The suspicion that AIDS might be a blood-borne infectious disease has existed since the earliest reports of the epidemic in 1981. This mode of transmission was considered because the disease was clustered in sexually active gay men and drug addicts — groups known to have high frequencies of infections with viruses that are also transmitted by blood transfusions.

It was not until December 1982, however, that investigators at the University of California San Francisco and Irwin Memorial Blood Bank reported the first case of apparent transfusion-associated AIDS (TAA) in an infant who had received a blood component from a donor who later developed AIDS. The Centers for Disease Control (CDC) first reported the existence of multiple cases of TAA in 1984. Unfortunately, by this time thousands of blood recipients were already infected with Human Immunodeficiency Virus (HIV).

That HIV can be transmitted by blood transfusions is now beyond doubt. The most convincing evidence for this mode of transmission comes from two national studies in the United States: (1) the CDC Donor Study in which suspected donors to transfusion-associated AIDS cases were recalled; HIV was cultured from the blood of 88% of them; and (2) the Transfusion Safety Study which has tracked recipients of blood donors whose stored serum later tested positive for antibodies to HIV — this study has found that over 90% of recipients of antibody positive blood are infected with the virus.

Progressive Steps to Safeguard the Blood Supply

In early 1983 U.S. blood banks began to act on the assumption that AIDS was caused by a blood-borne infectious agent. The first step toward preventing TAA was to avoid recruitment of groups with a high incidence of AIDS. Individuals from such groups were asked to "self-exclude" themselves from donating blood. Specific screening questions were asked of prospective donors to detect possible AIDS or exposure to patients with AIDS, and donors were required to sign a statement denying AIDS risk-factors.

In addition, several methods were introduced to give donors a confidential means to notify the blood bank that they had donated should not be transfused. These methods were necessary because occasional high-risk donors continued to donate because they had been regular donors and were afraid that to discontinue donation might lead to the undesired suspicion that they were homosexual.

The HIV Antibody Test

In early 1983, the first rapid test for HIV was developed. The licensed tests made available to blood banks have a very low positive rate. One such test, the HIV Antibody Test, was an enzyme-linked immunoassay (ELISA) test. The licensed tests made available to blood banks have a very low detection cut-off in a deliberate attempt to make the test as sensitive as possible in the hope that no AIDS virus carriers will be missed.

After much study and debate, some blood banks did institute surrogate tests. For example, Irwin Memorial began testing blood for antibody to hepatitis B core antigen in May 1984. In retrospect we know that this surrogate test reduced the risks of HIV in blood transfusion by about one-third, in the process resulting in the exclusion of about 5% of donors, almost all of whom were not at any risk for AIDS.

The HIV Antibody Test

Once HIV was isolated from several AIDS patients and determined to be the etiologic agent of the disease, a test to detect antibody to HIV was developed with unprecedented speed. The test was licensed by the Food and Drug Administration and made available to U.S. blood banks in March 1985. The test method, designed for the mass screening needs of blood banks, was an enzyme-linked immunoassay (ELISA) test. The licensed tests made available to blood banks have a very low detection cut-off in a deliberate attempt to make the test as sensitive as possible in the hope that no AIDS virus carriers will be missed. When applied to known cases of AIDS or ARC, these ELISA tests have proven to be highly sensitive and specific, detecting HIV infection in over 99% of these individuals.

It was correctly anticipated that a high degree of nonspecificity would occur when the test was applied to the already screened blood donor population. As experience accumulated in the blood banks, it became apparent that the vast majority of ELISA positive blood donor tests were false positives.

Providing appropriate education and counseling to blood recipients has posed some unique and challenging problems...

Many of these people have had great difficulty accepting and dealing with their potential or actual HIV infection.
Transfusion-Associated AIDS...

continued from cover

Blood banks have relied on the results of separate confirmatory tests to distinguish between true and false positive ELISA tests. The favored confirmatory test is the Western Blot, which allows one to detect specific antibodies that react with a characteristic series of viral proteins. Unfortunately 5-10% of Western blot results are still equivocal. The best way to clarify the true HIV status of these donors is to re-test them at a later date, since most adults infected with HIV will show typical antibodies to the virus within six months of exposure.

The True Positive Donor

During the first two years of antibody testing Irwin Memorial identified over 100 donors whose ELISA positive tests were confirmed by Western blot (true positives). The frequency at which these donors was found has declined from an initial rate of two per 1,000 to the current rate of one per 4,000. Viral culture studies on these donors have confirmed that virtually all are persistently infected with HIV. These donors are told that they are infected with HIV, and they are counseled to prevent their own health and to prevent the spread of the virus to others.

