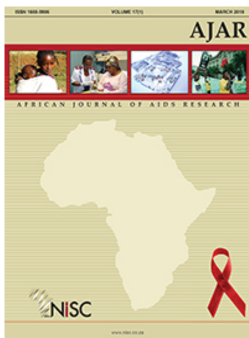

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The role of community health workers in supporting South Africa's HIV/ AIDS treatment programme

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Community health workers deployed around South Africa's primary health care clinics, supply indispensable support for the world's largest HIV/AIDS treatment programme. Interviews with these workers illuminated the contribution they make to anti-retroviral treatment (ART) of HIV/AIDS patients and the motivations that sustain their engagement. Their testimony highlights points of stress in the programme and supplies insights into the quality of its implementation. Finally, the paper addresses issues about the sustainability of a programme that depends on a group of workers who are not yet fully incorporated into the public sector.

Keywords: HIV/AIDS, anti-retroviral treatment, community health workers, volunteerism, social accountability, sustainability

Introduction

In Africa, South Africa's anti-retroviral treatment (ART) programme is unusual for its scope and because state facilities rather than private agencies undertake most prescriptions. With 3.5 million patients in 2016, the programme is the biggest in Africa and a significant extension of state commitment to primary health care. Even so, the programme depends heavily on community health workers (CHWs), a vital group of ancillaries recruited from and remaining within civil society.

This paper draws upon the experiences and perceptions of CHWs who help care for patients treated in government-run clinics.

We provide first a background explaining how the ART programme is organised and the national extent to which CHWs are engaged in the care of HIV-positive patients. This section also discusses the recent changes in the organisation and deployment of these workers. After describing how informants were selected, we use CHW testimony to explore in detail the kinds of care they supply for their patients. We then consider the commitment and motivation of the CHWs. Drawing upon their perceptions to illuminate the on-the-ground functioning of the ART roll-out. Finally, we address questions about the programme's sustainability. Is the programme's dependence upon a group of workers not fully incorporated into the public sector a source of strength or vulnerability? And given the likelihood that more of these workers will be needed when everybody who needs the medication receives it, will government be willing or able to pay for them? Addressing these questions prompts a wider consideration of the issues that might have an impact on the sustainability of the ART programme.

Scope of services and who is providing them

Today, nurses working in primary health clinics dispense 90% of the anti-retroviral (ARV) medicine (Bekker et al., 2014). This is a recent development: in 2009 most ART provision was "reliant on centrally located hospitals and medical doctors" (Barron et al', 2009, pp. 30, 56). Currently, with fewer seriously ill AIDS patients requiring hospitalisation, most health care supplied to HIV-positive South Africans is from nearly 3 600 government-run primary healthcare clinics. In these clinics labour is divided between medical professionals and CHWs, and the community care givers who mainly address the needs of children orphaned by AIDS. In April 2012 the clinics were staffed by 10 000 nurses certified to initiate ART treatment, up from 250 in February 2010 (Bekker et al., 2014). An official audit in 2010–2011 identified 73 000 community-based health workers (van Pletzen & MacGregor, 2013). So auxiliary CHWs supporting the ART roll-out outnumber nurses at a ratio of around 7:1. Nurses do most of the HIV testing and dispensing as well as treatment for other infections contracted by HIV-positive patients. CHWs undertake indispensable support functions.

Many of the CHWs receive stipends following basic training, a practice first introduced by government in 2003. There are four levels of ancillary health care certification on the National Qualifications Framework (NQF) and for certain provinces the level 3 qualification is a requirement (South African Department of Health, 2011). In 2011, though, an officially commissioned survey found that many health workers had received no training and most who had been trained had no certification (Ogunmefun & Madale, 2011). Until recently, in most provinces the CHWs were not directly paid by government. In 2011 the Department of Health was

funding 1 260 non-governmental organisations (NGOs) to pay 41 000 stipends (van Pletzen & Macgregor, 2013). This situation is changing.

Initially, CHWs were supervised by and received a stipend by NGOs that operated in partnerships with government. Stipends would vary among provinces within a range of ZAR500–1 500. However, in 2011 more than 10 000 CHWs were purely voluntary, and received no stipend at all (South African Department of Health, 2011: 9). From 2010, however, a new policy of "re-engineering" primary health envisaged the direct recruitment and deployment of "outreach teams" of CHWs managed directly by the nurses working in the clinics (van Pletzen & MacGregor, 2013, p. 6). This shift is still happening and today direct state employment of CHWs is expanding in all nine provinces. In mid-2016 outreach teams were working in 2 590 of the total of 4 392 of South Africa's local government wards (South African Department of Health, 2016). This re-engineering of the way the CHWs are managed and their incorporation into a wider system of primary health care is part of a more general effort to shift health care out of the clinics into the community and is directly inspired by Brazil's preventative Family Health Strategy (Barlow, 2013).

