Why some people don’t want to start HIV treatment

When ART became available in Canada and other high-income countries in 1996, regimens were complex—they had specific food and water requirements, contained many pills, had to be taken up to three times a day on an exact schedule and had many side effects.

Surveys of HIV-positive people around that time found that there were at least the following barriers to starting treatment:

- fear of side effects
- not wanting to take many pills several times a day
- difficulty integrating pill-taking into their lives

Nearly 20 years after ART became available, therapy is much simpler (often once a day and there are entire regimens available in one pill), safer and more effective. However, there are still HIV-positive people who do not wish to start therapy, though there are many benefits to starting early. At the level of the individual, early use of ART can reduce the amount of HIV in the body. This reduction in HIV helps relieve ongoing damage to the immune system, brain, heart, lungs, kidneys and other vital organs and systems. At the level of thousands of people in a city or region (what researchers call “population level”), taking ART every day exactly as directed and getting regular checkups for sexually transmitted infections helps to greatly reduce the future risk for spreading HIV. This is an important benefit for the community.

Researchers in the European Union and Australia conducted a survey of HIV-positive patients and their doctors about perceived barriers to starting ART. Analysis of the survey results suggest that in the current era barriers to initiating therapy still exist but are different from those of the late 1990s. A primary barrier among HIV-positive people today is that they may not feel sufficiently unwell and they lack serious symptoms that would hasten their entry to treatment. Major reasons by doctors for delaying the initiation of ART include that they perceived some of their patients to be suffering from a degree of depression, that there was active substance use and that patients did not understand the need to adhere to HIV medicines.

Study details

Between November 2011 and October 2012 researchers recruited 508 HIV-positive patients with the following average profile:

- age – 37 years
- 84% men, 16% women
- time since HIV diagnosis – between one and four years

Transmission groups

- 67% men who have sex with men (MSM)
- 6% people who shared equipment for injecting drugs (IDUs)
- 25% heterosexual
- 2% were classed by researchers as unspecified “other”
- HIV viral load – 10,000 copies/ml
- CD4+ count – 568 cells

Most participants had none or very mild symptoms of HIV disease and were distributed into the following CD4+ cell count ranges:
• less than 350 cells – 8%
• between 350 and 499 cells – 27%
• 500 or more cells – 65%

During the same period, 114 doctors were recruited, 60% of whom had at least 10 years of experience treating people with HIV.

All participants were administered an extensive survey about perceived barriers to initiating ART.

**Results—HIV-positive people**

The main reason that HIV-positive people gave for delaying the start of ART was as follows:

- “I rely on my body to tell me when to start.”

This reason was relatively common regardless of CD4+ cell counts.

Another answer was that they would delay starting ART until symptoms occurred.

Interestingly, researchers stated that 47% of respondents did not wish to start therapy because they did not want to be reminded about their HIV status. This wish was also relatively common regardless of CD4+ count.

**When to start**

Treatment guidelines increasingly call for considering initiating ART shortly after testing HIV positive, regardless of CD4+ count. When participants were queried about starting ART the distribution of some of their responses was as follows:

- 50% of participants with a CD4+ count less than 500 cells were not ready to start
- 30% of participants with a CD4+ cell count less than 500 cells were “ambivalent” about starting

**Doctors**

Most doctors (93%) said that the recommendations in ART guidelines about starting therapy were suitable for their patients. When researchers asked if patients who have less than 350 CD4+ cells should start therapy, 46% of physicians said “no.” Researchers were surprised by this response because all guidelines in high-income countries recommend that ART be initiated if the CD4+ count falls below this threshold. So they asked physicians about their reluctance to prescribe ART according to patients’ cell counts. Here is what they found:

**Below 350 CD4+ cells**

- patient is too depressed
- patient does not understand key issues about HIV treatment
- patient uses harmful substances

**CD4+ count between 350 and 499 cells**

- have not known patient for a long enough time
- patient is too depressed
- patient does not understand key issues about HIV treatment

**500 or more CD4+ cells**

- have not known patient long enough
- family, relatives not aware of patient’s HIV infection
- job prevents good adherence to medicines

The researchers conducting the survey were surprised by the reluctance of some doctors to treat substance users because studies have shown that with appropriate intervention and support people can be safely transitioned from substance use to opiate substitution (methadone, buprenorphine) and with psychosocial support and education,
they can successfully use and adhere to ART and demonstrate long-term recovery from addiction.

Limitations and strengths

The survey had a relatively small proportion of participants with less than 350 CD4+ cells. This problem may arise because ART is being initiated at higher CD4+ counts. Also, the researchers did not collect data on cultural differences that may have existed among countries about medicines and health.

On the other hand, the survey was one of the largest exploring these themes in high-income countries.

For the future

The survey’s findings are important and provide valuable clues as to how some doctors and patients perceive barriers around the initiation of ART. As programs to expand the offer of an HIV test followed by counselling and swift referral for treatment are increasingly implemented as ways of not only improving the health of HIV-positive people but also reducing the general spread of HIV, the issues raised in the survey will increasingly be encountered. Finding ways to address the themes raised in the survey will be essential if ART is to be more widely used.

As a follow-up to this type of research, focused interviews with a small group of patients about their feelings on starting ART have the ability to uncover deeper and perhaps more meaningful psychological issues that underpin their stated reluctance and ambivalence about initiating therapy.

—Sean R. Hosein

REFERENCES:

Disclaimer

Decisions about particular medical treatments should always be made in consultation with a qualified medical practitioner knowledgeable about HIV- and hepatitis C-related illness and the treatments in question.

CATIE provides information resources to help people living with HIV and/or hepatitis C who wish to manage their own health care in partnership with their care providers. Information accessed through or published or provided by CATIE, however, is not to be considered medical advice. We do not recommend or advocate particular treatments and we urge users to consult as broad a range of sources as possible. We strongly urge users to consult with a qualified medical practitioner prior to undertaking any decision, use or action of a medical nature.

CATIE endeavours to provide the most up-to-date and accurate information at the time of publication. However, information changes and users are encouraged to ensure they have the most current information. Users relying solely on this information do so entirely at their own risk. Neither CATIE nor any of its partners or funders, nor any of their employees, directors, officers or volunteers may be held liable for damages of any kind that may result from the use or misuse of any such information. Any opinions expressed herein or in any article or publication accessed or published or provided by CATIE may not reflect the policies or opinions of CATIE or any partners or funders.

Information on safer drug use is presented as a public health service to help people make healthier choices to reduce the spread of HIV, viral hepatitis and other infections. It is not intended to encourage or promote the use or possession of illegal drugs.

Permission to Reproduce

This document is copyrighted. It may be reprinted and distributed in its entirety for non-commercial purposes without prior permission, but permission must be obtained to edit its content. The following credit must appear on any reprint: This information was provided by CATIE (the Canadian AIDS Treatment Information Exchange). For more information, contact CATIE at 1.800.263.1638.

© CATIE

Production of this content has been made possible through a financial contribution from the Public Health Agency of Canada.

Available online at: