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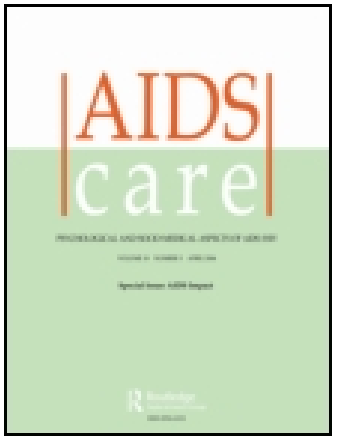

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Quality of life and social support among patients receiving antiretroviral therapy in Western Uganda

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Quality of life and social support among patients receiving antiretroviral therapy in Western Uganda

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Quality of life (QOL) among patients with HIV/AIDS has been shown to improve once treatment with antiretroviral therapy (ART) has been initiated. We conducted a cross-sectional study in Western Uganda to examine the factors associated with QOL among patients who had received ART for the duration of at least six months.

We interviewed 330 patients attending the HIV/AIDS clinic at two government-supported hospitals in Western Uganda. We measured QOL using a culturally adapted version of the Medical Outcomes Study (MOS-HIV) tool and calculated the physical health summary (PHS) and mental health summary (MHS) scores. In addition, data were collected on sociodemographic factors, three-day self-reported adherence, social support, sexual behavior, CD4 count and viral load.

Informational social support was significantly positively correlated with PHS ($p = 0.001$) and MHS ($p = 0.002$). Affectionate support was also significantly positively correlated to PHS ($p = 0.05$) and MHS ($p = 0.03$) but tangible support was not (PHS p value $= 0.85$ and MHS p value $= 0.31$). In the univariate analysis, older age, rural dwelling, alcohol use, CD4 count less than 200, and ART duration of less than one year were significantly associated with lower PHS scores. Lower PHS scores were also associated with sexual inactivity. In multivariate analysis, higher scores on informational social support and CD4 > 200 were associated with higher PHS score and past or recent alcohol consumption was associated with lower scores on MHS.

Optimizing ART to restore CD4 count and provision of informational and affectionate social support but not tangible support, to HIV/AIDS patients may improve their QOL.

Keywords: quality of life; social support; AIDS; antiretroviral; Uganda

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Introduction

Antiretroviral therapy (ART) reduces morbidity and mortality due to AIDS in the developed countries (Palella et al., 1998; van Sighem et al., 2003). With reduced mortality and longer survival, quality of life (QOL) becomes an important goal of treatment (Wu, 2000). HIV/AIDS leads to severe impairment in the health-related QOL for the patients (Hughes, Jelsma, Maclean, Darder, & Tinise, 2004; O'Keefe & Wood, 1996; te Vaarwerk & Gaal, 2001). For most patients, ART use results in significant improvement in QOL including cognitive functioning (Jelsma, Maclean, Hughes, Tinise, & Darder, 2005; Liu et al., 2006b; Parsons, Braaten, Hall, & Robertson, 2006; Sacktor et al., 2006).

The majority of studies on QOL have been conducted in Western societies, and few studies have recently been done in the resource-limited settings (Louwagie et al., 2007; Wouters, Meulemans, Van Rensburg, Heunis, & Mortelmans, 2007). The studies in the west (Bing et al., 2000; Carrieri et al., 2003; Gill et al., 2002; Liu et al., 2006a; Murri et al., 2003) and one of the few recently in Africa (Stangl, Wamai, Mermin, Awor, & Bunnell, 2007) have identified factors associated with improved QOL among patients receiving ART. Determination of factors associated with QOL, particularly ones that are the modifiable, identifies areas that are a target for interventions to optimize the effect of ART on QOL (Liu et al., 2006b).

In this study, we measure health-related QOL among patients receiving ART in Western Uganda using a culturally adapted and validated instrument (Mast et al., 2004). The primary purpose was to identify factors associated with lower QOL measures and, in particular, factors that are amenable to interventions that may result in improvements in QOL among these patients. The study measures

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social support and sexual behavior among these patients and the association between these factors and QOL measures.

