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‘You must make a plan or […] some story’: Community Health Workers’ Re-appropriation of the Care Manual

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Abstract

This paper investigates community health workers’ negotiation between the prescribed ‘manual’ for care and the lived realities of their field, exploring how standards of public health are re-appropriated through the micro-politics of everyday practice. What inventiveness, agency and tactical maneuvers are woven between abstract ideals and situational demands and what are the implications for our understanding of carework? The paper shows community health work, as a model for care, to be complex and demanding – a composite of practices prescribed by a range of institutions with diverging interests. To add to this, this onerous care manual is expected to be delivered by a cadre of lay health workers positioned at the interface between communities and clinics - with minimal training, limited resources and little authority. Within this demanding occupational terrain, careworkers have crafted space for agency and tactics. Through a series of improvisations, respondents mediate between the often-incongruent demands of patients, employers, funders and state policy, whilst also negotiating their own self-care and aspirations for upward mobility. In a policy context that has sought to standardise, systematise and regulate carework, this practice is contrastingly inventive and adaptive. The makeshift, unplanned and chancy nature of carework is often far from its original design, calling into question how the success of this model should be understood.

Introduction

This paper explores community health workers' negotiation between prescribed models of care and the everyday realities of their work. It asks how community health workers interpret the guidelines and protocols relayed to them and how these are complicated by the context in which carers operate. The public health model for community health work prescribes community-based, community-driven and holistic services, surveyed and measured on the basis of performance targets. It has foregrounded individual human rights and empowerment, while also adopting a utilitarian public health approach. This paper explores how the immense demands of this care manual are re-appropriated, negotiated and contested by careworkers. In doing so, it illustrates how care programmes, often prescribed at organisational, national and even global levela, are operationalised and challenged in local contexts, through a repertoire of improvised tactics.

Field research for this study used a range of qualitative methods that sought to examine the practice of care amongst a cohort of fifteen community health workers. These careworkers serve as antiretroviral (ARV) adherence supporters in two Kraaifontein primary healthcare clinics, located on the outskirts of Cape Town. Termed 'patient advocates'(PAs), respondents are employed by the non-government organization 'Kheth'Impilo', whose mandate is to support the South African government in delivering primary healthcare. Data collection included three months of intensive observation and partial job shadowing at Kheth'Impilo clinics, 30 in-depth interviews with patient advocates, three key informant interviews with managers at Kheth'Impilo, a year-long internship at the Kheth'Impilo national office and a six-week body-mapping project with a group of six patient advocates. Data were analysed using procedures from Grounded Theory (Glaser & Strauss, 1967). Pseudonyms are used throughout to protect the anonymity of respondents.

Prescriptions of Primary Healthcare

This research is located in a policy context in which care is increasingly posited as a community-held obligation (De Wet, 2011: 111; DOH, 2001; Marais, 2005: 65; Walt, 1990: 3), thereby transporting care from centralised hospitals to communities and their cadres of caregivers. The formulation of primary healthcare in the 'Alma Ata Declaration' (1978) and 'Health for All' policy (WHO, 1981) solidified this global trend, advocating for community participation and the shifting of specified tasks from professionals to lay health workers (WHO, 2007). Since the onset of HIV/AIDS, community-based primary healthcare has been a key strategy for highly-affected countries, whose under-resourced health systems have been unable to cope.

In response to an escalating AIDS epidemic, immense health worker shortages, and the massive roll-out of antiretrovirals (ARVs), community health workers have been increasingly incorporated into South African social policy. This formalisation of community health work has resulted in the occupation taking on a newly ambiguous form: somewhere between volunteerism and formal labour, homes and health facilities, non-state and state, traditionalist conceptions of communal care and the job-creating impetus of a remunerated, upwardly-mobile sector. The experience of carers operating within this fluid occupational space has not been adequately explored (Schneider & Lehman, 2010: 60; Van Pletzen *et al.*, 2009: 1), despite the ever-more fervent championing of this model in national health policy (Barron *et al.*, 2010; DOH & DSD, 2009; Morrell *et al.*, 2011).

In the past few years, the Department of Health (DOH) has been formulating plans to 're-engineer primary healthcare' in South Africa (Barron *et al.*, 2010; SANAC 2011), situating community health workers as drivers of primary healthcare services. Kheth'Impilo's community health worker programme, which serves as the case-study for this thesis, closely resembles the model prescribed in these 're-engineering' plans, though with a less comprehensive package of services. Given these similarities, this study is well poised to interrogate what is soon to become the standard for community health work in South Africa.

Care as Community-Driven

A key tenet of primary healthcare is that it be accessible to communities and promote their participation. From its inception, Kheth'Impilo has positioned itself within a primary healthcare paradigm, providing community-based care driven by community-sourced lay health workers:

> 'Our model is that we have somebody from that particular community who understands the dynamics of that community, the culture, the norms, the accepted standard of living and accepted ways of doing things within a particular community […]' (Phumzile, Kheth'Impilo national office, 19 May 2011).

This understanding of care-as-community-driven is reproduced by respondents, at times verbatim. In the excerpt below, Miriam also makes reference to "the norms" of Bloekombos in explaining the importance of selecting patient advocates from the clinic's surrounding community:

> 'Our organisation want[s] the people of that community to work there because the people of Bloekombos, they know me […] I know the norms of Bloekombos and the people are used to me, you know' (27 June 2011).

Similarly, Caroline remarks:

> 'It is good [to work in the community where you come from] because you know your community. You know […] their belief[s], their religions. […] You must understand mos your people' (8 June 2011).

Hence respondents in this study are well-versed proponents of care-as-community-driven, citing how knowledge of their target population aids the delivery of quality care. In addition, many acknowledge the practicality of community health workers living and working in the same community, since they are equipped to navigate the area. "Where you stay […], you know where to find the address […] But if you don't know, you get lost" (Mpho, 9 June 2011). This serves as an indication of respondents' ability to 'talk' the organisational 'talk' despite the challenges of providing care in their own communities, which will be illustrated below.

A frequent worry for respondents is that once their position at the clinic is known, their presence in the community is perceived as a threat.

> 'I saw people here that stay nearby [me] and they are not impressed at all because now I'm here [at the clinic] and I'm going to see their status. [I'm going to] know that they are HIV positive. And then they think I'm going […] to spread the word around that this one I saw at the clinic, he's HIV positive […]' (17 May 2011).

It is precisely because patient advocates traverse both the clinic and community realms that they are considered dangerous, since they are able to carry information from one sphere to another. So the key premise of community-oriented care, which advocates for a closer alignment of clinic and community, carries its own threats and challenges.

