

# Quality of Life of HIV-Infected Persons in Croatia

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## ABSTRACT

*The aim of this study was to examine health-related quality of life among Croatian HIV infected individuals, and to assess the impact of socio-demographic and disease-related variables on health-related quality of life. This was a cross-sectional study of 111 HIV-infected adults who received care at the University Hospital for Infectious Diseases in Zagreb, Croatia. The World Health Organization Quality of Life Questionnaire for HIV brief version (WHOQOL-HIV BREF) was used to assess each patient's quality of life. Ratings of quality of life differed across age, marital status, level of education, health status and »currently ill« status. Subjects who perceived themselves as not ill and their health status as better reported better quality of life for all quality of life domains ( $p < 0.01$ ). Subjects who were in relationships gave higher ratings for the social relationships domain ( $p < 0.01$ ). Subjects with higher level of education gave significantly higher ratings within the independence ( $p < 0.05$ ) and environment ( $p < 0.01$ ) domains. Younger subjects perceived their psychological state as better ( $p < 0.05$ ). The findings demonstrate a moderate degree of overall quality of life ( $X = 112.2$ ;  $SD = 18.92$ ) with main concerns related to social relationships. These results highlight the need for better access to psychosocial support and medical and legal services for people living with HIV/AIDS in Croatia.*

**Key words:** quality of life, HIV, Croatia, WHOQOL-HIV BREF

## Introduction

Since the advent of antiretroviral therapy, a primary goal in the management of the human immunodeficiency virus (HIV) has been enhancing quality of life for patients in addition to extending its duration<sup>1</sup>. The World Health Organization (WHO) has defined health as a »state of complete physical, mental, and social well-being and not merely the absence of disease and infirmity.« Accordingly, the health care community has strived to promote health outcomes that include not only improvements in the frequency and severity of disease, but also in overall quality of life<sup>2</sup>.

For this study, we adopted the WHO's definition of Quality of Life. As such, we defined quality of life as an individual's perception of his position in life within the context of the culture and value systems in which he lives, and in relation to his goals, expectations, standards, and concerns. Quality of life is a broad ranging, complex concept shaped by an individual's physical health, psychological state, personal beliefs, social relationships, and environmental factors<sup>3</sup>.

Quality of life among HIV-infected individuals has been studied extensively, and prior research has attempt-

ed to both assess quality of life and determine predictors for good or poor quality of life. Recent studies have reported differing results, particularly when determining predictors of poor quality of life.

Contradictory results have been given in regard to gender as a socio-demographic factor that might influence quality of life of HIV infected people. Some researches have documented low performance for women in some aspects of quality of life (QoL)<sup>4,5</sup> while in some other studies difference according to gender was not found<sup>6</sup> or have even shown the opposite<sup>7,8</sup>. Some reports in literature find younger age to be related with better QoL<sup>8-10</sup>. Comparisons between educational groups showed that those with less education reported significantly poorer QoL than those with more education, according to some authors<sup>5,11-13</sup>.

Croatia is a moderately developed country in South-eastern Europe. Since 1998, antiretroviral (ARV) therapy has been available free of charge for all HIV infected persons in Croatia. With the introduction of ARV, morbidity and mortality associated with HIV infection have significantly decreased<sup>14</sup>. Immediate threats to physical

existence have been largely replaced by other concerns. Patients are burdened by difficult medication regimens and medication side effects, which are constant reminders of illness. These uncertainties can have a negative impact on QoL<sup>15</sup>. Stigma and discrimination also contribute to the difficulties faced by PLWHA<sup>5</sup>. People with HIV often experience discrimination and prejudice in the realms of employment, housing, insurance, and medical care.

The primary aim of this study was to evaluate the health-related quality of life among Croatian HIV-infected patients treated at the University Hospital for Infectious Diseases »Dr. Fran Mihaljević«, Zagreb. Secondary aims were to assess the impact of demographic and disease-related variables on health-related quality of life and to provide baseline data on quality of life in HIV patient population in Croatia. To date, no studies of QoL for people living with HIV have been conducted in Croatia.

