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# "I am not alone with tears": embodying stigma and longing among youth living with perinatally acquired HIV in Tanzania through a collaborative artsbased approach

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Contributorship Statement:

KH drafted the initial manuscript. All authors were involved in design of study; KH, DM, and HN facilitated data collection; all authors interpreted data. All authors critically reviewed and edited the final version of the manuscript. DD and KS contributed equally to this paper as senior authors.

The *Sanaa ya Vijana* youth collaborative (see collaborator statement below) participated in data generation and interpretation.

Declarations of interest:

Supplemental Video Captions:

Supplemental File 1:

*[Swahili] Kwa hiyo, nilichora kwa upana kuonyesha kwamba wako wengine wanalia* | [English] I drew [the tear] in the widest sense to show that there are others [with HIV] crying.

Supplemental File 2:

*[Swahili] Sasa elimu zilizokuja ni nyingi mpaka apa kileleni elimu ni nyingi. [Inaudible] kuna baathi ya watu—unyanyapaa umepungua* | [English] Now, the education that came is plentiful, until, at the top, there is plenty of education. For some of the people, stigma has reduced.

Supplemental File 3:

*[Swahili] Safari ya maisha bado ipo* | [English] The journey of life is still there.

Supplemental File 4:

**[Title]** The journey of life still continues. Art exhibit GVE 045, AIDS 2022 (Montreal, Canada).

*Bienvenue*. Welcome.

**KH**: What do you think about the exhibit?

**Thabani Nyoni (he/him), Postdoctoral research fellow, Factor-Inwentash faculty of social work, Toronto, Ontario, Canada**: Thank you, Kalei, for the beautiful exhibit. I think it's amazing. I work with—my research works with adolescents who are living with HIV, perinatally-infected. And one of the things that is amazing with this is—I find that they often struggle to communicate using words most of the time, but I find that this is a creative, very creative, accessible way where they can draw pictures and images and explain what is going on in their lives. But I also love is that—it is sort of—what I would say is that there are messages of hope. It's not just about dying and being sick. It's about being full of life, what keeps them going, what keeps them doing what they have to do to live because there is so much to live for. So that to me is the most amazing piece. Not just reducing it to one specific condition. That their lives are more than just taking medicine and being HIV-positive. There is more meaning, hope, and faith. So, this is why I think it is beautiful. So, thank you for sharing your stories. You people are amazing. Keep hoping, keep fighting. We are here to support.

[*Thabani Nyoni granted permission for use of this supplemental video. Note: background sound for this video comes from iMovie; users are licensed by Apple to use iMovie sound on a royalty-free basis*]

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## Abstract

It is estimated that four million youth ages fifteen to twenty-four years live with HIV globally, 85% of whom live in sub-Saharan Africa. For youth living with perinatally acquired HIV (YPHIV), stigma is frequently linked with negative health outcomes. YPHIV face distinct HIV stigma experiences across the lifespan, particularly because of the centrality of the family context in their HIV experience and the reality that they have lived with HIV since birth. Nevertheless, our understanding and measurement of stigma remains limited. One way to improve our understanding of HIV stigma for YPHIV is through in-depth exploration of embodied narratives of HIV experience. This paper is based on fieldwork that incorporated a collaborative arts-based approach with a group of six YPHIV in Tanzania. Using artwork and a theoretical framework of *embodiment*, this paper phenomenologically describes their narratives of HIV experience, perceptions of stigma over time, and imaginations of the future. This paper highlights that collective solidarity, *habitus*, and participants' desire to reframe others' perceptions about them and relieve the suffering of others shape the embodied experience with HIV. Moreover, this paper argues that stigma experiences for YPHIV are temporal and have changed over time with increased age, interventions, and biomedical advances. Broadly, while HIV stigma continues to exist, participants report responding to stigma with agency by creating alternative solidarities and pushing boundaries of possibility, reframing others' perceptions of them, and acting on dreams for better futures.

### Keywords

stigma; embodiment; collaborative arts-based research; HIV/AIDS; Africa/Tanzania

## Introduction

It is estimated that four million youth ages fifteen to twenty-four years live with HIV globally, 85% of whom live in sub-Saharan Africa (UNAIDS 2018). For youth living with perinatally acquired HIV (YPHIV), stigma is frequently linked with negative health outcomes as a result of decreased adherence to antiretroviral therapy (ART) (Rao et al. 2007; Rongkavilit et al. 2010). Growing up with HIV, YPHIV face distinct biomedical realities, such as the effect of HIV on growth and neurodevelopment (Flynn and Abrams 2019). Moreover, YPHIV face distinct stigma experiences across the lifespan, particularly because of the centrality of the family context in their HIV experience and the reality that they have lived with HIV since birth (Proulx-Boucher et al. 2017; Flynn and Abrams 2019). Developing strategies to reduce stigma and discrimination faced by YPHIV is a high priority for global HIV research and programming (Penazzato et al. 2018).

Our understanding and measurement of stigma for YPHIV remains limited (Stangl et al. 2013). There are no specific stigma measurement scales for youth living with HIV in sub-Saharan Africa, where the majority of YPHIV live. Moreover, stigma is difficult to measure, making it challenging to identify and assess the effectiveness of stigma-reducing interventions. For instance, in a recent mental health intervention pilot trial (2016 to 2020) in Moshi, Tanzania, there was no significant quantitative change in stigma for youth who completed the intervention compared to the control group; however, qualitative narratives included clear descriptions of stigma reduction and self-acceptance (Dow et al. 2020). Sensitive measurement of stigma from the perspective of YPHIV is lacking. There is a need to re-evaluate how we understand and measure stigma in light of the distinct lived experiences of YPHIV in sub-Saharan Africa and globally.

One way to improve our approach to stigma is through a theoretical lens of embodiment. YPHIV are immersed in embodied experiences of HIV, where they navigate the meaning of their HIV diagnosis in the context of illness, social relationships, and body image (Alexias, Savvakis, and Stratopoulou 2016). We can understand embodiment as a process of "incorporating practices that define our being in the world" (Roodenburg 2004, 216). As sociologist Pierre Bourdieu explains: "We learn bodily. The social order inscribes itself through this permanent confrontation, which may be more or less dramatic but it is always largely marked by affectivity, and more precisely, affective transactions with the environment" (Bourdieu 2000, 141). According to Bourdieu, *embodiment* is mediated by our *habitus* or "socially constituted system of cognitive and motivating structures" (Bourdieu 1977, 76).

