

## The implications of ART for local AIDS care and support programmes

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**Monica Zono was seriously ill and debilitated when she began ART with a CD4 count of 28. With a CD4 count of 280 she is again mobile and feeling more positive about the future. Here she is visited by Thandi Mzizi, one of the co-authors.**



### INTRODUCTION AND METHOD

With national-level obstacles to the provision of antiretroviral therapy (ART) cleared, and provincial roll-out programmes being implemented in a limited way, there is need and opportunity to reflect on the challenges of delivery at local level.

Whereas public sector ART programmes are planned and implemented at provincial health facilities, they require the co-operation of all those organisations working locally providing treatment, care and support to people with HIV and AIDS. This requires a marked scaling up of efforts to co-ordinate and integrate the activities of local AIDS support organisations and services, that have until now not needed to be closely linked operationally on a case-by-case basis. The objective of this study is to map out some of the manifold challenges faced in this respect.

More particularly, we present the findings of a case study aimed at understanding the implications of ART programmes for local programmes of support and care for people with HIV and AIDS, with a focus on the involvement of a local Hospice which provides home-based care (HBC) services.

Information for this analysis was collected through: a focus group conducted with home-based carers working at primary health care clinics and a local Hospice association; a focus group with HIV-positive people, some of whom are on treatment programmes; reflections on the experience of a Hospice staff member designated as a psychosocial worker (one of the co-authors); an interview with the Hospice Director; an interview with a member of the antiretroviral therapy (ART) programme task team; and, attendance at a task team meeting.

A thematic analysis was conducted to identify the key issues which need to be resolved in the development of an integrated local ART programme.

### THE CONTEXT

The ART programme under consideration is based at Settler's Hospital, Grahamstown, one of seven focal points (pilot sites) for ART in the Eastern Cape Province. The hospital serves a population of approximately 140 000, covering two municipalities. The ART programme was launched in May 2004 and by late November 2004, 87 clients were on ART, 31 were awaiting treatment eligibility assessments, and 20 had complete eligibility assessments awaiting review by a multidisciplinary team. It is thus apparent that there is some back-up in the process of assessment and review. The total number of clients on ART is at about 6% of those currently needing treatment (assuming that 10% of the HIV population needs ART).

The programme employs a full-time project manager, social worker and administration officer. Two doctors, a public health technical advisor and an information officer have limited weekly sessions. A hospital pharmacist and nutritionist are also involved in the programme although they are not seconded and their salaries are not funded by the programme. Two community 'health visitors' have been selected from five community health workers (who also conduct home-based care) in each of nine ART accredited primary health care clinics, and trained to assist in home visits and treatment eligibility assessments. Some clinics and a hospital in the

area covered by the focal point were not accredited, so the reach of the ART programme is not evenly spread across the two municipalities.

The local task team have had to adapt or develop forms and procedures for recruiting people into the ART programme, using national and provincial materials as reference. This has involved substantial work and not merely adapting guidelines to local circumstances. It has also involved developing training procedures for frontline workers. There have been few opportunities to share learning experiences with other pilot sites, and the team has had little support in its development of implementation procedures, apart from an initial three-day training on ART.

Grahamstown Hospice provides care and support to people with active, progressive and incurable diseases, including people with AIDS. It experienced a 1500% increase in AIDS clients between January 2002 and November 2003. There was an AIDS client load of 112 in October 2004 with 20% being under 10 years of age and 60% between the ages of 21 and 40 years. Twenty eight per cent of the 87 clients currently on the ART programme are Hospice clients. Currently 78% of the Hospice case load is AIDS clients, but less than one in four of these are currently receiving ART, meaning that Hospice involvement in ART provision in the future will grow considerably.

Hospice has the support of its own professional interdisciplinary team but has struggled to extend the quality services it has offered in the past to a much larger group of clients, with a budget that has not kept pace with the growth in client numbers.

## **THE DEMANDS OF THE ART PROGRAMME**

### **Treatment readiness assessment**

The national guidelines for ARV treatment say that "final decision to treat will be taken by the multidisciplinary team at the ART centre". The process for selecting clients likely to succeed on treatment has had to be worked out by the local task team and the 'final decision' to commence treatment or to 'defer' is made by a 'review team' which conducts a weekly meeting to discuss treatment eligibility assessment reports.

Hospice conducts treatment eligibility assessments for clients already in its care. It should be highlighted here that this work falls outside of the usual scope of work of Hospice. Hospice is involved because by conducting the assessment itself it fast-tracks the process of entering the ART programme for its clients. Furthermore, given that the ART programme has not until very recently had a full-time social worker or trained health visitors, the success of the programme to date must be partly attributed to Hospice, which accounts for 28% of the clients on the programme.

