ART SUPPLEMENT

Health systems’ responses to the roll-out of antiretroviral therapy (ART) in India: a comparison of two HIV high-prevalence settings

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The government of India launched the free anti-retroviral therapy (ART) initiative in 2004 and the programme has since scaled up expansion in a phased manner. Programme authorities acknowledge problems in scale-up, yet discussions have been restricted to operational constraints, with little consideration for how local health system responses to HIV/AIDS influence the delivery of ART. This paper draws on the perspectives of key informants and people living with HIV (PLHIV) to compare delivery of ART in two ART centres in the States of Maharashtra and Andhra Pradesh at two distinct points of time. In 2005, data were collected through key informant interviews (KIIs) using interview guides and a survey of PLHIV using a semi-structured interview schedule. Differences were observed in the functioning and resources of the two centres, indicating different levels of preparedness which in turn influenced PLHIV’s pathways in accessing ART. We examine these differences in the light of programme leadership, ownership and the roles of public, private and non-governmental organisation actors in HIV care. KIIs conducted during a follow-up visit in 2009 focused on changes in ART delivery. Many operational problems had been resolved; however, new challenges were emerging as a result of the increased patient load. An understanding of how ART programmes evolve within local health systems has bearing on future developments of the ART programme and must include a consideration of the wider socio-political environment within which HIV programmes are embedded.

Keywords: public sector programmes; anti-retroviral therapy; health systems; India

Introduction

In 2004, Indian government launched a phased scale-up programme to provide free anti-retroviral therapy (ART). Initially, ART centres were set up in six high-prevalence States1 and from January 2005, the programme expanded to include seven more States. The goal for scale-up was to increase the number of ART centres to 100 by end of 2005 and to offer free treatment to 100,000 people living with HIV (PLHIV) through public sector by end of 2007 (Sankaran, 2006).

Initially, ART roll-out in India faced several challenges. Early reports of operational barriers in meeting targets indicated differences across States (National AIDS Control Organisation [NACO], 2008a; PANOS INDIA, 2007). In Maharashtra, problems included drug shortages, weak infrastructure, burnout of counsellors and weak monitoring; while in Andhra Pradesh, the “staggering” numbers of PLHIV requiring treatment combined with the presence of private sector created difficulties for ensuring treatment adherence and monitoring (PANOS INDIA, 2007).

While these well-documented issues partly indicate the growing pains of a new programme, State-wide variability in performance suggests differences in States’ capacity to deliver ART through existing health systems. The National AIDS Control Programme (NACP) provides framework for HIV care delivery, yet State-level differences in the epidemiology of HIV, the socio-political and policy responses to HIV/AIDS, affect capacity of local health systems to allocate and absorb the resource requirements of ART delivery into their organisational culture (Cohen, 2004; Steinbrook, 2007). While there is evidence of ways in which local health systems are adapting available health system resources for ART delivery in African countries (Gilks et al., 2006; Harries et al., 2004; Torpey et al., 2009), a health systems “probe” (Blaauw et al., 2004) have not been used to examine the Indian ART experience.

Present paper draws on data from PLHIV and key informant interviews (KIIs) collected in 2005 and 2009 from two high-prevalence districts, Ajaynagar and Vijaynagar (pseudonyms) in Maharashtra and
Andhra Pradesh in order to contrast the early evolution of ART roll-out in these States. We examine differences in ART delivery in these districts as a function of physical and human resource inputs in the respective health systems. We attempt to situate some of the differences observed in the context of social and political relations among key actors within the ART delivery scenario (Schneider et al., 2006; Van Damme, Kober, & Kegels, 2008).

Background

India’s NACO was established in 1991. It coordinates the NACP at national level and the State AIDS Control Societies (SACS) in the States (Sankaran, 2006). The current phase of the NACP (2007–2011) emphasises the provision of ART (NACO, 2007). Despite the overarching framework of public sector HIV care there is evidence that a sizeable proportion of patients receives private ART and HIV care (MAAS-CHRD, 2006; Ramchandani et al., 2007). Several non-governmental organisation (NGO) and community-based organisations (CBO) work on HIV/AIDS at local, State and national levels.

