QUALITY OF LIFE OF PEOPLE LIVING WITH HIV AND AIDS IN ESTONIA

Kristi Rüütel[1,2], Anneli Uusküla[2], Anastassia Minossenko[3], Helle-Mai Loit[3]
[1]Development Center, National Institute for Health Development, Tallinn, Estonia
[2]Department of Public Health, University of Tartu, Tartu, Estonia
[3]Department of Prevention of Chronic Diseases, National Institute for Health Development, Tallinn, Estonia

SUMMARY

The assessment of quality of life is central to understanding how people's lives are affected by HIV infection. Estonia – the smallest of three Baltic countries – has experienced massive outbreak of HIV infection. Yet, little is known about the quality of life of HIV infected people in Estonia. The purposes of the present study were to adapt the World Health Organization's Quality of life HIV instrument (WHOQoL-HIV) into Estonian setting and to assess the quality of life in a sample of HIV-infected persons in Estonia.

Key words: quality of life, HIV infection, injecting drug use, socioeconomic situation, unemployment, Estonia

Address for correspondence: K. Rüütel, National Institute for Health Development, Hiiu str. 42, Tallinn 11619, Estonia.
E-mail: kristi.ruutel@tai.ee

INTRODUCTION

HIV does not only affect the physical well-being of an individual but also the overall quality of life (QoL) of those infected. The assessment of QoL is central to understanding how people's lives are affected by HIV infection. It helps to evaluate the human and financial costs and benefits of new programmes and interventions, and could be used to monitor and evaluate the efficacy and cost-effectiveness of community level interventions, such as support groups, home care, voluntary counselling and testing. At the individual level, QoL assessment can help health care providers in planning of individual interventions for those areas and subgroups where QoL is a significant problem (1, 2, 3).

There have been no systematic studies on QoL of HIV infected people in Newly Independent states of former Soviet Union. These countries have witnessed massive outbreaks of HIV infections. In 2005, the number of new HIV-cases per million habitants was 461 in Estonia and 247 in Russian Federation.

A total of more than 6,200 HIV infections have been reported since the epidemic began in Estonia (4). The current estimated prevalence of HIV in Estonia is estimated to be between 0.4–2.1% of the population (5). Little is known about the quality of life of HIV infected people in Estonia.

The current study had two main objectives:

1. To adopt QoL instrument into the infectious diseases clinic setting and to conduct training among physicians teaching and demonstrating methods of QoL measurement among HIV infected patients in care.
2. To assess the feasibility and acceptability of the QoL instrument for the HIV infected in care.

METHODS

Background

Administratively, Estonia is divided into 15 counties. The largest is the county including and surrounding the capital city Tallinn, and the second largest, North Eastern county, is located at the North-Eastern border with the Russian Federation.

The HIV-epidemic in Estonia was first recognized in the North Eastern county in 2000. Already the next year the number of cases increased also in the capital city Tallinn. In 2005 43% of new cases were diagnosed among the North Eastern county residents, 45% among residents of capital area and 12% elsewhere (4).

Setting and Sample

A convenience sample from a group of patients attending for a routine HIV clinical care visits at three largest infectious diseases clinics in capital city Tallinn (N=1) and in North Eastern county (N=2) was recruited. Altogether these 3 infectious disease hospitals serve more than 95% of all HIV infected patients in care in Estonia.

Each of the three participating centres were required to recruit a minimum of 150 adult HIV-positive patients. Eligibility criteria included persons more than 18 years old, able to read and write in Estonian or Russian, and being aware of their HIV status more than 3 months.

Measurements

1. Quality of life data were collected using World Health Organization's Quality of life HIV instrument (WHOQoL-HIV) which has good psychometric properties and has been tested for reliability and validity. Findings suggest that it is suitable for as-

sessment of QoL in people living with HIV (PLWH) across a range of different socio-economic and cultural backgrounds (6, 7, 8).

The WHOQoL-HIV contains 29 facets, each with four items, which are subsumed in six domains: physical, psychological, level of independence, social, environmental and spiritual. There is also one general facet score that measures overall quality of life and general health. Five facets are specific to PLWH: symptoms of HIV, social inclusion, death and dying, forgiveness and fear of future. Items are rated on a 5-point Likert interval scale where 1 indicates low, negative perceptions and 5 indicates high, positive perceptions. Higher scores indicate better quality of life. Facet scores are the mean of the four items in each facet. Domain scores are obtained by adding the facet means in the respective domain, and dividing by the number of facets in that domain, and multiplying by 4, so that scores ranged from 4 (worst possible QoL) to 20 (best possible QoL).

