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When ART is not a magic bullet: Tailored care for vulnerable people living with hiv in the era of treat-all in Shinyanga, Tanzania

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ABSTRACT

Community health workers (CHWs) play a crucial role in supporting retention in HIV care in Tanzania under the World Health Organization's Treat-All policy. While the WHO promotes the differentiated service delivery (DSD) model for stable clients, not all people living with HIV (PLHIV) can achieve sustained viral suppression independently. Using ethnographic case studies of one CHW and three vulnerable clients in Shinyanga, Tanzania (2022–2023), we examine how CHWs adapt patient-centred care in the current era of Treat-All. The findings demonstrate that treatment adherence for highly vulnerable groups, particularly children and older adults, relies on collaborative care involving families, neighbours, religious actors, non-governmental organizations, and health providers. CHWs' flexibility and community embeddedness enable them to identify individuals at risk of disengagement and mobilize these care networks. Increased formalization of CHWs within health systems, though beneficial, risks undermining their embeddedness and limiting their capacity to detect need and respond effectively. The study highlights the need for continued financial support for community-based care systems that recognize and support CHWs' relational and moral labour.

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Introduction

> A nurse once said to me harshly, 'How could you take an ill person like that to live with you, what if he dies on you?' … A few months later, I showed up with the same boy at the clinic. She could not recognise him anymore, a healthy and handsome looking young man. … This boy was passed on from one family to another, but he never got better. What he was missing was someone who could closely care for him and supervise his treatment.

In the above, Rebeka, a Community Health Worker (CHW) employed in the Test & Treat Project implemented in Shinyanga region, Tanzania, discusses a boy living with HIV/AIDS who, even after being enroled in a care and treatment programme, experienced acritical condition of AIDS. In resource-limited settings, CHWs like Rebeka are the linchpin in the provision of personalised care to the most vulnerable. Their job, as informal and non-medically trained care workers, allows them to go the extra mile to help those in need (Kyakuwa, 2011; Moyer, 2014). Moreover, it is their care that makes visible the often-complex, intersecting vulnerabilities that may lead PLHIV from vulnerable groups, such as the elderly and young people who lack stable familial support, to disengage from care (Mwangala et al., 2023; Settergren et al., 2021; Siedner, 2019).

Since 2016, the WHO has promoted the Differentiated Service Delivery (DSD) approach, which prioritises client-centred care for clinically stable PLHIV and advanced support for PLHIV who are in danger of discontinuing antiretroviral treatment (ART) (World Health Organization, 2021). This study focuses on the roles of CHWs in mobilising such care and support in the current *treat-all* era. We examine three cases of

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collaborative care in which highly vulnerable people, including one older and two younger people with dysfunctional family relations, struggle to regain their health despite having access to life-saving antiretroviral therapy (Settergren et al., 2021; Siedner, 2019).

'Collaborative care' in this paper refers to support beyond the household level, involving non-kin, organisations, and others in helping individuals during health crises (Kielmann & Cataldo, 2010; Mattes, 2011; Moyer & Igonya, 2014; Ogden et al., 2006; Robins & Robins, 2005). Formal collaborative care programmes often focus on the integration of health services, whether for different conditions (Pyne et al., 2011; World Health Organization, 2021); between biomedical and non-biomedical health systems, such as collaborations with traditional healers (Sundararajan et al., 2021); or religious leaders (Lambert et al., 2021); or between different cadres within the health system, for example, clinical and community health workers (Lambert et al., 2021; Pyne et al., 2011).

Closely related to the collaborative care concept is collective care, a form of care that is particularly critical in the current neoliberal context, where health systems increasingly emphasise decentralisation and individual responsibility for self-management (Raap et al., 2021). The key distinction between the two concepts lies in scope: collective care focuses on strengthening local care arrangements and infrastructures within families and communities, while collaborative care extends beyond these local networks to include local and international organisations, donors, and other health stakeholders. This broader framing of collaborative care acknowledges the multi-layered ecosystem of actors necessary to sustain HIV treatment in resource-limited settings like Tanzania. In this paper, the two concepts are presented fluidly as the authors demonstrate both the reality of fragmented local infrastructures of care and the need for external support to achieve successful treatment.

In the three cases examined here, it was the extraordinary collaborative care choreographed by Rebeka that retained the individuals in care. While community health workers often provide the extra time and attention that some patients need to thrive (Moyer & Igonya, 2014; Mukherjee et al., 2016; Perry et al., 2014; Tseng et al., 2019); neither the cases nor the work undertaken by Rebeka should be considered typical. Still, they provide insight into the essential work that CHWs undertake to save lives and, by extension, what good care might look like. Considering such cases also invites us to consider what happens to the extremely vulnerable when CHWs lack time to provide care beyond the clinic walls.

Typically, CHWs are responsible for health education, promotional, preventive, and basic curative services within their communities (Campbell & Scott, 2011; Hodgins et al., 2021; Perry et al., 2014). Widely, CHWs have been working as frontline responders during disease outbreaks, health programme focal persons, and gap fillers within local health system structures (Schneider et al., 2022). They are particularly recognised for their flexibility in responding to community needs and for extending care to populations that are underserved or beyond the reach of formal health systems (Hirschhorn et al., 2023).

Historically, CHWs have played a vital role in HIV care, in part because they could counter stigma by visiting people in the privacy of their homes; over time, however, the tasks of CHWs have shifted for a variety of reasons, including issues related to supervision, incentives and remuneration, and identity/professionalisation (Hodgins et al., 2021; Kapologwe et al., 2023; Perry et al., 2014). In the current *treat-all* era, which strives to identify and pharmaceutically medicate all people with HIV, CHWs have proven crucial in helping to identify PLHIV in need, and to link them to and retain them in care (Mukherjee et al., 2016; Perry et al., 2014; Reynolds et al., 2023).

While formalisation may provide job security and recognition for CHWs, it also may result in their work being centred in facilities rather than in the community (Hodgins et al., 2021; Mgawe & Maluka, 2021; Tseng et al., 2019). This development threatens CHWs' unique position, which allows them to recognise and respond to the often-complex social problems underlying failing treatment regimens (Campbell & Scott, 2011; Hodgins et al., 2021; Meinert, 2015; Mgawe & Maluka, 2021; Perry et al., 2014). This question is relevant given recent efforts to integrate CHWs into mainstream healthcare systems in Tanzania and elsewhere across Africa (Kapologwe et al., 2023; Mgawe & Maluka, 2021; Tseng et al., 2019; Zulu et al., 2015), largely to address healthcare worker shortages (Hodgins et al., 2021; Mgawe & Maluka, 2021).

By exploring the extraordinary efforts of one clinic-based CHW, we ask what collaborative care entails in a fragmented landscape of health care, where government HIV care and treatment programmes coexist with multiple temporary donor projects, community care networks, religious communities, and familial kin

networks, and where different moral values around what 'good care' is circulate. In doing so, we explore cracks in local care infrastructures for some groups of highly vulnerable PLHIV, especially as projects end.

Materials and methods

The test & treat intervention trial

In 2016, Tanzania's HIV/AIDS policy shifted to incorporate the WHO-recommended 'treat all' approach (), which focuses on initiating treatment as early as possible. The arguments in this article are based on the findings from an ethnographic study conducted within a health intervention (the 'Test & Treat Project') in Shinyanga, Tanzania, which ran from 2017 (a year after the policy shift) to 2022. The project sought to implement a differentiated and community-based approach to HIV care. The project implemented differentiated community-based testing, mobilised by CHWs; immediate linking of clients to treatment services assisted by CHWs; and the introduction of community-based adherence clubs supervised by nurses and later CHWs.

In a collaboration with the Diocese of Shinyanga, the project was implemented in four Catholic mission health facilities and the regional government hospital. The project ran parallel to and adhered to the national HIV-care guidelines. PLHIV deemed 'stable' (engaged in treatment for six or more months, with an undetectable viral load) were able to receive ART through community-based drug dispensing. The rest continued to receive facility-based standard care. Both facility-based and community-based clients were clinically monitored when drugs were dispensed.

We identified three categories of CHWs working within the project. The first comprises formally trained CHWs who completed a one-year accredited course and are facility-based, providing services such as vaccination, antenatal education, and record keeping. The second includes volunteer CHWs, often referred to as Home-Based Carers (HBCs), who are selected by their communities and receive short, programme-specific training to support government or NGO health campaigns. The third category consists of expert patients—individuals living with HIV who serve as lay counsellors, receive training similar to HBCs, and work across both facility and community settings on fixed-term HIV projects.

The intervention project engaged all three categories of CHWs. They were central to mobilising community-based testing, linking clients to care, monitoring adherence, and supervising adherence clubs. The largest group comprised HBCs, who primarily worked with NGO projects on an incentive basis and were responsible for mobilising clients, facilitating testing campaigns, and linking patients to care. In addition, the project hired eight salaried CHWs, drawn from all three categories, who operated across health facilities and communities. These CHWs assisted with testing campaigns, administrative tasks, health education, and adherence monitoring. Rebeka, a case study in this paper, was part of this group. The formally trained CHWs were specifically tasked with managing community adherence clubs for clinically stable clients. In this paper, the term 'CHWs' refers collectively to all three categories.

The Test & Treat Project aimed to bring HIV services to remote settings. The ethnographic study discussed here, was embedded within the Test & Treat Project and took place in two of the four Catholic missionary health facilities in urban and rural areas. While *treat-all* was the general policy of the Tanzanian Ministry of Health, the CHW-centred differentiated care model was a novel intervention within the Test & Treat Project (De Nardo et al., 2020).

The project enroled both stable and vulnerable clients through the hub (facility-based) and club (community-based) model. Following HIV diagnosis, clients were immediately enroled for standard care at health facilities. After six months of treatment, those who demonstrated clinical stability, confirmed through adherence and viral suppression, were invited to join community adherence clubs as part of the DSD model. Details of the DSD model are reported in a separate publication.

Data collection

In-depth ethnographic research was conducted parallel to and after the implementation of the project. From July 2019 to April 2020, the lead author observed the implementation of the project at the clinic settings and nearby communities to become familiar with the project, environment and the people. This

work included conducting more than 30 observations together with informal talks with healthcare providers and HIV clients in the health facilities and communities where the project took place. Between 2020 and 2022, COVID-19 safety measures halted research activities. As the project's implementation ended in 2021, the study was reconceptualized to focus on the project's after-effects and sustainability. From November 2022 to June 2023, follow-up ethnographic research was conducted, including in-depth interviews with PLHIV (73), healthcare workers (5), and CHWs (8). Focus group discussions (FGDs) were also held with general community members (10) and PLHIV (9). In this paper, we present an in-depth case study drawn from eight interviews with CHWs, focusing on Rebeka and three of her clients as illustrative examples. We purposively relied on repeated in-depth interviews and observational data to capture the depth, contextual detail, and complexities of each case. Data from other sources, including FGD addressing related topics, were analysed and reported in separate publications.

Recruitment

During both periods of fieldwork, the researcher gained in-depth insights into the roles, work experiences, and impacts of CHWs in improving care, particularly for vulnerable PLHIV. All eight CHWs in this study were salaried workers hired by the Test & Treat Project. The lead author created rapport with CHWs through informal chats at health facility settings, joining them during routine visits to clients' homes, and sitting with them in their offices to help with administrative activities. The CHWs' work schedule was demanding. Access was gained by joining CHWs and nurses during community HIV-testing campaigns to observe testing services in communities. On weekends, the lead author spent time with CHWs in their home environments. After the Test & Treat Project ended, CHWs who were hired by the project became redundant.

All participants were provided with information about the study, and consent to participate was obtained in writing for all formal interviews and orally for informal conversations. During routine home visits to PLHIV in both phases, the CHWs introduced the lead author to clients and asked permission to have the researcher observe the visits. Since CHWs were trusted and respected in communities, clients and guardians willingly welcomed the researcher into their medical and social spaces. These interactions provided the researcher with an opportunity to learn and observe the real-time experiences of both clients and CHWs.

Among the eight CHWs engaged in this ethnographic study, Rebeka stood out as a trusted point of reference for both clients and the project implementers. Her work was particularly notable, making project implementers frequently select her to provide targeted support to clients experiencing adherence challenges and at risk of discontinuing treatment. Rebeka's experience as an expert patient, coupled with project-based on-the-job training and a demonstrated commitment to care that extended beyond her formal job description, positioned her as an illustrative case for in-depth analysis of collaborative care.

Analysis

Interviews were conducted in Swahili, the national language spoken fluently by the researcher/lead author. All CHWs fluently spoke both Swahili and Sukuma (the ethnic language in the Shinyanga region). For a few clients who spoke only Sukuma, CHWs assisted with translation. Interviews were tape-recorded and transcribed verbatim. For observations and informal talks, notes were written. Analysis was an iterative process that started in the field during data collection and encounters with CHWs, and continued with formal interviews. Data interpretation involved listening to audio files, reading transcripts and observation notes, and discussing the findings with the co-authors. Data were stored and coded using the software programme QRS NVivo 14.

Rebeka, based on her background as 'an expert patient'— having lived with HIV herself, was eager to share what she observed in communities and with clients. The analysis of the three cases was possible because of the knowledge Rebeka had about her clients. We used a framework known as 'pattern matching strategy' suggested by Yin (2002); pattern matching is a technique for analysing case studies where data are linked to certain theoretical propositions. All interviews and fieldnotes were read repeatedly to achieve familiarisation with the data and identify patterns. Initial open coding was conducted inductively to capture

recurring practices, meanings, and relational dynamics in CHWs' care work. These codes were then iteratively refined and grouped into analytical themes that were informed by, but not limited to, our conceptual framing on collaborative care, invisible care work, and integrated health systems.

Pattern matching was subsequently used as an analytic strategy to relate these empirically derived themes to existing theoretical propositions. Our data interpretation was validated through triangulation across data sources (interviews with CHWs, project implementers, and clients; observational fieldnotes), analytic memo writing to document interpretive decisions, and debriefing among the research team.

Ethical approval

This PhD study falls under the overall research project 'Feasibility of universal access to HIV Test & Treat in Shinyanga and Simiyu regions, Tanzania', ethically cleared by the National Institute of Medical Research (NIMR) under NIMR/HQ/R.8a/Vol.IX/2711. The PhD study, 'After effects of a Test & Treat differentiated model of care: Sustaining patient and community networks of support and responsibility in Shinyanga, Tanzania', received independent ethical clearance from the Amsterdam Institute of Social Science Research (AISSR) and from NIMR under NIMR/HQ/R.8a/Vol.IX/4130.

Results

In the following, we present three cases of collaborative care organised by Rebeka, a CHW employed by the Test & Treat Project. The narrations detail the care Rebeka provided during the project's implementation; clients were again visited after the project ended to see how they were faring. Like some CHWs, Rebeka was an expert patient, but unlike others, she had a background in teaching rather than community health work. In the project, she was hired as CHW under the category of a Home-Based Carer to work in the mission facility in Shinyanga town. She was responsible for conducting follow-up visits with newly diagnosed HIV clients to ensure their initiation on and adherence to treatment. Facility-based tasks included running the *darasa/class,* where health care workers educated newly diagnosed PLHIV on nutrition and adherence before-treatment initiation, and completed administrative tasks at the clinic, including registering clients, locating their files, and directing clients to the doctor's consultation offices. Rebeka showed a good work ethic and was awarded a two-week official Home-Based Carer certification course, validating her competence in her new role. When the project ended, Rebeka's contract ended as well.

The case of Ana becoming an'Adult child': Structural vulnerability, Care burden, and treatment disruption

Ana (16 years old), born HIV positive, was abandoned by her parents and raised by her paternal grandparents. During an informal conversation, Ana recalled having begun ART as a child, but like many children, she did not know what the medicines were for. She only remembered her grandmother asking her to swallow pills every day. Unable to comprehend the nature of her illness and why it persisted despite medication, she often wondered: 'Where do the pills go?' Her grandmother died when Ana was nine years old, marking the beginning of an even more complicated chapter of her life. Left in the care of her grandfather and two uncles (both of whom were addicted to alcohol and drugs), Ana's care and treatment supervision was severely lacking. Her aunt, who lived with them, suffered from epilepsy and was unable to provide treatment support for Ana. Because caregiving responsibilities in Sukuma society mainly fall on women, Ana was expected to step into her grandmother's role as the primary caregiver in the family, despite her young age. Overnight, Ana's life changed; she became an 'adult child', taking over all the household chores, including cooking, her own HIV treatment management, and schooling.

Ana began missing doses, and her health began to decline. Her situation was further exacerbated by the abuse she suffered at the hands of her uncles. She recalled, 'When they got drunk, they would beat me and sometimes follow me to school and bring me back home to do house chores.' Ultimately, she dropped out of school. Ana spent most of her time with adult women in her neighbourhood rather than socialising with girls of her own age, further isolating her.

From crisis to stability: Integrating clinical tasks and moral obligation to foster adherence

One day, after the death of her grandmother, Ana went to the clinic (where Rebeka was working) for her drug refill. What struck Rebeka as particularly concerning was that Ana came to the clinic alone, whereas most children are accompanied by their parents or guardians. Rebeka further noticed that Ana was covered in rashes and appeared weak during clinic visits. Rebeka decided to start paying regular visits to Ana's home to follow up.

During these visits, Rebeka observed the critical state of Ana's health and the severe lack of care, support, and supervision at home. She asked the Test & Treat Project for permission to step in. With her grandfather's permission, Ana was placed in Rebeka's care and moved into her home. For the next two years, Ana lived with Rebeka, and Rebeka closely supervised her ART use. During this time, the Test & Treat Project supported Ana with free health care and food. Ana's health improved significantly. Her condition stabilised, and her viral load became undetectable (the clinically stable condition for PLHIV). Rebeka stated that she viewed Anna as part of her family: 'It reached a point where Ana started to address me as mama.' Eventually, Ana was able to return to school and to her family. Rebeka's care for Ana transitioned to ART adherence surveillance through periodic home visits and pill counting, and Ana continued receiving food support from the Test & Treat Project.

The fragility of collaborative care and project-based support in sustaining treatment outcomes

Two years after returning home and after the Test & Treat Project ended, Rebeka lost her job, and Ana had to rely solely on facility-based standard care. Food support also ended. As a result, Ana could not adhere to ART as she used to during the project. Once again, Ana was listed among those with alarmingly high viral loads. According to the national guidelines, high VL was greater than 200 copies/mL. Ana's viral load reached 3,758 copies/mL.

When she was 14 years old, Ana faced another tragedy: her grandfather fell gravely ill, suffering from full-body paralysis for several months before passing away. This complicated Ana's already overwhelming situation, and she increasingly struggled to balance all her responsibilities: at home and school, her medication routine, and her grandfather's illness and eventual death. She said, 'When I was staying with Rebeka, I used to get proper meals, and she took care of me. … Here at home, we barely get food; most of the time, we only drink porridge.' Ana occasionally received food or financial support from the church community and from generous people in the community.

While most of the CHWs working under the Test & Treat Project were laid off after the project ended, a few remained at the health facility as volunteers because they had been doing that before the Test & Treat Project employed them. One of them, Mattias, was hired for another small donor-funded project designed to monitor adolescents with high viral loads and identify any conditions that led to their non-adherence. The new project was implemented in the same facility as the Test & Treat Project.

Mattias's involvement in Anna's care started before the Test & Treat Project but was limited to occasional home visits for adherence education. Although he understood her difficult home conditions and poor adherence, he could not help beyond home visits. Mattias learned about Ana again when she was listed by the new project amongst adolescents with a high viral load and was assigned to follow up to learn about her challenges. Mattias knew very well about Anna's history and how Rebeka was involved in her care. To help, Mattias connected Anna with a small NGO supporting vulnerable children to undertake technical school. Anna dreamt of becoming a tailor, which Mattias helped with by finding support for her school. Within the new project, CHWs crafted solutions with adolescents and their carers to ensure they stayed on and adhered to treatment. With this support, Ana's viral load was again reduced, this time from 3,758 copies/mL to just 58 copies/mL, in only three months. According to Mattias, one of the major barriers to adherence among adolescents was a lack of supervision, particularly for those who had no one to care for them at home and for those in boarding schools, where maintaining a strict medication regimen can be challenging.

In Ana's case, these factors intersected with limited treatment literacy, a fragile family care system with older and chronically ill relatives, and sudden events, such as the death of her grandfather, as well as the ending of the Test & Treat Project. Collaborative care between CHWs, family members, the project, the

church, and neighbours ensured Anna's health stabilisation and adherence. Her case, however, also shows the vulnerability of this collaborative care, which is contingent on moral obligation and short-term in nature.

The case of baraka self-management burden: Adolescent responsibility and lack of supervision

The researcher first met Baraka when he was hospitalised in one of the Test &Treat Project's health facilities. At the time, Baraka was 16 and gravely ill, lying in a hospital bed, visibly pale and emaciated, weighing only 22 kg, and very restless. The healthcare providers at the clinic were concerned about Baraka's frequent hospitalisations and the persistent severity of his condition. At the age of 19 years, when he was interviewed for this follow-up study, Baraka shared his story. He was born HIV positive and was initially raised by his mother following the death of his father when he was little. His mother later remarried in a polygamous marriage, and the stepdad took part in raising Baraka. Throughout his childhood, Baraka took medication daily. When he inquired about the purpose of the medicine, his mother told him it was for treating a cough. He learned about his HIV status when he was 14. At that time, his mother and stepfather separated, and Baraka relocated to Shinyanga town with his mother and two younger stepsisters, where they lived in a single rented room in a suburban area. His mother started working as a barmaid, which provided for their basic needs, particularly food. As the eldest of the children and because his mother was often working, Baraka cared for his siblings and had to manage his ART treatment by himself.

