"I attend at Vanguard and I attend here as well": Bifurcated care among older South Africans living with HIV and NCDs

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SHORT ABSTRACT:

South Africa has one of the highest HIV prevalence rates worldwide, and with the rollout of ART beginning in 2003, the number of infected individuals in older ages is increasing. Yet, little is known about the experiences of older person's access to HIV care. Further, evidence suggests that HIV-positive older people have higher rates of chronic disease than their younger counterparts in South Africa. Thus, understanding the experiences of managing treatment and navigating health services with HIV and NCD co-morbidities is a crucial gap to fill in the literature. Using data from a small qualitative case study, we show how bifurcated care may be having negative health consequences for older South Africans living with HIV in an urban setting. These data suggest the importance of steering health policy in HIV-endemic and aging populations toward integrated care with focused services to help older persons manage HIV and NCDs simultaneously.

LONG ABSTRACT: We plan to add to each aspect of the paper, including adding in direct quotes and additional analysis in the results section.

Introduction: South Africa has one of the highest HIV prevalence rates in the world, and with the rollout of ART beginning in 2003, the number of infected individuals in older ages is increasing (Gómez-Olivé et al., 2013; Hontelez et al., 2011; Mills et al., 2011; Mills, Bärnighausen, & Negin, 2012; Mutevedzi & Newell, 2014). Thus, it is essential to understand their needs in relation to health care services. Most data on HIV incidence, prevalence, voluntary counseling and testing, and ART uptake focus on those aged 15-49. Yet, HIV prevalence is only slightly lower among those aged 50-plus than those in the next younger age groups (Hontelez et al., 2011; Mills et al., 2012; Mutevedzi & Newell, 2014; Negin & Cumming, 2010).

While barriers to ART access and adherence have been studied (Chang et al., 2013; Jemmott et al., 2014; Nakimuli-Mpungu et al., 2014; Wouters, Masquillier, Ponnet, & le Roux Booysen, 2014); and there have been a number of successful interventions in Africa that used support groups for HIV-positive individuals to encourage access and adherence (G. Foster et al., 2014; S. D. Foster et al., 2010; Jaffar et al., 2009; Mathes, Antoine, & Pieper, 2014; Wouters et al., 2014); nearly all focused exclusively on adults under 50 years of age (Negin, Rozea, & Martiniuk, 2014). Analyses of older Africans show their barriers to health care broadly include a lack of money for transport and care, unkind treatment, and health staff who have few resources and little understanding of older persons' needs (Mabuza, Poggenpoel, & Myburgh, 2010; Waweru, Kabiru, Mbithi, & Some, 2003). There are also emerging data from high-income countries that older adults' access and adherence to ART is distinct. Although it appears that ART adherence is better among older populations, cognitive impairment can reduce adherence and treatment outcomes (Nachega, Hsu, Uthman, Spinewine, & Pham, 2012; Newman et al., 2012).

While it is important to focus on HIV in a country with extremely high prevalence, among aging populations, non-communicable diseases [NCD], e.g., hypertension, high blood pressure, diabetes, and stroke, are often the primary cause of illness and death. In fact, along with the growing prevalence of HIV among older persons, there is also an emerging NCD epidemic in South Africa (Kahn et al., 2006; Mayosi et al., 2009, 2012; National Department of Health, 2013; Westaway, 2010). Evidence suggests that HIV-positive older people have higher rates of chronic disease than their younger counterparts in South Africa, although not different from other older people, but those with HIV are more likely to have poorer overall health, including lower BMI and weakness than other older people (Negin et al., 2012). So in addition to commonly occurring co-morbidities older people are potentially also more at risk of other chronic conditions.

In Uganda research suggests that older people living with HIV are able to access care more regularly and better and this may explain why they are more likely to know if they have another chronic condition that those without HIV (Mugisha et al., 2016). This is possibly linked to high rates of older people with HIV who are accessing treatment (Negin, Nyirenda, Seeley, & Mutevedzi, 2013). In addition, other research in Uganda suggests that older people who are HIV-positive have visited a clinic more recently that those who are HIV-negative possibly as a result of improved engagement in care (Mugisha et al., n.d.). Chronic communicable disease, including HIV, has been found to be an important predictor of health care usage in a study of older persons' access to care in a rural region of South Africa (Ameh, Gómez-Olivé, Kahn, Tollman, & Klipstein-Grobusch, 2014), suggesting that these people do link to care. However, there is limited evidence to date the experiences of older South Africans' living with HIV and their access to the complex health services they may require. In addition, much of the work on older South Africans' experiences of being affected and infected by HIV have been conducted in rural areas (Bohman, van Wyk, & Ekman, 2011; Knight, Hosegood, & Timæus, 2013; Nyirenda et al., 2012; Ogunmefun, Gilbert, & Schatz, 2011; Schatz, 2007). We aim to explore in-depth the experiences of health care seeking by older people living with HIV in one urban community.

