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From "Secret" to "Sensitive Issue": Shifting Ideas About HIV Disclosure Among Middle-Aged and Older Rural South Africans in the Era of Antiretroviral Treatment

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Abstract

Objective: As HIV shifts from 'death sentence' to 'chronic condition', disclosure of HIV status to intimate partners and family are significant components of both prevention and treatment adherence. While disclosure is closely considered in many studies, few examine middle-aged and older persons' (age 40+) perspectives or practices. We trace older rural South Africans' views on HIV disclosure to their partners and family members in a high prevalence community over a period of extensive antiretroviral treatment (ART) rollout.

Methods: Community focus group discussions (FGD) conducted in 2013 and 2018 show shifts in older persons' thinking about HIV disclosure.

Findings: Our FGD participants saw fewer negative consequences of disclosure in 2018 than in 2013, and highlighted positive outcomes including building trust (partners) as well as greater support for medication collection and adherence (family).

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Discussion: Particularly as the epidemic ages in South Africa and globally, tracing changes in older persons' views on disclosure is an important step in developing messaging that could enhance treatment as prevention and ART adherence.

Keywords

Aging; Antiretroviral Treatment; HIV disclosure; South Africa

Introduction

As HIV shifts from a death sentence to a chronic condition (Conroy et al., 2013), disclosure of a positive HIV status among sexual partners is a particularly significant part of treatment as prevention (Chambers et al., 2013; Harris et al., 2018; Negin et al., 2012). Disclosure to family members also can provide support around antiretroviral adherence (Scanlon & Vreeman, 2013; Schatz et al., 2018). Reasons for and practices of status disclosure also have been shown to change with the increasing availability of antiretroviral treatment (Conroy et al., 2013). While disclosure is something that has been closely considered in a broad set of studies (Bott & Obermeyer, 2013; Britto et al., 2016; Gabbidon et al., 2020; Tam et al., 2015), very few of these consider the disclosure practices of those who are over the age of 40 (exception is papers from high-income countries, e.g., Emlet, 2008). Older persons' reasons for disclosing or not disclosing may differ due to their family circumstances, as they are more likely to be unpartnered and to live in multi-generational households (Mojola et al., 2015; Schatz et al., 2015). Using community focus group data from a rural South African community, we document the ways in which older persons talk about their beliefs and perceptions of why and how disclosure (should) happen with their partners and kin, and examine how these ideas have shifted as ART availability went from being limited (2013) to widespread (2018).

Prior to ART being available in sub-Saharan Africa, HIV-related stigma had an inhibitory effect on HIV positive status disclosure to both partners and family members (Emlet, 2006; Treves-Kagan et al., 2016). The advent of ART as a life-saving medication has lessened stigma, and for some disclosure has become more acceptable (Chan et al., 2015; Green et al., 2018). And yet, Africans continue to report relatively low levels of disclosure of HIV positive status to others, including to their sexual partners (Kalichman et al., 2020; Treves-Kagan et al., 2016). Anticipated stigma remains a major reason for non-disclosure (Bhatia et al., 2017) and fear of discrimination and rejection pose barriers to disclosure practices even within families (Evangeli & Wroe, 2017). Despite a tremendous increase in access to ART in sub-Saharan Africa over time (UNAIDS, 2014), these barriers to disclosure continue to limit individuals' desire to disclose (Bhatia et al., 2017; Treves-Kagan et al., 2016). Non-disclosure can have a strong negative influence on ART medication adherence (Lyimo et al., 2014). On the other hand, when individuals disclose their positive status, there is evidence of lower risk of HIV transmission to partners, and improved social support from partners and family resulting in better quality of life (Evangeli & Wroe, 2017; Foster & Gaskins, 2009; Grodensky et al., 2015; Maeri et al., 2016).

