Seroconversion Narratives and Insights for HIV Prevention

Olga Grinstead, PhD, MPH

More than half the people living with HIV in the United States are men who have sex with men. While the general consensus is that most people who know they are HIV-positive are careful to avoid transmitting the virus, some seropositive individuals continue to report unprotected anal sex with partners of unknown serostatus.  

Narrative therapy provides an alternative framework from which to explore new approaches to HIV prevention for HIV-positive people. Narrative therapy is based in the constructivist perspective that people’s lives are shaped by the meanings they ascribe to their experiences—not by the experiences themselves. According to narrative therapy practitioners, reality is created as an individual tells and retells his or her story or “narrative.” In counseling, through a process described as “re-authoring,” clients actively revise the meaning of previous events in their lives, suggesting a relationship between the rewriting of the narrative and the process of behavior change. 

Narrative therapy is the basis for the Seroconversion Narratives for AIDS Prevention (SNAP) study, a qualitative investigation of HIV-positive participants’ understandings of their seroconversion events. This article describes SNAP’s most compelling findings. 

An HIV-positive individual’s understanding of how and why he or she was infected could have an impact on how that person chooses to protect or not to protect sexual and needle sharing partners. This link between an individual’s personal theory about HIV infection and subsequent behavior is supported by several studies in which researchers found that attributions of blame for infection, and attributions of responsibility for protection, were both associated with HIV transmission risk behavior among men living with HIV. 

Given this connection, the modification of a seroconversion narrative (a person’s story about how he or she believes that he or she was infected with HIV) through specific counseling approaches may help reduce behavior that risks HIV transmission. A counseling intervention based on narrative therapy might involve collaborating with a client to author and then review and “re-author” his or her narrative toward a more empowered perspective and to develop a more balanced and self-affirming set of attributions to explain the seroconversion event. 

The SNAP Study

The purpose of the SNAP study was to elicit seropositive gay and bisexual men’s stories about how they believed they came to be HIV-infected. This pilot study sought to learn if respondents could produce a detailed and coherent narrative even if this event occurred years before, if there were identifiable themes across the narratives, and if the individual, interpersonal, and structural attributions in these narratives were related to an individual’s current HIV transmission risk. The goal was both to contribute to the development of innovative counseling interventions and to provide information about the contexts in which HIV infections are currently occurring. 

To be eligible for the study, participants had to be male, identify as gay or bisexual, be over 18 years of age, and be interviewed in English. The average age of study participants was 34 years, with a range of 19 to 44 years. Of the 28 men, 39 percent described themselves as White, 36 percent as African American, 14 percent as Latino, 7 percent as Native American, and 4 percent as Asian or Pacific Islander. 

To minimize differences among interviews based on memory loss and on changes in the HIV treatment and prevention environment over time, researchers recruited men who believed they had been infected with HIV during the prior two years, acknowled
Perhaps the most basic instrument in the therapy toolbox is a client’s story. All clients tell stories, but counselors use these narratives in different ways depending on their therapeutic approach.

One sure approach, narrative therapy, emphasizes the way a person describes his or her feelings and experiences, because, as Olga Grinstead states in this issue of FOCUS, “people’s lives are shaped by the meanings they ascribe to their experiences, not by the experiences themselves.” Both articles in this issue discuss applications of narrative therapy theory to HIV counseling.

Grinstead examines “seroconversion narratives,” the words an HIV-positive person uses to describe the incident during which he or she might have contracted HIV, to help understand the factors that most influence transmission and the ways in which people think about these factors. While Grinstead's article focuses primarily on the use of narratives to conduct research, she believes that understanding the process of narratives may lead to counseling approaches that could increase a person's capacity to prevent transmission. Further, Grinstead believes that the presentation of narratives at public forums can promote a healthy discussion of HIV prevention challenges.

