Increasing Return Rates for Disclosure Sessions

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Clients who test for HIV but do not return to receive their results—often referred to as “no-show” clients—represent missed prevention and treatment opportunities and raise the financial costs of HIV prevention programs. This issue of the FOCUS Supplement explores some of the factors that may deter clients from returning for disclosure sessions and suggests strategies to increase return rates.

A Statistical Profile of Return Rates

The Office of AIDS of the California Department of Health Services examined testing data representing nearly one million tests performed at state-funded testing programs from July 1994 through June 1998. During this period, 19 percent of all clients, nearly 180,000 people, testing at state-funded programs did not return to receive their test results within 60 days.* Between the first 12 months of the study period and the last 12 months, the overall no-show rate increased from 17 percent to 21 percent. Return rates were similar for clients whose results were seropositive as for those who were seronegative.

Further analysis of several factors revealed variations in return rates. No-show rates were substantially higher for clients who tested in confidential (34 percent) rather than anonymous settings (13 percent). The high no-show rate in confidential settings is likely a reflection of many factors, including different motivations of clients who choose confidential testing and privacy fears that lead people not to receive results in settings in which counselors know their identity.

Among types of programs, the highest no-show rates were for clients testing through sexually transmitted disease (STD) clinics (36 percent), mobile van programs (34 percent), and detention facilities (28 percent). The lowest no-show rates were for clients who tested through traditional Alternative Test Site programs (11 percent), family planning clinics (15 percent), and other types of health department clinics (20 percent).

A demographic comparison of groups found relatively little difference in no-show rates for men (17 percent) and women (19 percent). African Americans (30 percent) and Latinos (22 percent) had higher no-show rates than Whites (14 percent). The no-show rate for adolescents (26 percent) was notably high.

Men who had sex with men had very low no-show rates (8 percent) as did bisexual men (11 percent). However, there were much higher no-show rates for injection drug users (25 percent) and for clients who exchanged sex for drugs or money (20 percent).

Maximizing Rates of Return

Given the high no-show rates revealed in the study, it is important to consider how test counselors can maximize return rates. During the 1990s, the Office of AIDS has made numerous recommendations to counseling and testing programs to increase return rates. First, counselors should determine during the risk assessment session whether a client will be ready to receive a result and can make a commitment to return for the result. Second, counselors might encourage clients to defer testing if it appears that such clients would be unlikely to return for results. Third, it is important to ensure adequate confidentiality, accessible services, and, at confidential test sites, consistency in obtaining contact information. Finally, the Office of AIDS has implemented a tiered funding system that ties reimbursement to whether disclosure counseling was provided.

In addition to these approaches, counselors and administrators can look more
closely at HIV counseling and testing statistics specific to their program and determine if there are certain demographic groups, such as injection drug users or adolescents, that exhibit a pattern of being less likely to return for test results. The HIV4 computer program, available to counseling and testing programs, provides these statistics. With this information, agency staff will be better equipped to develop strategies to improve service delivery to these groups. Staff can ask, for instance, are there any factors that might serve as barriers to these clients? What changes might make the HIV testing clinic more appealing? Location, demographics of staff, the clinic “atmosphere,” and other factors could affect clients’ decisions to return for results. Administrators and counselors might consider the extent to which their programs can be flexible in working with clients who are unable to set a specific time for a return appointment. Can the program allow some clients to “drop-in” for results? Can counselors schedule disclosure sessions at a more convenient site? Are counselors able to make field visits to deliver results to a person in his or her home or other location?

