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A livelihood intervention to reduce the stigma of HIV in rural Kenya: longitudinal qualitative study

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Abstract

The scale-up of effective treatment has partially reduced the stigma attached to HIV, but HIV still remains highly stigmatized throughout sub-Saharan Africa. Most studies of anti-HIV stigma interventions have employed psycho-educational strategies such as information provision, counseling, and testimonials, but these have had varying degrees of success. Theory suggests that livelihood interventions could potentially reduce stigma by weakening the instrumental and symbolic associations between HIV and premature morbidity, economic incapacity, and death, but this hypothesis has not been directly examined. We conducted a longitudinal qualitative study among 54 persons with HIV participating in a 12-month randomized controlled trial of a livelihood intervention in rural Kenya. Our study design permitted assessment of changes over time in the perspectives of treatment-arm participants (N=45), as well as an understanding of the experiences of control arm participants (N=9, interviewed only at follow-up). Initially, participants felt ashamed of their seropositivity and were socially isolated (internalized stigma). They also described how others in the community discriminated against them, labeled them as being “already dead,” and deemed them useless and unworthy of social investment (perceived and enacted stigma). At follow-up, participants in the treatment arm described less stigma and voiced positive changes in confidence and self-esteem. Concurrently, they observed that other community members perceived them as active, economically productive, and contributing citizens. Participants in the control arm described continued stigma with none of these changes. In

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summary, our findings suggest a theory of stigma reduction: livelihood interventions may reduce internalized stigma among persons with HIV and also, by targeting core drivers of negative attitudes toward persons with HIV, positively change attitudes toward persons with HIV held by others. Further research is needed to formally test these hypotheses, assess the extent to which these changes endure over the long term, and determine whether this class of interventions can be implemented at scale.

Keywords

AIDS/HIV; social stigma; Kenya; qualitative research

Introduction

HIV is highly stigmatized throughout sub-Saharan Africa [1–3]. While drivers of negative attitudes toward persons with HIV are context-specific, several core motivations have been described [4]. These motivations include instrumental concerns about interacting with persons with HIV (e.g., fears of acquisition through casual contact [5] resulting in desires for social distance [6,7]) and unease about the symbolic meaning of HIV (e.g., its association with death and disability [8] or with behaviors perceived to be deviant or immoral [9]). Since Goffman's [10] classic treatise on stigma, other theorists have elaborated further on specific dimensions of his conceptualization. Negative attitudes toward persons with HIV frequently manifest in discriminatory acts, ranging from social rejection to physical violence, a phenomenon known as *enacted stigma* [11]. Persons with HIV may perceive these negative attitudes and expect rejection from others, irrespective of whether enacted stigma actually occurs, a phenomenon described as *anticipated stigma* [12] (or *felt stigma* [11]). Persons with HIV may also come to accept these negative attitudes as valid, internalize them, and develop self-defacing beliefs about themselves [12,13]; this *internalized stigma* (sometimes described as *self-stigma* [14]), in turn, has been linked to self-isolation and depression [12,15–19]. All of these factors – stigma, isolation, and lack of disclosure – pose critical barriers to HIV testing and can compromise antiretroviral treatment (ART) adherence and engagement in care [20–22]. Thus, HIV stigma is a major public health problem that has the potential to undermine “test and treat” campaigns in sub-Saharan Africa [23–25].

Despite the public health urgency of improving uptake of HIV testing and treatment in sub-Saharan Africa [26], the evidence base of interventions to reduce the stigma attached to HIV has remained underdeveloped. Program implementers convincingly argued that ART scale-up would have the effect of reducing HIV stigma [27,28], and while these arguments have been partially vindicated in recent empirical studies [29–31], HIV still remains highly stigmatized throughout sub-Saharan Africa. Most studies of anti-HIV stigma interventions have focused on improving HIV-related knowledge or tolerance of persons with HIV through the use of psycho-educational strategies such as information provision, counseling, and testimonials, and these have had varying degrees of success [32,33]. The vast majority of these interventions have been administered to “stigmatizers” and assessed intervention impact among “stigmatizers”, or have been administered to “the stigmatized” and assessed intervention impact among “the stigmatized.” Few studies, if any, have administered

interventions to “the stigmatized” and assessed intervention impact among “stigmatizers.” (Neither does the study we describe here accomplish this assessment. Rather, we interviewed “the stigmatized” to assess their *perceptions* of impact on “stigmatizers.”) Recently Tsai et al. [8] suggested that economic interventions could potentially reduce HIV stigma by weakening the instrumental and symbolic associations between HIV and premature morbidity, economic incapacity, and death. This hypothesis, while conceptually attractive and consistent with available evidence, has not been directly or indirectly examined.

To address this gap in the literature, we conducted a qualitative study to explore longitudinal changes in stigma among persons with HIV participating in a randomized controlled trial in rural Kenya. Treatment-arm participants received a livelihood intervention, called *Shamba Maisha* (meaning “farming life” in Kiswahili), and our goal was to explore the intervention’s perceived impacts on HIV stigma and to understand the mechanisms through which any stigma-related changes may have occurred.

