QUALITY OF LIFE

and Sexual Behaviors of Patients on Anti-Retroviral Therapy (ART) in Cambodia:

Findings from a three-year patient-based assessment of people living with HIV in Battambang, Cambodia

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From humble beginnings in 2003, the Royal Cambodian Government has rapidly scaled up care and treatment services to serve the thousands of Cambodians living with HIV (PLHIV). At the end of 2008, more than 92% of PLHIV—or 31,989 adults and children—have accessed anti-retroviral therapy (ART) in 77 government-run Continuum of Care (CoC) sites across the country. With so many more people receiving life-prolonging treatment, the National Centre for HIV/AIDS, Dermatology and STDs (NCHADS) and Family Health International (FHI) wanted to assess the quality of life, well-being and sexual behaviors of PLHIV on ART. More specifically, we were interested in understanding:

- What is the quality of life of PLHIV on ART and does this change over time?
- What kinds of stigma and discrimination do PLHIV face within their families? What support are they provided by family members?
- Does sexuality change when one is HIV positive and what risky behaviors do PLHIV have (if any)?

A THREE-YEAR LONGITUDINAL STUDY

The Battambang Referral Hospital, one of the first CoC sites in the country – was chosen as the assessment site. This largely agrarian province in the northwestern region of the country boasts a population of more than one million persons and is also a "hotspot" for HIV.

Beginning in March 2005, all patients over 18 years of age who were initiating ART at the Battambang Referral Hospital were asked to participate in the Enhanced Patient-Based Longitudinal Assessment. Outpatient clients who knew their HIV status for at least three months and were at WHO Stage III or IV with CD4 counts below 200 cells/ul were considered eligible to participate. Patients with severe opportunistic infections, or co-infections (e.g. TB/HIV), were ineligible.

The "cohort study" followed up 259 male and 290 female patients, assessing improvements in their quality of life and changes in their sexual behaviors at three (3), six (6), 24, 30 and 36 months. Data collection was integrated into the routine patient monitoring system of the Referral Hospital and all face-to-face questionnaires were administered by PLHIV volunteers to ensure that information was collected in the most sensitive and confidential manner possible.

Out of 1443 HIV positive patients seen at the Battambang Referral Hospital, 549 (38%) persons joined the study. Four percent of these patients were lost to follow-up, 7% died, and 6% were transferred to other hospitals during the life of the study, which concluded in January 2008[1].

[1] *Those lost to follow up did not differ from others at enrollment for demographics, biological and biometric measures.*

ART PATIENT PROFILES

Patients receiving ART in Battambang are mostly poor subsistence farmers, many of whom face significant financial difficulties. The study learned that, at enrollment, PLHIV had the following profile:

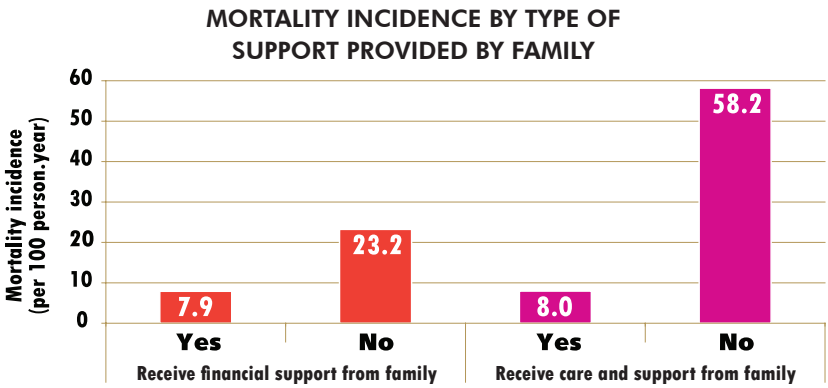
- 47% of patients had borrowed money in the last three months to buy food
- Less than 50% of patients had full-time work
- Compared to men, women were younger, less likely to have reached secondary level of education (14% versus 36%), less likely to be married or cohabiting (37% versus 73%), and more likely to be widows (56% versus 12%)
- Almost 95% had disclosed their HIV status to their family

Even though most of the cohort had recently been diagnosed with HIV, the study results indicated that, generally, ***PLHIV are reaching health services at a late stage.*** In Battambang, both men and women displayed low Body Mass Index (BMI) and few CD4 cells.[2] Men were most likely to be at more advanced stages of the disease.

