

Thesis for doctoral degree (Ph.D.)
2010

HIV-infected African Parents Living in Stockholm, Sweden – Social Networks, Disclosure, Parenthood, and Knowledge About HIV-transmission.



Ann-Sofie Åsander

Thesis for doctoral degree (Ph.D.) 2010

Hiv-infected African Parents Living in Stockholm, Sweden

Ann-Sofie Åsander



**Karolinska
Institutet**

200
1810 – 2010 *År*



**Karolinska
Institutet**

200
1810 – 2010 *År*

INFECTIOUS DISEASES UNIT,
DEPARTMENT OF MEDICINE
Karolinska Institutet, Stockholm, Sweden

**HIV-INFECTED AFRICAN PARENTS
LIVING IN STOCKHOLM, SWEDEN –
SOCIAL NETWORKS, DISCLOSURE,
PARENTHOOD, AND KNOWLEDGE ABOUT
HIV-TRANSMISSION.**

Ann-Sofie Åsander



Stockholm 2010

The cover picture is drawn by my 12 year old son Samuel Hertsberg Åsander.

All published papers were reproduced with permission from the publisher.

Published by Karolinska Institutet. Printed by [Larserics AB]

© Ann-Sofie Åsander, 2010
ISBN 978-91-7409-774-0

ABSTRACT

Background: HIV-infected individuals born in Africa constitute about 30 percent of the about 5000 persons who are living with HIV in Sweden, and represent the largest group of those infected through heterosexual contact. Thus, most children of HIV-infected persons in Sweden have a parent of African origin. **Aim:** The overall aim of this thesis is to deepen our knowledge and understanding of the psychosocial situation of HIV-infected parents with African origin living in Stockholm/Sweden, as to identify and improve support strategies for these families.

Methods: The studies were carried out at the units for HIV care at the Department of Infectious Diseases at Karolinska University Hospital in Stockholm. The first study was a quantitative cross-sectional study performed among 47 HIV-infected African parents who were guardians of children younger than 18 (paper I and II). The semistructured interviews centred around four main areas; demographic and medical issues, social network and disclosure, knowledge of HIV-transmission, and future planning for their children. Data were recorded in the SPSS, and the variables were tested with the chi-square test. The second study was an explorative qualitative study among 12 HIV-infected Ugandan parents (paper III and IV). In-depth interviews were performed and the interview guide included two content areas: the participants' experience in relation to the disclosure of HIV status (Paper III), and their experience of being a parent, in Sweden as well as in Uganda (Paper IV). In the analysis process I used conventional content analysis. In this thesis, I have been inspired by and used several theoretical frameworks when discussing the study results. I used ecological system and social network theory as to discuss the results on the participants' social networks (paper I), and coping theory to discuss the findings on disclosure about the HIV-infection (paper III). In paper IV I used some dimensions of a cultural variability model to discuss the study results related to differences in parenthood in Uganda and Sweden.

Results: Most participants had small social networks consisting mainly of contacts with partners and children, and more than two-thirds of the participants had no relatives in Sweden informed about their HIV status. All had contact with at least one professional person who they regarded as important to them, and contact with social workers at the HIV clinic and at the social welfare office increased the probability of disclosure about HIV infection. Many had developed new friendships among members of churches and NGOs. The participants had basic knowledge of HIV transmission, although a third thought that HIV could transmit in non-scientifically verified ways, and there were uncertainties about whom to inform about the HIV infection (paper I). Only women had informed their children about their HIV status, and only to eight of 59 children older than six years. Half of the parents had talked to someone about future custody arrangements, and most parents wanted their children to be cared for by a relative in Sweden or by their HIV-negative partner (paper II). The thematic results in paper III revealed that the participants main reason to avoid being open about their HIV status was fear of being treated differently. Strategies they used were to omit the word HIV in conversations, and to pretend to have other illnesses when communicating with their children. A previously not described form of silent communication about HIV status when meeting other HIV-infected persons in voluntary organisations was described. They also reported about discrimination from medical personnel outside the HIV clinic. In paper IV thematic results revealed that Ugandan fathers in Sweden were expected to perform what they described as female tasks such as cooking and taking care of the children, and the Ugandan mothers were expected to share important family decisions with their husbands. All participants had access to ARV-treatment which seemed to function as a buffer as the parents continued to feel healthy. Other difficulties than HIV, such as how to manage being a parent and a husband or wife became more prominent. Parents also expressed fear of transmitting the HIV-virus to their children through daily contact.

Conclusions: HIV-infected African parents in Stockholm had small social networks with few persons informed about their HIV status. Lack of closeness to relatives seemed to have been compensated for by psychosocial support received from staff at the HIV clinic but also by support from voluntary organisations for HIV-infected persons. The parents mainly chose cognitive and/or behavioural coping to avoid openness about HIV status to children, relatives and friends. An 'African-Swedish method' was described where parents had integrated a more Swedish way of talking and being close to their children, but in relation to their HIV status they used what they described as the African style of not informing their children. As time passed and with the positive effects of ARV treatment parents tended to be less worried about leaving their children as orphans. Reported experiences of discrimination from medical personnel outside the HIV clinic, implies a need for education of health personnel at primary healthcare centres. Health care personnel need to pay attention to these HIV-infected African parents' cultural dilemmas and adapt medical information accordingly and repeat information about how the virus is and is not transmitted.

Keywords: African parents, collectivism-individualism coping and adaptation ,disclosure, HIV/AIDS, parenting, social network, Sweden, Uganda

LIST OF ORIGINAL PAPERS

- I. Åsander, A.-S., Belfrage, E., Pehrson, P.-O., Lindstein, T., & Björkman, A. (2004). HIV-infected African families living in Stockholm/Sweden: Their social network, level of disclosure, and knowledge about HIV. *International Journal of Social Welfare*, 13, 77-88.
- II. Åsander, A.-S., Björkman, A., Belfrage, E., & Faxelid, E. (2009). HIV-infected African parents living in Stockholm/Sweden: disclosure and planning for the future of their children, *Health & Social Work*, 34 (2), 107-115.
- III. Åsander, A.-S., Björkman, A., Nilsson Schönnesson, L. & Faxelid, E. *Fear of stigma and silent disclosure among HIV-infected Ugandan parents in Sweden*. In manuscript.
- IV. Åsander, A.-S., Rubensson, B., Munobwa, J., & Faxelid, E. *HIV-infected Ugandan parents in Sweden: "We have taken care of our children according to an African-Swedish method"*. In manuscript.

LIST OF ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Treatment
ARV	Antiretroviral
AZT	Azidothymidine
CDC	Centres for Disease Control
EU	European Union
EUR	Euro
GDP	Gross domestic products
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
IBM	International Business Machines
IDU	Injecting Drug User
HTLV-III	T-lymphotropic virus type III
KI	Karolinska Institutet
LAV	Lymphadenopathy-associated virus
MSM	Men who have sex with men
NBHW	National Board of Health and Welfare
NGO	Non-Governmental Organisation
PI	Protease inhibitor
RAV	The Swedish Reference Group for Antiviral Therapy
SCB	Statistics Sweden
SEK	Swedish Crown
SMI	Swedish Institute for Infectious Disease Control
SPSS	Statistical Programme for the Social Sciences
UNAIDS	Joint United Nations Programme on HIV/AIDS
USD	United States dollar
UNGASS	United Nations General Assembly Special Session on HIV/AIDS
USK	Stockholms Office of Research and Statistics.
WHO	World Health Organisation

CONTENTS

PREFACE	1
1 Introduction and background	3
1.1 The HIV-infection – short history	3
1.2 HIV in the world- Africa	4
1.2.1 HIV in Western Europe.....	5
1.3 The Swedish context.....	6
1.3.1 The Swedish Healthcare system	7
1.4 HIV in Sweden	7
1.4.1 Families living with HIV-infection in Sweden	8
1.4.2 The Swedish Communicable Diseases Act	9
1.4.3 National strategy against HIV/AIDS and certain other contagious diseases	10
1.4.4 Health care for HIV-infected persons in Sweden.....	10
1.5 Rationale for the studies	10
1.6 Theoretical framework	12
1.6.1 Ecological systems theory.....	12
1.6.2 Social network theory.....	13
1.6.3 Theoretical model on the underlying dimensions of coping skills	13
1.6.4 Dimensions of cultural variability	14
2 Objectives	16
2.1 General objective	16
2.2 Specific objectives	16
3 Methodology.....	17
3.1 Study setting.....	17
3.2 Study designs	17
3.2.1 Quantitative approach	17
3.2.2 Qualitative approach	18
3.3 Data analysis	19
3.3.1 Quantitative	19
3.3.2 Qualitative	19
3.4 Ethical considerations.....	20
4 Main findings.....	21
4.1 Disclosure	21
4.1.1 Social network and disclosure (I, II, IV)	21
4.1.2 Reasons and strategies to avoid and/or to be open about HIV status (III).....	23
4.1.3 Disclosure to children (II, III)	26
4.1.4 Professional contacts (I, III)	27
4.1.5 Contact with organisations (I, III).....	28
4.2 Knowledge about HIV/AIDS transmission and The Swedish Communicable Diseases Act (I, IV)	29
4.2.1 HIV transmission (I, IV)	29
4.2.2 The Swedish Communicable Diseases Act (I).....	29
4.3 Changing Ugandan parenthood in the Swedish context (II, IV).....	30

4.3.1	Parenting: Distance and Communication (IV).....	32
4.3.2	Sociocultural, legal and economic conditions for raising children (II, IV).....	34
5	Discussion.....	37
5.1	Methodological considerations	37
5.1.1	Validity and reliability	37
5.1.2	Trustworthiness	39
5.1.3	The use of theoretical models	41
5.2	Discussion of findings	42
5.2.1	Social network and disclosure	42
5.2.2	Communication and HIV disclosure to children.....	47
5.2.3	Fear of disclosure and stigma	49
5.2.4	Knowledge about HIV-transmission and The Swedish Communicable Diseases Act	51
5.2.5	Changing Ugandan parenthood in the Swedish context	52
6	Conclusions	54
7	Implications and recommendation for future research.....	56
8	Acknowledgements	58
9	References	61

PREFACE

The beginning of my research journey started in 1986. I was planning for my last period as a trainee, which was part of my education at the School of Social Work at the University of Stockholm. I planned to do my period as a trainee in the United States, and a friend gave me an article published in the Newsweek, thinking it would be of interest to me. It was an article about the "AIDS treatment team", and doctor Gerald Friedland in New York. After reading the article I was clear that I wanted to find a trainee job working with people infected with HIV. I was recommended to contact Jan-Olov Morfeldt at the Statens Bakteriologiska laboratorium (now The Swedish Institute for Infectious Disease Control). He gave me some addresses, and I got a very positive response from the Montefiore Medical centre in New York where they had a Department of Social Work with a large student unit including a placement in their AIDS services. Not until one week before I left I realized that I was going to the same team as the article in the Newsweek was about, and that I was going to have Monnie Callan as my field instructor, the first medical social worker working with HIV in New York (there was actually a picture of her in the article). Her guidance and being part of the team set the ground for my professional life for the following 20 years to come, up to now. Her work was characterised by great dedication, empathy and braveness. The "AIDS treatment team" worked multiprofessionally and the treatment of patients was family-oriented. In their team were both a lawyer and a priest. Monnie Callan was extremely dedicated to her patients, and ran support groups in the evenings. When I saw her work I became very inspired and felt this was something I wanted to continue with after my education.

In 1988, after I had finished my education at the University of Stockholm I got a job at the open clinic for dermatology and venereology at Huddinge Hospital. Here I met my first patient infected with HIV as a trained social worker. In 1990, I was employed at the HIV unit at the Infectious Diseases Department at Danderyds Hospital. Soon after I started, the paediatrician in our team, Erik Belfrage approached me and encouraged me to join him in a research project looking at the social situation of HIV-infected women in Stockholm. We then found that women from high-endemic areas in Africa had more children than other groups, but also the most insufficient social network. The results were published in *läkartidningen* (Åsander, Belfrage, Bohlin, Bengtsson, Lidman & Lindgren, 1994). At our clinic at that time there was an HIV-infected African single woman, mother of two children. For many years we co-operated with the social authorities, planning for what to do if/when the mother died and who would take care of her children. Arrangements were made and a foster family was engaged. However, two weeks before the mother died she did not bother about the previous planning, instead she asked her sister back in Africa to come to Sweden to look after her children. We realized we needed more culturally-specific understanding about how to best assist these African families affected by HIV.

This was the starting point for the first study in this thesis where we performed semi-structured interviews with 47 HIV-infected parents of African origin in Stockholm. During the research process antiretroviral treatment was introduced. In the beginning, we could not foresee the dramatically improved prognosis for HIV-infected patients

due to this treatment. It was like a bridge over the river Styx, leading from the dead to the living.

We extended our study and performed a comparative study in Padova (Italy), Kampala (Uganda) and Dar es Salaam (Tanzania), using the same questionnaire as in Stockholm. Additionally 150 interviews were collected, but due to lack of funding, and as the years went by and antiretroviral treatment was introduced at the two African hospitals we finally let go of our initial planning of doing comparative analysis between the four settings. After the half time control, I changed the direction of my research and decided to concentrate my thesis on the situation for HIV-infected African parents living in Stockholm.

Most of the time during the years as a PhD-student (except for the last couple of years) I have been working at my regular job as a medical social worker at the out patient clinic for HIV care. This was my starting point, and has been my most important journey, allowing meetings with many fantastic people who have been infected with HIV. Through these encounters and by being privileged to take part in so many life journeys, I have been able to understand, analyze and draw conclusions from the studies included in this thesis.

1 INTRODUCTION AND BACKGROUND

1.1 THE HIV-INFECTION – SHORT HISTORY

In less than 30 years the HIV/AIDS infection has developed to a pandemic threatening human health and development. HIV was first identified among gay men in the United States in 1981. These previously young and healthy men started to have rare opportunistic infections and a rare malignancy which was described as Gay Related Immunodeficiency Syndrome (Gottlieb et al., 1981, Centres for Disease Control (CDC), 1981; 30:21). However, soon it became apparent that also intravenous drug users (Masur et al., 1981), Haitians, and haemophiliacs had the unusual symptoms (CDC, 1982; 31:26). The syndrome was renamed to AIDS (Acquired Immune Deficiency Syndrome) (CDC, 1982; 31:37). It was found that the disease could also be transmitted by blood transfusions (CDC, 1982; 31:48), from mother to child (CDC, 1982; 31:49), and to female sexual partners of males with AIDS (CDC, 1983; 31:52). There were reports of the disease starting to occur in several European countries and in Uganda. Around this time a number of theories were developed about the possible cause of the syndrome, and knowledge about the disease was changing so quickly that certain explanations were shown to be unfounded just a few months later. There was a lot of concern about contagiousness since so little was known about transmission. AIDS transmission became a major issue and there was considerable fear in many countries causing alarm and prejudice in the general population. The haemophiliacs were described as the "innocent victims" of AIDS whereas men who had sex with men (MSM) and injecting drug users (IDU) were seen as having brought the disease upon themselves. In 1983 the retrovirus that causes the syndrome was discovered by two different groups of researchers. The research team in France called the virus lymphadenopathy-associated virus (LAV) (Barré-Sinoussi et al, 1983) and the researchers in the United States called it human T-lymphotropic virus type III (HTLV-III) (Gallo et al, 1984). In 1985, a second retrovirus was found in West African patients with AIDS, this virus was called LAV-2. The first test for the presence of antibodies to HTLV-III/LAV was launched in 1985. The different names of the retroviruses raised concerns and in 1986 an international committee changed the name again to the name it still has today - Human Immunodeficiency Virus (HIV) (Coffin et al., 1986). Thus, HTLV-III and LAV-1 are called HIV-1 and LAV-2 is now called HIV-2.

In 1986, there was dramatic progress in the medical treatment for AIDS when clinical tests showed that the drug azidothymidine (AZT) slowed the attack of HIV (Fischl et al., 1987). Many governments still denied that HIV or its risk behaviours existed in their countries. However, step-by-step, policy makers and the public reluctantly realised that the virus was spreading relentlessly over the world.

In 1996, there was great excitement and optimism about the treatment of HIV-infected people, as many improved enormously when they started taking triple combination therapy normally including protease inhibitor (PI). This started a new era with the Highly Active Antiretroviral Treatment (HAART) leading to a tremendous decrease of morbidity and mortality among patients with HIV/AIDS who had access to the treatment (Pallela et al., 1998; Vittinghoff et al., 1999).

1.2 HIV IN THE WORLD - AFRICA

Today every country in the world acknowledges and reports HIV-infection and/or AIDS in its population (Figure 1.1). Recently even the South African president Zuma declared his commitment to fight AIDS, where the former president Mbeki had previously denied the connection between HIV and AIDS.

Globally, there were an estimated 33.4 million [31.1 million–35.8 million] people living with HIV in 2008, and nearly 27 million people have died of AIDS. Women account for half of all people living with HIV worldwide. The global HIV epidemic has reached a steady situation in most regions and about one percent of the world adult population is infected. In Eastern Europe and in Asia the prevalence continues to rise due to new HIV infections (UNAIDS, 2009).

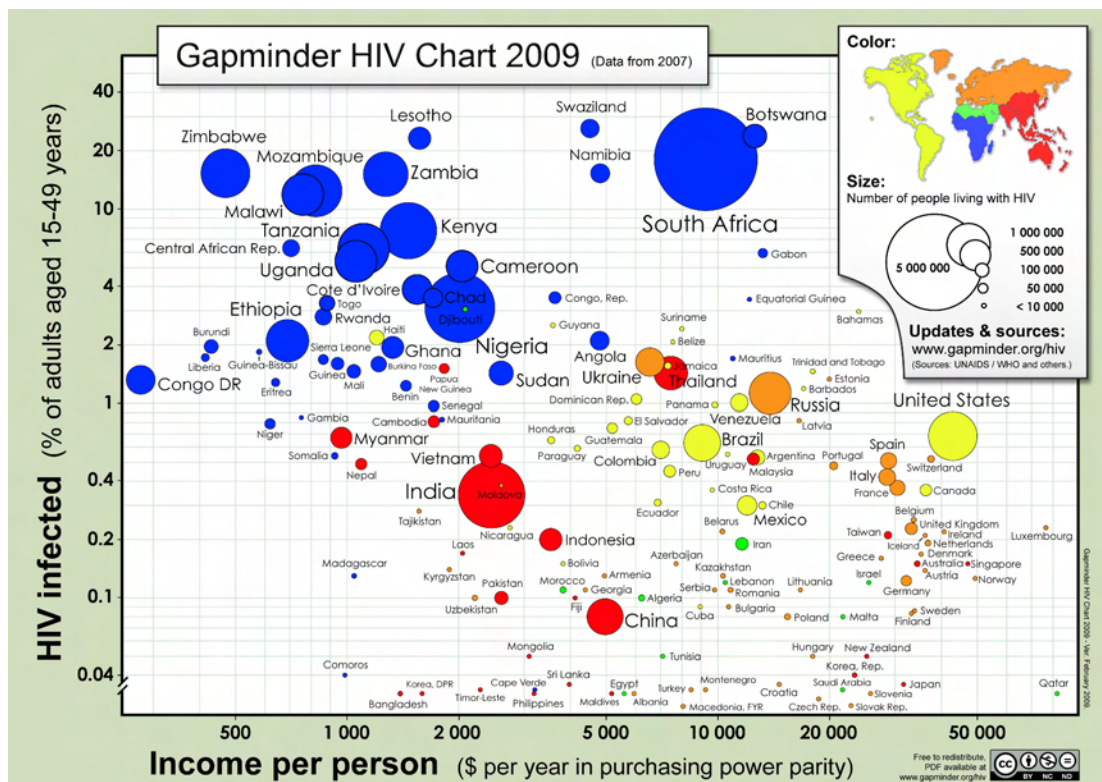


Figure 1.1: GAPMINDER HIV Chart, Source: (Gapminder, 2009)

Sub-Saharan Africa is home to 67 percent of all people living with HIV and 91 percent of all new HIV-infection among children. The region accounted for 72 percent of all AIDS-related deaths in 2008. Recent research among MSM indicates that they account for an important, previously undocumented, part of the HIV prevalence in many African countries (UNAIDS, 2009). Half of the world's HIV-infected persons live in a few countries in Eastern and Southern Africa with four percent of the world population. In southern Africa, average life expectancy at birth is estimated to have declined to below 50 years for the subregion as a whole (UNAIDS, 2008). There are no clear answers to why this region is so heavily affected. It could be because multiple concurrent sexual partners are believed to be more common in this part of the world and this, in conjunction with high viral load during acute HIV infection, has led to such high HIV prevalence (Epstein, 2007). HIV prevalence in East Africa has either reached

a plateau or is receding. In Uganda, adult HIV prevalence has stabilised at about five percent, but reported increases in sexual risk behaviours remain a source of concern (UNAIDS, 2009). However, many African countries have the same relatively low HIV prevalence as in most of the world and there are considerable variations of HIV-prevalence also within countries.

About 14 million children (under age 18) have lost one or both parents to AIDS in sub-Saharan Africa (UNAIDS, 2009). This has led to a change in the family structure and disturbed the capacity of the extended family to respond to the needs of family members affected by HIV and AIDS (Ankrah, 1993, Foster, 2000). Most traditional African cultures are built around patrilineal kinship systems where the fathers family is expected to care for orphans but there are also matrilineal systems where property and children follow the female lines (Amadiume, 1997; Gordon, 1996). The traditional safety net of aunts and uncles has often changed to the alternative safety nets of grandparents or other relatives. Or worse children are left to themselves and form child-headed households (Foster & Williamson, 2000). The epidemic has particularly harsh effects on women, who account for approximately 60 percent of estimated HIV infections in Africa, and represent two thirds of all caregivers for people living with HIV (UNAIDS, 2009). A positive development is that HIV prevalence among young women attending antenatal clinics has declined since 2000-2001 in 14 of 17 African countries. In the end of 2008, about 44 percent of children and adults in Sub-Saharan Africa who were in need of ARVs had access to treatment (WHO, United Nations Children's Fund, UNAIDS, 2009).

The global HIV epidemic cannot be reversed, and gains in expanding treatment access cannot be sustained without greater progress in reducing the rate of new HIV infections. Although young people between 15–24 years of age account for 45 percent of all new HIV infections, many of them still lack accurate, complete information on how to avoid exposure to the virus (UNAIDS, 2008). There is a general agreement on the necessity of a multilevel approach where behavioural HIV prevention needs to be integrated with biomedical structural approaches, and treatment for HIV-infection (Horton & Das, 2008; Merson, O'Malley, Serwadda & Apisuk, 2008; Padian, Buve', Balkus, Serwadda & Cates, 2008). "The focus is now is back on prevention. It is only by stopping the HIV-transmission that the world will be being able to deal with it. Drugs are too costly. Have we had the vaccine, or when we will get the vaccine, that is something more effective, but the drugs are very costly for the poor. Not the drug in itself but the care and treatment, which is needed around it" (Rosling, 2009).

