

# WHAT'S BEHIND SEXUAL RISK TAKING?

EXPLORING THE EXPERIENCES OF CHLAMYDIA-POSITIVE, HIV-POSITIVE,  
AND HIV-TESTED YOUNG WOMEN AND MEN IN SWEDEN

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Umeå 2006

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## WHAT'S BEHIND SEXUAL RISK TAKING?

Exploring the experiences of Chlamydia-positive, HIV-positive and HIV tested young women and men in Sweden.

### ABSTRACT

The overall aim was to explore the experiences of sexual risk taking among Chlamydia Trachomatis-positive (CT+), HIV-positive (HIV+), and HIV tested young women and men. The specific aims were to explore, from a gender perspective, the events, the norms, considerations and emotions involved in sexual risk taking in CT+, explore the perception of sexual risk taking in HIV+ youth, and their understanding of why they caught HIV and look at how the Law of Communicable Diseases Act influenced their sexuality. Moreover, to investigate why young adults test for HIV, how they construct the HIV risk, and what implications testing has for them. In total, 42 informants between 17-24 years of age were recruited from a youth clinic in Umeå and from three infection clinics for HIV patients in Sweden. In-depth interviews and focus group interviews were tape-recorded, transcribed verbatim, and analyzed using a grounded theory approach. In two of the studies, follow-up interviews were done.

The findings revealed that sexual risk taking is influenced by the drive to go steady, where lust and trust guided whether sex would take place. For one-night stands, women were expected to be less forward than men. We found an uneven responsibility concerning condom use; men expected women to be "condom promoters." When contracting CT, women experienced guilt, whereas men felt content through knowing "the source of contamination." Among the HIV+ youth, socio-cultural factors—such as lack of adult supervision, naiveté, love, alcohol, drugs, the macho ideal, and cultures of silence—blinded the informants to the risks and made them vulnerable. By grouping narratives according to degree of consensus in sexual encounters, sexual risks seemed to be connected to gendered power relations where the informants had varied agency. The Law of Communicable Diseases Act implied both support and burden for these HIV+ youth. A lot of responsibility was put on them and to be able to handle the information duty they tried to switch off lust, switch off the disease, or balance lust and obedience. Among the HIV tested youth, HIV was seen as a distant threat. Many had event-driven reasons for testing for HIV, such as having multiple partners. Risk zones (e.g., bars) were perceived to be a milieu that often was expected to include one-night stands. Responsibility for testing was a gendered issue: "natural" for women although an escape from responsibility for men. Receiving a "green card" confirmed healthiness and provided relief and made the informants feel "clean." They could restart with new ambitions, including reconsidering risk.

The findings can be used in public health and in health care sectors that work with young people. We present suggestions on how to decrease the spread of STIs: to implement how men could play an equal part in sexual and reproductive health; to promote general CT screening for men; to encourage liberal HIV testing among both young women and men; to promote safer sex behavior by uninfected youth, especially focusing on men; to consider the role of gender and social background in the context of risky behaviors; to provide positive rewards for HIV disclosure; to diminish the risk for HIV transmission.

Key words: youth, sexual risk taking, qualitative methods, risk, gender, agency, Chlamydia trachomatis, HIV-positive, HIV test



# SAMMANFATTNING PÅ SVENSKA

Det övergripande syftet med detta forskningsprojekt var att undersöka erfarenheter av sexuellt risktagande bland tre grupper av unga kvinnor och män; Chlamydia Trachomatis-positiva (CT+), HIV-positiva (HIV+) och HIV-testade unga. De specifika syftena för de fyra delarbetena var att:

- genom att använda ett genusperspektiv undersöka normer, händelser, överväganden och känslor som var inblandade i sexuellt risktagande bland CT+ unga kvinnor och män (artikel I)
- undersöka föreställningar om sexuellt risktagande bland HIV+ unga kvinnor och män samt undersöka hur dessa unga personer själva tror att de har blivit smittade (artikel II)
- undersöka hur den svenska smittskyddslagen påverkar de HIV+ unga kvinnorna och männen, med särskilt fokus på deras sexualitet (artikel III-manus)
- undersöka varför unga vuxna testar sig för HIV, hur de konstruerar risken för att få HIV, samt vilka innebörder HIV testning får för dessa unga kvinnor och män (artikel IV)

Sammanlagt 42 unga informanter mellan 17-24 år deltog i projektet. De unga kvinnorna och männen som fått diagnosen Chlamydia, samt de unga som HIV testat sig och fått veta att de var HIV negativa rekryterades från Umeå ungdomsmottagning. De HIV+ unga kvinnorna och männen rekryterades från tre HIV-mottagningar för HIV positiva patienter i Sverige; Huddinge, Karolinska och Umeå. I de två delprojekten där CT+ och HIV+ medverkade gjordes individuella intervjuer och i HIV test projektet gjordes fokusgruppsintervjuer. Intervjuerna spelades in på band och skrevs ut ordagrant och analyserades med kvalitativ metod, inspirerad av grounded theory. I två av delprojekten gjordes uppföljande intervjuer.

Resultaten visade att bakom sexuellt risktagande fanns bland många av de unga en drivkraft till att få ett förhållande. Lust och tillit styrde om det skulle bli sex. När det gällde sex första kvällen, så förväntades de unga kvinnorna att vara mindre försigtvamma i jämförelse med de unga männen. Vi fann en ojämn ansvarsfördelning när det gällde kondomer, där de unga männen förväntade sig att kvinnorna skulle vara "kondombefrämjande". Genom att drabbas av chlamydia, så kände kvinnorna skuld och kände sig rädda för att ha smittat andra, medan männen istället kände sig nöjda med att få snabb behandling och att de trodde sig veta vem "smittkällan" var.

Bland de HIV positiva unga kvinnorna och männen beskrevs sociala och-kulturella faktorer som; bristande stöd och uppsikt från föräldrar, naivitet, kärlek, alkohol,

droger, macho ideal och tysta kulturer, och dessa faktorer bidrog till att förblinda de unga för risker och gjorde dem sårbara. Genom att sortera deras berättelser utifrån graden av samtycke vid sexuella möten, så visade det sig att deras sexuella risktagande skedde i ett sammanhang av könade maktrelationer där informanterna hade varierad förmåga att handla (agenskap). Kategorin från frivilligt till ofrivilligt samlag visar hur olika informanterna agerar i specifika sexuella situationer.

När smittskyddslagen diskuterades med de HIV+ informanterna framkom det att lagen innebar både stöd och belastning, men med betoning på belastning. Ett tungt ansvar vilade på de unga med HIV och för att kunna hantera informationsplikten i smittskyddslagen användes olika strategier. Några informanter ”stängde av lusten”, medan andra ”stängde av sjukdomen” och ytterligare några balanserade mellan lust och lydnad.

De HIV-testade unga kvinnorna och männen såg HIV som ett avlägset hot, långt borta och oroade sig därmed inte för att drabbas av HIV. Många av dessa unga hade personliga och rimliga skäl för att HIV-testa sig som exempelvis; många partners. Andra skäl var att man önskade vara ”ren” när man startade en ny relation, otrohet, sex utomlands, oskyddat sex, testat droger eller hypokondri. Riskzoner som exempelvis barer och diskotek beskrevs som miljöer som underlättade sexuella kontakter och ofta förväntades avslutas med tillfälliga sexuella kontakter. Ansvar för testning beskrevs som ett könat tema, ”naturligt” för kvinnor, medan män istället gärna flydde från sitt ansvar och kände ett motstånd mot att testa sig. Genom att få ett ”grönt kort”, det vill säga; ett negativt HIV-test besked, så fick de unga en bekräftelse på att de vara friska, och de kände sig lättade och ”rena”. Nu kunde de starta igen med nya ambitioner, som för de allra flesta innebar att de tänkte mer på att skydda sig, medan några också beskrev nya ”onda cirklar” av sexuellt risktagande. Deltagandet i fokusgruppsdiskussionen var för de allra flesta en ögonöppnare som bidrog till att de flesta började reflektera mer omkring sitt eget sexuella risktagande.

Resultaten från avhandlingen kan användas i folkhälsoarbete och inom förebyggande hälsoarbete som rör de unga. Här följer några förslag som kan leda till minskad spridning av sexuellt överförbara infektioner; genomföra hur män och pojkar kan bidra till jämställdhet när det gäller sexuell och reproduktiv hälsa, bidra till ökad klamydia testning eller ”screening” av pojkar och män.

Frikostig HIV testning av både unga kvinnor och män

Bidra till ”säkrare sex” beteende från friska unga kvinnor och män, och med särskilt fokus på män

Överväga den roll som genus och social bakgrund har i sammanhanget riskbeteenden. Ge mycket positivt beröm till de HIV+ som ”öppnar upp” och berättar att de är HIV+. Detta kan på sikt bidra till minskad risk för spridning av HIV bland de unga.

## ORIGINAL PAPERS

The thesis is based on the following papers:

I. Christianson M, Johansson E, Emmelin M., Westman G. "One-night stands"- risky trips between lust and trust: qualitative interviews with Chlamydia trachomatis infected youth in north Sweden. *Scandinavian Journal of Public Health* 2003; 31: 44-50.

II. Christianson M, Lalos A, Westman G, Johansson EE. "Eyes Wide Shut"- Sexuality and risk in HIV-positive youth in Sweden: A qualitative study. *Scandinavian Journal of Public Health* 2006; 1-7.

III. Christianson M, Lalos A, Johansson EE. "You stand there with all the responsibility"-Impact of the Law of Communicable Diseases Act on sexual behaviour among HIV-positive youth in Sweden. Manuscript 2006.

IV. Christianson M, Lalos A, Johansson EE. Concepts of risk among young Swedes tested negative for HIV in primary care. *Scandinavian Journal of Primary Health Care* 2006; 1-6.

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# Contents

- PRELUDE 3
- INTRODUCTION 5
- THE CONSTRUCTION OF SEXUALITY 5
- SWEDISH RESEARCH ON YOUNG PEOPLE AND SEXUALITY 8
- SEXUAL RISK TAKING BEHAVIOUR AMONG YOUNG PEOPLE  
– A GLOBAL TROUBLE 10
- RISK 13
  - Risk as a cultural construction* 13
  - The cultural and symbolic perspectives of risk* 14
  - The role of risk in society* 15
  - Risk and trust* 15
- AGENCY 17
- WHAT IS GENDER? 18
  - Sexual behavior and doing gender* 18
  - A gender order* 20
- THE SWEDISH MODEL 22
  - The Law of Communicable Diseases Act* 22
  - Campaigns* 22
  - Chlamydia testing* 23
  - HIV testing* 23
  - Sex education* 24
  - Youth clinics* 24
- SEXUAL TRANSMITTED INFECTIONS 25
  - Chlamydia trachomatis* 25
  - HIV* 27
- MY PROJECT 29
- AIM 30
- METHODS 31
  - Qualitative research–A brief overview* 31
  - Grounded theory* 32
  - Focus group interviews–The methodology* 33
  - The informants* 34
  - Project I: Young people with Chlamydia* 34
  - Project II: Young people with HIV* 35
  - Project III: Young people who were tested for HIV but negative* 35
  - The recruitment* 36
  - The settings* 38
  - The individual interviews* 38
  - Focus group interviews* 41
  - Data analysis* 45
  - Analysis of the CT project* 45

<i>Analysis of the HIV+ project</i>	48
<i>Analysis of the HIV test project</i>	50
METHODOLOGICAL CONSIDERATIONS	52
<i>Limitations</i>	52
<i>Reflexivity</i>	55
<i>Ethical considerations</i>	56
MAIN FINDINGS, DISCUSSION, AND COMMENTS	60
<i>Paper I:</i>	
<i>Findings</i>	60
<i>Discussion</i>	61
<i>Comments</i>	62
<i>Paper II:</i>	
<i>Findings</i>	64
<i>Discussion</i>	65
<i>Comments</i>	66
<i>Paper III:</i>	
<i>Findings</i>	68
<i>Discussion</i>	70
<i>Comments</i>	72
<i>Paper IV:</i>	
<i>Findings</i>	74
<i>Discussions</i>	75
<i>Comments</i>	76
THE MAIN DISCUSSION	80
<i>The day-to-day practices concerning risk</i>	80
<i>Risk and the never ending Otherness</i>	81
<i>Risk and agency</i>	83
<i>Sexual risk taking and doing gender</i>	85
CONCLUSION	88
IMPLICATIONS FOR PRACTICE	89
RESEARCH IN THE FUTURE	92
ACKNOWLEDGEMENT	93
REFERENCES	96

## WHAT'S BEHIND SEXUAL RISK TAKING?

### Exploring the experiences of Chlamydia-positive, HIV-positive, and HIV-tested young women and men in Sweden

## PRELUDE

During the mid-1990s, the County Council of Västerbotten in Sweden decided to encourage health care staff with an average-long education—such as, nurses and midwives—to initiate research projects by supporting them with funding. I applied and received research money from the council. When the first project started, I worked at a youth clinic and I still work there one day per week. For me, the work at the clinic together with research is a perfect match of theory and practice that produces exciting opportunities. For thirteen years, I have been working as a midwife at the clinic and met thousands of young people who wanted to be tested for Chlamydia (CT), HIV, and sometimes gonorrhoea, herpes, and hepatitis. Many patients were provided with contraceptives, and love, sexuality, drugs, living conditions, education, and family matters were often discussed with them. When my first project about CT started, the numbers of CT cases had been rather low. After a decrease in the trend of CT in the mid-1990s, the trend changed. Every year since 1997 there has been an increase of CT in Sweden: the major increases are seen among young people between 15 and 24 years of age ([www.smittskyddsinstitutet.se](http://www.smittskyddsinstitutet.se)). This increase may mean that young people's sexual behavior might be changing. That is, compared to the mid-1990s, young people may be having more unprotected sex with casual partners and more partners.

Many of the young people I meet at the youth clinic are surprisingly open about their sexual experiences, raising my curiosity about why people put themselves at risk. Did they think about the risk of catching CT or HIV? If they thought about the risk, how did they construct the risks? If they did not think about it, why was it so? Could the risks be prevented? I was eager to explore how these young people viewed their situation. Because many of the previous quantitative studies could not explain what was behind sexual risk taking, I decided to use qualitative methods to examine this phenomenon. The project initially focused on young persons with CT, but expanded to include young HIV+ and young women and men tested negative for HIV.

A lot of water has run in the Umeå River since the first project started. Everyday this autumn while sitting in front of the computer I always stopped working and dreamingly

looked on this excellent view outside as I ruminated on this project. Those really bad days when no clever thoughts passed my mind I thought that I would go crazy just sitting, while those creative days made my research feel rather joyful. Now, it is not the same river as it was when the research process first took place. (According to the Greek philosopher Hericlitus; “can you cross the same river more than once?”). I have been reading a lot of research articles and I realize how little I know, the more I learn, compared with the days (twenty years ago) when I graduated as a midwife and thought that I knew everything worth knowing. This risky project has been fun and worthwhile, but sometimes also painstaking and tiresome. Most of all I enjoyed meeting the informants and was amused when it just felt good to write.

Umeå, December 2006

# INTRODUCTION

Many young people are sexual risk takers, but perhaps without knowing it. This thesis seeks to grasp a “risk in context” approach that explores the multiple concerns young people have to take into account in their everyday lives. The approach used individual in-depth interviews and focus group discussions. The thesis starts with historical points concerning the construction of sexuality, followed by broad aspects of young peoples’ sexuality in Sweden, international research about sexual risk taking, theoretical concepts about risk, agency and gender, and thereafter a presentation of my own research with its strengths and limitations, and ending with theoretical comments.

## THE CONSTRUCTION OF SEXUALITY

This project is situated in a certain time when the HIV pandemic is threatening the health of young people globally, while at the same time the norms and culture in Sweden encourage young people to have sex as long as they take responsibility for their actions. Youth clinics aim to give a balanced and positive view of sexuality. It is often taken for granted that the Swedish society mostly has a liberal and supportive approach and attitude towards teenagers and young peoples’ sexual relations and sexual health issues (Edgardh 2002a). Equality between the sexes is an established goal even if the society has not yet fully reached this goal. Family values, traditions, religion, economic standards, and environmental milieu influence young people’s sexual decision making. This will influence how young women and men act.

Sexual behavior and practice and morality and ideology are always in a state of change (Caplan 1987). This very brief odyssey in the history of sexuality points to the constant changes concerning sexual behavior over time and that sexuality cannot be understood in purely biological terms. Instead, sexuality is more a social construct. The first use of the term “sexuality” appeared in the Oxford English dictionary in 1800. The concept came into existence with modern society and became a product of the development of sexology (Bergenheim and Lennerhed 1997). Before this, there was nothing that was labeled sexuality even if people had a sexual life. According to Bergenheim and Lennerhed, sexuality cannot be taken for granted: it is a product of negotiation, struggle, and human activity. Sexuality can only be understood in a historical context, shaped in relation with other individuals, culture, and society.

In ancient history, the control of the desire made virtue a necessity (Johannisson 1994). The dualism of marriage and reproduction was important to ensure the survival of the species, and sexual activity was aimed at procreation. Men and boys in ancient Greece who were devoted to male sexuality, they also expected to receive spiritual interchange from each other. This relation, however, was based on domination-subordination, where the older man had all power (Rydbeck 1997). A grown up man in Athens could only have sex with social or political inferiors; however, sobriety and self-control dominated the sexual mores of the time. For example, to lose control of the body and soul or to lose control over a woman was degrading. Christianity, developed in the late ancient intellectual milieu, attempted to reconcile desire and reproduction. This conflict developed the norm for reproductive sexuality. The growth of the bourgeoisie shaped a culture that denied body sensations, valuing spiritual and intellectual resources over sexual desire. The Victorians, at least publicly, were extremely hostile to expressions of sexuality. During this time (the 1800s), the market for prostitution and pornography exploded as well as STIs. One interpretation might be that the forbidden sexuality became a market for the well off (men). While homosexuality (among men) or sex between men with different social status and age was accepted in the ancient Greece, Christianity rejected all expressions of sexuality that did not aim at reproduction. Deviant sexuality was born. What the church, the law, or the science viewed as sinful in the 1700s became a crime during the 1800s, and “immoral” sexual practices were classified as abnormal. For example, masturbation and homosexuality were seen as unnatural because this behavior was not linked to reproduction. In medicine, behavior that was not linked to reproduction was diagnosed as perversions and “pathologies” that were harmful for people’s health. The sexually “perverted” became a concern for the doctor, not for the priest or the judge. By the early twentieth century, sexual behavior was a field in which anthropologists initiated research (Crawford and Unger 2000). For example, Margaret Mead studied people’s sexuality in Samoa, a cultural context that differed from her own. Her work created an understanding that there is cross-cultural variability in sexual norms and practices.

During the 1950s and soon after, researchers in the US, such as Kinsey and Masters and Johnson, studied sexual behavior among women and men. Most of their participants were educated white people. The researchers did not consider the limitations of their sample. They thought that the basics of human sexuality were similar for all people. They believed that sexuality was biologically determined and universal (Bergenheim and Lennerhed 1997). This essentialist approach does still exist in the western societies. Although the idea that sexual activity is “natural” and driven by instinct is present, history suggests that another approach is needed. There is no single way of being sexual that is “natural”. In *The Will to Knowledge*,

first published in 1976, Foucault concluded that “sexuality must not be described as a stubborn drive” (Foucault 1998). He suggested that it could be seen as a dense transfer point for power relations: between men and women, young people and old people, parents and their children, teachers and students, priests and laity and administration and population. Sexual norms and values and sexual behavior change over time. Every society has its own sexual culture. In *Transformation of Intimacy*, Anthony Giddens described the changes concerning sexuality during the last hundred years (Giddens 1992). He has developed the concept “plastic sexuality” to describe sexuality based on pleasure. Giddens discusses the pure relationship, a relation between two partners that is not based on sexual purity but refers to a situation where social relations are built for its own sake, where pleasure is a mutual exchange. Love that is tied up with sexuality and marriage, the so-called romantic relation, is mostly a relation that is based on a gendered order that is strengthened by established differences between masculinity and femininity, man and woman, and dominance and submission. Romantic love stands in contrast to what Giddens describe as the confluent love. Confluent love provokes the “for-ever”, the “one-and-only” qualities in that this love does not necessarily have to be monogamous or have a specific connection to heterosexuality but can also be practiced in same sex relations. This type of relation, however, can also be structured around difference. Sexuality can be expressed in many ways among men, women, and men and women. People have sex for various reasons and in different ways in different contexts and this must be taken into account. This brings us back to a contemporary Swedish context concerning sexuality among teenagers and youth in Sweden.

# SWEDISH RESEARCH ON YOUNG PEOPLE AND SEXUALITY

A collection of current research on young people, sexuality, trends, and tendencies within the field are summarized in a review published by Forsberg on behalf of the National Institute of Public Health (Forsberg 2006). This review reports that most students in senior high school have been in love and around three quarters have had stable relations. One quarter of teenagers had their sexual coital debut at the age of fifteen, while two quarters debuted at the age of eighteen. This trend is stable from the sixties, but these numbers are average and by breaking down the numbers there are factors that influence sexual behavior like gender, ethnicity, and class. Girls with Swedish background are found to have sexual intercourse slightly earlier compared with Swedish boys, while girls with a foreign background debut much later and boys with a foreign background debut earlier or at the same time as Swedish boys. High school students attending vocational programs have an earlier onset of sexual intercourse compared with students in the theoretical programs (Hägström-Nordin et al. 2002).

