

Psychosocial Factor Influence on Disclosure Behaviors in Those Newly-Diagnosed with HIV  
Under “Treatment for All” in Namibia

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A thesis  
submitted in partial fulfillment of the  
requirements for the degree of  
Master of Public Health  
University of Washington  
2018

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Program Authorized to Offer Degree:

Global Health

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**Abstract**

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**Background:** Namibia has one of the world’s highest HIV prevalence rates. As of 2016, Namibia adopted the World Health Organization (WHO) recommendation that all newly diagnosed HIV-positive individuals begin ART, regardless of CD4 cell count. This new Treatment for All (TfA) approach requires patients to maintain continued engagement in HIV care and high ART adherence to achieve viral suppression. However, research suggests that a TfA approach may amplify existing disclosure barriers in HIV+ adults. This study explores how psychosocial factors influence the disclosure process of those who newly initiated ART under TfA guidelines. Understanding how psychosocial factors influence the disclosure process may help inform disclosure interventions as well as identify PLHIV with avoidance-focused disclosure goals who may need additional support.

**Methods:** Qualitative data on psychosocial influences on disclosure behaviors were collected through semi-structured interviews (n=63) with newly diagnosed adults living with HIV in Namibia. Chaudoir et al’s (2011) framework on The Disclosure Processes Model (DPM) guided qualitative content analysis.

**Findings:** Participants described a range of psychosocial factors including locus of control, support networks, future oriented concerns, and work relationships relating to the DPM’s avoidance and approach goals as well as the disclosure event that influenced the disclosure process.

**Conclusion:** By understanding individual’s attitudes about HIV as well as the context of that individual’s social support system, we can create stronger and more curated messages and programs to support PLHIV disclosure to support systems for better overall health outcomes.

## **Background and Introduction:**

Namibia has one of the world's highest HIV prevalence rates. According to 2016 UNAIDS data, the national adult population prevalence sits at 13.8% with an estimated 217,000 people living with HIV (PLHIV) with 64% of those individuals on antiretroviral therapy (ART)(1, 2). Although the number of new HIV infections has begun to decline, HIV prevalence in Namibia remains high and continues to burden the health care system, fuels new infections and poses serious developmental challenges.

In 2016, the World Health Organization (WHO), made the recommendation that all newly diagnosed HIV-positive individuals begin ART, regardless of CD4 cell count(3). Namibia adopted this new Treatment for All (TfA) approach in its most recent edition of the National Guidelines for Antiretroviral Therapy released in December 2016(4). The hope is to lower the risk of mortality, decrease progression to AIDS, reduce the risk of developing non-AIDS related diseases, and reduce the risk of transmitting HIV to an uninfected partner(3). For TfA to achieve these goals requires patients to maintain continued engagement in HIV care and high ART adherence to achieve viral suppression(3). While lifelong medication adherence can be challenging for anyone, research suggests that a TfA approach may amplify existing adherence and disclosure barriers in HIV+ adults(5-12). Some studies have shown that adherence of HIV positive pregnant women who began ART regardless of CD4 count, an approach commonly referred to as Option B+, is lower than women started on ART because of a low CD4 count(5). Patients initiating ART soon after diagnosis may have less time to gain an understanding of HIV and the importance of actively managing their medication(5-11). These patients have less time to overcome psychosocial barriers and build acceptance of their diagnosis and process their fear of

stigma (12-16). Additionally, they have less time between diagnosis and starting treatment to disclose their HIV+ status to those in their social networks who could potentially support them in their treatment.

Disclosure of HIV status is one of the most complex psychosocial challenges facing PLHIV and yet is a crucial first step in gaining HIV-specific social support. Social support systems may include sexual partners to enable safer sexual choices, to health-care workers to access treatment and care services and to family and community members to gain various forms of support. When disclosure of one's HIV+ status is made to unaccepting individuals, it may create a harmful environment for PLHIV, leading to stigmatizing reactions such as social ostracism, physical harm, or even workplace discrimination(12-14, 16). Conversely, disclosure to a supportive social network has been shown to significantly improve ART adherence. The literature from Sub-Saharan Africa suggests key positive motivators to disclosure include maintaining a positive identity and social role, future-focused life goals/wish to survive, positive patient-provider relationship and experience with ART programs, and high agency/autonomy and self-efficacy(6, 11, 17-26). Additionally, both positive and negative experiences with psychosocial factors, which encompass social, cultural, and environmental influences that affect an individual's or group's psychological health or behavior, impact how PLHIV reach disclosure(27). Psychosocial factors may include both individual and structural factors such as stress, anxiety, depression, hostility, job control, financial control, safety, or the environment alongside other factors which may include relationships, needs and circumstances of PLHIV, support, and fear at the time of disclosure. It is critical to understand how PLHIV reach the decision to disclose and determine factors that influence the overall benefit patients derive from

disclosure. However, in Namibia, there is limited information on how psychosocial factors of patients newly-diagnosed with HIV under TtA guidelines influence the disclosure process.

