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HEALTH-RELATED QUALITY OF LIFE AND HIV- RELATED STIGMA IN CHILDREN LIVING WITH HIV IN SWEDEN

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”Håll mitt hjärta håll min själ. Lägg ditt huvud i mitt knä. Säg att du menar och vill mig väl. Håll mitt hjärta håll min själ. Som jag väntat alla år. Du kan läka mina sår. Ta mina händer och gör mig hel. Ta mitt hjärta ta min själ. Håll mitt hjärta håll min själ. Låt mig bara stanna här. Så allt jag ber dig, allt jag begär: Håll mitt hjärta håll min själ, håll min själ.” Björn Skifs

ABSTRACT

In settings where combination antiretroviral therapy is generally available, HIV has changed from being a fatal disease to a chronic condition. In contrast to the era before combination antiretroviral therapy, children with prenatally or early acquired HIV are expected to survive childhood and live an adult life. Since this is a new and growing group of young people in society who are in contact with health care, it is essential to be able to provide the support these children and their families need. To be able to do this, it is essential to investigate perceptions of health-related quality of life and HIV-related stigma among these children. Previous research is limited and has mainly focused on children living in households where one or more members are living with a known HIV infection but where the child's HIV status is unknown. The overall aim of this thesis is therefore to gain an increased understanding of health-related quality of life and HIV-related stigma in the context of children and young adults living with HIV infection in Sweden. The thesis comprises four papers, one based on a qualitative study (I) and three based on a quantitative study (II-IV).

In paper I the aim was to explore the young adults' experiences of growing up with HIV in urban Sweden. Data were collected using semi-structured interviews with ten young adults (5 female and 5 male; aged 15-21) with early acquired HIV. Qualitative content analysis of the transcribed interviews revealed five main categories describing the experiences of growing up and living with HIV in Sweden. The categories are about protecting oneself from being stigmatized, being in control, losses in life, the importance of health care and having faith in the future despite living with an HIV infection.

The quantitative study is cross-sectional, nationwide and consists of three papers (II-IV). The participants in papers II and III comprise 58 children aged 8-18 years; 37 of those younger than 17 were, together with one of their legal guardians, included in paper IV.

In paper II the aim was to test and adapt a short version of an HIV stigma scale adapted for children. The results from the psychometric evaluation of the short version of the HIV stigma scale for children indicated that three dimensions: *negative self-image*, *public attitudes* and *disclosure concerns*, were acceptable to use among children with early acquired HIV, whilst the fourth dimension *personalized stigma*, was not acceptable to use due to high non-response.

In paper III the aim was to describe health-related quality of life and HIV-related stigma among the participating children. Further, the relation between health-related quality of life and HIV-related stigma was examined by structural equation modeling. The results indicated that participants rated their health-related quality of life as high in relation to children with other chronic conditions and expressed low extent of HIV-related stigma related to *negative self-image* and *public attitudes*. However, the results indicated a more pronounced HIV-related stigma related to *disclosure concerns*. Furthermore, the results revealed a negative association between health-related quality of life and HIV-related stigma.

The aim of paper IV was to describe how legal guardians assess their children's health-related quality of life and HIV-related stigma in relation to their children's own ratings by using both child and proxy versions of the DISABKIDS Chronic Generic Module and HIV stigma scale. In the analysis it was found that there was a high consistency between legal guardians' ratings and the children's own ratings of health-related quality of life and HIV-related stigma.

The main findings of this thesis, based on data from a nationwide sample from the total population of children living with perinatally or early acquired HIV infection, indicate that children living with HIV in Sweden do well in terms of self-reported health-related quality of life and HIV-related stigma. However, since it is known that, among adults, HIV-related stigma may affect health-related quality of life negatively, this may also be a risk among children; the data of the present thesis supports the negative relation between health-related quality of life and HIV-related stigma previously shown in adults. In order to obtain a more comprehensive picture of the living situation of these children and families, more studies are needed in which children are asked about their experiences regarding HIV-related stigma. Supplementary research is also required to further understand the relationship between HIV-related stigma and health-related quality of life in children living with HIV, and how this affects them and their families in daily life.

Key word: HIV, health-related quality of life, stigma, children, adolescents, young adults.

LIST OF PUBLICATIONS

This doctoral thesis is based on four papers, referred to in the text by their Roman numerals

I. Rydström, LL., Ygge, BM., Tingberg, B., Navér, L. & Eriksson, LE. *Experiences of young adults growing up with innate or early acquired HIV infection - a qualitative study*. J Adv Nurs, 2013. **69**(6): p. 1357-65.

II. Wiklander, M., Rydström, LL., Ygge, BM., Wettergren, L., Navér, L. & Eriksson, LE. *Psychometric properties of a short version of the HIV stigma scale, adapted for children with HIV infection*. Health Qual Life Outcomes, 2013. **11**: p. 195.

III. Rydström, LL., Wiklander, M., Navér, L., Ygge, BM. & Eriksson, LE. *HIV-related stigma and health-related quality of life among children living with HIV in Sweden*. (submitted).

IV. Rydström, LL., Wiklander, M., Navér, L., Ygge BM. & Eriksson, LE. *Children with HIV infection and their legal guardians' ratings of the child's health-related quality of life and HIV-related stigma* (submitted).

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LIST OF ABBREVIATIONS AND DEFINITONS

AIDS	Acquired Immune Deficiency Syndrome
AZT	Azidothymidine
cART	Combination antiretroviral treatment
CFI	Comparative fit index
CRC	Convention on the Rights of the Child
DCGM-37	DISABKIDS Chronic Generic Module
EU/EEA	European Union and European Economic Area countries
HIV	Human immunodeficiency virus
HIV affected	Living in HIV infected families, but do not have to be HIV infected
HSSC-8	HIV stigma scale for children
ICC	Intraclass Correlation
INFCARE	A decision support and a quality register for the Swedish HIV care, available at http://infcare.se/hiv/sv/
LEGAL GUARDIAN	Refers to all who have a legal responsibility for the child and includes biological parents, foster parents, adoptive parents, and other forms of legal guardian.
NOBAB	Nordic network for children's rights and needs in healthcare
NVF	Doctoral School in Health Care Sciences
PCA	Principal Component Analysis
PDCGM-37	DISABKIDS Chronic Generic Module – proxy version
PHSSC-8	HIV stigma scale for children – proxy version
Proxy	Outcome data furnished by someone other than patient/child and which distinguishes the origin of the outcome from a self-report (patient-reported outcome) directly from the patient (Snow, Cook, Lin, Morgan, & Magaziner. 2005).
RMSEA	Root mean square error of approximation
TLI	The Tucker-Lewis index
SEM	Structural Equation Modeling
SD	Standard Deviation
UN	United Nations
WHO	World Health Organization

1 INTRODUCTION

Since 1989 I have been a registered nurse, working as a regular nurse in pediatric care. In the beginning of the 1990s, after my training to become a pediatric nurse, I was asked to be involved in a new team for HIV-infected children. At that time children with human immunodeficiency virus (HIV) infection were expected to die as children and my aim was to help them live their short lives as well as possible. The situation for these children and their families changed when antiretroviral treatment (cART) became available and HIV became a chronic condition; however it remained associated with much guilt and shame. Families were thought to keep the HIV diagnosis a secret from everyone, including the HIV-infected child, to protect the family and the child from the risk of being stigmatized. Living with the fear of becoming stigmatized can be a factor influencing a person's health-related quality of life negatively, although little is known about how children perceive HIV-related stigma and how they perceive their health-related quality of life.

In my work as a pediatric nurse working with children with HIV and their families, I have seen how many of these families struggle with difficulties related to both their own history and society's ignorance and prejudices about people living with HIV. These experiences made me think about how children and their legal guardians perceive HIV-related stigma and health-related quality of life. This became my trigger to further develop the care of, and methods to support, these children and their families, and provide them with tools to manage life with an HIV infection. Hopefully, my research can make a contribution so that these children and their legal guardians are better able to cope with HIV-related stigma, and the children experience their health-related quality of life as good.

I started to work with these questions in 2007 by writing an ethics application to prepare for what later became this project. In 2010 I became a doctoral student within the Health Care Sciences Doctoral School (NFV). I have accomplished my studies in parallel with part-time work at the Department of Quality and Patient Safety at Astrid Lindgren Children's Hospital.

2 BACKGROUND

2.1 HIV

Today HIV has become a chronic condition with normal life expectancy in settings where treatment is available, as is the case in Sweden, and under efficient treatment the risk of transmitting the infection to others is almost nonexistent as long as the treatment is working and no resistance to the drugs has emerged (Albert et al. 2014; Fetting, Swaminathan, Murrill, & Kaplan. 2014). If available, treatment will also decrease the risk of mother-to-child transmission to less than 2 % (Townsend, Cortina-Borja, Peckham, & Tookey, 2008; Mepham, Bland, & Newell. 2011). Although every year there are a number of HIV-infected women who give birth in Sweden, there are only a handful of children who have become HIV-infected through mother-to-child transmission since preventive treatment was introduced. Despite this, the number of children with HIV infection in Sweden is increasing due to immigration. To be able to understand the difficulties of living with an HIV infection, it is important to know a little about the history of the virus.

In 1981 there were reports of a new disease causing immunodeficiency among gay men (Gottlieb et al 1981) and intravenous drug users (Masur et al. 1981) in the United States, but soon patients with the same kinds of symptoms were also observed in places in Europe and Africa. The patients displayed symptoms such as reduced CD4+ cell counts, opportunistic infections and Kaposi's sarcoma and this led to the disease being named Acquired Immune Deficiency Syndrome (AIDS).

It was concluded that the disease was transmissible and soon it became apparent that the disease also affected other groups of people, for example transfusion recipients, female sex partners of intravenous drug users and hemophiliacs. The first report of children with AIDS was published in 1982 (Centers for Disease Control and Prevention. 1982). In 1983-1984 two different research groups independently identified the virus causing the disease (Barre-Sinoussi et al. 1983; Gallo et al. 1984): later given the name Human Immunodeficiency Virus (HIV).

One of the most important fears during the beginning of the HIV era was about contagiousness and transmission, and this became a major issue causing anxiety and prejudice among people. Further, to handle this new situation science and the media started to talk about risk groups (e.g. gay men and intravenous drug users).

In the middle of the 1980s the first medical treatment was discovered, azidothymidine (AZT), a treatment that slowed down the pathogenic effects of the virus. However, the early antiretroviral drugs had short-lived effects due to the emergence of viral resistance (Palella et al. 1998), but the development of treatment continued and a new era started when researchers discovered new ways to combine medications. Treatment with cART meant that the virus could be reduced to almost undetectable levels and CD4 cell counts increased, which translated into improved clinical outcomes and a dramatic reduction in HIV-related morbidity and mortality (Hawkins. 2010).

2.1.1 HIV in the world and Sweden

Despite the fact that today there are effective treatments that make HIV a chronic condition, the situation varies around the world, since access to treatment varies. Sadly it is in the poorest countries, where the highest number of people with HIV infection live, that access to treatment is lowest. This is illustrated by the reports of HIV infections in populations globally (figure 1). In 2013, there were an estimated 35.3 million people living with HIV. Of these, 3.2 million were children, and just over a quarter (9.7 million people) had access to antiretroviral therapy (World Health Organization. 2014). Of the 35.3 million people living with HIV, 25 million live in sub-Saharan Africa, which is more than two-thirds (70 percent) of all people living with HIV. The global HIV epidemic can be reversed and stopped by increasing access to treatment all over the world, as treatment is the best prevention of HIV (Palmisano & Vella. 2011); for those with access to it, treatment has a major effect on their lives and AIDS-related deaths have, from a world perspective decreased by 30% since the peak in 2005 (World Health Organization. 2014).

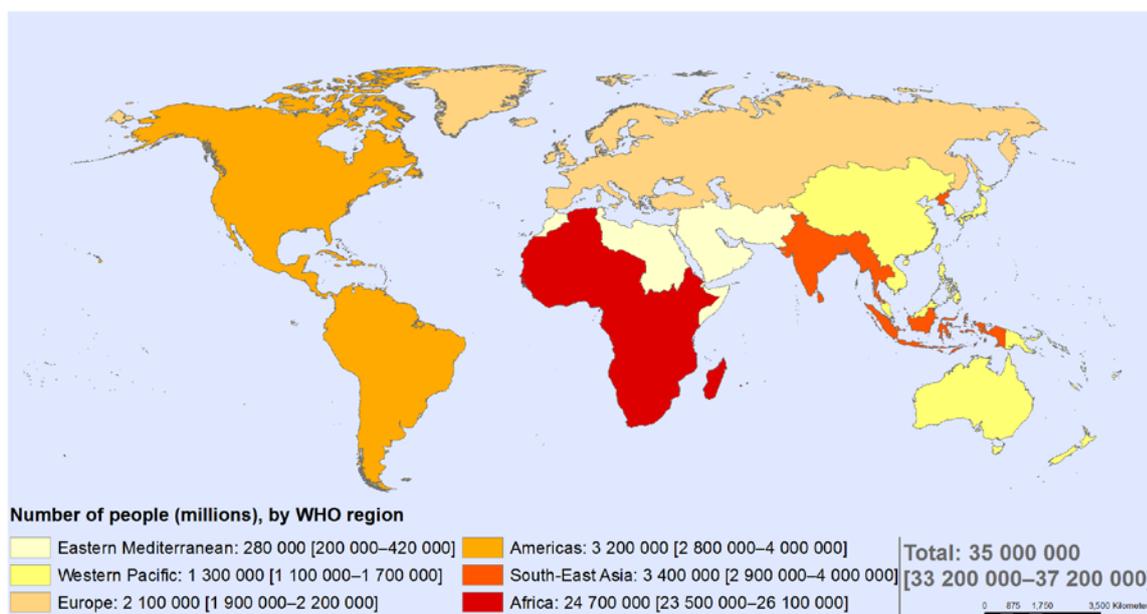


Figure 1: (Published with permission from WHO). Adults and children estimated to be living with HIV 2013. The number in brackets indicates that there is uncertainty about the exact number of people living with HIV worldwide.