1.2.1 HIV in Western Europe

In **Western and Central Europe** an estimated 850,000 people were living with HIV in 2008. Men who have sex with men continue to be the group most at risk of acquiring HIV within most Western European countries. Indeed, the number of new HIV diagnoses attributed to unprotected sex between men has increased sharply in recent years in Western Europe. In general, injecting drug use accounts for a smaller share of new HIV infections than before (UNAIDS, 2009).

In Western Europe individuals of African origin represent the second largest group of people with HIV infections, after men who have sex with men (EuroHiv, 2007). There

is an increase of people infected with HIV through heterosexual contact who originate from African countries with generalised HIV epidemics (Hamers & Downs, 2004). The majority of them are first generation immigrants from sub-Saharan Africa. Many of these persons are parents and the proportion of children born to HIV-infected women from sub-Saharan Africa has increased, while the proportion of children born to HIV-infected women with a history of intravenous drug use born in Europe has decreased (European collaborative study, 2004).

1.3 THE SWEDISH CONTEXT

Sweden has about nine millions inhabitants. Most immigrants in Sweden have come from the neighboring Nordic countries and from elsewhere in Europe. For non-EU nationals, immigration is strictly regulated today. In the end of 2008, about 90,000 individuals born in Africa were reported to be living in Sweden (representing about 1 % of the Swedish population) (SCB, 2008).

About two million people of the inhabitants of Sweden are under 18 years of age. A parental allowance is paid out for a total of 480 days when a child is born or adopted. All children born in Sweden are entitled to child allowance. The benefit is paid from the month after the birth of the child or later if the child moves to Sweden and continues until the child becomes 16 years. In 2009, the child allowance was SEK 1.050 (100 EUR) per child per month. All children have to attend school for at least nine years. There are no school fees. Children start school at the age of seven (six-year-olds attend preschool classes). Children between 6 and 12 years of age are offered day care before and after school. Eighty percent of all children have a mother who goes out to work, and 90 percent have working fathers (The Swedish Institute, 2009). Table 1.1 presents key Swedish demographic, health and socioeconomic indicators.

Table 1.1: Selected demographic, health and socio-economic indicators.

Characteristics/Indicators	Value
Area (km ²)	450,000
Population (millions)	9
Population Growth rate (%)	0.158
Life expectancy men (year)	78
Life expectancy women (years)	83
Infant mortality rate	2.75 deaths/1,000 live births
Maternal mortality rate	8/100 000 live births
Under 5 mortality rate	4/1000 live births
Total fertility rate	1.67 children born/woman
Literacy rate (%)	99
GDP per capita per year (USD)	38100
Government expenditure on health as a % of GDP	9
Net migration rate	1.66 migrant (s)/1000
Unemployment rate (%)	6.2

Source: CIA, The World Fact book, 2009

1.3.1 The Swedish Healthcare system

In Sweden, the health care system is government-funded, and all citizens are entitled to health care services. The responsibility for providing health care is decentralized to 20 county councils, and one municipality, the island of Gotland. Primary care has traditionally played a less important role in Sweden than in many other European countries, but now the aim is to make it the basis of the health and medical care system. About 25 percent of health centers are privately run by enterprises commissioned by county councils. Special clinics are provided for children and expectant women as well as family planning clinics for teenagers. Sixty hospitals provide specialist care with emergency room services 24 hours a day. Eight of them are regional hospitals where specialized care is offered and where most teaching and research is located. Seventy-one percent of health care is funded through local taxation, and county councils have the right to collect income tax, the average level being eleven percent. Contributions from the state represents 16 percent, while patient fees only account for three percent. The remaining ten percent come from other sources.

The fee for staying in a hospital is SEK 80 (7.5 EUR) per day, and to consult a primary care physician range from SEK 100 to 150. An appointment with a specialist will cost more. For children a visit to primary care physician is free of charge. For the individual there is a high-cost ceiling, which means that after a patient has paid a total of SEK 900 (84.5 EUR), medical consultations in the twelve months following the date of the first consultation are free of charge. A similar ceiling exists for prescribed medication, so no one pays more than SEK 1,800 (169 EUR) in a year (The Swedish Institute, 2009). However, undocumented migrants in Sweden do not have access to health care as described above (Platform for co-operation on undocumented migrants, 2007). For HIV-infected persons without document and in need of antiretroviral treatment, this can cause a life threatening situation.

1.4 HIV IN SWEDEN

In the end of 2007 it was estimated that 0,086 percent of adults aged 15 to 49 years were infected with HIV in Sweden (Gapminder, 2009). Totally 8,455 cases of HIV-infection (70 % men and 30 % women) have been reported between the year 1985 up to the end of 2008. Of those, 3,609 (43 %) have been infected through heterosexual contact, out of which 2,437 had African origin (40 % men, 60 % women) (Figure 1.2). Additionally, 2,931 were infected (35 %) through homo/bisexual contact, 1,092 (13 %) through intravenous drug use, and the remaining 819 (10 %) through blood or unknown transmission (M. Arneborn, SMI, personal communication, October, 2009).

Additionally it is estimated that approximately 10-20 percent of all HIV-positive individuals are unaware of their status (Gapminder documentation, 2008). The majority of persons infected through heterosexual contact with African origin come from East Africa: Uganda, Ethiopia, Burundi, Somalia, Eritrea, Kenya and Tanzania. Totally, 23 percent of all individuals infected with HIV have been reported to be infected in Sweden through homo/bisexual contact, 11 percent through intravenous drug use and only seven percent through heterosexual contact (the remaining 59 % were infected outside Sweden) (M. Arneborn, SMI, personal communication, October, 2009).

Compulsory HIV testing before blood donation was introduced in 1985, and since then no one has been HIV-infected by blood products in Sweden. In the national screening

programme for pregnant women 287 women have been detected with HIV-infection between the year 1986 and 2008. Of these 176 (61 %) were born in Africa (M. Arneborn, SMI, personal communication, October, 2009). The reported number of diagnosed cases of HIV-infection in Sweden remained relatively stable between 1994 and 2002 with approximately 250 new cases each year. The number of new cases increased during the years (2003- 2008) to approximately 400-500 reported cases per year. A small increase has been noted among men who have sex with men (SMI, 2009).

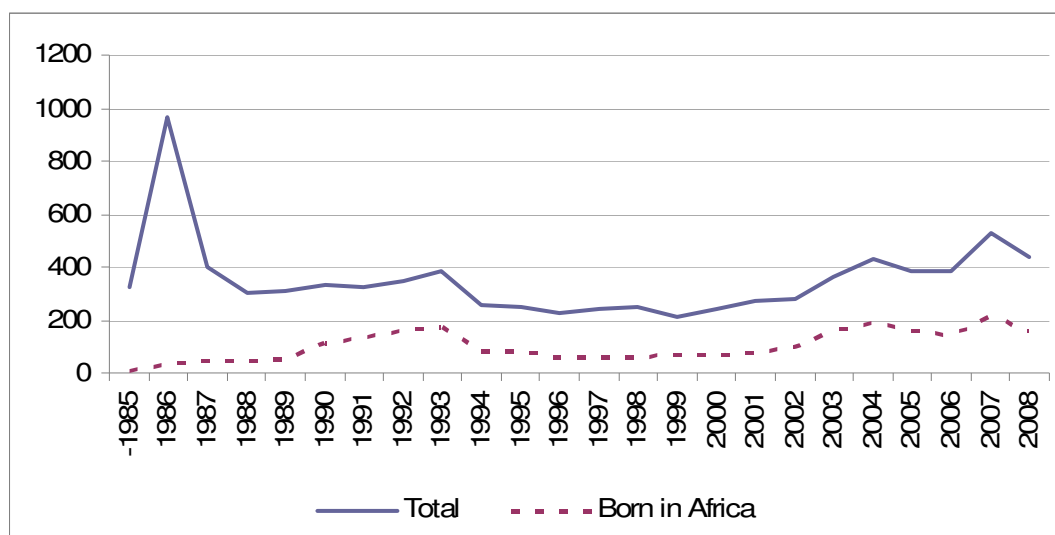


Figure 1.2 : Clinically reported cases of HIV-infection in Sweden 1985-2008 (n = 8,455), Source: (SMI, 2009)

In October 2009, 5,049 HIV-infected individuals were connected to the Swedish data base InfCare. Of those, 1,540 were born in Africa (30 %), and 116 were children below the age of 18 years (E.-L. Fredriksson, Karolinska University Hospital, personal communication, October 16, 2009). The InfCare HIV-programme is a combined tool for clinical care, quality assurance, remote decision support and a research database. It covers all HIV-infected persons treated at infectious diseases clinics, as well as most of the paediatric cases in Sweden.

1.4.1 Families living with HIV-infection in Sweden

About every fifth HIV-infected person in Sweden lives with a child/ren younger than 18 years of age (Åsander, 2007). These persons are parents to about 1,400 children. Approximately 70 percent of these parents have African origin, 20 percent have Swedish origin, and 10 percent have Asian origin, mainly from Thailand. An estimated assessment of the number of children to HIV-infected parents was performed by staff at all infectious diseases departments and clinics for venereal diseases in Sweden treating HIV-infected individuals in 2007 (Figure 1.3). Since the investigation is built on estimates, the real number of children is probably higher. Cities with less than five children are not included.

- Borås 16
- Eskilstuna 30
- Falun 40
- Gävle 30
- Göteborg 110
- Helsingborg 21
- Jönköping 53
- Kalmar 15
- Karlstad 20
- Linköping 30
- Lund 38
- Luleå 44
- Malmö 75
- Norrköping 25
- Stockholm 395
- Sundsvall 36
- Umeå 90
- Uppsala 56
- Västerås 55
- Växjö 15
- Örebro 36
- Östersund 10

Square= NGO for HIV-infected persons

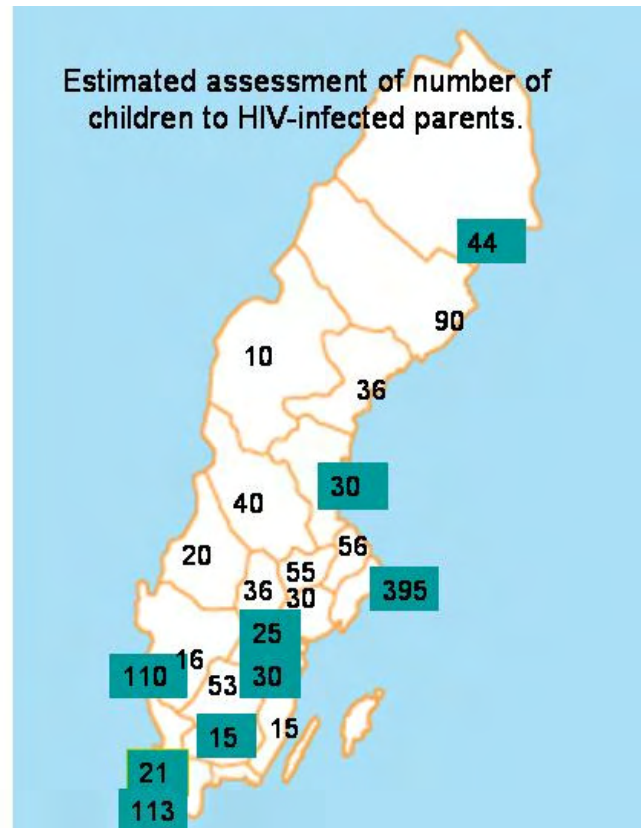


Figure 1.3 : Estimated assessment of number of children to HIV-infected parents in 2007, Source: (Åsander, 2007)

1.4.2 The Swedish Communicable Diseases Act

The Swedish Communicable Diseases Act declares that the responsibility for the work to combat communicable diseases lies with the County Medical Officer (The Swedish Communicable Diseases Act, 2004). According to the law, an HIV infection has to be notified to the County Medical Officer for communicable disease control and to the SMI at the national level. The notification is anonymous and contains a code with the patient's year of birth and the last four digits in the personal social-security number. The law states that if a person has a reason to suppose that he/she has been infected with HIV he/she should consult a physician without delay and allow the physician to carry out an HIV test. When a person is found to be HIV positive, he or she is immediately referred to a special HIV clinic and is required to have regular contact with a physician for the rest of his/her life. The physician is obliged to treat the patient free of charge and to give needed practical instructions to prevent the spread of infection. Partner notification is compulsory and persons infected with HIV are expected to identify their partners and facilitate the tracing of contacts carried out by specially trained counsellors at HIV clinics (Åsander, Berglund, Persson, & Ramstedt, 1996). Disclosure of HIV status is mandatory to persons at risk of becoming infected, such as sexual partners, and physicians. A county administrative court can issue a compulsory isolation order if a person does not voluntarily comply with the above instructions and if the lack of compliance entails a clear risk for the spread of HIV infection. The law is controversial and there is criticism that the law marginalizes the most vulnerable of the HIV-infected persons, such as migrants, persons with less education (Danziger, 1998) and youth (Christianson, Lalos, & Johansson, 2008).

1.4.3 National strategy against HIV/AIDS and certain other contagious diseases

In 2005, a new policy for the prevention of the spread of HIV was introduced in Sweden called the “National Strategy against HIV/AIDS and Certain Other Contagious Diseases” (Government Bill 2005/06:60). The National Board of Health and Welfare, (NBHW) received a mandate for the planning, coordination and monitoring of the strategy and began its work in June 2006. There is a National Council for the Coordination of HIV Prevention consisting of one chairperson appointed by the government and nine other members. The overall objectives and initiatives for the national strategy are to limit the spread of HIV and other STIs and to limit the consequences of these infections for society and for the individual.

INTERIM OBJECTIVES ARE:

- The number of newly registered cases of HIV infection where the infection has been transmitted in Sweden is to be halved by 2016.
- HIV infection among people seeking asylum and newly arrived relatives is to be identified within two months, and for others who have visited regions with high prevalence, within six months.
- Knowledge of HIV and of AIDS and how to live with HIV is to be improved in the public sector, in working life and in society at-large.

The Unit for National Coordination of HIV Prevention is located at the NBHW, and is the operative unit for planning, coordination, monitoring and management of a targeted government grant (UNGASS,2008).

1.4.4 Health care for HIV-infected persons in Sweden

In Sweden, patients with HIV infection are offered care and treatment at general outpatient clinics for infectious diseases. In larger cities there are specialized outpatient clinics for HIV/AIDS, usually connected to clinics for infectious diseases. Some patients get their care at clinics for venereal diseases. In Stockholm, there are two major units for HIV-infected patients (one primarily targets men who have sex with men). Children are mostly treated at paediatric clinics.

In larger cities, newly diagnosed HIV-positive persons are immediately referred to multidisciplinary teams at special HIV clinics and assigned a doctor, a nurse, and a medical social worker. In smaller cities, it is not obligatory to assign a medical social worker for psychosocial follow-up.

The Swedish Reference Group for Antiviral Therapy (RAV) has formulated guidelines about treatment and management of viral infections such as HIV since 2002. The main aim for RAV is to promote the rational use of antiviral drugs in Sweden (RAV, 2009).

1.5 RATIONALE FOR THE STUDIES

HIV-infected individuals born in Africa represent about 30 percent of the about 5,000 persons who are living with HIV in Sweden (SMI, 2009). They constitute the largest group of those infected through heterosexual contact. Thus, most children of HIV-infected persons in Sweden have a parent of African origin (Åsander, 2007). In 1994 we described the general social situation of HIV-infected women in Stockholm, and

found that women from Africa had more children than did other women, as well as the most insufficient social networks (Åsander et al., 1994).

HIV-infected parents of African origin experience in many respects, a vulnerable situation. Most are first generation immigrants and they are often unaware that they are infected with HIV when they migrate. Usually they have a test and receive their HIV diagnosis soon after their arrival, adding an additional trauma to an already unstable situation. A complex bureaucratic immigration process and having to adapt to a new culture are other challenges for these families. They come to Sweden, a country that is largely unknown to them, having only vague knowledge about its society and culture. In addition, they may not be able to rely on the traditional extended family support that they are used to (Thorne, Newell, & Peckham, 1998).

Coming from countries in sub-Saharan Africa, to countries in Europe constitutes a special situation, and study results among HIV-infected persons from other continents such as from North America cannot automatically be applied. The lack of studies about the situation of HIV-positive parents of African origin has previously been highlighted in a review of studies carried out among HIV-infected people of African origin in Europe (Prost, Elford, Imrie, Petticrew & Hart, 2008). A European multicenter study also addressed the importance of taking a family perspective when caring for HIV-infected parents and their children (Nöstlinger, Bartoli, Gordillo, Roberfroid, & Colebunders, 2006). As there were no previous studies on HIV-infected parents born in Africa but living in Sweden, my first study was initiated out of a need to know and understand more about these parents' social networks, disclosure of HIV status and knowledge about HIV so as to improve our support to them in the clinical care setting (paper **I** and **II**). The questionnaire was influenced by the situation of HIV-infected persons in 1997/1998, when the risk of becoming an orphan was a reality for many children with HIV-infected parents. At that time, soon after the introduction of ARV treatment, we did not foresee the dramatically improved prognosis for HIV-infected patients due to this treatment. After eight years, the majority of the study parents who still lived in Sweden were alive. Despite the success of treatments, parenthood issues such as whether or not children are and should be informed about their parents' HIV status and custody planning remain relevant, especially for the immigrant families who lack proximity to their extended families. In Sweden about two-thirds of HIV-infected people take ARV medication. Side effects from ART are common (Nolan, Reiss, & Mallal, 2005), which might evoke questions and worries among children. In an investigation on the support to children of HIV-infected parents in Sweden, it was estimated that out of about 1,400 children who lived with HIV-infected parents, fewer than ten percent had knowledge of their parents' HIV status (Åsander, 2007). The rationale for paper **III** was to deepen the understanding of the underlying reasons and strategies for the low HIV disclosure rate among these parents, which was one of the findings in the first study. As the study group in the first study consisted of parents from different African countries I wanted to get a deeper understanding about the cultural experiences of parents from one particular country. I then chose to perform a qualitative study among HIV-infected Ugandan parents as they represented the largest group of participants in study one and because Ugandans are one of the largest groups of HIV-infected Africans in Sweden. In order to get a deeper understanding of the psychosocial situation of these parents, I also considered it relevant to obtain more

information about the particular cultural experiences of these parents; how it is to be a Ugandan mother and father in Sweden and how that might influence their experience of parenthood. This was the rationale for my last paper **IV**, to understand the particular cultural experiences of HIV-infected parents with Ugandan background.

1.6 THEORETICAL FRAMEWORK

The word theory comes from the Greek *theoria*, which means “looking at” (Shoemaker, Tankard & Larsorsa, 2004). In this thesis, I have been inspired by and have used several theoretical frameworks, to “look at” and broaden the conceptual understanding when discussing the study results.

I used ecological systems and social network theories as to discuss the results about the participants’ social network systems in Sweden and Uganda, and I found that Moss’ (2002) theoretical model on the underlying dimensions of coping skills provided an interesting model to discuss the findings regarding disclosure about the HIV infection. Finally, Hofstede and Hofstede’s (2005) dimensions of cultural variability gave me an interesting explanatory framework for the study results regarding cultural parenthood differences in Uganda and Sweden. I will give a descriptive overview of the included theoretical models. In the discussion section I will further describe how they connect to the study results.

1.6.1 Ecological systems theory

The ecological systems theory emphasises that human development is dependent on an ever-expanding and deepening set of social networks (Bronfenbrenner, 1979, 1992, 1995). The individual and the environment are interconnected and interdependent. Urie Bronfenbrenner has developed a framework for analysing the developmental environment as a system of interdependent, interacting networks, consisting of immediate face-to-face settings to more distant social contexts such as cultures and belief systems. Human development takes place through a process of complex reciprocal interactions over an extended period of time – proximal processes –. These processes take place in the *micro-system*, which is the immediate setting, the place individuals inhabit, as well as the people who are there with them and the relationships between them (e.g. the relationships between mother and child, among siblings etc). The *mesosystem* is the interconnectedness between two or more settings; that is, a system of microsystems (e.g. the relation between home and school, work, government, church, etc.). The *exosystem* consists of one or more settings that do not involve a person’s development but do affect it (e.g. the relationship between school and political agencies). *Macrosystems* consist of the pattern of micro-, meso- and exosystems in a given culture or other social contexts. They are the belief systems, the ‘blueprint’, and they reflect people’s shared assumptions, lifestyles, and ideologies. This theory has previously been used, primarily, in connection with research on different aspects of child and adolescent development. However, because of the multilevel approach, the ecological systems theory has also been used with regard to analysis of cultural adaptation (Sternberg & Grigorenko, 2001).

1.6.2 Social network theory

Social network theory focuses on identifying conditions in society that influence the social network and the way it functions (Garbarino, 1983; Hesse, 1995; Klefbeck & Ogden, 2003). Garbarino (1983) describes a social support network as a set of interconnected relationships among a group of people that provides enduring patterns of nurturance and provides contingent reinforcement for efforts to cope with life on a day-to-day basis. For example, it has been found that the ethnic community in the new country is vital and buffers immigrants from stress, and enables them to function while gradually becoming assimilated (Bourdieu & Wacquant, 1992; Boyd, 1989). In the absence of a direct family relationship, having a friend or even someone from the same village might ease the transition into the new society. To be able to integrate with the new society, the immigrant needs to assimilate through a process of network building. An important variable in migration research is length of stay. This variable reflects length of exposure to the environmental conditions in the host country and the stage in the adaptation process (Kasl & Berkman, 1983). The pattern of refugee adjustment over time can be divided into four periods: 1) the initial arrival period of the first month; 2) the first and second years; 3) after four to five years; and 4) after a decade or more (Stein, 1986).

It is well documented that a network of support persons is important for coping with stressful life events (Bor & du Plessis, 1997; Caplan, 1974; Gore, 1978; Lazarus, 1984) and against illness progression and death (Berkman & Syme, 1979). For immigrants the reestablishment of a social network in the new country has been shown to reduce psychological distress (Furnham & Shiekh, 1993; Kuo & Tsai, 1986; Vega, Kolody & Valle, 1987). Several studies have reported the importance of support from friends and family for HIV-infected persons and how it has been shown to reduce stress (Crystal & Kersting, 1998) and depression (Namir, Alumbaugh, Fawzy & Wolcott, 1989; Ostrom Delaney, Serovich & Lim, 2009; Turner, Hays & Coates, 1993; Vyavaharkar, Moneyham, Corwin, Saunders, Annang & Tavkoli, 2009). Social networks are also important targets of HIV prevention, as they influence HIV risk behaviours (Latkin & Knowlton, 2005).

1.6.3 Theoretical model on the underlying dimensions of coping skills

Moss (2002) characterizes coping skills with respect to focus and method (Table 1.2). The focus of coping skills is either to approach or to avoid, and the method is either cognitive or behavioural. Approach coping is often problem-focused and it reflects cognitive and behavioural efforts to master or resolve life stressors. Avoidance coping tends to be emotionally focused and reflects cognitive and behavioural attempts to avoid thinking about a stressor and its implications, or to manage the effect associated with it (Moss, 1993).

