# From the nurse's mouth: the Fezile Dabi ART assessment site experience

HIV/AIDS, together with the implementation of a public sector antiretroviral treatment (ART) programme and the transformation of the health system, places unprecedented pressure on facilities with insufficient nursing personnel. Based on information gathered from group interviews, this paper presents the experience of nurses working at ART assessment sites in Fezile Dabi. Empirical data represent the following domains: perceptions and experiences surrounding the impact of ART, general and staffing needs, training, patient drug-readiness training, the value of volunteers, support and supervision from ART programme managers, and emotional support for and coping mechanisms of staff. Recommendations take account of floor-space, management, additional staff, confidentiality, practical training, drug-readiness training, and coping strategies.

# Uit die mond van die verpleegkundige: die Fezile Dabi ART assesseringsfasiliteitervaring

MIV/VIGS, tesame met die implementering van 'n openbare sektor-antiretrovirale terapieprogram (ART), en die transformasie van die gesondheidsisteem plaas ongekende druk op fasiliteite met beperkte verpleegpersoneel. Gebaseer op data uit groepsonderhoude, het hierdie artikel ten doel om die ervaring van professionele verpleegpersoneel by ART assesseringsfasiliteite in Fezile Dabi te ondersoek. Die empiriese data dek die volgende areas: persepsies en ervaring rondom die impak van ART, algemene en personeelbehoeftes, opleiding, pasiënt-medikasiegereedheidsopleiding, die waarde van vrywilligers, ondersteuning en toesighouding deur ART-programbestuurders, asook emosionele ondersteuning aan en hanteringsmeganismes van die personeel. Aanbevelings hou rekening met die volgende: vloerruimte, bestuur, addisionele personeel, vertroulikheid, praktiese opleiding, medikasiegereedheidsopleiding en hanteringstrategieë.

Ms S du Plooy, Centre for Health Systems Research & Development, University of the Free State, P O Box 339, Bloemfontein 9300; E-mail duplooys.hum@mail.uovs.ac.za

In South Africa, nurses presently fall into four basic categories: professional nurse (registered nurse); professional midwife (registered midwife); staff nurse (enrolled nurse) and nursing auxiliary (enrolled nursing auxiliary) (Subedar 2005: 98, Van Rensburg 2004: 335-8). For the purposes of this paper, a professional nurse<sup>2</sup> may be defined as

a person who is educated and competent to practise comprehensive nursing; assumes responsibility and accountability for independent decision making in such practice; and is registered and licensed as a professional nurse under the Nursing Act (Subedar 2005: 99).

This contribution is primarily concerned with the professional nurse working in the public sector ART programme. In this regard, public sector health facilities may be described as facilities where full subsidisation of drug-costs, routine monitoring tests and consultations are offered to persons without medical aid who use public sector resources for the provision of services.

Globally, regionally, nationally and locally HIV/AIDS is often described as the greatest health crisis of our time. An estimated 42 million people worldwide carry the human immunodeficiency virus (HIV), 95% of whom live in resource-limited areas. An additional five million are newly infected and 3.1 million die annually. This rate daily translates into 14 000 new HIV cases and 8 500 deaths from AIDS. Sub-Saharan Africa is the worst infected region in the world. An estimated 3.2 million people in this area acquired HIV in 2003, while approximately 2.3 million died of AIDS in the same year (Stewart *et al* 2004: iii; cf also WHO 2004: 1-6). By the end of 2003, 5.6-6.5 million people in South Africa were HIV-positive (NDoH 2005: 1, Pelser 2005: 11). Both the national and Free State prevalence rates among antenatal clinic attendees for 2004 are 29.5 (with confidence intervals of 28.5-30.5 and 26.1-32.9 respectively) (NDoH 2005: 6-7), while 40 128 new AIDS cases are

- I am grateful to the professional nurses who enthusiastically shared their views during the group interviews in Fezile Dabi. Without their frank input, this article would not have been possible. Further, I extend my gratitude to my colleague Dr Christo Heunis for his comments regarding an earlier draft of this article.
- It should be borne in mind that although there are separate registers for nurses and midwives; in practice all nurses who have completed a four-year training programme will register as a nurse (general, psychiatric and community) and midwife. In South Africa it is not possible to register as a midwife without having completed a course in general nursing.

estimated for 2005 (Pelser 2005: 13). According to the Medical Research Council (MRC) of South Africa, 487 772 people in the Free State were already living with HIV/AIDS in 2002 (Dorrington *et al* 2002: 4). The annual AIDS mortality for 2000 was 10 067 and the AIDS deaths expressed as a percentage of the total deaths for the same period amounted to 28.9%; while the projected figures for 2010 are 55 899 AIDS deaths and 68.6% AIDS deaths as a proportion of the total deaths in the Free State (Pelser 2005: 8-9).

Due to the severity of HIV/AIDS as a major cause of disease in South Africa (presently as well as in the future) and amidst growing pressure from national and international quarters, the government launched the national Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa (Comprehensive Plan) in November 2003. In response to the Comprehensive Plan's challenge, the Centre for Health Systems Research & Development (CHSR&D) commenced a project titled Public sector antiretroviral treatment: Documenting, monitoring, evaluating and facilitating implementation of the national treatment plan in the Free State. Within the larger project, one of the component projects is an appraisal of ART service (treatment and assessment) sites. The main research questions posed are: how/in what ways/to what extent are health services (including facilities, other programmes and staff) influenced by the ART programme, and vice versa, and how are the health services (facilities, other programmes and staff) reacting to the ART programme? The appraisal of ART assessment sites in a longitudinal survey partially responds to this question. In so doing, the clinic/community health centre (CHC) manager and health workers/managers responsible for key primary health care (PHC) programmes complete a questionnaire battery. The survey also entails group interviews with professional nurses at the facility, including ART and non-ART personnel. The data forthcoming from the said first-wave group interviews in Fezile Dabi is the primary charge of this paper.

