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Journal

Journal of the International AIDS Society, 20(4)

ISSN

1758-2652

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Publication Date

2017-12-01

DOI

10.1002/jia2.25023

Peer reviewed

RESEARCH ARTICLE

Redemption of the “spoiled identity:” the role of HIV-positive individuals in HIV care cascade interventions

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Abstract

Introduction: The concept of “therapeutic citizenship” has drawn attention to ways in which public testimony, the “story-telling in the public sphere” undertaken by people living with HIV (PLHIV), has shaped the global response to the epidemic. This paper presents qualitative findings from two large studies in eastern Africa that reveal how the advent of population-based HIV testing campaigns and efforts to accelerate antiretroviral “treatment for all” has precipitated a rapidly expanding therapeutic citizenship “project,” or social movement. The title of this paper refers to Goffman’s original conceptualization of stigma as a social process through which a person’s identity is rendered “spoiled.”

Methods: Data were derived from qualitative studies embedded within two clinical trials, Sustainable East African Research in Community Health (SEARCH) (NCT# 01864603) in Kenya and Uganda, and START-ART (NCT# 01810289) in Uganda, which aimed to offer insights into the pathways through which outcomes across the HIV care continuum can be achieved by interventions deployed in the studies, any unanticipated consequences, and factors that influenced implementation. Qualitative in-depth semi-structured interviews were conducted among cohorts of adults in 2014 through 2015; across both studies and time periods, 217 interviews were conducted with 166 individuals. Theoretically informed, team-based analytic approaches were used for the analyses.

Results: Narratives from PLHIV, who have not always been conceptualized as *actors* but rather usually as *targets* of HIV interventions, revealed strongly emergent themes related to these individuals’ use of HIV biomedical resources and discourses to fashion a new, empowered subjecthood. Experiencing the benefits of antiretroviral therapy (ART) emboldens many individuals to transform their “spoiled” identities to attain new, valorized identities as “advocates for ART” in their communities. We propose that the personal revelation of what some refer to as the “gospel of ARVs,” the telling of personal stories about HIV in the public sphere and actions to accompany other PLHIV on their journey into care, is driven by its power to redeem the “spoiled identity:” it permits PLHIV to overcome self-stigma and regain full personhood within their communities.

Conclusions: PLHIV are playing an unanticipated but vital role in the successful implementation of HIV care cascade interventions.

Keywords: HIV-infected adults; HIV-related stigma; therapeutic citizenship; HIV care cascade; HIV care continuum; sub-Saharan Africa

Received 7 March 2017; Accepted 5 October 2017

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1 | INTRODUCTION

This paper addresses an important research question on the role that people living with HIV (PLHIV) are playing in progress towards achieving global HIV prevention and treatment goals: What is the evidence that an emerging “therapeutic citizenship” on the part of PLHIV is having a vital, but unanticipated effect on universal HIV test and treat interventions? We present accumulated evidence and describe social processes that drive this phenomenon and its effects. First, we explain the concept of “therapeutic citizenship.”

Among the contributions of Hannah Arendt’s thought and work is her premise, presented in *The Human Condition* [1], that the revelation of the self occurs in the *polis*, or public realm. Human beings constitute themselves as individuals only through action and speech that can be witnessed by others: “to insert one’s self into the world and begin a story of one’s own” is to become fully a person. Undercurrents of Arendt’s philosophy can be seen in the scholarship concerned with “citizenship” in relation to biomedicine, in particular to the era of HIV/AIDS. Within anthropology the term citizenship encompasses more than just the link between an individual and a

nation state. Rather, it refers to a range of complex social processes through which “belonging, exclusion, duties and rights” are defined in societies [2]. Ecks proposed the term “pharmaceutical citizenship” [2] to describe how pharmaceuticals, for instance to treat depression, enabled a “biomedical promise of demarginalization” among stigmatized patients in India. Nguyen, in turn, proposed the concept of “therapeutic citizenship” [3,4], moving beyond an analysis of the relationship between drugs and citizenship to draw attention to how the “story-telling” in the political sphere undertaken by PLHIV in southern Africa has shaped the global response to the epidemic.

Broadly, this conception of citizenship vis-à-vis the HIV/AIDS epidemic refers to a biosocial and biopolitical process of change in people’s identity resulting from their HIV diagnosis and social interactions with biomedical authorities. HIV organizations are seen to exert power through the resources they offer, and HIV status can be used to claim resources from public programmes or non-governmental organizations [4]. These organizations exert power through the discourses they promulgate about the rights and responsibilities of PLHIV; PLHIV are exhorted to claim their rights to treatment access [5], and to behave as “responsible” HIV citizens by adhering to antiretroviral therapy (ART) [3] or practicing safer sex. The fashioning of therapeutic citizenship thus involves power relations and techniques, including people’s frictions and negotiations with the “moral frameworks” or “moral economies” that govern their health behaviour [4,6,7].

Nguyen and colleagues used the concept of therapeutic citizenship to explain high levels of ART adherence in early HIV treatment projects in Africa [3]. They also viewed the effectiveness of political activism in the HIV/AIDS era (exemplified by the South Africa Treatment Action Campaign) via the lens of therapeutic citizenship. These scholars described how PLHIV used techniques and resources derived from HIV/AIDS programmes (e.g. testimonials, or what Nancy Rose Hunt had termed the “confessional technologies” of self-help groups), in order to fashion themselves into effective advocates. These early activists then made claims on the wider global economy of the pharmaceutical market and HIV policy architecture: “The issue of access to ART in effect simultaneously provided both a therapeutic goal and the means of sustaining the therapeutic quest. Bluntly put, skill at telling the right stories got activists drugs, and kept them alive.” [3] (p. S34). Nguyen notes that in political economies of inequality and resource scarcity, therapeutic citizenship has been bartered for resources such as life-saving HIV medications. He argues that international public health NGOs created a market for testimonials, which became a basis for rationing treatment in West Africa; PLHIV were compelled to engage in public disclosure and self-transformation, with those who shy away from disclosure disadvantaged by the “triage” that determined who lived or died [8].

