



UvA-DARE (Digital Academic Repository)

Concealment tactics among HIV-positive nurses in Uganda

Kyakuwa, M.; Hardon, A.

Published in:
Culture, Health & Sexuality

DOI:
[10.1080/13691058.2012.716452](https://doi.org/10.1080/13691058.2012.716452)

[Link to publication](#)

Citation for published version (APA):
Kyakuwa, M., & Hardon, A. (2012). Concealment tactics among HIV-positive nurses in Uganda. *Culture, Health & Sexuality*, 14(S1), S123-S133. <https://doi.org/10.1080/13691058.2012.716452>

General rights

It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations

If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: <https://uba.uva.nl/en/contact>, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.

Concealment tactics among HIV-positive nurses in Uganda

Margaret Kyakuwa^{a*} and Anita Hardon^b

^aCollege of Humanities and Social Sciences, Makerere University, Kampala, Uganda; ^bFaculty of Social and Behavioural Sciences, University of Amsterdam, Amsterdam, The Netherlands

(Received 4 May 2012; final version received 25 July 2012)

This paper is based on two-and-a-half years of ethnographic fieldwork in two rural Ugandan health centres during a period of ART scale-up. Around one-third of the nurses in these two sites were themselves HIV-positive but most concealed their status. We describe how a group of HIV-positive nurses set up a secret circle to talk about their predicament as HIV-positive healthcare professionals and how they developed innovative care technologies to overcome the skin rashes caused by ART that threatened to give them away. Together with patients and a traditional healer, the nurses resisted hegemonic biomedical norms denouncing herbal medicines and then devised and advocated for a herbal skin cream treatment to be included in the ART programme.

Keywords: HIV-positive nurses; concealment; secrecy; ART; side-effects

Introduction

AIDS activists have long advocated openness around HIV and AIDS. People living with HIV are encouraged to live ‘positively’ and to disclose their status to their sexual partners, families and the community at large (UNAIDS 1999). But the moral injunction to disclose one’s HIV status is not always appreciated by communities and families (Cusick 1999; Körnera 2007). In sub-Saharan Africa, many people remain ashamed of HIV due to its association with sexual promiscuity and its implications for family honour (Bok 1984; Iliffe 2005) and both men and women fear being abandoned by their partners if they disclose (WHO 2003; Obermeyer, Baijal, and Pegurri 2011). People living with HIV must therefore balance conflicting moralities: that of the HIV and AIDS movement and care organisations, with their call for openness, and that of their communities¹ and families, which values discretion and concealment.

The injunction to disclose one’s HIV status has become part and parcel of anti-retroviral treatment (ART) programmes, which have transformed the HIV landscape in sub-Saharan Africa (Hardon and Dilger 2011). Nowadays, ART programmes usually demand that people disclose their HIV status to a treatment buddy, meaning that they have to disclose to at least one person to access life-saving treatment. In many countries, tasks are delegated down the medical hierarchy – from doctors to non-physicians such as nurses and from nurses to nursing assistants and non-professional or lay ‘expert patients’ (Lehmann and van Damme 2009; Mdege, Chindove, and Ali 2012). Expert patients are role models in HIV clinics. Following the activist principle that ‘silence is death’, they publicly disclose their HIV

*Corresponding author. Email: margaretkyakuwa@yahoo.com

status and encourage people who have been diagnosed with HIV to do so too (Mattes 2011; Thentani et al. 2012). One recent ethnographic study in Ghana suggests that patients are more comfortable disclosing their HIV status and illness experiences in support groups and in clinic counselling sessions than at home (Dapaah 2012).

Whereas (expert) patients in HIV clinics openly discuss their sero-status, this is not the dominant practice among HIV-positive nurses. Dieleman and colleagues (2007) describe how in two rural districts in Zambia, HIV-positive nurses did not talk about their illness, choosing instead to suffer in silence, while risking emotional exhaustion and burnout. With meagre resources, nurses already have to attend to ever-increasing numbers of patients diagnosed with HIV (Minnaar 2005; Zelnick and O'Donnell 2005). HIV-positive nurses additionally suffer the burden of their illness and (fear of) enacted stigma.