Patient advocates are uncomfortably aware of their reputation as gossipers, but disclosing the status of their patients often happens unwittingly – even unavoidably. Once the role of the careworker is known, anyone seen with them, whether at the clinic or outside it, is designated HIV-positive by association. In order to limit the attention they might attract to patients, respondents find ways of disguising their job description – often telling lies about why they are roaming the community in search of particular addresses, or why a given household was visited.

Janet speaks about patient advocates having to “make a plan” in an attempt to conceal their purpose:

> ‘If you are looking for someone [a patient] that you didn’t see [before], but you have got the name from the facilitator […], [then] she [the community member] is gonna say […] “Okay I’m gonna show you where this one stays” [Then she will ask] “[…] Why do you want this one? Is this one owing you [money]? Or is this one wanted there by Wallacedene clinic?” You must make a plan or you must make some story just to avoid giving them information’ (17 June 2011).

Some patient advocates claim to be lost and in search of a friend, others pretend to be selling insurance, furniture or handbags, while others still find more subtle disguises. When I asked Sinazo how she explains her job to community members, she said:

> ‘[I say] we are the community workers making sure people are taking their treatment – even if it’s not – because I’m not specific about ARVs – because people here are curious. I’m just saying even if its TB treatment, high blood treatment […]’ (17 May 2011).

Interestingly, this bears many similarities to respondents’ descriptions of patients who are “in denial” - those who lie, omit or disguise information. Just as Sinazo does here, many of these patients are said to acknowledge TB whilst denying HIV. Since TB is curable, and not contracted through sexual intercourse, it carries a lesser stigma than HIV, and is therefore easier to disclose (Daftary *et al*, 2007: 574). The high prevalence of TB/HIV co-infection might also have translated into TB functioning as a convenient euphemism for HIV (Daftary *et al*, 2007: 574), which many are afraid to name. Hence, instances of shirking and disguise are employed both by carers and cared-for, resulting in complex tactical manoeuvring. It is respondents’ membership to the community that necessitates disguise, since privileged clinic information runs the risk of infiltrating the community space. But it is also respondents’ membership to the community that enables disguise, allowing for cover-ups like “I was just passing”.

The necessity of deception and improvisation only adds to the demands of the patient advocate’s position. Nurses, doctors and counsellors are not required to live and work in the same community, or to transport their care services into the neighbourhoods and homes of patients. While social workers have been called into patients' households, their status as professionals assists them in asserting authority. Community-embeddedness is cited amongst respondents as a key difference careworkers and medical professionals, where the latter is faced with the complexity of the social world and the former need only treat the corporeal body.

The difficulty of concealment when living and working in the same community is not simply that one may unwittingly reveal too much as privileged information of the clinic enters the community domain, but also that one is unable to reveal anything when the role of health worker usurps that of community/family member.

It is not unusual for careworkers' friends or relatives to also be patients at the clinic, presenting a unique challenge for respondents, which Mpho illustrates below:

> 'I have a brother […]. This brother fell in love with a client […] When he fall in love, this lady - she is on ARVs […] My brother is having an STI […], which means he didn't use condom[s] […] But I didn't have the power to tell my brother [that] this lady is on ARVs. That is not my part to play, you see. It's difficult. And I was having [another] client. My client was in love with my uncle. My uncle is married. You must understand that is very painful. I know [them] very well. They've been married for many years. They have a beautiful daughter and a son […] I don't have the power to tell my uncle […] I must protect my client, not my family' (9 June 2011).

Respondents, as community health workers, must occupy two roles simultaneously – that of community/family member and that of impartial health worker. But these two positions do not suggest the same normative demands: while health workers are expected to speak openly and frankly with their patients in a conventionally confidential setting, the context in which respondents work requires continual euphemism and shirking in a highly unconfidential space. Furthermore, while family members conventionally protect one another and share important intimacies, the role of health worker requires discretion and the protection of information.

While the clinic prescribes that care be community-embedded, it is ironically those respondents who are least immersed in the community that receive the most trust from patients:

> ‘They [the patients] trust me. That I could see. Because I’m not a talker. They know I don’ t mix with [people]. Those that know me know I’m only at home’ (Anna, 27 June 2011).

Care as Community-Based

In order to foster contextually specific, accessible health services, primary healthcare has not only advocated for community-driven care but also for community-based care. Many clinics have sought to increase the reach of services, not only by situating clinics close to people’s homes, but by extending care services into homes, where governmentality (Foucault, 1978/79) permeates further into the intimacy of people’s lives.

Home-based consultations are the fundamental task of patient advocates whose job success is measured by the number of home visits they are able to complete. Regular home visits are used as a marker of Kheth’Impilo’s ‘holistic’ care strategy, since it is on the basis of the home visit that referrals are made to social workers and counsellors, and patients are assisted with social grant applications.

Either as a repetition of pervasive organisational discourse, or a genuine affirmation of the home-based strategy, respondents have also celebrated home visits, or at least recognised them as a model for care.

> ‘When you go there at home to visit, you […] see the situation at home. You see […] where the place is. Maybe the place is not good […] If you don’t see, you’re going to take for granted, but if you […] see the situation, you [are] going to do something about that. Maybe you [will] refer the client to the social worker or somebody else’ (Tumi, 29 June 2011).

Similarly, Jacob talks about home visits as a space for holistic care, where patient advocates address social, psychological and economic concerns, rather than simply focusing on the medical needs of patients.

> ‘When we are at home, I’ll try not to focus on the HIV thing, you understand, like just to get to know this person. What is going on in your life? Not just to always go there to get information about this patient’s status: “What’s going on now, how do you feel now, are you okay?” […] But then just get to know, “What is going on about your life? What are you doing? Okay, you’re not working but what do you do about that? Are you trying to find a job? Are you still willing to work?”[…]’ (28 June 2011)

As an extension of clinic governance, Jacob extends his attention to all areas of his patient's everyday life. While in some sense this speaks to the increasing intrusion of health authorities, it also serves as Jacob's attempt to de-medicalise the care he delivers. Occupying the dual position of community member and clinic worker becomes all the more fraught in the home space, as the systematised, pragmatic operations of the clinic collide with the intimate domesticity of the home. Here, Jacob attempts to construct a consultation that is decidedly less rigid and less clinical – appropriated to the home space.

Despite championing home visits in rhetoric, patient advocates encounter a myriad of difficulties in and around the home, which is fiercely guarded by family gatekeepers, the threat of stigma and established boundaries of intimacy and distance. "Sometimes they [the household members] don't want you", says Mpho. "[There are] those that are still on denial. Others they chase you [away]" (24 May, 2011).

