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# “It is still very little; I cannot pass it on”: a qualitative study of experiences of diagnosis and treatment of acute HIV infection in Eswatini

Esther Mukooza [a], Bernadette Schausberger[a], Nqobile Mmema[a], Velibanti Dlamini[a], Aung Aung [a], Bernhard Kerschberger[a], Iza Ciglenecki[b], Lenhle Dube[c] and Alison Wringe[d]

[a]Médecins sans Frontières (OCG), Mbabane, Eswatini; [b]Médecins sans Frontières (OCG), Geneva, Switzerland; [c]Eswatini National Aids Programme (ENAP), Mbabane, Eswatini; [d]London School of Hygiene and Tropical Medicine (LSHTM), London, UK

**ABSTRACT**
Acute and early HIV infection (AEHI) is rarely diagnosed in sub-Saharan Africa, despite its potential contribution to incidence reduction. This qualitative study in Eswatini explored the experiences of health workers, people diagnosed with AEHI, and their partners towards AEHI diagnosis, to inform its scale-up. In-depth interviews were undertaken with 11 women and four men diagnosed with AEHI. Three patients’ partners were interviewed about their understanding of AEHI and six health workers were interviewed about experiences of delivering AEHI services. Data were coded inductively and analysed iteratively following the principles of grounded theory. Experiences with AEHI diagnoses were shaped by (i) understanding the nature and consequences of AEHI, and (ii) social norms that influence disclosure and sexual behaviour. AEHI was a new concept for health workers who struggled to explain it to patients, leading to some confusion over their HIV status and misunderstandings around its high transmissibility and prognosis. Disclosure tended to occur to primary partners, if at all, limiting the ability to provide partner services, and one relationship breakdown was reported. If AEHI diagnosis and care interventions are to realise their full potential, it will be essential to reinforce the accompanying counselling sessions and closely monitor for potential social harms.

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## Background

In 2019, following nearly two decades of progress in rolling out antiretroviral therapy (ART), Eswatini was the first country in sub-Saharan Africa to achieve the UNAIDS 90-90-90 targets (Akullian et al., 2020; UNAIDS, 2021). However, despite substantial declines in HIV-related mortality and incidence, epidemic control has not been achieved, and infection rates remain high among key populations and adolescent girls and young women (UNAIDS, 2021). The challenge in curbing new infections despite high ART coverage has led to a renewed focus on expanding various biomedical and behavioural HIV prevention measures (Akullian et al., 2020).

It has been estimated that up to 20% of HIV transmissions occur during the acute and early HIV infection (AEHI) phase, defined as the time-period between the acquisition of HIV until early sero-conversion, characterised by the detection of HIV antibodies (Rutstein et al., 2017). AEHI diagnosis occurs at least 11–21 days after exposure to HIV, when patients may present with a myriad of symptoms including high fever, cold-like symptoms, skin rash and concurrent sexually transmitted infections (Kerschberger et al., 2021). Although the diagnosis of AEHI is routinely performed in many developed countries, it is rarely undertaken in sub-Saharan Africa, because it cannot be detected with routinely available point-of-care rapid diagnostic tests (RDTs) and instead relies on HIV viral load tests or fourth-generation laboratory assays that detect both antigens and antibodies (Cowan et al., 2021).

AEHI is characterised by a high viral load which renders the infected person highly infectious. As such, AEHI screening and diagnosis has the potential to identify additional cases of HIV beyond those found through standard HIV testing algorithms, and to reduce HIV transmission, if followed by timely antiretroviral therapy (ART) initiation to suppress the virus and the adoption of additional prevention measures until viral suppression is achieved (Kerschberger et al., 2021).

