it [HIV]...”* (W 1) and as a test of tight family bonds *“...if they [relatives] can't handle that I have it [HIV] I'm very disappointed, and it went just like I thought... [Acceptance by his relatives]”* (M 5)

7.4.2 Reasons for concealing HIV diagnosis from others

Even though all participants had disclosed their HIV diagnosis to their significant others, most of them mentioned reasons for concealing it from other people. Negative past experiences, sparing others from suffering, intimate concern and negative self-perceived others' behaviours were the reasons behind concealing.

Negative past experiences. Past experiences are a guide for individual conduct. Two participants mentioned how negative past experiences had made them cautious about disclosing their disease:

“...especially when those two former friends...left me because of my infection [HIV]...after that I become more aware of risks of disclosing...” (W 2)

“...I told...after that we haven't been in contact...this shows that nowadays one must think carefully to whom and why he discloses [HIV diagnosis to others]...” (M 1)

Sparing others from suffering. Thinking about how others may react and handle the information, was a concern for some participants. They preferred to conceal their HIV diagnosis from others if they thought that such inform would cause unnecessary suffering to others:

“...why should I enhance their [people in general] pain by disclosing...” (W 2)

One participant wanted to conceal the information from his family members because he did not want to generate extra emotional burden on them and at the same time he did not want his siblings to change their interaction with him. This was described as follows:

“...I don't want my relatives to think that I have some kind of death leading disease. I don't want them to think about it during family encounters. If I let them to know, then they will check me and try to find some changes. If I get flu for sure they will think that is related with it [HIV]...my mother she is so old that I think that she couldn't understand it and how she would keep it inside of her. Same principle for my brothers and their families...” (M 1)

Similar to the interviewee above, also other participants brought up their parents' advanced age and diminished cognitive capacities as a motive for concealing their HIV diagnosis. This was described as follows:

“...to my parents I haven't told, they are so old...for sure they will think about it for the rest of their lives and perhaps they couldn't understand the facts and would be worried. I really don't understand why I should make my parents unhappy.” (W 1)

Intimate concern. One of the reasons for concealing was the principle of personal privacy. Some participants wanted to keep their HIV infection diagnosis as a personal affair that does not need to be shared to everyone, thus protecting themselves. This was described as follows:

“...not everyone needs to know about it, it's my own thing...” (W 2)

“...I don't run around telling to people that I'm HIV positive...It doesn't belong to everyone [to know about HIV diagnosis], it's my own private thing...” (W 1)

Negative self-perceived others' behaviours. Anticipation of others' reactions was mentioned by some participants as a cause for concealing their HIV diagnosis:

“...at my work nobody knows...because I'm a teacher, there will always be parents with whom this [HIV] could be a problem...if they get to know there will always be parents that have the opinion that an HIV-positive can't teach.” (W 1)

“...there a lot of people that I haven’t told about it [HIV]...there are always someone who gossip around...they can’t not understand...it’s a waste of my time and energy trying to explain them...they will never understand it and plus they would disseminate the information immediately...” (M 1)

7.4.3 Regulating personal information

One of the crucial features on disclosure is how private information is regulated. Participants described it in terms of disclosure since the time of diagnosis, getting to know others first and in terms of selective disclosure.

Disclosure since the time of HIV diagnosis. Disclosing HIV diagnosis to others was discussed by most of the participants as a stressful event. When it is the right time to disclose to others? Disclosure since the time of getting HIV diagnosis varied from immediately to half a year. Telling immediately to a close friend was described by two participants: *“...I told him immediately as soon as I got the preliminary results.” (M 7)* and *“...he’s a nurse...For some reason I told him immediately after getting the results.” (M 1)*

Others told disclosing their HIV diagnosis to others after some self-reflection on the matter: *“...yes it took several weeks and maybe months, before I told to those people I have told...I pretty much self-reeled and then told to others. However I didn’t tell immediately about it [HIV]” (M 6)* and *“...I told the first time after six months...one year and a half I told to my mother...this year I have told to about ten people...” (W 2)*

Getting to know others first. As noted before, most participants disclosed their HIV diagnosis to those who they knew the best. One participant described how he informed his sexual partners about his HIV infection. For this participant during first meeting(s) his seropositivity is kept in secret. He describes the situation as follows:

“...if I want to find...sexual company or something more serious I tell about my infection very quick...of course first I see and become acquainted with him and then I tell. I don’t hide after getting to know...at the first encountering I never tell but perhaps at the second...However, if at the first encountering we have sex for sure it would be very safe sex. At the first encountering I wouldn’t tell but as soon as possible...” (M 2)

Selective disclosure. How disclosed one's HIV diagnosis is to others involves selective deliberation. Selectivity was described by the participants in terms of to whom to disclose and how much information they are ready to disclose.

"...almost in all the groups there are people who know about it [HIV infection]...this was, well a very selective process to whom to disclose and to whom not to disclose...the working mates that I have at the moment they know, we are a kind of small circle of mates. However, not all who have been for a couple of weeks working with us know it. No they don't know. Mostly those with whom I make all the time work know." (M 6)

By using selective disclosure some participants protected themselves against potential source of HIV related stigma. Fear was the main reason for the usage of selective disclosure. Moreover, protective disclosure was closely associated what has been already said of protective behaviours against stigma. This was described by one participant as follows:

"...not so many people know about it [HIV infection]...only a small close group of friends...well this is closely linked with a certain kind of discrete situation, that is wanted to be kept in small circle, in a secret...only to my best friends I have told..." (M 7)

One participant had disclosed both his HIV infection and also his bisexual orientation. Double disclosure made him in the beginning to lie to his son but to tell the truth to his daughter:

"...I told to my daughter [about my HIV infection]...later on I also told her that I also have sex with men. She accepted and understood it very well...To my son I was afraid to tell [about HIV] because he was a teenager and HIV was very strongly the disease of homosexuals and drugs addicts e...however I thought that if I tell him about my HIV I tell at the same time that I'm homosexual. But I lied; I told him that I got it [HIV] in a brothel. It was easier to come out in this way. Later on I told him everything, I told him that I have found another facet of myself and that I can be with men in bed also." (M 2)

7.4.4 Others' reactions to disclosure of HIV diagnosis

Some participants described others' reactions of hearing about their HIV infection from being positive to negative. Positive reactions were the foremost others' reactions. These reactions will be discussed in detail below.

Positive reactions after disclosure. Most of the participants had received positive reactions from others in terms of acceptance and staying in the relationship regardless of their HIV infection. For them these positive reactions were taken as support. One participant described the topic:

“...our friendship continued the same despite it [HIV infection]. Nothing has happened...to those to whom I have told, happened that, well it didn't happen anything. In my opinion it is a kind of support. Nobody has turned their back on me...” (M 6)

For another participant it was important that those who were informed about her HIV infection did not change their behaviour and continued to visit her and share the same glass.

“... nobody reacted negatively, they haven't stop visiting us. My sister has a small boy...we have a shared summer place, and we share it, it continues the same as before. She [sister] hasn't policed my mugs and food, nothing really nothing...” (W 1)

Rejection. Rejection after disclosure was the foremost negative reaction from others, mentioned by some participants. Rejection was strongly associated with HIV related stigma particularly the fear of contagion. Rejection by friends was described by two participants as follows:

“... besides the two [friends]...they left me by my own” (W 2)

“...well this [HIV diagnosis disclosure] caused in one my friend that after it we haven't been in touch. I have tried to call him after a few weeks but he never answered to my phone calls. Ok, it is his own problem if it was such a big thing to him.” (M 1)

Two participants reported refusal acts in medical care:

“...dentist. I always inform...that I have this immunodeficiency...he refused saying that he can't treat me...go to university hospital...” (M 3)

“...while working I got a nail on my foot...the doctor hold my foot and had a look at it...I told him about my HIV...just jumped away and said you should have told me before...he sent me away to another doctor. He said that he couldn't find anything because it went to deep...” (M 6)

7.4.5 Unintended disclosure

Disclosure may occur also undeliberately. Two participants described information welled-up and HIV medications inadvertent exposure to others as a source of apprehension due to unintended disclosure.

Information welled-up. Information welled-up within medical records was an issue that created in one participant stress and fear of possible further disclosure of his HIV infection by third-parties:

“...once against my wishes my situation welled-up, this happened because of these public health care systems...it welled-up against my will...public health care and their systems are not totally confidential. This happened; well I had an HIV laboratory referral...” (M 7)

HIV medications inadvertent exposure to others. One of the participants was on HIV treatment. He kept his medicines on the bathroom’s cabinet and one of his sexual encounters found them and discovered the participant’s HIV infection:

“...well it went naturally. He saw my pills on my bathroom’s cabinet, I had some pills for gastric problems, on the bottle of those pills was written to be taken in case of heartburn caused by HIV pills. He was of the opinion that I should have told him before...but then he understood it that I didn’t had yet the opportunity to say it...I don’t what it would happen if I would have told him immediately, would he be around...we have been together for about 10 years...” (M 1)

Even the fear of reactions of others to HIV infection was the reason for concealing the diagnosis, the unintended disclosure due to HIV medications inadvertent exposure turned out to be a positive rather than negative experience for the participant.

7.5 Human relationships and social networks

The scope of human relationships and social support received were linked mainly with the degree of openness the participants had regarding their HIV diagnosis. On another hand, total concealment one’s HIV diagnosis did not affect the participants’ normal interaction with others, as one participant mentioned:

“...it didn’t affect [social interaction with others] at all because outside from this group [people who knows about his HIV infection] I’m healthy...” (M 5)

The interviewees described their human relationships networks as multifaceted and reciprocal. Downsizing of social networks was associated with death of significant others, normal social reduction due to other reasons that HIV disclosure to others and self-breakdown from social life.

Human relationships-social networks support	Multifaceted social networks	Strong large friendship circle
		Net chat rooms
		Meeting new people
	The importance of support	Emotional support from friends
		Family support
		Support from health professionals
		HIV support group
	Downsize of social network	No need of support
		Death
Normal friendship circle reduction due to other reasons than HIV diagnosis disclosure		
		Self-breakdown from social life

7.5.1 Multifaceted social networks

Most of the participants described their social networks as strong composed of variety of different people. Some included net-chat rooms on their social networks.

Strong large friendship circle. The friendship circle of the majority of the participants was good, large and strong due to their active participation in social life. Two participants described their social networks as follows:

“...normal [social network]. Working mates, friends from my field of interests, and then HIV positive friends, old school friends who have moved back to Finland...Quite normal. Quite large, quite large. Well I’m also an active person...” (M 6)

“...I have a very good and big friendship circle...men and women constitutes my social network...I have friends everywhere. I had motorcycle as a hobby, from it I have a lot of friends...then I have long-term friends from my school time that I know since my childhood...” (W 2)

Net chat rooms. Net chat rooms are one way of finding sexual partners, as described by one participant as:

“...today I’m going to meet one guy...it’s that chat room, a gay chat-room. I have been there since last winter and from it I have met one guy a couple of weeks ago, we have chatted...” (M 2)

One participant was involved in a chat room where HIV positive people anonymously shared their life experiences. For him the chat room offered an opportunity to get knowledge about how people cope with their disease:

“...I have sought this kind of connections...fate comrades...mostly I’m interested to know how those who have been infected longer than me, well what has happened in their life...well a kind of curiosity and at the same time what the future might be for me as I age...I never have met anybody, we just chat and change opinions...” (M 7)

Meeting new people. For some participants HIV positivity had brought along new acquaintances by means of participating in HIV related meetings and belonging to HIV peers groups.

