The Outreach-Assisted Model of Partner Notification with IDUs

SYNOPSIS

Objective. This analysis describes the Outreach-Assisted Model of Partner Notification, an innovative strategy for encouraging seropositive injecting drug users (IDUs) to inform their partners of shared human immunodeficiency virus (HIV) exposure. The analysis focuses on two core components of the notification process: the identification of at-risk partners and preferences for self-tell vs. outreach assistance in informing partners of possible exposure to the virus.

Methods. Using community outreach techniques, 386 IDUs were recruited for HIV pretest counseling, testing, and partner notification over a 12-month period. Of these, 63 tested HIV seropositive, and all but three returned for their test results. The 60 who were informed of their serostatus were randomly assigned to either a minimal or an enhanced intervention condition. Participants assigned to the minimal (self-tell) group were strongly encouraged to inform their partners of possible exposure. Those assigned to the enhanced (outreach-assisted) group had the option of either informing one or more of their partner(s) themselves or choosing to have the project's outreach team do so.

Results. Together, the 60 index persons who received their results provided names or at least one piece of locating information for a total of 142 partners with whom they perceived having shared possible exposure to the virus within the past five years.

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By itself, drug use accounted for half of all partners named. Sexual behavior alone accounted for 25% of named partners. Eighty-two percent of the enhanced group preferred to have the outreach team tell at least one partner; the team was requested to notify 71% of the total number of partners whom this group named.

Conclusions. Findings suggest that IDUs want to notify their partners of shared HIV exposure. Outreach assistance was the preferred mode in the majority of cases. Expanding traditional community-based HIV outreach activities to include delivering street-based counseling, testing, and partner notification appears to be a positive and workable prevention strategy.

hile partner notification has a long history of acceptance as a general public health strategy, its use with transmission of the human immunodeficiency virus (HIV) has been controversial. During the early years of the acquired immunodeficiency syndrome (AIDS) epidemic, health officials and other interested parties resisted contact tracing as a prevention tactic because confirmatory tests and therapeutic technologies were not available for asymptomatic infected individuals.1 With recent innovations in the clinical options available to people with HIV, prospects for and acceptance of partner notification have changed. Strong arguments now exist to support voluntary HIV screening in combination with partner notification as an HIV control strategy.²

The benefits of partner notification are many. One major advantage is that, upon learning of exposure, notified partners can seek counseling and HIV testing and can begin early medical treatment if needed. This knowledge is particularly important for women, as the presentation of HIV infection is confusing and manifestations often are misdiagnosed unless the virus is suspected.³ Partner notification also has important implications in reducing vertical transmission. Results from randomized, placebocontrolled clinical trials indicate that administering zidovudine to HIV-infected pregnant women and their newborns significantly reduces perinatal infection.⁴ Being notified of possible exposure also can help to curb transmission among individuals who have been exposed to the virus but who are not yet infected. Knowledge of direct HIV contact can potentially motivate seronegative individuals to change their risk behavior to remain negative. Finally, from an epidemiological standpoint, following the chain of notification process from one HIV-infected individual to another within and across social networks permits public health investigators to chart the course of the epidemic.

Although studies show that voluntary HIV screening is viable, even in states requiring mandated reporting and third-party notification,⁵ the large number of contacts typically involved makes tracing and screening partners a formidable task. For example, Rutherford and colleagues⁶ found that 51 heterosexual index persons named 135 opposite-sex partners of whom 34 permitted testing; seven were found positive. Research by Jones and colleagues,⁷ in a rural health district in South Carolina with a population of 182,000, discovered that 25 index cases yielded 207 partners living in the geographic area. Of these partners, 202 (98%) agreed to be HIV tested and counseled. Lee and associates⁵ interviewed 106 seropositive individuals about their sex and needle partners, for a total of 219 named contacts.

Ideally, individuals who test HIV positive will voluntarily contact their partners to alert them of exposure. In reality, many individuals avoid disclosing a positive test result, fearing negative consequences for their partner relationships.⁸ How many infected individuals actually do tell their partners is unknown.9 One study of gay males showed that 52% of those sampled reported telling their current partners, and 10% claimed to have told past partners, although no validity checks of these self-reports were made.¹⁰ Even if accurate, these figures suggest that a substantial number of partners are never told. In this regard, Kegeles and colleagues¹¹ found that 12% of the sample they surveyed did not intend to tell their primary partners, and 26.8% did not intend to tell their former partners. Based on results from a study of 129 seropositive individuals in the general population, Perry and colleagues¹² conclude that many HIV-positive adults "need assistance in informing others.'