In Uganda, around 30% of the nurses working in HIV-related care are thought to be HIV-positive (Ministry of Health 2005). How do they experience their dual roles as patients and care-givers? Do they disclose their status to their colleagues and patients, following the disclosure imperative central to AIDS activism and care? How do they relate to the expert patients involved in HIV-related care who present themselves as persons living with HIV and role models for truth-telling? This paper explores the experiences of HIV-positive nurses in two rural ART clinics in Uganda and their acts of concealment to negotiate social stigma in the workplace. We approach their acts of concealment as 'tactics' – that is, an art of the weak (De Certeau 1984) deployed to survive in an HIV-care environment, where the rules of the game have been formulated by others. We describe three such tactics that build upon each other and that together lead to a radical change in the local implementation of the HIV-care programme.

Methodology

This paper makes use of data derived from a sub-study of a larger ethnographic investigation conducted at two sites: a mobile NGO-run health facility and a public health facility, located in two different rural districts in Uganda. The larger study has been included in a doctoral thesis (Kyakuwa 2011). The present sub-study involved 20 nurses working in the two facilities, of whom 7 were HIV-positive. The narratives and 'small stories' that make up this study – 'the ones we tell in passing, in our everyday encounters with each other ... the *real* stories of our *lived* lives' (Bamberg 2006, 367, emphasis added) – were obtained after several months of rapport-building in which the first author established trust with a limited number of nurses.

The first author pursued participant observation in the clinics for two years. She had informal conversations, recorded life histories, analysed nurses' diaries and held open-ended in-depth interviews and informal group discussions. In order to have a useful participant role in the overburdened health clinic, she trained and worked in the clinic as a volunteer counsellor (and followed the confidentiality guidelines that counsellors are expected to adhere to). The nurses engaged in this sub-study valued her role as a counsellor and were well aware that she was also doing fieldwork. The first author always clarified her role as a researcher when engaging in informal interviews or discussions for research purposes. The HIV-positive nurses were pleased to participate in the study, hoping that their stories would be beneficial to nurses working elsewhere.

Participant observation allowed delving into new issues that emerged during the course of the study, such as the making of a herbal cream to treat and conceal the side-effects of AIDS medicines. While presenting the findings of the study below, we also report on the research process that led to the exploration of new issues affecting the everyday lives of nurses living with HIV.

The research sites were HIV clinics located in the rural Luweero and Masaka districts of central Uganda, a region with a HIV prevalence rate of 9.4% – one of the highest in the country (Ministry of Health 2005). The Uganda National Council of Science and Technology and the ethics committees at the two HIV clinics approved the ethnographic study, aware that in such studies, objectives are expanded and elaborated along the way. The participants were given detailed information about the study during the three-month exploratory fieldwork visit and gave their verbal consent. They were repeatedly informed that they could drop out of the study at any time. To ensure the confidentiality of the participants, we have used pseudonyms. All HIV-positive nurses verbally consented to their views being written down in the research report.

Results

Though both facilities provided all aspects of ART care, none of the seven HIV-positive nurses received treatment from the clinics where they worked, citing not only practical reasons but also fear of social stigma associated with promiscuity, unsafe sex and fear of contagion. As the nurses often repeated, ‘What is the point in disclosing to everyone at the workplace, where there is so much prejudice, fear, and no psychosocial support for staff?’ To be seen receiving the same treatment as their patients would entail displaying their own vulnerability and alleged lack of self-control in their own lives (Kyakuwa 2009).

Nurses in both sites stated that they feared their bodies would give them away through the signs and symptoms of AIDS or the side-effects of medication, the most visible being the rashes associated with nevirapine. Being healthcare professionals in the middle of the biomedical hierarchy, they feared losing the respect of both patients and doctors were their HIV status to be made public.

To disclose or conceal: challenging global activist culture at the public clinic

Prim and Florence are HIV-positive nurses at the public ART clinic where the first author conducted ethnographic fieldwork. During one of the usual informal evening conversations, the first author asked if they had ever disclosed to their colleagues their HIV status and the fact that they were on ART. They frowned and responded quickly:

Prim: I, Prim! Are you joking?

Researcher: No I am not, why?