*Longing* is also an important part of embodied experiences. Philosopher Gilles Deleuze considered desire as a kind of *longing*; a *longing* to rise above lived realities amounts to what Deleuze called *becoming*, or "individual and collective struggles to … shake loose, to whatever degree possible, from determinants and definitions" (Biehl and Locke 2010, 317). Sociologist Arthur Frank proposes distinct general problems of embodiment that arise during illness that include *other-relatedness* ("what is my relationship, as a body, to other persons who are also bodies?") (Frank 2013, 35) and *desire* ("what do I want, and how is this desire expressed for my body, with my body, and through my body?") (Frank 2013, 36).

Artwork creation has been described as a method for articulating embodied experiences of illness. As a "pre-reflective, non-discursive mode of knowing, symbolizing, and being-in-the world" (Chaplin 2005, 1) artwork can become "a symbolic articulation of our embodied experience and understanding of the world" (Chaplin 2005, 3). Guillemin argues that the act of drawing narratives of health and illness is "an embodied process of knowledge production" (Guillemin 2004, 224). When used strategically, artwork creation may allow for "[attaining] a deeper understanding of [individuals'] social lives," going "beyond the privileged use of denotative language characteristic of most traditional social science methodologies" (Goopy and Kassan 2019, 1).

This paper is based on in-depth participatory fieldwork that incorporated a collaborative arts-based approach with a group of YPHIV in Tanzania. Using artwork and a theoretical

framework of *embodiment*, we phenomenologically describe participants' narratives of HIV experience, perceptions of stigma over time, and imaginations of the future.

## Methods

We collected data in Moshi, Tanzania, between March and August 2021. We utilized semi-structured interviews and participant-observation in combination with collaborative artwork creation in response to prompts (see Supplemental Table 1). Additionally, reflexive qualitative thematic analysis (Braun and Clarke 2019) and arts-based engagement ethnography (Goopy and Kassan 2019) informed the research process from data collection to theme generation, interpretation, and writing.

### Study setting

Approximately 190,000 youth ages 15 to 24 live with HIV in Tanzania (UNAIDS 2021). Additionally, 6% of the global population of adolescents living with HIV live in Tanzania (UNICEF). ART is available free of charge and widely accessible in HIV clinics across Tanzania (Tanzania). We generated all data at the [Anonymous] Institute's ([Anonymous]) satellite site at Majengo Hospital in Moshi, Tanzania (referred to as [Anonymous] Majengo).

Inclusion criteria for participants included prior enrollment in the *Sauti ya Vijana* (*SYV*; "The Voice of Youth") mental health intervention pilot study. We recruited seven highly motivated YPHIV participants to participate in monthly artwork creation and in-depth interviews. We began recruitment at a local Moshi Youth Community Advisory Board (CAB) meeting, a forum of highly motivated and passionate youth. We approached former *SYV* participants in attendance individually to gauge interest. In attempt to create gender balance, we individually called additional female former *SYV* participants to invite them to participate in this study.

### Positionality of Key Researchers

Here, we briefly introduce HN and KH[1]—members of the research team who primarily facilitated data generation—as their positionality directly influenced the research process. HN – a community leader and social welfare volunteer from the Kilimanjaro region with established rapport with many youth – primarily recruited and communicated with participants and led interviews in Swahili. HN had full involvement in the research process, and her presence maximized the variety and depth of participants' responses. While acknowledging his positionality being fourth-generation Asian-American within the global health research space, KH's prior work experience with people living with HIV, young adult status, affiliation with the ongoing [Anonymous] University-[Anonymous] Medical Centre collaboration, and comfort in conversational Swahili helped to build trust and facilitate storytelling.

[1]At the time of data collection, KH (MD) was an MD candidate and National Institutes of Health Fogarty Global Health research fellow with background and training in qualitative research. Credentials of senior authors: MD (DD, BT), PhD (BT, KS)

## Data generation and analysis

Our data included participant-observation, multiple in-depth interviews with the same participant, and individual artwork creation in sketchbooks. Participants were familiar with the study site, [Anonymous] Majengo, as *SYV* sessions were also held in the same building. At the start of the study, we gave participants given individual sketchpads, which they could either keep locked in [Anonymous] Majengo or take home with them (all participants elected to keep their sketchpads at [Anonymous] Majengo); pencils, pens, crayons, oil pastels, and paint were available for use.

Each month, we held alternating semi-structured in-depth interviews and individual artwork creation in response to structured, general prompts (see Supplemental Table 1). We opened a conference room at [Anonymous] Majengo once per month for approximately two hours to provide a working space for participants to create individual artwork on sketchpads that would be discussed during subsequent interviews[2]. We began each "art day" with a prompt posed by co-facilitators on which participants based their artwork. We did not hold formal discussions on these art days. Following each "art day," we scheduled one-hour follow-up individual semi-structured interviews with each participant, during which participants responded to a set of semi-structured interview questions in addition to further sharing thoughts behind their artwork. We conducted a total of four in-depth semi-structured interviews, two art-focused supplemental interviews, and a short, structured interview on demographics with each participant. Multiple rounds of interviews and artwork creation with the same participant enabled us to achieve data saturation, which we defined by reaching a point where "new data began to exceed the research scope" (Otake and Tamming 2020). Demographics information was supplemented by the *SYV* pilot study database.

Observations, fieldnotes, in-depth interviews, and artwork all focused on stigma change over time and imaginations about the future. The research team co-created interview guides (Supplemental Table 1). HN and KH conducted in-depth interviews (range: 30 to 80 minutes) in Kiswahili, and we audio-recorded the interviews (see Supplemental Table 2 for interview topics). We employed an iterative approach to interviewing, where we clarified responses that were unclear from previous interviews (upon review of the audio tape) in subsequent interviews. We first built rapport and slowly introduced new topics over time. We reminded participants from time to time that there are no right or wrong answers, and that our primary goal was to learn from them and their stories. Research assistants transcribed and translated interviews (Swahili and English) verbatim.

KH coded and generated themes on transcriptions and memos on a regular basis (using NVIVO to organize codes) with HN's input, which iteratively informed the next phase of art prompts, participant-observation, and semi-structured interviews (Holmes 2012; Braun and Clarke 2006) (see Supplemental Table 3 for codebook). We derived themes from the data. With participants' consent, we took photographs of original artwork using a *CANON EOS Rebel* DSLR camera to maintain a high quality of images. We managed data on [Anonymous] University's *BOX* account, a secure cloud-based data storage platform.

[2]Tanzanian government guidelines for COVID-19 precautions were followed, including handwashing, encouragement of mask-wearing, and social distancing

Following a semi-ethnographic approach situated within interpretive medical anthropology, we collaboratively interpreted data in the context of participant-observation and utilized a reflexive approach to thematic analysis. KH primarily coded and generated themes, and HN, DM, and DD assisted in refining and interpreting themes. We discussed themes with participants, who provided feedback and input on each theme. Along with Braun and Clarke, we maintained an approach to research that is "creative, reflexive, and subjective," a process that prioritizes meaning, meaning making, and storytelling (Braun and Clarke 2019). In line with interpretive qualitative methodology and reflexive thematic analysis, our themes were active and generative, representing "particular patterns of stories of shared meaning" (Braun and Clarke 2019, 2020).