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The likelihood of disclosure depends both on the characteristics of the person disclosing and the person to whom they are disclosing. Disclosure to a partner, for example, follows different patterns depending on whether individuals are married/cohabiting, or whether the partner is new or not (Brittain et al., 2018). Most studies find higher rates of disclosure among married participants (Brittain et al., 2018), women (Simbayi et al., 2017), as well as individuals who are employed, have higher levels of education, and greater knowledge about HIV (Simbayi et al., 2017). Despite high levels of disclosure recorded in some studies, other studies find that less than half of the participants had disclosed to partners (Kalichman et al., 2020). The majority of these studies, however, focus on pregnant women or adults under the age of 40, making it hard to know whether relationship status, age or other factors might make disclosure a different experience for older adults. The fact that in much of sub-Saharan Africa the majority of older persons are widowed or divorced makes partner disclosure moot (Mojola et al., 2015); even if partnered, many older persons may be sexually inactive, likely reducing the need and desire to share one's status (Houle et al., 2018). One study in Kenya found that older adults were less likely than their younger counterparts to disclose positive status to partners (Trinh et al., 2016); older adults may also be more reluctant to start new relationships, and in such cases, there is no partner to disclose to (Emlet, 2007; Grodensky et al., 2015).

While disclosure to romantic and sexual partners is important for reducing transmission, as well as other forms of support, people living with HIV (PLWH) also often disclose to family members (Foster & Gaskins, 2009; Maman et al., 2014). These decisions are generally guided by perceived social support benefits or risks, rather than issues of transmission and protection (Emlet, 2008). In many settings, adults report stigmatization, discrimination, and rejection following disclosure to family members, reducing the desire to disclose and causing significant stress (Akhtar et al., 2017). However, older persons living with HIV (OPLWH) in Uganda reported a high preference for family disclosure and a positive outcome of post-disclosure social support (Kuteesa et al., 2014; Schatz et al., 2018). Adult children were perceived by some participants in the study as reliable sources of support and likely to keep HIV disclosure information confidential (Kuteesa et al., 2014), and grandchildren provided support in the form of reminders to take ART (Schatz et al., 2018). Given the intergenerational nature of rural South African households (Schatz et al., 2015), family is likely to be an important locus of status disclosure. Even so, disclosure of positive status remains a delicate topic, and older persons living with HIV may carefully weigh to whom, how, when and for what purpose they disclose their status.

Setting, Data & Methods

The data for this paper come from community-based focus group discussions (FGD) that were part of the HIV40/*Izindaba Za Badala* study which began in 2013, and included a follow-up in 2018 (Mojola et al., 2015, 2020). *Izindaba Za Badala* aims to provide insight into the lives of and health decision-making by older African adults in the context of a severe HIV epidemic. The study includes older adults living in villages that are part of the Agincourt Health and Socio-Demographic Surveillance System (henceforth "Agincourt") located in Mpumalanga Province and run by the MRC/Wits Rural Public Health and Health Transitions Research Unit at the University of Witwatersrand (see Kahn et al.,

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2012 for study site details). At the time of our study, this community has a population of approximately 90,000 – about 12% of which is over the age of 50, and the majority of whom, particularly the women, are divorced or widowed. In data from 2011, 59% of women and 14% of men over the age of 60 were widowed (Houle et al., 2018; Mojola et al., 2015). High levels of unemployment and circular labor migration, particularly among younger persons, create a context in which older persons are important household contributors through both in kind care and pension funds (Schatz et al., 2015; Schatz & Ogunmefun, 2007). Multigeneration households are the norm for older persons, with 70% of those 50-plus living in households with at least 3 generations in 2010 (Ralston et al., 2019).

HIV prevalence among those aged 40 and older was 23% in 2015–16 (Gómez-Olivé et al., 2020). While Voluntary Testing and Counseling have been available in Agincourt since 2002 and ART rollout began at area district hospitals (outside of the site) between 2004 to 2005, availability of ART in the site began in 2007 in a private clinic and then 2008 in public clinics, but wide availability in Agincourt began in 2011 (Mee et al., 2016); during the period we study (2013 to 2018), there was a steady increase in both availability and uptake of ART. Two other important contextual factors occurred during this period. First, a majority of those aged 40+ in the site (nearly 70%) had at least two chronic health conditions (e.g., combinations of cardiometabolic conditions, cardiometabolic conditions and depression, HIV and anemia and combinations of mental disorders) (Chang et al., 2019). Further, during this time there was also a dramatic decrease in mortality from AIDS-related illnesses – both a result of the increasing access to ART, and a reason for those who tested positive to initiate treatment (Mojola et al., 2020). Thus, our discussions of disclosure occur in a context of increasing access to ART, but also shifting experiences of morbidity and mortality from HIV (perceived reduction) and other chronic conditions like hypertension, diabetes and cancer (perceived increase).

