

Eliud Wekesa and Ernestina Coast
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Living with HIV postdiagnosis: a qualitative study of the experiences of Nairobi slum residents

Eliud Wekesa,¹ Ernestina Coast²

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ABSTRACT

Objectives: To characterise the experiences of heterosexual men and women living with HIV postdiagnosis and explain these experiences in relation to their identity and sexuality.

Design: Qualitative study using in-depth interviews and a theoretically informed biographic disruption theory.

Setting: Interviews were conducted in two Nairobi slums (Kenya).

Participants: 41 HIV-infected heterosexual men and women aged 18 years or older.

Results: People living with HIV have divergent experiences surrounding HIV diagnosis. Postdiagnosis, there are multiple phases of identity transition, including status (non-)disclosure, and attempts at identity repair and normalcy. For some people, this process involves a transition to a new self-identity, incorporating both HIV and antiretroviral treatment (ART) into their lives. For others, it involves a partial transition, with some aspects of their prediagnosis identity persisting, and for others it involves a rejection of HIV identity. Those people who were able to incorporate HIV/AIDS in their identity, without it being disruptive to their biography, were pursuing safer sexual and reproductive lives. By contrast, those people with a more continuous biography continued to reflect their prediagnosis identity and sexual behaviour.

Conclusions: People living with HIV/AIDS (PLWHA) had to rework their sense of identity following diagnosis in the context of living in a slum setting. Men and women living with HIV in slums are poorly supported by health systems and services as they attempt to cope with a diagnosis of HIV. Given the availability of ART, health services and professionals need to support the rights of PLWHA to be sexually active if they want to and achieve their fertility goals, while minimising HIV transmission risk.

INTRODUCTION

Sub-Saharan Africa (SSA) is the region most affected by the HIV/AIDS pandemic, accounting for over 68% of the total global burden.¹ A total of 1.6 million Kenyans are currently living with HIV and Kenyan adult

ARTICLE SUMMARY

Article focus

- Slum populations are under-researched, and very little empirical research examines the experiences of people living with HIV postdiagnosis.
- Impact of HIV postdiagnosis identity on sexual behaviour.

Key messages

- Men and women living with HIV in slums are poorly served by health services postdiagnosis.
- Health service provision and support does not incorporate the increasing needs of people living with HIV and AIDS to navigate their sexual and reproductive lives.
- The sexual behaviours of PLWHA are influenced by their HIV postdiagnosis identity transformation.

Strengths and limitations of this study

- The first in-depth study of the experiences of people living in slums following an HIV diagnosis in relation to their identity and sexuality.
- We did not include the perspectives of relevant stakeholders such as partners or policymakers.

HIV prevalence is estimated to be at 6.2%, higher than that of the SSA region (4.9%).²

The introduction of antiretroviral therapy (ART) has improved the prognosis of HIV, with the potential to transform it into a chronic condition. Access to ART in low and middle income countries has expanded rapidly, with 6.6 million people now receiving treatment, nearly half of those eligible for treatment.¹ Seventy-two per cent of Kenyan adults and children with advanced HIV infection receive ARV.³ With ART, the future life opportunities of PLWHA can change, including those related to sexuality and reproduction.⁴⁻⁶ However, research has focused on issues of access and adherence to ART for treatment effectiveness.⁷⁻⁹ Recently, evidence about the relationships between stigma and ARV availability and uptake has emerged from low-income settings.¹⁰ At the individual level, ARV adherence is negatively affected by

¹London School of Economics—Social Policy, London, UK

²Population Council, Reproductive Health Program, Nairobi, Kenya

Correspondence to

Dr Eliud Wekesa; ewekesa@popcouncil.org

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stigma from partners,^{11–13} although self-stigma has been shown to decline in contexts of increasing access to treatment,¹⁴ and stigma changes over the life course.¹⁵ While the provision of ARV has the potential to reduce stigma about HIV/AIDS¹⁶ in a wide range of low-income contexts,^{17–19} this relationship is not universal.²⁰ The relationship between ART and status disclosure to partner(s), family and community is also poorly understood, with the majority of evidence coming from high-income settings.²¹ Research from SSA suggests a distinctive pattern of disclosure that relies on third parties and intermediaries, especially religious leaders, as instruments of disclosure.²² The sexual health rights and needs of PLWHA remain under-researched and poorly understood,^{5 23 24} even though issues of stigma and disclosure are likely to be closely related to sexual behaviour postdiagnosis. There are policy concerns about treatment optimism, with an increase in riskier sexual behaviour as more people become aware that HIV/AIDS is a manageable condition with ART.^{25–28} Sexuality is a crucial element of being human and sexual health (pleasurable and safe sex) is an important component of overall health.²⁹

