





**KRISTI RÜÜTEL**

HIV-epidemic in Estonia:  
injecting drug use and  
quality of life of people living with HIV



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*To my parents*



# CONTENTS

LIST OF ORIGINAL PUBLICATIONS .....	9
ABBREVIATIONS.....	10
INTRODUCTION.....	11
REVIEW OF LITERATURE.....	13
1. General overview of human immunodeficiency virus infection.....	13
1.1. Epidemiology of human immunodeficiency virus.....	13
1.2. Injecting drug use and HIV-infection.....	14
1.3. HIV epidemic in Estonia .....	15
1.4. HIV and injecting drug use in Estonia.....	16
2. Quality of life.....	16
2.1. General concept of quality of life .....	16
2.2. Health-related quality of life.....	17
2.3. Quality of life measurement .....	18
2.4. Quality of life studies in Estonia.....	21
2.5. Quality of life in HIV infection .....	21
2.6. Factors associated with quality of life of people living with HIV ..	25
2.6.1. Socio-demographic characteristics .....	25
2.6.2. Health and treatment-related aspects .....	26
2.6.3. Social and psychological factors.....	29
AIMS OF THE RESEARCH .....	32
MATERIAL AND METHODS .....	33
3. Study designs .....	33
3.1. Statistical analysis.....	35
4. Assessment of the performance of Estonian and Russian versions of WHOQOL-HIV instrument .....	35
4.1. Description of WHOQOL-HIV instrument .....	35
4.2. Original WHOQOL-HIV instrument performance.....	36
4.3. Translation procedure .....	36
4.4. Performance of the translated versions.....	36
RESULTS.....	38
5. HIV-prevalence and related risk-behaviours among injecting drug users .....	38
5.1. Socio-demographic and other background data.....	38
5.2. Risk factors for HIV infection .....	40
6. QoL among Estonian people living with HIV and the impact of socio- demographic, disease-related, and psycho-social factors on QoL .....	43
6.1. Socio-demographic and other background data.....	43
6.2. Quality of life and factors influencing quality of life .....	45
7. Adoption of WHOQOL-HIV instrument.....	50

7.1. Feasibility and acceptability of the Estonian and Russian versions of the WHOQOL-HIV instrument .....	50
7.2. Reliability and validity of Estonian and Russian versions of WHOQOL-HIV instrument.....	52
7.2.1. Internal consistency .....	52
7.2.2. Criterion-related validity .....	54
7.2.3. Concurrent validity .....	55
7.2.4. Construct validity .....	57
DISCUSSION .....	58
8. HIV-prevalence and related risk-behaviours among injecting drug users .....	58
9. QoL of people living with HIV .....	59
10. Performance of Estonian and Russian versions of WHOQOL-HIV instrument.....	62
GENERAL DISCUSSION .....	65
CONCLUSIONS .....	67
REFERENCES .....	68
SUMMARY IN ESTONIAN .....	82
ACKNOWLEDGEMENTS .....	87
PUBLICATIONS .....	89

## LIST OF ORIGINAL PUBLICATIONS

- I Platt L, Bobrova N, Rhodes T, Uusküla A, Parry JV, Rüütel K, Talu A, Abel K, Rajaleid K, Judd A. High HIV prevalence among injecting drug users in Estonia: implications for understanding the risk environment. *AIDS* 2006;16:2120–2123.
- II Rüütel K, Uusküla A, Minossenko A, Loit HM. Quality of life of people living with HIV and AIDS in Estonia. *Cent Eur J Public Health* 2008; 16:111–115.
- III Rüütel K, Pisarev H, Loit HM, Uusküla A. Factors influencing quality of life of people living with HIV in Estonia: a cross-sectional survey. *J Int AIDS Soc* 2009;12:13.
- IV Rüütel K, Loit HM, Uusküla A. Psychometric properties of Russian version of WHOQOL-HIV instrument: a cross-sectional survey (submitted for publication in *BMC Medical Research Methodology*).

### **Contribution of Kristi Rüütel to the original publications:**

- Paper I: Participation in study design, data collection and writing the manuscript.
- Paper II: Study design, participation in the translation and piloting the questionnaire, writing the first draft of the manuscript to which other authors contributed.
- Paper III: Study design, writing the first draft of the manuscript to which other authors contributed.
- Paper IV: Study design, data analysis, writing the first draft of the manuscript to which other authors contributed.

## ABBREVIATIONS

AIDS	acquired immunodeficiency syndrome
AOR	adjusted odds ratio
ARV	antiretroviral
Asymp	asymptomatic
CI	confidence interval
ESPAD	European School Survey Project on Alcohol and Other Drugs
EST	Estonian
HAART	highly active antiretroviral treatment
HIV	human immunodeficiency virus
HRQoL	health-related quality of life
IDU	injecting drug use, injecting drug user
N	number
NGO	non-governmental organization
OR	odds ratio
PLHIV	people living with HIV
QoL	quality of life
RDS	respondent driven sampling
RUS	Russian
SD	standard deviation
SEP	syringe exchange program
SRPB	spirituality, religion and personal beliefs
Symp	symptomatic
TB	tuberculosis
UNAIDS	United Nations Program on HIV/AIDS
WHO	World Health Organization
WHOQOL Group	World Health Organization's Quality of Life Group

## INTRODUCTION

It has been said that human immunodeficiency virus (HIV) is a lens through which the underlying problems of the health care and public health can be examined. Besides health care, many other factors drive HIV epidemic and influence the quality of life (QoL) of people living with HIV (PLHIV) (Friedman *et al.*, 2009; Poundstone *et al.*, 2004). Understanding these factors is important in order to plan and implement interventions to slow the spread of HIV and provide accessible, comprehensive and effective HIV treatment and care services.

Injecting drug use (IDU) is a major risk factor in the HIV-epidemics of several regions in the world, including Eastern European countries (UNAIDS 2008). It has been documented that HIV can spread extremely rapidly among injecting drug users (IDUs), with the HIV seroprevalence rates going up to 40% or higher within a period of 1 to 2 years (Des Jarlais 1999).

Estonia has witnessed one of the most rapidly expanding HIV epidemics with the highest incidence and prevalence of HIV in the European Region (Hamers *et al.*, 2006). As of 31 July 2009, there were 7,152 officially diagnosed HIV cases in Estonia (Health Protection Inspectorate). It is estimated that the actual number of PLHIV could be 11,000 to 12,000 (Lai *et al.*, 2009). HIV outbreak was first detected among IDUs in 2000 and is still concentrated among this population group. HIV prevalence rates as high as 56% have been described among IDUs (Uusküla *et al.*; 2007). High rates of sexual risk behaviour and inadequate knowledge regarding prevention of disease transmission in Estonia emphasise the threat of a sex-related HIV epidemic (Rüütel *et al.*, 2006).

Advances in treatment have resulted in a notable decline in HIV-related mortality (especially in developed countries), improved the survival times for PLHIV, and changed the disease from an acute illness to a chronic, debilitating disease (Fleming *et al.*, 2000; Levi *et al.*, 2000). As a result, QoL and more specifically, health-related quality of life (HRQoL), have become important clinical outcomes, and assessing the factors that impact PLHIV's perceptions of QoL has become a major concern of clinicians and researchers in the field (Jia *et al.*, 2004).

QoL assessment can be used to answer questions in clinical care and health policy. At the level of the individual caregiver, optimizing QoL among patients with HIV will be essential to improving adherence with treatment regimens and hence prolonging overall survival. Several scales and instruments have been developed over the years to measure QoL and HRQoL mostly in order to evaluate new and existing treatment strategies. These measures can also serve as important tools in the evaluation of programs and services (Wu 2000). The scientific literature offers guidelines on how to conduct surveys in cross-cultural settings. Translation into local languages and back translation are necessary but insufficient steps to safeguard cross-cultural validity (Bhopal *et al.*, 2004).

Public health interventions to prevent the spread of HIV in Estonia are mostly implemented in the framework of National HIV Prevention Strategy for 2006–2015. The top priorities of the strategy include harm reduction services for IDUs and health care services for PLHIV. In order to be able to offer the best possible prevention and care services to IDUs and PLHIV, groups that are very heterogeneous, the knowledge of the situation should be increased and the outcomes of the existing services evaluated. In order to achieve these goals, appropriate instruments have to be developed and base-line evaluations implemented.

Therefore, our primary aims for this research were to evaluate the prevalence of HIV and related risk behaviours among IDUs as a HIV-infection core group in Estonia, to adapt WHOQOL-HIV instrument into Estonian and Russian, and to assess the QoL and the factors influencing QoL of PLHIV in Estonia.

All studies for the dissertation were carried out in collaboration between National Institute for Health Development and Department of Public Health, the University of Tartu.

# **REVIEW OF LITERATURE**

## **I. General overview of human immunodeficiency virus infection**

### **I.1. Epidemiology of human immunodeficiency virus**

HIV infection induces a wide range of immunological changes resulting in the progressive immunosuppression, which leads to the development of opportunistic infections (tuberculosis, pneumocystis pneumonia) and malignancy (Kaposi sarcoma, lymphomas). The last stage of HIV-infection is called AIDS or HIV disease. Today, there is no cure against HIV infection. Therapeutic management of patient is focusing more on delaying the suppression of the immune system and on controlling and preventing opportunistic infections and cancer (Casado 2005). Since the implementation of highly active antiretroviral treatment (HAART), the survival of PLHIV has increased considerably and HIV is no longer viewed as a death sentence but rather as a chronic disease (ART-LINC Collaboration and ART-CC groups 2006; Hall *et al.*, 2006).

HIV remains a global health problem of unprecedented dimensions. Unknown 30 years ago, HIV has already caused an estimated 25 million deaths worldwide and has generated profound demographic changes in the most heavily affected countries. Recent estimates by the joint United Nations Program on HIV/AIDS (UNAIDS) suggest that there were 33 million PLHIV worldwide in 2007, an estimated 2.7 million people were newly infected with HIV and 2 million died because of AIDS in 2007. While the percentage of PLHIV has stabilized since 2000, the overall number of PLHIV has steadily increased as new infections occur each year, HIV treatments extend life, and as new infections still outnumber AIDS deaths. Women account for half of all PLHIV worldwide. Over the last 10 years, the proportion of women among PLHIV has remained stable globally, but has increased in many regions. Young people aged 15–24 account for an estimated 45% of new HIV infections worldwide (UNAIDS 2008).

Many sub-Saharan African countries face generalized epidemics sustained in the general populations; epidemics in the rest of the world are primarily concentrated among populations most at risk, such as men who have sex with men, IDUs, sex workers and their sexual partners. Injecting drug use is a major risk factor in the epidemics of several Asian countries, including India and China, and to a lesser extent in Latin-American countries. HIV epidemics in Eastern Europe and Central Asia are concentrated largely among IDUs, sex workers, and their various sexual partners. Of the new HIV cases reported in this region in 2006 for which information on the mode of transmission is available, about 62% were attributed to IDU (UNAIDS 2008).

## 1.2. Injecting drug use and HIV-infection

Injecting drug use has been documented in more than half of the countries in the world and reports on HIV infection among IDUs have been described in 128 countries/territories (Mathers *et al.*, 2008). UNAIDS estimates that one third of all new HIV infections outside of sub-Saharan Africa occur among IDUs (UNAIDS/WHO 2007). It is estimated that there are about 16 million (range 11–21 million) individuals who inject drugs worldwide and around 3 million (range 1–7 million) injectors might be living with HIV (Mathers *et al.*, 2008).

It has been documented that the efficiency of HIV transmission varies widely by exposure, with parenteral exposure giving a significantly higher risk for transmission (Centers for Disease Control and Prevention 2005). When HIV was first noted among IDUs, it was clear that sharing needles and syringes would be a relatively efficient method for transmitting a new infectious agent. When drugs are injected intravenously, blood is usually first drawn into the barrel of the syringe to ascertain that a vein has been located. Pushing the plunger completely into the barrel of the syringe does not, however, completely empty the syringe of the blood/drug mixture. A small residue will be left in the syringe and the needle. Multi-person use ("sharing") of drug-injection equipment thus leads to micro transfusions of potentially infectious blood from one injector to another (Des Jarlais 1999). Sharing of drug mixtures and other injecting paraphernalia (vials, cookers, etc.) may also lead to transmission of blood-borne pathogens. Given the efficiency of parenteral transmission in many areas, HIV has spread extremely rapidly among IDUs, with the HIV seroprevalence rates (the percentage of IDUs infected with HIV) increasing from less than 10% to 40% or higher within a period of 1 to 2 years (Des Jarlais 1999).

High levels of HIV-infection among IDUs in different parts of the world were described already in the early 1990ies, with prevalence rates of 40% in Bangkok, 35–40% in Geneva, 50–60% in New York, 50% in Manipur, and 75% in Myanmar. On the other hand, less than 5% of prevalence rates were described in Athens, Glasgow, Sidney, and Toronto, and rates between 10–20% in Berlin, London, Naples, and Rome (Stimson 1995). For example, New York experienced the first and largest HIV epidemic among IDUs. HIV spread rapidly among IDUs during the late 1970ies and early 1980s (Des Jarlais *et al.*, 1989). Self-organized risk reduction and community education efforts led to stabilization of the epidemic with prevalence of approximately 50%. Large-scale implementation of syringe exchange programs in the mid-1990s led to a substantial decline in HIV incidence among IDUs (Des Jarlais *et al.*, 2005). Several factors have been associated with the rapid spread and different prevalence rates of HIV among IDUs, including sampling biases, biological variations, lack of awareness of HIV and AIDS as a local threat, changes in risk behaviours, restrictions on the availability and use of new injection equipment, and epidemiological saturation of high risk groups and mixing patterns among various subgroups of IDUs, which may facilitate further viral spread (Blower 1991; Des Jarlais 1999; Stimson 1995). Evidence also suggests that, once HIV prevalence among a high-risk population of IDUs reaches a level of about 10–

20%, HIV epidemics can become self-perpetuating, with even modest levels of risk behaviour leading to substantial rates of infection (Des Jarlais *et al.*, 2000; Holmberg 1996). It is likely that the departure point for rapid epidemic growth occurs when the infection infiltrates the most locally connected individuals. High-risk behaviour and high HIV prevalence can occur within isolated subgroups with no impact on further transmission. What seems to be important is the mixing of different segments of the population (Des Jarlais 1999; Stimson 1995).

### **1.3. HIV epidemic in Estonia**

Following the introduction of HIV antibody testing in 1987, the first case of HIV in Estonia was diagnosed in 1988. The number of newly reported HIV cases in Estonia has decreased over the past few years – from 1,474 in 2001 (1,080 per one million population) to 545 in 2008 (406 per one million population) (National HIV Reference Laboratory, Statistics Estonia). Nevertheless, the estimated adult national HIV prevalence of 1.3% (0.6%–4.3%) in Estonia in 2005 was the second highest in all of Europe (after Ukraine). Among European Union countries, the highest rates in new HIV diagnoses in 2005 were reported in Estonia (467 cases per million) and Portugal (251 cases per million), and the lowest rates were reported in the Czech Republic (9 cases per million) and Slovakia (4 cases per million) (Hamers *et al.*, 2006). The total number of registered HIV-cases in Estonia by the end of 2008 was 6,909 (National HIV Reference Laboratory). It is estimated that the actual number of PLHIV could be 11,000–12,000 (Lai *et al.*, 2009).

In 1988–1999, HIV spread in Estonia mainly through unprotected sex (both homo- and heterosexual transmission) (Kalikova N, personal communication, 2002). Since 2000, the infection has been transmitted mainly through the sharing of contaminated syringes and other injecting paraphernalia. In the past years, there is evidence of increasing sexual transmission (mostly from IDUs to their sexual partners). Thus, according to the AIDS counselling centres, IDUs accounted for 90% of new HIV-cases in 2001, 66% in 2003 and only 45% in 2008 (National Institute for Health Development).

The majority of HIV cases have been men but the proportion of women has increased in recent years. In 2000, women accounted for 20% of all new cases but in 2008, the proportion of women in new cases was 41%. The mean age of the newly diagnosed HIV cases is increasing – in 2001, 92% the new cases were younger than 30 years of age, in 2007 the respective percentage was 62% (National HIV Reference Laboratory).

In 2000, the explosive spread of HIV-infection occurred in Ida-Virumaa county, in North-Eastern Estonia, especially in the city of Narva. New HIV cases registered in this region accounted for 92% of all cases in 2000. In comparison with the year 2000, the proportion of HIV-cases diagnosed in the capital city Tallinn increased considerably in 2001–2002. The number of new HIV-cases per 100,000 population was 166 in North-Eastern Estonia and 54 in

Tallinn in 2008. The estimated adult prevalence rates are also unequally distributed across the country (National HIV Reference Laboratory, Statistics Estonia).

#### **1.4. HIV and injecting drug use in Estonia**

The use of illicit drugs has grown rapidly in Estonia in the past 15 years. The upward trend is confirmed by the findings of the European School Survey Project on Alcohol and Other Drugs (ESPAD) 1995, 1999, 2003, and 2007 surveys. In 1995, 8% of the Estonian school youth aged 15–16 years had experience with some illicit drug. In 1999, the same figure had gone up to 16%, and in 2007, it was 30%. Injecting drug use started to increase during the 1990s (Uusküla *et al.*, 2002). According to ESPAD, the proportion of youth aged 15–16 years who had injected drugs during their lifetime was 0.2% in 1995, 0.7% in 1999, 1.3% in 2003, and 0.5% in 2007 (ESPAD Report 1995; ESPAD Report 1999; ESPAD Report 2003; ESPAD Report 2007).

The first reports describing IDU outbreak and the size of IDU population in Estonia are based on field reports and expert opinions. They describe about 10,000–15,000 IDUs in Estonia (Kalikova 2001). In 2004, the estimated number of IDUs was 13,800 and the adult IDU prevalence rate 2.4%. Injecting drug use prevalence is the highest in North-Eastern Estonia and in the capital city Tallinn (Uusküla *et al.*, 2007). A study among a convenience sample of 159 IDUs visiting syringe-exchange program (SEP) in Tallinn described 56% prevalence of HIV in participants in 2003–2004 (Uusküla *et al.*, 2007).

## **2. Quality of life**

### **2.1. General concept of quality of life**

Shortly, QoL can be defined as the degree of well-being felt by an individual or group of people. The World Health Organization's Quality of Life Group (WHOQOL Group) defines QoL as individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns (WHO 2002). It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, their relationship to the main features of their environment, and their spiritual, religious and personal beliefs (Skevington 2002).

Many researchers have reviewed literature on QoL and there is general agreement that a meaningful definition of QoL must recognize that there are two linked dimensions to the concept – a psychological and an environmental one. With respect to the first dimension, other terms have been used, for example individual/personal QoL, subjective well-being, or life satisfaction. For

the second dimension there are different levels and terms used, for example, urban QoL, community QoL, environmental QoL (Massam 2002).

At its most fundamental level, QoL is understood to be both subjective and multidimensional. Person's QoL is dependent on the exogenous (objective) facts of people's life, and the endogenous (subjective) perceptions they have of these factors. Although the objective dimension is important, for example in defining a patient's degree of health, the person's subjective perceptions and expectations translate that objective assessment into the actual QoL experienced, i.e. objective dimensions are ranked proportionally by their subjective importance (Testa *et al.*, 1996). Some argue that as QoL is a subjective experience it cannot be measured with objective criteria. Hence, the best person to assess QoL is arguably the individual him- or herself (Skevington 1999). Thus QoL is best measured from the person's (patient's) perspective (Cella 1994) and should be person- (patient-) centred (Aranda-Naranjo 2004).