For the Hospice psychosocial worker this involves an initial home visit followed by a screening interview to collect information relevant to treatment adherence using a standard questionnaire developed by the review team. It also involves ensuring that the client undergoes necessary medical tests, and assisting the client through the process of disclosing to a family member or close friend who acts as a 'supporter'. The client's circumstances have to be closely considered and both the client and supporter are taken through an education process to understand the implications of being on ART.

When the client is accepted for ART the Hospice worker facilitates the process of enrolment into the programme for those patients in Hospice care. When clients are not accepted onto treatment the client is 'deferred' until eligibility criteria are met. About 1 in 10 of all clients (less in the case of clients who have been in Hospice care) are not accepted onto the programme for a range of reasons including CD4 counts that are too low, alcohol abuse, untreated medical conditions, insufficient social support or other reasons related to adherence risk. In such cases the patient is assisted to the point of meeting eligibility criteria.

Hospice is occasionally asked to assess clients who are not Hospice clients, as the demand for assessment has exceeded the capacity of the ART social worker and clinic staff to cope. The ART programme developed without the necessary staff capacity and Hospice has absorbed some of the load. On top of this the assessments have led to greater referrals to Hospice and a greatly increased workload at the level of assisting to develop the system and attending review meetings. Perhaps the most important point here is that the availability of the ART programme has increased the workload of Hospice considerably, reflecting in various ways insufficient resources within the public sector system.

### **Local co-ordination and integration**

There are nine different health administration systems within the area covered by this focal point and there are also public sector programmes conducted by education and social development departments that need to be aligned with the ART programme. In addition to this, there is a constellation of loosely bonded non-governmental AIDS support organisations independently providing services to people with HIV and AIDS.

It is a significant challenge to align these agencies in the interest of supporting ART and to co-ordinate and integrate their various services to a greater degree. Even finding meeting times for the ART task team and review team has proved difficult.

To date the ART programme has received little systematic support from government departments apart from Health. Departments of Social Development and Education need to align their care and education programmes respectively, and much remains to be done to elicit supportive contributions for ART from the many NGOs involved in AIDS support, the local university and community media such as local newspapers and radio stations. Developing public awareness and developing community-level awareness and support, are challenges ahead.

The lack of integration of programmes and services means that the care and support organisations which have most direct contact with those who use such services, carry an added burden of making the system work in an integrated way for users. The process of applying for a disability grant for a bedridden client illustrates the point. Normally this would involve an appointment with a district surgeon, obtaining affidavits relating to marriage and employment at a police station, and application forms being completed and sent to the Department of Social Development. The Hospice psychosocial worker has to facilitate such processes on behalf of clients. This sometimes extends, for example, to transporting government officials to the sick client's home for the purposes of obtaining an affidavit. The point is that local care and support agencies like Hospice have to create such bridges between other agencies. Functionally integrated systems would involve these 'linking functions' devolving to service providers and it would involve agreed upon standard procedures and referral systems. For example, in order to find ways of linking NGO VCT services to the ART programme, referral and information management systems need to be developed, and such challenges lie ahead.

There is also a need for greater co-operation with informal and traditional health systems. Let a case make the point. A client on ART was required by family custom to undergo a particular ceremony. She previously had a drinking problem but had not taken alcohol since she had been recruited onto the ART programme and was doing well on the programme. The ceremony required her to drink brandy. The direct consequence of this was a relapse to alcohol abuse, serious side-effects and significant deterioration in her health status. With better co-operation with the traditional leaders facilitating the ceremony, this situation may have been averted. Similarly, better sharing of information and co-operation would help to alleviate clients taking additional patent and traditional medicines together with ART regimens. Until other systems of health support are involved in the programme, at least at an informational level, they run the risk of being a liability to clients. Hospice has had to resolve a number of issues related to such matters again showing how the problems of inadequately developed systems become the problems of frontline service providers.

ART clients are required to attend a specialist clinic on a monthly basis, and when they become established ART users with good compliance and improvement in health status, the plan is to refer them to their local clinic for ongoing support. For now the process of educating clients about antiretroviral compliance, side-effects, nutrition and related matters is done at the specialist clinic, by medical practitioners, a pharmacist and a nutritionist. But this often does not suffice and the psychosocial worker at Hospice and clinic-based community health workers are faced with the need to further educate and assist clients and their supporters in an ongoing way.

