



City Research Online

City, University of London Institutional Repository

Citation: Eriksson, L. E., Nordström, G., Berglund, T. & Sandström, E. (2000). The health-related quality of life in a Swedish sample of HIV-infected persons. *Journal Of Advanced Nursing*, 32(5), pp. 1213-1223. doi: 10.1046/j.1365-2648.2000.01592.x

This is the unspecified version of the paper.

This version of the publication may differ from the final published version.

Permanent repository link: <https://openaccess.city.ac.uk/id/eprint/3506/>

Link to published version: <https://doi.org/10.1046/j.1365-2648.2000.01592.x>

Copyright: City Research Online aims to make research outputs of City, University of London available to a wider audience. Copyright and Moral Rights remain with the author(s) and/or copyright holders. URLs from City Research Online may be freely distributed and linked to.

Reuse: Copies of full items can be used for personal research or study, educational, or not-for-profit purposes without prior permission or charge. Provided that the authors, title and full bibliographic details are credited, a hyperlink and/or URL is given for the original metadata page and the content is not changed in any way.

Title**The Health-Related Quality of Life in a Swedish Sample of HIV-Infected Persons**

Running head: HRQOL in HIV-infection

Authors: Lars E. Eriksson,^{1,2} RN, doctoral student, Gun Nordström,² RN, Ph.D., associate professor, Torsten Berglund,¹ B.Sc., doctoral student and Eric Sandström,¹ MD, Ph.D., professor

¹Gay Mens Health Clinic, Stockholm Söder Hospital, Sweden

²Department of Nursing, Karolinska Institute, Stockholm, Sweden

Address for correspondence and requests for reprints: Lars E. Eriksson, RN, doctoral student, Department of Nursing, Research and Development, Karolinska Institute, Box 286, SE-171 77 Stockholm, Sweden
E-mail: m65le7k1@students.su.se

Sources of support

This study was supported by grants from the Committee for the Health and Caring Sciences at the Karolinska Institute, the Stockholm Söder Hospital, the Swedish Foundation for Health Care Sciences and Allergy Research, and the Physicians against AIDS Research Foundation.

Number of words used

Abstract: 229

Manuscript: 4,142

ABSTRACT

The purposes of the present study were 1) to assess the health related quality of life (HRQOL) and the subjective health status in a sample of HIV-infected persons, 2) to relate the results to different male population groups and 3) to investigate the relationship of medical and demographic variables with HRQOL. A total of 72 HIV-infected men were included. They answered the Swedish Health-Related Quality of Life Questionnaire and the Health Index. Demographic and medical data were obtained from the medical records. The data collection took place before entering a therapeutic HIV vaccine trial. The results showed a more negative impact on the HRQOL and subjective health status in the HIV-positive subjects, compared with male population groups. The dimensions of emotional well-being were most affected. When comparisons were made according to the medical and demographic variables for different subgroups within the HIV sample, differences in the physical-dimension scales were most prominent. Symptomatic HIV infection or AIDS, anti-retroviral treatment, sick leave or disability pension, low income and basic education were associated with worse HRQOL and health status. In conclusion, it is of the utmost importance to take into account aspects of the patients' emotional well-being in nursing, as well as in medical care and interventions. Moreover, individualised caring programs are needed since the disruptions in HRQOL fluctuated within the HIV sample.

Keywords: Quality of life, health status, HIV infection, AIDS, CD4, antiretroviral therapy, SWED-QUAL, HI

INTRODUCTION

In recent decades, the health-related quality of life (HRQOL) has increasingly gained importance as an outcome measure in health care (Guyatt *et al.* 1993; Testa & Simonson 1996), especially as regards interventions for patients with various chronic diseases (Patrick & Eriksson 1993).

The Human Immunodeficiency Virus Type 1 (HIV) is a retrovirus which causes chronic, progressive, immunological dysfunction. Infection with HIV is characterised by a long period with no or minor symptoms, but the virus causes declining levels of T-helper (CD4-positive) lymphocytes. Low levels of CD4-positive lymphocytes are associated with increased risk of the Acquired Immunodeficiency Syndrome (AIDS), defined by opportunistic infections and HIV-related cancers. HIV infection is also associated with different psychological and neuropsychiatric disorders. Today, there is no cure against HIV infection. Treatment is concentrated on delaying the HIV's suppression of the immune system and on controlling and or preventing opportunistic infections and cancers (Catalan 1990; Saag 1994).

Globally, the estimated number of persons infected with HIV since the beginning of the pandemic is 30.6 million, of whom over 12.9 million have developed AIDS (World Health Organization 1997) and the estimate for the end of the century is more than 40 million infected people (UNAIDS/WHO Working Group on Global HIV/AIDS and STD Surveillance 1997). The reported number of HIV-infected individuals in Sweden is 4,737 (1,571 AIDS), of whom 994 have died (Swedish Institute for Infectious Disease Control 1998), and approximately one new case is reported each day. Out of the Swedish HIV-carriers, the reported mode of transmission is male to male sex (42%), male to female sex (35%), intravenous drug use (16%), blood products (4%), mother to

child (1%) and other or unknown (2%) (Swedish Institute for Infectious Disease Control 1998).

