While the risk of developing AIDS increases based on the length of time a person has been infected with HIV, a major study of HIV survival among gay and bisexual men has found that after 13 years, one-third of those with HIV had still not developed AIDS. The San Francisco City Clinic Cohort Study has looked at 562 gay and bisexual men and found that less than 1% of subjects with HIV developed AIDS within two years of infection, 12% within five years, 51% within 10 years, and 68% within 13.8 years.1 Furthermore, people who have progressed to AIDS are now living longer than ever. A study of people diagnosed with AIDS between 1978 and 1983 showed that 5% to 10% survived for three years despite low T-helper cell levels; data since the late 1980s show that 15% to 20% of people with AIDS survive at least three years after being diagnosed.2 Recent developments are even more encouraging. Results of the Multicenter AIDS Cohort Study of 5,000 gay men, including a group in Los Angeles, show that men diagnosed with AIDS in 1991 have twice the survival time of those diagnosed in 1984 because of improvements in medication and health care.3 In a 1990 study of 4,323 people with AIDS, the median survival time after development of AIDS was 12.5 months, with 8.7% of people surviving three years and 3.4% surviving five years.4 Studies of survival have been conducted primarily among gay, white men. Less is known about survival trends or differences that may exist among others, such as women, African Americans, Latinos, and Asians.
Spectrum of Disease

T-helper cell counts, which normally range between 800 and 1,200 in uninfected people, measure one of many cells of the immune system that help the body fight HIV; although little understood, T-helper cell counts are used as a marker to track progression of HIV disease. HIV infection is associated with a rapid decline in T-helper cells during the first 18 months after infection. During this period, a person’s T-helper cell count may fall by as much as one-third. For instance, a person who had a T-helper cell count of 1,000 before becoming infected may have a count of 700 by the end of 18 months. After this initial decline, T-helper cell counts generally fall at a slower rate, with total counts becoming relatively stable at below-normal levels and staying that way, often for many years.

When T-helper cell counts fall below 500, many people begin treatment with antiviral drugs, such as AZT, ddI, and ddC. When the T-helper cell count is below 200, a person is diagnosed with AIDS and is likely to develop opportunistic infections. Preventive treatment against opportunistic infections, such as *Pneumocystis carinii* pneumonia, generally begins only when a person’s T-helper cell count falls below 200.5

People can survive at each stage of infection for long periods. Of the survivors followed in the San Francisco City Clinic Cohort Study, after 13 years, 27% had T-helper cell counts above 500, 48% had counts between 200 and 500, and 25% had counts below 200.1

A variety of studies give a general picture of the physical health of people with HIV. Most people initially infected with HIV have no symptoms. About 50% to 70% have a brief illness, with symptoms similar to those of mononucleosis.6 The longest period of HIV infection, particularly the early stage of this period, is accompanied by no serious health problems. As infection progresses, many people become increasingly symptomatic, experiencing diarrhea, fatigue, swollen lymph glands, fever, night sweats, and other debilitating conditions. Such signs of illness can interfere with daily activities and greatly affect quality of life.7

The Concorde study has faced significant criticism, and because of some methodological weaknesses, its findings have been discounted by some researchers. However, partly in response to the study’s findings, an expert panel brought together by the National Institute of Allergy and Infectious Diseases (NIAID) in late June established new guidelines for antiviral treatment. The new guidelines are less aggressive in recommending AZT at earlier disease stages, allowing more choice to patients and physicians. New recommendations place more emphasis on disease symptoms, rather than on T-helper cell counts alone.

T-Helper Cells and Survival

T-helper cell counts of 593 gay men infected with HIV 10-15 years.1

*Based on the definition of AIDS prior to January 1, 1993. On this date, the definition was revised to include people with T-helper cell counts below 200.