During the risk assessment session, counselors can directly affect client motivation to return for results by emphasizing the importance of the disclosure session appointment and discussing client concerns about learning results. In clinics in which clients’ primary concerns are services other than HIV antibody testing—such as STD clinics or pregnancy planning centers—counselors can increase return rates by recommending HIV testing only when a client’s risk history suggests that it is pertinent and when clients express interest in learning their HIV status and an ability and willingness to return for results. While data show lower return rates related to demographic characteristics, counselors must individually assess each client’s motivation to return. The need to discuss returning for disclosure sessions is particularly important with clients who, when asked, are unclear in their commitment to return or who say that they have difficulty showing up for appointments. Ask clients how they feel about receiving test results, if they faced any emotional or logistical obstacles to showing up for the risk assessment session, or if they can foresee anything that might keep them from returning for the disclosure session. Such an exploration may include asking clients what it would mean for them to receive a seropositive or seronegative result, a question that may reveal other barriers to returning.

It is also useful for counselors to take time during the last portion of the risk assessment session to review client plans for the period between the risk assessment and disclosure session, including discussing returning for results with others and any commitments the client has made to contemplating, getting ready for, or actually changing behaviors. Using techniques as simple as shaking hands on these agreements can reinforce them as commitments. Counselors can also focus on details, such as asking a client to double-check that the return appointment is scheduled for a time that works for the client. It is also important to review with clients how they can reschedule test sessions if necessary. Counselors should encourage clients to call the counseling and testing program if they miss an appointment. Clients may call not necessarily to reschedule appointments but to discuss risk-reduction strategies and perhaps strategize another, better time to test when they think they will be more prepared to return to receive the result.

In some cases, clients may state that they expect they will not return to receive their results. For example, a client might say, “I’ve tested several times, but I have a lot of trouble getting up the nerve to come back.” In this case, the counselor can respond by asking the client what it is like to test and not receive a result. Ask clients how they feel about receiving test results, if they faced any emotional or logistical obstacles to showing up for the risk assessment session, or if they can foresee anything that might keep them from returning for the disclosure session. Such an exploration may include asking clients what it would mean for them to receive a seropositive or seronegative result, a question that may reveal other barriers to returning.

Counselors and program administrators might also consider instituting incentives to make it more likely that clients will return for results. Incentives might be particularly valuable for clients who are at

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high-risk for infection or for not returning for results. Some outreach programs offer food vouchers, prepaid telephone calling cards, and medical services to clients both when they test and when they return for results.

When Clients Do Not Return

Counselors in anonymous counseling settings do not have the opportunity to contact clients who do not return to receive results, while, in confidential settings, counselors may have a number of options for reaching clients. In anonymous settings, it is, therefore, that much more important in the risk assessment session to build rapport and to evaluate a client's motivation to return for the disclosure session. It may be appropriate to refer clients who, in consultation with the counselor, believe they will have a difficult time returning for results to seek counseling and testing services from a confidential testing program where follow-up services are possible.

Research shows that efforts to reach clients who test in confidential settings and do not return for results can be successful. However, such efforts often are not undertaken, even though the state provides reimbursement for these services. Between July 1997 and June 1998, counseling and testing programs sought to provide follow-up services to only eight percent of those who tested in confidential settings and did not return to receive results. Of those for whom staff undertook follow up efforts, 39 percent subsequently received their results.

To perform follow-up services, counselors must first gain the client's consent to be contacted and learn how the client can be contacted. Telephoning a client is generally the most efficient approach, but, in some cases, telephone contact may not be possible. The client may live with others, may not feel comfortable receiving a call from a counselor, or may not have a telephone. In these cases, counselors should learn if there are other ways to reach a client—such as through an agency from which the client receives other services—while still respecting the client's privacy. In some cases, and depending on test-site policy, counselors might ask for a client's address and offer to provide a result there if the client does not return for the disclosure session.

To prepare clients for the possibility of contact outside the disclosure session, counselors should clarify that the client's contact information may be useful if the site or clinic needs to reach him or her. Stating this at the outset reduces the chances that a client will view contact as being invasive of his or her privacy. Nonetheless, it is inappropriate for counselors to say that this information is used to ensure that clients return for results, because clients may perceive such comments as authoritarian or coercive.

