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Perceived HIV stigma and life satisfaction among persons living with HIV infection in five African countries: A longitudinal study

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INTRODUCTION

By the end of 2007, over 33 million people around the world were living with HIV/AIDS, and more than two-thirds of those were living in sub-Saharan Africa (UNAIDS, 2007). AIDS is

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the leading cause of death in sub-Saharan Africa (UNAIDS, 2007). The HIV pandemic is global, affecting people's quality of life (QoL) and the costs of care. Stigma and discrimination continue to affect those living with and affected by HIV disease as well as their health care providers, particularly in Southern Africa, where so many people are infected and the burden of the disease is so significant. Stigma has also become a substantial barrier to accessing primary and secondary HIV and AIDS care and prevention services (Rao et al., 2007, Weiss and Ramakrishna, 2001). It is a barrier to voluntary testing and counseling (Newman et al., 2002), and thus may result in delays in accessing care and treatments, and consequently increase illness and death. In Southern Africa, many health care workers feel that stigma must be addressed in order to overcome HIV (Uys, 2000).

The literature regarding HIV/AIDS-related stigma is not easily synthesized. Various scientists have defined stigma, explored its correlates, and tried to measure it, but often have not clearly distinguished between the causes of stigma, the stigma behaviors themselves, and the outcomes of stigma. In order to fill this gap, Holzemer and colleagues (2007) developed a conceptual model of perceived HIV/AIDS-related stigma, based on data from focus groups with 251 people. In the model, HIV/AIDS stigma is described as a process, with four dimensions: triggers, stigmatizing behaviors, types of stigma, and outcomes of stigma. The outcomes of stigma — for example, poor health — may also serve as triggers, starting the process again. The stigma process occurs within the environment (political, social, etc), and in the context of the health care system and the individuals who may enact stigma. A decrease in quality of life was identified as one of the outcomes of HIV stigma (2007).

Quality of life is an existential concept with multiple definitions. In general, health-related QoL can be defined as the value assigned to the duration of life as modified by the impairment, functional status, perceptions, and social opportunities that are influenced by disease, treatment, and health care delivery (Patrick and Erickson, 1993). As AIDS becomes a more chronic and manageable illness and health behaviour plays such an important role in the process of illness in people living with HIV/AIDS (PLHA), factors that might influence their health motivation are important variables. The value people place on their own lives (an essential component of QoL) has to play an important role in health motivation and it is therefore important to explore the factors that affect QoL.

Few studies have empirically explored the relationship between quality of life and perceived HIV stigma over time in persons living with HIV infection in sub-Saharan Africa. The study reported here examined how stigma and quality of life, as measured by validated instruments, change together over time in a sample of people living with HIV infection in five African countries.

BACKGROUND

Discussion of stigma often begins with Goffman's (1963) definition of an attribute that is "significantly discrediting" (p.3). Herek defines AIDS stigma as "prejudice, discounting, discrediting, and discrimination directed at people perceived to have AIDS or HIV, and the individuals, groups and communities with which they are associated" (1998).

A number of studies have reported on QoL for people living with HIV/AIDS, but have not linked this specifically to HIV stigma. For instance, Phaladze, et al. (2005) reported on QoL in a sample of 743 persons living with HIV infection in four sub-Saharan African countries. Quality of life in this sample was defined primarily as overall functional ability and control over symptom intensity.

In other studies QoL is linked to variables that could be linked to HIV stigma. Geurtsen (2005) explored the meanings people living with HIV/AIDS attach to quality of life; the author

further categorized these themes into variables that could be perceived as stigmatizing. For instance, the researcher found that themes such as the ability to maintain life functioning, isolation, getting sick and current hardships were all variables that affected the quality of life of a person living with HIV/AIDS. The study further reported that themes such as secrets and silence about their HIV status, selective disclosure to some and not to others, living in the present rather than thinking of the future, and hopefulness were ways in which the participants felt they were achieving their own quality of life outcomes. Another study of women in the South-Eastern United States found that social and psychological factors are important in their influence on quality of life in women (Sowell et al., 1997). In South Africa a series of group support sessions and provision of a nutritional food parcel to HIV infected persons was found to increase their general life satisfaction and QoL (Roux et al., 2006).

In some studies the link between HIV stigma and QoL was directly explored. For instance, Neely-Smith (2003) reported that women's oppression in a patriarchal society and HIV-associated stigmas have resulted in decreased QoL and shortened life span of Bahamian women. Heckman, Smlai, Sikkema, Keely & Franzoi (1997) reported that improved physical and functional well-being, increased social support, more frequent use of active coping strategies, and fewer incidents of AIDS-related discrimination and stigma predicted higher levels of general life satisfaction. One empirical clinic-based study explored the relationship between stigma and quality of life in Chennai, India (Thomas et al., 2005). The sample of 203 persons living with HIV infection reported that the actual stigma experienced was much less (26%) as compared to the fear of being stigmatized (97%). Internalizing stigma was found to have a highly significant negative correlation with QoL in the psychological domain and a significant negative correlation in the environmental domain. Individuals are vulnerable to feelings of self-hatred. However, those who did experience actual stigma seemed more determined to have a good quality of life (Thomas et al., 2005).

Few studies have empirically explored the relationship between quality of life and perceived HIV stigma over time in persons living with HIV infection in sub-Saharan Africa. The study reported here examined how stigma and quality of life, as measured by validated instruments, change together over time in a sample of people living with HIV infection in five African countries.