Allan Peterkin describes another application of narrative therapy: a therapeutic writing group for people with HIV. He, too, suggests that writing may bring out a deeper truth about the way a person constructs his or her reality, but he emphasizes the interactive and creative process of expressing a narrative when it unfolds in a therapeutic writing group and the capacity of this process to help people cope.

Both articles suggest that the words and concepts people use to recount their experiences may have benefit beyond the obvious application of narrative therapy: the seroconversion narrative and current prevention practices. Every interview began with the question, “Tell me the story about how it happened that you were infected with HIV.” After the respondent had the opportunity to recount the story of his seroconversion without interruption, the interviewer probed, as necessary, for details about work, relationships, drug use, and other contextual factors that existed at the time the respondent believed he was infected. Further interview questions addressed the participant’s life after seroconversion, including current attitudes and behaviors related to preventing HIV transmission. Interviews lasted up to two hours and researchers gave participants a $50.00 cash incentive.

Data analysis involved three steps. First, to understand the overall content of the interviews, the research team identified themes that emerged across the interviews. Second, the team focused specifically on the seroconversion narratives and labeled each one with a narrative type that described the nature of each story. These types emerged over repeated readings and discussions about each narrative. Third, the team identified post-seroconversion prevention practices across the interviews and noted the presence or absence of a pledge to protect others from HIV infection. Final analyses focused on the relationship among narrative types, prevention practices, and various demographic and contextual variables.

**The Seroconversion Narratives**

The team found first that a diverse group of gay and bisexual men recently infected with HIV were willing to participate in in-depth interviews regarding seroconversion...
and that nearly all of the men could produce a coherent narrative rich in contextual detail. While the sample included a few men who injected drugs, almost all men related sexual seroconversion events. The following three narratives illustrate the range of stories:

I first got infected in 2001. It was me and my ex-lover . . . . I had tried to visit his brother and his brother wasn’t there. And he just happened to come over too . . . . and we were just sitting there talking and everything. We went to talking about our past relationship and everything and we still cared for each other. And we ended up kissing, and once we started kissing we ended up in the bed. . . . That was actually the day that I became positive. Then come to find out he’s messing with this other guy. . . . He infected my ex-lover and my ex-lover infected me.

I hooked up with this guy and we basically, like, had unprotected sex. I had met him on a chat line. . . . And I remember giving him the condoms, and I think I put it on. But I think it either broke or he took it off or something like that. . . . I think I told him to put on the condom and I think he expressed that he didn’t like to wear them. I think he, like, assured me that he didn’t have any STDs and that he doesn’t have anything. . . . I was, I think, 16 at the time, so I kind of went along with him, or something . . . .

I’m in recovery now but at the time I was using crack cocaine. I lost my job and I lost my will to live and my resources and started engaging in risky behavior. . . . and then I started actually prostituting and shoplifting. There was a man and he was paying me to have sex. . . . [H]e asked if he could fuck me. . . . Then he wanted to do it without a condom and I said no at first. And he said he would give me $50.00 more, and he did fuck me without a condom.

Narrative Themes and Types

As demonstrated by these examples of narratives, most interviews included multiple themes. Some of these themes—such as the role of substance use and sexual communication—were consistent with previously reported predictors of HIV seroconversion among gay and bisexual men.7,8

Many respondents reported extreme isolation and the use of drugs and alcohol to cope with difficult feelings.

Other themes were unexpected. For example, some respondents reported travel or other geographical displacement or a significant loss immediately preceding the seroconversion event. Participants also communicated themes of resilience and coping, including spiritual awakening, family support, and volunteerism.

The six most common themes, in order of frequency, were: drug and alcohol use; loss; disclosure and sexual communication; assumptions; responsibility; and resilience/coping. It is notable that most respondents had taken steps to reduce their risk of becoming infected, using a wide range of rules and guidelines, but each interview represents an instance when a strategy had failed.

