

# “I Have to Push Him with a Wheelbarrow to the Clinic”: Community Health Workers’ Roles, Needs, and Strategies to Improve HIV Care in Rural South Africa

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## Abstract

With a 19.2% HIV prevalence, South Africa has the largest HIV/AIDS epidemic worldwide. Despite a recent scale-up of public sector HIV resources, including community-based programs to expand HIV care, suboptimal rates of antiretroviral therapy (ART) initiation and adherence persist. As community stakeholders with basic healthcare training, community health workers (CHWs) are uniquely positioned to provide healthcare and insight into potential strategies to improve HIV treatment outcomes. The study goal was to qualitatively explore the self-perceived role of the CHW, unmet CHW needs, and strategies to improve HIV care in rural KwaZulu-Natal, South Africa. Focus groups were conducted in May–August 2014, with 21 CHWs working in Msinga subdistrict. Interviews were audio-recorded, transcribed, and translated from Zulu into English. A hybrid deductive and inductive analytical method borrowed from grounded theory was applied to identify emergent themes. CHWs felt they substantially contributed to HIV care provision but were inadequately supported by the healthcare system. CHWs’ recommendations included: (1) sufficiently equipping CHWs to provide education, counseling, social support, routine antiretroviral medication, and basic emergency care, (2) modifying clinical practice to provide less stigmatizing, more patient-centered care, (3) collaborating with traditional healers and church leaders to reduce competition with ART and provide more holistic care, and (4) offsetting socioeconomic barriers to HIV care. In conclusion, CHWs can serve as resources when designing and implementing interventions to improve HIV care. As HIV/AIDS policy and practice evolves in South Africa, it will be important to recognize and formally expand CHWs’ roles supporting the healthcare system.

## Introduction

**I**N SOUTH AFRICA, where 7 million people currently live with HIV, the adult prevalence is 19.2%, constituting the largest HIV/AIDS epidemic worldwide.<sup>1,2</sup> Since 2005, the percentage of AIDS-related deaths has decreased from its peak at 50.8–31.1%.<sup>3</sup> This is attributable primarily to the government’s rapid scale-up of public sector HIV resources to make antiretroviral therapy (ART) widely available.<sup>4</sup> Initiated in 2004, these plans and policies, which included providing ART free of charge and using community-based programs to expand HIV care provision,<sup>5</sup> have improved HIV care throughout the country.<sup>6</sup>

Despite these successes, only 42% of people living with HIV were on ART as of 2013,<sup>7–15</sup> and at least one-third of all deaths in South Africa can still be attributed to AIDS.<sup>3</sup> Studies reveal unnecessary delays in ART initiation<sup>7,10,16</sup> and also an increasing likelihood that a patient will default as time passes.<sup>17</sup> Barriers to linkage to and retention in HIV care include denial, stigma, insufficient patient education, poor social support, socioeconomic limitations including transportation issues, fear of long-term therapy and its side effects, and lack of efficiency and accessibility within the healthcare system.<sup>7,8,10–12,14,18–22</sup> However, research on strategies to improve linkage to and retention in ART in sub-Saharan Africa remains limited.<sup>23</sup>

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In the setting of an already overburdened and rapidly expanding healthcare system, one component of the aforementioned scale-up has been the increasing use of community health workers (CHWs). The umbrella term “community health worker” was proposed in 1989 by a World Health Organization Study Group to describe a variety of community health aides who have “shorter training than professional workers,” are “supported by the health system but not necessarily a part of its organization,” are “members of the communities where they work,” “selected by the communities,” and “answerable to the communities for their activities.”<sup>24</sup> As community stakeholders with basic healthcare training, CHWs act as human resources, bridging their communities with the world of evidence-based medicine.<sup>25</sup> Strong evidence supports using community-based interventions to strengthen health services such as HIV/AIDS, tuberculosis (TB), and maternal and child health.<sup>5,26–30</sup> Recent systematic reviews demonstrate that treatment outcomes among patients primarily receiving care from CHWs or nurses are comparable to outcomes among patients cared for by doctors.<sup>31,32</sup> In addition, CHW systems are cost-effective and rapidly scalable units of the healthcare system.<sup>33</sup>

