

HIV Disclosure Experiences Among Women with HIV/AIDS in Jakarta, Indonesia

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THESIS

Submitted as partial fulfillment of the requirements
for the degree of Doctor of Philosophy in Public Health Sciences
In the Graduate College of the
University of Illinois at Chicago, 2015

Chicago, Illinois

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This dissertation is dedicated to Raymond, Wibisono and Ramakandra, without whom it would never have been accomplished. You are my air, starlight and sunshine; you give me love, laughter, and music to live.

ACKNOWLEDGEMENTS

I would like to thank my dissertation committee – Dr. Judith Levy, who is also my advisor, Dr. Ronald Hershow, Dr. Geri Donenberg, Dr. Joan Kennelly and Dr. Sally Freels – for their advice, feedback, guidance and support during this research journey. They have been absolutely invaluable. I would also like to thank to Dr. Mary-Ellen Mackesy-Amity for giving me a brilliant lecture in statistics and helping me better understand statistical analysis.

Without financial support from The Fogarty UIC-AIDS International Training and Research Program (UIC-AITRP, #5D43TW001419), I would not have been able to accomplish my study. My highest gratitude goes to Dr. Judith Levy as Director of the UIC-AITRP, who has opened the door for me to pursue my doctoral degree. Being a fellow for Fogarty UIC- AIDS International Training and Research Program (AITRP) is one of the best experiences in my life. I also wish to thank Saima Chaudry, Aimee Wiebel, and the UIC-AITRP staff: Kathy, Joanna, and Michelle , who provided continual help and support during my studies at UIC.

I am also grateful for the ongoing support and positive encouragement from the greatest and humblest person who has made a big contribution in making one of my dreams come true. Thank you to Dr. Irwanto who always trusts in me to do something that I thought impossible and difficult. In addition, I want to thank Dr. Juliana Murniati, Dean of Faculty

ACKNOWLEDGEMENTS (continued)

of Psychology, Atma Jaya, which is the institution where I worked for her support during my study in UIC.

A number of individuals in data collection sites were helpful to me during field work. I would like to thank Anindita Gabriela from the AIDS Research Centre, Atma Jaya, Caroline Thomas from the Spiritia, Ibu Nitta from Yayasan Kusuma Bangsa, dr. Nita from Lentera Anak Pelangi, Hussein and Mira from KIOS, Atma Jaya, and *Mas* Yudi from the Kotex Foundation. I would like to thank the interviewers – Natasya, Sisi, Emmy, and Arum – as well as the data team – Angel, Inez, and Nadia – for their genius work to manage the data process on schedule.

My sincere gratitude also goes to the UIC-AITRP fellows: Eric, Ona, Ping, Naning, Gambit, Iko, and Very, for being my discussion partners during the completion of my study. In particular, I would like to thank to Lisette and Yi, for walking together with me in a good and bad moment as a PhD student. I also want to thank PWKI Chicago's entire friend who provided support to my family so we could adjust so well to this country. Special thanks to Felicia, Rina Petersen, and Magda Locklin who always have fun ways to motivate and cheer me up in any unfortunate condition.

ACKNOWLEDGEMENTS (continued)

I am grateful for having the best friends: Jo, Aya, Wieka, and Lisa Arman, who always have their thoughts and love with me as I weathered all the storms and difficulties during my study and life journey. Thank you for the best years we have been through, sharing and caring for each other.

I would also thank to my amazing family in Jakarta: Mas Aji, Mbak Anas, Panji, Carla, Mas Wawan, Mbak Perti, Anton, Luci, dan Oscar, who have supported me in various ways during my study in Chicago and my fieldwork in Jakarta.

This study is meaningful because of all the wonderful women who participated in my research. I would like to thank them for sharing their personal lives, teaching me how to be brave and tough, and especially for making the study possible.

Finally, I wish to thank my wonderful mother, Christina Soepardjijah for her unconditional love and prayer. She is my greatest role model; she has made me a strong, tough and persistent woman. My truly appreciation also goes for my beloved mother-in-law, Lies Tambunan, who also has done everything to support me.

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LIST OF ABBREVIATION

AEM	Asian Epidemic Model
AIDS	Acquired Immune Deficiency Syndrome
AJCU	Atma Jaya Catholic University of Indonesia at Jakarta
ANOVA	Analysis of Variance
ARV	Anti-retro viral
ART	Antiretroviral Treatment
CPM	Communication Privacy Management
DPM	Disclosure Privacy Management
DKI	<i>Daerah Khusus Ibukota</i> , or Special Capital Region
GLM	General Linear Model
HIV	Human Immunodeficiency Virus
IDUs	Injecting Drug Users
IBBS	Integrated Biological-Behavioral Surveillance
IRB	Institutional Review Board
NAC	National AIDS Commission
MoH	Ministry of Health
MSM	Men who have Sex with Men
NGO	Non-Governmental Organization
PI	Principal Investigator
PMCTC	Preventing Mother-to-Child Transmission of HIV
SPSS	Statistical Package for the Social Science
UNAIDS	United Nations Program of HIV/AIDS
VCT	Voluntary Counselling and Testing
WHO	World Health Organization

SUMMARY

In developing countries, HIV prevalence is predicted to increase among women, which, in turn, is expected to lead to a rise in infections among children. This trend of the feminization in HIV/AIDS cases in Indonesia and the critical role of disclosure for HIV/AIDS intervention programs make conducting research related to women's HIV disclosure experience a crucial emerging field of inquiry. This study was designed in particular to examine how women access social support and utilize ART.

This study was carried out using a quantitative, cross-sectional approach. Face-to-face interviews were conducted with 142 HIV positive women in Jakarta who had disclosed their HIV status to at least one person. Information on demographics, first and second disclosure experiences, social support, HIV care retention and ART adherence were collected and presented through descriptive data and statistical testing using bivariate and multivariate analyses.

In this study, women disclosed their HIV status to various significant others and gained support from their confidants. Women who first disclosed their HIV status to a family member tended to choose a family member, partner or relative as their second confidant. Women who chose their partners as their first confidants usually had family members as their second confidants. Women who first disclosed their HIV status to their relatives (extended family members) tended to choose family members (nuclear family members) as their second

SUMMARY (continued)

confidant. Women who chose friends as their first confidants generally chose friends as their second confidants.

Based on communication privacy management (CPM) theory, these findings suggest that culture, gender, motivation or reason and timing are criteria that influence HIV disclosure. In the culture of a family-oriented society, a strong and supportive family is one of the first lines of defense when facing societal discrimination and other hardships related to HIV/AIDS. As found in this study, women primarily disclosed to and gained support from their family members. Women were more likely to disclose their HIV status to people of the same gender (i.e. females such as mothers, sisters, female friends, aunts, mothers-in-law, and nieces). The motivations or reasons for disclosure varied among women. The most common reason for the first disclosure was to fulfill interpersonal needs or to have close and supportive relationships, while the most common reason for the second disclosure was to fulfill personal needs (e.g. catharsis). Time served as a contextual factor, influencing the decision of women to let others learn about their HIV status. In this study, about 70% of women had disclosed their status to their first confidants and almost half of women had disclosed their status to their second confidants within one month of learning their HIV status.

The findings reveal that HIV disclosure experiences were associated positively with receiving support from confidants. Multiple linear regression showed that there were four

SUMMARY (continued)

predictors of the type of instrumental support (the provision of tangible help in managing practical concerns such as assistance with household chores, financial assistance, and other specific aid or goods) women would receive based on the individuals they confided in (female family member, $\beta = .61$, $p=.000$; male family member, $\beta = .533$, $p=.001$; partner, $\beta=.862$, $p=.000$; and relative, $\beta=.324$, $p=.036$). Female family member was the only predictor for support satisfaction ($\beta = .609$, $p=.049$). Moreover, three predictors (i.e. close and supportive relationship, duty to inform and reason of catharsis) significantly explained the type of instrumental support (the provision of advice, feedback, or other information which helps the individual appraise his situation) with $\beta=.167$, $p=.005$; $\beta=.115$, $p=.015$; $\beta=-.131$, $p=.001$ respectively. The desire for close and supportive relationships and the duty to inform significantly predicted the emotional support (the provision of warmth and nurturance to another individual that consists of behaviors such as listening, caring, or providing companionship and reassuring the person that he or she is a valuable person who is loved and cared about) with $\beta=.21$, $p=.000$; $\beta=.118$, $p=.002$ respectively. The desire for close and supportive relationships and reason of similarity were two significant predictors of informational support ($\beta = .23$, $p=.000$; $\beta = .12$, $p<.002$ respectively). Lastly, the desire for close and supportive relationships significantly predicted support satisfaction ($\beta = .15$, $p=.032$).

According to the disclosure process model (DPM), disclosure affects outcomes via social support as a mediating factor. Moreover, support resulting from disclosure has an effect on

SUMMARY (continued)

individual outcomes, including psychological, behavioral, and health effects. Previous studies also suggest that support received after telling others about the HIV diagnosis is likely to affect women's quality of life and physical coping with HIV. However, in this study, there were no associations between support variables and retention to HIV care. Nevertheless, all types of support and support satisfaction were predictors of ART adherence with $\beta=6.278$, $p=.027$; $\beta=9.568$, $p=.013$; $\beta=8.633$, $p=.004$; and $\beta=4.238$, $p=.012$ respectively. Furthermore, female family member was the sole predictor of ART adherence among the confidant categories ($\beta=7.204$, $p=.041$). Women who felt supported were more likely to adhere to ART, and most participants in this study had good ART adherence.

This study yielded some recommendations that can be applied to HIV programs in Indonesia. The HIV programs targeting women should involve significant others who can help women cope with HIV. Psychological counseling programs are recommended in order to assist women and their families or significant others in dealing or coping with the issues of HIV/AIDS. Family-focused intervention programs are needed to empower families who are living with HIV/AIDS. In addition, community based interventions and supportive counseling would also be a promising approach to increasing rates of sero-status disclosure and to supporting women's health. Further intervention research and multi-disciplinary research should combine quantitative and qualitative methods in order to study many possible areas related to HIV disclosure and interventions.

I. INTRODUCTION

A. Background

The HIV epidemic in Indonesia is one of the fastest growing epidemics in Asia (UNAIDS, 2007). According to the latest global report from the United Nations Programme on HIV/AIDS (UNAIDS), published in November 2012, approximately 370,000 people are living with HIV in Indonesia, and that number is predicted to increase in the following years. The HIV prevalence in Indonesia in the general population is 0.3 percent, and the rate of new HIV infections has increased by more than 25 percent between 2001 and 2011. Indonesia is one of only nine countries that showed an increasing trend while hundreds of other countries exhibited trends that either stabilized or declined (UNAIDS, 2012).

Data from the Indonesia Ministry of Health (MoH) in 2009 showed that of the approximately 333,200 adults living with HIV in Indonesia, 25.5 percent were women. Furthermore, the AIDS epidemic in Indonesia is predicted to feminize, meaning that the number of new infections among women, especially women with low risk, will increase every year. This increase in infections among low-risk women may also lead to an increase in the number of new HIV infections among children.

More than decades, the public health strategies to reduce HIV transmission rates has been included programs that aim to identify individuals who are HIV-positive, contact their high risk partners, inform those partners of possible HIV exposure, and offer them testing and other

services (CDC, 1988; Toomey and Cats, 1989). The success or failure of these efforts depends on the willingness and ability of HIV positive individuals to directly or indirectly reveal their HIV status (Demas et al., 1995). Studies have shown that disclosure is an important public health goal for a number of additional reasons. HIV-infected individuals who disclose their sero-positive status have been found to need fewer physician visits and have better immune functioning (Pennebaker et al., 1990). In addition, disclosure may result in less social isolation, and help facilitate access to social support, health care and social services (Cline and Boyd, 1993). According to research conducted by Serovich (2001), persons living with HIV who chose to disclose their status tend to feel better emotionally and to be less stressed than those who do not. Moreover, Serovich (2001) states that suppressing thoughts or failing to communicate about difficult experiences has been found to increase the likelihood of stress-related problems. Other benefit of HIV disclosure is that person who disclosed their HIV status had safer disclosure of positive HIV safer sex practices and better antiretroviral therapy (ART) adherence than those who did not (Patel, et al., 2012; Weddell & Messeri, 2006).

Studies about antiretroviral treatment (ART) adherence among patients living with HIV/AIDS in Thailand (Li, et al, 2010) have shown that HIV disclosure is a significant predictor of increased adherence to ART. The findings suggest that it is very important for physicians to know their patients' disclosure status before administering ART and that disclosure should be discussed during pre-ART counseling. Health care providers have an urgent role to explain the importance of disclosure for the success of ART. Therefore, to help ensure the effectiveness of

ART and to help HIV positive women live healthy lives, it is very important to establish a supportive environment that will facilitate the disclosure decision.

Along with conveying these benefits, however, HIV status disclosure also poses a number of potential risks for individuals. Research conducted by Leonard and Ellen (2008) illustrates how disclosure can complicate life instead of making it easier. They found that disclosure of HIV positive status in some contexts did produce expected social support, but instead resulted in more anxiety and stress. Additionally, disclosure does not always bring relief, and may be followed by regrets. A number of researchers have reported that disclosing one's HIV-seropositive status often leads to stigmatization and discrimination rather than to increased social support (Gerbert, et al., 1991 in Sowell, et al., 1997). Among individuals living with HIV, there is a conflict between fear of stigmatization and the need for social support (Yep, 1992). Therefore, disclosure of an HIV positive status can create an internal struggle about whether or not to disclose and with whom they can share their status.

A qualitative study of women with HIV (Kimberley, et al., 1995) showed the six steps women might experience as they navigate the disclosure process. These include: adjusting to the diagnosis, assessing one's disclosure skills, deciding whom to tell, evaluating potential recipients' circumstances, evaluating the recipient's reaction and having a motivation to disclose. The steps involved in the HIV disclosure decision are difficult to follow and must include to whom, when, where and how to reveal one's status to others. Stigma and negative reactions or responses from others are likely to affect the way people living with HIV process

the decision to disclose their infection (Greene, Derlega, Yep, & Petronio, 2009). Studies reporting various responses to HIV disclosure have showed different results. In an early study, Stempel et al. (1995) showed that participants in their sample reported experiencing more negative reactions from male family members and primary sexual partners than from friends. Meanwhile, research conducted by Hays et al. (1993) found that friends and partners provide more helpful responses than family or colleagues. Several years later, research conducted by Mdlalose (2006) with HIV positive women in Tshwane, South Africa indicated that some of the most problematic actual responses to HIV disclosure involved partners and family members. Her result of the study indicated that the highest proportion of unsupportive reactions were from family members, and, over time, people with HIV received the most support from friends and other individuals with HIV, and received the least support from family members. In summary, results from the literature suggest that there is a wide range of actual responses to HIV disclosure, only some of which matches expected reactions.

Supportive responses and social support can improve coping with HIV and quality of life, and have been demonstrated to improve the ART adherence among patients (McCoy, 2008). Waddell & Messeri (2006) reported that for some HIV positive people, the availability of support from family members improved their odds of entry into medical care, regardless of whether they were already receiving (or not receiving) support from ancillary HIV services.

Greater adherence to ART and consistent utilization of primary care services will result in longer survival and improve quality of life for persons living with HIV (Mellins, Kang, Leu,

Havens & Chesney, 2003). However, not all persons living with HIV/AIDS are able to take advantage of medical treatment due to a variety of factors. Research from Mellins, et al (2003) presented that low-income and HIV-infected women are particularly at risk for suboptimal adherence to ART and utilization of medical services. The finding shows that a specific stressor for women that reduced adherence to medical treatment was self-disclosure of HIV status to their families, especially to their children. Nevertheless, the participants who had already disclosed their status to one or more of their children were more likely to attend their medical appointments compared to women who had not.

B. HIV/AIDS in Indonesia

In 1987, the first case of AIDS in Indonesia was reported in Bali. Since then, data from Indonesian National AIDS Commission showed that the number of cases has increased rapidly (NAC, 2010). Based on the Indonesian Ministry of Health (MoH) quarterly report (2012), the new and cumulative number of reported HIV infections and AIDS cases in Indonesia has risen sharply, especially from 2010 to 2011.

As can be seen in Figure 1, the highest percentage was consistently found in the age group 20-49 (83.9%) and among males (70 %). According to the MoH report, from January 2012 to June 2012, there were 2,224 new AIDS cases, with 83.6 % found in the age group 20-49 years old and 61.8 % found among men. Of women living with AIDS in Indonesia, 32.58 % were housewives (MoH, 2012). In general, HIV infection was reported in 300 districts in 32 provinces, and the highest prevalence rates of HIV from 1987 to June 2012 occurred mostly in

industrialized sites such as DKI Jakarta, Papua, East Java, West Java, and Bali (MOH annual report, 2012). Moreover, based on the report, from January 2012 to June 2012, Central Java, Yogyakarta and South Sulawesi were categorized as three of the five provinces with the highest number of new AIDS cases while Papua remained in first place and Bali continued to rank as one of the five.

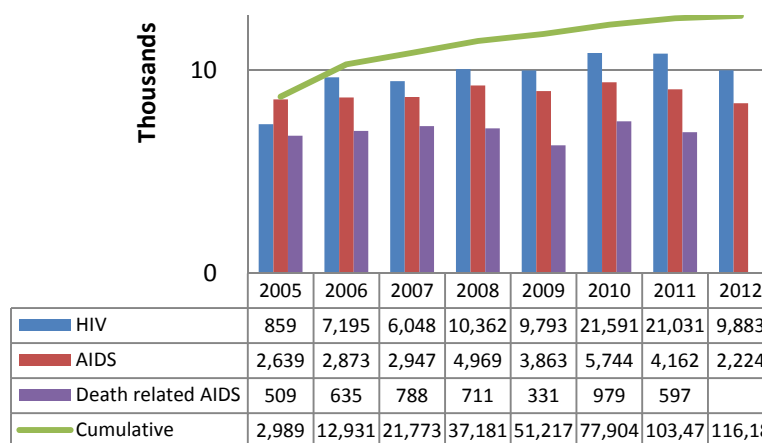


Figure 1. New and cumulative number of HIV/AIDS cases. (MoH quarterly report, 2012)

The National AIDS Commission (NAC) reported in 2012 that the Indonesian HIV epidemic had not changed from a concentrated epidemic since 2000 (MoH, 2012), with HIV prevalence continuing to occur at greater than 5% in four key affected populations: injecting drug users (IDUs), sex workers, transgender people (*waria*), and men who have sex with men (MSM). The 2011 Integrated Biological and Behavioral Survey (IBBS), as presented in the NAC report (2012),

indicated that transgender sex workers (43%), male sex workers (34%), and direct female sex workers (FSW) (10%) continued to have high rates, whereas the prevalence of HIV infection among IDUs declined from 53% in 2007 to 34% in 2011. The NAC (2011) reported that the five provinces most affected by IDUs were DKI Jakarta, East Java, West Java, North Sumatra and South Sulawesi. Among direct FSWs, the highest prevalence of HIV occurred in the Land of Papua and the island of Bali. The highest prevalence of HIV among indirect FSWs – women who work in bars, cafes, and massage parlors while also carrying out sex work intermittently – was found in Batam and Jakarta.

Currently, the dominant mode of transmission of HIV infection is through unprotected sex, particularly among people with multiple or a high number of partners. This transmission route, which rose in 2001-2009 from 37% to 71 % (2011), replaced unsafe injecting behavior (34%) (NAC 2012; NAC 2010). The report is consistent with the latest data from the MoH 2012 quarterly report from January 2012 to June 2012, which showed that about 82.6% of AIDS cases occurred through heterosexual transmission. In regards to HIV heterosexual transmission, high risk men are men who are frequent clients of FSWs and hold occupations such as truck drivers, seafarers, dock workers, and moto taxi drivers. It is these high risk men who can be seen as an important 'bridge' between the key population and the general population (NAC, 2011). A high proportion of these men are likely to have sex with FSWs and most of them were married (Winarti, 2010). Therefore, spouses of the high risk men are also vulnerable to HIV infection.

1. Future Projection of HIV in Indonesia: Feminizing

Future projection is very useful for properly planning HIV and AIDS prevention programming in Indonesia and in determining the type of services that will be needed to prevent new infections in the future. The NAC (2012) uses the Asian Epidemic Model (AEM) shown in Figure 2 to derive future projections of the HIV epidemic in Indonesia. The AEM begins by identifying significant factors influencing HIV infection. It uses a variety of data on behavior within the population at risk, including HIV prevalence, as calibrating data. Based on the figure, it estimates that HIV prevalence will increase in the future among people age 15-49. The highest percentage is expected to occur among clients of sex workers, followed by low risk women, FSWs, MSM, IDUs, and low-risk males. HIV infections are expected to increase among women which, in turn, will lead to a rise in infections among children. This prediction is drawn from the fact that some clients of sex workers are married, some men who have sex with men (MSM) also engage in heterosexual relationships, and the female sex partners of male IDUs include a number of FSWs.

The projected number of people living with HIV in Indonesia also depends on the effectiveness of the country's intervention programming and its level and quality of care. In addition, critical to successfully addressing and curbing the epidemic are support and treatment services guaranteeing universal access and a supportive environment that reduces stigma and discrimination towards people living with HIV/AIDS (PLHIV) and other key affected people. The NAC (2012) predicted that if the goals of the national action plan and universal access are achieved by 2014, there will be 630,000 number of PLHIV in 2014 and 912,000 number of PLHIV

in 2025. In contrast, with low or limited intervention and failure to achieve the universal target access, the number of PLHIV in Indonesia will be 924,000 in 2014 and 2,117,000 in 2025.

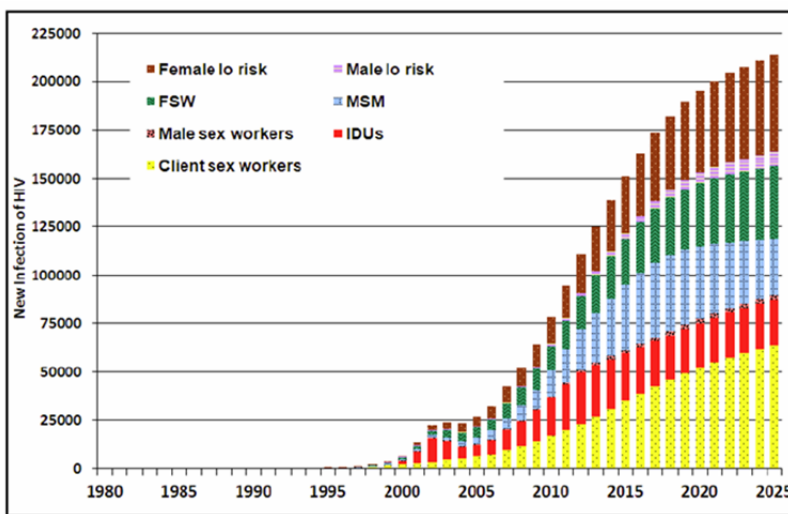


Figure 2: Future Projection (National AIDS Commission, 2012)

2. Indonesia and the course of the HIV epidemic

To recap, the November 2012 UNAIDS Global Report reported that the rate of new HIV infections in Indonesia increased, while most other countries experienced a decline during the same time period. Possible explanations are as follows:

- **Voluntary Counseling and Testing (VCT).** Data from the NAC (2012) reports that in 2008, there were about 547 VCT site across Indonesia, which in turn, contributed to increase the number of people who get tested. However, even

though the VCT seemed to have reached more than 75% of key populations targeted to get tested, success in HIV prevention over the last 10 years has been low.

- **Coverage.** According to UNAIDS data (2012), coverage of HIV prevention programs among sex workers and MSM was very poor (below 25 %). Also, the number of syringes per person distributed through needle and syringe programs for IDUs was considered inadequate (below 100/ person/year). At about 24%, the ART coverage was also very low, a missed opportunity that will increase the risk of transmission.
- **Access.** The availability of programs has increased and expanded between 2005 and 2008. For example, only 17 sites in 2005 delivered harm reduction programming, while in 2008, there were 182 sites and also 245 service units for sexual transmission programming. Nonetheless, given that the country's overall coverage of prevention programming remains low, it appears that integration of HIV programs into the existing health system is not yet optimal. Services and programs are not fully accessible due to multiple factors, which include: risk populations' transportation problems (cost and distance) in accessing services, negative perception and distrust toward government services, and the effects of stigma and discrimination.

The three social-structural factors that also contribute to the rising rates of HIV in Indonesia are population diversity, religion, and gender inequality. In general, population

diversity contributes to the richness of a nation. As an archipelago, Indonesia has a unique situation in terms of cultural and ethnic diversity. Nonetheless, cultural diversity becomes one of the obstacles to effective communication and resource distribution in terms of successfully confronting HIV. Furthermore, different modes of transmission require different methods and intervention strategies. These multiple permutations of culture, ethnicity and risk complicate the development and delivery of HIV effective prevention, treatment, and care. Religion also affects knowledge, behavior and attitudes toward HIV/AIDS. Religion functions as a “control factor” in promoting sexual abstinence in Muslim countries. In Indonesia, Muslim males are obligated to be circumcised as a part of their beliefs. Nevertheless, most religious leaders hesitate to endorse public health perspectives such as safe sex practice. Several Indonesian local governments do not promote condom use as an HIV prevention method out of a desire to avoid conflict with religious leaders. Gender inequality is discussed further in the next sub-section below.

C. Challenges for Women with HIV/AIDS in Indonesia

The United Nations Programme on HIV/AIDS (UNAIDS, 2010) describes the social drivers of HIV in terms of social and structural factors, such as poverty, gender inequality, and human rights violations that are not easily measured but increase people’s vulnerability to HIV infection. Auerbach, Parkhurst, and Caceres (2011) explain social drivers as the core social processes and arrangements that reflect social and cultural norms, values, networks, structures and institutions. These drivers operate around and in concert with individual behaviors and

practices to influence HIV epidemics in a particular setting. Gender inequality is a main driver that has contributed greatly to the epidemiology of HIV/AIDS among women in Indonesia.

A growing body of literature discusses how religion, culture and the state influence gender inequality among women in Indonesia (Sears, 1996; Blackburn, 2004; Bennet, 2005; Widyaningrum, 2005; Jacobowsky, 2008; Hayati, 2011; Khoriroh, 2011, Imelda, 2011). In terms of religion, Indonesia is the most populous Muslim country in the world, with more than 200 million people or about 90 % of the Indonesian population practicing Islam as their religion (French, Eisenberg, Vaughan, Purwono & Suryanti, 2008). Khoriroh (2010) argues that the patriarchy is a form of Islamic teaching through the chapters in the Qur'an. However, the teachings of the Qur'an tend to be misinterpreted as legitimating the discrimination, segregation and subordination of women, implying that men as leaders or superiors cannot be challenged even if they wrong. According to Khoriroh (2010), the more serious practical implications of the issue of gender inequality is how religious leaders interpret the patriarchy as giving men rights toward women. In the context of marriage, it is believed that Islam dictates that wives have the obligation to satisfy the sexual needs of husbands and husbands have exclusive sexual access to their wives' bodies. These misinterpretations increase women's risk of having HIV because they cannot easily negotiate for safer sex, such as using condom. In addition, Jacobowsky (2008) sees gender inequality among Indonesian women as a result of traditional beliefs and practices. Jacobowsky cites these – such as polygamy, early marriage, and contract marriage – along with religious morality as practices that contribute to women's vulnerability to HIV infection.

As a country with a Muslim majority, Indonesian people have strong moral views that effect how the society perceives HIV, producing social stigma and discrimination against people with HIV/AIDS and key risk populations. According to Hasnain (2005), there are three main challenges for people living with HIV/AIDS in Muslim countries: social stigma, gender inequality, and misinformation about HIV/AIDS. The first relates to the social stigma attached to HIV/AIDS due to the religious doctrine regarding illicit sex and drug related practices. Religious leaders perceive AIDS as the punishment for sexual sin, resulting from immoral behavior, an attitude that perpetuates stigma toward key population risk groups and also people living with HIV/AIDS (Orobuloye, Caldwell, 1993 as cited in Winarti, 2010). For example, a new controversial statement made by one of the Indonesian Senate Representatives argues that people with HIV/AIDS should be punished or negatively sanctioned by the government through denial of free access to ART (Aditiasari, 2013). In addition, according to the report from the Jakarta Globe (2009), hundreds of hard-line Moslem party members urge the government to close down brothels, ban condoms, and support the application of *Shariah* in an Islamic caliphate to stop the threat of HIV/AIDS.

As described above, in addition to religious traditions, gender inequality poses a second challenge. Specifically in Indonesia, the interplay between religion and the state helps shape the gender ideologies that place women in lower positions than men. Gender inequality is constructed by a patriarchal system that is strongly internalized through cultural and religious practices (Hayati, 2011). In many sectors, an imbalance of power between men and women places women in subordinate positions. This makes them easy targets for abusive relationships

and makes it more difficult for them to cope with HIV once infected. Low levels of education and low social protection contribute to their lack of awareness of their civil, legal and sexual rights and make them economically vulnerable and largely dependent on men (UNAIDS, 2011). In addition, women face health issues, such as a high fertility rate and a high maternal and infant mortality rate caused by a lack of access to health facilities (UNAIDS, 2011).