### **Health care**

Current policy places chronic care as a primary health care competency and five home-based carers are based in each primary health clinic, supervised by senior clinical health workers. They have to walk their HBC rounds and are paid a small stipend. Their supervisors are reportedly not all trained for the task of supervising and do not have enough time to devote to supporting community health workers who interact with AIDS clients at home. There are no doctors in clinics and it is acknowledged by the ART task team that training for supporting ART programmes at clinic level is not sufficient in many respects. There are also unmet challenges in providing adequate security for the drugs and for managing drug inventories. From this it should be apparent that there is much need for training, and improvement of human resources at clinic level. These are problems identified by the ART task team and there are plans afoot to address them. In addition, the ART team has identified the need to have a palliative care unit at the focal point hospital and has developed a proposal and begun fundraising. This will provide considerable relief to home care workers and hospital wards faced with the highly intensive task of dealing with chronically ill clients. Many AIDS clients suffer from conditions which are not opportunistic infections, such as cancers, sometimes connected to sexually transmitted conditions such as hepatitis B and C. Facilities for the medical treatment of such chronic and debilitating conditions, or terminal illnesses, would free home-based care workers and health visitors based at clinics to devote more of their time to preparing clients for ART and supporting them once enrolled.

It must be noted that these problems are also the problems of the PHC system more generally, but are having to be directly faced by the local task team, highlighting the extent to which local implementers are having to develop local systems of health care. It has become evident that PHC system development is necessary before ART challenges can be adequately met at clinic level. Such ART challenges at clinic level include supporting and monitoring ART compliance, nutrition monitoring, supporting back-referrals (clients referred from the specialist clinic for ongoing ART at PHC level), education related to treatment literacy, education about use of available services (home care is an educating as well as a caring process), family support, treatment readiness assistance for clients not accepted onto ART programmes, and all of the functions discussed under psychosocial support below.

Hospice home-based carers and the psychosocial worker face similar challenges because of inadequate basic health infrastructure and systems. Often clients are referred to the psychosocial worker and Hospice has to be cautious not to take on the problems of the broader system of care and support. There is also some caution on the part of Hospice to not be engulfed by the demands of the ART programme and AIDS health support needs. There is some concern that non-AIDS clients not be neglected given the pressures of scaling up the ART programme.

### **Psychosocial support**

Three psychosocial support issues are discussed below: disclosure and stigma; mental health; and, disability grants. Whilst specific problems and solutions in each area are discussed, there is clearly no shortcut to creating social mechanisms for supporting people on ART. The Hospice psychosocial worker and clinic-based caregivers face many basic client needs for support for which they feel it is their responsibility to find solutions. They are lumped with all of the inadequacies of the care and support contexts and system: when there is a problem of availability of water for care of AIDS clients; when there are problems with funeral policies or government grants; when there are relatives who squander grant money; when alcohol use in the home poses a risk to a client who is abstaining after a previous alcohol

problem; when there is depression; and, a host of other problems. The need for developing adequate systems of assistance and referral is vital if programmes are to be scaled up further, to improve the efficiency of home-based carers, and to parcel out the burden to other resources for social support. Simple availability of services is not enough. There is need for education around services, for instance regarding the availability of social workers, nutritionists, psychologists and other professionals.

The burden of psychosocial support is particularly high in the first three months after commencing treatment, when clients tend to suffer side-effects most severely. In future it is planned that clients who are doing well on the programme will be 'back-referred' for ongoing management at local PHC clinics, without need for regular visits to the specialist clinic. It is likely that the burden on home visitors will again be increased as they take on the responsibility of supporting life-long compliance.

### **Mental health**

The national treatment guidelines suggest that eligibility for ART is compromised by depression or alcohol abuse. There has been very little research on either of these problems among HIV-positive South Africans, but international literature and the reports of home carers suggest that they are fairly frequently encountered. Social isolation, shame and insecurity are also commonly encountered. Mental stability and emotional robustness are necessary to endure the first few months of treatment where side-effects tend to be experienced and any kind of psychological instability threatens ART adherence at the 95% level needed to prevent resistance.

Client's are mostly not 'ready' for or oriented to treatment and its requirements, and mental health professionals, medication (e. g. for depression) and psychosocial support systems are needed.

The idea that support groups for people on ART would meet psychosocial support needs, as well as education and information needs, is proving to be difficult to realise. There is low and inconsistent attendance at existing support groups and it is felt that perhaps these do not offer enough to be perceived to be of value to clients. Participants in the focus group for HIV-positive people gave mixed appraisals of the value of support groups, from 'very useful' to 'not at all useful'.

Conducting support groups which go beyond information and education provision requires an understanding of group processes and facilitation skills. There has been some progress towards this end, but these efforts draw on limited local expertise and much of such development work is conducted in a remarkable vacuum of higher level support, and often without access to pioneering work that has been done in other contexts.