In Sweden, HIV/AIDS became notifiable under the Infectious Diseases Act 1983. Since then, over 10,000 cases of HIV infection have been reported and at the end of December 2014 there were approximately 7,000 people (prevalence of 0.07 %) with a known diagnosis of HIV living in Sweden (Folkhälsomyndigheten. 2014).

2.1.2 HIV and children

The first child in Sweden with a known HIV infection died in 1982; the diagnosis was made retrospectively using stored serum (Nemeth et al. 1986). Before treatment was available some children died due to their HIV infection. Since then Sweden has

became a country where HIV treatment is available to everyone who needs it, meaning that every HIV-infected child should have access to treatment. This in turn means that HIV-infected children are expected to live as long as anyone else and live a similar life to healthy children, interacting with peers and attending school.

New cases of children living with HIV in Sweden are mostly due to immigration (Inficare 2014) and today there are about 140 known cases of children living with early acquired HIV infection in Sweden (Inficare 2014) which is a very low prevalence from a global viewpoint.

From a global perspective, 91 percent of children with HIV live in Africa (World Health Organization. 2013b). Furthermore, the most common way for a child to become HIV-infected is through mother-to-child transmission, and even if there are still many newly infected children in the world, the transmission rate has basically been halved since 2001 (World Health Organization. 2013a) due to access to prophylactic treatment for the prevention of mother-to-child transmission. The risk of mother-to-child transmission in Sweden today is less than 0.5 percent and only three cases of children born in Sweden have been diagnosed with an HIV infection related to mother-to-child transmission during the last 10 years (Naver et al. 2014). This means that the majority of children living with HIV infection in Sweden are immigrants infected before entering the country.

2.2 THE CHILD AND CHILD HEALTH CARE

The view of children is something that has varied over time, between different cultures and even within cultures (Thuen. 2008). In general, however, the trend has gone from considering children as "little adults" to children being regarded as actors in their own lives and in society. In the 18th century, the perception of children and their needs was changed and it became known that children have special needs (e.g. medical treatment). This changed approach also meant that health care came to realize that children were different from adults and in 1764 the first Swedish pediatric textbook was published by Nils Rosen von Rosenstein (Blomquist, Jonsell & Orelund. 2013; Weiner. 1995) and the Karolinska Institutet in Sweden established the world's first professorship in pediatrics in 1845 (Weiner. 1995). During the 19th century, the Swedish state began to raise concerns that the children of working families received inadequate care due to the family's low social status. This led to the first laws to protect children, the so-called child protection laws (Sundkvist. 1994), being established in 1902. In the same period, physicians in Sweden had the responsibility to report, monitor and fight epidemics (Sundin, Hogstedt, Lindberg, & Moberg. 2005). Both these factors had a positive impact on children's health.

In 1959, the Declaration of the Rights of the Child was accepted and in 1990 the Convention of the Rights of the Child (CRC) was adopted for all countries belonging to the United Nations (UN). In the same year, Sweden was one of the first countries that ratified the CRC (Förenade Nationerna. 2010). One of the CRC statements is that all children are entitled to have their basic needs met. Primarily, it is legal guardians that have the responsibility for their child's wellbeing and upbringing. Legal guardians must also protect the child and ensure that the child is not exposed to danger to its life, or

harmed physically or mentally. Further, all children are in need of love and need stimuli and support (United Nations. 1982).

The CRC defines a child as any person below the age of 18 years of age and applies to all children who are in a country that has ratified it. Further, the CRC means that the child's best interests must be a primary consideration in all actions concerning children. The CRC contains fifty-four articles, four of these are considered as basic principles that should govern the interpretation of the Convention's other articles. These four articles are 2, 3, 6 and 12, and the main messages of these articles are:

- Article 2 states that all children have the right to be treated equally, with dignity and rights. No one shall be discriminated against.
- Article 3 states that the child's best interests should be the primary consideration in all actions concerning the child. In each case, it must be determined what is the best for each child, and the child's own opinion and experience should always be taken into account.
- Article 6 emphasizes every child's right to life, survival and development.
- Article 12 emphasizes the child's right to form and express their views and have them taken into account in all matters affecting the child at a level of participation appropriate to the child's age and maturity (United Nations. 2015).

Translated to health care, the articles from CRC mean that health care workers have a responsibility to provide children with care which enables compliance with the Convention. This means for example that staff should always prepare children well, so that the children are involved in their care and feel part of the care process, and to be able to provide this, staff who work with children need special training (Bischofberger, Dahlquist et al. 2004).

In 1980, the Nordic network for children's rights and needs in health care (Nordisk Förening för Sjuka Barns Behov, NOBAB) was formed in Lillehammer, Norway and has since continued to work on the improvement of the situation for children in the health care system. In line with the CRC, NOBAB works with children's rights to be given information, be involved in decisions concerning their treatment and care, and be treated and cared for by health professionals with specific child competence (Nordisk Förening för Sjuka Barns Behov. 2014).

Child health care in Sweden has undergone major changes during the last century (Sundin et al. 2005). Nowadays, the view is that children who seek care have the right to good quality care and to meet professionals with relevant training. This means that, even if the health care law does not specifically mention children as patients, all care should be of good quality and meet patients' need for security (Söderbäck. 2010). This includes children having access to health care professionals with pediatric expertise, which can be especially essential for children with chronic conditions (Hughes. 2008). One such group is children living with HIV infection. To these children, as well as to other children with uncommon diagnoses, the situation is not always optimal. Even if the majority of children with HIV have access to pediatric expertise (Rydström. 2009), some children are treated at infection clinic for adults, since prevalence is low and HIV-infected children are spread all over the country (Infcare 2014). The largest clinic in

Sweden treating HIV-infected children is the Astrid Lindgren Children's Hospital at Karolinska University Hospital in Huddinge, where around 50 percent of all HIV-infected children in Sweden are treated. The remaining 50 percent are treated all over the country and different clinics treat from one child up to 15 children.

2.3 FAMILY-CENTERED CARE

In the nursing discipline it is central to identify and meet the needs of patients (e.g. children) and their families and build relationships with them. To be able to support children with special needs (e.g. early acquired HIV) and their families, it is essential to understand the basic components of caring for children and families. One way to achieve this is by family-centered care, which has been described as a partnership approach to health care decision-making. Family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. (Wright, Watson, & Bell. 2002; Shields, Pratt, Davis, & Hunter. 2007; Stange et al. 2010; Wagner et al. 2005).

The essence of family-centered care is the relationship between families and health professionals. Professionals must have an attitude of openness, practice respect and collaboration, and support the families' normality. Further, all communication should be performed in an open and honest two-way communication including both the child and his/her family in planning the care and treatment (Harrison. 2010; Wright et al. 2002). This ensures that care is planned and involves the whole family, and all the family members are recognized as care recipients and that the family is perceived as a unit where all the family members are in focus at the same time (Shields, Pratt, & Hunter. 2006; Wright et al. 2002).

2.4 THE CONCEPT OF HEALTH AND QUALITY OF LIFE

2.4.1 Health

The relevance of health was pointed out by Florence Nightingale already in the mid 19th century (Selander. 1998). Since then, health has been considered with different degrees of specificity, and the view of health has changed and evolved by nursing theorists and scientists (Wiklund Gustin & Lindwall. 2012).

Historically health has been seen as absence of disease while disease is associated with weakness (Sartorius. 2006). But already in 1948, WHO underscore in their definition of health that "*Health is a state of complete physical, mental and social-wellbeing and not merely the absence of illness or infirmity*" (World Health Organization. 1948) and Dahlberg and Segesten (2010) further points out that health as a concept does not exclude the presence of disease, since having a disease does not necessarily exclude the possibility to feel well and be able to do things one enjoys. Thus, since how a person experiences health, among other things, is dependent on biological body functions and existential questions regarding understanding of the self, the concept of health is multidimensional and complex; it is dependent on each individual's life experiences and life situation, and is an integrated part of life (Dahlberg & Segesten. 2010).

2.4.2 Quality of life

Even if there is no consensus in the definition of quality of life, WHO has defined it as *“an individual’s perception of their position in their life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns”* (“The World Health Organization quality of life assessment (WHOQOL): Position paper from the World Health Organization” 1995). Quality of life incorporates objective and subjective indicators, a broad range of life domains, and individual values. It also allows for objective comparisons to be made between the situations of particular groups and what is normative. Further, there is an agreement regarding quality of life as multidimensional and, according to Felce and Perry (1995), it can be categorized within five dimensions: physical wellbeing, material wellbeing, social wellbeing, emotional wellbeing, and development and activity.

2.4.3 Health-related quality of life

Health has become the most central concept in health care and can be considered as a component of the more general concept of quality of life. Furthermore, health-related quality of life could be viewed as one dimension of quality of life. Both quality of life and health-related quality of life are essential factors when studying public health and medical outcomes (Schmidt et al. 2006) and are often used as outcome variables in nursing research when describing the lives of persons with chronic conditions (Fayers & Machin. 2009). However, there is no consensus regarding the definition of health-related quality of life; the definitions that exist are broad and individual-based, defined as aspects of quality of life that relate to each individual’s own health, that is, to evaluate to what extent treatment and disease influence essential parts of function and wellbeing, for example social, psychological and physical (Fayer & Machin. 2007). For example, the WHO definition of health (see above) clearly emphasizes that physical, psychological and social factors are important to consider when discussing health and by including “complete” in the definition, it gives an expression of an ideal of health promotion in the community rather than an individual’s health status; therefore health-related quality of life could be defined as the aspects of life that relate to an individual’s health. As health-related quality of life is a distinct component when focusing on the impact of health on an individual’s well-being it can advantageously be measured by using self-reports (Hays et al. 1995).

In this thesis health-related quality of life is seen as a multidimensional construct with physical, mental, emotional, behavioral and social aspects of well-being and function as perceived by children, as defined by the DISABKIDS group (Bullinger, Schmidt, Petersen, & DISABKIDS-Group. 2002).

2.4.4 Children and health-related quality of life

When measuring health-related quality of life in children one has to deal with special methodological difficulties related to differences in children’s ability to understand at different ages, together with legal guardians influence on the child’s perceptions (le Coq, Boeke, Bezemer, Colland, & van Eijk. 2000). Also, when studying children’s health-related quality of life it may be important to keep in mind that children may have

a different view to adults on health-related quality of life. Children seem to see quality of life and health as separate concepts, where physical wellbeing and function are perceived as health while psychological well-being is seen as quality of life (Das, Mukherjee, Lodha, & Vatsa. 2010; Helseth & Misvaer. 2010). Further, it seems as if adolescents see quality of life as a definition of how well their relations with friends and family function as well as how pleased they are with themselves (Helseth & Misvaer. 2010). The different approaches of adults and children have been explained by factors such as different life experiences and priorities in life (Wee, Chua, & Li. 2006).

Children with disabilities generally rate their health-related quality of life lower than children from the average population and health-related quality of life appears to vary between different diagnostic groups (Varni, Limbers, & Burwinkle. 2007). However, there are other factors apart from disabilities that might have an effect on children's estimates of health-related quality of life. Studies have indicated that age (Cremeens, Eiser, & Blades. 2006) and gender (Eiser & Morse. 2001; Theunissen et al. 1998) might be relevant factors as well as legal guardian's education level (Sato et al. 2013). For example, it was found in a Swedish study that girls with diabetes had lower health-related quality of life than boys with the same diagnosis (Chaplin et al. 2009), whereas other studies have failed to demonstrate any differences in the estimates depending on the children's gender (Lundberg, Lindh, Eriksson, Petersen, & Eurenus. 2012).

2.5 STIGMA

The term stigma dates back long before the 20th century. The Greeks used to cut or burn marks into the skin of criminals, slaves, and traitors in order to identify them as tainted or immoral people that should be avoided. These marks became the bearer's hallmark of being different, resulting in alienation and hence stigmatization. It is also a term used in Catholicism to explain when a person gets marks and bleeds in the same places as Jesus did at the crucifixion. Later it became a term signifying alienation (Nationalencyklopedin. 2015).

One of the first to define the concept of stigma as it is used today was Goffman (1963). He defined it as "an attribute that is deeply discrediting" (p. 3) and divides it into three kinds of stigma: *bodily stigma*, a physical handicap, *character stigma*, such as drug abuse and *group stigma*, including religion, ethnicity, class and gender. Further, stigma is often related to a variety of health associated conditions, such as if someone looks different or has twitches, as well as conditions that are invisible (Goffman. 1963). Since Goffman (1963) defined stigma, the definition of stigma and the conceptualizing of stigma has progressed and become applicable in various fields. For example, as Weiss and colleagues (Weiss, Ramakrishna & Somma. 2006) have in the same way as Goffman (1963) defined stigma as "typically a social process" meaning that stigma is associated with experiences and/or anticipation characterized by exclusion, rejection, blame, or lack of self-confidence as a result of a social judgment about a person or group. They also say that the emotional impact of social disqualification adds to the burden of any illness, and that stigma may delay help-seeking for health problems and lead to low treatment compliance. This sometimes causes stigma to be a greater source of suffering than the symptoms of the disease (Weiss et al. 2006).