Misinformation about HIV/AIDS is the third challenge. According to Hasnain (2005), there is a strong assumption that all HIV infections are transmitted only through immoral sexual behaviors. Due to a lack of knowledge about HIV/AIDS, society is unaware that HIV can be transmitted indirectly from mother-to-child, through accidental perforating of skin, through accidental contact with contaminated blood (as in the case of health care professionals), or from a spouse who acquired HIV through sexual or drug-related contact with other infected persons.

Most women living with HIV in Indonesia face all three challenges, which make their situation more complex than that of men. The Indonesian National Commission on Violence Against Women (Asrianti, 2010) reported that in Indonesia, women with HIV/AIDS have a greater risk of violence including sexual abuse, coerced abortion and marriage. Conducted by the Indonesian Positive Women's Network in 2011 (Rivona & Mukuan, 2013), research among 122 women living with HIV in eight provinces showed that 64 percent had experienced some form of violence. These included forced sterilization (14%), sexual violence (30%), other forms of physical violence (25%), and psychological violence (31%). Research by Damar and DuPlessis

(2010) reported that women in their study were devastated to learn that they were HIV positive because of the strong stigma attached to women with HIV in Indonesia. In contrast to how HIV positive men are treated, people tend to automatically think that women with HIV must be immoral, and negative things will be said about them.

The existing social, cultural and religious frameworks described above do not provide an environment for any safe disclosure for infected persons, especially women (Hasnain, 2005). A qualitative study from Anindita, Shaluhiah, and Suryoputro (2013) related to Prevention Mother-to-Child Treatment (PMTCT) among pregnant women in Indonesia found that the non-disclosure of HIV status among them affects their decision to follow the PMTCT program. They found that women are often discriminated against because some people associate HIV infection with behaviors known to cause infection (e.g., commercial sex work and IDUs). In addition, women in their study were not inclined to disclose their HIV status to their partners, out of fear of abandonment or of being labeled as a bad or unfaithful person. There are many HIV positive women who are labelled as “women without morals” or “bad girls,” but unluckily, many of them have to work more after their husbands are diagnosed with HIV (Wibisono, 2011 as cited in Anindita, Shaluhiah, and Suryoputro, 2013).

D. Statement of the Problem

Given the socio-cultural context, disclosure of HIV infection by women may not only present unique risks and stress, but also entail a complex process. A substantial and growing amount of literature on disclosure of HIV among women in the United States has shown how

women decide to disclose or not disclose their HIV status to others and how they experienced risks and benefits of disclosure. One reason for disclosure is to attain social support from significant others (Greene, et.al, 2006). In addition, the reaction of the confidant is one of the most important factors predicting the effects of disclosure (Chaudory & Fisher, 2010). When an HIV-positive person anticipates a recipient will respond negatively or is unsure of the target's response, the person will not likely disclose that information (Serovich et al., 1998). In contrast, if the expected response is positive or supportive, the person will likely disclose it. The benefit of disclosure is that it can result in access to social support.

Numerous studies show that social support is an important variable to promote a positive sense of emotional well-being among people living with HIV (Green, 1993). Consistent with Green (1993), Turner & Turner (1999) also suggests the vital role of social support systems for buffering HIV-related psychological distress and physical symptom, and enhance access to resources or significant persons and improved health-related behaviors (Kalichman, et.al, 2003).

Family, as the closest unit in the individual, is regarded as the primary source of support for people facing serious illness (Kalichman, et al., 2003). Normally, biological family members provide practical, emotional, and social support during a time of illness, however, unlike other serious illnesses; HIV limits this typical pattern of support (Bor and Elford, 1998 as cited in Kalichman, et al., 2003). Due to the limit or absence of family involvement, individuals with HIV might have to find the alternative sources of social support. Consequently, literature on social

support among HIV positive individuals presents differing conclusions. Older studies found that greater support frequently came not from family but from friends and partners, especially those who were also HIV positive (Hays, 1993; Stempel, 1995). After ten years, these findings have shifted, as HIV has become better understood and treatable. Kalichman et al. (2003), for example, found that individuals with HIV receive greater support from family and friends after disclosing their HIV status. Li et al. (2007) discovered that due to their strongly family oriented society, most participants in their study in China received family support and that disclosure itself has strengthened family relationships.

Research suggests that patterns of support may differ for people infected with HIV for several reasons. Study from Crandall and Coleman (1992) showed that one of reason is the stigma surrounding how HIV was acquired. Study from Katz (1997) and Kalichman & Nachimson (1999) found that the reason is related to the perception and/or belief that a positive HIV status implies engagement in negative behaviors. Additionally, there may be a high intolerance toward women with HIV in cultures where gender-associated traditional values are emphasized (Ichikawa & Natpratan, 2006). A study of women with HIV in Djibouti (Kajura's, 2010), for example, found that women identified as being HIV positive were likely to be accused by their partners and/ or family members of infidelity and prostitution, and therefore are often socially rejected. Under such conditions, disclosing one's positive HIV status within a relationship or among family member is unlikely to be possible or easy.

E. Purpose of the Study

The purpose of this study is to learn about HIV disclosure experiences and their associations with social support and ART utilization among women with HIV/AIDS in Jakarta, Indonesia. In this study, the term “confidant” refers to the first and second people whom the women personally told about having tested HIV positive. The term “disclosure network” refers to the constellation of people whom the women either personally told or who learned of their HIV status through other sources. The study has four specific aims:

Specific Aim 1. To examine the experiences of Indonesian women in disclosing having tested HIV-positive by identifying: (a) whom they told first and second; (b) the reason for telling each of these two confidants; (b) the reaction of each of the two confidants in learning of the woman’s HIV status; (c) the period of time between the first confidant and the second; and (d) the total size (number) and composition (personal relationships) of the woman’s overall disclosure network.

Specific Aim 2. To describe the social supports that women received from their disclosure networks by identifying: (a) their sources of support; (b) how the support person learned about woman’s HIV status; (c) type of support received; (d) the woman’s satisfaction with support and (e) association between disclosure to specific confidants and social support.

Specific Aim 3. To identify which individual characteristics of the women (if any) predict the sources and type of social support that they receive from members of their disclosure network.

Specific Aim 4. To describe women's participation within the HIV cascade of care in terms of: (a) entry into HIV care; (b) retention in care; and (c) adherence to ART among those women currently receiving treatment.

F. Research Question and Hypotheses

This study investigates a series of research questions concerning disclosure experiences, social support, and ART utilization among women with HIV/AIDS.

1. The women's experience in disclosing to a first and second confidant
 - a. To whom did women first disclose their HIV status? Why this person was chosen? How long after HIV diagnosis was this person told?
 - b. Do women tell a second confidant? If yes, to whom do the women tend to disclose second about their HIV status? Why was this second person chosen? How long after telling the first person did the second disclosure occur?
 - c. What was the reaction of first and second confidant to the HIV disclosure? Did the reaction of the first person influence the timing of the second disclosure?
 - d. Does an association exist between the reaction of the first and second confidant and the number, composition, and types of social support that the women received from them in coping with HIV?

- e. Does an association exist between the reaction of the first and second confidant and women's satisfaction with the support that they received from them?
- f. What are the reasons that women give for personally disclosing their HIV status to their first and second confidant?
- g. Does an association exist between the main reason that the women give for disclosing their status and the specific relationship (mother, father, sibling, etc.) that they select as first and second confidants?
- h. Are the women satisfied with the social support that they receive (if any) from their first and second confidants?
- i. Are there reasons for disclosure that predict the support from the confidant?
- j. Given the importance of family ties in Indonesia, do women confide in family members first before disclosing to others?

Hypotheses:

- 1) Type of reaction to HIV disclosure would be associated with number of people women later told of their HIV status
- 2) Type of reaction would be associated with types of support received and satisfaction with support received from first confidant and second confidant

- 3) Reason to disclose would be associated with types of support and support satisfaction women perceived from first and second confidant
- 4) There are different reason to disclose to first confidant and second confidant
- 5) Reasons for disclosure will predict the types of support women received
- 6) Reasons for disclosure will predict the level of support satisfaction

2. Sources and receipt of social support related to the women's disclosure networks

- a. How many people in total did women personally inform that they were HIV positive?
- b. Whom did the women tell?
- c. In terms of those who provide social support to the women in coping with their HIV status, how many of these sources learned from direct disclosure and how many learned through indirect (other party) disclosure ?
- d. What types of support do the women receive from their disclosure network?
- e. Are the women satisfied with the support that they received from these sources?
- f. Are there association between disclosure to specific confidants and social support?

Hypotheses:

- 1) There are different types of support and support satisfaction women receive from their support sources
- 2) There are associations between disclosure to specific confidants and social support
3. Individual characteristics associated with the social support that the women receive in coping with HIV
 - a. Are there individual characteristics of the women (age, marital or partnering status, working status, mode of transmission) that predict the number of support sources upon which they draw in coping with HIV?
 - b. Are there individual factors (age, marital or partnering status, working status, mode of transmission) that predict the types of social support received?
 - c. Are there individual characteristics of the women (age, marital or partnering status, working status, mode of transmission) that predict the women's satisfaction with the support that they received?

Hypotheses:

- 1) Individual characteristics (age, marital or partnering status, working status, mode of HIV transmission) will predict the number of support sources

- 2) Individual characteristics (age, marital or partnering status, working status, mode of HIV transmission) will predict the type of support received
 - 3) Individual characteristics (age, marital or partnering status, working status, mode of HIV transmission) will predict the level of support satisfaction with support among women with HIV/AIDS
4. Social support and utilization of the HIV cascade of care
- a. Are there characteristics of social support (availability, type, and recipient's satisfaction) that are associated with women's entry or non-entry into HIV care?
 - b. Are there characteristics of social support (availability, type, and recipient's satisfaction) that are associated with women's greater retention in care?
 - c. Are there characteristics of social support (availability, type, and recipient's satisfaction) that are associated with women's greater adherence to HIV treatment?

Hypotheses:

- 1) The presence of a strong social support (type of support and level of support satisfaction) would be associated with a high percentage of women's entry in HIV care

- 2) The presence of a strong social support (type of support level of support satisfaction) would be associated with the level of retention in HIV care
- 3) The presence of a strong social support (type of support and level of support satisfaction) would be associated with adherence to ART among those currently in HIV care

G. Significance of the Problem

Given the potential risk of an HIV/AIDS epidemic in Indonesia, the trend of feminization on HIV/AIDS cases and the important role of disclosure for HIV/AIDS intervention programs, there was a clear need to study the experience of first HIV disclosure and how it influences disclosure networks, social support and ART utilization among women in Indonesia. There have been numerous studies of HIV disclosure among women from different countries; however, there were very few empirical literatures and disclosure studies among women in Indonesia and other Asian countries. There were no published empirical studies describing and exploring HIV disclosure influence on social support and ART utilization among women in Indonesia, and this study attempts to fill this gap. It was also important to know the people who women considered as significant others or as support systems because they can potentially serve as priority targets of HIV prevention efforts.

H. Significance of the Study

This study is significant on descriptive, theoretical, practical, and policy levels. On the descriptive level, this study is expected to provide information about HIV disclosure experiences, social support received by women, and ART utilization among women with HIV/AIDS in Jakarta, Indonesia. On theoretical level, this study is expected to contribute to the public health literature, particularly the important role of HIV disclosure in gaining social support and increasing positive outcomes among women with HIV in Indonesia. On the practical level, the information regarding to whom women disclose their HIV status and from whom they gain support will have significant implications for HIV/AIDS care efforts in Indonesia. At the policy level, this study could provide a foundation to develop interventions that are more sensitive to women's specific needs related to Indonesian culture.

II. CONCEPTUAL FRAMEWORK

A. Theories of Disclosure

Theoretically, HIV disclosure can be defined as a complex, multifaceted, and selective process of making a voluntary or involuntary decision about whom to inform one's sero-status, as well as why, when, where and how to do it (Eustace & Ilagan, 2010). Disclosure of HIV status takes place in so many context of relationship, not only relationships between parents, siblings and children, but also between partners and friends. It may also occur unintentionally in public spaces like hospitals or clinics where people are identified by subtle indicators, such as sitting in a specific area for people who wish to see HIV specialist doctors (Mills and Magazi, 1999 as cited in Mills and Maughan-Brown, 2009).

1. Disease Progression and Consequences Theory

Serovich (2001) examined two theories: the disease progression theory and the consequences theory of HIV disclosure and nondisclosure. According to Serovich (2001), the disease progression theory proposes that individuals disclose their HIV-positive status as their HIV progresses to AIDS because they can no longer hide their illness in the face of hospitalizations and physical deterioration. The consequences theory, based on the social exchange theory, suggests that the relationship between disease progression and disclosure is moderated by the consequences one anticipates resulting from the disclosure. In other words, as the disease progresses, stresses accumulate and result in the conflict between to reveal or

conceal their HIV status to others. On this stage, individuals need to evaluate the negative or positive consequences of disclosure. According to this theory, persons with HIV are likely to reveal to significant others and sexual partners once the rewards or benefits for disclosure are greater than the associated costs or negative consequences.

2. Communication Privacy Management (CPM)

Petronio (2000) developed the theory of communication privacy management (CPM) to explain the following: private disclosures are dialectical; people's choices about revealing or concealing private information are based on criteria and conditions that they perceive relevant; and individuals fundamentally believe they have a right to own and regulate access to their private information. "To tell and not tell" is a part of strategies that Petronio called balancing privacy and disclosure (Petronio, 2000). As a rule-based theory, CPM proposes that individuals develop rules to aid decisions about whether to reveal or conceal private information, and thus to best protect personal privacy (Petronio, 2002). Five privacy rules based on culture, gender, motivation, contextual variables and risk-benefit criteria are used in determining the following: who will receive a disclosure, when and how much information will be disclosed, where the disclosure will occur, and how information will be revealed or concealed.

Cultural criteria. According to this theory, cultural values are fundamental to privacy rules for individuals (Altman, 1977; Moore, 1984; Spiro, 1971; Yep, 2000 as cited in Greene et

al., 2009). Through cultural expectations for privacy, people open or protect their boundaries to varying degrees (Petronio, 2002).

Gender criteria. Gender and sexual orientation serve as criteria on which people judge whether to reveal or conceal their HIV status to others. For example, heterosexual men might face different challenges in revealing their HIV status because people have come to associate the disease with one particular sexual identity (Greene et al., 2009). A study conducted by Dindia and Allen (1992) showed that women disclosed more than men, and sex differences in self-disclosure were significantly greater to female and same-sex partners than to opposite-sex and male partners.

Motivations. Motivational criteria influence the establishment and enactment of rules to regulate boundaries around private information and the willingness to disclose (Reis & Shaver in Petronio, 2002). Some people have a high need to tell others because it helps them to cope with their illness while others find it difficult to disclose because they may not be able to tackle dealing with their illness or because they are in denial about their condition (Greene et al., 2009).

Contextual Criteria. Contextual criteria represent a decision base that accounts for changes in the situation (Greene et al., 2009). There are two elements that serve as a basis for contextual criteria: the physical elements or social environment aspects of the communication process that include setting and timing of disclosure (Petronio, 2002).

Risk-benefit ratio. This criterion is quite similar to the consequences theory derived by Serovich (2001). Individuals calculate the risks and benefits of disclosing or concealing their private information (Petronio, 2002). The way people assess the risks and benefits of disclosure matters in terms of the rules that they use to decide whether to disclose, how much to disclose, or the extent to which they might wish to conceal their health status.

Because of the sensitivity of the information, people are more likely to calculate how much they want to tell, when they want to tell, and who they want to tell (Petronio, 1991, 2002). People who are HIV positive must confront a series of difficult decisions when they consider disclosing their HIV status. Disclosure is an ongoing process, and therefore, when the five rules above become ineffective, people need to develop new disclosure criteria to meet their needs. For example, before finding out about having HIV, someone may have been very open with his or her mother about private matters. After receiving the diagnosis, the same individual might feel uncomfortable being so open with his or her mother, especially about health related issues. As a result, the disclosure norms do not function as effectively as they once did in this relationship with the parent. Greene, Derlega, Yep & Petronio (2003) examine the three main issues affecting one's judgment about disclosing his/her HIV status. First, there is the issue surrounding HIV-related stigma. It underscores the importance of the risk-benefit criterion used to make disclosure decisions. This is quite similar to the consequences theory, according to which people make rules for revealing and concealing based on level of perceived risk. Second, there is the motivation that people have to conceal or reveal the diagnosis and the subsequent decisions they make for sharing or concealing their sero-status. Third, the CPM

theory contends that decisions regulating privacy boundaries depend on relational and contextual issues.

3. Disclosure Process Management (DPM)

Another disclosure theory is the Disclosure Process Management (DPM) that is derived by Chaudoir and Fisher (2010). According to Chaudoir and Fisher (2010), the DPM advances current disclosure theories in three important ways. First, the DPM theory postulates that disclosure must be conceptualized and studied as a single process that involves decision-making and outcomes processes. The theory highlights the impact of five main components to the disclosure process: process-antecedent goals, the disclosure event itself, mediating processes, outcomes and a feedback loop. Chaudoir and Fisher (2010) suggest that previous frameworks have included some combination of these components (Omarzu, 2000; Greene et al., 2006; Petronio, 2001), but none have exposed the mediating mechanisms involved in disclosure. Second, the DPM suggests that avoidance motivations or negative outcomes (such as social rejection, stigma, and relationship conflict) trigger disclosure behavior, and expresses how these motivations can shape each successive stage of the disclosure process that shows in disclosure events and the long term outcomes. Attention of antecedent goals (both approach and avoidance goals) provides a framework for considering when disclosure would be beneficial. Third, the DPM suggests that the relationship between disclosure event (content of disclosure and reactions of confidant) and a wide range of is a multiply mediated process. Comprehensively, the DPM discusses more specifically the effect of disclosure at the level of

individual, dyadic, and social contextual outcomes through three types of mediating processes: alleviation of inhibition, social support, and changes in social information.

The DPM indicates that when individuals disclose information about their concealable stigmatized identities, such as HIV/AIDS to other people, disclosure affects people's lives through two mechanisms: social support and changes in social information. The mechanism of social support includes the concept that interpersonal disclosure might lead to individuals vulnerable to social evaluation that can result in either the individual will get social support or even stigmatization. The second mechanism is changes in social information. This involves the idea that interpersonal disclosure essentially changes the nature of social interactions among disclosures, their confidants and their broader social contexts.

B. HIV Disclosure among Women

As mentioned in the previous sub-section above, gender serves as a criterion upon which people decide to reveal or conceal their health status to others. Among all women, additional factors of race, class and poverty converge to make a very complicated decision package in determining whether or not to conceal the information about their HIV status (Cline & McKenzie, 1996; Greene & Faulkner, 2002; Kimberly, Serovich, & Greene, 1995; Weeks, Grierradda, & McKinley, 1999 in Greene, et al., 2006).

Many studies document various patterns and rates of disclosure among women. For example, a study by Kalichman and Nachimson (1999) in the U.S. setting, found that women's disclosure rates to sex partners was below 50 %. Meanwhile, a study from Carter (in Kalichman

and Nachimson, 1999) showed that 76 % of the 107 HIV positive women had disclosed their status to their primary sex partners. Another study from Petrak, Doyle, Smith, Skinner, and Hedge (2001) conducted in East London, indicated that disclosure of HIV status was highest for partners, followed by friends, and lowest for family members. The findings were similar, with earlier research conducted with people of different cultures, such as Latinos, African-American, and Whites (Marks et al., 1992; Mason, Marks, Simoni, Ruiz, & Richardson, 1995; Simoni et al., 1995, as cited in Petrak et al., 2001) showed that, for those respondents who were in an intimate relationship or married, both men and women were more likely to disclose their HIV status to partners and friends, while lower rates of disclosure were found in telling immediate family members or coworkers.

Because of the characteristics and nature of disclosure differ depending on context (e.g. age, culture, mode of transmission), the pattern and rates of disclosure may differ in a patriarchal culture. For example, a review of disclosure studies in several countries in Africa showed that the level of disclosure to partners is generally low (Obermeyer & Osborn, 2007). In Tanzania, only 22 % of women told their partners their status after two months post-diagnosis, and only 40 % had disclosed their status after 4 years (Antelman et al., 2001; Killewo et al., 2001). In Burkina Faso, only 18 % of women had disclosed to their partners (Nebie et al., 2001). Such decisions may be more likely to occur when women are financially dependent upon their male partners, addicted to drugs, or lack coping skills or other social resources (Gielen et al., 1997; Moneyham et al., 1996; Rothenberg et al., 1995; Sherr, 1996). A study from Warren in 1992 (Simoni et al., 2000) about injection drug users (IDUs) showed that women were less

likely than men to disclose to sexual partners (51% vs. 72%) and delayed disclosure for longer periods of time than did men. In addition, a woman's disclosure of her HIV infection to sexual partners may trigger violent episodes. A number of studies (Rothenberg and Paskey, 1995; Zierler et al., 2000, Simoni et al., 1995) report that while partners of women who disclosed frequently are as emotionally supportive as others who are told of their status, they are also more likely to become angry and withdraw, with 20% subsequently leaving her. Gielen et al (1997) found that one-fourth of women in their study had experienced negative consequences of disclosure, some of which included rejection, abandonment, and verbal and physical abuse.

It is probable then, that the expected costs of HIV disclosure, such as abandonment and violence, counter the more usual tendencies for women to reveal intimate information. Furthermore, in terms of age, the tendency to disclose is split; younger women were more likely than older women to disclose according to Simoni et al. (1995), but that finding is contradicted by Sowell et al. (1997).

C. Social Support

Social support is a complex and multidimensional construct. House, Umberson, & Landis (1988, in Renwick & Halpen, 1999) categorized social support into three aspects: (1) social integration, or the number of people in the network and frequency of interaction with them; (2) social network structure, or reciprocity; and (3) longevity of relationships and relational content, or the aspects of relationships that buffer stress. Edwards (2006) operationalized the construct into items such as perceived satisfaction with support, type of

support, and membership in social networks, or sources of support. In a simple way, Wills (1991) defined social support as the perception or experience of being loved and cared for, esteemed and valued, and part of a social network of mutual assistance and obligations. Edwards (2006) then described the difference between perceived support and received support. Perceived support is defined as the perception by individuals that support is available to them, however, is not always actually received. On the other hand, received support, or actual support, refers to any specific behaviors enacted by others that are meant to be supportive or viewed by the recipient as helpful. Satisfaction with support has been found to be more important than the received support or frequency of supportive behaviors in explaining health and psychological well-being (Doeglas, Suurmeijer, Briancon, Moum, Krol, Bjelle, Sanderman, & Van Den Heuvel, 1997 in Renwick, et al., 1999). Turner (1994) also suggests that perception of support or subjective perception of being supported has been found to be more beneficial than actual supportive behavior for psychological well-being.

The approach to categorizing social support is to distinguish types of support. Research classifies the support into three types or categories (Cohen & Wills, 1985; Schwarzer, Dunkel-Schetter, & Kemeny, 1994; Renwick, et.al, 1999; George et al., 2009). The first is instrumental support. Instrumental support involves the provision of tangible help in managing practical concerns such as assistance with household chores, financial assistance, and other specific aid or goods. Second is the informational support. Informational support occurs when one individual provides advice, feedback, or other information which helps an individual appraise his or her situation. Third is the emotional support. Emotional support involves providing

warmth and nurturance to another individual that consists of behaviors such as listening, caring or providing companionship and reassuring the person that he or she is a valuable person who is loved and cared about.

Many researchers' approaches vary in identifying sources of support. Some refer only to "significant others" or "supportive others" (Zich & Temoshok, 1987) while other researchers specify the relationships. For example, Kalichman, et al., (1999) referred to family, partner, or friend relationship while Waddell & Messeri (2006) used "specific networks" to refer to family and friend relationships to explain the sources of support.

George et al. (2009) suggests two categories of social support sources: formal and informal. The formal sources consist of professional support systems such as health care and social service providers, and the informal sources consist of family, friends and other member of community organizations. According to George et al (2009), in managing HIV, informal social support networks, particularly kin, are acknowledged as critical sources of social support.

1. Women and Support

Previous investigators have studied gender variations in the nature of interpersonal relationships (Turner, 1994). Vaux (1985, 1988) specifically suggests that gender, more than any other social status variable, is significantly associated with a number of factors and conditions relevant to the gaining and experience of social support. According to Vaux (1998), it appears that men and women often differ in both the quantitative and qualitative aspects of their relationships. Both aspects are including the size and composition of their social networks, the

amount of support they report receiving, and the degree of emotional exchange and intimacy that characterize their relationships. This finding is confirmed by several studies that show women have significantly larger networks than men (Turner, 1994). Study from Turner (1994) shows that women appear to have larger, more multifaceted networks and they tend to maintain more kin relationship and generally report receiving more social support than do men. Although the findings reviewed consistently show that women have larger and various support networks, a study from Depner and Ingersoll-Dayton (1985) found that women report both receiving and providing less support to their spouse than do men. Men tend to rely only on their spouses while women also have other significant persons, such as children and friends to rely on. Turner (1994) also suggests that women are considered both as recipients and providers of support for men.

D. Antiretroviral Treatment Utilization

Since 1996, HIV care drastically shifted with the initiation of antiretroviral therapy (ART) (Health Resources and Service Administration, HIV/AIDS Bureau, 2006). It is recommended for people living with HIV to enter medical care soon after diagnosis to get benefit from life-prolonging HIV care (Fagan, Bertolli, McNaghten, 2010). Their study suggests that the early initiation of ART may reduce treatment-related complications, improve immune function, and reduce HIV-related morbidity and mortality. In addition, an early medical care also provides additional opportunities for preventive counseling, which may reduce further HIV transmission. However, despite these benefits, many adults enter care late in the course of HIV infection,

countering the benefits of timely access to HIV services and missing opportunities for risk reduction (McCoy, 2006).

The successful management of HIV requires consistent engagement in medical care through lifelong appointments with a physician, and uninterrupted medication use (Wohl, et al., 2010). According to Bertolli, Gardner, and Marks (2011), linkage and retention in care are important for the following reasons: (1) the early initiation of HIV treatment and long-term adherence leads to better health outcomes and reduces transmission of infection, (2) linkage to care shortly after HIV diagnosis provides opportunities for intervention to prevent transmission, and (3) many persons living with HIV are not linked to care shortly after HIV diagnosis or do not stay in care.

The Health Resources and Services Administration, HIV/AIDS Bureau (2006) stated that in light of the complexities of defining “in care,” an engagement in care continuum provides a more flexible definition that can help service providers and policymakers design programs to meet variable needs. The continuum of engagement care (as can be seen on figure 3) presents the line of those not in the treatment to those in fully engage treatment. Based on the figure, it shows that at one end are those completely unaware of their HIV status, either not tested or never received results and thus not in care. At the other extreme are those fully engaged in continuous HIV medical care and in between are different status and degrees of care engagement. According to the US Department of Health and Human Services (2006), the definition of engagement in care is referred to as the period during which patients visit one

primary care facility every 3-4 months. Below is the figure that explains the continuum of engagement care (Cheever, 2007 in Bertolli, Gardner, and Marks, 2011).

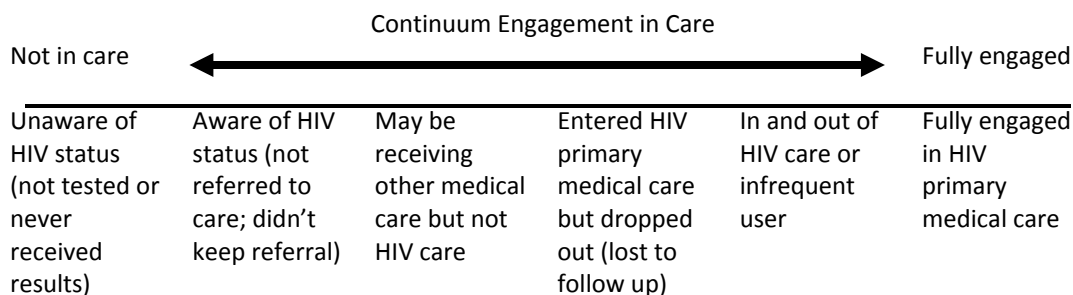


Figure 3 : Continuum of engagement in care. (Cheever, 2007; HRSA/HAB,2006)

According to the figure above, the concept of “in care” includes relationships with the care system that may vary in their level of consistency and durability, and that may change over time (Bertolli, Gardner, and Marks, 2011). The terms linkage to care, engagement/ retention, reengagement in care and re-entry to care reflect the degrees of relationships with the care system. Each step of care requires different intervention activities.

A UNAIDS global report (2013) set out new HIV treatment guidelines, which were provided by the World Health Organization (WHO) and issued in June 2013. It recommends starting treatment when an individual's CD4 count falls below 500 cells/ μ L. There are specific groups who recommended beginning the treatment immediately, such as pregnant women, HIV positive partners in serodiscordant couples, children younger than five and people with

HIV-associated tuberculosis and Hepatitis B. The 2013 WHO guidelines on HIV treatment will require substantially faster scale-up, coupled with innovation and programmatic adaptation, to ensure that those who are eligible for HIV treatment receive it. Indonesia is one of 30 countries where 90 percent of people have an unmet need for antiretroviral treatment live (UNAIDS, 2013).

Some barriers to antiretroviral treatment access and utilization include substance use, mental illness, provider communication, medication side effects, lack of social support, poverty, and homelessness (Doshi, et al., 2012). Among vulnerable populations, interpersonal level and structural-level factors are as likely to be predictors of ART utilization. For example, study conducted by Knowlton, et al. (2010) showed the association between support and the ART adherence. Their finding indicated that among HIV-infected injection drug users in Baltimore, Miami, New York, and San Francisco who had better patient-provider communication, higher levels of social support, stable housing, access to drug treatment, and medical coverage were associated with improved access to ART (Knowlton, et al., 2010).

E. Disclosure, Social Support and the Antiretroviral Treatment Utilization

Studies suggest that the most effective supports are those that are closely related to specific stressors (Cohen & Wills, 1985 in Friedland, Renwick, & McColl, 1996). People with HIV/AIDS have specific stressors to which supports can be directed, but they have an added barrier or difficulty in that their disease impacts directly on the support level that they receive (Lam, King, & Wright, 2007). For example, the stigma attached to the illness makes it difficult to

gather some forms of support, and the unpredictable progression of the disease makes it difficult for caregiver to sustain the high levels of support needed (Folkman et al, 1994 in Friedland, et al., 1996). Friedland, et al. (1996) suggest that previous studies showed consistently that significant others, such as family ties and friendships, can offer a psychological buffer against life stress, anxiety and depression. However, in the case of HIV/AIDS, disclosure of an HIV positive status may either evoke responses of supportive or unsupportive reactions from the confidants.

Research has demonstrated that voluntary self-disclosure of HIV status may contribute to improve psychological well-being if those disclosed to respond in a supportive manner. Significant others can provide HIV-infected individuals with a wide range of valuable resources that are both tangible and emotional (e.g. information about treatment options, financial assistance, care in sickness, sharing feelings and reassurance that one is loved and valued).

Referring back to the theoretical framework of disclosure process model (DPM) from Chaudory & Fisher (2010), disclosure affects outcomes via social support as a mediating factor. Support resulting from disclosure has an effect on individual outcomes, including psychological, behavioral, and health effects. A study by Wohl, et al., (2011) showed that women who had disclosed most likely had more network members and associated with retention in HIV care. Social support has been found to improve adherence in most studies. For example, Simoni, Frick, and Huang (2006), studied a working model of how social support enhances adherence, based on their previous work in 2002. On the basis of a cognitive-affective framework, the

model stresses functional over structural aspects of support. In other words, it assumes that perceptions of received support are more important than the size or density of one's social network. In line with functional analyses of support, it highlights specific types of support identified by social support theorists (i.e., instrumental, emotional and informational). This might include informational support in the form of the provision of facts, advice, and guidance about HIV disease, ART regimens, and adherence strategies, which are capable of bolstering ART knowledge. According to Simoni, Frick, and Huang (2006), because of the stigma surrounding HIV/AIDS, social support may be especially important for persons on ART. Tangible support in the form of getting a ride to the clinic or picking up medications, although not examined in this preliminary study, might also facilitate adherence among those with few resources. Kalichman et al. (2003) found that individuals with less social support were more likely to be less to non-adherent in the past two days compared to those with higher levels of support. A study in the southern U.S. found that an unmet need for a support group was independently associated with not currently taking any HIV medications, even after adjusting for CD4+ cell count, symptom status, and demographics (Mc.Coy, 2006). To conclude, to encourage HIV positive persons to consistently engage with a physician and adhere to ART, they need social support networks of family or friends. The support network may offer them such as support that needed, for example, to remind them of upcoming appointments, to provide transportation to the clinic and to remind them to take medicine (Wohl, et al., 2011).

F. Summary

This study adopts the CPM and DPM theory in building the research framework. CPM theory is very important to describe and explore the act of disclosure, specifically focusing on how five privacy rules (culture, gender, motivations, context and risks-benefits ratio) are used and how individuals coordinate the disclosure pending others' response to learning of their seropositivity (Petronio, 2002). The way that decisions to disclose, and subsequent reactions to those disclosures, fit together provides a whole picture of the event. Given the reluctance of those infected with the HIV virus to reveal their health status, examining boundary access rules to privacy is a first step in locating ways to encourage others to disclose. The privacy access rules depend on an individual's reasons to disclose and his/her judgment about the appropriateness of disclosure recipients. In other words, an individual with HIV generally has hierarchical privacy rules for who is most and least likely to hear about their medical condition.

The DPM provides a series of testable hypotheses that explain the disclosure decision-making process to answer two critical questions: when and why disclosure is beneficial (Chaudoir & Fisher, 2010; Chaudoir, Fisher, & Simoni, 2011). Figure 4 describes the process of disclosure from decision making to the outcomes in the DPM's five main components.

For the purpose of this study, there are only three main variables that will be explored in this dissertation: disclosure event, mediating process, and outcomes. Disclosure event, described by Chaudoir & Schiffer (2010), is an event when individuals describe information about their identity to the chosen confidant. This model also focuses on the verbal

communication (characterized in terms of the breadth, depth, duration and emotional content) and the reaction it garners from the confidant. In this dissertation, the disclosure event refers to an individual's disclosure of their HIV status to the first person (primary disclosure), reason for telling and the reaction of the confidant to the disclosure. How this primary disclosure influences the subsequent disclosure and the disclosure networks will also be examined.

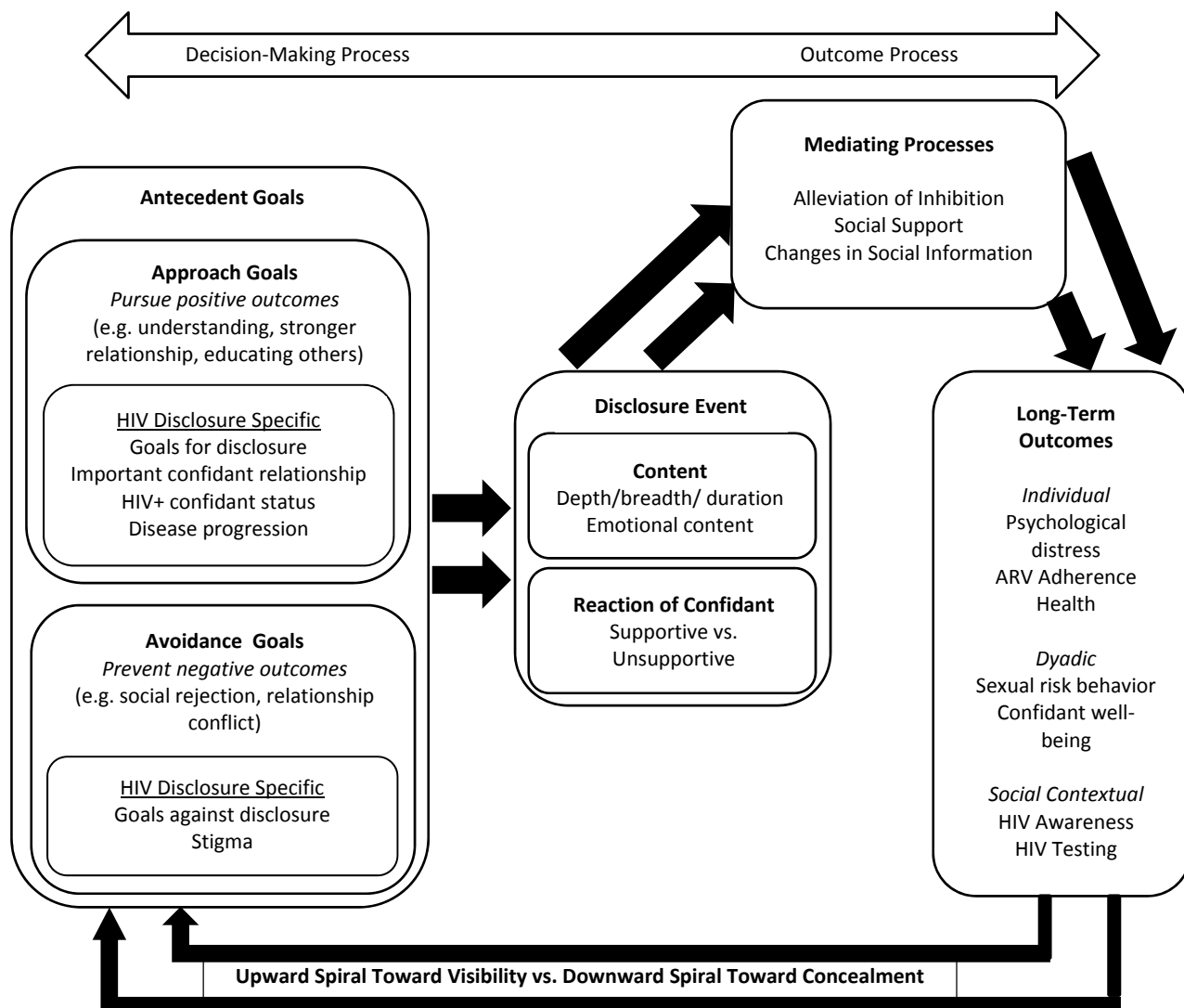


Figure 4. Disclosure processes model adapted for HIV disclosure. (Chaudoir and Fisher, 2010)

In mediating processes, this study will specifically focus on social support. Social support is considered as the most consistent mediator between disclosure and individual well-being (Beals et al., 2009 as cited in Chaudory & Fisher, 2010). Several studies have also showed that social support is an important aspect of psychological adjustment for many people living with HIV infection (Green, 1993), and that receiving social support requires disclosing their HIV-status (Huber, 1996). According to Chaudory and Fisher (2010), disclosure can be a multiply mediated process wherein disclosure can be beneficial to the extent that it allows individuals to obtain social support. In addition, a number of studies also suggest that disclosure's ability to gather social support can yield psychological and health benefits (Griffith & Hebl, 2002; Lepore, 2000; Rodriquez & Kelly, 2006 as cited in Chaudory & Fisher, 2010). However, when someone receives anything less than fully supportive reactions, disclosure can be detrimental to well-being (Corrigan & Kleinlein, 2005) and can lead people to experience greater psychological distress. For the outcomes, this dissertation will focus on individual outcomes that relate to ART utilization. Adopting from CPM theory and the DPM framework, the research framework can be seen in Figure 5 below:

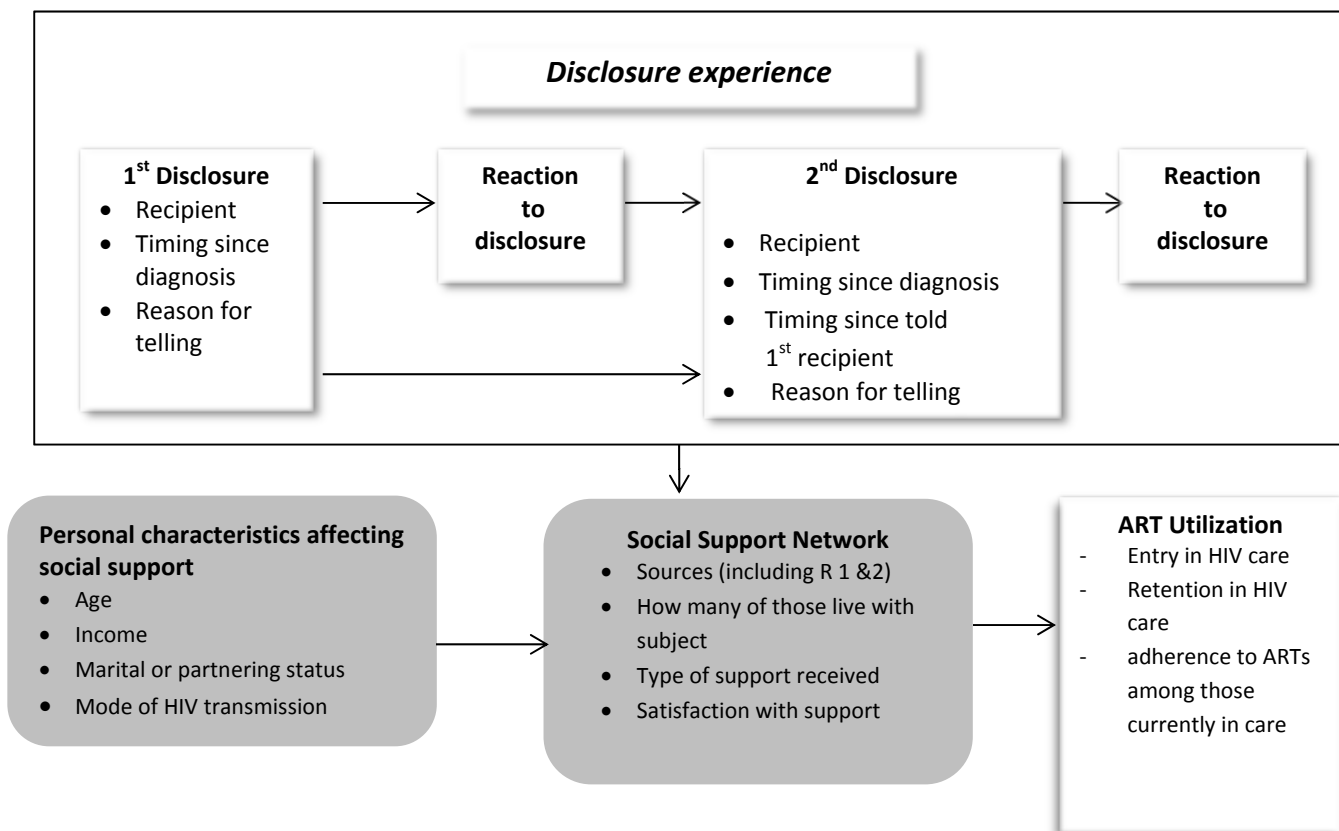


Figure 5: Research framework.

III. METHODS

A. Design

A cross sectional design using semi-structured interviews was used to investigate the disclosure experience of HIV-positive women and their experiences' association with the support they received and their utilization of ART. The data were administered by a face to face interview. This study's analysis is divided into four parts: (1) examination of the women's first HIV disclosure experience; (2) description of the social support that women received from the confidants and support networks; (3) predictors of social support based on individual characteristic; and (4) the effects of the women's social support on their entry into, retention, and adherence to HIV care.

B. Setting

The study was conducted in Jakarta Province, a city with a continuously high HIV prevalence on the island of Java, Indonesia. According to the quarterly report from the Indonesian Ministry of Health in March 2014 (MoH, 2014), until March 2014, the HIV prevalence in Indonesia was approximately 134,053 people, with highest percentage in Jakarta Province (22.4%). The cumulative AIDS cases until March 2014 were approximately 54,231 people and about 28.8% of them were women (MoH, 2014). According to the report, the highest number of AIDS cases among women was among housewives who acquired it from the sexual transmission.

C. Sample

1. Recruitment Procedures

Convenience sampling was used in recruiting women for the study through referrals from two recruitment sites that provide HIV services. *Spiritia*, a large nongovernment organization (NGO) in HIV/AIDS, agreed to refer potential participants to their networks: *Yayasan Kotex* and *Yayasan Kusuma Bangsa*. Atma Jaya Catholic University (AJCU) in Jakarta maintains two HIV/AIDS service sites that also referred potential participants: (1) *Lentera Anak Pelangi*, a site that working with children and family infected with HIV/AIDS, and (2) *Kios*, a field station with a comprehensive HIV program for drug users.

Staff members at the four sites informed prospective participants about the study using a 3-step procedure. First, during the course of delivering standard services and/or routine visits, NGO staff informed their women clients that a study is being conducted in which they might want to participate. Second, using the NGO script and distributing the study informational flyer (which has been included in the Appendix), the NGO staff member briefly described the study to potential participants. Third, the NGO staff provided potential participants with the researchers' contact information (Study Contact Card) so that those women who thought that they might want to participate could contact the researchers themselves to learn more about the study and what participation would entail.

NGO participation in the study ended with this referral process. At no time did the NGO staff collect or share contact information from potential participants with the

investigators. Their role was limited to inviting potential participants to contact the investigators directly.

After receiving initial information about the study from an NGO staff person, prospective participants who thought that they might be interested in participating contacted the research team by phone or by visiting the AJCU project office to hear more about what participation entailed and for eligibility screening. Upon meeting with study staff, the purpose and procedures of the study were explained to each potential participant who was interested in learning about or joining the study.

2. Selection and Enrollment of Participants

A brief screening interview was used to ensure that women met inclusion criteria. To be eligible to participate in the study, the women had to be: (1) HIV positive, (2) age 18 years old or older, (3) living in Jakarta or a nearby suburb of Jakarta (Bogor, Depok, Tangerang, Bekasi), and (4) have disclosed their HIV status to at least one person. Informed consent was obtained from those women who agreed to participate in the study.

3. Sample Size

Power estimates were conducted using G*Power 3.1.7 software to calculate the total sample needed for each analyses. This study planned to use Pearson Correlation, Repeated Measures ANOVA and Linear Regression to examine correlation between two variables, the differences among groups and the predictors' factor of dependent variable. Based on the study hypotheses described on previous chapter, the calculation of sample size

was tested by several statistical analyses. Multiple Linear Regression was utilized for the hypothesis related to predictors of social support based on reasons to disclosure (with 6 independent variables). With an effect size (f^2) of 0.25, α (alpha) error probability of < 0.05 and the power < 0.90 , the total sample needed to be recruited was 77. For Pearson Correlation and Repeated Measures ANOVA (using four independent variables of social support), the total sample needed was below 120. Therefore, the total sample needed for these three different statistical methods was estimated at 120. Projecting that approximately 15 % of participants recruited or enrolled in the study might not show up for or decline to complete their interview, the investigator requested IRB approval to recruit up to 150 subjects if necessary. Of the 147 potential participants who contacted the research staff, 5 did not meet the study's sample criteria and were not enrolled. The remaining other 142 women met the study's edibility criteria and were enrolled. All 142 completed their interview.

D. Data Collection

Data collection for this study was conducted from April 21st through May 29th 2014 using a face to face structured interview. The interviews were conducted in seven different locations based on the participants' preference or a scheduled visit for services at one of the recruitment site. The locations were: an Atma Jaya office, *Gambir* Community Health Centre, *Boncos* Harm Reduction site, *Yayasan Kusuma Bangsa*, *Yayasan Kotex*, *Klinik Jelia* and Saint Carolus Hospital. All seven sites provided interviewing space that afforded privacy so that what was said could not be overheard by others.

1. Interviewer Training

The interviewer team consisted of the principal investigator and four research assistants (RAs) who were recruited from Faculty of Psychology at AJCU and AJCU AIDS Research Centre. Two RAs had graduated from the department of Psychology, AJCU and the other two RAs held master's degrees of Health Psychology and Public Health.

Prior to the interview process, the RAs completed the following training:

- a. Training on protection of human subject. All the RAs have been updated with Research Ethic online course provided and certified by the AJCU IRB which train Indonesian based researchers on ethics pertaining to human subject research. The content of the training covers: (1) the history of research ethics, (2) regulations for human subject protection, (3) ethical principles, (4) research with vulnerable subjects.
- b. Structured interview training. The PI trained all the RAs to conduct the interview and administer the instrument to be used to collect the study's data. The PI also provided the basic listening skills material as preparation for conducting the interviews.

2. Administration of the Study's Questionnaire

Five interviewers (principal investigator and four research assistants) administered the questionnaire, which took between 60 to 120 minutes to complete. No identifying information was collected and anonymous identification numbers were used instead of names

on all study documents including the questionnaire. Because some of the questions were very personal in nature and might make participants feel uncomfortable, participants were advised that they could refuse to answer any of the questions and/or withdraw from the study at any time. None of participants declined to continue the interview or refused to answer any of the items in the questionnaire. In the event of the study participants' possible need for health and psychological services as a result of being interviewed, the PI arranged in advance for potential of the women for psycho-social counseling, HIV care and/or treatment. None of the participants requested referral.

Participants were compensated \$10 USD (equivalent with 100,000 IDR) for their time spent answering the questionnaire and for transportation expenses. An individual meal box also was provided for each participant that they could eat either before or after the interview depending on their preference.

E. Instrumentation and Measures

The instruments for this study were selected to measure: 1) demographic/ personal characteristics/ variables, 2) HIV disclosure experience including whom the women told, when they told, and reasons for telling, 3) social support, and 4) ART utilization. The instruments were adopted from previous studies and some items modified to adjust it with local culture and language.

Pilot Testing of the study's measures. This study used measures which were previously developed and used in English, predominantly in the US. The sample for this study was Indonesian women, and most of them speak only Indonesian language (Bahasa). Therefore, a small pilot testing was conducted to establish the appropriateness of the measures that were planned to be used in Jakarta. The first step for the pilot was translated all the instruments into Indonesian language. The translation process included back-translation and a pretest procedure. The back-translation was reviewed by the bilingual experts who mastered it in both English and the Indonesian language.

The pilot was conducted with five participants who subsequently were asked to comment on the items which they did not understand. All participants seemed to understand the questions but they requested that the interviewers read each item more slowly. There were no significant changes made for the questionnaire.

1. Demographic characteristics

Women participating in the study were asked to provide information on their socio-demographic status (age, education, employment status, and income), family (number of siblings, children, living arrangement, and number family with HIV positive) and current marital status.

2. Knowledge of the Women's HIV Status within their Ego Networks

Three questions examined the percentage of women's networks (family members, friends, and neighborhood) that knew their HIV status and two questions examined the number and nature of the relationship between the women and people to whom they disclosed their HIV status.

3. HIV Disclosure Experience

The women's experience in disclosing their positive HIV status was measured using three sets of items to capture. The three sets are : (1) who in their ego networks knew about their status; (2) whom they told first about testing HIV positive; and (3) if they told at least one more person, whom they told second and what the time interval between the first and second telling was.

a. Women's HIV Disclosure to a First and Second Confidant

Participants were asked to whom they first disclosed their HIV status using the following choices: mother, father, brother, sister, current husband, ex-husband, boyfriend/sex partner, other relative, female friend, male Friend, or other. If they had disclosed to a second person, they were asked to report this using the same categories.

b. Timing of Disclosure

A qualitative study by Varga, Sherman, and Jones (2006) asked their participants to describe the time that elapsed between learning that they were HIV positive and disclosing to the first person and second person whom they told. Based on their study, the time after diagnosis and first disclosure in this study were divided into five categories: one week or less, up to one month, two to six months, more than six months, and don't know the time. The time

between first and second disclosure were divided into the same five categories: less than one month, one month to six months, six months to one year, more than a year, and don't know the time.

c. Reasons for HIV disclosure

A summation index scale developed by Derlega et.al (2002) was used to measure the reason for or against HIV disclosure with both the first and second disclosure. The instrument consists of 24 potential reasons that might influence a person's decision to tell. Respondents are asked to indicate to what extent each reason influenced their decision to inform a specific person after being diagnosed as HIV-positive. Response categories range from "1" (not at all a factor) to "5" (very likely a factor) influencing their decision to tell. The Cronbach Alpha for the scale when used in Derlega's study was 0.9.

Derlega et.al's scale measures reasons for HIV disclosure according to six theoretical dimensions. Examination of the Cronbach Alphas for each of the six dimensions in this study was quite similar to the coefficients in the original scale, as shown below and as listed as a whole in Table I:

- 1) Catharsis (e.g. "I didn't want to have to carry this information around inside me all by myself"). The Cronbach's Alpha for this dimension ranged from .75 to .81. In this study, the Cronbach's Alpha for this dimension was 0.88.
- 2) Need to inform (e.g. "I felt obligated to tell [...]"). The Cronbach alphas for this dimension ranged from .88 to 0.89. In this study, the Cronbach's Alpha for this dimension was 0.82.

- 3) Duty to educate (e.g. "I wanted to educate him/her about what the disease is like"). In this study, the Cronbach's Alpha for this dimension was 0.82.
- 4) Test other's reactions (e.g. "I wanted to see how [...] would feel about me after I told him or her"). The Cronbach's Alpha for this dimension ranged from .73 to .81. In this study, the Cronbach's Alpha for this dimension was from 0.9
- 5) Close and supportive relationship (e.g. "We had a close relationship"). The Cronbach's Alpha for this dimension ranged from .85 to .90. In this study, the Cronbach's Alpha for this dimension was 0.88.
- 6) Similarity (e.g. "We had a lot in common"). The Cronbach's Alpha for this dimension ranged in Derlega's study ranged from .60 to .69. In this study, the Cronbach's Alpha for this dimension was 0.76.

Table I summarizes the Item-Analysis for all 24 items. In earlier examination for Cronbach's Alpha on each dimension showed that the range was from 0.76 to 0.9. The overall alpha for this the scale when used in this study was 0.899, which is considered excellent among most researchers (George and Mallery, 2003 as cited in Gliem and Gliem, 2003).

TABLE I
SUMMARY ITEM-ANALYSIS OF REASON TO DISCLOSURE SCALE FROM SPSS OUTPUT

Cronbach's Alpha and Item Statistics of the Scale of Psychological Capital from 2008 to 2014						
Statistic for Scale		Mean	Variance		SD	N
		90.654	342.865		18.5166	24
	Mean	Minimum	Maximum	Range	Maximum/Minimum	Variance
Item Means	3.777	2.125	4.537	2.412	2.135	.312
Item Variances	1.977	.710	3.030	2.320	4.269	.423
Inter-Item Correlations	.280	-.177	.871	1.048	-4.926	.036
Item Total Statistics		Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted
Item 1 (Catharsis)		86.890	321.462	.605	.342	.899
Item 2 (Catharsis)		86.713	321.110	.706	.409	.897
Item 3 (Catharsis)		86.559	317.789	.741	.529	.894
Item 4 (Need to inform)		86.515	315.852	.610	.553	.894
Item 5 (Need to inform)		86.993	312.037	.468	.496	.895
Item 6 (Need to inform)		86.610	318.047	.775	.465	.896
Item 7 (Need to inform)		86.588	313.488	.764	.561	.894
Item 8 (Duty to educate)		86.478	316.133	.568	.545	.894
Item 9 (Duty to educate)		87.199	305.597	.828	.584	.893
Item 10 (Duty to educate)		87.301	306.775	.837	.542	.894
Item 11 (Duty to educate)		87.199	301.953	.712	.654	.891
Item 12 (Test other's reaction)		87.110	303.610	.725	.693	.890
Item 13 (Test other's reaction)		87.081	304.149	.729	.668	.891
Item 14 (Test other's reaction)		87.044	302.235	.793	.707	.890
Item 15 Close and supportive relationship		86.559	311.004	.674	.634	.892
Item 16 Close and supportive relationship		86.404	321.250	.674	.494	.895
Item 17 Close and supportive relationship		86.654	321.991	.612	.422	.897
Item 18 Close and supportive relationship		86.118	326.964	.664	.499	.896
Item 19 Close and supportive relationship		86.324	323.791	.746	.477	.896
Item 20 Close and supportive relationship		86.213	325.369	.667	.513	.896
Item 21 Close and supportive relationship		86.485	324.311	.705	.426	.897
Item 22 Similarity		87.706	322.254	.485	.302	.900
Item 23 Similarity		88.529	336.207	.478	.080	.905
Item 24 Similarity		87.779	317.107	.480	.418	.897
		<u>Alpha</u>		<u>Standardized Item Alpha</u>		
Reliability Coefficients for Item 24		.899		.903		

d. Reaction of Confidant about Disclosure

To examine the first and second confidants' reactions to the women's disclosures and their possible influence on subsequent telling, data were collected using six items with "yes" or "no" response categories that the PI constructed based on findings from two qualitative studies: (1) Serovich, Kimberly, & Greene (1998) that explored family members' reactions to women's HIV disclosure) and (2) Greene & Faulkner (2002) who studied the expected versus actual responses to disclosure in relationships of HIV-positive African American adolescent females. Three items measured the non-supportive reactions and three items measured the supportive reactions. The Cronbach's Alpha for the supportive reaction was 0.64 and for the non-supportive reaction was 0.45 (see Table II and Table III below). As the Cronbach's Alpha levels were below 0.70 (the standard cut-off used by most investigators), this proposed component of the study was dropped from the final analysis. Tables II (Positive Reaction) and Table III (Negative Reaction) below present the poor Alpha level of the items that was used to decide to drop the scale from this study.

TABLE II
ITEM-ANALYSIS OF POSITIVE REACTION TO DISCLOSURE SCALE FROM SPSS OUTPUT

Statistic for Scale	Mean		Variance		SD	N
	5.600		.587		.7662	3
	Mean	Minimum	Maximum	Range	Maximum/Minimum	Variance
Item Means	1.867	1.793	1.943	.150	1.084	.006
Item Variances	.113	.054	.165	.111	3.048	.003
Inter-Item Correlations	.378	.262	.466	.205	1.781	.009
Item Total Statistics	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted	
Item 1	3.65	.417	.390	.171	.633	
Item 2	3.73	.297	.465	.224	.508	
Item 6	3.81	.212	.550	.304	.389	
		Alpha	Standardized Item Alpha			
Reliability Coefficients for Item 3		.637	.646			

TABLE III
ITEM-ANALYSIS OF NEGATIVE REACTION TO DISCLOSURE SCALE FROM SPSS OUTPUT

Statistic for Scale	Mean		Variance		SD	N
	5.754		.315		.5610	3
	Mean	Minimum	Maximum	Range	Maximum/Minimum	Variance
Item Means	1.918	1.880	1.986	.106	1.056	.003
Item Variances	.074	.014	.106	.092	7.589	.003
Inter-Item Correlations	.250	.146	.324	.178	2.214	.007
Item Total Statistics	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted	
Item 1	3.87	.126	.359	.160	.175	
Item 2	3.87	.145	.285	.082	.344	
Item 6	3.77	.265	.295	.108	.438	
		Alpha	Standardized Item Alpha			
Reliability Coefficients for Item 3		.448	.500			

4. Social support

According to Green (1993), a lack of consensus exists about how social support should be conceptualized or measured. One of theoretical problem in measuring social support lies in its socio-economic and cultural variation when used with differing populations. Green (1993) reviewed previous research and concluded that support structures vary according to gender, social class, household type and race. Therefore, the study of social support among people with HIV is complex because the population is heterogeneous in nature.

