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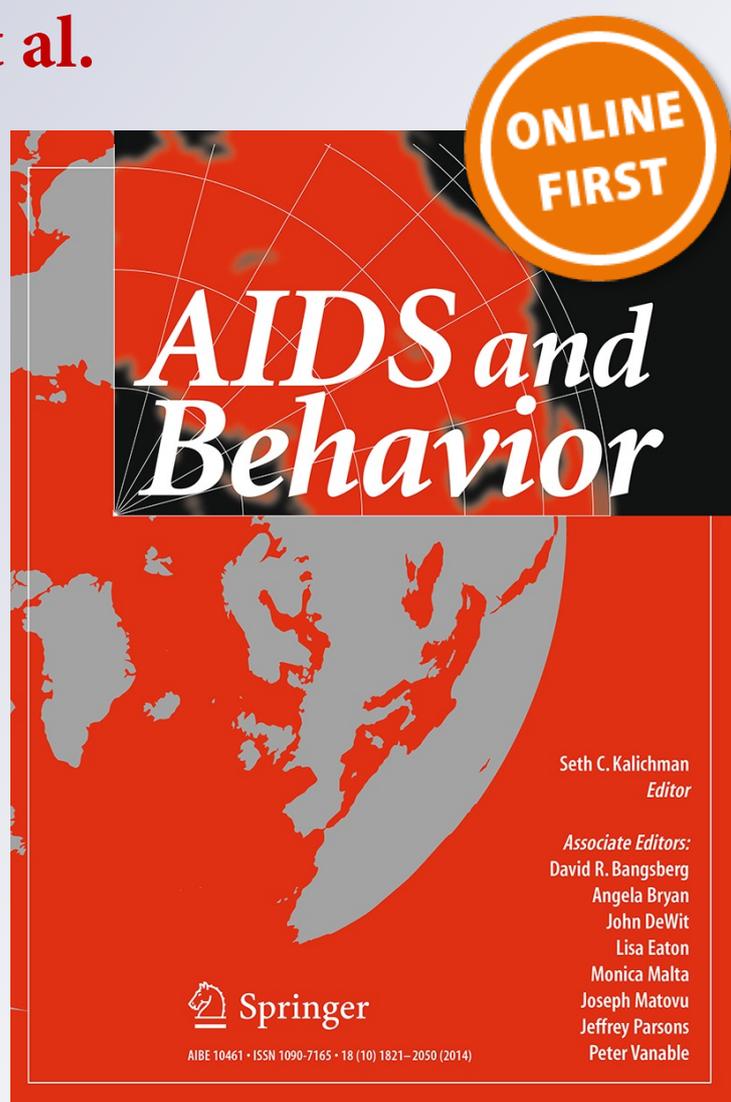
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# Understanding Treatment Refusal Among Adults Presenting for HIV-Testing in Soweto, South Africa: A Qualitative Study

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**Abstract** HIV treatment initiatives have focused on increasing access to antiretroviral therapy (ART). There is growing evidence, however, that treatment availability alone is insufficient to stop the epidemic. In South Africa, only one third of individuals living with HIV are actually on treatment. Treatment refusal has been identified as a phenomenon among people who are asymptomatic, however, factors driving refusal remain poorly understood. We interviewed 50 purposively sampled participants who presented for voluntary counseling and testing in Soweto to elicit a broad range of detailed perspectives on ART refusal. We then integrated our core findings into an explanatory framework. Participants described feeling “too

healthy” to start treatment, despite often having a diagnosis of AIDS. This subjective view of wellness was framed within the context of treatment being reserved for the sick. Taking ART could also lead to unintended disclosure and social isolation. These data provide a novel explanatory model of treatment refusal, recognizing perceived risks and social costs incurred when disclosing one’s status through treatment initiation. Our findings suggest that improving engagement in care for people living with HIV in South Africa will require optimizing social integration and connectivity for those who test positive.

