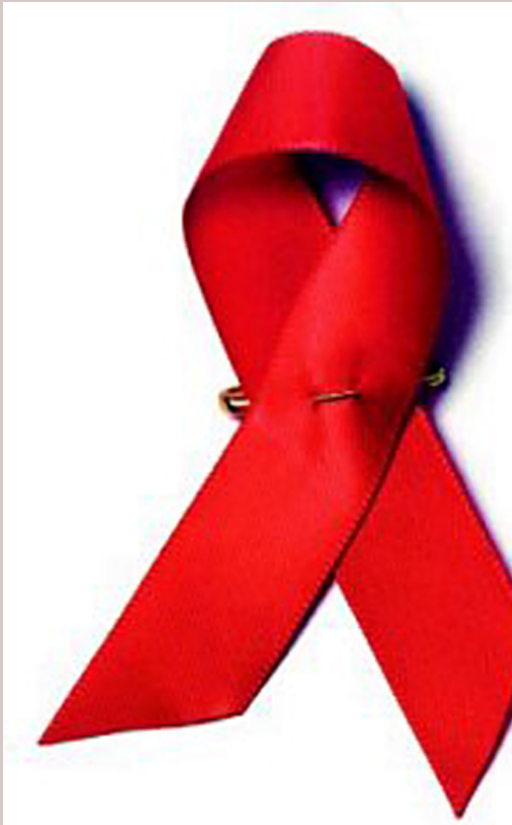
Living Conditions and Quality of life among People Living with HIV in Norway

English summary



Fafo

Arne Grønningsæter (ed.)

Living Conditions and Quality of life among People Living with HIV in Norway

English summary

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Preface

In 2002 Fafo carried through a national study of living conditions and quality of life among people living with HIV in Norway. The study was commissioned by Pluss - Norwegian Association Against Aids (PLMA), and The Royal Norwegian Ministry of Health and Social Affairs; and was partly financed with the aid of EXTRA funds from the Norwegian Foundation for Health and Rehabilitation. This report contains an English summary of the report from the project (which is in Norwegian) as well as a short presentation of how different stakeholders used the results. This short report in English is commissioned by PLMA and will be presented at the international Aids conference in Bankok July 2004.

The original report from 2002 – "Levekår og livskvalitet blant hivpositive" – was written by Katrine Fangen, Arne Grønningsæter, Thomas Lorentsen and Siv Øverås. Arne Grønningsæter has edited this English language report and written the English summary. Per Miljeteig has written the paragraphs on the use of the results. Olav André Manum has translated the manifesto into English and done the language cleaning of the full text. Thanks also to Jon Lahlum in the publication department of Fafo for the good work with layout and printing

As far as we know this study is unique, also in an international context. The original report contains 250 pages with data and analyses. It is therefore difficult to give a fair presentation of this rich data material through a short summary like the one we present here. We hope, however, that we have managed to present enough to give an input to policy development in this field. It is important, also in this context, to say thanks to the informants and respondents that made the study possible. For the researchers involved, the project became a series of meetings with people struggling to keep their dignity and integrity in a challenging life situation. We hope that we have been able to mediate some of their voices in this presentation.

Oslo, June 2004
Arne Grønningsæter

Background

Living conditions can be defined as the individual's access to recourses that can be used on different arenas for the control and management of conditions of life. (NOU 1993:17). Components of living conditions include e.g.:

- Health and access to medical treatment
- Employment and labour conditions
- Economical resources and consumption
- Competence and access to education
- Family and social relations
- Housing and access to services in the local community
- Recreation and culture
- Security for life and property
- Political resources and democratic rights

The Scandinavian countries have a long tradition of national surveys of the living conditions of the population. The Scandinavian tradition of living conditions research has had limited interests in the connection between objective living conditions and subjective quality of life. Fafo and other social science research institutions in Norway have developed studies of the living conditions of specific groups. Examples of this approach are studies of living conditions among people with allergies, gays and lesbians, deaf young people etc. We have tried to include issues of the experienced results on the quality of the person's conditions of life.

The original project proposal included a range of issues. Among these issues are:

- Social participation and integration
- Socio economic resources
- The use of and experiences with the health services
- Living with HIV
- Differences between the various affected groups
- What is the impact of the new medicines and the fact that many have got new life expectancies
- How do PLWH handle health issues and side-effects of the medication
- Stigma and the feeling of doubts

Background

About the report

This report contains a summary of the report that was published in 2002 and presented on the World Aids day on the 1. December 2002. We use the same division in chapters and present some main findings within each issue. We have chosen the following headlines:

1 Background
2 Methods
3 Who are the PLWH in Norway
4 Income and economy
5 Employment
6 Housing
7 Openness
8 Isolation or cohesion
9 Sexuality, love and partnerships
10 Parents with HIV
11 Mental health
12 Somatic health and the use of medication
13 Experiences with the health services
14 Experiences with other public services
15 Recommendations

It is now more than a year since the original report was published. There is no reason to believe that the situation has changed in any fundamental manner since the project was finished. The tables and comments are therefore based on the situation in 2001/ 2002 and the analyses draw a picture that mirrors the situation towards the end of 2002. Two issues are added to make the report as updated as possible. The figures for the development of the epidemic include figures from 2003, and we have added a chapter on stakeholders' use of the results.