Methodology: This small-scale qualitative case study explored the experiences of people over the age of 50 living with HIV in an urban part of Cape Town called Langa. Data was collected from 6 individuals using in-depth semi-structured qualitative interviews. The interviews, were conducted by a trained and experienced qualitative interviewer in Xhosa and focused on experiences of living with HIV, with particular questions on the domains that facilitate or create barriers to older persons' ART access and adherence, as well as questions related to health care utilization more generally.

The sample for this paper was nested within the Prospective Urban and Rural Epidemiological (PURE) Study (Corsi et al., 2013; Teo et al., 2009), a longitudinal survey on non-communicable disease among people over the age of 35. The PURE survey is conducted in Langa, a predominantly black, mixed formal and informal settlement township established under apartheid, which is located 10 miles outside of Cape Town. While PURE focuses on the health of adults, their work mainly has centered around NCD; however, they also collected self-reported data about HIV status from all respondents at each interaction with respondents. Interviewees who reported being HIV-positive at any of the data collection waves within PURE and aged 50 or over at the time of data collected were selected for inclusion in our study. These selection criteria limited the sample somewhat because the bulk of the interviewees in PURE who fit our criteria were between the ages of 50 and 60 years and were women. Further, almost half of those originally identified could not be interviewed

because they had either relocated from Langa or had died since the last PURE data collection. The resulting sample included 5 women and 1 man between the ages of 50-70 who are living with HIV and are residents of Langa.

Data was transcribed and translated into English from Xhosa. The transcripts were then read by the two researchers for familiarization with the data and to identify emergent themes. The themes emerging from the transcripts included problems with ART adherence related to food security or hunger, a sense of loneliness and isolation amongst the older people despite often living with family and finally the bifurcated nature of access to care for their multiple conditions. This paper focuses on the latter theme and explores the experiences of these older persons living with HIV in accessing care. The data were analysed using thematic analysis.

The community of Langa, a predominantly black township established under apartheid, is located 10 miles outside of Cape Town. Langa is a predominantly black, mixed formal and informal settlement. The community has relatively good access to health services with an established clinic situated in the center of the community allowing for with relatively easy access to residents. This facility is a government run primary health care facility providing HIV, AIDS and TB-related treatment, care and support services. The Langa Clinic offers treatment for opportunistic infections and maternity services for pregnant women. The Vanguard Community Health Centre, is a second health facility used by residents of Langa. It is situated in Bonteheuwel, another suburb located across a main road. TheVanguard Community Health Centre is also a government run facility that provides similar services to the Langa Clinic; however, it also provides adult curative acute and chronic care. The Health Centre is about 2.5kms away from the Clinic and it takes about 30 minutes to walk between the two facilities. Services at both facilities are heavily subsidized and there is limited or no cost for the services themselves.

Results: The respondents within the study were all HIV-positive and all reported taking ARTs at the time of the interviews and had been doing so for various periods of time. Access to ART within the community in which people lived was provided at the dedicated HIV and TB Clinic in Langa. In addition, two respondents reported having had TB in the past, for which they had received treatment at the Langa Clinic. All respondents reported at least one other chronic condition that required specific treatment. These treatments entailed the respondents being enrolled in, and regularly accessing, health care in addition to ART care. The chronic conditions that they reported included high blood pressure, arthritis, diabetes and mental illness, in addition one respondent had experienced a stroke. While all the respondents accessed their ART at Langa, the services for management of and access to treatment for these chronic conditions were provided at the Vanguard Community Health Centre. A few of the respondents had been referred to other facilities mostly hospitals for in-patient or tertiary care but their most regular interactions with health care service providers was at the Health Centre.