**Keywords** Antiretroviral refusal · Engagement in care · South Africa · Treatment refusal · Linkage to care · ART initiation

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## Introduction

South Africa holds a unique position globally, having the largest number of people living with HIV in the world, estimated at 6.3 million as of 2013 [1]. The country has also been the single largest recipient of funding from the President’s Emergency Fund for AIDS Relief (PEPFAR), which has helped underwrite the cost of care for 2.5 million South Africans currently in treatment [2, 3]. Despite South Africa’s implementation of the world’s largest antiretroviral treatment (ART) program [4], only a third of the over 6 million people living with HIV are actually in care [5]. Those who do choose to initiate ART often have very low CD4<sup>+</sup> cell counts and high rates of co-morbidities, such as tuberculosis or other opportunistic infections, putting them at exceedingly high risk of early mortality [6]. The goal of achieving population-level reductions in the transmission of HIV in South Africa will not be achieved until all ART-

eligible individuals are actually on treatment [7], and people living with HIV no longer wait to start ART until they have symptoms of advanced AIDS [6, 8].

There is expanding literature focused on understanding why millions of ART-eligible individuals in South Africa are not engaging in care [6, 9–11]. This is particularly relevant in light of increasing evidence of the importance of treatment in individuals living with HIV as a form of prevention to uninfected partners [12–14]. Now with a shift in funding allocations from PEPFAR, and a move towards decentralization of care [15], there is a greater need to understand how to engage individuals living with HIV in a timely manner to avoid potential treatment delays [2].

We previously identified treatment refusal as an important cause of failure to link to care [16]. Our initial findings in a cohort of individuals presenting for testing in Soweto showed that 20 % of those who qualified for treatment refused to initiate ART, and the leading reason for ART refusal was given as “feeling healthy” (37 %), despite clients having a median CD4<sup>+</sup> cell count of 110 cells/mm<sup>3</sup> and triple the rate of active tuberculosis as seen in non-refusers. Other groups have now recognized the impact of ART refusal on engagement in care [11, 17–21].

These early findings suggest that people living with HIV may have a subjective feeling of health and wellness that is not intrinsically related to their actual clinical status. Understanding factors that drive treatment refusal will help identify at-risk individuals and strategies for effective, targeted interventions to improve linkage to HIV treatment and care. This research is essential to prevent what may be an early roadblock to “test and treat” strategies aimed at improving ART initiation and outcomes by offering immediate ART to individuals upon testing positive. We undertook this qualitative study at the site of our prior research in Soweto, South Africa to inductively identify reasons for ART refusal from patients’ and providers’ perspectives, and develop a comprehensive explanation of why patients who presented to an urban voluntary counseling and testing (VCT) center refused to initiate treatment.

## Methods

### Study Design and Overview

We performed a qualitative, patient and provider focused study using semi-structured interview guides. Our goal was to understand why adults who presented for testing and learned they were HIV positive and eligible for ART, ultimately refused to initiate treatment. Qualitative research allowed us to gain a deeper conceptual understanding of an under-studied phenomenon, and provide a

basis for developing our explanatory model of ART refusal.

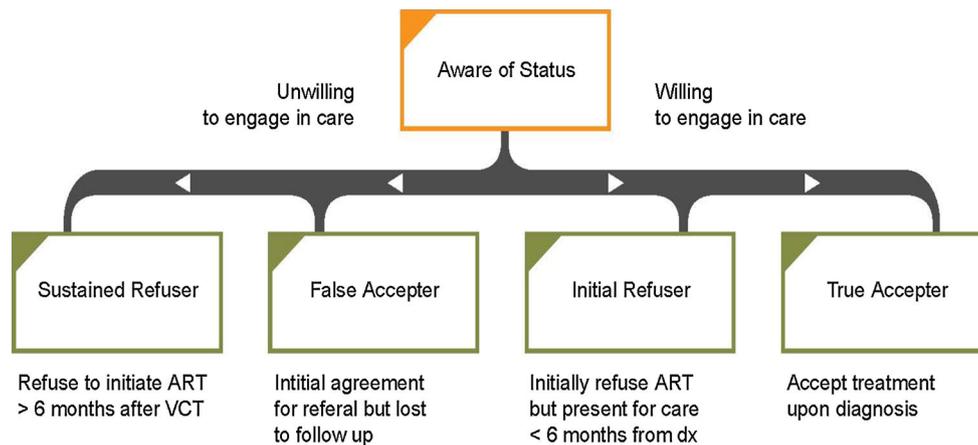
### Study Site

Zazi Testing Center is a VCT center affiliated with the Perinatal HIV Research Unit and Chris Hani Baragwanath Hospital in Soweto, South Africa. Baragwanath is third largest hospital in the world, serving the entire population of Soweto [22]. Individuals presenting for VCT sign a consent form, have blood drawn, and receive a rapid HIV test. Approximately 35 % of clients test positive for HIV. Those who test positive are asked to return 1 week later for CD4<sup>+</sup> results and referred for treatment as appropriate. The current South African Antiretroviral Treatment Guidelines recommend treatment for any individuals whose CD4<sup>+</sup> count  $\leq 350$  cells/mm<sup>3</sup> irrespective of WHO clinical stage, or anyone with tuberculosis or with WHO stage 3 or 4 irrespective of CD4<sup>+</sup> count [23]. We chose this VCT clinic because it was the site of our prior research identifying ART refusal, and we felt it would provide the most focused understanding of this phenomenon.