METHODS

Study Aim

This study measured how perceived HIV stigma changed over time in a cohort of persons living with HIV infection in five African countries. It also explored whether quality of life is related to changes in perceived HIV stigma. The analysis described here was part of a larger study about HIV stigma in Africa (Chirwa et al., 2009, Dlamini et al., 2007, Greeff et al., 2008, Greeff et al., 2008, Holzemer et al., 2007, Holzemer and Uys, 2004, Holzemer et al., 2007, Kohi, 2006, Makoae et al., 2008, Naidoo et al., 2007, Uys et al., 2005, Uys et al., 2009).

Research Design

A repeated measures cohort design was used to follow persons living with HIV infection in five African countries. Data were collected over a one-year period in a three-wave longitudinal design, measuring both stigma and health-related QoL.

Protection of Human Subjects

The Institutional Review Boards / Ethical Committees of the universities involved in the study each approved the research protocol. In addition, the country principal investigators received permission from local and central governmental agencies to conduct the study, as necessary.

Each potential participant was given information in their local language about the purpose and format of the study, and was informed that participation was completely voluntary at all times. If the person agreed to participate, s/he signed a written consent form. Surveys were conducted in English or the local language of the particular country.

Settings and Sample

Data were collected at three points in time, over 12 months (baseline, six months and 12 months). Data collection took place from December 2005 to March 2007. Each country principal investigator sought to recruit 300 people living with HIV, using purposive sampling. Potential participants were recruited in a variety of ways, including from HIV/AIDS clinics, or through support groups, flyers, and word of mouth. Those who were interested in participating arranged convenient times and locations to meet with data collectors to complete the surveys. In general, participants completed the surveys on their own, but the field workers were available to assist them when necessary. Participants were given lunch, and received a reimbursement for their transportation costs.

Instruments

Four instruments were used in this analysis:

1) Demographic Questionnaire—A questionnaire was used to obtain demographic and illness background data from the participants. These items included age, gender, education level (the highest school grade passed and, if applicable, the highest post-school education completed), marital status, number of children, number of people living in the same home, work for pay (yes/no), adequacy of household income to meet needs (enough, barely adequate and totally inadequate), currently taking ARV medications, CD4 value, year of HIV diagnosis, disclosure of HIV status to friends/relatives, and participation in support groups. The instrument also included seven items that assessed exposure to anti-stigma events within the participant's community over a period of three months (eg. a prominent person in the community disclosed they were HIV-positive; a religious leader talked about acceptance of people living with HIV/AIDS; positive media coverage — TV/radio/newspaper — about people living with HIV/AIDS).

2) HIV/AIDS Stigma Instrument — PLWA (HASI-P) (Holzemer et al., 2007)—This 33-item instrument measures six dimensions of HIV-related stigma: verbal abuse (defined as behaviour or actions intended to harm the PLWA such as being insulted or ridiculed); negative self-perception (a negative view of oneself based on HIV status, including feeling worthless or ashamed); health care neglect (patients offered less care than expected, or denied care or treatment); social isolation (being intentionally excluded from social events); fear of contagion (people avoiding a PLWA for fear of contracting HIV, eg. "I was made to eat alone"); workplace stigma (being denied opportunities due to HIV status); and total perceived stigma. Responses were measured on a 4-point Likert scale. Scores were computed by taking the mean of the individuals responses range from 0 to 1, with a higher score meaning greater perceived stigma. The Cronbach alpha reliability coefficients for the scale scores range from 0.76 to 0.90. The instrument was developed in a three phased process, in which items were generated based upon qualitative interviews with persons living with HIV infection and nurses caring for HIV-positive people in each of the five participating countries. The instrument was translated and back translated into the local languages of the five countries: seSotho in Lesotho; Chichewa in Malawi; Afrikaans, seTswana, seSotho and IsiZulu in South Africa; seSwati in Swaziland; and Swahili in Tanzania. The instrument was validated based upon this sample's baseline data. For the purpose of the multilevel growth model analysis, the mean of the total stigma score was used.

3) HIV/AIDS Targeted Quality of Life Instrument (HAT-QOL) (Holmes and Shea, 1998)—This quality of life measure is a validated 34-item instrument that is HIV disease-specific and measures nine dimensions: overall function, life satisfaction, health worries, financial worries, medication worries, HIV mastery, disclosure worries, provider trust, and sexual function. Holmes and Shea (1998,1999) reported on the development and validation of the scale. As the setting for the study reported here was in developing countries, some of the dimensions were not appropriate given the social and economic conditions. This decision was supported by results yielded in the initial pilot study, which showed poor response rates on the dimensions that were removed. In this analysis only the life satisfaction subscale was used. The subscale consists of four Likert-scaled items rated 1 (none of the time) to 5 (all of the time): In the past 4 weeks, I've enjoyed living; In the past 4 weeks, I've felt in control of my life; In the past 4 weeks, I've been satisfied with how socially active I am and; In the past 4 weeks, I've been pleased with how healthy I've been. The subscale is scored so that the final score is transformed into a linear 0 to 100 scale, where 0 is the worst score possible and 100 is the best score possible. The Cronbach alpha reliability coefficient of this 4-item revised scale was 0.86 in this sample.