Methods

Study population and setting

We conducted a cross-sectional study at Kitagata and Mbarara Hospitals, located in rural and urban Southwest Uganda, respectively. Kitagata and Mbarara Hospitals are located about 380 and 280 kilometers, respectively, from the capital Kampala. The clinics at each of these hospitals offer ART as part of a government-supported program to scale up ART in the country. The HIV clinic at Kitagata Hospital has been providing ART since December 2004 and at Mbarara since 2000. Both clinics use Triommune® (Stavudine, Nevirapine and Lamivudine) as first line therapy and it is the most prescribed regimen at each clinic. Protease inhibitor (PI)-containing regimens are available as second line regimens at both hospitals.

Between April and December 2006, we conducted two cross-sectional studies among patients at Kitagata and Mbarara Hospitals. Patients were eligible to participate if they were 18 years or older and had received ART for at least six months. We recruited all patients meeting the eligibility criteria at Kitagata Hospital. We consecutively recruited a similar number of patients at Mbarara Hospital. We interviewed patients to obtain information on sociodemographic characteristics, self-reported adherence to ART within the last three days, social support, QOL and sexual behavior. We also performed a blood draw to measure CD4 counts (BD FACS Count, Flow Cytometry) and plasma HIV RNA concentration (Roche Amplicor®). At Kitagata, we abstracted information from patients' medical records including duration being on ART, WHO stage at the time of treatment initiation, and weight.

We classified participants who reported sexual intercourse within the previous six months as being sexually active, and patients with a plasma viral load of less than 50 copies per ml as being virologically suppressed. We interviewed the respondents about the amounts of various alcoholic drinks they had consumed over the last month. Based on information available about the alcoholic content of each drink, we calculated the total amount of alcohol consumed in grams over the previous month.

Quality of life (QOL) measures

QOL is a multidimensional construct with a number of domains, and each of these domains has a number of items on the scale. Our study used a validated form of the Medical Outcomes Study (MOS-HIV) that had been culturally adapted and suitable for a rural population (Mast et al., 2004). The questionnaire was translated into Lunyankole, the most widely spoken local language in the area. The questionnaire measures 11 dimensions of QOL which include perceived health, bodily pain, QOL, role functioning, social functioning, vitality, mental health, health distress, cognitive functioning, physical functioning and health transition. We asked patients to rate their health status at the time of the interview and retrospectively at six months ago using a "then test" question (Nieuwkerk, Tollenaar, Oort, & Sprangers, 2007). This approach avoids the response shift bias associated with longitudinal assessment of self-reported health outcomes (Schwartz & Sprangers, 1999). The responses to the health rating questions were one of five responses ranging from excellent to poor.

Social support

We measured tangible, affectionate, and informational support using a widely utilized instrument (Sarason, Levine, Bashman, & Sarason, 1983). Tangible support (four items) is defined as provision of material support, and affectionate support (four items) is the receipt of emotional comfort that serves to gratify an individual's basic social needs for nurturing, approval, esteem and belonging (Swindells et al., 1999). Informational support (eight items) is the receipt of information on a variety of issues including advice, guidance and suggestions on how to deal with personal problems. Summary scores were computed from each scale and analyzed as continuous variables.

Analysis

QOL scores for each dimension were linearly transformed to fit on a scale ranging from 0 to 100, with 0 indicating poorest health and 100 as the best health (Murri et al., 2003). From the 11 dimensions of QOL, we calculated two summary scores, the physical health summary (PHS) and the mental health summary (MHS) as previously described (Revicki, Sorensen, & Wu, 1998). The summary scales are scored by using a method that standardizes the scores so that the mean is 50 and the standard deviation is 10. We used the student *t*-test to compare PHS and MHS summary scores according to CD4 count strata, gender, three-day self-reported adherence to ART (100% vs. <100%). We used the Pearson rank correlation to determine the relationship between MHS and PHS scores with social support and

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calculated Cronbach's alpha to estimate internal consistency or reliability of the scales.

