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# The Contextual Environmental Factors Shaping Disclosure of HIV Status across Populations Groups in Sub-Saharan Africa

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Additional information is available at the end of the chapter

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## Abstract

Disclosure of HIV-positive status is a public health intervention strategy to reduce HIV infections and improve HIV treatment and care. While disclosure occurs for different reasons for different population groups, the focus of studies has been on programmatic concerns such as disclosure to sexual partners to prevent HIV transmission or to prevent mother to child transmission of HIV. However, HIV disclosure occurs within a broad range of social and cultural contexts. Disclosure is facilitated or deterred by relationships at play within the social context beyond just the need for prevention of HIV. This chapter will highlight how the construction of HIV as an incurable, fatal, and contagious disease, stigma and discrimination, cultural and societal norms, secrecy, and the contextual environment influence HIV disclosure across different population groups. The chapter further demonstrated that stigma is the threat that connects the contextual environment and negatively influences disclosure across different population groups. This chapter is based on disclosure studies conducted in South Africa and extensive findings from disclosure research from sub-Saharan Africa. The data comprise qualitative studies on disclosing HIV to perinatally infected children by caregivers, the parental disclosure of own HIV-positive status to HIV-negative children, disclosure to sexual partners, disclosure to parents, and adolescent self-disclosure to romantic partners and friends.

**Keywords:** disclosure, stigma, secrecy, people living with HIV, cultural context, Southern Africa

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## 1. Introduction

Disclosure has been an area of concern since the beginning of the HIV epidemic and the focus of research for decades. Extensive research has been done to explore the different types of

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disclosure, the process of disclosure, and patterns of disclosure. HIV disclosure includes an array of behaviors associated with the practice in which HIV-infected persons disclose their HIV serostatus to their partners, family members, or friends; or when a child is informed of her/his own HIV status [1]. Disclosure of HIV-positive serostatus is an integral component of public health prevention and treatment interventions and has been associated with many potential benefits. To sexual partners, disclosure occurs to enable safer sexual choices, to access prevention of mother to child transmission (PMTCT) of HIV programs, to gain emotional and financial support, and to protect the partner from HIV infection. To family members, disclosure occurs to gain various forms of support such as support for treatment adherence, emotional support, and protecting others from HIV. Lastly, to healthcare workers, disclosure occurs to access treatment and care services [2]. Although it is accepted that disclosure is associated with many beneficial outcomes such as increased social support, improved treatment adherence, decreased experienced stigma, greater well-being, and healthier behaviors. HIV disclosure also carries important risks evident by low disclosure rates among different population groups in sub-Saharan Africa (SSA).

The emphasis of most disclosure studies has been on the individual factors affecting low disclosure rates of the different population groups, while disclosure of HIV-positive serostatus is a complex phenomenon in which social, economic, political, cultural, and environmental aspects are interrelated. Disclosure is complicated by the close and complex relationship between disclosure, stigma, and culture which impacts on each other [3]. Furthermore, HIV disclosure is a complex and difficult personal matter that entails communication about a potentially life threatening, stigmatized, and transmissible infection [4]. The attempt to normalize nondisclosure by people affected by and infected with HIV, makes disclosure even more complex, given that the desire to maintain silence about an HIV test persists in many societies. In fact, there seems to be some level of normalcy when people living with HIV (PLHIV) do not talk about their illness when they anticipate and or experience stigma and discrimination [2, 5]. The normalization of silence is also shaped by the general understanding and evidence that disclosure is not always beneficial, positive, or advantageous to the individual. In fact, it is argued that HIV disclosure carries with it higher levels of risk and vulnerability [6], as the individual who discloses can never predict the response or reaction elicited by the disclosure.

The perception of HIV-related stigma shapes people's concerns about what might happen if they disclose. Consequently, people scan their social environment before they decide whether or not they should disclose their HIV status, and disclosure is deterred if individuals live in communities where HIV stigma is present [7, 8]. Steward et al. [9] argue that PLHIV do not need to encounter actual enactments of stigma to fear its social consequences, but being acutely aware of the potential for stigma or having witnessed stigmatization and discrimination against PLHIV raises the fear of stigma and shape their patterns of disclosure. This fear of stigma leads to people affected and infected by HIV adopting coping strategies such as disclosure avoidance or secrecy and silence to protect self from stigma [10].

