# 'We are left in the cold': Nurses' perceptions and responses to antiretroviral treatment roll-out in the Free State, South Africa

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# **Abstract**

The unprecedented roll-out of antiretroviral therapy (ART) in South Africa is a complex process where no previous endeavour exists that can measure, predict, or direct an intervention of this scale. In the Free State province, unique characteristics and problems distinguish its ART programme, although countrywide problems also occur within the province. The Free State province faces high vacancy rates among its health-care workers, the programme has lower patient enrolment rates because of an obsession with quality to the detriment of quantity, and various incidents of ART shortages have also shook the province. The ART roll-out intervention thus far has been largely nurse-driven (however not nurse initiated), and they form what many refer to as the 'backbone' of the programme. In order to respond to the challenges faced by these front-line ART providers, continuous transformations inevitably take place to respond to new needs associated with the roll-out programme, but also to strengthen the primary health-care system in general. The objective of this article is to present a typology of contradictory contextual factors in the antiretroviral programme as identified through group interviews that were conducted with PNs at public health-care clinics in the five districts of the Free State province during 2005 and 2006. We intend to show that transformations often have contradictory and problematic outcomes as expressed and perceived by the nurses themselves. This unprecedented endeavour of ART roll-out inevitably has to treasure and support its most valued implementers, i.e. the front-line providers who are not only professionals in the health-care setting, but also social agents in a wider contextual framework.

Keywords: nurses, HIV and AIDS, antiretroviral treatment, Free State, South Africa.

# Résumé

Le déploiement sans précédent de la thérapie antirétrovirale (ART) en Afrique du Sud est un processus complexe au sein duquel aucune tentative précédente n'existe permettant de mesurer, de prévoir ou de diriger une intervention d'une telle échelle. Des caractéristiques et problèmes uniques distinguent le programme d'ART déployé dans la province de l'Etat Libre, bien que des problèmes d'ordre national apparaissent également dans la province. La province de l'Etat Libre se trouve confrontée à des taux de postes vacants élevés au sein des professionnels de la santé, le programme disposant des taux d'inscription de patient les plus faibles en raison d'une obsession pour la qualité au détriment de la quantité, différents incidents de manques d'ART ayant également affecté la province. L'intervention de déploiement des ART a jusqu'à présent été largement motivée par les infirmières (mais non initiée par celles-ci), ces dernières constituant ce à quoi il est fait référence par la « colonne vertébrale » du programme. Afin de répondre aux défis auxquels ces fournisseurs d'ART de première ligne se trouvent confrontés, des transformations continues s'opèrent inévitablement afin de répondre aux nouveaux besoins associés au programme de déploiement, mais également afin de renforcer le système de soins de santé primaire (SSP) en général. L'objectif de cet article est de présenter une typologie des facteurs contextuels contradictoires dans le programme antirétroviral (ARV) tels qu'identifiés au moyen d'entretiens en groupes conduits avec des infirmières professionnelles dans ces centres de santé publics dans les cinq districts de la province de l'Etat Libre au cours de 2005 et 2006. Nous souhaitons montrer que les transformations font souvent l'objet de résultats contradictoires et problématiques, tels qu'exprimés et perçus par les infirmières elles-mêmes. Cet effort sans précédent de déploiement des ART doit inévitablement protéger et soutenir ses maîtres d'œuvre les plus précieux, c.à.d. les fournisseurs de première ligne, qui sont non seulement des professionnels dans l'environnement des soins, mais également des agents sociaux dans un cadre contextuel plus large.

Mots-cles: Infirmières, VIH et SIDA, traitement antirétroviral, Etat Libre, Afrique du Sud.

### Introduction

The unprecedented roll-out of antiretroviral treatment (ART) in the South African public health sector poses manifold and complex challenges. Nationally and internationally, no equivalent intervention can be applied to measure possible outcomes on health-care providers and on the health system (Stein, Lewin & Fairall 2007). Also, no 'evaluated, evidence-based policy' exists

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to measure the possible repercussion of such an intervention in a resource-limited setting (Gupta, Irwin, Raviglione & Yong Kin 2004:320). In the South African context, the health system is already under heavy strain given crises linked to human, financial, and physical resources, high demands on the health system related to elevated morbidity, inequality between the public and the private health sectors, but also the high expectations of the general population after the demise of apartheid in 1994 and the promise of 'a better life for all'. The announcement in 2003 indicating the universal access to ART in the country is a concrete transformation in the domain of caring for people infected with HIV and in need of treatment. This programme reifies a main part of the nursing profession, namely the ability to restore to health patients suffering from illness, in this case HIV and AIDS (Du Plooy 2006; Lehmann & Zulu 2005; Tobi, George, Schmidt & Renton 2008). This component of caring has been absent from the profession in the wake of mortality associated with the disease. ART has prolonged and saved many lives, despite the fact that national antiretroviral (ARV) coverage is well below its stated national and provincial objectives (Booth 2008). The Free State province only has coverage of 25.8% of patients in need of treatment (Adam & Johnson 2009). Between December 2008 and February 2009, the Free State province faced serious challenges in its roll-out programme, characterised by the moratorium placed on new patient enrolments onto the programme. Insufficient financial resources were said to be the root cause for halting the enrolment of new patients on treatment (Treatment Action Campaign (TAC) 2008). The general shortages are also threatening to interrupt treatment regimens of those already receiving ART. The ART roll-out programme in the Free State province has been aptly described elsewhere (Stein et al. 2007; Van Rensburg 2006; Van Rensburg, Steyn, Schneider & Loffstadt 2008). The obsession with implementing a quality programme within the Free State paved the way to compromising wider and quicker access (Van Rensburg 2006). Countrywide, the programme was also characterised by vertical, conditional, and ring-fenced grants (Schneider 2006).

