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‘Looking for greener pastures’: Locating Care in the Life Histories of Community Health Workers

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Abstract

The question of who does the caring and why is fundamental to understanding the dynamic practice of AIDS care in post-apartheid South Africa. This paper explores motivations to enter carework as part of the life narratives of fifteen young South Africans – all pursuing ‘the good life’ in a country where high emancipatory expectations clash with tremendous structural constraints. Drawing on over ten hours of interview data focusing primarily on respondents’ life stories, the paper explores the moment of entering carework as part of a largely improvisatory set of tactics to ‘get by’ and hopefully ‘move up’ in post-apartheid South Africa. For some, becoming a carer felt like a well-considered choice, but for most it was an opportunistic ad hoc move amidst a range of other contingencies in their daily lives.

Introduction

In an effort to understand who provides AIDS care and why, this paper locates the moment of entering carework in the life histories of fifteen community health workers serving as antiretroviral (ARV) adherence supporters in Kraaifontein, Cape Town. Respondents in this study are employed as 'patient advocates' (PAs) by the non-governmental organisation 'Kheth'Impilo', whose mandate is to support the state in delivering primary healthcare. Interview data were analysed using procedures from Grounded Theory (Glaser & Strauss, 1967). Pseudonyms are used throughout to protect the anonymity of participants.

Growing up in black urban townships and rural villages of the 1980s and 1990s, respondents' childhoods were marked by rapid urbanisation and socio-political change. The late 1980s saw the beginning of a transition period to democracy and 'free' markets[1]. At the same time AIDS was taking root in South Africa, marking the beginning of a 'new death' (Posel, 2002: 51) – an epidemic that would quickly become the most severe in the world (Marais, 2005: 7). It was also during the late 1980s that black families with newfound mobility began building homes on the urban peripheries of Kraaifontein, signifying the beginning of the two informal settlements where this research is based. These young people, the place where they live and work, the post-apartheid moment in which they find themselves, and the epidemic they must confront, are all coming-of-age in significant ways, shaping the place of carework in their lives.

This paper should be read in the context of a changing epidemic and a changing AIDS response in South Africa. Over the past eight years, the introduction of a public sector antiretroviral roll-out programme and increased task-shifting to lay community workers (Callaghan *et al.*, 2010; Schneider *et al.*, 2008: 180; WHO/UNAID/PEPFAR 2008) has resulted in monumental changes in the nature of AIDS care – from palliative services to chronic illness management, from centralised hospitals to community clinics, from the charity of grandmothers caring for sick relatives and orphaned children, to the improvisations of young aspiring professionals seeking skills and upward mobility. In addition, the growing influence of international aid agencies in the mass roll-out of ARVs in Africa (Edström & MacGregor, 2010; Hanefeld & Musheke, 2009) has translated into the ideologies of global health initiatives infiltrating the AIDS response through funding support (Edström & MacGregor, 2010).

[1] This was later solidified in the Growth Employment and Redistribution (GEAR) policy of 1996, which offered 'freedom' through deregulation and the liberalisation of trade.

On the one hand, care has been progressively de-professionalised through task-shifting to lay workers, while on the other, there is a simultaneous formalisation of lay health work through growing standardisation, accreditation and remuneration (Hermann *et al.*, 2009: 31; Schneider *et al.*, 2008: 181). The transforming AIDS epidemic in South Africa, along with concomitant shifts in the nature of community care, have endowed carework with new appeal for those seeking not only to address the impact of the AIDS epidemic, but also to access training, jobs and potential upward mobility. The recasting of AIDS care as a lucrative 'industry' rather than a volunteered service has repositioned carework as a potential site for young black South Africans to fashion themselves as heirs of South Africa's liberation, promising empowerment, affirmation and prosperity.

Who Cares?

Following global and national trends (Lehman & Sanders, 2007: 7), carework at Bloekombos and Wallacedene clinics remains intensely gendered, with two men and eighteen women serving as patient advocates. Both men are below the age of 25 with no family obligations. In contrast, 9 of the 13 women I interviewed are mothers. Most are single parents whose salary serves as the primary income for the household, creating a clear security incentive for entering and staying in carework.

Mothers' monthly salaries are supplemented by child support grants of R260 per month (as of 1 April 2011)[2]. The child support grant, introduced in 1998, aims to alleviate poverty by providing primary caregivers, mostly black women, with financial support (Lund, 2006: 164; Goldblatt, 2005; Triegaardt, 2005: 250). All patient advocates qualify for the grant given a monthly salary of R1 800, which is below the R2 500 cut-off level[3]. Some mothers like Cindy and Miriam make extra money by working additional jobs. During the research period, Cindy worked part-time at McDonald's, while Miriam sold Tupperware through a catalogue system.

All except one of the patient advocates are black and most are Xhosa speaking. Participants' ages range between 21 and 35, but most are below 30. The older respondents have worked for Kheth'Impilo the longest, some for almost 8 years, and entered carework during their mid-twenties. Younger patient advocates appear to be leaving carework earlier: of the two who resigned during my fieldwork, one had been with Kheth'Impilo for two years and another only eight months. This may be a function of younger patient advocates having fewer

[2] http://www.westerncape.gov.za/eng/directories/services/11586/47468
[3] *Ibid*

dependents and thus being less swayed by the security incentive to remain in their position. The expectations and aspirations of young respondents also appear to foreground upward mobility and skills training over stability.

