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Managing identity impacts associated with disclosure of HIV status: a qualitative investigation

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Abstract

Disclosure of HIV status to potential and current sex partners by HIV-positive people (HIVPP) is a complex issue that has received a significant amount of attention. Research has found that disclosure depends upon the evaluation by HIVPP of potential benefits and risks, especially of the risks stemming from the profound social stigma of HIV and AIDS. Drawing on concepts from Goffman's classic stigma theory and Anderson's more recently developed cultural-identity theory of drug abuse, we analyzed data from in-depth, post-intervention qualitative interviews with 116 heterosexually active, HIV-positive injection drug users enrolled in a randomized trial of a behavioral intervention to prevent HIV transmission. We explored how disclosure experiences lead to "identity impacts" defined as: (1) identity challenges (i.e. interactions that challenge an individual's self-concept as a "normal" or non-deviant individual); and (2) identity transformations (i.e. processes whereby an individual comes to embrace a new identity and reject behaviors and values of an old one, resulting in the conscious adoption of a social and/or public identity as an HIV-positive individual). Participants engaged in several strategies to manage the identity impacts associated with disclosure. Implications of these findings for research and prevention programming are discussed.

Keywords

HIV disclosure; injection drug use; social identity; HIV prevention

Introduction

Disclosure of HIV status to potential and current sex partners by HIV-positive people (HIVPP) is a complex issue that has received a significant amount of attention (Ciccarone et al., 2003; Crepaz & Marks, 2003; Kalichman, DiMarco, Austin, Luke, & Williams, 2003). Sex without disclosure is relatively common among HIVPP, with less than 50% disclosing their status prior to vaginal, anal or oral sex, although fewer reported unprotected vaginal or anal sex without disclosure (Ciccarone et al., 2003). The notion that disclosure consistently leads to safer sex behavior has received mixed support (Crepaz & Marks, 2003; Latka et al., 2006; Simoni & Pantalone, 2004). Among HIV-positive men who have sex with men (MSM) a curvilinear relationship has emerged with inconsistent disclosure associated with high-risk sex as compared with both consistent disclosure and consistent *non*-disclosure (Hart et al., 2005; Parsons et al., 2005). Because consistent disclosure is seen as a risk reduction strategy, several studies have described HIVPP's inconsistent or selective disclosure (Parsons, VanOra, Missildine, Purcell, & Gomez, 2004b; Serovich & Mosack, 2003) and various categories, such as "eventual" and "context-based," of disclosers have been described (Parsons, Missildine, Purcell, & Gomez, 2004a).

Disclosure has been framed as the outcome of a complex calculus by which HIVPP evaluate its potential benefits and risks (Anderson, 1998; Black & Miles, 2002; Cusick & Rhodes, 1999). The risks and adverse consequences associated with disclosure stem from the stigma of HIV (Kalichman, Nachimson, Cherry, & Williams, 1998; Klitzman & Bayer, 2003; Klitzman et al., 2004). Such consequences are particularly acute among current and former drug users, who often are already stigmatized (Luoma et al., 2006; Room, 2005). Parsons and colleagues (2004b) identified several adverse effects of disclosure for HIV-positive injection drug users (IDUs) related to HIV stigma – e.g. rejection, and loss of intimacy and material resources. Others have found that some sex partners have a violent reaction to disclosure or other HIV-related communications (el-Bassel, Gilbert, Rajah, Foleno, & Frye, 2000; Rothenberg & Paskey, 1995).

In addition to these risks, disclosure can be viewed as having identity impacts (Arnold, Rice, Flannery, & Rotheram-Borus, 2008). Goffman's (1963) classic stigma theory and Anderson's (Anderson, 1994; Anderson, 1998; Anderson & Mott, 1998) cultural-identity theory of drug abuse provide a theoretical frame within which to understand disclosure as something consequential to feelings of social identity. According to Goffman, people possessing a stigmatizing characteristic, such as HIVPP, are identified by society as "deviant" or possessing "spoiled" identities and may try either to avoid "identity challenges," social interactions that disconfirm a non-deviant individual self-concept, or may undergo "identity transformations," attempts to achieve a non-stigmatized identity. Anderson (1998) identifies several experiences particularly consequential to identity change, such as "status passages," experiences that fundamentally alter an individual's social status, and "felt loss of control in defining an identity," social interactions whereby others fundamentally define a person's social identity for them.