The ART roll-out intervention thus far has been largely nursedriven (however not nurse initiated), and they form what many refer to as the 'backbone' of the programme. However, in 2005, it was estimated that the public health-care system had a 37% vacancy rate of nursing positions within the Free State province (Du Plooy 2006). This occurrence renders this 'backbone' fairly weak, especially in light of the immense weight that it is carrying.<sup>2</sup>

In order to respond to the challenges faced by frontline ART providers, continuous transformations inevitably take place to respond to new needs associated with the roll-out programme, but also to strengthen the primary health-care (PHC) system in general. The latter approach is often referred to as 'comprehensive PHC'; with the special emphasis on the aim of the ART roll-out to serve to strengthen the health-care system as a whole. However, various studies deal with the malfunctioning of health systems in developing countries (Jaffré & Olivier de Sardan 2003), of malpractice within these (Fassin 2008; Jewkes, Naeemah & Wodumo 1998), and more recently, with specific problems relating to ART roll-out, especially concerning the human resource crises (Marchal, De Brouwere & Kegels 2005; Van Rensburg *et al.* 

2008). Despite progressive and elaborate policy changes characterising the South African health-care landscape, implementing these policies remains problematic for policy makers, politicians, implementers, and the ill. With specific reference to the nurses managing ART roll-out at public health-care facilities, this historical event of unparalleled ART access entails a host of policy changes, new rules, practices, and knowledge to cope with these rapid transformations. However, given the pace at which change is taking place (or fails to materialise), these policies and changes are often inadequately implemented, poorly understood, or arbitrarily exercised. This leads to nurses having to improvise as they go along and manage the contradictions of the system, thus becoming 'street-level bureaucrats' (Walker & Gilson 2004), using their own discretion and often neglecting the rules and procedures as stipulated by the grand, national policies, and consequently compromising ethical practice as universally understood (Fassin 2008). The character of the medical profession, which includes gestures such as acting on bodies, having the power to decide on a patient's well-being, and exercising technical know-how foreign to the patient, renders this profession sensitive to ethical procedures and behaviour. This is a central dilemma experienced by many nurses, as the 'professional conscience' and 'professional ethos' of nurses are guiding factors when they refer to their roles (Mathauer & Imhoff 2006:2). However, not fulfilling these professional guidelines due to the manifold and complex constraints, impediments, and contextual factors leads nurses to feeling 'unmotivated and frustrated' (Mathauer & Imhoff 2006:2). Following a grounded theory approach, the objective of this article is implicitly, to give nurses working in the Free State ART programme a voice, by explicitly, presenting a typology of contradictory contextual factors in the ARV programme as identified through group interviews that were conducted with professional nurses (PNs) at public health-care clinics in the five districts of the Free State province during 2005 and 2006. We intend to show that transformations often have contradictory and problematic outcomes as expressed and perceived by the nurses themselves. These inconsistencies influence how nurses feel about the work they perform on a daily basis, which could probably lead to consequences relating to their caring practices as well. In the tradition of symbolic interactionism, we try to reflect on how our participants interpret and create meaning of their lived experiences in the workplace.

In the article, we will first look at the research process before turning to discussing the findings of the study. The discussion of the findings can be categorised under the following subsections as identified through the process of constructing themes: policies and contradictory outcomes; health systems weaknesses; lay workers irregularity and non-professionalism; the absence of management structures; quantity training to the detriment of quality; and lastly, the limitations of nurses' own coping mechanisms.

# The research process

Since the commencement of the ART programme in the Free State province, South Africa, the 'Effective ART in the Free State' research project has endeavoured to ascertain the most effective way to deliver the treatment by conducting extensive research at a patient and facility level, applying both quantitative

Table 1. Summative interview schedule for group interviews

#### Interviewee group

#### **Group interview themes**

PNs

Please discuss your job satisfaction (positive) and job frustrations (negative)./In what ways (positive and negative) has the expansion of the ART programme impacted on this facility (if at all)? What is the impact of the ART programme on this facility (what changes occurred)?/What is the impact (positive and negative) of the ART programme on your work as nurses (what changes occurred)?/What is the impact (positive and negative) of the ART programme on other staff (other than PNs)?/Your patients: Please describe and discuss your role/work with ART patients. What is the impact (positive and negative) of the ART programme on your patients (what changes occurred)? What needs of ART patients are not being met at this facility? Are there any needs of ART patients which could be addressed by you as PNs, but for some reason you can not provide? If yes, please explain./What is the impact (positive and negative) of the ART programme on other programmes in the facility (what changes occurred)?/To what extent is ART integrated with the other programmes at this facility? How is it done? What should be done?/What are the shortfalls in this a) facility and b) nurses' needs relative to the demands of the ART programme?/Have the staffing needs changed as a result of the ART programme? If so, how? Please comment on staff (professional and administrative) numbers; the skill mix required to perform a good service; as well as the mix of staffing categories for the ART programme./ls the staff adequately informed, skilled, and educated to cope with the demands of the ART programme? If not, please explain what is needed additionally?/How do (a) lay counsellors and (b) home-based carers assist the ART programme? Please discuss the value of, or frustrations experienced with, (a) lay counsellors and (b) home-based carers working in the ART programme./ What is their value in the ART programme?/Please discuss the nature of support and supervision you receive from ART programme managers (i.e. outside managers). Do you find it to be sufficient?/(a) How is the ART programme impacting on you emotionally and psychologically? (b) How do you cope with the stresses of HIV/AIDS? What coping mechanisms have you developed? (c) What official strategies or measures are in place and accessible to you, should you need special emotional or psychological support? (d) What official strategies and measures do you think should be in place and accessible to you, should you require special emotional and psychological support?

and qualitative approaches. A component of this larger project is a *facility appraisal*. Among others, group interviews with professional staff at all the PHC facilities dispensing ART were conducted.<sup>3</sup> This article draws on the interviews that were carried out during 2005 and 2006. During the data collection, 16 group interviews were conducted with PNs at the ART sites in the Free State province. Depending on the number of participants and the group dynamics, the group discussions with nurses lasted between 30 and 80 min.

The interview schedule comprised 15 broad, open-ended questions with the principal aim to elicit PNs experiences and perceptions of the ART roll-out programme. (cf. Table 1).