Materials and Methods

Ethics Statement

All study participants provided written informed consent. Participants were not required to disclose their seropositivity to others as a condition of enrollment, and because the different components of the intervention were potentially available to any resident of the area, enrollment did not necessarily disclose participants’ seropositivity to others in the community. Ethical approval for the study was granted by the Committee on Human Research at the University of California at San Francisco (CHR #11-07435) and by the Ethical Review Committee of the Kenya Medical Research Institute (SSC #2178). The trial was registered at ClinicalTrials.gov (NCT01548599).

Study Design

This qualitative study was embedded in a pilot randomized controlled trial conducted in the Rongo and Migori districts of the Nyanza region, Kenya. The prevalence of HIV in the region is 15.1%, nearly three times the national average [34], and HIV is highly stigmatized [35]. The local economy is largely based on subsistence agriculture and fishing, and food insecurity is common, especially among persons with HIV [36].

Details about recruitment, design, and implementation of the parent study have been described elsewhere [37,38]. In brief, the trial was conducted in the Rongo and Migori districts at government health facilities supported by Family AIDS Care and Education Services (FACES), a collaboration between the University of California at San Francisco and the Kenyan Medical Research Institute. FACES sites were selected because each had an adequate number of persons with HIV on ART; subsistence agriculture was the primary means of livelihood among persons living in the area; and they had similar rainfall patterns, topography, and soil composition. Study participants were eligible for inclusion if they were aged 18–49 years; taking ART at the time of enrollment; had access to sufficient land and water for irrigation; either were classified as moderately to severely food insecure on the

Household Food Insecurity Access Scale [39], or had a body mass index < 18.5 documented in FACES medical records at any time during the year prior to enrollment; and expressed willingness to save the down payment (approximately \$6 USD) required to qualify for a loan that was provided as part of the intervention. The livelihood intervention consisted of a small loan (approximately \$125 USD) to purchase a locally available handheld water pump and associated agricultural implements and commodities, along with an eight-session training program on agriculture and financial management. The training sessions were group-based. The intervention did not contain any of the psycho-educational components (e.g., information provision, counseling, or testimonials) that typically characterize anti-HIV stigma interventions [32]. Participants in the control arm were subject to the same inclusion criteria but did not receive any components of the livelihood intervention; however, after 12 months they were eligible to receive the intervention.

A total of 140 participants were enrolled in the randomized controlled trial. Analysis of baseline data showed that, while participants in the treatment and control arms were largely similar on most characteristics, mean monthly household income was greater among control-arm participants [38]. The primary analysis of data from the parent study showed that the intervention led to improvements in food security, frequency of food consumption, CD4+ T lymphocyte cell count, and HIV-1 RNA viral load suppression [37].

For the longitudinal qualitative sub-study, we conducted in-depth interviews with 54 participants total: 45 in the treatment arm and 9 in the control arm. Purposive sampling was employed to ensure that the perspectives of both men and women, and persons of all ages, were well represented in the data. Participants were recruited into the parent study in April 2012. The first qualitative interviews began three to five months after enrollment. At this point, participants had completed the initial trainings and had begun planting, but had not yet begun harvesting. The follow-up interviews occurred at the end of the intervention, at 12-month follow-up. The control-arm participants were interviewed at follow-up only because the decision to conduct qualitative interviews with participants in the control arm was not made until after the 3–5 month qualitative interviews were completed. Although the qualitative data from the control-arm participants cannot be used to construct an accurate counterfactual, our sampling strategy ensured that the qualitative data included perspectives from men and women of a broad range of ages who were both exposed and unexposed to the intervention. Including control-arm participants in the qualitative study helped to understand the extent to which the experiences of persons unexposed to the intervention were different from the experiences of persons exposed to the intervention. No one approached for the qualitative study declined to participate.

Three research assistants who were fluent in a local language (Dholuo or Kiswahili) conducted study interviews at participants' homes or at other locations of their choosing. These research assistants each received two weeks of intensive training on qualitative interviewing techniques, including how to elicit participant responses in an exploratory, non-judgmental manner and how to probe for richer descriptions of participants' experiences. Standardization across interviewers was facilitated with the use of mock interviews and pilot interviews, group review of early transcripts, and feedback on interview and probing style. Interviews generally lasted between 60–90 minutes and were guided by semi-structured

qualitative interview guides. The aim of these interviews was to understand participants' lived experiences. As such, the interview guides covered a broad range of topics focused on poverty, food insecurity, farming and other livelihoods, stigma and discrimination, HIV treatment adherence, HIV transmission risk behavior, and mental health. For participants in the treatment arm, the interview guides also contained specific probes about their experience with the livelihood intervention. Consistent with local etiquette and custom, we provided an incentive of 400–500 Kenyan Shillings (KSh) (approximately \$4–5 USD at the time of the study) per interview to compensate participants for their time.

