



# HIV Disclosure



## Question

What literature exists that addresses disclosure of HIV status to children, family-members and intimate partners? More specifically, what does the evidence document as factors that facilitate or inhibit disclosure; challenges experienced before, during and after disclosure; and the role of support systems? Additionally, have any effective disclosure models been developed?

## Key Take-Home Messages

- Experiences of and processes to disclosure are extremely diverse and can be impacted by ethnicity, race, gender, sexuality, age, nationality, culture and class.
- Disclosure can have a significant impact on adherence to medical regimens, virus transmission, access to support services and reductions in mental health symptoms.
- Several disclosure models have been developed relevant to particular identity groups or communities, but none that could be considered 'universal'
- Effective support systems, the presence of a confidant and increased level of HIV awareness ease the disclosure process

## The Issue and Why It's Important

Disclosure of HIV positive serostatus is an ongoing process that is gaining significant attention in HIV literature. Decisions of if, how, to whom, and when one will disclose are intimately personal but have a considerable effect on families, communities, service-delivery systems and policy-making bodies. Effective disclosure has been linked to reductions in HIV transmission (1), adherence to medical regimens (2;3), access to support services (4), reductions in mental health symptoms (5), and effective adaptation to living with HIV.

## EVIDENCE INTO ACTION

The OHTN Rapid Response Service offers HIV/AIDS programs and services in Ontario quick access to research evidence to help inform decision making, service delivery and advocacy. In response to a question from the field, the Rapid Response Team reviews the scientific and grey literature, consults with experts, and prepares a brief fact sheet summarizing the current evidence and its implications for policy and practice.

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Alternately, ineffective disclosure can lead to strains on relationships, changes or loss of employment, discrimination and even violence (6;7). It is therefore vital that service providers and researchers understand the intricacies of the process and the unique paths that individuals take to disclosure. A Toronto-based community health centre dedicated to the needs of women of colour is developing a disclosure model relevant to Black, African and Caribbean women in Canada and has requested a review of the literature to document previous investigations into the diverse processes of HIV disclosure.

## What We Found

Much of the early research on disclosure addressed disclosing a child's own HIV status to the child. More recently, much is being done to understand other dimensions of disclosure and the ways people in different relationship to the person with HIV are affected. To keep within the parameters of this Rapid Review, this response addresses broad themes of disclosure across identity groups and relational networks and then focuses more specifically on three sets of literature; studies addressing disclosure to one's children, disclosure to other family-members and disclosure to partners and significant others.

The research shows that experiences of the disclosure process are affected by many aspects of social location including race and ethnicity (8;9), sexual identity (10), nationality (11;12), age (5;13-15), gender (7;16;17), geographic location (18) and culture (19;20). Membership in different identity or cultural groups is particularly salient to disclosure in terms of the individualist or collectivist nature of those groups. (10) For example, an individual with a collectivist-orientation will consider different ramifications when making decisions to disclose than an individual whose been cultured to value individual success and consequence while a person who maintains multiple memberships, perhaps within a collectivist ethnoracial group and an individualist gay, lesbian, bisexual and transgender community, may feel torn by these contradicting influences. Additionally, distinct disclosure processes have been uncovered in particular communities. A Kenyan study found three disclosure patterns that appear to be unique to Africa. (12) "These include (a) intermediaries as vehicles for disclosure to family, (b) indirectness as a communication strategy, and (c) church pastors as common targets for disclosure." (12,p.586) A review of studies with heterosexual adults living with HIV indicates that disclosure rates are higher among women, young, White and Latino(a) communities than among men, older adults and African American communities. (9) Interestingly, other studies have shown relative stability across identity groups when it comes to level of disclosure in one's community, family and relationships. (21;22)

