

**Iwelunmor, J, Okoror, T. & Airhihenbuwa, C.O. “Rethinking HIV/AIDS disclosure among women within the context of Motherhood in South Africa.”**

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## **Introduction**

With an estimated 5.5 million people currently living with HIV in South Africa,<sup>1</sup> the factors that influence disclosure on a collective level (i.e. disclosure to family members and/or community members) warrants urgent attention. Most of the previous literature on HIV/AIDS disclosure in South Africa explored factors related to disclosure of sero-positive status to partners and its implication with sexual risk behaviors.<sup>2,3</sup> Furthermore, these studies have solely focused on investigating individual level and behavioral determinants that shape the disclosure of sero-positive status.<sup>2,3</sup> Although knowledge of these factors are clearly important for effective HIV prevention, few attempts have been made to explore the factors that influence disclosure on a broader collective level (such as disclosure to family members and/or community members). Individuals are not isolated entities as they are embedded in collective contexts such as families and communities. In fact, one can expect that family and community contexts may play a crucial role in shaping individual decisions to conceal or reveal sero-positive status. Thus, any concerted effort to explore HIV/AIDS disclosure in South African settings must consider the role of the collective (i.e. family, and/or community contexts) in shaping decisions to disclose HIV sero-positive status.

To effectively address the disclosure of HIV sero-positive status on a collective level, it is imperative to adopt a collective-based approach (which is best exemplified as culture-centered approach) as it offers insights into the factors that shape disclosure in multiple contexts such as family, community and socio-cultural contexts. According to Dutta and Basnyat, 'a culture-centered approach values the cultural context of the participants and the location of the broader socio-cultural environments that shapes their attitudes, beliefs and behaviors.'<sup>4</sup> In the discourse on HIV/AIDS disclosure, a collective-based approach assumes a new metaphor that is framed within boundaries of acceptance, support, and expectations. It explores how persons living with HIV/AIDS navigate between the positive benefits (acceptance and support) of disclosure as well as the negative costs (fear of contagion, non-acceptance, stigma and discrimination).

One collective based approach that values the cultural context of African people while offering a defining anchor for exploring individual decisions to disclose sero-positive status is motherhood. In South Africa and throughout Sub-Saharan Africa, motherhood represents a form of collective identity whose agency embodies as well as extends the roles and expectations of every individual.<sup>5</sup> African scholars argue that motherhood is sacred in traditions of many African societies and it facilitates the formation of the individual identities in relation to collective identities.<sup>6,7,8</sup> What is most unstated about motherhood in the African socio-cultural context is that it is a lifelong commitment as one remains a child to one's mother regardless of one's age.<sup>6,9</sup> In the context of HIV/AIDS disclosure, this notion of motherhood becomes imperative particularly as persons living with HIV/AIDS (PLWHA) contend with decisions to reveal or conceal their sero-positive status.

Understanding motherhood within the context of HIV/AIDS disclosure can serve as a useful guide for exploring the factors that influence decisions surrounding disclosure of sero-positive status on a collective level. Thus, the present study expands the current literature by exploring whether motherhood plays a role in influencing decisions to disclose sero-positive status. Since motherhood occupies an important context around which individual and collective identities are structured<sup>6</sup>, we argue that it can provide an

anchor within which PLWHA can gain acceptance and support as well as buffer the negative factors associated with HIV/AIDS infection such as stigma, and discrimination. Also, since disclosure of sero-positive status is typically examined at the level of the individual, we argue that the critical but often neglected agency of motherhood offers an example for illustrating a collective-based approach to HIV/AIDS disclosure in South Africa. In this paper, we explored whether motherhood plays a role in generating positive, existential (unique), or negative consequences with disclosure of sero-positive status. Given that issues surrounding HIV/AIDS disclosure are central to notions of identity, expectations, and belongingness, we explored these boundaries using the PEN-3 cultural model developed by Airhihenbuwa.<sup>5,10,11</sup>