Despite promising evidence regarding the potential contribution of diagnosing and treating AEHI to

**CONTACT** Esther Mukooza esthermukooza@gmail.com

**Table 1.** Table of participant characteristics.

| Sample category | Male | Female | Total |
|---|---|---|---|
| Patients | 4 | 11 | 15 |
| Partners | 2 | 1 | 3 |
| HCWs | 2 | 4 | 6 |
| Total | 8 | 16 | 24 |

reducing incidence, the World Health Organisation has not released guidance on its use, partly due to insufficient evidence in several areas, including experiences of patients and health workers in receiving an AEHI diagnosis (Owusu, 2022; WHO, 2015). The effectiveness of AEHI interventions is likely to be influenced by patients' understanding of their diagnosis and the meaning that they attribute to it in the context of their daily realities, as well as the array of social norms that influence disclosure and the adoption of safer sexual practices (Remien et al., 2009; Siegler et al., 2015; Van Der Elst et al., 2019; Wandell et al., 2017), which in turn may be influenced by health worker practices. Furthermore, concerns have been raised regarding the risk of social or even physical harm following an AEHI diagnosis, given that individuals are likely able to attribute the source of their infection to a particular individual. There are also legal considerations given that in some countries, transmitting HIV to a partner without informing them of their known HIV status is criminalised. The potential risks of AEHI diagnoses, therefore, need to be carefully weighed up against the potential benefits of identifying additional and earlier infections that would be picked up through existing HIV testing algorithms in sub-Saharan African countries.

In 2019, Médecins sans Frontières (MSF) undertook a mixed methods study to assess the positivity rates of AEHI diagnoses, describe AEHI care outcomes in a public sector setting and assess the feasibility and acceptability of AEHI diagnosis and treatment in Shiselweni, Eswatini (Kerschberger et al., 2021). This paper concerns the qualitative component of the study which aimed to explore the experiences and attitudes towards diagnosis and treatment of AEHI among patients who were diagnosed with AEHI, their partners and health workers.

## Methods

### Study setting

The Shiselweni region of Eswatini with a population of 210,000 has an HIV prevalence among adults (aged 15–24 years) of 31% (Eswatini. Health Research Unit, 2019). MSF has been supporting the Ministry of Health to deliver HIV services in the region since 2007, including through the public sector health centre in Nhlangano, which provides HIV counselling and testing, HIV care and treatment services, and prevention services like condom distribution and pre- and post-exposure prophylaxis.

### Sampling and recruitment

The recruitment of participants for AEHI testing and inclusion in the broader study has been described in detail elsewhere (Kerschberger et al., 2021). In brief, patients presenting at the out-patient department of a secondary health care facility were screened for AEHI symptoms and invited to test. Diagnostic viral load testing was used for the detection of AEHI in the absence of reactivity to routine RDTs.

Between April 2019 and November 2020, health workers involved in the AEHI study, patients diagnosed with AEHI, and their partners between 18 and 49 years of age were eligible for enrolment in the qualitative study.

### Patients with AEHI

Out of 30 individuals who were diagnosed with AEHI (25 women and 5 men), 15 patients were purposively sampled for the qualitative study, ensuring an age and sex distribution similar to the parent study (Table 1). As is widely recommended for qualitative research, the sample size was based on pragmatic considerations, including the anticipation of reaching "thematic saturation" (Green & Thorogood, 2004) given the relatively narrow scope of the study objective, alongside the use of repeat interviews to enable evolving perspectives on AEHI to be documented (Akullian et al., 2020; Vincent, 2013). Health workers in the AEHI study invited sampled participants to attend an interview and provided information about the study, with those expressing an interest contacted by a qualitative researcher to arrange an interview. There were no refusals among the sampled participants.

### Partners of AEHI patients

All 30 AEHI patients were given a partner referral slip inviting them to present at the health facility to test for HIV and other sexually transmitted infections. Thirteen partners attended the health facility, including three partners (out of 27 reported partners) of the 15 participants in the qualitative study. All three agreed to an interview.

### Health workers

All six (two male and four female) health workers (nurses, medical doctors and counsellors) who were involved in the AEHI study agreed to be interviewed.

### *Data collection*

In-depth interviews (IDI) were conducted with patients, their partners and health workers.

Patients were interviewed twice (at least one month after diagnosis and at least two months after the first interview) to explore their knowledge and attitudes towards their diagnosis at different time points. Topic guides for the initial IDI included understanding of AEHI, experiences following their diagnosis, decision-making regarding ART initiation, disclosure and sexual practices. In the second interview, discussions centred on understanding whether any changes had occurred since the previous interview.

Interviews with patients' partners were undertaken once and covered their attitudes towards their partner's AEHI diagnosis as well to the HIV, STI and prevention services (including PrEP).