Partner Notification with Injecting Drug Users

In general, inducing drug users to seek HIV testing, learn their results, and notify their partners poses numerous challenges. As is true for the general population, common barriers to notification among injecting drug users (IDUs) include worries about partner retaliation, stigma, social ostracism, concerns about legal exigencies, and perceived inability to cope.¹³ These concerns are exacerbated when individuals perceive little or no incentive for revealing their status, particularly in situations where the benefits of self-disclosure appear overshadowed by personal costs.

In general, HIV testing and partner notification among IDUs pose a unique set of concerns differing from those of other at-risk groups discussed in the professional literature. IDUs are less likely than the general population to use private providers or seek health department site testing. Quite frequently, drug-dependent individuals feel rejected or unable to cut through the bureaucratic mazes of the health care system to gain the testing, medical care, and services they need.14 When it comes to informing partners, many chronic users, particularly those who exchange sex for money or drugs, do not know the names of some or all of their needle or sex partners or do not have sufficient information to locate them. Contact between IDUs and some needle and sex partners may be casual, at best, and they are unable to locate their partners for notification. Connections between partners may involve illegal activities, making them reluctant to call attention to these associations in the process of notification. Given these barriers, it is vital to employ effective means to increase testing among IDUs, find ways to deliver pretest and posttest counseling more effectively, and encourage partner notification so that those who have been exposed can be tested, start treatment, and use social services if needed.

Based on methods developed for syphilis and other sexually transmitted diseases (STDs) in the general population, two models currently are being used in AIDS testing and partner notification.¹⁵ In the patient referral model, infected individuals assume sole responsibility for informing their own partners and contacts. Alternatively, in the provider referral model, the infected individual assumes responsibility for notification of partners or the provider takes joint or sole responsibility for notification. While the provider referral model has proved successful in medical and drug intervention settings, many IDUs rarely receive medical care or enter drug treatment.¹⁶ Consequently, they seldom come into contact with health care providers who could assist them in notifying their at-risk partners.

Experience has shown that IDUs often can be more readily accessed using community-based indigenous staff members as "street educators" and pretest and posttest counselors. The Outreach-Assisted Model of Partner Notification builds on the success of such community outreach methods by adding contact tracing and partner notification to the role of the outreach staff. Thus, the model constitutes an innovative form of the provider referral approach that coincides with the health care utilization patterns and lifestyles of the IDUs whom it targets. This chapter examines the model, including early results from its implementation and evaluation.

The Outreach-Assisted Model of Partner Notification

The Outreach-Assisted Model of Partner Notification expands traditional community-based HIV outreach activities to include having indigenous outreach workers take a more active role in delivering street-based HIV counseling, testing, and partner notification. Services are delivered at the community level from a converted storefront or other neighborhood facility by a two-person outreach team who are known to and accepted within the neighborhood. As part of their daily responsibilities, the outreach team walks through the neighborhood delivering AIDS education and HIV prevention materials. They also counsel high risk IDUs and their sex partners about the benefits of voluntary HIV testing and partner notification. Anonymous testing is offered at the neighborhood location by an HIV counselor who provides pretest and posttest counseling plus assistance, if needed, in identifying at-risk partners. The HIV counselor works with index persons to determine how notification of the various partners will be accomplished. The counselor also counsels index persons in how to inform partners whom they wish to tell personally. If the index person prefers to have the outreach team contact and inform the partner, locating information is collected, and the HIV counselor gives this locating information to the outreach team. The outreach staff never knows the identity of the index person, and all notification is conducted without revealing the name or any information about the individual who tested positive.

The outreach team locates and notifies partners whom they have been requested to contact as part of their daily rounds and within the context of their other duties. Thus, the team's social interaction with people in the neighborhood during the course of their work does not necessarily signal to others that they are searching for someone who requires notification of HIV exposure. Outreach staff members are well suited to assist in the notification process as an extension of their traditional role as street educators. They possess intensive knowledge of the social linkages and contact nodes of a particular neighborhood. Their regular presence at field sites and on the streets offers ready and familiar access for IDUs to obtain counseling, get advice about locating and notifying their partners, and seek help when a situation is perceived as threatening.