## **2.2. Health-related quality of life**

Terms QoL and HRQoL are oftentimes used synonymously (Wu 2000). However, QoL comprises all factors (social functioning, health status, economic status, life satisfaction and well-being) that may affect individual's experience, HRQoL focuses on those factors, as they relate to health, emphasizing patient's symptom status, functional status, and general health perceptions.

Major aspects of HRQoL include the extent of physical and emotional symptoms, as well as physical, emotional, social, and cognitive functioning; mobility and self-care; and patient perception of health and well-being (Wu 2000). Testa *et al.* (1996) summarizes that the term "health-related quality of life" refers to the physical, psychological, and social domains of health, seen as distinct areas that are influenced by a person's experiences, beliefs, expectations, and perceptions. Schumaker *et al.* (1997) proposes the following definition of HRQoL: "Health-related quality of life refers to people's subjective evaluations of the influences of their current health status, health care, and health promoting activities on their ability to achieve and maintain a level of overall functioning that allows them to pursue valued life goals and that is reflected in their general well-being. The domains of functioning that are critical to HRQoL include: social, physical and cognitive functioning; mobility and self-care; and emotional well-being". He further stresses the subjective essence of the concept of HRQoL and concludes that it is not necessarily observable. In order to distinguish HRQoL from the broader area of QoL, the construct is limited to those life influences that fall within a health-specific milieu (i.e. current health, health care, and health promotion) (Schumaker *et al.*, 1997).

QoL and HRQoL are sometimes confused with health status. Smith *et al.* (1999) argue that QoL and health status are distinct constructs, and that the two terms should not be used interchangeably. His meta-analysis of the results of 12 chronic disease studies indicates that, from the perspective of patients, QoL and health status are not the same. When rating QoL, patients give greater emphasis

to mental health than to physical functioning. The major implication is that questionnaires designed to measure health status may be inappropriate for assessing QoL (Smith *et al.*, 1999).

Clinical and research interest in HRQoL began more than 55 years ago with the World Health Organization's definition of health as not just the absence of disease but a state of physical, mental, and social well-being (Webb *et al.*, 2004). Improving the QoL of individuals is becoming a goal of increasing importance in many fields, including health care and psychology. There is a growing field of research concerned with developing, evaluating, and applying QoL measures within health-related research (e.g. within randomised controlled trials), especially in health services research. Many of these focus on the measurement of HRQoL, rather than a more global conceptualisation of QoL. QoL is an important outcome measure also in treatment or service evaluation studies and clinical trials for medication. Decisions on what research or treatments to invest in the most are closely related to their effect on a patient's QoL (Nilsson Schönnesson 2002; Skevington 2002).

### **2.3. Quality of life measurement**

The measurement of QoL is not an easy task. The increasing numbers of the scales and instruments illustrates the lack of a single gold standard for measurement and in general, there is no consensus on how one should assess HRQoL (Robinson 2004; Webb *et al.*, 2004; Tzasis 2000). Which components of daily life should be used to evaluate one's HRQoL has been debated, and as a result, a number of scales have been validated. At a minimum, they include the following dimensions: physical function and symptoms, performance of social roles, emotional status, cognitive functioning, and how the patient feels about his or her health. All of these concepts can be measured adequately using sets of questions, which are deployed in standardized questionnaires (Wu 2000).

Most researchers measure each QoL domain separately, by asking specific questions pertaining to its most important components. Because many of the components of QoL cannot be observed directly, they are typically evaluated according to the classic principles of item-measurement theory. This theory proposes that there is a true QoL value,  $Q$ , that cannot be measured directly, but that can be measured indirectly by asking a series of questions known as "items," each of which measures the same true concept or construct. These questions are then asked of the patient, and the answers are converted to numerical scores that are then combined to yield "scale scores," which may also be combined to yield domain scores or other statistically computed summary scores. Variation in QoL questionnaires is often related to the degree to which they emphasize objective as compared with subjective dimensions, the extent to which various domains are covered, and the format of the questions, rather than differences in the basic definition of QoL (Testa *et al.*, 1996).

QoL measures are classified as generic or disease specific, with the former designed to assess QoL in all populations and the latter to assess QoL in

specific groups. Generic instruments are used in general populations to assess a wide range of domains applicable to a variety of health states, conditions, and diseases. They are usually not specific to any particular disease state or susceptible population of patients and are therefore most useful in conducting general survey research on health and making comparisons between disease states. Disease-specific instruments focus on the domains most relevant to the disease or condition under study and on the characteristics of patients in whom the condition is most prevalent. Disease-specific instruments are most appropriate for example for clinical trials in which specific therapeutic interventions are being evaluated (Testa *et al.*, 1996).

Clinicians and researchers without a suitable QoL measure in their own language have two choices: (1) to develop a new measure, or (2) to modify a measure previously validated in another language, known as a cross-cultural adaptation process. Several researchers have proposed recommendations and guidelines to maximise cross-cultural adoption of QoL questionnaires (Bhopal *et al.*, 2004; Bowden *et al.*, 2003; Herdman *et al.*, 1997; Herdman *et al.*, 1998; Skevington 2002).

In general, to be useful in research and clinical applications, QoL measures, like other scientific measures, must be *reliable* and *valid*. Traditionally, reliability and validity are considered the two fundamental characteristics of a measuring instrument (Hays *et al.*, 1992). Reliability refers to the extent to which a consistent score is obtained on different administrations of the instrument when all relevant conditions remain essentially constant. Validity is the extent to which an instrument's scores reflect the construct it is intended to measure and not what it was unintended to measure.

In more detail, *reliability* is the "consistency" or "repeatability" of the measures. Instruments must be able to measure HRQoL accurately and consistently (Schumaker *et al.*, 1997). Reliability is defined as the degree to which repeated administrations of a questionnaire produce equivalent results under controlled conditions. Reliability can be estimated and there are four general classes of reliability estimates, each of which estimates reliability in a different way:

1. Inter-rater or inter-observer reliability – used to assess the degree to which different raters/observers give consistent estimates of the same phenomenon;
2. Test-retest reliability – used to assess the consistency of a measure from one time to another;
3. Parallel-forms reliability – used to assess the consistency of the results of two tests constructed in the same way from the same content domain; and
4. Internal consistency reliability – used to assess the consistency of results across items within a test.

An estimate of reliability can be indirectly obtained by looking at the consistency of the observed scores through these repeated administrations. In case repeated administration is not possible, Cronbach's  $\alpha$  coefficient can be used as an estimate of the test reliability, instead of the test-retest correlation coefficient. No absolute standard for reliability coefficients exists. However, the

range 0.70–0.90 is considered as the minimum acceptable values of reliability for group comparison and for making individual decisions (Bucciardini *et al.*, 2006; Holmes *et al.*, 1997; Schumaker *et al.*, 1997; Zimpel *et al.*, 2007).

On the other hand, a measurement instrument is said to be *valid* if it actually measures what it is supposed to measure (Bucciardini *et al.*, 2006). Validity can be further divided into:

1. Criterion-related validity is estimated when the performance of the operationalization is checked against some criterion ('golden standard') (Coons *et al.*, 2000; Mathews *et al.*, 2007; Robinson 2004; Schlenk *et al.*, 1998). Some authors call this concept concurrent validity (Murdaugh *et al.*, 2006).
2. Concurrent validity assesses the operationalization's ability to distinguish between groups that it should theoretically be able to distinguish between. For example, do different HIV status groups (symptomatic/asymptomatic) differ statistically in HRQoL scores (Bucciardini *et al.*, 2006; Lubeck *et al.*, 1997; Riley *et al.*, 2003). Some authors call this concept discriminant validity (Bonomi *et al.*, 2000; Bowden *et al.*, 2003; Fang *et al.*, 2002; Kemmler *et al.*, 2003) or consider it to be a part of construct validity (Coons *et al.*, 2000).
3. Construct validity is the approximate truth of the conclusion that the operationalization accurately reflects its construct. It includes convergent and divergent validity.
  - 1) Convergent validity examines the degree to which the operationalization is similar to (converges on) other operationalizations that it theoretically should be similar to. Similar scales (for example positive feelings and self-esteem) should correlate in the predicted direction and size (Hublely *et al.*, 2005; Kemmler *et al.*, 2003).
  - 2) Divergent validity examines the degree to which the operationalization is not similar to (diverges from) other operationalizations that it theoretically should be not be similar to. Dissimilar scales (such as pain and social support) should have weak correlations. Some authors call this concept discriminant validity (Hublely *et al.*, 2005).

In addition, *responsiveness to change* is an important feature of the instrument. Some researchers have argued that the ability of a QoL instrument to detect clinically important changes over time, "responsiveness," is a distinct psychometric property from the measure's reliability and validity. Some others consider responsiveness as one indication of a measure's validity (Hays *et al.*, 1992). In terms of HIV QoL measures, this is a particularly difficult criterion for instrument developers to meet as the measures must be sensitive from the asymptomatic to severely symptomatic stages of the disease (Schumaker *et al.*, 1997) and must have the ability to detect small changes (Robinson 2004). Problem which is often raised is the issue that QoL measures that are reliable and valid in cross-sectional patient samples may not be responsive to changes over time and although these measures have sufficient power to detect changes between groups of patients, they may not accurately identify changes in individual patient scores (Webb *et al.*, 2004).

The *ceiling and floor effects* should also be considered. Ceiling indicates the percentage of subjects achieving the highest score for a dimension and floor indicates the percentage of subjects achieving the lowest score for a dimension (percentages of 20% are considered to be substantive and to indicate a problem with either a ceiling effect or floor effect) (Robinson 2004). These effects make it difficult to distinguish between groups (concurrent validity) or to detect changes over time (responsiveness to change). Ceiling effects are particularly likely to be present when asymptomatic subjects are asked to complete QoL instruments designed for chronic diseases. Ceiling effects represent a major threat to the utility of QoL instruments because these effects make it difficult to discern differences between relatively healthy subjects or to detect subsequent improvements in status (Smith *et al.*, 1997).

## **2.4. Quality of life studies in Estonia**

Several studies to measure HRQoL in different patient groups in Estonia have been implemented over the years. Local versions of different disease-specific HRQoL instruments and patient measured outcome questionnaires have been adapted (Herodes *et al.*, 2001; Korrovits 2008; Lukmann 2002; Macht *et al.*, 2007; Uibo *et al.*, 2008; Urban 2006; Vaht *et al.*, 2004; Vibo *et al.*, 2004). Among generic HRQoL questionnaires, SF-36 is the most widely used (Krikmann *et al.*, 2002; Lai *et al.*, 2001; Tender *et al.*, 2003) together with EQ-5D (Kanarik *et al.*, 2005). The subject of the methodology of adaptation and psychometric properties testing of these instruments has not been widely discussed in scientific literature. Some of the most comprehensive overviews on psychometric properties testing for HRQoL instruments are reported by Tammaru and colleagues for rheumatoid arthritis quality of life scale (RAQoL) (Tammaru *et al.*, 2004; Tammaru *et al.*, 2006) and for Health Assessment Questionnaire's Disability Index (HAQ-DI) (Tammaru *et al.*, 2007). Tammaru and colleagues have also proposed recommendations on strategies for patient-completed instrument adaptations in Estonia (Tammaru *et al.*, 2006).

## **2.5. Quality of life in HIV infection**

In HIV, the first applications of QoL assessment coincided with the advent of antiretroviral therapy in the middle of 1990ies. The routine clinical evaluation of HRQoL improves quality of care in PLHIV by effectively assessing and optimising treatment outcomes, enhancing patient adherence, improving communication between patients and clinicians, and documenting changes in patients' health status over time (Webb *et al.*, 2004). Understanding the nature and prevalence of HIV-related disability would help policy makers to plan for accessible, comprehensive and effective HIV care services. HRQoL measures can also serve as important tools in the evaluation of programs and services. Periodic surveys will help to establish the extent of disability in PLHIV, and

help the health-care community design benefit plans and care. When PLHIV live normal or near-normal life spans, the most important questions will be how to maximize QoL. Increased life expectancy dictates extending consideration to dimensions of QoL such as reproductive health and sexual functioning. Research will be needed to evaluate the effectiveness of the many medical, psychological and social interventions that are available for PLHIV. QoL research can improve the quality of clinical AIDS research and add to its value, thus helping to improve the lives of PLHIV (Wu 2000).

Numerous measures are currently used in research trials, although no comprehensive tool has been developed specifically for use with HIV disease in the clinical setting. The instruments most commonly used to assess QoL in HIV population include the Medical Outcome Study SF-36 form (MOS-HIV), which is also widely used to assess QoL in general population with chronic diseases; the HIV/AIDS-Targeted Quality of Life instrument (HAT-QoL); and the Multidimensional Quality of Life Questionnaire for HIV/AIDS (MQoL-HIV). However, most of these instruments were developed before the HAART era, and were tested in a single cultural setting (for example, white gay men) usually in the developed world (Mutimura *et al.*, 2007). For example, the MOS-HIV, developed in 1987, was one of the first disease-targeted measures available for this population and is widely used in clinical trials and other research and evaluation studies. However, the MOS-HIV has had relatively limited use in populations of women, in groups with lower socio-economic status and in injecting drug users (Wu *et al.*, 1997). The World Health Organization has developed a standardized set of instruments to assess subjective QoL in different medical conditions, including HIV infection (O'Connell *et al.*, 2003; WHOQOL HIV Group 2003; WHOQOL HIV Group 2004).

Generic and disease-specific (HR)QoL measures frequently used in patients with HIV are summarized in Table 1.

**Table 1.** Overview of most commonly used instruments for measuring (health-related) quality of life in HIV/AIDS

Instrument	References	Dimensions and scoring	Properties
EuroQoL (EQ-5D)	Wu <i>et al.</i> , 1997; Wu <i>et al.</i> , 2002; Louwagie <i>et al.</i> , 2007	5 dimensions of health (mobility, self-care, usual activity, pain/discomfort, and anxiety/depression) at 3 levels, which range from “no problem” to “extreme problem”	Self-administered or interview formats; ceiling effect has been described for all items
HIV/AIDS Quality of Life (HAT-QoL)	Holmes <i>et al.</i> , 1997; Holmes <i>et al.</i> , 1998; Holmes <i>et al.</i> , 1999; Penedo <i>et al.</i> , 2003	42 items, 9 dimensions: overall function (a combination of physical, role, and social function), sexual function, disclosure worries, health worries, financial worries, HIV mastery, life satisfaction, medication concerns, and provider trust; Likert-style, frequency response option format is used for all items (‘all of the time’, ‘a lot of the time’, ‘some of the time’, ‘a little of the time’, and ‘none of the time’)	Self-administered; Cronbach’s $\alpha$ coefficients range from 0.54 to 0.89 for subscales; ceiling effect has been described for provider trust dimension
Medical Outcomes Study HIV Health Survey (MOS-HIV); several short versions available	Badia <i>et al.</i> , 1999; Delate <i>et al.</i> , 2001; Mast <i>et al.</i> , 2004; Revicki <i>et al.</i> , 1998; Shahriar <i>et al.</i> , 2002; Wachtel <i>et al.</i> , 1992; Wu <i>et al.</i> , 1991; Wu <i>et al.</i> , 1997	35 questions in 11 dimensions, including General Health Perceptions, Pain, Physical Functioning, Role Functioning, Social Functioning, Mental Health, Energy/Fatigue, Health Distress, Cognitive Function, Quality of Life, and Health Transition; all items can be answered on ordinal scales with 2, 3, 5, or 6 response options; MOSHIV subscales are scored by linearly estimating to a 0–100 scale, with higher scores indicating better HRQoL; in addition a Physical Health Summary score and a Mental Health Summary score can be generated	Self-administered or interview formats; takes only 5 minutes to administer; Cronbach’s $\alpha$ scores 0.53–0.94; ceiling effects have been described for the role functioning and social functioning scales and a floor effect for the role functioning scale

Table continues

**Table 1.** Continued

Instrument	References	Dimensions and scoring	Properties
Multidimensional Quality of Life Questionnaire for HIV/AIDS (MQoL-HIV)	Smith, <i>et al.</i> , 1997; Smith <i>et al.</i> , 1999	40 items in 10 domains: physical functioning; social functioning; cognitive functioning; sexual functioning; physical health; social support; partner intimacy; mental health; medical care; financial status; each item in the MQoL-HIV is assessed using a 7-point frequency response scale ranging from 'never' to 'always'	Self-administered; Cronbach's $\alpha$ coefficients range from 0.64 to 0.86 for domains; ceiling effect has been described for physical functioning domain
WHOQOL-HIV; has a short version: HIV BREF	O'Connell <i>et al.</i> , 2003; Starace <i>et al.</i> , 2002; Zimpel <i>et al.</i> , 2007; WHOQOL HIV Group 2003; WHOQOL HIV Group 2004	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 QoL and general health; five facets are specific to PLHIV: symptoms of HIV, social inclusion, death and dying, forgiveness and fear of future; items are rated on a 5-point Likert interval scale	Self-administered; Cronbach's $\alpha$ scores 0.45–0.87

## 2.6. Factors associated with quality of life of people living with HIV

A large body of previous research has provided important information on the correlates of (HR)QoL in PLHIV. Socio-demographic characteristics such as age, gender, and unemployment, and disease-related variables such as CD4 count, viral burden, and HIV disease stage have been shown to be significant predictors of different dimensions of (HR)QoL. The association between psychosocial factors (e.g., social support, coping, and disclosure) and patient outcomes has been increasingly a focus in HIV studies.

### 2.6.1. Socio-demographic characteristics

Socio-demographic characteristics such as age, gender, race/ethnicity, education, income, employment, etc. have been shown to be significantly related to QoL.

**Gender.** In general, female gender has been associated with significantly diminished QoL (Campsmith *et al.*, 2003; Douaihy *et al.*, 2001; Eller 2001; Hays *et al.*, 2000; Kohli *et al.*, 2005; Mrus *et al.*, 2005; Preau *et al.*, 2004; Rao *et al.*, 2007). However, the information on gender-specific differences in QoL outcomes is controversial. In several studies conducted in western countries age and gender have showed no major impact on QoL (Hays *et al.*, 2000; Kemmler *et al.*, 2003; Starace *et al.*, 2002).

**Age.** Even though the mortality among older patients is higher, it does not necessarily mean that their self-reports of QoL are lower compared to their younger counterparts. Nokes (2000) compared PLHIV older and younger than 50 years of age. As can be expected, older participants reported significantly more medical conditions such as diabetes or hypertension, more limitations in physical functioning, and self-disclosure of HIV infection to fewer people. There were no significant differences on any of the other variables, including depression and mental health (Nokes *et al.*, 2000). Older HIV-infected patients may be more vulnerable to social isolation, have less access to support resources or may themselves choose not to access such resources because of social stigma, guilt or embarrassment (Cederfjäll *et al.*, 2001).

**Ethnicity.** The effects of race and ethnicity on QoL are complex. Generally poorer QoL among certain ethnic minority groups seems to be related to social inequality, ostracism, discrimination, or social stigma related to HIV. These factors may contribute to poor social well-being for diverse populations of PLHIV (Campsmith *et al.*, 2003; Rao *et al.*, 2007; Vidrine *et al.*, 2003).

**Education.** Several studies report that higher educational level is related to better physical and mental QoL (Adewuya *et al.*, 2008; Ruiz-Perez *et al.*, 2006; Turner *et al.*, 2001; Vidrine *et al.*, 2003).

