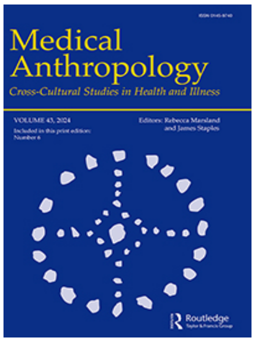

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Precarity and Hope at the Intersections of HIV and Cervical Cancer in a Johannesburg Clinic

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ABSTRACT
In a tragically ironic twist, antiretroviral therapy (ART) that promised an end to AIDS ushered in a syndemic of viral cancers, transforming hope to despair. In this article we draw from the illness narratives of HIV positive women attending a cervical cancer screening clinic in Johannesburg, South Africa, and chart their pathways from HIV to cancer, and their quest for treatment. Our interlocutors described protracted struggles to access surgical procedures to prevent the onset of cervical cancer. Dealt a double blow of HIV and cervical cancer, women's narratives reveal the intersections of exposure to pathogens and the precarity of hope.

KEYWORDS
AIDS; cervical cancer; HIV; hope; precarity; South Africa

In a tragically ironic twist, the widespread availability of antiretroviral therapy (ART) promised an end to AIDS, but ushered in a syndemic of viral cancers, transforming hope to despair. Universal access to ART in southern Africa has extended the lives of those who face inevitable and torturous AIDS illness and death. However, the extension of life heightens the risk of cancers further complicated by HIV co-infection. Consequently, the celebratory and hopeful narratives that echo discourses about an "end to AIDS" (Kenworthy et al. 2018) turn to disillusionment and despair as treatment "expose(s) the deadly relationship between cancer and HIV" (Livingston 2012:11).

The emergence of a cervical cancer and HIV syndemic in sub-Saharan Africa is a growing public health concern (Shiels et al. 2011). Accounting for 22 percent of all cancers in women, cervical cancer is the most frequent cause of cancer related death (Anorlu 2008; Ports et al. 2015). Moreover, an estimated 64 percent of women with cervical cancer are also living with HIV (Stelzle et al. 2021). High-grade lesions[1] among HIV-infected women are five times higher than in HIV negative women (Hawes et al. 2006). In addition, the burden of cancer in the region is projected to increase by more than 85 percent by 2030 (Morhason-Bello et al. 2013). Yet, with regular screening and early treatment, cervical cancer is decidedly preventable. In the US, rates of cervical cancer declined dramatically after the introduction of screening and preventive treatment, although inequitable access to these technologies continues to shape cancer morbidity and mortality (Jain 2013).

Screening for cervical cancer commonly uses a Pap (Papanicolaou) smear, the removal of cervical cells for examination, a visual inspection with a solvent or a colposcopy,[2] with positive results confirmed though biopsy of the affected tissue. Treatment options vary, depending on the stage of the cancer, and can be preventive, if applied early on. Lesions and tumors can be removed through cryosurgery (freezing), or the surgical removal of a small part of the cervix (Anorlu 2008). However, these technologies are ineffective in contexts where screening is scarce and linkages to

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care are weak. Limited facilities for the detection and treatment of precancerous lesions, as well as poor quality care and follow-up of screen-positive women, translate into low rates of survival and high rates of mortality (Anorlu 2008). The not unreasonable fears associated with testing for cervical cancer, and its relative obscurity in public health programming, also contribute toward low testing rates in sub-Saharan African settings (Livingston 2012; Malambo and Erikson 2018; Mendenhall et al. 2019).

In South Africa, rates of cancer screening and follow-up have been described as "sub-optimal" (Ports et al. 2015), mainly owing to inadequate screening and treatment services, the financial costs of accessing health care, low rates of awareness of the disease and its symptoms, and social factors (Anorlu 2008). "Cultural" understandings of the disease can play a role in discouraging women from getting screened (Wood et al. 1997). However, explanations that frame cultural knowledge as a barrier to health, tend to obscure the role of material circumstances such as the disproportionate allocation of resources and lack of priority afforded to cervical cancer. Global funding priorities favor HIV AIDS programming (Malambo and Erikson 2018), despite recommendations to combine HIV and cervical cancer screening (Ports et al. 2015).

The implication of delayed screening is that by the time women seek help at a health facility, their disease is often highly advanced and potentially untreatable (Denny and Anorlu 2012). At an urban referral hospital in South Africa, the average number of months between first diagnosable opportunity (contact with a health care professional upon noticing signs and symptoms of cervical cancer) and diagnosis was 17.3 months, ranging from 11.8 months for urban women to 28.4 months for rural dwellers (van Schalkwyk et al. 2008). Women are often given nothing more than over-the-counter pain medication when first seeking help for symptoms of cervical abnormalities such as heavy menstrual bleeding. In another study, almost half of those patients diagnosed using pap smears did not follow up with treatment at colposcopy clinics (Knegt 2014).

