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Dlamini, T.T.T.

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CHAPTER 3

‘Lost to Follow up’: Rethinking delayed and interrupted HIV treatment among married Swazi women

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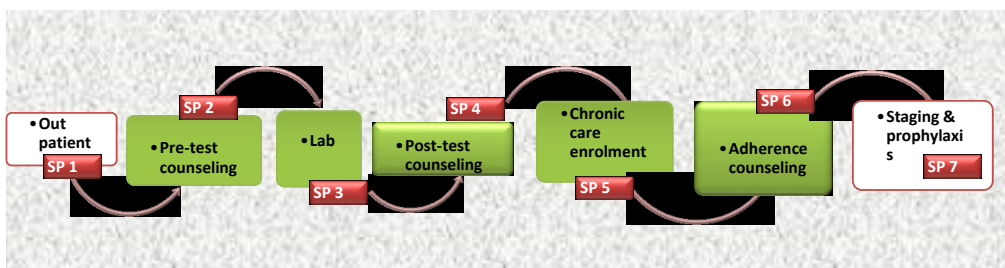
Abstract

Through various campaigns and strategies more women are being tested for HIV in countries with a high prevalence of the virus. Despite the ready availability of treatment at government clinics in sub-Saharan African countries like Swaziland, women consistently report difficulty in maintaining access to treatment. Drawing on two individual case studies selected from a larger study of the so-called leaky cascade in Swaziland, we illustrate the protracted journeys married women undertake to initiate treatment. We demonstrate how women manoeuvre tactically after diagnosis, highlight factors that influence their decisions related to initiating treatment, and detail the actors involved in the decision-making process. Our research shows the persistence of structural factors that inhibit access, including economic constraints, gender inequality and patriarchal social norms. Patients referred as 'lost to follow up' are in many cases actively pursuing treatment within a context that includes the biomedical health system, but also extends well beyond it. We argue that the phrase 'lost to follow up' conceals the complex social navigation required by women to initiate and maintain access to treatment. Further, we suggest that many of the logistical challenges to monitoring and tracking people with HIV can be better addressed by taking into account the structural and social aspects of delayed treatment initiation.

Introduction

The large-scale expansion of HIV testing in Africa has proven an effective means of diagnosing more people (Weigel et al. 2009; Larson et al. 2010; Creek et al. 2007). However, keeping patients in care continues to present challenges for treatment programmes (Bassett et al. 2010; Rosen 2007). In 2010, the attrition rate of clients between the moment of HIV diagnosis and the initiation of treatment was estimated to be around 50% in sub-Saharan African countries (Ahoua et al. 2010; Larson et al. 2010). In Swaziland, the last couple of years have witnessed increased efforts by NGOs and the state to increase uptake of treatment among those known to be HIV positive. One component of these efforts has been the institution of fixed definitions and timelines to monitor client compliance. If clients fail to adhere to these timelines they are labelled as ‘treatment defaulters’ or ‘lost to follow up’. This strict monitoring procedure to increase participation in treatment has led to a situation in which people wishing to test for HIV are required to pass through seven service points on the day of diagnosis.

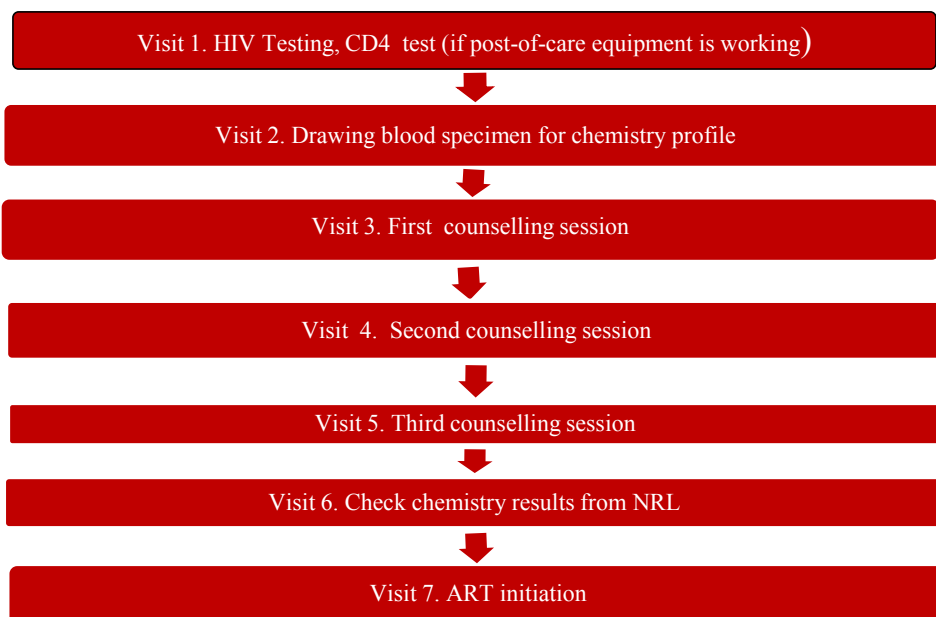
Figure 1: Service point (SP) for clients testing HIV positive on day of diagnosis