The impact of HIV stigma on those who are the “stigmatizers” (HIV uninfected) is often not distinguished from the individuals who are HIV infected. Therefore, Earnshaw and Chaudoir (2009) have articulated a framework designed to support the clarification of conceptualization and measurement of HIV stigma. This framework acts as a tool to help individuals to understand the impact of HIV stigma at an individual level. A lack of clarity in the conceptualization and measurement of HIV stigma might be a barrier to HIV prevention and treatment. Therefore it is essential to understand how stigma mechanisms affect both HIV infected as well as uninfected individuals.

Earnshaw and Chaudoir (2009) suggest that stigma mechanisms among HIV uninfected persons are represented by psychological responses; that people living with HIV infection might possess moral blemishes and be a threat to the health of HIV uninfected persons (e.g. risky sexual behavior). Psychological responses among HIV infected individuals represent the understanding that they themselves could be to blame for being the ones dishonored for their social behavior and therefore subjected to other peoples negative treatment actions (Earnshaw & Chadoir. 2009). Further, the descriptions of the stigma mechanisms among uninfected individuals are: *prejudice* that is experienced by individuals as an emotion, *stereotypes* experienced as a cognition and *discrimination* as a behavior. The description of the stigma mechanisms among HIV-infected persons are: *internalized stigma*, meaning that the person actually believes the stereotypes, *anticipated stigma*, meaning the extent to which a person living with HIV expects to experience threats against the identity, and *enacted stigma*, meaning the extent to which an individual experiences prejudice and/or discrimination emanating from others (Earnshaw & Chadoir. 2009). Furthermore, *internalized stigma* can be particularly damaging, since such stigma occurs when a person is aware of a social stigma and accepts, or internalizes, society’s negative views of a phenomenon, such as HIV (Earnshaw & Chadoir. 2009). This is supported by findings in studies where it has been found that HIV-related stigma might lead to HIV-infected persons imposing stigmatizing beliefs and actions on themselves (Ogden & Nybladet. 2005).

2.5.1 Stigma and children

Children and adolescents living with HIV face unique illness-related stressors. As most children living with HIV in Sweden have an immigrant background they might have a fear of being stigmatized for at least two reasons, being an immigrant and the disease itself (Orban et al. 2010). However, little is known about how HIV-infected children experience HIV-related stigma (Bhana. 2008) as most studies are implemented on HIV affected children (Deacon & Stephany. 2007), that is children living in an HIV context with unknown HIV status. Children that are HIV affected are often socially vulnerable and may in some cases have lost one or both parents because of HIV even if they are not HIV infected themselves (Deacon & Stephany. 2007). To be a child living in a family where one or more of the family members are living with an HIV infection affects the child’s life and the child risks being affected by how the legal guardians experience HIV-related stigma. It is known that children (age 7-14 years) can be aware of courtesy stigma related to parental HIV (Murphy, Roberts, & Hoffman. 2002). Courtesy stigma can be explained as the stigma that attaches to those who are merely associated with a stigmatized person (Goffman. 1963)

and due to the fact that children are intimately connected with their legal guardians, this entails that the stigma their legal guardian's experience will be felt equally by the children themselves (Cree, Kay, Tisdall, & Wallace. 2004).

In studies about children with other chronic conditions (e.g. epilepsy) children have expressed fear of being stigmatized. It has emerged that they are worried that others will discover their condition, and they become annoyed and stressed when people look at them. Other issues are being questioned about their illness, friends talking about them and their condition to others, as well as preventing their friends from disclosing their condition to others (Lambert & Keogh. 2015). Further, it is known that relationships with peers are a key issue for children and that children are sensitive to being different from their friends, which in turn is of importance for the development of the child's self-esteem. Low self-esteem and feelings of exclusion are strongly associated with poor mental health (Hallström & Lindberg. 2009; Leary, Schreindorfer, & Haupt. 1995).

2.5.2 Proxy-measures

Proxy data can be explained as data collected from someone who speaks for a person who cannot, will not, or is unable to speak for him/herself (Snow et al. 2005). This someone can be for example a legal guardian, other relatives or caregivers. Proxy measures have been a common way to measure health-related quality of life among children, justified on the grounds that children lack the cognitive and linguistic skills necessary to respond to health-related quality of life measures. However, it has been found that children as young as four years or even younger are able to use rating scales and therefore would be able to assess their own health-related quality of life (Chaplin, Koopman, & Schmidt. 2008; Cremeens, Eiser, & Blades. 2006). Despite this, legal guardians' reports are likely to retain a certain value in pediatric care due to differences in the understanding of health-related quality of life between adults and children. Also, to get information from different sources (e.g. proxy measures from legal guardians' and children's self-reports) is beneficial as information from multiple sources provides an even broader perspective of the child's health-related quality of life and leads to the possibility of giving the child and family the right support (Eiser & Morse. 2001; Eiser & Varni. 2013; Pieper & Garvan. 2015).

To use legal guardians' proxy measures to measure children's health-related quality of life and HIV-related stigma can present difficulties as children and their legal guardians might have different views on children's health-related quality of life and experiences of HIV-related stigma (Eiser & Morse. 2001; Snow et al. 2005; Eiser & Varni. 2013). The different approaches between adults and children can be explained by factors related to different life experiences and priorities in life (Wee et al. 2006). However, most often the disagreements regarding health-related quality of life tended to be minor. Also, several studies have reported that the agreement between legal guardian and child was more concordant for concrete, observable characteristics, such as physical health whilst other studies found higher levels of disagreement for psychosocial domains such as social and emotional functioning (Upton, Lawford, & Eiser. 2008; Varni, Burwinkle, Rapoff, Kamps, & Olson. 2004). These findings might

indicate that the proxy problem may be smaller than expected and its extent may differ per population (Sattoe, van Staa, & Moll. 2012).

2.6 RATIONALE FOR THE STUDY

The introduction of effective cART has meant that children living with HIV can have relatively normal longevity. This means that these children have become a new and growing group of children with a chronic condition that may be in need of care and community resources. Furthermore, it is known that adults experience HIV-related stigma, and also that HIV-related stigma and health-related quality of life in adults have a negative relationship (Sayles, Ryan, Silver, Sarkisian, & Cunningham 2007). For example, adults experiencing HIV-related stigma have been shown to have an increased risk of mental problems (Vanable, Carey, Blair, & Littlewood. 2006). This might entail that the situation is the same among children and that in turn might lead to that children becoming alienated.

Since children are considered to experience health-related quality of life differently from adults (Das et al. 2010; Helseth & Misvaer. 2010) it is relevant to study how children living with an HIV infection perceive their health-related quality of life. Furthermore, it is relevant to study how children experience HIV-related stigma and to explore the relation between HIV-related stigma and health-related quality of life in children, as little is known about this. Moreover, most studies on how children perceive HIV-related stigma are performed among HIV affected children (children with unknown HIV status living in HIV infected families) in developing countries with high HIV prevalence. Therefore, it is relevant to study how HIV-infected children perceive their health-related quality of life and HIV-related stigma in contexts with low prevalence, as the context where a child lives might impact how children experience their health-related quality of life and HIV-related stigma.

Finally, as a family-centered care approach requires a focus on the whole family (Wright et al. 2002), it is relevant to explore legal guardians' views of their children's perception of health-related quality of life and HIV-related stigma. Such knowledge could be helpful in medical care when interventions are being developed to provide these families with the best care possible. Altogether, this knowledge will increase the possibilities to initiate efforts to reduce HIV-related stigma, both HIV-related stigma the individual imposes on him/herself as well as HIV-related stigma stemming from society.

3 AIMS

The overall aim of this thesis is to gain an increased understanding of health-related quality of life and HIV-related stigma in the context of children and young adults living with HIV infection in Sweden.

3.1 SPECIFIC AIMS

The specific aims are:

- To explore the experiences of young adults growing up and living with HIV in urban Sweden.
- To test an adapted short version of the 40-item HIV Stigma Scale (HSS-40), adapted for 8-18 years old children with HIV infection living in Sweden.
- To describe HIV-related stigma and health-related quality of life among children with early acquired HIV living in Sweden, and to investigate the relationship between the two factors in the same group.
- To describe how legal guardians assess their HIV-infected children's health-related quality of life and HIV-related stigma in relation to their children's own ratings.

4 METHODS

4.1 STUDY SETTINGS AND DESIGN

This thesis consists of two studies, one using qualitative and one using quantitative methods. The data collection for the qualitative study (paper I) was carried out during 2008 at Astrid Lindgren Children's Hospital at Karolinska University Hospital in Huddinge. The data collection for the quantitative study (papers II-IV) was nationwide and carried out during October 2011 to November 2012 in all clinics in Sweden where children with HIV infection are treated. The data collection for the quantitative study involved both infectious disease clinics and pediatric clinics.

4.2 QUALITATIVE STUDY (PAPER I)

4.2.1 Participants

This study of young adults with early acquired HIV infection was performed at a pediatric university hospital clinic that cares for the majority of HIV-infected children in Sweden. Due to a small population size, the intention was to invite all the clinic's registered young adults with early acquired HIV infection who fulfilled the inclusion criteria to participate. The inclusion criteria were that participants should: (1) have a perinatal or early acquired HIV infection; (2) have been treated at a pediatric clinic in Sweden for more than 5 years; (3) be aged between 15-21 years; (4) have been informed about his or her HIV infection; and (5) understand and speak Swedish fluently. All eligible young adults (n=14 fulfilling the inclusion criteria) and their legal guardians (for those under the age of 18 years) were informed about the study by letter. Thereafter, their responsible nurse also informed them in connection with a regular visit to the clinic.

Of the 14 eligible young adults 10 accepted participation, five females and five males, with a mean age of 18 years (range 15-21). Six of the participants were born in Sweden and four were immigrants, seven had an African background and three had at least one parent with a Swedish background (all three born in Sweden).

Of the four remaining young adults, three declined participation because their legal guardians dissuaded them from participating and one preferred not to think about the HIV infection except when attending the hospital.

4.2.2 Data collection

Semi-structured interviews were conducted between January and August 2008 by a senior pediatric nurse who was not involved in the regular care of the patients. All interviews were performed at a location chosen by the participants. The interview guide contained general questions about origin, family and living conditions of the participants as well as more specific questions regarding their experiences from growing up with early acquired HIV infection. The interviews were conducted as

open conversations based on the interview guide. Follow-up questions were asked regarding subjects that the participants introduced. The interviews lasted between 45-90 minutes and were tape-recorded and thereafter transcribed verbatim.

4.2.3 Data analysis

Data analysis of the interview transcripts was based on qualitative content analysis, which is a systematic approach describing a certain phenomenon by objective means (Downe-Wamboldt. 1992; Elo & Kyngas. 2008; Graneheim & Lundman. 2004). This analytical approach is descriptive, striving to stay close to the underlying meaning of the text (Graneheim & Lundman. 2004), and was chosen to gain an understanding of young adults' experience of growing up and living with HIV in urban Sweden.

First the text was read repeatedly by myself and one of my co-researchers, both together and separately, after which we discussed the findings and found tentative themes in the participants' descriptions of their experience of growing up with early acquired HIV infection. These themes were sorted into content areas and thereafter the text was divided into meaning units that were condensed, abstracted and labeled. In the next step the meaning units were compared for differences and similarities, and then sorted into sub-categories that were discussed back and forth between the authors. These discussions resulted in agreement about how to sort the codes, which, after being clustered, were entered into five categories (table 1).

Table 1: Description of the steps using content analysis

Meaning units	Sub-categories	Categories
<p>“ To tell someone you have HIV makes people afraid, they just run”</p> <p>“I was there one week and during that time I might have taken my medication only three times”</p>	<p>1.The secrecy around HIV</p> <p>2. Afraid of others opinions</p>	<p>Protecting oneself from being stigmatized</p>
<p>“ You choose a special friend to tell about your HIV to avoid difficulties and misunderstandings”</p> <p>“Yes, some I would tell. It feels good that they know, but some of them talk so much about me”</p>	<p>1.Child, family and society’s knowledge</p> <p>2. Who is to be given knowledge</p>	<p>Being in control</p>
<p>“ My mother died when I was three...I have been thinking a lot about how life would have been if she was alive”</p> <p>“I have not thought about it until that singer was not welcome to that country to sing”</p> <p>“ I have bigger secrets than HIV”</p>	<p>1. Loss of family members</p> <p>2. Loss of freedom to travel</p> <p>3. Other secrets in life</p>	<p>Losses in life but HIV is no big deal</p>
<p>“Yes I have needed counseling”</p> <p>“If I’m sad or feel alone, I would call my social worker for an appointment... we can meet and talk, not only about the test results.”</p>	<p>1.Health care</p> <p>2.The importance of having someone to talk to</p>	<p>Health care/health care providers</p>
<p>“Whether to have children has been a problem... Now I have decided that it is no problem”</p> <p>“I will be able to have a family and children”</p>	<p>1.The possibility to see a future</p> <p>2.Having a family</p>	<p>Belief in the future</p>

