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Partner Notification for Youth Living with HIV in 14 Cities in the United States

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Abstract

Background—Identifying factors associated with partner notification among youth living with HIV is critical for effective HIV prevention and treatment strategies.

Methods—A total of 924 male and female behaviorally-infected youth ages 13-24 across 14 U.S. cities completed an audio-computer assisted self-interview including questions about demographics and experiences with patient- and provider-referral partner notification.

Results—The majority of participants self-identified as male (82.5%), Black/non-Hispanic (70.1%), and Hispanic/Latino (18.2%). Most males (93.4%) reported engaging in male-to-male sexual contact. Over three-quarters (77.6%) reported that all or some of their partners were contacted, while 22.4% indicated that none were contacted regarding potential HIV exposure. Most (52.4%) reported that only one person talked to them about notifying partners including the HIV tester (36.5%) followed by their health care provider/doctor (27.6%). Less than a fifth (18.3%) were themselves notified of their own exposure to HIV. Using multivariable logistic regression, three factors were associated with successful partner notification: 1) when more than one person talked to participants about partner notification (AOR=1.87, 1.33-2.62); 2) if they themselves had been notified of their own HIV exposure (AOR=1.83, 1.13-2.95); and 3) if their

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education included some college or technical school versus less than high school (AOR=1.72, 1.04-2.85).

Conclusions—Partner notification among youth living with HIV is unsuccessful at least 22.4% of the time, although minimal criteria for partner services are being met almost universally. Partner notification might benefit from enhanced guidelines that call for both HIV testers and HIV care providers to discuss this important strategy with HIV-positive youth.

Keywords

partner notification; youth living with HIV; behaviorally-infected; United States

Introduction

Adolescents and young adults in the United States (U.S.) continue to become infected with HIV at alarmingly high rates. In 2014, the Centers for Disease Control and Prevention (CDC) reported that 22% of all new HIV diagnoses in the U.S. were among youth aged 13 to 24, the majority of whom were Black/African American or Hispanic/Latino gay, bisexual, and other young men who have sex with men.¹ Among 18 to 24 year olds, it was estimated in 2012 that 44% of youth living with HIV (YLWH) were unaware of their infection, the highest percentage of undiagnosed HIV in any age category.² Identifying those who are unaware of their HIV infection is imperative to prevent further transmissions and to link and retain YLWH into medical care.³

Partner notification, a type of voluntary and anonymous contact tracing supported by the CDC, has been a central component of sexually transmitted disease control programs for decades.⁴⁻⁶ The latest guidelines on partner notification for HIV indicate that all newly diagnosed individuals should be offered partner services at least once.⁷ The term *partner* refers to an individual that the person with HIV, the *index case*, has had sexual contact with or with whom they have shared needles. When the index case contacts their partners themselves it is known as *client*, *patient*, *self-referral*, or *passive*. When a health care professional notifies the partner(s) of the index case, it is *provider referral*. For those unwilling or unable to notify their partner(s), it is the responsibility of the health care professional to use confidential procedures to assure that the partner(s) is/are contacted.⁶

Prior research conducted with adults in the U.S. indicates that partner notification has shown some success in identifying new cases.⁸⁻¹¹ The prevalence of HIV among sexual partners of those newly diagnosed range anywhere from 15% to 30%.¹²⁻¹³ In 2001, the CDC and North Carolina Department of Health and Human Services found a 20.5% prevalence of HIV among previously undiagnosed sexual partners contacted through partner notification.¹⁴ Similarly, in 2014 The San Francisco Department of Health found that 22.6% of sexual partners were infected with HIV but unaware of their status.¹⁵

Previous studies among adolescents and young adults in the U.S. have investigated partner notification for sexually transmitted infections (STIs) in general but not specifically for HIV, and these studies were predominantly conducted among females. Most youth report

preferring patient referral, although this method often results in a lower percentage of sexual partners being notified and treated for an STI in comparison to provider referral.¹⁶⁻¹⁹

Factors found to be associated with an increase in partner notification for STIs among youth include older age (> 20 years), relationship type (main partners), and relationship quality (strength of relationship).²⁰ Furthermore, self-efficacy has been recognized as a strong predictor of partner notification of STIs, particularly among female adolescents.^{21,22} Negative associations have been identified between partner notification and perceived violence or rejection,²³ especially if there has been a history of domestic violence within the relationship.²⁴

To our knowledge, there have been no studies to date that have examined partner notification specifically among male and female YLWH in the U.S. The current study sought to examine the history of partner notification among youth behaviorally-infected with HIV receiving treatment and care at 14 Adolescent Medicine clinics throughout the U.S.