The majority of narratives required more than one seroconversion narrative type to accurately describe them. The most common type was substance use (16 narratives). Among the other most frequently coded types were: consistent risk taker (nine narratives); displacement (nine narratives); assumption about partner (six narratives); loss/depression (five narratives); and misinformation about partner (four narratives). Narrative types coded in three or fewer interviews were: hot/horny; internet; sex worker; abuse/trauma; failed algorithm; freak accident; love/romance; misinformation about HIV; and naive boy.

Some of the types that emerged were simply descriptive. Others require some definition. “Failed algorithm” describes a story in which the respondent was exercising a consistent and previously successful HIV prevention plan, for example, having only oral sex, that, in this instance, failed to protect him. “Freak accident” describes a story in which a series of rare or improbable events led to the respondent being exposed to HIV, for instance, the case of a respondent who was traveling and engaged with a casual partner who bit his penis. “Assumption” describes a story in which the respondent made an erroneous assumption, generally about the partner’s serostatus, in contrast to “misinformation about HIV” in which the respondent received untrue information about, for example, his partner’s risk behavior or serostatus.

Post-Seroconversion Prevention Responses

Respondents reported using multiple post-seroconversion prevention strategies, changing these strategies over time, and using different strategies in different contexts. 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. Others reported a period of unprotected sexual activity followed by celibacy as a period of reflection or during the early stages of alcohol or drug recovery.

As with narrative themes, most interviews included more than one prevention strategy. Among these strategies were: condom use (14 narratives); celibacy (seven narratives); disclosure (seven narratives); strategic selection of specific sexual practices (six narratives); partner selection (five narratives); reducing the number of sexual partners (four narratives); reducing drug/alcohol use (four narratives); no strategy (four narratives); using clean needles (three narratives); and stabilizing life (one narrative). Twelve of the narratives (44 percent) mentioned a pledge or intention to avoid transmission.

This pilot study did not uncover a clear and consistent relationship between narrative types and post-seroconversion prevention strategies. This may have been due to limited sample size, limitations of the survey guide, or the complexity of characterizing both narrative types and current prevention practices. Some trends, however, may be useful in considering future counseling interventions.

First, there were several cases in which respondents whose seroconversion narratives involved improbable or unlikely events—for example, being infected through oral sex—later chose celibacy as their prevention strategy. 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?

Second, it appeared that men who had been infected for longer periods of time were more likely than those who had been infected for shorter periods of time to express a pledge or clear intention to protect partners from HIV infection. Is it possible that there is a process over time for people with HIV whereby prevention strategies become clearer, more intentional, and more effective? Could this knowledge and experience be harnessed to assist the newly diagnosed in developing effective prevention strategies?

Third, of the men who reported having no plan to prevent HIV transmission, all had been coded as the “consistent risk taker” narrative type. However, there were other consistent risk takers who did have prevention plans. Could this information be useful in tailoring prevention counseling to address the needs of those most likely to transmit HIV?

Implications and Recommendations

The study findings clearly support the often stated need for accessible drug and alcohol treatment and for interventions that address loss, isolation, and sexual communication. But it was what happened after the study was completed that suggested a powerful and unexpected intervention.

In order to disseminate the study findings and involve community stakeholders in further analysis and recommendations, the researchers developed a presentation for providers. Audiences consistently indicated that the experience of hearing the seroconversion narratives was, in itself, an intervention. The presentation stimulated emotionally charged discussions about the nature of HIV transmission and prevention in the gay community.

The effect was particularly striking in audiences comprised primarily of gay men, who noted the lack of opportunities for specific discussion of HIV prevention failures. Audience members recommended seroconversion narrative readings as part of provider, volunteer, and board member training and, when followed by a facilitated discussion, as a prevention intervention for community members. They suggested that this intervention would increase awareness of prevention challenges and promote discussion and support for both HIV-positive and HIV-negative men.

Narratives retain the power and immediacy of seroconversion events. Their collection, analysis, and dissemination can help providers understand the factors that contribute to and might prevent new HIV infections.