Growing Up

Respondents in this study grew up in urban townships or rural villages in black South African households of the 1980s and 1990s. Eleven participants were raised outside of Cape Town – nine in the Eastern Cape and two in the Northern Cape. Most of these respondents moved to the Western Cape as adults in search of jobs. The majority of participants were not raised by either of their parents, many of whom worked away from home. The apartheid policy of influx control sought to restrict the flow of black people into urban areas, limiting opportunities for permanent residence in the cities. Black people in the Western Cape were at a particular disadvantage given the Coloured Labour Preference instituted from 1962 (West, 1982: 465). Despite this, many black inhabitants lived illegally in the cities, with an estimated 42% of the black population deemed illegal in 1981 (West, 1982: 465). Lifting restrictions on black urbanisation in 1986 resulted in high rates of black migration into the Cape (Ndegwa *et al.*, 2007: 225).

While it was initially men who worked as migrant labourers in urban areas, the 1980s saw increasing numbers of female migrants to Cape Town (Ndegwa *et al*., 2007: 226). Many women moved to the cities to look for work, while their children were supported by grandparents. Eight respondents were raised by grandmothers. While their mothers worked in the cities, they could benefit from their grandparents' pension. In 1999, these pensions were more than twice the median per capita monthly income of black households, significantly increasing the health and wellbeing of household dependents (Schatz *et al.,* 2011: 5).

In addition to many respondents having migrant mothers, the vast majority had absent fathers. A number of patient advocates made no mention of their fathers, others said their fathers had left home, and still others said their fathers had passed away. In order to support themselves and their families, some respondents' mothers worked as domestic workers or child minders, two owned businesses including taxis and spaza shops[4], while four respondents said their parent(s) was/were unemployed for large parts of their childhood. Hence most of the households in which these young carers grew up survived off a mixture of social grants, intermittent income from unstable jobs and small monthly salaries from regular unskilled labour. This money had to go far, since many participants

[4] Small local convenience store

grew up in large households with numerous children to support. Cousins lived together and some had up to seven siblings.

While those who grew up outside Cape Town went to one or two schools, those in urban environments moved a lot – some attending up to five schools as they moved from one relative or location to the next. Today, respondents are able to live with their children in the city, rather than migrating for work as many of their mothers did. In contrast to their parents, the children of careworkers also move less from one family member to the next. In reflecting on their upbringing, some respondents[5] regretted growing up without their biological parents, saying that it disadvantaged them to stay with extended family. Many expressed a commitment to the idea that parents should be primarily responsible for raising their children[6]. A relatively secure job close to where respondents live allows for these domestic arrangements and preferences, where mothers have more stable and continuous relationships with their children.

In order to give a richer account of the lives of respondents before entering carework, I will use the stories of Sinazo and Caroline as examples of urban and rural experiences respectively and as an entry point to discussing emerging themes in respondents' narratives. While Sinazo and Caroline's stories will be carried throughout the remainder of the paper, the reflections of other respondents will be brought in to enliven themes and strengthen key arguments.

Sinazo is 28 years old and has worked as a patient advocate for the past five years. As is the case for many other respondents, she is unmarried without a stable partner. But unlike most of the women in this study, she does not have children and still lives with her parents. Sinazo is one of four respondents who grew up in Cape Town. She has lived in three Western Cape townships – Gugulethu, Nyanga and now Wallacedene. Sinazo grew up with her sisters and cousins and is one of only two respondents to be raised by both her parents. In order to support the family, Sinazo's mother worked as a domestic worker, while her father was a gardener. In 1993, her father was in an accident and has since been disabled.

Sinazo is one of four respondents who grew up with a sick or disabled family member that required care. Anna quit school at the age of 16 to care for her mother who had arthritis; Kholekile dropped out of school while his mother struggled with cancer; and Miriam cared for her diabetic father. Today, six respondents care for sick or disabled household members. Nandipha cares for her sister with TB, Cindy cares for her HIV-positive baby, Janet cares for her disabled child, Anna cares for her aging mother, and Thandeka supports her

[5] Nandipha (19 May 2011), Cindy (11 May 2011)
[6] Janet (25 May 2011), Mpho (25 May 2011), Thandeka (18 May 2011)

brother and mother who are both HIV-positive and on ARVs. Finally, Bulelwa supports her HIV-positive cousin who regularly defaults on treatment.

School Years

Sinazo completed her first two years of school in Gugulethu before her parents transferred to the developing informal settlement in Kraaifontein. Because schools had not yet been built in the newly-emerging Kraaifontein townships, Sinazo moved in with her aunt in Crossroads, Nyanga, to continue schooling. Kraaifontein townships became increasingly developed throughout the 1990s as escalating numbers of black families moved to the outskirts of the city, and the state began to roll-out services to settlements on the urban peripheries. When Hector Peterson High School was built in 1998, Sinazo was able to complete her schooling while living with her parents.

Despite often arduous circumstances, all but one of the respondents in this study passed matric. Three temporarily left school to care for an ill family member. The shame and indignity these respondents attach to dropping out, which one describes as "derailing" his life and causing him to be seen as a "failure", points to their high regard for education. Affirming previous research among township youth in Cape Town (De Lannoy, 2007), respondents positioned academic success as a determinant of one's future prospects and a marker of character. But given that respondents' matric certificate was often rendered insignificant in their desperate scramble for work, their reverence for education may have been amplified in their self-presentation to an educated researcher.

