

Aging with HIV

Background

When the anti-retroviral drugs (ARV) became widely available in the mid 90's, HIV changed from being a fatal infection to becoming a chronic disease. People living with HIV live longer and as a consequence the number of HIV-positive people over the age of 50 increases. A rough estimate indicates that between 40 and 50 per cent of HIV positive persons in Norway are more than 50 years old. This indicates that more than 2000 people over 50 live with HIV in the country.

The main question in this study is: How do people living with HIV experience getting older? Through a broad approach considering living conditions and quality of life, we have wanted to bring forth the challenges of getting older with HIV. The following topics have been central:

- The individual's story about living with HIV
- Experienced health and the encounter with the health and social services
- Openness, living conditions and quality of life, as well as family, networks and social relations.
- Individual strategies
- Concerns and hope for the future

The main data source is 20 qualitative individual interviews.

Findings

Only two of the informants are in regular full employment, eight are retired pensioners and eight are living fully or partially on a disability grant. Three of the informants got a disability grant at an early age because of HIV. When their health improved due to ARV, they failed to return to the labor market. Two of the informants are refugees and experience barriers when they try to enter the Norwegian labor market. Those who have lived for a long time with HIV, have chosen different life strategies. These choices have affected their present living conditions. Some did e.g. sell his/her housing with the aim to live well during the time he thought he had left. Others chose to live as normally as possible. Those who made the latter choice are better off today than

those who made the former. Most informants are thus currently outside the labor market. Most of them say that this is not due to their living with HIV.

The informants describe their own health as good, even though many still struggle with health issues. Some have been seriously and life-threateningly ill. Some of the informants had major health challenges before the roll out of HIV medications in 1996. Some of them even fulfilled the criteria for the AIDS diagnosis. Some of those who were infected in recent years have had a serious HIV infection before the physicians realized that they were in fact infected with HIV. The distinction between what is age-related and what is HIV-related is hard to draw. For the individual HIV positive person, the most important issue is his/her overall health situation.

There are also great variations in challenges regarding mental health. Some live an active life without pronounced mental health problems, while others report about loneliness, anxiety and concern for their own health. Several informants use the term long-term survivor. American researchers define long-term survivor syndrome with the following characteristics: anxiety, nervousness, or a sense of feeling constantly 'on guard', depression, irritability or flashes of anger, lack of future orientation, low self-esteem and self-worth, substance abuse, social withdrawal and isolation and survivor's guilt. These symptoms are recognizable among several of our informants, although they do not report all these issues at once. All of them have extensive experience with the health services. Several informants believe that health personnel underestimate health problems as side effects of medication. Some of them criticize their doctors for not entering into a dialogue about these side effects.

Of the twenty informants, only four say they are fully open about their HIV status. The others state that they have told a very limited circle of people about their positive HIV status. Among the people who have been told are often their partner or close relatives. Our HIVpositive informants and the authorities agree that openness about a positive HIV status is an important part of the prevention strategy, not least with the aim to reduce stigma. The majority of our informants are concerned, however, that the level of openness must remain the individual's own choice.

Family and children are important for the quality of life. Some of the women who were infected in the early stage of the epidemic talk about grief because they have had to choose not to have children. When the medicine came, it was too late. Almost half of the informants are single. Some have had long lasting relationships and remained alone after the partner died or they have been divorced. Others have not been in formalized relationships.

Several are concerned about entering old age without having a partner or a boyfriend..

Three of the male informants talked about loneliness. They long for a partner. Although they have a social life, they experience a loneliness linked to the lack of an environment where being HIV positive is natural and unproblematic. The lack of openness can create a situational sense of loneliness. For some, Aksept, HivNorway, Gay and Lesbian Health Norway and other similar forums were important places for meeting other people living with HIV.

At an earlier stage of the epidemic, it might have been easier to become part of a smaller organized group, identify with this group and its attitudes and handle stigma and discrimination in this way. Also: For some of the informants different stigma interact. On the other hand: Some informants find that their everyday life is not characterized by stigma associated with living with HIV. Each informant carries his/her own experiences of how he or she is met at work and by society as a whole. This again is mirrored in the way that same individual encounter the society and the local community

There are concerns among the informants about the services for the elderly. Will they get access to assistance when needed? Are the services for the elderly able to adapt to the needs of the individuals? In order for the ARVs to be effective, they must be taken regularly. Consequently, there is a concern about the control of the use of medication. Among the challenges experienced by HIV positive people, we find doubts about the competence on HIV and its treatment among those working in care for the elderly. Furthermore, we find anxiety about attitudes and possible prejudices against so-called key populations affected by HIV (men who have sex with men, immigrants, drug users, etc.). Each person carries his/her own concerns and the consequences they might engender in terms of both experience of need and treatment.