Home visits are most difficult when the patient has not disclosed to their family, or in cases where the careworker is unsure of the levels of disclosure in the household. Both male and female careworkers report encountering their patients' partners during home visits, who assume that the stranger approaching the house is their partner's lover. Thandeka tells a story of visiting a patient's home, only to be greeted at the doorway by his wife:

> 'I said, "I'm looking for Fredrick Makonyana [pseudonym]". She said, 'What! Are you looking for my husband?' […] I was not going to tell her that I come from [the] ARV clinic, you know. I was supposed to hide what I want to talk to her - to the husband [about]. So she was […] shouting. And I said, "No I want the water". And she was going to fetch the water outside so that I can talk to the boyfriend [and ask], "Did you tell your wife that you are [HIV-positive]?" So he said yes. Then when she came back, I told her. "No sister, I was not going to tell you because I don't have the right to tell you that your husband is HIV positive *[...]"* Maybe she thought that I'm the girlfriend of the husband […] She was going to pour me with the water. Boiling water' (18 May 2011).

Thandeka's story reveals not only the extent to which careworkers must improvise in order to disguise their purpose and protect their patients, it also shows that the home space is one where strangers are viewed with suspicion. Those who enter the privacy of the home must be invited in and intrusion is not taken lightly. Careworkers bring potentially disruptive news and ask to enter a place of intimacy, frequently unannounced. "Sometimes it feels like you are invading someone else's space" (16 May 2011), says Andile.

The 'strategy' of employing community members to conduct home-based visits is intended to make care more amenable to patients, to infiltrate care into the existing social environment and to build relationships in the community. The assumption is that having a careworker visit the patient's home will somehow normalise and integrate the place of care in their everyday life. In reality, home visits are distinctly abnormal, placing strain on families and communities, attempting to construct some level of normalcy in the face of a stigmatised epidemic. The extent of intrusion and surveillance which households are expected to accept under this model would most likely not be tolerated in middle-class settings.

Lethu speaks of having to come to terms with the atypical nature of home visits when she first started working for Kheth'Impilo:

> 'The work was difficult at first because they told us you are going to visit […] this house - doing this, be there, and monitor and everything. And I was so scared. How can I just go to that house and knock? It's so strange, you see. The thing is, I never saw you! [Maybe] I saw you once at the clinic or once somewhere else, but the thing is now it's strange [to] knock at the door looking for this person […] And I ask myself what am I going to do about this? This thing of knocking at the door and ask[ing] "How are you doing? Who is this? Where is this person? I'm looking for this?" And […] I'm so scared of asking these things because of this disclosure thing. So you decide oh no I won't ask anything. Let me just ask how they are doing – [say] that I was just passing' (11 May 2011).

Like Lethu, many other respondents report using, "I was just passing", as a strategy to disguise their work. In doing so, they pretend to be a friend or acquaintance of their patient because the genuine nature of their relationship poses a threat. Paradoxically here, careworkers remain professional and aloof by fabricating closeness. "You have to do by all means to protect - or to hide what you are going for. You have to tell another story", says Pumeza (24 May 2011).

In cases where careworkers do in fact know their patients on a personal level - whether they are family or friends - the opposite occurs. Respondents must maintain an air of distance and professionalism to mask the genuine intimacy of their relationships. Hence, to provide community-based care successfully is to adopt improvisatory strategies that disguise and fabricate relationships, negotiating the lines between public and private, proximity and distance.

Care as Community-Based: Challenges of Disclosure and Confidentiality

As illustrated, patient disclosure is a key issue for careworkers, especially on home visits. Disclosure is positioned as a pre-requisite for accessing ART in the

South African public health sector (Deacon 2005:77; Mills & Maugh-Brown, 2009: 2), which requires that ARV-users disclose their status to at least one person who can serve as their “treatment buddy”. Disclosure facilitates improved adherence (Norman *et al.*, 2007; Mills *et al.,* 2006) and familial support (Haricharan, 2010: 18), whilst also enabling access to state funding, including disability grants and other forms of social care (Mills & Maughn-Brown, 2009: 2). Thus disclosure is central to South Africa’s care ‘strategy’, serving as part of a broader project to ‘normalise’ HIV. Organisations like the Treatment Action Campaign have used disclosure as a political tool to give testimony to the efficacy of ARVs (Robins, 2007: 23), decrease stigma and encourage greater involvement of people with HIV (Nguyen, 2005a).

When Andiswa first enrolled as a patient at the clinic, she had anticipated a model of care in which she would be expected to openly disclose and discuss her status through the mechanism of regular support groups. As is exemplified by TAC, Andiswa had envisioned a scenario where HIV-positive activists tell their stories in a ritualised fashion, invoking redemption and transformation (Robins, 2006).

> ‘[When I first met the patient advocates] I thought “Ah these people!” I thought they were all HIV [positive] […] Yes I thought that. I was like “Yo! They’ve got lots of experience. They’re free with their status, so they want everyone to be free […]”. When I first went there inside [the patient advocate’s room], I thought it was a support group. People like that. So I went in and she [the patient advocate] wanted to speak with me inside that support group. And I didn’t want to speak!’ […] (20 June 2011).

Over time, Andiswa has come to deliver a similar model of care, using her own experience with HIV and antiretroviral treatment as an example for her patients. But it is reported that other patients at the clinic do not readily accept the notion of openly disclosing one’s status, especially in a group setting. “Some [people]”, says Andiswa, “see it as a bad thing to publish yourself, to stand in front of people and tell them [about your status]” (20 June 2011).

In general, disclosure at Wallacedene and Bloekombos clinics has not been advocated as a “confessional technology” (Nguyen, 2005b) or a form of ritualised testimonial (Robins 2006, 2007). Rather, as is the standard in the South African public healthcare, it is promoted as an adherence aid to enable support and eradicate the need to hide one’s medication.

Joan, former manager of the patient advocate programme, explains how each patient who is prepared for treatment at Kheth’Impilo is allocated a counsellor, who will ask whether they have disclosed to their family, viewing non-disclosure as a significant barrier to successful treatment:

> ‘So you may say that you didn’t disclose. You’ve told no one. And that to us is a big barrier. If you have not disclosed your status, how are you going to take medication?’ (17 March 2011)

Because the clinic’s model of care advocates that patients disclose to at least one friend or family member who can serve as a treatment buddy, disclosure is understood as a pre-requisite for treatment. This has resulted in cases where patients pretend to have disclosed to a family member in order to qualify for treatment, but when a careworker visits their home, she finds that the patient has not in fact disclosed.

> ‘They [the patients] can say yes I am disclosed, I’ve […] disclosed to my husband. They are saying that - lying things - and then you believe that they are doing this. But when you go there at home, you see their reality’ (Caroline, Wallacedene, 25 May 2011).