Nearly three-quarters (72%) of urban residents in SSA live in slums³⁰ where single-room homes are densely packed.³¹ The poor health status of slum residents reflects on the poor environmental conditions and infrastructure, limited access to treatment and preventive health services as well as relying on poor quality and informal and regulated health services.³² Urban slums and their residents are an important, but under-researched, aspect of life in SSA. We undertook a qualitative study of the sexual and reproductive experiences and intentions of heterosexual men and women living with HIV in Nairobi slums.

METHODS

Theoretical framework

We organised and analysed our data using the theoretical concept of biographical disruption,³³ to understand how HIV acts as a disruptive experience on an individual's life, social relations and identity.^{34–36} There are three components to biographic disruption—disruption of an individual's former behaviour or assumptions; changes in an individual's perceptions of self and an attempt to repair or change one's biography. Biographical disruption of HIV has been studied in the global North, and the extent to which it applies to PLWHA in other settings is much less well understood.^{35 37 38} Prior to the widespread availability of ART, evidence of the ways in which identity formation was affected by a HIV diagnosis focused on the mortality implications,³⁵ stigma³⁹ and any subsequent disclosure.³⁴ Earlier analyses tended to be based on quantitative questions in surveys³⁴ with limited analytic insights. Recent analyses have incorporated evidence from qualitative and mixed methods studies and highlight the ways in

which identity postdiagnosis has been used as a social and political force to improve treatment access.⁴⁰ Research in Zambia, conducted pre-ART and post-ART roll-out, suggests that while ART makes disclosure easier, it also changes the context in which an individual discloses.⁴¹ Research into sexual behaviour post-HIV diagnosis in SSA has tended to focus on quantitative measures of sexual behaviour (number of partners, frequency of sex, concurrency, condom (non-)use⁴² with much of the research coming from South Africa, with some exceptions.^{43 44}

Study context

Data for this study were collected from two slum communities (Korogocho and Viwandani) in Nairobi, Kenya. Housing conditions in these slums are temporary, typically single rooms constructed from mud, iron sheets, cardboard boxes and polythene.³¹ The settings are characterised by overcrowding, insecurity, poor sanitary conditions, poverty, high unemployment levels, poor amenities and infrastructure, limited access to preventative and curative services and reliance on poor quality, usually informal and unregulated health services.^{32 45} These conditions contribute to poor health outcomes for slum residents relative to other subpopulations in Kenya, including higher levels of mortality and morbidity, HIV prevalence, risky sexual behaviours, unmet need for contraception and unintended pregnancies.^{46–49}

Sampling and recruitment

We analyse qualitative data collected as part of a larger mixed methods study of PLWHA (18 years and above) conducted in 2010. The study adopted a sequential design, with quantitative survey interviews (n=513) followed by in-depth interviews with a subsample (n=41) drawn from the survey. The quantitative sample size was determined on the basis of sample size calculations.⁵⁰ Respondents were recruited from the Nairobi Urban Demographic and Health Surveillance System through quota sampling on the basis of seroprevalence ratios and sociodemographic characteristics in the study sites.⁴⁹ Purposive selection of respondents for the qualitative interview was based on analyses of the survey data, and identification of a range of experiences. Key informant interviews (n=14) were conducted with health providers. Eight research assistants (RA) (four per site) were recruited for the quantitative survey, of which two per site were retained for the qualitative in-depth interviews. All RA had several years' experience of data collection in the study sites, were trained HIV/AIDS counsellors, and one RA was a PLWHA. Interviews were conducted in Kiswahili and the qualitative interviews were recorded, transcribed verbatim, translated into English and analysed using NVivo.⁵¹

Ethical considerations

We obtained written consent from all respondents and all interviews were conducted in a setting of the

respondent's choice. Privacy in home settings in slums is difficult to achieve, and respondents were given the option of being interviewed in the offices of a local health organisation. A small grocery package was provided as compensation for each respondent. Approval for the study was granted by the Kenyan Medical Research Institute and the London School of Economics. Our analyses use pseudonyms for the presentation of data.