“...I have been in some international HIV conferences...I have met really fantastic people, especially when I was in Sweden and met other Scandinavian women, it was really nice to talk...” (W 2)

“...along with my organizational participation I have gathered a lot of friends and very fast...very nice people, cheerful people...” (M 3)

7.5.2 The importance of support

As reported above, most participants had a multifaceted and large social network composed of several persons. Participants experienced the support from friends, family, health professional and HIV peer group, as the most important support in their lives. Some mentioned no need of any kind of support due to their HIV infection.

Emotional support from friends. For some participants friends had offered emotional support by becoming important mentor persons in participants’ lives. This support was crucial for dealing with the disease. Those who had supporting friends did not need to digest the hard information alone.

“...friends have provided me a kind of support, a very important support...” (M 6)

“...when I got infected I had one long term friend...we become my support person for many years. I really don’t know if I would feel so well as now if I won’t have someone, he was a nurse and we had a good friendship relation...we spoke many hours on the phone...” (M 1)

“...in the beginning he helped me a lot, especially emotionally...for sure the shock would be longer if I hadn’t have him and needed to deal with the situation alone. I had this kind of emotional support person who helped me a lot...I passed rather quickly over the shock because of the support I got...” (Ma7)

Emotional support from family. Those participants who had disclosed their HIV diagnosis to their relatives described family support from parents and siblings in terms of spiritual and instrumental support:

“...one of my sister’s sons knows about me also...he works in health care and has worked with HIV positive patients...he was really a big if not the biggest support...My aunt, she looks after me...last Christmas she took me to Romania...quite often I’m in contact with my cousins, sister and brother, with my brother everyday...” (W 2)

Support from health professionals. Some participants had received informational and emotional support from specialized health professionals.

“...I went to therapy, I had a doctor and I was seeing a crisis therapist...” (W 2)

“...one Finnish nurse who was working as an international coordinator...told me that because of it [HIV infection] I won’t be admitted in a psychiatric hospital. Then I understood it.” (M 4)

Information about HIV infection disease was the main reason for turning to health professionals’ help. This was described by two participants as follows:

“...I haven’t sought for any kind of emotional support from health professionals, no not at all. Mostly I sought for information...” (M 7)

“...when I got to hospital...my knowledge about the disease was very poor...from there I got a lot of information, knowledge, facts about the disease [HIV] and its treatment. It was a big help for me, it calmed down me and gave a sense of good feelings...” (M 6)

HIV group support. Being in contact with other HIV infected individuals gives a sense of belonging by means of sharing lived experiences in living with HIV/AIDS. This feature was found to be important for self-acceptance and identity construction as HIV positive. Moreover, for those who attended the support groups, sharing lived experiences with others was a source of optimism regarding ageing with HIV/AIDS:

“...for me it was very nice...I noted that it was a nice experience, some take pills from their bags and took them. Well it was a kind of free feeling; you can somehow behave freely here. Ah now it’s my pills time and someone take the pills out from the bag. Well it’s a kind of feeling...we are at the situation, it was really nice...” (W 1)

“...I really feel at home here [in support group]. I don’t need to be afraid of anything...we are at the same boat...When I went there to AIDS [group]... a couple of years ago, one guy said there, he

had HIV for nine years and he doesn't have anything yet, it was quite nice feeling...and I thought that can happen to me also.” (M 5)

“...here [support group] I can be myself as a gay and as a HIV positive, I don't need to assume any role...I found myself through the support group...The best support I ever got was from it...Here is the only place where I dare to be myself, dare to cry and smile, dare to speak about...The emptiness that I had been filled by the support group. I got everything from here, when we speak about a big issue such as HIV/AIDS back in 98 when knowledge about the disease and its treatment was under development and rather poor, it was very important to sit nearby HIV positive persons and listen to their life stories and how was their health at the moment, how the medicines were working or not working.” (M 2)

No need of support. Those participants who mentioned having no shock reaction after learning about their HIV positive diagnosis, said that they never needed any kind of support from the outside. One participant brought it out by saying:

“...Well I never needed. Because of my HIV infection I never needed any kind of support...no I never needed because I didn't see it as something special.” (W 1)

7.5.3 Downsizing of social networks

Death. The social networks of two participants had recently been reduced due to death of their parents and partner. Losing one's significant other is a source of a new period of shock and depression. These times of losses and grieves were described by the interviewees as follows:

“...I met two years after being diagnosed with HIV infection a wonderful man with whom I moved in. He died last spring...my mother is dead and father is dead...” (W 1)

“...she [mother] died of surgical complications. It was a new crisis and a new shock that led to a bad depression which lasted for two years. Then one year after my mother's death, my father died. Then one year after my father's death my grandson died. Well it was a really bad five years.” (M 2)

Normal Friendship circle's reduction due to other reasons than HIV diagnosis disclosure.

People's social networks tend to shrink by advanced ageing. Being in a long-term relationship or a normal decline of number of friends were issues mentioned in the interviews. The quality of current relationships was appreciated over their quantity:

“...I used to have plenty of friends before; friends and friends more fellows I think, this circle with time have squeezed to a small group of good heart friends...” (W 2)

“...I have a group of friends with whom I seldom keep contact with. Well I think that when people know that you are in a relationship and have such a close life with other just like I have, people tend to leave us in peace, they don't disturb and they are not worried about me. However I have actively being in contact with those who are important for me.” (M 1)

Self-breakdown from social life. Downsizing of social network after being diagnosed with HIV infection can be also self-induced process depicted by two participants as follows:

“...the working environment was my social network. My hobbies, my work ended at the same time. When my work ended, ended my social life. Well I broke intentionally with everything...” (M 2)

“...I have been for about 15 years very active in all kind of organizations...when I got infected I left everything...I was 10 years without any kind of organizational affiliations...” (M 1)

8. DISCUSSION

8.1 Credibility of the study

HIV/AIDS is a very sensitive issue in individuals' lives and requires a non-invasive approach to research it. Using interviews as the method of data collection, proved to be the most adequate one. By using it was possible to collect a series of facts of participants' lives. The participants were encouraged to express their feelings and concerns as a HIV positive. Bowling (2002, 378) described the usefulness of interviews as a way "*...to obtain true meanings that individuals assign to events, and the complexities of their attitudes, behaviours and experiences. This method allows the respondents to tell their own stories in their own words...*"

The researcher has taken into account that during interviews respondents may omit some events, change facts, forget some past events or even try to please the research by answering in a more socially acceptable ways to the posed questions. To overcome these potential biases, the interviewer made hand notes during the interviews and later on posed some reformulated questions to the participants to test the validity and consistency of earlier obtained answers.

The instrument used in collecting data, open-questions, was pre-tested before applied. These questions proved to be adequate for the aims of the research.

The interview scheme was composed of four main questions to which respondents were kindly requested to answer. In every interview additional questions and different questions were inserted depending upon the course and the content of each interview. Individuality of interviews was taken into account. The reason behind such procedure underpins the need to obtain as much as possible detailed information from the participants. This procedure assured that participants answered in an adequate and logical way (internal validity) (Cutcliffe, McKenna 1999).

Transcription of interviews was a process that took a lot of time but at the same time it has enabled the researcher to get deep in the content of the interviews. Therefore, the difficulties pointed out by the use of voice recorders (see Grönfors 2008) proved to be beneficial.

To maximize the validity and trustworthiness of the data, the researcher discussed actively with his supervisors during the analysis process (Cutcliffe, McKenna 1999). This proved to be necessary not only to increase the reliability of the study but also to help the researcher to understand the principles that which rule qualitative research. Furthermore, active brainstorming with supervisors were done during the whole process of research, since selection of the topic, questions formulation and data collection principles, analysis methods and reporting the results. Since inductive inquiry was used for the first time by the researcher, interchange of ideas between researcher and his supervisors permitted the researcher to follow the right path on analysis process, by avoiding constantly the use of previous knowledge to interfere with data interpretation, increasing therefore the credibility of the results (Mhyre 2010).

The venue where interviews were planned to take place was previously agreed with the director of Positiiviset. Most of the interviews took place at Positiiviset facilities, a familiar and neutral environment for the participants, away from potential outside distractions. During the interviews it was possible to note that the participants discussed their life issues with calmness and tranquility. The role taken by the researcher during the interviews, neutral and empathic, helped the participants to develop a sense of trust and willingness to participate.

One of the challenges in using content analysis is the ability of the researcher to remain objectivity during the process analysis. Thus, it was crucial to detect at any point of the process analysis self-subjectivity, which could constitute a bias and therefore form a threat to the trustworthiness of the study. Previous knowledge or professional experience should therefore be put apart at all times (Cutcliffe, McKenna 1999, Mhyre 2010). This problem can be overcome when interviews are analyzed by their contents. The use of a second person is useful to achieve such goal (Mhyre 2010).

The obtained material was translated from Finnish to English language by the researcher. Whenever translating texts is impossible to translate word by word, sometimes is necessary to translate by the meaning of the sentence. Therefore, it assumes a structuralistic cognitive process. To overcome the linguistic barrier the researcher has translated some quotations from Finnish to English with a help with dictionaries and a Finnish language native person. However, some translation errors are possible to be found.

Authentic translated quotations were added in the results part to make visible how interpretations were made by the researcher and how categories and sub-categories were built.

The topic of this study is so far unexplored in Finland, therefore inductive analysis is the most reliable qualitative method (Elo, Kyngäs 2008).

8.1.1 Strengths of the study

As stated above in chapter 3.3.1., this subject is the first one in Finland that focuses on people aged 50 years and older living with HIV/AIDS. The purpose of this study is to produce new knowledge of this growing group of people.

Secondly, this study made visible the importance of HIV organizations in the lives of individuals living with HIV/AIDS at later adulthood.

Thirdly, the questions used in this study has proved to be a good instrument for collecting a wide spectrum of data, which can be used as a point of departure in other qualitative future studies on HIV/AIDS issues.

Fourthly, the use of the method of inductive content analysis, discussed in detail above, has increased the understanding of HIV infected people's lived experiences.

8.1.2 Limitations

Every study has its own limitations and this study is not an exception. There are three major limitations of this study: first, the sample ($n=9$) was rather small; secondly, the data consists of people willing to participate and most of them were active in group support organizations, therefore those less active are not represented. Finally, in order to maintain study participants anonymous and to avoid possible identification within the small group of study, detailed participants' characteristics were avoided. Therefore, the findings of the study are context bonded and cannot be generalized to other people HIV/AIDS infection.

8.2 Interpretation of the findings

1. Most of the participants' reacted negatively to their HIV positive diagnosis. As expected, shock was the most often form of reaction by all the participants. This finding was in line with those of previous studies dealing with individuals' reactions to HIV positive diagnosis (Stevens, Tighe Doerr 1997, Malone 1998, Stevens, Hildebrandt 2006, Baumgartner 2007, Hult, Maurer & Moskowitz 2009, Anderson et al. 2009, Baumgartner, David 2009) and with individuals' reactions to a other chronic disease diagnosis (Kralik, Brown & Koch 2001). In addition to shock, fear of HIV's visibility and thoughts about death were other sort of negative reactions shared by most of the participants who were infected in the 90's. The participants attributed these negative reactions to the lack of sound information and negative media discourses around HIV/AIDS disease. These findings are parallel to the findings of Nichols his colleagues (2002) on older adults infected with HIV in the 90's. These thoughts reflect the tempestuous time lived around the first decades of HIV/AIDS syndrome (Maia 2010). However, two participants had described that hearing about their HIV diagnosis caused them no shock. Past experiences with HIV infection and other chronic diseases and acknowledgment of belonging to a risk group were the reasons given by the participants for no shock reaction, supporting the earlier findings of Emlet, Tozay & Raveis (2011) and Skaggs & Barron (2006)

The consequences of above negative thoughts and feelings had triggered excessive use of alcohol in two participants. This behavioural reaction to negative life events was also noted by Immonen, Valvanne & Pitkala's (2010) in their study on reasons for alcohol consumption among older adults in Finland. The people explored in that study said that they used alcohol to relieve their anxiety and depression. They concluded that these behaviours can put older adults at risk of becoming alcoholics, especially if the use of alcohol is employed as a source of emotional problems relieve. (Aira, Hartikainen & Sulkava 2008, Immonen, Valvanne & Pitkala 2010).