Lacking supervision at home, Baraka fell ill frequently. Although his mother made sure Baraka got his ART refills as needed, it was up to him to take his medication daily. Baraka hated taking his drugs, and he started hiding his pills in his school bag, fooling his mother. 'My mother used to leave at night and return in the morning. She would only be there for me when I got seriously ill and hospitalised', explained Baraka. The situation became more challenging when his mother became pregnant. She could not continue working as a barmaid, exacerbating their financial difficulties. As a result, the family struggled to afford necessities such as food and rent, relying heavily on the generosity of neighbours. During this period, Baraka's health worsened significantly, prompting his mother to hide him inside the house, fearing people would find out about his illness, which would affect her job opportunities. Baraka consequently dropped out of school.

Challenging norms of responsibility in HIV care networks: Collaborative care and expert knowledge

Baraka recalled a period of severe illness coinciding with his mother's advanced pregnancy. As his mother took him to the hospital for treatment, a neighbour named Aisha, who worked as a street food vendor, noticed the condition the family was in and felt compassion for them. Recognising the urgency of their circumstances, Aisha offered to care for Baraka, allowing his mother to focus on giving birth. His mother accepted Aisha's offer, and Baraka moved in with Aisha's family. Under Aisha's care, Baraka was well cared for and supported. He resumed school and began his secondary education.

Aisha's actions stemmed from her connection with an organisation dedicated to supporting children in challenging circumstances like Baraka. She reached out to the organisation, which agreed to support Baraka with essential resources, including food and school supplies. During his time with Aisha, Baraka felt integrated into her family and well cared for. However, despite the care and support, Baraka's health continued to deteriorate. Because Aisha was unfamiliar with ART, Baraka remained responsible for managing his medication, and continued taking his treatment irregularly. He explained, 'My health was getting even worse when I was living with her. Although she used to make a follow-up of everything, she had no idea how ART was supposed to be used. Therefore, I was just swallowing the pills anyhow, without following the rules of the regimen.

When Baraka was hospitalised, the project lead of the Test & Treat Project saw the situation Baraka was in and decided to enrol Baraka in enhanced monitoring and support and assign Rebeka, who resided near Baraka and his mother, to provide close follow-up and support. Baraka recalled, 'When I came to the hospital, I was very ill. That was when they said I needed someone to care for me closely. This was why Rebeka had to take me to live with her.'

The decision to offer Baraka accommodation was met with resistance and criticism. Although Baraka's mother was happy for Rebeka to take Baraka to live with her to help care for him, his grandmother felt it was a mother's responsibility to care for her child rather than a stranger's. Rebeka also met with resistance from health workers in the clinic. One nurse even questioned Rebeka's decision in front of Baraka when she said: 'How can you take an ill person like that to live with you? What if he dies on you?' Rebeka was upset by these statements but undeterred. She was convinced that Baraka had a chance to live, provided he received proper care and supervision for his treatment.

Eventually the responsibility for Baraka's well-being was transferred to Rebeka and the Test & Treat Project took over from the NGO Aisha had arranged. While Aisha and the NGO had provided essential social and moral support, they could not oversee Baraka's ART regimen. Rebeka, as expert patient living with HIV herself and a CHW, assumed full responsibility for Baraka's care, including cooking, laundry, and medication supervision, both in terms of consistency and correctness, as well as supporting him in school. Baraka's mother remained involved in his care: she supported Rebeka by contributing food and other assistance as needed. The Test & Treat Project provided Baraka with free medical treatment and monthly food supplies.

By the time Rebeka took Baraka into her home, he had already dropped out of school due to his deteriorating health and the bullying and stigma he faced from his fellow students. Rebeka recalled: 'Some students called him 'skeleton' or '*marehemu mtarajiwa*' [the expected deceased].' While living with Rebeka, Baraka's health improved significantly; he steadily gained weight, and after a few months he weighed over 40 kg.

The transformation in Baraka's health was remarkable. Everyone, including the nurse who had mocked Rebeka's decision to take him in, was astonished. Baraka went back to school to resume his studies. Rebeka confronted the teachers, demanding to know the students who bullied him when he was sick. The teachers informed her that those students had been disciplined for their behaviour. After a year, Baraka's health had completely recovered, and his viral load was undetectable, and he returned to live with his mother. Just like with Ana, his return home was not without challenges. His mother had become addicted to alcohol and could not care for or provide for her children.

The precarity of donor-dependent support systems

As with Ana, Baraka's health deteriorated again, to the extent that Rebeka and the Test & Treat Project had to intervene. For a second time, Baraka returned to live with Rebeka. When the project ended, Baraka was a vibrant 19-year-old man, capable of caring for himself and managing his treatment independently.

Just like Ana's, Baraka's story shows the importance of collaborative efforts of several actors. Each contributed in various ways to Baraka's care and recovery. However, all collaborators were externally funded, and care was contingent on the availability of funding. Baraka's story, like Ana's, also shows that life events, such as pregnancy and family members' problems like addiction and illness, create crises of vulnerability that may have an immediate effect on treatment adherence and stable health. Baraka's case furthermore shows the importance of disease-specific knowledge, such as that held by expert patients like Rebeka. CHWs not only have specialised knowledge but also feel a moral obligation to care for those in need. Although Rebeka's caregiving as a CHW went far beyond her job description, she was able to do so as part of her job, although the way in which she did that was relatively flexible.

