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A Longitudinal Study of Adolescents with Perinatally or Transfusion Acquired HIV Infection: Sexual Knowledge, Risk Reduction Self-efficacy and Sexual Behavior

Lori S. Wiener, Haven B. Battles, and Lauren V. Wood

HIV/AIDS Malignancy Branch, National Cancer Institute, National Institutes of Health, 9000 Rockville Pike, Building 10, Pediatric Clinic I-SE, Room I-6466, Bethesda, MD 20892, USA

Abstract

As HIV-positive children are surviving to adolescence and beyond, understanding their HIV knowledge and sexual behavior is critical. Forty HIV+ adolescents/young adults were interviewed twice, approximately 21 months apart (mean age 16.6 and 18.3 years, respectively). Data on demographics, safer sex knowledge, sexual risk behaviors, risk reduction self-efficacy, and Tanner stage were collected. Twenty-eight percent of HIV+ youth at Time 1 and 41% at Time 2 reported being sexually active. HIV transmission/safer sex knowledge was low, increased with age, and both self-efficacy for and actual condom use was relatively high. Secondary prevention messages should be incorporated into routine medical settings.

Keywords

HIV; Adolescents; Knowledge; Sexual behavior; Condoms

Introduction

Children who became infected with HIV early in life are now living into adolescence and young adulthood. Likewise, with the success of efforts to reduce HIV perinatal transmission through the use of voluntary HIV testing and antiretroviral therapy for pregnant HIV-infected women and their infants, the incidence of children age 13 and under who were diagnosed with AIDS declined over 90% between 1992 and 2003 [Centers for Disease Control and Prevention (CDC), 2004]. With very few young children becoming infected with HIV in the United States, those who were infected 10 or more years ago comprise an increasing proportion of the pediatric/ adolescent HIV patient population.

Early in the epidemic, children born with HIV infection were not expected to survive past childhood. Accordingly, parents and health care providers often did not anticipate these children would face the conventional challenges of adolescence, including decisions regarding sexual and other risk behaviors. As treatment advances emerged and it became evident that HIV-infected children were indeed entering adolescence, concerns pertaining to virus transmission, diagnosis disclosure, and complicated medical regimens began to take priority for parents as well as providers (Grubman et al., 1995).

Despite highly active antiretroviral treatment (HA-ART), some HIV-infected youth will become symptomatic and develop AIDS. However, this does not preclude sexual behavior or necessarily facilitate safer behavior (Brown et al., 2000). Boys and girls with moderate or

e-mail: wienerl@mail.nih.gov.

Several studies have examined the sexual behavior of adolescents and young adults infected with HIV early in life. Frederick et al. (2000) conducted a cross-sectional, retrospective study of older children, adolescents, and young adults enrolled in the CDC Pediatric Spectrum of HIV Disease (PSD) study. A supplemental data abstraction instrument was used to collect data on a one-time basis in 1997. Of 131 adolescents HIV-infected as children (mean age 15.5 years), 18% (n = 24) reported consensual sexual relations. Of those who were sexually active, 80% reported using condoms, but only one-third reported consistent condom use. A significant association was found between older age and sexual activity. This study was limited by the lack of sexual behavior data for 53% of the sample and its retrospective nature. Nevertheless, the findings suggest that despite their illness, perinatally infected adolescents engage in sexual activity and are a potential source of HIV transmission.

longitudinal sexual knowledge of adolescents and young adults infected with HIV early in life.

In an older population of 111 HIV-infected adolescents with hemophilia (mean age 18.5 years) 59% reported previous sexual intercourse and 63% reported condom use during their last sexual intercourse experience (Brown et al., 2000). Zorilla and colleagues in Puerto Rico examined the factors associated with sexual activity and pregnancy in eight perinatally HIV-infected adolescents or young adults with a history of pregnancy and eight controls-perinatally HIVinfected females with no history of pregnancy (Zorilla et al., 2003). While their sample size was too small for generalization, their findings suggest that the sexual behavior of perinatally infected women is similar to that of HIV negative adolescents and adults. Sexual experience in each of these studies is lower than that reported for a cohort of adolescents with sexually acquired HIV infection (n = 323, mean age 17 years) which found 65% were sexually active across all six study visits, with approximately 43% consistently reporting *unprotected* sex at last intercourse (Murphy et al., 2001). In a review of trends of sexual behavior in U.S. high school students, 53% of high school students reported ever having sexual intercourse in 1991 while 47% reported the same in 2003. In addition, the percentage of currently sexually active students who used a condom during last sexual intercourse during this time frame increased significantly (46-63%; Grunbaum et al., 2004). While these studies suggest that rates of sexual behavior reported by HIV-infected adolescents resemble those of their uninfected peers, direct comparisons cannot be made between these groups due to age, assessment, and measurement differences.