[2] 43% of both men and women entered with Body Mass Index <18.5. 90% of men and 79% of women entered with CD4 count <200 cells/ microliter.

Not surprisingly, mortality generally occurred during the first three months of follow-up, but overall patient survival was high after initiation of ART. Consistent with other studies, a ***low BMI and low CD4 count at ART initiation appeared to be the strongest predictors of mortality.***

Patients who received financial support or care and support from their family had significantly higher survival rates.



QUALITY OF LIFE

Eight scales are used to measure changes in the quality of life (QoL) of patients on ART. Each QoL scale includes a series of questions in which respondents report their self-perceptions about their physical, emotional, social and cognitive functioning.

Over the three-year assessment, the following remarkable changes were observed:

ART significantly improved the quality of life of those PLHIV followed at Battambang Referral Hospital. The observed increase in all quality of life measures demonstrated the positive effect of ART on the lives of PLHIV.

QUALITY OF LIFE MEASURES

8 QoL Scales	Definition
Global health	perceived health status
Physical functioning	ability to perform basic daily tasks
Role functioning	work related limitations
Social functioning	limitation in performing social activities
Emotional well-being	anxiety and depression
Cognitive functioning	ability to focus and reason
Bodily Pain	how pain interferes with daily activities
Energy/fatigue	absence of fatigue

ART has a major impact on economic production. Many patients in this study were in their mid 30s, an age at which they can and should be the most productive to their community and family. The sharp increase in patients' having full-time work (from 49% at initiation to 96% at one year of treatment) illustrates the major impact of ART delivery in patients' ability to return to work and consequently on economic production at both household and community levels.

Discrimination from family members decreased over time, although all patients reported discrimination from the community at some point during the assessment. Between ART initiation and one year of follow-up, disclosure of HIV status to family increased from 95% to 99.8% while discrimination from family dropped from 9% to 1%. Those reporting

discrimination by the family had significantly lower quality of life scores. The main type of reported discrimination from the community was being gossiped about, being checked by voyeurs and having lost customers.

Not all patients experience significant improvements in their QoL. Some patients did not benefit greatly from ART and continued to suffer physical and/or psychosocial difficulties known to favor poor adherence to treatment. The proportion of patients reporting significant body pain decreased from 97% at ART initiation to 46% at the 18th month and 18% at the 24th month of follow-up.

Factors Associated with Improvements in QoL	
Gender:	Men had higher overall QoL scores than women
Employment:	Patients working had higher QoL scores than those not working
Wealth:	Poorest patients had lower QoL scores
Discrimination:	Discrimination by family was associated with lower QoL scores
Age:	Younger patients reported higher cognitive functioning scores
CD4 count:	Patients with higher CD4 counts reported suffering less pain
BMI:	Patients with higher BMI generally had higher QoL scores (except for social and cognitive functioning scores)

CHANGES IN SEXUAL BEHAVIORS

As quality of life improves, it is not surprising that sexual activity also increases. While PLHIV have the right to a healthy sexual life, there remain concerns about the potential for risky behaviors, including unprotected sex with multiple partners. PLHIV who engage in unsafe sexual behaviors risk transmitting HIV to others as well as re-infecting themselves with different strains of the virus.