Recognizing the need for broader and more effective screening coverage and preventive treatment, medical researchers in South Africa and Burkina Faso proposed screening HIV positive women for high-risk Human Papilloma Virus (HPV) genotypes, which would give advanced warning of cervical cancer. A high proportion of HIV positive women are exposed to HPV which places them at risk of developing cervical cancer (Liu et al. 2018). The novel screening tests are considered to be sensitive and cost effective in detecting abnormal cells (Devine et al. 2021). Known as the HPV in Africa Research Partnership (HARP), clinical researchers recruited HIV positive women, screened them for HPV and Cervical Intraepithelial Neoplasia (CIN) or abnormal cellular growth, and referred them to local tertiary hospitals for preventive surgery.

The success of cancer screening interventions to improve health outcomes in the HARP study depended to a large extent on patients accessing surgical procedures to remove precancerous cells, thereby preventing the future onset of cancer. In the Johannesburg HARP clinic where we were based, of the 129 women who were diagnosed with CIN, 98 (76 percent) were treated, some only after considerable delays. Patients in the HARP clinic delayed seeking treatment, following biopsies that had indicated either CIN grade 2, or more seriously, CIN grade 3.[3] On average, the delay between referral and hospital consultation was six and one quarter months. The longest delay was 24 months, while the shortest was 1 month.

Methods

In this article, we draw from the illness narratives of HIV positive women enrolled in the HARP clinic in Johannesburg. We sampled our 30 informants from the 129 women enrolled in HARP to take part in interviews. For those who were willing, follow up interviews were conducted when they returned for further clinic tests. Interviews were on average 90 minutes long and were held in clinical consultation rooms in the HARP clinic.

JS conducted 12 of the interviews together with a research assistant, while the remaining 18 were interviewed by a trained interviewer. Interviews were conducted in a language chosen by the interviewee, often a combination of English with SeSotho and IsiZulu. We obtained written informed consent for the interviews and a separate signed consent for audio recording and a detailed explanation of the interview process.

The average age of our interlocutors was 38, ranging from 28 to 46. And of the 30 women we interviewed, 16 had been surgically treated for cervical cancer, 3 were unreachable, and 1 was booked for treatment. Our interviews sought to explore the reasons for delayed treatment and to uncover women's accounts of the circumstances of infection and illness, diagnosis, prognosis and treatment for cervical cancer. In other words, we sought to locate the specifics of delayed care within the broader trajectories of women's illness biographies. Responding to questions about their everyday lives, their experiences and perceptions of diagnosis and treatment, women's narratives offered rich and detailed accounts of corporeal and structural violence within public and domestic domains and in the institutional settings of public-sector health clinics and hospitals. They recounted being deprived of the basic needs for survival, of being physically and sexually abused, and of exploitation, neglect, and scorn. They also described the collapse of networks of kinship and support and conflict in intimate relationships. Their social suffering was inscribed upon their bodies in the shape of infections, illnesses, social distress and emotional stress (Das 1997). Our interviews therefore sought to resurface women's everyday experiences and reposition a potentially life-saving clinical procedure within the context of their lives. Individual life histories and illness narratives offer insights into the collective experiences of cohorts whose lives are shaped by experiences of the broader social, economic and political contexts, and also reveal how individuals interpret and make sense of their lives through narration (Fassin 2008).

Precarity and hope

A recurrent theme in the narratives we collected portrayed the erosion of economic stability and social relations of support that had reduced life to a struggle for survival. For the majority of South Africans, the systematic destruction of rural economies through colonial and apartheid policies since the turn of the twentieth century, the forced dependency on migrant wage labor, and the subsequent decline in employment prospects, are implicated in conjugal and domestic instability, the marginalization of independent single women, and the gendered burden of HIV infections (Hunter 2007; Marks 2002). Moreover, South Africa's public health system, in the context of the AIDS epidemic, is poorly prepared to meet the need for care.

Rooted in the history of racial discrimination and violence, South Africa's health care system is highly inequitable. Private institutions, funded mainly by medical aid contributions, have undergone significant growth since the 1970s, but only serve a minority of the population, while the cost per person far exceeds that of public care (Coovadia et al. 2009). The public health care sector is largely free but widely regarded as the end of the road for the poor and sick.

In the post 1994 era, the South African health system is often characterized as "stressed" by infrastructural breakdowns, overworked medical staff, inadequate health outcomes, as well as institutional and interpersonal violence directed primarily toward women (Le Marcis et al. 2015). South Africa's adoption of a decentralized health system in 1994 was expected to promote equity of health service delivery, notably for maternal and child health including cervical cancer. The system is supposed to ensure a flow of patients referred from primary health care clinics to district hospitals and eventually tertiary hospitals. Yet, this policy often means that patients face the "arbitrary violence" (Gupta 2012) of the health systems that refuse to accept them as legitimate patients, and disregard their suffering.