Table 1.2: Underlying Dimensions of Coping Skills, Source: (Moos 2002)

Type of coping	Approach coping	Avoidance coping
Cognitive	Logical analysis	Cognitive avoidance
	Positive reappraisal	Acceptance of resignation
Behavioural	Seeking guidance and support	Seeking alternative rewards
	Problem solving	Emotional discharge

I found this theory suitable as disclosing or not disclosing the HIV status is part of a cognitive and behavioural process of coping. In previous studies about disclosure the concept of coping has been used in a more general sense (Holt, et al., 1998) to assess disclosure decisions in women (Sowell, Seals, Phillips & Julious, 2003) or to quantitatively study statistical correlation between disclosure and different coping strategies (Lee & Rotheram-Borus, 2002; Simoni, Demas, Mason, Drossman, & Davis, M, 2000; Steward et. al., 2008).

1.6.4 Dimensions of cultural variability

Hofstede and Hofstede (2005) describe five dimensions of cultural variability: femininity versus masculinity, power distance (from small to large), collectivism versus individualism, uncertainty avoidance (from weak to strong) and long-term orientation. A dimension is an aspect of a culture that can be measured relative to other cultures. Culture is defined as the collective programming of the mind that distinguishes the members of one group or category of people from another. The work of Geert Hofstede was from the beginning developed from a large body of survey data about the values of people in more than fifty countries around the world. The participants consisted of employees at IBM (International Business Machines), and represented almost perfectly matched samples, as they were similar in all respects except for nationality.

Together, the dimensions form a model of differences between national cultures where each country is characterised by a score on each of the dimensions. Replications of the IBM research have been performed by several researchers statistically confirming the dimensions (De Mooij, 2003; Merrett, 2000; Shane, 1995; Van Nimwegen, 2002). In each country there exist, of course all kinds of individual differences that do not match the national characteristics.

We found some dimensions of cultural variability- femininity versus masculinity, power distance and individualism-collectivism- useful for discussing and understanding our study results. In our qualitative study the participants came from Uganda which from this perspective has a masculine, collectivist, culture with a relatively high scored power distance, but they are also immigrants to Sweden which has a feminine, individualistic culture with a relatively low scored power distance (Hofstede & Hofstede, 2005).

A society like Uganda is defined as masculine when emotional gender roles are clearly distinct: men are supposed to be assertive, tough, and focused on material success, whereas women are supposed to be more modest, tender and concerned with the quality of life. A society, like Sweden, is called feminine when emotional gender roles overlap: both men and women are supposed to be modest, tender, and concerned with the quality of life (Hofstede & Hofstede, 2005).

Power distance is defined as the extent to which the less powerful members of institutions and organisations within a country expect and accept that power is distributed unequally. Institutions such as the family, the school, and the community are the basic elements of society. Organisations are the places where people work. In countries with relatively high power distance such as in Uganda, the traditional socialization is to teach children obedience, discipline and respect for the elders (Karuhanja, 2008; Opolot, 1982; Otiso, 2006). In countries with low power distance like in Sweden, parents are characterized to treat their children as equals, and the children in their turn consequently treat their parents and older relatives as equals (Hofstede & Hofstede, 2005).

Hofstede & Hofstede (2005) describe Sweden as an individualistic society, a society in which the interest of the individual prevails over the interest of the group. The ties between individuals are loose. Everyone grows up to look after him or herself and his or her immediate (nuclear) family only. Countries in East Africa like Uganda are scored as collectivist cultures where people are born into extended families or in other groups that continue protecting throughout people's lifetime in exchange for loyalty. Collectivist countries are societies where the interest of the group prevails over the interest of the individual (Hofstede & Hofstede, 2005).

2 OBJECTIVES

2.1 GENERAL OBJECTIVE

The general objective is to deepen our knowledge and understanding of the psychosocial situation of HIV-infected parents of African origin living in Stockholm, Sweden, as to identify and improve support strategies for these families.

2.2 SPECIFIC OBJECTIVES

- A) To explore and describe HIV-infected parents of African origin and their:
- 1) networks of important persons; families, relatives, friends (in Sweden and abroad), professionals, and contacts with organisations,
 - 2) knowledge about HIV/AIDS transmission and the Swedish Communicable Diseases Act (Paper **I**).
 - 3) HIV disclosure to their children and custody planning for their children (Paper **II**).
- B) To deepen our understanding of the underlying reasons and strategies for the low HIV disclosure rate among HIV-infected Ugandan parents in Stockholm (Paper **III**).
- C) To deepen our understanding about the views and experiences of parental roles among HIV-infected Ugandan parents in Stockholm (Paper **IV**).

3 METHODOLOGY

3.1 STUDY SETTING

These studies were conducted in Stockholm, the capital of Sweden. There are about 2 million inhabitants in the county of Stockholm, of which 40,000 are born in Africa. The city of Stockholm is a municipality consisting of 18 town districts divided into 33 parishes. The city has about 810,000 inhabitants, of whom about 180,000 were born abroad and/or have foreign citizenship (about 25,000 have African origin). Most of these immigrants live in segregated areas such as in Rinkeby-Kista, Skärholmen and Spånga-Tensta. About five percent of the inhabitants are unemployed and of these 44 percent have foreign citizenship (USK, 2009).

The studies were carried out at the units for HIV care at the Department of Infectious Diseases at Karolinska University Hospital in Solna and in Huddinge. At the time of the studies there were two units for HIV care at the Department of Infectious Diseases, both in Huddinge and in Solna. The Department of Infectious Diseases at Karolinska University Hospital has the largest HIV unit in Sweden with multidisciplinary teams of doctors, nurses, and medical social workers.

3.2 STUDY DESIGNS

In this thesis both quantitative and qualitative methods have been used.

3.2.1 Quantitative approach

Design (Paper I, II)

This was a cross-sectional study performed among HIV-infected African parents living in Stockholm. Face-to-face interviews using a questionnaire were performed.

Participants and procedures (Paper I, II)

At the end of 1997, 41,424 individuals aged over 18 years, born in Africa, were reported to be living in Sweden (SCB, 1997). Totally 773 were reported to be HIV-infected (SMI, 1997). This represents 28 percent of all HIV-infected persons reported in Sweden. At the time of the study, 241 HIV-infected persons born in Africa were followed up at the two Departments of Infectious Diseases in Stockholm; 103 of them were the guardians of children younger than 18. Sixty-five consecutive patients were asked to participate in the study when they came to the clinics for their usual visits and 47 of them agreed to participate. Fourteen patients declined without giving any further explanation. Another two said that they had no time, one said that the study was stigmatising, and one felt psychologically unstable. All participants were individually interviewed in Swedish or English. One interview was performed by telephone and with the help of an interpreter.

Method (Paper I, II)

Semistructured interviews were performed between November 1997 and October 1998 by the staff (nurses, social-workers, and one doctor) at the Infectious Diseases Outpatient Clinics at Karolinska University Hospital in Solna and Huddinge, and at the Social Family Clinic at Karolinska University Hospital in Huddinge. The questionnaire was also translated into English to be used for those who wished or who felt that they had insufficient knowledge of Swedish. The interview centred around four main areas: demographic and medical issues; social network and disclosure; knowledge of HIV-transmission; and future planning for their children. In a personal social network map the interviewee was asked to list important persons for him/herself, including relatives, children, friends, co-workers, and professional contacts in Sweden and abroad. A similar social network map has previously been used in Sweden (Olsson 1994; Samuelsson & Thernlund 1988; Svedhem, 1991) as well as in the United States (Tracy & Whittaker, 1990). The interviewee was asked if, to whom and when he/she had disclosed his/her HIV status. Contact with different organisations was asked for, such as Noah's Ark/Red Cross Foundation (a voluntary organisation providing support to HIV-infected individuals), immigrant organisations, political organisations, sports clubs or religious organisations.

In 2003/2004, five years after the main study, medical information concerning antiretroviral treatment, and how many who had died were taken from the patients medical records. These results are reported in paper **II**.

3.2.2 Qualitative approach

Design (Paper III, IV)

This was an explorative study among HIV-infected Ugandan parents living in Stockholm.

Participants and procedures (Paper III, IV)

Between May and July 2006, 48 HIV-infected Ugandans were patients at the Department of Infectious Diseases in Stockholm. Of those, 35 (27 women and 8 men) were parents. Participants were selected purposively, using information from their medical records to include persons with different backgrounds. Initially a clinic nurse or I contacted 15 patients by phone, or when they came to the HIV clinic for a routine visit. They were given information about the purpose of the study, and information on how to contact the research team. Two women declined to participate without giving any additional explanation, and one woman could not participate because she was going abroad. Twelve participants (eight women and four men) were thus included. They were assured of confidentiality, that participation was voluntary, and also that they could terminate the interview at any moment without this influencing their healthcare. Informed verbal consent was obtained before performing the interview.

Method (Paper III, IV)

The qualitative in-depth interviews were carried out by me. Data collection was performed just beyond a point of saturation where data became redundant with recurring themes (Guest, Bunce & Johnson, 2006). The interview guide included two

content areas: the participants' experience in relation to the disclosure of HIV status (Paper III), and their experience of being a parent, in Sweden as well as in Uganda (Paper IV). Both open-ended questions and probes were included in the interview guide so that the participants could answer freely, but also specific questions so that the core areas were addressed with each participant. I modified and expanded the interview guide as additional interviews were conducted. As to create an open environment and to make the participants free to express themselves, I followed the participants as they sometimes answered several questions in a row, using the interview guide to support and make sure that all core areas were covered. Interviews were conducted in Swedish or English according to the participant's own choice in a room outside the HIV clinic or in the participant's home. Two persons preferred to have the interview in their own home, and two interviews were conducted in English. The room outside the HIV clinic was chosen as a neutral place where the participants would have the possibility to be anonymous, not having to risk meeting someone they knew at the HIV clinic. Each interview lasted one to two hours. The interviews were tape-recorded and transcribed verbatim by me.

3.3 DATA ANALYSIS

3.3.1 Quantitative

Paper I, II

The data were recorded in the statistical programme for social sciences (SPSS, version 12). The demographic and medical background factors were: sex, age, country of origin, number of years in Sweden, legal position in Sweden, civil status, number of children <18 years, education, housing conditions, religion, income, years since HIV diagnosis, and clinical status. In paper I the relations between the background factors and the size of the person's social network, level of disclosure, contact with larger organisations, knowledge of HIV transmission and the Swedish Communicable Diseases Act were studied as possible explanatory variables. In paper II the relations between the demographic and medical factors and disclosure to and future planning for their children were studied as possible explanatory variables.

For each background parameter, the study group was sub-divided into two groups of approximately the same size in relation to the median value, to enable statistical comparison. The nominal variables were cross-tabulated and the relationships between the variables were tested with the chi-square test. Fisher's Exact Test was used when the expected value was less than five. Only relationships revealing statistical significance at the five percent significance level are commented upon.

3.3.2 Qualitative

Paper III, IV

In the analysis process I used conventional content analysis in which relevant theories are addressed in the discussion section of the study (Hsieh & Shannon, 2005). The analysis of the results is descriptive, close to the underlying meaning of the text (Graneheim & Lundman, 2004). First I performed multiple readings to get a sense of the material and to inductively identify tentative themes that emerged from the participants' descriptions of their situation. For each content area we identified meaning

units by underlining key phrases in the text. These meaning units were condensed though kept close to the text, and subcategories were abstracted from the meaning units that shared the same commonalities. These were further compared, reorganized and abstracted into categories, and subthemes. In this process we worked to find categories that were exhaustive and mutually exclusive, and where no data should fall between two categories or fit more than one category (Graneheim & Lundman, 2004). However, the meaning units about disclosure to children belonged to both content areas. This was solved by putting the meaning units about disclosure to children into the first content area about disclosure (paper **III**). The results about disclosure to children were then added into the introduction to paper **IV**.

In paper **III**, the initial coding was first carried out by me, and then together with the last author, until we reached agreement about the codes, categories, subthemes and theme. In paper **IV**, the coding was initially carried out separately by the third author and myself. The coding was then compared and discussed until agreement about the emergent codes, categories, subthemes and theme had been reached. The coding in both paper **III** and **IV** was then also discussed among the co-authors until agreement was reached.

3.4 ETHICAL CONSIDERATIONS

The studies have received ethical approval from the regional research ethics committee in Stockholm. Participants who agreed to participate were given written information about the purpose of the study and information on how to contact the research team. The participants were assured of confidentiality, that participation was voluntary, and also that they could terminate the interview at any moment without this influencing their healthcare. Informed verbal consent was obtained before performing the interviews. Because of the risk for emotional reactions, e.g. regarding reflecting on the possibility of one's children becoming orphans, all interviews were performed by health staff. If necessary, patients received support directly, or were offered one or two follow-up sessions with a social worker with special training in counselling.

4 MAIN FINDINGS

The research areas were investigated both quantitatively and qualitatively and the results are here presented thematically under the headings: disclosure, knowledge about HIV-transmission and pertinent legislation, and changing Ugandan parenthood in the Swedish context

4.1 DISCLOSURE

Under this heading and the following subheadings I have integrated the results regarding different aspects of disclosure about the HIV status with the results regarding the participants' social networks of relatives, friends, children, and professionals as well as contact with organisations.

4.1.1 Social network and disclosure (I, II, IV)

In the first study the interviewees were all first-generation immigrants (for background variables see Table 1, paper I). They had a median of three important family/relatives and friends living in Sweden and more than twice as many when important persons abroad were included (Table 4.1). Half of the study group had one or more close relatives living in Sweden, while the remaining participants had none (Table 4.2). The social network of important family/relatives and friends was of similar size in Sweden and in the home country. Those who reported more than three important persons in their social network in Sweden ($n = 23$) had to a greater extent informed more relatives in Sweden about their HIV status [$p < .05$]. The participants who had at least two important persons in Sweden ($n = 31$) had lived in Sweden for a longer time, than those having fewer important persons in their social network [$p < .05$].

Table 4.1: Number of important persons* for each interviewee – median (range) (N=47)

	In total	Informed of HIV status
Important persons* in Sweden	3 (0-17)	1 (0-7)
Important persons* Abroad	3 (0-22)	0 (0-11)
All important persons*	8 (1-35)	2 (0-16)

* Children and professionals excluded

Table 4.2: Number of important persons and degree of disclosure of HIV status

Important persons	Number and (percentage) of interviewees (<i>N</i> =47)	Disclosure of HIV status number and (percentage)
Partner	31 (66)	31/31 (100)
Children	47 (100)	5/47 (11)
Relatives in Sweden	23 (49)	14/23 (61)
Relatives abroad	39 (82)	16/39 (41)
Friends in Sweden	32 (68)	13/32 (41)
Friends abroad	11 (23)	3/11 (27)
Work/study mates	16 (34)	2/16 (13)
Professionals	47 (100)	47/47 (100)

Single women were an especially vulnerable group. The eleven single women with a total of 25 children in study one appeared to be more isolated and had a smaller social networks with only one or no person important to them in Sweden. They had fewer informed relatives in Sweden, but instead a larger number of informed relatives living abroad [$p < .05$]). The five single men had, as compared with the group of single women, larger networks, with two or more important people in Sweden. Four of the five single men had informed a relative in Sweden (paper II).

In paper IV the participants described the social networks in Uganda and in Sweden. Several single mothers experienced a lack of assistance with childcare in Sweden. They missed the support from their family and relatives, as one female participant said: “You’re expected to have all responsibility [in Sweden] and to take care of your child. You do not have relatives, and if you have, they’re not at home, they’re working, everybody is working, that’s difficult”.

In Uganda the situation was described as reverse because there was always someone there to assist with childcare. One mother fantasised about combining the economic situation in Sweden with the access to the social networks in Uganda: “If I had a Swedish economic standard, and the same access to assistance with my children as in Uganda I would have 100 children”.

The partners were in general informed about the participants’ HIV status before relatives and friends (Paper I). About a quarter of all relatives and friends were informed about the participant being infected with HIV (Table 4.2). Half of the study group (24) had only informed one person in Sweden. Five participants had not informed anyone. Relatives living in Sweden were to a greater extent informed than were relatives living abroad (Table 4.2). Mostly the participants disclosed their HIV status to relatives and friends at the time they received their HIV diagnosis. Disclosure did not affect these relationships, with one exception, which was a relative abroad who became very upset and broke off contact with the participant. Two of the ten persons who had a full-time job had informed their fellow workers about the infection. They had informed six and seven people, respectively. One of the two was working for a

voluntary organisation that supported people infected with HIV. Less than half of the participants had disclosed their HIV status to at least one person in Sweden who was important to them (Figure 4.1). They appeared to a greater extent to have more education prior to arrival in Sweden, and more important persons in their social network ($p < 0.05$). They also had seemed to have more contact with both an important professional person at the social welfare office and a social worker at the HIV clinic [$p < .05$]). The degree of disclosure did not appear to be associated with knowledge about HIV transmission.

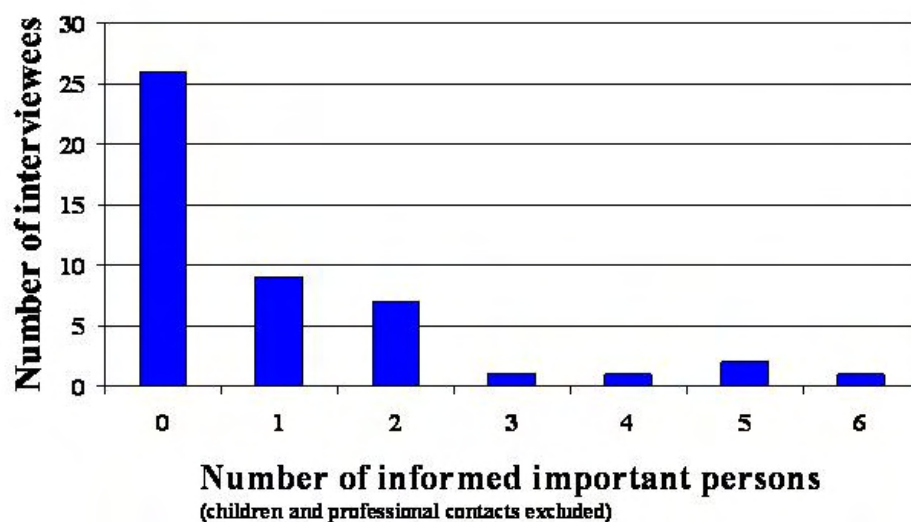


Figure 4.1: Number of important persons informed about the HIV infection (Partner/ex-partner excluded)

4.1.2 Reasons and strategies to avoid and/or to be open about HIV status (III).

In paper III, during the analysis process an overall theme emerged: reasons and strategies to avoid and/or to be open about HIV status. This theme included four subthemes: (1) reasons to avoid being open about HIV status, (2) strategies to avoid being open about HIV status, (3) reasons to be open about HIV status, and (4) strategies to be open about HIV status (Table 4.3). The first two subthemes on avoiding openness about HIV status included more than 75 percent of all meaning units (for background variables see Table 1, paper III).

Table 4.3: Main theme, subthemes and categories identified in HIV-infected Ugandan parents concerning openness about HIV status

Main Theme:	Subthemes:	Categories:
Reasons and strategies to avoid and/or to be open about HIV status	Reasons to avoid being open about HIV status	Avoiding negative reactions Protecting myself and my family from distressing emotions It is not necessary to tell anyone about your HIV status The children are too young
	Strategies to avoid being open about HIV status	Omitting HIV in conversations Avoiding/resisting visits to the HIV clinic Pretending to have other illnesses/problems
	Reasons to be open about HIV status	Receiving support A feeling of togetherness
	Strategies to be open about HIV status	Meeting HIV-infected persons in HIV organisations Telling someone trustworthy and close

A more detailed description of each category is presented below under this heading but also under the headings: disclosure to children, professional contacts and contacts with organisations.

Reasons and strategies to avoid being open about HIV status

Avoiding special treatment. The participants described their fear of being negatively treated if their HIV status were to become known to their children, relatives, friends, and health personnel outside the HIV unit, but also to acquaintances and to the community as a whole. They used phrases such as “they will pity me”, and “they will think I’m going to die”. One participant described the situation: “If you talk to someone you know, you cannot tell them about your HIV infection because the moment you tell someone that you have HIV or you’re taking medicine they will shrink away”. Another reason to avoid openness was the belief that people would gossip and talk behind their backs if they knew about the HIV infection.

According to the participants, if other people knew about their HIV status, it would be the same as being associated and identified with the HIV infection. As one participant expressed it: “I want to be like everybody else. Not belonging to a special group. I want to be just like you”. For some it was considered a problem for the whole African community: “Unfortunately that is the problem. In our group, HIV is the same as being discriminated against”. One participant expressed the fear of being treated negatively and isolated from society:

It is very, very difficult to tell anybody about the HIV infection. If you think how it has been for many years, how people with HIV have been stared at. It’s been really difficult. You get isolated from society, you get left out.

Protecting myself and my family from distressing emotions. The participants wanted to protect themselves as well as their family members from distressing emotions. By avoiding talking about HIV, the participants did not have to experience feelings such as “sadness”, “panic”, “discomfort”, “pain”, “tiredness” and “fear”. One participant explained: “I don’t want to talk about HIV because I only get sad, and I don’t want to be sad any longer. I get tired, and sad, very tired”.

Participants wanted family members to be protected from feelings of “stress”, “shock” and “helplessness”. One participant wanted to protect his mother from knowing about his HIV status:

I have lost six brothers and sisters, and cousins, maybe I’ve lost almost 25 from my family because of HIV . . . My mother is quite old, if I tell her about my HIV infection, she knows directly that I’m going to die. She doesn’t know that it takes time.

It is not necessary to tell anyone about your HIV status. Some participants did not see any reason why they should inform their children and others about their HIV infection and said things like: “I see no need for that” and “It doesn’t help”.

Omitting HIV in conversations. This was one strategy to avoid being open about HIV status. The participants expressed how they and also their family members omitted the word HIV in conversations. Six of the participants explained how they talked about everything else except HIV if they happened to meet someone they knew at the HIV clinic. One man described how he used to visit a friend working for a voluntary organisation for people living with the HIV infection, but they never talked about HIV or whether they themselves were infected. Relatives who knew about the HIV status “never mentioned” the word HIV. One participant assumed that her relatives understood her condition because she gave them partial information about her husband’s death, but without mentioning the word HIV: “I think they know, but they dare not ask. They can’t ask if you haven’t told them first”.

Reasons and strategies to be open about HIV status

Receiving support. Support received from relatives, from other HIV-infected persons in support groups and from health personnel at the HIV clinic was a major reason for being open and for continuing to be open about their HIV status. One woman who had informed a relative in Uganda said:

I talked to my eldest sister. She accepted me, and told me not to worry. “You’re in a developed country, you can get access to medicine. If you don’t have HIV you can die of something else”. So she kind of counselled me. We cried when we finished.

Telling someone trustworthy and close. This strategy was mostly used in connection with relatives in Uganda. One participant expressed it like this: “I believe it’s something that you can share with somebody you trust. I think what I did was enough, to share it with my sister”.

Another participant who had disclosed his HIV status to his wife explained how his wife was there for him: “There are people who don’t have anyone at home to talk to. I have my wife. She’s at home, so there’s always someone there for me to talk to”.