Interviews with health workers were conducted twice, approximately nine months apart. The first interview covered their knowledge and understanding of AEHI, while the second explored their attitudes and experiences regarding AEHI service delivery and any changes in knowledge and understanding of AEHI since the first interview.

Interviews were conducted by one male and one female fieldworker matched to the participants by sex, except for one interview conducted by the lead qualitative researcher because the participant was known to the research assistants. Interviews were conducted in quiet, private rooms at the health centre, or at the MSF office if the participant preferred. The interviews were conducted in Siswati with AEHI patients and partners, and in either Siswati or English with health workers according to the participant's preference. Interviews were audio-recorded with consent and lasted approximately 60 minutes. Participants received lunch and 60 Emalangeni (approx. 3.8 USD) to cover travel costs.

### *Data management and analysis*

Debriefing sessions were held after each interview with the research team.

Audio-recordings were uploaded to a secured computer server before being transcribed and translated into English. Data were analysed iteratively alongside ongoing data collection to enable gaps or emerging themes to be further explored in subsequent interviews. Data were coded inductively, with the aid of Nvivo11, and drawing on principles of grounded theory (Strauss & Corbin, 1998), whereby the meaning is derived from the generated data.

### *Ethics*

Ethical clearance for the study was granted by the Eswatini Health and Human Research Review Board (reference number NHRRB982/2018) and the MSF ethics review board.

## Results

Two key themes emerged from the analysis as influencing the experiences of AEHI diagnoses: (i) knowledge and understanding of AEHI and (ii) social norms that limit disclosure and influence sexual behaviour.

### *Knowledge and understanding of AEHI*

For most health workers, the concept of a differential diagnosis for AEHI was relatively new, while most patients were not familiar with the term. Several health workers explained that despite training, they counselled patients about HIV in general terms, emphasising ART initiation, rather than the characteristics and implications of acute and early HIV infection which was perceived to be confusing for patients.

> When we talk to them, we do not even mention acute HIV not to confuse the clients. (HCW)

Limited explanations may also have initially been due to a lack of understanding of AEHI by health workers at the start of implementation. When health workers did offer some explanations of AEHI to patients, this could lead to misunderstandings, whereby ironically some patients understood they were not yet infectious, thus limiting the risk of transmitting HIV to their partners:

> … They said I cannot pass it on to anyone, it [the virus] is very small. They said it is not active … my understanding is that they are saying you can stay with the virus for 6 years without it being active. (Female patient #3, first interview)

> I think the HIV that I have does not have the power to affect you, and I think the one diagnosed using RDT is a bit dangerous and can be easily transmitted because it is now all over the body… (Male patient #2, second interview)

Some patients believed that they might even recover, with some inferring that they had been told this by health workers:

> They told me I might be lucky, that it completely gets finished, because really, it was still small, you see. (Female patient #3, second interview)

Some patients who understood they were in the early stages of HIV infection questioned why they could not be prescribed post-exposure prophylaxis, rather than daily, lifelong ART:

> My problem was, if I have a virus that I got in the past 12 hours, they were supposed to have something like a morning after pill, you see? Something that would kill the thing. Say it has been 24 hours in your blood, to kill it, finished … Not telling me to take the pills just like the others. That is the thing that is not giving me peace of mind. (Female patient #3, first interview)

Reticence among newly diagnosed patients to commence ART was considered challenging for health workers, with some going to great lengths to encourage treatment initiation:

> We cannot be defeated by a client. We need to convince the client until they understand. Usually, you find that when they have difficulties accepting. I do call the nurse so that she assists to say whatever she can until the client accepts ART. It is not like we put pressure on the client for them to agree, but it is just to help the client. (HCW)

However, some patients did not trust their diagnosis, driven by the lack of familiarity with the AEHI testing procedures which were perceived to be still "under trial".

> "so you say this one is just a study and so it is not approved yet … okay what if I wait for two months … no I think I'm not ready" and so … you see that they just didn't trust the results from the start … (HCW)

This mistrust could lead patients to opt for a second opinion, with their doubt over their diagnosis further compounded when RDTs did not confirm their positive diagnosis.