More than 500 t-helper cells

25% did not have AIDS

200-500 t-helper cells

11% had a recent T-helper cell test

6% died prior to diagnosis, or had not had a T-helper cell test

64% developed AIDS

27% had counts between 200 and 500, 48% had counts above 500, 25% had counts below 200.1

25% did not have AIDS

200-500 t-helper cells

11% had a recent T-helper cell test

64% developed AIDS

27% had counts between 200 and 500, 48% had counts above 500, 25% had counts below 200.1

The Concorde study has faced significant criticism, and because of some methodological weaknesses, its findings have been discounted by some researchers. However, partly in response to the study’s findings, an expert panel brought together by the National Institute of Allergy and Infectious Diseases (NIAID) in late June established new guidelines for antiviral treatment. The new guidelines are less aggressive in recommending AZT at earlier disease stages, allowing more choice to patients and physicians. New recommendations place more emphasis on disease symptoms, rather than on T-helper cell counts alone.

Role of Treatments

Treatment with AZT has been considered at various times to be a significant factor in extended survival and health. Recent studies, however, have seriously questioned the effectiveness of AZT.

Studies in the 1980s found AZT to effectively prolong people’s lives when they develop AIDS.9 On the basis of early evidence, the medical community and treatment advocates proposed that AZT be given to people without symptoms, and AZT received federal approval for widespread use in 1987.10 The medical community was, therefore, set back by results of the Concorde Study at the Ninth International Conference on AIDS in early June 1993. This study, conducted in Europe, suggested that people without symptoms who were taking AZT had similar rates of progression to AIDS as those not on AZT. This has been interpreted by some as a failure of AZT at early stages of infection; others see it as a predictable result of the ability of HIV to resist treatment.

The Concorde study has faced significant criticism, and because of some methodological weaknesses, its findings have been discounted by some researchers. However, partly in response to the study’s findings, an expert panel brought together by the National Institute of Allergy and Infectious Diseases (NIAID) in late June established new guidelines for antiviral treatment. The new guidelines are less aggressive in recommending AZT at earlier disease stages, allowing more choice to patients and physicians. New recommendations place more emphasis on disease symptoms, rather than on T-helper cell counts alone.
Quality of life is one factor in considering whether antivirals are ultimately beneficial and in determining at which stage of infection they might be taken. Side effects of antiretrovirals clearly diminish quality of life. AZT causes several adverse reactions including anemia, headaches, nausea, and vomiting. Both ddI and ddC cause painful neuropathy, sometimes even after the drugs are no longer being used. But, all three, taken in combination or independently, have demonstrated an ability to boost the immune system.¹¹

**Survival Strategies**

Among survivors in various studies, no single method of medical therapy predominates, and survivors have taken what may appear to be conflicting approaches. For instance, while some people who have survived many years have used antiviral therapies, others have not taken any treatments.¹ Personal testimonials of many survivors support the view that lifestyle changes, and not treatment-related choices, may well prolong symptom-free infection.

The ability to cope with infection appears to play a large, but still unclear, role in the mental and perhaps physical health of those with HIV. A common characteristic among those who have survived with HIV or AIDS is that their attitude toward life has changed following diagnosis. Most speak of having made their lives “fulfilling”; they have reduced stress and self-destructive influences, opened themselves to living and focused their lives on building a future. [For more on this, see “Related Issue: Characteristics of Long-Term Survivors,” below.]

There is little scientific data to explain why personal attitudes may influence survival, but there are some interesting observations that support such claims. While studies have not found a direct link between physical symptoms of disease and conditions such as anxiety and depression, some researchers believe that a person’s ability to cope may be affected by anxiety and depression.¹² It has even been shown that an “active coping style” promotes the activity of natural killer cells, a specialized cell that is little understood but is a possibly vital part of the immune system.¹³

A ground-breaking study of female breast cancer patients participating in support groups showed the average survival time was twice as long for participants as for those not participating in groups.¹⁴ Because groups emphasized coping with terminal illness, similar results may be seen in people with HIV. As people continue to live with HIV for extended periods, a great deal more may be learned about characteristics of survivors.

