

Disclosure and Nondisclosure Among People Newly Diagnosed with HIV: An Analysis from a Stress and Coping Perspective

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Abstract

Disclosing HIV status to friends, family, and sex partners is often stressful. However, HIV disclosure has been associated with improved physical health, psychological well-being, and improved health behaviors. The aim of this study was to address some of the gaps in the literature regarding the disclosure process by conducting a mixed-methods study of disclosure in people newly diagnosed with HIV and the relationship of disclosure to stigma and social support. The CHAI (Coping, HIV, and Affect Interview) Study was a longitudinal cohort study that followed individuals who were newly diagnosed with HIV. The study took place from October 2004 to June 2008 in the San Francisco Bay Area. This sample includes data from 50 participants who were interviewed 1, 3, and 9 months following diagnosis with HIV. We identified four main approaches to HIV disclosure that revealed distinct differences in how participants appraised disclosure, whether disclosure was experienced as stressful, and whether disclosure or nondisclosure functioned as a way of coping with an HIV diagnosis. Implications of these findings for disclosure counseling are discussed.

Introduction

TESTING POSITIVE FOR HIV is stressful for many people.^{1–3} The year following diagnosis is characterized by a cascade of potentially stressful events, including the need to make decisions regarding when and to whom to disclose one's seropositive status.^{4,5} Disclosure of HIV status to friends, family, and sex partners has been of interest to researchers since the early days of the HIV epidemic, and disclosure of HIV status is generally associated with benefits in terms of physical health,⁶ psychological well-being,⁷ and health behaviors,⁸ including increased adherence to highly active antiretroviral therapy (HAART).⁹ Studies have also found that HIV-positive individuals who disclosed their status had little regret over time.^{10,11}

Despite the frequent association of disclosure with beneficial outcomes, disclosure of HIV status is not universally positive. Research findings have been mixed and point to the need for more in-depth study of the social and psychological context in which decisions about disclosure are made. For instance, many studies of disclosure of HIV and other sexually transmitted diseases focus specifically on disclosure to sex

partners and the relationship between disclosure and sexual risk behaviors.^{12–14} Most of these studies limit their sample to men who have sex with men (MSM).^{14–18} In a review of the literature on disclosure and safer sex practices, Simoni and Pantalone¹⁹ found conflicting results and concluded that disclosure did not necessarily lead to safer sex.

Other studies of HIV disclosure indicate that the association of disclosure and mental health outcomes varies depending on the targets of disclosure and the quality of those relationships.^{5,20} Race, ethnicity, gender, and culture also likely play a role in the effects of serostatus disclosure. For example, a study of Latino men found that disclosure is related to greater quality of social support, increased self-esteem, and lower levels of depression,⁷ whereas another study found that greater disclosure was linked to increased depression in Latinas but found no relationship between disclosure and mental health among African American and white women.²¹

In trying to understand the predictors, obstacles, benefits, and disadvantages of disclosure, researchers have focused on variables such as the preferred targets, outcomes of disclosure, and reasons for disclosing or not disclosing.^{5,22,23} However, these studies have generally been cross-sectional

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and asked participants to describe their disclosure experiences retrospectively many years after their diagnosis. A recent review of the disclosure literature support the need for longitudinal research that examines disclosure as a process that unfolds over time rather than a single event in which the disclosure is made to a given individual and is then finished. In their review, Chaudoir et al.²⁴ also noted that of the 210 disclosure studies they reviewed, 69% focused on factors antecedent to the disclosure and 56% assessed an outcome of disclosure, but only 7% examined aspects of the disclosure process *per se*.

Disclosure and Stress and Coping Theory

Disclosure has been found to be a recurrent stressor following HIV diagnosis.⁴ Both disclosing and not disclosing one's HIV status can serve as a way of coping with being positive.⁴ From the perspective of stress and coping theory,^{25,26} the process of coping with HIV begins with an appraisal, defined as the individual's evaluation of the personal significance of HIV, and his or her perception of the adequacy and availability of coping resources. An appraisal of HIV as stressful prompts coping. Coping refers to the thoughts and behaviors a person uses to regulate distress or manage the problem causing distress and can include aspects of disclosure such as disclosing to garner social support and even decisions not to disclose HIV status. The process then continues, depending on the effectiveness of the coping response, and reappraisal and additional coping attempts can occur. Appraisal and coping both generate emotion throughout the coping process. The process of coping is dynamic, with appraisal, coping, and emotion influencing each other as time goes on following initial diagnosis. For example, if the thought of telling your loved one your diagnosis is perceived as threatening, it will lead to fear and anxiety, and nondisclosure can be a coping response to reduce those distressing emotions. Coping is contextual in that what is appraised as threatening, the emotions that appraisal engenders, and the possibilities for coping in response to that appraisal depend, in large part, on the individual's social and historical context.

