

## Project Staff

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## Main Findings

- In our study, HIV+ gay and bisexual men who recently seroconverted were able to produce a coherent narrative detailing the time, location and circumstances during which they became infected with HIV.
- Respondents described a wide variety of themes, narrative types, and a broad spectrum of post-diagnosis prevention practices.
- There may be some relationship between narrative types and post-infection prevention practices; however, additional research is needed to explore this question.
- The seroconversion narratives themselves may be used in HIV prevention programs to stimulate meaningful, emotionally-based discussion of HIV prevention practices among gay and bisexual men.

## Background

As people are living longer and healthier lives with HIV, the risk of HIV transmission through unprotected sexual intercourse or sharing injection equipment continues to grow. While the general consensus is that most people who know they are HIV+ are careful to avoid transmitting the virus, it is estimated that one third of HIV+ gay/bisexual men continue to engage in unprotected sex. There is now a growing call to develop targeted and effective prevention strategies addressing the specific needs of people living with HIV.

## Narrative Therapy and HIV Prevention

Finding out that one is infected with HIV is an experience that is constructed by each individual; there is no universal, "true" or expected response. HIV+ individuals' understanding of how and why they were infected could have an impact of how they choose to protect or not to protect their sexual and needle sharing partners. One approach, narrative therapy, provides an innovative framework from which to explore HIV prevention for HIV+ people. The theory is that a person's life is shaped by the meaning they ascribe to their experience, not by the experience itself. According to narrative therapy, individuals tell their stories (narratives), and their reality is created by the telling and retelling of the story. Through a process described as "re-authoring", clients actively revise the meaning of previous events in their lives. The focus of therapy becomes helping someone change their narrative, "rewriting" their story and

developing positive behavior change. If there is indeed an association between the content of someone's seroconversion narrative (how he understands how he became infected with HIV) and his current HIV transmission risk behavior, changing these narratives through counseling may have an impact on reducing risk behavior.

## Why this project?

The SNAP study focused specifically on participants' narratives about how it happened that they became infected with HIV, their "seroconversion narratives." It was a pilot study to learn if gay and bisexual men who had recently seroconverted had a coherent seroconversion narrative, if they would be willing to share their narrative in a research interview, if the interview guide elicited useful information, and if there were identifiable themes in the interviews that could be coded and interpreted. The research team also planned to explore the relationship between participants' understanding about how they came to be infected with HIV and their current attitudes and behavior related to the prevention of HIV transmission.

## SNAP Interview Procedures

### Recruitment

We recruited participants from community-based ASOs (AIDS Service Organizations) in San Francisco that provided services for HIV+ gay and bisexual men. ASO staff distributed flyers to potential study participants and posted flyers on agency bulletin boards. We also encouraged men participating in the study to refer by word of mouth. Callers were screened to assure that they met the eligibility criteria which included: being male, identifying as gay or bisexual, being over 18 years of age, believing that they were infected with HIV in the previous 2 years, and being able to be interviewed in English.

### Interview Procedures

All interviews were conducted at a centrally located San Francisco ASO. Informed consent was obtained by reviewing the consent form approved by the UCSF Committee on Human Research, reading aloud the most critical paragraphs, and having the respondent sign the consent form. Interviews lasted 1.5 to 2 hours. At the end of the interview, participants were given referrals to local services as needed and received a \$50 cash incentive.

## Table 1: SNAP Interview Guide

### Part I: Seroconversion Narrative

1. Tell me the story about how it happened that you were infected with HIV.
2. When did you first test positive for HIV?

### Part II: Current Prevention Practices

1. What does your life look like now since you became infected with HIV?
2. How do you express yourself sexually now?
3. Tell me about the last time you had sex where you were confident that there was no risk of transmitting HIV.
4. How about the most recent time you had sex where you thought there might have been some risk to transmit HIV?
5. Have you changed anything about the ways that you use drugs or alcohol since you were infected with HIV?
  - 5a. (Ask only injection drug users (IDUs)) What about needle use?
  - 5b. (Ask only IDUs) Tell me about the last time you injected drugs around other people where you were confident that there was no risk of transmitting HIV through needle use.
  - 5c. (Ask only IDUs) How about the most recent time injected drugs where you thought there might have been some risk to transmit HIV?
6. What message would you give to a gay/bisexual man who is HIV+ and wants to avoid transmitting the virus to others? What would you tell that person to do?
7. What message would you give to someone who is HIV- and wants to avoid getting HIV?
8. Is there anything I didn't ask you that you would like to tell me about? Anything that is important for me to better understand your story?