Clearinghouse: HIV Narratives

References


Human beings use stories to invent themselves, to connect with others, and to navigate challenges in their lives. Among people with HIV, an unfolding challenge—an unfolding story—over the past few years has been the successes of HIV antiviral treatments and the conception of HIV as a “chronic illness.” Ads for these new drugs have shown muscular men climbing mountains, representing a new, grateful, action-oriented “survivor narrative” to describe living with HIV. Yet many people had other, unresolved stories they needed to tell—“old stories” of loss, stigma and frustration—stories they have increasingly felt discouraged from telling.

Writing has been used as a therapeutic tool for many years and offers a way of helping people tell these stories and understand their significance. Research has shown it to be helpful in a number of clinical populations including people living with HIV.1,2,3

At Mount Sinai Hospital in Toronto, clinicians applied narrative theory to develop a new form of therapeutic writing called Narrative Competence Psychotherapy, around which they structured a therapeutic group. This article reviews the literature on therapeutic writing and outlines its evolution into narrative competence psychotherapy and its utility as a group approach.

**Therapeutic Writing and Narrative Competence**

The evolution of narrative competence psychotherapy was deeply rooted in the growing literature on therapeutic writing. James Pennebaker’s pioneering study developed a key protocol that has been replicated in many other studies.4 Pennebaker had invented a writing instruction to write non-stop for 15 minutes on each of four consecutive days. In Pennebaker’s study and the follow-up studies that followed, the writing task, which incorporated a stress-based or emotionally charged narrative, could be linked to a wide range of health benefits. Among these were: increased Epstein Barr virus antibody concentrations, decreased clinic visits, decreased depression scores, and psychosocial benefits such as higher grades or quicker re-hire times among the newly unemployed. Most recently, an Australian study using the Pennebaker Protocol among people with HIV demonstrated rises in CD4+ cell counts in individuals writing on emotional topics.2

Perhaps the most compelling example of specific health effects linked to a writing task found that writing about stressful events reduced symptoms of patients living with rheumatoid arthritis and asthma.5 Smyth also published a meta-analysis of all writing studies up to 1990 and documented three trends that proved instrumental in the formation of the group therapy model based at Mount Sinai.4 First, men appeared to experience greater health benefits than women, significant because 90 percent of patients at the Mount Sinai Clinic were men. Second, writing about recent trauma appeared to be more beneficial than writing about historical trauma, which would allow clinic participants to address new, as well as old, stressors. Third, writing over time conferred a larger benefit than short-term writing instructions.

Narrative competence psychotherapy is a “two-pronged” clinical intervention: participants write personal, narratively competent stories and then share these narratives in a group over time. Narrative competence, as operationally defined, means that a story is coherently organized and has a beginning, middle, and end; it can be understood by a listener or reader; and it incorporates the author’s feelings or stance and insights about an incident.

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**Committing a story to the page externalizes a client’s thoughts:** “Some things are easier to write and read on the page than to say.”

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See also references cited in articles in this issue.
This two-pronged approach also provides support and feedback regarding a participant’s written expression, making it a hybrid between a writing workshop and a psychotherapy group. Group support had been a long-proven, community-accepted intervention for people living with HIV. The idea of a working group, however, establishes a shared task for members, emphasizing a creative act, rather than interpersonal processing, conflict resolution, or improving communication styles. Comments, disputes, and questions that emerge in a narrative competence group would be resolutely re-directed to the narrative: that is, what made this story powerful, painful, resonant, contentious, or disturbing?

Group Membership and Process

Selection criteria for the narrative competence psychotherapy group were relatively simple. Individuals had to be HIV-positive and had to express an interest in writing, whether or not they had experience writing before. They had to be able to attend regularly—barring any new illnesses—and to be willing to share and receive feedback about personal stories read each week. This prerequisite also implied the capacity to hear stories that might deal candidly with sexuality and all its expressions as well as stories dealing with death, loss, abuse, and stigma.