In South Africa, CHWs, also known as community caregivers or home-based caregivers, have been employed by NGOs and the Department of Health for the duration of the HIV/AIDS epidemic. The CHW role varies depending on the community’s healthcare needs; they most commonly serve as educators and mediators between patients with HIV or TB and the formal healthcare system.<sup>25,34</sup> However, CHWs often take on a larger role that is underappreciated and unrecognized,<sup>35</sup> making it difficult to identify approaches for improving CHW effectiveness. Thus far, research on the inner workings of CHW systems has been sparse,<sup>25,36</sup> but it is urgently needed to ensure appropriate and sustainable implementation of community-based interventions across sub-Saharan Africa.<sup>33</sup>

The CHW perspective is valuable, as it encompasses both patient and healthcare provider perspectives. By means of CHWs’ frequent contact with patients in their home environments, CHWs are privy to information that patients do not share with healthcare providers in the formal clinic setting. CHWs also directly witness—and attempt to mitigate—patients’ daily challenges. Thus, CHWs are uniquely positioned to provide insight into potential strategies to systematically improve HIV care and overall health outcomes. They are also the individuals who are best situated to elucidate the resources that CHWs need to provide and expand community-based care to better meet patients’ needs. The goal of this qualitative study was to describe the self-perceived role of the CHW, identify unmet needs that prevent CHWs from fulfilling this role, and explore recommended strategies for addressing barriers to the provision of optimal HIV care.

## Methods

### Setting

Approximately 180,000 traditional Zulu people live in the rural, resource-limited Msinga subdistrict<sup>37</sup> of the KwaZulu-Natal Province of South Africa. This province, where 37.4% of pregnant women are infected with HIV, has the highest HIV prevalence in the world.<sup>38</sup> Healthcare in Msinga is

provided by a 350-bed district government hospital, 16 satellite primary healthcare clinics, and a local NGO.

### Participant recruitment and informed consent

Twenty-one CHWs with  $\geq 2$  years of experience working in Msinga were recruited by phone for participation in one of three focus groups.<sup>21</sup> To provide a sample with broad geographic representation of the Msinga neighborhoods, these participants were purposively selected from a list of all 51 CHWs working for the aforementioned local NGO’s home-based care branch.<sup>21</sup> Since it was founded in 1999, this NGO has been employing CHWs for community outreach, with a particular focus on HIV/AIDS. Thus, the CHWs interviewed represent a convenience sample. Participants gave written informed consent allowing focus group interviews to be recorded and were reimbursed for travel expenses.

### Data collection

In a private conference room, the lead researcher together with a native Zulu-speaking research team member conducted three focus groups, each of 2.5 h duration (seven participants per group). A semi-structured interview guide was used to explore CHWs’ perspectives on their roles in their patients’ healthcare, ways in which patients can be supported regarding ART and HIV care, challenges that limit CHWs’ abilities to support their patients, and potential strategies to address barriers to HIV care. Open-ended questions and probes were used to facilitate open discussion. Audio-recorded interviews were professionally transcribed and translated into English.

### Data analysis

Thematic analysis of transcripts was conducted using an established hybrid approach of deductive and inductive coding borrowed from grounded theory.<sup>39–42</sup> Initially, a codebook was constructed using deductive (theory driven) themes from the literature. Transcripts and notes were reviewed during data collection to detect emerging inductive (data driven) themes and to revise the interview guide as necessary. Using Atlas.ti software, the final coding guide was applied to the entire dataset. Prominent patterns and themes were identified by means of data displays for relevant codes and simple frequencies.

### Ethics

This study was approved by institutional review boards at the South African Medical Association (SAMA) in Pretoria, South Africa and Yale University in New Haven, Connecticut.

## Results

All 21 CHWs were women, of mean age  $44.3 \pm 11.7$  years, and were working in a cumulative total of 21 neighborhoods served by 12 different clinics. Fourteen had  $\geq 10$  years of experience working as CHWs.

### CHWs’ roles and unmet needs

CHWs’ main roles included providing a consistent, long-term source of education, counseling, and treatment support

for patients and their families, and facilitating linkages to healthcare and social services. This involved helping patients to understand the role of ART in their lives, facilitating evolving motivations for treatment adherence over time, and combating pill fatigue (Table 1, Quotes 1–3). For example, patients who initially began ART due to fear of dying and then subsequently recovered found themselves needing to focus on new reasons for remaining on treatment. Some patients noticed their improving physical health, including trends in viral loads and CD4 counts, and decided they were