In this study the data of the length of shock varied from some weeks to years. The shock period was somewhat higher amongst those participants who were infected in the 90's. For some participants the length of shock was associated with their inner need to cope with their changing health either individually or with the help of health professionals. On the other hand, those infected at the age of 50 or older attributed the shortness of their shock period to with having someone to talk with and with their own strengths. As Dittmann-Koli & Jopp (2007) have stated, throughout life, individuals

gather a wide set of lived personal experiences that in older age are incorporated in their identities. Hence, the way older adults react to certain some life changing events may vary from the reactions of their younger counterparts'. This heterogeneity (Malone 1998) rather than homogeneity in older age is conceptualized by Dittman-Koli & Jopp (2007) as wholesome knowledge, which can offer a plausible explanation for different lengths of shock among the participants. What remains uncertain is whether it is the age itself or having someone to talk with or both that influence the length of shock. To my knowledge there are no studies in which reasons behind the length of shock among older adults infected with HIV virus have been explored.

2. When discussing life changes after receiving HIV positive diagnosis, the participants assessed them more positively than negatively. Becoming braver and experiencing life enrichment were aspects mentioned by some participants. This was in accordance with studies of Barroso and Powell-Cope (2000) and Nichols and colleagues (2002) who noted that those individuals who had found positive meanings in living with HIV/AIDS were normally able to develop good coping mechanisms to deal with daily-to-day life. Early retirement, for some of those who were infected with the HIV virus in the 90's, was described by the participants as a positive life change event. By early retirement these interviewees had acquired more time for themselves and for their families. These findings support the disengagement theory according to which, by getting older individuals pass through a series of social disengagements which enable them individual to have more time for themselves and for others (Phillipson, Baars 2007). The way individuals minimize their losses and maximize their gains enable them to maintain a high level of functioning and well-being (Dittmann-Koli, F., Jopp, D. 2007).

One way of coping with chronic diseases is seeking relief from religion. By means of praying or mediating one participant was able to be in contact with his inner self and a higher divine force. This was in accordance with the findings of previous studies according to which increase in religiousness after being diagnosed with HIV is a source of spiritual well-being, overall quality of life improvement and development of efficient coping mechanisms. (Barroso, Powell-Cope 2000, Ironson, Stuetzle & Fletcher 2006, Kremer, Ironson 2009)

In this study most of the participants had readjusted their sexual behaviours after being diagnosed with HIV infection. Some participants carried on with a normal sexual activity under some more strict protective measures; others opted for celibacy and self-masturbation as a form of cutting any sexual encounter and induced sexual satisfaction Fear of cross infections (STDs) and protecting

others against HIV virus, were the most mentioned protective measures. According to Emlet, Tozay & Raveis (2011) these protective measures reflect an increased interest in the health and well-being of infected persons themselves and their significant others. These findings are in accordance with Baumgartner and David (2009) and Maticka-Tyndale and colleagues (2002) who noted that individuals tend to suppress their sexual desire and opt to be in a state of celibacy after being diagnosed with HIV infection. Fear of rejection by others after disclosure play an important role in individuals' sexual behaviour change. Maticka-Tyndale and colleagues (2002) also suggested that individuals tend to find other ways to satisfy their sexual needs instead of sexual intercourse. The current study showed that regardless of HIV infection, sexual life still prevails at older age. Being in relationship with an HIV negative partner did not influence the practice of sex. This finding supported those of the study of Baumgartner & David (2009) where the need for sexual activity and safe sex within steady relationships was established.

In this study searching for meaning in life as HIV positive was described as natural and necessary to self-development and better coping with the disease. Most of the participants found themselves able to see HIV/AIDS as a small part of one's identity reflecting a successful internal decentralization of HIV from self by means of reintegration in social life as an individual with a chronic disease rather than as an individual with HIV infection. These results reinforce the findings of Baumgartner (2007) of 18 adults aged from 23 to 45 years living with HIV/AIDS who noted that "*the respondents realized that they were more than their HIV/AIDS identities*" (Ibid. 925) and Nichols and colleagues (2002) who also noted the minor importance that older people gave to HIV infection in their lives.

One participant blamed HIV infection for being guilty for his felt loneliness. His felt loneliness was associated with his unwillingness to disclose his HIV infection outside of his family circle. This unique case is in accordance with Skippy and Karpiak (2005) findings. In their study on older PLWHA social networks they noted that individuals' unwillingness to disclose their HIV infection to others was linked with loneliness feeling. On other hand Emlet (2007) found that loneliness was associated with HIV related self-stigma and personalized stigma. Given these results felt loneliness can be seen as self generated and HIV infection induced.

3. HIV/AIDS related stigma, whether felt or self-stigma, influenced participants' social interactions and had significant impact on disclosure patterns. Emlet (2007) noted that stigma is both an intrapersonal and interpersonal process, which influence each other in symbiotic way.

HIV/AIDS related stigma triggered a set of reactions from others. Fear of contagion was the most felt source of stigma experienced by the participants. In some cases it had led to forms of rejection from both friends and health professionals. The findings of HIV-related discrimination associated with stigma were in accordance with previous studies (Emlet 2006, Karpiak, Shippy & Cantor 2006, Emlet 2007, Power, Bell & Freemantle 2010). In her dissertation study on University students' attitudes towards HIV/AIDS in Finland and in Kenya, Kajjaleena (2008) found that Finnish students had more negative attitudes and discriminatory behaviours towards HIV infected patients than Kenyan students. The level of knowledge on HIV/AIDS disease did not correlate with negative feelings. Having few contacts and experiences with HIV/AIDS was the main reason found for the negative feelings among Finnish students. Similar findings were found in earlier studies on attitudes of health sciences students' towards HIV/AIDS patients. Fear of contagion was the main concern shared by all the students which led to negative attitudes towards HIV infected individuals and influenced the care received or offered. (Parker, Bhugra 2000, Ganczak et al. 2007). In line with findings of earlier studies, current study showed that, regardless of the level of knowledge, HIV/AIDS related stigma still prevails in our society. The most worrying finding in this study is that HIV related stigma exists among future health professionals who may jeopardize HIV infected individuals right to a proper health care. (Power, Bell & Freemantle 2010)

In the present study, experiences of negative self-image were positively associated with felt stigma or perceived stigma from others. The experience of self-stigma and its sources corroborate earlier findings on HIV/AIDS related stigma in older PLWHA (Emlet 2007, Power, Bell & Freemantle 2010). Emlet, Tozay & Raveis (2011) found that self-stigma is a response to the experienced or fear of enacted stigma. In the data of that study felt and enacted stigma were related not only with HIV/AIDS disease but also with ageist behaviours. The current study did not find any source of ageism in participants' talks. This could be explained by socio-cultural differences between different countries and values deposited on older people.

Being a risk to others was the most common shared negative self image by some of the participants. These self-stigma constructs impacted negatively on sexual and social interactions with others. The experience of being a risk to others is consistent with the findings of Emlet (2007) who found that

older PLWHA tend to consider themselves as “feeling others” or “I’m radioactive”(746). On another hand, the findings of this study are in line with those of Nichols and colleagues (2002) who found that older female adults with HIV/AIDS tend to see themselves as something dirty and blame themselves for the infection. According to Ferreira (2010), sex is socially and symbolically linked with reputation which is strongly gender based. HIV infection is still associated with high rotation of sexual partners. In men this rotation is seen as a form of masculinity but in women as a source of stigma and bad reputation. This position may explain different forms of self-stigma described by women and men in this study and in the study of and Nichols and colleagues (2002).

Fear of enacted stigma led to some participants to develop some self-protective behaviour which were attributed to past experiences and perceived stigma. Non disclosure and protective walls were the protective behaviours that emerged from the interviews. This protective silence is consistent with findings of Emlet (2008) according to which older PLWHA feared reactions of others if they disclosed their HIV infection. The fear associated with stigma might be the reason why older adults are more reluctant to disclose their HIV infection than their younger counterparts (Nokes et al. 2000, Emlet 2006a).

4. The main challenge faced by the participants was the question of disclosing their HIV status to others. Being open to others, may lead to experience stigma, changes in social networks and to receive support (Greene et al. 2003b).

Even though limited in scope, the research on older PLWHA infection have found the impact of disclosure, negative and positive, in lives of older PLWHA. Emlet (2008) noticed that reasons to disclose and conceal HIV diagnosis from others among older PLWHA, depended heavily on concerns regarding stigma, rejection and discriminatory behaviours, whether experienced or perceived. The deliberation between risks and benefits is balanced with the individuals’ need to share with someone their agony or anxiety of being HIV positive and with the need of getting support from others. This might explain the differences of disclosure patterns found among the participants of this study.

Anticipatory disclosure is mediated, by positive and negative perceived reactions of others. The individuals tend to be very selective to whom and when to disclose (Emlet 2008). This selectivity represented the way the study participants manage their private information for protecting themselves and others. Selective disclosure has been reported also in studies of other socially high

stigmatized diseases such as mental illness (Bos et al. 2009). Sparing others, especially family members from suffering, is a finding consistent with that of prior studies (Schrimshaw, Siegel 2003). In the context of this study, this mode of behaviour was related with the patents advantaged age. Skippy & Karpiak (2005) found in their study on older PLWHA that extreme selectivity is rather harmful than beneficial because it might jeopardize potential support from others leading to social isolation and loneliness. The participants of the current study have turned out to be very careful with their selectivity patterns; loneliness and social isolation were topics rarely articulated in their talks.

Friends were the first members of the social network to whom the participants had disclosed their HIV infection. Disclosing one's HIV infection to friends or at least to those most close and trustworthy was a common feature found both in previous studies (Karpiak, Shippy & Cantor 2006, Emlet 2008, Power, Bell & Freemantle 2010) and in the current study. Contrary to conclusions suggested by previous studies (Karpiak, Shippy & Cantor 2006, Power, Bell & Freemantle 2010), in this study family and health professionals assumed a secondary place on disclosing. Reasons behind such finding were unexplored.

This study brought out the double disclosure of sexual orientation and HIV infection which loads an extra burden on the individuals. Emlet (2006) found that double disclosure may have an impact on how much information older PLWHA are ready to disclose to others.

Concerns of increased stigma and changes in relationships were related with reactions of others to HIV diagnosis and unintended disclosure. In general, the argumentation on the topic was more positive than negative. Findings from previous studies on the issue are somehow contradictory. Some have found no change and improved relationship after disclosure (Power, Bell & Freemantle 2010). Others have found that negative reactions were the most felt reactions (Karpiak, Shippy & Cantor 2006). These findings show that more research on disclosure patterns among older PLWHA is needed to overcome with this controversy.

A preoccupying issue was related with unintentional disclosure. Emlet (2008) found that violation of confidentiality occurred from different sources. Landau & York (2004) discussed unintentional disclosure as an ethical concern which might be the source of potential gossips and stigma. These concerns were expressed on the participants' talks.

