CARE2TALK ABOUT SEX?!

Research on the sexual health of HIV positive heterosexuals from black and minority ethnic backgrounds in the Netherlands.

SOAIDS

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Care2talk about sex?! Sexual health of HIV positive heterosexuals from black and minority ethnic backgrounds in the Netherlands.

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Summary of the Study

This study was carried out as part of the project ‘sexual health of people living with HIV’ (PLHIV) executed by the program Intermediaries, STI AIDS Netherlands in order to obtain data for a sexual health protocol for PLHIV. ‘Prevention efforts to stop new infections are as important as providing […] care and treatment to those already living with HIV’ (1). This should include sexual health. Before the onset of antiretroviral therapy in 1996, many persons with HIV developed AIDS and were often too weak and sick to have sexual intercourse. With the coming of antiretrovirals in the Netherlands in 1996, people living with HIV/AIDS to all intents and purposes, have had their sexual life returned to them; people now live longer because of the medicines that ward off opportunistic infections that would otherwise render them (sexually) inactive. Mortality and morbidity have been significantly reduced. Sexual health has become an important issue for PLHIV again.

People now have to think about how they can have sex again, especially considering their HIV positive status. They must deal with such issues as disclosure to sexual partners, whether to use protection for themselves against other STIs from sexual partners, if they will protect others from the HIV they carry and explore institutions or individuals who can support them in their quest for their new sexual health. The psychologist A.H. Maslow mentions ‘social needs’ as the third layer in his hierarchy of needs, after physiological and safety needs are fulfilled (2). Maslow states that social needs include emotionally based relationships such as friendship, having a family and sexual intimacy. We would therefore argue that good sexual health is essential for the good overall functioning of a human being.

This study has looked at how the HIV specialist nurses perceive the ‘sexual health services’ they deliver to their HIV positive clients on one hand, while on the other hand the study also addresses the patients on what their needs on sexual health are, how they perceive the help they get from the HIV specialist nurses and the challenges they face in trying to practise positive prevention.

The main conclusions of the study are:

HIV specialist nurses:

1 *Job description and tasks.*

The HIV specialist nurses see ‘sexual health’ as part of their job. As a professional group HIV specialist nurses do not use a standard definition of ‘sexual health’ and there is no consensus within the professional group on what the role of the HIV specialist nurse is in terms of sexual health care and support.

There is no uniform understanding of the job tasks with regard to encouraging and supporting ‘safe sex’ within the HIV treatment centres. Most HIV specialist nurses are afraid that too much focus on safe sex and sexual health will endanger the relation with the patient.

A national sexual health protocol is necessary.

2. *Training (Lack of expertise in dealing with sexual health)*

There are differences among HIV specialist nurses concerning skills, knowledge and attitudes with regard to discussing sexuality and offering support to HIV positive clients. Furthermore, there are differences in terms of the approach used in working with people from different cultural backgrounds. Training in these fields is needed.

3. *Environmental factors*

The environmental factors need to be improved; such as a more comprehensive and nationally coordinated approach on for example: shelter for undocumented clients, more routine screening of STIs, the fight against stigma and social exclusion, more efficient interpreter-system and empowerment of women.

HIV positive clients

1. *Task of HIV specialist nurse*

The HIV specialist nurse is the best person with whom to discuss issues of sexual health.

Up till now most HIV specialist nurses have not shown much interest in discussing sexual health issues and most HIV positive clients were unaware of the possibility of bringing up these issues themselves. Mostly only reproductive health is discussed with HIV positive women who wish to become pregnant.

2. *HIV and HAART impact on their sexual health*

Patients feel that HIV as a disease and the medication for HIV (HAART) affect their sexual health; HIV makes them sick and HAART can cause disfigurement, next to other side-effects, and make them sexually unattractive.

3. *Training.*

Gender and empowerment: training is needed for the HIV positive clients, especially women, on issues of sexual health and sexual relations so that they get the necessary life skills to disclose their status and negotiate safer sex. Women from minority ethnic communities need to be empowered to take advantage of the Dutch gender environment where the Dutch welfare system offers other alternatives in terms of, for example, income and protection, which can free them from oppressive sexual relationships. Training is also needed on dealing with self enacted stigma among HIV positive people themselves and stigma in general in the environments they live.

4. *Environmental factor*.

HIV positive clients need a better grounding in how the Dutch social and judicial system works. This should improve their understanding of process and structures pertaining to their right of leave to remain in the country and right of HIV positive persons to treatment, care and support.

This study has focused on the important role of the HIV specialist nurses in providing care and support to HIV positive clients concerning their sexual health. The recommendations are therefore primarily aimed at the task of the HIV specialist nurses. Needless to say that in order to effectively handle this issue, concerted efforts and commitment are needed not only of the HIV specialist nurses but also of the HIV specialist physicians, the interest groups for PLHIV such as the HIV Association among others, the STI clinics, general practitioners and the different black and minority ethnic communities in the Netherlands.

Dutch summary/ Samenvatting

Deze studie is gedaan in het kader van het project ‘seksuele gezondheid van mensen met hiv’ dat wordt uitgevoerd door het programma Intermediairs van Soa Aids Nederlands. Doel van deze studie is het verzamelen van informatie die als basis kan dienen voor een verpleegkundig protocol om de seksuele gezondheid van mensen met hiv te bevorderen. Dit protocol is bedoeld om de verpleegkundige ondersteuning aan mensen met hiv te verbeteren op het terrein van seksueel welbevinden alsmede hen te ondersteunen in het volhouden van veilig vrijen. Een separate studie onder mensen met hiv van niet-Nederlandse komaf bleek nodig. Uit een literatuurstudie van de Universiteit Maastricht (15) bleek dat er weinig bekend is over culturele achtergrond in relatie tot hiv en seksuele gezondheid. Allereerst is er vaak een taalbarrière. Hierdoor hebben mensen uit migrantengroepen over het algemeen meer problemen met het vinden van goede banen en zijn ze economisch kwetsbaarder dan autochtone Nederlanders. Ze leven vaker geïsoleerd binnen hun eigen gemeenschap en weten minder goed toegang te vinden tot zorg en behandeling. Dit geldt vooral voor degenen die (nog) geen legale verblijfsstatus hebben.Voorts hebben mensen uit andere culturen andere opvattingen of gewoontes voor wat betreft seksualiteit, seksuele gezondheid en gezondheid in het algemeen. Kortom, in meerdere opzichten is de positie van etnische minderheden verschillend en vaak achtergesteld ten opzichte van andere groepen mensen met hiv in Nederland. Bovendien is de hiv-prevalentie onder migrantengroepen in Nederland relatief hoger dan onder de autochtone Nederlandse bevolking. Extra zorg en aandacht zijn daarom nodig.

Vóór de beschikbaarheid van antiretrovirale therapie in 1996 ontwikkelden de meeste mensen met hiv uiteindelijk aids en waren zij veelal te zwak om een goed seksueel leven te hebben. Sinds de komst van HAART is de gezondheid van mensen met hiv/aids drastisch verbeterd. Mensen met hiv/aids blijven langer leven en hebben weer toekomstperspectief. Dankzij de medicijnen worden opportunistische infecties voorkomen, die vroeger mensen met hiv vaak seksueel inactief maakten. Sinds 1996 is het aantal mensen met hiv/aids dat overlijdt als gevolg van hun hiv-infectie drastisch gedaald. Feitelijk hebben mensen met hiv hun seksuele leven teruggekregen en is seksuele gezondheid een belangrijk thema geworden. Mensen worden opnieuw uitgedaagd om over hun seksualiteit na te denken, speciaal in relatie tot hun hiv-status. Ze hebben een verantwoordelijkheid om hun (seks)partner(s) te

beschermen tegen hiv. Ze hebben mogelijk vragen over de invloed van hiv en HAART op hun seksuele gezondheid en gaan op zoek naar informatie en ondersteuning op dit gebied.

Een goede seksuele gezondheid lijkt therapietrouw te bevorderen en mensen met een goede seksuele gezondheid voelen zich beter en vrijen over het algemeen veiliger. Dit zijn belangrijke redenen om hieraan de extra aandacht te schenken.

Deze studie heeft enerzijds onderzocht wat hiv-consulenten verstaan onder ‘seksuele gezondheid’ en in hoeverre zij deze bespreken in hun dagelijks werk met hiv-positieve cliënten. Hiervoor zijn negen hiv-consulenten en één maatschappelijk werker geïnterviewd. Anderzijds heeft de studie gekeken naar de behoeften van hiv-positieve personen op gebied van ondersteuning bij seksuele gezondheid en veilige seks. Er is onderzocht hoe zij de door de hiv-consulenten geboden ondersteuning op gebied van seksuele gezondheid ervaren en welke uitdagingen en mogelijke problemen zij ondervinden in het (volhouden van) veilig vrijen. Twintig mensen met hiv, tien vrouwen en tien mannen afkomstig uit een etnische minderheid, hebben een diepte-interview gehad met de onderzoekers.

De belangrijkste conclusies:

Hiv-consulenten:

1. *Taakomschrijving*

De hiv-consulenten zien ondersteuning bij seksuele gezondheid als een belangrijk onderdeel van hun werk. Als beroepsgroep hanteren hiv-consulenten geen standaard definitie van ‘seksuele gezondheid’ en er is geen consensus binnen de beroepsgroep wat precies de taken zijn op gebied van ‘seksuele gezondheid’ en ondersteuning daarvan. De meeste hiv-consulenten hebben moeite met het bespreekbaar maken van onderwerpen als seksuele gezondheid en veilig vrijen. Ze hebben een zekere angst dat te veel aandacht hiervoor de relatie met de patiënt schaadt.

Een nationaal verpleegkundig protocol ‘verpleegkundige ondersteuning bij seksuele gezondheid van mensen met hiv’ is nodig.

2. *Training*

Er bestaan verschillen betreffende de vaardigheden, kennis en attitudes in het bespreekbaar maken en ondersteunen van seksualiteit en seksuele gezondheid door de hiv-consulenten. Bovendien zijn er verschillen in de aanpak en benadering van het werken met mensen uit diverse culturele en etnische minderheden. Op deze terreinen is extra training nodig.

3. *Randvoorwaarden*

Een aantal randvoorwaarden behoeft verbetering. Zoals een breed en nationaal gecoördineerde aanpak van opvang van illegale patiënten met hiv, een efficiëntere screening van soa, de strijd tegen stigma en sociale uitsluiting, een beter tolkensysteem en verbetering van de positie van de vrouw.

Hiv-positieve cliënten:

1. *Taak van de hiv-consulent*

Volgens de respondenten is de hiv-consulent de meest aangewezen persoon om vragen omtrent seksuele gezondheid mee te bespreken. Totnogtoe hebben de meeste hiv-consulenten weinig belangstelling en openheid getoond rond vragen aangaande seksuele gezondheid. Daarnaast waren de meeste patiënten niet op de hoogte van de mogelijkheid deze kwesties met de hiv-consulent te bespreken. Seksuele gezondheid (reproductieve gezondheid) komt voornamelijk aan de orde wanneer hiv-positieve vrouwen zwanger zijn of zwanger willen worden.

2. *De impact van hiv en HAART op de seksuele gezondheid*

Patiënten zien hiv als een ziekte en de antiretrovirale middelen hebben een effect op hun seksuele gezondheid. Hiv maakt mensen ziek en HAART kan verandering van het lichaam en libidoverlies veroorzaken. Hierdoor voelt men zich seksueel onaantrekkelijk.

3. *Training*

Gender en weerbaar maken (empowerment): training is nodig voor hiv-positieve patiënten, vooral vrouwen, opdat ze de nodige sociale vaardigheden leren om hen sterker en weerbaar te maken rond zaken als het vertellen van hun hiv-status en het bespreekbaar maken van veilige seks. Betere kennis van het Nederlandse gezondheidssysteem alsmede van de positie van de vrouw in Nederland zijn nodig opdat vrouwen op de hoogte zijn van alternatieven op gebied van bescherming en inkomen. Extra aandacht voor stigma, al dan niet zelfopgelegd stigma, is nodig.

4. *Randvoorwaarde*

Hiv-positieve cliënten afkomstig uit een etnische minderheid dienen een beter begrip te hebben van het Nederlandse wetstelsel. Bijvoorbeeld, de mogelijkheid of het recht op een verblijfsvergunning en het recht op behandeling, zorg en ondersteuning.

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Last but not least, we would like to thank the twenty HIV positive persons from black and minority ethnic backgrounds in the Netherlands who took part in this study. Thank you for giving us insight into your sexual lives with HIV. Without you this study would not have achieved the depth it has attained. We hope that one day, when the era of stigma and discrimination against PLHIV has passed, we can publish your names.

Iris Shiripinda & Bertus Tempert

List of abbreviations and acronyms:

AIDS	Acquired Immunodeficiency Syndrome
CBS	Central Bureau for Statistics
HAART	Highly active antiretroviral therapy
HIV	Human Immunodeficiency Virus
HMN	HIV Monitoring Foundation Netherlands
IDU	Injecting drug user
MSM	Men who have sex with men
PMTCT	Prevention of mother to child transmission
PLHIV	People living with HIV
RIVM	Rijksinstituut voor Volksgezondheid en Milieu
STIs	Sexual transmitted infections
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organisation
WVAC	Working group of HIV specialist nurses

Throughout the report we use quotes from the respondents of our research. These quotes are printed in italics.

1. INTRODUCTION

As of 1 June 2005, the Dutch HIV Monitoring Foundation has confirmed as registered a total of 10,854 patients with HIV in the Netherlands. This registered number of patients form the national observational cohort on HIV, encompassing 8,326 men (76.7%) and 2,432 women (22.4%) 13 years of age or older. Ninety-six of the patients (0.9%) are younger than 13 years (3).