Disclosure, Social Support, and Stigma

Newly diagnosed people's need for social support on the one hand and their concerns about stigma on the other contribute to the complexity of the disclosure process. Both have been found to be correlated with disclosure.²⁷ Social support is an important resource for people diagnosed with HIV, but accessing this resource for HIV-related issues requires disclosure of one's status. Evidence suggests that multiple kinds of social support, including emotional, informational, and instrumental, are generally beneficial to people living with HIV. For example, studies of social support among people with HIV have found that satisfaction with social support is inversely related to depression^{23,28} and is also related to quality of life²⁹ and clinical outcomes like viral load.³⁰

Experiences of HIV-related stigma and fear of being stigmatized are major concerns for people living with HIV³¹⁻³³ and might negate the possibility of attaining HIV-related social support. Stigma is related to avoidance of disclosing HIV status, poorer medical adherence³⁴, depression, anxiety, stress, and feelings of hopelessness among people with HIV.^{35,36} Stigma fears seem to be particularly strong among

persons of color.³² In addition to fear of being stigmatized, some individuals internalize society's negative views concerning HIV, which can result in internalized stigma and self-hatred.³⁵

In the present article, we explore the longitudinal process of disclosure over the first 9 months after testing positive for HIV. Unlike most previous studies that tend to focus only on sex partners or family members, the interview goal was to include every disclosure episode no matter who the participant disclosed to. Using a qualitative approach, we focused on participants' appraisals of disclosure to discover if and why disclosure was appraised as stressful or not, and how these appraisals influenced subsequent disclosure decisions. We identified reasons for disclosure, participants' goals for disclosure, reactions from those told, and how the participants felt about each encounter.

Methods

Participants and procedures

The CHAI (Coping, HIV, and Affect Interview) Study was a longitudinal cohort study that followed individuals who were newly diagnosed with HIV, with the aim of understanding the process of adjustment to HIV diagnosis. Participants in the study were interviewed seven times over the course of 18 months after notification of HIV positive serostatus. The approximately 2-h interviews consisted of interviewer-administered quantitative questionnaires and qualitative interviews. Interviews were digitally recorded and transcribed verbatim. The study received human subjects approval from all participating institutions.

Participants were recruited in the San Francisco Bay Area through local HIV testing sites and clinics between October 2004 and June 2008. Each participant was given \$30 at the completion of each interview. To be included in the study participants had to (1) have been informed for the first time that they were HIV positive within the previous 8 weeks (actual range 1 to 14); (2) speak English; (3) be 18 years or older; and (4) have the ability to provide informed consent. HIV status and date of diagnosis were verified with the referring clinic or provider. Evidence of severe cognitive impairment or active psychosis, as assessed by trained interviewers, resulted in exclusion from the study.

This study focuses on data from the first 50 participants who completed the three interviews (baseline, 3-month, and 9-month) that included questions concerning their experience of disclosing their HIV status. Of the first 75 participants enrolled in the CHAI Study, 50 had complete disclosure narratives from the baseline, 3-month, and 9-month interviews (17 dropped out of the study by 9 months postdiagnosis and 8 had incomplete narratives).

Narratives and qualitative analysis

At the baseline interview (an average of 6.5 weeks after diagnosis), the participants recounted who, if anyone, knew of their HIV status; how those who knew found out (whether the participant told them or they found out some other way); and whom they told first, second and so on. In subsequent interviews, participants were asked who else knew about their serostatus. Participants were asked follow-up questions if they reported that anyone else knew their HIV status in

order to elicit the story of each disclosure episode including: reasons for disclosure, how the disclosure happened, reactions to disclosure, and the emotions accompanying each episode.

We used a qualitative/quantitative mixed-methods approach that began with descriptive and thematic analyses by case.³⁷⁻⁴⁰ We developed case summaries of the disclosure process for each participant. A case consisted of the disclosure sections of the baseline, 3-month, and 9-month interviews for each participant. A case summary consisted of descriptions of which people the participant disclosed to (or who found out) at each time point; why the participant decided to disclose; how he or she conveyed the information; how the disclosee responded; and how the participant felt about the response. We noted if disclosure was appraised as stressful or as positive, and if the participant gained the desired response by disclosing. Relevant and illustrative quotes were included in each summary. The case summaries were written by two members of the qualitative team and verified by a third member.

After we completed the process of verification, the analytic team proceeded to a cross-case analysis,⁴¹ and the participants were grouped according to thematic similarities around disclosure issues.³⁸ Only after the groups were formed did we turn to the quantitative data and compare the groups on a number of measures relevant to the themes that had emerged. The goal of the quantitative analysis was not to predict outcomes but to elaborate on and to verify the qualitative findings.

Quantitative measures and analysis

Social support. We administered the Social Provisions Scale,⁴² a 24-item scale, at 2 months postdiagnosis to assess six dimensions of social support. The scale has shown sufficient reliability and validity in previous studies, with reliability coefficients between 0.87 and 0.91 in several different populations.⁴² The six subscales measure Attachment (e.g., I have close relationships that make me feel good), Social Integration (e.g., There are people who like the same social activities I do), Reassurance of Worth (e.g., There are people who admire my talents and abilities), Reliable Alliance (e.g., There are people I can count on in an emergency), Guidance (e.g., I have a trustworthy person to turn to if I have problems), and Opportunity for Nurturance (e.g., There are people who call on me to help them).