The Disclosure Processes Model (DPM), as shown in Figure 1, provides a framework to understand and assist in disclosure in order to maximize its overall potential benefits. The DPM provides a theoretical framework describing when and how disclosure is beneficial for PLHIV and includes an array of potential health outcomes. The DPM outlines five major areas relevant to the disclosure process: antecedent goals, the disclosure event itself, and mediating processes and outcomes as well as a feedback loop (18, 19, 28, 29). Antecedent goals, i.e. goals prior to the disclosure event itself, can be approach-oriented (anticipating positive outcomes) or avoidance-oriented (anticipating negative outcomes). Psychosocial factors will mediate these antecedent goals and the disclosure event itself and subsequently influence individual health ARV adherence and sexual risk behavior, psychological distress, fear, self-stigma, and dyadic intimacy. The disclosure process also impacts cultural stigma and community norms towards disclosure, which then feeds back into how individuals newly diagnosed with HIV anticipate the results of disclosure.

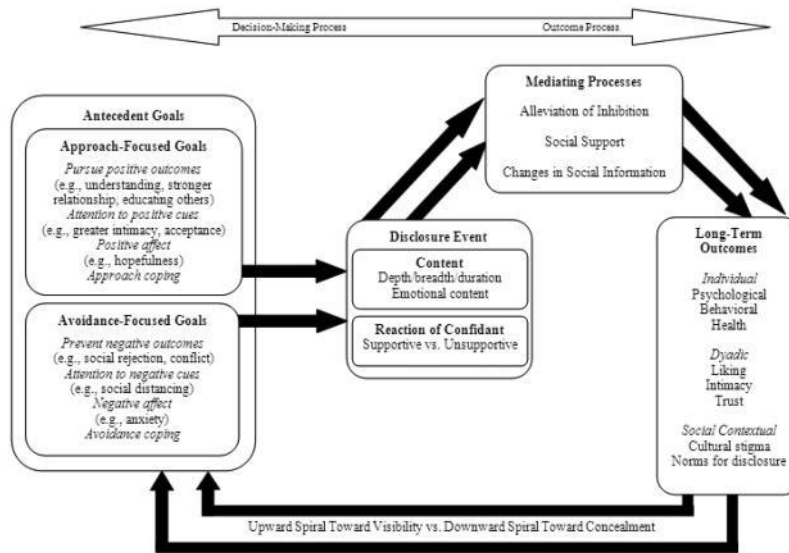


Figure 1: Disclosure Process Model (18, 29)

This study explores how psychosocial factors influence the disclosure process of those newly initiated on ART under TfA guidelines. Understanding how psychosocial factors influence the disclosure process may help inform disclosure interventions as well as identify PLHIV with avoidance-focused disclosure goals who may need additional support.

## Methods

Between July and September of 2017, a semi structured guide was used to conduct in-depth interviews with 63 ART clients in 8 purposively selected MoHSS facilities in the Khomas, Ohangwena, and Zambezi regions. Facilities were chosen on the basis of having been implementing TfA for a minimum of six months as part of the MoHSS TfA pilot. Facilities were located in rural and urban areas and were inclusive of intermediate hospitals (IH), district hospitals (DH), health centres (H/C), and clinics.

Six-to-eight eligible patients at each facility who were attending the clinic the day the interview team was present were interviewed at each site. Interview participants were adults ( $\geq 18$  years old) newly initiated on ART following the implementation of Treatment for All guidelines.

Forty females and twenty-three males were included in the study. Of the 40 female participants 20 were pregnant, and 11 were currently breastfeeding. Health status at ART start included 32 in WHO clinical stage 1-2 with the remaining 31 at WHO clinical stage 3-4. Duration on ART ranged from 1-12 months. Interviews sought to understand the experience of HIV diagnosis followed by immediate referral for ART, the potential barriers and facilitators to HIV disclosure within that TFA context, and the perceived benefits, risks and consequences of disclosing one's HIV status.