Stigma is often correlated with disclosure as internal and perceived external stigma weigh heavily on the decision to disclose. "AIDS stigma and discrimination...limit access to voluntary counseling and testing, inhibit disclosure, and are, thus, barriers to care, support and prevention ." (4) A study in Eastern China found that intention to disclose increased when felt stigma decreased. (23) A South African study consisting of 594 interviews revealed high levels of anticipated stigma in the community. (4) When asked to consider, hypothetically, how people would respond to them disclosing a positive test, 86% of respondents thought the community would gossip about them, 82% anticipated being treated differently and 70% expected they would lose membership in social groups. Additionally, 59% thought that they would be

denied medical attention by the community. In the US, a qualitative investigation with older adults found stigma correlated to depression and higher levels of stigma among African American respondents when compared to White respondents. Sixty percent of the sample reported 'protective silence' [nondisclosure] as a method of avoiding stigma. (14)

Some studies have drawn links between identity development and HIV disclosure, documenting steps adapting to living with HIV and their corresponding approach to disclosure. (9;24) One study, (24) with an overrepresentation of White gay men, noted three steps in the process (the model is included in Appedix I): 1) the Diagnosis phase was associated with disclosure only to significant people; 2) Immersion, in which one becomes increasingly involved with the HIV community and HIV is increasingly central to identity, was associated with public disclosure; and 3) the Integration phase was linked to situational disclosure, where HIV status becomes an integrated aspect of identity and is disclosed thoughtfully, with differing levels of discretion. The move to creating new relational networks post-diagnosis has surfaced in several investigations as a means of dealing with loss of relationships or the fear of such loss. (12;25)

Theoretically, most disclosure models have utilized Consequence Theory (5;13) and Social Influence Theory. (26;27) The theories combine to create a framework for understanding disclosure decision-making. As individuals weigh the potential consequences of disclosing, their perceptions of anticipated reactions inform the process. For example, a US study of HIV+ Latino gay men found that perceived positive consequences were associated with greater disclosure to family, friends and casual partners while anticipated negative consequences led to less disclosure to friends and family members. (27) Social Influence theory contributes the tenet that disclosure is facilitated or inhibited by the communities one associates with. Some gay men find disclosing status less stressful due to their involvement in a community where HIV is better understood. (27)

Factors that facilitate or inhibit disclosure are incredibly diverse. A Ugandan study (17) noted that being married, having attended HIV services for more than two years and having knowledge of partner's serostatus were all factors that increased disclosure. 87% of respondents reported that it was easy to disclose. Alternately, the same study noted that fear of abandonment and a history of abuse inhibited disclosure. Motivators to disclose included a desire to reduce further transmission, to increase access to support services and to prevent vertical transmission. With older adults, [generativity](#) arises as a motivator as these people with HIV want to see their HIV status affect the 'greater good.' (13) Another African study involving 39 focus groups in five countries found factors such as a need to break the silence, seeking understanding from others and a request for prayers motivated disclosure. (6) Disclosure was inhibited by anxiety, denial, fear of stigma, and fearing the ramifications against other family members. External factors that made disclosure possible included counseling, education, strength from faith and peer support systems. Several studies in developing countries found that people with HIV were wary of disclosing to health care professionals as they felt that the professionals would further disclose to others in the community. (6) They also feared others discovering their HIV status if nurses visited or if they were seen accessing clinics.

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A French study utilizing a national sample of 2,932 individuals identified six typologies of disclosure. (3) The first was labeled *systematic disclosure*, characterized by a high level of disclosure except to children and colleagues, and included younger informants who were less likely to be migrants and more likely to report alcohol misuse. They also reported more experiences of discrimination from relatives, friends and sexual partners. The second grouping, labeled *selective disclosure to fewer significant others*, was characterized by low levels of concern for disclosing to fathers, children, other relatives and colleagues and often uncontrolled disclosure to friends. The group included an overrepresentation of women and injection drug users and those with lower levels of education. Third was the *uncontrolled disclosure to colleagues* group, which used a mixed disclosure strategy, namely disclosure to friends, concealment from children and family, and matching levels of disclosure and concealment to parents and siblings. These respondents were mostly male with higher education and socioeconomic levels, half of whom had contracted HIV through drug use. The fourth group, *uncontrolled disclosure to relatives*, included participants who disclosed freely to family, particularly parents, and were more likely to misuse alcohol and to have lower education levels. Fifth were individuals who reporting having neither family nor colleagues and most often concealed their status. This group, labeled *concealment from fewer significant others*, was older and contained more migrants and individuals with lower education levels, more women and an overrepresentation of men infected through sex with men. The final cluster was composed primarily of migrants and newly diagnosed individuals and was characterized by *systematic and successful concealment*, except to a few close friends. This group was the most likely to conceal their serostatus from their principal partners. Interestingly, both concealment and uncontrolled disclosure were correlated with poor adherence to medical regimens.