The only exclusion criteria were acute suicidality or psychosis or a personality style inconsistent with respectful sharing or receiving constructive feedback. The capacity to frame and contain personal concerns while doing the work of the group, that is, reflecting on a story was also important.

Each week, the group facilitator instructed members to write for about 45 minutes on one of the suggested “launch pad” topics. The prompts were deliberately broad and lent themselves to HIV-related or non-HIV-related content. Topic examples included “write about a gift” or “write about a good experience writing before.” The facilitator invited two volunteers to read a piece. All stories were confidential within the group. Readers refrained from replying to specific feedback until the group had asked questions and shared their response to the work. Facilitators coached participants on how to give feedback, to encourage safety and respect within the group. Among the other instructions were: do not assume that the reader was the narrator in order to allow the teller some distance from his piece; begin discussion with emphasis on the strengths of the narrative and disclosure of personal, emotional responses to the story; then, consider suggestions for potential edits to make the writing clearer or more emotionally resonant; and suggest creative possibilities for the author, detailing where the writer might go next with the story.

After receiving feedback, the author could clarify the incident or emotional state that informed the piece or comment on specific choices made in the writing process. Authors could also re-read, at a later date, a story they had re-worked in order to get further feedback from the group.

Reaching Beyond other Psychotherapy Models

According to John McLeod, narrative work is different from psychotherapy. Writing is a universal skill in literate populations and is, by definition, a non-medical act that can be self-initiated at no cost. Even stories fleshed out in psychotherapy tend to emphasize problems, conflicts, or points of being “stuck,” while written narratives that are not prompted by a “problem agenda” are “opened wide” and can celebrate pleasure, beauty, or an emerging sense of mastery.

Likewise, stories told with others in mind tend to be clearer than journal entries, the form of writing most often used in therapeutic contexts. Stories are more crafted than journal entries and allow for playful experimentation with voice, character development, and metaphor. The storyteller can also re-discover multiple selves. For example, for many in the narrative competence group, writing was an opportunity to honor the pre-AIDS self alongside the self as patient.

Any story can have multiple interpretations and can counter prevailing sexual or cultural consensus narratives about what life with HIV might mean. Individual group members were often surprised by the interpretations members gave their stories, suggesting that there is “always a story underneath a story” and that most accounts have more than one pos-

References


Comments and Submissions

We invite readers to send letters responding to articles published in FOCUS or dealing with current AIDS research and counseling issues. We also encourage readers to submit article proposals. Send correspondence to rmarks@itsa.ucsf.edu or to Editor, FOCUS, UCSF AIDS Health Project, Box 0884, San Francisco, CA 94143-0884.
"It occurs to me, in my now exhausted state, that my assignment for group is to write about loss. So, sitting on the couch, I begin to string my decade-worth of losses [along with] the last strand.”

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Allan Peterkin, MD, FCP, FRCP is Associate Professor of Psychiatry and Family Medicine at the University of Toronto and a psychiatrist at the Clinic for HIV-Related Concerns at Mount Sinai Hospital. He is the author of six books including Carrying For Lesbian and Gay People: A Clinical Guide (co-authored with Cathy Risdon; University of Toronto Press, 2003). He will be editing a collection of HIV narratives called Still Here: A Post-Cocktail AIDS Anthology. Dr. Peterkin expresses special thanks to Julie Hann, OT; his co-therapist, and to Guy Allen, PhD, who has provided guidance and feedback about the complex task of writing.

It occurs to me, in my now exhausted and fed-up state, that my assignment for group is to write about loss. So, sitting on the couch, I begin to string my decade-worth of losses together as I complete the last, rather basically-patterned, strand. I have long since given up on intricate variations, it is now four cranberries, followed by four pieces of popcorn, less if they happen to fall off in the stringing. I now no longer care about consistency.