In the first phase we translated WHOQoL-HIV instrument into Estonian and Russian, following the guidelines of WHO. In the second phase two focus group discussions were conducted involving 10 HIV-positive persons to ensure the comprehensibility of the instrument.

2. Socio-demographic information was also obtained on the respondent's age, sex, education, marital status, socio-economic background as well as the self identified route of infection and the underlying risk factors associated with HIV transmission.

3. A standardized questionnaire was developed for study physicians for data abstraction from the medical records on the stage of HIV infection, CD4 count, viral load, co-infections and treatment.

Training

All study physicians received in-house training regarding standardization of study protocol, procedures to ensure confidentiality, and methods of effective recruiting and interviewing technique.

Procedures

After determining eligibility and securing informed consent, all participants filled in the WHOQoL-HIV instrument, which was designed for self-administration and required approximately 45–60 minutes to complete.

Participants received a food voucher for supermarket with the value of 6.4 EUR as an incentive for study participation.

Ethical Committee

The study was approved by the Tallinn Medical Research Ethics Committee and all participants provided signed informed consent.

Statistical Analysis

Data entry was done centrally using Microsoft Access. Statistical analysis was performed with SPSS 14.0 for Windows. The Students' t-test was used for comparing means by regions, gender, average monthly net income per family member, route of infection and CD4 count. The Analysis of Variance (ANOVA) was used for comparing means by disease stage. Pearson's χ^2 test was used for estimating the differences of routes of infection, region, disease stage by gender, education, employment etc.

RESULTS

A total of 562 HIV-infected patients were invited to participate in the study between 1st June and 31st August 2005. The number of those who refused was 56. Fourteen people were younger than 18 years and 41 were aware of their status less than 3 months. The study procedure was completed by 451 respondents (uptake 80%).

Sample Characteristics

The mean age of the participants was 25 years (SD ± 6.9 years) and 80% were younger than 30 years. 46% were women. 85% were ethnic Russians, 11% ethnic Estonians, and 4% representatives of other nationalities. 40% had secondary education or less. 60% of the participants self-reported injection drug use (sharing needles) as a potential source of HIV infection. In terms of HIV 61% of the respondents were asymptomatic, 37% symptomatic and 2.7% had AIDS. At the time of the study 22% of the study subjects were on active antiretroviral therapy (HAART), 2.2% had had active tuberculosis and 61% were co-infected with hepatitis B and/or C. Two thirds (63%) had national medical insurance.

Quality of Life

The overall quality of life score for the whole sample was 2.90. Among the 29 facets the highest scores were for the bodily image and appearance (4.04), activities of daily living (3.75) and pain and discomfort (3.59). Three facets where the score was below the mid-scale point of 3.00 could be considered as areas of poor quality of life and these included physical safety and security (2.82), positive feelings (2.81), and financial resources (2.45).

The results for overall quality of life and general health perceptions, six main domains, five facets specific to PLWH (symptoms of HIV, social inclusion, death and dying, forgiveness and blame, and concerns about the future) and an additional seven facets on areas about health and socioeconomic situation according to gender, region, income, route of infection, disease stage and CD4 count are presented in Tables 1 and 2. We found no major differences in QoL scores based on education.

Analysis for gender showed that women reported significantly better overall QoL and better QoL for social inclusion, concerns about the future, pain and discomfort, energy and fatigue, sleep and rest, financial resources, health and social care and social support.

HIV infected people in care from capital city Tallinn reported better QoL in all main domains, five HIV-specific facets and several non-HIV specific facets describing different aspects of health and socioeconomic situation in comparison to their counterparts from North Eastern county.

We observed significant differences in quality of life by the reported income. Namely, participants with average monthly net income per family member more than 128 EUR [national minimum in 2005 according to Statistical Office of Estonia (9)] reported better QoL for all facets except forgiveness and blame, concerns about the future and death and dying.

Analysis of the route of infection showed that those people who reported being infected through injection drug use reported poorer QoL in both overall quality of life, and five domains out of six. They also reported poorer symptoms, social inclusion, pain,

Table 1. *Quality of life scores according to regions, gender, and average monthly income per family member*