## Methods

### Subjects

This was a cross-sectional study of health-related quality of life in a sample of HIV infected men and women living in Croatia. Participants were recruited from among those seeking treatment at the University Hospital for Infectious Diseases »Dr. Fran Mihaljević« during 6 months period, from March to September 2004. The University Hospital for Infectious Diseases is the only hospital that treats HIV patients in Croatia, and patients from throughout the county visit the clinic for HIV care. The sample consisted of 111 HIV adults. The patients used a self-administered questionnaire. Subjects were classified into three diagnostic groups (asymptomatic, symptomatic, AIDS), according to Euro HIV classification system<sup>16</sup>. Data was gathered on gender, age, marital status, level of education, health status, currently ill status, and years since diagnosis.

### Questionnaire

The World Health Organization Quality of Life Questionnaire for HIV brief version (WHOQOL-HIV BREF) was used to assess each patient's quality of life. The WHOQOL is a multidimensional, conceptualized, generic, 31-item QoL instrument<sup>11</sup>. Its questions cover the respondent's perception of the overall quality of life within the following 6 broad domains and within each domain, there is a series of sub domains (facets) of the quality of life that summarizes that particular domain:

- Physical health describes 4 facets: pain and discomfort, energy and fatigue, sleep and rest and symptoms related to HIV. For example an item in this domain asks »How much are you bothered by any physical problems related to your HIV infection?«.
- Psychological state describes 5 facets: positive feelings, concentration, self esteem, bodily image and appearance and negative feelings. For example, an item in the positive feeling facet asks »How much do you enjoy life?«.
- Level of independence describes 4 facets: mobility, activities of daily living, dependence on medication and treatment and work capacity. For example, an item in the work capacity facet asks »How satisfied are you with your capacity for work?«.
- Social relationships domain describes 4 facets: personal relationships, social support, sexual activity, social inclusion. For example, an item in the social support facet asks »How satisfied are you with the support you get from your friends?«.
- Environment describes 8 facets: physical safety and security, home environment, financial resources, health and social care: accessibility and quality, opportunities for acquiring new information and skills, participation in and opportunities for recreation/ leisure activities, physical environment (pollution/noise/traffic/climate), transport. For example, an item in the financial resources facet asks »Have you enough money to meet your needs?«.
- Spirituality, religion and personal beliefs describes 4 facets: personal beliefs, forgiveness and blame, concerns about the future, death and dying. For example, an item in forgiveness and blame facet asks »To what extent are you bothered by people blaming you for your HIV status?«.

WHOQOL questions are answered on a 5-point Likert-type scale ranging from 1 to 5 and containing additional verbal descriptors. The employed scoring system inverts scores where necessary, though higher scores generally indicate better quality of life. Each domain scores theoretically range between 4 and 20 and overall QoL scores theoretically range between 31 and 155. The questionnaire has been validated and used widely in HIV studies<sup>17</sup>.

In this study, internal consistency analysis of Croatian version of WHOQOL-HIV BREF instrument showed reasonably good reliability for domains (0.51–0.80) as shown by the Cronbach's alpha coefficients. Reliability coefficient for physical domain was  $\alpha=0.51$ , for psychological domain was  $\alpha=0.74$ , for level of independence domain was  $\alpha=0.75$ , for social relationship domain  $\alpha=0.80$ , for environment domain was  $\alpha=0.80$  and for the spirituality domain was  $\alpha=0.67$ .

### Data analysis

In addition to computing descriptive statistics, within group differences were compared according to socio-demographic and disease-related characteristics with t-tests and one-way ANOVA. Statistical significance was set at  $p\leq 0.05$ . All data analyses were performed using the Statistical Package for the Social Sciences 11.0<sup>18</sup>.

## Results

### Subjects

One hundred thirty-four HIV infected patients were asked to participate in the survey. Twenty-three subjects

(17%) refused to participate, citing insufficient time. The overall response rate for participating in the survey was rather high (83%). This response rate is similar to that of previous studies<sup>8</sup>. Patients may hesitate to participate since some prefer not to reveal their identity to strangers (researchers), or talk about their illness. Some may feel that they have participated in too many studies already, as in the present case of the small HIV population available in Croatia.