RESULTS

The sociodemographic characteristics of the qualitative study participants are summarised in [table 1](#).

We present detailed analyses of three typical case studies, purposively selected from the qualitative sample in order to draw out the complexities of biographical disruption following diagnosis with HIV.

By selecting three case studies, we contribute to a deeper understanding of the ways in which individual trajectories unfold postdiagnosis, acknowledging the complexity of biographical disruption. We selected these case studies to represent a range of sexual behaviour reported by the wider qualitative subsample ([table 2](#)).⁵²

Table 1 Sociodemographic characteristics of respondents (n=41), 2010

Characteristic	Per cent (n=41)
Slum of residence	
Korogocho	59
Viwandani	41
Sex	
Female	56
Male	44
Ethnicity	
Kikuyu	34
Luo	24
Luyia	20
Kamba	15
Other	7
Education	
No schooling	7
Primary	66
Secondary and higher	27
Marital status	
Married/cohabiting	41
Divorced/separated	17
Widowed	29
Never married	12
Age	
18–29	22
30–39	32
40–49	32
50+	15
Treatment status	
Receiving ART	56
Not receiving ART	44

ART, antiretroviral treatment.

Reactions to a diagnosis of HIV

HIV diagnosis is the first step in incorporating HIV/AIDS into an individual's identity, challenging their identity as a healthy person. Most research on HIV testing in SSA focuses on its benefits, costs and barriers,^{53 54} with little understanding of people's experiences of having a test.⁵⁵ Safari's narrative is typical of a health provider's response and management early in the epidemic

INT: So how did you know your status?

Safari: I kept going to *Hospital*. That is when I heard doctors saying things like HIV/AIDS and they started pointing fingers at me. Those days things were so bad; not like these days...He told me; you know, there is a disease that has come out. It does not have a cure. It is not known what kind of disease it is, and Safari, you have that disease.

Diagnosis often occurred during a health crisis

Jambo: I had a chest problem and when I went to hospital they told me that I had to be tested for HIV. I knew I had TB, but when I was tested for HIV...Oh no! aaayaa! I was surprised to be told that I was HIV+.

Being diagnosed with HIV/AIDS elicits multiple reactions, both negative (eg, shock) and positive (eg, relief).^{34 56} People struggled to grapple with the meaning of a positive test and its implication for their life. Their biographies were initially disrupted and needed reworking to accommodate HIV/AIDS. These initial emotions evolved and changed with time. Malaika's reaction was of distress and denial

Malaika: I was very angry. I wished I was not alive because I saw myself as a dead person. I thought about killing myself. I wanted to kill my children but it was just that they were still very young. I did not suspect I was HIV positive because I did not go out with other men.

Safari feared being associated with prostitutes, a marginalised and stigmatised group

Safari: I will be put with the people who are cursed in life. A person called a prostitute is a cursed person. People would think that I came to Nairobi to be a prostitute. I hated myself. I took it as a curse.

Jambo's narrative involved putting on a brave face, a reaction that is rarely reported in studies of diagnosis reactions.^{34 57} Jambo displayed a 'masculinity script'⁵⁸ by reporting himself to be brave, fearless and emotionless upon testing HIV positive

Jambo: I wasn't angry because I am a man. You are only scared if you are not a man.

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Table 2 Summary characteristics of three case study respondents

Characteristics	Case study
Sexually abstinent	Malaika, female, 29 years, widowed, known HIV status for 3 years. After her husband's death in 2003, she was briefly 'inherited' by her brother-in-law. This is a traditional practice involving a widow becoming the de facto sexual partner of her dead husband's brother
Sexually active, monogamous relationship, consistent use of condoms and/or contraception	Safari, female, 34 years, currently cohabiting, known HIV status for 15 years
Sexually active, multiple partners, inconsistent use of condoms and/or contraception	Jambo, male, 55 years, widower, known HIV status for 9 years

Diagnosis represented a first step in HIV identity formation, followed by decisions about whether to disclose their status.