Stigma. We assessed stigma with a combined scale consisting of 12 total items selected from two stigma scales ($\alpha=0.81$): Perceived stigma⁴³ and Internalized stigma³⁵ at 6 months postdiagnosis. Four subscales included Social Rejection (e.g., Some friends have rejected you because you have HIV), Internalized Shame (e.g., You feel others think you are to blame for having HIV), Social Isolation (e.g., You feel set apart from others who are well), and Internalized Stigma (e.g., You are embarrassed that you have HIV).

Demographics. At baseline we assessed self-reported race/ethnicity as African American, Hispanic, White, Asian/Pacific Islander, or other. Because of the small numbers in the Hispanic, Asian/Pacific Islander, and other categories, we combined them for analysis. Sexual orientation was assessed as gay, heterosexual, and bisexual/other.

Physical Health was assessed at baseline and 9 months by CD4 cell count, a measure of the strength of the immune system and viral load assays, which are both indicators of HIV progression. Physical Symptoms were assessed using a modification of the scale developed by the AIDS Clinical Trials Group.⁴⁴ Participants are asked whether they have experienced each of a series of 22 possible symptoms (e.g. cough or trouble catching your breath, headaches, loss of appetite) in the preceding 30 days as well as how much the symptom bothered them.

Differences among the four disclosure groups on continuous measures were assessed with one-way analyses of variance. Pairwise differences were assessed with *post hoc t* tests. These, like other *post hoc* tests except the Scheffé, do not protect the overall α , but they do maximize power with our modest sample sizes. Exact tests were used for contingency tables with categorical differences between groups.

Qualitative results

The 50 participants in this sample mostly were male (92%), and 78% of the men identified as gay. Sixty-three percent were white, 19% African American, and 12% Latino. This breakdown by gender, sexual orientation, and ethnicity mirrors that of the larger population of people newly diagnosed with HIV in the San Francisco Bay area from which the sample was drawn, with the exception of Latinos, who are slightly underrepresented in this sample.⁴⁵

As in previous research, there was a wide range of disclosure over the 9 months after HIV diagnosis. Some participants disclosed to no one or only to their current partner, whereas other participants disclosed to their entire family as well as a wide circle of friends and acquaintances. For those who did disclose, they typically disclosed first to their significant other (primary partner), friends, or family, then later to nonprimary sex partners. Fifty percent of the sample had not disclosed to any family members by 9 months postdiagnosis. Of those who did disclose to family, the mother was the most common person disclosed to, with fathers and other siblings disclosed to less frequently. Other relationship domains in which participants disclosed included past sex partners, housemates, support groups, co-workers, and acquaintances. Most participants recounted disclosing to sex partners either just previous to engaging in sexual activity or by seeking out sex partners with the same HIV status in advance (serosorting). Of the 50 participants in our study, 12 reported lying about their serostatus at any point, but only 2 lied to sex partners. Three participants were "outed" against their wishes, 2 by family members and 1 by a medical provider.

The cross-case analysis revealed distinctive thematic patterns that delineated four groups among the participants: Stigma Concerns, Social Isolation, Strategic Disclosure, and Universal Disclosure. The participants in the four groups differed qualitatively on how they appraised disclosure and on the process of disclosing or not disclosing. These patterns were evident in whom they chose to tell or not tell, how they disclosed, whether the disclosure or nondisclosure was appraised as stressful in itself, and whether it served as a way of coping with an HIV diagnosis. Furthermore, the groups differed on how or whether stigma concerns and social support needs affected disclosure decisions.

Stigma Concerns (n= 16)

When I first became HIV positive, I thought I had to tell everyone? And I started telling people, and then realizing how some people reacted to it, it's just like, I don't want to deal with it right now, so, no, I haven't told anyone else. [Male, White, age 37]

The participants in this group tended to have disclosed to a few people at the baseline interview, then had little additional disclosure at months 3 and 9. The initial disclosures in this group tended to be to their partners and a few close friends. Of the 16 participants in this group, only 4 had disclosed to any family members by the 9-month interview.

Early disclosure was typically described as an attempt to cope with their new status as HIV positive by garnering social support. In this group, these attempts were, for the most part, unsuccessful. Many participants felt that they were not given the kind of support they wanted or needed.

I felt like I wanted to be close to her again, so I told her, which in retrospect, wasn't a good idea. 'Cause she's not capable of being there for me. [Male, White, age 50]

Participants in this group frequently had at least one negative reaction when disclosing their status.

I called her in tears and said, "Mom, I just tested positive," and she said, "Look what you've done to yourself." It made me feel horrible. [Male, White, age 36]

It is possible these early negative disclosure experiences played a role in the limited additional disclosure among this group.

Participants in this group cited a number of reasons for not disclosing their status to others, including not wanting to be a burden, and not feeling educated enough about HIV themselves to be able to educate others. But, more commonly these participants described feeling shame and guilt and other concerns related to stigma, such as fearing that people would share the information with others.