And so I recite my Christmas rosary of woe.

I have lost the family that I never really had. I have lost the friends who couldn’t talk about AIDS, the ones who talked of nothing else and the ones who now talk to me only in my dreams.

I have lost in the trade-off of career versus care. I have lost the power of choice which came with the loss of a pay check.

I have lost my pride, because pride doesn’t serve me well in meetings with my social worker. I have lost the hope that I will ever have a home of my own. I have lost my unconditional awe for the medical profession. I have been told too many times, what is, and it hasn’t been. I have lost the partial use of my right eye, some weight, my fear of death, and a few toenails.

I have lost the heart to risk love, and this makes me heartsick. I had on one occasion, lost my will to live, only to be told that I had simply lost my sanity. It found me sitting in the Wellesley psych-ward.

The last cranberry has been fished from the bag and gored into place. As I drape my Christmas project over the tree, I know that in all this loss there is one thing I have kept. I still believe there is a Santa Claus, and I know by the gifts he sends me from time to time, that I am on his nice-list.

Conclusion
According to an anonymous questionnaire, most writing group members have viewed the experience positively. Participants have appreciated the ways in which the group offers a “varied perspective” and requires them to “think [stories] through rather than tell them off the cuff like in therapy.” They also have felt empowered by the process of creating a final product that could be revisited and modified and shared with friends and family or in other therapeutic contexts.

For CRB, and clients like him, the process of discerning key metaphors, of thinking stories through, of making them coherent, and of then describing to fellow travelers what may be “easier to write and read than say” can create a foundation for emotional breakthrough. In CRB’s case, writing out his litany of loss enabled him to contemplate a future while acknowledging a past so often defined by illness and bereavement.
Recent Reports

HIV Narratives of Substance Users


Narratives elicited from HIV-positive drug users went beyond the experiences of loss to describe physical, psychological, and spiritual benefits related to their HIV diagnoses.

Researchers conducted in-depth, semi-structured interviews with 60 HIV-positive active heroin and cocaine users in Hartford, Connecticut in 1999 and 2000. The sample was 48 percent Puerto Rican and 45 percent African American. The average age was 41, and 68 percent of participants were male.

Researchers identified three frameworks for the narratives: a benefit orientation—the individual acknowledged ways HIV had directly or indirectly caused positive changes in physical, psychological, or spiritual life; a loss orientation—the individual focused on ways he or she had experienced physical or psychological hardship; and a status quo orientation—the individual viewed his or her HIV status with a sense of indifference.

Many benefit orientation narratives involved reports of better physical self-care since an HIV diagnosis. Additionally, many participants viewed an HIV diagnosis as an opportunity to start over or to connect with family members and friends.

Loss orientation narratives commonly focused on physical symptoms of HIV. It is notable that most participants were significantly more distressed by visible symptoms—especially those that might have marked them as having HIV—than by symptoms that caused more severe pain or by those with more serious health implications.

Status quo orientation narratives were characterized by a calm resignation about HIV and the inevitability of death. This perspective may be the result of a social context in which poverty, drug use, and violence are often more immediate threats for these individuals than the risk of AIDS-related death.

Seroconversion Narratives of Gay Men


Themes of relationship, control, and risk management are prominent in the narratives of recently seroconverted men, according to an Australian study that collected descrip-

Next Issue

As many as half of the people with HIV in the United States are homeless or at imminent risk of homelessness, and HIV is more than three times as prevalent among homeless people than it is among people who are housed. In the March issue of FOCUS, Barry Zevin, MD, Medical Director of Tom Waddell Health Center in San Francisco, reviews the biological, psychosocial, and spiritual factors affecting homeless people with HIV.

Also in the March issue, Michael Cooley, the Prevention with Positives Program Manager at the STOP AIDS Project in San Francisco, recounts his own experience of homelessness, its roots and its relation to his own seroconversion. He also suggests interventions that might have altered these events.
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