The minimum requirement for participants of the group interviews was that the informant occupied the position of PN at the ART site. All PNs present at the 16 sites were invited to participate, thus making the sampling technique purposive. The number of respondents per group ranged between 3 and 10, and totalled 70 in 2005 and 77 in 2006. Table 2 summarises the composition of the PN groups per district. Said respondents included managers, ART programme managers, PNs working on the ART programme, as well as those working in other programmes. Interestingly, only 8 (2005) and 13 (2006) were male, 84.29% (2005) and 90.9% (2006) were black, and 15.71% (2005) and 9.1% (2006) were white, while their average age across the province was 39.52 years (2005) and 41.6 years (2006), respectively, with a median age of 40 years in 2006. Their ranks were very evenly distributed between the three categories of PN viz. chief PN, senior PN, and PN, and the average duration that a PN had been employed at a specific facility was 5.11 years (2005) and 6.1 years in 2006.

The interviews were predominantly conducted in English, while informants were assured that they were welcome to respond in

their mother tongue, if they wished to. The advantage of having a multilingual research team (one facilitator and one recorder) who are proficient in a range of local languages not only greatly facilitated the rapport building in the early stages of the interviews, but also the participants' willingness to respond during later stages of the interviews . Before commencing with each group interview, the objectives and importance of the research were explained; permission and informed consent were obtained to tape-record and transcribe the sessions for research purposes. Permission to conduct the research was granted by the Faculty of Health Sciences at the University of the Free State. Since the group interviews were tape-recorded, the concern of PNs to ensure their anonymity had to be taken seriously. To this end, only the facilitator and the interview recorder had access to the original interviews, and no personal name is chronicled in the group interview transcriptions nor are participants' names recorded in this article. Facility names are also not utilised to limit linking individual responses to a particular facility. The tape-recordings and interview transcriptions remain the property of the Centre for Health Systems Research and Development, where they are securely stored.

The facilitator made verbatim transcriptions of the group interviews with PNs. Where necessary, the detailed transcriptions of each recording were translated, and validated by re-transcribing – a task assigned to the person who was responsible for the recording.

Various researchers actively pursued the promotion of the validity throughout the analysis stages. Firstly, the facilitator and another researcher independently extracted commentary on broad themes emanating from the transcribed interviews following the coding and categorisation of the data. Secondly, a fourth individual worked through the verbatim transcripts and the coded and categorised data to create her own themes. The combined themes

Table 2. Summary of group interview particulars as seen per district					
	Number	Female	Male	Age <sup>a</sup> – Average (Median) <sup>b</sup>	Employment <sup>a</sup> – Average (Median) <sup>b</sup>
Lejweleputswa					
2005	13	9	4	45.3	4.2
2006	15	13	2	42.8 (40)	5.5 (4)
Motheo					
2005	12	11	- 1	37.8	6.9
2006	18	14	4	41.7 (41)	8.3 (8)
Thabo Mofutsanya	na				
2005	13	11	2	38	4.9
2006	17	13	4	42.2 (41)	5.8 (4)
Xhariep					
2005	17	16	- 1	34.8	4.9
2006	16	14	2	37.9 (38.5)	6.1 (3.8)
Fezile Dabi					
2005	15	15	0	41.8	4.3
2006	11	10	1	43.4 (39)	4.6 (1)

<sup>&</sup>lt;sup>a</sup>The average and median age, and average and median duration of employment of participants for 2005 and 2006 may not be a true reflection of the situation. The reasons for this, among others include: the informants (1) may not have indicated their age on the register, and (2) may have indicated the total number of years they have been working as PNs, instead of indicating the number of years they had worked at the specific facility.

were then synthesised and the picture that emerged is what we present in this article. The six themes that eventually emerged from the data - generally represented as conflicting contextual factors - are useful constructs to represent the results of the study more broadly.

# Findings and discussion

The lack of, or contradictory outcomes of support structures which oftentimes leave front-line workers feeling inert and stymied are exacerbated when their professional duty and the daily adversity collide head-on. This section is dedicated to elucidating the six contradictory contextual factors, understood as an umbrella term and a useful construct with which to represent the results that emanated from the two rounds of interviews.

### **Policies**

The ultimate aim of any new policy is improvement through transformation. In the case of the ART roll-out, this policy has ripple effects well beyond its core objective. Firstly, this intervention is also to target improved service delivery to end-users (making the roll-out part of a greater comprehensive PHC plan). Secondly, it indirectly influences employment by creating new positions and specialisations. Thirdly, the availability of ART also contributes to making nurses feel 'functional' again as they find themselves in the position to treat HIV-positive patients in a concrete manner. This treatment is giving new hope to HIVpositive individuals, but also to those who care for them (e.g. nurses), not only in their professional role, but also in their social role, as they are also 'social actors, not just health-care providers' (Walker & Gilson 2004:1259).

Some nurses expressed that they are better informed about ARVs, HIV, and AIDS since the roll-out and that their facilities are better equipped than many other clinics because of this programme. (C13:06). Some consider that this programme is a learning experience (C8:05); but that the generalised ART programme is a new responsibility. It was mentioned that the exceptionality and urgency of the programme conjured up extraordinary measures. One of these is that ART patients are fast-tracked and assisted even after hours at some clinics.

The policy changes are closely linked to the system changes. However, nurses, as described by Walker and Gilson (2004:1261) acting as 'street-level bureaucrats', are 'potentially both a resource for, and possible obstacle to, policy change. The legitimacy of a new policy must be recognised by the streetlevel bureaucrats ultimately responsible for its implementation'. This makes them important actors when measuring successes or failures of policy transformation.

# The contradictions and the impositions of policies

Official policy implementation is often imposed, i.e. a 'top-down approach' is followed when introducing a new policy (Walker & Gilson 2004:1251). This often results in the creation of 'idealtype' scenarios, ignorant of real-life situations, contextual variations, the limitations of bureaucracy, and contradictory protocols.