Prim: I can’t disclose to fellow workers here. I have to keep this as my secret as long as I can. I see no point in telling colleagues at work because they won’t help me other than be unkind to me, which I don’t like, because to me that is more stigmatising! ... Everything I do wrongly will be judged, not according to my ability but to my HIV status and the nevirapine, efavirenz, or whatever I am taking, and sometimes with the bad jokes of non-adherence from all corners even when [I] am with my patients ... I am not sure I can stand that.

Florence: I hear my colleagues sometimes make cynical comments and fun of Harriet [another HIV-positive nurse who disclosed her status at work] when she is late or does something wrong and they sometimes mention the HIV/AIDS treatment she is using. ... Like, ‘Oh, it is AZT making her mess up work’. You know, I can’t take it. No! I have to hide my HIV status as long as I can.

These responses reveal that nurses fear their new identity (of being a patient) as well as stigmatising attitudes and behaviour at work. They were not ready to stand 'that kind of treatment'. Underlying this was the fear of shame of not performing to expected standards and of being judged on the basis of being patients themselves. This would make matters worse for they felt they would be judged unfairly. While such treatment may not be a daily occurrence, it impacted upon how Prim and Florence perceived their colleagues and the atmosphere at work. To cope with the dual role of being HIV-positive and being a nurse, they opted for secrecy about their HIV status in their workplace.

The genesis of the secret Open Up circle

After months of fieldwork, the first author requested a focus-group discussion with four female nurses. Two of them (both working at the NGO clinic) had disclosed to their colleagues their HIV-positive status and the fact that they were using ART, though they collected their pills at another clinic. The other two nurses had privately disclosed their HIV status during in-depth interviews. Based on her previous conversations with all four nurses, the first author requested that the discussion focus on their experiences as ART providers, to which they enthusiastically agreed.

During the focus group, conducted at the public clinic at the end of the working day, the nurses' initial enthusiasm turned into emotional outbursts and sobbing as they talked about pressing issues at work and in their personal lives. The focus group took on a new twist, turning into a space for emotional release that lasted well over four hours. The general mood kept swinging between laughter and tears, their insights leading the first author to reflect on how the healthcare system deals with HIV/AIDS. The nurses delved into the realities of hiding their shame, dealing with life after testing HIV-positive and the contradictions within HIV-related care. They narrated tales of frustration, strength, hope and despair. After listening to the two nurses who had disclosed speak about their experiences, the two nurses who had maintained secrecy at work decided to reveal that they were HIV-positive, right there in the focus group. It became a moment of revelation as the nurses revealed their secrets to their colleagues. However, they made it categorically clear that they did not want anyone else at the clinic to know.

As a researcher, the first author was caught off-guard. In the heat of the discussion, she dropped the role of researcher, stopped asking questions and became a facilitator as the conversation developed among the four nurses, only contributing to the discussion every now and then to calm emotions and fears. She was helped by the fact that she was dealing with a more or less homogeneous group in terms of professional background, experience and gender. At the end of the focus-group discussion, the four nurses decided to adopt and change it into something more personal. So began the Open Up group meetings. The group was formed as a secret sharing network, based on trust that the four members would not tell others about the group, refer new people in or reveal the content of the meetings or the status of the two nurses who maintained secrecy. The meetings were secretive and sporadic, taking the form of gatherings at each other's homes or in other public yet discrete locations, such as a church garden, to share experiences and offer each other much needed psychosocial support. The name Open Up comes from a famous television talk show in Uganda, where people go on air to express usually painful experiences in their lives, such as the search for lost loved ones, overcoming traumatic experiences, like defilement or rape, and issues in everyday family life, such as domestic violence.

On several occasions during the fieldwork, the nurses invited the first author to their group. This gave her the opportunity to follow up on key issues over a long period and helped

her gain insight into the backstage of their lives. The nurses often began by discussing their personal experiences at work and many other topics would then follow. She was thus able to observe and document the nurses' journeys to arrive at a shared understanding of their experiences with HIV, as both patients and as healthcare providers. Their invitations were usually not openly framed as being related to the research – which was common knowledge at the clinic – but to share a cup of tea or a meal. It was a way to disguise their agenda and not raise suspicions among co-workers about the Open Up meetings.