Methods

Participants and Recruitment

In the Adolescent Medicine Trials Network for HIV/AIDS Interventions (ATN), a study to evaluate the success of HIV treatment among YLWH entitled “ATN-125 PHASES: Provision of HIV Treatment at ATN Sites: An Evaluation for Stakeholders” was conducted from February 2015 through February 2016. Participants were recruited from 14 Adolescent Medicine clinics located in U.S. cities with established HIV epidemics. Inclusion criteria were: a) being 13-24 years old; b) behaviorally-infected with HIV; c) currently receiving or planning to receive medical care at one of the participating sites; d) ability to understand English; and e) ability for research staff to access medical records. The study was approved by the Institutional Review Boards (IRBs) at each of the sites.

Study Procedures

After the initial screening process, eligible youth were provided with an explanation of the study, invited to participate, and if interested, consented for study procedures. Participants completed an audio-computer assisted self-interview (ACASI) that took between 60 and 90 minutes to assess demographics as well as past experiences with HIV partner notification. Participants were reimbursed a small incentive determined by the sites' IRB.

Measures

Using ACASI, participants' demographic characteristics were assessed including age, gender, race, ethnicity, education, annual income, and living situation. We defined successful partner notification as any sexual partner that was reported as being contacted by the index case or health care professional regarding potential exposure to HIV. Four questions asked about HIV partner notification. First was: “Who talked to you about notifying your sexual partners?” Responses were 1 = “The person who tested you for HIV”; 2 = “Your doctor/ health care provider”; 3 = “Someone from the Department of Health (DOH) / Disease Intervention Specialist (DIS)”; 4 = “Someone from a community clinic or agency”; 5 = “A

friend or family member”; and 6 = “Other.” Participants were able to select “all that apply” for this question. Next was: “Were some, all or none of your partners contacted?” Responses were 1 = “Some”; 2 = “All”; and 3 = “None.” Then: “Did you contact some or all of your partners yourself?” Responses were 1 = “Some”; 2 = “All”; and 3 = “None.” Lastly: “For partners that you did not contact yourself, did you give all of their names and contact information to someone else so that they could be contacted?” Responses were 1 = “Yes” and 0 = “No”. Participants were then asked whether they had been contacted through partner notification themselves to get tested for HIV immediately before their own HIV diagnosis: “Did you get tested for HIV because someone notified you that you were exposed to HIV by someone else?” Responses were 1 = “Yes” and 0 = “No”.

Statistical Analyses

All analyses were performed using Statistical Analysis System (SAS), version 9.4 software (SAS 9.4, 2013; SAS Institute, Cary, NC). Descriptive statistics (e.g., means, standard deviations) were used to describe sample characteristics, and frequencies were used to examine responses to the questions about HIV partner notification. Chi square tests were performed to determine differences in sample characteristics between youth whose partners were contacted and those whose partners were not contacted. Statistical significance was set at $p < .05$. Rates of partner notification were calculated per site. Univariate and multivariable logistic regression models were fit for partner notification with “some/all” as the event. Variables for the multivariable model were selected based on statistical significance in the univariate model, factors related to partner notification in the existing literature, and collinearity considerations. Alternative analyses were explored. All models included site as a stratification factor. Odds ratios, 95% confidence intervals, and p-values are reported.

Results

Participant Characteristics

For the current analyses, 924 youth had complete data for demographics and notification of their own HIV exposure. The mean age was 21.4 years ($SD = 2.1$). The majority of participants self-identified as male (82.5%), Black/non-Hispanic (70.1%) and Hispanic/Latino (18.2%). In addition, 93.4% of the males reported engaging in male-to-male sexual contact. Some participants reported less than a high school education (22.6%), most had completed high school or earned a GED (40.0%), and over one-third (37.4%) had additional education beyond high school. Only 17.6% reported annual incomes of \$12,000 or more. Nearly half of the participants (43.1%) indicated that they currently live in their parent's residence. The majority of participants (69.5%) reported knowing that they had been living with HIV between 1 and 5 years. Table 1 provides further details on participant demographics and HIV-related characteristics.