### Sampling and Recruitment

We used a purposive sampling strategy to select HIV positive adults who presented for VCT and were found to be treatment-eligible [24]. Our recruitment strategy was informed by research literature showing a range of treatment-related decision-making among adults accessing HIV testing in sub-Saharan Africa [25], and our understanding of clients presenting for testing at Zazi. Our goal was to represent a comprehensive spectrum of decision-making. To this end, we defined the following four groups: “Sustained refusers” were individuals who declined ART after learning they were eligible for treatment, and chose not to initiate ART for at least 6 months after testing; “False acceptors” initially agreed to start treatment, but failed to present for care within at least 6 months after learning of their treatment eligibility; “Initial refusers” declined ART when counseled at testing, but ultimately entered care within 6 months; and “True acceptors” were individuals who agreed to start ART at testing, and who shortly thereafter presented for care. Our purposive sampling strategy is represented schematically in Fig. 1.

Additionally, we interviewed health-service providers who worked at the testing center or the PEPFAR-funded treatment center, where most patients were referred, to gain insight into provider and delivery-level factors related to treatment refusal among adults who presented for testing. Service providers included counselors and social workers who delivered test results, as well as treatment providers.



**Fig. 1** Spectrum of decision-making

For this study, we chose to recruit a total of 50 participants in order to reach saturation in each subgroup.

### Eligibility Criteria

ART decision-makers eligible for this study were: (1) age >18 years at the time of enrollment, (2) presenting for VCT at Zazi, (3) willing to have blood drawn for HIV testing and CD4<sup>+</sup> count, (4) tested positive for HIV and found to be eligible for ART based on CD4<sup>+</sup> criteria (CD4<sup>+</sup> count  $\leq 350$  cells/mm<sup>3</sup>), (5) residents of Soweto, and (6) willing and able to give informed consent. Children and pregnant women were excluded, since they were enrolled in a separate HIV care program, which included more aggressive follow-up and linkage to care procedures than would be standard for routine adult care.

Eligibility criteria for medical and social-service providers included: (1) age >18 years, (2) direct contact with clients presenting for VCT or treatment, and (3) willing and able to give informed consent. Language spoken by the participant was not an exclusion criterion for this study.

### Informed Consent

We designed the informed consent procedure for this study to maximize understanding of potential risks. To insure correct use of language, all consent forms were translated into Zulu and Sesotho, and back translated into English. In addition, the research assistant (RA) read consent forms aloud to participants. After reading the consent forms, she requested participants summarize the study and explain the reasons why they wanted to participate, prior to seeking a signature. Individuals were provided with information on how to contact the study staff to report adverse events or other concerns associated with the study.

As part of the informed consent process, participants were informed of how confidentiality of participation would be insured. Specifically, all data were coded by subject number. Paper copies of data were kept in locked cabinets and only provided to study personnel. Electronic data were de-identified and were stored in a secure, password protected site, only available to study staff. Interviewers and support staff were trained on procedures for maintaining privacy and signed a pledge of confidentiality. This study was approved by Partners Healthcare Institutional Review Board, Boston, MA and University of Witwatersrand Human Research Ethics Committee, Johannesburg, South Africa in October 2011. All study participants provided written informed consent.

### Data Collection and Preparation

Semi-structured, in-depth interviews, in which questions were standardized but open-ended, were performed with participants between April 2012 and April 2013. All interviews took place in a private location at the testing center, and lasted approximately 60–90 min. Topics included:

- (1) Beliefs and experiences involving testing.
- (2) Experiences of learning one's HIV status and qualifying for ART.
- (3) Beliefs regarding ART efficacy, side-effects, and the importance of adherence.

