

Prisoners with HIV/AIDS: A Participatory Learning and Action (PLA) initiative in Malaysia

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Summary

Rapid participatory research and project development is possible within a tightly controlled social context such as a prison. Having gained access, based on trust and mutual respect, external agents may then facilitate significant change. Given adequate support, incarcerated people with HIV/AIDS and limited medical access may be able to develop mutual-care, social support and income generating activities. In the Malaysian context, we estimated in 1998 that up to one quarter of prisoners with HIV had indicators of significant disease. We estimated that significant indicators remained unrevealed among between one half and two thirds of these. Given prevailing conditions, these would probably only be amenable to peer-based care.

Introduction

Detainees are explicitly deprived of certain rights, including by definition the right to freedom of movement. The apparent legitimacy of any form of detention depends to an extent upon local and international social norms, just legal processes, reasonable and appropriate enforcement and a consideration of extenuating individual circumstances. HIV/AIDS has challenged a range of situations prevalent in some custodial structures. UNAIDS has usefully highlighted many of these¹.

A primary question is that of prevention of the spread of HIV in detention. This is sometimes being tackled –

through video, educator and peer-based education². Some institutions have also experimented with tangible harm reduction measures³. Human rights issues such as segregation and compassionate release are also sometimes raised. However, little emphasis has been given to the issue of care for detained people with HIV/AIDS. There appears to be an implicit assumption in published literature, that care inside will be roughly equivalent to care outside. There are also some fascinating (if not globally replicable) prison hospice initiatives in North America⁴.

In 1998 in Malaysian prisons and government drug centres (Pusat Serenti), inmates who were known to have HIV tended to be put together in separated quarters. (There was limited daytime mixing with those not known to have HIV.) The Prisons Department tended to relocate prisoners known to have HIV, to one of a handful of prisons around the country. However, each of the 29 Pusat Serenti housed its own detainees with known HIV.

In the Malaysian incarceration context, Choo has noted that, 'health and health care are seen as a "means" towards the achievement of institutional goals and functions, and health is not generally viewed as an end in itself.'⁵ In December 1997, knowledgeable clinicians estimated that they only regularly followed-up around 10% of Malaysians known to have HIV (unpublished observation⁶). Within the social context, it is not therefore surprising to note that hardly any incarcerated people with HIV in Malaysia received regular specialist medical appointments.

Bearing this in mind and building on observations and contacts made whilst engaged in religious ministries inside prisons and Pusat Serenti, we approached the Prisons Department with a view to enhancing the care of incarcerated people with HIV/AIDS. We chose a large-scale approach, with a minimal budget, utilising community development principles. We re-focused the concept of 'peer-support' in prison communities onto the care, social and structural issues; not just on education.

Methods

We chose to use a participatory assessment process rather than more formal interviews and surveys. We modified a

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- 1 Prison and AIDS. *Best Practice Collection Point Of View*. Internet: UNAIDS, April 1997, <http://www.unaids.org>
 - 2 HIV/AIDS Education and Prevention Programs For Adults in Prisons and Jails and Juveniles in Confinement Facilities – United States, 1994. *Morbidity and Mortality Weekly Report* 1996;**45**.
 - 3 Nelles J, Fuhrer A, Hirsbrunner HP, Harding TW. Provision of syringes: the cutting edge of harm reduction in prison? *British Medical Journal* 1998; **317**:270-273.
 - 4 Internet: National Prison Hospice Association, April 1997, <http://www.npha.org>
 - 5 Choo KK. Health and Health Care in Correctional Institutions in Malaysia: Implications for a Relevant Behavioural Model. In: Haliza MR, Pataki-Schweizer KJ, eds. *Behavioural Models in Medico-Health Research and Health Intervention*. Kuala Lumpur: Institute for Medical Research/WHO, 1998:81-98.
 - 6 During a consultation between the Ministry of Health, Malaysian AIDS Council affiliates and AIDS specialist clinicians – 6 December 1997 – Marriott Hotel, Kuala Lumpur.

set of tools called Participatory Learning and Action (PLA)⁷. MacRorie⁸ has described the use of a similar approach – the Rapid Participatory Appraisal – in health project development and has outlined some of its benefits.

Three prisons were chosen from an initial Prisons Department list of eight, in which to evolve the modified appraisal process. Nine PLA tools were then chosen, modified or devised for use in the first prison. This was cut to seven PLA tools for the second and larger prison group. The PLA was refined to its final form in the third and largest prison group.

Each PLA was carried out in two phases over separate half days. The first phase was a rapid needs assessment using the PLA tools. PLA tools ultimately used were: an *institutional timeline*; *needs mapping*; *general problem ranking*; *authority analysis*; *daily profile*; *resource mapping* and *medical problem ranking*. A *personal time line* was used in one prison and remained an option where time permitted. If the group did not spontaneously highlight informal forms of mutual support, we ultimately introduced it as our agenda. (This was virtually a condition for our prison access.)

