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Testing when I know my status: The social dynamics of household HIV testing in HPTN 071 (PopART) trial communities, South Africa

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ABSTRACT

Landmark studies demonstrating a reduction in onward HIV transmission and improved survival have informed a shift in global antiretroviral therapy policy to a 'treat all' approach. Global HIV stakeholders have called on countries to urgently scale up their HIV programs, involving responsibilities for various health system actors for accelerating HIV epidemic control. In this article we explore how community members in South Africa who were part of a large-scale 'Universal Testing and Treatment' trial made decisions around taking up home-based HIV testing, a major component of the trial's intervention and the entry point to a comprehensive continuum of HIV prevention and care. Drawing on data collected with a qualitative cohort of purposively selected households in the study intervention communities between 2016 and 2018 we describe how the goal of achieving HIV epidemic control was internalized, enacted, and potentially transformed in the interactions between community members and health workers in high HIV burden community settings. Further, we consider the implications for how community members related to their individual health and a collective responsibility to a broader public health good (in this case HIV epidemic control). Our findings suggest that in contexts of precarity – where there is low social cohesion – a community-wide health intervention can create an avenue for people to perform being good, moral citizens. Our findings reveal how complex community and social dynamics inform decisions to take up health interventions, rather than purely 'rational' understandings of individual and collective health benefit.

1. Introduction

Over the last decade, landmark studies have confirmed the clinical benefits of starting immediate antiretroviral treatment (ART) upon HIV diagnosis, irrespective of CD4 cell count, and the preventive benefits of viral suppression among people living with HIV (PLHIV) – an approach referred to as 'treatment as prevention' (Brault, Spiegelman, Hargreaves, Nash, & Vermund, 2019; Cohen et al., 2011; Hayes et al., 2019; Tanser, Barnighausen, Grapsa, Zaidi, & Newell, 2013; TEMPRANO ANRS 12136 Study Group, 2015; The INSIGHT START Study Group, 2015). These studies, all carried out in sub-Saharan Africa, led to a shift in global HIV policy towards the promotion of an HIV 'treat all' approach (World Health Organization, 2015). Highlighting the importance of this moment, global HIV stakeholders such as the Joint United Nations Programme for HIV/AIDS (UNAIDS) and the President's Emergency Plan for AIDS Relief (PEPFAR) called on countries to 'seize this historic opportunity' and urgently scale-up their HIV programs (Sidibé, Luiz Loures, & Badara, 2016), with PEPFAR touting that 'for the first time in modern history, we have the opportunity to change the very course of the HIV pandemic by actually controlling it without a vaccine or a cure' (PEPFAR,

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2017). What these stakeholders are calling for is for national governments, frontline health workers, PLHIV, and individual citizens to take responsibility for accelerating HIV epidemic control. While this rhetoric of responsibility is not novel to HIV, it is amplified with the shift to the HIV 'treat all' policy and its promise of hastening an end to AIDS.

South Africa's HIV epidemic makes up more than 20% of global HIV infections, and more than 15% of new HIV infections (UNAIDS, 2022a). In some South African provinces and settings, the HIV prevalence among some age-categories of women is as high as 66%, creating hyperendemic scenarios (Allinder & Fleischman, 2019; Epicentre Health Research, 2018). The ubiquity of HIV and the persistence of government and civil society efforts to address the epidemic (which have involved massive information and advocacy campaigns to promote HIV testing and safe sex practices for example), have made HIV an inevitable and inescapable part of South African collective consciousness. The South African Department of Health moved to provide ART for all PLHIV from September 2016, in line with WHO recommendations (Department of Health: Republic of South Africa, 2016). Successful implementation will require a near-doubling of the number of people on ART, from 4.7 million to an estimated 8.2 million PLHIV (Department Statistics: South Africa, 2021; UNAIDS., 2022b). This ambitious treatment policy has sparked calls for an 'all of government, all of society response' and an emphasis for every person in South Africa to 'know their HIV status and get treatment as soon as possible' (South African National Aids Council SANAC, 2017). Towards this goal, the national government released a national HIV testing services policy (National Department of Health, 2016), outlining approaches for community-based HIV testing including home-based HIV testing, and HIV self-screening to achieve the first UNAIDS target of having 90% of PLHIV know their status by 2020.[1]

In this article we work from the premise that global HIV directives and priorities that propound a hope for and urgency to achieve an end to HIV create responsibilities for national governments, PLHIV, and community members, in a global HIV response. We focus on the client-level to explore how community members in South Africa who were part of a large-scale 'Universal Testing and Treatment' (UTT) trial – HPTN 071 (PopART) – made decisions around taking up home-based HIV testing, a major component of the trial's intervention and a critical entry point to a comprehensive continuum of HIV care and treatment. Drawing on qualitative data collected from 2016 to 2018, we 1) describe how the goal of achieving HIV epidemic control was internalized, enacted, and potentially transformed in the daily interactions between community members and health workers in high HIV burden community settings, and 2) consider the implications for how community members related to their own individual health and a collective responsibility to a broader public health good (in this case HIV epidemic control).

2. Conceptual approach

Our interpretive approach was informed by two conceptual and epistemological positions: (1) interrogating the assumption that public health operates as a rational 'common good', and (2) an awareness of the particular social context of both cohesion and discord in South African communities where public health services are offered. We use these two framings to understand what informed people's decision to take up HIV testing in a community-based UTT trial, and how these decisions were aligned or stood in tension with global narratives of responsibility for achieving HIV epidemic control.