4) The Revised Sign and Symptom Checklist for Persons with HIV Disease (SSC-HIVrev) (Holzemer et al., 2001)—The SSC-HIVrev is a checklist that captures the frequency and intensity of 72 common HIV signs and symptoms. The SSC-HIVrev has three parts: Part I consists of 45 HIV-related physical and psychological symptoms, clustered into eleven factor scores, along with a total score, with reliability estimates ranging from 0.76-0.91; Part II consists of 19 HIV-related symptoms that do not cluster into factor scores but may be of interest from a clinical perspective; Part III consists of eight items related to gynecological symptoms for women. Only the 64 symptoms relevant to both males and females were used in this analysis.

Data Analysis

Multi-level growth models, an iterative statistical model development methodology, was used to analyze change over time. Statistical Package for the Social Sciences (SPSS) for Windows Version 15.0 software (2007) was used for all analyses. An important feature of the five-country cohort design of this study was that the reported QoL scores may vary by country. In deriving the final model, (Model D), each variable identified in Tables 1, 2, and 3 was entered in the model for its impact in the initial baseline status, and the variable's interaction with time was modeled. Variables that had non-significant p values (greater than 0.05) were dropped from the model to maintain a parsimonious model. However, in Table 4, some variables that were dropped in the model are shown as non-significant (ns) to provide consistency to the reader on the variables' initial influence and influence in change over time on the life satisfaction scores. Time-varying (level one) covariates were modeled as randomly varying and the variables that did not significantly improve the model fit assessed by the Chi squared difference between the log-likelihood deviance statistic were removed from the analysis.

Evaluations of model fit were carried out by estimating the Chi squared difference between the log-likelihood deviance statistic in the models. A significant reduction in the subsequent model indicates a better model fit to the data. In addition, model fit was evaluated using the Akaike's information criterion (AIC), and the Bayesian information criterion (BIC), where a lower result indicates a better model fit. Residuals (the total unexplained variance in the model) were assessed by plotting them in a proportion-observed-to-proportion-expected (P-P) plot to assess normality of the residual distribution. If the model residuals are normally distributed, then the model is a plausible model that is generalizable to the population.

Results

The participants were from Lesotho (18.8%, n=273), Malawi (17.7%, n=258), South Africa (21.8%, n=317), Swaziland (21.0%, n=304), and Tanzania (20.7%, n=302). At baseline the average age for the sample participants (n=1,454) was 36.8 years (SD=8.8) and 72.7% (n=1,056) were female. The participants' levels of education were: 85.6% were credentialed at the certificate level, 10.5% had a diploma level education, and 1.6% had post-basic/advanced education, 1% held a bachelors degree; and 1.3% had a post-graduate level education. Only 27% of participants identified themselves as employed for pay initially, with the percentage employed remaining constant over the one-year period. Of the initial 392 employed participants, 168 of the initially employed remained employed at the second assessment period, with an additional 199 previously non-employed individuals reporting being employed for pay. During the third assessment period, a total of 279 individuals reported being employed for pay, 124 consistently reported being employed for the one year period, and 155 individuals, who were not employed for pay at baseline, reported being employed at the end of the study. Their marital status was: 35% (n=490) never married, 28% (n=392) married, 23% (n=325) widowed, 8% (n=119) divorced, and 6% (n=88) cohabitating.

The HIV illness characteristics show the mean years living with HIV to be 3.2 years (SD=2.7), 62.7% (n=470) reported a co-morbid illness and 49.0% (n=698) are presently taking ARV medications with 8.8% taking medications six months or less, 18.9% taking ARVs six months to one year, 42.7% taking ARVs for one to two years, and 29.6% for greater than two years. The mean CD4 count was 330 cells/mm³ (SD=219). Additional demographic data are presented in Table 2.

The overall participant loss during the study was 31% (n=446) over the one year period (Table 1). The attrition percentages varied by country with Swaziland losing 48% of their participants, Tanzania losing 40%, Lesotho losing 33%, Malawi losing 20%, and South Africa losing 10% of their participants over the course of the year. Participant loss generally occurred between the second and third assessment period. Comparative analysis of participants who stayed and those who left the study over time showed that gender, age, marital status, taking/not taking ARVs, or stigma rating did not have an influence on attrition. However, individuals who completed the study and who answered the QoL questions had significantly higher life satisfaction scores at baseline (mean = 62.08, SD=32.0) than those who left the study (mean = 56.56, SD=30.46, t=3.007, df=1,374, p=0.003). Additionally, individuals who lived in an urban or peri-urban areas were significantly more likely remain in the study than those from rural settings ($\chi^2=7.63$, df=2, p=0.02).

The mean life satisfaction QoL score over the three measures ranged from 60.4 to 71.0 out of a possible score of 100, while the mean total stigma score ranged from 0.28 to 0.43 out of a possible score of one. By the end of the study period, an increasing percentage of participants reported disclosing their HIV status to a friend over the last three months ($\chi^2 = 12.36$, df= 1, p ≤0.001) and the majority reported positive media coverage over the same period (Table 3).

Analysis of Initial Life Satisfaction QoL Status and Change Over Time

Sociodemographic, illness characteristics, and economic conditions were measured and compared by country and assessed for their contribution in reducing the variances in the described models framework. This section reports on four models describing the iterative process in model assessment using multilevel longitudinal growth models (Table 4). The modeled trajectories of life satisfaction QoL change over time and the dependent variables that significantly contribute to the initial and change over time values are presented. In all models, all parameters are statistically significant at the p < 0.01 level except where noted.

The first model (Table 4, Model A) quantifies the total variation in the life satisfaction scores. Model A tested each individual's initial life satisfaction score and its associated variation from the group mean life satisfaction score value. The model showed a mean total life satisfaction score of 64.16, SE=0.61.