HIV infection affects several HRQOL domains, and studies of HIV and the quality of life have shown that, compared with patients with various other chronic conditions, patients with symptomatic HIV scored their HRQOL as poorer, while patients with asymptomatic HIV scored it better (Wu *et al.* 1991; Wachtel *et al.* 1992). Of the HIV patients in different disease stages, asymptomatic patients scored their HRQOL better than symptomatic HIV carriers (Ragsdale & Morrow 1990; Wu *et al.* 1990; Wachtel *et al.* 1992). The most affected group seemed to be the group of patients with AIDS-related complex (ARC) (Ragsdale & Morrow 1990). In a qualitative study of 25 HIV patients, Laryea & Gien found indications that the investigated patients felt doubly stigmatised and "that the HIV-positive diagnosis had a profound impact on the individual's psycho-social aspects of life" (Laryea & Gien 1993 p. 245). Similarly, Ragsdale & Morrow found in their study of 95 HIV patients in various disease stages that the psycho-social dimension seemed to be the most affected (Ragsdale & Morrow 1990).

Several studies have focused on the quality of life of HIV-positive individuals (Hays & Shapiro 1992; Wu & Rubin 1992; Wu & Rubin 1994; Holzemer & Wilson 1995), but comparisons with general population samples have been unusual. Most HIV-carriers are treated in out patient clinics and many of them are judged as symptom free. Therefore the specific aims of the present study were to assess the HRQOL and the subjective health status of an out patient sample of HIV-infected persons and to relate these results to different general population groups and medical and demographic variables.

METHODS

Instruments

The participants were asked to complete two questionnaires regarding their HRQOL and subjective health status. These questionnaires are designed for self-administration and were answered before entering a therapeutic HIV vaccine trial. In addition, demographic and medical data were obtained from specific questions added to the instruments and from the medical records. The following instruments were used.

The Swedish Health-Related Quality of Life Questionnaire (SWED-QUAL)

The SWED-QUAL was developed by Brorsson, Ifver & Hays (Brorsson *et al.* 1993) from the measures used in the USA Medical Outcomes Study (MOS) (Stewart *et al.* 1988; Tarlov *et al.* 1989; Stewart *et al.* 1992; Ware & Sherbourne 1992). The questionnaire is designed to measure the HRQOL and consists of 70 items, of which 63 form two single-item and 11 multi-item dimension scales of Likert type: physical functioning (7 items), mobility (1 item), satisfaction with physical ability (1 item), role limitations due to physical health (3 items), pain (6 items), positive affect (6 items), negative affect (in this study expressed as "absence of negative affect" (6 items)), role limitations due to emotional health (3 items), sleep problems (7 items), satisfaction with family life (relations with parents, siblings, children etc. (4 items)), relation to partner (6 items), sexual functioning (4 items) and general health perception (9 items). The relation to partner section was, in the present study, slightly modified to make it usable for the investigated group (i.e. the word "spouse" was replaced by "partner"). Each separate scale is transformed into a 0-100 index. The higher the score, the better the perceived HRQOL. In a

general population sample, the internal-consistency reliability coefficients (Cronbach's α) ranged from 0.79 to 0.89. Brorsson *et al.* have also reported preliminary support for the construct validity (Brorsson *et al.* 1993).

Furthermore, the SWED-QUAL has been used in several populations of Swedish patients (Larsen *et al.* 1996; Wändell *et al.* 1997a; Wändell *et al.* 1997b; Lindqvist & Sjöden 1998).

Health Index (HI)

The HI questionnaire, first published by Nordström *et al.* 1992, consists of 10 items concerning energy, temper, fatigue, loneliness, sleep, vertigo, bowel function, pain, mobility and general health. For each statement, the participants were asked to rate their health status during the previous week on a four-grade Likert scale, which ranged from 1 to 4 (very poor to very good). The scores are summarised to form a health index ranging from 10 to 40. The higher the score, the better the self-rated health (Nordström *et al.* 1992).

A factor analysis performed by Nordström *et al.* defined two factors: emotional well-being (EWB), consisting of four items (energy, temper, fatigue and loneliness), and physical well-being (PWB), consisting of five items (mobility, sleep, vertigo, bowel function and pain). The general health item was related to general well-being and was thus excluded from the specific subsets (Nordström *et al.* 1992).

The HI has been tested for reliability in different patient populations with satisfactory results (Cronbach's α 0.77 to 0.85) (Nordström *et al.* 1992; Langius *et al.* 1993; Forsberg 1996) Data from a Stockholm population group showed a Cronbach's α of 0.74 (Forsberg & Björvell 1993). The instrument also have shown to have discriminant validity (Nordström *et al.* 1992).

The SWED-QUAL instrument was selected because it derives from an internationally used instrument, tested for reliability and validity in Sweden and because data from a Swedish reference group are available (Brorsson *et al.* 1993). The HI was used because it is short and includes items not found in the SWED-QUAL. Moreover, the HI has been used in a Stockholm population group (Forsberg & Björvell 1993).

Subjects

The subjects were recruited from a group of patients who were entering a pharmaceutical study of a therapeutic HIV vaccine at the Stockholm Söder Hospital. The inclusion criteria were HIV seropositivity, an estimated CD4 count of $>200 \times 10^6$ cells/l based on previous test results (i.e. $>300 \times 10^6$ cells/l within 3 months or $>200 \times 10^6$ cells/l within 1 month prior to study entry), age >15 years, a judgement that the patient was able to complete blood tests and other procedures required and absence of current acute disease, leucopenia, thrombocytopenia, hepatic abnormality, hypersensitivity to insect cells or baculo virus, pregnancy or plans to be pregnant during the coming two years or drug or alcohol abuse, neurological or psychiatric dysfunction which could negatively interfere with the patient's ability to participate in the study. Further details regarding the patient selection for the therapeutic trial have been presented elsewhere (Sandström & Wahren 1999).

Oral and written information about the study were given to the patients in connection to an ordinary, scheduled visit to the clinic. If they agreed to participate, they were asked to complete the questionnaires, marked with an anonymous identification number, and to return them in a closed envelope.