The distribution of new HIV diagnoses between 2000 and 2005 were as follows: the majority of the male population with HIV is of Dutch origin (508 patients, 37%), sub-Saharan Africa (493 patients, 35.9%), whilst 138 patients (10.1%) originate from Latin America and 75 (5.5%) from the Caribbean.

In the female population, the most frequent region of origin was sub-Saharan Africa (975 patients, 49.0%) with 494 women (24.8%) originating in the Netherlands. The proportions of female patients from Latin America and the Caribbean were similar to those of male patients: 9.5% (188 patients) and 5.8% (116 patients) respectively. The HIV Monitoring Foundation has recorded a decrease in the number of new HIV infections among heterosexual migrants coming from HIV endemic areas, especially Sub-Saharan Africa. Yet the number of pregnancies among HIV positive women from Sub-Saharan Africa in the Netherlands is still on the rise, as well as the number of women being treated with HAART before or during pregnancy (3).

Other sexually transmitted infections (STIs) are also a problem among persons from ethnic minority backgrounds. For example, in a large population-based pilot study on Chlamydia trachomatis (2002/2003) carried out by Soa Aids Nederland and four municipal health services (4) the overall prevalence was 2.0% (Cl:1.7-2.3); 2.5% (2.0-3.0%) in women and 1.5% (1.1-1.8) in men. Prevalence was significantly higher among Surinamese-Antillean participants: 8.2% (Cl: 3.9-12.5).

The RIVM (Rijks Instituut voor Volksgezondheid en Milieu) reported in 2005 the following figures on the prevalence of HIV:

Table 1: Number of HIV cases by transmission risk group and region of origin

Region of origin	MSM (%)	Heterosexual (%)	IDU (%)
The Netherlands	4113 (74%)	1025 (30%)	376 (67%)
Western Europe	424 (8%)	106 (3%)	99 (18%)
Central Europe	59 (1%)	55 (2%)	8 (1%)
Eastern Europe	21(0.4%)	11(0.3%)	10 (2%)
Sub-Saharan Africa	71(1%)	1539 (44%)	6 (1%)
Caribbean	147 (3%)	193 (6%)	5 (1%)
Latin America	331 (6%)	327 (9%)	22 (4%)
North America	134 (2%)	7 (0.2%)	6 (1%)
North Africa & Middle East	29 (0.5%)	54 (2%)	13 (2%)
Australia & Pacific	17 (0.3%)	1 (0%)	1 (0.2%)
South East Asia	153 (3%)	132 (4%)	10 (2%)
Not reported/not known	43 (0.8%)	7 (0.2%)	7 (1%)
Total	5556	3465	563

RIVM report 441100022/2005

The incidence of HIV by regions of origin actually calls for a critical look at the group defined as the 'migrant' population, in the Netherlands often referred to as 'allochtonen'. According to the definition of the CBS an 'allochtoon' is a person whose parents or one of them was not born in the Netherlands, or he or she, him/herself, was not born in the Netherlands. Using this definition, and looking at the distribution of HIV between the non-Dutch and the Dutch, there is reason for concern since HIV is over-represented in the first group.

There is a serious concern because some regions represent serious prevalence: 35,9% of the new HIV infections in the Netherlands is found among men from Africa south of the Sahara. The women from this region represent 49% of the HIV infections among women in the Netherlands. (3) It can be concluded that, compared to the Dutch population and given that migrants form only 11% of the population, the HIV prevalence is relatively high among persons from ethnic minority backgrounds. There have been various explanations put forward to explain this disproportionate distribution of HIV infection between the Dutch and non-

Dutch; namely that there is an increase in mobility between the Netherlands and home countries with high HIV prevalence and that the non-Dutch more often engage in high-risk behaviour.

Since the statistics of HIV and sexually transmitted infections generally are rising slowly among the heterosexual population in the Netherlands, it has become increasingly important to facilitate prevention at different levels: primary, secondary and tertiary. Primary prevention focuses on people with and without HIV in order to prevent further spread of HIV. The secondary level focuses on early detection by testing and ensuring that PLHIV do not get other STIs or other HIV strains. At a tertiary level PLHIV are supported so that they do not suffer unnecessarily from the effects of HIV. Besides the aim to delay disease progression, this also involves support on sexual well being and intimate relationships.

There is a growing need to understand the sexual behaviour of HIV positive persons from ethnic minorities, since they are the second worst affected group in the Netherlands. It was agreed by the advisory commission for sexual health that it is necessary that people living with HIV are included within the sexual health study if positive prevention is to work. According to UNAIDS:

> The response to HIV and AIDS must contain comprehensive prevention and treatment strategies in order to prevent new infections while providing critically needed care and treatment for those already living with HIV (The status and the impact of the three diseases, UNAIDS/WHO, 2004).

This study builds on the STI/AIDS policy (5) of STI AIDS Netherlands. On 1 January 2004, the Dutch Ministry of Health has actualised the national STI/HIV prevention policy. Within this plan, it was explicitly stated that more attention be paid to HIV/STI prevention among the black and minority ethnic population, drug users, and PLHIV. The HIV Association Netherlands has an important task in this and the programme Intermediaries of STI AIDS Netherlands specifically has a role in providing support for professionals in the HIV treatment centres. A special ad hoc advisory team was set up to advise on work pertaining to the sexual health of HIV positive persons in the Netherlands in general; this study on ethnic minorities is part of this project.

The advisory commission for sexual health is unanimous in their opinion that there is little being done, besides among men who have sex with men (MSM), in terms of prevention of further STI/HIV transmission by the HIV infected - positive prevention. Another more important reason is that there is now a growing realization that the HIV infected persons,

thanks to antiretroviral drugs, increasingly are engaging in sexual relationships. PLHIV might need support to have healthy sexual lives, in order not to spread on HIV or other STIs, and to protect themselves against contracting other STIs or other strains of HIV from their sexual partners, which might adversely affect their health.

The STI clinics and the HIV treatment centres have over the years been more occupied with providing information on medication and surviving with HIV than with the sexual health of the HIV infected patients. With the advent of antiretrovirals and the prospect of many more healthy years for those living with HIV/AIDS, the sexual behaviour and health of patients is being put back on the agenda. We hope this study contributes data that will help formulate the protocol on the sexual health of PLHIV for the HIV specialist nurse.

1.1 The HIV health care system in the Netherlands

In the Netherlands the general HIV health care works as follows. After the diagnosis of HIV or AIDS, a patient is sent through to a Central Hospital, often referred to as HIV Treatment Centre. There are 23 HIV Treatment Centres in the Netherlands. These HIV Treatment Centres were established by the Dutch Minister of Health to provide clinical care for HIV infected clients in the Netherlands. The patient is referred to the department of Internal medicine where, among other illnesses, HIV is managed. The internist, HIV specialist physician, is responsible for all the technical aspects of HIV treatment, such as establishing a diagnosis, recommending clinical tests, and all other medical related aspects of the health of the patient. The visits to an internist used to be scheduled on a three monthly basis, but since the number of follow-up patients has increased without a commensurate increase in the number of physicians, it has become increasingly difficult to plan these routine visits for every patient (3). Although it would be better if that was possible so that there could be early detection of undesired medical developments in the patient, less frequent follow up does not necessarily have to have adverse effects on the patient.

In these HIV Treatment Centres there are specially trained nurses (HIV specialist nurses) who are supposed to see HIV positive clients two to four times a year, after their routine check-up appointment with the internist/physician. The HIV specialist nurse often has more time for the patient than the internist. The specialist nurse is responsible for giving extensive information to the patient on their medical condition, and social and psychological support. The information ranges from the epidemiology of HIV, how it develops itself within the human body, how it can be controlled by medication, aspects of the medication, the

importance of adherence to the regimen and any other information that a nurse might consider important for the patient in terms of dealing with HIV/AIDS. The last point can also entail discussing the sexual health of a patient in as far as it can impact on the progression or deterioration of their medical condition.

This study has focused on HIV positive clients in order to find out from them what their needs are concerning sexual health and also what their experiences are with their HIV specialist nurses who are the only professionals, other than the internist, whom they see in respect of their sexual health. There are HIV infected persons who do not see the HIV specialist nurses, such as those who are not under treatment or others who just do not see the necessity for this. Moreover, not every HIV infected person who is on treatment is assigned to an HIV specialist nurse.

The study was necessary to gain an impression of how HIV specialist nurses are dealing with the sexual health of HIV positive clients and how the patients experience this service. It was important to find out if there are any differences among HIV specialist nurses regarding their tasks, their responsibilities, the space they have in dealing with patients (how far their work is dictated by protocol) and if they are adequately trained or experienced enough to deal with issues of sexuality. Another question that was fundamental was how the different HIV specialist nurses in the different HIV treatment centres conceptualised sexual health and if sexual health is dealt with in the HIV treatment centres.

Due to some brief research by members of the sexual health advisory commission it was clear before the commencement of the study that there are no real guidelines for HIV specialist nurses on how to handle the sexual health of PLHIV. There is therefore a need for a better understanding of how decisions are made on the issues surrounding the sexual health of the HIV positive patients.

1.2 Justification of the study

A study on persons with HIV from social and cultural backgrounds other than Dutch was necessary because of the different social, economic and cultural contexts that these people, as foreigners, experience within the Dutch society, how they experience their lives with HIV in their communities and, ultimately, how they live their sexual lives. Some studies

have shown that migrants and minorities are insufficiently incorporated into the economic and institutional context of the Netherlands (6).

Generally speaking, persons originating from other countries in the Netherlands are less educated and less economically empowered, compared to those born in or to Dutch parents in the Netherlands. At the moment the Dutch government is concerned to redress this disparity between the non-Dutch and the Dutch. This is being done through the provision of an integration course that is supposed to improve the migrant's level of knowledge of the Dutch language and of Dutch 'norms and values'. This integration course is expected to have the effect of eventually closing any social and economic gaps between the Dutch and non-Dutch population.

There are more than 100 minorities of different ethnic origin living in the Netherlands. It is, of course, pretentious to speak of 'ethnic minorities' as if they were one homogenous group, with the same experiences of living with HIV/AIDS. While acknowledging the fact that the experiences of an African woman infected with HIV might not be the same as that of an African man, let alone of that of a woman from Latin America, there is less social and economic distance between the non-Dutch of different minority ethnic backgrounds than with the general Dutch population. There are more experiences among the migrants that bring them closer to each other than to the Dutch; poor integration into the Dutch society partially excludes them from benefiting fully from services, as does their being 'other' and sometimes being visibly non-Dutch, especially in the case of black minority ethnic background. The Dutch language may form a barrier to optimal utilisation of the Dutch medical health system for all people who have to learn Dutch as their second, third or even fourth language. Being a foreigner in the Netherlands usually means having to build up a totally new social support network, living among a small group of persons from the same countries or region, or other non-Dutch, which makes social control and dealing with one's sexual health more challenging.

1.3 Steps taken towards preparing this study:

In preparation for this research a number of steps were taken:

- Fact-sheets (literature) on the support on sexual health of both homosexuals and heterosexuals with HIV were gathered.
- The fifteen-minute introduction of a video made by the HIV Association Netherlands on responsibility issues in sexual contacts was watched in order to see relevant issues for persons living with HIV/AIDS. The rest of the video is used for in-house training only.

- Preparations towards the development of a protocol were started by some HIV specialist nurses in the hope of refining their work when the quick scan was complete.
- An advisory group was set up to help with the research on sexual health for people with HIV. It is this group that recommended that research be carried out on the sexual health of HIV infected persons from black and minority ethnic backgrounds.

The members of this advisory commission are:
Ronald Berends, STI AIDS Netherlands
Maartje Liebregts, HIV Association Netherlands
Gerjo Kok, University of Maastricht
Anneke van IJperen, Working group of HIV specialist nurses (WVAC)
Bouko Bakker, Schorer
Jan van Bergen, STI AIDS Netherlands
Iris Shiripinda, STI AIDS Netherlands

2. GENERAL OBJECTIVE:

To obtain empirical information from HIV specialist nurses and HIV positive heterosexual clients from black and minority ethnic backgrounds in order to produce a sexual health protocol for HIV positive heterosexual persons. This protocol is meant to be used by the HIV specialist nurses to support HIV positive clients in their sexual well-being and encourage and/or enforce safer sex.

Specific Objectives:

1) To hear the opinions the HIV specialist nurses have on assuming a role in enforcing and/or encouraging HIV prevention among the HIV infected.
2) To find out if HIV specialist nurses would like to take it upon themselves to deal with the sexual health for HIV positive patients, beyond concentrating on medication issues.
3) To know whether HIV specialist nurses feel adequately trained to handle issues on sexual health with patients.
4) To learn how HIV positive persons from black and minority ethnic backgrounds perceive the sexual health services offered to them by the HIV specialist nurses to date.
5) To learn whether HIV positive persons feel the HIV specialist nurses should be the focal point for addressing their sexual health issues/problems.
6) To find out if the HIV positive persons feel there is need for such a service/protocol for their sexual health and, if so, in which areas.
7) If men, women and young HIV positive clients have the same or different needs in terms of sexual health, and what these specific needs are when pertaining to support from HIV specialist nurses.

3. METHODOLOGY

This study was a quick survey, research carried out within a limited period of time, with a small number of participants and a limited budget. The disadvantage of a brief survey is that the sample is too small to warrant claims that it is representative of established phenomena over the general population. However a quick scan is useful to indicate issues that are of importance to the group studied and the research can be easily organized.

3.1 In-depth interviews with participants

The research was done by means of in-depth interviews to dig deep into issues. These interviews were in the form of semi-structured questionnaires that tackled all necessary issues relevant to sexual health: physical aspects such as libido, psychological and social-relational aspects (7). The structure of the questions allowed enough space for the interviewer to ask additional questions as the interview unfolded and for the respondent to raise pertinent issues that the researchers had not included in the study.

