



hiv
DANMARK

HIV AND LIVING CONDITIONS

– A SURVEY OF LIVING CONDITIONS AND QUALITY OF LIFE OF PEOPLE LIVING WITH HIV IN DENMARK

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HIV-DANMARK 2008



PREFACE

From April 2005 to October 2007, Hiv-Danmark, a nationwide patient's organisation for all people living with HIV carried out the first national survey of the living conditions and quality of life of people living with HIV. The work resulted in a 185-page report in Danish (Hiv og levekår – en undersøgelse af hiv-smittedes levekår og livskvalitet i Danmark, Hiv-Danmark, 2007).

In the spring of 2008, a 30-page summary of the report was published. This English report is a translated and edited version of the 30-page Danish summary.

The survey is unique in an international context in terms of data gathered. Similar studies have been carried out in other countries, but nowhere has such a large percentage of people living with HIV responded to a questionnaire focusing on living conditions and life quality as in this Danish survey. The success of the survey is due in part to the great willingness among Danish people living with HIV to participate, as well as the cooperation with the Danish HIV Cohort Study, which provided assistance in distributing questionnaires through the HIV treatment centres.

The survey received financial support from the Danish National Board of Health, the Danish AIDS Foundation, Aase og Einar Danielsens Fond, Carlsbergs Mindelegat, Fabrikant Mads Clausens Fond, Tips- og Lottopuljen 2006 and 2007, the Danish Haemophilia Society & Merck, Sharp and Dohme, all of whom we thank for their support.

But most of all, we would like to thank the many people who took the time to complete the lengthy questionnaires containing both boring and highly personal questions; and a special thanks to all the men and women who provided us with insight into their lives during the interview process.

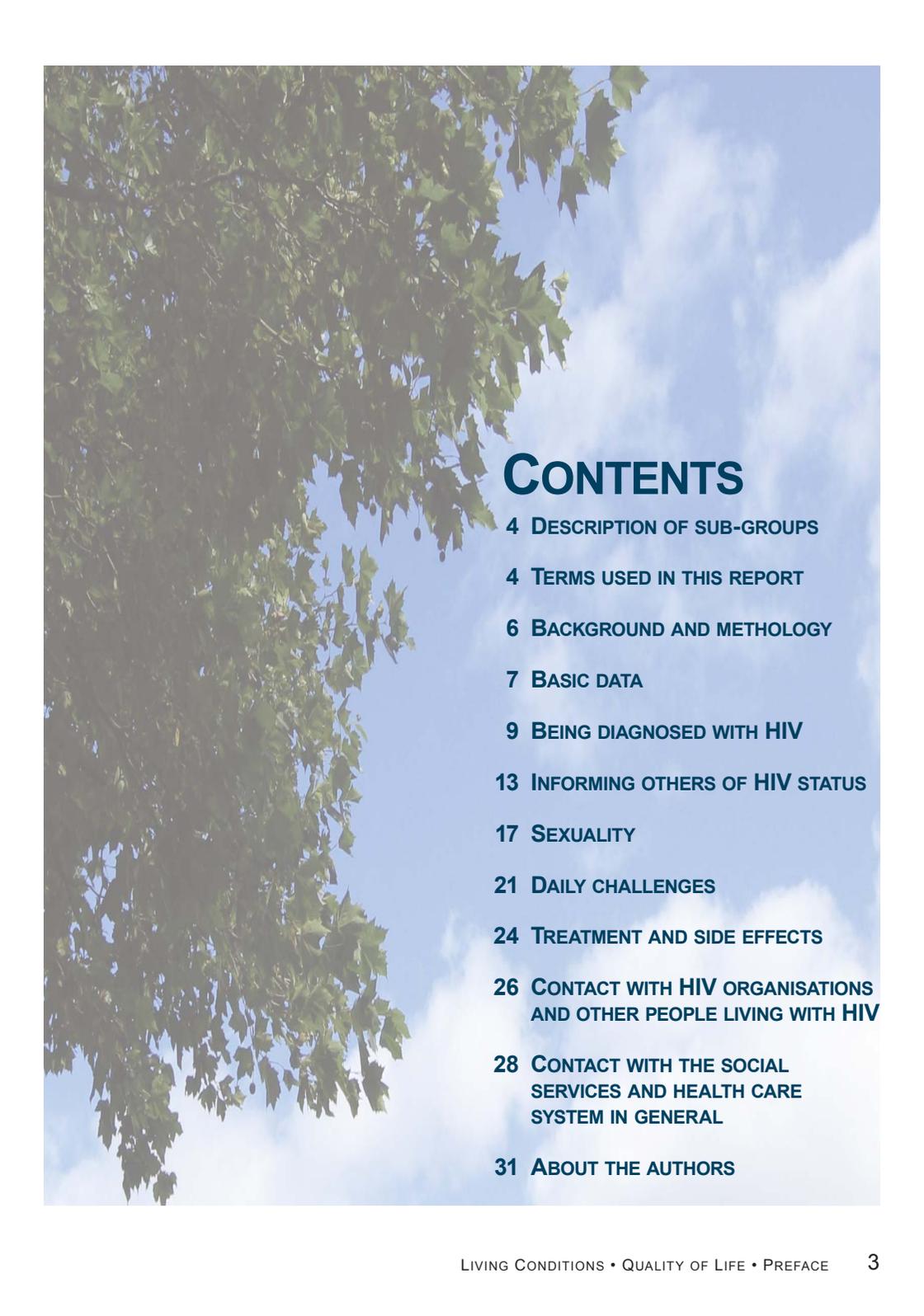
The names of the interviewees have been changed and to ensure that confidentiality of individual stories is protected, different names are used throughout the survey when several citations are attributable to the same interviewee.

This report is available to be downloaded at www.levekaar.dk. The site contains English translations of the original questionnaire and a number of tables not included in this summary.

Mie Carstensen & Anders Dahl

We would like to point out that it is important to read the introductory section entitled 'Description of sub-groups' in order to avoid misunderstanding while reading this report. For example, 'heterosexual men' refers to Danish-born heterosexual men for the purposes of this report.

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DESCRIPTION

In order to facilitate comprehension of the tables and sub-groups utilised in this survey, we have included a description of the sub-group categories – that is, who is included in which sub-group, and what the 'maximum number' of respondents per sub-group would have been if all respondents had fully completed their questionnaires. The numbers of respondents in the bisexual and drug user sub-groups are rather small, and therefore the reader should be cautious of drawing firm conclusions about these sub-groups based on interpretation of the tables found in this report.

Respondents divided according to sub-group

ALL (1,212 respondents) is equivalent to the number of accepted questionnaires either fully or partially completed. (952 men and 260 women)

TERMS USED IN THIS REPORT

In a report concerning people living with HIV, there are a number of terms, designations and categories that ought always to be used if one wishes to be correct. But this is neither easy nor reader-friendly. Take for example drug users who inject drugs intravenously. Should they be called intravenous drug users, IV-drug users, or should the English term IDU be used – or what about another choice altogether? The same principle applies to the terms used to designate men who have sex with men. Is gay a good choice of words, or would homosexuals be preferable? And when writing about HIV-infected persons who belong to ethnic minorities, should they be designated as such each time they are mentioned in order to avoid causing offense?

We have chosen to prioritise reader-

friendliness over correctness, and have therefore selected the following terms for use in this report:

HOMOSEXUAL MEN – men who identify themselves as homosexuals,

HETEROSEXUALS – men and women who consider themselves heterosexual and who have indicated that they were born in Denmark,

BISEXUAL MEN – men who identify themselves as bisexual,

MIGRANTS – men and women who have indicated that they were born outside of Europe,

OF SUB-GROUPS

HOMOSEXUALS (637 respondents) include those who indicated on the question concerning sexual identity that this category best fits them, irrespective of country of origin. (636 men and 1 woman)

HETEROSEXUALS (340 respondents) include only Danish-born men and women who indicated that they consider themselves to be heterosexual. (184 men and 156 women)

BISEXUALS (70 respondents) include men and women who indicated that they consider themselves to be bisexual, irrespective of country of origin. (64 men and 6 women).

MIGRANTS (133 respondents) include men and women born outside of Europe, irrespective of sexual identity. (51 men and 82 women)

DRUG USERS – men and women who indicated that they were most likely infected with HIV through intravenous drug use,

THE OLD – persons infected with HIV prior to 1 January 1997,

THE NEW – persons infected with HIV after 1 January 1997,

INFORMANTS – persons employed in HIV treatment centres, HIV organisations and other service providers who were interviewed for the purposes of this survey,

RESPONDENTS – persons who completed the questionnaire,

DRUG USERS (39 respondents) include all of those who indicated that they were most likely infected with HIV through intravenous drug use. (24 men and 15 women). These respondents do not necessarily still have an active drug habit.

THE OLD (634 respondents) include those who indicated that they were diagnosed with HIV in 1996 or earlier. (498 men and 136 women)

THE NEW (558 respondents) include those who indicated that they were diagnosed with HIV in 1997 or later. (439 men and 119 women)

Drug users and migrants are thus included in both the 'drug users' and 'migrants' categories as well as the sexual identity category they selected on the questionnaire.

INTERVIEWEES – 25 people living with HIV who participated in semi-structured qualitative interviews,

HIV TREATMENT CENTRES – designation for the eight Danish hospitals with specialised treatment centres for people living with HIV (out-patient or in-patient facilities).

GENERAL POPULATION – data for the Danish general population was obtained from: 'Sundhed og sygelighed i Danmark 2005', National Institute of Public Health, University of Southern Denmark; 2006 and 'Udviklingen i befolkningens levekår over et kvart århundrede', The Danish National Institute of Social Research: 2003.



1. BACKGROUND AND METHODOLOGY

With this survey, Hiv-Danmark aimed to increase awareness and knowledge of the living conditions and quality of life of persons infected with HIV in Denmark. The survey is based on interviews with almost 40 organisations or institutions that work with HIV patients or with the prevention of HIV, a questionnaire given to all people living with HIV that attend a check-up at a HIV treatment centre, and qualitative interviews with 25 people living with HIV.

Statens Serum Institut estimates that today (2007) there are more than 5,000 HIV-infected individuals living in Denmark. Every year between 250 and 300 patients are diagnosed as infected by HIV, and this number has been stable for a number of years. Up to the middle of the 1990s between 175 and 240 people died of AIDS every year. With the introduction of improved ARV treatments in 1996 this number fell drastically, and for the last 5-6 years between 20 and 30 deaths have been registered as a consequence of AIDS.