During the period August 1993 to April 1995, a total of 86 HIV-infected male out-patients were eligible for this study and 72 were included (2 declined to enter the vaccine trial, 3 were, by mistake, not asked to participate in this study, 1 was excluded owing to difficulties understanding the Swedish language and 8 declined participation in the present study).

All the participants ($n=72$) had HIV seropositive status documented by at least two laboratory tests (two repeated ELISA tests or one ELISA test and one Western Blot investigation).

Population groups

The SWED-QUAL questionnaire has been used in a sample of Swedish citizens ($n=1443$) (Brorsson *et al.* 1993). Details regarding the selection procedure have been presented by Brorsson *et al.* 1993. From this group, the results from men in the age-range 20-64 years, corresponding to that of the study population, were extracted and used for comparison (Swedish population group ($n=390$) (Brorsson, B. (1999) Personal communication)).

For comparison of the HI, a reference group of randomly selected, healthy persons living in Stockholm County, Sweden, was used ($n=180$) (Forsberg & Björvell 1993). Details regarding the selection procedure have been presented elsewhere (Forsberg & Björvell 1993). From this group, the results from men in the age-range 26-65 years were extracted and used for comparison (Stockholm population group, $n=60$).

Definitions

The demographic and medical variables are defined as follows:

Classification of subjects with diagnosed HIV are defined according to the Centers for Disease Control (CDC) at the U.S. Department of Health and Human Services (1986) (Centers for infectious disease control 1986): Group I, acute infection; group II, asymptomatic infection; group III, persistent generalised lymphadenopathy; and group IV, other diseases. Subjects in group IV are assigned to one or more of six subgroups (A, B, C1, C2, D and E), two of which consist of subjects with AIDS defining conditions (C1 and D).

The material is stratified into two groups regarding the initial CD4 value: $\leq 400 \times 10^6$ cells/l and $> 400 \times 10^6$ cells/l. This grouping was chosen based on results of previous therapeutic HIV vaccine trials (Bratt 1998).

Three income groups based on the stated income for the year 1993 are used: low ($< 150,000$ SEK), middle ($150,000$ - $200,000$ SEK) and high ($> 200,000$ SEK) (1 GBP = 11.71 SEK and 1 USD = 7.80 SEK (mean rate 1993. Source: Skandinaviska Enskilda Bank, Dept. of Foreign Currency)).

Educational level is defined as follows: basic (compulsory school), middle (upper secondary school/high school) and high (university studies).

Subjects who were being given anti-retroviral treatment (for example, AZT, ddI, ddC, 3TC) at the time of the investigation were compared with those who were not on such treatment.

Statistical methods

Statistical calculations were performed with the assistance of the personal-computer programmes SPSS for Windows, version 9.0.0. The criterion for statistical significance was $p < 0.05$. Since not all the scales fulfilled the assumptions of normal distribution, mainly non-parametric methods were used: the Kruskal-Wallis test and the Mann-Whitney U -test (Polit 1996). The former test was used initially in order to identify differences in the comparisons involving three groups and the latter for comparisons involving two groups. The subgroups compared are described in the definitions and or results sections. The Mann-Whitney U -test was also used for pairwise, *post hoc* comparisons, following statistically significant, Kruskal-Wallis tests. In order to control the Type I error rate for multiple comparisons of three groups, a 0.01667 significance criterion (Bonferroni adjustment) was used for the *post hoc* comparisons. In performing comparisons between the study group and the population groups, two-tailed, one-sample t -tests were used, since individual scores were not available in the published studies.

Ethical Committee

The study was approved by the Regional Ethical Committee at the Karolinska Institute.

RESULTS

Sample

The mean age was 37 years (SD 9, range 22-64 years). The inclusion criteria that stated an estimated CD4-value of $>200 \times 10^6$ cells/l resulted in a mean CD4 count of 431×10^6 cells/l (SD 193, range 110-1080). The mean duration of HIV infection for the 57 participants, where it was possible to estimate this, was 4.9 years (SD 3.3, range 0.4-10 years). Further data are shown in Table 1. The 13 participants who were on anti-retroviral treatment had a mean of 11 months since start of such treatment (SD 18, range 1.5 - 71 months). Furthermore, they had 247×10^6 cells/l in mean CD4 value (SD 115, range 110-520) and their CDC status was as follows: CDC group III ($n=3$), CDC IV C1 ($n=2$), CDC IV C2 ($n=6$), and CDC IV D ($n=2$).

The HRQOL and subjective health status related to population groups

The results of the SWED-QUAL scales for the 72 men included in the study are shown in Table 2. Statistically significant differences between the study group and the Swedish population group were found for all scales, except for physical functioning, satisfaction with physical ability and pain. The respondents in the study group stated their HRQOL worse, as compared with the population group.

The results of the HI for the 72 men in the study are shown in Table 3. The HIV-positive males stated their subjective health poorer (statistically significant), compared with that of the Stockholm population group.

The HRQOL and subjective health status related to medical variables

CDC status

Comparisons of the HRQOL between the groups of asymptomatic (CDC II/III; $n=50$), symptomatic (CDC IV, except C1 and D; $n=16$) and AIDS (CDC IV C1 and D; $n=6$) subjects are shown in Table 4. Statistically significant differences were found between the three groups, as regarded several of the SWED-QUAL scales. *Post hoc* contrasts showed statistically significant differences between the asymptomatic group and the AIDS group, as regarded the following SWED-QUAL scales: physical functioning ($p < 0.01$), mobility ($p < 0.001$) and satisfaction with physical ability ($p < 0.01$). Statistically significant differences were also found between the symptomatic group and the AIDS group, as regarded the SWED-QUAL scales for mobility ($p < 0.01$), satisfaction with physical ability ($p = 0.01$), and role limitations due to physical health ($p < 0.01$). No differences were seen, as regarded the HI.