Nurses recollected this dilemma by explaining the silo-like way different programmes run within a single facility:

We can have millions of tablets of Nevirapine, we are not allowed to take one, from ARV to give to PMTCT. No, the

bThe first number denotes the average age/duration of employment of the participants of the group interviews as calculated per district, while the number indicated in round brackets, e.g. (45.2). designates the median age/duration of employment of said participants calculated in years

patients on PMTCT programme will go without the Nevirapine because this Nevirapine is for ARV. Whereas I feel, if you have the Nevirapine, whether it's Ingalime or whether it's Aspen, it doesn't matter, the patient needs it – this redtape bureaucracy of this vertical things...it's making life extremely difficult! (C7:06)

A respondent at another facility highlighted a problem in the protocol guidelines set out by different programmes. He mentioned that the ART protocol encourages that an HIV-positive person be given a prophylaxis to counter the possible development of TB. However, the PMTCT guidelines discourage the introduction of a prophylaxis.

Equally, most of the patients need grants, and assisting with obtaining these is outside the scope of the PNs' capability. What are you supposed to say to these people? Please go home and wait for your CD4 count to go below 200? (C13:06) Having a CD4 count below 200 does not guarantee that a patient will be approved a grant. He mentioned that some of the ART patients default in order to retain or be eligible for a disability grant. Some come here only in the hope of getting a grant. (C13:06) According to respondents, if patients are unable to procure a grant, the failure rate of the programme is elevated considerably.

A nurse shared her predicament when educating patients about 'positive living'. She despondently asked what she is supposed to say about healthy eating when she knows for a fact that this client has no income. Another participant reiterated this dilemma:

Our biggest frustration is in order to prevent some of the side effects, we must give the patient high-protein diets, and we receive zero support from the Nutrition Department of the province. (...) but you know, if we say we need this product they will just deny us that. For me, it feels almost like they are not faced with the problems that we are sitting with in a practical sense. If we need to give high proteins, how do we give it to people who are not having an income? It takes you months to get them onto a grant, if you do get them onto a grant. (C8:06)

The lack of adequate patient nutrition, together with the problems they have in securing grants, places a palpable pressure on these front-line providers. A respondent lamented: 'We are dieticians and social workers ... everything. This is on top of our work!' (C12:06)

It has been recorded that nurses are rarely involved when decisions are made pertaining to policy changes. At one clinic, a respondent commented on the roll-out policy in the following manner: It was never planned for, it was just dumped here, it was never given the appropriate and the necessary attention. (C11:05). Another claimed that: the greatest problem is structure. They don't have structures, proper structures to render the service. (C1:06)

Nurses expressed that they are often unaware of policies and policy changes and that this is due to inadequate communication linked to poor management. At one clinic it was stated: *You know*,

I wouldn't really call it support. I think the biggest problem for me is that we started off with something and we didn't have policies, we didn't have guidelines, we were having nothing. (C10:05)

These accounts relate the sense of isolation nurses feel, but also reveal some of the contradictory outcomes related to policy implementation.

## Health system changes

One of the main debates around ART roll-out and the health system revolves around successes and failures of integrating this service into the broader PHC context. Ideally, the roll-out has to strengthen the existing health system, has to complement it, and has to function within its parameters. This objective has been achieved, according to some nurses: Even before the introduction of the ART, I've been dealing with HIV-positive patients. So, it wasn't a problem at all for us, to integrate ART, because the problem already existed. (C3: 06)

According to some respondents, the ART programme is adding new resources to the system, and puts the focus on an integrated service. Nurses in one of the districts commented on the quality of care that has improved, because too often in conventional PHC programmes, the patients *fall through the system*. (C5:05) The success of treatment is having a positive impact on patients: and their adherence is very good on treatment, they improved since they started taking treatment. (C5:05)

It was often reiterated that the availability of treatment decreases stigma related to HIV and AIDS, which in turn influences the health system as a whole. There is better acceptance of the illness and its treatment, of voluntary counselling and testing (VCT), and of disclosure, and some nurses felt that end-users view the clinic with new hope. These positive attitudes and effects of treatment ripple out into the community, thus improving the attitude towards public health-care facilities: This treatment is a blessing! They have less fear now. (C2:06) Nurses consider that patients are educating one another, sharing experiences, and that there is better compliance of the medication. At another facility, nurses felt more positive about the ARV programme during the second round of interviews in 2006 compared with the first round in 2005. They too mentioned that it was not only their own attitude that had improved, but also that of the community:

we are having patients, ARV patients who have disclosing in the community. So when we talk about ARV, it's no more ... a kgokgo (worm) in the community. They know about it, they know the service is there. They see the programme as an overall benefit to the system as a whole. (C10:05)

The novelty of the programme, the resources, and the challenges also incited some of the nurses to be part of its development: *This programme came with personnel, equipment, medicine, so there is no negative impact. It's a new programme which challenges nurses.* Nurses want to work in that programme. It's a developing programme that is interesting. (C2:06)

# The exceptionality of ART laying bare the health system weaknesses

The ART programme - despite its manifold challenges - has brought about a generalised feeling of enhanced functionality and importance. This is experienced by the front-line providers and by the users benefiting from the life-saving treatment, and in some cases a smoother running system. However, this improved reputation leads to the added cost of more patients attending these designated facilities, even for minor ailments, although these patients do not come from the immediate catchment area, which is a criterion for accepting a patient at a specific health-care facility. This amelioration in service and reputation has led to the 'flooding' of clinics by patients. This increase in patient numbers is, however, not met by appointing more staff. At one specific facility, two PNs resigned without being replaced. Initially, one person could manage the ART initiation, but as the programme expanded, so too did the demands linked to it. A nurse opined that there is an exodus of personnel and that staff leave to seek greener pastures. (C2:06) The latter alludes to nurses being recruited by other provinces or succumbing to the allure of emigrating.