The case of naomi when family care fails: severe illness, stigma, and the limits of kinship care obligations

Naomi, a 55-year-old woman, was diagnosed with HIV in early 2020 through provider-initiated testing after a series of frequent hospitalisations. Overwhelmed by the diagnosis, Naomi found herself outside the hospital, unable to hold back her tears. A Catholic nun, the doctor-in-charge of the health facility where Naomi regularly received care, noticed her distress. As she had come to know Naomi well over the years, she approached her with concern. Sensing the gravity of the moment, she gently inquired what was troubling Naomi. Naomi shared the news of her diagnosis. The doctor urged Naomi to stop crying while saying words of encouragement to her. Naomi recalled these words, 'Is that what you are crying about? Stop crying, start medication, and you will be fine'. The doctor's message resonated deeply with Naomi,

giving her the strength she needed, and renewed her mind. Naomi went back inside the hospital and initiated ART right away.

Despite this moral support and encouragement, Naomi's condition deteriorated rapidly, leading to further frequent hospitalisations. Her illness progressed to a severe stage; she could no longer control her bodily functions and became increasingly dependent on others for care. Naomi's relatives, who had been her primary caregivers, were overwhelmed by the level of care she required and abandoned her at the clinic. At this critical juncture, the Test & Treat Project, which was being implemented at the clinic where Naomi received care, stepped in. Recognising her dire situation, the project enroled Naomi, providing her with continuous follow-up and assistance. Clinic nurses were tasked with caring for her during her hospitalisation, and Naomi received free care and treatment, including the cost of meals.

'I will be her child': Moral obligation beyond professional care

Unfortunately, Naomi's deteriorating condition was not only a burden to her family but also to other patients and nurses. Her illness caused a strong, unpleasant odour, which led to discomfort among other patients at the hospital. Many avoided being near her; even some nurses found it unpleasant caring for her. Witnessing the extent of Naomi's abandonment and the stigma she endured, the Test & Treat Project assigned Rebeka to provide Naomi with the personal care and attention she needed.

Rebeka started to care for Naomi at the clinic, but she felt a growing desire to help her beyond the responsibilities assigned to her by the Test & Treat Project. This desire solidified after Rebeka visited Naomi's home. Naomi had gone through a difficult divorcee from a polygamous marriage, which ended due to her inability to have children, and then had been taken in by a church friend. Her church friend's family had welcomed and treated her as a relative and a sister in the family for 20 years, but this bond vanished when Naomi became ill. During her visit, Rebeka asked for clean clothes for Naomi's stay at the hospital. She was handed dirty, soiled sheets and stained garments with various bodily fluids. Naomi's relatives were dismissive and indifferent, telling Rebeka that no one had time to wash her clothes as they were all busy with other things. Rebeka took the soiled clothes and sheets without hesitation and vowed, 'I will be her child'.

For Rebeka, caring for Naomi felt like caring for her own mother, a duty she embraced with her whole heart. As a person living with HIV herself, Rebeka was not scared of the intense physical care Naomi needed. Rebeka was assisted by members of the Catholic Church, where Naomi had been a dedicated member. Naomi's illness sparked a deep sense of compassion among the church leaders and congregants. The church initiated a clothing donation campaign to ensure Naomi had fresh, clean clothes during her hospital stay. Her neighbours from the community even donated blood for Naomi when they heard she needed blood, demonstrating the power of community solidarity in times of crisis.

Rebeka's choices highlight the intrinsic motivation and empathy necessary to care for some patients. She expressed a profound sense of purpose and freedom in supporting clients who shared a similar HIV status to hers. The care she provided, however, would not have been possible without the support from the Test & Treat Project and the Catholic Church community in Shinyanga, which was a key member of the Test & Treat Project consortium. Church leaders maintained close communication with Rebeka, regularly checking in on Naomi's condition and providing moral and material support. Their involvement underscored the church's commitment not only to Naomi's physical well-being but also to her emotional and spiritual healing.

Like Ana's and Baraka's stories, Naomi's story shows how sometimes families fail to care for family members, making non-kin care and support necessary. In all three cases, this care was a collaboration of neighbours, church communities, NGOs, and CHWs as representatives of the health system, made possible by their job descriptions as extension workers.

Rebeka's commitment to her work as a CHW was grounded in moral obligation rather than a job description. Her actions were met with opposition, both professionally and personally. Her colleagues were unhappy with Rebeka for not keeping to her job description. Some of them were discontented with the attention and support she received from the project and the church for her efforts. Rebeka acknowledged this: 'They got mad at me because I don't stay sitting at the desk in the office… because… I cannot see someone lying on the floor who clearly needs help. Just because it's not my job, I should not move from my desk to help?! ... No, I will move and help at any time when help is needed.

In this sense, Rebeka is an outlier: she crossed the boundaries of her assigned care work and addressed the vulnerabilities that can lead to non-adherence. Despite the crucial work Rebeka did in facilitating adherence, her contract ended when the Test & Treat Project finished in 2021. She went to work as a food vendor on her street, and occasionally she kept in contact with her clients.

Discussion

In light of increasing efforts to mainstream CHWs in health facilities (Hodgins et al., 2021; Mgawe & Maluka, 2021; Perry et al., 2014) the three cases presented here reveal CHWs' pivotal role in mobilising collaborative care networks for highly vulnerable PLHIV, who would otherwise not be able to sustain treatment adherence independently. Overall, we found that collaborative care for highly vulnerable PLHIV was mobilised around health crises resulting from a 'crisis of vulnerability'. In all three cases, non-adherence led to a health crisis that was characterised by frequent hospitalisations and ill health, which alarmed a CHW. These health crises, often requiring intense physical care, revealed the invisible gaps and cracks in existing community care networks of neighbours and family, and showed the limits of a self-management paradigm present in the current treat-all approach (Mkhwanazi & Manderson, 2020; Moyer & Igonya, 2014; Raap et al., 2021; Wicaksono et al., 2024).