To examine factors associated with higher PHS and MHS, we dichotomized the summary scores at the 25th percentile such that participants with scores below the 25th percentile were considered as having poor physical and mental health. We used logistic regression to determine the factors associated with lower PHS and MHS and to adjust for the potential confounding effect of site differences in a multivariable analysis. We report the adjusted odds ratios (ORs) and the 95% confidence intervals (CIs). We analyzed data from the "then test" questions using an Ordinal Quasi Symmetry (OQS) modeling for categorical analysis to determine whether there was a significant change in patient self-rating of QOL functioning. This kind of analysis is appropriate for responses from the same patient that are considered statistically dependent (Agresti, 1996). OQS modeling was fit using the PROC GENMOD procedure in SAS. All the analyses were carried out using SAS Version 9.1 (SAS Institute, Cary, NC).

Ethical review

The study was approved by the Institutional Review Board at The University Hospitals of Cleveland, USA, Mbarara University of Science and Technology and the Uganda National Council of Science and Technology.

Results

Baseline characteristics

We interviewed 330 patients. Of these 175 (53.2%) were at Kitagata and 155 (46.8%) at Mbarara (Table 1). All the patients requested to participate in the study accepted and consented to participate, except for one patient at Mbarara Hospital. The distribution of age and gender were similar at both sites (Table 1).

The proportion of patients who had achieved successful virologic suppression was higher at Kitagata compared to Mbarara Hospital ($p = 0.01$) but a larger proportion of patients at Mbarara had CD4 count above 200 ($p = 0.02$). The patients at Mbarara had been on ART for a longer period and were more likely to report 100% adherence over the last three days.

Internal consistency reliability and rating of health

We tested the reliability for the QOL measures that had at least two items. The internal consistency reliability was high, at least 0.70, for all the scales except for role functioning (Cronbach's alpha = 0.66). In rating their health, only five patients (1.6%) rated their health as being poor at the time of the interview compared to 134 (42.3%) patients at six months prior to the interview (Table 2). There was a significant change in the proportion of responses showing overall improvement in the rating of the health status ($p < 0.0001$ for the row effect).

Quality of life (QOL) and social support

Informational support was positively and significantly correlated with PHS ($r = 0.18$, $p = 0.001$) and MHS ($r = 0.17$, $p = 0.002$) (Table 3). PHS and MHS were also positively and significantly correlated with affectionate support ($r = 0.11$, $p = 0.05$ and $r = 0.12$, $p = 0.03$, respectively) but not with tangible support ($r = 0.01$, $p = 0.85$ and $r = 0.06$ and $p = 0.31$, respectively). Health distress and perceived health measures were significantly associated with all forms of social support. Patients who reportedly received more social support perceived their health to be better than those who received less social support and also patients receiving social support experienced less distress about their health situation.

Factors associated with lower scores in quality of life (QOL) measures

Older age was associated with lower scores on the PHS scale ($p = 0.04$) but not on the MHS scale ($p = 0.9$) (Table 4). Mean PHS and MHS scores did not vary significantly by gender, virologic suppression, pill burden or being 100% adherent to ART. Current or past alcohol use compared to never use was associated with lower scores on both the PHS and MHS scales ($p = 0.001$ and 0.0003, respectively). Drinking alcohol in the previous six months was significantly associated with lower scores of MHS ($p = 0.04$) but not PHS ($p = 0.2$). Having a CD4 count of 200 cells or lower was associated with lower PHS scores ($p = 0.005$) but not MHS scores ($p = 0.9$).

Quality of life (QOL) and sexual behavior

In general, higher mean PHS and MHS scores were associated with being sexually active (Table 4). In addition, higher PHS scores were seen among patients who rated their current interest in sexual activity as being normal compared to those who ranked their current interest as being low (p value = 0.02). The differences in the scores were not significant on the MHS scale. In addition, patients who experienced a decrease in their interest in sexual activity since starting ART had lower PHS and MHS scores ($p = 0.015$ and 0.04, respectively)

Table 1. Characteristics of patients receiving ART at Kitagata and Mbarara Hospital in Western Uganda, April–December 2006.