Precarity is, however, not limited to the instability of material realities and relations, but is affective, linked to peoples' expectations of a better and healthier life. We argue that the individual illness narratives of HIV positive women who participated in the cancer clinic portrayed a cyclical recursive pattern of hope and disillusionment; from the promise of an end to AIDS to the disappointment of a prognosis of cancer, to the despair and frustration of the struggle to access lifesaving treatment. Precarity was produced through the constant disappointment of prospects of health and a better future.

A good example of this idea can be found in Prince's analysis of middle-class Kenyan's search for care and treatment (Prince 2023). Prince refers to the "cruel optimism" that is engendered by the hopefulness promoted by privately accessed cancer treatment technologies and care capitalism that denude the life savings of desperate Kenyan cancer patients. Precarity in this sense is "tied to hopes and expectations that always remain unfulfilled, creating constant anxiety and exhaustion" (Prince 2023:597). Along similar lines, Desai describes states of "immaterial precarity" that are engendered by empowerment workshops for young Indian girls who live in contexts of severe deprivation. Desai notes that the speculative aspirations within contexts of material depravity "entrenches depravity further" by creating an anticipation of improved lives (Desai 2023:7).

The HIV positive women who participated in the HARP cervical cancer screening were offered a prognosis and a pathway to lifesaving procedures, giving them hope for the future. Yet this cannot account for the complex and multi-layered issues that women faced that impacted their health. While the HARP diagnostic procedures for screening cervical cancer made cancer visible and created expectations of a biotechnical solution, this simultaneously rendered the individual histories and lives invisible, and obscured the real dangers of living with cancer (Banerjee 2019). The biotechnical imaginary of cancer creates discourses of survivorship and hope, produced by promises of treatment and cures. Yet, these also serve to disguise the realities of people's lives (Banerjee 2019; Jain 2013), and renders their histories and circumstances "unknowable."

Biotechnological innovations such as those used in the HARP clinic actively "unknow" social inequalities and create "zones of unknowing" (Geissler 2013:16). In clinical research contexts, social difference is "absent from public speech and scientific texts," and therefore actively ignored (Geissler 2013:13). As a result, fields of knowledge, experiences, and histories are marginalized and rendered invisible, even though these are pertinent to understanding individual exposure to pathogens and patterns of morbidity and mortality. Cycles of poverty, exploitation, interpersonal violence, and vulnerability to disease are inexorably interconnected, but also invisibilized and normalized (Bourgois 2009). This has implications not only for exposure to pathogens, but also in understanding the constraints on individual agency in preventing and managing disease (Bourgois et al. 2004:260). The production and reproduction of ignorance can also be portrayed as an epistemic fault line between "witnessing disease" at the population level, and "witnessing illness" at the individual level. The focus of prevention and treatment programs on disease and the cost benefits of prevention and treatment, means that the individual struggles to manage afflictions in the context of everyday life are hidden from view (Patton et al. 2011 cited in Adam 2011).

The discussion that follows is divided into two parts. In the first, we explore women's narratives of infection and illness and the embodiment of social stress and emotional distress. The second presents detailed accounts of clinical encounters within the settings of the HARP clinic, and within public hospitals. Describing how they moved from one rejection to the next, these encounters illustrate the cyclical and recursive patterns of hope and disappointment.

Narratives of infection and illness

Our interlocutors narrated shared histories of instability, violence that produced vulnerabilities to HIV infection, and the possibilities of cervical cancer in their futures. Critical studies in medical anthropology strive to understand how "(. . .) historically engrained, large-scale, political-economic forces wreak havoc on the bodies of the socially vulnerable" (Bourgois 2009:18) and therefore shift the focus from pathologies, behavior and blame to understanding how "various large-scale social forces come to be translated into personal distress and disease" (Farmer 1996:261). This approach casts light on how broader power relations converge to shape young women's vulnerabilities to infection

(Bourgois et al. 2004). Structural violence is reproduced and legitimized through "symbolic violence" that naturalizes social and economic inequalities and their consequences (Dewey et al. 2018).

Agnocia, a 39-year-old woman from Tembisa, an industrial township east of Johannesburg, described her relationship with her abusive husband and a constant struggle to support her three children. Although she worked part time as a cleaner at the offices of a taxi association, her earnings were insufficient to support the household. Her husband, a grill chef in a city restaurant, seldom brought home groceries and, even less so, cash for food. He preferred to eat for free at the restaurant. Agnocia alleged that he spent his earnings on his multiple extramarital affairs. As a result, there was seldom sufficient food for daily meals at home. She rationed the bread and hid food in her washing machine to prevent her husband from eating it. At times, Agnocia and her children ate rice or maize porridge (*pap*) for supper without meat or vegetables. Pointing to his extramarital affairs, she accused her husband of infecting her with HIV. While Agnocia frequently attended an HIV clinic to refill her script for antiretrovirals (ARV), her husband usually refused to attend, and when he did, he sat and read a newspaper to show his disinterest, and impatiently asked whether it was time to leave. Yet, when he became ill with tuberculosis and lost his job, Agnocia begrudgingly nursed him for the sake of their children.