Several variables are likely to affect whether an adolescent practices safer sex behaviors. Selfefficacy, the belief that one can actually perform a specific behavior, is one possible determinant. A direct relationship between self-efficacy and the performance of health promoting behavior has been found in adolescents (Goldman & Harlow, 1993). Whether or not an individual is sexually active, assessing their self-efficacy around HIV transmission risk reduction may be helpful in identifying their potential ability to engage in risk reduction behaviors. In addition, HIV transmission knowledge may also impact whether individuals engage in risk behaviors. With little known about the sexual risk behavior of HIV-positive adolescents and young adults who have been infected since early life or the relationship between delayed puberty and sexual behavior, this prospective exploratory study was designed to examine the sexual behavior, self-efficacy for risk reduction, sexual behavior attitudes, and levels of sexual knowledge of HIV-positive youth infected early in life.

Method

Participants and Procedures

HIV-infected adolescents and young adults participating in clinical trials at the National Cancer Institute (NCI) during 2001–2003 completed two sets of identical interviews, an average of 21.2 months apart (median = 22.0, interquartile range 2.75). Forty-eight individuals participated at Time 1 (T1) and 40 of those participated at Time 2 [T2; Mean age at T1: 16.6 years (range: 12–24), T2: 18.3 years (range: 13–24)]. Eight of the original participants dropped out for the following reasons: four were lost to follow up, two were too ill to participate, one died, and one was referred to an adult treatment facility when she became pregnant. Only the 40 individuals who participated at both time points are included in the current analysis. Sixtythree percent (n = 25) of participants were female, 55% (22) were white, 25% (10) were Black/ African American, 13% (5) were Hispanic, 8% (3) were "other"; 65% (26) acquired HIV perinatally, and 35% (14) through a transfusion.¹ At T1, 15% of participants had absolute CD4 counts below 200 and at T2, 33% had CD4 counts below 200, a level of immune suppression not unexpected given the duration of the study population's HIV disease. Ninety-eight percent of study participants were receiving antiretroviral therapy and of these, 85% at T1 and 88% at T2 were receiving HAART.

Eligibility criteria included: (a) documented HIV infection for at least 13 years, (b) 13–24 years of age at study enrollment, (c) enrollment in an active treatment protocol at the NCI during the preceding 5 years, (d) ability to understand and read English, (e) awareness of HIV diagnosis, (f) absence of psychotic symptoms, and (g) absence of cognitive impairment (Full Scale IQ > 75). Families were approached by the Principal Investigator during a clinical visit and asked to participate in the study. Participating adolescents age 18 and over and caregivers signed informed consent and adolescents under the age of 18 gave written assent. All measures were administered by either the Principal Investigator or a trained research assistant. In accordance with NIH Clinical Center and PHS guidelines for reducing the risk of HIV transmission, participants who reported being sexually active were provided counseling pertaining to risk reduction and partner notification as described in the study's informed consent.

Measures

Youth Survey

This questionnaire combined items from two existing surveys. The first, the Youth Risk Behavior Survey (YRBS), is published by the CDC to obtain information about adolescent health risk behaviors (Grunbaum et al., 2004). The survey is administered every 2 years to a national sample of high school students and monitors six categories of priority high-risk behaviors among youth and young adults. The demographics and sexual activity sections from the 2001 YBRS were administered in the current study and data from the 2001 and 2003 YBRS were used as comparison data for analysis as they were the closest to completion of each study time point. The questions used for these analyses asked whether the participant had ever had vaginal or anal intercourse, oral intercourse, whether they used condoms at last vaginal/anal or oral intercourse, whether they used alcohol or drugs at last intercourse, and the number of sexual partners in the past 3 months and in their lifetime. The second is a survey developed by the New York State Department of Health (NYSDOH) AIDS Institute to assess HIV transmission knowledge, self-efficacy regarding HIV sexual risk reduction and attitudes toward condom/ barrier use (NYSDOH, 1995). Transmission knowledge questions were in a true/false format, while self-efficacy questions were worded, "How sure are you that you