Once diagnosed, clients are then required to endure another protracted process to determine if they are eligible for treatment and, if so, another process to initiate treatment (see Figure 2). Each service point means another queue, another waiting period, greater frustration and

greater likelihood that clients will fail to access care.

Figure 2: Clinic visits required to initiate ART at clinics



This article examines the logistical and social dynamics that contribute to HIV-positive women ‘falling out’ of the biomedical health care system in Swaziland. The study on which this article is based was conceived to inform the use of lower treatment thresholds as a way of scaling up HIV treatment, in anticipation of shifting global health guidelines. These new global guidelines mean that people testing positive for HIV in many countries will be encouraged to start treatment earlier, often before they feel sick or have developed any symptoms of disease. The ultimate public health goal of this approach, known globally as ‘Treatment as Prevention’, or TASP, is to prevent new infections by using antiretroviral treatment (ART) to lower HIV viral loads to undetectable levels among infected individuals, which will dramatically lower the risk of them infecting others. For TASP to be effective, many more HIV-positive people will need to be enrolled in treatment. In Swaziland, to date,

most attempts by donors and the state to increase access to care have focused on the health system, including point-of-care diagnostics to shorten the time between testing and patient diagnosis, and the introduction of a new tracking system based on individual patient numbers. While these logistical fixes are important, we question the extent to which they will improve treatment uptake.

In this article, we focus on married women that is, all women who reported being in a long-term, committed relationship regardless of legal marital status, who are present in high numbers in health clinics. Because it is mandatory for pregnant women to be tested for HIV in Prevention of Mother-to-Child Transmission (PMTCT) programmes, the majority of people attending clinics at the time of our study were married women who had been diagnosed with HIV when they were pregnant; there were far fewer men or unmarried women attending clinics. PMTCT programmes are among the most widespread and least contested HIV-treatment programmes in Swaziland and elsewhere in Africa. Focusing on married women thus provides a good lens onto the treatment cascade, as they are more likely to have earlier and repeated encounters with HIV-treatment programmes.

Although we found that unmarried women were also constrained by patriarchal social norms in Swaziland as elsewhere (Furuta and Salway, 2006), married women faced particular challenges due to economic dependency on spouses and significant social vulnerability, which results from the fact that most married women prioritized honour in marriage and performance of being a good wife over seeking treatment and risking stigmatization. Conversely, single women can work far from home, most importantly, single women are not required to negotiate with spouses to work or engage in migrant labour opportunities. Although they usually seek permission from their natal families, the process is more straight forward and does not involve consulting with wider kin network. Although a few married women we interviewed were

involved in informal trade to supplement household income or worked in factories (especially those from peri-urban areas), the majority did not report an independent income.

Spousal negotiation shapes nearly all spheres of life for married women, including decision related to health care. Wilson and colleagues (2007) and (Campbell, 2002) report that women who suffered partner violence ranked healthcare needs of their children over their own. Generally, Swazi women strive to conform to norms of being a good mother and wife, prioritizing honour in marriage and over personal desires and needs for healthcare, including seeking HIV treatment, which would risk bringing stigma to themselves, their household and their kin. Married women usually must consult with a wider circle of people before seeking health care; decisions regarding which therapy to pursue are often made on a woman's behalf. The circle is made up of a woman's husband and kin from both sides of the family, constituting a large and unwieldy 'therapy management group', a term coined by Janzen (1987: 68), to define a 'constellation of individuals (kinsmen, maternal or paternal, friends, associates) who, during an overwhelming problem, i.e., illness episode, emerge to take charge of the sufferer'.