### **Theoretical Framework**

In order to explore the broader socio-cultural factors that influence the disclosure of HIV/AIDS status on a collective level, the PEN-3 cultural model was used as the framework of this study. Developed by Airhihenbuwa,<sup>5,10,11</sup> the PEN-3 cultural model addresses African health behaviors from a collective perspective rather than an individual perspective.<sup>10</sup> It has been used to guide a cultural approach to HIV/AIDS in Africa,<sup>12,13,14</sup> as well as to examine the influence of culture in nutrition practices;<sup>15,16</sup> and in exploring cultural constructs in cancer-related research.<sup>17,18,19</sup>

The PEN-3 cultural model focuses on contextual domains (such as culture) that influence health beliefs and actions.<sup>5</sup> This model proposes that cultural appropriateness in health promotion should not focus on the individual, but instead, in the context that nurtures the person and his or her family and community. The model consists of three dynamically related dimensions 1) relationships and expectations, 2) cultural identity, and 3) cultural empowerment. In the first dimension (relationships and expectation), the model posits that the construction and interpretation of behaviors are usually based on the interaction between the perceptions people have about the behavior, the resources and institutional forces that enable or disable actions, and the influence of family, kin, friends and most importantly culture, in nurturing the behavior. With the second dimension (cultural empowerment), factors that are critical to behavior change are evaluated for attributes that are positive, existential, and negative. The PEN-3 cultural model promotes the positive, recognizes and affirms the existential, and contextualizes the negative such that all factors for change are understood. The third dimension (cultural identity) removes the assumption that all interventions should be focused solely on the individual. Instead, it incorporates the context of person, extended family and neighborhood to identify the intervention point of entry that addresses the context of behavior change. The PEN-3 cultural model emphasizes the need to explore collective factors in the development, implementation and evaluation of health intervention programs.<sup>5,10,20</sup>

### **Methods**

#### **Design**

This study is part of a five-year capacity building project that utilizes the PEN-3 model as a cultural framework for exploring HIV/AIDS stigma in South Africa. Focus group methodology was used in this study to explore HIV/AIDS Stigma (for a detailed description, see<sup>14</sup>). This study specifically focuses on 11 focus group interviews

conducted during the second of the project in two communities in Western Cape: Gugulethu and Mitchell's Plains. The study was reviewed and approved by the ethics committee of the Penn State University and Human Sciences Research Council in South Africa.

### **Sample**

A purposive sampling approach was used to identify and recruit eligible participants for the focus group interviews. In this study, the 7 focus group interviews and 4 in-depth interviews were conducted with a total of 46 women living HIV/AIDS. The size of the focus groups varied from 5-7 participants, while the in-depth interviews were conducted with one individual participant. The groups only met once. Participants were informed of the objectives of study and they read and signed an informed consent form.

### **Focus Group and In-depth Interview Guide**

In this study, we focus only on the questions on disclosure that was posed to all participants. Specifically the question asked participants to describe their experiences with disclosure of sero-positive status. Participants were asked: *Who was the first person that you shared news of your status with, why did you choose that person, and what was the reason behind your disclosure?* Probes were used in the focus groups and in-depth interviews as required. Also, based on the three predominant languages spoken in Western Cape, the focus group interviews were conducted separately in English, Xhosa, and Afrikaans. All interviews were audio-taped with permission from participants. Interviews conducted in Xhosa and Afrikaans were first transcribed and then translated into English.

### **Data analysis**

All data collected from the discussions were loaded into Nvivo 2.0 qualitative software to facilitate management of the data. Nvivo is a qualitative software program designed by QSR which aids in organizing data collected from qualitative research.<sup>21</sup> The data analyzed for this study used the four processes described by Morse & Field; comprehension, synthesizing (decontextualization), theorizing, and recontextualization.<sup>22</sup> Following the guidelines of Morse & Field, these processes occurred sequentially, allowing data analysis to reach a reasonable level of comprehension, before being able to synthesize (make generalized statements about the participants), theorize and finally recontextualize.<sup>22</sup> As described by Morse & Field, the process of data analysis facilitates comprehension.<sup>22</sup> Specifically, through coding the data, the researchers were able to sort the data to uncover underlying meanings in the text. Intraparticipant microanalysis or line-by-line analysis of the interviews allowed the researcher to identify patterns of experiences<sup>22</sup> that were salient to HIV/AIDS disclosure on a collective level. In synthesizing the data, composite descriptions on the factors that influenced HIV/AIDS disclosure in conjunction with specific examples from the data were generated using Nvivo software for qualitative research. Both interparticipant analysis (comparison of transcripts from several participants) and the analysis of categories, sorted by commonalities,<sup>22</sup> consisting of specific participants (such as women living with HIV/AIDS) interviewers, and location (Gugulethu and Mitchell's Plains) were employed in synthesizing the data. With theorizing, Morse & Field suggests that theories are