An alternate approach was taken in a US study with men who have sex with men. (28) The typologies identified in this paper were of the methods of disclosure, not the individuals and their overall disclosure patterns. They identified five typologies which included point blank disclosure; stage-setting, whereby an individual provides clues leading up to a direct disclosure; indirect; buffering, or asking a third party to disclose; and seeking similar, or recreating community with others who are HIV positive.

Intervention research is emerging that seeks to understand the impact knowledge and esteem development can have on comfort with disclosing. (29) One intervention, aimed to change risk behavior in HIV-positive men and women, documented increases in disclosure to sex partners among the intervention group, as well as decreases in unprotected sex and non-disclosure sex. (30) Other efforts have been directed at developing assessment tools to understand personal efficacy in disclosing. (31) These efforts are empirically supported as, "...higher stigmatizing attitudes were correlated with less HIV service utilization as well as unwillingness to tell anyone about an HIV-positive diagnosis." (11)

Older adults with HIV are among the least supported members of the HIV community and non-disclosure is the primary reason for lack of emotional, social or practical supports. (32) As one respondent noted, "I don't want everybody to know, so I just don't bother asking nobody for help" (33) This is concerning as having a confidant has been correlated to disclosure and

improvements in adjusting. (5)

A South African study cited above noted that daily exposure to television increased the likelihood of HIV-disclosure. (4) Another study, also conducted in South Africa, noted, "consistent positive effects of mass media on HIV/AIDS knowledge...and on risk reduction behaviors but few statistically significant effects on condom use, risk perceptions or interpersonal communications about HIV/AIDS." (34)

A sample of previously developed disclosure models are attached in Appendix I.

### **Disclosing a Mother's HIV Status to her Children**

The considerations of whether and when a mother should disclose her HIV status to her children are distinct from other forms of disclosure. Some mothers feel that not disclosing is way to protect their children (35), to keep their childhood carefree (16;36), or to keep the child from telling others (16;37). Depending on the method of transmission, a mother may also choose not to disclose to avoid implicating a husband, spouse, or partner. (38) Additional barriers to disclosure to children include not knowing how to tell a child, concern about behavioral problems, fear of rejection, feeling that the child is too young to understand (37) and needing to deal with the information themselves before they can support a child through the process. (16)

Mothers also report a range of motivations to disclose including wanting the news to come directly from her, feeling that the child has a right to know, preparing the child for what may happen in the future, (39;40) and feeling that it is 'the right thing to do.' (41) A study conducted in New York with 188 HIV+ mothers found that roughly half had disclosed to at least one of their children and disclosure was not related to ethnicity or level of illness. (42) Also noted was the insight that disclosure decisions are often made on a child-by-child basis rather than for all children as a whole. (42) Such decisions are also influenced by the developmental level of the child and older children are more likely to be informed of their mother's status. (43)

Prior to birth, concerns about disclosure can be heightened for pregnant women as they may feel they are under evaluation for their fitfulness as mothers (44) counteracted by a desire to ensure adequate infant care to prevent vertical transmission to the child. (45)

A Canadian study found a correlation between parenting style and the timing of disclosure. (16) Protective parents postponed disclosure and experienced significant distress before, during and after disclosure while parents who nurtured independence were keen to tell their children sooner, though not too soon, and tended to focus on the child's maturity and ability to cope. Parents who emphasized solidarity disclosed the earliest and most freely.