Sometimes, when the first author wanted to pursue the role of a pure researcher, she would request a specific meeting with the nurses, which often took the form of a focus group or interactive group discussion. The nurses welcomed the requests for more focused discussions, reasoning that my questions helped them deal with fundamental issues such as tensions and the atmosphere at work, about which they gained new insights from each other.

Content of the secret meetings

During the first and subsequent Open Up meetings, the four nurses talked about receiving their HIV-positive diagnosis, their difficulties with treatment and adherence, the stress of dealing with side-effects and persistent symptoms and strains in their interactions with colleagues. Their narratives differed greatly. Some saw HIV through a religious lens, accepting all that comes one's way as the will of God (with the attendant notions of love, forgiveness, bearing a cross and punishment). Other narratives were related to the (earlier) popular cultural model of AIDS as a disease that will eventually kill you, where the side-effects of treatment (which is no cure) only accelerate the suffering. Other stories related illness experiences to the traditional cultural model of ancestral spirits and misfortune, of why other people dislike you and misfortune befalls. Yet other narratives referred to the biomedical imperative of disclosure and adherence as promoted by mainstream support groups.

In the meetings, typically one nurse would raise an issue and discuss it in the context of her experiences, framed within certain beliefs and knowledge systems. The nurses described their experiences, debated and argued with each other, raised unanswered questions and advised each other on how to deal with the challenges. In particular, they saw the group as a place to find relief from their emotions and feelings:

When we meet, we also openly take care of each other's psycho-social needs which are often never talked about even in what one calls ART counselling. You know secrets can keep you sick. I remember two of us, even after having been through all the routine counselling at some NGO-run clinic, still had so many painful emotions which we had never let out simply because we were too afraid to talk about them or never got someone who would really listen. We need to be listened to and here in our group we really listen to each other and feel listened to. Some of us used to get very emotional and even burst out crying like babies during the Open Up meetings as we shared very personal experiences related to ourselves or our patients at work. This shows how much pain we had kept in our hearts . . . pain related to many things. (Dorothy)

The group meetings became a powerful forum for expression and social support, which the nurses treasured and seemed unable to find elsewhere. They sought sharing, discussion, debate and a listening ear, and rationalised the secret group as both a de-stressor and an empowering space of expression free of prejudice, discrimination and stigma from others:

Opening up means sharing a lot. Sometimes it's quite intimate stuff. We find ourselves advising each other on how to deal with a rowdy child, a drunkard boyfriend, the school fees loan, the rotational NIGINA [women's cash and property giving cycles], the demanding boss

at work, the non-adherent patient, the upcoming family function, the side-effects of HAART, what other remedies to try, etc. (Harriet)

This group became our *kibegabega* [shoulder to cry and to lean on]. It is a real invaluable de-stressor. I always look forward to these moments. These are moments when you experience care and feel cared for. (Prim)

Concealment and bodily disclosure due to ART side-effects

The nurses were particularly concerned with the side-effects of ART, such as skin rashes that threatened to reveal their HIV-positive identity to patients. Molly from the NGO clinic narrates how she experienced ART-related side-effects and persistent opportunistic infections that did not respond to ART:

I always feel uneasy having to go to treat my patients with rashes all over my body. I got severe rashes when I started taking ART. This was a terrible side-effect. I wondered if I should just stop taking the drugs but I knew I needed them and my deteriorating condition convinced me the more. I felt so sorry for myself and sometimes I think about it and I get a bit uncomfortable because the rash was really severe – you can't imagine how terrible it was. And then, encountering patients, talking [to] patients, they added salt to injury. . . . A patient friend of mine once shared what newly recruited patients for ART were saying about me while we prepared to initiate them. They were wondering how the drugs we would give them could help when for two months they were seeing me always full of rashes and herpes! I had told them the drugs work and they restore one to full health. But what about me – why did I look the way I did? . . . I suffered severe emotional pain from their shocked stares and their babbling about my condition. I felt bad that I was being a bad role model.

Molly's statement clearly reveals the clash between the biomedical narrative of ART as bringing health and the lived reality of its adverse side-effects. Just as AIDS and its associated symptoms can indirectly give away one's status, so too can ART, through side-effects such as lipodystrophy, muscle wasting and severe rashes. Complicating the matter further, the side-effects show ART to be a technology with serious down sides, thus rendering the message about ART ambiguous – something the nurses found challenging as it diverged from the professional message they were expected to preach to enhance adherence. The nurses were told to inform patients about the drugs – and tell them things that they knew through personal experience were not true, or at least not wholly true.