 $^{^{1}}$ Adolescents with transfusion associated HIV acquired their infection prior to implementation of standard HIV screening of the blood supply.

would be able to:____' followed by descriptions of specific condom use behaviors. Response categories included *Not at all sure, Somewhat sure, Very sure*_ and *Don't know*. A summary score was calculated for overall condom use self-efficacy using the six items that refer specifically to condom use. Dichotomized condom use self-efficacy scores were summed to create a possible range of 0–6. Internal consistency for the overall condom self-efficacy summary scale was acceptable. Cronbach's alpha = 0.78 at T1 and 0.76 at T2.

Adolescent Questionnaire

This questionnaire was designed by the investigators to obtain information on different personal and disease-related factors.

Chart Abstraction

Tanner stage of development and demographic variables were abstracted from medical charts along with CD4 T-lymphocyte subset values and HIV-1 RNA levels (Roche Amplicor[®], lower limits of detection 50 copies/ml) drawn on the day the questionnaires were administered.

Data Analysis

Independent sample *t*-tests were used in analyses examining differences in continuous variables between two distinct groups. Paired sample *t*-tests were used to evaluate differences in means of continuous variables between T1 and T2. Pearson chi-square analyses were used to evaluate differences in two categorical variables between T1 and T2. All tests were assessed against an alpha level of 0.05. For analyses of sexual behavior, data were looked at overall and stratified by grade level. For analyses of risk reduction self-efficacy, individual items are reported as well as the overall score for condom use self-efficacy.

Results

Sexual Behavior

Twenty-eight percent of the total sample at T1 and 41% of the sample at T2 had ever had oral, vaginal or anal sex (referred to as "sexually active" from now on). Rates of sexual activity were examined by age/ grade. Approximately one-third of participants in 9-12th grade were sexually active versus between one-third and one-half of those over grade 12 (Table 1). Among those who have ever had sex, participants reported a median of 2.0 partners in the past 3 months (T1 and T2) and 2.0 and 2.5 lifetime partners at T1 and T2, respectively. Twenty-five percent of participants at T1 and 45% at T2 were in Tanner stage V, indicating full sexual maturity. At both time points, those who were sexually active were at a higher Tanner Stage of Development than those who were not sexually active, T1: t(38) = 2.6, P < 0.05; T2: t(37) =2.4, P < 0.05, with 50% of those in Tanner Stage V at T1 and 65% of those at Tanner Stage V at T2 reporting ever having had sex vs. 33% in Tanner Stage IV at T1 and 22% at T2. There were no differences between perinatally and transfusion acquired participants in whether they had ever had sex. Of those who were sexually active at each time point, 73% at T1 and 88% at T2 reported using a condom during last episode of vaginal or anal sex, with the rest reporting that no method was used to prevent the transmission of HIV. Of those who have ever had oral sex (n = 11 at T1, n = 15 at T2), only 40% used condoms the last time they had oral sex. Eighteen percent of the sample (n = 7) reported ever having been pregnant or having gotten someone pregnant.

At T1, those with a lower CD4 count were more likely to be sexually active, t(38) = 2.8, P < 0.01, but there was no difference based on HIV-1 RNA levels. At T2, there was no association of either parameter with sexual activity.

Self-efficacy for Risk Reduction

Among those who were sexually active or who planned to become sexually active within the next 12 months (n = 18 at T1, n = 23 at T2), self-efficacy around condom use was moderate to high. Participants were most confident about their ability to: abstain from sex if their partner refused condom use (88% very sure at T1, 77% at T2), purchase condoms in a store (77% very sure at T1, 73% at T2), insist on condom use even if their partner did not want to (65% very sure at T1, 82% at T2), correctly use a condom (65% very sure at T1, 68% at T2), and use a condom correctly every time they have sex (65% very sure at T1, 59% at T2). The lowest scores were for being very sure that they would be able to totally abstain from sex (12% at T1, 19% at T2), abstain from sex even if all their friends are having sex (24% at T1, 19% at T2), and being able to use a condom even after drinking alcohol or using marijuana (41% at T1, 46% at T2). Efficacy for discussing the prevention of HIV/AIDS with one's partner was moderate, with just over half the sample confident that they could have such a discussion (59% very sure at T1, 55% at T2).