Study settings

Maharashtra and Andhra Pradesh have an estimated 0.5 million PLHIV each (NACO, 2008b). In January 2006, there were five ART centres in Maharashtra and three in Andhra Pradesh. Based on the HIV Sentinel Surveillance both study districts were listed as “Category A” districts by NACP with more than 1% HIV prevalence among antenatal clinics (ANC) attendees (NACO, 2007). ART delivery was initiated in December 2004 in Ajaynagar and January 2005 in Vijaynagar.

Method

Study design

Data collection for the study occurred at two points in time, first round was from November 2005 to January 2006 and second was in March 2009. The first round was undertaken as part of a larger study conducted in 2005 in three high-prevalence districts in the States of Maharashtra, Andhra Pradesh and Orissa (MAAS-CHRD, 2006). This study presented an opportune moment to examine differences in ART service delivery in Ajaynagar and Vijaynagar, where the ART programme was functional at that time. Data were collected through KIs using interview guides and a survey of PLHIV using a semi-structured interview schedule. The representative survey sample of 229 PLHIV was derived from NGOs and PLHIV networks in the two study districts, so as to include PLHIV who had experiences in the private sector as well. Thirty-one key informants (KIs) from the public, private and NGO sectors and PLHIV networks were purposively identified through snowballing and interviewed (Table 1). These interviews provided the broader context and underlying dynamics of HIV service delivery in

| Type of key informants | 2005 | 2009 | 2005 | 2009 |
|------------------------|------|------|------|------|
| Nodal officer – ART centre | 1 | 1 | – | 1 |
| Medical officer (MO) – ART | – | – | 1 | 1 |
| MO rural hospital | 2 | – | – | – |
| MO (Faculty medical college) | 1 | 1 | – | – |
| NGO director | 1 | 1 | 4 | 2 |
| PLHIV network president | 1 | 1 | 1 | 1 |
| Private HIV specialist | 2 | 1 | 1 | 1 |

| Type 2 key informants (front-line staff) | 2005 | 2009 | 2005 | 2009 |
|------------------------|------|------|------|------|
| ART counsellor | 1 | 1 | 1 | 1 |
| Medical social worker at district hospital | – | – | – | – |
| TCC counsellor | – | – | 1 | 1 |
| VCTC counsellors | 4 | – | 4 | – |
| NGO counsellor | – | – | 2 | – |
| NGO social worker | 1 | – | – | – |
| NGO field coordinator | 1 | – | 1 | 1 |
| Total | 15 | 8 | 16 | 10 |

*aKey informants who were also interviewed in 2005.*
the study settings. The survey elicited data on HIV care-seeking behaviour, specifically on the first access points and their experiences while seeking ARVs.

In March 2009, researchers returned to spend one week each in the same study sites. They discussed changes with KIs, specifically focusing on ART delivery. The 18 KIs interviewed included: programme managers, administrators, professionals and front-line staff of which 14 were interviewed previously (Table 1).

Data management and analysis
In Vijaynagar, the KIIs were conducted in English; interviews with PLHIV were in Telugu. In Ajaynagar, all interviews were conducted in Marathi. Field-notes taken during the KIIs were expanded after interview. Open-ended data from PLHIV interviews were recorded as notes in the interview schedule and later expanded. In both rounds of data collection, notes in Marathi and Telugu were translated into English. Translations were verified by field supervisors. After several readings of the textual data, a thematic coding system was prepared which included, “access to ART”, “public sector response” and “health systems interface”, etc. Interviews were coded manually. Retrieved coded segments were used to contrast health systems resources available in the two sites, the socio-political context of ART delivery in 2005 and the significant changes in ART scenario in 2009.