TABLE 1. QUOTES RELATED TO COMMUNITY HEALTH WORKERS' ROLES AND UNMET NEEDS

*CHWs' roles and unmet needs*

- 1 "A patient should not be stigmatized... we have to love them. I think showing them love is important so that the patient is happy to see you, they will not run away."
- 2 "I encourage them to keep [taking their treatment on] time, eat healthy, make sure that they do not miss their treatment date because that is another problem—when they are told to come back on the 15th to collect treatment but instead the person goes on the 20th. Those are dangers that I need to encourage the patients not to do... .. If you do not adhere to your treatment, the disease will start again and you will be sick again."
- 3 "Sometimes when you are sitting down with the patient asking, 'You were doing very well with your treatment, what is the problem now?' The patient will just say, 'But how long do you think I would take this treatment? I am tired.' ... Then I will tell the patient,... 'You should take your treatment for the rest of your life. Even in the clinic you were told this, you were advised that when you are starting your treatment you need to continue for the rest of your life.'"
- 4 "Sometimes some patients stop taking treatment as soon as they feel better from the pains they were suffering from before. When the patient is now able to walk unlike before and feeling much better, the patient would feel that his health is better, not knowing that the sickness is not yet over."
- 5 "If they do not accept, you need to sit down with the family and teach them about the disease, how it goes step by step, until they accept: If you see that you are failing as the caregiver, you inform the home-based carer. If they also fail there, you ask the social workers to come and educate the family about this disease... When talking to them during your home visit, you do not just start talking about the disease... We first educate them about different kinds of diseases, until you start touching on the topic [of HIV] that brought you there. Some end up accepting and understanding because you are always going to educate them... always making sure you are visiting them."
- 6 "It is good to always go and get tested, we tell the whole family while educating them, they would slowly adapt to the issue... Slowly and slowly, we do not give up. We keep on reminding them that life is precious, you need to look after yourself, know your status. After you know your status, you must not sit and ignore, continue with the process that you were told to follow."
- 7 "They advise us that, when we encounter a difficult situation, we must also consider ourselves. But you cannot ignore a situation when you meet a sick patient who does not have food and has not yet received the [disability] grant. You do [have to] provide the patient with something that you have... You do not know how you can make the patient take treatment without food in the stomach."
- 8 "It becomes a big problem if you also do not have anything—you are forced to get whatever [food you have] so that you are able to provide for that needy person to keep the person alive."
- 9 "I have encountered that problem where I had to care for two patients. Both of them did not have anyone taking care of them. They were critically ill. I had to make food for both of them and help them in taking their treatment. While I was preparing food for one patient, the other patient needed me. I had to wake up early in the morning and make everything very fast so that I am able to satisfy both of them... but when they are better there are no difficulties."
- 10 "I always come to the social workers because of the situation that I always work under with my patients. I talk to them, ask them to pay us a visit. The social workers do not come to visit the patients."
- 11 "On the issue of the ambulance we are having a lot of problems... we are not taught how to assist in delivering babies... we are now doing that job of assisting patients during labour because... maybe at night they would tell you that there are no ambulances until the next morning... The patient will call you as the caregiver to come and assist..."
- 12 "We do not have the working materials. When you are going to the community you find that, in a family, a granny or a member of the family is suffering from cancer; maybe it is ovarian cancer. The person needs pads, we do not have pads and the patients do not have pads. As the person who is working for the community, the patient is expecting it from you. If you are going to ask from the clinic, they do not have [them]. We would like to ask assistance for working material, things like pads, gloves and masks so that we are also protected from the diseases as we are working with the community."
- 13 "The hospital does not know me, people from the ambulances do not know me, even if I give my name and surname they will still not recognize me."
- 14 "I am going with my patient to SASSA (South African Social Security Agency) or to the clinic, maybe the doctor gave the patient a letter of approval to apply for the grant. When I get there with the patient, there is no difference between us. But if I had a name tag, the officials can be able to differentiate [me from the patient] so that we work together and they can quickly help us. SASSA officials can be able to identify me and the department I am coming from. That makes it easy for us to get assistance. Even in the community it makes our work easy. I am encouraging that point that we would like to get assistance and the support so that there is a difference between us as community homebased carers and the ordinary community people..."

cured or had reached a state of health where it would now be safe to skip ART doses (Table 1, Quote 4).

CHWs worked to encourage ART initiation and adherence by continually reinforcing the education that patients received during HIV/ART counseling and literacy classes. Furthermore, CHWs felt they could address denial by repeatedly visiting patients at home and carefully educating them together with their families on general health issues, including, but not limited to, HIV. Through this type of sustained interaction, some patients and family members who initially refused to believe in the existence of HIV as a disease eventually came to terms with their HIV diagnosis and accepted the necessity of taking ART (Table 1, Quotes 5 and 6). For patients who were concerned about ART side effects or were struggling to reconcile the idea of evidence-based ART with their traditional belief systems, ongoing support and counseling from CHWs and family members, especially after the literacy classes at the healthcare facility had ended, was crucial for successful ART initiation and adherence. For patients choosing not to disclose their HIV status to partners or family members, their CHWs were the only community members positioned to reinforce their ART adherence and monitor their disease progression.