**Genetic and Viral Differences**

Researchers have proposed that genetic differences, which are not yet understood, may explain why some people with HIV survive or remain relatively free of symptoms for longer periods than others. In addition, researchers have reported that differences in disease progression may be partly based on the virulence of the specific HIV strain in which a person is infected. A survey of six people who were infected during a blood transfusion from the same donor found that five of the six, as well as the blood donor, remained symptom-free, and with normal T-helper cell

### Related Issue: Characteristics of Long-Term Survivors

Health care providers report a variety of characteristics among long-term HIV survivors.¹ The following are some of the most common characteristics:

- Optimism
- Feeling that they are personally responsible for, and can influence, their health
- Feeling satisfied with the quality of life
- Belief that life is meaningful
- Belief that life has become more meaningful as a result of infection
- Experience of having dealt with or healed emotional wounds
- Able to employ healthful coping mechanisms
- Able to avoid feeling negative effects of difficult people or situations
- Involvement in meaningful life and activities
- Involvement in fitness or exercise programs
- Pragmatic and realistic outlook
- Able to take each day as it comes
- Have sought HIV-related medical care
- Skill in communicating their needs
- Have sought physicians they can trust. They expect to be treated as equals and collaborators and will change doctors if not satisfied
- Good medical consumers; they stay informed about medical developments and assertively demand the best treatment possible
- Generally not obsessed by T-helper cell counts
- In some cases, have survived other life-threatening or psychologically disturbing circumstances
- Involvement in helping others — socially, politically or in other meaningful ways
Implications for Counseling

Many clients do not understand the meaning of a positive test result as it relates to survival and illness. For instance, some clients believe a positive result means a person is in immediate danger of becoming ill, while others do not recognize that HIV infection is life-threatening. Attitudes about the severity of HIV and surviving infection greatly affect how a person responds to being infected. Someone who views HIV infection as life-threatening but manageable may seek health care and want to stay alive, while someone who views HIV as a “death sentence” may approach life fatalistically, doing nothing to prolong survival.

Pre-Test Counseling

In pre-test counseling, assess attitudes and awareness about the severity of HIV by asking what a positive test result means to the client. This may include a discussion about the client’s attitudes toward survival, if he or she were to test positive, as well as how the client views those who are infected. Taking time to discuss this in the pre-test, rather than post-test, session gives the counselor a chance to clarify misinformation the client may have. In addition, it gives the client an opportunity, perhaps for the first time, to consider what it would mean to receive a positive result. Even if the client later tests negative, such a dialogue can help the client determine the seriousness of HIV infection and be motivated to avoid infection in the future.

Pre-test counseling is also ideal because it is a setting in which information can be exchanged without the overwhelming feelings that can arise in post-test counseling. In post-test positive sessions, clients who test positive may be in too much shock to receive information, while clients who test negative may have little interest.

Make sure clients understand the spectrum of HIV infection. Clients may have outdated beliefs about survival that they formed in the early- and mid-1980s when survival times were far shorter. Explain that a few people become seriously ill soon after infection but that most people remain in good health for many years, and some have lived more than 12 years without becoming ill.

When possible, explain the following stages of infection, their length and how they are managed:

1) the symptom-free period;
2) the period in which some symptoms of disease, including minor illnesses, occur; and
3) the period in which a person has developed serious symptoms and conditions, some of which constitute an AIDS diagnosis.

Present statistics about each period when this will be useful; be aware, however, that statistics may unnecessarily complicate discussion and general statements are often more helpful.

Ideally in the pre-test session, explain the relevance of taking care of oneself, for example, by establishing ongoing medical management as soon as possible; maintaining proper nutrition; getting appropriate exercise and rest; and managing stress in non-destructive ways. Make sure clients understand that a positive HIV test result does not indicate when a person was infected with HIV.

For clients who do not respond to a dialogue about the meaning of a positive result, suggest that they consider postponing testing until they have had more time to think about this, either on their own or through follow-up counseling.

Post-Test Counseling

Discussions of survival can be especially challenging in post-test counseling sessions when a counselor discloses positive results. This is a time in which the counselor is trying to focus not on the future, but instead on the client’s needs and feelings in the moment and the time immediately after the counseling session. Despite this, discussion of survival issues can take place, and in some cases, such dis-
“I’ve lowered my expectations of drug treatment. Five years ago, I had high hopes about AZT, and I assumed that people testing positive would be healthy until a cure came along. That’s not the reality today, and I don’t like to face the reality. But, if I don’t, I’m deceiving the client and deluding myself.”