Children experience many emotions upon learning their mother has HIV including anger, fear, worry (46) and emotional distress. (47;48) These emotional responses sometimes, but not always, lead to behavioral problems in the child. (49-51)

"Child behavior problems were related significantly to the mother's psychological distress and marginally to her having illness-related activity restrictions, but not to other measures of maternal physical health, stigma or disclosure of her HIV to the child. Two child dispositional factors, productivity and independence, and two family factors, adaptability and a

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54. Raj A, Cheng DM, Levison R, Meli S, Samet JH. Sex trade, sexual risk, and nondisclosure of HIV serostatus: Findings from HIV-infected

good parent-child relationship, were related to better child functioning, but family cohesion was a risk factor for poorer adjustment in this sample [of New York HIV+ mothers]" (50)

A different US study found depressive symptoms among children who had recently learned of their mother's HIV status, however these symptoms lessened over time. (51) After accounting for variability in child-reports and mother-reports, the researchers surmised that, "it appears that children whose mothers have disclosed their HIV serostatus are not experiencing significant psychological distress in response to the disclosure. In fact, these children may be functioning better psychologically than children who are unaware of their mother's status." (51) Reactions to disclosure among a sample of South African mothers included many constructive responses, however secondary disclosures often led to rejection, stigmatization and the withholding of financial support. (45)

### Disclosure to Family-members

Stigma within the family is significant as noted by a consortium of HIV researchers in the US: "Disclosure about HIV is constricted by fears of stigma that may result in rejection by family and friends. Yet secrets and lies within families have ramifications for dynamics and interactions, including conflict, domestic violence, risk-taking behavior, availability of social supports, and custody planning, among other things." (52) Alternately, when discussing hypothetical positive test results, one study conducted in South Africa shows that 69% of those interviewed anticipated it being easy to discuss with partners and 61% thought it would be easy to disclose to family members. (4) Disclosure to neighbors was considered, by these respondents, to be the most difficult.

A study from the UK found that White, gay men were more likely to have disclosed to a parent than heterosexual Black and African individuals; and all groups addressed were more likely to have disclosed to their mothers than their fathers. (8) Gay men were also more likely to have disclosed to a sibling. (8) Several studies document that older people with HIV are less likely to disclose to family members, neighbors or church members. (5;14) A Ugandan study noted above found that men were more likely to disclose to brothers and sex partners while women were more likely to disclose to their sisters. (17)

### Disclosure to Partners

Despite campaigns of many varieties that have encouraged harm-reduction approaches to safer sex, including discussions regarding HIV status, many people with HIV have sex, protected and unprotected, without disclosing. A recent US study found that many people do disclose, but do not do so until after the sex act. (53) In terms of casual sexual encounters, disclosure is difficult to predict. An American study documented that multiple sex partners in the past six months and paying or trading for sex decreased the likelihood of disclosure, although only men had paid or traded for sex. (54) Sexual minority participants were less likely to disclose to casual partners. Drug and alcohol use was not correlated to disclosure. Victims of sexual abuse were six times less likely to disclose, however a history of physical abuse showed no such relationship. (54) A South African survey revealed that the 42% of participants who had had sex without disclosure were more likely to have multiple partners, HIV negative partners, partners of unknown HIV status and unprotected sex with discordant sex partners. (55) Additionally, "not disclosing their HIV status to partners was...

associated with having lost a job or a place to stay because of being HIV positive.” (55)

Studies conducted in the US do not indicate a relationship between laws that make nondisclosure a felony and attitudes towards disclosure nor disclosure patterns. (56;57) It has been noted that much of the attention on disclosing to sex partners has focused on casual encounters and skills, models, and tools have not been developed that address longer relationships. (58)

## Factors that May Impact Local Applicability

This global scan of the literature returned significant evidence that disclosure is unique to each individual, community, family and geographic location. We have attempted to, at a minimum, note throughout this review the nationalities, gender, and significant characteristics of the samples for most studies as these will impact their applicability in a Canadian context.