Anti-retroviral treatment

On comparing the persons treated with anti-retroviral drugs at the time of investigation vs. those who were not treated with such drugs, the former group scored significantly lower on the following SWED-QUAL scales: physical functioning, mobility, satisfaction with physical ability, sleep problems and general health perception (Table 5).

As regarded the total HI, as well as the EWB and the PWB subscales, the persons treated with anti-retroviral drugs stated their subjective health worse than persons not treated with these drugs (Table 5).

CD4 values

Comparison of the two CD4 groups ($CD4 \leq 400 \times 10^6$ cells/l vs. $CD4 > 400 \times 10^6$ cells/l) showed a statistically significant difference, as regarded the SWED-QUAL physical functioning scale ($p < 0.05$). Those with the higher number of CD4 values scored their physical functioning as better (median 100, range 85.7 - 100) than those with the lower number of CD4 values (median 95.2, range 47.6 - 100). No differences were seen, as regarded the HI.

The HRQOL and subjective health status related to demographic variables

Sick leave/disability pension

On comparing the respondents who were on sick leave or had disability pensions at the time of the investigation ($n=27$) with those who were working full- or part-time ($n=45$), the former group scored statistically significantly lower on a majority of the SWED-QUAL scales (Table 6).

As regarded the HI, statistically significant differences were found between the two groups, i.e. those on sick leave or with disability pensions scored lower on the total HI and the EWB and PWB subscales than those working full- or part-time (Table 6).

Having a partner or not

On comparing the participants who had partners with those who had not, no statistically significant differences were seen for either of the instruments.

Income level

The comparisons of the SWED-QUAL scales between the three income groups (low, middle and high) showed statistically significant differences for some of the scales (Table 6). *Post hoc* contrasts showed statistically significant differences between the low- and the middle-income groups, as regarded the pain scale ($p < 0.01$) and the general health perception scale ($p = 0.016$) and between the low- and the high-income groups, as regarded the general-health-perception scale ($p < 0.01$). Although a statistically significant difference was found between the groups on the scale for role limitations due to physical health (Kruskal-Wallis test), no statistically significant, pairwise, *post hoc* contrast between any of the stated groups could be identified (Mann-Whitney *U*-test).

As regarded the HI, there was a statistically significant difference for the total HI score and for the EWB subscale (Table 6). Results of the *post hoc* contrasts showed that the low-income group scored lower than the high-income group on the EWB subscale ($p < 0.01$). Although a statistically significant difference was found between the groups for the total HI (Kruskal-Wallis test), no statistically significant, pairwise, *post hoc* contrast between any of the stated groups could be identified (Mann-Whitney *U*-test).

Education

The comparisons of the SWED-QUAL scales according to the three education groups (basic, middle and high) showed statistically significant differences for two of the scales (Table 6). *Post hoc* contrasts showed statistically significant differences between the basic- and the high-education groups, as regarded the pain scale ($p < 0.001$). Statistically significant, *post hoc* contrasts were also

found between the basic- and the middle-education groups, as regarded the sleep problems scale ($p < 0.01$).

As regarded the HI, statistically significant differences between the groups were found for the PWB subscale (Table 6). Results of the *post hoc* contrasts for the PWB subscale showed that the basic-education group scored lower than the middle-education group ($p = 0.013$).

Reliability of SWED-QUAL and HI

In the present study, Cronbach's α reliability estimates for the 11 SWED-QUAL, multi-item scales indicated good internal consistency, i.e. for physical functioning 0.79, role limitations due to physical health 0.93, pain 0.92, positive affect 0.91, absence of negative affect 0.87, role limitations due to emotional health 0.93, sleep 0.85, satisfaction with family life 0.85, relation to partner 0.79, sexual functioning 0.83, and general health perception 0.88.

Good internal consistency was also indicated for the total HI and for the EWB subscale (α 0.86 and 0.80 respectively). The internal consistency for the PWB subscale was α 0.68.

DISCUSSION

Although HIV infection is normally characterised by a long period (several years) with no or minor symptoms, the infection affects several dimensions of the HRQOL. In the present investigation, the SWED-QUAL and Health Index instruments were used in order to assess the HRQOL and the subjective health status in 72 HIV carriers. The results of the present study indicated that these two instruments are reliable and valid for use in HIV-positive patients. Adequate internal consistency was found for both instruments. Both instruments also showed to have discriminant validity. Although a high proportion of the patients scored highest possible values in different scales, the instruments discriminated between groups in several of the subgroup comparisons (for example the working status groups (working vs. not working) and the anti-retroviral treatment groups (treatment vs. no treatment) respectively). The shorter HI (approx. 5 minutes to complete) however, was a little less able to discriminate between groups than the longer SWED-QUAL (approx. 15 minutes to complete). The instruments' sensitivities to changes over time have still to be investigated.

The overall result showed that the investigated group of patients had a clearly negatively affected HRQOL and subjective health status, compared with the general-population samples used. In order to discover whether the differences between the study group and the population groups depend on the HIV infection or have other influences (for example, sexual orientation), further investigations are needed.

On comparing the investigated group with the population groups, it was the dimensions of emotional well-being that were found to be most affected. These results may be explained by the fact that the subjects in this study consisted of

relatively healthy HIV carriers, who are not so physically affected by the disease. Similar results have also been shown by Ragsdale & Morrow 1990.

The instruments used in the present study have also been used in studies investigating the HRQOL and subjective health status in other disease groups, for example, patients with glaucoma, diabetes mellitus, breast cancer and urostomies (Nordström *et al.* 1992; Larsen *et al.* 1996; Wändell *et al.* 1997a; Wändell *et al.* 1997b). It seems that these groups are more physically affected and less emotionally affected than the investigated HIV group. This seems logical, as a majority of the studied group had no or minor physical symptoms of their infection.