The true positive donors are largely from among those whose behaviors place them at high risk for AIDS. On follow-up confidential interview, the vast majority have either been men who admitted to previous unprotected sexual contact with other men or individuals with a history of intravenous drug abuse. These donors had either not read the information they received before donation or were unable to accept it. A small number of the identified true positive donors apparently acquired HIV through transfusions or unprotected heterosexual contact with high-risk individuals.

The False Positive Donor

Once HIV antibody testing started, blood from ELISA-positive donors not confirmed by Western blot (false positives) was discarded. Those donors were initially not informed because of uncertainty as to what the results meant. Within months, however, large numbers of false positive donors were returning to donate again. These donors were being accepted with the full knowledge of the blood banks that the units would be discarded.

Blood banks now inform these donors of their test results. We feel that it was wrong to let these donors continue to donate on the mistaken assumption that their blood was being used to treat patients. The donors are told that their HIV test result is believed to be a false positive, but that a guarantee that it is false cannot be given. Many of these individuals experience considerable anxiety.

At Irwin Memorial we have detected and notified over 500 false positive donors. Over the past two years we have followed over 100 of these donors with repeated HIV antibody and culture studies. Not a single Western blot negative donor has been found to be infected with the virus. Recently, the FDA has approved a policy which allows those individuals who test negative six months following their original ELISA positive donation to be reinstated as eligible donors.

The Current Status of TAA

There were 732 cases of AIDS reported to the CDC as of April 20, 1987 with no evident risk factors other than a previous blood transfusion. These cases account for 2.1% of the total reported AIDS cases in the United States. An additional 325 cases of AIDS have occurred among hemophiliacs in the U.S. Recent seroepidemiologic surveys indicate that over 50% of hemophiliacs who received clotting-factor concentrates prior to 1984 (when heat-treatment was begun) are infected with HIV.

Virtually all reported TAA cases received their transfusions between 1977 and 1985, before the antibody test for the AIDS virus became available. The risk to recipients obviously varied greatly during this period. Following the first reports of TAA cases and the introduction of self-exclusion policies and surrogate testing, the risk of HIV in transfused blood began to decline. We know now that the risk in San Francisco in 1984 was about one in 500, since samples from that year were frozen for later testing as part of the Transfusion Safety Study.

Since the introduction of routine screening of donor blood for antibodies, the risk has declined to the range of 1:100,000 per transfused unit. This persistent low risk is due to the possibility that people may donate within the first few months following infection, prior to developing detectable antibody. One episode in which this occurred was recently reported.

Further reduction of the risk of HIV in transfusions will require a more sensitive test for the presence of the virus itself or some method to destroy the virus in a donated unit. The latter approach has been applied successfully to concentrates of blood coagulation factors manufactured to treat hemophilia, but no physical or chemical approach to destroy intracellular viruses without harming the cells is available at this time.

Lookback

Despite virtual elimination of HIV from the current blood supply, reports of TAA cases continue to accrue at an increasing frequency. The recently reported TAA cases received their transfusions between 1977 and 1985, before the test for HIV antibodies became available.

Since the mean incubation period of transfusion-transmitted HIV infections is at least 5 years and may be as long as 15 years, the majority of blood recipients infected with HIV during the high-risk years probably remain asymptomatic. In the future we anticipate that many additional cases of TAA from blood transfused during these years will be reported.

Blood banks have pursued a program called "Lookback" in an effort to identify asymptomatic individuals who may have been exposed to HIV via transfusions during the high-risk period. The primary goals of this program are identification, testing and counseling of potentially exposed recipients so that they might seek appropriate medical care and prevent further spread of HIV to their intimate contacts.

As originally formulated, lookback policies dealt only with recipients of the rare AIDS patient who acknowledged being a prior donor. To this was added the more common situation in which a current blood donor with a previous donation history was found to be anti-HIV positive. However, since the vast majority of high-risk donors self-deferred when asked to do so in 1983, most infected previous donors have not returned to blood banks for testing. Other efforts are required to find such infected donors in order to trigger lookback notification of potentially exposed recipients. [Editor's note: health officials estimate that there are currently 10,000 living recipients of HIV-infected blood in the U.S.]

At Irwin Memorial we have pursued several additional avenues for identifying HIV antibody positive donors: (1) active identification of reported AIDS patients who were previous blood donors, and (2) active investigations of donors implicated in reported TAA cases.

Once identified, the past recipients of currently infected donors are notified of their possible exposure via letters to the hospitals. To date, over 1,250 lookback notification/information packets have been sent to the hospitals served by Irwin Memorial. The hospitals pass this information on to the previous recipients' physicians, who can either notify the patients themselves or request that the blood bank's trained counselors initiate contact. Any decision that it will do more harm than good to tell a patient of potential exposure is made by the personal physician.