2.1. *Public health as a rational 'common good'*

'Public health' has broadly been concerned with a 'search for effective means of securing health and preventing disease in the population' (Tulchinsky & Varavikova, 2014). The achievement of public health has subsequently come to be understood as a moral and ethical good and has brought together notions of utilitarianism and collective action (Anomaly, 2021; Lee & Zarowsky, 2015) and allowed states sovereignty to govern their populations towards health (Foucault, 2008; Lemke, 2011). In the 21st century, it has become almost taken for granted that neoliberal nation states take on the responsibility for the health of their populations, often through democratized healthcare (Rose & Miller, 1992). A central concern remains how to promote individual uptake of health interventions, however. Many public health approaches to uptake rest on the assumption that individuals will buy into an intervention if they 'rationally' understand the benefits for their own health, and the health of other 'publics'. In this logic, rational decision-making, risk-benefit calculations, and even altruism are imagined as vectors for uptake in target communities and populations; the latter especially present in the HIV 'treatment as prevention' discourse (Tan, Lim, & Chan, 2021; UNAIDS, 2018). Studies into the social determinants of health show that this does not neatly translate to the lived realities of those who are the targets of interventions and services; social contexts and environments are critically influential in shaping health behaviors and outcomes (Bond et al., 2021; Bronfenbrenner, 1979; Lippman et al., 2018).

2.2. *Health, social cohesion, and the post-apartheid community*

In considering social context, 'social cohesion' has emerged as a key characteristic with the potential to importantly shape individual behavior and community health outcomes (Lippman et al., 2018). Social cohesion is broadly understood as the 'shared trust, connectedness, or unity experienced by members of a residential area or social group' (Lippman et al., 2018, p. 99) and the 'glue' that holds society together (Barolsky, 2012, p. 135) – it has been found to be a catalyst for collective action and working together for a 'common good' (Sampson, Raudenbush, & Earls, 1997), including improved health behaviors and health outcomes (Gordeev & Egan, 2015; Grover et al., 2016; Lippman et al., 2018; Lyu et al., 2021). The concept was first developed and tested in higher income country contexts in the global north, settings with well-established democratic nation-states (Barolsky, 2016); in low- and middle-income country (LMIC) health settings such as South Africa limited research is available on the relationship between social cohesion and health behaviors.

The concept of social cohesion is novel in the South African context and complicated by a colonial and apartheid past which expressly worked to undermine unity, fraternity, and trust (Barolsky, 2012, 2016; Pillay, 2008). In this historical context, questions of community and belonging have remained contentious and loaded topics in South Africa, post-apartheid. While a democratic government came to power in 1994, constitutionally enshrining the rights of all citizens, many South African communities continue to reflect the persistent social, economic, and psychological effects of the country's past, with important implications for individual behavior and health outcomes (South African Government, 2008).

In this paper we explore how a public health intervention that incorporated notions of individual health and collective responsibility towards a 'common good' landed in communities characterized by precarity and significant social adversity – a tension discussed in other qualitative analyses (Bond et al., 2016, 2021; Viljoen, Bond, et al., 2021). Further, we consider how implicit public health logics (as outlined in 2.1 above), personal choices, and broader social dynamics informed and shaped uptake of HIV testing in a community-based UTT trial.

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[1] The UNAIDS released its 90-90-90 'ambitious treatment target' for achieving HIV epidemic control aiming that by 2020 90% of all PLHIV know their HIV status, 90% of all people with diagnosed HIV infection receive sustained ART, and 90% of all people receiving ART achieve viral suppression (UNAIDS, 2014). In 2021 the UNAIDS increased these targets with the goal of achieving 95-95-95 by 2025 (UNAIDS, 2021).

3. Methods

3.1. Trial context and setting

The HPTN 071 (PopART) trial was a three-arm cluster-randomized HIV prevention trial implemented from 2013 through 2018 in 9 South African and 12 Zambian study communities (Hayes et al., 2019). The trial demonstrated the impact of a multi-component HIV prevention package on HIV incidence and offered a platform through which to explore the question of how a more intensive HIV testing approach was implemented, what it meant for recipients, and the potential impact on the HIV control program. As a community-randomized trial, notions of community were central to the framing of the trial design and implementation.

Communities were randomly assigned to either of two intervention arms (Arm A or B) or a control arm (Arm C). In intervention arm communities the intervention package included household HIV testing delivered by community health workers and either immediate access to ART irrespective of CD4 cell count (Arm A), or ART delivered according to government guidelines (Arm B).[2] Concerns around stigma and the need for privacy were part of the logic behind the decision for the trial to promote a strategy of community-wide household HIV testing. The household HIV testing approach implemented in the trial also gave the best chance for achieving the desired universal HIV testing coverage (the first UNAIDS '90'). Communities were enumerated and community health workers attempted to reach household members aged 15 and above at least once each year, a requirement necessary to test whether a UTT strategy could impact community-level HIV incidence.

In the South African component of the trial on which this article is based,[3] about 500 community health workers were employed across the 6 intervention study communities (community health workers were not active in the three Arm C communities as these communities served as controls). The community health workers – called Community HIV Care Providers (or CHiPs) – delivering the intervention package were specifically recruited for the trial. They were demographically similar to recipients of the intervention by way of race and class, with residence in the study communities a preference. As such, they were also fluent in the dominant language(s) spoken in each community. Familiarity with the communities formed part of the rationale for mostly employing residents as community health workers on the trial. For trial funders and stakeholders, it also provided the opportunity to give back to the study communities by offering employment in a context of exceptionally high unemployment (The World Bank, 2023). These considerations trumped concerns over the potential for stigma and fear of HIV status disclosure that could affect uptake of the intervention if community health workers were themselves residents. To mitigate some of these potentialities, community health workers were assigned to work in areas of the community a distance from where they lived and received on-going training and supervision. This included accompanied home visits with CHiPs supervisors, and follow-ups with intervention recipients about their experiences. The trial also involved on-going community engagement and sensitization, and consultation with Community Advisory Boards. Analyses show that high uptake of household HIV testing was achieved in the trial (Floyd et al., 2020). Viljoen et al. (2021) detail the recruitment, training, and characteristics of the community health workers employed on the trial.