The expanded outreach model offers communitybased testing without the bureaucratic obstacles that frequently prevent IDUs from using public health HIV testing services. In this regard, evidence suggests that people are more likely to return for posttest counseling and test results at freestanding HIV test sites in their community than at other service delivery centers.¹⁷ Also, the indigenous staff delivers pretest and posttest counseling to members of targeted drug-using networks using culturally sensitive language and methods. This insider's status helps to build the trust and confidence needed to assist IDUs in locating and informing partners, particularly those who may be linked to the index person through injecting drug use and other illegal activities.

The Outreach-Assisted Model of Partner Notification in action. The Partners in Community Health Project, where the Outreach-Assisted Model of Partner Notification is being implemented and tested, is located in a converted storefront within a high-crime, economically depressed neighborhood on the west side of Chicago. Residents are largely low-income African Americans, although a large Latino community resides nearby. The staff consists of an HIV counselor and a male-female team of two outreach workers. They are former users themselves and know and are trusted by the local drug-using networks. All three are experienced in HIV counseling or partner notification by the Centers for Disease Control and Prevention (CDC).

Specifically, the HIV counselor:

- Provides pretest and posttest counseling and risk reduction education.
- Delivers HIV test results.
- Helps the index persons identify at-risk partners.
- Counsels the index person about how to tell partners of shared exposure.
- Solicits locating information for partners whom the index person prefers to have notified by the outreach team.
- Distributes locating information to the outreach staff.

Specifically, the outreach team:

- Provides street-based HIV risk reduction education.
- Distributes HIV prevention materials, including condoms and bleach.
- Recruits members of high risk, drug-using networks for anonymous HIV testing and counseling.
- Conducts contact tracing of partners selected for outreach-assisted notification.
- Anonymously notifies partners that they have been exposed to HIV.

Sample. Participants for the project are recruited by the outreach team during their daily strolls through the neighborhood, copping areas, and shooting galleries. In

the process, they recruit active injectors for HIV counseling, testing, and partner notification if needed. They also remind project participants to keep scheduled appointments with the HIV counselor or return for reinterviewing as part of the project's research component. Over the first 12 months of the project, this method was used to recruit 386 IDUs for HIV pretest counseling, testing, and partner notification.

Random assignment and data collection. Upon enrollment in the study and after giving informed consent, subjects are interviewed about their drug and HIV risk behavior and are provided with HIV pretest counseling and prevention materials. Blood is drawn, and participants are scheduled to return in two weeks. At the two-week appointment, subjects are reinterviewed about their risk behavior in the interim since being tested. Next they meet with the HIV counselor for further HIV counseling. At the end of the counseling session, they are given the opportunity to leave immediately or learn their results. Those who elect to receive their results and who test HIV negative are counseled in how to remain negative and thanked for their participation in the study. Those who choose to receive their results and who test HIV positive are randomly assigned to either the self-tell (minimal) or outreach-assisted (enhanced) group. Irrespective of group assignment, all index persons receive:

- Referral to case management services.
- Help in identifying and naming at-risk partners.
- Reasons to inform their partners.
- Counseling in how to do so.

Participants randomly assigned to the minimal (selftell) group are strongly encouraged to inform their partners of possible exposure. Participants assigned to the enhanced (outreach-assisted) group are encouraged to select between informing one or more of their partners themselves or having the outreach team do so in any combination or permutation. That is, they can choose to tell all partners themselves, have the outreach team tell all partners, or tell some themselves and have the outreach team tell others.

Following group assignment, the HIV counselor works with each index person to determine current and former sex and needle partners with whom he or she may have shared HIV exposure in the past five years. Names, identifying characteristics, and locating information are collected for all identified partners regardless of group assignment. All index persons are then asked to return for reinterview three months later. In the interim, the index persons in both groups are asked to notify all partners whom they intend to notify personally. At the same time, the outreach team attempts to locate and inform all partners whom the outreach-assisted group members have asked them to notify.

Upon returning in three months, index persons assigned to both groups are reinterviewed about their risk behavior and partner relationships since receiving their test results. A booster session of HIV prevention counseling follows. The HIV counselor then asks the index person for permission for the staff to verify those partners whom the individual reports having personally told. For human subject reasons, only those partners for whom this permission is given are ever contacted for verification.