> … they advised me to take the pills and I took them, but when I got home, I went to three different clinics, but they were not finding it … So how come you are the only ones that see it? (Female patient #3, first interview)

In contrast, some patients quickly accepted their status and appreciated the benefits of an early diagnosis:

> I am happy to test and start ART early, because what will happen to my children if I die? I don't have a sister and I don't have a mother. What will happen with them? (Female patient #1, first interview)

## *Social norms that limit disclosure and HIV prevention efforts*

Many patients did not disclose their HIV status for fear of their partner's reaction or because it seemed too complicated to explain:

> I do not know … eish this thing [AEHI] is new to me you see? I am not able to explain it. (Female patient #8, second interview)

Others who had not disclosed tried to avoid sexual relations with their partner:

> when it comes to sex, I am no longer active, so that is it. I think the poor man also questions himself, a week passes by when I refuse. When he tries, I complain about some sickness. I fear! I haven't told him about this … (Female patient4, first interview)

Although some partners were linked to testing services, others reportedly did not feel ready:

> I came back and told him, but he refused to go and test … . He told me that he will not go there by force, he will go there when he feels something in his body. (Female Patient #3, second interview)

> I didn't tell him anything … I gave him that paper and he was like "people are able to live with this thing as long as you eat healthy". (Female patient #1, first interview)

The possibility of identifying the source of HIV infection affected disclosure, with some patients reporting consequences for their relationships.

> I was very angry, and I don't want to lie, since then I have never spoken to him. (female patient1, second interview)

However, some AEHI patients' partners were accepting of their partner's status:

> I just told myself that I should accept the situation and not judge after what has happened. (Partner)

Although condom use was encouraged during counselling, it was inconsistently adopted by patients and their partners.

> Sometimes he uses a condom … Fortunately, he is circumcised; I met him when he was already circumcised. (Female patient #2, first interview)

Some partners did not want to use condoms because of the perceived protection they obtained through PrEP use.

> eh … I feel like she hasn't yet accepted her status … because each and every time we have to have sex she wants protection and this confuses me since I'm taking PrEP and she wants us to use condoms and then I'm like what is the purpose of me taking PrEP yet we are also using condoms? (Male Partner)

Some women also complained about condoms hurting them and their use sometimes led to fights:

> At times she says the condoms are hurting her … at the same time she wants condoms … it's confusing and we end up fighting because of protection … protection … (Male Partner)

For some participants, prevention efforts were also not considered very important because of the belief that contracting HIV in Eswatini was inevitable and a matter of fact.

> This [acquiring HIV] was meant for my life [fate] … and in this environment, it is impossible to avoid the virus. (Female patient #1, first interview)

## Discussion

Our study explored the experiences of patients, their partners and health workers with diagnoses of acute and early HIV infection in the context of a mixed methods study to investigate the outcomes of AEHI diagnoses and care in a rural Eswatini setting.

We found various factors that influenced experiences of AEHI diagnoses which may undermine its potential effectiveness as an intervention if not addressed. Firstly, while some people appreciated the opportunity to learn their AEHI status and initiate ART earlier than they would have otherwise done, others found the perceived contradiction between negative HIV results from RDT and positive results for AEHI obtained through diagnostic viral load testing caused worry, confusion and in some cases, fostered a sense of denial in the results, or mistrust in the provided services. This aligns with findings from a smaller South African study (Wolpaw et al., 2014). Other studies have shown that a negative experience of HIV testing can undermine subsequent engagement with ART (Horter et al., 2020; Kerschberger et al., 2020).

Since one of the anticipated benefits of AEHI diagnoses is prompt ART initiation to limit onwards transmission, scheduling ongoing counselling sessions with patients who initially struggle to accept their results will be essential, as concluded by other studies (Remien et al., 2009; Van Der Elst et al., 2019). However, good quality counselling requires confidence on the part of the health worker to explain the diagnosis, something which was initially lacking in our setting, despite training efforts (Kerschberger et al., 2021). Of greater concern was our finding that some patients had erroneously understood that their earlier diagnosis meant either reduced severity or duration of their HIV infection. Rigorous training of health workers involved in AEHI care and assessing their understanding of AEHI and ability to tailor messages is therefore critical if the intervention is to promote more effective HIV prevention effects.