In 2013, the community FGD included 77 respondents (36 men, 41 women) in nine FGD, stratified by age group (40s, 50s, 60-plus) and gender (men, women, mixed gender) (Kitzinger, 1994). In 2018, we conducted ten FGD with 84 participants (39 men, 45 women); the FGD were the same as in 2013 with one exception – there were two mixed-gender FGD among people aged 60-plus. In both years, participants were recruited from locations where older persons regularly congregate (e.g., markets, home verandas); each person approached was asked to bring same-sex and age group-peers to the FGD. We included both single-gender and mixed-gender FGD to assess if there would be differences in the ways that older persons talked about HIV and health more broadly if men and women were speaking to one another versus in same-gender groups. While socializing in this community largely happens in single-sex groups, some interactions – e.g., within couples, church services, time at the health center, and funerals, often have men and women interacting and sharing information. We thought it was important to consider the ways HIV and health more broadly are talked about among men and women separately, but also when they are together.

While the FGD in 2013 and 2018 did not include the same participants, in each year they included individuals in the same age groups. HIV status was not an inclusion or exclusion criteria, nor were participants directly asked about their own status, yet a number

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of participants disclosed their status during the discussions. The interview guide for the FGD included semi-structured questions and vignettes highlighting hypothetical scenarios that might be experienced by older men and women in the community (Barter & Renold, 1999). [See https://hivafter40.princeton.edu/instruments for access to FGD interview guides.] While topics ranged from norms about sexual behavior and aging, social roles, and life events unique to adults in transition to older ages, in this paper we focus specifically on questions related to norms and perceived perceptions of those living with HIV in the community, and particularly how and why disclosure of HIV status does or does not happen.

It is important to note that the interview guides for the 2013 and 2018 FGD focused on similar topics but were not identical. While survey research is interested in asking the same questions in successive waves to ensure ability to compare responses over time, this is less critical in qualitative research. It makes it a bit more complicated to say conclusively that the responses to specific questions was different in 2013 and 2018, but had we asked the same questions, we would not have been responsive to the very real changes in context: for example, that ART was widely available in the community (Mee et al., 2014; Rohr et al., 2019), that morbidity and mortality rates from AIDS-related illnesses were notably lower (Kabudula et al., 2014, 2017), and that multimorbidity and non-communicable disease was on the rise (Clark et al., 2015). That said, we want to acknowledge that our categories and the norms articulated in the analysis are, in part, a byproduct of the different vignettes, follow-up questions, and probes asked in the two years. In 2013, the key categories of interest were collective experiences and changes pre- and post-apartheid, including the impact of HIV; sexual risk and HIV; HIV risk perception; HIV testing; and ART. In 2018, the longer FDG guide covered the following topics: community change since 2003 (15 years) – including the impact of HIV *and* rollout of ART, HIV testing motivations and experiences; ART – including an explicit question of whether a person is likely to tell others that they are on treatment; experiences of other chronic diseases; clinic experiences as people age; and questions about the most important challenges, health issues, and unsolved issues in the community. Thus, in 2018, respondents may have been more primed to think about HIV and disclosure as normative, because they were presented more in the context of health and healthy behavior than in the context of sex and sexual risk – for example, in 2018, there was more discussion about disclosure in the context of health and all chronic conditions, getting support for ART use, and relationships, rather than a focus on disclosure primarily in the context of sex and intimate relationships, where they were most relevant in 2013.

All FGD were conducted in the local language (XiTsonga/Shangaan) by a pair of locally trained resident interviewers (one facilitator, one note-taker). FGD were then translated and transcribed by members of the local study team and were subsequently reviewed by the study PI and co-I for clarity. All participants provided signed informed consent, and all research was approved by the authors' institutions as well as the Mpumalanga Province Research and Ethics Committee.

The two lead authors (ES & ID) developed a set of codes through open coding of several FGD from 2013 and 2018, which focused on older persons' views on when, to whom, and why disclosure occurs, and the barriers to disclosure among themselves and their peers.