The Langa Clinic, where respondents accessed HIV and TB care was within the community in which the people lived, and although some respondents lived further away on the outskirts of the area, it was accessible for all of them. Even those with physical difficulties, making walking far difficult, were able to make their way to the Clinic. Proximity meant that most people could walk reducing travel costs. In some cases, where they were adherent and stable on treatment, respondents received ART for up to a period of three months at a time. This limited these individuals' need to return every month to the clinic. In addition to relative ease of access to this facility for HIV care in general the respondents' experience of this clinic was

relatively positive. Respondents reported minimal problems with the quality of care and did not complain about common reported complaints of public services in similar contexts in South Africa such as long queues, waiting times and poor service or staff treatment.

Since all of the respondents were seeking care for co-morbidities at Vanguard Health Centre, they also spoke about their experiences of accessing care for these chronic conditions. One of the specific experiences they spoke about was the complexity of accessing care at Vanguard compared to the Langa Clinic. One initial barrier was the distance respondents needed to travel from their homes to the facility, which resulted in the older people having to make decisions about how to travel or negotiate assistance. The walk to the facility was far and a challenge especially for those with physical difficulties and or disability. Public transport was available making relatively easy to get to the facility, but not without a number of potential impediments. Despite some respondents having access government provided monthly social welfare support in the form of a disability or old age pension, the respondents complained of the cost of the taxis. They also complained about overcrowded taxis and at times long queues and waiting times for taxis particularly at peak hours. These various barriers to accessing the clinic resulted in complaints of tiredness and pain they experienced either as a result of having to walk to the facility or because of the time spent waiting at the facility. While the quality of care at Vanguard was considered good by our respondents, respondents complained that at Vanguard, unlike at Langa clinic, there were long queues and waiting times, which sometimes led to them miss being able to see a doctor or attend an appointment.

The problems with accessing the Vanguard facility for their non-HIV related chronic conditions were compounded when respondents got the dates wrong for their appointments and were turned away. There were also examples provided of where the respondents had clashing appointments for the Langa Clinic and Vanguagd Community Health Centre, making them have to choose which to attend or which to be late for.

Conclusions: The complexity of ensuring access to care and delivering treatment for co-morbidities to those living with HIV is not a problem unique to older people. Within the South African health system services for those with HIV and co-morbidities has been focused on integration between HIV and TB services with minimal integration of health services for other conditions. The problems associated with this are brought strongly into the spotlight in the community of study where the Langa Clinic situated within this community is only equipped to provide HIV, TB and some maternal and child health services with no availability of adult chronic health services or access to treatment. This despite the fact that older people within this study, as with those in other research, are dealing with the realities of multiple, mostly chronic, conditions (Mugisha et al., 2016; Negin et al., 2012, 2013; Nyirenda et al., 2012). Like findings in other studies in both South Africa and Uganda the older and HIV-positive respondents in this study were all enrolled in and accessing care. This was not without difficulty and complexity that in this case is related to the lack of integration of HIV and NCD health services. Older people are also faced with particular difficulties in accessing care that relate to physical barriers to access, but also financial and logistical barriers. In addition, the clinic providing them with care for their non-HIV chronic conditions also presented barriers once the person was there in terms of queues and waiting times. These challenges have the potential to have negative consequences for the health of older people.

The results of this study suggest that the needs to be more exploration of multimorbidity in older people in HIV-endemic areas. Even if those who are living with HIV experiencing chronic conditions at a similar rate to older persons not living with HIV, and even if older

persons living with HIV may be more effectively linked into care and treatment as a result of their HIV status (Mugisha et al., 2016; Negin et al., 2013), there is a need to assess and address bifurcated care. In this urban South African community, older persons living within HIV and experiencing co-morbidities are faced with significant barriers in their ability to access health care for their needs because of bifurcated care. Integration of care needs to consider not only the needs of the population 15-49 years old, which most often deals with TB as a co-morbidity, but also prioritize the needs of those who are older. Older people with HIV in this context are both aging with HIV and also newly diagnosed and requiring treatment for a complex array of medical conditions. Therefore services are required to address their needs particularly, which the results of this study suggest are simultaneous care for HIV and chronic conditions. Thus, health policy needs to address the need to integrate HIV and NCD care as the population living with HIV continues to age and the likelihood of those living with HIV also living with other chronic conditions including NCDs continues to increase.

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