More recent literature has examined favourable impacts of therapeutic citizenship on HIV care programmes. In particular, the concept has been used to inform an understanding of processes through which PLHIV in Uganda have become “responsible self-managers” of their condition [9–11]. Russell and colleagues (*ibid.*) have described processes through which, with guidance of health care providers, PLHIV reconceptualize their condition and situation more positively, and thereby motivate their self-management, develop new social support

networks and acquire skills and knowledge for emotional coping and practical self-management tasks. In contrast, other scholarship on therapeutic citizenship has focused on ways it exerts power over them “in a Foucaultian sense, shaping patient identities to lead responsible and disciplined lives and be compliant with authorities, based on expectations about the ‘right’ way to behave” [9] (p. 3). Persson and colleagues [12], for example examined the implications for citizenship among people with HIV who refuse or delay recommended medication in Australia. They found that “moral and normative expectations emerging in the new HIV ‘treatment revolution’ have the capacity to both demarginalize and marginalize people with HIV” (p. 1), and argued that “pharmaceutical citizenship does not simply pull people from the edges, it also pushes them there” (p. 20). Whyte [13] has described a disempowering form of therapeutic citizenship in Uganda, proposing the term “therapeutic clientship” to describe how PLHIV are framed as recipients of “the professional expertise provided to them by rational bureaucratic organizations” who perform for their patrons in the health system a “discipline of self-care,” “a practice encouraged by others who inspect your medicines and to whom you can display virtue.” [14] (p. 163). In their summary of literature on patient citizenship and ART, Papparini and Rhodes have argued that conceptualizations of the HIV care cascade and the scale up of ART may have accentuated a “remedicalization” of HIV and a new emphasis on individual responsibility for HIV management, muting a necessary attention to links between therapeutic citizenship and broader care and treatment demands in the context of competition for public funding and resources [15]. This article thus references a literature that is ambivalent because of the potential of therapeutic citizenship for both empowerment and coercion, both its promise and its limits.

1.1 | The hypothesis of “therapeutic citizenship”

This paper presents qualitative findings from two large randomized controlled trials conducted in eastern African communities. We posit that the advent of widespread testing campaigns and efforts to accelerate antiretroviral “treatment for all” in these communities has precipitated a rapidly expanding therapeutic citizenship “project.” Our analysis draws upon contemporary anthropological work on therapeutic citizenship, on its context of spirituality and evangelical Christianity in Africa, as well as Goffman’s [16] original conceptualizations of stigma as a social process through which a person’s identity is rendered “spoiled.” In these settings, PLHIV use the resources and discourses of HIV biomedicine and its programmes to fashion a new empowered subjecthood; this social process is experienced as a particularly spiritual or even religious “redemption of the spoiled identity.” We deliberately use religious or “moral-economic” terms to describe this project, in fidelity to the language used by PLHIV in these settings. Nguyen observed in South Africa that people’s testimonials about the benefits of using ART were often “couched in an evangelical idiom:” “living through the ‘resurrection’ one experiences after one has been ill and has recovered because of the drugs [...] only confirmed the evangelical aura that surrounds HIV and its treatments.” [3] (p.S34). Similarly, Whyte has observed that in the era of Christian revival in the post-Amin Uganda, “being born again in Jesus and born again

as an enlightened client of an ART programme were mutually reinforcing”[14] (p. 13), and indeed that discourses of salvation, faith and hope, for example the practice of “witnessing” as part of AIDS education, were well-established in Uganda even before the ART era.

1.2 | Research Setting

The analysis for this paper is derived from qualitative research projects within two studies in Uganda and Kenya. Both studies, broadly, are designed to test strategies that harness the potential of ART to bring about large-scale reductions in HIV-related illness and to dramatically decrease the continued spread of HIV. These studies were motivated by evidence that although ART holds remarkable promise for efficacious treatment of HIV infection, as well as for large-scale prevention through a “treatment as prevention” strategy [17–19], a gap exists between this potential and actual engagement in care across the cascade – thus undermining realization of this promise [20].

The *Streamlined ART Initiation Strategy (START-ART)* study (NCT# 01810289) tested a multi-component strategy designed to target health care workers in Uganda to accelerate initiation of ART among eligible HIV-infected patients. This study aimed to test a clinic-based strategy for widespread adoption of accelerated ART initiation for eligible patients, including same day start, in a “real world” health systems setting. Implemented in 20 clinics in Uganda from May 2013 to October 2014, START-ART achieved a dramatic uptake in the proportion of patients who started ART on the same day they were found to be eligible (70.8%, compared to 18.3% pre-intervention) [21]. The qualitative sub-study within START-ART explored the potential pathways for uptake of the intervention.

The *Sustainable East African Research in Community Health (SEARCH)* study is an ongoing community cluster-randomized controlled trial (NCT# 01864603) in 32 communities of approximately 10,000 persons each in three regions in Kenya and Uganda (334,512 persons in total), which aims to demonstrate whether a universal HIV testing and treatment (“test and treat”) strategy for HIV can reduce cumulative HIV incidence and improve health, economic and education outcomes, through a hybrid mobile HIV testing approach, described in detail elsewhere [22]. SEARCH demonstrated the effectiveness of its model for high HIV “cascade coverage,” and increased population viral suppression from 45% to 81%, exceeding the UNAIDS 90-90-90 cascade target within two years in intervention communities [23]. A longitudinal qualitative research study embedded within SEARCH aims to examine how the introduction of test and treat influences beliefs, attitudes and behaviours regarding HIV and, in turn, how these changes influence the uptake and success of test and treat strategies.