Over the 36-month period, the study found that:

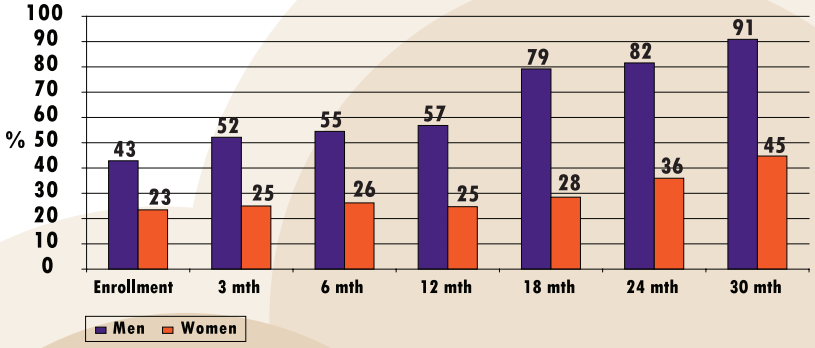
Sexual activity increases steadily over time. As expected, the proportion of HIV positive sexually active patients on ART increased over time as their quality of life improved. Women showed a less dramatic and delayed increase than men.

Key factors associated with increased sexual activity included being young, male, single, or having a higher education, higher BMI, or higher physical functioning QoL scores.

Men are five times more likely than women to have multiple partners.[3] Up to one-quarter of those patients who were sexually active reported having multiple partners during the follow-up. Single males, with a high BMI, were most likely to report having sex with multiple partners.

Young, married women are more exposed to unprotected sex. Findings showed that when young, married women (or women living with a regular partner) re-engaged in sexual activity they were more exposed to unprotected sex.[4] These married women having unprotected sex are particularly vulnerable to re-infection.

SEXUALLY ACTIVE IN THE PAST 6 MONTHS, BY GENDER AND DURATION OF FOLLOW-UP



[3] *Men were more likely than women to have sex with multiple partners in the past 6 months, Hazard Ratio=5.1, p<.001.*

[4] *Women were more likely than men to have unprotected sex in the past 6 months, HR=3.8, p<.05.*

PROGRAMMATIC RECOMMENDATIONS

Now that the Enhanced Patient-Based Longitudinal Assessment has ended, what does it mean for our programs? How can we continue to enhance improvements in the quality of life of all PLHIV and support these individuals to have healthy, safe sexual lives?

Programmatic recommendations can be grouped into three broad areas:

1 Quality of patient care within the CoC must be the focus of Cambodia's care and treatment efforts.

- Innovative strategies should be developed to reach PLHIV early enough to allow ART initiation in time before quality of life is drastically impaired. High quality post-test counseling must be emphasized as well as strong linkages with CoC sites and home-based care teams as soon one learns his or her HIV positive status.
- Discrimination by the family should be continuously addressed and support by the family should be strongly encouraged.
- Fighting against discrimination by the community should not be neglected and be continuously addressed.
- Specific medical care and psychosocial support should be developed for those PLHIV who do not experience marked improvement of their quality of life under ART and remain in difficulty. Chronic pain, after effects of severe opportunistic infections, impaired cognitive functions or severe ART side effects are specific conditions altering patients' QoL and their ability to return to work and should be specifically addressed.

2 Positive prevention initiatives must be integrated into a number of key entry points along the prevention to care continuum.

- Innovative and non-discriminating approaches to address and reduce sexual risky behaviors of PLHIV should be implemented within the CoC.
- Specific strategies to target single PLHIV men (potentially having multiple partners) and young married PLHIV women (most likely to have unprotected sex with their partners) should be implemented.
- Strategies to facilitate disclosure of HIV status to partners should be developed.

- Specific strategies to improve safe sex practices, including condom use, with both discordant or non-discordant HIV couples, should be adapted to the Cambodian familial context and implemented.
- Family planning and reproductive health messages and education should be adapted to PLHIV needs and widely available within the CoC in order to avoid unwanted pregnancies and improve knowledge about how to safely become pregnant.
- Facilitated and supported access to PMTCT services should be strengthened.

3 Linkages with other key support services – such as vocational training, income generation, legal aid, etc. – must be improved.

- Strong and effective psychosocial support should be developed within the CoC for those patients still in need.
- Income generation strategies for PLHIV should be developed but also integrated with activities aimed to fight against poverty at the community levels.

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