It is accepted that there is an overall staff shortage, particularly of professional nurses,<sup>3</sup> not only in the Free State but also in the broader

Drawing on the work of Lipsky et al (2004:1252) liken nurses with "street-level bureaucrats". Within the context of this paper, they are public health care workers "who interact directly with citizens in the course of their work and who have substantial discretion in their treatment of clients". However, the conditions they

South African public health sector (Kober & Van Damme 2004: 106, Van Rensburg 2005b). Given the time and energy spent on the manifold aspects related to HIV/AIDS and the concomitant ART programme, comparatively little attention is devoted to the heart and driving force — the key resource — of the public sector health service, and in particular the ART programme, *i e* the professional nurse. The aim of this paper is to communicate, "from the nurse's mouth", the experiences, perceptions and needs of professional nurses working at ART assessment sites in Fezile Dabi about matters relating to the ART programme.

# 1. Methodology

The general advantages of group interviews are well-known and do not require discussion here. Decifically pertaining to the component project, however, group interviews triangulate well with the structured battery of questionnaires completed by the programme co-ordinators (or responsible persons) at the facilities. In other words, group interviews are useful instruments for providing in-depth information that supplements data obtained from other components of the appraisal. In addition, future follow-up appraisals of these facilities will make it possible to observe changes over time. Although the application of triangulation is relevant for the purposes of the larger project, only the group interview data is relevant here. Furthermore, this technique lends itself well to the collection of more detailed data, and offers the opportunity to probe when necessary.

During the week of 6-10 June 2005, three group interviews were conducted in Fezile Dabi<sup>5</sup> and depending on the number of participants and the group dynamics, the group discussions lasted between 30 and 80 minutes. An interview schedule comprising 15 broad, open-ended questions guided the discussion. In this regard, professional nurses were

- work in are for the most part, not conducive to adequate service delivery. Negating the high demand for their service is a dearth of resources (organisational and personal) necessary to do a good job.
- 4 Cf Baker 1994: 188, Lindlof 1995: 174-5, Timmerman et al 1998: 54-5, Varkevisser et al 2003: 184-5.
- 5 Fezile Dabi, previously known as the Northern Free State, is one of the five health districts in the Free State province. The three ART assessment sites in this district are currently located in the local service area of Metsimaholo.

asked about the impact of the ART programme on the facility, their work, on patients, on other staff, as well as on other programmes presented at the facility. Problems encountered, coping mechanisms applied by professional nurses, and the availability of support received attention. Questions were posed in English, but informants were encouraged to respond in their mother tongue (if desired), since the research team conducting the group interviews (one facilitator and one recorder) were conversant in a range of local languages. The aim was to ensure that all participant-responses were understood and translated accordingly, guarding against loss of relevance and meaning. Before commencing with each group interview, the objectives and importance of the research were explained; permission was obtained to tape-record and transcribe the sessions for research purposes; and participants completed a list (register) indicating their rank, duration of employment at the facility as well as the programme they worked on most of the time. Where necessary, the detailed transcriptions of each recording were translated, and validated by re-transcribing. Qualitative analysis of data was performed by thematic categorisation.

Since the number of participants did not lend itself to division, the groups were not stratified; however, inclusion required that the informant minimally occupy the position of professional nurse at the ART assessment site in Fezile Dabi. A precise sampling frame from which respondents were selected was not employed; instead all professional nurses (and two enrolled nurses) present at the three individual assessment sites were invited to participate. The number of respondents per group ranged between four and seven and totalled 15 participants in this district. The said respondents included clinic/CHC managers, ART programme managers, professional nurses working on the ART programme, as well as those working in other programmes. All the respondents happened to be female; thirteen were black and two were white, while their average age was 42 years. Their ranks were evenly distributed between the three categories of professional nurse *viz* chief professional nurse, senior professional nurse and professional nurse, and the duration of employ-

<sup>6</sup> Two enrolled nurses participated in the group discussions as they were qualified and working as professional nurses, although their formal registration had not yet been completed.

ment at the specific facility ranged from two months to thirteen years, with the average period of employment being four years.

### 2. Results and discussion

From the accumulated data, the following themes relating to the ART programme emerged: impact of the ART programme, needs, training, drug-readiness, volunteers, support and supervision, as well as coping mechanisms and emotional support.

# 2.1 Impact of the ART programme

The ART programme impacts on participants in numerous ways. For the purposes of this discussion, attention is paid to the effects and influences on facilities, nurses and their work, patients, other staff, and other programmes presented in the facility. The particular objective is to elicit professional nurses' experience and perception regarding the changes that have occurred since the implementation of the ART programme.

# 2.1.1 Impact on facilities

According to participants, the ART programme's main impact on the facilities relates to space. Directly or indirectly, the increased number of patients drawn to the clinics, because of the HIV/AIDS, and consequently the ART programme, puts pressure on the often meagre infrastructural capacity of the facilities; a point confirmed by Janse van Rensburg-Bonthuyzen (2005). Participants predict that this matter will cause even more serious problems in the future, as the number of known HIV/AIDS patients increase and more patients receive ART. Not only are waiting areas bursting at their seams to accommodate the masses of people seeking an array of treatments, but consultation rooms are often shared with other health care personnel, such as physiotherapists or lay counsellors doing counselling. Two *verbatim* responses

7 In this case, "space" is used to signify the area provided for conducting clinic/CHC health services and activities (floor-space), while "infrastructure" is applied by respondents to indicate the basic physical structural components of the clinic/CHC and installations needed for performing their health service activities (*i e* the building itself — walls, roof, plumbing, electricity).