From the start of our research, we questioned the assumption that health system fixes alone – decentralization of care, antiretroviral medications, defaulter tracing, etc. – would resolve the challenges of timely access to HIV treatment. Underlying that assumption is the notion that patients make healthcare choices solely based on biomedical information, need and availability of health services, while ignoring wider social, economic and cultural factors. We also questioned how health systems commonly refer to patients not accessing care as 'treatment defaulters' or 'lost to follow up', terms that define patients from the perspective of the healthcare system. We argue that such terms are particularly problematic given the limited capacity of health facilities in Swaziland and elsewhere in Africa to track patients who do not

return for recommended care. Many patients who were referred to as ‘lost to follow up’, in the study sites were found to be actively navigating various social and economic challenges in an effort to initiate treatment. Power structures within families, lack of autonomy to choose preferred therapies, pressure to abide by gender norms and concerns for family honour constrain married women from accessing treatment, even when available and desired.

In order to understand why people diagnosed with HIV ‘fall out of care’, we must recognize that, despite their HIV status, they remain social as well as medical beings. Because an HIV diagnosis has the potential to disrupt marital and family relations, and bring dishonour to the individual and the extended family, those who have the most to lose socially and economically will be the most careful in disclosing their status to loved ones (Moyer 2012; Hardon and Posel 2012; Iliffe 2006). This is often true for married Swazi women, a fact that becomes particularly problematic if disclosure is required before ART can commence. Although in Swaziland people are not required to disclose their status before they can access treatment, married women often find it necessary to do so in order to explain clinic visits, the presence of medicines in the house, exclusive breastfeeding practices, the need to give medicine to children or the need to get money for transport to the clinic. Our approach, with its focus on the larger social and logistical context, differs from rational choice models commonly employed in health systems research, which assume that individual clients consciously (and rationally) choose appropriate medical services when they are offered (Victoor, 2012).

In the case of married HIV-positive Swazi women, understanding family dynamics is essential for gaining insight into the reasons they delay treatment. Ideally, our research would have entailed following women into their home environments and witnessing their struggles as they attempted to disclose their status to partners and other family members in their quest for therapy. Given the sensitive nature of the topic and the fact that women were already feeling quite pressured by the health system, we decided it would be unethical to do so. As such, our

arguments are based on interviews with individual women contacted through ART clinics and our ethnographically informed understanding of Swazi cultural norms and family dynamics.

Theoretical Framework: Social navigation of therapeutic itineraries

In order for married women to access treatment, they must navigate the risky terrain of their domestic worlds (Vigh 2009). Though a married woman receives the same information in health facilities as anyone else who tests positive for HIV, she is generally not free to act on that information before discussing it with her husband and, often, her mother-in-law and others who make up her therapy management group (Janzen 1987). This constraint is exacerbated when a woman is financially dependent on her partner because she will need money for transport.

French anthropologist Marc Augé (1985) coined the term ‘therapeutic itineraries’ to describe the protracted routes patients take before finding desired and efficacious treatment. By examining the detours and roadblocks patients encounter in search of treatment we can gain insight into the institutional causes for delayed access to treatment. Stopping at the institutional borderlands of health facilities, however, risks overlooking the importance of the wider contexts – structural, social and personal – that give contour to the diverse maps patients follow in their quest for therapy. Building on Vigh (2009: 420), we argue that ‘social navigation’ is an analytically useful concept because it allows us to capture an ‘alternative perspective on practices and the intersection between agency, social forces and change . . . it grants us an analytical optic which allows us to focus on how people move and manage within situations of social flux and change’. Similar to the way a global positioning system (GPS) can help a traveller navigate unknown terrain and reach a desired destination, a woman’s knowledge of the realities that can constrain her access acts as signposts that guide her as she

navigates potentially dangerous social terrain on the road to ART.