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The code list, which was the same for the 2013 and 2018 FGD, was then used to code the remaining FGD in NVivo 13 (Strauss & Corbin, 1990, 1994). In 2013, ART had only been widely available for about a little over a year so there is some mention of change from previous years, but the starker contrast is between 2013 and 2018, by which time the accessibility and acceptability of ART had increased substantially. Thus, the primary comparison we focus on is change in norms related to disclosure across these two time points. By examining FGD data, we are able to capture norms and perceptions about disclosure that reflect the ways community members talk about known and unknown HIV infection around them, and how the availability of ART shifted (or did not shift) these norms and perceptions. The changes over time were more salient than any distinctions by age group or in men-only/women-only/mixed-gender FGD, so although we outline the age and type of group, we do not analyze differences resulting from age group and gender across FGD.

Findings

Starting in 2011, when ART rollout began in earnest, people in this community saw large numbers of people who had been dying, continuing to live, and for many live well, on ART (Kabudula et al., 2014, 2017; Mojola et al., 2020). Thus, important shifts in norms and perspectives about living with HIV and disclosure occurred between 2013 and 2018 in this community. Over this period of increasing ART access and uptake, we trace the ways in which men and women in their 40s, 50s, and 60-plus, talk about the need for and benefits of disclosing one's HIV status to members of their families and current/potential partners. Comparing the norms and perspectives from 2013 and 2018, we see considerable change in the ways people understand the chronicity of HIV, the benefits of sharing one's status with partners and family, and norms about disclosure.

HIV disclosure in 2013: Still "my secret"

Ambivalent conviction – disclosure in early ART era

Even though 2013 was still early in the rollout of ART in this area, older adults' views of what HIV 'was' had changed from a death sentence to a chronic condition, decreasing stigma and changing disclosure discourse. In one mixed gender FGD in 2013, persons in their 40s discussed how HIV is not as stigmatized now as in the past,

> At the beginning a person who had HIV was not treated well. They were also not welcome in the community. Meaning, if anyone or everybody knows that someone has HIV, they were even afraid to hold their hand, or to go near them. But for now, the one who has HIV is treated well and they also give them advice and remind them to take their pills or treatment. (MW40s)

Despite this changed perspective, another man in this group contended that people living with HIV in 2013 were still not necessarily fully accepted in the community,

> According to me people love you, but they don't accept you like they used to [before you had HIV]. They think you wanted to be positive. Even at home or community people laugh. So, you have to be strong and learn to live with it and tell yourself that it's not the end of life. They are not being treated good. Some people

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> they pretend to love them and others they don't want to eat with them. They think if they eat with them, they will get infected (MW40s).

Yet another man in the group agreed saying, "Yes, he is telling the truth, it changes you when you are HIV positive, because people start to treat you somehow like you are not a human being (MW40s)." Yet another respondent in this group returned to the idea that HIV is a secret, "When you have HIV, you don't tell anyone… you don't tell anyone. It is your own issue (MW40s)." Thus, despite some movement toward disclosure being seen as positive, a sense of ambivalence about disclosure was evident for a variety of reasons. Disclosure to both family and partners was deemed important, but the likelihood of disclosure and reasons underlying it differed.

Disclosing to Partners: "I will not tell him that I'm sick"

In the 2013 FGD, while disclosure to a partner was about preventing transmission and sharing one's status as a form of intimacy and trust, even with spouses there was reluctance to do so. So, while our participants' narratives highlighted an ideal of disclosing positive status to partners, they also expose the reality that this is harder to achieve than to advocate.

In a FGD of women in their 50s, the following discussion ensued while discussing appropriate sharing of information with sexual partners,

> W2: There is a problem. You find that I am HIV positive and there is a man proposing me, I will not tell him that I'm sick. We will have sex and when he receives that HIV, he spreads it because he is not dating you alone. When he finishes having sex with you, he will go to another woman he is dating, and she will be infected. And you find that woman is dating other men and HIV spreads in that way. That is why I don't think this illness will come to an end, because it's spreading a lot. …
>
> W3: … For [HIV] to come to an end I think it will be problem, because when a person is HIV positive they don't say it. … You find that if that person is given ART she doesn't use them saying she is bewitched. Then she gets sicker and when men propose to her, she won't refuse, she continues to have sex with them. Meanwhile she is sick. … It is because when someone is infected, they don't disclose to the partner, they hide their status then it spreads in that way. … The HIV spreads to the whole country. Some when they have tested positive, they don't follow what they have been told to do (W50s, 2013).