The community health workers worked in pairs and each pair was allocated a geographic zone in the community which made up approximately 500 enumerated households for which they were responsible to deliver the intervention in annual rounds. As the study community catchment areas were relatively small, between ~1500 and 2500 m^2 each, the community health workers' presence was notable. About once or twice a year they also organized mobilization activities, during which they would move around the community in larger groups and use loudhailers to sensitize the community ahead of the next round of household HIV testing. As the intervention was designed to promote the UTT strategy, the community health workers were trained on the individual clinical benefits of earlier ART initiation and the public health benefits of reduced likelihood of transmission with viral suppression.

Nested within the trial, toward a secondary aim of understanding the uptake of the intervention, implementation, experiences, and community level outcomes, was a multi-method social science component from which we draw our data. A full description of the trial design and methods, including the different social science components, is available (Bond et al., 2021; Hayes et al., 2014; Viljoen, Myburgh, & Reynolds, 2020).

3.2. Nested qualitative cohort – design, sampling, recruitment, and data collection

There were three components of the social science design; Broad Brush Surveys, Story of the Trial, and a qualitative cohort (Bond et al., 2021). The qualitative cohort was designed as an ethnographic approach, implemented to explore the varied lives of people in the study communities, how they intersect with HIV and health more broadly, and with the aim of contextualizing trial outcomes over time. We conducted community observations and collaborated with community health workers delivering the intervention in the study communities to purposively sample for diversity and to saturation a cohort of 89 households – representing approximately 280 individuals – across the nine South African study communities. In the six intervention communities (Arms A and B) included in this analysis, a total of 65 households are represented. The characteristics of these communities and households are described in detail (Bond et al., 2021; Hoddinott et al., 2018). We defined a household as individuals (relatives or not) who for various reasons considered themselves to be part of the same home, including for familial, friend, romantic, or economic interests. Households were sampled purposively to ensure diversity by trial arm, proximity to a local health facility, HIV experiences (including self-reported HIV status and engagement in HIV care), age, gender, and household structure. The sampling approach also followed the principle of extreme cases to include people at greater risk of HIV acquisition and who experience social marginalization – including cisgender female sex workers, men who have sex with men, transgender women, people living with disabilities, and young people aged 15 to 24. At least half of the households recruited to the cohort had at least one person who self-reported living with HIV.

During recruitment researcher pairs recruited an index household member into the study, and upon subsequent visits, invited other household members. Completing a genogram in the first study visits gave researchers insight into the household's composition. While all household members were eligible to participate, including children aged 12 and older, most of those who participated in the research were adults aged 18 and older. Parents and caregivers could also consent to information on minors being included.

Researcher pairs collected predominantly qualitative data with

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[2] South African government guidelines for initiating ART changed twice over the course of the trial, following global recommendations to expand ART eligibility for PLHIV. In 2013, at the start of the trial, community clinics in Arms B and C provided ART at a CD4 cell count of 350 or below. In 2014, ART eligibility for PLHIV was increased to a CD4 cell count of 500 or below. In September 2016, the government adopted the HIV 'treat all' approach, at which time clinics in Arm B and C communities moved to deliver ART regardless of CD4 cell count. Adoption of this guideline made Arm B study communities equivalent to Arm A study communities (with both delivering household HIV testing with immediate ART). Details on how these guideline changes influenced primary outcome analyses are available in Hayes et al. (2019).

[3] Our analysis focuses on data collected in the South African component of the PopART trial only (excluding Zambia) with the aim of locating the findings relative to the particular history of care and citizen-state dynamics in South Africa. As described elsewhere (Viljoen, Mainga, et al., 2021), the study communities were urban and peri-urban, densely populated (with a mixture of formal and informal housing), and fell within the lower socio-economic bracket.

household members through multiple research visits over the course of 18 months between 2016 and 2018. Data collection was structured into six themed rounds collaboratively created by the study team as an ethnographic approach with a short time frame, with the aim of understanding participants' perspectives in context. These included: 1) household, kin, and relational networks, 2) community, place, and space, 3) getting by, 4) sex, love, and romance, 5) HIV service access, and 6) horizons, ambitions, and fears. Data collection was informed by ethnographic research principles and often involved participatory activities to facilitate discussions. For example, all interactions with participants happened *in situ* in the study communities – usually in participants' homes, but also often as they moved about the study community completing their daily activities. Researchers used study-specific topic guides to implement each of the six data collection rounds sequentially but with flexibility to iterate between topics. Researchers visited each household multiple times over the course of the data collection period (and at least 10 times) and most households were visited between two and three times in a three-month period to complete one data collection round. Different sections of the topic guide were covered in each interaction. Each of these household interactions was between one and 4h in length, and, depending on the topic and activity, involved multiple household members in individual interviews and/or group discussions. Researchers also remained in contact with household members while in the vicinity visiting other households, or via calls and text messages; these practices were important for building rapport over time. Oftentimes, rather than 'neat' interview exchanges, data collection happened in the everyday flow of life in the community, with neighbors, friends, and family coming and going, and participants interacting with or making observations of people and the goings-on outside their homes. This embedded approach allowed researchers to gather varied perspectives of household members, and to ask follow-up questions of participants as needed. It also made them privy to general changes in the household over time in terms of composition, relationships, and life events, as well as the everyday interactions between members of the community and household. The researchers recorded discussions (in participants' language of choice, where possible) with voice recorders and semi-structured field notes and took pictures of research activities. Upon returning to the office, they also documented their reflections on the household visit, the data they collected, and its significance for the study outcomes. All participants were asked to provide written informed consent, and we followed a continuous informed consent process with all household members who agreed to participate in the study, confirming their voluntary participation at each visit, and answering any questions about the study. Parents and caregivers signed consent for minors. In this paper we refer to the study communities using the same numbering convention assigned to them in the trial (S13–S21), which served to anonymize the communities while the trial was ongoing.

