Risk Behavior Disclosure during HIV Test Counseling

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ABSTRACT

ELIZABETH A. TORRONE: Risk Behavior Disclosure during HIV Test Counseling
(Under the direction James C. Thomas, MPH, PhD)

Personalized risk assessments during Human Immunodeficiency Virus (HIV) testing are an integral component of HIV prevention counseling, an individual-level behavior change intervention to reduce the spread of HIV. Aggregated data from risk assessments are used to track behaviors in the testing population, evaluate federally-funded Counseling, Testing and Referral (CTR) programs, and inform prevention programs and allocation of resources. Unfortunately, risks disclosed during HIV test counseling may not be accurate, with stigmatizing behaviors underreported during face-to-face assessments. To understand the limitations of the CTR risk behavior data and guide interventions to improve the validity of the risk assessment, we conducted a mixed methods study of young men in North Carolina (NC). We linked two statewide HIV databases which contained individual-level data on men newly diagnosed with HIV in NC, comparing client-reported gender of sex partners at the time of testing to those reported during post-diagnosis partner notification (n=641). Of the 212 men who told their HIV test counselor that they had only had female sexual partner(s) in their lifetime, 62 (29.2%) provided contact information for male sex partner(s) during partner notification. Of the 25 men who reported no lifetime sex partners during test counseling, 22 (88.0%) provided partner notification information for sex partners in the last year. We then interviewed young men accessing HIV testing services in a southeastern United States city. Based on data collected via an Audio and Computer Self-Administered Interview (n=203), over 30% of young men reported that they were not accurate during the risk assessment. Participants reported numerous interpersonal barriers to accuracy during the risk assessment. During qualitative interviews (n=25), many participants revealed that they did not understand the purpose of the risk assessment nor perceive an individual benefit to complete risk behavior disclosure. Findings from this study suggest that the risk assessment completed during HIV test counseling may be incomplete which has implications for both the efficacy of individual prevention counseling and aggregate behavioral statistics. Modifications to the risk assessment process, including better explaining the role of the risk assessment in prevention counseling and using alternate assessment methods, may increase the validity of the data.

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List of abbreviations

Abbreviation	Definition
ACASI	Audio and Computer Assisted Self-Interview
AIDS	Acquired Immune Deficiency Syndrome
CDC	Centers for Disease Control and Prevention
CI	Confidence Interval
CTR	Counseling, Testing and Referral
CTR-identifier	Counseling, Testing and Referral unique identification number
CTS	Counseling and Testing System
DIS	Disease Intervention Specialist
DCHD	Durham County Health Department
FTFI	Face to Face Interview
HARS	HIV/AIDS Reporting System
HARS ID	HIV/AIDS Reporting System Identification Number
HIPAA	Health Insurance Portability and Accountability Act
HIV	Human Immunodeficiency Virus
IDU	Injection Drug User
IRB	Institutional Review Board
LHD	Local Health Department
MSM	Men who have Sex with Men
MSM-IDU	Men who have Sex with Men who are also Injection Drug Users
MSMW	Men who have Sex with Men and Women

Abbreviation	**Definition**
MSW	Men who have Sex with Women
NC	North Carolina
NC-CTR	North Carolina Counseling, Testing and Referral
NCDHHS	North Carolina Department of Health and Human Services
NTS	Non-traditional Test Site
OR	Odds Ratio
PCRS	Partner Counseling and Referral Services
QDS^{TM}	Questionnaire Development System
STD	Sexually Transmitted Disease
STD*MIS	Centers for Disease Control and Prevention software for management of STD control data
UNC-CH	University of North Carolina at Chapel Hill
US	United States

Chapter One: Introduction

Problem statement

In the 1994 Counseling, Testing and Referral (CTR) guidelines for providers offering Human Immunodeficiency Virus (HIV) testing, the Centers for Disease Control and Prevention (CDC) promoted use of a client-centered, prevention counseling model which combines an individualized risk assessment and risk reduction counseling as part of the testing process.[1] The prevention counseling model has been shown to reduce high-risk behaviors for HIV,[2, 3] but may create a barrier to testing for some providers and clients.[4] In an effort to increase access to testing, the CDC revised the CTR guidelines in 2006. Guidelines currently promote universal, routine testing for adolescents and adults and remove the prevention counseling recommendation for providers offering tests in healthcare settings.[5]

Although no longer part of the CDC guidelines, the test counseling risk assessment continues to play an important role in HIV prevention and surveillance. First, many providers continue to offer prevention counseling and the CDC acknowledges that the risk assessment/risk reduction model is "still strongly encouraged for persons at high risk for HIV in settings such as sexually transmitted disease (STD) clinics."[6] Additionally, federally-funded CTR sites are required to submit risk assessment data to the CDC on all clients accessing testing services.[7]

Aggregate CTR data are used to track behaviors in the testing population,[8] evaluate CTR programs[9-11] and inform prevention interventions.[7] Furthermore, HIV risks disclosed to medical providers influence services offered, including type of test offered[12-14] and level of counseling provided.[5]

Although the risk assessment can be conducted in a variety of ways, the majority of HIV test counseling in North Carolina (NC) occurs at publicly-funded sites, such as STD clinics, where the risk assessment is completed by a trained HIV test counselor in a face-to-face interview.[15] Unfortunately, research has shown that the accuracy of self-reported risk behaviors, especially potentially stigmatizing behaviors such as same sex contact, may not be accurate in face-to-face interviews.[16-18] Risk behaviors disclosed during HIV test counseling may also be used to determine mode of transmission among individuals testing positive.[19] In reviews of mode of transmission in HIV surveillance databases, numerous studies have documented underreporting of stigmatizing behaviors when validated with a more sensitive measure of risk behaviors.[19-23]

CTR data are collected in all 61 US states and territories,[7] yet the validity of self-reported risk behaviors in the CTR database remains undocumented. In addition, to guide interventions to improve the validity of the risk assessment, further research is needed to understand barriers to accurate risk behavior disclosure. Accuracy of self-report is determined in part by social context and motivational biases[24] and interactions with the test counselor and clinic characteristics may facilitate or hinder complete disclosure. Preliminary research indicates that clients do not prefer a race and/or gender matched counselor,[25, 26] but clients' other perceptions of the test counselor and of the counseling session may impact risk behavior disclosure during the risk assessment.

Specific Aims

The goal of this mixed methods study was to quantify underreporting of risk behaviors by young men during HIV test counseling and to identify aspects of HIV test counseling which can affect the accuracy of reported risk behaviors. This was accomplished by comparing documented risk assessments in two pre-existing, statewide databases. We linked the NC-CTR database, which contains socio-demographic and self-reported risk behaviors collected during HIV testing in publicly-funded clinics, and NC Partner Counseling and Referral Services (PCRS) charts which document in-depth, post diagnosis interviews which include partner notification. Audio and Computer Assisted Self-Interviews (ACASI) and semi-structured interviews were used to elucidate barriers to risk behavior disclosure among a sample of men completing HIV pre-test counseling in a publicly-funded clinic in NC.

Specific Aim #1: Quantify incomplete or inaccurate self-reported gender of sex partners during HIV pre-test counseling among HIV positive men, aged 18-30, who tested at publicly-funded clinics through:

1. Collaboration with the NC Department of Health and Human Services to link NC-CTR and PCRS data on each of the approximately 700 men, aged 18-30,

who tested newly positive for HIV in publicly-funded clinics between 2000 and 2005.

2. Estimation of the accuracy of risk behavior classification in the NC-CTR data through comparison with PCRS chart data and calculation of sensitivity, specificity, kappa and conditional kappa statistics.

Specific Aim #2: Determine the prevalence of incomplete or inaccurate risk behavior reports during HIV pre-test counseling in a sample of men testing for HIV in a publicly-funded clinic and self-reported barriers to disclosure through:

1. Survey of 200 men who attended a pre-test counseling session in a publicly-funded clinic, administered using an ACASI.
2. Determination of the frequency of incomplete or inaccurate risk behavior report during pre-test counseling and of reported barriers to non-disclosure.

Specific Aim #3: Describe the individual, social and structural characteristics of the HIV test counseling session that influence the complete and accurate disclosure of HIV risk behaviors among young men attending publicly-funded clinics through:

1. Semi-structured interviews with men aged 18-30 who attended a publicly-funded test site for HIV pre-test counseling.
2. Analysis of interview transcripts using constant comparative analysis to inductively determine themes of barriers to risk behavior disclosure.

Organization of dissertation

This dissertation has six chapters. Following this introductory chapter, Chapter Two provides background to the research including an overview of the collection and use of CTR data, a discussion of indications of inaccuracies during the test counseling risk assessment and review of possible barriers to complete risk behavior disclosure during the risk assessment. Chapter Three outlines the data sources and analysis plan for each of the specific aims. Chapters Four and Five present the results of the dissertation in the format of two, stand-alone research manuscripts. Chapter Six summarizes the key findings, outlines the strengths and limitations of the work, discusses public health significance and suggests areas for future research.

Chapter Two: Background

HIV test counseling in the United States

Human Immunodeficiency Virus (HIV) counseling and testing programs play a critical role in HIV prevention efforts in the United States (US).[27] In the US, universal screening of blood donors has almost eliminated transmission through blood transfusions.[28] Mother-to-child transmission of HIV has decreased significantly since the Centers for Disease Control and Prevention’s (CDC) 1995 recommendation of routine HIV testing during prenatal care.[29, 30] Prenatal screening combined with prophylactic treatment with antiretrovirals has reduced vertical transmission rates to less than 2%.[31] Testing programs have had a less dramatic impact on the prevention of sexual transmission of HIV, perhaps due in part to limited, targeted screening efforts;[5] however, counseling and testing services provide multiple opportunities for preventing future transmission. For persons who are uninfected, test counseling provides an individual-level intervention opportunity for risk education and risk reduction skill development to reduce future infection.[2, 3, 32-35] For persons who are already infected, diagnosis provides the opportunity for treatment which can prolong the onset of symptomatic HIV disease. Treatment for HIV infection can result in lower viral loads which decrease transmission probability preventing further spread of disease.[36] In addition, persons who are aware of their infection are likely to decrease behaviors that may transmit infection to others[37-40] and through partner notification services, persons who have been exposed to HIV can be contacted and tested.[41-43]

HIV counseling and testing data. The HIV Counseling and Testing System (CTS) has been used by the CDC to monitor all federally-funded test counseling programs since 1989, with a name change to the HIV Counseling, Testing and Referral (CTR) System in 2005. Through cooperative agreements, the CDC currently funds 59 state health departments to provide CTR programs.[44] CTR programs are prevention-focused with the goals of assisting clients in 1) knowing their HIV status and 2) reducing their risk for HIV.[5] One requirement of the CDC's funds is the collection of individual-level data on all persons accessing CTR services, including demographics, self-reported behaviors and test results. To standardize data, a list of required variables with definitions and coding conventions is provided to all funded sites and sites are encouraged to use machine-readable (scan-tron) standardized forms. CTR programs are required to submit quarterly reports to the CDC either at the individual-level or in aggregate data form.[7] These data are used at the state and national level to monitor trends in the testing population,[7, 8] as well as evaluate the effectiveness of the CTR program in reaching targeted, high-risk populations with testing opportunities.[9-11]

CTR data also are used to inform the Integrated Epidemiological Profile. In 2005, the CDC and Health Resources Services Administration recommended that public health officials responsible for collecting and interpreting HIV surveillance data use Integrated Epidemiologic Profiles, which expand beyond counts of nationally reported HIV and Acquired Immune Deficiency Syndrome (AIDS) cases, to more efficiently monitor the epidemic.[45] One of the key questions to be addressed in the expanded monitoring of the epidemic, "What are the indicators of risk for HIV infection…in your service area?", can be answered by use of CTR data.[46] For persons testing positive, the risk behaviors reported during HIV testing counseling provide an important piece of HIV surveillance efforts.

Guidelines for HIV test counseling

In 1987, the US Public Health Service made HIV test counseling a priority prevention strategy and recommended testing for all clients seeking sexually transmitted disease (STD) treatment.[47] In 1994, CDC provided CTR guidelines for providers offering HIV testing and promoted use of a client-centered, prevention counseling model.[1] The revised 2001 CDC CTR guidelines further emphasized the prevention counseling model recommending test counselors complete individualized risk assessments with each client to develop client-specific risk reduction strategies.[48] The prevention counseling model focuses not only on identifying new infections and facilitating entry into care through referrals, but in primary prevention through an individual-level behavior change intervention.

In 2003, in response to increasing rates of HIV infection among men who have sex with men (MSM) and heterosexuals, the CDC launched a new initiative, Advancing HIV Prevention: New Strategies for a Changing Epidemic.[49] One of the four proposed strategies focused on increasing early diagnosis of HIV by making

HIV testing a routine part of medical care. In 2006, the CDC released revised CTR guidelines for testing in healthcare settings which furthered the initiative's emphasis on routine testing.[5] In order to minimize barriers to testing, the CDC currently recommends that healthcare providers offer routine, opt-out testing without the need for a risk assessment or risk reduction counseling. While the revised, opt-out guidelines have garnered support from 35 of 74 national professional societies,[50] others have expressed concern over legal issues,[51-53] cost-effectiveness[54] and consequences of the elimination of prevention counseling.[52, 55, 56] The CDC has developed an evaluation metric to determine the long-term consequences of the new guidelines.[50] While the evaluation is underway, many testing sites continue to use the prevention counseling model. Even under the new guidelines, the CDC acknowledges that the risk assessment/risk reduction model is "still strongly encouraged for persons at high risk for HIV in settings such as sexually transmitted disease (STD) clinics."[6]

Client-centered, prevention counseling model. The use of a combined risk assessment/risk-reduction model has been found to be a feasible, cost-effective method of reducing risk behaviors.[2, 3] In a randomized control trial of over 5700 patients in five public STD clinics ("Project RESPECT"), patients receiving either brief or enhanced prevention counseling had 20% fewer STDs at a 12 month follow-up compared to patients receiving only didactic educational messages.[2] Although previous research had found prevention counseling to be infective for some populations, such as women,[57] adolescents[58] and patients already infected with an

STD,[59] a sub-analysis of the Project RESPECT data reported that both brief and enhanced counseling reduced incident STDs in these high-risk populations.[3]

The brief counseling arm of the Project RESPECT trial, shown to reduce risk behaviors as measured by reported condom use and incident STDs, was based on the prevention counseling model recommended by the CDC in the 1994 guidelines. Under the model, clients meet with a trained counselor at least two times. During the first counseling session (the "pre-test"), the counselor implements a personalized risk assessment, in which the client is encouraged to disclose all past risk behaviors for HIV transmission, such as sexual behaviors and drug use. The CDC suggests that risk-assessment be completed through use of open-ended questions about risk behaviors versus a check-list of behaviors. Then, based on the risk assessment, counselors work with the client to develop a behavior change goal that will reduce, not eliminate, the client's risk of acquiring HIV. During the second session (the "post-test"), clients are provided their test results, the risk-reduction plan is reviewed and/or revised and appropriate referrals provided.[48]

<u>HIV test counselors.</u> The CDC CTR guidelines recommend that HIV prevention counselors need not have advanced degrees or medical training, but should have developed skills in prevention counseling, including ability to "engender a supportive atmosphere and build trust with [clients]".[48] In addition, counselors should be evaluated periodically to ensure that counseling objectives, including personalized risk assessments for all clients, are being adequately met. Currently the majority of research on HIV test counseling has focused on effectiveness in changing

behaviors.[35, 37] There is limited evaluation evidence on the test counseling process, including test counselor training, characteristics and skill.[56, 60] Preliminary research suggests that CTR sites may not fully implement the CTR guidelines. In a study of 30 publicly-funded clinics in Pennsylvania, researchers used participant actors to evaluate staff-client interaction.[61] While almost 90% of providers conducted a risk assessment, only 43% discussed changing behaviors with their clients.

The role of the risk assessment during HIV test counseling

<u>The foundation of prevention counseling.</u> As part of the prevention counseling model, HIV counselors complete a risk assessment during which the client's past behaviors, such as number and gender of sexual partners, use of injection drugs and use of drugs/alcohol before sexual activity are discussed.[48] Based on the specific risk behaviors disclosed, the client, with the help of the counselor, develops an individualized risk reduction plan. In an analysis of 24 qualitative interviews with HIV test providers in Canada, counselors named "individualization of the risk assessment" as one of the most important aspects of the prevention counseling session.[62] The efficacy of the prevention intervention may rely on the accuracy of the individualized risk assessment. For example, a male client may have unprotected sex with men and women, but only discloses to his HIV counselor that he has sex with women. In this case, there is a missed opportunity to provide risk education and develop a risk reduction plan specific to same gender sexual contact (e.g. the differential risks related to insertive versus receptive sex).

Influence on services offered. The revised 2006 CDC CTR guidelines clearly state that a risk assessment should not be used to determine if HIV testing is offered,[5] as there is potential to miss diagnosing someone already infected.[63, 64] In practice, risk based screening occurs. In a survey of primary care physicians in Washington State, 53% responded that they "ask specific questions about sexual practices to determine if [STD/HIV] testing is necessary".[65] For some settings, such as high-volume medical centers, evidence suggests that risk based assessments may be more cost-effective in identifying new infections compared to routine screening.[66] Additionally, under the 2006 CDC opt-out guidelines, providers are encouraged to offer additional services to clients disclosing high-risk behaviors (e.g. multiple sex partners, exchanging sex for drugs or money) including prevention counseling and targeted referrals.[5] Consequently, accurately assessing client's risk plays a key role in effectively offering services.

In some settings, the risk behaviors that patients choose to disclose to providers may influence the type of test that patients receive. In a study of clients attending HIV test counseling clinics which offer both confidential and anonymous testing, providers admitted to "push[ing] patients who are at high risk of HIV to test confidentially".[12] In an analysis of over a thousand gay and bisexual men attending STD clinics in three US cities, men who disclosed a high-risk behavior (anal sex) were more like to be tested for gonorrhea then men who failed to disclose (67% vs. 49%).[13] In addition, new screening techniques, including testing for acute HIV infection using viral RNA testing (as opposed to the standard antibody test) may be offered to patients based on reported risk behaviors. For example, a targeted screening criterion was recently developed for use in a low-resource clinic to determine which patients are most likely to be infected with acute HIV based on demographic, clinical and reported risk behaviors, such as the number of sex partners in the past two months.[14]

Risk assessment used to inform surveillance statistics. In CTR sites, the information gathered by the test counselor during the test counseling risk assessment is used to complete the CTR data collection form. Variables standardized across test sites contain the patient's past and current risk behaviors including: gender of sex partners, use of injection drugs, trading sex for drugs or money and occupational exposures. The CDC publishes aggregate data from all federally-funded sites in CTR reports,[7, 67] highlighting distribution of risk behaviors stratified by race/ethnicity and test result. The most current report available suggests that CTR data should be used "to guide the development of HIV prevention programs in response to the needs of various communities" (p.4).[7]

At the individual-level, the test counseling risk assessment may be used to help determine likely mode of transmission for patients testing positive. All providers who diagnosis a case of HIV must complete a standardized HIV/AIDS case report form which is submitted to the CDC for tracking of national statistics.[68] The case report form includes a "patient history" section which asks for documentation of risk behaviors prior to diagnosis including gender of sex partners. For patients diagnosed at a CTR site, data from the risk assessment documented during pre-test counseling is likely used to complete this form.

Indications of risk assessment inaccuracies

As the reported likely mode of transmission in clients with reactive test results is based in part on patient's self-disclosed risk during pre-test counseling, one validity assessment of risk behavior disclosure comes from review of mode of transmission data. Current research indicates that specific risk behaviors, including gender of sex partners, are often inaccurately measured. In a sample of HIV positive clients in six US states, in-depth interviews were used to validate reported mode of transmission; 14% of men classified as heterosexual or "no reported risk" were found to be MSM and 13% were found to be injection drug users (IDU). Fourteen percent of women previously classified as heterosexual or "no reported risk" reported IDU.[19]

In Chicago, mode of transmission was verified in a sample of 395 "heterosexual" transmission cases reported from 1991 through July 1995 using medical records. Eighty-five percent required reclassification, with 69% (272 of 395) of cases reclassified into non-heterosexual risk exposure categories.[21] In a review of HIV surveillance records in southern Florida, 30% (50 of 168) of "heterosexual" AIDS cases in a 13-month period were found to have a mode of transmission other than heterosexual contact when supplemental data sources were reviewed.[22] Similar findings in a review of "heterosexual" HIV cases in Kansas found 58% of cases were reclassified to MSM or IDU when cases were compared with medical records and post-diagnosis interview records.[23]

Bias in face-to-face interviews. The CDC recommends that HIV prevention counseling be conducted in face-to-face interviews (FTFI).[48] While FTFIs allow for additional probing questions, explanation of unfamiliar terms and clarification of clients' responses,[69, 70] numerous studies have shown that there is substantial underreporting of risk behaviors during FTFIs when compared with alternate data collection methods, such as Audio and Computer Assisted Self-Interviews (ACASI) and written questionnaires.[16, 17, 69-76] In a study of clients attending a public STD clinic, face-to-face clinician interviews resulted in fewer reports of risk behaviors such as trading sex for money/drugs, number of sexual partners and orogenital contact when compared to an ACASI.[16] Similar inaccuracies in FTFIs have been found in other studies of STD clinic clients[17, 18, 72] and in other populations such as clients in drug abuse treatment centers,[73] national surveys,[77] clients participating in syringe exchange programs,[78] and HIV positive IDUs.[71, 75]

Underreporting of stigmatizing behaviors. Studies of disclosure of risk behaviors report that non-normative and/or stigmatizing behaviors such as same gender sexual contact and illegal drug use are often underreported. In an analysis of sexual history completeness during STD exams, 22% of men who reported same gender sex during a computer-assisted interview failed to disclose that during a clinician interview.[17] During semi-structured interviews in a qualitative study of 50 MSM in Boston, 26% of men stated that they had not told their current healthcare provider that they had sex with men[79] and among the 452 MSM surveyed in the New York City National HIV Behavioral Surveillance Project almost 40% reported not disclosing same gender sex to their healthcare providers.[80] In an assessment of underreporting of illicit drug use in general population telephone surveys conducted by human interviewers, use of telephone-ACASI increased reports of use of marijuana (5.7% to 10.0%), cocaine (0.7% to 2.1%), and IDU (0.3% to 1.6%), $p<0.01$ for all measures.[74]

Social exchange theory proposes that persons choose who and when to disclose sensitive and/or stigmatizing information based on the expected benefits and anticipated costs of disclosure.[81] The perceived cost to disclosure may outweigh the benefits for patients engaging in highly stigmatizing behaviors, such as MSM and IDU. In a comparison of self-reports of sexual history from face-to-face clinician interviews and ACASIs in an urban, public STD clinic, ACASI reports were more complete for “socially sensitive” behaviors, such as same gender sexual partners and illicit drug use. “Socially rewarded” behaviors, such as condom use and previous testing history, were more frequently reported in clinician interviews.[17]

Barriers to accurate risk assessments

In a review of self-reported sexual risk behavior, Schroeder and colleagues propose that there are two primary factors influencing accuracy of retrospective self-report of behaviors.[24] First, persons may have memory error due to length of the recall period (e.g. a 2-week report may be more accurate than a 12-month report), level of measurement (e.g. number of sex acts without a condom may have more errors than a dichotomous measure of condom use) and frequency of behavior (e.g. high frequency may lead to forgetting and underreporting). Second, accuracy of self-report is determined by social context and motivational biases. Termed “self-presentation bias”,[82] clients wish to be viewed in a positive light and socially desirable behaviors (e.g. monogamy) may be over-reported while undesirable behaviors (e.g. trading sex) may be under-reported. Additionally, patients' perceptions of confidentiality and credibility of the risk assessment may impact their motivation for level of accuracy.

Based on the standardized CTR assessment form, the HIV test counseling risk assessment tracks dichotomous answers to risk behaviors which would be expected to maximize accuracy. The assessment period is lengthy (lifetime exposure or past year) potentially leading to recall bias, however a shorter, potentially more valid period (e.g. 2 weeks) would not fully capture patient's exposure and decrease the usefulness of the measure. As the counseling risk assessments take place in FTFIs, social context and motivational biases likely influence accuracy during the risk assessment. Barriers to complete and accurate risk behavior disclosure may occur on a variety of levels, including intrapersonal, interpersonal and structural.

Intrapersonal. The level of self-presentation bias may be related to client characteristics as social norms around sexual behavior vary by gender, age, race/ethnicity and sexual orientation.[82] Durant et al found in a survey that assessed "perceived question threat" on items such as unprotected sex and number of sexual partners, women perceived greater threat across a range of behaviors.[83] In the study of reclassification of "heterosexual" mode of HIV transmission in six US states, the age group of men most likely to be reclassified was 20-29 with odds of reclassification two times that of men younger than 20 (Odds Ratio(OR)=2.1 95%

Confidence Interval (CI) 1.5, 3.1) and 1.7 times (95% CI 1.1, 2.6) that of men over 30.[19] Among STD clinic patients, compared to older patients, those under 25 were less likely to admit to trading sex for drugs during FTFIs (validated by ACASI).[16] Differences in attitudes toward non-heterosexual activity by race have been documented[84, 85] which may translate into differential social desirability patterns regarding sexual orientation.

In addition to self-presentation bias, clients may have other motivations for level of accuracy. Patients with a self-interest in the survey may be more likely to provide thoughtful and accurate answers.[82] Patient accuracy in response to sexual behavior questions may also be related to their general comfort in their sexual identity and in their overall candor. In a study of lesbians' experiences during healthcare, women who were more "out" were more likely to disclose their sexual orientation to their provider; however, women's perceived "gay positivity" of their provider was a stronger predictor of disclosure suggesting interactions with providers are also important.[86]

Interpersonal. As the majority of CTR risk assessments are conducted in FTFIs, client's interactions with the test counselor likely influence accuracy. The theory of social influence, used primarily in counseling research, proposes that it is not only the message given during the therapy, but the client's perception of the counselor that influences effectiveness.[87] For example, client's perceptions of level of knowledge of the counselor and the counselor's comfort level may also impact success of the counseling session.[82, 87] The counselor's ability to connect with the client may also influence risk disclosure. In a study of young adults in the mid 1970s, researchers studied participants' reported sexual behavior and reactions to their interviewer. Study participants reporting greater "rapport" with the interviewer also reported more sexual behaviors.[88]

In research studies, characteristics of the counselor-client interaction often studied include race/ethnicity and gender matching, as concordant characteristics may allow for a better understanding of behavior motivations[89] through shared cultural beliefs,[90] language[91] and social experiences, as well as reduce fear of discrimination.[17] An alternate theory of patient-provider matching would suggest that discordance may *increase* risk behavior disclosure as the patient may perceive the test counselor to be removed from their social network, reducing the fear of breach of confidentiality.

Studies of accuracy of response on sexual behavior surveys have found few differences by gender of the interviewer;[88, 92, 93] however the majority of the research is dated, likely due in part to the increased use of computer-based surveys. One recent study examined behavioral risks disclosed during sexual health exams by gender of the practitioner implementing the survey.[, 3] Upon review of over 11,000 electronic medical records, there were no differences in the number of sexual partners, report of commercial sex work or condom use by gender of the provider.