Due to their reluctance to leave clinically deteriorating patients to fend for themselves, CHWs often found themselves providing food for patients or collecting ART on their behalf in ways that extended beyond their scope of work (Table 1, Quotes 7–9). For this reason, CHWs called for stronger support from their supervisors and other members of their CHW networks, including more consistent patient follow-up from social workers (Table 1, Quote 10). CHWs also frequently had to intervene during extenuating circumstances such as life-threatening illness or childbirth when the ambulance's arrival was delayed. Thus, CHWs requested access to supplies, particularly gloves, for personal and patient protection against infection (Table 1, Quotes 11 and 12). CHWs also expressed a need for clinic-issued badges or nametags that would formalize their roles in the healthcare system, thus enabling them to advocate for patients at clinics, hospitals, and police stations (e.g., when patients needed to obtain legal documents to facilitate their healthcare) (Table 1, Quotes 13 and 14).

#### *Recommended strategies to improve ART initiation and adherence*

Reducing stigma from healthcare providers and family members through education. To minimize the patient experience of stigma and isolation, CHWs suggested that medical staff discontinue stigmatizing practices such as dividing patients into separate waiting areas based on HIV status or using hand gestures to indicate a patient's status (Table 2, Quotes 1–3). Healthcare staff should be reminded that, despite the high prevalence of HIV in this region, a diagnosis of HIV is never routine for the individual patient and always requires thorough pre- and post-test counseling (Table 2, Quote 4).

In addition to medical staff training, community awareness and education campaigns were suggested as a way to disseminate knowledge to uninfected family members regarding signs and symptoms of HIV, how ART works and how to use it, and what to do if a family member tests HIV positive. Overall, this strategy would potentially reduce stigma both in the community and at home by helping community members

to appreciate HIV as a medical illness and to become more supportive of patients taking ART.

Reducing competition by collaborating with alternative medicine providers and establishing HIV/ART community support groups. CHWs advised their patients not to take traditional herbs concurrently with their ART because of their potentially dangerous side effects and the lack of knowledge about possible drug interactions with ART. For example, patients amenable to taking ART would likely have difficulty doing so if they simultaneously used herbal remedies that caused nausea and vomiting (Table 2, Quote 1). Nevertheless, CHWs reported that many patients demonstrate unwavering faith in traditional healing and religion, in which case discouraging the use of herbal remedies or prayer could conceivably erode patients' trust in the healthcare system (Table 2, Quotes 2 and 3). To better reach this patient population and reduce competition-related barriers to patients' linkage to and retention in ART, CHWs suggested that the healthcare system join forces with traditional healers and religious leaders through education and collaboration (Table 2, Quote 4 and 5). Cooperation between traditional and formal healthcare systems would be attractive to patients and likely to positively impact their engagement in care and adherence to treatment.

CHWs also felt that education campaigns could help patients living in communities with strong traditional influence begin to recognize their HIV-related symptoms as having a biomedical, as opposed to spiritual, origin (Table 2, Quote 6). Given the positive and empowering impact of social networks, community-based patient support groups, where patients can actively observe the health benefits of ART in their peers with HIV, were suggested to reduce community stigma and encourage patients to initiate ART (Table 2, Quote 7). It was noted, however, that these interventions would need to be sensitively designed to encourage sufficient participation from these stigmatized patients.

Reducing transportation barriers to healthcare access. CHWs expressed an urgent need to find alternative ways to help patients obtain their medications and access emergency care (Table 2, Quote 1). One suggestion was the designation of a nonemergency vehicle that would be used to support home-based care services for patients who intermittently need help with ART collection and transportation to the hospital (Table 2, Quotes 2–4). In addition, designating community halls or other physical structures to be used as shelters for ART collection during bad weather might allow mobile clinic units to continue distributing ART to patients living in areas only serviced by mobile clinic units. Finally, patients from rural areas frequently moved to bigger cities for temporary employment, which required them to transfer care to their new local clinic. CHWs felt that the transfer-of-care referral process was complicated, inconvenient, and confusing for many patients (and even CHWs), and they recommended simplifying or streamlining the process to improve retention rates among mobile patients (Table 2, Quote 5).