Even though a large number of people completed and returned the Living Condition Survey questionnaire, the universe of respondents is not representative of the people living with HIV in Denmark. In the Living Condition Survey there is a clear under-representation of men and women that have been infected heterosexually, of drug users and of HIV-infected individuals of a non-Danish background.

We should also mention here in the introduction that for both ethical and practical reasons, we have chosen to disregard HIV-infected haemophiliacs and HIV-infected children under the age of 18, in the survey.

The preliminary interviews with organisations and institutions that work with people living with HIV or with the prevention of HIV were conducted to get their input on which areas should be investigated more closely. On the basis of these interviews a questionnaire with 154 questions was developed within 12 subjects (see the box on this page).

A total of 1,357 questionnaires were re-

- General questions on living conditions and quality of life: education, occupation, housing & income
- Social life: relationships with family and friends, social network
- Reactions of others: stigma and discrimination, informing others about HIV-infected status
- Sexuality and sex life
- General health
- Use of alcohol, tobacco and drugs
- Contact with social services
- Contact with medical and mental health care services
- Contact with HIV out-patient clinic (including use of interpreter)
- How the respondent experiences treatment
- Contact with HIV organisations
- The penal system, foreign travel, pension scheme & children

turned, but not all had been completed. 1,212 questionnaires were either fully or partially completed and these responses were used to develop the analyses included in the report.

As a supplement to the questionnaire we conducted 25 interviews with HIV-infected individuals. The interviewees should, ideally, cover a broad spectrum of people living with HIV in different life situations; recently diagnosed ('the new') and patients that have known their HIV status for many years ('the old'), men and women, heterosexuals, bisexuals and homosexuals, people born in Denmark and people born abroad, people from metropolitan areas and people from outlying areas, and drug users.

The purpose of the interviews was to gain insight into some of the areas that are not easily uncovered by a questionnaire; for example relationships with other people, difficulties and problems with respect to disclosing one's HIV status, which considerations are made in this connection and so forth.

Questionnaires typically give a very static picture of life. With the interviews we could also gain insight into the complexity that characterises everyone's life. It could also be said that where questionnaires can give insight into the average and the representative situation, the interview can provide a possibility of understanding the background for this.



2. BASIC DATA

In the questionnaire a number of traditional questions regarding living conditions have been posed, which are meant to clarify ‘who’ the HIV-infected individuals are, and the conditions in which they live. In this chapter a number of these data will be presented.

The questionnaires were collected during the period from 1 September 2005 to 31 July 2006 from individuals living with HIV that during this period had been in touch with an HIV treatment centre, and that were at least 18 years of age. This group is comprised of altogether 3,191 persons, which means that with 1,212 responses we have achieved a response rate of 38 %.

Age-wise the respondents are between 20 and 77 years old and the median age is 44 years. As far as marital status, 18 % of the respondents are married and 16 % are living in a civil partnership. In the general population the equivalent figures are respectively 55 % and 1 %. It is not surprising that in the Living Condition Survey there is a much larger proportion of people living in a civil partnership, since the share of homosexuals in this population is much larger than in the general population. It is however surprising that a much bigger share of the respondents of the Living Condition Survey are separated and divorced (respectively 2 % and 14 %) – in the general population the figures are 1 % and 8 %.

It also appears that more people living with HIV live alone than the general population. More than 40 % responded that they

live alone – in the general population there are 30 % that say they do. There is no appreciable difference between the different sub-groups – if we disregard the migrant sub-group, where only 19 % have stated that they live alone.

The questionnaire also contained questions regarding the individual’s educational background. If this information is compared with information from the Danish National Institute of Social Research on educational levels in the general population, there are remarkable differences. There are twice as many in the general population that have an apprenticeship or basic vocational training than amongst the respondents, but conversely there are twice as many of the respondents to the Living Condition Survey that have a medium-term or long-term higher education. In all of the sub-groups, apart from drug users, there are a higher number of people with a medium-term or long-term education than there are in the general population. Also the migrant sub-group is better educated than the general population, but this is not apparent with respect to the economic opportunities that this sub-group has, as shown in table 2.1.

In the questionnaire it was also asked whether the respondent had avoided applying for admission to an education, primarily because of HIV. Quite a few, more than every tenth, answered affirmatively to that question. But it is apparently an issue that more from ‘the old’ sub-group than from ‘the new’ sub-group have come across – and that is hardly surprising. ‘The old’ were diagnosed during a time when the disease had a completely different character in Denmark than it has today. The treatment options were severely limited, and there was no real possibility of medicine prolonging the life of the individual – there was no prospect of a long life. That meant that many patients “cancelled

Table 2.1 Household income for selected sub-groups as compared with general population

Household income	Living Conditions Survey				General population
	Homo-sexuals	Hetero-sexuals	Migrants	All respondents	
0-199.000 DKK	13 %	18 %	32 %	18 %	17 %
200.000-399.000 DKK	22 %	27 %	19 %	23 %	24 %
400.000-599.000 DKK	29 %	26 %	24 %	28 %	24 %
600.000 DKK and up	31 %	23 %	13 %	25 %	24 %
Does not wish to respond	2 %	3 %	3 %	2 %	2 %
Don't know	3 %	2 %	9 %	3 %	9 %
Total	100 %	99 %	100 %	99 %	100 %

Table 2.2 Respondents' occupations in comparison with general population

	General population	Living Conditions Survey
Employed	58 %	56 %
Flex-job/subsidised salary	-	5 %
Attending education/training	10 %	8 %
Pensioner/early retirement/transition pay	26 %	29 %
Unemployed	4 %	8 %
Other/homemaker	2 %	1 %
Total	100 %	107 %

their life” so to speak, which among other things meant that many deselected their education, since they did not count on living long enough to finish it.

In the questionnaire respondents were also asked about their primary occupation. We have mainly been interested in clarifying to which extent the respondents are working and/or receiving education, or whether there is a large group of people that are outside the labour market and that are either unemployed or are receiving disability benefits because of HIV.

Data from the Living Condition Survey are compared in Table 2.2 with the general population (although it does not have a separate category of people in flex-jobs or receiving subsidised salaries). By a comparison it must also be taken into account that the general population age-wise comprises a much broader group than the respondents in the Living Condition Survey.

Because it was possible to indicate several choices in the Living Condition Survey questionnaire, the percentages add up to more than 100 %.

There are no large differences between the respondents in the Living Condition Survey and the general population, with respect to the proportion of people actually in employment. The figures do, however, show a tendency towards more of the respondents in the Living Condition Survey being unemployed. There are, however, large differences between the sub-groups. For example, quite a few more of the homosexuals are employed than those respondents in the other sub-groups.

Those respondents that are without

work or are pensioners were asked whether HIV was the cause of them quitting work. Almost half of the total group of respondents answered that HIV was the cause or partly the cause. It is among homosexual men that the most (57 %) have ceased working because of HIV, in the other sub-groups the figure is between 30-45 %.

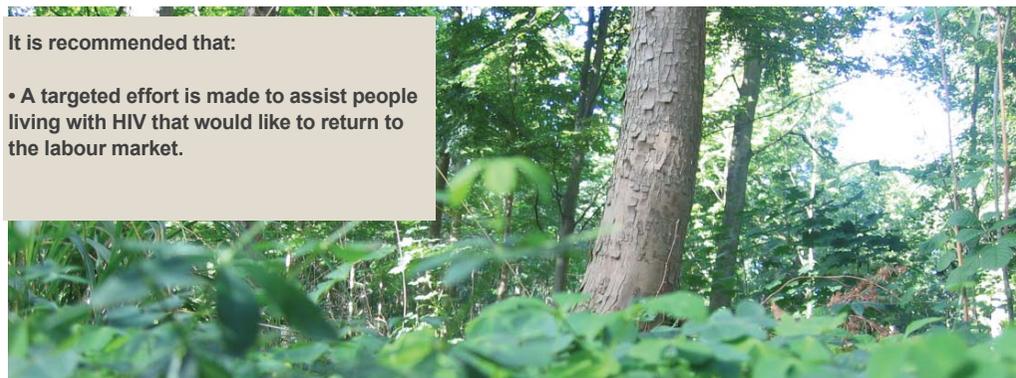
If the results are split up between ‘the old’ and ‘the new’ a significant difference can be ascertained. Many more of ‘the old’ have stopped working because of HIV. This indicates that the disease today affects labour market participation to a lesser extent than it did previously.

The same relationship is the case for respondents that are retired. Many more of ‘the old’ than ‘the new’ are retired because of HIV.

Finally it can be seen from the answers that quite a few of those living with HIV who are either unemployed or retired would like to rejoin the labour market – on either a full-time or part-time basis. It is the case for all of the sub-groups that 40 % of those that are not working would actually like to have a job, and for the migrant sub-group it is almost 80 % that would like to have a job.

It is recommended that:

- A targeted effort is made to assist people living with HIV that would like to return to the labour market.



3. BEING DIAGNOSED WITH HIV



There is no indication that being diagnosed as HIV positive today is any less traumatic than it was 15 or 20 years ago, despite current treatment possibilities. Nor is there anything to indicate that the optimism that ARV has evoked in many other areas has had any influence on the reaction of the individual who receives the diagnosis that he or she is infected with HIV.

Although HIV may be less feared than it was prior to 1996, being informed that one is HIV positive is still a profound shock to almost everyone who has been given the diagnosis. In many of the interviews, the most difficult aspect for interviewees was discussing what it was like to receive the diagnosis. Many people became very emotional and had tears in their eyes, or wept. Learning that one is HIV positive is an overwhelming and existential event for the vast majority of people, and this is also confirmed by informants working at the testing centres.

The specific situation

In the context of prevention it can be important to know if the individual was aware of the specific situation in which he or she was infected with HIV – even though this is an almost unexplored area. Respondents were asked this question and almost 4 out of 10 replied that they were in fact aware of the specific situation in which they were infected with HIV.

More than half of the Danish heterosexual respondents responded that they were aware of the specific situation in which they were exposed to HIV infection. Presumably this is attributable to the fact that Danish heterosexuals, if nothing else, probably have fewer sexual partners with increased risk of HIV infection, and therefore the individual can more easily point to the situation in which he or she was infected.

HIV prevalence among Danish men who have sex with men is estimated at 5%, that is, approximately one in every twenty in this sub-group is HIV positive. For the

individual homosexual or bisexual man who has had many sexual partners, it can be much more difficult to uncover the specific situation in which HIV infection took place – unless one practises safer sex exclusively. Among homosexual and bisexual men, a third of all respondents believe that they know when they were infected with HIV.