essential tools, critical to all methods of inquiry, particularly qualitative research.<sup>22</sup> Furthermore, without theories, qualitative research would be without structure, without application and disconnected from the greater body of knowledge.<sup>22</sup> Thus, in theorizing the data, alternative explanations were continuously and rigorously selected and revised until the best theoretical schemes that fit the data was developed. The final outcome of this process was the development of a model that provided the most comprehensive and coherent method of linking the influence of collective factors with HIV/AIDS disclosure experience in South Africa. With recontextualization, Morse & Field suggests that the goal is to place the results in the context of established knowledge and to clearly identify those results that support the literature or that clearly claim new contributions.<sup>22</sup> In this study, the established theories of the PEN-3 cultural model play a critical role in recontextualizing the data as it provided the context in which to fit the new findings and thus advance knowledge on the factors that influence HIV/AIDS disclosure in South Africa.

## **Results**

As stated earlier, a total of 46 women living with HIV/AIDS participated in 7 focus group discussions and 4 in-depth interviews. 42 women participated in the focus group sessions, while 4 women participated in the in-depth interviews. While participants varied in age, most of these women were single and never married and they lived in the semi-urban areas of Gugulethu and Mitchell Plain. Participants reflected on decisions surrounding disclosure of sero-positive status and in congruence with the PEN-3 cultural model, the findings reflect three significant themes; Positive factors (the location of mothers), Existential factors (the roles and expectations of mothering practices), and Negative factors (the failure of mothering practices).

### **Positive factors-The location of mothers**

In deciding to disclose sero-positive status, over 50% of the women in the sample reported that they disclosed first to their mothers. Respondents were asked why they choose their mothers and few reported that it was their close relationship and the fact that their mothers were the only one that they could count on with their situation. In particular, one participant remarked that:

*for me it was easy because I am sharing a bed with my mother so I took that opportunity and told her at night, I said that this is the situation please don't be shocked and I don't expect you to take it the wrong way, so anyway its like that there is nothing I can do to change that. She encouraged and counseled me saying that I shouldn't worry I'll always be by your side.*

The location of mothers became more indispensable as the women dealt with the knowledge of their sero-positive status. Several women emphasized that mothers were the first and most commonly sought after source for disclosure because they knew that their mothers would provide emotional care and support. The location of mothers was recognized particularly for its ability to garner protection, trust and support for living with HIV/AIDS. One participant described her experience with disclosing to her mother by saying:

*I don't know maybe it was because she's a mother and I know she's always trying to protect and I don't know who else I must tell because I trusted my mother. And I just think she must be the first person to know these things....The best thing is I must tell her today.*

Accordingly, the process of deciding to inform one's mother is born out of the inherent trust in motherhood. There seems to be an inherent belief that mothers will not reject their children as seen from the responses of the two previous participants. Beyond the rhetoric of naming friends and loved ones as a primary confidante to whom sad news should be shared first, the reality of the news of HIV evokes an awakening of the pivotal location of mothers in times of problems and difficulties as noted by this participant:

*Ok I for one I decided to tell my mother because they ask you at the clinic as to who are you going to tell as your confidant, people have a tendency of taking for granted that question, and the frequent response would be my boyfriend to answer that question or sometimes my friend, and all along this is a serious question; it suddenly changes after you get your results because you are told to be HIV positive and you have to be serious now as a result of that you end up being caught in a dilemma as to who should be the first one to know because you know for fact that your boyfriend is not going to conform with your results because he is maybe fragile. You start to think again as to who should I tell, then that is where you think of your mother as the only person whom can seriously succumb and take you out of the problem.*