The second model (Table 4, Model B) estimated the change over time in life satisfaction in order to obtain the individual and between-person growth trajectories. In this model with no predictor variables, the mean life satisfaction score at baseline was 59.76. On average, the overall cohort showed steady improved life satisfaction scores over the one-year period. The variance components associated with the baseline intercept trajectories for life satisfaction scores show significant between-person variation in initial status (308.0, SE=43.47), and there is significant variation within the group in their life satisfaction scores. However, life satisfaction scores improved in most individuals in all countries over the one-year period. This trend in positive growth trajectories is reflected by the non-significant variance in the rate of change (10.36, SE=13.89). The goodness of fit statistics relative to Model A are significantly improved by the addition of the growth variable, as indicated by the significant χ^2 value decrease of 88, which is greater than the χ^2 critical value of 13.89 for two degrees of freedom. The estimates of variation from these two unconditional models were used for subsequent model comparisons to assess any reduction in variance and improved model fit by adding both level one (time varying) and level two (time invariant) variables to further describe the sample and to reduce variation.

Country Level Differences in Life Satisfaction QoL

The results from Model B trajectories over time prompted an analysis for differing growth trajectories by country. Table 4, Model C shows an analysis of change in life satisfaction QoL scores by country. This analysis revealed significant differences in the initial status and/or over time in most of the five countries. While Model B revealed that most participants improved their life satisfaction QoL scores over time, Model C reveals that the amount of improvement varied significantly by country (Figure 1). Whereas Lesotho (68.58, SE=2.41, $p \leq 0.001$), South Africa (61.81, se=0.77, $p \leq 0.001$) and Tanzania (58.25, SE=0.48, $p \leq 0.001$), participants had initial mean life satisfaction QoL scores that were above the average cohort score of 57.04 (SE=1.67), both Malawi and Swaziland showed lower than average mean initial scores (52.63, SE=1.27; and 55.54, SE=0.60, $p \leq 0.001$ respectively). Over the one-year assessment period, Lesotho showed a consistent QOL score pattern that increased slightly, but not significantly so. The other four countries, however, showed significant increases in life satisfaction scores, ranging from an increase in 0.58 points in Tanzania to 3.9 points in Malawi. Goodness of fit log likelihood deviance statistics revealed a significantly improved model ($\chi^2 = 217$, df=2, $p \leq 0.001$) compared to the unconditional growth model (Model B).

The final model (Table 4, Model D) shows the effects of adding additional dependent variables to help to explain the variation in initial status and rate of change over time. There were no significant differences in scores by gender, age, years living with HIV, or urban/rural setting. Time varying variables assessed in this model included stigma and symptom intensity. Only significant parameters were retained in the model. Again, in Table 4, many variables that were dropped are shown in the table as non-significant (ns) to provide consistency to the reader on the variables' initial influence and influence in change over time in life satisfaction scores. This model revealed significant variation in individual initial life satisfaction scores with a mean of 67.16, but there was no significant overall change in the mean life satisfaction scores.

Variables Significantly Affecting Life Satisfaction in Model D

Stigma—In initial status, life satisfaction scores decreased by an average of 13.61 points for every unit increase in reported stigma, holding all other variables constant. The relationship is

maintained in each subsequent assessment period as indicated by the non-significant change (either an increase or decrease) in life satisfaction scores as a result of the report of stigma, holding all other variables constant.

Positive HIV media messages—In initial status, participants who reported experiencing more media campaigns supporting HIV treatment, life satisfaction scores by 5.54 points. This effect is maintained over time, as there is no significant change in life satisfaction scores as a result of media messages, holding all other variables constant.

Taking ARV medications—In initial status, there was no significant difference in life satisfaction scores between those taking and not taking ARVs. Over time, those taking ARVs had significantly increased life satisfaction scores compared to those who are not taking ARVs, by 2.90 points.

Disclosure to a friend—In initial status, individuals who reported having disclosed their HIV status to a friend had a higher average life satisfaction score by 5.67 points. Over time, this difference decreased significantly to be 4.06 points lower than the average, holding all other variables constant.

Symptom Intensity—In initial status, the effects of the total intensity of reported HIV-related symptoms significantly decreased life satisfaction scores by 0.17 points. This effect is maintained over time, as there is no significant change in life satisfaction scores as a result of symptom intensity changes, holding all other variables constant.

In the final model, the country level differences in initial status and in change over time show that those countries having initial mean scores that were higher than the group mean in initial status showed smaller initial value estimates in the final model whereas those countries having lower than average mean life satisfaction scores had larger values estimates in the final model (Table 4).

There is significant remaining unexplained group variation in life satisfaction QoL scores and in the initial total QoL scores. The addition of the level 2 predictor variables significantly improved the model fit as indicated by the significant χ^2 values. The improved goodness of fit statistics in the final model relative to the previous models suggest that this final model is acceptable. Graphical and tabular analyses of the residual estimates of the unobservable statistical error in the final model showed a near normal distribution providing further evidence that the model is plausible in the sampled population.

LIMITATIONS

The attrition rate should be interpreted in the context of the participants having a life-threatening illness which often leads to changes in living conditions. Comparative analysis of participants who stayed and those who left the study over time showed that gender, age, marital status, taking/not taking ARVs, or stigma rating did not have an influence on attrition. However, individuals who completed the study and who answered the QoL questions had significantly higher life satisfaction scores at baseline than those who left the study. It is possible that the location of the individuals may have an impact on the difficulties in transportation of the participant for follow up assessment as indicated by the statistically significant finding that individuals who lived in an urban or peri-urban areas were significantly more likely remain in the study than those from rural settings. Other reasons for these losses may be that more rural participants migrated to access health care, but it may also mean that more of them died due to poorer services.