A general assumption among researchers and policy makers working in the field of HIV prevention was that the availability of antiretroviral treatment (ART) and the beneficial outcomes

of ART would increase the rates of disclosure in SSA. However, the low rates of HIV disclosure are an indication that the availability and increased access to ART in SSA are not changing the underlying structural causes of stigma contributing to the reluctance of people to disclose. Extensive research in SSA indicates that HIV-stigma is continuing to deter disclosure [11, 12]. Research indicates that disclosing one's HIV status carries an extraordinary degree of exposure [5], and that by disclosing, the person no longer struggles with concealing a secret, but may now be exposed to stigma [13]. The reluctance of individuals to disclose their HIV status is despite evidence that taking ART assist PLHIV to return to a healthy state by halting or reversing the progression of the diseases thereby hiding the physical and visible stigmatizing attributes of HIV.

Research suggests that the process of normalizing HIV through ART is socially complex, slow, and uneven in many communities in SSA [5, 14, 15]. Since the wide access to ART has not succeeded in increasing the rates of disclosure, there is a need to revisit how disclosure is conceptualized by individuals infected and affected by HIV in their contextual environments under which disclosure is more or less likely to occur.

## **2. Research on disclosure across populations**

While disclosure occurs for different reasons for different population groups, the focus of studies has been on the reasons for disclosure and nondisclosure for the individuals. The chapter will use empirical data to demonstrate that disclosure is not driven by behavior only but by the contextual environment within which disclosure should occur or occurs. The chapter also uses findings from qualitative research conducted from 2009 to 2013 in South Africa to demonstrate how the construction of HIV, stigma and discrimination, secrecy, cultural norms, and the contextual environment influence HIV disclosure across different population groups [16–21].

The chapter will further demonstrate that the contextual environment is comparable across population groups, and that stigma is a constant factor which influences the social context of all population groups and a key factor in the reluctance of people affected and infected with HIV to disclose.

### **2.1. Study design and population**

This chapter reports on the findings of four qualitative studies. The study design employed for three of the studies was qualitative explorative, and the fourth study used grounded theory design. The study participants included caregivers of perinatally infected children aged 6–13 years, HIV-positive parents of negative children aged 7–18 years, HIV-infected postnatal women in PMTCT program, and perinatally infected adolescents aged 12–18 years.

### **2.2. Study settings**

All the studies were conducted in primary health facilities (PHC) and ART clinics of four hospitals in Mpumalanga and Gauteng provinces, South Africa. The four ART clinics were based

in three community hospitals and one tertiary hospital and 34 health facilities providing ART services to adults and children living with HIV through the nurse-initiated and managed antiretroviral treatment initiative. The health facilities in Mpumalanga province were located in the rural subdistricts of Nkangala district, whereas the Gauteng province facilities were located in urban Tshwane district.

### **2.3. Data collection**

The studies used focus group discussions (FGDs) and in-depth interviews (IDIs) to collect data with purposely selected participants for all the studies. The investigators (author as a principal investigator and a coinvestigator), Master of Public Health students and research assistants conducted the interviews. All interviews were conducted in local languages.

### **2.4. Data analysis**

Data from three of the studies were analyzed using thematic analysis of the verbatim transcribed interviews. NVivo version 10, qualitative data analysis software, was used for coding. All the analyses were conducted either by the author or under the direct supervision of the author. The grounded theory study was analyzed by the author using constant comparison analysis.

### **2.5. Ethics**

All the studies received ethical clearance from Medunsa Campus Research and Ethics Committee of the University of Limpopo; the author was affiliated with the institution at the time of the conduct of the studies. Permissions to conduct the studies were obtained from relevant provincial, district, and facility authorities of the two provinces. Written informed consent was obtained from all the participants who could legally consent, and assent was obtained from adolescents who were below 18 years of age. Participation for all the participants was voluntary, and privacy and confidentiality were safeguarded.