Also, mothers were central in providing a medium through which participants shared the news of their sero-positive status to the rest of their family members. In situations where participants struggled with revealing their sero-positive status to the collective, our focus group interviews revealed that mothers served as mediators. Thus mother's knowledge is implied to be collective (family) knowledge since mothers represented the conduit through which emotional balance is sought by knowing whom to contact, in which order, and at what point to inform other family members. This finding is clearly embodied in the words of a participant who simply states: *the first day I just phoned my mother, then my mother phoned my sister, from there to my father, and so the whole family knows that I am HIV positive.*

### **Existential (unique) factors-The roles and expectations of mothering**

Existential factors refer to "values and beliefs that are practiced in the culture but pose no threat to health" (see 5, 10). The findings of our study indicate that the roles and expectations of mothering are existential (unique) factors that significantly shaped the disclosure of sero-positive status as it reinforced the notion that 'threats to health do not occur in a vacuum.'<sup>23</sup> For most participants, both the emotions and motives for HIV/AIDS disclosure were significantly linked to their roles as mothers. Also, given the numerous roles and responsibilities of motherhood, it becomes inherently difficult to keep knowledge of sero-positive status to oneself as stated below;

*But for us as women it's difficult because if you test positive today you won't keep it for yourself for a long time. Because it's gonna work on you, you see your children, you see your husband, you see your family so it's working on you so you rather come out.*

Also, it appeared that expectations of mothering practices were another crucial factor that influenced disclosure of sero-positive. In South Africa most women discover their HIV status during routine antenatal testing available through programs such as the prevention of mother-to-child transmission (PMTCT).<sup>24</sup> These women are then faced with the pressure of having to disclose not only to their partners,<sup>25</sup> but also to family members,<sup>26</sup> particularly female elders who often manage pregnancy and childbirth. After birth, the female elders tend to look after the young mother, ensuring that she adheres to traditional caring and feeding practices. Breastfeeding is a conduit through which elder women offer vital lessons of motherhood to young mothers.<sup>5</sup> In the context of disclosure, the rationale underlying breastfeeding was essential as it was common for young mothers to disclose their sero-positive status because of questions about their breastfeeding practices. One participant verbalized the need to stop lying in part because it was not in agreement with the breastfeeding expectations of motherhood:

*I told my mother I got this status because she asked why don't I breastfeed the baby. The first time I lied and the second time I told myself I'm sick and tired of lying.*

In addition to breastfeeding practices, family meetings were an existential avenue through which mothers of participants disclosed the sero-positive status of their daughters to the collective. Participants recognized that family meetings promoted and posed no threat to their health, instead it garnered support from the collective. This existential finding was best articulated in the following statement as one participant noted that upon disclosing to her mother:

*She called the family members, cousins and they told me I shouldn't worry they will help me with everything I need.*

It seemed that mothers initiated these meetings so as to discuss how to deal with knowledge of sero-positive status within the collective as remarked by this participant:

*She came to me and we spoke about it and then she told the whole family about it and the family stood by me to deal with it.*

### **Negative factors: the failure and potential costs of mothering practices.**

Negative factors refer to “health beliefs and actions that are known to be harmful to health.” (see 5, 10) Airhihenbuwa suggests that these “health beliefs should be examined within their cultural, historical, and political contexts before attempting to change them.”<sup>5, 10</sup> In South Africa, since the dawn of the apartheid regime, families have experienced drastic changes such as dislocation and forced removals from their communities and relatives.<sup>27</sup> Also, researchers suggest that inequality, mobility and violence<sup>28</sup> along with

contemporary, historical, social, cultural, and economic processes have shaped families, individual, and household responses in activities within domestic spheres.<sup>29</sup> Magazawa notes that apartheid, along with race and socio-economic situations have truly affected mothering practices in the South African context.<sup>30</sup> Also, the discourse on motherhood in South Africa becomes particularly complex in the era of HIV/AIDS as women continue to account for about 90% of new HIV infections.<sup>1</sup> Given the stigmatizing and discriminatory nature of HIV/AIDS, alongside the historical and political contexts of South Africa, it is possible that traditional and societal expectations of mothering practices may erode.