The two last chapters therefore contains:

16 A manifesto issued by Norwegian NGOs
17 How the stakeholders used the results

Background

Methods

The study was based on three main methodological approaches:

- Analysis of previous national and international relevant research
- A survey among people in Norway knowing that they are infected by HIV
- In dept interviews with 19 individuals.

There is no registry of PLWH in Norway, and consequently it is not possible to draw a representative selection of respondents. We had to choose an alternative strategy. Our idea was to reach out to as many persons as possible in the universe through as many available channels as possible. We chose to use a snowball approach and the following tracks:

- Members of Pluss – the Norwegian organisation for PLWH
- Hospitals and clinics specialised in HIV related treatment
- Organisations and networks that have contact with relevant groups, e.g. drug users, immigrants[1], gay men etc.

At the end of 2001 we estimate that app. 15-1600 were people living with HIV in Norway. Of those 311 responded to the questionnaire. We therefore believe that we reached out to app. 20% of the universe. The survey covered the following issues[2]:

- Background
- Health
- Welfare state services
- Family and friends
- Employment
- Housing
- Economy

[1] In this report we use the concept immigrant for refugees, asylum seekers and immigrants born outside Norway

[1] The questionnaire was produced both in English and in Norwegian. The English version can be downloaded at www.fafo.no/pub/rapp/402.

Background

In the qualitative part of the study we conducted 19 in depth interviews. The informants represent different groups of HIV infected people. HIV/Aids is still a disease with a lot of stigma linked to it and it was more difficult than expected to find people willing to be interviewed. We had especial problems finding active drug users and heterosexually infected Norwegian men.

The interview guide covered the following issues. The informants were asked to tell their story with emphasis on situation that lead to change in the following arenas:

- Job, education, housing, economy
- Expectations of the future
- Thoughts about body and sexuality
- Relations to friends, family, colleagues and lovers
- Thoughts about being HIV positive
- Mental and somatic health
- Health and social services
- Children, partners
- Use of drugs
- Status in Norway (e.g. asylum seekers)

Respondents, informants - and who are the PLWH in Norway?

Overall figures

HIV infections in Norway per 31 December 2003. MSIS report 8/2004. Norwegian Institute of Public Health

Way of transmission	83–93	94	95	96	97	98	99	00	01	02	03	Total	%
Heterosexual	374	33	47	63	67	58	92	132	106	151	152	1274	45,6
when living in Norway	175	11	23	29	33	22	27	39	27	28	34	444	-
before coming to Norway	199	22	24	34	34	36	65	93	79	123	118	830	-
Homosexual	519	37	45	35	30	30	36	32	39	30	57	890	31,9
Drug use (needles)	378	12	11	9	11	8	12	7	8	16	13	486	17,4
Blood products	45				1							46	1,6
Mother to child	12			4	1	1	4	3	2	2	5	34	1,2
Others/unknown	16	12	2	5	3	1	3	2	3	6	11	67	2,4
Total	1344	94	105	116	113	98	147	176	158	205	238	2793	100

In 2001 158 persons were diagnosed with HIV in Norway. Of those 102 (65%) were men and 56 (35%) were women. From 1996 to 2001 the yearly average number of new diagnosed were 130 and the figures from 2000 shows 176 new diagnosed. Among the 158 that got the HIV diagnosis in 2001 91 (58%) were of foreign origin, and were infected before they arrived in Norway. In 2001 there were conducted 109 586 HIV-tests. At the end of 2001 there were 2351 persons diagnosed with HIV. Out of those an estimate of 800 persons are either dead or have left the country (Nilsen 2001). We therefore believe that 1500 – 1600 persons live in Norway and know that they are HIV infected at the time of the survey.

The figures from 2003 show a new increase in the number of diagnosed men infected through homosexual contacts.

Respondents, informants - and who are the PLWH in Norway?

Who are the respondents?

Reported ways of transmission in the population and among the respondents. Norwegian Institute of Public Health and Fafo. Percent

	Institute of Public Health	Fafo
Heterosexual	41,3	25,0
Homosexual	34,2	46,8
Needle exchange	19,4	6,5
Blood / blood products	2,0	2,3
Mother to child	1,1	-
Other / unknown	2,0	19,4
Total	100,0	100,0
N	2351	308

Almost 20% of the universe responded to the survey[1]. We found this relatively satisfying, considering the difficulties in reaching the actual group of people. Our respondents represent, however, a biased selection. Experience points to that those with most resources tend to be over represented. Consequently we had problems getting response from drug users and people with strongly handicapping somatic symptoms in this study. We therefore believe that there is a positive selection of respondents. The comparison between the figures from national statistics and our figures also points to the probability that certain groups are over or under represented. Heterosexually infected are under represented while cases of homosexual transmission is over represented in the sample.[2]

[1] When we use the word respondent in the report we refere to the quantitative survey

[2] The full report in Norwegian (Fafo report 402) conatins a more thorough discussion about the selection and its consequences.