In this context, TAC’s model of care, in which support group participants orate treatment testimonies as a mode of ‘empowerment’ (Robins, 2007), is not easily ingested. Real or perceived stigma has resulted in both patients and careworkers adopting various forms of disguise to avoid openly declaring patients’ status’.

When I asked Dora what differentiated her current work from her work with TAC, she said:

> ‘The work is still the same […] but now it’s a lot! […] We’re facing a lot of things here. In TAC we were just going to the schools and […] teaching children how to disclose. But here we do home visit[s] and we see lots of problems, you know. People are in denial. They don’t want to disclose. So it’s different [...]’ (Dora, 1 July 2011).

Not only does Dora consider her current work more taxing, she also notes that unlike her experience at TAC, people “don’t want to disclose” and are “in denial”. In this context, the prescription of patients living openly and positively becomes tenuous, as patients and careworkers manoeuvre presumed threats to their social or professional relationships.

While respondents are expected to encourage their patients to disclose, they are also trained to respect “the rights” of patients (Joan, Kheth’Impilo national office, 17 March 2011) – with a particular focus on the right to confidentiality. Indeed, patient advocates have to sign a confidentiality clause as part of their contract. Illustrating the challenges in protecting patient confidentiality, Thandeka tells of visiting a male client’s home, where she arrived only to be greeted by her patient’s girlfriend. Unsure of the level of disclosure in the household, Thandeka introduced herself, but could not reveal that she was visiting from the clinic. She remembers struggling over what to say to the woman in the doorway:

> 'If I say [that] her boyfriend is HIV positive, then she can go to the police station to say this person said my boyfriend is HIV positive. Then I can (mimes handcuffs suggesting she could be arrested). So I'm supposed not to tell' (18 May 2011).

Thandeka is aware that disclosing a person's status without their permission is deemed illegal on the basis of their constitutional right to privacy. This is why she makes reference to the possibility of her arrest. But it is not simply the illegality of disclosing a patient's status without their consent that makes respondents so adamant to protect confidentiality; there is also the matter of reputation. Both patient and carer are at risk should the status of the patient be inadvertently disclosed. The patient faces potential community or familial stigma, and the careworker compromises her relationship with both patient and clinic. Patient advocates have to try and build trust with their patients, reassuring them that their status will not be discussed outside the clinic but with little certainty that it will not be inadvertently revealed.

In spite of the dual prescription of encouraging open disclosure whilst protecting patient confidentiality, the realities of the field are that careworkers struggle to achieve either. Patients' proximity to one another, coupled with their proximity to their careworkers, delimits confidentiality. In addition to the difficulty of maintaining privacy, the perception of high levels of stigma militates against open disclosure. As a result, while much is known, little is openly acknowledged.

Nandipha explains:

> 'We always promise our clients that we have privacy: We keep your stuff that you're telling us. But with many ears, it's not that private, you see. And they can see each other [...] Even if I'm talking to you now and the other [patient advocate] is sitting on the chair talking to the other [patient]. Maybe those people are neighbours and they didn't know [about one another's status], [because] no one tells the other that I'm HIV positive. So they will meet on that room [the patient advocates' room], they will see each other there. They will know that okay she is also taking ARVs and I'm also taking ARVs […] Some of them, they don't want to get in that room [the patient advocates' room] because […] people know what you are doing there […] They sit on those benches [in the waiting room] for the same problem, you see, […] but when you call them, some of them, they don't respond […]. Because she sees that my neighbour is here also, so if I get in there, she will know what I'm doing there' (21 June 2011).

In this excerpt, Nandipha identifies the multiple barriers to ensuring confidentiality. Given the demarcation of specific spaces for patients on antiretrovirals, when community members see one another at the clinic, they understand why their neighbours are there. This setting makes it near impossible for patient advocates to protect confidentiality, despite the fact that this is promised to patients from the outset.

Just as there is inadvertent disclosure in the clinic, when patient advocates pay visits to people's homes it situates the visited household as the object of attention. Sinazo tells this story, illustrating how patient advocates, almost unavoidably, disclose the status of their patients through their daily work:

> 'There was this man, but he passed away. And […] I was [once] there [at his house]. Then my mother says "Hey I hear something from the neighbour saying that they saw [you] going there in that house". And then that speaks a lot, because now they know that, that man was HIV positive. If I go into the house, it's disclosing already' (8 June 2011).

Sinazo's story suggests a community of high visibility, where news carries quickly. In Wallacedene and Bloekombos townships, living quarters are close, walls are flimsy, and the insecurity of these conditions produces an atmosphere of being continuously on guard:

> 'When you ask someone who grew up in a township […] about privacy, they don't know such [a] thing as privacy. People, where I'm from, they would hear a sound outside [and] everyone […] would try to find out what is going on. Only to find that it was just something falling from the roof' (Andile, 7 June 2011).

Although - and perhaps because - privacy is limited, patients are adamant to preserve what little confidentiality they can. As Nandipha mentions, some do not respond to their own name being called in the waiting room, and some choose not to disclose to their families or neighbours, while others chase patient advocates from their homes. In this context, managing the concomitant prescriptions of open disclosure and the right to confidentiality becomes insurmountable.

When I asked Sinazo how she felt about her inability to avoid inadvertently disclosing her patients' status, she responded by saying:

> 'I don't know what to feel, but all I know is I don't talk about people's status. Everything is private and it's confidential […] So if anyone knows that you're HIV positive maybe they hear it from you, maybe you are together from here [the clinic]. So I know my job' (8 June 2011).

Sinazo has resigned herself to the fact that information carries beyond her control and she is unsure how to feel about it. Despite this, she is determined to hold to her professional commitments, which demand that she keeps her engagements with patients ‘private and confidential’. This amounts to a work environment in which what is seen is not spoken, and euphemism and disguise become constitutive of care. These improvisatory tactics are necessitated in the mediation of a care ‘strategy’ seemingly impervious to the complexities of its social context.

Care as Socially-Embedded

In line with Alma Ata’s aim to treat health ‘holistically’ as a product of social, economic and political conditions, Kheth’Impilo has sought to address socio-psychological aspects of health, with the understanding that care should not only be medical and curative but also preventative and socially-aware.

> ‘In terms of the […] community adherence programme, it’s looking at all those kinds of aspects - the biological issue, the biomedical issue, the psychological issue, the social issue, and on top of that the economic issue […] We [are] looking at the individual holistically […] This person should live longer and healthier [as well as being] psychologically well, economically well and socially well’ (Phumzile, Kheth’Impilo national office, 9 May 2011).

