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Abstract

This study examines challenges to HIV-positive people's involvement in AIDS policy making and project design and implementation in Asia. Forty-eight interviews were conducted with key players in the HIV sector in Cambodia, India and Indonesia. The major barrier to involvement is AIDS-related stigma. Most people are diagnosed late in infection and have poor access to antiretroviral drugs. The majority of positive people working in HIV/AIDS have no training in public health or organisational management and few training opportunities are available. Respondents in all countries said NGOs exploit positive people in order to enhance funding opportunities. Representation on policy making bodies is low because the few people well enough to take on these roles often lack the confidence to assert their needs in front of doctors and government officials. Positive activists need advocacy skills to become more effective, encouragement and support to take on roles as educators and counsellors, sustainable incomes, and medication to stay alive. ***Asia Pac J Public Health 2007; 19(1): 8–13.***

***Keywords*: GIPA, HIV-positive people, people living with HIV, HIV/AIDS policy, involvement of people with HIV.**

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Challenges to the Meaningful Involvement of HIV-Positive People in the Response to HIV/AIDS in Cambodia, India and Indonesia

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Background

Many international agencies, governments and AIDS organisations recognise the vital role of people living with HIV (positive people) in response to the AIDS crisis: they confront societal myths about HIV and break down fear and stigma, they have important roles to play as educators and peer counsellors and can make important contributions to policy[1–4].

In 1994, leaders of 42 countries signed the Paris AIDS Summit Declaration, acknowledging the central role of positive people in the formulation and implementation of national and international policies and programs[5]. This commitment was later adopted by UNAIDS as the GIPA (Greater Involvement of People with HIV/AIDS) Principle[6]. UNAIDS developed an analytical framework aimed at refining the understanding of GIPA[7]. The GIPA pyramid describes involvement from a broad base (weak or no involvement; positive people are targets for HIV/AIDS interventions). Involvement increases progressively towards the apex of the pyramid where it reaches its zenith in the form of positive people as decision makers. Population Council / Horizons developed a similar framework for analysis as a result of research on GIPA in India, Burkina Faso, Ecuador and Zambia[8,9]. The Population Council / Horizons model demonstrates advantages and disadvantages at each level of involvement and maps the wide range of areas of involvement, from using, supporting and delivering services, to designing services, and at the peak of involvement, management, policy development and strategic planning. They describe greater involvement as characterised by high visibility and considerable decision-making power and autonomy. In 2001, the United Nations General Assembly on AIDS reaffirmed commitment to GIPA and acknowledged that GIPA was a priority for a successful response to AIDS.

The GIPA Principle is important for several reasons. Publicly acknowledged involvement (that is people who are open about being HIV-positive) helps to overcome fear and prejudice and reduce stigma and discrimination. Furthermore, positive people bring the unique perspective

of their experience to organisations working in AIDS policy development and perform valuable support functions as health workers and AIDS educators[6].

Currently there appears to be a lack of commitment to pro-actively involving and integrating positive people in the development of national HIV/AIDS policies and programmes. Of the few positive activists who become involved in the AIDS sector, although many describe benefits to their health because of their involvement, many also feel exploited by their role[8,9]. Literature is sparse on the role of positive people in the global response, particularly at the policy-making level, and the support required from government, organisations and agencies to sustain optimal involvement. People with HIV are variously portrayed as either the subjects of prevention, patients in need of care and support, or members of vulnerable groups and communities, and therefore objects of discrimination and human rights violations. There is little understanding of how positive people can influence HIV/AIDS policies and programmes or wider health agendas and how the new forms of knowledge and expertise possessed by positive people can be properly utilised and integrated. The World Health Organization's "3 x 5" Initiative, which committed to ensuring three million positive people received antiretroviral medicine (ARVs) by the end of 2005, increased the momentum of the entry of GIPA into the international and national HIV/AIDS agenda, and exerted more than moral pressure on NGOs and governments to take positive involvement seriously. Increasingly, international donor agencies require a demonstrated commitment to involving positive people. While there may be a level of international policy commitment to GIPA, the rationale underlying it has rarely been grasped by key figures with the responsibility to implement it. There is little comprehension of the complex work of developing and sustaining organisations whose members face the uncertainty of HIV, and who have to cope with the challenges of a shifting membership as people become sick or burnt out[10].

This study investigates the challenges to GIPA in HIV/AIDS design and implementation of policy and programmes in three Asian countries. Both authors of this paper are HIV-positive. This is an example of the increasing opportunities available to positive people in the developed world to turn the experience of living with the virus into meaningful involvement. However, as we argue throughout this paper, the opportunities available to people elsewhere remain limited.