## **3. Disclosing a child's HIV status**

A grounded theory study was conducted to explore how a sample of caregivers of children receiving ART view and experience HIV disclosure to perinatal infected children. Nine FGDs were conducted with 52 caregivers of children between 6 and 13 years. Data were collected between November 2009 and March 2010. Four main themes emerged from the data: thoughts of death and dying, the influence of media, fear of discrimination, and secrecy illustrate how the contextual environment is influencing disclosure and nondisclosure to infected children.

Caregivers delayed disclosure to children because they believe that their children would live in fear of death and dying. HIV disclosure to children was also influenced by the fear of stigma that the caregivers perceived to be present in their communities, and they feared that the children would be discriminated, mocked, teased, and socially rejected.

*The thing is..., whenever you mention HIV, they know that AIDS kills, so..., when you tell her, she will know that she is going to die. That is what we are afraid of..., because the child will live thinking that she is going to die. Isn't it we hear that AIDS kills..., that when you have AIDS, you die? When you tell the child about it she will think she is dying (37-year-old mother of a 6-year-old).*

*I am afraid it will be known by everyone in my neighborhood and they will start saying "we don't want to play with this one he is HIV positive; he will infect us" (36-year-old mother of an 11-year-old).*

Nondisclosed caregivers maintained silence to protect their children from stigma, discrimination, mockery, and social rejection, while disclosed caregivers kept the child's diagnosis secret from families and neighbors. The fear that the child would not keep the secret but would tell other children at school and in the neighborhood that he/she has HIV and subject the family to stigmatization featured strongly as a reason for delaying disclosure to infected children.

*When I told him I said this is your secret because I am afraid of stigma, I told him it's only the family that knows because I see the way other people lack knowledge about this thing [HIV]. I am afraid of rejection (32-year-old mother of a 9-year-old).*

*We didn't tell him to talk or not to talk, but the way I see it, he does not talk, I wouldn't like him to talk (24-year-old brother of an 8-year-old).*

#### 4. Disclosing parental status to children

Focus group interviews were conducted to explore the disclosure of parent's own HIV-positive status to HIV-negative children accessing ART from an academic hospital in South Africa. Six FGDs were conducted between November 2010 and January 2011 with 47 HIV-positive parents of children aged between 7 and 18 years. The data present four main themes fear of death and dying, the influence of media, fear of discrimination, and secrecy to highlight the social context influencing disclosure of parental HIV status to children.

Parental disclosure occurs within an environment where children think that AIDS kills and the thoughts of fear of death and dying characterized the discussions of disclosure of parent's HIV status to children. Parents delayed disclosure because they believed that children believe that AIDS kills and would be concerned that their parents may die too.

*Children know that people infected with HIV die, you become afraid to tell because the child will say "my mother is going to die" so you become afraid to tell (Mother of 2 children).*

*I am scared that he will feel miserable and maybe think my mother is dying, my father is dead, my mother is also going to die..., so who are we going to be left with..., what is going to happen? (Widowed mother of 2 children).*

Parents perceived the television and media as negatively influencing children's perceptions of HIV-positive people. They were concerned that media portrays HIV as a debilitating, fatal disease. This created fear for parental disclosure of HIV status to children.

*My child watches HIV-related drama on TV, many of these dramas show that a person who is HIV positive end up dying. That thing is the one that makes me afraid to tell my child. That is the reason why I am afraid to tell (Father of 3 children).*



Fear of stigma and discrimination was one of the main reasons parents delayed HIV status disclosure to children. They had fears that the child may not be able to keep the parent's HIV status secret and were concerned that the family will be subjected to stigma, discrimination, and isolation.

*The reason for not telling my child is that I have one child who is 7 years old. It is good and not good to tell taking into consideration the child's age and the stigma surrounding this disease (Mother of 1 child).*

*My reason for not telling is because a child does not have a secret, we have not accepted this disease as a community. Because my child cannot keep a secret, you are going to see people looking down at me (Father of 1 child).*

As a result of stigma and discrimination, parents went to considerable lengths to keep their HIV-positive status secret from their children, family members, and community members. Disclosed parents instructed their children to keep the disclosure secret and even when parents did not give their children instructions not to tell other people, they believed that their children understood the nature of the disease and knew that they would not tell people outside the family.