KwaZulu-Natal was the vanguard of the new approach. In 2011 the province stopped funding NGOs for CHW stipends and started contracting the workers individually instead (South African Department of Health, 2011). These contracts are for 20 days' service a month. In addition to the workers who received a stipend from provincial departments of health, there are the 17 000 officially designated community care givers supported by the Department of Social Development. After re-engineering, CHWs "play primarily a surveillance and health promotion role in communities" (Pletzen & MacGregor, 2013, p. 20). Although CHWs will continue to encourage people to undergo HIV testing and to support patients' adherence to ART, home-based care of very sick patients will be delegated to "carers" managed by NGOs. CHWs combine a range of functions and are the largest group of people engaged in the delivery of ART.

Methodology

The methodology undertaken for this study was qualitative. It involved 3 focus groups with Treatment Action Campaign (TAC) activists using an interview schedule, 55 interviews with CHWs using questionnaires and 6 in-depth interviews with leadership from AIDS organisations, using an interview schedule. Before the study began, ethical clearance was obtained from the Humanities and Social Sciences Research Ethics Committee, University of KwaZulu-Natal. In addition, permission to undertake interviews was obtained from TAC, Section 27 and the South African National AIDS Council (SANAC). Consent forms were also used before each focus group/interview. Focus group participants were selected by TAC which elected to have representatives from three provinces participate: three from Gauteng, four from KwaZulu-Natal and three from Limpopo. Given that part of the study ethos was to capacitate participants, the focus group participants received a training session on qualitative methodology from the researchers. Following the focus groups each activist undertook at least five interviews with CHWs — they selected interviewees from the pool of CHWs they work with daily, using convenience sampling. Approaching the CHWs through the agency of the activists ensured we would have selected a group predisposed to be critically assertive. In-depth interviews were then carried out by the researchers amongst leadership of TAC, Section 27 and SANAC. In most cases leadership and activists were comfortable being named, but all the CHWs were anonymised to ensure they would be more open to sharing their views this way. The study primarily applied coding and thematic data analysis.

Our fieldworkers interviewed 55 CHWs, 22 in Gauteng, 16 in KwaZulu-Natal and 17 in Limpopo. Of the 55 only 8 were men. They were mostly aged in their thirties or forties and were generally secondary educated. Twenty members of the group never received stipends, though several of these said they were supposed to. The rest were receiving stipends, though not regularly. In Limpopo and Gauteng, interviewees were mainly paid and managed by NGOs whereas in KwaZulu-Natal, interviewees were contracted and paid directly by the Department of Health and belonged to teams managed by the nurses at the clinics. Four of the interviewees were paid through NGOs by the Department of Social Development and would have been designated officially as community care givers, though their work was similar to that of the others. We therefore included their experiences in our analysis. Informants sometimes described themselves as community care givers even when it was evident that they would have officially been CHWs, receiving a stipend from the Health Department; the two terms were often used interchangeably within the group we interviewed.

The main objective of this research was to explore the perceptions and experiences of the CHWs. Ideally, it would have been helpful to compare their perceptions of their interactions with clinic staff with the views and recollections of nurses. This should be a topic for future investigation.

Tasks and functions

In the early stages of South Africa's provision of community-based ART much of the work undertaken by community-based health workers was directed at the pre-treatment counselling to prepare patients for the routine of daily medication as well as for any side-effects. Workers employed as counsellors would run "treatment readiness classes". Pre-treatment preparation times have now become much shorter and the counselling is cursory, a consequence of ministerial pressure to meet enrolment targets (Mark Heywood interview 17 April 2015) and the inception in 2016 of treatment immediately following testing. Our data reflect this for only a few of the informants referred to tasks associated with pre-treatment phase: that is "identification" of potential patients (G21; L16) and their preparatory "initiation" including prompting of patients "to come forward and share about their status" (L3).

When asked about daily routines, 29 of our informants described activities located in their clients' homes. Nearly half the CHWs were supporting very sick patients taking ARV medication. In such cases, "*We assist those patients with almost everything in their homes*" (G11). And indeed, the

CHWs cooked for very sick patients and helped them eat, they bathed them (G1, G4, G10, G11, KZN10), exercised bed-ridden patients, and they changed soiled linen (G11, KZN2, KZN3, KZN4, KZN5). In undertaking these functions the CHWs were likely to have fulfilled other caring needs: "*we come by and comfort her or him and make her or him feel loved again*" (G14).