Although rarely considered within the literature on HIV-treatment itineraries, more than two decades of ethnographic studies of reproductive health decision making have convincingly argued against the utility of rational choice models that presume an uncomplicated relationship between women's reproductive desires and fertility outcomes (Bledsoe 2002; Cornwall, 2007; van der Sijpt 2014). Similarly, seminal research by Schoepf (1992) on HIV prevention and condom use in Zaire questioned the extent to which socially and economically marginalized women were able to negotiate safer sexual practices with lovers and husbands. Building on Vigh's work on social navigation, van der Sijpt (2014: 279) has put forth a model of reproductive navigation that attempts to account for the 'ways in which people give direction to their reproductive trajectories'. Her model resonates strongly with earlier arguments made by Johnson-Hanks (2005) about the creativity and contingency of reproductive decision making in uncertain contexts in Cameroon, as well as Cornwall's (2007) findings on the ways that Nigerian women utilize both strategies and tactics (following de Certeau [1984]) to navigate the complex terrain of the extended family in relation to reproduction.

Using individual case studies from Swaziland, we demonstrate that women's decision making around initiating HIV-related health services can be best understood through a lens of strategic and tactical navigation, whereby married women must navigate the multiple and often dangerous social terrains inhabited by the therapy management group. The first such terrain a woman must navigate following her diagnosis is her own marriage, while disclosing her HIV status to her partner. Then she must navigate the terrain of spousal resources, in an attempt to elicit financial, emotional and psychological support from him. The third terrain is that of the wider kinship network. For most married women, it is only after these dangerous terrains are

successfully navigated that they are able to initiate ART. Especially for economically vulnerable women, remaining adherent to a treatment regimen is likely to require travelling those dangerous terrains again and again.

Gender in Context: The good wife

The research for this study was conducted in two community-based, government-run ART clinics. One was located in a peri-urban area, 8 km from the capital city, Mbabane; the second was located in a rural area, 200km from Mbabane. In both settings, the expectation was that women would not work outside the home. Although a few married women we interviewed were involved in informal trade to supplement household income or worked in factories (especially those from the peri-urban clinic), the majority did not report an independent income. Cultural norms in Swaziland that require women to consult with their husbands before seeking health care are combined with women's lack of independent income, both of which constrain women's agency to manage their own health.

The Swazi constitution of 2006 upgraded the status of women, making them equal under the law to their husbands. In practice, however, little has changed within the domestic sphere. Women live under the guidance of their fathers until marriage and under their husbands thereafter. They are expected to be loyal to elder kin, especially mothers-in-law. A woman must get permission from her husband for almost everything; doing so is a sign of submission and an important attribute of a good wife. Such submissiveness is recognized both as a performance of Swazi tradition and is shaped by a Christian ethos of how a wife ought to relate to her husband. Disregarding a husband's wishes and authority is considered a serious transgression, as a husband can use it as the basis to separate from and divorce his wife. A failed marriage brings disgrace and dishonour to the bride's family. In most cases, a wife would rather shoulder discomfort and try to live peaceably with her in-laws than bear the

shame of returning to her parents.

Although a woman may find herself subjected to patriarchal norms, there are contexts in which she may benefit. As a wife she may be vulnerable, but as a mother and mother-in-law, she can exert power over her own children, especially sons – even when grown – and also over her eventual daughters-in-law. Although a husband may control his wife, his mother often also controls him; if she is not happy with her daughter-in-law, her son may separate from his wife to assuage his mother. Because of this, most married women work hard to be seen as a good wife and a good daughter-in-law. Although this portrayal of married women as submissive to both husband and mother-in-law is somewhat simplistic, the lead author's experience as a highly educated and economically independent Swazi woman suggests that even for comparatively empowered women, it is necessary to approach negotiations within the confines of the marriage carefully to limit unwanted interference and judgment from in-laws and the wider community

Methods

Most of the data presented in this article was collected over one year (June 2012–June 2013) in a sub study. The larger parent study continued for another year, permitting us to follow-up on the two cases discussed in this article. The larger study sought to understand why patients (not just married women) drop out of care following a diagnosis, what is often called the 'leaky cascade' in public health (Fox and Rosen 2011; Eberhart.2013).

As ethnographers, we approached data analysis as an iterative process, allowing themes to emerge over time from interview material as well as extensive participant observation. Using this approach, we rather quickly detected a pattern: most women attributed missed appointment to spousal dynamics. In addition to mining field notes for recurring themes, we also developed a preliminary coding system to reflect the reasons offered by the women for

missing an appointment. These were applied soon after each interview. As recurring themes were observed our coding system evolved to allow us to identify the most commonly reported problems. When data collection was completed, we used the same coding system as the basis for exhaustive coding and content analysis facilitated by NVIVO.