Patient's preferences for the race and gender of their medical providers are often studied, usually within the context of health disparities and perceived discrimination.[94-100] Few have focused on preference during HIV test counseling.[25, 101] Preliminary evidence suggests race/gender matching between client and counselor plays a minor role in patient comfort. In a study of counselor preferences during HIV post-test counseling, 27% of African American clients said that they would prefer a gender matched counselor and only 9% reported that they would be more comfortable with a race-matched counselor.[25] A qualitative study of African American's preference for STD providers found that for about half of participants (8 out of 18) race was not a factor, with two of the eight preferring a white provider so they could get "better treatment" and more confidentiality.[102] In a simulation study of client cooperation in partner notification for STD infection, race and gender of the counselor did not increase client intended participation rates.[26] The only study that has directly examined counselor matching during HIV pre-test counseling was a sub-analysis of the Project RESPECT intervention.[101] The authors concluded that matching client-counselor dyads on race and/or gender was not associated with the effectiveness of prevention counseling, as measured by acquisition of a new STD in the following year.

The influence of perceived sexual orientation matching on risk behavior disclosure has not been well studied. Having a heterosexual medical provider was mentioned as a possible barrier to risk discussion in a qualitative study of MSM in Massachuttess.[79] Additionally, some of the non-heterosexual participants (n=3) in a qualitative study of "the test counseling experience" stated that it was "important" to have a gay test provider.[103] Further research is needed to understand how a counselor of the same sexual orientation might facilitate disclosure. Similar to theories around racial matching, sexual orientation concordance may increase comfort through shared culture and language or may create additional barriers through fear of loss of confidentiality through shared social networks.

<u>Structural.</u> The physical and structural aspects of the test counseling session may create barriers to accessing STD[104] and HIV testing[103] and may also influence risk behavior disclosure. The physical location of the clinic, such as in a community center or local health department, may affect perceived confidentiality as clients may know providers or office staff. In addition, for test sites using electronic and/or paper medical charts, clients may hesitate to provide personal information that will be documented in a record.[103]

Data collection forms and phrasing of risk assessment questions which limit sexual identity may present additional barriers. In a study of lesbians' experience with the healthcare system, many women complained that they felt invisible to providers.[105] A participant in a focus group stated:

> "Heterosexism is the assumption that everybody's heterosexual unless you say you aren't; it's really debilitating. And I think so much of it occurs in the way demographics are collected in the healthcare system, the way questions are framed…when you fill out a form, and you get that 'single, married, divorced, widowed' stats, I always ask myself 'Is this a real good form that I'm filling out?'"

In addition, subtle heterosexual messages of the clinic, such as lack of same gender couples on health education brochures and health awareness posters in the counseling rooms, may create addition barriers for patients with non-heterosexual sexual identities and/or behaviors.[86, 106]

Assessing the accuracy of the risk assessment

There is no “gold standard” for risk behavior disclosure;[82] however, multiple methods are used to quantify accuracy. Participants may be directly asked to report on their candor through surveys that are perceived as more confidential, such as anonymous self-assessments.[88] Under the assumption that a higher incidence of reported behaviors equals more accurate information,[24] multiple assessments can be completed and compared, such as comparisons of sexual history completeness from a clinician interview to an ACASI.[16, 17] Denial of risk behaviors can also be verified by biological markers. For example, in an assessment of reliability of self-reported recent, unprotected sex, vaginal specimens from 332 female sex workers were tested for prostate-specific antigen (PSA).[107] Presence of PSA in 21% of samples from women who claimed no sex confirmed inaccuracies in the risk assessment.

Compared to the behaviors measured during the CTR risk assessment, other assessments may be more complete for certain measures. Sites funded by the CDC for CTR programs must also offer partner counseling and referral services (PCRS).[108] The purpose, length, frequency and timing of the CTR and PCRS risk assessments are different. (Table 2.1.) PCRS counselors conduct voluntary, post-diagnosis interviews with clients who test positive for HIV to assist with partner notification of past sex and needle-sharing partners, counsel clients on prevention of subsequent risk behaviors and facilitate referrals for treatment and services.[108] Clients may perceive increased benefits to complete disclosure of gender of sex partners during PCRS interviews compared to the CTR risk assessment. For example, as accurate disclosure during partner notification helps ensure all past partners can be tested and receive treatment if infected, clients may feel a social desirability to provide accurate information on all sex partners. Additionally, after being informed of communicable disease control measures which require past partner notification and clients may feel legally obligated to disclose. During test counseling, clients may not understand or perceive the benefits to accuracy during the assessment and the social desirability bias may limit disclosure. Consequently, PCRS interviews may be a more accurate measure of gender of sexual partners than the HIV counseling risk assessment.

Summary

HIV CTR data are collected in all 61 US states and territories,[7] yet the validity of self-reported risk behaviors in the CTR database remains undocumented. Evidence of underreporting of risk behaviors during face-to-face clinician interviews[16, 17] and in the national HIV/AIDS reporting database[20-23] suggests inaccuracies during the test counseling risk assessment are likely. This misclassification of risk has important consequences at both the individual and population-level. For the individual, the effectiveness of the HIV prevention counseling model is likely contingent on clients' disclosure of risk behaviors. In addition, for healthcare providers streamlining HIV testing per the CDC's 2006 revised guidelines, accurate risk assessment ensures high-risk clients are offered more comprehensive counseling and effective and appropriate referrals. At the population-level inaccurate statistics can skew evaluation of the CTR program, as well as lead to inappropriate and/or ineffective resource allocation. Determining the patterns of risk behavior disclosure during CTR counseling is necessary to understand the limitations of the database.

To guide interventions to improve the validity of the risk assessment, further research is needed to understand barriers and facilitators to accurate risk behavior disclosure, including interpersonal and structural aspects of the counseling session. Additionally, as a required face-to-face risk assessment may present a barrier to testing for HIV for men with potentially stigmatizing behaviors, such as IDU and non-heterosexual contact,[109, 110] information on how to reduce barriers to risk behavior disclosure may have the secondary impact of increasing access to HIV testing.

Table 2.1. Characteristics of the risk assessment during CTR and PCRS in NC.

	CTR	**PCRS**
Purpose	To identify client's risk behaviors to form the basis of a risk reduction plan for primary prevention of HIV. To collect standardized data for the NCDHHS CTR data collection form	To identify client's risk behaviors to form the basis of a risk reduction plan for secondary prevention of HIV. To identify client's past sex and needle-sharing partners to assist with state-mandated partner notification.
Timing	During the pre-test counseling session	During post-diagnosis interview(s)
HIV status at time of assessment	Unknown	Diagnosed as HIV positive
Frequency/length	One, 10-20 minute counseling session	Often multiple times with varied lengths
Setting	Clinic or NTS location	Varied, including clinic, home, work, public place
Counselor	Clinic or NTS staff member trained in state counseling curriculum (3-day training)	PCRS counselor trained in state counseling curriculum (3-day training) <u>and</u> in PCRS partner notification curriculum (10-day training)
Assessment of gender of sex partner(s)*	Assessed as yes/no for each gender through the question "Do you have sex with men women or both", along with additional open-ended probes	Assessed as yes/no for each gender based on partners provided during partner notification efforts

CTR: Counseling, Testing and Referral; PCRS: Partner Counseling and Referral Services; NC: North Carolina; NCDHHS: North Carolina Department of Health and Human Services; NTS: Non-traditional test site

*: as used in this analysis

Chapter Three: Methods and data sources

Study overview

As part of an on-going investigation of HIV in young men,[111-114] the primary study population for this dissertation is men aged 18 to 30. We investigated the accuracy of the HIV test counseling risk assessment and determined barriers to full risk behavior disclosure. Currently only publicly-funded Counseling, Testing and Referral (CTR) sites uniformly collect risk assessment data, so our study population is further restricted to men accessing CTR testing services. The different specific aims limit analyses to sub-populations. (Figure 3.1) Specific Aim #1 validates self-reported gender of sex partners in the CTR database using Partner Counseling and Referral Services (PCRS) charts. As PCRS interviews are only completed for men with reactive test results, this analysis is limited to young men who were newly diagnosed with HIV in NC between 2000 and 2005. Specific Aims #2 and #3 investigate accuracy and comfort during the risk assessment in the general testing population and describe the individual, social and structural characteristics of the HIV test counseling session that influence accuracy during the risk assessment. For these two aims, we collected data in a publicly-funded clinic in Central NC from August 2007 to April 2008. As the positivity percent was less than 1% during the data collection period, the majority of the study participants were likely uninfected.

Combined, this dissertation takes a mixed methods approach. We make efficient use of two pre-existing statewide datasets for Aim #1, but the analysis is limited by a restricted study population and lack of information on barriers. We supplement this analysis with primary data collection in Aims #2 and #3. By collecting quantitative (Specific Aim #2) and qualitative (Specific Aim #3) data simultaneously, we examined the primary research questions from different perspectives and overcome limitations of each of the methods.[115, 116] By triangulating between data, we were able to cross-validate findings, seeking convergence and corroboration to strengthen credibility.[115, 117] A mixed methods approach also increased our scope of inquiry as the qualitative data allowed us to expand on barriers to risk behavior disclosure not captured quantitatively.[117]

This study was approved by the University of North Carolina at Chapel Hill (UNC-CH) Public Health-Nursing Institutional Review Board (IRB).

Specific Aim #1: Quantify incomplete or inaccurate self-reported gender of sex partners during HIV pre-test counseling among HIV positive men, aged 18-30, who tested at publicly-funded clinics.

Study design overview

In order to identify HIV positive men who did not accurately report the gender of their sexual partners during HIV pre-test counseling, we collaborated with the NC Department of Health and Human Services (NCDHHS) to link two statewide HIV datasets which contain individual-level behavioral information on all newly diagnosed cases of HIV in NC. We estimated agreement of reported gender of sex partners in the CTR database and in data abstracted from PCRS charts through calculation of Cohen’s kappa statistic. As we hypothesized PCRS charts to have more complete measures of gender of sex partner, we calculated sensitivity, specificity and conditional kappa statistics assuming PCRS charts as a “gold standard”. We quantified how inaccurate reports of gender of sex partners in the CTR database may alter surveillance statistics through assignment of CDC risk categories based 1) only the CTR database, 2) only the PCRS database and 3) the union between both databases.

Study population

The study population consists of men aged 18-30 years newly diagnosed with HIV at a CTR site between 2000 and 2005 in NC. NC Counseling, Testing and Referral (NC-CTR) sites are HIV testing sites publicly-funded by the NCDHHS and provide services to all 100 counties in NC. Locations include traditional sites, such as local health departments, as well as non-traditional sites (NTS). NTS sites were added to the NC-CTR program in 1997 in response to community concern over barriers of confidential testing. The NTS program targets populations who may not regularly access traditional services and includes outreach testing at locations such as drug treatment centers, clubs and bars. NC-CTR sites may include county jails if the jail health service is provided by the local health department. The number of NC-CTR sites varied over the six year period from 138 to 169, with the number of NTS ranging from 12 to 15.

Over 100,000 persons test for HIV in NC-CTR sites each year, with less than 1% testing newly positive for HIV. Due to NC's integrated HIV surveillance system, newly reported positives are able to be identified from persons testing positive who had a previous reactive test result in NC. In 2004 (the most current published NC-CTR data), the population accessing HIV tests in NC-CTR locations was generally female (61%), African American (56%) and most often reported having had a previous negative test (62%). After limiting the NC-CTR population to those persons testing HIV positive, the majority of the population is male, African American, and report only heterosexual risk behaviors. While the majority of HIV tests conducted in NC occurred in CTR sites, only about a third of newly reported HIV infections are diagnosed in NC-CTR sites.[118] Findings from this study can help inform future research on risk behavior disclosure in non-public testing facilities and among females.

CTR data

Overview. The NC-CTR dataset contains socio-demographic and self-reported risk behaviors, including gender of sex partners, for all persons testing for HIV in publicly-funded clinics. Maintained by the NCDHHS, NC-CTR is the only statewide program to monitor behavioral trends in the testing population. During the data collection period, all NC-CTR sites were mandated by the NCDHHS to provide client-centered prevention pre- and post-test counseling for all clients receiving an HIV test. NC-CTR site staff providing counseling were trained in a state counseling curriculum based on Project RESPECT, a national intervention shown to change high risk behaviors and prevent new STDs.[2] The prevention counseling model combines an individualized risk assessment with the development of a behavior change, risk reduction goal. HIV test counselors document data collected during the counseling session on standardized scan-tron forms with a nine-digit unique identifier. (Appendix B.1.) Prior to July 2005, the scan-tron recorded patient's gender, race/ethnicity, previous testing history, and reported risk behaviors. After July 2005, additional patient identifiers (name and address) were also captured on the scran-ton. (Appendix B.2.) Scan-trons are submitted to the NCDHHS lab along with patient blood samples. The scan-tron is entered directly into the NC-CTR electronic database along with documentation of seropositivity of the blood sample. The NC-CTR database is stored on a secure server at the NCDHHS.

The NC-CTR database contains highly confidential data that are not available for public use. Limited statistics in aggregate form are released to the public through yearly epidemiologic reports and to NC-CTR sites for program monitoring. These data are occasionally used for research;[119, 120] however, use of individual-level data are highly restricted. This study has the full support of the NCDHHS which agreed to allow the analysis to be completed. The NCDHHS state HIV/STD Medical Director and HIV epidemiological manager facilitated access to the NC-CTR dataset.

<u>Assessment of gender of sex partners.</u> Although the NC-CTR scan-tron records the risk assessment as a list of behaviors with dichotomous responses (yes or no), the counselors are encouraged to collect data through an informal, client-centered counseling approach. HIV counselors are trained to ask clients the gender of their

sex partner(s) as “Do you have sex with men, women or both?” along with other open-ended questions (data captured as yes/no for each gender). Gender of sex partner is documented on the scan-tron as “since 1978” which for the study population (men aged 18-30) is lifetime. Beginning in July 2005, the time frame used to assess the risk period was changed to “in the last year.”

PCRS data

Overview. HIV infection has been a name-based reportable disease in NC since 1990. All providers are required to report reactive test results to the NCDHHS, including non-CTR facilities such as family physicians, emergency rooms, blood banks and prisons. In 1989, the NCDHHS began offering PCRS services to all reported cases of HIV and syphilis. Organized into seven regions across NC, each PCRS region covers approximately fifteen counties, employs one regional supervisor and a team of PCRS counselors, also called Disease Intervention Specialists (DIS). Each reported case of HIV is assigned to a PCRS counselor, who after verifying that the case is a new HIV infection, contacts the patient’s medical provider to review the patient’s medical records, collecting clinical and demographic information. The PCRS counselor then attempts to arrange a confidential, voluntary interview with the patient to assist with partner notification of past sex and needle-sharing partners, counsel patients on prevention of subsequent risk behaviors and facilitate referrals for treatment and services. With almost 90% of all reported HIV cases interviewed, often multiple times, this database contains the most comprehensive statewide individual-level behavioral data available on HIV positive persons in NC.[3]

Information collected by PCRS counselors is maintained in hard copy, paper charts located in secure locations in each of the seven regions. In addition, selected data from the charts are entered into a computer database, STD*MIS, by the corresponding PCRS counselor and each patient is given a unique PCRS case number. Reported risk behaviors are included in the STD*MIS, however the STD*MIS has two flaws; first, additional misclassification of risk behaviors is possible due to data entry errors and second, the STD*MIS has limited fields for risk behaviors and categories are not exhaustive. Hard copy PCRS charts, which include printouts of the STD*MIS database, as well as the PCRS counselor's written notes, provide more complete representation of patient risk behaviors. Therefore, we used a dataset that contains information abstracted from the PCRS hard copy charts. This dataset was previously abstracted as part of on-going surveillance monitoring of young, HIV positive men in NC by the NCDHHS and UNC-CH Infectious Disease Department. Using a case abstraction form, data were abstracted from the standardized fields and written narratives of the PCRS charts by trained research assistants and entered into an Access database (Microsoft Corporation, Redmond, WA). Variables abstracted included client demographics and risk behaviors.

Similar to the NC-CTR dataset, the abstracted PCRS database is highly confidential and is not for public use. Through our partnership the NCDHHS and the UNC-CH Infectious Disease Department, we have obtained permission to use the PCRS dataset for this analysis.

Assessment of gender of sex partners. PCRS counselors document gender of sex partners in the likely infection period (for chronic infections, the default period is one year). Gender of sex partners is deduced through partner notification efforts, where clients provide counselors with names and contacting information for past and current sexual partners. Gender of sex partners was abstracted from the PCRS charts as yes/no for each gender.

Case identification

Overview. The study sample of newly diagnosed male cases aged 18-30 was identified through PCRS chart abstraction. The primary NCDHHS HIV surveillance database, the HIV/AIDS Reporting System (HARS), contains all newly reported HIV cases in NC and consequently may contain cases that are not new diagnoses (e.g. the patient was diagnosed three years in another state, but moved to NC and was reported when he sought medical treatment). In order to limit the dataset to new diagnoses, during PCRS chart abstraction, research assistants noted the date of the first positive HIV test anywhere and the dataset was restricted to men first diagnosed between January 1, 2000 and December 31, 2005.

Missing data. Using the PCRS dataset to define cases more accurately reflects new diagnoses in NC compared to HARS; however, the PCRS dataset may be missing some cases. PCRS counselors attempt to interview all newly reported cases of HIV in the state, but approximately 10% of cases are not able to be interviewed.[42]

Patients not interviewed are unlikely differential by race or ethnicity, however patients testing at publicly-funded clinics are more likely to be interviewed by PCRS counselors compared to patients testing in private facilities such as blood banks or plasma donations centers.[42] Possible reasons for missing interviews include: lack of locating information (e.g. the patient is homeless or gave false information), the patient refuses to meet with the PCRS counselor, the patient is deceased, or the patient leaves the state immediately after diagnosis. The probability of missingness is not random and *may* be related to the "true" measures of interest for this analysis (gender of sex partner). For example, if someone is unwilling to disclose a potentially stigmatizing risk behavior, such as same gender sexual contact, they may provide inaccurate risk behavior information to their test counselor and then refuse to meet with the PCRS counselor and/or give false locating information. Unfortunately, because these data are not missing at random, techniques for dealing with missing data, such as multiple imputation, were not appropriate.[121] Based on published reports of the NC PCRS system, including interview rates, missing data are likely to be less than 10%[42] and should have a minimal impact on statistical analysis.

Chart linkage

<u>Overview.</u> The PCRS database was not able to be linked directly to the NC-CTR dataset as the datasets do not contain a shared patient identifier. The PCRS database contains patient name, HARS identification number, date of birth and a unique PCRS case number. The only patient identifier in the pre-July 2005 NC-CTR database was the nine-digit CTR-specific identifier. We first determined which

patients in the PCRS dataset had likely been diagnosed in a NC-CTR site. We then located the CTR-identifier using other NCDHHS datasets, as well as local medical record review. We merged the PCRS dataset to the NC-CTR dataset by the CTR-identifier, resulting in a final dataset with reported patient demographic and risk behaviors from both the 1) PCRS dataset and the 2) NC-CTR dataset.

<u>Identification of men testing in NC-CTR sites.</u> Identifying clients who tested at a NC-CTR site and their corresponding CTR-identifier was a multi-step process. (Figure 3.2.) We began with the dataset of all cases of young men newly diagnosed with HIV between 2000 and 2005 in the PCRS database (n=1450).

1. Facility of diagnosis was missing for some of the cases in the PCRS dataset, as it was not uniformly abstracted from the PCRS charts. We linked the PCRS dataset to HARS by HARS ID and abstracted facility of diagnosis and if available, the patient's CTR-identifier.
2. We identified patients as *not* testing in a NC-CTR site if the facility of diagnosis listed in HARS <u>and</u> the PCRS dataset was not a health department, jail or NTS (e.g. it was an emergency room). (n=505)
3. Conversely, we classified the remaining clients (n=945) as "possibly testing a NC-CTR site" if they had a facility of diagnosis that was 1) a likely NC-CTR facility (e.g. local health department); 2) discordant between HARS and the PCRS database; or 3) missing.
4. We first attempted to confirm the patient as testing in a NC-CTR site by searching for the CTR-identifier in two other NCDHHS datasets: HARS and

Labtrak (an internal NCDHHS database). Although there is a field for CTR-identifier in both databases, it is often missing even when the client tested at a CTR site. A located CTR-identifier with a reactive test result confirmed that the client was diagnosed at a NC-CTR site (n=390).

5. For clients classified as “possibly testing in a NC-CTR site” without CTR-identifier in HARS or Labtrak (n=585), we accessed the patient’s medical record by client name at the facility of diagnosis. If no facility was listed, we looked at each of health departments in the region of diagnosis. At each facility, we pulled the patient’s medical record and checked for a copy of the NC-CTR test results which contains the CTR-identifier. A located CTR-identifier with a reactive test result confirmed that the client was diagnosed at a NC-CTR site (n=267).
6. Cases were determined as not testing in a NC-CTR site (n=272) with the following criteria: 1) there was no record of the client testing at the reported facility of diagnosis or county health department; or 2) in the local chart, a private provider was listed as diagnosing the patient.

This process resulted in 673 men identified as tested in a NC-CTR site and 777 classified as testing with a private provider. Of the 673 men classified as testing in a NC-CTR site, 657 CTR-identifiers were located (97.6%). The 16 clients without a CTR-identifier were confirmed as being diagnosed in a NC-CTR site, but their CTR-identifier was not available.

Matching to the CTR database

We merged the PCRS abstraction dataset with the NC-CTR electronic database by CTR-identifier. Six hundred and forty one records were matched (97.6%). The 32 cases (16 without a CTR-identifier and 16 that didn't match to the NC-CTR database) were not statistically different by client race, age, region of diagnosis or method of CTR-identifier retrieval (HARS, Labtrak or local chart review). (Table A.1.) Non-matched clients were more likely to have been previously incarcerated or have a history of IDU, but the low prevalence of non-matched cases (<5%) should have a minimal effect on the analysis.

Other than the primary measure of interest for this analysis (gender of sex partners), there are few variables that overlap between the PCRS and NC-CTR databases. We compared overlapping available measures (race, gender and diagnosis date) between databases to ensure correct matches. Over 80% matched on all three variables (n=528) and 100% matched on at lease one of the three variables. For cases diagnosed post-July 2005 in which name was available in both datasets, 100% of records matched on name (n=79). We included all records in the analyses (n=641). To examine possible bias do to incorrect matching, we repeated all analyses restricted to only cases that matched on all variables (n=528). Key findings remained robust. (Table A.2. and Table A.3.)

Data analysis

<u>Description of the study population.</u> We compared our study population of men with newly reported HIV who were diagnosed in a NC-CTR site to men with newly

reported HIV who tested in other facilities, such a private physicians offices, on available demographics using Pearson chi-square statistics.[122] Analysis was completed in SAS v9.13 (SAS Corporation, Cary, NC).

Comparison of gender of sex partners. Client self-report of gender of sex partners during HIV test counseling (NC-CTR) was compared to behaviors documented in post-diagnosis interviews (PCRS). In each dataset, men were categorized as men who only had sex with men (MSM), men who only had sex with women (MSW), men who had sex with men and women (MSMW) and men who reported no sex partners. Datasets were cross-tabulated in a 4x4 table and we calculated Cohen's kappa with a 95% CI as a measure of overall agreement.[122] (Table A.4.)

We created three 2x2 contingency tables (MSM: yes/no; MSW: yes/no; MSMW: yes/no) comparing gender of sex partners in the PCRS and CTR datasets and calculated Cohen's kappas and 95% CIs for each contingency table. As we hypothesized the PCRS data to be a more complete measure of gender of sexual partner, we calculated conditional kappas,[123] sensitivity and specificity and corresponding 95% CIs using the PCRS measure of gender of sex partner as a "gold standard". Conditional kappa calculates agreement conditional on an affirmative response (e.g. MSM=yes) in the PCRS data.[123]

We conducted stratified analysis by race, as we hypothesized that disclosure patterns during test counseling may be different due to different social norms around sexual orientation.[84, 85] Analysis was completed in SAS v9.13 (SAS Corporation, Cary, NC).

Risk assessment period. For the majority of the study period, there is imperfect overlap in the PCRS and NC-CTR risk assessment time periods. The pre-July 2005 NC-CTR dataset documents risks from 1978 (which is "lifetime" for this population of 18-30 year old men). The PCRS database documents sexual partners during the likely infection period, which for men with a chronic infection is operationalized as the last year. Consequently, there may be some misclassification in measures of agreement. For example, a man may have accurately reported to his test counselor that he had sex with both men and women in his lifetime, but may have accurately provided contact information for only female sex partners in the last year to the PCRS counselor. Therefore, some men may be falsely classified as inaccurately disclosing gender of their sex partner to their test counselor when differences are due solely to the assessment time frame. (Table 3.1.)

Using cases whose NC-CTR data was recorded on the revised scan-tron (post-July 2005) which had perfect time frame overlap (n=75) as a validation sample, we conducted a probabilistic analysis to account for misclassification in the full dataset by re-classifying men based on distributions in the validation sample.[124] For the each of the three 2x2 contingency tables of reported gender of sex partners (MSM, MSW and MSMW) in the validation sample, we calculated the sensitivity and specificity (and associated standard deviations) of the NC-CTR as verified by the PCRS. Drawing from a normal distribution of the proportions, we simulated a thousand contingency tables for each of the three tables of reported gender of sex partners. Using the simulated data, we re-calculated measures of agreement (kappa, conditional kappa, sensitivity and specificity) and report "corrected" estimates and 95% CIs. The 95% confidence intervals account for sampling variability in the complete data set as well as uncertainty in the observed proportions from the validation sub-set that are used to compute the corrected tables. Analysis was completed Excel (Microsoft Corporation, Redmond, WA).

Classification of hierarchy of risk. During the CTR risk assessment, clients may report more than one risk factor (e.g. sex with men and IDU). For summary reporting of CTR data, the CDC assigns clients into fifteen risk categories using a combination of the risk factor information documented on the CTR scan-tron and the client's gender. Categories are hierarchically ordered based on the HIV transmission hierarchy used in CDC HIV/AIDS surveillance, with categories ordered from the most probably transmission route to the least likely. The 15 risk categories are then collapsed into 5 risk categories. (Table 3.2.)

To quantify how differences in gender of sex partners in the datasets may alter aggregate CTR statistics, we assigned risk categories based on the CDC's hierarchy of risk[7] using reported gender of sex partners in 1) only the NC-CTR database, 2) only the PCRS database and 3) the union between both databases. Analysis was completed in SAS v9.13 (SAS Corporation, Cary, NC).

Other risk behaviors

The NC-CTR and PCRS databases contain self-report of IDU, but the overall prevalence of IDU is low in NC (<7% among new cases of HIV infection) and we did not have the statistical power to test for differences in self-report. CTR captures additional behaviors such as healthcare exposures, having a STD diagnosis and having sex while using non-injection drugs. These measures of risk were not abstracted from the PCRS charts.

Specific Aim #2: Determine the prevalence of incomplete or inaccurate risk behavior reports during HIV pre-test counseling in a sample of men testing for HIV in a publicly-funded clinic and self-reported barriers to disclosure.

Study design overview

To determine self-reported accuracy and comfort during the risk assessment portion of the HIV prevention counseling session, we interviewed a convenience sample of 203 young men accessing HIV testing services in a publicly-funded clinic in NC. Participants completed anonymous ACASI on a laptop at the completion of their HIV pre-test counseling session. The ACASI also measured participants' self-reported barriers and facilitators to complete risk behavior disclosure during the risk assessment.

Setting

In 2007, NC had 169 publicly-funded test sites, including 155 permanent locations and 14 NTS, which consist of on-site testing at bars, clubs and community based organizations. This analysis was conducted using data collected at one of the permanent testing locations in an urban county in Central NC, the Durham County Heath Department (DCHD).