While it might be easy to assume that these older women are talking about the 'bad behavior' of young people, later in the FGD, the first speaker says older persons are no different, "Even older people, some they don't tell, they just keep quiet." She went on to tell a story about an exchange she overheard where one person said that they *would* disclose if they were positive, and the other person scolded them saying, "you will eat late [*meaning that she won't find a partner.*] We don't disclose our status (W50s, 2013)." Instead, she said that people indirectly or non-verbally "disclose their status" by encouraging their partners to go test, or suggesting that they test together as a couple, rather than directly disclosing that they know their status is positive (Schatz & Knight, 2018).

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Even when one's partner is a spouse, women in their 50s claimed that disclosure was not a given, "W6: I have to go there alone because my husband doesn't want to [test], even if I tell him to go to the clinic, or you have headache and your husband refuses to go for testing, you will go alone…and when I find that I'm HIV positive, I will keep quiet I won't tell him (W50s, 2013)." A man in his 50s from the mixed-gender FGD admitted he would keep his status from his spouse, as well, but would suggest they test together (the strategy outlined above),

> "M1: …if I tested and they said I am positive I won't go and tell them at home. I will leave the medication at the cattle's kraal. I will take the medication secretly. I will take the condoms at the clinic because I am afraid of the nurses and the doctors but I won't go home with it. I told myself if I can see that I am HIV positive. Even if I am afraid of my wife, I can't tell her. [Instead, I will say,] "Let's go and test." When we come from testing if she wants to beat me, I will leave her and eat my pills. Because they say if you have HIV you take the medication your whole life [they all laugh] (MW50s, 2013).

He, like his female peers, wants to disclose and start ART, but has fears about sharing this information directly. While still not sharing this information directly, he is doing something to try to expose his 'secret'.

Disclosure to kin: 'Only the family will know'

While the intimate partners were not yet to be trusted with this knowledge, due to worries of accusations and stigma, in 2013, there was an increasing recognition that disclosing to one's family could lead to support. Disclosure to one's family, particularly children, siblings or grandchildren, was both more common *and* had clear benefits, as it enlisted kin to assist with ART adherence in a number of ways. Two women in their 60s agreed that, "W1: His family will take care of him. The community is not involved [pause] because some people believe that this disease is a secret not anyone will know, only the family will know. … W2: That's it (W60s, 2013)."

A discussion among several women in the oldest mixed-gender FGD, which was raised in the context of talking about HIV testing and ART, reinforced this notion that disclosing to kin has benefits:

> W5:… I will tell them at the clinic to test me for all the diseases. If I find out that I have it, I can call all my children that I have it. So that you will be able to come with apples, bananas, pears. When I wake up in the morning, I will wake up eating the fruits so that it can eat the fruits. … (W2): …I told [my sister] to test and that they will give her medication and she will be cured… She went to the doctor after she was tested, she phoned me saying that she has HIV. … I told her to tell them to give her the correct medication. She took the medication even now she is alive and has gone back to work. She showed my other siblings her medication and asked them if it is not the same medication, that she is better and told them to take their medication… W2: Nowadays it's easy, if you have accepted your status and you have disclosed to your children, you can send them to go and collect your treatment. If you are old like me, you have to tell your children that

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> you are collecting treatment at Bhubezi [Clinic]. At Bhubezi it's easy. They don't refuse when you send someone to collect treatment for you. When you arrive there, you tell them that my father has sent me to collect his treatment (MW60plus, 2013).

The reliance on family for emotional support, food to take with ART, and assistance in collecting ART may have been a natural outcome for older women, many of whom are widowed and thus when sharing information with children and siblings are not risking disclosure to their husbands or partners. They also often live with their adult children or grandchildren, creating a situation where they see advantages to sending someone to fetch ART from the clinic in the way they might send someone to fetch water or firewood in order to conserve their own time and energy (Schatz & Seeley, 2015).

HIV disclosure in 2018: ART available, no longer a secret

Shifts in ideas about disclosure

Five years later, in 2018, we returned to the same community, and again conducted community focus groups with individuals in their 40s, 50s, and 60s-plus, and again asked questions that elicited discussions about HIV status disclosure. In the seven years since ART rollout (in 2011), ART had become more "normal" and thus part of the public's understanding about how to live with HIV. We began to see shifts in the ways that disclosure was viewed and discussed. Participants seemed convinced that now HIV, particularly once living well on ART, was less severe and life-altering than other illnesses, especially non-communicable diseases like diabetes (Mojola et al., 2020). Thus, disclosure of HIV status was less problematic than in the past, particularly with partners and families.