I think that it's a burden...it's big news, as far as (chuckles) I'm concerned. It's not like finding out you have diabetes or arthritis. I mean, this is a different kind of information. And I don't want to tell people and burden them unnecessarily. And then another part of it is when you tell people this - I mean, obviously - I'm not saying that I feel ash...well, I do feel ashamed. So I think that when I tell people that I'm HIV positive, of course they're going to sympathize, but then on some level they're going to want to know how it happened. [Male, White, age 47]

This group had high rates of stigma expressed in their narratives, with 75% (12) either mentioning fear of being stigmatized if they disclosed or describing feelings of self-stigmatization, shame, or guilt over their diagnosis, as reasons for not disclosing. Additionally, 6 of the 16 participants in this group had lied about their status to someone during the 9 months since testing positive, the highest percentage of lying in any group.

There's such weird stigma about it. I think our society still is not great. I just don't feel like people are really prepared to be able to handle it. And sometimes I feel like it's better just not to tell people. [Male, White, age 50]

The Stigma Concerns group appraised their HIV diagnosis as stressful and they also appraised disclosure as stressful. For

most, their stigma fear and their internalized stigma informed their stress appraisals. This group's initial efforts at coping with their diagnosis by disclosing to garner social support were often unsuccessful. It seems that these negative experiences in turn contributed to their stigma concerns and made them less likely to disclose in the future.

Social Isolation (n= 8)

Interviewer: Have you told anyone that you are HIV positive?

Participant: No.

I: No family, no friends? Partners?

P: No.

I: Any plans on telling anybody?

R: No plans. [Male, White, age 41]

This group disclosed to no one or almost no one. Two of the 8 participants in this group disclosed to one person initially, but over the 9 months postdiagnosis, they did not disclose to anyone else. The central aspect that characterized this group was their preexisting life context of social isolation. Five of the 8 participants in this group were so socially isolated that they did not have even a minimal group of close friends or family. For them, disclosure to gain support was not an option because they did not possess a basic support network. A number of these participants expressed a sense of themselves as being "private" and having clear boundaries with other people.

I'm a rather shy person. I tend to be rather private. I don't expose a whole lot about me, and this is the way I have always lived my life. People will tell you what they want you to know, that's it. I'm not nosy and I can't stand nosy people. [Male, African American, age 48]

Of the 3 participants in this group who were in partnered relationships, and so presumably had at least one confidant, 2 disclosed to their partners, and 1 of these disclosers ended the relationship between the first- and third-month interviews. The third partnered participant did not disclose to his partner over the entire 9 months. (He also said that he did not have sex with his partner during this time).

Stigma concerns appeared as a secondary thematic similarity in this group, and these concerns were offered as explanation of their nondisclosure. Six of the 8 participants expressed a fear of being stigmatized.

A lot of people when they get HIV positive or something, the first thing they think is that you're gay, you know. And not that that's a bad thing, but that's where people's minds go, and, "You brought it on yourself," those types of things. [Male, African American, age 53]

The concern about stigma apparently led 3 participants in this group to lie about their HIV diagnosis. For example, 1 participant lied when asked directly about her serostatus.

Because I was losing a lot of weight. One asked me was I positive and I told her no. They said, "Girl, you lost so much weight." I said, "After my surgery I've just been losing weight and I'm still losing it. I just don't eat as much as you all." [Female, African American, age 51]

Internalized stigma, which is another dimension of stigma, overlapped the fear of being stigmatized by others and deterred participants from disclosing. Four of the 8 participants in this group articulated clear internalized stigma in their narratives.

I try to get into a relationship with someone and I can't because it's so stressful for me. So in my mind I'm trying to understand that I could have relations, but for me it's like I cannot have relations, because it's so hard for me to get it out of my mind that, for me, I'm poison. [Male, Latino, age 42]

For the Social Isolation group, not disclosing was in part a result of the transactions between person and context, that is, being people who did not interact a great deal with others and who also lived in a context that did not offer many opportunities for social interactions. In addition, not disclosing served as a way of coping by avoiding potentially stressful encounters with others who these participants feared would stigmatize them. Not being open about their HIV serostatus served as a way of managing the stress of their own internalized stigma.

Strategic Disclosure (n= 15)

I was very methodical about this—group one, two, and three. One was gay men, secondly would be my straight friends, and third would be family, and I haven't gotten down to group two or group three yet, the straight friends or the family. I told the ones that I anticipated would be more supportive. Those that I'm not as close to or would use the information against me or would not offer support or I can imagine they would say things that would piss me off or have no clue about my emotions, I steered clear of telling them or I told them later and more matter of factly. [Male, White, age 56]

This group disclosed their HIV serostatus selectively within their social network. For the most part, this group disclosed gradually to more people over 9 months, although a few disclosed to a chosen circle and then disclosed no further. The people disclosed to might have included their current primary partner, friends, former primary partners, former and current sex partners, coworkers or bosses, and doctors. But even those participants who disclosed to a fairly wide circle were selective in their choice of confidant(s), disclosing to one friend, for example, but not another.

Interviewer: So how do you decide to disclose? How do you make those choices?

Participant: You know, I kind of put the question to myself, like, "Do I want to tell so-and-so?" And see how I feel. If I get nervous, then I won't do it. So I'm kind of going on gut instinct here, and relying on the fact that I'll tell somebody when I'm ready to tell somebody. And that there's no timeline. [Male, White, age 30]

The same selectivity held true for disclosure to family members. Seven participants disclosed to some family, selectively not disclosing to other family. For example, 1 participant disclosed to his mother and brother, both of whom were supportive, but did not disclose to his father.