## Interview Guide

The SNAP interview guide included two major sections: 1) the seroconversion narrative (each respondent's detailed story about how he became infected with HIV), and 2) current prevention practices (what does each respondent do, if anything, to avoid transmitting HIV to others?). Each section included open-ended questions followed by a series of optional probes. Every interview began with the question "Tell me the story about how it happened that you were infected with HIV," following which the interviewer allowed the participant to give his full narrative before probing. See Table 1.

## Data Analysis

Interviews were audiotaped and transcribed verbatim. The five-member research team was diverse with respect to age, ethnicity, serostatus and gender and included the study interviewers. Each member of the research team read the entire interview and participated in an in-depth discussion devoted to each interview during which main themes were identified. Main themes were identified across the 28 interviews and rated by frequency.

In the next phase of data analysis we read each narrative a second time and labeled each one with seroconversion narrative types, describing the predominant content of the story.

We then categorized each interview into a prevention type based on the respondent's prevention practices as an HIV+ man. Prevention practices were further coded based on the presence or absence of a pledge or intention to protect others from HIV infection. The final step of the analysis was to explore the relationship between narrative type, prevention types and various demographic and contextual variables.

## Selected Key Findings

### Study Sample

Twenty-eight eligible men were recruited to the study. The average age of study participants was 34 years, with a range of 19-44 years. Regarding ethnicity, 36% (10) were African-American, 39% (11) were Caucasian, 14% (4) were Latino, 4% (1) was Asian and 7% (2) were Native American. Although all participants were screened by telephone before coming to be interviewed, it became clear in the course of some in-depth interviews that their seroconversion event had occurred prior to 2 years ago. Still, 60% of our participants had been infected less than 2 years, and 82% had been infected less than 3 years.

## What did we learn from SNAP?

- Our first lesson was that a diverse group of gay and bisexual men recently infected with HIV were willing to participate in an in-depth interview regarding their seroconversion event, and that nearly all of the men could produce a coherent narrative rich in contextual detail. This supports the feasibility of narrative interview research with this population.
- Themes and prevention types drawn from the narratives provide a picture of the types of issues men are experiencing at the time of infection, and may suggest specific vulnerabilities that could be addressed in intervention (e.g. times of loss or transition).
- Prevention types describe the wide range and multiple combinations of strategies that men engage in to avoid infecting others, and reinforce the repeated finding that most HIV+ persons do make some effort to prevent transmitting HIV to others.

## Overall Themes

The most common themes that emerged in our initial phase were: Drug and Alcohol Use, Loss, Disclosure and Sexual Communication, Assumptions, Prevention and Responsibility, and Resilience/Coping. Additional themes included: Abuse/Sexual Violence, Internet, Partner Choice, Prevention Strategies as an HIV+ Man and as an HIV- Man, Travel/Displacement and Trust.

Most interviews included more than one theme. Some of these themes were consistent with previously reported findings, such as the role of alcohol and drug use (particularly methamphetamine) and assumptions about partners in new HIV infections among gay and bisexual men. Other themes in the seroconversion narratives were less expected, such as travel or other geographical displacement and the prevalence of narratives involving a significant loss immediately preceding the situation in which respondents believe they were infected with HIV. We also noted that, without being prompted to do so, participants often related themes of resilience and coping, describing their experiences of spiritual awakening, family support and volunteering to help others.

The research team was struck by the sense of profound isolation many respondents reported (e.g. being away from their closest support--family or close friends), their lack of communication with their sexual partners (resulting in assumptions or misinformation), and the frequency with which drug and alcohol were used as a way to cope with difficult feelings. See Table 2 for examples of quotes by theme.