This method was chosen above ‘focus group discussions’ to avoid socially acceptable and/or politically correct answers. People generally do not find it easy to talk about their sexual life and sexual health (8). They might be reluctant to answer personal questions in a group session.

Looking at different issues such as ‘sexual health’, ‘safer sex’ and ‘unsafe sex’, we considered that focus group discussions would not be advisable. To some extent this also applies to the HIV specialist nurses. In the presence of colleagues the HIV specialist nurses might feel forced to give politically acceptable answers to delicate issues such as their personal opinions about sexual perceptions of patients from other cultures, which would not be beneficial to the research. On the other hand there were practical difficulties in organising a group meeting of HIV specialist nurses within a short time. Therefore we spoke to nine HIV specialist nurses individually. From the total of nine HIV specialist nurses we interviewed, eight out of them work with adults and one with adolescents. The reason for including an HIV specialist nurse for children in the research was to find out when and how sexual health becomes an issue in the work of HIV specialist nurses with young HIV positive clients. We also spoke to one social worker, since some of the PLHIV with difficult socio-economical situations told us that the social worker was very important to them, also at the hospital. The ages of these ten respondents ranged from 34 to 59 years of age.

The interviews were all done within four weeks. Nine were with HIV specialist nurses, one with a social worker and 20 with heterosexual clients from ethnic minority background (10 men and 10 women).
The interviews were done with persons from the following countries;

Women:	Age:	Men:	Age:
Nigeria	26	Uganda	32
Zimbabwe	33	Suriname	40
Rwanda	23	Peru	43
Mexico	40	Cape Verde	47
Cameroon	37	Cameroon	33
Thailand	40	Sudan	41
South Africa	40	Sierra Leone	28
Kenya	34	South Africa	40
Suriname	34	Ethiopia	22
Columbia	36	Nigeria	38

These persons live in the following places throughout the Netherlands: Amsterdam Centre, Amsterdam South-East, Amsterdam Osdorp, Utrecht, Papendrecht, Almere, Tilburg, Amersfoort, The Hague, Leeuwarden, Elburg and Culemborg.

3.2 Language:

All questionnaires and interviews were made and carried out in English. The reason for this was to see how good and comfortable the HIV specialist nurses were in English, since most of their consultations with their clients from black and ethnic minority are in a foreign language. By doing the interview in English we simulated the real life situation, as if the HIV specialist nurse was talking to a non-Dutch speaking client from ethnic minority background.

3.3 The HIV specialist nurses:

One member of the advisory commission Sexual health is an HIV specialist nurse. She contacted all members of the WVAC through e-mail inviting them to take part in the research. The response was not high and came mostly from the four big city hospitals (Amsterdam, Rotterdam, The Hague and Utrecht). On the basis of these responses appointments for interviews were made. On three occasions the researchers made contact directly, which

resulted in Radboud University Hospital, Nijmegen and Sophia Children's Hospital, Rotterdam joining the study. On average these interviews took one and a half to two hours and were all recorded on tape. The main topics in a four pages questionnaire that contained 41 questions were:

- How do you define sexual health?
- What do you think about making the sexual health of HIV positive clients a task of the HIV specialist nurse?
- How comfortable are you in discussing sexual health issues? With women from ethnic minority backgrounds? With men from ethnic minority backgrounds?
- Do you think your clients from ethnic minority backgrounds practise safe sex?
- Is there a difference in sexual health delivery services between documented and undocumented clients?
- What are the most common sexual health problems reported to you by women? By men?
- Do you think HIV or HAART has an impact on sexual health?
- What are the specific problems of undocumented migrants concerning sexual health?
- What can be done by the HIV specialist nurse in order to improve the sexual health of HIV positive migrants?
- How can the HIV specialist nurse support the client in practising safer sex in the long term?

(See appendix page 71)

3.4 The HIV positive clients

Sampling of the respondents

At the very outset of the study, the researchers contacted two organizations that carry out activities with and for people living with HIV. We also made contact with two African women, one who is living with HIV herself and is a coordinator and facilitator of a group of PLHIV, Josephine Okumu, and another who also does a lot of work in supporting PLHIV, Sara Mwiza. These two African women key informants are well versed with the field of HIV and AIDS in the Netherlands and were instrumental in facilitating contacts especially with people from African backgrounds living with HIV. The two organisations helped us to make contact with patients of non African origin. For the assignment, we found it important to bring out the different experiences of PLHIV from diverse ethnic and cultural backgrounds.

The researchers actively sought to interview as many men as women in order to have a comparative approach in terms of the sexual health needs of men and women. One of the researchers approached the members of the different organizations for PLHIV and openly invited persons who wanted to take part in the study. The response was overwhelming. A total of 23 women wanted to take part in the study, while 19 men registered their willingness to participate. Due to time constraints and that the study was meant to be just a quick scan, the PLHIV participants were limited to 20.

A selection of PLHIV was made, based on the legal status of the person in the Netherlands, age, sex, education level, whether they had an HIV specialist nurse and if they would be willing to talk openly about their sexual health and activities within the framework of the study. We chose to interview participants that were documented, but also those who were undocumented in order to see whether their experiences to sexual health care was influenced by their leave to remain in the country status. We chose ten men and ten women.

The interviews with the clients were all done by one researcher, who herself is from an African background, with some help from African women. There is ample evidence to support the advantages of carrying out research among one's own community (9, 10). The HIV positive persons also expressed their ease at discussing their intimate sexual lives with a 'sister' from their community rather than an outsider, a white, male Dutch person. Explicit permission was always sought by telephone first and the researcher enquired if they preferred seeing the researcher alone or with one of the facilitators. Most of the respondents chose to meet the researcher alone. They found the presence of a third person intrusive and did not want to feel 'watched'.

It has remained difficult for white people/native Dutch people to carry out research among people of black and ethnic minority backgrounds on sensitive issues such as sexuality or HIV (11). Some persons in the study said that they do not feel that people from other cultures (Dutch in this case) do research among them because they want to help them, but because they want to score in their work without necessarily coming back to them with tangible solutions or help for their problems. Some even felt that some white people always come up with biased findings just to put them down. Two respondents referred to a study recently published by GGD Amsterdam. This study reported that young girls, mostly from Suriname and Antillean background, between the age of 12 and 17 living in the Amsterdam South-East were having sex in exchange for cigarettes or a drink (12).

The researcher would go to a clients' house or invite the client to come over to her house. On one occasion one participant preferred to meet in a public place. None of the participants wanted the interview taped. These interviews took between the two to three hours each. The six pages questionnaire consisted of 83 questions and focussed on the following issues:

- Has your sexual life changed in anyway, positive or negative, since you heard about your HIV status?
- Do you get sex whenever you want it?
- Do you think HIV and/or HAART have an impact on your sexual well-being?
- What problems do you have in terms of sexual health, both psychologically and physically?
- Do you think the HIV specialist nurse is the appropriate person with whom to discuss your sexual health?
- What do you think of the service on sexual health offered by the HIV specialist nurse at this moment?
- What needs do you have in terms of sexual health?

(See appendix page 65)

Although the questionnaire was long, with many questions, the participants did not complain about it, but actually even came up with other issues that they felt had to be taken up in the proposed protocol. Most of the participants said they felt appreciated, since they were being asked to participate in a process that would be used to formulate a protocol that would affect their sexual health. One man even exclaimed, *'Finally, even the medical establishment is waking up to see that our lives are not only about HIV and medication, but that we also are normal human beings that also like to have a good sex life!'* Such sentiments were expressed by the other participants.

3.5 Data analysis

This study has been both quantitative and qualitative. The sample size was twenty for PLHIV and nine HIV specialist nurses and one social worker. While the figures of the participants in the study can be seen as being too small as to warrant generalizations to the general population, the experiences of twenty PLHIV cannot be dismissed as insignificant in terms of representation.

Analysis of data

The data was ordered and coded. Since most of answers were to open questions, all answers to certain questions were listed and answers that seemed to belong together were categorized under different codes/themes. The result of this was that all the answers were re-listed again but now under the different codes, resulting in a few meaningful categories each with a characteristic key word. Some categories were further split up to create room for prioritizing certain answers. Interpretations were then made about perceptions of the sexual health service from HIV specialist nurses by PLHIV and their perceptions of their sexual health needs and the role of the HIV specialist nurse.

The same exercise was done for the HIV specialist nurses.

4. RESEARCH FINDINGS

HIV specialist nurses

4.1) Definition of sexual health

According to the World Health Organisation sexual health is:

> 'The integration of somatic, emotional and social aspects of sexual being in ways that are positively enriching and that enhance personality, communication and love' (13).

All HIV specialist nurses see 'sexual health' as part of their job and all have incorporated this issue to some extent in their daily work. *'HIV is mostly transmitted through sex, so how can we not talk about it?'* was a common remark by the HIV specialist nurses. However they do not see it as the most important part of their job. *'We are nurses and we have skills, but we are not experts in counselling. Sexual health is a difficult, but very important issue'.*

At the same time there does not seem to be any consensus nor standard definition among the HIV specialist nurses on what 'sexual health' actually is. All HIV specialist nurses said something different that varied from a good sexual life to safe sex and reproductive health.

Most frequently mentioned were:

- Sex is a primary need and a crucial part of everybody's life
- Sex is not only about safe sex
- Being able to have a fulfilling sexual life as far as possible
- That people can live with HIV and still have a good sexual life
- Not harming yourself or others
- Not being used or abused
- To be aware of what is still possible sexually when one is HIV positive
- The hope that HIV is not influencing someone's sexual life
- To practise safe sex not only to prevent transmission to others but also to prevent re-infection and other STIs
- How someone experiences his/her own sexual well being
- Whenever having sex, it has to be safe
- Sex is not necessarily penetrative, there are other alternatives

All HIV specialist nurses agreed that talking about safer sex and sexual health is necessary and an ongoing process. They expressed their wish to halt the further spread of HIV and STIs since '*This is not good for anybody's immune system and the public health in general'*.

4.2) <u>Ability and willingness to talk about sexual health.</u>

In general most HIV specialist nurses were quite comfortable discussing sexuality and sexual health, although they all agreed that it is generally not easy to bring up sexual issues for discussion with clients. *'It takes trust and confidence, and this takes time'*. Most HIV specialist nurses said they are most comfortable discussing sexual health issues with gay men since these men seem more at ease discussing sex.

Only a few HIV specialist nurses bring these issues up during the first contact, most HIV specialist nurses wait until there is a basis of trust. The HIV specialist nurses said that while they generally find it difficult to discuss sex with clients from ethnic minority backgrounds, it was relatively easier to discuss sexual health with women from black and minority ethnic backgrounds. The HIV specialist nurses find it most difficult to talk about sexual issues with men from ethnic minority backgrounds. This generally takes more time. One HIV specialist nurse said that '*It also depends on how long they have been living in the Netherlands. I find it difficult to bring up subjects like condom use and safe sex. I have the feeling that black men do not like to discuss their sexual life with a younger woman, even if you are a nurse. With women it is much easier, then I have more the feeling of woman to woman, you know, women's issues are universal'*.

Seven out of nine of the HIV specialist nurses we spoke to are women and this is seen as an advantage for the women patients. Some HIV specialist nurses claimed that they had the idea that heterosexual male clients prefer to talk to a male HIV specialist nurse, given that they rarely bring up issues of sexual nature. This is not always possible because most of the HIV specialist nurses are women.

- **Who brings up the subject of sexual health?** The HIV specialist nurse or the client? All HIV specialist nurses said that this depends on the client and the situation. In 50% of the cases the HIV specialist nurse brings up the subject and in the other half leaves it up to the client. One HIV specialist nurse stated that '*It is not in my system to talk about sexual health, unless I know a patient better. I focus more on the medication'*.

In general most HIV specialist nurses said that speaking about sexual issues with patients was not fixed. They leave it to chance or if there is a connection, time, trust, or if an opportunity presents itself to discuss this.

- **What do women clients know about their body and sexuality?**
  Some HIV specialist nurses said that they had the impression that some women from black and minority ethnic backgrounds had little knowledge about the functions of their bodies and sex in general. For example, one young woman who tested HIV-positive and was pregnant claimed she had never had sex in her life. *' I swear I'm still a virgin!'* she said. She had no clue how she became pregnant, neither did she have any idea about how she became HIV positive. Some other HIV specialist nurses also gave examples that showed that some women indeed did not have a complete understanding of their bodies. *'Women might need some training on the basic functions of their bodies. Transference of information is often made complex because some women are illiterate, but also because of unclear ideas on what sex entails'*.
  Early this year a picture book that explains the most elementary issues of HIV, different ways in which HIV is transmitted, condom use, pregnancy and how HIV-medication works, was published by Soa Aids Nederland in close co-operation with the WVAC (14). All HIV specialist nurses claimed to know this book and all were positive about it. However, only one of the ten respondents has actually used this book. She stated that the shortcoming of the book was that it did not have a visualisation of the HIV resistance. Five HIV specialist nurses said that they had not used the picture book because they did not have any new non-Dutch speaking clients with whom they could use it.

4.3) **<u>Time pressure</u>**:

All HIV specialist nurses told us that they have between 20 to 45 minutes per patient, even less if the workload is high. Their focus is on medical issues, medication and the interpretation of test results. Most HIV specialist nurses we spoke to said that they have a caseload of between 300 to 400 patients per year.

