Background

Large-scale provision of antiretroviral therapy (ART) for HIV/AIDS began in South Africa in 2004 and has scaled up steadily since then. A decade later, large numbers of patients are now reaching five, eight, or even more years on ART. The long-term biomedical outcomes of treatment have been well documented in South Africa, where antiretroviral provision has been associated with reductions in HIV-associated mortality and increases in life expectancy.

Much less is known about the "non-biomedical" outcomes of treatment, in South Africa and elsewhere. A handful of studies have considered the implications of ART for quality of life, employment, and other economic and social indicators, but these studies have largely been limited to the one to two years after initiation of treatment. They have generally reported large improvements in the indicators they measured in the first 6-24 months after treatment initiation. In view of the lifelong commitment that ART requires, however, it is important to know whether these improvements persist, increase, or deteriorate in later years on treatment.

To begin to describe the long-term effect of ART on patients’ economic well-being, we conducted a 6-year study of symptom prevalence, ability to perform normal activities, employment and job performance, and reliance on external support. Each of these outcomes reflects the ability of South African ART patients to contribute to their own, their households’, or society’s economic activity.

Methods

In 2005-06, we enrolled patients in the study from three ART clinics in South Africa: a public hospital HIV clinic in Johannesburg, a primary care clinic serving informal settlements in Gauteng Province, and a nongovernmental HIV/AIDS clinic in rural Mpumalanga Province. HIV positive adult patients who were not on ART or had initiated ART less than 6 months before could enroll. We interviewed these patients at enrollment and then whenever possible during their routine clinic visits over the next 5-6 years. Data collection ended in 2011.

The questionnaire we used focused on self-reported health conditions and engagement in economic activities. It asked about general symptoms: whether the patient had any bodily pain or headache or felt tired or fatigued last week. It asked if participants were able to perform their normal primary activity during the last 5-day work week, whether they had a job, and, if employed, about their performance at work. Patients were also asked whether they were receiving a disability grant at the time of the interview and whether they relied on someone else to take care of them.

For the results reported here, interviews conducted between 3 months before starting ART and 63 months after starting ART were used. Time on ART extended from 90 days (3 months) pre-initiation to 1980 days (5.5 years) post-ART initiation. Time intervals were categorized as 90 days pre-ART, 0-30 days on ART, 31-90 days on ART, and 90-day intervals during the rest of the first year on ART, followed by 180-day intervals through 5.5 years.

Outcome variables were modeled with logistic regression, with dummy variables for time category on ART, sex, age group (18 to 29 years, 30 to 39 years, 40 to 49 years and 50 years old or more), CD4 count category at ART initiation, and CD4 count category closest to interview date.

Results

879 patients were eligible for this analysis. Seventy-eight percent were female, and about half the patients were in their 30s at study enrollment, with a quarter in their 20s and a quarter over age 40. The median starting CD4 cell count was 104 cells/mm³. Each patient was interviewed an average of 7.6 times over the course of the study. Table 1 describes the study patients’ main activities.

Table 1. Primary activity when feeling well enough to perform normal activities (% of cohort)

<table>
<thead>
<tr>
<th>Activity</th>
<th>When starting ART</th>
<th>4 years after starting ART</th>
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<tbody>
<tr>
<td>Employed in formal sector</td>
<td>224 (26%)</td>
<td>198 (36%)</td>
</tr>
<tr>
<td>Work in informal sector or self employed</td>
<td>172 (20%)</td>
<td>112 (20%)</td>
</tr>
<tr>
<td>Unemployed, seeking work</td>
<td>207 (24%)</td>
<td>130 (24%)</td>
</tr>
<tr>
<td>Housework or family care (unpaid)</td>
<td>229 (26%)</td>
<td>91 (17%)</td>
</tr>
<tr>
<td>Other (studying, retired, leisure, service, missing)</td>
<td>47 (5%)</td>
<td>18 (3%)</td>
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</tbody>
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1Center for Global Health and Development, Boston University, Boston, USA; 2Health Economics and Epidemiology Research Office (HE2RO), Wits Health Consortium, Department of Medicine, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa; 3Brown University, School of Public Health, Providence, RI, United States.

For further information about this project and detailed results, please contact Professor Sydney Rosen, sbrosen@bu.edu. Funding for this work was provided by a grant to Boston University from the U.S. Agency for International Development in South Africa.

As illustrated in Figure 1, the probability that patients reported pain and fatigue in the previous week fell continuously over the full 5-year period after ART initiation. The probability of experiencing pain in the previous week, for example, decreased from 69% in the months preceding ART initiation to 35% after 3 years on ART and then fell further, to 17%, after 5 years on ART. (Nausea and skin problems showed a similar pattern of decline.)

The probability of being unable to perform normal activities in the previous week also fell steadily throughout the 5 years of follow-up, from 47% in the 3 months prior to initiation to just 5% by the end of 5 years (Figure 2). Among those who reported impairment, the number of days unable to perform normal activities in the last 5-day workweek decreased from 3.7 days in the month prior to ART initiation to 2.9 days after five years on ART.

Over the same time period, the probability of having a job rose from 32% to 44%—though the national unemployment rate did not change—and of having difficulty doing that job fell from 56% to 6%. Much of the improvement in overall employment came from those who said they were unemployed but not looking for work at ART initiation. By their last interview, 30% of these patients had found jobs and 53% were now looking for work. It thus appears that many patients joined the active labor force within five years of initiating ART.

Before starting treatment, 18% of patients reported receiving a disability grant. This proportion then increased over the first year on treatment to a high of 29%, before gradually declining again back to a low of 13% after 4-5 years (Figure 3). The increase in grants in the first year may reflect the fact that new ART patients are offered access to social services such as the disability grant when they enroll in the treatment program, while the decrease in later years may reflect improving health over time on treatment.

Finally, a large proportion of subjects reported having a caretaker in the 3 months prior to ART initiation (81%) and in the year following the beginning of treatment. After 1.5 years on ART the need for caretakers dropped steeply, to fewer than 1% of patients. (We couldn’t estimate longer than 2.5 years because so few patients needed caretakers after that.)

**Policy relevance**

In South Africa, about 6% of working-aged adults are already on ART. Considering how effective ART is in prolonging survival, new ART initiation guidelines that expand the treatment-eligible population, and the national goal of treating at least 80% of those eligible, this number will likely rise steadily over the coming years, as will the share of ART patients who have been on treatment for more than just one or two years. It is thus of critical importance to patients, their households, their employers, and society as a whole that ART do more than simply delay mortality: it must produce people who feel healthy enough to lead normal lives, support their families, and participate in the economic and social life of their communities.

This study suggests that, for HIV-infected adults who remain on ART, the benefits of treatment for economic engagement are large and sustained and continue to increase steadily over at least the first five years on treatment. Almost all outcomes assessed continued to improve even in the 4th and 5th years after starting treatment. The phrase “for adults who remain on ART” is an important caveat, however. Nearly half the patients originally enrolled in our study had dropped out of the study clinics’ treatment programs by the time data collection ended. Continuing to improve retention in ART programs should thus remain a major goal of treatment providers and funders, in South Africa and elsewhere.