Interviews were digitally recorded and transcribed by the research assistant who conducted the interview. For these transcriptions, research assistants adopted an *emic* orientation, using words and phrases to retain local meanings that otherwise would not be translated accurately. Each transcript was reviewed by at least one investigator (AMH, SK, SDW) to ensure clarity of the translation and to provide feedback to the research assistant on areas where additional probing would be warranted in future interviews. Interview transcripts were indexed with a unique participant identification code to permit linkage of data between the first and second interviews, and then labeled based on the location, age, gender, and treatment assignment of the participant.

Data Analysis

The qualitative data were managed and analyzed using Dedoose software (SocioCultural Research Consultants, LLC, Manhattan Beach, Calif.), a qualitative data management software program that permits real-time access to a secure database by multiple persons. In collaboration with field staff, four investigators (AMH, SK, SLD, SDW) developed a thematic coding framework based on topics covered in the interview guides, and then imported the codes into Dedoose. Next, three investigators (AMH, LLH, MN) highlighted large sections of the transcripts and placed them within wide, thematic broad codes. We established inter-rater reliability by double-coding a selection of transcripts and then holding a series of training phone calls amongst the coders and a senior supervising investigator (SDW). Lastly, two investigators (AMH, LLH) diverged from the interview guide and developed fine codes for unforeseen sub-themes that emerged inductively.

After coding was complete, analytical reports were generated for each broad code. These reports synthesized the findings and presented the evidence alongside illustrative quotations, including emphasis on outliers or divergences in opinion. Longitudinal changes in perspectives were explored by comparing data from participants' first interviews with the data from their second interviews. Additionally, data from treatment-arm participants were compared with data from control-arm participants to assess the extent to which the reported impacts were unique to participation in the intervention. Analytical reports were shared and critiqued by at least one other member of the research team, making the writing process itself an additional mechanism for establishing the credibility of the findings. In this manuscript, we provide representative quotations and divergent perspectives, using context-rich descriptions whenever possible.

Results

Stigma Prior to Intervention

In total, there were 28 men (52%) and 26 women (48%), with a median age of 38 years (Table 1). The median time on ART was 4 years (interquartile range [IQR], 2–6). Study participants in both the treatment and control arms were keenly aware of prevailing negative attitudes that community members harbored against persons with HIV (felt stigma) and were often isolated and excluded on the grounds of their seropositivity (enacted stigma). In this environment, study participants themselves came to accept these negative attitudes and prevailing stereotypes as valid (internalized stigma), resulting in shame, psychological distress, and self-isolation. It was clear throughout the interviews that HIV stigma had caused immense emotional suffering for many participants. Below we describe these themes in greater detail.

Felt stigma—Participants described how, prior to the intervention, other people in the community harbored negative attitudes toward persons with HIV. These perceptions tended to cluster into a small group of stigmatizing beliefs that were driven by both instrumental and symbolic concerns. Specifically, study participants frequently described how others viewed them as “weak,” “useless in the society,” “people who will never progress in life,” and “already dead.” One 30-year old woman in the treatment arm described how people in her village viewed those living with HIV as “corpses.” Several men and women similarly explained how their neighbors viewed them as “lifeless”:

They viewed us as lifeless people [*pauses to think*]. Before joining Shamba Maisha we were viewed as people with no value. [*repeats slowly*] With no value. (36 year-old man, treatment arm, interviewed at 3–5 months)

Much of this association with worthlessness was rooted in the perception that persons with HIV were incapable of being financially and agriculturally productive:

In our community, those who are infected with HIV are viewed as dead people; people who will not live long. Such people are considered weak and unable to perform energy-intensive tasks that can sustain them. (42 year-old man, treatment arm, interviewed at 3–5 months)

Enacted stigma—In general, enactments of stigma appeared to be limited to exclusion and isolation. As 37 year-old man explained at his 3–5 month interview, living with HIV in these communities often meant being socially ostracized. This man lamented that, as an HIV-positive person, “there are places you cannot go. If you see people do not welcome you, then you are not supposed to go there.” A few participants spoke of being subject to “backbiting” among neighbors and of being verbally abused. One older man recounted a story about how someone else in the village had been involuntarily and publicly revealed as a person with HIV—a sharp memory that had prompted him to stay hidden about his own seropositivity:

I have heard someone abusing his [HIV-positive] friend when they disagreed. He was a drunkard so he abused the other fellow by telling “so and so, you are under

[the influence of] drugs...” And the news spread in the entire village. This really brought him shame. So that is the reason I stay reserved with the information, since [disclosing] this will not help me be on good terms with the neighbors. (43 year-old man, treatment arm, interviewed at 3–5 months)

Another participant related a story that an extended family member had learned of his seropositivity and “after around five months he started going throughout the village abusing me, saying that I am HIV positive; it was very painful.”