Most adolescents seem to be rather content with their sexual experiences. Both sexes describe positive emotional qualities of their sexual experiences like intimacy and excitement (Edgardh 2002a). This may mirror the fact that young people today have more lifetime sexual partners than young people had in the sixties. A study from 1967 showed that women had 1.4 lifetime partners, and men had 4.7 partners (Forsberg 2006). In the latest population-based study on sexuality in Sweden from 1997, it was found that young people between 21-25 years of age had a median of 5.4 lifetime sexual partners (Lewin 1997). Today many young people have a laissez-fair attitude towards sex and a recent published study show that it is common to have three or more sexual partners during one year (Herlitz and Ramstedt 2005). Increasing numbers of CT and increased abortions among teenagers indicate that there might be a change in young people's sexual behavior towards more risky sexual behavior (Edgardh 2002a). There is a tendency that our intimate relationships are going through a transformation: a love ideology where there is a clear rise in the number of lifetime partners, increased casual sex events, openness towards group sex, and "fuck-buddy" relationships, and sexual intercourse outside stable relations. The traditional heterosexual "script" that exists in the social world of many teenagers today implies that "sex is permitted when you are in love" or when you feel "mature enough", but there is also a shift towards sex "just for fun" (Edgardh 2002a). There is also a more open attitude towards same-sex relations, and more people experiment with same-sex relationships today compared with



15 years ago, and more people “come out” with their homosexual or bisexual orientation. The Internet has become a powerful arena where communication about sexuality as well as easy access to casual sex with non-steady or anonymous partners can be facilitated. The globalization, migration, and internationalization are shaping new domains for intimate relations among young people.

# SEXUAL RISK TAKING BEHAVIOUR AMONG YOUNG PEOPLE – A GLOBAL TROUBLE

Sexual health and sexual risk are not only a concern in Sweden; the problem is global (Robinson and Rogstad 2002). Many young people worldwide have unprotected sexual intercourse. For some of them, this behavior does not cause any trouble at all, whereas others find trouble. A troublesome behavior can cause severe sexual and reproductive health problems, such as unwanted pregnancies, abortions, and STIs (Sexual transmitted infections) that in turn can cause devastating effects on future fertility (Blum and Nelson-Mmari 2004). This thesis will focus on HIV and CT. These STIs deserve special attention because of their high prevalence, and they often go undetected and untreated. The actual prevalence can be even higher due to underreporting of cases. Of the estimated 333 million new STIs that arise in the world yearly, young people under the age of 25 contract 111 million STIs. Half of all HIV infections worldwide are diagnosed in people under the age of 25 ([www.undp.org](http://www.undp.org)). Even if HIV/AIDS is the second leading killer of young people globally, the pandemic seems to be rather invisible both for young people and for society. Often young people carry HIV for years without realizing that they are infected. This factor can fuel the epidemic that is one of the greatest threats of the health of adolescents and youth globally.

Health and wellbeing among young people are complex and many factors such as age, gender, ethnicity, family structure, relations to family and friends, knowledge, values, education influence sexual behavior (Spear and Kulbok 2001). Research about sexual risk taking behavior indicates that several factors can be related to risky sexual practice. For example, smoking, alcohol use and misuse, multiple sexual partners, and early coital debut are associated with a negative sexual risk taking behavior (Fergusson and Lynskey 1996, Ellström- Andersson et al. 1997, Jonsson 1998, Novak and Karlsson 2005). Early puberty and onset of sexual intercourse before the age of 15 and lower level of theoretical education correlate to risky sexual practice among 17 year old boys in Sweden (Edgardh 2002b). In addition, 17 year old girls had a similar behavioral pattern: for example, sexual intercourse before the age of 15, early menarche, and high perceived social age increased the risk of these “early starters” for contracting STIs and becoming pregnant (Edgardh 2000). These conclusions agree with many sex surveys. Instead of focusing mainly on factors such as smoking, alcohol, or “early starters”, the reasons for these factors should be examined. Some psychologists believe personality character explains risky behavior. A quantitative review on sexual risk taking and personality revealed that sensation seekers and impulsive behavior were connected to risky sexuality (Hoyle

et al. 2000). For instance, high-risk sensation seekers might view high-risk activities as less risky compared with low sensation seekers. Certain situational factors, e.g., casual sex with unknown partners can increase the likelihood of contracting HIV or other STIs. Some of these high-risk encounters often worsen by increased consumption of alcohol or other drugs (Hoyle et al. 2000). Sex with a stranger also poses a risk for inter-personal violence. Many researchers believe that peers can influence sexual risk taking. A young person's sexual norms and behaviors can be predicted by the sexual behavior of one's peers (Aalsma et al. 2006). For example, attitudes and subjective norms and values of one's peers can affect the use or non-use of condoms. A lack of condom use is seen among those who have peers that do not use condoms (Sheeran 1999a), and those who have negative attitudes towards condoms will not use them. A recent study on condom use reveals that one of the strongest factors associated with non-condom use is the use of oral contraceptives (OC) (Novak and Karlsson 2005). Negative influences from "deviant" peers, a lack of control from parents, or a more coercive control from parents are important social and psychological phenomena involved in sexual risk taking (Metzler et al. 1994).

Knowledge about a partner's sexual history, e.g., number of sexual partners and venereal disease can motivate people to protect themselves to a higher extent (Poppen and Reisen 1997, Sheeran 1999b); however, people may not use condoms if they perceive that their casual partners are safe (Hoffman and Cohen 1999). In a focus group study from California, the participants noted that they caught STIs because they relied on visual and verbal cues to judge whether their partners were disease-free. Another study from US suggests that strong feelings of affection for a partner also might mean people will underestimate the risk (Reisen and Poppen 1999). That is, love and attraction can place one at risk. There are several studies that support a common perception among young people that there is no risk or low risk to have unprotected sex with someone they know (Williams et al. 1992, Lear 1995, Lear 1996, Hammer et al. 1996, Lock et al. 1998). Some studies relate this lack of risk evaluation depends on gender. For example, few young women expect their male partner to have a concurrent sexual relationship, and there are few young people who dare to ask such a sensitive question, and if they ask, there is a risk of getting false information from their partners (Lenoir et al. 2006). There is a risk that young people in more long-term sexual relationships do not use condoms as a result of building trust. In a focus group discussion among students (grade 9 to 12), some of the groups voiced the opinion that it could be less risky to contract STIs in one-night stands because "people have sex only once", while stable relations do not automatically protect from STIs as "people do not always tell the truth" (Hoppe et al. 2004).

A devastating socio-economic and neglectful psychosocial milieu can harm the development of responsible behavior. This is recognized in a “vulnerable ethnography” study among inner-city Detroit residences where the lives of six Afro-American HIV+ young people seem to have deliberately sought HIV exposure (Tourigny 1998). Teenagers may also take risks because they underestimate the probability of things going wrong. Research from California challenges this common perception about risk and vulnerability (Millstein and Halpern-Felsher 2002). It is often discussed that teenagers underestimate risks and view themselves as invulnerable to harm due to their young age, but the young adults in this study were more eager to take risks compared with teenagers because they had experienced that most of their risky behaviors did not lead to negative outcomes.

# RISK

There is a field of theoretical perspectives that highlights the social, cultural, or political nature of risk. In this thesis, especially three of the theorists' viewpoints, Lupton (1999a, 1999b), Douglas (1992), and Giddens (1990) were helpful for understanding how young people perceived risk.

There are several ways to define risk. In psychology, the term risk is often defined and regarded both as part of abnormal as well as normal development, carrying negative and positive consequences (Sharland 2006). Constructive risk taking is seen as essential equipment for young people to go on with their lives (Wyatt and Peterson 2005). Positive risk taking will strengthen health and will result in discovery and establishment of one's identity as well as growth and maturation. The risk becomes negative when it endangers young people's health. Young people need to avoid certain practices, e.g., drinking too much to reduce the risk of accidents (Fischhoff et al 2000). Young people's risk taking needs to be addressed by policymakers, doctors, social workers, sociologists, and the general public. These institutions are concerned with identifying and managing young people who are both troublesome and risky (Sharland 2006). Risk is an important part of growing up and young people must learn how to avoid outcomes they do not like, yet young people need to properly evaluate risk taking behavior: "making decisions effectively requires accurate assessment of the probabilities of uncertain events" (Fischhoff et al 2000). Hence young people are faced with greater ranges of uncertainties and choices than they needed in the 1970s (Lupton 1999a:104-122). These choices are not for everyone in the society; it may be a matter of gender, ethnicity, class, or age that influences different opportunities for young people that will mediate the capacities of individuals to act as reflexive subjects in relation to risk.

## **Risk as a cultural construction**

Lupton (Lupton 1999a:1-16) examines how the concepts of risk operates in western societies at the end of the twentieth century and describes the implications for how we think about ourselves, others, organizations, institutions, and governments. Lupton identifies some major categories of risk: environmental, life-style, medical, economical, criminal, and interpersonal risks. Risk can be understood as a human responsibility both in its production and management, rather than the outcome of fate or destiny, as was the case in pre-modern times (Lupton 1999b:1-11). The term risk did not exist in the pre-modern era; fortune was the term used. The word risk is supposed to have stemmed from a Spanish nautical word, meaning running

into danger or to go against a rock. The term danger that is often used today at an earlier time was called misfortune.

Today, risk means choice, calculation, and responsibility (Lupton 1999a:107). Many people might accept that risk awareness is important to avoid certain risks and thereby aiming to prevent the risks by taking accountability of their own actions. People might take expert knowledge into account, but this is ambiguous as people also judge their risk by their own everyday experiences. These responses to risk are cultural because people construct their own risks with or without a professional's advice. There are risk positions that emerge from people's own experiences and the social milieu and the communicative networks (for example, mass media). These positions are constantly shifting and changing and depend on influence from mass media, experts, and lived experiences (Lupton 1999a:108). For instance, people might feel that the perception of risk is too uncertain, and this perception makes them move between different risk positions at different times, sometimes to control risk and other times a fatalistic approach towards risk (Lupton 1999a:120) by simply accepting a negative outcome. Risk is linked to subjective judgments about risks although the autonomous and reflexive citizen that is hoped for in the west sometimes responds to risk in a less reflexive way.

Within medicine and epidemiology, risk is often viewed as an objective phenomenon (Lupton 1999b:2) to be identified and mapped according to causal factors and to build models of risk and propose ways to limit the risks. A rational (technical/scientific) or realistic view of risk makes it objective and measurable independent of social and cultural processes, whereas the weak constructionist perspective deals with risk as an objective threat or danger that interferes with social and cultural processes (Lupton 1999a:35). A third epistemological approach to risk is the strong constructionist perspective: nothing is a risk in itself, instead risk it is a way of seeing or understanding risk. One could say a discourse on risk that is time dependant. What are considered to be a risk is conceptualized differently in different historical and cultural contexts (Lupton 1999b:5). According to Lupton, risk pervades all the human existence: it is a central aspect of human subjectivity; it can be managed through human interventions; and it is associated with choice, responsibility, and blame.

## **The cultural and symbolic perspectives of risk**

Douglas, in her earlier work on purity and contamination, sees risk as a locus of blame where the "risky" groups or institutions are singled out as the dangerous ones

(Lupton 1999b:3). In western contemporary societies, the concept of risk can be used to maintain cultural boundaries between self and other where a risky other may serve as a threat to the integrity of one's own physical body or to the symbolic body of the community or society to which one belongs. For example, infectious diseases qualify as real dangers and infected people become dangerous to others (Douglas 1992:83-101). Infectious diseases can eradicate whole populations by crippling, mutilating, or killing. The infected person may not necessarily show any signs of malady, unless he/she wears a symbol that shows what he/she is suffering from, or directed to stay in restricted areas, or is forced to declare the condition in public. The contact with the infected can be unperceived and the carrier can go unsuspected. If the carrier is viewed as someone who can cause significant harm to others and if the infection is linked with immoral behavior, there is a great risk of social exclusion. To be viewed as marginal and thereby excluded, there must be consensus around the issue of rejection in that supportive accusation about that the marginal person causes damage and becomes a public trouble.

## **The role of risk in society**

The risks in late modernity are thought to have increased compared with the ancient times in history as they now become globalized (Giddens 1990). This makes risk more difficult to calculate and to avoid or manage. Central to Giddens writings on risk is the lack of control in late modernity because governments, industry, and science are the main creators of risk. His metaphor about living in the modern world is more like "riding a juggernaut" than being in a carefully controlled and well-driven car (Giddens 1990:53). The expression "riding the juggernaut" reflects an attempt to control a world that is difficult to predict and control. To harness the juggernaut, we can minimize the dangers and maximize the opportunities. People conceptualize and deal with dangers in a more reflexive way today and tend to become choosing agents instead of weak-minded victims of their own fate. The theorist argues that all human action has a reflexive approach. This means that people respond to conditions that arouse fear or anxiety because people today have developed a reflexive approach and a heightened sensitivity to risk.

## **Risk and trust**

The risk and uncertainties are a part of daily life, and people mostly avoid thinking about risk because it would psychologically disturb or even paralyze one's ordinary day-to-day life (Giddens 1990). Risk is best understood in relation to trust. Gid-

dens addresses the polarities of risk and trust. A prime condition for trust is a lack of full information. All trust is blind trust and people have to trust what Giddens calls the “moral uprightness” or the good intentions of others. Being in love, for instance, to put confidence in a partner or a relationship makes one “a moral hostage to fortune” (Giddens 1990:33). Trust can be defined as confidence in the reliability of a person or system regarding a given set of outcomes where the confidence expresses the faith in the love of another human being or the faith in an abstract system (like technical knowledge). In conceptualizing trust, Giddens discusses chance versus risk: where there is risk, there is chance. There are situations where people take a “calculated” risk, aware of the hazards; however, there are also risky situations where individuals are unaware of the danger. Risk and trust are intertwined with each other where trust minimizes the dangers. Risk is an individual action as well as part of an “environment of risk”, e.g., nuclear war, ecological disaster, or HIV/AIDS, CT that collectively affects large populations.



## AGENCY

The theorem agency was rather unknown to me when my research started. Here follows a short presentation about the concept that will be further elaborated on in the method section and in the main discussion.

Giddens' theoretical point of departure is that agency is located in the actions of human actors in their day-to-day life (1984), a routine where people learn knowledge-ability. This means that human beings structure their social practices and learn by repeating cognitive skills (Giddens 1984:2-3). Human beings are purposive agents in that they have their reasons for their specific acts and are able to discuss, explain, or elaborate on these reasons and even lie about them. Agency refers to people's capacity to act and to monitor other people's actions in a way that is satisfactory (at least for the person with the agency). From Giddens' perspective, agency does not refer to the intentions people have in doing things, but their capability of doing things in the first place. To possess human agency, implying power, there must be an intention to act; otherwise, there is no agency. An individual has the capacity to act or intervene. The agent is the doer and agency refers to doing. For example, a specific event that happens could at any time or anywhere in this process of flow have taken another direction *if* the agent had acted differently. According to Giddens, action is a continuous process where the actor maintains a reflexive monitoring: "Whatever happened would not have happened if the individual had not intervened" (Giddens 1984:9). However, actors can do things unintentionally. When an act is intentional, the agent knows or thinks that she/he knows what the outcome will be and act in such a way to get this quality. Because Giddens wants to separate what an agent does from what is intended or the intentional aspects of what is done, he concludes that the consequences of what actors do, intentionally or unintentionally, are events that would not have happened if the actor had behaved differently, but the act was not in the scope for the actor to control as the power to control, limited by the context of action or interaction.

As mentioned before, the agent must possess some power to be able to "make a difference" or "acting otherwise". To act otherwise means to intervene or refrain from intervening where both decisions will influence a process or situation. Even if agents do not always have the same amount of power, he means that the one who is judged to be more subordinate can also influence the activities of the more superior. According to Giddens, there is always a choice.

## WHAT IS GENDER?

This question is often raised, and especially among people that are critical to gender theory. However, there are many and varied understandings and theories in the gender field, which makes the question very complex to answer briefly. Hirdman uses a pragmatic explanation about the word gender (Hirdman 2001). She wants us to understand and use gender, to be able to see what we did not see before. In this thesis, the sexual relations are in focus and Fenstermaker and West (2002), Connell (1995, 2002) and Connell and Messerschmidt (2005) have been valuable for me.

The concept of gender has for many years been used to a wide extent within social and humanistic sciences, while there seems to be a continuing resistance towards gender perspective within the field of medical science (Risberg et al. 2006). According to the authors of this recent published paper, some of the difficulties could stem from a misunderstanding of the term gender where gender is wrongly used as synonymous with biological sex. For instance, a common misunderstanding is that researchers sometimes replace sex with gender. The Oxford English Dictionary defines gender as “in mod. (especially feminist) use, an euphemism for the sex of human being, often intended to emphasize the social and cultural, as opposed to the biological, distinctions between the sexes” (Dowsett 2003). Hence, where there are human beings there is also biology involved, and in medicine it is impossible to omit the physical bodies human beings have (Hamberg 2003). To embrace that there is also biology involved does not collide with the concept gender if biology is looked upon as changeable and dependant on living conditions and culture. For example, research about sex differences cannot automatically be labelled gender research; however, if biology and biological differences between the sexes are placed in a social and cultural context, it can. Hence in biological and medical research, there is a risk that the division between sex and gender becomes a scientific trap (Hamberg 2005). When is sex the appropriate concept and when is gender? While discussing health behavior, human performances, and sexual relationships, the term gender fits better than the term sex. Today, there are several ways to look at gender and take into account other factors that intersect with gender, such as race/ethnicity, age/generation, social class, and sexual orientation (Dowsett 2003).

### **Sexual behavior and doing gender**

Doing gender and doing difference is a major contribution to the gender field (Fenstermaker and West 2002). Fenstermaker and West were among the earliest to develop feminist research in sociology. Their body of thinking was inspired by

Garfinkel's ethno-methodology, an approach that examines how people produce everyday events, occasions, settings, actions, or people. Fenstermaker and West focus on how people do and recognize gender in their day-to-day practices, exposing aspects of gender otherwise ignored. West and Zimmermann published in 1987 a first paper on doing gender where they argued and proposed that this doing is an achieved property of situated conduct, focusing on interaction and institutional arenas (West and Zimmerman 2002:4). The authors suggested that it is individuals who do gender, but the doing is situated in how individuals organize their many activities to express gender and is arranged to perceive others behavior in a similar light. Sex is a biological criterion for classifying people as female or male according to their genitalia at birth or chromosomal typing before birth. Sex category is established and sustained by the socially required identifications shown that tells which category one belongs to. However, these categories are provisional and vary independently and can place people in the sex category when the sex criterion is not there. Gender, on the other hand, is an activity of managing situated doings in light of normative ideas, attitudes, and activities that are right for one's sex category. To recognize how these elements operate and interact with one another is important for an understanding on how they function and interact with "being" a gendered person in society. The authors call the view that male and female are naturally and clearly defined categories of beings, predicted from their reproductive functions where differences between the two categories are seen as fundamental and stable as "naïve biological determinism". This is sort of "men are men" and "women are women" perception that is rooted in biology. Instead, the authors argue that gender is a product of social doings that is constituted through day-to-day interaction. The authors conclude that to "do" gender is not always to live up to normative perceptions of femininity or masculinity; it could be that to "do" gender is to engage in behavior at the risk of gender judgment. The authors note that it is probably unavoidable to "do" gender as long as a society is divided into essential differences between men and women and placed in an obligatory sexual category. What exactly does doing gender mean? According to West and Zimmerman, it is the creation of difference between the sexes, a difference that is not natural, essential, or biological, but a doing that strengthens the "essentialness" of gender. Sex category and gender are managed possessions of behavior that depend on the judgments and responses from others where gender is something that one does repeatedly in interaction with others. Doing gender is not only behavior between individuals, but also a product of cultural and institutional arrangements. If we fail to do gender correctly, we may be called to explain our motives or characters. Finally, the authors conclude that if we want women and men to be treated as equals, we must ask why there needs to be two sex categories at all. Re-conceptualizing gender as a vital dynamic of social orders gives a new perspective on the network of gender

relations, how gender is created, continued, how resistance might work, and how social change might occur. There are both choices and constraints that look into the cultural practices that help sustain the subordination of women or the oppression of homosexual people.

## **A gender order**

Unlike Connell (2002), it is common to define gender as the cultural difference of women and men based on the biological division between male and female. Connell wants us to move from difference to relations. According to Connell, gender relates to social relations within which we all act as individuals or as groups. In this gender order, we structure our social practices or day-to-day activities. This is a practice that refers to bodies and what the bodies do, but it has nothing to do with biology. In short, gender is socially constructed. This practice can entail desire and/or to have sex. This practice is gendered as it refers to masculinity or femininity, but these traits are arrangements of the social practice. Connell is elaborating on the gender order, a structure based on gender relations. Hence these gender relations do include both difference and dichotomies, but it also includes hierarchies of power among men. In the contemporary world, these massive hierarchies of masculinities are ordered in a hierarchical system (Connell 1995), a concept that Connell calls the hegemonic masculinities. These structures could be seen in US and the rest of the western world (and worldwide) where structures are organized in power relations where the main one is the domination of men and subordination of women (Hirdman 2001), the patriarchal gender order, as well as gender relations that intersect with class and race. According to Connell, there are dominant, subordinated, complicit, and marginalized masculinities that are linked to each other in an important chain. Few men practice the hegemonic masculinities, but the majority of men gain from supporting the hegemony the complicity. The overall oppression of women helps sustain a gender order where men generally earn higher salaries and thereby have greater power over decisions. The subordination of homosexual men by heterosexual men also could be seen as an oppression of femininity (for example, the gay man is a wimp). Although there are several masculinities, it is important to see how they relate to one another in the gender order. According to Connell, hegemonic masculinity is not a fixed and stable hierarchy; it can be challenged by groups or individuals. Responding to critiques of the hegemonic model, Connell and Messerschmidt argued that there is a need to reconsider hegemonic masculinity (2005). Basically, the critics attacked the notion of gender hierarchy. Oppression can create resistance and change. The protest of masculinity can both incorporate and oppress women at the same time. By solely focusing on masculinity women

could be excluded. Many women are mothers, girlfriends, sexual partners, wives, and grandmothers and they are central features in many processes that force boys and men to construct masculinities. This emphasis on femininity falls in line with or could even sustain patriarchy and is common in societies worldwide. The authors suggest that research on hegemonic masculinities pay attention to the practice of women and the past interaction between masculinities and femininities and incorporate a more holistic understanding of the hierarchy, admitting that there is action among subordinated groups and there is power among the dominating groups that recognize the gender dynamic and other social dynamics.

# THE SWEDISH MODEL

There are several ways in which Sweden tries to prevent and decrease the spread of STIs among the general population. County councils, communities, voluntary organizations, and the government are engaged in this work. Knowledge, information, and education are all important channels, but it is difficult to measure how effective this work is (Lalos 1997). For example, targeted information and campaigns towards university students might have a positive effect on their sexual behavior and safer sex practice (Tydén 1996), but sexuality is complex and therefore it may be difficult to influence sexual behavior.