In the context of HIV/AIDS disclosure, the failure of mothering practices stems from ‘circumstances that make mothers fail in their mothering duties as mothers with children living HIV/AIDS. For example, there is a generally held view that all mothers are expected to provide emotional care and support for their children. Although we do not disagree with these notions, with disclosure of sero-positive status, our findings revealed that to some extent, such expectations of mothering practices are futile as one participant remarked that:

*After disclosing in 2004 and then what happened was she got drunk, and after getting drunk she actually swore at me and said “You must leave my house, take our clothes and go, I don’t want you here in my house. You’ve got AIDS and you gonna give us AIDS” and that was two o’clock in the morning and then at seven I got up, packed my clothes and I went to stay with a friend of mine.*

For this mother, the threat of possible HIV infection form part of the reasons for her failure in the generally assumed expectations of mothering practices. HIV/AIDS has challenged the known rule of the ill-self as a responsibility of the collective and so it’s not surprising to note that the perceived knowledge of the contagious nature of HIV sero-positive status leads to failure with societal expectations of mothering practices.

Often, “contradictions between what societies expect of mothers and what mothers themselves do,”<sup>30</sup> form part of the reasons why mothers weigh the potential of disclosing of HIV sero-positive status. As noted earlier, breastfeeding is a powerful conduit through which young women learn lessons on motherhood from female elders in the family. While we acknowledge that it is an existential factor that influences disclosure of sero-positive status, in situations in which mothers tried to balance their HIV/AIDS status with the collective expectations of breastfeeding, disclosure of sero-positive status was challenging. One participant spoke of having to negotiate between the expectations of breastfeeding and disclosure of her HIV status:

*you know how grandmothers are she wanted me to breastfeed and I did not know how I would even start to explain to my grandmother why I was not breastfeeding, I gave her excuses that there is something wrong with my breast or the child is full I would give excuses but I found that she is forcing me to breast feed the child and I know that she does not know the situation I am in I can not tell her this and this is what is happening*



For this mother, the mothering practice of breastfeeding created an internal pressure as she struggled with decisions about whether or not to disclose her sero-positive status. This finding is consistent with a previous study conducted in Johannesburg, South Africa which highlighted how mothers often engage in elaborate strategies to justify avoidance of breast-feeding to family members.<sup>31</sup>

Also, disclosure was significantly shaped and nurtured by a consideration of the potential effect of a sero-positive status on the well-being of collective (i.e family members such as one's children). The potential costs of disclosing HIV sero-positive status often outweighed the benefits for some mothers (and in some instances sisters) living with HIV/AIDS. Our findings indicate that difficulties with disclosing sero-positive status were linked to situations that made mothers weigh the potential costs of their mothering duties. For example one participant highlighted that with disclosure to her children:

*I was scared and needed advise on ways to disclose to my children. I was worried, will my children be repulsed by me.... Will I be able to cook for my children, will they eat my food....*

Also, the inability to care for one's siblings was seen as factor that lead to the difficulties with disclosing sero-positive status as noted by this participant: *The fact that...I was the only one that my mommy could trust with my brothers and my baby sister now. She could go to work...and come back, knowing that everything is going to be fine, and now...there is nobody that she can tell, this is what you have to do So...that made it.. difficult to tell her.*

### **Discussion and Conclusion**

We explored the factors that influence disclosure of HIV/AIDS on a collective level among women living in South Africa. Using the PEN-3 cultural model, our findings revealed how women living with HIV/AIDS navigate between positive factors, existential factors and negative factors with disclosure of sero-positive status. These themes also highlight how notions of motherhood are central in shaping decisions to conceal or reveal HIV sero-positive status.

The importance of the collective in shaping decisions surrounding disclosure of HIV sero-positive status was important for the following reasons. First, the location of mothers was an important context for women living with HIV/AIDS as it represented a pivotal agency and medium for decisions with disclosure not only with themselves, but also with the collective. The results of this study confirm previous findings in South Africa which suggests that mothers were most often the first source with disclosure of HIV sero-positive status.<sup>32, 33</sup> Our findings also reaffirm the agency of mothers to be indispensable with HIV/AIDS disclosure as they often garnered protection and support for living with HIV/AIDS.