This conception of care as a comprehensive intervention, rather than being narrowly biomedical, has infiltrated respondents’ conceptions of care:

> ‘It’s about trying to find out everything about that person - then help that person. Like Kheth’Impilo [says], the PA will have to go and do the psychosocial at home and find out everything. Even if there is an intervention that needs to be done by the social worker […] the social worker must go in there and check at home: How is the social background? What is going on with this person at home?’ […] (Jacob, 29 April 2011).

Patient advocates attempt to address the ‘social’ in a number of ways. First, respondents are trained to assist patients in applications for social grants and registration with home affairs. Second, careworkers screen household members to ensure the broader health of the family. Finally, patient advocates refer to counsellors, social workers and psychologists in cases of domestic violence or other socio-psychological problems. Hence ‘holistic’ care is reduced to a referral network at the clinic or a paperwork maze at government departments. These mechanisms of governance are inherently distancing, as intimacy is lost through a chain of staff members or a series of forms. Sometimes neither the clinic referral network nor the grant application process amounts to a resolution:

> ‘You refer the patient […] The social worker played his/her own role into this situation. [But] still the problem is still there […] and there’s nothing I can do about it. That is what is killing me the most’ (Jacob, 29 April 2011).

Despite having an understanding of care that recognises the need for social, economic and psychological interventions, patient advocates are ill-equipped to provide care beyond limited biomedical advice, basic emotional support and treatment literacy. Anything more must be processed through a referral system of nurses, counsellors and social workers. In addition, neither patient advocates nor Kheth’Impilo have the capacity to alter the socio-economic circumstances of their clients: social workers and counsellors are over-burdened and lack the necessary resources to dramatically alter patients’ lives. To add to this, applications for social grants are slow and payout is minimal.

In light of this, careworkers - who are themselves struggling to provide for their families - become deeply frustrated as their conception of care-as-holistic comes into conflict with their incapacity. This affirms what has been illustrated throughout the paper, that the expectations of what patient advocates can/should deliver under this model of care are often absurdly high:

> ‘Maybe we would like to help this client [who does not have food], but no. […] [There is] no food parcel in this organization, you see. […] It is painful […] really because when they saw us they think that we are going to help them. Then we are going to help them about medication and everything, but when it comes to the food parcels, it is very hard’ (Caroline, 25 May 2011).

Like Caroline, many respondents speak about the high expectations of patients, who assume that the arrival of a careworker will amount to a dramatic transformation in their lives:

> ‘Maybe now the client is struggling. She doesn’t have anything. When she saw you entering the gate, she will have that uh … hope. She has that [feeling that] ‘This person is going to help me’ […] [Then] you have to sit down and explain everything, the steps you are going [to take], so she loses hope’. (Miriam, 24 May 2011)

Here Miriam reflects on her inability to live up to the expectations of clients. She speaks specifically about her patients losing hope when she explains the ‘steps’ of the referral process. In cases where the referral system is ineffective, respondents are left feeling redundant, unable to provide the holistic care that is both needed by patients and prescribed by the organisation. In some sense this points to the idealism of primary healthcare as a broad vision, which expects a radical transformation in socio-economic and political structures, and which organisations like Kheth'Impilo cannot hope to deliver. However in another sense, it reveals the anomalies of a care model where those who provide care are equally in need.

As Andile remarks:

> 'It's sad, but take it from me, […] we can turn the tables: I also don't have! So I don't get too attached to that kind of stuff, because I also don't have. If I had I would have provided' (7 June 2011).

Similarly, Miriam reflects on cases when she has been distressed by the living conditions of her patients:

> 'Yo! You feel bad man. You feel bad. It seems you can take the client with you to stay with you. But even you […]- like I'm earning this stipend. How can you take another person to stay with you? You get so little money' (24 May 2011).

Careworkers evidently experience immense grief when they cannot help their patients, commenting, "it's killing me", "it's sad", "it is painful" and repeating phrases like "you feel bad". In order to manage the emotional weight of such cases, some careworkers attempt to distance themselves: "I stop getting emotional. I stop getting too involved. I just do my job, do my monitoring and stuff", says Anna (27 June 2011). Similarly, Jacob remarks that he doesn't "get too attached"(7 June, 2011). This amounts to a tactical withdrawal, where the expectations of the care strategy seem insurmountable.

Chronic Care

The emergence of HIV as a chronic, rather than a terminal, illness has reshaped AIDS care in favour of increased surveillance, where even health patients demand ongoing attention. This in turn has complemented public health approaches, which designate entire populations as targets of health interventions. Here, medical intervention moves beyond the corporeal body or the hospital and into populations designated as 'at risk.' Coupled with the health-promoting, preventative and treatment literacy impetus of primary healthcare, HIV/AIDS care is now such that individuals, households and families are viewed as potential future health hazards to be screened and surveyed, regardless of whether one is currently sick or not. In this way, and specifically in the case of HIV, people are seen as living precariously between health and illness, unsettling conceptions of care as 'tending to the sick'.

Struggles with stable patients are common as respondents grapple with the meaning of care within a therapeutic context of chronic illness. I asked Sinazo what it was like to care for stable patients who had been on treatment for a long time and she replied:

> 'I don't think for me it's necessary because you find that these people doesn't […] even remember if they've got HIV […] because now it's their everyday lives, their everyday thing […] You still have to visit them every month and I don't think it's on […] If we could at least put them to the side, then we could focus on these ones [who have just started treatment]. I think [then] there won't be any confusion, because it's really confusing me' (17 May 2011).

Sinazo struggles to make sense of a conception of care as tending to the healthy. She considers caring for healthy patients to be a waste of time and resources, given that there are new patients in need of greater care. Similarly, Andile describes his experience caring for stable patients as "pretty awkward", as healthy patients resist ongoing surveillance.

> 'We find that sometimes they say "Ah you are wasting your time because I'm fine. You should be going to someone else who is much sicker". Because also people […] get tired of seeing you, [saying], "You don't have to come this time. You don't have to come" […]' (16 May 2011).

But many patient advocates consider the surveillance of healthy patients to be particularly important. Because many people struggle to reconcile taking medication when they feel well, healthy patients are often potential defaulters. This suggests a conception of care where health, while celebrated, is also precarious, calling for increased surveillance (Armstrong, 1995: 395-396):

> 'If they [the patient] see I'm beautiful, I have a figure, [then] I will stop using a condom and I will stop my treatment. […]' (Mpho, 24 May 2011)

Similarly, Miriam says:

> 'If the clients are sick, they take the medication correctly. And then others, if they get right [and] they are not sick any more […], they don't want the medication. That's why we follow up, looking what is going on now when your client is alright' (24 May 2011).

This conception of care as constant, pre-emptive health promotion is well illustrated in this excerpt from Andile:

> '[…] We are all sick, but its just a matter of time until we get our sickness […] Its like no one will ever be born and die without any sickness. Somewhere, somehow we will encounter that you have some kind of

> sickness' (16 May 2011).