### **Data management and analysis**

All interviews were audiotaped and translated (where relevant) and transcribed on-site by the interview teams. All transcripts were coded via an interactive process by a single analyst, using both a priori and inductive coding using Atlas.ti software. The analyst also led one of the interview teams and conducted some of the interviews herself and so was familiar with the transcripts before formal coding began. Transcripts were coded for general thematic content first, and then more specifically to understand the disclosure process. Data analysis focused on how psychosocial factors affect disclosure as well as to capture the experiences of PLHIV to mitigate the barriers and facilitators of disclosure.

### **Ethical Considerations**

Approval to conduct this study was obtained from the University of Washington (UW) Human Subjects Research Division, the U.S. Centers for Disease Control, and the MOHSS Ethical Review Committee. Study staff were trained in interview methodology and informed consent procedures and study details were discussed with members of MOHSS and participating sites. All participants provided written informed consent.

### **Findings**

Participants described a range of psychosocial factors relating to the DPM's avoidance and approach goals as well as the disclosure event.

### **Psychosocial Factors Influencing Avoidance-Focused Goals**

#### *Locus of Control*

Participants commonly described being afraid of being “found out” about their HIV status and ultimately “being forced” to disclose either in the workplace, in the home, or at the clinic instead of processing the potential benefits to disclosure. An older-female said,

*“It’s just that I haven’t gotten to (that place) yet. When I get there, I will tell them. I just haven’t.”*

A young man reported,

*I don’t want other people to see. I don’t want my wife to see or know. I have to hide.”*

One participant revealed he was forced to disclose at work due to not having money to get to the clinic,

*“I don’t have transport money to come to the clinic. I had to tell someone at work so I could come here. I had to tell them so I am not sick.”*

Participants described reasons why they feared other people knowing their status as a lack of understanding of what HIV is, death or poor health outcomes, being fired from work, unfaithfulness in their relationship, disappointment from family members, “being evil” or “cursed”, as well as negative self-judgement. For example, a man spoke of not being able to come to the clinic in fear of his work colleagues finding out his status,

*“There was a time I didn’t come (to the clinic) because of work because I was on duty that day and I cannot tell my boss. I don’t know what he would do.”*

One young woman reported being scared of being “found out” by her father in the clinic,

*“Uhh...besides that fact, there was a point where I thought I would find my dad here since he is an elderly person and he normally comes and takes pills here, there was a time where I thought I would run into him before I told him and I was like that was like why I was dreading the fact of telling him. I don't know how.”*

#### *Lack of confidence in support networks*

Participants vocalized stress, fear and negative mental well-being or self-doubt and described disclosure to potential supports system as a stressful event. Participants cautiously considered to whom to disclose and what benefits of disclosure would hold for them. For example, a 24-year-old male, reported,

*“It took me about two weeks. Before I refused because I was thinking, what are my friends going to say about me and such things. So, it was playing on my mind for about two weeks. Later I decided now I should go get proper information and medicine because after all it's my life and if they are my friends they will support me”*

#### *Future orientated concerns*

When deciding to disclose, participants stressed concerns of judgement as well as being seen in the clinic or at work and in the home and a fear of what that means for their future.

*“Sometimes it is the thought of people, the thought of what other people might think and what my friends may say or who I might run into here, but, yeah. What would they say? Who would they tell? I would lose my friends. I would lose my job.”*

An older man said,

*“I expected them to be more like (pause) to (pause)... how should I put it? A bit too clean to me. To always have gloves on when they touch me or to make me feel like a person with a disease, who wants that?”*

A young woman reported,

*“There was a time that I was actually out and I (pause) no, I was at work and I had to go out and it was time for me to drink my pill. I was actually a bit (pause)... how should I say? Shy to take it out and drink it. I was a bit “what would people think”? What would people ask me? Why are you drinking that? What is that?” And all of that. So yeah.”*

Younger participants reported that they were concerned about how their status would affect having children or finding a new partner and were hesitant to disclose their status because they were concerned they would be judged. Participants also emphasized concerns about the threat of abnonnement in their marriage or partnership. For example,

*“There was even a question that raised in mind, will I ever be able to have kids? And I was like, well, maybe I should scratch out that thought totally. But my younger sister’s friend was pregnant and I found her here, we spoke, and I, she gave birth I think on Wednesday and yesterday she called my sister and I was like, okay, ask her if she was put on another pill or ask her was she stopped from drinking the pills when she got pregnant or when she found out she was pregnant, what happened actually? Or did they treat her differently? Or what? Can I have a baby with being sick and how can I handle it or how can I handle the child to avoid passing it on to my child?”*