2 | METHODS

For START-ART, the qualitative sub-study conducted in five health care facilities that composed the third wave of the study, were representative of large and small clinics across the geographical area for the trial; two of the clinics were

urban, in the complex of a national referral hospital, whereas the rest were in rural settings. In-depth semi-structured interviews were conducted with health care providers and patients two months prior, and seven to twelve months after the intervention was introduced in March and April 2014. The analyses for this paper were limited to interviews with individuals engaged in or overseeing ART and HIV care delivery and counselling in the clinics. These included two (2) nurses, five (5) counsellors and six (6) medical officers; as well as nine (9) PLHIV in care (peer counsellors). A total of 22 pre-intervention and 19 post-intervention provider interviews were conducted (three of the providers interviewed pre-intervention had left clinics by post-intervention). Interviews were performed by trained study staff and conducted in local languages. In this article, we present transcript excerpts of interviews with the PLHIV who worked as peer educators.

For SEARCH, various sampling and data collection methods were used, including annual observations of Community Health Campaigns (CHCs), focus group discussions with CHC attendees and in-depth interviews. All activities were conducted by a gender-balanced team of trained qualitative researchers from Uganda and Kenya who were native speakers of local languages, under guidance from the lead investigator. Interview data were collected at baseline (February to August 2014) with 50 health care providers, 32 community leaders and 112 members of 8 of the 32 communities. Providers were selected purposively to represent a range of cadre involved in ART delivery, community leaders were selected purposively for gender balance and composed key informants who were engaged by the study to help mobilize communities, and community members were randomly selected from a stratified random sample within SEARCH (including HIV-positive and HIV-negative community members). One year later (September 2014 to July 2015), follow-up interviews were conducted with 41 of the health care providers, the same 32 community leaders and 107 of the members of the eight communities (attrition in the cohorts was due to deaths and refusals at follow-up). Follow-up year interview guides were tailored with individualized questions based on baseline responses. This article presents findings from interviews with PLHIV across all of these sampling categories; all excerpts are from transcripts with PLHIV. In total, across studies and time periods, 217 interviews were conducted with 166 individuals.

In both studies, data collection team members transcribed and translated audio recordings. Analyses were informed by constructivist grounded theoretical approaches (as explained by Charmaz) [24] and selected social and behavioural theories; we used Atlas.ti software [25]. For START-ART, the lead investigator and study investigators and team members defined an initial coding framework and refined it a second time following a review of the data. In SEARCH, the lead investigator, project coordinator and team members collaboratively defined an analytical coding framework following review and discussion of the first sets of transcripts, and the full research team iteratively refined the framework during the continued data collection and review process. For both studies, coding of transcripts was undertaken in teams. Codes were extracted as query reports, which were reviewed and used for development of analytical memos during the theory-construction process. This research received ethical approval from the

University of California San Francisco Committee on Human Research, the Ethical Review Committee of the Kenya Medical Research Institute, the Makerere University School of Medicine Research and Ethics Committee and the Uganda National Council for Science and Technology.

3 | RESULTS

In the narratives we present, PLHIV undergo a process of “re-making themselves:” a diagnosis of HIV, whether recent or in the past, precipitates experiences of shame and self-stigma, introduces anxieties surrounding concealment or disclosure of an HIV-positive status, and leads to experiences of stigma, including sometimes extreme forms of enacted stigma (especially against women). Processes whereby individuals enrol in HIV care and treatment and take up ARVs that visibly renew their health and vitality, and then offer an opportunity to undertake a process through which the stigmatized identity is shed, and a transformed, valorized social identity is created via the performance of citizenship. As documented in prior scholarship, this involves public testimonials of personal experience, followed by exhortations to others to get tested, link to care and adhere to ART.

Not yet well-documented, but apparent in our narratives, are the ways in which these processes are not dependent on the participation of PLHIV in remunerated roles in health systems or NGOs, nor on their participation in political activist or self-help groups, nor does it appear to be driven by specific efforts such as stigma-reduction interventions. Rather, it is a spontaneous uptake, among PLHIV successfully engaged in care, of a publicly recognized advocacy role. This may be as a lay health worker/peer educator or counsellor, whether paid or volunteer; alternatively it is a spontaneous uptake of a more informal advocacy undertaken with family, friends, neighbours and strangers, in clinics, streets, markets, bars and churches. The independent findings that support the emergence of these themes in the data are presented below, organized by study.

3.1 | START-ART

“I have experience in this medicine, and now I teach others.” Results from the START-ART study are from interviews conducted with peer educators/counsellors. These are PLHIV successfully engaged in HIV care who work in clinics supported by MJAP, the NGO working in partnership with the Ugandan Ministry of Health to deliver HIV care and treatment. They are the lowest level of cadre in clinics, with low remuneration. In many settings they provide administrative and clerical support, registering patients and tracing those lost to follow-up, whereas in other settings (typically, in more rural clinics) they provide counselling. In more urban settings, counselling is done by a formal cadre of certified HIV counsellors, who are typically university-trained, in contrast to the lower socio-economic status, less well-educated peers. Lacking other recognized expertise, the peer counsellors use the expertise they have accumulated through their own personal experience with HIV care and treatment. Critically, peers officially tasked with counselling are given the same “script” and protocol that is used by the formal HIV counsellors, which includes information

about HIV testing and treatment, and advice regarding nutrition, adherence, alcohol use, safer sex and so forth; to our knowledge no entity or organization is advising peer counsellors specifically to disclose their own personal experiences with patients. Yet, as the narratives below show, the sharing of personal stories is a large part of what they do with patients. Every peer in ART programmes revealed sharing personal experiences with ART as part of counselling either in pre- or post-intervention interviews. In contrast, none of the HIV counsellors reported disclosing their HIV status or discussing any personal matters with patients (including any personal experience with ART) in either pre- or post-intervention interviews. Indeed, study team members report that it may be considered unprofessional for counsellors to do so, and this may be communicated in training programmes for the cadre.