HIV Partner Notification

Table 2 presents data on the number and percentages of participants for the questions on HIV partner notification. Almost all (99.0%) participants reported that someone spoke to them about notifying their sexual partners. Among those, more than half (57.1%) reported that the person who tested them for HIV talked to them about notifying their sexual partners

followed by their health care provider/doctor (53.1%) and a Department of Health representative/Disease Intervention Specialist (33.4%). Slightly more than half (52.4%) reported only one individual talked to them about notifying their sexual partners. Of those who reported that only one person talked to them about partner notification, the person who tested them for HIV (36.5%) was identified most frequently by participants followed by their health care provider/doctor (27.6%) and Department of Health representative/Disease Intervention Specialist (21.1%). Of those who reported two or more individuals talked to them about partner notification, the majority of the time (63.5%) it was the person who tested them for HIV and health care provider/doctor together or in combination with one or more of the other options (someone from the Department of Health / Disease Intervention Specialist, someone from a community clinic or agency, a friend or family member, or other).

HIV Exposure Notification

Of the 924 participants, 81.7% reported that no one notified them of the possibility of exposure prior to them being tested for HIV.

Differences in Factors for Partners Contacted/Not Contacted

Univariate and multivariable logistic regression models, with site as a stratification factor, showed three factors to be significantly associated with successful partner notification. Table 3 presents these results. Significant differences were found in demographic characteristics among participants whose partners were notified as compared to those who were not. Participants who talked to more than one person about partner notification (AOR 1.87; 95% CI [1.33-2.62]) or who were themselves notified of HIV exposure (AOR 1.83; 95% CI [1.13-2.95]) were almost twice the odds of being successful in this process. Additionally, those who had some college or technical school (AOR 1.72; 95% CI [1.04, 2.85]) were more likely to engage in successful partner notification.

The multivariate model was re-run comparing “some” versus “all” to determine if there might be any differences between how the responses were categorized. Age was the only factor that was significant. This finding supports the creation of our original model. Time since HIV diagnosis (< 1 year, 1-5 years, and 5 years) was also added to the multivariate model. Although we found that by itself time since HIV diagnosis was significant, suggesting that patients who have been positive longer had greater odds of contacting some/all partners, it was not significant in the multivariate model.

Differences in partner notification were also noted between sites with a range of 62.0%-93.3% and a median of 76.4%. All but two sites had greater than 70% notification.

Flowchart of the HIV Partner Notification Process

Figure 1 displays a flow chart to illustrate how participants engaged in the HIV partner notification process. Of the 924 individuals who participated in this study, 419 (45.3%) reported that “All” and 286 (31.0%) reported that “Some” of their partners were notified; 219 (23.7%) indicated “None” of their partners were contacted. Of the 705 participants who indicated that their sexual partners were notified, 364 (51.6%) reported that “All” and 235

(33.3%) reported that “Some” were contacted by the participant. If partners were not notified by participants, then participants indicated that partner contact information was provided to someone else in 72.3% of cases (245/339).

Discussion

To our knowledge, this is the first large, nationally-distributed cohort study of youth behaviorally-infected with HIV to examine their history of partner notification. Our results indicate that: 1) almost all participants reported that someone had talked to them about notifying their sexual partners; 2) some partner notification occurred for more than three quarters of the index cases and no partners were notified for almost a quarter of index cases; 3) just over half the time only one person discussed partner notification with YLWH; 4) factors associated with successful partner notification included having talked to more than one person about partner notification, level of education, and having oneself been tested for HIV because of notification of exposure.

An important finding from this study was that when more than one person talked to participants about partner notification it influenced the outcome. This is particularly important given that current CDC guidelines recommend that partner notification services should be offered at least once to those newly diagnosed.⁷ Consideration should be given to enhancing these recommendations.

Findings also showed that a large percentage of participants reported that all or some of their sexual partners were notified about their potential exposure to HIV. In most cases, participants reported that they contacted all or some of their sexual partners themselves. This is consistent with prior research indicating youth prefer contacting their sexual partners themselves as opposed to contact from their health care provider.¹⁷⁻²⁰

It was somewhat surprising that we did not find a significant difference in partner notification by gender. Prior research has suggested that female adolescents are more likely to notify their sexual partners regarding a potential exposure to a STI than male adolescents.²¹⁻²² However, this difference may be due to a number of factors identified in earlier research that have less to do with gender that showed relationship type, relationship quality, and self-efficacy to all influence the likelihood of partner notification.²⁰

Similar to past research on STI notification, our multivariable model showed marginal significance for older adolescents being more likely to engage in partner notification than younger ones.²⁰ In comparison to older adolescents, younger adolescents may fear retaliation or loss of a relationship, lack an understanding or concern for the long-term consequences of HIV, or worry about potentially being embarrassed or stigmatized by revealing that they and possibly their sexual partner(s) are infected with HIV.¹⁷ Younger adolescents may lack the ability or confidence to notify their partners due to inexperience with this process in comparison to older adolescents.