A tale of two clinics in 2005
In the early phase of the ART programme, the care-seeking trajectories of PLHIV were strongly influenced by the presence of private medical practitioners (PMP), NGOs and PLHIV networks in both sites. Almost half (48%, 54/113) of the PLHIV from Ajaynagar and more than one-fifth (22%, 26/116) from Vijaynagar were on ARVs. More than three-quarters (83%, 45/54) of these PLHIV from Ajaynagar and more than two-thirds (69%, 18/26) from Vijaynagar had first started taking ART from the public sector. The remaining nine from Ajaynagar and eight from Vijaynagar had started ARVs in private sector. Ten of these 17 patients eventually switched over to public sector-run ART programme, only after incurring high financial and social costs. For example, RP, a 25-year-old married woman from Vijaynagar was first started on ARVs following the advice of a PMP. Her parents had borrowed money on interest and whenever they ran out of money, RP had to stop taking ARVs. By the time RP was enrolled in the district ART centre, her parents had spent Rs. 50,000 (~1170 US$) on treatment.

In 2005, ART centres in both Ajaynagar and Vijaynagar were located at District hospitals attached to Government medical colleges. The ART team supervising the functioning of the programme was comprised of faculty from the Department of Medicine and contractual staff. PLHIV were generally referred to ART centres from Voluntary Counselling and Testing Centres (VCTC), ANC, rural hospitals and designated microscopy centres for TB, PLHIV networks, NGOs and PMPs. NACO provided ART centres with treatment protocol and supplied ARVs through an annual procurement mechanism. Most patients were started on ART within a month of their first visit at both centres, however, differences were observed with regard to day-to-day functioning and system resources, indicating the overall system preparedness to address operational issues at both sites.

The centre in Vijaynagar functioned on a daily basis while the centre in Ajaynagar functioned weekly with space shared with other outpatient clinics. This resulted in long queues and waiting hours, increasing the burden on ART programme staff and on the conduct and functioning of outpatient clinics run by other departments:

I come here in the morning at 8, then stand in queue for making pass and case papers. Three times I have to stand in queue, so my entire day time is spent standing in queues. (Unemployed 57-year-old male, Ajaynagar)

Both centres suffered from staff shortages, and relied heavily on NGO staff to help manage their patient loads:

There is problem of time management. ART clinic is held only on Tuesdays . . . 500–600 patients attend this clinic. If each patient is given 10–15 minutes, then it is not possible to counsel every patient on the same day. The workload is huge and there is scarcity of staff. (PLHIV Network Representative, Ajaynagar)

In Ajaynagar, NGOs and PLHIV networks, with branch offices in rural areas of the district, played a crucial supportive role by directing and guiding PLHIV to ART centre, getting them registered and counselling them. One NGO appointed a staff member full-time at ART centre to coordinate referrals specifically from rural areas. In Vijaynagar, a local NGO provided counselling before referring PLHIV to the centre and adherence counselling following initiation of ART. Medical officer at the centre referred 90% of the patients to the adjacent Treatment Counselling Centre (TCC) run by PLHIV network for counselling before initiation of ART as well as for follow-up counselling.
While ART centre in Vijaynagar was fully functional in terms of its ability to deliver care, in Ajaynagar, the constraints on trained staff and physical resources affected the centre’s ability to continue ensuring high standards of care. Basic items like disposable gloves and testing kits were in limited supply (Table 2).

Although CD4 count machine was available, there was no trained technician available to operate it. ART medical officer consequently did not lay emphasis on CD4 count while enrolling PLHIV on ART. He was candid in describing the situation regarding implementation of operational guidelines for ART:

Before starting ART rollout there was a draft regarding steps to be taken before starting ART… that draft was not being followed meticulously in Ajaynagar. All the required steps before starting ART were not being tick-marked… omitting some important steps, there was a direct jump to the last step of dispensing ARV drugs. (Former medical officer, ART programme, Ajaynagar)

In both sites, people responsible for the overall functioning of ART centre viz. senior medical officers and counsellors had received training before the programme was rolled out. In Ajaynagar, this training was perceived to be of limited value.