Due to her severe rash and herpes zoster, Molly felt she was being a bad role model to her patients and a bad representative of the power of ART. She decided to confront her situation and, by doing so, helped both herself and patients in similar situations:

We felt we should do something about this, especially not to kill the confidence of our patients. Later, I asked my colleague to consult with the patients what they were using to fight such rashes. I went on to do my own research with the patients whom I was more close to as my friends. . . . We did this in all four districts and it was amazing what people knew and used.

HIV-positive nurses advocate the Mobile cream (named after the mobile clinic)

After one month of research among patients on what they used to treat ART-related side-effects and persistent opportunistic infections, Molly and her colleague Herman had heard all sorts of interesting answers. They then related these remedies to their colleagues. Molly went on to say:

During our office day1 meeting, I shared my experience with the rest of the staff. Many had ill feelings but given that I was a living test who had become a testimony for what the patients had given me, I managed to convince them, with Herman helping me. I proposed to them what I thought we could do, and they debated and finally agreed to it because I had all these interesting things from our clients. When I tried them, my skin cleared within two weeks. And

this was self-evident from my skin condition, but I also had the help of Herman and two other nurses who had been following my progress with the herbs. We agreed and convened three different meetings on the subject with different clients and came up with a standard recipe. In the first meeting, we invited all the patients who were interested in the use of traditional herbs to our offices and gave them a transport refund. We assured them that we genuinely wanted to learn from them how they managed their persistent illness-related challenges as well as their experiences with herbs.

The first author then asked Molly how it felt to turn the tables and sit and learn from her patients:

At first it felt awkward, strange, unethical. . . . But soon we realised that patients knew so much. We generally stopped being too judgemental and uncomfortable and became easy with them. . . . We were enjoying learning and sharing their deeper experiences. But you know, the language thing of professionals, always wanting to be and to show that you are in control and are the knowledgeable one. We had to set rules for respecting each other's views, and I must say on our part it took, ooh, it takes a lot of humility and effort. But again we realised that is truly what caring is all about. . . . Yes, and I mean it . . . to care is humility.

The Mobile cream is born

Molly explained how agreeing on the recipe involved several meetings with a group of patients who had shown exceptional expertise in herbs during the first meetings:

During a second round of meetings in which back and forth suggestions were given by the patients on useful herbs, we, the nurses, listened, asked questions, and took notes and minutes. It was one of those moments when as nurses we became students learning from our patients and taking interest in each and every detail and asking questions of clarification. . . . It was a great experience, they knew so much. In the beginning, there were several disagreements and contradictions on the multiplicity of usages for certain herbs and their safety. We finally resolved to contact a local herbal expert on the recipe that the patients had given us.

Molly and her colleague Herman, together with some patients, visited the local herbalist (paying a small fee), who confirmed the recipe. The healer subsequently came to the clinic and taught the nurses and the expert patients how to prepare it. After a long process of negotiation, the nurses, patients and the herbalist agreed on the recipe shown in Table 1.

The first author visited the herbalist, who had taught the nurses how to prepare the cream. He was a well-composed, smart man in his seventies and lived in an extremely

Table 1. Recipe for mobile cream.

Ingredients	Preparation
1. 1 kg Vaseline	Melt Vaseline for 5 min then add 6 tablespoons of <i>kanzironziro</i> , then boil for 5 min
2. 6 spoons of <i>kanzironziro</i> powder	Add 5 pinches of salt and wait for 1 min
3. 1 tablespoon of <i>abasi</i> powder	Add 1 tablespoon of <i>ABASI</i> powder
4. 5 pinches of <i>magadi</i> salt	Add 2 ml of water to enable <i>ABASI</i> to dissolve in the <i>kanzironziro</i>
5. 4 ml of water	Soak and mix all freshly pounded ingredients in 2 ml of water
6. Freshly pounded <i>pawpaw</i> leaves	Thoroughly mix all contents together
7. Freshly pounded mango tree bark	Keep mixed contents boiling for 5 min covered
8. Freshly pounded <i>lantana camara</i> leaves and seeds	Remove from fire and wait to cool a bit
9. Freshly pounded <i>namirembe</i> leaves	Filter into a container and leave to cool completely in jelly-like form
10. Freshly pounded <i>bombo</i> leaves	Now it is ready for use