Agnocia attributed her dwindling CD4[4] count to her constant anxieties about her partner's infidelity. She blamed her partner for cheating on her and infecting her, resulting in her experiencing uncontrollable anger and stress: "I am always stressed – even if I am not angry, I just become stressed. It looks like it is in my blood. I experience pains in my neck and at the back of my head." One Sunday she was unable to see properly and experienced temporary blindness. Agnocia's stress not only impacted her health but that of her children as well. When her daughter collapsed at school struggling to breathe, Agnocia deduced that this was directly related to the ongoing tensions in the household.

Agnocia's case was not unusual amongst the cohort of women attending the HARP clinic, who narrated similar accounts of conjugal conflict, and the collapse of social support structures under post-industrial capitalism (Han 2018). The erosion of economic stability and social relations of support reduces life to a struggle for survival, resulting in a "presentism" that "has reconfigured temporality." In this way, "precarity forecloses the future" eroding hope (Hyde and Denyer Willis 2020:299).

Kealeboa, at 32 years of age, was an orphan. Her biological mother had abandoned her when she was two years old and Kealeboa had been raised by her great aunt. At 21, she had her first child. She sought help from her mother's sister who managed a tavern (*shebeen*) from home. When she asked her mother's sister for financial assistance, she was told, "Go to Hillbrow [an inner city suburb] and sell your vagina."[5] Distraught, Kealeboa turned to one of her aunt's friends for help, who offered to take her grocery shopping. But this, too, turned into an attempt to coerce Kealeboa into sex work. When she protested, the older woman said, "This is Gauteng [Province], you mustn't be stupid." At home, when her aunt heard about what had happened, she refused to let her eat. Later her aunt tried to convince Kealeboa to accept a marriage proposal from a man; he had placed cash on a saucer at the back door of the house. Kealeboa attributed her HIV infection to these forced sexual encounters.

It was only toward the end of our interview that Norah revealed the massive emotional burden of her life story. Having spoken rapidly throughout our interview and with little prompting, she sobbed as she recounted being sexually assaulted as a young girl by her maternal uncle and stepfather, who also threatened to kill her and her mother. The adults in her life were of little help: her mother died soon after Norah was raped, and her father's sister discouraged Norah from talking about her abuse.

At 46 years of age, Norah struggled to find work to support herself and her dependents. Having arrived in Johannesburg from her rural home in KwaZulu-Natal, Norah lived with her husband and together they raised two children. However, soon after giving birth to her second-born, Norah's husband absconded. Unable to support her children, by early 2000 Norah was facing starvation. She walked the streets of Johannesburg foraging for potatoes and cabbages that had been discarded by vegetable hawkers. Noticing that women were queuing up next to an abandoned building, she "asked them what they were doing. They said I must go to work and after giving me a condom I went inside [the building].” Norah recalled,

> things went okay for me because I woke up with two hundred and seventy [Rand] then I went and bought a stove [a two-plate electric hob], I bought food and then later I went back and then things were okay.

Although at first, she could earn up to R400 (USD 40) per day from sex work, when she became better known to customers, she earned less and less, eventually coming home with only R30 (approx. USD 3) for a day’s work. Beaten by taxi drivers who berated her for “selling her vagina,” arrested by the police, who would pick her up and then dump her together with other sex workers in an area far away, and conned by clients who avoided paying, this was a rough time for Norah. She remembered,

> I was smoking and drinking, I was like a street person. I was not the Norah that you know now. I didn’t mind being drunk from today until month end so that I can forget about the men I was having sex with.

This continued for nine years until 2009 when she tested positive for HIV.

At the time of the interview, Norah was supporting her children from a monthly child support grant of ZAR620 (approximately USD50). She managed the household budget, buying one bag of maize meal, five kilograms of meat and a bag of potatoes to last the month. Yet she struggled to afford clothes for her oldest boy, who wore torn shirts to school and shoes full of holes. Her oldest daughter had become more independent; Norah suspected she had a boyfriend who bought her clothes, and remarked “as you know, girls know how to look after themselves.” Given her meager income and her health problems, Norah regarded her primary purpose in life to care for her children.

The women who arrived at the HARP clinic experienced everyday violence that had shaped their vulnerabilities to disease (Bourgois et al. 2004). They drew attention to the physical symptoms, psychological distress and social stress associated with living with HIV, and the uncertainties of a cancer prognosis. Their precarious life circumstances were intermingled and entangled with their individual histories (Manderson and Warren 2016:6). Writing on the syndemic of trauma, diabetes and HIV, Mendenhall (2016) point to the interconnectedness of illnesses as a network of afflictions that cannot be easily untangled: “ . . . women demonstrate that their ‘semantic illness network’ (Good 1977) for diabetes and distress cannot be divorced from AIDS, the prevailing form in which sickness is now communicated and understood in their community” (Mendenhall et al. 2015:11).