In these three cases, disengagement from care/non-adherence was a result of complex intersecting vulnerabilities, often related to age and gender, dysfunctional families, limited familial support, and adverse life events. These findings are not new in the critical global health literature. As Kenworthy et al. (2018) argue in the article *Critical perspectives on the 'end of AIDS'*, simplistic global health interventions and targets may veil the challenges to adherence that some patients face. Age-specific factors play a role. For young people, these include treatment literacy, stigma from peers in school, and lack of supervision (Onyango et al., 2021; Settergren et al., 2021). Older people's adherence (usually good) is often affected by severe illness and family care, transportation needs, and food security (Mwangala et al., 2023; Siedner, 2019; Sijtsma, 2020; Taylor et al., 2018; Yang et al., 2024).

Our cases show that, for those managing adherence in vulnerable circumstances and without stable familial care networks, it was often an adverse life event that shifted a precarious balance to non-adherence even after acquiring a clinically stable status. These complexities and the care they require do not meet the programmatic possibilities of care and treatment programmes. In target-driven health interventions, such as the Test & Treat Project, the subtle dimensions of vulnerability to non-adherence often become invisible. CHWs employed by the project were tasked with adherence surveillance, but they were also involved in community-based testing and follow-up with those who refused to start treatment, and in educating newly diagnosed PLHIV. These roles kept them bound to clinical tasks while minimising their socially oriented tasks, which are of critical importance for biomedical treatment success (Campbell & Scott, 2011). This meant that clinic-based work posed a demand on their community-based time. Adherence surveillance was often done on the weekends, in CHWs' free time.

Technological biomedical solutions, in this case antiretroviral medicine, have often been described as 'magic bullets' for HIV treatment, but this loses sight of the complex structural conditions that shape people's adherence (Biehl & Petryna, 2013; El-Sadr, 2021; Meinert, 2015; Yates-Doerr et al., 2023). Moreover, interventions enlisting CHWs in providing care are often funded by temporary non-governmental projects. As Meinert, (2015) shows, such projects build networks of relations, both positive and negative, that often reach beyond the time of the project. The temporal nature of CHW interventions presents a significant challenge to the sustainability of successes achieved during the project's implementation. Scholars in the field of science implementation have cautioned that CHW programmes can be costly and necessitate stable funding, accompanied by critical evaluation to ensure evidence of impact, thereby preventing the scaling up of underperforming CHW initiatives (Hodgins et al., 2021).

In the Test & Treat Project, CHWs' work revealed the complexity of care needs, but these were once again invisibilized when the project, salaries, and contracts ended, resulting in CHWs withdrawing from community-based work (see also Meinert, 2015). Although the Test & Treat Project was followed by other donor-funded projects that created new possibilities of care, some of these efforts were shut down or required still other configurations of care to assist those falling through the gaps.

Our findings show that expert care is often needed to re-engage and stabilise PLHIV in care. This expert care consisted of what Mol calls 'good care', meaning collaborative efforts marked by the attunement of knowledge (expert knowledge) to the body of the patient, as well as attunement to the complexity of each person's life (Pichelstorfer, 2012). Although Mol's arguments are based on research conducted in Dutch clinical settings, her description of good care also holds for Shinyanga, where good care is conceptualised as compassionate, inclusive, and attentive (Raap et al., 2021).

CHWs were uniquely positioned to facilitate early treatment initiation, identify potential non-adherence and provide care and support needed. Collaborative care networks, however, were temporary and generally focused on the health crisis of a person. The care networks available drew on personal networks of the PLHIV, such as church and family members, neighbours, and participants in HIV care and treatment programmes, and on the personal networks of the CHW (Simbaya, 2016; Twebaze & Whyte, 2014). Care efforts within these networks were often driven by moral obligations rooted in shared experience (being HIV positive); religious, biomedical, and personal values; and kinship and community norms. Our cases also show the importance of treatment literacy for caregivers; care, despite best intentions, can fail when it is not accompanied by treatment literacy and the plurality or multiple layers of support infrastructure (de Klerk, 2012; Raap et al., 2021).

Similarly to collaborative care, Raap et al., (2021) suggest that collective care, such as that provided by community networks, aims to repair cracks in local care infrastructures shaped by institutional contexts that promote care as a self-management and individual responsibility. Studying collaborative care and collective care shows the role of alternative values, such as the moral obligation of kin, biomedical HIV expertise, attentiveness, touch, inclusion, and hope (Mol et al., 2010; Raap et al., 2021). This collective and collaborative care paradigm, aimed at taking communal responsibility for each member's wellbeing, was epitomised by CHWs like Rebeka, who can go the extra mile beyond their work boundaries for treatment success (Kyakuwa, 2011; Raap et al., 2021). At the same time, the temporary nature of the collaborative care networks around highly vulnerable PLHIV, and the pushback Rebeka received as an outlier, highlight how the possibilities of care (and of mobilising it) are contingent on 'the transforming ethics, politics, pragmatics, and socialities' that make care relationships inherently 'unsettled' (Cook & Trundle, 2020).