**Employment and income.** As PLHIV adjust to living with a chronic illness, many new challenges emerge, among them issues of occupational functioning and employment. With regard to controlling for disease severity,

employed PLHIV report significantly higher level of perceived overall QoL than those who are unemployed (Blalock *et al.*, 2002; Cowdery *et al.*, 2002; Low-Beer *et al.*, 2000; Mrus *et al.*, 2006; Sowell *et al.*, 1997). Income has also been shown to be independently associated with different aspects of QoL (Friedland *et al.*, 1996; Nicholas *et al.*, 2005).

### **2.6.2. Health and treatment-related aspects**

QoL in HIV infection has been shown to be directly associated with disease stage and disease symptoms (Cunningham *et al.*, 1998; Tozzi *et al.*, 2004).

#### **Comparison with people with no HIV infection**

Numerous studies measuring HRQoL in PLHIV have been published. However, relatively few of them have directly compared HRQoL in individuals with and without HIV-infection. This information could be useful to decision makers because it enables estimates to be made of the morbidity losses that could be avoided by preventing HIV transmissions and by modifying the progression of the condition in already infected individuals (Miners *et al.*, 2001).

Not surprisingly, PLHIV report lower physical and mental health related QoL than the general population does (Kowal *et al.*, 2008, Mast *et al.*, 2004; Meng *et al.*, 2008; Miners *et al.*, 2001, Onwumere *et al.*, 2002). In a study conducted by Hays and colleagues (2000), HIV-positive people who were asymptomatic or had CD4+ lymphocyte count above 500/mm<sup>3</sup> had similar perceived physical health and functioning as HIV-negative people. On the other hand those PLHIV who were symptomatic or had CD4+ lymphocytes below 200/mm<sup>3</sup> had worse perceived physical health and functioning compared to HIV-negative people. In the same study, patients in various stages of HIV disease reported comparable emotional well-being, but significantly worse emotional well-being than the general population and patients with other chronic diseases except depression. Bing *et al.* (2000), on the other hand, found that emotional health of asymptomatic HIV-positive people was comparable to HIV-negative people but better than among symptomatic HIV-positive people.

Patients with advanced AIDS report lower overall QoL than do individuals with other chronic conditions such as cancer, diabetes, epilepsy or depression with disease-related factors contributing to their poor QoL (Douaihy *et al.*, 2001; Eller *et al.*, 2001, Hays *et al.*, 2000, Onwumere *et al.*, 2002; Schlenk *et al.*, 1998).

#### **HIV-related symptoms and other clinical aspects**

The functioning and well-being of PLHIV is inextricably linked to the symptoms they experience and clinical findings. Changes in HRQoL have been found to be strongly and consistently associated with changes in symptoms (Lorenz *et al.*, 2006).

**CD4 count.** Several studies have shown that patients with higher CD4 cell counts (measured in CD4 cell count per mm<sup>3</sup>) report better QoL, both physical,

social, and mental (Call *et al.*, 2000; Campsmith *et al.*, 2003; Chandra *et al.*, 2006; Jia *et al.*, 2007; Kemmler *et al.*, 2003; Kohli *et al.*, 2005; McDonnell *et al.*, 2000; Murri *et al.*, 2003; Nicholas *et al.*, 2005; Shor-Posner *et al.*, 2000; Vidrine *et al.*, 2003). It has been demonstrated that individuals whose CD4 counts decreased also had accompanying significant declines in disability, general health, social functioning, pain, and symptoms (Lubeck *et al.*, 1997). Vosvick *et al.* (2003) argue that the significant association between CD4 cell counts and social and role functioning suggests that sicker patients are less able to actively engage in social activities such as visiting with friends or close relatives and are less able to perform work-related tasks at work, home, and in educational settings.

**Viral load.** Many studies have proved also the relationship between viral load (measured in HIV-1 RNA copies per mm<sup>3</sup>) and physical health scores or physical QoL scores (Burgoyne *et al.*, 2004; Chandra *et al.*, 2006; Delate *et al.*, 2001). Viral load has been described as an independent predictor of role-physical, bodily pain, and vitality scores (Call *et al.*, 2000).

**Disease stage and duration of HIV-infection.** HRQoL typically decreases with disease progression and is inversely correlated to frequency of hospitalisation and increasing symptoms (Kemppainen 2001; Lubeck *et al.*, 1997; Te Vaarwerk *et al.*, 2001). Patients' HRQoL dimensions also change over time as patients adjust to chronic nature of their HIV infection (Jia *et al.*, 2007). Some have found that the stage of HIV infection is not related to psychological well-being as much as to physical. More crucial to psychosocial QoL seems to be the amount of time elapsed since HIV testing. PLHIV learn to meet the adaptive challenges of illness over time and develop coping mechanisms in order to deal with the emotional and social stresses of living with HIV (Rao *et al.*, 2007; Te Vaarwerk *et al.*, 2001). They experience self-transcendence and their lives take on new meaning as they live with this illness (Schlenk *et al.*, 1998).

**Sleep disturbances.** There is a well-documented phenomenon of sleep pattern disturbances in PLHIV that far exceeds the proportion of sleep pattern disturbances found in healthy populations (Dreher 2003). Sleep quality has been found to be associated with length of time living with HIV and use of HIV antiretroviral medications, symptom severity, depressive symptoms, daytime sleepiness, functional status, and state anxiety (Nokes *et al.*, 2001). Sleep quality has been found to be associated with HRQoL in PLHIV, independent of the individual's stage of illness, more so with mental HRQoL than with physical HRQoL (Phillips *et al.*, 2005).

**Sexual dysfunction** is common in HIV/AIDS and can affect both physical and emotional aspects related to HRQoL (Bouhnik *et al.*, 2008). PLHIV are confronted with many factors that may interfere with their sexual well-being: the psychological impact of the HIV infection itself, the stigma associated with the infection, hormonal abnormalities, fear of transmitting the infection to others, depression, illnesses, and the side effects of drugs such as antiretrovirals (Koole *et al.*, 2007). Focus group discussions among PLHIV performed in Europe have shown that sexual well-being in general was felt to be a crucial part of overall HRQoL and that sexual dysfunction was perceived to decrease it

significantly (Koole *et al.*, 2007). Bova *et al.* (2003) report higher levels of sexual functioning in women with HIV who report better mental health, more positive meaning attributed to life with HIV infection, better QoL, and fewer HIV-related symptoms.

**Hepatitis C.** The additional burden generated by hepatitis C (HCV) infection in PLHIV can worsen their QoL. Co-infected patients report more symptoms and poorer QoL (Tsui *et al.*, 2007). However, these effects can be mediated through other factors. Braitstein *et al.* (2005) showed that the impact of HCV on QoL, depression and fatigue were better explained by the socio-demographic factors related to poverty and IDU than by HCV itself. Costenbader *et al.* (2007) argue that especially in a population with multiple risk factors, for example, typically among IDUs, HCV may play a less central role in affecting HRQoL than in other groups.

**Survival.** QoL has been found to be predictive for survival of PLHIV with higher QoL having lower death rates (Cunningham *et al.*, 2005; Jacobson *et al.*, 2003).

### **Treatment related issues**

Quality of life can be altered by both the immediate effects and the longer-term consequences of treatment, especially in the case of chronic diseases.

**Antiretroviral treatment.** QoL has been shown to improve with ARV treatment (Allavena *et al.*, 2008; Echeverria *et al.*, 1999; Fumaz *et al.*, 2002; Liu *et al.*, 2006; Louwagie *et al.*, 2007; Nieuwkerk *et al.*, 2000), though the effect may differ depending on the person's baseline QoL (Nieuwkerk *et al.*, 2001). Persons with advanced HIV disease and low QoL scores have demonstrated significant improvements in QoL with ARV treatment (Cohen *et al.*, 1998; Nieuwkerk *et al.*, 2001), while those with asymptomatic HIV and higher QoL scores have shown short-term impairment of QoL mainly due to the known adverse effects of drugs (Zinkernagel *et al.*, 1999). In long term HRQoL, outcomes of people on ARV treatment reflect both the impact of treatment and disease progression and depend on many factors including CD4 cell count and QoL at the start of the treatment (Revicki *et al.*, 1999). Casado (2005) argues that among patients, especially those who have chronic, incurable diseases, HRQoL may be the most important outcome to be considered when assessing treatment effectiveness. Patients in clinical studies of ARV drugs have reported a decline in mental health and other aspects of QoL over the study period. These findings confirm that clinical outcome measures alone are not sufficient for determining the effect of new treatments as commonly used end-points (CD4 level, viral load, opportunistic diseases) are inadequate to catch the complexity of treatment outcomes (Low-Beer *et al.*, 2000; Wu 2000).

**Side-effects** of HIV treatments impact QoL and adherence to care, and influence decisions about health care. In research with PLHIV on HAART, side effects have been found to be related to several aspects of QoL, including physical and mental health scores and social functioning (Eriksson *et al.*, 2005; Johnson *et al.*, 2004; Protopopescu *et al.*, 2007). Patients who discontinue medication due to insufficient efficacy, toxicities or at their own request show

less favourable changes in QoL compared with patients who continue their regimen (Nieuwkerk 2001).

**The lipodystrophy syndrome** associated with HAART involves metabolic abnormalities and body fat redistribution, with atrophy of subcutaneous adipose tissue. Lipodystrophy reduces QoL in patients with HIV/AIDS by limiting physical and social activities, affecting body image, and lowering self-esteem, often leading to depression (Huang *et al.*, 2006a; Huang *et al.*, 2006b). Lipodystrophy symptoms have been found to be associated with lower QoL of PLHIV and discontinuation of antiretroviral therapy (Guaraldi *et al.*, 2008; Martinez *et al.*, 2001; Mutimura *et al.*, 2007; Nicholas *et al.*, 2005). The special diet and counselling of PLHIV who have lipodystrophy have been shown to significantly improve the QoL (Reid *et al.*, 2007). Yet in other studies neither the mental nor physical QoL components have been found to be significantly associated with lipodystrophy (Steel *et al.*, 2006).

**Adherence** is known to contribute to improved HIV clinical outcomes, which could result in a better QoL. QoL may also influence adherence, as persons with better QoL may have a greater ability to adhere to their ARV regimens. Tolerability, appearance-related side effects, long-term safety concerns, convenience, dosing flexibility, and drug interactions may negatively impact adherence and HRQoL (Sax *et al.*, 2005). Studies have shown that adherence and QoL share some determinants. Both QoL and adherence have been associated with HIV viral load levels, HIV disease stage, and symptoms (Mannheimer *et al.*, 2005). While some aspects of QoL have been shown to impact ARV adherence, little is known about the effect of ARV adherence on QoL (Holzemer *et al.*, 1999). Limited data suggest HRQoL dimensions, notably cognitive functioning, financial status, and medical care, are closely associated with ARV therapy adherence (Carballo *et al.*, 2004) but it is not known what degree of adherence is required to achieve QoL benefits (Mannheimer *et al.*, 2005). Some others have failed to show the relationship between adherence and HRQoL (Applebaum *et al.*, 2009). A recent meta-analysis on ARV adherence among IDUs concluded that findings suggest that HIV-infected drug users tend to be inappropriately assumed to be less adherent and unlikely to achieve desirable treatment outcomes when compared to non drug users (Malta *et al.*, 2008a; Malta *et al.*, 2008b).

### **2.6.3. Social and psychological factors**

Many PLHIV struggle with psychosocial problems like stigma, depression, substance abuse, domestic violence etc., which can affect their QoL, motivation for seeking health care and social support services, and adherence to treatment. All this ultimately influences health outcomes. It has been shown that psychosocial factors contribute to HRQoL (Au *et al.*, 2004) and patient's perceptions of their QoL are related to their ability to function in society and their ability to succeed in activities of daily life (Parsons *et al.*, 2006). Inadequate social support, ineffective coping skills, and lack of spirituality have

been identified as factors that can significantly diminish QoL of PLHIV (Douaihy *et al.*, 2001; Eller 2001; Hays *et al.*, 2000).

**Social support.** Considerable evidence has now accumulated to suggest that social support is a means of buffering the negative health outcomes that result from stressors, including the stress of serious illness (Chandra *et al.*, 2003). In the field of HIV/AIDS study, several researchers have reported the direct impact of social support on the patients' HRQoL as well as the link between social support and psychological well-being of the patients. In several studies, more partner and familial support has predicted better QoL over time (Jia *et al.*, 2005; Rao *et al.*, 2007). Satisfaction with social support in PLHIV is associated with mental health, general health perception, depression, QoL, pain, energy, and self-esteem (Adewuya *et al.*, 2008; Bastardo *et al.*, 2000; Cowdery *et al.*, 2002; Friedland *et al.*, 1996; Hirabayashi *et al.*, 2002; Jia *et al.*, 2004; Jia *et al.*, 2007; Onwumere *et al.*, 2002; Reynolds *et al.*, 2007; Safren *et al.*, 2002). Supportive social environment, including community acceptance, is especially important for mental aspects of PLHIV (Ichikawa *et al.*, 2006). Social support has also been found to be associated with physical QoL, overall physical functioning, and fewer disability days (Jia *et al.*, 2004; Ruiz Perez *et al.*, 2005).

**Disclosure of HIV-status.** Those people, who have not disclosed to anyone other than health care professionals, may prevent potentially negative social, personal and material consequences but may also limit their own opportunities for social support, an important factor in coping and recovering from physical illness. Disclosure may result in greater social support, which in turn has positive effects on psychological well-being (Zea *et al.*, 2005). Furthermore, PLHIV who are integrated in social networks have higher levels of psychological well-being than those who are not, which in turn improves the overall QoL of the individual (Chandra *et al.*, 2003, Gielen *et al.*, 2001). Cederfjäll *et al.* (2001) found that those who had not talked to anybody outside the hospital about their HIV status seemed to have better positive well-being. They argue that maybe by keeping their identity without a connection to HIV, people do not experience that they have "become their illness".

**Mental health.** Depression associated with the infection and/or disease significantly impacts the individuals' QoL (Jia *et al.*, 2004). People with depression report lower QoL (Adewuya *et al.*, 2008; Mrus *et al.*, 2006, Tate *et al.*, 2003) and an increase in QoL has been shown when depression decreases (Gore-Felton *et al.*, 2006). Even suicidal ideation has been found to be associated with QoL of PLHIV (Haller *et al.*, 2003). A better mental QoL is associated with having social support and absence of mental illness (Ruiz Perez *et al.*, 2005). Limited social support and unemployment predict depression among people with AIDS, which is itself a strong predictor of decreased QoL in patients with advanced AIDS (Kemppainen 2001). Cognitive-behavioural stress management therapy for PLHIV has been shown to positively affect QoL (cognitive functioning, health distress, and overall health perceptions) (Lechner *et al.*, 2003; Molassiotis *et al.*, 2002).

**Coping skills.** Inadequate coping skills and feelings of hopelessness are also associated with diminished QoL, whereas higher levels of active coping are

positively related with QoL and predict improved life satisfaction, even in patients with advanced HIV disease (Jia *et al.*, 2007; Safren *et al.*, 2002). Cognitive-behavioural bereavement coping group interventions for PLHIV have demonstrated improvements in general health-related and HIV-specific QoL (Sikkema *et al.*, 2005).

**Spirituality** and religion are ways of coping and re-framing one's life and they bring a sense of meaning and purpose to one's life in the face of a disease such as HIV. Greater levels of spirituality have been found to be associated with better HRQoL of PLHIV (Mrus *et al.*, 2006). However, spiritual aspects of the QoL have been studied little. WHOQOL SRPB Group (2006) has developed an instrument to assess spiritual dimensions of QoL. The preliminary findings of their work show that SRPB appears to be related to psychological and social qualities. All dimensions of QoL contributed to the general QoL domain but spiritual, religious, and personal beliefs made a smaller contribution than the environmental, psychological or social domains. They argue that spirituality, religion, and personal beliefs may not be as important as traditional QoL indicators such as energy, positive feelings, and activities of daily life. This is probably a very culture-specific issue (WHOQOL SRPB Group 2006).

**Smoking** among PLHIV has been found to be independently associated with lower scores for general health perceptions, physical functioning, bodily pain, energy, role functioning, and cognitive functioning (Turner 2001).

**Substance abuse.** Heavy alcohol use and illicit drug use negatively affect physical health status and thereby HRQoL (Bonkovsky *et al.*, 1999; Bonkovsky *et al.*, 2007; Foster *et al.*, 1998; Foster *et al.*, 1999). Studies focusing on QoL in specific minorities such as drug users remain limited and are oftentimes based on a "drug maintenance treatment programs" recruitment basis (Costenbader *et al.*, 2007). Some studies have shown that a history of IDU (and what is experienced with it) is detrimental to HRQoL and that active IDUs have lower levels of HRQoL, both physical and mental, compared to people infected sexually (Campsmith *et al.*, 2003; Kemmler *et al.*, 2003; Ruiz Perez *et al.*, 2005). Individuals who have been HIV-infected through IDU may be even more socially vulnerable than HIV-negative IDUs due to the dual nature of their need for support (support for HIV and for drug use). In this specific population, the burden of co-morbidities (HCV, HBV, tuberculosis) as well as delayed access to antiretroviral treatment may have an additional negative impact on HRQoL (Carrieri *et al.*, 1999; Ruiz Perez *et al.*, 2005).

## **AIMS OF THE RESEARCH**

The general aim of the research was to evaluate the prevalence of HIV and related risk behaviours among injecting drug users as a HIV infection core group in Estonia and assess the quality of life and the factors influencing quality of life of people living with HIV in Estonia.

The specific aims of the research were as follows:

1. To study HIV-prevalence and related risk-behaviours among IDUs as a HIV infection core group in Estonia;
2. To examine QoL among Estonian HIV-infected individuals and the impact of socio-demographic, disease-related, and psycho-social factors on QoL in order to inform public health policy and services;
3. To assess the feasibility and acceptability of the WHOQOL-HIV instrument for the HIV-infected patients in care;
4. To assess the performance (reliability, validity) of the Estonian and Russian versions of the WHOQOL-HIV instrument.

## MATERIAL AND METHODS

The current work is based on the results of two cross-sectional studies:

1. Cross-sectional study among IDUs to estimate HIV-prevalence and risk behaviours (IDU study);
2. Cross-sectional study among PLHIV to estimate QoL and related factors (QoL study).

### 3. Study designs

Description of the IDU and QoL study designs is presented in Table 2.