Few participants described enactments of stigma that involved threat or physical harm. Yet because persons with HIV were viewed as economically incapacitated, participants described being subjected to another form of enacted stigma: exclusion from local solidarity networks of mutual aid and/or income generation. One participant, for example, described how such exclusion threatened his ability to earn money as a sole breadwinner for his family of four children:

There are people who once they realize you are HIV positive, they do not involve you in any projects thinking you will not be productive. They think that you may die at any moment... Such a person is excluded by the community; they are not visited or included in other important talks or involved in activities that can be beneficial to them. (42 year-old man, treatment arm, interviewed at 3–5 months)

Internalized stigma—Some participants internalized these negative attitudes toward persons with HIV, had feelings of shame about their seropositivity, and had difficulty disclosing their seropositivity to others. One 43 year-old man explained that his HIV diagnosis felt like “a psychological blow,” and he ruminates over the many others in his community who had died from HIV in the past. Another participant described how shame prevented her from openly seeking HIV care at the local clinic:

Before [Shamba Maisha] I had a lot of shame and I even had difficulty in attending clinic as I was afraid of people seeing me and when I came I did not even want to greet the next person. (30 year-old woman, treatment arm, interviewed at 3–5 months)

This self-isolation and shame reinforced the isolation and rejection of enacted stigma. The language participants used to articulate their feelings of isolation and self-isolation was often sharply illustrative of the disruptions in relationships they experienced and subsequent devaluation that occurred once someone was diagnosed with HIV. As one young man said of his extended family, “They no longer saw me as a relative but as a stray dog.”

Changes Experienced by Participants

Changes in self-esteem—Treatment-arm participants interviewed at 12-month follow-up described a number of positive psychosocial changes that had occurred as a result of their participation in the intervention. Many spoke of having “hope” for a better life and “living my life without looking at myself as sick.” These changes in self-appraisals of their worth and ability were often linked explicitly to the livelihood intervention, as exemplified by one participant:

Because of Shamba Maisha, we have learned that there are many more avenues in life and the fact that we are HIV positive doesn't block us from doing what others are doing. We now know that we are just like them... and that being positive is not the end of life. (38 year-old man, treatment arm, interviewed at 12 months)

Another younger man expressed a sense of purpose and felt he had a new identity that was not tied to his illness:

Personally I say we are leading a "new life" because we are healthy. When you take yourself as a sick person is when you lose. In fact I told myself that I want to live positively and will die just like any other person but not because of my HIV status. (31 year-old man, treatment arm, interviewed at 12 months)

Thus, as a result of their participation in the intervention, participants believed they were no longer socially dead, able to live "like any other person." As is described in more detail below, these changes were paralleled by changes in community perceptions, leading study participants to regain the status of the "living."

Changes in internalized stigma—For many participants, the increased confidence and self-esteem they derived from the intervention helped them to talk more openly about their seropositivity:

Besides farming, I have developed a positive attitude about my life because earlier on when the disease came about, people did not want to acknowledge the fact that they are sick, so this has encouraged me and I am free talk about it and it's not something that I hide. (44 year-old man, treatment arm, interviewed at 12 months)

Whereas previously participants reported "hiding" from the community in shame, subsequent to their participation in the intervention they felt less shame about their seropositivity and felt freer to disclose. In the 3–5 month interview, one man reported disclosing his status only to his immediate family, but at the 12-month interview he says:

I now disclose my status to other people. I encouraged three people to be tested and get help instead of literally dying of shame in their homes because of fear of their status being known. (33 year-old man, treatment arm, interviewed at 12 months)

As another example, one participant initially described his fear of disclosure as paralyzing, leading him to avoid attending the HIV clinic. At the first interview, he explained that his wife was "the only one who knows how we are, but other people around us – especially our neighbours – we don't want them to know what is going on." However, when re-interviewed at 12 months, he reported greater confidence about disclosing his seropositivity:

I could hide a lot [*laughs*] due to fears that people would know my status... I used to hide a lot at the clinic when I got to the gate thinking that anybody who sees me will automatically know why I have gone there. But now I am very free and comfortable, it is normal to me. Currently I am very confident and can even teach HIV positive people a few things that can help improve their lives without any fear. (28 year-old man, interviewed at 12 months)

Moreover, he articulated ways in which his own views of himself had shifted towards determination, productivity, and a sense that he was able to work:

Since I found out that I was HIV positive, even if I went to the farm I used to worry a lot about my life—wondering whether I would die that year or in two years time before I am able to see the fruits of my effort. But when we joined [Shamba Maisha] we were encouraged to work hard as usual and not to think about such things. Since then I have been very determined, I am even surprised that people who are HIV positive can work harder than people who are not! So since our joining [Shamba Maisha] we have been very encouraged and it shows us that we should not just sit around because we are sick but instead work like any other person. And that is why currently I feel that my life has changed as compared to before I joined [Shamba Maisha].

