AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV

HIV disclosure among adults living with HIV

E. Mayfield Arnold Ph.D a, E. Rice b, D. Flannery b & M. J Rotheram-Borus b

a Wake Forest University School of Medicine, Winston-Salem, NC
b UCLA Center for Community Health, CA, US

Published online: 15 Feb 2008.

To cite this article: E. Mayfield Arnold Ph.D , E. Rice , D. Flannery & M. J Rotheram-Borus (2008): HIV disclosure among adults living with HIV, AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV, 20:1, 80-92

To link to this article: http://dx.doi.org/10.1080/09540120701449138

PLEASE SCROLL DOWN FOR ARTICLE

Full terms and conditions of use: http://www.tandfonline.com/page/terms-and-conditions

This article may be used for research, teaching, and private study purposes. Any substantial or systematic reproduction, redistribution, reselling, loan, sub-licensing, systematic supply, or distribution in any form to anyone is expressly forbidden.

The publisher does not give any warranty express or implied or make any representation that the contents will be complete or accurate or up to date. The accuracy of any instructions, formulae, and drug doses should be independently verified with primary sources. The publisher shall not be liable for any loss, actions, claims, proceedings, demand, or costs or damages whatsoever or howsoever caused arising directly or indirectly in connection with or arising out of the use of this material.
HIV disclosure among adults living with HIV

E. MAYFIELD ARNOLD1, E. RICE2, D. FLANNERY2, & M. J. ROTHERAM-BORUS2

1Wake Forest University School of Medicine, Winston-Salem, NC, and 2UCLA Center for Community Health, CA, US

Abstract
Research on disclosure among heterosexual adult person(s) living with HIV (PLH) was reviewed, omitting disclosure of parental HIV to children. Disclosure has been studied within five additional relational contexts: with partners, family members, friends, healthcare professionals and in work settings. Disclosure is higher among women than men, among Latino and white compared to African-American families, and among younger compared to older HIV-positive adults. Most PLH disclose to their sexual partners and family members, yet there is a significant minority who do not disclose. Similarly, rates of disclosure to employers range from 27–68%, suggesting broad variability in perceived consequences of employment disclosures. Of concern, 40% of PLH do not consistently disclose to their healthcare professionals. Rather than examine HIV disclosures in the context of relationships, it is possible to understand disclosures around personal identity. Disclosure decisions are often made to tell everyone (making HIV status a central attribute of one’s identity), no one (requiring strategies for securing social support while remaining anonymous) or some people (requiring strategic decisions based on context). Given that disclosure decisions are central to personal identity, future data on disclosure and interventions designed to increase disclosure or comfort with disclosure must focus on communication strategies adopted by PLH to present a coherent identity.

Introduction
Information is power, particularly in western society. Each person decides what, how, when, to whom and in what manner to share information about themselves. Disclosures, therefore, shape identity on a daily basis, not only one’s self-perceptions but also others’ impressions of you. Many key personal attributes are observable (e.g. gender, age and race), yet many important aspects of identity reflect personal choice. HIV advocates have fought hard to protect the individual choice for disclosing their serostatus or not.

Disclosure of serostatus is critical, based on its significant links to reductions in transmission acts (Crepaz & Marks, 2003), adherence to health regimens (Kalichman & Nachinson, 1999; Remien et al., 2007) and its relationship to mental health symptoms (Lam et al., 2007; Lee & Rotheram-Borus, 2002; Rotheram-Borus et al., 1997). However, disclosure has not been routinely investigated as part of adapting to HIV serostatus (Rotheram-Borus et al., 1997). Most existing research focuses on parents’ disclosure to children. A review of disclosure to children demonstrates the importance of this topic to both parental and child adjustment (Murphy et al., 2001), yet there are many other relationships in which disclosure may or may not occur (Glynn & Rhodes, 2005). We examine the disclosure patterns and impact of disclosure in non-parental relationships. At least five types of relationships are highly relevant: relationships with partners, family members, friends, healthcare providers and in work settings.

It is important to consider how disclosure fits into the identity of adult person(s) living with HIV (PLH). Yet the existing literature rarely examines disclosure as a reflection of one’s identity. Researchers have typically examined disclosure as a summary of behaviors in discrete relationships. We reframe the existing literature to suggest that there is at least one other critical perspective that should be adopted in future studies of disclosure: examining how disclosure fits into one’s social identity.

In research on this topic, disclosure has typically been considered to be a mediator of the probability of disclosure within specific types of relationships or settings. Individual disclosure patterns are categorized based on the transmission category of the PLH: homosexual, heterosexual, or injecting drug user. This classification system of the US Centers for Disease Control has dominated the literature. Despite this focus in the existing literature, it is
important to consider that PLH develop decision-rules about disclosing their serostatus that may actually mediate disclosure.

Individuals’ behaviors are more than probability markers, however, and are co-ordinated to present a cohesive identity by each individual. Being HIV-positive may clash with the person’s desired social presentation or enhance one’s identity, depending on context and type of relationship. Therefore, in this paper we examine the literature on disclosure in two sections: (1) a summary of the existing findings on heterosexual adult relationships (not including children) and reasons promoting disclosure and barriers against disclosure; and (2) a summary of how individuals organize their disclosures into a strategy for their identity, not as a behavioral probability.

Articles included in this review focused on the following: (1) adults living with HIV (or the article included adults in the sample and presented findings specific to adults); and (2) those self-identifying as heterosexual (or the article included heterosexual adults as part of the sample). Articles were excluded that focused exclusively on children and adolescents or focused on mothers disclosing to their children.

The purpose of the review is to focus on adult PLH in the context of their relationships with other adults. We include articles from both the US and other countries as we assert that it is important to consider differences between western ideas about disclosure and those of countries where attitudes toward HIV may be quite different. Throughout the paper, we note findings unique to specific cultures and pay close attention to the issue of stigma that can have a dramatic impact on disclosure.