Respondents, informants - and who are the PLWH in Norway?

Qualitative interviews

Informants divided in groups, and gender

	Men	Women
Homosexuals	5	
Immigrants from Africa and Asia	2	3
Drug users		1
Previously drug users	1	1
Heterosexual Norwegians	2	5
Total	10	9
Of those		
Women living outside Oslo		2
Men living outside Oslo	3	
Women with children		4
Men with children	3	

The aim of the qualitative interviews was to get a better understanding of how different aspects of the situation of people living with HIV is experienced[1]. We asked for concrete situations on how their lives were changed when they were diagnosed and how they handled the situation in different areas. The information was used in the process of interpretation of the data from the quantitative survey. Although these interviews do not give a representative picture we believe that they reveal important knowledge of problems linked to being HIV infected.

The informants represent a range of social groups; immigrants, active drug users, previous drug users, gay men, heterosexual men, women. We had special problems in getting informants among heterosexual men. It was also a challenge to get hold of drug users. It was easier to get hold of previous drug users (methadone users) than active drug users. Most of the informants were recruited through the networks of relevant organisations. We wanted to get hold of people who were both inside and outside of these network. To some extent we did managed to do that, but the interviews are nonetheless characterised by a bias towards people with an active participation in these networks.

[1] When we use the word informant in the report we refer to the qualitative interviews.

Income and economy

Income

Gross income 2000

	Fafo	SSB*
1–99999 NOK	19	19
100–199999 NOK	29	29
200–299999 NOK	29	28
300–499 999 NOK	18	19
500 000 NOK or more	4	5
Do not know	2	-
Total	100	100
	(302)	(3495102)

* Figures from Statistics Norway show distribution of income for the entire population over 17 years of age.

The table shows a comparison of gross income between the respondents and in the general population. The figures are more or less identical. This, to some extent, is surprising since people living with HIV are supposed to represent economically marginalised groups. We know from previous research that the average income among gay men is higher than the average in the general population (Hegnar; Kristiansen and Moseng 1999). We may therefore assume that there are relatively great differences among the affected groups, and that immigrants and drug users are the worst off. This is confirmed by our findings and it seems that social status is more important for the level of income than HIV status.

Income and economy

Economic problems

Problems with managing running expenses for food, transport, living etc. the last year. Percent.

	Fafo-survey	SSB's living conditions survey 1998*
Yes, often	27,1	3,0
Yes, once in a while	19,7	6,3
Yes, occasionally	13,9	8,6
No, never	39,3	81,8
Do not know		0,3
Total	100 (295)	100 (3449)

Ability to manage unforeseen bill of 3000 NOK .Percent

Yes	47	83
No	53	17
Total	100 (293)	100 (3429)

Source: Fløtten 2002

The level of income does not necessarily give a full picture of the every day economy of the person. Many of the informants report on extra expenses for nutrition and nutritional supplements. We asked the respondents two questions also used in the National living conditions survey. The first question is "During the last year, has it happened that your house hold has had difficulties with managing running expenses for food, transport, living etc.?" The second question is "Were your finances such that you/the household, for a greater part of the year, could have managed unforeseen bill for NOK 3000 for, e.g. dentist or repairs?" We use these questions to measure how the respondents experience economical problems. People living with HIV have more often financial problems than the average population.

The great differences between the general population and the respondents is in contrast to the fact that the income level in general is the same among the respondents and the general population. This phenomenon can be seen as a result of a combination of three processes. It can be the result of a combination of growing expenditures, loss of overview of the economy due to the fact that life crises make you loose control, and individuals can experience a short-term reduction in income. When there is a low level of income it adds an extra burden to being HIV positive. The consequence is limited space for doing thing that can improve the social conditions of the person.

Employment

- 39% of the respondents are working full time.
- 15% of the respondents are working part time
- 7% of the respondents are unemployed, or seeking work.
- More than half of the respondents have wages as their main income.
- More than half of the respondents receive pensions and/or social benefits as part of their income or their whole income.

We have not found many examples of people being discriminated in the form of being fired. Several informants do, however, tell us that they do not dare to be open about their HIV status because they are afraid of loosing the opportunity to be promoted at their work place.

A link to the working life is seen as positive for the individual, but at the same time as quite stressful and implying hard work. It seems to be a great challenge to the employers to create a working environment that makes it easier to be open about one's HIV status. This is one of the presuppositions that needs to be fulfilled if we want to make working conditions adopted to the needs and possibilities of the individual.

Housing

The quantitative material points to a good standard of housing for the majority of the respondents.