The use of the HIV/AIDS Targeted Quality of Life Instrument (HAT-QOL) developed by Holmes and Shea (1998) may have been another limitation. Although the scale was used in all three time periods of this cohort study and was translated in the local languages, due to the social and economic context of the five countries, certain items may have not been appropriate. Another possible limitation of the study is the high number of women in the sample (73%). This should be seen in the context of HIV diagnosis being linked to pregnancy and the initiation of Prevention of Mother to Child Transmission programmes. In all stigma studies, it is a limitation that one can only study the stigma experience in people who have already been identified as being HIV-positive and who are willing to make themselves accessible to the researchers.

External validity of the study results is limited by the potential for selection bias through the convenience sample method for obtaining the cohort and the community sources of contact from these populations as these may not be entirely reflective of the HIV-positive community in these five countries. Another potential limitation is that all of the instruments were self-reported scales. However, all the instruments used are validated scales with adequate reported reliabilities. Finally, in any longitudinal analysis of change over time, significantly high or low scores that change significantly over time may reflect a regression towards the mean. While considered a form of study bias, this statistical phenomenon is an untoward benefit of longitudinal analysis. In cross-sectional studies, a single period analysis may suggest variable relationships that are not a true reflection of the relationships between the variables that are evidenced over time. Despite the limitations, the study has notable strengths, including the multiple country sample, adequate power, and the use of validated instruments. We believe the year-long longitudinal cohort study of these variables and their relationships to the outcome of life satisfaction outcome adds value in understanding these influences.

DISCUSSION

Model A indicates that the life satisfaction of individual participants varied significantly at baseline. This is followed by Model B, which analyzed changes over time and showed that individual life satisfaction scores all generally improved over time.

Model C - Country level differences in the report of stigma

A large amount of model variation in initial stigma ratings and in change over time is attributed to country level differences. While there was a demonstrated overall increase in life satisfaction QoL scores over time for all five countries, a possible reason for these country site initial and trajectory variations may be due to site recruitment and follow-up locations of the participants. For many cases, individuals were initially contacted through HIV/AIDS clinics and community support groups with subsequent follow up surveys administered either at the support group site or at the participant's home. In other cases, the HIV-positive interviewers knew of participants in the community and asked if they wished to participate in the year-long study. In all countries, there was a mix of clinic/support group administered surveys and also home administered surveys. Although there was no significant difference in life satisfaction reports for those in the support groups and those who were not, the researchers in Lesotho and South Africa noted that there were many home-administered surveys, whereas in the other countries, most were conducted at community-based HIV support sites.

Stigma

The model revealed that at initial status, as the report of stigma increased, life satisfaction scores decreased by an average of 13.61 points for every unit increase in reported stigma. Over time, decreased life satisfaction scores were noted. This finding provides evidence that perceived HIV stigma has a significantly negative and constant impact upon life satisfaction

QoL for people living with HIV infection. Similar findings are documented in a multinational study reported by Holzemer, et al (In press). In a cross-sectional analysis of 775 participants that empirically tested the effects of stigma and quality of life, stigma provided a significant and negative correlation and alone explained 7% of the total variance in the model.

Positive HIV media messages

In initial status, the effects of media campaigns supporting HIV treatment increased life satisfaction scores by 5.54 points. This effect is maintained over time, as there is no significant change in life satisfaction scores as a result of media messages holding all other variables constant. The finding that positive HIV media messages are positively related to higher life satisfaction supports the finding of a study by Hutchinson, Mahlalela and Yukich (2007) in South Africa, that positive media coverage improves knowledge levels and decreases stigma so that disclosure is promoted. They found that this was particularly true for women, and that the radio and television played the greatest roles. The global summary of the HIV epidemic as presented in the UNAIDS report (2004) found that in countries where there were developed and continuous HIV mass media campaigns, there was an evident increase in HIV counseling and testing, and promoting HIV awareness and healthy behaviour. Similarly, Petrak, Doyle, Smith et al (2001) found that cultural background, satisfaction with social support and medical and psychological variables were factors that were associated to self-disclosure among PLHAs.

Taking ARV medications

In initial status, there was no significant difference in life satisfaction scores between those taking and not taking ARVs. Over time, those taking ARVs had significantly increased life satisfaction scores compared to those who are not taking ARVs by 2.90 points. One question in the life satisfaction dimension of the HAT-QoL related to feeling in control of one's life. This may reflect the fact that those taking medications are actively taking a step to treat their illness compared to those not receiving ARV treatment. The link between self determination and improved ability to cope is addressed by Jamil and Murisa (2004), who explored how the NGOs that focus on the development of social capital in Uganda has been successful in mitigating the challenges of HIV AIDS. They say that "By initiating dialogue about their conditions and comprehensive self-responsibility, self-determination to live and public participation, the organizations have developed and successfully promoted perspectives that go beyond self to civic responsibility' (P.18).

Disclosure to a friend

In initial status, individuals who reported having disclosed to a friend had a higher average life satisfaction score of 5.67 points. This initial relationship between disclosure and life satisfaction again points to a relationship between self-determination, as outlined by Jamil and Murisa (2004) and life satisfaction. According to Field (2003) social capital involves to the premise that social networks in which trust and tolerance is involved, as valuable assets. Building social capital therefore might be one of the stigma interventions. Over time, this difference decreased significantly to be 4.06 points lower than average holding all other variables constant.