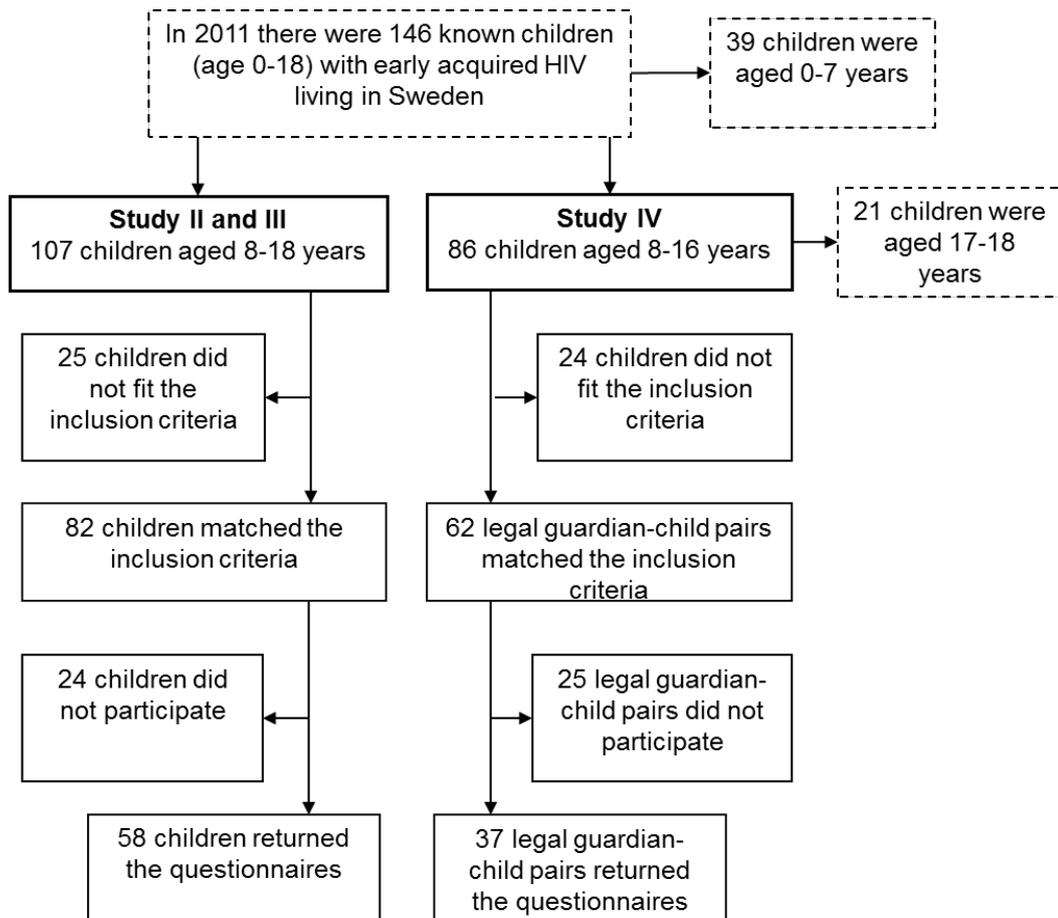
4.3 QUANTITATIVE STUDIES (PAPERS II-IV)

The quantitative studies were based on a nationwide cross-sectional data collection using questionnaires and performed among children with early acquired HIV infection and their legal guardians living in Sweden.

4.3.1 Participants

The number of known cases of HIV-infected children in Sweden was 146 in the years 2011-2012 when the data collection was conducted (figure 2). Of these children 107 were in the target age group, 8-18 years; however, 25 did not fit the inclusion criteria (papers II and III). In paper IV, 86 children were in the target age group, 8-16 years; and 24 did not fit the inclusion criteria. Reasons for non-fit of inclusion criteria were that the child was newly arrived in Sweden, did not speak or understand Swedish or had other underlying diseases. The remaining 82 (age 8-18 years; papers II and III) respectively 62 (age 8-16 years; paper IV) who fulfilled the inclusion criteria were targeted to be invited to participate in the study. In paper IV the participants were children and one of their legal guardians, meaning there were 62 legal guardian-child pairs that matched the inclusion criteria (figure 2).

Figure 2



Recruitment of the sample of children (papers II-IV) and their legal guardians (paper IV) from the population of known children living with early acquired HIV infection in 2011-2012

Potential participants were asked to participate by their responsible registered nurse or physician in connection with a regular visit to the clinic. Those that accepted were asked to complete the study by answering the study questionnaires (see Data collection 4.3.2) at the clinic. In some cases the participants preferred to take the questionnaires home to answer and then return them in a postage-paid envelope. Written informed consent was obtained from all participants and, for participants under the age of 15 years, consent was also obtained from legal guardians.

4.3.2 Data collection (Papers II - IV)

Data were collected through self-administered questionnaires during October 2011 to November 2012.

4.3.2.1 Instruments

Two instruments, the DISABKIDS Chronic Generic Module 37 items (DCGM-37) and the HIV Stigma Scale for Children 8 items were used in child and proxy versions (table 2) together with a study specific part and data collected from medical records.

Table 2: Schematic presentation of papers in which the questionnaires were used

	Paper II	Paper III	Paper IV
DCGM-37	X ^a	X ^b	X
PCGM-37			X
HSSC-8	X	X	X
PHSSC-8			X

^a Three dimensions from the DCGM-37 were used: *emotions*, *social inclusion* and *social exclusion*, ^bthe dimension *treatment* was excluded from the analysis as not all participants were receiving treatment.

4.3.2.1.1 DISABKIDS Chronic Generic Module 37 items (DCGM-37; Papers II-IV)

The DCGM -37 is designed to assess health-related quality of life in children (aged 8-18 years) with chronic conditions. The instrument was developed in a partnership between six European countries and is available in six languages including Swedish. The instrument has been used in several conditions (Bullinger et al. 2002; Jervaeus, af Sandeberg, Johansson, & Wettergren. 2014; Petsios et al. 2013; Simeoni et al. 2007) but has not previously been used in children with HIV. The instrument consists of 37 items divided into six dimensions measuring mental, social and physical domains of health-related quality of life. The mental domain is measured by the dimensions *independency* and *emotions*, the social domain by the dimensions *social inclusion* and *social exclusion*, and the physical domain by the dimensions *physical limitations* and *treatment*. The items, formulated as questions (e.g. Does your condition make you feel bad about yourself?), are answered on a five point Likert-scale ranging from 1

(never) to 5 (very often). In accordance with the standard scoring algorithms of the instrument, raw scores are coded for each question then summed and transformed into a 0-100 scale where 0 is worst possible health-related quality of life and 100 is best possible health-related quality of life.

4.3.2.1.2 DISABKIDS Chronic Generic Module 37 items, proxy version (PDCGM-37; Paper IV)

The proxy version of DCGM-37 (Froisland et al. 2012) has the same content as the DCGM-37 but the items are adapted to measure a legal guardian's ratings of their child's health-related quality of life (e.g. Does your child's condition make him/her feel bad about him/herself?). The items of the PDCGM-37 are answered on the same Likert-scale and treated in accordance with the same scoring algorithms as in the DCGM-37 (see above). The PDCGM-37 has been used for proxy measures in several conditions for example asthma and cystic fibrosis (Bullinger et al. 2002; Petsios et al. 2011) but has not previously been used with legal guardians of children with HIV.

4.3.2.1.3 The HIV Stigma Scale for Children 8 items (HSSC-8; Papers II-IV)

The HSSC-8 is an instrument shortened and adapted for children from the widely used 40-item HIV stigma scale designed to assess HIV-related stigma in adults (Berger, Ferrans, & Lashley. 2001). The process of translating, shortening and adapting the HIV stigma scale involved translation and back translation of items by a bilingual Swedish-English expert committee, selection of items by an expert panel and testing of the items by think aloud interviews with children living with HIV. This is described in detail in paper II. The first version of the HSSC consisted of 12 items (HIV Stigma Scale for Children 12 items, HSSC-12); however, based on a result in paper II, four of the items were deleted (see Findings section, Paper II 6.2.1). Consequently, the HSSC-8 consists of eight items divided into three dimensions of HIV-related stigma, *disclosure concerns* (2 items), *negative self-image* (3 items) and *concerns with public attitudes* (3 items). The items are phrased as statements (e.g. "Having HIV makes me feel I'm a bad person") and the responses are rated on a four-point Likert-type scale ranging from "strongly disagree" (1) to "strongly agree" (4). The scores from the eight items can be summarized to give an overall scale score with a possible range from eight to 32, where higher scores represent higher degrees of HIV-related stigma. Similarly, for the three item dimensions, *negative self-image* and *concerns with public attitudes*, the possible dimension score ranges from three to 12 and for the two item dimension, *disclosure concerns*, the possible dimension score ranges from two to eight.

4.3.2.1.4 The HIV Stigma Scale for Children 8 items, proxy version (PHSSC-8; Paper IV)

The proxy version of HSSC-8 (PHSSC-8) has the same content as the HSSC-8 but the items are adjusted to assess a legal guardian's ratings of their child's experience of HIV-related stigma (e.g. "Having HIV makes my child feel he/she is a bad person"). The items of the PHSSC-8 are answered on the same Likert-scale and scored in the

same way as in the HSSC-8 (see above). Prior to the data collection for the quantitative study, the phrasing of items and response alternatives of the PHSSC-8 were tested by think aloud interviews with five legal guardians of children living with HIV, with satisfying results.

4.3.2.1.5 Study-specific questions and data from medical records (Papers II-IV)

The study-specific part of the questionnaire contained questions regarding social situation, family, treatment adherence and the child's disclosure of his or her HIV status to people outside the hospital. The study-specific part for legal guardians contained the same questions as in the child's questionnaire but from the legal guardian's point of view.

Disease and treatment related data were collected from medical records. The information collected also included data about the child's origin.

4.3.3 Data analysis

The data analyses of the material for the three quantitative papers are summarized in table 3. All statistical calculations were conducted using IBM SPSS 20 and 22. In paper III AMOS was also used (IBM Corp., Armonk, NY). P-values <0.05 were considered statistically significant.

Table 3. Outcomes, participants, measures and analyses in the three quantitative papers

Paper	Study outcomes	Participants	Measures	Analyses
II	Psychometric properties of a short version of the HIV stigma scale.	58 of 82 eligible participants completed the questionnaire.	HSSC-12, HSSC-8 DCGM-37	Independent samples <i>t</i> -test, χ^2 -test, Spearman's ρ , principal component analysis with varimax rotation, Kaiser-Meyer-Olkin measure of sampling adequacy and Bartlett's test of sphericity, Kaiser's criterion, floor and ceiling effect, Cronbach's alpha.
III	Children's perception of HIV-related stigma and health-related quality of life. The relationship between HIV-related stigma and health-related quality of life.	58 of 82 eligible participants completed the questionnaire.	HSSC-12, HSSC-8 DCGM-37	Descriptive statistics, χ^2 -test, independent samples <i>t</i> -test, structural equation modelling.
IV	Legal guardian's ratings of their child's HIV-related stigma and health-related quality of life in relation to child's own ratings.	37 of 62 eligible children-legal guardian pairs.	HSSC-8 PHSSC-8 DCGM-37 PDCGM-37	Paired sample <i>t</i> -test, Intra Class Correlation Coefficient, χ^2 test, independent <i>t</i> -test, Paired sample <i>t</i> -test, Wilcoxon signed ranks test.

DCGM-37 = DISABKIDS Chronic Generic Module, PDCGM-37 = DISABKIDS Chronic Generic Module proxy version, HSSC-12 = HIV Stigma Scale 12 items, HSSC-8 = HIV Stigma Scale 8 items, PHSSC-8 = HIV Stigma Scale 8 items proxy version

4.3.3.1 Paper II

In this paper a principal component analysis (PCA) with varimax rotation was used for exploration of factor structure, Kaiser-Meyer Olkin and Bartlett's test of sphericity was used to test the adequacy of the data for factor analysis (Field. 2009) and factors were extracted by using Kaiser's criterion of retaining factors with eigenvalues of >1 (Cattel. 1966). Further, Cronbach's α was used to assess internal consistency reliabilities of the scale and its subscales, and values between 0.70 and 0.80 were considered acceptable (Machin, Campebell, & Walter. 2007). For evidence of convergent validity Spearman's ρ correlations were used between the final version of the HSSC- 8 (overall scale and the three dimension scores) and three subscales

from the DCGM-37 (*emotion, social exclusion and social inclusion*). The percentage of responses at the minimum and maximum of the scale was presented by a floor/ceiling effect (Fayers & Machin. 2007). To test if there were differences between non-participants and participants, an independent *t*-test was used to compare age and χ^2 to compare gender.

4.3.3.2 Paper III

In paper III the methods of analysis used were descriptive statistics (mean and standard deviation), χ^2 -test, independent samples, *t*-test and Structural Equation Modeling (SEM). SEM is a comprehensive method and explicitly takes into account measurement error, that is ubiquitous in most disciplines, and typically contains latent variables (Rykov. 2006). SEM uses constructed variables that are not measured directly, so-called latent variables, and makes it possible to explicitly capture the unreliability of measurement in the model (Blunch. 2013). To test if there were differences between participants and non-participants χ^2 was used to compare sex and an independent samples *t*-test to compare age. For the results section of the thesis (section 6.3.1), an independent samples *t*-test was also used to compare the DCGM-37 results of the investigated group of HIV-infected children with normative data from published DCGM-37 results of children with other chronic conditions.

For the SEM, health-related quality of life as measured by dimensions from the DCGM-37 and HIV-related stigma as measured by dimensions from HSSC-8, were used as latent variables. Measurement models representing associations between stigma and health-related quality of life were estimated (figure 2). In the SEM analysis only five of the six measured dimensions of the DCGM-37 were used. The sixth dimension, *treatment*, was not used because some of the participants (n= 8) were not receiving treatment (i.e. no treatment dimension score could be calculated). Treatment with cART was used instead as an exogenous observed dichotomous variable (treatment vs no treatment).