The DCHD offers free, walk-in HIV testing services Mondays, Wednesdays, Thursdays and Fridays from 8:30 – 11:00 am and 1:00 – 4:00 pm and Tuesdays from 8:30 – 11:00 am and 1:00 – 6:00 pm. All STD patients are offered HIV tests as part of a comprehensive exam, including gonorrhea, syphilis, Chlamydia and trichomoniasis screening and treatment. STD services are provided on a first-come, first-served basis. STD exams are provided during times overlapping the HIV walk-in hours with the exception of Friday afternoons when STD exams are not completed.[125]

All clients requesting or accepting HIV testing are pre-test counseled by a DCHD staff member (an "HIV counselor") trained in the state HIV counseling curriculum based on Project RESPECT.[126] An individualized risk assessment is completed during the counseling session which serves as the basis for individualized prevention counseling. The assessment is documented on a standardized NC-CTR form provided by the NCDHHS. (Appendix B.2.) The form is sent to the NCDHHS with the blood sample and entered into the NC-CTR database. A copy of the assessment form is also placed in the patient's medical record kept at the DCHD. Clients have their blood drawn for the HIV test in the clinic laboratory. The blood is sent and tested at the NCDHHS state lab for HIV (Enzyme ImmunoAssay + Western blot) and includes a screening for acute HIV.[120]

Clients receiving the HIV prevention counseling session as part of a comprehensive STD exam also are seen by a medical provider, a DCHD nurse practitioner or a resident physician on rotation from a local hospital. The provider takes a clinical history which includes a risk assessment and completes the physical exam, including a urethral swab. Clients are offered free Hepatitis B/C vaccines and other health information (e.g. smoking cessation information). The STD risk assessment is also documented and placed in the DCHD medical record. Clients are instructed to call back to receive their STD exam results, but must return in person for a post-test counseling session to receive their HIV results.

During the data collection period, there were two HIV test counselors at the DCHD, both of similar demographics (Caucasian females, mid 30s). One test counselor was employed for the entire data collection period. The other counselor was hired half way through. Both counselors had completed the state HIV counseling curriculum. All of the DCHD STD providers were female, but resident physicians were both male and female.

The DCHD was selected as a study site as it provides a large number of HIV tests for men aged 18-30 (over 1200 per year) allowing for timely participant recruitment. In addition, DCHD clients are comparative to the testing populations in other publicly-funded clinics in NC, increasing the generalizability of the sample. (Table 3.3.) In the most current available statistics available from NCDHHS during study design (2004), DCHD provided a higher proportion of tests to African American and Hispanic men compared to state averages of publicly-funded clinics. (Data provided by the NCDHHS upon special request) This is likely due to differences in the county demographics; in the 2000 census Durham County reported an African American population of 38.4% and a Hispanic population of 10.4% compared to state average of 21.6% and 6.1%, respectively.[127] Most reported risk behaviors and reasons for testing were similar between DCHD clients and other NCDHHS clinics.

Participant recruitment

As the Health Insurance Portability and Accountability Act (HIPAA) prevented study personnel from recruiting participants directly (knowing men were there for a HIV test would be a violation of privacy), participants were recruited by the HIV test counselor. At the completion of the HIV prevention counseling session, the HIV counselor read all eligible men a recruitment script. Eligibility criteria were: 1) self-identified as male, 2) aged 18-30, 3) able to speak English and 4) completion of the pre-test counseling session at the clinic. Both gender and age are routinely collected during the pre-test counseling session so the HIV counselors did not have to ask additional screening questions. As the study personnel who obtained consent was not bilingual, the survey was only offered to men who spoke English. The recruitment script informed men that researchers from UNC-CH were conducting a survey to help improve HIV testing services in NC and for completion of an anonymous, approximately 15-minute long survey, in English, on a computer, they would receive a $10 gift card.

Men expressing interest in participating in the study were given a small card and asked to go to the interview room at the end of their clinic visit. The recruitment card contained a code to identify which counselor completed the risk assessment. Men agreeing to participate entered a private room within the STD clinic where they were provided additional information by the study interviewer. To allow the survey to be anonymous, a waiver of signed consent had been obtained from the IRB. Men verbally consented for participation and were given a fact sheet. All men completed the ACASI on the day of their pre-test counseling session, so they had not been provided their results. With an aggregate positivity of less than 1% during the data collection period, the majority of these men likely were uninfected at time of the interview.

Since DHCD staff was not informed of which men participated and some men were tested for HIV more than once during the data collection period, there was potential for men to be recruited more than once. As part of the consent process men were asked if they had participated previously, with the understanding that they could participate again. The study ID code of any man affirming previous participation was noted and those observations were removed from the data set prior to analysis.

Non-participation was measured through comparison of the number of men who completed the ACASI survey to the number of eligible men pre-test counseled during the days the study interviewer was at the clinic. Counts of eligible men were provided daily by DCHD staff. Per HIPPA regulations, no demographic information was provided to study personnel on men who did not participate. As a substitute, the study population was compared to aggregate data on the population of men, aged 18-30 testing at the DCHD and in all NCDHHS permanent clinics during the data collection period. (Data provided by the NCDHHS upon special request) The NCDHHS was not able to restrict by English-speaking capacity so the inclusion criteria does not overlap completely.

Subjects were recruited between the end of August 2007 and mid April 2008. A study interviewer was in the clinic on average three and half days a week. Two hundred and eighty-three men were recruited by their HIV counselor and 205 agreed to participate in the study, were consented and completed the ACASI resulting in a response rate of 71.7%. Two men participated twice and their second interviews were removed, resulting in a final sample of 203.

Data collection

Men consenting to participate completed an ACASI using Questionnaire Development System (QDS^{TM}) software. (NOVA Research Company, Bethesda, USA) ACASI has been documented to have higher validity than face-to-face interviews, especially with socially stigmatizing behaviors and is acceptable in STD clinic populations.[16-18, 72] Using headphones and a laptop, participants listened to a digitally recorded female voice read questions from the survey aloud as they appeared on the computer screen. Participants entered responses directly into the computer. Using a predetermined skip pattern based on the study questionnaire, the computer selected the next question to be administered.[128] Screen shots of the ACASI can be seen in Appendix B.3.

The survey had been pre-tested, revised and was at less than a 5th grade reading level. (Appendix B.4.) All participants completed non-invasive practice questions with the study interviewer prior to self-administration to ensure client comfort with the laptop and mouse, QDS^{TM} program and question format. During the interviews, the study interviewer remained in the room, but was not able to see the laptop screen.

ACASI questions focused on participant's self-reported overall comfort and accuracy during the risk assessment, with questions on specific risk behaviors. Risk behaviors were selected for overlap with the CTR surveillance form (gender of sexual partners and drug use) and other key HIV risk factors: number of sexual partners,[129] condom use[130] and type of sex (anal, vaginal and oral).[131] Additional information was gathered on client demographics, testing history and risk behaviors, including sexual activity in last six months and drug use. Participant preferences for counselor characteristics were assessed through a series of Likert-scale type questions starting with "It would be easier to talk to my HIV counselor about my risk behaviors if she or he were the same…" Characteristics assessed were race, age, gender and perceived sexual orientation. Clients were able to write-in responses when indicated by the ACASI question and all questions had a "refuse to answer" option. Men completing the ACASI were compensated with a $10 gift card to a local grocery store.

Results from the ACASI were downloaded daily to a password protected, external hard drive. When data collection was complete, data were exported into a SAS dataset. (SAS Corporation, Cary, NC) All datasets were stored on a secure, password protected hard drive. As participant identifiers were not collected, unique study identification numbers were substituted for participant names.

As the study involved an assessment of DCHD staff and client's interactions with DCHD staff, the study interviewer made conscious efforts to distance herself from association with the DCHD. She wore a name badge identifying her affiliation with UNC-CH prominently and repeated multiple times during the consent process her role as a researcher and the anonymity of the survey and the confidentiality of the data collected (e.g. no individual-level data provided to the DCHD staff).

Data Analysis

Using aggregate NC-CTR data provided by the NCDHHS, we compared characteristics of the study sample to larger testing populations of the same age and gender during the data collection period. (Table 5.1.) We documented patient-report of completion of the risk assessment during the prevention counseling session. (Table A.5.) We reported descriptive statistics of participant-reported levels of accuracy and comfort during the risk assessment, both overall and by specific behavior assessments. (Table 5.2.) We investigated differences in characteristics and opinions of men by reported level of comfort and accuracy. First, we used a 3-level measurement ('completely comfortable', 'somewhat comfortable', 'completely uncomfortable' and 'told everything', 'told some things', 'told nothing'). (Table A.6. and Table A.7., respectively) We then collapsed two categories for each variable to compare men who reported being completely comfortable to men not completely comfortable and men who reported being completely accurate to not completely accurate (Table A.8. and Table 5.3., respectively). All comparisons were completed using Pearson chi-square statistics. When expected cell counts were less than 5, exact chi-square statistics were used.[122]

We calculated frequency of reported facilitators and barriers to risk behavior disclosure. (Table 5.3.) Although preferences for counselor characteristics were collected on a 5-point Likert-type scale, (Table A.10.) for ease of data presentation and interpretation, we collapsed the two extreme categories into “Agree” and “Disagree”. (Figure 5.1.) We investigated if preference for counselor characteristics varied by client demographics (race, age, sexual orientation) and report Pearson chi-square statistics. When expected cell counts were less than 5, exact chi-square statistics were used.[122] Analysis was completed in SAS v9.13 (SAS Corporation, Cary, NC).

Sample size

Power calculations during study design were based on a target sample of 200 men. In a sample of 200 men, to estimate the proportion of men who did not fully disclose their risk behavior to their HIV pre-test counselor, we would have, at worst, a margin of error (radius of the 95% confidence interval) of 0.7%.[132] With a sample size of 200, an alpha of 0.05 and an H_0=0.50 (worst case scenario), we had over 80% power to detect a difference in proportions between characteristics of men who disclosed and men who did not (assuming a non-disclosure prevalence of approximately 40%) of 0.20. Under the same assumptions, if there was less non-disclosure (e.g. 10%) we would only have had 80% power to detect differences in proportions of approximately 0.30.[132]

Specific Aim #3: To describe the individual, social and structural characteristics of the HIV test counseling session that influence the complete and accurate disclosure of HIV risk behaviors.

Study design overview

To complement the quantitative measures of barriers and facilitators to full disclosure during the HIV counseling risk assessment and explore men's testing experiences in more depth, we conducted one-on-one interviews with a sub-sample of men completing the ACASI survey. All interviews were transcribed verbatim and using a constant comparison method were inductively coded and analyzed to identify prevalent themes.

Recruitment

Participants were a sub-sample of the men who completed the ACASI. Consequently, the same initial inclusion criteria applied: 1) self-identified as male, 2) aged 18-30, 3) able to speak English and 4) completion of the pre-test counseling session at the clinic. We used purposeful sampling to recruit the sample.[133] Initially all men completing the ACASI were recruited to participate with the final screen on the ACASI containing a recruitment script for participation in the qualitative portion of the study. After ten qualitative interviewers, we reviewed qualitative participant characteristics as reported on their ACASI. As we had more participation from men who expressed complete comfort and accuracy during the risk assessment, we revised the recruitment selection criteria to oversample men expressing less than complete comfort and/or accuracy.

Clients recruited for participation in the qualitative interviews were given the option to complete the interview immediately or return within the next week. Clients who elected to return were instructed to bring back their recruitment card with their unique ACASI identification number. Once a client agreed to participate, they verbally consented so that participation remained anonymous. All participants were given a fact sheet about this portion of the study. Non-participation was calculated through comparison of the number of men who completed a qualitative interview to the number of men recruited, which was tracked by the ACASI program. All participants were identified by the ACASI identification number allowing qualitative and quantitative data to be linked.

Forty-eight of the men completing the ACASI were recruited for the qualitative interview and 26 (54.2%) agreed, consented and participated. The digital recording of one interview was corrupted, resulting in a sample size of 25. There did not appear noteworthy differences in demographics of non-responders compared to men participating in the qualitative interviews. (Table A.11.) Purposeful sampling provided a sample that reported slightly lower levels of complete comfort during the risk assessment compared to the full study population (56.1% vs. 61.6%). All men completing the qualitative interview were provided a $40 gift card to a local grocery store.

Data collection

We used in-depth, one-on-one interviews to investigate clients' experiences during their HIV counseling experience. In-depth interviews are useful for highly sensitive subject matters and to obtain detailed information.[134] Using a semi-structured interview guide, (Appendix B.5.) clients were asked open-ended questions by a single female study interviewer. Use of the guide increased the likelihood of comprehensive data across the sample, but allowed for flexibility to tailor interviews to particular individuals.[116]

With the participant's consent, interviews were digitally audio-recorded. The study interviewer kept memos on non-verbal aspects of the interview, initial thoughts and emerging patterns in the interviews. Interview questions focused on five key constructs: 1) experience with the HIV counseling session; 2) motivation for accessing HIV testing at a publicly-funded clinic; 3) preference for concordance in test counselor characteristics, including perceived sexual orientation; 4) experience and comfort discussing risk behaviors; 5) suggestions for improvement of HIV testing. Although key constructs remained consistent throughout the data collection period, continuous reviews of memos kept by the study interviewer throughout the data collection were used to modify and finesse the interview questionnaire, including development of additional prompts. Interviews lasted between 35 and 65 minutes.

Data analysis

All interviews were transcribed verbatim by the primary study researcher completing the interview. Transcribed interviews were formatted and imported into ATLAS.ti v.5.2. (Scientific Software Development GmbH, Berlin, Germany) Electronic versions of interviews (digital recordings and transcripts) were stored on a password protected secure server. Digital recordings were destroyed at the completion of data analysis.

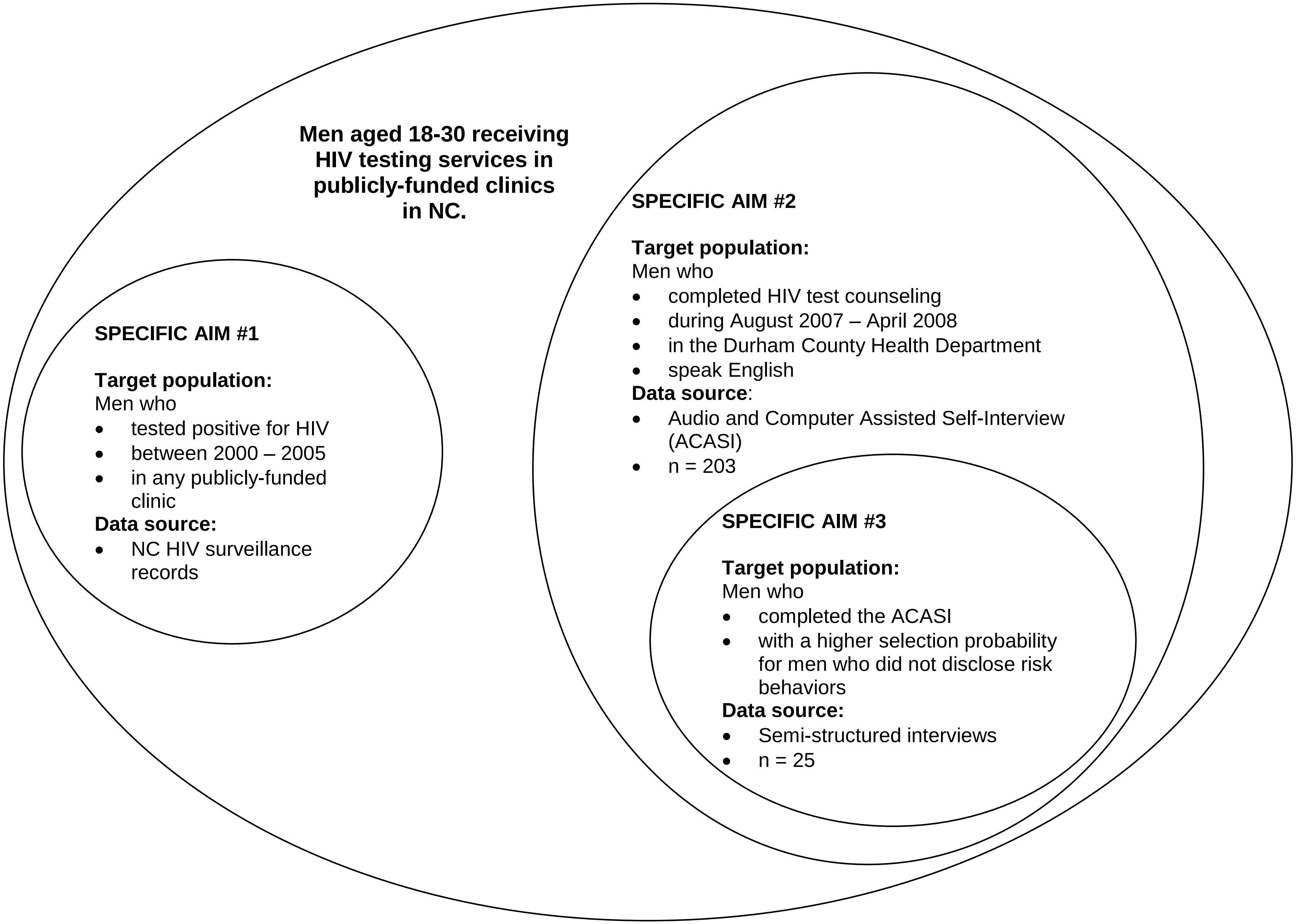
Constant comparative analysis was used by reviewing transcribed interviews one at a time and comparing with others to conceptualize relations between the data.[135] All interviews were read initially for general content, supplementing the data collection memos. Narratives were then topically coded using deductive constructs outlined in the interview guide. To develop themes within constructs, inductive coding was used with the development of the codebook documented in an on-going memo. The final codebook with deductive and inductive codes is shown in Table 3.4. Coding was primarily conducted by one researcher. A second primary investigator coded a random sample of interviews (10%) and discrepancies in coding were discussed and analysis refined where relevant.

Driven by the primary research question of barriers to complete risk behavior disclosure, the coded text of the semi-structured interviews were analyzed for emergent themes. Data reduction was primarily completed by one researcher, but two additional researchers reviewed code reports of relevant passages to identify emerging themes within and between constructs. Quotes were selected to illustrate each theme.[116] Final thematic findings were triangulated with quantitative measures in the ACASI to identify areas of corroboration and contradiction,[116] as well as additional barriers not captured in the ACASI.[117] (Table 3.5.)

Sample size and generalizability

We used a small, purposeful sample for this analysis which we anticipated would give us reasonable coverage based on the primary research question (n=25).[136] Although thematic saturation can be used to indicate when to cease recruitment,[137] a restricted data collection period prohibited use of this measure of credibility in coverage.

Similar to quantitative research, the degree to which qualitative research can be applied to other populations depends of the generalizability of the study population.[116] Using unique identifiers that linked participants to their ACASI data, we described the study population by participant’s self-reported demographics and opinions. We provided demographics of men completing a qualitative interview along the population that completed the ACASI and men who were tested in other NCDHHS clinics during the data collection period for reviewers to determine if the transferability is warranted.[137]



Men aged 18-30 receiving HIV testing services in publicly-funded clinics in NC.

SPECIFIC AIM #1

Target population:
Men who
- tested positive for HIV
- between 2000 – 2005
- in any publicly-funded clinic

Data source:
- NC HIV surveillance records

SPECIFIC AIM #2

Target population:
Men who
- completed HIV test counseling
- during August 2007 – April 2008
- in the Durham County Health Department
- speak English

Data source:
- Audio and Computer Assisted Self-Interview (ACASI)
- n = 203

SPECIFIC AIM #3

Target population:
Men who
- completed the ACASI
- with a higher selection probability for men who did not disclose risk behaviors

Data source:
- Semi-structured interviews
- n = 25

Figure 3.1. Study population stratified by specific aims.

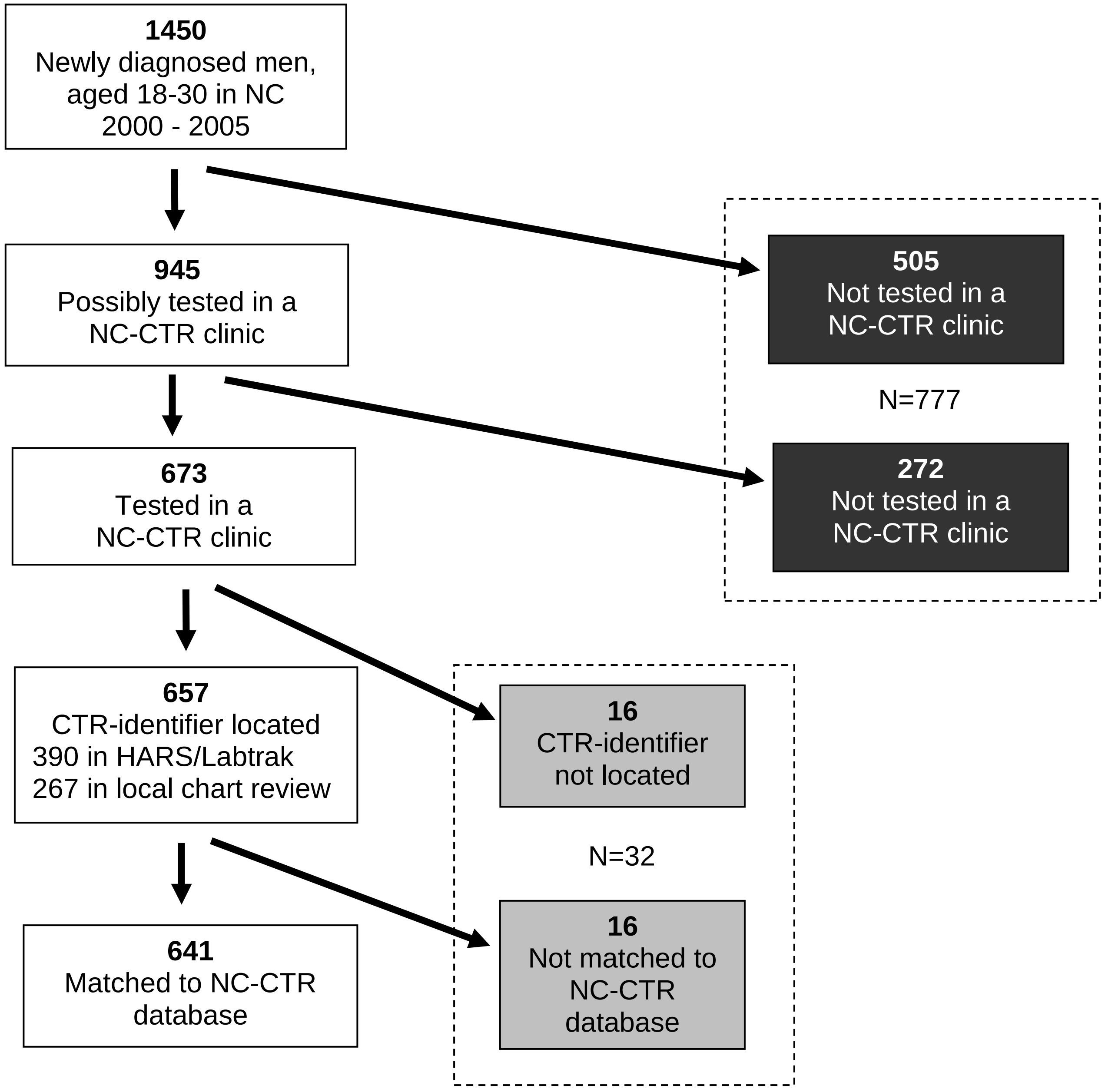


Figure 3.2. Identification of men testing in NC-CTR sites and linkage to PCRS charts.

Table 3.1. Identification of disclosure status of gender of sexual partners and other risk behaviors using the CTR and PCRS risk behaviors.

CTR (lifetime)	PCRS (last year)	Description	Agreement?
Women Women No sex No sex	Men Men and women Men Men and women	Men who denied ever having MSM during HIV test counseling, but were found to have MSM during PCRS interviews	Non-congruent due to difference in self-report
Men Men No sex	Women Women and men Women	Men who denied ever having MSW during HIV test counseling, but were found to have MSW during PCRS interviews	
Women Men Men and women No sex	Women Men Men and women No sex	Men whose reported lifetime sex partners gender matches report during PCRS interviews	Congruent
Men and women Men and women Men Women Men and women	Men Women No sex No sex No sex	Men who reported ever having MSM, MSW or MSMW during HIV test counseling, but only reported one gender or no risk during PCRS interviews	Non-congruent due to difference in self-report or different assessment time periods

CTR: Counseling, Testing and Referral; PCRS: Partner Counseling and Referral Services; MSM: men who have sex with men; MSW: men who have sex with women; MSMW: men who have sex with men and women; No sex: no sex partners

Table 3.2. CDC Counseling, Testing and Referral hierarchy of risk algorithm[7].

Step 1 **Risk Factors Reported by Person Tested**	**Step 2** **Risk Factor Category Assigned through a Hierarchy**	**Step 3** **Risk Categories Used in This Report**
The counselor selects each risk factor reported. More than 1 risk factor may be selected.	*CDC classifies each person into a risk factor category by using a combination of the reported risk factor(s) (see step 1) and the person's sex (i.e., male or female). This classification is based on the presumed hierarchy of HIV transmission.*	*The codes from the hierarchy are reported as 1 of 5 risk categories, as indicated below.*
☐Sex with male ☐Sex with female ☐Injection drug use ☐Sex while under the influence of noninjection drugs ☐Exchange of sex for drugs/money ☐STD diagnosis ☐Sex with injection drug user ☐Sex with man who had sex with a man ☐Sex with person with HIV/AIDS ☐Sex with person with other HIV/AIDS risk factor ☐Child of woman with HIV/AIDS ☐Hemophiliac/recipient of blood or blood products ☐Health care exposure ☐Victim of sexual assault ☐No acknowledged risk	01 = Male-to-male sexual contact and injection drug use 02 = Male-to-male sexual contact 03 = Injection drug use 04 = Sex with partner at risk 05 = Perinatal exposure 06 = STD diagnosis 07 = Exchange of sex for drugs/money 08 = Sex while under the influence of noninjection drugs 09 = Hemophilia/receipt of blood or blood products 10 = Victim of sexual assault 11 = Health care exposure 12 = No acknowledged risk 13 = Heterosexual contact; no other risk 14 = Other 15 = Not specified	Male-to-male sexual contact and injection drug use (01) Male-to-male sexual contact (02) Injection drug use (03) Heterosexual contact • Sex with partner at risk (04) • STD diagnosis (06) • Exchange of sex for drugs/money (07) • Sex while under the influence of noninjection drugs (08) • Victim of sexual assault (10) • Heterosexual contact; no other risk (13) Other • Perinatal exposure (05) • Hemophilia/receipt of blood or blood products (09) • Health care exposure (11) • No acknowledged risk (12) • Other (14) • Not specified (15)

Table 3.3. Testing population characteristics of the Durham County Health Department and averages of all NC publicly-funded clinics, for men aged 18-30 in 2004.