When the HRQOL and subjective health status were compared according to the medical and demographic variables for the different subgroups within the studied group, differences in the physical-dimension scales were most prominent. The disease stage (i.e. CDC status) seemed to affect the HRQOL. Patients included in the AIDS group scored lower on several SWED-QUAL physical-dimension scales, compared with the asymptomatic and symptomatic disease groups. Similar results have also been shown by several investigators, using various instruments (Ragsdale & Morrow 1990; Wu *et al.* 1991; Lubeck & Fries 1992; Schag *et al.* 1992; Wachtel *et al.* 1992; Revicki *et al.* 1995; Hughes *et al.* 1997; Peterman *et al.* 1997; Smith *et al.* 1997). It should be noted that Burgess *et al.*, like the present investigators, found significant relations between the disease stage and the scales measuring physical and functional aspects of the quality of life and, also like the present investigators, they found only a few significant relations on most of the psychological measures and global ratings of the quality of life (Burgess *et al.* 1993).

The patients who were on anti-retroviral treatment were more physically affected and stated their general health as worse, compared with those not so treated. Lenderking *et al.* however, found better perceived health in patients experienced in anti-retroviral treatment, compared with patients inexperienced in this treatment (Lenderking *et al.* 1997). Since the present study was not randomised according to anti-retroviral treatment, there could be some medical differences between the groups. The treated patients seemed to have lower CD4 counts, and more patients seemed to be symptomatic, compared with those not treated. It remains to investigate if the affected HRQOL was induced by disease stage or by side effects of the ongoing treatment. Further studies are needed to follow the disease progression's impact on HRQOL and to follow the effect of anti-retroviral treatment on the HRQOL.

CD4 values seemed to be poor predictors of how the HIV-infected subjects stated their HRQOL. Only one of the measures used, the SWED-QUAL physical-function scale, differed significantly as between the two CD4 subgroups. However, in this study, only a small fraction had CD4 values <200. Similar results have also been found by other groups (Ganz *et al.* 1993; Lenderking *et al.* 1997; Murri *et al.* 1997)

Studies highlighting differences between HIV carriers who are able to work and those who are not able to work are scarce. Not surprisingly, the present investigation showed that those who were on sick leave or had disability pensions stated their health status as worse, compared with those working full- or part-time. Similar results were also found by Hansen *et al.* in a HIV-positive sample (Hansen *et al.* 1993) and by Nordström *et al.* in a group of patients with ileal-conduit, urinary diversion (Nordström *et al.* 1992).

A study by Kendall showed, in a sample of HIV-positive, homosexual men, that close relations were the most important aspect of well-being (Kendall 1996). Moreover, it has been shown that living with a partner or not has an impact on the perceived well-being of pre-dialysis patients (Klang *et al.* 1996) and colo-rectal- and gastric-cancer patients (Forsberg *et al.* 1995). One could thus expect that having a partner or not would influence the HRQOL. In the present study, however, having a partner or not had no impact on the subjects' stated HRQOL. Similar findings have also been made by Hansen, Norlin & Björvell who found no differences between the HIV patients who lived with someone vs. those who lived alone (Hansen *et al.* 1993).

Basic education and low income were related to poor HRQOL in the present study. These results confirm the findings of previous studies (Stewart *et al.* 1988; Wachtel *et al.* 1992; Cunningham *et al.* 1995; Holmes & Shea 1997).

CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

In conclusion, in the group of HIV-positive subjects, their disease seems to have a negative impact on the emotional well-being, compared with the reference groups. In combination with the fact that current anti-retroviral treatment options are expected to decrease the HIV-disease progression rate, this increases still more the importance of taking into account aspects of the patients' emotional well-being in nursing, as well as in medical care and interventions. One example could be multiprofessional support groups aiming to increase the patient's knowledge about the disease, treatment effects and how to cope with the situation. Such support groups could also give the patients the opportunity to exchange experiences with other people living with HIV and to decrease social isolation. Moreover, since there were major fluctuations of the impact on the HRQOL and subjective health status within the study group, this calls for individualised caring programs.

ACKNOWLEDGEMENTS

We would like to thank the nurses and physicians at the Gay Mens Health Clinic at Stockholm Söder Hospital for their help in administering the instruments to the participants. We would also like to acknowledge the assistance of the participants, who gave time and effort to respond to the questionnaires.

This study was supported by grants from the Committee for the Health and Caring Sciences at the Karolinska Institute, the Stockholm Söder Hospital, the Swedish Foundation for Health Care Sciences and Allergy Research, and the Physicians against AIDS Research Foundation.