In addition to the standardized questions, we explored areas participants identified as relevant to their decision-making, including: religion and faith, stigma, fate, mental health, notions of health and wellness, and structural factors. Interviews were conducted by a trained RA in English, Zulu, or Sesotho, based on the choice of the participant. The RA underwent a detailed training with the primary

author, and was supervised by the second author. The senior author, an expert in socio-behavioral research with over 20 years of experience performing qualitative research, provided guidance for study design and interviewer training.

We pilot-tested the interviews with a small group of eligible individuals in advance of recruiting our full sample to insure participants would have a full understanding of the questions posed in the interview. Participants for our pilot interview included both providers and ART-eligible individuals. The pilot test involved using our semi-structured interview guide to interview participants. We gauged evidence of comprehension through a dialogue with the participant after the interview, as well as a review of transcripts by two authors (ITK and GT). All interviews were audio-recorded with permission, and were transcribed and translated to English. All transcripts were reviewed for quality by ITK, GT, and KR

### Data Analysis

The goal of the analysis was to develop an explanatory model of treatment refusal based on participants' reasons for accepting or declining ART treatment. Using a category construction approach, we began our inductive analysis with a detailed review of all the transcripts to identify factors related to ART refusal. We used open coding and memoing for our initial evaluation of the transcripts, in which interview data were repeatedly reviewed line by line to identify sections of text related to treatment decision-making [26]. We then moved into a deductive phase of coding, referred to as descriptive coding. For this phase, we were guided by our research question, and used QSR International's NVivo 9 software to aid in organizing categories. We assigned labels to each category, and identified illustrative quotes from interview transcripts. We ensured trustworthiness of the data by having two authors participate in this process (ITK, KR).

We used the same process of data analysis for healthcare providers and adult VCT participants. Once we had identified our categories, we re-examined our data and developed broader concepts linking these categories. We ultimately developed an explanatory model of treatment refusal, based on our findings. The categories supporting this model are presented below.

## Results

### Participant Characteristics

Ninety-nine individuals were identified as eligible to participate in the study upon review of clinic files, and 50

**Table 1** Characteristics of cohort

Characteristics	<i>n</i> or mean	% or SD
Male sex	21	48.8
Age (years)	33.8	6.5
Nationality, South African	41	95.3
Marital status, married/co-habiting	8	18.6
Marital status, divorced/single	35	81.4
Ethnicity, Zulu	20	46.5
Ethnicity, Sesotho	9	20.9
Employed	18	41.9
Unemployed/student	25	58.2
Education, some high school or less	15	34.9
Education, matriculated or higher education	26	60.5
Residence, brick house or family house	28	65.2
Residence, shack, back room, or hostel	14	32.6
Residence, owner	24	55.8
Residence, rental	18	41.9
Self-referral	36	83.7
Referral from local clinic or other	7	16.3

agreed to participate and were consented (51 %). We interviewed 43 ART-eligible adults ("patients") presenting for testing at Zazi and 7 service providers. Of the 43 patients, 21 were women and 22 were men. Twelve were sustained refusers, 11 were false acceptors, 5 were initial refusers, and 15 were true acceptors. Of the seven care providers, three were women and four were men. Table 1 provides a summary of participant demographics.

### Risks Perceived in Starting Treatment

Participants who refused to initiate treatment framed their concerns in a context of costs or risks associated with starting ART. These risks were categorized as follows.

#### *Losing Health or Beauty*

Participants who refused to start treatment often framed decisions related to their health and well-being. Many described feeling "too healthy" in the moment of decision-making to consider ART initiation (see Table 2, Quote 1). Being "healthy" and "beautiful" off of medication was often juxtaposed against visual and physiologic side-effects associated with being on certain types of treatment. Starting treatment was often described in graphic terminology related to body dysmorphic syndromes ("They change your shape, you will have a huge stomach and your arms look like weight lifters, and you will be ugly and dark in complexion"), and a decline in physical and mental health ("These tablets change people – they become dark and have nightmares and lose their mind"). Others associated

**Table 2** Categories identified by participants regarding the risks and protective factors associated with ART initiation