Our results also showed that level of education matters in terms of partner notification among YLWH. Those with some college education may have greater health literacy as compared to those who have not graduated from high school. Educational programs targeted

to those with less than a high school diploma or GED regarding the importance of contacting partners and getting treatment immediately after being exposed to HIV could help to increase efforts in partner notification. Health care professionals may need to spend extra time with less educated youth in order to ensure their understanding and ability to engage in the partner notification process.

It also appears that notification regarding a potential self-exposure to HIV affects the partner notification process for YLWH. This finding suggests that youth who were contacted themselves about potentially being exposed to HIV are more likely to contact their sexual partners regarding their partner's possible exposure to HIV. Alternatively, those who were not notified of their own exposure might need more support and encouragement in order to engage in partner notification.

Taken together, findings suggest that the factors that influence the partner notification process for YLWH need to be taken into consideration by health care professionals and others. Individually-tailored interventions may need to be developed that specifically focus on level of education and take into consideration the individual's own notification regarding a potential self-exposure to HIV. Ideally, more than one person would discuss this important intervention in order to more effectively achieve partner notification.

Our findings are subject to several limitations. First, this was a clinic-based cohort of YLWH who were currently engaged in care in the U.S. Thus, our findings may not generalize to all eligible YLWH outside of the ATN sites. That is, it may be that YLWH in care are more compliant and more likely to notify their partners than those out of care. Second, our results are based upon self-report data, which may be subject to recall bias as well as social desirability bias. The majority of our sample included youth who had been living with HIV for 1-5 years and were not newly diagnosed, and it might have been difficult for some youth to remember what transpired during the partner notification process. Furthermore, the process of partner notification may have differed or changed over time, making it difficult to know if the process was standardized between participants and at different sites. Additionally, youth may have over reported partner notification as this behavior is viewed as favorable. Nevertheless, we used ACASI in order to minimize any possibility of social desirability bias or errors. Third, the information we collected does not allow us to assess the effectiveness of HIV partner notification in terms of partner testing outcomes among YLWH. In addition, we did not ask participants to specify which partners were contacted by them or their health care professional(s). Results were based on the assumption that participants notified their partner(s) themselves or were notified by a health care professional because contact information was provided to the health professional by the participant. Fourth, we did not ask participants to identify their number of sexual partners. Almost a quarter of YLWH indicated that none of their partners were notified of exposure but we do not know how many partners this represents. Furthermore, we do not know how many of these partners are anonymous for whom no contact information was available.

It is notable that while most participants reported notifying sexual partners, over 80% reported that they themselves were not notified of their own HIV exposure and need for testing. It is possible that attempts were never made to contact them, that partners had no

contact information for them, or that attempts to contact them were not successful. It is also conceivable that they were tested before their partners become aware of their own infection.

Additional research is clearly needed in several areas. This includes understanding how the strength of the relationship between the index case and the health care professional that is provided to YLWH may influence the partner notification process. Moreover, an evaluation of the nature of counseling for partner services and whether this contributes to differences in partner notification based upon the method used is important for future research. It will also be important for future work to identify the number of anonymous sexual partners and to determine how significantly they contribute to the number of partners who are not contacted. We recognize that anonymous partners may make up a significant number of people who were not notified but new and innovative strategies, such as the use of social media, are being used by some health care professionals to reach these anonymous partners.²⁵

In spite of these limitations, this study's strengths include data from a large, national sample of YLWH that is reflective of the U.S. HIV epidemic, and it also represents one of the first studies to examine partner notification among YLWH. Additional research is needed to determine if the identified trends present ways to impact this powerful intervention for both HIV prevention and linkage to care. Results highlight some of the opportunities that exist to increase the number of YLWH who are aware of their status. It is important to understand why only one health care professional is talking to YLWH about contacting their sexual partners regarding a possible exposure to HIV. It is also imperative for further research to explore why a large percentage of YLWH reported not being contacted themselves regarding their own potential exposure to HIV. This is especially critical for addressing the high number of adolescents and young adults who are and may continue to be unaware of their HIV infection.