*Eish..., you know, this child, if you tell him, he is going to tell his friends that my father is going to die; he is having AIDS (Father of 3 children).*

*At seventeen, she knows that it is a family secret and then if you tell she will never talk (Single mother of 3 children).*

## 5. Disclosure to sexual partner

The study used FGDs to explore HIV disclosure to sexual partners and significant family members among HIV-positive postnatal women enrolled in a PMTCT program. FGDs were conducted with 25 women aged between 18 and 40 years between November 2010 and January 2011. Three main themes stigma and rejection, protecting the HIV status, and fear of violence highlight the social context influencing disclosure to sexual partners.

The most common reasons for nondisclosure to family members were fear of social rejection and discrimination. Women were fearful of disclosure because they felt that they will be rejected by their family. They further associated disclosure to sexual partners to the risks of discrimination, abandonment, and rejection.

*My mother has serious problems with HIV-positive people (27yrs single mother).*

*After I had tested HIV positive, I asked my husband to get tested too, and he was HIV negative. Since that day he never came back home, he has another woman he is staying with now (43yrs married woman).*

*I told him that I was pregnant and HIV positive, he was happy that I was pregnant, but the issue of me being HIV positive, he did not take it so well. It was the last time I saw him, he left (31yrs single mother).*

Concealing the HIV status was commonly used as a strategy for protecting self from stigma and rejection. However, participating in PMTCT subjected women to scrutiny and questioning and the women devised strategies to continue hiding their HIV status from partners, families, and the community.

*My grandmother asked me why I was not breastfeeding my baby and I told her that I was having problems with my breasts and I cannot breastfeed (30yrs single mother).*

*With my tablets, immediately after collecting them from the clinic, I empty them into sachets, and I throw away the ARVs bottles so that if somebody finds me drinking my ART medication, they would not know what I am taking (26yrs single mother).*

The women who did not disclose their HIV-positive status to their sexual partners found disclosure difficult. They were fearful that their partners would react with violence to the disclosure or accuse them of being responsible for the infection.

*The main thing that is worrying me is how he is going to feel when I tell him. I'm scared to tell him because he is one person that will want to tell everybody about my status in his family that I'm the one who gave it [HIV] to him (24yrs single mother).*

## 6. Adolescents onward self-disclosure to others

In-depth interviews were conducted with 37 perinatally infected adolescents between December 2012 and July 2013. The study explored how perinatally infected adolescents experienced living with HIV and examined their perceptions and experiences about disclosure and onward self-disclosure to friends, romantic partners, and others. Three themes reaction to knowing HIV diagnosis, fear of stigma and discrimination, and secrecy illustrate the contextual environment within which adolescents receive disclosure and disclose.

Adolescents experienced both positive and negative effects of disclosure. Some described the disclosure event as extremely shocking and hurtful, and some felt like they were dying. They could not figure out how they could have been infected if they did not engage in sexual activities and expressed ambivalent feelings of self-blame.

*When I discovered about my HIV status, I did not feel good at all. You think about a lot of things. You think that you no longer have a life. You feel that people can see that you are HIV positive (Male participant; 17yrs).*

*I was very shattered, and I asked myself what I did before God that I should be infected with HIV (Male participant; 17yrs).*

Adolescents were aware of the secret nature of their HIV diagnosis, and they considered their HIV diagnosis a secret. Fear of being gossiped about and stigmatized was an important consideration for keeping their HIV status secret.

*My status is my secret and will remain my secret until I am older. It is a secret; the only people who need to know are your family (Male participation, 17yrs).*

*You must only tell your family members who will not tell other people outside because others are gossipers and will tell other people that this child is HIV positive (Female participant, 14yrs).*

Disclosure to friends resulted in stigmatization for some of the adolescents who felt the need to disclose to friends. The subsequent experience of stigma led to secrecy and emotional trauma for the adolescents.



*I did not know whom to tell, my mother was always crying, always under stress, and I did not know whom to tell. I told myself that I have to break the silence once and for all, then I told my friends, and they started isolating me (Female participation, 14yrs).*

*I told my friend, and after I had told him, he told others; whenever I pass them, they bothered me (Male participation; 15yrs).*

Adolescents expressed a strong message that their HIV status was truly their secret and expressed anxiety at how difficult disclosure would be. They also feared that their romantic partners and friends would react in a negative way to disclosure.