Promoting patient-centered care by mitigating food insecurity and triaging patients based on socioeconomic and medical need. CHWs consistently found themselves defending the formal healthcare system to patients to counteract dissatisfaction due to long wait times and negative

TABLE 2. QUOTES RELATED TO RECOMMENDED STRATEGIES  
TO IMPROVE ANTIRETROVIRAL THERAPY INITIATION AND ADHERENCE

*Reducing stigma from healthcare providers and family members through education*

- 1 “I think the change that can be made regarding collection of treatment... I wish they [clinic staff] can make them [HIV patients] stick together with the sick people and not be separated from others. Only the patient must know while sitting in the queue which side are they going to when getting inside [with] the nurses to collect treatment, without being discriminated from the outside.”
- 2 “I had a complaint that I raised at one clinic... When it was the day for the ART treatment collection, the patients that were coming to collect their treatment would be kept aside on their own, and those that are coming to see the [regular] doctor would be kept separate too. People of the community were complaining about that arrangement, that it did not feel right for them to be separated from the others... They were made to sit on the veranda. There was even a saying from other patients that when it was the day for the ART treatment collection, other [HIV-negative] patients would say, ‘I am not going to the clinic today because it is the day for the ART’, in an insulting manner. I requested a meeting with the [head nurse] sister... We had to tell her everything about it. In that way the issue was sorted. Now when they are coming to collect their treatment, they sit with everyone and follow the same queue like everyone else in the clinic and take their treatment without others knowing what they are there for... The clinic became a better place. Really we do appreciate the acknowledgement of that issue.”
- 3 “My suggestions, like raising the three fingers [to indicate that a patient is coming to collect ART], if those [staff members] that are doing it can stop, because I think it is not done in all the clinics.”
- 4 “The people [patients] who are already on treatment... are doing well so they [counselors] also assume that they [new patients] will eventually be alright too with the help of the homebased caregivers. I would not say all the counselors are like that but I have seen on many occasions things like that happening. That is also the cause of why people are defaulting after being initiated on the ART programme...”

*Reducing competition by collaborating with alternative medicine providers and establishing HIV/ART community support groups*

- 1 “It is bad because... the treatment does not work properly because of the traditional medicine. These traditional medicines cause running stomach (diarrhea) and people lose weight; they [traditional healers] ask people to use the syringe (enema) and they [patients] lose weight and become weak.”
- 2 “You will start feeling sick even after taking the ART treatment, then you will think otherwise—that ‘this is not the disease I am suffering from so let me just go and see the traditional healer so that I can be told what I am suffering from.’... When you go to the traditional herbalists, they do not advise you to continue taking your treatment given at the clinic and see as the days go by if you will be getting any better, because they are also in business—they want money. The traditional healer will tell that person that they need to perform some traditional ritual, this and that... It depends on that person, how committed is the person going to be to their treatment without getting the ideas that it is something else [causing their symptoms] rather than the disease. If the person has gotten in their minds that it is something else [other than HIV], it becomes difficult to talk to that person out of that idea.”
- 3 “The situations that we come across... [patients] being lied to and accepting things that they hear from people... telling you to ‘Stop taking your treatment. We are going to lay hands on you, in the name of Jesus.’ You will stop taking your treatment but after a while the sickness will come again. It does not care about laying of hands, [the] illness will be back... When others hear about the [herbal remedy] bottles, they just stop taking treatment and follow those bottles, while we have seen that the ART [medications] are the ones that are important.”
- 4 “If there can be some way to try and teach the traditional herbalists [and] healers that if a person is sick they need to try and tell the person the real truth that the person needs to go to the clinic. They [the traditional healers] will still get the money, even if they are telling this truth, because the patient will leave the consultation fee. They need to direct the person to the right place at the clinic and tell them to go to the clinic, they will get that little money for consultation, they should not be worried about the money.”
- 5 “It would be better if they [the traditional healers and church members] are educated. Even themselves they are dying of this disease—how come they are not cured themselves?”
- 6 “Can we not have the awareness campaigns? Where we can educate the community that has been infected and those that are not infected but [need to] be made aware that this disease is there... Just to encourage them that if you find yourself in that situation or your child is infected, you must have knowledge of the processes to be followed.”
- 7 “I think it would help that, [for] those that have certain [traditional] beliefs, we should have some support groups for them in the area. They should encourage each other about adhering to the treatment... It would also help [with adherence]. Maybe some patients will realize, when they see the other people getting better [on ART], those patients will realize that ‘I will also get well.’ So it would be better if they encourage each other.”