We systematically recorded the personal accounts of women and analysed data on an on-going basis. Saturation was reached after sitting in 40 counselling sessions with women. Of 40 women, 24 were married and interviewed up to two times. However, two women were interviewed the most (6-8 times each) because they proved the most accessible to us (in terms of both willingness and availability to share their trajectories). This article draws on a series of in-depth interviews over a year conducted with two women, Sibongile and Nkunku, whose cases typify the experiences of many other women we encountered in the field. Figure 3 provides an overview of their demographic background.

Figure 3: Demographic characteristics

	Nkunku	Sbongile
Age	Late 20s	Late 40s
Education level	Primary	Primary
Marital status	Married for 7 years	Married for 18 years
Gainful income	No	No

The study was approved by the ethics board at the University of Amsterdam and the Swaziland Committee for Scientific Research. All interviews were conducted by the lead author in SiSwati and audio-recorded with permission of the interviewees. The lead author also transcribed and translated all interviews into English. The second author assisted with analysis and writing. The transcription of all interviews, including those of Sibongile and Nkunku, were coded and subjected to thematic analysis.

Findings

The reasons provided by women who dropped out of care were tied to gendered social norms that went beyond health system shortcomings. Married women commonly offered spousal justifications for missed appointments leading to delayed ART uptake; men did not. The following table summarises reasons given by women for delaying treatment.

Figure 4: Reasons for missed appointments for married women

Rationale	Frequency
1. Spouse denies HIV infection and refuses to test	4
2. Spouse forbids use of ARVs within the home	3
4. Fear to disclose status/ARVs cannot be taken secretly/risk expulsion by partner or discrimination	5
5. Economic dependence on spouse limits ability to make autonomous health decisions	5
6. Fear of side effects that would make women less desirable to spouses (changes physique/ affects libido)	7
Total	24

Overall, the female defaulters in the sub-study were rarely gainfully employed and most were economically dependent on their spouses. They placed great value on their marital relations and stated that making healthcare decisions prior to consulting spouses would jeopardise those relations. The two cases discussed in detail below reflect these common concerns. The HIV-related treatment trajectories of these two women illuminate the gendered social complexities that make married women more likely to delay treatment and prioritize spousal wishes over their own.

Case 1: Gender, economic vulnerability and delayed ART initiation

Sibongile

It was just before noon on a warm summer day when I met Sibongile.ⁱ She had known her HIV status for three years and, although she had disclosed it to her husband, she had never sought medical follow up. She had not been feeling well and suspected her deteriorating health might be related to her HIV status. Though she did not appear ill, a CD4 test revealed her count was an extremely low 36, indicating she should start treatment as soon as possible or risk death in the near future. A normal CD4 is considered to be above 350; ART should be initiated when the CD4 count is below 350. When the counsellor asked her why she had not sought follow-up care as advised when she had tested positive three years earlier, she sidestepped the question, replying, ‘In fact, I came to the clinic today to follow up on previous advice’.

She was a kind and free-spirited lady who reminded me of my mother in many ways. As she was being assessed and registered, our conversation seemed to unfold naturally. Although I generally guarded myself from becoming too emotionally involved with patients, I was drawn to Sibongile and became concerned about her. I drew comfort from the fact that she did not look seriously ill and reassured myself that, as long as she finished the required steps (Figure 2) quickly and started ART, she would be fine.

At the time, I met Sibongile she was in her late 40s and married with three children. She talked constantly about her young children, saying they were the main reason she came to the clinic, as she did not want to die and leave them without a mother. A few weeks after getting to know her a bit, I visited the clinic to follow up with some of the other clients and discovered her file had been added to the pile of defaulters; she had not come for a scheduled adherence counselling session, which was required before treatment could start.

After this ‘no show’, I tried but failed to contact her. She did not have a phone, and the phone of her sister, whom she had registered as her contact, was not working. My desire to reach her went beyond research. I was concerned for her health, not only because I knew how important timing was to her condition, but also because we had connected. Although tracking her down became a personal project, I eventually had to give up and trust that fate would bring her back to the clinic in time. My experience of trying to find Sibongile illustrates the difficulties of contacting patients; patients often do not have phones, others, not wishing to be contacted at home, provide false numbers or numbers that are out of service. Such patients are assumed to be lost to follow up.