Critical to the success of AEHI diagnosis and care is an effective provision of partner services. However, although most participants reported multiple partners, few disclosed their status, and only to their primary partners. Other studies from the region have shown that disclosure decisions are made by PLHIV after weighing up the risks of stigma and family break-up against the benefits of being able to live openly with their HIV status and accessing various forms of support (Ismail et al., 2021). This process of reflection often requires time, and it may therefore be necessary to continue to encourage people diagnosed with AEHI to disclose their status during follow-up visits.

The benefits of AEHI interventions must be weighed up against the risks of social harms associated with potentially being able to identify the person from whom HIV infection was acquired, including the risks associated with legal repercussions (amFAR, 2022). Our study suggested that the risk of social harms arising from an AEHI diagnosis was relatively low, largely due to few participants choosing to disclose their status to a partner, and a sense of fatalism about the inevitability of HIV transmission that may have reduced negative reactions. Nevertheless, while no reports of gender-based violence were received, there was at least one report of a relationship breakdown which was directly attributed to a participant deducing that their partner was the source of their newly acquired HIV infection.

There are several limitations to this study. Firstly, the research was conducted in the context of a well-resourced pilot study, and attitudes towards AEHI diagnoses may evolve in the future, or in less well-resourced settings. Secondly, the recruitment of patients' partners was challenging, limiting our ability to garner their perspectives on the extent to which AEHI messaging was understood and acted upon. Furthermore, partners who participated were likely those most open to accessing the HIV services being proposed.

In conclusion, our findings suggest that if AEHI diagnosis and care interventions are to realise their full potential, it will be essential to reinforce accompanying counselling sessions and partner notification services, which in turn will require ongoing training and supervision of health workers. Close monitoring and reporting of social harms resulting from partner notifications also need to be considered as a critical component of future AEHI programming.

## Disclosure statement

No potential conflict of interest was reported by the author(s).

## ORCID

*Esther Mukooza* http://orcid.org/0000-0002-8037-7873
*Aung Aung* http://orcid.org/0000-0003-1793-0119

## References

Akullian, A., Morrison, M., Garnett, G. P., Mnisi, Z., Lukhele, N., Bridenbecker, D., & Bershteyn, A. (2020). The effect of 90-90-90 on HIV-1 incidence and mortality in Eswatini: A mathematical modelling study. *The Lancet HIV*, *7*(5), e348–e358. https://doi.org/10.1016/S2352-3018(19)30436-9

amFAR. (2022). *Blinded by our own data – recency testing in PEPFAR*. https://www.amfar.org/wp-content/uploads/2022/05/amfar_recency_report_20220531.pdf

Cowan, E. A., McGowan, J. P., Fine, S. M., Vail, R. M., Merrick, S. T., Radix, A. E., Hoffmann, C. J., & Gonzalez, C. J. (2021). *Diagnosis and management of acute HIV*. Johns Hopkins University. http://www.ncbi.nlm.nih.gov/books/NBK563020/

Eswatini. Health Research Unit. (2019). Swaziland HIV Incidence Measurement Survey 2: SHIMS2 2016-2017.

Green, J., & Thorogood, N. (2004). *Qualitative methods for health research* (2nd ed., pp. 198–202). Sage Publications.

Horter, S., Seeley, J., Bernays, S., Kerschberger, B., Lukhele, N., & Wringe, A. (2020). Dissonance of choice: Biomedical and lived perspectives on HIV treatment-taking. *Medical Anthropology*, *39*(8), 675–688. https://doi.org/10.1080/01459740.2020.1720981

Ismail, N., Matillya, N., Ratansi, R., & Mbekenga, C. (2021). Barriers to timely disclosure of HIV serostatus: A qualitative study at care and treatment centers in Dar es Salaam, Tanzania. *PLOS One*, *16*(8), e0256537. https://doi.org/10.1371/journal.pone.0256537

Kerschberger, B., Aung, A., Mpala, Q., Ntshalintshali, N., Mamba, C., Schomaker, M., Tombo, M. L., Maphalala, G., Sibandze, D., Dube, L., Kashangura, R., Mthethwa-Hleza, S., Telnov, A., de la Tour, R., Gonzalez, A., Calmy, A., & Ciglenecki, I. (2021). Predicting, diagnosing and treating acute and early HIV infection in a public sector facility in Eswatini. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, *88*(5), 506–517. https://doi.org/10.1097/QAI.0000000000002794