HIV status disclosure: to tell or not to tell

Managing the flow of information about HIV status, including (non-)disclosure of HIV status is central to how people manage their identity postdiagnosis. Decisions to disclose evolve over time, encompassing a process beginning with non-disclosure and sometimes ending in forced disclosure

Safari: My mother was told but not by me. When you live with people in the house they will know something and they will start talking and word goes round. After all, my body betrayed me.

Safari's disclosure was articulated as subsequently driven by a desire to educate and inform others about HIV/AIDS, a disclosure motive that has also been documented in the USA⁵⁹

Int: Why did you tell other relatives then?

Safari: ...So I wanted to educate them more about HIV/AIDS. How you can get it and how to take care of it and how you can live with it.

Neither Malaika nor Jambo had disclosed their status to anyone beyond healthcare providers. A major barrier to their disclosure was fear of stigma and discrimination

Malaika: It is very difficult for me to disclose my status because people will start talking ill about me, they will not feel good when their children play together with my children and they will look down upon me. That is why I don't want to disclose it to any one and just want it to be my secret.

Jambo's explanation of his non-disclosure refers instead to issues of confidentiality

Jambo: How can I reveal matters affecting my body to anyone; that I have HIV? Why? Are they my doctor? Why should they know?

Key informant interviews reported similar negative social responses experienced by PLWHA

Nurse: I can remember a client...a man who came to me... he had been tested and we were just sharing with him. He told me when he went home and shared his HIV status with the wife, the wife packed and left.

Incorporation of HIV into people's identity is shaped by both individual reaction and the reaction of others and is a process of transition involving decisions about (non-)disclosure.

Assimilation and resources for identity normalisation

The third phase involves reorganisation and/or reconstruction of biographies towards some kind of normality, possibly different to that preceding HIV diagnosis, and requires resources for support and encouragement.⁶⁰ The two main resources identified in our data include social capital and ART. Three major sources of social capital were identified as HIV support groups, government healthcare services and faith-based organisations. HIV support groups can provide confidential spaces where experiences and issues about HIV such as disclosure, sexuality and adherence are shared

Safari: We visit support groups where we learn a lot together. From there you just feel you belong to the society. You just feel you are [like HIV] 'negative' and not 'positive'. We are taught so many things about living positively with the disease.

Of our three in-depth case studies, only Safari had fully disclosed her status; she had assimilated her HIV status into her life and it had become central to her identity. For this group of people, social support groups played an integral role in creating and maintaining an HIV-positive identity, forming a biosociality to decipher biomedical information (eg, CD4 cell counts, viral loads and treatment side-effects), over and above individual clinic consultations. Safari developed her identity as a new 'career',⁶¹ and formed a support group to provide social support for PLWHA and income generation activities (eg, selling beads and poultry farming)

Safari: I used to hate myself before, but now I am a very informed person living positively with HIV. I disclosed to many people and they began calling me *mama ukimwi* (mother AIDS), but I didn't mind. I have educated myself from newspapers and the television. I have a very

big dream of changing the community. I chair a support group and have a dream of educating the community about HIV/AIDS. I overcame stigma and want to help other PLWHA.

Second, social capital from health workers is accessed postdiagnosis by PLWHA, regardless of their disclosure status. Community health workers are often the only sources of social capital for PLWHA who have not disclosed their status. PLWHA were assigned community healthcare workers (CHWs) who operate in the PLWHA's residential area, and are meant to meet at least once per week

Clinical Officer: They [CHWs] are the ones who deal mostly with these clients. They support them in the community so they can cope with the HIV situation. They are the ones helping us to do community outreaches, door to door training, door to door campaign on TB and HIV.

However, evidence from respondents suggested that this regular contact was rarely maintained, in part because community health workers often had multiple jobs in order to maximise their own incomes.

Third, faith-based social networks also play a role in helping people to shape their new identities, including the management of anxiety and depression⁶²

Safari: Because I am not taking ART I know one day, God will heal me by faith. It has been 15 years since I knew my status but I have not taken any of these drugs.