Our findings on the nature of collaborative care and the intricate roles of CHWs as signalers and mobilisers show that current CHW models are dependent on context and funding. While the pivotal role of CHWs in ensuring care for vulnerable groups, particularly for older people and adolescents, is widely recognised (Hirschhorn et al., 2023); our findings also show that their efficacy is compromised when CHW funding ends. Stable outreach systems, not reliant on temporary funding, are necessary to provide CHWs with recognition, job security and satisfaction, and to create space for the hard, invisible work of flexible and 'unmeasurable' community-based roles of signalling and mobilising (Sijtsma, 2020; Taylor et al., 2018). Current moves in many African countries, including Tanzania, to integrate CHWs into mainstream health systems, will create more job security for CHWs and reduce the pressure of the shortage of staff on the health system (Kapologwe et al., 2023). Yet these developments might further invisibilize the complex vulnerabilities and care needs of some clients and the expertise needed to re-engage them in care.

Schneider and Lehmann (2016) advance the notion of a 'community health system' as a distinct sphere through which community systems and formal health systems can be integrated in a precise and context-specific manner (Schneider & Lehmann, 2016). Integrating CHWs into this framework offers both opportunities and challenges. On the one hand, integrating CHWs into the formal health system has the potential to shift programme ownership to the state, thereby aligning CHW activities more closely with national health priorities and fostering sustained, life-supporting webs of care rather than fragmented engagements driven by multiple organisations with short-term targets (Hodgins et al., 2021; Raap et al., 2021). On the other hand, such integration requires governments to finance CHW programmes through domestic resources, which can be particularly challenging in LMIC already overburdened by multiple disease priorities. In these contexts, sustaining CHW programmes solely through government funding may be unrealistic and continue to necessitate external support (Kapologwe et al., 2023).

Another potential pitfall of CHW integration is that, while formalisation can enhance recognition, it may also transform CHWs into quasi-professional health workers by shifting their roles toward clinically oriented tasks while diminishing the social support and community-based care that constitute the most critical aspects of their work (Campbell & Scott, 2011; Mgawe & Maluka, 2021). Mgawe and Maluka (2021) and

Hodgins et al., (2021) caution against the creation of an additional cadre of semi-professionals who are neither fully recognised as clinical staff nor fully accepted within communities due to weakened local embeddedness. Consequently, without careful and critical evaluation, CHW programmes risk becoming costly while underperforming in their intended roles (Hodgins et al., 2021).

Conclusion

Against a wider effort to mainstream CHWs into the formal health system in Tanzania, this study examined the role of CHWs in signalling the vulnerability of PLHIV who are unable to self-manage their treatment and in supporting their enrolment in HIV-treatment programmes. Using a case of CHW's exceptional care, which she mobilised and provided for three vulnerable clients, we explored what collaborative care for highly vulnerable PLHIV entails and how it is grounded in differing values around 'good' care. All clients we presented in this article were PLHIV who were identified in the clinic as potentially non-adherent based on physical symptoms and who were retained in care through intensive supervision and the organisation of collaborative care. These extreme cases make visible the cracks in existing care and support systems, especially for older people and adolescents.

We used the term 'collaborative care' to describe networks of stakeholders mobilised to support individuals living with HIV. These networks, comprising NGOs, neighbours, churches, HIV programmes, and community members, were typically temporary and loosely coordinated. Within this context, CHWs serve as key liaisons, mobilising and coordinating care networks to ensure successful treatment outcomes. Their pivotal role in delivering comprehensive, patient-centred care is essential for achieving health goals. As paraprofessionals, CHWs possess the flexibility to go beyond formal duties, often drawing on moral economies to assist those in need. While formalising or institutionalising CHWs is necessary, it must be approached cautiously to avoid creating quasi-professionals who are neither fully recognised as clinical staff nor fully embedded and accepted within their communities as trusted health focal persons.

Our article also raises an ethical-moral question. The declining health of the three clients Rebeka tended to shows that even though CHW-based programmes are in place, there are always people who will need more care to survive. The treat-all policy's emphasis on care decentralisation for clinically stable clients assumes that clients can independently manage their health. However, our findings reveal that achieving and maintaining clinical stability is not a linear, one-time accomplishment but an ongoing process requiring sustained collaborative support. For vulnerable clients, stability is precarious and repeatedly threatened by social, economic, and structural factors that individual responsibility alone cannot address. While CHWs are uniquely positioned to respond to these complexities, stable systems of care for highly vulnerable PLHIV are needed for 'magic-bullet' approaches to be successful.

Recommendation

Institutionalising community health workers is essential, but their roles must remain flexible and prioritise quality over quantity. Performance evaluation should centre on the relational and responsive care work that typically goes unmeasured, identifying individual needs, building trust, adapting support to changing circumstances, rather than the quantifiable metrics that dominate current accountability frameworks. This shift would preserve CHWs' embeddedness in their communities, where shared histories and sustained relationships enable them to provide the contextually attuned care that vulnerable populations require. By valuing the 'invisible' care work that produces biomedical outcomes, institutionalisation could strengthen rather than bureaucratise the collaborative care infrastructure that makes HIV treatment sustainable.

Strengths and limitations of the study

Conducting this research after the project's conclusion offered a valuable opportunity to explore the long-term effects and sustainability of care to vulnerable PLHIV. However, one notable challenge was locating PLHIV and health workers who participated in the project. Most health workers had been hired on fixed-term contracts, which ended when the project concluded in 2021. Also, locating the clients who participated in the project depended on getting in touch first with health workers who cared for them during the

project implementation. Despite this, the researcher's prior engagement during the implementation phase allowed her to maintain contact with many of the project staff. This facilitated access to those who either continued working at the same health facilities or remained in the Shinyanga region where the project had been implemented, but are no longer working at the same facilities. Additionally, Rebeka's is typical and an outlier; although it is conceptually valuable and crucial in learning collaborative care for vulnerable clients, the quantitative generalisability of the findings is limited.

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Data availability statement

Due to the sensitive nature of this research, supporting data is not publicly available.

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