4.4) Experience of nurses in HIV/STI work:

Some of the HIV specialist nurses we spoke to have been working for almost 20 years in the field of HIV prevention and care. Others are relatively new, with the shortest serving nurse working for two years. In general, a significant number of the HIV specialist nurses have a great amount of experience in working in health care, working in the HIV field for more than 15 years. The length of service did not seem to have much influence on the ability to talk about sexual health issues. We did not find much difference in the level of ease or discomfort in discussing sexual health issues with their clients in relation to the length of years working in the HIV field. *'I'm working almost 20 years in this field and I still find it difficult to go into depth about sexual health. I can give some basic information, but I'm not an expert on sexual health. Sex is not a subject that one speaks about easily, especially when there's HIV involved, when there are feelings of guilt and shame involved and all this in a language that for the both of us (HIV specialist nurse and client) is not our mother-tongue'.*

4.5) Language

The level of English of the HIV specialist nurses we spoke to was reasonable to excellent. Some HIV specialist nurses also speak French, Spanish or Portuguese. On several occasions clients bring a relative or friend who translates. However some HIV specialist nurses said that in these cases it is sometimes difficult to know whether the translation is done properly and objectively. In most hospitals there is the possibility of using interpreters; however they are not always available and have to be arranged well in advance. In cases where there is a third party involved for translation it is difficult to talk about personal and private matters such as sexual health and sexual well-being, so these conversations do not go much further than giving information about safe sex. In the hospitals we visited the HIV clients population consists of 25 to 35 different nationalities.

4.6) Whether HIV specialist nurses enforce HIV prevention or just give information:

All HIV specialist nurses we spoke to said that they encourage but they do not enforce safe sex. They said that everyone is responsible for their own actions. The general belief was that too much focus on safe sex might scare off the clients and that they might not come back. One HIV specialist nurse said that: *'I want to have a good contact with my client and I do not want to control him/her. I am a nurse and not a policeman'.* Most of the HIV specialist nurses

emphasised that they were always in dilemma of wanting to encourage safe sex but not becoming moralistic and risk scaring away patients.

4.7) Motivational Interviewing

Two of the HIV specialist nurses related having been involved in the development of a programme 'HIV & Sex' concerning prevention of HIV amongst HIV positive MSM (15). Basic elements of this programme are bibliotherapy (16) and Motivational Interviewing (17). Bibliotherapy can be described as the use of written materials in order to support people in solving problems or changing behaviour. The Motivational Interviewing method is a directive, client-centred counselling style for eliciting behaviour change by helping clients to explore and resolve ambivalence. Compared with non-directive counselling, it is more focused and goal-centred. The examination and resolution of ambivalence is its central purpose and the counsellor is intentionally directive in pursuing this goal. As part of the programme 'HIV & Sex', a self-aid guide for HIV positive MSM was developed. (6).

The two HIV specialist nurses explained that they used the Motivational Interviewing method in their counselling with HIV positive MSM and they are having positive outcomes. They said by using this method that during the first consultation with the client they would identify an issue (what do you want to change?) to work on. They would look at the issue (for example safe sex), make an intervention plan and come back to it during the next appointment. Both HIV specialist nurses said this Motivational Interviewing might also work for clients from black and minority ethnic background.

4.8) Sexual health problems of women mentioned by the HIV specialist nurses:

- How to find a partner with whom to have a relationship (sex)
- How to protect themselves against STIs and re-infection of HIV
- Fear of starting new relationships
- Fear of infecting another person
- Feelings of insecurity about their (skinny) body, poor self-image, fear that HIV shows
- Lack of sexual desire and enjoyment
- Side effects of medication: lipoatrophy, lipodystrophy
- Difficulty of bringing up condom use, practising safe sex
- Dependency on men
- Disclosure and fear of isolation

4.9) Sexual health problems of men mentioned by the HIV specialist nurses:

- Libido loss and erection problems
- Difficulties in finding a partner
- Difficulties in practising safe sex
- Poor self-image, feeling dirty
- More difficulties in talking about sex and sexual issues
- Premature ejaculation
- Fear of having sex, fear of infecting others

4.10) Problems caused by HIV itself and by HAART:

The HIV specialist nurses explained that they find it difficult to tell whether problems of sexual health were caused by HIV or by HAART. Some clients, they said, had problems with sex since HIV was transmitted through sex. *'Sex is a direct confrontation with their HIV status'*. Other clients complained about profound fatigue and feelings of depression, but it is difficult to pinpoint the origin of the problem. The same applies to loss of libido and erection problems. Some HIV specialist nurses told of experiences of clients who were convinced that HAART was the source of their erection problem. *'HAART has stuff in it that kills the libido'* and *'Ever since the medication, my sexual appetite has diminished'*. Some clients ask for Viagra. The HIV specialist nurses sometimes had the idea that Viagra was prescribed too easily, without really looking at the sexual health problem first. It was obvious to the HIV specialist nurses that physical changes (like lipodystropfy and wasting), as a side-effect of HAART, would influence sexual appetite negatively.
They all said that it would be useful to do more research on the effects of HAART on the sexual well being of people taking antiretrovirals.

4.11) Undocumented clients.

All HIV specialist nurses deal with patients who are undocumented. They mentioned that most come to the hospital very sick and in a miserable condition. Often they need to be admitted to the hospital because of serious, sometimes life-threatening health problems. *'For a large number of these undocumented clients not having a proper home, clothes or food, sexual health is the least of their problems. Basic things like help with their administrative paperwork, housing, food and clothing come first. The only thing I might talk about in these situations is safe sex, but there is absolutely no time or space to talk about sexual health'*.

At the time of the research, the Netherlands was in the midst of a political campaign in which a minister with a firm stance on immigration was a contestant. Some HIV specialist nurses expressed their fears that the health service delivery would become even tighter if the right-wing liberal, Rita Verdonk, became leader of her party. They complained that the 'Koppelingswet' (Linkage Act 1998) already makes it almost impossible for undocumented 'migrants' to get medical health care.

One HIV specialist nurse and the social worker stressed that it was important to create stable circumstances in the lives of the HIV infected if positive prevention is to work. *'You can go on and on about how they have to use condoms and protect themselves and others, but if they have to use sex in order to get shelter and food, you can just forget it. It is crucial to look at all those other factors that determine a patient's ability to negotiate safe sex or not'.* The social worker told us numerous cases where they had to intervene with housing and income on behalf of the clients.

4.12) Stance on disclosure of status to partners:

All HIV specialist nurses said that in the hospitals in which they work there is no standard policy on disclosure. They stated that in most cases it should be left to the patients themselves to inform their partner, if they so wish. Patients may enlist the help of the HIV specialist nurse in telling a partner, but the HIV specialist nurses should never pressure patients to disclose their condition. In some cases the team of HIV specialist nurses makes a decision to put on pressure to inform a partner, for example when there is a pregnancy involved. On one occasion an HIV pregnant woman wanted to wait to tell her partner until after the baby was tested negative six months after birth.

One HIV specialist nurse told that *'After disclosure, usually partners stay on and it is the delay in telling and not HIV itself that causes the most problems'.* She also said that in a few cases a person has gone to court when he/she found out that the partner was HIV infected and that the hospital had not informed the partner about the HIV status.

The HIV specialist nurses said that issues of disclosure remain a critical area since most HIV positive patients do not want to inform partners, yet responses are often positive when they do.

4.13) Pregnancies:

Amongst 661 of the women diagnosed with HIV 847 pregnancies were registered (3). Of the pregnant women 97% were diagnosed before their first pregnancy or a maximum of three months into that pregnancy. In the remaining 3% HIV was diagnosed more than nine months after the date pregnancy was first registered. Amongst pregnant women the majority (61%) were from sub-Saharan Africa (3).

In general most HIV specialist nurses are positive about the wish of an HIV positive woman who wants to become pregnant. In most cases these women are referred to the academic hospital in Amsterdam (AMC), which has the most advanced methods and experiences on antenatal care of HIV positive women.

There are, however, certain conditions that HIV specialist nurses take into consideration, psychical, psychological and social conditions. *'When the amount of CD4 cells is very low and when the viral load is high I would advise this lady to think twice about getting pregnant. And when she has no house, I strongly advise against having a baby. Sometimes I see a couple on consultation talking about their child wish. If it becomes clear from the conversation that their relationship is going badly and they think or hope that a baby will bring their lives back to normal, I advise them to wait and resolve their problems first. It's all so normal and human, HIV is just a factor that makes it more complicated. In other words there has to be a certain psychological and social stability.'*

The hospital requires that the HIV positive pregnant woman agrees to the rules and take antiretroviral medication during the last weeks of pregnancy. After birth the infant takes antiviral medication for at least four weeks (18). There have been very good results here. About 200 children from HIV positive mothers to date have been tested HIV negative. The counsellors and the mothers are pleased with these results although it still remains to be seen if the medicines ingested during pregnancy for PMTCT have any effect on the children later on in life.

4.14) Stigma and HIV infected persons

Stigma and discrimination are one of the biggest challenges people with HIV/AIDS face and fear. All HIV specialist nurses mention that AIDS and being HIV-positive are still taboo subjects even after twenty-five years, even among Dutch people. HIV is not talked about easily. HIV positive clients in general fear isolation, discrimination and stigmatization both socially and economically. The HIV specialist nurses said that most persons from black and ethnic minority background came from countries where they had had negative

experiences concerning HIV/AIDS. *'Think back to the murder of Gugu Dhlamini in South Africa at the eve of an AIDS Conference. Then all those documentaries on PLWHA being deserted by families'*. Some HIV specialist nurses mentioned that education on HIV transmission is crucial since HIV is still largely associated with sexuality, promiscuity and certain bad lifestyles, and therefore easily subject to prejudice. Compounding this is the fact that clients from ethnic minority backgrounds are often in a more vulnerable position. As well as exclusion from acceptance and integration into the Dutch culture, persons from ethnic minority background sometimes face further exclusion from their own communities because of HIV/AIDS.

The HIV specialist nurses also said sometimes patients initially had bad perceptions of stigma and discrimination, and often came to the realization that reactions were often better than they had anticipated. Most HIV specialist nurses said they still felt that the stigma of the PLWHA in the Netherlands among ethnic minority communities could be worked on and improved since the medical and social facilities in the Netherlands are so good. The PLWHA does not have to look bad or depend on others. One HIV specialist nurse was not optimistic about stigma and discrimination: '*Nowadays it is seen as someone's own fault when a person now is diagnosed HIV positive and this leads to stigma'*.

4.15) Adherence to HAART

Adherence is of great importance in making sure that HAART is effective and successful. HIV specialist nurses think that clients from ethnic minority background face more problems with adherence than other patient groups. The reasons they mention are:

- In different non-western cultures there is a sense of distrust of modern medication. They are not brought up to take pills but prefer local medicine, special herbs or traditional healing methods. Especially when someone is not feeling ill, it is sometimes difficult to convince a client of the importance of adherence. '*I have patients coming to my ward being very sick. At that stage they're willing to take the medication, but once they feel much better they want to stop, because they do not feel sick any longer. Or they save the pills for the moment they get sick again.'*
- Quite often PLWHA who take antiretroviral medication do not tell anybody about their HIV status and medication. Thus they cannot count on support for adherence to their regime, something which does help significantly. Sometimes family members are not aware of the HIV status of a sibling. The client is afraid of exclusion, stigmatization or discrimination. When visiting family in the country of origin it is

difficult to take the necessary medication daily and secretly. Therefore clients regularly take a HAART break when visiting family.

- In particular, HIV positive clients who live in an asylum seekers centre or who do not have a house of their own have difficulties in taking their daily medication privately. Again fear of disclosure, exclusion and stigmatization play a role.

4.16) <u>Identity of HIV specialist nurses</u>

We tried to explore the extent to which the HIV specialist nurses were aware of how their identity as counsellors can impact on the kind of relationship they have with the patient (woman/man, young/old, black/white, homosexual/heterosexual). Several social scientists have done studies that point out to the importance of 'situatedness' or the politics of identity when researching (19,20). Most HIV specialist nurses do not seem to problematise their own identity as givers of health-care and how this impacts on the health-seeking behaviour of the patient. Only one HIV specialist nurse acknowledged the importance of identity of a care-giver in relation to the patient. *'Sometimes I think it would be good if we had a more native looking nurse to stress certain issues to patients in a culturally acceptable manner, because we are all so white!'*.

Most HIV specialist nurses seem not to be aware that health seeking behaviour of persons from different cultural backgrounds might not be the same as that of Dutch people; language, explanations on how to use medicines or how the medication regimen can be fitted into their life routines. Failure to take this into account can pose problems in terms of adherence if the intake time conflicts with routine activities of patients (21).

4.17) (<u>Policy) changes that have affected the work of HIV specialist nurses:</u>

a) Most HIV specialist nurses were at a loss at this question. Some gave the answers that the 'identification obligation' at hospitals coupled with the 'Koppelingswet' has made lives especially of 'undocumented immigrants' very difficult in accessing medical care at hospitals. We also noticed big posters on the hospital doors stating that one has to show the ID plus insurance card before seeking treatment. Some HIV specialist nurses said that they had made agreements with the front office staff not to send anybody away but to first call a doctor to see the patient. Even so, it is highly unlikely that most 'undocumented' would have the courage to argue with the porters and get to see the doctors who would assess their personal cases. The sense of entitlement among the 'undocumented' is not very high.

b) Most HIV specialist nurses have the impression that HIV nowadays is not a big issue anymore. According to the HIV specialist nurses, HIV is not on the political agenda, the government thinks that everything has already been said about HIV and the budget for prevention is reduced and with the focus only on high-risk groups.

c) HIV/AIDS is no longer regarded as a terminal disease, neither is it considered as incapacitating. Up to five years ago an HIV diagnosis would, according to some HIV specialist nurses. lead almost directly to a disability to work settlement (disablement insurance benefit, WAO) even though some people did not feel sick at all. They had to leave their jobs that they liked, and life seemed to be over. Nowadays people are deprived of the disability insurance benefit (WAO) and forced back to work. They are not used to working anymore, and a full time job often is too much to ask. The government is seen as rigorous and hard. One HIV specialist nurse expressed that '*The whole WAO-issue is a spending- cut in disguise. From the WAO into the Bijstand (Social security) is even worse for the patients. Their standard of living goes lower what might interfere with their medication management'*.

d) Some HIV specialist nurses criticised the fact that contraception is no longer given on prescription by the general practitioner for 21 year- olds and above. Quite often women of ethnic minority background are more vulnerable economically and now they have to pay upfront. Sometimes they do not have money to buy contraception with the result that they might become pregnant. This fact is supported by figures showing that women from black and ethnic minority background undergo ten times more abortions than Dutch women in the Netherlands (22).