- A number of immigrants and drug users have very small houses/apartments.
- 1/5 of the respondents think that their housing is not adjusted to the special needs they have as a consequence of their health situation.

Most of the people living with HIV have a stable housing situation, but an unstable housing situation makes life complicated. Immigrants in general have a lower standard of housing than the general population. There is a need for stable housing. For the few that does not have a stable housing situation, this is an additional burden. It seems to be an increasing need for specially adjusted housing conditions for people with chronic conditions as e.g. HIV infection.

Openness about HIV status

Have you told any of the following that you are HIV positive?

	Percent	N
Parents	60	164
Siblings	62	176
Own children	29	40
Friends	77	224
Others	67	161

Have you told any of your present or former colleagues that you are HIV positive?

Yes	46
No	48
Have not been working	5
Total	100
N	278

We find that people living with HIV's relation to other people is closely connected to the level of openness about HIV status.

It seems to be less important to inform colleagues at work than to inform people closest to the respondents, be they family or close friends. Less than half of the respondents have told one or more colleagues about their HIV infection. The majority of those who has been open towards colleagues have experiences this as a relief. More than half of the respondents found it easier to relate to their colleagues after they told them about their HIV status, and almost half of them say that they have got more understanding from their colleagues afterwards.

Most people living with HIV are open towards somebody, but in many cases it seems that these people represents a very limited circle. Some communities are, however, very closed. Many tell us about positive experiences with being open about HIV status. Although the negative experiences are fewer, they are significantly present.

All the groups of infected – except for heterosexual men – report on a better mental health if they have told their friend that they have HIV.

3rd world seem to be the ones that to the largest degree keep quiet about their HIV infection.

Openness about HIV status

To chose to keep quiet about HIV infection

Why have you not told your parents, siblings, children or friends that your are HIV positive?

	Percent	N
I am afraid they will reject me	15	43
I know that they will not accept it	10	28
They will be afraid of me	18	54
I am too ashamed	16	48
I am scared	14	40
It just has not happened	14	41
Other	24	70

Why have you not told your present or previous colleagues that you are HIV positive?

Afraid that this will reduce my career opportunities	21	35
Afraid of being socially excluded	34	56
Afraid of loosing my job	23	38
View it as a personal matter	58	96
Wish to spare the family	21	35
Do not wish to be given special consideration	23	39
Other	11	18

Many people living with HIV are selective when it come to who they are open towards. In many cases we see that they are only open towards people that they trust, and choose to be silent toward others. Most of the informants are open towards at least a few persons, more often than not it seems that these are the nearest family or a few very close friends. The qualitative interviews points towards the fact that the majority keep quiet about their HIV status towards at least as many as those they are open towards. There seams to be a wide range of reasons why people chose silence. Shame and the idea that "others will be scared" are the most used ones.

Among those that have not told colleagues, a vast majority say that their HIV status is a private matter. One out of three are afraid to be socially excluded at work. If we compare the different groups of HIV infected, the immigrants from countries in the 3rd world seem to be the ones that to the largest degree keep quiet about their HIV infection.

Isolation or belonging

To what extent have you, as a consequence of your HIV status felt that you are isolated?

In large or some degree	49
In small or no degree	51
Total	100
N	288

Our study confirm previous research saying that HIV positive people have a special need for relating to organisations, communities and interest groups (Emaus 1998) Those with good connections to "Aksept" (a psycho-social centre for PLWH and their relatives) get support, respect and help to handle conflicts. Those who get this kind of support help and understanding from other persons might have less need for this kind of communities. In all probability, however, these persons will also benefit from network organisations. To be connected to a network of people in the same situation seems to be important for all categories of people living with HIV.

Some people living with HIV avoid contact with network organisations. They do not want to focus too much on their identity as HIV positive. We know e.g. that this is the case for some heterosexual men. We see, however, that this is a group who struggles more than other groups with being HIV positive. It does not seem to be a good personal strategy to be alone with your HIV status.

On the other hand it might also be a problem to build your whole life and identity around being HIV positive. Some make it a full time engagement to be HIV positive. This can lead to another form for isolation.

Relatively many feel isolated as a result of their HIV infection. A little more than 1/3 of the respondents have experienced less contact with friends and family as a consequence of being HIV positive. Half of the respondents feel that they are isolated. We see that network organisations are important and that people living with HIV outside Oslo (the Norwegian capital) lack good offers of network close to where they live.