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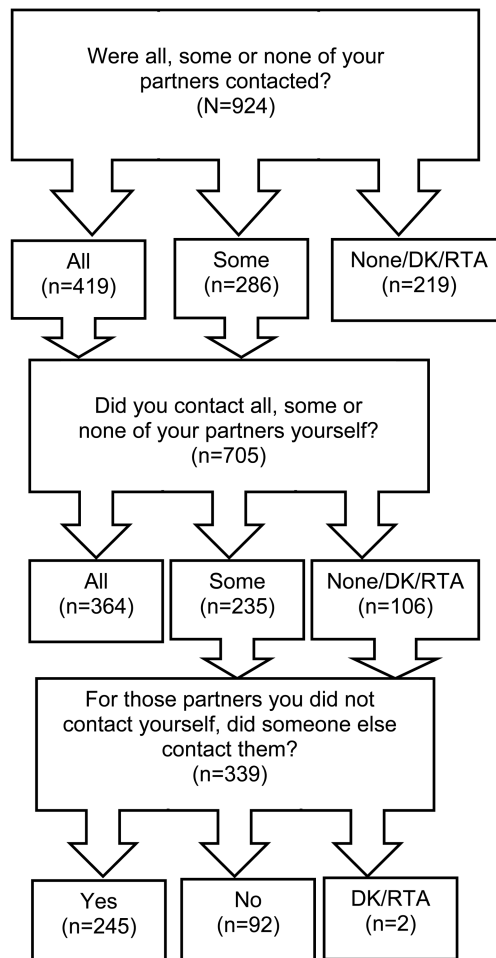


Figure 1. HIV Partner Notification Flowchart

Note. DK = Don't Know; RTA = Refuse to Answer

Table 1
Demographic and HIV-related characteristics of sample (N=924)

| Demographics | | |
|------------------------------------|--------------|-----------------|
| | Mean (SD) | Median (Q1, Q3) |
| Age * | 21.4 (2.1) | 22 (20, 23) |
| | n (%) | |
| < 18 | 46 (5.0%) | |
| 18 | 877 (95.0%) | |
| Gender (at birth) | | |
| Male | 762 (82.5%) | |
| Female | 162 (17.5%) | |
| Race/Ethnicity * | | |
| Black/non-Hispanic | 642 (70.1%) | |
| Hispanic/Latino | 167 (18.2%) | |
| White | 40 (4.4%) | |
| Other | 67 (7.3%) | |
| Gender of Sex Partners * | | |
| Males | | |
| Men who have sex with men | 712 (93.4%) | |
| Men who have sex with women | 48 (6.3%) | |
| Females | | |
| Women who have sex with men | 160 (100.0%) | |
| Education * | | |
| Less than high school | 208 (22.6%) | |
| High school or GED | 369 (40.0%) | |
| More than high school | 345 (37.4%) | |
| Income (annual) | | |
| < \$600 | 207 (22.4%) | |
| \$600-\$5,999 | 276 (29.9%) | |
| \$6,000 to < 12k | 149 (16.1%) | |
| \$12,000 | 163 (17.6%) | |
| Don't know/Refuse to answer | 129 (14.0%) | |
| Living situation (current) * | | |
| Own house/apartment | 263 (28.5%) | |
| Parents' house/apartment | 397 (43.1%) | |
| Other house/apartment | 180 (19.5%) | |
| Other | 82 (8.9%) | |
| HIV-related characteristics | | |
| HIV partner notification * | n (%) | |

| Demographics | | |
|--|-----------------|-----------------|
| Some/all | 705 (77.6%) | |
| None | 204 (22.4%) | |
| | Mean (SD) | Median (Q1, Q3) |
| How long known to be living with HIV * | 2.4 years (2.1) | 2 years (1, 4) |
| | n (%) | |
| < 1 year | 193 (21.0%) | |
| 1-5 years | 641 (69.5%) | |
| 5 years | 88 (9.5%) | |

* Note: Missing values: Age=1; Race/Ethnicity=8; Gender of Sex Partners=4; Education=2; Living Situation=2; Partner notification=15 (4= "Refuse to answer"/11= "Don't Know"); Known Living with HIV=2