CHWs invested effort in ensuring patients ate adequately. As they noted: "*people who take their medication on an empty stomach you cannot expect them to adhere to their treatment*" (G7). Members of the Gauteng teams referred to soup kitchens that they run. In one case an NGO manager "who is cultivating crops at the clinic" donated vegetables. Businesses could supply support: one of the CHWs referred to obtaining "braai-packs" from Pick and Pay to "*give to needy people*" (G12). Gauteng CHWs also raised money through door-to-door solicitations. More commonly, the CHWs provided food taking "*money from our own pockets*" (G6, G8, G14, G18, G19, G22, KZN11, L1, L6). Councillors might help: one of the Gauteng group mentioned their local ward councillor "*who is assisting with food parcels*" (G12). Nursing staff could be sympathetic: "*If the patient is malnourished I report to the clinic and sister will provide porridge*" (KZN3, KZN4, KZN5); here direct supervision of the workers by the clinical staff was evidently beneficial. In KwaZulu-Natal as well, local agencies of the Department of Social Development supply food parcels on request, though "*we don't get [them] as much as we want*" (KZN6). In Gauteng, too, the department provides food vouchers for people on ART: here the officials "*really do respond*" a local TAC organiser told us (Gauteng FG: 2).

Aside from meeting basic needs, CHWs support patients medically. Several Gauteng CHWs and most of the Limpopo group undertook "DOT" or directly observed therapy, systematic monitoring of patients taking their medication for tuberculosis (TB). Most of our informants perceived their major purpose was to maintain patients' adherence to their ART regimes, "*teaching our patients to adhere to treatment as the best option*" (G7 and G3). For this purpose, KwaZulu-Natal CHWs run "adherence clubs", indeed for some of them that task is, "*the point of our job-scope*" (KZN16). Adherence clubs were originally introduced by *Medecins sans Frontieres* in the Western Cape in 2011 in conjunction with TAC, significantly raising adherence. CHWs were trained to monitor adherence systematically (KZN4). Several CHWs said that they actually undertook the delivery of ART medication to bed-ridden patients (G2; KZN4, KZN8, KZN9, KZN11). Gauteng and Limpopo CHWs reported they were assigned by their clinics to trace treatment 'defaulters'[1] (G2, G6, G9, G12, G20, L1, L6, L7, L8, L9, L17). CHWs often accompanied sick patients on visits to clinics paying for them to make the journey.

The efforts these CHWs undertake to ensure patients remain on their treatment are probably their most useful contribution. Eleven of the CHWs our fieldworkers spoke to observed that in their vicinities treatment "defaulters" were reducing: "*the number of defaulters has dropped in our community*" (G9; see also G2, G6, G7, G11, G12, G20, G21, KZN9, L14). Most of these affirmative perceptions were from the Gauteng group. This is a particular instance in which it would be helpful in future research to seek corroboration from officials and nurses of the CHWs' effectiveness in limiting lack of adherence. National statistics of lack of adherence rates are not routinely released. But the Gauteng Member of the Executive Council (MEC) or more informally, provincial "minister" for Health, Hope Mafo, admitted in September 2013 that the figure was 4 410 in 2011. Given the provincial total treatment statistics in which 80 000 patients joined Gauteng's ART coverage in 2011, the figure is in line with the results of systematic tracking of a cohort of patients at a single Johannesburg clinic: 95% of patients remained on treatment a year after starting it (Clouse et al., 2013). A more alarming picture was presented by the health minister, Dr Aaron Motsoaledi, in his budget speech in June 2014: his figure indicated 37% of patients "lost to follow-up" 3 years after beginning treatment. (Editorial, NSP Review, 11, 2014: 1).

At the clinics, CHWs function as paramedicals. The Limpopo group were especially engaged in TB screening (L3; L4; L10). For CHWs, TB screening has become one of their major functions nationally and may be displacing other activities. One of the Limpopo CHWs noted that though "*we are home-based carers*", when reporting for work at the clinic she and her fellow workers were often told that "*we must stay at the clinic to screen people for TB*" (L4). Limpopo CHWs also mentioned helping with blood tests (L11, L13), and "*taking vital signs, malaria tests and diabetic tests*" (L11 and L15). They organise queues for vaccinations and provide basic health education at the clinic and door to door. Door-to-door activities include condom distribution (KZN12, KZN15, KZN19, L5), and encouraging men to undergo circumcision (KZN12) — even though customarily "*women are not allowed to even discuss that*" (G6). Countering the stigmatisation of HIV-positive people and overcoming patients' fear of stigma was a key preoccupation: "*We are working very hard to mitigate stigma so that our clients will come freely to the health-centre to fetch their medicine*" (KZN16, and also G6, G16, G22. L3).