The second phase facilitated the group to conceive relevant project proposals. Considering a review of the first phase results, prisoners brainstormed possible projects. Ideas were then discussed by the group. Each idea was scored (from 0-3) on three parameters: amount of peer-control, amount of needs met and likely freedom to implement. These ideas were prioritised by adding and/or multiplying the three scores. Intuitive discussion was next used to modify the priority scores if the group wanted. Finally, a core of prime proposals for presentation to prison officials through the facilitators was agreed. Dissemination of the content of the appraisal and project development process was expected, by attendees amongst their colleagues.

Results

Getting from the initial project conception to its start took 16 months. The PLA process evolved over the four weeks during which PLA sessions were conducted.

Prison A

This group was composed of all eight female prisoners known to be HIV+ in the Malaysian Peninsula's central region. All had been in this unit for less than 18 months.

Medical needs were ranked highest by this group and allocated a relative weight of 1.0. A need for more social activities was ranked second with a relative weight of 0.4. Access to broadcast media was third with a relative weight of 0.2. Dietary, emotional, religious and personal hygiene needs were all accorded a 0.1 weighting.

Medical symptoms recalled within their mutual prison experience suggested quite a range of HIV-related and gynaecological illness. One prison colleague had died within the 18 months of their communal history. No prisoners had regular specialist medical appointments.

The group's principal project proposals were: a mutually tutored arts and crafts activity club, an emotional support group and peer-based symptomatic care.

Prison B

This prison was responsible for 56 men with known HIV infection. Ten were selected for phase one of the PLA, with an additional two joining the group for phase two the following day. All of the initial ten attendees except one, were transferred into this prison en masse within the previous six months. Prisoners were accommodated in large dorms with up to 25 people. Dorms were locked for around 13 hours per day in addition to musters. Certain social activities were sometimes possible in the dorms after lock-up. Prisoner/authority dialogue occurred occasionally through mutually acceptable prisoner representatives.

Dietary and medical needs took equal, highest priority, with a relative weight of 1.0. Welfare needs were ranked third with a relative weight of 0.8. Cleanliness (including toiletries and water supply) was ranked fourth with a relative weight of 0.5.

Medical symptoms/signs recalled within their community also suggested major as well as minor signs of AIDS. The three commonest problems – rashes, open sores and lymphadenopathy – did not overlap with the three most worrying ones – fever, diarrhoea and constitutional signs. No prisoners were then in hospital. The group felt that a minimum of 20 prisoners had significant current symptomatology (around one third). Five prisoners had regular specialist appointments.

In order of preference, project proposals were: peer-based symptomatic care, growing vegetables for nutrition and small-scale income generating for hygiene essentials.

Prison C

This prison had responsibility for 363 men known to have HIV. Phase one of the PLA was repeated on three consecutive mornings for three separate groups of 10 prisoners. Prisoners were chosen by sympathetic, co-operative, front-line staff, using our guidelines to represent certain sub-sections of the community including the more marginalised. Phase two of the PLA brought 28 of the former attendees together with 2 new nominees.

7 Jayakaran RI. *Participatory Learning and Action (PLA) User Guide and Manual*. World Vision of India.

8 MacRorie RA. Births, deaths and medical emergencies in the district: a rapid participatory appraisal in Nepal. *Tropical Doctor* 1998;**28**:162-165.

Previous results were shared among the three groups and needs prioritised before moving on to the project development section.

Of the original 30 attendees, 27 had been in this unit for less than 18 months this time around. Cells generally housed up to eight prisoners and were locked up for at least 16 hours a day in addition to the musters.

Dietary needs were ranked highest with a relative weight of 1.0. Over-confinement was the second priority, weighted 0.9. Medical needs came third with a weight of 0.7. Water supply was fourth, weighted 0.5. Toiletries (fifth) were weighted 0.2 and insufficient activities ranked sixth, with a relative weight of 0.1.

Medical symptoms recognised within their mutual experience suggested some major as well as minor indicators of AIDS. Three of the five commonest symptoms were also rated three of the five most worrying symptoms: fever, diarrhoea, constitutional signs. Of the 363 prisoners accounted for with known HIV, 2 were in a local hospital, 2 were in the official prison sick bay, 8 were in an unofficial cell block sick room and 22 were in unofficial cell block Tuberculosis treatment rooms. In other words, 9% had a current, revealed medical problem. Triangulating using several different estimation techniques, the group concluded that approximately 60 more prisoners (~15%) were not revealing significant symptoms. In total, around a quarter of the prisoners with HIV probably had symptomatic HIV-disease. No prisoner was known to have regular, medical specialist appointments.

The groups project proposals in order of preference were: peer-based symptomatic care, small scale income generation to buy hygiene essentials and supplementary food, regular prisoner/authority dialogue, in-prison drug rehabilitation and finally, access to a vocational workshop.