Sinazo said she "liked school" and was "bright in all her subjects"[7]. Others said, "It was good […] I enjoy being in school. I love school […']"[8]or "I was clever at school. Nothing was wrong"[9]. Those who claim to have enjoyed school attribute their positive experience to financial support, saying their guardians bought them uniforms and paid their school fees[10]. Following this, those who did not enjoy school often cited a lack of resources.

One respondent who suffered through school was Caroline, a 32-year old single mother who lives alone with her child and has been working for Kheth'Impilo for the past four years. Caroline grew up with five siblings in the Eastern Cape. Her father passed away when she was young and her mother was frequently unemployed, which meant that she and her siblings often did not have their basic needs met.

[7] 17 May 2011
[8] Dora (26 May 2011)
[9] Thandeka (18 May 2011)
[10] Thandeka (18 May, 2011); Bulelwa (11 May 2011)

> ‘I came with a poor family […]. It was too difficult to raise us […] I am the last born. I am the only one who passed matric because it was too difficult to pay us school fees [and] everything. Other [siblings of mine] they went to school [but] no matric […] It was too difficult really because [my mother] was unemployed. It was too difficult really’ (25 May 2011).

Caroline mentions the difficulty of her upbringing four times in this short excerpt and the hardship is felt, especially with reference to school.

> ‘I did enjoy [school], but sometimes because I was different to other school [kids]. Sometimes I don’t have shoes, you see. I don’t have shoes, no food […] It was sad to me because sometimes I have –I want to drop out in school […]’ (25 May 2011).

Caroline experienced humiliation at school because her family was unable to afford full uniforms, setting her and her siblings apart from their classmates. Similarly, Janet remembers battling to meet her school peers’ standards but explains her inadequacy as an inability to practice conspicuous consumption.

> ‘My time at school was so hard because you see mos at school, at that time we have to buy, we have to go out, we have to wear fashions. You know mos at that time? Especially when you are at high school, you have to wear a fashion […] and whenever we go out, we have to have money […] So I was struggling because my granny wasn’t giving you more than R5. She always give us R5 because when – we are a lot – we were many children in our house so she can’t give R10 to the other then R20 [to] the other. You have to treat us equally’ (25 May 2011).

Here, Janet speaks about the importance of consumption during her school years. Young people seemed to be expressing their freedom, aspirations and belonging by accumulating fashion brands. Cindy reported that, where she grew up, people “liked brands” (20 June, 2011). The immense pressure to consume is felt strongly in Janet’s excerpt – “we **have** to go out, we **have** to wear fashions […] we **have** to have money” – suggesting an unquestionable imperative. Buying, going out, wearing fashion and having money were in some sense constitutive of a conforming high school student, but Janet was unable meet this prescription because money in her household was thinly spread amongst the many dependents living off her grandmother’s pension. This serves as a useful example of the incongruency between young people’s high aspirations, fostered by the seemingly endless possibilities of a ‘new’ South Africa, and the constraints of their post-apartheid reality.

Desires for demonstrable prestige are already evident in the childhood aspirations of respondents. When I asked Janet about her childhood ambition to be a nurse, she said:

> ‘To be a nurse – man – was the most thing that I like is that high heels shoes. And also – [laughs and mimes a nurse’s shoulder epaulettes] and also the white – they always wear mos a white uniform with the pantyhose. And I say it is – these are the ladies! What I was thinking was that if I can be the teacher they would be no different, because I wear the clothes like the others, because there’s no uniform for the teachers. And also for the nurses they’ve got the uniforms, you’ll see “oh this one is a nurse” by their uniform [laughs]’ (25 May 2011).

The four respondents with childhood nursing aspirations attribute this to a combination of altruism and a desire for professional prestige. In the excerpt above, Janet admires nurses’ uniforms for their ability to manufacture, and make visible, social distance. Unlike teachers who simply blend in, nurses are marked as exceptional. Janet can name every detail of a nurse’s attire – the pantyhose, the epaulettes, the whiteness – and she associates this aesthetic with dignity and refinement, using the immensely aspirational phrase “these are the ladies!”

For those respondents who aspired to nursing and social work from a young age, entering carework may not have been quite as arbitrary as it was for others. While there is little doubt that earning an income was primary when they applied for the position, once in carework respondents made an effort to exemplify the erudite and authoritative dress of the health workers they aspired to. While nurses’ uniforms are imbued with authority, patient advocates must find their own aesthetic tactics in order to claim the authoritative position. Some come to work in pantyhose and long skirts, making an effort to distinguish themselves through smart, conservative dress – “these are the ladies!”

Consumer culture amongst black South Africans has been linked to broader conceptions of liberation in a capitalist democracy, in which emancipation is conceptualised as conspicuous success and measured in material terms (Posel, 2010). This is particularly pertinent among youth, including respondents in this study, who are crafting their identities and ambitions during a time of new political and economic freedoms.

My conversation with Cindy about her future prospects is illuminating in this regard. I asked what she hoped to be doing in five years and she responded:

> ‘I hope and I pray that I will be in a better job, driving my car’.
> **Interviewer**: ‘And you want a car so that you can travel?’
> ‘Yes I always dream about that, with my baby in the back [seat] with me, [with] the music [on] and the baby dancing. I always dream about that and I’ll smile sometimes if I’m in the taxi […] I don’t know the name of this car but it’s got a H – Honda! It’s not black but its dark navy. I like it. I saw it when I go passed [the car dealership] with the taxi’ (11 May 2011).