4.18) <u>Impressions HIV specialist nurses have on :</u>

a) Migrant clients concerning safe sex.

All HIV specialist nurses think that all people in general, Dutch and non-Dutch, find it difficult to practise safe sex. Three HIV specialist nurses think that people from ethnic minority backgrounds (especially from Africa) are naturally more promiscuous than Dutch people. Fifty percent of the HIV specialist nurses said that they think that especially men from black and minority ethnic backgrounds have more difficulties practising safe sex than the general Dutch population. The reason for this might be the fact that generally people from black and ethnic minority backgrounds find it even more difficult to talk about sex. When people from black and ethnic minority backgrounds

have an STI they feel generally more embarrassed and shocked since this is a big taboo. On the other hand HIV specialist nurses immediately added that they have the impression that also a lot of gay men practise unsafe sex. For both groups (people from black and ethnic minority backgrounds and MSM) a lack of social skills is one of the reasons why people contract STIs regularly. '*Some people simply miss the skills to negotiate and practise safe sex. Somehow they keep on getting infected with STIs over and over again. In some scenes or groups you don't need to take off your pants to get an STI',* one HIV specialist nurse said.

One HIV specialist nurse was under the impression that 20% of the clients have no problems in practising safe sex, but that 80% do. Most HIV specialist nurses state that condoms are expensive and they have the impression that clients from black and ethnic minority backgrounds generally have less money to spend on condoms. '*I quite often hear from clients that they had to choose between spending the money on food and public transport or condoms'.*

The HIV specialist nurses said that only few of their clients from black and minority ethnic backgrounds were diagnosed with other STIs, especially compared to Dutch MSM living with HIV.

b) Cultural differences and health seeking behaviour

All HIV specialist nurses said that they thought it important that they acquire more knowledge of the cultural and sexual background of their clients. They see it as a gap in building trust. For example, in some cultures 'sperm' is seen as 'giving power and strength' which may not accord with condom use. If the HIV specialist nurses knew this, together with the patient, they could try to find solutions. In some cultures (African, Caribbean, Suriname) it is more common for men have multiple sex partners. Condom use is not seen as 'macho', and is therefore not popular. This puts women at risk. Some women are afraid of loosing their partners, who support them financially, and therefore end up having unprotected sex.

Another cultural difference that was mentioned is the perception of illness and medication. This claim by the HIV specialist nurses is supported by research elsewhere that has shown that a patient's culture does affect the experience and expression of symptoms (23). HIV specialist nurses stated that when clients are sick they are willing to take their HIV-medication. After they feel better they quite often do not see the need to continuing taking the medication.

'I'm not sick anymore, so why should I take these pills? I don't need them any longer. Only when I get sick again I might need them again', a client told the HIV specialist nurse. The HIV specialist nurses said they were afraid this would result in resistance building to HAART and often find it more difficult to convince their clients of the importance of adherence.

The HIV specialist nurses sometimes find it difficult to recognise differences among patients from different cultural backgrounds. Most of the HIV specialist nurses did not seem to realize or to know how they could be culturally sensitive and/or appropriate to the patients of black and minority ethnic backgrounds. They did their work as if they were dealing with white Dutch people.

Another cultural difference that was mentioned by some HIV specialist nurses was that they have had experiences with Africans who often were prepared to leave their complex medical situations to God rather than having to deal with complex rules of medication.

5. Research findings HIV specialist nurse for children

5.1) Introduction

In 2004 the World Health Organisation reported 2,200,000 children under the age of fifteen with HIV. Each year there are 640,000 newly infected children, that means 36 newly infected children every 30 minutes. (1) In the Netherlands there are 177 children with HIV of whom 95% have at least one parent who is of non-Dutch background and since 1997 five children have died. (3) Four hospitals, Utrecht, Groningen, Amsterdam & Rotterdam, have a special unit for children with HIV, including specialist nurses for children. Almost all children are treated with antiretroviral medication. The one HIV specialist nurse we interviewed reported that they have problems finding the right combination of medication and finding the most suitable form of administering it to the children. Most common challenges the children face are delayed puberty and growth, lipodystropfy and lipoatropfy. The HIV specialist nurse said that most children expressed their fear of isolation and stigma because of HIV/AIDS.

Most of the children were born with HIV and have lived with it all their lives. This group is growing into teenagers now and forms the biggest group of infected children. Sixty percent of the children's group is older than 12 years. Six out of the sixty-two teenage patients in the Rotterdam hospital became HIV infected through sexual contact, both forced and consensual. Most children are from an African background or have at least one parent who is from African origin.

5.2) Disclosure and stigma

The HIV specialist nurses for children see their patients four times a year and the consultation takes about 40 minutes each time. Children usually come with their parent(s) or a guardian to the hospital, so that the HIV specialist nurses have contact at a family level in order to get a good long-term relationship with the young client.

Treatment with HAART has enabled most children to lead relatively normal lives with a future in prospect. The HIV specialist nurse said that HIV is usually a secret the children carry and therefore they feel isolated. In general the experiences with disclosure to friends are good. It seems that young people are quite easy in dealing with HIV. The fear of isolation and stigma is worse than what happens in reality.

In some cases even siblings do not know about the HIV status of their brother or sister. Feelings of isolation and fear of disclosure are therefore important issues. The HIV infected

youths are confronted with other issues common to other non-HIV infected teenagers such as making friends or starting relationships and discovering sexuality. To quote the HIV specialist nurse: '*These teenagers want to belong to their peers. Illness is not their thing. During a psychological test on seven HIV positive teenagers six of them answered 'no' on the question if they thought they were ill. They only think about HIV if they have to make big decisions like starting a relationship'.*

5.3) Talking about sexuality

The HIV specialist nurses for children usually find it easy to talk about sexuality with the young clientele, especially because this is a subject that the clients are interested in themselves. '*Children do not find it weird if you discuss sexuality openly. Of course they giggle a bit, like all kids do, but they are really interested in knowing about sex and sexuality and they have all kinds of questions.'*

Depending on the maturity of the child, the HIV specialist nurses start with discussing sexuality. They use a CD-ROM and other educational materials to involve parents and guardians in preparing youths on sexuality. The HIV specialist nurse also tries to also give information about safe sex and sexuality to the parent or encourages a parent to discuss this issue with their child. *'Quite often it looks like parents do not know enough about sex or find it complicated to discuss sexuality with their child. The reasons for this are that some parents feel ashamed that their child was born HIV positive (the child got HIV through sex) or they have little knowledge themselves'.*

Sometimes parents ask the HIV specialist nurses to discuss certain sexuality issues with their child. The HIV specialist nurse said she often has to repeat information regularly because of the experience that these children/teenagers forget easily. '*Each year I repeat the facts about the virus, viral load, the medication and other issues, because I have the impression that the facts do not stick. Children are busy with other things than HIV.'*

As the teenager grows older she/he expresses the wish to see the HIV specialist nurse without a parent or guardian and the HIV specialist nurse said they often respect this.
The HIV specialist nurse emphasised that it is also important to educate the parents (or guardians) about sexuality and sexual health.

Concerning what the young patients might need in terms of sexual health, the HIV specialist nurse said, most children are not yet sexually active. The majority of children do not have sexual experience and do not know whether HIV or HAART cause problems concerning

sexual health or where they may need support. At the moment the main concern is more about how to tell their friends about their HIV status.

Most children are motivated not to spread HIV and the few who are sexually active say they practise safe sex, although, there is always the risk that people will give socially acceptable answers. '*Sometimes I think that they just tell me what I want to hear. A few HIV positive girls got pregnant and they said that the condom broke. I also hear quite often that condoms are expensive'.*

The HIV specialist children's nurse we spoke to said none of her clients had contracted any other STI.

5.4) Breaking the bonds of stigma and discrimination

In order to break the stigma and discrimination the HIV specialist nurses for children started in 2002 a support group for teenagers with HIV from 12 to 21 called 'The Young Ones'. Three times a year the HIV specialist nurses organise a special day or weekend for this group. Besides fun and entertainment, they organise workshops and discussions about subjects like 'self-image', 'how to tell a friend that you have HIV', 'stigma' or 'medication'. The favourite topic is 'sexuality and relationships'. In this group the teenagers feel safe, they do not have to hide their secret (or pills) and they exchange ideas and experiences on issues such as beginning relationships, disclosing HIV status and also support each other. For example 'pregnancy' is a vital issue for most girls and it is very encouraging for them to meet an HIV positive young mother with a healthy HIV negative baby.

The Young Ones also participate in (international) congresses and symposia where they give presentations or actively take part in discussions or debates in order to break the taboo on young people with HIV.

Around the age of twenty the teenagers are advised to join the adult hospital. The HIV specialist children nurses help by preparing their clients to take this step. All teenagers see this as a major change. They feel they have to leave 'their safe surroundings' and sometimes they look at adult life as too serious and frightening. The HIV specialist nurses usually support these clients in making this transition by teaching them self-respect and giving them tools to deal with their lives.

6. Research findings on HIV positive heterosexual clients

6.1) Introduction

Many studies done so far in the Netherlands have been largely on the sexual health of men who have sex with men (MSM) rather than on heterosexuals. This is because HIV transmission has largely taken place among MSM and has slowly moved to the heterosexual population. Most of the infections among heterosexuals have been among migrants born outside the Netherlands where HIV prevalence was high, such as Sub-Saharan Africa.

When we began the research, we were not sure what kind of reactions we would get from the PLHIV. We were worried that the participants would give us only socially desirable answers, especially when we had to ask about their sexual practices in terms of safe sex. Although we decided against using focus group discussions and chosen in-depth interviews on a one to one basis, we were still curious about how this would go. Research experiences with other migrant groups elsewhere had taught us that Africans and other migrants like to discuss their sexual lives, within the appropriate context (9,10). After explanations on the uses for the data collected from the interviews, interviews were held. The researcher was well received by all participants who were confident about their role in shaping the future sexual health protocol for sexual health of HIV positive persons in the Netherlands.

There were equal numbers of HIV positive men and women in the study, ten of each. The ages ranged from 22 to 47 years of age. There were some general findings that were applicable to both men and women in the study group. There were also some findings that we can say were more common among women or among men. All the respondents agreed that having HIV had changed their sexual life in some way.

6.2) Socio-economic status

All the participants but one had some kind of income. The lowest paid was receiving 70 Euros a month and the highest almost 3,000 Euros. Women on average received much less than men, while men earned more, mostly through hustling. The lowest paid person was a woman.

Nine persons had a University degree, ten persons had had more than eleven years of schooling. There was one female in the study who was illiterate.

6.3) Sexual health definition according to heterosexual PLHIV

The respondents had different understanding of what sexual health was. Most of the definitions pointed to reproductive health, social access to partners and general physical sexual satisfaction and functioning of sexual organs. Issues that they thought covered sexual health were the following: good physical functioning of the sexual organs, a good mental state so one can engage in sexual intercourse with pleasure, being able to become pregnant and have an HIV free baby without endangering the mother's life, being able to find other people who want to have sexual relationships with them or even just keep them company.

6.4) Role of HIV specialist nurse in sexual health care

Seventeen out of the 20 participants agreed that the HIV specialist nurse was the best person to talk to them about their sexual health. They said that the specialist nurse was the only medical contact they had, besides the internist, with whom they could discuss medical related issues. One woman said that although there were clinics for sexual health, the situation of a PLHIV requires more specialised help than one can get from sexual health clinics. She mentioned that since the hospital already have all her medical records, they would be more suitable help than if she had to explain everything afresh to other medical personnel.

Most of the respondents suggested that sexual health should be taken up with the HIV specialist nurse because it would improve their medical condition. '*When one gets good sex, they are more motivated to live longer, and will take their medication properly. There is little else left to live for if one has HIV and no sex*'.

Two women and one man were of the opinion that sexual health issues were none of the HIV specialist's business, unless if one had a sexually related medical problem such as an STI. The three thought that it was easier and more appropriate for people to discuss their sexual lives and health with friends and family members. One African woman said, '*When one cannot find a partner, it is your friends and family that help to hook you up with someone. If a man has problems with his back (erection) then it's his fellow men who know where to get the concoctions from. Let's not think too European. Our people are specialists in these things; that is helping women get children and men good erections'.*

6.5) (Lack of) discussion on sexual health by HIV specialist nurses

The general impression among the patients was that the HIV specialist nurses do not discuss sexual health with them at all. The initial answer was that HIV specialist nurses always had too little time to cover any issues that fell out of 'medication prescriptions and

HIV related physiological complaints'. Eighteen of the twenty respondents claimed that there was little or no discussion on sexual health, such as sexual feelings, ability to get sexual partners or even physical sexual problems such as erection problems with the HIV specialist nurses.

One respondent stated: '*The visit to the specialised nurse is still too much of pill talk and not sex talk. They concentrate on how I should take my medicine. If you do not open your mouth to ask, you can stay with the problem forever. I have been having problems with getting and maintaining an erection for years now. I had to ask the doctor what I could do about it. And it was not easy to come out to another man that I had such a problem'*.
This man also argued, like others, that sexual functioning, whether it is about the bodily organs or getting access to sexual partners should be a basic question of the HIV specialist nurse. Some respondents claimed that the separation between HIV as a medical condition and sex as a social function dictated the way the medical establishment dealt with HIV patients. *'Men who need Viagra are expected to finance it themselves because sexual practices are not seen as a medical necessity. Otherwise the Viagra would be covered by the medical insurance'*.