Follow-up studies have shown that about half of the traced recipients actually died of their underlying disease within a year of transfusion. Of the living lookback recipients referred back for testing, slightly over 50% have tested positive for HIV. The more remote the date of transfusion, the lower the likelihood that a past recipient was infected.
The ultimate fate of individuals infected with HIV through transfusions is uncertain. However, as recipients come in for testing and follow-up, our epidemiologic knowledge about TAA grows. Clinical symptoms related to HIV infection clearly increase with the duration of the infection. In our studies of seropositive recipients 30% manifest symptoms of AIDS or ARC at a mean follow-up of about four years. Of the healthy seropositive recipients, we can culture HIV from over 80%, indicating that the majority are persistently infected with the virus. Several sexual contacts of infected recipients have tested positive, and one infected recipient has given birth to two infected infants. These findings underscore the important public health implications of transfusion-transmitted HIV infections.

In addition to notification and testing, the blood bank lookback program considers education of recipients and the community to be primary objectives. The blood bank provides educational materials and consultation for health care professionals and patients. We also have available a number of follow-up studies for targeted antibody positive donors and recipients.

Providing appropriate education and counseling to blood recipients has posed some unique and challenging problems. Until recently, recipients have been an unsuspecting and uninformed group, with a striking lack of formal support services. Many of these people have had great difficulty accepting and dealing with their potential or actual HIV infection. They display a variety of reactions, including denial, anger, hystena, victimization, somatization, and occasionally, morbid depression. Confidently and potential transmission to intimate contacts are major concerns.

Although we have at times provided referrals to help infected recipients cope with adverse reactions, they seem not to use them. As a rule the recipient population feels alienated from the support services available to other risk groups in the community. As a result, this generally older, heterosexual group has few community resources and relies heavily on the staff of the blood bank for ongoing support. Meeting the multitude of complex needs of blood recipients in a limited counseling context has posed several unique problems.

It must be acknowledged that, despite our lookback efforts, it is unlikely that blood banks have identified the majority of infected previous recipients. The recent general CDC recommendation that recipients of multiple units of blood from high risk regions consider being tested for HIV is a reflection of this fact. Irwin has now developed a policy offering all concerned previous recipients the opportunity for testing and counseling.

Summary
Since the first case of transfusion-associated AIDS was reported in December 1982, more than 500 cases have been reported nationally. Measures to safeguard the blood supply from HIV, and particularly donor self-exclusion policies and anti-HIV screening, have been highly effective in many developed countries.

Yet, we continue to experience the serious repercussions of HIV infections transmitted by blood transfusion that took place prior to the availability of these screening procedures. Hence TAA cases will likely continue to account for at least 2% of reported AIDS cases for the next several years. In an effort to identify individuals who may have been exposed to HIV via transfusions during the high-risk period, blood banks have pursued lookback programs which trace and notify recipients of recently identified HIV seropositive donors. The clinical outcome of infected transfusion recipients appears to be comparable to that observed with other risk groups.

Diagnosis/Treatment/Prevention

Counseling the HIV Seropositive Transfusion Recipient
Denise Deitch, MFCC

In the early years of the AIDS epidemic, health officials identified transfusion recipients as one of the risk groups for AIDS. Now our understanding of risk for HIV infection focuses on high-risk behaviors rather than on membership in a clearly defined group. However, even in those early days, transfusion recipients rarely allowed themselves to consider seriously their own risk for infection.

Armed with the fact that only 2% of AIDS cases in the United States have been transfusion related, both private and public medical sectors have minimized this risk from transfusions. In a sense, we as a society have colluded with the individual transfusion recipient to deny the potential risk. The need to notify those who have received HIV antibody positive blood can be an understandably difficult task. However, concern for the unknowing further spread of the virus makes this necessary.

Counseling Issues
Through efforts such as the "Lookback" program, hundreds of unsuspecting individuals have been notified by their physicians that the blood they received came from a donor who was seropositive for HIV. These recipients are asked to be tested to clarify their antibody status and to receive counseling. Others who donate blood are found occasionally to be seropositive, and these donors are also notified of their antibody status. In both instances, the notification of seropositivity most often comes quite unexpectedly. It is this profound shock that differentiates the counseling given to these individuals from the kind of counseling given to other seropositives who, by virtue of their membership in high AIDS incidence groups, have often dealt with the possibility of their being infected. Those notified of their antibody status through the blood bank may have actually received their transfusion several years ago. Notification then brings with it the sometimes frantic concern that the individual has unknowingly infected a spouse or sexual partner. Following the initial shock and psychological adjustment to the news, the individual is counselled to consider informing his or her past or present sexual partners so they might also have the opportunity to be tested.

The need to provide supportive counseling to family members is also important as families may often feel unable to talk to their usual support systems because of fear or rejection or stigmatization.