Sexuality, love and partnerships

At present, are you …? Percent

Married (to a person of the opposite sex)	14
Partner (to a person of the same sex)	8
Cohabitant (to a person of the same sex)	9
Cohabitant (to a person of the opposite sex)	7
Divorced/separated	10
Unmarried/not cohabiting, but with a girlfriend/boyfriend	11
Unmarried/not cohabiting, but without a girlfriend/boyfriend	41
Total	100
N	302

At present, are you …? Divided in gender and sexual orientation. Norwegian. Percent

	Female heterosexual	Male heterosexual	Male homosexual	Male bisexual
Married/partner	19	23	14	35
Cohabitant	12	20	15	4
Divorced/separated	17	20	8	26
Unmarried/not cohabiting, but with a girlfriend/boyfriend	21	9	7	9
Unmarried/not cohabiting, but without a girlfriend/boyfriend	31	29	55	26
Total	100	100	100	100
N	42	35	111	23

Many HIV positive people live with a partner or a girlfriend/boyfriend. Among the respondents approximately half are in a relationship, with a partner, a cohabitant or a girlfriend/boyfriend. Slightly less than half of the respondents are single. In the general population (age 20 – 79) 16% are cohabiting and 53% are married. Our finding also seem to show that relatively fewer of the gay men have a partner compared to the other groups of HIV positives. Among heterosexuals and bisexuals there are a much higher rate of persons in permanent relationships than among gay men.

There are more Norwegians in relationships than there are Asians and Africans, while there are more of the Asians and Africans that are married.

Sexuality, love and partnerships

Closeness

To what extend have you, as a result of being HIV positive, experienced some of the following?
Percent

	To a large or some extent	To a little or no extent	Total	N
Received less physical closeness	43	57	100	280
Feel "contagious" and keep physical distance from others	37	63	100	281
Your sex life has become severely limited	75	25	100	297
You no longer dare to have sex	55	44	100	290

There are several studies of the HIV infection's importance for the sexual activity of gay men. (e.g. Prieur 1988, Middelthon 2001, Træen 1990), and some studies when it comes to drug users (Middelthon og Prieur 1992). There are much less about heterosexual women and men. There seems to be a complete lack of knowledge about the consequence of HIV infections on people's sexual lives related to other groups than men having sex with men and drug users.

A little less than half of the respondents say that they get less physical contact after they were infected. More than on third feel "contagious" and keep more distance to other people. Two thirds think their sexuality has been strongly limited by the virus. More than half abstain from sex.

When we compare the Norwegian respondents we see that men experience greater consequences with regard to closeness and sexuality than women. Gay and bisexual men seems to experience a feeling of being infectious and tend to keep other people at a distance. This might be due to the stigma on people living with HIV in the gay community

There is great concern about not infecting others and many find it difficult to establish relationships. Some also experience that their partners do not want safe sex. It is difficult to handle sex partners' negative reactions. Some find it difficult to tell their sex partners that they are HIV infected, because they are afraid of being rejected.

The individual differences are bigger than e.g. gender differences in these issues.

Parents with HIV

Children, the age of the children and parents' custody of the children. Percent

	Yes	No	Total	N
Do you have children of your own?	33	67	100	305
Are any of these children under 18 years of age?	52	48	100	98
Do you have total or part time custody of any of these children?	76	24	100	54

Do you have total or part time custody of any of these children? By nationality. Percent

	Yes	No	Total	N
Born in Norway	83	17	100	42
Born in Africa or Asia	67	33	100	9

Some people living with HIV became parents before they were infected, while others did so after they were diagnosed with HIV. There seems to be fare more women than men with children. Approximately ¼ of the male and half of the female respondents have children

From our qualitative data we know that some of the men from Africa and Asia have wives that are left behind in their home countries with the children. A lower number of those from Africa and Asia than of those from Norway are responsible for the care of their children. Their numbers in the quantitative data are, however, too low to to tell us the reason for that.

Some says that the most important change in their lives when they got the diagnosis, was that they stopped wanting/planning to have children. Periodically health issues limits a persons stamina as a parent. This is especially the case among people infected in Africa and who has been without medication for many years. It is also the case among drug users that were for a long time without medication due to their life style

The relationship with the children does not seem to be influence by the fact that the parents are HIV positive. With today's medical treatment there are few reasons why HIV positive people cannot have children. The hindrance is mostly linked to emotional aspects and the fact that it is difficult to make plans for a long life.

Mental health

How much time during the last 14 days have you experienced any of the following? Percent*

		All the time or most of the time	Some of the time	Not at any time	Total	N
Been troubled by nervousness and inner anxiety	Fafo	32	38	30	100	289
	Moum	4	12	85	101	8096
Been troubled with fear or vorry	Fafo	27	34	39	100	283
	Moum	1	4	95	100	8096
Feelings of helplessness regarding the future.**	Fafo	34	36	30	100	283
	Moum	2	6	92	100	8096
Been depressed and melancholy	Fafo	28	43	29	100	286
	Moum	2	8	90	100	8096
Been worried and restless	Fafo	32	43	25	100	290
	Moum	2	8	90	100	8096

* The categories of answers are not identical in Fafo's and Moum's studies. Moum uses the categories: Not burdened, a little burdened, quite a lot burdened and very much burdened. The two last categories are joined together.

** In Moum's study the question is formulated as hopelessness for the future.

The quantitative data indicates that a relatively large part of people living with HIV have psychiatric problems. In the table question 1, 2 and 5 is seen as indications of anxiety and question 3 and 4 of depression. (reference to Moum et al 1991). The comparison with Moum's figures indicates that symptoms of both anxiety and depression are very common among people living with HIV, compared to the general population.