During another visit to the clinic a few weeks later, Sibongile showed up while I was sitting on the veranda. I was happy and relieved to see her. We briefly spoke about her condition before I invited her to talk more extensively once she finished her visit. We had a lengthy discussion that day, followed by one more in-depth discussion two months later. Through these conversations, I learned why it had taken her five weeks instead of one to return for her appointment.

Sibongile was economically dependent on her husband: ‘He controls the money we make together through farming and selling vegetables and only gives me money when he thinks it’s a priority’. To get to the clinic she took two buses, making bus fare a constraint for timely access to care (cf. Hardon et al. 2007). She told me, ‘Sometimes when I ask for permission to go to the clinic he gives me the silent treatment. His silence is ambiguous – it could mean disapproval or just that there is no money’.

When Sibongile had learned at her previous visit to the clinic that she could start ART immediately, she said she was happy and looked forward to the benefits of ART: regaining weight, productivity and health. When I asked her to tell me what had happened since I last

saw her, she replied:

I promptly informed my husband of the date I would need to return to the clinic to fulfil the pre-ART enrolment steps. As the date drew near, I reminded my husband, but the date passed and I received neither permission nor funds to travel to the clinic. When I brought the matter to my husband's attention, he told me that because he had to pay school fees, there was no money left for my clinic visit. Weeks passed and I could not get to the clinic; all the while my condition was deteriorating. Thinking I might die waiting for money from my husband, I asked permission to visit my father to ask for money. My father lived far away, but I could walk there, so I decided to try to walk or hitchhike to his home. My husband couldn't allow that and he gave me the money. He would be shamed if my parents were to learn that he is not able to take care of my needs. It would be an insult to his ego to lose respect with his in-laws.

Her husband's refusal to give her bus fare resulted in Sibongile delaying five weeks before returning for her first adherence-counselling session. She also had to negotiate for funds for two more trips to attend two more adherence-counselling sessions. She lost even more time waiting for the results of her liver function test. A total of three months passed before treatment could begin. Since Sibongile did not have a phone, I could not contact her and did not learn of her outcome until eight months later, in June 2013, when I returned to the clinic. I enquired when she was due for her next appointment to see how she was responding to the treatment. It was then that I learned that Sibongile had died two months earlier, in April.

Ideally, no more than a month should pass between when a patient becomes eligible for treatment and when treatment begins. In Sibongile's case, the first delay resulted from her waiting three years after her HIV diagnosis to get a CD4 count. Once she had the CD4 test, she was required to attend three adherence-counselling sessions and have liver and kidney

function tests. Had she shown up for her scheduled appointments at the clinic, this would have likely been a one-month process. Because she had to negotiate with her husband to get bus fare before each appointment, however, she was repeatedly delayed: five weeks before her first counselling session and a total of three months before she initiated treatment. There is no doubt that these delays, caused by her desire to be a good wife and her economic dependence on her husband, reduced the likelihood that treatment would be effective and very likely contributed to her death.

Case 2: The complexity of treatment delay

Nkunku

I met Nkunku, a young married woman in her late 20s, at the clinic when a counsellor informed me there was a patient I should interview for my study who had 'refused ART'. It seemed the counsellor was hoping I would succeed where she had failed in convincing Nkunku to start ART. The donor responsible for paying counsellors' salaries, pressures counsellors to get patients' treatment initiated quickly; counsellors often saw my engagement with patients who were refusing treatment as a way to help them reach their targets. Since Nkunku's profile seemed to fit within my research parameters, I agreed to interview her, but did not pressure her to initiate treatment.

As I talked with her I could see that she was deeply aggrieved. In tears, she told me 'the counsellors are putting pressure on me to take antiretroviral medication; they refuse to understand my situation. Two times they [two counsellors and the clinic's head nurse] tried to convince me to start treatment, telling me I will die if I refused. The head nurse even threatened to send the police to arrest me if I continued to refuse'.

Nkunku was pregnant with her second child when we met. She had learned her HIV status seven years earlier, when she was pregnant with her first child, who was born with HIV.