Variable	Kitagata Hospital $N = 175$ (%)	Mbarara Hospital $N = 155$ (%)	p-Value
Age category			
Less than 35 years	69 (39.4)	62 (39.7)	0.9
Over 35 years	106 (60.6)	93 (60.3)	
Gender			
Male	64 (36.6)	43 (27.9)	0.1
Female	111 (63.4)	111 (72.1)	
Education			
More than seven years	60 (34.3)	69 (45.1)	0.14
Seven years or less	93 (53.1)	68 (44.4)	
None	22 (12.6)	16 (10.5)	
Monthly income (US dollars)			
Over 30	41 (23.4)	43 (28.5)	0.42
6–30	49 (28.0)	45 (29.8)	
Less than 6	85 (48.6)	63 (41.7)	
Religion			
Catholic	56 (32)	48 (31)	0.002
Anglican	102 (59)	76 (50)	
Muslim	4 (2)	15 (10)	
Other	12 (7)	14 (9)	
Marital status			
Never married	4 (2)	15 (10)	0.04
Married monogamous	57 (33)	57 (37)	
Married polygamous	18 (10)	12 (8)	
Separated/Divorced	21 (12)	17 (11)	
Widowed	74 (43)	54 (35)	
CD4 count			
200 cells or less	48 (27.4)	19 (15.7)	0.02
More than 200 cells	127 (72.6)	102 (84.3)	
Viral load suppression			
Yes	147 (84)	108 (72.5)	0.01
No	28 (16)	41 (27.5)	
ART duration			
One year or less	134 (76.6)	58 (37.4)	0.001
Over one year	41 (23.4)	97 (62.6)	
Three-day self-report adherence			
100% Adherence	149 (85.1)	148 (96.7)	0.0003
Less than 100%	26 (14.9)	5 (3.3)	
Alcohol use in last month			
None	141 (80.6)	135 (86.5)	0.15
Less than 200 g	25 (14.3)	11 (7.1)	
Over 200 g	9 (5.1)	10 (6.4)	
Current regimen			
One pill per dose	117 (67)	81 (53)	0.01
More than one pill per dose	58 (33)	71 (47)	
WHO stage of disease*			
Stage 2	23 (13.4)	–	
Stage 3	90 (52.3)	–	
Stage 4	59 (34.3)	–	

*WHO staging at start of ART data available for Kitagata site only.

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Table 2. Rating of current health state and at six months prior to interview for patients receiving ART at Mbarara and Kitagata Hospitals in Southwest Uganda between April and December 2006.

Rating	Rating of health at interview	Rating of health six months prior to interview
Excellent	41 (12.9)	12 (3.8)
Very Good	114 (35.8)	24 (7.6)
Good	123 (38.7)	66 (20.8)
Fair	35 (11.0)	81 (25.5)
Poor	5 (1.6)	134 (42.3)

compared to those whose interest had increased or remained the same.

We assessed high-risk sexual behavior among the patients who were sexually active. Among these sexually active patients, those who reported having protected sex at their last intercourse also scored significantly higher on the PHS compared to those who reported having unprotected sex at their last intercourse (means 52.2 vs. 48.7, respectively, p value $=0.03$). There was no significant difference observed with the same analysis using scores on the MHS with scores of 51.5 vs. 50.6 among those who had protected and unprotected sex, respectively, at their last intercourse ($p=0.6$).

In a multivariate logistic regression analysis (Table 5), CD4 count and informational social support were protective of having a lower PHS score after adjusting for age, duration of ART and alcohol consumption. Alcohol use was associated with over 90% increase in the odds having a lower MHS score after adjusting for age, duration of ART and alcohol consumption.

Discussion

This cross-sectional study conducted in rural Western Uganda shows that informational social support and CD4 counts are independently associated with having better QOL among patients receiving ART for at least six months. Previous studies have shown that social support is significantly associated with better QOL scores (Jia et al., 2005; Jia et al., 2004; Swindells et al., 1999) but have all been done in the industrialized countries. In our study, this relationship was significant for informational and affectionate social support but not so for tangible support. This association implies that informational and affectionate social support may be important for patients receiving ART in order to maximally realize their QOL functioning. Provision of material support to these patients may not necessarily be associated with higher QOL function.