Mental health

Medication and professional support

During the last 12 months, have you used sedatives, sleeping pills, antidepressants or other means to lessen mental or physical health problems? Percent. (N=299)

Yes	51
No	49
Total	100

Have you been in contact with a psychologist during the last 12 months? By gender and sexual orientation. Norwgian. Percent

	Female heterosexual	Male heterosexual	Male homosexual	Male bisexual
Have not been in contact	78	80	77	88
Have been in contact	22	20	23	12
Total	100	100	100	100
N	27	30	77	17

If we look at the different categories of Norwegian respondents, Homosexual men are the ones that most often use medication for psychiatric problems.

To get HIV for most people has consequences for their mental wellbeing. Those with good support and network seems to handle the situation quite well, but even those with most the resources among the informants have been struggling from time to time. There is a need for a more professional support apparatus around the people living with HIV. This apparatus must also be able to handle serious psychiatric problems. Organisations and networks can in some cases fill that function, but some need support from the psychiatric health services. The competence and knowledge on the special needs of people living with HIV does not seem to be good enough.

The psychiatric problems following an HIV diagnosis are parallel to the psychiatric problems following other serious diagnoses.

Somatic health and the use of medication

Evaluation of own health. Percent

Very good	27
Good	39
Neither good nor bad	25
Bad	9
Very bad	0
Total	100
N	301

We see that approximately 2/3 of the respondents evaluate their health as good or very good. This is surprising, taken into consideration that all of the respondents have an HIV diagnosis, and that we therefore would expect great health problems. This might be a result of the possibility that they evaluate their health in comparison with expectations of something fare worse. Health is evaluated in comparison with expectations and worst-case scenarios. The result is in line with other health and living conditions surveys that show that people might have several health problems parallel to not experiencing their health as being generally poor. (Øveråas 1995, Barstad 1997). The drug users face the worst health situation.

We got many reports on side effects of medication. This is linked to stories about how the health services underestimate the importance of such symptoms. Many informants question the health services approach to these issues. Medical doctors are criticised for only being interested in T4 counting. Some patients are aware that changes in life style might improve their health or contribute to keeping it good and they could do with some help and advice from the health services. These changes demand strength, as do the follow up of treatment.

The patient need to be "professional" to be able to demand according to needs. There are offers that you need to be a "professional" patient to find, and to know how to benefit from.

As one of our informants pointed out: "You have to be healthy to be sick".

Experiences with the health services

- 82% of the respondents are regularly in touch with one general practitioner in addition to contact with the clinics specialised on HIV treatment.
- Approximately 1/3 of the respondents feel that they are treated better by the health services after they were diagnosed with HIV
- 45% feel that the treatment in general is as it was before they were diagnosed with HIV.
- There is no difference between the different groups of HIV positives when it comes to the use of health services.

People living with HIV are often in contact with the health services. In spite of some negative experiences, most of them feel that they are well treated. Many think that th general practitioners lack knowledge about HIV and protection against infection.

There is one issue going through the interviews when it comes to the critisisms of the specialised health services; the doctor's way of thinking is to narrow. Why do they e.g. not give advices on general life style issues that have to do with the immune system? Many informants express a need for a broader and more holistic treatment than they actually get. They want e.g. information about nutrition and the use of nutritional supplements.

The negative stories are often seen as exceptions. On the other hand the positive experiences are often seen as a result of being lucky. The informants often use the expression "… but I have been lucky …".

Experiences with the health services

Demand for information

Do you need more information about any of the following, or do you feel that the information you get is satisfactory?

	Percent	N
Infectious behaviour	17	49
A safe sex life	25	72
Use of medication and side effects	49	142
Diet	55	161
Alternative medicine	66	189

The need for more advice about nutrition and alternative medicine is also often mentioned issue in the qualitative interviews. 55 percent of the responds say they need more information on nutrition, and the number of those who want better information about alternative medicine is even bigger. People living with HIV seem to ask for a more holistic approach to the medical treatment of their condition. It is also worth mentioning that almost half of the respondents ask for more information about medication and side effects.

Experiences with other public services

- The local employment offices[1] are strongly criticised for not understanding the situation of people living with HIV, and for giving wrong information
- The immigration authorities[2] are equally strongly criticised. The staff is described as lacking knowledge, as well as being prejudiced. We also got stories about violation of the rules for confidentiality.
- The municipal social service departments[3] get both negative and positive comments. 40% say they get good treatment and 46% say they get bad treatment. We see the same duality in the qualitative interviews. The good stories are often linked to a meeting with a positive person in charge of the case.
- In the valuation of the social security offices[4] we see the same tendency. 35% say they get good treatment and 28% say they get bad treatment. Some of the informants see this as a huge bureaucracy and are afraid that their case will be spread among many employees. This is especially the case in small communities.

