



ART REVITALISES BELEAGUERED NURSES – FOR NOW



When making a difference motivates compassion.

The long-awaited provision of life-saving ARV drugs has inspired an enthusiastic and virtually unprecedented self-sacrificing work ethic among primary health care clinic nurses in the Free State, a qualitative joint scientific study has found.

Motivated by actually saving patients instead of watching them wither and die, the revitalised nurses regularly make home visits, conduct voluntary counselling and testing and provide emotional support, much of it unpaid and in their own time.

This is in spite of intense work pressure caused by severe understaffing, poor ART uptake planning and deficient ARV drug supplies. The Free State has a 29.5% HIV prevalence and more than 100 000 patients are estimated to be eligible for ART.

The uplifting findings come from a study published late last year and conducted by the University of Cape Town's Knowledge Translation Unit, the MRC's Health Systems Research Unit and the London School of Hygiene and Tropical Medicine.

With 40 000 nursing positions vacant in the South African public sector,

researchers expected hard-pressed nurses to be ambivalent about ART implementation, given the additional training and workloads involved.

The study says levels of commitment among nurses went 'far beyond the call of duty', and 'appeared to be motivated by intense personal investment in the ART programme'.

Previous official initiatives to motivate nurses to change their clinical practices (i.e. TB diagnosis and care and mental health) had met with limited success, partly because of an entrenched system of task-oriented care. However, the ART roll-out proved to be a very different story.

With drug adherence excellent and the roll-out saving countless lives, the researchers urged government, historically reluctant and purveying confusing treatment messages, to grasp this unique opportunity to consolidate support for nurses and doctors. 'The hope and commitment shown by health care professionals must be met with the

provision of proper containment and support, as well as national planning to address the human resource crisis in South Africa's public health sector. Without these, it seems likely that as numbers of patients on treatment escalate, this commitment will falter and the opportunity to strengthen a struggling public health system will be lost,' they warn.

The findings may allay the fears of those government officials who were pessimistic at the prospect of transferring a patient-centred ART adherence model from the context of NGO pilot projects into the provincial public health sector.

How long before HR overwhelm?

Human resource planners will have to take into account that 18.9% of our health care workers have full-blown AIDS (alternatively viewed as 2 745 nurses suffering from AIDS annually while nursing colleges turn out 1 896 graduates per annum).

The somewhat consoling new study draws on data collected at 15 primary health care clinics in 2004 and 2005 during the first stage of the ART roll-out in the Free State, and the five district hospitals to which these feeder clinics refer. Data collection methods included focus group discussions, face-to-face semi-structured interviews with doctors and nurses, and participant observation of nurse training for ART delivery and patient training for drug adherence.

The Free State ART programme, like most of its counterparts in South Africa, is primarily nurse driven because of the dire shortage of doctors. Generalist nurses were interviewed in addition to ARV nurses because the former are being relied upon to deliver VCT and treat opportunistic infections.

The researchers said despite the wide-ranging challenges, the enthusiasm with



which the Free State nurses greeted the envisaged ART roll-out in April 2004 was 'striking'.

They quoted one as saying, 'when we look inside our clinic, April is too soon, but when we look outside our clinics it cannot be soon enough'. Said another, pre roll-out, 'When we studied to be nurses we were studying to save lives. Now we spend our days packing up corpses'.

The only health system problem identified by respondents in the survey was the slowness of the ART roll-out. Facilities offering ART found themselves serving patients throughout their districts instead of only those in their catchment area, as originally intended.

Beyond working hours

The study says levels of commitment among nurses went 'far beyond the call of duty', and 'appeared to be motivated by intense personal investment in the ART programme'. The nurses attributed this to their close bonds with their local communities, and often to having nursing family members and/or close personal friends suffering from AIDS.

One nurse, who had just lost a 20-year-old niece to AIDS and whose second 18-year-old niece was ill, broke down in tears when asked whether she was worried about her own children. Eventually she said, 'you know it hurts, HIV, it hurts, because these were people who were well behaved, decent people'.

Another, asked what the most difficult part of treating people with HIV was, replied: 'The unfairness of it. It can happen to anyone. A virgin bride, a baby and then it makes you think. Here I am, I'm married, I'm so sure of myself. But how sure can you really be, you know? And the saddest part is the children with their fluffy hair and swollen hands that are so painful. I've

got a baby, a 10-month-old baby now, and every time I say, "Thank God, my child, you know, I've been spared".'

One nurse, caring for a bed-ridden younger sister with AIDS at home, visited her patients at their homes and provided AIDS education at factories, schools and mining hostels. She did this in her free time because it was 'the only way to get it done'.

When asked if she was coping, she did not try to express the extent of her burden but instead argued that it was easier for her to do this extra work than not to do it.

'I can cope. If I don't do it, it's like - I don't know how to put it. If I do it, I can say, "Thanks to God for what I've done." But if I didn't do it, I'd feel some sort of guilt'.

Nurses saw their self-sacrifice as necessary to sustain the ART programme and viewed their work as empowering people with AIDS to take greater control of their own care and to impart knowledge so that they could access services.

All the specialist ART nurses interviewed felt that they should ideally follow up ART patients at home, despite the fact that policy guidelines suggest voluntary home-based carers provide this service. All emphasised the need to provide ongoing emotional support to patients and spoke of their own emotional difficulties in providing VCT and achieving disclosure in the face of stigma.

Patients feared disclosure to sexual partners and family members upon whom they often depended for emotional and financial support. Nurses carried a strong sense of responsibility for any unintended negative outcomes.

'Sometimes you go home and you are thinking again and again and you imagine the situation in the person's house. And you think, "I didn't do enough,"' said another.

One nurse acknowledged that she used antidepressants to cope with the emotional impacts of her work. She said these were readily available from those 'sympathetic' doctors who recognised the extent of their challenges. Little if any formal provision has been made at provincial level, however, for providing such support to nurses. The researchers said lack of managerial support was commonly reported.

One respondent epitomised the nurse commitment by saying, 'Some patients, once they are better, will go back to their old ways (but) if they are on ARV and they disappear, we run like ten devils to find them'. She added that she thought human resources in the clinic would ultimately prove to be the biggest problem.

Nurses saw their self-sacrifice as necessary to sustain the ART programme and viewed their work as empowering people with AIDS to take greater control of their own care and to impart knowledge so that they could access services. The researchers said a social contract seemed to be entered into with ART provision. Only those patients who were prepared to behave responsibly with regard to treatment and prevention were accepted into the programme - basically because ART demand so dramatically outstripped supply.

Studies conducted prior to ART provision in South Africa showed nurses expressing ambivalence about their own capacity to initiate change and fatalistic and defeatist attitudes towards delivery of care.

Chris Bateman