Management and coordination

How were our informants managed? In KwaZulu-Natal the CHWs are deployed in outreach teams directed by the nurses at the clinics. Their testimony suggests systematic assignment of patients and reporting on their experiences. They referred to monthly quotas of between 40 and 80 household visits and weekly "war room" debriefings. The war room is a feature of KwaZulu-Natal's Operation Sukuma Sakhe (Stand Up and Build), in which a range of anti-poverty programmes delivered by different departments are coordinated at different levels beginning with the ward-based war rooms (KwaZulu-Natal Province, 2015). Team supervisors supplied direction in the field; two of these were among our informants. Despite these health auxiliaries now being subject to direct public management, strikingly, all of them continued to refer to themselves as "volunteers". Meanwhile in Limpopo, though the CHWs still receive stipends from NGOs which also supply them with cell-phones and "uniforms" (T-shirts), they seem to work under close supervision by clinic staff. They are expected to sign a register left by their NGOs at the clinic at the beginning and end of the working day. Limpopo informants complained

about the lack of adequate debriefing sessions at which they could report on issues encountered in the field (L7). More positively, however, their status as NGO-managed seems to have enabled them to retain a degree of autonomy: one of the Limpopo home-based CHWs understood her duties to include "*monitoring the availability of treatment at the clinic by asking the patients questions*" (L7).

In Gauteng, most of our informants were under the supervision of "project managers" attached to the NGOs which paid their stipends and these managers seem have a range of responsibilities. Several of the Gauteng CHWs referred to local fundraising undertakings coordinated by their NGOs, and project managers paid for feeding or transporting patients. Mostly, the Gauteng CHWs confirmed they worked cooperatively with local clinic staff: "*our local clinic works hand in hand with us*" (G6). They felt valued by the clinics, taking pride, for example, in a prize awarded to their health centre "*because of the job well done by community health workers in our community*" (G8). Conversely, at certain times, "*at our clinics sometimes they don't want our help*" (G18). As with members of the Limpopo group, Gauteng informants also complained about not having debriefing sessions (G21). They also spoke about managerial neglect, and two from the same vicinity described what seems to have been a major dispute within the NGO that provided their stipends:

> *The biggest challenge is that some of the community health workers have been fired from the NGO. Some don't have matric certificates but they are good at what they do. Every time they got fired they took the matter to arbitration but the manager always wins and never pays them though the court says they must be paid... She fired the workers and hired her family and friends* (G11).

In Gauteng, at the time of our fieldwork, the NGO-managed CHWs were a shrinking group as in 2015 the province was transferring them to its own payroll in line with national policy. In time Gauteng will deploy the CHWs in teams managed from the clinics, but today many, though paid directly by the Department, remain NGO-managed. Those who have joined the ward-based clinic-managed outreach teams are supposed to receive higher monthly stipends of ZAR2 263, in recognition of standardised working times (which in fact may be no longer than the hours put in by notionally "voluntary" NGO-managed workers who receive a stipend). At least one of our Gauteng informants was working for a ward-based outreach team, though she said the team leader's "*attitude was not good*" (G2). At least in theory, in Gauteng, the outreach teams are mainly intended to be engaged in household visits rather than working at the clinics, again in line with official policy (Gauteng Province 2012).

Without the deployment of these community-based auxiliaries, the scale of ARV prescription from primary healthcare centres could not have been achieved or sustained. As is evident from their routines, these activities are decisive in patients maintaining their adherence to ART and in supporting people who would otherwise need to be hospitalised. As SANAC former chair and TAC leader Mark Heywood pointed out, "*The role of the community health workers is absolutely critical… they are needed for so many things*" (Interview 17 April 2015).

Motivation and commitment

So how well do these arrangements work and what are the main points of stress in this community-based programme of treatment and care?