**Table 2: SNAP Quotes by the Most Common Themes**

**Alcohol and Drug Use**

"I would normally use condoms but when I was high on cocaine or drunk, I didn't...I was risky myself, I know that. And every time on the following day, I always thought "oh, you did it again." But the fact that I've been doing it for one or two years and it never happened to me, I thought I was doing okay. I was always careful with the guys I went with...So I was having sex with cool, normal guys who looked pretty healthy and were not sick at all. And if I was sober I would have used condoms, but I have to tell you, that when I was high, either drunk or high on cocaine or something, I never used condoms."

**Loss**

"My mom passed in December. I kind of like gave up for a minute. You know...I started doing drugs and hanging out and drinking and not giving a damn, you know. I was doing crack, I was doing marijuana and I was drinking alcohol....All these drugs were daily...It was tearing me up, actually. I was killing myself inside, trying to bring my mother back and replace her."

**Disclosure/Sexual Communication**

"I only disclose my status to potential boyfriends or people that I know that I really like, and that I'm interested in trying to pursue something with. It's kind of liberating. I can be honest with myself and I can know that I'm doing the right thing by being honest with someone else, regardless of what their position was. I'm not as honest with casual partners that I'm HIV+. I'm kind of battling and struggling with that because I want to be honest but then I don't know how they're going to react."

**Assumptions**

"There's an assumption that a lot of people make when you look at their ads on the Internet or you talk to them. All of a sudden I was on the other side of the fence from where the guy was who had sex with me and exposed me to HIV. All of a sudden I was in his shoes thinking, 'wow, I can see it from this side now too,' which is really weird. Thinking I know why he assumed I was positive, because I was fucking without a condom."

**Prevention/Responsibility**

"My dating habits have changed. I've just made the decision not to date HIV- people so I have found that I disclose quite quickly in any type of possible situation. I don't want to date HIV- people because I'm not a condom wearer. I never have been. I know that there are other things that I can catch out there. But I have no desire to be with somebody that I could possibly infect."

**Resilience/Coping**

"Those things do not make me in any way, shape or form--the label on my clothes or the price tag on my clothes. And prior to HIV those things were significant to me. I'm still in the process of rebuilding my life from where it had been destroyed. It's almost like after a war, you know? Like the whole reconstruct after the Civil War in the South. That's how it is. The infrastructure and everything is just gone. And so I'm in the process of rebuilding. But I'm rebuilding for a different purpose. Right now I definitely want to do something as far as a career choice, something that benefits people outside of the realm of external benefits. But they are going to be benefits for my internal growth also."

**Seroconversion Narrative Types**

In the second phase of our data analysis we attempted to assign each narrative a primary type. We discovered, however, that many of the narratives included more than a single type of story and we assigned multiple types. Following are the types of seroconversion stories that emerged from this analysis, followed by the number of times each type was coded: Drug Use (16), Consistent Risk Taker (9), Displacement (9), Assumption about Partner (6), Loss/Depression (5), Freak Accident (4), Misinformation about Partner (4), Hot/Horny (3), Internet (3), Sex Worker (3), Abuse/Trauma (2), Failed Algorithm (2), Love/Romance (2), Misinformation about HIV (2), Naïve Boy (2).

Some of these narrative types are descriptive of their content (e.g. love/romance, hot/horny, consistent risk taker), and others require some definition. Failed algorithm, for example, described a story in which the respondent was exercising a consistent and previously successful HIV preven-

tion plan that failed to protect him in the instance of his seroconversion. Freak accident describes a seroconversion story in which a series of rare or improbable events led to the respondent being exposed to HIV. Assumption describes a story in which the respondent, without specifically communicating with his partner, made an erroneous assumption about that partner. This is in contrast to Misinformation about Partner in which the respondent received specific information about his partner that was not true. Most men did take steps to reduce their risk of becoming infected by using a wide range of rules and guidelines; this is interesting because each interview represents a case in which the respondent's strategy ultimately failed to protect him.