There is a distinction between those who have lived for a long time with HIV and were infected before the ARVs and those infected in the 2000's. Some had a very poor immune system when the medicine entered their lives. Many of them have lost friends to a disease that they themselves carried. Although there is a distinction between long-term survivors and those who have received an HIV diagnosis in recent years, this distinction is less clear than expected. Some of the informants have lived with HIV for almost all of their adult lives. Today they live relatively safe and good lives, but some also struggle with mental and in some ways somatic side effects of a life with HIV. Some persons were infected in old age. That means elderly people have sex and can get HIV. Notions about who belong to the risk groups should not determine which diagnoses that are considered which is something they

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Om å bli eldre med hiv

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have experienced. Notions associated with the elderly and sex can be an obstacle to both HIV prevention and diagnosis.

Homosexuals were among those effected by the HIV epidemic in its early stages. The gay community is described by our informants as excluding. We also find examples of double discrimination and fear linked to possible double discrimination in care and welfare services for the elderly.

The women talked more than men about health problems. Several of the long-term survivors have been seriously ill. Some of those who have lived a long time with HIV have used medication that has led to major bodily stresses.

Heterosexual men with HIV constitute an invisible group. In this group of informants, there are several people talking about loneliness. However, there are also people in this group who talk about support from family and local communities. The presence of heterosexual men suggests that there is a need to focus more on the experiences and relationships of this group.

Among the informants with an immigrant background, we find that some have had problems accessing information in their own language and getting interpreters connected to their consultations with their medical doctors. They also have concerns about what it will be like growing old in Norway that get an extra dimension when voiced by people with a background from countries where care for the elderly to a lesser extent is taken care of by the public. It is worth pointing out three phenomena related to getting older with HIV and having an immigrant background: Lack of family and networks in Norway, difficulties in entering the Norwegian labor market and the ethnic dimension also places the need to be seen as a whole person at the forefront.

Dimensions

In the findings referred to above, we found some recurring dimensions.

Uncertainty about the future

The HIV epidemic has changed dramatically over 30 years. Therefore, there is also an uncertainty associated with the future epidemic. We do not know how the HIV epidemic will develop over the next twenty years or how the development will turn out in terms of prevention and treatment. It is likely that the anxiety we see in this study is rooted in the interaction between the general doubts associated with the care for the elderly and a more specific fear related to living with HIV.

Openness and personal strategies

All our informants have told someone that they are HIV positive. Most of them, however, share the information about their diagnosis with only a limited group of people. As a person expects to live a long life with HIV, the result might be that he/she becomes more reluctant to inform others about their HIV status. There seems to be a kind of privatization in how the individual manages his/her situation. The personal choice of strategy is based on an understanding of the risk connected to being open.

To be seen as a whole person

The individual's anxiety for the future should be seen in a context. They might have experienced being defined only by their HIV status, only by their sexual identity and not seen as a whole person. The worry is that they fear this can be worsened when they reach the stage where there is a greater need for assistance from public health care systems for the elderly. To be seen as a whole person promotes dignity, but the opposite implies a risk of poor treatment or discrimination.

Diversity

There is a distinction between those who were infected before and after 96, the year when the ARVs were first rolled out. There are also other distinctions along dimensions like gender, sexual orientation and country of birth. Some of our informants may belong to several of these dimensions. For example, the sum of being gay or female and having an HIV infection or coming from an immigrant background and being HIV positive (or all or several of these) can represent a personal challenge. Another combination of characteristics may be female, former drug addict and HIV positive. The interaction between such positions is not necessarily negative. To belong to an environment of people living with HIV can provide new social capital that can make it possible to free oneself from a marginalized position.

Meeting the welfare services

The main challenge posed to the health services based on our findings is to see the patient. It is to meet them with an openness for different health challenges along different dimensions. It is easy for health care professionals to give HIV some kind of priority when they meet people living with HIV. Therefore, it is important that all health challenges are taken seriously, regardless of whether they are HIV-related or not. The public health care systems for

the elderly are challenged in terms of knowledge about HIV and in terms of meeting their users without prejudice.

Positive and challenging pictures

The Norwegian welfare state provides services that in principle are available independently of social positions. People living with HIV can face challenges in the welfare state's service, but they do have a right to access these services. Many people living with HIV seem to experience a development towards less stigma and more knowledge in the welfare state apparatus. But at the same time, many people living with HIV are in a vulnerable position because they have a stigmatized chronic disorder and because many belong to groups exposed to discrimination and the risk of marginalization. Many carry dramatic disease stories that may become heavier as one gets older. The keywords dignity, risk, vulnerability represent important aspects of the findings.

For consideration

The study concludes with a call to the authorities, to health services and to user organizations. The sum of these challenges is that the situation for older people with HIV must be put on the agenda in various forums. It concerns prevention, welfare services, and it is about fighting prejudices and building knowledge and competence. This building of competence must take into account different needs in different groups and strengthen dignity for the individuals who get older and live with HIV.