Let us begin by considering the motivation of the CHWs and the effect on this of the government's re-engineering of their deployment. A significant proportion of these 73 000 CHWs are unpaid volunteers motivated by altruism. But even among the informants who received stipends there was plenty of evidence of idealism. Many had long histories of looking after people living with AIDS and had originally engaged with them as pure volunteers. As noted, members of the KwaZulu-Natal outreach teams habitually called themselves volunteers. As one of them explained, "*We do this work willingly, not by being forced and it is for the love of our community*" (KZN4). Clearly the voluntary ethos inherited from the pre-stipend era still affects commitment. For example, in Limpopo, CHWs are enjoined to "*help the patient when they need help even if it is in the holiday or at weekends*" (L13). The almost universal extent to which our informants reported paying for patients' food or transport is another telling instance of their idealistic motivation, and sometimes this can elicit wider generosity: "*We often take from our pockets and ask neighbours for help*" (KZN11). Their reputation as voluntary workers may also make them more approachable than professional medical workers. In KwaZulu-Natal, "*Since the community knows us as community volunteers they alert us of any sick patients*" (KZN5; see also L11).

The original scheme of providing modest stipends but keeping these auxiliaries under the direction of NGOs acknowledged the value of this altruism, though as is evident in KwaZulu-Natal it does not seem to have been checked by the changing employment arrangements. Without their payment it seems unlikely that such a large number of health workers could be mobilised for long-term full-time service. Most of the CHWs, despite their self-description of themselves as volunteers, nevertheless understood the stipends as remuneration, though a few used the term "*compensation*" (KZN1) and seemed to accept using their stipends to pay for patients' expenses. But what was alarming was the frequency of cases in our sample in which stipends, though promised, were not being paid. In this respect, from our data the Gauteng authorities appeared to be more efficient than those of the other two provinces; only one of our Gauteng informants reported serious hold-ups in the payment of her stipend. In 2014 Gauteng officials claimed to have more than 8 000 CHWs receiving stipends directly as "service providers", not employees (www.SAnews.gov.za 12 February 2014). However, several of our Gauteng CHWs were not receiving stipends; their NGOs had applied for these but had been informed that there were no funds "*after they have done with those that are already getting it*" (G12, G16, G17). Altogether, 35 of our informants were supposed to be receiving stipends and, of these, 15 were being paid very irregularly.

One official explanation for these delays is that NGOs struggle to process payments quickly (Schneider, English, Tabana, Padayachee, & Orgill, 2014). The termination of NGO funding for stipends in KwaZulu-Natal was

accompanied by references to instances of NGO venality (South African Department of Health, 2011). In this province, however, the Department of Health's assumption of responsibility for direct payment to individuals has not ended inefficiencies. Press reports elsewhere drawing upon the complaints of CHWs and their NGO managers suggest that the inefficiencies in payment of stipends are a consequence of delays in their payment *to* NGOs and are a consequence of poor administration in provincial health departments (Bambalele, 2012). In South Africa, an official investigation in 2009 found that various expenses connected with the ART roll-out including, most significantly, pharmaceutical orders, were not budgeted for and became in effect "unfunded mandates". One reason for this was that provinces did not always receive adequate sums in their HIV "conditional" (that is, ring-fenced) grant allocations, because these tended to be based on the "equitable" formula customarily used by the Treasury, and this formula did not consider variations between provinces in the numbers registered for ART (Barron et al., 2009, pp. 32–36).

The re-engineering of primary health care, in which community workers will be absorbed into teams managed by clinics and individually contracted as "service providers" on provincial payrolls, is at its most advanced stage in KwaZulu-Natal. Several of our informants were working in Umgungundlovu district, one of the pilot areas designated in 2011 for primary health care re-engineering. The CHWs to whom our fieldworkers spoke belonging to these teams seem to be working contentedly with their clinics despite payment inefficiencies. In Limpopo, where the older arrangements often remained, many of our informants favoured the prospect of change: "*The government should absorb us… NGOs must end because they are using us, they don't treat us well*" (L5, L7 and L10). Senior TAC officials were also disparaging about the role of the NGOs that manage these CHWs:

> *Most of these workers are outsourced to NGOs, most of whom are service delivery and not advocacy orientated so they will not be challenging the state on behalf of the workers…Some of these NGOs are nothing more than labour brokers* (Vuyiseka Dubula, Interview 12 May 2015).