	Durham County Health Department	Average of all NC publicly-funded clinics†
Total # of tests performed	924	128.7
Total # of positive tests	10 (1.1%)	0.9 (0.7%)
Race/ethnicity		
White, non-Hispanic	95 (10.3%)*	46.0 (35.7%)
African American, non-Hispanic	568 (61.l5%)*	62.8 (48.8%)
Hispanic	241 (26.1%)*	16.3 (12.7%)
Asian/Pacific Islander	5 (0.5%)	0.9 (0.7%)
American Indian/Alaskan Native	1 (0.1%)	1.3 (1.0%)
Other	13 (1.4%)	0.9 (0.7%)
Undetermined	1 (0.1%)	0.1 (0.1%)
Missing	0 (0%)	0.4 (0.3%)
Average age	23.8	23.3
Reason for visit		
Symptomatic	1 (0.1%)	0.1 (0.1%)
Client referral	2 (0.2%)	0.6 (0.5%)
Provider referral	12 (1.3%)	1.7 (1.3%)
STD related	6 (0.6%)	1.0 (0.8%)
Drug treatment related	12 (1.3%)	1.7 (1.3%)
Family planning	1 (0.1%)	0.3 (0.2%)
Prenatal	0 (0%)	0.2 (0.1%)
Tuberculosis related	0 (0%)	0.7 (0.5%)
Court ordered	0 (0%)	0.1 (0.1%)
Immigration/travel	1 (0.1%)	0.1 (0.1%)
Occupational exposure	0 (0%)	0.1 (0%)
Retest	2 (0.2%)*	8.6 (6.7%)
Requesting HIV test	763 (82.6%)*	79.7 (61.9%)
Other	10 (1.1%)	1.4 (1.1%)
Missing	117 (12.7%)*	32.7 (25.4%)
Reported risk behaviors‡		
Sex with male	88 (9.5%)	12.4 (9.7%)
Sex with female	861 (93.2%)	114.8 (89.2%)
Injection drug use	7 (0.8%)	2.3 (1.8%)
STD diagnosis	340 (36.8%)*	33.0 (25.7%)
Sex w/ IDU	2 (0.3%)	2.0 (1.6%)
Sex w/ MSM	76 (8.2%)	7.5 (5.8%)
Sex w/ person w/ HIV	15 (1.6%)	1.8 (1.4%)
Sex with person w/ HIV risk	101 (10.9%)*	28.4 (22.0%)
Child of women w/ HIV	0 (0%)	0 (0%)
Blood recipient	2 (0.2%)	0.8 (0.6%)
Healthcare exposure	3 (0.3%)	1.4 (1.1%)
Victim of sexual assault	3 (0.3%)	1.7 (1.3)
No reported risk	11 (1.2%)	18.3 (0.2%)

†Total of 166 publicly-funded clinics.

‡Not mutually exclusive categories

* p-value for difference in proportions between columns (t-test) is less than 0.05

NC: North Carolina; MSM: Men who have sex with men; IDU: Injection drug user

Table 3.4. Codebook for qualitative analysis.

Deductive Codes (based on interview guide)

Code name	Definition	Key construct in guide	Example question	Example probe
C: Testing process	Description of the HIV testing process	Experience with the HIV counseling session	Tell me about the HIV test counseling session you had.	What happened when you got back into the exam room?
C: Reasons for testing at DCHD	Motivation for seeking testing at the DCHD	Motivation for accessing HIV testing in a publicly-funded clinic	How did you decide where to be tested?	How did you know about the DCHD?
C: Interactions with test counselor	Any interaction with the HIV test counselor	Preference for concordance in test counselor characteristics	Tell me about your test counselor.	What would make it easier to talk to your test counselor?
C: Risk assessment	Any information specific to the risk assessment	Experience and comfort discussing risk behaviors	What questions did the counselor ask you?	What did the counselor do with the information?
C: Accuracy	Any mention of level of accuracy during the risk assessment		How accurate were you during the risk assessment?	How accurate where you the first time you tested?
C: Comfort	Any mention of comfort during the visit		How comfortable were you during the risk assessment?	What did the counselor do to make you comfortable?
C: Improving HIV testing	How HIV testing can be improved (in and out of the clinic)	Suggestions for improving HIV testing	How do you think the HIV test counseling session should be done?	What would make it easier to get tested?

Inductive Codes (developed through constant comparative analysis)

Code name	Use when participant…	Notes
Age of counselor	Mentions (age/race/gender/sexual orientation) of the counselor	Cross-code with sorting code (Test counselor) to indicate participant is speaking about counselor and not STD provider
Race of counselor		
Gender of counselor		
Sexual orientation of counselor		
Advice/support	Mentions getting advice or support from test counselor	
Alternative risk assessment methods	Mentions alternative way for risk assessment to be completed	
Being seen	Mentions being seen in or outside of the clinic	
Confidentiality	Mentions confidentiality	Includes confidentiality of risk assessment as well as general confidentiality of clinic
Cost	Mentions financial cost of HIV testing.	
Exam room	Discusses characteristics of the exam room.	
First time testing	Discusses the first time he was tested for HIV	Related to reasons for accuracy and previous testing experience
Getting results	Discusses the process of getting HIV or STD results	
Great quotes	Provides a quote that stands out as especially informative	Sorting code to identify quotes that stand out
HIV lab test type	Discusses lab test (blood draw, orquick, etc.)	
Location of health department	Discusses the physical location of the health department	
Missed opportunities for testing	References a time when HIV testing was not offered	

Multiple risk assessment	Discusses multiple risk assessment during visit	
Other reasons for being at the health department	Lists other reasons why people are at the clinic	
Pharmacy location	Discusses location of the clinic pharmacy.	
Positive	Mentions something positive about the experience	Sorting code to provide feedback to health department
Purpose of risk assessment	Discusses reasons why risk assessment data was collected	
Reasons for not testing	Mentions reasons for not testing for HIV	May be personal or general
Reputation of the health department	Provides opinion the health department	May be individual or general
Risk reduction message	Discusses counseling risk reduction message	Specific to counseling session, not general prevention messages
Routinizing testing	Discusses routine testing.	
Separate HIV counselor	Is talking about the test counselor	Sorting code to identify interaction with test counselor
Personality of counselor	References counselor’s personality	
Other places to test	Lists other places available to access HIV testing	
Previous testing experience	Discusses a previous HIV testing experience	Includes at LHD or other location
Doctor office	Mentions private provider in reference to testing	Related to previous testing experience, other places to test and missed opportunities for testing
School	Mentions in reference to testing, including high school, college and student/campus health	
Work	Mentions work in reference to testing	
Outreach/Neighborhood	Mentions neighborhood (community center, etc.) in reference to testing	

Table 3.5. Data reduction matrix for triangulation with ACASI results.

Themes	Illustrative quotes	Triangulation with ACASI
Intrapersonal barriers to disclosure	**Embarrassment** *…stating how many other partners you have…and the reason for that is that they get nervous and they want to like 'golly this is kind of embarrassing, saying I have sex with more than one female, you know…and it goes back to point like 'I hope she don't know me and be telling my wife' or something like that.* **First time testing** *The first time…you might be a little tempted to lie or leave some stuff out…* **Treated appropriately** *Well, they can't fix you if they don't know everything that's wrong. And withholding information is not going to help if you're trying to get something fixed.* **Comfort** *..if I was a person that was kind of like insecure about how I really felt, I probably would have just lied about the sex partners and if I was infected before…*	**Convergence** ● Men who had been previously tested were more likely to be accurate ● Embarrassment and personal comfort discussing personal issues are barriers. **Expansion**: ● The need to fully disclose in order to be treated appropriately

Interpersonal barriers to disclosure	**Counselor's demographics** *You know, black, white, green or yellow. It doesn't…really, you know, as long as we can talk civilized, I would say. You know, and talk with an educated mind.* *…cause grandma ain't gonna understand what's going on today, you know…I would think that grandma would be like 'oh, you should be with one person only' and have no open mind to what young people have going on in their lives…* **Counselor's personality** *I feel like if you can show that you are more of a people person and that you show that you can actually care and can hold on a conversation to see how they are doing. Then I think that more people will open up.* **Knowing the counselor** *I mean for most people the problem comes when lying to people that you know, you know what I'm saying? It's not really hard to tell the truth to somebody that you don't know, cause you don't know them.*	**Convergence** • Minimal preference for race or gender matched counselors. • Split preference for matched age of the counselor • Importance of counselor's personality **Expansion** • Better context for preferences (e.g. why age is important)
Structural barriers to disclosure	**Confidentiality** *…but when you answer questions like during the STD or HIV thing…that's what…they document what you say and they keep it as a record with your name on it and everything. And even though they say it's confidentiality also, evidentially somebody is gonna see something, you know.* **Purpose of the risk assessment** *I believe that is probably used more for statistics like to show certain behaviors that may lend more easily to becoming infected so yes it's very important for research purposes.*	**Convergence** • Perceived lack of confidentiality is a barrier **Expansion** • Not understanding the purpose of the risk assessment • Frustration at multiple risk assessments • Not receiving individualized risk reduction counseling

Structural barriers to disclosure (continued)	**Multiple risk assessments** *I mean the person you already got comfortable with…now you gotta go and transition to looking at a whole new face …it should be like, one person…drawing the blood and everything.* **Risk reduction message** *I don't know, they've never really taken me to another step, other than just "make sure you use condoms", that's about the only thing. That's about it. I guess if it sounds bad they'll give you the condom message.*	
Ways to improve accuracy of the risk assessment	**ACASI** *I feel more comfortable answering the questions on a computer screen then actually telling someone…you know…someone asking me these questions face to face…yeah…well, the laptop does well.* **Ways questions are asked** *…it was relaxed. It wasn't like I was getting drilled with the questions from her. She would just ask a question and move on. She didn't dwell on it. I had a couple of them be like 'wow did you really do that'…like 'ok, where are you going with that?'. She was pretty good.* **Paper surveys** *Um…the questions I guess, when they get into the details about oral, anal…all that….Cause I think a lot people do lie when they are asked the question…I think it is more truthful if you are actually writing them down.*	**Expansion** • ACASI increases perceived confidentiality and may impact efficiency of the interview • Paper surveys may be more comfortable for some men • The ways the risk assessment questions are asked impacts disclosure

Chapter Four: Glen or Glenda: Reported gender of sex partners in two statewide HIV databases

Abstract

Background**.** HIV risk behavior data are used to monitor trends, inform prevention programs and help identify likely mode of transmission. We investigated differences in client-reported gender of sexual partners in two statewide HIV databases which contain behavioral data.

Methods**.** Counseling and Testing (CTR) records on all men aged 18-30 who tested newly positive for HIV in North Carolina between 2000-2005 were matched to data abstracted from Partner Counseling and Referral Services (PCRS) charts. We compared client-reported gender of sex partners at the time of testing (CTR) to those reported during post-diagnosis partner notification (PCRS).

Results**.** PCRS records appeared to be a more complete measure of gender of sexual partners. Of the 212 men who told their HIV test counselor that they had only had female sexual partner(s) in their lifetime, 62 (29.2%) provided contact information for male sex partner(s) during partner notification.

Conclusions**.** During the test counseling risk assessment, many men did not fully report the gender of their sexual partners after comparison to information provided during partner notification suggesting CTR data may not fully capture client risks.

Introduction

To monitor trends in people testing for Human Immunodeficiency Virus (HIV) and inform prevention programs, the Centers for Disease Control and Prevention (CDC) funds the collection of individual-level data on all persons accessing counseling, testing and referral (CTR) services in publicly-funded test sites, including demographics, self-reported risk behaviors and test results.[7, 8] CTR data are also used to track the effectiveness of the CTR program in reaching targeted, high-risk populations with testing opportunities.[9] In North Carolina (NC), CTR data comprise the largest surveillance database of uniformly collected measures of individual-level risk behaviors.[15]

CTR behavioral data are collected at the time of HIV testing. Risk assessments are usually completed in face-to-face, in-depth interviews with a trained HIV counselor as part of a client-centered, prevention counseling approach.[2] Although the CDC no longer mandates pre-test counseling,[5] prevention counseling is encouraged for high-risk clients, such as patients in sexually transmitted disease (STD) clinics.[6] Behaviors, including gender of sex partners, disclosed to the counselor inform the development of a behavioral change goal to reduce the client's risk of HIV acquisition. Consequently, the effectiveness of the risk reduction model may be contingent on the accuracy of the risk assessment. Additionally, risk behaviors disclosed to providers influence services offered to clients. In a study of patients attending clinics which offer both confidential and anonymous HIV testing, providers admitted to "push[ing] patients who are at high risk of HIV to test confidentially".[12] Among gay and bisexual men attending a STD clinic, men who disclosed a high-risk behavior (anal sex) were more like to be tested for gonorrhea then men who failed to disclose.[13]

CTR data collected during test counseling are recorded on standardized forms and are submitted CDC quarterly for tracking of national statistics.[7] Gender of sexual partners (measured as male, female or both male and female), along with other past behaviors including injection drug use (IDU) and occupational exposures, are used to classified individuals into risk categories. At the population level, the distribution of risk categories is used to guide development of prevention programs in specific populations. At the individual-level, for clients testing positive, risks recorded on the CTR form may be used to determine likely mode of transmission, along with medical record review. Inaccurate report of gender of sex partner can result in ineffective allocation of prevention funds, as well as skew surveillance statistics.

It is likely that non-heterosexual behaviors are under-reported during the CTR risk assessment. In a study of sexual history completeness during STD exams, 22% of men who reported same gender sex during a computer-assisted interviewed failed to disclose that during a face-to-face clinician interview.[17] Almost 40% of men surveyed in the New York City National HIV Behavioral Surveillance Project reported not disclosing same gender sex to their healthcare providers.[80] Social exchange theory proposes that persons choose who and when to disclose sensitive and/or stigmatizing information based on the expected benefits and anticipated costs of disclosure.[81] During HIV test counseling, the perceived cost to disclosing non-heterosexual behaviors may outweigh the perceived benefits. Clients may not completely report the gender of their sexual partners (e.g. report only sex with women, when they had sex with both men and women). To date, no study has quantified the completeness of disclosure of gender of sexual partners in a CTR database.

There is no “gold standard” for self-reported risk behaviors,[24] but other behavioral databases may be more complete in measuring gender of sexual partners when compared to a CTR database. In NC, the Partner Counseling and Referral Services (PCRS) program is part of the NC Department of Health and Human Services (NCDHHS) field services office. PCRS counselors conduct voluntary, post-diagnosis interviews with clients newly infected with HIV to assist with partner notification of past sex and needle-sharing partners, counsel clients on prevention of subsequent risk behaviors and facilitate referrals for treatment and services.[15, 42] Often meeting with clients multiple times, PCRS counselors stress the importance of partner notification to provide persons exposed to HIV the opportunity to be tested, as well as remind clients of communicable disease control laws which mandate partner notification. Clients may perceive increased benefits to complete disclosure of gender of sex partners during PCRS interviews compared to the CTR risk assessment which is completed in a test counseling session prior to diagnosis. Consequently, PCRS interviews may be a more complete measure of gender of sexual partners than the HIV counseling risk assessment.

In this study, we link CTR records to data abstracted from PCRS records on all young men newly diagnosed with HIV in NC. We compare client-reported gender of sexual partners at the time of HIV testing (CTR records) to those reported during post-diagnosis partner notification (PCRS) calculating measures of agreement. This study was approved by University of NC Public Health-Nursing Institutional Review Board.

Methods

Study population

As part of an ongoing investigation of the HIV epidemic in young men,[111-114] this study includes all men aged 18-30 years newly diagnosed with HIV between 2000 and 2005 in NC. Since the CTR dataset is limited to tests performed in NCDHHS funded clinics, the analysis of gender of sex partner disclosure during HIV test counseling excludes men diagnosed by a private provider.

CTR data

Confidential CTR services are provided in all 100 counties in NC.[15] CTR sites are primarily county health departments and outreach venues, but may include county jails if the jail health service is provided by the health department. Data are collected at CTR sites using a scan-tron form with a unique client identifier and document individual-level demographics for each client tested, including a standardized risk assessment. The CTR data collection form was revised in July 2005 to include additional client identifiers (name and address) and a slightly modified risk assessment. Data are stored in an electronic database at the NCDHHS.[15]

During the study period, counselors in NCDHHS funded clinics used the prevention counseling model, which combines an individualized risk assessment with the development of a risk reduction behavioral goal.[2] Risk assessments were conducted by HIV test counselors trained in a state-sponsored curriculum.[126, 138] Counselors are trained to ask clients the gender of their sex partner(s) as “Do you have sex with men, women or both?” (with data captured as yes/no for each gender) with additional open-ended probes. Gender of sex partner is documented on the scan-tron as “since 1978” which for this young population is lifetime. Beginning in July 2005, the time frame used to assess the risk period was changed to “in the last year”.

PCRS data

HIV infection is a name-based reportable disease in NC. All providers are required to report reactive test results to the NCDHHS, including non-CTR facilities such as family physicians, emergency rooms, blood banks and prisons. Although the majority of HIV tests are performed at CTR sites in NC, only about 35% of new HIV reports are made by CTR sites.[15] In 1989, the NCDHHS began offering PCRS services and a review of the program in 2001 indicated 90% of clients testing positive in a CTR site were interviewed by PCRS counselors.[42] PCRS charts document information gathered from providers and clients in electronic and hard copy charts.[15] Using a case abstraction form, data were abstracted from the standardized fields and written narratives of the PCRS charts by trained research assistants and entered into an Access database (Microsoft Corporation, Redmond, WA). Variables abstracted included client demographics and risk behaviors. Further information on the abstraction can be found elsewhere.[111-114]

PCRS counselors document gender of sex partners in the likely infection period (for chronic infections, the default period is 1 year). Gender of sex partners is deduced through partner notification efforts, where clients provide counselors with names and contacting information for past and current sexual partners.

Case identification and chart linkage

The study sample of newly diagnosed male cases aged 18-30 was identified through PCRS chart abstraction. Using a unique state identification number, PCRS charts were linked to NC's HIV/AIDS Reporting System (HARS) which contains client name, diagnosis facility and for clients testing in a publicly-funded test site, their unique CTR-identifier for their reactive test. For clients testing in a publicly-funded test site (identified by diagnosis facility) who's CTR-identifier was not found in HARS, we abstracted the identifier from the CTR test site medical record. The PCRS abstraction dataset was then merged with the CTR electronic database by CTR-identifier. We compared client demographics between databases to ensure correct matches and conducted a sensitivity analysis by repeating all analyses restricted only to observations that matched on all demographics.

Comparison of reported gender of sex partners

Client report of gender of sex partners during HIV test counseling (CTR) was compared to behaviors documented in post-diagnosis interviews (PCRS). Men were categorized as men who only had sex with men (MSM), men who only had sex with women (MSW), men who had sex with men and women (MSMW) and men who reported no sex partners.

Although the CTR database contains measures of IDU, the overall prevalence of IDU is low in NC (<7% among new cases of HIV) and we did not have the statistical power to test for differences in self-report. CTR captures additional behaviors such as healthcare exposures, having a STD diagnosis and having sex while using non-injection drugs. These measures of risk were not abstracted from the PCRS charts.

The statistical analysis is limited by the risk assessment time frame in each dataset. For example, a man may have accurately reported to his test counselor that he had sex with both men and women in his lifetime, but may have only had sex with women in the last year and accurately provided contact information for only female sex partners to the PCRS counselor. Therefore, some men may be falsely classified as inaccurately disclosing gender of their sex partner to their test counselor when differences are due solely to the assessment time frame. Using cases whose CTR data was recorded on the revised scan-tron which had perfect time frame overlap (n=75) as a validation sample, we conducted a probabilistic analysis to account for misclassification in the full dataset by re-classifying men based on distributions in the validation sample.[124]

Agreement of reported gender of sex partners was calculated using Cohen's kappa.[23] As we hypothesized the PCRS database would be more complete, we calculated conditional kappas,[123] sensitivity and specificity using PCRS as the "gold standard". Conditional kappa calculates agreement conditional on an affirmative response (e.g. MSM=yes) in the PCRS data. Measures of agreement for each classification (MSM, MSW and MSMW) are reported for the original dataset and the reclassified dataset as described above. We conducted stratified analysis by race, as we hypothesized that disclosure patterns during test counseling may be different due to different social norms around sexual orientation.[84, 85] To quantify how differences in report of gender of sex partners may alter aggregate CTR statistics, we assigned risk categories based on the CDC's hierarchy of risk[7] using reported gender of sex partners in 1) only the CTR database, 2) only the PCRS database and 3) the union between both databases. Analysis was completed in SAS v9.13 (SAS Corporation, Cary, NC) and Excel (Microsoft Corporation, Redmond, WA).

Results

Of the 1450 men aged 18-30 who were newly diagnosed in NC in the 6 year period with available PCRS records, 673 (46.4%) were diagnosed in a CTR site. Compared to men testing in private facilities, men diagnosed at CTR sites were younger, had been tested for HIV previously and reported more risk behaviors, such as using recreational drugs. (Table 4.1.) Six hundred and forty one of the records of men testing in a publicly-funded facility were successfully linked between the PCRS and CTR databases. Records that didn't match (n=32) were not statistically different by client demographics or region of diagnosis. Non-matched clients were more likely to have been previously incarcerated or have a history of IDU, but the low prevalence of non-matched cases (<5%) should have a minimal effect on the analysis. Comparing the demographics of records matched between the PCRS and CTR record, 82% of records matched on all available demographic variables and 100% matched on at least one. All records were included in the analyses and a sensitivity analysis using only the records matching completely showed no substantive differences in results.

Overall agreement of reported gender of sex partners was low (kappa=0.44, 95% Confidence Interval 0.39, 0.49). Of the 212 men who told their HIV test counselor that they had only had female sexual partner(s) in their lifetime, 62 (29.2%) provided contact information for male sex partner(s) during partner notification. Of 25 men who reported during test counseling that they had never had sex in their lifetime, 22 (88.0%) gave contact information for at least one sex partner during post-diagnosis interviews. A majority of the men (83%, 373/449) who named a male sex partner during PCRS interviews disclosed MSM behavior to their test counselor. Less than half of the men who provided both male and female contacts during PCRS disclosed having sex with both men and women to their HIV test counselor (54/110). Although small cell counts reduced power to detect statistical differences, there appeared some differences in congruence of MSMW disclosure by race with PCRS and CTR data agreeing for white men in over 76% of cases and in black men in less than 45% of cases (p=0.08).

Considering PCRS charts as a more complete measure of gender of sex partners, the risk assessment of gender of sex partners during HIV test counseling had lowest agreement and sensitivity for non-heterosexual sexual behaviors. (Table 4.2.) After assigning a risk category using the CDC hierarchy of risk,[7] 32.8% of men were assigned to “heterosexual” based on CTR data alone compared to only 22.8% using both CTR and PCRS datasets (p<0.01). (Table 4.3.) Inversely, the proportion of cases assigned to “MSM” increased from 61.6% to 72.9% (p<0.01) when both data sources were used.

Conclusions

We compared reported gender of sex partners in two statewide HIV databases which contained individual-level risk behavior data on newly diagnosed young men in NC. PCRS charts, which document post-diagnosis interviews for partner notification, provided higher self-reports of non-heterosexual behaviors compared to CTR data collected at time of testing.

The difference in reported gender of sex partners may be partially attributed to the different rationales for the PCRS and CTR risk assessments. During PCRS counseling, the risk assessment helps counselors identify sexual and needle-sharing contacts and complete information is important to perform partner notification fully. This is different than CTR counselors who are trained to use the risk assessment as a foundation for prevention counseling and may not focus on obtaining complete information on sex partners. As a result, PCRS and CTR counselors use different techniques and may have different skill levels and/or persistence in obtaining sensitive information from clients. PCRS counselors also have the opportunity to meet with clients multiple times in different locations, while CTR counselors usually have limited time for test counseling. The difference in reported behaviors may also be attributed to the difference in diagnoses during the two interview periods. At the time of the CTR risk assessment, clients may perceive themselves as HIV-uninfected, while at the time of the PCRS interview they have been diagnosed. The knowledge of the infection likely affects client's reflection on their past behaviors and may influence disclosure.

Clients may also perceive different cost-benefit ratios to complete disclosure during PCRS counseling compared to CTR counseling. For example, as accurate disclosure during partner notification helps ensure all past partners can be tested and receive treatment if infected, clients may feel a social desirability to provide accurate information on all sex partners Additionally, PCRS counselors review communicable disease control measures with clients which require past partner notification and clients may feel legally obligated to disclose. During test counseling, clients may not understand or perceive the benefits to accuracy during the assessment and social desirability bias may limit disclosure. Alternatively, for some men the perceived costs of complete disclosure might be higher during PCRS counseling (e.g. fear of partner retribution)[139] than during CTR counseling which may be perceived as more confidential.

MSMW behavior had the lowest level of agreement between the databases and had the lowest sensitivity measure in the CTR database. Patterns of disclosure were varied, with some men naming sexual partners of both genders during partner notification and disclosing only MSM to their test counselor. This suggests that for some men disclosing MSM is different than disclosing MSMW. Differences in disclosure patterns of MSMW by race may indicate different social norms around reporting these behaviors.

Similar to previous research on risk behavior disclosure to clinicians during medical exams,[16, 17] non-heterosexual behaviors were under-reported. Additionally, studies on the validity of mode of transmission report men classified as heterosexual often have to be reclassified when additional data, such as research driven in-depth interviews,[19] medical and surveillance record review[23] or both[21, 22], are used. This study is the first to quantify accuracy of self-reported gender of sex partners during the CTR risk assessment; however, the analysis was limited to young men. Patterns of disclosure of gender of sexual partners may vary in women and older men. In this sample, men diagnosed at CTR sites differed from men testing in private facilities by demographics and reported risk behaviors. It is possible that they also differ in disclosure patterns of those behaviors. The analysis was limited to cases that were reported to the NCDHHS and entered into the PCRS system. However, with almost 90% of all cases contacted, PCRS is the most comprehensive statewide behavioral database of HIV infected persons.[42] In the study sample, data missing on specific variables, including cases that were not able to be linked between PCRS and CTR was less than 5% and should have a minimal impact on the results. Additionally, it is theoretically possible that a client changed behaviors in the time between the test counseling session and the PCRS interview (e.g. reported no sex partners, but immediately had sex after the test counseling session); unfortunately we were not able to assess this. Although the risk assessment time frame differed between the datasets (past year vs. lifetime) for the majority of the data resulting in possible misclassification of non-congruence of reported gender of sexual partners, we adjusted agreement statistics using a sample with perfect assessment period overlap. The majority of estimates changed only slightly, suggesting that non-concordance was unlikely influenced by assessment period issues. The validation sample was not random, but rather based on the last 6 months of the study period when the risk assessment period had changed. Consequently, the validity of our corrected estimates rests on the assumption that the validation sample is an accurate representation of the true congruence between the datasets over the entire study period.

After comparing the gender of sex partners disclosed by clients during HIV test counseling and during post-diagnosis PCRS interviews, we document that many clients disclosed the gender of sex partners differently, which suggests that behavioral surveillance data should be interpreted with caution. In this sample, CTR data on gender of sex partners appears less complete than PCRS data. At a population level, the misreporting of risks impacts the evaluation of the CTR programs as the database may not accurately describe the population testing at CTR sites. In this study, 30% of the men classified as heterosexual based on CTR data were reclassified when both CTR and PCRS data were used to assign risk categories. If CTR data are used exclusively to inform mode of transmission, surveillance data in the HARS may be skewed as well. At the individual-level, incomplete risk behavior disclosure may affect the efficacy of risk reduction counseling. For example, a male client may have unprotected sex with men and women, but only disclosed to his HIV counselor that he has sex with women. In this case, there is a missed opportunity to provide risk education and develop a risk reduction plan specific to same gender sexual contact (e.g. the differential risks related to insertive versus receptive sex). Our findings also underscore the ineffectiveness of using a risk assessment to screen for testing. For example, the 25 men who reported no lifetime sex partners may not have been tested and subsequently diagnosed.