Differences in operational functionality in the two sites were linked to differences in the availability and quality of physical, human and social resources (Table 2). These differences resulted in different patient pathways as illustrated:

SD, a 23-year-old widow from Ajaynagar, lives 120 km from district headquarter. Following the death of her HIV-positive husband, a villager employed with an NGO working in HIV, advised her HIV test and took her to VCTC. After testing positive, SD started getting sick frequently, NGO worker accompanied her to the ART centre. She was advised to get HIV and CD4 count tests done in a private laboratory. SD received information on HIV from an NGO worker. The doctor elicited SD’s family history and after obtaining written consent from her, informed her that it was her responsibility to seek treatment from other sources if drugs were not available at the centre. SD had to collect medicines once a week from the busy ART clinic. She walked two km from her home to reach bus station and waited five hours in two separate queues before she received ARVs. She spent Rs. 150 (~3.5 US$) on travel and food each time she visited the centre. SD wanted to stop ARVs due to severe side effects. The NGO worker from her village convinced her not to do so and accompanied her to a private HIV specialist in the city, who gave her medicines to relieve the side effects. SD continued her ART in public sector.

PK, a 25-year-old unmarried man from Vijaynagar, lives 78 km from district capital. Two years ago, PK started getting sick very frequently. After attending an HIV/AIDS awareness campaign held in his village, he went to get tested at VCTC near his village and was diagnosed as HIV positive. Seeing his illness history, the counsellor at the hospital immediately referred PK to ART centre, where he underwent HIV and CD4 count tests. He was counselled regarding lifelong adherence to ART and enrolled on ART immediately due to his poor physical condition. PK had relatively easy access to the daily ART centre. He was diagnosed with TB a few months after starting ART, because of which he was unable to collect his monthly ARVs. The outreach workers from TCC helped him register for DOTS in a nearby PHC and informed the ART centre regarding PK’s TB status.

Differences in patients’ pathways highlight the role of resource inputs in local health systems. However, it is important to consider the socio-political context of the two programmes in order to better understand how resource inputs are mobilised by different actors.

The wider context: programme ownership and the role of the State, NGOs and PLHIV networks

State-level leadership, ownership and action

In Andhra Pradesh, SACS provided strong and dynamic leadership to the HIV programme, and was supported by the Chief Minister of the State. The SACS programme manager was lauded in public awareness campaigns for her leadership and political will to address challenges of ART delivery.

In contrast, State-level leadership in Maharashtra was perceived to be weak, almost invisible during ART roll-out. Districts in the State were arbitrarily divided between the SACS and an internationally funded agency, ACTION-HIV (pseudonym) for programme prioritisation and implementation. Lack of a unified line of command for HIV programme activities affected the ART programme; there was little sense of district ownership of the programme in Ajaynagar. HIV prevention activities were coordinated by ACTION-HIV, while ART roll-out was SACS’s responsibility. ACTION-HIV had good working relationship with NGOs, but not with public sector programme, while SACS failed to provide leadership to the ART programme and in developing partnerships with NGOs. The comments of the director of an NGO involved in HIV prevention,
Table 2. Table showing comparative ART scenario at *Ajaynagar* and *Vijaynagar* in 2005 and 2009.

| Sr. No. | ART roll-out scenario | Ajaynagar | Vijaynagar |
|---------|------------------------|------------|------------|
| 1       | ART centre             | Located in the general outpatient department (OPD) of the district hospital | NGO built new hall for the ART centre on the premises of the district hospital | Located in a single room of the Department of Medicine in the district hospital | Public sector authorities accommodated the ART centre in the newly constructed building of the general hospital |
| 2       | Adult PLHIV on ART (approximately) | 1000 | 6000 | 1100 | 5000 |
| 3       | ART OPD                | Once a week ART OPD | Every day OPD | Every day OPD | Every day OPD |
| 4       | ART centre coverage    | Six to eight neighbouring districts | Only Ajaynagar district | Eleven districts throughout the State | Four to five neighbouring districts |
| 5       | ART centre cabins/rooms | Temporary table arrangement shared with the hospital OPD | Work of creating separate cabins (rooms) for counsellors, medical officers was underway | Room arrangement shared with the Department of Medicine staff | ART centre now well equipped with necessary cabins/rooms for counsellors, medical officer, data entry operator, etc. |
| 6       | HIV testing kits       | Second and third kits for confirmation of HIV-positive status not available | Second and third kits for confirmation of HIV-positive status still not available | All essential HIV testing kits available | All essential HIV testing kits available |
| 7       | CD4 count machine      | Non-functional due to the absence of technician | Functional | Functional | Functional |
| 8       | ART centre staff       | Post of senior medical officer (SMO) vacant | All required and recommended staff in place | Medical officer had been delegated the responsibility of SMO and the rest of the staff was in position | All the required staff except SMO and medical officers were in place |
| 9       | ART counsellor         | Not present | Present | Present | Present |
| 10      | Trained CD4 machine technician | Unavailable | Available | Available | Available |
| 11      | Treatment care and counselling (TCC) project | Not functional | TCC project under-staffed, struggling to function properly | TCC project well functional | TCC project well functional |
| 12      | Link ART centre        | Not applicable | Programme was in the pipeline | Not applicable | Programme was in the pipeline |
| 13      | Paediatric ART programme | Not applicable | Programme was in place | Not applicable | Programme was in place |
| 14      | Clinton foundation paediatric initiative to support nutritional needs and transport costs of children living with HIV | Not applicable | Programme was in place, but supposed to end in April 2009; no plans reported for sustaining the programme | Not applicable | Programme was in place, plans to merge this initiative with the ongoing programme of Balasahyoga* |