5. Having someone to rely on or belonging to a group was expressed as an important issue in participants' lives. Research has shown that having a good supportive network is essential for individuals' well-being and QOL (Chesney et al. 2003, Mavandadi et al. 2009, Golden, Conroy & Lawlor 2009). Having friends, family or belonging to a supportive HIV group fosters good individual coping strategies and help individuals to cope with the challenges imposed by the process of ageing and living with HIV/AIDS infection (Malone 1998, Shippy, Karpiak 2005, Heckman et al. 2006).

Older PLWHA have been found to be at risk of being isolated (Skippy, Karpiak 2005) and suffering from loneliness more than their younger counterparts (Emlet 2006). Contrary to these findings, the social networks of the participants of the current study were rather large and supportive. With HIV infection came along new friends, especially HIV positive friends, with whom the participants could share life experiences and build strong identities as a HIV positive or as a gay. The importance of belonging to a group of similar, whether anonymous (net chat rooms) or not, had enabled the participants to build hope towards growing old with HIV infection. Hope and optimism towards the future, was a constant in most of participants' talk.

When discussing about their social ties, the participants referred constantly to two kinds of their social networks: to those who knew and to those who were unaware of their HIV infection. The support obtained from those who were unaware of the participants' HIV infection was considered as important as before being infected with HIV virus. This could be seen as a strategic plan linked with coping processes: people want to live a life as normal as possible. Nevertheless, the support offered from those aware of participants' HIV infection was rated as good and sufficient. This finding highlights the continuity theory, according to which individuals by growing older tend to maintain their social ties even in face of life change events which in turn promote good life adaptation and foster self-esteem and QoL. (see Ebersole et al. 2005 and Bond et al. 2007).

Emotional support to participants was offered by friends and family always when needed. These findings were contradictory to those of Schrimshaw & Siegel (2003), Shippy & Karpiak (2005) and Karpiak, Shippy & Cantor (2006) who found that emotional and instrumental supports were highly unmet among older PLWHA. This was explained by Skippy & Karpiak (2005) by selective disclosure and by Schrimshaw & Siegel (2003) by stigma issues, death of friends due to AIDS, sparing others from suffering and unavailability of nuclear family. The authors concluded that the before mentioned themes are risk factors for social isolation among older people living with

HIV/AIDS. In the current study concealing the disease from others did not have an impact on the support obtained.

Alterations in social networks of the participants were in accordance with normal ageing life course process (Askam, Ferring & Lamura 2007). Losses of spouse, family and friends due to death, retirement and other reasons such as moving from one city to another, all together made up the realities of ageing individuals involved in the study more than their health status.

Despite some controversial findings between the current and earlier studies, all of them suggest that relationships in older age tend to be rather quality than quantity driven and are distinguished by their emotional closeness. Moreover, older people tend to select and manage selectively their social networks (Askam, Ferring & Lamura 2007) with the aim of highlighting positive aspects of life and reducing potential sources of negative stigma experiences. In their metasynthesis on people living with HIV infection Barroso & Powell-Cope (2002) found that individuals tend to break intentionally those social networks that do not offer any support and replace them with social networks that serve their needs better. These new social networks came along with the new boundaries set by HIV disease (Greene et al. 2003b) and age.

6. After living some years with HIV infection, the participants had gathered a wide set of experiences, both negative and positive ones. These experiences were taken as an opportunity and translated into a good balanced life. For Baumgartner (2007) and Baumgartner & David (2009) this represents a so called “self-integration” process which boosts individuals’ self-esteem, increases sense of well-being and self acceptance (Karpiak, Shippy & Cantor 2006, Emler, Tozay & Raveis 2011). At the same time, these findings highlight the principles of the symbolic interactionism foundation of social gerontological theory composed by the continuity and activity theories, which are based on individual’s personality traits and social skills in maintaining and adopting new roles, by means of engaging in meaningful social activities that in turn will determine individual’s QoL.

Besides the classical gerontological theories, discussed above, the findings of the current study can be interpreted in light of two successful ageing theories. The Preventive-Corrective Proactivity (PCP) Model of Successful Ageing developed by Kahana & Kahana (2001) comprises a set of social and psychological factors that influence individual’s quality of life and fosters positiveness in life. Secondly, the Selection, Optimization and Compensation (SOC) model developed by Baltes & Baltes (1993) suggests that successful ageing depends upon the ability to set, pursue and maintain

personal goals, associated with cultural and individual cognitive appraisals which are mediated by processes of selection, optimization and compensation. These processes enable older people to maintain positive thinking and functioning in face of negative health change events. The talk of the participants in the interviews exhibited features of successful ageing proposed by these two models (e.g., optimism, normal life, mentor, good relationship with HIV infection).

Despite their initial negative reactions to their HIV positive diagnosis, many of the participants reported positive attitude towards HIV infection in their lives and stressed the positive aspects of their daily live. This is consistent with the concept of resilience. Ong and colleagues (2006) found that resilience refers to individual's ability to cope with and recover positively from negative events in later adulthood. It also coincides with the findings of Emlet, Tozay & Raveis (2011) who have noted that older people living with HIV/AIDS have a strong will of living moderated by their resilience to adapt to negative life events. Siegel, Raveis & Karus (1998) have characterized this as wisdom. Both terms, resilience and wisdom, refer to the ability to recognize strengths and limitations and take advantage of them in a most positive and rational way. In the current study these aspects had helped the participants to move forward with their lives instead of being trapped with negative thoughts.

Mentoring others was conceptualized by Erikson as generativity (Newman, Newman 2008). Generativity reflects the inner need of older adults to help others by means of education, as a way to pass knowledge to future generations. In the current study mentoring was pursued by the participants as a preventive HIV infection measures towards youngsters and future health professionals as well as an emotional support to others infected with HIV virus. This finding agree with the earlier study findings of Emlet, Tozay & Raveis (2011), that old PLWHA have a inner need to educate and help others.

The process of generativity reflects a level of wisdom. Siegel, Raveis & Karus (1998) found wisdom to be one of the advantages in being HIV positive in later adulthood. Wisdom is defined by The Oxford English Dictionary (2001, 1065) as "*the body of knowledge and experiences that develops within a specific society or period*". This concept of wisdom reflects therefore a degree of maturity. In the current study the participants mentioned maturity as one of the advantages of being HIV positive in later adulthood. Maturity was associated with the ability to cope with HIV infection in a more rational way.

8.3 Ethical considerations

Research involving human subjects must take into account ethical considerations as the core stone for a good research practice. In the present study, all of the participants ($n=9$) were HIV positive. Being infected with HIV/AIDS, as mentioned before in the literature review, is often characterised by social stigma and discrimination, which may have impact on persons' overall well-being. To avoid causing harm, ethical considerations were carefully taken into account in planning and conducting the study:

- Ethical consent to carry out the research, was granted by the director of Positiviiset, Sini Pasanen;
- The anonymity of the interviewees was secured by omitting the names and other information from which the participants could be recognised from the data;
- The articles 6, 11, 22, 23 and 33 from the Helsinki declaration were respected and revised before the interviews (World medical association declaration of Helsinki 2008, appendix 1)
- The participants were informed by the director of Positiviiset and by the researcher about the purpose and content of the study, respecting the participants' autonomy and free participation by means of informed consent;
- Other ethical research issues such as nonmaleficence "... *an obligation not to inflict harm on others*" (Beauchamp, Childress 2001, 113) and beneficence "*Morality requires not only that we treat persons autonomously and refrain from harming them, but also that we contribute to their welfare*" (Ibid., 165) were assessed before, during and after the research;
- Any kind of moral judgements during the interviews by the interviewer was not made, respecting therefore participants' individuality and their openness regarding the themes discussed (Ibid., 384-385), and finally,
- Before each interview permission to use a digital voice recorder was asked.

- The permission of using the information of the interviewees' gender was asked from each participant.

8.4 Public health implications and further research proposals

As this study showed the concept of stigma persists on playing a central role on disclosure of HIV infection. Reduced disclosure and delayed search for help and access to support are impacted by the fear of HIV related stigma. In the current study, informal support was found to be of crucial importance in dealing with HIV infection and as a source of emotional well-being. Group support proved to be a good instrument for a new identity construction. In addition to, support groups available to people should be tailored to individuals' one needs. In Finland the support groups available offer help to HIV infected people of all ages, should it be more appropriated to have an organization dedicated only to those individuals' over 50 years, as in USA and UK? Is Positiiviset able to offer holistic support where specific needs of older people infected with HIV are taken into account?

Before developing any comprehensive program or support group for older PLWHA, the findings of this study could be used by public health and elderly care organizations for developing good living standards to older PLWHA in Finland. Despite its above limitations, this study may also serve to open up new areas on gerontological research care. Hopefully this study would conduct to fruitful discussions by awakening more comprehensive and supportive tools of care for the most fragile and until now forgotten segment of Finnish population: OLDER PEOPLE LIVING WITH HIV/AIDS.

As the number of individuals aged 50 years and older living with HIV infection is increasing gradually, more research in this field is needed using qualitative methods with bigger sample sizes and with infected individuals from all kind of cultural and social settings in order to know how they deal with their day-to-day social and health challenges.

9. CONCLUSIONS AND RECOMMENDATIONS

This study was carried out to explore and describe older PLWHA's psychosocial aspects of living and coping with HIV/AIDS, in Finland.

Among the participants of this study getting HIV positive diagnosis had triggered several negative emotional reactions. Shock was the often most reported individual negative emotional reaction. However, over the years, the study participants had learned to cope well with the disease, either with help of health professionals or simply supported by their significant others. The different types of support obtained in different phases of the disease, was considered to be of primordial importance in coping efficiently with HIV infection. Furthermore, others positive reasons after disclosing HIV diagnosis played an important role in self-acceptance as a HIV positive. Therefore, participants' considered life changes launched by their to HIV infection as something positive which has enriched their lives. Being HIV positive after the age of 50 years was seen as a positive thing from several perspectives.

Stigma and questions of disclosure were discussed by the participants as stressful issue. Stigma, whether enacted or self-stigma, restricted social relationships by means of rejection actions by others due to fear of contagion. Self-stigma, felt by some of the participants influenced their social interactions with others. On the other hand, disclosure was described as a dilemma, to whom, when and how to disclose were issues that were source of distress among participants. This was closely associated with fear of HIV/AIDS related stigma and fear of social networks breakdown. Moreover, unintentional disclosure whether directly (HIV medication unintentional exposure) or indirectly (information welled-up by a third-party) and sexual orientation disclosure upon HIV diagnosis disclosure to others, were aspects that caused in the participants some hesitation. Protective silence was a mode of non disclosure which served as a protection shield against exterior potential stigma. Stigma and disclosure are the cornerstones of individuals' private information management. The symbiotic relationship between the two concepts rose the question of constant self-rationing.

Yet, the participants mentioned having a good balanced life at the moment, which were attributed to their multifaceted and large social networks support and selective disclosure patterns.

This was the first research conducted in Finland on older PLWHA. The findings of this study show that above all the offered group support by the Positiiviset and good social networks support have had a great impact on participants' well being. Given this, it is strongly recommended that further research studies on older PLWHA would be planned from sociological rather than from biomedical perspective. The most urgent need is to study those who are not attending or attached to any support groups. Medicalization of HIV/AIDS should be avoided at all times. Psychological well-being is the foundation of good physical and social health as the study has demonstrated.