Currently, HIV testing guidelines for NCDHHS funded clinics require a risk assessment be documented as part of the testing process.[126] To improve the completeness of the assessment data, further research is needed to understand barriers and facilitators to risk behavior disclosure. NCDHHS guidelines suggest that the assessment can be performed in a variety of ways, including a self-administered questionnaire.[126] One method that may allow for more complete risk disclosure is audio and computer assisted self-interviews (ACASI). In a survey of blood donors using ACASI, 67% said they were more truthful than in face-to-face interviews and thought methods were clear (91.8%) and private (92.3%).[140] Among clients using ACASI in an STD clinic, 56% reported preference for ACASI compared to face-to-face clinician interviews and 82% reported more honest responses.[17] Further investigation of the feasibility and cost-effectiveness of widespread use of ACASI for risk assessments during HIV test counseling in publicly-funded clinics may be warranted.

Table 4.1. Demographics of men aged 18-30 newly reported with HIV between 2000-2005, stratified by testing facility type, North Carolina.

		Testing facility*		
	Total population n=1450	Publicly-funded clinic† n=673	Non-public facility n=777	p
Age				
18-21	324	179 (26.6)	145 (18.7)	<0.01
22-24	232	121 (18.0)	111 (14.3)	
25-27	427	213 (31.7)	260 (33.5)	
28-30	421	160 (23.8)	261 (33.6)	
Race				
White, non-Hispanic	295	91 (13.5)	204 (26.3)	<0.01
African American, non-Hispanic	962	494 (73.4)	468 (60.2)	
Hispanic	157	71 (10.5)	86 (11.1)	
Other, non-Hispanic	33	14 (2.1)	19 (2.4)	
Missing	3	3 (0.4)	0 (0)	
Region				
Black Mountain	34	10 (1.5)	24 (3.1)	0.27
Charlotte	382	179 (26.6)	203 (26.1)	
Winston Salem	330	157 (23.3)	173 (22.3)	
Raleigh	361	158 (23.5)	203 (26.1)	
Fayetteville	145	71 (10.5)	74 (9.5)	
Greenville	119	55 (8.2)	64 (8.2)	
Wilmington	79	43 (6.4)	36 (4.6)	
College student	191	109 (16.2)	82 (10.6)	<0.01
Previously incarcerated	281	140 (20.8)	141 (18.1)	0.20
Documented previous HIV test	355	197 (29.3)	158 (20.3)	<0.01
Gender of sex partners				
Men	745	355 (52.7)	390 (50.2)	<0.01
Women	357	163 (24.2)	194 (25.0)	
Men and women	217	116 (17.2)	101 (13.0)	
No sex partners	100	27 (4.0)	73 (9.4)	
Missing	31	12 (1.8)	19 (2.4)	
Used recreational drugs	866	435 (64.6)	431 (55.5)	<0.01
Injection drug use	26	11 (1.6)	15 (1.9)	0.67
Traded sex for drugs/money	165	79 (11.7)	86 (11.1)	0.69
Number of sex partners				
0-1	386	147 (21.8)	239 (30.8)	<0.01
2-5	662	345 (51.3)	317 (40.8)	
6-10	133	78 (11.6)	55 (7.1)	
11+	90	48 (7.1)	42 (5.4)	
Missing	179	55 (8.2)	124 (16.0)	
Sex partner with known HIV	263	152 (22.6)	111 (14.3)	<0.01
Co-infection with early syphilis‡	89	45 (6.7)	44 (5.7)	0.42

*: n (%), Pearson chi-square test

†: publicly-funded clinics are those that receive state funds for HIV testing services

‡: includes primary, secondary and early latent syphilis

Table 4.2. Congruence of reported gender of sex partners between the Partner Counseling and Referral Services (PCRS) program and the Counseling, Testing and Referral Services Program, men aged 18-30, North Carolina, 2000-05.

		PCRS as gold standard		
	Cohen's Kappa	**Conditional Kappa**	**Sensitivity**	**Specificity**
Original				
Sex with females only	0.64 (0.58, 0.71)	0.82 (0.74, 0.89)	0.88 (0.83, 0.93)	0.84 (0.81, 0.87)
Sex with males only	0.48 (0.41, 0.54)	0.35 (0.28, 0.43)	0.59 (0.53, 0.63)	0.90 (0.87, 0.94)
Sex with males and females	0.23 (0.15, 0.31)	0.31 (0.23, 0.39)	0.49 (0.40, 0.58)	0.78 (0.75, 0.82)
Corrected*				
Sex with females only	0.65 (0.46, 0.84)	0.85 (0.67, 1.0)	0.90 (0.78, 1.0)	0.84 (0.77, 0.92)
Sex with males only	0.53 (0.36, 0.71)	0.39 (0.24, 0.58)	0.61 (0.51, 0.73)	0.95 (0.89, 1.0)
Sex with males and females	0.33 (0.05, 0.56)	0.38 (0.08, 0.55)	0.54 (0.33, 0.67)	0.81 (0.75, 0.87)

*: Data corrected by probabilistic re-classification using a validation sub-sample; 95% confidence intervals account for sampling variability in the complete data set as well as uncertainty in the observed proportions from the validation sub-set that are used to compute the corrected tables

Table 4.3. Risk categories based on risk assessment during test counseling (CTR), partner notification (PCRS) and both, men aged 18-30, North Carolina, 2000-05.

	Based on CTR	Based on PCRS	Based on CTR & PCRS
MSM-IDU	5 (1.0%)	4 (1.0%)	9 (1.4%)
MSM	395 (61.6%)	445 (69.4%)	467 (72.9%)
IDU	3 (0.5%)	4 (1.0%)	4 (1.0%)
Heterosexual	210 (32.8%)	152 (23.7%)	146 (22.8%)
Other	28 (4.4%)	36 (5.6%)	15 (2.3%)

CTR: Counseling, Testing and Referral; PCRS: Partner Counseling and Referral Services; MSM: Men who have sex with men; IDU: Injection drug user; MSM-IDU: Men who have sex with men who are also injection drug users

Chapter Five: Risk behavior disclosure during HIV test counseling

Abstract

Background: Individualized risk assessments during HIV testing are an integral component of prevention counseling and are the source of aggregate behavioral statistics which inform prevention programs and allocation of resources.

Methods: To quantify client-reported accuracy during the risk assessment and identify barriers to risk behavior disclosure, we interviewed young men accessing HIV testing services in a southeastern United States city using mixed methodology.

Results: Based on data collected via an Audio and Computer Assisted Self-Interview (n=203), over 30% of young men reported that they were not accurate during the risk assessment. Participants reported numerous interpersonal barriers to complete disclosure. During qualitative interviews (n=25), participants revealed that many did not understand the purpose of the risk assessment.

Conclusion: Findings from this study suggest that the risk assessment completed during HIV test counseling may be inaccurate. Modifications to the risk assessment process, including better explaining the role of the risk assessment in prevention counseling, may increase the validity of the data.

Introduction

In the 1994 Counseling, Testing and Referral (CTR) guidelines for providers offering Human Immunodeficiency Virus (HIV) testing, the Centers for Disease Control and Prevention (CDC) promoted use of a client-centered, prevention counseling model which has been demonstrated to reduce high-risk behaviors.[1] During the pre-test prevention counseling session, the counselor implements a personalized risk assessment in which the client is encouraged to disclose all past risk behaviors for HIV transmission. Based on the risk assessment, the counselor works with the client to develop a behavior change goal that will reduce the client's risk of acquiring HIV.[141] In an effort to reduce barriers and routinize testing, the CDC removed the pre-test counseling requirement in healthcare settings in the revised 2006 guidelines.[5] Nonetheless, prevention counseling is "still strongly encouraged for persons at high risk for HIV in settings such as sexually transmitted disease (STD) clinics."[6]

The risk assessment serves as the foundation for prevention counseling and is also used to document risk behavior trends in the testing population.[7, 8] Federally-funded CTR sites are required to collect individual risk assessments on all patients testing for HIV, submitting quarterly reports to the CDC.[7] Aggregated data at the state and national level monitor trends in the testing population[8] and are used to evaluate CTR programs to ensure testing programs are reaching populations identified by state health departments as high-risk.[9-11] Although not currently recommended by the CDC,[5] risk assessments combined with risk reduction counseling have been suggested as more cost-effective in both identifying undiagnosed infections and preventing further transmission compared to routine opt-out testing.[54, 66]

Accuracy of the HIV counseling risk assessment

Few studies have attempted to quantify the accuracy of risk disclosure during the HIV test counseling risk assessment. Previous research in North Carolina (NC) documented that young men newly diagnosed with HIV were more likely to accurately disclose the gender of their sexual partners during post-diagnosis partner notification and referral services interviews than during pre-test counseling.[142] In the study, almost thirty percent of men who stated during the pre-test counseling risk assessment that they only had female sexual partners provided contact information for male sex partner(s) during post-diagnosis partner notification. The analysis was limited to men infected with HIV and risk disclosure patterns may differ in the general testing population. Additional research has shown that STD clinic patients provide more or different information when completing an Audio and Computer Assisted Self-Interview (ACASI) than in clinician interviews[16-18] suggesting that a face-to-face, counselor implemented HIV counseling risk assessment may also be incomplete.

Reasons for level of accuracy

Barriers to risk behavior disclosure during the HIV counseling session are likely multi-faceted. Self-presentation bias (wishing to be viewed in a positive light) may result in patients underreporting behaviors they perceive to be stigmatizing.[82] In a comparison of self-reports of sexual history from clinician interviews and ACASIs in an urban, public STD clinic, ACASI reports were more complete for “socially sensitive” behaviors, such as same gender sexual partners and illicit drug use. “Socially rewarded” behaviors, such as condom use and previous testing history, were more frequently reported in clinician interviews.[17]

Characteristics of the HIV test counselor may also influence client’s accuracy. The theory of social influence, used primarily in counseling research, proposes that it is not only the message given during the therapy, but the client’s perception of the counselor that influences effectiveness.[87] Characteristics often studied include race/ethnicity and gender of the counselor in relation to the client, as matched characteristics may allow for a better understanding of behavior motivations[89] through shared cultural beliefs,[90] language[91] and social experiences, as well as reduce fear of discrimination.[17] Additionally, client’s perceptions of trustworthiness and level of knowledge of the counselor may also impact success of the counseling session.[87]

Numerous studies have examined patient’s racial and gender preferences for medical care provision.[94-100] Few have focused on preference during HIV test counseling[25, 101] and none on the impact on risk behavior disclosure. Preliminary evidence suggests race/gender matching between client and counselor plays a minor role in patient comfort. In a study of counselor preferences during HIV post-test counseling, 27% of African American clients said that they would prefer a gender matched counselor and only 9% reported that they would be more comfortable with a race-matched counselor.[25] A qualitative study of African

American's preference for STD providers found that for about half of participants (8 out of 18) race was not a factor, with two of the eight preferring a white provider so they could get "better treatment" and more confidentiality.[102] In a simulation study of client cooperation in partner notification for STD infection, race and gender of the counselor did not increase client intended participation rates.[26] The only study that has directly examined counselor matching during HIV pre-test counseling was a sub-analysis of Project RESPECT,[101] an intervention which evaluated the effectiveness of HIV prevention counseling.[2] The authors concluded that matching client-counselor dyads on race and/or gender was not associated with the effectiveness of prevention counseling, as measured by acquisition of a new STD in the following year.

Client's preference for concordant race and gender may have minimal impact of HIV pre-test counseling; however, other counselor demographics, including age and perceived sexual orientation, have not been as well investigated. Additionally, there is little information on other possible barriers to complete risk behavior disclosure, such as anticipated response from the counselor (e.g. judgment) and perceived confidentiality.

As part of an ongoing investigation of the HIV epidemic in young men,[111-114] this study uses a convenience sample of English-speaking men aged 18-30 years who completed a pre-test counseling session in a publicly-funded STD clinic in NC. Using mixed methodology, we quantify young men's self-reported accuracy and comfort in the HIV counseling risk assessment and determine barriers to complete risk behavior disclosure. To increase validity of the quantitative measures, we used an ACASI, documented as a feasible and acceptable method to obtain sensitive information.[140, 143] Semi-structured qualitative interviews were used to triangulate and expand upon quantitative measures,[117] exploring men's testing experiences in more depth. This study was approved by University of North Carolina at Chapel Hill Public Health-Nursing Institutional Review Board.

Methods

Setting

Data were collected in a STD clinic in a local health department (LHD) located in an urban county in Central NC. Based on aggregate CTR data, the LHD is comparable in terms of reported risk behaviors to the testing population in other publicly-funded clinics in NC. As the county has a higher proportion of minorities than other areas of the state, there are some demographic differences in the testing populations. On average, the LHD tests about twelve hundred men aged 18-30 each year, with a percent HIV positivity of less than 1.0%.

The LHD offers free walk-in HIV testing and all STD patients are offered HIV tests as part of a comprehensive exam. All clients accepting HIV testing are pre-test counseled by a LHD staff member (an "HIV counselor") trained in the state HIV counseling curriculum based on Project RESPECT.[126] A face-to-face risk assessment is completed during the counseling session which serves as the basis for individualized prevention counseling. The assessment is documented, sent to the NC Department of Health and Human Services (NCDHHS) and entered into the CTR database. After consent is obtained, a blood sample is drawn and sent to the state lab for antibody testing, as well as acute HIV screening.[120] HIV test results are provided in person approximately two weeks after the pre-test counseling session. During the data collection period, there were two HIV test counselors at the LHD, both of similar demographics (Caucasian females, mid 30s). STD exams were completed separately by medical providers.

ACASI

Data collection

Clinic clients meeting the eligibility criteria (men, aged 18-30 and English speaking who had an HIV test that day) were read a recruitment script by a LHD staff member at the completion of the HIV pre-test counseling session. To calculate response rates, LHD staff provided aggregate counts of men meeting the eligibility criteria each day of data collection.

Men agreeing to participate met with the study interviewer in a private room within the clinic. To allow the survey to be anonymous, a waiver of signed consent was obtained and men verbally consented to participate. Participants completed an ACASI on a laptop using Questionnaire Development System (QDS^{TM}) software (NOVA Research Company, Bethesda, USA). The survey had been pre-tested, revised and was at less than a 5th grade reading level. All participants completed non-invasive practice questions with the study interviewer prior to self-administration to ensure client comfort with the laptop and mouse, program and question format. ACASI questions focused on participant's comfort and accuracy during the risk assessment with specific questions on risk behaviors for HIV infection. Risk behaviors were selected for overlap with the CTR surveillance form (gender of sexual partners and drug use) and other key HIV risk factors: number of sexual partners,[129] condom use[130] and type of sex (anal, vaginal and oral).[131] Additional information was gathered on client demographics, risk behaviors and preferences for counselor characteristics. All men completed the ACASI on the day of their pre-test counseling session, so their test results were not requested. Men completing the ACASI were compensated with a $10 gift card to a local grocery store.

Analysis

At the end of data collection, a complete dataset was exported from the QDS™ program and analyzed in SAS v9.13 (SAS Corporation, Cary, NC). We report descriptive statistics of participant-reported levels of accuracy and comfort during the risk assessment, facilitators and barriers to risk behavior disclosure and preferences for counselor characteristics. Additionally, we investigate if preference for counselor characteristics varied by client demographics. We report participant demographics and opinions stratified by level of reported accuracy during the risk assessment, using Pearson chi-square tests. When expected cell counts were less than 5, exact chi-square statistics were used.[122]

Qualitative interviews

Data collection

A sub-sample of men completing the ACASI was recruited for one-on-one qualitative interviews. We used purposeful sampling[133] to oversample men expressing less than complete comfort and/or accuracy during the ACASI. Initially all men completing the ACASI were recruited to participate; the final screen on the ACASI contained a recruitment script for participation in the qualitative portion of the study. After ten qualitative interviewers, we reviewed participant characteristics as reported on their ACASI. As we had more participation from men who expressed complete comfort and accuracy during the risk assessment, we revised the recruitment selection criteria to oversample men expressing less than complete comfort and/or accuracy. Clients recruited were given the option to complete the interview immediately or return within the next week.

Using a semi-structured interview guide, clients were asked open-ended questions by a single female study interviewer. Interview questions focused on participant's experience with the HIV counseling session, accuracy and comfort during the risk assessment, and barriers to risk behavior disclosure, including preference for concordance in test counselor demographics. Although these key constructs remained consistent throughout the data collection period, continuous reviews of memos kept by the study interviewer throughout the data collection were used to modify and finesse the interview guide, including development of additional prompts. Interviews were digitally audio-recorded and transcribed verbatim. All men completing the qualitative interview were provided a $40 gift card to a local grocery store.

Analysis

We used constant comparative analysis, reviewing transcribed interviews one at a time and comparing with others to conceptualize relations between the data.[135]

All narratives were first topically coded using deductive constructs outlined in the interview guide. To develop themes within constructs, we used inductive coding with the development of the codebook documented in an on-going memo. Coding was primarily conducted by one researcher using ATLAS.ti v.5.2. (Scientific Software Development GmbH, Berlin, Germany). A second primary investigator coded a random sample of interviews (10%) and discrepancies in coding were discussed and analysis refined where relevant. The research team periodically reviewed code reports of relevant passages to identify emerging themes within and between constructs. Final thematic findings were triangulated with quantitative measures in the ACASI to identify areas of corroboration and contradiction,[116] as well as additional barriers not captured in the ACASI.

Results

Data collection was completed between August 2007 and April 2008. The study interviewer was in the clinic on average three and half days a week. Two hundred and eighty-three men were recruited and 205 agreed to participate in the study, consented and completed the ACASI (a response rate of 71.7%). Two men participated twice and their duplicate interviews were removed, resulting in a final sample of 203. Due to confidentiality, we were not provided demographics of men who refused participation. When study participants were compared in demographics to a similar testing population at the LHD during the same time period, there were some differences. (Table 5.1.) The testing populations at the LHD had a larger percent of men of “other” race (which included Hispanics), likely do to the study language inclusion criteria. There were also some differences in risk behaviors, which could be due in part to the different modes of assessment (counselor interview versus ACASI).

The majority of men participating in the study self-identified as African American (88.2%), had a high school diploma or more (81.3%) and had previously been tested for HIV (72.4%). Only 10 men (3.5%) were there exclusively for an HIV test and the majority of men reported their primary motivation for the visit was that they had symptoms of an STD (39.9%). Primary reasons for choosing to visit the LHD were because they “knew it was free” (36.0%) and that they had “been here before” (19.2%). Drug use was prevalent (68.8%) with the majority attributed to marijuana. No item on the ACASI was missing more than 3%.

Forty-eight of the men completing the ACASI were recruited for the qualitative interview and 26 (54.2%) agreed, consented and participated. The digital recording of one interview was corrupted, resulting in a sample size of 25. There were no demographic differences between men participating in the qualitative interviews and non-responders. Purposeful sampling provided a sample that reported slightly lower levels of complete comfort during the risk assessment compared to the full study population (56.1% vs. 61.6%). Interviews lasted between 35 and 65 minutes.

Comfort and accuracy during the risk assessment

During the ACASI, all of the men reported completing a risk assessment with a HIV test counselor. Almost 80% discussed all five key behaviors measured on the ACASI and 97% discussed three or more of the behaviors. Type of sex (vaginal, anal or oral) was least frequently discussed during the prevention counseling session with the main reason reported that the “counselor didn’t ask” about it. Overall, the majority of men reported that they were “completely comfortable” and told their test counselor “everything” during the risk assessment. (Table 5.2) Still, over 30% reported not fully disclosing risk behaviors during the assessment. Level of disclosure and comfort in discussing specific risk behaviors varied, with men reporting lowest levels of comfort and accuracy for answering questions about the type of sex they had (among those who discussed it with their counselor).

There were few client demographics associated with self-reported level of accuracy during the risk assessment. (Table 5.3.) Men who reported non-heterosexual behaviors were more likely to not fully disclose all of their risks, although comfort with their own sexual orientation was associated with full disclosure. Education level was associated with level of accuracy; 50% of men with less than a high school education reported an incomplete risk assessment compared to 72.5% of men with a high school diploma ($p=0.04$). Men who reported complete comfort in discussing risk behaviors with the test counselor were more likely than men who weren’t completely comfortable to report full disclosure ($p<0.01$).

Barriers to comfort and accuracy

Among men who reported fully disclosing their risk behaviors to the counselor during the ACASI (n=136), the majority (47.1%) attributed their accuracy to the counselor’s characteristics; including perceived trust, level of caring and a lack of judgment. (Table 5.4) Among men who provided incomplete information during the assessment (n=67), the majority reported intrapersonal barriers, such as embarrassment and unwillingness to disclose personal information.

Similar to the quantitative measures of facilitators to full risk behavior disclosure, men discussed the importance of their perception of test counselor including her personality and level of caring during the one-on-one interviews.

> *And the [test counselor], she was cool, but it was a professional cool, you know, where I wouldn't feel condemned or damned for talking to her. I felt like she was genuine and really cared about me as a patient. I don't know if that was a therapeutic thing that she was pulling or...I felt like I could talk to her, like I could be easy with her.*
>
> -24 year old, African American

Men also related that *how* the counselor asked the questions during the risk assessment related to their comfort and the accuracy of their responses. Some men preferred a straightforward list of questions, while others felt that the standardized measures made the counseling feel less individualized.

> *…they ask you straight up, like…how many partners you've had, have you used unprotected sex…when the last time you had unprotected sex…and I think by them asking you straightforward like that …they get a lot of straightforward answers….*
>
> -25 year old, African American

> *It felt like scripted….like she had a set of questions she had to say, her little spiel about HIV and once she was done that was it. It wasn't like…it wasn't like…the whole thing wasn't made to make me feel comfortable.*
>
> -22 year old, African American

Additionally a few of the men stated that their main reason for disclosing their behaviors during the counseling session was that they felt like it was important in order to be treated appropriately.

> *Well, they can't fix you if they don't know everything that's wrong. And withholding information is not going to help if you're trying to get something fixed.*
>
> -24 year old, African American

In the quantitative portion of the study, the prevalence of self-reported complete disclosure was higher among men who said they had previously been tested in a publicly-funded clinic compared to men with no previous test (88.6% vs. 69.4%). Similar trends were seen in the qualitative data, as some men reported that the first time they tested they were more likely to provide incomplete risk data.

> *The first time [testing]…you might be a little tempted to lie or leave some stuff out…*
>
> -23 year old, African American

Matching to test counselor demographics

In the ACASI, most men disagreed that it would be easier to talk about risk behaviors if they had a counselor matched to their demographics. (Figure 5.1) Only 33 men (16.3%) said having a counselor of the same race would increase comfort and only a quarter of men preferred a counselor that was their age. When we examined preferences for matching by client characteristics, men who reported non-heterosexual orientation were more likely to want a counselor of the same sexual orientation than men with heterosexual orientation (61.9% vs. 32.8%, p=0.01).

Similarly in the qualitative interviews, the majority of men interviewed stated that having a counselor matched to their race, gender or sexual orientation wouldn't affect their comfort and accuracy during the counseling session.

> *Race doesn't matter to me. I don't think it really matters to me…everyone is the same, so…it wouldn't make a difference. It wouldn't make it more comfortable or uncomfortable.*
>
> -20 year old, Caucasian

> *I look at the counselor as, I'm not looking at their race or their, uh, gender. I'm looking at them to get an answer, cause I know they have rules and regulations also within the clinic. So I trust them.*
>
> -26 year old, African American

Furthermore, a few men articulated that the counselor's experience and/or personality would trump the effect of matched physical characteristics.

> *You know, black, white, green or yellow. It doesn't…really, you know, as long as we can talk civilized, I would say. You know, and talk with an educated mind.*
>
> -29 year old, African American

Only a few participants stated that sharing the demographics of their counselor would increase comfort due to shared understanding.

> *…even though race shouldn't be a factor in this, but we have to be realistic…it is. And most people feel more comfortable and more open, you know to speak on stuff with people they feel like is a part of them, in a certain way you know.*
>
> -23 year old, African American

A few men mentioned that having a counselor who looked like them would increase the likelihood that they knew each other which would thus be a barrier to disclosure.

> *I'd rather have somebody that's different, different race or something. Somebody that I've never seen before…because it's like they don't know you, you know what I'm saying? That's not good…I don't need that. I'd rather have somebody of another race.*
>
> -24 year old, African American

In the ACASI the majority of men disagreed that having a counselor of the same age would increase comfort; however, preference for age of the counselor was split evenly in the qualitative interviews. About half of the participants did not want to talk to a counselor who was much older than them, preferring to talk to someone closer to their age.

> *Have I ever lied? Yeah, I lied when they had the little 78 year old dude in there asking me questions, but you know…I still pretty much gave the same stuff, but on some of the questions he was asking me like "how many sex partners have you had in the last 60 days" or something like that. And I was like "one" you know because I know he knows that I was married, so I didn't want to tell him that. That's about the only thing that really made me feel uncomfortable was the age.*
>
> -24 year old, African American

> *Um, it's like…I don't really like talking to older adults like that. It's like, you know, I feel they give you this look like, a down look, like 'you shouldn't be doing stuff like that'. I don't know, I guess if it was like somebody my age was in there, or something like I'd kind of feel more comfortable.*
>
> -21 year old, African American

The men who preferred a counselor who was not their age related it to the likelihood of seeing the person outside of the clinic or to their general comfort in discussing risks with someone their age:

> *… I personally would feel more comfortable talking to an older person than closer to my age that I would probably run into some where*
>
> -23 year old, African American

> *I would say, somebody older is easier…um I guess somebody around your age is going to be more judgmental.*
>
> -25 year old, African American

Risk assessment process

Not originally hypothesized as a barrier to risk behavior disclosure during the risk assessment and not measured in the ACASI, a theme that emerged from the qualitative interviews was that many men didn’t understand the risk assessment portion of the pre-test counseling. When probed on why they were asked questions about their risk behaviors, no respondent reported a personal benefit. Although when asked about reasons for accuracy one respondent indirectly referenced the role of the risk assessment in prevention counseling:

> *I feel like…if she doesn’t know everything and if I hide something then that could hurt me down later on in life…like she could be giving me advice on something I may already know or I may already be doing, but I said I wasn’t doing it*
>
> -21 year old, mixed heritage

The majority of participants either didn’t know why the risk assessment questions were asked or suggested that the information was for general statistics or was just of interest to the HIV counselor.

> *…that’s the reason why she probably asked that…to get a…to educate herself probably on like, what guys my age are actually doing.*
>
> -23 year old, African American

> *I believe that is probably used more for statistics like to show certain behaviors that may lend more easily to becoming infected so yes it’s very important for research purposes.*
>
> -26 year old, African American

Men who received a physical STD exam in addition to the HIV test reported that two risk assessments were completed, one by the STD provider and one by the HIV counselor. Men expressed frustration at having to answer the same risk behavior questions twice, not understanding the purpose of multiple assessments.

> *Yeah! Very private questions and after a while you get kind of tired of answering the same questions. You’ll be like ‘can you just pass the sheet to the next person so they know what’s going on’. Cause, like, ok, I’m answering all these questions, but where is the information going. Cause obviously it’s not going to the next person.*
>
> -22 year old, African American

> *I mean the person you already got comfortable with…now you gotta go and transition to looking at a whole new face …it should be like, one person…drawing the blood and everything.*
>
> -24 year old, African American

> *…besides…it's probably to catch somebody, catch you somewhere.*
> *Interviewer: Catch you?*
> *In a lie.*
>
> -20 year old, African American

Alternatives methods for risk assessment

During the qualitative interviews, participants were asked how the risk assessment could be improved to increase accuracy. Some men spoke to how the test counselor should ask the questions, as mentioned above. Interestingly, no participants suggested *not* collecting risk data, but some men suggested alternate ways of documenting their behaviors during the visit. Men proposed that answering questions on a laptop would be preferable for perceived confidentiality, improved accuracy and to decrease the amount of time spent in the clinic.