The development of this study's questionnaire was based on the "Social Support Inventory for People Living with HIV," developed by Renwick & Halpen (1999) and later modified using the guidelines of social support from George, et al., (2009). The "Social Support Inventory for People Living with HIV" assesses four dimensions of received support: *have*, or whether support is received; *want*, or whether the individual wants the support; *satisfaction*, or how satisfied the individual is with the support received; and *source*, or who provides the support. According to Renwick and Halpen (1999), these four dimensions can be measured using three subscales: instrumental, informational and emotional.

The items used to measure all dimensions in the inventory that Renwick and Halpern developed are closed-ended with the exception of source. The item measuring "source" of support was structured to allow interviewees to name the wide range of persons from whom they might receive support. Qualitative information about the respondents' source(s) of support was elicited by asking respondents to name and state their relationships with at least 3

people (excluding first and second confidant) who provide help or support in each category.

Items for the *satisfaction* dimension were rated on a scale ranging from one to five (1= not at all satisfied, 2= slightly satisfied, 3= moderately satisfied, 4= very satisfied, 5= extremely satisfied).

The *want* items had yes/no response choices. The *have* items had three response choices: 1= Never; 2= Sometimes and 3= always.

The questionnaire was presented in a detailed format to elaborate on the availability of three types of support received and support satisfaction from two categories of sources: (1) first and second confidant and (2) other support network. Social support questions for the first and second confidants were presented together in the HIV disclosure format to make it easier for participants to connect their first or second confidants with the support they receive from them. For other support networks, participants were asked to list three people from whom they received support. The list was classified as sources from other support network.

Renwick, Halpen, Rudman & Friedland (1999) had specifically developed the 17 items on the Social Support Inventory based on their qualitative study. Their validation study reported that the reliability scale for the instrumental subscale was 0.45, emotional subscale was 0.82 and the informational subscale was 0.66. Considering the low reliability of the instrumental and informational subscale, this study therefore used the guidelines of social support for people living with HIV that was derived by George, et al (2009) from their qualitative study. This study modified the instrumental and informational subscale by using the areas of care from George, et al., (2009) and used the emotional subscale from Renwick, et al.,

(1999) in order to have better reliability scale. The modification of items in this subsequent instrument can be seen in the table below:

TABLE IV
EXAMPLES OF TYPES OF SOCIAL SUPPORT RECEIVED FOR DIFFERENT AREAS OF CARE (George, et al., 2009) AND SOCIAL SUPPORT INVENTORY (Renwick & Halpen, 1999)

Types of Support	Areas of Care		
	George, et.al (2009)	Renwick & Halpen (1999)	Items modified for this study
Instrumental	Transportation support (rides, loan of car); family members attending appointments, housework and errands, financial	Help get things done Give practical assistance Help manage finances Help with living arrangements Help with caregiving	Cook meals for you Clean house Help with caregiving Give you rides to health providers Accompany you to appointments with your health care providers Help you to remember your medication Provide financial assistance
Informational	Information about health and diagnosis, information about medication and other resources	Help evaluate situation Help keep perspective People to compare self with Provide information about health Provide information about diagnosis	Your feeling about being HIV positive Medical problems that you might have that are related to your HIV How to tell others about having HIV Taking your HIV medication
Emotional	Encouragement with medication adherence, keeping appointments and follow up care, talking, going out with other	Makes you feel valued Makes you feel you belong Makes you feel cared for People you can count on Provide understanding Help keep spirits up Provide diversion	Make you feel valued Make you feel you belong within your circle of friends and family Make you feel cared for Understand your feelings Help to keep your spirits up Make you feel that you have someone on whom you can count on for help

Table V presents the item analysis of social support scale. The total number of items in the scale was 18, and these consisted of seven items measuring instrumental support, six items measuring emotional support and five items measuring informational support.

TABLE V
ITEM-ANALYSIS OF SOCIAL SUPPORT SCALE FROM SPSS OUTPUT

Statistic for Scale	Mean		Variance		SD	N
	39.986		56.985		7.5489	18
	Mean	Minimum	Maximum	Range	Maximum/Minimum	Variance
Item Means	2.221	1.554	2.799	1.245	1.801	.179
Item Variances	.502	.206	.772	.566	3.756	.032
Inter-Item Correlations	.325	.033	.857	.824	25.802	.032
Item Total Statistics	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted	
Item 1 Instrumental	38.432	52.421	.349	.447	.892	
Item 2 Instrumental	38.388	51.616	.447	.448	.888	
Item 3 Instrumental	38.086	50.152	.561	.559	.884	
Item 4 Instrumental	38.194	49.810	.534	.778	.885	
Item 5 Instrumental	38.122	50.123	.557	.783	.884	
Item 6 Instrumental	37.899	48.526	.681	.655	.880	
Item 7 Instrumental	37.942	50.272	.545	.520	.885	
Item 8 Emotional	37.302	52.633	.552	.554	.885	
Item 9 Emotional	37.187	53.298	.526	.683	.887	
Item 10 Emotional	37.309	51.809	.610	.726	.884	
Item 11 Emotional	37.345	51.836	.528	.690	.885	
Item 12 Emotional	37.194	53.245	.509	.703	.887	
Item 13 Emotional	37.317	51.986	.555	.621	.885	
Item 14 Informational	37.777	51.464	.533	.610	.885	
Item 15 Informational	37.554	52.147	.462	.556	.887	
Item 16 Informational	38.237	52.617	.342	.273	.892	
Item 17 Informational	37.640	48.986	.661	.715	.880	
Item 18 Informational	37.827	47.854	.688	.652	.879	
		Alpha	Standardized Item Alpha			
Reliability Coefficients for Item 18		.891	.897			

As can be seen from the table V, this study conducted a reliability test to determine the Cronbach's Alpha for each dimension. The result showed that the Cronbach's Alpha for instrumental support was 0.84, the Cronbach's Alpha for emotional support was 0.92 and the Cronbach's Alpha for the informational support was 0.8. The overall Alpha for the inventory was 0.89, which can be considered as very good scale.

5. Antiretroviral Treatment Utilization

ART utilization was measured using self-report questionnaires that identify three aspects: (a) entry into HIV care; (b) retention in HIV care; (c) adherence to ARTs among those currently in care.

a. Entry and Retention in Care

According to Bertolli, Gardner, and Marks (2011), the definition of "care" involves a patient who has attended an initial HIV medical care visit with an HIV care provider (authorized to prescribe medication), following the receipt of an HIV diagnosis. Based on the definition posited by Bertolli, Gardner, and Marks, "retention" was defined as "a patient who has attended at least two HIV medical care visits within a span of three months."

Measures used to assess the sample's utilization of HIV health care are based on a study of medical treatment conducted by Meade, Hansen, Kochman, and Sikkema (2009). Items drawn from their study asked participants to indicate if they were enrolled in HIV treatment (yes, no, or previously but not now). If yes, they were asked to self-report the

number of visits they had HIV primary care providers in the last 30 days and within the last three months. Number of visits per participant were summed and then recoded as a dichotomous variable of outpatient visits (0 versus ≥ 1). As HIV patients were recommended to have at least one outpatient visit every three months, this variable provided a measure of outpatient treatment utilization.

b. Adherence to Antiretroviral Treatment

Adherence to ART was measured using a self-reported 3-item scale of medication adherence from Wilson, et.al (2013). The questions examined adherence to treatment plans in the last 30 days: (1) *How many days in the last 30 days did you miss at least one dose of any of your HIV medicines?* (2) *How good a job did you do at taking your HIV medicines in the way you were supposed to?* Participants were asked to respond according to a range from “1” (very poor) to “6” (excellent); (3) *How often did you take the HIV medicine?* ; with response choices ranging from 1 (never) to 6 (always), and a higher score indicating greater adherence to ART.

Wilson et al., (2013) calculated the item responses for three adherence items by linearly transforming them to a 0-100 scale. Based on their study, the Cronbach’s Alphas for the three-item scale were quite high, ranging from 0.86-0.89 with the overall alpha of 0.86. Nonetheless, in this study, the Cronbach’s alphas for the three-item scale were considered low, with the overall alpha of 0.636. Table below presented the reliability statistic for three items.

TABLE VI
ITEM-ANALYSIS OF ART ADHERENCE SCALE FROM SPSS OUTPUT

NEW ANALYSIS OF ATTACHMENT SCALE FROM SPSS OUTPUT						
Statistic for Scale	Mean		Variance		SD	N
	241.8182		1746.919		41.79616	3
	Mean	Minimum	Maximum	Range	Maximum/Minimum	Variance
Item Means	80.606	66.515	96.515	30.000	1.451	227.479
Item Variances	335.542	204.360	435.757	231.397	2.132	14105.313
Inter-Item Correlations	.342	.152	.681	.529	4.480	.069
Item Total Statistics	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted	
Item 1	145.3030	1346.238	.187	.038	.808	
Item 2	175.3030	676.513	.584	.464	.312	
Item 3	163.0303	730.794	.628	.471	.248	
		Alpha	Standardized Item Alpha			
Reliability Coefficients for Item 3		.636	.609			

Because using all the three items was only 0.64 was questionable value, therefore the investigator dropped item number one and composited score in two items analysis. After deleting the first item, the Cronbach's Alpha for two items was 0.812.

F. Data Management

A database program was developed that permitted easy data entry and retrieval. The program also was structure to help reduce inconsistency or mistakes in entering responses from the participants. All responses were coded and entered into the database, which subsequently was converted to an SPSS data file for analyses. If a participant voluntarily disclosed names or personal identifiers during data collection, these names were not entered

or in any way linked to responses entered into the data base. Only the respondents' anonymous code numbers were used. Completed interview were stored in a locked cabinet and a password protected database.

G. Statistical Analyses

Once all the interviews were completed, the PI analyzed the data by using the statistical software SPSS version 22. A series of descriptive analyses were conducted to examine demographic data of the participants, description of HIV disclosure experiences, social support, and ART utilization. The *t*-test was used to examine the following: (1) the different reactions of confidant in first and second disclosure; (2) the different reason for telling between first and second disclosure experience; (3) the different support between first and second confidant. The Pearson Correlation Test was used to examine: (1) the correlation between reaction of first confidant and timing of second disclosure; (2) the correlation between reason to disclosure and timing of second disclosure; (3) association between social support and the ART utilization. The Repeated Measures ANOVA test was used to examine the different social support among all support sources. The Regression Analysis was used to examine (1) the predictor of social support based on to whom the women confided; (2) the predictor of social support based on reason to disclosure; (3) the predictor of social support among the personal characteristic; (4) the predictor of number of support sources among the personal characteristic; (5) the predictor of ART Utilization based on to whom women confided; (6) the predictor of ART Utilization based on social support women received. Supplementary analysis was conducted by using the

Chi-Square test to see the different HIV disclosure network among women based on mode transmission.

H. Ethical Protection of The Study's Research Participants

The protocol and instrument of the study was approved by the University of Illinois at Chicago (UIC) Institutional Review Board in protocol #20014-0074, and by the Ethical Board of Atma Jaya Catholic University of Indonesia (AJCU), Jakarta, in approval #138/III/LPPM-PM.10.05/02/2014.

The issue of disclosure HIV status is very sensitive and strongly related to privacy. Therefore, the main ethical issue with this study was to assure the confidentiality and privacy of the participants. Some precautions were taken to protect subject privacy during the identification of subjects, recruitment, and collection of data.

- During the initial identification of subjects, the NGO staff member who informed the women about the study did not provide, collect, or share contact information about potential subjects to the research team. The NGO staffs informed the prospective participants of the study during the course of receiving standard services and/or routine visits to community clinics and the NGO. The NGO staff also provided potential participants with the researchers' contact information (study contact cards) so that the subjects could contact the researchers themselves to learn about the study and possibly participate.

- None of the NGO staff played any role in the formal recruiting, consenting or interviewing procedures that followed this initial informing/advertising phase.
- Screening, consenting, and interviewing were conducted in a private office at the AJCU, or at location of the participant's choosing where she could be screened, consented and interviewed in private without being overheard or interrupted. Research team members did not reveal to others who among the prospective participants had consented or declined to participate.
- Interviews were not recorded and the instrument was administered by the investigator or a member of the research staff. The qualitative data that came from additional information from the participants were only noted in the instrument. During the interview process, the participants not only answered the questions but quite often shared or added other information. Therefore, the interviewers needed to make some notes of additional data.
- NGO staffs were not recruiters or eligibility screeners. They merely informed women about the study and its eligibility requirements to those whom they have reason to believe might be eligible. They then directed those who are interested to contact the research staff for screening and subsequent informed consent if they decided to participate.
- No identifying information was collected in the data, and only the personal identification numbers were used in lieu of names to identify subjects. This study requested a waiver of documentation of informed consent as the participants' signatures would be a piece of identifying information. Those prospective

participants who provided verbal informed consent to enroll in the study were assigned an anonymous code number that appears on the interview instrument instead of a name or other personal identifier. Participants were asked not to reveal their identities to the interviewer. The interviewers were instructed not to record participants' identities on the interview instrument and only used the code numbers.

- Once prospective participants had been found eligible and had enrolled in the study, she was assigned an anonymous participant ID that was used on all study documents instead of her name or other personal identifiers. No subject identifiers were maintained with the data. No personal identifiers appeared in the coded interview data; only anonymous code numbers were listed.
- All data were sealed in plain, unmarked envelopes and transported inside locked briefcases in person to AJCU.
- The potential participant's name and phone number were temporarily noted in the log book so that the researchers could call them back to make appointments. The names and phone numbers were destroyed as soon as a potential participant declined to participate or was determined to be ineligible to participate. Only the names and phone numbers of participants who enrolled in the research were kept until the end of data collection.
- The log book that contained the names and phone numbers of participants who enrolled in the research were stored in a locked secure file cabinet and were destroyed after data collection had been completed.

- The completed hard copies of data collection instruments were stored in a locked file and inside a locked office at AJCU during the period in which interviews were being conducted. All completed interviews were destroyed after data collection ended and entry of the data into the study's computerized database has been completed. The study anticipated that all final data entry occurred approximately three weeks after the last interview was completed. Only the PI had the key needed to access the file cabinet. The PI and the interviewers did not make copies of any screening data and completed interviews. Only non-identifiable data were transferred electronically on password-protected portable devices by the PI.

Although safeguards had been taken, the study posed other potential risks that included loss of privacy and psychosocial harm. It was possible that people might learn or see participants interacting with the research team and associated it with a study of unusual conditions. With the study focusing on HIV positive women, it was possible that participants would experience emotional distress and humiliation due to questions that may be sensitive in nature. In this study, most participants were not only answering the main questions in the interview. They also voluntarily shared their feeling and disclosure experience to the interviewers. Some of the women cried in the middle of interview when they remembered their first disclosure experiences. The interviewers listened and waited until the women finished their stories and they felt comfortable to continue the interviews. After the interview, most of participants told that they felt relief for having had someone listen to their feelings. They told

the interviewers that they really need to share their burdens as women with HIV/AIDS, and they had not had a chance to share all their feelings to other people without being judged.

Counseling services were provided from AJCU Counseling Service at no cost. In addition, in anticipation of other health concerns after answering the questions, the study prepared a list of health service providers in Jakarta who are accessible to participants.

The research had no direct benefit to the participants. The study offered a chance for the women to talk about disclosure issues, support and ART utilization, and to help connect them with local resources for psychological counseling, basic health care and HIV treatment services.

IV. RESULTS

This chapter describes the study's descriptive, bivariate and multivariate analyses in addressing the specific aims of the study and answering its research questions. The Pearson Correlation test was used to examine the correlation between independent variables and dependent variables. The Chi-Square, the independent sample *t*-test and the linear regression were used to analyze between-subjects factors; the paired *t*-test and the General Linear Model (GLM) procedure using the Repeated Measures ANOVA test were used to analyze within-subjects factors.

The chapter is divided into several parts. Part A describes the demographic characteristic of the 142 participants, and Part B describes their HIV profile. Part C answers the study's research questions that ask about the participants' experiences with disclosing to a first and second confidant, examines the timing of disclosure, the social network to which they disclosed, and reasons for disclosing. Part D answers the study's research questions concerning whom the social support that the women received from their first and second confidant and also examines the other support sources that women might have after disclosure. Part E investigates personal factors predicting the support: number of persons in the participants' social support network, types of support received, and support satisfaction. Part F examines the predictors of social support based on to whom the women confided. Part G examines reasons for disclosure as predictors of the support the women receive. Part H describes the ART utilization that includes the entry to HIV care, retention to HIV care and the ART adherence.

This part also answers the research question related to tests for a possible association between social support received and retention in HIV care and also investigates the effect of support on the ART adherence. Part I summarizes the study's results.

A. Demographic Characteristics of the Participants

The age of participants in the study ranged from 20 to 49 years with an average age of 32 years. Most of the women (63%) had finished high school and about 10% had graduated from a diploma program or had earned a bachelor's degree. Slightly more than half of the participants were married or living with a significant other, and 43% had been married but were either divorced (14%) or widowed (28%) at the time of the interview. During the interview, 10 (14%) of the 76 women who were married reported that they were in their second marriage, seven (9%) were on their third marriage, one woman was on her fourth marriage, and one woman had both a husband and boyfriend. About 27 (44%) of the divorced or widowed women reported having a boyfriend. When it combined together, about 74 % of the total sample had a current sex partner.

In general, the occupation of women in the study can be divided into three categories. The first category includes women (22%) who worked full- time as salaried employees. These women often were employed as field coordinators, case managers, outreach workers, counsellors, and administrative staff members in an HIV/AIDS organization or NGO. The second category parallels the first occupationally, but consists of women (11%) who only worked part time. The third category includes those women (25%) who obtained money in any way that they could work outside the formal labor sector. They often combined more than one source

of income (helping a family or relative's business, working in the households for their neighbors as a maid or servant, driving as a motorbike's driver, street parking valet, street musician), informal sex work (working in bars, karaoke, spa and beauty salon), and drug dealing.

In this study, monthly income was defined as total household income including from a spouse, or financial support from other household member, relatives and other charity. About 79% of the participant had income \$200 per month or less. The minimum wage in Jakarta province is about \$213 per month. Basically, their income only covered food, transport and other basic needs. More than 90 percent of the women had at least one child, and half lived with their parent or other relatives. They reported that their parent or relatives had to support their children's needs and also contribute toward the women's additional living expenses, health supplements and medication costs.

Women who were active IDUs (about 10%) appeared to have the lowest standard of living when compared to other participants in the sample. Almost all of them lived together in the *Boncos* neighborhood, which is one of the poorest in Jakarta. They reported renting one room for two or more people to sleep at night, at a cost of about \$3 per month per person. Those who could not afford rent slept in the street or asked neighbors if they could sleep in front of their houses. However, two women reported that they had income more than US\$200 per month for working as a drug seller. Of the 43 women with a history of injection drug use, about 67% had entered a methadone program excluding the 33% who remained active at the time of their interviews.

As explained above, the Table VII below reports the demographic characteristics of the 142 women who participated in the study.

TABLE VII
DEMOGRAPHIC CHARACTERISTICS (N = 142)

Variable Demographic	Mean and SD	N	%	Range
Age (mean and standard deviation)	M = 32.33;SD= 4.993			20-49
Marital Status				
Not married		5	3.5	
Married		76	53.5	
Living with someone but not married		2	1.4	
Divorced		20	14.1	
Widowed		39	27.5	
Number women with partner sex (husband and boyfriend/other)		101	71	
Education				
Elementary school		11	7.7	
Junior High School		28	19.7	
Senior High School		89	62.7	
Diploma		12	8.5	
University		2	1.4	
Working status				
Employed full-time with salary		31	21.8	
Employed part-time with salary		16	11.3	
Getting money however they can		37	25.3	
Unemployed		58	41.5	
Income				
≤ 200 US \$ permonth		112	78.9	
≥ 200 US \$ permonth		29	20.4	
Don't know		1	0.7	
Number of child				
None		13	9.2	
1-2 children		101	71.1	
3-4 children		25	17.6	
> 4 children		3	2.1	
History of Injecting Drugs (n=43)				
Active IDUs		14	9.6	
Ex IDUs (currently in methadone therapy)		29	20.42	
Number of person living in a house				
None (living alone)		9	6.3	
1-4 person		77	54.2	
4-8 person		36	25.4	
> 8 person		19	13.4	
Decline to or not answer		1	0.7	

B. HIV Profile of the Participants

Table VIII below presents the HIV profile of participants.

TABLE VIII
HIV PROFILE OF PARTICIPANTS

Variable	N	%
Women who had family with HIV positive		
No	29	20.4
Yes	113	79.6
N of family having HIV positive = 169		
Mother	1	0.6
Father	1	0.6
Brother	3	1.8
Sister	3	1.8
Husband	42	24.85
Ex-husband	60	35.5
Child(ren)	59	34.9
Number of children died because of HIV/AIDS	29	49
Amount of Years Diagnosed		
1 year or less	29	20.4
2 to 5 years	64	45.1
6 to 10 years	43	30.3
>10 years	6	4.2
Mode of transmission (Acquired HIV)		
Blood Transfusion	1	0.7
Heterosexual transmission	99	69.7
Injection Drug Use	39	26.8
Don't know	3	2.1

About 80% of participants reported having a total number of 169 family members with HIV/AIDS, most often their ex-husband, child, and current husband (see Table VIII below).

Overall, the women reported having had 59 children infected with HIV of whom 29 (49%) had died due to AIDS. Almost half of the women were first diagnosed with HIV between two and

five years ago. More than half of the participants were thought to be infected with HIV through heterosexual transmission. Of these, most (42%) were housewives who likely acquired HIV from their husband; approximately nine participants who worked as an informal sex workers perceived that they had been infected by one of their clients. Almost 27% of the women attributed their HIV infection to risky drug injection.

C. HIV Disclosure Experience

This part will examine the HIV disclosure experiences to first and second confidant by identifying: (a) to whom women first and second disclosure regarding their HIV status; (b) the timing of first disclosure since HIV diagnosis and the timing of second disclosure since first disclosure; (c) size and composition of a woman's disclosure network (number and relationship of persons women disclosed to); (d) the reason for telling first and second confidants.

1. First Disclosure Experience

As can be seen in Table IX, women disclosed to various people but most frequently to family members. Among the family members, mother was the most common person chosen by the participants as the first confidant, followed by sister. In the partner category, about 16% of the women revealed to their husband or ex-husband. Only 4% women chose to tell a boyfriend or other sex partner as their first confidant. Relatives and friends were chosen by an equal number of women (about 13%) with a female friend (11%) greatly outranking a male friend (1%).

TABLE IX
FIRST DISCLOSURE

Study Variable	First Disclosure (n=142)	
	N	%
First Confidant		
• Family (n=69)		
Mother	35	24.64
Father	10	7.04
Brother	6	4.23
Sister	18	12.67
Child	3	2.11
• Spouse/partner (n=29)		
Husband	18	12.68
Ex-husband	5	3.52
Boyfriend/sex partner	6	4.23
• Other relative	18	12.68
• Friend (n=18)		
Female friend	16	11.27
Male friend	2	1.4
• Other	5	3.52
How long women told the HIV status since diagnosis?		
≤1 week	95	66.9
2 week to 1 month	9	6.3
2-6 month	16	11.3
> 6 month	21	14.8
Don't answer	1	0.7
HIV status of first confidant		
HIV negative	109	76.8
HIV positive	24	16.9
Don't know/decline to answer	9	6.3
Live with participant		
Yes	67	47.2
No	75	52.8

2. Second Disclosure Experience

The second disclosure pattern was relatively similar to the pattern of first disclosure with a family member (mother, father, brother, sister) as the most frequently cited person whom the women told. As with a first disclosure, more women chose their mother as their

second confidant over other family members. A female friend ranked as the most frequently reported second confidant. Boyfriend was the least common category of person whom women chose as the second confidant (TABLE X).

TABLE X
SECOND DISCLOSURE

Study Variable	Second Disclosure (n=120)	
	N	%
Second Confidant		
• Family (n=50)		
Mother	19	15.83
Father	12	10
Brother	8	6.67
Sister	11	9.1
Child	2	1.67
• Spouse/partner (n=20)		
Husband	9	7.5
Ex-husband	6	5
Boyfriend/sex partner	5	4.17
• Other relative	19	15.83
• Friend (n=25)		
Female friend	20	16.67
Male friend	5	4.17
• Other (n=4)	4	3.33
How long women told the HIV status since told the first confidant?		
< one month	56	46.67
1 month – 6 month	29	24.17
6 month – 1 year	10	8.33
More than a year	25	20.83
HIV status of first confidant		
HIV negative	96	80
HIV positive	17	14.17
Don't know/decline to answer	7	5.83
Live with participant		
Yes	42	35
No	78	65

In both first and second disclosure events, five women chose their children as first and second confidant. One participant told her child since she was nine years old because her child was HIV positive and she needed to give simple information about HIV to make her understand why she needed to take medicine every day. The other women told either their daughters or sons when the children were 18 years old or older. Most of the confidants were HIV negative and were living separately from participants.

3. First and Second Disclosure Order

While Table IX and X show the overall frequency with which women report whom they told first and then second, it does not link the specific category of persons whom they told first to whom the specific category of persons whom they told second. The Matrix in Table XI on the next page allows us to see the frequencies of those whom they tell second if they tell their mothers first or their fathers first, and so on.

Among 142 participants, about 120 women (85%) had disclosed to a second confidant and 15% women had only disclosed to first confidants. Those 22 women who had no second confidant only disclosed to their mothers (22%), father (4%), husband (27%), relatives (18%), female friend (18%), male friend (4%), or other person (4%).

TABLE XI
MATRIX OF FIRST AND SECOND DISCLOSURE ORDER

First Confidant (N=142)		Told no one (n=22)	Second Confidant (N=120)												
Sources	N of each 1 st confidant		N of each 2 nd confidant	Mother n(%)	Father n(%)	Brother n(%)	Sister n(%)	Child n(%)	Husband n(%)	Ex-Husband n(%)	Boyfriend n(%)	Relative n(%)	Female Friend n(%)	Male Friend n(%)	Other n(%)
Mother	35	5 (22.3)	19	0	5 (14.3)	3 (8.57)	5 (14.3)	0	3 (8.57)	1 (2.9)	3 (8.6)	7 (20)	2 (5.7)	0	1 (2.8)
Father	10	1 (4.5)	12	6 (60)	0	2 (20)	0	0	0	0	0	1 (10)	0	0	0
Brother	6	0	8	2 (33.3)	1 (16.7)	0	0	0	0	1 (16.7)	0	0	2 (33.3)	0	0
Sister	18	0	11	3 (16.7)	3 (16.7)	0	1 (5.6)	1 (5.6)	4 (22.2)	0	1 (5.56)	2 (11.1)	2 (11.1)	1 (11.1)	0
Child	3	0	2	1 (33.3)	0	0	0	0	0	0	0	0	2 (66.7)	0	0
Husband	18	6 (27.3)	9	1 (5.56)	2 (11.1)	1 (11.1)	3 (16.7)	0	0	0	0	2 (11.1)	1 (5.6)	1 (5.6)	1 (5.6)
Ex-husband	5	0	6	1 (20)	0	0	0	0	0	0	0	2 (40)	1 (20)	1 (20)	0
Boyfriend	6	0	5	1 (16.7)	0	1 (16.7)	1 (16.7)	0	0	0	1 (16.7)	0	2 (33.3)	0	0
Relative	18	4 (18.2)	19	3 (16.7)	1 (5.56)	1 (5.56)	1 (5.56)	0	0	2 (11.1)	0	4 (22.2)	2 (11.1)	0	0
Female friend	16	4 (18.2)	20	0	0	0	0	1 (6.3)	2 (12.5)	2 (12.5)	0	0	5 (31.3)	1 (6.25)	1 (6.3)
Male friend	2	1 (4.5)	5	0	0	0	0	0	0	0	0	0	1 (50)	0	0
Other	5	1 (4.5)	4	1 (20)	0	0	0	0	0	0	0	1 (20)	0	1 (20)	1 (20)

As can be seen from the matrix in Table XI, it can be seen that those women who chose mothers as first confidants mostly chose relatives followed by father or sister as second confidant; father as first confidant, mostly chose mother as second confidant; brother as first confidant, mostly chose mother and female friend as second confidant; sister as first confidant, mostly chose husband, mother and father as second confidant; husband as first confidant, mostly chose sister, father and relatives as second confidant; ex-husband as first confidant, mostly chose relative as second confidant; boyfriend as first confidant, mostly chose female friend as second confidant; relatives as first confidant, mostly chose relatives and mother as second confidant; female friend as first confidant, mostly chose female friend as second confidant; male friend as first confidant, mostly chose female friend as second confidant; and women who chose their neighbor (other) as first confidant chose various person such as mother, relative, male friend or other neighbor as second confidant.