Respondents who indicated knowledge of the specific situation in which they were infected with HIV were also asked to indicate whether they knew that the situation in question involved particular risk. A third of these respondents indicated that they were aware of the risk.

All things considered, it must be noted that quite a few people living with HIV have both the awareness of the situation in which they have been infected, and of the fact that the specific situation carried a special risk. This finding demonstrates that there is a massive challenge for HIV prevention – many people are apparently infected in spite of them knowing that they are specifically exposing themselves to infection. This indicates great difficulty in translating knowledge of risk into concrete – and relevant – action. For all sub-groups, it is about a third of the respondents that have knowledge of the specific situation in which they were infected by HIV, and who also knew that they were in a situation that involved a special risk.

Satisfaction level with counselling during the first months

One of the themes we wanted to focus on in the Living Condition Survey was the information and counselling that was provided to people living with HIV in the first months after they had been given their diagnosis. Therefore the questionnaire contained a question that asked: “During the first six months following your diagnosis as HIV-positive, how was the information and advice that you were given?” Since it is not of immediate interest to examine how

counselling was done in the ‘old days’, we have looked specifically at the data from the years 2000-2005. This period comprises altogether 392 respondents.

It turned out that there was very high satisfaction with the counselling and information. Almost 80 % were either “very satisfied” or “satisfied”. By means of comparison it is just 11 % that think the information and advice given them during this initial phase was “bad” or “very bad”.

However, the answers do not reveal what it is the respondents are satisfied or unsatisfied with. Is the individual newly diagnosed HIV patient aware of what information he or she should be given during this initial phase? Supposedly this is to a larger degree a ‘satisfaction survey’, which answers the question of whether respondents are satisfied with the medical personnel they have met during the first six months after obtaining knowledge of their HIV status.

In the interviews it was also quite obvious that by far the majority of the interviewees are happy with the personnel at the HIV treatment centres. But being happy with the personnel is not the same as having been given the advice and guidance that is needed. From the interviews with the informants at the HIV treatment centres there was a clear picture showing that there was a significant difference between how thoroughly and how long the staff there had talked with the patients.

It has not been possible to investigate with the Living Condition Survey questionnaire what information and advice the individual respondent was given in the initial period after the diagnosing of HIV. In several of the answers from the survey there is however an indication that the people living with HIV have a problematic level of knowledge in this respect.

Particularly sensitive subjects such as sexuality and sex-life are difficult and time-consuming to discuss, and expressions such as: “We are probably not that used to talking to patients in depth about sexuality and the problems there might be” and “Are we even qualified to talk to the patients about sexuality?” are repeated often among personnel in quite a few of the HIV-treatment centres.

The need for more information

It is a difficult task to advise a newly diagnosed HIV patient. Not only are we talking about a person going through a deep crisis that personnel must assist him or her in getting through appropriately, the staff is at the same time in a situation where they must convey a lot of information to the individual regarding progression of the disease, medical treatment, safer sex, sexuality, tracing the source of infection (partner notification), the penal code, the possibility of PEP-treatment, whether they should talk to others about their HIV status and if so how that should be done, etc. This information should not just be conveyed; it also must be ensured that the individual understands and remembers it.

Ways of transmission is one of the things that any person living with HIV

Table 3.1 How many respondents feel they need more information on the risk of HIV transmission through ...

	... ordinary social interaction with other	... sex
All	9 %	18 %
Homosexuals	4 %	14 %
Heterosexuals (DK)	12 %	18 %
Bisexuals	18 %	32 %
Migrants	23 %	37 %
Drug users	33 %	33 %
The old	7 %	14 %
The new	12 %	22 %

must have thorough knowledge of during their initial phase as a newly diagnosed – everything else will counteract that the individual will be able to take responsibility for his or her sex life. In the questionnaire the individual was asked whether he or she is in need of more information about risk of infection in connection with normal social interaction and about risk of infection in connection with having sex.

As shown in table 3.1, every tenth person expresses a need for more knowledge of risk of infection in connection with ordinary social interaction, and if we look at the sub-groups of bisexuals, migrants and drug users, then the need for information is greater. It is also remarkable that among ‘the new’ there is almost twice as great a need for more information as there is for ‘the old’.



The numbers are surprisingly high. HIV is not transmitted by ordinary social interaction with others, but yet the numbers more than indicate that a very large group of people living with HIV are unsure of this fact. We do not know the reason why so many are expressing a need for more information in this area, but it is a signal that is important to listen to.

The insecurity is even greater – or at least the need for information is – when it comes to the need for more information regarding risk of infection in connection with sex. Here it is almost every fifth person that expresses a need for more information. Again it is a much higher number among bisexuals, migrants and drug users – here it is every third person that indicates they need more information. And, as before, the need for more information is much higher among ‘the new’ than among ‘the old’.

These numbers are also surprisingly high. HIV is transmitted sexually, and if as an HIV-infected person one does not have a precise and accurate knowledge of modes of transmission, it can in principle cause two effects: Either that the person puts limits on his or her sexual activity, because they are afraid of infecting others, or – if they do not limit their sexual activity – that they risk infecting others.

We cannot determine whether people have not been given the information, have been given it at a wrong time or just need to have confirmed that what they think is right is indeed correct.

But the figures indicate that information about transmission in general and about sexual transmission in particular, must be given different priority than it has been until now.

Partner notification

During the last few years there has been more focus on counselling and partner notification (tracing the source of infection) – or, rather, there has been focus on the lack of systematic counselling and partner notification in connection with the diagnosing of people that are infected with HIV. By partner notification, contact can be made to former and present sexual partners, who

can also be infected with HIV, and partner notification is therefore an important part of prevention work. Thereby it will be possible to offer counselling and testing to individuals that have exhibited risk behaviour, and so called “infection-chains” can be broken.

In the Living Condition Survey we therefore asked the respondents whether they had been spoken to about partner notification. And almost 40 % of ‘the new’ say that no one has. It is important to bring forth the question about partner notification for two reasons: Many are worried that they can perhaps have infected others, without them necessarily wanting to make contact with the people in question. And for the purposes of prevention it is important to find people that are infected but do not know that they are.

The Penal Code

Apart from the medical subjects, people living with HIV also need to have knowledge of the possible sanctions in the penal code that can be used towards people living with HIV that expose others to the risk of infection. A person living with HIV can be sentenced to a term of imprisonment if he or she avoids using a condom and at the same time does not inform the sex partner about their infection-status. This information should be one of the standard pieces of information that everyone must be given in connection with diagnosis.

In the questionnaire it was attempted to uncover awareness of the penal code in this connection and therefore the following question was posed: “Do you think you can receive a prison sentence if you, as someone who is HIV-positive, have unsafe sex with a person who is not HIV positive?” and with this there were several options given and the possibility of selecting more than one answer if the person was in doubt.

Only 55 % of the respondents were able to cross off the correct answer, namely that people can be penalised for having unsafe sex with a person if they have not informed that person that they are HIV-infected – and that they can be penalised after just one occurrence of unsafe sex. No signifi-

cant difference was evident between the sub-groups.

It does not appear appropriate or reasonable that so many people living with HIV do not have knowledge of the provisions of the penal code. Since the first trial in 1993-94, cases have been brought more than once a year against a person living with HIV for exposing other people to the risk of infection.

Being told by your GP

No GPs were interviewed as part of this survey about their procedure in connection with giving HIV positive responses. But we have spoken to those interviewees that have been tested and found positive by their GP about their experiences, and these are very diverse. Several respondents report unsatisfactory experiences, and it should be considered if those people that have an HIV-test carried out by their GP can be en-

sured better counselling. There is however no precise answer as to how this is ensured – continuing education for GPs could be a possibility, and another possibility could be to consider whether the services offered by Skejby Hospital to GPs in the Aarhus area should be expanded to include GPs nationwide.

At Skejby Hospital a permanent offer is available to the GPs about a consultancy function that provides an HIV counsellor present along with the GP when he or she informs the patient of a positive test result. The offer is intended to ensure that the patient that needs to be informed that he or she is infected receives the best possible support and counselling immediately from the start.

As it appears in this chapter, there is a need to examine how it can be ensured that all people living with HIV – both newly diagnosed and those that have been infected for many years – are given sufficient and relevant information.



It is recommended that:

- it is prioritised that good and qualified counselling is given to newly diagnosed HIV-infected persons in the initial period after the diagnosing,
- a standard (and written procedures) will be produced at the HIV-treatment centres for how the procedure for newly diagnosed HIV-infected persons is handled,
- the individual will be regularly updated with information that takes its starting point within his or her actual life situation,
- it is considered how the individual is ensured qualified counselling – it could be by the staff being continuously educated and supervised in ‘difficult dialogues’ and/or by considering the model that Skejby Hospital uses, where an HIV-advisor is employed to take care of the counselling in the initial phase with the newly diagnosed.
- it is considered to set goals at the individual centres for the level of knowledge of the patients and for safer sex behaviour. This could be achieved by relatively simple questionnaires for the patients and be a part of ensuring both a continuous collection of knowledge about the needs and behaviour of the patients, and insight into where to make a relevant effort in the future.

4. INFORMING OTHERS OF HIV STATUS

All people living with HIV is confronted with the problem of telling or not telling others about their HIV status. The issue is not only whether to tell others, but also who should be told, how they should be told, and for many people, the order in which they should be told.

Experiences gained from this survey have revealed multiple issues; for one that a distinction is typically made between telling your sexual partners (casual or regular) about your HIV status and telling your social network, and that the social network is typically divided into family, friends and workplace.

The survey also showed that for most respondents, sharing information with others about one's HIV status is an ongoing process. Unless the respondent has chosen 'full disclosure' or 'no disclosure', he or she will face situations where the decision must be taken as to how much information will be disclosed and how. One of the nurses interviewed during the preliminary phase of this survey described the process as follows:

» People living with HIV must go through a process every time they tell someone about their HIV status, and it is essential that they are accepted by the person they choose to disclose to. I am therefore careful to talk to those who have just been infected about who they should tell first, so that they get positive experiences and to ensure that they don't regret the disclosure later on. I also make a point of telling people that there is no rush to go out and tell everyone – they can take all the time they need. Each time they tell someone, they have to deal with it. My advice is to take it slow and choose carefully when it comes to deciding who to tell.

A minority of people living with HIV are open about their HIV status. The vast majority are very careful about who they select for disclosure about their HIV status, and for many, the act of disclosure is itself dif-

ficult and gives rise to a number of considerations.