Of the studies reviewed, 28 were from North American (1 from Canada); 7 from Africa (South Africa, Uganda, Kenya, Lesotho, Swaziland, Malawi and Tanzania); 2 from Europe (England and France); 2 from South America (Brazil); and one each from Australia and China.

Across all the studies, Black, African, Caribbean, and African American heterosexuals and White men who have sex with men were often overrepresented. Mode of transmission was not regularly reported.

## What We Did

We located the studies used in this summary through electronic database searches and selected citation searches among particularly relevant studies. We searched the Cochrane Collaboration HIV/AIDS review group and [www.Health-Evidence.ca](http://www.Health-Evidence.ca) for relevant reviews and searched Medline and Embase using the following combination of search terms: (HIV or Acquired Immunodeficiency Syndrome) AND Disclosure (n=419 hits). Due to the large returns the following studies were excluded from this review: studies prior to 2000, studies particular to disclosing a child's own HIV status, and studies that could not be located by electronic means.

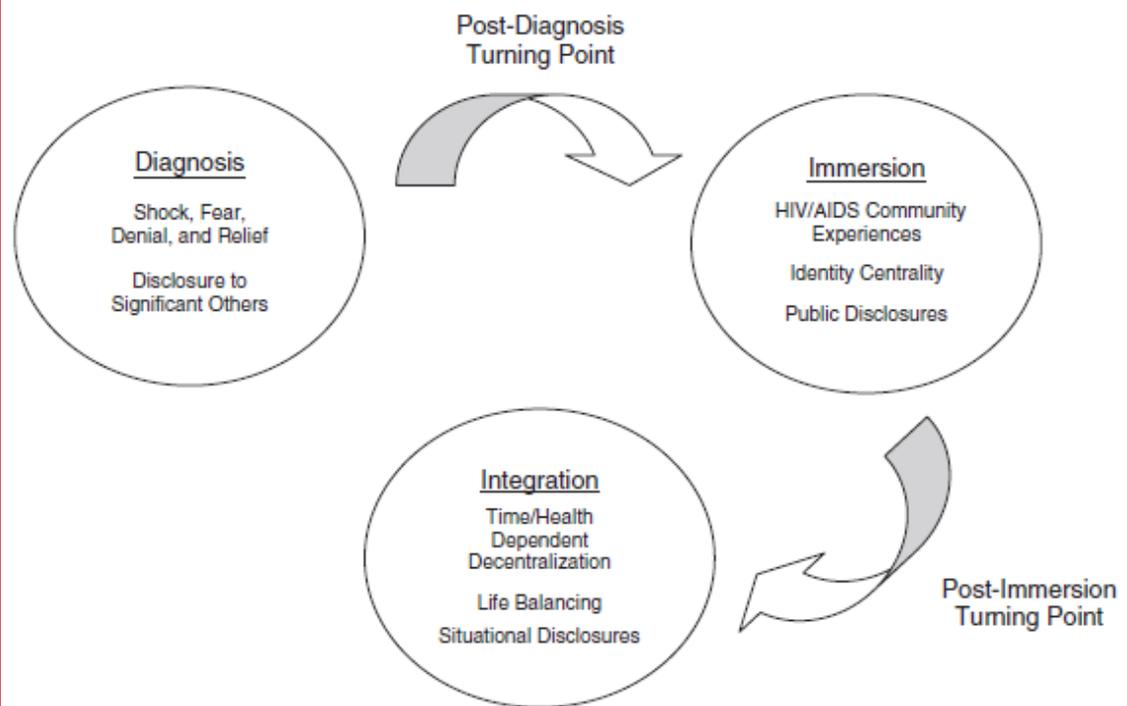
persons with a history of alcohol problems. *AIDS and Behavior* 2006;10(2):149-57.