Changes in Community Perceptions

Change in status from “unproductive” to “contributing”—In parallel to these changes in self-appraisals, many participants felt that the intervention was changing the way *others* in the community viewed persons with HIV. Rather than being viewed as unproductive or promiscuous, study participants felt they were now viewed “just like any other person,” being equally capable of providing for their families and making positive contributions to the community. For example, at the 3–5 month interview, a widow spoke of times when her family could afford to eat nothing but porridge, and when she was forced to “go begging from other people”. She shared:

In this place, people taking ARVs are taken as people who are going to die anytime. You may find them being discussed in a bad light. (30 year-old woman, treatment arm, interviewed at 3–5 months)

At the 12-month interview, she described a new ability to sell her vegetables for extra money along with a feeling of satisfaction that others in the community had noticed her new contributions:

There is a difference. Currently, people are even surprised that those they thought were worthless can do very well... They have always perceived us to have a very short life span, but now they see our health changing for the better and we are doing our work just normally. That is really challenging them because now they know that these people they view to be worthless can work successfully.

One sugarcane farmer, new to vegetable farming, delighted in describing the way his fortunes had changed for the better. Whereas at 3–5 months he described having to beg for money or rely on family support at times, at 12 months he reported that others perceived him differently. His neighbors saw him no longer as a “weak” person with HIV, but rather as an “active, dutiful” member of the community:

They have just been wondering why all of a sudden I am so [active in the farm]... I am supposed to be the ‘weak’ one and yet I am more active than even the ‘healthy’ ones. Nobody has said that outright, but I can read that in their faces. They find me more active in the farm and tending to more duties than they are... And I am the

one supplying them with vegetables while they are supposed to be supplying me!
(42 year-old man, treatment arm, interviewed at 12 months)

Change in status from “dying soon” to “living”—Community members, observing these changes in productivity and work output, no longer viewed study participants as being imminently near death. A young woman poignantly described how her extended family had previously made plans to take away her household possessions, believing that her death was imminent:

I remember people used to talk behind our back saying that we would die of HIV/AIDS. When we bought a chair, there is a brother-in-law of mine who could say, “These will be ours, these people will die and leave us these things”. When we bought a cow he said the same thing. (28 year-old woman, treatment arm, interviewed at 12 months)

Yet, after starting the intervention, this young woman described her brother-in-law’s change of heart as he began to view both her and her HIV-positive husband as alive and robust:

But now he is very humbled when he sees the kind of a life we are living... He started acting very friendly and nowadays he eats in my house. In fact I have already prepared his food now. I think he came to realize that not only people who are HIV positive will die—everyone will. I think he has come to realize that we won’t be dying any time soon.

Notably, none of the study participants reported any challenges—despite being directly probed by research assistants about this potential concern—with their produce being refused by others in the community (e.g., due to fears about HIV acquisition through casual contact). People in the community appeared to be willing to purchase vegetables from study participants despite, in many cases, having knowledge of their seropositivity.

Change in status from “burden” to “benefactor”—In describing the positive changes in social integration that they had experienced, many participants were aware that there was an instrumental basis behind these renewed relationships, because their identities had changed from being “parasite” to “benefactor.” One study participant was a young widow with five children, who often faced food shortages in the household. At the 3–5 month interview, she disclosed that her youngest child had recently died of malnutrition. In her view, few people visited her because they believed that “if they come they would ‘contract’ HIV.” She further described how “[people in my village] did not want me to join” social and support groups, “saying I could die anytime.” Yet at the 12-month interview, she described a shift in how she interacted with her neighbors—people who rarely visited her in the past now regularly came to her house to borrow food:

People know when you have good things, and at that time they really love you. They come asking you to give them vegetables; others have no maize so they come to ask for flour and you just give it to them. So you are someone who can be borrowed from unlike before when you could be seen as useless. Now they can come begging from you and you can help them. (29 year-old woman, treatment arm, interviewed at 12 months)

One important mechanism underlying these changes in community attitudes was the transition that many participants experienced, from being a “burden to the household” to being a “productive member of the family.” As one widow explained, “People saw me as a burden to the family because they thought I would be bedridden and add to their expenses.” After participating in the intervention, this woman reported having a very different experience:

They thought I would be a burden but they come to me asking for help like for vegetables because they don't have [any]... There is a difference because they now want to be near you since they know that you have something of value. Like now I have a pump that somebody can use during a drought. (40 year-old woman, treatment arm, interviewed at 12 months)

Many participants reported that neighbors also paid visits to their farms in order to obtain “points of consultation” in agricultural matters. The personal contact generated through these interactions provided study participants with further opportunities to reinforce perceptions of economic competence. For many participants, these changes in community perceptions were also accompanied by changes in status. As one 36 year-old man described at 3–5 months, others in the village “say that we are worthless” for being HIV-positive. He also had difficulty obtaining enough food for family consumption, and there certainly was no surplus food to sell for extra money. At 12 months, he expressed:

Since I joined Shamba Maisha, I have experienced a big change and now I have a name! Nowadays when I hear anyone who wants to purchase vegetables I just urge them to come to my home and they will get them... I am now really widely known; wherever I walk anywhere people just seem to recognize me. (36 year-old man, treatment arm, interviewed at 12 months)

A few participants even described how the intervention gave them increased power and influence over decisions within the community. For example, one man who had experienced an early intervention response described how his economic status translated into influence in the village committees:

They now view us as people. And in case of any problem and the village committees ask for contributions, I make mine immediately. This makes them realize that I am powerful and that I am also a human being. (36 year-old man, interviewed at 3–5 months)

Persistent Stigma Despite Intervention

While most participants in the treatment arm experienced the changes described above, a few participants did not describe these themes. One widowed man described facing persistent enacted stigma from neighbors who intentionally scared off his potential partners by warning them about “the disease in that family.” As a result, he was circumspect about disclosing his seropositivity to others:

I realized I was positive after losing my first wife. Since then, any person from the community who meets any lady I bring in as my wife usually asks them “Oh! So you have come for it! Do you know that that disease is in that family?”...

Whenever [potential partners] hear about it, they don't stay, they usually leave me. From these experiences, I always hesitate to tell my community about my status. If they get to know about my status, I feel uncomfortable. (34 year-old man, treatment arm, interviewed at 3–5 months)

At the follow-up interview, this study participant reported an increased intake of vegetables and better health. He also described himself as the most productive member of his training group, with other group members frequently consulting with him in the hopes of cultivating more productive farms. However, he retained a sense of caution about disclosing his seropositivity:

Some people would laugh or tell others about it. That is the reason why I am not comfortable telling others about it at home and in meeting places like in the groups.

Similarly, the same 30 year-old woman (quoted above) who described feeling greater esteem from some community members still felt that there was a prevailing negative view of persons with HIV:

[Persons with HIV] are perceived to be worthless, people who are very vulnerable to death, and can die any time. That is how they are perceived. At times you will hear people say, "she is sick, she is about to die," but if you are someone who understands oneself and who has been enlightened then such things should not worry you. (30 year-old woman, treatment arm, interviewed at 12 months)

While she stated that these perceptions did not bother her, she nonetheless remained guarded about disclosing her seropositivity:

The problem is that there are people who when you tell, they would start revealing to others that the group is for people who are HIV positive. That is not good. We are not allowed to reveal our HIV status everywhere we go; there are places you can talk about your HIV status and places you can't.

Stigma in the Absence of Intervention

Participants in the control arm, who were interviewed only at follow-up, universally described felt, enacted, and internalized stigma. In the words of one woman:

Most people don't know that I am on ARVs. I think it is only my family and those we go with to the clinics who know. I take the drugs at 7 am and 7 pm, so nobody finds me taking them and I also don't talk about my status with people. HIV positives are looked down on and not seen as people. That is why we don't tell them our status because they will perceive us to be stupid and not want to meet or associate with us. (40 year-old woman, control arm, interviewed at 12 months)

Despite her experiences, this woman expressed anticipation that, when it came time for her to receive the intervention, she would benefit from the training so that she could show others that persons with HIV "are still important" and "independent."

Another control participant recounted a story in which his son was subjected to courtesy stigma when applying for a job. His son's experience distressed him greatly:

There was a time my son went and did a job interview in a certain school and the head of the school is from our place. So he asked the child, “Whose son are you?” The child told him [our family name] and then [the head of the school] went ahead and asked, “How did your sick father manage to teach a child up to form 4?” and the boy couldn’t answer him. Can you tell me how that makes the child feel? The child came home to tell me about it and I just told him to just look for another opportunity somewhere else because a stranger can help you better than a relative. Such are the reasons why we are still unable to reveal our status to relatives, instead of them talking to you well as a relative all they do is discourage you. The community views your family as people who will never progress in life. (45 year-old man, control arm, interviewed at 12 months)

When asked to reflect on any possible changes that may have occurred in the past year, few described any positive changes. Only one person described a shift in self-esteem. However, she attributed this change to her own personal decision to begin disclosing her seropositivity to others. No participants in the control arm described any changes in community perceptions, whether related to their work productivity, status as being imminently near death, or contributions to the community. One man in the control arm did describe improvements in felt stigma, but he specifically attributed these changes to the increasing prevalence of HIV in the community:

[Persons with HIV] are despised and looked at as those whose time is up...we are considered odd people. We are looked at as people without anything to offer and aren’t even welcome in some places. It is just now that the stigma is diminishing because the disease is widespread and people fear making bad comments because they don’t know what tomorrow holds for them. I think it’s because the disease is infecting more people whom we are close to, so if someone laughs at you today, tomorrow it will be a son, sister, themselves or close relatives who are facing the problem. (46 year-old man, control arm, interviewed at 12 months)