**Disclosure in adult heterosexual relationships**

Table I presents an overview of studies focusing on general disclosure and, in specific types of relationships, to partners, family members, friends, healthcare providers and employers. In some instances, the article focuses on a specific type of individual within a category, such as mothers in the ‘family member’ category. The studies vary in their methodology and sample size. For those studies that include multivariate analyses, only the findings from the multivariate analyses are presented.

**General disclosure.** While many studies focus on HIV disclosure within a specific type of relationship, others focus more on disclosure in general. In one study of African-American women, 90% of participants reported that they made a disclosure (Simoni et al., 2000). Gielen and colleagues (2000a) documented slightly higher rates (97%) in their research with HIV-positive women; of those who disclosed, 64% disclosed to five or more individuals and only 3% told no one about their HIV status. Similarly, among a sample of HIV-positive patients in England, Petrak and colleagues (2001) found an overall rate of disclosure to ‘important others’ of 68%, and 42% had disclosed to all ‘important others’.

The amount of time since diagnosis may also be a factor in the disclosure process. The length of time that one is HIV-positive may impact the number or type of individuals to whom the PLH decides to disclose (Gielen et al., 2000b). Some research suggests that the period immediately following diagnosis is when many individuals decide to share the information with others. For example, 78% of female PLH in the southeastern US disclosed within the first week after diagnosis (Sowell et al., 2003).

The decision to disclose is often fraught with mixed emotions (Levy et al., 1999). Some research suggests that those who do not disclose tend to report more emotional distress (Kalichman & Nachimson, 1999; Lam et al., 2007). However, for those with high rates of disclosure to people in their lives, stigma is negatively associated with psychological functioning (Clark et al., 2003). It is also important to consider the possible psychosocial consequences of disclosure, as researchers have documented that almost half of PLH (44%) experience one or more negative events as a result of their disclosure, most commonly the loss of friends, being insulted or rejection by family members (Gielen et al., 2000a).

**Disclosure to partners.** Rate of PLH’s disclosure to sexual partners tends to vary by study, depending on the country. In the US, 68% of women indicated that they told their current partner of their HIV status (Sowell et al., 2003). In contrast, 86% of sexually active PLH in London disclosed to their partners (Dave et al., 2006). Rates of disclosure to sexual partners in non-western countries may be lower and sex without disclosure may be highly related to stigma. In Indonesia, 67% of drug-using PLH disclosed to their spouse, with the same percentage reporting their spouse was ashamed of them (Ford et al., 2004). Rates of disclosure to partners among female PLH in Tanzania increased over time, with 22% disclosure at two months rising to 40% at four years after learning HIV status (Antelman et al., 2001). People living with HIV at South African AIDS service organizations are almost all sexually active (85%), yet only 58% disclosed their status to recent sexual partners (Simbayi et al., 2006). In addition, non-disclosers were about 28 times more likely to have a partner of unknown serostatus.

