



*Citation for published version:*

Skevington, SM 2012, 'Is quality of life poorer for older adults with HIV/AIDS? International evidence using the WHOQOL-HIV', *AIDS Care - Psychological and Socio-medical Aspects of AIDS/HIV*, vol. 24, no. 10, pp. 1219-1225. <https://doi.org/10.1080/09540121.2012.661838>

*DOI:*

[10.1080/09540121.2012.661838](https://doi.org/10.1080/09540121.2012.661838)

*Publication date:*

2012

*Document Version*

Peer reviewed version

[Link to publication](#)

This is an Author's Accepted Manuscript of an article published in Skevington, S. M., 2012. Is quality of life poorer for older adults with HIV/AIDS? International evidence using the WHOQOL-HIV. *AIDS Care - Psychological and Socio-medical Aspects of AIDS/HIV*, 24 (10), pp. 1219-1225., copyright Taylor & Francis, available online at <http://dx.doi.org/10.1080/09540121.2012.661838>

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**Is quality of life poorer for older adults with HIV/AIDS?**

**International evidence using the WHOQOL-HIV**

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Sources of Support: World Health Organisation, Geneva, Switzerland; Univ. of Bath, UK.

Keywords: HIV, international, quality of life, old age, WHOQOL-HIV

Running Head: International quality of life in older adults with HIV

Words 3049



## Abstract

Increasingly older adults are being diagnosed with HIV/AIDS. In 2002, UNAIDS indicated that 13 aspects of quality of life (QoL) were poorer for older adults, but only sparse, inconsistent cross-cultural evidence is available. This statement was investigated using a reliable, valid measure (the WHOQOL-HIV) distributed in nine cultures (8 countries). HIV positive and well adults (n= 2089) were assessed across 30 QoL facets; 403 were 40+ years. It was confirmed that sleep, fatigue and sex-life were poorer areas of QoL for older HIV adults than younger. Furthermore they could be misinterpreted as normal ageing signs. Moreover, older people reported greater dependency on medication. However, older HIV adults had better QoL than expected on 11 dimensions; negative feelings, social inclusion and several environmental and spiritual facets. This highlights the extent of poor QoL in younger adults. After accounting for culture and gender, overall QoL and health in older HIV adults was explained by eight facets comprising 61.3% of the variance. Social relationships were paramount, especially personal relationships (41%), but support and sex-life also. Energy, negative feelings, cognitions, financial resources and HIV symptoms also contributed. Social interventions for ageing communities would improve wellbeing. This evidence could support global ageing and HIV policy.

Words = 200

## **Is quality of life poorer for older adults with HIV/AIDS?**

### **International evidence using the WHOQOL-HIV.**

More people with HIV are surviving into old age (Centre for Disease Control and Prevention, 2006), although exact numbers are unknown (Shippy and Karpiak, 2005). With reduced fertility, older people are unlikely to suspect they are infected (Ward, Disch, Levy et al, 2004). When seeking diagnostic testing for HIV, older people typically present with a later disease stage (Lekas, Schrimshaw and Siegal, 2005), and earlier detection would help them stay healthier longer and reduce transmission. Consequently, invisible older adults with HIV present a public health challenge, and research recruitment difficulties.

Health professionals are poorly informed about this issue. Symptoms misinterpreted as 'normal' ageing can result in misdiagnosis and/or treatment delays (Emlet, Gerkin and Orel, 2009). Variable attitudes towards sexually active older patients mean that some practitioners are reluctant to discuss sexual behaviour (UNAIDS, 2002). Where awareness is higher, confidence about how to broach this subject can be low, as health education evidence is sparse for this age group. Even prosperous countries with long-standing epidemics have been slow to take action. By 2004, only 15 US States had adapted their HIV education literature to older audiences (Orel, Wright and Wagner, 2004). Shaping professional attitudes is seen as crucial to tackling this epidemic internationally (UNAIDS, 2002).

Little is known about the quality of life (QoL) of older adults with HIV. Research samples tend to be less than 100 (e.g. Speer, Kennedy, Watson et al, 1999), and recruited from a single centre. Most studies investigate one ethnic group and are usually conducted in USA. 'Objective' economic indicators are often preferred over 'subjective' QoL assessment (e.g. Sankar, Luborsky, Rwabuhemba et al.1998). Although generic instruments are

infrequently used, an advantage over HIV-specific measures is the integration of QoL impact of a disease with its co-morbidities e.g. tuberculosis (Avis and Smith, 1998). The generic EQ-5D has been used to assess HIV age groups although no QoL differences were found (Sherr, Harding, Lampe et al, 2009).