Previous applications of identity concepts to HIVPP have emphasized the importance of feeling and appearing "sick" or alterations to corporeal function to identity transformations and challenges (Charmaz, 1994; Charmaz, 1995; Kelly, 1992; Tewksbury & McGaughey, 1998). Recent diagnosis and/or being asymptomatic is associated with non-disclosure

(Crepaz & Marks, 2003), suggesting that people may seek to avoid the stigma of identification as HIV-positive when they can. Yet, in the post-HAART era many HIVPP learn of their status not because they are symptomatic and, thus, face the challenge of integrating an identity as a “sick” or “deviant” person when they feel well and are able to conceal their stigmatized status (Arnold et al., 2008).

In this paper, we describe how HIV-positive IDUs manage the identity impacts associated with status disclosure in the post-HAART era. Using data from in-depth interviews with 116 HIVPP who participated in the Intervention for Seropositive Injectors – Research and Evaluation (INSPIRE) study, an HIV prevention intervention described in more detail below, we describe: (1) strategies that HIVPP IDUs use to manage the identity challenges that do or are anticipated to arise from disclosure; (2) HIVPP who have undergone identity transformations and publicly identify as HIV-positive; and (3) the influence that participation in INSPIRE had on both disclosure of HIV status to sexual partners and social identity impacts. We discuss our results as we present them and conclude with implications for research and practice.

Methods

In-depth post-intervention interviews were conducted with 116 HIV-positive heterosexually active IDUs (defined as having had an opposite sex partner in the three months prior to the study and having injected in the 12 months prior to the study) who participated in the INSPIRE study. Briefly, INSPIRE was a randomized controlled trial of a 10-session HIV prevention intervention and included experimental and attention control arms. It was conducted in four US cities (Baltimore, Miami, New York, San Francisco) between 2001 and 2005 (see Purcell et al., 2004a). The experimental condition was theory-based with seven group sessions, two individual sessions and one peer volunteer activity (for details on the intervention see Purcell et al., 2007); in addition to skills-based risk reduction work, participants were encouraged to take on new “social roles” via peer mentoring, discussing safer sex and drug use with their peers, and disclosure of HIV serostatus or consistent condom use/sterile needle use or other risk reduction strategies. The control condition consisted of eight sessions in which information was presented on topics relevant to participants’ lives, such as employment/work, discrimination, drug use and abuse, and basic HIV prevention information, and a facilitated discussion ensued. Participants in both conditions reported significant reductions in sexual HIV risk behavior, with no statistically significant difference between the groups (Purcell et al., 2007).

In order to understand how INSPIRE was experienced by participants, qualitative interviews were conducted in 2005 with 68 participants from the experimental condition and 48 from the control condition. Participants were eligible for inclusion in the qualitative sub-study if they had completed at least four group sessions and the 12-month follow-up survey.

Procedures

Four trained site interviewers conducted the interviews 12–24 months after participants had completed their last group session; using interview guides, interviews ranged from 45–90 minutes, and participants were reimbursed \$25. All interviews were audiotaped and transcribed verbatim. Content areas included general and specific impacts of the INSPIRE program and the experience and impact of the peer mentoring component (for experimental condition participants). Specific questions on HIV disclosure to friends, family, and sex partners before and after the intervention were included.

Analysis

Our analytic approach was based on grounded theory, which seeks to develop knowledge based on information and insights provided by the people who experience a particular phenomenon (Straus & Corbin, 1998). We used two strategies – contextualizing and categorizing – to analyze the data (Patton, 1990; Straus & Corbin, 1998). First, the transcripts were summarized in a “digest” that identified the major themes of the interview. In addition, a contextualizing strategy of describing the social and cultural context of each research site was included in the digests. Using Atlas.ti 5.0 qualitative software (Scientific Software Development, Berlin), we conducted coding of the data in three steps. First, based on the summaries and transcripts read by the cross-site analytic team, a list of analytic areas represented in the data were composed and given a code (from a “closed code” list). Second, each site analyst reread the transcripts and identified blocks of text to be given a descriptive label (either a label from the closed code list or an original one, termed an “open code”). Next, the open-coded data were organized under and integrated into the closed code list. Third, the data under the code “disclosure” were re-read and recoded into sub-categories in order to refine the analytic categories used (Straus & Corbin, 1998). Within the disclosure codes, we identified several identity-associated themes, including “managing identity challenges associated with disclosure,” “identity transformations and disclosure” and “effects of INSPIRE on disclosure.” In our results, we present quotations from the disclosure codes that illustrate these themes, identifying the study site, study condition, sex of participant and a dummy identification number.