## The Law of Communicable Diseases Act

In the Nordic countries (Sweden, Denmark, Norway, Finland, and Iceland), specific laws about sexual transmitted infections (STI) were introduced between the First and Second World Wars (Moi 2001). The Law of Communicable Diseases Act prescribes that Chlamydia (since 1988) and HIV/AIDS (since 1985) are among about 50 other infections notified in Sweden. To break the chain of transmission, free programs that treat STIs and trace and notify partners are covered by The Law of Communicable Diseases Act (Tydén and Ramstedt 2000). This law permits registration of infected people, compulsory partner notification and tracing, and for HIV+ people, once diagnosed with HIV, people are required by law to inform current and future sexual partners about their infection and adopt safe sex behaviors, such as obligatory condom use ([www.regeringen.se](http://www.regeringen.se), The Law of Communicable Diseases Act 2004:168). On July 1, 2004, a few minor changes in the law were made: physicians have the duty to warn or inform sexual partners of a patient infected with HIV if the patient fails to do so, and isolation should be considered only when other solutions are tried and found to be less successful ([www.regeringen.se](http://www.regeringen.se) Regeringens proposition 2003/4:30).

## Campaigns

During the late 1980s, a number of campaigns were undertaken to prevent the spread of HIV (Herlitz and Ramstedt 2005). Every household received written information on HIV and how it was transmitted. Today, there are no national campaigns, but efforts target certain risk groups such as adolescents, immigrants, and refugees from endemic countries, gay men, travelers, and HIV+ persons and their relatives. Recently, more focus has been put on campaigns, such as Chlamydia

Monday, that encourage Chlamydia test. Three years ago Chlamydia Monday started. Lafa (Landstinget förebygger AIDS) in Stockholm initiated the campaign that was spread to all county councils in Sweden. Every year, on a special Monday in September, people are offered a Chlamydia test. In September, there was a peak of new cases among the youth due to unprotected sex during the summer vacations. The campaign made young people aware that sex, love, and pleasure could also cause less pleasant memories in the form of a Chlamydia infection.

## **Chlamydia testing**

Today Chlamydia is the most common STI in Sweden and most cases are seen in people between 15-24 years of age. There is no mandatory screening of CT within the population, but all visitors at the youth clinics in Sweden can have a test done. Testing people over the Internet is a new approach (Novak and Karlsson 2005).

## **HIV testing**

In Sweden, voluntary, free, and anonymous HIV testing is available for everyone, and there are national screening programs for pregnant women and blood donors (Brännström et al. 2005). HIV testing for blood donors is mandatory, and there is systematic but voluntary testing for pregnant women, women having abortions, intravenous drug users, STI patients, immigrants, refugees, and deceased with autopsies.

During the beginning of 1990s, more than five and a half million HIV tests were done in Sweden, and became thereby the country in Western Europe where most HIV tests were done within a population. So many people were tested in Sweden that it was considered irrelevant to promote testing within the population (Danziger 1999). In a conference talk on public health in the late 1990s, it was said that around 170-190 000 HIV tests were done yearly in Sweden (Ramstedt 1999). Today, in Sweden, there are no national statistics on how many HIV tests are done. A recent article describes a new phenomenon, namely "late testers" (Brännström et al. 2005). These people are unaware of their infection until they fall ill and develop AIDS. People with foreign origin and Swedish-born heterosexual men that are infected abroad are more often found in these groups. Around 60 new people diagnosed with HIV have had an HIV test before they were diagnosed (Ramstedt 1999). Testing is claimed to be a primary prevention method for preventing people from contacting HIV. Testing and counselling procedures should contribute to risk reduction.

## **Sex education**

In Sweden, there is an openness and shared vision among many people towards sexuality. Social tolerance has been concerned with responsibility for the sexual health of young people. Since the 1950s in Sweden, sexual education in the schools is mandatory. Countries where sex education is accepted, in combination with family planning services have the lowest rate of pregnancies and abortion on demand (Ruusuvaara 1999). During recent decades, youth clinics have been established with the aim of giving young people a balanced and positive view of sexuality, including respect, responsibility for both young women and men, and gender equality, where especially women should understand their rights to determine what happens to their own bodies.

## **Youth clinics**

In 1970, the first youth clinic was established. During the 1980s, the youth clinics expanded. By 2006, there were around 230 clinics all over the country. The staff members have medical, social, and psychological competence ([www.fsum.org](http://www.fsum.org)). In 1988, the Swedish Society for Youth Clinics was founded and in 1992 the first policy program was published. Youth clinics aimed to prevent social and psychosocial problems, unwanted pregnancies, STIs, as well as the abuse of alcohol, tobacco, and other drugs among young women and men. Lifestyle questions are discussed to visualize attitudes, strengthen self-esteem, and influence behavior. Sexuality and sexual health and other sensitive topics are essential to discuss at the youth clinics, and sex education for students are offered.



# SEXUAL TRANSMITTED INFECTIONS

This thesis focuses on *Chlamydia trachomatis* and HIV/AIDS. These infections are briefly described below. Other STIs (such as gonorrhoea, syphilis, herpes, and hepatitis) are not the focus of this thesis.

## **Chlamydia trachomatis**

Globally, in 1999 about 92 million adults had CT ([www.who.org](http://www.who.org)). CT is the most common, curable sexually transmitted infection in the western world. The infection is often without symptoms, but it can lead to severe consequences (Duncan and Hart 1999a). Compared to HIV/AIDS, the infection might be viewed as harmless, but left untreated CT can lead to serious ill health problems such as salpingitis, epididymitis, tubal infertility, ectopic pregnancy, chronic pelvic pain, and arthritis (Tydén 1996, Chen et al. 2005). The bacteria can negatively influence the ejaculate, causing lower motility, lower volume, and concentration of sperm (Veznik et al. 2004).

In Sweden since 1997, CT cases have increased (Table 1). The main increase of cases is seen among people between 15-24 years of age ([www.smittskyddsinstitutet.se](http://www.smittskyddsinstitutet.se)). In 2005, 33 168 cases were reported. The yearly prevalence of CT is around 4-5%, and most persons are transmitted in Sweden. Those cases that were transmitted abroad, many of them reported that they got their infection in countries like Thailand, Spain, and Great Britain.

Half year <b>statistic on chlamydia</b>	Women	Men	Sex unknown	Total
1997:1	3869	2698	0	6567
1997:2	4350	2986	2	7338
1998:1	4291	3118	9	7418
1998:2	4632	3147	2	7781
1999:1	4326	3166	2	7494
1999:2	5356	3853	5	9214
2000:1	5034	3817	11	8862
2000:2	6013	4400	9	10 422
2001:1	5914	4576	2	10 492
2001:2	6739	5032	3	11 774
2002:1	6596	5025	5	11 626
2002:2	7454	5597	11	13 062
2003:1	6701	5099	5	11 805
2003:2	8602	6387	8	14 997
2004:1	8557	6542	16	15 115
2004:2	9654	7291	15	16 960
2005:1	8858	6840	18	15 716

**Table 1.** Chlamydia-notified patients from 1997-2005

# HIV

At the end of 2004, the number of adults and children living with HIV/AIDS was estimated by WHO/UNAIDS to have reached 39 million worldwide and over 25 million people have died since 1981. An estimated 10.3 million young people aged 15-24 live with HIV/AIDS, and half of all new infections (over 7000 daily) occur among young people (www.who.org 2006). In 1982, the first case of HIV was diagnosed in Sweden (Bredström 2006). A couple of years earlier, some physicians in New York and San Francisco had discovered a strange disease that hit young and rather healthy homosexual men. HIV (human immunodeficiency virus) is a retrovirus that invades the C4 cells in human bodies (Nettleton 1995). These cells are depleted, the virus becomes prevalent, and immunity reduced. For example, Kaposi's sarcoma and Pneumocystis carinii are diseases that are linked to AIDS (acquired immunodeficiency syndrome).

In Sweden, the spread of HIV has been low and constant over the years. The prevalence of HIV is very low in Sweden in comparison with most European countries (Blaxhult et al. 2004). In total, 7400 cases of HIV were notified from 1985 to November 2006 (www.smittskyddsinstutet.se). Around 4000 are living with HIV in Sweden. Compared with Chlamydia, there are very few young people with HIV. Figures from Sweden report less than 50 cases and up to 62 cases in the age category 15-24: 42 women and 20 men (www.regeringen.se SoU 2004, Tötterman and Rahman 2002). From 2001 to 2006, there was a small but steady increase of reported cases of HIV among young people between ages 15-29 (Table 2). It is, however, hard to find exact figures since there is no law demanding registration when HIV+ people move out of the country or die. Stockholm has the highest rate of positive youth.

Age group 15-29	2001	2002	2003	2004	2005	2006
Prior to arrival in Sweden	27	28	40	47	50	31
Resident of Sweden, infected in Sweden	7	5	4	6	10	12
Resident of Sweden, infected abroad	2	1	2		4	
Data not available	2			4	2	4
Total	38	34	46	57	66	47

**Table 2.** Reported HIV cases 1 six months of year 2001-2006 in the age group 15-29 divided by place of residence at time of infection.

The situation in Sweden mirrors the global epidemic because around two-thirds of HIV+ people are infected before coming to Sweden. There is no cure for HIV so far, but in the western world the introduction of HAART (Highly Active Antiretroviral Therapy) in 1996 has decreased the death of the disease by 80% (Brännström et al. 2005).

## MY PROJECT

It is now time to connect the introduction with my own research to answer this question: What's behind sexual risk taking? This thesis comprises three projects focusing on young women and men and their risky sexual behavior. The project is designed according to qualitative approaches with a limited amount of informants; 42 young women and men between 17-24 years of age who live in Sweden contribute with their own experiences. The first study consists of young women and men infected with CT (Paper I). The second study consists of young women and men transmitted with HIV (Paper II). This study also explores how the Law of Communicable Diseases Act influences young HIV+ women and men by focusing on sexual behavior (Paper III). The last study comprises of young women and men that are tested for HIV and found to be HIV negative (Paper IV).

## **AIM**

This project aims to gain an in-depth understanding of sexual risk taking by exploring different experiences of young women and men infected with CT and HIV and young women and men who were tested for HIV but found to be HIV negative.

Specifically, the aim was to explore, from a gender perspective, the course of events, the norms, considerations, and emotions involved in sexual risk taking in CT+ people. Furthermore, the aim was to explore the perception of sexual risk taking in HIV+ youth, and their understanding of why they caught HIV. The aim was also to look at how the Law of Communicable Diseases Act influences young HIV+ women and men in Sweden by focusing on sexual behavior. Finally, the aim was to investigate why young adults test for HIV and how they construct HIV risk and what the implications of testing have for them.

# METHODS

## Qualitative research—A brief overview

Because all three projects in this thesis are based on qualitative methods, I will start this section with some characteristics of the methodology from the standpoint of some knowledgeable researchers with experiences in the field of qualitative methodology (Glaser 1978a, Lincoln and Guba 1985, Strauss and Corbin 1990, Starrin et al. 1991, Morse 1992, Dahlgren et al. 2004). My own project will be presented with the pros and cons that are part of the methodology. Although the task to present the basis for qualitative research in as few words as possible is difficult, the method can be explained with terms, such as like understanding, inter-subjectivity, theory generation, soundness, discovery, variation, and, perhaps the most important one, curiosity (Starrin et al. 1991). Qualitative research is an approach where the researchers work with a smaller amount of informants (Dahlgren et al. 2004), compared to quantitative research where thousands of informants might take part. In this thesis, the young informants shared parts of their life stories with me and they contributed with their own experiences concerning sexuality and risk. Qualitative methods are based on findings not arrived from statistical procedures, but from people's stories, behaviors, and lives (Strauss and Corbin 1990). One could say that the informants contributed with different and similar accounts concerning sensitive and emotional issues. The method is suitable when little is known about an area or when new knowledge is asked for in an area where a lot already is known (or thought to be known) or when details about a phenomenon is requested. Looking at the amount of research that is already produced in the field of sexuality and risk, one can wonder what kind of new inquiries can possibly be made. At this stage of inquiry, it can be good to cheer up and remember that the world is changeable; therefore, not everything has been discovered yet. In contrast to the more positivistic research traditions, the naturalistic inquiry holds a position that there is not *one* reality that can be predicted or controlled, but the realities are multiple, constructed, and holistic (Lincoln and Guba 1985). Morse describes the features that distinguish qualitative from quantitative research—namely the emic, the holistic, and the inductive and interactive process of inquiry (Morse 1992). An emic perspective can best be understood by words such as eliciting meaning, experience, or perception from the participants' point of view. This means that it is the informant's experiences, perceptions, values, or beliefs that should be elicited. However, because research is value-bound, researchers need to identify their pre-understanding, expectations, and biases (Dahlgren et al. 2004). A holistic view supports that a phenomenon under study is always context-bound and the phenomenon under

study cannot be isolated from the context. Therefore, it is important to incorporate both the informant's beliefs and the underlying values as well as to include the informant's milieu.

The inductive and interactive process of inquiry is related to the researcher who is driving the analytic process in a certain direction and will gain growingly insights about the phenomenon that raised curiosity. This process is two-fold as both the researcher and the informant can learn from each other in this procedure. An emergent design is taking place (Dahlgren et al. 2004) where new concepts, hypothesis, or sometimes even theories can be discovered. Some of the different types of qualitative methods are grounded theory, ethnography, the phenomenological approach, life histories, conversational analysis, and case study (Strauss and Corbin 1992, Dahlgren et al. 2004). In this project, grounded theory is used as the research method. Nevertheless, this does not mean that I hold a purist view, but the decision was to stay within one research tradition (Dahlgren et al. 2004) as it suited the purpose of the research question: What's behind sexual risk taking?

## **Grounded theory**

What is going on in young peoples' minds when they interact with others in sexual situations? To answer this question, we chose an explorative research strategy with in-depth interviews, focus group discussions, and an analysis based on a grounded theory approach. The method was collaboratively developed by Glaser and Strauss in the 1960s. They studied the experiences of dying patients in hospitals. Their study resulted in three books: *Awareness of Dying* (1965), *Discovery of Grounded Theory* (1967), and *Time for Dying* (1968). However, the two innovators of grounded theory split, mostly because of disagreement on *how* the analysis should be done (Walker and Myrick 2006). Strauss started a coalition with Corbin, which resulted in a rather pragmatic book (1990) on how to conduct grounded theory, an approach that I have found useful. Basically, "grounded theory" refers to data that is grounded in reality and the theories are generated from the data. The research process involves some basic steps: collect data, code, compare, categorize, theoretically sample, develop a core category, and generate a theory (Walker and Myrick 2006). The researcher looks for the process that is involved rather than static conditions. Instead of posing an already clear hypothesis and verifying this assumption, the data directs the hypothesis or the researcher and the informants are on a "joint venture" (Dahlgren et al 2004:22) where knowledge is constructed together. I thought that doing research together with the informants sounded like a new and fresh approach.



To describe the steps in grounded theory procedure is not so easily done, but here what follows are some cornerstones of the methodology. The method aims at discovering new concepts, hypotheses, or theories, *but* these eventual theories emerge from the data source. The theory must work and must have practical relevance and all theories can be modified (Starrin et al. 1991:32-34). To not “contaminate” oneself with knowledge from other sources, such as scientific literature, the first step is to perform the study and afterwards use relevant literature (Glaser 1978a). To generate a theory is to discover and unveil basic social and structural processes. These discoveries always start with ideas that fit, work, and are practically relevant for the empirical data. The advice to “cross traditional boundaries for analysis, theories and concepts” (Starrin et al 1991:36) is challenging. The concept *theoretical sensitivity* (Strauss and Corbin 1990) refers to the quality of the researcher, the person’s insights, and capacity to understand and give meaning to the data. For example, to have professional experience within the field represents one source of theoretical sensitivity, while literature is another source. Additionally, for Glaser (1978a) sensitivity relies on the researcher being sensitive in that there should be as few predetermined ideas and hypothesis as possible. The analytical process will also create theoretical sensitivity, a process of learning by doing. The insights and understandings will increase when one interacts with the data.

## **Focus group interviews—The methodology**

As said before, qualitative methods are useful for exploration and discovery and focus groups can teach about topics or groups of people that are poorly understood. In the health care sector, focus groups are often used (Morgan 1998) and can be useful when a topic is sensitive (Robinson 1999) and the method can provide valuable insights in the field of sexual health among young people (Hyde et al. 2005). The method can be used to examine what people think and how they think and why they think that way (Kitzinger 1995).

From the 1950s to 1980s, focus groups were mostly used in marketing research, but it has its basis in social science (Emmelin 1999), and Merton initiated the research method in the 1940s. According to Merton (Merton 1987), the groups should not be too large as this could be an obstacle for some group members to raise their voice. He recommends a group to have between 4 and 12 members. The members must have knowledge about the topic that will be discussed. Fundamentally, there is a three-part process of communication where the team members decide what they need to hear from the group members (Morgan 1998:9). It is a focused interview. In this case, we wanted to know more about HIV testing and the

link to sexual risk taking behavior. The focus group members create a conversation around the chosen topic (HIV test) and the research team summarizes what they have heard and learned from the informants in the groups. The researchers select the topics and the group members provide the data that the researchers collect and analyze. One important distinction between focus groups and individual interviews is the interaction that occurs between group members (Wilkinson 1998, Kitzinger 1994). This interaction is vital to include in the analysis. Another advantage is that there is a less risk of power imbalance compared with one-to-one interviews where the researchers often have more power (Wengraf 2001). In a focus group discussion, there is even a possibility that the members empower each other (Morgan 1998). Three things define focus groups: research, a focused topic, and group discussions. A common misunderstanding is that focus groups are cheap and less time consuming than in-depth interviews. However, there is time saving advantages with focus groups compared to one-to-one interviews, but you cannot compare the methods as you get less in-depth knowledge about each informant in the focus group, but the focus group can examine how knowledge and ideas are developed and operate in a given cultural context (Kitzinger 1994).

## **The informants**

In total, 42 young people took part in the projects: 5 women and 4 men (n 9) in the CT+ project and 5 women and 5 men (n 10) in the HIV+ project. In total, 19 people took part in individual in-depth interviews and 14 women and 9 men (n 23) took part in focus group interviews. A number of non-probability sampling strategies exist that aim to be theoretically representative of the study population by maximizing the scope of variation in the subject of study (Hudelson 1994). There are different types of purposive samplings where snowball sampling, convenience sampling, and typical case sampling are some examples. In the CT project and the HIV+ project, a criterion sampling was used as the purpose was to investigate in-depth a particular type of case and identify all sources of variation. In the HIV test project, a homogenous sampling was used to facilitate group interviewing. The informants that received a HIV negative test result were between 18-24 years old and Swedish speaking.

## **Project I: Young people with Chlamydia**

Five young women and four men age 18-22 participated. Eight of them met me when coming for CT testing and/or treatment. One informant was recruited by

another midwife. They all lived in Umeå at the time of the interviews. Four of them were in senior high school. Five had finished senior high school. Four of these were working and one was unemployed. Seven of them were raised by both biological parents while two were raised by single mothers. Five informants had stable relations and four were single at the time of the interview. Four of the women used oral contraceptives. Two women attended the youth clinic for partner notification while three came for a routine check-up. All the men came as part of partner notification. All the informants were heterosexual. Age of first sexual intercourse varied from 14-20.

## **Project II: Young people with HIV**

The informants were 17-24 years of age, five women and five men. Six were single, and four had stable relationships. Five worked full time, two were on sick-leave, and three were studying. Most had finished senior high school; one dropped out of school, but had started senior high school studies. Seven informants were born in Sweden, three were immigrants. Three informants had experimented with illicit drugs but did not inject drugs. All had a place to live. First sexual intercourse varied from 12-18 years. As far as the interviews could tell, all five women and two men were heterosexual. Three men were homosexual. Time from HIV diagnosis to interview varied from seven months to five years with an average time of two years. Four females contracted HIV by having sex with men. One immigrant woman was uncertain whether it resulted from sexual intercourse or a blood transfusion. Two men contracted HIV after sex with women, three with men. Four men and two women took antiretroviral therapy. All of the informants underwent medical check-ups and the majority had contact with a psychologist or social counsellors. Seven of the informants spoke fluent Swedish, two combined Swedish and English, and one of them spoke Spanish.

## **Project III: Young people who were tested for HIV but negative**

In total, 23 young women and men between the ages 17-24 participated. Twenty-one of them were born in Sweden and two were born in the Middle East. More than half of them were studying: thirteen at the university, one at senior high school, four of them worked, four were unemployed, and one woman was on sick-leave. Their sexual orientation mirrors the most frequent visitors at the youth clinic as the majority of them had a heterosexual orientation, while two men had a homosexual orientation and one woman had a bisexual orientation. The median

number of HIV tests they had taken was 1, with a range from 1-3 among the women and 1-7 among the men. First sexual intercourse varied from 14-18 with a median age of 15 among the women, and the men varied from 15-18 with a median age of 17. Five of the women had tried other drugs than alcohol or smoking, such as marijuana.

## **The recruitment**

**Project I/CT+:** During 1996, young people who currently were diagnosed and were being treated for CT were asked by the midwives that worked at the youth clinic to participate. They received written and verbal information.

Five young women and four men age 18–22 participated. Eight of them had met me when coming for CT testing and/or treatment; one was recruited by another midwife. A 16-year-old boy was recruited, but cancelled because his mother disapproved. Five additional people were asked to participate by other midwives. Three refrained and two never came to the agreed interview.

**Project II/HIV+:** This project was the most time-consuming and difficult to carry out. First, I contacted the heads of three infection clinics for HIV in Sweden to investigate if the study was feasible. Next, I met the chiefs at the different clinics, two in Stockholm and one in Umeå to present and discuss the study. I was also able to discuss the project with four counsellors and one nurse that worked at the different clinics. In one infection clinic in Stockholm, 17 of the 650 HIV+ patients were born in 1975 or later (the youngest was born in 1979) and more than half of them were born in African countries (e-mail November 1999). At another infection clinic in Stockholm, 16 people were born between 1975 and 1981 (e-mail February 2000). Of these, six were asked to participate. The rest of them were not considered as appropriate to ask because of language or other reasons. Another clinic revealed that one young woman could be willing to be interviewed.