The HIV status of the sexual partner is an important consideration for disclosure. With partners of unknown serostatus, 81% of individuals
<table>
<thead>
<tr>
<th>Study</th>
<th>Disclosure to . . .</th>
<th>Variables related to disclosure</th>
<th>Variables not related to disclosure</th>
<th>Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antelman et al. (2001)</td>
<td>P, FM  (female relative)</td>
<td>Disclosure to partner: being married or cohabiting, occupation as 'public house' or 'other', number of lifetime sexual partners, prior disclosure to female relative or ever having used a modern form of contraception. Variables increasing likelihood of disclosure: more than six lifetime partners and knowing someone with HIV/AIDS. Disclosure to female relative: being married less than two years, financial dependence on others, knowing two or more people with AIDS, social support, attendance at weekly self-help group meetings.</td>
<td>Disclosure to partner: daily expenditure on food and ever having used modern contraception. Disclosure to female relative: knowing one person with AIDS, occupation, education, partners' sociodemographic characteristics.</td>
<td>1,078 HIV-positive pregnant women in a clinical trial in Tanzania</td>
</tr>
<tr>
<td>Armistead et al. (1999)</td>
<td>P, FM, F</td>
<td>Disclosure to partner: Associated with lower level of depression. Disclosure to father and friends: CDC stage predicts disclosure (i.e. more ill individuals are more likely to disclose).</td>
<td>Number of categories of individuals to whom the participant disclosed was not related to depression. Disclosure to father: time since HIV diagnosis and physical symptoms. Disclosure to other family and friends: CDC stage predicts disclosure, time since HIV diagnosis, and physical symptoms.</td>
<td>100 HIV-positive African-American women in New Orleans, LA</td>
</tr>
<tr>
<td>Asander et al. (2004)</td>
<td>F, FM, P, E (co-workers)</td>
<td>Christian, more education, greater social network, contact with social welfare ‘important professional’ and an HIV counsellor; those with greater symptoms informed relatives abroad.</td>
<td>Gender, work, age, time of HIV diagnosis, knowledge of HIV transmission, knowledge of laws regarding disclosure, contact with large organizations in the community.</td>
<td>47 HIV-positive men and women who were guardians of one or more children in Sweden</td>
</tr>
<tr>
<td>Batterham et al. (2005)</td>
<td>P</td>
<td>Pre-HAART: Time since diagnosis increased odds of disclosure; sex with casual partners and those known to be HIV-negative decreased odds of disclosure. Post-HAART: Time since diagnosis and number of sex acts increased odds of disclosure.</td>
<td>Pre-HAART: Disclosure not related to number of sex acts. Post-HAART: Disclosure not related to partner being HIV negative or sex with a casual partner.</td>
<td>574 HIV-positive individuals ages 13–24</td>
</tr>
<tr>
<td>Chandra et al. (2003)</td>
<td>FM, F, HP</td>
<td>Higher rates of disclosure to family members than friends or HP.</td>
<td>Gender, stage of illness.</td>
<td>68 HIV-positive men and women in India</td>
</tr>
<tr>
<td>Charbonneau et al. (1999)</td>
<td>HP (dentists)</td>
<td>Gender (female), main source of payment for dental care, disclosure to family, disclosure to co-workers, and trust in confidentiality with dentist.</td>
<td>Age, education level, route of infection, presence of HIV symptoms, disclosure to friends, type of dental care setting.</td>
<td>463 HIV-positive individuals in Quebec, Canada</td>
</tr>
<tr>
<td>Clark et al. (2003)</td>
<td>FM, F</td>
<td>Higher levels of stigma were related to lower levels of disclosure.</td>
<td>N/A</td>
<td>98 HIV-positive and 146 non-HIV-positive African-American women in New Orleans</td>
</tr>
<tr>
<td>Conyers &amp; Boomer (2005)</td>
<td>E</td>
<td>Those requesting accommodations: those in managerial positions were more likely to disclose (higher rates of knowledge of rights under ADA among managers as compared to non-managers). Those not requesting accommodations: number of years since diagnosis (longer); interference with ability to get one's job done.</td>
<td></td>
<td>84 HIV-positive employed individuals</td>
</tr>
<tr>
<td>Study</td>
<td>Disclosure to</td>
<td>Variables related to disclosure</td>
<td>Variables not related to disclosure</td>
<td>Sample</td>
</tr>
<tr>
<td>---------------------------------</td>
<td>---------------</td>
<td>--------------------------------------------------------------------------------------------------</td>
<td>-------------------------------------------</td>
<td>-------------------------------------------------</td>
</tr>
<tr>
<td>Crepaz &amp; Marks (2003)</td>
<td>P</td>
<td>Disclosure more likely with HIV-negative partners than with those of unknown HIV status; having sex with partner more than 3 times; those who had known that they were HIV-positive for more than 3 years; with lovers as compared to other partners.</td>
<td>Disclosure not associated with safer sex.</td>
<td>105 HIV-positive men at outpatient clinic in Los Angeles (includes MSM)</td>
</tr>
<tr>
<td>Dave et al. (2006)</td>
<td>P</td>
<td>Knowledge of partner’s HIV status.</td>
<td>Gender, ethnicity, CD4 count, HIV viral load, time since diagnosis, being on antiretroviral treatment, condom use at last vaginal sex.</td>
<td>142 HIV-positive individuals at an outpatient clinic in London</td>
</tr>
<tr>
<td>Derlega et al. (2002)</td>
<td>F, P, FM (parent)</td>
<td>Disclosure: Females more likely to identify a particular reason for disclosure than males and a particular reason for non-disclosure.</td>
<td>Disclosure: To friends and partners: perceived stigma, catharsis, to test others’ reactions, duty to inform/educate and similarity.</td>
<td>145 HIV-positive men and women</td>
</tr>
<tr>
<td></td>
<td></td>
<td>To parents: perceived stigma and duty to inform/educate. To partner and friends: close supportive relationship.</td>
<td>To parents: catharsis, to test others’ reactions, close supportive relationship and similarity.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Non-disclosure: To parents: perceived stigma and communication difficulty. To partner: privacy and communication difficulty. To friends: wanting to protect the friend.</td>
<td>Non-disclosure: To parents: privacy, self-blame, fear of rejection, protecting the parent, superficial relationship. To partner: stigma, self-blame, fear of rejection, protecting the person, and superficial relationship. To friends: stigma, privacy, self-blame, fear of rejection, communication difficulty, superficial relationship.</td>
<td></td>
</tr>
<tr>
<td>Duru et al. (2006)</td>
<td>P</td>
<td>Sex without disclosing was less likely among those with drug use, those in longer partnerships, women (versus MSM), among those with perceived responsibility to disclose to all partners, and with partners of known status. Higher rates of sex without disclosure with occasional or one-time sex partner.</td>
<td>Sex without disclosing was not related to race/ethnicity, education, alcohol use, health status, perceived responsibility to disclose to ‘at risk or concerned’ partners, religiosity, negative partner reactions, perceived reaction of friends to not disclosing, HAART-related optimism, beliefs about HAART, self-efficacy to disclose, laws regarding non-disclosure, having a primary sex partner, sexual partner with unknown HIV status, age difference with partner, involvement in commercial sex, victimization in partnership.</td>