The life satisfaction dimension also included a question on social activity. While those who disclosed to a friend had initially significantly higher scores, this may reflect the fact that the time frame of the question was the last four weeks. In the initial assessment, it may have been construed as ever disclosed to a friend and in the subsequent assessments, significantly more individuals reported disclosing to a friend. While these results may be reflective of regression toward the mean, the reported data may suggest a relationship between those who are disclosing that is related to their decreased life satisfaction, thus leading them to disclose. Further, disclosure may have been encouraged by participation in the year-long study and these

individuals may perceive themselves as having lower life satisfaction. While not a primary focus of this study, the analysis of independent factors related to disclosure and its impact on life satisfaction is an important research question for future study.

Symptom Intensity

In initial status, the effects of the total intensity of reported HIV-related symptoms significantly decreased life satisfaction scores by 0.17 points. This effect is maintained over time, as there is no significant change in life satisfaction scores as a result of symptom intensity changes holding all other variables constant. One question in the life satisfaction dimension of the HAT related to satisfaction with health. This result reflected the expected lower life satisfaction scores for those reporting increased symptom intensities. Similar results have been documented in cross-sectional studies (Cunningham et al., 1998, Nicholas, 2005, Sousa et al., 1999)

This cohort study is the first to document empirically, in a longitudinal sample, that perceived HIV stigma has a significantly negative and constant impact upon quality of life for people living with HIV infection. In the absence of any intervention to address and reduce stigmatization, individuals will continue to report poorer life satisfaction evidenced by reduced living enjoyment, loss of control in life, decreased social interactivity, and decreased perceived health status.

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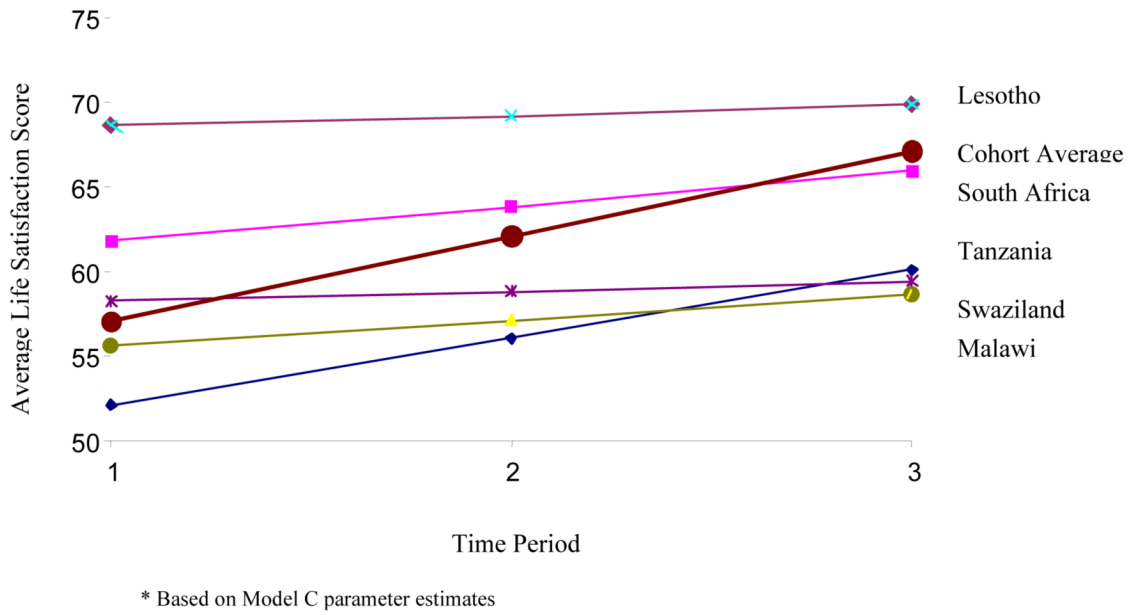


Figure 1.
Country Level Growth Trajectories in Life Satisfaction Scores*

Table 1

Sample Size by Time for Each of the Five Countries

| Country | Time1 | Time 2 | Time 3 |
|--------------|--------------|--------------|--------------|
| | %(n) | %(n) | %(n) |
| Lesotho | 18.8% (273) | 20.1% (251) | 17.4% (175) |
| Malawi | 17.7% (258) | 19.9% (246) | 20.4% (206) |
| South Africa | 21.8% (317) | 24.1% (299) | 28.3%(285) |
| Swaziland | 21.0% (304) | 15.4% (191) | 15.8% (159) |
| Tanzania | 20.7% (302) | 20.5% (255) | 18.1% (182) |
| Totals | 100% (1,454) | 100% (1,242) | 100% (1,007) |

Table 2
Sample Characteristics and Study Attrition Analysis Comparing Participants who Left the Study with those who Stayed.