## Ethical considerations

Youth participants provided written, informed consent to participate in this study in Kiswahili. We obtained additional informed consent from the three participants whose audio we are presenting in supplemental files. We reimbursed participants for travel based on a sliding scale depending on location of residence and offered snacks and drinks as a symbol of gratitude for participation. To keep participants de-identified, we refer to them in this paper by number (e.g., "Participant 1") instead of by age and gender. Regarding dissemination, participants preferred to be recognized as the *Sanaa ya Vijana* youth collaborative.

This study was a nested study of *SYV*, approved at [Anonymous] University, the [Anonymous] Medical University College Ethics Committee, and the Tanzanian National Institute for Medical Research.

## Patient and public involvement

We involved YPHIV in this project from conception to dissemination. The priorities, experience, and preferences of YPHIV informed this study's collaborative arts-based approach. We presented the initial study design to a group of youth affected by HIV at a local Moshi youth CAB meeting. Youth attending that meeting directly offered their input on the project, refined research questions, and provided enthusiastic feedback on the use of arts-based methods (as noted above, we also initially recruited from CAB). We did not directly ask youth to assess the burden of the intervention and time required to participate in the research.

We closely involved our participants in plans to disseminate the results to participants and relevant wider patient communities. While we did not return transcripts to participants for comments and/or correction, we held several individual and group meetings with participants to discuss and refine themes and listen to their feedback. As part of local dissemination, we held an arts-based workshop at the local CAB meeting for other youth affected by HIV, where participants had the opportunity to present their artwork and study themes to their peers. Further, we presented collaborative artwork generated in this study as an exhibition at *AIDS 2022* (July-August 2022) in Montreal, Canada, with the intent of providing a wider youth community an opportunity to engage with the study results.

## Results

We contacted thirteen highly motivated YPHIV (five males, eight females) to be participants in this study. Five (of five) males and two (of eight) females agreed to participate; six females declined to participate. Three females moved away from the research site and could not participate; three who lived near the research site were interested but declined participation due to competing household work or livelihood priorities. One female participant who agreed to participate as a co-participant discontinued involvement after two interviews due to moving far from the research site and juggling competing family priorities. In this paper, we present data from six YPHIV participants (five males and one female with a median age of 22.5 years).

Born between 1997 and 2001, participants lived through a changing HIV care landscape. All participants were born prior to the availability of free antiretroviral therapy (not readily accessible until 2004), and all had perinatally acquired HIV. Important demographics (see Table 1) include that four of six participants experienced the death of their mother—three of whom lost both parents—and the majority had caregivers who were not a biologic parent.

Artwork and longitudinal interviews offer insight into participants' lived realities of stigma and imaginations for the future. Below, we discuss five key themes that emerged during the research process and highlight nine representative art pieces.

### 1. Stigma as it has changed over time

There was a broad understanding that stigma has changed over time with education about HIV and as antiretroviral therapy became available. Participant 6 explained: "Stigma is still there but it is not big. … I see stigma decreasing as days go on." Participant 5 described the ways that they have seen stigma change over time.

> I could say [stigma has changed as time has passed] because nowadays, many of us living with HIV come out unlike in the past. … Because in the past, I think we were few. Some were maybe afraid of going to get tested [for HIV]. But for now, because we are many, even stigma has declined. … Among us, there could be ministers, religious leaders, different types of leaders. … When we relate to the community, they also appreciate what we are doing. So, stigma declines further. People forget that there is stigma.

One participant used the imagery of Mount Kilimanjaro (often visible in Moshi, Tanzania) to describe stigma as it has changed over time (Figure 1a and Supplemental Audio 1):

> Let's say we are talking about people living with HIV. … There was a time [at the beginning] people did not have education [about HIV], they were suffering. … Many people were dying. … [As] you climb, there is a lot of suffering, that is, there are people [with HIV] who are stigmatized. As they climb, the mountain gets steeper. The steeper it gets, the worse the suffering. … At the top, education is plentiful, stigma has reduced. … You find that people's lives have decreased stigma, they are taking their medication on time, deaths have reduced, transmission from mother to child has reduced. … After getting education, stigma decreases.

**Disclosure and Anticipated Stigma—**While participants felt that stigma has changed over time, some questioned the extent to which that they have seen it change. Most participants described a fear of others discovering their HIV status, anticipating that they would be subjected to stigma and discrimination upon others finding out that they live with HIV. All participants felt that there was not yet enough education about HIV in the community for them to be fully open about their status—including romantic partners for some youth. Participant 3 explained in an interview:

> Interviewer (HN): Why aren't you ready to disclose [your HIV status]?
>
> Participant 3: It is something, I mean, it is a disease that is not easy to tell somebody I live with these things. That is not sensible at all. Just following a person, even if he is your friend and telling him man, I live with this and this—no. I have a friend we came out of the [orphanage] together, we went to school together, we stayed in a room together for more than four years. He used to see me taking medication and he knew it was medication for the chest that was all. I never told him anything.
>
> Interviewer (HN): What was your biggest fear?
>
> Participant 3: I see that people stigmatize others [with HIV], so I don't see why I should talk about my health.

## 2. Changing Experience of Stigma Over Time

In addition to seeing stigma change over time in the broader community, the way participants experienced stigma has also changed. Several participants shared that as they adjusted (*-zoea*) to life with HIV, "accepted" (*-jikubali*) the fact that they live with HIV and became more "self-aware" (*-jitambua*) and self-confident (*-jiamini*), their "internalized stigma" diminished. For most participants, education about HIV played an important role in their journey with HIV. For example, Participant 2 shared: "I received good education and it changed me. … To a large percentage, [it] made me believe in myself [and]. … I can mix myself with groups without any problem. If it happens that [others] start a discussion about [HIV], I will be ready to educate them." Participant 6 elaborated on how their life has changed through education. They shared that they used to hold onto "wrong beliefs" (*akili matope, lit. "dirty mind"*), such as believing "that this disease [of HIV] was human-made and when you have it, you cannot conceive of a child." "[Now] I am a [parent] with a family and my child does not have [HIV]." Participant 7 stated that an important moment in their life trajectory was learning the difference between AIDS and HIV. They explained that AIDS is a deficiency of cells that help to protect your body, but "if I take my medicines, I can live year after year (*miaka na miaka*) and I can have children without HIV."