Methods

The aim of the study was to examine the nature and extent of positive people's involvement in the AIDS response and the range of parameters, including cultural contexts, which impact on their involvement.

Forty-eight semi-structured interviews were conducted with targeted key informants from three countries (Cambodia 18, India 14, Indonesia: 16). The key criteria for selection of interview respondents was that they were in positions of moderate to high-level decision making at state or national level. A cross section of informants was selected from state and national positive people's networks, AIDS organisations/agencies and government officers involved in HIV/AIDS policy and planning.

Interviewees represent 12 positive people's organisations, national and state (21 interviews); 12 peak non-government organisations (17 interviews); six government officers (from state &/or national AIDS councils); three UN staff. Almost half of the sample (21 respondents) was HIV-positive. Interviewees have been involved in the HIV/AIDS field from one to 13 years. The interview guide focussed on:

- examining the level of involvement of positive people optimally in the national AIDS response in each country;
- examining the challenges to implementing the GIPA Principle and any barriers to utilising positive people optimally in the response;
- examining how AIDS-related stigma impacts on the involve-ment of positive people in HIV/AIDS programs;
- assessing necessary mechanisms to sustain positive people's involvement and minimise any negative impact on the health and well being of positive activists.

Baseline interviews (13 in each country) were conducted in India and Indonesia in April 2002, and in Cambodia in May 2003. Second round interviews (with different respondents) were conducted from May 2003 to May 2005. Interviews were audiotaped and transcribed, then analysed using standard thematic analysis.

Results

There is consensus among respondents that there is a dearth of confident, articulate and skilled positive people to take on positions of responsibility, due to a range of diverse factors.

Stigma and Discrimination

In all countries, respondents said the greatest barrier to GIPA is the stigma of being identified as positive. In India and Indonesia, respondents said people have been driven out of their villages; such incidents make people afraid to come out. In Cambodia, the only country with specific HIV anti-discrimination legislation and the highest HIV prevalence in Asia, respondents said discrimination is decreasing but stigma and shame prevail. Concern about destroying the family reputation is strong motivation for people to carefully guard the secret of their diagnosis.

"Who is going to come out if you are not getting any security from that? The barriers in coming out are the security issues. Also, being an em-

barrassment to the family. Shame on a deep level."

(NGO Officer, Indonesia)

Medical Support

Another critical challenge to involvement is that many people are diagnosed late, when they have AIDS-defining illness. Despite increased access to ARVs globally over the past three years, they are available to a limited number of people, in major centres, and knowledge about their use is still low. Quality treatment and care are in short supply in most regions and hospice and palliative care is almost unavailable. People often travel vast distances to receive treatment. In reality, free medical care remains extremely limited throughout most of Asia, and often there is no choice of ARV regimes. Government hospitals offering free services usually come at a price (such as payments to a head nurse or watchman).

"Some PLHA get their medicine from the nurse and they just tell them, 'Just take this and this'. They don't tell them that this medicine is to treat fever or TB. They don't know what it is for. So training positive people is good. They do not know much about the technical aspects but if we train them in treatment, I feel they can teach their friends to take it properly."
(HIV-Positive Employee, Cambodia)

Lack of Counselling

The lack of accessible, quality, confidential counselling was cited by many respondents as a serious problem. Counselling is often directive and of poor quality. Several respondents said positive people need ongoing support to disclose their status to their families before considering becoming involved in advocacy. Indian women face particular difficulties and restrictions from families[11], and counselling can help dispel negative responses.

"We need a care centre with voluntary counselling where people can come and get counselling and information… For people living with HIV to come out, support is very necessary, organisational support, family support, social support, and sometimes they are missing. If I come out, what am I going to get? Nothing. This scares people."

(Positive Volunteer, State Network, India)

In Indonesia, one positive activist introduced a peer support group into a Balinese jail, and after much advocacy work established voluntary counselling and testing there. This is a rare model of positive involvement in policy making. Some respondents said positive people make "extraordinarily good" counsellors. They have greater sensitivity to their clients' needs because they understand the experience of living with HIV. The Karnataka state government in India has agreed to employ a positive woman as a peer counsellor in each district as a result of advocacy by the national positive women's network. Many respondents said there is a real and urgent need to train more positive people as counsellors and for governments to actively promote their employment within the health sector.

"If the people living with HIV have the capacity to do counselling it will be great. Who will know more about it than people living with HIV? It encourages people to live."

(NGO Officer, Cambodia)

"They really understand. They have empathy. And that's very important. Even if we haven't met before, I will introduce myself as positive and they will be open."
(HIV-Positive Counsellor, Indonesia)

Financial Survival

Respondents in all countries discussed problems of financially sustaining themselves once they become involved in the HIV/AIDS sector. Most positive people begin as volunteers, and financial survival remains difficult. Because of the high incidence of widows and single parents, particularly in India and Cambodia, income generation and financial sustainability remain major priorities and the issue is rarely addressed.