4.1.3 Disclosure to children (II, III)

Eight of 59 children older than six years in five families were informed about their parents' HIV infection (Paper II). The median age when being told was 11 years (range: 8–16). Only mothers had informed their children, and three of these mothers were single. None of the five HIV-infected children, all below six years of age, knew about their own infection.

In seven families, 14 children, all older than six years, were informed by their mothers about where they would live if the parents died, while in 40 families the parents had not informed any of their children (Table 4.4). Three of the seven women had also told their children about their own HIV status. These seven women appeared to be more likely to be single (five of seven, as compared with six of the remaining 40) and more likely to have no informed relative in Sweden (four of seven, as compared with five of 40 [$p < .05$]). Informing children did not appear to be associated with clinical status or ARV treatment.

Table 4.4: Information given to the children in relation to child's age

Age	No. of children (%)	No. informed of parent's HIV-Infection	No. informed where they would live if parents would die
0 – 6	28 (32)	0	0
7 – 12	40 (46)	5	10
13 - 17	19 (22)	3	4
Total	87 (100)	8	14

In paper III the participants described different reasons to avoid being open to their children. The parents described their fear of being negatively treated if their HIV status were to become known to them. Some participants feared that their children would get harassed in school. One man said: "I want my child to grow up as a normal human being". Some also feared that if a child was informed about the parent's HIV infection the child would not be able to keep silent about their parent's HIV status. Most participants wanted their children to be protected from feelings of "worry", "fear", and "sadness". One participant said: "I don't want to tell them about my infection now because they might have problems concentrating on their studies". Several participants said that it was not necessary to tell their children. The participants used expressions like: "it will not help them" and "nothing positive comes out of that". Some participants said that if they were going to die they would tell their children, but not now when they felt well. One woman talked about how the HIV epidemic in Uganda has different consequences for children in Uganda compared with children in Sweden:

Here in Sweden maybe you should tell the children if there is a cause for it. But if the HIV thing is not very, very alarming you should not involve kids to scare them

about life and about happiness. But if the situation is like in Uganda, I think there is a reason to tell them what is happening, because Ugandan kids somehow lost parents because of AIDS so there is a need to know.

Several participants said their children were too young to understand and be informed about their parents' HIV infection. They wanted to wait until the children became older. One participant said: "I think that some time maybe when they get older . . . I'll maybe sit down and educate them about this problem so that they can be careful and not have the same problem that I'm going through".

As a strategy to avoid being open about their HIV status to their children most participants pretended to have other illnesses/problems when the children saw them taking their HIV medication. Instead of saying that they were HIV positive they said "I've got a pain in my stomach" or "I've got a headache". One mother explained: "When my daughter was eight I told her I took tablets not to get pregnant. But I don't know if she understands because sometimes she asks me if I'm going to take my medicine".

Another strategy was to omit HIV in conversations with their children. One participant had talked about her HIV status to her daughter with the assistance of a medical social worker. This happened when her daughter was 14 years old, but since then the participant and her now 20-year-old daughter had never talked about HIV again. When asked why they did not talk about it the participant answered that the daughter did not ask. The participant went on to explain: "I personally, I don't want to talk about it. I don't want to hear anything, that word".

4.1.4 Professional contacts (I, III)

In paper I all the interviewees reported having contacts with at least one important professional and 46 said that the important contact was a member of the staff at the Infectious Diseases Department. About one-third (18) reported a professional working at the social welfare as an important person in their social network. Fifteen of them had contacts both with a person important to them at the social welfare office and a social worker at their HIV clinic.

All participants experienced positive support from staff at the HIV clinic that knew about their HIV status (Paper III). They appreciated meeting the same health personnel from time to time. This was a reason to continue to be open about their HIV status. Several participants described how grateful they felt, and how pleased they were with the support they received. It gave them a sense of security: "It's very good that we have the same assistant nurse, the same nurse. You meet the same people so you don't have to explain".

At the same time the HIV clinic was a place most participants wanted to avoid, a place that reminded them of their HIV status, and where they might risk meeting someone they knew from their own country (Paper III). When they happened to meet an acquaintance they would not greet each other: "I've met many that I know. They do like this [turns head away and looks in another direction]".

Some participants expressed a wish to obtain medical assistance without having to meet other patients. One participant explained how he used to dress in such a way that he would not be recognized when he visited the clinic. Another participant said how the staff at the HIV clinic quickly helped her into a separate room, knowing her reluctance to sit in full view of others in the corridor.

Some participants who had had the HIV infection for several years explained that over time they had changed as far as their resistance to visiting the HIV clinic was concerned. Instead, a feeling of togetherness was developed and this became a reason for the participant to accept being open about HIV. As one woman expressed it:

I am afraid of meeting someone so there might be a lot of talk about me, that's what I said before, but now I think like this, that if you're here and you meet me here, that means you're also going to see the doctor, doesn't it . . . so we're in the same boat, that's how I see it, but it took time before I felt this relaxed . . . 10 years.

Seven of the participants had experience of receiving medical treatment from healthcare settings outside the HIV unit. They had all informed the medical staff about their HIV infection, and six of them experienced negative treatment. This gave them a reason to avoid being open about their HIV status. As one woman explained:

When you go to a health centre you have to tell them "I've got HIV". Some people aren't used to treating HIV patients, and somehow you can see the difference, like when they receive you . . . you can see the person, their body language everything, some behave kind of differently . . . it affects them too that you have HIV. I don't like it, and that's why I don't like going there.

4.1.5 Contact with organisations (I, III)

Thirty-six participants reported (paper I) that they had contacts with organisations in Sweden. Although the organisations were mainly religious, either Christian or Muslim, 16 participants reported frequent visits to Noah's Ark/Red Cross Foundation, and 16 to immigrant organisations. The most commonly reported reason for visiting a large organisation was to participate in its activities and to meet and interact with other people. The group of participants who had visited a religious organisation was homogeneous and did not seem to differ with regard to any of the background factors. Those who had been in contact with Noah's Ark/Red Cross Foundation appeared to have more HIV-related symptoms [$p < .05$]. Eleven participants, mostly women, had not been in contact with any large organisation in Sweden. Contact with a large organisation in Sweden did not appear to be associated with contacts with healthcare staff or disclosure of HIV status.

In paper III the participants described how meeting HIV-infected persons in HIV organisations was the most common strategy used by the participants to be open about their HIV infection. Here the participants described how they communicated their HIV status in a silent and passive way to other persons by just being there. When meeting other HIV-infected people in groups, several participants commented on how everybody automatically knew about each other's HIV status. Therefore they did not have to tell each other about the infection. They experienced a feeling of togetherness, which made them accept their HIV status. One person had been the spokesperson for

one of the voluntary organisations for HIV-infected people in Sweden, and yet had never actually told anybody openly about his/her own HIV status: “When we meet in the group . . . there are many of us, everybody knows, there is nothing to be ashamed of because we know that we are all in the same situation”.

When they talked to other HIV-infected people in groups it was possible for the participants to be open and discuss different aspects of HIV such as “symptoms”, “medication”, and side-effects”. Participants gave each other support and advice about different situations connected to HIV:

In the beginning you knew that if you have HIV, then you are going to die, no medicine. You didn’t know that you can live a long time. That’s what they told me here at school but I didn’t trust them, or I didn’t believe them. I thought maybe they were lying. But then when I met other HIV-infected people, they told me “I have lived for 6, 10 years”. Then I felt safe.

4.2 KNOWLEDGE ABOUT HIV/AIDS TRANSMISSION AND THE SWEDISH COMMUNICABLE DISEASES ACT (I, IV)

4.2.1 HIV transmission (I, IV)

Almost all of the participants (45) knew that HIV can be transmitted through blood and sexual intercourse, but 16 also stated that HIV might be transmitted through kissing (Paper I). In five of the six couples included in the study, one of the partners believed that HIV could be transmitted through kissing, while the other did not. Four participants believed that the HIV virus could be transmitted through blood in swimming pools and/or in the sauna. Adequate knowledge about HIV transmission did not seem to be associated with degree of disclosure.

Some parents described how receiving information about their HIV status created a change in their parenting role (Paper IV). After the diagnosis they expressed a fear of transmitting the HIV virus to their children. One mother explained:

I am a bit careful, she [the daughter] can not be too close to me. She can be close and I can hug her. How can I explain? Sometimes she wants to use my towel but I do not allow her. She does not understand since before we used the same towel, but not any longer.

4.2.2 The Swedish Communicable Diseases Act (I)

In the first study the participants were first asked whom they *thought* had the right to know about their HIV infection, and then who *should* be informed according to the Swedish Communicable Diseases Act (paper I). According to Swedish law the patient’s doctor, nurse, dentist and sexual partner have to be informed. All those interviewed knew that the doctor had to be informed. Seven participants did not think that their sexual partner had the right to be informed, and six of these seven participants did not know that their sexual partner should be informed according to the law. Yet, in this study all steady partners had been informed about the patient’s HIV status. About a quarter of those interviewed thought that the public authorities, children older than 12, and parents to the participants had the right to know about their HIV infection. Twelve

of the participants (24%) also believed that the law required that the public authorities should be informed about their HIV infection.

Those who reported further education in Sweden appeared to have better knowledge of the Swedish Communicable Diseases Act [$p < .05$] (Table 4.5). Further education in Sweden refers to all kind of studies after finishing studies in Swedish, for example studies at upper secondary high school or vocational training.

Table 4.5: Effect of education level on the perception of the Swedish Communicable Diseases Act.

		Knowledge about who must be informed according to law		
		Adequate ¹	Not adequate ²	Total
A. Length of education in country of origin (not significant)	<12 years	14	7	21
	>12 years	18	4	22
	No answer	3	1	4
	Total	35	12	47
B. Further education in Sweden ($p < 0.5$)	No	11	10	21
	Yes	21	2	23
	No Answer	3	0	3
	Total	35	12	47

¹Answer includes all four categories, i.e. partner, doctor, dentist and nurse.

²Answer includes fewer than the four categories, or 'do not know'.

4.3 CHANGING UGANDAN PARENTHOOD IN THE SWEDISH CONTEXT (II, IV)

Moving to Sweden created a completely new situation for the Ugandan parents in relation to parenting, but also from the perspective of the new Swedish sociocultural, legal and economic context. Our findings in paper IV are presented according to the emerging main theme: "Changing Ugandan parenthood in the Swedish context" and the two subthemes; "Parenting: distance and communication" and "Sociocultural, legal and economic conditions for raising children" (Table 4.6).

When the parents described their experiences related to parenthood from Uganda they used examples both from their own upbringing and their relationships with their own parents and from their own experiences of how it was to be a parent in Uganda.

Table 4.6: Main theme, subthemes and categories identifiable in HIV-infected Ugandan parents concerning parenthood in Uganda and in Sweden.

Theme:	Changing Ugandan parenthood in the Swedish context				
Subthemes:	Parenting: distance and communication		Sociocultural, legal and economic conditions for raising children		
Categories:	*The mother/father role in Uganda and in Sweden	*Changing mother/father roles	*Social network in Uganda and in Sweden	*Custody practices and regulations in Uganda and in Sweden	*Economic conditions in Uganda and in Sweden
Codes:	*Children are not as close to their mothers as in SW (Ug) *Parents do not talk to the children especially not about serious subjects (Ug) *Children are close to the mother (SW) *Parents talk to the children also about serious subjects (SW)	*Ugandan fathers cook and take care of their children (SW) * Ugandan parents learn to talk and have contact with their children (SW) * HIV-diagnosis influencing relationship to children	*Assess to assistance with child care (Ug) *Lack of assistance with child care (SW)	*The fathers are in charge of the children (Ug) *The law is written for women and children (SW). * Future planning with relatives in Ug * Future planning with relatives in SW * ARV and custody practices	*There is no parental leave (Ug) * Most people can afford a housemaid (Ug) *Schools are free and you get allowance for food (SW) * There are insurances and social care for orphans (SW)

4.3.1 Parenting: Distance and Communication (IV)

Mother and father roles

Mother and father roles in Uganda. The participants described how the mothers in Uganda have the prime responsibility for the home and for raising the children. The mothers were often assisted in these tasks by housemaids, and mothers were described to be less close to their children.

Fathers in Uganda were described as being responsible for the family economy, thus paying for school-fees and medicine. They were not supposed to cook or to take care of the children. To be able to get money for the household the fathers were often described as being away from home doing different kinds of profitable work. As a consequence, they did not have much contact with their children. This was also expressed as a physical distance between fathers and sons, where the son was not in a position in which he could initiate physical contact with his father. One man described:

Like the experience I had with my father who was a teacher. He was away during the day and came home when he had some time he was supposed to be home. Weekends he was rarely at home. In Uganda generally most people engage in business where you have to be away for some days or a week. I had an experience with my uncle, who did not know exactly the names of his kids, because he was off and on, off and on, so he could take a kid to the hospital and say to the kid, “what are you called?”

Some men described that it was common for men in Uganda to see their friends at bars after work: “Men they really want to go out to sit . . . We always meet men together. You wonder where their wives are? They are at home taking care of their children”. When the fathers came home they were described as being authoritarian: “Everyone has to be quiet. He gives orders for the next day”.

The participants described how the Ugandan fathers and mothers are distanced from their children: “the children are on one side and the parents on the other, and the children rarely go to their parents”. One woman explained: “in my culture you have borders to your children, but here [in Sweden] the parents are like this [the participant holds her hands together]. In my culture you start to get close to your parents at age 20-25”. One man said: “parents are not together with their children a lot, so the children get more information from the school than from their parents”. This distance seemed to create a sense of lovelessness as one participant expressed: “In my homeland I experienced that I as a child did not get as much love from my parents as children do here in Sweden”.

The Ugandan parents were described as not communicating much with their children, exemplified in the following quotes: “In Uganda you do not mix, you do not talk with the children, especially not about serious issues” and “In my country you can live with an illness, but the children know nothing about it”. Children were taught not to ask questions: “We Africans do not question the adults very much. When adults say to the children what they want, the children do not question”.

Mother and father roles in Sweden. The Ugandan parents perceived Swedish parents to be closer and to communicate more with their children compared to Ugandan parents. They talked about the absence of housemaids in Sweden. They experienced the Swedish mothers to be very engaged in the daily tasks of taking care of their children, and to have a very close relationship with them. One woman explained: "The mothers in Sweden are together a lot with their children. They are close to their children". Several women commented on the heavy responsibility especially for the mothers in Sweden with the daily tasks of taking care of home and children without the assistance of housemaids. This created a sense of lack of freedom, and gave the mothers little time for themselves. As one female participant described:

Mothers in Sweden have a lot of responsibility for the children, they're together all the time, you're not able to do whatever. All the time you think about the children here in Sweden but we as mothers, we do not have a life of our own.

Swedish fathers were said to take a great deal of responsibility for the daily care of their children. One woman expressed surprise at how fathers were involved in taking care of very young children:

I can see men walking with the pram. Sometimes I just stand and look as they are trying to change the diaper, [laughter]. In Uganda you do not see men who can change diapers [laughter] the situations are very different.

Swedish fathers were also perceived to take great part at home and at school. A divorced man said: "In Sweden there is almost 50/50 responsibility between the parents".

Changing mother and father roles.

After moving to Sweden the Ugandan fathers had started to assist with the daily tasks in the home to a larger extent than before. This was a new situation where the men had to learn new tasks like cooking and taking care of their children. These new tasks also brought the fathers closer to their children. One man described how his son sometimes initiated physical contact with him, something he could never do with his own father. Another man described:

When I came to Sweden I started to cook, it was the first time for me. In Uganda men are not supposed to cook . . . the children get to know you more, since you shower them, cook, feed them and take them to school . . . I think that's good.

Both the men and the women experienced that moving to Sweden had changed their relationship with their children. The parents talked more with their children and considered that they had become closer to their children. As one woman said:

In the beginning I was very surprised to see women talking to their children. I thought that the children can not understand anything, and I wondered why they talked to them. But that's something I've learnt, to talk and to have contact with my children.

One father described an incident in Uganda when he was there on a visit with his children. He explained how he had been talking with his children for some time when a man who had been watching them approached him:

Inquisitive he was so forced to ask me "what do you really talk to these kids about?" He was so surprised because small kids of 8-10 what can you talk with them? He realized we have been talking and talking, so he was so interested because for him he had never talked with his kids.

Another father described how he had handled the difference between being a parent in Uganda and in Sweden: "to be close to each other is the European way, and to have a difference and a distance is the African style . . . We've taken care of our children according to an African-Swedish method, where we combine the two methods".

4.3.2 Sociocultural, legal and economic conditions for raising children (II, IV)

Custody practices and regulations in Uganda respectively in Sweden. (II, IV)

In paper II the majority of the participants (30 of 47) described how they had planned that their HIV-negative partner or a relative in Sweden would care for their child if the parent died (Table 4.6). Half of the study group (17 women and 7 men), with a total of 43 children, had talked to an important person in their social network about a future scenario. Twenty-one had directly addressed the person they wanted to care for their children, and three had addressed social authorities about the need for a foster family. Three parents had also written a last will and testament in which they formulated custody arrangements.

A majority of those who had made long-term plans by directly addressing someone seemed to a greater extent to be single women (9/24, as compared with 2 of the remaining 23) [$p < .05$]). This group who had made long-terms plan also seemed to be more likely to have had contact with a social worker at the social welfare office and with a social worker at the HIV clinic (11/24, as compared with 4 of the remaining 23 [$p < .05$]). Long-term planning did not appear to be associated with clinical status or ARV treatment.

Table 4.6: Future Planning for the Children among HIV-Positive Parents of African Origin (N=47)

Planning Status	Social Authorities	Relative in Sweden	HIV-Negative Partner	HIV-Positive Partner	Relative Abroad	Nobody	Total
Have talked to someone about who will care for the children	3	10	6	3	2	0	24
Have <i>not</i> talked think it is possible that the children can be cared for by:	2	5	9	0	5	2	23
Total	5	15	15	3	7	2	47

As time passed after the HIV diagnosis the parents tended to worry less about dying and leaving their children as orphans, as one woman expressed in paper **IV**:

I feel strong. I feel I have a life. I am not going anywhere, not now anyway. I feel like I did before. I live my life as good as I can, but at this moment I feel I have a life . . . I feel there will be time [for custody arrangements].

This feeling of being less worried was for most parents described as a result of having access to antiretroviral treatment:

I am less worried for the future. I have taken [medicine] for 4 years now, maybe I will continue like this [laughter]. You think like this; you want to live longer, until the children become grown-ups. That is what I hope, to live longer, 30 years. Then they can take care of themselves.

However, one single mother was very worried. She said that she had no one to talk to and taking antiretroviral medication made her think even more about the future of her child.

In paper **IV**, the participants described how in Uganda the children belong to the father and his relatives. If a mother in Uganda dies the children are placed with the father and his relatives, especially the wealthy relatives. One man explained that if a woman finds another man she will leave the children with their father and go to the other man. On the contrary, some mothers explained that in case of divorce or separation the fathers would not continue to support their children economically: “In my culture if you are divorced, you are divorced, the men do not care, they say that the women can take care of the children themselves”.

The participants perceived that in Sweden children belong to the mother, and that the Swedish law is written for women and children. One father described a situation of a Ugandan family living in Sweden where the police and a social assistant had been called because of a fight between the husband and wife. This man said that both the police and the social authorities were in favour of the woman and her opinion of what had happened. One woman explained:

Here [in Sweden] if the women do not have a problem with alcohol, it is difficult to take the children from her and give them to the man, but in my country [Uganda], it is as if all children belong to the man and his relatives.

Swedish legislation was considered a problem in relation to custody planning. Several single mothers had applied for visa for their sister or mother to come and take care of their children in case they themselves would die. However, the Swedish immigration authorities had rejected their applications. The immigration authorities had also time after time refused the applications of some fathers who had applied for their biological children under age 18 to come to Sweden. These men had left some of their biological children in Uganda with their ex-partner, the mother of the children. One father explained:

The immigration authorities told me that I had punished my children because I left them in Uganda, but at that time when I came to Sweden they had a mother who was there to take care of them. It was OK, but when she died I started to take my

responsibility for them, already in 1997 up till now. I do what I can for my children, but they [the immigration authorities] have no right to say to me that my children are not allowed to come here because I left them. They say that since I have never lived with them, I do not need to be with them now, but I am their father. They are my children. You can not change that fact. I love them, and they love me. In fact, they need me.

Economic conditions in Uganda and in Sweden (IV)

The economic situation for having children in Uganda was described as opposed to that of Sweden. The participants explained how there were no allowances for taking care of children in Uganda, as opposed to Sweden with child allowances, as well as parental leave. In Uganda there were school-fees and fees for medical care for children, compared to Sweden where schools and medical care for children are free of charge. One mother described how she could easily sign an insurance contract in Sweden and if she was accidentally killed her children would not suffer since the social authorities would step in and take care of her children. She continued to describe:

Here [in Sweden] I wait for my allowances and they will come. They're really helpful, and if my child gets ill, I will go to the medical doctor . . . it's more difficult [in Uganda]. You've to think your whole life, how shall I support my children? How shall I get them to school? And what about the rent?

Several participants explained how cheap it is to hire a housemaid in Uganda. One woman said: "You can hire someone for a month for 300 Swedish Crowns, to take care of the children, to clean, to do everything".

5 DISCUSSION

5.1 METHODOLOGICAL CONSIDERATIONS

5.1.1 Validity and reliability

The concepts of validity (internal validity), reliability, objectivity and generalisability (external validity) are often used to assess the quality of quantitative research (Cook & Campbell, 1979, Kazdin, 1998). Validity (internal validity) refers to whether a measurement is measuring what it is designed to measure. Reliability refers to the consistency of the measurement and whether an instrument measures the same way each time it is used under the same conditions and with the same subjects. Objectivity refers to a more general principle that the research should be impartial and neutral. Generalisability (external validity) refers to the degree to which the results of the study can be applied in other contexts/settings.

Internal validity

The semi-structured questionnaire used in the quantitative study (paper I and II) was developed by a multidisciplinary team of social workers, nurses, a sociologist, and physicians (including a paediatrician). In connection to this, a methodology guide was prepared for the interviewers. The study was initiated and implemented by medical staff, which can have resulted in a reporting bias, e.g. overestimating the importance of medical professionals as important contact persons.

The size of the material was too limited as to make multivariate analysis techniques relevant which was a limitation in the sense that I could not calculate effect modification, interaction and confounding among and between the variables and the outcomes. I have tried to compensate for this limitation through theoretical and logical consideration of possible confounders. For example the association between length of education and number of informed important persons, where I found that those with more education before arriving to Sweden had to a greater extent informed more important persons in their social network about their HIV status. Here being Ugandan could be a cofounder as Ugandans as a group had more education than the other participants before arriving to Sweden. As to make sure that this was not the case, I manually calculated number of Ugandan participants among those with more education prior to coming to Sweden before generally commenting on the whole group. Hence I perform a theoretical assessment of what seems theoretically relevant, but still one should be careful when drawing conclusions about the association between dependent and independent variables.

Reliability

To improve the reliability of the quantitative study and reduce measurement errors (random or systematic) I pilot tested the questionnaire and adjusted it several times I got feedback from the respondents regarding how easy or hard the measure was and information about how the testing environment affected their performance. I chose medical professionals to perform the interviews and I gave them thorough guidance and information so that they were not inadvertently introducing error. Third, when I entered the data I double-checked thoroughly that I was typing the same data in the SPSS data file as was written in each interview.