*Reducing transportation barriers to healthcare access*

- 1 “Sometimes you find that you called in the morning around 8:00 but the ambulance will only arrive at 3:30 and the person is sick. If it was someone in labour, the ambulance will arrive after the patient has given birth at home. I would please like to ask if they can keep the time, not to keep on telling lies that they are closer when they are not. You will wait and wait until the sunset.”

(continued)

TABLE 2. (CONTINUED)

*Reducing transportation barriers to healthcare access*

- 2 “I have a big problem... a patient that is very ill. I have to push him with a wheelbarrow to the clinic. It is very difficult for me because the clinics are too far away from homes. I see a need for a clinic car so that, if there is someone who is very ill and unable to reach the clinic, that patient should be able to get the car assistance that is going to come and fetch the patient. It becomes difficult when the patient does not have money. You do not know how you will travel with that patient. Even you [the CHW]... do not have money to hire the car to take that patient to the clinic. It costs a lot of money to hire a car.”
- 3 “To add on the point that was raised by my sister about the small cars... We started going to the clinic. At the clinic they said it was too much for them, the patient needs to go to the hospital... I was forced to take the last money in my pocket and stop the cars that were passing by to assist me with this patient.”
- 4 “If [the hospital] can assist each and every clinic by arranging some cars that are always going to be there to assist in the case of emergencies at night.”
- 5 “We are also having some problems on that issue of what needs to be done... Some people need to come back and collect the treatment [on] this side while working [on] that other side... I do not know what needs to be done... if you have to start and be given a letter to use [at] the other side... there are so many of them who call and ask us to collect the treatment on their behalf [at] a certain time, like after three months. And then [they] come back for a check-up. I have a problem—I do not know about the others—because I do not know how that process goes.”

*Promoting patient-centered care by mitigating food insecurity and triaging patients based on socioeconomic and medical need*

- 1 “They brought the woman here to the hospital. She was not attended to. They just made her sleep on the benches and suffer until she went to the traditional healer.”
- 2 “In most cases we are taught that if the person has a problem we must not encourage that person to go to the traditional healers but to go to the clinics and the hospitals. This is making us liars in front of the community.”
- 3 “The government, or it is the hospital, they need to get involved in the situation at the clinics. There are clinics that are not working on Saturday and Sunday... When you are bringing a person to the hospital, you need to bring the referral letter from the clinic. If the person is sick on a Saturday and you take him to the hospital, they will tell you to go to the clinic but the clinics are closed on Sunday until Monday. Some people are dying while you are taking them to the hospital, the person will die on the benches while you are still waiting because you did not bring the [clinic] referral letter. We have lost a lot of people through that process... the person can really die just because of this clinic letter.”
- 4 “Some patients, sometimes even if they are critically ill, the hospital will not admit the patient and you get confused about how are you going to manage at night as the patient has to go back home.”
- 5 “I wish when looking at the patient [that] they [could] differentiate the needy person and understand that person’s situation and get involved in helping.”
- 6 “The clinic needs to look closer at the wellbeing of the patients, things like the background of the patients, where they are coming from.”
- 7 “The patient should not just be given the treatment without [the clinic] knowing about their background, not knowing if the person is coming from the bush, where does the patient sleep. They should also enquire about the children, how many children does the patient provide for in the family.”
- 8 “They complain to us about how they are supposed to take treatment on empty stomach. Like some are not working and not getting a [disability] grant, but they are sick. That makes it hard for them as they have to adhere to treatment, even after following all the processes. But it is hard to take treatment without eating anything.”
- 9 “If they [healthcare staff] are coming [to see the patients], they should please bring food parcels. The patients [think], ‘Why did they come to see me if they are not bringing something for me?’ If you are bringing something it shows the love to the patient.”

ART, antiretroviral therapy; CHW, community health worker.

interactions with healthcare staff (Table 2, Quotes 1 and 2). Since low socioeconomic status frequently limited patients’ abilities to access healthcare and remain adherent to treatment, CHWs strongly recommended a triaging system to help clinic staff become more attentive to particularly resource-limited or “high-risk” patients (Table 2, Quotes 3–7). Such patients’ hospital and clinic visits were typically rare, invaluable opportunities to enable ART initiation and adherence as well as pivotal moments in patients’ lives where dissatisfaction might lead them to choose traditional healing over ART.