The nurses, social counselors, and physicians that worked at these HIV infection clinics in Sweden invited young HIV+ persons to participate when they were visited the clinics for regular check-ups or visited their counsellors at their infection clinic. After informing young HIV+ patients about the study, the clinic staff asked them if they would like to participate during their regular check-ups. They were informed in writing and verbally. Those with a recent HIV diagnosis and those with severe psychological problems were not asked to participate. The inclusion criterion was that the young people must speak Swedish or English. Seven of those invited declined because of emotional problems or time constraints. A criterion sample

of nine informants between 17 and 24 years old were recruited from hospitals; I recruited one informant from a voluntary HIV organization. The first person was recruited in spring 2000 and the last one in the autumn of 2003. Due to the limited number of HIV+ patients and the narrow exclusion criteria, the recruitment of informants proceeded slowly; it took three years. I frequently contacted the staff at the hospitals to remind them about the study. We also advertised in a Swedish magazine (T-Cell Magazine June 2001), but nobody was recruited this way.

When an informant agreed to participate, the staff contacted me to schedule a meeting. Two informants, one man and one woman, initiated telephone contact with me themselves, while the others were first contacted by me. During the primary phone conversation, the informants received more information about the study. This phone call was also helpful to establish a relationship between the informant and me.

**Project III/HIV tested:** The health care providers at the youth clinic in Umeå were informed about the project during a meeting at the clinic. They discussed the study, raise questions, and offered suggestions that concerned the planning and the recruitment. The study was met with curiosity and was perceived to be feasible.

Young people between 18-22 years of age were asked to participate when they were tested for HIV at a youth clinic in Umeå. They received verbal and written information about the study. The midwives, the physicians, and a receptionist recruited young people. The recruitment started in spring 2004 and closed in spring 2005. The inclusion criterion was that the informants should be HIV-negative (HIV-) and speak Swedish. I phoned the informants and decided in collaboration with the informants when the FG (focus group) should take place. Six groups with 23 people, 14 young women and 9 young men took part in the FG. The first FG was held in June 2004 and the last one was in May 2005. Five women wanted to participate, but did not show up at the time for the FG. Two of these participated in the next FG. One man had accepted, but he did not show up and refused to participate in another group. Fourteen young women did not participate because they did not want to discuss sensitive issues in a group, did not have the time, planned to move abroad, had experienced deaths in the family, or lived in the countryside. Fifteen young men did not participate because they did not have the time, thought that research was unimportant, were too tired, did not like group discussions, did not live in the city, or did not mention any reasons.

## **The settings**

Two of the studies—the CT project and the HIV test project—were done at the youth clinic in Umeå, a university town with approximately 100 000 inhabitants situated in the northern part of Sweden. In 1993, the clinic started in Umeå, one of the largest clinics in Sweden, where six midwives, three psychologists, two general practitioners, one receptionist, and one nutritionist works. The clinic is open from Monday to Friday and is located in the city centre. It is free of charge and available for young people under the age of 23. The clinic had around 7000 visits during 2005. The midwives act as “spiders in the net” as a great amount of the visits concern sexual health and sexual and reproductive health issues. The midwives provide advice and prescriptions of contraception. To test for HIV, to test for CT, and to trace partners, CT treatment and notification are important parts of the work done by midwives. The formal responsibility for partner tracing is put on the physicians, but this work is often delegated to social counsellors or midwives (Tydén and Ramstedt 2000), as in this case. During 1996, we tested 1381 young patients for CT and around 50 cases were CT+. During 2006, we took 1613 CT tests and 154 of these were positive. During 2004 and 2005, 224/141 HIV tests respectively were taken and they were all negative.

In Project II, the HIV+ project, the setting was Umeå and Stockholm, the capital of Sweden. Three infection clinics in Sweden; Karolinska, Huddinge, and Umeå were engaged in the recruitment. Interviews were conducted at a time and place decided on in collaboration with the informants. Four informants preferred to have the interview at their hospital, two at their workplace in Stockholm, two at a hotel in Stockholm, one at her home outside Stockholm, and one at a youth clinic. Seven of the informants spoke fluent Swedish, and two informants combined Swedish and English. A professional interpreter was used during one interview.

## **The individual interviews**

In Project I, the interviews were carried out at the youth clinic and lasted from one to two hours. The participants received written and verbal information about the study when they were recruited. They were also informed that the interview would be carried out at the youth clinic, a setting they were familiar with. This was the first project and the first research interview. I think that I was more nervous than the young women and men that I met. The interviews started with a short chat to make the informant feel relaxed. This was done to make interviewee as comfortable as possible, so they provide more information. The belief is that a tense or

uncomfortable interviewee does not provide as much information as a comfortable interviewee (Dahlgren et al 2004:22). Moreover, all informants were told again that they were not obliged to take part in the research if they did not want. After this short introduction, the interview started. I followed an interview guide, but not rigorously. Open questions around certain themes were posed:

- Reactions when diagnosed with Chlamydia
- Has this infection affected you in any way?
- Why did you get Chlamydia? Explanation models?
- Do you lack knowledge concerning STIs?
- Attitudes towards sex education in school
- Relations towards sexual partners: How was it? For example, were you in love? Attracted? Disgusted? Afraid? Passive? Desire and reluctance
- Attitudes towards condoms
- Differences between the sexes
- Domination and submission
- Need for having sex

During some interviews, we took short pauses whenever an informant wanted. After each interview, they all said I could contact them again. My planning of the project, own expressions from the interview, method and analysis leaves an audit trail, evidence that is highly desirable in qualitative research. I recorded my reflections in three memo books, one for each project (Sandelowski and Barroso 2003). In one memo book (number I 1996 04 24), I wrote about the first interview:

*“I feel stressed because of the tape-recorder. Thinking a lot about how I pose my questions. The interview person “Madeleine” is signaling to me; signals that I interpret as confirming that I am saying the right things. I sometimes think that I don’t pause long enough, but I do not dare wait. Difficult to know when to finish the interview and afterwards it feels like I didn’t catch everything like I should.*

Ten years later I do not find the tape-recorder to be such a threat. Instead, it is my “good companion” that catches everything while I listen to the informants.

One year later, from October 1997 to April 1998, each informant was invited back to the youth clinic to discuss the preliminary analysis. Six of the informants participated; one girl and one boy did not return and one telephone interview was carried out. At this meeting the informants corrected or confirmed concepts and

interpretations, and we discussed the preliminary results. They also told me about their present life situation. This time, I did not use the tape recorder, but I did take extensive notes.

In Project II, the interviews were planned more thoroughly compared with the CT project. Partly this was due to the sensitive issue and that I felt a greater need to be prepared as I had less knowledge about HIV. In addition, the pitfalls of the first study could be avoided. For instance, during the first study I did not have much background information and in this study one certain theme concerned this condition. I also bought a decent and new tape recorder. An interview guide with three main themes was elaborated. These broad themes concerned their life situation, sexuality, and risk taking and consultations from the health care.

Before the interviews took place, there were some nervous hours before I finally met the informant. Out of the ten informants, I had only met one. Most of the interviews were done in Stockholm, which meant a higher cost of money due to travel and time compared with the projects that were situated in Umeå. Because these informants did not know me, I thought they could withdraw. This apprehension, however, was overstated: only one young woman did not show up for the interview.

We sat down together and had a short conversation before the interview started. They were informed that they could read their interviews, delete parts they did not approve, and that they did not have to participate if they were dubious or felt forced to take part. I checked again that it was okay to use a tape recorder, and they all agreed on that. The tape recorder was carefully checked, and we took breaks when needed. For example, if an informant cried, wanted to smoke, needed some fresh air, or just wanted to have a break, we took a pause.

During the interviews the following issues were brought up:

- background of the informant
- current life situation
- family relations
- views on sexuality
- sexual partners
- love
- thoughts about HIV
- reactions when receiving a positive HIV test result
- how were you met by the health care providers
- the future



The informants were encouraged to tell me about their background, sexual encounters, risk attention, and how they thought they contracted HIV. In addition, I encouraged them to tell me about the reactions that emerged when they got the diagnosis, their view of health care providers, and their immediate and long-term futures. After each interview, I asked them if they wanted to read their interview and if I could contact them again. All the informants allowed me to contact them again. I phoned or e-mailed the informants shortly after the interviews to discuss how they experienced the situation. Both positive and negative responses were common. “Sara” told me how happy she felt afterwards:

*“I felt so light and I almost laughed when we left each other on that Saturday afternoon.”*

Johan, however, had a different reaction:

*“It’s so hard for me to talk about sex. After the interview, I went out, but it was hard to let go of the emotions that the interview raised.”*

Another young girl from Africa told me she almost regretted taking part in the interview:

*“I told you too much and I almost regret it. When I talk to adults, later on I always think that I said too much.”*

The informants received 100 Swedish crowns as a compensation for travel costs.

## **Focus group interviews**

In Project III, the six interviews followed focus-group research principles. During one session of supervision, we decided that I should be the moderator for all the group discussions to practice the method empirically. I wanted to *learn* how to do by doing. It is often a myth that focus groups need a professional moderator (Morgan 1998); instead it could be more important that the moderator have experiences that are relevant for the topic and participants in the project. Another aspect of the “do it yourself” approach is that often the moderator writes the interview questions, as in this case. In addition, at the end of the project, it is the same person who analyzes the data and writes the final report. Therefore, we decided that I should be the moderator, and my main supervisor served as an observer.

A first step in this process was to collect the groups. This was not as easy as I had imagined. We had to reach consensus on which day would be suitable and agree on a time and day that suited all group members. A lot of phone calls, energy, and efforts were done to make it work. For example, A and B could come on Wednesdays, but C could only come on Thursdays while D preferred Mondays. Many young persons are very busy, studying or working, doing sports activities, or traveling. Finally, when a decision was made, we met at the youth clinic at “D-day” at seven o’clock in the evening. This facility suited both us and the informants well as they already had visited the clinic. A conference room was rearranged to work as a group room with a round table in the middle. We had bought some beverages, candy, chips and fruits, and started the ceremony with a warm welcome. One young man said to us that it really looked nice with lighted candles on the table. The session started with a brief introduction (MC and EEJ), and I presented the research process. The identities of the participants were not revealed. However, in two of the groups, in one male and one female group, two people already knew each other. In this group of men, the prerequisite to take part was to have a friend that joined the session. Sometimes it is unavoidable that people know each other and it does not have to be a problem either (Morgan 1998). As in this special case, to know each other increased these men’s comfort in the group.

They were informed that the information given must be kept confidential and that they all had an obligation to respect the privacy of the other members of the group by not disclosing any personal information discussed during the meeting. We were aware of the fact that discussing sexuality could be sensitive. We informed the group members that if the situation became stressful, we would take a break before continuing. The group members had a chance to ask questions if they wanted, but most of them were already well informed. After this, the themes that were going to be discussed were written on a white board and were shown to them:

- Thoughts about HIV
- What’s behind sexual risk and chance taking?
- Why test for HIV?
- Responsibility for testing
- Has the test changed anything/something that concerns sexuality and risk?
- How was the consultation from the staff?

After sound checking, the tape-recorded session started. Nobody had any second thoughts about recording the group discussion. I invited and encouraged everyone in the group to share their experiences of HIV testing and sexual risk-taking. I tried

to give all of them space to express their thoughts. The observer (EEJ) took notes during the sessions. The whole session took two hours. Afterwards, each informant completed a brief questionnaire regarding background data (Table 3), and they were given the opportunity to share their private thoughts and comments about the group session. According to Kitzinger, this can be beneficial (Kitzinger 1995). In this special case, we read their comments afterwards; they liked to take part in the group. They thought that it was important and up-to-date issue to discuss and they claimed that it had been fun. Only one of them did not have any comments. Each of the informants received two movie tickets as a gift for taking part and sharing their time with us.

<b>Characteristics</b>	<b>Women (n=14)</b>	<b>Men (n=9)</b>
<b>Age</b> median years (range)	22 (21-23)	23 (18-24)
<b>Ethnicity</b> born in Sweden born in Sweden (parents mixed ethnicity) born in the Middle East	12 2 0	7 0 2
<b>Education</b> university secondary high school high school	7 11 3	6 9 0
<b>Present occupation</b> student employed unemployed sick-leave	7 3 3 1	7 1 1 0
<b>Sexual orientation</b> heterosexual homosexual bisexual	13 0 1	7 2 0
<b>Number of HIV-tests</b> median (range)	1 (1-3)	1 (1-7)
<b>Sexual debut</b> median yrs (range)	15 (14-18)	17 (15-18) <sup>1</sup>
<b>Number of sexual partners</b> median (range)	14 (7-30) <sup>2</sup>	8 (0-33) <sup>1,2</sup>
<b>Drug use</b> Tobacco regular use tobacco on occasion snuf alcohol other drugs occasionally none	5 2 10 13 5 0	0 4 3 <sup>3</sup> 7 0 1
<b>Present contraceptive use</b> oral contraceptives condom use both condom & oral contraceptives none	7 1 2 4	- 4 2 2 <sup>2</sup>

**Table 3.** Some characteristics of the informants (n=23): <sup>1</sup>one virgin; <sup>2</sup>one did not answer; <sup>3</sup>on occasion

## Data analysis

Because it is vital to use cautiously the term “doing grounded theory,” I prefer to say that I was inspired by grounded theory or that a grounded theory *approach* was used. There are stages concerning the method that do not rigorously follow all the principles of grounded theory. By describing the process and unveil the pitfalls as well as the strengths can perhaps foresee some of the critics that could be raised from experts in the field. According to Strauss and Corbin, there are three steps concerning the analysis, the open, axial, and selective coding of the data. Glaser refers to two steps; the open and selective coding (Glaser 1978a, Walker & Myrick 2006). During these steps, the data are broken down, conceptualized, and put together in new ways, and this is the central process of building a theory. The following describes the analysis procedures where each of the three projects is described separately, step-by-step. This explanation on how theoretical insights are built is important to remove “mysticism” that often bounds grounded theory (Barbour 2001).

## Analysis of the CT project

In the first study, the interviews were done from April to September 1996, and they were tape-recorded. Follow-up interviews were done from autumn 1997 to spring 1998 and notes were taken during these interviews. After each interview, I listened carefully through the tape and a preliminary analysis started. The tape-recorded interviews were transcribed verbatim by me and the transcriptions included pauses, interruptions, coughs, laughs, and silences. A one hour interview took around ten hours to transcribe. This was a time-consuming process, but this repetitive work made me grasp almost everything that was said in the interviews and was part of the analytic procedure where my creativity was challenged. Upcoming ideas were noted in my memo book. Memos are sentences, paragraphs, or a few pages and the point is to document ideas, “to get them out”. Good prose is not necessary at this stage; it is better to write the ideas quickly, before you lose them. These memos can in turn lead to abstractions and is an ongoing process from coding data to the end products (Glaser 1978b). According to Glaser, if one does not write theoretical memos, one is not doing grounded theory. For instance, some thoughts about young people’s sexual risk taking acts were brought up and I wrote in my memo book (1996 10 30) the following:

*“It is bad to have sex with someone one does not know. It is better to say that one seems to know the person, and it is not that bad to have sex with someone who was a friend, whom one had an acquaintance with and*

*so on. But what is it that makes people feel like they know someone they meet accidentally? What is the code to know that you know? Is it appreciation or flattery or what??”*

The first two interviews were performed in April and May 1996 and after transcription open coding started. Open coding is the part of analysis that pertains to the naming and categorizing of phenomena through close examination of data. This is a process of examining, comparing, conceptualizing, and categorizing the data (Strauss and Corbin 1990). There are several different ways of approaching the process of open coding: line-by-line coding, code by sentence or paragraph. A third way is to code the entire document. I did the line-by-line coding. First, the interview was read carefully and I underlined sentences or parts that I perceived to be important. In the next step, the text was broken down in parts where each part got a name that described the phenomenon, occurrence, or emotion. I wrote down concrete words at the margins of the text. This stage was rather down to earth and here are some examples of unsorted open codes from the text:

*unknown, difficult, in love, condom, terrible, extreme, parents, unplanned, attraction, trust, obstacle, prepared, dirty, scapegoat, fit each other, flirt, fear.*

In the next step, I sorted the open codes together to build categories. Here are two examples. The words *in love, trust, attraction, couple, closeness*, and *fit each other* were constructed as the category “stable relation” (of course, if another researcher did a study about lovers and unfaithfulness from the same open codes, the researcher would construct another category *or* could construct the same). The next example refers to the negative emotions that surround a CT infection. The open codes *terrible, dirty, filthiness, unknown, fear, shock, sadness, shame*, and *scapegoat* create the category “emotions when getting CT.”

When these first two interviews were coded, several questions were raised: What is the most striking thing here? What does it represent? Are there contradictions? Did they struggle with their sexuality? During the summer and autumn of 1996 seven new interviews were done. These interviews were built on the preliminary results from the first two interviews. These seven interviews were transcribed in October 1996 and all interviews were coded and analyzed at the end of 1996 and in the summer of 1997. Meanwhile, I was working at the youth clinic and during the spring of 1997. I took a first course in qualitative method to understand theoretically and practically how to code and interpret the data more systematically. At that point, I had so many conceptual codes that the whole project seemed like a total

mess. This is, however, common among beginners in the field. Nevertheless, these concepts needed to be grouped to condense the data into categories.

The axial coding was the next phase that reorganized and put together the data in new ways. The concepts that seemed to pertain to the same phenomenon were categorized. This process involves several steps but in a more focused way. This was done using a coding paradigm where categories related to consequences (the outcome or results of action and interaction) or conditions (the events, incidents, and experiences that led to the development of a phenomenon) were integrated when acting in certain ways. In the axial coding, these categories were linked to subcategories, and these subcategories were thereafter related to categories. These *subcategories* are also categories, but they are related to categories in some form of relationship. One example of a subcategory in the category emotions when getting CT was *shame*. To arrange all subcategories and make them clear, the different subcategories were written on large sheets of paper. In total, there were around sixty subcategories. Thereafter, I scrutinized the interview text to find sentences that would explain the subcategory. Sentences were cut out from the text and were put in envelopes with a title of each subcategory on the front. For instance, in the envelope with the title *alcohol*, sentences like this were used:

*“We were drunk when we slept with each other. If we hadn’t been drunk, we would have never slept with each other”- a young man*

*“When you’re drunk you don’t care”- a young woman*

Looking at the large sheets of paper, I started to draw lines between the subcategories that would fit together. During this analysis, I got a thorough content of the study material. It is important to sort the data that is relevant when trying to answer the research question (Malterud 2001). The subcategories that did not fit were left out. This procedure meant a back and forth movement between subcategories and data, looking for similarities and differences, an act that Strauss refers to as “a constant interplay between proposing and checking” (Strauss and Corbin 1990:111). With help of my supervisors (EEJ and GW) and a contributor (ME), the final version of the article emerged. This group had a varied disciplinary background and professional knowledge concerning qualitative methods. They worked as a multiple coding group in this project. This involved cross checking of coding strategies and interpretations of data (Barbour 2001), and they sometimes worked as the “devil’s advocates” when they disagreed on my interpretations. They read the interviews, but did not code the documents. They did bring their insights into the discussions in the emergent coding framework.

The first interview was done in April 1996 and the last one in April 1998. During that time, several of the informants came back to the youth clinic for other reasons, as they were my patients. This prolonged contact and the follow-up interviews from autumn 1997 to April 1998 that seven of the informants took part in helped to make the preliminary findings credible. At follow-up, six of the informants came to the youth clinic and one telephone interview was done. At this proceeding, we discussed the preliminary results and their present life situation. Two informants did not want to participate. The end product finally saw its light in 2003 (Christianson et al. 2003 paper I).

## **Analysis of the HIV+ project**

The first study stopped after developing the concepts, and we did not come up with a core category. This, however, could be important; otherwise, it is not a grounded theory study (Glaser 1978a). In this study on HIV, we chose an explorative research strategy with in-depth interviews and open questions (Wengraf 2001) and based our analysis on grounded theory (Glaser 1978a, Strauss and Corbin 1990, Dahlgren et al. 2004). The first ten interviews were tape-recorded and lasted 1.5 – 2.5 hours and were transcribed verbatim by me. Transcribing was a way to ensure the informants' anonymity because I was the only person who would hear their voices. Transcribing also helped me clear my emotions these interviews had raised. I do not want to exaggerate, but the first week after an interview my head was filled with emotions like sadness and I could not get the informants' narratives out of my mind. I felt isolated and I did not want anyone to disturb me at that point. The transcribing procedure was perhaps a substitute for a therapeutic session. After each interview, I listened through the tapes and wrote memos as part of the analysis. Each transcript was sent to the informant for review. Two did not read the transcripts. Follow-up interviews, by phone or in person, allowed the informants to comment, explain, correct, or delete parts. Notes were taken during these interviews. I wrote the following in my memo book (number II 2001 03 12):

*“She (Hope) told me that I asked her too much and she wonders what I will do with the material that I collected (her interview). I try to explain, but it is not that easy to explain a research-design to someone that is not a researcher. I told her that the research is voluntary and if she wants to withdraw it is okay. She responds that she wants to participate, but she wants to know what I am writing. I really feel that she does not trust me at all.”*



Collection of data, transcription, and preliminary analysis were simultaneous. This statement might sound bizarre for the uninitiated, but below is a description of this simultaneous process.