Results

Study participants

Sociodemographic characteristics are shown in Table 1. This sample was representative of the larger study sample (Purcell et al., 2004b).

Managing identity challenges associated with disclosure

Participants managed the anticipated identity challenges associated with status disclosure in several ways, including not disclosing, timing disclosure or selectively disclosing to minimize the negative effects on identity. Some partnered only with other HIVPP and a few actively concealed their status or described having done so in the past (data not shown). Often the stated rationale for these strategies referenced shame and anticipated rejection due to their status.

One female participant reported that she had not told her partner of 18 years about her status because of how he and his family had reacted to a relative’s disclosure. This reinforced for her the knowledge that an HIV-positive status represented what Goffman (1963) called a “spoiled” identity:

Mmm cause uh, his cousin? When she, when she uh, uh told us about she had it? All of us was in the same house. Him and his brother and mother and they like, flipped out about it, you know how, you know? So I still got that in my head, how they acted towards her ... Then an- ... c- ... they went and got cups – they didn’t want her drink out they cups and stuff you know? ... And I still think about this, how they act towards her ... Cause she was, she was cryin’ to me. Yeah. BA 1001
Control Condition

This participant’s fear of rejection was due to witnessing what Anderson (1998) has called a “status passage” – an interaction that makes an individual feel deviant or different from important others and radically alters their social position relative to such people.

Managing identities and avoiding anticipated challenges, some participants engaged in strategies that allowed time for their new partner to get to know them before revealing their HIV status. These participants wanted first to be seen and experienced as not deviant in order to eventually lessen the negative impact of disclosure. One male participant, in explaining why he did not disclose his status to a casual sex partner with whom he had protected sex once, said:

And you know, I just wanted ... to get to know M, and let M get to know me, and see the type of person that I am before I disclosed my ... you know, my status.
NYC 1006 Control Condition

A few participants reported feeling unfairly burdened by having to be the one who discloses, particularly in cases where assumptions about status were based on perceptions that confirmed a desired social identity, that is, that they are seen by the outside world as without the stigmatizing status of being HIV-positive:

People out there, they think because a person looks marvelous(?), or handsome, or cute ... you know, and they look clean, you know, they think that it's okay. And this is the information that needs to go out there, that it's not necessarily okay. You know, if you wanted to be with that person, you have to find out about that person. (Pause). In order to protect yourself. NYC 1004 male Experimental Condition

Another male participant revealed that he resented what he perceived as HIVPP being fully responsible for disclosure and for whether protection was used:

I feel, one, I feel that everybody is responsible. I'm not, you know, it's like I resent the fact that it is sort of like society is pointing their finger at the HIV-positive person ... as if he is responsible for protecting everybody ... but it's like, it's unfair. NYC 1005 Experimental Condition Male

Thus, some participants appear to be interpreting the messages in recent "Prevention with Positives" programming (Centers for Disease Control and Prevention [CDC], 2003a, Centers for Disease Control and Prevention [CDC], 2003b) as signaling that they are solely responsible for disclosure and use of protection, thereby increasing pressure on them to disclose. Resentment may result when disclosure is experienced as a particularly challenging social interaction or it initiates what Anderson (1994) has called a "felt loss of control in defining identity." Such a loss of control may be particularly difficult for those who perceived themselves as "normal" and not deviant (Goffman, 1963) or are not visibly sick.

Identity transformations and disclosure

Some participants voluntarily exposed themselves as stigmatized, moving from what Goffman (1963, p. 100) terms a "discreditable" person to a "discredited" one. A handful were either "public" disclosers, who presented their status as part of their public face, or "consistent" disclosers, whose status was not necessarily part of their public face but who reportedly consistently disclosed to all potential sex partners. One female participant observed that not disclosing and actively concealing her status reflected a fundamental discomfort with one's identity. She elaborated on how her social identity as an HIV-positive person influenced her disclosure to a potential romantic partner:

I cain't do that. (not disclose) I cain't do that. I cain't live like that. I'm – I have to be comfortable with – in ME. You know, I, I would be terrified! That he would find out. And too many people know I got it! Cause I was so open with it, you know? We'd be on the – I mean people walk up to me everywhere – when me and him are out? And you know "You been down to [AIDS service organization]?" You know? (Laughs). "They got the AIDS walk" you know? (Laughs). So ... he would look at

me like “The WHAT?” (Laughs). So. It was quite easy. (to disclose) BA 1008
Experimental Condition

Participants who were publicly open about their status often had the fewest or easiest disclosure discussions either because they partnered with other HIVPP or because potential partners knew about their status beforehand. They were typically adamant about disclosing, regardless of partner type or sexual activity. They often felt empowered by disclosing publicly and became local HIV experts. One participant described how she used her status to educate and inform people in her community:

One of the guys say, uh, started calling me ... you got any condoms? “Cause I don’t wanna get that stuff.” I said, “What stuff?” He say “That AIDS stuff.” I said “Well, you know what? I have HIV, and that next to AIDS.” And he say “What?” and he forgot all about that girl, and he sit down, and then his friend came, and asked him what’s takin’ him so long, he say “I’m talking to XX about somethin’ that’s personal” (whispers) “About AIDS (?)” And he sit down and he listen. So I had about four or five people – between a boy – men, and the ages of ... thirteen clean up to eighteen! SF 1010 Experimental Condition

However, not all participants articulated an identity impact associated with HIV diagnosis or disclosure. One participant reported that he did not conceptualize HIV as part of his identity:

I’m HIV positive. It’s just somethin’ I have. It’s not me. You know, it didn’t change the me that I’ve always been. I’m just HIV positive. And that’s it (chuckles). That’s it. NYC 1009 Experimental Condition

Effects of Intervention for Seropositive Injectors – Research and Evaluation (INSPIRE) on disclosure and identity

For some experimental arm participants, INSPIRE provided a highly practical forum to practice disclosing skills and the language for doing so. Several reported an improved ability to communicate their status, which had identity effects. INSPIRE participant publicly identified as HIV-positive, if only to the intervention group to which they were assigned. For some, this was the only occasion that they identified themselves in a group setting and/or to relative strangers. Participation was also consequential to identity in that participants met and interacted with others who readily disclosed their status, providing behavior and identity models, as well as examples of how public disclosure as a positive experience. INSPIRE, then, facilitated “identity transformations,” which may include the negation of a former identity and the adoption of a new one (Travisano, 1970). One participant stated:

It put me around persons who were in this entity, and they were OK with the fact that they had a – they had disclosed, and there were no negative repercussions ... And then it got easier as I began to circulate in the community of disclosure, and meeting people that were OK with it. So it made it easier and easier and easier to be more comfortable disclosing, and with that disclosure comfortability (sic), it made me OK with the fact that I do have this condition. SF 1013 Experimental Condition

Furthermore, INSPIRE offered a space for participants to present a public face as an HIV-positive person. One male participant stated:

But you know, bein’ around other people that was HIV...and listenin’ to them share, and me share ... you know, better helped me to be able to let people know. “Hey, this is it, I’m HIV.” MI 1018 Experimental Condition

Participation also helped to alleviate some of the shame or self-stigma (Link, Yang, Phelan, & Collins, 2004) associated with being HIV-positive. Several experimental arm participants described how discussing their status within the groups helped them to disclose outside the

groups. This in turn enabled them to become HIV experts, offering hope, information and models to others as their fellow participants had offered to them:

Because that was the first time I had ever been on the outside of my INSPIRE group, with other people that I didn't know. And ... like I said (chuckles), INSPIRE helped me to open up and feel comfortable about bein' HIV. And I didn't feel ashamed ... or feel sorry for myself talkin' about it when I went to the – outside my group ... INSPIRE gave me, like I said, the whole inner will within myself, so when I went outside of my group, I was able to talk to somebody else and give THEM a little hope ... MI 1019 Experimental Condition

Limitations

There are several limitations to these findings. First, each interview covered a range of topics; while accounts of disclosure were identified, several important threads were not explored during the interviews due to time constraints. It is important to note that the INSPIRE design also may have influenced our results. Thus, the relationship observed between disclosure and identity may reflect the content of the experimental arm, which sought to influence identity via peer mentoring. However, we found that some participants in the control arm used similar language and provided disclosure accounts similar to those in the experimental arm, suggesting that these impacts may be universal. It is possible that the similarities stem from the fact that both sets of participants disclosed their HIV status within the groups. Finally, it is important to note that these data represent the perspectives of a self-selected group: HIVPP IDUs who first chose to disclose their HIV status to a study interviewer and then to a group of strangers. Furthermore, the data were collected between one and two years after the end of the study, thus the results presented on how the INSPIRE intervention influenced disclosure and identity may reflect only the most profound and lasting effects.