External validity

When considering generalisability, both the study site and the characteristics of the participants are important aspects. The sampling strategy for our quantitative study was connected to the general objective of the study. As a medical social worker I was interested in improving the support strategies for these parents. In Sweden approximately 70 percent of all HIV-infected parents have African origin, 20 percent have Swedish origin, and 10 percent have Asian origin. Eighty five percent of the participants in study one were from East African countries (Uganda, Ethiopia, Burundi, Somalia, Eritrea, Kenya and Tanzania), which mirrors the situation for the whole group of HIV-infected persons in Sweden with African background. There are cultural differences between these countries and also between the ethnic groups within these countries. However, as no previous studies had been performed among these parents I was initially interested about any particular characteristics of the whole group. I believe that HIV-infected parents of African origin generally have much in common: they have all arrived to a new culture, leaving their previous networks, and the majority have received their HIV-diagnosis in close connection to their arrival. All have had to learn a new language, find work, find somewhere to live and try to settle in the new Swedish sociocultural environment. In this sense, their situation is very different from HIV-infected persons who have lived in Sweden for their whole life. However, the above described psychosocial situation is also shared with other HIV-infected first generation immigrants, but in study one I was particularly interested in describing the largest group of parents living with HIV in Sweden: HIV-infected parents of African background.

At the time of performing study one (paper **I** and **II**) the intention was to ask all 103 patients who were guardians of children younger than 18, and who were followed up at the two Departments of Infectious Diseases in Stockholm. However, due to changes in the hospital organisation there were at times difficulties for the staff to find time to recruit parents to the study, which explains why only 65 out of the total number of 103 parents were asked to participate. However, these episodes occurred from time to time during the whole recruitment period when there were no changes in the normal visit procedures of patients coming to the clinic. Thus, the study group in study one reflects the situation of about half of the HIV-infected African parents who at the time of the study were followed at the two Infectious Diseases Departments in Stockholm. I believe that the persons included in the study were representative of the whole group in that they had similar general characteristics. There were no obvious and significant differences regarding sex, age or country of origin between those who agreed to participate and those who did not. However, there could be a possibility that those who declined to participate differed from those that did participate in the sense that they declined as a result of experiences of mistrust and stigma from health care staff. The situation might also be different for HIV-infected patients living outside Stockholm, in smaller towns or rural areas. Greater distance to specialised HIV clinics and humanitarian and immigrant organisations might create a more isolated situation for the patient. The patients in this study had immigrated to Sweden from different parts of Africa. The country diversity corresponded well with the general profile of HIV-infected Africans in Sweden (SMI, 1999). Ugandans were, however, somewhat over represented in our group (47% compared with 35% of HIV-infected Africans

living in Sweden). This was probably because they came relatively early to Sweden and have had more time to acquire children of their own and/or bring to Sweden children who might have been left behind in Uganda.

The purpose of this study was descriptive and explorative, and I am aware of the dilemma of carrying out a large number of tests each with the significance level set at 5 percent and that some tests would be significant by chance alone (Machin, Campbell & Walters, 2007). At the same time the low number of observations leads to low power. It is thus low chance to identify (with significance tests) even highly relevant differences between subgroups. It is possible to have a relationship which displays a strong association but is not significant with a sample size at 10, but it is also possible to have a relationship which displays a very weak association but is significant when the sample size is 15 000. In this study, significant relationships can only be seen as indications and not necessarily as causal relationships. The study should be seen as hypothesis-generating and the results should be followed up in further studies.

5.1.2 Trustworthiness

There are broadly three variations in perspectives on how qualitative research should be evaluated (Rolfe, 2006). Researchers holding the first perspective hold that qualitative research should be judged according to the same criteria as in quantitative research (Miles & Huberman, 1994). In the second perspective, researchers believe that a different set of criteria is required. Lincoln and Guba introduced the concept of trustworthiness to fit the assumptions of qualitative research (Lincoln & Guba, 1985). They argued that qualitative research relies on other assumptions than quantitative research and has to be validated by using other criteria. Thus, the concepts of credibility, transferability, dependability and confirmability have been developed to fit qualitative research. Credibility corresponds with the quantitative concept of internal validity and refers to how well aim, data and analysis fit together. Transferability corresponds with the quantitative term external validity or generalisability and refers to what extent the findings can be transferred to other settings or groups. Dependability corresponds with the term reliability and has to do with whether the process of research is logical, traceable and clearly documented. Finally, confirmability corresponds with objectivity/neutrality, and has to do with establishing that findings are clearly derived from the data. Researchers that have the third perspective argue that these concepts are not useful as they still rest on the assumption that there is only one reality, and that they do not consider the multiple dimensions of qualitative research (Sandelowski, 1993, Rolfe, 2006).

As to enhance trustworthiness, and give the possibility to assess the qualitative study (paper III and IV) I have given an audit trail of detailed description of the research process (Rolfe, 2006). As to further improve the quality, I have used triangulation, peer review, respondent validation, and reflexivity.

Triangulation

Triangulation is based on the idea that no single method can solve the problem of rival explanations. Combinations of methods and sources make it possible to add different perspectives to the same research area, which increases the credibility of the results. There are four kinds of triangulation: methods triangulation, analyst triangulation,

theory/perspective triangulation and triangulation of sources (Patton, 2002). In my research I used the first three types of triangulation.

I used method triangulation by combining quantitative and qualitative research methods. In paper **I** and **II**, I quantitatively explored and described the psychosocial situation for HIV-infected African parents and then in paper **III** and **IV**, I qualitatively addressed some of the same research questions such as social network of important persons, disclosure, and parenthood.

Analyst triangulation was used by including co-authors with different professions (doctor, nurse, psychologist, and social workers), gender, ages and cultural background (Swedish and Ugandan).

In paper **III**, the initial coding was first carried out by me, and then together with the last author, until we reached full agreement about the codes, categories, subthemes and theme. In paper **IV** the coding was carried out separately by me and the third author, a male social worker from Uganda living in Sweden. The coding was then compared and discussed until agreement about the emergent codes, categories, subthemes and theme had been reached. The coding in both paper **III** and **IV** was then also discussed among the co-authors until agreement was reached.

Theory triangulation was used by applying different theoretical perspectives. The purpose of using theory triangulation is to understand how different theoretical perspectives affect findings and interpretation. In paper **I**, I used social network and ecological systems theory, and in paper **III** Moss' (2002) theory of underlying dimensions of coping skills. In paper **IV**, I found that Hofstede and Hofstede's (2005) dimensions of cultural variability provided an interesting explanatory framework, especially the dimensions of femininity versus masculinity, power distance and individualism-collectivism.

Peer review and member validation

For paper **III** and **IV** I conducted peer review and debriefing with researchers both inside and outside the research team (Long & Johnson, 2000). This was done to supplement the perspectives on the emerging categories and themes, and to check for consistency among the researchers. Thus I have changed and revised the categories and themes during the analysis process.

Respondent validation is a technique in which the investigator's account is compared with those of the research subjects, and where the participants' reactions are incorporated into the study results (Mays & Pope, 2000). This technique has been criticized as it has been argued that expert researchers and the respondents can not be expected to come to the same conclusions as reality is multiple and constructed (Sandelowski, 1993, Rolfe, 2006). To increase the quality in the qualitative study, I used a form of respondent validation. In connection with transcription I went back to the participants for feedback and clarification in all instances when I could not understand what the participant was saying on the tape, or if I did not understand the meaning of what was said. This was part of a process of error reduction (Mays & Pope, 2000).

Reflexivity

Reflexivity is a research technique focusing on how the research process is influenced by who is conducting the research and how this is accounted for in the research process. The researcher is the most important “instrument” of the research where gender, professional background, social status, and ethnic background will influence the research process. Reflexivity stresses the importance of self-awareness, political/cultural consciousness, and ownership of one's perspective (Patton, 2002). To be reflexive involves an ongoing process of questioning, examining and understanding one's own part in the research process.

My previous almost twenty-year background as a medical social worker at an HIV clinic has implications for this thesis. In the qualitative study (paper III and IV), I had had previous contact with four participants in my role as a medical social worker. This might have prevented the participants from being critical to a person representing the healthcare setting. However, prolonged involvement and previous knowledge about the area and about some participants could also create a safer environment for the participants to express themselves, and might make it easier for them to participate.

Transferability

In qualitative inquiry the individual subjective answers are central, and findings are not seen as facts that can be generalised to the whole population. Qualitative findings can be applied within specific settings and increase our understanding (Patton, 2002). Thus, the qualitative findings in paper III and IV should be seen in relation to the Swedish context. However, HIV-infected Ugandans constitute one of the largest groups of HIV-infected Africans in Western Europe and the Swedish sociocultural and economic context has similarities with many other European countries such as Denmark and Norway. Furthermore, I have given a thorough description of my research. Therefore it is likely that the results can be transferred to settings and study populations similar to the ones in these studies.

5.1.3 The use of theoretical models

Hsieh & Shannon (2005) describe three approaches to qualitative content analysis: conventional, direct and summative. With a direct approach to content analysis the goal is to validate or extend conceptually a theoretical framework. With a summative approach the researcher identifies and quantifies keywords before and during data analysis. I have used a conventional approach to content analysis and have derived the codes from the data. With this approach, relevant theories can be addressed in the discussion section as to broaden the comprehensive understanding. I used conceptual frameworks in the qualitative papers III and IV as well as in the first quantitative paper I. In addition to the chosen theoretical frameworks, I have reviewed several other theoretical frameworks such as acculturation, stigma theory, transcultural nursing, and Afrocentric worldview. We have also discussed different theoretical frameworks in the research team and during seminars involving other researchers. Then I choose a framework for each of the paper I, II and IV that, according to my understanding, best suited the data.

5.2 DISCUSSION OF FINDINGS

In this thesis I have been inspired by and used several theoretical frameworks when discussing the study results. In paper **I** I used ecological systems and network theory, in paper **III** coping theory and in paper **IV** some of Hofstede's (2005) dimensions of cultural variability.

As I brought all four papers together it became evident how the ecological systems and network theory used in paper **I** has similarities and intertwines with Hofstede's dimensions of cultural variability in paper **IV**. The ecological system theory's description of *Macrosystems* as the belief systems reflecting people's shared assumptions, lifestyles, and ideologies, shares commonalities with Hofstede's dimensions of cultural variability. For example, the dimension of individualism-collectivism could be described with how countries differ with respect to social networks. The ecological systems' concept of proximal processes also shares similarities with the cultural dimension of power distance. I suggest that these proximal processes, which are described as a complex reciprocal interaction over an extended period of time can be seen as a form of child-rearing. For children these processes take place between the parents and the child. Hofstede implies that this relationship between a parent and child is influenced by a country's degree of power distance.

When I discuss all four papers, I have been guided by the results, which are supported by the different conceptual frameworks. Thus, the theoretical frameworks will be in the background, and not presented in order. For a more refined description of how each theoretical framework connects to the results please see the respective papers.

5.2.1 Social network and disclosure

The interviewees in the first study had small microsystems consisting mainly of contacts with the immediate family, partners and children, and only every other one reported having contact with an important relative in Sweden (paper **I**). Their previous micro- and mesosystems in Africa had been disrupted and new ones had developed with important persons in Sweden such as relatives, friends and staff at the hospital. It is to be expected that patients lose contact with their relatives and friends abroad and make new friendships while in Sweden. Hence, with time the importance of the social network in Sweden increased. The larger the size of the network, the more the relatives in Sweden was informed about HIV (**I**). Serovich (2000) suggests that the size of one's social network is as important as the quality of such relationships. The building of a new network provides vital resources for individuals in the resettlement process (Bourdieu & Wacquant, 1992). Parts of the microsystems left behind in Africa were still important for more than three-quarters of the interviewees. The relatives in Africa were the first to be informed about HIV-related symptoms. I believe that these microsystems, as well as the cultures and belief systems in the countries of origin still have a strong influence on the interviewees.

Despite a rather large social network of important persons, more than two-thirds of the participants had no informed relatives in Sweden, and five had not informed anyone at all. This low disclosure rate is consistent with several other European studies where HIV-infected Africans have also been found to be less likely to disclose their HIV status to partners, family members and friends compared with other HIV-infected

groups (Bungener, Marcand-Gonod, & Jouvent, 2000; Erwin, Morgan, Britten, Gray, & Peters, 2002; Peretti-Watel, Spire, Pierret, Lert, Obadia, & THE VESPA GROUP, 2006; Petrak, Doyle, Smith, Skinner, & Hedge, 2001). Lack of close relatives and friends among the participants might explain why I did not find (III) the previously reported coping strategy among HIV-infected Africans to use intermediaries as vehicles for disclosure (King et al., 2008; Miller & Rubin, 2007). Consistent with prior studies, one strategy the participants used was to be open about their HIV status with persons they trusted and felt close to (Calin, Green, Hetherington & Brook, 2007; Derlega, Winstead, Greene, Serovich & Elwood, 2004).

Women and social network

The results in studies I, II, and IV all point to the special situation of women, particularly single women, with small microsystems. Single women represented slightly less than a quarter of the patients in study one (paper I). These women had a vulnerable situation, living in very isolated circumstances with very limited social networks, with few relatives and friends who knew about the family being affected by HIV.

Larger networks have been reported to correlate with better mental health and overall quality of life (Gielen, McDonnell, Wu, O'Campo & Faden, 2001). Greater anxiety and depression symptoms among HIV-infected minority women in the United States, where the majority were single, have also been found to be associated with less social support (Catz, Gore-Fenton & McClure, 2002). In a sample of black African HIV-infected women in London, better mental health was predicted by practical coping style and higher social support (Onwumere, Holttum & Hirst, 2002).

The single women in paper I had developed new mesosystems, and had to a greater extent extra support both from a person important to them at the social welfare office and a counsellor at the HIV clinic. These professional contacts did not, however, seem to lead to more social contacts or a greater degree of disclosure.

The women in the study group also had fewer contacts with large organisations than did the men. Apart from support strategies such as motivation and encouragement, these women needed help with childcare in order to broaden their network and to find the time and energy to go out and meet other people. A study involving immigrant women in Canada reported that they lacked information about the resources available to them and that they needed help from professionals to develop social contacts within the community (Lynam, 1986).

Only women had talked to their children about their HIV infection, where the children would live if they were to be orphaned, or both (paper II). Single women had also done more future planning for their children than had other subgroups. Previous studies have not shown any association between sex and HIV disclosure (Rotheram-Borus, Draimin, Reid & Murphy, 1997; Thorne, Newell & Peckham, 2000). I believe this has to do with the vulnerable social situation of these women: being immigrant, single mothers, often without work and with few relatives informed of their HIV status. A sense of isolation may make these women more inclined to involve their children. These mothers cannot rely on their extended family to the degree that others can (Thorne et al., 1998). I did not find any association between disclosure and clinical status or receiving ARV

treatment. I suggest that the higher disclosure rate among women to their children is attributable to their isolated psychosocial situation, not their health status.

The parents in my studies had not only lost their previous social networks, but they had also arrived to a different country. Sweden is, according to the cultural dimension of individualism-collectivism, described as an individualistic society, a society in which the interest of the individual prevails over the interest of the group (Hofstede, 2005). Everyone grows up with the expectation to look after him- or herself and his or her immediate (nuclear) family. Particularly single mothers expressed how they missed relatives and friends, who could help them with their children (IV). Parenthood is a time when social networks and relationship patterns change with an increased emphasis on kin connections (Hammer, Gutwirth & Philips, 1982). The single mothers were vulnerable since they lacked the support from previous networks of relatives and from the child's father. HIV-positive African women in London have also reported about missing support from kinship networks (Doylan & Anderson, 2005). Countries in East Africa like Uganda are scored as collectivist cultures where people are born into extended families or into other groups that continue protecting them in exchange for loyalty. Collectivist countries are societies where the interest of the group prevails over the interest of the individual (Hofstede, 2005). Migrants from African countries, the African diaspora, and their remittances to family and friends in their home countries have been shown to be important sources of economic aid (Koser, 2003; Mercer, Page & Evans, 2008).

In many African countries mothers are described as the ones providing support for their children both by ensuring that others do so and by giving support directly themselves. Child caretakers are used as a routine such as the practice of involving children in the care of younger siblings (Wesiner, 1997). Since distribution of nurturance within the family unit are at the heart of cultural values throughout Africa (Serpell, 1992), the loss of family and community support systems became a major concern for especially the single mothers in my study. In Ugandan studies the investment in social capital – social networks/clans, has also been described as essential, especially in case of crises when these networks are expected to give support (Ankrah, 1993; Karuhanga, 2008). A central concept for the collective approach in many African countries is called *Obuntu*, which means: "I am what I am because of who we are" (Mbiti, 1970, Murithi, 2006). Some female participants described how they felt confined by the Swedish more narrow approach of defining the family system. The Swedish mother role was perceived as being too focused on the children, leaving little time for the mothers themselves.

Professional networks

All participants in study one (paper I) had developed mesosystems with important professional staff, to a higher degree than what has previously been reported (Andrews, Williams & Neil, 1993; Beedham & Wilson-Barnett, 1995; Irving, Bor & Catalan, 1995; Keogh, et al, 1994). This might be due to their lack of important relatives living in Sweden, but also to the fact that newly diagnosed HIV patients in Stockholm are immediately referred to special HIV clinics with multidisciplinary teams. One-third of the participants reported important contacts with social workers at both the HIV clinic

and the social welfare office. These participants were more inclined to disclose their HIV status and to make future custody plans for their children. I believe this is as a result of the trusting relationship that was formed and the information provided by the professional support persons. Social workers play an important role and are usually one of the first Swedish professionals that the HIV-infected African individual meets after arriving to Sweden. The medical social worker has information about the HIV infection, information that the patient considers very private and sensitive. This might suggest that counsellors at HIV clinics facilitate the patient's contacts with the social welfare authorities. When immigrants get permanent visas in Sweden, they are assigned to a social welfare office, where they usually have contact with a social worker for economic support while they are studying or looking for a job. In a Canadian study on HIV-infected parents, as many as 86 percent of participants expressed a need for a professional with whom they could talk (DeMatteo, Wells, Goldie, & King, 2002). However, those participants who declined to participate in the study might have had a more negative attitude towards health personnel and might also have declined participation because the interviewers were health workers.

As found in other studies (Mayfield Arnold, Rice, Flannery & Rotheram-Borus, 2008; Petrak et al., 2001), the participants in paper **III** reported that the main reason for continuing to be open about their HIV status was the support they received from health personnel at the HIV clinic and in the HIV organisations. According to coping theory, this can be described as using a cognitive coping approach to be open about their HIV status in order to receive support. Overall, the participants were positive about the non-discriminatory care and support they received from the health personnel at the HIV clinic. I contend that these contacts should function as a tool in the process of integration: giving patients assistance in and information on living with HIV and how to adapt and integrate into Swedish society. The risk is, however, that the professionals may become part of the interviewees' networks and thus diminish the need for other contacts. These professional contacts should be used to mobilize a patient's own social network to counteract the patient's isolation and assist him or her in the integration process.

However, in paper **III**, participants who had visited healthcare settings outside the HIV clinic reported discriminatory behaviour from medical personnel when telling them about their HIV status. This behaviour counteracts the law and confirms the participants' fear, and gives them a reason to use both cognitive and behavioural avoidance coping to avoid being open about their HIV status. Discrimination from health personnel against HIV-infected persons has been described in studies and reports from other parts of the world since the beginning of the HIV epidemic (Kegeles, Coates, Christopher, & Lazarus, 1989) and also more recently (Holmzemer & Uys, 2004, Anderson, Elam, Gerver, Solarin, Fenton & Easterbrook, 2008). HIV-infected Africans in London have reported about how medical health workers refuse to feed patients with HIV-infection (Erwin & Peters, 1999). Discrimination needs to be counteracted by increased education addressing practices and attitudes (UNAIDS, 2007). As the care of the majority of HIV-infected persons in Sweden are concentrated in major HIV units, the development of co-operation with general practitioners at some chosen primary healthcare centres outside the HIV unit could be one solution to give direct education and supervision to health personnel who have HIV-infected persons as

one of their target groups. From the perspective of the ecological systems theory this is an example on how an improved development of the exosystem between the HIV units and the primary health centres could positively influence the care situation for the individual HIV-infected patient. I believe that in countries with low HIV prevalence, the reduction of stigma and stigmatization among health personnel is best addressed by targeting some primary healthcare centres rather than providing continued healthcare education for the majority of healthcare staff who are not likely to encounter with HIV-infected persons. Additionally, persons with HIV infection live longer with higher treatment costs and as hospital management emphasise devolution it is necessary to increase and develop co-operation between the HIV clinics and primary healthcare centres.

Contact with organisations and silent disclosure

The participants had developed new mesosystems, and most often they reported churches and mosques as their main contact organisation (paper I). Also in London, HIV-infected African women have reported how they regularly visit the church and how religious support was a major source of support (Erwin & Peters, 1999). Considering that many participants in the study were religious, churches and mosques could play a significant role in HIV education. The influential effect of church leaders and their potential support to members concerning HIV has previously been pointed out by Miller and Murray (1999), and in Malawi religious teachings has been described to influence HIV prevention (Trinitapoli, 2009). Immigrant organisations and Noah's Ark/Red Cross also had a relatively high contact frequency, i.e. they were visited by a third of the participants. Noah's Ark/Red Cross was mainly visited by patients with HIV-related symptoms, which suggests that there is a gradual need to meet and interact with other HIV-infected people as the illness progresses. Some participants also reported having looked for support in immigrant organisations. Contact with organisations did not, however, seem to influence the degree of disclosure. Neither did contacts with an organisation that focused on HIV-related issues, such as Noah's Ark/Red Cross. Perhaps meeting other HIV-infected people fulfils a need to share and to be honest with oneself, without this leading to further disclosure to relatives and friends.

A strategy, which has not previously been described in the literature, was how the participants were open about their HIV status in a passive way when they met other HIV-infected persons in support groups (paper III). This behavioural approach to coping was the most common strategy for being open about their HIV status, even to the extent that the spokesperson of one of the voluntary organisations for HIV-infected people in Sweden, had actually never told anybody openly about his/her HIV status. Even though the participants expressed a strong fear of meeting other HIV-infected persons, half of them had looked for support in HIV organisations. The meetings in the support groups created a feeling of togetherness, which for some developed over time. The previous feeling of fear that the HIV diagnosis could involuntarily be acknowledged by Ugandan friends or acquaintances changed to a feeling of togetherness, where the participants perceived that all the persons at the HIV clinic had HIV in common. In this way, previous cognitive avoidance coping changed to cognitive approach coping, where they positively reappraised their situation of being

HIV positive. The participants did not actually disclose, but with time they seemed to be more relaxed about their HIV status and it did not matter if other patients at the HIV clinic understood that they were HIV-positive. A form of passive communication took place, both in the HIV support groups and at the HIV clinic, implying a silent disclosure of their HIV status.