The present study represents an international investigation of subjective QoL in older adults with HIV, as culturally appropriate measures are now available for use across the life-span and disease course. The World Health Organisation definition of QoL guides this research: *“An individual’s 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”* (The WHOQOL Group, 1994). Drawing from this framework and a unique methodology (Skevington and O’Connell, 2003), multiple language versions of the WHOQOL-HIV are now available that have better semantic and conceptual equivalence between cultures than before (Bowden and Fox-Rushby, 2003)

From a UNAIDS ‘fact sheet’ (UNAIDS, 2002), we deduced that 13 areas of QoL were poorer for older people with HIV. However international conclusions seemed limited by piecemeal results from various cultures using different methods. This policy brief also suggested that older people delayed seeking testing because early HIV symptoms of fatigue (Siegal, Bradley and Lekas, 2004), poor memory, breathlessness, sleeplessness and weight loss are commonly misinterpreted as ‘normal’ ageing signs (UNAIDS, 2002). Compared to younger adults, older adults appear to report more negative feelings, greater stigma (Emlet, Gerkin and Orel, 2009) and social exclusion (Schrimshaw and Siegal, 2003; Shippy and Karpiak, 2005), less health and social care access, lower social support (e.g. Skevington,

Norweg, Standage et al, 2010), a poorer sex-life and fewer financial resources. These 13 QoL issues can be operationalised by facets of the WHOQOL-HIV.

The present research aimed to test UNAIDS' (2002) observations about age differences using international data obtained from this single multi-lingual instrument. The fact sheet provides predictions that older adults with HIV would have poorer QoL than younger adults on 13 of the 30 WHOQOL-HIV dimensions. By also testing age differences in a well comparison group, we could examine whether any differences found between HIV age groups were attributable to ageing or to disease. Lastly, these dimensions were examined to find out whether they predicted overall QoL and health in older people with HIV.

## **Method**

**Sampling and Design:** Secondary analysis was conducted on merged data from two published surveys designed to test the psychometric properties of the WHOQOL-HIV (O'Connell, Skevington, Saxena and the WHOQOL-HIV Group, 2003; O'Connell, Saxena and Skevington for the WHOQOL-HIV Group, 2004). The combined sample contained 2234 adults recruited in 9 centres (cultures) located in 8 countries with an HIV epidemic. Two samples were contributed from Melbourne, Australia (total n=331); Porto Alegre, Brazil (n=452); Bangalore, S. India (n=350); New Delhi, N. India (n=194), and Bangkok, Thailand (n=158); and one sample each from Harare, Zimbabwe (n=149); Rome, Italy (n=150); Dniepropetrovsk, Ukraine (n=300), and Phnom Penh, Cambodia (n=33).

Recruitment was across the adult age-range. Quota sampling targets for gender were 50% men/women. For disease stage the quota was 33% for three groups in one

survey (AIDS, symptomatic-HIV and asymptomatic-HIV) (O'Connell, Saxena and Skevington for the WHOQOL-HIV Group, 2004), and 25% in the other, as a fourth 'well' group was added (O'Connell, Skevington, Saxena and the WHOQOL-HIV Group, 2003). AIDS was defined as major disease signs/symptoms e.g. Kaposi sarcoma, weight loss. Symptomatic-HIV was defined as minor disease; asymptomatic-HIV as a positive diagnosis without signs. Well people did not report any signs or symptoms.

**Procedures:** The World Health Organisation (Geneva) gave international ethical approval, and local approvals were obtained. The WHOQOL-HIV was self-administered or interviewer-administered (e.g. Brazil), in communities, outreach clinics and hospital out- and in-patient departments. Well people were recruited from the same localities.

**Measure:** Language versions of the WHOQOL-HIV were developed simultaneously in the centres, and the structure, contents and protocols were internationally agreed at each stage (O'Connell, Skevington, Saxena and the WHOQOL-HIV Group, 2003; O'Connell, Saxena and Skevington for the WHOQOL-HIV Group, 2004; The WHOQOL-HIV Group, 2003). Concepts are positively framed wherever possible. Response scales extend to the upper end of wellbeing.