Some authors warn that 'the expansion of access to ART can come at the expense of other vital health-care services, such as maternal and child health-care services, or lead to an unintended diversion if attention and resources away from HIV prevention' (McCoy, Chopra, Loewenson, Aitken, Ngulube, Muula, *et al.* 2005:19). This finding was confirmed by a respondent:

the implementation of the ARVs... we really experience a constraint in the other Primary Health Care programmes. It is as if the ARV is the priority. People are really not interested in the rest of PHC, it's only ARV. What's going on, how many patients... you know, how many on treatment, how many on screening? Whereas, if you look at the bigger part of PHC services, it actually our core of our function, is not only ARV. For me it's really frustrating, it is as if, you know, ARV is this golden cap that you must wear all the time. (C10:05)

Some respondents deemed that it is too difficult to wholly integrate the ART programme with the rest of the PHC, while some said that a separate service will compromise confidentiality. The majority of respondents felt that, ideally, all the services should be integrated, but that this is not always practical. For example, all the consultation rooms would have to be fully equipped for ART preparation and treatment. The ART programme itself, according to an informant, is designed to be separate. Conversely, some nurses argued that: (...) with the increase in incidence of HIV, most will become positive thus not making it viable to want to separate the services, perhaps even working from a separate building. (C7:06)

Another dilemma is that patients in the ART queue are fast-tracked, because some of them are very ill:

It gives a lot of stress for us. And also for the patients because they see that others are being favoured and being taken as VIPs. That person has just come in but he is being called to be helped first. (C13:06) Other problems, of a more logistical nature, also weaken the health-care system. For example, the waiting period from the time a patient qualifies for treatment, i.e. when the CD4 count is below 200, until she commences treatment may be anything as long as 8 months. According to the nurses, the greatest delay is at treatment sites, where it is common for only one doctor to assess patients. To illustrate, at rurally located clinics, there is only one doctor who visits the clinic once a week.

After the initial euphoria of treatment access, the low morale of front-line providers is linked to widespread drug unavailability in the Free State (TAC 2008). During the 2005 round of interviews, an informant explained some of the problems they experienced at their facility. The quote below not only speaks to the generalisability of the situation province-wide, but is just as applicable to the treatment shortages and financial problems of 2008/2009.

I think a concern for me also is the sustainability of the medicines for the ARV programme. Because we had a nasty hick-up in November, December, beginning January ... with the supply of medicine. You know, and you are pushing this patient to get there and to be drug ready and when he gets there, we must say "OK, wait, sorry, we are playing for time now". So that you know, that is cruel. But how to resolve it, I don't know, really. You know, this thing of "yes put them on" and "no, you must stop again", and "yes put on", and "no, stop" ... If we must sustain the programme then we must have a sustainable supply of medicine as well. (C10:05)

Petersen and Swartz (2002:1010) argue that it cannot be expected that PHC personnel 'provide comprehensive, empowering care when little containment or support is provided by the system as such'. The health system has to provide the parameters within which front-line providers act. If the system fails, it will be detrimental to the efforts of these individuals to render health care in general and ART roll-out, in particular.

### Lay workers

It is acknowledged that the scaling-up of ART in the country will have to be accompanied by the training of non-professional workers in order to delegate some tasks and functions (Marchal et al. 2005). The sheer volume of logistical arrangements for patients already on treatment, and the need to enrol more patients on this treatment regimen combined with the role of tracking defaulting patients and supervising compliance and side effects, open up an opportunity as never before for lay workers to be trained to assist health professionals. At this point in time, the lay worker cadre is still a confused combination of individuals, often referred to as 'volunteers', working for various non-governmental organisations or faith-based organisations. Regulating mechanisms are put in place and the policy framework is being revised in order to standardise these practices (Lehmann & Matwa 2008).

Some nurses identified the importance of lay workers within the clinic, as lay counsellors do pre- and post-test counselling. Lay workers were considered to be valuable in fulfilling this role

and they also act as peer counsellors, which makes it easier for community members to identify and relate to them, and to come for testing. One nurse related: *I am very glad they are here, because I think without them we wouldn't be able to access the community as well* (C8:06), while another acknowledged their important role outside of the clinic: *It's like they are nurses in the community, some of them. I feel very positive.* (C7:06)

According to another PN, without volunteers and their hard work, the nurses would not be able to cope. The lay counsellors, for example, do VCT, are involved in campaigns, and they assist with drug-readiness training (DRT). However, it was emphasised that these lay workers need more training in order to fulfil their roles satisfactorily. In an attempt to involve the volunteers more, at one facility, they attend clinic meetings, where they have an opportunity to voice their concerns or opinions, and make suggestions. Elsewhere, the home-based carers (also lay workers) report on patients experiencing problems to the nurses, ask and receive advice, and if necessary, refer them back to the clinic.

One PN maintained that although *in the clinic they are nothing* (C9:06), they significantly alleviate the work burden experienced by the professional staff. This nurse continued by stating: *I just feel that they are neglected but really they are so important, we value their presence.* (C12:06)

### The irregularity and non-professionalism of lay workers

The issue of confidentiality relating to lay worker activities (especially counselling) seemed to be the main preoccupation of the professionals. At one facility, nurses refrain from distinguishing between ART patients and other sick patients, because with ARV we are sometimes a bit afraid, due to the confidentiality part of it, because we are really not 100% sure of them [lay workers] that they will keep that secret. (C1:05)

At another clinic, a nurse expressed the same view:

I think they [lay workers] should be trained extensively as far as confidentiality is concerned' (...) 'Because some of the people, when you refer them to the lay counsellors, they are refusing – simply saying that they are going to be discussed throughout the townships. So I think they should be trained. (C6:06)

Another respondent developed this thought slightly further by distinguishing between themselves as professionals and the lay workers as non-professionals: I usually say that, our lay counsellors, they are not professional. If she doesn't feel like coming, she doesn't come. (C3:06) A feeling of distrust and unreliability could accompany this sentiment as voiced by a PN. The home-based carers are supposed to do home visits and care for patients, but the PNs are uncertain of the accuracy of their reports. The monitoring system is flawed: you know, an imaginary patient can be there. (C1:06) According to some of the respondents, a form that the patients must sign is not fool proof because some of the patients cannot write. At another facility, it was said that:

They [lay workers] are of value, but they are not regular. They don't come every day, they come, then they come for two days, three days, and then they vanish for a month. (C4:05) This feeling sometimes took on even more drastic proportions with a nurse questioning the motives of people doing lay work:

The question is that ... you keep on saying "let's bring in the volunteers", but one can ask the question whether they understand what voluntary work entails? I was talking to some of the volunteers this week, and you can read between the lines that the reason for them to get the job was to volunteer, there is a short cut to volunteer, so that they could get the job. So in essence, the person – the question of commitment, that's where I start as far as people who are volunteering are concerned, it's very minimal, you know. I didn't want the volunteers because I could do without them. Others could be committed and others won't be. So it's a vicious circle. (C1:06)

On a different level, nurses indicated that they pity lay workers, given their poor compensation and lack of employment security. According to a PN from one facility, the lay counsellors also complain that their psychological well-being is being neglected, and are calling for debriefing sessions. Some nurse respondents considered this to influence the lay workers' work ethic, thus also explaining their frequent absence. In addition, some nurses were not aware what the roles of lay workers were. At one clinic, nurses did not know that volunteers were allowed to assist with DRT for ART. They only found out during the group interview that they are able to substitute nurses to train potential ART patients.