Support from HIV organisations and positive contact with healthcare personnel at the HIV clinic has previously been reported from research involving HIV-infected Africans in London (Doylan & Anderson, 2005). It seems as if HIV-infected Africans in Europe compensate for the lack of closeness to relatives with psychosocial support received from professionals such as the staff at the HIV clinic and support in voluntary organisations for HIV-infected persons. This emphasizes the importance of co-operation between these two agencies. This co-operation has, however, diminished in Sweden after the introduction of antiretroviral medication (Åsander, 2007). It is thus important to revitalize the co-operation between the HIV clinics and the voluntary organisations. This is another example of how an improved co-operation of the exosystem between the HIV units and voluntary organisations could be used to positively influence the care for the individual HIV-infected patient. The World Health Organisation (WHO) has highlighted the importance of using multi-sectorial strategies in low-income countries to achieve public health goals (WHO, 2005). My study addresses the need for a continued multi-sectorial strategy also in high-income countries in order to maximize support for HIV-infected persons, especially for migrant families who might not be able to rely on support from the extended family.

5.2.2 Communication and HIV disclosure to children

In paper **II** and **III** the participants brought up different aspects of disclosure of the HIV diagnosis to their children and in paper **IV** they addressed perceived cultural differences in Uganda and Sweden with regard to communication with their children.

Only every 10th parent had informed their children about their HIV status (**II**). This is consistent with the low disclosure rates to children previously found among HIV-infected parents of African origin in European studies (Calin et al., 2007; Chinouya, 2006; Nöstlinger et al., 2004). Concerns for their children and how to handle their own HIV status with regard to disclosure seemed to put extra stress on these HIV-positive parents (Calin et al., 2007; Chinouya, 2006; Flowers, Davis, Hart, Rosengarten, Frankis., & Imrie, 2006).

The participants exclusively chose cognitive and behavioural coping strategies to avoid disclosing their HIV status to their children (**III**). Thus, none of the HIV-negative children under 18 years were informed about their parents' HIV status. The study participants did not mention one single reason why they should talk about their HIV status with their children. As has previously been reported, the parents were concerned about the children's vulnerability, and regarded non-disclosure as protective for the children (Ostrom Delaney, Serovich & Lim, 2008). In accordance with previous studies, I found that one main reason for not telling the children was that they were considered too young to be told (Murphy, 2008). However, the intention to talk to the children when they grew older was rarely realized, because only one participant had

talked to one of the seven children over 18 years of age. In paper **II** the participants had informed only 16 percent of their adolescent children about the parents' HIV status, which is much lower than what has been shown in studies from the United States, where up to 75 percent of adolescents have been informed about their parents' HIV status (Lee & Rotheram-Borus, 2002). Also in one of the few studies published on disclosure to children in Uganda, the median age of children informed about their parents' HIV status was as old as 18 years (Rwemisisi, Wolff, Coutinho, Grosskurth, & Whitworth, 2008). As found in other studies (Kirstenbaum & Nevid, 2002; Rotheram-Borus et al., 1997), after initially giving their children some information about the parents' health problem, the participants did not go on to tell their children the real cause of the parent's illness (**III**). Most participants concluded that it was not at all necessary to talk about their HIV status to their children. Several participants pretended to have other illnesses thus using behavioural avoidance coping. Obviously cultural aspects play an important role in how HIV-infected Ugandan parents behave toward their children in Sweden. This can explain why the participant who was assisted by a medical social worker to disclose the HIV infection to the daughter did not achieve any further communication about HIV with the daughter. A single intervention from healthcare staff without additional follow-up might not change interpersonal communication strategies.

Hofstede's dimension of power distance provides an explanation for the lack of communication and the low disclosure rate to their children found among our participants. Power distance is defined as the extent to which the less powerful members of institutions and organisations within a country expect and accept that power is distributed unequally. Institutions such as the family, the school, and the community are the basic elements of society (Hofstede & Hofstede, 2005). In countries with relatively high power distance, such as Uganda, traditional child socialization focuses on obedience, discipline and respect for the elders (Karuhanga, 2008; Opolot, 1982; Otiso, 2006). Children are, for example, not allowed to speak when parents have a conversation (Conrad, 2004; Moemeka, 1996). This implies an uncommunicative environment about sexuality in many African countries where it is considered inappropriate for children to discuss sexual matters with their parents (Nam, Fielding, Alalos, Gaolathe, Dickinson & Gessler, 2009). In my study the parent-child relationship in Uganda was described as a distance between parents and children, as if they were on different sides (**IV**).

In countries with lower power distance like in Sweden, parents treat their children more as equals. The children in their turn consequently treat their parents and older relatives as equals. The Ugandan parents experienced that Swedish parents were very close to and talked with their children about everything. From the perspective of cultural ecology, the child-rearing practices are never irrational or random, they form part of a culturally organized system, which evolves through generations of collective experiences to meet environmental needs (Ogby, 1981).

The participants described how the social environment in Sweden had affected their communication with the children. In my study both fathers and mothers described that they had changed some of their child-rearing practices and that they talked more and felt closer to their children. Especially the fathers expressed how positive they felt

about the increased physical and emotional closeness to their children. Thus, in the acculturation process the parents had, to some extent, integrated a more Swedish way of communication and closeness to their children. In relation to their HIV status, the parents seemed to have kept what they described as the Ugandan style of not informing the children (Conrad, 2004). This shows how some of the proximal processes between the parent and the child change as a consequence of moving to the new social context in Sweden. A father described it as if he had raised his children using an 'African-Swedish method'. However, we do not know to what extent Swedish HIV-infected parents actually talk to their children either.

There are no conclusive data on child functioning regarding the value or impact of parental HIV status disclosure. Several researchers in the United States have reported that HIV-infected mothers and their children have very different perspectives regarding the effects of disclosure. Two studies on young children between six and eleven years of age have revealed positive effects of disclosure for the children, such as better self-esteem (Murphy, Marelich, & Hoffman, 2002) and better understanding of HIV/AIDS (Shaffer, Jones, Kotchick, Forehand, & the Family Health Project Research Group, 2001). A qualitative study of children between 10 and 18 years of age showed however, opposite results, with the mothers experiencing positive effects of disclosure, such as a closer relationship to the child, but the children reporting strong negative emotions, such as fear and sadness (Vallerand, Hough, Pittiglio, & Marvicsin, 2005). Other investigators in United States have reported that disclosure had a negative impact on adolescent behaviour—for example, increased alcohol or drug use and increased unprotected sexual intercourse—compared with the behaviour of adolescents who were not informed (Lee & Rotheram-Borus, 2002; Rotheram-Borus et al., 1997). Adolescent depression has also been reported to be associated with parental HIV disclosure (Lee, Detels, Rotheram-Borus, Duan & Lord, 2007), and young adolescents (ages 10 through 14) who had been informed about their mothers' HIV status were reported to be more likely to be clinically depressed than those who did not know (Brackis-Cott, Mellins, Dolezal & Spiegel, 2007).

The issue of HIV disclosure to children is complex and neither my study results nor the described previous studies on the consequences for children support the idea that it is always in the best interest of the child to be informed about their parent's HIV status. However, it is important that those counselling parents about HIV-disclosure issues first consider each family and child individually before recommending whether, and when, a child should be informed. Parents who are planning to disclose their serostatus to their children should be advised to plan for psychosocial follow-up subsequent to disclosure (Murphy, Roberts, & Hoffman, 2006). For future research, I suggest conducting in-depth interviews with HIV-negative adolescents who are aware of their African parents' HIV status. In this way we would gain additional understanding about these children and possible benefits and/or negative consequences of informing them about their parents' HIV status.

5.2.3 Fear of disclosure and stigma

I believe that the low level of disclosure found in my studies is related to the special cultural and social conditions of belonging to a minority group of first-generation

immigrants. Fear of stigma and discrimination has been reported as the main cause of the low disclosure rate among HIV-infected Africans in Europe (Flowers, et al. 2006; Petrak, et al., 2001; Prost et al., 2008). In the United Kingdom, HIV-infected Africans report experiences of racism, and discriminatory behaviour from relatives, friends and healthcare staff (Sigma Research and National AIDS Trust, 2004), and they have been reported to be three times more likely to experience discrimination compared with HIV-infected white British people (Weatherburn, Ssanyu-Seruma, & Hickson, 2003). The use of disclosure-avoidance techniques have been shown to be associated with stigma (Steward et al, 2008), and discrimination related to HIV diagnosis has also been found to be a barrier to parental disclosure to children (Letteney, 2006; Letteney & Laporte, 2004).

Disclosure of HIV status involves a complex process of decision-making (Derlega et al, 2004), where positive and negative consequences are considered (Serovitch, 2001). It is important to consider how disclosure fits into one's social identity and situation (Mayfield Arnold et al., 2008). Of prime concern when considering disclosure is the type of the relationship, e.g. sexual partner, family member, friend, employer or a professional person (Bairan, Taylor, Blake, Akers, Sowell & Mendiola, 2007). The decision to disclose is selective and consists of several steps (Kalichman, DiMarco, Austin, Luke & DiFonzo, 2003). The longer the time that has passed since the HIV diagnosis, the more likely it is that HIV-infected persons have disclosed their status (Emler, 2006; Petrak et al., 2001; Serovich, Esbensen, & Mason, 2007). Coming from countries in sub-Saharan Africa, to countries in Europe constitutes a special situation, and study results among HIV-infected persons from other continents such as from North America cannot automatically be applied.

The social stress of moving to a new country and receiving an HIV diagnosis can overwhelm these parents with external and internal stressors. Pervasive losses, including changes of domicile and shifting parental and sibling systems among ethnic minority families in the United States, have been reported to result in avoidance of emotionally charged topics (Fulmer, 1983).

In paper **I**, negative consequences such as rejection and stigmatisation because of HIV disclosure to children, relatives and friends could not be confirmed. There was only one relative living abroad who did not want to have further contact with the HIV-infected person after disclosure. In all other cases the frequency of contacts remained the same, though the results do not say anything about the quality of the contacts. However, as I previously described (paper **III**) the participants did have experiences of stigmatisation when visiting healthcare settings outside the HIV clinic. For most participants, being open about their HIV status was associated with fear of being treated differently, both in relation to close relatives and more distant acquaintances. Several studies have found that fear of discrimination or rejection is the main reason for not disclosing one's HIV status (Greff et al., 2008; Mayfield Arnold et al., 2008; Prost et al., 2008), and can lead to negative consequences such as emotional and physical abuse (Gielen, Fogarty, O'Campo, Anderson, Keller & Faden, 2000, Manfrin-Ledet & Porche, 2003).

The participants further described that they were afraid of being associated and identified with HIV and wanted themselves and their family members to be treated just

like a normal family (III). By avoiding being open about HIV they also avoided the more indirect forms of stigmatization: being stared at, pitied, and being the target of gossip. Goffman (1963) labels this as wanting to “pass” as normal, which is one of the central aspects of stigma theory. These parents are likely to experience the fear of a double stigma: being both immigrants and HIV-infected. The colour of the participants’ skin puts them also at risk of being exposed to racial stigma in Sweden, and thus to multiple stigma (Nyblade, 2003), which has been explained as being one reason why stigma is so persistent and difficult to change (Link & Phelan, 2001). Being an immigrant is in itself a stressor (Greenwood et al., 1996; Smith, 1985), and often ethnic subgroups are formed, where gossip of any kind is easily spread (Smith, Kenya, Lucas & Latkin, 1999). This could make immigrants with HIV even more afraid to disclose their HIV status.

In my studies all the participants had informed their partners about their HIV status, all had access to ARVs, and all had an income. The lack of closeness to relatives seemed to have been compensated for by psychosocial support received from staff at the HIV clinic and support in voluntary organisations for HIV-infected persons. Thus, weighing up the pros and cons, and choosing a cognitive and/or behavioural avoidance coping strategy to restrict openness about their HIV status seem to be a rational decision. Previous research among HIV-infected Africans in London and among women (mainly of African origin) in Stockholm has found little evidence that a larger number of persons being informed result in more well-being in the HIV-infected person (Calin et al., 2007; Cederfjäll, Langius-Eklöf, Lidman, & Wredling, 2001). I believe that the choice of coping strategy has to be seen in the environmental context where people live. Avoidance coping strategies such as restricting openness about HIV can in this sense be both beneficial and adaptive.

5.2.4 Knowledge about HIV-transmission and The Swedish Communicable Diseases Act

Despite good basic knowledge of HIV transmission, more than a third of the participants thought that HIV could be transmitted through kissing, and some even thought that HIV transmits through swimming pools and/or saunas (paper I). Similar results were reported among HIV-infected individuals in Canada who feared causal transmission within the family despite good basic knowledge (DeMatteo, Wells, Goldie, & King, 2002). I believe the HIV information about kissing provided by medical staff is difficult to grasp. Patients are normally told that HIV cannot be transmitted through kissing unless the patient is bleeding from his /her gums, has a sore on the lips or engages in deep kissing, but what is deep kissing, and what does bleeding from the gums indicate? Discordant opinions on HIV transmission, recorded in five couples, have particular implications, especially for children. Some of the participants in paper IV also expressed fear of transmitting the HIV-virus to their children through daily contact. This places unnecessary restriction on the family with regard to daily activities; kissing, hugging and visiting public swimming pools.

In the first study all partners of the HIV-infected patients had been informed about the HIV status. Six participants, however, did not know that their sexual partner had to be informed according to Swedish law. HIV-infected patients in Sweden are informed

about HIV prevention and who they have to inform about their HIV status. However, after the development of more effective but also toxic medications, more time is spent explaining the complexity of secondary effects and clinical blood tests. At the time of diagnosis, the patient is overwhelmed by an immense input of information and impressions. At the same time, he/she is most often in a state of crisis, which makes it difficult to assimilate new information (Cullberg, 1975). My findings confirm the necessity of repeating information about transmission and legal aspects of HIV until the patient is able to fully integrate the information. The information has to be thorough and explicit about how the virus is and is not transmitted. In paper I, knowledge about HIV transmission did not seem to have influenced the degree of disclosure. This suggests that it is not fear of rejection because of an easily spread virus that prevents patients from disclosing their situation, but rather other aspects such as fear of stigmatisation and shame.

Education level prior to arrival to Sweden seemed to have an impact on the participants' assimilation process, as persons with more education appeared to have found employment to a greater extent and had informed more important persons in their social network about their HIV status. Bronfenbrenner (1979) considers education to be part of the macrosystem. School is a place where the patterns of beliefs and behaviours that characterise society are transmitted from one generation to the next through the process of socialisation. What is it about education that produces such effects? Bronfenbrenner elaborates on the importance of higher education and explains it as the further a person goes in school the more likely he/she is to experience freedom from supervision, to have opportunities for developing self-direction and to experience an overall development in independent thinking and behaviour (Bronfenbrenner, 1979). Kohn (1995) considers that the substantive complexity of education affects the personality, and that education thus is a determinant of future job conditions. In this study we see how activities in one setting, such as number of years in school in Africa, seem to have implications for the settlement process in another setting. It appears that persons with less education before arriving to Sweden are more vulnerable and need extra psychosocial support in the settlement process in Sweden.

5.2.5 Changing Ugandan parenthood in the Swedish context

Moving from Uganda to Sweden was for both men and women described as a real challenge to their parental roles. The role for the men seemed to undergo the largest transformation (paper IV).

Hofstede and Hofstede (2005) define a country like Uganda as masculine, patriarchal society where men traditionally are breadwinners and owners of most of the productive resources, especially land (Tuyizere, 2007; Therborn, 2006). They make most of the social and economic decisions of their families but play a minor domestic role (Otiso, 2006). Fathers in East Africa traditionally do very little of the caregiving of young children such as dressing, feeding or bathing them (Harkness & Super, 1992).

Sweden is according to Hofstede and Hofstede (2005) described as a feminine society. When Ugandan men arrive to Sweden, they are suddenly expected to share the domestic chores with the women as well as let women be part of the major family

decisions. In an explorative study in London, male HIV-infected Africans described how it was more difficult for them to sustain male control in the United Kingdom. They felt that women were given unfair advantages in employment, benefits and other services, and that men became economically dependent and were unable to control their own household (Doylan, Anderson & Apenteng, 2005). In the United States, the acculturation process of Ugandan immigrants has been described as striking at the very heart of the Ugandan male identity (Conrad, 2004). In my study, the Ugandan fathers described how they were expected to perform low status tasks such as cooking and taking care of the children. For the mothers it was the opposite. They came from a situation where they were disadvantaged with respect to cash, land and other resources and arrived to a reverse situation where they were expected to take part in important family decisions.

Restrictive Swedish immigration policies made it difficult for the parents to stay in contact with parts of their social network in Uganda since relatives were not allowed to come to Sweden. This was particularly serious for some Ugandan fathers who despite several attempts had not been allowed to bring all their children to Sweden. This left the fathers with a sense of powerlessness and frustration of not being able to assist their own children.

There were contradictory descriptions about who takes care of the children in case of a separation in Uganda. Some mothers stated that the men do not take any responsibility while a father explained that it is mothers who do not take any responsibility for their children. In unpublished material from the quantitative study I found similar results when we asked the participants who had the right to decide where children whose parents have passed away should live according to the norms in the country of origin. Female participants stated to a greater extent that it is the women's relatives that decides, compared to the male participants that to a greater extent stated that it is the men's relatives that decides. The Ugandan participants did not differ in this respect. This may mirror changing patterns of child care in Uganda where previous traditional expectations of paternal kin care are changing to placement with maternal kin (Oleke, Blystad & Rekdal, 2005; Roby, Shaw, Chemonges & Hooley, 2009), but it could also be an expression of ethnic differences (Otiso, 2006) among the participants as we did not ask them which of the ethnic groups in Uganda they belonged to.

As the life expectancy for HIV-infected parents is now prolonged, questions about disclosure and future planning for children should be seen within this new perspective. However, mortality is still expected to be high among these parents, and lifelong treatment and side effects still highlight the importance of information and understanding from a child's perspective. However, as time passed and with the positive effects of ARV treatment, parents tended to be less worried about leaving their children as orphans. The ARV treatment seems to function as a buffer as the parents continue to feel healthy, putting thoughts about HIV infection into the background. Other difficulties than HIV became more prominent such as how to manage being a parent and a husband or wife.

6 CONCLUSIONS

The findings in this thesis highlight the psychosocial situation of HIV-infected parents of African origin living in Sweden.

Paper I.

- Most had small microsystems consisting mainly of contacts with the immediate family, partners and children, and more than two-thirds of the participants had no informed relatives in Sweden. The lack of a social network was especially prominent among single women.
- The social networks were found to be generally of similar size in Sweden and in the home country.
- Other important mesosystems had been developed among professional contacts and friends and members of churches and NGOs. Lack of closeness to relatives seemed to have been compensated for by psychosocial support received from staff at the HIV clinic but also with support from voluntary organisations for HIV-infected persons.
- All had contact with at least one professional person they regarded as important to them, and contact with social workers at the HIV clinic and at the social welfare office increased the probability of disclosure about HIV infection.
- The participants had basic knowledge of HIV transmission, although a third thought that HIV transmits in more ways than are scientifically verified. There were also uncertainties about whom to inform about the HIV infection according to the Swedish Communicable Diseases Act.

Paper II.

- Only women had informed their children about their HIV status, and only to eight of 59 children older than six years.
- Half of the parents had talked to someone about future custody arrangements. These parents reported more contact with a social worker at the social welfare office and with a medical social worker at the HIV clinic. Most parents wanted their children to be cared for by a relative in Sweden or by their HIV-negative partner.
- Neither disclosure nor custody planning seemed to be associated with clinical status or antiretroviral treatment, suggesting that the higher disclosure rate among these women is attributable to their isolated psychosocial situation, not their health status

Paper III.

- The parents chose cognitive and/or behavioural coping to avoid openness about HIV status to children, relatives and friends.
- They feared being treated differently, omitted the word HIV in conversations, and pretended to have other illnesses in the communication with their children. The fear of a double stigma—that of being both immigrant and HIV-infected—is likely the main barrier to disclosure of HIV infection.
- A previously not described form of silent communication about HIV status when meeting other HIV-infected persons in voluntary organisations was described.
- Reported discrimination from medical personnel outside the HIV clinic, was described as a reason to avoid disclosure.

Paper IV.

- The father and mother roles of these parents undergo radical transformations when they move from Uganda to Sweden where fathers are suddenly expected to perform

female tasks such as cooking and taking care of the children, while mothers are expected to share important family decisions with their husbands.

- The new sociocultural, legal and economic context in Sweden gives economic relief, but is also a restriction with regard to closeness and possibility to bring relatives and children to Sweden.
- Parents expressed fear of transmitting the HIV virus to their children through daily contacts, which placed unnecessary restrictions on the family with regard to daily living.
- An 'African-Swedish method' was described where parents had integrated a more Swedish way of talking and being close to their children, but in relation to their HIV status they used what they described as the African style of not informing their children.
- As time passed and with the positive effects of ARV treatment, parents tended to be less worried about leaving their children as orphans.

7 IMPLICATIONS AND RECOMMENDATION FOR FUTURE RESEARCH

For the policy makers

Lack of closeness to relatives among the HIV-infected parents of African origin had in my studies been compensated with psychosocial support received from professionals such as the staff at the HIV clinic and support in voluntary organisations for HIV-infected persons. This emphasizes the importance of co-operation between these two agencies. This co-operation has, however, diminished in Sweden after the introduction of antiretroviral medication. It is thus important to revitalize the co-operation between the HIV clinics and voluntary organisations. This addresses the need for a continued multi-sectorial strategy in order to maximize support for HIV-infected persons, especially for migrant families who might not be able to rely on support from the extended family.

The HIV-infected parents of African origin reported about experiences of discrimination from medical personnel outside the HIV clinic. As the majority of HIV-infected persons in Sweden are concentrated in major HIV units, the development of co-operation with general practitioners at some chosen primary healthcare centres outside the HIV unit could be one solution to give direct education and supervision to health personnel who have HIV-infected persons as one of their target groups. Persons with HIV infection live longer with higher treatment costs and as hospital management emphasise devolution it is necessary to develop and increase co-operation between the HIV clinics and primary healthcare centres.

For health care providers

The support strategies aimed at broadening HIV-infected African parents' social network and breaking their isolation should be continued and strengthened. This includes using networking as a tool, assisting the families to mobilise their social networks and encouraging the establishment of links between the various parts of the network. Women, particular single women, need information and assistance in contacting organisations, and persons with less education before arriving to Sweden need extra support in their settlement process.

The lack of knowledge about HIV-transmission, and about whom to inform about the infection stresses the importance of improved counselling. Health care personnel need to pay attention to these HIV-infected African parents' cultural dilemma and adapt medical information accordingly. It is important that they repeat information about legal aspects of HIV and how the virus is and is not transmitted until these parents are able to fully integrate the information.

Personnel counselling parents about the complexity of HIV-disclosure issues should first consider each family and child individually before recommending whether, and when, the child should be informed. Parents who are planning to disclose their serostatus to their children should be advised to plan for psychosocial follow-up subsequent to disclosure.

Recommendation for future research

For future research, I suggest in-depth interviews with HIV-negative adolescents who are aware of their African parents' HIV status. In this way we would gain additional understanding about these children and possible benefits and/or negative consequences of informing them about their parents' HIV status.