55. Simbayi LC, Kalichman SC, Strebel A, Cloete A, Henda N, Mqeketo A. Disclosure of HIV status to sex partners and sexual risk behaviours among HIV-positive men and women, Cape Town, South Africa. *Sexually Transmitted Infections* 2007;83(1):29-34.
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# Appendix 1

## Sample Disclosure Models

**Figure 1**  
**Model of the HIV/AIDS Identity Incorporation Process**



Baumgartner LM. The incorporation of the HIV/AIDS identity into the self over time. *Qualitative Health Research* 17(7)(pp 919-931), 2007 Date of Publication: Sep 2007 2007;(7):919-31.

## Appendix 1

### Sample Disclosure Models

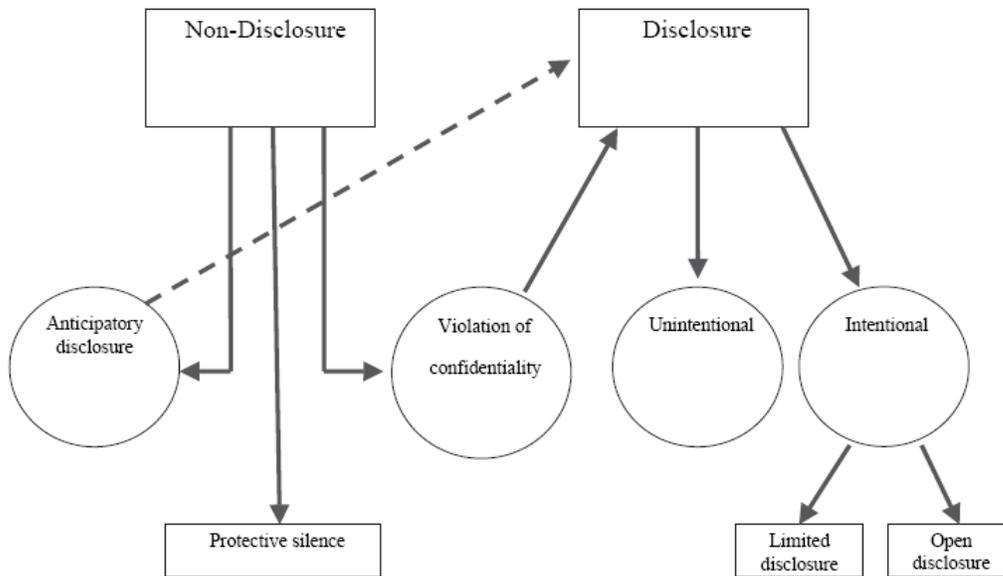
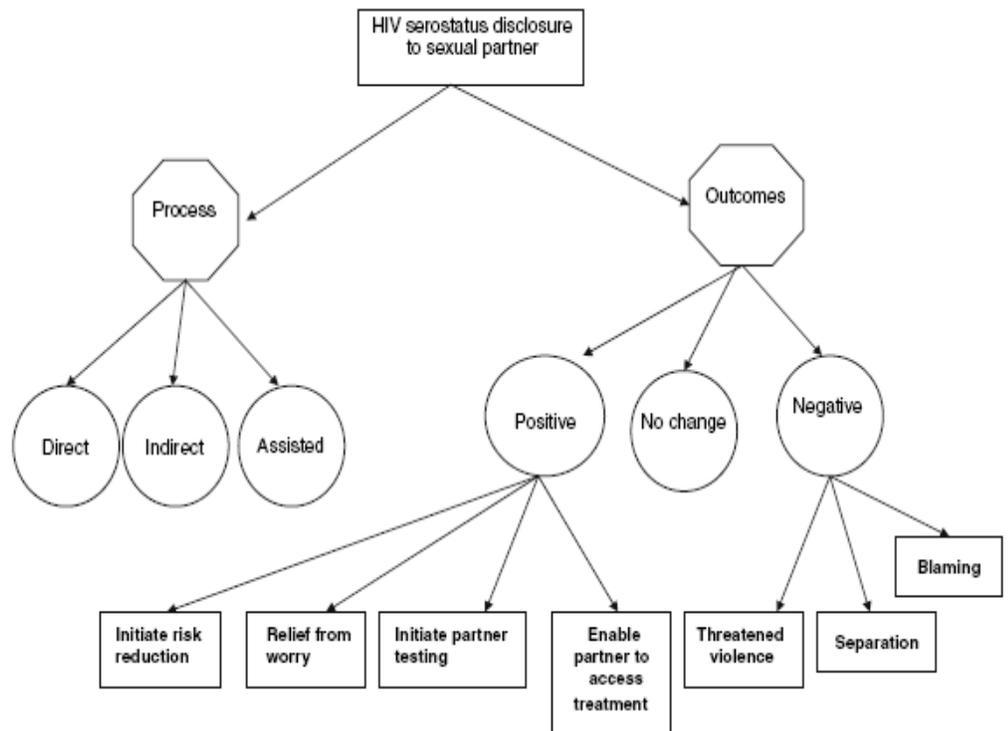