The only person I've specifically not told is my father, and it's not because we're not close. It's more because it would cause him unnecessary distress and also he's got medical problems of his own. [Male, White, age 34]

Seven participants disclosed to no family members. They gave as their reasons either that they did not have a close relationship with their family, that they wanted to protect themselves from distress, or that they wanted to protect family members from distress.

My family does not know. I'm not going to tell them. That would not serve anybody. People that love me and care about

me and are involved in my life, and need to know, they all know. [Male, White, age 47]

Interviewer: Is there anyone you wanted to tell but didn't?

Participant: My mother.

I: Why haven't you told her yet?

P: 'Cause I just, I don't see where any good would come from it. She won't love me less, she won't love me more, but she will worry more. And there's a good chance that I will outlive her, you know. She's older and she has high blood pressure, and as you get older your health deteriorates, and I just don't want to add this kind of stress to her. [Male, Latino, age 32]

Interviewer: Any plans on telling your mom? Because I know that was one of the things that you were thinking about?

Participant: No... not wanting to say that to her. Still feeling that it would just be too non-productive, too disruptive. I'm not putting myself through that. I don't need it. She doesn't need it. But mostly, I don't need it. (Chuckles). You know, I have enough stress in my life. [Male, White, age 57]

This group used both disclosing and not disclosing as coping. Most of the participants in this group coped with the stress of their HIV diagnosis by disclosing to get emotional or informational support from others.

Participant: I said, "Well, I tested positive for HIV. And I'm in a state of shock. I wasn't expecting that." And she just hugged me and said, "Well, let me know what we need to do. You know that we're here for you, and anything you need will be taken care of."

Interviewer: How did you feel when you had the conversation with her?

P: I felt good about it, because I knew that I was loved and that I would be taken care of! And that's a huge load off my mind. [Male, White, age 57]

I'm extremely lucky in that I have a partner who I'm very close to and very honest with. My immediate family is fairly close knit. I disclosed to my mother the evening that I tested positive and to my sister the next day—being confident that I could expect back sympathy, support, and...inspiration. I have a close network of friends, some of whom are positive and have been a source of great inspiration, hope, and guidance! [Male, White, age 34]

A few disclosed simply to experience the relief of telling someone. One participant gave as his reason for disclosure "to make it real."

I felt relieved. Because I find myself getting very nervous when I tell people? That kind of panicked—almost like that "I'm gay" conversation I had to have with my parents when I was younger (laughs), you know? That sense of "If I get it out, then it will be better" and that's how it felt. So I was relieved after I told her. And it was a nice conversation. I'm glad that I did it. [Male, White, age 37]

In addition, a few participants disclosed as a way of coping with a personal moral/ethical commitment, feeling that it would be wrong not to disclose.

I just felt like I should tell people and it should be something that people know. Not everybody, but my close friends at least. [Male, African American, age 29]

For most, this moral obligation was particularly true of disclosure to former or potential sex partners.

Interviewer: And when you're making the decision to disclose to your sex partners, how do you do that?

Participant: I don't know, it just seemed like that although there was no legal obligation, it just seemed like for me there's a very high moral obligation because they need to know. I mean, I would want to know. [Male, Latino, age 32]

Just as disclosing for this group was a way of coping, not disclosing was also coping. In this case, nondisclosure was a way of avoiding a potentially stressful situation for themselves because of the reaction they knew they would receive, or because disclosing would require too much effort on their part at a time when they felt depleted. In other cases, not disclosing was a way of protecting another person from harmful distress.

I had a female roommate for 16 years. I would give my right arm for her because she's this woman I just love. And she's somewhat emotionally unstable. She's on medication. She's disabled because of her anxiety and depression. And for her to know wouldn't do her well. [Male, White, age 47]

For the most part, this group's strategic choices for disclosure had the desired result of feeling supported, or feeling relief, or feeling a sense of acting in concert with their personal values. Some participants received mixed reactions, some positive, some negative, but they did not seem daunted by the negative responses, possibly because those reactions were outweighed by positive reactions.

Only 2 participants of the 15 in this group expressed a fear of being stigmatized because of their HIV serostatus. In both cases, the support they received appeared to diminish this concern considerably.

You know, it's like all those things are coming to uplift me. I really felt for the first 3 weeks—I was really in a deep, deep, deep, deep, deep hole, like black hole that there's no light, there's no hope for me. I thought that everybody would just reject me. But then...even with straight people, I really felt that I was loved. And I knew then that I can count on people, that I fall some day, I will have a fish—a, a safety net. [Male, Other Ethnicity, age 35]

Unlike the Stigma Concerns and Socially Isolated groups, that had higher rates of participants lying about their status, only 1 participant in this group lied about having HIV. The incident occurred while visiting his parents, when his mother found his medications and asked what they were for, and he did not say they were medications for HIV.