> *I mean the questions have to be asked, so there's really no way…unless it was on a computer screen…and that may help.…I know myself…I feel more comfortable answering the questions on a computer screen then actually telling someone…you know…someone asking me these questions face to face…yeah…well, the laptop does well.*
>
> -29 year old, African American

Two men suggested that to increase accuracy the risk assessment should be self-administered, but could be completed on a sheet of paper. One participant compared this method of administering the risk assessment to how information is collected during other health exams, such as visits to a doctor's office.

> *Um…the questions I guess, when they get into the details about oral, anal…all that….Cause I think a lot people do lie when they are asked the question…I think it is more truthful if you are actually writing them down.*
>
> -25 year old, African American

> *The uncomfortable part, I guess, of actually somebody you don't know asking you personal questions. That's taken out. You just answer them, like a survey I guess. It's basically like if you go to the doctor and you gotta…if it's your first time at the doctor's office, they ask you about your past, your medical history and are you at risk, are people in your family have this thing. That's how I see it….then I can just check off like 'yes, yes, no, no'.*
>
> -25 year old, African American

Discussion

In this mixed methods study, we investigated the accuracy of the risk assessment during the HIV test counseling session as reported by young men accessing services in a STD clinic in a publicly-funded clinic in NC. About a third of the men in the sample reported that they did not disclose all of their risk behaviors to the HIV counselor during the face-to-face risk assessment. These results echo similar studies of risk disclosure to medical providers.[16, 17, 80] Although a previous analysis documented inaccuracies in the CTR surveillance database for HIV positive young men,[142] this is the first to document likely CTR inaccuracies among the broader testing population of young men, the majority of whom were likely HIV negative based on the LHD's average percent positivity.

Accuracy level in the risk assessment was associated with few client demographics. In this study, men with less education were more likely to not fully disclose risks. Lower education levels may be a marker for distrust in healthcare providers[144] which in turn affected disclosure level. Intrapersonal characteristics, such as comfort with sexual orientation, were associated with higher levels of accuracy suggesting that there are non-clinic related factors impacting disclosure.

This study furthers the discussion on the accuracy of the risk assessment by elucidating barriers to complete risk behavior disclosure. Captured in both the quantitative and qualitative data, participants reported numerous interpersonal facilitators to complete disclosure. Perceptions of the counselor as non-judgmental and as truly “caring” about the client appeared to increase comfort more than concordant counselor demographics. Only a minority of men stated their comfort would increase when speaking to a counselor with concordant race, gender or sexual orientation, although matching of sexual orientation may be important for clients identifying as non-heterosexual. While not triangulated clearly across the ACASI and qualitative interviews, the age of the counselor seemed influential in decisions about disclosing behaviors for some men. These findings support prior research on race and gender matching[25, 26, 101, 102] and newly document that the age and perceived sexual orientation of the counselor may affect comfort for some clients. These additional measures should be included in future assessments of clients’ preferences for counselors; however, based on research to date there is no clear indication for standardized counselor matching by demographics. As suggested in both the qualitative and quantitative measures in this study, a perception that the counselor is well-trained and compassionate may influence accurate disclosure more than concordant demographics.

When asked about the purpose of the risk assessment, some men in the qualitative portion of the study articulated population-level benefits (e.g. accurate statistics), but participants did not understand that the risk assessment was being used as part of individualized prevention counseling. In reviews of risk behavior disclosure on surveys, participants with a self-interest are more likely to provide honest answers.[82] In this study, not understanding the individual benefit may have resulted in a less than accurate risk assessment. Additionally, in the context of an STD exam, men reported having multiple risk assessment by multiple providers. For these men, they were forced to answer similar questions twice without understanding the purpose. To help maximize accurate responses, part of the counseling session should include an explicit explanation by the counselor of the purpose of the risk assessment, including both individual and population-level benefits.

Barriers and facilitators to risk behavior disclosure are complex. Our use of a mixed methods approach, collecting quantitative and qualitative data simultaneously allowed us to examine the primary research questions from different perspectives and overcome limitations of each of the methods.[115, 116] By triangulating between data sources, we were able to cross-validate findings, seeking convergence to strengthen credibility and contradiction to generate future research questions.[115, 117] A mixed methods approach also increased our scope of inquiry as the qualitative data allowed us to expand on barriers to risk behavior disclosure not captured quantitatively.[117]

Still, there are several limitations to this study. The sample was limited to English speaking young men testing in one clinic in NC and the results may not be generalizable to other testing populations, such as woman, older populations and clients accessing testing services outside of publicly-funded clinics. We were not able to quantify differences in men selecting not to participate in the ACASI. Our study population appeared similar to aggregate demographics of young men testing in the LHD during the data collection period; however, they may have differed on non-measured characteristics, such as socioeconomic status. Furthermore, we excluded men not accessing care in the clinic, of which a portion might be the most uncomfortable and/or inclined to be inaccurate during their risk assessment.

The data collected was based on participants' self-report of accuracy and comfort. Although we used an ACASI, thought to increase validity when measuring sensitive information, it is possible that social desirability bias influenced men's answers. Additionally, qualitative interviews were completed by a single, Caucasian female study interviewer which may have influenced participants' responses, specifically regarding preferences for counselor characteristics, although triangulation with the self-administered questionnaire helped increase credibility.[116] Additionally, we did not observe the counseling sessions and are not able to document if the counselors properly implemented the NC state prevention counseling curriculum.

Findings from this study suggest that the risk assessment completed during HIV test counseling may be incomplete which has implications for both the efficacy of individual prevention counseling and the interpretation of aggregate behavioral statistics. If the risk assessment continues to be required by CTR programs, alternative methods may be more appropriate to obtain accurate data. As suggested by study participants, ACASI or paper-based assessments may increase accuracy through decreased embarrassment, as well as having time to answer questions thoughtfully. In a recent feasibility study, Cohall and colleagues showed that an

ACASI risk assessment as part of the HIV counseling session was acceptable to patients in a community setting.[145] ACASI assessments may also streamline the testing process allowing more time for health education and targeted risk reduction by a trained counselor. Additionally, changes in the test counseling risk assessment process, including simply explaining the purpose of the risk assessment may help increase perceived benefit of complete risk behavior disclosure.

Table 5.1. Demographics of men aged 18-30 testing for HIV between August 2007 and April 2008, North Carolina.

			Study participants	
	Men testing in NCDHHS clinic n=17,142	Men testing at LHD n=892	Men completing ACASI n=203	Men completing qualitative interview n=25
Age				
18-21	6034 (35.2%)	289 (32.4%)	82 (40.4%)	7 (28.0%)
22-25	6182 (36.1%)	308 (34.5%)	66 (32.5%)	11 (44.0%)
26-30	4926 (28.7%)	295 (33.1%)	55 (27.1%)	7 (28.0%)
Race				
White	4602 (26.8%)	61 (6.8%)	11 (5.4%)	2 (8.0%)
African American	9186 (53.6%)	653 (73.2%)	179 (88.2%)	21 (84.0%)
Other	2316 (13.5%)	173 (19.4%)	11 (5.4%)	2 (8.0%)
Missing	1038 (6.1%)	5 (0.6%)	2 (1.0%)	0 (0%)
Previous HIV test				
Yes	10120 (59.0%)	581 (65.1%)	147 (72.4%)	18 (72.0%)
No	6702 (39.1%)	308 (34.5%)	56 (27.3%)	7 (28.0%)
Missing	320 (1.9%)	3 (0.3%)	0 (0%)	0 (0%)
Injection drug use				
Yes	297 (1.7%)	4 (0.4%)	8 (3.9%)	1 (4.0%)
No	16,845 (98.3%)	888 (99.6%)	195 (96.1%)	24 (96.0%)
Sexual partners*				
Male	1493 (8.7%)	80 (9.0%)	19 (9.4%)	2 (8.0%)
Female	14789 (86.3%)	819 (91.8%)	182 (89.7%)	22 (88.0%)
Male and female	546 (3.2%)	18 (2.0%)	8 (4.0%)	0 (0%)
No sex	491 (2.9%)	11 (1.2%)	5 (2.5%)	1 (4.0%)
Missing	0 (0%)	0 (0%)	1 (0.5%)	0 (0%)

NCDHHS: North Carolina Department of Health and Human Services; LHD: Local health department; ACASI: Audio and Computer Assisted Self-Interview;

*:Not mutually exclusive; Last year for all NCDHHS and all DCHD clients; last 6 months for study participants

Table 5.2. Reported comfort and accuracy in discussing risk behaviors during HIV test counseling, among men aged 18-30 accessing services at a publicly-funded clinic, North Carolina (n=203).

	Discussed behavior	Comfort in discussing risk behaviors			Level of disclosure of risk behaviors		
		Not at all	Somewhat	Completely	Nothing	Some things	Everything
Overall	--	7 (3.4%)	71 (35.0 %)	125 (61.6%)	7 (3.4%)	60 (29.6%)	136 (67.0%)
Specific behaviors							
Drug use	185 (91.1%)	2 (1.1%)	37 (20.0%)	145 (78.4%)	8 (4.3%)	40 (21.6%)	138 (74.6%)
Type of sex (vaginal, anal or oral)	179 (88.2%)	2 (1.1%)	56 (31.3%)	121 (67.6%)	2 (1.1%)	48 (26.8%)	127 (70.9%)
Condom use	196 (96.6%)	0 (0%)	41 (20.9%)	155 (79.1%)	2 (1.0%)	48 (24.5%)	146 (74.4%)
Gender of sex partners	199 (98.0%)	3 (1.5%)	34 (17.1%)	162 (81.4%)	6 (3.0%)	29 (14.6%)	162 (81.4%)
Number of sex partners	191 (94.1%)	3 (1.6%)	40 (20.9%)	147 (77.0%)	1 (0.5%)	45 (23.6%)	143 (74.9%)

Table 5.3. Reported reasons for level of accuracy in risk assessment during HIV test counseling, men aged 18-30 accessing services at a publicly-funded clinic, North Carolina (n=203).

*Facilitators for full disclosure**	
I knew the information would be kept confidential	42 (30.9%)
I trusted him/her	25 (18.4%)
He/she seems to really care	21 (15.4%)
I didn't feel like he/she was judging me	18 (13.2%)
He/she asked	16 (11.8%)
Other	14 (10.3%)
*Barriers to full disclosure***	
I was embarrassed	27 (40.3%)
It's none of his/her business	12 (17.9%)
Other	10 (14.9%)
He/she wouldn't understand	6 (9.0%)
I thought he/she would judge me	5 (7.5%)
I didn't trust him/her	3 (4.5%)
I didn't think it would be kept confidential	2 (3.0%)
Missing	2 (3.0%)

*: among men reporting complete accuracy (n=136)
**: among men reported less than complete accuracy (n=67)

Table 5.4. Characteristics of men, 18-30 by reported level of disclosure of risk behaviors during HIV test counseling in a publicly-funded clinic, North Carolina (n=203).

	Not completely accurate N=67	Completely accurate N=136	p-value*
Type of visit			
HIV test only	5 (3.7%)	65 (97.0%)	1.0
STD exam + HIV test	2 (3.0%)	131 (96.3%)	
Age			
18-21	24 (35.8%)	58 (42.7%)	0.65
22-25	23 (34.3%)	43 (31.6%)	
26-30	20 (29.9%)	35 (25.7%)	
Race			
African American	59 (89.4%)	120 (88.9%)	1.0
Non-African American	7 (10.6%)	15 (11.1%)	
Education			
Did not complete high school	19 (28.4%)	19 (14.0%)	0.04
High school diploma/GED	22 (32.8%)	58 (42.7%)	
More than high school	26 (38.8%)	59 (43.4%)	
Previous test			
Yes, at local health department	27 (40.3%)	70 (51.5%)	0.08
Yes, not at local health department	23 (34.3%)	27 (19.9%)	
No	17 (25.4%)	39 (28.7%)	
Any drug use			
Yes	48 (71.6%)	91 (66.9%)	0.52
No	19 (28.4%)	45 (33.1%)	
Injection drug use			
Yes	6 (9.0%)	2 (1.5%)	0.02
No	61 (91.0%)	134 (98.5%)	
Non-heterosexual behavior**			
Yes	10 (15.6%)	9 (6.7%)	0.07
No	54 (84.4%)	125 (93.3%)	
Sexual orientation†			
Heterosexual	56 (84.9%)	125 (91.1%)	0.14
Not heterosexual	10 (15.1%)	11 (8.1%)	
Comfort with sexual orientation			
Completely	51 (76.1%)	125 (92.6%)	<0.01
Not completely	16 (23.9%)	10 (7.4%)	
Comfort during risk assessment			
Completely	30 (44.8%)	95 (69.9%)	<0.01
Not completely	37 (55.2%)	41 (30.2%)	

*: Pearson exact chi-square

**: based on reported gender of sex partners in last 6 months

†: client identified sexual orientation

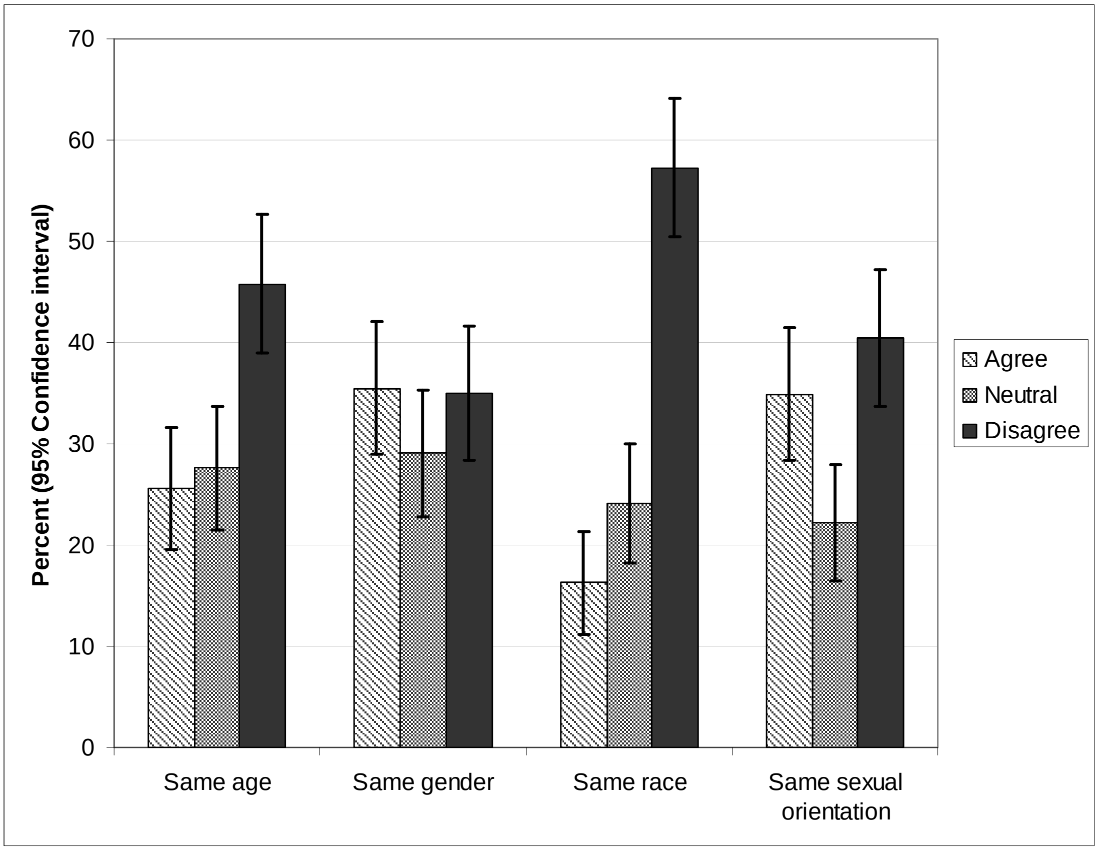


Figure 5.1. Reported preferences for characteristics of HIV test counselor to make it easier to discuss risk behaviors, men aged 18-30, North Carolina (n=203).

Chapter Six: Discussion

Summary of findings

As part of an ongoing investigation of the HIV epidemic in young men,[111-114] we investigated the accuracy of risk assessments conducted during HIV test counseling and identified under-reporting of risk behaviors and misclassification of gender of sex partners. Using mixed methodology, we identified barriers to full risk behavior disclosure during the HIV test counseling risk assessment.

We first compared self-reported gender of sex partners in two statewide HIV databases which contained linkable, individual-level risk behavior data on newly diagnosed men in NC. Partner notification and referral services (PCRS) charts, which document post-diagnosis interviews for partner notification, provided higher self-reports of non-heterosexual behaviors compared to Counseling, Testing and Referral (CTR) data collected at time of testing. Of the 212 men who told their HIV test counselor that they had only had female sexual partner(s) in their lifetime, 62 (29.2%) provided contact information for male sex partner(s) during partner notification. Less than half of the men who provided both male and female contacts during PCRS disclosed having sex with both men and women to their HIV test counselor (54/110). A few men who provided information in the opposite direction (e.g. told their HIV counselor they were a MSM, but only provided female sex partner names to the PCRS counselor). This may indicate for some men the perceived costs of complete disclosure of non-heterosexual behaviors might be higher during PCRS counseling. Additionally, men who self-reported only female sex partners during both assessments may actually have male partners and chose not to disclose accurately during either assessment. Although the majority research on PCRS programs indicates that clients are willing to provide contact information for partner noftification,[139] MSM and IDU may differentially participate. In a study of STD clinic patients in New York City over 90% of self-identified heterosexuals said they would provide contact information for sex partners, while only 80% of MSM said they would provide contact information.[146] During a formative research study of 25 qualitative interviews with drug users, over 50% said that they would not participate in counselor initiated partner notification.[147]

When reported gender of sex partner was used to assign a risk category based the CDC hierarchy of risk,[7] the distribution of categories shifted. Using CTR data alone, 32.8% of men were assigned to “heterosexual” compared to only 23.7% when data from the PCRS datasets was used ($p<0.01$). Inversely, the proportion of cases assigned to “MSM” increased from 61.6% to 69.4% ($p<0.01$) when risk behaviors reported in the PCRS database were used.

To investigate accuracy and comfort during the risk assessment in the general testing population of young men at a CTR site, we interviewed 203 young men in a local health department who had completed an HIV prevention counseling session. During an anonymous ACASI, over 30% of participants self-reported not fully disclosing their risk behaviors during the HIV counseling risk assessment. There were few client demographics associated with level of accuracy during the risk assessment, signifying men who are likely to be inaccurate can not be identified prior to the assessment. Intrapersonal characteristics, such as comfort with sexual orientation, were associated with higher levels of accuracy suggesting that there are non-clinic related factors impacting disclosure.

Captured in both the ACASI and semi-structured interviews, participants reported numerous interpersonal facilitators to complete disclosure. Perceptions of the counselor as non-judgmental and as truly “caring” about the client appeared to increase comfort more than having a counselor with concordant race, gender or sexual orientation, although matching of sexual orientation may be important for clients identifying as non-heterosexual. While not triangulated clearly across the ACASI and qualitative interviews, the age of the counselor seemed influential in decisions about disclosing risk behaviors for some men.

We identified that many men did not understand the role of the risk assessment in the prevention counseling session. When probed on why they were asked questions about their risk behaviors, no respondent reported a personal benefit. Although when asked about reasons for accuracy one respondent indirectly referenced the role of the risk assessment in prevention counseling, the majority of participants either didn’t know why the risk assessment questions were asked or suggested that the information was for general statistics or was just of interest to the HIV counselor.

Strengths and limitations

The HIV epidemic in NC is disproportionately distributed across its residents. Of continual concern is racial disparities in new infections; the rate of HIV among

African Americans is over seven times the rate of non-Hispanic Whites.[148] Of growing concern is the shifting of the epidemic back to men. Between 2000 and 2006, the proportion of male cases increased from 66% to 73% and the highest rate of infection in 2006 was among black men (108.5 per 100,000). Sparked by an outbreak of acute HIV in young men in 2002, the NCDHHS in collaboration with the UNC-CH School of Medicine began a systematic investigation into the changing epidemic in young men.[112] This research is embedded within this investigation and used pre-existing relationships with the NCDHHS to gain access to highly confidential, individual-level HIV data and made use of three years of systematic PCRS chart abstractions.

Due to the constraints of the data sources, this research is limited to young men accessing testing services in CTR sites. In the sample of HIV positive men, clients diagnosed at CTR sites differed from men testing in private facilities by demographics and reported risk behaviors. It is possible that they also differ in disclosure patterns of those behaviors. Patterns of risk behavior disclosure and facilitators and barriers to accurate risk assessments may also be different in women and older men.

This study is the first to identify inaccuracies in self-reported gender of sex partners in a statewide CTR database. We maximized study efficiency by linking two routinely collected statewide datasets of individual-level data on HIV positive men. The trade-off was that our analysis was limited to cases that were reported to the NCDHHS and entered into the PCRS system. The probability of not being in the PCRS system is not random and *may* be related to the patient's risk behaviors. For example, if someone is unwilling to disclose a highly stigmatizing risk behavior, they may provide inaccurate risk behavior information to their test counselor and then refuse to meet with the PCRS counselor and/or give false locating information. Unfortunately, because these data are not missing at random, techniques for dealing with missing data, such as multiple imputation, were not appropriate for our analysis.[121] Based on published reports of the NC PCRS system,[42] including interview rates, missing data are likely to be less than 10% and should have had a minimal impact on statistical analysis.

Additionally, by using routinely collected data we were limited by risk assessment periods that did not overlap perfectly between the two datasets we compared. This resulted in possible misclassification of non-congruence of reported gender of sexual partners. Although we adjusted for misclassification in agreement statistics using a sample with perfect assessment period overlap, the validation sub-sample (n=75) was based on the last 6 months of the study period when the risk assessment period had changed. Consequently, it is not strictly random and the validity of our corrected estimates rests on the assumption that the sample is an accurate representation of the true congruence over the entire study period.

An additional limitation to the first analysis was that it was restricted to HIV positive men and findings may not be generalizable to the general testing population of young men. Our prospectively collected data at the DCHD allowed us to overcome this limitation by sampling men completing a pre-test counseling session at a CTR site. By interviewing men prior to their receipt of test results, our sample represents the testing population, although we restricted our sample in other ways due to logistic constraints. The sample was limited to English speaking young men testing in one clinic in NC and the results may not be generalizable to the growing Hispanic population or testing populations in other areas on NC. Although our study population appeared similar to aggregate demographics of young men testing in NCDHHS clinics during the data collection period, they may have differed on non-measured characteristics, such as socioeconomic status. Furthermore, we excluded men not accessing testing services in the clinic, of which a portion might be the most uncomfortable and/or inclined to be inaccurate during their risk assessment.

Our use of mixed methodology, collecting quantitative and qualitative data simultaneously, enabled us to examine the primary research questions from different perspectives and overcome limitations of each of the methods.[115, 116] A mixed methods approach allowed us to expand on barriers to risk behavior disclosure not captured quantitatively. For example, without the qualitative interviews we would not have documented that many men did not understand the purpose of the risk assessment.

The data collected at the DCHD was based on participants' self-report of accuracy and comfort. Although we used an ACASI, thought to increase validity when measuring sensitive information, it is possible that social desirability bias influenced men's answers. Additionally, qualitative interviews were completed by a single, Caucasian female study interviewer which may have influenced participants' responses, specifically regarding preferences for counselor characteristics. For example, the majority of men interviewed was African-American and was racially discordant from the study interviewer. These men may have been more apt to say that race concordance doesn’t matter. We were not able to assess this bias, but triangulation with the self-administered questionnaire on race and gender preferences helped increase credibility.[116] Additionally, we were not able to measure actual effectiveness of the prevention counseling or document proper implementation of the NC state curriculum during the counseling session.

Public health significance

After comparing the gender of sex partners disclosed by clients during HIV test counseling and during post-diagnosis PCRS interviews, we document that many clients disclosed the gender of sex partners differently, which suggests that aggregate behavioral data should be interpreted with caution. In this sample, CTR data on gender of sex partners appears less complete than PCRS data, with non-heterosexual behaviors under-reported. At a population level, the misreporting of risks impacts the evaluation of the CTR programs as the database may not accurately describe the population testing at CTR sites. When CTR data are used exclusively to inform mode of transmission, surveillance data may be skewed. In this study, 30% of the men classified as heterosexual based on CTR data were reclassified when both CTR and PCRS data were used to assign risk categories. At the individual-level, incomplete risk behavior disclosure may affect the efficacy of risk reduction counseling. Results also underscore the ineffectiveness of using a risk assessment as a criterion to determine who is offered HIV testing. For example, although eventually diagnosed as HIV positive, the 25 men who reported no lifetime sex partners (none reported IDU either) to their HIV test counselor may not have been offered testing based on their self-reported risk behaviors.

Findings from the investigation on barriers to risk behavior disclosure support prior research on race and gender matching, [25, 26, 101, 102] with few participants in our study stating that a counselor with matching demographics would increase their comfort in discussing risk behaviors. This study is the first to document that the age of the counselor may affect comfort for some clients. Additionally, for non-heterosexual men, perceived sexual orientation of the counselor may facilitate risk behavior disclosure. Measures of age and perceived sexual orientation should be included in future assessments of clients' preferences for counselors; however, based on research to date there is no clear indication for standardized counselor matching by demographics. As suggested in both the qualitative and quantitative measures in this study, a perception that the counselor is well-trained and compassionate may influence accurate disclosure more than concordant demographics. Specifically regarding disclosure of non-heterosexual behaviors, the perceptions of the counselor's level of acceptance may play a role. In a study of lesbians' disclosure of sexual orientation during medical care, perceived "gay positivity" of provider predicted disclosure.[86] Similar perceptions may increase accuracy of responses during the HIV risk assessment.

To help maximize accurate responses, part of the counseling session should include an explanation by the counselor of the purpose of the risk assessment, including both individual and population-level benefits. Research on accuracy of self-report of sexual behaviors suggest that patients with a self-interest in the survey are more likely to provide thoughtful and accurate answers.[82] Without a clear perceived individual benefit to complete disclosure, the costs of disclosure may outweigh the perceived rewards resulting in a less than accurate risk assessment. Additionally, in the context of an STD exam, men reported having multiple risk assessment by multiple providers. For these men, they were forced to answer similar questions twice without understanding the purpose. As more healthcare providers integrate HIV testing into existing services in an effort to routinize testing, this barrier is likely to become more prevalent if the CTR risk assessment process is not modified appropriately.

Future research

Currently, all federally-funded CTR sites are required to submit risk behavior on clients accessing their services to the CDC.[7] The NCDHHS guidelines for CTR in NC suggest that the risk assessment can be performed in a variety of ways, including a self-administered questionnaire.[126] One method that may allow for more complete risk disclosure is ACASI. ACASI has been shown as practical and acceptable to diverse populations including clinic populations,[16-18, 72] low-income populations,[149] minority populations,[150] persons with mental illness,[151, 152] and in the general population during household surveys.[153] In a survey of blood donors using ACASI, 67% said they were more truthful than in face-to-face interviews and thought methods were clear (91.8%) and private (92.3%).[140] Among clients using ACASI in an STD clinic, 56% reported preference for ACASI compared to face-to-face clinician interviews and 82% reported more honest responses.[17] In a study measuring the feasibility of ACASI among gay men and IDUs in a longitudinal trial, both populations (60.2% and 58.7%, respectively) reported that ACASI was likely to yield more accurate responses.[154] A few studies have found ACASI to be a less sensitive measure of behaviors compared to other techniques; however, the participants were specific populations, such as adolescents in the juvenile justice system[155] or men with low computer literacy in an international setting.[156]

In a recent feasibility study, Cohall and colleagues showed that an ACASI risk assessment as part of the HIV counseling session was acceptable to patients in a community setting.[145] The majority of participants in the study (78%, n=39) said that they would prefer to use ACASI in future risk assessments. Participants cited increased perceived privacy as a facilitator to “honest” answers. ACASI assessments may also streamline the testing process allowing more time for health education and targeted risk reduction by a trained counselor. Further investigation of the feasibility and cost-effectiveness of widespread use of ACASI for risk assessments during HIV test counseling in publicly-funded clinics may be warranted.