*It will be too painful to me to tell my friends because they will perceive me differently (Female participant; 12yrs).*

*If I tell him, he will leave me (Female participant; 18yr).*

*I don't want them judging me, and I am afraid that my best friend will refuse to play with me (Male participation; 14yrs).*

## 7. Environmental contextual factors shaping disclosure

### 7.1. Construction of HIV

HIV testing and disclosure are influenced by cultural and social contexts and to a greater extent by the understandings of HIV and AIDS which are grounded in broader understandings of the long-term illness, death, and social danger [4, 22]. From the beginning of the HIV epidemic, HIV was conceptualized as highly stigmatizing, incurable, fatal, contagious, a threat to the life of others, physically degenerative and disfiguring, and associated with a painful or anesthetic death [23]. Many decades after the first cases of HIV and AIDS, people continue to perceive HIV and AIDs as meaning death and dying in many societies in SSA. People perceive AIDS as a deadly disease and often make no distinction between HIV and AIDS. Having HIV and AIDS is associated with being sick and approaching death and often people are afraid to test while HIV-positive people see no reasons for disclosure from the anticipation of severe stigma [5, 22, 24–27].

Earlier arguments about the construction of HIV/AIDS as meaning death and dying came from the knowledge that in African settings where ART was not readily available, HIV infection was a death sentence [28]. It was therefore anticipated that with the advent of ART the context of stigmatization due to fear of imminent death might be changing. However, despite the increased access to ART and the positive outcomes of treatment, people continue to perceive HIV as signaling death and dying. Jürgensen et al. argue that the memories of AIDS are embedded in narratives and experiences of the death of people and have been imprinted in people's minds [24].

The fear of death and dying is also evident in the way HIV is constructed by perinatally infected children. HIV is primarily constructed in relation to a language of sickness even when children are on ART and are relatively healthy. Perinatal infected children, who started ART at an early age, have no experience of life pre-HIV [14]. Therefore, their construction of

HIV is influenced by that of the adults whose context of HIV is that of a debilitating illness. Daniel points out that in the case of children, adults ignore to emphasize the positive health that people on ART enjoy. As a consequence, children associate HIV with illness and weakness and horror stories about the physical appearance of other people living with HIV [14, 29]. While this negative view of HIV might have been instilled by the adults who care for them and the society as a whole, Domek argues that for some of the children the association of AIDS with death and dying is real. As some of the children have been exposed to the devastating effects of HIV and had seen their parents or other significant family members die [30].

The first public health prevention campaigns perpetuated negative perceptions and heightened the fear of HIV/AIDS. The original billboards used in HIV/AIDS awareness campaigns depicted HIV/AIDS as debilitating, frightening, and fatal disease, by focusing on negative images of sick, dying, and disfigured persons. The portrayal of HIV as a grossly disfiguring disease resulted in individuals relating an HIV-positive test to a death sentence [31–33]. Research indicates that people continue to have ambiguous feelings about physical contact with HIV-positive people and that HIV stigma is still unintentionally reinforced by campaigns addressing HIV/AIDS [34].

Given the fact that the levels of HIV/AIDS-related knowledge are often inversely correlated with stigma [35], it was anticipated that providing people with factual information about HIV/AIDS would lead to stigma reduction in high HIV prevalence settings [36]. However, stigma lingers on; current research from the Democratic Republic of the Congo shows that the fear of HIV/AIDS prompted people to avoid and stigmatize PLHIV through the use of derogatory labels used to portray PLHIV. Labels commonly used, described PLHIV as walking corpses, dangers to others, or people deserving to die before others get infected. Being labeled made PLHIV suffer in silence and afraid to disclose their status [37].

## 7.2. Contextual environment

HIV disclosure occurs within a broad range of social and cultural contexts that influence the way individuals infected with HIV and affected by HIV perceive risks, the way they make decisions to take or not to take an HIV test, and the way disclosure takes place [4]. The contextual environment comprises the setting and potential contextual factors under which disclosure is more or less likely to occur. HIV-positive individuals, their families, communities, and their sociocultural and political norms constitute this environment [38]. Bailey and Darak refer to the contextual environment as spaces of disclosure and discrimination and point out that disclosure is influenced by spaces of disclosure which ranges from the clinic or hospital, spouses, family members, relatives, and others [39]. While Hardon et al. identified five social spaces that are considered to shape disclosure practices which include international recommendations, household and family settings, couple relationships, parental relationships, and patient-health worker relationships [40]. According to Bailey and Darak [39], these spaces of disclosure are also spaces of discrimination.