It is also important to investigate possible differences in disclosure rates to children among HIV-infected parents of Swedish origin and to compare them to my study results. In this way we would gain more understanding about the cultural impact on parental disclosure to children.

8 ACKNOWLEDGEMENTS

I would like to express my warm and sincere gratitude to all the people who have supported and contributed directly or indirectly to this thesis, especially thanks to: The participants at the Infectious Diseases Department at Karolinska University Hospital, for so generously sharing your experiences. Without you this thesis would not have existed. I also want to thank all the patients I have been privileged to meet in my role as a medical social worker at the outpatient clinic for HIV.

Ophelia Haanyama and **Caroline Odera** at the Noah's Ark Foundation in Stockholm, for your bravery and for being such a source of inspiration. I am impressed with how you dare to be spokespersons for people living with HIV, conquering stigma and discrimination.

Elisabeth Faxelid, Associate Professor and my main supervisor, for your patience and detailed comments on my writing. I have always felt supported by you. You have been there for me, even in the bus line, or in the taxi, to trustfully talk and discuss any problem at any time.

Anders Björkman, Professor, my supervisor and former main supervisor who encouraged me to become a PhD-student. Thank you for your rich and valuable comments on my two first manuscripts and for your criticism assisting me in the process to find my strength and trust in my own capacity.

Thomas Lindstein, my former supervisor, for your support and for introducing me to social network theory and the work of Bronfenbrenner. I will never forget having supervision with you in the most beautiful headmaster room at Ersta Sköndal University College, looking out at the beauty of Stockholm.

Mariann Olsson, Senior Lecturer at Karolinska Institute and my tutor, for being such an inspiration and a model, showing me that it is possible to keep a psychosocial perspective even in the midst of medical hierarchy. Thank you for reading and supplying constructive comments on parts of the cover story.

Monnie Callan, my "American mother", for being such a source of inspiration, showing me the essence of social work: dedication, commitment, empathy and to have the courage to stand up for the clients.

My co-authors, **Jimmy Munobwa**, **Lena Nilsson-Schönnesson**, **Pehr-Olof Pehrson**, **Birgitta Rubensson** for your contribution and sharing your knowledge, and to **Erik Belfrage**, "HIV paediatrician", for introducing me to research and for always being there with your kind friendship supporting me with all my problems and concerns. Previous co-authors who inspired me to continue with research: **Ann-Britt Bohlin**, **Susanne Lindgren**, **Ann-Britt-Bengtsson**, **Kristina Ramtedt** and **Torsten Berglund**.

Gunilla Rådö, you employed me at the Infectious Diseases Department at Danderyds Hospital in 1990, and I think you are a bit surprised that I am still there 20 years later. Thank you for your continuous trust in me and for being there during all these years. I always felt that you have seen my genuine interest and dedication in my work.

Knut Lidman, my informal tutor and former head physician of the out patient clinic for HIV care at Karolinska University Hospital, for your loving presence and constant kind support. You have been like my "professional father"-always there, showing me what true continuity of care means.

Ann-Magret Petterson, former head nurse for the outpatient clinic for HIV care at Danderyds Hospital, your pioneering spirit led the way in the treatment of HIV-infected persons in Sweden. You taught me that you have to live, laugh, and enjoy life even in the midst of death. I will always remember you.

Elsa Tynell, "HIV physician", for your friendship and advice in my research process; for reading and supplying constructive comments on the cover story. You helped me to feel connected and part of the research at the division of medicine, and we almost succeeded in going to "Friskis and Sveltis" at least once a year!

Ulla Backe Nylund and **Kenneth Fjällborg** for patiently coordinating the research for study one.

Britt-Marie Johansson, Pehr-Olov Pehrson, , Lena Andersson, Maria Engholm, and Christina Ralsgård for assistance with participants and/or interviews.

The current and former heads of the Unit of Infectious Diseases at Karolinska University Hospital for support and granting a leave of absence to complete my studies.

Ami Lexmark, head administrator, for always being there with your friendly helpful assistance in principally any matter concerning our clinic. You are the hub around which the Unit of Infectious Diseases circles.

Ulf Bronner, Margareta Edin, and Helene Andersson for friendship and our work with the International group of Infectious Diseases.

To all present and former wonderful friends and colleges at the Department of Infectious Diseases at Karolinska University hospital who I have been fortunate to meet during the years, and especially to the personnel at the outpatient clinic for HIV care. Thank you for sharing my everyday life and work with dedication to patients and to the many joyous, sad, painful and friendly discussions in the coffee room or in the corridor.

Bo Anzén and **Lena Rolfhamre** at the Department of Obstetrics and Gynecology, for friendship and invaluable expertise, guidance and co-operation around HIV-infected pregnant women and their families.

Kristina Broliden and **Mats Kalin** for support and giving me a feeling that I do belong to the Division of Medicine and to **Kjerstin Björkholm** for support and discussions in the coffee room.

I want to express my sincere gratitude to the Department of Social Work and to the director **Britt Strand**. I have always felt supported by you. You gave me a home during my period as a researcher.

Karin Aluko, my closest "boss", for your support, always trying to find ways to facilitate my research process, and giving me the possibility to grant leave of absence to complete my studies.

The FoUU-group of medical social workers: **Mariann Olsson, Kjerstin Larsson, Ulla Forinder, Catharina Gåfväls, Aina Johanson, Berit Björkman, Catharina Löf, Lisa Sand, Liisa Hammar, Kristina Rane, Marie Nilsson, Maria Flink and Tina A Lundberg** for support and sharing of your knowledge.

The medical social workers at floor 4 in "elevhemmet" for supporting and treating me so nicely, always greeting me friendly in the corridor or cofferroom spending some moments chatting about life.

Sazzad Alie and **Ann-Kersti Tibblin**, administrators at the Department of Social Work, for your support, sharing the end of the corridor at floor four. Thank you Sazzad for assisting me with all my computer problems.

Division of Global Health/IHCAR for providing me a second home during the last years. I always felt welcome to your different seminars and groups. The research group: **Lynn Muhinbuura Atyambe, Anna-Berit Ransjö-Arvidson, Staffan Bergström, Gorrette Nalwadda, Jolly Beyeza, Ketkesone Phrasisombath, Vanphanom Sychareun, Eva Johannson, Petra Löfstedt, and Annette Aronsson** for support and sharing of your knowledge. Especially thanks to **Sarah Thomson, Annika Johannson, and Gorrette Nalwadda** for supporting me with challenging comments at my pre-disputation seminar.

Elin Larsson, PhD-student at IHCAR, for friendship and support. You have been my special link to IHCHAR, always there to discuss and assist me in any matter. Thank you for your comments on paper three, and parts of the cover story.

Anastasia Pharris, PhD-student at IHCAR, for friendship and support. Thank you Anastasia for reading and supplying constructive comments on paper four and the cover story.

Malin Arneborn, epidemiologist, for friendship, always being there to discuss and provide valuable data on National statistics on HIV-infection in Sweden.

Stig Elofsson, and **Mesfin Tessma**, statisticians, for statistical support and good discussions on methodological considerations.

Marie Källberg, head librarian and her fantastic staff at the library at Karolinska University Hospital in Solna for their patience and friendly professional support.

Anita Dorazio for friendship and assistance with helping us with patients when the Swedish government failed. You are my inspiration with your endless capacity to show true humanity to people "without a paper", without a home and a belonging.

To all dear and wonderful friends and relatives for making my life so full and rich. My mother **Anna-Stina**, sister **Kristina**, brother **Göran**; Ulrikas mother **Kerstin** and **Ralph**, father **Björn**, aunt **Inger**, sister **Helena** and **Per** for all your love and support: childcaring, painting, moving, rebuilding, planting potatoes, cleaning the refrigerator, cooking, baking etc.; to my friend **Margareta H-Norin** for your endless support and friendship.

Ulrika my dearest and loving lifecompanion, and to our wonderful children **Samuel** and **Johannes**. You are my real treasures, filling my life with joyous life and endless loving support.

This thesis was supported with grants from the National Board of Health and Welfare (former National Institute of Public Health), the Memorial Fund of Groschinsky, and the Swedish Physicians Against AIDS Research Fund.

9 REFERENCES

- Amadiume, I. (1997). *Reinventing Africa: Matriarchy, religion & culture*. Zed Books Ltd. London & New York.
- Anderson, M., Elam, G., Gerver, S., Solarin, I., Fenton, K., & Easterbrook, P. (2008). HIV/AIDS-related stigma and discrimination: accounts of HIV-positive Caribbean people in the United Kingdom. *Social Science of Medicine*, 67, 790-798.
- Andrews, S., Williams, A. B., & Neil, K. (1993). The mother-child relationship in the HIV-1 positive family. *Image: Journal of Nursing Scholarship*, 25, 193-198.
- Ankrah, E. M. (1993). Impact of HIV/AIDS on family and other significant relationships: the African clan revisited. *AIDS Care*, 5, 5-22.
- Åsander, A.-S., (2007). *Rapport-kartläggning och analys av de insatser som görs för att stödja barn med anknytning till smittade personer* [Report-survey and analyze of interventions to support children to infected persons] (NBHW, Division of HIV prevention, Stockholm, Report No. 2007-128-45).
- Åsander, A.-S., Belfrage, E., Bohlin, A.-B., Bengtsson A.-B., Lidman, K., & Lindgren, S. (1994). HIV infekterade kvinnors barn: En utsatt grupp [Children to HIV-infected women: A vulnerable group]. *Läkartidningen*, 91, 499-502.
- Åsander, A.-S., Berglund, T., Persson, C., & Ramstedt, K. (1996). Prevention mot HIV med kontaktsparning: Uppföljning av personer med nydiagnosticerad infection [HIV prevention through partner notification: follow-up on newly infected.]. *Läkartidningen*, 93: 3907-3910.
- Bairan, A., Taylor, G. A. J., Blake, B. J., Akers, T., Sowell, R., & Mendiola, R. (2007). A model of HIV disclosure: disclosure and types of social relationships. *Journal of the American Academy of Nurse Practitioners*, 19, 242-250.
- Barré-Sinoussi, F., Chermann, J.C., Rey, F., Nugeyre, M. T., Chamaret, S., Gruest, J., Dauguet, C., Axler-Blin, C., Brun-Vezinet, F., Rouzioux, C., Rozenbaum, W., & Montagnier, L. (1983). Isolation of a T-Lymphotropic retrovirus from a patient at risk for Acquired Immune Deficiency Syndrome (AIDS), *Science*, 220, 868-870.
- Beedham, H., & Wilson-Barnett, J. (1995). HIV and AIDS care: consumers' views on needs and services. *Journal of Advanced Nursing*, 22, 677-686.
- Berkman, L. F., & Syme, L. (1979). Social networks, host resistance, and mortality: a nine-year follow-up study of Alameda county residents. *American Journal of Epidemiology*, 109, 186-204.
- Bor, R., & du Plessis, P. (1997). The impact of HIV/AIDS on families: an overview of recent research. *Family Systems Medicine*, 15, 413-427.
- Bourdieu, P., & Wacquant, L. (1992). *An invitation to reflexive sociology*. Chicago, University of Chicago Press.
- Boyd, M. (1989). Family and personal networks in migration. *International Migration Review*, Special silver anniversary issue, 23, 3.
- Brackis-Cott, E., Mellins, A. C., Dolezal, C., & Spiegel, D. (2007). The mental health risk of mothers and children: the role of maternal HIV infection. *Journal of early adolescence*, 27 (1), 67-89.
- Bronfenbrenner, U. (1979). *The ecology of human development*. Cambridge, MA, Harvard University Press.
- Bronfenbrenner, U. (1992). Ecological systems theory. In: Vasta R, ed. *Six theories of child development: revised formulations and current issues*. London, Jessica Kingsley, pp. 187-249.
- Bronfenbrenner, U. (1995). Developmental ecology through space and time: a future perspective. In: Moen P, Elder GH, Luscher K, eds. *Examining lives in context*. Washington, DC, American Psychological Association.

- Bungener, C., Marchand-Gonod, N., & Jouvent, R. (2000). African and European HIV-positive women: psychological and psychosocial differences. *AIDS Care*, 12(5), 541-548.
- Calin, T., Green, J., Hetherington, J., & Brook, G. (2007) Disclosure of HIV among black African men and women attending a London HIV clinic. *AIDS Care*, 19(3), 385-391.
- Caplan, G. (1974). *Support systems and community health*. New York, Behavioural Publications.
- Catz, S, Gore-Felton, C., & McClure, J. B. (2002), Psychological distress among minority and low-income women living with HIV. *Behavioural Medicine*, 28, 53-60.
- Cederfjäll, C., Langius-Eklöf, A., Lidman, K., & Wredling, R. (2001). Gender differences in perceived health-related quality of life among patients with HIV infection. *AIDS PATIENT CARE and STDs*, 15(1), 31-39.
- Centres for Disease Control (CDC). (1981). Pneumocystis pneumonia – Los Angeles. *Morbidity and Mortality Weekly Report*, 30(21), 250-252.
- Centers for Disease Control. (1982). Opportunistic infections and Kaposi's Sarcoma among Haitians in the United States. *Morbidity and Mortality Weekly Report*, 31(26), 353-354,360-361
- Centers for Disease Control. (1982). Pneumocystis carinii Pneumonia among persons with hemophilia A. *Morbidity and Mortality Weekly Report*, 31(27), 365-367.
- Centers for Disease Control. (1982). Current Trends Update on Acquired Immune Deficiency Syndrome (AIDS)- United States. *Morbidity and Mortality Weekly Report*, 31(37), 507-508, 513-514.
- Centers for Disease Control. (1982). Possible Transfusion-Associated Acquired Immune Deficiency Syndrome, AIDS- California. *Morbidity and Mortality Weekly Report*, 31(48), 652-654
- Centers for Disease Control. (1982). Unexplained Immunodeficiency and Opportunistic Infections in Infants- New York, New Jersey, California. *Morbidity and Mortality Weekly Report*, 31(49), 665-667.
- Centers for Disease Control (1983). Immunodeficiency among female sexual partners of males with Acquired Immune Deficiency Syndrome (AIDS) - New York. *Morbidity and Mortality Weekly Report*, 31(52), 697-698.
- Chinouya, M. (2006). Telling children about HIV in transnational African families: tensions about rights. *Diversity in Health and Social Care*, 3(1), 7-17.
- Christianson, M., Lalos, A., & Johansson, E. E. (2008). *Vulnerable Children and Youth Studies*, 3(3), 234-242.
- CIA (2009). *The World Fact book*. Retrieved September 17, 2009, from <https://www.cia.gov/library/publications/the-world-factbook/>
- Coffin, J., Haase, A., Levy J.A., Montagnier, L., Oroszlan, S., Teich, N., Temin, H., Toyoshima, K., Varmus, H., Vogt, P., & Weiss, R.A. (1986). What to call the AIDS virus? (Letter), *Nature*, 321, 10
- Cook, T. D., & Campbell, D. T. (1979). *Quasi-experimentation: Design & Analysis Issues for Field Settings*. Rand McNally & Co, US.
- Conrad, N. L. (2004). Ugandan Americans. In: J. N. Giger & R. E. Davidhizar, Eds. *Transcultural Nursing: assessment & intervention, fourth edition*. Mosby, Inc. St. Louis, Missouri.
- Crystal, S., & Kerstin, R. C. (1998). *Stress, social support, and distress in a statewide population of persons with AIDS in New Jersey*. *Social Work in Health Care*, 28 (1), 41-60.
- Cullberg, J. (1975). *Kris och utveckling* [Crisis and development]. Natur och kultur.
- Danziger, R. (1998). HIV testing and HIV prevention in Sweden. *British Medical Journal*, 316(7127), 293–295.
- DeMatteo, D., Wellis, L. M., Goldie, S., & King, S.M. (2002). The 'family' context of HIV: a need for comprehensive health and social services. *AIDS Care*, 14(2), 261-278.
- De Mooij, M. (2001) Convergence and divergence in consumer behaviour. *Buyer behaviour*, October, 30-33.

- Derlega, V. J., Winstead, B. A., Greene, K., Serovich, J., & Elwood, W. N. (2004). Reasons for HIV-disclosure/nondisclosure in close relationships: testing a model of HIV-disclosure decision making. *Journal of Social and Clinical Psychology, 23*(6), 747-767.
- Doylan, L., & Anderson, J. (2005). 'My fear to fall in love again.....' How HIV-positive African women survive in London. *Social Science of Medicine, 60*, 1729-1738.
- Doylan, L., Anderson, J., & Apenteng, P. (2005). *I want to survive, I want to win, I want tomorrow: an exploratory study of African men with HIV in London*. London. Terence Higgins Trust. Retrieved June 3, 2009, from <http://www.tht.org.uk/informationresources/publications/policyreports/iwanttosurvive.pdf>
- Emler, C. A. (2006). A comparison of HIV stigma and disclosure patterns between older and younger adults living with HIV/AIDS. *AIDS PATIENT CARE STDS, 20*(5), 350-358.
- Epstein, H. (2007). *The invisible cure: Africa, the west, and the fight against AIDS*. Farrar, Straus and Giroux. New York.
- Erwin, J., Morgan, M., Britten, N., Gray, K., & Peters, B. (2002). Pathways to HIV testing and care by black African and white patients in London. *Sexually Transmitted Infections, 78*, 37-39.
- Erwin, J., & Peters, B. (1999). Treatment issues for HIV+ Africans in London. *Social Science of Medicine, 49*, 1519-1528.
- EuroHiv, (2007). *HIV/AIDS Surveillance in Europe End-year report 2006, No 75*. Retrieved March 27, 2008, from http://www.eurohiv.org/reports/report_75/pdf/report_eurohiv_75.pdf
- European Collaborative study. Prepared by Hankin, C., Thorne, C., Peckham, C., & Newell, M.-L. (2004). The health and social environment of uninfected infants born to HIV-infected women. *AIDS Care, 16*(3), 293-303.
- Fischl, M. A., Richman, D. D., Grieco, M. H., Gottlieb, M. S., Volberding, P. A., Laskin, O. L., Leedom, J. M., Groopman, J. E., Mildvan, D., Schooley, R. T., et al. (1987). The Efficacy of azidothymidine (AZT) in the treatment of patients with AIDS and AIDS-related complex, a double-blind, placebo-controlled trial. *The New England Journal Of Medicine, 317*, 185-191.
- Flowers, P., Davis, M., Hart, G., Rosengarten, M, Frankis, J. & Imrie, J. (2006). Diagnosis and stigma and identity amongst HIV positive Black Africans living in the UK. *Psychology and Health, 21*(1), 109-122.
- Foster, G. (2000) The capacity of the extended family safety net for orphans in Africa. *Psychology, Health & Medicine, 5*(1), 55-62.
- Foster, G., & Williamson, J. (2000). A review of current literature on the impact of HIV/AIDS on children in sub-Saharan Africa. *AIDS, 14* (suppl 3), 275-284.
- Fulmer, R. H. (1983). A structural approach to unresolved mourning in single parent family systems. *Journal of Marital and Family Therapy, 9*, 259-269.
- Furnham, A., & Shiekh, S. (1993). Gender, generation and social support correlates of mental health in Asian immigrants. *The International Journal of Social Psychiatry, 39*, 22-33.
- Gallo, R.C., Salahuddin, S. Z., Popovic M., Shearer, G. M., Kaplan, M., Haynes, B. F., Palker, T. J., Redfield, R, Olesko, J., Safai, B., et al. (1984). Frequent detection and isolation of cytopathic retrovirus (HTLV-III) from patients with AIDS and risk for AIDS. *Science, 224*, 500-503.
- Gapminder (2009). *HIV in Gapminder world*. Retrieved December 12, 2009, from <http://www.gapminder.org/videos/ted-talk-2009-hans-rosling-hiv-facts/>
- Gapminder documentation (2008). *Documentation for HIV indicators in countries & territories*. Retrieved December 12, 2009, from http://www.gapminder.org/wpcontent/uploads/2008/10/gapdoc006_version001_2.pdf
- Garbarino, J. (1983). Social support networks: Rx for the helping professionals. In: Whittaker JK, Garbarino J, eds. *Social support networks: informal helping in the human services*. New York, Adline Publishing Company, pp. 3-28.

- Gielen, A., Fogarty, L., O'Campo, P., Anderson, J., Keller J., & Faden, R. (2000). Women living with HIV, disclosure, violence and social support. *Journal of Urban Health: Bulletin of the New York Academy of Medicine*, 77(3), 480-491.
- Gielen, A. C., McDonnell, K. A., Wu, A., O'Campo, P., & Faden, R. (2001). Quality of life among women living with HIV: the importance of violence, social support, and self care behaviours. *Social Science & Medicine*, 52, 315-322.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs, N.J. Prentice Hall.
- Gordon, A. A. (1996). *Transforming capitalism and patriarchy: gender and development in Africa*. Lynne Rienner Publishers, Inc.
- Gore, S. (1978). The effect of social support in moderating the health consequences of unemployment. *Journal of Health and Social Behaviour*, 19, 157-165.
- Gottlieb, M. S, Schroff, R., Shanker, H. M., Weisman, J. D., Fan, P. T., Wolf, R. A., & Saxon, A. (1981). Pneumocystis carinii pneumonia and mucosal candidiasis in previously healthy homosexual men. *The New England Journal of Medicine*, 305, 1425-1431.
- Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24, 105-112.
- Greenwood, D., Szapocznik, J., McIntosh, S., Anton, M., Ironson, G., Tejada, M., Clarington, L., Samuels, D., & Sorhaindo, L. (1996). African women, their families, and HIV/AIDS. In: Resnic RJ, Rozensky RH, et al., eds. *Health psychology through the life span: practice and research opportunities*. Washington, DC, American Psychological Association, pp. 349-359.
- Greff, M., Phetlu, R, Makoae, L. N., Dlamini, P. S., Holzemer, W. L., Naidoo, J. R., Kohi, T. W., Uys, L. R., & Chirwa, M. L. (2008). Disclosure of HIV status: Experiences and perceptions of persons living with HIV/AIDS and nurses involved in their care in Africa. *Qualitative Health Research*, 18, 311-324.
- Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field methods*, 18, 59-82.
- Hamers, F. F., & Downs, A. M. (2004). The changing face of the HIV-epidemic in Western Europe: what are the health implications for public health policies? *Lancet*, 364, 83-94.
- Hammer, M., Gutwirth, L., & Philips, S. L. (1992). Parenthood and Social Networks. *Social Science of Medicine*, 16, 2091-2100.
- Harkness, S., & Super, C. M. (1992). Shared child care in East Africa: sociocultural origins and developmental consequences. In: M. E. Lamb, K. J. Sternberg, C-P. Hwang & A. G. Broberg, eds. *Child care in context: cross-cultural perspectives*. Hillsdale, n. J. L. Erlbaum.
- Hessle, S. (1995). *Sociala nätverk i kris, utveckling och fördjupning: nätverksstudier på barnbyn Skå med psykosocialt utsatta familjer* [Crises in social networks, development and deepening: studies of social networks in psychosocial vulnerable families at Skå]. Rapport i socialt arbete nr. 74. Socialhögskolan, Stockholms universitet.
- Hofstede, G., & Hofstede, G. J. (2005). *Cultures and Organisations: Software of the mind: Intercultural cooperation and its importance for survival*. New York McGraw-Hill cop.
- Holmzemer, W. L., & Uys, L. R. (2004). Managing AIDS stigma. *SAHARA Journal*, 1(3), 165-174.
- Holt, R., Court, P., Vedhara, K., Nott, K. H., Holmes, J., & Snow, M. H. (1998). The role of disclosure in coping with HIV infection. *AIDS Care*, 10(1), 49-60.
- Horton, R., & Das, P. (2008). Putting prevention at the forefront of HIV/AIDS. *The Lancet*, 372, 421-422.
- Hsieh, H.-F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), 1277-1288.
- Irving, G., Bor, R., & Catalan, J. (1995). Psychological distress among gay men supporting a lover or partner with AIDS: a pilot study. *AIDS Care*, 7, 605-617.