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illustrating the situation include: "The space is too small. So, that's the impact. The programme, on its own, it is a wonderful programme, and it is working, but the space part of it", and "Size ... size, we don't even want to mention it ... It's laughable ... honestly".

In one instance, the entire clinic operates from a two-consultation room, prefabricated structure, while the allotted building has stood roofless for over two years. As an outcome of the reform for health care and the health care system in South Africa, a wide-ranging rural "clinic building and upgrading programme" was put into operation (Van Rensburg & Pelser 2004: 163). However, as seen from the citation below, renovations or upgrading of facilities were not always completed, having disastrous effects for and because of the ART programme. The words of an informant put the situation into perspective:

For the clinic's building, there haven't happened something now for two years. And we have been promised, that it would be finished in March, and the next March come, and nothing is happening. So, it is really frustrating for us in this clinic, especially ... And because of the building that was there, there was a time that we had very bad weather, and the water was flowing in from this slip that came through this clinic — From that building, into this one. So we had to sweep the water out every time. And we had to take a shovel and go out in the rain, make some ... a way for the water to go out.

The staff and community's desperation with the situation is reflected in the action taken: a letter requesting intervention was eventually written to Parliament, after exhausting all other avenues. To date, nothing has been done to rectify the circumstances. Such circumstances do question the site selection procedure in the Free State, as well as what exactly so-called "good service delivery" entails in the minds of health and particularly ART decision makers in the province.

Related to the problem of space, are the issues of confidentiality and privacy. Indirectly, the space problem adversely affects privacy during consultations. Participants also feel that confidentiality is compromised when working in such close confines, a finding also presented by Mayers (2005: 33). Ramkissoon *et al* (2004: 31-2) relate that consultations

8 To the contrary, Mugyenyi's (2005) assessment of the Ugandan experience shows that alternative arrangements if renovations are underway, or unconventional substitutes like tents in the absence of other structures, only minimally disrupt services. could be observed in 20% and overheard in 11% of consultations with STI clients in their survey of South African public sector facilities. Also infringing on patient privacy and confidentiality is the dearth of separate queuing, primarily because of space constraints.

Since the implementation of the ART programme, an added burden was placed on the already congested facilities. In some cases infrastructural alterations were made, but that has not always been the case. In one clinic, what used to be the antenatal clinic — one room — had been subdivided into three inadequately small rooms, now servicing the ART programme. In their survey of sexually transmitted infection (STI) and HIV prevention and management services in PHC facilities in South Africa, Ramkissoon *et al* (2004: 31) found that the number of consulting/examination rooms ranged from one to seventeen, with over 50% of facilities in the Free State having a maximum of two such rooms. Although the said findings are generalised, they do not portray a picture contrary to the one at ART assessment sites.

The increase in patient numbers may also be ascribed to the fact that the ART sites service large areas within the individual district. As soon as further ART sites are up and running, one would assume that the patient numbers at the existing sites will decline (or stabilise), as there will be more sites, perhaps closer to home, that patients can access, which would alleviate the space problem in the future.

As may be expected, an increase in utility expenses such as phone, stationery and laboratory bills relating to the ART programme and increased patient numbers, are further causes for concern among respondents. Among other things, calling patients to make follow-up appointments and running daily blood and sputum tests, contribute to this situation.

# 2.1.2 Impact on nurses and other staff

On the positive side, participants cite that the ART programme has a favourable bearing on themselves and on their work. Since the implementation of ART, professional nurses relate that they can now at least do something about the plight of the many patients who could previously not be helped; responses also expressed by Jacobs (2005) and Lehmann & Zulu (2005: 47) among others. The implementation of the ART programme has empowered nurses in a certain sense.

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At another level, many staff members are moved from existing staff complements into the ART programme — a sentiment which is reiterated by Engelbrecht (2005) and Van Rensburg (2005c: 23), but refuted by the findings of Louwagie et al (2004: 1), who state that they found a "high level of support for recruiting dedicated staff from within the clinic's existing staff complement to lead the ARV programme [...] and replacing these staff with additional appointments".

According to informants, this means elevated workloads for the remaining professional nurses as additional staff are seldom employed. Buvé (2005) and Ramkissoon *et al* (2004: 46) do not fault this conclusion. An extract from the group discussion transcription corroborates this point:

Ja, the workload has increased. The workload has increased really a lot. ... Because we have to do all the clinics and sometimes you find yourself being one in the clinic. People are going to courses for two weeks ... and you have to do everything in the clinic.

Even when personnel are not away, a staff shortage is felt when the clinic manager, for example, assists with the ART programme, leaving it to the remaining professional staff to pick up the slack on the PHC side.

For the participants who primarily work in the ART programme, a number of effects are particularly evident. Firstly, their work is emotionally laden. They are in effect handing over a death sentence to a community member or a friend. According to Louwagie *et al* (2004: 2), the levels of stress experienced by professional staff escalates proportionally to the sense of personal involvement that exists within the patient-carer relationship. Secondly, it is seldom acknowledged that consultations with ART patients take up much more time, and that professional nurses are chastised for not always seeing the required quota of 35 patients per day. This often takes the form of covert rebukes. However, this is not representative for all non-ART participants. In praise of one of her colleagues, a professional nurse had the following to say:

I mean this thing was imposed on them, really I commend them ... Those people working at ARV, it was a new theme for them and you know it was this training 'come here ... come here' ... But honestly, the way they are ... sometimes they do not even come and drink tea here. They do not even have their lunch here ... we hardly see them. Honestly, I really commend them the way they are working.