Being able to disclose safely within one space or social environment has been shown to increase disclosure rates and enable people to manage HIV stigma [2, 41]. However, the social contexts influence disclosure in a positive and negative way, and the social relations and

family dynamics within the spaces of disclosure play a fundamental role in the decision individuals take to disclose or not disclose. Extensive research shows that stigma is often perpetrated within the family and interpersonal space of marriage. Women, in particular, face unique barriers when disclosing within the marital relationship or to sexual partners in the context of high levels of HIV stigma [36, 42–44]. In many settings in the SSA, the risk of being discriminated and rejected is higher on women because more women get tested for HIV and the burden of disclosing is often on them [45].

The importance of and role of cultural context in the practice of HIV disclosure has been reported upon extensively in research. Cultural values affect decisions on HIV disclosure and different cultural contexts shape the disclosure patterns of individuals, families, and communities [1, 43, 46]. HIV is a socially unacceptable disease and results in the community discriminating against an individual who is perceived to have been infected through their lifestyle and personal behavior [6, 47]. HIV is associated with morally disapproved behavior, and contracting HIV is viewed as the responsibility of the individual, exposing people to blame and judgment [23]. Cultural norms continue to play a significant role in the blame-related stigma and shame associated with HIV/AIDS in many communities in SSA [10, 48]. Community beliefs and societal norms also perpetuate gender inequality, further influencing the social, cultural, and personal spaces for disclosure for women. These shared norms influence a woman's decision regarding HIV disclosure thus shaping HIV and disclosure communication within interpersonal space of marriage and intimate relationships [49].

HIV disclosure to infected children is influenced to a greater extent by the cultural and social contexts in the community [4, 38]. The context of disclosure of HIV status to perinatally infected children is fraught with complexities that relate to the social, familial, and cultural environment of the child in which caregivers are reluctant to discuss the diagnosis with their HIV-infected child [50, 51]. It is argued that parental HIV disclosure to children cannot be expected under circumstances where most PLHIV find it hard to disclose to significant adults such as spouse or partners and family members [52].

### 7.3. Stigma and HIV

Stigma has been a component of HIV/AIDS since the onset of the pandemic. Stigma compromises AIDS responses and is increasingly regarded as one of the key drivers of the spread of HIV in sub-Saharan Africa. The perception of stigma or the fear of the consequences of stigma prevents people from adopting preventive behavior, getting tested, disclosing their serostatus, accessing treatment and care, and adherence to medication [24, 33, 36, 53]. Alonzo and Reynolds defined stigma as “a powerful discrediting and tainting social label that radically changes the way individuals view themselves and are viewed as persons” [23]. The definition by Parker and Aggleton, describe stigma and stigmatization as being shaped by structures of power and culture and a result of the consequences of collective action by groups rather than that of individual behavior [53]. While HIV stigma is defined as socially shared knowledge about the devalued status of PLHIV [9].

Since HIV is a socially unacceptable disease, it is a highly stigmatized condition compared to many other chronic conditions. HIV stigmatization is not only driven by the physical and

visible attributes of an HIV-positive person but by social and cultural processes rooted in communities [27, 47, 54]. HIV stigmatization can include avoidance, exclusion, rejection, isolation, violence, service denial, physical distance, awkward social interaction, and blaming [55]. Nonetheless, the fear of gossip is pronounced as a primary form of HIV stigma throughout SSA [5].

#### **7.4. Stigma and disclosure**

HIV stigma affects and is affected by HIV disclosure, while high stigma levels severely hamper disclosure rates and results in silence and secrecy [45], disclosure can lead to stigmatization. Stigmatization is considered a significant barrier to HIV disclosure because HIV disclosure may be deterred if individuals live in communities where HIV stigma is present. The fear of stigma discourages disclosure because PLHIV are more likely to disclose in low-stigma contexts where they expect fewer negative consequences [6, 7, 43, 56].