Other dichotomous variables used were age and sex to observe if age and/or sex were significant to the model. The latent variable (L1) in the model represents all omitted causes and any random or measurement error. The fit of the model was evaluated by examining various statistics. Chi-square statistics were used to assess the magnitude of the discrepancy between the sample and fitted covariance matrices. A significant test indicates a poor fit (Blunch. 2013). The following goodness of fit indices were used to assess the model fit:

- Comparative fit index (CFI) - range from 0 (indicating poor fit) to 1 (indicating perfect fit); a value > 0.90 indicates acceptable fit to the data (Blunch. 2013).
- Root mean square error of approximation (RMSEA) - range from 0 to 1; values in the range of 0.00 to 0.05 indicate close fit, those between 0.05 and 0.08 indicate fair fit, and those between 0.08 and 0.10 indicate mediocre fit. RMSEA values above 0.10 indicate unacceptable fit (Blunch. 2013).
- The Tucker-Lewis index (TLI) - range from 0-1 with values near 1 being a sign of good fit (Blunch. 2013).

4.3.3.3 Paper IV

In paper IV the intraclass correlation coefficient (ICC) was used to measure the strength of agreement between a child's and their corresponding legal guardian's measurements of health-related quality of life and HIV-related stigma. The values of ICC should be as close as possible to 1, as 1 indicates a perfect agreement between subjects. The following interpretations of ICC coefficients were used: 0.5 as acceptable, 0.7 as good, 0.8 as optimal and 0.9 as excellent agreement between measurements (Fayers & Machin, 2007). Paired sample *t*-tests were used to test whether there were differences in how children and legal guardians rated the child's health-related quality of life and HIV-related stigma (*negative self-image* and *concerns with public attitudes* dimension). The HIV-related stigma *disclosure concerns* dimension scale showed low internal consistency (Cronbach's α 0.22 for the proxy version) which is why the two items assigned to this dimension were treated as single items with comparisons between the legal guardians' and the children's ratings made with the non-parametric Wilcoxon signed-ranks test.

A χ^2 -test was used to analyze potential differences between children and legal guardians regarding frequency of reported disclosure of the child's HIV status to friends and adults outside the family. The potential relation between the child's gender and the concordance between child-legal guardian ratings was analyzed using the *t*-test for independent samples to compare the delta scores (legal guardian's score minus child's score) for the pairs with male versus female children.

5 ETHICAL CONSIDERATIONS

The studies have received ethical approval (Dnr 2007/1530-31, 2008-03-03, 2011/1120-32, 2011-07-07 and 2012/6-32, 2012-01-09) from the Regional Research Ethics Committee in Stockholm.

Research involving human beings has to follow certain ethical principles; an international standard is the Declaration of Helsinki, revised in 2013 (World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects. 2013). The declaration includes three key ethical principles included in most guidelines: beneficence, respect for human dignity and justice, and the actions taken to adhere to those principles (Polit & Beck. 2012).

All participation was voluntary and all participants were given written and oral information before consent. This information described the purpose of the studies and information about how to contact the research team. The participants were assured of confidentiality and all participants were informed that they could terminate their participation at any time without influencing their health care. All participants gave their written consent and for those under 16 years of age legal guardians had to also give their written consent, which is consistent with the principle of respect for human dignity and justice from the Declaration of Helsinki (Polit & Beck. 2012).

Approaching children and young adults can be sensitive due to their status as a potentially vulnerable group (Polit & Beck. 2012) and to ask them about or discuss issues related to their HIV infection can cause negative feelings especially as living with HIV is associated with guilt and shame. In planning both the qualitative and quantitative data collections, the potential risk of causing distress among the participants was weighed against the benefit of possibly using the results as a basis for actions to improve the future of children living with early acquired HIV. This is consistent with the principle of benefit including risk from the Declaration of Helsinki (Polit & Beck. 2012). For the qualitative study, invented names were used for quotes in the text so that it is not possible to identify individual participants in the manuscript; this was consistent with the principle of justice including confidentiality from the Declaration of Helsinki (Polit & Beck. 2012). Furthermore, in both data collections all participants were informed that if they felt the need for support this could be mediated through the research team. If necessary, referral could be made to a social worker with special training in both HIV-related issues and counseling.

6 RESULTS

6.1 PAPER I

The aim of this study was to explore the experience of young adults growing up and living with HIV in urban Sweden. The participants in the interviews were five young men and five young women aged 15-21 years.

6.1.1 Findings

The results of the qualitative content analysis of the texts from the semi-structured interviews revealed five main categories. These categories were (1) protecting oneself from being stigmatized, (2) being in control, (3) losses in life but HIV is not a big deal, (4) health care/health care providers and (5) belief in the future.

The first main category included descriptions of the significance of protecting oneself from stigmatization but also information about living with a dark secret, a secret the participants wanted to get rid of. Interestingly, some of the participants expressed that HIV was not the secret that had greatest impact on their life. The participants referred to other secrets of greater importance without revealing the nature of those secrets. Further, the secretiveness around HIV meant that the participant scarcely ever talked to anybody except health care workers about their infection. Even within the family HIV was sometimes a secret between family members. The secretiveness regarding taking medicine was a problem for the participating young adults and even though the participants were aware of the risk of medication resistance problems they sometimes chose to interrupt their treatment to keep their HIV a secret. As a result of the secretiveness, the second main category included descriptions of how the participant felt they had to be in control so that they themselves were in charge of deciding if and whom they should tell about their HIV infection. Those who had told a friend expressed that they felt calmer and thought it was an advantage to have a friend to be totally open with. Further, religion was a factor that was of importance to some of the participants. For example HIV could, for some, be a test from God and God would be the one to decide if and when to eradicate the HIV infection and make them healthy. The third category contained different losses, for example losses of family members and origin, but also more practical things like loss of the possibility to travel freely and not having the same ability as others to study abroad. Notwithstanding losses in life, the participants expressed that, over time, they had developed an acceptance of their condition and life situation. The fourth category showed that the participant was satisfied with the health care they had received during their upbringing and expressed the importance of continuity. The last category showed that the participating young adults had communicated that they believed in the future and that they thought that they had the same possibilities in life as their uninfected peers.

6.2 PAPER II

The aim was to test an adapted short version of the 40-item HIV Stigma Scale (HSS-40), adapted for 8-18 year old children with HIV infection living in Sweden. Fifty-eight out of 82 eligible children completed the study (figure 2). The respondents were 27 females and 31 males, aged between 9 and 18 years (mean 13.9, SD 2.5). The majority of the participants were immigrants of non-European origin.

6.2.1 Findings

The analysis showed that three of four subscales of the HSSC-12 had a feasibility that made them suitable for use. These three scales were: *public attitude* (3 items), *negative self-image* (3 items) and *disclosure concerns* (2 items). The fourth subscale measuring *personalized stigma* had unacceptably high rates of missing values, as did one of the items concerning *disclosure concerns*. Consequently the dimension *personalized stigma* and one of the *disclosure concerns* items were excluded. Based on these results, the remaining analyses were performed on the eight-item scale version with three subscales, the HSSC-8. The HSSC-8 had a good internal factor structure with items loading on factors in parity with the subscales of the original HIV stigma scale 40 items for adults. Further, the HSSC-8 was shown to be feasible and generally reliable (overall scale and *public attitude* and *negative self-image* subscales; although the *disclosure concerns* subscale showed a reliability coefficient α below the accepted standard of 0.70). Higher levels of HIV-related stigma correlated with poorer health-related quality of life (the DCGM-37 dimensions *emotion*, *social inclusion* and *social exclusion*), which supports evidence for external validity.

6.3 PAPER III

The aim was to describe HIV-related stigma and health-related quality of life among children with early acquired HIV living in Sweden and to investigate the relationship between the two factors in the same group. The sample consisted of the same 58 children as described in paper II above.

6.3.1 Findings

The analysis shows that there is a strongly negative association between health-related quality of life and HIV-related stigma (standardized β -0.790) (figure 3). The HSSC-8 showed a mean score of 17.6 (SD 5.0; possible range 8-30) for the total scale and with the highest dimension mean score for *disclosure concerns* (mean 6.7, SD 1.5, possible range 2-8). Health-related quality of life as measured by DCGM-37 presented a mean score of 80.7 (SD 14.1) for the total scale; the highest mean was in the dimension *social exclusion* (mean 89.5, SD 13.5). The lowest mean was in the dimension *social inclusion* (mean 71.0, SD 18.1). The participating children seem, in comparison with children with other chronic conditions, to rate their health-related quality of life similarly or better (table 4). Further, it was not uncommon that the participating children had told someone other than the family and health care staff about their HIV infection (figure 4).

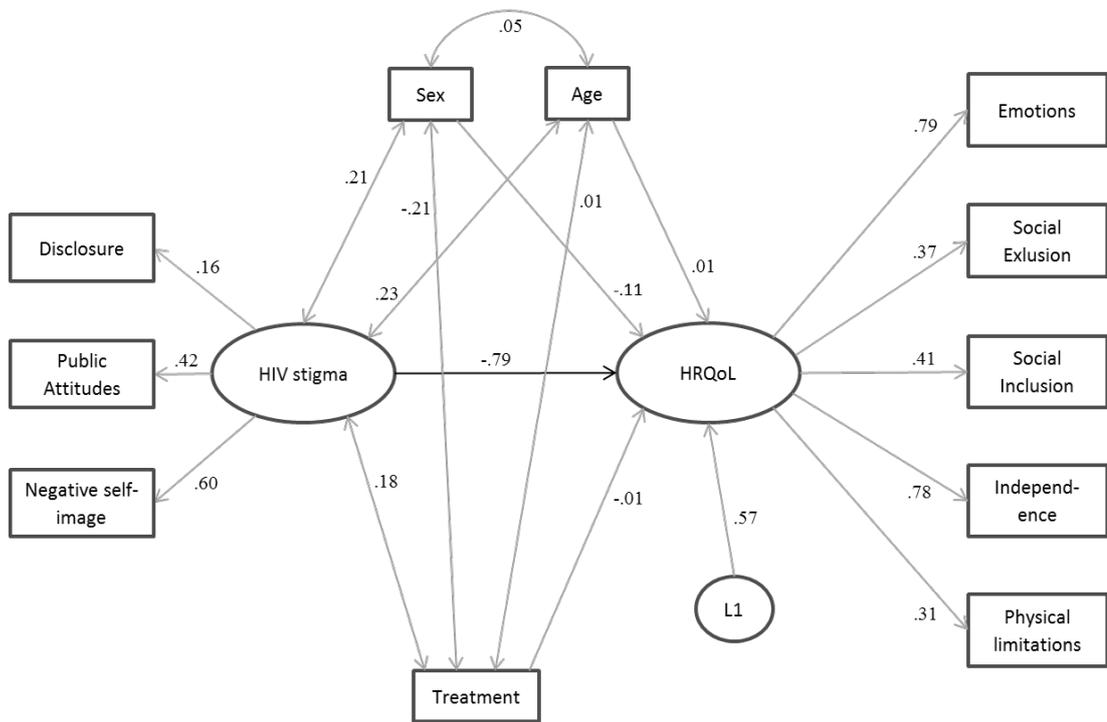


Figure 3: This figure shows structural equation modeling of the relation between the latent variables analyzed in the model. The latent variables are shown as circles and the observed variables as squares. The standard coefficients that can be interpreted as variance in a regression model are shown next to each arrow. The arrow between HIV-related stigma and health-related quality of life represents the variables that have an effect on health-related quality of life; the two-way arrows show correlations.

Table 4: Comparison of mean values in estimates of health-related quality of life measured by DISABKIDS Chronic Generic Module 37 Items (DCGM-37)

	Children with HIV (n=58) Age range (8-18 years) Mean (SD)	DCGM-37 normdata ^a (n=1152) Age range (8-16 years) Mean (SD)	Children with diabetes ^b (n=217) Age range (12-19 years) Mean (SD)	Children with limb reductions ^c (n=140) Age range (8-16 years) Mean (SD)	Children with asthma ^d (n=504) Age range (8-14 years) Mean (SD)
Emotions	77 (22)	76 (21)	70 (20)**	85 (16)***	75 (22)
Social exclusion	90 (14)	86 (16)	78 (14)***	83 (17)***	86 (17)
Social inclusion	71 (18)	75 (18)	82 (15)***	80 (14)***	68 (12)
Independency	83 (17)	77 (18)**	76 (16)***	82 (13)	78 (17)**
Physical limitations	83 (15)	73 (18)***	68 (17)***	82 (13)	53 (10)**
Treatment	73 (24)	72 (23)	70 (23)	-	67 (22)
Total Scale	81 (14)	77 (14)*	74 (15)***	82 (12)	57 (21)***

Mean values from the DCGM-37, SD= Standard Deviation, * statistically significant difference in relation to the investigated sample of children living with HIV (<0.05), independent groups *t*-test (*<0.05, **<0.01 and ***<0.001), ^a (Schmidt et al. 2006) ^b (Petersson, Huus, Samuelsson, Hanberger, & Akesson. 2015), ^c (Ylimainen, Nachemson, Sommerstein, Stocksélius, & Hermansson. 2010), ^d (Petsios et al. 2011).