Protection of human subjects. Testing positive for HIV can culminate in an individual being socially ostracized or rejected by others. The seropositive individual realistically may fear violence or other threats from those who perceive themselves as having been exposed to infection. Adversity involving child custody, housing, employment, or insurance can affect both the individual and any partners. Psychosocial symptomatology (such as depression, anxiety, or suicidal impulses) among those reporting high risk behavior may increase due to the knowledge of having placed themselves at risk. For these reasons, the project employs stringent procedures for protecting the confidentiality and well-being of its participants. Project protocols specify that:

- All HIV testing is voluntary and anonymous.
- Subjects are never paid for receiving test results.
- Only the HIV counselor knows who tests positive.
- Only the HIV counselor knows who names partners.
- All naming of partners is entirely voluntary.
- All notifications are conducted anonymously without identifying the index person.
- Informed consent is obtained twice, before enrollment in the study and three months later prior to contacting self-tell partners to verify notification.

- Index persons can stop the notification process at any time.
- Safety protocols exist for handling possible notificationrelated violence.
- All HIV-positive index persons or partners are offered case management services.

Results

Over a one-year period, 386 IDUs were recruited through street outreach for HIV pretest counseling, testing, and partner notification. Of these, 376 (97%) received their results, and 63 (16%) tested seropositive for the virus. Of these, 73% were African American, 15% were Latino, and 1% were white. Most (73%) were male. All but three of the 63 (95%) who tested HIV seropositive asked for their results and were randomly assigned as index persons to the minimal (self-tell) or enhanced (outreachassisted) groups.

As a core component of our evaluation, we were interested in determining whether IDUs would want to inform their partners and, if so, whether they would prefer to do so themselves or have some form of outreach help. Together, the 60 index persons who received their results provided names or at least one piece of locating information (address, hangout, physical description), for a total of 142 partners with whom they perceived having shared possible exposure to the virus within the past five years. Only one participant declined to provide a name or any identifying information about his partners. Averaged together, the 60 index persons named 2.4 partners each. No significant differences were found in the proportion of partners named per treatment group.

Figure 1 reports exposure for 142 partners by risk category for the 60 index persons. Clearly, by itself, high risk drug use accounts for half of all partners named.

When partners who share both high risk sexual behavior and drug use are added to that 50%, 75% of all partners named can be attributed to some form of risky drug-related involvement. Sexual behavior by itself accounted for 25% of partners named. When considered as a whole, half of all partners named were either at risk solely through sexual activity or through sexual practices combined with risky drug use.

It is important to note that the statistics in Figure 1 represent named partners and not individuals. As is true elsewhere, most of our sample practiced their drug-related behavior within ego-centered networks that intersected with other user networks. Consequently, one index person unknowingly may name a partner named by someone else, and that individual will be represented more than once in these statistics. Such overlaps occasionally are discovered through the ego-centered relational maps that we keep for each index person (see Figure 2). In this example we see a 40-year-old male who named two partners and a 49-year-old female who named four. The darkest circle indicates a partner whom they unknowingly have in common. The individual named is both a sex and needle partner of the male index person and a needle partner of the female index person. The fact that two people may be naming the same partner does not reduce risk exposure for either index person or for the partner in common. Indeed, the partner shown in the darkest circle is what we call a high risk "sandwich" individualsomeone who is seronegative but exposed to the virus from two or more sides.

Next, we examined whom the index persons named as risk partners by their relationship to the index person. Results are reported in Figure 3. By far, injection drug use within the context of more casual relationships (those who are neither kin nor a current or former "significant other") accounts for the greatest number of partners named. Still, of the 142 partners identified by the 60 index persons, 31% (44) were current or former significant others (25% and 6%, respectively) and 10% (14) were family members.

If given the option, do IDUs want the outreach team to notify any of their partners for them? If so, whom would they want the team to inform? To examine these questions, we turn to the preferences of IDUs assigned to the outreach-assisted intervention, as they have the opportunity to make this choice.





Examination of tallies recording which index persons in the enhanced group requested outreach assistance indicates that 82% preferred to have the outreach team tell at least one partner. Together, the enhanced group named a total of 77 partners with whom they shared possible HIV exposure (Table 1). Of these partners, the outreach team was requested to notify 71%. Believing that individuals would want personally to inform someone with whom they were particularly close, we were surprised that the outreach team was asked to notify more than one-fourth (28%) of the significant others who were named. Nonetheless, social proximity clearly is at work. Overall, IDUs appear to prefer self-disclosure with partners with whom they have immediate ties (significant others and family members) and have the outreach staff inform those with whom they have a more socially distant relationship (former significant others and nonfamily members). Few index persons elected personally to tell any of their needle partners, except in cases also involving current sexual partnerships.