Finally, the current study and all the studies that have explored the life of older PLWHA have shared a common plea: more research is needed to gain a better understanding of how older PLWHA experience and live with their HIV infection. There will be more, not only elderly people but also elderly people with HIV infection more and more in years to come. Outcomes from scientific research on the lives of this rapidly growing population would enable to develop appropriated public health interventions for ensuring sound services and good QoL for all.

10. ACKNOWLEDGEMENTS

I would like to express my sincere gratitude to both of the two supervisors of my thesis: Senior Assistant Professor Tapio Kirsi, PhD, and Adjunct Professor Jari Kylmä, PhD, for all the support given and great orientation since the beginning of process.

I want to thank to my head nurse Tettu Törtsi for granting me all the necessary off leave from working duties during my master's studies.

I would like to express my gratitude to Kirsi Liitsola from THL for helping me in getting the necessary Finnish epidemiological data on older adults living with HIV infection.

I want to thank to RY positiiviset director Sini and all the participants for the warming environment and interest in the research, without you this project would not be possible. Therefore, this work is dedicated to all of you. Thank you.

I wish to thank to my parents Maria de Fátima and Venâncio, my brother José and my good friend Raúl for all the support and encouragement they have been given during my life.

I would like to thank to all my colleagues (Wagma, Roun, Batulo, Olotu, Beatrice, Kirsi, Tomomi and Mara) and professors of Public Health at the Tampere School of Public Health for all the support and expertise.

Finally, I want to express my deepest thanks to my boyfriend Jari both for all the love and support that he has been given me for more than one decade and particularly for his contribution as my research assistant during the process of completing my thesis.

References

- Alpert, J.S. 2005, "Viagra: The risks of recreational use", *The American Journal of Medicine*, vol. 118, no. 6, pp. 569-570.
- Aira, M., Hartikainen, S. & Sulkava, R. 2008, "Drinking alcohol for medicinal purposes by people aged over 75: a community-based interview study", *Family practice*, vol. 25, no. 6, pp. 445-449.
- Anderson, M., Elam, G., Solarin, I., Gerver, S., Fenton, K. & Easterbrook, P. 2009, "Coping with HIV: Caribbean people in the United Kingdom", *Qualitative health research*, vol. 19, no. 8, pp. 1060-1075.
- Askam, J., Ferring, D. & Lamura, G. 2007, "Personal relationships in later life" in *Ageing in society*, eds. J. Bond, P. Sheila, F. Dittmann-Kohli & G. Westerhof, 3rd edn, Sage Publications Ltd, London, pp. 186-208.
- Bhavan, K.P., Kampalath, V.N. & Overton, E.T. 2008, "The aging of the HIV epidemic", *Current HIV/AIDS Reports*, vol. 5, no. 3, pp. 150-158.
- Baltes, P.B. & Baltes, M.M. 1993, "Psychological perspectives on successful aging: The model of selective optimization with compensation" in *Successful aging: prespectives from the behavioral sciences*, eds. P.B. Baltes & M.M. Baltes, Cambridge University Press, Cambridge/ Great Britain, pp. 1-34.
- Barroso, J. & Powell-Cope, G.M. 2000, "Metasynthesis of qualitative research on living with HIV infection", *Qualitative health research*, vol. 10, no. 3, pp. 340-353.
- Battaglioli-DeNero, A.M. 2007, "Strategies for Improving Patient Adherence to Therapy and Long-Term Patient Outcomes", *Journal of the Association of Nurses in AIDS care*, vol. 18, no. 1, Supplement 1, pp. S17-S22.
- Baumgartner, L.M. 2007, "The incorporation of the HIV/AIDS identity into the self over time", *Qualitative health research*, vol. 17, no. 7, pp. 919-931.
- Baumgartner, L.M. & David, K.N. 2009, "Accepting being poz: the incorporation of the HIV identity into the self", *Qualitative health research*, vol. 19, no. 12, pp. 1730-1743.
- Beauchamp, T.L. & Childress, J.F. 2001, "Nonmaleficence" in *Principles of biomedical ethics*, eds. T.L. Beauchamp & J.F. Childress, 5th edn, Oxford University Press, New York, pp. 113-114.
- Bengtson, V.L., Burgess, E.O. & Parrott, T.M. 1997, "Theory, explanation, and a third generation of theoretical development in social gerontology", *The journals of gerontology. Series B, Psychological sciences and social sciences*, vol. 52, no. 2, pp. S72-88.
- Bible gateway.com , *Genesis 2:18*. Available:
<http://www.biblegateway.com/passage/?search=Genesis+2:18&version=NIV> [2010, 05/14].

- Biernat, M. & Dovidio, J.F. 2003, "Stigma and stereotypes" in *the social psychology of stigma*, eds. T.F. Heatherton, R.E. Kleck, M.R. Hebl & J.G. Hull, Guilford Press, United States of America, pp. 91-99.
- Bodley-Tickell, A.T., Olowokure, B., Bhaduri, S., White, D.J., Ward, D., Ross, J.D., Smith, G., Duggal, H.V. & Goold, P. 2008, "Trends in sexually transmitted infections (other than HIV) in older persons: analysis of data an enhanced surveillance system", *Sexually transmitted infections*, vol. 84, no. 4, pp. 312-317.
- Bogart, L.M., Cowgill, B.O., Kennedy, D., Ryan, G., Murphy, D.A., Elijah, J. & Schuster, M.A. 2008, "HIV-related stigma among people with HIV and their families: a qualitative analysis", *AIDS and behavior*, vol. 12, no. 2, pp. 244-254.
- Bos, A.E., Kanner, D., Muris, P., Janssen, B. & Mayer, B. 2009, "Mental illness stigma and disclosure: consequences of coming out of the closet", *Issues in Mental Health Nursing*, vol. 30, no. 8, pp. 509-513.
- Bond, J., Peace, S., Dittmann-Kohli, F. & Westerhof, G. 2007, *Ageing in society*, 3rd edn, Sage Publications Ltd, London, 384 pp.
- Bowling, A. 2002, "Unstructured interviewing and focus groups" in *Research methods in health: investigating health and health services*, ed. A. Bowling, 2nd edn, Open University Press, United States, pp. 378-379.
- Bronfenbrenner, U. 1979, "An ecological orientation" in *The ecology of human development*, ed. U. Bronfenbrenner, Harvard University Press, United States of America, pp. 20-26.
- Bury, M. 1982, "Chronic illness as biographical disruption", *Sociology of health & illness*, vol. 4, no. 2, pp. 167-182.
- Capeau, J. 2010, "Ageing, metabolism and HIV", *Retrovirology*, vol. 7, pp. I6.
- Casau, N.C. 2005, "Perspective on HIV infection and aging: emerging research on the horizon", *Clinical Infectious Diseases*, vol. 41, no. 6, pp. 855-863.
- Chesney, M.A., Chambers, D.B., Taylor, J.M. & Johnson, L.M. 2003, "Social support, distress, and well-being in older men living with HIV infection", *Journal of acquired immune deficiency syndromes (1999)*, vol. 33 Suppl 2, pp. S185-93.
- Cloud, G.C., Browne, R., Salooja, N. & McLean, K.A. 2003, "Newly diagnosed HIV infection in an octogenarian: the elderly are not 'immune'.", *Age & Ageing*, vol. 32, no. 3, pp. 353-354.
- Colbert, A.M., Kim, K.H., Sereika, S.M. & Erlen, J.A. 2010, "An Examination of the Relationships Among Gender, Health Status, Social Support, and HIV-Related Stigma", *Journal of the Association of Nurses in AIDS care*, vol. 21, no. 4, pp. 302-313.
- Cutcliffe, J.R. & McKenna, H.P. 1999, "Establishing the credibility of qualitative research findings: the plot thickens", *Journal of advanced nursing*, vol. 30, no. 2, pp. 374-380.

- Das informationssystem der Gesundheitsberichterstattung des Bundes 07 Feb. 2011-last update. Available: <http://www.gbe-bund.de> [2011, 02/08].
- Deacon, H., Stephney, I. & Prosalendis, S. 2005, "Responding to stigma" in *Understanding HIV/AIDS stigma: a theoretical and methodological analysis*, eds. H. Deacon, I. Stephney & S. Prosalendis, HSRC Press, Cape Town, pp. 31-32.
- Devine, P.G., Plant, E.A. & Harrison, K. 1999, "The problem of "us" versus "them" and AIDS stigma", *American Behavioral Scientist*, vol. 42, no. 7, pp. 1212-1228.
- Dittmann-Koli, F., Jopp ,D. 2007, "Self and life management: wholesome knowledge for the third age" in *Ageing in society*, eds. Bond, J., Peace, S., Dittmann-Kohli, F., Westerhof, G., 3rd edn, Sage Publications Ltd, London, pp. 268.
- Dovidio, J.F., Major, B. & Crocker, J. 2003, "Stigma: Introduction and overview" in *The social psychology of stigma*, eds. T.F. Heatherton, R.E. Kleck, M.R. Hebl & J.G. Hull, Guilford Press, United States of America, pp. 3-5.
- Earnshaw, V.A. & Chaudoir, S.R. 2009, "From conceptualizing to measuring HIV stigma: a review of HIV stigma mechanism measures", *AIDS and behavior*, vol. 13, no. 6, pp. 1160-1177.
- Ebersole, P., Hess, P., Touhy, T.A. & Jett, K.F. 2005, "Psychological, cognitive and social aspects of aging" in *Gerontological nursing & healthy aging*, eds. P. Ebersole, P. Hess, T.A. Touhy & K. F. Jett, 2nd edn, Elsevier Health Sciences, St. Louis/ US, pp. 108.
- Edwards, L.V. 2006, "Perceived social support and HIV/AIDS medication adherence among African American women", *Qualitative health research*, vol. 16, no. 5, pp. 679-691.
- Elo, S. & Kyngäs, H. 2008, "The qualitative content analysis process", *Journal of advanced nursing*, vol. 62, no. 1, pp. 107-115.
- Emler, C.A. 2006, ""You're awfully old to have this disease": Experiences of stigma and ageism in adults 50 years and older living with HIV/AIDS", *The Gerontologist*, vol. 46, no. No. 6, pp. 781-790.
- Emler, C.A., Tozay, S. & Raveis, V.H. 2011, ""I'm not going to die from the AIDS": resilience in aging with HIV disease", *The gerontologist*, vol. 51, no. 1, pp. 101-111.
- Emler, C.A. 2005, "Measuring stigma in older and younger adults with HIV/AIDS: an analysis of an HIV stigma scale and initial exploration of subscales", *Research on Social Work Practice*, vol. 15, no. 4, pp. 291-300.
- Emler, C.A. 2008, "Truth and consequences: a qualitative exploration of HIV disclosure in older adults", *AIDS Care*, vol. 20, no. 6, pp. 710-717.
- Emler, C.A. 2007, "Experiences of stigma in older adults living with HIV/AIDS: a mixed-methods analysis", *AIDS Patient Care and STDs*, vol. 21, no. 10, pp. 740-752.
- Emler, C.A. 2006a, "A comparison of HIV stigma and disclosure patterns between older and younger adults living with HIV/AIDS.", *AIDS Patient Care & Stds*, vol. 20, no. 5, pp. 350-358.