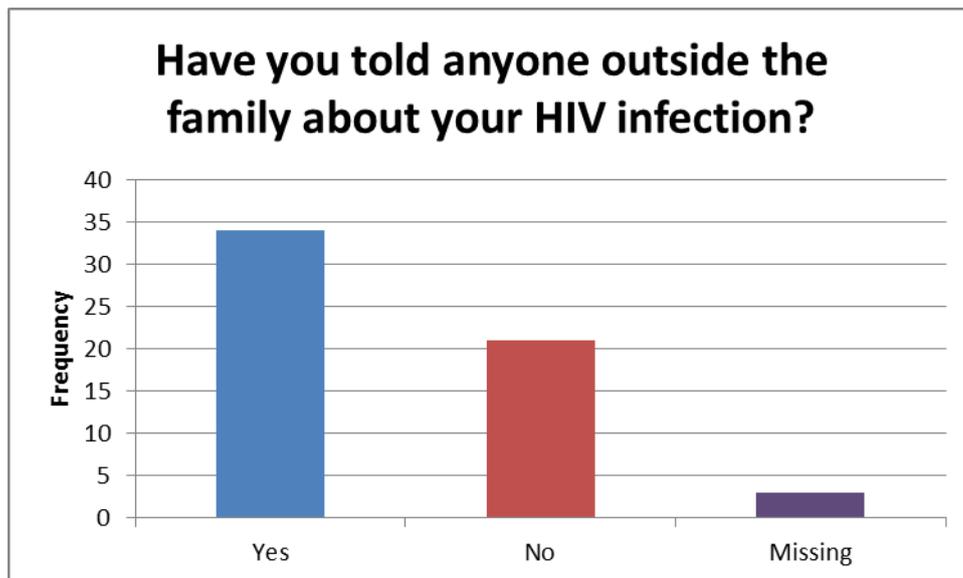


Figure 4: Describes participants disclosure or non-disclosure about their HIV infection to persons outside the family (n=55).

6.4 PAPER IV

The aim of this study was to describe how legal guardians assess their HIV-infected children's health-related quality of life and HIV-related stigma in relation to their children's own ratings. The participants were 37 legal guardian/child pairs. The participating children were 18 girls and 19 boys, aged 8-16 years, (mean age 13.1, SD 2.2). One legal guardian of each child participated, 25 mothers or stepmothers, 10 fathers or stepfathers and two others. The origin of the participating children was non-European (n=31), European (n=5) and for one the origin was not known. Information about the origin of the legal guardians was not collected.

6.4.1 Findings

The results showed that the concordance between legal guardians' and children's ratings of the children's health-related quality of life was acceptable to excellent. Regarding HIV-related stigma the concordance was good to optimal. Further, there were no statistically significant differences between how legal guardians and children rated the children's health-related quality of life or HIV-related stigma. Neither did the results show that the child's gender had any relation to the concordance between the responses. As regards questions about disclosure of their HIV-status, considerably more of the participating children stated that they had told people outside the immediate family or health care about their HIV infection than their legal guardians had estimated ($\chi^2(1, n=30)=5.12, p=0.024$) (figure 5).

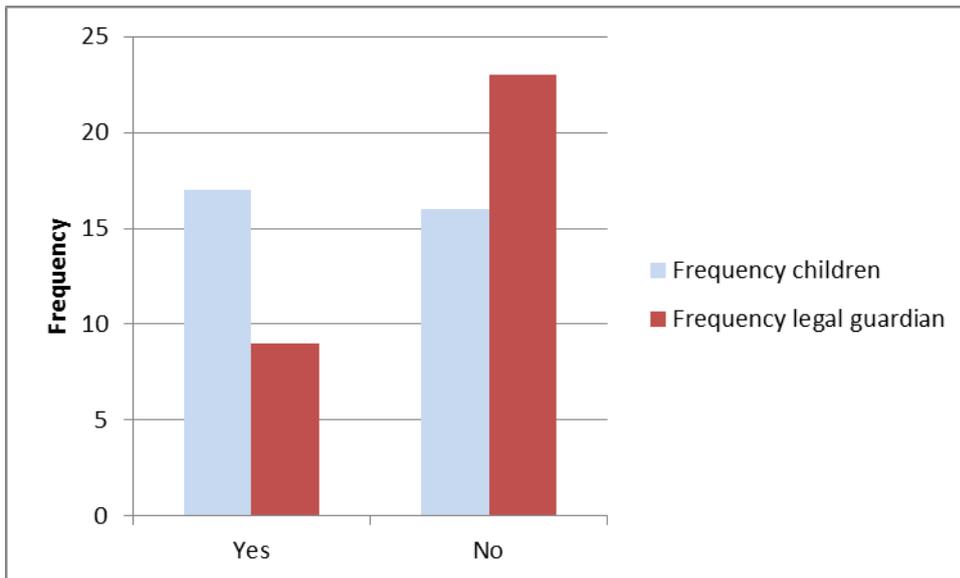


Figure 5: Description of the distribution of responses regarding whether a child had told others or not, and their legal guardian's estimates of the extent to which they believe that their child had told people outside their own family.

Furthermore, the participating children revealed that the persons they had told were friends, boy- and girlfriends and school nurses. One third had told the school nurse and half of the children said that they had told more than one person outside the family about their HIV-status. Legal guardians believed that their children had only disclosed to professionals such as school nurses and teachers (figure 6).

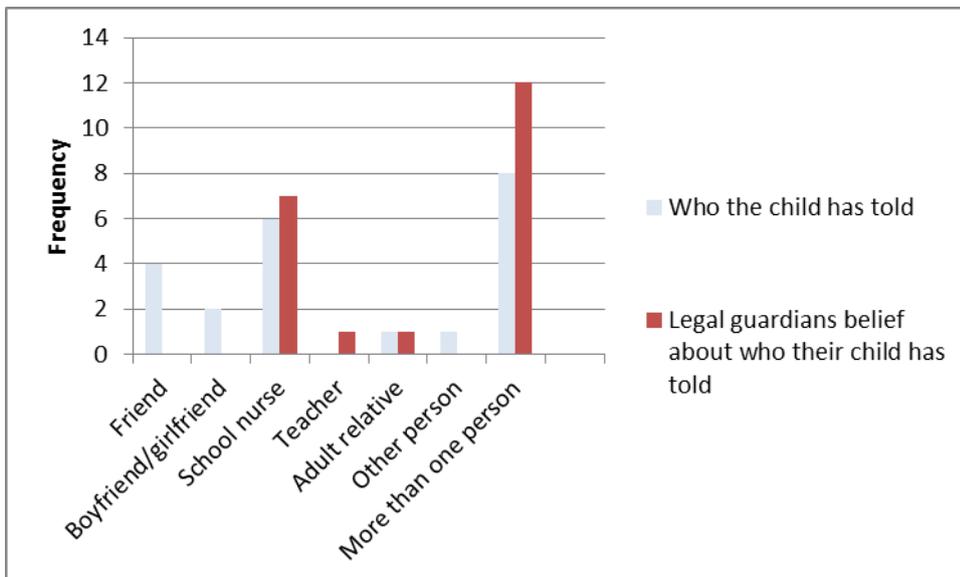


Figure 6: Pattern of children's description of disclosure to others and the corresponding pattern of how legal guardians estimated their children's disclosure to people outside the family. Twenty-two children and 21 legal guardians answered this question.

7 DISCUSSION

The overall result from this thesis reveals that children living with perinatally or early acquired HIV in Sweden seem to do well in terms of self-reported health-related quality of life and HIV-related stigma (paper III). Also in interviews with young adults living with early acquired HIV it seemed that they perceived low HIV-related stigma and had a belief in the future (paper I). Further, the perception of HIV-related stigma primarily seems to be related to disclosure about their HIV-status (paper III). It also seems as if legal guardians and their children have a consensus regarding how children perceive their health-related quality of life and HIV-related stigma (paper IV). Furthermore, when young adults describe what it is like to grow up with an early acquired HIV-infection, they express feelings of having a good life and believe they are able to live a life similar to their uninfected peers (paper I). However, there were areas where this group of children and young adults expressed that they felt different. One such area was living with a secret even if they also expressed that these secrets were not always related to their HIV infection (paper I). Since they did not reveal what these secrets were about, one can only speculate, but it might be that these secrets were about social issues or problems, for example ethnicity and immigration or parents with substance abuse (based on clinical experience).

7.1 HEALTH-RELATED QUALITY OF LIFE

It appears as if HIV has low impact on how children living with HIV in Sweden perceive health-related quality of life, since they express that they can do basically the same things as their peers (papers I and III). When comparing data from the participating children with DISABKIDS norm data and data from children living with other chronic conditions (Das et al. 2010; Gupta, Nanda, & Kaushik. 2013; Lundberg et al. 2012; Schmidt et al. 2006; Ylimainen, Nachemson, Sommerstein, Stockslius, & Hermansson. 2010; Petersson, Huus, Samuelsson, Hanberger, & Akesson. 2015; Petsios et al. 2011) children living with HIV in Sweden tend to rate their health-related quality of life at parity or sometimes higher than children with other chronic conditions (paper III and further analyzed in section 6.3.1). This is despite the fact that the majority of HIV-infected children in Sweden come from families with low education, who live in socio-economically weak areas and have an immigrant background (personal contact with L.Navér; Asander, Rubensson, Munobwa, & Faxelid. 2013). Due to these factors it would not be inconceivable that children living with HIV infection lacked faith in the future as a result of their illness and their life situation. However, in the comparisons between children living with other chronic conditions it seems as if it is the opposite. The participating HIV infected children seem to perceive their health-related quality of life as high, whilst children with other chronic conditions, rate their health-related quality of life lower. This is despite the fact that many children from the compared groups of children with chronic conditions might live in less vulnerable population groups. Furthermore, if the family have emigrated from a country where HIV may still be a fatal disease due to difficulties receiving cART, legal guardians and children might feel a relief and gratitude that make the child (paper I) and the family (paper IV) look more favorably on the child's health-related quality of life. Furthermore, both legal guardians and children might feel that it is possible for the

child to live a life similar to their uninfected peers as long as they themselves are in control of who has knowledge of their HIV status (paper IV). However, to live with a secret is always difficult, and might have a negative effect on a child's life, especially as emotional development is one of the critical parts of a child's normal development (Patton & Viner. 2007).

All children go through different normal development stages. One phase is a question of emancipation from their legal guardians, where children begin to develop their own thinking (around nine years of age). As they grow older, the opinions their friends have of them become more important and it is essential to be like your friends (Hallström & Lindberg. 2009). During this period in a child's life it is not unusual that children with chronic conditions perceive difficulties in treatment adherence because it is essential to be like everyone else (Anderson. 2012; Taddeo, Egedy, & Frappier. 2008). In line with this, even though the young adults interviewed (paper 1) were aware of the risk of developing treatment resistance, they sometime chose not to take their medication to avoid feeling different from their friends and also to avoid the risk that their friends might discover that they were different and had to medicate.

When a person is aware that he/she is doing something wrong, as these young adults in refraining from taking their medication, it might lead to them feeling that they have to keep this (in this case non-adherence) a secret from their health care workers. This in turn might lead to these young persons finding it more difficult to face their health care worker, who, as shown in paper 1, sometimes might be one of the few people that these young people trust (paper I). Furthermore, this might lead to these young persons beginning to live a more risk-taking life (Kalichman. 2008), which could mean that they also expose other people to risk, not least because an untreated or inadequately treated HIV infection means an increased risk of passing on the infection to others in connection with sexual contact (Reynolds et al. 2011). One way to identify these problems might be through use of individual measures of health-related quality of life in clinical practice. In adult care there is some evidence that using individual measurements of health-related quality of life as a tool could be useful and helpful in treatment, and could have positive effects on the communication between physicians and patients (Varni, Burwinkle, & Lane. 2005). On the other hand, the effectiveness of implementing such tools in clinical care has so far been rarely investigated.

It is important to children and their families to have continuity in care and to be able to meet the same physicians, nurses and counselors when they come for a health care visit (paper I). It is not just the medical treatment that is essential; this also includes issues related to emotional and social wellbeing (Das et al. 2010). Among HIV-infected adults, studies have found that when treatment and health care works satisfactorily, living with HIV has become associated with less negative feelings (Johnson et al. 2001; McDowell & Serovich. 2007; Oppong Asante. 2012) leading to adults living with HIV infection tending to rate their health-related quality of life as high (Bakiono et al. 2014; Basavaraj, Navya, & Rashmi. 2010). This might be an indication that health care works satisfactorily for the majority of children living with HIV infection in Sweden as the participating children rated their health-related quality of life as high.

It is essential to work with the whole family to improve the understanding of the child's health (Hallström & Lindberg, 2009). One way this can be done is by using the method of family-centered care (Shields, et al. 2006) and one step on the way to gaining more knowledge regarding the family's understanding of the child might be by using proxy measures. However, it is debatable if proxy measures really show how the child feels as such measurements will also be affected by the proxy rater's emotional status (Fayers & Machin, 2007). There are several other factors that may have a bearing on the correspondence between children's and legal guardians' ratings of children's health-related quality of life. For example, social factors might have an impact on the child's own ratings (Baumann, Chau, Kabuth, & Chau 2014) as well as the legal guardian's ratings (Snow et al. 2005). It is common that legal guardians to children with chronic conditions feel guilt because of the child's illness and live with chronic sorrow which, even if they try to ignore it, might impact on legal guardians' ratings of children's health-related quality of life (Antle, Wells, Goldie, DeMatteo, & King, 2001), especially in cases when the legal guardian also could be viewed as the indirect "cause" of the child's condition (e.g. HIV through mother-to-child transmission) (Dalheim Englund, Rydström, & Norberg, 2012). Furthermore, given that legal guardians of HIV-infected children often have their own negative experiences related to their disease (it is likely that several of the participating mothers themselves are HIV-infected and that many are first-generation immigrants from low income countries (Baumann et al. 2014)) this might entail legal guardians rating their children's health-related quality of life more negatively. However, this seems not to be the case for the participating legal guardians and their children investigated in this thesis work (paper IV). Furthermore, to disclose to the child about the child's HIV infection and the difficulties of living with HIV infection, might mean that children and parents gain a greater understanding of each other and an increased closeness. This close relationship may in turn be the reason that the concordance between legal guardians' and children's ratings is high. According to Upton (2008) high levels of agreement indicate high levels of legal guardian involvement around relevant issues of health. Therefore, proxy measures together with children's own ratings may be useful to gain an indication of the interplay between the child and the legal guardian on issues related to the child's HIV infection and thus serve as a guide for health care worker's efforts to support the family. However, there are several factors that should be taken into consideration when using proxy measures, for example the education level and socio-economic status of the rater, which might influence the discrepancies between legal guardian's and children's ratings and the rated construct (Snow et al. 2005).