3.3. Data analysis

Our analysis focused on discussions with household members in the six South African intervention communities (Arms A and B) where household HIV testing was being delivered, focusing on 'HIV service access' (round 5 of 6 of data collection in the cohort). These discussions were conducted towards the end of 2017, while the household HIV testing intervention was in its fourth year of being implemented, and many of our participants had experienced significant exposure. The 'HIV service access' data collection round included discussions about popular understandings of HIV in the community and challenges along the HIV care continuum particular to the participant's community, i.e., with regards to HIV testing, starting ART, and staying on ART (based on UNAIDS 90-90-90 treatment targets) (UNAIDS, 2014). A large part of the discussion guide included questions about participants' perceptions and experiences of the household HIV testing intervention, the community health workers delivering the intervention, and asked about participants' uptake of the intervention. Participants were also asked to share their perceptions about the household intervention coming to an end as this data collection round was implemented towards the end of the trial.

Using ATLAS.ti software we applied both inductive and deductive coding strategies to the verbatim transcripts and translations of the audio recordings of these discussions. Our analysis aimed to expose 'rationales' for HIV testing uptake – implicit and explicit – to explain if and how participants expressed sentiments of individual and collective responsibility for HIV testing and treatment in these high HIV burden contexts. We analyzed participant data within and across cases, looking for instances in the data where participants shared their views of the burden of HIV in the community, including the perceived HIV risk to themselves and other community members, their perceptions of the community health workers and household HIV testing, their views of their own and others uptake of the household HIV testing intervention, including discussion of rationales for HIV testing, and their responses to the trial's community presence ending.

3.4. Ethics statement

The trial – including all nested social science – was approved by the London School of Hygiene and Tropical Medicine, University of Zambia, and Stellenbosch University research ethics committees. All participants signed written informed consent per guidance of the in-country research ethics committee. Household participation was by consensus of all household members. All data are stored securely and reported on using pseudonyms to protect participant confidentiality.

4. Findings

We organize our findings in two parts to describe how community members experienced the household HIV testing intervention delivered in the trial (part A), and to consider how their experiences align with notions of individual health and collective responsibility to a broader public health good (part B). In Table 1 we present the number and characteristics of the cohort participants in the trial's intervention communities included in this analysis. The quotes we include are the most illustrative of particular sentiments we identified across interview transcripts.

4.1. Part A: community members' experience of the household HIV testing intervention

Our analysis revealed four sentiments among participants that shaped uptake of community-based household HIV testing in the trial intervention communities. First, participants considered the community health workers delivering the household HIV testing intervention to manifest a caring presence in the community. Second, participants believed that the household HIV testing intervention allowed opportunities to care for oneself and others in the context of HIV. Third, participants felt that HIV testing with the community health workers was accessible and easy which allowed their regular testing uptake. Fourth, participant narratives suggested a tenuous 'normalization' of an HIV diagnosis with the availability of ART which made participation in an HIV testing initiative acceptable, even as the condition remained highly stigmatized. Below, we explore each of these sentiments in more detail.

4.1.1. Community health workers delivering the household HIV testing intervention created a caring presence in the community

Many participants perceived the household HIV testing intervention positively and considered it to create a caring presence in the community. The CHiPs (the trial community health workers) had been active in intervention communities since 2014. They were easily visible and recognizable with their maroon t-shirts, data collection devices, and cooler bags containing HIV testing kits. As they conducted their work on foot, walking around the community daily in pairs and interacting with community members and their colleagues in passing, they created a sense

Table 1
Number and characteristics of cohort participants in intervention communities (Arms A and B).

Cohort participants in Arms A and B	n = 199
Gender	
Women	120
Men	69
Transgender women	10
Age	
11 and younger	2
12–17	21
18–24	42
25–34	62
35–44	30
45–55	23
56 and older	19
Vulnerable/key populations	
Men who have sex with men (MSM)	14
Cisgender female sex workers	17
People living with disabilities	14
Previously incarcerated	31
HIV status	
HIV-positive	52
HIV-negative	100
Don't know/don't want to share	45
HIV testing[a] **(participants 12 and older)**	n = 197
Ever tested for HIV	166
Tested at facility, mobile, or elsewhere	130
Tested with the CHiPs	86
Tested for HIV with the CHiPs[b]	n = 86
1-2 times	68
3-5 times	11
more than 5 times	7

Most cohort participants in the six intervention communities were women and were aged between 18 and 44. More than 84% (n = 166) indicated that they had ever tested for HIV, either at facility/mobile/other services and/or with the CHiPs. Of the participants who had ever tested for HIV, 52% (n = 86) indicated that they had tested with the trial's community health workers. The number of people known to be living with HIV in our cohort (n = 58) should be considered when interpreting the relatively small proportion of participants who indicated having tested with the CHiPs (n = 86 or 44%).