- Emlet, C.A. 2006b, "An examination of the social networks and social isolation in older and younger adults living with HIV/AIDS", *Health & social work*, vol. 31, no. 4, pp. 299-308.
- Emlet, C.A., Gerkin, A. & Orel, N. 2009, "The graying of HIV/AIDS: preparedness and needs of the aging network in a changing epidemic", *Journal of gerontological social work*, vol. 52, no. 8, pp. 803-814.
- Eustace, R.W. & Ilagan, P.R. 2010, "HIV disclosure among HIV positive individuals: a concept analysis", *Journal of advanced nursing*, vol. 66, no. 9, pp. 2094-2103.
- Ferreira, P.M. 2010, "Parceiros, relacionamentos e trajetórias sexuais" in *Sexualidades em Portugal: comportamentos e riscos [Sexualities in Portugal: behaviours and risks]*, eds. P.M. Ferreira & M.V. Cabral, 1st edn, Editorial Bizanco, Lisbon-Portugal, pp. 104.
- Fisher, M. 2010, "Ageing with HIV: next challenges", *Retrovirology*, vol. 7, pp. 14.
- Fonseca, A.M. 2006, "O Envelhecimento - Uma Abordagem Psicológica" [Ageing - A psychological approach], 2nd edn, Universidade Católica Portuguesa, Lisboa.
- Gallo, R.C. & Montagnier, L. 2003, "The discovery of HIV as the cause of AIDS", *The New England journal of medicine*, vol. 349, no. 24, pp. 2283-2285.
- Ganczak, M., Barss, P., Alfaresi, F., Almazrouei, S., Muraddad, A. & Al-Maskari, F. 2007, "Break the silence: HIV/AIDS knowledge, attitudes, and educational needs among Arab university students in United Arab Emirates", *The Journal of adolescent health : official publication of the Society for Adolescent Medicine*, vol. 40, no. 6, pp. 572.e1-572.e8.
- Gilbert, P.B., Mckeague, I.W., Eisen, G., Mullins, C., Guéye-Ndiane, A., Mboup, S. & Kanki, P., J. 2003, "Comparison of HIV-1 and HIV-2 infectivity from perspective cohort study in Senegal", *Statistics in Medicine*, vol. 22, no. 4, pp. 501-664.
- Goffman, E. 1986, *Stigma: Notes on the management of spoiled identity*, 1st Touchstone Edition, Simon & Schuster, United States of America.
- Golden, J., Conroy, R.M. & Lawlor, B.A. 2009, "Social support network structure in older people: underlying dimensions and association with psychological and physical health", *Psychology, Health & Medicine*, vol. 14, no. 3, pp. 280-290.
- Gorman, E.M. & Nelson, K. 2003, "From a far place: social and cultural considerations about HIV among midlife and older gay men" in *Gay and lesbian aging: research and future directions*, eds. G. Herdt & B. de Vries, Springer Publishing Company Inc., New York, pp. 73-95.
- Greene, K., Derlega, V.J., Yep, G.A. & Petronio, S. 2003a, "Decisions to disclose or not disclose about an HIV positive diagnosis" in *Privacy and disclosure of HIV in interpersonal relationships*, eds. K. Greene, V.J. Derlega, G.A. Yep & S. Petronio, Lawrence Erlbaum Associates, New Jersey.
- Greene, K., Derlega, V.J., Yep, G.A. & Petronio, S. 2003b, *Privacy and disclosure of HIV in interpersonal relationships*, Lawrence Erlbaum Associates, New Jersey.

- Grov, C., Golub, S.A., Parsons, J.T., Brennan, M. & Karpiak, S.E. 2010, "Loneliness and HIV-related stigma explain depression among older HIV-positive adults", *AIDS Care*, , pp. 1-10.
- Grönfors, M. 2008, , *Laadullisen tutkimuksen kenttätutkimusmenetelmät*. Available: http://homepage.mac.com/vilkka/Kirjat/Laadullisen_tutkimuksen.pdf [2011, 05/10].
- Hawkins, M. 1997, "Defining social Darwinism" in *Social Darwinism in European and American thought, 1980-1945*, ed. M. Hawkins, Cambridge University press, United Kingdom, pp. 1-39.
- Health Protection Agency Centre for Infections, Health Protection Scotland & UCL Institute of Child Health. 2010, , *United Kingdom: new HIV diagnosis to the end of June 2010: Table 6*. Available: http://www.hpa.org.uk/web/HPAwebFile/HPAweb_C/1237970242135 [2011, 02/08].
- Heckman, T.G. 2003, "The chronic illness quality of life (CIQOL) model: explaining life satisfaction in people living with HIV disease", *Health psychology : official journal of the Division of Health Psychology, American Psychological Association*, vol. 22, no. 2, pp. 140-147.
- Heckman, T.G., Barcikowski, R., Ogles, B., Suhr, J., Carlson, B., Holroyd, K. & Garske, J. 2006, "A telephone-delivered coping improvement group intervention for middle-aged and older adults living with HIV/AIDS", *Annals of Behavioral Medicine : A Publication of the Society of Behavioral Medicine*, vol. 32, no. 1, pp. 27-38.
- Heckman, T.G., Heckman, B.D., Kochman, A., Sikkema, K.J., Suhr, J. & Goodkin, K. 2002, "Psychological symptoms among persons 50 years of age and older living with HIV disease", *Aging & mental health*, vol. 6, no. 2, pp. 121-128.
- Heinrich, L.M. & Gullone, E. 2006, "The clinical significance of loneliness: a literature review", *Clinical psychology review*, vol. 26, no. 6, pp. 695-718.
- Herek, G.M. 1999, "AIDS and stigma", *American Behavioral Scientist*, vol. 42, no. 7, pp. 1106-1116.
- Holzemer, W.L., Human, S., Arudo, J., Rosa, M.E., Hamilton, M.J., Corless, I., Robinson, L., Nicholas, P.K., Wantland, D.J., Moezzi, S., Willard, S., Kirksey, K., Portillo, C., Sefcik, E., Rivero-Mendez, M. & Maryland, M. 2009, "Exploring HIV stigma and quality of life for persons living with HIV infection", *The Journal of the Association of Nurses in AIDS Care : JANAC*, vol. 20, no. 3, pp. 161-168.
- Hult, J.R., Maurer, S.A. & Moskowitz, J.T. 2009, "'I'm sorry, you're positive': a qualitative study of individual experiences of testing positive for HIV", *AIDS Care*, vol. 21, no. 2, pp. 185-188.
- Immonen, S., Valvanne, J. & Pitkala, K.H. 2010, "Older adults' own reasoning for their alcohol consumption", *International journal of geriatric psychiatry*, .
- Instituto Nacional de Saúde Dr. Ricardo Jorge 2009, , *Infecção VIH/SIDA-Situação em Portugal a 31 de Dezembro de 2008*. Available: http://www.aidsportugal.com/recursos/VIH-SIDA_Dezembro_de_2008.pdf [2010, 03/26].

- Ironson, G., Stuetzle, R. & Fletcher, M.A. 2006, "An increase in religiousness/spirituality occurs after HIV diagnosis and predicts slower disease progression over 4 years in people with HIV", *Journal of general internal medicine*, vol. 21 Suppl 5, pp. S62-8.
- Jones, E.E., Farina, A., Hastorf, A.H., Markus, H., Miller, D.T. & Scott, R.A. 1984, *Social stigma: The psychology of market relationships*, Freeman, New York.
- Jylhä, M. & Jokela, J. 1990, "Individual experiences as cultural: a cross-cultural study on loneliness among the elderly", *Ageing and Society*, vol. 10, pp. 295-315.
- Jylhä, M. & Saarenheimo, M. 2010, "Loneliness and ageing: Comparative perspectives" in *The Sage handbook of Social Gerontology*, ed. P.C. Dannefer Daniel, Sage Publications Ltd, , pp. 317-328.
- Kahana E. & Kahana B. 2001, "Successful aging among people with HIV/AIDS", *journal of clinical epidemiology*, vol. 54, pp. S53-S56.
- Kaijaleena, S. 2008, *University students' attitudes towards HIV/AIDS in Finland and in Kenya*, Faculty of Medicine, Institute of Health Sciences, University of Oulu.
- Karpiak, S.E., Shippy, R.A. & Cantor, M.H. 2006, *Research on Older Adults with HIV. New York: AIDS Community Research Initiative of America*. Available: <http://www.acria.org/files/ROAH%20Final.pdf> [2011, 03/26]
- Kimberly, J.A., Serovich, J.M. & Greene, K. 1995, "Disclosure of HIV-positive status: five women's stories", *Family relations*, vol. 44, pp. 316-322.
- Knipscheer, C.P.M, Broese Van Groenou, M.I, Leene, G.F.J, Beekman, A.T.F & Deeg, D.J.H 2000, "The effects of environmental context and personal resources on depressive symptomatology in older age: a test of the Lawton model", *Ageing and Society*, vol. 20, no. 2, pp. 183-202.
- Knodel, J. & VanLandingham, M. 2002, "The impact of the AIDS epidemic on older persons", *AIDS (London, England)*, vol. 16 Suppl 4, pp. S77-83.
- Knodel, J., Watkins, S. & VanLandingham, M. 2003, "AIDS and older persons: an international perspective", *Journal of acquired immune deficiency syndromes (1999)*, vol. 33 Suppl 2, pp. S153-65.
- Ko, N.Y., Lee, H.C., Hsu, S.T., Wang, W.L., Huang, M.C. & Ko, W.C. 2007, "Differences in HIV disclosure by modes of transmission in Taiwanese families", *AIDS Care*, vol. 19, no. 6, pp. 791-798.
- Kralik, D., Brown, M. & Koch, T. 2001, "Women's experiences of 'being diagnosed' with a long-term illness", *Journal of advanced nursing*, vol. 33, pp. 594-602.
- Kremer, H. & Ironson, G. 2009, "Everything changed: spiritual transformation in people with HIV", *International journal of psychiatry in medicine*, vol. 39, no. 3, pp. 243-262.

- Kroenke, C., H., Kubzansky, L.D., Schernhammer, E.S., Holmes, M.D. & Kawachi, I. 2006, "Social networks, social support and survival after breast cancer diagnosis", *Journal of clinical oncology*, vol. 24, no. 7, pp. 1105-1111.
- Kylmä, J., Rissanen, M., Laukanen, E., Nikkonen, M., Isola, A. & Juvakka, T. 2008, "Ainestolähtöisellä sisällönanalyysillä tietoa hoitotyön kehittämiseen- Esimerkkinä syöpää sairastavan nuoren vanhemman toivon vahvistaminen", *Tutkiva Hoitotyö*, vol. 6, no. 2, pp. 23-29.
- Kylmä, J., Rissanen, M., Laukanen, E., Nikkonen, M., Isola, A. & Juvakka, T. 2007, "Kuvaileva laadullinen terveystutkimus", *Permissi*, vol. 5, pp. 42-46.
- Kylmä, J. 2005, "Dynamics of hope in adults living with HIV/AIDS: a substantive theory", *Journal of advanced nursing*, vol. 52, no. 6, pp. 620-630.
- Landau, G. & York, A. 2004, "Keeping and disclosing a secret among people with HIV in Israel.", *Health and social work*, vol. 29, pp. 116-126.
- Lawton, M. P. & Nahemow, L. 1973, "Ecology and the aging process" in *Psychology of adult development and aging*, eds. C. Eisdorfer & M. P. Lawton, American Psychology Association, Washington, DC, pp. 619-674
- Lazarus, J.V. & Nielsen, K.K. 2010, "HIV and people over 50 years old in Europe", *HIV medicine*, vol. 11, no. 7, pp. 479-481.
- Lee, R.S., Kochman, A. & Sikkeman, K.J. 2002, "Internalized stigma among people living with HIV-AIDS", *AIDS and Behavior*, vol. 6, no. 4, pp. 309-319.
- Levy-Dweck, S. 2005, "HIV/AIDS fifty and older: a hidden and growing population", *Journal of gerontological social work*, vol. 46, no. 2, pp. 37-50.
- Lieberman, R. 2000, "HIV in older Americans: an epidemiologic perspective", *Journal of midwifery & women's health*, vol. 45, no. 2, pp. 176-182.
- Linsk, N.L., Fowler, J.P. & Klein, S.J. 2003, "HIV/AIDS prevention and care services and services for the aging: bridging the gap between service systems to assist older people", *Journal of acquired immune deficiency syndromes (1999)*, vol. 33 Suppl 2, pp. S243-50.
- Lovejoy, T.I., Heckman, T.G., Sikkema, K.J., Hansen, N.B., Kochman, A., Suhr, J.A., Garske, J.P. & Johnson, C.J. 2008, "Patterns and correlates of sexual activity and condom use behavior in persons 50-plus years of age living with HIV/AIDS", *AIDS and behavior*, vol. 12, no. 6, pp. 943-956.
- Magalhães, M.G., Greenberg, B., Hansen, H. & Glick, M. 2007, "Comorbidities in older patients with HIV: a retrospective study.", *Journal of the American Dental Association*, vol. 138, no. 11, pp. 1468-1475.
- Maia, M. 2010, "Práticas de risco no contexto das relações homossexuais" in *Sexualidades em Portugal: comportamentos e riscos [Sexualities in Portugal: behaviours and risks]*, eds. P.M. Ferreira & M.V. Cabral, 1st edn, Editorial Bizanco, Lisbon-Portugal, pp. 387-416.