Partners – building trust through disclosure

While the respondents in 2018 felt that both women and men could be reluctant to disclose their HIV status to partners, they also believed disclosure to one's spouse was very important regardless of the consequences. In the mixed-gender 50s group, an older man said that a man "must disclose to his wife when he comes home (MW50s)." Similarly, in a mixed-gender group of those 60 and older, a man claimed, "If he knows that he is HIV positive, he must disclose to his wife and he must also give his wife ART (MW60-plus, 2018)." Women in their 40s also highlighted the same thing, except their focus was on women: "But it is important that she tells her partner about her status. If the partner really loves her, he will marry her no matter what (W40s, 2018)." In response to a vignette about "Thandi," an older woman who tests HIV positive and is considering dating (a new vignette proposed in 2018), men in their 60s agreed to the importance of partner disclosure, saying, "Thandi should explain her situation to her partner that she is positive. If the partner agrees to that, then she will have a partner, but if the partner refused, then she won't have a partner (M60s, 2018)."

Disclosure, love, and marriage are seen as linked. Thus, it is not that there are not potential consequences to disclosure, but it is still deemed necessary in ways we did not hear in 2013 – showing that disclosure was now part of the practice of building trust and openness in relationships. These stories and recommendations highlight a more straightforward

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disclosure to partners and spouses than was outlined in 2013, when ‘sending someone to test’ or ‘testing together’ was more common.

Disclosing to family: Supporting treatment

Similar to 2013, the FGD in 2018 highlighted the growing importance of disclosure to family members, e.g., one’s children and grandchildren, to reduce stigma and increase ART adherence (because family will remind you to take your medication), further motivating disclosure as something positive. Women in their 50s and 60s, in particular, talked about the importance of sharing one’s status with family and children. They said things like, “it is better to disclose to your family member that you are taking treatment [so that they] will not laugh at me,” “She can tell her children,” and “Her children cannot discriminate against her; they will keep it as a family (W50s, 2018),” as well as comments that highlight the role that family can play “… she must also disclose her HIV status to one of her children to remind her when is the time of taking her treatment” (W50s, 2018).

The women in their 60s were even more explicit about the benefits of sharing with their children. One woman said, “If it was me, I will disclose to my child so that will remind me if it is time to take ART” (W60-plus, 2018). Other women in their 60s further explained, “It will be good if she can disclose to her children” and “She can send them to the clinic to collect her ART” (W60-plus, 2018). Collectively, these comments show a willingness to share information with family and the added importance of disclosure for ART adherence through assistance with picking up medication *and* reminding one to take it. While these themes existed in 2013, they were both more common, perhaps because asked about more directly, but also more emphatic in 2018.

Expanding circles of influence – beyond families and partners

In 2018, FGD participants reported that they perceive that disclosure is more acceptable in public as well as private forums than in the past, as one woman in her 40s said, “I think that nowadays there is no longer secret if people are HIV positive because they could disclose to other people and this will help others to be free and accept also” (W40s, 2018). The evidence they gave for greater disclosure was knowing more individuals living with HIV in the community who had willingly disclosed their status.

Our participants in 2018 also noted that an important contribution of disclosure was the ways it allowed individuals to also share HIV prevention and management information in community. A woman in her 50s explained,

> Yes, I attended something somewhere and then a woman stood up and disclosed her HIV status, she is beautiful, and she looks healthy. Her husband died because of HIV, she went to the clinic and test, she tested positive, and she has engaged and stayed in HIV care. She also mentioned that as women we [can’t] have secret, we must disclose our HIV status because we will help others in our community and in our villages (W50s, 2018).”

Examples emerged that showed a new comfort with HIV disclosure, in part because of the use of ART, and as in the previous quote as a means of helping to care for others within their

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community (Angotti et al., 2018). For example, an older woman in the 60-plus FGD not only disclosed her own status to the group, but also highlighted the benefits of disclosure, “Yes, like myself I am not afraid to tell people that I’m on ART because I want people to know and to help if I can default treatment (W60s, 2018).” In this same vein, in the 2018 FGD, respondents talked about people taking ART at funerals and family gatherings, “To add on that, sometimes we meet as women, some of us, are taking ART they are disclosing their HIV status. I remember someone said, “Let me eat food is time to take my ART (MW50s, 2018).” Thus, within families and partnerships as well as out in the community, the increased availability of ART, the increased openness of others, and the evidence of ART’s life-sustaining nature, increased the willingness to share one’s positive status and to call on their networks for help in adhering to the daily ART regime.