Relationships with other YPHIV have also played a role in influencing one's experience of stigma. Participants described attending clinic days with YPHIV peers as an important part of their journey. Shown in Figure 2 (image and poem; translation of the poem can be seen in the caption below the Figure) and presented in Supplemental Audio 2, one participant used the image of a tear to represent their HIV experience as one of solidarity – a journey alongside other youth who also grew up with HIV. This participant explained they drew the

picture and wrote the poem because they are “not alone.” “We [think] we are alone because we cannot reach our goals, as there is nobody to help us reach them. So, I drew [the tear] in the widest sense to show there are others [with HIV] crying.”

### 3. “They look at us as if we don’t deserve to be here”

There was a sense that some community members continue to consider YPHIV as not being “suitable.” When asked about how the world perceives people living with HIV, Participant 5 shared:

> “Their attitude towards us is not very positive, not very positive. They see it as a … bad curse. … They look at us as if we don’t deserve to be here.”

> One participant shared that some in the community believe that a youth with HIV is subjected to an early “death and … cannot do anything.” This participant explained:

> “The world … considers [people with HIV] as different. … Like … let us say that they see [people with HIV as] not needed. … For example, they consider one rotten fish is all fish. … So, I think that they consider them like. … [a person with HIV] is not needed in society and cannot bring any *maendeleo* (translated as progress or development).

> Participant 3 explained that while some may believe that people living with HIV cannot do hard work, “It is not true. We can do any work.”

The sense that the community views people living with HIV as not being able to work hard is not theoretical; instead, stigma related to others seeing HIV as a kind of employment disability is something participants have seen and experienced. One participant shared that if others discover their status, trust and “job opportunities [may] decrease.” Another participant described they were treated differently by their boss after disclosing their HIV-status. While they were not sure if their HIV status played a role in losing their job, this person reflected that while the boss did not show them stigma directly, “[my boss] made me feel like I cannot do the work.”

There was also a strong sense among the participants that the general public sees people living with HIV as having limited lifespans and futures. Participant 1 explained their thoughts behind why: “I mean how this disease (HIV) got in and the way the media was talking about it—that this disease is dangerous, and it decreases the national workforce—so, [our] society has perceived that the person with HIV cannot do any work.”

When reflecting on challenging experiences living with extended family, Participant 5 commented:

> They see you like a person who will die. … They think that you will not reach your goals. Yes, I do not know why but it is because they do not have evidence of a person who has been like this [with HIV] and they reach their goals. I have not known what the problem is, but most of [my relatives] normally do not have good perception about me.”

In response to a prompt, "How does the world see people with HIV," the art piece in Figure 1b represents one participant's belief that the world considers someone living with HIV as a person who does "not have many days."

> This art shows how the world considers people living with HIV. As you can see, this is a young man and the society is pointing fingers at him and speaking bad words to him … like he is going to die, he does not have many days to live. … [Society] sees him like a bad person, a person who is not wanted in society.

From participants' perspective, external perceptions about HIV can lead to despair and diminish future aspirations when internalized – particularly for youth who feel they are alone living with HIV. In the context of the community seeing people living with HIV as having limited potential for productivity and shortened lifespans, Participant 7 explained their understanding of internalized stigma (*kujinyanyapaa mwenyewe*) as a condition of despair or giving up (*kukata tamaa*) and "wanting to die rather than live." Moreover, when internalized, HIV stigma can lead to a kind of de-valuing of or not accepting of one's self and believing one has diminished potential for contribution to society. Participant 1 explained: "There are some young people [living with HIV who say], 'Because I live with the virus, I cannot do hard work,' you see? Or 'Because I am taking [ART] medication, I cannot do hard work.'"

Participants maintained that community stereotypes could also lead to self-isolation from others out of anticipation or fear of stigma. Despair in the context of stigma can lead to decreased adherence to ART and poor health outcomes. Participant 7 explained: "If you say you give up (or despair), your immune system will be low, and death … will follow you." There was a collective sense that self-isolation, diminished engagement with society, and sickness will affirm community stereotypes and invite stigma, discrimination, and questions about one's HIV status. Participant 5 shared that their strategy of preventing being stigmatized by others is to "take [ART] properly, exercise normally, and do other activities that others do, as usual." Participant 5 explained: "[If] you start saying, 'I am sick, I am sick, I am sick,' it reminds people that this person [has been sick]. … Adhering to medication [helps] to avoid pain and misunderstanding."

### 4. Desire to reframe others' perceptions

Artwork revealed desires to reframe others' perceptions about HIV. As part of a sketch representing their goals for the future (art prompt #2), Participant 2 created an art piece depicting their understanding that accomplishing their goals for the future would improve the way friends or relatives in the community perceive someone living with HIV (Figure 1c). They explained their drawing in a caption (on the right side of the art piece: "*kabla ya kutimiza malengo, marafiki wananitenga; baada ya kutimiza malengo, rafiki wanajirudi*"): "Before achieving my goals, friends isolate me. … After achieving my goals, friends return to me." They further elaborated:

> This art [shows] a youth living with HIV. He has many goals, [but] stigma is still there. Some of his relatives, friends, are running away from him because he lives with HIV. We see that after reaching his goals, his dreams, … he has a good life.

> We see relatives realize … HIV is nothing—one can do something. … Friends and relatives start to follow him.

In contrast to some thinking that people living with HIV do "not have many days" or the ability to bring good to their communities, participants maintained that they and the larger HIV community *can* bring and *are* bringing good to their communities. Participant 7 shared that it is important to advise peers living with HIV that they can accomplish their dreams. Figure 3a is Participant 1's depiction of how world should perceive people living with HIV. They explained:

> [The community] should consider [people living with HIV] as [people] who can bring *maendeleo* (progress or development). … because there are some people living with HIV [the world] cannot recognize. … They are engineers, others are garage [workers], others are our mothers. … They are able to bring *maendeleo* to the community. … The world should see people with HIV [as if] they can bring (or make) *maendeleo* to the community and bring (or make) their own personal *maendeleo*.

There was a sense among participants that in their experience, productivity and hard work not only reduces internalized stigma but also is a step toward challenging community stereotypes about HIV and reducing HIV stigma in the community. Participant 7 explained: "Working for people living with HIV [prevents the community from] thinking, 'This person is HIV positive].' And also, it makes the youth confident that if she can work, she can work at even higher levels. … Discriminating against [a youth who works hard] will be difficult."

Participants maintained that accomplishing their dreams and goals would reduce stigma and challenge community stereotypes about people with HIV. Participant 5 shared their belief that when people in the community enjoy the things that people living with HIV do, they "forget [about] stigma." Participants also collectively felt that being productive and accomplishing goals would contribute to a feeling of individual importance and value. For instance, Participant 5 explained that accomplishing their current and future aspirations would "make [them] feel that [they are] still needed somewhere."