Prayer and religiosity played a pivotal role in some PLWHA's lives, providing an essential source of spiritual support. Evidence from the UK suggests that religion can help to manage anxiety and depression postdiagnosis.⁶²

ART can strengthen social relationships and self-identity because it improves people's capacity to work, important for social and economic viability and validation, allowing people to play their societal role as a breadwinner, parent or adult. For many PLWHA, hope and uncertainty coexist, leading to contrasting and ambivalent views about ART, even among those individuals who have developed a positive identity

Safari: I should have started using the [ART] drugs, but I said no. The doctor was pushing me to start the drugs, but I refused.

Int: Why did you refuse?

Safari: Let me tell you, I fear those drugs. The thing that makes me fear them is the reactions they cause. I have seen the problems they cause to people. The swelling of the feet, then there is one that removes all the fat from the body and it brings to one side. You find one's breast has grown fat; you have a bad shape. That is why I fear them.

For many PLWHA, being HIV-positive is simply a medical label and not a defining feature of their identity

Int: So life goes on as usual?

Jambo: Yes ... people might say that I have HIV, but for me that is not important...My main problem is that I have no means to earn a living, I have many challenges. I am usually rained on in this house whenever it rains, but I cannot [afford to] migrate from here.

For those PLWHA who experienced a dissonance between their HIV status and their perceived health status, this tended to lead to the rejection of an HIV identity

Malaika: That thing [HIV diagnosis] is very painful that I even don't want to think about it. I don't even want be going to the NGOs to read those things about HIV/AIDS because I know I have it. I just want to stay 'bubu [dumb] style'.

Malaika had decided not to use ART because she had concerns about the requirement for good nutrition in order to be able to take the drugs

Int: Are you on ART?

Malaika: I am not on any treatment, I just stay like that... I don't see the need to use these drugs when I don't feel any pain in my body. In fact, I hear you need to eat well when you take those drugs and sometimes you don't have the means to buy food.

Lack of food as an issue in non-adherence to ART was highlighted by healthcare providers

Clinical Officer: We have experienced some clients who complain that they cannot take the drugs as instructed due to lack of food since the drugs are quite strong.

Our case studies illustrate the range of experiences around people's identities post-HIV diagnosis. Safari, with full disclosure, had started to make a career out of her HIV status, although she preferred to place her faith in religion, rather than ART, to maintain her health. Safari had completely assimilated a new HIV identity. Jambo, on the other hand, was motivated to adhere to ART in order that he would be able to work, but he had not disclosed his status to anyone outside the healthcare system. Jambo sought to maintain his biographic continuity, not allowing his identity to be affected by HIV diagnosis. For Malaika, an HIV diagnosis meant a biographical disruption, with neither incorporation of a new identity postdiagnosis nor adaptation of her identity. We explore how these different responses are associated with sexual behaviours.

Malaika's biographical disruption has implications for her sexual life

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Malaika: No, I have not had sex since I knew about my status. I lost sexual desire completely. I don't even long for a man... I actually hate them [men]. You know when a woman loses feeling? I don't have [sexual] feeling at all.

Those PLWHA who were able to incorporate HIV/AIDS in their identity without it being disruptive to their biography were pursuing sexual lives. At the time of her interview, Safari was sexually active with a steady partner and reported consistent condom use

Safari: The man I am with, the first thing is, I am the person who will put the condom on for him. I do not want him to do it himself. Even if it is at night the lights have to be on, because a man is just a man, he might cut the condom and add me more viruses.

By contrast, Jambo's more continuous biography reflected his prediagnosis identity

INT: Did you use a condom during your last sex?

Jambo: Aaahi! How can I have sex with a woman while using a condom? Am I to fuck the condom or her vagina...so my blood gets into her?! Then I go and throw away my semen in the toilet, why? I don't want it, if it's a question of condoms, I would rather do away with a vagina because it will not benefit me in any way.

From Jambo's perspective, the need for sexual gratification involving sexual fluid exchange outweighs condom use.⁶³

DISCUSSION

There are multiple complex responses to diagnosis with HIV, in an era of ART availability, set against a backdrop of life in a Nairobi slum. For some people, this process involves a transition to a new self-identity, incorporating both HIV and ART into their lives⁶⁰; for others, it involves a partial transition, with some aspects of identity persisting, and others redefined.^{35 37 64} Multiple phases of identity transition, including diagnosis, (non-)disclosure, positive living and attempts at repair and normalcy, play out in people's narratives and their sexual lives and futures.