[a] 13 participants indicated that they had never tested for HIV, and for 18 participants data were unavailable.

[b] 69 participants indicated that they had not tested with the CHiPs, and for 42 participants data were unavailable.

of activity and busy-ness. Remarking on their experience of the intervention, two participants shared:

> 'The community looks much better, much quieter, and it looks healthier. Especially to see them [the CHiPs] walking here with the red outfits, then you can at least see [the community looks] a bit healthier.' Woman, 37 years old, not living with HIV, S20

> 'I think that it [the intervention] is something very good – you see that there is interest in the community … an interest in people's health.' Woman, 27 years old, not living with HIV, S19

In these excerpts from interviews participants shared how they perceived the CHiPs presence as a visible manifestation of care in the community[4] – a presence that was often experienced as lacking in post-apartheid communities where the quality of the physical environment and of service delivery may reflect a general lack of stewardship and care and negate a sense of camaraderie and unity. Such environments are not considered conducive to healthy behaviors and lifestyles, or rather, community members often achieve them *despite* their environments, and the social and economic challenges (e.g., poverty, unemployment, violence, and drug use) faced by community members themselves reflect this.

4.1.2. Household HIV testing allowed opportunities to care for oneself and others in the context of HIV

The majority of participants consistently expressed negative perceptions and experiences of their communities and of others living there – reflecting what has been argued earlier in this paper about the social divides and distrust that punctuate many post-apartheid communities. As such, participants regularly and openly recounted stories about other community members that included themes of violence, drug use, abuse, and poverty, as well as recognition of how difficult it was to rise above these circumstances. In this context of impoverished infrastructure and high levels of social and economic instability, some participants made a further association with the household HIV testing intervention as promoting care for oneself and for others in the community. Many participants juxtaposed the external form of care they perceived the CHiPs to provide against a lack of 'internal' care (or care for oneself) that they perceived among community members. These participants argued that in a context where people seemingly took little care of themselves and their health, such an external form of care was essential to ensure that people accessed the services that they needed. Many participants further explicitly linked the need for HIV services in the community to their perception that 'HIV is a big thing, it's a reality here' and that a community intervention that made HIV services more accessible was especially important 'because of how the community lives and not care to make an effort to get tested' (woman, 27 years old, not living with HIV, S19).

The importance some participants tied to the care they perceived the intervention to promote in their communities was especially evident in their exclamations of surprise and hopelessness to our reminders that the trial was ending. 'What will become of the world?' one participant asked, going on to explain that 'people are too lazy to test themselves' (woman, 37 years old, not living with HIV, S20). Another participant shared that 'there is little chance for us as a human race' when the intervention ends (woman, 65 years old, not living with HIV, S20), while another expressed the worry that 'they [community members] will die … when [the CHiPs] are not here', ending with 'where is help going to be?' (woman, 69 years old, not living with HIV, S20).

Some participants attached decidedly negative judgements to those who they saw as avoiding testing with the CHiPs in the household intervention, labelling them as 'lazy', bad', 'stubborn', or 'negligent'. Another participant explicitly framed such individuals as '[not wanting] to cooperate, to stand together with the community', and linked participation in the intervention to an ultimate goal of achieving HIV epidemic control, saying 'if they stand with the community then … a word like that [HIV] won't exist in South Africa' (woman, 33 years old, not living with HIV, S14).

While many acknowledged HIV stigma in their communities and how it could affect people's uptake of testing and treatment (noting that people often openly wondered about, suspected, and pointed out those who are thought to be living with HIV), many participants who were participating in the intervention proudly scoffed at the potential of being the target of HIV stigma to show that it would not put them off testing. Such narratives suggested that HIV testing was potentially demonstrative and performative, rather than simply diagnostic. Indeed, being suspected of living with HIV was one of the potential risks of participating in our research cohort, as the social science researchers wore the same maroon t-shirts donned by the CHiPs who provided HIV testing and who helped to link those testing positive to care, often with recurring household visits. Our cohort participants often similarly scoffed about the potential judgements of outside onlookers about our research visits to their households.

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[4] How the household HIV testing intervention was perceived varied across participants and communities. In a few instances cohort participants expressed distrust of the professionalism, confidentiality, and quality of service offered by the CHiPs (see Viljoen, Mainga, et al., 2021).

4.1.3. Regular uptake of household HIV testing was possible in intervention communities

Many participants shared that the availability of household HIV testing in their communities had allowed HIV testing to become routine. Participants consistently expressed how testing with the CHiPs was quick and easy, and compared this with their experience at health facilities where they found the process to be long and tedious. A participant described how the encounter with the CHiPs motivated her to take up testing: 'it's not easy to just stand up and say "I'm going to test [at the clinic]". But if they [the CHiPs] arrive saying "sister can we test you?" and explain to you properly … After that [explanation] you understand that you don't have a choice [it is important to test]' (woman, 40 years old, living with HIV, S14). For another participant, testing at home 'felt more personal' and allowed a level of privacy she described as more difficult to maintain at health facilities. She similarly shared a reluctance to visit a health facility, quipping that 'I am even lazy to go to the clinic for [contraception]' (woman, 27 years old, not living with HIV, S19). Narratives about the ease of taking up HIV testing with the CHiPs further cemented participants' views of those not willing to test with the CHiPs as 'lazy' and 'apathetic'.