**Table 2.** Study designs in IDU and QoL study, Estonia 2005

	IDU study	QoL study
Target population	Current IDU <sup>1</sup> (a person reporting injecting drugs within the last two months)	People infected with HIV in care
Sample size	450	451
Eligibility criteria	Male or female, 18 years or older, spoke Russian or Estonian, reported injecting drugs, able to give informed consent	Male or female, 18 years or older, able to read and write in Russian and/or Estonian, being aware of their HIV-infection status for more than 3 months, able to give informed consent
Place and time of data collection	Tallinn and Kohtla-Järve, May–June 2005	Tallinn, Kohtla-Järve, and Narva, June–September 2005
The study site	Syringe exchange programs at NGO Convictus (Tallinn) and NGO We will help you (Kohtla-Järve)	Infectious diseases out-patient clinics in West-Tallinn Central Hospital (Tallinn), Ida-Viru Central Hospital (Kohtla-Järve), and Narva Hospital (Narva)
Sampling method	Respondent-driven sampling (RDS) <sup>2</sup> . Number of seeds <sup>3</sup> : six seeds in Tallinn and two in Kohtla-Järve	Convenience sampling among HIV-infected people in HIV-care
Measurements	Interviewer administered questionnaire; biological sample (dried blood spot) collection for anti-HIV antibodies detection <sup>4</sup>	A self-administered questionnaire; standardized form for collecting clinical data from medical records
Questionnaire adapted from:	Imperial College London Survey of HIV Prevalence and Risk Behaviour Among Community Recruited Injecting Drug Users (Rhodes et al., 2002; Rhodes et al., 2005; Rhodes et al., 2006)	WHOQOL-HIV instrument (O’Connell et al., 2003; WHOQOL HIV Group 2003; WHOQOL HIV Group 2004)

Table continues

**Table 2.** Continued

	IDU study	QoL study
Incentives (for study participation)	Primary incentive (for participating) – gift coupon for grocery store, value USD 5; secondary incentive (for recruiting peers) – gift coupon for grocery store, value USD 5	Gift coupon for grocery store, value USD 10
Ethical Committee’s approval	The Ethics Review Committee on Human Research at the University of Tartu and The Riverside Ethical Committee in the UK	Tallinn Medical Research Ethics Committee
Data management and analysis	Data entry was done centrally using Epi-Info. Statistical analysis was performed with STATA 7.0 and RDS analysis Tool v. 5.0.1	Data entry was done centrally using Microsoft Access. Statistical analysis was performed with R 2.4.0, a language and environment software for statistical computing and graphics, and STATA 10.0

- <sup>1</sup> To ensure that respondents were active IDUs, their skin was checked for injection marks and/or they were asked to describe the process of preparing drugs for injection.
- <sup>2</sup> Respondent-driven sampling (RDS) is a chain-referral method that yields samples of target populations. For hidden populations, this method is particularly useful because there is no sampling frame as the size and boundaries of the populations are not known. Previous studies have shown the usefulness of RDS to recruit IDUs (Heckathorn 1997; Heckathorn *et al.*, 2002). The RDS procedure starts with the recruitment of initial “seeds” who are provided with numbered coupons they have to distribute to the next eligible recruits known as the ‘first wave’. The first wave participants, after completing the study procedures, are given numbered coupons to distribute to new recruits within their IDU networks for recruitment of a ‘second wave’. Recruitment is thus achieved using the coupon system and continued until the desired sample size is reached. In our study, we used a dual incentive system: first incentive for study participation and another for peer recruitment.
- <sup>3</sup> RDS seeds were carefully selected to represent the demographic profile and socially and geographically diverse injecting networks of IDUs in Tallinn and Kohtla-Järve. Six seeds were selected in Tallinn and two in Kohtla-Järve (ethnic Russian IDUs, ethnic Estonian IDUs, female IDUs, commercial sex worker IDUs, IDUs using amphetamines, IDUs using opiates).
- <sup>4</sup> Testing for HIV antibodies was performed at the Virus Reference Department Laboratory, Health Protection Agency Centre for Infections, UK. Dried blood spot specimens were collected using single-use disposable lancets and neonatal Guthrie cards to detect antibodies to HIV (anti-HIV) (Guthrie *et al.*, 1963; Judd *et al.*, 2003). Specimens were screened using anti-HIV IgG antibody-capture enzyme-linked immunosorbent assay (GACELISA), reactive specimens were confirmed using anti-HIV IgG antibody-capture particle adherence test (GACPAT) immunoassay, with confirmatory testing conducted on discordant results using the HIV blot 2.2 Western blot assay (Abbott Murex, Abbott Park, Illinois, USA) (Parry *et al.*, 1995).

### **3.1. Statistical analysis**

As for descriptive statistics, mean, median, standard deviation (SD), and/or range were used for continuous variables in the study. For categorical variables, relative (%) and absolute frequencies (N) were presented.  $\chi^2$  test, Fisher exact test, Wilcoxon and Kruskal-Wallis rank sum tests were used to explore differences in covariates and prevalence of HIV antibodies. RDS adjusted population estimates and homophily were calculated with RDS analysis Tool v. 5.0.1.

For the purposes of the factors of QoL analysis, participants were divided into two groups based on the mean score of the facet (range 1 to 5) or domain (range 4 to 20). Participants with mean score  $>3.0$  or  $>12.0$  were categorized as having good QoL and their counterparts (mean score  $\leq 3.0$  or  $\leq 12.0$ ) as having poor QoL. After identifying variables that differed significantly between patients showing good QoL and poor QoL, a multivariate analysis was performed using logistic regression, taking QoL (good/poor) as binary dependent variable and the variables related to QoL in the univariate analyses as the covariates to evaluate the independent contribution of variables to QoL. The magnitude of the association between covariates and QoL in univariate and multivariate analysis was evaluated through odds ratios (OR), together with their corresponding 95% confidence intervals (CI).

P-values of less than 0.05 were considered as statistically significant.

## **4. Assessment of the performance of Estonian and Russian versions of WHOQOL-HIV instrument**

### **4.1. Description of WHOQOL-HIV instrument**

The WHOQOL-HIV instrument contains 29 facets, each with four items. Facets are subsumed in six domains: physical, psychological, level of independence, social, environmental, and spiritual. In addition, there is also one additional facet that measures overall QoL and general health perceptions (overall QoL). In all facets, items are rated on a 5-point Likert interval scale where usually 1 indicates low, negative perceptions and 5 indicates high, positive perceptions. Some facets are not scaled in a positive direction, meaning that for these facets higher scores do not denote higher QoL. These need to be recoded so that high scores reflect better QoL. Facet scores are the mean of the four items in each facet. Domain scores are obtained by adding up the facet means in the respective domain, 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) (WHO 2002).

## **4.2. Original WHOQOL-HIV instrument performance**

WHOQOL-HIV instrument has been developed based on WHOQOL-100, which shows excellent psychometric properties of internal consistency reliability, content and construct validity, and divergent validity (Bonomi *et al.*, 2000; Skevington 1999). Moreover, unlike with many other instruments, there is extensive proof for the conceptual, item, operational, and measurement equivalence and some proof for the semantic equivalence of WHOQOL instrument, based on what the WHOQOL-HIV has been developed. The processes involved in developing and testing the WHOQOL have more rigorously evaluated equivalence than those with other instruments. Therefore, conclusions about the use of the WHOQOL are more likely to provide reliable and valid interpretations across countries (Bowden *et al.*, 2003; Herdman *et al.*, 1997).

WHOQOL-HIV instrument itself has been translated into several languages, has good psychometric properties, and has been tested for reliability and validity. Findings suggest that it is suitable for assessment of QoL in PLWH across a range of different socio-economic and cultural backgrounds such as Australia, India, Thailand, Brazil, Zimbabwe (O'Connell *et al.*, 2003; WHOQOL HIV Group 2003; WHOQOL HIV Group 2004). Several authors have also reported evidence for the acceptability, reliability and validity of the local versions of the WHOQOL-HIV (Molassiotis *et al.*, 2002; Starace *et al.*, 2002; Zimpel *et al.*, 2007).

## **4.3. Translation procedure**

In the first phase, we translated the WHOQOL-HIV instrument into Estonian and Russian. Panels of bilingual people discussed the translation and negotiated the “best fits” for items. After that, a focus group discussion was conducted, involving ten PLHIV (recruited through NGO Convictus Eesti and NGO ESPO) to ensure the comprehensibility of the instrument. Finally, the translations were compared to the original instrument.

## **4.4. Performance of the translated versions**

We evaluated the performance of the Estonian and Russian version of the WHOQOL-HIV by examining feasibility and acceptability (study participation rate, percentage of missing responses, and floor/ceiling effects), reliability (internal consistency) and validity (criterion, concurrent, and construct validity).

Statistical analysis was performed with STATA 10.0. Items scaled in negative direction were first recoded so that higher scores would reflect better QoL. Items relating to each of the dimension/facet were combined to produce means and standard deviations for each subscale.

We looked at the general distribution of scores to check that patients were using the full range of possible scores – that is, that they were not giving uniformly low or high assessment responses. We also checked that scores did not show evidence of skewness (that the distribution of scores was roughly symmetrical about the mean) or kurtosis (that the distributions were not too peaked or too flat).

We used proportions or means with standard deviation (for continuous data) to describe socio-demographic (age, region, gender, education, employment status, average monthly net income per family member) and health-related factors (disease stage, routes of infection, CD4 count) in different QoL groups.

To assess feasibility, we used study participation rate, percentage of missing responses, and floor/ceiling effects (percentage of subjects scoring the lowest and the highest scores).

To assess internal consistency (reliability), we calculated average inter-item correlations, average item-total correlations, and Cronbach's alphas (the average of all possible split-half estimates) within all facets, overall QoL score and domains.

To assess criterion related validity we calculated correlations between domains/facets and overall QoL (defining the latter as the 'golden standard'). Some authors have used CD4 count as a criterion (Mathews *et al.*, 2007) but in our sample we had lots of missing data regarding CD4 count.

To assess concurrent validity, we tested whether the instrument was sensitive to differences between people with different health status. One of the most consistent findings in the PLHIV QoL literature is that patients with more advanced disease (having symptoms) report lower QoL than those at the asymptomatic stage of the disease (Cunningham *et al.*, 2005; Jia *et al.*, 2007; Tozzi *et al.*, 2003). We therefore predicted that our scale should find disease stage-specific differences in QoL scores. One-way ANOVA was used for comparing means (adjusted for age and gender) by disease stage.

To assess construct validity, we sought proof for convergent and divergent validity calculating correlations between facets in different domains.

Pearson coefficient was used to evaluate inter-item, item-total, inter-facet, facet-domain, and inter-domain correlations and correlations between domains/facets and overall QoL.

## RESULTS

### 5. HIV-prevalence and related risk-behaviours among injecting drug users

#### 5.1. Socio-demographic and other background data

For participation in IDU study, 350 respondents were recruited from Tallinn (78% of the total sample) and 100 from Kohtla-Järve (Ida-Virumaa, North-Eastern Estonia).

Over half of the sample in both cities was under 25 years of age, of Russian nationality, and over 80% were men (data not shown). In Kohtla-Järve, a higher proportion of participants than that in Tallinn reported not having a regular source of income (77% versus 52%, respectively). Injecting drug use and risk behaviour characteristics varied by city. Greater proportions of IDUs in Tallinn reported shorter injection careers, whereas fewer reported injecting daily (38% versus 75%, respectively). The prevalence of HIV was 54% (95% CI 49.0–59.5%) in Tallinn and 90% (95% CI 83.8–95.9%) in Kohtla-Järve ( $p < 0.001$ ). More detailed data on socio-demographic and other background variables by city are presented in Table 3.

In RDSAT analysis all observed sample proportions fell within the 95% CI of the RDS adjusted population estimates (data not shown).

**Table 3.** Comparison of characteristics of injecting drug users in IDU study, Kohtla-Järve and Tallinn, Estonia 2005<sup>1</sup>

Characteristic	Kohtla-Järve (N=100)		Tallinn (N=350)		Comparison of Tallinn with Kohtla-Järve sample	
	N	%	N	%	$\chi^2$	p-value
Socio-demographics						
Age (years)						
≤24	53	53	198	57	0.4	0.5
>24	47	47	152	43		
Gender						
Male	85	85	291	83	0.2	0.6
Female	15	15	59	17		
Secondary education						
Incomplete	60	60	194	55	0.7	0.4
Complete	40	40	156	45		
Main source of income in the last 4 weeks						
Job	22	22	163	47	19.6	<0.001
Other	77	77	183	52		

Table continues

**Table 3.** Continued

Characteristic	Kohtla-Järve (N=100)		Tallinn (N=350)		Comparison of Tallinn with Kohtla-Järve sample	
	N	%	N	%	$\chi^2$	p-value
<b>Ethnicity</b>						
Estonian	5	5	48	14		
Russian	91	91	280	80		
Other	3	3	22	6	7.7	0.02
<b>Injecting drug use characteristics</b>						
<b>Duration of injection career (years)</b>						
≤2	3	3	47	14		
3–5	21	21	94	27		
6–9	42	42	134	38		
≥10	34	34	75	21	14	<0.01
<b>Frequency of injection</b>						
<daily	25	25	217	62		
daily	75	75	133	38	42.8	<0.001
<b>Number of injections on the last day</b>						
1	9	9	82	23		
≥2	90	90	268	77	9.9	0.002
<b>Main drug injected in the last 4 weeks</b>						
China White <sup>2</sup>	2	2	258	74		
Mak <sup>3</sup>	86	86	2	1		
Amphetamine	10	10	73	21	358	<0.001
<b>Injecting risk behaviours</b>						
<b>Shared needles or syringes during the last 4 weeks</b>						
No	81	81	237	72		
Yes	18	18	90	28	3.5	0.06
<b>Injected with used needles or syringes of sexual partner in the last 12 months</b>						
No	79	83	227	71		
Yes	16	17	92	29	5.5	0.02
<b>Average number of times a needle is reused</b>						
1	57	57	47	15		
≥2	43	43	267	85	83.1	<0.001
<b>Sexual risk behaviours</b>						
<b>Number of sexual partners in the last 12 months</b>						
0/1	43	43	143	41		
≥2	57	57	204	58	0.1	0.75
<b>Ever had a sexually transmitted infection</b>						
No	73	73	277	80		
Yes	25	25	69	20	1.4	0.23
<b>Environmental factors</b>						
<b>Ever been in prison</b>						
No	41	41	123	35		
Yes	59	59	227	65	1.2	0.28

**Table continues**

**Table 3.** Continued

Characteristic	Kohtla-Järve (N=100)		Tallinn (N=350)		Comparison of Tallinn with Kohtla-Järve sample	
	N	%	N	%	$\chi^2$	p-value
Ever received drug treatment <sup>4</sup>						
No	35	35	209	60		
Yes	65	65	139	40	19.7	<0.001
Ever attended a needle exchange program						
No	19	19	71	20		
Yes	81	81	279	80	0.1	0.78
Prevalence of blood-borne infections						
Anti-HIV-antibodies						
Positive	89	90	190	54		
Negative	10	10	160	46	41.6	<0.001

<sup>1</sup> Missing data not shown

<sup>2</sup> Street name of illegally produced fentanyl

<sup>3</sup> Street name of home made poppy liquid

<sup>4</sup> Includes substitution treatment, short/long-term detoxification, participation in drug-free rehabilitation programs, self-help or support groups

## 5.2. Risk factors for HIV infection

Associations between antibodies to HIV (the outcome of interest) and covariables were explored univariably and by multiple logistic regression for the Tallinn sample only. In the univariate analysis, increased odds of HIV-seropositivity were associated with non-Estonian ethnicity (OR 2.1; 95% CI 1.1–4.0), duration of injection career, daily injection (OR 1.8; 95% CI 1.2–2.9), and mainly injecting China White (OR 4.6; 95% CI 2.6–8.2). HIV-seropositivity was also associated with using needles/syringes of sex partners in the last 12 months (OR 2.7; 95% CI 1.6–4.5%), a history of imprisonment (OR 1.6; 95% CI 1.0–2.5), ever receiving drug treatment (OR 2.4; 95% CI 1.5–3.8), and ever having attended a needle/syringe exchange program (OR 2.2; 95% CI 1.2–3.8).

After adjustment, only three variables remained significantly associated with increased odds of HIV-seropositivity. IDUs who mainly injected China White had three times the odds of being anti-HIV positive than those who injected amphetamines (OR 3.3; 95% CI 1.7–6.4); those injecting with used needles/syringes of their sex partners in the past 12 months had twice the odds (OR 2.4; 95% CI 1.4–4.3); and those who were receiving drug treatment services had 1.8 times the odds of being HIV-seropositive (95% CI 1.1–3.0). More detailed data is presented in Table 4.

**Table 4.** Univariate and multivariate risk factors associated with HIV among injecting drug users in IDU study, Tallinn, Estonia 2005

Characteristic	HIV+ (%)	Univariate analysis			Multivariate analysis		
		OR	95% CI	p-value <sup>1</sup>	OR	95% CI	p-value <sup>2</sup>
<b>Socio-demographics</b>							
Age (years)							
≤24	55	1.0			1.0		
>24	53	0.9	0.6–1.4	0.7	0.8	0.5–1.3	0.4
Gender							
Male	53	1.0			1.0		
Female	59	1.3	0.2–2.3	0.4	0.9	0.4–1.8	0.7
Main source of income in the last 4 weeks							
Job	50	1.0			1.0		
Other	57	1.3	0.9–2.0	0.2	1.4	0.8–2.2	0.2
Ethnicity							
Estonian	38	1.0			1.0		
Russian/other	57	2.1	1.1–4.0	0.01	1.6	0.8–3.6	0.2
Injecting drug use characteristics							
Duration of injection career (years)							
≤2	30	1.0			1.0		
3–5	51	2.5	1.2–5.3		1.3	0.5–3.2	
6–9	63	4.0	2.0–8.3		1.9	0.8–4.5	
≥10	57	3.2	1.4–7.0	<0.001	1.4	0.5–3.7	0.4
Frequency of injection							
<daily	49	1.0			1.0		
daily	63	1.8	1.2–2.9	0.01	1.1	0.7–2.0	0.6
Main drug injected in the last 4 weeks <sup>3</sup>							
Amphetamine	26	1.0			1.0		
China White	62	4.6	2.6–8.2	<0.001	3.3	1.7–6.4	<0.001
Injecting risk behaviours							
Shared needles or syringes during the last 4 weeks							
No	51	1.0			1.0		
Yes	60	1.5	0.9–2.4	0.1	1.1	0.6–2.0	0.8
Injected with used needles or syringes of sexual partner in the last 12 months							
No	45	1.0			1.0		
Yes	67	2.7	1.6–4.5	<0.001	2.4	1.4–4.3	<0.001
Sexual risk behaviours							
Number of sexual partners in the last 12 months							
0/1	55	1.0			1.0		
≥2	54	1.0	0.7–1.6	0.9	1.5	0.9–2.6	0.1

Table continues

**Table 4.** Continued

Characteristic	HIV+ (%)	Univariate analysis			Multivariate analysis		
		OR	95% CI	p-value <sup>1</sup>	OR	95% CI	p-value <sup>2</sup>
Environmental factors							
Ever been in prison							
No	47	1.0			1.0		
Yes	58	1.6	1.0–2.5	0.05	1.4	0.8–2.3	0.2
Ever received drug treatment <sup>4</sup>							
No	46	1.0			1.0		
Yes	67	2.4	1.5–3.8	0.01	1.8	1.1–3.0	0.03
Ever attended a needle exchange program							
No	38	1.0			1.0		
Yes	58	2.2	1.2–3.8	<0.001	1.4	0.7–2.5	0.4

<sup>1</sup> p-value derived from  $\chi^2$  test

<sup>2</sup> p-value derived from Wald test

<sup>3</sup> Mak was excluded because only two IDUs reported injecting Mak

<sup>4</sup> Includes substitution treatment, short/long-term detoxification, participation in drug free rehabilitation programs, self-help or support groups

## 6. QoL among Estonian people living with HIV and the impact of socio-demographic, disease-related, and psycho-social factors on QoL

### 6.1. Socio-demographic and other background data

A total of 562 HIV-infected patients attending their regular medical check-ups at infectious diseases out-patient clinics were invited to participate in QoL study. Out of 507 eligible people, 56 refused. The study procedure was completed by 451 respondents (uptake 89%), out of whom 150 participated in Tallinn and 301 in Ida-Virumaa (Kohtla-Järve and Narva).

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 IDU (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 received ARV treatment. The proportion of people on ARV treatment was lower among those infected through IDU compared to those infected sexually (17% vs. 28%,  $p=0.008$ ) and somewhat lower in Ida-Virumaa compared to Tallinn (20% vs. 27%,  $p=0.08$ ). 2.2% of the participants had had active tuberculosis and 61% were co-infected with hepatitis B and/or C. Two thirds (63%) had national medical insurance. More detailed data on socio-demographic and other background variables are presented in Table 5.