A young woman reported,

*“It’s my life and I wanted to tell my partner, that my body is changing and it is not as normal as it used to be. I used to feel ill suddenly and my temperature would just rise drastically, but I didn’t know what was the cause of these feelings and I didn’t want to tell my partner. I couldn’t tell my partner. He would leave me.”*

Other psychosocial factors such as depression or hopelessness were heavily impacted by work environment or family dynamics. For example, one participant revealed,

*“I was shocked. I was tested and I was diagnosed and I was shocked. I was also questioning myself and asking myself how did I get myself into this situation. I wanted to tell my family about my diagnosis. There are certain people in my family that I don’t trust so I had to just find someone that I trust. I don’t know if I do.”*

### **Psychosocial Factors Influencing Approach-Focused Goals**

#### *Locus of Control*

Participants with more positive outlooks on life and experiencing positive psychosocial factors were more likely to disclose their status. Positive attitudes regarding diagnosis were referenced by participants. However, being positive is more than just positive thinking. It involves active coping, self-efficacy, expressing and positively processing HIV diagnosis, finding meaning and purpose in life, and staying connected with spiritual beliefs and with others as well as remaining engaged in life. Positive psychosocial experiences with clinic staff, current partners, and family members influenced optimistic feelings. For example,

*“There have been people who have been living with HIV for twenty years and they are still fine. It’s from them where I motivate myself...knowing they have HIV and are fine. It’s where I gain my strength. It’s from them I know I can tell my boyfriend”*

Participants also reported spirituality as facilitators to disclosure. By finding meaning in life and having an optimistic view of the clinic, participants were able to stay connected to their beliefs and find the motivation to seek out support systems and networks. For example,

*“I just had faith in God that I am going to start the treatment and even I find my neighbor there, it is just a part of life. Even if she is maybe not in that situation, maybe one of her family members are in this category as well.”*

One woman revealed,

*“I mean there was a thought that came to mind after hearing my colleague tried to kill herself, I was thinking like. Okay. But then I decided that it’s not worth it. My life is not worth it. I can try and live healthy and see how it goes. Just ending it is not... You must have faith that it will all be okay.”*

#### *Positive facility counselling experiences facilitated disclosure*

Counselors were reported as important to creating a safe environment where participants felt comfortable vocalizing concerns or questions they had regarding their treatment. Participants said they felt connected to nurse counselors and listened to them about finding support outside of the clinic to help them take their medication and adhere to treatment. Most interviewed patients described their desire to disclose after counseling was due to being treated well by counselors and their ability to feel safe in the clinic. Participants suggested that counseling was a means to receiving better quality care and treatment, and therefore increased the motivation to disclose to support networks.

*“I overcame them after the counseling. They told me that I shouldn’t be worried and that it is not the end of the world and I realized that I am not the only one who is infected and that I should tell my family and friends. They will help me.”*

It was also noted,

*“They told me I must never be thinking about bad stuff or listen to what people have to say.... I can live a long normal life with HIV...I should find people to support me.”*

### *Confidence in network support*

Those who reported they had disclosed to supportive family and friends said that they would help them financially if needed.

*“I cannot hide it from them because if I find myself not having money to come to the clinic, they are the ones to help me. I can't be home without them knowing. They are my parents. They are the ones to assist me if I should fall ill. They also will be the ones to remind me or to ask me what I was told every time I come to the clinic.”*

### *Work relationships*

Some men reported that work was encouraging to disclosure since they traveled for work, they would need to refill medication while away from home and disclosing to other HIV positive men they worked with, aided in fostering a community and motivation.

*“I travel for work and they told me that I need to bring my health passport. Other guys bring them too and we sometimes go to the clinic together. We make sure we drink our medications and we are healthy to do our work.”*

### **Disclosure-Event Effects on Psychosocial Factors**

Disclosure events that elicit more negative responses are more likely to be less beneficial to PLHIV. Participants discussed at length their marital and sexual relationships and how they may impede disclosure decisions. One female stated,

*“I told him that day before I went for testing. When I told him he just said that he is not infected. I don't know now if he went for testing wherever he is but when he comes home he hides his health passport. Every time I ask him, he doesn't answer me. He won't tell me, yes or no.”*

Another young woman said of her disclosure event,

*“I was in a relationship with a South African guy and he, uh, he made a funny statement that his sister had a dream about me and everything and then I decided that I, okay, I am going to go to the pharmacy and buy an HIV test. (pause) I did (pause). I tested myself at work and I found out I was positive and I informed him and I informed him, okay, we should both get tested. So, he opted to go to his private doctor, which I can't afford to go to a private doctor, I don't know if he ever went. We don't talk anymore.”*