The authors read each interview separately and did the open coding that described an experience, a response, or an episode. Four persons with different disciplinary backgrounds were in the group. The diversity of the members affected the coding procedure. While I did the line-by-line coding, the others had a range of coding procedures, from one page coding to whole document coding. When an interview was coded, we had a supervision session where we systematically compared our codes, discussed the similarities and differences, and these reflections were introduced into the analysis. Because each interview was scrutinized before the next interview took place, I was able to check emergent ideas and interpretations with the next informant. After completion of all interviews, we made a thorough analysis that considered gender and emergent ideas were tested and a deeper understanding of the complexity of HIV transmission sought. As part of this complexity concerning HIV transmission, I decontextualized parts that concerned specific sexual situations and lifted out all parts where the informants told about similar issues (Malterud 2001). An emerging pattern of varied power to act in sexual situations was outlined. In the next step, I recontextualized the parts. This made sure that these emergent patterns still agreed with the context from which they were collected, and they mirrored the informants' accounts of their reality. The theoretical concept *agency* was used to outline the frame of action for the informants (Giddens 1984). Here, agency referred to the options these young people used to reflect and act on in sexual situations. We revised the interviews and organized and grouped the codes to create categories and subcategories, the axial coding. One subcategory, *from consensual to forced sex*, emerged, a subcategory that described their power to act during sexual encounters. The different properties in this subcategory were *consensual*, *non-consensual*, *transition*, and *overriding*. The other subcategory, *socio-cultural blinds*, described the different determinants that formed their sexual actions. Finally, we made a selective coding, the higher and more abstract phase of analysis. Selective coding is the process of selecting the core category. To achieve this, it is important to formulate a description about the central phenomenon of the study. This central phenomenon has to be given a name, sometimes from a category in the text, but in this case it was invented. The selective coding implied leaving concrete thinking and entering abstract thinking (Strauss and Corbin 1990). We focused on agency and interaction to contextualize the findings and make the final integration. This was an extremely difficult process that took a long time where different tracks were elaborated on. However, the informants seldom described themselves as victims; they were all acting ("playing the sexual game"), but our analysis disclosed a spectrum of capacity

for deciding their line of action as sexual agents in a frame of gender order (Connell 2002). Therefore, the informants were perceived to be actors on a sexual arena with both choices and constraints that guided their actions. The core category; *varying agency on the gendered sexual arena* elicited their performances on the sexual scene.

To enhance credibility of the findings and for ethical reasons, four informants were asked to read and comment on the preliminary manuscript. Together we read the draft of the article. The perception was that these young people might have additional knowledge to add, especially about the context of their actions. This type of respondent validation should not be assumed to always work like a direct validation, but it can be regarded as another source of data that can give new insights (Silverman 1993). According to Barbour, respondent validation can help to refine explanations, but it can also cause more trouble than it is worth (Barbour 2001). I think that it can be valuable to show the preliminary results and discuss interpretations, but it can be exploitative and distressing especially in projects where vulnerable persons are taking part. For instance, one young person cried when he read the draft because he felt sorry for some of the other informants in the study. Another young woman thought it was interesting to see the different views and realities.

In “You Stand There with all the Responsibility—The Impact of the Law of Communicable Diseases Act on Sexual Behavior among HIV-positive Youth in Sweden,” is in part from the HIV+ project where the informants spoke about their sexual behavior and views on the law. The different steps of coding included open, axial, and selective coding as described above.

## **Analysis of the HIV test project**

This is the last study in my thesis, and the focus group method seemed to be a feasible alternative, especially the speed of data collection, since focus group interviews take less time compared to individual interviews. Indeed, to meet five informants and collect data in two hours felt seductive compared to meet ten informants in three years (the HIV+). These tape-recorded conversations lasted 90 minutes, were transcribed verbatim by me, and analyzed according to a grounded theory approach (Strauss and Corbin 1990, Glaser 1978a, Dahlgren et al. 2004). After each focus group discussion, my supervisor (EEJ) and I had a debriefing discussion where a preliminary analysis started and emergent ideas were checked in the following group. This debriefing also helped me evaluate my own role in the research process as I got immediate critical and positive remarks from the observer (EEJ). Memos were

written in my third memo book, for example, about impressions from the sessions. In memo book III (2004 10 25) I noted the following:

*“Girls take tests the whole time even if they don’t have anything. Girls also think that they more easily get contagions – and that they are the vectors.”*

The final analysis took part when the six focus group interviews were done. I read the interviews several times, asking questions of the data: What’s going on here? How are these young people viewing HIV? Why do they distance themselves from HIV? How do they discuss risk? Where is gender visible? My open coding started. The other two researchers (also my supervisors EEJ and AL) independently read the transcriptions and coded the text. These labels described events and experiences concerning HIV testing and risk-taking. The interviews were reread in detail and the codes were reorganized and grouped to build categories. I summarized the main points from all interviews to organize the data and to not drown in data. All open codes from my own coding including the open codes from my co-authors were integrated into categories. Below are a few examples.

Open codes such as; *a responsibility thing, to be able to have sex, to be able to have unprotected sex, do not want to contaminate others, a genuine precaution for others, want to trust myself, do not want to spread ill health in serious relationships, a stable relation, a new relation, and a soothed phase* were clustered together in the category *reasons for testing*. In the next step, I searched through all six interviews to gather information about statements about reasons for testing and we ended up with 100 codes and conceptual labels concerning different aspects of testing. These codes were grouped into categories. One subcategory that evolved was *responsibility*.

In the axial coding, subcategories were integrated to categories that included context, causes, and consequences. The authors then evaluated the categorization to find consent. By constant comparison between categories, interview texts, and memos a higher and more abstract phase of analysis began and the final categories and a core category were evolved. For instance, *Responsibility—a gendered issue* covers generally how and why responsibility is perceived a female characteristic among the group members. To produce the end product, I thought about the story line. To grasp the story is one important way of ordering the data. Here the *beginning* of the story starts with the informants’ perceptions of HIV, followed by descriptions of intimate relationships, *a middle* that shows how gender constructions and testing worked together and *the end* of this story finishes with a negative test result. The core category *reconsidering risk* is the central phenomenon around which the other categories/themes are integrated.

# METHODOLOGICAL CONSIDERATIONS

## Limitations

In the first study on CT, informants that caught CT spoke of their own experiences, but there are limitations to doing research on patients. They might feel dependant on the researcher and withhold information. Interviews about sexuality are sensitive and can be difficult unless they are based on mutual trust, which is the cornerstone in qualitative research (Lincoln and Guba 1985). These informants were my patients and they visited the youth clinic several times for other matters. This prolonged engagement and the follow-up sessions helped to make the data credible and improved the findings. During the study on HIV+ people, I was not employed by the HIV units. Because these informants were not my patients, they may have felt that they could reveal sensitive issues. However, to discuss a sensitive issue like sexuality can be difficult and there are limitations of qualitative methods when researching sexual behavior and HIV/AIDS (Uys 2002). For instance, in a qualitative study on sexual behavior one has to be aware of the risk of social desirability bias distorting the findings. Social desirability bias is defined as a situation where the informants say what they think that the researcher wants to hear. In the HIV+ study, it was important to motivate the informants to take part because sexual behavior among HIV+ youth in Sweden was an ignored research issue. Because the informants were all informed about how vital their contribution was, the questions concerning sexual behavior might have had a legitimate purpose for the informants that made them more likely to provide truthful answers. Some of them hoped that their participation would benefit other young HIV+ persons, while others saw the possibility to share issues that were important to them. Several spoke about difficulties concerning their sexuality and they had a “burning” need to discuss this topic.

A brief questionnaire regarding sexual behavior can sometimes provide more valid data than a qualitative study because it is taking place under conditions of privacy and anonymity compared with individual interview or focus group discussions (Uys 2002). Focus group discussion involves sharing information with other people, a situation that does not protect anonymity (Morgan 1998). To protect the privacy of focus group members, we administered a brief private questionnaire with some sensitive questions concerning sexual behavior. In one group, there were only two women that took part because the other three invited women did not show up. Hence this “group” was a focused interview with interaction between the two informants, and a lot of important data emerged. In retrospect, thinking about the recruitment difficulties, the decision to include this group interview was relevant.

There is also a risk that people that voluntarily take part in research on sexual issues differ compared with non-volunteers on some dimensions, such as a more positive attitude towards sexuality, less sexual guilt, and more sexual experience (Strassberg and Lowe 1995). These informants or perhaps a major part of them might have been more interested in sexuality and more talkative and that is why they decided to participate in this study. An HIV diagnose, with all the disadvantages on sexual behavior, makes young HIV+ people reflect on sexuality to a higher extent than young people in general will do. Likewise, one of the heads at an HIV infection clinic stated that “precisely sexual issues concern young HIV+ persons a lot and they have a need to discuss this issue.” With other people and in other circumstances the results might have been different. For instance, in the focus group discussions 29 of the 52 people that were HIV tested and invited to participate refused, perhaps due to the sensitive topic. It was also more difficult to recruit young men. This could reflect a resistance towards sharing intimate experiences with other young people, and we do not know the opinions from those who did not take part. This is true for the other two studies as well. In the HIV+ project, 17 young people were invited, but 7 of them refused. People without permit residence in Sweden, those who were on drugs, or those who had severe psychological problems were not even asked. It would, of course, have been very interesting to interview them because there is now an unrepresentative sample of people whose voices may be ignored, the “hidden populations” (Bell et al. 2003). Still, over forty interviews with three groups of young people with different experience of sexual risk taking can be regarded as sufficient for theoretical saturations to understand *partly* what is behind sexual risk taking. This creative combination to use measures from different angels is called triangulation (Malterud 2001). Triangulation increases the understanding of complex phenomena. Collecting accounts from three groups of participants, differently positioned within the context, this *data triangulation* allows for extension, in-depth description, and illumination from several standpoints (Tindall 1994). For example, in the CT project, I did not have a theme that concerned the background and upbringing or family conditions. This was a category that needed to be addressed and was one theme that was discussed in the HIV+ project. The use of *investigator triangulation*, using other researcher from different disciplines and perspectives relies on multiple viewpoints and enriches the findings (Tindall 1994). My collaborators and supervisors have acted as “friends willing to act as enemies”; during the research process, they raised constructive critique. In addition, the *theoretical triangulation* embraces more than one theory, to gain a fuller contextualized picture. Here, risk, agency, and gender were included. But the decision to know when “enough is enough” is delicate. Does a project reach saturation? According to Glaser, theoretical saturation of a category occurs when coding and analyzing does not produce new categories: the same categories continually emerge as one goes th-

rough the full extent of data (Glaser 1978a). Whenever a new interview takes place, there are always new things that will be brought up. Hence during the interviews there were patterns and categories that were recognized and that came up repeatedly. For instance, in the HIV+ project, the problematic upbringing and backgrounds among the informants was outlined from the start until the end. One informant mentioned during the first interview that he did not have a complex upbringing, and this could perhaps refer him to be a negative case, demonstrating that further refinement of the original process probably can be useful.

There are few informants in each project and critical voices may claim that generalization is problematic. Scientists who prefer a quantitative research tradition may even argue that it is impossible to generalize the findings from a qualitative study to a broader population because the participants are so few. Quantitative and qualitative research traditions are two different research techniques aimed at gathering different information (Uys 2002, Johansson et al 2003). The biomedical framework in medical research is perceived to be objective and neutral in contrast to qualitative research that often is regarded as soft and subjective and perhaps with a more dubious aim, not evidence but understanding. (Risberg et al. 2006). Qualitative research is not about exploring the frequency of behavior among large research populations, but is a method for understanding the drive behind behavior. As an alternative to generalization, the term transferability is better suited in qualitative research (Hamberg et al 1994, Malterud 2001). In short, these methods are founded on an understanding of research as a systematic and reflective process for development of knowledge that can somehow be contested and shared, implying ambitions of transferability beyond the study setting. It cannot be stated that these informants that participated represent all young people in Sweden, but they are voices from consumers in health care with various experiences and backgrounds. The findings from these specific projects are worth considering in Scandinavia and in Western Europe or perhaps globally. A recent review on qualitative research studies concerning young people and sexual behavior suggests that there are striking similarities in sexual behavior worldwide (Marston and King 2006), whereas other researchers conclude that there are no studies that are universally transferable, and there is no general approach to sexual health promotion that will work in all global contexts (Wellings et al. 2006).

## Reflexivity

Contemporary qualitative or naturalistic research belongs to the traditions of post-modernism and social-constructionism where the researcher does not expect definite answers, but instead looks for mutual knowledge developed concerning the research topic (Malterud 2001, Tindall 1994). It is important to discuss the relation between the interviewer and the interviewee. To hold an objective standpoint is not possible, and qualitative research does not claim to be objective. Subjectivity is not a problem in qualitative research; it is a resource (Parker 1994). However, it is necessary to explore how the subjectivity of the researcher has influenced the research path (Hamberg and Johansson 1999). Performing qualitative research will have effects on both the interviewer and the interviewee. There is always an interaction between the two parts in an individual interview session, and it is important to discuss the position of the researcher, in this case me. This is called *personal reflexivity* (Tindall 1994) because personal interest and values are declared. Here my professional interest is declared. During the time when I was studying to become a midwife, I wanted to have a position at a youth clinic and now I do. This work has provided me with specific knowledge concerning youth cultures. This implies that there is a perceived familiarity between the informant and interviewer (Hodkinson 2005). The language is internalized as well as a wide range of experiences is recognized. However, I am not an absolute insider as I am an adult, and my contribution in the HIV+ project was more from an outsider perspective. Still, my experience at the clinic in Umeå has made it clear to me that it is important to treat young people with respect, engagement, and curiosity by listening, talking, and treating them as equals. This experience shaped the interactions between the young people and me during the interviews and created both valuable and unpredictably data. The research topic that I have chosen is professionally significant as I am very engaged in my work with young people.

During the initial phase of planning the HIV+ project, one colleague mentioned that if some of the HIV+ young people reveal that they had unprotected sex, it was my duty to report it to the authorities. This felt troublesome. Could such behavior be justified when the informants' eventual openness of this kind would be turned against them? Fortunately, one expert from the Medical Ethics Research Committee assured me that I did not have to act as the police as I was a researcher. Instead, if such information occurred, it would be an important research finding and such discoveries are important to elicit and can improve the work of health care providers. *Functional reflexivity* refers to the researcher role in the research process (Tindall 1994) and how who I am will shape the course of the research and the eventual outcome. For example, the first interview in the HIV+ project was with

a young man who asked me (before the interview started) who I was advocating for? I answered, "I am on your side." However, this question was rather unexpected; I thought that I would be the one who would ask questions. Was it possible to promise to be on his and the other young HIV+ side? Now, I would claim that it can be possible. To let informants read their interviews, to respect their will to delete parts from the interviews, to not reveal everything that is coming up in an interview when writing an article, and to ensure anonymity are ways to be sensitive to the informants' needs. In two of the projects (CT+ and HIV+), some interview data were excluded because it was perceived to be too sensitive to disclose. It is also vital to admit that in a research process the researcher is part of the constructed knowledge. Another interviewer would perhaps come up with rather similar results, or different, depending on the researcher's perspective and background. These results could be interpreted differently.

## **Ethical considerations**

Research ethics has at least two dimensions. Research ethics defines how research should be conducted when it involves human beings (or animals), as in this case and researchers' own moral obligations, such as honesty (Dahlquist 2006). All projects in this thesis are reviewed by an outside committee, but it is still important to consider whether these projects put the participants at risk. I would like to emphasize some ethical guidelines that are important to discuss and follow before, during, and after the research is done (Kvale 1997). Informed consent, confidentiality, consequences, and the role of the researcher are some of the principles discussed in relation to these three studies. In the first study (CT+) and third study (HIV test), there was a risk that some of the young people could have felt dependent towards the youth clinic in general and towards me as the interviewer as they were "patients" at the youth clinic. They might feel that they had an obligation to participate in the study. Therefore, much effort was put into carefully informing the participants, both verbally and in writing, about the aim of the study and the voluntary nature of the study. In addition, they were told that their decision to participate or not participate or drop out would not in any respect affect their future contact with the youth clinic. The statement that an individual can withdraw from a study, as she/he has the freedom to withdraw can sometimes be problematic in reality (Ringheim 1995). The term "free will" is a cultural construct that implies both autonomy and awareness of individual rights that can vary across societies and subgroups within a society. For instance, young people may, compared with adults, know less about their rights in research. This was emphasized and discussed with all the informants.



To increase the level of confidentiality, the informants in the CT+ and HIV+ studies were asked to choose a pseudo-name. These names were written on the tapes. I also promised to transcribe all tapes myself as a way to protect their anonymity. In the HIV test study, the participants were not promised “true” anonymity, but they were assured confidentiality: information gathered would be carefully protected and that unit of analysis was the group, not the individual. Furthermore, they were also informed about the obligation to respect the privacy of the other members by not disclosing any personal information that they shared during the focus group discussion. One important issue that especially concerns focus groups is over-disclosure. By setting boundaries before the group session starts, the acceptable limits are defined (Morgan 1998). This issue was raised right from the start. We declared that the participants were not encouraged to say anything that they might later regret. Monitoring ethical boundaries can be difficult, and it can be easy to miss the fact that someone is showing signs of stress. The groups were no larger than four to five persons, which could be a recommended number when a sensitive topic is discussed (Arsenault-Côte and Morrison-Beedy 2005). Because the groups were rather small, this made it easier to “keep an eye on” negative or stressful reactions and all groups consisted of me as the moderator and a supervisor as an observer and as an assistant moderator (EEJ) who provided a second set of eyes and ears. The interview tapes are in a locked compartment at the Department of Family Medicine.

Conversation about sexuality and STIs, such as HIV and CT, can bring up emotions of discomfort, and it was important for me as an interviewer to be sensible and aware of this fact. In two articles that included in-depth interviews (paper I and paper II) identifiable parts of the interviews have been changed and some sensitive parts have been excluded. Approaching a vulnerable group raises ethical considerations (Ringheim 1995). Interviewing HIV+ persons might evoke emotional distress. This risk was discussed thoroughly, and we could have decided to approach others who were perceived to be less vulnerable. Hence young HIV+ people in Scandinavia are an ignored research group, so this specific knowledge that these HIV+ people had would not have been obtained if we had chosen another group. These ethical issues were discussed with the heads at each infection clinic during the planning of the study and all informants had the opportunity to see a psychologist after the interviews. The majority however said that talking about HIV and sexuality with an interested researcher was a relief, and perhaps for some of them even a therapeutic experience. In a study such as this, the informants might use the researcher as a “witness” to their stories and telling them may change their understanding of their story (Parker 1994). One informant was newly diagnosed (7 months) when he accepted to be the interviewed. This may not be ethically sound, but in this case the staffs that provided care to him ensured that he would

manage, and his family was also very positive towards the interview. This was my last interview in this project and my experience of interviewing HIV+ persons had been growing. Hence there is always a risk that people that are in an emotional transition phase may disclose more than they would otherwise reveal (Kylmä et al. 1999). In this special case, the impression was that he did not say more than he wanted. An interpreter was used during this interview. Whenever an interpreter is used, there is a risk that interviewees exclude sensitive topics that they would have revealed if a third person had not been there. The follow-up interview made it possible to check how he felt after the interview. He told me that the topics that were discussed during the interview were in fact things that concerned him a lot, and for him the interview had been a rather positive event.

When a project enters the after stage, there are important questions that start around issues of closure, cutting off relationships with informants, and leaving the environment one tried to become part of (Roberts and Sanders 2005). This problem is discussed only in relation to the second project concerning young HIV+ people, not because the other two projects are less important, but because the informants in the HIV project are more vulnerable compared with the other informants because of their diagnose. Today, HIV in the western world is seen as a severe chronic disease without cure and this makes the life situation very complex for people with HIV. Those adolescents who are HIV+ are often confronted with the issue of life and death among many others stressful life events compared to healthy adolescents (Hosek et al. 2002). During these interviews, many sensitive issues were revealed. Researchers can sometimes experience role conflict when hearing distressing stories that informants may tell (James and Platzer 1999). The prolonged contact with the informants and the narratives of emotional and intimate character developed trust between me and most of the informants. This can create a form of interpersonal dependency that parallels the relationships that are established with vulnerable people in psychotherapy and counseling (Cutcliffe and Ramcharan 2002). This role conflict, being a researcher and not a counselor, can sometimes create helplessness, but I knew that the informants could get counseling at their clinics if they needed. Despite this knowledge, I was to a high extent involved emotionally. I worried about their physical and emotional health. In particular, in qualitative research, the questions the researcher may ask, and the direction the study may take cannot be specified at the start (James and Platzer 1999). Although these potential risks and benefits must be discussed before the project starts, it is rather difficult to predict in advance how people that are involved in sensitive research projects will react during the research process. The maintenance of some relationships as a product of the research interview can be both necessary and ethically sound (Cutcliffe and Ramcharan 2002). All informants had the possibility to

contact me if they wanted, and some of them did. Hence the greater part of the contacts with the informants ended naturally, and I do hope and I do think that the informants did not experience the interviews as “hit-and-run” events as they had a chance to give feedback to me.

The Medical Ethics Research Committee of Umeå University approved Study I dnr 96-126 (1996).

The Medical Ethics Research Committee of Karolinska Institute and Umeå University approved Study II dnr 00-064 (2000).

The Medical Ethics Research Committee of Umeå University approved Study III dnr 02-386 (2002).

# MAIN FINDINGS, DISCUSSION, AND COMMENTS

**Paper I;** “One-night stands”–risky trips between lust and trust: qualitative interviews with *Chlamydia trachomatis* infected youth in north Sweden. *Scandinavian Journal of Public Health* 2003; 31: 44-50.

## Findings

The findings started with the “accidental meeting” and were followed by why and how the “sex act” happened and finished with the realization that CT in fact could happen to them. We found that an essential drive behind the informant’s sexual risk taking was a drive to “go steady.” All intimate relationships had a start and for these informants a discotheque, a pub, or bar were where they met their sex partner. The purpose was to have fun, dance, drink, and see friends, but entering these arenas supplied pathways to intimate relationships. Flirting, joking, dancing, talking, or making the first move was described by both young women’s and men’s perspective, as a strategy to build trust and an important input for “getting to know each other.” Lust and trust were the guidelines whether sex was going to happen. These young women and men searched for confirmation, often through sexual relations, but there were gender-specific patterns for what actions were suitable. Discussing one-night stands, gender stereotypes were noted. From the young men’s point of view, girls were expected to be less forward compared with men. There was also an uneven distribution of responsibility concerning condom use. The men expected young women to be condom promoters, while the majority of the young women already took the pill and therefore had played their part in preventing unwanted pregnancies. Most of the young women did not desire sexual intercourse on the first date. They preferred small talk or fondling, giving them equal or more satisfaction compared with penetration. The young men, on the other hand, said that sexual intercourse strengthened their manhood and easily gave sexual satisfaction, while fondling was perceived to be too intimate and nothing to do with “strangers.” Both women and men claimed that one-night stands could be lustful, but to establish a stable relationship, the first sexual intercourse with a new partner should be postponed; that is, it was “better to wait.”