*Balasahyoga is project in Andhra Pradesh that translates as “active support to the child”, that aims to improve the quality of life of children infected and affected by HIV/AIDS and their families by expanding the coverage of comprehensive HIV/AIDS care, support and treatment services in all the 23 districts of Andhra Pradesh.
treatment and advocacy activities in Ajaynagar are revealing:

We really could have had a better system ... I think what happens with a vertical programme is it comes from above not from the local community of doctors or system establishment ... they got the guidelines from the top you know, but they had no ideas as to how to do this properly and then when they had ideas nobody was willing to listen to them.

(Director, NGO, Ajaynagar)

District-level response

The District Collector of Vijaynagar played a key role in paving the district health management system’s readiness and response to launch the ART programme. The Department of Health and other social development departments were held accountable through regular monitoring for generating awareness on HIV prevention and treatment programmes. Social mobilisation campaigns undertaken by ACCESS (pseudonym) project on STD/HIV prevention around the launch of ART programme were strongly endorsed by the Collector. Further, elected representatives and religious leaders from Vijaynagar were sensitised regarding HIV prevention and treatment programmes by bringing them together to address mass awareness campaigns and public meetings held throughout Vijaynagar. The district-level PLHIV network, CBOs and other local NGOs were involved in advocacy and social mobilisation campaigns from the launch of the programme and later lobbied for access to ART.

On the other hand, the district administration’s efforts to mobilise the district health management in Ajaynagar were sporadic and patchy, failing to generate accountability towards the programme. HIV awareness campaigns were in fact, arranged by NGOs with minimal engagement of public sector district health administration. NGO campaigns held prior to the launch of ART programme were supported by ACTION-HIV; however, their reach remained restricted to the organising NGOs’ operational areas. In part, this is due to the failure of State-level administration to ensure consistent “control” over the district health management team and its programme activities. As a result, NGOs and PLHIV networks became actively involved during implementation and played an important role in guiding PLHIV to the programme and in supporting programme staff.

The current scenario in 2009

By January 2009, ART provision had rapidly expanded and ART centres had been established in almost all districts of both States. There were 37 functional ART centres in Maharashtra and 28 in Andhra Pradesh (NACO, 2009).

Over a period of three years, the physical infrastructure of ART centres in both sites had changed drastically (Table 2). The centre in Vijaynagar had been accommodated in a newly constructed building. In Ajaynagar, a local NGO had helped construct an outpatient hall for the ART centre:

The ART centre did not have ... any kind of infrastructural support ... there were floods in Ajaynagar and they were treating or giving ARVs in the Ajaynagar civil hospital basement. It was so unhygienic ... so terrible and they were herding this community like sheep. We stepped in ... accessed funds. We built the ART centre for them ... (Director NGO, Ajaynagar)

A child-friendly corner, drinking water and toilet facilities were already in place in Vijaynagar, while these facilities were still non-existent in Ajaynagar. Although the recommended contractual staffs were present at both the sites, Vijaynagar had only one medical officer to take care of more than 5000 enrolled PLHIV. The centre had retained its reputation and popularity as one of the oldest hospitals and one of the first to start the ART programme.