Our findings are also consistent with findings from several other studies that have shown that CD4 count above 200 was associated with better QOL functioning (Chandra et al., 2006; Gill et al., 2002; Murri et al., 2003). Treatment with ART generally results in the restoration of the immune system function with the associated increase in CD4 count (Angel et al., 1998; Bart et al., 2000; Kaufmann, Bloch, Zaunders, Smith, & Cooper, 2000; Staszewski et al., 1999). In our study, MHS was not different among the two CD4 strata, and whereas an explanation for this is not apparent, a ceiling effect in the

Table 3. Correlation between eleven dimensions of quality of life and social support for patients receiving ART at Mbarara and Kitagata Hospitals, April–December 2006.

	Tangible support		Affectionate support		Informational support	
Quality of life measure	Correlation	P value	Correlation	P value	Correlation	P value
Quality of life	0.00007	0.99	0.063	0.26	0.035	0.55
Pain	−0.0071	0.89	0.078	0.16	0.10	0.07
Physical functioning	0.0067	0.90	0.03	0.59	0.11*	0.05
Role functioning	−0.056	0.32	0.036	0.52	0.11*	0.04
Social functioning	−0.0015	0.98	0.085	0.13	0.11*	0.04
Mental health	0.087	0.12	0.098	0.08	0.13*	0.02
Vitality	−0.0096	0.86	0.064	0.26	0.11*	0.04
Health distress	0.13*	0.02	0.16*	<0.01	0.22*	<0.01
Cognitive functioning	0.019	0.73	0.063	0.26	0.14*	0.01
Perceived health	0.11*	0.05	0.18*	<0.01	0.19*	<0.01
Health transition	−0.0043	0.94	−0.042	0.46	0.0033	0.95
Physical health summary score	0.01	0.85	0.11*	0.05	0.18*	<0.01
Mental health summary score	0.06	0.31	0.12*	0.03	0.17*	<0.01

*Significant at 0.05 level.

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Table 4. Factors associated with lower QOL scores among patients receiving antiretroviral therapy.

Characteristics	Mean PHS score	*p* value*	Mean MHS score	*p* value*
Age				
35 years or younger	51.4		49.9	
Over 35	49.1	0.04†	49.9	0.90
Gender				
Female	50.4		49.8	
Male	49.1	0.29	50.3	0.75
Educational level				
None	51.1		51.2	
Seven years or less	50.1		50.0	
More than seven years	49.5	0.41	49.5	0.68
Monthly income				
Over 30 USD	49.7		50.2	
6–30 USD	51.8		51.3	
Less than 6 USD	48.6	0.06	48.9	0.06
Site				
Rural	48.7		49.6	
Urban	51.5	0.01†	50.4	0.92
Alcohol use				
Never	51.8		52.2	
Ever	48.2	<0.01†	47.9	<0.01†
Alcohol in six months				
No use	50.3		50.5	
Used	48.4	0.20	47.4	0.04†
CD4 levels				
200 cells or less	46.3		49.2	
More than 200	50.3	<0.01†	49.3	0.90
Self-report adherence				
Non-adherent	48.6		47.3	
Adherent	50.1	0.45	50.3	0.13
ART duration				
More than one year	52.1		50.5	
One year or less	48.5	<0.01†	49.5	0.42
Viral load				
Detectable	49.7		49.4	
Undetectable	49.9	0.80	50.1	0.65
WHO stage AIDS‡				
2	49.6		49.0	
3	50.4		51.2	
4	45.9	0.02	47.5	0.06
Drug regimen				
Triommune	49.5		49.1	
Other regimens	50.6	0.32	51.2	0.07
Weight change at six months‡				
Gained weight	49.4		49.5	
No change or lost	45.9	0.13	49.4	0.88
Sexually active				
Yes	51.2		51.1	
No	48.7	0.03†	48.6	0.03†
Current interest in sexual activity				
High	47.8		51.1	
Normal	52.2		51.3	
Low	48.9	0.02	49.1	0.16

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Table 4 (*Continued*)

Characteristics	Mean PHS score	*p* value*	Mean MHS score	*p* value*
Interest in sex since ART start				
Increased	49.3		50.6	
Remained the same	52.1		51.6	
Decreased	48.6	0.02	48.6	0.04
Interest in sexual activity in future				
Will Increase	47.9		47.8	
Will remain the same	52.3		51.9	
Will decrease	48.6	<0.01	48.9	0.02

*All *p* values were obtained using the *t*-test for independent sample means.
†Significant at the 0.05 level.
‡Data available for Kitagata Hospital only ($n = 145$).