There is no simple explanation for not 'just' involving everyone else in your situation. For some people, there are concerns that the news would upset those who learned of it, others see it as a personal issue, while others are most concerned about how people will react. For most people, it is a combination of several different explanations that delineates the reason why people living with HIV opts for relatively limited disclosure.

Very few people (however, 5 % of all respondents) have not told anyone else about their HIV status. But as shown in table 4.1, there are quite a few people who have told only a small number of friends or family members about their HIV status – more than every third respondent. The number is quite high when it comes to the bisexuals, migrants and 'the new' sub-groups.

There is every indication that a significant number of people living with HIV keep their HIV status to themselves to a large extent. The difference in the figures between 'the old' and 'the new' strongly indicate that fewer people now disclose their HIV status than they did in the past. In other words, more people keep their HIV status a secret today.

It is important to emphasise that disclosure of HIV status is not a goal in itself, and that the aim is not to have as many



Table 4.1 How many people have you told that you are HIV positive? (Health care professionals and HIV/AIDS counsellors should not be counted)

	Haven't told anyone	Have told maximum five people*)
All	5 %	35 %
Homosexuals	2 %	26 %
Heterosexuals (DK)	6 %	34 %
Bisexuals	10 %	55 %
Migrants	10 %	68 %
Drug users	0 %	22 %
The old	3 %	23 %
The new	6 %	47 %

*) Includes those who have not informed anyone else.

people as possible being open about their HIV status – after all, illness is a personal matter. However, there is a great deal of indication that this is not the only reason that many people decide to keep their HIV status to themselves. Fear of negative reactions also plays a large role in the decision.

This survey has also revealed that not all people living with HIV choose to tell more and more people about their HIV status; that is, to become more and more open about their situation. For some people, the tendency has been to move in the opposite direction: earlier, they were relatively unconcerned about disclosing their HIV status to others, but as a result of different circumstances over time, they have since chosen to be more careful about disclosing their HIV status.

Reasons for choosing non-disclosure

The questionnaire asked respondents the reasons why they chose not to tell others about their HIV status. Almost a quarter of the respondents answered that the reason they chose not to tell others about their HIV status was that it is ‘none of their business’.

Twenty percent of respondents selected the statement: ‘it is a life-threatening disease and you don’t want them to be sad’. Both ‘the new’ and the migrant sub-groups made frequent choice of this statement. Family and close friends are often saddened by the news that someone close to them has become infected with HIV, and it generally requires a great deal of consideration to decide whether to disclose HIV status to close relatives and friends when this reaction is feared.

There were also many respondents – nearly twenty percent – who do not wish to ‘be seen as someone who is HIV positive’. Despite the wealth of information about HIV and AIDS, there is still a great deal of stigma attached to being a person infected with HIV, a stigma associated with the way that other people view those infected with HIV.

Almost every eighth respondent answered

that one of the reasons for non-disclosure of HIV status was fear of rejection. Among migrants, more than one in five selected this response. These figures clearly reflect the stigmatisation feared by many people living with HIV. There are few other illnesses that carry the ‘side effect’ of widespread fear of rejection as a result of disclosure.

Several of those interviewed explained that disclosing HIV status is associated with a number of risks. One example is of a young homosexual man named Andreas who had only been aware of his HIV status for approximately 10 months prior to the interview. Andreas explained that he had decided to disclose his HIV status to others because he wanted people to still be able to trust him. Nevertheless, he did feel at times as though he was exposing himself through disclosure. He explains:

» ‘Exposing myself’ means that I tell someone about my illness ... something that when it comes right down to it doesn’t really concern them. It somehow makes me feel uncomfortable, but I also don’t want people to say that I’m a liar; that they’ll be able to say I’m not to be trusted.

A number of those interviewed indicated that it would have been easier if they suffered from another illness – one that was not associated with so much stigma and prejudice. Peter, a man in his mid-40s who has only told a few people about his HIV status, replied that he would have been more open to disclosure if he had been diagnosed with lung cancer instead:

» Yes, the difference is that ... it is such a taboo subject but ... I probably would have told people about it if I had had a blood transfusion [i.e. been infected that way] ... I have decided not to disclose my HIV status because of the way that I got HIV. Definitely ... yes, that is definitely the reason. But yes, if I had been diagnosed with cancer then I would have told people ... immediately. No doubt about it.



Reactions to disclosure

A large number of the respondents have thus taken great care in selecting those to whom they disclosed their HIV status and the way in which it was done. The reason for this is that most people wished to avoid unpleasant situations such as the one described by Pia.

Pia, a Danish woman who is married with children, had just found out that she was infected with HIV in the year 2000. One day she was out shopping at a supermarket where she ran into a woman with whom she was acquainted, but did not know very well. The woman shouted loud enough for the whole store to hear: “Hey Pia, what’s this I hear about you having AIDS?” Pia reacted by approaching the woman and saying: “Oh, you heard those rumours, did you? There’s absolutely no truth to them.” Pia was unhappy about the incident. “That was pretty weird,” she says. “It would have been different if she had just come up and asked me quietly,” says Pia.

Fortunately, more than half of the respondents experienced predominantly positive reactions when they disclosed their HIV status to others. However, it is important to remember that those told were typically chosen with great care by the respondents. In this context it is perhaps more surprising to note that almost every fourth respondent reported receiving mixed reactions to the disclosure (i.e. both positive and negative).

Alice is a young 29-year-old Danish woman whose HIV infection was revealed in 2004 by a blood donor screening test. She too is very careful about disclosure, and

only her parents, one of her friends, and one of her mother’s friends know of her HIV status. Alice says that she fears being ostracised and therefore has no plans to tell anyone else, not least due to her perception that there is a great deal of ignorance among ordinary people when it comes to HIV.

Drug users in particular have experienced the least positive reactions upon disclosure, and in fact most have experienced negative reactions. Migrants also differ in that they experience a relatively high rate of negative reaction in comparison with the other sub-groups.

Reasons for non-disclosure of HIV status include fear of being talked about behind one’s back and being ostracised by others. And apparently this fear is not entirely groundless – approximately every seventh respondent reported experiencing people gossiping about their HIV status and the same number reported experiencing rejection and ostracism by others.

Having control

The survey also showed that for many people living with HIV, the ability to control knowledge of one’s HIV status is very important. This desire for control underlies the finding that many people have told relatively few people about their HIV status as well as the fear of how people will react if they find out. Thus it is every third respondent – see table 4.2 – who answered affirmatively that they are nervous that rumours about their HIV status may go around among people they know. Many of those interviewed described the various ways in which control was important to them, and how (the sense of) lack of control can throw them off balance and cause anxiety.

A young Danish heterosexual woman named Anna who has disclosed her HIV status to only a few people explains that she is incredibly frightened of the consequences of telling others. Telling one person means having to wonder if they will tell their spouse, children, friends and acquaintances, and suddenly the person living with HIV loses control over who and how many

Table 4.2 Are you nervous that rumours may go around among those who know you that you are HIV-positive?

	Yes	No	Don't know
All	36 %	50 %	14 %
Homosexuals	30 %	59 %	11 %
Heterosexuals (DK)	42 %	44 %	14 %
Bisexuals	42 %	39 %	19 %
Migrants	54 %	25 %	21 %
Drug users	36 %	46 %	18 %
The old	28 %	60 %	12 %
The new	46 %	38 %	16 %

people know about her HIV status. Anna says:

» ... as long as I can keep it a secret, nobody will know. But as soon as you start telling people, you have no idea who knows about it ... At that point you're no longer in control of who knows.

For the migrant sub-group, the issue is important because it is closely associated with the fear of being the subject of gossip in the ethnic community. An African woman named Jennifer explains her personal fear of being the subject of gossip in her community:

» African women can confide in one another, and each may tell the other about her HIV status, but when they leave there is a huge risk that the information will be passed on to others. That's why I don't tell very many people that I am infected with HIV ... I want to control who knows and who doesn't. I also worry about the role ignorance plays in this kind of talk.

Disclosure in the workplace

People living with HIV are not required to inform the workplace of their HIV status. However, like all other people with a serious illness, they are obligated to inform the employer about health issues that may have serious impact on their employment, including increased absence from the workplace or significant limitations to job performance.

However, even though it is not required, many employees choose to inform co-workers and/or managers about serious illnesses as a natural part of workplace social relations. These can include health problems such as breast cancer, diabetes, multiple sclerosis or other serious illnesses. Disclosing a serious illness may reflect a desire to share it with people one interacts with on a daily basis, and it is presumed that many people share such information based on an expectation of support and un-

derstanding from co-workers and management during difficult periods. This survey asked those in paid employment whether they had disclosed their HIV status to anyone at their current workplace. It is worth noting that significantly more than half of all respondents answered 'no' to the question of whether they had told anyone at work. And among migrants, 84 % reported that they had not told anyone at work.

This tendency was also noted in the interviews. Only one interviewee currently in paid employment had disclosed his HIV status at work – and very few of the other interviewees who were previously employed had disclosed their HIV status in the workplace. The interviewee who disclosed his HIV status in the workplace is a homosexual man who is generally very open about being HIV positive.

Those subjects who had disclosed their HIV status at work were also asked if they regretted the disclosure or if they were satisfied with their decision. More than half reported that they were satisfied with their decision. It is however worth noting that a number of respondents, particularly heterosexuals, reported that they regretted their decision to disclose their HIV status in the workplace.

The goal should not necessarily be to disclose one's HIV status in the workplace. However, for some people, fear of disclosure can have a negative impact. One HIV/AIDS counsellor interviewed for the survey explains that, in her experience, a certain group of people living with HIV do not want the social services interfering in their working life. They may be well aware of the fact that they cannot handle a full-time job, but instead of going through official channels to establish a flex-job, they will negotiate with the workplace on their own terms to reduce working hours or take a part-time position. They are also willing to accept the pay cut that this entails.

For some individuals this may be a good solution, but if it is motivated by fear of disclosing their HIV status to their workplace – and thereby losing their rights or the potential to remain in the job market – then the issue is problematic. And there are indications that this is actually the case for some of the survey's respondents.



It is recommended that:

- campaigns are implemented with a view to combating stigmatisation of people living with HIV and increased information on the low risk for HIV transmission – many people have an exaggerated fear of the risk of transmission,
- special attention is given to the area of workplace issues so that fewer people are subjected to discrimination in the workplace, and fewer give up their rights to reduced working hours, lighter work and existing avenues of support,
- focus is placed on disclosure of HIV status – both in relation to newly diagnosed cases but also for those who have been HIV positive for many years, since for many people this issue leads to numerous and difficult considerations.