The impact of the ART programme on professional nurses and its effects on patients seem closely related. In this context, participants draw attention to patients' financial constraints and transport problems. They argue that patients do not complete drug-readiness; do not comply with follow-up visits; or do not replenish treatment because of the above problems, which then indirectly impacts on nurses. It frustrates them that in other districts special transport arrangements are made for patients, yet in their district, patients have to make and finance their own transport arrangements. Louwagie et al (2004: 4) report that even where commuter transport does exist (for example between Tshiame Clinic, Harrismith and Manapo Hospital, Qwaqwa), the demand often "exceeds the availability of their once daily service". The informant complains that in "Lejweleputswa, people from Virginia or Henneman ... they have a commuter that takes them from their site to the treatment site". Doherty et al (2005: 15) add the obvious: "the more remote the facility the more crucial the transport system becomes". These authors' recommendation regarding transport is that a number of systems should be considered, for example patient transport vouchers and local taxi services. Furthermore, the slow pace of the rollout and deferral of treatment for patients negatively affects staff morale (Doherty et al 2005: 19). One respondent expresses this situation as follows:

You will find that a person completed drug-readiness in February, she has not yet been on treatment, up to now. And you know, even if they apply for the 'social development' [grant] it's gonna take time to approve it.

# 2.1.3 Impact on patients

Professional nurses feel that the ART programme has a positive impact on patients since there are discernable health improvements in patients on ART. It is their contention that the promise of treatment offers renewed hope and a willingness to be tested, as seen in the ensuing excerpt.

But I think it is a positive impact on patients, because at least they know there is treatment. It's not like before when we had nothing to give them. This time they've got hope. And this also motivates other clients too ... you know, to come for the test, before you can even introduce VCCT.<sup>9</sup>

9 Within the context of HIV/AIDS, the acronym VCCT denotes voluntary confidential counseling and testing.

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The nurse respondents, however, also acknowledge that within the social organisation of the family and the often denialist attitude, knowing your status is not always embraced openly. In fact, knowing your status sometimes contributes to conflicts between husband and wife. One participant relates how one spouse, usually the wife, wants to know her status, but the husband is dead set against it. On the other hand, if a wife is found to be HIV-positive, the husband accuses her of adultery, when in reality she had been faithful to him, and he is the party that strayed on one or more occasions.

# 2.1.4 Impact on other programmes

Professional nurses relate that the ART programme positively contributes towards comprehensive care. They feel that they can integrate their knowledge from a number of programmes and diagnose and treat patients more successfully. For example, the progression from VCCT to prevention of mother to child transmission (PMTCT), and ultimately the management of patients on ARV medication, now all fall within their capabilities. Furthermore, the interrelationship between ART and PHC is apparent to them. The example of the close relation between TB and HIV is often cited to demonstrate the point of holistic care. From the above, it seems that there is a degree of integration of ART treatment programmes with general health services and with other HIV-related programmes; and consequently a moving away from specialised, vertical operating silos among health programmes.

One may wonder if there is too much emphasis on ARVs and ART and not enough on other programmes offered at the facilities. A participant responds as follows:

It may look like there is too much emphasis: it's because it is the time for ARV. Like I say: 'it is about time'. There was a time for TB; there was a time for hypertension and all those. Now, it is going to have to focus on this ARV.

# 2.2 Needs and staff requirements related to demands of the ART programme

When asked about the shortfalls in the facility, and their needs relating to the demands of the ART programme, nurses are vocal about the following issues. Infrastructural shortfalls, together with furniture and

equipment shortages reportedly remain a pressing problem. Chairs, desks, and cabinets are in dire demand, as are essential pieces of equipment such as blood pressure kits and stethoscopes, to mention but two. According to Doherty *et al* (2005: 15), "inadequate equipment leads to the delivery of sub-standard care and health worker frustration".

The appointment of an array of clerks and administration staff is repeatedly cited as a need not yet met. A consequence of these shortfalls is having to deal with large numbers of patients, while the administrative tasks of lower-level workers leave professional nurses feeling ill-supported and unheeded; findings reiterated by Doherty *et al* (2005: 11). A frustrated participant sketches the following bleak picture.

In our facility, two personnel members have been taken from our staff establishment: a senior professional nurse and a clerk who has qualified as a nurse. No-one has replaced the clerk, so the tasks she was allocated are suffering. When we come out of the consultation rooms we have to go to the front and admit clients ourselves. It is such a mix up. Clients don't like it; they are complaining that the waiting period is too long. The problem is that management will forget that they have taken some of our staff — the people who were doing these tasks nè. What happens is that we've got to finish our regular tasks, then we have to rush over to try and cover other areas that are problematic. So, on such a day we have to use volunteers to be the clerks. The local area manager does not want that, but there is no other way. We have to ask them to come and help.

In response to the above, another participant explains why this problem prevails. According to her, the clerk position that became vacant, was not advertised, and therefore could not be filled. The respondent is adamant that management must become organised, and regularly update the staff establishments at facilities, advertise vacant posts, fill them and remunerate personnel according to their qualifications. Van Rensburg (2005a, 2005c: 23) has, for example, echoed such claims a number of times. Similarly, the posts of professional nurses working in the ART programme who resigned remain unfilled. In the Free State Province the current nurse vacancy rate is 37%; out of 5 210 posts available only 3 302 are filled (Doherty *et al* 2005: 11, 12). Kober & Van Damme (2004: 105) draw attention to the national AIDS treatment plan's aim of creating 12 000 new posts, but question how this is likely to materialise if in 2004, already 29 000 positions in the public health sector were unfilled. To augment this deficit, in the Strategic Priori-

ties for the National Health System, 2004-2009 the emphasis is *inter alia* on filling posts and implementing the Human Resource Plan (NDoH 2004b: 5).