Discussion

Participatory development concepts are well outlined by Burkey⁹. Referring to rural communities, he suggests that these are best achieved utilising certain principles that I have paraphrased and commented on:

i) *Social transformation as a primary goal.* This can appear very threatening to prison authorities and prevent access for 'change agents' if it is over-emphasised. We hoped however, that certain skills would be taken out into the non-prison environment for mutual support of those – particularly drug users – who returned to marginalised lifestyles. We also hoped

to boost the low sense of autonomy and self-respect we generally find amongst Malaysian drug users.

- ii) *Highly homogeneous groups.* Separated HIV+ prisoners in Malaysia generally have a more homogeneous background than the general prison population – having predominantly drug-related backgrounds – and appear to make a viable, mutually identifying group. However, within the prison, there is a mesh of seen and unseen authority. It may be almost impossible for an external 'change agent' to take account of all these networks. It may affect willingness to participate or it may generate 'acceptable' (but not real) emphases within group discussions. We noted a number of occurrences and probably missed some hidden ones.
- iii) *Strong and early group self-reliance.* Since we only have occasional access to work with the prisoners, they need to be self-reliant from very early on.
- iv) *Long-term, unpredictable processes.* The prisoners we worked with had a high turnover rate. They used an extremely restricted space, had a tightly controlled timetable and rigid authority structures. Also, external access was limited in time, extent and confidentiality. It became necessary to operate an extremely compressed participatory process, with a number of predictable elements and externally imposed boundaries. It still appears worthwhile to us.
- v) *External 'change agents'.* This appears to be the only way to initiate programmes in otherwise exceptionally controlled social environments.
- vi) *Research and action rooted in community participation.* Participatory research (PLA) has been fundamental to building rapport, trust and motivation. Prison life otherwise normally dictates that initiative be suppressed and prisoners are often afraid to do more than merely follow orders.
- vii) *Conscientisation.* We forewarned the groups that the process might suggest viable projects that were not allowed, in addition to unfeasible ones. (Ultimately prisoners have only been permitted to develop symptom based peer-care initiatives.) Raising unrealistic expectations was a risk we fended off from the beginning – utilising PLA tools that enabled the group to examine their operational boundaries in a realistic way. Conscientisation is bound to occur during the process. The benefits include the possibility that lessons will be applied, outside of the prison in the future, by attendees. Risks include prisoners using the awareness and organisational skills gained, to disrupt prison life. There may also be frequent requests, particularly early in the process, for representative advocacy.

⁹ Burkey S. *People First: A Guide to Self-Reliant Participatory Rural Development.* London: Zed Books Ltd, 1993.

viii) *Small scale groups*. PLA attendance for some appeared to be merely a highly diverting social opportunity. For some, it indicated an element of hierarchical prestige. It also seemed hard to mitigate against peer-pressure in eventual project development. But whilst it was not usually feasible to work with a whole prison population in the PLA process, it did seem appropriate to consider a whole HIV-infected prison population the beneficiary group. Project management was controlled by a semi-representative committee in the largest male prison.

ix) *Sustainable economic development activities*. Some of the groups were keen to improve their micro-economic circumstances, since health and social welfare were expected to follow. For the time being, the prison authorities have delayed agreement on new micro-economic initiatives, however.

x) *Independence and autonomy*. Autonomy was essential for the prisoners' groups; it appeared to be one of the only ways to maintain their motivation. It proved a challenge to explain to other external parties that the women's group did not want to be taught crafts by outside trainers. Rather, they wanted to learn each other's skills, facilitated merely by materials. (Their mutual support craft group proposal has initially been turned down.)

xi) *'Don't do anything for people that they can do for themselves.'* We would endorse this fully. Prisoners are already tightly controlled. We seek to introduce an element of freedom rather than just add another link to their chains.

Permission was limited to symptom based peer-care projects, even though these were not universally of highest priority in terms of need or group motivation. Only Prison C receives continuing input. A Community Health Worker now runs a training programme for volunteer peer-carers in this largest of male prisons. Over fifty peer care trainers have been trained in the year since late 1998¹⁰. Basic training in symptomatic support by a peer trainer is now a regular part of the induction process for HIV-infected prisoners newly transferred in.

In conclusion, given time, mutual respect and trust, it may not be unreasonable to attempt to use participatory appraisal and project development methods even in highly controlled, marginalised and disempowered communities. A degree of methodological compromise will probably be inevitable, however.

Prior presentation

A brief oral summary of this material was presented at a track session of the fifth International Congress on AIDS in Asia and the Pacific (ICAAP 5) in Kuala Lumpur, Malaysia, on 24 October 1999. The summary will be printed in the conference proceedings.

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Notes

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10 George C. (Oral presentation to a track session of the Fifth International Congress on AIDS in Asia and the Pacific ICAAP 5 – title to be decided for the forthcoming Proceedings *in press*.) Malaysia: Malaysian AIDS Council, 1999.