References

- Bratt, G. (1998) *HIV-1 patient assessment and treatment. From Multitest to co-receptor (CCR5) gene polymorphism. From rgp160 immunization to highly active antiretroviral treatment (HAART)* Disertation, Karolinska Institute, Stockholm.
- Brorsson, B., Ifver, J. & Hays, R. D. (1993) The Swedish Health-Related Quality of Life Survey (SWED-QUAL). *Quality of Life Research* **2**, 33-45.
- Burgess, A., Dayer, M., Catalan, J., Hawkins, D. & Gazzard, B. (1993) The reliability and validity of two HIV-specific health-related quality-of-life measures: A preliminary analysis. *Journal of Acquired Immunodeficiency Syndrome* **7**(7), 1001-1008.
- Catalan, J. (1990) Psychiatric manifestations of HIV disease. *Baillière's Clinical Gastroenterology* **4**(2), 547-562.
- Centers for infectious disease control. (1986) Classification system for human T-lymphotropic virus type III/lymphadenopathy-associated virus infections. *Mortality and Morbidity Weekly Report* **35**, 334-349.
- Cunningham, W. E., Hays, R. D., Williams, K. W., Beck, K. C., Dixon, W. J. & Shapiro, M. F. (1995) Access to medical care and health-related quality of life for low-income persons with symptomatic human immunodeficiency virus. *Medical Care* **33**(7), 739-754.
- Forsberg, C. (1996) *The sense of well-being in a group of patients with gastro-intestinal cancer. Aspects of health-related quality of life and coping* Dissertation, Karolinska Institute, Stockholm, Sweden.
- Forsberg, C. & Björvell, H. (1993) Swedish population norms for the GHRI, HI and STAI-state. *Quality of Life Research* **2**, 349-356.
- Forsberg, C., Björvell, H. & Cedermark, B. (1995) Well-being and its relation to coping ability in patients with colo-rectal and gastric cancer before and after surgery. *Scandinavian Journal of Caring Sciences* **10**, 35-44.
- Ganz, P. A., Schag, C. A. C., Kahn, B., Petersen, L. & Hirji, K. (1993) Describing the health-related quality of life impact of HIV infection: Findings from a study using the

- HIV Overview of Problems-Evaluation System (HOPES). *Quality of Life Research* **2**, 109-119.
- Guyatt, G. H., Feeny, D. H. & Patrick, D. L. (1993) Measuring health-related quality of life. *Annals of Internal Medicine* **118**(8), 622-629.
- Hansen, S., Norlin, M. & Björvell, H. (1993) HIV-patienters självskattade hälso och funktionella status. Grund för individanpassad omvårdnads-planering. (The self-rated health and functional status of HIV patients. Basis for the individually adapted planning of care). *Vård i Norden* **2**, 9-11.
- Hays, R. D. & Shapiro, M. F. (1992) An overview of generic health-related quality of life measures for HIV research. *Quality of Life Research* **1**, 91-97.
- Holmes, W. C. & Shea, J. A. (1997) Performance of a new, HIV/AIDS-targeted quality of life (HAT-QoL) instrument in asymptomatic seropositive individuals. *Quality of Life Research* **6**, 561-571.
- Holzemer, W. L. & Wilson, H. S. (1995) Quality of life and the spectrum of HIV infection. *Annual Review of Nursing Research* **13**, 3-29.
- Hughes, T. E., Kaplan, R. M., Coons, S. J., Draugalis, J. R., Johnson, J. A. & Patterson, T. L. (1997) Construct validities of the Quality of Well-Being Scale and the MOS-HIV-34 Health Survey for HIV-infected patients. *Medical Decision Making* **17**, 439-446.
- Kendall, J. (1996) Human association as a factor influencing wellness in homosexual men with human immunodeficiency virus disease. *Applied Nursing Research* **9**(4), 195-203.
- Klang, B., Björvell, H. & Clyne, N. (1996) Quality of life in predialytic uremic patients. *Quality of Life Research* **5**, 109-116.
- Langius, A., Björvell, H. & Lind, M. G. (1993) Oral- and pharyngeal-cancer patients' perceived symptoms and health. *Cancer Nursing* **16**(3), 214-221.
- Larsen, J., Gardulf, A., Nordström, G., Björkstrand, B. & Ljungman, P. (1996) Health-related quality of life in women with breast cancer undergoing autologous stem-cell transplantation. *Cancer Nursing* **19**(5), 368-375.

- Laryea, M. & Gien, L. (1993) The impact of HIV-positive diagnosis on the individual, Part 1. *Clinical Nursing Research* **2**(3), 245-266.
- Lenderking, W. R., Testa, M. A., Katzenstein, D. & Hammer, S. (1997) Measuring quality of life in early HIV disease: The modular approach. *Quality of Life Research* **6**, 515-530.
- Lindqvist, R. & Sjöden, P.-O. (1998) Coping strategies and quality of life among patients on continuous ambulatory peritoneal dialysis (CAPD). *Journal of Advanced Nursing* **27**(2), 312-319.
- Lubeck, D. P. & Fries, J. F. (1992) Changes in quality of life among persons with HIV infection. *Quality of Life Research* **1**, 359-366.
- Murri, R., Ammassari, A., Fantoni, M., Scopperttuolo, G., Cingolani, A., Luca, A. D., Damiano, F. & Antinori, A. (1997) Disease-related factors associated with health-related quality of life in people with nonadvanced HIV disease assessed using an Italian version of the MOS-HIV Health Survey. *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology* **16**, 350-356.
- Nordström, G., Nyman, C. R. & Theorell, T. (1992) Psychosocial adjustment and general state of health in patients with ileal conduit urinary diversion. *Scandinavian Journal of Urology and Nephrology* **26**, 139-147.
- Patrick, D. L. & Eriksson, P. (1993) *Health Status and Health Policy: Quality of Life in Health Care Evaluation and Resource Allocation*. New York: Oxford University Press.
- Peterman, A. H., Cella, D., Mo, F. & McCain, N. (1997) Psychometric validation of the revised Functional Assessment of Human Immunodeficiency Virus Infection (FAHI) quality of life instrument. *Quality of Life Research* **6**, 572-584.
- Polit, D. F. (1996) *Data Analysis & Statistics for Nursing Research*. Saratoga Springs, New York: Humanalysis, Inc.
- Ragsdale, D. & Morrow, J. R. (1990) Quality of life as a function of HIV classification. *Nursing Research* **39**(6), 355-359.