From the pattern of the disclosure matrix, it seemed that women who first disclosed to either family members or relatives usually also had second confidant who were other family members or relatives. Meanwhile, women who first disclosed to boyfriends, female and male friends usually had second confidants from among their other friends.

4. Timing of Disclosure

About 70 percent of participants disclosed to the first confidant in one month or less after they learned that they were HIV positive (see table 9 above). Only 15 percent of the women waited more than six months to tell someone about their HIV status. From Table X, it

can be seen that nearly 18% tell a second person within a month of their first disclosure, but 21% report waiting as long as a year.

5. Women's Disclosure Network

Table XII below shows the women's disclosure network.

TABLE XII
DESCRIPTION OF HIV DISCLOSURE NETWORK

Variable	N	%	Variable	N	%
Number of people have women disclosed their HIV status			Family disclosure network		
<5 person	39	27.5	None	13	9.2
5-10 person	31	21.8	About 25 %	61	43.0
>10 person	72	50.7	Half (50%)	22	15.5
			About 75 %	19	13.4
			All	27	19.0
Number of Disclosure (n= 624)			Friend disclosure network		
Family (n=271)	271	43.43	None	28	19.7
Mother	(84)	(30.99)	About 25 %	56	39.4
Father	(59)	(21.77)	Half (50%)	29	20.4
Brother	(53)	(19.56)	About 75 %	13	9.2
Sister	(71)	(26.2)	All	16	11.3
Children	(7)	(2.58)			
Spouse/partner) (n=108)	108	17.3	Others disclosure network		
Husband	(57)	(52.78)	None	96	67.6
Ex-husband	(24)	(22.22)	About 25 %	33	23.2
Boyfriend	(27)	(25)	Half (50%)	6	4.2
Other relative	67	10.74	About 75 %	3	2.1
Friend (n=140)	140	22.44	All	4	2.8
Female friend	(83)	(59.28)			
Male friend	(57)	(40.71)			
Other	35	5.6			

About half of the women had disclosed to more than 10 people since first being diagnosed. Women had the highest disclosure rate to family members compared to four other categories (spouse/partner, relative, friend and others). Women primarily disclosed to their

mothers and female friends, with a disclosure rate close to 60% when both are considered together. Mother had a high percentage of disclosure, followed by sister and other relative. Meanwhile, disclosure rates to children were considered very low. In general, 43 percent of women had 25% of the family disclosure network, 40 percent of women had 25% of the friend disclosure network, and only 32 percent of participants had other disclosure network.

a. Women's Disclosure Network Based on Marital/Living with Partner Status

The next analysis examines the HIV disclosure rate among women who were married or living with someone versus unmarried women (not married but possibly has a sex partner, divorced or widowed). First and second confidants were categorized by female family member (mother, sister, and daughter), male family member (father and brother), partner (husband/ex-husband and boyfriend), relative and friend (Table XIII).

TABLE XIII
FIRST AND SECOND CONFIDANT AMONG WOMEN MARRIED OR LIVING WITH PARTNER AND NON-MARRIED

Variable	Married/Living with Partner (N=78)		Non-married women (N= 64)	
	N	%	N	%
First Disclosure				
Female family member	28	35.9	28	43.75
Male family member	8	10.3	8	12.5
Partner	21	26.9	8	12.5
Relative	12	15.4	6	9.4
Friend	9	24.4	14	21.9
Second Disclosure				
Female family member	14	17.9	18	28.1
Male family member	12	15.4	9	14.1
Partner	12	15.4	8	12.5
Relative	12	15.4	7	10.9
Friend	15	19.2	13	20.3
Told no one	13	16.7	9	14.1

As the table shows, a female family member (mother and sister) is the most likely person chosen as the first and second confidant. A friend was the least likely first confidant among women who married or were living with partners, while relative was the least likely second confidant among non-married women. Of the 78 women who married or were living with a partner, only 33 or about 42% chose to tell partner as their first or second confidant. About 25 of them (32%) had not disclosed to their current husbands or partners and 26% told their husbands after they disclosed to first and second confidant.

Table XIV shows the comparison of the women's disclosure networks based on marital or living with partner status. The independent *t*-test showed that there was a difference in family disclosure networks between the two groups. The mean of the family disclosure network was higher in non-married women than in married women or those who living with partner ($t = 2.414$, $p < .05$). Meanwhile, the family and others disclosure networks differed insignificantly between the two groups.

TABLE XIV
CONTRAST OF MARITAL/LIVING WITH PARTNER STATUS FOR NETWORK DISCLOSURE

Dependent Variables	Married/Living with partner (N= 78)		Non-Married (N= 64)		t	df	Sig.(2 tailed)
	M	SD	M	SD			
Family disclosure network	2.667	1.2239	3.188	1.3437	-2.414	140	.017
Friend disclosure network	2.487	1.2352	2.578	1.2319	-.437	140	.663
Others disclosure network	1.449	0.8775	1.547	0.9246	-.647	140	.518
Number of disclosure network	2.211	0.8535	2.297	0.8485	-.598	138	.551

b. Women's Disclosure Network Based on Mode of Transmission

The independent *t*-test was conducted as an additional analysis to see whether there was a different HIV disclosure network among women who acquired HIV from the needle transmission and women who acquired HIV from heterosexual transmission. From three dependent variables of disclosure network, there was only friend disclosure network that significantly differed between two groups. As can be seen in the table below, the *t*-test indicated that there was a significant difference in friend disclosure network between the two groups. The friend disclosure network was higher in women who acquired HIV from needle transmission than in women who acquired HIV from heterosexual transmission. Meanwhile, the family and others disclosure network were not significantly different between two groups.

TABLE XV
CONTRAST OF MODE HIV TRANSMISSION FOR NETWORK DISCLOSURE

Dependent Variables	Sexual Transmission		Needle transmission		t	df	Sig.(2 tailed)
	M	SD	M	SD			
Family disclosure network	3.019	1.2984	2.590	1.2715	1.770	140	.079
Friend disclosure network	2.359	1.1277	2.974	1.3858	-2.719**	140	.007
Others disclosure network	1.505	.9169	1.462	.8537	.256	140	.798
Number of disclosure network	2.301	.8145	2.108	.9364	1.187	138	.237

** . The mean difference is significant at the 0.01 level.

6. Reason for Disclosure

Figure 6 below visualizes the estimated marginal means of differences in reasons given by the women for disclosing to their first versus second confidants. Both reasons for disclosure to first and second confidant were likely similar but the need to inform was the least common reason for disclosure to second confidant, and reason of similarity was the least reported reason for disclosing to first confidant.

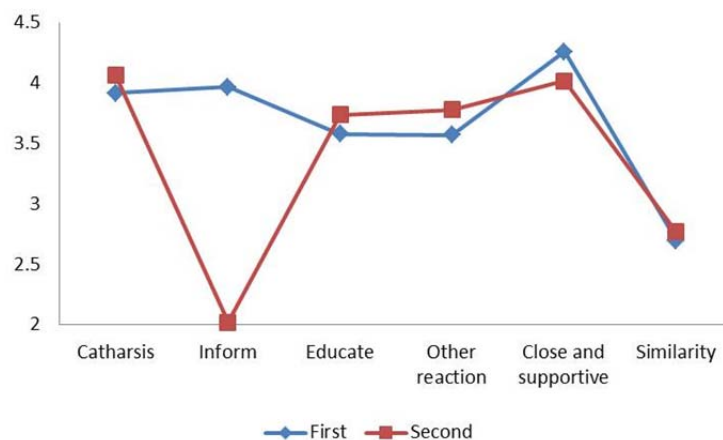


Figure 6: Estimated marginal means of reason to disclosure among first and second confidant.

a. Contrasts of First and Second Confidant for Reason to Disclosure

The paired *t*-test was used to compare each dimension of reasons among two groups. The result showed that among six dimensions of reason, there were two reasons that were significantly different. The reason of duty to inform to first confidant was reported significantly higher to second confidant ($M=2.05$, $SD=1.14$), $t(1) = 19.49$, $p<.000$). The reason of

close and relationship to first confidant was higher than to second confidant ($M=.301$, $SD=1.47$), $t(1) = 2.995$, $p<.003$).

TABLE XVI
CONTRASTS OF FIRST AND SECOND CONFIDANT FOR THE REASON TO DISCLOSURE

Reason to Disclosure	First Confidant		Second Confidant		t	Df	Sig. (2-tailed)
	M	SD	M	SD			
Catharsis	3.9249	1.26004	4.0750	1.12477	-.199	120	.842
Duty to inform	3.9734	1.15484	2.0254	.58678	19.491**	117	.000
Educate	3.5845	1.31410	3.7416	1.22688	-.837	119	.404
Test other's reaction	3.5697	1.41339	3.7787	1.16629	-.642	118	.522
Close and supportive relationship	4.2641	.84793	4.0131	.99579	2.995**	117	.003
Similarity	2.6974	1.30012	2.7703	1.30604	-.228	118	.820

** . The mean difference is significant at the 0.01 level.

D. Social Support

This set of analyses describes the support networks of the sample by identifying the: (a) social support received from first and second confidant; (b) social support received from other support persons and (c) the differences in support women perceived from their first confidant, second confidant and other sources.

1. Social Support from First and Second Confidant

The graphic in figure 7 below portrays the level of each type of support (instrumental, emotional, and informational) and support satisfaction resulting from first and

second disclosure. As showed in the picture, emotional support was the most common type of support that women received from the first and second confidant, followed by informational and instrumental support. The graphic also indicates that the participants were satisfied with the support received from their first and second confidants.

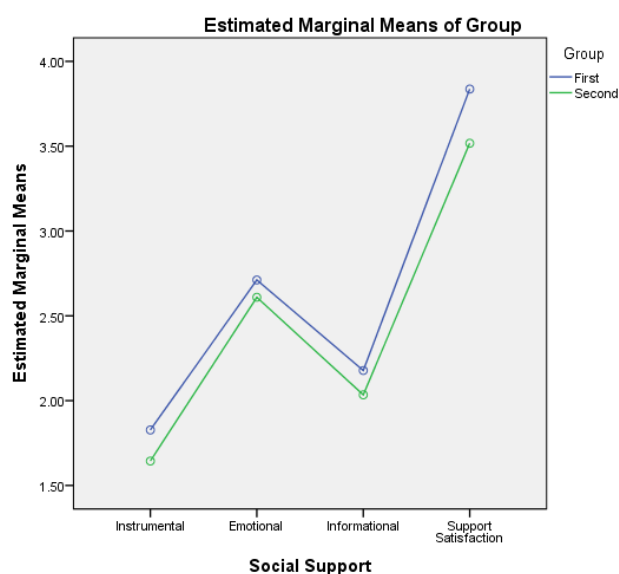


Figure 7. Estimated marginal means of first and second confidant for social support.

The paired *t*-test was conducted to examine the different social support (type of support and support satisfaction) women received from first disclosure and secondary disclosure experiences. Three out of four variables demonstrated statistically significant differences between first and second disclosure. As can be seen in Table XVII, instrumental and informational support differed between first and second disclosure. Women were more likely

to receive greater instrumental and informational support from the first confidant than from the second. No differences in emotional support were found between first and second confidants, but the mean score of emotional support indicated that most participants received greater emotional support from first confidants when compared to other types. In general, the women reported greater satisfaction with the support received from the first confidant when compared with that of the second.

TABLE XVII
CONTRAST OF FIRST AND SECOND DISCLOSURE FOR TYPES OF SUPPORT AND
SUPPORT SATISFACTION

CONCEPTS							
		First Disclosure		Second Disclosure		Statistical Testing	Sig.(2-tailed)
		n= 142		n=120		t-test	
		Mean	SD	Mean	SD		
Type of support							
	Instrumental	1.82	0.53	1.65	0.55	2.58*	.011
	Emotional	2.7	0.46	2.61	0.57	1.34	.137
	Informational	2.17	0.55	2.02	0.59	2.03*	.026
Support satisfaction		3.87	0.99	3.56	1.14	2.46*	.015

*. The mean difference is significant at the 0.05 level.

To what extent did the women perceive that they needed social support in coping with their illness? Analysis of scores from the '*want support*' scale that measured whether the women needed or wanted the support suggested that most women (97%) in this study sought emotional support and more than 85% of women wanted informational support from their first and second confidants. In contrast, however, about 61% of participants in the first disclosure group and 70% of participants in the second disclosure group did not indicate a need for

instrumental support. An independent *t*-test was conducted to examine the different types of support women received between the group that wanted the support and the group that reported that they did not need it. Results indicated that there was a different informational support received between women who wanted the support and women who did not want the support. Women who perceived that they wanted or needed instrumental support experienced greater support than women who had not wanted instrumental support. Furthermore, the Chi-Square test was conducted to test the different types of support that women wanted in first and second disclosures. The result also shows that women received different instrumental support based on whether they wanted or did not want the support between first disclosure and second disclosure. A statistical test to examine the emotional and informational support cannot be conducted because of the imbalance in the sample number between the group who wanted emotional and informational support and the group who did not want support (TABLE XVIII).

TABLE XVIII
CONTRAST OF FIRST AND SECOND DISCLOSURE FOR THE “WANT” DIMENSION OF SUPPORT

Variable	First Disclosure					Second Disclosure				Chi-Square Test	Asymp. Sig. (2-sided)
	n= 142					n=120					
	N (%)	Mean	SD	t-test	N(%)	Mean	SD	t-test			
Want Instrumental										4.539 ^a	0.033
No	87 (61.3)	1.58	0.47	-8.53**	85 (70.83)	1.46	0.44	-6.65**			
Yes	55 (38.7)	2.26	0.43		35 (29.17)	2.09	0.53				
Want Emotional										--	
No	4 (2.8)	2.04	0.55	--	4 (3.33)	1.42	0.63	--			
Yes	138 (97.2)	2.72	0.45		116(96.7)	2.66	0.53				
Want Informational										--	
No	15 (10.56)	1.64	0.45	--	18 (15)	1.48	0.47	--			
Yes	127 (89.4)	2.23	0.55		102 (85)	2.13	0.55				

** . Correlation is significant at the 0.01 level (2-tailed).

a. 0 cells (.0%) have expected count less than 5. The minimum expected count is 13.82.

2. Other Support Sources

After the first and second disclosure experience, participants were asked to list up to three other supportive persons who knew their HIV status. The data shows that most participants had at least one other person to whom they could go for social support, excluding the first and second confidant. Table XIX below presents the number of other support sources women had beside the first or second confidant. About 89% of women had one other support person, 59% of women had two other support people and 37% of women had three other support people.

Unlike the first and second confidants to whom women personally disclosed being HIV positive, other support sources learned of the women's HIV status both directly and indirectly. As can be seen from the Table XIX, more than half of other support people were told directly by the participants, and the remainder learned indirectly from a friend, relative, doctor or other medical staff member or as the result of finding the woman's medication. As with first and second confidants, other support sources were likely to be HIV negative and to reside separately from the participants. While a family member was most frequently named as the recipient of a first or second disclosure, other support sources (3-5) were mostly friends, especially female friends. Health care providers and children were also considered support sources by a few women.

TABLE XIX
DESCRIPTIVE SUMMARY OF OTHER SUPPORT SOURCES

	Support Person#3 N=127		Support Person#4 N=84		Support Person #5 N=52	
	N	%	N	%	N	%
Type of Disclosure						
Direct	67	52.76	53	63.09	33	63.46
Indirect	59	46.46	31	36.91	18	34.61
DataMissing	1	0.78			1	1.94
Relationship						
• Family n=61	19		26		13	25
Mother	7	5.51	5	5.95	0	0
Father	1	0.008	6	7.14	1	1.92
Brother	5	3.94	4	4.76	5	9.61
Sister	6	4.72	12	14.28	7	13.46
Child	2	1.57	0	0	0	0
• Spouse/partner n=36	26	20.47	3	3.57	8	
Current husband	18	14.17	1	1.19	5	9.61
Ex-husband	1	0.008	0	0	1	1.92
Boyfriend/sex partner	7	5.51	2	2.38	1	1.92
• Other relative n=35	12		11		9	17.3
• Friend =94	43		33	39.29	15	
Female Friend	37	29.13	16	19.05	10	19.23
Male Friend	10	7.87	17	20.24	4	7.69
• Other	27		12		8	5.77
HIV status of support source						
HIV negative	73	57.48	60	71.43	42	80.77
HIV positive	46	36.22	23	27.38	8	15.38
Don't know	8	6.3	1	1.19	1	19.23
Live with participant						
Yes	28	22.05	15	17.86	13	25
No	98	77.17	69	82.14	39	75
Other (sometimes)	1	0.008	-		-	

Table XX summarizes the combined social support women received from their first confidants, second confidants and other sources by five main categories: family, spouse/partner, relative, friend and other. Based on the data shown in the table, family was considered the most support source for women, followed by friends.

TABLE XX
SUMMARY OF TOTAL SUPPORT SOURCES AMONG THE WOMEN

Sources Category (N= 525)	Support #1		Support#2		Other Sources Support	
	(First Confidant) N=142		(Second Confidant) N=120		N=263	
	N	%	N	%	N	%
Family; n=183 (38.67%)	69	48.6	53	44.17	61	23.19
Spouse/partner; n=82 (15.62%)	28	19.72	18	15	36	13.69
Relative; n=83 (15.8%)	27	19	21	17.5	35	13.3
Friend; n=140 (26.7%)	18	12.7	28	23.33	94	35.74
Other; n=37 (7.05%)	0	0	0	0	37	14

A GLM procedure using the Repeated Measures ANOVA test (within subject effects) was used to examine the differences in types of support and support satisfaction between three groups: first confidant, second confidant and other sources. These findings and the outcomes of the estimated marginal means and the comparison tests are described for each type of support in the following section.

Instrumental Support. Table XXI below presents the estimated marginal means of instrumental support by levels of support group sources. The women perceived higher instrumental support from their first confidants when compared with their second confidants and others. Table XXII shows the results used to test whether or not the results are likely to represent a real difference or are due to chance variation.

TABLE XXI
THE ESTIMATED MARGINAL MEANS OF INSTRUMENTAL SUPPORT BY LEVELS OF
SUPPORT SOURCES

Support sources	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
First Confidant	1.817	.049	1.721	1.914
Second Confidant	1.646	.050	1.547	1.746
Others Sources	1.479	.041	1.399	1.560

As can be seen from Table XXII, all four multivariate tests of significance revealed a significant differences of instrumental support between first confidant, second confidant and others, $F(2, 116)=14.052$, $p=.000$.

TABLE XXII
GLM PROCEDURE USING THE REPEATED MEASURES ANOVA TEST FOR
INSTRUMENTAL SUPPORT

Effect		Value	F	Hypothesis df	Error df	Sig.	Partial Eta Squared
Instrumental Support	Pillai's Trace	.195	14.052 ^b	2.000	116.000	.000	.195
	Wilks' Lambda	.805	14.052 ^b	2.000	116.000	.000	.195
	Hotelling's Trace	.242	14.052 ^b	2.000	116.000	.000	.195
	Roy's Largest Root	.242	14.052 ^b	2.000	116.000	.000	.195

a. Design: Intercept

Within Subjects Design: Instrumental Support

b. Exact statistic

Post hoc comparisons using the Bonferroni test revealed that women perceived higher instrumental support from first confidants than from second confidants and other sources (see below). Women also perceived higher instrumental support from second confidants than from other sources.

TABLE XXIII
BONFERRONI POST HOC COMPARISONS FOR INSTRUMENTAL SUPPORT

Group (I)	Group (J)	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
First Confidant	Second Confidant	.171 [*]	.066	.034	.010	.332
	Others	.338 [*]	.064	.000	.183	.493
Second Confidant	Others	.167 [*]	.062	.025	.016	.319

*. The mean difference is significant at the 0.05 level.

Emotional Support. The descriptive table below (Table XXIX) presents the estimated marginal means of emotional support by levels of support group sources. The means were slightly difference among three groups. The next table (Table XXV) shows whether there were differences in emotional support among the three groups or whether those differences were due to chance variation.

TABLE XXIV
ESTIMATED MARGINAL MEANS OF EMOTIONAL SUPPORT BY LEVELS OF SUPPORT SOURCES

Support sources	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
First Confidant	2.710	.042	2.628	2.793
Second Confidant	2.615	.053	2.511	2.719
Others Sources	2.598	.043	2.513	2.683

While instrumental support was found in an earlier analysis to differ between the three groups, the Repeated Measures test showed no significant differences in emotional

support between the groups. This result suggests that women tend to perceive the same level of emotional support from all three groups.

TABLE XXV
GLM PROCEDURE USING THE REPEATED MEASURES ANOVA TEST FOR EMOTIONAL SUPPORT

Effect		Value	F	Hypothesis df	Error df	Sig.	Partial Eta Squared
Emotional Support	Pillai's Trace	.035	2.091 ^b	2.000	117.000	.128	.035
	Wilks' Lambda	.965	2.091 ^b	2.000	117.000	.128	.035
	Hotelling's Trace	.036	2.091 ^b	2.000	117.000	.128	.035
	Roy's Largest Root	.036	2.091 ^b	2.000	117.000	.128	.035

a. Design: Intercept Within Subjects Design: Emotional Support

b. Exact statistic

Informational. The descriptive table below (Table XXVI) presents the estimated marginal means of informational support by levels of support group sources. The means seemed slightly difference between first confidant and the other two groups, but it seemed similar among second confidant and other sources. Table XXVII shows whether there was different informational support among the three groups or whether it was due to chance variation.

TABLE XXVI
ESTIMATED MARGINAL MEANS OF INFORMATIONAL SUPPORT BY LEVELS OF SUPPORT SOURCES

Support sources	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
First Confidant	2.175	.051	2.074	2.275
Second Confidant	2.025	.054	1.918	2.132
Others Sources	2.036	.057	1.923	2.148

As can be seen from the Table XXVII, the finding shows no significant difference for the informational support between three groups. It suggests that women might perceive the same level of informational support from all three groups.

TABLE XXVII
GLM PROCEDURE USING THE REPEATED MEASURES ANOVA TEST FOR
INFORMATIONAL SUPPORT

Effect		Value	F	Hypothesis df	Error df	Sig.	Partial Eta Squared
Informational Support	Pillai's Trace	.048	2.910 ^b	2.000	116.000	.058	.048
	Wilks' Lambda	.952	2.910 ^b	2.000	116.000	.058	.048
	Hotelling's Trace	.050	2.910 ^b	2.000	116.000	.058	.048
	Roy's Largest Root	.050	2.910 ^b	2.000	116.000	.058	.048

a. Design: Intercept

Within Subjects Design: Informational Support

b. Exact statistic

Support Satisfaction. The descriptive table (Table XXVIII) presents the estimated marginal means of support satisfaction by levels of support group sources. The means seemed difference between first confidant and the other two groups, but there was a slightly different level of support satisfaction between the second confidant and other sources. The next table (Table XXIX) shows whether there was a difference of support satisfaction among the three groups or if it was due to chance variation.

TABLE XXVIII
THE ESTIMATED MARGINAL MEANS OF SUPPORT SATISFACTION BY LEVELS OF
SUPPORT SOURCES

Support sources	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
First Confidant	3.874	.091	3.693	4.055
Second Confidant	3.555	.105	3.348	3.762
Others Sources	3.445	.089	3.269	3.622

The findings on Table XXIX indicates that there was significant difference of support satisfaction among three groups, $F(2,117)=6.832$, $p=.002$.

TABLE XXIX
GLM PROCEDURE USING THE REPEATED MEASURES ANOVA TEST FOR SUPPORT SATISFACTION

Effect		Value	F	Hypothesis df	Error df	Sig.	Partial Eta Squared
Support Satisfaction	Pillai's Trace	.105	6.832 ^b	2.000	117.000	.002	.105
	Wilks' Lambda	.895	6.832 ^b	2.000	117.000	.002	.105
	Hotelling's Trace	.117	6.832 ^b	2.000	117.000	.002	.105
	Roy's Largest Root	.117	6.832 ^b	2.000	117.000	.002	.105

a. Design: Intercept Within Subjects Design: Support Satisfaction

b. Exact statistic

Table XXX presents the post hoc analyses using the Bonferroni post hoc criterion for significance. The test reveals that women perceived higher support from first confidants when compared to other sources. Support satisfaction received from the first confidant was higher compare to second and other confidants. However, the support satisfaction received from second and other confidants were not different.

TABLE XXX
BONFERRONI POST HOC COMPARISONS FOR SUPPORT SATISFACTION

Group (I)	Group (J)	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
First Confidant	Second Confidant	.319 [*]	.130	.046	.005	.634
	Others	.429 [*]	.121	.002	.135	.722
Second Confidant	Others	.109	.136	1.000	-.221	.439

*. The mean difference is significant at the 0.05 level.

E. Individual Factors Predicting Social Support

The Multiple Linear Regression Analysis Test was conducted to examine: (a) the influence of individual factors (age, marital status, working status and mode of transmission) in predicting the number of support, (b) the influence of individual factors (age, marital status, working status and mode of transmission) in predicting types of support and support satisfaction.

1. Individual Characteristics and Number of Support Sources

What factors predict the number of sources from which the women obtain social support? To answer this question, the analysis turns to an examination of the association between the individual characteristics (age, education, marital status, working status and mode of transmission) and number of social support sources using multiple linear regressions.

The first hypothesis to predict the social support was “individual characteristics will predict the number of support sources.” Women who are older were expected to have a higher number of support sources; married women would have a higher number of support sources than unmarried women; working women would have a greater number of support

sources than non-working women and women who contracted HIV sexually would have a higher number than women who contracted it through injecting drug use. Table XXXI presents a multiple linear regression analysis examining scores reflecting number of support. Data indicated that overall the model was statistically significant, $F(4,137)=3.525$, $p<.05$. Furthermore, the model explained about 9.3% of the variance in the dependent variable number of support ($R^2=.093$, Adjusted $R^2=.067$).

Among four variables of individual characteristics (age, marital status, working status, and mode of transmission), there were two variables, working status and mode of transmission (needle transmission), that emerged as predictors of number of support. It was found that working status increased the number of support sources ($\beta = 0.485$), while the mode of transmission through needle injecting transmission reduced the number of support sources ($\beta = -0.52$).

TABLE XXXI
MULTIPLE LINEAR REGRESSION ANALYSIS FOR VARIABLES OF INDIVIDUAL FACTORS
EXAMINING NUMBER OF SUPPORT

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
(Constant)	3.281	.335		9.797	.000
Age	.074	.100	.061	.739	.461
Marital Status	.152	.197	.063	.772	.441
Working Status	.485	.197	.201	2.455	.015
Mode of transmission	-.520	.221	-.192	-2.35	.020

Note. For Model: $R^2=.093$, Adjusted $R^2=.067$, $F(4,137)=3.525$, $p<.05$.

2. Individual Characteristic and Social Support

The second hypothesis in predicting social support was “individual characteristics will predict the type of support women received from the first confidant.” The table below presents the Linear Regression Test to examine the four variables of individual characteristics in predicting the type of support (instrumental, emotional and informational) and support satisfaction.

The results of the statistical test on the tables below (Table XXXII to Table XXXV) show that there were no individual factors that predicted all the types of support (instrumental, emotional and informational) women received from their first confidants. Similarly, there were no individual factors that predicted the support satisfaction women received from first confidants. Individual factors were not significant predictors of social support.

TABLE XXXII
MULTIPLE LINEAR REGRESSION ANALYSIS OF VARIABLES INDIVIDUAL FACTORS TO PREDICT THE INSTRUMENTAL SUPPORT

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
(Constant)	1.822	.165		11.06	.000
Age	.023	.049	.041	.475	.635
Marital Status	-.090	.097	-.079	-.924	.357
Working Status	-.086	.097	-.075	-.885	.377
Mode of transmission	.093	.109	.072	.852	.396

TABLE XXXIII

MULTIPLE LINEAR REGRESSION ANALYSIS OF VARIABLES INDIVIDUAL FACTORS TO PREDICT THE EMOTIONAL SUPPORT

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
(Constant)	2.627	.132		19.86	.000
Age	.054	.040	.116	1.368	.174
Marital Status	-.028	.078	-.031	-.366	.715
Working Status	-.064	.078	-.069	-.823	.412
Mode of transmission	-.117	.087	-.113	-1.34	.184

TABLE XXXIV

MULTIPLE LINEAR REGRESSION ANALYSIS OF VARIABLES INDIVIDUAL FACTORS TO PREDICT THE INFORMATIONAL SUPPORT

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
(Constant)	2.201	.167		13.20	.000
Age	-.019	.050	-.033	-.382	.703
Marital Status	.053	.098	.046	.537	.592
Working Status	-.022	.099	-.020	-.227	.821
Mode of transmission	.049	.111	.038	.442	.659

TABLE XXXV

MULTIPLE LINEAR REGRESSION ANALYSIS OF VARIABLES INDIVIDUAL FACTORS TO PREDICT THE SUPPORT SATISFACTION

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
(Constant)	3.909	.299		13.059	.000
Age	-.058	.090	-.056	-.647	.519
Marital Status	.140	.176	.068	.792	.429
Working Status	.022	.177	.011	.124	.902
Mode of transmission	.066	.199	.028	.329	.742

F. Whom the Women Confided in as a Predictor of Social Support

The Multiple Linear Regression Analysis examined social support regressed in order of first and second confidant. All confidants in first and second disclosure order were divided into five categories: female family member (consisting of mother and sister), male family member (father and brother), partner (husband, ex-husband and boyfriend), relative and female friend.