During telephone contact, counselors must use the same counseling skills as they would use in person. Express genuine curiosity and concern about what might have prevented the client from returning for the original appointment. While the primary purpose of the call is to reschedule the appointment and encourage the client to show up for this appointment, such calls also build upon the rapport established during the risk assessment session and establish that the counselor and counseling site are “safe” resources to approach. The call also presents the counselor as being open to problem-solving and as being supportive of the client in taking steps to eliminate obstacles.

In any follow-up contact outside the disclosure session, it is important for counselors to make sure they are not implying that such contact signifies a seropositive test result. A good way to prevent this is to establish a standard policy for following up on all confidential testing clients who do not return for results. To set the context for follow-up phone contact, for instance, counselors can say, “This is a follow-up call we make to everyone who does not return for results.”

Conclusion

It is important for administrators and counselors to examine the issue of clients who do not return for results. Administrators and counselors should consider demographic similarities of clients who do not return for results, and if there are patterns, examine what this
might mean. Likewise, it is useful to look at test-site procedures and approaches to see if there is anything that might inhibit clients from returning. Beyond this, it is important to consider each client's individual profile. Finally, counselors must be sure that the risk assessment session encompasses not only a client's behavioral risks, but also the risk that he or she will not return to receive a test result.

**Case Example: Preparing for the Disclosure Session**

Johnny is a 20-year-old heterosexual who occasionally injects drugs. He says he is seeking HIV testing because he learned that an acquaintance who injects drugs is HIV infected, and he wants to know if he is. Olivia, a counselor working in an anonymous setting, asks Johnny about his knowledge of HIV transmission and the specifics of his HIV risks. He says he sometimes shares needles with friends and that he has had sex in the past year with only one person—his girlfriend, who insists on condom use during vaginal and anal sex.

**Responding to Risk**

Olivia asks Johnny if he has tested before, and he says he tested once four months ago but did not return for the result: “I got into other things” Johnny says. Olivia asks if he expects to return for his result this time, and he says, “of course I will.” Olivia returns to a discussion of Johnny’s risks, knowing that they will come back later to the subject of the disclosure session.

Olivia learns that Johnny has no intention to stop injecting drugs and is not interested in referrals to help him stop, but Johnny says he does want to stop sharing needles and he plans to continue using a condom during sex. Olivia presents interventions appropriate to his stage of maintaining his commitment to using a condom during sex. Olivia asks more about what these things might mean. Likewise, it is useful to look at test-site procedures and approaches to see if there is anything that might inhibit clients from returning. Beyond this, it is important to consider each client's individual profile. Finally, counselors must be sure that the risk assessment session encompasses not only a client's behavioral risks, but also the risk that he or she will not return to receive a test result.

Johnny says he does not like doing so: “Being positive would mess with my life. I don’t want to hear that.”

Although Olivia previously asked if Johnny planned to return to receive his result this time, she has sensed that as the session has progressed he has become more aware of his concerns about testing and receiving a result. She asks the question again. He says, “I'm not totally sure about coming back. If it's negative, I want to get it. But not if it's positive.” Olivia acknowledges that receiving a seropositive result might be difficult for Johnny. She states that his counselor in the disclosure session would provide him support and lead him to other services to help him.

**Between Sessions**

Olivia and Johnny consider what he can do between now and the disclosure session to increase the likelihood he will return for his result. Johnny says he is uncomfortable telling his girlfriend that he has tested, but that he has a brother he could talk to and get support from for returning.

Olivia says she remembers Johnny's statement earlier in the session that he had not returned for his result previously because he had “gotten into other things.” She asks more about what these things might have been, and he replies that it was probably an occasion in which he had been using drugs. Olivia asks whether it might be useful or possible for him to curtail his drug use between now and the next session. He says this could be useful and he will try to do this. He also says he will ask his brother, who does not use drugs, to help him with this.

Olivia asks Johnny if it was difficult for him to come to the risk assessment session. He says he was reluctant to show up, but that he made it nonetheless. She encourages him to remember his ability to overcome his reluctance should he struggle to return for the disclosure session. The session ends as Olivia validates Johnny for the steps he plans to take to reduce his risks and to return for the disclosure session.