Reactions to notification are often dominated initially by anger as the individuals feel betrayed by the medical establishment, by their doctors, or by fate.

Transfusion recipients who are not additionally at risk from other factors now find themselves infected as a direct consequence of accepting medical treatment. They had placed implicit trust in their physicians, hospitals, and blood banks. The very treatment that was meant to heal them has now catapulted them into a life-threatening situation which in most countries is associated with unacceptable behavior.

The client often experiences a sense of betrayal and a lack of trust both of the medical establishment and possibly for themselves having made a choice to take a particular course of treatment. The ability to attribute blame to an outside source, e.g. the medical establishment, can be a very useful coping tool for the individual and should not be taken from them.

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Helping professionals must validate as normal responses the accompanying anxiety, anger, and depression which may occur among these individuals. Validating these feelings is critical in the process these individuals must go through to make a successful adjustment to their new circumstance. In acknowledging these feelings, helping professionals must be prepared to hear and understand what may sometimes be some disturbing degrees of anger directed towards them.

The patient may also swing to the other extreme and spend much time taking care of the helping professional, commenting on how difficult it must have been for them to be the "bearer of bad tidings". It is critical that we not collude with the patient in taking the focus away from themselves in this way. Follow-up over the longer term is critical to assess the client's level of adjustment and to provide appropriate additional resources.

Problems in Management

Of all the populations labeled initially as risk groups, transfusion recipients had the least reason to identify themselves as part of an actual group. In general, gay men, hemophiliacs, and intravenous (I.V.) drug users share a common sexual orientation, chronic disease, or lifestyle. Transfusion recipients are unique in that they do not maintain as part of their identity the fact that they were transfusion recipients. As a result, transfusion recipients lack a sense of commonality with others. The treatment of choice for supportive counseling for other risk groups may well be a small group format. This may not be a viable option, however, if the primary identifier is that of a transfusion; it may not be enough to allow for bonding within a support group context. This has been apparent by the lack of success in maintaining sustained group attendance among seropositive transfusion recipients. In most cases, these individuals choose not to give such a group a try.

Additionally, there are many elderly people in the pool of seropositive transfusion recipients. While the large number of such individuals might suggest providing some kind of group intervention, a variety of reasons contribute to precluding this option, including a lack of mobility, accepted levels of isolation either with a life-partner or by oneself, and a reluctance to join a group. Interviews with many elderly transfusion recipients in particular have generally revealed the values and beliefs of American society. Both the fear that they may be identified as associated with the other early risk groups (gay, bisexual, I.V. drug users) and that they might be viewed as needing psychological help should they attend a support group are undesirable, if not unacceptable, options for many of these individuals.

Counselors and health care providers should provide not only information in their effort to support self-awareness, knowledge or risky behaviors, and positive behavior changes, but also should make interventions relevant and operational for the individual.

Alternative Supportive Services

Establishing informal telephone support networks has achieved some degree of success in providing longer term support for women affected by HIV or AIDS. With the help of an intermediary who creates the connection in a way that feels safe to participants, seropositive transfusion recipients could remain on their own turf, in the emotional safety of their own homes, and still give and receive support from others. While this program does not currently exist, such a network for seropositive transfusion recipients may offer a means of providing some continued support.

Blood banks, hospitals, and physicians generally do not provide opportunities for ongoing support services tailored to individual needs. While there is increasing acknowledgement that education and counseling is vital, resources have not been allocated to meet this challenge. While it may not be practical for medical institutions and private practitioners to provide such support, it may be in the best interests of the transfusion recipient population at risk for HIV infection to create their own independent resources or to obtain services from existing resources, such as AIDS hotlines and AIDS service agencies.

Conclusion

Transfusion recipients come from all walks of life. Counselors must consider many possible variables — economic, social, and cultural influences — in assessing appropriately the needs of the seropositive transfusion recipient and in making appropriate interventions and referrals. Other health care professionals can be essential resources to work in concert with transfusion recipients to address their special needs.

* Individuals interested in developing resources for transfusion recipients at risk for AIDS are encouraged to contact Ms. Deitch at (415) 548-8283.

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Next Month

In June more than 6,000 AIDS researchers, health care providers, and educators gathered in Washington, D.C. for the Third International Conference on AIDS. The 1300 research papers and poster sessions presented at the conference reflect the explosive growth of AIDS research and public interest in controlling the epidemic. Although the media provided extensive coverage of the Washington conference, the more detailed research findings of importance to health care providers often went unreported.

In the August issue of FOCUS, Cheri Pies, MSW, MPH and Michael Helquist will review the latest findings from studies of psychosocial issues, antibody testing, risk reduction education, public health, and experimental therapies. Pies is the Health Educator for the Alameda County (CA) AIDS Services Program; Helquist is the Editor of FOCUS.