Discussion

In this longitudinal qualitative study embedded within a randomized controlled trial for persons with HIV in rural Kenya, we report several findings. Felt, internalized, and enacted HIV stigma were common among study participants prior to their participation in the intervention. Their experiences of enacted stigma usually took the form of being labeled as “already dead,” economically incapacitated, and unworthy of social investment. At the follow-up interview, both men and women described less stigma and voiced positive changes in self-appraisals that had occurred as a result of their participation in the intervention. These personal shifts were accompanied by what they perceived to be favorable changes in community members’ attitudes centered around their increased productivity as farmers. Few of these changes, if any, were described by participants in the control arm. Our most concise explanation of the data is a theory of stigma reduction in which the livelihood intervention reduced HIV stigma through two key mechanisms: positive changes in core self-evaluations and enhanced social capital.

A prominent driver of stigma in our data was the association between HIV, premature morbidity, and economic incapacity. Surprisingly, even though study participants had been on ART for a median of 4 years, they still described how others thought of them as “weak,” “useless,” and “already dead” and therefore unable to be agriculturally and financially productive. This finding is consistent with data from one HIV cohort study from southwestern Uganda [40]: while ART was associated with reductions in internalized stigma over time, there was a “floor effect” in that these improvements plateaued even after 48 months of observation. More generally, in sub-Saharan African settings of generalized poverty where formal social protection schemes are limited, it has been observed that one’s contributions to networks of mutual aid represent an important dimension of social life [8,41]. Targeting group members for stigmatization in such contexts, e.g., on the basis of HIV seropositivity, may be a behavioral adaptation designed to minimize defections from this norm and to encourage all members to engage in reciprocal exchange [42,43]. This form of stigma is symbolic in that HIV is strongly associated with death [44], but it is also instrumental in that it serves the purpose of enforcing the expectation that all members of a community contribute equally to reciprocal aid [8].

According to our data, the intervention reduced internalized HIV stigma by producing positive changes in how participants perceived themselves as well as positive changes in how they were perceived by others in the community. Because we did not interview community members as part of this study, we were necessarily reliant on study participants’ perceptions of community members’ perceptions. The “core self-valuations” construct aptly summarizes a channel through which the intervention reduced HIV stigma. This construct is conceptualized as a disposition towards positive self-concept [45], or a “basic, fundamental appraisal of one’s worthiness, effectiveness, and capability as a person” [46] (p. 304). Psychometric analyses have identified four factors that are closely related, both conceptually and empirically: generalized self-efficacy, self-esteem, locus of control, and emotional stability. In the data, we observed that intervention participants believed they were no longer viewed by others as incapable of making positive economic contributions to the community and perceived themselves as being able to “work like any other person.” They explained how they no longer ruminated on “worries” and other negative aspects of living with HIV and instead believed that they could accomplish desired life outcomes.

These changes in self-perceptions were accompanied by actual changes in status. Not only did study participants view themselves as economically competent, but others in the community also came to view them as making positive contributions to society. It is notable that, even though nearly one-third of Kenyans have reported in a national survey that they would not purchase vegetables from an HIV-positive vendor [47], participants’ status improvements appeared to have been powerful enough to overcome these prevailing preferences for social distance. One of the mechanisms through which these status changes occurred was through skill sharing: as participants increasingly demonstrated their skills in farming techniques, others in the community approached them for advice. The instrumental basis for these new (or renewed) relationships is consistent with the model of reciprocity transactions as a source of social capital described by Portes & Sensenbrenner [48]. It is also consistent with data from a large qualitative study conducted in Nigeria, Tanzania, and Uganda by Ware et al. [49], who found that successful HIV treatment adherence was

explained by a virtuous feedback loop between networks of mutual aid and reciprocity exchanges: instrumental support enabled study participants to consistently adhere to HIV treatment, and participants adhered to treatment in order to fulfill their social obligations to network ties, thereby ensuring that instrumental support would be available in the future.

These twin channels through which the livelihood intervention was observed to reduce HIV stigma—positive changes in core self-evaluations and enhanced social capital—suggest a theory of HIV stigma reduction in which livelihood interventions may be construed as potential anti-HIV stigma interventions [8]. By uncoupling HIV infection from premature morbidity and economic incapacity, the livelihood intervention provided study participants with opportunities to demonstrate economic competence and redefine their value to community members who had previously viewed them as “worthless” and “already dead.” In some ways, the livelihood intervention might also be viewed as a contact intervention [50] in which community members were led to revise their negative attitudes towards persons with HIV through a process known in the social psychology literature as “recategorization” [51]. Indeed, some participants reported that their newfound expertise was widely recognized and that they had occupied new roles as agricultural “consultants” in their villages. Consistent with this view, study participants felt they were perceived “just like any other person” without regard for their serostatus.