clean dwelling. His demeanour and appearance gave him credibility as a herbalist with 50 years of experience. He talked with passion and authority. 'I care for all kinds of patients and God cures them', he said. He relied on his knowledge not only of herbs but also of God. He took pride in the fact that there were people who wanted to use his knowledge to reduce the suffering of others when he passed on – and particularly that *abasawo* (professional nurses) had come to consult him, which for him was recognition of his work. It seemed that the nurses trusted the herbalist for his expertise in alleviating suffering and patients were trusted in their ability to find remedies that worked for them.

Once the formula for the cream had been finalised, two further meetings involving patients and the NGO administration were held where it was agreed that the patients would supply the hard-to-find ingredients (one has to find them in the bush, dig up the roots, then dry and grind them into a powder). After some negotiation, the administration agreed upon a satisfactory remuneration to the patients for the ingredients. It was then agreed that the nurses would take responsibility for preparing the cream. The nurses invited the herbalist to their offices to demonstrate the preparation until they had perfected it themselves. They now prepare the Mobile cream once a month, which is used for skin-related problems and is very popular among patients.

Discussion

HIV-positive nurses working in HIV-related care in Uganda face a double burden. Not only do they face daunting working conditions with meagre resources, so aptly described by Wendland (2010) in the case of a Malawian hospital. They also suffer the fear of enacted stigma for being HIV-positive – were it to become known. Being healthcare professionals in the middle of the biomedical hierarchy also means being vulnerable to losing the respect of both patients and doctors. The nurses weighed the benefits of disclosure against its costs, and acted accordingly. What tactics did they employ to improve the quality of their lives and to resist the disclosure imperative that prevails in HIV-related care?

We observed three different tactics, which together led to a radical change in the local implementation of HIV-related care. The first tactic, employed initially by two of the nurses, was individual: they simply kept their HIV status a secret in the workplace. In doing so they avoided stigma from colleagues and maintained their positions as 'professionals' in the medical hierarchy. This tactic was employed by the nurses working in the public health centre, where the 'Greater Involvement of people with HIV/AIDS' principle has been implemented less than in the NGO clinic, where the nurses did disclose. This tactic, however, comes at a cost. Not disclosing to colleagues means that they have to confront the burden of the disease on their own. It is, moreover, hard to maintain the secret as the side-effects of ART threaten to give them away.

The second tactic emerged from a focus-group discussion that the first author conducted with four nurses (two who had disclosed and two who had not). This meeting formed the beginnings of a 'collective' secret space for nurses to share their experiences, the so-called Open Up group. This open space provided them with much needed care and support. While other social support groups are public and open to the referral of new members, the four nurses in the Open Up group remained secretive about the existence of the group and its activities in a setting where they feared losing their authority as healthcare providers. Keeping the 'collective' secret required strong, ongoing trust. By choosing to whom, when, where and how to tell, avoid, disclose and interact, the nurses created a space around themselves where they could feel free from prejudice and speak openly about their problems, even if only for the moment. In this safe space, the nurses felt

that their honour and respect were maintained. Nevertheless, their collective enterprise remained at risk. Two nurses were open about their HIV status at work, the two others were not. Those who had disclosed at work thus had to keep the others' secret. In doing so, they defied the imperative that support groups are public places for HIV-positive individuals to discuss their concerns. The Open Up group also failed to acknowledge the needs of other HIV-positive nurses who were not part of the secret group.