**Table 5.** Characteristics of the participants in QoL study, Tallinn and Ida-Virumaa<sup>1</sup>, Estonia 2005<sup>2</sup>

Characteristic	N	%
Socio-demographics		
Gender		
Male	240	53.2
Female	210	46.6
Age		
≥30 years	80	17.7
<30 years	371	82.3
Place of living		
Ida-Virumaa <sup>1</sup>	297	65.8
Tallinn	132	29.3
Other regions	22	4.9
Ethnicity		
Russian	383	84.9
Estonian	45	10.0
Other	20	4.4

Table continues

**Table 5.** Continued

Characteristic	N	%
Education		
≤9 years of formal education	180	39.9
>9 years of formal education	269	59.7
Occupation		
Unemployed	161	35.7
Employed and/or studying	284	63.0
Partnership		
Legally married	106	23.5
Other	336	74.5
HIV disease-related		
HIV transmission category (self-report) <sup>3</sup>		
Injecting drug use	269	59.7
Sexual transmission	163	36.1
Other <sup>4</sup>	15	3.3
Time of HIV diagnosis (self-report)		
<12 months	87	19.3
1 to 2 years	107	23.7
≥3 years	245	54.3
Stage of HIV-infection (data abstracted from medical records)		
No symptoms	268	59.4
Early HIV disease	163	36.1
AIDS	12	2.7
Last CD4 count (data abstracted from medical records)		
≥300 cells/mm <sup>3</sup>	240	53.2
<300 cells/mm <sup>3</sup>	102	22.6
Current ARV treatment (data abstracted from medical records)		
Yes	97	21.5
No	352	78.0
Co-infections		
Ever had tuberculosis (data abstracted from medical records)		
Yes	10	2.2
No	439	97.4
Ever had hepatitis B or C (data abstracted from medical records)		
Yes	268	59.4
No	182	40.4

<sup>1</sup> Includes data from Kohtla-Järve and Narva, cities in a county called Ida-Virumaa, located in North-Eastern Estonia

<sup>2</sup> Missing data not shown

<sup>3</sup> Participants reporting both “sexual transmission” and “injecting drug use” as possible HIV-transmission routes were categorized “under injecting drug use”

<sup>4</sup> Tattooing, piercing etc

## 6.2. Quality of life and factors influencing quality of life

The overall QoL 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 QoL and these included “physical safety and security” (2.82), “positive feelings” (2.81), and “financial resources” (2.45). Mean scores by region, gender, and route of infection are presented in Table 6. Mean scores by first language are presented in Table 9.

In a univariate analysis, the factors, which significantly increased the likelihood of good QoL in the facet, “overall QoL and general health perceptions”, included: female gender (48% vs. 37% in males,  $p=0.03$ ); age under 30 years (45% vs. 29%,  $p=0.009$ ); living in the capital city (57% vs. 36% in Ida-Virumaa,  $p=0.0001$ ); being employed and/or studying (52% vs. 38% in unemployed,  $p<0.0001$ ); being legally married (55% vs. 39% in people in other types of relationships,  $p=0.004$ ); being infected with HIV sexually, not through injecting drug use, based on self-report on the mode of HIV acquisition (53% vs. 38%,  $p=0.002$ ); being aware of their infection for less than 12 months (54% vs. 41%,  $p=0.02$ ); having no HIV-related symptoms, based on abstraction from clinical records (51% vs. 28%,  $p<0.0001$ ); and CD4 count above 300 cells/mm<sup>3</sup>, based on abstraction from clinical records (54% vs. 32%,  $p=0.0003$ ) (Table 7). In multivariate analysis (logistic regression model), after including gender, age, region, and variables significant in univariate analysis into the model variables such as being currently employed and/or studying (AOR 2.3, 95% CI 1.2–4.4), and the absence of HIV-related symptoms (AOR 2.3, 95% CI 1.2–4.3) were identified as independent predictors of good QoL (Table 7).

Similar univariate and multivariate analysis was performed separately for all six domains and 29 facets. The summary of the factors related to good QoL in domains and facets is presented in Table 8.

**Table 6.** Quality of life scores among HIV-infected persons (by region, gender, and self-reported route of infection) in QoL study, Tallinn and Ida-Virumaa, Estonia 2005

Domain/facet	Region		Gender		Route of infection	
	Tallinn	Ida-Virumaa	Male	Female	IDU	Sex
I Physical	14.36	12.71 <sup>3</sup>	12.92	13.70 <sup>1</sup>	12.81	14.12 <sup>3</sup>
Pain and discomfort	3.83	3.47 <sup>3</sup>	3.48	3.71 <sup>2</sup>	3.44	3.85 <sup>3</sup>
Energy and fatigue	3.46	3.02 <sup>3</sup>	3.10	3.25 <sup>1</sup>	3.08	3.33 <sup>3</sup>
Sleep and rest	3.61	3.19 <sup>3</sup>	3.16	3.52 <sup>3</sup>	3.15	3.66 <sup>3</sup>
Symptoms of PLHIV	3.49	3.02 <sup>3</sup>	3.16	3.22	3.11	3.32 <sup>1</sup>

Table continues

**Table 6.** Continued

Domain/facet	Region		Gender		Route of infection	
	Tallinn	Ida-Virumaa	Male	Female	IDU	Sex
II Psychological	14.38	13.36 <sup>3</sup>	13.55	13.91	13.55	14.03 <sup>1</sup>
Positive feelings	3.05	2.67 <sup>3</sup>	2.75	2.89	2.74	2.96 <sup>2</sup>
Thinking, learning, memory	3.50	3.36 <sup>1</sup>	3.34	3.49 <sup>1</sup>	3.33	3.53 <sup>2</sup>
Self-esteem	3.55	3.26 <sup>3</sup>	3.29	3.41	3.46	3.27 <sup>1</sup>
Bodily image	4.11	4.00	3.93	4.17 <sup>2</sup>	4.03	4.06
Negative feelings	3.66	3.38 <sup>2</sup>	3.54	3.40	3.49	3.52
III Level of Independence	15.69	13.81 <sup>3</sup>	13.97	14.99 <sup>2</sup>	14.2	15.04 <sup>1</sup>
Mobility	3.91	3.35 <sup>3</sup>	3.40	3.69 <sup>3</sup>	3.55	3.83 <sup>1</sup>
Activities of daily living	3.64	3.97 <sup>3</sup>	3.67	3.84 <sup>1</sup>	3.85	3.72
Dependence on medication or treatments	3.85	3.32 <sup>3</sup>	3.35	3.65 <sup>2</sup>	3.77	3.39 <sup>1</sup>
Work capacity	3.91	3.47 <sup>3</sup>	3.50	3.77 <sup>2</sup>	3.74	3.60
IV Social relationships	14.52	13.59 <sup>3</sup>	13.52	14.36 <sup>2</sup>	13.60	14.42 <sup>2</sup>
Personal relationships	3.78	3.48 <sup>3</sup>	3.49	3.70 <sup>2</sup>	3.73	3.50 <sup>2</sup>
Social support	3.29	2.96 <sup>3</sup>	2.96	3.20 <sup>2</sup>	2.94	3.27 <sup>3</sup>
Sexual activity	3.46	3.37	3.37	3.43	3.39	3.39
Social inclusion	4.02	3.70 <sup>3</sup>	3.69	3.95 <sup>1</sup>	3.73	3.94 <sup>1</sup>
V Environment	12.95	11.94 <sup>3</sup>	12.08	12.56 <sup>1</sup>	11.97	12.86 <sup>3</sup>
Physical safety and security	2.93	2.75 <sup>2</sup>	2.92	2.70 <sup>3</sup>	2.83	2.82
Home environment	3.39	3.28	3.24	3.40	3.46	3.26 <sup>1</sup>
Financial resources	2.81	2.26 <sup>3</sup>	2.33	2.58 <sup>2</sup>	2.25	2.76 <sup>3</sup>
Health and social care	3.23	2.90 <sup>3</sup>	2.91	3.12 <sup>2</sup>	2.93	3.13 <sup>2</sup>
New info and skills	3.44	3.24 <sup>1</sup>	3.24	3.44 <sup>2</sup>	3.49	3.25 <sup>2</sup>
Recreation	3.12	3.07	3.08	3.15	3.18	3.09
Physical environment	3.23	3.00 <sup>2</sup>	3.05	3.13	3.18	3.07
Transport	3.64	3.18 <sup>3</sup>	3.23	3.46 <sup>2</sup>	3.55	3.26 <sup>2</sup>
VI Spirituality/Religion/Personal beliefs	13.64	12.30 <sup>3</sup>	12.93	12.59	12.74	12.84
SRPB	3.23	2.97 <sup>2</sup>	3.01	3.12	3.19	2.99 <sup>1</sup>
Forgiveness and blame	3.39	3.11 <sup>2</sup>	3.22	3.19	3.14	3.28
Concerns about the future	3.27	2.98 <sup>2</sup>	3.22	2.93 <sup>2</sup>	3.19	2.94 <sup>1</sup>
Death and dying	3.72	3.24 <sup>3</sup>	3.47	3.34	3.39	3.41
VII Overall QoL	3.20	2.75 <sup>3</sup>	2.80	3.02 <sup>2</sup>	2.78	3.10 <sup>3</sup>

<sup>1</sup> <0.05  
<sup>2</sup> <0.01  
<sup>3</sup> <0.001

**Table 7.** Factors associated with good QoL in overall QoL facet among HIV-infected persons in QoL study, Estonia 2005

Characteristic	Good QoL (%)	OR	95% CI	p-value	AOR	95% CI	p-value
<b>Socio-demographics</b>							
<b>Gender</b>							
Male	37	1.0			1.0		
Female	48	1.5	1.0–2.2	0.03	0.6	0.3–1.1	0.1
<b>Age</b>							
≥30 years	29	1.0			1.0		
<30 years	45	2.0	1.2–3.4	0.009	1.6	0.7–3.3	0.2
<b>Place of living</b>							
Ida-Virumaa	36	1.0			1.0		
Tallinn	57	2.4	1.6–3.6	0.0001	1.1	0.6–1.9	0.8
<b>Ethnicity</b>							
Russian	42	1.0					
Estonian	56	1.7	0.9–3.3	0.1			
<b>Education</b>							
≤9 years	38	1.0					
>9 years	45	1.3	0.9–1.9	0.2			
<b>Occupation</b>							
Unemployed	38	1.0			1.0		
Employed and/or studying	52	3.1	2.0–4.8	<0.0001	2.3	1.2–4.4	0.01
<b>Partnership</b>							
Other	39	1.0			1.0		
Legally married	55	1.9	1.2–3.0	0.004	1.3	0.7–2.4	0.5
<b>HIV disease-related</b>							
<b>HIV transmission category (self-report)<sup>1</sup></b>							
Injecting drug use	38	1.0			1.0		
Sexual transmission	53	1.9	1.3–2.9	0.002	1.4	0.7–2.6	0.3
<b>Time of HIV diagnosis (self-report)</b>							
≥12 months ago	41	1.0			1.0		
<12 months ago	54	1.8	1.1–2.9	0.02	1.2	0.6–2.5	0.6
<b>Stage of HIV-infection (data abstracted from medical records)</b>							
Early HIV disease/AIDS	28	1.0			1.0		
No symptoms	51	2.7	1.8–4.0	<0.0001	2.3	1.2–4.3	0.008
<b>Last CD4 count (data abstracted from medical records)</b>							
<300 cells/mm <sup>3</sup>	32	1.0			1.0		
≥300 cells/mm <sup>3</sup>	54	2.5	1.5–4.1	0.0003	1.7	0.9–3.3	0.09
<b>Current ARV treatment (data abstracted from medical records)</b>							
No	40	1.0					
Yes	48	1.4	0.9–2.1	0.1			

**Table continues**

**Table 7.** Continued

Characteristic	Good QoL (%)	OR	95% CI	p-value	AOR	95% CI	P-value
Co-infections							
Ever had tuberculosis (data abstracted from medical records)							
Yes	40	1.0					
No	42	1.1	0.3–3.9	0.9			
Ever had hepatitis B and/or C (data abstracted from medical records)							
Yes	40	1.0					
No	46	1.7	0.9–1.9	0.2			

<sup>1</sup> Participants reporting both “sexual transmission” and “injecting drug use” as possible HIV-transmission routes were categorized “under injecting drug use”

**Table 8.** Factors associated with good QoL in facets and domains among HIV-infected persons in QoL study, Estonia 2005

Facet/domain	Significant independent variables, which increase the probability for good QoL
I Physical	HIV transmission category (sexual) <sup>2</sup> , last CD4 count ( $\geq 300$ cells/mm <sup>3</sup> ) <sup>3</sup>
Pain and discomfort	HIV transmission category (sexual) <sup>1</sup> , last CD4 count ( $\geq 300$ cells/mm <sup>3</sup> ) <sup>1</sup>
Energy and fatigue	Occupation (employed and/or studying) <sup>1</sup> , stage of HIV-infection (no symptoms) <sup>2</sup> , last CD4 count ( $\geq 300$ cells/mm <sup>3</sup> ) <sup>2</sup>
Sleep and rest	–
Symptoms of PLHIV	Place of living (Tallinn) <sup>1</sup> , last CD4 count ( $\geq 300$ cells/mm <sup>3</sup> ) <sup>1</sup>
II Psychological	–
Positive feelings	Occupation (employed and/or studying) <sup>1</sup> , stage of HIV-infection (no symptoms) <sup>1</sup>
Thinking, learning, memory	Partnership (legally married) <sup>1</sup>
Self-esteem	Occupation (employed and/or studying) <sup>2</sup> , stage of HIV-infection (no symptoms) <sup>2</sup>
Bodily image	–
Negative feelings	–
III Independence	Last CD4 count ( $\geq 300$ cells/mm <sup>3</sup> ) <sup>3</sup>
Mobility	Last CD4 count ( $\geq 300$ cells/mm <sup>3</sup> ) <sup>1</sup>
Activities of daily living	Stage of HIV-infection (no symptoms) <sup>1</sup> , last CD4 count ( $\geq 300$ cells/mm <sup>3</sup> ) <sup>2</sup>
Dependence on medication or treatments	Stage of HIV-infection (no symptoms) <sup>3</sup> , last CD4 count ( $\geq 300$ cells/mm <sup>3</sup> ) <sup>1</sup>
Work capacity	Place of living (Tallinn) <sup>1</sup> , occupation (employed and/or studying) <sup>1</sup> , stage of HIV-infection (no symptoms) <sup>1</sup> , last CD4 count ( $\geq 300$ cells/mm <sup>3</sup> ) <sup>2</sup>

**Table continues**

**Table 8.** Continued

Facet/domain	Significant independent variables, which increase the probability for good QoL
IV Social relationships	Partnership (legally married) <sup>1</sup>
Personal relationships	Last CD4 count ( $\geq 300$ cells/mm <sup>3</sup> ) <sup>1</sup>
Social support	HIV transmission category (sexual) <sup>1</sup>
Sexual activity	Partnership (legally married) <sup>3</sup> , last CD4 count ( $\geq 300$ cells/mm <sup>3</sup> ) <sup>1</sup>
Social inclusion	HIV transmission category (sexual)*, last CD4 count ( $\geq 300$ cells/mm <sup>3</sup> ) <sup>1</sup>
V Environment	Ethnicity (Estonian) <sup>1</sup> , occupation (employed and/or studying) <sup>1</sup> , time of HIV diagnosis (<12 months) <sup>2</sup>
Physical safety and security	Gender (male) <sup>2</sup> , nationality (Estonian) <sup>1</sup>
Home environment	Occupation (employed and/or studying) <sup>2</sup> , income ( $\geq 2000$ EEK) <sup>1</sup>
Financial resources	Occupation (employed and/or studying) <sup>2</sup> , income ( $\geq 2000$ EEK) <sup>2</sup>
Health and social care	Stage of HIV-infection (no symptoms) <sup>1</sup> , time of HIV diagnosis (<12 months) <sup>1</sup> , ethnicity (Estonian) <sup>2</sup>
New info and skills	Occupation (employed and/or studying) <sup>1</sup>
Recreation	Education ( $\geq 9$ years) <sup>2</sup>
Physical environment	Place of living (Tallinn) <sup>1</sup>
Transport	Occupation (employed and/or studying) <sup>1</sup>
VI Spirituality/Religion/Personal beliefs	–
SRPB	Ethnicity (Estonian) <sup>2</sup> , last CD4 count ( $\geq 300$ cells/mm <sup>3</sup> ) <sup>2</sup>
Forgiveness and blame	Place of living (Tallinn) <sup>1</sup>
Concerns about the future	Place of living (Tallinn) <sup>1</sup> , HIV transmission category (injecting drug use) <sup>1</sup>
Death and dying	Place of living (Tallinn) <sup>2</sup>
VII Overall QoL	Occupation (employed and/or studying) <sup>1</sup> , stage of HIV-infection (no symptoms) <sup>2</sup>

<sup>1</sup> p<0.05

<sup>2</sup> p<0.01

<sup>3</sup> p<0.001

## 7. Adoption of WHOQOL-HIV instrument

### 7.1. Feasibility and acceptability of the Estonian and Russian versions of the WHOQOL-HIV instrument

Items relating to each of the facets/dimensions were combined to produce means and standard deviations. When we checked the distribution of the data, we found that responses on all sub-scales were normally distributed and there was a full range of responses on each scale (from 1 to 5) (data not shown).

To assess the feasibility, we used study participation rate and percentage of missing responses. The overall study uptake was 89%. Proportion of missing responses in facets (at least one missing response to 4 questions in a facet) in Russian version ranged between 1.3–4.7% (the highest in the facets “concerns about the future” and “energy and fatigue”). The highest number of missing responses in domains was observed for the Environmental domain (12.5%) (data not shown). Proportion of missing responses in facets in Estonian version ranged between 0.0–8.9% (the highest in the facets “pain and discomfort” and “social support”). The highest number of missing responses in domains was observed for the Psychological domain (11.1%) (data not shown).

Floor effect for Russian version ranged between 0.0–8.8% (the highest for facets “dependence on medication or treatments” and “financial resources”) and ceiling effect between 0.0–15.7% (the highest for facets concerning “dependence on medication or treatments” and “death and dying”) (Table 9). Floor effect for Estonian version ranged between 0.0–9.3% (the highest for facets “death and dying” and “financial resources”) and ceiling effect between 0.0–31.1% (the highest for facets concerning “dependence on medication or treatments” and “work capacity”) (Table 9).