The WHOQOL-HIV contains 120 items organised in 30 facets and scored as six domains: physical, psychological, independence, social, environment and spiritual QoL. It integrates 100 generic items from the WHOQOL-100 (25 facets of 4 items) with 20 HIV-specific items organised in five HIV facets on HIV symptoms, social inclusion, forgiveness/blame, death and dying and concern about the future (O'Connell, Saxena and Skevington for the WHOQOL-HIV Group, 2004). Information is gathered on gender, age, and years infected. High scores reflect good QoL. A General facet assessing overall QoL and



health is not scored, unlike the 29 specific facets. The WHOQOL-HIV is reliable and valid (O'Connell, Skevington, Saxena and the WHOQOL-HIV Group, 2003; O'Connell, Saxena and Skevington for the WHOQOL-HIV Group, 2004).

**Analysis:** Although age 49 years internationally defines the lower age range of older adults, using this would have excluded from the analysis many older participants from developing countries where life expectancy was lower (e.g. Zimbabwe 44 years) at the time of data collection (1999-2001). Forty years was therefore selected to distinguish older (40-76) from younger (10-39) age groups.

Centre data was examined for normality. Two-way ANOVA (repeated measures) compared young and old across four HIV status groups and six QoL domains (Scheffe). One-way ANOVA tested age differences for 13 predicted facets. *Post hoc* tests were used for the 17 unpredicted facets, and well age groups.

Hierarchical multiple regression analysis tested which predicted QoL dimensions (independent variables) significantly explained overall QoL and health (dependent) in older people with HIV. Dummy gender and centre variables were entered into the model at step 1. Stepwise procedures assessed facet contributions at step 2.

## Results

**Sample:** A total of 2089 participants were analysed, aged 10-76 years. Of these, 77% were younger and 23% older; 63% men and 37% women. Fifty% completed secondary schooling, 26% tertiary education, and 24% primary/no education. Thirty-four % were asymptomatic, 32% symptomatic, 19% had AIDS, 15% were well. The mean duration of HIV infection was 23 years.

Of the 403 HIV-positive adults over 40, Australia contributed 43%, Brazil 20%, Bangalore, India 11%, Italy 9%, Ukraine 5%, Zimbabwe 5%, Thailand 4%, Cambodia 3% and New Delhi, India 1%. Seventy-seven % were 40-49 years, 19% 50-59 and 4% 60+ years. Thirty-five% were HIV-asymptomatic, 32% HIV-symptomatic, and 33% had AIDS. Men constituted 78%; the gender distribution was similar across decades. Less than 20% were women in Australia, New Delhi and Cambodia. Twenty-two % had no/little education, 42% secondary schooling and 34% tertiary education.

### **INSERT TABLE 1 HERE**

#### **1. Is quality of life poorer for older adults with HIV than younger adults?**

A main effect for age was found ( $F = 9.39$ ,  $(df 1, 2080)$   $p < .002$ ) but against prediction, QoL was poorer for younger adults with HIV than older people. Older adults with HIV reported better psychological, environmental and spiritual QoL than younger adults (see Tables 1 and 2). Quality of life was best for well people (3.8), then asymptomatic (3.5), symptomatic (3.1), and AIDS (2.9) ( $F 137.64$  ( $df 3, 2080$ )  $p < .0001$ ) (age differences  $p = .028$  to  $p = .0001$ ), but the interaction was not significant ( $F = .840$ ,  $p = .472$ ).

Age groups were compared for the 13 predicted QoL facets (**bold** Table 1). Within this subgroup, five QoL dimensions where early HIV signs and ‘normal’ ageing might be confused were first considered. Of these, older adults reported significantly less energy and poorer sleep, but no age differences were found for cognitions, body image and HIV symptoms. For the remaining predicted facets, only poorer sex-life was confirmed for older adults. Consequently, only three out of 13 predicted facets showed that older people with HIV had poorer QoL.

Furthermore, there were three contradictory results. Older adults with HIV reported significantly less negative feelings, lower social exclusion, and greater access to health care than young. However age differences were not found for overall QoL and health, personal relations, social support or perceived financial resources. Quality of life relating to financial resources was poor, and the poorest dimension on the profile.

Age differences investigated for 17 unpredicted facets showed that nine were significant (see Table 1). However, only dependence on medication and treatment was poorer for older people. In contrast, QoL on eight facets was better for older people than young: positive feelings, physical safety, home environment, recreation, physical environment and transport, and spiritual facets on forgiveness/blame and concern about the future.