The third tactic emerged out of the impossibility of keeping one's HIV status secret. In the Open Up group the nurses discussed how rashes and other HIV or ART-related changes in the body made disclosure virtually unavoidable. We have shown how one nurse, Molly – following a troubling period of self-doubt and secrecy as what she told her patients was contradicted by what her body was communicating – came to advocate herbal remedies in the NGO clinic environment, one that was relatively open to patient participation. Molly felt that she could not tell her patients that she, like them, was on ART and that it was partly responsible for her outward appearance. This would contradict her essential message about ART – a message of healing, of relief from symptoms and pain, of hope and a new life. It was precisely this that made her feel like a bad role model. Molly liaised with expert clients and traditional healers to develop the herbal cream – the third tactic described in this paper. In doing so, Molly and her colleague Herman defied another hegemonic discourse – that once on ART, patients should not use complementary therapies, specifically local traditional herbal remedies that may counteract the ART and cause bodily harm. What is unique in the case of the Mobile cream is that the nurses did not simply recommend patients to find pre-existing complementary remedies. Rather, they learnt about alternative remedies from their patients, worked with them to find the ingredients and then processed them into a novel product, highly valued by ART users suffering from skin rashes.

We also saw how Molly and her colleagues successfully challenged the official view on herbal remedies and how the organisation adopted the herbal concoction, even naming it after the NGO mobile clinic to give the cream legitimacy. After observing the positive changes in symptom severity and recovery time among patients who reported using extra or alternative remedies, Herman and Molly (who had themselves used herbal alternatives on their patients' advice) negotiated with the programme's administrative and management staff for more formal integration of such remedies into their practice.

The few anthropological studies of HIV-related care in Africa have emphasized the disciplining role of healthcare workers in ensuring that patients adhere to treatment (see Mattes 2011). This study has shown that for a select group of HIV-positive nurses in Uganda, identification with patients led them to resist biomedical hegemony and introduce innovations in patient care that also improved their own health and professional lives. It also allowed some nurses, who were initially intent on keeping their status secret, to disclose their HIV status without being socially rejected and without changing their positions along the blurry boundary between patients and healers. The innovation, however, only took place in the NGO clinic, which was relatively open to expert patient participation in HIV-related care. The HIV-positive nurses in the public clinic, where expert patients had less power, continued to keep their HIV status secret.

Note

1. One Monday every fortnight is dedicated to office work and the sharing of experiences. The day begins with morning prayers with all staff. Anyone with an experience, question or challenge in the previous two weeks is then given a chance to share it. This is followed by office work where teams meet to tally records, account for activities and write field reports.