- Malcolm, A., Aggleton, P., Bronfman, M., Galvão, J., Mane, P. & Verrall, J. 1998, "HIV-related stigmatization and discrimination: its forms and contexts", *Critical Public Health*, vol. 8, no. 4, pp. 347.
- Mallon, P. 2010, "Bone ageing and HIV", *Retrovirology*, vol. 7, pp. I31.
- Malone, M.A. 1998, "HIV-positive women over fifty: how they cope", *AIDS Patient Care and STDs*, vol. 12, no. 8, pp. 639-643.
- Markowitz, F.E. 1998, "The effects of stigma on the psychological well-being and life satisfaction of persons with mental illness.", *J Health Soc Behav.*, vol. 39, no. 4, pp. 335-347.
- Martin, C.P., Fain, M.J. & Klotz, S.A. 2008, "The older HIV-positive adult: a critical review of the medical literature.", *American Journal of Medicine*, vol. 121, no. 12, pp. 1032-1037.
- Maticka-Tyndale, E., Adam, B.D. & Cohen, J. 2002, "Sexual desire and practice among people living with HIV and using combination antiretroviral therapies", *Canadian journal of human sexuality*, vol. 11, no. 1, pp. 33-40.
- Mavandadi, S., Zanjani, F., Ten Have, T.R. & Oslin, D.W. 2009, "Psychological well-being among individuals aging with HIV: the value of social relationships", *Journal of acquired immune deficiency syndromes (1999)*, vol. 51, no. 1, pp. 91-98.
- Mckinlay, J.B., Skinner, K., Riley, J.W. & Zablotsky, D. 1989, "On the relevances of social science concepts and perspectives" in *AIDS in an ageing society: what we need to know*, eds. M.W. Riley, M.G. Ory & D. Zablotsky, Springer Publishing Co Inc, United States of America, pp. 129-130.
- Mhyre, J.M. 2010, "Assessing quality with qualitative research", *Canadian journal of anaesthesia = Journal canadien d'anesthesie*, vol. 57, no. 5, pp. 402-407.
- National Centre in HIV Epidemiology and Clinical Research 2010, , *HIV, viral hepatitis and sexually transmissible infections in Australia Annual Surveillance Report* [Homepage of The University of New South Wales, Sydney, NSW]. Available: <http://www.ncheer.unsw.edu.au> [2011, 02/08].
- Ncama, B.P., McInerney, P.A., Bhengu, B.R., Corless, I.B., Wantland, D.J., Nicholas, P.K., McGibbon, C.A. & Davis, S.M. 2008, "Social support and medication adherence in HIV disease in KwaZulu-Natal, South Africa", *International journal of nursing studies*, vol. 45, no. 12, pp. 1757-1763.
- Negin, J. & Cumming, R.G. 2010, "HIV infection in older adults in sub-Saharan Africa: extrapolating prevalence from existing data", *Bulletin of the World Health Organization*, vol. 88, no. 11, pp. 847-853.
- Newman, M.B. & Newman, P.R. 2008, " Development through life: a psychological approach", eds. M.B. Newman & P.R. Newman, 10th international edn, Cengage Learning, Inc, Belmont, US.

- Nguyen, N. & Holodniy, M. 2008, "HIV infection in the elderly", *Clinical Interventions In Aging*, vol. 3, no. 3, pp. 453-472.
- Nichols, J.E., Speer, D.C., Watson, B.J., Vergon, T.L., Vallee, C.M. & Meah, J.M. 2002, "The experience of older adults living with HIV" in *Aging with HIV: psychological, social and health status* Elsevier Science, San Diego, California, pp. 33-82.
- Nokes, K.M., Holzemer, W.L., Corless, I.B., Bakken, S., Brown, M., Powell-Cope, G.M., Inouye, J. & Turner, J. 2000, "Health-related quality of life in persons younger and older than 50 who are living with HIV/AIDS", *Research on aging*, vol. 22, no. 3, pp. 290-310.
- Ong, A.D., Bergeman, C.S., Bisconti, T.L. & Wallace, K.A. 2006, "Psychological resilience, positive emotions, and successful adaptation to stress in later life", *Journal of personality and social psychology*, vol. 91, no. 4, pp. 730-749.
- Orchi, N., Balzano, R., Scognamiglio, P., Navarra, A., De Carli, G., Elia, P., Grisetti, S., Sampaolesi, A., Giuliani, M., De Filippis, A., Puro, V., Ippolito, G., Girardi, E. & SENDIH group 2008, "Ageing with HIV: newly diagnosed older adults in Italy", *AIDS Care*, vol. 20, no. 4, pp. 419-425.
- Oxford dictionaries 2001, *Oxford dictionary of current English*, 3rd edn, Oxford University Press, Oxford/ Great Britain.
- Parker, A. & Bhugra, D. 2000, "Attitudes of British medical students towards male homosexuality", *Sexual and relationship therapy*, vol. 15, no. 2, pp. 141-149.
- Parsons, J.T., VanOra, J., Missildine, W., Purcell, D.W. & Gomez, C.A. 2004, "Positive and negative consequences of HIV disclosure among seropositive injection drug users", *AIDS Education and Prevention : Official Publication of the International Society for AIDS Education*, vol. 16, no. 5, pp. 459-475.
- Peplau, L.A. & Perlman, D. 1979, "Blueprint for a social psychological theory of loneliness" in *Love and attraction*, eds. M. Cook & G. Wilson, Pergamon, Oxford, England, pp. 99-108.
- Peterson, J.L. 2010, "The challenges of seeking and receiving support for women living with HIV", *Health communication*, vol. 25, no. 5, pp. 470-479.
- Pettigrew, S. & Roberts, M. 2008, "Addressing loneliness in later life", *Aging & mental health*, vol. 12, no. 3, pp. 302-309.
- Phillipson, C. & Baars, J. 2007, "Social theory and social ageing" in *Ageing in societies*, eds. J. Bond, S. Peace, F. Dittmann-Kohli & G. Westerhof, Third edition edn, Sage Publications Ltd, Great Britain, pp. 68-84.
- Poindexter, C.C. & Linsk, N.L. 1999, "HIV-related stigma in a sample of HIV-affected older female African American caregivers", *Social Work*, vol. 44, no. 1, pp. 46-61.
- Power, L., Bell, M. & Freemantle, I. 2010, , *A national study of ageing and HIV (50+)*. Available: <http://www.tht.org.uk/binarylibrary/peopleexperienceofhiv/50-plus-final-report.pdf> [2011, 02/10].

- Public Health Agency of Canada 2010, , *HIV/AIDS in Canada. surveillance report to December 31, 2009: Table 4b* [Homepage of Surveillance and risk assessment division, centre for communicable diseases and infection control. Public health agency of Canada]. Available: <http://www.phac-aspc.gc.ca/aids-sida/publication/survreport/2009/dec/pdf/2009-Report-Rapport.pdf> [2011, 02/08].
- Quinn, D.M. 2006, "Concealable versus conspicuous stigmatized identities" in *Stigma and group inequality*, eds. S. Levin & C. van Laar, Laurence Erlbaum Associates, United States of America, pp. 83-84.
- Rahmati-Najarkolaei, F., Niknami, S., Aminshokravi, F., Bazargan, M., Ahmadi, F., Hadjizadeh, A. & Tavafian, S.S. 2010, "Experiences of stigma in health care settings among adults living with HIV in the Islamic republic of Iran", *Journal of the international AIDS society*, vol. 13, no. 27.
- Reblin, M. & Uchino, B.N. 2008, "Social and emotional support and its implication for health", *Current opinion in psychiatry*, vol. 21, no. 2, pp. 201-205.
- Reece, M., Herbenick, D., Schick, V., Sanders, S.A., Dodge, B. & Fortenberry, J.D. 2010a, "Condom use rates in a national probability sample of males and females ages 14 to 94 in the United States", *The journal of sexual medicine*, vol. 7 Suppl 5, pp. 266-276.
- Reece, M., Herbenick, D., Schick, V., Sanders, S.A., Dodge, B. & Fortenberry, J.D. 2010b, "Sexual behaviors, relationships, and perceived health among adult men in the United States: results from a national probability sample", *The journal of sexual medicine*, vol. 7 Suppl 5, pp. 291-304.
- Reeves, P.M., Merriam, S.B. & Courtenay, B.C. 1999, "Adaptation to HIV infection: the development of coping strategies over time", *Qualitative health research*, vol. 9, no. 3, pp. 344-361.
- Root, R. 2010, "Situating experiences of HIV-related stigma in Swaziland", *Global public health*, vol. 5, no. 5, pp. 523-538.
- Ross, M.W., Tebble, W.E.M. & Viliunas, D. 1989, "Staging of reactions to AIDS virus infections in asymptomatic homosexual men", *J Psychol Hum Sex*, vol. 2, pp. 93-104.
- Ross, M.W. 1990, "Psychovenereology: psychological aspects of AIDS and other sexually transmissible diseases" in *Behavioral aspects of AIDS*, ed. D.G. Ostrow, Springer science + Business media, New York, pp. 34-36.
- Roth, N.L. & Nelson, M.S. 1997, "HIV diagnosis rituals and identity narratives", *AIDS Care*, vol. 9.
- Santos, E.C.M., França, I.J. & Lopes, F. 2007, "Quality of life of people livingwith HIV/AIDS in São Paulo,Brazil", *Revista de Saúde Pública*, vol. 41(Supl. 2).
- Sarason, I.G., Levine, H.M., Basham, R.B. & Sarason, B.R. 1983, "Assessing social support : the social support questionnaire ", *Journal of personality and social psychology*, vol. 44, no. 1, pp. 127-139.
- Scambler, G. & Hopkins, A. 1986, "Being epileptic: coming to terms with stigma", *Sociology of health & illness*, vol. 8, no. 1, pp. 26-43.