<td>875 HIV-positive patients in the HIV Cost and Services Utilization Study</td>
</tr>
<tr>
<td>Emlet (2006)</td>
<td>General</td>
<td>Disclosure was associated with using formal HIV services, having a confidant, and time since HIV diagnosis (multivariate findings).</td>
<td>Age, ethnicity, gender, heterosexual exposure, education, employment, instrumental social support.</td>
<td>88 HIV-positive individuals in the Pacific Northwest</td>
</tr>
<tr>
<td>Gielen et al. (2000a)</td>
<td>P</td>
<td>Receiving help with disclosure was related to HP offering to help with disclosure, HP stating that the individual had to disclose to partner, HP indicating that they would notify the partner and woman indicating fear of disclosure.</td>
<td>N/A</td>
<td>310 HIV-positive women ≥18 years old.</td>
</tr>
<tr>
<td>Study</td>
<td>Disclosure to</td>
<td>Variables related to disclosure</td>
<td>Variables not related to disclosure</td>
<td>Sample</td>
</tr>
<tr>
<td>-------</td>
<td>---------------</td>
<td>-------------------------------</td>
<td>-----------------------------------</td>
<td>--------</td>
</tr>
<tr>
<td>Gielen et al. (2000b)</td>
<td>G</td>
<td>64% disclosed to five or more people. Length of time since diagnosis was positively correlated with number of people to whom one disclosed.</td>
<td>Social support.</td>
<td>257 HIV-positive women ages 18-44</td>
</tr>
<tr>
<td>Jeffe et al. (2000)</td>
<td>HP</td>
<td>Race (white compared to African-Americans except with OB/GYN), CD4 count differences (&gt;200 cells/mm versus ≥200).</td>
<td>Gender.</td>
<td>202 HIV-positive African American and white men and women</td>
</tr>
<tr>
<td>Kalichman &amp; Nachimson (1999)</td>
<td>P</td>
<td>Non-disclosure was associated with lower rate of condom use for anal sex for males and lower condom self-efficacy. Non-disclosure was related to emotional distress and lower self-efficacy for disclosure (lower for women than men).</td>
<td>Substance use; unprotected sex for women; self-efficacy for discussing safer sex and sexual risk refusal.</td>
<td>266 HIV-positive men and women in the community</td>
</tr>
<tr>
<td>Kalichman et al. (2003)</td>
<td>F, FM</td>
<td>Perceived social support (for disclosure to immediate family members) and perceived stress of disclosure.</td>
<td>Perceived social support from friends and extended family members.</td>
<td>331 HIV-positive men and women- (includes MSM)</td>
</tr>
<tr>
<td>Landau &amp; York (2001)</td>
<td>F, FM, P, E (included in 'other')</td>
<td>Educational level (lower), mother's educational level (higher), gender (male).</td>
<td>Time since diagnosis, depression, intent to disclose, shame.</td>
<td>65 HIV-positive men and women from Israel HIV centers</td>
</tr>
<tr>
<td>Latkin et al. (2001)</td>
<td>F, P</td>
<td>Index participant characteristics: Longer of time since diagnosis, no current drug use, greater than high school education, and current employment.</td>
<td>Index participant characteristics: depression, physical impairment, age, gender.</td>
<td>161 low-income current and former IDUs who were HIV-positive</td>
</tr>
<tr>
<td>Nicolai et al. (1999)</td>
<td>P</td>
<td>Consistent condom use (made disclosure more likely) and being in a monogamous relationship (for African-Americans).</td>
<td>Current drug use, gender, age, employment status, risk factor for HIV infection, history of an STD.</td>
<td>147 HIV-positive patients from a public STD clinic</td>
</tr>
<tr>
<td>O’Brien et al. (2003)</td>
<td>F, P, FM</td>
<td>Non-disclosure was related to age and CD4 count. Women were more likely to disclose to relatives not in their immediate family than men.</td>
<td>Age, gender and CD4 count were not related to disclosure for casual sexual partners.</td>
<td>269 HIV-positive patients from outpatient HIV clinics in New Orleans, LA</td>
</tr>
<tr>
<td>Petrarke et al. (2001)</td>
<td>P, F, FM</td>
<td>Overall disclosure: length of time since testing HIV and ethnicity. Disclosure to friends and family: ethnicity; lower rates for African-American &amp; Asians versus Caucasians; social support was positively correlated with disclosure for friends but not with overall disclosure or disclosure to family.</td>
<td>Gender, sexual orientation. Disclosure to friends and family: length of time since testing positive for HIV.</td>
<td>95 HIV-positive outpatients in London</td>
</tr>
<tr>
<td>Shehan et al. (2005)</td>
<td>FM (mothers)</td>
<td>Younger and less educated (less than high school education), having AIDS, having more severe symptoms and exposure through homosexual contact increased likelihood of disclosure.</td>
<td>Contracting HIV through a transfusion, IV drug use, or heterosexual contact; race, rural versus urban residence, family support, marital/partner status, time since diagnosis, avoidance coping style and age.</td>
<td>166 HIV-positive men in the Southeast</td>
</tr>
<tr>
<td>Simbeyi et al. (2006)</td>
<td>P</td>
<td>Not disclosing: having experienced discrimination (job, housing), low self-efficacy for disclosing, whether the individual has talked with a friend about AIDS, and fear of others' reactions.</td>
<td>Not disclosing: reporting difficulty telling others about one’s HIV infection, hiding one's HIV status, reporting being treated differently by family after disclosure.</td>
<td>1,054 HIV-positive individuals in southern Africa receiving HIV/AIDS services</td>
</tr>
<tr>
<td>Study</td>
<td>Disclosure to . . .</td>
<td>Variables related to disclosure</td>
<td>Variables not related to disclosure</td>
<td>Sample</td>
</tr>
<tr>
<td>------------------------</td>
<td>---------------------</td>
<td>---------------------------------</td>
<td>------------------------------------------------------------------</td>
<td>---------------------------------------------</td>
</tr>
<tr>
<td>Simoni et al. (2000)</td>
<td>P, F, FM</td>
<td>Drug use.</td>
<td>Age, ethnicity, T-cell count, having a steady partner.</td>
<td>143 Black Hispanic and Black non-Hispanic women in NY</td>
</tr>
<tr>
<td>Sowell et al. (1997)</td>
<td>P, FM, F, HP</td>
<td>African-Americans had lower rates of sibling disclosure; those with highest income disclosed to more types of individuals; disclosure to partners varied by stage of illness.</td>
<td>Age.</td>
<td>82 HIV-positive women in rural Georgia</td>
</tr>
<tr>
<td>Sowell et al. (2003)</td>
<td>P, F, FR, HP</td>
<td>Three types of disclosure: full, criteria for disclosure, and emotional disclosure. Among those with specific criteria for disclosure, three factors influenced the decision to disclose: relation to the person, quality of the relationship, and perception of whether the individual would keep the information confidential.</td>
<td>N/A.</td>
<td>322 HIV-positive women from the Southeast</td>
</tr>
<tr>
<td>Stein et al. (1998)</td>
<td>P</td>
<td>One sexual partner as compared to multiple partners, high spousal support, whites and Latinos more likely to disclose than blacks.</td>
<td>Friend support, gender.</td>
<td>129 HIV-positive patients at two urban hospitals</td>
</tr>
<tr>
<td>Yang et al. (2006)</td>
<td>G</td>
<td>70% would disclose if they were HIV-positive; disclosure negatively associated with HIV misconceptions (for men and women) and stigma (for women only); never marrieds were less likely to disclose.</td>
<td>No differences in willingness to disclose by age or educational level.</td>
<td>4,208 migrants in China 18–30 years old</td>
</tr>
</tbody>
</table>