"There are many, many NGOs working on HIV and AIDS in Cambodia, but there is no opportunity for PLHA to have a job in these NGOs. They think the positive people are very uneducated people and they think PLHA are stupid, very bad people… They don't want to listen to what we are talking about."
(HIV-Positive Employee, Cambodia)

Lack of Skills Training

Positive leaders, particularly people involved in policy making, may not have the confidence or skills to sustain positions of responsibility, or may get overburdened. Many are thrust into positions without training and with little regard for the technical support they need to contribute effectively. Building self-esteem and confidence is a high priority. Positive advocates also need basic information about HIV and treatments.

In all countries, most activists learn in the field. Many now want skills in counselling, organisational development, public speaking and advocacy. Some respondents said non-government organisations (NGOs) dictate the training they offer. Positive respondents said that over the past few years, awareness of their rights has increased, but not necessarily their ability to negotiate and advocate for them.

Tokenism and Exploitation of Positive People by NGOs

Although it was acknowledged that there are many supportive NGOs in each of the study countries, a common theme across the region was exploitation of positive people to enhance organisations' funding opportunities. Many respondents said that many people are unable to conceive the real value of involving positive people. They are used in tokenistic ways and "exhibited as showpieces" to indicate NGO compliance with donor expectations of involvement. Respondents in every country talked of NGO "ownership" and "control" of

positive people; they are assets to affirm NGOs' credibility. Several respondents said many NGOs utilise positive people as speakers for events, limiting them to telling their personal story. In return, the NGO provides medical or other services, so some people feel beholden to the organisation. They are expected to perform this role even if at times they feel uncomfortable doing so.

Several respondents discussed suspicions about the sincerity of some NGOs to involving them at the policy level. Indian and Cambodian respondents said some NGOs without public health backgrounds moved their interest from unrelated fields to HIV because of available funding. In India, some AIDS organisations are compelled under the state policy to employ a positive person; however, these positions are usually low-paid and the "partnership" is unbalanced.

"Volunteers are free labour. They basically have no right, no voice… Depending on the NGO, they are encouraged to do public speaking without any training, often testimonial-type. With some NGOs, they are pretty much coerced into doing that. Most of the time the organisation is almost ignoring them, just providing them with services and therefore retaining them."

(Programme Manager, Positive People's Organisation, Indonesia)

Some respondents said they believed some NGOs feel threatened by a partnership with positive people, fearing their funding base will decrease, so they actively avoid employing positive people or giving them the power to influence decisions.

Constraints of Government

Many positive respondents feel their government does not listen to them and has no clear understanding of how to involve them effectively. Several talked of their inability to influence government priorities, or shape the government agenda on HIV. As an example, an Indian respondent recounted how state government officials saw involvement as a means to help meet policy and programme goals which were not developed in consultation with positive people and did not address the needs identified by the positive community.

"We had government organisations asking people living with HIV in one state to do work with prevention with tourists when they said that what they actually want is a drop-in counselling centre. They want people living with HIV to be part of their agenda rather than be able to do what they can do and they are more comfortable to do."

(Programme Manager, Positive People's Organisation, India)

Respondents in each country said their government has not demonstrated a keen commitment to GIPA. While national level anti-discrimination legislation may exist (e.g. Cambodia), there are no written policies in place to implement GIPA in any of the study countries. Measures to reduce stigma and discrimination, including legislation are very important, however, the practical application of GIPA requires detailed policy guidance, funding and support that stimulate involvement and detail the steps required to implement and sustain it.

The peak national AIDS committees have an appointed position available for one positive person. Some positive people are placed on high-level committees, such as the Country Coordinating Mechanisms of Global Fund applications, with no concept of training them towards meaningful involvement. They are not able to be active decision-makers. Several respondents said it takes a lot of confidence and capacity building before positive people can be active on committees. Some argued for more designated positions on high-level committees so positive people can share the load and have greater opportunities to make their needs heard; this view is not necessarily shared by government.

"If the person living with HIV is just one person sitting and trying to bring out the issues with these high level people, it's very difficult unless a person is talking very much. That is why we need at least two or three positive people. At least they can pull together and then they can put forward their problem."

(NGO Worker, India)

In some instances, positive people are hand-picked to sit on particular committees because they are unassertive, keep quiet throughout meetings and agree to majority decisions without having any impact. One Indian activist said the government does not want people who express ideas that might be critical of government policy. Indonesian respondents said awareness of the importance of GIPA at the national level is growing but their problem is trying to find enough skilled positive people to take on positions. The national network is attempting to address this in a number of ways, including conducting strengthening visits to provinces to increase involvement at the local level, and by mentoring positive people as program managers.