The informants did not expect to catch CT. They thought that they had been informed and cautious. All of them knew that condoms gave protection and they had intentions to use condoms if/when they had sex with “strangers,” but they had only

sex with people they “knew.” To “know” somebody varied from months, weeks, and hours. When they caught CT, two salient emotions guilt and shame were elicited. The young women experienced guilt and worried about having infected others, while the young men were content with knowing “the source of contamination.” Even if most informants felt shame, they acted differently. Some of the young women sought support from friends, mothers, or sisters, while some of the men did not talk about it with anybody.

## **Discussion**

The informants were between 18-22 years old, a transition phase from adolescence into young adulthood, where partner-seeking was seen as an essential drive and part of an ultimate goal for many of them. In the Nordic countries, it is perceived as normal and acceptable to have a sexual relationship, at least for older teenagers and young adults (Traeen et al. 1992). Heterosexual relations are part of the social norm where “steady” relationships are important processes of social and emotional maturation. The norms and expectations that are related to sexuality are represented as “sexual scripts.” These scripts prescribe what appropriate behavior is and in what circumstances this behavior can occur. It is generally endorsed that both young women and men can enjoy premarital sex in Sweden, but this was only partly confirmed in our study. The expectations, conditions, and course of actions were rather different. Young women were not supposed to be demanding, and mostly it was up to the young man to act. Girls had a narrow field of action. Motives for sexual intercourse given by men can be to have fun, pleasure, or to relax, while for the women motives for having sex are often based on love, commitment, and emotions. In our study, some of the young women provoked the general norm, as they talked about lust and enjoyed sex with a casual partner they were not in love with. We saw a clash between lustful sex described by the women and sex described by the men. The women mostly preferred fondling while the men wanted to strengthen their manhood by having sexual intercourse. During the sex act, we found an uneven distribution of responsibility concerning condom use. Four of the five girls in the study used OC (oral contraceptives), and had thus taken their part of responsibility for unwanted pregnancies, while the men expected women to be “condom promoters”, and if a woman did not suggest using condoms, the men did not use condoms.

Their risk calculations were based on intuition and emotions. They did not think that CT would happen to them, partly because they mostly had sex with people they knew, liked, or loved. These positive emotions are cornerstones in building trust. The informants did not trust strangers or people they knew had multiple sexual partners,

but trust is certainly “lack of full information” (Giddens 1990). When the informants caught CT, guilt and shame had more extensive gender association. The girls felt like female scapegoats, and felt guilty about transmitting CT to others, while the men were content because they had been contacted by the “source” and quickly received treatment.

## Comments

Ideally, in the Nordic countries both young women and men are considered to have equal rights to express their sexuality and the rules are supposed to be the same for both sexes (Traeen et al 1992). This perception is grounded in a perfect world that does not exist yet. There are few if any societies that are based on gender equality between the sexes (Connell 1995), but there is still hope for a world changing for the better. This study was done ten years ago and changes are on its way. For example, to have sex with a “fuck-buddy” or to have sex “just for fun” may also exist in Sweden (Edgardh 2002a). Do these results mirror that young women take what they want sexually or that men use girls as “fuck-buddies” until they find a stable relation with a “decent girl?” In sexual surveys, the sexual repertoire for women has been growing, but there is still a “double standard” for both men and women (Connell 2002:73). A Swedish researcher, (Berg 2002) discusses what she calls the love project. Berg sees love as a context of meaning in that young heterosexual women find it meaningful to have sex with a partner that is a boyfriend compared with the less meaningful experience, temporary sexual relations. These informants thought that love was beneficial and trustworthy forces that were sought in the sexual interactions with boyfriends. In a stable relationship, the sexual practices were transformed from being self-centred to sexual reciprocity and care. Moreover, Berg discusses the love-project, the somewhere in-between project, and culturally split femininity. Not all young girls can enter into love-projects. For instance, if a young woman has sex on the first date, she might be defined as “used” from a male viewpoint or even be labelled “slut”. In order for the love-project to work, young women who were perceived to be somewhere in-between, belong to a positive category of femininity, could enter into a love-project. Berg asks: Who wants to start a love project with a “slut?” I remember “Veronica” who told me about the objectification she sensed concerning having “one-night stands” with men: *“They look upon you like a toy they can take home from the pub.”* “Fredrik” claimed, *“it’s the guy who should initiate the flirt, and girls might be regarded as promiscuous if they have a similar manner.”*

We found an imbalanced sharing concerning condom use. This is one important gender issue. Lear addresses how gender and sexual orientation influence the abil-

ity to negotiate safer sex and how gender relations can be a barrier to safe sex (Lear 1995). Within heterosexuality, sexual intercourse is located in gendered power relations, where sexual encounters can be seen as a struggle between the exercise and acceptance of male power and male definitions of sexuality and a woman's ambivalence and resistance. To use or not to use a condom is not so much a discussion about perceived risk, but instead an effect of negotiation between two sexual partners with unequal power. Asking a new partner to use a condom can be difficult because young girls might fear that it will destroy an intimate situation (Ekstrand et al. 2005). In our study, the young women also expressed difficulties and ambiguities in asking for and promoting condom use and most of them took OC. A meta-analysis on heterosexual condom use report that relationships that are perceived to be sexually exclusive are key markers of steady relationships, relationships associated with the use of OC instead of using condoms (Sheeran et al. 1999a). A recent study on condom use reveals that one of the strongest factors associated with non-condom use is the use of oral contraceptives (OC) (Novak and Karlsson 2005). Young women in Sweden are more concerned with not getting pregnant than catching STIs, while many young men can be perceived to have a lack of concern, both concerning pregnancies and catching STIs. In our study, for both women and men, asking for a condom when the woman was on the pill was interpreted distrust, which felt inconvenient in intimate situations. It can also be trickier for young women to suggest condom use in casual relations as society's image of female sexuality gives priority to stable relations with the development of emotional closeness, whereas condoms can be associated more with frivolity (Bajos and Marquet 2000). This perspective does not ring well with the struggle for equality between the sexes in northern Europe, nor does it provide progress towards egalitarian relationships at least for young women and adolescent girls, who do not have the autonomy and status that men and boys may have. Thus it is also important to understand that sexual encounters, especially early in the relationships, are rather nonverbal (Lear 1996). It can be too much to demand from young people that they speak about sex in a direct and erotic way, even if this straight vocabulary perhaps would diminish many risks and misunderstandings during sexual encounters.

In our study, more women felt guilty compared with the men who were rather content with receiving fast treatment for CT. At the time when our study started, women were taking the majority of CT tests. Today more tests for CT are done on women. The risk for female scapegoats is clear if we focus solely on women. This is a problematic issue when screening is sex specific (Duncan and Hart 1999a, 1999b). In a more recent qualitative study, the same researchers showed that for the 17 women who took part in the study, when the women were CT diagnosed, all of them were shocked and reported feeling mild disgust to distress, and they feared

negative reactions from partners (Duncan et al. 2001). We concluded that as long as CT screening is focused on women there is a risk that women define themselves as “sources of contamination,” while men do not see themselves as transmitters. Despite the fact that it could be the other way around, more men are vectors in the spread of STIs, the blame is put on women. In public health, it is high time to encourage men to play an equal part in sexual health. Today, in Sweden, at least in the county of Västerbotten and the county of Västra Götaland the Internet provides CT testing for both young women and men (Novak and Karlsson 2006), and this is a method that achieved a high participation of male testers. To test men is a necessary step as it cannot be cost effective to test women repeatedly as there is a risk that many heterosexual women have sex with untested men.

**Paper II.** “Eyes Wide Shut”—Sexuality and risk in HIV-positive youth in Sweden: A qualitative Study. *Scandinavian Journal of Public Health* 2006; 000:1-7.

## Findings

We focused on agency and interaction. The informants seldom described themselves as victims, but the core category; *varying agency in the gendered sexual arena* disclosed a spectrum of capacity for them to decide their line of action as sexual agents in a frame of gender order. The subcategory *sociocultural blinds* blinded the informants risk perceptions. *Lack of adult supervision, naivety, being in love, alcohol and drugs, the macho ideal, and cultures of silence* blinded them to the risk of unprotected sex and made them vulnerable. Eight informants described a problematic upbringing where parental or other adult support was negligible. The majority never worried about HIV, and being in love concealed the risk of HIV awareness. The culture of silence had two dimensions: sexuality in intimate relations and uninformed society. In private relations, some women said that it was difficult or even impossible to negotiate safe sex with men. For one of the women, the only strategy was for her to test for HIV *after* a relationship ended, acting as a responsible agent. One informant’s experience reflected the attitude of the silent and uninformed society. She never worried about HIV although relatives and neighbors had died because in her African country nobody talked about HIV/AIDS (in fact-during the interview this informant told me that people in her home country sometimes mentioned HIV as “the disease,” but the word HIV was not outspoken). Alcohol and drugs contributed to risk behavior. Some of the young men claimed that if they were drunk, the risk of having unprotected sex was evident. One informant lived in an environment where drugs and criminality was a daily routine for him, and this background did not make safe sex a priority. The focus was on drugs and



how to get them instead of focusing on protected sex. The macho-ideal determined the positions for three men. This type of masculinity were understood as having sex with multiple partners, sex with prostitutes, or “conquering” girls to raise the status in the group of men they knew. A gay informant thought that to be the inserter during anal sex reduced the risk for HIV.

The various narratives concerning sexual encounters were categorized according to how agreement or disagreements during sexual interactions were expressed. The subcategory *from consensual to forced sex* described context-bound experiences in their sexual practice and these events were divided in four properties: *consensual sexual activity*, *transition between consensual and non-consensual sexual activity*, *non-consensual*, and *overriding sexuality*. We focused on gendered relations to clarify how the dimensions of power guided their sexual encounters. *Consensual sexual activity* covered voluntary liaisons that were portrayed positively, such as long-term romances, or sex based on the free will. *Transition between consensual and non-consensual sexual activity* were the subtle borders between approval and forced sex. The nagging from a sexual partner who wanted to “ride bareback” made one informant become persuaded to be the receiver of unprotected intercourse even if he disliked it. The third property was *non-consensual sexual activity* where the encounters were neither desired nor intended and not based on the free will. This type of power relation that ended with a rape was told by one male informant. The fourth property, *overriding sexuality* was interpreted as a risk-prone version of masculinity, where sexuality was described as a habit based on excitement and desire, where the sexual partners mostly were anonymous and “one in a row.”

## Discussion

For now, HIV is not a widespread problem for Swedish youth, but this pioneering study elicits various mechanisms that can help us understand why and how young people are at risk of contracting HIV. For instance, we found a consistent pattern of difficulties during childhood, such as loss of parents, divorces, foster care, fragile parents, or few other adults that could serve as role models. This complex and manifold problematic background of the informants may have contributed to their vulnerability. Many preventive strategies suppose that individuals can make logical choices concerning their sexuality (Rhodes and Cusick 2002), but we found a lack of or restricted agency that put these young persons at risk. There are many more young people in Sweden that live in comparable contexts and are exposed to the same social and sexual vulnerability as the informants here. They might also lack the agency necessary to keep them safe.

Not surprisingly, most of the informants did not see themselves as part of a typical risk group, and they did not think that they would catch HIV, but they did. They acted with their eyes wide shut; their sexuality became a rather non-reflected action with little if any risk calculation. Although risk is associated with a negative outcome, sexual behavior was multifaceted and the term risk was also the same as *chances* worth taking. Several of the informants spoke about love and trust in intimate relations, and one informant thought that she was ready to take a chance to see what sex was like.

Sexual behavior is embedded in culture. Many young women globally have little power to negotiate safe sex (Türmen 2003, Wood et al. 1998). In our study both young women *and* men had difficulties negotiating safe sex or discussing HIV risk with their partners, and both women and men in the study had experience of involuntary sex. There are diverse mechanisms that contribute to vulnerability and varied agency among young people that needs to be considered in the HIV epidemic: the social background and the role of gender in the context of risky behaviors.

## Comments

In Europe, HIV risk is influenced by situations, timing, emotions, power, the meaning of the relationship, and the status of risk (Bajos and Marquet 2000). In our study on HIV+ people, we tried to take hold of some of these relational dimension, but we do not know how the sexual partners of the informants would grasp the interpretations we based our findings on. It would have been interesting to interview them if it had been possible.

The interviews with the informants revealed both positive and negative stories about sexual relationships. The term status passage, described by Glaser and Strauss in 1971, is a process in a person's life (Dahlgren et al. 2004:128-129) and recent research has used the term to describe process of becoming a vegan (Larsson et al. 2003). In my study, status passage with the properties, degree of desirability, degree of reversibility, degree of repeatability, and degree of control and this theorem was helpful in sorting the data concerning intimate relationships. To understand the dimensions of intended and unintended sexual intercourse, status passage was in my study replaced with the category *from consensual to forced sex*. Five informants thought that they knew the exact moment when they were transmitted with HIV, whereas the others felt unsure and mentioned likely encounters. The category *from consensual to forced sex* is an example of a process that led the informants into catching HIV and this changed a lot in these young people's life. This study focused on whether the event was something

nice or unpleasant for the individual, the event could take different directions, the event could happen more than once, and the individuals were in charge of the process. To be in charge was defined as having control, and having control was linked to possessing power. The concept of agency was outlined.

A devastating socio-economic and neglectful psychosocial milieu can harm the development of responsible behavior. This is recognized in a “vulnerable ethnography” study among inner city Detroit residences. This study described how six HIV+ African-American young people almost deliberately sought HIV exposure (Tourigny 1998). The author elicits different mechanism that can contribute to sexual risk taking. An insecure environment with gang membership, violence, and crime can create feelings of hopelessness and futility, and these negative emotions put these young people in despair and self-destruction. Adolescents may take risks because they have this exaggerated feeling that they are not going to live (Fischhoff et al. 2000), perhaps in the same way as the Detroit youth. An ignored research group within medicine is male-to-female transgender youth. One recent study concludes that especially male-to-female transgender youth of color are at extremely high risk of acquiring HIV (Garofalo et al. 2006). However, the interviewed young people faced a wide range of risk factors where HIV was only one of them. Homelessness, economic hardship, forced sex, selling sex, legal troubles, high rates of substance use, and limited familial support, especially concerning contact with their fathers, influenced their health and well-being. Teenagers may also take risks, because they may underestimate the probability of things going wrong. Research from California challenges this common perception about risk and vulnerability (Millstein and Halpern-Felsher 2002). It is often discussed that teenagers underestimate risks and view themselves as invulnerable to harm due to their young age, but this study shows the contrary. Young adults in this study were more eager to take risks compared with teenagers, as they had experienced that most of their risky behaviors did not lead to negative outcomes (Millstein and Halpern-Felsher 2002). These participants were a homogeneous sample of white, middleclass individuals who reported low rates of risky behavior. Their social context significantly differed from the young informants in Detroit (see Tourigny 1998) as they lived in an optimistic social and economic environment. Power and social status will clearly affect how people from different socioeconomic background will judge risks (Lupton 1999a:23-24). Living in a safe environment will automatically increase the possibilities of not having troubles. In Sweden, HIV is a rare disease perhaps due to rather high economic standards and a continuing struggle for gender equality. Especially poverty and gender inequality are detrimental factors that will affect sexual behavior in a broader social context (Wellings et al. 2006). In our study, most of the informants did not think about HIV as a real threat as for many of them HIV was not part of their social world. The view that HIV is not a

problem in Sweden has implications for young persons living in our country. Today, there are few messages that talk about the risk for HIV and young people in Sweden are less knowledgeable about HIV and other STIs than they were twenty years ago. This ignorance from authorities can in fact lead to increasing numbers of HIV among young people in Sweden.

**Paper III** “You stand there with all the responsibility” –The impact of the Law of Communicable Diseases Act on sexual behavior among HIV-positive youth in Sweden. Manuscript 2006.

**Findings**

All of the HIV+ informants underwent medical check-ups, and the majority of them had contact with psychologists or social counsellors. Time from HIV diagnosis to interview varied from seven months to five years with the average time of two years. Four men and two women took antiretroviral therapy. Detection of HIV varied (Table 4).

Detection of HIV/Diagnose
Immigration/ HIV diagnosis 7 months ago
Incarcerated in youth prison/ 2 years ago
Kaposi Sarcoma/ 2 years ago
Fever and severe bodily pain/ 2 years ago
Partner notification/ 2.5 years ago
Immigration/ 1.5 years ago
Pregnancy/ 2 years ago
Partner notification/ 2 years ago
Immigration/ 3 years ago
Induced abortion/ 5 years ago

**Table 4. Detection of HIV/Diagnose**

*Support* and *burden* were subcategories that described the informant's double-edged experiences regarding the law. Detection of HIV offered free medical check-ups and treatment of HIV and social/psychological counseling. Once diagnosed, they did their best to lower the risk of transmission. Several of them claimed "*at least nobody will get HIV from me now*". Some informants emphasized that a mandatory law for informing sexual partners was a good backup; others were seriously bothered with how to handle the information duty; while other informants thought that it was not easy to follow the law. Because their own family or friends were not always informed, it was important that they received support from psychologists or counselors to accept the situation and take control: "*To be able to tell something like this you must become stronger and have a lot of guts*".

The information duty was burdensome. When they were exposed to temptations, to handle the information duty was problematic. The probability of finding a willing sexual partner declined. Having HIV was a stigma, being seen as "them"—the dangerous transmitters and not the "us"—the healthy people at risk of exposure. During sexual intercourse, condoms had to be used. Misconduct could lead to a threat of juridical reprimands. Condoms became a disease reminder for some of the men, and some women felt that the responsibility to "put it on" was all theirs. If men did not want to use condoms spontaneously, the power to persuade them was restricted, but the duty to convince them was a female issue and a double responsibility. One informant could not persuade her partners to use condoms: "*If they [the authority] want, they can lock me in. If you behave badly several times then maybe they would.*"

They needed to reflect on and discuss "bad behavior," such as unsafe sex. They also feared the consequences both for themselves and for the physician. They worried about punishment and they worried that physicians would lose their medical legitimacy if they refrained from reporting cases of unprotected sex.

To *switch off lust*, *switch off the disease*, and *balancing lust and obedience* were strategies the informants used to manage their sexual relations. To *switch off lust* they suppressed sexual needs because they were afraid that disclosure would imply risk of rejection and a risk of transmitting HIV if they refrained from informing others. In retrospect, sexual drive had been positive before they were infected and risked transmitting the virus.

To *switch off the disease*, two informants suppressed the thought of HIV to turn on lust. They related unsafe sex experiences. Afterwards, they regretted their behavior and felt anxiety. A decision to take responsibility or not also depended on the contextual milieu. The Swedish law did not reach overseas and going abroad implied a feeling of freedom: "*Well I'm driving ugly so to speak . . . when I'm going abroad I have a lot of sex.*"

*Balancing lust and obedience* during encounters that “could-be” sexual, the emotions of desire and fear were balanced. When the information duty did not work, the threat of juridical sanctions guided their actions. Lust was not allowed to take over, and some informants repressed their sexual emotions: “*You have HIV. Now stop girl! Don’t go too far. You have already gone too far. Stop it!*”

Internet was a shortcut to find a sexual partner. Dating over the net was one arena where anonymous sexual contact facilitated nondisclosure, but this informant had safe sex. Barriers of fear and self-disgust made it hard to enjoy sex with others. The reciprocal fear affected sexuality negatively and could induce negative emotions of unworthiness: “*I feel like I am a second-class.*”

Negative encounters with health care were noted. After a condom-breakage, an informant’s stable partner received post-prophylactic treatment at the clinic. A nurse scared his boyfriend by calling into question whether he wanted to have a HIV+ partner. The gay informants wanted to find a HIV+ partner. Women also thought that to have a HIV+ partner would be less problematic, but for them health and reproduction were closely related, which explained their preference for HIV-negative men. Two female informants thought that their sexuality was “normal” and that condoms were easy to use. Sex without condoms was not a choice for them even if the partner proposed it.

## **Discussion**

Besides the burden of being HIV+, these young people had vast problems concerning their sexuality. Receiving care could have helped them be more informed and articulate. The informants were *cultivated to take sexual responsibility* and the law meant both *support* and *burden* for them. Although they got support from the medical health care in forms of free medical check-ups, treatment of HIV, and social or psychological counseling, the obligation to protect others from HIV and fear of transmission was always part of their sexuality. They referred to the law as putting an extra burden on their responsibility to protect others, and they feared juridical sanctions, such as isolation or even jail if they refrained from disclosing their HIV+ status to their sexual partners. The information duty was problematic and they sought different solutions to overcome problems. When, where, and how to disclose were questions that health care providers must respond to and address in a supportive way. The informants were only partly content with the health care support in these difficulties, and they indicated that the law hindered confidence and honesty because they feared that the physicians could report “*bad behavior.*” The findings also addressed negative

attitudes among the staff and the need for further education. Working with young HIV+ people and their sexuality is delicate. They might be treated more paternalistic and fostered by threats instead of information and support. Are young HIV+ people expected to abstain from having sex to a higher degree compared with HIV+ adults? These interviews were performed before the new law was implemented in 2004. This new law is supposed to be less repressive compared with the law from 1985. We do not know if these informants would respond differently today. Hopefully, they will be able to discuss “*bad behavior*” with their doctors without reprimands and receive guidance that will strengthen the ability to become responsible as the law suggests.

Some of the informants lacked ability to handle the information duty. They feared others’ reactions or rejections. They suppressed sexual needs and avoided sex, which is probably the first response as newly diagnosed although not feasible in the long run. Partner-seeking and unplanned sex is common among many young people in Sweden, but this type of sexual relationship was difficult for several of the informants. Two informants “*switched off the disease*” and had unsafe sex without disclosure on occasion. Hence unsafe sex is the single most prevalent factor in spreading HIV. To handle these risky situations, more discussions around sexual behavior with non-judgmental staff are needed. Perhaps, with the new law in the foreground, these people and others will be better advised in the near future. Research has showed that disclosure can give negative reactions, but also that it can give positive rewards, such as alleviation of stress and improved health (Paxton 2002). Information about the positive effects on wellbeing is important for empowering young HIV+ people to disclose their status.