Home-based care workers report sometimes facing hostility from community members, they are often nervous about their personal safety in walking the streets on their home visits, they have to be secretive in visiting some homes as a visit may be tantamount to disclosure to the neighbourhood that a person has AIDS, and they are continuously faced with complex family and psychological problems which they often do not have the means to resolve. Furthermore, training, mentoring and support for their work is in short supply. This is a poor context for them to take on this arduous and emotionally challenging work.

Hospice has some experience in running support groups for mothers of chronically ill children and also for people with cancer, and sees the need to extend this to people with AIDS under Hospice care. However, this is a resource-intensive activity and provision of support groups specifically for ART seems to extend beyond the mandate of Hospice to care for chronically sick people.

Clients who are deferred until problems such as alcohol use or clinical depression are resolved, need to be referred to appropriate agencies cognisant of the specific challenges they face as candidates for ART. Ad hoc arrangements are made, but again, this needs to be

systematised, so that each new case is not exceptional, and the client does not need to be hand-held through the process by the initial referral source.

To date the ART programme has not involved the assistance of psychologists or spiritual counsellors, although a social worker is involved, and there has been no involvement yet of traditional community support systems. The staff at clinics are not trained to identify or deal with mental health problems associated with AIDS and psychotropic drugs are not stocked at clinics.

It is clear that mental health needs are being addressed only in a rudimentary way and much development and guidance in this area is required.

### **Disclosure and stigma**

The ART programme involves family members or close friends acting as treatment supporters, and this requires disclosure, at least to the supporter. If clients have not already disclosed to someone who might act as a supporter, they are assisted to identify such a person and a home visitor makes an appointment to meet with the potential supporter. Such reaching out to the immediate social context of support extends the psychosocial support system and is ultimately supportive of treatment compliance, but it is challenging and labour intensive to develop such support systems in preparation for treatment. Such home visits are seen as ideally being conducted by social workers, but in reality contact with the immediate social context is by home carers who have only basic training in home care and AIDS support, and are not tutored, or closely supervised on how to build social support systems.

Those who have not previously disclosed to anyone are a problem and there have been cases of poor compliance when the family does not know, and where, for example, the drugs are kept and taken at a friend's house. Without disclosure there are problems in visiting clients and Hospice has sometimes to park away from the home even when there is family disclosure, as the Hospice car is now associated with AIDS. An HIV-positive focus group participant says: "You should hear the buzz when a house has been visited by a nurse, they will say 'there is one there at number 8'. This is what we are faced with." They report that experiences of being ostracised are common for those who have disclosed their status.

Maintaining secrecy about HIV and AIDS is a client need that Hospice has to respect, and at the same time to gradually dissolve. The positive effects of treatment often give clients a more positive attitude towards their condition and create the psychological ground for greater openness. Being a midwife to this process is yet another task for the frontline worker. It must be some concern that not more is known about the processes required to achieve disclosure and that community-level approaches to diminishing stigma have not been developed.

### **Assistance with grants**

The provision of disability grants to people with CD4 counts below 200 is emerging as a significant problem. Technically as clients respond positively to ART they become ineligible for grants. This is perceived by HIV-positive people as a disincentive although as yet there have not been reports of failed adherence because of this. For those with temporary disability grants which need to be renewed at either six or 12 months, it will almost certainly be the case that clients will lose their grants. For those with permanent disability grants, unless a regular reapplication process is instituted, this is not an immediate risk.

Disability grants are often used to supplement nutrition. The loss of disability grants, given the unlikelihood of most clients finding employment with high unemployment in the area, is likely to lead to a deterioration in their socio-economic circumstances. Opinions are divided in the ART task team about how the State should respond to the need to provide some form of assistance to cover the real costs of having AIDS and being on ART. There is a need to review this matter at a national level, and to develop viable and sustainable forms of support conducive to treatment adherence and efficacy.

The assistance needed in applying for disability grants is part of a broader process which has to be facilitated by the Hospice psychosocial worker around optimising the effects of the grant. Clients have to be assisted not only in obtaining such grants, but also to make decisions about how best to use these.

### **Resource needs**

Inasmuch as there needs to be local development, co-ordination and integration of resources, services and systems, there needs to be national and provincial support for the same. Unfortunately there is little evidence of guidance in terms of resourcing local health systems for AIDS response. There are many complexities involved considering that HIV/AIDS programmes in provincial departments of health are funded through nine different conditional grants and provincial departments of education and social development receive their own conditional grants. Making these grants work in an integrated way at local level is a challenge that is far from addressed. Proposals to decentralise systems for disbursement to district municipalities may exacerbate rather than resolve bureaucratic logjams, and since it would take some time to establish new systems there would be further lags in system development.