Figure 1. Conceptual model of paths to serostatus disclosure among older adults with HIV infection.

Emlet CA. Truth and consequences: A qualitative exploration of HIV disclosure in older adults. *AIDS Care - Psychological and Socio-Medical Aspects of AIDS/HIV* 20(6)(pp 710-717), 2008 Date of Publication: Jul 2008 2008;(6):710-7.

# Appendix 1

## Sample Disclosure Models



King R, Katuntu D, Lifshay J, Packer L, Batamwita R, Nakayiwa S et al. Processes and outcomes of HIV serostatus disclosure to sexual partners among people living with HIV in Uganda. *AIDS and Behavior* 12(2)(pp 232-243), 2008 Date of Publication: Mar 2008 2008;(2):232-43.

# Appendix 1

## Sample Disclosure Models

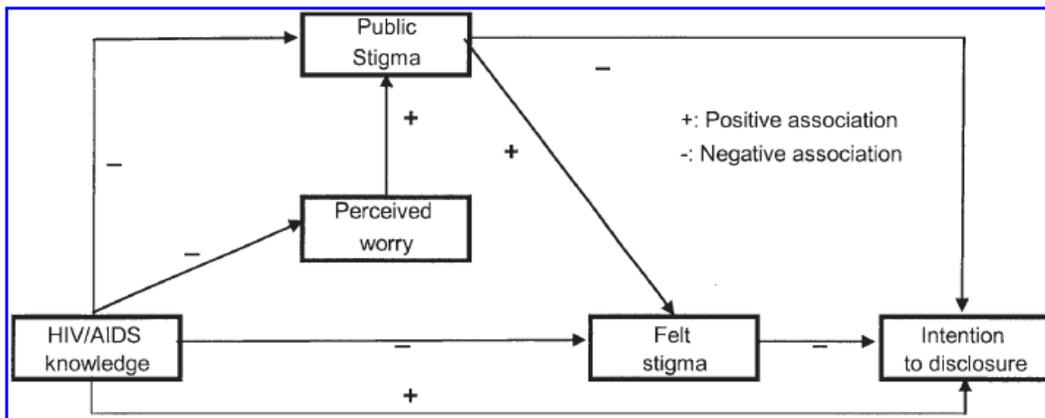


FIG. 1. Hypothesized relation-path diagram.

Liu H, Hu Z, Li X, Stanton B, Naar-King S, Yang H. Understanding interrelationships among HIV-related stigma, concern about HIV infection, and intent to disclose HIV serostatus: A pretest-posttest study in a rural area of eastern China. *AIDS Patient Care and STDs* 20(2)(pp 133-142), 2006 Date of Publication: Feb 2006 2006;(2):133-42.