A participant – who was a traditional healer and knowledgeable about public healthcare – shared her reasons for repeat testing, which resonated with public health discourses of the benefits of early treatment and treatment as prevention: 'I test regularly … so that I quickly take treatment. I like testing regularly because I don't want to infect someone when that accident happens [and] maybe I find myself having it [HIV]' (woman, 44 years old, not living with HIV, S14). This participant clearly articulated her rationale for repeat testing, framing becoming infected with HIV as something that was potentially inevitable and out of her control (i.e., 'when that accident happens'), and explicitly positioned regular testing for HIV as what will enable her to 'quickly take treatment' in order to avoid transmitting to someone else. For this participant, her own potential HIV infection seemed to be perceived as beyond her control, while she framed herself as agentic in her personal responsibility towards others.

By contrast, the narratives of many others focused primarily or exclusively on an understanding that regular HIV testing was good for their own health. In some cases, participants seemed to see the act of testing as a part of a regimen of self-care, like this 33-year-old woman:

> Woman: 'I'm thinking maybe I tested more than fifty times, for real.'
>
> Interviewer: 'Fifty?'
>
> Woman: 'Over fifty' (laughs). 'I call them [the CHiPs] and they say to me "No, no, I won'*t*-test you, you cannot test over/again." I say "No I will look again for one person [a particular CHiP], they are always looking for people [to test]". We fill up [their quota] for them [even if they came here already]. *I love my health.*"

This participant positioned regular HIV testing as good for her health ('I love my health') and mentioned how the continuous presence and efficiency of the household HIV testing intervention in the community allowed her to test as regularly as she liked (more than fifty times, as she likely exaggerated). She did not articulate a sense that testing might serve a broader public health benefit.

In many other discussions with people who tested regularly with the CHiPs, it was less immediately clear what participants' reasons were for testing. Some participants stated that they knew their status to be negative or did not perceive themselves to be at risk for HIV, and yet still were comfortable to test repeatedly and publicly, such as this 32-year-old woman:

> 'I'm not shy, I know I don't have AIDS (meaning HIV). I let [the CHiPs] test me here in the road … [They give me the results] immediately, I don't care if there are many people standing around, I say [to the CHiPs] "you don't hide my business". Now that's how they know me already – they [the CHiPs] say "geez, if there was a prize [for testing], you'd win it."'

At another point in her interview, however, the same participant expressed an intense fear of HIV, stating that she would 'throw herself under a train' if she were to test HIV-positive. This sentiment in the context of her repeat testing suggested that her testing uptake was potentially motivated by her belief that 'I don't have AIDS' and that the act of HIV testing held meaning other than the potential of an HIV diagnosis.

Another repeat tester – a 37-year-old woman – articulated the importance of the CHiPs' relational work with community members. Her comfort with the testing process was shaped by her positive interactions with the CHiPs in her community, which helped her to frame their work as important and caring. She explained:

> 'I always want to be tested. When they [the CHiPs] come here then I just say yes, even though I know I don't sleep around … They're just so positive, chat nicely with a person … They [focus on HIV and tuberculosis (TB)] and they know how to have a good chat. It's the same people who come [each time].'

Neither of these women's narratives supported conventional public health discourses of testing uptake, i.e., linked their repeat participation in the household testing intervention to a perceived risk of HIV and subsequent need to start treatment. What is shared between the two women are presumptions about their HIV status as negative and a comfort with testing with the CHiPs, demonstrating how a household HIV testing intervention can become part of a regimen of self-care.

4.1.4. 'Normalization' of HIV and ART in communities made HIV testing acceptable

Participants spoke about HIV in their communities in ways that reflected that HIV had become part of the social fabric and health landscape of South Africa. A participant in a high HIV burden community explained:

> '[Being HIV-positive] it's not a secret anymore. Everyone has it – you are lucky if you don't have it … This whole community understands about HIV … They talk about it … and they always point [to] people who have it.' Woman, 43 years old, not living with HIV, S14

In a context where HIV was perceived to be so pervasive participants could easily share their attitudes and reflect on HIV in their communities more broadly. These attitudes and perceptions suggested that HIV had become 'normalized' with the availability of ART. The same participant explained: 'they love [sex], even though [the] HIV rate is high; it's as if … they don't even care about HIV … *A person who takes treatment is alright, is normal, it's as if they have nothing*'.

However, this 'normalization' was tenuous. Most participants juxtaposed the biomedical normalization of HIV with ART, i.e., the ability of ART to transform a once deadly disease into a chronic manageable condition, against continued stigmatizing attitudes around the disease's acquisition. The inherent tension between the biomedical normalization of HIV and continuing HIV-associated stigma and discrimination that negatively shaped how people perceived and experienced having HIV was evident in how participants spoke about it. For example, participants could list euphemisms or *slang* for HIV that were used in their communities in general terms but reverted to 'HIV' when describing their own experiences. While euphemisms allowed people to speak about HIV in more indirect and comfortable ways, they attached decidedly negative and stigmatizing connotations to the disease. An example of this tenuous, complicated 'normalization' are the experiences of a woman participant from S20. She would regularly use the term '*AIDS gat*' (which translates to ‘AIDS arse’)[5] when talking about PLHIV in her community. Yet, she also provided palliative care to a close friend of her daughter who had comorbid HIV and drug-resistant TB. She did so on a makeshift bed in the living room of the small home she shared with her daughter and foster child, deciding to take her in as the woman's own mother had refused to care for her. The participant used her meagre household resources to do so.

4.2. Part B: alignment of community members’ experiences with public health calls for individual health and collective responsibility

Our participants' narratives and experiences with the household HIV testing intervention delivered in the trial revealed an array of implicit and explicit rationales for HIV testing. Some of these narratives resonated with rational public health logics of the HIV ‘treat all’ policy in which participants demonstrated an understanding of the benefits of HIV testing for their own health and the health of others. The traditional healer who framed regular testing as important for early initiation onto ART, along with her recognition that this was to protect others, is one example. Similarly, this was evident in the narratives of many others who framed HIV testing as good for their health, demonstrating a regimen of active self-care in their adoption of health promoting behavior, although participants did not tie their testing to treatment.