Peer counsellors said that when patients see and hear about their personal experiences, they become open to starting ART. So, they openly discussed their own experiences as a strategy to persuade the patients to enrol in care. The peers often began this testimony with an accounting of their own CD4 cell counts, recalling their own “death to life” experiences, and offered themselves as a “social proof” of the efficacy of ART:

“Now people have seen others [on ART], and are open to ART [...] I started ARVs when I had 9 CD4s, now I have 896. I tell them and they feel encouraged. [...] I feel so happy because I see from them where I have come from; I teach them from my experience and I encourage them and I feel proud of it. [...] Others worry, ‘if I take this medicine, won’t it be too strong and I die?’ [...] I even tell them, ‘look at myself; am I dead? I am ok’, and they feel strong.” (Peer counselor at small rural clinic, pre-intervention)

“I comforted her and told her ‘if you had seen me, I was wasted. As for you, you have 97, me I had 9.’ [...] I showed her how I was and where I had reached.” (Peer counselor at small rural clinic, post-intervention)

“I always give them a testimony. I acquired the virus long time ago— I got it in 1988. [...] So I tell someone that I am in 20 years with the virus, and if I show him that I have no problem, then the person also feels strengthened.” (Peer counselor at rural, high-volume HIV clinic, post-intervention)

The peers’ personal testimonies led to a quality of interaction that was often emotionally intimate. This, peers said, was important for patients; it may also have been helpful for peers themselves. In contrast to narratives of conversations between patients and counsellors or clinicians, peers’ narratives include accounts of crying with patients. The experience of close sharing and crying with patients seemed in some instances to have been emotionally cathartic for the peers:

Now when he cried, this is when you feel that the tears have come near and then you also feel like crying, so I cried a bit, [...] He narrated to me that he was thinking that, now that he has acquired HIV, his time for dying has arrived. When I

told him that I am 20 years and more with the virus, he became happy and said, “let me also try, so that I can also make like 20 years.” [...] I felt good. (Peer counselor at rural, high-volume HIV clinic, post-intervention)

It was often important to patients that the peers were actually on ARVs – and peers sometimes felt challenged to prove it by showing their pill bottles or ART clinic identification cards:

“Some of them ask me, ‘Musawo [doctor], I hear some of you tell us that you are on ARVs, and yet you are not. Is that true?’ Now when a patient asks you such kind of question just know there is a big issue that you need to handle and explain. [...] So I now move with my card [...], such that if there is a patient who asks me such a question, I show them that card. [...] That will encourage them to also go and swallow their medicine well. [...] I tell them that, you are not swallowing this medicine for yourself alone, but also for your family...” (Peer counselor at national referral and teaching hospital, post-intervention)

“I was trying to counsel her so that she does not fail to take her medicine. I even gave her an example of myself— I always do that, to give them courage when they seem like they are stumbling. [...] Some cannot even believe me. They think that we are told to lie to them so that they get strength, but I tell them I am not lying. I am on ART. Some [believe] myths that when you start ART, you are going to die [...] And I tell them, ‘How come I am not dead? I am taking the same regimen like the one you have been given, it has been 6 years [...] and yet I am alive.’” (Peer counselor at small but busy rural clinic, pre-intervention)

Providers across all cadre appeared to be gratified by helping people, and were strongly intrinsically motivated to provide high quality care. Peer educators seemed particularly motivated by the social valorization and respect they gained from their role in clinics:

“[[What strengthens me] is counseling, because if you counsel someone and he meets you and he tells you, ‘you got me from far that I had gone!’, that is the most important part, it is the part that motivates me. You see people respecting you.” (Peer counselor at small rural clinic, post-intervention)

“Someone is sick and [she] brings for you a pineapple, now do you think someone can bring you such a thing when you have not done for him something? She also denies herself but she brings it for you.” (Peer counselor at small rural clinic, post-intervention)

Tellingly, even in settings in which peer educators are specifically tasked with only administrative functions, they often inserted themselves in counselling roles. The following narrative describes the intervention two peers undertook when they saw a woman crying during a group pre-test counselling session:

“It was a young university lady. She came here and while she was sitting among the others, she started crying. When some of us realized it, I went over and asked her to come and we talk. [...] She came crying but by the time she left, she was laughing because we talked to her.” (Peer counselor at rural, high-volume HIV clinic, pre-intervention)

Peers had repeated encounters with patients both in clinic and community settings, and often helped patients with disclosure to spouses and children, over time.

In one narrative, a peer counsellor discusses the case of a school headmaster, who on learning about his status, felt suicidal. Through repeated encounters with him at clinic and his home, the peer counsellor helped him to come to terms with his diagnosis. This counsellor discussed embracing open disclosure of her status as a way to fight stigma, and she advises patients to take the same approach:

“I tell them that personally I had to deal and do away with stigma from people. [...] By the time you think about doing rumors about me, I will have explained my status already. [...] If you fall in love with this medicine, the next thing to do is to make sure you take it, and take it at the exact time we tell you to take it. The moment you accept what you are and your status, everything becomes good and even at home you get peace [...]” (Peer counselor at national referral and teaching hospital, post-intervention)

Peers and patients often stayed personally connected to one another and maintained their advocacy role, in both the clinic setting and in communities. It seemed they were never “off-duty” from their responsibility for representing the ART programme:

“I don’t leave the station before I give out my telephone number and I tell them, whoever needs help should call me. [...] If I am not here in the clinic, patients call me all the time and not only patients of this clinic” (Peer counselor at national referral and teaching hospital, pre-intervention)

“Now at the end when he took the drugs [started on ART], he thought that in one month, the drugs will bother him, but they didn’t... he called me and told me, ‘what I was thinking? It’s not the way it is— I became fine, so there!’ He said, ‘the drugs, people lie about them.’ (Peer counselor at rural, high-volume HIV clinic, post-intervention)