“Considering that the news about treatments is discouraging, it helps me to know that people are surviving by taking care of themselves, often times without drug treatment. This helps me replace disappointing news about treatments with useful information that if people take care of themselves, they can live with HIV.”

“To be present with clients, I have to work harder now to separate from the epidemic. Outside the workplace, I stay away from HIV. And I stay away from areas of the city where a lot of people I knew have died. And, I’ve slowed my pace. Years ago, I saw clients’ needs as urgent and put them ahead of my own. Now, I put my needs first.”

“I didn’t think people would test positive or seroconvert after 1990. I’ve had to change my ideas of how long-lasting the epidemic would be.”

“In the ‘80s, HIV seemed so much simpler, and we could assume there’d be a cure. Now, we know a lot more about how hard it is to treat HIV, without really knowing anything about how to treat it. We’re faced with concepts like prophylaxis, recombinant gene therapy, and cellular immunity. I acknowledge to clients that these things aren’t tangible or simple.”

“I can’t say anything absolute about survival rates. But, by qualifying what I say, I can make positive statements about survival.”

cussion may be especially relevant to the feelings or thoughts the client is having during the session. For instance, the client who has lost sight of the belief that people can live with HIV for many years may gain some relief from being reminded of this.

This reminder about survival can also help clients counter the sense of urgency often felt, and it can alter the decision-making process from one that occurs in a hurried context to one in which decisions can be made at a more measured pace. Assure clients that there is time to reflect, discuss and consider options, even though the client may feel a decision or resolution must be made immediately. Recognize, too, that a client who denies his or her infection will have time to adjust, and may later develop plans for managing news of his or her infection.

When receiving a positive test result, clients often present counselors with a variety of questions. A commonly expressed concern is whether a positive result means a client is going to die. The counselor’s direct answer to this type of question may be less useful than a discussion of the client’s feelings about and reasons for asking the question. Exploring these may help the client learn more about his or her thoughts related to living and dying, and about receiving a positive result. Affirm the client’s fears or other feelings about illness or death, and provide factual information the client can integrate with his or her perceptions.

While it is important to communicate messages of hope, it is necessary that counselors not respond to clients with inaccurate information that could lead to unrealistic hopes or expectations. Beyond discussions of long-term survival, questions about the prospect of death can be answered in a variety of ways. Counselors might state that although it is true that all people are going to die at some time, people with HIV are at increased risk of earlier death. Acknowledge that while a few people with HIV become ill and die soon after their infection, most people remain healthy for many years after being infected, and some people are still alive and healthy more than 12 years after being infected.

Whenever aspects of the future are discussed, it is important to continue to be alert to clients’ feelings in the moment, and to address immediate needs for support. Clients may ask about the future to avoid the present. Counselors can
keep the focus on immediate feelings while confronting the future by discussing the value of facing life today, rather than the possibility of death at an unknown time in the future. Be attentive to and respect clients’ revelations about spiritual beliefs or values. These can provide an indication of how clients view the future and issues of illness and death.

Counselors may meet with little apparent success in discussions about survival even when clients ask questions about it — and must accept that clients may be unwilling or unable to have such a discussion. Survival and living and dying can be better dealt with in follow-up and ongoing support groups or psychotherapy. Make clients aware of these options.

**Survival Strategies**

Understanding the value of survival strategies may be confusing for both clients and counselors because some long-term survivors have used techniques that others have not. For instance, some have used antiviral therapy, while others have not taken any medication.

Be prepared to discuss the range of survival strategies people with HIV use. Encourage clients to investigate strategies that interest them. State that there is little specific evidence about which steps are more likely to lead to longer survival, but that it is clear that people survive for longer periods with HIV now than they did early in the epidemic, based in part on improvements in medical care and treatments. State that others report improved quality of life as a result of actively working toward survival. Personal testimonials of many long-term survivors support the view that taking care of oneself can prolong symptom-free periods.

Support groups are perhaps the most useful strategy to discuss during post-test counseling because such groups relate both to surviving with HIV infection as well as meeting immediate needs for support. State that HIV support groups have been shown to improve attitude and outlook — in part by offering a shared experience with others in a similar situation — and that these benefits may extend life expectancy. Group involvement may also allow people to more effectively mobilize resources. Make referrals to such groups, and to the state’s Early Intervention Program (EIP), in areas where sites are located. This program offers support groups as a central part of its services.