[1] In Norwegian: Arbeidskontor
[2] In Norwegian: Utlendingmyndighetene
[3] In Norwegian: Sosialkontor
[4] In Norwegian: Trygdekontor

Recommendations

Based on our analyses there are issues where we find a need for change. In the following policy recommendations we stick to issues with a direct influence on the living conditions and the quality of life of people living with HIV.

A need for better information

- Better information to the public with the aim of reducing prejudice and stigma is needed.

- People living with HIV need information about the consequences of their HIV status and of their rights and opportunities

- HIV positive people see it as a burden to have to inform their closest people. There is a need for a better following-up of families and communities.

Refugees and asylum seekers

- There is a need for improved care for refugees and asylum seekers testing positive after arriving in Norway. They need information about medication, health and psychosocial issues.

- An HIV positive asylum seeker will often be deprived of treatment and medication if they are sent out of the country. This should to a larger extent be taken into consideration in the handling their cases.

Heterosexual men and women

- This group is specially concerned about anonymity. Questions of family and children need more attention. There is also a need for a further and better focus on establishing networks and caring environments.

Drug users

- Active drug users with HIV tend to fall out of the system. There is a need to develop services that can handle their situation.

Recommendations

Gay men

- The growing number of newly infected and diagnosed gay men is a concern.
- Stigma in the gay community needs more attention

The welfare service

- There is a need for a more holistic approach in the health services
- In the general primary health services and in the psychiatric clinics in particular, there is a need for better knowledge about HIV
- Also in the local labour offices and among those handling asylum seekers the need for more knowledge is evident.

Psychosocial support

- There is a need for better services for those living outside of Oslo
- Better access to counselling about sex, family and pregnancy

Private economy

- The issue of economic problems following long term illness need more attention
- There is a demand for economic compensation for expenses to immune strengthening nutrition and alternative measures.

Inclusion and openness in working life

- How can an inclusive work place care for people living with HIV? The social partners should pay more attention to HIV positive people's situation in the work place.

The stakeholders' use of the results

Pluss-Landsforeningen mot aids (PLMA) is the central NGO in Norway working for the interests of people living with hiv (PLWH). It is an organization that has both individual members – mostly people directly affected by the epidemic – and organizations that are concerned with hiv/aids in their work nationally and internationally. Some of the member organizations are involved in development co-operation concerning HIV/Aids in Third World countries. The main focus of PLMA is to influence policies at national level and to promote the rights and welfare of people living with hiv/aids in Norway.

The lack of factual information on the living conditions of PLWH has been a concern in the work of the organization. Most of our work was previously based on anecdotal information. Realizing the need for more specific information PLMA commissioned the study from the Fafo Institute for Applied Social Science (FAFO). The study was funded by the Norwegian Ministry of Social Affairs and the Norwegian Foundation for Health and Rehabilitation

Although the study covers a small sample of the population, it covers the whole spectre of situations that PLWH in Norway experience. As expected, there is a wide variety in the standard of living among PLWH in Norway. The research also gave new information on the isolation and stigmatization most PLWH feel. Regardless of their material and health situation, most of the respondents reported that they feel their HIV status is restraining them in their social and emotional lives. This gives reason for concern as there is little – if any – formal discrimination in the labour market or the health and welfare system. People still feel they have a diagnosis strongly associated with taboo. Because few people dare disclose their condition, few people know that there are PLWHs in our society. This again makes PLWH feel extremely marginalised. Thus, a vicious circle is established, and one could also speak of a certain degree of self stigmatization.

Another, more general experience many PLWH share is that our social security, health care and labour market arrangements are not very well suited to cater to the interests of people with chronical diagnoses. A person who ends up with disability pension at an early age receives an amount that is less than needed to live an active life. The labour market is not well suited to offer work to people who may not be able to work full time the whole time, but are willing and capable of having work as their main income source.

The stakeholders' use of the results

With the results of this study, our organization and its partners have got an important tool for planning future activities and for advocacy and lobbying vis-à-vis the government and the public. Shortly after the publication of the study we met to formulate a common platform for our work, the "HIV manifesto 2003". This platform has served as a galvanizer between our organisation and others that work for similar goals, and is used vis-à-vis government and health authorities in joint lobbying activities. It also served as the basis for a joint information campaign aimed at the general public in 2003.

Hiv-manifesto 2003

The research report "Living conditions and life quality among people living with HIV" was finished in 2002. The report was commissioned the Pluss-LMA and The Norwegian Department of Health. Fafo, carried out the actual research. It is against the findings and recommendations of this report that the Pluss-LMA, The Gay Men's Health Crisis in Norway, African Health Watch and Aksept have produced a manifesto setting the agenda for the four organisations' future collaboration.

1. Preventive information about HIV/Aids will have to be strengthened.

The knowledge about HIV is very poor in the general population and especially among young people. This leads to ignorance, prejudice and risky situations, and consequently a spreading of the virus. Neither are the people working within the services of public health and social welfare knowledgeable enough about hiv. This leads to discrimination and inadequate treatment.