Physical symptoms of illness were narrated in emotional and psycho-pathological terms, inseparable from nervous conditions, breakdowns, distress and emotional trauma. Nomvula, who, at 28 years old, was one of the youngest women we interviewed, described excruciating headaches that started when she was first diagnosed with HIV. She attributed these headaches to a lack of sleep. “Even if I go to bed at eight, sometimes when I check the time it will be past twelve and I’m still not asleep.” But she also recalled that as a young girl she was preoccupied with a fear of dying in her sleep and would try to stay awake all night. She linked her current insomnia to these early childhood experiences, and felt it was exacerbated by her current illness.

“Stress” was used as a catch-all category to describe illness experiences, and the nexus between stress and HIV was articulated in women’s narratives of illness events. Emotional distress and stress were embodied ailments, manifesting in the body as “high blood pressure.” Receiving the twin diagnosis of HIV and cervical cancer invoked references to the dangers of negative thinking, or as many put it, “*thinking too much*,” which they argued could lead to anxiety and stress. The idiom, “thinking too much,” is documented in multiple settings, globally (Kaiser et al. 2015), as a folk ailment (Good 1977; Patel et al. 1995), and can be the manifestation of “collective social anxiety,” the expression of “symbolic protest,” or a “meta-commentary on social injustice” (Kaiser et al. 2015:171). Similarly, our informants correlated “thinking too much” with stress that exacerbated their worsening health status.

For some, avoiding thoughts about distressing life events was a strategy to stay healthy. Stress could result in their conditions worsening, or even lead to death. As Busi (34) noted, “stress is a big enemy of HIV positive people; many people have died from stress.” She tried to forget that she was HIV positive, but was reminded of her illness every day when she took her medication. Referencing the power of what she called "positive thinking," Bertha (34) felt this was important to counteract the psychological distress caused by HIV. She told us:

> Life is about how you drive it. What you think is what can build you or break you. So, if you allow things to break you, that means you want to be broken, you are destroying yourself - so that's how I took it. I didn't want to allow HIV to kill my brain or the positive way I look at life.

Others agreed with these sentiments. Cindy, who had witnessed the death of her sister from AIDS, and lived with her mother and brother who were both HIV positive, reflected on her emotional state when she too was diagnosed as HIV positive.

> I was thinking about it [HIV], like if I stay with it for a long time maybe it will end up killing me [. . .] And the thing is I was always thinking about it, "You know what? I am going to die." I was just waking up at night thinking about it, like, eish! [exclamation] Now I am HIV positive.

Health workers supported this model of stress and illness, referring to the impact of depression and psychological stress on the immune system, a theory often communicated in health promotion campaigns for HIV positive people to live positively. Yet, for many HIV positive women in South Africa and the region, co-infection with HPV signified an uncertain future and the possibility of terminal illness and death from cervical cancer. It threatened to cut short the hope represented by powerful, lifesaving pharmaceuticals, and the revitalization of personhood that came with surviving AIDS (Robins 2006).

Unhealthy encounters: Hope and disappointment

The HARP cancer clinic, through the novel application of genotype testing for HPV, represented a solution for women facing the potential threat posed by cervical cancer: the combination of the screening procedures being trialed by the research clinic, the care the clinicians offered, and the referrals for preventive treatment. Care and support was played out through interactions with the clinic staff.

For instance, when Gloria, a 40 year old unemployed woman tested positive for HPV and CIN, she was encouraged by a clinic nurse.

She tried to comfort me. She said that it is good that I found out early, unlike my sister. She discovered [her cancer] late and did not manage to follow the procedures. But for me, I have a chance, I will be alright. This is a small thing, it will be resolved. She also told me that other women had been referred to the hospital and they had returned here [HARP] looking fine. I had hope even though I was not sure.

The HARP clinic also encouraged a feeling of solidarity amongst the patients, who shared familiar stories of their illnesses and discussed the possibilities for care and a cure. Constance, remarked, "there were the ones who were much sicker than me. So, we talked, and it was nice. You know we talked a lot. Even at the stage that I am at, there are people who do not yet have AIDS yet, but they are still [HIV] positive [not ill] and there are those people who are much better. So, we used to meet and talk." Dikeledi offered support to her fellow patients, by reassuring them of the procedures. "There were those [patients] who looked scared when they arrived. I said 'there is nothing difficult. You just need to be strong because we need help to stay alive.' So, by the time we saw the doctor, no one was stressed."

Medical settings, especially those which deal with life threatening diseases, are often spaces of hopefulness. In these settings, clinicians and patients invest in the "political economy of hope," as a critical part of the therapeutic process (DelVecchio-Good et al. 1990) and as a necessary condition for clinical research; experimental clinical research is sustained by hope for cures and effective treatment (Pollock 2019; Saethre and Stadler 2017). Yet, as Mattingly (2010:3) points out, hope and disillusionment are different sides of the same coin. While hope is future oriented, she observes that it "is on intimate terms with despair." For many of the women who attended the cancer research clinic, hope was fleeting and ephemeral.