CHWs reported that patients were notably more receptive to healthcare staff when food parcels were provided during

home-based care visits; patients seemed to feel that this gesture was a sign that their struggles were being acknowledged and that providers cared about their overall well-being (Table 2, Quotes 8 and 9). Provision of food parcels or social welfare grants to reward patients who initiate, regularly take their ART, and achieve viral suppression would encourage adherence while simultaneously helping to strengthen patient–provider relationships and address food insecurity.

### Discussion

People with HIV in sub-Saharan Africa report a need for support ranging from “instrumental” support (i.e., material,

medical, and financial assistance) to informational and emotional support.<sup>21,43</sup> CHWs serve a key role in HIV-related care by providing a consistent source of home-based HIV/ART education, counseling, and support for patients and family members. By building relationships with patients over time, CHWs can effectively mitigate barriers to care such as stigma, denial, inadequate patient education, and poor social support.<sup>25</sup> Evidence also suggests that patients would benefit from the formal expansion of CHW roles to include patient support group activities<sup>44,45</sup> and collaborative partnerships with traditional healers.<sup>46,47</sup> This is consistent with studies from Mozambique and Lesotho showing that there is an unmet patient need for health-related social support<sup>43</sup> and suggesting that this need can be met, at least in part, by CHWs.<sup>36</sup> Beyond the scope of the CHW role, CHWs spoke to a need for the expansion of government assistance programs to reduce socioeconomic barriers to care and for modifications to routine clinical practice to provide less stigmatizing, more patient-centered care. These recommended strategies target barriers to care for the individual patient as well as the broader social drivers of HIV/AIDS described in formerly published frameworks for HIV prevention and treatment such as Auerbach's socio-economical model.<sup>48,49</sup>

Through longitudinal education and counseling, CHWs are uniquely positioned to intervene at points in the HIV care continuum highly susceptible to attrition.<sup>25,50</sup> Emerging evidence suggests that counseling can be adapted to facilitate rapid ART initiation in a way that reduces pre-ART loss to follow-up without later compromising patient adherence.<sup>51</sup> To support this type of intervention, CHW training should include enhanced HIV/ART education and counseling skills.<sup>52</sup> Closer working relationships with clinic staff, nurses, and social workers, for example, would fortify CHWs' skills and also provide opportunities to obtain guidance on managing difficult patients. Although in Mozambique patients most often receive informational and emotional support from family or friends, as opposed to healthcare staff,<sup>43</sup> these types of support may be especially effective when provided by CHWs. Specifically, CHWs' community membership may make them more approachable to patients while their working relationship with the healthcare system provides them with a level of healthcare knowledge and ability to navigate the system that surpasses the average community member.

CHW programs must be sufficiently structured and monitored to prevent challenges that many such programs have faced in the past, namely unmanageable workloads, lack of clear scope of work, insufficient supervision, lack of accountability, inadequate resources to effectively perform their assigned tasks, and lack of recognition from official healthcare providers.<sup>53</sup> In South Africa, the current CHW role does not formally include responsibilities such as providing extended home-based care for physically weak or socially isolated patients, helping with logistical issues such as transportation to a healthcare facility, collecting medications, and assisting with childbirth while waiting for an ambulance. Nevertheless, CHWs feel compelled to act in these capacities, because it is clear to them that providing these services improves patient outcomes and, in their absence, patients will suffer. The extent of the CHW role must be recognized so that CHWs can be appropriately trained and equipped to engage in such activities.<sup>53,54</sup> Deployment of CHWs without the supplies and resources they require to

accomplish tasks is unproductive, discouraging to CHWs, and detrimental to CHW credibility,<sup>53</sup> and it exposes CHWs to unnecessary risk. Failure to define their scope of work also creates risk of unmanageable workloads and demands that compete with their primary responsibilities.<sup>55</sup>

Engaging medically stable patients in community support groups, or "community-based adherence clubs", is a promising and low-cost strategy for improving HIV care, particularly retention in ART. Often facilitated by CHWs, such groups can provide support within the community, reduce challenges associated with denial and stigma, and reduce the frequency of patient visits, thus minimizing congestion at local clinics.<sup>44</sup> A 2015 study in urban Cape Town demonstrated that patients engaged in adherence clubs had significantly lower viral loads and higher CD4 counts after 4 and 12 months on ART compared with patients managed at primary care facilities.<sup>45</sup> This type of group intervention could be adapted for use in rural South Africa and facilitated on a monthly basis by experienced CHWs selected by their local clinics or communities.