If this was the case, that the NGOs were chiefly agencies in an exploitative "outsourcing" arrangement, then their exclusion from primary health care might not represent a setback, though in the individual contracting of workers as rightless "service providers" is also open to the criticism of being exploitative. But in certain settings the NGOs do seem to be playing a wider and more creative role than mere labour brokers in meeting the needs of HIV/AIDS patients. As one of the Gauteng CHWs observed: "*The government wants to cut the NGOs and yet people are dying of poverty*" (G19). In general, the way our informants spoke about the NGOs that managed them did rather suggest that many of them were primarily formed in response to the government's need to contract out the role of managing these ancillary workers. Insights from other settings suggest "demand driven" local agencies are very susceptible to elite capture (Schou, 2009). However, these predispositions can be challenged effectively when a strong local culture of activism exists as was evident from the testimony we collected.

The chairperson of SANAC, Fareed Abdullah, was also critical of the government's relegation of NGOs. In Abdullah's view this move "*is quite disruptive to a system that was working relatively well and it is disruptive because the NGOs have had a huge role to play in the success of the treatment roll-out*. Moreover, he added, putting the health workers on the state's payroll "*will invite a culture of public service which is not great in this country*" (Interview 29 April 2015); his implication here is that civil servants often behave in a self-serving way. There are other concerns about the changing status of these workers. A study commissioned by the Caregivers Action Network warned that if public funding for these auxiliary workers was limited to the new clinically-directed teams "*some elements of the spectrum of care and support, most notably home-based care, may no longer be provided*" (van Pletzen & McGregor, 2013, p. 7).

These anxieties reflect real issues. In the original scheme for the government's absorption of the CHW on to the payroll, the number of people joining the clinical task teams was set at 41 440, considerably below the actual total of existing CHWs in 2015 (Malan, 2014). The 250-household quotas that are supposed to be assigned to these workers suggest that they will be providing much more perfunctory care than the range of attentions reflected in the testimony reported in this article which is from CHWs with much smaller caseloads. Even our KwaZulu-Natal informants who were now in clinical teams had their caseloads set at 80 households.

There have already been cases of re-engineering excluding experienced health workers, ostensibly because of their lack of formal educational qualifications, most notably in the Free State, where 2 200 workers lost their stipends. And as is evident from the testimony we have collected, a substantial proportion of the caregiving to AIDS patients is supplied by unpaid volunteers who still hope for government recognition and support. Demoralisation as a consequence of such disappointments can seriously weaken commitment as one of the unpaid KwaZulu-Natal CHWs confirmed: "*some of the community health workers have resigned and we are seriously shorthanded in my district*" (KZN2). As contracted service providers, the CHWs remain excluded from benefits and security. Limpopo interviewees made it clear that they disliked their status as contracted service providers: "*Government should absorb us as nurses… we want to be permanent, not carers*" (L5 and also L6, L8, L10, L15); "*Government should employ the CHWs, even as cleaners would be okay*" (L7).

Is the roll-out programme functioning effectively?

Are there other indications in the testimony collected by our fieldworkers that the system of primary health care is struggling to cope with the tasks assigned to it in the roll-out? Two of our informants suggested there had been medical shortages at their clinics (G4, G17) and others told us (G17, L6, L7) their clinics were inadequately staffed. In general, though, the main impression we obtained from the Gauteng CHWs was that their clinics were functioning effectively and that they enjoyed good relationships with clinical staff. Their testimony did not suggest a system experiencing severe stress. Though four of the CHWs suggested they were

treated badly by clinic staff (G1, G5, G18, G21), a rather larger number of our respondents offered positive sentiments about their own treatment and their commentaries suggested that the clinics were maintaining an effective ART regime: "*We are now on the right path under the leadership of our nurses and doctors and our community has turned a new page*" (G10, G6, G8, G11, G14, G20, KZN 1-5, KZN 10-15). The absence of such optimistic assessments was a noticeable feature in the interviews with the Limpopo CHWs who of the three groups appeared the most demoralised. Several of them felt the numbers of patients needing attention at clinics meant they were neglecting their home-based patients. In contrast, generally the KwaZulu-Natal testimonies suggested systematic allocation of tasks by nursing staff and relatively efficient performance.