Here, Andile effectively highlights the precariousness of health. His argument is in favour of a normalisation of illness, but it is also a position in which normality is to anticipate illness. In this context, care is ongoing regardless of one's current state of wellbeing. Patient advocates often talk of their healthy patients as if they are on the verge of regressing, and similarly sick patients are miraculously revived. Here, the lines between health and illness are blurred, suggesting that health demands ongoing maintenance.

Care as Surveillance

When asked to describe the content of the care that patient advocates provide, the most common response is about monitoring and surveillance – that careworkers oversee patients' adherence levels, side effects and general health. This is in line with interpretations of the 'new' public health as 'surveillance medicine' (Armstrong, 1995). Patient advocates are describes as "the eyes and ears" of the clinic: "They see what is happening because they do visit the patient. They also hear what the patient is saying and […] will relay that kind of information" (Phumzile, Kheth'Impilo National Office, 9 May 2011).

There is indication that some patients consider careworkers to be enacting a form of vigilant surveillance, making the metaphor of patient advocates as "the eyes" all the more pertinent. I asked Andile whether he thought his patients felt as though he was watching them, after he commented on spotting one of them drinking in the tavern:

> 'Maybe sometimes, especially those ones who are new on the treatment. They feel like "Hey this guy's on my back" because now I have to monitor every day for a week. I have to be there by your house every day […] Now it feels weird. Sometimes they feel like you are a stalker because the moment they turn their face you are here' (7 June 2011).

That patients feel as though they are under continuous scrutiny aligns this model of care with Michel Foucault's concept of panoptic governmentality (Foucault, 1978/79; Reynolds & Fitzpatrick, 1999). Here, subjects regulate their own behaviour as a result of feeling under incessant surveillance. Given that patient advocates live and work in the same communities, surveillance permeates beyond the clinic, into streets and homes, and beyond working hours. For Mpho, this is what differentiates patient advocates from nurses:

> 'We go to the community [and] we see the real[ity] […] Because someone can lie here at the clinic […] But when he's at home, he's like [an]other person. Us, we just find [out] everything about them [...] Some

> of them say no I don't drink [when they are] here at the clinic […] But you have clients where you are staying, so when you just walk, you see a client with a beer drinking' (9 June 2011).

This can amount to a form of ongoing policing, which is complemented by Kheth'Impilo's community-driven and community-based approach. "We are staying at the same community, so it's easy for us to catch them, more especially on the weekends", says Nandipha (21 June 2011). "They don't give us right information until we dig the information. We dig it until we find it […]" (19 May 2011). In a context where the role of carers includes "digging" information and "catching people", it is no wonder that careworkers are sometimes perceived as occupying the role of 'informer', calling their loyalty to the community into question.

When I asked Mpho how she responded when she caught patients drinking on weekends, she answered this way:

> '[The patient will say] "No don't tell the sisters!" Me I just say, "I'm watching you". I just say that: "I'm watching you". Because it's his life and he's lying to me. So I don't have a right to come to Sister and say I saw him, because they are going to hate me because of that. They say I'm impimpi and I don't want to be impimpi. I just say "Watch out!" And when you are sick I say, "You see. It's that beer […] I told you [to] stop that thing […] You see why you are like this?" (9 June 2011)

The use of the term "impimpi" is significant here. Under apartheid, "impimpi" referred to a police informant who had betrayed the liberation struggle and sold out to the security police. Alleged impimpi were often victims of mob justice (Harris, 2001). Here, in line with the conception of patient advocates as "the eyes and ears of the clinic", Mpho is positioned as an informer, despite her best efforts to avoid this label.

If it is the case that respondents who report their patients' behaviour to nurses are called "impimpi", then the clinic is being equated to a form of governance - a new security police. Lethu explicitly states that some patients view her constant monitoring as a form of policing, owing to her allegiance to the clinic. Reflecting on one of her patients who defaulted on treatment, she says:

> 'And then when you meet with her [it is] as if you are police or something. [She is] running [from] you and avoiding you as if you are her security [police]' (3 June 2011).

The positioning of careworkers as police adds to the challenge and complexity of the job, where patients mistrust the motives of carers and make a concerted effort to avoid being found out when they breach clinic rules. Patients' shirking and deception results in mutually reinforcing mistrust, as patient advocates desperately attempt to dig up the truth, further provoking evasive tactics. Respondents don't want to be seen as "impimpi" because, as in the apartheid years, disloyalty holds dangerous ramifications. Such ramifications could include damaged social networks or increased mistrust from patients.

But although it is not straightforwardly applied, the governance strategy of care-as-surveillance is embraced tactically. The secrets gathered by respondents form part of an arsenal of threats, punishments and blame which govern relations with patients. This allows Mpho to say things like, "Watch out" and "I told you". These assertions convey subliminal threats and reprimanding without exposing what has been seen. This way, careworkers keep the promise of discretion while still being able to use the information gathered as a tactical means of eliciting compliance. Tracking patients through ongoing surveillance is not only necessitated by a need to monitor and promote adherence, it is also necessitated by the reporting imperatives of funders. Because global and national funders require on-going bureaucratic monitoring and evaluation, carers are consumed by gathering information.

Global Care Corporations

The prescriptions of bureaucratic funding agencies, dubbed 'i-funders', dictate targets and priorities for Kheth'Impilo's care programme and necessitate the use of complex monitoring tools. For example, due to the priorities of funders, prevention of mother-to-child-transmission [PMTCT] became a key focus area for Kheth'Impilo:

> 'PMTCT became very important […] so we developed a [training] module for that. And at the moment because our funding is coming from Global Fund - […] one of our big indicators is number of mother and infant pairs attached to PAs - so we're really focusing a lot on that now' (Joan, Kheth'Impilo national office, 17 March 2011).

This not only illustrates how funding agencies are able to dictate the agenda of the organisation but also the importance of 'indicators'. Outcomes must be measured and quantifiable in order to meet reporting requirements. Here, the success of the PMTCT programme is measured quantitatively, in terms of the **number** of mother and infant pairs attached to patient advocates. This understanding of care - as something measurable, quantifiable and target-driven – emerges frequently in conversations about careworkers' performance.

Shortly after representatives of another funding agency (USAID) paid a procedural visit to Wallacedene clinic, I observed a meeting between patient advocates and one of their supervisors, who I shall call Thuli. Given clinic shortfalls and the imperative to meet targets, Thuli insisted that careworkers fit more visits into their working day. Patient advocates were instructed to plan their days efficiently and work productively. “What counts is the number of patients visited and not so much the number of visits per patient”, said Thuli, putting emphasis on the quantity of visits.