Categories	Gender	Treatment decision	Representative quotation
<i>Risk</i> Losing health or beauty	F	Sustained refuser	<b>QUOTE 1:</b> "I [feel] very healthy. I found out in 2004 that I am HIV positive [...] I was not understanding negative and positive. They said, 'You are HIV positive,' and I said, 'I am not HIV positive.' [...] I told myself that I am beautiful and they say I am HIV positive. Are they sick? I said, "No, they are mad. How can they say that?" I am very healthy"
<i>Risk</i> Stigma associated with disclosure	F	Initial refuser	<b>QUOTE 2:</b> "In a rural area, it's a small place even though you trust the nurses and stuff like that. People who are in the clinic, they know that you go to that door when you are HIV positive. You come in this way, so they will notice, "Wow, she is also HIV positive." So they will start talking, I have got my ex's in this area"
	F	Initial refuser	<b>QUOTE 3:</b> "I think the main thing is that you get it by having sex. That is the problem... so people think that when you are HIV positive you have been sleeping around, maybe you have been selling your body or something... you have been careless with your body. So people are scared that they are going to be labeled as a person who has been so selfish as someone who has been sleeping around. That's why people are so scared to be known as being HIV positive"
<i>Risk</i> Increased financial burdens	F	False acceptor	<b>QUOTE 4:</b> "I even told [the counselor] that they had referred me to start taking ARV's, but my problem is that sometimes I do not have food to eat at all. How can I take [ARVs] when I don't have food to eat? So now that means that I will default, but if I knew that I had money then I would take them"
	F	False acceptor	<b>QUOTE 5:</b> "To tell you the truth, where I am currently staying, it's difficult for me, to the point that there was an argument this past Saturday and...they told me I should go and look for a place to rent. Alright, I don't buy food because I don't work and they also complained about that. So you see, this thing is emotionally hurting me... I was even saying that if I was working, I would move out and live elsewhere and I would not go to bed on an empty stomach... I would be able to take my tablets... I don't deny that I need to take ARV's, but I am looking at my living conditions, and the fact that I might take them and then default"
<i>Risk</i> Religious mores	M	Initial refuser	<b>QUOTE 6:</b> "So, when I went to church with my brother, they discussed HIV as a disease, but there was an element to say that it is for promiscuous people and they push prayer more than they push ARVs... For people who are strong believers, [I believe] they can really be cured. I think with God - what is impossible with man is possible with God"
<i>Risk</i> Role of traditional healers and alternative therapies	M	Sustained refuser	<b>QUOTE 7:</b> "I don't use ART. I use the traditional herbs that I am used to, like 'ingwe' [an herbal remedy known as an immune booster]. It also tries to kill the virus. It also helps to maintain a healthy life and not lose weight. It boosts the immune system"
	M	Sustained refuser	<b>QUOTE 8:</b> "My mom went and brought me some medication that they sell for around three hundreds or four hundred rand at Clicks [a department store] - The ones that boost the immune system. I took them for about a week and I felt that they were not helping me. I told her that I don't want medication...My father told me to keep on taking the medication..."
<i>Protective</i> Social support	M	True acceptor	<b>QUOTE 9:</b> Interviewer: "Who exactly have you told in your family?" Participant: "I told everyone, I first told my brother, and then my sister when I got home. I then called my Aunt. They said that I should accept [my HIV diagnosis] and take treatment" Interviewer: "Oh they told you that as long as you take treatment you will be okay?" Participant: "Yes, and there is nothing discriminating that they do since they know, like not allowing me to do certain things"
	M	True acceptor	<b>QUOTE 10:</b> "I come from a very supportive family, when you make mistakes they are supportive. And with other families, when [they learn you are HIV positive] they start to exclude you and tell neighbors, 'Don't see him like this. He has Z3 [slang reference for the three letters in the HIV acronym]- he has HIV.' You get what I'm saying?"
	F	Sustained refuser	<b>QUOTE 11:</b> "I would like to meet some people who are in the same situation [living with HIV] - like support groups, stuff like that, so that I could get courage. And then I can see that I am not alone in that situation"