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Informing partners of shared HIV exposure can be daunting. An important component of providing partner notification services lies in helping individuals identify partners with whom they have shared risky contact. Our experience with this identification process indicates that there are common misconceptions about which partners are at risk and why. Also, when thinking back five years,



(n)	Significant other		Former significant other		Immediate family		Casual relationship	
	S	0	S	0	S	0	S	0
	(15)	(6)	(1)	(4)	(1)	(3)	(5)	(42
Sex	9	1	0	3	0	0	T I	9
Needle	0	0	0	0	1	3	4	25
Both	6	5	I	T	0	0	0	8

individuals often find it difficult to recall the identity or location of former casual partners with whom they have shared unprotected sex or risky drug-related behavior. Thus, posttest counseling that helps index persons to target partners for notification constitutes both a valuable service and a critical step in the notification process.

When informing others, the index person brings his or her own interpretation of the disease into the disclosure process. Counseling that helps to identify partners for notification offers an important opportunity for HIV education that benefits index persons and their partners. Indeed, the index person who self-discloses is central to the diffusion of AIDS information from one individual to another. This exchange can be carried out in a manner that is threatening or nonthreatening, factually correct or incorrect. The message that index persons carry to their partners is important and should be accurate. Skill building in notification strategies for HIV-positive individuals can be helpful in reducing unnecessary stress and avoiding the transmission of misinformation. Moreover, in some instances, a trained and experienced outreach staff member may be better equipped to notify a partner effectively and humanely than an index person who is reluctant to do so.

Evaluation of the success of partner notification traditionally has focused on the number of infected individuals who are newly discovered. This approach, while useful for encouraging early treatment, largely ignores the importance of identifying partners who are free of infection despite high risk exposure. Of the 386 injectors recruited through street outreach in our study, 316 (82%) tested seronegative. Partner notification can be an important tool to identify and target such high risk individuals for focused prevention so that they can remain negative. The "sandwich individuals" who are at risk through double exposure are a particularly critical group.

Opposition to programmatic attempts to ensure partner notification often revolves around fear of the negative consequences for index persons and partners. For example, HIV testing is believed (but not scientifically demonstrated) to increase instances of self-inflicted violence, including self-injury and suicide. It also is believed to be highly likely to incite domestic violence, especially for women in ongoing abusive sexual relationships.¹⁸ Other concerns include worry that seropositive individuals or their partners may express or displace their anger or fear of AIDS onto their sex and needle partners or others in the community. However, in carefully monitoring the outcomes of more than 100 notifications, we have not encountered a single suicide. Neither have we become aware of any instance of violence directly attributable to partner notification, despite probing for such occurrences during follow-up interviews, street outreach encounters, reports from other outreach projects located in the neighborhood, and case management sessions. Moreover, recruitment for testing from networks where notification has occurred remains seemingly unabated, a situation unlikely to occur if members perceived study participation and notification to be dangerous. Logically, we expect retaliatory violence to occur, and notification projects, including ours, must be prepared for the possibility. Partner notification theoretically can become a trigger to domestic and other violence in the same way that such simple acts as burning a piece of toast or asking a partner to use a condom or clean a syringe can trigger a violent outburst between partners. Our experience, however, suggests that notifying a partner does not carry the high risk for physical retaliation that many critics fear.

Our data also suggest that IDUs want to notify their partners about exposure, an act of individual responsibility they show toward others in their immediate and larger social networks. Of the 60 individuals who tested positive and received their results, only one declined to identify at least one at-risk partner.

When offered the choice, 82% of those who tested positive asked to have outreach staff notify at least one or more partners. Rather than consider third-party notification an unwanted intrusion into their lives as some critics fear,² many IDUs preferred this help over self-managing the difficult task of informing others. In short, outreachassisted notification provides seropositive IDUs with a confidential and humane way to warn others of risk or possible infection. At the same time, it helps to resolve the ethical dilemmas of "duty to warn" that generate much concern among service providers offering HIV testing services.^{19,20} Based on these two important benefits, expanding traditional community-based HIV outreach activities to include delivering street-based counseling, testing, and partner notification seems to be a positive and workable prevention strategy.

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