There was a sense among several participants that YPHIV have the opportunity to be exemplars in the community to both those who are HIV-uninfected and those who live with HIV. Participants on the whole wanted others in the community to know that YPHIV are capable of productivity and are people who have the potential to accomplish their dreams. Figure 3b shows Participant 6's vision for the way the world should see people living with HIV. They explained:

> We people living with HIV are supposed to be an example to emulate. … Aren't we? … At the end of the day, those who knew me as living with HIV, I become an example to the younger ones. That this man lives with the virus, but he had his goal. He didn't stay idle, no self-denial. That I stop medication, so I don't work? No. I take my medication, I work, I survive.

### 5. "Safari ya Maisha Bado Inaendelea" (The journey of life Still Continues)

In contrast to a belief that people with HIV have limited futures, participants saw their lives as a kind of work-in-progress – people with lives yet to come to fruition. Participant 6 described the importance of seeing HIV as "not the end of dreams nor the end of life." One participant considered their life as a journey that has not yet been completed: "The way I live with HIV, I can do all jobs. I can do everything. It makes you think, 'The journey of life is still there.'" (see Supplemental Audio 3 for audio clip).

In response to an art prompt asking participants to create art that represents their life journey, Participant 1 drew a Northern Tanzania highway (Figure 3c). At the far right of the artwork, there is a sign that states, "Work Ahead" (*Kazi Mbele*). They explained:

> My journey of life – I have considered it like a road. Along the road, you can come across many obstacles. … The road means that you have dreams of reaching ahead but there are obstacles we meet. … [Here in the front] it shows, 'Work ahead.'

For this participant and others, there was a strong sense that life is not static but dynamic and much greater than the present moment. In spite of "obstacles" that include stigma, participants described working hard toward good goals and dreams for the future that include livelihood stability, having families, and supporting others in the community. As Participant 3 shared, "I have not yet moved forward [in accomplishing my dreams for the future], but I fight to move at least one point [toward my dreams]."

There was a strong desire among participants to also help their peers living with HIV in their life journeys. Participant 5 shared, "[Peers] are still suffering, and some have no support. … Therefore, I could say my biggest dream is just to give them hope." Two participants have sent creative videos of themselves taking ART in Whatsapp groups for youth living with HIV to encourage others to take ART. "We make such videos so that we can convince the youth who think ARVs are not effective or maybe not useful, because … some youth don't take their medication properly or they stop using [them]." Several participants volunteer at an adolescent HIV clinic, providing HIV education to youth peers and their caregivers. Participant 6 explained why they volunteer in the clinical setting: "I want the upcoming community or the future generation not to be as narrow-minded as we were."

Several participants have taken it upon themselves to reduce stigma in the community around them through education. Participant 7 described that a couple of years ago, they were stigmatized by people in the community who knew their HIV status, which caused them to be fearful of interacting with others. They explained their situation to the village elder, who convened a session with members of the community and decreed that people "should not be stigmatized due to their [health] status. It is just a condition of life." Other participants shared that in their volunteer roles, they have educated family members of other youth with HIV about stigma and worked to improve the situation of their peers (Figure 4a).

From participants' perspective, ART is a prerequisite for being on their life's journey and preventing experiences of stigma. Participant 1 shared that their greatest fear is if "[ART] medicines are out of stock." They explained: "Because if they are not available you know our health will—we shall not be in good health you see. Because for us, our lives depend on

medication." Participant 2 identified ART as a source of hope: "what gives me hope [in life] are my medications. … You know, when I am using my medications, the virus is suppressed and I am far away from opportunistic infections, and in turn, I can do my things."

Participants collectively expressed an understanding that they can only reach their goals with healthy bodies, and that good goals for the future encourage adherence to ART (see Figure 4b). Participant 6 explained: "There is no one who takes [ART] medicines and does not know what their goal is." From participants' perspective, inadequate adherence to ART will lead to AIDS-related symptoms and put them at risk of being stigmatized in their community. Healthy bodies will not only allow one to accomplish future dreams but also prevent stigma.

While it was not the primary intent, "art days" became a space for friendship, group support[3], and sharing ideas. Several participants saw artwork creation as a kind of educational training to improve mental wellbeing, reduce internal stigma, cope with past memories and future fears, and address stigma in society through art. Participant 2 referred to art creation as a kind of education in stigma-reduction:

> It is true stigma is in the society – now the education that we are given [in this project] is helping us with how to cope with stigma. Even if we do not have stigma, there are few who are stigmatized, so we educate them how to help themselves with stigma.

> The space of art creation also allowed participants to think about their future trajectories. Participant 7 reflected, "[In this project], [we] draw something relevant that you desire in the future. … We are not thinking about the past but about the future. … I will be a light in the community."

## Discussion:

This paper phenomenologically describes YPHIV participants' perceptions of stigma and narratives of their HIV experience. Through participants' artwork and their detailed descriptions of life with HIV, this paper offers insight into their lived and embodied realities with HIV stigma. Collective solidarity, *habitus* and desires for the future (individually and collectively) shape participants' perceptions and experiences of HIV stigma.

Sociologist Arthur Frank describes that people living with illness often seek to resolve a problem of *other-relatedness*—that is, "how does our shared corporeality affect who we are … for each other?" (Frank 2013, 35). Participants maintain that relationships with other YPHIV were important in forming their HIV identity and helping them to see that they are not alone with HIV; this is consistent with what other groups have shown in studies of youth living with HIV (Chaplin 2005; Hosaka KRJ 2021). The solidarity described is unique in that there is strong sense of *shared suffering*. As seen in Participant 5's image of a tear as a metaphor for their experience of collective suffering alongside other YPHIV (Figure 2), YPHIV bear witness not only to their experiences of stigma and loss but also to that of their

[3]KH brought his guitar and DSLR camera to art days for participants to experiment with not only to build rapport but also to assist with generating ideas for artwork creation

peers. As Frank puts it, YPHIV "see [their] suffering in the bodies of others" (Frank 2013, 49). Figure 2 is an example of how embodied experience of stigma is felt socially ("I am not alone with tears") and temporally (i.e., a movement from past trauma to present tears and future dreams).

Narratives and artwork demonstrate that HIV stigma is context-specific and the product of a distinct *habitus*. The social backdrop of the HIV epidemic in Tanzania—including the timeline of availability of ART—has influenced community attitudes toward YPHIV and patterns of discrimination. The relationship between participants' *habitus* and stigma is demonstrated in Participant 2's depiction of the "world" pointing fingers at a young male because of his HIV status (Figure 1b), as they would "a criminal [or] a person who is not suitable in the community"—someone without "many days." For Bourdieu, *habitus* is a "system of durable, transposable dispositions… predisposed to function as structuring structures" (Bourdieu 2000, 72). Community-wide stereotypes about people living with HIV that participants described in interviews and artwork (e.g., PHYIV are sick, cannot work hard, have limited futures, and "will die in not many days") are part of this socially constructed *habitus* that not only may lead to feelings of despair and diminished hope but also can guide future behavior (e.g., adherence to ART).