References

- Bamberg, M. 2006. Biographic-narrative research, quo vadis? A critical review of 'big stories' from the perspective of 'small stories'. In *Narrative, memory and knowledge: Representations, aesthetics, contexts*, ed. K. Milnes, C. Horrocks, N. Kelly, B. Roberts, and D. Robinson, 63–79. Huddersfield, UK: University of Huddersfield Press.
- Bok, S. 1984. *Secrets: On the ethics of concealment and revelation*. Oxford: Oxford University Press.
- Cusick, L. 1999. The process of disclosing HIV positive status: Findings from qualitative research. *Culture, Health & Sexuality* 1, no. 1: 3–18.
- Dapaah, J.M. 2012. *HIV/AIDS treatment in two Ghanaian hospitals: Experiences of patients, nurses and doctors*. Leiden, The Netherlands: African Studies Centre, University of Amsterdam.
- De Certeau, M. 1984. *The practice of everyday life*. Berkeley: University of California Press.
- Dieleman, M., G. Biemba, S. Mphuka, K. Sichinga-Sichali, D. Sissolak, A. van der Kwaak, and G.J. van der Wilt. 2007. 'We are also dying like any other people': Perceptions of the impact of HIV/AIDS on health workers in two districts in Zambia. *Health, Policy and Planning* 22, no. 3: 139–48.
- Hardon, A., and H. Dilger. 2011. Global AIDS medicines in East African health institutions. *Medical Anthropology* 30, no. 2: 136–57.
- Iliffe, J. 2005. *Honour in African history*. Cambridge: Cambridge University Press.
- Körnera, H. 2007. Negotiating cultures: Disclosure of HIV-positive status among people from minority ethnic communities in Sydney. *Culture, Health & Sexuality* 9, no. 2: 137–52.
- Kyakuwa, M. 2009. Ethnographic experiences of HIV-positive nurses in managing stigma at a clinic in rural Uganda. *African Journal of AIDS Research* 8, no. 3: 367–78.
- Kyakuwa, M. 2011. Going the extra mile: An ethnography of care-giving and care designing among nurses in Uganda. Unpublished thesis, University of Amsterdam.
- Lehmann, U., and W. van Damme. 2009. Task shifting: The answer to the human resources crisis in Africa? *Human Resources for Health* 7: 49–54.
- Mattes, D. 2011. We are just supposed to be quiet: Patient adherence to antiretroviral treatment in urban Tanzania. *Medical Anthropology* 30, no. 2: 158–83.
- Mdege, N.D., S. Chindove, and S. Ali. 2012. The effectiveness and cost implications of task-shifting in the delivery of antiretroviral therapy of HIV-infected patients: A systematic review. *Health Policy and Planning*, June 26 (Epub ahead of print).
- Ministry of Health. 2005. *Strategy for antiretroviral therapy 2005–2010*. Kampala: Earnest Publishers.
- Minnaar, A. 2005. HIV/AIDS issues in the workplace of nurses. *Curationis* 28, no. 3: 31–8.
- Obermeyer, C.M., P. Bajjal, and E. Pegurri. 2011. Facilitating HIV disclosure across diverse settings: A review. *American Journal of Public Health* 101: 1011–23.
- Tenthani, L., C. Cataldo, A.K. Chan, R. Bedell, A.L. Martiniuk, and M. van Lettow. 2012. Involving expert patients in antiretroviral treatment provision in a tertiary referral hospital in Malawi. *BMC Health Services Research* 12, no. 1: 140.
- UNAIDS. 1999. *From principle to practice: Greater involvement of people living with or affected by HIV/AIDS (GIPA)*. Geneva: UNAIDS.
- Wendland, C. 2010. *A heart for the work: Journeys through an African medical school*. Chicago, IL: University of Chicago Press.
- WHO. 2003. *Gender dimensions of HIV status disclosure to sexual partners: Rates, barriers and outcomes*. Geneva: World Health Organization.
- Zelnick, J., and M. O'Donnell. 2005. The impact of the HIV/AIDS epidemic on hospital nurses in KwaZulu Natal, South Africa: Nurses' perspectives and implications for health policy. *Journal for Public Health Policy* 26, no. 2: 163–85.

Résumé

Cet article rend compte d'un travail de terrain de deux ans et demi, mené dans deux centres de santé ruraux en Ouganda pendant une étape de l'élargissement de l'accès à la thérapie antirétrovirale. Environ un tiers des infirmières qui exerçaient dans ces deux centres étaient elles-mêmes séropositives au VIH, mais la plupart d'entre elles gardaient secret ce statut sérologique. Nous décrivons comment un groupe d'infirmières séropositives a constitué un cercle secret qui leur a permis d'échanger sur la difficulté que représentaient pour elles, en tant que professionnelles de

santé, leur séropositivité au VIH ; et comment elles ont élaboré des méthodes de soins innovantes pour gérer les rashes cutanés qui, résultant de la prise des antirétroviraux, menaçaient de les conduire à l'échec thérapeutique. Avec les patients et les guérisseurs traditionnels, ces infirmières ont résisté aux normes biomédicales hégémoniques qui désapprouvent l'usage de médicaments à base de plantes, puis échafaudé un plaidoyer pour l'intégration d'une crème à base de plantes aux protocoles de traitement par médicaments antirétroviraux.

Resumen

Este artículo se basa en un trabajo de campo etnográfico de dos años y medio de duración en dos centros sanitarios rurales de Uganda durante un periodo en el que aumentó el uso de antirretrovirales. Aproximadamente un tercio de las enfermeras en estos dos centros eran seropositivas pero la mayoría ocultaba su estado. Aquí describimos cómo un grupo de enfermeras seropositivas crearon un círculo secreto para hablar de su difícil situación en calidad de profesionales de la salud infectadas con el VIH y cómo desarrollaron técnicas innovadoras de cuidado para curar las erupciones cutáneas causadas por los antirretrovirales que amenazaban por delatar su estado. Junto con los pacientes y un curandero tradicional, las enfermeras rechazaban las normas biomédicas hegemónicas que critican los medicamentos a base de plantas, y más tarde idearon y apoyaron la introducción de un tratamiento en forma de crema para la piel a base de plantas en el programa de antirretrovirales.