#### **7.5. Stigma, ART and disclosure**

The increasing availability of ART in high prevalence settings did not necessarily reduce stigma and discrimination as anticipated. Extensive research indicates that stigma persists among people on ART and significantly impacts their ability to access treatment and disclose their HIV serostatus [12, 15, 24]. Earlier research on HIV stigma assumed that the increased uptake of ART in many settings in sub-Saharan Africa would reduce some of the stigmatizing characteristics of HIV as disease progression is halted or reversed and PLHIV look healthy. To a lesser extent, ART has made it easier for people to disclose to a closed network particularly within the family setting [5]. However, people still fear, anticipate, and experience stigma from others because ART has not been able to change the underlying causes of stigma, particularly, the moral discourses that judge and blame women and men for contracting HIV [12]. Concerns and fear of being stigmatized are also enduring because HIV stigmatization is not only driven by the physical and visible attributes of an HIV-positive person but also by the underlying structural causes of stigma which ART cannot eliminate [52].

Structural stigma refers to the ways in which societal ideologies and institutions perpetuate or exacerbate a stigmatized status [12]. While structural discrimination relates to accumulated institutional practices that work to the disadvantage of stigmatized groups and can operate in the absence of individual prejudice and discrimination [57]. Research suggests that stigma may be increasing at the individual level for people on ART. It is argued that attending an HIV clinic and adhering to ART medication draw attention to HIV-positive people, making their HIV-positive status visible because of taking ART and regular clinical visits and increase HIV stigma [15, 58].

#### **7.6. Secrecy and silence**

Secrecy and silence have characterized the HIV/AIDS epidemic in many societies in sub-Saharan Africa. The perceptions of HIV as a stigmatizing and deadly and contagious disease and the fear of stigma often compels PLWHI people affected by HIV to adopt secrecy and silence as a strategy to manage the HIV stigma [5, 10, 12, 25]. Secrecy is defined as any action



taken to attempt to conceal the distinguishing marks that would categorize one in a stigmatized group [59, 60]. In the case of HIV, PLHIV conceal HIV-positive status, clinical signs, ongoing treatment, and visits to the treatment center [61].

Secrecy may be used as a strategic tactic to avoid losing control to others as to how they view one [62]. In these situations, silence is used as a strategy of protecting self and to live as normal a life as possible in social contexts where disclosure would have adverse outcomes [26]. Though the focus of research on the use of silence as a strategy is on individuals, Cohen [63] refers to cultural silence as a strategy that is adopted by the whole community or society. One of the reasons for silence at the cultural level is that the group or the community keeps silent about matters which are based on deep-seated cultural taboos whose open discussion would threaten its self-image. Cultural silence explains the normalization of secrecy and silence around the HIV status among population groups across societies.

Secrecy and silence are also used by caregivers of perinatally infected children to protect the children from discrimination [50, 51, 64]. In SSA, culture is also used to explain silence, particularly in the case of children. Adults use cultural silence as an excuse not to communicate to children by saying that “in our culture, we don't talk to children about death they are too young to understand” [29]. The same argument is used to conceal the HIV diagnosis to perinatally infected children by saying the child is too young to know and understand HIV. As a consequence of the secret nature of HIV and the wide acceptance and adoption of cultural silence, children infected with HIV mimic the behavior of the adults around them. Research has shown that children conceal their HIV diagnosis from friends and people outside of their family network as they have seen their caregivers do and as their caregivers have taught them [29, 41, 65].

However, the use of silence or secrecy as a coping strategy has disadvantages; it can be expensive forcing PLHIV to travel far to access ART. It can also reinforce stigma by not challenging it and fuel gossip and blame. Furthermore, silence can inhibit potential social support, compel PLHIV to conceal medicines, and can lead to death and continued HIV transmission [2, 5, 66, 67]. In the case of children affected by HIV, silence undermines their competence, self-worth, confidence, self-esteem, and increases their anxieties [41].

## 8. Conclusion

The four case studies highlight that undeniably, disclosure of HIV status across different population groups occurs within the social contexts of thoughts of death and dying, the influence of television, unjust discrimination, and a need for secrecy and silence. Within these contexts, individuals manage the disclosure in such a way as to attempt to keep the situation as normal as possible.