- Scambler, G. 1998, "Stigma and disease: Changing paradigms", *Lancet*, vol. 352, no. 9133, pp. 1054-1055.
- Schrimshaw, E.W. & Siegel, K. 2003, "Perceived barriers to social support from family and friends among older adults with HIV/AIDS", *Journal of health psychology*, vol. 8, no. 6, pp. 738-752.
- Seedat, S., Scott, K.M., Angermeyer, M.C., Berglund, P., Bromet, E.J., Brugha, T.S., Demyttenaere, K., de Girolamo, G., Haro, J.M., Jin, R., Karam, E.G., Kovess-Masfety, V., Levinson, D., Medina Mora, M.E., Ono, Y., Ormel, J., Pennell, B.E., Posada-Villa, J., Sampson, N.A., Williams, D. & Kessler, R.C. 2009, "Cross-national associations between gender and mental disorders in the World Health Organization World Mental Health Surveys", *Archives of General Psychiatry*, vol. 66, no. 7, pp. 785-795.
- Shippy, R.A. & Karpiak, S.E. 2005, "The aging HIV/AIDS population: Fragile social networks", *Aging & Mental Health*, vol. 9, no. 3, pp. 246-254.
- Shisana, O., Rehle, T., Simbayi, L.C., Zuma, K., Jooste, S., Pillay-van-Wyk, V., Mbelle, N., Van Zyl, J., Parker, W., Zungu, N.P., Pezi, S. & the SABSSM III Implementation Team 2009, , *South African national HIV prevalence, incidence, behaviour and communication survey 2008: A turning tide among teenagers?* [Homepage of HSRC. Press]. Available: <http://www.mrc.ac.za/pressreleases/2009/sanat.pdf> [2011, 02/08].
- Siegel, K., Raveis, V. & Karus, D. 1998, "Perceived advantages and disadvantages of age among older HIV-infected adults", *Research on aging*, , no. 20, pp. 686-711.
- Singh, N., Berman, S.M., Swindells, S., Justis, J.C., Mohr, J.A., Squier, C. & Wagener, M.M. 1999, "Adherence of Human Immunodeficiency Virus-Infected Patients to Antiretroviral Therapy", *Clinical Infectious Diseases*, vol. 29, no. 4, pp. 824.
- Skaggs, B.G. & Barron, C.R. 2006, "Searching for meaning in negative events: concept analysis", *Journal of advanced nursing*, vol. 53, no. 5, pp. 559-570.
- Ssali, S.N., Atuyambe, L., Tumwine, C., Segujja, E., Nekesa, N., Nannungi, A., Ryan, G. & Wagner, G. 2010, "Reasons for disclosure of HIV status by people living with HIV/AIDS and in HIV care in Uganda: an exploratory study", *AIDS Patient Care and STDs*, vol. 24, no. 10, pp. 675-681.
- Stevens, P.E. & Hildebrandt, E. 2006, "Life changing words: women's responses to being diagnosed with HIV infection", *ANS.Advances in nursing science*, vol. 29, no. 3, pp. 207-221.
- Stevens, P.E. & Tighe Doerr, R. 1997, "Trauma of discovery: Women's narratives of being informed they are HIV-infected", *AIDS Care*, vol. 9.
- Steward, W.T., Herek, G.M., Ramakrishna, J., Bharat, S., Chandy, S., Wrubel, J. & Ekstrand, M.L. 2008, "HIV-related stigma: Adapting a theoretical framework for use in India", *Social science & medicine*, vol. 67, no. 8, pp. 1225-1235.
- Stoff, D. M., Khalsa, J. H., Monjan, A. & Portegies, P. 2004, "Introduction: HIV/AIDS and Aging", *AIDS (London, England)*, vol. 18 Suppl 1, pp. S1-2.

- Stolley, K.S. & Glass, J.E. 2009, "Overview of HIV and AIDS" in *HIV/AIDS*, eds. K.S. Stolley & J.E. Glass, Greenwood Publishing group, United States Of America, pp. 8-9.
- Strombeck, R. 2003, "Finding sex partners on-line: a new high-risk practice among older adults?.", *Journal of acquired immune deficiency syndromes*, vol. 33 Suppl 2, pp. S226-228.
- Sun, H., Zhang, J. & Fu, X. 2007, "Psychological status, coping, and social support of people living with HIV/AIDS in central China", *Public health nursing (Boston, Mass.)*, vol. 24, no. 2, pp. 132-140.
- Tangenberg, K. 2004, "Mental health dimensions of HIV/AIDS in women over 50" in *HIV/AIDS and older adults*, ed. C.A. Emlet, Springer Publishing Company Inc., New York, pp. 73-79.
- Teri T. B., Jane L., Susan G. S., John M. P., Robert N. G., Diana O. P., Julie B. & Dwight L. E. 2004, "Changes in neuropsychological functioning with progression of HIV-1 infection: results of a 8-year longitudinal investigation", *AIDS and Behavior*, vol. 8, pp. 345-355.
- THL 2010, *HIV Suomessa ikäryhmittäin*. Available: <http://www.ktl.fi/ttr/gen/rpt/hivika.html> [2010, 03/26].
- Tomaka, J., Thompson, S. & Palacios, R. 2006, "The relation of social isolation, loneliness, and social support to disease outcomes among the elderly", *Journal of aging and health*, vol. 18, pp. 359-384.
- Tornstam, L. 1989, "Gero-transcendence: a reformulation of the disengagement theory", *Aging (Milan, Italy)*, vol. 1, no. 1, pp. 55-63.
- Tsasis, P. 2000, "Health-related quality-of-life measurements in HIV/AIDS care", *AIDS Patient Care and STDs*, vol. 14, no. 8, pp. 427-438.
- Tucker, J. S., Orlando, M., Burnam, M.A., Sherbourne, C. D., Kung, F. Y. & Gifford, A. L. 2004, "Psychosocial mediators of antiretroviral nonadherence in HIV-positive adults with substance use and mental health problems", *Health psychology : official journal of the Division of Health Psychology, American Psychological Association*, vol. 23, no. 4, pp. 363-370. UNAIDS December, 2003, , *UNAIDS fact sheet on stigma and discrimination*. Available: http://data.unaids.org/publications/Fact-Sheets03/fs_stigma_discrimination_en.pdf [2010, 11/4].
- UNAIDS 2010, 2010-last update, *UNAIDS report on the global AIDS epidemic*. Available: http://www.unaids.org/documents/20101123_GlobalReport_em.pdf [2011, 01/15].
- UNAIDS and WHO 2009, , *AIDS epidemic update. November 2009*. Available: http://data.unaids.org/pub/Report/2009/JC1700_Epi_Update_2009_en.pdf [2010, 03/26].
- Van der Meer, M., Fortuijn, J. D & Thissen, F. 2008, "Vulnerability and environmental stress of older adults in deprived neighbourhoods in the Netherlands", *Tijdschrift voor Economische en Sociale Geografie*, vol. 99, no. 1, pp. 53-64.
- Vance, D.E. & Woodley, R.A. 2005, "Strengths and distress in adults who are aging with HIV: a pilot study", *Psychological reports*, vol. 96, no. 2, pp. 383-386.

- Villamil-Cajoto, I., Losada-Arias, E., Prieto-Martinez, A., Lires-Moledo, C. & Quintela-Vazquez, P. 2006, "[HIV infection in patients aged 50 years or older in the HAART era]", *Enfermedades infecciosas y microbiologia clinica*, vol. 24, no. 6, pp. 382-384.
- Weiner, B. 1995, "The anatomy of responsibility" in *Judgments of responsibility*, ed. B. Weiner, Guilford Press, New York, pp. 14-22.
- Wolitski, R.J., Pals, S.L., Kidder, D.P., Courtenay-Quirk, C. & Holtgrave, D.R. 2009, "The effects of HIV stigma on health, disclosure of HIV status, and risk behavior of homeless and unstably housed persons living with HIV", *AIDS and behavior*, vol. 13, no. 6, pp. 1222-1232.
- World medical association declaration of Helsinki 2008, 2008-last update, *Ethical principles for medical research involving human subjects*. Available: <http://www.wma.net/en/30publications/10policies/b3/17c.pdf> [2011, 02/08].
- Wright, E.R. 2003, "Travel, tourism, and HIV risk among older adults", *Journal of acquired immune deficiency syndromes*, vol. 33 Suppl 2, pp. S233-237.
- www.avsf.bm/HIVphases.html , *HIV phases*. Available: www.avsf.bm/HIVphases.html [2011, 02/08].
- Zunzunegui, M.V., Minicuci, N., Blumstein, T., Noale, M., Deeg, D., Jylha, M., Pedersen, N.L. & CLESA Working Group 2007, "Gender differences in depressive symptoms among older adults: a cross-national comparison: the CLESA project", *Social psychiatry and psychiatric epidemiology*, vol. 42, no. 3, pp. 198-207.

APPENDIX 1

World medical association declaration- Ethical principles for medical research involving human subjects.

- 6- In medical research involving human subjects, the well-being of the individual research subject must take precedence over all other interests.

- 11- It is the duty of physicians who participate in medical research to protect the life, health, dignity, integrity, right to self-determination, privacy, and confidentiality of personal information of research subjects.

- 22- Participation by competent individuals as subjects in medical research must be voluntary. Although it may be appropriate to consult family members or community leaders, no competent individual may be enrolled in a research study unless he or she freely agrees.

- 23- Every precaution must be taken to protect the privacy of research subjects and the confidentiality of their personal information and to minimize the impact of the study on their physical, mental and social integrity.

- 33- At the conclusion of the study, patients entered into the study are entitled to be informed about the outcome of the study and to share any benefits that result from it, for example, access to interventions identified as beneficial in the study or to other appropriated care and benefits.

APPENDIX 2

Table 3: Number of new HIV diagnosis by year in people aged 50 years old and older, in selected countries

Years	United Kindgom	Canada	Australia	Finland	Portugal	Germany
1994 and early	1695			48		509
1995	228			7		243
1996	216			3		190
1997	241			5	604	235
1998	230			5	121	188
1999	256			9	107	190
2000	314		1622	10	99	198
2001	391		80	12	134	161
2002	442		103	13	147	174
2003	486	4247	143	10	175	196
2004	590	324	131	21	179	219
2005	688	331	144	23	154	262
2006	639	349	150	25	144	282
2007	721	383	158	48	131	313
2008	812	400	135	21	130	341
2009	856	362	159	36	53	373
2010	306			26		

APPENDIX 3

Inductive content analysis process example used in the present study.

The following example is extracted from HIV/AIDS related stigma section

Phase 1:

After a careful reading, the following participants' expressions were extracted from the interviews and formed sub-categories. The following table shows the process of data reduction.

Extracts from the interviews	Sub-categories
<i>"...I had a sort of feeling...that I was somehow <u>dirty</u>..."</i>	Dirty
<i>"...it was <u>self-blaming</u> and everything like that...well crazy thoughts..."</i>	Self-blame
<i>"...I'm sure that he doesn't want go further with the relation or doesn't want to be in a relationship where he would be constantly thinking how big <u>risk I'm for him</u>..."</i>	A risk to others
<i>"...for me <u>self-stigma is something endogenous</u>, I stigmatise myself...I</i>	Self-construct stigma

Phase 2:

Once sub-categories were created, a representative category was obtained.

Sub-categories	Category
Dirty	Negative HIV related self-image
Self-blame	
A risk to others	
Self-construct stigma	

Phase 3:

After obtaining all the categories, a common theme was obtained.

Categories	Theme
Fear of contagion	HIV/AIDS related stigma
Negative HIV related self-image	
Free from self-stigma	
Self-protective behaviours against stigma	