The respondents gave several reasons why they thought HIV specialist nurses did not discuss their sexual health with them. *'They know I am a widow and might think widows do not have sex'. 'They have a wait and see attitude'. 'They expect you to tell them your problem'. 'You are just a number. They are in a hurry to see you off. They should take more interest in the human side of our lives, not just behaving like human servicing garages.'*

African men in particular felt that the nurses were rather reluctant to discuss sexual health with them. One respondent said that: '*Sometimes you just feel that they already made their conclusions. They think we are irresponsible and sleep with a lot of women. Maybe they think black men can always get women, but they forget with this HIV it becomes a real challenge. They cannot even imagine that a black man can have problems with getting an erection. You know those things they wrote about black men and how they are oversexed and are irresponsible? They need some serious re-schooling on our sexual behaviour and experiences. It does not help us in any way. You are forced to turn back to our own medicine men on issues of your manhood. The danger is that those African medicines can disturb the working of the antiretrovirals'*.

During the study it also became clear that if infected by another STI, some people did not know where they could go for help. Most of the participants said they would go to their internist or HIV specialist nurse. Most were not aware of the existence of STI clinics. One

woman explained that she experienced extreme physical pain during sexual intercourse, making it difficult to have sex. She explained that she had been experiencing this problem for over three years and when questioned whether she had informed her doctor about this she replied in the negative. '*My doctor is a man and I do not want him looking at my private parts'*. Asked whether she had ever considered asking her doctor to have a female nurse examine her, she said that she had never thought it was possible.

6.6) HAART and sexual feelings

Out of the twenty respondents, nineteen were on antiretroviral therapy. There was a strong feeling among some African participants that HAART affected their sexual health by diminishing their sexual appetite. One man told of the problems he was having maintaining an erection and also mentioned another person '*whose sexual life was totally destroyed by anti-retrovirals. This man has even had to leave Holland because he could not be helped to get his erection back. He moved to England where he now has a girlfriend*'.

Another participant had been struggling with erection problems for three years and was convinced that it was because of the medication. He had asked neither his internist nor the HIV specialist nurse whether there was anything they could do to help him with his erection disorder. He confessed to have contemplated stopping his medication in order to regain 'the power of his manhood' but was scared out of it by a fellow patient who got seriously ill after interrupting his medication intake. One woman explained that she used to feel so sexually aroused that at one point she had to masturbate 14 times in one day. She claimed that after starting with the antiretroviral medication she was lucky if she felt like having sexual contact twice a month. She firmly believed that this was due to the medicines.

There also seemed to be general ignorance among the women and men about the possibilities of referrals for sexual health problems. The African participants mostly laughed about the idea but expressed their willingness to use the facility if offered to them.

6.7) Physical deformation

Two female respondents mentioned physical changes that were caused by the medications as problematic and having an impact on their sexual lives. '*I used to take Viracept, Zerit and 3TC. My breasts became bigger and my ass is gone. I had diarrhoea for five years. How can you have sex while having diarrhoea all the time? The doctor kept telling me that it was normal. I practically used to pee my poo. I became 10 kilos underweight and*

those kilos never came back after I stopped Zerit and got other drugs. I look very unattractive, too thin and the long time of illness has left me looking feeble and sexually unattractive'.

The other respondent who had also been remarkably changed by lipoatrophy - fat displacement in the face and legs - had this to say: '*People always turn around to look at me because they can tell that there is something going terribly wrong with me. This presents you with an extra challenge to finding a partner. You become visibly marked as a sick person*'. This lady had very thin legs and arms and claimed to be ashamed to put on short sleeved clothes or even shorts. '*I know this is not a pretty sight, if not scary altogether*'. These physical changes thus created personal problems for individuals in terms of their environment since people could see they were sick.

Another lady complained that ever since she started taking medication, she sweats a lot. This has spoilt her sexual relationship because her HIV negative boyfriend always became nervous when she was sweating because he knew her HIV status. During love making he would use a towel to keep the sweat from getting of him, which annoyed her immensely. She broke off the relationship.

One woman said she always felt a sense of disgust at having sex since the experience was too confrontational, since she had been infected through sexual intercourse.
Other patients did not experience the diverse effects of the medication for which they could readily blame their poor sexual health.

6.8) Desire for children and pregnancy

Women had the most exposure information about reproductive health from the HIV specialist nurse, and this was mostly if they were pregnant.
'There is no way they cannot touch on that issue. They have to help you make sure that the child is born HIV free. They guide you with taking medication, advise in not taking unnecessary risk in your sexual behaviour lest your baby gets infected and they want to make sure that the baby does not get infected during delivery. They even did a caesarean on me in 2003 to make sure that my baby was born healthy. It helped!'

All of the women in the study have had children or became pregnant after their HIV status was known, except for one woman who said she did not want children and had had two abortions after her HIV status was known. All the women but one gave birth to HIV free babies. The one who had an HIV positive baby explained that the hospital had not screened her because she was not considered as being from a high-risk group. Sixty one percent of

pregnancies among HIV positive women are from women born in Africa south of the Sahara (3).

It appeared that women felt the need to have children after an HIV positive diagnosis. All the women, except one, said having children gave them a new goal in life, to love and nurture their children. There was not one woman who said she had discussed having a child with her partner with the full knowledge of her status. The women either discovered during routine pregnancy checks that they were HIV positive or they sought partners who had no knowledge of their HIV status and conceived by them.

6.9) Sex (safe and unsafe)

All the respondents who had partners who were also HIV positive did not use condoms. Unprotected sexual intercourse with fellow infected partners was the norm. They all said that it was a conscious decision they made with their partners since they all knew what they had. As one man said *'The last thing I have is my sexual organs that can give me the nicest thing of life. A condom is not nice. It is interfering. A positive partner has the choice to refuse unprotected sex. We are adults. We can decide for ourselves. I have chosen to have unprotected sex even though I know that I can get re-infected with another strain of HIV. But so what?'*

There were two women in the study who claimed to be having unprotected sex with men who were not aware of their HIV status. One of the ladies who was having unprotected sex said, '*Why should I go around telling everyone I have HIV? I got this disease from someone else who knew and did not tell me. Under normal circumstances I would not do this but the Dutch state has made my life tough. I get less than 70 Euro per month for food and upkeep. Who in this country can live off such little money? I know for sure that if I would tell my status, I would not get a lover anymore. At one point while homeless, I stayed with a man who used to ask me to have sex with his friend too. One time he complained of itchiness on his penis and he beat me up accusing me of sleeping with other men. I got scared and moved out because I knew that he would kill me if he ever came to know of the HIV'*.

The other woman said that she did not like using condoms since they interfere with the *'real taste of sex. You know it tastes best when you can feel it live and the man can come into you. I hate condoms because they make me itch too. So I do not use them'*. This lady had multiple sexual partners. She even boasted that one of her boyfriends once went for an HIV test and was still negative. *'He did not push me into testing, because he thought I was negative like him. I believe there are people who are immune to HIV, like him'*.

There was also one man who was having unprotected sex with a woman who did not know that he was HIV positive. He said that she always insisted on having 'naked sex' and he was tired of insisting on using protection. '*I have considered telling her about my HIV positive status but I am really scared for her reaction. She makes terrible remarks whenever something on HIV comes on television. So I almost know how she will react. After all, she is the one who keeps insisting on unprotected sex'.*

We asked the question whether PLHIV would readily have unprotected sex with an HIV negative person or one whose status is not known. Eighteen persons said they would rather have unprotected sex with a person who was HIV positive since they knew that their physical health was being regularly controlled and they would not be having other STIs. This of course was not based on evidence since HIV positive persons are not regularly checked on all sexually transmitted infections. However, we found out from the HIV specialist nurses that in most HIV treatment centres not only HIV positive MSM are regularly tested on syphilis, but also other all other PLHIV each time they come for their blood tests.

Seventeen respondents expressed a high degree of responsibility for protecting others when having casual sex with partners who did not know about their HIV status. One African man and another from South America both had two girlfriends each. They said they had unprotected sex with their HIV positive girlfriends but used condoms with the other ones whose status was unknown. In general the men said it was easy for them to practise safe sex if they wanted.

6.10) Reasons for having sex

We asked the respondents the reasons why they had sex. Everyone mentioned the need to experience sexual satisfaction and being appreciated as the main reason for having sex. We also wanted to know, from the women especially, if they felt that they had to have sex in order to get money or other material goods from their partners. The woman from Thailand, like all the women from Africa, said that they expected a man to look after the woman he slept with. They were not sleeping with the man to get money, but they expected the money because the man who slept with them had to take financial responsibilities from them. The respondents found the link made between having money and sex as too gross and that we were oversimplifying things and that their relations were not like those of prostitutes.

Men on the other hand said they had sex with women primarily to satisfy their sexual urges and also as a way of keeping the woman happy. All the African men in the study said they thought it was their responsibility to financially support their girlfriends so they would not look for other men. There was not one man who admitted getting some kind of benefit from a woman lover in the form of money. The men reported though that women rewarded their sexual efforts by taking good care of them. This care was in the form of doing laundry, cooking and cleaning for them.

6.11) Other STIs

One of the questions we asked the respondents was whether they had ever had other sexually transmitted infections after their HIV positive diagnosis. Only one person said he had an STI after his HIV diagnosis. One woman said she often had pain and itching when having sex.

6.12.a) Fear of disclosure

Having HIV made people reluctant to start new relationships because of the need of disclosure or fear of being found out. One man reported that '*When I had a girlfriend and she stayed over at my place, it became difficult for me to take my medication. I did not want her to see that I was on medication in case she would find out what the medicines were for. I only have one room so it was difficult to have any privacy. I was also always tense during sex for fear that the condom would break and I would infect her. I decided to end the relationship'*. The fear of having sex because of the need to inform or prevent the infection of the partner was common in more than 70% of the women. Sometimes the fear was so great they went on to have sex without disclosing and finished the relationship when there was chance of being discovered. On the other hand, in some cases women endured much to avoid disclosure. Women's fears of aggression by partners seemed justified because when asked if they had ever been forced to do things they did not like during sexual contact with a partner, 90% of the women reported having been forced to have anal intercourse, perform oral sex with the man and have him ejaculate in their mouth, to take part in group sex or had even been raped by partners.

There were other factors that made it difficult to disclose their status. Women who did not have their own sources of income and depended on boyfriends as sole providers for their livelihoods said they always found it difficult to insist on protected sex especially if their partner did not want it. '*If you keep insisting on a condom, he might think that you have an*

STI or worse still that you have other boyfriends'. Even among the women who had an income, eight out of the ten also relied heavily on boyfriends to top-up their income. Sex was used as a salient exchange commodity. All the women agreed that when a woman relies on a man, then she has to go all the way in being his woman, which includes having unprotected sex in order to show the seriousness of the relationship.

Three other women who claimed to be having protected sex with their partners, who did not know of their HIV positive status, expressed different reasons for not disclosing this information to their partners. One woman said that she was scared of the reaction of her partner, even though she had been protecting him. The other one said that there was no need for disclosure since she always impressed on him that it was important to use a condom. This lady said that her partner sometimes forced her to have sex without a condom and that *'If he catches the HIV, he will know it is not my fault. I have always handed him a condom and he has chosen not to use it.'* The third woman said that while she tried to protect her lover, she also had to protect herself by making sure that she did not antagonise her lover, on who she was dependent on for shelter, a livelihood and her residence permit. She confessed that it had 'happened a few times' that they did not use protection. She said her boyfriend seemed strong and was never sick and she hoped he was not HIV positive.

6.12.b) Experiences around disclosure

Experiences around disclosure among the women varied. Some women even went on to hide their status from partners if they discovered they had an HIV positive status during their pregnancy.

One woman only informed her partner that she was HIV positive and their baby HIV negative six months after delivery. She said that she had particularly asked the nurses not to tell her husband since she felt that he would be more understanding if their child was not infected, and she could only have that confirmed when the baby was a bit older.

One woman was very upset since she blamed her HIV specialist nurse for having made her disclose her HIV status to her partner without properly planning it first. She said her boyfriend deserted her after hearing the HIV result at six months pregnant. *'The HIV specialist nurse asked me to bring my partner to the hospital when I was six months pregnant. I just thought that she wanted to make him to get a bit more involved in my pregnancy since he never came with me to the hospital. Unfortunately she told him about my HIV status and that was the last time I saw him'.* This was also the experience of another young African

woman who also claimed that her HIV specialist nurse had coerced her into disclosing her status while she was pregnant. Her partner left her.

The need to disclose at an appropriate time as determined by the patient was echoed by most of the respondents. Responding to our question on whether it is the job of the HIV specialist nurse to inform the partner, almost all the respondents said it was better that this decision was left to the client. The specialist nurses could help by guidance in how to break the news, and only help disclose at the invitation by their patient.

The overall impression of the researchers was that most women wish to disclose but in practice they find this rather difficult because of bad experiences in disclosure.

6.13) Adherence to antiretroviral therapy

Out of the twenty participants more than 70% were already on the second line treatment. There was an average to poor understanding of issues of compliance and medication. Many of the participants struggled to explain what compliance meant and especially the term 'undetectable'. Three of the participants were even convinced that they had become HIV negative, but that they would have to stay on antiretroviral medication in order to maintain their good health.