When HARP patients were referred to tertiary care institutions for surgical procedures they encountered barriers in negotiating the complex "biobureaucracy" of the hospital (Strong 2020). Several who were referred to the Chris Hani Baragwanath Hospital (a 3200 bed hospital in Soweto south of Johannesburg) and the Johannesburg General Hospital (approximately 1000 beds) in the inner-city were told to return at future dates or referred on to yet other hospitals. In some cases, patient files were lost by the hospital administrators. This caused delays, sometimes of several months and even years, seriously jeopardizing their health.

Hope deferred

Gladys, a 43 year old security guard, was diagnosed with HIV when she gave birth to her first child in 2006: "it's not good to know that I am going to die you see and how my partner will take this you see, and how my family will understand this. And what will happen when I start becoming sick; what will people say about me you see?" When she gave birth to her second child, her husband left her. In 2011, Gladys gave birth to her third child, having started a new relationship in 2010. Gladys fell ill, which she attributed to the stressful circumstances of having three children with two different fathers. She was enrolled in an ART treatment program when her CD four count was recorded as 71. Although her first born had received prophylaxis to prevent HIV transmission, he tested positive at four years of age after being admitted to hospital for pneumonia.

At the HARP clinic Gladys was given a thorough physical examination. The medical team informed her that she had fibroids and took a sample for laboratory analysis and handed her a referral letter to the Johannesburg General Hospital. Upon arriving there she was told to return at another time without being told why. When she returned she was told that because she did not have a file with the hospital, she needed to consult at a hospital that was closer to where she resided; "they said they 'don't take people from here.' I was supposed to go back, but that lady [nurse] told me no, no, no you are not. Like she asked me where do you stay and then I told her that I am renting in Regents Park [in the south of Johannesburg]. So she said 'no you must go to your nearest clinic.'"

The HARP nurse told her to return to the study clinic, but Gladys took the advice of a friend and went to Rahima Moosa, a district hospital located in the southwest of Johannesburg. Here Gladys was told the same: to consult at a clinic in the same district where she resides. Eventually the HARP clinic staff gave her a referral to the Chris Hani Baragwanath Hospital (CHBH) who accepted her letter and agreed to open a file for her. Gladys lied about where she resided and did not admit that she was employed. Previously she had worn her official security guard uniform from work and suspected that this may have been the cause of the rejections. At CHBH she was yet again diagnosed with fibroids and a tissue sample was taken. Gladys said she "felt bad because I thought it will be something that can be done quickly, and I was expecting this to be done quickly because they said I must do it as soon as possible." At our final interview Gladys had still not had the fibroids removed and was uncertain about her future.

Agnocia's (who we introduced in the previous section) first response to a cancer prognosis, which she described as "something growing in the mouth of [my] womb," was of extreme fear. "I had already told myself, I am dead," even though the HARP study nurse told her that she was fortunate to have found the growth early and that there was still time to go to hospital to have it removed. However, Agnocia had first-hand experience of seeing her aunt die from cervical cancer in 2010 and was filled with feelings of dread. She described witnessing her aunt's death in detail.

> My aunt went to the hospital because blood was coming out [of her vagina] a lot, and I suspected it might be cancer. By the time we got her to hospital she had lost too much blood and she passed away because of that. She

> had something growing inside her womb. The thing that made me is scared is, I watched my aunt bleeding too much, you see? She was always in and out of hospital. If you looked at her you could see that she didn't have blood anymore; her skin was so tight. But when they found that it was too late.

Agnocia was very close to her aunt; she had visited her daily in hospital during her final days. Her aunt appeared in dreams telling Agnocia to contribute toward a burial plan as she will be next to die. While acknowledging that her aunt's death was largely due to her presenting late for care, Agnocia's faith in the health services was undermined by her experiences of trying to admit her aunt to hospital amidst a national public service sector wage strike in South Africa in August 2010. Clinics and hospitals had remained open, but the entrances were blockaded by striking healthcare workers. Agnocia was angry; not with the health workers but with the state that, as she put it, was "selfish because if they gave them the money they wanted they wouldn't be on strike."

When the HARP study clinic offered a referral letter to a tertiary care facility to remove her own pre-cancerous lesions, Agnocia decided on the Johannesburg General Hospital. Although far from her home in the east of the city, she was wary of local hospitals, believing "they have no care." At the Johannesburg General Hospital, she was given a date for an appointment for six months' time. Agnocia was worried; she felt extremely unwell and wanted to be seen immediately. At her appointment six months later, the doctor performed a biopsy and referred her to return for a follow-up pap smear. She was instructed to call in for her results. Agnocia had little cash to spend on telephone calls, pointing out "you know, a cell phone chews money." When she did get through to the correct ward, she was given the result of her pap smear but was unable to book for a follow-up consultation. Only after waiting a further six months was Agnocia given a second appointment. When she arrived at the hospital, she was told that the person who had booked her was not available, and she would have to make yet another appointment and return.