I asked what Cindy hoped to be **doing** in five years, but the content of her response was less concerned with what she would **do** as what she would **own.** Cindy hopes to own a car, and whilst increased mobility and independence are important to her, she is also interested in aesthetics, naming the brand and colour of her dream car.

Further, while my question was about a medium-term goal, Cindy's answer had the quality of a fantasy. In asking about the next five years, I had anticipated an answer with some semblance of planning that gave details about what work Cindy aspired to and how she might be able to attain her goal. Instead, Cindy resorts to "hopes" and "prayers" to bring her a better life. While Cindy mentions in fairly vague terms that she would like a better job, her answer takes the form of a daydream from the taxi window.

Continuing the fantasy, I asked Cindy where she would go if she won her dream car tomorrow. She answered "America" because it "looks nice" on television. That America is not reachable by car is precisely the nature of this unattainable fantasy-world, filled with glitz, globalism and high consumer aspirations – all in glaring contrast to the realities of Cindy's current life in which she confronts (frequently gruesome) sickness and daily financial struggle. Cindy's daydream functions as a form of escapism, where escaping from township life and embracing socio-political freedom is intimately linked to accumulation and enrichment.

Before becoming a mother, Cindy's primary incentive to work was so she could buy new clothes and "look good on parties"[11]. Patient advocates make an effort to dress fashionably for work and regularly comment on one another's outfits. This is reflected in the regular purchasing of expensive hair weaves, which are often brought to the clinic to be admired by patients and careworkers. Given the small income of patient advocates, it is significant that money is spent on cosmetic items like weaves and false nails on a fairly regular basis. Aesthetics are used as a means to mark and even manufacture social distance between carers and patients.

Hence, carework offers these young South Africans an opportunity to seize the fruits of democracy and modern capitalism through materialism, style and opportunities for upward mobility. Their childhood aspirations for accumulation and prestige illustrate high expectations of what a free country had to offer them. But careworkers have grabbed at progress and new life in the face of death and deprivation in their everyday lives. This is illustrated in the number of respondents who care for sick and disabled family members. In this context, carework serves not only as an imagined springboard to modernity, progress and

[11] 11 May 2011

status, but also as a means to confront the antithesis of these things in their everyday lives. For the most part, however, respondents did not enter carework out of an intrinsic desire to serve but rather as a means of accessing stable employment and improving their social standing.

The Stuff of Dreams

In South Africa, the promise of new democracy signals a post-apartheid moment in which young black South Africans aim for positions of higher status than those available to their parents (Stead, 1996: 672), exhibiting high emancipatory expectations. But highly optimistic career goals are increasingly recast as fantasies as they discover the realities of working life (Watson *et al.* 2010: 728) in which 34% of matriculated youth between the ages of 25-29 remain unemployed (National Treasury, 2011: 13). The planned, methodical trajectory associated with pursuing a career goal is replaced by opportunistic, arbitrary and often desperate attempts to get by. This supports previous research (De Lannoy, 2007; Ramphele 2002; Robbins *et al.*, 2003: 611) which indicates that township youth are unsure of how to attain their career goals, resulting in a process of ongoing trial and error where young people 'steer by the stars' (Ramphele, 2002).

My conversation with Janet about childhood aspirations is particularly illuminating in this regard:

> 'When I was at school I was dreaming – my dreams was to be a nurse because whenever I see the sick people, I say that 'hey if I was a nurse!' […]' (25 May 2011).

Here, Janet deliberately inserts the word 'dream' into her response, perhaps suggesting that she is no longer as idealistic.

> **Interviewer:** 'Did a lot of children at your school want to be nurses?'
>
> 'Ja – most of us because we're doing biology, maths and physics so that we gonna be the doctors, else we might be the nurses. And that is – was our dreams' (25 May 2011).

Again, Janet is careful to point out that these were childhood **dreams**. More significantly she says, 'that **is** –'and then corrects herself saying 'that **was** our dreams', asserting that these dreams are in the past tense. Today, childhood fantasies seem unattainable. Janet has to care for her disabled son, who is in constant need of medical attention.

School Leavers

Education is a predominant theme in respondents' life narratives and many tell stories of personal and family sacrifices that enabled them to matriculate. While obtaining a matric has allowed respondents to meet the minimum requirements for carework, for the most part education has failed these young people, whose insecure futures – so far from their childhood aspirations – reflect a continuous scramble for 'the next best thing'.

After a monumental struggle, Caroline became the only person in her large family to finish school. Soon after, she moved to Cape Town in search of work. Finding a job was difficult, but Caroline was eventually hired to sell toilet paper on commission. After being the first in her family to obtain a matric, with high aspirations for the future, this reality makes plain the harsh contradictions of democratic South Africa, in which both everything and nothing is promised.

After selling toilet paper for a year, Caroline became pregnant. In an effort to support her newborn baby, she opened a business selling beer and wine. Although the business started off well, the success did not last. Caroline took up a job as a cleaner but quit soon after due to regular illness. For most of the following year, she and her son lived without income, until she was employed as a farm labourer. Again, Caroline was working on commission without straight wages. In 2006, when Caroline was attending Kraaifontein Day Hospital, she noticed a poster advertising vacancies at Kheth'Impilo and immediately applied. Being offered a position at Kheth'Impilo gave Caroline a secure, regular income – something that she had never had in her life.