Easy access to casual sex with non-steady or anonymous partners does not facilitate disclosure. The Internet was described as an arena for sexual contacts where the information duty was ignored and the responsibility for protection was supposed to be shared. Marginalized persons find the Internet attractive, but they seldom disclose their HIV+ status although often they try to take the necessary steps to reduce transmission (Ciccarone et al 2003).

The informants related negative experiences of having HIV-negative partners. Fear of transmission and fear of condom-breakage was destroying their lust. Some of them felt like “*second-class*” sexual partners. To reach a balance and to enjoy sex, the gay informants hoped for a HIV+ partner, whereas the women sought to find a HIV-negative partner because they wanted healthy children and a father that could be the caregiver if the disease progressed. Two women lived with HIV-negative men. For them, using condoms was a routine to protect their counterparts, as they would never risk the health of their partners.

## Comments

This study reveals the serious problems young HIV+ people must handle. First, they must accept that they have HIV. Time from HIV diagnoses to interview varied from seven months to five years where adaptation phase differed among them. Those with a more recent diagnosis faced problems that those who had lived longer with HIV perhaps had overcome. The adaptation phase was, however, not the scope of this project, so it is difficult to speculate about this issue. Research from US indicates that strong emotional reactions or suicidal feelings are rare among young gay men when they learn that they have HIV (Rotheram-Borus and Miller 1998). Instead, a brief period of distress was reported. The contrary was expelled from the gay informants in my study. Two of them sometimes have had suicidal thoughts and a third person tried to commit suicide shortly after he was diagnosed. The other seven told about recurrent sessions of “ups-and-downs,” implying that the adaptation phase can go on for a long time.

Second, to live in Sweden, the law requires these informants to always disclose that they have HIV before they have sex. In the US, risky sex without disclosure of sero-status is common among adults with HIV (Ciccarone et al. 2003). A limited amount of research from the US indicates that HIV+ youth continue transmission acts after knowing that they are HIV+ (Rotheram-Borus and Miller 1998, Rotheram-Borus et al. 2001), and female and male youth are twice as likely as adults to engage in risky behavior (Diamond and Buskin 2000). Another study from Switzerland among HIV+ adults of both sexes showed that several subgroups—such as, women, those at age 15-30 years old, those with HIV+ partners, and those with occasional partners were more likely to report unsafe sex (Glass et al. 2004). In our study, most of the informants did their very best to be responsible in the case of protecting others from transmitting HIV, but the interviews cannot reveal exactly *how* well they will manage every time they have sex and does not tell whether they will disclose their status when they are entering into new sexual relationships in the near future. There might be more than these two informants who will have unprotected sex without disclosure. The progress of antiretroviral therapy in the Western world can offer young HIV+ people a longer life today and address and improve safer sex issues among long-term HIV-infected people who are sexually active (Butler et al. 2003).

Third, HIV-infected people need a lot of courage. They also need agency. *Cultured to take responsibility* means that the informants were not only educated, but they were required under legislation to govern the transmission of HIV, and this is not a passive act. The law might even be counterproductive for some of the informants in that the burden for the diseased is too heavy to carry, or that the state reduces a



person's agency in such a way that it inhibits the HIV+ person's capacity to fulfill the law's requirements. With threats of isolation or incarceration, there is a risk that young people with HIV do not favor the support that they can get, but solely refer to what they perceive to be the negative consequences of having the law. The HIV+ young people must be in a position to exercise responsibility, but HIV is still an infection that is surrounded with prejudices, stigma, and deviance. In an interview study with 75 HIV+ informants from African countries and the Asia-Pacific region, subjects revealed feelings of shame, loss, and worthlessness after they were diagnosed (Paxton 2002). However, the possibility to "go public" with their HIV diagnose gave positive benefits and was "extremely rewarding" for most of them. To speak out can be empowering, a way to take control over one's life and to re-establish personal dignity and pride. Most people need time to come to terms with HIV, and in Paxton's study the average time between diagnosis and disclosure was 2.6 years. For a young person with HIV, a lifespan of two years can be regarded as a rather long period. To overcome or prevent situations of unsafe sex, significant effort must be put into giving positive rewards concerning disclosure to diminish the risk for transmission. To disclose can be stressful, but it can be even more disturbing to keep quiet.

According to one gay informant, negative emotions from health care providers can also influence wellbeing. "The unpopular patient" does mean a patient that is not following the clinical regimen and will be regarded unfavorably by the staff (Robinson 1998). This informant acted as a responsible agent after a condom-breakage and received post-prophylactic treatment for his boyfriend, but some of the nurses and physicians reacted negatively when the gay couple sought care: "*maybe you shouldn't do the deep kissing.*" This sort of negative attitude from the staff was rarely spelled out by the informants. Most of them were grateful for the warmth and support they got from the staff. Recent research from Sweden notes that generally both the nursing staff and nursing students express empathic attitudes towards HIV-infected patients (Röndahl 2003).

To control HIV transmission in Sweden, there is mandatory HIV testing for blood donors and systematic but voluntary testing for pregnant women, women having abortions, intravenous drug users, STI patients, immigrants, refugees, and deceased with autopsies (Regeringens proposition 2003/4:30). HIV testing should only take place after informed consent is given. Table 4 shows that two of the informants were diagnosed due to partner tracing. The other informants were diagnosed for reasons, such as illness, legal abortion, pregnancy, incarceration, or immigration.

It might be challenging to discuss whether the law prevents more cases of HIV. It is important to keep in mind that the most dangerous phase in HIV/AIDS transmis-

sion occurs during the asymptomatic period, which can last for years when people do not know that they are infected. Unprotected sex is common among young people and unsafe sex is the single most prevalent factor in the spread of HIV. Therefore, more attention must be paid to the public and their own responsibility to protect themselves from HIV.

**Paper IV** “Concepts of risk among young Swedes tested negative for HIV in Primary Care: Focus Group Interviews.” *Scandinavian Journal of Primary Health Care* 2006; 1-6.

## Findings

The core category *reconsidering risk* was related to four categories. The first category, *HIV– a distant threat*, starts with the informant’s perceptions of HIV. In most groups, HIV was discussed as a distant threat, present in Africa, Asia, and big cities, but not part of their social world. Many concluded that since few were HIV+ in Sweden, they did not worry about contracting HIV. They discussed “people at risk” and people that were not. For example, immigrants, prostitutes, drug addicts were perceived to be at risk, while heterosexuals or average Swedes were not. Strangers, older, young and dumb, “fuck-arounders”, “sick-in-the-head,” “sloppy” and “blue-eyed” were examples of stereotypical images they connected with risk. Tattoos or intimate piercing could also be warning signs. Their risk calculations were often based on conventional feminine or masculine appearances, such as “blonde flirty bimbos”, “prince charming”, or “players”. Hence as the discussions continued, they realized that “ordinary” people, like themselves, could catch HIV because of “bad luck.”

The second category, *the risk zone*, could be charter travel, and closer risk zones were “bars.” Many women discussed the “silent rules” of expected behavior when interacting with men in bars; going home with a new partner often ended in sex, even if many of the women said that they wanted to know the partner first. These situations were complex to handle for them. Some men also described situations where they sometimes regretted one-night stands, but they blamed it on instinct by referring to the reptile brain: “*you’re not more than a mammal in some ways.*” The informants had personal grounds for testing: unprotected sex, many partners, experimenting with drugs, sex abroad, infidelity, needle-stick injuries, condom breakage, recently single, initiating relations, or hypochondria. The women also expressed a fear of transmitting partners.

The third category, *responsibility—a gendered issue*, revealed that the informants saw testing as a gendered issue that was “natural” for women, whereas young men need to overcome different barriers against testing. In explaining “natural” the informants referred to upbringing. Girls were brought up to be caring, whereas boys were not. Both women and men talked about “irresponsible” men. This irresponsibility could be considered normal or even masculine and could perhaps also explain why men seldom took tests. They discussed how rooted these attitudes were in society. Sex education in schools teach girls “*mostly about risks and less about pleasure*”, whereas boys could “*sleep around*”, girls worried about contamination, and boys never considered themselves as transmitters. Men generally resisted testing due to shame and fright, fear of painful examinations, deformity concerning their genitals or worries about STIs. They suggested that involving men could increase their willingness to be tested.

*A green card* was the fourth category. Few women and men worried about HIV. They tested to ensure that they were healthy. Most informants said that the test result allowed them to start again with renewed ambitions. Receiving a negative HIV test result was a relief and confirmed healthiness. They received *a green card* to show a potential partner. However, receiving a green card also proved that HIV “could not happen to them”, and one man claimed that for him the green card could mean new “vicious circles” of unprotected sex. For many of them, the visits into the risk zone were seen as passages that would end when people matured or found stable partners. A reflective process *reconsidering risk* started. Reconsidering risk in a counseling conversation following a HIV test may be a good idea.

## Discussions

The informants described HIV as a distant threat, a quite realistic view in Sweden with below 50 HIV+ persons of their age (18-24 years of age) infected. In the focus groups, stereotypical images of risk actors emerged, but most informants perceived these images to be clichés, and they thought that “ordinary” people with bad luck, including themselves, could be at risk. Many of them had event-driven and rational reasons for testing for HIV, multiple sexual partners being one. The women and men had a median of 14 and 8 partners respectively, which is more partners than average in their age group.

The risk zone was not only distant but also nearby, in “the bar.” Here social norms promote increased alcohol consumption and sexual networking. Bars can also be arenas where gender is reproduced because conventional dichotomized social/cul-

tural constructions for expected feminine and masculine behavior are displayed (West and Zimmermann 2002). Women in our study perceived that bar dating implied sex afterwards although they said that they preferred small talk. The men could not say no to sex either when they got the chance. Not all of the informants felt “trapped” in these “given” roles. They argued their right to say yes or no, but all of them discussed the gendered sexual arrangements in bars.

Women said it was natural and responsible to be tested, whereas men avoided testing: “*men rather escape from responsibility.*” For the young women, it was “natural” to get tested. They worried about infecting their sexual partners and the young men seldom thought about themselves as transmitters. Young men might also resist testing due to shame, fear of painful examinations, deformity of their genitals, or STIs. In addition, men linked testing to maliciousness.

In our study, people decided to take a test for HIV because of risk taking and receiving confirmation of healthiness. All informants thought that receiving a negative HIV test was a relief. By getting “a green card,” they felt “clean” and restarted with renewed ambitions that for them included reconsidering risk.

## Comments

Most groups perceived HIV as a distant threat. In an earlier study from Umeå (Lindblad 1995) examined how senior high students perceived HIV. HIV was a new and fairly unknown phenomenon for those young students as they did not know any HIV+ people. A Finnish study of teenagers indicated that HIV remained somewhat distant to these adolescents (Muinonen et al. 2002). We found that most people in the focus groups did not worry about catching HIV either. One reason for this thinking was that they did not know anybody with HIV. However, some of the young people had in fact met people with HIV, and one of the girls personally knew another person who had been diagnosed recently. For them, HIV became more real.

Stereotypical images of risk actors emerged, but most informants perceived these images to be clichés, and they thought that “ordinary” people with bad luck, including themselves, could be at risk. Perhaps they thought this because more than half of the informants were university students and they “knew” what to say. In reality, it can still be possible that they judge people in a stereotype manner where the “blond bimbo” or “prince charming” will be regarded as possible sources of contamination, whereas the blue-eyed brunette without piercing or the nice male

university student will not be seen upon as risky. Therefore, it is important to teach that it is impossible to tell whether someone has an STI on the basis of stereotypes (Green et al. 2000).

The informants thought the following were risk groups: immigrants, gay men, prostitutes, or drug addicts. They thought these people were not like “the average Swede.” One female group thought that men who infect others were underrepresented for spreading of HIV. The male sex actor was represented by the traveler or an injecting drug user, but in a rather small town like Umeå the young female informants claimed that the social control would revoke his anonymity fast, and before having sex with such a person, people would think twice or simply avoid having sex with him.

The constructed “sub-life” in bars encourages sexual relations and one-night stands (Peart et al. 1996), and the informants often referred to this as a risk zone. Research indicates that bars were associated with higher HIV risks (Latkin and Knowlton 2005). The setting may promote higher risk behaviors or behavioral engagement with high-risk individuals. Here the social norm promotes increased alcohol consumption and individuals who frequently visit bars tend to drink more over time. This setting, however, is typically for heterosexual people and is not regarded as a place with higher HIV risks (Peart et al. 1996), but a setting that provides a short-lived sexual network for heterosexuals. “*You can trash him the next day*” like a young woman in group 3 suggested. The concept of risk is not neutral but gendered and heterosexualized or a construct of the heterosexual identity as safe in terms of HIV/AIDS. Bars were in this study also arenas where gender was reproduced. West and Zimmermann argued and proposed that this is an achieved property of a situated conduct, focusing on interaction (West and Zimmermann 2002). In our study, these were the expected rules of expected feminine and masculine behavior concerning one-night stands. The bars served as institutional arenas for gendered expressions—these situated doings for both sexes were made possible for the individuals. The authors suggested that it is individuals who do gender, but the doing is situated in that individuals organize their many activities to express gender and they are arranged to perceive other people’s behavior in a similar light. More young women in our study mentioned that they did not want to have one-night stands although most of them had. The young men could also regret one-night stands, but they blamed it on instinct. A short conversation from a focus group discussion reveals that the situated doings are viewed differently depending on what sex the person is:

*“When we were in high school, a girl who pets with some guys it was like whore” (girl 3).*

*“Mm”(girl 4).*

*“And the guys they turned down that bird at once” (girl 3).*

*“A guy he is just normal if he goes out to a bar and have fun and that is because guys are like that, but a girl who does the same, she will not be a whore, but she is still loose” (girl 4).*

All informants spoke about the “green card” as their proof of healthiness. Other metaphors described were “a license to drive,” “a certificate,” or “inspection,” which are terms that are linked to motor vehicles. It is interesting to compare the youth in this study with young men in Tanzania who spoke about AIDS like “something that strikes randomly like a car accident” or “an accident that is hard to prevent” (Haram 2005). They also used a similar discourse, even if they did not discuss the green card, to describe how AIDS would hit them. This imagery is also similar to the image of “riding the juggernaut.”

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Voluntary counseling and testing can be one component in preventing HIV by educating people about HIV, but a test by itself may not change behavior and reduce the risks (Myers et al. 2003). Where and when the HIV test is taken and how well the pre- and post-test conversation goes is also important. From our findings, contradictory reflections were expelled. In some groups, the test had started reflexive thinking: “unnecessary to take new risks,” “think more now,” “think before,” “I am changing myself now—do not want to take another test,” “will definitely use protection from now on,” “will be easy to use condoms now.” The contradictory was also supported: “I can fall back again,” “I still do not think,” “small risk to get anything,” “maturation makes one change—not an HIV test,” and “nothing has changed.” We did not expect these young people to claim that the test had changed their eventual risk behavior although it was fascinating to learn that for many of them a reflexive process concerning the HIV risk had started. This is a good beginning. We strongly reinforce that *reconsidering risk* in a counseling conversation in a non-judgmental environment can be a very good idea. In the article, this advice was directed to general practitioners, but midwives, social councillors, and nurses are equally important in this preventive work.

There is a growing consensus in Europe that to increase HIV testing can have public health benefits (Renzi et al. 2004). Testing can improve survival and quality of life and treatment of infected individuals. However, there are many people that do not seek HIV tests for various reasons (Smith et al. 2005) and HIV testing in the

US is especially low among 18 and 19 years old and in Europe low among young adults (Renzi et al. 2004). In a US study among university students, only 7.7% of 344 people who were never HIV tested but sexually active (mainly white females) stated they would be tested for HIV in the next six months (Hou and Wisenbaker 2005). In Europe, it is estimated that one in three HIV infected people are unaware that they are HIV+ (Editorial 2006). Although 94% of Europeans know that HIV can be transmitted by having unprotected sex with a HIV+ person, only 41% said that they protected themselves when they had sex. This is a more serious problem.

## THE MAIN DISCUSSION

Like all research, this research is performed in a specific social and cultural context and at a specific time that influences the outcome; hence this research can give a partial picture of the whole. These studies are taking place in Sweden, a country where sexual relations of all sorts between young people are mostly accepted. This generally open and liberal attitude towards sexuality does not mean that *all people* in Sweden are tolerant. There are subgroups within the population that for religious, cultural, or other more hidden reasons condemn sex before marriage or disapprove of homo/bisexual relations. Some of these informants are immigrants from Africa or South America and their experiences might not reflect the circumstances in Sweden. Some informants are born and raised in Sweden but have one or two parents from Middle East, Africa, United States, South America, or Finland and these informants' ethnicity may or may not influence their views on sexual behavior. Most of the informants raised in Sweden have parents of Swedish ethnicity, and some of these informants are raised in families with religious values, although most are not. The majority of the informants identified themselves as heterosexual and some identified themselves as homosexual. One informant had a bisexual orientation.

### **The day-to-day practices concerning risk**

There is an emergent interest in youth sexuality where one dominant idea is that youth are a "group at risk." The sexual practices of the young people have been mapped effectively, asking what, where, with whom, and how often (Manderson et al. 1999). Hence there is a need to not impose questions on sexual risks, but instead let young people express their own thoughts about what sexuality and risk means to them, to understand the reasons behind sexual behavior, and to catch descriptions of what is happening during sexual encounters. For that broad aim, a qualitative method is more suitable method (Marston and King 2006). During the analysis of the interviews, themes concerning sexual risk were hidden in the text and most of the young people did not overtly discuss risk. For example, in the CT+ project young people generally did not think that they would catch CT, and in the HIV+ project the informants "acted with their eyes wide shut," not reflecting on risks. In the HIV test project, HIV was perceived as a distant threat that would not happen to them. Instead, going out, seeing friends, drinking, and dancing were ways to meet new partners for stable or casual sexual relationships. To have sex meant pleasure, excitement, intimacy, or love. Sometimes sex meant exchange for money, to raise status among friends, or to simply feel like Don Juan.



It can be difficult to see the risks that are involved in the day-to-day actions. They did not judge their day-to-day doings as risky; instead, it was part of their ordinary life where these informants did not consider HIV or STIs in general to be a health issue for them. They did not view sex as a source of infection. These responses to risk are cultural, as people construct their own risks with or without the professional advice (Lupton 1999a:107-108). There are risk positions that emerge from one's own experiences as well as the social milieu and the communicative networks. These positions are constantly shifting and changing and depend on influence from mass media, experts, and lived experiences. The changing risk position is elicited when ten of the informants are diagnosed with HIV. Now, they constantly worry about the risk of transmitting HIV to others. Moreover, the young HIV+ people must follow the Law of Contagious Diseases Act and accept the information duty and inform their current and future sexual partners and always use a condom. Certainly, trust is required for these individuals to manage and interact in such ways that they do not contaminate others. People trust abstract systems, in this case the law, by expecting HIV+ youth always to tell the truth; i.e., to inform others about their HIV infection. In a Swedish unpublished report (Westrell 1999), one HIV+ person suggested that "all people should act as if their sex-partners have HIV." That is, use a condom.

In conceptualizing trust, Giddens discusses chance versus risk; there is risk and there is chance involved. For instance, in the CT project going out to clubs and bars provided a chance to meet a new partner. There are situations where people take a "calculated" risk: they are aware of the hazards that are involved in the risk taking, but there are also risky situations where individuals are unaware of the danger they run. Risk and trust are intertwined with each other where trust minimizes the dangers. By flirting, joking, dancing, talking, and making moves allow young people to "get to know each other" and they start building trust. Trust and lust were the guidelines that determined whether sex was going to happen, and sex might be the first start of a stable relationship.

## **Risk and the never ending Otherness**

The informants in the HIV test study mentioned risk groups for HIV, such as immigrants, gay men, prostitutes, or drug addicts. These people were perceived as if they were not like "the average Swede." According to Lupton, by focusing on risk as "otherness," there is a tendency for certain social groups to become marginalized and defined as the "risky other" (Lupton 1999a:123-147). The Swedish authorities today rhetorically note that "AIDS is catching us all" (Bredström 2006), but despite

this message, the focus is still on certain risk groups instead of risk practices. Risk, however, is not defined only in terms of sexual identities; these identities are ordered hierarchically in terms of risk where for gay or bisexual men, they are defined as high risk and heterosexuals at low risk (Adkins 2001). Heterosexual practice is presented as a normal, innocent, and a relatively risk free activity, despite the rising numbers of CT within the population. In our study on CT, these informants did not expect to catch CT. They thought that they had been informed and cautious, and they had intentions to use condoms if/when they had sex with “strangers,” but they had only sex with people they “knew,” liked, or loved. The informants did not trust strangers or people they knew had multiple sexual partners. On the whole, the “hetero Swedes” they are portrayed as rather risk free.

Risk can be a context-bound practice. For example, travelling abroad, being young, and being an immigrant are bound with risks (Bredström 2006). The informants in the HIV test study described HIV as a distant threat. According to Lupton, it is typically members of marginalized groups—women, poor, unemployed injecting drug users, gays, lesbians, and non-whites—who are constructed as “grotesque bodies” (i.e., open, polluted, irrational) and therefore “at risk” (Lupton 1999a:147). The young women reacted strongly when they were diagnosed with CT. To be “the source of contamination” was a metaphor in line with Lupton’s writing on marginalization where women are perceived as other, with open and polluted bodies, whereas the young men were content with “knowing the source of infection.” Similarly, some of the HIV test group members claimed that HIV “*is the African’s problem.*” In the colonial era, the black body was often singled out as the “other, uncivilized, uncontrolled, and dirty” (Lupton 1999a:131), and during the years of the HIV pandemic there has also been a risk to picture black men as vectors (Manderson et al. 1999).