The TAC activists we met in our focus groups were much more critical and their perceptions were informed by a wider range of perspectives. Both the Gauteng and Limpopo groups referred to experiencing ARV medical "stock-outs" at their clinics. Certain Gauteng clinics were severely understaffed, for example, in a clinic near Pretoria, in Shoshanguve, "*you'll only find 4 nurses for 400 patients — 1 nurse for ART and 1 nurse for TB*" (Gauteng FG: 2). To be fair, in this particular clinic, in response to complaints, the government had recently invested ZAR25 million in new facilities due for completion in July 2015. The Limpopo activists believed that staffing had improved at the clinics they were working with, "*though there is still not enough staff*". But treatment numbers had expanded they said, and with respect to "roll-out" of ARVs in the community, "*it has improved*". Even so, a major challenge remained that "*not enough medicine is given to clinics*" (Limpopo FG: 4). They all referred to local ARV shortages as routine occurrences: "*and when you report these, as we have to, [the nurses] get angry and accuse you of spying*" (Limpopo FG: 4). In KwaZulu-Natal, apparently, medicine shortages were a consequence of breakdowns in the supply chain between the depots and the clinics, not an effect of overall provincial shortages: "*In KZN we have stock-ins but the medicine is still at the depots; it hasn't been distributed yet*" (KwaZulu-Natal FG: 2). Generally, a rural organiser said, "*medicines normally are available at the clinics*" (KwaZulu-Natal FG: 3). Local organisers identified staff shortages especially at rural clinics as the key concerns: "*rural clinics are more likely to be understaffed because staff keep asking for transfers*" (KwaZulu-Natal FG: 3).

In 2013 a national investigation based on a survey of 2 144 clinics found that 1 in every 8 were experiencing an "*on-going persistent supply problem at the time they were called*" (Lines, van Cutse, Shroufi, & Wang, 2013, p. 20). In certain provinces the causes may be related to the government's budgetary system and high level maladministration as other researchers have suggested (Hodes & Grimsrud, 2011). Testimony collected in the research for this paper, however, suggests that often causes are more localised and can be put right quickly if downward local accountability mechanisms exist. The examples we were given of how difficulties could be corrected is illustrative. In one KwaZulu-Natal district, clinic managers needed more access to budgeting information. Local TAC organisers "*did a survey and when we reported we presented the survey to the district health office; they were receptive and acted on the information. Now as a result of our recommendations, operational managers attend quarterly meetings*" (KwaZulu-Natal FG: 3). This is a rather striking illustration of the ways in which NGOs can shape official policies locally through engagement, embodying as they do this a creative policy-making network; such networks are a distinctive feature of other African multi-sector HIV/AIDS delivery procedures (Kabayakgosi & Mpule, 2008). It is a process that requires proximity and collaborative relationships, often quite difficult to combine with advocacy, though this can happen. As other commentaries have shown in different contexts, contrary to widely shared beliefs, working with government does not always reduce partners to becoming mere agents (Batley & Rose, 2011; McLoughlin, 2011).

This kind of anecdotal material suggests that patients, CHWs, activists and even clinic-based staff are networked in such a way that a dynamic of social accountability can function around the clinics. One effect of the degree to which the performance of primary healthcare clinics is subject to local monitoring is the absence of evidence of local venality. Only two of our informants referred to corruption, both speaking about the same incident. In 2003 an academic study conducted in Gauteng in 2003 found that only 1% of survey respondents had been asked to pay for health services (Paredes-Solis, Sergio, Anderson, Ledogar, & Cockroft, 2011). Recent assessments of corruption in the health service suggests that it is mainly located at much higher levels particularly around tendering (Rispel, Laetitia, de Jager, & Fonn, 2015), though investigations of the Eastern Cape's health department found that venality had "even taken root in clinics" (Kardas-Nelson, 2012, p. 15). Honesty at the point of delivery in primary health care is quite unusual in developing countries, so South Africa's relatively good record in this respect merits emphasis.

The strength of such accountability dynamics is probably the consequence of the way in which universal roll-out of ART in South Africa has been engendered by civil society activism in a setting in which social movements and NGOs helped to shape the way that treatment would be organised. But today, as we have noted, the localised NGOs that have managed community-based care for AIDS patients are being dispensed with or sidelined by the Department of Health.

Sustainability

How sustainable are these arrangements for the support and care of HIV-positive South Africans, arrangements depending so crucially on the deployment of this large group of community-based auxiliary health workers? This is a good time to ask such a question as the way they are organised is undergoing important changes, as we have seen. For two decades, care for HIV-positive patients depended heavily on voluntary efforts. A striking feature of the testimony we collected was the extent to which our interviewees still perceived themselves as volunteers. They supplied plenty of evidence of their idealistic dedication. It is arguable that this kind of commitment might reduce if the CHWs are subjected to very close supervision by nursing staff, though this did not seem to have been the case amongst the CHWs interviewed in KwaZulu-Natal working in the clinic directed outreach teams. There is also the risk that removing the intermediary