- Revicki, D. A., Wu, A. W. & Murray, M. I. (1995) Change in clinical status, health status, and health utility outcomes in HIV-infected patients. *Medical Care* **33**(4), AS173-182.
- Saag, M. S. (1994) Natural history of HIV-1 disease. In S. Broder, J. Thomas C Merigan & D. Bolognesi (Eds.), *Textbook of AIDS Medicine* (pp. 45-53). Baltimore: Williams & Wilkins.
- Sandström, E. & Wahren, B. (1999) Therapeutic immunisation with recombinant gp160 in HIV-1 infection: a randomised double-blind placebo-controlled trial. Nordic VAC-04 Study Group. *Lancet* **353**(9166), 1735-1742.
- Schag, C. A. C., Ganz, P. A., Kahn, B. & Petersen, L. (1992) Assessing the needs and quality of life of patients with HIV infection: Development of the HIV Overview of Problems-Evaluation System (HOPES). *Quality of Life Research* **1**, 397-413.
- Smith, K. W., Avis, N. E., Mayer, K. H. & Swislow, L. (1997) Use of the MQoL-HIV with asymptomatic HIV-positive patients. *Quality of Life Research* **6**, 555-560.
- Stewart, A. L., Hays, R. D. & Ware, J. E. (1988) The MOS Short-form General Health Survey: Reliability and validity in a patient population. *Medical Care* **26**(7), 724-735.
- Stewart, A. L., Sherbourne, C. D., Hays, R. D., Wells, K. B., Nelson, E. C., Kamberg, C. J., Rogers, W. H., Berry, S. H. & Ware, J. E. (1992) Summary and discussion of MOS measures. In A. L. Stewart & J. E. Ware (Eds.), *Measuring Functioning and Well-Being. The Medical Outcomes Study Approach* (pp. 345-371). Durham, NC: Duke University Press.
- Swedish Institute for Infectious Disease Control. (1998) HIV and AIDS statistics, 1985 up to and including 31 March 1998. *Smittskydd* **4**(4), 49.
- Tarlov, A. R., Ware, J. E., Greenfield, S., Nelson, E. C., Perrin, E. & Zubkoff, M. (1989) The Medical Outcomes Study. An application of methods for monitoring the results of medical care. *JAMA* **262**(7), 925-930.
- Testa, M. A. & Simonson, D. C. (1996) Assessment of quality-of-life outcomes. *The New England Journal of Medicine* **334**(13), 835-840.

- UNAIDS/WHO Working Group on Global HIV/AIDS and STD Surveillance. (1997) *Global HIV, AIDS and STD surveillance. Report on the global HIV/AIDS epidemic, December 1997*. Geneva: UNAIDS/WHO.
- Wachtel, T., Piette, J., Mor, V., Stein, M., Fleishman, J. & Carpenter, C. (1992) Quality of life in persons with human immunodeficiency virus infection: Measurement by the Medical Outcomes Study Instrument. *Annals of Internal Medicine* **116**(2), 129-137.
- Ware, J. E. & Sherbourne, C. D. (1992) The MOS 36-Item Short-Form Health Survey (SF-36). I. Conceptual framework and item selection. *Medical Care* **30**(6), 473-483.
- World Health Organization. (1997) Global AIDS surveillance, Part I. *Weekly Epidemiological Record* **72**(48), 359.
- Wu, A. W., Mathews, W. C., Brysk, L. T., Atkinson, H., Grant, I., Abramson, I., Kennedy, C. J., McCutchan, J. A., Spector, S. A. & Richman, D. D. (1990) Quality of life in a placebo-controlled trial of Zidovudine in patients with AIDS and AIDS-related complex. *Journal of Acquired Immune Deficiency Syndromes* **3**(7), 683-690.
- Wu, A. W. & Rubin, H. R. (1992) Measuring health status and quality of life in HIV and AIDS. *Psychology and Health* **6**, 251-264.
- Wu, A. W. & Rubin, H. R. (1994) Approaches to health status assessment in HIV disease overview of the conference. *Psychology and Health* **9**, 1-18.
- Wu, A. W., Rubin, H. R., Mathews, W. C., Ware, J. E., Brysk, L. T., Hardy, W. D., Bozzette, S. A., Spector, S. A. & Richman, D. D. (1991) A health status questionnaire using 30 items from the Medical Outcomes Study. *Medical Care* **29**(8), 786-798.
- Wändell, P. E., Brorsson, B. & Åberg, H. (1997a) Quality of life in diabetic patients registered with primary health care services in Sweden. *Scandinavian Journal of Primary Health Care* **15**, 97-102.
- Wändell, P. E., Lundström, M., Brorsson, B. & Åberg, H. (1997b) Quality of life among patients with glaucoma in Sweden. *Acta Ophthalmologica Scandinavica* **75**(5), 584-588.

Table 1. Demographic and medical data regarding a Swedish sample of HIV-infected men ($n=72$)

	No of subjects	Percentage
Mode of transmission		
Male to male	69	96
Female to male	3	4
Ethnic group		
White	68	94
Asian	3	4
Other (mixed)	1	2
CDC status		
II	20	28
III	30	42
IV A	1	1
IV C1	2	3
IV C2	15	21
IV D	4	5
CD4 group		
$>400 \times 10^6$ cells/l	37	51
$\leq 400 \times 10^6$ cells/l	35	49
Anti-retroviral treatment, Yes/No	13/59	18/82
Sick leave, Yes/No	16/56	22/78
Disability pension, Yes/No	11/61	15/85
Having a partner, Yes/No	40/31	56/43
Not stated	1	1
Income		
Low (<150,000 SEK)	21	29
Medium (150,000-200,000 SEK)	33	46
High (>200,000 SEK)	15	21

Not stated	3	4
Education		
Basic	11	15
Medium	29	40
High	28	39
Not stated	4	6

Table 2. The Swedish Health-Related Quality of Life Questionnaire. Comparisons of the HIV-seropositive males ($n=72$) with the Swedish population group ($n=390$).