The ART clinic in Ajaynagar was held on a daily basis as opposed to once-weekly in 2005, and staffing levels had improved. The patient load was manageable, as PLHIV from other districts were sent back to their native districts for follow-up.

In Vijaynagar, TCC continued to flourish with support of PLHIV network and had been allotted space within the ART centre. In Ajaynagar, TCC was struggling to find its roots, though on the whole, the centre’s ability to deliver ART services had improved, largely in response to the pressures of NGOs and PLHIV.

Director of one of the NGOs in Ajaynagar used the issue of non-availability of HIV testing kits at ART centres to explain how the pressure from PLHIV demanding better services had forced the government to provide better services:

I think now we can see a lot more government involvement and engagement ... in the initial stages we didn’t have kits for testing and NGOs would go on complaining “testing kit nahin hai ...!” (testing kits are not there) ... now when there are no testing kits, the PLHIV are standing out there and shouting and saying “kahan hai testing kit?” (where are the testing kits?) ... initially it was a vertical programme ... it was the interest (initiative) of the State, but now I think ... the response on the ground has forced the vertical programme to change ...
respond . . . to give better services . . . (Director NGO, Ajaynagar)

Discussion and conclusion

In this paper though we did not set out to conduct health systems analysis of the ART programmes in the two sites, the differences in availability and quality of infrastructure, equipment and trained staff prompted questions pertaining to health system preparedness to deploy resources for ART delivery. ART programmes in both sites were launched within a context of varying levels of political will and leadership, which can be traced partly to the States' autonomy in health systems governance in India (India Ministry of Health and Family Welfare [MOHFW], 2002). In Vijaynagar, the ART programme was built on foundations laid by community-level social mobilisation campaigns and district- and State-level interests and programme ownership. In contrast, the programme in Ajaynagar was initiated more tenuously through "islands" of NGO and PLHIV network initiatives in a sea of public sector indifference towards the programme.

However, the paper also points to how the functioning of an essentially vertical, compartmentalised programme is "co-opted", in both negative and positive ways, by other actors in the health system. In the profiles presented above, it is not only the presence or absence of counsellors and doctors within the ART centres, but also the links with family members, NGO workers, private specialists and private laboratory technicians outside of the centres that shape the HIV care-related trajectories of these patients. The limited insights gained from these stories point to the importance of future research on the "culture of service delivery" (Schneider et al., 2006) within ART centres in India as well as the informal and formal "working" relationships these centres have with private sector providers and organisations supporting PLHIV.

In the years following the launch of the programme, we saw that many of the initial operational problems faced had been resolved, while new challenges emerged with increasing patient loads (Table 2). This originally unintended "comparison" of two points in time raises questions about the "response time" required for the health system to absorb a new programme. Ajaynagar NGO director's comment "... the response on the ground . . . forced the vertical programme to change" suggests the importance of close attention to the ways in which ART programme in India – despite vertical implementation – is adapting guidelines and available resources to meet the context-specific needs and constraints of the many.

"... concurrent and interrelated HIV epidemics" across India (Steinbrook, 2007).

ART programme performance is influenced by the health system and socio-political environment within which these programmes are embedded; yet to date, there are limited number of studies applying a complex "systems thinking" to examine "performance" of HIV programmes (Atun, McKee, Drobiewski, & Coker, 2005; Schneider et al., 2006; Van Damme & Kegels, 2006). We hope to have contributed some modest insights in understanding the dynamics and future developments of the ART programme in Indian context.

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Notes

1. Maharashtra, Tamil Nadu, Karnataka, Manipur, Andhra Pradesh and Nagaland are the HIV high-prevalence States in which ART was started in eight hospitals.
2. At the start of the programme the operational guidelines for the ART centres were in the draft stage. These guidelines evolved over time and were changed so as to overcome some of the operational problems faced during implementation. They were first made available on the NACO website in March 2007.
3. The guidelines provided detailed eligibility criteria for setting up ART centre, including information on infrastructural requirements, equipment and staffing in addition to the processes for requisition and acceptance of ARV drugs.

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