It was unclear whether age differences found for those with HIV were due to ageing or illness, so age differences for well adults were also compared. Well older people reported better body image ( $F=5.98$ ,  $p=.015$ ) and personal relationships ( $F=5.04$ ,  $p=.026$ ) than well younger people. However, no significant differences were found for these facets in the HIV group (Table 1). Furthermore, the well group did not show significant age differences on any facet where differences were found in HIV (Table 1). This indicates that age differences in the HIV group cannot be entirely explained by ageing.

#### **INSERT TABLE 2 HERE**

The Table 2 domain means for age and health status groups showed that QoL was better for older well (3.8) and HIV-positive (3.5) groups than younger well (3.8) and HIV (3.0) adults, respectively. Only the physical domain was better for younger well people than older, as expected.

MANOVA was also used to explore the QoL interaction for age and country and was significant ( $F=2.06$ ;  $p<.037$ ). Poorer QoL for older people compared to young was reported in Australia, N. Delhi and Ukraine. Poorer QoL for younger people was found in Harare, Thailand and Cambodia; QoL was similar for age groups in Brazil, Bangalore and Italy. Overall the poorest QoL was in India.

## **2. Predicting quality of life and health for HIV-positive older adults.**

Testing which predicted QoL facets best explained overall QoL and health in older adults with HIV, hierarchical multiple regression showed that a substantial 65.3% of the total variance was explained (see Table 3). Four % of this was explained by culture (centre) and gender but then eight facets entered into the model explained a further 61.3% of the variance. The social relationships domain best explained overall QoL and health in older adults with HIV (43.6%). Within this, personal relationships explained a substantial 41.1%, with significant contributions from social support (1.5%) and sex-life (1.0%). Physical QoL was mainly explained by energy and fatigue (10.3%); HIV symptoms had low impact (0.4%). In the psychological domain (7.4%), negative feelings and cognitions were equally important. The impact of perceived financial resources was small (0.5%).

**INSERT TABLE 3 HERE**

## **Discussion**

This study provides the first substantive international evidence on subjective QoL in older adults with HIV. The WHOQOL-HIV data contained QoL information from nine diverse cultures, and its 30 dimensions enabled a fine-grained multi-dimensional appraisal to

be made. As older adults with HIV become more visible in seeking health care, empirical information about their QoL will be essential to policy-making and resource planning.

Although UNAIDS (2002) indicated that 13 QoL dimensions were poorer for older adults with HIV, our international findings only confirmed three: sleep, energy and sex-life. Furthermore, when the 17 remaining dimensions were explored, only dependence on medication and treatment was poorer for older adults. Consequently, only four out of 30 QoL dimensions are significantly poorer for older people. As age comparisons for well people showed that older people had better body image and personal relationships than young, these findings support the conclusion that the four differences found for HIV adults arise more from disease impact than ageing.

Although few QoL features predicted from the UNAIDS facet sheet distinguished old from young, several of these dimensions proved to be good predictors of overall QoL and health in older HIV adults. After culture and gender were accounted for (4%), eight QoL facets explained 61% of this variance. Social QoL was of overriding importance, and in particular, personal relationships were paramount (41%) alongside support and sex-life. Combined with few negative feeling and good cognitive QoL in the over 40s, the psychosocial impact of HIV on QoL substantially exceeded its physical impact. Community interventions tailored to address social relationships in older adults, e.g. Stepping Stones (Welbourn,1995), therefore have considerable promise in being most effective in facilitating significant improvements to wellbeing in older people (Sovetkina, Skevington and Gillison, unpubl.).

These four characteristics of poor QoL provide valuable markers when caring for older adults and warrant closer clinical attention. They represent common physical and

functional problems that are readily treatable through effective medications and behavioural interventions e.g. CBT. A subjective measure like the WHOQOL-HIV could assess QoL routinely, where older people report ambiguous symptoms. Completed simultaneously with physical investigations e.g. blood tests investigating a viral cause for fatigue, this assessment has potential to improve diagnosis and inform treatment choice.

A new finding was that although the QoL of older people with HIV was not very good, they reported more positive QoL on 11 dimensions than younger people; a third of the total dimensions measured. When set alongside the four negative dimensions this indicates a positive life balance that simultaneously demonstrates ‘active ageing’ (World Health Organisation, 2002) among over 40s with HIV. Choice of the WHOQOL-HIV measure is relevant to these findings as unusually, this assessment was designed to include positive concepts and record the upper end of wellbeing. It therefore presents a range of positive dimensions for older people with HIV to rate, that have not been assessed together previously. The results are also commensurate with the WHO definition of QoL which enables positive ‘goals’, ‘expectations’ and ‘standards’ to be addressed with problem-centred ‘concerns’.