	HIV-seropositive males		Swedish population group	<i>p</i> -value
	Mean	SD	Mean	
SWED-QUAL				
Physical functioning	94.8	10.1	94.1	NS
Mobility	95.4	12.9	98.8	<0.05
Satisfaction with physical ability	77.0	26.2	78.5	NS
Role limitations due to physical health	78.7	31.0	92.0	<0.01
Pain	80.5	27.8	85.9	NS
Positive affect	65.5	26.1	76.7	<0.001
Absence of negative affect	59.4	29.2	76.3	<0.001
Role limitations due to emotional health	79.4	30.4	89.9	<0.01
Sleep problems	65.3	28.1	75.8	<0.01
Satisfaction with family life	63.8	26.7	83.5	<0.001
Relation to partner	76.4	19.9	85.4	<0.01
Sexual functioning	76.6	27.5	91.5	<0.001
General health perception	67.6	26.2	85.2	<0.001

NS = non-significant

Table 3. Health Index. Comparison of the HIV-seropositive males ($n=72$) with a Stockholm male population group ($n=60$).

	HIV-seropositive males		Stockholm population group	<i>p</i> -value
	Mean	SD	Mean	
Health Index (HI)				
Total (nine items)*	28.0	4.4	30.5	<0.001
Total (ten items)	31.1	5.0		
Emotional well-being (four items)	11.6	2.3		
Physical well-being (five items)	16.4	2.5		

* The general-health item was excluded in the Stockholm population group in calculating the total HI. Thus, the score ranges between 9 and 36.

Table 4. Health-related quality of life related to disease stage. Median and range are given for the scales on which statistically significant differences were found between groups.

	Disease stage			<i>p</i> -value ^a
	Asympt.	Sympt.	AIDS	
	Median	Median	Median	
	(Range)	(Range)	(Range)	
SWED-QUAL				
Physical functioning	100	100	81.0	<0.05
	(71.4-100)	(76.2-100)	(47.6-100)	
Mobility	100	100	66.7	<0.001
	(33.3-100)	(66.7-100)	(66.7-100)	
Satisfaction with physical ability	100	66.7	50.0	<0.05
	(0-100)	(33.3-100)	(0-66.7)	
Role limitations due to physical health	100	100	61.1	<0.05
	(0-100)	(33.3-100)	(22.2-88.9)	
Pain	-	-	-	-
Positive affect	-	-	-	-
Absence of negative affect	-	-	-	-
Role limitations due to emotional health	-	-	-	-
Sleep problems	-	-	-	-
Satisfaction with family life	-	-	-	-
Relation to partner	-	-	-	-
Sexual functioning	-	-	-	-
General health perception	-	-	-	-

^a Kruskal-Wallis test

Table 5. Health-related quality of life and subjective health status related to anti-retroviral treatment. Median and range are given for the scales on which statistically significant differences were found between groups.

	Anti-retroviral treatment		<i>p</i> -value ^a
	Treated	Not treated	
	Median	Median	
	(Range)	(Range)	
SWED-QUAL			
Physical functioning	95.2 (47.6-100)	100 (71.4-100)	<0.01
Mobility	100 (66.7-100)	100 (33.3-100)	<0.01
Satisfaction with physical ability	66.7 (0-100)	100 (0-100)	<0.05
Role limitations due to physical health	-	-	-
Pain	-	-	-
Positive affect	-	-	-
Absence of negative affect	-	-	-
Role limitations due to emotional health	-	-	-
Sleep problems	42.9 (16.7-92.9)	78.6 (14.3-100)	<0.05
Satisfaction with family life	-	-	-
Relation to partner	-	-	-
Sexual functioning	-	-	-
General health perception	44.4 (25.0-88.9)	77.8 (11.1-100)	<0.01
Health Index (HI)			
Total	28 (20-35)	33 (20-40)	<0.05

Emotional well-being	10 (7-13)	12 (6-16)	<0.05
Physical well-being	15 (10-19)	17 (11-20)	<0.05

^a Mann Whitney *U*-test

Table 6. Health-related quality of life and subjective health status related to demographic variables. Median and range are given for the scales on which statistically significant differences were found between groups.

[illegible]

Role limitations due to	77.8	100	<0.01	-	-	-	-	-	-	-	-
emotional health	(0-100)	(0-100)									
Sleep problems	42.9	83.9	<0.01	-	-	-	-	35.7	82.1	75.0	<0.05
	(14.3-100)	(16.7-100)						(21.4-92.9)	(14.3-100)	(16.7-100)	
Satisfaction with family life	-	-	-	-	-	-	-	-	-	-	-
Relation to partner	-	-	-	-	-	-	-	-	-	-	-
Sexual functioning	-	-	-	-	-	-	-	-	-	-	-
General health perception	58.3	83.3	<0.01	44.4	77.8	88.9	<0.01	-	-	-	-
	(11.1-100)	(16.7-100)		(16.7-100)	(11.1-100)	(30.6-100)					
Health Index (HI)											
Total	28	34	<0.01	29	33	34	<0.05	-	-	-	-
	(20-39)	(20-40)		(20-39)	(21-39)	(20-40)					
Emotional well-being	11	12	<0.05	11	12	12	<0.05	-	-	-	-
	(8-15)	(6-16)		(6-15)	(8-16)	(8-16)					
Physical well-being	15	17	<0.05	-	-	-	-	15	17	17.5	<0.05
	(10-20)	(12-20)						(12-18)	(11-20)	(10-20)	

^a Mann-Whitney *U*-test; ^b Kruskal-Wallis test