The construction of HIV as signaling a death sentence influence disclosing the child's HIV-positive status, disclosing parental status to HIV-negative children, and disclosing HIV-positive status to family, particularly to elderly parents. The fear of death and dying remains a barrier for caregivers who continue to delay disclosure to perinatally infected children and



parental self-disclosure of HIV-positive status to HIV-negative children. The fear of death and dying is intricately linked to the fear-based messaging used on TV campaigns designed to create HIV/AIDS awareness in South Africa. When HIV is perceived as meaning death and dying, disclosure is delayed despite parents and children receiving ART for an extended duration of time and experiencing the positive gains of ART medication.

The construction of HIV as death and dying also influenced the perceptions of perinatally infected adolescents about disclosure significantly. Perinatally infected adolescents experienced receiving disclosure of their HIV diagnosis as painful and traumatic and described their HIV diagnosis as a death sentence.

Fear of death and dying also deterred postnatal women from disclosing their HIV-positive status to their elderly parents. They also described their HIV diagnosis as a death sentence and perceived their parents as too old and frail to deal with the death sentence that their child had just received.

HIV disclosure across the different population groups was surrounded by secrecy and silence. Secrecy was used to a larger extent by caregivers of perinatally infected children and HIV-positive parents to protect children from harmful emotional consequences of disclosure such as fear of death and dying and stigma and discrimination. Postnatal HIV-positive women also used secrecy to protect their HIV status from their family member, partners, and the community as a whole. Caregivers of perinatally infected children, HIV-positive parents, and HIV-positive postnatal women devoted considerable energy to manipulate their social and contextual environments to conceal the HIV status for as long as possible. They commonly substituted HIV for socially accepted diseases and used false names to describe their illness, used various strategies to hide ART medication, or rescheduled the time for taking ART medication.

Perinatally infected children subsequently mimic the behavior of the adult caregivers around them and also conceal their HIV diagnosis. Perinatally infected adolescents argue that their HIV status is their secret and maintained secrecy to be accepted by their peers but also to protect themselves from stigma and isolation. The fear of HIV-related stigma compels HIV infected and affected individuals to adopt coping strategies of secrecy and silence to protect self and or family from stigma and discrimination. Secrecy is viewed as an effective strategy for maintaining a normal life and has been greatly normalized in society.

Stigma and discrimination were a constant barrier for disclosure to sexual partners, family members, perinatally infected children, HIV-negative children, and romantic partners. Since HIV disclosure takes on different meanings for different population groups even within similar contextual environments, the fear of the different manifestation of stigma is experienced differently by population groups. Stigma was more pronounced for disclosing HIV status to infected children and during parental self-disclosure of HIV-positive status to children. The fear of stigma was also a key consideration for nondisclosure to romantic partners and friends by perinatally infected adolescents. Stigma is such a powerful barrier to disclosure such that even when individuals affected and infected with HIV do not experience enactments of stigma, being aware of the potential for stigma in their contextual environments shapes their disclosure pattern.

Given that disclosure of HIV status to perinatally infected children is more complex than that of adults, it is imperative that disclosure of HIV status to others by HIV-positive adults is understood because the social and cultural contexts of the adults providing care to perinatally infected children shapes the disclosure to children. As a result, self-disclosure to romantic partners by perinatally infected adolescents is as complex as that of disclosure among adults because their contextual environment is shaped by that of the adults too. The complexity of disclosure to perinatally infected children is aggravated by the fact that they may experience two aspects of disclosure; first, when they receive disclosure about their HIV-positive status and second when they receive their parental HIV-positive status. Both disclosure occurrences are saddled with sociocultural challenges affecting disclosure to adults within the communities.

A clear understanding of the contextual environment where disclosure occurs should inform interventions to create enabling environments for safe disclosure for the different population groups. It is imperative that the extent and effect of stigma and discrimination should not be underestimated or ignored by healthcare workers and other key stakeholders such as policy makers who have a vital role to play in reducing stigma. The challenge for researchers is to explore how HIV-related stigma could be overcome to enable people to disclose safely within their spaces or contextual environments. The understanding of the contextual environment or the spaces where disclosure and discrimination occurs will greatly influence the development of interventions to address stigma as being influenced by structural factors beyond behavior.

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