While these individual and public health rationales for HIV testing uptake were present in some of the narratives of our cohort participants, they were not dominant. Rather, our analysis revealed another more pervasive and implicit rationale that shaped uptake, i.e., the notion that participation in the HIV testing intervention was a ‘common good’. We saw this in how participants framed the intervention as a manifestation of interest and care in their communities and in their experience of the intervention as motivating community members to care for themselves. This idea that the intervention was a ‘common good’ for the community importantly shaped how participants attached meaning to their own and others uptake of HIV testing in the intervention. Participating in the intervention became a proxy indicator of care for yourself (‘individual health’) and a demonstration of a desire to support a better, healthier community (a ‘collective responsibility’). As such, we saw participants attach strong moralizing and ethical interpretations to participation in the intervention; testing appeared almost to become virtuous. With testing tied to virtue, those not testing were subsequently labelled as ‘lazy’, ‘negligent’, or ‘apathetic’, demonstrating carelessness for self and others. Such individuals were understood as shirking both a responsibility to their individual health and a collective responsibility towards the community.

The meaning that participants attached to participation in the intervention as virtuous thus resulted in negative and stigmatizing attitudes towards those not taking up the intervention. Such attitudes towards those not taking up the intervention were exacerbated by how easy and accessible participants experienced HIV testing with the CHiPs. According to this reasoning, if HIV testing was delivered right at your doorstep, and is good for you and for the community, how can you not test?

While non-participation was potentially stigmatizing, participants were also aware of the potential for HIV stigma that could result from testing for HIV with its potential for a positive diagnosis. Our participants recognized such fears as possible reasons for why some community members did not take up the offer to test. However, in keeping with our argument about how taking up testing showed a desire for a healthier and more cohesive community, testing despite such fears proved an even more robust commitment to the ‘common good’. By attaching virtuosity to HIV testing in the intervention, participating in the intervention could thus grant a person moral standing, potentially regardless of ‘undesirable’ behaviors (e.g., drug use, infidelity, and sexual promiscuity) which participants conventionally considered to go against the good of the community. According to this logic that participants presented, a person could hypothetically be considered moral while being involved in multiple concurrent partnerships – behavior that participants often attached to individuals who knowingly spread HIV – if they were understood to also practice healthy behaviors by testing regularly and accessing treatment if needed. Without explicitly tying participation in the household HIV testing intervention to the public health logic of the HIV ‘treat all’ policy (in which early and immediate ART is framed as a personal and collective good), instead, community members' participation in the intervention or not became a ‘test’ of their commitment to the good of the community, and an opportunity to practice being good and moral citizens.

5. Discussion

In this paper we aimed to explore how a public health initiative framed around an assumption that individuals make rational health-related decisions based on both a concern with their own health and with a broader community benefit, or public good, was taken up in South African communities characterized by precarity and social adversity. Contrary to dominant public health discourses, which assume that regular uptake of HIV testing signifies individuals' alignment with the broader global agenda of HIV epidemic control, we found that the everyday logics that informed HIV testing uptake were not always framed around a concern for individual and collective health. Instead, these logics were intensely local and relational, focused more on strengthening social relations than improving health. Specifically, our findings show that while the availability of ART has helped to ‘normalize’ HIV biomedically and make HIV testing more acceptable in South Africa, for many participants testing for HIV in the intervention became an avenue to practice being good and moral citizens. We saw this in two ways. First, some participants articulated a sense that they should take up HIV testing as part of a sense of individual responsibility to prevent and control HIV. This aligns with a documented shift towards individual ‘responsibilisation’ (Robins, 2005; Rose & Miller, 2008) for HIV epidemic control. Second, participants articulated that HIV testing demonstrated their desire or commitment to fashion a healthier, more cohesive community through aligning their actions to a broader ‘common good’. Both these responsibilities, when unfulfilled, resulted in stigmatizing attitudes directed at non-participation in the intervention. In particular, our study participants associated a refusal to take up HIV testing in the intervention with a lack of care for and cooperation with their community.

The strengths of our findings are that they are drawn from rich, longitudinally collected ethnographic data, analyzed from two interrelated conceptual and epistemological positions. Our large sample and grounding of findings in longitudinal data collection in a context of community dynamics facilitates transferability. Our analysis does not include Zambian comparative data and is limited to a largely urban South African context. Further, we focus on the community dynamics that shape uptake of a household HIV testing intervention, which excludes consideration of how HIV-related stigma may present in households themselves and shape individual household members’ motivations, rationales, and participation in the home-based HIV testing intervention. Our sample is skewed by gender and age, with the voices of women and those aged between 25 and 44 overrepresented. Further analyses and studies should focus on the experiences of men who have consistently lower uptake of HIV services and are often underrepresented in research on communities and households, as well as those of young people. Limitations to the generalization of our findings are due to the unique social, political, and economic histories in South Africa, which profoundly shape how participants respond to the offer of HIV testing. Analyses in similar global South contexts with low social cohesion are needed to explore how these findings translate to comparable settings.