Information on the socio-demographic characteristics and the results of the data collected on disease related variables of the sample are presented in Table 1.

**TABLE 1**  
DEMOGRAPHIC AND DISEASE-RELATED CHARACTERISTICS  
OF TOTAL SAMPLE (N=111)

Variable	%	Frequency	X (SD)
Age (years)			39.64 (9.52)
Gender (Male)	78.4	87	
Education			
Elementary	10.8	12	
High school	59.5	66	
College	29.7	33	
Marital status			
Married or in relationship	40.5	45	
Single	59.5	66	
Health status			
Poor	3.6	4	
Neither poor nor good	27.0	30	
Good	55.0	61	
Very good	14.0	16	
Currently ill status (Yes)	30.6	34	
HIV status			
Asymptomatic	47.7	53	
Symptomatic	28.8	32	
AIDS	23.4	26	
Years since HIV diagnosis			4.84 (4.69)

Most participants were male (78.4%) with a mean age of 40 years. The majority of participants had graduated from high school (59.5%) and a similar number (59.5%) reported being single at the time of data collection. Fifty-three (47.4%) subjects had asymptomatic HIV infection stage while 32 (28.8%) were symptomatic. Twenty six participants (23.4%) had diagnosed AIDS.

When asked to evaluate their own health, 14.0% rated their health as very good, 55.0% as good, 27% as neither poor nor good, and 3.6% as poor. 30.6% of all subjects reported that they were currently ill. The mean time since diagnosis of HIV infection for the sample was 5 years.

### Quality of life

Participants reported moderate to very good satisfaction with overall QoL with a mean score of  $X=112.2$  ( $SD=18.92$ ) on WHOQOL HIV-BREF scale.

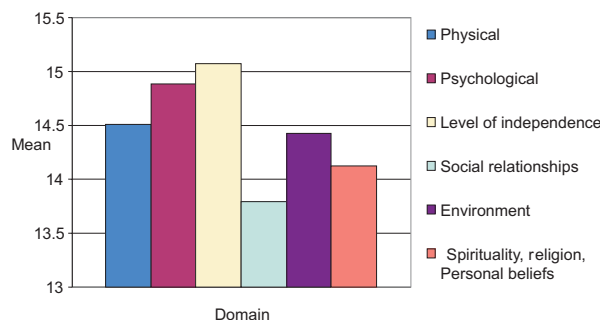


Fig. 1. Average data for quality of life domains (N=111).

Figure 1 presents the average quality of life scale scores according to each domain. The lowest mean score was in the social relationships domain ( $X=13.79$ ;  $SD=3.88$ ) and the highest ( $X=15.07$ ;  $SD=2.92$ ) was in the level of personal independence domain, difference between those two domains was significant as shown by t-test ( $t=4.27$ ,  $p<0.001$ ).

This descriptive analysis highlights that the main concern for patients were related to social relationships aspects of QoL.

### T-test and ANOVA

We examined differences between domains of quality of life to ascertain whether ratings differed significantly by demographic characteristics or health status (Table 2).

The results from Student's t-test and one-way analysis of variance (ANOVA) showed that ratings of quality of life differed across age, marital status, level of education, health status, and currently ill status. Subjects who perceive themselves as physically well gave significantly higher ratings, indicating better quality of life for all domains. Subjects who are married or in relationship reported better QoL for the social relationships domain. Those with more education reported significantly better QoL for the »level of independence,« »relationships,« and »environment« domains than those with less education. And finally, younger subjects reported better psychological adjustment than older subjects. Ratings did not differ by gender or stage of HIV infection.

### Discussion

The quality of life scores obtained in this study of PLWHA in Croatia show that participants perceive their quality of life as »good« to »very good.«<sup>17,19</sup> This result is consistent with the findings of previous studies of the quality of life for the general patient population in Croatia.<sup>20</sup> Quality of life for HIV patients in Croatia, however, appears to be lower than for patients in other countries such as Italy<sup>6</sup>.