At these clinics, lay workers were only supposed to work 4 h a day and after presenting DRT, for example, they were meant to return home. However, when patients come from afar, especially in rural areas, these patients cannot be shown away. In such circumstances, the lay counsellors have to stay, *sacrificing her time, and present another session, working more hours and she cannot be refunded.* (C13:06) The opposite of this problem was also mentioned. Apparently, at times there has been not one single patient who was willing to voluntarily test for HIV, and therefore no need for counselling by the lay workers.

In discussing the value of volunteers at facilities, but particularly in the ART programme, a respondent pensively asked: *I sometimes wonder if we want too much from them?* (C12:06) Introducing a new cadre of health-care workers in the problematic and conflict-ridden public health-care system is bound to bring about interesting developments. Regulating and protecting them, standardising practices, and defining roles are processes that are slowly taking place to structure this new domain. They can serve both as a massive stress reliever at public health-care facilities, or as a group easily exploited, undermined, or deemed inconsequential by professionals with qualifications, technical skills, and more experience.

#### Management structures

The hierarchy of authority at the time of the ART roll-out was similar to the health profession more generally. There are

managers, facility managers, and district coordinators whose role consists of offering some form of support, advice, and supervision. Some clinics' PNs applauded the clinical support they get from the Centre of Excellence<sup>4</sup> and some individuals there, in particular doctors. Only at one clinic did nurses claim that the support from district and provincial managers was satisfactory. According to them, the support and the visits are regular, especially from the former.

Despite the hierarchical structure in place, nurses mostly gave disapproving accounts of this essential form of support. This can be closely linked to the importance of trust between employees and all levels of management in the workplace. The lack of trust, which is inevitably widespread given the level of dissatisfaction with managers, probably has adverse effects on the 'attitudes and behaviours towards patients' and this influences the 'extent of trust between patients and providers' (Gilson, Palmer & Schneider 2005:1419).

#### The reported absence of management structures

Problems linked to management mainly dealt with little or no support, feeble communication between the different levels, promises failing to come to fruition, and a lack of recognition of nursing personnel. Managers were not available or even known to nurses at some facilities. This in turn led to poor communication, support, and unmotivated staff:

You know, to come to that point of other managers – it's very difficult and it's zero percent communication between us and our own management. We only see our managers after a year or after a few years. Even if you can make an appointment; "can you please come and see us, we really have a problem", they won't come. So it's even worse to call our outside managers, even if our own managers are failing. (C3:06)

Another nurse lamented: There is no support. I don't see any support! (C8:06) It was said that if nurses try to enter a dialogue, maybe questioning the value of an idea, managers would say: It is not open for discussion, and the respondent continued by stating: I think, at the end of the day, for anything to work, you have to have motivated staff. You can sometimes work with limited resources, but if your staff is motivated and happy, it makes a big difference. (C8:06) At another clinic in the same district, a similar opinion was raised: If you do not look after your personnel, you do not get productivity. If you have negative personnel, your productivity goes down. It is not only money that motivates people. (C7:05)

Nurses feel that their various grievances were not considered by the managers at various levels, and that the latter only react when patients lodge complaints against the staff or the facility. A PN related that senior managers do not visit facilities: they think that when we ask for things it is unnecessary, but if there is a complaint from the clinic [i.e. from patients], they will come immediately! Then it's a case, [a] disciplinary hearing. (C9:05) Several nurses maintained that they do not get the support expected from outside managers: especially when it [the ART programme] is so finely being scrutinised by so many people. (C2:05) Apparently, the supervisors do not even telephonically

communicate with the professional nursing staff from the various facilities. Nurses from another clinic felt that there is a lack of support and supervision: we see only a lot of work, piles and piles of work. (C9:06) The same accusation was repeated elsewhere: we don't get any support from anyone. Not even when we have worked hard there is a pat on your shoulder saying "well done". Not even that is available. (C3:06) Another nurse there added: (...) and even the South African Nursing Council, they are always... seeing us guilty. They don't even protect us. (C3:06)

The feeling of being rejected and ignored by their guiding body could be linked to the fact that many nurses feel that only empty promises are made to them regarding improving their working conditions. This specifically relates to the 'rural allowance' that nurses are meant to be receiving when working in specific facilities. In a rural district, a nurse pointed this out:

But I also think – incentives like the rural allowance that they promised – it's just empty promises (...) because they promise, and keep on promising and keep on promising, and the MEC will come and they will resolve it and this one will come and they will attend to it. But it doesn't happen. (C10:05)

A PN opined that a rural allowance may be a drawing card with which to attract PNs to the area, and to the facility specifically. However, if this undertaking is not honoured, nurses might experience little compunction in leaving. The 2006 group discussions revealed that some nurses were still not receiving a rural allowance. Yet another grievance coming from the group interviews was that nurses were told that they were permanent ART staff and were taking on the responsibilities as required of an ART trained nurse, but never receiving a confirmation letter of appointment, nor the necessary salary adjustment. A direct consequence of this continued situation is a lack of job security, but also just another reason to mistrust the leadership.