Our analysis resonates with those of other empirical studies and theories. For example, Bond et al.‘s (2016: 332) research showed how the

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[5] This term implied that a person is riddled with AIDS and was often associated with ‘rotting’ from inside.

treatment as prevention discourse created new, moral responsibilities for PLHIV 'for containing the virus' and that failing at executing this responsibility resulted in blame. The household HIV testing intervention implemented in the trial similarly brought the responsibilities of community members into relief – a responsibility to the collective, 'common good' that had perhaps not existed or was less overt before the intervention was implemented. Moreover, failing to take up this moral responsibility made individuals less moral people. Golub and Fikslin (2022) discuss how HIV interventions have the potential to inadvertently activate stigma for PLHIV, and call for researchers and implementers to be cognizant of and disrupt such potentialities in their interventions. While analysis shows that the HIV testing intervention did not significantly influence HIV-associated stigma in HPTN 071 (PopART) trial communities (Hargreaves et al., 2022), our findings demonstrate how non-participation itself (regardless of HIV status) holds potential stigma. There is now broad evidence for an evolution in how HIV-associated stigma manifests in contexts of more accessible HIV testing and treatment services, with implications for individual responsibility (Bond et al., 2016; Viljoen, Bond, et al., 2021). Barolsky (2016) argues that because humans are social creatures, our ethics are principally social (collective), rather than purely individual, and that these values principally shape social order and sociality. As such, 'ethical personhood, as opposed to mere existence, is realized through the collective and by means of actively carrying out duties and obligations to kin and community' (Barolsky, 2016, p. 6) – a premise that shaped how our study participants attached meaning to participation in the intervention as being for or against the community, social or anti-social (McVeigh, 1974; as cited in Barolsky, 2016). Ross' (2010) ethnographic research in South African communities has bearing here. She shows how, despite their difficult environments, a yearning for a sense of community and belonging, and a concomitant aspiration towards a permanent, respectable, decent home and life punctuate the lives of many poor South Africans. She explains that 'people internalize normative models about the good life and how to live it' and 'seek to accomplish and adhere to a liberal model of decency that is extremely difficult to achieve' (Ross, 2010, p. 210). While research shows that high social cohesion leads to positive health outcomes (Lippman et al., 2018; Sampson et al., 1997), our findings suggest that in contexts of low social cohesion, community members' desire for a sense of community, unity, and belonging, can similarly encourage health promoting behaviors. A community-wide health intervention can thus create an avenue for people to practice or perform such decency and a desire for a 'good life'.

The high uptake of HIV testing achieved in the HPTN 071 PopART trial (Floyd et al., 2020) and its association with a 'common good' would not have been possible without scaled-up access to ART in South Africa. Intense efforts by the national government and civil society over nearly three decades, have inserted HIV into a collective South African consciousness in which the knowledge that you should take up HIV testing and consistently use condoms is an ingrained and inescapable aspect of self-care – regardless of whether one complies or not. While ART has been instrumental in biomedically 'normalizing' living with HIV and has contributed to making HIV testing more acceptable, this 'normalization' remains tenuous, however. It continues to exist alongside intense stigmatizing attitudes and language directed at PLHIV. As Mazanderani and Paparini (2015) illustrate, the 'normalization' of HIV is full of 'challenges and contradictions', even in well-resourced and functioning health settings such as the United Kingdom where ART has been available for a much longer time than it has been in South Africa. As such, even as ART has the potential to make the person with HIV 'regular [and] unremarkable' (Squire, 2010), this 'normalcy' is not extended to the entire person. Many South Africans thus hold contradictory opinions, beliefs, and experiences in a high HIV burden setting such as South Africa, where 1 in 5 people are estimated to be living with HIV and every South African is affected. Holding this knowledge – that HIV is an almost expected consequence of life – in a context in which HIV stigma persists complicates access to HIV care, including HIV testing, as people often attempt to navigate their illness privately in living conditions and health facilities that often do not support their need for privacy (Bond et al., 2019; Viljoen, Bond, et al., 2021; Viljoen et al., 2020).

The World Health Organization frames HIV testing services as a vital component of an effective national and global HIV response, essential to achieving and maintaining low HIV incidence, and a service to which every person living in high HIV burden settings should have easy access (World Health Organization, 2019). Many countries, including South Africa, are moving towards differentiated HIV testing approaches to maximize access in the population. Contrary to experiences of facility-based HIV testing, where HIV testing is most often provider-initiated, thus positioning individuals as passive recipients of care, regular community-wide household HIV testing has the potential to offer participants a greater sense of decision-making power and participation in a collective effort, thus framing the individual as an important actor and agent of the 'common good'. In the context of a community-wide household HIV testing intervention, community members were given the opportunity to assume responsibility both for themselves and for the community, and to frame themselves as agents in doing so.

Our findings add to the scholarship on public health practices in settings characterized by lasting histories of colonialism and oppression such as South Africa, with implications for policy. In such contexts, histories of race-based oppression and ongoing inequalities powerfully shape the relationships between community members, between citizens and states, between health workers and patients, as well as individuals' sense of responsibility to a broader public collective. In their lasting legacies, such histories are present in how public health discourses for achieving HIV epidemic control materialize and find expression with community members who are the target of health interventions. As we have shown, participation in a health intervention can become much more than a desire to improve individual health or the health of the public; in contexts of precarity it can also become a demonstration of and desire for a good, decent life, and for a more socially cohesive community. This shift, from individual health to individual responsibility, and from collective health to 'common good', should be explicitly reflected in HIV policy and guidelines. Specifically, recommendations by global HIV stakeholders such as UNAIDS, PEPFAR, and the WHO, need to accommodate the moral discourse and risk of stigma that may result from implementing HIV treatment and prevention interventions. More research is needed to understand how complex community and social dynamics that inform individuals' decisions to take up health interventions manifest in different settings.

Author statement

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Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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