1. Variable of Confidant and Instrumental Support

Table XXXVI below shows a multiple linear regression analysis examining the instrumental support. Data indicated that overall model was statistically significant, $F(5,256)=17.531$, $p<.001$. Furthermore, the model explained about 25.5% of the variance in the dependent variable instrumental support ($R=.255$, Adjusted $R=.241$). Among six predictors, there were four predictors that explained sources instrumental support. It is found that disclosure to specific confidants is associated with instrumental support. Female family member, ($\beta=.610$, $p=.000$), male family member ($\beta=.533$, $p=.001$), partner ($\beta=.862$, $p=.000$), and relative ($\beta=.324$, $p=.036$) significantly predicted instrumental type of support.

TABLE XXXVI
MULTIPLE LINEAR REGRESSION ANALYSES OF VARIABLES CONFIDANT TO PREDICT
THE INSTRUMENTAL SUPPORT

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
(Constant)	1.255	.131		9.581	.000
Female family member	.610	.141	.515	4.329	.000
Male family member	.533	.154	.330	3.462	.001
Partner	.862	.149	.599	5.804	.000
Relative	.324	.154	.201	2.107	.036
Female friend	.003	.154	.002	.018	.985

Note. For Model: $R=.255$, Adjusted $R=.241$, $F(5,256)=17.531$, $p<.001$.

2. Variable of Confidant and Emotional Support

Table XXXVII shows that none of the categories of confidants predict the emotional type of support.

TABLE XXXVII
MULTIPLE LINEAR REGRESSION ANALYSES OF VARIABLES CONFIDANT TO PREDICT
THE EMOTIONAL SUPPORT

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
(Constant)	2.500	.138		18.164	.000
Female family member	.240	.148	.222	1.623	.106
Male family member	.122	.162	.083	.753	.452
Partner	.143	.156	.109	.915	.361
Relative	.149	.162	.101	.920	.358
Female friend	.106	.162	.071	.656	.512

3. Variable of Confidant and Informational Support

Table XXXVIII shows that none of the categories of confidant predict informational support.

TABLE XXXVIII
MULTIPLE LINEAR REGRESSION ANALYSES OF VARIABLES CONFIDANT TO PREDICT
THE INFORMATIONAL SUPPORT

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
(Constant)	1.929	.153		12.631	.000
Female family member	.269	.164	.221	1.637	.103
Male family member	.104	.179	.063	.579	.563
Partner	.259	.173	.175	1.496	.136
Relative	-.047	.179	-.029	-.265	.791
Female friend	.212	.180	.126	1.176	.241

4. Variable of Confidant and Support Satisfaction

Table XXXIX below presents a multiple linear regression analysis examining support satisfaction. Even though the data indicated that overall the model was statistically significant, $F(5,255)=2.695$, $p<.05$, the model explained only about 5% of the variance in the dependent variable instrumental support ($R^2=.050$, Adjusted $R^2=.032$), which is considered very low. Among the confidant categories, only female family member predicted support satisfaction ($\beta=.609$, $p=.049$).

TABLE XXXIX
MULTIPLE LINEAR REGRESSION ANALYSES OF VARIABLES CONFIDANT TO PREDICT
THE SUPPORT SATISFACTION

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
(Constant)	3.357	.285		11.760	.000
Female family member	.609	.307	.266	1.981	.049
Male family member	.264	.335	.085	.789	.431
Partner	.480	.324	.173	1.482	.140
Relative	-.006	.335	-.002	-.017	.986
Female friend	.115	.336	.037	.342	.733

Note. For Model: $R^2=.050$, Adjusted $R^2=.032$, $F(5,255)=2.695$, $p<.05$.

5. Supplementary Analysis: Gender of Confidants as Predictor to Social Support

A Simple Linear Regression analysis was conducted to test the predictor of social support based on variable gender of confidant, as can be seen on Table XL through Table XLIII. Data indicated that the model was statistically significant, $F(1,260)=9.893$, $p<.05$. However, the model explained only about 3.7 % of the variance in the dependent variable of instrumental support ($R^2=.037$, Adjusted $R^2=.033$), which is considered very low. Furthermore, the tables

show that the gender of confidants affected instrumental support ($\beta=.221$, $p=.002$) but was not significantly associated with emotional support, informational support or support satisfaction.

Table XL
SIMPLE LINEAR REGRESSION ANALYSES OF VARIABLES CONFIDANT'S GENDER TO
PREDICT THE INSTRUMENTAL SUPPORT

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
(Constant)	1.882	.055		34.021	.000
Gender (female)	-.221	.070	-.191	-3.145	.002

Note. For Model: $R^2=.037$, Adjusted $R^2=.033$, $F(1,260)=9.893$, $p<.05$.

TABLE XLI
SIMPLE LINEAR REGRESSION ANALYSES OF VARIABLES CONFIDANT'S GENDER TO
PREDICT THE EMOTIONAL SUPPORT

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
(Constant)	2.620	.051		50.958	.000
Gender (female)	.067	.065	.063	1.018	.310

TABLE XLII
SIMPLE LINEAR REGRESSION ANALYSES OF VARIABLES CONFIDANT'S GENDER TO
PREDICT THE INFORMATIONAL SUPPORT

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
(Constant)	2.090	.058		36.101	.000
Gender (female)	.025	.074	.021	.340	.734

TABLE XLIII
SIMPLE LINEAR REGRESSION ANALYSES OF VARIABLES CONFIDANT'S GENDER TO
PREDICT THE SUPPORT SATISFACTION

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
(Constant)	3.670	.109		33.759	.000
Gender (female)	.057	.138	.025	.410	.682

G. Reasons to Disclose as Predictors of Social Support in First Disclosure Experiences

Bivariate analyses and Linear Regression Analysis tests were conducted to examine: (a) the association between reason to disclosure and social support, and (b) which dimension of reasons to disclosure (catharsis, need to inform, need to educate, test other reaction, close and supportive relationship and similarity) as predictors to types of support and support satisfaction.

The Pearson Correlation test was used to examine the association between reason to disclose and social support. As showed in Table XLIV, there was an association between some dimensions of reason and social support. The need to inform and educate others, to test others' reactions and form close and supportive relationships were associated with instrumental support ($r=.323, p<0.01, r=.206, p<0.01, r=.327, p<0.01$, respectively). The need to inform, form close and supportive relationships, and similarity were associated with emotional support ($r=.337, p<0.01, r=.437, p<0.01, r=.172, p<0.05$, respectively). Testing other's reactions and forming close and supportive relationships were associated with informational support ($r=.172, p<0.05, r=.355, p<0.01, r=.258, p<0.01$, respectively). Finally, the need to inform, close

and supportive relationships and similarity were associated with support satisfaction ($r=.225$, $p<0.01$, $r=.281$, $p<0.01$, $r=.179$, $p<0.01$, respectively).

TABLE XLIV
CORRELATION BETWEEN SIX REASONS TO DISCLOSURE AND SOCIAL SUPPORT

	Instrumental	Emotional	Informational	Support Satisfaction
Catharsis	-.082	.124	-.058	.014
Need to inform	.323**	.337**	.148	.225**
Need to educate	.206*	.128	.117	.113
Test other's reaction	.266**	.141	.172*	.122
Close and supportive relationship	.327**	.437**	.355**	.281**
Similarity	.021	.172*	.258**	.179*

** . Correlation is significant at the 0.01 level (2-tailed).

* . Correlation is significant at the 0.05 level (2-tailed).

While there were associations between several reasons for disclosure and social support, the next step was conducting the regression analysis to test if the six dimensions of reason to disclose significantly predicted the social support from the first confidant.

1. Reasons for Disclosure and Instrumental Support

Table XLV below presents a multiple linear regression analysis examining the instrumental support. Data indicated that the model of reasons for disclosure was statistically significant, $F(6,129)=6.256$, $p<.001$. The model explained about 22.5 % of the variance in the dependent variable instrumental support ($R^2=.225$, Adjusted $R^2=.189$). As can be seen from Table XLV, the results of the regression analysis indicate that three predictors explained the instrumental type of support. It was found that close and supportive relationships significantly

predicted instrumental support ($\beta=.167$, $p=.005$) as did duty to inform ($\beta=.115$, $p=.015$), but the reason of catharsis reduced instrumental type of support ($\beta=-.131$, $p=.001$).

TABLE XLV
MULTIPLE LINEAR REGRESSION ANALYSIS FOR VARIABLES OF REASON TO DISCLOSURE PREDICTING
INSTRUMENTAL SUPPORT

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
(Constant)	.997	.256		3.892	.000
Need to catharsis	-.131	.039	-.287	-3.366	.001
Duty to inform	.115	.047	.236	2.458	.015
Need to educate	-.023	.046	-.053	-.496	.620
Test other reaction	.075	.044	.189	1.715	.089
Close and supportive	.167	.058	.252	2.864	.005
Similarity	-.006	.037	-.012	-.151	.880

Note. For Model: $R^2=.225$, Adjusted $R^2=.189$, $F(6,129)=6.256$, $p<.001$.

2. Reason to Disclosure and Emotional Support

Furthermore, a regression test was conducted to examine the predictors of emotional support. Data indicated that the model of reasons for disclosure was statistically significant to predicting emotional support, $F(6,129)=7.675$, $p<.001$. The model explained about 26.3 % of the variance in the dependent variable instrumental support ($R^2=.263$, Adjusted $R^2=.229$). The results from Table XLVI show that the reason of close and supportive relationship significantly predicted emotional support ($\beta=.21$, $p=.000$) as did duty to inform ($\beta=.118$, $p=.002$).

TABLE XLVI
MULTIPLE LINEAR REGRESSION ANALYSIS FOR VARIABLES OF REASON TO DISCLOSURE
PREDICTING EMOTIONAL SUPPORT

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
(Constant)	1.442	.205		7.028	.000
Need to catharsis	.010	.031	.027	.323	.747
Duty to inform	.118	.037	.297	3.169	.002
Need to educate	-.042	.037	-.117	-1.118	.266
Test other reaction	-.042	.035	-.128	-1.189	.236
Close and supportive	.208	.047	.382	4.440	.000
Similarity	.058	.029	.159	1.970	.051

Note. For Model: $R^2 = .263$, Adjusted $R^2 = .229$, $F(6,129) = 7.675$, $p < .001$.

3. Reason to Disclosure and Informational Support

For the next type of support, the regression test in Table XLVII indicates that the model of reasons for disclosure was statistically significant, $F(6,129) = 5.636$, $p < .001$. The model explained about 21 % of the variance in the dependent variable informational support ($R^2 = .210$, Adjusted $R^2 = .173$). Among six reasons to disclose, the variables of close and supportive relationship significantly predicted informational support ($\beta = .23$, $p = .000$) and so did similarity ($\beta = .12$, $p < .002$).

TABLE XLVII
MULTIPLE LINEAR REGRESSION ANALYSIS FOR VARIABLES OF REASON TO DISCLOSURE PREDICTING
INFORMATIONAL SUPPORT

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
(Constant)	1.141	.264		4.329	.000
Need to catharsis	-.069	.040	-.150	-1.735	.085
Duty to inform	.037	.049	.074	.756	.451
Need to educate	-.058	.049	-.132	-1.202	.232
Test other reaction	.024	.046	.059	.518	.605
Close and supportive	.226	.060	.336	3.745	.000
Similarity	.120	.038	.265	3.144	.002

Note. For Model: $R^2=.210$, Adjusted $R^2=.173$, $F(6,129)=5.636$, $p<.001$.

4. Reason to Disclosure and Support Satisfaction

Based on the table below, the overall model was statistically significant, $F(6,129)=5.139$, $p<.001$. The model explained about 19.4 % of the variance in the dependent variable instrumental support ($R^2=.194$, Adjusted $R^2=.156$). Furthermore, the result presented in table XLVIII shows that close and supportive relationship significantly predicted the support satisfaction ($\beta=.432$, $0=.000$), so did the similarity ($\beta=.15$, $p=.032$).

TABLE XLVIII
MULTIPLE LINEAR REGRESSION ANALYSIS FOR VARIABLES OF REASON TO DISCLOSURE PREDICTING SUPPORT SATISFACTION

	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
Need to catharsis	-.057	.073	-.068	-.786	.434
Duty to inform	.163	.088	.180	1.854	.066
Need to educate	-.080	.087	-.100	-.920	.359
Test other reaction	-.047	.082	-.064	-.571	.569
Close and supportive	.432	.109	.357	3.964	.000
Similarity	.148	.068	.183	2.163	.032

Note. For Model: $R^2=.194$, Adjusted $R^2=.156$, $F(6,129)=5.139$, $p<.001$.

H. Antiretroviral Treatment Utilization

The results below describe the ART utilization among women with HIV positive which specifically identified three aspects: (a) entry in HIV care; (b) retention in HIV care; (c) adherence to ARTs among those currently in care. Furthermore, a Linear Regression Analyses was conducted to examine: (a) which types of support as predictors to retention in HIV care, (b) which type of confidant as predictor in ART Adherence, (c) which types of support as predictor in ART adherence.

1. Entry in HIV Care

As shown in Table XLIX, the majority of participants had entered HIV care. Approximately 80% of participants were receiving ART, 4 % had received ART (but currently were not in treatment) and about 15.5% had never received ART treatment. The ratio those who entered HIV care and those who never did or were not anymore was not balanced.

Therefore, a statistical analysis cannot be conducted to measure the association between variable of entry to care and other variables.

Some participants were recommended to enter the HIV care; however, some of them preferred not to enter care. They reported that their reasons for entering HIV care, which also impacted their not taking ART, such as fear of the side effects of ART, myths about getting skin burns because of the medication, having no support systems, financial stress, still actively IDU, feeling desperate with the medication and preferring to go with alternative medication.

2. Retention in HIV Care

Most participants who enter into HIV care (80%) visited the clinic once in the past 30 days and about 69% of women at least visited the clinic three times within the last three months. Those who entered HIV treatment received HIV health care in hospital-based clinics, primary health clinics or the NGO's clinic specializing in HIV/AIDS. They went to the clinic especially for ARTART medication and/or brief consultations with doctors about their health. From the descriptive data, the majority of participants had good retention to HIV care from at least one visit to a clinic within 30 days.

TABLE XLIX
RETENTION TO HIV CARE AND ART TREATMENT STATUS

Variable	N	%
Frequency to clinic (within 30 days)		
Never	28	19.7
1 to 2 times	106	74.6
3 to 4 times	5	3.5
5 times or more	3	2.1
Frequency to clinic (within 3 months)		
Never	28	19.7
1 to 2 times	20	14.1
3 to 4 times	85	59.9
5 times or more	12	8.5
ART Treatment status		
Recently in a treatment and care	114	80.3
Have ever received medical treatment but not anymore (dropped a treatment care)	6	4.2
Never entry a treatment care	22	15.5

Furthermore, the Pearson Correlation was used to test the relationship between social support and the level of retention in HIV care. As can be seen in Table LII below, it shows that there was no correlation between the types of support and support satisfaction and the frequency of visiting the clinic within 30 days or 3 months.

3. Adherence to Antiretroviral Treatment

The adherence to ART was assessed by three items on a self-report questionnaire. However, one item was dropped because of poor reliability and consistency, therefore; only two items were analyzed in this study. The participants needed to report of the last 30 days: (1) how good a job did they do at taking their HIV medication in the way they were supposed to and (2) how often did they take their HIV medicines in the way they were supposed to.

The item responses for the two adherence items were linearly transformed to a 0-100 scale. An index of the individual adherence items was calculated as the mean of the two individual items. Table L below presents the description of the total ART adherence and two items of adherence.

About half of participants reported that they had a good to excellent performance of taking ART in the last 30 days. Likewise, most participants almost always did take their medicine as they were supposed to. The mean total for the study's two items for ART adherence suggested that the women's ART adherence can be considered according to these measures as good ($M=72.6$, $SD=18.52$) .

TABLE L
ART ADHERENCE AMONG WOMEN WHO IN HIV CARE

Variable	n=114	%	Mean	SD
Performance of taking ART in the last 30 days				
Very poor	1	0.7		
Poor	13	9.8		
Fair	29	19	66.23	20.854
Good	33	22.5		
Very Good	23	17.5		
Excellent	15	10.5		
Frequency of taking ART in the last 30 days				
Never				
Rarely	0	0		
Sometimes	7	4.9		
Usually	11	7.7	78.8	19.49
Almost always	24	15.4		
Always	40	28		
	32	23.8		
ART adherence (total)			72.5	18.52

a. Predictors to ART Adherence among Those Currently in HIV Care Based on Identity of Confidants

A simple Linear Regression analysis examined the association between confidant categories of social support based on to whom the women confided (female family member and non-female family member) and ART adherence. As we can see in table LI, female family member significantly predicted increased ART adherence the ($\beta=7.204$, $p=.041$). Even though the model was significant ($F(1,112)=4.274$, $p<.05$), however, the model only explained about 3.7% ($R^2=.037$, Adjusted $R^2=.028$) of the variance in the ART adherence.

TABLE LI
SIMPLE LINEAR REGRESSION ANALYSES OF VARIABLES CONFIDANT TO PREDICT THE ART ADHERENCE

Variable	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
(Constant)	69.608	2.214		31.446	.000
Confidant categories (Female family member)	7.204	3.485	.192	2.067	.041

Note. For Model: $R^2=.037$, Adjusted $R^2=.028$, $F(1,112)=4.274$, $p<.05$.

b. Relationship Between Social Support and Adherence to ARTs among Those Currently in HIV Care

As showed in the Table LII, there was a significant correlation between emotional support and the day of missed the ART ($r= -0.248$, $p<0.01$). The more women had emotional support, the lesser of day of missed the ART. In addition, there was a correlation between all

the types of support (instrumental, emotional, and informational) with the performance of taking the ART with the $r=0.19, p<0.05, r=0.24, p<0.05, r=0.25, p<0.01, r=0.22, p<0.05$ respectively. The more women had the instrumental, emotional and informational, the better they did at taking their HIV medication in the way they were supposed to. Similarly, there was a correlation between all the types of support with the frequency of taking the ART with the $r=0.19, p<0.05, r=0.19, p<0.05, r=0.25, p<0.01, r=0.21, p<0.05$ respectively. The more women received the instrumental, emotional and informational support, the more often they take their HIV medicines in the way they were supposed to. There was also a correlation between support satisfaction with the performance of taking the ART ($r=0.22, p<0.05$) and with the frequency of taking the ART ($r=0.21, p<0.05$).

TABLE LII
SUMMARY OF INTER-CORRELATIONS ON THE SUPPORT, RETENTION TO HIV CARE AND ART ADHERENCE

Variables	1	2	3	4	5	6	7	8	9
Social Support									
Instrumental	-								
Emotional	0.36**	-							
Informational	0.53**	0.46**	-						
Support	0.52**	0.65**	0.56**	-					
Satisfaction									
Frequency to clinic									
Within 30 days	0.05	0.11	0.11	0.14	-				
Within 3 months	-0.1	0.09	0.08	0.08	0.77**	-			
Adherence to ART	0.207*	0.233**	0.269**	0.235*	-0.03	-0.087	-		
Performance of taking ART	0.19*	0.24*	0.25**	0.22*	0.003	0.863**	0.923**	-	
Frequency of taking ART	0.19*	0.19*	0.25**	0.21*	-0.06	-0.12	0.31**	0.912**	-

** . Correlation is significant at the 0.01 level (2-tailed).

* . Correlation is significant at the 0.05 level (2-tailed).

c. Testing Variables of Social Support as Predictor of ART Adherence

Simple linear regression analysis examined the association between social support and ART adherence. As can be seen from Table LIII to LVI, of the 5 forms of social support, it indicates that all the three types of social support and support satisfaction were significantly predictors for the ART adherence with the $\beta=6.278$, $p=.027$; $\beta=9.568$, $p=.013$; $\beta=8.633$, $p=.004$; and $\beta=4.238$, $p=.012$ respectively.

Even though the overall model of support was significant for each variable, however, each model only explained a very low percentage of the variation in the ART adherence. For the independent variable of instrumental support, the model only explained about 4.3% of the variation on ART adherence ($R^2=.043$, Adjusted $R^2=.034$). Furthermore, it is only about 4.3 % ($R^2=.043$, Adjusted $R^2=.034$) of the variation on ART adherence is accounted for by its relationship with instrumental support; only about 5.4% ($R^2=.054$, Adjusted $R^2=.046$) of the variation in ART adherence is accounted for by its relationship with emotional support; only about 7.2% ($R^2=.072$, Adjusted $R^2=.0640$) of the variation in ART adherence is accounted for by its relationship with informational support; and only about 5.5% ($R^2=.055$, Adjusted $R^2=.047$) of the variation in ART adherence is accounted for by its relationship with support satisfaction.

TABLE LIII
SIMPLE LINEAR REGRESSION ANALYSIS FOR VARIABLES OF INSTRUMENTAL SUPPORT
PREDICTING THE ART ADHERENCE

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
(Constant)	60.281	5.730		10.521	.000
Instrumental Support	6.728	3.008	.207	2.236	.027

Note. For Model: $R^2=.043$, Adjusted $R^2=.034$, $F(1,112)=5.001$, $p<.05$.

TABLE LIV
SIMPLE LINEAR REGRESSION ANALYSIS FOR VARIABLES OF EMOTIONAL SUPPORT PREDICTING
THE ART ADHERENCE

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
(Constant)	46.399	10.453		4.439	.000
Emotional Support	9.568	3.779	.233	2.532	.013

Note. For Model: $R^2=.054$, Adjusted $R^2=.046$, $F(1,112)=6.410$, $p<.05$.

TABLE LV
SIMPLE LINEAR REGRESSION ANALYSIS FOR VARIABLES OF INFORMATIONAL SUPPORT
PREDICTING THE ART ADHERENCE

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
(Constant)	53.598	6.622		8.094	.000
Informational Support	8.633	2.923	.269	2.953	.004

Note. For Model: $R^2=.072$, Adjusted $R^2=.064$, $F(1,112)=8.721$, $p<.05$.

TABLE LVI
SIMPLE LINEAR REGRESSION ANALYSIS FOR VARIABLES OF SUPPORT SATISFACTION PREDICTING
THE ART ADHERENCE

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
(Constant)	56.122	6.630		8.465	.000
Support Satisfaction	4.238	1.657	.235	2.557	.012

Note. For Model: $R^2=.055$, Adjusted $R^2=.047$, $F(1,112)=6.54$, $p<.05$.

I. Summary

The following section reviews the research questions and hypotheses that were examined in the study. Figure 8 below visualizes the summary of linear regression analyses that tested the association between the explanatory and dependent variables.

To begin with the participants' disclosure experience, the analyses showed that the women exhibited similar patterns of first and second disclosure experience. Mother was the person whom the women tended to tell first about their HIV status, followed by sister and current husband. Male friend was the least common person to whom they disclosed, with ex-husband and boyfriend nearing the bottom.

First and Second Disclosure. The matrix of disclosure order shows that women who first disclosed to either family members or relatives would also secondly disclosed to family members or relatives. On the contrary, women who first disclosed to non-family members or relatives would mostly have second confidant from their friends. Specifically, once a first disclosure had been made, female friend was the person the women told second about their

HIV status, followed by mother and other relative. Boyfriend was the least person to whom they disclosed, followed by the ex-husband and male friend. More than half of the participants disclosed to the first confidant in one week or less, and about 40 percent of participant disclose to second confidant in less than a month after disclosed to first their confidant. More than half participants disclosed to the second confidant in less than six months after first disclosure.

Size of Disclosure Networks. Analysis of the size of women's disclosure networks shows that about half of women had disclosed to more than 10 persons. Among women who were married or living with a partner, about 58% choose not to inform their partner as their first or second confidant. About 26% of women told their partner after they disclosed to first and second confidant and about 32% had not disclosed to their partner. Non-married women reported larger family disclosure networks than married women and women living with a partner. The friendship disclosure network of women who acquired HIV through needle transmission was higher than women who acquired HIV through heterosexual transmission.

Reasons for disclosure. The reasons for disclosure were differed by first and second disclosure. Having a close and supportive relationship was the reason most reported for disclosure to a first confidant while catharsis was the most cited reason of disclosing to a second confidant. Similarity was the least reported reason of disclosure. The reason of close and supportive relationship from first confidant was higher than from second confidant. The result confirms that mothers as the most first confidant were perceived as a close person and supportive compare to other family members. The multiple regression analyses found that

there were some reasons to disclosure that predicted the social support women received. The reason of close and supportive relationship, need to inform and need to catharsis significantly predicted the instrumental type of support. The reason of close and supportive relationship and need to inform significantly predicted the emotional type of support. The reason of close and supportive relationship and similarity significantly predicted the informational type of support. Lastly, the reason of close and supportive relationship significantly predicted the support satisfaction.

Sources of social support based on to whom the women disclosed. Descriptive analyses showed that emotional support was the most frequently reported social support that the women needed and received was from their first and second confidant. There was a significant difference in instrumental support between first and second disclosure, however, there was no significant difference in emotional and informational support between two groups. While mother was the most supportive person in the first and second disclosure, female friend was the most other support sources for women. By comparing all the support sources among women, it showed that there was a different instrumental support and support satisfaction from first, second confidant and other three support persons. A Bonferroni test revealed that women perceived higher instrumental support from first confidant compared to their second confidant and other sources; but perceived no different instrumental support from second confidant and with other sources. Moreover, the test also revealed that women perceived higher satisfaction of support from first confidant compare to other sources, however, there was no difference support satisfaction between first and second confidant and there was no

difference support satisfaction between second confidant and other sources. The non-significance different of emotional and informational support might showed that these type of supports were received from all the sources.

Predictor of social support based on to whom the women confided. From five categories of confidant, there were four categories: female family member, male family member, partner and relative as predictors to instrumental type of support. There were no categories that significantly predicted the emotional and informational type of support. From five categories of confidant, it was found that only female family member category were significantly predicted the support satisfaction. There was association between gender and instrumental support. It was found that female confidant was significantly predicted the instrumental type of support.

Reasons to disclosure as predictors of types of social support received. From six dimensions of reasons to disclosure, three predictors (close and supportive relationship, duty to inform and reason of catharsis) were found to be associated with significantly increased instrumental type of support. Next, the reason of close and supportive relationship and duty to inform were significantly predicted the emotional support. Furthermore, the close and supportive relationship and reason of similarity were two significant predictors for informational support. Lastly, the close and supportive relationship was significantly predicted the support satisfaction.

Individual factors as predictors of support sources. From four variables of individual factors (age, working status, marital status and mode of transmission), only working status and

mode of transmission could predict the number of support sources. However, none of the variables predicted the types of support received and support satisfaction.

Predictor of ART Adherence based on to whom the women confided. Linear Regression showed that among the five categories of confidants, only female family member significantly predicted increased ART adherence.

Social support and the ART utilization. The Pearson Correlation showed no association between social support and level of retention in HIV care. However, for the ART adherence it showed that there was a correlation between all the type of support with the performance and the frequency of taking the ART. Similarly, there was a correlation between support satisfaction with the performance and the frequency of taking the ART. The regression analyses revealed that all the types of support and support satisfaction were significantly predicting the ART adherence.

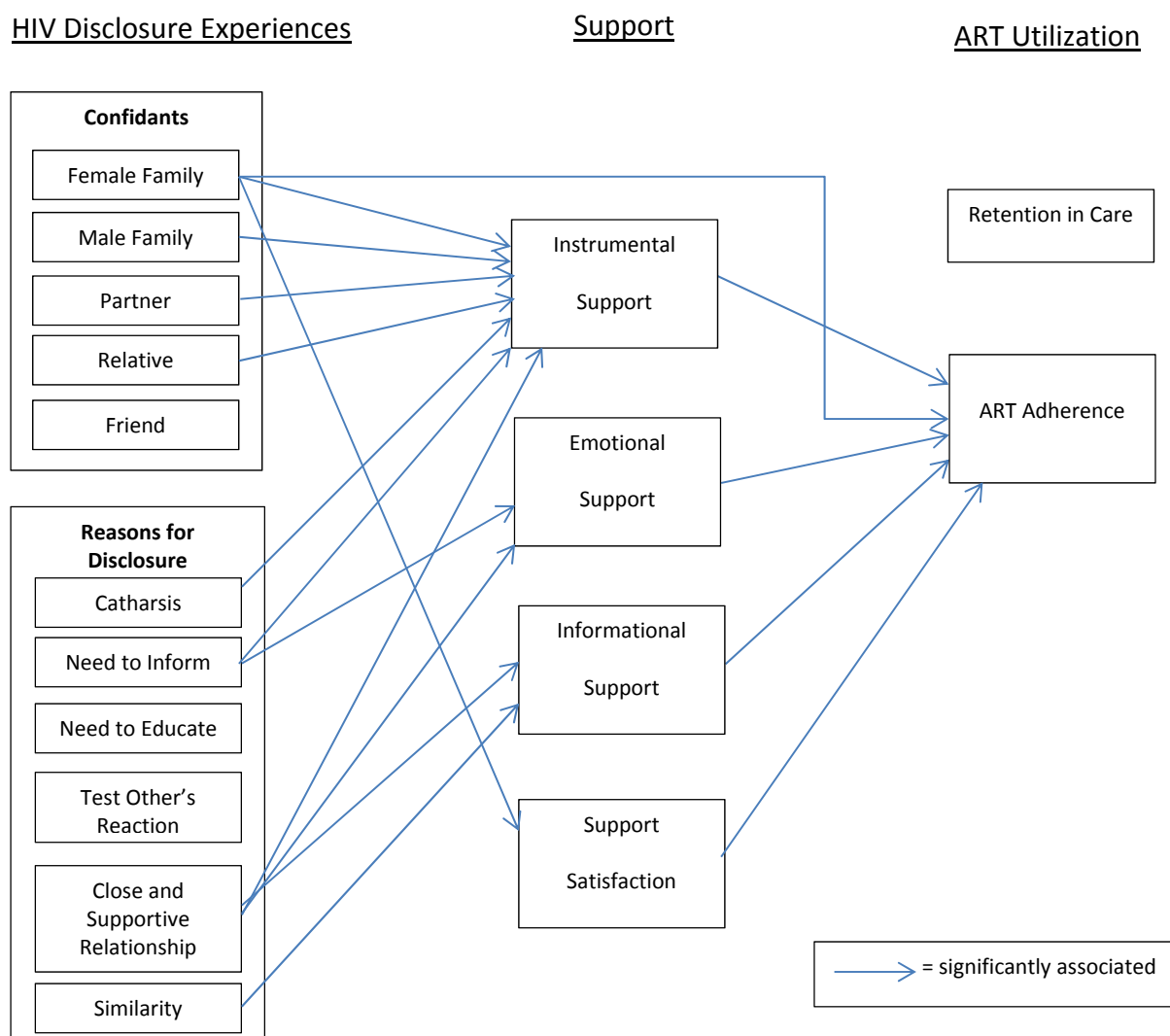


Figure 8: HIV disclosure experience, social support and ART utilization.