Table 2
Discussing partner notification

| | n (%) |
|---|--------------|
| Youth living with HIV acknowledging that someone spoke to them about notifying their sexual partners (n=924). | 915 (99.0%) |
| The following were identified by youth living with HIV as persons who talked to them about notifying their sexual partners? (n=915) | |
| HIV tester | 522 (57.1%) |
| Health care provider/doctor | 486 (53.1%) |
| Department of Health/Disease Intervention Specialist | 306 (33.4%) |
| A friend/family member | 215 (23.5%) |
| Community clinic or agency representative | 130 (14.2%) |
| Other | 36 (3.9%) |
| The number of persons who talked to youth living with HIV about notifying their sexual partners was/were: (n=915) | |
| One | 479 (52.4%) |
| Two | 200 (21.9%) |
| Three | 155 (16.9%) |
| Four | 55 (6.0%) |
| Five | 25 (2.7%) |
| Six | 1 (0.1%) |
| Among youth living with HIV that reported only one person talked to them about partner notification, the following individuals were identified: (n=479) | |
| HIV tester | 175 (36.5%) |
| Health care provider/doctor | 132 (27.6%) |
| Department of Health representative/Disease Intervention Specialist | 101 (21.1%) |
| Community clinic/agency representative; friend/family member; and other | 71 (14.8%) |
| Among youth living with HIV that reported two or more people talked to them about partner notification, the following combinations were reported: (n=436) | |
| HIV tester and Health care provider/doctor (Just these two [n=86] or these two plus others [n=191]) | 277 (63.5%) |
| All other combinations of two or more individuals | 159 (36.5%) |

Table 3

Univariate and Multivariable Logistic Regression Models with Site as a Stratification Factor for Partners Notified. Event modeled is some/all partners notified

| Characteristics of YLWH | OR (95% CI) | p-value | AOR (95% CI) | p-value |
|--|-------------------|---------|-------------------|---------|
| Age | | | | |
| 19-20 vs <18 | 1.46 (0.85, 2.53) | 0.17 | 1.27 (0.70, 2.31) | 0.43 |
| 21-22 vs <18 | 1.92 (1.15, 3.21) | 0.01 | 1.60 (0.90, 2.83) | 0.11 |
| 23-24 vs <18 | 2.25 (1.33, 3.81) | <0.01 | 1.77 (0.97, 3.20) | 0.06 |
| Gender | | | | |
| Male vs Female | 1.14 (0.76, 1.72) | 0.52 | | |
| Race/Ethnicity | | | | |
| Hispanic vs Black non-Hispanic | 1.23 (0.77, 1.94) | 0.38 | | |
| White non-Hispanic vs Black non-Hispanic | 1.08 (0.44, 2.68) | 0.86 | | |
| Other non-Hispanic vs Black non-Hispanic | 0.89 (0.49, 1.64) | 0.71 | | |
| Education | | | | |
| High School Grad or GED vs Less than High School | 1.20 (0.81, 1.78) | 0.36 | 0.98 (0.64, 1.51) | 0.94 |
| Some college/Tech vs Less than High School | 2.02 (1.29, 3.19) | <0.01 | 1.72 (1.04, 2.85) | 0.03 |
| Tech, College Grad or Grad School vs Less than High School | 1.96 (0.97, 3.95) | 0.06 | 1.40 (.66, 2.97) | 0.39 |
| Annual Income Earned | | | | |
| 12K or more vs < 12K or Don't know/refuse to answer | 1.36 (0.86, 2.14) | 0.18 | | |
| Living Situation | | | | |
| Parents' house/ apartment vs own house/apartment | 0.59 (0.39, 0.89) | 0.01 | 0.69 (0.45, 1.07) | 0.10 |
| Other house/apartment vs own house/apartment | 0.65 (0.40, 1.06) | 0.08 | 0.70 (0.43, 1.16) | 0.17 |
| Other vs own house/apartment | 0.53 (0.29, 0.97) | 0.04 | 0.69 (0.36, 1.34) | 0.27 |
| Number of people who talked to you about notifying your partners | | | | |
| More than one person vs one person | 1.88 (1.35, 2.62) | <0.01 | 1.87 (1.33, 2.62) | <0.01 |
| Why were you tested for HIV? | | | | |
| I was notified that I had been exposed to HIV vs I was not notified that I had been exposed to HIV | 1.75 (1.10, 2.79) | 0.02 | 1.83 (1.13, 2.95) | 0.01 |

YLWH = Youth Living with HIV