Careworkers were further instructed that even when patients were not at home, these attempts should be recorded as visits, with the qualification that the patient was not found. “Even if it is just a phone call, a form needs to be filled out”, Thuli said. For the sake of efficiency, the coordinator encouraged patient advocates not to spend too much time with each patient – “Don’t chat too much even though you have that relationship with them”. The key message of this conversation was that care should be outcomes-based, and furthermore, outcomes should be measured. “At the end of the day, they [patient advocates] need to collect data [...]” (Phumzile, Kheth’Impilo manager, Woodstock 9 May 2011).

During my fieldwork, a management technique dubbed “PA of the Month” was introduced in an attempt to reinforce target-driven care. The concept is derived from ‘Employee of the Month’ competitions run in many businesses on the basis of productivity. Here, care is situated within a corporate paradigm, where patients and health workers are rendered consumers and providers respectively. This corporatisation of non-government organisations through the directions of global aid agencies has been described as forming part of a development agenda, now equivalent to “Development Incorporated” (Powell & Seddon, 1997).

The sub-district coordinator arrived at Bloekombos clinic one morning bearing a poster that showed a large thermometer indicating temperatures from hot to cold to be displayed in the waiting room. Patient advocates who met their monthly targets (in terms of number of visits completed) would have their names displayed as ‘hot’, and those who did not would have their names displayed as ‘cold’. In addition, the careworker who performed the best each month would be positioned as “PA of the Month”. In order for the system to be successful, it would need to be driven by co-worker competition, fear of public shaming and a fiercely target-driven approach to care. Interestingly, the ‘PA of the Month’ chart soon disappeared from the clinic, perhaps suggesting patient advocates’ rejection of this measure of care. Instances like this serve as examples of small resistances in which respondents attempt to re-assert care and challenge management techniques in their daily work.

To Care is to Report

As a result of funders' reporting requirements, the success of Kheth'Impilo's care programme is often measured in terms of outcomes, particularly the number of patients enrolled, visited and retained in the system. Quantifiable proof is required in order to demonstrate work completed.

> 'We are told that it is important to fill in the forms because […] it's proof […] there are funders to the organisation, so you need the forms […] as back up that you are doing the job' (Jacob, 28 June 2011).

Like many respondents, Caroline feels immense anxiety at the prospect of returning to the clinic with nothing to report. Despite her supervisors having condoned it, she does not subscribe to the practice of recording cases where patients are not found as visits. Here, she reflects on instances where she has failed to find a particular patient:

> 'You can work that four hours for nothing because you are looking [for your patient] […] Then you can go [back to the clinic] without nothing. And when your facilitator needs the paperwork? Nothing paperwork' (8 June 2011).

While the utility and efficacy of the care provided is assessed on the basis of quantitatively reported outcomes, the **content** of care appears to be given less attention. Illustrating the potential consequences of this, Andile speaks about the number of home visits he completes per day:

> 'The most I've done on one day was 11. Because why? Sometimes you don't find the people, so there's not wastage of time. Then you go to the following [visit]. Sometimes you do find 6 out of those 11 [patients at home]. So four they are also visits even though [no one was home]' (7 June 2011).

Here, Andile suggests that when he does find his patients at home, it is possible that time might be "wasted" talking. But if no one is home, "there's not wastage of time" and the visit is still recorded in daily statistics. So cost efficiency is measured in terms of the number of visits a patient advocate is able to complete (or more accurately, report) in one afternoon. Ironically, this goal is impeded when patient advocates spend quality time with patients.

Hence, in an effort to provide good care (defined by meeting measurable targets), patient advocates run the risk of providing an uncaring service. Andile tells a story of a patient who felt she was being 'used' by careworkers: "[She felt that] we are using them because we just want to work" (16 May 2011).

Here, Andile's patient is pointing to the instrumentality of care, not only as a means for careworkers to access employment but also to demonstrate work completed, where patient visits are an instrumental means to improving statistics. The tragedy of the story comes towards the end when, after trying to console the patient, Andile bemoans having to sit and converse with her.

> 'After I finished now, I couldn't just leave because now she's starting to tell me about all her problems - family, how she's struggling. Now I have to sit there and listen to all that stuff. And otherwise I cannot do anything about it' (16 May 2011).

Andile's frustration gives two insights into the care programme: first, because successful care is measured in terms of number of visits completed, lengthy engagements with patients are paradoxically detrimental to the provision of 'good' care; and second, because patient advocates are fundamentally unable to address socio-economic concerns, conversations about familial, social and economic struggles can put emotional strain on them.

While Andile's excerpts above seem to imply a commitment to outcomes-based, quantity-driven care, it may be that Andile is simply expressing the pressures of working within a target-driven paradigm. His supervisors expect reports that reflect a high number of visits completed. Similarly, Kheth'Impilo's care programme must operate within the target-driven paradigm of funders, appeasing authorities of its own. Hence, some of the demands of the prescribed care manual are technical and distanced. These include reporting, monitoring, recording and quantifying. But this aspect of carework runs concurrently and uncomfortably alongside the emotional, supportive and more intimate demands of care.

Andile's comments above do not indicate that he wholly subscribes to target-driven care, but rather that he works within the confines and pressures of this paradigm. Indeed, later in the same interview, he remarks:

> 'The most important part [of my job], **they** say it's the visitation. But the most important part to **me** is not about the visits. It's about are they doing well? Are they taking their medication correctly?' [emphasis added] (7 June 2011).

Here, Andile acknowledges that visits completed are positioned as the most important measure of care, but he is more interested in whether his patients' health.

Although Andile, like many other patient advocates, may attempt to distance himself from patients' personal struggles, especially in cases where he is unable to assist, at other times he will strongly assert the emotional role of patient advocates. In his first interview, Andile described the primary role of patient advocates as technical - "[We] try to monitor people. Are they using their medication correctly? Are they using it well? Are they getting better from it?"(16 May 2011). But in the following interview, he ascribed that which is technical to nurses by saying, "the nurses have to be practical, give the medication, find out how do they [the patients] feel on a physical level […] To us its more like emotional support than physical" (7 June 2011).

Similarly, while supervisors and managers at Kheth'Impilo promote a target-driven, measurable and numbers-oriented approach to care in order to meet the reporting needs of funders, they also make claims that patient advocates should be compassionate and take their time, further highlighting the tensions and complexities of the prescribed care manual.

> 'If you've been to a clinic, everything happens fast and there's very little time that this Sister and this counsellor can spend with a patient. So if we can get that relationship building […] with the PAs - because you do find patients saying, "You know what, I didn't have a chance to ask the Sister this"'(Joan, Kheth'Impilo, 17 March 2011).