Universal Disclosure (n = 11)

I didn't put a lot of thought into telling my close friends. Because I feel like any kind of secrecy I have around it and not wanting to tell people I really trust and love, I feel like it might be really unhealthy to store that inside right now, any kind of guilt or shame, because it's not how I feel about it. [Male, White, age 40]

The participants in this group disclosed their HIV status to many different people in their social network. They typically disclosed to an initial group of people right after getting diagnosed, and then told an increasing number as well as a wider circle of people by 3 and 9 months after diagnosis. The participants in the Universal Disclosure group told people in many different domains of their life about their status, including partners, friends, close family, relatives, employers, and work colleagues. Participants in this group generally disclosed because they believed that it was unhealthy to keep this type of information to themselves, that it would be stressful to keep secrets from people around them, and that some people should know and have to be told.

I didn't want to tell her the news, but at the same time, I didn't want to hide the news from her, and have to keep hiding the news whenever something might come up about it. Or about my health or something. So that's why I decided to tell her. But it's upsetting, you know, I knew it would be upsetting for her, and it's upsetting for me. I knew it wasn't going to make her happy (chuckles). [Male, White, age 43]

I don't know, I was just feeling that certain people that are in my life, that are important to me and I'm important to them. It's like, a good thing to talk to them about it. [Male, White, age 26]

They're my three closest friends. They needed to know because they need to know. [Male, African American, age 43]

The participants in this group sometimes reported concern about causing other people to worry, but in most cases, this concern did not restrain them from disclosing.

In contrast to the other groups, by 9 months after diagnosis, all but 1 in this group had told some or all family members. The one who did not disclose to family had no family to tell. Eight of the 10 disclosers to family experienced the family's reaction as supportive; 2 received mixed reactions.

I think the most important part of telling my family was telling my parents, and they were the people I worried about the most, and they were the ones that reacted the most supportive. Not sympathy, not judgment, but understanding and compassion, and I don't mean compassion in, like, they made it a sad thing because compassion isn't sad. They listened. They asked questions. They looked at my paperwork and looked at the numbers and they understood that I was doing something responsible in reaction to finding out that I was positive. [Male, Latino, age 37]

Participants in this group disclosed to gain support, but disclosure did not always achieve this goal. All the members of this group experienced one or more negative response(s) when they disclosed. For example, a participant described his distress when a friend he had disclosed to became enraged at him:

Oh, I just wanted to die! I'm already dealing with this disease, and now I'm telling somebody who I deeply care about and who I would hope was just going to hold me right now, because that's what I needed...and it just, just...this monster, who can't even, like, look at themselves in the mirror, because they're so angry, you know? I thought it was going to be the death of me. [Male, White, age 32]

Another participant recounted that his friend remonstrated with him:

Participant: He gave me a long lecture about not having to depend on other people to help. And that I should've caught—even though I had—I'd—anyway... a lecture on independence, and how he handled it differently when HE was notified.

Interviewer: And how did that make you feel?

P: Angry. [Male, White, age 43]

In contrast to the Stigma Concerns group, receiving negative reactions from others did not deter the Universal Disclosure participants from continuing to disclose. However, over time, 3 participants in this group did become more selective in their disclosure.

I have a friend of mine who told me, unless it is important for the basis of your relationship to continue, nobody really needs to know! [Male, African American, age 43]

Very few individuals in this group expressed concern about being stigmatized as a result of disclosure, and only 2 members of this group lied about their status. Many of the participants already knew people that were HIV positive, and some felt comforted by being able to discuss and share experiences with other people in their own situation.

I realized that they were talking about HIV, when we were just hanging out, and so I felt I could just chime in and not really be too concerned about how I would be perceived because we were all going through the same thing. So how could you perceive someone different? I mean, there are three people in the room and they're all going through the same thing. There are no judgments, there are no apprehensions. It actually was convenient for all of us to be able to talk to each other because we can all bring something to the table, and could talk about any kind of a resource that they have found, which is good. [Male, Latino, age 37]

In sum, these four groups differed on how they appraised disclosure, both in the general sense of whether disclosure was stressful for them, and in the more specific sense of what about disclosure was understood to be stressful or not stressful. Their reasons for disclosure and nondisclosure also differed. Furthermore, because disclosure is a transactional process, the groups differed not only on what kind of responses they received from those disclosed to, but also on how they felt about the responses. In this way, the groups illustrate the importance of context to understand a complex process such as disclosure.

Group differences on quantitative measures

We tested group differences at baseline and 9 months on demographics, physical health, stigma, and social support

(see Table 1 for demographics by group, Table 2 for stigma and social support). There were significant differences among groups on race/ethnicity. Specifically, whereas African Americans made up 18% of the total sample, they comprised 63% of the Social Isolation group (exact test $p=0.02$) There were no other group differences on demographics or physical health.

The four disclosure groups showed significant differences on Internalized Stigma ($F_{3,47}=5.04, p<0.01$; Table 2). Confirming our qualitative analysis, *post hoc* tests showed that the Social Isolation and Stigma Concerns groups scored significantly higher on internalized stigma than the Universal Disclosure group.