> I asked them "what must I do because I am sick now?" They told me that they are fully booked and I said "what must I do? "It is not my fault, it's your fault as I phoned … " You know, the nurses don't have care … Those nurses, they do what they like. There is no doctor there, he's in the wards and he's busy.

Agnocia was understandably worried and desperate, as she had not had normal menstrual flow for six months. The experience of being repeatedly screened, deferred and postponed was frustrating. Indeed, six months was the typical waiting period for patients returning for services. Agnocia remarked, "and when you have finished that six months, you think you need to go for a checkup. When you get there, they will give you another six months to wait for your consultation." Toward the end of our second interview, she reflected on her experiences, framing them as a consequence of the inequalities that structure access to care. Her words were a harsh reminder of the structural violence exerted on the poor and the vulnerable: "You know, people who are safe are people who have got medical aid [health insurance]. But us who don't have it, we are not safe."

Medical negligence

When Norah was first diagnosed with HIV, she was scheduled to begin ART, but initially refused, and by 2011 had become critically ill. Norah was admitted to the intensive care unit (ICU) at the Johannesburg General Hospital. In addition to HIV, she tested positive for type 2 diabetes, while at the same time suffering with asthma. Believing that she was dying, Norah argued with the nurses, accusing them of not measuring her blood sugar levels and destroying her medical files. The doctor in charge told her later that she seemed to have gone "mad" because of her illness. Following an intensive period of counseling, Norah started ART treatment and was soon happy to see that she was gaining weight and her health was improving. After being discharged she heard about the HARP study from a friend and enrolled as a participant in the study clinic. Learning from the screening that she had a "growth" in her womb, Norah was referred to the Johannesburg General Hospital. Here, she was scheduled for a hysterectomy. Despite protesting against the procedure, she eventually agreed to have it done. But due to her diabetes her surgery was delayed. Her account of the events that took place help us to understand why she initially resisted the surgery.

It began with Norah being mistreated by the nursing staff at the ward. She recalled that she was initially refused a bed and had to sit on the cold vinyl floor of the ward for most of the day. When the ward doctor eventually arrived, Norah informed him that she was HIV positive. In the evening Norah was finally accommodated in a bed and was told that she would be taken to surgery in the morning. Her mistreatment did not end there, however. The ward sister began to accuse Norah of using up resources and not paying for services and publicized Norah's HIV status.

> The sister in charge of the ward where I was, asked me if I take ARV's - in front of everyone! I don't want to lie; I was not happy about what she said to me in front of everyone. I said, "I know when I need to take my pills." And she said "you know what? Here we don't want people who don't listen." I left her and went to bath. When I came back, she said, firstly that I [Norah] don't pay [for hospital services]; that I just want to use hospital beds without paying. I said, "I paid eighty Rand [8 USD] for the bed, that's why they admitted me. So, if I don't have money for treatment, I don't have it, there is nothing I can do." She kept on saying horrible things, such as she is there to work, and she needs to be paid and so that's why I should also pay to use the hospital.

This left a long-lasting impression on Norah: "The way they treated me is still in my heart." Summing up her experiences with health care providers, she said "They didn't take me as a person who is sick, they just take me as a person who is difficult for them." Later she remarked, "I will rather die at home than go to hospital again."

In the eyes of the clinic staff, Norah was a problematic case: overweight, asthmatic, diabetic, with cervical cancer and HIV. Norah did not fit in with the "prescribed structure" of flows of patients through the "biobureaucracy" of the hospital clinic, because she possessed an "unpredictable body" (Strong 2020:90). Yet her indictment of the health services highlighted her feelings that far from being a troublemaker, she was a sick person needing assistance and care.

While familiar narratives of the health system as structural failure are used to frame the mistreatment of patients, this misdirects attention away from the systematic and intentional abuse and neglect of vulnerable patients. Heckert argues that shifting attention toward inadequate health infrastructure allows for care providers to avoid personal culpability, and therefore allows medical negligence to become normalized (Heckert 2016:691).

Those who lack formal documentation as South African citizens face additional barriers to care and treatment in public health institutions. Medical citizenship in South Africa is often denied to undocumented foreign nationals. "Medical xenophobia" is entrenched in public health facilities, and evident in the negative dispositions and actions toward people identified as "foreigners." These are not idiosyncratic nor isolated phenomena, but should be seen as systemic state legitimized violence against the sick and disenfranchised (Crush and Tawodzera 2014).

Zama, who we interviewed late in 2014, had not acted on a referral to have the cancer that was growing in her womb removed. After undergoing screening at the HARP clinic, she was told that she urgently needed to seek medical care for the removal of the pre-cancerous cells. "I was told that they have to operate immediately and if not, I am going to die." Despite this scare, Zama's status as a Zimbabwean made her hesitant to go to hospital. A few months previously she handed her passport over to a broker to travel to Zimbabwe and return with a stamp, making it possible for Zama to reinstate her visitor's visa. Yet, the man returned without her passport, claiming that he had lost it. Without any means of identification Zama felt she would likely be denied treatment at a state hospital.