G = General; P = Partners; FM = Family members; F = Friends; H = Healthcare providers; E = Employers.
chose not to disclose (Duru et al., 2006). The longer and more involved the relationship, however, the more likely disclosure occurred (Duru et al., 2006). Being married or cohabiting is associated with disclosure (Antelman et al., 2001), having sex with a partner more than three times (Crepaz & Marks, 2003) or having just one sexual partner (Stein et al., 1998) increases disclosure. In contrast, high rates of sex without disclosure are associated with having an occasional or one-time sex partner (Duru et al., 2006).

Non-disclosure to sexual partners appears to cluster with multiple transmission risks (Niccolai et al., 1999). Ciccarone and colleagues (2003) found that unprotected sex tends to occur in sexual relationships without disclosure of HIV status. It also appears that some PLH use safer sex as a method of avoiding disclosure (Kalichman & Nachimson, 1999). In one study of female PLH, 20% of partners left after disclosure of their HIV status (Simoni et al., 1995), indicating that the fear of rejection may be justified.

Despite the potential negative consequences, there may also be benefits to the PLH's health and reduced transmission associated with disclosure to one's sexual partners. For example, when Greek PLH who were non-adherent to antiretroviral treatment (ART) disclosed their serostatus to their HIV-negative partners, their adherence also improved (Stirratt et al., 2006). Similarly, use of highly active antiretroviral treatments (HAART) may precipitate disclosure (Klitzman et al., 2004). Disclosure is often associated with more discussions of safer sex, including condom use and safer sexual activities (Crepaz & Marks, 2003; Marks & Crepaz, 2001). Among PLH from an STD clinic, those who used condoms consistently were 2.7 times more likely to disclose their HIV status to a partner than those who did not regularly use condoms (Niccolai et al., 1999).

Variations in disclosure based on race, gender and age yield controversial findings. White and Hispanic individuals have been found to be more likely to disclose to partners than African-Americans (Stein et al., 1998), yet other research suggests that race (Dave et al., 2006) and ethnicity (Simoni et al., 2000) do not play a role. Although Stein and colleagues (1998) found that women are more likely to disclose than men, most existing research suggests that gender is not associated with partner disclosure (Asander et al., 2004; Dave et al., 2006; Niccolai et al., 1999; O’Brien et al., 2003). Younger age has also been associated with higher disclosure (Simoni et al., 1995). Other researchers, however, have documented a relationship between youth and non-disclosure (O’Brien et al., 2003). Of note, O’Brien found that PLH aged 18 to 22 were 5.92 times more likely not to disclose their HIV status to a partner, friend or relative than those over 35 years old. However, the majority of the research focusing on partners or including partners does not find that age increases disclosure (Asander et al., 2004; Latkin et al., 2001; Niccolai et al., 1999; Simoni et al., 2000; Sowell et al., 1997).

Disclosure to family members. Existing studies on disclosure to family members yield several trends. First, family members are often the first to learn of an individual's HIV status. In a US study, women disclosed first to a parent (33%) (Sowell et al., 2003). Second, adults more likely disclosed to their mothers than fathers, with women more likely than men to disclose to their mothers (Kalichman et al., 2003; Sachperoglou & Bor, 2001). Additionally, sociodemographic factors influence disclosure. People living with HIV with less than a high school level education are seven times more likely to disclose to their mothers than those with more education, and older men are less likely to disclose to their mothers than younger men (Shehan et al., 2005). However, other recent studies have found that siblings were disclosed to more than parents or any other type of individual (Landau & York, 2004; Sachperoglou & Bor, 2001).

There also appear to be some racial trends in disclosure. Disclosure rates tend to be highest among whites, as compared to Asians and African-Americans (Petarak et al., 2001); other research, however, suggests that race may not be related to disclosure by men to their mothers (Kalichman et al., 2005). Among female PLH, lower rates of sibling disclosure was found among African-Americans (Sowell et al., 1997).

One of the issues directly related to the importance of disclosure to families is caregiving. In many instances, family members care for those who become too ill to care for themselves. Fear of rejection is a barrier to family disclosure and some PLH may be afraid to disclose to family members even when they need assistance (Schrimshaw & Siegel, 2003; Smith & Rapkin, 1996). Although family members typically take a caregiving role, some may not have complete or accurate information about the PLH's condition. Often there is a family secret (Lee & Rotheram-Borus, 2002) despite family members sharing the same understanding or suspecting an HIV diagnosis (Chimwaza & Watkins, 2004).

Disclosure to friends. Rates of disclosure to friends tend to vary, with estimates ranging from 61% in Israel (Landau & York, 2004) to 86% in the US (O’Brien et al., 2003). Among older PLH, 20% in Shippy and Karpiak’s study (2005) reported disclosing to none of their friends. Age appears to play a
role in disclosure to friends as younger PLH are more likely to disclose to friends than older PLH (O’Brien et al., 2003). The nature of the friendship is important to consider as disclosure to an acquaintance but not to a close friend is associated with psychological distress (Lam et al., 2007), yet the presence of a close, supportive relationship with a friend is related to disclosure (Kalichman et al., 2003; Petrak et al., 2001). However, the desire to protect the friend is also a factor in failing to disclose (Derlega et al., 2002).