Second, roles and expectations of mothering practices significantly shaped decisions surrounding disclosure of HIV sero-positive status as it reinforced the notions illustrated by Smith and colleagues which suggests that threats to health is not independent of the person's context.<sup>23</sup> Given the numerous roles and responsibilities of motherhood, majority of the mothers living with HIV/AIDS expressed that it becomes

difficult and challenging to keep sero-positive status to oneself. Thus, it's not surprising to note that reasons for disclosure often centered on expectations of motherhood as a nurturer (i.e. breastfeeding, protecting children). Also, our findings indicate that mothers served as conduits with disclosing participant's HIV/AIDS status to the rest of the family. This process of disclosing PLWHA's status to the rest of the family often resulted in family meetings. It is important to note that these family meetings are existential features of the collective as our participants indicated that they often function to address and help them in dealing with their status.

Finally, our findings indicate that disclosing HIV sero-positive status often leads to failure with mothering practices among mothers with children living with HIV/AIDS. Also the potential costs of mothering practices resulted in difficulties with disclosing HIV sero-positive status among mothers (or sisters) living with HIV/AIDS. Our findings indicate that disclosure of HIV sero-positive status did not often result in the societal expectations of mothering practices with children living with HIV/AIDS. Failure to breastfeed and as a result disclose HIV sero-positive status created an internal struggle for mother's living with HIV/AIDS as their actions were viewed as not in alignment with traditional mothering practices. Also, difficulties in disclosing sero-positive status arose when participants struggled with the pressure of addressing it's impact on other aspects of mothering practices such as cooking and caring for children and/or siblings. This finding is consistent with previous research that suggests mothers living with HIV/AIDS often perceive the possible costs of revealing HIV sero-positive to their children as prevailing over the possible benefits.<sup>34</sup>

These findings are influential in that they highlight the role of the collective in shaping and hindering disclosure of HIV sero-positive status among women living with HIV/AIDS. The findings move beyond individual reasons for disclosure to probe the broader collective contexts in which individual decisions regarding revealing sero-positive status are made. In this study, exploring HIV/AIDS disclosure within the context of motherhood draws attention to the interplay between individual identities and collective identities. It highlights the positive and unique aspects of the collective which promote disclosure, while drawing attention to the negative factors. What is important from an intervention standpoint is that notions of mothering in the South African context play a crucial role as individuals decide to conceal or reveal HIV sero-positive status. As stated earlier, these findings reinforce the general notion that 'threats to health do not occur in a vacuum,' as consideration of the collective is salient when deciding to disclose HIV sero-positive status. This finding has important implications as any effort to design and implement effective interventions on HIV/AIDS disclosure among women living with HIV/AIDS should consider the role of the collective in influencing decisions surrounding disclosure.

This study has several limitations that must be acknowledged, but yet fully explicated given the nature of our study. First, the relatively small sample size of participants may not be considered representative of women living with HIV/AIDS in South Africa. We argue that in qualitative research and in particular focus group discussions, small number of participants are ideal because they encourage participants to interact freely and completely about their attitudes, opinions, and experiences on the subject matter.<sup>35</sup> The small number of participants also enabled the investigators to

substantively elucidate the process by which women disclose knowledge of their HIV sero-positive status.

Also, while caution should be exercised with generalizing these findings to other geographical location (outside of Sub-Saharan Africa), we argue that our interpretations of motherhood (in terms of the positive and existential features) may be applicable in other African settings. Although this study focused on the disclosure experiences of women living with HIV/AIDS, future studies should explore the experiences of men living with HIV/AIDS in comparison to women to address whether the role of the collective is important in shaping individual decisions to disclose HIV sero-positive status. In general, it is important to note that collective identity is an important context for exploring disclosure of HIV sero-positive status among women living HIV/AIDS. Future interventions may consider using this context, (in particular notions of motherhood) to promote as well as to address difficulties surrounding disclosure among women living with HIV/AIDS. The findings have important implications for addressing HIV/AIDS not only within the sphere of the individual, but also in addressing the impact of HIV positive status on the collective.

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