Discussion

This longitudinal qualitative study examined beliefs and experiences around HIV status disclosure among older adults in rural South Africa. While HIV disclosure was severely limited in the early years of the epidemic due to extreme stigma, and the fact that HIV was viewed as a death sentence (Gilbert & Walker, 2010; Posel et al., 2007), it is clear that by 2013, individuals in this community were already changing their perspective about HIV and the viability of sharing one’s status with others. This preliminary shift in perspective provides a basis for the ambivalence about disclosure in 2013 – status should be known and shared, but actual disclosure was not easy nor widely practiced. By 2018, however, there was a growing conviction about the need for and advantages of disclosure and more widespread practice of doing so.

There are some limitations to our study that might affect the interpretations of the findings. It is important to note that the FGD in 2013 and 2018 were not comprised of the same groups of people, which could have influenced the findings; however, the differences across the FGD in 2013 and 2018 suggest that norms had shifted. In addition, the introduction to the FGD and their stated purpose was slightly different in the two years. In 2013, the greater focus was on community change since the end of apartheid and the ways HIV has impacted the community and people their age. When we returned 5 years later, the introduction was more focused on community experiences of HIV and AIDS, and specifically, changes in the past 5 years and those brought about by the wide-scale introduction of ART. Thus, from the outset, the respondents in 2018 were primed to think about the treatment cascade, and perhaps more likely to openly discuss disclosure. However, as was mentioned above, the shift in questions was appropriate for this methodological approach, as they reflected changes our study team knew were happening in the community (e.g., rollout of ART, reduced AIDS-related morbidity and mortality, increasing prevalence and awareness of NCDs), and so asking new questions that elucidated responses to these changes was essential to understanding the norms and experiences of older persons in this community at that time.

Our respondents generally supported the idea of disclosure, but the purpose and likelihood of disclosure depended on whether one is disclosing to partners or other family members. While everyone in the 2013 FGD might have agreed that disclosure is important in the

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abstract, since not knowing could hurt you or your sexual partner, their desire to share information about their own health with others was limited and connected to a yearning for privacy, which may not have been unique to HIV or related to stigma. There were shifts by 2018, as the negative consequences of disclosure for the individual lessened with the expansion of ART (Zuch & Lurie, 2012). In addition, the importance of sharing in wider circles to teach others about the benefits of ART (community), build trust (partners), and get support with medicine collection and adherence (family) emerged.

The FGD reveal considerable rhetoric and expectations that communities should treat those living with HIV well, like anyone else. Many said both in 2013 and 2018, that people living with HIV are accepted in society and no longer shunned (Campbell et al., 2013). However, at earlier points in time, rumors seemed to be the primary way of knowing others' status since disclosure remained limited, and was considered unwise, especially beyond partners and family (Watkins, 2004). In this period, if they tested positive, they may have disclosed to a spouse or partner, but even that disclosure was deemed risky in the 2013 FGD. In 2018, FGD participants reported more confidence that disclosure to one's partner was important, even if it remained complicated (Green et al., 2018; Odiachi et al., 2018).

Although our FGD indicate that disclosure remains a delicate decision or a 'sensitive issue', there was a clear shift from 2013 to 2018. In 2013, our participants regularly talked about HIV as someone's 'secret'; by 2018, the normative discourse was that while people living with HIV have to choose carefully to whom they disclose their status, it was important to relationships and one's own health to do so. A number of discussions supported the idea that partner disclosure was not only important, but about building on the love and trust in relationships whereas pre-ART, if a partner was HIV positive or asked to use condoms, these discussions were often seen as a signal of lack of trust or betrayal within the couple (Bhatia et al., 2017). While a majority of older persons are divorced or widowed, the opportunity this new discourse on disclosure offers suggests that disclosure is being or can be recast as a symbol of love and trust, rather than of betrayal, similar in ways to disclosure in younger persons' relationships (Green et al., 2018). Older men, for example, who are widowed or otherwise single, may need or want someone to take care of them. Thus, re-partnering, and disclosing one's status, with a woman who may be HIV positive herself, is one way to get the necessary support for activities of daily living (for cooking, cleaning, and caretaking). While for young people, disclosure might risk their 'reproductive life projects' – building a family, children, marriage (Smith & Mbakwem, 2010), for older persons there is not that same threat, and in fact, there may be greater benefits as it enlists support to live healthily (Angotti et al., 2018). Given that many of our respondents in the FGD, and older persons in this community more generally, are living with multi-morbidities – sometimes HIV and another chronic condition like hypertension or diabetes, or multiple other chronic conditions, it is important to note that dependence on family and community to 'live healthily' was not just happening in the context of HIV and ART (Chang et al., 2019; Mojola et al., 2020).