role played by the NGOs in managing the CHWs might weaken the downward local accountability mechanisms just referred to above as well as reducing possibilities of CHWs undertaking the kinds of creative initiatives they mentioned when interviewed. Then the range of services our informants provided for patients indicate an intensity of supportive care that would not be possible if the CHWs were assigned the kinds household quotas conceived in the re-engineering scheme. However, as the scope of the roll-out broadens it may well be that there will be fewer very sick AISA ^DO YOU MEAN AIDS?^ patients needing intensive home care. But the other consideration that affects sustainability is financial. Deploying all the CHWs in clinic-based outreach teams as is envisaged in the re-engineering scheme will certainly cost considerably more than the government spends on them at present; as we have noted from the interviews, stipends varied and many were very small. If all the 73 000 workers were receiving the top level monthly ZAR2 263 stipend paid by the Gauteng government, that would cost a little less than ZAR2 billion. Most are paid much less today. But even the top level stipend is much lower than the minimum monthly wage of ZAR3 500 that government itself is proposing for all South African workers. And as was indicative from the Limpopo testimony it is likely that many CHWs, their idealism notwithstanding, would like to be employees with accompanying entitlements, not contracted service providers. As the numbers of patients on treatment expand more CHWs will be needed: 200 000 TAC believes, if the government is to meet its targets (Teke, 2016).

Government leaders cite much lower figures. In 2016 the health minister suggested at the Durban conference that the aim should be for 40 000 "trained" CHWs and referred to the Brazilian model in which each worker looks after 150 or so households (Mpulo, 2016). It is possible, then, that there will be budgetary pressure for economies in the care of HIV/AIDS patients. South African political leadership maintains that generalised and comprehensive treatment of all HIV-positive South Africans is quite affordable and to date roll-out has not resulted in major expansion of health budgets. But two considerations might make universal roll-out less affordable. First, South Africa still receives a significant quantity of external funding which contributes greatly to the relevant NGOs active in the field of HIV/AIDS prevention and support for patients. This is in decline.

The second risk is that Treasury forecasts about the sustainability of treatment are based on assumptions that infection rates will continue to fall and that treatment itself is efficient. Public data about infection rates do not suggest sharp overall declines in new infections; the figures cited by the Human Sciences Research Council (HSRC) for 2012 and by Statistics South Africa in 2015 suggest rates that still remain above 400 000 a year. Certainly, the target set by the National Strategic Plan for halving the rate of new infections between 2012 and 2016 is not going to be met.

Official projections about whether South Africa can afford universal treatment are based on assumptions about the efficiency of roll-out which are questionable in the light of experience to date. Too many HIV-positive people are lost to the programme either after testing or even after beginning treatment. The government may be underestimating the contribution made to the programme by non-government agencies many of which rely on external support which may not be forthcoming in the future. In a setting in which government is under pressure to economise in its expenditure, the supportive tasks performed by the health workers may yet be viewed as expendable.

Conclusions

What have we learned? First, our evidence makes it clear just how dependent the expansion of the numbers of patients on ART is on the efforts of CHWs. They meet a range of needs of bedridden patients and also play a major role in motivating other patients to adhere to treatment. They also supplement the personnel available in severely understaffed clinics, enabling nurses to expand their patient quotas.

The continuing engagement of CHWs in caring for people living with AIDS is not a certainty. The government's proposals for the auxiliary roles to which these workers will contribute in a re-engineered system of health care omits certain functions they perform and may exclude many of the people who carry them out. The side-lining of NGOs implicit in the government's policy may have the effect of weakening the altruistic motivations inherited from volunteerism. To a degree CHWs' commitment is the product of civic activism around AIDS. This fosters a climate in which primary health care is subject to local social accountability. Here, obviously, advocacy organisations like TAC continue to correct administrative shortcomings. TAC's effectiveness depends upon the wider networks of civic activism embodied in community-based workers. A re-engineered system under tighter official supervision may become less downwardly accountable.

To conclude, huge-scale provision of ART through deployment of autonomous groups of ancillary workers and volunteers mobilised by NGOs has enabled a very rapid expansion of treatment to a huge numbers of patients at low cost. However, after 10 years of functioning in this way, the system may be exhausting its stocks of altruism. Moreover, the government's efforts to recast it by eliminating NGOs and contracting individual service providers may weaken social accountability dynamics, increase costs, reduce services delivered and, finally, fail to meet the workers' expectations. Government plans appear to be based on an only partial appreciation of the contribution these workers make to attempts to end the AIDS epidemic. Tighter budgets are likely to accentuate their insecurity and vulnerability.

Note

[1] The term "defaulter" was commonly used amongst study participants.

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