# 2.3 Training

Training reportedly receives much emphasis. A number of nurse respondents testify that even if they do not directly work in ART, they have received ART training. This is perceived positively. For those participants who have as yet not been trained in ART, no feeling of being left-out is experienced, as they know their turn will come. By the end of 2002, 21% of PHC nursing staff were trained in HIV counselling in the Free State Province (Ramkissoon *et al* 2004: 11, 19-20). In their study of Cape Town clinics, Lehmann & Zulu (2005: 45) report that 10-20% of nurses have completed management of HIV and HIV counselling courses. Integration is therefore facilitated and well-informed personnel are fostered when training is not selective, but inclusive of all levels including both ART and non-ART staff (Louwagie *et al* 2004: 2).

With respect to ART training, two further matters in particular warrant discussion. Participants working on the mobile clinics feel that they should enjoy a degree of priority when it comes to ART training. Their argument is that they perform all the programmes from their mobile base. In cases where the mobile clinic nurse has not undergone ART training, patients are referred to the fixed facility to which she is attached. Further, assistant nurses' credibility in the eyes of the community reportedly diminishes when they can not answer community-posed questions because they are not ART trained. Health care workers who are often not directly employed in HIV-related services/programmes, are the first point of contact for patients, therefore they should receive ART training (Mayers 2005: 31, Stewart et al 2004: 43). According to participants, this matter also received attention at the March 2005 ARV Conference held in Bloemfontein. Unfortunately, no conclusive resolution was reached, but indications were that enrolled nurses and even data capturers are set to receive ART training in the future.

Conversely, some professional nurses feel that they are forced into certain programmes, having to complete designated courses in short periods of time. In this regard, the overwhelming feeling is that large amounts of information are theoretically presented in very brief time

slots. This leaves participants wanting when they have to practically implement the knowledge once they are back at the facility. A challenge particularly common in developing countries, is coping with the limited experience of ART across the board, and addressing the lack of pre-existing curricula for rapid training of health workers (Stewart *et al* 2004: 33-34). Respondents suggest that longer, more in-depth courses, with a decisive practical element should be the norm, a theme also raised by Lehmann & Zulu (2005: 45). If this is the response from participants, it seems that the lesson Sozi & Armstrong (2003: 58-61) mentioned in their Joint United Nations Programme on HIV/AIDS (UNAIDS) study, *viz* "Training should include hands-on experience as well as basic instruction during workshops", was not brought to fruition.

Participants also suggest that a "sensitivity-refresher course" become compulsory. They feel that all personnel, including volunteers, should attend obligatory sensitivity training. This concern emerged when speaking of the "shocking" ways in which some patients learn their HIV status. The following account by a professional nurse demonstrates the need for heightened sensitivity. A lay counsellor was doing health talks with pregnant women, trying to encourage them to go for VCCT. Of the ten women, one was HIV-positive. The woman learnt her status when the lay counsellor, in front of other people and without specific counselling, explained that the two lines on the rapid test meant that the expectant woman was HIV-positive. Without any support afterwards, the woman was left to deal with the results on her own. The way this woman became privy to her status is in direct contrast with the NDoH's guidelines outlining that pre- and post-HIV test counselling should be undertaken in a confidential manner with suitably qualified personnel, such as doctors, nurses or lay counsellors (NDoH 1999).

# 2.4 Drug-readiness training

When asked to talk about drug-readiness training (DRT), a number of issues repeatedly come to the fore. Participant responses are mixed — some positive, some negative.

# 2.4.1 Negative comments revolving around DRT

### Length

Professional nurses agree that the three-week intermittent DRT that prospective ART patients undergo, together with the length of each session, is too long. <sup>10</sup> According to them, sick patients find it difficult to concentrate for as long as an hour. For example, when presenting the training, respondents can see the "vacant looks when you know that no information is being absorbed", or "sometimes patients just sit and sleep".

Purportedly the length of time that elapses from the moment the patient commences DRT to the point he/she actually begins treatment also presents a problem. A number of factors contribute to this delay. Sometimes patients become too ill and have to interrupt their DRT. Patients' financial constraints can also hinder their attendance, and subsequently their treatment. Alternatively, they complete DRT, but fail to attend follow-up appointments. Delays may also arise when dieticians or social workers, for example, do not complete patient reports timeously. When TB is suspected, but the results are inconclusive, a culture is taken which adds another six-week waiting period before treatment commences. Then there is the issue of the length of TB treatment which is unclear and often changed in official policy. At one stage, TB patients had to be on treatment for two months, then they had to finish TB treatment; and now it has again reverted to being on treatment for two months (cf NDoH 2004a: 18, 43). In total, patients may have to wait anything from one to six months before receiving their first ARV medications. A respondent eloquently sums up the problem as follows: "Actually we are losing patients who are waiting for treatment, rather than those who are already on treatment ... because of the procedures".

#### DRT contents

The content of the DRT is consistently criticised. The feeling is that the training is too technical for often illiterate and poorly educated persons, while the language in which the modules are compiled is also problematic. For professional nurses, translating modules is extremely

10 Three modules encompass the DRT syllabus. One module is presented per week, and each individual session lasts anything from one to three hours, depending on the presenter of the training, as well as the extent to which patients/clients participate.

time-consuming, and demotivating for patients at the same time. Participants urge that the teaching materials, including information, education and communication (IEC) Khomanani pamphlets and posters should be available". Their suggestion is that the existing material be translated into the home language of patients, and not be presented in English only. Although such materials are used, according to professional nurses, there is frequently not enough to go around.