Benefits of Involving People with HIV in the Response to AIDS

Most respondents concur that there are great benefits of involving positive people in AIDS programmes, particularly as AIDS educators, counsellors, advocates and policy makers, because they are the people who know what programmatic and policy approaches have worked for them, and as importantly what has failed them.

Several respondents discussed the invaluable role of HIV-positive people as AIDS educators, particularly to health workers and to young people in schools and colleges. Many said that seeing what positive people look like helps to break down stereotypes, reduce fear and stigma and create a positive image.

Many deem that more effective prevention and more sensitive care programmes can be developed, programmes that cater to the community's

needs, if positive people are involved in the decision-making.

Some respondents, both HIV-positive and others, discussed the importance of utilising positive people as role models. Commonly, government and media portray people as dying but positive people's networks promote people as living healthily and productively, and thus reach out to other positive people and inspire them to become more involved.

"People with HIV have personal experiences very different from the rest of us that enrich the team."

(NGO Officer, Indonesia)

"Doctors here are the toughest people to work with because they have been believed as a god or goddess in the country. Changing them is the biggest challenge in the whole of the HIV/AIDS field."

(Doctor, India)

"Positive people can become the linkage that we need to develop between the patient, the authorities and the health profession… They can be good agents of conveying messages. They are also much better peer educators because they speak of their experience."

(Government officer, India)

Discussion

The Horizons study[8] identified several similar limiting factors to involvement of positive people including: fear of stigma and discrimination; poor health; lack of access to treatment, care and counselling; poverty; lack of skills training; and lack of confidence about one's ability to become involved. Roy and Cain[3] studied the involvement of positive people in the response in Canada and found similar constraints, including fear of disclosure, tokenism, negative attitudes to employing positive people, health concerns, excessive demands placed on people's time and energy, and value defined almost exclusively in terms of formal education or professional work experience. Findings presented here provide further evidence that many of these individual, institutional and social factors challenge positive people's involvement in policy-making throughout Asia. Fear of stigma and discrimination critically prevents positive people from advocating for their needs[12]. The significance of stigma in the lives of positive people is central to effectively engaging with the public health response to AIDS.

The intensely personal experience of living with HIV provides the deeper basis for the expertise people bring to involvement. Recognition of experience-based expertise has yet, in the case of positive people, to move beyond the limited scope reported here. Lack of support for involvement is indicative of the continuing marginalisation of positive people, and as importantly, represents a missed opportunity to strengthen the wider public health response to the epidemic.

Recommendations

Positive people's meaningful involvement requires that NGOs, national HIV/AIDS programmes and the international donor community rethink the role of positive people in the HIV/AIDS prevention and care continuum. Establishing and sustaining meaningful involvement is contingent on a number of interlinked factors. Access to life saving ARVs is the fundamental priority. Positive people also need to be trained in their appropriate use. Peers, rather than doctors, may be best equipped to carry out this education[13]. Increased HIV testing will accompany increased ARV access and psychological support for those newly diagnosed is necessary. Support for peer counselling programmes is an urgent priority as evidence suggests that positive people may be more effective than non-positive counsellors. This is especially important with regard to the low level of skills and directive nature of the counselling reported in this study.

HIV-positive people in Asia also require support to develop and build a range of basic skills. There is need for targeted skills to enhance the expertise of positive people, including skills in negotiation of rights, policy making, as well as organisational and financial management. A mentoring approach to involving new activists is an important model that can be used to encourage meaningful involvement.

Women living with HIV face significantly greater levels of AIDS-related discrimination than do men[11] but they are also more likely to have greater impact in changing people's attitudes[2]. Particular focus is therefore needed in supporting and sustaining networks of positive women and increasing their opportunities for involvement. NGOs and government agencies can support autonomous groups to develop teams of positive public educators, peer treatments' educators and counsellors, with sustainable incomes.

If these measures are seen as integral components of the response to HIV/AIDS, they will help to increase meaningful involvement. The GIPA Principle suggests an agenda of empowerment through recognising and supporting the voices of positive people in decisions that most affect them. We recognise that a fuller implementation of GIPA requires the dismantling of structural barriers that affect policy and programme participation in a broad underlying sense. While it was not the purpose of this research to analyse these factors, many, including poverty, marginalisation due to sexual identity, lifestyle (for example injection drug use), and resistance by health professionals and managers, require a long term approach. Nevertheless, the evidence of the importance of GIPA is beginning to mount, if it continues to be ignored the danger of the current approach is the slide towards tokenism.

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