3.2 | SEARCH

PLHIV in Kenya and Uganda were engaging in advocacy and encouraging others to test and seek care, during base-line year of SEARCH. While many PLHIV were living in denial, concealing their HIV status from others, or actively engaged in HIV care and treatment outside of their communities in order to avoid stigma, others were quite open about their HIV status. Their personal narratives describe influencing friends, family members and neighbours to participate in

testing campaigns, make appointments to initiate ART, and adhere to medications. Many had already suffered from stigma, and reported that while stigma persisted, it was less extreme than in years past. Anticipated stigma and fears of disclosure among PLHIV were ubiquitous across regions. Yet many of those successfully engaged in HIV care at the time of interview already had been acting as strong “advocates” for HIV testing and uptake of ART:

“My neighbor [...] was complaining that ARVS were making her feel very sick... she was thinking of not taking them [...] I was talking to her to encourage her to continue adhering to drugs, telling her that the side effects will not last for long. (Female community member, married, age 25, Kenya)

“Those who refused to take ARVs have since died. I tell my children ‘if you feel you often fall sick and you test HIV positive, please take ARVs.’” (Female community member, widowed, age 60, Kenya)

Interviewers asked community members, ‘If someone you knew told you that they were infected with HIV, how would you react?’ and elicited accounts of the most recent conversations they had had about HIV with someone. PLHIV were affirming of others living with HIV:

“If I see that you have it [HIV], I advise you to be strong because I am in the same situation, so we should work together to go and get treatment.” (Female community member married, age 19, Uganda)

“I can’t think negatively of this [HIV positive] person. I can only give him advice [...] encourage him that “HIV is like any other disease and I too could be sick just like you [...] seek medical care and please adhere to care and treatment.” And if he looks hesitant, then I can take a further step of making sure that I take him to the hospital. [...] I will make sure that he honours his appointments. I will treat him as my friend and become his buddy in treatment till he is enrolled in care and initiated into ARVs.” (Male community member, separated, age 45, Kenya)

SEARCH employed teams of community mobilizers to publicize the study and encourage participation in CHCs, and used a variety of strategies designed to de-stigmatize and “normalize” HIV testing by offering it alongside multi-disease services. Initially these strategies were met with suspicion in some communities. Data from baseline interviews suggest that while some PLHIV were remunerated for helping with mobilization, many other PLHIV voluntarily played a role in encouraging CHC attendance:

“I want to tell you, that what you are doing is good [...] I came back home one day when my children reported that one KEMRI-SEARCH staff tested them at home when they did not expect. One made fun; “if I knew he was coming to test, I would have ran away.” They were happy with their results and I encouraged them to regularly do the tests

while advising them to be good always to maintain their negative result. (Female community member, widowed, age 41, Kenya)

“Even this morning I talked to somebody about HIV/AIDS. [...] I was encouraging another lady that it is better for her to go for the test and know her status in order to be helped early, instead of waiting.” (Female Community leader, age 44, widowed, Kenya)

Narratives in follow-up year interviews reflected an increasing openness in discussions about HIV; the content of conversations had changed.

After community-wide HIV testing campaigns were introduced, along with facilitated linkage to care and treatment with ART for those who tested positive, the content of conversations about HIV among community members shifted away from discussions about negative attitudes towards PLHIV (even if, in the baseline year, stigmatizing attitudes were said to be already changing). In follow-up year interviews, these conversations more often concerned decision-making and experiences related to HIV testing and accessing ART. The beneficial effects of ART appeared to have emboldened many PLHIV to openly engage in care despite anticipated stigma. As more individuals experienced benefits of ART they engaged in advocating for others to initiate ART, and to stay in care. The following narratives illustrate participants’ perceptions that PLHIV had become more open about their status in the past year:

“Some people in the past stopped having stigma. These people started talking about their status openly, and this motivated others to come out of their cocoons and feel free with their status. They would say, “if so-and-so is disclosing her status to people, why not me? [...] These people were also empowered by others who had started disclosing their status freely. It is something that is slowly catching up, and these days the infected approach the newly infected who are still in hiding and they give them support by giving advice: “just be free with your status...” (Female community leader, age 60, widowed, Kenya)

“You will find that at the lake one out of many is probably not in care, so majority will be talking about HIV care. Another person may take his drugs out to swallow [at] the time for taking it, and you hear him say, ‘these days you just take your drugs in the open...there is no point of fearing’” (Male community member, age 38, married, Kenya)

“I used to fear to be seen at the health facility [...] I would first look around so that no one ever gets to see me entering the tent [...] and walk around the health facility to see if there was any one that I knew. If there was none, I would proceed to the tent to receive services. But now that does not bother me at all... I thought to myself “instead of dying, I’d rather be embarrassed.” (Female community member, aged 19, married, Uganda)

4 | DISCUSSION

We have found evidence of social change underway in communities in eastern Africa through the engagement of PLHIV in a therapeutic citizenship project wherein they are taking on a public advocacy role, telling their stories, encouraging community members to test for HIV, and assisting other PLHIV to enrol and stay engaged in HIV care and treatment. This finding has emerged from analysis of narratives from qualitative investigations of two large studies in eastern Africa, one implementing community-wide HIV testing and treatment (SEARCH) and the other testing an intervention to accelerate initiation of ART among eligible HIV-infected patients (START-ART).