At T1, there was no difference between those who were sexually active or those who were not sexually active but planned to become so in the next 12 months in terms of their overall condom use self-efficacy, while at T2, those who were sexually active reported higher efficacy, t(38) = 3.1, p < 0.01. There were several sig-nificant differences in the individual efficacy items. Individuals who had had sexual intercourse were more confident that they could properly use a condom, T1: χ^2 , (1, n = 17) = 4.0, P < 0.05; T2: χ^2 , (1, n = 22) = 13.7, P < 0.01, and could walk into a store and buy condoms, T1: χ^2 , (1, n = 17) = 3.6, P < 0.10 (marginal association); T2: χ^2 , (1, n = 22) = 17.7, P < 0.01. In addition, at T2, those who were sexually active were more con-fident that they could abstain from sex if their partner refused to wear a condom, χ^2 , (1, n = 22) = 6.9, P < 0.01.

Sexual Behavior Attitudes

Five attitude items were added to the Youth Survey at T2 (Kaiser Family Foundation, Hoff, Greene, & Davis, 2003) and are reported here. Seventy-seven percent agreed that "Waiting to have sex is a nice idea, but no one really does"; 61% agreed that "there is pressure to have sex by a certain age"; 43% agreed that "once you have had sex, it is harder to say no the next time"; 41% agreed that "if you have been seeing someone for a while, it is expected that you will have sex"; and 23% agreed that "oral sex is not as big a deal as sexual intercourse". There were no significant differences in having had sexual intercourse between those that endorsed any of these items and those who did not. The only sexual attitude for which there was a significant difference in sexual risk behavior knowledge was, "There is pressure to have sex by a certain age" with those agreeing with the item having higher overall sexual risk behavior knowledge than those not agreeing with the item, t(37) = 2.2, P < 0.05.

Sexual Behavior Knowledge

This cohort reported low knowledge of HIV sexual transmission risk behaviors. Only 18% of participants at T1 answered all six questions correctly (see Table 2), while 28% answered them all correctly at T2, t(39) = 3.3, P < 0.01. Overall, 55% exhibited increases in sexual risk behavior knowledge between T1 and T2, 28% stayed the same and 18% exhibited a decrease in knowledge. The one item for which knowledge did not improve over time was, "Is washing oneself after having sex a good way to protect oneself from getting infected with HIV?" However, two-thirds of the cohort knew the statement was false.

Comparisons were made between demographic variables and number of items answered correctly at each time point. At both time points, older participants (\geq 18 years) answered more items correctly than younger participants (<18 years), t(38) = 3.8, P < 0.01 at T1, t(38) = 2.8, P < 0.01 at T2. Those who had transfusion-acquired HIV had significantly greater knowledge

at T1 than those who had perinatally acquired HIV, t(38) = 2.6, P < 0.05. This finding may have had more to do with age than mode of transmission as transfusion-acquired participants were substantially older [mean age 19.4, 21.1 years (T1, T2) compared to 15.2, 16.2 years (T1, T2) for perinatally infected participants] and the finding diminished at T2 as the cohort grew older.

Those who indicated using a condom at last intercourse had significantly higher sexual risk behavior knowledge than those who did not at T1, t(9) = 3.1, P < 0.05; at T2, the difference was in the same direction, but was not significant. Sexual risk behavior knowledge was correlated with overall condom efficacy at each time point. Decreased condom self-efficacy was significantly associated with decreased sexual risk behavior knowledge at each time point, r = 0.57, P < 0.05 at T1; r = .42, P = 0.05 at T2. There were no significant differences in sexual behavior knowledge based on race/ethnicity or between those who reported ever having had sexual intercourse (T1: n = 11, T2, n = 16) and those who had not at T1 or at T2.