The perception also exists that supplementing DRT with audiovisual materials will enhance the information conveyed to and retained by patients. This corresponds with the idea that "passive health education" is also useful (cf Janse van Rensburg-Bonthuyzen 2005). Such a series of audiovisuals intended to educate about HIV/AIDS was released in Botswana in 2003 (Stewart *et al* 2004: 43). Professional nurses also feel that playing audiovisuals in the general waiting areas will be beneficial to all programmes. While the suggestion of audiovisuals is a good one, logistically it should be borne in mind that very few facilities have access to televisions and VCRs. That too would necessitate intervention.

### Confidentiality

When DRT takes place in a group, the issue of confidentiality surfaces. <sup>11</sup> Patients are in effect disclosing their status to others whether they want to or not. Compounding the situation is that fellow patients might in turn divulge this information to others. According to participants, the stigma associated with being HIV-positive is so rife that some patients refuse to return to the ART assessment site.

# 2.4.2 Positive comments revolving around DRT

DRT is not only effective for patients, but has particularly positive repercussions for staff and professional nurses as well. Regarding the former, DRT is primarily a learning opportunity. Admittedly, it is an opportunity in which patients learn about their disease, about transmission, and about the drugs. It is also an opportunity for patients to learn from one another. When DRT takes place in a group, it offers patients a chance to share with the group, and ultimately it fosters a

<sup>11</sup> Not all DRT takes place in a group, as the number of patients at a given time may rather lend itself to individual training sessions.

sense of solidarity and belonging. According to an informant: "With drug-readiness, I think it helps them to accept their disease. They do understand that 'I'm not the only one with HIV'. They feel that they got a group; that they belong somewhere. So it helps them". Contrary to the argument that the DRT sessions are too long, one participant reasons that it is precisely in these protracted sessions that patients have an occasion to open up and explore their feelings and problems.

It is furthermore argued that an added benefit of DRT is that well-informed patients can educate other community members in matters related to HIV/AIDS as well as ARVs. Further, there is a belief that DRT is effective in that it contributes to good adherence. Professional nurses would ideally also like to present "post-treatment sessions" to patients on ART. Their sentiment revolves around the notion that a post-treatment refresher talk or lecture would be advantageous to all involved. For patients, it will mean an opportunity to clarify aspects surrounding their treatment after actually being on ART for a time. From the participants' point of view, a post-treatment session every three months or so will do wonders to boost patient moral as well as to highlight the critical importance of strict adherence.

### 2.5 Value of volunteers

The question posed about the value or frustrations experienced with home-based carers and lay counsellors, elicits an overridingly positive response from professional nurses. Such a response is not undivided, as was evidenced at the ARV conference in Bloemfontein (Doherty et al 2005: 13). Participants praise the work done by these volunteers, and the commitment they show. On numerous occasions, one hears: "They are our mouthpieces and our hands". In line with this sentiment, Stewart et al (2004: 33) stated that volunteers could play an integral part in scaling-up ART programmes, because they are accessible to the community, and able to visit and assist clients at home without abandoning formal facility tasks. Professional nurses wholeheartedly agree that with the staff shortages experienced, facilities would fall far short if it were not for these dedicated persons.

<sup>12</sup> Adherence rates in the Free State are above 95% (Doherty et al 2005: 3).

At one of the facilities, lay counsellors assist and actually present DRT sessions. Participants from this site report that this helps immensely in the reduction of their workload. At another facility, this sharing of responsibility has not reached a comparable level. Lay counsellors here do not present DRT, nor are home-based carers privy to the status of the patients they attend — unless told by the patients themselves. In the case of the latter, patients on ART are referred to as "sick patients" and not ART patients. Professional nurses at this facility feel somewhat apprehensive about divulging patients' HIV-status for fear of breaking confidentiality. The following quote relays their fear: "Because we are not a hundred percent sure of them, that they will keep that secret".

According to Janse van Rensburg-Bonthuyzen (2005), assessment sites in the Free State have between two and six lay counsellors. Informants feel that their advice as to the appointment of more lay counsellors in the future needs to be observed. Doherty *et al* (2005: 11) add that clarifying the roles of volunteers "would aid in the streamlining and effective running of ART sites", a sentiment also expressed by a group of professional staff before the implementation of the ART programme in the Free State (Louwagie *et al* 2004: 2). As presented in the case above, Stewart *et al* (2004: 33) suggested that devolving responsibility to lower level staff reduced the workloads and subsequently partially addresses the issue of staff shortages (cf Kober & Van Damme 2004: 106).

# 2.6 Support and supervision from ART programme managers

Professional nurses at assessment sites in Fezile Dabi are very outspoken about their problems and dissatisfaction with management at district and local area levels; a finding not dissimilar to that of Mayers (2005: 34) and Van Rensburg (2005c: 23-4). Professional nurses, particularly those working within the ART programme do not have favourable things to say about the support and supervision they receive from external ART managers. In fact, the feeling is that there is no support to speak of. Participants frequently remark, "There is no support at all! I've never seen her here", or "She does not come here monthly as the ARV manager to see how we are doing ... She will only come here when something is wrong. Or only phone to tell us that there is training", or

"... the first and last time I saw her it was the photo session outside, posing for ARV", and "The only time when the MEC is here, then you see her". According to respondents, the ART programme is a new phenomenon, requiring hands-on, comprehensive guidance and support. Besides regularly visiting sites, managers should be accessible, willing, and able to work on matters raised by their subordinates. These sentiments correlate with those highlighted at the ARV Conference in Bloemfontein, when the catch-phrase "care for the carer" exemplified the concern of many a presentation (cf Doherty *et al* 2005: 19, Lehmann & Zulu 2005: 47, Mayers 2005: 34).