**Table 9.** Floor and ceiling effects of the Estonian and Russian versions of the WHOQOL-HIV instrument in QoL study, Estonia 2005

Dimension/Facet	Estonian version			Russian version		
	Mean ± SD	Floor (%)	Ceiling (%)	Mean ± SD	Floor (%)	Ceiling (%)
I Physical	14.5 ± 3.2	0.0	2.3	13.2 ± 3.1	0.3	0.3
Pain and discomfort	3.9 ± 0.8	0.0	8.9	3.6 ± 0.9	0.3	5.1
Energy and fatigue	3.4 ± 1.0	2.2	2.2	3.2 ± 0.9	1.1	1.4
Sleep and rest	3.7 ± 1.1	0.0	9.1	3.3 ± 1.1	3.2	6.2
Symptoms of PLHIV	3.5 ± 1.0	0.0	13.6	3.2 ± 0.9	1.1	3.0
II Psychological	14.0 ± 2.4	0.0	0.0	13.8 ± 2.3	0.0	0.0
Positive feelings	3.0 ± 0.8	0.0	0.0	2.8 ± 0.8	0.5	0.8
Thinking, learning, memory	3.4 ± 0.6	0.0	0.0	3.4 ± 0.6	0.0	1.3
Self-esteem	3.4 ± 0.7	0.0	2.3	3.4 ± 0.7	0.0	1.1

Table continues

**Table 9.** Continued

Dimension/Facet	Estonian version			Russian version		
	Mean ± SD	Floor (%)	Ceiling (%)	Mean ± SD	Floor (%)	Ceiling (%)
Bodily image	3.9 ± 0.9	0.0	4.7	4.1 ± 0.7	0.3	5.6
Negative feelings	3.6 ± 0.9	0.0	4.6	3.5 ± 0.8	0.3	1.3
III Independence	15.8 ± 3.0	0.0	2.4	14.4 ± 3.2	0.0	0.6
Mobility	3.9 ± 0.9	0.0	13.6	3.5 ± 0.9	0.5	3.5
Activities of daily living	4.1 ± 0.7	0.0	4.6	3.7 ± 0.8	0.3	3.2
Dependence on medication or treatments	3.7 ± 1.3	4.4	31.1	3.5 ± 1.2	3.5	15.7
Work capacity	3.9 ± 0.9	0.0	15.9	3.6 ± 1.0	2.1	10.1
IV Social relationships	14.6 ± 2.1	0.0	2.4	13.9 ± 2.6	0.0	0.0
Personal relationships	3.9 ± 0.6	0.0	2.3	3.6 ± 0.7	0.3	0.8
Social support	3.3 ± 0.9	0.0	2.4	3.1 ± 0.8	0.3	2.1
Sexual activity	3.5 ± 0.8	0.0	2.3	3.4 ± 1.0	1.1	4.0
Social inclusion	3.8 ± 0.7	0.0	6.7	3.8 ± 0.9	0.3	10.8
V Environment	13.3 ± 2.4	0.0	0.0	12.2 ± 2.0	0.0	0.0
Physical safety and security	3.1 ± 0.8	0.0	0.0	2.8 ± 0.6	0.3	0.0
Home environment	3.5 ± 1.0	2.3	6.8	3.3 ± 0.9	1.6	2.4
Financial resources	2.7 ± 1.1	9.3	2.3	2.4 ± 1.0	8.8	0.8
Health and social care	3.4 ± 0.6	0.0	0.0	3.0 ± 0.7	0.5	0.0
New info and skills	3.5 ± 0.8	0.0	2.3	3.3 ± 0.8	0.8	1.1
Recreation	3.3 ± 0.9	0.0	2.3	3.1 ± 0.7	0.3	0.3
Physical environment	3.5 ± 0.7	0.0	2.3	3.0 ± 0.7	0.8	0.0
Transport	3.6 ± 1.0	0.0	4.6	3.3 ± 0.9	0.8	1.6
VI Spirituality/Religion/ Personal beliefs	13.1 ± 3.0	0.0	0.0	12.8 ± 3.0	0.0	0.0
SRPB	3.5 ± 0.8	0.0	7.0	3.0 ± 0.8	1.4	1.4
Forgiveness and blame	3.2 ± 0.9	2.3	0.0	3.2 ± 0.9	0.5	4.1
Concerns about the future	3.0 ± 1.1	4.6	4.6	3.1 ± 1.0	2.5	3.6
Death and dying	3.4 ± 1.2	6.7	15.6	3.4 ± 1.2	3.2	15.6
VII Overall QoL	3.1 ± 0.9	0.0	2.3	2.9 ± 0.8	1.9	0.5

## **7.2. Reliability and validity of Estonian and Russian versions of WHOQOL-HIV instrument**

### **7.2.1. Internal consistency**

We expected that each dimension/facet would produce Cronbach alpha values of 0.7 or above, indicating internal reliability. For the Russian version, Cronbach alpha ranged between 0.88–0.93 for the six domains and was above 0.70 in 23 of the 29 facets and for the overall QoL facet. It ranged between 0.48 and 0.64 in the remaining 5 facets. For the Estonian version, Cronbach alpha ranged between 0.81–0.93 for the six domains and was above 0.70 in 24 of the 29 facets and for the overall QoL facet. It ranged between 0.58 and 0.68 in the remaining 6 facets (Table 10).

To further test for reliability, we tried to find out whether all four questions in every facet correlated significantly with each other and with the mean score of the facet and whether all facets in the domain correlated with each other and with the mean score of the domain. We expected the Pearson correlation coefficient to be higher than 0.30, indicating positive correlation. Results are provided in a matrix format showing the minimum and the maximum values of Pearson correlation coefficient (Table 10). In Russian version, inter-item and item-total correlations were satisfactory in 16 of the 29 facets and for the overall QoL score. Inter-item and item-total correlations within domains were satisfactory in three domains out of six (lower than 0.30 in Social Relationships, Environment, and Spirituality). In Estonian version, inter-item and item-total correlations were satisfactory in 19 of the 29 facets and for the overall QoL score. Inter-item and item-total correlations within domains were satisfactory in four domains out of six (lower than 0.30 in Social Relationships and Environment).

In addition, correlations between domains were calculated. In Russian version, each domain was significantly related with the other (Pearson correlation coefficient 0.45–0.81,  $p < 0.0001$ ). The lowest correlation was observed between Environmental and Spiritual and the highest between Physical and Independence domains (data not shown). In Estonian version, each domain was significantly related with the other (Pearson correlation coefficient 0.51–0.84,  $p < 0.0001$ ). Once again, the lowest correlation was observed between Environmental and Spiritual and the highest between Physical and Independence domains (data not shown).

**Table 10.** Internal consistency (reliability) of the Estonian and Russian versions of the WHOQOL-HIV instrument in QoL study, Estonia 2005<sup>1</sup>

Domain/Facet	Number of items	Cronbach $\alpha$		Correlation index (min-max)	
		EST	RUS	EST	RUS
I Physical	4	0.93	0.92	0.48–0.89	0.50–0.85
Pain and discomfort	4	0.79	0.83	0.35–0.85	0.47–0.85
Energy and fatigue	4	0.89	0.85	0.58–0.91	0.48–0.85
Sleep and rest	4	0.95	0.92	0.68–0.97	0.65–0.92
Symptoms of PLHIV	4	0.81	0.75	0.23–0.89	0.24–0.81
II Psychological	5	0.90	0.92	0.38–0.87	0.33–0.84
Positive feelings	4	0.80	0.81	0.34–0.88	0.39–0.87
Thinking, learning, memory	4	0.60	0.72	0.07–0.84	0.31–0.77
Self-esteem	4	0.78	0.77	0.25–0.86	0.30–0.85
Bodily image	4	0.83	0.77	0.35–0.87	0.31–0.81
Negative feelings	4	0.83	0.77	0.44–0.88	0.28–0.89
III Independence	4	0.94	0.93	0.48–0.84	0.45–0.85
Mobility	4	0.90	0.83	0.59–0.91	0.46–0.84
Activities of daily living	4	0.81	0.79	0.39–0.84	0.36–0.83
Dependence on medication or treatments	4	0.92	0.92	0.64–0.91	0.62–0.92
Work capacity	4	0.93	0.92	0.69–0.92	0.67–0.95
IV Social relationships	4	0.81	0.86	0.14–0.80	0.24–0.83
Personal relationships	4	0.65	0.62	0.13–0.79	0.15–0.75
Social support	4	0.68	0.64	0.15–0.84	0.12–0.80
Sexual activity	4	0.82	0.86	0.17–0.91	0.40–0.90
Social inclusion	4	0.58	0.75	0.09–0.81	0.31–0.86
V Environment	8	0.93	0.90	0.20–0.83	0.15–0.72
Physical safety and security	4	0.70	0.48	0.15–0.81	0.05–0.73
Home environment	4	0.93	0.87	0.71–0.93	0.57–0.88
Financial resources	4	0.88	0.88	0.49–0.93	0.52–0.89
Health and social care	4	0.75	0.76	0.15–0.86	0.27–0.82
New info and skills	4	0.80	0.75	0.42–0.84	0.24–0.82
Recreation	4	0.79	0.58	0.33–0.83	0.01–0.79
Physical environment	4	0.68	0.53	0.16–0.79	0.09–0.71
Transport	4	0.89	0.80	0.62–0.89	0.35–0.82
VI Spirituality/Religion/Personal beliefs	4	0.88	0.88	0.11–0.87	0.11–0.88
SRPB	4	0.89	0.81	0.51–0.93	0.43–0.84
Forgiveness and blame	4	0.60	0.73	0.08–0.81	0.21–0.81
Concerns about the future	4	0.73	0.80	0.29–0.79	0.44–0.81
Death and dying	4	0.91	0.91	0.65–0.94	0.63–0.91
VII Overall QoL	4	0.83	0.84	0.36–0.88	0.46–0.87

<sup>1</sup> Correlation of each question in the facet with the other questions in the facet (inter-item) and the mean score of the facet (item-total); correlation of each facet with the other facets in the domain (inter-item) and with the domain itself (item-total)

### 7.2.2. Criterion-related validity

To assess criterion-related validity, we calculated correlations between domains/facets and overall QoL facet (assuming the last as golden standard). We expected the Pearson correlation coefficient to be higher than 0.30. In Russian version, each domain was significantly related with overall QoL (0.48–0.82,  $p < 0.0001$ ). Each facet was significantly related with overall QoL (0.32–0.71,  $p < 0.0001$ ), too, with the exception of “forgiveness and blame” (0.25) (Table 11). In Estonian version, each domain was significantly related with overall QoL (0.61–0.83,  $p < 0.0001$ ). Each facet was significantly related with overall QoL (0.41–0.79,  $p < 0.0001$ ) with the exception of “health and social care” (0.20) (Table 11).

**Table 11.** Criterion-related validity of Estonian and Russian versions of the WHOQOL-HIV instrument in QoL study, Estonia 2005

Domain/Facet	Correlation with overall QoL facet	
	EST	RUS
I Physical	0.79	0.66
Pain and discomfort	0.66	0.47
Energy and fatigue	0.78	0.61
Sleep and rest	0.61	0.58
Symptoms of PLHIV	0.61	0.48
II Psychological	0.83	0.76
Positive feelings	0.73	0.71
Thinking, learning, memory	0.79	0.54
Self-esteem	0.69	0.63
Bodily image	0.54	0.48
Negative feelings	0.64	0.48
III Independence	0.73	0.67
Mobility	0.65	0.58
Activities of daily living	0.67	0.63
Dependence on medication or treatments	0.68	0.43
Work capacity	0.57	0.58
IV Social relationships	0.69	0.69
Personal relationships	0.57	0.64
Social support	0.41	0.54
Sexual activity	0.45	0.39
Social inclusion	0.59	0.55
V Environment	0.75	0.71
Physical safety and security	0.62	0.43
Home environment	0.56	0.52
Financial resources	0.60	0.55
Health and social care	0.20	0.43
New info and skills	0.55	0.52
Recreation	0.48	0.46

Table continues

**Table 11.** Continued

Domain/Facet	Correlation with overall QoL facet	
	EST	RUS
Physical environment	0.63	0.34
Transport	0.56	0.44
VI Spirituality/Religion/Personal beliefs	0.61	0.50
SRPB	0.69	0.54
Forgiveness and blame	0.43	0.25
Concerns about the future	0.41	0.32
Death and dying	0.42	0.38

### 7.2.3. Concurrent validity

To assess concurrent validity, we tested whether the instrument was sensitive to differences between people with different health status (asymptomatic versus symptomatic and AIDS). Because of low numbers of participants with AIDS (n=10), they were subsumed with symptomatic respondents. The mean scores were adjusted for age and gender. In Russian version, asymptomatic people did report significantly better QoL in physical, psychological, and independence domains and related facets compared to those with symptoms or AIDS giving proof to concurrent validity. Asymptomatic people also reported significantly better overall QoL facet (Table 12). In Estonian version, no differences in mean scores were observed between people with different health status (Table 13).

**Table 12.** Concurrent validity for Russian version of WHOQOL-HIV instrument (mean scores of facets/domains adjusted for gender and age) in QoL study, Estonia 2005

Domain/Facet	Asymp (N=225) (mean, 95% CI)	Symp (N=151) (mean, 95% CI)
I Physical	13.8 (13.3–14.2)	12.3 (11.8–12.9) <sup>1</sup>
Pain and discomfort	3.8 (3.6–3.9)	3.3 (3.2–3.5) <sup>1</sup>
Energy and fatigue	3.3 (3.2–3.5)	2.9 (2.8–3.1) <sup>1</sup>
Sleep and rest	3.5 (3.4–3.6)	3.0 (2.8–3.2) <sup>1</sup>
Symptoms of PLHIV	3.3 (3.1–3.4)	3.0 (2.9–3.2)
II Psychological	14.1 (13.8–14.4)	13.3 (12.9–13.6) <sup>1</sup>
Positive feelings	2.9 (2.8–3.0)	2.6 (2.5–2.7) <sup>1</sup>
Thinking, learning, memory	3.5 (3.4–3.6)	3.4 (3.3–3.5)
Self-esteem	3.5 (3.4–3.6)	3.2 (3.1–3.3) <sup>1</sup>
Bodily image	4.1 (4.0–4.2)	4.0 (3.9–4.1)
Negative feelings	3.6 (3.5–3.7)	3.3 (3.2–3.5)
III Independence	15.2 (14.8–15.6)	13.2 (12.7–13.8) <sup>1</sup>
Mobility	3.7 (3.6–3.8)	3.3 (3.2–3.4) <sup>1</sup>
Activities of daily living	3.9 (3.8–4.0)	3.5 (3.4–3.7) <sup>1</sup>
Dependence on medication or treatments	3.8 (3.6–3.9)	3.1 (2.9–3.2) <sup>1</sup>
Work capacity	3.8 (3.7–4.0)	3.3 (3.2–3.5) <sup>1</sup>

**Table continues**

**Table 12.** Continued

Domain/Facet	Asymp (N=225) (mean, 95% CI)	Symp (N=151) (mean, 95% CI)
IV Social relationships	14.1 (13.8–14.5)	13.4 (13.0–13.8)
Personal relationships	3.6 (3.5–3.7)	3.5 (3.4–3.6)
Social support	3.0 (2.9–3.2)	3.0 (2.9–3.1)
Sexual activity	3.5 (3.3–3.6)	3.2 (3.0–3.3)
Social inclusion	3.9 (3.8–4.0)	3.7 (3.6–3.9)
V Environment	12.4 (12.1–12.7)	11.9 (11.6–12.3)
Physical safety and security	2.8 (2.8–2.9)	2.7 (2.6–2.8)
Home environment	3.3 (3.2–3.4)	3.2 (3.1–3.4)
Financial resources	2.5 (2.4–2.6)	2.3 (2.1–2.4)
Health and social care	3.0 (2.9–3.1)	2.9 (2.8–3.0)
New info and skills	3.4 (3.3–3.5)	3.2 (3.1–3.4)
Recreation	3.1 (3.0–3.2)	3.1 (3.0–3.2)
Physical environment	3.1 (3.0–3.2)	3.0 (2.9–3.1)
Transport	3.4 (3.3–3.5)	3.2 (3.1–3.4)
VI Spirituality/Religion/Personal beliefs	12.8 (12.4–13.3)	12.7 (12.2–13.2)
SRPB	3.1 (3.0–3.2)	3.0 (2.8–3.1)
Forgiveness and blame	3.2 (3.1–3.3)	3.3 (3.1–3.4)
Concerns about the future	3.1 (3.0–3.3)	3.0 (2.9–3.2)
Death and dying	3.5 (3.3–3.6)	3.4 (3.2–3.5)
VII Overall QoL	3.0 (2.9–3.1)	2.7 (2.5–2.8) <sup>1</sup>

<sup>1</sup> statistically significant difference

**Table 13.** Concurrent validity for Estonian version of WHOQOL-HIV instrument (mean scores of facets/domains adjusted for gender and age) in QoL study, Estonia 2005

Domain/Facet	Asymp (N=35) (mean, 95% CI)	Symp (N=9) (mean, 95% CI)
I Physical	14.9 (13.8–16.1)	13.1 (10.7–15.5)
Pain and discomfort	4.1 (3.8–4.3)	3.5 (3.0–4.1)
Energy and fatigue	3.6 (3.3–3.9)	2.8 (2.1–3.5)
Sleep and rest	3.7 (3.3–4.1)	3.8 (3.0–4.5)
Symptoms of PLHIV	3.6 (3.3–4.0)	3.0 (2.3–3.7)
II Psychological	14.3 (13.4–15.1)	12.6 (10.4–14.7)
Positive feelings	3.2 (2.9–3.4)	2.6 (2.0–3.1)
Thinking, learning, memory	3.5 (3.3–3.7)	3.2 (2.7–3.6)
Self-esteem	3.5 (3.2–3.7)	3.3 (2.8–3.8)
Bodily image	4.0 (3.8–4.3)	2.9 (2.3–3.6) <sup>1</sup>
Negative feelings	3.7 (3.4–4.0)	2.9 (2.3–3.5)
III Independence	16.0 (14.9–17.1)	15.4 (12.9–18.0)
Mobility	4.0 (3.7–4.3)	3.7 (3.1–4.4)
Activities of daily living	4.2 (4.0–4.4)	3.8 (3.3–4.3)
Dependence on medication or treatments	3.8 (3.4–4.3)	3.2 (2.2–4.1)
Work capacity	4.0 (3.7–4.4)	3.4 (2.7–4.2)

**Table continues**

**Table 13.** Continued

Domain/Facet	Asymp (N=35) (mean, 95% CI)	Symp (N=9) (mean, 95% CI)
IV Social relationships	14.7 (13.9–15.5)	13.9 (12.0–15.7)
Personal relationships	3.9 (3.7–4.1)	3.7 (3.2–4.2)
Social support	3.4 (3.1–3.7)	2.9 (2.1–3.6)
Sexual activity	3.5 (3.2–3.8)	3.6 (3.0–4.3)
Social inclusion	3.9 (3.7–4.2)	3.5 (3.0–4.1)
V Environment	13.5 (12.6–14.4)	12.9 (11.0–14.8)
Physical safety and security	3.1 (2.8–3.4)	2.8 (2.2–3.4)
Home environment	3.6 (3.3–4.0)	3.0 (2.2–3.7)
Financial resources	2.8 (2.4–3.2)	2.7 (1.9–3.6)
Health and social care	3.5 (3.3–3.7)	3.3 (2.8–3.7)
New info and skills	3.5 (3.2–3.8)	3.4 (2.8–4.0)
Recreation	3.2 (2.9–3.5)	3.5 (2.8–4.2)
Physical environment	3.6 (3.3–3.8)	3.5 (2.9–4.1)
Transport	3.7 (3.3–4.0)	3.4 (2.7–4.1)
VI Spirituality/Religion/Personal beliefs	13.4 (12.3–14.5)	11.8 (9.4–14.3)
SRPB	3.7 (3.4–3.9)	3.1 (2.6–3.7)
Forgiveness and blame	3.3 (2.9–3.6)	3.2 (2.5–3.8)
Concerns about the future	3.0 (2.6–3.4)	2.6 (1.7–3.4)
Death and dying	3.5 (3.0–3.9)	2.9 (2.0–3.8)
VII Overall QoL	3.3 (3.0–3.6)	2.5 (1.9–3.2)

<sup>1</sup> statistically significant difference

#### 7.2.4. Construct validity

To assess convergent and divergent validity (construct validity) for both language versions, we correlated facets in different domains. The correlation coefficients of facets in Physical and Independence domains ranged from 0.43–0.76 (the highest for “energy” and “activities of daily living” – 0.76) and between facets in Physical and Psychological domains from 0.30–0.72 (the highest for “thinking, learning, memory” and “energy and fatigue” – 0.72), showing evidence of convergent validity. The correlation coefficients between facets in Psychological and Independence domains were somewhat lower, ranging from 0.29 to 0.61, with the strongest correlation between “activities of daily living” and “negative feelings” (0.61) (data not shown).