Table 2 continued

Categories	Gender	Treatment decision	Representative quotation
Protective Coping and resilience	F	Initial refuser	<b>QUOTE 12:</b> "In rural areas, we have fields where there is no one. I went there and I wrote a suicidal letter. It was addressed to my grandmother and my aunts. But then I thought of people who love me. I thought my teacher wouldn't like this. She wouldn't be proud of me, because she knows that I am a fighter. I am a hard-worker, and if I do this she will be disappointed. I just cried and cried and then I said, let me just pull myself together. I lost my mother. I got shot and I survived. So why am not going to survive this HIV thing?"
	F	True acceptor	<b>QUOTE 13:</b> "When I found out that I was HIV positive - you blame yourself... You feel like is your fault. Okay sometimes it is not your fault. Like myself I was married. My husband was gathering around with every girlfriend that he found. So I relied on myself saying, if I am faced with this, I am going to take whatever is coming at me. That is why today, I know how to stand up for myself. I am facing it... Whatever storm comes my way, I can take it"
Protective Positive messages from government or media	F	True acceptor	<b>QUOTE 14:</b> Interviewer: "What kind of information have you heard from our government about ARV's?" Participant: "It's that you have to start taking treatment with a CD4 of 350." Interviewer: "Do you think that the media is also involved in terms of talking about ARV's?" Participant: "Yes they are. I think that sometimes people need repetition. When you hear something over and over again, even if you don't want to listen, you end up listening. It's in your face and you can't run away from it. Things like Soul City [a non-governmental organization that produces a television show focused on living with HIV in a poor community in South Africa] - everything is educating these days"
Role of healthcare providers	M	True acceptor	<b>QUOTE 15:</b> "So I see that the HIV treatment is good, especially when I look at the statistics on TV. I can see that the babies are even protected, and I see that the rate is going down, and you can live a long time [on treatment]. Because there was this white guy who disclosed his status on TV, and said that he has been infected for 25 years. That's when I became motivated and encouraged [to start ART]"
	M	Sustained refuser	<b>QUOTE 16:</b> "The media is always talking about antiretrovirals all the time. They tell us to take ARV's so that we will live. Wherever you go, there are these people who are doing HIV testing on the streets, maybe on the radio and TV. They are always talking about antiretrovirals. I will not be influenced by the media. If I see something in my ear, hands, mouth or my genital area - it is only then that I will consider going to the clinic to initiate taking ARV's, because by then I would be in a bad condition"
			<b>QUOTE 17:</b> "The client was afraid to take treatment because [she believed] her sister was killed by treatment. I asked how the sister was killed by treatment and the client said that by the time the sister took treatment, she was very sick, and then she passed on. [The sister] had delayed, and refused. So it is because the sister passed away after starting ARV treatment [that the client now refused]. So I asked if the client found out if it is true that treatment can kill, and the client said the sister's death was the evidence. So, I explained to the client about how the treatment works in a human body, and maybe the sister started it late... Since she was sick, helpless and had HIV symptoms, that is why she passed away. I advised the client to start treatment because of her low CD4 count" <b>QUOTE 18:</b> "There was a client who did not want to take treatment because of the bad attitude by the clinic staff. The client was not given any explanation before testing for HIV, and was told to start taking treatment because it is a matter of life and death, so there was no one to explain why the client has to take ARV's. The clients were being shouted at for not using condoms. They were told that is why they got infected. So the clients would not take treatment because of the bad attitude they got"

starting treatment with a decline in health (“I was fine all along, but once I started the treatment, then I fell ill”) and a feeling of “heaviness” associated with lethargy, weakness, and general malaise.

### *Stigma Associated with Disclosure*

Participants recounted stories of both internalized shame they felt living with HIV, and externalized stigma they experienced in their community. Often, participants’ views on being physically disfigured or mentally altered on medication compounded self-defeating beliefs, leading to demoralization and a desire to conceal one’s status, and not be seen in clinic (see Table 2, Quote 2). Terms such as “trackers” or “starters” were used to refer to people who initiated treatment, or continued on treatment, and were framed as being derogatory by participants. The mode of HIV acquisition often compounded participants’ internalized stigma (see Table 2, Quote 3). The need to stay integrated into one’s community, and the fear of social isolation that would result from an HIV diagnosis, often led participants to refuse to initiate treatment in order to avoid disclosure.

### *Increased Financial Burdens*

Starting treatment was often viewed as an insurmountable challenge in a life already burdened with an inability to meet the basic needs of one’s family (see Table 2, Quote 4). Shame and stigma were often closely linked with poverty and its associated stressors (including food insecurity, unstable housing, and limited access to transportation to clinic). In poor communities, where neighbors often lived in close proximity to each other, participants often reported feeling ashamed and ultimately more stigmatized by the public nature of unwanted disclosures due to taking their medications. In addition, unstable housing often led participants to fear initiating treatment due to concerns about their ability to adhere (see Table 2, Quote 5).

### *Religious Mores*

Participants described faith and God as guiding forces that informed decision-making. Participants who started treatment discussed how they believed God was a “healer,” but that starting medication was necessary since they were “of flesh and earth,” and that God could only heal “if you take your medication.” Conversely, those who chose not to initiate treatment also invoked spirituality and faith as a reason not to need treatment (see Table 2, Quote 6). Religious mores that centered on morality and a strong belief in God as a provider and healer were commonly invoked. While certain congregations appeared to support

initiating treatment in the setting of a new HIV diagnosis, many participants discussed God as the larger force, and that HIV could be considered “a punishment” that only God has the power to cure.