Participants' narratives were rich with descriptions of the ways that community attitudes toward people with HIV, stigma, and their imaginations about the future have changed over time. HIV stigma is often described and measured as a stagnant phenomenon that is difficult to change even with the best evidence-based interventions (Penazzato et al. 2018; Earnshaw et al. 2022). Our participants maintain that HIV stigma is a fluid process that not only *has changed* over time but also *has the potential to change* over time. In reflecting on and depicting their life course, participants described how their embodied experiences of stigma evolved as 1) they received HIV education in the clinic and in the community, 2) antiretroviral therapy became more tolerable, potent, and widely available, and 3) they formed relationships with peers who also live with HIV. While several groups have looked at stigma temporally (Kang et al. 2021; Alonzo and Reynolds 1995)—notably, Alonzo et al.'s (1995) seminal work in analyzing the disease course of HIV/AIDS as a stigma trajectory—our study is one of the first to describe how stigma experiences for YPHIV in Tanzania are temporal and have changed over time with increased age, interventions (e.g., promotion of HIV education and gatherings of youth living with HIV), and biomedical advances in the region. This insight should inform structural approaches to care and intervention programming for this population.

This paper argues that desire and longing should be considered integral parts of YPHIV's embodied realities of HIV and stigma. In their artwork and narratives, participants described a deep longing to re-frame others' perceptions about them. For example, in contrast to existing negative stereotypes in the community about people living with HIV, participants want the world to know that YPHIV can succeed and fulfill their dreams (see Figure 1c) and are bringing *maendeleo* (progress or development) to society (see Figure 3a). Participants' longing to push against societal views about HIV is reminiscent of a Deleuzian philosophy that "emphasizes the primacy of desire over power and the openness and flux of social fields" (Biehl and Locke 2010, 317).

Participants not only long for their own individual wellbeing and success; they also desire for their YPHIV peers to achieve optimal physical and mental health. In other words, their desire is to "relieve the suffering of others" living with HIV (Frank 2013, 49). Several participants volunteer in clinic spaces helping other YPHIV, and as described above, two participants create videos to encourage their peers' adherence to ART. Participants also long to lead lives that would be an example for other YPHIV to follow (see Figure 3b). While longing has generally been an understudied and underappreciated aspect of the lived realities of YPHIV, it is gaining recognition in programming that targets this population. For instance, the 2021 International HIV & Adolescence Conference dedicated a plenary session to discussing youth living with HIV's hopes for the future that was entitled, "The World We Want" ("HIV & Adolescence 2021 - Program Book" 2021, 14).

A question we ask is: can a focus on the imaginary practically lead to strategies of stigma reduction? Participants' artwork and narrative descriptions both illuminate how participants envision stigma reduction practically occurring and symbolically represent embodied "efforts to exceed and escape forms of knowledge and power and to express desires that might be world altering" (Biehl and Locke 2010, 317). Working among youth in Eastern Congo, physician-anthropologist Rachel Niehuus argues that the imaginary can be transformative, allowing "invisible aspects of reality [to] be envisioned" (Niehuus et al. 2021). By bringing together real and imaginary perspectives, artwork creation enabled participants to uniquely express their desire to reduce stigma and work toward a better and more equitable world.

As seen in the figures presented in this paper, artwork added a level of depth and nuance that is not possible through interviews alone. Art-based methods are not new in HIV programming or research. Researchers, practitioners, and community health workers have widely used art-based methods for the purpose of health promotion in response to the HIV pandemic across sub-Saharan Africa. Art forms have included theater, music, film, storytelling, and the visual arts (Bunn et al. 2020). For instance, Chiedza's Song—a film highlighting the lived experiences of adolescents living with HIV in Zimbabwe—partnered with researchers from the London School of Hygiene and Tropical Medicine with the aim of reducing stigma, promoting community awareness, and highlighting individual stories of resilience (Ferrand 2016). The MASA community film project in Malawi used collaborative work alongside local artists to produce an interactive drama that would promote widespread conversation around HIV (Gibb 2014).

Art-based methods—particularly photovoice—have been used by researchers in recent years to gain a deeper understanding of perceptions of treatment, contextual understanding of stigma, and resilience among YPHIV (van Wyk and Teti 2020; Adegoke and Steyn 2017; Kimera et al. 2020). What is unique in our approach of artwork creation is that it enabled participants to directly tell narratives meaningful to them and also explore beyond present social realities, visually representing and imagining stigma reduction pathways (see Supplemental Video 4 for the *AIDS 2022* art exhibition). In addition, our approach not only highlighted participants' nuanced understanding of stigma but also their desire to reduce it and positively work toward future goals. While photovoice is a powerful method to understand and visually represent the social realities of YPHIV, we found the use of artwork

creation to be particularly informative in understanding participant's *becoming* or how they imagine "[shaking] loose" from the "intolerable conditions" of HIV stigma and respond to, redefine, inhabit, and redeploy experiences of stigma (Biehl and Locke 2010, 317). Future studies on HIV stigma should consider ways to creatively partner with YPHIV in exploring narratives from their perspective that could inform stigma measurement and stigma-reducing interventions.

### Limitations

There are several limitations of this paper. Despite efforts to balance male and female gender participants, the study included predominantly male narration. While females who were approached for participation were interested in the topic, most were hesitant to commit to the project, citing competing commitments to housework, raising children, and supporting their families. These gender differences underscore the social and economic inequalities for many young adult women to participate in research and pursue personal and professional opportunities in regions like Northern Tanzania. We suspect that future studies on stigma among older YPHIV (e.g., those in their twenties) in regions like Northern Tanzania that incorporate a livelihood component could be effective in increasing female participation (Hosaka et al. 2020; Kakuhikire et al. 2016). Moreover, while our small sample size may limit generalizability, using a smaller group of key participants was a strength of the study in allowing for a level of depth, extended interaction, and collaborative creativity that would not have been possible otherwise.

Despite our best efforts to achieve collaboration between participants and the research team, there were several challenges. This manuscript was written in English, which was a limitation in giving participants (native Kiswahili speakers) more voice in the dissemination process. We held several meetings with participants in which we presented main ideas from the study in Kiswahili and allowed participants to provide input. We also acknowledge the authors' educational and socioeconomic privilege as potential sources of bias. We saw this work as a pathway toward de-centralizing power, giving participants the opportunity to address topics important to them.