Sinazo passed matric but failed to qualify for university. Hoping to further her studies, she enrolled in a marketing course at Tygerberg College but dropped out after two years, saying she was bored and wanted to "start a new career". Sinazo was later granted a one-year contract with Love Life[12], conducting schools-based HIV/AIDS prevention programmes. Taking an interest in her decision to enter AIDS work, I asked Sinazo what attracted her to work for Love Life:

> 'I think just to say, uh, it was only the point – I didn't know that I was going for Love Life. Someone told me, 'Just send your CV here. It's gonna be a community thing' and then I send the CV – only to find that I'm sending the CV to Love Life'. (17 May 2011)

Initially, Sinazo searches for an appropriate explanation that might account for her interest in Love Life but then concedes that she had almost no information

[12] South African non-governmental organisation focusing primarily on HIV/AIDS prevention initiatives for young people

about the job she was applying for. Her decision to send her CV to Love Life was a moment of improvisation, which formed part of a disorganised, opportunistic search for work.

Three other respondents had also worked in HIV/AIDS programmes, volunteering their services to the Treatment Action Campaign (TAC). When I asked Janet why she joined TAC, she responded:

> 'I can't say that there's something that attracts me to work for TAC, but I said, 'let me volunteer first'. Maybe by the time I will be volunteering at clinic I [will] see some posters. That is what has happened. I saw the posters of ARK (Absolute Return for Kids, Kheth'Impilo's predecessor)' (25 May 2011)

I had expected an answer that situated TAC as a means to address the affects of HIV/AIDS in Janet's family and community and hold government accountable for the on-going and unnecessary deaths she was witnessing. Instead, Janet's answer was wholly pragmatic. Volunteering provided an entry point into the clinic where she hoped to find remunerated employment. This confirms existing research (Akintola, 2010) suggesting that many AIDS caregivers are motivated to volunteer by instrumental, career-related incentives. So volunteering, rather than being an act of selfless service, is positioned as a platform to future job opportunities.

> 'When you want a job, you have to have experience. […] sometimes when I'm off at Shoprite[13] I went to the clinic to help there – to see what is going on. And then they tell me when they were having vacancies. I started applying there' (Miriam, 24 May 2011).

Although Sinazo was paid very little at Love Life, she enjoyed the work and particularly appreciated the skills she gained during training. After her contract expired, Sinazo was again unemployed with no strategy for an alternative occupation or income. She enrolled in a short project management course at Damelin College[14] but struggled teaching herself the subject matter. Later, Sinazo was hired on a one-year contract to work as an operator in the Truworths[15] call centre. Despite this being another short-term contract position with no hope of a future career at Truworths, Sinazo describes the offer as "a big break" for her. Her salary at Truworths was R1000 more than her current monthly income, despite her present work being highly skilled.

[13] Supermarket franchise
[14] A South African college providing private tertiary education
[15] South African clothing retailer

Before working at Kheth'Impilo, most respondents had similar stories to Sinazo and Caroline – a series of unstable jobs taken up on an opportunistic basis. Some never qualified for the tertiary education required for their dream job, while others could not afford it. Only one of the 15 patient advocates in this study enrolled in university education. Some began at technical colleges but didn't finish due to a lack of finances or a loss of motivation. Others enrolled in short courses studying counselling, project management, administration or computers. However, the vast majority looked for jobs. Before working for Kheth'Impilo, respondents took up a range of positions including child-minding, home-based care, domestic work, petrol attendance, cashier work and farm labour. Many of these jobs were on a short-term contract basis.

After completing school, there is little or no planning in the lives of these young people. Instead, haphazard short-term opportunities are grabbed as they become available. Upon hearing Nandipha's story in which she spent a short time in technical college, waitressed at a tavern, worked as a petrol attendant, a cashier and a cleaner, I then asked why she had continued to look for new jobs despite holding a position at the time.

> 'It's only because you see you can be here, working here, but […] you didn't get an income that will satisfy you. We always think about – if I can get this and that and that then it will be better. So that's why even if you are at your own job, you have to be looking for the others. We [are] are looking for the green pastures' (19 May 2011).

Nandipha shows that while the constant search for better opportunities is motivated in part by dissatisfaction with the terms of her current position, it is also driven by an ongoing aspirational spirit – "If I can get this and that, then it will be better". Careworkers are practiced opportunists, continuously on the lookout for the next job opening.

Entering Carework

When Sinazo applied for a job at Kheth'Impilo, she was desperate.

> '[…] When I stopped working at [the Truworths call centre], I tried to find work for over a year and I kept telling myself that I'm going to get a job. I was submitting my CV everywhere but nothing was coming. So when I see here – and really it was just something so that I could have something. I won't lie saying that [it was] just because I have a passion or something. No there was no passion. I just needed the money' (17 May 2011).

Like many respondents, Sinazo was not particularly interested in carework when she applied for a post at Kheth'Impilo. She was not driven by a sense of duty or altruism, nor was she especially committed to the HIV/AIDS struggle despite having worked in prevention programmes before. She just "needed something so she could have something". Sinazo's use of a non-descript term like "something" to describe what she "needed" and what she hoped to "have" points to the extent of arbitrariness in respondents' undirected attempts at finding work. For many of these young carers, entering carework did not resemble a strategic choice but formed part of a series of opportunistic, often spontaneous moves.

When I asked Peter what made him decide to work for Kheth'Impilo, he immediately pointed out my mistake.