Conclusions and implication for future research and practice

These data offer several illustrations of how disclosure of HIV status was experienced by participants as being consequential to identity. They are consistent with earlier research that suggest that the stigma associated with HIV affects how and under what conditions HIVPP disclose (Parsons et al., 2004b; Kalichman et al., 2003; Tewksbury & McGaughey, 1998). However, the results move beyond describing people who engage in selective disclosure to an examination of how identity construction and maintenance processes influence disclosure in sexual relationships. Disclosure of HIV status, then, can be seen not only as communication behaviors based on rational cost–benefit analyses, but as actions with *identity-related* risks and benefits.

There are two important programmatic implications of these results. First, the INSPIRE intervention appeared to provide fertile ground for identity work among HIVPP. Thus, achieving consistent disclosure via the integration of HIV as central to self-concept and social identity may be facilitated in such environments. Group-level interventions that are socially interactive may be most useful as they match the interactive nature of disclosure. Second, although not its intention (Center for Disease Control and Prevention [CDC], 2003a; Janssen & Valdiserri, 2004), that some perceived the shift in national prevention policies (CDC, 2003a, 2003b), from shared or joint responsibility for protection to emphasizing the HIVPP's role as rendering HIVPPs wholly responsible is noteworthy. Programs must ensure that HIVPP understand that there are many ways to protect themselves and others, of which disclosure is only one.

Finally, suggestions for future research include exploring further identity and disclosure in the post- HAART era, particularly the relationship among HIVPP with overlapping and stigmatizing identities and focused research on gender differences. Arnold et al. (2008) provides a disclosure process model, involving identity concepts, which could guide such research. Conversely, more research should be conducted among non-drug using HIVPPs, whose experiences may be different or differently focused. Future research should also attempt to capture the socially interactive nature of disclosure by planning contrasts within studies and engaging in ethnographic or participant-observation research that would better reflect these processes than the data presented here and would illuminate how identity as an HIVPP is constructed and maintained through social interaction.

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Table 1

Comparison of INSPIRE participants who were randomized in the full trial with those who participated in the qualitative sub-study.

Characteristics	Randomized (n = 966)		Qualitative study participants (n = 116)	
Age (mean, SD)	42.4 (6.6)		43 (6.4)	
	9.5		7.4	
Duration of HIV infection (median, years)	n	(%)	n	(%)
Condition				
Experimental arm	486	(50.3)	68	(58.6)
Control arm	480	(49.7)	48	(41.4)
Biological sex				
Male	616	(63.8)	74	(63.8)
Female	350	(36.2)	42	(36.2)
Race/ethnicity				
White	88	(9.3)	8	(7.0)
African American	636	(67.4)	77	(67.5)
Hispanic	148	(15.7)	22	(19.3)
Other	72	(7.6)	7	(6.1)
City				
Baltimore	265	(27.4)	22	(19.0)
Miami	260	(26.9)	43	(37.1)
New York	217	(22.5)	25	(21.6)
San Francisco	224	(23.2)	26	(22.4)
Education				
Less than high school	416	(43.3)	59	(50.9)
High school or more	545	(56.7)	57	(49.1)
Any injection risk behaviors w/HIV-negative or unknown status in past three months				
Yes	271	(28.7)	35	(30.7)
No	673	(71.3)	79	(69.3)
Any unprotected v/a sex w/ HIV-negative or unknown status in past three months				
Yes	255	(27.2)	30	(26.3)
No	682	(72.8)	84	(73.7)
Sexual orientation				
Heterosexual	678	(70.9)	79	(68.7)
Bisexual	172	(18.0)	24	(20.9)
Homosexual	56	(5.9)	6	(5.2)
Unsure/none of the above	50	(5.2)	6	(5.2)
Sexual behavior				
Sex with opposite sex	670	(75.5)	79	(73.1)
Sex with both sexes	135	(15.2)	21	(19.4)
Sex with same sex	82	(9.2)	8	(7.4)