Disclosure to employers. Few studies have examined workplace disclosure among PLH, but rates of disclosure to employers appear to differ by region of the world. In the US, 52% of PLH use some type of job accommodation, even when they had not disclosed their HIV status to their employer (27%) (Conyers & Boomer, 2005). This finding suggests that some individuals may acknowledge the need for an accommodation but not attribute the need specifically to their HIV status. However, disclosure is higher among those who use accommodations (33 versus 21%), with the most common accommodation being time off for medical appointments. Almost all older PLH in Shippy and Karpiak’s (2005) New York study disclosed their HIV status to all, most or some of their healthcare providers, with only 1% not informing any of their providers of their serostatus. In France, 83% of PLH did not want their HIV status widely known, and 28% did not want to disclose to their work colleagues (Levy et al., 1999). Only 4% informed those at their workplace. Among drug using PLH in Indonesia, respondents commonly (83%) reported disclosing to employers and 100% reported emotional support from them after doing so (Ford et al., 2004).

Furthermore, disclosure to employers can be impacted by experiences disclosing to others in one’s social network. Simbayi et al. (2006) found that those who did not disclose to partners were 2.3 times more likely to report that they had lost a job or a place to stay because of being HIV-positive. Disclosures to employers can lead to possible negative outcomes including discrimination. Hence, those who experience workplace discrimination may be hesitant to inform others in their lives of their diagnosis. Previous research on employers suggests that fear of AIDS is negatively associated with knowledge of AIDS (Lim, 2003) and even in today’s world, employers may lack the knowledge to make fair and appropriate employment decisions for PLH.

Disclosure to healthcare providers. In US studies, rates of disclosure to all healthcare providers range from 69% (Jeffe et al., 2000) to 87% (Sowell et al., 2003) and rates of non-disclosure to any providers range from 4% (Sowell et al., 2003) to 9% (Jeffe et al., 2000). All drug-using PLH in Indonesia who chose to disclose to their healthcare provider were supported (Ford et al., 2004). One of the roles that healthcare providers can play is to help facilitate disclosure to others. Among PLH in a primary care clinic, about half of the women had a healthcare provider offer to help them disclose their status to a sexual partner and 57% were told by their provider that they had to disclose to their sexual partners (Gielen et al., 2000b).

Disclosure to dentists has received a fair amount of attention. First, there tends to be a fairly high rate of dental service use among PLH, with studies reporting a rate of about 80% (Charbonneau et al., 1999; McCarthy et al., 1995). However, some PLH report being refused dental care (McCarthy et al., 1995) and about half do not disclose to their dentist (Charbonneau et al., 1999). The main reason given for not disclosing to dentists is that universal precautions are systematically used in dental care (Charbonneau et al., 1999). Some studies find that women disclose more often than men (Charbonneau et al., 1999) but others do not (Chandra et al., 2003; Jeffe et al., 2000).

Reasons for non-disclosure. In Table II, we present findings from studies related to HIV disclosure that address reasons in support of disclosure and/or reasons against disclosure. The primary reason for disclosure tends to focus on the desire to receive support from others or out of duty to inform others about the possibility of transmission. Reasons against disclosing centred primarily on fear of discrimination or rejection from others.

Disclosure and identity

Interpretation of the existing data on disclosure is complicated by the shifting role of HIV disclosure over the course of the epidemic. In the early 1990s, learning that one was HIV-positive meant a substantially shortened lifespan and disclosure had a very different meaning from the situation confronting PLH today. As HAART has transformed HIV infection from a terminal illness into a chronic disease (Siegel & Lekas, 2002; Vittinghoff et al., 1999), disclosure has become a lifelong challenge that impacts adjustment. This focus obscures the underlying reality that any given act of disclosure is embedded in the process of ongoing social interactions over time. It is important to conceive of disclosure as an ongoing social and psychological process of communication about critical health information.
Table II. Reasons for disclosure or non-disclosure.