Nkunku was ready to start treatment, but there were obstacles: her husband was arrogant, she said, and in denial of her HIV, demanding that no one in his family take ‘those [ART] pills’. He even refused to allow their daughter to be tested for HIV even though she had been sick numerous times. When I asked her what ‘the situation’ was that the nurse and counsellors failed to understand, she responded at length:

The first year of my marriage was bliss, especially after I became pregnant. The child was a girl; this failed to please my husband and in-laws who were longing for a son to carry on the family name. A wife is highly esteemed in Swaziland if her first child is a son because it resolves inheritance uncertainties. Before the child was two years old, we began having problems in our relationship. I decided to leave my husband; my mother-in-law did not discourage me. That was a sign that she condoned his actions. My husband took another wife immediately after I left, but the new relationship did not last. Two years after their initial separation, my husband sought me out and we reconciled. Now I am pregnant with our second child, but my husband never learned of my or the first child’s HIV status. I fear I will be accused of contracting HIV during the period we were separated, and that I will be blamed for infecting my husband.

Such an accusation would likely result in her being expelled from her matrimonial family. Because Nkunku was an orphan with no siblings or extended family members to care for her, she was fearful of losing her only source of livelihood and refuge should she fall sick.

Nkunku also mentioned that their first child had been sickly since birth. Nkunku used her concern for the child to suggest that she be tested for HIV:

I was hoping for permission to test my child and then report the diagnosis to my husband. This was a tactic to inform my

husband that the child was HIV positive, also giving me the opportunity to inform him indirectly that I was also infected and had been since the birth of our first child.

Nkunku hoped that this approach might lead her husband to recognize that he was also infected and that he could have been the one who brought HIV into the relationship. By informing her husband of the presence of HIV in the family through their daughter, she could prove that she had been infected before she separated from her husband, preserving her reputation as a good wife and allowing her to take ARVs to protect her foetus.

As this plan proved futile, Nkunku devised another strategy. Her second plan was to give her daughter treatment behind her husband's back. However, that would be problematic because the child stayed with Nkunku's mother-in-law, who would have to give her the medication. And if the mother-in-law found out the child's HIV status, she would infer Nkunku's status: 'If my mother-in-law knows my status she will accuse me of infecting her son even though my husband could be the one who infected me. But my position as a wife does not allow me to say that'.

Nkunku knew the importance of taking ARVs to prevent her unborn child from HIV infection. Realizing that the route she was on would likely lead to failure, Nkunku sought out yet another route:

I had to make a tough decision. Should I devise secretive strategies to take ARVs, risk being caught, infuriate my husband and possibly lose my marriage, or should I just be an obedient wife to my husband and not take the drugs? I decided to take ARVs and tell my husband the medication was prescribed for the pregnancy.

Though successful, she knew her ploy would only work as long as she was pregnant. ‘But then what scheme should I devise for my seven-year-old sick child to get the drugs that can save her life, and what excuse will I tell my husband for continuing to take pills after delivery?’ asked Nkunku. The good thing about the route she was on, she said, was that it gave her the time to continue negotiating with her husband.

Discussion: The protracted journey to ART initiation

The delays Sibongile experienced in her attempt to initiate treatment illustrate the extent to which women must navigate within marriages to maintain continued access to medical care. Sibongile could not be described as an uncooperative patient who refused treatment. She wanted ARVs, but due to external factors she failed to access them in time. In her home, she dared not confront her husband in a combative manner, choosing to manoeuvre tactically until she succeeded in getting economic support. By protecting her husband’s ego, she was able to maintain her image as a good wife. She was constrained from initiating treatment because of her economic dependence on her husband and gender norms in Swazi marriages.

However, it was not just in the home that Sibongile experienced delays; a lengthy clinical process that did not allow for flexibility for women in Sibongile’s position also delayed her. From the first day, she visited the clinic she was prepared to start treatment, but bureaucratic clinical procedures prevented her. Despite Sibongile’s desire to initiate treatment and her efforts to navigate the terrain of her marriage, the detours and roadblocks she encountered prevented her from reaching her desired destination.

From Nkunku’s story we observe that women must navigate the dangerous terrain of their marriages to access treatment for themselves and their children, both born and unborn. Nkunku had thought of the various routes she might take to reach her desired destination. She strategically attempted to use her children as a means of disclosing her status and accessing

treatment, believing it to be the best way to protect her reputation in her marriage, provide good health for her and her children, and maintain good relations with her wider family.