These interpretations of our data are subject to several limitations. First, all participants were currently receiving ART, as this was one of the study’s inclusion criteria. HIV stigma is a well-known barrier to testing [52,53], serostatus disclosure [54], ART adherence [22], and linkage to care [21]. Therefore it is possible, even likely, that participants who enrolled in our study had internalized less of the stigma of HIV compared to other persons with HIV [40]. This sample selection bias may limit the generalizability of our findings. Second, we are unable to make causal claims in the sense that we do not know what themes would have emerged among participants in the treatment arm in the absence of the intervention [55,56]. For example, it has been shown that ART is associated with changes in status from “dying” to “living” and subsequent reductions in HIV stigma and improvements in self-esteem [40,57–60]. It is therefore possible that the changes in stigma resulted from ongoing HIV treatment rather than from the livelihood intervention. However, participants in both the treatment and control arms were receiving ART, so HIV treatment could not be a sufficient explanation for our findings. The qualitative design of this study does permit us to draw explanatory links between the intervention and changes in the constructs of interest [61], and the longitudinal design permitted us to assess changes over time in the perspective of treatment-arm participants. Third, and related to the above, even though the participants randomly assigned to the control arm in the parent study permitted Weiser et al. [37] to construct an accurate counterfactual for the quantitative analysis, in our qualitative substudy we interviewed only a fraction of the participants assigned to the treatment and control arms. Thus, even though qualitative data from the sample of control-arm participants permitted us to determine the extent to which the observed changes were unique to treatment-arm participants, selection on unobserved heterogeneity could have biased our findings away from the null. For example, if there was differentially greater disclosure of seropositivity among qualitative sub-study participants in the treatment arm, then this unobserved heterogeneity would have enriched the transcripts from those interviews toward a finding of

greater changes in perceived community attitudes toward persons with HIV. However, our preferred interpretation is supported by the fact that none of the control-arm participants described changes in stigma. It is also important to note that the two control-arm participants who reported increased confidence about disclosing their seropositivity explicitly tied these changes to the routine talks they had attended at FACES clinics. Fourth, for participants in the treatment arm, the first qualitative interviews did not occur until 3–5 months after enrollment. These data therefore cannot be regarded as pure “baseline” data. It is likely, for example, that early responders may have already experienced substantial benefit, in terms of stigma reduction, by that point in the study. However, at 3–5 months most participants had completed the trainings and had begun planting, but had not yet begun harvesting (and therefore were unlikely to have derived economic benefits from the intervention at that early stage). To the extent that such a phenomenon of early response did occur, it would have biased our findings about stigma reduction toward the null because any differences in the themes identified between the initial and follow-up interviews would have been less apparent. Fifth, we were unable to interview any of the participants who withdrew from the study (four from the treatment arm) or who died (two from the treatment arm). It is possible that these participants fared worse in the dimensions of economic gains and HIV stigma compared to participants who were retained in the study. Although the dominant narrative that emerged from the data was that the livelihood intervention reduced HIV stigma, failure to interview these few persons lost to follow-up could have exaggerated these impacts. Sixth, African societies are heterogeneous. Our data are derived from a single site in rural Kenya and may not generalize to other settings. However, our data are consistent with qualitative studies conducted in other settings throughout sub-Saharan Africa [8].

Despite these limitations, our study provides the first longitudinal evidence consistent with a novel conceptual model suggesting that a livelihood intervention may be a promising way to reduce the stigma of HIV [8]. While such socioeconomic support interventions have been explored, there is very little longitudinal evidence in this regard [62,63]. Importantly, the livelihood intervention implemented in our study was neither conceptualized nor explicitly operationalized to address HIV stigma [38]. That is, the intervention did not contain any of the psycho-educational components (e.g., information provision, counseling, or testimonials) that typically characterize anti-HIV stigma interventions [32]. The livelihood intervention tested in this study consisted solely of the previously described loan and eight-session training program, which focused on farming techniques and pre-/post-harvest handling and marketing [38]. Nonetheless, the narrative detail provided in our study suggests a theory of HIV stigma reduction: a livelihood intervention provided to persons with HIV can potentially lead to a cascade of change among persons not directly targeted by the intervention. In terms of extensions of this work, additional rigor can be brought to this field of research with the use of social network designs that assess stigma among both “stigmatizers” as well as “the stigmatized” [64]. Further research is needed to formally test these hypotheses, assess the extent to which these changes endure over the long term, and determine whether this class of interventions can be implemented at scale.

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Table 1

Characteristics of participants included in the study (N=54)

	Number (%) or Median (IQR)
Participant group	
Treatment arm	45 (83.3)
Control arm (12-month follow-up only)	9 (16.7)
Gender	
Female	26 (48.1)
Male	28 (51.9)
Age, <i>y</i>	38 (33–42)
Duration of HIV treatment, <i>y</i>	4 (2–6)
Marital status	
Married	20 (38.5)
Polygamous	11 (21.2)
Widow (single)	15 (28.8)
Widow (inherited)	6 (11.5)
Number of children	3 (2–4)
Farming experience, <i>y</i>	13 (5–20)