| Variable | Baseline (Time 1) | Stayed (Time 3) | Left (Time 1 minus Time 3) | X2 or t test | df | p |
|------------------------------|---|------------------------|----------------------------|--------------|-------|------|
| <u>Gender</u> | | | | | | |
| Female | 73% (n=1,056) | 73% (n=731) | 73% (n=325) | 0.01 | 1 | 0.94 |
| Male | 27% (n=396) | 27% (n=275) | 27% (n=121) | | | |
| <u>Age</u> | n=1408 M=36.8;SD=8.8 Range: 16-71 | n=983 M=36.0;SD=8.6 | n=425 M=35.4;SD=9.2 | 1.21 | 1,405 | 0.23 |
| <u>Post-School Education</u> | | | | | | |
| No post school | 74% (n=1,073) | 75% (n=755) | 71% (n=317) | 2.62 | 2 | 0.27 |
| Certificate | 22% (n=326) | 22% (=217) | 24% (109) | | | |
| Diploma/Advanced | 4% (n=55) | 3% (n=35) | 5% (20%) | | | |
| <u>Marital Status</u> | | | | | | |
| Never married | 35% (n=490) | 36% (n=348) | 33% (n=142) | 1.13 | 4 | 0.89 |
| Married | 28% (n=392) | 27% (n=270) | 28% (n=121) | | | |
| Widowed | 23% (n=325) | 23% (n=226) | 23% (n=40) | | | |
| Divorced | 8% (n=119) | 8% (n=79) | 9% (n=26) | | | |
| Cohabiting | 6% (n=88) | 6% (n=62) | 6% (n=57) | | | |
| <u>Work for pay</u> | | | | | | |
| Yes | 27% (n=392) | 26% (n=258) | 30% (n=134) | 2.98 | 1 | 0.08 |
| No | 73% (n=1,053) | 74% (n=742) | 70% (n=310) | | | |
| <u>Setting</u> | | | | | | |
| Urban | 42% (n=595) | 42% (n=411) | 42% (n=182) | 7.63 | 2 | 0.02 |
| Peri-Urban | 30% (n=427) | 32% (n=315) | 26% (n=112) | | | |
| Rural | 28% (n=396) | 26% (n=257) | 32% (n=139) | | | |

| Variable | Baseline (Time 1) | Stayed (Time 3) | Left (Time 1 minus Time 3) | X ² or t test | df | p |
|--------------------------------------|--|--|--|--------------------------|-------|-------|
| <u>Taking ARVs now</u> | | | | | | |
| Yes | 49% (n=698) | 48% (n=467) | 54% (n=230) | 3.79 | 1 | 0.052 |
| No | 50% (n=738) | 52% (n=504) | 46% (n=198) | | | |
| Missing | 1% (n=18) | n=988 | n=434 | | | |
| <u>Years HIV +</u> | n=1,423 Mean=3.2yrs SD=2.7 Range=0-18 | Mean=3.3yrs SD=2.8 | Mean=3.1yrs SD=2.9 | 0.71 | 1,420 | 0.47 |
| HAT Life satisfaction score Baseline | n=1,377 Mean = 60.38 SD = 31.60 Range = 0-100 | n=925 Mean = 62.08 SD= 32.0 Range = 0-100 | n=452 Mean=56.56 SD=30.46 Range = 0-100 | 3,007 | 1374 | 0.003 |
| Stigma Total Score Baseline | n = 1,449 Mean=0.43 SD=0.48 Range 0-3 | n = 1,006 Mean=0.44 SD=0.48 Range 0-3 | n = 442 Mean=0.43 SD=0.48 Range 0-3 | 1.85 | 1446 | 0.06 |

Table 3

Study Variables Measures at three points in Time

| Variable | Time 1 | Time 2 | Time 3 |
|--|--|--|---|
| HAT-Life satisfaction score | Mean=60.38 (n=1377) sd = 31.60 Range 0-100 Alpha 0.81 | Mean=63.69 (n=1163) sd = 31.18 Range 0-100 Alpha 0.88 | Mean = 71.0 (n = 1002) sd= 29.58 Range 0-100 Alpha 0.86 |
| Stigma Total Score | Mean=0.43 (n=1449) SD=0.48 Range 0-3 alpha 0.93 | Mean=0.44 (n=1240) SD=0.47 Range 0-3 alpha 0.94 | Mean=0.28 (n=1007) SD=0.39 Range 0-3 alpha 0.96 |
| Status Disclosure to Friend in past 3 months | Yes=47.4% (n=621) No=52.6% (n=689) | Yes=49.5% (n=615) No=50.5% (n=627) | Yes=54.8 (n=552) No=45.2% (n=455) |
| Positive HIV media in past 3 months | Yes=80.84% (n=1,147) No=19.2% (n=273) | Yes=83.5% (n=1,025) No=16.5% (n=203) | Yes=84.3% (n=846) No=15.7% (n=157) |

Table 4
Mixed Model Growth Analysis — Dependent Variable (DV) HIV Assessment Tool - Life Satisfaction Subscale