V. DISCUSSION

This following section will discuss the study's major findings, strength and limitations, and its implications for practical application and future research.

A. The Pattern of HIV Disclosure Experiences among Women

The demographic data show that most women were infected with HIV through sexual transmission (70%) and most were considered low risk populations or housewives who perceived that they were infected by their ex-husbands or current husbands. The data from the Indonesian Ministry of Health (MoH, 2012) confirms that an increasing number of women in Indonesia with HIV/AIDS contracted the virus as the spouses of high risk men (IDUs and clients of sex workers).

The study's descriptive findings regarding HIV disclosure experiences show the following: almost all participants voluntarily disclosed their HIV status to their first and second confidants; the timing was short between diagnosis and disclosure to first and second confidants; and more than half of the women had a high number of disclosure network. First, almost all participants voluntarily disclosed their HIV status to their first and second confidants. Among them, about 15% of women had only one HIV disclosure experience, which means that they only have one supportive person to help them cope with HIV/AIDS. The rest of the participants had more than one person as sources of support. Among women with HIV in Jakarta, findings from first and second HIV disclosure experiences demonstrate that women

disclosed to people with whom they have various relationship types. This finding is consistent with previous research that women have a significantly larger variety of people in their network than men (Turner, 1994).

Among the four categories of relationship types (i.e. family, spouse/partner, friend and relative), about 49% of women first disclosed their HIV status to family members, especially to mothers (25%), followed by spouse/partner and other relative. As Greene et al. (2009) stated, relational quality was the best predictor of willingness to disclose HIV infection to others. The HIV disclosure pattern in this study is consistent with previous studies (Kalichman, et al., 2003; Greene & Faulkner, 2002). A quantitative study from Kalichman et al. (2003) showed that in comparison to men, women were more likely to disclose to their mothers (85% versus 75%), followed by friends and sisters. A qualitative study among African American young women (Greene and Faulkner, 2002) also found that mothers were the first people to whom women disclosed their HIV status. Greene & Faulkner (2002) indicated that people disclosed their HIV infection to individuals who are closer to them emotionally and physically.

The second disclosure pattern was similar to the first disclosure pattern. The percentage of women whose second HIV disclosure experiences involved family members was almost as high as those whose first HIV disclosure experiences also involved family members. Mothers remained the most common second confidant in the family, followed by a friend, especially a female friend, and then other relative. However, the percentage of women who had female friends as a second confidant was slightly higher than those whose second confidants were

mothers (20% vs 16%). This finding indicates that for these participants, female friends could be considered as alternative significant support sources in addition to family members.

To conclude the discussion on the pattern of first and second HIV disclosure experiences, the matrix of disclosure order shows that women who first disclosed to either family members or relatives would most likely choose family members or relatives as their second confidants. Women who chose partners as their first confidants would choose family members as their second confidants. Meanwhile, women who first disclosed to friends would choose friends as their second confidants.

Among married women or women living with partners, about 42% of them chose their partners as their first or second confidant. About 26 % of women disclosed their HIV status to their partners after they told their first and second confidants. Consistent with this finding, research from Lowerthal & Haven (in Turner, 1994) showed that women are much less likely to identify their spouse as confidants than men who are most likely refer their spouse as confidants and support person. In particular, a study by Depner and Ingersoll-Dayton (1985) found that women report receiving and providing less support from and to their spouses. Therefore, it is possible that women in this study whose first and second confidants were persons other than their partners might anticipate receiving less support from them. Furthermore, about 32% of married women or women living with partners had not disclosed their HIV status to their husbands or partners. Some women who perceived that they acquired HIV from their ex-husbands reported that they were not ready for the potential negative

consequences of disclosing their status to their current husbands. Others told that they didn't want their husbands or partners to know that they were active IDUs. This finding is similar with previous studies conducted in Africa (Obermeyer & Osborn, 2007; Nebie et al., 2001) that found low levels of disclosure to partners due to several factors, such as financial dependency upon their male partners, addiction to drugs, or lack of coping or other social resources (Gielen et al., 1997; Moneyham et al., 1996; Rothenberg et al., 1995; Sherr, 1996).

There was a difference in the disclosure network of friends among women who were IDUs and acquired HIV from used needle exchange and among those who acquired HIV from sexual transmission. The IDUs were more likely to have a greater disclosure network of friends. The disclosure networks were not always same as the support networks. Even though the IDUs had a greater network of friends, their support sources came mostly from family members instead of friends. The data indicated that the IDUs had more friends who knew their HIV status but not all friends were supportive. There is limited literature discussing disclosure networks among IDUs, and yet existing literature on support networks among IDUs may help explain the disclosure networks found in this study. For example, Smith and Rapkin (1996) reported that HIV positive IDUs in the US relied on friends and family almost equally. A study from China (Li, et al., 2008), however, suggested that IDU participants relied more on family members for support than on their social networks. On the contrary, another study suggested different results. Knowlton, Hua & Latkin (2004) found that IDUs relied on support from active drug users because their lifestyle factors and the stigma associated with using drugs impacted the absence of support from family members.

B. HIV Disclosures among Women Based on the Communication Privacy Management

Theory

The communication privacy management (CPM) theory proposes five criteria for developing privacy rules for managing disclosures and concealing private information (Petronio, 1999; Petronio, 2002; Greene, et al., 2009). They include culture, gender, motivation, context, and risk-benefit ratio.

Cultural criteria. There were about 525 people that women perceived as their support sources (including first and second confidants). Among those people, about 39% were family members, 27% were friends, 16% were relatives and spouses/partners, and 7% were from others (e.g. neighbors, health care providers, and children). The descriptive data presents that family members and friends were women's primary support sources in comparison to other categories. The percentage of participants whose support sources were relatives equaled that of those whose support sources were spouses/others, thereby indicating that relatives or extended family can be considered as an important significant others for women with HIV. The multiple regression analyses also revealed that female and male family members, partners, and relatives were predictors of the instrumental type of support. Specifically, female family members were the only predictor of support satisfaction. The family structures in Indonesia depend on the family members' cultural affiliation. In Jakarta, most families are more nuclear, but there are variations in small cities and rural areas. Some extended family members live nearby and others live in the same house and commonly share the same responsibilities, such as looking after each other's children and taking good care of family members who are sick or in

hard situations. This explains why women in this study also gained support from extended family members. In total, about 65% of support sources came from a kinship unit (i.e. nuclear and extended family members). Similar to family structures in other Asian countries, Indonesia is a family-oriented society. It confirms why a majority of women in this study revealed their HIV status to family members and looked for and received support from them. As Li et al. (2008) stated, in the culture of a family-oriented society, a strong and support family is one of the first lines of defense when facing societal discrimination and other hardships related to HIV/AIDS. Their study in the Asian context showed that family support significantly affects people living with HIV/AIDS. Bor et al. (1993) suggested that when parents are too sick to take care of children themselves, the grandparents usually became the primary caregiver for their grandchildren. In Thailand, as well as many other countries, families affected by HIV/AIDS provide psychological and economic support to their family members (Manopaiboon et al., 1998). In contrast, previous studies (Castro, et al., 1998; Hays et al, 1993; Mdlalose, 2006) argued that the majority of family members displayed negative responses and unsupportive reactions to family members' HIV diagnoses. A study among Mexican family from Castro (1998) showed that unlike other studies, HIV became a catalyst of pre-existing family conflicts among the Mexicans.

Gender criteria. Another finding about disclosure and support networks involves the gender of confidants and support sources. In this study, most women were more likely to disclose their HIV status to the same gender or to females (e.g. mother, sister, female friend, aunt, mother in law and niece). Dindia and Allen (in Petronio, 2000) conducted a meta-analysis

of sex differences in self-disclosure and found that women disclosed and preferred to disclose to females rather than males. Consistent with this finding, several studies cited in Turner (1994) found that women experience more support from same-gender persons, whereas men rely heavily upon their partners or wives. Turner (1994) stated that the evidence suggests that women may be both better providers of support and the recipients of more supportive transactions. This study shows that the confidant's gender was a variable that predicted the instrumental type of support. Although there was no difference in emotional and informational support among the two genders, female confidants, in comparison to male confidants, were more likely to give instrumental support. In addition, support from female family members was the variable that significantly predicted the instrumental type of support and support satisfaction.

Motivational criteria. Motivational criteria, which varies from one individual to the next, is associated with the reasons for concealing or revealing one's HIV status (Greene, et al., 2009). People's motivations for HIV disclosure can be broadly categorized in three ways (Derlega, et al., 2002; Derlega, Winstead, & Folk-Barron, 2000). The first category entails decisions leading to disclosure that examine personal gain or the fulfillment of personal needs, such as catharsis. The second category entails decisions leading to disclosure that examine others' gains or the fulfillment of others' needs, such as a duty to inform or education. The third category entails decisions leading to disclosure that examine interpersonal gains or the fulfillment of interpersonal needs, such as testing others' reactions and establishing emotionally close and supportive relationships (Greene, et al., 2009). This study shows that there was a difference in

reason behind the first and second disclosures. In the first disclosure, the primary reason for telling confidants was based on a close and supportive relationship. The need for catharsis served as the primary reason for disclosure to second confidants. On the contrary, a previous study conducted by Derlega, et al. (2004) shows that testing others' reaction was the primary reason for HIV disclosure among women. In their study, women were more likely to reveal their HIV status to their partners or husbands. Therefore, HIV disclosure was viewed by the women as a way to ascertain how the intimate partner would react to their having HIV. In contrast, the reason of similarity was the least common reason for disclosure to both the first and second confidants. It indicated that the reason for disclosure was not driven by similar background or common experiences with confidants. The data about confidants' HIV status showed that only 15-17% of confidants were HIV positive or that only a small number of confidants had health problems or lifestyles similar to those of participants.

Contextual criteria. The contextual factors, which include setting and time of disclosure, are related to the physical elements or social environments of the communication process (Petronio, 1999; Petronio, 2001, Greene, et al., 2009). Since there is no data related to the setting of disclosure, this variable cannot be explained further. In regards to the time of disclosure, Derlega et al. (1993) suggested that timing plays an important role in disclosure episodes and appears to be significant in HIV disclosures. In this study, about 70% of women had disclosed to their first confidants, and almost half of women disclosed to their second confidants within one month of learning their HIV status. About 21% reported waiting at least one year. The short length of time between diagnosis and disclosure might be related to the

selection of confidants whom the women believe they can trust (Petronio, 2002). Previous research suggests that individuals with HIV believe it is better to immediately disclose their status rather than waiting (Adam&Sears, 1994, 1996 as cited in Greene, et al., 2009). Gielen et al. (1997) reported that many women with HIV disclosed right away, but some delayed any disclosure.

Risk-benefit ratio criteria. Individuals often calculate the risks and benefits of revealing and concealing private information. This criterion was not assessed through this study and therefore cannot be explained further.

C. Factors Contributing to Social Support

1. HIV Disclosure as a Predictor of Social Support

Disclosure has been identified as an important psychological stressor for HIV positive women (Semple, et al., 1993 as cited in Gielen et al, 2000). However, a number of studies showed that most women eventually do disclose their status to others. For example, previous studies (Gilman&Newman, 1996; Gielen, Campo, Faden & Eke, 1997; Carter, 1995 as cited in Gielen et al., 2000) of HIV positive women have reported disclosure rates in the range of 72%-98%. Those studies found that disclosure was positively associated with receiving more emotional and personal support and that very few women received no support. Consistent with previous studies, the participants in this study gained support after they first disclosed to significant persons and then eventually received support from other sources. In comparison to

men, women have broader social networks (Turner, 1994) from which they draw support to cope with an illness (Revenson et al, 2005).

In this study, almost all participants had other support sources aside from the first and second confidants. Whereas family members served as primary support sources (i.e. first and second confidants), friends, especially female friends, served as the second most common support sources. Unlike first and second confidants, other support sources learned of the women's HIV status through direct and indirect disclosures. Over half of the women directly told their support sources, but about 42% of support sources learned of the women's HIV status through indirect disclosure. Indirect disclosure includes learning from a family member, friend or relative, being informed by the doctor or other medical staff, and meeting the women in the hospital and accidentally finding their medication. Based on a previous study by Varga, Sherman & Jones (2003), involuntary or indirect disclosure might lead to negative consequences, including emotional rejection, ostracism and withdrawal of financial and other forms of material support. This study did not specifically examine the consequences of indirect disclosure. However, the statistical test showed that women had sufficient support from all the support sources. This indicates that women in this study most likely had the support they wanted regardless of the form of disclosure.

2. Individual Factors as Predictors of Social Support

Among four individual characteristics (i.e. age, marital status, working status and mode of transmission), there were two variables that served as predictors to a number of support sources. Working status increased the number of support sources while needle use transmission reduced the number of sources. This result was supported by previous research

that found employed people to report having larger social networks in comparison to unemployed people (Atkinson, Liem, & Liem, 1986). Prior research also suggested that the heterosexually infected individuals received greater support from families in comparison to those infected through injection drug use (Johnston et al., 1995; Smith and Rapkin, 1996). The finding is also consistent with the qualitative study among female IDUs in central Java, Indonesia that was conducted by Lazuardi, et al. (2012). Their study showed that women had very limited social networks and that their social circles were limited to their partners and his male friends. On the contrary, those four personal characteristic were not significant predictors to the type of support received by women. The result might be related with the participants' characteristic in this study. All the participants at least have one significant person as their confidant who also has role as women's support person. However, some participants might only have one support person while others have more than one support sources. Therefore, regardless of the age, marital status, working status and mode of transmission, women still had support from their confidant(s).

D. Role of Support in ART Adherence

This study has found that women received all types of support from confidants. According to the disclosure process model (DPM) by Chaudory & Fisher (2010), disclosure affects outcomes via social support as a mediating factor. Also, support resulting from disclosure has an effect on individual outcomes, which include psychological, behavioral, and health effects. In this study, most women were very satisfied with the support they received. Among the various types of support (instrumental, emotional and informational), emotional

support or “affective support” was the type of support most wanted by women and most received from their confidants. The second most common type of support wanted and received was informational support. The instrumental support was the support that women least wanted. Several studies showed the same result and found that emotional support was viewed as the most desirable type of support by people with HIV/AIDS (Namir et.al, 1989; Edwards, 2006). Furthermore, it has been found to be a correlate of well-being in persons with AIDS (Hays, Chauncey, et al., 1990). Results from a qualitative study by Edward (2006) suggested that emotional support was reported as a main concern and immediate need. For the women in this study, feeling unloved and uncared for was a social barrier to HIV medication adherence. The absence of love and care showed that others did not care about them and they consequently did not care about themselves either.

Congruent with a study by Edward (2006), this study shows the correlation between social support and ART adherence. All types of support and support satisfaction were correlated with the performance and frequency of taking ART. The multiple regression analysis test also shows that all the social support dimensions were predictors of ART adherence. Women who felt supported were more likely to be adherent and most participants had high ART adherence. This study was consistent with previous studies that linked social support to better medication adherence (Simoni, Frick & Huang, 2006; Amberbir, et al., 2008; DiMatteo & Robin, 2004).

Although social support has been associated with health care utilization for chronic diseases, this study reflects that there was no correlation between social support and HIV care retention. The absence or existence of support was not associated with the frequency of visit to the clinic within 30 days or 3 months. Consistent with a previous study conducted by Wohl et al. (2011), this study showed that social support was not a predictor of determining HIV care retention among Latino and African American MSM and women. In general, the retention in HIV care among women was considered high. Women went to the clinic at least once within 30 days and 3 months.

It is important to understand why social support might not play a strong role in HIV care retention among women in this study. Participants who had entered HIV care were linked to at least one HIV/AIDS institution or organization in Jakarta. Most of the institutions had regular supportive services for women, such as case management, transportation and support group meetings. One of case manager's major tasks is to ensure that their clients attend the clinics regularly to get their ART. Perhaps this providing explains the participants' high clinic attendance as well as why attendance did not correlate in this study with social support from the women's confidant(s). According to Mellins, et al. (2003), supportive services from organizations can facilitate consistent engagement of patients into medical care.

E. Strengths and Limitations of the Study

There are some strengths and limitations to this study. One strength is that it is the first study to investigate the HIV disclosure experience, social support and ART utilization among

women in Jakarta, Indonesia. There are a limited number of studies related to women with HIV/AIDS in Indonesia. Therefore, this study can contribute to practical and theoretical knowledge about disclosure patterns among women and the importance of disclosure networks as the support sources for women to cope with HIV and adhere to care. The two measures in this study (social supports and reasons for disclosure scales) have great internal consistency in regards to the items in the scale and can be used for future HIV research in the Indonesian context.

The questionnaire was administered via face-to-face interviews due to the sensitive nature of some questions. This mode of administration was also necessary in order to prevent the potential mistakes associated with self-administration. During the interview process, the interviewers found that this method encouraged participants to share their experiences and emotions. Some questions were very sensitive in nature and could act as emotional triggers for participants. The individual interview was not only a tool for collecting data, but also perceived as an emotional outlet for participants. All the interviewers received basic training in counseling skills, which enabled them to conduct the interview by listening and providing emphatic responses. At the end of the interviews, most participants reported that they felt emotionally relieved by sharing their experiences with the interviewer. Most of them were part of peer group activity programs at their NGO sites, but never received professional counseling. Even though the individually conducted interviews took a long time as data collection, however, the interview approach offered psychological benefits to the participants, which was considered as

strength of this study. The process of data collection while conducting interviews about HIV-related personal and sensitive issues can be viewed as a relieving tool for participants.

This study also has some limitations that may affect the interpretation and generalization of its findings. First, the sample was a convenience sample and therefore cannot be considered as being representative of women living with HIV/AIDS. The participants were recruited only from four NGOs and comprised of women from one city – Jakarta. Most study participants entering HIV care were of low economic class and unemployed. Even though there were a few numbers of IDU's and FSWs, the small number of them cannot represent those specific populations. Therefore, the women in this study could not provide a complete picture regarding the status of all women with HIV/AIDS in Jakarta. This includes women with higher socioeconomic class, women who had not entered HIV care, and key populations such as active IDUs and FSWs. The FSW populations were difficult to reach because a majority of them did not disclose their HIV status to anyone other than their caseworkers. Some of them cancelled or preferred not to participate in the study. One reason for nonresponse was that the study's compensation was not comparable with the compensation they would receive from their clients for the same amount of time required of the interview. The middle- and upper-class communities are rarely involved with the NGO community, thereby making it difficult for a researcher to access this group. Third, a lack of variability in the sample may have resulted in low detection power. Fourth, the findings were limited in that they are based on self-reports and therefore could have been influenced by social desirability and errors in memory.

Finally, particular attention needs to be paid to measure the reaction to disclosure. Unlike the social support scale and the reason for disclosure scale, the reaction to disclosure scale had low internal consistency in regards to the items in the scale. A limitation of this scale involved the number of the type of reactions to disclosure using a six item binomial response of “yes” or “no.” The reaction itself varies on a spectrum and possessed a qualitative gradation. For example, a reaction of “angry” in one participant may have a different definition or meaning for another participant. Because the answer options were either a “yes” or “no,” it is not possible to describe the degree of negativity or positivity of reactions received by women. Another concern was related to the congruence of perceived reactions by the participants. According to Serovich, Kimberly, And Greene (1998), the reactions identified by women may be different from those actually experienced by confidants. For example, women might perceive someone’s reaction as “angry” but the actual reaction from confidant was “sad” or “disappointed.” It is important to investigate reaction to disclosure with in-depth interviews using qualitative methods and involve the significant others for future research.

F. Implications for HIV Programs Targeting Women in Indonesia

This study has demonstrated the importance of disclosure in gaining support and how support can encourage women to further disclose their status to others, thereby allowing for the receipt of additional support. The study also indicates that support was one of other factors that correlate with ART adherence. Families, both nuclear and extended, are considered as important supportive assets for women. Interestingly, female friend are also considered as a

significant person for women who might not have family as their support source. Based on the results, there are some recommendations that can be applied to HIV programs in Indonesia.

First, based on future projections by the Indonesian National AIDS Commission (2012), HIV prevalence among women is estimated to increase in the following years. Therefore, HIV programs targeting women in Indonesia will be needed. There has been developments in program coverage and effectiveness related to prevention, care, support and treatment, but very few discussions or programs that address the psychosocial aspect or needs of people living with HIV. After learning about their HIV positive status, women need emotional outlets to express their feelings and to learn how to disclose their status to their significant others. Therefore, in addition to support programs that are usually offered in HIV by NGOs, psychological counseling programs are recommended in order to assist women or families in dealing or coping with the issues of HIV/AIDS.

Second, this study has confirmed previous studies that disclosure is an important factor influencing the psychosocial and medical aspects of people living with HIV. It is very important to make comprehensive disclosure guidelines for health care workers or NGO staff who deal with this issue. These guidelines should include principles on how to disclose one's HIV status to children. Furthermore, disclosure guidelines, education-related initiatives, and media campaigns should consider relevant socio-cultural factors. This includes the language used and the kind of messages that can be delivered, both of which should be applied to various cultural backgrounds in Indonesia.

Finally, women in this study disclosed their status to various significant others. It is clear that families have important roles for women with HIV but friends, especially female friends, are also considered as important support sources for women. Families (parents, siblings and extended family) as supportive sources should be included and involved in HIV intervention programs. There are programs involving partners or spouses, but very rarely are there programs involving family members. Therefore, family-focused intervention programs are recommended. Such programs need to include components such as guidelines on how to deal with HIV disclosures within families and communities and guidelines on how to cope with the stress or burden of being a caretaker to HIV positive family members. In addition, community based interventions and supportive counseling would also be a promising approach to increasing rates of sero-status disclosure and to supporting women's health.

G. Implications for Future Research

There is limited research related to HIV/AIDS among women in Indonesia. This study represents initial research in examining the disclosure experience, social support and ART utilization among women with HIV/AIDS in Jakarta, and these findings could be used as a baseline for future research. Several recommendations for future studies are proposed. First, using the quantitative method, this study has demonstrated the comprehensive data about disclosure experiences among women and how it can impact their support networks. However, a qualitative approach and in-depth qualitative analysis will be needed to increase understanding about the disclosure process itself. This is because HIV disclosure experiences and their consequences were considered as an ongoing process. Further HIV intervention

research should combine quantitative and qualitative method in order to study different aspects of HIV disclosure and interventions.

Disclosure is not solely a focus of study in the public health or psychology sector; it also requires a multidisciplinary approach that involves the disciplines of sociology and anthropology. Culture is considered to have an important role in the disclosure process. The themes of the disclosure process were related to communication issues. Communication aspects, such as style of communication and privacy issues, were related to social and cultural norms. For example, in the Indonesian context, disclosure was not considered as a 'private' matter as it would be in Western settings. During the data collection process, some participants reported that the NGO staff, doctor or health care provider sometimes revealed their HIV status to other family members without the women's permission or consent because the family members arrived together with the women in the clinics. Disclosing a 'secret' or sensitive information to other family members without permission is culturally accepted because a family member or partner is perceived to be as one unit with the participants. Therefore, studies about disclosure in health settings or NGO clinics will be beneficial in giving practical disclosure guidelines to HIV care providers. The other important variables that should be addressed in future research are related to sexual and drugs behavior among HIV/AIDS women. This study did not collect data on these two variables; and therefore it cannot discuss the risk behaviors that might be associated with disclosure. Lastly, research on the impact of family and/ or significant others involvement in HIV care effort also would be useful in better understanding the consequences of HIV disclosure.

APPENDICES

APPENDIX A : IRB APPROVAL LETTER

UNIVERSITY OF ILLINOIS AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7227

Approval Notice Initial Review (Response To Modifications)

April 22, 2014

Evi Sukmaningrum
Health Policy and Administration
Community Health Sciences
1603 W Taylor, M/C 718
Chicago, IL 60612
Phone: (773) 691-8980 / Fax: (312) 996-5356

RE: **Protocol # 2014-0074**
"HIV Disclosure Experience Among Women with HIV/AIDS in Jakarta, Indonesia"

Dear Ms. Sukmaningrum:

Your Initial Review application (Response To Modifications) was reviewed and approved by the Expedited review process on April 21, 2014. You may now begin your research.

Please note the following information about your approved research protocol:

The Board has determined that this research will require full review at a convened meeting for continuing review and all substantive amendments (20 copies required).

Please remember to insert the phone numbers that will be used to contact the Principal Investigator and the site contact on the Contact Cards, and to submit this version of the Contact Cards with the continuing review application packet.

<u>Protocol Approval Period:</u>	April 21, 2014 - April 21, 2015
<u>Approved Subject Enrollment #:</u>	150
<u>Additional Determinations for Research Involving Minors:</u>	These determinations have not been made for this study since it has not been approved for enrollment of minors.
<u>Performance Sites:</u>	UIC, Atma Jaya University
<u>Sponsor:</u>	NIH Fogarty International Center Training Grant
<u>PAF#:</u>	2011-00687
<u>Grant/Contract No:</u>	5 D43 TW001419
<u>Grant/Contract Title:</u>	UIC AIDS International Training and Research Program

Research Protocol:

- a) HIV Disclosure Experience among Women with HIV in Jakarta, Indonesia; Version 4;
04/09/2014

Phone: 312-996-1711

<http://www.uic.edu/depts/over:oprs/>

FAX: 312-413-2929

APPENDIX A : IRB APPROVAL LETTER (continued)

2014-0074

Page 2 of 3

4/22/2014

Recruitment Materials:

- a) Study Contact Card (English); Version 2; 02/19/2014
- b) Study Contact Card (Indonesian); Version 2; 02/19/2014
- c) Eligibility Screening Form PI (Indonesian); Version 2; 02/19/2014
- d) Eligibility Screening Form RA (English); Version 1; 02/19/2014
- e) Eligibility Screening Form PI (English); Version 2; 02/19/2014
- f) Eligibility Screening Form RA (Indonesian); Version 1; 02/19/2014
- g) Study Information Flyer (English); Version 3; 03/20/2014
- h) Study Information Flyer (Indonesian); Version 3; 03/20/2014
- i) NGO Staff Initial Contact Script (English); Version 3; 03/20/2014
- j) NGO Staff Initial Contact Script (Indonesian); Version 3; 03/20/2014

Informed Consents:

- a) Informed Consent (English); Version 2; 02/19/2014
- b) Informed Consent (Indonesian); Version 2; 02/19/2014
- c) A waiver of documentation of consent has been granted for this research under 45 CFR 46.117(c)(1) (minimal risk; signed consent document would be the only document linking subjects with HIV to the research and indirectly disclosing their status)

Please note the Review History of this submission:

Receipt Date	Submission Type	Review Process	Review Date	Review Action
01/23/2014	Initial Review	Convened	02/06/2014	Deferred
02/20/2014	Response To Deferred	Convened	03/06/2014	Deferred
03/20/2014	Response To Deferred	Convened	04/03/2014	Modifications Required
04/11/2014	Response To Modifications	Expedited	04/21/2014	Approved

Please remember to:

→ Use your **research protocol number** (2014-0074) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements on the enclosure,

"UIC Investigator Responsibilities, Protection of Human Research Subjects"

(<http://tiger.uic.edu/depts/ovcr/research/protocolreview/irb/policies/0924.pdf>)

Please note that the UIC IRB has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact OPRS at (312) 996-1711 or me at (312) 996-2014. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

APPENDIX A : IRB APPROVAL LETTER (continued)

2014-0074

Page 3 of 3

4/22/2014

Sincerely,

Sandra K Costello

Sandra Costello

Assistant Director, IRB # 2

Office for the Protection of Research Subjects

Enclosures:

- 1. UIC Investigator Responsibilities, Protection of Human Research Subjects**
- 2. Informed Consent Documents:**
 - a) Informed Consent (English); Version 2; 02/19/2014
 - b) Informed Consent (Indonesian); Version 2; 02/19/2014
- 3. Recruiting Materials:**
 - a) Study Contact Card (English); Version 2; 02/19/2014
 - b) Study Contact Card (Indonesian); Version 2; 02/19/2014
 - c) Eligibility Screening Form PI (Indonesian); Version 2; 02/19/2014
 - d) Eligibility Screening Form RA (English); Version 1; 02/19/2014
 - e) Eligibility Screening Form PI (English); Version 2; 02/19/2014
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 - i) NGO Staff Initial Contact Script (English); Version 3; 03/20/2014
 - j) NGO Staff Initial Contact Script (Indonesian); Version 3; 03/20/2014

cc: Jack Zwanziger, Health Policy and Administration, M/C 923
 Judith A. Levy (faculty advisor), Health Policy and Administration, M/C 923
 OVCR Administration, M/C 672

APPENDIX B: ETHICAL CLEARANCE FROM ATMA JAYA CATHOLIC UNIVERSITY OF INDONESIA



UNIVERSITAS KATOLIK INDONESIA
ATMA JAYA

LEMBAGA PENELITIAN DAN PENGABDIAN KEPADA MASYARAKAT
Institute of Research and Community Service
Jalan Jenderal Sudirman 51, Jakarta 12930, Indonesia
Telepon : +62 21 570 3306, 572 7615 ext. 139
Faks : +62 21 572 7461
Website : www.atmajaya.ac.id
E-mail : lppm@atmajaya.ac.id

17 Februari 2014

No. : 138/III/LPPM-PM.10.05/02/2014
Hal : *Ethical Clearance*
Lamp : 1 berkas

Yang terhormat,
Evi Sukmaningrum
PTB - Fakultas Psikologi
Unika Atma Jaya
Jakarta

Dengan hormat,

Setelah melakukan *peer review* terhadap proposal penelitian berjudul

HIV Disclosure Experience Among Women with HIV in Jakarta, Indonesia

dengan ini kami sampaikan bahwa Komisi Etika Penelitian Unika Atma Jaya menyatakan bahwa proposal penelitian tersebut dapat dilaksanakan dengan beberapa catatan dari tim komisi Etika Penelitian terlampir

Diharapkan setelah pelaksanaan, Saudara dapat memberikan laporan beserta uraian pelaksanaan penjaminan aspek etika penelitian tersebut.