Discussion

Adolescence is a time of sexual and lifestyle behavioral experimentation. Results from the current study suggest that youth with perinatally or transfusion acquired HIV infection are sexually active and have relatively low knowledge of sexual transmission risk behaviors. This sexual behavior knowledge is significantly related to age, risk reduction self-efficacy, and the belief that there is pressure to have sex by a certain age. Knowledge was not better for those who were sexually active than for those who were not, though it increased over time. Like their uninfected peers, HIV-infected youth perceive that most people their age are having sex and that there is indeed pressure to do so, both by a certain age and by a certain point in a relationship (Kaiser Family Foundation et al., 2003). The rates of sexual activity reported by 9–12th graders in the current, admittedly small sample, are lower than levels reported by 9-12th graders in the YRBS, while their rates of condom use were higher at T1 (73% study cohort, 58% YRBS; CDC, 2005) and at T2 (88% study cohort, 63% YRBS; Grunbaum et al., 2004). However, rates of sexual activity increased over time as the cohort aged, while condom use generally remained high. These results suggest that by late adolescence, a substantial number of youth with HIV acquisition early in life are sexually active and have moderate to high levels of condom use and moderate to high-condom use self-efficacy. Importantly, overall condom use self-efficacy was significantly correlated with sexual risk behavior knowledge, establishing an important link between knowledge of HIV sexual transmission risk behaviors and an individual's confidence in their ability to use condoms, a critical behavior in preventing HIV transmission. In contrast, the lowest self-efficacy scores in the cohort were observed for the ability to totally abstain from sex or abstain from sex even if all their friends are having sex, reinforcing the need for both abstinence and condom-based prevention messages.

HIV positive youth in the current study appeared to have a later onset of sexual risk behavior than a normative sample of U.S. high school students. This may be a result of delayed emotional maturity resulting from reduced expectations of survival and independent functioning and therefore greater dependence on their families (Battles & Wiener, 2002). Alternately, it may be a consequence of delayed puberty, a finding associated with HIV disease (Buchacz et al., 2003) since a majority of study participants were not mature sexually (Tanner stage IV or less) at both time points. Further analysis of the data revealed that by the time participants in the sample reached full sexual maturity (Tanner stage V), at least half reported being sexually active, compared to less than a third in the earlier stages of pubertal development. Noteworthy is the fact that the rates of sexual activity reported in this study are similar to rates of sexual activity reported in studies of adolescents with other chronic diseases such as cystic fibrosis and sickle cell anemia (Britto et al., 1998). Consistent with the findings of Brown et al.

(2000), health status as reflected by the level of severe immunosuppression (absolute CD4 counts below 200 cells/mm³) did not preclude adolescents from being sexually active.

Encouragingly, participants reported generally high rates of condom use at last intercourse. In support of this was the finding that those who were either sexually active or planned to become sexually active within the following year had moderate to high rates of condom use selfefficacy. Those who were sexually active were more likely to feel confident about the concrete aspects of condom use and notably, more likely to feel confident in their ability to abstain from sex even if all their friends were having sex or if their partner refused to wear a condom. Despite these findings, the observation that almost one fifth of the sexually active sample had either become pregnant or gotten someone pregnant in their lifetime suggests inconsistent condom use. Hence, confidence in one's ability to use condoms does not guarantee that individuals will indeed use them or use them consistently over time. Inconsistent condom use may be related to uncertainty regarding how to use them correctly or the inability to effectively discuss condom use with potential sexual partners. The fact that over one-third of participants who were sexually active or who planned to become so within the following 12 months were unsure that they would be able to use a condom correctly every time they had sex (35% at T1, 41% at T2) or discuss prevention of HIV/ AIDS with one's partner (41% at T1, 45% at T2) is of concern. Of further note was the decline in efficacy regarding one's ability to refuse sex without a condom/ barrier over time, consistent with the observation that 43% of the cohort reported that once a person has had sex, it is harder to say no the next time. Whether this trend is due to frustration, apathy, peer pressure or some other variable is unknown and clearly warrants additional investigation.

These results highlight the critical need to provide risk reduction education to adolescents who acquired HIV early in life regardless of whether or not they are currently sexually active and irrespective of their disease status. Routine medical visits are ideal times to pay particular attention to the specific issues relating to behaviors of HIV-infected youth, including sexual risk factors, psychological distress, and drug or alcohol use which may be associated with sex. These visits allow practitioners the opportunity to assess and maximize knowledge of sexual transmission, improve and reinforce consistency of correct condom use, and to repeatedly deliver abstinence and prevention messages. Risk reduction behavior is not always immediate nor sustained, and repeated messages surrounding HIV prevention are essential.