> 'In fact it was not a decision of working for Kheth'Impilo […] The other sister who was working here – I think she was a coordinator – so I knew her. I was not working. Then she told me that here [at the clinic] they want people […] So because I was not working that is why I came to Kheth'Impilo. Just to get a job. It was not about knowing exactly what is the job, what it's all about, what is being a PA [patient advocate]. So it was just a job for me'. (29 April 2011).

Peter is not the only respondent who had little knowledge about the work he was starting. Anna was interested in administration and had been volunteering as a receptionist at Kraaifontein Day Hospital. When she saw the position of "PA" being advertised, she thought it stood for 'personal assistant' (25 May 2011). It is significant that many careworkers were recruited through networks at the clinic, suggesting that 'model' patients are frequently co-opted into care delivery. Others were alerted to the position through their churches, which for many, serve as a significant social resource.

Although almost all respondents applied to Kheth'Impilo because they needed work, other factors seemed to play subsidiary roles. Significantly, six patient advocates have an HIV-positive family member who inevitably benefits from their position as carers. Careworkers' relatives get first access to doctors and drugs, and respondents are equipped to provide them adherence support. When I asked Bulelwa why she applied to work at Kheth'Impilo, she said nothing about needing the money.

> 'I was just interested because [of] my sister – [I mean] my cousin […]. So I used to go to Joburg by holidays. Then she was in the labour. So there were two nurses. Then the other one told the other one "It's that one who's got AIDS". Then I was like – I was shocked! […] The child was sick and then the child passed away […] and she was crying at home that she's HIV positive […] So I was interested because I just want to help her' (11 May 2011).

While Bulelwa is one of the only respondents to explicitly mention an HIV-positive family member as motivation for entering carework, I would imagine that the high number of respondents with HIV-positive relatives means that many more families have reaped the benefits of carework.

'It's in My Blood'

For two patient advocates, their own HIV-positive status provided the impetus to become patient advocates. Dora, a 25-year old who lives with her six-year old daughter, has worked as a community health worker for the past six years. Towards the end of her school career, she was diagnosed with HIV. Soon after, she began volunteering at Tygerberg Hospital, where she started a support group for HIV-positive children. During her time at Tygerberg, Dora started antiretroviral treatment and was referred to the TAC branch in Khayelitsha for support.

She describes volunteering for TAC as a revelatory experience in which she transitioned from a person in despair and denial to a person able to accept and disclose her status.

> I started volunteering there [at TAC] and I learn to accept that I'm living with HIV and I'm gonna die with this disease […] It's in my body, in my blood, so I have to respect and accept that […] I see the people that are living with this [virus] and I was like, "How can I be like them?" And then it's where I started motivating people, speaking to the people, telling the people about my status. So it goes on […] until I accepted that I'm living with disease and then I will go far with it' (26 May 2011).

Steven Robins (2006: 316) has remarked that the phrase "it's in my blood" functions both as a scientific statement about the presence of virus in the body and a metaphorical statement that "this is part of my being and my purpose". Dora's entrance into carework is not unlike entering a church – an experience familiar to many respondents. There is a sense in which Dora was 'saved' by the Treatment Action Campaign, which offered "new life" (Robins, 2006) and a form of rebirth through a sense of community and the promise of antiretrovirals. Today she is able to testify and preach the teachings of her own revelation, offering her followers "a long life".

> 'I want to show the people that if you are living with HIV, that does not mean your life just ended like that. You can live a long life. That is why when we start the patient I used to make example by me […] I say 'just look at me […] I was like you before but look where I am now' (26 May 2011).

Dora's motivation to care is slightly different to the improvisatory, instrumental decisions made by other respondents. In addition to needing paid work, she hoped to use her own experience with HIV to inspire and motivate others. Indeed, this has been Dora's only occupation since leaving school seven years ago.

About a year before I first met 23-year old Cindy, she tested positive for HIV at an antenatal clinic and received treatment for prevention of mother-to-child transmission. Despite preventing HIV transmission during pregnancy and delivery, Cindy later transmitted HIV to her child through mixed feeding[16]. Cindy and her baby attended the Wallacedene clinic regularly, where she was allocated a patient advocate. "Everyone at the clinic was in this with me", she said, "and I felt so lucky – or blessed" (11 May 2011). She recounts the "nice words" of her patient advocate who said:

> 'You can feel free, share everything you want to share, just talk. I'm here to help you. I'm your treatment buddy, I'm your friend, I'm your everything. You can call me whatever. I'm just here for you. It's not the end of the world. You can still do better […] you can still live a better life […]' (11 May 2011).

Here, Cindy's carework adopts American-style self-help rhetoric in her promotion of 'positive living'. Just as Dora spoke of her revelatory experience through TAC, Cindy speaks of the support and acceptance she found through health workers at Kheth'Impilo.

For Cindy, entering community health work formed part of a spiritual transformation. "It uplifts me. It makes me strong every day […]" (11 May 2011). But starting carework also correlated with a transition to adulthood, in which the clinic, along with its rhetoric of new life, hope and responsibility, has guided her through motherhood, illness and her relationship with her boyfriend, who also enrolled as a patient. In Cindy's life, the lines between friends and colleagues, relatives and patients, lovers and carers, are ambiguous and fluid. The clinic is "her everything", mediating love and motherhood, sex and reproduction, stigma and disclosure, as well as employment and opportunity. Hence, in addition to needing a paid job, Cindy's motivation to care is linked to her personal transformation through antiretrovirals and her absorption into the social world of the clinic.