Several studies have recognized the influence of traditional belief systems on ART success and the need for integrated healthcare services.<sup>46,47</sup> Consistent with our findings, at least one study in KwaZulu-Natal has demonstrated that the use of traditional medicine is associated with nonadherence to ART.<sup>47</sup> Healthcare providers and CHWs often express a mistrust toward traditional healers, yet they play an important role in Zulu and African culture and society.<sup>46</sup> Indeed, some traditional healers perceive themselves as having a complementary role in HIV care and do not necessarily view their remedies as substitutes for ART.<sup>46</sup> Neglecting to directly address the use of alternative medicine and the role of traditional healers in HIV care undermines patients' trust in the formal healthcare system and represents a missed opportunity to engage patients in the HIV care continuum through patient-centered, holistic medical care. Patient education in clinics and communities should address the controversial issue of religion and traditional healing and strategies for safely combining ART with traditional remedies so as to minimize medication interactions. CHWs recommended negotiation skill training for healthcare providers to help address patients' preferences for alternative therapies. CHWs can also support healthcare providers by brokering relationships between patients, healthcare providers, religious leaders, and traditional healers.

The need for improvements in clinical practice, particularly better patient-provider relations and systematized patient care engagement and follow-up, has emerged in other South African studies.<sup>21,56-59</sup> Acknowledging the limitations of an overburdened healthcare system, staff training should be designed to encourage the provision of destigmatized, patient-centered care and to ensure adequate patient counseling at time of diagnosis.<sup>50</sup> There is also growing evidence supporting the need to improve access to HIV care by addressing a patient's socioeconomic circumstances.<sup>21,48,60</sup> Food insecurity<sup>60,61</sup> and transportation costs<sup>62</sup> are common barriers to the maintenance of chronic medications and the receipt of emergency healthcare; loss to follow-up from ART is essentially unavoidable for patients without the financial means to reach the clinic to regularly collect medications.<sup>60,62</sup> Given long clinic waiting times that may require patients to return the next day, combined with CHWs' reports of patients becoming

acutely ill and dying at home for lack of means to reach a healthcare facility, government systems need to develop methods for assisting patients who present to the clinic appearing particularly ill or socioeconomically destitute.

CHWs in this study also offered several tangible strategies to directly mitigate socioeconomic strain, thereby contributing to the limited research on interventions to address financial barriers.<sup>63</sup> To ameliorate the burden of transportation costs and improve access to both urgent and routine care, CHWs suggested strengthening the ambulance system and devising alternative ways to distribute ART to patients for whom financial limitations are a major barrier. To further offset socioeconomic barriers to care, CHWs suggested the use of stipends and cash transfers, which have been effective at improving linkage to care and reducing loss to follow-up in countries such as Tanzania and Uganda.<sup>64</sup> Previously, in South Africa, patients with low CD4 counts could obtain disability grants,<sup>65</sup> but this practice was formally discontinued because of concerns, without clear evidence,<sup>65</sup> that patients were intentionally not taking ART to keep their CD4 low and thus remain eligible for disability.<sup>66,67</sup> Thus, government disability grants could be reframed to reward monthly ART collection or viral suppression and potentially re-categorized as chronic illness, basic income, or unemployment grants. Financial incentives, while logistically challenging to implement, may be more effective at encouraging engagement in care than merely subsidizing transportation costs and may also increase household and family support for ART.

The main limitation of this study was the lack of data triangulation. However, by design, this study was meant to focus on CHWs' unique experiences and allow for their meaningful self-reflection. Also, due to the qualitative nature of this work, our findings may not be generalizable beyond KwaZulu-Natal, South Africa. Despite these limitations, the synthesis of our findings with other recent studies lays the groundwork for several salient, practical, and potentially low-cost interventions to improve HIV-related healthcare in rural South Africa.

In summary, CHWs support HIV-related healthcare provision but feel that their role is unrecognized and, consequently, inadequately supported by the healthcare system. Their suggestions for improving HIV care include acknowledging and expanding CHWs' roles, and sufficiently training them to provide services, including education, counseling, social support, home- and community-based ART distribution, and basic emergency medical care. Clinic and hospital staff would benefit from additional training to reduce stigma, negative patient-provider interactions, and the perception of competition with alternative medicine. CHWs can also work more closely with healthcare staff and traditional healers to facilitate the provision of more patient-centered and holistic medical care. Finally, several strategies for reducing socioeconomic strain and disease-related disability were provided. Moving forward, policymakers may benefit from recognizing and expanding CHWs' roles supporting the healthcare system as well as obtaining feedback from CHWs regarding interventions to improve HIV care.

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