During one of the group interviews, an ART nurse maintained that if supervisors came to the facility on a regular basis to evaluate the programme, he would feel more confident to continue with his daily tasks. If the supervisor identified certain areas that should be improved, he would be able to *rectify the mistakes* and stop perpetuating them. He therefore saw regular evaluations as a positive feedback and a means to gauge his performance. Ultimately, he stated, *we need someone who will come and say, 'guys, you are on the right track'*. (C12:06)

#### Training

In light of the ART roll-out initiative, new competencies, knowledge, and skill need to accompany the process of a successful implementation. The obvious outcome of training – i.e. improved skills – was reported by some nurses. A large majority of group interview participants felt that the training they receive is sufficient. These nurses purported that they are constantly going on courses, and upon their return, give feedback, thereby expanding the knowledge of other PNs at the workplace. They maintained that after having attended training, PNs feel motivated to implement what they have learnt.

At some clinics, the complete nursing staff was trained to be able to rotate and thereby lessening the burden of caring for HIV-positive people on a permanent basis. Nurses opined that this ongoing care of HIV-positive patients could have a negative effect on them. At those clinics where not all nurses were trained on ART, there was a general feeling that this extra training for all the PNs would enhance the performance of the system as a whole.

# Quantity training to the detriment of quality intervention

Although strong emphasis is placed on training and acquiring relevant skills with relation to the ART programme, this focus can also lead to unwanted consequences and rushed results. A group interview respondent expressed her reservation about all nurses receiving ART training. Her diffidence was motivated by a concern that her patients, which are her primary charge, will be neglected. Speaking generally, another respondent echoed this sentiment by stating that when a nurse has undergone the training for a particular service, it is often assumed that that person will 'own' it, and therefore take full responsibility for its effective implementation. This could lead to an unbalanced distribution of workload in the facilities, as well as concentration solely on this service to the detriment of others, thus failing to strengthen the system as a whole.

Several nurses commented on the problem that when they are on training, they are not at the clinic, which puts even more pressure on the remaining staff to perform their daily duties satisfactorily. Also, respondents mentioned that they do not always receive sufficient, ongoing, or the right kind of training. This phenomenon is mainly linked to the time constraints they face when on training, and this in turn leads to very little room for re-explanation or practical training (cf. Du Plooy 2006; Lehmann & Zulu 2005). At another facility, some nurses complained that they were not getting trained at all, and the nurse asked the interviewer why nothing has been done about this grievance as they were complaining about it in 2005, and again in 2006. Another nurse at the same facility, who has received training, summarised it as follows:

I think the type of training that we do experience ... we are being pushed into a programme. Maybe go for a week [of] training. And then you come back with a lot of information, and you have to cope with doing that in a week's time. And I think we can't cope. Especially, I'm thinking of the dispensing course. People can't cope then. Really the course has been pushed into three days, and a doctor has been ... maybe learning for maybe a year or two. And you have to go and write the exam, it's impossible. It's very stressful. (C1:05)

According to the professionals, the training is predominantly theoretical and nurses are supposed to go back to their facilities and implement what they were taught, without some practical experience. Some informants experienced a lack of practical training or strategies to cope. For example, the dearth of information on implementing DRT left nurses to devise their own strategies, which they hoped to be similar to the original manual: There were so many things lacking in that training. It was just for us to implement and continue, and see the problems afterwards. (C13:06) Another neglected priority, according to a respondent,

related to what she called *maintenance training* (C10:05) to keep PNs updated on the developments in ART. Further training in counselling, screening, and the preparation of patients for treatment, including comprehensive training in DRT, is sought in order to make the presentation to patients more effective. One nurse decried: *After all, the reading of the manual to clients is not effective!* (C2:06)

Another complaint was the perceived insufficient training of all staff. It was said that lay workers and PNs are trained in ART, but not the assistant nurses. Nurses explained that patients sometimes need very simple information, only to have to wait for the PNs to become available to assist them. This is obviously a frustrating factor for the assistant nurses.

Some respondents took the topic of training to the next level, mentioning the need for training in coping skills and stress management. They felt that this area of training should complement the purely clinical courses devised for the nursing staff. The lack of training to cope with this need translates into nurses having to cope and invent as they go along, thus fulfilling the role as 'street-level bureaucrats'.

#### Own coping mechanisms

During the group interviews, we generally tried to comprehend if nurses are coping, in their own view, with the (new challenges of) ART roll-out. This very subjective account of nurses contemplating their working conditions ended with them relating their own initiatives regarding coping mechanisms. They find support in their peers, in joining the gym, or simply by taking vitamins to get through the day.

The roll-out and its unique challenges can lead to innovative ways in which to cope. According to nurses:

(...) with our ARVs we went the route of a team approach. So, if there's a meeting, everybody trained in ARV, whether you are a pharmacist, or a doctor, or the clerk, you must be there. And I think that the joint responsibility is actually what is making the programme to succeed in the end. Because it is not the nurses [who are] responsible, the clerks are having their responsibilities, the doctor is having hers—and they share the frustrations with one another, and the hick-ups are resolved. (C10:05)

Many of the nurses expressed the desire to be debriefed. At the time of the interviews, these sessions took place on a very irregular basis. The majority of nurses deemed these haphazard sessions insufficient to deal with the extent of their qualms related to treating HIV and AIDS patients. They also realised the omnipresent time constraints that characterise their daily routines, and although they wished to be debriefed regularly, they knew that this will be an almost impossible task given their workload and responsibilities.

It was also said that nurses started to accept patients with less difficulty, and that they realised that the problem of HIV and AIDS is not going to disappear, but has to be dealt with on a day to day basis. The realisation that ART is not a 'magic bullet' and

accepting the situation helped some PNs to better deal with the circumstances they find themselves in. A nurse summarised their situation: We all motivate ourselves just to do those jobs because it's our profession. (C5:06) At the end of the day, the professional ethos is repeated when referring to ways in which to cope with the challenges brought about by the ART roll-out.

# The 'Street-level bureaucrats' euphemism: limitations of own coping mechanisms

The failures or contradictory outcomes of institutionalised support and changing policies leave front-line providers of ART with little choice but to improvise and contrive their own coping mechanism. However, as we mentioned previously, this poses intricate questions as to the ethical conduct of the health profession. The general feeling of defective support, being understaffed, underpaid, and insufficiently trained and not being recognised for the roles they are fulfilling, encapsulates the dilemma in which nurses claim to find themselves.