### *Role of Traditional Healers and Alternative Therapies*

Those participants who felt medications were associated with being sick, often used herbs and sought the counsel of traditional healers instead (see Table 2, Quote 7). Both accepters and refusers sought out “immuno-boosters” in the forms of vitamins, and other supplements. These were often recommended by friends and family members, either as a way to enhance treatment, or as a substitute for it (see Table 2, Quote 8). “Traditional medications”, prescribed by “witch doctors,” were often referenced as being a cure-all, and being a more natural form of therapy.

### *Protective Factors Offsetting Risks of Starting Treatment*

Participants, particularly those who were willing to start treatment, identified multiple sources of support that offset the risks associated with treatment initiation.

### *Social Support*

Participants who described having strong social support from family, allowing them to disclose their status, often were able to mitigate the challenges associated with starting treatment (see Table 2, Quote 9). This support was characterized as providing a sense of humanity (“I felt like I was human after all”) and a buffer against normative stigmatizing beliefs (see Table 2, Quote 10). Conversely, treatment refusers reported wishing for a community support system to allow them to discuss their concerns about their diagnosis and treatment (see Table 2, Quote 11).

### *Coping and Resilience*

Coping emerged as a means by which participants attempted to manage stigma and move beyond perceived risks of starting treatment. Those who exhibited resilience in the face of a new HIV diagnosis often invoked their desire to live for others as a reason to overcome concerns about starting treatment (see Table 2, Quote 12). Many participants described living with adversity related to poverty, food insecurity, violence, and the stressors associated with volatile relationships or raising children alone, and called upon these inherent coping skills in order to initiate treatment (see Table 2, Quote 13). Ultimately, adaptive coping strategies that enabled participants to gain

acceptance of their diagnosis mitigated the perceived risks associated with treatment initiation.

#### *Positive Messages from Government or Media*

Participants described ubiquitous HIV educational messaging coming from many sources—most notably the South Africa Government, and media, through educational soap operas and other forms of entertainment (see Table 2, Quote 14). Real life experiences of media personalities living with HIV provided messages on how to overcome concerns about starting treatment (see Table 2, Quote 15). Others who refused to initiate treatment felt less of a desire to engage in the messaging being presented (see Table 2, Quote 16).

#### *Role of Healthcare Providers*

Healthcare providers had the potential to moderate the risk of ART refusal by creating an environment that provided compassionate care for patients who were concerned about initiating treatment. Specifically, a strong therapeutic alliance with providers could establish a refuge from HIV-associated stigma, and instill an understanding of the importance of ART initiation. One provider described her encounter with a patient who refused to initiate ART because she was concerned about the potentially lethal effects of starting medication (see Table 2, Quote 17). Conversely, healthcare providers also recognized that clinic staff could contribute to patients' sense of isolation, and feeling stigmatized (see Table 2, Quote 18).

#### *Explanatory Model of Treatment Refusal*

To integrate our core findings, we developed an explanatory model for understanding treatment refusal. One can best understand our model within a larger context of risk perception, which posits that people tend to make decisions about risks based on affect, stigma, or fear, and in general, are highly loss averse [27]. For individuals who choose not to initiate treatment, the perceived risk of starting treatment may ultimately outweigh the known life-saving benefits of being on medication.

Risk is embedded in an optimistic vision of one's general health and well-being off of ART, and in concerns about the harmful effects of being on medication. These concerns may be anchored in the knowledge that many prior medications made available to people living with HIV were known to have disfiguring side-effects, leading to the possibility of an unwanted disclosure of one's HIV-status. In communities where disclosure could lead to social isolation, starting treatment could be perceived as disrupting the fragile balance in which many people are living. Therefore in this context, avoiding treatment may be considered a safer

alternative than initiating ART. Conversely, individuals who are able to draw upon social support to minimize the harmful effects of life stressors are able to capitalize on their inherent resilience, and overcome fears related to starting ART. These findings support a broader more subjective interpretation of perceived barriers to treatment initiation that recognizes both the importance of social support and its impact on affective and cognitive judgments [28].