To the extent the client is actively interested, present other survival strategies, such as nutritional plans and ongoing medical care. If clients are not interested in this discussion, do not force it. Instead, focus on the client’s concerns and the benefits of immediate support, and provide referrals for follow-up services. EIP sites offer nutritional planning, health education, case management, and medical care, without charge.

When presenting survival strategies, explain that they relate to and complement other strategies. For instance, make sure clients understand that support groups are in no way a replacement for ongoing medical care.

---

**A Counselor’s Perspective**

“Talking about long-term survival is sometimes difficult because it involves discussing the future at a time when it’s important to focus on the present. Any time I talk about survival, I make sure the client is comfortable enough with what’s going on in the immediate moment, and then I conclude by coming back to what’s most immediate.”

Similarly, it is important to understand that a sound nutritional plan will have reduced value if a person uses alcohol or other drugs.

It is important for clients to feel comfortable with the strategies for survival they choose to apply. Some people with HIV have become preoccupied with investigating and implementing survival strategies at the expense of other pleasurable daily activities, such as work or social pursuits. For example, exercising or reading medical research reports may become a person’s most important pursuit at the expense of all other activity. This response, which is often a short-term one, may be normal and necessary for some people, including those who feel that priorities in their lives must change. Rather than discouraging this, encourage clients to assess the value of various strategies. The extent to which survival strategies can be integrated into and balanced with other parts of one’s life is especially important to a per-
Case Study

Mary, who is 26, has tested HIV positive and is convinced she is going to soon become ill and die. She has been in a primary relationship with an injection drug user for three years, and she says she was probably infected within their period. When she thinks of HIV or AIDS she thinks only of friends and others who have become suddenly ill, then died.

Counseling Intervention

Gain a better understanding of Mary’s impressions of HIV infection and AIDS, and determine the source of these. Mary’s experiences may be based on people she has known who did not test for HIV and did not seek medical care when symptoms of disease arose. They may have learned they had HIV only when they became seriously ill, perhaps many years after they were infected.

Explain that there are different profiles of survival, depending on physiological differences between people, as well as on how people respond to HIV infection. Also explain the spectrum of infection. State that some people do become sick relatively soon after being infected, but more commonly, people remain healthy for long periods, and evidence does not support the idea that illness and death are imminent for someone infected only three years. Do not deny, however, that HIV infection is life-threatening; acknowledge that illness and death can occur.

Because she has chosen to test now, help Mary see that, especially if she was infected not more than three years ago, she is giving herself a chance to take charge of her life and infection in a way she otherwise would not have. State that by managing her health, it is very possible she can remain as she is now for an extended period.

Stress that there have been improvements in managing HIV infection, both in terms of understanding the virus and in responding with primary and preventive treatment. These changes have extended survival, improved quality of life, and helped people better deal with illnesses that can arise.

Respect Mary’s fears and other feelings related to the illness and death of her friends. Recognize that it may be difficult for her to remember that a person can live with HIV in the face of such reminders. Such images may lead her to deny her infection. Point out that she can use her fears to motivate herself to actively face and manage her infection. In many cases, a person can reduce fears by facing them in a supportive environment.

It is important that Mary have contact with providers who can help her see that HIV infection is manageable, and who understand HIV issues affecting women. A support group for healthy people with HIV can be especially valuable in providing her with images of HIV-infected people who lead healthy, vigorous lives. Provide referrals to these resources, help her see how they can immediately benefit her, and help her access them. Include referral to the state’s Early Intervention Program (EIP), in areas where its services are available. Make sure referrals offer services appropriate to women.