6.14) Sexual health needs

The need to be in sexual relationships with other HIV positive persons was expressed by 18 of the respondents. They said that having a positive partner takes away a lot of stress in a relationship since HIV positive persons can better understand their HIV ordeal and comfort each other. This was echoed by a man whose girlfriend turned out to be HIV negative when tested. *'It became so difficult to enjoy sex with her. She was always busy with checking if the condom was still on, if it had not leaked and she wanted me to withdraw my penis as soon as I came. It became stressful. We even had to rush to the hospital one night because the condom had spilled some sperm'.*

Only one woman explicitly stated that she did not want a man with HIV in her life. She explained that it entailed taking care of the other and *'you know men can play being kids, no way!'*

Some respondents expressed the wish that HIV specialist nurses would support them in finding an HIV positive partner. They said that HIV specialist nurses could help them identify places or even introduce them to some of their patients. *'It would make life a lot*

easier if the HIV specialist nurse could help in hooking us up with other HIV positive persons. They have the whole register of patients'. When the researcher explained the oath of secrecy for medical personnel, the clients proposed that the HIV specialist nurses could even set up an anonymous meeting first or by telephone so that clients could decide if they wanted to meet the other person or not. '*This is what we need. Being asked about how we are doing sexually, if and how I can find a partner and what I can do to have an interesting sexual life even with HIV. I would not mind if the HIV specialist nurse would notice that my bums are too thin and recommend for some shots of botox*'.

The respondents all mentioned not having space and opportunity for to meet fellow HIV infected partners and that using regular channels for finding partners is made more complex by the HIV status, especially since they would have to disclose their status sometime in the relationship. For those who were aware of websites for HIV positive persons, they said these were not always reliable. There was one man who had met his partner through a website for HIV positive persons. Five persons in the research claimed that they did not know how to use Internet.

7. DISCUSSION

a) In most cases HIV specialist nurses only see the sick clients and they are probably the least sexually active. In practise an HIV specialist nurse sees a client two to four times a year. When a patient is doing reasonably well she/he very often sees the specialist even less frequently, quite often only for test results. A complaint that is now heard from both the internist and HIV specialist nurse is that they feel more and more like a mechanic. *'I only talk about cd4 counts and viral load. When these two aspects are okay, the machine seems to function well. There is hardly any room for personal well-being talk nor contact'*. The question, then, is how can the HIV specialist nurses reach the healthy HIV clients (who are doing well) and discuss sexual health, safe sex and sexual well-being with them?

b) Research about stigma/discrimination

Stigma and discrimination are still important issues among black and minority ethnic PLHIV, both self-enacted and from the black and minority ethnic communities. Stigma and discrimination have adverse effects on safe sex and adherence to medication. HIV specialist nurses could play a role in finding out if patients are affected by such things, and how they can help in minimising the effect.

8. CONCLUSIONS

8.1 From HIV specialist nurses

Job description and tasks:

- HIV specialist nurses see ‘sexual health’ as part of their job and would like to take it on as their task with HIV positive clients.
- However sexual health is not a regular part of the consultation. In most cases HIV specialist nurses wait until there is a basis of trust, when there is time or opportunity. This ‘wait and see’ approach allows for gaps and missed opportunities.
- HIV specialist nurses find it difficult to talk about sexual health, especially with men from ethnic minority background. They find it easier with Dutch MSM and women.
- There is no consensus on the definition ‘sexual health’.
- When HIV specialist nurses speak about sexual health it is mostly in terms of safe sex and with women about reproductive health and not about sexual pleasure.
- HIV specialist nurses encourage safe sex; they do not see themselves having a role in enforcing safe sex. They think this might scare away the patients so that they will not come back. Too much focus on safe sex is seen by the HIV specialist nurses as too moralistic. HIV specialist nurses need more tools to support patients in preventing further spread of HIV.

Training:

- There is a need for training about sexual health and STIs.
- There is a need of better understanding of sexual health issues and counselling skills specifically concerning sexual health.
- Some women clients have a lack of understanding on the basic functions of their bodies. Education on this is needed.
- Motivational Interviewing is a successful method in building a steady work relation with the client in order to deal with specific topics like sexual health.

Environmental factors:

- Language seems to be a barrier to patients, especially from Africa and especially when dealing with complex medical issues. Instruction leaflets are often in Dutch and hence patients do not always understand the importance of adherence.
- There is a need of better understanding of different cultures and that different people from different ethnic minority backgrounds might need different treatment.

- Clients from ethnic minority backgrounds generally have more problems with adherence because of poor access to information partially due to language difficulties but also due to some cultural based ideas about medication.
- One reason that some groups in particular are vulnerable to contract STIs is a lack of social skills.
- Undocumented clients are the most vulnerable group and face many basic problems such as housing, food, money and their legal situation. Sexual health is not necessarily the major issue on their list.
- HIV specialist nurses mostly see sick clients and they usually do not see the 'healthy ones' who come twice a year for their blood test check-up. These 'healthy' patients are likely to be more sexually active and therefore an important group to include in the sexual health protocol.
- An efficient interpreter-system is essential for clients who neither speak Dutch nor English. As long as patients do not speak Dutch, information and support in their own language on HIV transmission and treatment is of vital importance for the individual as well as for the community as a whole.
- The fear of exclusion, stigmatisation and discrimination is often mentioned as one of the biggest problems, although there are many positive reactions after disclosure, especially with younger clients. It seems that the fear often is worse than the reality.
- Women, in most cases, depend on men both financially and socially.

8.2 Conclusions from the HIV specialist nurse for children:

- HIV specialist nurses for children play a vital role in the development of a HIV positive teenager. Therefore they need good educational materials in order to inform and support their clients properly.
- Teenagers are interested in talking and learning about sexuality and safe sex and they find it easy to talk about this with their HIV specialist nurse.
- There has to be a constant repetition of issues like medication and safe sex, since teenagers seem to loose focus easily and the quarterly visit is a good moment to discuss these issues.
- It is beneficial to include and educate parents or guardians in sexual (health) issues. Parents or guardians should be asked if they know how to deal with sexual health issues.

- There is not a set age at which to bring up sexual health issues. This depends on the development and maturity of the child. It is crucial for HIV specialist nurses to judge the right time to put sexuality on the agenda with the youth.

8.3 From the HIV positive clients:

Task of the HIV specialist nurse:

- The HIV specialist nurse is the best person with whom to discuss issues of sexual health.
- Until now HIV specialist nurses have not shown much interest in discussing sexual health issues due to lack of time, reluctance, too much focus on the medical aspects of HIV and some prejudice or assumptions about people from other cultures than Dutch. This was the opinion especially of African men. Women had the most exposure to talk about sexual health issues, mainly because of pregnancy.
- Some HIV positive clients are unaware of the possibility of bringing up sexual health issues themselves. They also find it too difficult to talk about sexual health because of feelings of guilt and shame.
- It is important to wait for the appropriate time to inform partners about the HIV status. HIV positive clients should not be pushed to do so by HIV specialist nurses, however these can support the client in advising how to break the news, if the client so wishes.

The impact of HIV and HAART:

- HIV and HAART have affected sexual health of all respondents. Loss of libido, physical deformation, fatigue and feelings of shame and fear were most frequently mentioned.
- There is an average to poor understanding of issues of compliance and medication.

Environmental factors:

- The respondents have unsafe sex mostly with partners who are also HIV positive.
- Seventeen respondents expressed a high degree of responsibility for the protection of others from HIV. Three respondents have unsafe sex with partners whose HIV status is unknown.
- Eighteen respondents expressed a wish to have (sexual) relationships with other HIV positive persons. They think that the HIV specialist nurses should support them in finding HIV positive partners.
- One respondent reported having had another STI after the HIV diagnosis.

- Nine out of ten women stated that having children is important because children give them joy and a new reason to live and appreciate life, also with HIV.
- Especially women wish to disclose to their partners, however, they find this difficult because of bad experiences. Fear of disclosure to partners is an essential issue and sometimes the reason for unprotected sex.
- Women, in general, are more vulnerable, both economically and socially. A lot of them depend on men financially and socially.
- Some African clients mentioned the use of other medication, traditional herbs or divine intervention for boosting sexual healthy appetite.

9. RECOMMENDATIONS

Job description and tasks:

- WVAC should make a commonly accepted definition of sexual health.
- HIV specialist nurses should make sexual health standard procedure.
  A protocol on sexual health is needed.
- HIV specialist nurses should integrate sexual health issues in their daily consultation with their clients. They should make time to discuss this and evaluate and plan the steps taken during the next consultation.
- Issues of pleasurable sex should be included in the protocol, as should alternatives to penetrative sex for those who no longer want this.
- HIV specialist nurses should check whether their patients (especially the female patients) have sufficient understanding of the basics of their bodies and sexual organs. Some extra training on this might be needed.
- HIV specialist nurses should think of new ways to explain the importance of adherence.
- HIV specialist nurses have to think of ways of following up the healthy patients whom they usually do not see regularly.
- An efficient referral system of sexual experts and other experts, depending on the nature of the problem, is recommended.
- The political climate concerning undocumented patients has hardened the last couple of years. Although on a policy level hospitals are not supposed to refuse patients who need help, in reality the structures in place at hospitals make it practically impossible for undocumented to access treatment. Patients are usually bared from accessing the service through gatekeepers who have different instructions from their hospital bosses. The government should reconsider the ‘Koppelingswet’ and remove the identification obligation which pre-selects patients making it difficult for undocumented to demand treatment..
- For Children: A clear protocol should determine when HIV specialist nurses should start discussing sexual health issues with HIV positive youth. The role of parents and/or guardians should be clearly specified. It is also important that the teenager is involved in determining how much their parents or guardians are to be involved.

Training:

- HIV specialist nurses should be given better understanding (and recognition) of sexual health problems by extra training.
- HIV specialist nurses should be trained in recognising lack of social skills in their clients. These clients should be supported in developing social skills in order to protect themselves against STIs.
- Training on sexual health service delivery within multi-cultural communities for HIV specialist nurses is necessary.
- HIV specialist nurses should be trained in counselling skills concerning sexual health issues.
- The Motivational Interviewing method adapted to clients from ethnic minority background is recommended.
- A better understanding of different social and ethnic cultures and backgrounds is recommended.
- It is important for the HIV specialist nurses to be trained on the possibilities available for undocumented clients in their hospital.

Environmental factors:

- A study on the impact of fear of exclusion and stigma (and what actually happens) is recommended.
- Evidence-based research on the impact of HIV and HAART on the sexual health of HIV positive clients should be carried out.

<u>Recommendations from the clients</u>

Task of HIV specialist nurse:

- HIV specialist nurses should discuss sexual health and both HIV specialist nurses and clients should be more willing to do so. Nurses should actively enquire about the sexual life of the patient.
- HIV specialist nurses should ask if the patient knows where and how to contact other HIV positive persons.
- HIV specialist nurses should refer patients for other specialised care if they cannot deal with the sexual health problems.
- HIV specialist nurses should refer patients to appropriate institutions or persons that cater for other needs such as finances, housing etc.

- HIV specialist nurses should help patients to plan around issues of disclosure without coercion or pressure.
- HIV specialist nurses should ask about the socio- economic means of the person in order to assess level of risk of sexual abuse.
- HIV specialist nurses should take more time and expend more effort in explaining the importance of adherence, or refer to places such as ‘adherence clubs’, where the patient receives more attention.
- HIV specialist nurses should set up a system to communicate with those who do not see the HIV specialist nurse regularly or those who do not even have an HIV specialist nurse.
- HIV specialist nurses should ask if patients use any traditional medicines for their sexual health.

Training:

- Gender and empowerment: training is needed for the HIV positive clients, especially women, in gender empowerment, so that they get the necessary life skills to disclose their status and negotiate safer sex. Women need try to realize the advantages of the Dutch gender environment where the Dutch welfare system offers other alternatives in terms of, for example, income and protection.
- Training is also needed on dealing with self enacted stigma among HIV positive people themselves and those in the environments they live.

Environmental factor:

- HIV positive clients need a better understanding of the Dutch legal system. For example the right of leave to stay in the country and the right of HIV positive persons to treatment, care and support.

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Useful websites:

- www.soaaids.professionals
- www.wvac.nl

Appendixes

Questionnaires for: Participants
HIV specialist nurses
HIV specialist nurse for children

QUESTIONNAIRE FOR HIV POSITIVE HETEROSEXUAL CLIENTS

1) City and city area of residence in the Netherlands	
2) Country of origin	Southern Africa namely, Eastern Africa namely, West Africa namely, North Africa namely,
3) Marital	Married/living together Steady partner but living alone Single, multiple partners Single, without partner (why?) Single, occasional lover(s) Other kind of relationship namely...
4) Profession 5) Work status	 Legally/illegally
6) Income range (Excluding partner's income)	Less than € 780 per month Less than € 1,000 per month Less than € 1,500 per month Less than € 2,000 per month Less than € 2,500 per month More than € 2,500 per month
7) How long have you been in the Netherlands?	
8) Are you dependent on someone for	a) Financial well being b) Housing c) Staying permit d) Or is someone dependent on you?
9) Do you have children? 10) How many? 11) What are their dates of birth? Or ages? 12) Are they from one mother/father?	
13) What is the highest level of education you have attained?	a) Primary school b) Secondary school c) University or polytechnic d) Other, namely
14) When were you first told that you are HIV positive?	
15) What was your reaction in terms of sexual life/behaviour?	
16) What were the reasons for doing an HIV test?	

17) Has your sexual life changed in anyway, positive or negative since you heard about your HIV status? If so, how?	
18) What contraception do you or your partner use?	
19) How many times do you have sex in a week, on average?	
20) With whom?	
21) Do you always get sex whenever you want it? Explain!	
22) What other methods of contraception are you familiar with/ or have used?	
23) Why do you use the contraception you use now?	
24) Do you have any plans to have (more) children?	
25) Do you think you can have HIV free children?	
26) If yes/no, please explain.	
27) Any problems in getting children? Explain.	
28) Do you have any physical discomfort or pain in your genital areas?	a) Discharge b) Itching c) Pain and burning sensation d) Pain during love making e) Any unusual growths (e.g. pimples, wraths and rash) around your genitalia
29) If yes, please explain what the problem is and how you deal with this.	
30) Do you use any medicines (modern or traditional) to boost your sexual appetite? If yes, why and which ones?	
31) Do you have any problems with sexual appetite? You or you partner? Since when?	