Disclosure to family, in particular, was reported to be a common practice in the community by 2018 and was connected to the benefit of social and family support towards medication adherence. This is similar to what has been reported in other settings, perhaps particularly among older persons, that they disclose to their children and/or grandchildren who then

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collect and/or remind them to take their medication (Foster & Gaskins, 2009; Schatz et al., 2018). This practice may be even more common among older persons who want assistance due to mobility constraints or worries about remembering to take medication daily, whereas younger persons may be more likely to share with intimate partners than a wider set of family members (Tam et al., 2015).

There seemed to be a consensus in the 2018 FGD that family members were likely to be supportive when positive status is disclosed. This signaled a change from the norm in 2013, when few family members were informed, or at least had specific knowledge about their kin living with HIV. For communities like Agincourt, where the majority of older persons live in multigenerational households, becoming more open about one's status *and* calling on kin for support around medication adherence is an important finding. It builds on notions of mutual support and 'taking care' of others, ingrained in the roles older persons claim for themselves and their wellbeing (Angotti et al., 2018); it also provides an opening for interventions and messaging that might be used to increase ART uptake and adherence among older persons.

Conclusion

The 2018 data shows a shift in the rationale and rhetoric from 5 years earlier – disclosure is now necessary and directly connected to the life-saving nature of ART for older persons living with HIV. Although some worry about stigma remains in terms of wider disclosure in the community, ambivalence about sharing one's positive status, particularly with a trusted partner or kin, had all but disappeared. Participants cited wanting help with collecting ART and wanting reminders to take their medication as key reasons for sharing their positive HIV status with others. The majority of the participants believed that medication compliance is better when one's status is disclosed. Importantly, this belief was occurring at a time when many older persons in this community are dealing with multiple health conditions, making family and community support key to living healthily (Chang et al., 2019; Mojola et al., 2020). Participants also viewed disclosure practices as more common now than in the past, and believed living with HIV does not preclude someone from finding new partners even if they disclose their status to them.

Longitudinal data, that traces changes over time in older persons' views on disclosure to partners, family and beyond, are essential. They allow us to assess the gaps in older persons' needs around HIV prevention and treatment, particularly as the epidemic ages in South Africa and beyond. This remains true even if the actual participants and questions were not identical over time. It is important to capture the ways in which discourse and norms about disclosure have shifted (and the ways they have not) among older persons in a high HIV prevalence community. Disclosure to family, and even trusted partners, is discussed as normative among older persons. These data provide insights into the ways older persons' own discourses and actions can be used to think about or reframe messaging to encourage older persons to disclose their status to those from whom they may gain support. For example, signaling through open comments about needing food to take medication or taking ART out of one's bag at a funeral are becoming more commonplace.

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This age group is known to have lower HIV testing rates than their younger counterparts (Mtowa et al., 2017; Nabukenya & Matovu, 2018). The uptick in acceptance of disclosure, particularly due to its relationship to ART adherence, also could be used to normalize HIV testing in this age group. The combination of the current Test and Treat policy and the reduction in worry about community disclosure could be used to recast 'know your status' campaigns, prevalent for decades but targeting younger people, with images of grandchildren helping their grandparents remember to take their ART or children picking up medication for their parents. This declared desirable outcome of disclosure could be used as a push for older persons to request testing *and* to disclose their status. Family and partners are key support networks to leverage around medication adherence for older adults who are living with HIV. Policy makers should draw on the benefits of mutual support to tailor programs and policies to older populations, particularly as the population of people aging with HIV continues to grow.

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