Examples of evidence of divergent validity can be seen in low correlations (Pearson coefficient <0.30) between “sexual activity” and the following facets: “financial resources” (0.16), “health and social care” (0.12), “new info and skills” (0.20), „physical environment“ (0.18), „transportation“ (0.20); between “transportation” and “death and dying” (0.23), “forgiveness” (0.17) and “environment” (0.25) (data not shown).

## DISCUSSION

### 8. HIV-prevalence and related risk-behaviours among injecting drug users

In Estonia, the epidemic of injection drug use clearly preceded the expansion of HIV and it is still a major contributor to HIV spreading (Uusküla *et al.*, 2002; Rüütel *et al.*, 2006). The IDU study (conducted in 2005) documented extremely high prevalence of HIV among IDUs in Tallinn and Kohtla-Järve with significant difference in the prevalence of anti-HIV antibodies between the study sites: 54% in Tallinn and 90% in Kohtla-Järve. It is not since the explosive outbreaks of HIV among IDUs in South-East Asia in the mid-1980s that such high city estimates of HIV prevalence among IDUs have been reported (Rhodes *et al.*, 1999; Rhodes *et al.*, 2002). There is clearly a need to scale up HIV prevention programs targeting IDUs and their sexual partners (including syringe exchange and substitution treatment) in Estonia. The primary prevention approach (abstinence) might not be realistic for many persons. One of the best-documented reverse courses for a large HIV epidemic among IDUs was closely associated with legalization, funding, and expansion of a community-based syringe exchange (Des Jarlais *et al.*, 2000).

The association between duration of injecting drug use with HIV prevalence was significant in univariate analysis but did not reach significance levels in multivariate analysis ( $p=0.4$ ). It is important to note that the proportion of new injectors was relatively small (11% of the sample commenced injecting during the past 2 years). It gives some evidence to the undocumented speculations that the injecting drug use epidemic is stabilizing in Estonia.

Two risk factors for HIV infection, which appeared in multivariate analysis were injecting China White and sharing needles and/or syringes with sexual partners in the last 12 months. Illicit fentanyl produced in illegal clandestine laboratories, known by the street name of *China White*, and 3-methylfentanyl, known as a *White Persian*, were introduced to the drug market in Estonia in 2002 following a heroin shortage in 2001 (Talu *et al.*, 2003). In our study, those injecting phentanyl had 3.3 times the odds of being HIV positive (95% CI 1.7–6.4). The type of drug primarily injected can influence the frequency and intensity of injection and therefore the risk of HIV transmission (Talu *et al.*, 2009). Home-made opiates (Mak) use was almost exclusively reported by IDUs from Kohtla-Järve.

Previous findings also suggest that IDUs are more likely to share used injecting equipment with a sex partner and this may go unreported as syringe sharing but be rationalized as ‘safer’ than sharing with less intimate others (Barnard 1993; Rhodes *et al.*, 2004; Loxely *et al.*, 1995; Smyth *et al.*, 2005). HIV transmission/acquisition risk among IDUs is not limited to parenteral transmission. Transmission of HIV from IDUs to their non-injecting regular sex partners are believed to be critical aspects of the transition from injecting drug use HIV transmission to broader heterosexual transmission

(Lowndes *et al.*, 2003). Over half the sample in IDU study reported two or more sex partners in the previous year, which is an important finding for HIV prevention.

### **Limitations**

Our study has some limitations. The cross-sectional study design does not allow us to establish a causal relationship or a direction of causality. The sample size in Kohtla-Järve (n=100) was considered large enough to be a comparison group for Tallinn sample. On the other hand, we started RDS recruitment in both study sites with IDUs who were attending harm reduction programs and this together with a relatively small sample size may introduce bias. We may have included participants from a more or less the same network with its specific characteristics that need not necessarily pertain to other IDU networks in the Kohtla-Järve region. In the future, a comparable sample size from both cities should be recruited.

The selection of the original seeds, the size of personal network (number of IDUs a respondent personally knows), and levels of homophily (the extent to which recruiters are likely to recruit individuals similar to them) could cause bias in the RDS sample (Heckathorn 1997; Heckathorn *et al.*, 2002). However, RDSAT analysis suggests that there is only minimal bias in our sample.

Other potential sources of bias associated with the sensitive and illegal behaviors such as IDU and sexual behaviors are socially desirable responses and recall bias. Evidence suggests that behavioral self-reports of IDUs on drug use and HIV risk behaviors are reliable and valid (Darke 1998; Des Jarlais *et al.*, 1994).

## **9. QoL of people living with HIV**

This is the first study on QoL of PLHIV carried out in Estonia. The mean overall QoL score for the whole sample ( $2.90 \pm 0.84$ ) was slightly lower than that reported from similar studies from other regions. O'Connell and colleagues have described a mean overall QoL score (measured by WHOQOL-HIV instrument) of  $3.2 \pm 0.88$  for a sample of 590 HIV-infected persons from six culturally diverse sites from Australia, Brazil, India (two sites), Thailand, and Zimbabwe (WHOQOL-HIV Group 2003). Our results reveal major disparities in self-reported QoL. The poorest QoL among the whole sample was found in the dimensions of environment (especially economical situation) and spirituality – “concerns about the future” and “personal beliefs”.

Analysis for gender showed that women reported significantly better mean QoL scores for most facets and domains compared to their male counterparts. In multiple logistic analysis, “physical safety and security” was the only facet where gender was an independent contributor with men reporting higher scores. Starace and colleagues described comparable overall QoL scores (measured with Italian version of WHOQOL-HIV instrument) among men and women in a

sample of patients attending the largest infectious diseases hospital in southern Italy. The only exception was found in the physical appearance facet (body image and appearance) where average scores among women were significantly worse than those reported by men (Starace *et al.*, 2002). In a study conducted in South India, of the 29 facets of QoL (WHOQOL-HIV instrument), men reported significantly higher QoL in the following facets: positive feeling, sexual activity, financial resources, and transport, while women reported significantly higher QoL on the facets concerning forgiveness and blame. Of the six domains of QoL, men reported better quality of life in the environmental domain, while women had higher scores on the SRPB domain (Chandra *et al.*, 2009).

Close to two thirds of our study participants (60%) self identified IDU as a possible route of infection. In our sample, people infected through IDU reported significantly lower mean scores in most facets and domains, including overall QoL, compared to those infected sexually. In multiple regression analysis, IDU emerged as an independent factor of lower QoL in the facets “pain and discomfort“, „social support“, „social inclusion“ and in the Physical domain. Several authors report better physical health related QoL among former IDUs compared to current IDUs or among general population compared to IDUs (Costenbader *et al.*, 2007; Preau *et al.*, 2007). IDUs often struggle with multiple health risks due to social, economic, and psychological factors. Getting HIV care may not be their top concern since they face other more pressing daily challenges such as addiction, poverty, incarceration, homelessness, depression, mental illness, and past trauma (Galea *et al.*, 2002). In our study, the proportion of people on HAART was lower among those infected through IDU compared to those infected sexually (17% vs 28%,  $p=0.008$ ). Given this and the highly stigmatised nature of the illegal drug use, injecting drug users (both former and current) are less likely to receive HIV-related medical care, which is also the case in Estonia, and hence they may be under-represented in the clinical samples of PLHIV (WHO 2008).

An intriguing finding was the significantly better QoL of PLHIV living in the capital city of Tallinn compared to that of the participants from Ida-Virumaa (North-Eastern Estonia). Region also emerged as one of the independent contributors to better work capacity, physical environment, and several facets of the SRPB domain in Tallinn. In our study, PLHIV with higher income had better QoL measurements. In 2005, at-risk-of-poverty rate was lower in capital city than in North-Eastern Estonia (12.5% vs. 29.8%). In 2005, disposable income per household member in a month was EUR 262 in Tallinn and EUR 170 in North-Eastern Estonia (Statistics Estonia). Unemployment rate among study participants was 18.7% in Tallinn and 46.5% in North-Eastern Estonia. This was somewhat higher than the overall unemployment rate in these regions in 2005 (respectively 8.2% and 16.2%) (Statistics Estonia). The reasons for such significant differences in socio-economic situation of people in different regions of the country go back to the 1990ies when Estonia regained its political autonomy. In that period, 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.

Satisfaction with health and social care services was also higher among participants in the capital city of Tallinn. The proportion of participants on HAART was somewhat lower in Ida-Virumaa compared to Tallinn (20% vs. 27%,  $p=0.08$ ). The biggest infectious diseases clinic with most long-term experiences in the field of HIV is located in Tallinn where provision of HAART started as early as in the mid 1990ies. In North-Eastern Estonia, health care services for HIV-positive people were made available on a larger scale at the beginning of 2000 (National Institute for Health Development).

As can be expected, people with better health status and biological markers reported better QoL. Asymptomatic patients reported better QoL than those with symptoms or AIDS diagnosis. This factor is amenable for clinical interventions and QoL can be altered by both the immediate effects and the longer-term consequences of antiretroviral treatment (Cohen *et al.*, 1998; Nieuwkerk *et al.*, 2001). In univariate analysis, people with CD4 count more than 300 cells per  $\text{mm}^3$  had higher odds for good overall QoL, which is in accordance with previous research (Call *et al.*, 2000; Campsmith *et al.*, 2003; Chandra *et al.*, 2006; Jia *et al.*, 2007; Kemmler *et al.*, 2003; Kohli *et al.*, 2005; McDonnell *et al.*, 2000; Murri *et al.*, 2003; Nicholas *et al.*, 2005; Shor-Posner *et al.*, 2000; Vidrine *et al.*, 2003).

In our study, the independent and most influential contributors to the overall QoL and several facets and domains were person's employment status and clinician recorded HIV-disease stage. The employed participants, including those who were studying, were more likely to have good overall QoL than their not working counterparts. Our findings are consistent with previous research where employment (and higher income) has been demonstrated to be associated with a better QoL among PLHIV (Blalock *et al.*, 2002; Worthington *et al.*, 2005). Besides financial benefits, employment also provides a source for structure, social support, role identity, and meaning. In addition, stable income and employment have been associated with adherence to HAART (Blalock *et al.*, 2002). Employment may also provide resources, which buffer the effects of the stress of HIV infection and thus serve to maintain a sense of quality of life (Sowell *et al.*, 1997). Therefore, return-to-work programs and other interventions developed to enhance the economic and employment opportunities are important for PLHIV in Eastern Europe and Russian Federation where young injecting drug users are the main HIV risk group and unemployment rate among them is high.

Other disease-related factors and co-infection with hepatitis B or C were not associated with better overall QoL in our sample. Nevertheless, given the extremely high (>90%) HCV infection rates among IDUs in the region and the high proportion of IDUs among PLWH (Tefanova *et al.*, 2005; Uusküla *et al.*, 2007), HCV/HBV co-infections warrant attention. Several previous studies have suggested that HCV infection significantly reduces health-related QoL (Foster *et al.*, 1998; Bonkovsky *et al.*, 1999) and this effect can be reversed with antiviral treatment (Bonkovsky *et al.*, 2007). Chronic HBV infection also has

negative impacts on QoL (Herdman *et al.*, 2006). Complications related to HIV/HCV co-infection are becoming an increasingly important medical issue, as the improvements in HIV treatment have resulted in liver disease to become a major cause of hospitalisation and death in PLHIV. A proper prevention, screening, and management of co-infections are of great concern given the high rates of HCV and HBV infections in Estonia.

Our findings also have some implications for intervention strategies targeting PLHIV. 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.

### **Limitations**

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. We did not inquire about the duration of IDU nor about the types of drugs injected. Neither did we inquire about smoking or alcohol use. We did not collect data on any other co-morbidities besides tuberculosis and hepatitis. CD4 counts were available only for 76% of the participants.

Our study most likely overestimated the QoL of PLHIV in Estonia. 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 therefore 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.

## **10. Performance of Estonian and Russian versions of WHOQOL-HIV instrument**

Ethnicity and race-related variations have been described in the different aspects of the QoL of PLHIV as well as in risk factors related to HIV and other communicable and non-communicable diseases (Campsmith *et al.*, 2003; Lenderking *et al.*, 1997; Rao *et al.*, 2003; Vidrine *et al.*, 2003). One can argue whether these differences are accurate or a result of study/instrument artefact. In order for the cross-cultural comparison of results to be valid, it is necessary to be able to show equivalence between translated versions of the same questionnaire (Herdman *et al.*, 1997). To our knowledge, this is the first study reporting psychometric properties and validity of Russian and Estonian versions of WHOQOL-HIV instrument. We found that the instruments were internally reliable and valid when tested on a sample of HIV-infected patients in care.

The study procedure and instrument implemented was acceptable for PLHIV in care as witnessed by the 89% participation rate. Even though the questionnaire required up to 60 minutes to answer all the questions, the uptake of the study was good and the proportion of participants who had to be excluded from the analysis because of at least one missing response in a facet was very low (less than 5%). No considerable ceiling and floor effects were detected. Ceiling and floor effects deriving from the nature of the measuring instrument compromise variability of the characteristic of interest. These effects would make it difficult to distinguish between groups or to detect changes over time.

Analysis also revealed that each of the dimensions/facets was internally reliable – that is, the items asked related questions — and that scores on each dimension/facet were related to overall QoL facet, which suggests that they were all asking questions that had impact on patients' general QoL. The Cronbach alpha for the overall QoL score was 0.84 for Russian version and 0.83 for Estonian version, which are similar to the one reported by WHOQOL-HIV Group (0.86) and indicate high internal consistency reliability (WHOQOL HIV Group 2003).

Lower inter-item correlations as well as lower Cronbach alphas were observed in the facets concerning “personal relationships”, “social support”, “physical safety and security”, „recreation”, and „physical environment”. This is in accordance with the results of WHOQOL-HIV Group who also reported lower Cronbach alphas for “physical safety and security”, and “physical environment” (WHOQOL HIV Group 2003). These concepts (aspects of life) may be perceived differently in different cultures and direct translation of words and phrases in the questions may change the meaning (the core of the concept). Research is needed to help achieve linguistic equivalence of survey questions in cross-cultural research.

With regard to validity, the scale performed as predicted. Mean scores of domains and facets were in the expected direction (worse in symptomatic persons and AIDS patients versus asymptomatic patients) and the instrument was sensitive to differences in health status.

The correlations between domains and domains/facets and overall QoL score were good. Spiritual domain had the lowest inter-domain correlations and it also correlated the least with the overall QoL score. This indicates that the face and content validity of the questions in these facets should be controlled. WHO SRPB Group findings show that spirituality, religion, and personal beliefs (SRPB) appear to be related to other domains of QoL, in particular to psychological and social qualities. Yet, while all of the domains contribute to the general QoL domain, spiritual, religious, and personal beliefs may make a smaller contribution than the environmental, psychological or social domains (WHOQOL SRPB Group 2006).

In Russian version, the facet, which had the highest correlation with overall QoL score was “positive feelings” (0.71) and the domain with the highest correlation with overall QoL score was Psychological (0.76). In Estonian version, also Environmental and Independence domains had high correlations

with overall QoL score. This indicates that psychological and emotional aspects of life may contribute the most to the perceptions of QoL. HIV infection is a stressful life event. It is widely accepted that individuals with HIV infection are highly vulnerable to stress and that depression is common among them (Williams *et al.*, 2005). Depression and QoL in PLWH are definitely associated – people with depression report lower QoL (Jia *et al.*, 2004; Mrus *et al.*, 2006; Tate *et al.*, 2003). In our study, we did not collect data on mental health and therefore we could not test these associations. People with lower spirits and depression reporting lower scores uniformly in all facets and domains could be one explanation why we failed to provide solid proof for divergent validity. People who scored less in one domain also generally scored less in all others.

### **Limitations**

Due to the cross-sectional design of the study we were not able to assess the responsiveness (ability to detect changes over time) or the test-retest reliability (another indicator of the reliability) of the instrument. Despite potential non-response bias, learning/practice and maturation effects test-retest designs are still widely used and published. Responsiveness is regarded as additional evidence of an instrument's longitudinal validity (Hays *et al.*, 1992) and therefore further longitudinal studies would be important next steps to determine the instrument's sensitivity to change. The sample size for the testing of Estonian version was rather small (n=45), which may account to the somewhat lower internal consistency (reliability) and concurrent validity of this instrument compared to the Russian version of the questionnaire. Nevertheless, collectively, our results provide support for the validity and reliability of the Russian and Estonian versions of the WHOQOL-HIV instrument.

## GENERAL DISCUSSION

Estonia experienced a massive outbreak of HIV infection in late 2000 (Health Protection Inspectorate). Despite a decline in the incidence of HIV since 2002, Estonia still has the highest HIV incidence and prevalence rates in the European Region (Hamers *et al.*, 2006). HIV outbreaks were first detected among injecting drug users in North and North-Eastern Estonia and are still concentrated among this population group (Rüütel *et al.*, 2005).

In our study we aimed to evaluate the prevalence of HIV and related risk behaviours among the population group most affected by HIV – injecting drug users – and describe the quality of life and factors associated with the QoL of people living with HIV in Estonia.

Previous research has shown that HIV can spread extremely rapidly among IDUs, with HIV seroprevalence rates increasing from less than 10% to 40% or higher within a period of 1 to 2 years (Des Jarlais 1999). Prevalence rates as high as 75% have been described in Asian countries and 60% in Western countries (Des Jarlais *et al.*, 1989). Still, it has been documented that the course of high prevalence epidemics among IDUs can be averted (Bastos *et al.*, 2000; Des Jarlais *et al.*, 2005). In our study HIV prevalence among IDUs in Estonia was high – 54% in Tallinn and 90% in Kohtla-Järve. Comparable HIV-prevalence rates among IDUs in Tallinn have been described earlier (Uusküla *et al.*, 2007).

HIV-related risk behaviours (both IDU- and sexual behaviour-related) among IDUs recruited in Tallinn in 2005 were common. Scaling up HIV prevention programs targeting IDUs and their sexual partners is essential in order to prevent further spread of HIV among these groups and to the broader heterosexual population. Community-based syringe exchange programs have proven to be effective in reducing HIV transmission among IDUs (Des Jarlais *et al.*, 2000) and should therefore be scaled up in Estonia.

In addition, we sought to examine QoL among Estonian HIV-infected individuals and the impact of socio-demographic, disease-related, and psychosocial factors on QoL in order to inform public health policy and services. Quality of life has become an important clinical outcome (Jia *et al.*, 2004) and QoL instruments can be used in the evaluation of programs and services (Wu 2000). It is therefore necessary to adopt an appropriate QoL instrument to Estonian setting. For these purposes, WHOQOL-HIV instrument (O'Connell *et al.*, 2003; WHOQOL HIV Group 2003; WHOQOL HIV Group 2004) was translated into Estonian and Russian and a cross-sectional study was conducted among PLHIV attending regular medical check-ups in infectious diseases outpatient clinics. In general, the WHOQOL-HIV instrument was acceptable for PLHIV in care and both the Russian and Estonian versions of the instrument were internally reliable and valid. The instruments can be used in future studies to evaluate the outcome of public health and clinical interventions targeting PLHIV.