Scholarship on the concept of therapeutic citizenship in relation to HIV/AIDS, to date, largely has not been concerned with questions of what *drives* this project. We propose that this advocacy, the personal revelation of what some refer to as the “gospel of ARVs,” the telling of personal stories about HIV in the public sphere of communities and actions to accompany other PLHIV on their journey into care, is driven by its power to redeem the “spoiled identity.” It permits PLHIV to overcome self-stigma, refashion their identities and regain full personhood within their communities – as proposed by Arendt, the full personhood that is achieved through one’s actions and speech that is witnessed by others. When we speak of the public sphere, we are referring to Arendt’s concept of the *polis*, which is not just a physical location (the walled ancient nation-state of Athens) but also “the organization of the people as it arises out of acting and speaking together,” which does not always exist, and in which not everyone can participate. Arendt noted that in ancient Greece, women, slaves, and the “barbarians of antiquity” were excluded from the *polis*. Thus, systems of gender and other inequalities were fundamental to very notion of full personhood, which was achieved only through participation in the *polis*; and “to be deprived of it means to be deprived of reality, which, humanly and politically speaking, is the same as appearance.” (p. 199) In the contemporary era, as explained by Parker and Aggleton, HIV-related stigma acts to reinforce hierarchies of power and to systemically exclude those less enfranchised from society and render them invisible [26], “less than a human being.” Narratives from PLHIV in communities and in clinics reveal that whether or not they were remunerated, and whether they encountered other PLHIV in clinics or in communities, PLHIV in Kenya and Uganda are taking on new roles and self-conceptualizations that are transforming their “spoiled identity” as into a new valorized social identity, finding a moral “redemption” via their public advocacy of HIV testing and engagement in HIV care and treatment. We propose that the therapeutic citizenship described by the PLHIV we interviewed (per Arendt, their “sharing of words and deeds” that is witnessed by others), is tantamount to their storming the walls of the *polis* – a subversion of the systemic inequalities that are reinforced through stigma, and a restoration of their visibility and full personhood. In the narratives of PLHIV in these studies, this transformation seems to hold particular emotional power for individuals who had previously had been severely stigmatized in the past, usually in conjunction with their prior severe HIV-related illnesses. In the case of the peer educators who are systemically disempowered relative

to the professional cadre in health systems, its emotional power is derived precisely because of the ways in which it permits PLHIV to subvert hierarchies, because of the social valorization these individuals experience in clinics and communities.

This “redemption” occurs in a specific context of religiosity and evangelical Christianity, one characterized by what historian Adam Ashforth [27] has termed “spiritual insecurity,” to describe the efflorescence of religious “enthusiasm” that has converged with HIV/AIDS in sub-Saharan Africa in recent decades. Ashforth posits that this “spiritual insecurity” precipitated by HIV/AIDS, “the sense of danger, doubt, and fear arising from efforts to manage relations with invisible forces,” fed the new religious enthusiasms across Africa. ART, in essence, is providing a profound security for PLHIV. The discourses of public health, which have both led to favourable outcomes and also been coercive, have provided a power that people can deploy to manage these relations and insecurities. In doing so, PLHIV are not only creating a renewed, destigmatized subjecthood, but are leading opinions and playing a pivotal role in shaping new social norms and attitudes related to HIV testing and treatment in eastern Africa.

Because of the necessity to limit both scope and length of this article, the findings presented here include scant attention to counter-arguments, contradictions in our data, or deviant case analysis. We have elsewhere presented an in-depth analysis of anxieties surrounding and consequences of public disclosure of HIV status in narratives of PLHIV in the SEARCH study [28]. That analysis revealed that many individuals did resist disclosure because of anticipated stigma, and that there stark gender differentials in negative consequences of disclosure, with women more likely than men to experience violence or abandonment by partners. Our conclusions in that work more directly resonate with Nguyen’s accounts from West Africa [8] of the moral ambivalence surrounding disclosure, in which he describes how disclosure “can cut both ways: it can create social ties or, alternatively, it can dissolve social bonds.” (p. 173) Nguyen has described how disclosure has been deployed as a “weapon” in two overlapping “regimes:” a “confessional regime” that promoted disclosure in “a moral economy of solidarity” (and brokered people’s entrée into the gay subculture of Côte d’Ivoire) and a “regime of accusation” that anchored a political economy of inequality in West Africa in the pre- “treatment for all” era. Our conclusions in this article, if tentative, are that perhaps as the era of “triage” wanes and the activism that gave impetus to expanded treatment access begins to achieve some of its aims, the punitive forms of therapeutic citizenship may persist, but are also joined by renewed, liberatory forms of citizenship that promise to support the new forms of “biosociality” and subversions of familiar moral-economic regimes.

The research on the concept of therapeutic citizenship to date has not focused attention to its potential impacts on health systems more broadly, nor to its potential mechanisms of effect on HIV care cascade interventions. Our findings present a response to these new, pragmatic questions. PLHIV have not been conceptualized always as *actors* but rather as *targets*, usually, of HIV interventions. Their importance was not foreseen in START-ART and SEARCH. Yet, as “advocates for ART” in their communities, PLHIV are playing a vital role in the successful implementation of HIV care cascade

interventions. In SEARCH communities, PLHIV are a key social influence on stigma reduction, and are playing a critical role in expanding ART uptake. Thus, the therapeutic citizenship project is possibly a key means through which the universal test and treat approach (at least as deployed by the SEARCH study) may achieve its goals. In turn, there are features of universal test and treat that may enable social change and the functional role of PLHIV in it: in SEARCH, a bolus of persons became newly aware of their status, linked to others with shared experience, and to enhanced treatment resources.

Peers were not envisaged to play a key role in START-ART, but were enthusiastic boosters of the intervention, readily conveying the new messages employed in the intervention about the benefits of starting ART early. The interviews with peer educators in START-ART reveal evidence for potentially important mechanisms through which counselling by peers exerts an effect on patients' HIV care-seeking behaviours. Peers elicit behaviour change in others via what is termed in marketing "social proof," or, in behavioural theories, via improving positive expectancies regarding the efficacy of ART [29]; they also provide the "vicarious efficacy" that can elicit health-enhancing changes in behaviour. According to social cognitive theory [30], when I, an individual, observe another person socially similar to me, succeeding at performing a difficult behaviour (whether it be, in this context, HIV testing, disclosure, starting ART, or other behaviours), I experience "vicarious efficacy," the confidence that "therefore, I can do it too."