Appendix A. Additional tables

Table A.1. **Demographics of men aged 18-30 newly reported with HIV between 2000-2005, stratified who tested in a publicly-funded clinic by chart match status.**

	Total population N=673	PCRS chart matched to CTR database*		
		Yes N=641	No N=32	p‡
Age				
18-21	179	173 (27.0)	6 (18.8)	0.66
22-24	121	115 (17.9)	6 (18.8)	
25-27	213	203 (31.7)	10 (31.3)	
28-30	160	150 (23.4)	10 (31.3)	
Race				
White, non-Hispanic	91	87 (13.6)	4 (12.5)	0.97
Black, non-Hispanic	494	470 (73.3)	24 75.0	
Hispanic	71	68 (10.6)	3 (9.4)	
Other, non-Hispanic	14	13 (2.0)	1 (0.2)	
Missing	3	3 (0.5)	0 (0)	
Region				
Black Mountain	10	10 (1.5)	0 (0)	0.22
Charlotte	179	171 (26.7)	8 (28.1)	
Winston Salem	157	150 (23.4)	7 (21.9)	
Raleigh	158	155 (24.2)	3 (9.4)	
Fayetteville	71	65 (10.1)	6 (18.8)	
Greenville	55	50 (7.8)	5 (15.6)	
Wilmington	43	40 (6.2)	3 (9.4)	
Current college student	109	105 (16.4)	4 (12.5)	0.56
Previously incarcerated	140	127 (19.8)	13 (40.6)	<0.01
Documented previous HIV test	197	184 (28.7)	13 (40.6)	0.16
Gender of sex partners				
Men	355	339 (52.9)	16 (50.0)	0.90
Women	163	156 (24.3)	7 (21.9)	
Men and women	116	110 (17.2)	6 (18.8)	
No sex	27	25 (3.9)	2 (6.3)	
Missing	12	11 (1.7)	1 (0.2)	
Injection drug user	11	8 (1.2)	3 (9.4)	<0.01
Traded sex for drugs/money	79	72 (11.2)	7 (21.9)	0.07
Number of sex partners				
0-1	147	142 (22.2)	5 (15.6)	0.76
2-5	345	329 (51.3)	16 (50.0)	
6-10	78	73 (11.4)	5 (15.6)	
11+	48	46 (7.2)	2 (6.3)	
Missing	55	51 (8.0)	4 (12.5)	
Sex partner with known HIV	152	148 (23.1)	4 (12.5)	0.16
Co-infection with early syphilis	45	42 (6.6)	3 (9.4)	0.53

*: n (%)

†: publicly-funded clinics are those that receive state funds for HIV testing services

‡: Pearson chi-square test; exact where indicated

CTR: Counseling, Testing and Referral; PCRS: Partner Counseling and Referral Services

Table A.2. Congruence of reported risk behaviors between the Partner Counseling and Referral Services (PCRS) program and the Counseling, Testing and Referral (CTR) Program *restricted to men who PCRS/CTR records matched on all demographics.*

		PCRS as gold standard		
	Cohen's Kappa	**Conditional Kappa**	**Sensitivity**	**Specificity**
Original				
Sex with females only	0.65 (0.58, 0.73)	0.84 (0.76, 0.93)	0.89 (0.84, 0.93)	0.85 (0.81, 0.88)
Sex with males only	0.49 (0.42, 0.56)	0.37 (0.28, 0.45)	0.60 (0.54, 0.66)	0.90 (0.86, 0.94)
Sex with males and females	0.23 (0.14, 0.33)	0.31 (0.23, 0.40)	0.49 (0.39, 0.60)	0.78 (0.74, 0.82)
Corrected*				
Sex with females only	0.72 (0.47, 0.95)	0.90 (0.73, 1.0)	0.93 (0.82, 1.0)	0.87 (0.78, 0.98)
Sex with males only	0.70 (0.52, 0.88)	0.59 (0.38, 0.88)	0.74 (0.61, 0.92)	0.95 (0.89, 1.0)
Sex with males and females	0.36 (0.06, 0.59)	0.42 (0.07, 0.59)	0.51 (0.30, 0.67)	0.80 (0.70, 0.89)

*: Data corrected by probabilistic re-classification using a validation sub-sample; 95% confidence intervals account for sampling variability in the complete data set as well as uncertainty in the observed proportions from the validation sub-set that are used to compute the corrected tables

Table A.3. Risk categories based on risk assessment during test counseling (CTR), partner notification (PCRS) and both *restricted to men who PCRS/CTR records matched on all demographics.*

	Based on CTR	Based on PCRS	Based on CTR & PCRS
MSM-IDU	4 (0.8%)	3 (0.6%)	7 (1.3%)
MSM	331 (62.7%)	370 (70.14%)	387 (73.3%)
IDU	0 (0%)	3 (0.6%))	3 (0.6%)
Heterosexual	173 (32.8%)	121 (222.7%)	120 (22.7%)
Other	20 (3.8%)	31 (5.9%)	11 (2.1%)

CTR: Counseling, Testing and Referral; PCRS: Partner Counseling and Referral Services; MSM: Men who have sex with men; IDU: Injection drug user; MSM-IDU: Men who have sex with men who are also injection drug users.

Table A.4. Congruence of reported gender of sexual partners between the Partner Counseling and Referral Services (PCRS) program and the Counseling, Testing and Referral Services (CTR) Program.

		CTR (lifetime)				
		MSW	MSM	MSMW	No partners	Total
PCRS (in last year)	MSW	137	4	7*	8	156
	MSM	29	199	102*	9	339
	MSMW	33	18	54	5	110
	No partners	13*	6*	3*	3	25
	Total	212	227	166	25	630

Cohen’s Kappa: 0.44 (95% CI: 0.39, 0.49)

MSW: Female sex partner(s); MSM: Male sex partner(s); MSMW: Male and female sex partner(s); No partners: no reported sex partners; CI: Confidence interval
*: unable to determine reason for non-congruence.

Table A.5. Characteristics of men, 18-30 by reported level of disclosure of risk behaviors during HIV test counseling (n=203).

	Nothing N=7	Some things N=60	Everything N=136	p-value*
Type of visit				
HIV test only	1 (14.3%)	1 (1.7%)	5 (3.7%)	0.23
STD exam + HIV test	6 (85.7%)	59 (98.3%)	131 (96.3%)	
HIV counselor				
#1	5 (71.4%)	49 (81.7%)	110 (80.9%)	0.83
#2	2 (28.6%)	11 (18.3%)	26 (19.1%)	
Age				
18-21	4 57.1%)	20 (33.3%)	58 (42.7%)	0.61
22-25	1 (14.3%)	22 (36.7%)	43 (31.6%)	
26-30	12 (28.6%)	18 (30.0%)	35 (25.7%)	
Race				
African American	7 (100%)	52 (88.1%)	120 (88.9%)	0.73
Non-African American	0 (0%)	7 (11.9%)	15 (11.1%)	
Education				
Did not complete high school	4 (57.1%)	15 (25.0%)	19 (14.0%)	0.01
High school diploma/GED	3 (42.9%)	19 (31.7%)	58 (42.7%)	
More than high school	0 (0%)	26 (43.3%)	59 (43.4%)	
Previous test				
Yes, at health department	3 (42.9%)	24 (40.0%)	70 (51.5%)	0.02
Yes, not health department	0 (0%)	23 (38.3%)	27 (19.9%)	
No previous test	4 (57.1%)	13 (21.7%)	39 (28.7%)	
Any drug use				
Yes	5 (71.4%)	43 (71.7%)	91 (66.9%)	0.85
No	2 (28.6%)	17 (28.3%)	45 (33.1%)	
Injection drug use				
Yes	1 (14.3%)	5 (8.3%)	2 (1.5%)	0.04
No	6 (85.7%)	55 (91.7%)	134 (98.5%)	
Non-heterosexual behavior**				
Yes	0 (0%)	10 (17.5%)	9 (6.7%)	0.05
No	7 (100%)	47 (82.5%)	125 (93.3%)	
Sexual orientation[†]				
Heterosexual	5 (83.3%)	51 (85.0%)	125 (91.1%)	0.30
Non-heterosexual	1 (16.7%)	9 (15.0%)	11 (8.1%)	
Comfort with sexual orientation				
Completely	4 (57.1%)	47 (78.3%)	125 (92.6%)	<0.01
Not completely	3 (42.9%)	13 (21.7%)	10 (7.4%)	
Comfort during risk assessment				
Completely	4 (42.9%)	26 (43.3%)	95 (69.9%)	<0.01
Not completely	3 (57.1%)	34 (56.6%)	41 (30.2%)	

*Pearson exact chi-square

**based on reported gender of sex partners in last 6 months

†:client identified sexual orientation

Table A.6. Characteristics of men, 18-30 by reported level of comfort of risk behaviors during HIV test counseling (n=203).

	Not at all comfortable N=7	Somewhat comfortable N=71	Completely comfortable N=125	p-value*
Type of visit				
HIV test only	0 (0%)	2 (2.8%)	5 (4.0%)	0.78
STD exam + HIV test	7 (100%)	69 (97.2%)	120 (96.0%)	
HIV counselor				
#1	5 (71.4%)	56 (78.9%)	103 (82.4%)	0.68
#2	2 (28.6%)	15 (21.1%)	22 (17.6%)	
Age				
18-21	3 (42.9%)	26 (36.6%)	53 (42.4%)	0.71
22-25	1 (14.3%)	24 (33.8%)	41 (32.8%)	
26-30	3 (42.9%)	21 (29.6%)	31 (24.8%)	
Race				
African American	6 (85.7%)	63 (88.7%)	110 (89.4%)	1.0
Non-African American	1 (14.3%)	8 (11.3%)	13 (10.6%)	
Education				
Did not complete high school	0 (0%)	13 (18.3%)	25 (20.0%)	0.36
High school diploma/GED	5 (71.4%)	25 (35.2%)	50 (40.0%)	
More than high school	2 (28.6%)	33 (46.5%)	50 (20.0%)	
Previous test				
Yes, at health department	2 (28.6%)	34 (47.9%)	61 (48.8%)	0.42
Yes, not health department	3 (42.9%)	21 (29.6%)	26 (20.8%)	
No previous test	2 (28.6%)	16 (22.5%)	38 (30.4%)	
Any drug use				
Yes	6 (85.7%)	50 (70.4%)	83 (33.6%)	0.50
No	1 (14.3%)	21 (29.6%)	42 (66.4%)	
Injection drug use				
Yes	0 (0%)	4 (5.6%)	4 (3.2%)	0.60
No	7 (100%)	67 (94.4%)	121 (96.8%)	
Non-heterosexual behavior**				
Yes	1 (14.3%)	10 (14.7%)	8 (6.5%)	0.14
No	6 (85.7%)	58 (85.3%)	115 (93.5%)	
Sexual orientation†				
Heterosexual	1 (16.7%)	11 (15.5%)	9 (7.2%)	0.18
Non-heterosexual	5 (83.3%)	60 (84.5%)	116 (92.8%)	
Comfort with sexual orientation				
Completely	6 (85.7%)	57 (80.3%)	113 (91.1%)	0.10
Not completely	1 (14.3%)	14 (19.7%)	11 (8.9%)	
Accuracy during risk assessment				
Completely	2 (28.6%)	39 (54.9%)	95 (76.0%)	<0.01
Not completely	5 (71.4%)	32 (45.1%)	30 (24.0%)	

*Pearson exact chi-square

**based on reported gender of sex partners in last 6 months

†:client identified sexual orientation

Table A.7. Characteristics of men, 18-30 by reported level of comfort of risk behaviors during HIV test counseling (n=203).

	Not completely comfortable N=78	Completely comfortable N=125	p-value*
Type of visit			
HIV test only	2 (2.6%)	5 (4.0%)	0.71
STD exam + HIV test	76 (97.4%)	120 (96.0%)	
Age			
18-21	29 (37.2%)	53 (42.4%)	0.65
22-25	25 (32.0%)	41 (32.8%)	
26-30	24 (30.8%)	31 (24.8%)	
Race			
African American	69 (88.5%)	110 (89.4%)	1.0
Non-African American	9 (11.5%)	13 (10.6%)	
Education			
Did not complete high school	13 (16.7%)	25 (20.0%)	0.76
High school diploma/GED	30 (38.5%)	50 (40.0%)	
More than high school	35 (44.9%)	50 (40.0%)	
Previous test			
Yes, at local health department	36 (46.1%)	61 (48.8%)	0.24
Yes, not at local health department	24 (30.8%)	26 (20.8%)	
No	18 (23.1%)	38 (30.4%)	
Any drug use			
Yes	56 (71.8%)	83 (66.4%)	0.44
No	22 (28.2%)	42 (33.6%)	
Injection drug use			
Yes	4 (5.1%)	4 (3.2%)	0.71
No	74 (94.9%)	121 (96.8%)	
Non-heterosexual behavior**			
Yes	11 (14.7%)	8 (6.5%)	0.08
No	64 (85.3%)	115 (93.5%)	
Sexual orientation†			
Heterosexual	65 (84.4%)	116 (92.8%)	0.09
Not heterosexual	12 (15.6%)	9 (7.2%)	
Comfort with sexual orientation			
Completely	63 (80.8%)	113 (91.1%)	0.05
Not completely	15 (19.2%)	11 (8.9%)	
Comfort during risk assessment			
Completely	41 (52.6%)	95 (76.0%)	<0.01
Not completely	37 (47.4%)	30 (24.0%)	

*Pearson exact chi-square

**based on reported gender of sex partners in last 6 months

†:client identified sexual orientation

Table A.8. Client report of risk assessment during HIV test counseling (n=203).

		Of those that didn't discuss		
	Didn't discuss with counselor	Counselor didn't ask	Didn't apply to patient	Patient didn't want to talk about it
Condom use	7 (3.4%)	7 (100%)	0 (0%)	0 (0%)
Gender of sex partners	3 (1.5%)	1 (33.3%)	2 (66.6%)	0 (0%)
Type of sex	24 (11.8%)	17 (70.8%)	3 (12.5%)	3 (12.5%)
Drug use	18 (8.8%)	8 (44.4%)	8 (44.4%)	2 (11.1%)
Number of sex partners	12 (5.9%)	11 (91.7%)	1 (8.3%)	0 (0%)

Table A.9. Client report of number of items discussed during risk assessment (n=203).

	Discussed
All 5 behaviors	157 (77.3%)
4 of the behaviors	32 (15.8%)
3 of the behaviors	8 (3.9%)
2 of the behaviors	4 (2.0%)
1 of the behaviors	1 (0.5%)
Missing	1 (0.5%)

Table A.10. Reported preferences for characteristics of HIV test counselor to make it easier to discuss risk behaviors, men aged 18-30, North Carolina (n=203).

It would be easier to talk to my test counselor about my risk behaviors if she or he was the same…	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree	Missing
age as me	68 (33.5%)	25 (12.3%)	56 (27.6%)	23 (11.3%)	29 (14.3%)	2 (1.0%)
gender as me	57 (28.1%)	14 (6.9%)	59 (29.1%)	30 (14.8%)	42 (20.7%)	1 (0.5%)
race as me	86 (42.4%)	30 (14.8%)	49 (24.1%)	16 (7.9%)	17 (8.4%)	5 (2.5%)
sexual orientation as me	64 (31.5%)	18 (8.9%)	45 (22.2%)	21 (10.3%)	50 (24.6%)	5 (2.5%)

Table A.11. Characteristics of men recruited for qualitative interview, stratified by acceptance (n=48).

	Completed qualitative interview n=25	Refused qualitative interview n=23	p-value*
Type of visit			
HIV only	0 (0%)	0 (0%)	--
STD exam + HIV test	25 (100%)	23 (100%)	
HIV counselor			
#1	11 (44.0%)	13 (56.5%)	0.56
#2	14 (56.0%)	10 (43.5%)	
Age			
18-21	7 (28.0%)	12 (52.2%)	0.25
22-25	11 (44.0%)	7 (30.4%)	
26-30	7 (28.0%)	4 (17.4%)	
Race			
African American	21 (84.0%)	19 (82.6%)	1.0
Non-African American	4 (16.0%)	4 (17.4%)	
Education			
Did not complete high school	2 (8.0%)	2 (8.7%)	0.23
High school/GED	8 (32.0%)	13 (56.5%)	
More than high school	15 (60.0%)	8 (37.8%)	
Previous test			
No	7 (28.0%)	8 (34.8%)	0.67
Yes, at local health department	12 (48.0%)	8 (34.8%)	
Yes, not at local health department	6 (24.0%)	7 (30.4%)	
Any drug use			
Yes	14 (56.0%)	15 (65.2%)	0.57
No	11 (44.0%)	8 (34.8%)	
Injection drug user			
Yes	1 (4.0%)	0 (0%)	1.0
No	24 (96.0%)	2 (100%)	
Non-heterosexual behavior**			
Yes	2 (8.0%)	4 (17.4%)	0.41
No	23 (92.0%)	19 (82.6%)	
Sexual orientation†			
Non-heterosexual	4 (16.0%)	3 (13.0%)	
Heterosexual	21 (84.0%)	20 (87.0%)	
Comfort in discussing risk behaviors			
Completely	14 (56.0%)	11 (47.8%)	0.66
Somewhat	9 (36.0%)	11 (47.8%)	
Not at all	2 (8.0%)	1 (4.4%)	
Accuracy in discussing risk behaviors			
Everything	18 (72.0%)	17 (73.9%)	1.0
Some things	6 (24.0%)	5 (21.7%)	
Nothing	1 (4.0%)	1 (4.4%)	

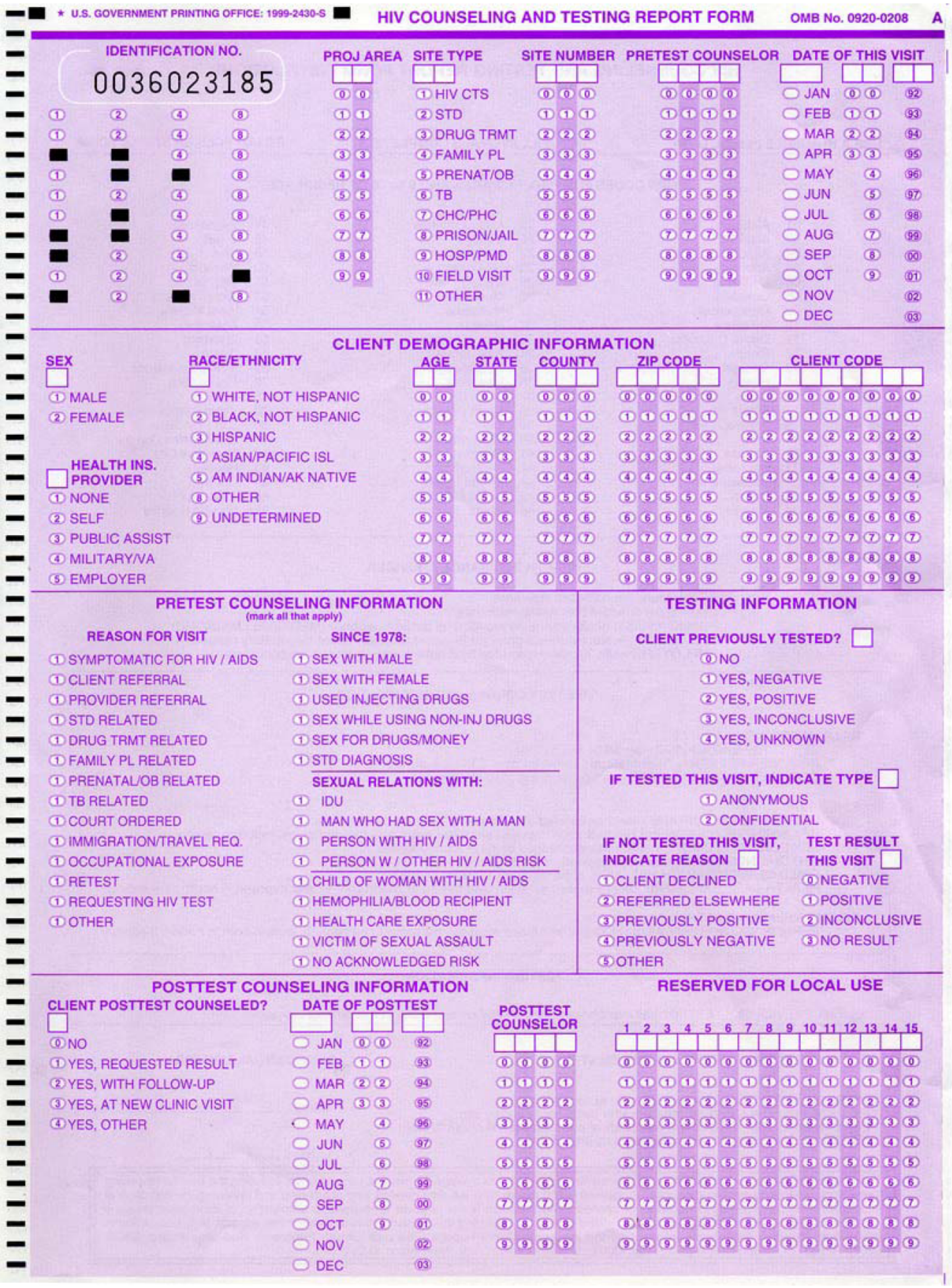
*Pearson exact chi-square

**based on reported gender of sex partners in last 6 months

†:client identified sexual orientation

Appendix B. Data collection materials

B.1. Counseling, Testing and Referral Form, pre-July, 2005



★ U.S. GOVERNMENT PRINTING OFFICE: 1999-2430-S

HIV COUNSELING AND TESTING REPORT FORM OMB No. 0920-0208 A

IDENTIFICATION NO.

0036023185

PROJ AREA

SITE TYPE
① HIV CTS
② STD
③ DRUG TRMT
④ FAMILY PL
⑤ PRENAT/OB
⑥ TB
⑦ CHC/PHC
⑧ PRISON/JAIL
⑨ HOSP/PMD
⑩ FIELD VISIT
⑪ OTHER

SITE NUMBER

PRETEST COUNSELOR

DATE OF THIS VISIT
○ JAN ⓪⓪ 92
○ FEB ①① 93
○ MAR ②② 94
○ APR ③③ 95
○ MAY ④ 96
○ JUN ⑤ 97
○ JUL ⑥ 98
○ AUG ⑦ 99
○ SEP ⑧ 00
○ OCT ⑨ 01
○ NOV 02
○ DEC 03

CLIENT DEMOGRAPHIC INFORMATION

SEX ☐
① MALE
② FEMALE

HEALTH INS. PROVIDER ☐
① NONE
② SELF
③ PUBLIC ASSIST
④ MILITARY/VA
⑤ EMPLOYER

RACE/ETHNICITY ☐
① WHITE, NOT HISPANIC
② BLACK, NOT HISPANIC
③ HISPANIC
④ ASIAN/PACIFIC ISL
⑤ AM INDIAN/AK NATIVE
⑧ OTHER
⑨ UNDETERMINED

AGE **STATE** **COUNTY** **ZIP CODE** **CLIENT CODE**

PRETEST COUNSELING INFORMATION
(mark all that apply)

REASON FOR VISIT
① SYMPTOMATIC FOR HIV / AIDS
① CLIENT REFERRAL
① PROVIDER REFERRAL
① STD RELATED
① DRUG TRMT RELATED
① FAMILY PL RELATED
① PRENATAL/OB RELATED
① TB RELATED
① COURT ORDERED
① IMMIGRATION/TRAVEL REQ.
① OCCUPATIONAL EXPOSURE
① RETEST
① REQUESTING HIV TEST
① OTHER

SINCE 1978:
① SEX WITH MALE
① SEX WITH FEMALE
① USED INJECTING DRUGS
① SEX WHILE USING NON-INJ DRUGS
① SEX FOR DRUGS/MONEY
① STD DIAGNOSIS

SEXUAL RELATIONS WITH:
① IDU
① MAN WHO HAD SEX WITH A MAN
① PERSON WITH HIV / AIDS
① PERSON W / OTHER HIV / AIDS RISK

① CHILD OF WOMAN WITH HIV / AIDS
① HEMOPHILIA/BLOOD RECIPIENT
① HEALTH CARE EXPOSURE
① VICTIM OF SEXUAL ASSAULT
① NO ACKNOWLEDGED RISK

TESTING INFORMATION

CLIENT PREVIOUSLY TESTED? ☐
⓪ NO
① YES, NEGATIVE
② YES, POSITIVE
③ YES, INCONCLUSIVE
④ YES, UNKNOWN

IF TESTED THIS VISIT, INDICATE TYPE ☐
① ANONYMOUS
② CONFIDENTIAL

IF NOT TESTED THIS VISIT, INDICATE REASON ☐
① CLIENT DECLINED
② REFERRED ELSEWHERE
③ PREVIOUSLY POSITIVE
④ PREVIOUSLY NEGATIVE
⑤ OTHER

TEST RESULT THIS VISIT ☐
⓪ NEGATIVE
① POSITIVE
② INCONCLUSIVE
③ NO RESULT

POSTTEST COUNSELING INFORMATION

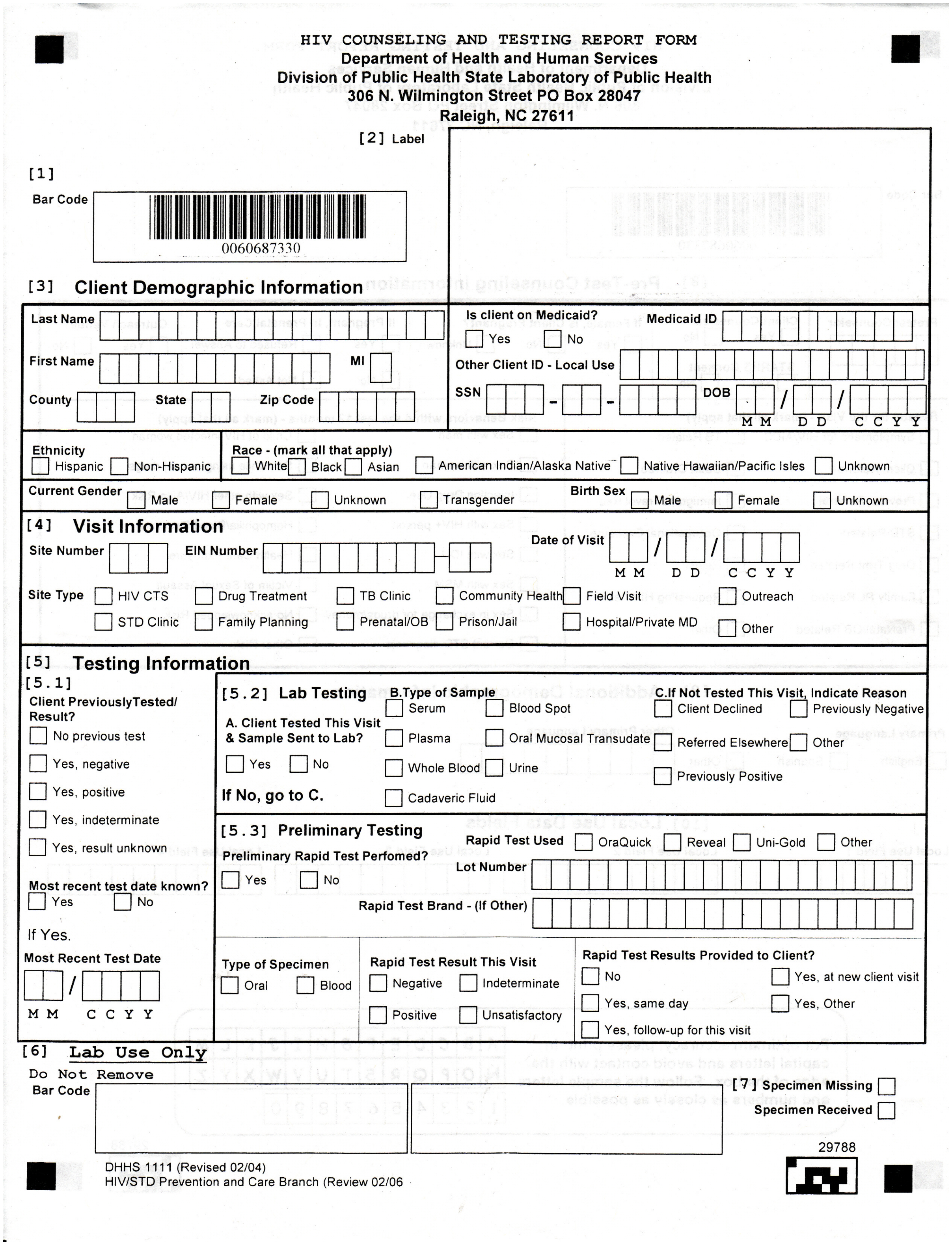
CLIENT POSTTEST COUNSELED? ☐
⓪ NO
① YES, REQUESTED RESULT
② YES, WITH FOLLOW-UP
③ YES, AT NEW CLINIC VISIT
④ YES, OTHER