5. SEXUALITY



Sexuality is an important part of life for most people and a major quality of life factor. Love and sexuality are closely linked in the minds of many, and being infected with HIV therefore has direct impact on the individual's potential to have a love life. Sexuality must be a central focus of any survey of quality of life among people living with HIV for a number of reasons, including the fact that HIV is sexually transmitted. Some people learn fairly well how to deal with a sexuality that can potentially transmit a life-threatening illness to sexual partners and for some it is a lifelong process, while others give up trying at some point.

Most people living with HIV experience a change in their sex life after receiving their diagnosis. This change is about more than just the 'mechanics' of sex – for example, that the person thinks that sex 'feels better' without a condom. Sexuality is also related to self-esteem, body image issues and fear of intimacy, relationship dynamics, body image distortion, and for many people living with HIV, sexuality is also tinged with a fear of infecting one's sexual partner.

HIV also makes it difficult for many people to find relationships or sexual partners, and the survey also reveals that almost two out of three respondents report fewer sexual partners after being diagnosed. Frederik's story illustrates some of the is-

issues faced by people living with HIV when meeting a new potential partner. Frederik is a heterosexual bachelor in his late 40s.

When you meet a girl and you have to tell her, it's very, very hard ... every time ... to do it ... and when! Should you try to do it beforehand, or should you ...? The best thing is to just get it over with. So, I've never had anyone say "forget it", but that's the risk you take.

For many people living with HIV, the dilemma of having to inform a new partner of one's HIV status can be difficult. How – and when – should the disclosure be made? Outside the urban context in particular, the issue of control over who knows about one's HIV status can be problematic. But it is not only when a person living with HIV is not open about his or her HIV status that it can be hard to find a partner. Lars, who is open both about his homosexuality and HIV status, is very interested in having a relationship. He says:

» I really want to find a partner [...] But I think that being HIV positive makes it more difficult. I need to 'sell' it to the other person, you know? The chance of being rejected is much greater.

The feeling that "the chance of being rejected is much greater" is applicable to

most of the respondents interviewed in connection with the survey, whether they are single or in a steady relationship.

Concerns about sex

Concerns about HIV transmission through sex are prevalent among some people living with HIV. In some cases the fear is so great that it has led them to stop having sex altogether. The period following diagnosis can be an especially difficult time for many; a person may fear infecting his or her partner, and some experience a feeling of becoming 'asexual'.

More than every fifth respondent reports feeling 'extremely worried' about transmitting HIV to a partner through sex. But it is not only the fear of transmission on the part of the person living with HIV that can cause difficulties. Some respondents report that their partners have expressed concerns about becoming infected, and this does not promote their confidence in finding a future partner.

Mia, who has been aware of her HIV status for six years, reports that she recently met a man with whom she fell in love and since she believes in always disclosing her HIV status to a new partner prior to the first sexual encounter, she did so on this occasion. They slept together, and Mia reports that afterward the man went home and thought about the issue for a week. During this time, Mia visited the man and provided him with brochures about HIV and its transmission. After the week had passed, the man told Mia that he couldn't become involved with her as he was too frightened of becoming infected with HIV. Mia was very upset: "It was awful," she says. "Suddenly you're in this situation that you never imagined you would have to endure." She describes it as a feeling of suddenly being rejected – not for who she is, but as a result of what she is bringing along.

14 % of all respondents have not had sex since being diagnosed HIV positive, with a large variation between the sub-groups. For the heterosexual sub-group it is nearly every fourth respondent who reports giving up sex, while among homosexuals it is 6

%. Among migrants and drug users, nearly every fifth respondent reports no longer (or until the time of reporting) having sex.

Not to be overlooked is the fact that for many of the respondents, their sex life isn't necessarily problematic – almost 40 % reported that their sexual needs are met completely or almost completely, almost every fifth does not have fewer partners than before and almost 10 % aren't at all concerned about infecting their partner during sex. It must however be concluded that for relatively many respondents, having a satisfactory sex life becomes difficult in the wake of receiving an HIV positive diagnosis.

Sexual difficulties

The issue of sexual difficulties among people living with HIV is – especially in Denmark – a relatively unexplored area. Thus the questionnaire contained a number of questions focusing on possible problems in this regard, and the topic was also given focus in the interviews.

Reduced desire or lack of desire can be a problem for many people living with HIV. Every fourth male respondent and every third female respondent reports experiencing reduced desire or lack of desire 'often' or 'all the time' within the last year. This is a considerably higher percentage than that found among the general Danish population, where 15 % of people report experiencing this issue. And among HIV-infected men, it was found that their risk of erectile dysfunction is three times greater than among the general Danish population. Among HIV-infected women, there is an increased risk of vaginal dryness, but the issue is not as pronounced in comparison with the general Danish population as that of male erectile dysfunction.

But not all respondents report experiencing sexual difficulties. Just under a third of all respondents indicated that they have not experienced any sexual difficulties since learning of their HIV positive status.

It is worth noting that homosexual and bisexual men represent the sub-groups most often in contact with HIV treatment centre personnel with regard to sexual difficulties. This may be due to the fact



that people in these sub-groups are better equipped to broach the topic with the personnel. The preliminary interviews at the HIV treatment centres revealed that many personnel found these conversations somewhat difficult. One HIV treatment centre nurse reports that:

» ... patients really want to talk about it [sex] when they get the chance. It's our responsibility to discuss it with them. But we have to be prepared for it ... we have to learn how to do it.

Unprotected sex

Safer sex is difficult for everyone – for those living with HIV and for those who are not. Safer sex (defined here as sex with a condom) sounds so easy and so simple, but reality has shown that this is not the case.

The extent of unprotected sex among people living with HIV (with non-infected persons) is central to the issue of continued HIV transmission. Thus the questionnaire asked respondents about the extent of unprotected vaginal or anal sex within the last year, these being the sexual practices carrying the greatest risk of HIV transmission.

As shown in table 5.1, 23 % of all respondents report that within the last year they have had unprotected vaginal or anal sex with a non-infected person or a part-

ner whose HIV status was unknown. Most of these were homosexual men, of whom almost every third respondent reported having had unprotected sex.

Respondents were also asked about the type of situations in which they have had unprotected sex, and a little more than every fifth respondent chose the response: 'Because you don't feel that you are very infectious'. Thus there are indications that 'treatment optimism' can be the reason or one of the reasons that some respondents engage in unprotected sex on some occasions. 'Treatment optimism' describes the phenomenon whereby current treatment possibilities for people living with HIV lead individuals to be less careful about practising safer sex, and leads them to have more unprotected sex. Most significant however is the observation that almost two out of three respondents chose the response: 'Because your partner didn't want to use a condom'. However, the questionnaire does not reveal whether the unprotected sex was a result of an explicit request on the part of the sexual partner or whether the respondent inferred that the partner desired sex without a condom.

The desire to become better at practising safer sex

The ability to have safer sex is of prime importance for the majority of people living with HIV – more than every fifth respondent indicated feeling 'extremely worried' about transmitting HIV to a partner through sex. This is a concern that should be able to be minimised if the individual has a strong knowledge of modes of HIV transmission and safer sex practices. In recognition of the fact that many people find it difficult to practice safer sex, the questionnaire asked respondents the following question: 'Would you like help or support to become better at practicing safer sex more consistently?'

Table 5.2 shows how respondents answered this question, with 12 % responding that they would like help to become better at practicing safer sex – and that figure must be compared with the 23 % of respondents who indicated in Table 5.1 that

Table 5.1 Of those who have had sex within the last year, how many have had protected and unprotected sex?

	Have not had sex within the last year	Have had sex within the last year, but have practiced safer sex	Have had unprotected sex within the last year	No response / Does not wish to respond / Don't know
All	23 %	40 %	23 %	14 %
Homosexuals	13 %	45 %	31 %	12 %
Heterosexuals (DK)	39 %	32 %	14 %	15 %
Bisexuals	10 %	54 %	26 %	10 %
Migrants	23 %	36 %	18 %	23 %
Drug users	38 %	18 %	23 %	20 %
The old	25 %	41 %	21 %	12 %
The new	19 %	41 %	26 %	15 %

they have had unprotected sex within the last year. Thus it can be seen that approximately half of those who have had unprotected sex would like help. However, this interest in support is divided unevenly across the sub-groups, with the least number of respondents found among homosexual men. Among the other sub-groups can be seen a relatively good accordance between the number of people who have had unprotected sex (table 5.1) and the desire for help to become better at practising safer sex (table 5.2). Respondents in the migrant and drug user sub-groups in particular appear to be especially interested in obtaining help to become better at practicing safer sex.

When respondents were asked to indicate who they thought should be responsible for providing this help or support, they indicated either their doctor and HIV treatment centre nurses, or other people living with HIV.

Neither people living with HIV nor health care personnel are used to talking about sex and doing so can feel very personal and uncomfortable, both for people living with HIV and for health care personnel. But when it comes to a sexually transmitted disease such as HIV, it is necessary for everyone to overcome their personal issues about discussing sex. And the need for information can arise long after one's diagnosis. For example, an HIV-positive woman named Ida, who for many years was married to an HIV-positive man, recently divorced her husband and found herself facing single life with HIV. Ida expressed the need to discuss new issues with hospital staff: "Such as ... how exactly is HIV transmitted? When is it that I must be very careful? ... if I should happen to meet a new man".

Having a satisfactory sex life is not just about improving quality of life for the individual. In the case of HIV, which in Denmark is transmitted primarily through unprotected sex, the issue is as much about assisting the individual in achieving a functioning sex life as it is about reducing the risk of exposing others to infection. It most likely requires a certain degree of insight into one's own sexuality and HIV status to expect people living with HIV

Table 5.2 Would you like help or support to become better at practicing safer sex more consistently?

	Yes	No	Don't know	Not applicable
All	12 %	46 %	10 %	22 %
Homosexuals	10 %	51 %	12 %	21 %
Heterosexuals (DK)	11 %	41 %	9 %	27 %
Bisexuals	17 %	50 %	10 %	16 %
Migrants	21 %	32 %	6 %	21 %
Drug users	28 %	26 %	10 %	23 %
The old	10 %	47 %	9 %	24 %
The new	14 %	46 %	12 %	20 %

to become able to practice safer sex more consistently. And it requires a very detailed knowledge of modes of transmission and the extent of various risks associated with different sexual practices.

It is well known that for many patients it can be difficult to bring up the subject of sex with health care personnel, just as it is well known that health care personnel in general find it difficult to broach sexual issues with patients.