7.2 HIV STIGMA

Stigma is dependent on the context (Goffman, 1963), and living in Sweden means living in a context where it is relatively unknown and unusual to be a child living with HIV infection. This in turn might be one reason why children living with HIV express having little experience of being stigmatized in relation to their HIV.

Although the results of this thesis suggest that the participating children have little experience of HIV-related stigma, it is essential to be observant in cases where children feel exposed to HIV-related stigma as stigma has a harmful role in society. This is also important in health care settings especially as these children and their families mainly

come from other cultural and social contexts. This means that HIV-infected children and their families are vulnerable to other forms of stigma such as stigma related to living in a new cultural and social context, not least because it is known that high levels of HIV-related stigma among adults are strongly associated with high levels of depression and a low level of self-efficacy (Logie, James, Tharao, & Loutfy. 2013; Sherr, Clucas, Harding, Sibley, & Catalan. 2011). If a child has symptoms of a low level of self-efficacy it might be a sign that the child feels threats against their identity, so called *anticipated stigma*, which has associations with behavioral and physical indicators of health and well-being (Earnshaw & Chadoir. 2009; Earnshaw et al. 2013). The ability to experience anticipated stigma increases with life experience, which might be a reason that the children's perceptions of this kind of stigma seems to be uncommon (paper III).

On the other hand, when young adults living with early acquired HIV talked about the importance of being in control and of protecting themselves from HIV-related stigma (paper I), this might have been a way to protect themselves from the fear of experiencing humiliating or degrading treatment. An important issue for these young adults was the possibility to have the right to decide who should have knowledge of their HIV-status. However, even though the young adults are informed about their HIV infection, they might feel that it is their legal guardians who decide if and to whom their HIV-status should be revealed as they have been taught by their legal guardians to keep their HIV-status a secret since they were small children (paper I). By teaching children to keep their HIV-status a secret, legal guardians might think the risk of stigmatization is decreased (Deacon & Stephany. 2007). Children and young adults on the other hand might interpret things differently and sometimes feel it is better to dare to disclose their HIV-status based on their experiences and frames of reference (paper I). This different perspective could be a source of problems between a legal guardian and the child (Upton et al. 2008).

Despite the fact that these children often seem to be taught to keep their HIV-status a secret, it seems that more children than expected choose to be open about their HIV infection to friends and people in school (paper IV). This despite both legal guardians and children rating disclosure concerns as high (paper III and IV). To dare to be open about their HIV infection may be a risk but children and young adults participating in the present thesis work have expressed that disclosure to individuals outside the family sometimes makes them feel better and more like their uninfected friends (paper I), and might ultimately lead to the young adults and children experiencing better psychosocial functioning. Furthermore, if a young person has the ability to take responsibility for disclosure of their HIV-status this has been shown to impact how the child will handle stigma and their life with HIV infection in the future (Gillard & Roark. 2013). However, being open about their HIV status among friends could also be associated with a risk of being alienated, and feelings of shame and guilt regarding their condition. This might, as has been seen among adults, lead to an increased risk of being depressed and denial of their HIV-status (Bogart et al. 2008; Campbell, Foulis, Maimane, & Sibiyi. 2005; Earnshaw et al. 2013). The secretiveness can also lead to self-stigma, so-called *internalized stigma* which includes feelings of being “less than” others, dirty or unclean, and/or justification of negative outcomes due to having HIV (Earnshaw et al. 2013).

Enacted stigma, which refers to overt acts of discrimination and humiliation directed at a person because of his or her stigmatized status, seems to be the stigma most difficult to understand as a child. The questions addressing *enacted stigma* required the child to think hypothetically if the child had no earlier experience of what would happen if their HIV status became known to others (paper II). As *enacted stigma* captures the interpersonal aspect of stigma, something real that a person has experienced (Earnshaw & Chadoir. 2009), the low awareness of children living in Sweden might contribute to children having difficulties with understanding *enacted stigma* related to HIV, as any experiences of discrimination and humiliation might be related to causes other than their HIV infection (e.g. immigration). Furthermore, as this kind of stigma can affect the whole family's life situation it is essential to be aware of an increased risk of psychological distress that can have emotional impact on children and/or legal guardians (Goldstein & Morewitz. 2011). This suggests that although children themselves might not have the ability to recognize *enacted stigma*, they still risk being affected, since the child is part of the family and recognizes when family members are feeling misery. The child's ability to be empathetic without knowing the source of the legal guardian's concern may cause fantasies in children, which often can be worse than the reality. Therefore, it is essential that health care professionals discuss these issues with the child and their family in a structured manner as it has been established that children who are open about their HIV status exhibit less fear and better psychosocial functioning (Goldstein & Morewitz. 2011).

7.3 HIV STIGMA - HEALTH-RELATED QUALITY OF LIFE - THE RELATION

In paper III it was found that the relationship between HIV-related stigma and health-related quality of life was negative. This might entail that children living with an HIV infection experiencing HIV-related stigma are at risk of impaired health-related quality of life as this has been shown among adults' experiencing HIV-related stigma (Sayles, Ryan, Silver, Sarkisian, & Cunningham. 2007). The relationship suggests that physicians, nurses and counselors have to be observant about children's experiences of life to be able to obtain a deeper understanding of how stigma affects children living with HIV and, based on that knowledge, provide adequate support to each individual.

7.4 METHODOLOGICAL CONSIDERATIONS

A variety of analyses are needed to understand complex and multifaceted realities (Fayers & Machin. 2007); this was achieved by using both qualitative and quantitative methods. The issues regarding children living with HIV in Sweden are complex as there are several factors, apart from HIV, influencing their life. The majority of the participating children were immigrants from high endemic areas (Inficare 2014) and lived in socio-economically deprived areas.

7.4.1 Paper I

The trustworthiness of a qualitative study can be considered from the concepts of credibility, dependability and transferability (Graneheim & Lundman. 2004). The

belief is that the findings from this interview study mirror the experiences of a group of young adults living with an early acquired HIV in an urban city in Sweden.

7.4.1.1 Credibility

To be able to reach as many young adults as possible it was decided to perform the study where most young adults with early acquired HIV were treated. Efforts were made to have representation from both genders and a spread in ethnicities and age among the participants. Further, the number of non-participants and the reasons for non-participation have been described (they didn't want to think about the infection or due to legal guardians' advice). The intention was to obtain a clear description of the participant's experiences by using interviews. When analyzing the interviews, efforts were made to avoid selecting too broad meaning units. To further strengthen the credibility, quotations were used for illustration in the presentation of the results.

The pre-understanding of one of the authors could be a problem, as it is possible that the analysis of the material might be based on assumptions and expectations instead of them being naïve. It was essential, therefore, that some of the researchers had no previous experience of working with children living with early acquired HIV infection. Furthermore, the person performing the interviews was a pediatric nurse with experience of data collection, but with no clinical experience of working with HIV-infected children. This was an effort to decrease the impact of pre-understanding regarding the target group to prevent the interviewer influencing the interview so that the answers fit the preconceptions (Kvale. 2009).

7.4.1.2 Dependability

The process of performing interviews may involve the use of an interview guide with open questions, thus gaining new knowledge from the subject which influences the follow-up questions that are posed (Graneheim & Lundman. 2004). The topic and the main questions were the same for all participants but follow-up questions were developed during the process and even though the interviewer was experienced, there may be a risk that relevant follow-up questions were not asked due to the interviewer's lack of knowledge about living with HIV infection. However, as the interviewer was a registered nurse with experience from both child care and youth clinics this risk was reduced. Furthermore, an open dialogue was ongoing between the interviewer and the research team throughout the period when the interviews were conducted.

7.4.1.3 Transferability

Transferability (Graneheim & Lundman. 2004) can be reached by describing the context and the method, including participants, data collection and analysis as well as a clear description of the findings.

It was judged that qualitative content analysis was a suitable method for gaining a description of young adults' views of growing up and living with early acquired HIV infection in Sweden and to get a deeper understanding regarding the target group's experiences of life. To enhance transparency, which refers to *the extent to which the findings can be transferred to other settings or groups* (Graneheim & Lundman. 2004 p. 110) and thereby trustworthiness, continuous discussions were held among all the

authors during the analysis procedure regarding the development of sub-categories and categories to make sure that the categories covered the data (Graneheim & Lundman, 2004) and were mutually exclusive. Seminar presentations and discussions with senior and fellow researchers were held in order to receive opinions on the material from others.

Furthermore, there is a risk for *selection bias* and a lack of variation as those who declined participation for various reasons could be those representing other aspects of life (Graneheim & Lundman, 2004).

7.4.2 Papers II – IV

It is essential to use valid and sensitive instruments and ensure the reliability and validity of a measure relevant for the population under study (Kimberlin & Winterstein, 2008). Therefore, in this thesis, the child and proxy DCGM-37, a tested instrument developed for a European context, were used to measure health-related quality of life. An adapted Swedish short version of the American HIV Stigma Scale, the HSSC-8, in both a child and proxy version were used to measure HIV-related stigma and as a complement, some study specific questions were initiated by the research team. All three papers II-IV were based on the same dataset. The following discussion about the quantitative study's validity and reliability is based on the definitions as outlined by Kazdin (2010).

7.4.2.1 Internal validity

The instrument used to measure health-related quality of life in this study is a commonly used psychometrically evaluated instrument that has been developed in a European collaboration, where Sweden is one of the participating countries (Schmidt et al, 2006). The DCGM-37 has undergone various steps of instrument development in a simultaneous cross-cultural approach. Items that are of potential relevance for chronic conditions were selected and processed separately and thereafter pilot tested (Petersen, Schmidt, Bullinger, & The DISABKIDS Group, 2006; Schmidt et al. 2006; Schmidt et al. 2008).

The HSSC-8 is, to our knowledge, the first HIV stigma scale adapted for children. Internal validity was supported by PCA suggesting a three factor solution with all items loading on the same dimension as in the original HIV stigma scale (Berger et al. 2001).

7.4.2.1.1 Construct validity

Further weaknesses were that, in the psychometric test, it was found that one of four dimensions, *personalized stigma* was not possible to use on children. This was due to the construction of the items, as the participants are expected to imagine things that the children had no experience of, which has meant that this form of stigma could not be studied in this thesis. However, the same problem occurred when the HIV stigma scale

(Berger et al. 2001) was used in an adult population in Sweden (Lindberg, Wettergren, Wiklander, Svedhem-Johansson, & Eriksson. 2014).

Furthermore, it was found that the way the items in the *disclosure concerns* dimensions of the HSSC-8 were constructed posed difficulties. This was particularly evident in the proxy version of the HSSC-8. The two items seem to measure different kinds of disclosure and therefore had to be considered as two separate items.

7.4.2.1.2 Conclusion validity

A limitation in using general instruments, as used in this study, is that these instruments are often broad in scope indicating that they may be unable to detect small but important differences in health in relation to, for example, age and gender (Bryant & Fernandes. 2011).

7.4.2.2 *External validity*

A strength of the quantitative study is that it is a nationwide sample and that the participants were recruited from all clinics in Sweden treating HIV-infected children. When adapting the HIV stigma scale (Berger et al. 2001) for children, think aloud interviews were conducted and each respondent was asked questions regarding their emotions and understanding of the statements in the instrument in connection with the think aloud interview. Thereafter pediatric experts and other experts working with HIV discussed the results from the interviews (paper II).

A limitation is that the sample is small and therefore is sensitive to attrition; the attrition in this thesis was relatively large 29 % (n=24) in papers II and III, and 40% (n =25) in paper IV. On the other hand, response rates between 60 -71% are often seen as good to very good response rates (Babbie. 2007; Groves. 2006). Reasons to refrain varied. Some actively declined participation, while for others health care staff might have acted as gatekeepers to protect children and their families against facing questions about difficult issues; the same could be true for legal guardians wanting to protect their children, but their reasons for refraining from participation were largely unknown. Furthermore, some children (n=25 in papers II and III and n=24 in paper IV) were excluded from participation due to not fulfilling the inclusion criteria, which were not speaking or understanding Swedish, having been treated for less than five years in Swedish health care, being uninformed about their HIV infection; this could be a selection bias.

When using proxy measures it is essential to be aware of whose perspective the measures are measuring (Upton et al. 2008). In paper IV it is the legal guardians' estimates of their children's experiences that are measured. When legal guardians estimate their children's experiences the results might differ depending on whether it is the father or the mother that makes the ratings (Allik, Larsson, & Smedje. 2006). Since it was mainly mothers that participated in paper IV, this might entail a risk that the result does not capture all aspects of legal guardians views regarding children's

experiences of living with an HIV infection; there is a possibility that concordance between children's and legal guardians' ratings might have been different if more fathers or if both legal guardians had participated.