For NGOs the problems are different. They struggle to obtain government funding for salaries or recurrent costs and this is the predominant need. The primary source of government funding support for Hospice has been capped since 1997, during which time there has been a large increase in client numbers. Other avenues of government funding have been subject to delays, which has been costly both financially and operationally. There are numerous smaller funding problems for Hospice, such as the case of a satellite project that cuts across municipal boundaries, which is problematic because government administration is organised along municipal boundary lines.

Facilitation of access to ART requires commitment of resources on the part of government and local service organisations. The introduction of ART programmes means that the AIDS support organisations, VCT centres, PMTCT programmes, AIDS education programmes and nutrition programmes, amongst others, have to develop in concert. Funds for such development are not necessarily available and lack of advance planning (and notice) for commitment of such resources in this financial year has meant that the roll-out process has placed resource pressure on all elements of the system. Growing demand for existing services for AIDS clients stretches current budgets, and the new services add additional resource demands.

Given the epidemiological risk of unsuccessful ART programmes, to say nothing of the human costs, resourcing of such systems cannot simply be left to the vagaries of local capacity.

The funding requirements for integrated ART systems need to be properly researched. What is the actual cost of having a person adhering to an ART programme, taking all of the local resource needs and opportunity costs into account? How are local integrated programmes best resourced, and how can logjams and inefficiencies be remedied?

A further and serious resource problem is transport. The national guidelines for selection of clients for ART say that 'demonstrated reliability' involves a client having attended three or more scheduled visits to an HIV clinic. "Clients should be able to attend the antiretroviral centre on a regular basis or have access to services that are able to maintain the treatment chain. Transport may need to be arranged for clients in rural areas or for those far away from the treatment site."

Given the numbers involved, the difficulties of unwell people travelling to the specialist clinic, the distances involved (more than 70 kilometres for some clients) and the lack of public transport returning from the specialist clinic (taxis leave the hospital only three times a day), transport must be seen as a significant obstacle. Step-down care is seen as something of a solution. Clients who are established on the programme and where there is low adherence risk are already being referred back to local clinics for ongoing follow-up and this assists, but in the recruitment phase and for most current clients transport is a problem. There are also challenges involved in getting home carers to clients. There are no ready-made solutions to

these problems, but they must nonetheless be highlighted as deserving of attention in rolling-out ART programmes.

The development of systems, models and local guidelines should also be regarded as a resource problem. National treatment guidelines need to be complemented by guidelines for developing local systems of care and support. Far too much has been left in the hands of local task teams. Whereas each focal point presents particular challenges, some of which may be unique, there is much being faced in this focal point which is in all likelihood shared with others. There is a need for technical support teams at provincial level which conduct operational research and formative evaluations of focal points, so that learning can be accrued and local learning shared. Whereas there is a designated provincial advisory institution there has been little forthcoming by way of guidance and support and, in many ways, the ART task team in this area appears to have been working in a vacuum.

## **CONCLUSIONS**

It is apparent that those with most direct and ongoing contact with AIDS clients often bear the brunt of the need to make social and health service systems work in the wake of poor preparation and infrastructure development. This situation prevails in the face of remarkably little district, provincial or national support for development of local implementation systems.

Infrastructure and procedure development needs to be strongly led by a team with experience in health systems development in a multi-agency context. In the context under review it is fortuitous that the necessary commitment and technical expertise is locally available. This is unlikely to be the case in many, if not most other ART sites.

The needs discussed above are not wish-list items, they are basic needs which local ART systems must have addressed if ART is to be successful. Whereas ad hoc arrangements and funding have sufficed to date, it is all too clear that servicing of the need is going to require systematisation of local functions far beyond what currently exists. Informal systems of co-operation between organisations which have previously sufficed are inadequate at ever-increasing scale and these need to be formalised and resourced.

We have looked at the challenge of ARV provision through the lens of an organisation that provides home-based care for AIDS clients. If we had looked through the eyes of pharmacists, professional nurses, social workers or nutritionists, there would undoubtedly be further issues to focus on, and this needs to be done. National treatment guidelines and provincial support programmes, to the extent that these are developed, need to be supplemented by a robust programme of support for local systems development. There is a need for a provincially co-ordinated strategy for operations research and formative evaluation, with a focus on how to develop, resource and maintain integrated and holistic local systems of ARV treatment. The national ARV treatment guidelines speak of a system which will be integrated from primary to tertiary level as well as from the clinic to the community and from pre-diagnosis to palliation, within the district health system framework. With what higher level operational guidance and support will this happen and where is the strategy for this?

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