Respondents highlight both management style and communication, or breakdowns in communication, as Van Rensburg (2005a) refers to it, between management and health professionals as areas of concern. The feeling is that good leaders should use praise and encouragement, and establish and work at interpersonal relationships. Instead, the fingered managers reportedly follow a very rigid "autocratic", from-a-distance style of communication and management, devoid of guidance. The following apt citation emphasises this, and also draws attention to participants' responses in such circumstances. Although writing on the implementation of free care, as a policy, and the factors influencing this policy's implementation, Walker & Gilson (2004: 1252, 1258) are adamant that "the isolation of front-line providers was only heightened by this distance from managers".

If you come and say: 'Do this Shirley!' ... it's a bit negative. So, I tend to regress a bit. Even if I had those suggestions and I was going to be productive ... But [their] manner of approach, it's going to make me ... to go back a bit, you know. Because now [they] are imposing, [they] are not suggesting, and [they] are not giving me time to go through things on my own and come back to [them]. That's the thing, you know. I think their management style is poor ... Interpersonal relationships is poor ... and communication skills are ... very poor.

Furthermore, respondents remark, 'Their vocabulary lacks 'Thank You'.

Lehmann & Zulu (2005: 44) present similar findings when they say nurses feel "left alone in the coal face of service delivery, they lack moral and practical support. They feel neglected by management." The essence of the problem is that the key resource of the public ART programme does not feel valued and cared for.

Participants state they feel despondent when "outside" managers are approached to solve a problem or attend to an issue, and nothing ever seems to be done about it: "Where you are giving info or reporting any incidence, it seems ... that nothing happens". One wonders whether there is a culture of laxity permeating the health system, and filtering over to the ART programme and obliterating any good the Batho Pele campaign espouses to achieve? It appears that the system of appointing managers, to manage the managers, is not working. Alternatively, the issue is the appointed managers are unfit to perform the tasks required of supervisors at that level (cf Van Rensburg & Pelser 2004: 164).

Contrary to the above criticisms and complaints of no support and interest, a participant defends the "outside" ART programme manager by saying that she meets with the facility ART co-ordinator every Monday, to discuss matters of importance. How useful these meetings are, is a matter to be examined. For during the group interview the body language and facial expression of the ART co-ordinator, were not convincing, and rather indicated that these meetings are of little value.

Recognising the significance of strengthening management systems also surfaced at the ARV Conference in Bloemfontein, 2005. Attention was drawn to the value of good management systems for the quality and long-term sustainability of the expanded ART programme, together with a warning that it should not be at the expense of other programmes (Doherty *et al* 2005: 9). This recommendation together with the findings above, serves as a wake-up call as to the severity of the problem as well as the priority that this matter deserves. According to Doherty *et al* (2005: 12), a number of strategies to improve staff moral and motivation should be set in place. Leadership, encouragement and the support of national, provincial and district health managers are vital. Regular support visits by provincial staff to sites are essential. The recommendation is that health managers should give feedback on visits, foster and promote local teamwork, and make concerted efforts to solve frustrations.

# 2.7 Coping mechanisms and emotional support

Three main issues receive attention in the discussion about coping mechanisms of and emotional support for nurses. Firstly, the aim is to determine whether informants have developed any coping mechanisms to deal with the stressors of HIV and AIDS. Secondly, a question arises as

to the availability of emotional support such as counselling or debriefing sessions, should the need therefore occur. Thirdly, and related to the former, is the question whether counselling and/or debriefing are necessary for nursing staff and what form they should assume. Coping mechanisms are understood as those devices or means professional nurses apply to manage or handle the situation in which they find themselves. Thus, how the stress and complexity of their day-to-day work is controlled (Walker & Gilson 2004: 1252).

Initially, professional nurses respond with reservation to probes about the coping mechanisms that they have developed for dealing with the enormous impact of HIV/AIDS. With hindsight, it occurs that this may be an extremely personal question to ask, and the diffidence and even the use of humour masks a reluctance to admit vulnerability — a trait that may make the task of the nurse near impossible to accomplish. Alternatively, respondents may rely on mechanisms they fear their colleagues will find unacceptable. Respondents make the following types of remarks: "We just say when the fifth day ends ... 'Thank God!'"; "Where is the time? It's just work, write, write, write, and four o'clock and then you have to go home"; and "We are just emotional, we get home and we are emotional!"

Professional nurses state that sharing experiences and feelings with colleagues is a major source of relief and a way to manage the stress associated with their jobs (Walker & Gilson 2004:1258). They say that without this outlet, they will not be able to cope with the normal stresses related to being a nurse, not to mention the added strain of HIV and AIDS patients. One professional nurse narrates that somebody who does not understand the "ins-and-outs" of nursing cannot comprehend the core stressors and offer appropriate empathy. For example, she said:

My family does not understand that ... they will say: 'Ag man, so what! But I can go cry on any of my colleague's shoulders. We understand each other. Or when I get angry or something, they understand why. That's to me my own mechanism of getting to it.

Secondly, participants collectively assert that no form of emotional support is available, barring the private pursuit of counselling. The ensuing extract gives a glimpse into the emotive realm of a professional nurse.

You know, and in my case, every time I do a VCT on a patient, and I find that the patient is positive. It hurts. You know, it's so hurting for me ... maybe if for counselling. I know that I am a professional nè, but I mean ... you can see that person is so young, this person is so full of life and then the person is HIV-positive. ... It's very hard. For me, it's very hard. Seeing the person that is HIV-positive and you don't know what to say ... I mean, you can't say: 'everything will be OK', you know. At that moment, that person is HIVpositive. You just take yourself, and put yourself in that patient's shoes ... 'What is she going to do when she gets home?' 'How is she going to cope with this?' And it also affects you, as a person. ... You have started to build a relationship with this patient, because you see this patient for a long time, and you really know the patient. So it's like family. Sometimes you'll be seeing that patient deteriorating and deteriorating until the patient dies. And you are not receiving any counselling. It's frustrating.