| | Unconditional Means Model | Unconditional Life satisfaction QOL Growth Model | Growth Model & country level Life satisfaction QOL | Growth Model with Country, Life satisfaction QOL & other Characteristics | Guide to Coefficients in Model D |
|--|---------------------------|--|--|--|--|
| Fixed Effects ^a | Model A. | Model B. | Model C. | Model D. | |
| Initial status - Intercept (Standard error SE) | 64.16 (0.61) | 59.76 (0.82) | 57.04 (1.67) | 67.16 (2.16) | 1. There is significant variation in individual initial life satisfaction scores about the mean of 67.16. |
| Initial status - Stigma | | | | -13.61 (1.13) | 2. In initial status, as the report of stigma increased, life satisfaction scores decreased 13.61 points holding all other variables constant. |
| Initial status - Media campaign supporting HIV treatment | | | | 5.54 (1.71) | 3. The effects of seeing media campaigns supporting HIV treatment increased life satisfaction scores by 5.54 in initial status holding all other variables constant. |
| Initial status - Taking ARV Medications | | | | ns | 4. There was no significant difference in initial life satisfaction scores between those taking or not taking ARVs. |
| Initial status - Disclosure to a friend | | | | 5.67 (1.87) | 5. Individuals who reported having disclosed their HIV status to friends had significantly increased initial life satisfaction status scores holding all other variables constant. |
| Initial status - Symptom Intensity | | | | -0.173 (0.02) | 6. In initial status, as the report of symptom intensity increased, life satisfaction scores were decreased by 0.173 points holding all other variables constant. |
| Initial status - Country = Lesotho | | | 11.58 (2.41) | 6.20 (2.12) | 7. Participants from Lesotho had significantly higher initial life satisfaction scores than the cohort average. |
| Initial status — Country = Malawi | | | -4.89 (1.27) | -13.62 (1.81) | 8. Participants from Malawi had significantly lower initial life satisfaction scores than the cohort average. |
| Initial status — Country = South Africa | | | 4.77 (0.77) | ns | 9. Participants from South Africa had initial life satisfaction scores that were near the cohort average. |
| Initial status — Country = Swaziland | | | -1.51 (0.60) | -3.02 (0.66) | 10. Participants from Swaziland had significantly lower initial life satisfaction scores than the cohort average. |
| Initial status — | | | 1.21 (0.48) | ns | 11. Participants from Tanzania had initial |

| | Unconditional Means Model | Unconditional Life satisfaction QOL Growth Model | Growth Model & country level Life satisfaction QOL | Growth Model with Country, Life satisfaction QOL & other Characteristics | Guide to Coefficients in Model D |
|---|---------------------------|--|--|--|---|
| Country = Tanzania | | | | | life satisfaction scores that were near the cohort average. |
| Rate of Change - Intercept | | 5.04 (0.51) | ns | ns | 12. In the overall cohort, on average all participants improved life satisfaction scores over the 1 year period. |
| Rate of Change - Stigma x Time | | | | ns | 13. Over time, those who reported higher stigma consistently had lower life satisfaction scores. |
| Rate of Change — Media campaign supporting HIV treatment x Time | | | | ns | 14. Over time, those who reported seeing HIV media campaigns consistently had increased life satisfaction scores |
| Rate of Change — Taking ARV Medications x Time | | | | 2.90 (0.90) | 15. Over time, those who were taking ARVs had significantly higher life satisfaction scores than those who were not taking ARVs. |
| Rate of Change — Disclosure to a friend x Time | | | | -4.06 (1.36) | 16. Over time, individuals who reported disclosing their HIV status to a friend had significantly lower life satisfaction scores. |
| Rate of Change — Symptom Intensity x Time | | | | ns | 17. Over time, those who reported higher total symptom intensity scores consistently had lower life satisfaction scores. |
| Rate of Change — Country = Lesotho | | | ns | ns | 18. Lesotho participant life satisfaction scores consistently were higher than the group average over time. |
| Rate of Change — Country = Malawi | | | 3.95 (0.66) | 5.13 (1.31) | 19. Malawi participant life satisfaction scores increased significantly over time. |
| Rate of Change — Country = South Africa | | | 2.07 (0.37) | 2.03 (0.90) | 20. South Africa participant life satisfaction scores increased significantly over time. |
| Rate of Change — Country = Swaziland | | | 1.54 (0.33) | 1.13 (0.44) | 21. Swaziland participant life satisfaction scores increased significantly over time. |
| Rate of Change — Country = Tanzania | | | 0.58 (0.24) | ns | 22. Tanzania participant life satisfaction scores consistently were near the cohort average over time. |
| Variance Components | | | | | |
| Within group variation | 760.63 (23.04) | 713.14 (29.94) | 656.37 (25.51) | 642.39 (40.14) | The variation in total group life satisfaction scores was reduced 10% (from model B.) by inclusion of the level |

| | Unconditional Means Model | Unconditional Life satisfaction QOL Growth Model | Growth Model & country level Life satisfaction QOL | Growth Model with Country, Life satisfaction QOL & other Characteristics | Guide to Coefficients in Model D |
|--|---------------------------|--|--|--|--|
| In initial status Life satisfaction scores | 211.28 (21.29) | 308.0 (43.47) | 256.20 (37.73) | 252.87 (57.18) | 2 variables. The variation in the initial life satisfaction scores was reduced by 18% (from model B.) by inclusion of the level 2 variables. |
| In rate of change Life satisfaction scores | | 10.36 (13.89)ns | 32.01 (20.32)ns | 21.14 (33.49)ns | Over time, life satisfaction scores improved in all countries. Variation increased by the addition of country level detail in model C, although additional level 2 variables in Model D explained and additional 33% if the variance from model C. |
| Goodness of Fit (Lower is better) | | | | | |
| Deviance statistic | 34288 | 34200 ^b | 33983 ^b | 20920 ^b | 21. The addition of the level 1 time varying covariate of media awareness and the level 2 predictor variables significantly improved the model fit as indicated by the significant χ^2 values. |
| Akaike Information Criterion (AIC) | 34295 | 34207 | 34006 | 20956 | |
| Bayesian Information Criterion (BIC) | 34313 | 34233 | 34080 | 21058 | |

NS: Not significant

^a All parameters are significant at the p<.01 level except where noted

^b χ^2 significant improvement in model fit