These findings have important implications for considerations of the role of peer counsellors in health systems. Many consider PLHIV to have played an important, or even critical, role in the public health response to HIV through a wide range of tasks from community engagement, counselling, tracing lost patients as well as administrative and clerical functions at overwhelmed facilities. Yet, without a formal role in the health system, the sustainability of peer activities has been questioned. Our findings affirm those of Moyer's study of the role of peers in the Kenyan health system, in which she concludes that while ART adherence is framed by administrators as the individual responsibility of patients, this framing "conceals the sociality of adherence and undervalues the work of peer mentors in treatment programmes." [31] While experiments to expand the role of peers in health systems are sometimes hampered by managerial challenges and continued questions regarding sustainability [32], efforts to involve PLHIV in delivering community-based HIV care show promise for improving adherence [33] and expanding models of care delivery in resource-poor settings [34]. Yet, there has been little research conducted, to date, to understand and make transparent both the unique effects of peers in public health practice, as well as their unique motivations, attitudes and beliefs about effective HIV care. Such work is needed in order to create a firm evidence base to optimize their role in extending the reach, effectiveness and sustainability of public health practice.

5 | CONCLUSIONS

From a policy and practice standpoint, to us, this ongoing therapeutic citizenship project offers tremendous opportunities for the global fight to end the HIV/AIDS epidemic. The benefits of

ART for prevention have been limited to date, because 40% (35% to 44%) of PLHIV do not know their HIV status, and 62% (59% to 65%) of PLHIV are not virally suppressed [35]. Yet many PLHIV are already bringing about the social change that can turn the tide of the epidemic and improve the health of their communities – their efforts must be supported. Yet, care must be taken to keep rights and justice in the forefront, and to let PLHIV lead efforts, rather than to exert new forms of control (for instance by demanding that PLHIV disclose their status – we know that for some, especially women, this can be dangerous – or demanding that all PLHIV must start ART as soon as they are diagnosed). Instead, new health systems–community partnerships should be envisioned, which involve PLHIV in leadership roles in interventions, programmes and services. Beyond strengthening the peer counsellor cadre, PLHIV could be empowered to help create new ways of accessing care for others in their communities. Community adherence groups (CAGs), "mentor mothers" for prevention of mother-to-child transmission (PMTCT) in prenatal clinics, HIV-discordant couples conducting outreach and counselling to other discordant couples, peer-led home-based care teams, or other models, could proliferate under the leadership of PLHIV. Above all, we are cautioned by Paulo Freire (in his theory of participatory education [36], to be mindful that the "horizontal process of peers talking among themselves and determining a course of action" is key to peer education's influence on behavioural and social change.

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COMPETING INTERESTS

The authors declare that they have no competing interests.

AUTHORS' CONTRIBUTIONS

CSC led the conceptualization and design of the study, data analyses, and writing. EDC, EG, MRK, DK, EAB, TDC, MLP and DVH contributed to conception and design of study. EG, EDC, FS, NS, JW, MG and LK contributed to acquisition, analysis and/or interpretation of data. EDC, EG and MG contributed to drafting the manuscript. All authors contributed to revising the manuscript critically for important intellectual content, and approved the version of the manuscript to be published.

ACKNOWLEDGEMENTS

We thank the individuals who participated in this research. We gratefully acknowledge Gideon Amanyire, Jennifer Namusoby, Richard Katuramu and other members of the START-ART investigator and data collection team, for their contributions to this research. We also gratefully acknowledge the contributions of SEARCH team members Irene Maeri, Lawrence Owino, Cecilia Akatukwasa, Naomi Sanyu, Dennis Tumwebaze, Harriet Itiakorit, Irene Agot, Jane Kabami, Florence Mwangwa, Kevin Kadede, Emmanuel Ssemmondo and other members of investigator and data collection team.

FUNDING SOURCES

Research reported in this paper was supported by Division of AIDS, NIAID of the National Institutes of Health under award number U01AI099959 and in part by the President's Emergency Plan for AIDS Relief, Bill and Melinda Gates Foundation, and Gilead Sciences. The content is solely the responsibility of the

authors and does not necessarily represent the official views of the NIH, PEP-FAR, Bill and Melinda Gates Foundation or Gilead.