It was not surprising to find that doctors and nurses are the most likely candidates from whom help or support is desired by people living with HIV. The interviews revealed a high level of satisfaction with these personnel groups, and the questionnaire confirmed this finding. On the question dealing with the quality of contact with the doctor and nurse at the HIV treatment centre, nine out of ten respondents chose 'good' or 'very good'.

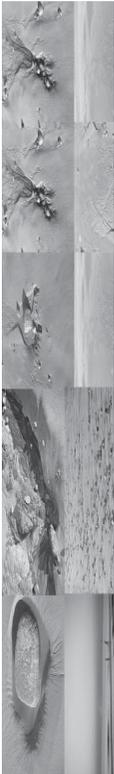
This satisfaction and trust towards HIV treatment center personnel ought to be used constructively to aid difficult discussions about sex. The questionnaire asked if respondents wished that doctors or nurses at the treatment clinic would take the initiative in discussing sexual issues at regular intervals – and almost every third respondent indicated 'yes'. This expressed desire on the part of people living with HIV to discuss sexual issues, including safer sex, ought to be acted upon. Often it takes very little to begin a constructive discussion on sexuality, and the fact that personnel demonstrate that they dare to take the initiative in discussing sexual issues will make it easier for people living with HIV to broach the topic when it arises.



It is recommended that:

- significant steps are taken in relation to the difficult conversations about sexuality and sexual problems,
- at the HIV-treatment centres, consideration is given towards performing an actual sexual anamnesis with all HIV-patients in connection with the diagnosing of HIV and to hold regular conversations (every one or two years) with everyone regarding sexuality, sexual problems and safer sex, so that it is ensured on a continuous basis that the patients have a possibility of discussing important questions with the staff,
- at the HIV-treatment centres it is contemplated to set up goals and indicators for example for the behaviour of the patients (unsafe sex) and the need for information,
- at the HIV treatment centres, that HIV counsellors are hired in a system similar to the one at Skejby Hospital (see page 12). The HIV counsellor will, in addition to performing the difficult and time-consuming conversations with newly diagnosed HIV-infected patients, also be able to supervise personnel during difficult conversations and to support the GPs that want help in connection with giving positive HIV test results.

6. DAILY CHALLENGES



During the interview process, we often encountered a degree of psychological fragility among interviewees who expressed views that it is often the small, unexpected aspects of daily life that cause confusion and, at times, constitute 'the last straw'.

Not all of the interviewees exhibited this fragility, but we came across the phenomenon to an extent to which we felt it deserved a closer look.

John, a homosexual man in his late 30s, is one of the respondents who demonstrated the above-mentioned fragility. When he was diagnosed with HIV five years ago his life became somewhat chaotic; for example, he took his exams before he was ready to do so. He wanted it to be over with – and this resulted in his failing the exams. John explained that at the time he felt a great need to get on with his life after being diagnosed with HIV. The pressure he felt during this time and his uncertainty about the future are largely gone now, he says. But he is still surprised that he continues to encounter everyday situations where he feels thrown off balance and as though he is losing control.

John explains that these episodes are often triggered by small things when he is un-

prepared or tired. Most of what can throw him off balance is situations that he had not foreseen, and it is only later, when he has more perspective about the situation, does he realise that the issues were small or insignificant.

He gives a recent example of having sought a small loan at a bank. When the loan had been approved, his bank manager mentioned that the bank would like John to take out a life insurance policy. This threw him completely off balance and he was very upset. The meeting with the bank manager had occurred on a Friday, and he cancelled all of his social arrangements for both Saturday and Sunday. During the weekend, John discussed the issue with his father and his partner, who assured him that he could just as easily get a loan at another bank or simply say that he was not interested in taking out a life insurance policy at the bank. When he called the bank on Monday, the bank manager had no problem with John declining the life insurance policy.

The questionnaire contains a number of questions intended to shed light on the daily challenges that people living with HIV are faced with. And the figures are rather surprising – in all aspects of daily life,

people living with HIV experience more difficulties than the general Danish population.

For the question of ‘how often within the last month have you felt able to cope with the irritations of daily life?’, 33 % of the general Danish population responded ‘very often’ while only 17 % of those people living with HIV chose the same response. Findings were similar for the question of how often the respondent felt in control of his or her daily life within the last month, with 33 % of the general Danish population reporting ‘very often’, while only 15 % of people living with HIV reported the same sense of control. And among the general Danish population, 5 % reported feeling that problems mounted to the extent that they could not deal with them ‘often or very often’ – while among people living with HIV, the number was three times higher.

This psychological fragility or increased difficulty coping with everyday life is both noteworthy and alarming. And the phenomenon is most widespread among migrants and drug users. Whether this is because they belong to so-called ‘double-discriminated’ groups – experiencing the discrimination of being HIV positive in addition to that of being migrants or drug users – is not known.

Whether these difficulties in dealing with everyday life are ‘merely’ an aspect of living with a life-threatening illness, or if they are specific to people living with HIV, is also not known. However, HIV differs from most other serious illnesses in that it is both transmissible and stigmatised.

Selina, a woman in her late 30s who was born in Africa, explains that hearing others – those who are not infected with HIV – talking about HIV can cause apprehension about the illness. She refers to a friend who is not aware of Selina’s HIV status. This woman has told Selina that when she is with people who are HIV positive she will not drink from the glasses they provide, but chooses instead to drink directly from the bottle.

Nearly every tenth respondent has experienced fear and ostracism from other people, but even more have experienced the feeling of ‘contagiousness’ and have therefore chosen to keep their distance from

others. Perhaps it is this feeling of contagiousness and distance – as well as the sense that other people are frightened and are keeping their distance – that causes many of the respondents to feel isolated. And in this aspect, too, the issue is more problematic for migrants and drug users.

The experience of feeling isolated can be easily influenced by the way in which a person experiences how others view him or her. How we see ourselves, our self-image, is generally filtered through the way other people see us. And negative thoughts and feelings can cause people living with HIV to distance themselves from other people. This experience of isolation also becomes clear in the responses to the question concerned with how often the respondent is alone when he or she really would prefer to be with other people. 14 % of people living with HIV responded that they are often alone and wishing that they weren’t – a number that is four times higher among this group than that found among the general Danish population.

Whether there is some connection between this experience and the above-mentioned psychological fragility and greater difficulty in dealing with everyday life is a matter of conjecture. A few respondents have made explicit reference to this feeling of loneliness, including Aaron, a migrant man, who explained:

» It’s hard to deal with the secrecy surrounding my HIV status, and it makes me feel very alone. It’s a lonely life.

Other respondents report only being able to fully relax in the company of others when they are together with other people living with HIV. This is not because they discuss illness and medical treatment, but because HIV is not a secret between them. They can be themselves and talk about whatever they like. One respondent reports that other people living with HIV are the only ones who truly understand what it is like for her to live with HIV.

The feeling of being isolated and alone when one would rather be with other people appears not to impact the extent to which respondents actually have friends and



spend time with them. People living with HIV have just as many friends as those who belong to the general population, and they see them just as often.

The questionnaire survey also revealed a high consumption of sleep medications and apparently also of sedatives. This consumption may perhaps be explained by the psychological fragility and feelings of loneliness and isolation that affect so many respondents.

Children

Being diagnosed with HIV poses many challenges when it comes to starting a family and raising children. For many people, it becomes a question of whether they can even have children, and if they already do, whether they should inform them that mom and/or dad is infected with HIV – and if so, then when and how the disclosure should be made. It can be seen from the interviews that there are many different ways of handling these children-related issues. For people living with HIV, having children presents a number of problems, particularly for those keeping their HIV more or less secret. Many of these people first experience a challenge to their secret when they have children.

The dilemma of whether or not to tell the children of one's HIV status has in some respects become more difficult over the years. These days, a person living with

HIV can keep it a secret for a longer period of time, and the decision to disclose can be more easily put off. This is not due to a conscious decision to postpone disclosure, but more a result of 'one day just blending into the next'. There is however no doubt that making the decision to disclose is extremely difficult for everyone. Most people are incredibly concerned about how the child or children will react, but some of the interviewees who have children have stated that they decided beforehand that they would not lie if the children asked outright questions about their HIV status.

During the interviews, many subjects explained how their dreams of having children became a preoccupation after being diagnosed HIV positive. This applies to both men and women, but it is particularly notable in women and not least, migrant women. A Danish woman reports that HIV impacts her life most in the areas of finding a husband and starting a family. She therefore spends a lot of time thinking about her love life:

» ... I do think about it ... because I do really want to have children at some point. Time passes, and although I know I'm still young ... but if you have to have lived with someone for two years first, then I'm running out of time. [In order to receive conception assistance from the Danish health care system, a couple must have lived together for two years prior to treatment.]

It is recommended that:

- attention is given to the psychological fragility and feelings of loneliness and isolation experienced by many people living with HIV, but especially among drug users and migrants,
- attention is given to the high level of consumption of sleep medication and sedatives and the reasons for this level of consumption,
- those involved in counselling people living with HIV are aware that they may need to refer the individual to a psychologist or psychiatrist – and especially in the case of newly diagnosed patients,
- the authorities ensure that sufficient information on conception assistance is made available to all those who may need it,
- counselling of people living with HIV who have children include discussion of the issues and difficulties that can arise in connection with disclosing HIV status to one's children.

7. TREATMENT AND SIDE EFFECTS

The medical treatment of HIV patients is a central issue in any discussion of the living conditions and life quality of people living with HIV. A radical change has taken place for many of "the old" HIV patients – in both the pathological picture and in the prognosis for the future – with the advent of new treatment options. Many people have had to learn to live with HIV instead of having to get accustomed to the prospect of dying of HIV.

Side effects

Many people living with HIV experience side effects from their treatment – for example, more than every third respondent suffers from fatigue. And the side effects loom large in the lives of many. A number of Living Conditions Survey interviewees expressed lacking information about the side effects of their treatment, and stated that they do not feel that health care personnel sufficiently acknowledge the extent of the side effects that can interfere with daily life (see Table 7.1).

There is a big difference between the respondents when it comes to medication side effects and how they are able to cope with them. During the interviews, we asked each subject about whether they had experienced side effects and about the impact that side effects had on their lives. In general, interviewees answered 'no' when asked if they experienced medication side effects, but when asked about specific side

effects such as diarrhoea, nausea or tiredness, many reported experiencing these side effects but considering them a natural part of their medical treatment, and that they had found it necessary to learn to live with them. For some respondents, the side effects had become such a part of 'everyday life' that they no longer thought of them as side effects at all.