#### **Discussion**

This qualitative study provides a novel understanding of why treatment-eligible adults may choose not to initiate ART. In our explanatory model, the decision to refuse treatment is based on an optimistic view of one's own health, and a belief that starting medications can be inherently risky due to potentially disfiguring side effects, resulting in an unwanted disclosure and social isolation. This may lead to seemingly irrational choices to avoid detection until disease progression renders further concealment impossible.

Central to this model is the meaning of ART initiation for participants, and the common belief that people living with HIV initiate treatment when they are sick, instead of starting it while healthy. As such, participants experience starting treatment as an acknowledgement of poor health, and potentially their own mortality. Fears of side-effects associated with ART, stigma from being identified as "sick", and concerns about one's own inability to adhere to treatment often augment the perceived risks inherent to treatment initiation [29, 30]. Prior qualitative research in South Africa has similarly shown that ART has often been viewed as signifying AIDS and approaching mortality [11].

In this context, social support proves critical to enhancing participants' ability to cope with the life changes that are required to overcome concerns related to ART side-effects, internalized and externalized stigma, potentially increased financial burdens, and the lure of seemingly safer alternative therapies. While little research has focused on the impact of social connectivity and adaptive coping on decision-making prior to ART initiation, social integration has been recognized as a core component of treatment adherence in resource-limited settings [31–33]. The importance of social support and integration are particularly salient in settings of extreme poverty where treatment barriers are highly prevalent [34–37] and social ties may be essential for survival [33, 38, 39], ultimately allowing people living with HIV to cope with internalized stigma [40].

People with early-stage disease are particularly at risk. First, they may not perceive the need for treatment because they have not yet experienced loss of physical function, a powerful motivator for behavior change [41]. Second, due

to the stigmatized status of HIV infection in many resource-limited settings [40, 42–44], people living with HIV with full functional status might have less motivation to disclose their status [45–48]. Nam et al. also found that ill patients experience faster acceptance of their HIV status, which facilitates HIV disclosure and activates their social support network [49]. Green and Wagner found that HIV disclosure is closely associated with the degree of tangible support HIV+ people receive from their network [50]. Taken together, these findings suggest that people with early-stage disease might not disclose their HIV status, might not activate their social ties, and might not mobilize social support to overcome the common structural barriers to HIV care in resource-limited settings; this could result in sub-optimal engagement in care and failure to initiate ART.

In addition, socioeconomic barriers to care may impede engagement in care, as has been described previously, despite the widespread availability of free treatment through PEPFAR and the Department of Health clinics [51]. These findings suggest that existing ART programs may be more successful if coupled with economic incentives to initiate and adhere to treatment, since this may provide economic stability that is necessary for treatment initiation and retention in care.

Our study has several limitations. First, within our purposively sampled targeted groups, we were limited to a convenience sample of patients who could be located and were willing to be interviewed; thus, our data may not capture the reasons for ART refusal among people who could not be located, or who were not willing to be interviewed. In addition, our data may not capture reasons for ART refusal in other locations in South Africa. Future studies should examine reasons for treatment refusal at multiple sites.

Despite these limitations, our study has many strengths. First, while treatment decisions have previously been dichotomized into “acceptance” or “refusal,” we found evidence for a spectrum of decision-making, and were able to interview participants in each category. In addition, the explanatory model that emerged from our qualitative research has several important implications for the public health strategies now being explored in areas of sub-Saharan Africa with high-HIV prevalence rates (e.g., universal voluntary testing with an immediate “test-and-treat” strategy [52, 53]) by providing a framework for understanding how and when people may delay starting treatment, despite optimal access to care. Finally, our results revealed several modifiable factors that could be targeted in future interventions to increase ART initiation, including: economic incentives, peer-based social support programs, and further education about the side-effects of ARTs currently available in South Africa.

## Conclusion

Optimizing engagement and long-term retention of adults living with HIV requires understanding decision-making in the pre-ART period. This qualitative study in Soweto, South Africa, provides a novel explanatory model of treatment refusal, which recognizes the relative importance of perceived risks associated with starting treatment in otherwise asymptomatic adults. These risks relate to the social costs incurred when disclosing one’s status in a community where being identified as “sick” from HIV may potentially be the tipping point in a life that may hang in a fragile balance. Conversely, social integration and connectivity may provide those who test positive with sufficient support to promote effective coping strategies and overcome fears related to treatment initiation. Future research should test interventions that target modifiable factors identified through this study to optimize engagement in care.

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