The mean overall QoL score for the whole sample (2.90) was slightly lower than that reported from similar studies conducted in other regions of the world (WHOQOL-HIV Group 2003). Nevertheless, our study most likely overestimated the QoL of PLHIV in Estonia. Receiving treatment and social support could have enhanced the QoL of our sample and, thus, the results cannot be extended to the general HIV-infected population in Estonia. Also, current IDUs may have been underrepresented in our sample.

Our results reveal major disparities in self-reported QoL, with men, people living in North-Eastern Estonia, and people infected through IDU reporting lower scores. Results reveal that psychological and emotional aspects of life may contribute most to the perceptions of QoL, which makes it important to also focus on psychological well-being of the patients and to offer psychiatric care and emotional support.

Most influential contributors to the different aspects of QoL were person's employment status and HIV-disease stage. Besides clinical interventions, return-to-work programs and other measures aimed at enhancing the economic and *employment* opportunities are important for the PLHIV in the region.

The proportion of people on HAART was relatively low (22%), especially among people infected through IDU. We should therefore focus on tailoring appropriate interventions to increase HAART coverage. Considering the large number of IDUs in Estonia and the high HIV prevalence among them, the future burden on health care system may be enormous.

## CONCLUSIONS

1. HIV prevalence among IDUs is high and HIV-related risk behaviours (both IDU- and sexual behaviour-related) are common. Rapid scale up of HIV prevention programs targeting IDUs and their sexual partners is of utmost importance.
2. The results of the QoL study reveal major disparities in self-reported QoL with men, people living in Ida-Virumaa and people infected through IDU reporting lower scores. Results reveal that psychological and emotional aspects of life may contribute most to the perceptions of QoL and therefore it is important to also focus on psychological well-being of the patients and to offer psychiatric care and emotional support.
3. Most influential contributors to the different aspects of QoL were person's employment status and HIV-disease stage. Besides clinical interventions, return-to-work programs and other measures to enhance the economic and employment opportunities are important for PLHIV in the region.
4. The WHOQOL-HIV instrument was acceptable for PLHIV in care and both the Russian and Estonian versions of the instrument were reliable and valid. Further research is needed to test the responsiveness and the test-retest reliability of the instruments. The instruments can be used in future studies to evaluate the outcome of public health and clinical interventions targeting PLHIV.

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## SUMMARY IN ESTONIAN

### HIV-epideemia Eestis: süstiv narkomaania ja HIV-nakatanud inimeste elukvaliteet

Alates 1980ndate algusest, mil AIDSist ja HIVist esmakordselt kõnelema hakati, on HIV-nakkus levinud üle maailma ning selle leviku ulatus sarnaneb 1918. aasta gripipandeemiale. Eestis on 21 aasta vältel diagnoositud 7 152 HIV-nakkuse juhtu (Tervisekaitseinspeksioon, 31.07.2009). Nende aastate jooksul on Eestist, kus oli väike HIV-levimus ja kus peamiseks ohuks peeti nakkuse levikut eelkõige seksuaalsel teel, saanud kontsentreeritud epideemiaga riik; Eestis on kirjeldatud Euroopa regiooni kõrgeim HIV-levimus süstivate narkomaanide (SN) seas (Hamers *et al.*, 2006). Eesti peamine HIV-nakkuse riskirühm on SNid, keda on hinnanguliselt 13 800 (Uusküla *et al.*, 2007) ja kellest valdav osa elab Tallinnas ja Ida-Virumaal. Varasemate uuringute andmetel on HIV-levimus antud sihtrühmas väga kõrge (Uusküla *et al.*, 2007).

HIV-nakkuse levikut ja HIV-nakatanud inimeste elukvaliteeti ei mõjuta mitte üksnes inimeste teadmised ja käitumine ning tervishoiusüsteem, vaid ka paljud keskkonnast, sotsiaalmajanduslikust ning õiguslikust olukorrast tulevad tegurid (Friedman *et al.*, 2009; Poundstone *et al.*, 2004). Nende tegurite mõistmine on oluline, et planeerida ja rakendada meetmeid eesmärgiga pidurdada HIV-nakkuse levikut ning parandada HIV-nakatanud inimeste elukvaliteeti.

Alates 1990ndate keskpaigast, mil võeti kasutusele nn kombineeritud antiretroviirusravi, on HIV-nakatanud inimeste elulemus oluliselt tõusnud ja HIVi ei peeta enam kiirelt surmaga lõppevaks, vaid pigem krooniliseks haiguseks (Fleming *et al.*, 2000; Levi *et al.*, 2000). Selle tulemusena on elukvaliteet ja tervisega seotud elukvaliteet muutunud oluliseks tulemiks tervishoius ning tegurid, mis mõjutavad HIV-nakatanud inimeste elukvaliteeti, on saanud paljude kliinitsistide ja teadlaste oluliseks uurimisteenaks (Jia *et al.*, 2004). Elukvaliteedi uurimine võib anda vastuseid küsimustele nii ravistrateegiatega kui ka tervisepoliitika valdkonnas (Wu 2000).

Selleks, et pakkuda kõrgeima kvaliteediga tervishoiu- ja ennetusteenuseid SNidele ning HIV-nakatanud inimestele – väga heterogeensetele rahvastikurühmadele – on oluline HIV-nakkuse leviku trendide tundmine riskirühmades ja olemasolevate teenuste tulemuste hindamine. Nende eesmärkide täitmiseks on vajalik sobilike instrumentide väljatöötamine ja/või kohandamine ning hetkeolukorra kaardistamine. Eesti varasemad uuringud SNide seas põhinevad reeglina käepärasel valimil süstlavahetusprogrammidesse kaasatud inimeste seas, mistõttu puuduvad täpsed andmed HIV-nakkuse levimusest selles rahvastikurühmas. HIV-nakatanud inimeste elukvaliteeti ei ole Eestis seni uuritud.

Nn raskesti ligipääsetavate rahvastikurühmade puhul, kus üldkogumi suurus ei teata ning klassikalisi valimi moodustamise meetodeid ei ole võimalik rakendada, on kasutatud mitmeid uuringusse kaasamise viise (näiteks lumepalli

meetod), millest kõige innovaatilisemaks peetakse uuritavate poolt uuringusse kaasamise meetodit (ingl *respondent driven sampling* RDS). Selle abil on võimalik uuringusse kaasata erinevate SNide kihte/kooslusi (soo, rahvuse, tarvitatava aine, sotsiaalse klassi jmt alusel), et saavutada uuringu valimi maksimaalne esinduslikkus. RDS on kaasaegne valideeritud meetod SNide kaasamiseks (Heckathorn 1997; Heckathorn *et al.*, 2003).

Elukvaliteedi uurimiseks on uurijatel kaks võimalust – kas ise välja töötada sobilik küsimustik või kohandada mõni rahvusvaheline. Viimane võimalus annab aluse osaleda rahvusvahelistes võrdlusuuringutes. HIV-nakatud inimeste seas korraldatud uuringutes on kasutatud arvukalt erisuguseid üldisi ja haigusspetsiifilisi küsimustikke, mida on tänaseni peamiselt rakendatud nii olemasolevate kui ka uute ravistrateegiade hindamiseks. Need küsimustikud võivad olla teenuste ning programmide hindamise oluliseks vahendiks (Wu 2000). Teaduskirjanduses on avaldatud mitmeid soovitusi olemasolevate küsimustike tõlkimiseks ja kohandamiseks. Küsimustiku valikul on oluline arvestada küsimustiku psühhomeetrilisi omadusi: usaldusväarsust, valiidsust, tundlikkust muutuste suhtes ja vastuvõetavust patsientide poolt (Bhopal *et al.*, 2004; Bowden *et al.*, 2003; Herdman *et al.*, 1997, 1998; Skevington 2002).

Eeltoodust lähtuvalt oli töö üldeesmärk hinnata HIV-nakkuse levimust ja riskitegureid SNide seas ning hinnata HIV-nakatud inimeste elukvaliteeti ja sellega seotud tegureid Eestis.

#### **Uurimistöö erieesmärgid olid:**

1. Määrata kindlaks HIV-nakkuse levimus ja sellega seotud riskitegurid SNide hulgas;
2. Kirjeldada tervishoiuteenuseid saavate HIV-nakatud inimeste hinnangut oma elukvaliteedile ning sotsiaaldemograafiliste, haigestumisega seotud ja psühhosotsiaalsete tegurite mõju elukvaliteedile;
3. Hinnata WHOQOL-HIV küsimustiku kasutatavust ja vastuvõetavust tervishoiuteenuseid saavatele HIV-nakatud inimestele;
4. Hinnata WHOQOL-HIV küsimustiku eesti ja venekeelse versiooni psühhomeetrilisi omadusi (usaldusväarsust ja valiidsust).

#### **Uurimistöö metoodika**

Käesoleva materjali kogumiseks ja analüüsimiseks viidi läbi kaks uuringut:

1. Läbilõikeline uuring SNide seas;
2. Läbilõikeline uuring tervishoiuteenuseid saavate HIV-nakatud inimeste seas.

Uuritavate poolt uuringusse kaasamise meetodi abil kaasati 350 SNi Tallinna ja 100 Kohtla-Järve süstlavahetusprogrammis. Iga uuritavaga viidi läbi anonüümne intervjuu, et koguda andmeid ülddemograafilise tausta, seksuaalelu ja süstiva narkomaaniaga seotud riskikäitumise, kriminaalse tausta ja narkomaania ravivõimaluste kasutamise kohta, ning võeti veretilk (filterpaberile) HIV-vastaste antikehade määramiseks.

HIV-nakatanud inimesed kaasati kolmest suurimast nakkushaiguste osakonnast Tallinnas, Kohtla-Järvel ja Narvas, igast linnast 150 inimest. Iga uuringus osaleja täitis iseseisvalt WHOQOL-HIV küsimustiku eesti- või venekeelse versiooni. Lisaks koguti haiguslugudest terviseseisundit ja ravi puudutavaid andmeid.

WHOQOL-HIV küsimustiku eesti ja vene keelde kohandamiseks rakendati teaduskirjanduses (Bhopal *et al.*, 2004) toodud soovitusi. Selles küsimustikus on 116 küsimust, millele tuleb vastata etteantud viieastmelise (Likerti) skaala alusel. Küsimused jagunevad kuueks valdkonnaks (füüsiline, psühholoogiline, sõltumatus, sotsiaalsed suhted, keskkond ja vaimsus) ja 29 alavaldkonnaks. Lisaks on veel üks iseseisev alavaldkond üldise elukvaliteedi hindamiseks (ingl *overall quality of life and general health perceptions*). Küsimustik tõlgiti eesti ja vene keelde, kakskeelsete spetsialistide rühmad arutasid tõlked läbi ja võrdlesid neid originaaliga. Edasi viidi kummagi küsimustikuga läbi eeluurimise HIV-nakatanud inimeste seas (N=10), kes kaasati HIV-nakatanud inimeste tugigruppidest. Küsimustike kasutatavust ja aktsepteeritavust hinnati uuringus osalemise ja puuduvate vastuste määra abil. Küsimustike usaldusväärsust hinnati Cronbachi alfa (soovitud väärtus >0,7) ning valdkondade ja alavaldkondade skooride korreleerimise abil (Pearsoni korrelatsioonikoefitsiendi soovitud väärtus <0,3). Kriteeriumvaliidsust hinnati üldise elukvaliteedi skoori ning alavaldkondade ja valdkondade skooride korreleerimise abil. Kaasnevat valiidsust hinnati HIV-nakkuse eri staadiumites olevate inimeste alavaldkondade ja valdkondade skooride võrdlemise abil. Konvergentset ja divergentset valiidsust hinnati alavaldkondade omavahelise korreleerimise abil.

### **Tulemused ja arutelu**

HIV-levimus SNide seas Eestis oli antud uuringus Tallinnas 54% ja Kohtla-Järvel 90%. Viimane näitaja on tänaseni teaduskirjanduses avaldatud kõrgeim HIV-levimus ühe piirkonna SNide seas (Mathers *et al.*, 2008). HIV-nakkuse levikuga seotud riskikäitumine (nii narkootikumide süstimist kui seksuaalelu puudutav) oli antud uuringus osalenute seas sage. Mitmemõõtmelises analüüsis selgusid peamiste HIV-nakkusega seotud riskiteguritena Tallinnas sünteetilise opioidi fentanüüli süstimine, süstalde/nõelte jagamine seksuaalpartneri(te)ga viimase 12 kuu jooksul ning osalemine narkomaaniaravi programmides. HIV-levimus lühema süstimisstaaziga SNide seas oli ühemõõtmelises analüüsis madalam kui pikema süstimisstaaziga SNide seas, kuid mitmemõõtmelises analüüsis antud seos püsima ei jäänud. Uuringusse kaasatud SNide hulgas oli siiski vaid 11% neid, kes olid süstimisega alustanud viimase kahe aasta jooksul. Jätkuvalt on vajalik laiaulatuslik kahjude vähendamise meetmete rakendamine SNide ja nende seksuaalpartnerite seas, et vähendada HIVi edasist levikut nii antud rahvastikurühmas kui ka kogurahvastikus.

HIV-nakatanud inimeste elukvaliteedi uuringus selgus, et kõigi uuritavate keskmine üldine elukvaliteedi skoor viiepalli skaalal oli 2,9, mis on skaala keskmisest madalam. Naiste hinnang oma elukvaliteedi eri aspektidele oli üldiselt kõrgem kui meestel. Vanuserühmade ja rahvuste vahel ilmnisid vaid üksikud olulised erinevused. Piirkondade lõikes olid Tallinna vastanute

keskmised tulemused võrreldes Ida-Virumaa vastanutega kõrgemad kõigis kuues elukvaliteedi valdkonnas ja HIV-nakatud inimestele spetsiifilistes alavaldkondades. Kaebusteta inimeste hinnang oma üldisele elukvaliteedile oli kõrgem kui kaebustega uuritavatel ja aidsihaigetel. Narkootikumide süstimisel nakatud inimeste hinnang oma üldisele elukvaliteedile oli oluliselt madalam kui neil, kes olid nakatud seksuaalvahekorra ajal. Madalamad tulemused olid neil mitmes elukvaliteedi valdkonnas (füüsiline, sõltumatus, suhted ja keskkond). Peamised tegurid, mis mõjutasid hinnangut üldisele elukvaliteedile, olid terviseseisund ning tööhõive. Kokkuvõtteks võib järeldada, et infektsionisti külastavate HIV-nakatud inimeste hinnang oma elukvaliteedile Eestis on rahuldav. Tulemusi ei saa aga üldistada kõigile Eestis elavatele HIV-nakatud inimestele, kuna uuringusse olid kaasatud vaid need, kellel on juba olemas ligipääs erinevatele tervishoiu- ja sotsiaalhoolekande teenustele, mistõttu nende elukvaliteet üldiselt võib olla parem.

Nii eesti- kui venekeelne WHOQOL-instrument oli patsientide poolt aktsepteeritav, mida näitab osalusmäär 89% ja madal vastamata küsimuste osakaal (<5% iga alaskaala puhul). Vald-konnad ja alavaldkonnad korreleerusid valdavalt oluliselt üldise elukvaliteedi skooriga ja Cronbachi alfa oli enamike alavaldkondade ja valdkondade puhul >0,7. Kõige enam üldise elukvaliteediga korreleeruv alavaldkond oli „positiivsed tunded“, mis näitab, et elu psühholoogilised ja emotsionaalsed aspektid võivad kõige enam mõjutada hinnangut elukvaliteedile. Erinevates HIV-nakkuse staadiumites olevate inimeste alavaldkondade ja valdkondade skoorid (kohandatuna vanusele ja soole) erinesid valdavalt olulisel määral. Eestikeelse versiooni tulemused olid mõne näitaja korral halvemad kui venekeelsel (nt kaasnev valiidsus), mis võib olla tingitud väiksemast eesti keelt kõnelevate inimeste osakaalust uurimuses (10%, N=45). Vaimse valdkonna ja selle alaskaalade usaldusväärsus ja valiidsus olid teiste valdkondadega võrreldes madalamad, mille üks põhjus võib olla antud valdkonna suur kultuurispetsiifilisus. Et tegemist oli läbilõikelise uuringuga, ei olnud võimalik hinnata instrumentide tundlikkust muutustele ajas.

## Järeldused

1. HIV-nakkuse levimus SNide seas Eestis on kõrge ja HIViga seotud riskikäitumine sage (nii narkootikumide süstimist kui seksuaalelu puudutav). Kiire ja laiaulatuslik süstivatele narkomaanidele ja nende seksuaalpartneritele suunatud HIV-ennetuse programmide rakendamine on ülioluline epideemia edasise leviku pidurdamiseks.
2. Hinnang oma üldisele elukvaliteedile HIV-nakatud inimeste seas oli alla keskmise. Ilmsid erinevused soo, piirkonna ja võimaliku nakatumise tee järgi. Kõige enam üldise elukvaliteediga korreleeruv alavaldkond oli „positiivsed tunded“, mis näitab, et elu psühholoogilised ja emotsionaalsed aspektid võivad kõige enam mõjutada hinnangut elukvaliteedile. Seetõttu on oluline pöörata tähelepanu patsientide vaimsele tervisele ning pakkuda vaimse tervise ja psühhosotsiaalse toetuse alaseid teenuseid.
3. Peamised üldist elukvaliteeti positiivselt mõjutavad tegurid olid hea terviseseisund (sümptomiteta) ja tööhõive (k.a õppimine). Lisaks tervis-

hoiuteenuste pakkumisele elukvaliteedi parandamiseks on oluline suurendada tööhõivet HIViga inimeste seas ning arendada selleks tööhõive programme.

4. WHOQOL-HIV instrument oli vastuvõetav tervishoiuteenuseid saavatele HIV-nakatunud inimestele ja nii eesti- kui venekeelne versioon on usaldusväärne ja valideeritud. Täiendava uurimistöö käigus on vajalik hinnata instrumentide tundlikkust muutustele ajas ja korduvate hinnangute vahelist kooskõla. Küsimustikke saab kasutada HIV-nakatunud inimestele suunatud rahvatervishoiu-alaste ja kliiniliste sekkumiste hindamiseks.

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## **PUBLICATIONS**

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1984–1995 Paide Gymnasium  
1998–2004 University of Tartu, Faculty of Medicine, undergraduate studies  
2004–2009 University of Tartu, Faculty of Medicine, Department of Public Health, postgraduate studies

## Professional Employment

2004– National Institute for Health Development

## Scientific work

Main fields of research:

- quality of life of people living with HIV
- risk behaviours related to HIVinfection among risk groups
- operational research related to HIV prevention and care services, including HIV testing and tuberculosis care

Nine scientific publications, 17 international conference abstracts and 10 other types of articles (including 6 in *Eesti Arst*)

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## Ametikäik

2004–	Tervise Arengu Instituut
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## Teadustöö kirjeldus

Peamised uurimisvaldkonnad:

- HIV-nakatunud inimeste elukvaliteet
- HIV-nakkusega seotud riskikäitumine riskigruppide seas
- Rakendusuurimused HIV-nakkuse ennetamise ja hoolekande teenuste valdkonnas, näiteks HIV-testimine ja tuberkuloosi ennetamine

Üheksa teadusartiklit, 17 abstrakti rahvusvahelistel konverentsidel ja 10 muud artiklit (k.a. 6 Eesti Arstis)

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