	Regions			Gender			Average monthly net income per family member		
	Tallinn	Eastern-Estonia	p-value	male	female	p-value	≤2000 EEK	>2000 EEK	p-value
Overall quality of life and general health perceptions	3.2	2.75	<0.001	2.8	3.02	<0.01	2.79	3.18	<0.001
Domains (range 4 to 20)									
Physical	14.36	12.71	<0.001	12.92	13.7	<0.05	12.86	14.29	<0.001
Psychological	14.38	13.36	<0.001	13.55	13.91	NS	13.46	14.29	<0.01
Level of independence	15.69	13.81	<0.001	13.97	14.99	<0.01	14	15.54	<0.001
Social relationships	14.52	13.59	<0.001	13.52	14.36	<0.01	13.64	14.54	<0.01
Environment	12.95	11.94	<0.001	12.08	12.56	<0.05	11.9	13.22	<0.001
Spirituality/Religion/ Personal beliefs	13.64	12.3	<0.001	12.93	12.59	NS	12.68	13.2	NS
Facets (range 1 to 5)									
Symptoms of PLWHA	3.49	3.02	<0.001	3.16	3.22	NS	3.09	3.42	<0.01
Social inclusion	4.02	3.7	<0.001	3.69	3.95	<0.05	3.72	4.02	<0.01
Forgiveness and blame	3.39	3.11	<0.01	3.22	3.19	NS	3.22	3.21	NS
Concerns about the future	3.27	2.98	<0.01	3.22	2.93	<0.01	3.09	3.12	NS
Death and dying	3.72	3.24	<0.001	3.47	3.34	NS	3.36	3.57	NS
Pain and discomfort	3.83	3.47	<0.001	3.48	3.71	<0.01	3.47	3.86	<0.001
Energy and fatigue	3.46	3.02	<0.001	3.1	3.25	<0.05	3.05	3.44	<0.001
Sleep and rest	3.61	3.19	<0.001	3.16	3.52	<0.001	3.22	3.59	<0.01
Financial resources	2.81	2.26	<0.001	2.33	2.58	<0.01	2.18	3.03	<0.001
Health and social care: accessibility and quality	3.23	2.9	<0.001	2.91	3.12	<0.01	2.92	3.24	<0.001
Social support	3.29	2.96	<0.001	2.96	3.2	<0.01	3.01	3.25	<0.01

Table 2. *Quality of life scores according to route of infection, disease stage, and CD4 count*

	Route of infection			Disease stage				CD4 count		
	IDU	sex	p-value	Asymp	Symp	AIDS	p-value	≤300	>300	p-value
Overall quality of life and general health perceptions	2.78	3.1	<0.001	3.06	2.67	2.4	<0.001	2.7	3.1	<0.001
Domains (range 4 to 20)										
Physical	12.81	14.12	<0.001	13.99	12.35	10.28	<0.01	12.12	13.91	<0.001
Psychological	13.55	14.03	<0.05	14.1	13.17	12.07	<0.01	13.24	14.02	<0.01
Level of independence	14.2	15.04	<0.05	15.33	13.33	9.14	<0.01	13.09	15.29	<0.001
Social relationships	13.6	14.42	<0.01	14.31	13.33	12.93	<0.01	13.22	14.39	<0.001
Environment	11.97	12.86	<0.001	12.54	11.99	11.98	<0.05	12.03	12.68	<0.05
Spirituality/Religion/ Personal beliefs	12.74	12.84	NS	12.84	12.76	11.81	NS	12.44	12.87	NS
Facets (range 1 to 5)										
Symptoms of PLWHA	3.11	3.32	<0.05	3.31	3.03	2.63	<0.01	2.92	3.29	<0.01
Social inclusion	3.73	3.94	<0.05	3.91	3.66	3.56	<0.01	3.61	3.97	<0.01
Forgiveness and blame	3.14	3.28	NS	3.19	3.25	3.02	NS	3.16	3.2	NS
Concerns about the future	3.19	2.94	<0.05	3.08	3.1	2.94	NS	3.09	3.03	NS
Death and dying	3.39	3.41	NS	3.44	3.35	3.29	NS	3.21	3.47	NS
Pain and discomfort	3.44	3.85	<0.001	3.78	3.35	2.79	<0.001	3.28	3.77	<0.001
Energy and fatigue	3.08	3.33	<0.01	3.37	2.91	2.39	<0.001	2.84	3.36	<0.001
Sleep and rest	3.15	3.66	<0.001	3.55	3.01	2.68	<0.001	3.08	3.5	<0.01
Financial resources	2.25	2.76	<0.001	2.56	2.29	2.21	<0.05	2.22	2.67	<0.001
Health and social care: accessibility and quality	2.93	3.13	<0.01	3.08	2.9	3.23	<0.05	3.13	3.13	NS
Social support	2.94	3.27	<0.001	3.12	2.96	3.31	NS	3	3.2	<0.05

energy, sleep, finances, social support, health and social care and concerns for the future.

WHOQoL instrument proved to be sensitive also to differences in HIV-related health status. Asymptomatic people and people with CD4 count more than 300 cells/ml reported significantly better QoL in all domains and facets which concern health status and symptoms compared to those with symptoms and/or CD4 count less than 300 cells/ml.