REFERENCES

1. Arendt H. *The human condition*. Chicago and London: The University of Chicago Press; 1958.
2. Ecks S. Pharmaceutical citizenship: antidepressant marketing and the promise of demarginalization in India. *Anthropol Med*. 2005;12(3):239–54.
3. Nguyen VK, Ako CY, Niamba P, Sylla A, Tiendrébéogo I. Adherence as therapeutic citizenship: impact of the history of access to antiretroviral drugs on adherence to treatment. *AIDS*. 2007;21: Suppl 5:S31–5.
4. Nguyen V-K. Antiretroviral globalism, biopolitics and therapeutic citizenship. In: Ong A, Collier SJ, editors. *Global assemblages: technology, politics and ethics as anthropological problems*. Oxford, UK: Blackwell; 2005. p. 124–44.
5. Cataldo F. New forms of citizenship and socio-political inclusion: accessing antiretroviral therapy in a Rio de Janeiro favela. *Sociol Health Illn*. 2008;30(6):900–12.
6. Cassidy R. Global expectations and local practices: HIV support groups in the Gambia. *AIDS Care*. 2010;22 Suppl 2:1598–605.
7. Mattes D. “We are just supposed to be quiet”: the production of adherence to antiretroviral treatment in urban Tanzania. *Med Anthropol*. 2011;30(2):158–82.
8. Nguyen V-K. The republic of therapy: triage and Sovereignty in West Africa’s time of AIDS. In: Appadurai A, Comaroff J, Frarquar J, editors. *Body, commodity, text: studies of objectifying practice*. Durham, NC: Duke University Press; 2010.
9. Russell S, Namukwaya S, Zalwango F, Seeley J. The framing and fashioning of therapeutic citizenship among people living with HIV taking antiretroviral therapy in Uganda. *Qual Health Res*. 2015;26:1447–58.
10. Russell S, Martin F, Zalwango F, Namukwaya S, Nalugya R, Muhumuza R, et al. Finding meaning: HIV self-management and wellbeing among people taking antiretroviral therapy in Uganda. *PLoS One*. 2016;11(1):16.
11. Schulman-Green D, Jaser S, Martin F, Alonzo A, Grey M, McCorkle R, et al. Processes of self-management in chronic illness. *J Nurs Scholarsh*. 2012;44(2):136–44.
12. Persson A, Newman CE, Mao L, Wit J. On the margins of pharmaceutical citizenship: not taking HIV medication in the “treatment revolution” era. *Med Anthropol Q*. 2016;30(3):359–77.
13. Whyte SR, editor. *Second chances: surviving AIDS in Uganda*. In: Adams V, Biehl J, editors. *Critical global health: evidence, efficacy, ethnography*. Durham, NC: Duke University Press; 2014.
14. Whyte SR, Whyte M, Meinert L, Twebaze J. Therapeutic clientship. In: Biehl J, Petryna A, editors. *When people come first: critical studies in global health*. Princeton, NJ: Princeton University Press; 2013.
15. Papanini S, Rhodes T. The biopolitics of engagement and the HIV cascade of care: a synthesis of the literature on patient citizenship and antiretroviral therapy. *Crit Public Health*. 2016;26(5):501–17.
16. Goffman E. *Stigma: notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice-Hall; 1963.
17. Granich RM, Gilks CF, Dye C, De Cock KM, Williams BG. Universal voluntary HIV testing with immediate antiretroviral therapy as a strategy for elimination of HIV transmission: a mathematical model. *Lancet*. 2009;373(9657):48–57.
18. Granich R, Gupta S, Suthar BA, Smyth C, Hoos D, Vitoria M, et al. Antiretroviral therapy in prevention of HIV and TB: update on current research efforts. *Curr HIV Res*. 2011;9(6):446–69.
19. Charlebois ED, Havlir DV. “A bird in the hand...”: a commentary on the test and treat approach for HIV. *Arch Intern Med*. 2010;170(15):1354–6.
20. Gardner EM, McLees MP, Steiner JF, Del Rio C, Burman WJ. The spectrum of engagement in HIV care and its relevance to test-and-treat strategies for prevention of HIV infection. *Clin Infect Dis*. 2011;52(6):793–800.
21. Amanyire G, Semitala FC, Namusobya J, Katuramu R, Kampiire L, Wallenta J, et al. Effects of a multicomponent intervention to streamline initiation of antiretroviral therapy in Africa: a stepped-wedge cluster-randomised trial. *Lancet HIV*. 2016;3(11):e539–48.
22. Chamie G, Clark TD, Kabami J, Kadede K, Ssemmondo E, Steinfeld R, et al. A hybrid mobile approach for population-wide HIV testing in rural east Africa: an observational study. *Lancet HIV*. 2016;3(3):e111–9.
23. Petersen M, Balzer L, Kwarsiima D, Sang N, Chamie G, Ayieko J, et al. Association of Implementation of a Universal Testing and Treatment Intervention With HIV Diagnosis, Receipt of Antiretroviral Therapy, and Viral Suppression in East Africa. *J Am Med Assoc*. 2017;317(21):2196–206.
24. Charmaz K. *Constructing grounded theory*. Rohnert Park: Sage; 2006.
25. Muhr T. *ATLAS.ti Software*. Berlin: Scientific Software; 2010.
26. Parker R, Aggleton P. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Soc Sci Med*. 2003;57(1):13–24.
27. Ashforth A. AIDS, religious enthusiasm and spiritual insecurity in Africa. *Glob Public Health*. 2011;6:S132–47.
28. Maeri I, El Ayadi A, Getahun M, Charlebois E, Akatukwasa C, Tumwebaze D, et al. “How can I tell?” Consequences of HIV status disclosure among couples in eastern African communities in the context of an ongoing HIV “test-and-treat” trial. *AIDS Care*. 2016;28 Sup3:59–66.
29. Fishbein M, Ajzen I. *Belief, attitude, intention and behavior: an introduction to theory and research*. Reading, MA: Addison-Wesley; 1975.
30. Bandura A. *Social foundations of thought and action: a social cognitive theory*. Englewood Cliffs, NJ: Prentice Hall; 1986.
31. Moyer E. Peer mentors, mobile phone and pills: collective monitoring and adherence in Kenyatta National Hospital’s HIV treatment programme. *Anthropol Med*. 2014;21(2):149–61.
32. Schneider H, Hlophe H, van Rensburg D. Community health workers and the response to HIV/AIDS in South Africa: tensions and prospects. *Health Policy Plan*. 2008;23(3):179–87.
33. Roth AM, Holmes AM, Stump TE, Aalsma MC, Ackermann RT, Carney TS, et al. Can lay health workers promote better medical self-management by persons living with HIV? An evaluation of the Positive Choices program. *Patient Educ Couns*. 2012;89(1):184–90.
34. Selke HM, Kimaiyo S, Sidle JE, Vedanthan R, Tierney WM, Shen C, et al. Task-shifting of antiretroviral delivery from health care workers to persons living with HIV/AIDS: clinical outcomes of a community-based program in Kenya. *J Acquir Immune Defic Syndr*. 2010;55(4):483–90.
35. UNAIDS. *Prevention Gap Report*. Geneva: UNAIDS; 2016.
36. Freire P. *Pedagogy of the oppressed*. New York: Seabury Press; 1970.