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MHS scale, i.e. the maximum level of MHS that can be achieved is reached, may explain this observation.

In our study, an undetectable plasma HIV RNA concentration was not significantly associated with QOL. A study relating viral load, CD4 count and QOL (Weinfurt, Willke, Glick, Freimuth, & Schulman, 2000) showed that at the start of ART, the relationship between viral load and QOL was strong but not so for CD4. It is not clear whether CD4 count predicts QOL functioning better than viral load after a longer period of ART, when a majority of patients has achieved virological suppression. In addition, in a recent study investigating factors associated with QOL among patients receiving HAART, older age and advanced HIV disease were associated with lower PHS scores (Liu et al., 2006a). Although these findings were observed in a population in the USA, they are similar to the findings in our population of HIV-infected persons in Western Uganda. Our study also shows the effects alcohol may have on PHS and MHS scores and these will need further evaluation in longitudinal studies. In addition, it is not clear whether the statistical differences observed translate into clinically significant differences.

It has been suggested that optimizing QOL among ART patients is important to achieve high levels of adherence (Wu, 2000). Adherence did not predict the performance on either the PHS or MHS scale. Other studies have shown an association between adherence and cognitive function (Carballo et al., 2004). The high levels of adherence in our study and the cross-sectional design of the study might have precluded the investigation of this factor.

Our study unveils a subtle but interesting association between sexual activity and QOL. A recently published study showed that a lower number of sexual partners were associated with lower PHS scores (Liu et al., 2006a). In our study, the association between unprotected sex and lower PHS scores raises concern. The findings from this study require further investigation particularly within the context of longitudinal studies.

Our study has some limitations. We used a cross-sectional design to collect QOL data at a single point. We did not collect QOL data prior to the initiation of ART to compare with QOL after start of ART as many conventional studies have done. However, we used the "then test" question and the results show that changes in QOL can be measured at a single time point. In support of the "then test" question, literature suggests a retrospective measurement of baseline QOL as opposed to a prospective

Table 5. Univariate and multiple logistic regression to show the factors associated with lower scores of QOL.

	Physical health summary*		Mental health summary*	
Characteristic	Univariate	Multivariable	Univariate	Multivariate
Older than 35 years	1.7 (0.9, 2.9)	1.27 (0.7, 2.3)	0.9 (0.5, 1.5)	0.66 (0.37, 1.2)
Past or recent (six months) alcohol	0.8 (0.4, 1.7)	1.71 (0.95, 3.1)	1.6 (0.85, 3.1)	1.92 (1.1, 3.4)†
CD4 over 200 cells	0.41 (0.23, 0.74)†	0.38 (0.20, 0.73)†	1.35 (0.71, 2.6)	1.2 (0.6, 2.5)
Over one year of ART	0.6 (0.34, 1.02)	0.73 (0.37, 1.41)	0.9 (0.5, 1.5)	1.2 (0.6, 2.3)
Informational social support (one unit increase)	0.98 (0.97, 0.99)†	0.98 (0.97, 0.99)†	0.98 (0.97, 0.99)†	0.99 (0.97, 1.002)

*Site of treatment also included in the multivariable regression.
†Significant at the 0.05 level.

measurement as is the norm in most of the studies measuring changes in QOL among ART patients (Schwartz & Sprangers, 1999). The patients' reference value of QOL, by which they assess their health status, shifts over time and therefore results in biased estimates of change in QOL obtained from longitudinal studies. In addition, a prospective design for our study population may not have detected changes in QOL in the short term given that patients had been on ART for at least six months. HAART initiation has been shown to result in significant increases in QOL, but most of this increase seems to occur early in the treatment and additional use of HAART does not show changes in QOL in the long term (Liu et al., 2006c). This implies that changes in QOL are seen quickly after initiation of HAART (Stangl et al., 2007), especially among the severely ill patients but thereafter the changes in QOL are only modest.

In conclusion, our study shows that higher CD4 count and availability of informational support are associated with higher scores of QOL functioning among patients receiving ART. ART programs should incorporate informational support in the treatment package.

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