A variety of QoL domains suffer in individuals with HIV, but consequences within the social domains dominate, suggesting the severest impact of HIV extends across social aspect of QoL but also influences other im-

**TABLE 2**  
COMPARISON OF MEAN SCORES OF QUALITY OF LIFE ACCORDING TO DEMOGRAPHIC AND DISEASE RELATED CHARACTERISTICS (N=111)

Variables	Physical	Psychological	Level of independence	Social relationships	Environment	Spirituality	
Age	< 35	14.88	15.57	15.34	14.41	14.57	13.73
	> 36 to 45	14.21	14.53	15.11	13.61	14.46	14.13
	< 46	14.41	14.45	14.69	13.22	14.20	14.62
	F	F=0.54	F=3.39*	F=0.45	F=0.92	F=0.15	F=0.50
Gender	Male	14.63	14.97	15.14	13.56	14.49	14.45
	Female	14.08	14.60	14.83	14.63	14.19	12.96
	T	t=0.82	t=0.56	t=0.45	t=-1.19	t=0.46	t=1.73
Education	Elementary	14.17	14.80	14.67	12.58	13.42	13.25
	High school	14.20	14.68	14.61	13.77	13.98	13.86
	College	15.27	15.35	16.15	14.27	15.70	14.97
	F	F=1.61	F=0.64	F=3.35*	F=0.83	F=5.07**	F=1.32
Marital status	Single	14.59	14.87	15.00	13.03	14.05	14.26
	Married	14.40	14.92	15.18	14.91	14.99	13.93
	T	t=0.34	t=-0.08	t=-0.31	t=-2.57**	t=-1.70	t=-0.44
Health status	Poor	11.75	12.20	10.25	9.25	10.38	13.00
	Neither poor nor good	12.43	13.15	13.10	12.03	13.10	13.50
	Good	14.93	15.20	15.61	14.31	14.92	13.87
	Very good	17.50	17.65	17.94	16.25	16.06	16.56
	F	F=18.06**	F=14.77**	F=22.09**	F=7.50**	F=8.45**	F=2.87*
Currently ill	Yes	12.56	12.99	13.00	12.00	13.07	13.21
	No	15.38	15.73	15.99	14.58	15.03	14.53
	T	t=-5.23**	t=-5.37**	t=-5.62**	t=-3.38**	t=-3.44**	t=-1.73
HIV status	Asymptomatic	14.89	15.02	15.47	13.81	14.50	13.85
	Symptomatic	13.88	14.78	14.28	13.38	14.61	13.88
	AIDS	14.54	14.77	15.23	14.27	14.06	15.00
	F	F=1.21	F=0.11	F=1.73	F=0.38	F=0.29	F=0.91

\* p<0.05, \*\*p<0.01

portant domains of health-related QoL<sup>8,11</sup>. This is expected, as people with HIV infection often experience social isolation, derogation, stigmatization, discrimination and marginalization<sup>8</sup>.

As expected, ratings of quality of life varied in patient groups defined by age, marital status, level of education, ratings of health status<sup>19</sup>, and currently ill status<sup>11</sup>.

Younger persons reported more positive feelings, better cognitive functioning, higher self-esteem, more satisfaction with physical appearance and body image, and generally more satisfaction within the psychological domain of QoL than older persons, confirming some reports in the literature<sup>5,8-10</sup>. These findings were expected, given the known effect of age on prognosis of patients with AIDS<sup>5</sup>. Additionally, young people are often diagnosed in early stage of disease while older individuals are more likely to be diagnosed once experiencing later stages of HIV infection.

Marital status influences quality of life. Subjects who are married or in relationship reported a higher level of QoL for the social relationships domain. Those in rela-

tionships may enjoy better social support. Moreover, a number of HIV-infected individuals are in long-term relationships with HIV-infected individuals, from whom they may derive additional stability and support. Those in a long-term relationship also need only disclose their serostatus to one person, their partner, thus alleviating some of the anxiety felt while revealing HIV-positive status.