An African woman named Johanna reported side effects including fatigue, nausea and dizziness, but she felt that these side effects were unavoidable during ARV treatment and she had learned to live with them. Unfortunately for Johanna, the side effects have since become so severe that she can no longer hold a full-time job.

Other studies have shown a low level of awareness about HIV and treatment, especially among migrants and drug users. Characteristic of the migrant sub-group is that they typically do not know who to ask or what to ask about, or in other words, they do not know how to utilise the Danish health care system as a patient, nor what the system can do for them as patients.

Fear of others discovering medical treatment

As shown in table 7.2, a relatively large number of respondents report being concerned that other people will find out that they take ARV medication. This is a big issue for the migrant sub-group in particular, and may be associated with the finding that

Table 7.1 To what extent have you experienced the following side effects or discomfort within the last month while you have been taking the ARV?

	Much or some	Slightly	Not at all
Tiredness	38 %	27 %	29 %
Impotence or reduced sexual desire	35 %	44 %	14 %
Reduced fat on the face, arms, buttocks or legs	35 %	44 %	11 %
Sleep difficulties	28 %	23 %	43 %
Increased fat on stomach, chest or neck	24 %	22 %	47 %
Diarrhoea or abdominal pain	21 %	28 %	43 %
Difficulty in concentrating	18 %	25 %	48 %
Headache	17 %	21 %	52 %

Table 7.2 Are you afraid that other people may discover you are taking medication?

	Yes, always or usually	No
All	18 %	40 %
Homosexuals	12 %	40 %
Heterosexuals (DK)	23 %	38 %
Bisexuals	27 %	39 %
Migrants	34 %	30 %
Drug users	13 %	48 %
The old	14 %	45 %
The new	25 %	32 %

many migrants with HIV disclose their HIV status to only a few other people. But the issue goes beyond the emigrant sub-group, and the fear of having others find out about their HIV medication extends throughout all of the sub-groups.

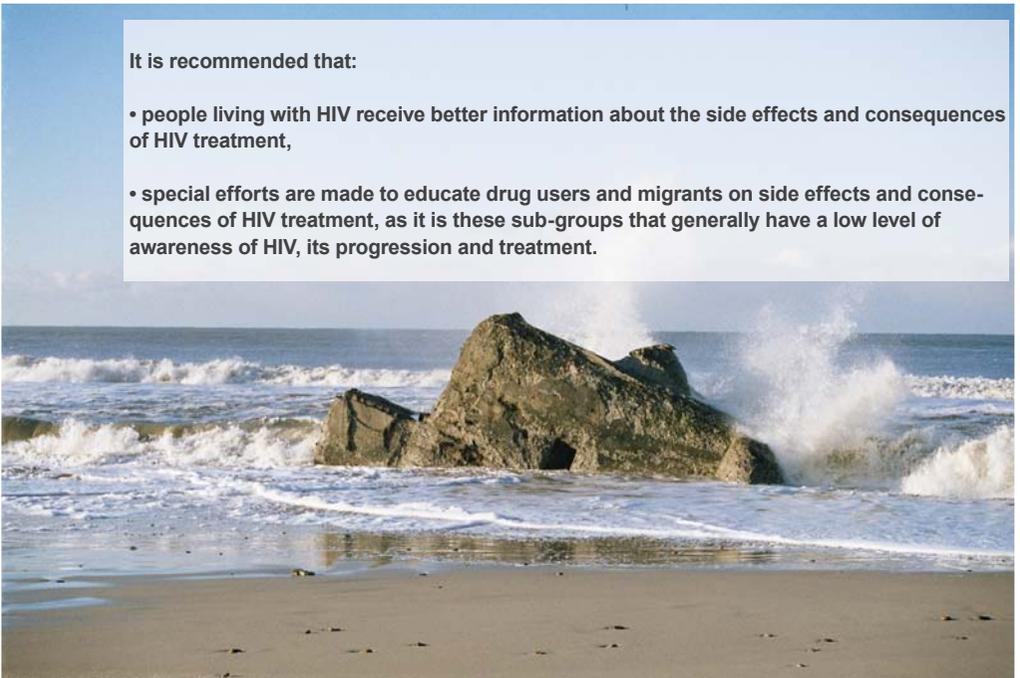
A homosexual man explains that even though he has been infected with HIV for nearly 20 years, he can still feel anxious about other people finding out that he takes medication, such as when he is out at a restaurant:

» When I'm sitting in a restaurant and have to take the pills out of my pocket, I can still catch myself thinking that I'd better not drop them on the floor – and I hope the other patrons don't notice that I'm taking a handful of pills, because I can't see if they're watching, can I? But I do it. I don't think about it too much. Taking the pills is a part of my daily routine.

Another man reports how he learned to take his medication without water. He is then able to medicate himself in public without anyone noticing.

It is recommended that:

- people living with HIV receive better information about the side effects and consequences of HIV treatment,
- special efforts are made to educate drug users and migrants on side effects and consequences of HIV treatment, as it is these sub-groups that generally have a low level of awareness of HIV, its progression and treatment.



8. CONTACT WITH HIV ORGANISATIONS AND OTHER PEOPLE LIVING WITH HIV

Working with this survey has clearly shown that HIV continues to be an illness burdened with a great deal of secrecy and silence, and one that many opt to disclose to few other people. We therefore found it important to identify the extent to which individuals living with HIV are acquainted with other people living with HIV, because for many people the ability to exchange experiences with others in the same situation can make life easier. Furthermore, we also wanted to identify the extent to which people living with HIV utilised the various options and services offered by HIV organisations.

Contact with other people living with HIV

Not surprisingly, the smallest number of people who did not know others living with HIV was found among homosexual men. Most of them knew many other people living with HIV. What is somewhat unexpected is the finding that approximately one in seven of ‘the old’ respondents did not know other people living with HIV. ‘The old’ respondents are those who have been aware of their HIV status for more than 10 years.

One in five of all respondents did not know anyone else living with HIV, and nearly 40 % know between one and five other people living with HIV (see table 8.1). Most of the people who did not know others with HIV were found among the heterosexual and bisexual sub-groups.

Meeting other people living with HIV in an organised group setting is fairly widespread among all respondents and one in ten reported regular encounters with such groups. There is no appreciable difference between sub-groups apart from some indication that there is a difference between ‘the old’ and ‘the new’ – nearly twice as many of ‘the old’ as ‘the new’ meet other people living with HIV in this way. Considering the degree of anxiety among

migrants when it comes to disclosing their HIV status, it is significant that this sub-group contains a percentage of people who meet with others living with HIV in a formal group setting that is similar to that of the other sub-groups.

Nearly every fourth respondent meets regularly with friends who are also HIV positive – most of these respondents are in the homosexual sub-group, where every third person meets other people living with HIV, with the smallest number found among the migrant sub-group, where it is only one in ten who regularly meets with friends who are also HIV positive.

However, not all respondents are interested in socialising with other people living with HIV. 40 % report that they do not feel the need to do so. It is perhaps more interesting to note that approximately every fourth respondent reports that the reason they do not meet with other people living with HIV is because there are no such groups where they live, or that they do not wish to participate in any of the established groups in their area.

The interviews clearly show that ‘the old’ respondents describe the most powerful experiences in meeting others in formal group settings. “You need to meet with other people with HIV during the first phase of your life with HIV. I’ve certainly benefited from it,” explains Jonas, who has been aware of his HIV status for 17 years.

But even among ‘the new’ respondents, good experiences have been reported. Lise, a woman in her late 20s who has been



Tabel 8.1 How many people do you know who are HIV positive?

	None	1-5 people	6-10 people	>10 people
All	20 %	39 %	14 %	27 %
Homosexuals	7 %	38 %	19 %	35 %
Heterosexuals (DK)	33 %	40 %	8 %	19 %
Bisexuals	30 %	49 %	7 %	14 %
Migrants	26 %	41 %	13 %	20 %
Drug users	15 %	36 %	15 %	33 %
The old	15 %	35 %	14 %	36 %
The new	24 %	44 %	13 %	17 %



aware of her HIV status for two years now, joined an organised group consisting of other women living with HIV after completing six months of counselling. Lise thinks that joining the group was an excellent decision, and explains that the members do more than talk about their illness. Occasionally someone will bring up a side effect or HIV-related issue, but otherwise they discuss everything imaginable. One of the reasons she enjoys meeting with her group is the feeling of liberation it gives her. The group has no secrets in terms of HIV status, and everyone feels – or at least Lise does – that this is a setting in which they can speak openly. For the most part, Lise has not disclosed her HIV status to anyone else.

Contact with HIV organisations

There is no appreciable difference between the sub-groups with regard to who utilises counselling or support offered by HIV organisations – approximately half of all respondents report that they have used such services at some time. But although many respondents have made use of these services, it can also be seen that a relatively large number of respondents – more than one in four – have no knowledge of these services. This is most prevalent among the migrant and drug user sub-groups. Nearly two out of three migrant respondents, and

one in two drug users, reported that they were unaware of the services.

Nevertheless there is nothing to indicate that people living with HIV generally do not have confidence in the organisations or do not find that the services on offer are good enough. It should however be mentioned that more than 80 % of the drug users have reported that the services on offer are not good enough. Even though we are talking about relatively few actual responses, it must also be noted that the HIV organisations do not have many specific services on offer for this particular sub-group.

Sofie is one of those respondents who have never been in contact with an HIV organisation. She was married for many years to a man who is also HIV positive. They did not need the services, she explains, and her husband was not the type “who does that sort of thing”. Instead, they depended on one another for support. But now they are divorced, and Sofie is still young, in her mid-30s. She is now beginning to think about making use of the services so that she can discuss her illness with others, not least those who are also living with HIV. She thinks that she could benefit from getting involved with others and exchanging experiences, perhaps in an organised group for conversation and an occasional coffee outing. Sofie is interested in advice and welcomes the idea of hearing about how others living with HIV deal with disclosing their illness to a new partner.

It is recommended that:

- HIV organisations, HIV treatment centres and substance abuse institutions join together to work towards increasing the levels of support and counselling targeted to drug users living with HIV,
- HIV organisations increase their efforts to involve high-functioning people living with HIV in organisation initiatives, as these people have a lot to offer with regards to exchanging experiences on living with HIV,
- it is considered whether the HIV organisations' offers of support and counselling are communicated well enough to newly diagnosed HIV-infected patients, since it is apparently only a fourth of these who take advantage of the offers within the first year,
- continued work is carried out with regards to strengthening the cooperation between the HIV organisations and the HIV treatment centres – and the establishment of a knowledge centre and/or the hiring of a coordinator to drive the process. Mutual awareness of expertise and cross-disciplinary cooperation will increase the possibilities of effective initiatives for patients – furthermore, there is a special need for continuing increased efforts aimed towards migrants and drug users.