## Conclusion:

Overall, this paper offers an in-depth phenomenological description of the embodied experience of HIV stigma for YPHIV in Northern Tanzania. Artwork and narratives highlighted participants' *habitus* that shape their temporal experience of HIV stigma and guide future behavior. HIV stigma is a fluid process that changes over time; while stigma is still present, participants report responding to stigma with agency by creating alternative solidarities and pushing boundaries of possibility, acting on dreams for better futures for themselves and the collective whole.

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## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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None

## Abbreviations:

| | |
|---|---|
| **YPHIV** | youth living with perinatally acquired HIV |
| **ART** | Antiretroviral Therapy |
| **SYV** | Sauti ya Vijana |

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**Collaborator Statement:**

The *Sanaa ya Vijana* youth collaborative refers to the youth participants and recognizes their distinct artistic contribution to this manuscript. Individuals preferred not to be individually named; instead, they preferred to be recognized collectively.


**Figure 1.**

(A—top left) The Mountain (Mlima): stigma changes over time with community education (see online supplemental audio 2 for audiovisual presentation of artwork). (B—top right). The world considers a person with HIV as someone who will die. He does not have many days. Caption: “You are looking at this person. He has energy, anytime he will die, that is, he does not have many days”. (C—bottom) Before achieving my goals, friends isolate me; after achieving my goals, friends return to me (Art prompt: create art that represents your goals for the future). Caption: “Many youth live with the infection (HIV). They have many goals but until the youth achieves his/her goals, you must pass many challenges like being stigmatized. But stigma comes as a way for a youth to succeed (kufanikiwa) and then friends and relatives with stigma (meaning: who stigmatize) return again and continue on a new life. So never ever give up my friends…”

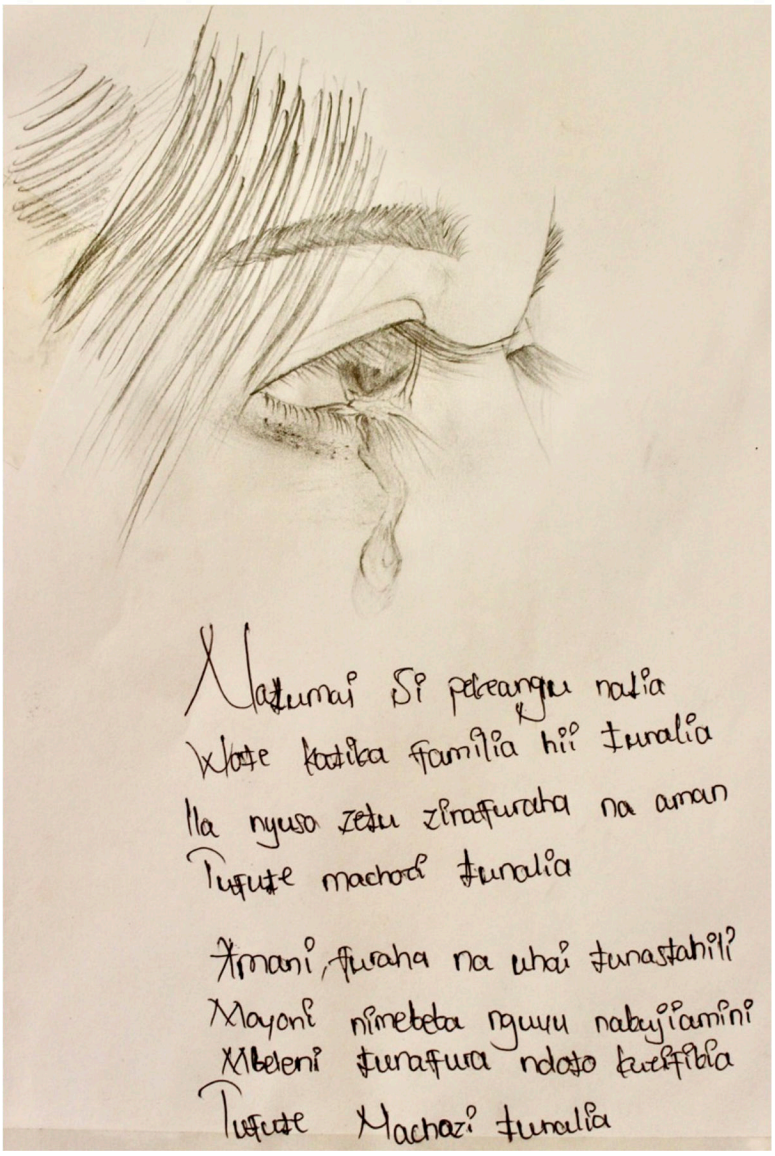


**Figure 2.**

Let us wipe away the tears we cry (see online supplemental audio 3 for audio-visual presentation of artwork). Poem: I believe I am not alone with tears/We are all crying in this family/But our faces are happy and peaceful/Let us wipe away the tears we cry/Peace, happiness, and life we deserve/In my heart I have carried strength and confidence/ In the future we rejoice to reach out our dreams/Let us wipe away the tears we cry.