Kerschberger, B., Schomaker, M., Jobanputra, K., Kabore, S. M., Teck, R., Mabhena, E., Mthethwa-Hleza, S., Rusch, B., Ciglenecki, I., & Boulle, A. (2020). HIV programmatic outcomes following implementation of the 'treat-all' policy in a public sector setting in Eswatini: A prospective cohort study. *Journal of the International AIDS Society*, *23*(3), e25458. https://doi.org/10.1002/jia2.25458

Owusu, A. Y. (2022). Experiences of new diagnoses among HIV-positive persons: Implications for public health. *BMC Public Health*, *22*(1), 538. https://doi.org/10.1186/s12889-022-12809-6

Remien, R. H., Higgins, J. A., Correale, J., Bauermeister, J., Dubrow, R., Bradley, M., Steward, W. T., Seal, D. W., Sikkema, K. J., Kerndt, P. R., Mayer, K. H., Truong, H.-H. M., Casey, C. Y., Ehrhardt, A. A., & Morin, S. F. (2009). Lack of understanding of acute HIV infection among newly-infected persons – implications for prevention and public health: The NIMH multisite acute HIV infection study: II. *AIDS and Behavior*, *13*(6), 1046–1053. https://doi.org/10.1007/s10461-009-9581-7

Rutstein, S. E., Ananworanich, J., Fidler, S., Johnson, C., Sanders, E. J., Sued, O., Saez-Cirion, A., Pilcher, C. D., Fraser, C., Cohen, M. S., Vitoria, M., Doherty, M., & Tucker, J. D. (2017). Clinical and public health implications of acute and early HIV detection and treatment: A scoping review. *Journal of the International AIDS Society*, *20*(1), 21579. https://doi.org/10.7448/IAS.20.1.21579

Siegler, A. J., Sanchez, T., Sineath, R. C., Grey, J., Kahle, E., & Sullivan, P. S. (2015). Knowledge and awareness of acute human immunodeficiency virus infection among mobile app-using men who have sex with men: A missed public health opportunity. *Open Forum Infectious Diseases*, *2*(1), ofv016. https://doi.org/10.1093/ofid/ofv016

Strauss, A., & Corbin, J. (1998). *Basics of qualitative research* (2nd ed). Sage publications.

UNAIDS. (2021). *HIV estimates with uncertainty bounds 1990-Present*. AIDSinfo/UNAIDS. https://www.unaids.org/en/resources/documents/2021/HIV_estimates_with_uncertainty_bounds_1990-present

Van Der Elst, E., Kombo, B., Mugo, P., Thiong'o, A., Kanungi, J., Wahome, E., Chirro, O., Graham, S., Operario, D., & Sanders, E. (2019). Adjustment to acute or early HIV-1 infection diagnosis to prompt linkage to care and ART initiation: Qualitative insights from coastal Kenya. *Psychology, Health & Medicine*, *24*(5), 631–641. https://doi.org/10.1080/13548506.2018.1549736

Vincent, K. A. (2013). The advantages of repeat interviews in a study with pregnant schoolgirls and schoolgirl mothers: Piecing together the jigsaw. *International Journal of Research & Method in Education*, *36*(4), 341–354. https://doi.org/10.1080/1743727X.2012.705276

Wandell, G.M., Molina, Y., Sánchez, H., Greer, A.C., Ríos, J., Bain, C., Segura, P., Lama, J. R., Sánchez, J., & Duerr, A. (2017). *Knowledge and preferences concerning acute HIV testing programs among both Peruvian men who have sex with men and transgender women -*. https://journals.sagepub.com/doi/abs/10.11770956462416685674

WHO. (2015). *Guideline on when to start Antiretroviral therapy and on pre-exposure prophylaxis for HIV*.

Wolpaw, B. J., Mathews, C., Mtshizana, Y., Chopra, M., Hardie, D., Lurie, M. N., De Azevedo, V., & Jennings, K. (2014). Patient experiences following acute HIV infection diagnosis and counseling in South Africa. *PLOS One*, *9*(8), e105459. https://doi.org/10.1371/journal.pone.0105459