PLWHA try to mobilise resources to help them deal with the diagnosis,^{35 36} including sources of social capital (eg, community health workers social groups, faith-based organisations) and ART. Such social networks provide support to mitigate psychological distress associated with an HIV diagnosis.⁶⁵ Studies from elsewhere in SSA have documented a positive relationship between social capital and health⁶⁶ and prayer/spirituality and quality of life among PLWHA.⁶⁷ Emerging evidence also shows that the availability of social networks such as treatment partners, healthcare workers and social support groups facilitates retention in care and adherence to ART,^{38 66 68} both associated with improved treatment outcomes.

The use of ART was a significant resource enabling PLWHA to regain positions as economically and socially productive and reproductive members of society, thereby fending off stigma.^{69 70} PLWHA face stigma in part because infection with HIV is associated with moral failures and a breach of social norms and taboos.³⁹ In the context of the high premium placed on parenthood,⁷¹ HIV posed a potential threat to peoples' identities as mothers and fathers. Resuming sex provides an opportunity for PLWHA to lead normal lives as well as to mitigate stigma and social disapproval.⁷² However, the inherent social rewards of childbearing, in the context of poverty and limited access to social security, and its inherent risk of transmitting the virus are complex issues in reproductive decisions among PLWHA.

Sampling participants from the slum community is a major strength of our study. Most studies on PLWHA sample from HIV health services where participants are likely to have better access to services and to have been better informed about SRH services and HIV prevention than the general population of PLWHA. However, our interviews had a heterosexual and consensual sex focus and it is highly unlikely that respondents would volunteer same-sex or forced sex activities. Since these sexual identities and activities are stigmatised in Kenya, a different approach might have helped the research process, although their under-reporting might still persist. Information on sexual behaviour and fertility preferences were entirely based on self-reports using face-to-face interviews. Given the sensitive nature of these topics, there is likely to have been social desirability bias. Both men and women misreport their sexual behaviour⁷³ and respondents might be inclined to under-report their unsafe sexual behaviour. Although we took precautions to limit social desirability bias—such as training interviewers to create a climate of trust that allows free talk about such matters and using non-clinical community interviewers—its effect cannot be completely eliminated.

In spite of these limitations, this study contributes to the empirical literature on sexual and reproductive health of PLWHA in a poor setting, an under-researched topic. PLWHA experience life with HIV and face challenges around stigma, managing ART, negotiating sexual intimacy and reproduction. Our data show the need to address living with HIV/AIDS infection holistically, asking broad questions about the lived experience of PLWHA, paying attention to structural elements of poverty, gender and sociocultural norms, recognising PLWHA as sexual and reproductive human beings. Research in developing countries that have addressed the sexual behaviour of PLWHA has focused on risky behaviour mostly using quantitative data from surveys.⁷⁴ Studies have considered the reproductive goals of PLWHA,^{75 76} suggesting that the sexual and reproductive behaviour of PLWHA should be understood by connecting sexuality to gender, reproductive goals and larger socioeconomic contexts.^{77 78}

The effect of ART on sexual and reproductive behaviour is attracting research and policy attention following ART rollout in resource-poor settings. The findings of the few studies that have examined how treatment affects sexual and reproductive behaviour in such settings have produced mixed results, highlighting the need for a better evidence base.^{25 79 80} There is a growing recognition of the need to support the rights of PLWHA to be sexually active, should they wish to be, while minimising HIV transmission risk,⁸¹ and this study is an effort in that direction. Meeting the sexual and reproductive health needs of PLWHA means more than just counselling on risk reduction. Psychosocial factors play a prominent role in sexual functioning, and diminished sexual interest and sexual abstinence are strongly associated with psychological distress, depression, anxiety and low quality of life, in addition to underlying ill-health represented by CD4 cell counts and duration or severity of illness.⁸² PLWHA could benefit from counselling around sexuality as a whole, not just risk reduction as is usually the case. Our findings speak to the need for interventions to help PLWHA to safely become sexually active if they want to. Because the process of incorporating HIV into an individual's identity is neither linear nor predictable, diagnosis presents an opportunity for healthcare providers to discuss these issues. Subsequent referrals for mental health services might, for example, become necessary depending on how individuals cope with their diagnosis

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Eliud Wekesa and Ernestina Coast

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