Having ascertained the need for formal psychological support,<sup>13</sup> an issue also established by Louwagie *et al* (2004: 2) and Mayers (2005: 34), it appears that some professional nurses prefer individual, one-on-one counselling. For this category of informants, confidentiality is very important. Group sessions also have an element of appeal, in that persons who have experienced the same thing and worked through the same problem may come with a set of possible strategies to apply to the dilemma. The added advantage is the realisation that "you are not the only one experiencing a particular problem, or feeling a certain way". A participant suggests that such group sessions should not be restricted to a singular facility, but be opened to the district, widening the range of experience on which to draw.

In addition, the suggestion that a combination of individual and group sessions may yield good results, depending on the type of problem, is a viable consideration. In a final remark about support, participants emphasised that all health care personnel, including home-based carers, should have access to the psychological support mentioned in this section.

13 The CHSR&D is currently conducting surveys in the Free State to establish nurses' well-being, work-related stress, and "burnout". Acknowledging that nurses are a key resource in public health care, concomitant workshops are run to address nurses' emotional burden.

# 3. The good, the bad, and some advice

To improve the level of job satisfaction among professional nurses, and circumvent the very real threats of leaving the public health service, or the country, two remediable aspects require attention. First, external ART management, comprising effective communication and mechanisms of authentic support and supervision from local area and district level managers, requires revision and a *bona fide* commitment to improvement. Secondly, additional professional and administrative staff must be appointed to co-ordinate clinic/CHC activities more efficiently, particularly those related to the ART programme.

Regarding the impact of the ART programme, a number of issues are noted. Firstly, the immediate, visible and interrelated impacts of the ART programme are experienced in an increase in patient numbers and the consequent imposition on space. Because consultation rooms are in short supply and waiting areas congested, privacy and confidentiality are compromised. Secondly, the ART programme empowers professional nurses; however, it has a number of negative consequences for professional staff. To begin with, it accentuates the critical issue of staff shortages, particularly when employees are recruited from existing staff establishments. The concomitant increase in the workload and compounded stress leave respondents burnt-out. Moreover, consultations with ART patients take considerably longer and are emotionally draining. The implication is that non-ART nurses often feel burdened with having to pick up the slack. Additionally, patients' financial and transport problems adversely affect their DRT attendance and ability to adhere to treatment, all of which informants find extremely distressing. The disparities in patient assistance programmes across districts exacerbate professional nurses' feeling of helplessness. Thirdly, ART has at least one positive bearing on other programmes. It contributes to the notion of comprehensive care, enabling nurses to make better diagnoses and offering better treatment options, primarily because the link is seen between the various programmes.

Concerning the needs of professional ART staff, there is a call to remedy three main problems: infrastructural shortfalls, the appointment of additional staff, particularly administrative employees, as well as the filling of vacancies. Such interventions will facilitate an environment which is conducive to good service delivery and less patient frustration, and a reduction in workload. Unfilled posts are a serious concern requiring immediate managerial attention.

The numerous courses and workshops attended by professional nurses contribute to a good skill mix and informed workers. However, professional staff are often away from the facility, leaving perhaps a single person to cope with all the programmes. For the supervising person this is extremely frustrating and fatiguing. Concerning ART in particular, all personnel should undergo the relevant training; it must follow a more practical-oriented curricula, though. A further suggestion concerning training is compulsory sensitivity refresher courses for all personnel.

The present drug-readiness training is too long and the content needs revision. When the content is revised, the length of individual sessions will be more appropriate for persons with a CD4 count of below 200 (*i e* weak, ill persons). Once the learning materials (manuals, posters, and pamphlets) are translated into languages other than English, the length also will be expedited appreciably. In addition, the length of time from when a patient commences DRT until they begin treatment is unnecessarily long. Hence the call is for a streamlined drug-readiness procedure. Further, the introduction of audiovisuals and the merits of "passive learning" for DRT deserve serious consideration.

Encouragingly DRT is a learning opportunity. Its objective to educate people about HIV, its transmission and AIDS treatment has the added advantage that patients can in turn instruct other community members. Additionally, the groups in which DRT take place foster a sense of belonging for many who feel marginalised by their communities. Ideally, post-treatment sessions should complement the existing pretreatment drug-readiness and other procedures.

Volunteers are indispensable resources to the everyday running of clinics/CHCs and their contribution to the ART programme must be acknowledged. Their particular value lies in their access and direct link to the community, and their direct contact with professional nurses at facilities. As a consequence they are able to extend clinic/CHC, specifically ART services into the community. If services like DRT are devolved to lay counsellors, the workloads of professional staff can be substantially reduced.

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Findings about coping mechanisms and emotional support need particular emphasis. When assessing the impact of the ART programme, seen together with the regular stresses and strains of nursing at a public health facility, the results are feelings of frustration, helplessness, and being unappreciated. When effective mechanisms and opportunities to deal with these are not available, problems become magnified and even insurmountable. Although the bond between colleagues and their communal understanding of the nursing experience promote a sharing of experiences, there remains a need for more professional assistance in the form of individual counselling and group debriefing sessions. Such forms of emotional support should not be limited to ART programme personnel, but should be accessible to the broader nursing fraternity as well as to volunteers working under stressful conditions. Caring for the carer should become a priority.

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