<table>
<thead>
<tr>
<th>Study</th>
<th>Reasons for disclosure</th>
<th>Reasons against disclosure</th>
<th>Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chandra et al. (2003)</td>
<td>Self-focused: expectations of material and emotional support.</td>
<td>Stigma; fear of discrimination; futility; disgrace to family and self.</td>
<td>68 HIV-positive men and women in India</td>
</tr>
<tr>
<td></td>
<td>Other focused: responsibility to do so</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Derlega et al. (2002)</td>
<td>Catharsis, duty/educate, supportive/close relationship</td>
<td>Privacy, self-blame, fear of rejection, protecting the other person.</td>
<td>145 HIV-positive men and women</td>
</tr>
<tr>
<td>Fesko (2001)</td>
<td>For those who fully disclosed in workplace: to explain choices made in job interview, to address concerns about work performance, and to request job accommodations.</td>
<td>For those who only disclosed selectively: privacy, nature of work environment, fear of others’ reactions.</td>
<td>18 HIV-positive individuals</td>
</tr>
<tr>
<td>Ford et al. (2004)</td>
<td>Increased emotional support, strengthening relationship with spouse/partner.</td>
<td>Fear of breakup of sexual relationship or marriage, estrangement from other drug users, employment discrimination, being neglected or disowned by family, spousal/partner physical abuse.</td>
<td>40 drug users in Indonesia</td>
</tr>
<tr>
<td>Levy et al. (1999)</td>
<td>N/A</td>
<td>Not having further sexual relations, partner already knew, took precautions to protect the other person.</td>
<td>174 HIV-positive patients in France</td>
</tr>
<tr>
<td>McCarthy et al. (1995)</td>
<td>N/A</td>
<td>Concern about dentist refusing to treat them, concern about being treated differently, want their HIV status kept confidential and not wanting people to know their HIV status.</td>
<td>101 HIV-positive patients at a London HIV care program</td>
</tr>
<tr>
<td>Parsons et al. (2004)</td>
<td>Among those who consistently disclosed, 62% stated that this was due to a sense of responsibility to partner.</td>
<td>Among those reporting sex with casual partners, 61% reported fears of sexual and personal rejection.</td>
<td>158 HIV-positive IDUs in New York City and San Francisco</td>
</tr>
<tr>
<td>Petrak et al. (2001)</td>
<td>Desire for support, breach of confidentiality, ethical duty, role of educating others.</td>
<td>Protecting others from distress; concerns about stigma, confidentiality, and discrimination; ‘timing, protecting self from others’ reaction and ‘almost’ disclosure’ (disclosing an illness but not AIDS); geographical distance.</td>
<td>95 HIV-positive outpatients in London</td>
</tr>
<tr>
<td>SachperogLou &amp; Bor, 2001</td>
<td>Felt they had to tell, wanted to tell, had a close relationship with the individual, needed support/help.</td>
<td>Geographical distance, afraid of reaction, did not want individual to know, individual did not have to know.</td>
<td>64 Greek HIV-positive individuals</td>
</tr>
<tr>
<td>Simoni et al. (1995)</td>
<td>For sexual partners: ethical responsibility, concern for others’ health.</td>
<td>For sexual partners: self-focused reasons for friends: other-focused concerns.</td>
<td>65 HIV-positive women at out-patient clinics</td>
</tr>
<tr>
<td></td>
<td>For parents and friends: Desire for support, medical reasons.</td>
<td>For parents: other-focused concerns, stigma, ignorance of family members Desire for support, medical reasons.</td>
<td></td>
</tr>
<tr>
<td>Yoshiiko &amp; Schustack (2001)</td>
<td>Obligation and to obtain support.</td>
<td>Protect their family from shame, protect their family from obligation to help them, avoidance communicating about personal information, family’s lack of knowledge of HIV.</td>
<td>16 HIV-positive Asian men from the Northeastern US</td>
</tr>
</tbody>
</table>

For many PLH, this process involves ‘testing the waters.’ Most PLH do not blurt out their HIV serostatus without first considering their target’s possible reaction. Rather, individuals who intend to disclose probe their target (e.g. partner, employer, family member) for stigma and perceptions about HIV. For example, a PLH may ask a friend about his or her attitudes toward laws that would mandate name-based reporting of HIV status to state and federal agencies. Probing for the friend’s perceptions of HIV is an attempt to anticipate his or her reaction to the disclosure event. Disclosure is consistently linked to perceptions of stigma (Clark et al., 2003; Derlega et al., 2002; Simbayi et al., 2006) and PLH are less likely to disclose when they perceive more HIV stigma. Similarly, the more social support a person perceives for himself or herself, the more likely he or she is to disclose (Kalichman et al., 2003; Petrak et al., 2001; Sowell et al., 2003). This process of disclosure usually occurs in incremental steps wherein the PLH probes for more information over time in an attempt to anticipate the target’s reaction to the disclosure event.

The process of disclosure, however, is not a universal one shared by all PLH across all social contexts. The choices PLH make regarding disclosure can be categorized into three pathways: (1) disclosure to everyone; (2) disclosure to some; and
Disclosure to everyone. People living with HIV who disclose to everyone in their social network about their serostatus, including doctors, friends, employers, partners and family. This pathway has a relatively simple coping style and requires few problem solving skills—the answer is always the same: disclose. Those who follow this pathway must be prepared to deal with stigma and prejudice. In our experience working with heterosexual PLH, most persons who follow this pathway hold a ‘take me as I am attitude’ and often are dismissive of those who do not respond well to their disclosure. Those who are accepting of the disclosure process will often form stronger bonds of intimacy and support with the PLH as a result of sharing such important health information.

For those who disclose to everyone, sources of social support are clearly defined and readily accessible. One source of support will come from those members of their pre-disclosure networks who accept their HIV serostatus. Not everyone in their pre-disclosure networks will be accepting; however, and some former sources of social support may be lost through the disclosure process. In place of these old social supports, new HIV-specific forms of social support become readily available, in the form of case workers, doctors and HIV support groups.

People living with HIV who disclose to everyone must be prepared to support the person to whom they disclose. They may have disclosed over and over again, across a period of years, but for the target of the disclosure, this is new and potentially shocking information. Some targets of disclosure may be wholly unprepared for such weighty and socially loaded personal health information. When targets of disclosure are thrown off balance, the discloser assumes a position of power in the interaction and often takes on the role of being an emotional caregiver, which may have appeal for some who pursue this pathway.

Disclosure to no-one. People living with HIV who disclose to no one keep their serostatus a closely guarded secret. This pathway also has a simple coping style that requires no active problem solving. As with those who disclose to everyone, the answer to any disclosure dilemma is always the same, only here that answer is to tell no-one. This pathway represents a risk-averse strategy. Those who tell no-one attempt to avoid exposure to stigma by keeping their serostatus to themselves. Often they are motivated by fears of stigma and the potential of alienating family or losing their jobs, friends and sexual partners.

By disclosing to no-one, individuals cannot mobilize their social support networks for help directly related to their HIV, despite the maintenance of their pre-existing social networks. Those who pursue this pathway are limited to individual coping strategies, such as self-talk, relaxation techniques, fitness and alternative medicine. They can only access support for HIV from anonymous sources such as hotlines or online communities. This sort of social isolation can often result in a sense of depression and can lead to substance abuse (Kalichman & Nachimson, 1999). Moreover, those who disclose to no-one run the constant risk of being exposed, which adds further stress to their lives.