The four disclosure groups also differed in several of the quantitative measures of social support. Analyses of variance showed significant group differences in Social Attachment ($F_{3,48}=4.10, p<0.05$), Guidance ($F_{3,48}=8.59, p<0.001$), and Reliable Alliances ($F_{3,48}=3.89, p<0.05$). More specifically, *post hoc* tests showed that the Social Isolation group scored significantly lower on Social Attachment than the Universal Disclosure and Strategic Disclosure groups, and lower than all other groups on Guidance. Both the Social Isolation and Universal Disclosure groups scored lower than Strategic Disclosure on the Reliable Alliances subscale.

Discussion

The present analysis reveals there are a number of approaches to HIV disclosure and no one approach is optimal. It is important for HIV test counselors and others working with those who are newly diagnosed to be aware of the variety of ways in which disclosure fits into the overall process of adjustment to an HIV diagnosis. Examining disclosure

TABLE 1. SAMPLE CHARACTERISTICS BY GROUP

	Group				
	Total (n=50)	Stigma Concerns (n=16)	Social Isolation (n=8)	Strategic Disclosure (n=15)	Universal Disclosure (n=11)
Gender (% male)					
Male	92	88	75	100	100
Race (%)					
Caucasian	63	62	25	86	60
African American	19	13	63 ^a	7	10
Latino	12	13	12	7	20
Asian	6	13			10
Sexual orientation (%)					
Gay	78	81	63	93	64
Heterosexual	8	13	25		
Bisexual/other	14	6	12	7	36
Education (%)					
High school	14	19	25		18
Some college	32	25	63	33	18
College graduate	30	37		40	27
Post college	24	19	12	27	37
Income (%)					
< \$10,000/year	30	38	25	13	45
\$10,000–\$40,000/year	38	12	50	54	45
\$40,000–\$100,000/year	20	38	25	13	10
\$100,000+ /year	10	12		20	
Age (mean, years)	40	42	44	40	37

^a $p=0.051$ by an exact test.

TABLE 2. SOCIAL SUPPORT AND STIGMA MEANS BY DISCLOSURE GROUP

	<i>Stigma Concerns</i>	<i>Social Isolation</i>	<i>Strategic Disclosure</i>	<i>Universal Disclosure</i>
Stigma				
Social Rejection	1.81	1.80	1.37	1.73
Internalized Shame	3.01 ^c	3.00 ^c	2.60 ^{c,d}	2.52 ^d
Social Isolation	2.39	2.54	2.24	2.24
Internalized Stigma ^a	3.04 ^c	3.00 ^c	2.47 ^{c,d}	2.09 ^d
Social Support				
Attachment ^b	3.30 ^{c,d}	2.84 ^d	3.67 ^c	3.43 ^c
Integration	3.05	2.84	3.25	3.07
Reassurance of Worth	3.20	3.09	3.18	3.25
Reliable Alliance ^b	3.52 ^{c,d}	3.19 ^d	3.78 ^c	3.36 ^d
Guidance ^a	3.32 ^d	2.70 ^e	3.72 ^c	3.45 ^{c,d}
Opportunities for Nurturance	3.13	2.81	3.14	2.87

^a*p* < 0.01.^b*p* < 0.05.^{c,d,e}Groups with differing superscripts differed significantly in *post hoc* tests.

narratives qualitatively from the perspective of Stress and Coping Theory revealed distinct differences in how participants appraised disclosure, whether disclosure was experienced as stressful, and whether disclosure or nondisclosure functioned as a way of coping with an HIV diagnosis. Our approach also allowed a view of the life contexts of stigma and social support in a way that incorporated these concepts as thematic aspects that played different roles among the groups.

Decisions about disclosure are made based on appraisal and life context. In our sample we found four ways in which life context shaped the disclosure process. For example, the reactions many in the Stigma Concern group received in response to a disclosure added to their stigma fears, and their own internalized stigma contributed to this stress appraisal. In contrast to the Social Isolation group, the Stigma Concerns group had a social network, but their early negative experiences in disclosing their HIV serostatus deterred them from additional disclosure. Not disclosing became their way of coping with their appraised stress of disclosure. For those in the Social Isolation group, disclosure was appraised as potentially very stressful, largely because of stigma fear and internalized stigma. In addition, their limited social network deprived them of using disclosure as a means of garnering social support to deal with the stress of their HIV diagnosis.

The Strategic Disclosure group did not appraise disclosure as stressful, but as a means of garnering desired informational, practical, or emotional social support, or as a way of feeling the relief of sharing difficult news. Not disclosing was also strategic—a way of protecting themselves from predictable bad reactions, or as a way of protecting cared-for others from distress. They disclosed selectively to friends, family, and their wider social network. A number of these participants also chose to disclose to former or current sex partners, not for support, but because they felt that they had a moral duty to do so. In those cases, not disclosing would have been appraised as stressful for them.

The Universal Disclosure group disclosed, for the most part, because they felt it would be more stressful not to disclose. They usually held the goal of disclosing to garner social support, but, like the Stigma Concerns group, they sometimes received negative and nonsupportive responses. Unlike the Stigma Concerns group, however, negative responses did not deter them from disclosing to an ever widening circle of friends, family, coworkers, and others.