9. CONTACT WITH THE SOCIAL SERVICES AND HEALTH CARE SYSTEM IN GENERAL

Like everyone else, people living with HIV are in contact with the public authorities. And since people living with HIV may have an increased risk of becoming ill (due to the HIV infection itself or side effects from ARV medication), we have chosen to examine the nature of their encounters with the social services and the health care system in general. Support and guidance are of crucial importance to the individual. When a person is ill, he or she is vulnerable and thus needs a system that can provide adequate support.

The social services

People living with HIV can have many reasons for contacting the social services. They may initiate a single contact to obtain specific information, they may need temporary help, or they may require ongoing support of a more permanent nature.

Among the respondents to the Living Condition Survey, many have experienced good treatment, while others report having had more unfortunate experiences of lack of understanding of the disease or a sensationalist reaction when personnel discover they are dealing with a person living with HIV. None of the interviewees have experienced actual discrimination by the social services.

A third of all respondents report some form of contact with the social services within the last year. The fewest were found among homosexuals, where only a fourth of the respondents had been in contact with the social services, while the highest percentage was found among migrants and drug users.

80 % of all respondents who have been in contact with the social services within

the last year have reported that they are infected with HIV. There are nearly twice as many among ‘the new’ as ‘the old’ who have not disclosed their HIV status to the social services. For some respondents, it is crucial that social services personnel are not aware of their HIV status, but for others it is important for them to be able to disclose their HIV status to social services. For still other respondents, it is not important – if at all – that social services be aware of their HIV status.

A Danish woman living in a small town explains that she has not informed the local social services of her HIV status. Her reason is that she knows both the social worker and the social worker’s family – not personally, but in a small town “everyone knows everyone else”. For this respondent, living in a small town creates a number of problems for her in terms of who knows of her HIV status and who doesn’t. She has considered changing to a new doctor because her current doctor – through an error – found out that she was infected with HIV, but there is no way to change one’s social services department.

Brenda, an African woman who is otherwise very close-mouthed about her HIV status, decided to tell the social services that she was infected with HIV. She explains that it is only other Africans she is concerned about, and she doesn’t care that “Danish people” know about her HIV status. Brenda fears that if other Africans learn that she is infected with HIV that her family in Africa will eventually find out, too. She is not worried that a “Danish person” at the social services might tell a co-worker or spouse of her HIV status, because they don’t know who she is anyway.

A relatively large percentage of respondents – more than one in four – who have





informed the social services of their HIV status are concerned that personnel will breach the rules of confidentiality and tell other people. This concern is seen particularly among migrants and drug users, and among 'the new' there is a large percentage of respondents who do not trust social services personnel. It is not clear how to interpret this relatively large percentage of respondents who fear disclosure of their HIV status by social services personnel. It may be an expression of a general lack of trust towards the personnel, but it is more likely that it represents the control that many people living with HIV wish to have over who is aware of their HIV status.

There are big differences in how people living with HIV experience the assistance they are getting from social services, and the expectations are in all likelihood also quite different. The survey shows that almost half of the respondents experience the assistance they receive as satisfactory, whereas a fourth of respondents experience it as poor. The drug user sub-group is the one in which the smallest number of respondents, just a third, characterise the assistance they have had at social services as good. It is also in this sub-group that the most respondents have indicated that they perceive the help as being bad.

The questionnaire also asked whether the individual experienced a change in the way they were treated by social services when personnel discovered the respondent's HIV status. Just under 4 out of 10 reported that they are treated approximately the same as before they disclosed their HIV status, and 14 % have actually experienced an improvement in the way that they were treated. The latter is the case especially among migrants and bisexuals. 7 % of all of the respondents report that they have experienced reluctance and prejudice as a result of disclosing their HIV status.

The survey has shown that there are two types of problems that people living with HIV in principle risk encountering at social services – one is concerned with the insight and inclusiveness of the social system and thereby the specific effort made, and the other is about the nature of the contact.

In connection with both informant interviews and interviews with interviewees

we have encountered several times that the social system is having difficulties in handling the people that have been infected for many years, and who have several health issues and/or illnesses. It can be hard for the administration to uncover what the primary problem is, and where the first effort should be made, which can influence the contact with the citizen.

It has also been mentioned that the migrants that are in touch with the social system generally do not have a very good experience with the contact. There are often substantial language difficulties and migrants experience trouble getting the help they need and are entitled to. Often they receive letters from the social services written in Danish, which they cannot read or understand. However, migrants are not more dissatisfied than other sub-groups with the help they receive from the social services. But that does not mean that the problems that actually occur cannot be more difficult than with non-migrant citizens. Perhaps the same issue is at play here as mentioned earlier; namely that migrants do not know how to 'use social services' – what can the social system be used for, and what are they actually entitled to.

Among the interviewees, several describe the way in which HIV can affect the contact between them and the social services personnel – how they experience the way in which personnel step out of their professional roles when they encounter someone with HIV. It is not described as discrimination, but it is a form of negative contact that the person living with HIV experiences as disturbing and unnecessary. HIV may only represent one aspect of an issue they need help with, but it can easily come to overshadow the interaction. Many interviewees take this to mean that social workers don't encounter people living with HIV very often.

Tina has been living with HIV for many years and is living on an early retirement pension. She reports that she still has adverse experiences in her encounters with the social services. Tina explains that when she discloses her HIV status to personnel, they forget about everything else and become preoccupied with the fact that she is HIV positive. The personnel typically ask Tina

questions about how she was infected “and that sort of thing”, and Tina feels uncomfortable when placed in these situations. She has since learned to use humour to deal with the problem, but at one time she found it dreadful. “I feel like asking if they would like to touch me,” she says.

The health care system in general

Just as with the social services, people living with HIV can have a wide range of reasons for contact with the health care system (in addition to the HIV treatment centre). These contacts include those with GPs, dentists, other hospital clinics or specialists.

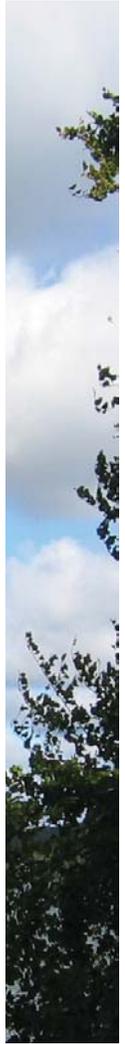
Many respondents contemplate who they should tell about their HIV status, and once the decision has been made, when the disclosure should take place. A number of respondents report careful consideration about telling their dentist about their HIV status. And still others say that they have not yet made the disclosure, but that they have decided to do so if they should require a major surgical procedure.

Much indicates that people living with HIV experience problems in connection with the health care system in general, and this deserves closer examination. A number of interviewees report unpleasant experiences with the health care system ‘outside’ of the HIV treatment centre – experiences that are surprising in light of the fact that health care personnel are trained

in these matters and might be expected to command a greater insight. These experiences have resulted in many people living with HIV establishing an agreement with the HIV treatment centre as first point of contact for all health care issues, in order to bypass the general health care system.

Charlotte, a woman who is HIV positive, reports a variety of reactions from the health care system when she has disclosed her HIV status. She explains that many personnel become ‘totally upset’ by the information. In recent years, Charlotte has had a number of experiences characterised by the experience that doctors and nurses either do not dare or wish to treat her. They refer constantly to the fact that she is HIV positive, and that this must be the cause of any health-related problem she might have. Therefore she is always being referred elsewhere and ultimately to the HIV treatment centre. “It’s like they get scared and give up, and they just want me to go away,” explains Charlotte. She has now made an agreement with the HIV treatment centre to use it as her first point of contact with the health care system. Charlotte feels uncomfortable with the reactions of other health care personnel, and feels that she is improperly treated.

For people living with HIV, it appears to require a degree of personal strength to deal with the general health care system. And with the psychological fragility we have seen exhibited by so many respondents, not everyone is capable of coping with the inappropriate reactions of some health care personnel.



It is recommended that:

- with respect to the social services, initiatives are taken to address the apparent lack of knowledge of what it is like to live with a chronic disease that does not necessarily have a stable course – and that patient organisations (for chronically ill people) can perhaps cooperate with each other on such an effort,
- in relation to the health care personnel ‘outside’ the HIV treatment centres, increased focus is put on HIV and modes of transmission – both in connection with the education of the health care personnel and by increased information for the already trained personnel.

ABOUT THE AUTHORS

Mie Carstensen (b. 1972), has a M.Sc. degree from the University of Roskilde from 2002 with graduate studies in social science and cultural encounters. Subsequently she was a Teaching Assistant at the University of Roskilde. She has been a volunteer advisor at the AIDS-Hotline in the period from 1995 to 2003, she has been a member of the governing council of the AIDS-Hotline, and from that she has many years of experience with HIV in Denmark. Furthermore she has worked with vulnerable groups in the Danish society employed as a consultant at the Asylum Department of the Danish Red Cross, and as a development consultant for the Committee on Labour Market in the Municipality of Copenhagen.

Anders Dahl (b. 1953), is an anthropologist from the University of Copenhagen from 1992. Since 1992 he has been working with the prevention of HIV. He is the co-author of a scientific research report on male prostitution in Denmark (1990) and has written a number of articles on male prostitution. He worked at the AIDS-Hotline from 1992 to 2003. Since then he has been a freelance consultant and worked for the National Board of Health, Sex & Samfund, Hiv-Danmark, Carl Bro A/S and others. He has worked with HIV-prevention in Vietnam since 2000 and has worked for UNFPA, VINAFPA (the Vietnamese Family Planning Association) and others as well as a number of local non-governmental organisations. He has been a temporary advisor for WHO during the development of the clinical protocol for the Europe region "Support for Sexual and Reproductive Health in People Living with HIV/AIDS" (2006). Furthermore he is an educator and a speaker.



Hiv-Danmark is a national organisation for all people living with HIV and those affected by HIV, living in Denmark, irrespective of method of infection, gender, sexuality or nationality.

Hiv-Danmark advocates for people living with HIV, relatives and bereaved. Hiv-Danmark is an umbrella organisation for individuals, self-help groups and other societies for people living with HIV as well as groups attached to HIV wards at hospitals.

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