But despite the reported 'salvation' of antiretrovirals and AIDS-care, neither Dora nor Cindy can be described as converts of the AIDS activist orthodoxy.

[16] Mixed feeding means the infant receives both breast milk and formula milk before 6 months of age. Exclusive breastfeeding presents a lower risk of transmitting HIV (4%) even in the absence of ARVs (WHO, 2007).

Neither has wedded herself to a life of advocacy, altruistic care or biomedical preaching. Both still subscribe to other explanations of healing, including religious miracles and traditional medicine. And both will continue to make pragmatic and opportunistic decisions in the hopes of attaining a better life.

In September 2011, Cindy retired from Kheth'Impilo, sacrificing her activist and altruistic incentives to work at McDonald's. There she would be paid over R1 000 more per month than at Kheth'Impilo with a lesser workload, allowing greater security for her and her baby. In August 2011, Dora was awarded a learnership to train as a social auxiliary worker and will spend the next year studying. This is despite her regular assertion that she aspires to a career in law – a dream divorced from her current trajectory. While an HIV-positive diagnosis played a critical role in Cindy and Dora's decision to enter carework, their attitudes towards their positions, despite genuine altruism, are ultimately no less pragmatic than their fellow respondents.

While Dora and Cindy may initially resemble models of "therapeutic citizenship", this is not in fact the case. Instead, these respondents have tactfully adopted AIDS activist 'talk' in line with the 'conversion' pedagogy of AIDS treatment programmes. While this is not wholly disingenuous, it also does not resemble the totalising conversion experience described by Robins (2006).

Gendered Care

Young women are the population group most affected by HIV/AIDS in South Africa, with 24.6% prevalence among women age 25–29 (DOH, 2011), and mostly women serving as carers in AIDS-affected households (Akintola, 2006; UNAIDS *et al.* 2004). Thus female careworkers are both more likely to be HIV-positive and to bear the responsibility of caring for sick family members. While financial security and personal advancement served as primary motivation for both male and female respondents to enter carework, it is particularly women who have benefitted from access to clinic resources due to their caregiving role, and in some cases their HIV-positive status.

Gendered trends in clinic attendance are also relevant here, since many careworkers are recruited through the clinic in response to posted advertisements or recommendations from a clinic worker. Research shows that men are less likely to attend clinics, particularly for ART treatment (Cornell *et al.*, 2011; Mills, E. *et al.*, 2009), which might serve as part of the explanation why fewer men are recruited to care. Because many patients are drawn into ART programmes through antenatal programmes, and because global funders have

made maternal and child health a priority for clinics, many health facilities in South Africa have targeted women (Cornell *et al.*, 2011: 628).

The majority of female carers in this study are single mothers, making a secure income a vital incentive. Despite consensus that the salary at Kheth'Impilo is too little to support a family and justify the heavy workload, it is significantly more than living off a child support grant and provides greater stability than the contract positions many respondents held in the past. Further, financial security has endowed female carers a degree of independence, with most serving as primary breadwinners in their households. Caroline was able to leave her boyfriend of twelve years[17] without losing all her financial resources, while finding permanent work empowered Mpho to escape an abusive four-year marriage[18].

Most respondents note that attrition among male careworkers is high. Given that male carers are often without familial responsibilities, they have the luxury of leaving when dissatisfied and are less tethered by the security incentive. In addition to fewer men applying for and being retained in carework, it is reported[19] that male candidates often appear nonchalant, scruffy and unreliable in interviews – failing to exude the requisite deportment.

Kholekile and Peter were the only two male patient advocates when I began fieldwork. The third, Simphiwe, had resigned a few months before to enrol in an information technology (IT) course. By the end of my fieldwork, only Kholekile remained since Peter had resigned. Kholekile intended to quit the following year, hoping to return to university, also to study IT. When I returned to the clinic in March 2012, he had been awarded a learnership to study phlebotomy, and at least six new patient advocates had been employed, none of which were men.

The two male carers in this study, neither of whom remained in carework, used their position as patient advocates instrumentally despite finding their work altruistically rewarding. Both were determined to be upwardly mobile, but while Peter hoped for a life of political activism, using his community work as leverage for position in local government, Kholekile's scramble for personal advancement is much more improvisatory. Kholekile is a product of the urban township, having lived in Cape Town informal settlements all his life. A regular at local taverns, he describes every weekend as 'déjà vu': "You do the same thing, hang out with friends, same place, same time" (16 May, 2011). Before working for Kheth'Impilo, Kholekile considered AIDS to be "none of his business" and harboured prejudices about the 'promiscuity' of people with HIV.

[17] Reported in an interview 25 May, 2011
[18] Reported in an interview, 24 May, 2011
[19] Informal conversation with sub-district coordinator

He can still be caught telling stigmatising jokes about AIDS and smokes despite scathing attacks from his colleagues who say he is setting a bad example for patients.

Despite such flouts of standard AIDS activism, Kholekile enthusiastically explains the importance of adherence to his patients and works especially well with men, challenging them on constructions of masculinity which discourage condom use and condone multiple and concurrent partners. But Kholekile's motivations to enter carework were not premised on principal, nor were they the outcome of an unwavering commitment to AIDS science. Instead, care served as an instrumental route to remuneration – a means to counter boredom and fund weekend recreation.