Some nurses feel that their peers might even decide not to exercise their profession anymore, and as one declared:

that's not due to so much to the ARVs I think. It's on the overall as well. (...) PHC has been and always will be a nurse-driven process. And if you take us away, then, what will happen? (...) Some will call an increase in salary (...). and that is contributing to the fact that we don't get enough ..., and besides the point that they always say that nursing is a caring profession, but money is the word today. If you don't have money, you can't survive anyhow. So now they [are] throwing money and all these extra things upon us (...), but we don't get the satisfaction, by getting more money. And that's why most of us, we either leave the profession or we leave the country. (C10:05)

The dissatisfaction of nurses in public health-care facilities is not a new phenomenon. The ART roll-out and its associated challenges only highlight the plight of these professionals, given the exceptional nature and the urgency of this intervention. The uniqueness of the South African health-care landscape, which includes high HIV and AIDS prevalence and TB co-morbidity, scarcity of professional health workers in the public sector, and immense inequalities between the private and the public health sectors, only exacerbates these challenges. Studies on 'burnout' (Van den Berg, Bester, Janse van Rensburg-Bonthuysen, Engelbrecht, Hlophe, Summerton, et al. 2006) deal with these multi-faceted aspects of the problem, including the social and psychological side of it. However, understanding the dilemma of public health-care nurses should also be considered in a historical manner (Marks 1994). The nursing profession, especially for African nurses, has a very distinctive character. For example, during apartheid, nurses in some PHC facilities (mostly rural and township areas) were left to their own devises to care for the catchment population. They were acting as doctors, because the latter did not want to work in these remote underserved areas. Ironically, this is still happening today, and even in the presence of a high-priority programme such as the ART rollout. One nurse made specific reference to this occurrence:

If you look at how PHC evolved, it's as if the nurses took over the role of the doctors completely. You know they are supposed to be like mini-doctors: they must diagnose, they must treat, they must be accurate... and that is also pressure because there are twenty patients waiting for you. So, you must hurry up, you must be very accurate, you must do things almost outside of your scope of practice. So, the roles of the nurse are much bigger and I think... if you compare the responsibilities that nurses carry compared to doctors—they are really not being paid. And they are not being recognised for their abilities. (C4:05)

The fact that nurses feel that they are acting beyond the scope of their skill, experience, and permitted practice reinforces the reliance on their own coping mechanisms. It can be expected that nurses' own coping mechanisms are not sufficient to respond to the manifold problems they encounter on a daily basis – on an emotional and technical level. A respondent declared: things have got worse, to the extent that we don't even have any passion for your work. (C8:06) A nurse from another clinic emphasised their perceived predicament by highlighting the following:

you talk about the affected and the infected. And the affected usually are in the families they refer to (...). But the affected doesn't actually include the very professionals, because they are left in the cold, they're just being exposed to this, you know, on a continuous basis and they are expected to perform. And you ask yourself, "why is the service dropping, why is the quality dropping, in the institution?". (...) There isn't that provision where you will sit down with the professionals, and say, "guys, you are stressed up, you are exposed to this dying patient every day. What does that do to you", you know. So, it's bad, it's bad. (C1:06)

We have identified but a few themes where contradictory contextual factors play a tangible role in nurses' everyday experiences of working at public ART roll-out sites. These factors are certainly not limited to ART roll-out sites, but epitomise the difficulties experienced by these front-line workers in the public sector as a whole.

#### Conclusion

Financial and non-financial incentives are called upon to recruit, but more importantly retain health workers in public health-care settings. Mathauer and Imhoff (2006) suggest that non-financial incentives and adequate human resources management tools are inevitable mechanisms to ensure worker satisfaction. They identify three such tools: 'acknowledging their professionalism', 'addressing professional goals such as recognition, career development, and further qualification', and developing the 'work environment' for health workers to be able 'to meet their personal and organisational goals' (Mathauer & Imhoff 2006:2). A more refined and contextual finding indicates that nurses dispensing ART in the Free State reported their most demanding task to be linked to their supportive and counselling responsibilities rather than to their clinical duties (Stein et al. 2007). The nursing sisterhood in the South African context of multiple challenges inevitably finds itself in a contradictory position: on the one hand, haunted by their professional conscience, and on the other, forced to improvise their daily practices due to contradictory contextual factors. An enormous problem resides in the fact that nurses, who form the backbone of the ART intervention, do not feel cared for or valued (Du Plooy 2006; Lehmann & Zulu 2005). If policy implementation can be an ongoing process instead of a once-off decision, a process that takes into consideration contextual differences, contradictory outcomes, and one which lends more weight to the "software' of health sector reform' (Blaauw, Gilson, Penn-Kekana & Schneider 2003), initiatives like the ART roll-out might attain more sustainable and far-reaching results. This unprecedented endeavour inevitably has to treasure and support its most valued implementers, i.e. the front-line providers who are not only professionals, but also social agents.

#### **Footnotes**

<sup>1</sup>In 1994, health care became a free commodity to pregnant women and children under the age of 6 years. In 1996, this free service was extended to all South African citizens who cannot afford health care. This policy decision in itself augments the workload of nurses, as they feel that patients are 'abusing' the system, reporting to the clinics with insignificant health problems and not appreciating the service, chiefly because it is free of charge (cf. Walker & Gilson 2004:1252).

<sup>2</sup>At the time, ART programmes were facing fewer vacancies than other primary health care programmes (15% versus 37.1%). This is due to the novelty and promotion possibilities within the ART programme. However, the lower vacancy rate is the result of 'lateral transfers' between, and 'drainage' within other sectors of the PHC system, therefore counteracting the general aim of the ARV programme, which is to strengthen the health system as a whole (cf. Van Rensburg *et al.* 2008).

<sup>3</sup>The implementation of the ART programme in the Free State commenced in 2004 following a staggered roll-out. Selected sites in each district of the province were earmarked to serve as ART sites, i.e. phase 1 sites. Phase 2 sites are the additional facilities that serve as ART sites as the programme expanded.

<sup>4</sup>The Centre of Excellence is a specialised unit at the regional Pelonomi hospital which deals with ART-related medical problems and provides assistance to all the ART dispensing sites.

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