Risk is a “way of seeing” or understanding risk. One could say that the Swedish authoritarian discourse on risk is time dependant. What are considered to be a risk is conceptualized differently in different historical and cultural contexts (Lupton 1999b:5), and risk is often associated with choice, responsibility, and blame. The term risk group has vanished in the authoritarian vocabulary, and the new terminology has been changed into target groups (Herlitz and Ramstedt 2005). Today, adolescents, immigrants, and refugees from endemic countries, gay men, travelers, and HIV+ persons and their relatives are targeted. Moreover, the “late testers” need to be reached. People with foreign origin and Swedish-born heterosexual men that are infected abroad are more often found in these groups of “late testers” (Brännström et al. 2005). White heterosexual men are new targets. An interesting development since there has been a tendency that heterosexual white men are not

seen as vectors in the epidemic (Manderson et al. 1999). This classification of targeting people could perhaps be a way “to give the world a structure” and to classify (“we perform acts of inclusion and exclusion”) because ordering is the central task of modernity; modernity attempts to fend off chaos (Lupton 1999a:131). In our study on HIV testing, this practice was perceived as a responsibility, but a gendered issue that was “natural” for women although not to the same extent “natural” among the young men.

In a study by Lupton on HIV testing, the issue of responsibility was brought up (Lupton et al 1995). Testing was something to do with keeping “the body in good order and safe.” She showed how the testing technique worked as an assumption of the cleanliness of the heterosexual. In our study, HIV test informants discussed repeatedly what it means to be “clean”. In accordance with Lupton, this cleanliness can work as a border against others and clean ones can only be infected by the outside, the contaminating others. Douglas sees risk as a locus of blame, where the “risky” groups or institutions are singled out as the dangerous ones (Lupton 1999b:3). In Western contemporary societies, the concept of risk can be used as maintenance of cultural boundaries between self and other, where a risky other may serve as a threat to the integrity of one’s own physical body or to the symbolic body of the community or society to which one belongs. This way of distancing oneself from risky others is very problematic because we all are living in the same world: what happens in another part of the world will sooner or later catch up to all of us because there is no us and them, but we.

## **Risk and agency**

In this thesis, the varied sexual agency of both young women and men is elicited. The subcategory *from consensual to forced sex* might be a useful concept because it acknowledges and examines both positive and negative experiences of sexual events, but the subcategory needs further refinements. Freedom from sexual coercion is essential for good health (Marston 2005) and to focus on both young women’s and men’s narratives on sexual experiences and to highlight both young women’s and men’s positive as well as negative experiences of their sexual encounters can be fruitful. Research among 18 year olds of both sexes from Northern Sweden revealed distressing results: 21% of the young women had experienced forced sex and 8% of the young men had the same experience (Novak and Karlsson 2005). These results, however, can be ambiguous as there is a risk that young men do not define coercion or pressure to have sex with the same vocabulary as young women do (Marston 2005).

Pressure from a partner might not be regarded as coercion from young men's point of view. In our study, the varied sexual experiences of both sexes were included. We focused on whether the event was something nice or unpleasant for the individual, whether the event could take different directions, whether it could happen more than once, and whether the individuals were in charge of the process. The subcategory *from consensual to forced sex* has its focus on feminine and masculine behavior, but it is gender neutral, which makes the concept valuable to be applied on many more young men and women than the ten informants in the HIV+ project. Hence an event can be described differently, when people have a distance to the event and face the "end product," while those sexual events that do "end" with a negative outcome (for example, HIV) can be viewed more negatively and involuntary. The further removed the consequences of an act are in time and space, the more likely that the agent describes the event as unintentional (Giddens 1984:11). From Giddens' theoretical point of departure, agency is located in the actions of human actors, in their day-to-day life; a routine where people learn knowledge-ability (Giddens 1984:2-3). This means that human beings structure their social practices and learn by repeating the practices, cognitive skills. Hence, Giddens' perspective does not take into account that most of the young people have less experience with sexual practices compared with most adults, and young people may have less agency. According to a recent publication on sexual agency among young women in a detention home in Sweden (Överlien 2003), there are few studies that have examined sexual agency. Överlien suggests that young women's agency must be investigated further to develop a pluralistic understanding of sex and gender, how girls and boys become precisely girls and boys, and what it is like to live in this world as a woman or a man.

For feminist theory, the concept of agency has been seen as problematic. In the 70s, second wave feminists reacted against a dominating Western stereotype where women were thought about as having poor access to agency or were denied agency, whereas men were seen as autonomous agents (Gardiner 1995). If women acted independently, they were regarded as selfish; female passivity was considered to be a good trait from some theoretical standpoints. Agency is always part of power relations and within some feminist theory the continued subordination of women results from both women's and men's actions. Therefore, if we claim that we live in a rather equal society and internalize social and cultural norms without questioning them, there is a risk that this belief will sustain a patriarchal structure and retard the changes that will benefit both men and women. How can actors act otherwise is one main question for feminist theory. Messer-Davidow (1995) sees agency as both practices and processes that co-produce actors and structures. Actors who would like to change the social order must act subjectively, interpersonally, and

social-structurally. For instance, young heterosexual women do not need to have one-night stands if they do not have that intention or prefer to decline even if they think that their casual partner wants to have sex. Young heterosexual men do not need to pressure or feel pressed to have sex with sexual partners or function like “mammals.” Instead, it is necessary to bring new workable actions into use where young people can act independently. That is, if young women would like to have sex, a one-night stand, and find a willing partner, it is an acceptable action if the action is based on mutual free will. Likewise, the contrary would be acceptable: young men who prefer to wait for sex, but they need agency to manage.

To disclose one’s HIV status, people need courage, but they also need agency. Responsibility assumes agency (Chan and Reidpath 2003), but agency is not equally distributed among the population. There are many factors that interact and influence the extent of agency. Young people must be in a position to exercise responsibility, and their agency can be constrained or restricted for reasons, such as negative influences from the social milieu and upbringing (Christianson et al paper II), viewed as “second class sex partners,” being young, being immigrants, the ethnicity, but most of all because of HIV, an infection that is still surrounded with prejudices, stigma, and deviance. We found that the lack of or restricted agency put our young HIV+ informants at risk, but there are numerous young people in Sweden who live in comparable contexts of social and sexual vulnerability, where they might lack the agency necessary to safeguard.

## **Sexual risk taking and doing gender**

Journal of Adolescent Health had a special issue 2006 where young people and their sexual risk taking were put on the agenda (Irwin 2006). A first suggestion for preventing STIs was that “abstinence is the best available option.” I believe some of my informants would have been critical of this advice by asking “in what century is he born?” But the editor’s message is that many young people are becoming sexually active during their teens and early twenties and health care professionals must instead encourage young people to healthy choices. One communicative message has been the ABC approach: A stands for abstinence; B for be faithful; and C for condoms. This message is inappropriate and too simplistic from a gender perspective (www.sida.se 2006). More recently, research has examined risky behavior and gender. Especially attention to gender has been given in the context of HIV. The early HIV/AIDS researchers were criticized for not paying attention to the impact of the epidemic in the lives of women globally (Manderson et al. 1999). Today, this “gendering” of the pandemic is considered in public policy and prevention

programs. Gender is seen as a central element of both individual and societal vulnerability (www.sida.se 2006), and empowering women and girls is seen vital for fighting the epidemic (Türmen 2003). The review from SIDA highlights the problems with the HIV epidemic, an epidemic that is suffering from gender blindness. For instance, the authors recognize that there is a power imbalance between men and women concerning sexual practices, where men tend to have more sex partners, decide whether to use a condom or not, and this makes it difficult (but not impossible) for young women to negotiate safe sex. There are also relations based on violence where the choice to have protective sex is simply not there. Especially risk behavior among heterosexual men have been absent in the discussion. Gender role norms are strong factors that influence sexual behavior. Risk is acceptable or sometimes encouraged for “real men” (Mane and Aggleton 2001). For instance, the link between dominant forms of masculinity and sexuality can encourage young men to think that to have multiple sexual partners is a positive behavior that will strengthen manhood, but this concept of manhood will increase the risk for HIV exposure for both sexes. In rural Zambia, male sexuality for some young men consisted of their ability to have extramarital sex “to prove whether they are real men” or “always feeling the desire for sex” (Ndubani et al. 2003). The majority of these young men thought that they were at risk of contracting HIV because they thought that they “lacked the ability to control their sexual desire.”

In Brazil, there are few epidemiological and strategic standard initiatives that are directed towards heterosexual men (Rasera et al. 2004). Many people instead believe that only gay men and drug users will be infected and that a virile man will not catch HIV. In Sweden, “late testers” are heterosexual men (Brännström et al. 2005). Why these men do not test for HIV earlier is questionable, but asking for help (having a test done) and caring for one’s health could be seen as feminine (Courteney 2000). Men and boys often reject healthy thinking and healthy behaviors to achieve manhood and set aside their own health care needs. This is how men are constructing gender. Our study on HIV testing revealed that men generally resisted testing due to shame and fright, fear of painful examinations, deformity of their genitals, or worries about STIs (Christianson et al. paper IV). In one group of young men, they claimed that for men STIs could be seen as maliciousness for men. The fear that something could be wrong, such as catching a STI, could “reduce a man’s status in masculine hierarchies and raise his self-doubts about masculinity” (Courteney 2000).

The bars were settings that facilitated sexual relations and hold a structure where the creation of difference between the sexes, a difference that is not natural, essential, or biological, but a doing that strengthens the “essentialness” of gender where

gender doings were taken place. To “do” gender does not always mean that young women and men live up to normative perceptions of femininity or masculinity (Fenstermaker and West 2002): if the feminine trait is considered to be passivity and the masculine trait means forwardness. Instead it could also be to engage in behavior at the risk of gender judgment, where some young women claimed that they were active agents to choose a partner, initiate contacts, or “buy a beer” for young men to check if he was interesting or not (Christianson et al. paper I). Young women who “take what they want” can perhaps be viewed as too self-centered. For young heterosexual women to have sex with a partner that is a boyfriend makes love beneficial because in a stable relation the sexual practice is transformed from being self-centered to sexual reciprocity and care (Berg 2002). Therefore, young women live up to feminine expectations. According to West and Zimmerman, they note that it is probably unavoidable to “do” gender as long as a society is divided into essential differences between men and women and a placement in a sexual category is obligatory.

There is a risk that the definition gender = woman hides that there are many distinctions between different women and different men and the influence of age, ethnicity, or class (Dowsett 2003). Hence thinking about gender as something feminine will tell us very little about men. The author reminds us all that we can focus on the distinctions between men and women, but we must focus on other distinctions as well, such as sexual orientation, age/generation, or the particular sexual culture of any given society. This type of focus will allow for a gender analysis based on gender without the “vulnerability of women” and “men’s perpetration”, focusing on the relational, cultural, and contextual social determinants of HIV risk that are operating in the spreading of STIs (Dowsett 2003). For instance, if we understand gender as static differences and divisions between men and women, there is a risk that women are seen as innocent victims or sources of infection while men are seen as perpetrators. These stereotypical representations of female and male traits, “two notions of gender,” where difference and separation are domineering, shape what looks “normal” and “natural.” Instead, we can look behind these feminine and masculine traits and change these prevailing ideas, recognize the problem, and act by seeking new ways to contribute to more healthier sexual lifestyles among many men worldwide (www.sida.se 2006). This would also contribute to women’s health in many positive ways.

# CONCLUSION

Paper I. As long as CT screening is focused solely on young women, the risk is that young women will both define and see themselves as “sources of contamination,” while young men do not see themselves as transmitters. Our findings highlight the potential harm that preventive measures focusing mainly on young women can do. It is important to speak out clearly regarding transmission and infection; it takes two to be infected and protection must be a shared responsibility. Public health interventions should be directed towards encouraging men to take equal parts in sexual health. CT screening of men is one important step.

Paper II. The view that HIV is not a problem in Sweden has implications for young people in our country. This study reveals mechanisms that contribute to vulnerability and varied agency, which is helpful for understanding why and how young people are at risk of catching HIV. To consider the role of gender and social background in the context of risky behaviors could be developed from these findings.

Paper III. The Law of communicable Diseases Act supports and burdens young HIV+ people. A lot of responsibility is put on them. Disclosure to sexual partners is often difficult. Lots of efforts must be put on positive rewards concerning disclosure to diminish the risk for transmission and to teach communication strategies in negotiating safer sex. Staff with extended education on sexuality would be a routine compliment in HIV care. Safer sex behavior from the uninfected young women and men is another must if an epidemic is to be avoided.

Paper IV. Participating in a focus group interview was an “eye-opener” for many. Therefore, reconsidering risk in a counseling conversation following an HIV test could be a good idea. Liberal HIV-testing among young men and women could evoke insights and maturation and start a process of reflection concerning their sexual risk taking behavior.



## **IMPLICATIONS FOR PRACTICE**

These preliminary suggestions are emergent ideas that can give a hint about what can be worked on within public health.

### **Gender and youth clinics**

When Jarlbro performed a study that concerned the staff and the visitors at the youth clinics in the mid 1990s, her results showed that 96% of the staff members were middle-aged women and 92% of the visitors were young girls and young women (Jarlbro 1998). Today, the majority is still young women and around 10% of the visitors constitute young men. This is problematic, as the target group for the youth clinics are “all young people,” which is not yet fulfilled. Therefore, it is important to facilitate a more gender sensitive approach towards the preventive work at the youth clinics in the near future. A gender sensitive approach does not solely mean that more men should be engaged in the work at the clinics; it also means that education about gender is necessary to understand why boys and men are not reached and what could be done to change this ongoing trend and how and why young women can gain from this change.

### **Gender education at youth clinics and other settings in primary care**

The structural level of prevention must address the role of gender. In settings such as youth clinics and primary care, to offer education that focuses on gender to the health care providers will help reduce the negative emotions that are surrounding Chlamydia testing. At the youth clinics in Sweden, CT testing is focused on young women as most of the visitors are young women and the risk is that young women both define and see themselves as “sources of contamination,” whereas young men do not see themselves as transmitters. This awareness has to be elicited among health care providers and politicians as there is otherwise an overt risk that we perceive young women to be scapegoats if testing solely is focusing on women. The cost effectiveness of having men tested should not be underestimated.

## **New testing routines that are gender specific**

To control HIV transmission in Sweden there is mandatory HIV testing for blood donors, intravenous drug users, STI patients, immigrants, refugees, and deceased with autopsies and systematic but voluntary testing is for pregnant women, women having abortions, but not for the women's partners. One suggestion would be that the male partners to pregnant women and women having abortions would also become tested. This suggestion would probably decrease the scapegoat-thinking and guilt many young women feel when testing is sex specific. The faster we reach both sexes, the faster we will decrease the spread of STIs.

Easier ways of CT testing is one strategy to diminish the gap between testing among women and men, not only in Sweden, but also in other countries in Europe and worldwide. Testing "over the net" seems to be a feasible alternative and is interesting for both women and men.

## **To offer HIV testing for young people to a higher extent in primary care**

The spread of HIV is very low among youth in Sweden, but the fast increase of CT among young people can change this situation if HIV is "introduced" in this group. The informants in the HIV test study had personal grounds for testing: unprotected sex, many sexual partners, experimenting with drugs, sex abroad, infidelity, needle-stick injuries, or hypochondria. After the negative test result was revealed, they felt "clean" and could restart with renewed ambitions. Hence taking a HIV test does not protect from future infections and how to teach preventive strategies is still not clear. Reconsidering risk in a counseling conversation following a HIV test is one proposal that needs further elaboration. Staff should be taught how to discuss reconsidering risk.

## **Statistics about HIV testing in Sweden**

Reliable statistics are needed that describe how many HIV tests are taken each year in Sweden. Today, there are no national statistics on HIV tests and we do not know the costs of testing.

## **The bars can facilitate safe sex**

As seen in this thesis, the bars, clubs, and dancehalls are settings that facilitate risky sexual behavior among both young women and men. To have easy access to condoms could be a feasible alternative for those young people who will have one-night stands.

## **How to work with disadvantaged young people**

To reduce the risk of catching HIV and to improve sexual health in general, disadvantaged young people, with or without HIV, must be met on an individual and gentle basis. They need time and empowerment rather than oppression. A positive and strengthening social background is important for possessing agency and dealing with difficulties during childhood. Loss or divorce of parents, fragile parents, and foster care are disadvantaged health factors that can contribute to vulnerability. There are many more young people that live in a comparable social and sexual context, such as the informants, and to strengthen their power to act is a concern that must be a prioritized public health issue.

## **Gender based knowledge in sexology**

The progress of antiviral therapy in Sweden can offer young HIV+ people a longer life today. There is a need to teach communication strategies in negotiating protective sex and extended education in sexology and gender for health care providers that are working with HIV+ young patients with heterosexual, homosexual, or bisexual orientation might be a good point. Perhaps there could be some changes in the law that supports this idea.

## RESEARCH IN THE FUTURE

- Future research should explore how pre-test and post-test counseling is experienced by young people who are HIV tested and found to be HIV negative at a youth clinic. The research can be extended to include health care providers at youth clinics and other settings in primary health care where HIV testing is offered and carried out.
- Future research should explore how pre-test and post-test counseling is experienced by young people who receive a HIV+ test result in Sweden and should investigate the emotional aspects of receiving a positive HIV test result. A self-administered questionnaire in 11 countries in Western Europe showed that 61% of the 963 people who received a HIV+ test result got a consultation that lasted less than 20 minutes and half of them felt that they did not receive adequate support when they were informed about being HIV+ (Schrooten et al. 2001). To analyze the interview data from the HIV+ project that concerns this issue will be important.
- The concept *from consensual to forced sex* has a tentative design that could be further refined, and interviews with more young people would be a challenging research task. Recruiting HIV+ people are difficult and time-consuming and to turn to other groups of young people as well could be fruitful. The voices from other young people could strengthen the findings. To involve young trained people of both sexes as interviewees could perhaps give more variation and soundness. To extend the research to include young people living in other countries than Sweden would be interesting.
- To do more gender-based research on sexual behavior with other groups of young people is also needed.
- It is important to inspire health care providers to start youth clinics in countries that are lacking this kind of excellent health care. It is also important to build a network of research exchange between youth clinics in Sweden and in other countries.

## ACKNOWLEDGEMENT

My research has been carried out at the Department of Family Medicine and the Institution of Public Health and Clinical Medicine in cooperation with Department of Gynecology and Obstetrics and National Graduate School of Gender Studies at Umeå University. The thesis was made possible and supported with grants from Swedish Research Council, the County Council of Västerbotten, Swedish National Institute of Public Health and Doctors for AIDS Research Foundation. There are many people I would like to express my deepest gratitude to whose input and collaboration have been important during the research process. Unfortunately, I cannot name them all but will mention the most cherished.

First, I would like to express my appreciation to **the young informants** who contributed with their richness of thoughts and own experiences. Without your great contribution there would have been no thesis. THANK YOU ALL.

The first and most important person during the research education has been my main and number one supervisor, **Eva E Johansson**. I would like to give my warmest gratitude to you for all the support, generosity, discussions, ideas, criticism, and good laughs during the years. You are so creative, curious, and a rapid reader and also so humorous and fun to be with! MANY THANKS dearest.

**Ann Lalos**, my number two supervisor, thank you for your diplomacy, wise comments, genuine interest in this research, and for reading drafts when you were on vacations and for being so calm and friendly. THANK YOU SO MUCH.

**Göran Westman**, my number three supervisor, thanks for “opening up” the gates when I was eager to start my research and rapidly wanted to be a doctoral student. Without your open attitude, I would perhaps have been retired before finishing my thesis. Thank heavens I am still going strong and you are too. MOST HEARTY THANKS.

**Britta Lundgren & Lena Eskilsson**, the two “inseparable” gender experts with a big E! It has been invaluable to be a student in National Graduate School of Gender Studies. Lots of thanks to you for everything, including discussions, courses and relaxation. Thanks to **Monica Forsell-Allergren** for always being kind and helpful.

**Maria Emmelin**, thanks for nice collaboration during the years we have known each other.

**Lars Dahlgren, Åsa Andersson, Elisabet Faxelid** thanks for the critical and constructive advices during my mid-seminar. Especially thanks to Lars for the book on qualitative methods.

**Kerstin Ternulf Nyhlin** thanks for introducing me to grounded theory with elegance.

**Lars Hjalmar Lindhom**, head of the department, thanks for your support and for giving me a room with a view! **Cia Norman**, thanks for all nice chats with you and fast administrative assistance. To the **Department of Family Medicine** and the friends at work, thanks.

**Birgitta Hovellius**, thanks for inspiring me to do research based on gender.

My friends and colleagues at the youth clinic in Umeå: **Karin Svensson, Li Wikander, Mari Rosenbaum, Ulla Larsson, Lisbet Nordin, Elisabet Essegård, Maria Isaksson, Eva Holmlund, Mona Seppelin, Ulrika Heribert Anna Karlsson, Roger Karlsson, and Eva Johansson**. Thank you for recruiting young people to the HIV test project and for shaping a cosy atmosphere at work.

**The staff and heads at the three HIV clinics in Sweden:** Special thanks to **Helena Granholm**, you really knew how to recruit young HIV+ people.

**Knut Lidman**, thanks for appreciating my research project and your kindness.

To **friends in the National School of gender studies**, to all the **midwives** I know, and to my **midwives researchers** and all **friends** of mine, thanks.

**Accent Språkservice Umeå**, thanks for checking my language.

**Pat Shrimton Umeå University**, thanks for language checking.

**Gunilla Bring**, many thanks for reading my thesis and checking the references.

**Carola Eriksson**, my dear friend, roommate, and companion in the hymen research and **Kersin Edin** and **Ulla Danielsson** for great talk about research and other important issues during our lunches at the Birch, thanks.

**Louise Rönqvist**, my dear and close friend for the last thirty years, thanks. Thank you for your “how to do research” advice and for turning me into a net-fishing-for-perch addict.

**John** and **Jacob**, you are my very special sons, whom I love from the bottom of my heart, but who sometimes, give me, pain in my heart.

**Olle** 🎵 *You make me so very happy; I'm so glad that you came into my life* 🎵 and thank you, honey, for all those cosy Fridays with wine, food, and everything else when I was stuck in my framework.

Last but perhaps the most important two persons are **mamma Anna-Lisa** and **pappa Lasse**. You have always encouraged me through thick and thin and thanks for helping me with all sort of things in life.

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