Although Kholekile's intention to return to university would not improve his income, acquiring a qualification would open up job opportunities. While considering study options, Kholekile also took a chance at a phlebotomy learnership, which despite being very different from IT, also affords skills, training and prospects for upward mobility. Both IT and phlebotomy would demand that Kholekile sacrifice his altruistic incentives; phlebotomy is a technical position, demanding little interaction with patients.

Kholekile's decision to take up phlebotomy indicates his intention to study was not a firm commitment to a particular career trajectory. Similarly, choosing phlebotomy was not a decision per se, but a contingent event amidst a range of other contingencies in Kholekile's life. Kholekile made this opportunistic move in pursuit of personal advancement, despite similar pay and less **care**work. Although the salary is similar, phlebotomy has fewer complex pressures and demands and perhaps a more apt weighting of salary to workload.

Peter is an ardent supporter of the Democratic Alliance (DA), committed to community activism and youth development. Unlike Kholekile, he doesn't have many friends, doesn't drink and doesn't party. Instead, Peter volunteers for after-school programmes in his spare time and is moving up quickly in the local DA. After resigning from Kheth'Impilo, Peter accepted a contract position in the provincial Sports and Recreation Department – a post with far less security than patient advocacy. When asked about his decision to resign, he said:

> 'I hate being in a position whereby you notice that there is not progress at all, you understand. You realise that, I mean, you could be here for fifty years, or for twenty years, or for many years, but there would be no progress in your life. I think that is junk! It's totally – I don't know how to describe it, but it's not right. If it's – some people who are still there, I sometimes wonder, what's going on with them? I mean there are people that I got them there, working there [at the clinic], and they are still there!

> And for me, I can tell there won't be any progress in their lives any time soon' (28 June 2011).

Although men are more able to give personal advancement primacy over financial security, the will to progress is a predominant theme in all respondents' narratives. While many became disillusioned with learnerships during my fieldwork, this aspect of Kheth'Impilo's programme positions carework as a springboard to a better life. "I know this patient advocate thing is an entry point for me to get somewhere", says Anna (25 May 2011). Similarly Peter comments:

> 'I'm working here [and] I'm using it as a learning curve for me. The experience that I'm getting here I want to use it in future […] **Of course I don't wanna be a PA [patient advocate] for the rest of my life!'** [emphasis added] (29 April 2011).

Peter's comment highlights the instrumentality of carework as a transient platform for upward social mobility in the eyes of respondents . In many ways, this is the promise of new democracy – that education and hard work will provide an escape from the townships and ensure formal employment. But since leaving school, respondents' lives have been a desperate, disorganised grab for opportunities – a kind of 'shooting in the dark' in the hope that they will get their 'big break'. Sinazo's reflection on her future illustrates a resignation to this life of uncertainty.

> 'I'm not even sure of [what I'll be doing in] five years time […] I still have to choose a career. And I think the career that I'm going to choose will be – I just need to do, something that – uh – I think I'll have to do something. Maybe in five years time I'll still be studying, still be stuck here, or somewhere' (17 May 2011).

Conclusion

This paper has sought to position care work as an improvisatory strategy in the life trajectory of fifteen young South Africans whose lives are filled with multiple contingencies as they attempt to survive and succeed in post-apartheid South Africa. For these respondents, the AIDS epidemic serves as a simultaneously stabilising and de-stabilising force: de-stabilising in the sense that many of their families and communities are wrought with challenges of AIDS illness, and stabilising in the sense that the epidemic has spawned an industry of remunerated, skilled labour which enables their survival and (in some cases) enrichment. In this context, AIDS care, which is frequently a space

of bodily decay, death and deprivation, becomes a potential site for accumulation and even glamour.
For respondents with sick or disabled family members, working at the clinic affords the training and resources to provide better care. Furthermore, patient advocates' knowledge of the social grants system allows them to navigate the complex bureaucracy of social security. Similarly, while AIDS brought instability and dissolution to the lives of the two respondents who are themselves HIV-positive, their diagnosis and consequent enrolment as care workers also brought stability, affirmation and purpose unlike either had had previously in their lives.

Many respondents had tumultuous childhoods, with absent parents and frequent migration from one relative to the next. While AIDS has destabilised the structures of countless families, working in AIDS care has also endowed a level of stability to the lives of respondents, which has allowed for less migration and increased financial security. Respondents, many of whom attributed positive school experiences to financial support, are able to provide some semblance of stability for their children.

Although completing high school qualified respondents for a post at Kheth'Impilo, where they continue to receive additional skills training, this has had limited benefits for upward mobility, whether professional, social or economic. Hence, despite the benefits of care work, many respondents continue to live precariously on the edge, increasingly disillusioned with their circumstances. Ultimately, these young South Africans will continue making ad-hoc and spontaneous decisions in an attempt to realise a better life, and care work will serve as one instrumental move in a broader set of ongoing contingencies. What is significant for the purposes of this dissertation is how this reality – driven by the socio-economic context of post-apartheid South Africa, the shaping of new identities and changes in the nature of the AIDS epidemic – shapes the dynamic *practice* of AIDS care.

What are we to make of a concept of care that has instrumental value, and often monetary value, for carers – where carework functions as a form of self-care? Furthermore, how do we make sense of a paradoxical situation in which AIDS care is simultaneously a tremendous burden and a career opportunity for carers? Here, there is potential for discourses of altruism, communalism and biomedical revelation to be assumed as instrumental strategies towards individualistic and pragmatic ends. But there is also potential for altruism, ambition and self-care to collide and coexist, where community health worker programmes could provide care for patients and carers alike.

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