For some PLH who tell no-one, their HIV symptoms disclose their serostatus for them. For those taking antiretroviral therapies, side effects such as lypodistrophy cause distinct changes to an individual’s body that are immediately recognizable to members of communities hard hit by HIV, such as men who have sex with men in urban centers in the US. Likewise, in communities where antiretroviral therapies are unavailable (e.g. many parts of sub-Saharan Africa), conditions such as wasting reveal disease status. Even in parts of the world where HIV stigma is great, those who disclose in this unspoken manner may lose their jobs, their neighbours may stop speaking to them and no-one may attend their funeral but HIV will still never be discussed. Fear and stigma may drive away members of their existing social support networks but they cannot access HIV-specific social supports without acknowledging the disease.

Disclosure to some people. In our experience working with PLH, this is the most common pathway to disclosure and it is also the most complex. This pathway requires constant pro-active decision-making and problem-solving about what information to share every time the HIV-positive individual meets someone new, has a new sexual partner, starts seeing a new doctor or gets a new job. For those who follow this pathway to disclosure, there are no simple answers for how, when, where and to whom to disclose.

As with other pathways for disclosure, disclosing to some has profound implications for how PLH access social support. Those who disclose to some are able to access social support regarding their HIV status from members of their pre-existing social
networks to whom they disclose and who accept their HIV serostatus. As with those who disclose to everyone, those who disclose to some have access to HIV-specific social support in the form of co-workers, doctors and HIV-specific support groups. Social interaction in groups can, however, become complicated quickly because the individual must remember who knows and who does not. In such contexts, there is always the chance that serostatus will be disclosed inadvertently and concerns about privacy can be great.

**Modelling the process of disclosure**

Very little research has looked at what decision rules guide disclosure and how these rules are formulated. Some work touches on these issues implicitly. For example, Crepaz and Marks (2003) demonstrate that disclosure is more often made to HIV-negative partners than partners of unknown serostatus. Surely some decision rule about the appropriateness of disclosure to non-infected partners underlies this finding. The full complexity of the social psychological process that results in such rules has not been adequately developed to date.

Regardless of the disclosure pathway pursued, a single social psychological process governs the process (Figure 1). Social identities and role relationships both affect the creation of decision rules regarding disclosure and these rules in turn motivate specific disclosure behaviors in a given social context. When we speak of social identities, we refer to broad social categories such as African American, woman, HIV-positive individual, doctor or AIDS activist (Hogg & Abrams, 1988; Tajfel & Turner, 1979; Turner; 1982; 1985; Turner et al., 1987). When we speak of role relationships, we refer to relational identities based on social roles such as mother, sexual partner, patient or friend (Burke, 1980; McCall & Simmons, 1978; Stryker, 1968; Turner, 1978). There are socially shared, taken-for-granted expectations for behaviors in any social context where social identity or role relationship is salient. In the case of HIV-positive individuals, this complex of expectations affects the creation of rules that govern disclosure, which in turn affect disclosure behaviors in specific social contexts.

For PLH who pursue disclosing to everyone or disclosing to no-one, the process is uncomplicated. For example, a person who discloses to everyone has clearly accepted his or her social identity as a PLH, and disclosure re-affirms this social identity by acknowledging it as part of his or her self. The social identity of the PLH is salient in all social relationships for those who follow this path and overrides the specific expectations of role relationships, at least with respect to the disclosure process.

The full complexity of the disclosure process manifests only for those who selectively choose to disclose to some but not all of the persons in their social network. Take, for example, the decision to disclose one’s serostatus to a new doctor. Most PLH who disclose to some have accepted to a certain extent the social identity of a PLH. The shared social expectation of responsible PLH is that they will disclose relevant health information to medical providers. Moreover, the potential discloser has expectations for the behavior of the new doctor. Doctors are expected to be caring, non-judgmental and helpful. Simultaneously, there are social expectations attached to the role relationships of patient and clinician, such as clinical honesty and openness with respect to disease and treatment, which also motivate the eventual disclosure. When all these factors are taken together, the PLH formulates a personal decision rule for this social context, ‘Always inform medical providers about my HIV serostatus’. This rule in turn motivates the specific disclosure behavior to his or her new doctor.

As more social identities and role relationships become salient to an interaction, the more complex the process of creating decision rules becomes. Consequently, the more sophisticated an individual’s coping skills and decision-making abilities need to be. Many social identities (e.g. woman or African American) and role relationships (e.g. friend or supervisor) carry ambiguous expectations for behaviors. Moreover, deciding when and how to disclose to an employer or a friend may involve weighing a set of conflicting expectations that derive from a myriad of social identities and role relationships, motivating the incremental nature of the disclosure process over time (i.e. testing the waters).

**Conclusion**

Disclosure is intimately related to how communities stigmatize or accept HIV and how individuals perceive themselves, their identities and their roles
in their communities. The disclosure process to date, however, has only been examined as an isolated behaviour engaged in with specific persons in specific social contexts, not as a reflection of a cohesive, integrated set of social identities and role relationships that affect decision rules. While our model is basic, it is more nuanced and complex than any model on disclosure to date. We believe that a more sophisticated model would best be developed in the context of a programme of empirical research that attends to the issues that we have delineated. This review attempts to spur a re-examination of existing data sets as to whether there are various pathways to disclosure, how these patterns may change over time and the benefits and consequences of the different lifestyle choices that are made. Disclosure is believed to affect health, mental health, disease transmission and the quality of relationships; the importance of disclosure behavior will only increase as treatments and life expectancies improve.

Acknowledgements
This study was funded by Grant DA-16742 to Dr. Arnold from the National Institute on Drug Abuse and by Grant R41 MH077559-01 to Dr. Rotheram-Borus from the National Institute of Mental Health.

References


Shehan, C.L., Uphold, C.R., Bradshaw, P., Bender, J., Arce, N., & Bender, B. (2005). To tell or not to tell: Men’s disclosure of their HIV-positive status to their mothers. *Family Relations*, 54, 184–196.