DISCUSSION

This is the first study reporting on quality of life in HIV-infected persons from the former Soviet Union. This paper describes the pilot testing of WHOQoL-HIV instrument for use in clinical care settings in Estonia. The main aims of this study were to adopt WHOQoL instrument by the infectious disease clinic settings and to examine the quality of life of HIV infected patients in Estonia.

The study procedure and instrument implemented was acceptable for HIV infected people in care as witnessed by the 80% participation rate. Even though the questionnaire required up to 60 minutes to answer all the questions the uptake of the study was good. For routine clinical practice a shorter version of WHOQoL HIV-instrument (WHOQoL-HIV BREF) may prove to be more convenient and less time consuming especially in case of repeated administration for QoL measurement.

The instrument proved to be easy to understand and it included explanatory notes which helped to ensure that the participants understood the scales and questions well. Infectious diseases physicians and nurses did not meet any major obstacles and problems related to recruitment of participants and administration of the instrument.

The results reveal major disparities in self-reported QoL. The poorest QoL among the whole sample is found in the dimensions of environment (especially economical situation) and spirituality – concerns about the future, personal beliefs.

Analysis for gender revealed better QoL of women. Close to two thirds of study participants (60%) self identified sharing contaminated injecting paraphernalia as a possible route of infection. In our study, people infected through sexual transmission reported better QoL than those infected through injecting drug use (IDU). Several authors report normal physical health related quality of life among former IDUs than current IDUs or among general population compared to IDUs (10, 11). In our sample the proportion of people infected through IDU was higher among men than women (78.4% vs 44.0%, $p<0.001$; data not shown) a finding that can contribute to the better QoL observed in women.

An intriguing finding is the significantly better QoL of HIV infected people living in capital city Tallinn compared to participants from Eastern Estonia. In our study HIV infected people with higher income had better QoL measurements. At-risk-of-poverty rate in capital city in 2005 was lower than in Eastern Estonia (12.5% vs 29.8%). Disposable income per household member in a month in 2005 was 262 EUR in Tallinn and 170 EUR in North Eastern Estonia (9). Unemployment rate among study participants was 18.7% in Tallinn and 46.5% in Eastern Estonia. This was somewhat higher than the overall unemployment rate in these regions in 2005 (8.2% and 16.2%, respectively) (9). The reasons for such great differences in socioeconomical situation of people in different regions of the country go back to 1990ies, when Estonia regained its political autonomy. Major changes in political, economic, and social structure took place and these changes had the most devastating effect on the lifestyle of people in North Eastern region of the country.

In our study the proportion of people infected through IDU in Tallinn was significantly lower than in Eastern Estonia (51.0% vs 68.3%, $p<0.001$, data not shown), a finding that can also contribute to the better overall QoL in Tallinn. For example – in the overall sample the unemployment rate was higher among people infected through IDU compared to those infected through sexual intercourse (46.3% vs 24.1%, $p<0.001$, data not shown). These findings highlight the need for further studying the factors which determine QoL.

Satisfaction with health and social care services was higher among participants in capital city Tallinn. The biggest infectious diseases clinic with most long-term experiences in the field of HIV is located in Tallinn where provision of HAART started already in the middle of 1990s. In Eastern Estonia health care services for HIV-positive people have been made available on a larger scale in the beginning of 2000. The proportion of IDUs on HAART was lower than those infected through sexual intercourse (16.7% vs 28.0%, $p<0.01$, data not shown).

As can be expected people with better health status and biological markers reported better QoL. Sick – well and CD4 count comparisons show that the instrument was sufficiently sensitive to differentiate between those that were asymptomatic and those with symptoms or AIDS.

Some methodological limitations and sample biases of our study should be mentioned. The assessment of illegal drug use and possible timing of infection were based on self-reports. The sampling strategy used (convenience sampling from the HIV treatment setting) does not allow direct generalisation of the results. Receiving treatment and social support could enhance the QoL of these people and because of that the results cannot be extended to general HIV-infected population in Estonia. The study was cross-sectional in nature and this does not allow us to make any causal statements regarding QoL scores.

Our initial findings suggest that the WHOQoL-HIV instrument is suitable for assessment of QoL in our socioeconomical and cultural context. It could be used as an one of the outcome measures in assessing the effects of interventions on HIV infected persons in care.

Our findings also have some implications for intervention strategies targeting people living with HIV. Besides offering quality health care services it is important to also focus on psychological well-being of the patients and to offer mental care services and emotional support. Considering the low proportion of current/active IDUs receiving HAART it is important to tailor appropriate interventions to reach IDUs and provide HAART. The validity of the Estonian and Russian version of WHOQoL instrument has to be confirmed and prospective studies are needed to determine the causal factors of QoL.

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