Reasons for attrition in paper IV are the same as in papers II and III but in addition children sometimes attended the clinics without a legal guardian, which prevented collection of legal guardian proxy reports, increasing the non-response rate for paper IV. As it is more common that older children attend the clinic by themselves it is a caused for underrepresentation of data from child-legal guardian pairs of the oldest children (i.e. those 15-16 years old). It might also have been that those (both children and legal guardians) who chose to participate could have been those feeling at their best and most willing to reveal their life situation whilst non-participants were those who experienced more health problems and more HIV-related stigma.

7.4.2.2.1 Reliability

The reliability of the study was dependant on the fact that all the material entered into SPSS was checked and double-checked by proofreading the entered data against the original source.

During the development of the DCGM-37 it was found that the instrument had an internal consistency illustrated by Cronbach's α values ranging from $\alpha = 0.70 - 0.87$ (child version), and $\alpha = 0.77 - 0.90$ (proxy version) for the dimensions, while the overall score displayed a consistency coefficient of $\alpha = 0.93$ (child version), respectively $\alpha = 0.95$ (proxy version) (Schmidt. et al. 2006). In this study the internal consistency in our study was found to be valid, illustrated by Cronbach's α values ranging from $\alpha = 0.64 - 0.88$ (child version), and $\alpha = 0.59 - 0.83$ (proxy version) for the dimensions. The overall score displayed a consistency coefficient of $\alpha = 0.93$ (child version), respectively $\alpha = 0.91$ (proxy version) indicating that the DCGM-37 is possible to use in the studied population. One threat to reliability is the weak Cronbach's α in one of three dimensions, *disclosure concerns* (papers II and IV) which might indicate that this dimension does not measure what it is intended to measure. The scale was shown to have acceptable consistency in two of three dimensions illustrated by Cronbach's α values: *negative self-image* $\alpha = 0.78$, *public attitudes* $\alpha = 0.80$, *disclosure concerns* $\alpha = 0.55$ and for the total scale $\alpha = 0.80$. The proxy version of the HIV stigma scale has not been psychometrically evaluated, but it was found that the consistency was acceptable for two of three dimensions (*negative self-image* and *public attitudes*); the third dimension *disclosure concerns* ($\alpha = 0.22$) seems not to measure the same aspects of disclosure. It is essential that items in a scale dimension measure the same thing (Fayers & Machin. 2007) and the results in paper II and IV indicated that this was not the case with the dimension *disclosure concerns*. This was therefore managed by measuring disclosure as two separate items. The PHSSC-8 also needs to be further tested and developed. Still, the study should be seen as hypothesis-generating and the results should be followed up in further studies.

7.4.2.2.2 Generalizability

Since the number of children living with early-acquired HIV is small, and quite a number of children and legal guardians have chosen not to participate in the studies included in this thesis, it makes it difficult to draw any generalizing conclusions from the results.

The majority of children living with an HIV infection live in underprivileged families in areas where education levels are low and unemployment is high. This might lead to potential participants who feel less privileged and excluded from society experiencing uncertainty towards the authorities and therefore choosing not to participate in the study.

However, the results might be an indicator that children who grow up in a context where it is relatively unknown that children with HIV infection exist in the community are at low risk of being exposed to HIV-related stigma. Further, there are no indications that these children's health-related quality of life is affected negatively.

A weakness in this study is that children (papers II-IV) and legal guardians (paper IV) who were unable to speak and understand the Swedish language or had children that had attended health care for less than five years were not invited to participate. The reason for this was that participants should have as much opportunity as possible to distinguish between HIV-related stigma and other kinds of stigma (e.g. immigration) and to ensure that their responses to the questionnaires were based on the situation of living with an HIV infection. However, if this group of children and legal guardians had been invited to participate the result might have reflected a broader perspective of how children perceive their health-related quality of life and HIV-related stigma. Further it might be difficult to transfer the results of this thesis to more highly endemic areas as the life situation in general is different depending on the social context.

8 CONCLUSIONS, NURSING IMPLICATIONS AND RECOMMENDATIONS FOR FUTURE RESEARCH

The results from this thesis might indicate that, due to them receiving treatment, many children and young adults living with early acquired HIV in Sweden think they have a good health-related quality of life and that they are able to do almost everything that their peers do. This is indicated both by the participating children themselves and their legal guardians. Furthermore, it seems that these children experience little HIV-related stigma with the exception of *disclosure concerns*, as indicated by the children's and legal guardians' caution regarding disclosure of the child's HIV-status to people outside the family in fear of the risk of being stigmatized.

Growing up with a disease that is associated with guilt and shame in society can make daily life difficult; being open and the risk of being exposed to various forms of stigma might affect the child's health-related quality of life. Ultimately, this in turn can affect how the child manages his/her life as an adult living with HIV Infection. It is hoped that the data emanating from this thesis may elucidate some, but not all, aspects of how children living with early acquired HIV perceive their health-related quality of life and HIV-related stigma. On the basis of the findings it might be possible to create new interventions in the care of these children and their families.

Although the participating children in this thesis seem to experience high health-related quality of life and low HIV-related stigma, it is important to be aware that the feelings and experiences are individual and that the non-participants might reflect children that have a different view of these aspects. Therefore, it might be appropriate to measure health-related quality of life and HIV-related stigma for each individual in clinical care to reach those with negative experiences of health-related quality of life and HIV-related stigma. This might be possible by using the same instrument as used in this work since the DCGM-37 has been developed for use in research as well as clinical care (Schmidt et al. 2006). The HSSC-8 needs to be further studied before it can be used as a clinical tool. However, if used, measurements could help to develop care and support based on the individual needs of each child and family. The area that both children and guardians most clearly expressed concern about in their responses was disclosure. This could be a signal to the nursing staff that this is an area where children and their families are in need of support. One way to provide this assistance could be by nurses conducting structured conversations using, for example, family-centered care as a framework.

Furthermore, to be able to individualize the care and support, it is important to understand both a child's and their legal guardian's perceptions of the child's health-related quality of life and the interplay between their perceptions of the child's health-related quality of life and HIV-related stigma. This understanding can serve as a basis for health professionals to strive to provide each child and their family with the support they need to manage and live with HIV infection.

Moreover, as it has been found that HIV-related stigma has a negative association with health-related quality of life, it is important to try to prevent children living with HIV

infection being exposed to HIV-related stigma. It is therefore essential that the community continues to take responsibility and educate its population about HIV as a way to reduce the risk of children being exposed to HIV-related stigma. Among children, this could be done by allowing school nurses to discuss stigma and HIV with all children in the school.

It is necessary to further study how children living with HIV experience HIV-related stigma and also how HIV-related stigma affects children's health-related quality of life, not least because the available treatments are being refined and society is constantly changing. Further, to gain a deeper understanding of how children with early-acquired HIV experience their life situation it is essential to get the children to tell their own stories, which could be done using interviews or focus groups. Areas of interest to explore would be, for example, whether young people living with HIV are receiving the right support from the community in areas dealing with sexuality and family planning, and whether they have forums where they can talk about vital issues. It might be possible to use the internet to carry out studies regarding these kinds of questions, as this makes it possible for participants to be anonymous and keep their identity secret from the other members of the group. Finally, it is also important to conduct longitudinal studies to investigate causal relationships and test the effects of interventions.

9 SUMMARY IN SWEDISH

Från början innebar att vara infekterad med hiv att man bar på en sjukdom som ledde till en förtidig död men i och med att det gjorts medicinska framsteg har antiretroviral kombinationsbehandling medfört att hivinfektion nu blivit en kronisk sjukdom i de delar av världen där behandling finns allmänt tillgänglig. Detta har i sin tur också medfört att de barn som i dag föds med en hivinfektion och får behandling förväntas leva ett relativt normallångt liv vilket medför att det ställs nya krav på sjukvården. För att kunna tillhandahålla rätt insatser är det därför viktigt att undersöka hur hivinfekterade barn upplever sin hälsorelaterade livskvalitet, men också om de upplever hivrelaterat stigma och hur hivrelaterat stigma påverkar barnens liv.

Det övergripande syftet med avhandlingen, som består av fyra delstudier, var att få en ökad förståelse för hur barn och unga vuxna som lever med en tidigt förvärvad hivinfektion i Sverige upplever sin hälsorelaterade livskvalitet och hivrelaterade stigma.

Studie ett är en kvalitativ intervjustudie där syftet var att utforska unga vuxnas erfarenheter av att växa upp med hivinfektion. Deltagarna i studien bestod av tio unga vuxna med tidigt förvärvad hiv; fem unga kvinnor och fem unga män i åldern 15-21 år. De unga vuxna som deltog intervjuades av en erfaren barnsjuksköterska varefter intervjuerna analyserades med hjälp av kvalitativ innehålls analys. Analysen resulterade i fem olika kategorier som belyser de unga deltagarnas erfarenheter av att växa upp med hivinfektion. Dessa kategorier handlar om att det för dessa ungdomar var viktigt att ha kontroll och skydda sig själv från att utsättas för stigma men också att de har haft förluster i livet. Det visade sig också att sjukvården spelade en viktig roll och att det bland dessa unga som lever med en hivinfektion fanns en framtidstro.

De övriga studierna som ingår i avhandlingen (studie två-fyra) är tre kvantitativa tvärsnittsstudier baserade på en nationell datainsamling med självrapporterade frågeformulär. Data samlades in under perioden oktober 2011 till november 2012. De frågeformulär som användes var; the DISABKIDS Chronic Generic Module för barn, ett frågeformulär för att mäta hälsorelaterad livskvalitet hos barn som lever med kroniska sjukdomar, och en kortversion av ett barnanpassat frågeformulär för att mäta hivstigma hos barn som lever med hiv. För studie fyra besvarade även vårdnadshavarna föräldraversionen av de båda frågeformulären, utformade så att det var vårdnadshavarens uppfattning om hur barnen upplevde hälsorelaterad livskvalitet och hivrelaterat stigma som mättes (s.k. proxymätningar). De som deltog i studierna två och tre var 58 barn med tidigt förvärvad hivinfektion (åldrarna varierade mellan 8 och 18 år); och i studie fyra användes data från 37 av dessa barn (de som var yngre än 17 år) tillsammans med data från en vårdnadshavare för varje barn.

I studie två var syftet att validera kortversionen av hivstigmaskalan som anpassats för barn. Detta gjordes med hjälp av principalkomponentanalys. I analysen framkom det att tre av originalskalans fyra delskalor (*negativ självbild på grund av hiv, bekymmer över allmänhetens attityder och bekymmer över att berätta om sin hivinfektion*) kunde användas för att mäta hivrelaterat stigma hos barn. Den fjärde delskalan (*personlig*

erfarenhet av stigma) exkluderades till följd av att allt för få barn hade svarat på påståendena inom den delskalan.

Syftet med studie tre var att beskriva hur barn som lever med tidigt förvärvad hivinfektion uppfattar hivrelaterat stigma och sin hälsorelaterade livskvalitet. I denna studie undersöktes också hur relationen mellan hivrelaterat stigma och hälsorelaterad livskvalitet såg ut. För att beskriva relationen mellan hivrelaterat stigma och hälsorelaterad livskvalitet användes strukturerad ekvationsmodellering (SEM). I resultatet visade det sig att det fanns en negativ relation mellan hälsorelaterad livskvalitet och hivrelaterad stigma. I studien framkom det även att de deltagande barnen tycks skatta sin hälsorelaterade livskvalitet högt i relation till barn med andra kroniska sjukdomar och att barn som lever med en tidigt förvärvad hivinfektion i Sverige inte verkar uppleva speciellt hög nivå av hivrelaterat stigma.

Syftet med studie fyra var att beskriva överensstämmelsen mellan barn och vårdnadshavares skattningar av barnens egna upplevelser av hälsorelaterad livskvalitet och hivrelaterat stigma. Resultatet visade att barn och vårdnadshavare hade hög samstämmigheten i sina skattningar av barnens hälsorelaterade livskvalitet och hivrelaterade stigma. Ett fynd som framkom i både studie tre och fyra var att både barn och vårdnadshavare kände oro för att andra skulle få kännedom om barnets hivinfektion.

Huvudresultaten av denna avhandling tyder på att många barn som lever med tidigt förvärvad hivinfektion i Sverige upplever hög grad av hälsorelaterad livskvalitet och låg grad av hivrelaterat stigma. Dock har studier på vuxna som lever med hivinfektion visat att hivrelaterat stigma kan ha negativ påverkan på den hälsorelaterade livskvaliteten; data från föreliggande avhandling tyder på att det kan finnas en negativ relation mellan hivrelaterat stigma och hälsorelaterad livskvalitet även hos barn.

Sjuksköterskan har ofta en viktig del i vården av kroniskt sjuka barn och detta gäller också för barn som lever med hivinfektion. Därför kan sjuksköterskan också fylla en viktig roll vid insatser som görs för att stötta hivinfekterade barn och deras familjer. Eftersom resultat från den här avhandlingen visar att många av de deltagande barnen och deras vårdnadshavare kände oro för att andra skulle få kännedom om barnets hivinfektion tyder det på att frågor om att vara öppen med sin hivinfektion är ett område där det finns behov av stödjande insatser. För att få en mer heltäckande bild av hur behoven av stödjande insatser ser ut behövs dock ytterligare studier där barnen själva får möjlighet att berätta om sin livssituation och om sina erfarenheter av hivrelaterat stigma samt hur detta påverkar dem och deras familjer. Det behövs också longitudinella studier för att få fördjupade kunskaper om hur orsakssambanden mellan hivrelaterat stigma och hälsorelaterad livskvalitet ser ut.

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