- Kalichman, S. C., DiMarco, M., Austin, J., Luke, W., & DiFonzo, K. (2003). Stress, social support, and HIV status disclosure to family and friends among HIV-positive men and women. *Journal of behaviour medicine*, 26(4), 315-332.
- Karuhunga, M. B. (2008). *Living with AIDS in Uganda; Impacts on banana-farming households in two districts*. Doctoral thesis. Stockholm, Karolinska Institute.
- Kasl, S. V., & Berkman, L. (1983). Health consequences of the experience of migration. *Annual Reviews Public Health*, 4, 69–90.
- Kazdin, A. E. (1998). *Research design in clinical psychology*. Needham Heights, MA 02194: Allyn and Bacon.
- Kegeles, S. M., Coates, T. J., Christopher, T. A., & Lazarus, J. L. (1989). Perceptions of AIDS: the continuing saga of AIDS-related stigma. *AIDS*, 3(suppl 1), 253-258.
- Keogh, P., Allien, S., Almedal, C., & Temahagili, B. (1994). The social impact of HIV infection on women in Kigali, Rwanda: a prospective study. *Social Science and Medicine*, 38, 1047–1103.
- King, R., Katuntu, D., Lifshay, J., Packel, L., Batamwita, R., Nakayira, S., Abang, B., Babirye, F., Lindkvist, P., Johansson, E., Mermin, J., & Bunell, R. (2008). Processes and outcomes of HIV serostatus disclosure to sexual partners among people living with HIV in Uganda. *AIDS Behaviour*, 12, 232-243.
- Kirshenbaum, S. B., & Nevid, J. S. (2002) The specificity of maternal disclosure of HIV/AIDS in relation to children's adjustment. *AIDS Education and Prevention*, 14(1), 1-16.
- Klefbeck, J. & Ogden, T. (2003). *Barn och nätverk*. [Children and social networks]. Stockholm, Liber AB.
- Kohn, M. L. (1995). Social structure and personality through time and space. In: Moen P, Elder GH, Luscher K, eds. *Examining lives in context*. Washington, DC, American Psychological Association.
- Koser, K. (2003). *New African Diaspora's*. Routledge, Taylor & Francis Group. London and New York.
- Kuo, W. H., & Tsai, Y. M. (1986). Social networking, hardiness and immigrants' mental health. *Journal of Health and Social Behaviour*, 27, 133–149.
- Latkin, C. A., & Knowlton, A. R. (2005). Micro-social structural approaches to HIV prevention: a social ecological perspective. *AIDS Care*, 17(Supplement 1), 102-113.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York, Springer.
- Lee, M. B., & Rotheram-Borus, M. J. (2002). Parent's disclosure of HIV to their children. *AIDS*, 16, 2201–2207.
- Lee, S.-J., Detels, R., Rotheram-Borus, M. J., Duan, N., & Lord, L. (2007). Depression and social support among HIV-affected adolescents. *AIDS Patient Care and STDS*, 21(6), 409-417.
- Letteney, S. (2006). Mothers disclosure of maternal HIV status to children: Key psychosocial correlates. *Journal of HIV/AIDS & Social Services*, 5(1), 67–84.
- Letteney, S., & Laporte, H. H. (2004). Deconstructing stigma: Perceptions of HIV-seropositive mothers and their disclosure to children. *Social Work in Health Care*, 38(3), 105–123.
- Lincoln, Y., S., & Guba, E. G. (1985). *Naturalistic Enquiry*. Beverly Hills, CA: Sage Publications.
- Link, B. G., & Phelan J. C (2001). Conceptualizing stigma. *Annual Reviews of Sociology*, 27, 363-385.
- Long, T., & Johnson, M. (2000). Rigour, reliability and validity in qualitative research. *Clinical Effectiveness in Nursing*, 4, 30-37.
- Lynam, M. J. (1986). Support network developed by immigrant women. *Social Science & Medicine*, 21, 327–333.
- Machin, D, Campbell, J. H., & Walters S. J. (2007). *Medical statistics: a textbook for health sciences*. John Wiley & sons, Ltd.

- Manfrin-Ledet, L., & Porche, D. J. (2003). The State of Science: violence and HIV infection in women. *Journal of the Association of Nurses in AIDS Care*, 14(6), 56-68.
- Masur, H., Michelis, M.A., Greene, J.B., Onorato, I., Stouwe, R.A., Holzman, R.S., Wormser, G., Brettman, L., Lange, M., Murray, H.W., & Cunningham-Rundles, S. (1981). An Outbreak of community acquired *Pneumocystis carinii* pneumonia: initial manifestation of cellular immune dysfunction. *The New England Journal of Medicine*, 305, 1431-1438.
- Mayfield Arnold, E., Rice, E., Flannery, D., & Rotheram-Borus, M. J. (2008). HIV disclosure among adults living with HIV. *AIDS Care*, 20(1), 80-92.
- Mays, N., & Pope, C. (2000). Qualitative research in health care, assessing quality in qualitative research. *BMJ*, 320, 50-52.
- Mbiti, J. S. (1970). *African Religions and Philosophy*. New York: Anchor.
- Mercer, C., Page, B., & Evans, M. (2008). *Development and the African Diaspora: place and the politics of home*. Zed Books. London & New York.
- Merett, A. (2000). Culture in the cockpit. Do hofstede's dimensions replicate? *Journal of Cross-Cultural Psychology*, 31(3), 283-301.
- Merson, M. H., O'Malley, J., Serwadda, D., & Apisuk, C. (2008). The history and challenge of HIV prevention. *The Lancet*, 372, 475-488
- Miles, M.B. & Huberman, A. M. (1994). *Qualitative data analysis: an expanded sourcebook*. London: Sage Publications, Inc. Thousand Oaks, California.
- Miller, R., & Murray, D. (1999). The impact of HIV illness on parents and children, with particular reference to African families. *Journal of Family Therapy*, 21, 284-302.
- Miller, A. N., & Rubin, D. L. (2007). Factors leading to self-disclosure of a positive HIV diagnosis in Nairobi, Kenya: people living with HIV/AIDS in sub-Saharan. *Qualitative Health Research*, 17(5), 586-598.
- Moemeka, A. (1996). Interpersonal communication in communalistic societies in Africa. In W. B. Gudykunst, S. Ting-Toomey & T. Nishida (Eds.), *Communication in personal relationships across cultures* (pp.197-214). Thousand Oaks, CA: Sage.
- Moss, R. H. (1993). *Coping Responses Inventory: Adult Form manual*. Odessa, FL: Psychological Assessment Resources.
- Moss, R. H. (2002). The mystery of human context and coping: An unravelling of clues. *American Journal of Community Psychology*, 30(1), 67-88.
- Murithi, T. (2006) Practical peacemaking wisdom from Africa: reflections on Ubuntu. *The Journal of Pan American Studies*, 1 (44): 25-33.
- Murphy, D. A. (2008). HIV-positive mothers' disclosure of their serostatus to their children: A review. *Clinical Child Psychology and Psychiatry*, 13, 105-122.
- Murphy, D. A., Marelich, W. D., & Hoffman, D. (2002). A longitudinal study of the impact on young children of maternal HIV serostatus disclosure. *Clinical Child Psychology and Psychiatry*, 7, 55-70.
- Murphy, D. A., Roberts, K. J., & Hoffman, D. (2006). Young children's reactions to mothers' disclosure of maternal HIV + serostatus. *Journal of Child and Family Studies*, 15, 39-56.
- Nam, S. L., Fielding, K., Alalos, A., Gaolathe, T., Dickinson, D., & Gessler, P. W. (2009). Discussing matters of sexual health with children: what issues relating to disclosure of parental HIV status reveal. *AIDS Care*, 21(3), 389-395.
- Namir, S., Alumbaugh, M. J., Fawzy, F. I., & Wolcott, D. L. (1989). The relationship of social support to physical and psychological aspects of AIDS. *Psychology and Health*, 3, 77-86.

- Nolan, D., Reiss, P., & Mallal, S. (2005). Adverse effects of antiretroviral therapy for HIV infection: A review of selected topics. *Expert Opinion on Drug Safety*, 4, 201–218.
- Nyblade, L. (2003). *Disentangled HIV and AIDS stigma. Overview of findings from a two year study in Ethiopia, Tanzania, and Zambia*. Retrieved March 6, 2008, from www.irc.org/docs/stigmaintro.pdf
- Nöstlinger, C., Jonckheer, T., de Belder, E., van Wijngaerden, E., Wylock, C., Pelgrom, Y., & Colebunders, R. (2004). Families affected by HIV: parents' and children's characteristics and disclosure to the children. *AIDS Care*, 16, 641-648.
- Nöstlinger, C., Bartoli, G., Gordillo, V., Roberfroid, D., & Colebunders, R. (2006). Children and adolescents living with HIV positive parents: Emotional and behaviour problems. *Vulnerable Children and Youth Studies*, 1, 29-43
- Ogbu, J. U. (1981). Origins of human competence: A cultural-ecological perspective. *Child Development*, 52, 413-429.
- Oleke, C., Blystad, A., & Rekdal, O. B. (2005). When the obvious brother is not there: political and cultural contexts of the orphan challenge in northern Uganda. *Social Science & Medicine*, 61(12), 2628-2638.
- Olsson, M. (1994). *Social support in bereavement crisis: Interaction between medical staff and bereaved relatives*. Unpublished doctoral dissertation, Karolinska Institute, Stockholm, Sweden.
- Onwumere, J., Holttum, S., & Hirst, F. (2002). Determinants of quality of life in black African women with HIV living in London. *Psychology, Health & Medicine*, 1, 61–74.
- Opolot, J. A. (1982). Ethnicity and child-rearing practices in Uganda. *The Journal of Social Psychology*, 116, 155-162.
- Ostrom Delaney, R., Serovich, J. M., & Lim, J.-Y. (2008). Reasons for and against maternal disclosure to children and perceived child reactions. *AIDS Care*, 20(7), 876-880.
- Ostrom Delaney, R., Serovich, J. M., & Lim, J.-Y. (2009). Psychological differences between HIV-positive mothers who disclose to all, some, or none of their biological children. *Journal of Marital and Family Therapy*, 35(2), 175-180.
- Otiso, K. M., (2006). *Culture and Customs of Uganda*. Greenwood press, London.
- Padian, N. S., Buve', A., Balkus, J., Serwadda, D., & Cates Jr, W. (2008). Biomedical interventions to prevent HIV infection: how to make them work better. *The Lancet*, 372, 669-684.
- Pallela, F. J., Delaney, K. M., Moorman, A. C., Loveless, M. O., Fuhrer, J., Satten, G. A., Aschmann, D. J., & Holmberg, S. D. (1998). Declining morbidity and mortality among patients with advanced human immunodeficiency virus infection. *New England Journal of Medicine*, 338, 853–860.
- Patton, M. Q. (2002). *Qualitative research & evaluation methods*. Thousand Oaks, California: Sage Publications.
- Peretti-Watel, P., Spire, B., Pierret, J., Lert, F., Obadia, Y., & THE VESPA GROUP. (2006). Management of HIV-related stigma and adherence to HAART: Evidence from a large representative sample of outpatients attending French hospitals (ANRS-EN12-VESPA 2003). *AIDS Care*, 18(3), 254-261.
- Petrak, J. A., Doyle, A-M., Smith, A., Skinner, C., & Hedge, B. (2001). Factors associated with self-disclosure of HIV serostatus to significant others. *British Journal of Health Psychology*, 6, 66-79.
- Platform for co-operation on undocumented migrants (2007). *Access to health care for undocumented migrants in Europe*. Retrieved 19 Oktober, 2009, from <http://www.hivportalen.se/publikationer/Sidor/ccesstohealthcareforundocumentedmigrantsineurope.aspx>
- Prost, A., Elford, J., Imrie, J., Petticrew, M., & Hart, G. J. (2008). Social, behavioural, and intervention research among people of sub-Saharan African origin living with HIV in the UK and Europe: Literature review and recommendations for intervention. *AIDS Behaviour*, 12(2), 170-194.
- RAV (2009). *Antiretroviral behandling av HIV-infektion 2009, uppdaterad version – Behandlingsrekommendation*. [Antiretroviral treatment of HIV infection 2009, updated version- Recommendation for treatment]. Retrieved 20 October, 2009, from http://www.smittskyddsinstitutet.se/upload/rav/rav_behrek_2009_090118.pdf

- Roby, J. L., Shaw, S. A., Chemonges, E. W., & Hooley, C. D. (2009). Changing patterns of family care in Uganda: Fathers absence and patrilineal neglect in the face of HIV/AIDS. *Families in Society*, 90(1), 110-118.
- Rolfe, G. (2006). Validity, trustworthiness and rigour: quality and the idea of qualitative research. *Journal of Advanced Nursing Science*, 53 (3), 304-310.
- Rosling, H. (2009). Video from talk at the TED conference. Retrieved October 1, 2009, from <http://www.gapminder.org/videos/ted-talk-2009-hans-rosling-hiv-facts/>
- Rotheram-Borus, M. J., Draimin, B. H., Reid, H. M., & Murphy, D. A. (1997). The impact of illness disclosure and custody plans on adolescents whose parents live with AIDS. *AIDS*, 11, 1159-1164.
- Rwemisisi, J., Wolff, B., Coutinho, A., Grosskurth, H., & Whitworth, J. (2008). "What if they ask how I got it?" Dilemmas of disclosing parental HIV status and testing children for HIV in Uganda. *Health and Policy planning*, 23, 36-42.
- Samuelsson, M., & Thernlund, G. (1990). Barns sociala nätverk – en ämförande metodstudie [The social network of children – a comparative methodological study]. *Socialmedicinsk tidskrift*, 2, 49-55.
- Sandelowski, M. (1993). Rigor or rigor mortis: The problem of rigor in qualitative research revisited. *Advances in Nursing science*, 16(2), 1-8.
- SCB, Statistics Sweden (1997). Befolkningsstatistik del 3. Tabell 2.9 [Vital statistics, part 3. Table 2.9].
- SCB, Statistics Sweden (2008). Tabeller över Sveriges befolkning 2008. Tabell 1.2.5 [Tables of vital statistics in Sweden, Table 1.2.5].
- Serovich, J. M., (2001). A test of two disclosure theories. *AIDS Education and Prevention*, 13(4), 355-364.
- Serovich, J. M., Brucker, P. S., & Kimberl, J. A. (2000). Barriers to social support for persons living with HIV/AIDS. *AIDS Care*, 5, 651-662.
- Serovich, J. M., Esbensen, A. J., & Mason, T. L. (2007). Disclosure of positive HIV serostatus by men who have sex with men to family and friends over time. *AIDS Patient Care STDS*, 21(7), 492-500.
- Serpell, R. (1992). African dimensions of child care and nurturance. In: M. E. Lamb, K. J. Sternberg, C-P. Hwang & A. G. Broberg, eds. *Child care in context: cross-cultural perspectives*. Hillsdale, n. J. L. Erlbaum.
- Shaffer, A., Jones, D. J., Kotchick, B. A., Forehand, R., & the Family Health Project Research Group. (2001). Telling the children: Disclosure of maternal HIV infection and its effects on child psychosocial adjustment. *Journal of Child and Family Studies*, 10, 301-313.
- Shane, S. (1995). Uncertainty avoidance and the preference for innovation championing roles, *Journal of International Business Studies*, 26(1), 47-68.
- Shoemaker, J. P., Tankard, J. W., & Larsorsa, D. L. (2004). *How to build social sciences theories*. Sage publications.
- Sigma Research and National AIDS Trust. (2004). *Outsider status- Stigma and discrimination experienced by Gay men and African people with HIV*. London: Sigma-NAT.
- Simoni, J. M., Demas, P., Mason, H. R. C., Drossman, J. A., & Davis, M. L. (2000). HIV' disclosure among women of African descent: association with coping, social support, and psychological adaptation. *AIDS and behaviour*, 4(2), 147-158.
- SMI, Smittskyddsinstitutet, [Swedish Institute for infectious disease control] (1997). Statistics.
- SMI, Smittskyddsinstitutet, [Swedish Institute for infectious disease control] (2009). Statistics.
- Smith, E. M. (1985). Ethnic minorities; life stress, social support, and mental health issues. *The Counselling Psychologist* 13: 537-579.
- Smith, L. C., Kenya, J., L., & Latkin, C. (1999). Rumour and gossip: social disclosure on HIV and AIDS. *Anthropology & Medicine*, 6, 121-129.
- Sowell, R. L., Seals, B. F., Philips, K. D., & Julious, C. H. (2003). Disclosure of HIV infection: how do women decide to tell? *Health Education Research*, 18 (1), 32-44.

- Stein, B. (1986). The experience of being a refugee: insights from the research literature. In: Williams CL, Westermeyer JW, eds. *Refugee mental health in resettlement countries*. Washington, Hemisphere Publishing Company.
- Sternberg, R. J., & Grigorenko, E. L. (2001). Degree of embeddedness of ecological systems as a measure of ease of adaption to the environment. In Grigorenko & Stenberg (Eds) *Family environment and intellectual functioning: A life-span perspective*. (pp.243-262). viii, 282pp.
- Steward, W. T., Herek, G. M., Ramaskrishna, J., Bharat, S., Chandy, S., Wrubel, J., & Ekstrand, M. L. (2008). HIV-related stigma: Adopting a theoretical framework for use in India. *Social Science of Medicine*, 67, 1225-1235.
- Svedhem, L. (1991). *Socialt nätverk och beteendeproblem i skolan hos 11-13-åringar: En teoretisk och empirisk grund för nätverksterapi* [Social network and school behavioural problems for adolescents between 11–13 years of age: A theoretical and empirical basis for network therapy]. Unpublished doctoral dissertation, Karolinska Institute, Stockholm.
- The Swedish Communicable Diseases Act. (2004). [Smittskyddslagen]. Retrieved July 12, 2008, from <http://www.notisum.se/RNP/SLS/LAG/20040168.htm>
- The Swedish Institute (2009). Retrieved September 17, 2009, from <http://www.sweden.se/>
- Thernborn, G. (ed.). (2004). *African families in a global context*. ISBN 91-7106-536-9. The Nordic Africa Insitute, Uppsala.
- Thorne, C., Newell, M. L., & Peckham, C. (1998). Social care of children born to HIV-infected mothers in Europe. *AIDS Care*, 10, 7–16.
- Thorne, C., Newell, M. L., & Peckham, C. S. (2000). Disclosure of diagnosis and planning for the future in HIV-affected families in Europe. *Child: Care, Health and Development*, 26, 29–40.
- Tracy, E. M., & Whittaker, J. K. (1990). The social network map: Assessing social support in clinical practice. *Families in Society*, 10, 461–470.
- Trinitapoli, J. (2009). Religious teachings and influences on the ABCs of HIV prevention in Malawi. *Social Science of Medicine*, 69: 199-209.
- Turner, H. A., Hays, R. G., & Coates, T. J. (1993). Determinants of social support among gay men: the context of AIDS. *Journal of Health and Social Behaviour*, 34: 37–53.
- Tuyizere, A. P. (2007). *Gender and development: The role of religion and culture*. Makerere University, Fountain Publishers, Kampala.
- UNAIDS (2007). *Reducing HIV Stigma and Discrimination: a critical part of national AIDS programmes*. Geneva: Joint United Nations Programme on HIV/AIDS. Retrieved January 2009 from http://data.unaids.org/pub/Report/2008/jc1420_stigma_discr_en.pdf
- UNAIDS (2008). *Report on the global AIDS epidemic*. Retrieved 21 October, 2009, from <http://www.unaids.org/en/KnowledgeCentre/HIVData/GlobalReport/2008/>
- UNAIDS (2009). *AIDS epidemic updae 2009*. Retrived 3 December, 2009 from http://data.unaids.org/pub/Report/2009/2009_epidemic_update_en.pdf
- United Nations general assembly special session on HIV/AIDS (2008). *Country Progress Report 2008, Sweden*. Retrieved December 2009, from http://data.unaids.org/pub/Report/2008/sweden_2008_country_progress_report_en.pdf
- USK (2009). Stockholms office of research and statistics. [Stockholms Stads Utrednings- och Statistikkontor AB]. Retrieved September 17, 2009, from <http://www.uskab.se/index.php/statistik-efter-aemne.html>
- WHO (2005). *Working with the non-state sector to achieve public health goals*. Retrieved January 15, 2009, from http://www.who.int/management/working_paper_2_en_opt.pdf
- WHO, United Nations Children’s Fund, UNAIDS (2009). *Towards universal access: scaling up priority HIV/AIDS interventions in the health sector. Progress report 2009*. Geneva, World Health Organisation.
- Van Nimwegen, T., Soeters, J., & van Luijk. (2004). Managing values and ethics in an international bank. *International Journal of Cross Cultural Management*, 4(1), 101-122.

- Vega, W. A., Kolody, B. & Valle, J. R. (1987). Migration and mental health: an empirical test of depression risk factors among immigrant Mexican women. *International Migration Review*, 21, 512–531.
- Vallerand, A. H., Hough, E., Pittiglio, L., & Marvicsin, D. (2005). The process of disclosing HIV-serostatus between HIV-positive mothers and their HIV negative children. *AIDS Patient Care and STDs*, 19, 100–109.
- Vittinghoff, E., Scheer, S., O'Malley, P., Colfax, G., Holmber, S. D., & Buchbinder, S. P. (1999). Combination antiretroviral therapy and recent declines in AIDS incidence and mortality. *Journal of Infectious Diseases*, 179, 717–720.
- Vyavaharkar, M., Moneyham, L., Corwin, S., Saunders, L., Annang, L., & Tavkoli, A. (2009). Relationships between stigma, social support, and depression in HIV-infected African American women living in the rural Southeastern United States. *Journal of the Association of Nurses in AIDS Care*, Oct 29, [Epub ahead of print]
- Weatherburn, P., Ssanyu-Seruma, W., & Hickson, F. (2003). *Project NASAH: An investigation into the HIV treatment, information and other needs of African people with HIV, resident in England*. Sigma Research, NAM Publications, National AIDS Trust and African HIV Policy Network.
- Weisner, T. S. (1997). Support for children and the African family crises. In: T. S. Weisner, C. Bradley & P. L. Kilbride PL. In collaboration with A. B. C. Ocholla-Ayayo, J. Akongá and S. Wandibba, Eds. *African families and the crises of social change*. Bergin & Garvey. London.