Demikian dapat kami sampaikan. Atas perhatiannya kami haturkan terima kasih.

Komisi Etika Penelitian Unika Atma Jaya,

Dr. Lidia L. Hidajat, MPH, Psikologi
Sekretaris



Dr. Alexander Seran
Ketua

APPENDIX C: QUESTIONNAIRE

HIV Disclosure Experience among Women with HIV/AIDS in Jakarta, Indonesia

Evi Sukmaningrum
Principal Investigator,
School of Public Health, University of Illinois at Chicago, USA

Participant ID # _____

Date of Interview: ____/____/____
 D D M M Y Y

Place of Interview: _____

Interviewer ID # _____

Time Starting Interview: __:__ (AM/PM)

Interview

APPENDIX C: QUESTIONNAIRE (continued)

I would like to thank you again for taking part in this study. Remember that all the information that you give me will be kept confidential and your name will not appear anywhere on this interview. Please answer the questions honestly. If you don't know the answer, please do not guess, but rather respond with "Don't know". This interview will take about 90 - 120 minutes to complete.

1. PERSONAL DATA

*First, I would like to ask you some questions about your background.
Interviewer: Please write or circle the answers given to you.*

A. Socio demographic

- A1. How old are you? _____ years
- A2. What is your highest level of education?
- | | | |
|------------------------|-------|----|
| Never been to school | | 01 |
| Elementary /equivalent | | 02 |
| Junior High/equivalent | | 03 |
| Senior High/equivalent | | 04 |
| Diploma degree | | 05 |
| University | | 06 |
| Don't know | | 97 |
| Decline to answer | | 98 |
- A3. Which city do you currently live in?
- | | | |
|-----------|-------|----|
| Jakarta | | 01 |
| Bogor | | 02 |
| Depok | | 03 |
| Tangerang | | 04 |
| Bekasi | | 05 |
| Banten | | 06 |
- A4. Please tell me about your work. Are you...
- | | | |
|---------------------------------|-------|----|
| Employed full- time with salary | | 01 |
| Employed part-time with salary | | 02 |
| Getting money however you can | | 03 |
| Unemployed | | 04 |
| Don't know | | 97 |
| Decline to answer | | 98 |

APPENDIX C: QUESTIONNAIRE (continued)

A5. If you combine all sources (including spouse's income), approximately how much was your income in rupiah in the last 30 days?

< Rp. 1,500,000	01
Rp. 1,500,000 – 2,500,000	02
Rp. 2,500,001 – 4,500,000	03
> Rp. 4,500,000	04
Don't know	97
Decline to answer	98

B. Family and Marital Status

Now, I'm going to ask you about your family and your marital status

B1. What is your current marital status?

Never married	01
Married	02
Living with someone but not married	03
Divorced	04
Widowed	05
Don't know	97
Decline to answer	98

B2. How many children do you have? _____ [0 for none], if 0 skip to B4.

B3. How old is/are your child(ren)?
 _____ months/ years old
 _____ months/years old
 _____ months/ years old
 _____ months/ years old
 _____ months/ years old

B4. With whom do you live? Do you live..... (interviewer: please circle all that apply)

Alone	01
With relative(s)	02
With husband or sex partner	03
With children	04
Other Specify _____	05
Don't know	97
Decline to answer	98

APPENDIX C: QUESTIONNAIRE (continued)

C. Family HIV Status

Now, I would like to ask you some questions about your family members who are HIV positive. Remember that all the information that you give me will be kept confidential. You don't need to mention your family members' names.

C1. Do you have any other family members (parents, siblings, husband, child(ren)) who are HIV positive?

No	01, skip to part 2
Yes	02, continue to C2
Don't know	97, skip to part 2
Decline to answer	98, skip to part 2

C2. If yes, could you tell me which other family members are HIV positive? *(Interviewer: please circle all that apply.)*

Mother	01
Father	02
Brother	03
Sister	04
Current husband	05
Ex-husband	06
Child(ren)	07
Decline to answer	98

2. ART UTILIZATION

2A. Entry and Retention in HIV Care Program

Now I would like to ask you a few questions about your experiences with having HIV (Interviewer: Please write or circle the answers given to you.)

D1. When were you diagnosed with HIV? Month_____ Year_____

[write in number]

D2. How do you think you acquired HIV?

From a blood transfusion	01
From sexual acts	02
From used needle exchange	03
Other (specify) _____	04
Don't know	97
Decline to answer	98

D3. Have you ever received any medical treatment or care for your HIV?

No	01, skip to part 3
Yes	02, continue

APPENDIX C: QUESTIONNAIRE (continued)

D4. If yes, are you currently receiving any medical treatment or care for your HIV?

No	01, skip to part 3
Yes	02, continue
Don't know	97, skip to part 3
Decline to answer	98, skip to part 3

D5. Where do you go most often to get medical care for HIV? (*Interviewer: Circle all that apply.*)

Public hospital	01
Private hospital	02
Community health center (<i>Puskesmas</i>)	03
Private clinic / health center	04
HIV NGO service	05
Other	Specify _____	06
Don't know	97
Decline to answer	98

D6. In the last 30 days, how many times did you go to a clinic for HIV services?

Never (0)	01
1-2 times	02
3-4 times	03
≥ 5 times	04
Don't know	97
Decline to answer	98

D7. In the past 3 months, how many times did you go to a clinic for HIV services?

Never (0)	01
1-2 times	02
3-4 times	03
≥ 5 times	04
Don't know	97
Decline to answer	98

2B. Use of HIV Medications and ART Adherence

Now I would like to ask you a few questions about your HIV medication.

E1. Have you ever taken antiretroviral medication for HIV?

No	01, skip to part 3
Yes	02, continue to E2
Don't know	97, skip to part 3
Decline to answer	98, skip to part 3

APPENDIX C: QUESTIONNAIRE (continued)

E2. Currently, are you taking antiretroviral medication for HIV?

- | | |
|-------------------------|--------------------|
| No | 01, skip to part 3 |
| Yes | 02, continue to E3 |
| Don't know | 97, skip to part 3 |
| Decline to answer | 98, skip to part 3 |

E3. In the last 30 days, how many days did you miss at least one dose of any of your HIV medicines?

Write in number of days: ____ (0 – 30)

E4. In the last 30 days, how good a job did you do at taking your HIV medicines in the way you were supposed to? Would you say that you did a very poor, poor, fair, good, very good, or excellent job of taking you medications in the way that you were supposed to?

- | | |
|-----------------|----|
| Very poor | 01 |
| Poor | 02 |
| Fair | 03 |
| Good | 04 |
| Very good | 05 |
| Excellent | 06 |

E5. In the last 30 days, how often did you take your HIV medicines in the way you were supposed to? Would you say that you never, rarely, sometimes, usually, almost always, or always took your medication in the way that you were supposed to?

- | | |
|---------------------|----|
| Never | 01 |
| Rarely | 02 |
| Sometimes | 03 |
| Usually | 04 |
| Almost always | 05 |
| Always | 06 |

APPENDIX C: QUESTIONNAIRE (continued)

In the next part, I would like to ask you questions about your family, friend, and other networks who know your HIV status.

3. EGO NETWORK KNOWLEDGE OF HIV STATUS

F1. Which of the following circles best describes how many of your family members know that you are HIV positive? The white (blank) circle indicates that none of your family members know that you are HIV positive and the black one indicates that all your family members know.



None



About 25 %



Half (50 %)



About 75 %



All

F2. Which of the following circles best describes how many of your friends know that you are HIV positive? The white (blank) circle indicates that none of your friends know that you are HIV positive and the black one indicates that all your friends know.



None



About 25 %



Half (50 %)



About 75 %



All

F3. Which of the following circles best described how many people around you (other than family and friends) know that you are HIV positive? The white (blank) circle indicates that none of others know that you are HIV positive and the black one indicates that other people around you know.



None



About 25 %



Half (50 %)



About 75 %



All

F4. With how many people in total have you disclosed your HIV positive status?

- | | |
|-------------------|----|
| <5 person | 01 |
| 5-10 person | 02 |
| >10 person | 03 |

F5. To whom in the following list have you disclosed your status, if any? (*circle all that apply*)

- | | |
|-----------------------------|----|
| Mother | 01 |
| Father | 02 |
| Brother | 03 |
| Sister | 04 |
| Current husband | 05 |
| Ex-husband | 06 |
| Boyfriend/sex partner | 07 |
| Other relative | 08 |
| Female Friend | 09 |
| Male Friend | 10 |
| Other Specify _____ | 11 |
| No one | 12 |

APPENDIX C: QUESTIONNAIRE (continued)

3.1. HIV Disclosure Experience and Social Support

I am going to now ask you about the first disclosure experience.

G. Primary Disclosure (HIV Disclosure to first person)

G1. Have you ever personally told anyone that you are HIV positive?

No	01, skip to part 4
Yes	02, continue to G2

G2. Who is the first person to whom you told your HIV positive status (excluding any health workers)?

Mother	01
Father	02
Brother	03
Sister	04
Current husband	05
Ex-husband	06
Boyfriend/sex partner	07
Other relative	08
Female Friend	09
Male Friend	10
Other Specify _____	11

Interviewer: For questions G3 through G6, H1 through H8, and I1 through I2 , please refer to the answer given in G2 (first confidant). For example: How long after your diagnosis did you disclose your HIV positive status to (your mother/father/ etc)?

G3. Is your _____ HIV positive?

No	01
Yes	02
Don't know	97
Decline to answer	98

G4. How long after diagnosis did you disclose your HIV positive status to your _____?

1 week or less	01
Up to 1 month	02
2-6 month	03
More than 6 month	04
Don't know	97
Decline to answer	98

APPENDIX C: QUESTIONNAIRE (continued)

G5. Now, I am going to read you a list of reasons that people give for disclosing their status. Thinking of your _____ (first confidant), please tell me how much each of these reasons was a factor that influenced your decision to tell him/her that you are HIV positive :

1 = Not at all a factor

2 = Somewhat unlikely a factor

3 = Neither likely or unlikely a factor

4 = Somewhat likely a factor

5 = Very likely a factor

(Interviewer: Please give respondent flash card A and circle the answer)

Reasons to tell	Flash Card A				
	Not at all a factor	Somewhat unlikely a factor	Neither likely or unlikely a factor	Somewhat likely a factor	Very likely a factor
1. I didn't want to have to carry this information inside all by myself	1	2	3	4	5
2. I would be able to get the information off my chest	1	2	3	4	5
3. It would be releasing to be able to tell someone	1	2	3	4	5
4. I felt obligated to tell him/her	1	2	3	4	5
5. I didn't want to risk any health problems for me or her/him	1	2	3	4	5
6. This person had the right to know what is happening to me	1	2	3	4	5
7. I felt a sense of duty to tell him/her	1	2	3	4	5
8. I wanted to prepare that person for what might happen to me	1	2	3	4	5
9. I wanted to educate him/her about what the disease is like	1	2	3	4	5
10. My goal was to teach him/her about the disease	1	2	3	4	5
11. I wanted to make sure that he/she knew how serious this disease is	1	2	3	4	5
12. I wanted to see how he/she would feel about me	1	2	3	4	5
13. I wanted to find out if she/he wanted to be with me	1	2	3	4	5
14. I wanted to see how he/she would react to this	1	2	3	4	5
15. We love(d) one another	1	2	3	4	5
16. We have/had a mutually supportive relationship	1	2	3	4	5

APPENDIX C: QUESTIONNAIRE (continued)

Reasons to tell	Flash Card A				
	Not at all a factor	Somewhat unlikely a factor	Neither likely or unlikely a factor	Somewhat likely a factor	Very likely a factor
17. We had/had a close relationship	1	2	3	4	5
18. I trust(ed) that person	1	2	3	4	5
19. She/he could be of help	1	2	3	4	5
20. That person would be able to provide support	1	2	3	4	5
21. That person would provide me with assistance	1	2	3	4	5
22. We had a lot in common	1	2	3	4	5
23. We both had similar types of experiences	1	2	3	4	5
24. We tended to think alike about things	1	2	3	4	5

G6. When you told your _____ about your HIV positive status, how did she/he react? People sometimes have more than one reaction, so please tell me all the reactions that seemed true for _____. Would you say that he/she _____:

Reaction	No	Yes
1. Was angry with you	1	2
2. Blamed you for getting the virus	1	2
3. Expressed sympathy	1	2
4. Promised to be there for you	1	2
5. Encouraged you express or talk about your feelings	1	2
6. Was physically violent (slapped/kicked/hit) toward you	1	2

Now, I would like to talk about any support that you received from your _____.

H. Social Support for Coping with HIV from the first confidant

H1. Does your _____ live with you?

No 01
Yes 02

H2. Do you need help from your _____ in doing regular household or other tasks because of your HIV?

No 01
Yes 02

APPENDIX C: QUESTIONNAIRE (continued)

H3. What kind of help or support or help do you get from your _____? Does _____ never, sometimes, or always:

Item	Never	Sometimes	Always
Cook meals for you	1	2	3
Clean house	1	2	3
Help with caregiving	1	2	3
Give you rides to health providers	1	2	3
Accompany you to appointments with your health care providers	1	2	3
Help you to remember your medication	1	2	3
Provide financial assistance	1	2	3

H4. Is receiving emotional help from your _____ important to you in coping with your HIV?

No 01

Yes 02

H5. Does your _____ provide you with any of the following types of emotional help? Does _____ never, sometimes, or always:

Item	Never	Sometimes	Always
Make you feel valued	1	2	3
Make you feel you belong within your circle of friends and family	1	2	3
Make you feel cared for	1	2	3
Understand your feelings	1	2	3
Help you to keep your spirits up	1	2	3
Make you feel that you have someone on whom you can count on for help	1	2	3

H6. Do you ever feel the need to talk with your _____ about your HIV?

No 01

Yes 02

H7. How often do you and _____ talk with each other about your HIV? Would you say that you never, sometimes, or frequently talk with your _____ about:

Item	Never	Sometimes	Always
Your feelings about being HIV positive	1	2	3
Medical problems that you might have that are related to your HIV	1	2	3
How to tell others about having HIV	1	2	3
Taking your HIV medication	1	2	3
Keeping your medical appointments	1	2	3

APPENDIX C: QUESTIONNAIRE (continued)

H8. Overall, how satisfied are you with the level of support that your _____ gives you?

- | | |
|----------------------------|----|
| Not at all satisfied | 01 |
| Slightly satisfied | 02 |
| Moderately satisfied | 03 |
| Very satisfied | 04 |
| Extremely satisfied | 05 |

I. Secondary Disclosure

Next, I am going to be asking you about the second disclosure experience

I1. After you told _____ about your HIV status, did you tell anyone else about having HIV?

- | | |
|-----------|-------------------|
| No | 01 Skip to part 4 |
| Yes | 02 Continue to H2 |

I2. How long after you told your _____ did you disclose your HIV positive status to a second person?

- | | |
|--------------------------|----|
| Less than 1 month | 01 |
| 1 month – 6 months | 02 |
| 6 months – 1 year | 03 |
| More than a year | 04 |
| Don't know | 97 |
| Decline to answer | 98 |

I3. Who is the second person to whom you told your HIV positive status (excluding any health workers)?

- | | |
|-----------------------------|----|
| Mother | 01 |
| Father | 02 |
| Brother | 03 |
| Sister | 04 |
| Current husband | 05 |
| Ex-husband | 06 |
| Boyfriend/sex partner | 07 |
| Other relative | 08 |
| Female Friend | 09 |
| Male Friend | 10 |
| Other Specify _____ | 11 |

Interviewer: For questions I4 through I6 and J1 through J8, please refer to the answer given in I3 (second confidant). For example: How long after your diagnosis did you disclose your HIV positive status to (your mother/father/ etc)?

I4. Is _____ HIV positive?

- | | |
|-------------------------|----|
| No | 01 |
| Yes | 02 |
| Don't know | 97 |
| Decline to answer | 98 |

APPENDIX C: QUESTIONNAIRE (continued)

15. Now, I am going to read you a list of reasons that people give for disclosing their status. Thinking of your _____ (the second person), please tell me how much each of these reasons was a factor that influenced your decision to tell her/him that you were HIV positive:

1 = Not at all a factor

2 = Somewhat unlikely a factor

3 = Neither likely or unlikely a factor

4 = Somewhat likely a factor

5 = Very likely a factor

(Interviewer: Please give respondent flash card A and circle the answer)

Reasons to tell	Flash Card A				
	Not at all a factor	Somewhat unlikely a factor	Neither likely or unlikely a factor	Somewhat likely a factor	Very likely a factor
1. I didn't want to have to carry this information inside all by myself	1	2	3	4	5
2. I would be able to get the information off my chest	1	2	3	4	5
3. It would be releasing to be able to tell someone	1	2	3	4	5
4. I felt obligated to tell him/her	1	2	3	4	5
5. I didn't want to risk any health problems for me or her/him	1	2	3	4	5
6. This person had the right to know what is happening to me	1	2	3	4	5
7. I felt a sense of duty to tell him/her	1	2	3	4	5
8. I wanted to prepare that person for what might happen to me	1	2	3	4	5
9. I wanted to educate him/her about what the disease is like	1	2	3	4	5
10. My goal was to teach him/her about the disease	1	2	3	4	5
11. I wanted to make sure that he/she knew how serious this disease is	1	2	3	4	5
12. I wanted to see how he/she would feel about me	1	2	3	4	5
13. I wanted to find out if she/he wanted to be with me	1	2	3	4	5
14. I wanted to see how he/she would react about this	1	2	3	4	5
15. We love(d) one another	1	2	3	4	5
16. We have/had a mutually supportive relationship	1	2	3	4	5

APPENDIX C: QUESTIONNAIRE (continued)

Reasons to tell	Flash Card A				
	Not at all a factor	Somewhat unlikely a factor	Neither likely or unlikely a factor	Somewhat likely a factor	Very likely a factor
17. We have/had a close relationship	1	2	3	4	5
18. I trust(ed) that person	1	2	3	4	5
19. She/he could be of help	1	2	3	4	5
20. That person would be able to provide support	1	2	3	4	5
21. That person would provide me with assistance	1	2	3	4	5
22. We had a lot in common	1	2	3	4	5
23. We both had similar types of experiences	1	2	3	4	5
24. We tended to think alike about things	1	2	3	4	5

16. When you told your _____ (second confidant) about your HIV positive status, how did she/he react? People sometimes have more than one reaction, so please tell me all that seemed true for _____ in terms of his/her first reaction. Would you say that he/she _____:

Reaction	No	Yes
1. Was angry with you	1	2
2. Blamed you for getting the virus	1	2
3. Expressed sympathy	1	2
4. Promised to be there for you	1	2
5. Encouraged you express or talk about your feelings	1	2
6. Was physically violent (slapped/kicked/hit) toward you	1	2

Now, I would like to talk about the support you received from your _____

J. Social Support for Coping with HIV from the second confidant

J1. Does your _____ live with you?

No 01

Yes 02

J2. Do you need help from your _____ in doing regular household or other tasks because of your HIV?

No 01

Yes 02

APPENDIX C: QUESTIONNAIRE (continued)

J3. What kind of support or help do you get from your _____? Does your _____ never, sometimes, or always:

Item	Never	Sometimes	Always
Cook meals for you	1	2	3
Clean house	1	2	3
Help with caregiving	1	2	3
Give you rides to health providers	1	2	3
Accompany you to appointments with your health care providers	1	2	3
Help you to remember your medication	1	2	3
Provide financial assistance	1	2	3

J4. Is receiving emotional help from your _____ important to you in coping with your HIV?

No 01

Yes 02

J5. Does your _____ provide you with any of the following types of emotional help? Does your _____ never, sometimes, or always:

Item	Never	Sometimes	Always
Make you feel valued	1	2	3
Make you feel you belong within your circle of friends and family	1	2	3
Make you feel cared for	1	2	3
Understand your feelings	1	2	3
Help you to keep your spirits up	1	2	3
Make you feel that you have someone on whom you can count on for help	1	2	3

J6. Do you ever feel the need to talk with someone about your HIV?

No 01

Yes 02

J7. How often do you and _____ talk with each other about your HIV? Would you say that you never, sometimes, or frequently talk with _____ about:

Item	Never	Sometimes	Always
Your feelings about being HIV positive	1	2	3
Medical problems that you might have that are related to your HIV	1	2	3
How to tell others about having HIV	1	2	3
Taking your HIV medication	1	2	3
Keeping your medical appointments	1	2	3

APPENDIX C: QUESTIONNAIRE (continued)

J8. Overall, how satisfied are you with the level of support that your _____ gives you?

- | | |
|----------------------------|----|
| Not at all satisfied | 01 |
| Slightly satisfied | 02 |
| Moderately satisfied | 03 |
| Very satisfied | 04 |
| Extremely satisfied | 05 |

4. OTHER SUPPORT SOURCES

Is there anyone who knows that you are HIV positive and has supported you but you have not yet discussed them during this interview?

- | | |
|-----------|-----------------------|
| No | 01, end the interview |
| Yes | 02, continue |

If your answer is ‘yes’, I would like you to list up to 3 persons who are most supportive and what kind of support you get from them.

[Interviewer: For each of the 3 support persons, please write the relationship of the person on the line and the accompanying number in the box below the line. For example, if the participant answers “Mother” as one of the 3 support persons, please write “Mother” on the line and “01” in the box below the line.]

Question	Answer Person 1	Answer Person 2	Answer Person 3																								
<p>K1. Relationship with you:</p> <table style="width: 100%; border-collapse: collapse;"> <tr> <td style="text-align: right;">Mother</td> <td style="text-align: right;">01</td> </tr> <tr> <td style="text-align: right;">Father</td> <td style="text-align: right;">02</td> </tr> <tr> <td style="text-align: right;">Brother</td> <td style="text-align: right;">03</td> </tr> <tr> <td style="text-align: right;">Sister</td> <td style="text-align: right;">04</td> </tr> <tr> <td style="text-align: right;">Current husband</td> <td style="text-align: right;">05</td> </tr> <tr> <td style="text-align: right;">Ex-husband</td> <td style="text-align: right;">06</td> </tr> <tr> <td style="text-align: right;">Boyfriend/sex partner</td> <td style="text-align: right;">07</td> </tr> <tr> <td style="text-align: right;">Other relative</td> <td style="text-align: right;">08</td> </tr> <tr> <td style="text-align: right;">Female Friend</td> <td style="text-align: right;">09</td> </tr> <tr> <td style="text-align: right;">Male Friend</td> <td style="text-align: right;">10</td> </tr> <tr> <td style="text-align: right;">Health care provider</td> <td style="text-align: right;">11</td> </tr> <tr> <td style="text-align: right;">Other Specify_____</td> <td style="text-align: right;">12</td> </tr> </table>	Mother	01	Father	02	Brother	03	Sister	04	Current husband	05	Ex-husband	06	Boyfriend/sex partner	07	Other relative	08	Female Friend	09	Male Friend	10	Health care provider	11	Other Specify_____	12	<div style="border-bottom: 1px solid black; width: 100%; margin-bottom: 5px;"></div> <div style="text-align: center;">(relationship)</div> <div style="border: 1px solid black; width: 50px; height: 40px; margin: 0 auto;"></div>	<div style="border-bottom: 1px solid black; width: 100%; margin-bottom: 5px;"></div> <div style="text-align: center;">(relationship)</div> <div style="border: 1px solid black; width: 50px; height: 40px; margin: 0 auto;"></div>	<div style="border-bottom: 1px solid black; width: 100%; margin-bottom: 5px;"></div> <div style="text-align: center;">(relationship)</div> <div style="border: 1px solid black; width: 50px; height: 40px; margin: 0 auto;"></div>
Mother	01																										
Father	02																										
Brother	03																										
Sister	04																										
Current husband	05																										
Ex-husband	06																										
Boyfriend/sex partner	07																										
Other relative	08																										
Female Friend	09																										
Male Friend	10																										
Health care provider	11																										
Other Specify_____	12																										

APPENDIX C: QUESTIONNAIRE (continued)

Now, I am going to ask you several questions about the support you get from the persons you've listed above.

Interviewer: Please ask each question in reference to each support person and write the answers in the corresponding boxes.

Questions	Answer	Answer	Answer
	Person 1: _____ (relationship)	Person 2: _____ (relationship)	Person 3: _____ (relationship)
K2. Does your _____ currently live with you? No 01 Yes 02	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
K3. How did your _____ find out that you are HIV positive? I told her/him 01 Friend or relative told her/him 02 Doctor told her/him 03 Medical staff told her/him 04 Found medication 05 Other 06 Don't know 97 Decline to answer 98	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
K3. Is your _____ HIV positive? No 01 Yes 02 Don't know 97 Decline to answer 98	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
K4. Do you need help from your _____ in doing regular household or other tasks because of your HIV? No 01 Yes 02	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

APPENDIX C: QUESTIONNAIRE (continued)

K5. What kind of help do you get from your _____? Does your _____ never, sometimes, or always:						
Item	Never	Sometimes	Always			
Cook meals for you	1	2	3			
Clean house	1	2	3			
Help with caregiving	1	2	3			
Give you rides to health providers	1	2	3			
Accompany you to appointments with your health care providers	1	2	3			
Help you to remember your medication	1	2	3			
Provide financial assistance	1	2	3			
K6. Is receiving emotional help from _____ important to you in coping with your HIV? <div style="text-align: right; margin-right: 50px;"> No 01 Yes 02 </div>				<input style="width: 40px; height: 40px;" type="checkbox"/>	<input style="width: 40px; height: 40px;" type="checkbox"/>	<input style="width: 40px; height: 40px;" type="checkbox"/>
K7. Does _____ provide you with any of the following types of emotional help? Does _____ never, sometimes, or always:						
Item	Never	Sometimes	Always			
Make you feel valued	1	2	3			
Make you feel you belong within your circle of friends and family	1	2	3			
Make you feel cared for	1	2	3			
Understand your feelings	1	2	3			
Help you to keep your spirits up	1	2	3			
Make you feel that you have someone on whom you can count on for help	1	2	3			
K8. Do you ever feel the need to talk with your _____ about your HIV? <div style="text-align: right; margin-right: 50px;"> No 01 Yes 02 </div>				<input style="width: 40px; height: 40px;" type="checkbox"/>	<input style="width: 40px; height: 40px;" type="checkbox"/>	<input style="width: 40px; height: 40px;" type="checkbox"/>

APPENDIX C: QUESTIONNAIRE (continued)

K9. How often do you and _____ talk with each other about your HIV? Would you say that you never, sometimes, or frequently talk with _____ about:						
Item	Never	Someti mes	Always			
a. Your feelings about being HIV positive	1	2	3			
b. Medical problems that you might have that are related to your HIV	1	2	3			
c. How to tell others about having HIV	1	2	3			
d. Taking your HIV medication	1	2	3			
K10. Overall, how satisfied are you with the level of support that _____ gives you?						
Not at all satisfied 01				<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Slightly satisfied 02						
Moderately satisfied 03						
Very satisfied 04						
Extremely satisfied 05						

Do you have any questions about the issues we've talked about?

[Thank the respondent for their time and end the interview]

Time Ending Interview: __:__ (AM/PM)

Observation Note:

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