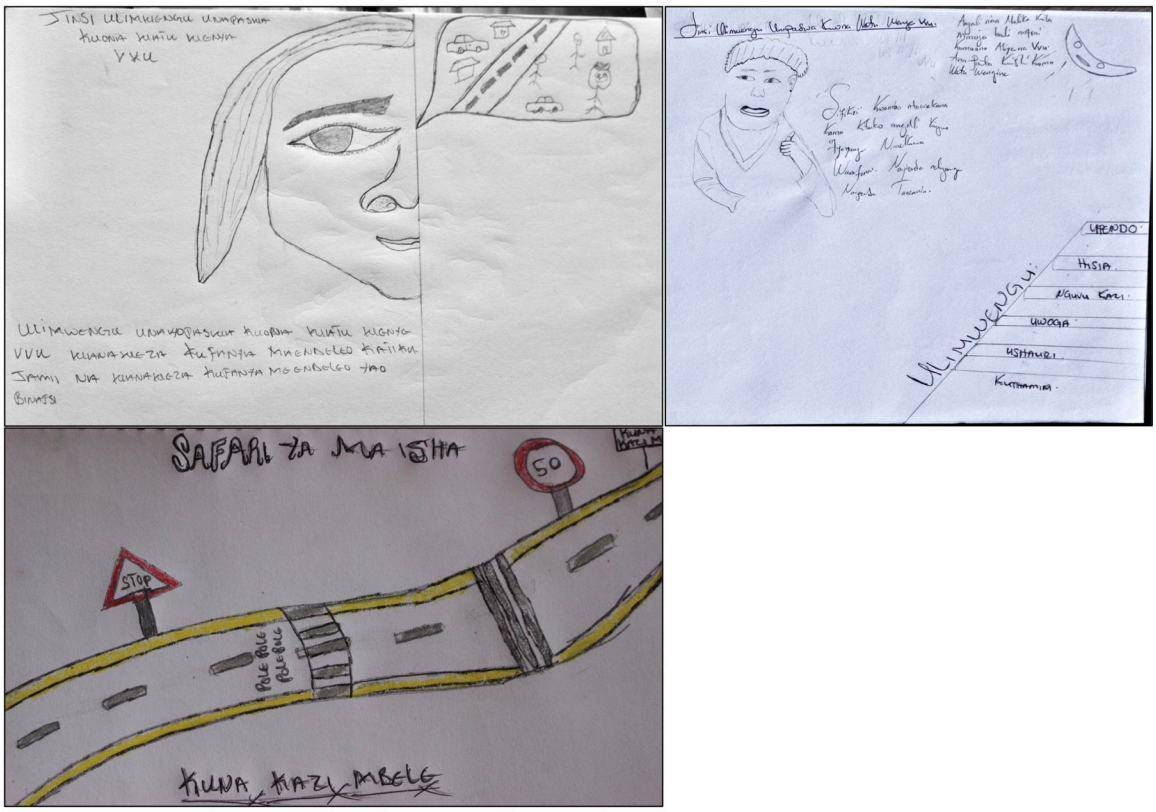


**Figure 3.**

(A—top left) The way the world should perceive people living with HIV. “The world should see people living with HIV [as if] they can bring (or make) maendeleo (progress or development) to the community and bring (or make) their own personal maendeleo”. (B—top right) The way the world should see people living with HIV. “I do not think that I will look like a freak, if I have known my health, I have been an example. I love my country, I love peace”. (Sun: top right) “I am shining on everyone, but I am happy to see him who has HIV, he has life like others”. Ladder: (bottom to top) to value, advice, fear, hard work, emotion, love. (C—bottom) ‘Kuna Kazi Mbele’ (There is Work Ahead). The Journey of Life. (C—bottom) ‘Kuna Kazi Mbele’ (There is Work Ahead). The Journey of Life.

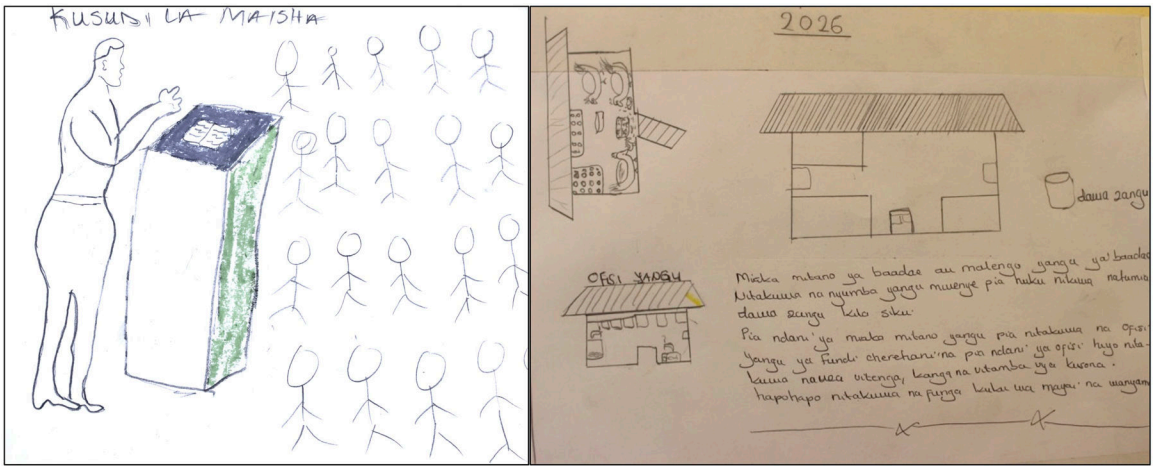


**Figure 4.**

(A—top left) ‘Kusudi la Maisha’ (The Purpose of Life). (B—top right) “My medicines” (dawa zangu) Five years later/my goals of the future: I will have my own house. Also there, I will take my medicines every day. Also, within my five years, I will have my tailoring office and also in the office indeed I will be selling vitenge, kanga, and sewing threads. There, I will have eggs and animals.

**Table 1.**

Demographics of study collaborators at the end of data collection (August 30, 2021)

| | N=6 |
|---|---|
| **Age** | |
| Mean (Standard Deviation) | 22.2 (1.7) |
| Median (Quartile 1, Quartile 3) | 22.5 (22, 23) |
| Minimum, Maximum | 19, 24 |
| **Sex, male**, n (%) | 5 (83.3%) |
| **Highest level of education** | |
| Primary | 1 (16.7%) |
| Secondary | 3 (50%) |
| College | 1 (16.7%) |
| Vocational | 1 (16.7%) |
| **Current Living Situation** | |
| Lives alone | 3 (50%) |
| Live with non-nuclear extended family | 2 (33.3%) |
| Live with friends | 1 (16.7%) |
| Lived in 2 or more places in the last 12 months | 6 (100%) |
| **Socioeconomic**, n (%) | |
| House has electricity | 6 (100%) |
| House has indoor plumbing | 5 (83.3%) |
| Own cell phone | 6 (100%) |
| Own smartphone | 2 (33.3%) |
| Own computer | 3 (50%) |
| **Primary Caregiver** | |
| Mom or dad | 2 (33%) |
| Aunt or Uncle | 3 (50%) |
| Grandmother or Grandfather | 1 (17%) |
| **Biological Parents** | |
| Biological mother not alive | 4 (67%) |
| Biological father not alive | 3 (50%) |
| Biological mother and biological father not alive | 3 (50%) |
| **Daily Livelihood** | |
| Currently working | 4 (66.7%) |
| [If not currently working, held job in last 12 months] | 2 (100%) |
| Income per month | |
| No income | 2 (33.3%) |
| ≤ 100,000/= T. Shillings (approx. $43 USD) | 3 (50%) |
| > 100,000/= T. Shillings | 1 (16.7%) |
| Rent per month | |
| No rent | 3 (50%) |
| ≤ 30,000/= T. Shillings (approx. $13) | 3 (50%) |

| | N=6 |
|---|---|
| "I have enough food to eat every day" | |
| No | 2 (33.3%) |
| Not all of the time | 3 (50%) |
| All of the time | 1 (16.7%) |
| **Career goal** | |
| Self-employment | 3 (50%) |
| A stable job | 1 (16.7%) |
| Creative arts | 2 (33.3%) |

*Categories are not mutually exclusive.

[a]One response missing