Creating "zones of abandonment" (Biehl 2013) and new forms of exclusion (Marsland and Prince 2012:460), women's experiences of health care institutions perpetuated suffering and intensified abjection. Treatment delays, and the absence of treatment altogether, threatened health futures and contributed toward their abandonment, social stress and emotional distress. Despite the existence of advanced technologies – in this case the use of novel screenings to identify potential cancerous lesions – that promised to resolve high rates of cervical cancer amongst HIV positive women, structural and symbolic violent encounters obviated this promise. While caregiving is essentially a social good, it can also be, as Biehl puts it, a technology of "disregard." He explains that this is what transpires when care is appropriated as a "technological intervention rather than relational practice" (Biehl 2013:383). Care, in this regard, can end up becoming its opposite.

Conclusions

Toward the end of the 2000s, after many years of unmanageable illness and unimaginable death, universal access to ART finally offered hope to the AIDS ill when these lifesaving drugs were made available in public health clinics and hospitals (Mbali 2013). The subsequent triumphalist narrative of the "pharmaceutical salvation" (Biehl 2006) of South Africa's HIV epidemic embodied widespread optimism for the normalization of HIV (Leclerc-Madlala et al. 2018).

Yet, the pharmaceuticalization of HIV can also obfuscate the shared histories of suffering, the social inequalities that produce vulnerabilities to infection that form barriers to accessing treatment (Hardon et al. 2007), and the implications of treatment for social relations and hunger (Kalofonos 2010), therefore highlighting the limitations of biomedical models of global health (Decoteau 2013). The "end of AIDS" produces a universalizing discourse that ignores diversity, discrimination and the very conditions that continue to give rise to life threatening afflictions and suffering. The social contexts of infections, illnesses and violence are overlooked, and, as we have argued, the focus on HIV treatment, while prolonging life, risks ignoring the emergence of co-infections and syndemics, such as cervical cancer. In the article, we argue that hope in this context is highly precarious, especially for HIV positive women who sought care for a cancer prognosis.

The HARP clinic proposed a solution to the emerging epidemic of cervical cancer, using novel biotechnologies to prevent disease spread through early detection. Clinical researchers and medical authorities mobilized the "cultural power of the medical imagination," to produce hope (DelVecchio-Good 2001:397), not solely to prevent and cure disease, but to transform women's lives. These sentiments are widely shared in the medical community. Lynette Denny, a professor of Obstetrics and Gynaecology, narrates the success of implementing screening for cervical cancer in Khayelitsha, a historically Black township in Cape Town. "Many of them [women with precancerous lesions] had tried to access healthcare up to eight times before somebody examined them properly, made a diagnosis and sent them for care. The injustice around it, and the suffering, really infuriated me, particularly because it was so clear that we could … prevent it." Denny's sentiments are echoed by Western Cape Health Department, Dr Keith Cloete: "It's not just research and implementation, but it's also empowering women and addressing the situation of women in our societies" (Metelerkamp 2022).

Documenting the experiences of HIV positive women who faced the uncertainties of a prognosis of cervical cancer, we show how the optimistic and hopeful rhetoric of biomedical technologies were eroded by the experience of waiting. Patients from the HARP clinic waited for test results, surgical appointments and treatment, and faced recurrent delays and rejections when attempting to access care. While sustained by optimism and hope for a disease-free future, waiting also generated precarity; the longer the delay between testing and treatment, the greater the risk of cancer, and ultimately of death. Occupying a perpetual zone of waiting patients experienced the effects of power that compels people to wait but at the same time sustains hope (Auyero 2011). The patients whose experiences we documented appeared powerless to challenge the circumstances of their intimate relations in the domestic domain, as well as when seeking institutional care.

Such waiting evokes passivity and the absence of agency, reinforcing a conceptual distinction between inactive "hope" and active "desire" (Crapanzano 2003). However, there is evidence that cancer clinic patients were actively engaged in waiting (Mujere 2020). By defying the bullying encountered in the hospital ward, and repeatedly deploying different strategies to access care, patients attempted to challenge the endless delays they encountered. Nonetheless, "active waiting" did not slow down the progression of disease; hope in this respect was greatly diminished, tempered by the growth of cancerous cells and the uncertainties of care.

Notes

1. High grade lesions are abnormal cells indicating cancerous growth.
2. A colposcopy is an examination of the cervix to check for abnormal tissue, using a lighted microscope (colposcope) that magnifies the vaginal and cervical tissue.
3. The numbering indicates the seriousness of the growth of abnormal cells.
4. A CD4 count measures the number of white blood cells in the body that fight infection.
5. Hillbrow, a dense transient inner city suburb, gained notoriety in the 1980s as a site of sex work, with many brothels located in hotels and apartment blocks.

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