For adolescents who are sexually active or considering becoming sexually active it is important in health care settings to attempt to facilitate both condom use negotiation and diagnosis disclosure to sexual partners so that further sexual transmission of the virus can be avoided. Since most HIV-infected adolescents and young adults who acquired their disease perinatally or early in life are diagnosed within the first decade of life, partner notification was not a relevant issue at diagnosis. However, it is critical that consideration be given to addressing this routinely during health care visits once puberty begins. This is particularly important among adolescents who may fear the consequences of disclosure of their diagnosis and lack: (a) the skills to discuss such sensitive topics with their partners, (b) confidence in their ability to abstain from sex, or (c) adequate knowledge of safer sex behaviors to prevent further transmission of the virus. This suggests that interventions designed to reduce the risk of sexually transmitting HIV by this population require developmentally appropriate psychological and social approaches that target perceptions of peer influence and emotional well being (Brown et al., 2000).

The need to incorporate secondary prevention messages into primary care for this population is further challenged by issues that arise surrounding the need for adolescents to transition from pediatric to adult health care as they age. Anxiety associated with having to break ties with pediatric health care providers with whom these adolescents have had longstanding

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relationships can compromise a successful transition. If these youth become disengaged from the health care system, the opportunities to provide prevention messages and to achieve prevention goals are lost, a situation to be avoided at all costs given the alarming public health implications of potential transmission of multi-drug resistant virus by youth that are heavilytreatment-experienced.

Several important limitations to this study need to be noted. The current cohort consists of adolescents from families resourceful enough to enroll their children in clinical trials and hence our sample may not be representative of perinatally HIV-infected adolescents who may be living with greater socioeconomic challenges and mental health issues in the household. Neither disclosure to sexual partners nor consistent condom use were directly measured in the current study and similar to other published reports, the sample size is small thereby limiting its power. Not having a prospective comparison group, being limited to historical comparisons cited in the literature, and the use of different assessment tools among studies are methodological problems that can compromise the findings. It is important that future studies address these design limitations.

Nevertheless, this is the first study to longitudinally assess HIV risk knowledge of adolescents and young adults infected with HIV perinatally or early in life. Although a substantial proportion of adolescents were sexually active, our study documented significant deficiencies in knowledge of risk behaviors associated with HIV transmission and an association between sexual knowledge and condom use self-efficacy. As the pediatric HIV population approaches adulthood, they are faced with the challenges of learning to manage their chronic illness, adjusting to living independently, making decisions about initiating sexual relationships and disclosing potentially damaging information about themselves to their sexual and romantic partners, while simultaneously needing to acquire the knowledge and skills that will permit them to engage in risk reduction practices should they choose to become sexually active. It is important that programs and future studies are designed to help this emerging population successfully address these issues. The critical need for providing consistent and continuous secondary prevention messages cannot be overemphasized, given the troubling public health implications that could result from a failure to do so.

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Sexual behavior	9–12th grade		>12th grade	
	$T1^{b} (n = 17)$	T2 ($n = 22$)	$\mathrm{T1}^{b}(n=16)$	T2(n = 17)
Ever had sexual intercourse Used condoms last intercourse ^a Used alcohol/drugs last intercourse ^a	5.29% 3.60% 0%	7.32% 6.86% 0%	6.38% 5.83% 0%	9.53% 8.73% 2.22%
^d Of those who ever had sexual intercourse				

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 $\boldsymbol{b}_{\text{Seven cases}}$ are missing from T1 because they were below grade 9

Table 2

HIV Sexual transmission knowledge and sexual behavior

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Sexual transmission knowledge: question (Answer)	Percent correct T1 $n = 39^a$	Percent correct T2 n =39
Is anal sex without a condom one of the safer sex practices? (<i>No</i>)***	(20) 51%	(30) 77%
Can people get infected with HIV by having oral sex without a condom/barrier? (Yes)	(27) 69%	(32) 82%
Should Vaseline or baby oil be used with a condom during sex? $(No)^*$	(19) 49%	(25) 64%
Is it easier for a male to get HIV from an infected female than for a female to get HIV from an infected male? (<i>No</i>)	(21) 54%	(27) 69%
Is washing oneself after having sex a good way to protect oneself from getting infected with HIV? (<i>No</i>)	(26) 67%	(26) 67%
Does drinking alcohol or using drugs increase the chances that a person could transmit or become infected with HIV? $(Yes)^{***}$	(18) 46%	(28) 72%
Percent who answered all items correctly ***	(7) 18%	(11) 28%

 a One person did not complete these questions at T2. Because responses were being compared from T1 to T2, this case was eliminated from T1 for this table

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** p < 0.05

p < 0.05

p < 0.01