Older people who lead an active sex-life beyond their fertile years may not be concerned that their behaviour is risky. Greater awareness among the older population about the ambiguous nature of sleep disorder and fatigue, could prompt earlier diagnostic testing which could sustain life and wellbeing, by pre-empting higher viral loads that are so much harder to treat. Public health campaigns about risky unprotected sex would reduce onward virus transmission, and health costs. However to be effective, strategies sensitively tailored to older audiences are needed. Moreover, given exponential growth in the global ageing

population, routine training in how to address these issues appropriately and effectively with older adults will be required for all health professionals, not just gerontology and immunology specialists.

Both ages registered concern about poor financial QoL and insufficient resources to meet their needs. Low income and pensions are associated with poor QoL in older people in USA (Speer, Kennedy, Watson, et al, 1999), and sub-Saharan Africa (e.g. Nyambedha, Wandibba and Aagaard-Hansen, 2001), where the financial burden is accentuated by HIV-related problems e.g. caring for destitute children and sick relatives. In low GDP countries, income poverty for older people with HIV is exacerbated by medication, care and nutrition costs. However, older people value their environmental QoL across many other dimensions. Ageing affords perceptions of greater physical safety and security and access to recreation and leisure, a better home and physical environment, and transport. Unusual among QoL measures in health, the WHOQOL environment domain permits these important issues to be documented.

Older adults reported that dependence on medication was detrimental to a good QoL although paradoxically, anti-retroviral drugs sustain life by controlling the viral load. However, more recent changes like the greater effectiveness of HAART, and simplified medication schedules, may have changed QoL on this dimension. By transforming the status of HIV from terminal to chronic illness, HAART is likely to have changed QoL wherever it is now widely available. A contemporary QoL survey is needed.

Other methodological observations are offered. Adopting a 40 year criterion crucially enabled older people from developing countries to be included, and this could be incorporated into future international research. Some small centre samples precluded reliable

cross-cultural analysis. Despite international quotas for age and gender recruitment, variable numbers of older people were recruited. Country recruitment partially reflected the age and sexual orientation of their general population, and was influenced by when its epidemic began. For example, the recent Ukrainian epidemic meant that few older adults had HIV. Legal and stigmatising consequences from HIV disclosure in India affected sampling as well as QoL. These limitations should be addressed in new cross-cultural investigations. Using a short-form measure like the new WHOQOL-HIV BREF (O'Connell, Skevington, and the WHOQOL-HIV Group, 2010) would reduce completion burden and improve response rates. Data from other cultures e.g. sub-Saharan Africa is urgently required.

The Valletta declaration on older adults with HIV (Help the Aged and UN, 2005) urged policy-makers to be aware of the epidemic impact on older people and address their QoL needs. Our evidence provides underpinning for new international policies.



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**Acknowledgements**

I am indebted to the WHOQOL-HIV Group which comprises a coordinating group of collaborating investigators: Dr R. Billington, Dr J. Orley, Dr S Saxena, Ms M. Lotfy, Mr M Bartos, Dr P. Chandra, Dr M. Fleck, Dr L Bun Hor, Dr R. Bhargava, Prof F. Starace, Dr S. Pkhidenko, Dr K. Meesapya, Dr A Haworth, Dr J. Mutimbirwa and Dr K. O'Connell.

Further information on the WHOQOL can be obtained at

[http://www.who.int/mental\\_health/media/en/613.pdf](http://www.who.int/mental_health/media/en/613.pdf) and <http://www.bath.ac.uk/whoqol>

I am grateful to Help the Aged and United Nations International Institute on Ageing, and colleagues who attended the Commonwealth Heads of Government Expert Workshop on HIV/AIDS and Older people, Valletta, Malta in 2005.