DATE OF POSTTEST
○ JAN ⓪⓪ 92
○ FEB ①① 93
○ MAR ②② 94
○ APR ③③ 95
○ MAY ④ 96
○ JUN ⑤ 97
○ JUL ⑥ 98
○ AUG ⑦ 99
○ SEP ⑧ 00
○ OCT ⑨ 01
○ NOV 02
○ DEC 03

POSTTEST COUNSELOR

RESERVED FOR LOCAL USE
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15

B.2. Counseling, Testing and Referral Form, July, 2005 - on



HIV COUNSELING AND TESTING REPORT FORM
Department of Health and Human Services
Division of Public Health State Laboratory of Public Health
306 N. Wilmington Street PO Box 28047
Raleigh, NC 27611

[2] Label

[1]
Bar Code 0060687330

[3] Client Demographic Information

Last Name

First Name MI

County State Zip Code

Is client on Medicaid? ☐ Yes ☐ No

Medicaid ID

Other Client ID - Local Use

SSN - -

DOB MM / DD / CCYY

Ethnicity ☐ Hispanic ☐ Non-Hispanic

Race - (mark all that apply) ☐ White ☐ Black ☐ Asian ☐ American Indian/Alaska Native ☐ Native Hawaiian/Pacific Isles ☐ Unknown

Current Gender ☐ Male ☐ Female ☐ Unknown ☐ Transgender

Birth Sex ☐ Male ☐ Female ☐ Unknown

[4] Visit Information

Site Number

EIN Number -

Date of Visit MM / DD / CCYY

Site Type ☐ HIV CTS ☐ Drug Treatment ☐ TB Clinic ☐ Community Health ☐ Field Visit ☐ Outreach
☐ STD Clinic ☐ Family Planning ☐ Prenatal/OB ☐ Prison/Jail ☐ Hospital/Private MD ☐ Other

[5] Testing Information

[5.1]
Client PreviouslyTested/ Result?
☐ No previous test
☐ Yes, negative
☐ Yes, positive
☐ Yes, indeterminate
☐ Yes, result unknown

Most recent test date known?
☐ Yes ☐ No

If Yes.
Most Recent Test Date
MM / CCYY

[5.2] Lab Testing

A. Client Tested This Visit & Sample Sent to Lab?
☐ Yes ☐ No

If No, go to C.

B.Type of Sample
☐ Serum ☐ Blood Spot
☐ Plasma ☐ Oral Mucosal Transudate
☐ Whole Blood ☐ Urine
☐ Cadaveric Fluid

C.If Not Tested This Visit, Indicate Reason
☐ Client Declined ☐ Previously Negative
☐ Referred Elsewhere ☐ Other
☐ Previously Positive

[5.3] Preliminary Testing

Preliminary Rapid Test Perfomed?
☐ Yes ☐ No

Rapid Test Used ☐ OraQuick ☐ Reveal ☐ Uni-Gold ☐ Other

Lot Number

Rapid Test Brand - (If Other)

Type of Specimen
☐ Oral ☐ Blood

Rapid Test Result This Visit
☐ Negative ☐ Indeterminate
☐ Positive ☐ Unsatisfactory

Rapid Test Results Provided to Client?
☐ No ☐ Yes, at new client visit
☐ Yes, same day ☐ Yes, Other
☐ Yes, follow-up for this visit

[6] Lab Use Only
Do Not Remove
Bar Code

[7] Specimen Missing ☐
Specimen Received ☐

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DHHS 1111 (Revised 02/04)
HIV/STD Prevention and Care Branch (Review 02/06

HIV COUNSELING AND TESTING REPORT FORM

Department of Health and Human Services
Division of Public Health State Laboratory of Public Health
306 N. Wilmington Street PO Box 28047
Raleigh, NC 27611

Bar Code 0060687330

[8] Pre-Test Counseling Information

Pretest Counselor ☐☐☐☐☐

Client Counseled ☐ Yes ☐ No

STARHS Consent ☐ Yes ☐ No

If Female, Is Client Pregnant? ☐ Yes ☐ No ☐ Unknown

If Pregnant, In Prenatal Care ☐ Yes ☐ Refused to Answer ☐ No ☐ Not Asked

Outreach Venue? ☐ Yes ☐ No

Reason for the Visit - (mark all that apply)

- ☐ Symptomatic for HIV/AIDS
- ☐ Client Referral
- ☐ Provider Referral
- ☐ STD Related
- ☐ Drug Trmt Related
- ☐ Family PL Related
- ☐ PreNatal/OB Related
- ☐ TB Related
- ☐ Court Ordered
- ☐ Immigrant/Travel Req
- ☐ Occupational Exposure
- ☐ Retest
- ☐ Requesting HIV Test
- ☐ Other

Risk Behaviors within the last 12 months - (mark all that apply)

- ☐ Sex with man
- ☐ Sex with woman
- ☐ Injection Drug Use
- ☐ Sex with HIV+ person
- ☐ Sex with IDU
- ☐ Sex with MSM
- ☐ Sex in exchange for drugs/money
- ☐ Current STD diagnosis
- ☐ Child of HIV infected woman
- ☐ Sex while using non-inj drugs
- ☐ Sex with other HIV/Aids Risk
- ☐ Hemophilia/Blood Recipient
- ☐ Health Care Exposure
- ☐ Victim of Sexual Assault
- ☐ No acknowledged Risk
- ☐ Other Risk

[9] Additional Demographic Information

Primary Language ☐ English ☐ Spanish ☐ Other

Other Primary Language ☐☐☐☐☐☐☐☐☐☐

[10] Local Use Data Fields

Local Use Field 1 ☐☐☐☐☐☐☐☐☐☐

Local Use Field 2 ☐☐☐☐☐☐☐☐☐☐

Local Use Field 3 ☐☐☐☐☐☐☐☐☐☐

Local Use Field 4 ☐☐☐☐☐☐☐☐☐☐

For optimum accuracy, please print in capital letters and avoid contact with the edge of the box. Follow the sample letters and numbers as closely as possible.

A	B	C	D	E	F	G	H	I	J	K	L	M
N	O	P	Q	R	S	T	U	V	W	X	Y	Z
1	2	3	4	5	6	7	8	9	0			

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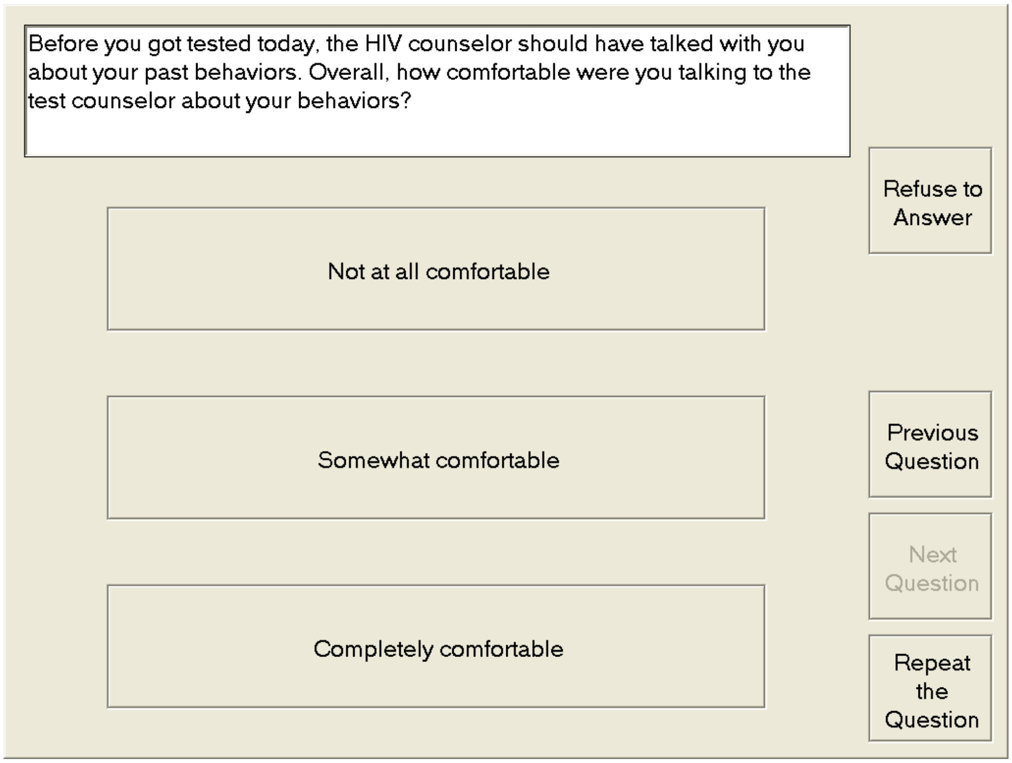
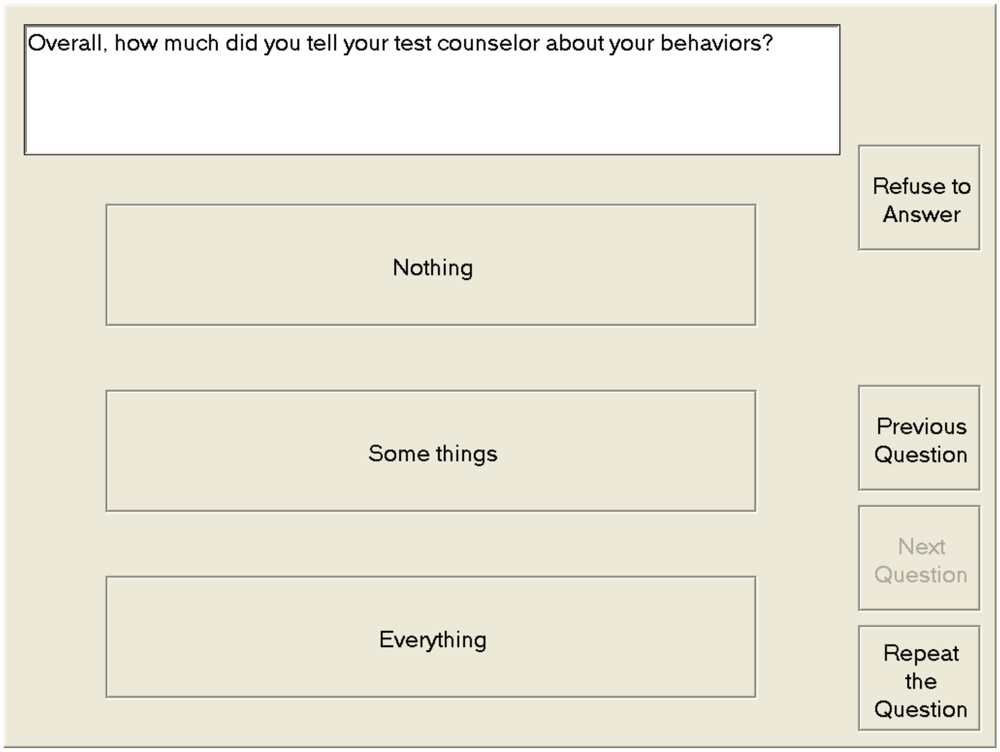
B.3. Screenshots of Audio and Computer-Assisted Self Interview


Before you got tested today, the HIV counselor should have talked with you about your past behaviors. Overall, how comfortable were you talking to the test counselor about your behaviors?


Overall, how much did you tell your test counselor about your behaviors?

B.4. Audio and Computer-Assisted Self-Interview script

Practice questions

P1. What is your favorite color? [check one]

Red
Blue
Green
Yellow
Purple
Orange
Pink

P2. Which of the following are days of the week? (Check all that apply) [check all that apply]

Monday
December
Saturday
Sunday
April
Earth
Thursday

P3. Please type in the year. [Number pad]

P4. What is your favorite food? [write in]

P5. How much do you like the color blue? [Likert-type scale 1-5]

Strongly agree to Strongly disagree

Please press "Yes" to begin the survey. [Check one]

Yes
No

Thank you for agreeing to complete this survey today.
This survey is completely anonymous.
Your answers will NOT be linked to your name.
Your answers will NOT be given to your test counselor.
Your answers will NOT be put in your medical record.
You will NOT have to give your name.

Q1. Before you got tested today, the HIV counselor should have talked with you about your past behaviors. Overall, how comfortable were you talking to the test counselor about your behaviors? [check one]

Not at all comfortable → **Q1A.**
Somewhat comfortable → **Q1A.**
Completely comfortable → **Q1B.**

Q 1A. What is the main reason that you were not completely comfortable with the test counselor? [check one]

I didn't trust him/her
I know him/her outside of the clinic
The counselor was rude/offended me
I was embarrassed
I don't talk about personal things
I thought he/she would judge me
Other → **Q1AA.**

Q1AA. What is the main reason you were not comfortable with the test counselor? [write in]

Q1B. What is the main reason you were completely comfortable with the test counselor?

I trusted him/her
I know him/her outside of the clinic
I didn't feel like he/she was judging me
He/she seemed to really care
I knew the information would be kept confidential
Other → 1BB.

Q1BB. What was the main reason you were comfortable with the test counselor? [Write in]

Q2. Overall, how much did you tell your test counselor about your behaviors? [Check one]

Nothing → **Q2A.**
Some things → **Q2A.**
Everything→ **Q2B.**

Q2A. What is the main reason that you didn't tell the test counselor everything about your behaviors? [Check one]

It's none of his/her business
I didn't think it would be kept confidential
I didn't trust him/her
I was embarrassed
He/she wouldn't understand
I thought he/she would judge me
Other → **Q2AA.**.

Q2AA. What is the main reason you didn't tell the counselor everything about your behaviors? [Write in]

Q2B. What is the main reason you told the test counselor everything about your behaviors? [Check one]

I trusted him/her
He/she asked
I didn't feel like he/she was judging me
He/she seemed to really care
I knew the information would be kept confidential
Other → **Q2BB.**

Q2BB. What was the main reason you told the test counselor everything? [Write in]

Q3. Did you and the test counselor talk about drug use? [Check one]

Yes
No → **Q3A.**

Q3A. Please pick the main reason why you didn't talk to the test counselor about drug use. [Check one]

She/he didn't ask → **Q6.**
She/he asked, but it didn't apply to me → **Q6.**
She/he asked, but I didn't want to talk about it → **Q6.**

Q4. How comfortable were you talking with the test counselor about your drug use? [Check one]

Extremely comfortable
Somewhat comfortable
Not at all comfortable

Q5. How much did you tell the test counselor about your drug use? [Check one]

I told him/her everything
I told him/her some things
I didn't tell him/her anything

Q6. Did you and the test counselor talk about how often you and your sex partners use condoms? [Check one]

Yes
No → **Q6A.**

Q6A. Please pick the main reason why you didn't talk to the test counselor about your condom use. [Check one]

She/he didn't ask → **Q9.**
She/he asked, but it didn't apply to me → **Q9.**
She/he asked, but I didn't want to talk about it → **Q9.**

Q7. How comfortable were you talking with the test counselor about your condom use? [Check one]

Extremely comfortable
Somewhat comfortable
Not at all comfortable

Q8. How much did you tell the test counselor about your condom use? [Check one]

I told him/her everything
I told him/her some things
I didn't tell him/her anything

Q9. Did you and the test counselor talk about the type of sex (anal, vaginal, oral) that you had? [Check one]

Yes
No → **Q9A.**

Q9A. Please pick the main reason why you didn't talk to the test counselor about the type of sex you had. [Check one]

She/he didn't ask → **Q12.**
She/he asked, but it didn't apply to me → **Q12.**
She/he asked, but I didn't want to talk about it → **Q12.**

Q10. How comfortable were you talking with the test counselor about they type of sex you had? [Check one]

Extremely comfortable
Somewhat comfortable
Not at all comfortable

Q11. How much did you tell the test counselor about the type of sex you had? [Check one]

I told him/her everything
I told him/her some things
I didn't tell him/her anything

Q12. Did you and the test counselor talk about the gender of your sex partners? By gender, we mean whether your sex partners are male or female. [Check one]

Yes
No → **Q12A.**

Q12A. Please pick the main reason why you didn't talk to the test counselor about the gender of your partners. [Check one]

She/he didn't ask → **Q15.**
She/he asked, but it didn't apply to me → **Q15.**
She/he asked, but I didn't want to talk about it → **Q15.**

Q13. How comfortable were you talking with the test counselor about the gender of your partners? [Check one]

Extremely comfortable
Somewhat comfortable
Not at all comfortable

Q14. How much did you tell the test counselor about the gender of your sex partners? [Check one]

I told him/her everything
I told him/her some things
I didn't tell him/her anything

Q15. Did you and the test counselor talk about how many sex partners you have had? [Check one]

Yes
No → **Q15A.**

Q15A. Please pick the main reason why you didn't talk to the test counselor about the number of your partners. [Check one]

She/he didn't ask → **Q18.**
She/he asked, but it didn't apply to me → **Q18.**
She/he asked, but I didn't want to talk about it → **Q18.**

Q16. How comfortable were you talking with the test counselor about the number of your sex partners? [Check one]

Extremely comfortable
Somewhat comfortable
Not at all comfortable

Q17. How much did you tell the test counselor about the number of your sex partners? [Check one]

I told him/her everything
I told him/her some things
I didn't tell him/her anything

Q18. Please respond with how much you agree/disagree with the following statements.
It would be easier to talk with my test counselor about my behaviors if she/he was the same age as me. [Likert-type scale 1-5]

Q19. It would be easier to talk with my test counselor about my behaviors if he/she was the

same gender (male/female) as me. [Likert-type scale 1-5]
Strongly agree to Strongly disagree

Q20. It would be easier to talk with my test counselor about my behaviors if she/he was the same race as me. [Likert-type scale 1-5]
Strongly agree to Strongly disagree

Q21. It would be easier to talk with my test counselor about my behaviors if he/she was the same sexual orientation (gay/straight/bi) as me. [Likert-type scale 1-5]
Strongly agree to Strongly disagree

Q22. I'm not worried about getting HIV because there are treatments available. [Likert-type scale 1-5]
Strongly agree to Strongly disagree

Q23. I'm not worried about getting HIV because I think there will be a cure soon. [Likert-type scale 1-5]
Strongly agree to Strongly disagree

Q24. I'm not worried about getting HIV because I don't think my sex partners have it. [Likert-type scale 1-5]
Strongly agree to Strongly disagree

Q25. I'm not worried about having sex without condoms because I don't think I will get HIV. [Likert-type scale 1-5]
Strongly agree to Strongly disagree

The next few questions ask you about your previous sexual partners and behaviors.

Q26. In the past 6 months, how many women have you had sex with? [Number pad] if >0 → **Q26A.**

Q26A. Which of the following types of sex have you had with women in the past 6 months? Check all that apply. [Check all that apply]
Anal
Vaginal
Oral (you went down on your partner)
Oral (your partner gave you a blowjob)

Q27. In the past 6 months, how many men have you had sex with? [Number pad] if >0 → **Q27A.**

27A. What types of sex have you had with men in the last 6 months? [Check all that apply]
Anal (you were the top)
Anal (you were the bottom)
Oral (you gave your partner a blowjob)
Oral (your partner gave you a blowjob)

Q28. Five years from now do you see yourself having sex with: [Check one]
Men only
Women only
Men and Women
I won't be having sex

Q29. In the past year, which of the following drugs have you used? Check all that apply. If you have not used any drugs please check "Not Applicable" [Check all that apply]

Ecstasy (X, E, MDMA)
Powdered Cocaine
Crack Cocaine
Methamphetamine (meth, tina, crystal, crank)
Marijuana
Heroin
Other → **Q29A.**

Q29A. Please list the other drugs you've done in the last year. [Write in]

Q30. In the past year have you injected any drugs (heroin, crack, methamphetamine, etc)? [Check on]

Yes → **Q30A.**
No

Q30A. Which drugs have you injected? Check all that apply. [Check all that apply]

Crack Cocaine
Heroin
Methamphetamine (meth, tina, crystal, crank)
Other → **Q30B.**

Q30B. Please tell us which other drugs you have injected. [Write in]

You're almost done! This last set of questions asks you about your age, race, gender, and HIV testing experiences.

Q31. How old are you? [Number pad]

Q32. What racial/ethnic group do you belong to? Please check one. [Check one]

African American, Black of African descent
Alaskan Native
American Indian
Asian/Pacific Islander
Hispanic, Latino
White, Caucasian
Mixed heritage/race → **Q32A.**
Other → **Q32B.**

Q32A. In the previous question you selected Multiracial. Please select which of the following races/ethnicities apply to you. [Check all that apply]

African American/Black/Black of African descent
Alaskan Native
American Indian
Asian/Pacific Islander
Hispanic, Latino
White, Caucasian

Q32B. You checked that you consider your race to be "Other". Please type in your race. [Write in]

Q33. Which category best describes your educational background? [Check one

Did not complete high school
High school diploma or GED
Some college or Associate's Degree
Bachelors Degree
Masters, Doctoral, or Professional Degree(s)

Q34. What was your sex at birth? [Check one]

Male
Female

Q35. What is you current sex/gender identity? [Check one]

Male
Female
Transgender; Male to Female
Transgender; Female to Male

Q36. How would you identify yourself in terms of your sexual orientation? [Check one]

Heterosexual (straight)
Homosexual (gay, queer)
Bisexual
Other → **Q36A.**
Don't know

Q36A. Please tell us your sexual orientation. [Write in]

Q37. How comfortable are you with your sexual orientation? [Likert-type scale 1-5]

Very comfortable to Very uncomfortable

Q38. How much do you agree with this statement? I think I have been at risk for getting HIV. [Likert-type scale 1-5]

Strongly agree to Strongly disagree

Q39. Including today, how many times have you been tested for HIV? [Check one]

1
2 → **Q39A.**
3→ **Q39A.**
4→ **Q39A.**
5 or more→ **Q39A.**

Q39A. When was the last time you were tested for HIV? (Do not include today) [Check one]

In the last 3 months → **Q39B.**
3-6 months ago → **Q39B.**
6-12 months ago → **Q39B.**
More than a year ago → **Q39B.**

Q39B. Not including today, where have you been tested for HIV? Check all that apply [Check all that apply]

Health department
Outreach site (street fair, club)
Doctor's office
Hospital
Community/Free clinic
Over the counter/at home test
Student/University health
Substance abuse treatment center
Jail, prison, or juvenile detention center
Employer
Church
Blood bank/plasma center
In the military
Other → **Q39C.**

Q39C. Please tell us where else you have been tested for HIV. [Write in]

Q40. What is the main reason you came to the clinic today? [Check one]

I had symptoms of an STD
My partner asked me to get tested
My partner has an STD/HIV
I was told I was exposed to an STD/HIV
I thought I might have HIV
It was time for my regular HIV test
I had an exposure to HIV (like a needle stick) at work
I am starting a drug treatment program
Other → **Q40A.**

Q40A. Please tell us what other reason you have for coming to the clinic today. [Write in]

Q41. What is the main reason you came to this clinic (Durham County Health Department) today? [Check one]

I knew it was free
It is close to home/school/work
I didn't know where else I could go
I was told I had to come here
I like the people here
I knew it would be confidential
I've been here before
I had a ride here
Other → **Q41A.**

Q41A. Please tell us why you came to this clinic today. [Write in]

Q42. Is there anything about your test counseling session that you would like to tell us? [Check one]

Yes → **Q42A.**
No

Q42A. What else would you like us to know about the counseling session? [Write in]

Thank you very much for completing the survey. Your answers are very important to us.

Please see the Research Assistant for additional information and to collect your gift card for completing the computer survey.

[END]

As an additional part of this study, we would like to talk more with you to explore some of the themes and issues from the computer survey but in a more in-depth fashion.

We recognize your time is extremely valuable and we will provide you with a $40 dollar gift card as an incentive after completion of the face to face interview. These interviews will last approximately 45 minutes. You will not have to give your name.

This interview can be conducted now or you can schedule a time with the research assistant to return at a later date.

Please see the Research Assistant for additional information and to collect your gift card for completing the computer survey.

[END]

B.5. Semi-structured interview guide

1. **Tell me about the HIV counseling session you had.**
    - **Opinion**:
        - What did you like about it?
        - What did you not like about it?
        - Was it similar/dissimilar to other test counseling sessions?
    - **Interaction with counselor**
        - How did the counselor ask you questions?
        - How did the counselor ask you about risk behaviors?
        - How long did you talk to the test counselor?
    - **Physical**
        - What was the room like?
        - How long did you wait?
        - How many people do you know in the clinic?

2. **How did you decide which clinic to be tested at?**
    - **Access**
        - Where else do you know about being tested?
        - How difficult was to get here? (transportation, work, etc.)
    - **Knowledge**
        - Have you been to this clinic before?
        - Where do most people go to be tested?
    - **Confidentiality**
        - How confidential are HIV counseling sessions?
        - How confidential are HIV counseling sessions at this clinic?

3. **Tell me about your test counselor.**
    - How comfortable were you talking to him/her?
    - How well do you think they understood you?
    - What would make it easier to talk to your test counselor?
    - What if they were the same age? Race? Sexual orientation?

4. **How should test counselors ask about risk behaviors?**
    - How honest do you think people are about their risk behaviors to their test counselor?
    - What are some reasons that people don't tell all their behaviors?
    - What are some reasons that people do tell all their behaviors?
    - What would make it easier to talk about risk behaviors?

5. **How do you think the HIV test counseling session should be done?**
    - Where should it be offered?
    - If it were offered in the health dept, where in the building should it be?
    - When should it be offered? At the beginning or end of the visit?
    - Who should do the test counseling?
    - How long do you think you should talk to a test counselor?

6. **What haven't talked about that you think is important for us to know about how to improve the test counseling process?**

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