32) What kind of problems are these?	
33) Do you have any physically visible sexual problems?	a) Premature ejaculation b) Erection problems c) Lack of arousal d) Lack of orgasm e) Drying up of the vagina f) Other, namely
34) Do you suffer from a mental block as far as your sexual life is concerned?	a) Total lack of interest in sex b) Failure to come c) 'Feeling nothing' during sex d) Other reason, namely
35) For how long have you had this problem?	
36) What kind of help have you sought up to date?	
37) Have you (or your partner) had a need to have an abortion?	
38) Is the service easily available? Where?	
39) Since your HIV infection, have you ever had an STI infection?	
40) When was this and how did you get rid of it?	
41) If not, would you know where to find help if it happened?	
42) Can you give some reasons about why you have sex with the person(s) you have sex with?	a) For money b) To keep the relationship c) For pleasure d) To spread the virus e) As a hobby f) Other reasons, namely....
43) What do you think of the service on sexual issues offered by the HIV specialist nurse at the hospital? Explain.	
44) What can they do to improve their service to you concerning your sexual life?	
45) Have you tried to find (or found) a sexual partner through	a) The internet b) Night life c) Through contact advertisements d) Other ways, namely...

46) Did you succeed? Give examples of successes or failures.	
47) What do you think about satisfying yourself sexually?	
48) Have you ever done this? How do you do this?	
49) Is there any area of your sexual life where you feel could be made better by the medical establishment?	
50) Do you think that the Dutch system deals 'privately' enough with your details about your HIV and your sexual health?	
51) As a black person, what do you think about the help you are given? Is it	a) The same as for the white people b) Worse than what's given to white people c) Cannot really judge
52) Please explain your answer if its b or c	
53) Does your partner know about your positive HIV status?	
54) If yes, after how long did you tell your then previous partner about your positive result?	
55) What about the current partner? When did you tell?	
56) Explain your reasons for telling when you told or for not telling	
57) What do you think about the suggestion that the hospital disclose the HIV status to client's partner if they are not prepared to do it themselves?	a) Great, would make life easier for the infected b) Should leave the infected person to tell their partner if they want c) No opinion
58) Is there anything to gain by using a condom when having casual sex as an HIV positive person?	
59) If there are any risks, explain which ones these are?	

60) Which person is likely to pose more risk to you when having unprotected sex	a) A fellow HIV infected person b) One whose status is unknown c) Both
61) What does 'undetectable' mean when talking about HIV infected persons?	
62) Can you infect someone with HIV if the viral load is undetectable?	
63) Given the information you have till now about HIV medicines and your sexual life, would you like more information on	a) How the medicines (antiretrovirals) really work in the body b) The advantages of using condoms when HIV infected c) How to improve your sexual life with HIV d) Where to get partners when HIV infected e) None of the above
64) How easy would it be for you to get a condom at short notice if you needed it?	a) Impossible, would not even dare to buy it myself b) Very easy c) Very difficult but could get it if really necessary
66) Do you think that fellow HIV infected persons use condoms?	
67) Have you ever had sex with a person of the same sex?	
68) Have you ever been forced to have sex? By whom?	
69) Have you ever had to do things that you did not like during sex?	
70) If yes, explain what these things were if you please.	
71) Have you ever used a female condom?	
72) In your relationships, is it you or your partner(s) who take the initiative to use a condom? If you use one.	
73) Who do you discuss your sexual life/problems with?	a) Doctor b) Friends c) Traditional healers d) Parents e) School teacher f) Others namely,

74) How many partners have you had in the last two years?	
75) Do you use drugs of any kind (hard or soft drugs)	a) Yes b) No
76) Have you ever had sex when drunk or high and without a condom?	a) Yes b) b) No
77) What are the reasons why you have not used a condom sometimes?	
78) How do you rate the risks of having oral sex (with your mouth) for STIs?	a) Minimal to nil b) Average c) High
79) Have you ever slept with a man who also has sex with man?	a) No b) Yes If yes, how often?
80) How sure are you of the fact that your man has never slept with another man?	
81) Do you think that the HIV specialist nurse is the best person to ask you about your sexual problems at the hospital?	a) Yes, very much so b) No, they should only talk of HIV and HAART
82) If your answer is no, can you suggest the persons who could do this?	
81) Have you ever had 'accidents' with condoms after your HIV positive status was already known? What did you do about it?	
82) Are you on medication? Which ones? How is the taking of the medication going?	
83) Do you think that stigma still rests on HIV infected persons. Give one example, if you have one, when you feel you were the victim of discrimination discriminated because of your positive HIV status	

Thank you for giving this interview!!!!

QUESTIONNAIRE FOR HIV SPECIALIST NURSE

1) In which hospital do you work? What city?	
2) How long have you been in the HIV/AIDS field? How does this affect your work?	
3) How many of your patients are from ethnic minority backgrounds? (and how many are Dutch?)	
4) What do you think about making the sexual health (including safe sex) of HIV positive clients, a task for the HIV specialist nurse? Explain.	a) Very good b) Not so good c) Bad idea
5) What do you understand by sexual health?	
6) From which countries do you patients from ethnic minority backgrounds come?	
7) Does your clientele consist of more men or women?	
8) Do you also have young clients (15-25)? How many?	
9) How comfortable are you discussing the sexuality of a man from an ethnic minority background? (safe sex, if they have sex with other men, etc) Please explain why.	a) Very comfortable b) Uncomfortable
10) How comfortable are you discussing the sexuality of a woman from an ethnic minority background? (safe sex, having children when HIV positive) Explain why.	a) Very comfortable b) Uncomfortable
11) What are the most common sexual health problems mentioned by men in your consultations?	
12) What are the most common sexual health problems mentioned by women in your consultations?	

13) How do you feel about a HIV positive woman who wants children? What would you advise them?	
14) Do you feel you are adequately trained to discuss sexuality with your clients?	a) Yes b) No
15) Do you have any African male client who admits to having sex with other men or who has discussed sexual health particular for MSM?	a) Yes b) No
16) Which problems do the most HIV positive youths (15-25) from ethnic minority backgrounds face sexually in your work?	
17) What impression do you have about your clients from ethnic minority backgrounds concerning safe sex? Do you think they practice safe sex or not. Please support your answer.	
18) Which people are more likely to have unsafe sex, native Dutch people or people from an ethnic minority background? Explain your answer.	a) People from an ethnic minority background b) Native Dutch people c) No difference
19) How much time are you supposed to spend with a client per visit? Do you think you need extra time in order to deal with the sexual health of your clients?	
20) Do you handle any problems of undocumented clients concerning sexual health? Can you tell me how you dealt with these cases?	
21) What is the hospitals' current policy about informing partners of your clients about their HIV positive status?	
22) What has your experience been with clients' disclosure of their HIV positive status to partners? Give a score out of ten.	

23) Do you think that there is still a need to work on safer sex with HIV positive clients? Why do you say so?	a) Yes b) No
24) How do you rate the work of HIV specialist nurses on sexual health with HIV positive clients done so far? (e.g. planning pregnancies, prevention of STIs)	a) Less than 30% b) 50% c) More than 75 % d) 100 %
25) Who usually takes the initiative to discuss sexual health problems of clients in your work?	a) The HIV specialist nurse b) The client
26) Which sexual problems are most cited by the male HIV positive clients from ethnic minority backgrounds in your work?	
27) Which sexual problems are most cited by the female HIV positive clients from ethnic minority backgrounds in your work?	
28)) What problems does HIV infection and HAART cause for the sexual health of your clients?	a) Yes b) No
29) Do you think we are winning or losing the battle against HIV/AIDS?	
30) What is the largest problem that your clients face? Stigma? Adherence?	
31) What is your stance on the following: People who spread HIV must be deported from the Netherlands People from ethnic minority backgrounds like sex and engage in unsafe sex more than Dutch people Africans are naturally promiscuous and are the major culprits in the spread of HIV in the Netherlands	 a) Yes b) No a) Yes b) No a) Yes b) No

Working on sexual behaviour change can work with people from ethnic minority background Please explain the answers given above	a) Yes b) No
33) Do you think there are any advantages attached to you being a (white/black/older/ younger/female/male) HIV specialist nurse when working with HIV positive clients from ethnic minority backgrounds?	
34) What changes have you noticed in both policy and in institutions concerning HIV/AIDS/STI prevention and care over the last years? What policies have been desirable and which not?	
35) Would you have sex with a person infected with HIV, while HIV negative yourself? Please explain.	a) Yes b) No
36) What do you think should be done with HIV positive clients that keep getting infected with STIs?	
37) What are the chances of being infected with HIV from a needle prick?	a) Less than 2% b) More than 5% c) More than 50% d) No idea
38) Has your work with HIV/AIDS STI's become better or worse over the past years? Explain.	a) Better b) Worse
39) Which people from ethnic minority backgrounds do you think need the most help in terms of sexual health?	a) Africans south of the Sahara b) People from the Caribbean c) Surinamese and Antilleans d) Moroccans e) Any others namely…….
40) Do you think you would like to take the task of encouraging safe sex among your HIV positive clients? Please explain.	
41) Are there any issues that we did not touch on what you think should be definitely be included in the protocol for the sexual health of your clients?	

QUESTIONNAIRE FOR HIV SPECIALIST NURSE FOR CHILDREN

1) At which hospital do you work?	
2) How long have you been in the HIV/AIDS field? How does this affect your work?	
3) How many of your patients are from ethnic minority background? (How many are Dutch)?	
4) What do you think about making the sexual health (including safe sex) of HIV positive clients, a task for the HIV specialist nurses? Please explain.	a) Very good b) Not so good c) Bad idea
5) What do you understand by sexual health?	
6) From which countries do your patients from ethnic minority backgrounds come? Or their parents?	
7) Does your clientele consists of more girls or boys? What is their age-range?	
8) Are (some of) your clients sexually active? At what age?	
9) How comfortable are you discussing the sexuality of the children/teenagers? At what age do you start discussions? What do you do when there is a sexually related problem?	a) Very comfortable b) Uncomfortable
10) What are the most common sexually related topics you discuss with these children?	
11) What are the most common sexual health problems mentioned by boys? And by girls?	
12) Do you discuss safe sex with your young clientele? What advice do you give?	

13) What do you do if the boy or the girl has unsafe sex without telling their partner?	
14) Do you feel you are adequately trained to discuss sexuality with your clients?	a) Yes b) No
15) Do you have any boys or girls who have sex with the same sex? (gay boys or lesbian girls?)	a) Yes b) No
16) What problems do you face (if any) with clients from ethnic minority backgrounds concerning their sexuality?	
17) What impression do you have about your clients from ethnic minority backgrounds concerning safe sex? Do you think they practice safe sex?	
18) Which HIV positive teenagers are most likely to have unsafe sex, native Dutch or those from an ethnic minority background? Explain your answer.	a) Native Dutch people b) Persons from an ethnic minority background c) Same
19) How much time are you supposed to spend with a client per visit? Do you think you need extra time in order to deal with sexual health issues?	
20) Do you have any undocumented children under your care? How do they find their way into the health system?	
21) What do you think will happen with the undocumented clients from ethnic minority background who need medical health care in the future given the new changes in the medical health system?	
22) What is the hospitals' current policy about informing partners of your clients about their HIV positive status?	
23) What has your experience been with clients' disclosure of their HIV positive status to partners? Give a score out of ten.	

24) Do you think that there is still a need to work on safer sex with HIV positive clients? Why do you say so?	a) Yes b) No
25) How do you rate the work of HIV specialist nurses on sexual health with HIV positive clients up to date (e.g. planning pregnancies, preventing of STIs?)	a) Less than 30% b) 50% c) More than 75 % d) 100 %
26) Who usually takes the initiative to discuss sexual health problems of clients in your work?	a) The HIV specialist nurse b) The client
27) Which sexual problems are most cited by the boys in your work? In which areas do you think they still need help?	
28) Which sexual problems are most cited by the girls in your work? In which areas do you think they still need help?	
29) Do you think you it is your the task to encourage safe sex among your HIV positive clients? Please explain.	a) Yes b) No
30) Do your clients complain of stigmatisation because of their HIV status? Can you give examples?	
31) What is your stance on the following: HIV positive children should only have relations with other HIV positive children. Boys are more likely to have sex without protection than girls. Africans are naturally promiscuous and are the major culprits in the spread of HIV in the Netherlands. It is the duty of the HIV positive person to protect their lover because they are aware of their HIV status. Every person has a responsibility for safe sex, irrespective of HIV status	a) Yes b) No a) Yes b) No a) Yes b) No a) Yes b) No a) Yes b) No

32) What changes have you noticed in both policy and in institutions concerning HIV/STI prevention and care over the last years? What policies have been desirable and which not?	
33) Would you have sex with a person infected with HIV, while HIV negative yourself? Please explain	a) Yes b) No
34) What are the chances of being infected with HIV from a needle prick?	a) Less than 2% b) More than 5% c) More than 50% d) No idea
35) Do you think we are winning or losing the battle against HIV/AIDS?	
36) What problems does HIV cause to the sexual health of the clients?	
37) What problem does HAART cause to the sexual health of the clients? Do clients complain of any problems?	
38) Do you have cases of STIs among your clients?	
39) Do you think there are any advantages attached to you being a (black/white/older/ younger/female/male) HIV specialist nurse when working with children?	
40) Are there any issues that we did not touch on what you think should definitely be included in the protocol for the sexual health of young HIV positive persons?	