In the quantitative analysis, the one difference on demographic variables was the higher proportion of African Americans in the Social Isolation group. Other research has found ethnic differences in both rates of disclosure and social isolation when comparing persons of color and white populations.^{46–48} The Social Isolation group also showed a higher degree of internalized stigma. It seems possible that some African Americans who test positive for HIV might be more vulnerable to social isolation and to stigmatizing attitudes, however, other studies have not found this to be the case.³⁵ In our data, the Stigma Concerns group also had significantly higher internalized stigma, but did not differ on race/ethnicity compared to the Strategic Disclosure or Universal Disclosure groups. The possible relationship between race, social isolation, and internalized stigma are not clearly understood. The fact that none of the other demographic variables differentiated among the groups indicates that demographics are not a reliable indicator of how disclosure decisions are made.

In contrast to studies that have found an association between disclosure and physical health^{6,49}, there were no differences among our qualitatively derived groups on CD4, viral load, or self-reported symptoms. It is not that participants in our sample were all early in the disease course, and therefore, healthier. Although the participants were newly diagnosed, they were at different points in the progression of the disease, and, whereas many had very low CD4 counts and were highly symptomatic, others were healthy. In the early years of the epidemic, before the introduction of highly active antiretroviral therapies (HAART), becoming obviously symptomatic was very often the point at which people with HIV/AIDS disclosed their status, either because they needed the support or because their symptoms allowed others to guess their status. Currently, with HIV having become a chronic rather than an imminently terminal disease, disclosure decisions seem less likely to be driven by health levels.

There were some clear distinctions among the disclosure groups regarding social support. In particular, the Social Isolation group had more restricted social networks than the other three groups. This is reflected in both the interviews and in significantly lower scores on the scale measuring social attachment. The Social Isolation group also reported lower degrees of reliable alliances (e.g., people one can count on in an emergency), as did the Universal Disclosure group. It seems reasonable that the participants in the Social Isolation group were less likely to report reliable alliances because this group had so few social supports. But the lower degree of reliable alliances in the Universal Disclosure group is more difficult to understand. The qualitative data help to explain this finding in terms of different motivations for disclosing. The Universal Disclosure group did not appear to disclose their HIV status primarily to receive support. The respondents in this group generally presented other reasons for disclosure such as disclosing being the morally right thing to do, and having the conviction that people around them

should know about their HIV status. This group relied less on other people for support and help in coping with their disease than the Strategic Disclosure group. The Strategic Disclosure group differed from the other groups in that they had strong social ties and relied on other people to assist them both with emergencies and provide them with support regarding personal problems. This level of understanding of the complexities of the function of social support for the individual can only be revealed by looking at the disclosure process longitudinally and in the context of people's lives.

The longitudinal nature of our data raises the question of whether one's approach to disclosure is dispositional and fixed or whether the approach can be more fluid and changeable over time. Certainly there was evidence from the Strategic Disclosure group that individuals may try different approaches to disclosure. A number of those in the Strategic Disclosure group initially disclosed more universally, but received negative responses and learned to be more selective in their disclosure targets. For others, however, without a change in their social context, there is likely little possibility for change in disclosure patterns. Individuals in the Social Isolation group are unlikely to make a huge leap to universal disclosure given the constraints of their social network. Although our data were longitudinal, they covered a relatively short period following HIV diagnosis, and a longer term study may reveal different patterns of change, which could be beneficial to understanding the disclosure process over time.

Our qualitative approach provided an understanding of the way individuals view themselves in the world, their social and cultural context, and the transactions that transpire in the disclosure process. In turn, the outcome of disclosure events feeds back and influences one's identity. Disclosure practices are one avenue for identity shifts, although in certain cases preexisting identities or social/cultural contexts may hamper such shifts. For example, the Social Isolation group had a view of their identity as "I'm a private person" and this affected their disclosure, and by extension, identity changes that might result from interactions with others about HIV.

Stress and coping theory informed our analysis of the disclosure narratives. Our theoretical perspective allowed us to understand that disclosure can be both a stressor and a way of coping with stress. Likewise, nondisclosure and even lying can be sources of stress or methods of coping. Few studies (with the notable exception of Holt) have recognized nondisclosure as a way of coping. Our finding of the individual context being important in the disclosure process is consistent with the transactional nature of the coping process.

This study is novel in that it focuses on the disclosure process longitudinally from the time of HIV diagnosis. The prospective design of the study meant that the narratives did not depend on recall of events from some years previous and the longitudinal aspect of the study adds dimension and depth often absent in previous studies. Although disclosure is an issue that individuals counseling those newly infected with HIV frequently deal with, they are not generally trained to help people with disclosure decisions.¹⁶ Our study indicates that there is no generic template for disclosure counseling that could be developed that would be helpful for all people newly diagnosed with HIV. Effective disclosure counseling needs to take into consideration an individual's life context and appraisal of HIV, as well as stigma concerns and needs for social support. Understanding these dynamics

will then allow for the development of education for counselors. Future work could focus on the creation of specific screening questions that would help counselors identify an individual's likely disclosure pattern and tailor post-test counseling accordingly in order to increase the likelihood of adaptive adjustment to HIV.

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