We also found that subjects with higher education reported better QoL in the independence and environment domains. These findings support those reported by Muri et al.<sup>21</sup> who found difference in mental health by education level, and with O'Connell et al.<sup>11</sup>, who found large difference for the environment domain by education level.

Subjects who reported that they were currently ill also reported poorer QoL, a finding consistent with prior studies<sup>11</sup>. Those who are sick are burdened with physical symptoms of the disease, which in turn, impairs QoL<sup>1,5,22,24</sup>.

The mean QoL summary scores for patients reporting deterioration in health status were significantly lower

than for patients reporting stable or improving health status. This finding, which is consistent with other studies, indicates that those in good physical health enjoy greater overall quality of life<sup>19</sup>.

This study did not show significant differences among QoL domains with stages of HIV infection. Again this finding supports previous research, which did not find differences in the psychological domain<sup>6</sup>, in social functioning, mental health, general health and vitality<sup>1,22</sup>, and in physical functioning, mental health, or bodily pain<sup>23</sup>.

This study had some limitations. First, its cross-sectional design does not allow us to draw conclusions regarding the direction of the relationships or causality among QoL and socio-demographic and disease related variables. Second, the study population was not a random sample of HIV-infected people living in Croatia. The subjects surveyed were the one who were actively seeking routine medical care. Those who do not schedule and/or keep regular clinic visits were not included and consequently, the results of this study may not generalize to all HIV patients in Croatia.

It is remarkable that despite all HIV-related stressors many women and men believe in the value of life and re-

port good quality of life. Quality of life is an ongoing process. Effective medication regimens alone are not sufficient to ensure good quality of life so in order to provide a route to improve QoL for PLWHA it is very important to have good access to psychosocial support, medical and legal services and also have interventions directed towards education of general population as well as health professionals and to raise awareness about HIV. Physicians must also be educated how HIV disease affects a patient's quality of life. With improvement of provider's understanding, how HIV affects patients' quality of life, we can improve the doctor-patient relationship and allow the patient to receive more complete care.

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## **KVALITETA ŽIVOTA OBOLJELIH OD HIV-A U HRVATSKOJ**

### **S A Ž E T A K**

Cilj ovog istraživanja bio je ispitati zdravstveno povezanu kvalitetu života skupine HIV oboljelih osoba liječenih u Klinici za infektivne bolesti »Dr. Fran Mihaljević« u Zagrebu te ispitati učinak socio-demografskih karakteristika i karakteristika povezanih s bolešću na kvalitetu života. Ovo je kros-sekcijsko istraživanje u kojem je sudjelovalo 111 HIV pozitivnih žena i muškaraca iznad 18 godina starosti. WHOQOL-HIV BREF upitnik je korišten za procjenu kvalitete života svakog pacijenta. T-test i jednostavna analiza varijance ukazuju da se procjene kvalitete života razlikuju s obzirom na dob, bračni status, nivo obrazovanja, trenutni zdravstveni status i bolesnički status ( $p < 0.01$ ). Osobe koje su u vezi davale su više procjene za domenu socijalnih odnosa ( $p < 0.01$ ). Također osobe s višim nivoom obrazovanja davale su značajno više procjene u domenama nivo samostalnosti ( $p < 0.05$ ) te povezanost sa značajnim okolinskim obilježjima ( $p < 0.01$ ). Mlađi ispitanici procjenjuju da je njihovo psihološko zdravlje bolje u odnosu na starije ispitanike ( $p < 0.05$ ). Dobiveni nalazi ukazuju na umjereni stupanj kvalitete života ( $X = 112.2$ ;  $SD = 18.92$ ), sa socijalnim odnosima kao najviše narušenim aspektom kvalitete života. Rezultati naglašavaju potrebu za boljim pristupom psihosocijalnoj podršci, medicinskim i pravnim uslugama za osobe koje žive s HIV-om u Hrvatskoj.