References

Test Yourself on Survival and HIV

Review Questions

1. True or False: In one large study, less than 1% of those infected with HIV were still alive 13 years after the beginning of the study.
2. True or false: Survival times for people with AIDS are becoming shorter.
3. True or false: AZT use is urged for everyone with HIV.
4. Involvement in support groups a) may allow a person to mobilize resources, b) may prolong the life of the person with HIV, c) has been found to have no value in extending the life of someone with a terminal illness, d) a and b are correct.
5. A large study found median survival time after the development of AIDS to be a) 3 months, b) 8 years, c) 12.5 months, d) 7 years
6. True or false: A survey of gay men with HIV found that roughly half live at least 10 years without developing an AIDS-defining condition.
7. True or false: It has been conclusively proven that progression of HIV is entirely halted by an “active coping style.”
8. True or false: People with HIV employ a wide variety of coping skills with great differences among individuals.

Discussion Questions

1. Clients with HIV infection may or may not survive for long periods of time after they learn that they are infected. How can counselors present information about the prospects for long-term survival in a responsible manner?
2. Attitude is believed to be strongly linked to survival trends. How can this message best be conveyed in the limited time the HIV test counselor has with the client?
3. How can HIV test counselors remain current with information on antiviral drugs and other issues related to survival?
4. How can counselors best describe various survival strategies to clients?
5. How can counselors fairly present information about non-traditional survival strategies? How can information about any unproven, but potentially useful, strategies be presented?

Answers to Test Yourself

1. False. One-third of people in the SFCCC study have survived thirteen years.
2. False. Survival times are becoming longer.
3. False. Recommendations to use AZT are not made for everyone. They are based upon such factors as the presence of symptoms of disease, a person’s T-helper cell count, and an individual assessment made by both physician and client.
4. D. Both a and b are correct.
5. C.
6. True.
7. False. An active coping style increases the number of certain useful “killer” cells in the immune system; however, it is still unclear if these cells directly affect the progression of HIV disease.
8. True.

Reader Response

PERSPECTIVES encourages counselors to respond to discussion questions presented in each issue. Replies may help in planning future issues. Share your thoughts related to the questions by writing: Editor, HIV Counselor PERSPECTIVES, UCSF AIDS Health Project, Box 0884, San Francisco, CA 94143.

Using PERSPECTIVES

PERSPECTIVES is an easy-to-read educational resource for HIV test counselors and other health professionals. Each issue explores a single topic. A Research Update reviews recent research related to the topic. Implications for Counseling applies the research to the counseling session. Also included are a Case Study, and two sets of questions for review and discussion.

HIV Counselor PERSPECTIVES

Volume 3 Number 5 October 1993

Writer and Editor: John Tighe
Writer and Researcher: Tamara Simon
Clinical Consultants: JD Benson, MFCC; Marcia Quackenbush, MFCC; Jaklyn Brookman, MFCC
Production: Leslie Samuels
Administrative Support: Roger Scroggs

PERSPECTIVES is an educational publication of the California Department of Health Services, Office of AIDS, written and produced by the AIDS Health Project of the University of California San Francisco. Reprint permission is granted, provided acknowledgment is given to the Department of Health Services. PERSPECTIVES is based largely on input from antibody test counselors and other health professionals. Among those who had a significant influence on this issue: Lanz Lowen, Alejandra Acuna, Greg Smith, Kelly Butler, Jordana Raiskin, Susan Thompson and Jack Hertzberg.

AIDS HEALTH PROJECT

Director: James W. Dilley, MD
Publications Manager: Robert Marks
Designer: Saul Rosenfield

Department of Health Services, Office of AIDS, P. O. Box 942732, Sacramento, CA 94234, (916) 445-0553.

UCSF AIDS Health Project, Box 0884, San Francisco, CA 94143-0884, (415) 476-6430.

Printed on recycled paper.
DID YOU KNOW?

You can access a FREE searchable archive of back issues of this publication online! Visit http://www.ucsf-ahp.org/HTML2/archivesearch.html.

You can also receive this and other AHP journals FREE, at the moment of publication, by becoming an e-subscriber. Visit http://ucsf-ahp.org/epubs_registration.php for more information and to register!

ABOUT UCSF AIDS HEALTH PROJECT PUBLICATIONS

The AIDS Health Project produces periodicals and books that blend research and practice to help front-line mental health and health care providers deliver the highest quality HIV-related counseling and mental health care. For more information about this program, visit http://ucsf-ahp.org/HTML2/services_providers_publications.html.