Both stories demonstrate that when a married woman has been diagnosed with HIV, she is not free to initiate treatment, even when it is prescribed. Neither is she free to decide on her own to return to the clinic, especially if doing so requires money. As Janzen (1987) found, therapy is often only successfully taken up after consultation with husbands and other kin, including mothers-in-law. In a quest for therapy this wider social group rallies with information, makes decisions on behalf of the patient, and arranges therapeutic consultations, brokering between the sufferer and the providers of relief. It is normally presumed that a sick person's therapy management group will make decisions with the best interests of the patient in mind, but the above examples suggest that other concerns, including maintaining gender and generational power relations, and preserving family honour, also guide the decision-making process.

For most married women in Swaziland, the husband, mother-in-law and wider kinship network constitute the therapy management group. Even when they do not directly accompany women who have been diagnosed with HIV on their therapeutic itineraries, they can greatly influence the routes taken. For a married woman with HIV in Swaziland, her ability to call upon a therapy management group is limited due to concerns about how she might be perceived by her in-laws and how their anticipated rejection might dishonour her birth family. She may feel compelled her to conceal her infection from family members in order to preserve her marriage and family.

Extending Janzen's theory, our findings show that the therapy management group goes beyond providing advice and information on therapy: it prescribes the route a woman ought to follow as a good wife or daughter-in-law. For married women in Swaziland, the route to HIV treatment can be precarious and protracted as a result of these social and structural

complexities. Finding a way to navigate this route requires a woman to be both determined and creative. Labelling women who are actively seeking ways to access care as ‘lost to follow up’, ‘non-compliant’ or ‘treatment defaulters’ obscures and depoliticizes the challenges women face, as well as the creativity they employ to counter those challenges.

Conclusion

The expectation that married women who test HIV positive will act upon information gained from health facilities within narrow timeframes set by global norms seems to be based on a logistical fantasy. It ignores ample evidence that women’s decision making around reproductive and sexual health is often contingent upon social and economic circumstances (van der Sijpt 2014; Johnson-Hanks 2002; Cornwall 2007). Being diagnosed with HIV or declared eligible for ART is not sufficient motivation to submit to a biomedical process that is likely to damage marital and filial reputations. Current HIV treatment targets and guidelines, which measure ‘compliance’ with pre-established timelines for HIV disclosure, the taking of laboratory tests, and completion of adherence counselling, may do more harm than good. As Nkunku’s case shows, taking ARVs to prevent mother-to-child transmission of HIV or enrolling a child in HIV treatment may result in being expelled from family and social networks. It is important that programme implementers focus on building women’s capacity to navigate within their cultural milieu when ART is desired.

HIV treatment programmes in Swaziland, as elsewhere in Africa, are under enormous pressure to demonstrate success through measures and global indicators that overlook local realities. This can lead to nurses and HIV counsellors pressuring clients to make difficult decisions before they are ready and/or refusing to initiate someone on ART despite clear and imminent need. Similarly, in cases when clients test HIV positive without exhibiting any other signs of ill health, undue pressure from health care practitioners may spur clients to withdraw from the

care altogether, only to return when their condition has worsened dramatically.

We can deduce from our research that clients rarely drop out of care voluntarily. In the course of our larger research with so-called treatment defaulters, we never met a client who opposed the idea of ART. Instead, women were not enrolled in treatment because they had not yet figured out how to disclose their status without risking personal and family honour or how to find sufficient economic support to attend necessary clinic appointments. Also, five participants in the study whom counsellors reported as 'refusing ART' in fact returned to seek treatment, but this was outside the timelines set by clinics.

For most, the time between HIV diagnosis and ART initiation was a period of serious contemplation, introspection and weighing of options. Rather than pressuring clients during this period, it is important to recognize there might be clients unable to start treatment as advised. As the future for ART is to enrol all HIV-positive clients as early as possible, having an expert counsellor in each clinic to deal with such issues could help, as well as a dedicated supervisor for counsellors (there are none at the moment) who can mentor counsellors when they are met with difficult cases and provide professional development.

Our research suggests that women are more likely to remain linked to care when the health care practitioners they encounter are flexible in terms of scheduling. The bureaucratic processes for ART initiation can be made less rigid by streamlining processes to be client-friendly and reducing waiting times. Provided they live long enough, most women seem to find their way back to the system. Many of the women we interviewed in our larger study eventually returned to care. Even Nkunku's efforts finally paid off. Fourteen months after we first met, she finally convinced her husband to be tested for HIV and to allow their oldest child to be tested as well. By September 2013, Nkunku, her husband and their daughter had all begun HIV treatment and all reported good health.