**Prevention Strategies as HIV+ Men**

In the third phase of the analysis, we examined respondent's prevention strategies as HIV+ men. Our findings reflect the complex nature of individual's efforts to prevent HIV transmission.

Respondents reported using multiple strategies, changing strategies over time, and using different strategies in different contexts (e.g. with different types of partners or in different settings). For example, several men reported initially choosing celibacy out of fear of transmitting HIV to others, and later returning to sexual activity with specific risk reduction intentions in place. Others reported a period of unprotected sexual activity immediately following their diagnosis, and later choosing celibacy as a period of reflection or during the early stages of alcohol/drug recovery. Prevention strategies are listed here, followed by the number of times each was coded: Condoms (14), Disclosure (8), Celibacy (7), Strategic Selection of Specific Sexual Practices (6), Reduce Number of Sexual Partners (6), Partner Selection (5), Reduce Drug/ Alcohol Use (4), No Strategy (4), Clean Needles (3), Stabilize Life (1).

In an effort to capture the complexity of these prevention strategies, we later also coded whether the narrative included a pledge or intention to avoid HIV transmission. Twelve of the 28 respondents (44%) mentioned having made a pledge or set a specific intention not to infect others.

### Dissemination of Study Findings

In order to share the data with the community and involve community HIV prevention stakeholders in further data analysis, we developed a presentation that included the study methods and a thematic presentation of the actual narratives. For this presentation we chose themes that were prevalent in the interviews (e.g. alcohol and drug use, loss) as well as topics of current interest in HIV prevention (e.g. disclosure, assumptions about partners). Our goal was to generate a discussion of the findings that would further illuminate the data analysis and generate implications for HIV prevention interventions. These presentations involved introducing each theme that emerged from the data analysis, then having members of the research team reading aloud actual narratives and a series of quotes from different respondents related to that theme. See Table 2.

The research team was struck by the consistency with which audience members (including researchers, community-based service providers and managers, volunteers and policy makers) indicated that the experience of hearing the narratives aloud was itself an intervention. Audiences reported that hearing the voices of the participants, all of whom are now living with HIV, was extremely powerful. Audience members were deeply moved by the stories; the presentations stimulated intense, emotionally-charged discussions about the nature of HIV transmission in the gay community and both individual and community-level influences that prevent and facilitate

effective prevention. This effect was particularly striking in audiences comprised of gay men who related the impact of hearing the quotes to the level of isolation in their community, noting the lack of opportunities to openly and explicitly discuss HIV prevention failures.

### Implications/Recommendations

One of the goals of this pilot study was to examine the relationship between seroconversion narrative types and prevention practices as an HIV+ man. While a clear relationship did not emerge in this pilot study, some trends were observed in our analysis. These may be used to guide future exploration of seroconversion narratives for HIV prevention.

- There were several cases in which celibacy was chosen as a prevention strategy by men whose seroconversion narratives involved improbable or unlikely events (e.g. men who described being infected through oral sex). Is it possible that men who felt they had become infected by what they perceived to be a random event were less likely to risk any sexual involvement? Could these men be counseled to better understand the mechanics of preventing HIV infection and to reduce their anxiety about accidental transmission?
- It also appeared that men who had been infected for longer periods of time were more likely to express a pledge or clear intention to protect partners from HIV infection. Is it possible that there is a developmental process whereby over time, HIV+ persons gain clearer, more intentional and more effective prevention strategies? Could this knowledge be harnessed and used to model and assist the newly infected in developing effective prevention strategies?
- All the men who reported having no plan to prevent HIV transmission in the third phase of the data analysis had been coded as consistent risk takers in their narrative type. There were other consistent risk takers who had developed prevention plans, however. Could this information be useful in tailoring prevention counseling to address the needs of those most likely to transmit HIV?
- In a completely unexpected finding, audiences hearing our presentation of the study data have consistently recommended that readings of the seroconversion narratives be conducted for staff and volunteer training, board meetings and other agency events. Hearing the narratives, especially together with other gay men and followed by a facilitated discussion, has been recommended as an intervention to increase awareness of prevention challenges for both HIV+ and HIV- men.

For more information on the SNAP Study, please contact:  
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