Care Bureaucracy

Reporting demands at Kheth'Impilo translate into high levels of bureaucracy. Bureaucracy is an essential technology in the self-governance of the organisation, driven by ideals of 'accountability' and 'transparency'. The quantity of paperwork that patient advocates are expected to process means that 50 – 60% of carers' daily activities are consumed by administration. The paperwork load has become overwhelming for many respondents who complain of having no time for their families or part-time study. "We are not laptops", Miriam once said.

Amidst a highly bureaucratised system of care, respondents find ways to strategise and improvise, appeasing authorities while attending to other pressures. Sinazo admits she sometimes cheats the system, choosing not to fulfil all the paperwork requirements: "I'm not doing all the paperwork […] I don't follow all those procedures" (17 May, 2011).

Respondents must not only negotiate the paperwork burden for themselves, but also for its affects on patients and community members. Other than the heavy workload, the most pressing concern about high levels of bureaucracy is the attention that forms and booklets can draw when careworkers are out on home visits. Perhaps illustrating the extent to which social services have become synonymous with high levels of bureaucracy, when respondents are seen carrying forms community members become curious:

> ‘The neighbours when they see you carrying papers, they are curious and asking you, “What is that?” Or else you’ll see when you just enter the house the neighbour is going to follow you because they want the disability grant even if they are not sick. They think that maybe you are the social worker and they come after you […] So I don’t carry the papers […] If it’s necessary for me to get the paper, I’m going to put the paper in my pocket then when I’m there I open the pocket and write something’(Bulelwa, 11 May 2011).

Similarly, when Jacob carries paperwork with him, people ask: “Are you looking for people? Are you hiring people?’ […] What are these forms for?” (7 June 2011). “Then what am I going to say now? So it’s easier when you don’t have to carry something” (Jacob, 7 June 2011). Thus carrying paperwork can ruin a careworker’s attempts at disguise and attract unnecessary attention. To mitigate this, many do not carry forms with them but instead try to remember the details of their visit and record them when they return to the clinic.

Patients are also reported to tire of the forms, around which each and every consultation is structured, producing a highly systematised form of care delivery.

> ‘These clients are getting bored. You see the psychosocial screening [form]? Now it’s like a book! […] Then you have to sit almost an hour doing this thing. […] You have to talk, you have to give an education to this person first, you have to do everything. And then you follow this booklet thing […] They [are] getting bored of the questions’ (Nandipha, 21 June 2011).

In order to defuse the highly structured consultations crafted around forms, some respondents deviate to more relaxed modes of conversation:

> The time we are going to do the psychosocial [screening form], I don’t just ask the questions, I start to talk […] Some of the things you don’t have to read and just write, […] You just talk […] For example, there are questions like “Are you using a condom when you are having sex?” […] I mean those kinds of things you can’t just read on the paper and ask those things. And […] some of the things you already got the information about them, like the question ‘do you have a partner?’ I don’t have to look on the paper and say “do you have a partner?” *[...]* I talk to them. Just ask ‘Ok listen I want to know everything about you at home […]’ By that time we are not on the form yet. We are still trying to communicate’(Jacob, 29 April 2011).

Not only does Jacob attempt to create a less systematised mode of conversation than that stipulated by the forms, he must also find ways to elicit responses to the highly invasive questions he is expected to ask. So patient advocates negotiate bureaucracy both for themselves and their patients. In a sense, navigating the maze of a highly bureaucratised clinic and social services system is part of the care they provide.

Just as patient advocates must navigate a range of complex reporting tools, patients must navigate a highly systematised clinic system, which demands consultations with doctors, counsellors, nurses and patient advocates, as well as filling out numerous complicated documents. Similarly, accessing social grants requires familiarity with the process and the documentation required. A large part of the care provided by respondents is assisting patients through this bureaucratic maze, thereby rendering systems of governmentality more amenable in their application.

Conclusion

This paper has shown the care manual for community health work to be immensely, even absurdly, demanding. The model for care is shaped by multiple sources, including national and international policymakers, global funding agencies and organisational rhetoric. As a result, the care manual has established a complex, onerous and ambiguous set of standards for the ideal carer. Careworkers are expected to function as bureaucratic cadres pursuing quantified performance, as altruistic careworkers and advocates for their community, as technical officers within the clinic system, and as emotional support to patients. In addition to the interests of external parties, respondents have their own incentives to care, which include providing for themselves, their families and their communities and pursuing personal advancement.

To add to this, this demanding model of care is expected to be delivered by a cadre of carers whose status as health workers is highly precarious. The paper has shown that careworkers are unable to deliver on idealistic conceptions of holistic primary healthcare, thwarted by the incapacity of their organisation and their own socio-economic position. Unlike other staff at the clinic, community health workers are recruited from the same areas in which the work. This has contributed to the ambiguity of their position, since their obligations to the clinic have called their loyalty to the community into question and produced various levels of mistrust. While social workers are expected to fulfil a similar role, traversing both the community and the clinic, the community health workers' position is weakened by their low status.

This paper has illustrated the ways in which careworkers tactically appropriate, subvert and manoeuvre around the care manual, making it more manageable for themselves, and at times, for their patients. Hence, careworkers' agency and inventiveness has produced a practice that rarely resembles the original design, one which is able to function by virtue of its re-invention.

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The Centre for Social Science Research

The CSSR is an umbrella organisation comprising four research units:

The **AIDS and Society Research Unit** (ASRU) supports innovative research into the social dimensions of AIDS in South Africa. Special emphasis is placed on exploring the interface between qualitative and quantitative research. Focus areas include: AIDS policy in South Africa, AIDS-stigma, sexual relationships in the age of AIDS, the social and economic factors influencing disclosure (of HIV-status to others), the interface between traditional medicine and biomedicine, the international treatment rollout, global health citizenship, and the impact of providing antiretroviral treatment on individuals and households.

The **Democracy in Africa Research Unit** (DARU) supports students and scholars who conduct systematic research in the following four areas: public opinion and political culture in Africa and its role in democratisation and consolidation; elections and voting in Africa; the development of legislative institutions; and the impact of the HIV/AIDS pandemic on democratisation in Southern Africa. DARU has also developed close working relationships with projects such as the Afrobarometer (a cross-national survey of public opinion in fifteen African countries) and the Comparative National Elections Project, which conducts post-election surveys over 20 countries across the world.

The **Sustainable Societies Unit**'s (SSU) mission is to explore the social and institutional dimensions of economic development and the interaction between human society and the natural world. Focus areas include: winners and losers in South African economic growth and the interplay between ecological and economic concerns. The SSU was previously known as the Social Surveys Unit and still works on a number of survey projects, including the Cape Area Panel Study.