**Table 1: Differences in the quality of life of HIV-positive older and younger adults from eight cultures, using the WHOQOL-HIV**

<b>Domains</b>	<b>Facets</b>	<b>Young Age &lt; 40 n=1379</b>	<b>Old Age &gt; 40 n=402</b>	<b>F</b>	<b>P</b>
<b>Physical</b>	Pain and discomfort	3.13	3.10	.36	.546
	<b>Energy and fatigue</b>	<b>3.15</b>	<b>3.01</b>	<b>7.29</b>	<b>.007*</b>
	<b>Sleep and rest</b>	<b>3.35</b>	<b>3.19</b>	<b>8.62</b>	<b>.003*</b>
	<b>Symptoms of HIV</b>	<b>2.90</b>	<b>2.91</b>	<b>.06</b>	<b>.805</b>
<b>Psychological</b>	Positive feelings	2.90	3.08	14.16	.0001*
	<b>Cognitions: thinking etc</b>	<b>3.34</b>	<b>3.36</b>	<b>.28</b>	<b>.593</b>
	Self esteem	3.31	3.38	2.93	.087
	<b>Body image and appearance</b>	<b>3.50</b>	<b>3.51</b>	<b>.09</b>	<b>.890</b>
	<b>Negative feelings</b>	<b>3.12</b>	<b>3.29</b>	<b>10.32</b>	<b>.001*</b>
<b>Independence</b>	Mobility	3.65	3.63	.22	.641
	Activities of daily living	3.37	3.39	.19	.660
	Working capacity	3.32	3.26	1.09	.298
	Dependence on medication	3.03	2.70	23.75	.0001*
	<b>Personal Relationships</b>	<b>3.38</b>	<b>3.35</b>	<b>.53</b>	<b>.468</b>
<b>Social</b>	<b>Social support</b>	<b>3.21</b>	<b>3.27</b>	<b>1.72</b>	<b>.190</b>
	<b>Sex-life</b>	<b>2.85</b>	<b>2.65</b>	<b>15.53</b>	<b>.0001*</b>
	<b>Social inclusion</b>	<b>3.10</b>	<b>3.34</b>	<b>30.91</b>	<b>.0001*</b>

<b>Environment</b>	Physical safety and security	3.05	3.30	35.76	.0001*
	Home environment	3.14	3.51	57.56	.0001*
	<b>Financial resources</b>	<b>2.62</b>	<b>2.68</b>	<b>1.56</b>	<b>.212</b>
	<b>Health and social care</b>	<b>3.15</b>	<b>3.42</b>	<b>42.28</b>	<b>.0001*</b>
	Information and skills	3.23	3.33	3.48	.062
	Recreation and leisure	2.95	3.08	8.15	.004*
	Physical environment	3.21	3.42	25.79	.0001*
	Transport	3.29	3.61	40.55	.0001*
<b>Spiritual</b>	Spirituality, religion and personal beliefs	3.21	3.21	.03	.861
	Forgiveness and blame	2.95	3.28	29.92	.0001*
	Concern about the future	3.01	3.59	106.39	.0001*
	Death and dying	3.03	3.14	2.92	.080
	<b>Overall QOL and health</b>	<b>3.05</b>	<b>3.13</b>	<b>2.98</b>	<b>.084</b>

**Bold =** Age differences predicted by UNAIDS

**Table 2: WHOQOL-HIV domain means (and standard errors) for younger and older people with HIV/AIDS compared to well.**

<b>WHOQOL-HIV Domains</b>	<b>Well Young</b>	<b>Well Old</b>	<b>HIV Young</b>	<b>HIV Old</b>
<b>Physical</b>	3.92 (.04)	3.78 (.09)	2.41 (.03)	3.05 (.06)
<b>Psychological</b>	3.76 (.04)	3.86 (.07)	3.21 (.03)	3.32 (.05)
<b>Independence</b>	4.10 (.05)	4.18 (.09)	3.27 (.04)	3.27 (.07)
<b>Social</b>	3.63 (.04)	3.84 (.07)	3.11 (.03)	3.15 (.05)
<b>Environment</b>	3.33 (.04)	3.43 (.07)	3.07 (.02)	3.29 (.05)
<b>Spiritual</b>	3.85 (.05)	3.91 (.09)	3.03 (.04)	3.30 (.06)



**Table 3. Which dimensions best predict overall quality of life and health in HIV-positive adults over 40 years?**

<b>Step/Variables</b>	<b>Adjusted R square</b>	<b>R square change %</b>	<b>F change</b>	<b>p change</b>
1. Centre & Gender	.036	4.0	8.40	.0001
2. Personal relations	.447	41.1	297.58	.0001
Energy and fatigue	.550	10.3	91.21	.0001
Negative feelings	.590	4.1	39.97	.0001
Cognitions	.622	3.3	34.61	.0001
Social support	.636	1.5	16.04	.0001
Sex-life	.646	1.0	11.55	.001
Financial resources	.650	0.5	5.95	.015
Symptoms of HIV	.653	0.4	4.10	.043

**df = 1, 390-8**