The more positive the psychosocial factor experience was, the more likely disclosure will be beneficial. A younger woman spoke of her will to live as the reason to disclose,

*“I was actually standing outside and I was thinking should I go home and just forget about this or go home and just ignore it but then I thought, if I ignore it it's going to get worse and I am going to get more ill by the day. So, I decided, okay let me just do it. To just do it even if I see someone I know and just okay, it happens, I came and I went into the room and I spoke to the ladies and they asked a lot of questions and then I came out and I was like, okay, how do I tell my family? That's the biggest burden that I was carrying. I was like, ugh. I didn't actually want to tell my mom. My sister forced me. You should, you should, you should. Your mom should know about this. She's your mom, she's going to take care of you. So, I was like, okay, I will tell her.”*

Another participant revealed,

*“I told myself that there are a lot of people who are infected and I am not the only one and it is not the end of my life. It shouldn't be a burden to my life. I felt disappointed at the beginning but after the counseling I was fine. I felt at ease. I wasn't thinking about it over a long period of time, when I left the hospital I already felt at ease so when I got*

*home I told my parents. I told my parents that I was at the clinic and I was tested positive. I just told them openly and they accepted my outcome.”*

Participants also emphasized strong partner relationships as justification to the disclosure event. Relationships were shown to encourage active-coping, help to motivate and find meaning in life as well as create positive life outlooks.

*“I told him after I was tested before we went home that I am diagnosed. He told me okay, now that you are diagnosed you should just take your medication and you shouldn't have any doubts. It will be okay. I am here.”*

Another woman reported,

*“There's no way I was going to hide because those people I told are close to me and I stay with my boyfriend. He is the one who can see when I'm sick. He is the one to help me.”*

## **Discussion**

Psychosocial factors influence avoidance and approach-focused goals to the HIV disclosure process of PLHIV under TfA in Namibia. Positive and negative psychosocial factors shape disclosure process which may encourage future-focused life goals, a will to survive with a HIV+ diagnosis, create or maintain supportive social networks, foster positive patient-provider relationships, and high self-efficacy, spiritual beliefs and optimism.

The Disclosure Processes Model can be used to understand psychosocial influences of either avoidance or approach-focused goals and the resulting negative or positive experiences. Our interviews show how locus of control, self-efficacy and autonomy contribute to disclosure to a supportive community. Participants who were approach-oriented stated they felt confident in their ability to confide in peers because they were sharing an experience or knew someone with a

shared experienced. Participants who described actively coping with their diagnosis, being optimistic, or having faith saw disclosure as an opportunity for engaging in life, removing fear and stigma of their diagnosis, resulting in a stronger sense of self-worth. Alternatively, participants who reported forced disclosure described intensified feelings of stigma and fear and avoidance-oriented goals.

Current TfA literature discusses many benefits to disclosure, and says PLHIV may only disclose if they are engaging in approach-focused goals and believe there is a direct benefit to disclosure(4, 30, 31). We found this in our own study as well. Participants revealed if they felt supported by their partner, specifically during a disclosure event, they would disclose to other members of their support systems such as other family or friends. However, participants discussed they would be less likely to disclose when they have strong feelings against disclosure and perceive potential high levels of stigma such as an immediate negative disclosure event to their partner.

These findings provide evidence in support of the complexity of the HIV disclosure process among those recently diagnosed under TfA. The study sheds light on the manner in which PLHIV in Namibia may choose to disclose based on overarching approach or avoidance-focused goals as well as how positive or negative experiences with psychosocial factors influence this disclosure process. Approach vs. avoidance goals are influenced by observable differences between positive and negative psychosocial experiences.

### **Conclusion and Limitations**

Avoidance and approach-focused goals impact the disclosure process to sexual partners, to health-care workers, and to family and community members. How people experience different psychosocial factors directly impacts if, when, and why someone decides to disclose

their status to potential support systems and whether disclosure is beneficial to their overall well-being and health.

Limitations to this study include having no comparative data about the disclosure process from individuals diagnosed in a non-TfA context during our same study period. However, since TfA approaches are rapidly becoming the standard globally, information from our study population may be informative for other ministries of health in designing interventions to aid the disclosure process. By understanding individual's attitudes about HIV as well as the context of that individual's social support system, we can create stronger and more curated messages and programs to support PLHIV disclosure to support systems for better overall health outcomes.

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