2. People with HIV are invisible in society.

Most HIV-positives are very closeted about their status. In the cases where this is a choice based on fear, this kind of situation leads to mental health problems, isolation and a reduced quality of life. Thus the social inclusion of people with hiv is being made more difficult.

3. People with HIV are still stigmatised at all levels.

Due to lack of information, invisibility and prejudice, people with hiv are still stigmatised at all levels in society. This applies to experiences in private life, the workplace and in their meeting with the public health system.

4. The living conditions of people with HIV are not satisfactory.

Despite efficient medication, the living conditions of people with HIV are still very difficult. Side effects, immunity, lack of money, the lack of a proper holistic approach from the relevant health authorities, ruined networks, homophobia, a problematic sex life and low self esteem, are all factors contributing to reducing the individual's quality of life.

Hiv-manifesto 2003

5. HIV-positive immigrants are neglected.

There are very few or no strategies to meet the HIV-pandemic among immigrants and asylum seekers. The authorities, the municipalities, asylum shelters and the already established immigrant societies are meeting with a colossal challenge.

6. The global situation is dramatic.

There is no solution to the HIV-pandemic that threatens the world today. International solidarity is a necessary part of the work that needs to be done in Norway.

Through co-operation, the distribution of tasks and co-ordination coupled with a profound respect for each others identity and experience, we wish to meet these challenges together and for the benefit of all people with HIV, all exposed people and every one affected by HIV.

The new challenges and the resources we need to meet them should not lead to cuts in areas where we are already making an effort. Parliament granted Pluss-LMA 1 million NOK in 2002 to be spent on a public consciousness-raising campaign about HIV. This will be the first area of collaboration between the four aforementioned organisations.

Pluss-LMA is a countrywide organisation working with HIV- and aids prevention, voluntary participation and the rights and interests of people with HIV in society. The task Pluss-LMA has set itself is to spread information about HIV and increase the awareness about the virus, engage and activate people with HIV and others and see to it that the rights of people living with HIV are heeded at all levels in society.

The Gay and Lesbian Health Comitte is a voluntary organisation working with HIV-prevention among men who have sex with men. The organisation takes a positive view of sexuality and homosexuality as the staring point for its preventive work and actively opposes all discrimination of HIV-positives.

Aksept is a psycho-social centre for everybody affected by HIV. It is run by Kirkens Bymisjon in Oslo. Aksept offers support and following up on an individual basis, open surroundings, various therapies and shelter. Aksept wishes to be seen as an oasis, a haven and a meeting point for people with hiv and everybody else affected by HIV.

African Health Watch is a recently formed organisation working with HIV-prevention among immigrants, especially Africans, in Norway. The organisation also wishes to guide recently arrived Africans as far as possible in the workings of the Norwegian health care and social welfare systems. AHW also runs therapy groups among HIV-positive Africans.

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Contact address

Fafo, P.O.Box 2947 Tøyen, NO-0608 Oslo, Norway.
Visiting address: Borggt. 2b, Oslo
Telephon: +47 22 08 86 60
Fax: +47 22 08 87 00

Pluss - Norwegian Association Against AIDS

The special interest organisation for HIV-positive people, Pluss, and The National Association Against AIDS, two organisations who fight against HIV and AIDS, merged in 1999. The result became Pluss-The National Association Against AIDS (Pluss-LMA).

Pluss-LMA is a nationwide membership organization

- We work to better HIV-positives living conditions
- We make visible HIV-positive peoples interests in the society
- We work preventive
- We aim to have local groups in the biggest cities

Pluss-LMA operates : A National centre against HIV and AIDS

- We aim to develop new strategies on preventive issues
- We have comprehensive web-pages
- We offer a news magazine and electronic news letters
- We arrange lectures, conferances and seminars

Consultative services for Hiv-positive

- You can get advice about social security – welfare – and the right to work program
- You can get advice about how it is to live with HIV
- You can get advice about different ways of getting infected

The organisation consists of individual members and organisational members.

- Hausmannsgate 7 - N-0186 OSLO
- Telephone +47 21 31 45 80
- Telefax +47 21 31 45 81
- E-mail; post@pluss-lma.no

Fafo carried through a national study of living conditions and quality of life among people living with HIV in Norway in 2001/2002 . This report contains an English summary of the full report in Norwegian. We have also added a short presentation of how different stakeholders used the results. As far as we know the study is unique, also in an international context. The study covers issues like income and economy among people living with HIV, employment, housing, openness about HIV status, isolation or belonging, sexuality and partnerships, mental and somatic health, and experience with the health services and other public services.

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PLUSS - Norwegian Association Against AIDS
Hausmansgt 7
NO-0186 Oslo
www.pluss-lma.no

Fafo

Borggata 2B/P.O.Box 2947 Tøyen
N0-0608 Oslo
www.fafo.no

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