Network of communities in the fight against AIDS: local actions to address health inequities and promote health in Rio de Janeiro, Brazil
Kátia Edmundo, Wanda Guimarães, Maria do Socorro Vasconcelos, Ana Paula Baptista and Daniel Becker
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sharing tools to judge a programme’s performance. In particular, there is a desire to create a theoretical framework, based on practical application, to specifically assist local programmes. Other demands were to define, choose and sustain initiatives in a complicated context. At last, and on several occasions, there has been a demand to dispose of research information that allows for distinguishing between what and why. The idea is to avoid the black box syndrome which makes changes in structural elements appear in diverse results, making it impossible to link cause and effect. Without a clear control of this link, it becomes hard to generalise an experience in a single community, and even harder to understand and translate it to another one.

For this special issue, we have selected Katia Edmund and her Brazilian colleagues’ article which describes a programme in a disadvantaged setting. Other presentations were made on this theme, but her article underlines the importance of cultural factors when implementing programmes.

Kátia Edmundo, Wanda Guimarães, Maria do Socorro Vasconcelos, Ana Paula Baptista and Daniel Becker

Network of communities in the fight against AIDS: local actions to address health inequities and promote health in Rio de Janeiro, Brazil

Abstract: When combined with major social inequities, the AIDS epidemic in Brazil becomes much more complex and requires effective and participatory community-based interventions. This article describes the experience of a civil society organisation, the Centre for Health Promotion (CEDAPS), in the slum communities (favelas) of Rio de Janeiro, Brazil. Using a community-based participatory approach, 55 community organisations were mobilised to develop local actions to address the increasing social vulnerability to HIV/AIDS of people living in squatter communities. This was done through on-going prevention initiatives based on the local culture and developed by a Network of Communities. The community movement has created a sense of “ownership” of social actions. The fight against AIDS has been a mobilising factor in engaging and organising communities and has contributed to raising awareness of health rights. Local actions included targeting the determinants of local vulnerability, as suggested by health promotion workers.

A pandemic, AIDS substantially decreases the life expectancy of generations of people in many socio-political contexts. In Brazil, the connection between AIDS and poverty becomes even more complex when associated with the inequities that characterise Brazilian society and involves complex issues such as sexuality, gender inequity, drugs, and violence (Parker & Camargo, 2000). Given the multidimensional and synergistic nature of this epidemic, the involvement of all sectors of society is required in the fight against AIDS (Singer, 1994).

AIDS first reached Brazil in the early 1980s. The first individuals affected had access to the media, causing immediate repercussions and guaranteeing social outreach. In some ways, this contributed to forming a social movement to fight AIDS based essentially on the ability of organised civil society to develop effective answers (Galvão, 2000). The Brazilian response to this epidemic, which was to provide universal access to antiretroviral drugs, has been successful in improving the quality of life of those living with AIDS in Brazil.

The spread of AIDS in impoverished communities, however, presents continuous challenges to assistance and prevention interventions that must involve groups and low-income communities in the fight against AIDS. Until now, urgent social problems have been placed at the top of the list of community struggles and AIDS has been a second priority. The community intervention experience described in this article, however, indicates that AIDS is becoming a concern for low-income communities, as shown by the increase in the number of community-based organisations involved in the fight against AIDS in Rio de Janeiro.

In Rio de Janeiro, impoverished populations totalling more than one million people live in slums or squatter communities (favelas) and on the outskirts of the city. These areas are characterised by a lack of social policies

Keywords
- AIDS prevention
- equity
- poverty
- empowerment
- community capacity building
and the presence of the oppressive, controlling forces of drug traffickers. There are also historic factors that contribute to creating community environments prone to the development of illnesses, including AIDS. In the case of the AIDS epidemic, the term “vulnerability” (Ayres, 2002) has been used to describe an array of social, political, physical, religious, emotional, and cultural aspects interacting with the concepts of health, illness, and exposure.

The relationship between vulnerability to HIV infection and social inequity has been consistently and frequently observed (Bastos & Swarcwald, 2001), reinforcing the importance of interventions based on the direct participation of the groups and communities involved. In order to tackle social vulnerability, it is essential to develop individual and collective empowerment processes (Vasconcelos, 2000) that provide greater autonomy and awareness of rights to stakeholders.

The work of the Centre for Health Promotion (CEDAPS), a civil society organisation active in Rio de Janeiro, is part of an effort to involve low-income communities in the process of developing social answers based on local culture. The aim of this article is to demonstrate the feasibility and effectiveness of placing AIDS issues on the agendas of popular social movements by emphasising the involvement of community leadership in the daily struggle against this epidemic (Edmundo, 2003).

**Intervention method**

The approach to AIDS prevention implemented by CEDAPS in low-income communities is based on participatory methodologies developed from the needs and demands presented by the communities. In 1996, an institutional programme known as COMUNICSE—Community Consulting Services in Health and Education—was created and has since become a technical reference for consultation and support for the community prevention efforts conducted in and by the communities. The number of communities involved in the project has increased from six in 1996 to 55 in 2004. Each of the participating community health leadership groups went through a capacity-building process, followed by an assistance phase to develop local actions based on two complementary axes: the creation of prevention centres and the implementation of local action plans designed by the community health leadership group.

In thirteen communities, Community Prevention Centres (CPC) were set up as a strategy to maximise information intake and promote discussion of AIDS in the communities. The word centre presumes a catalysing hub that centralises the implementation of educational actions. Using trained residents as Community Prevention Agents (CPA), various initiatives have been implemented, including educational stands at the Centres; individual advice and orientation; educational activities at events, schools, and in streets and alleys; distribution of condoms using a list of residents; and several other strategies based on the local culture, such as the “educational street vendor”, a mobile stand in the streets and alleys of the community that distributes health education and information materials (Edmundo, 2003).

To assist in the development of local action plans based on the identification and knowledge of the local reality, we used the Problem Solving for Better Health® (PSBH) methodology developed by the Dreyfus Health Foundation, which has been applied in 29 countries. This methodology is based on identifying the problems faced by individual stakeholders, taking into account local realities and finding the resources needed to address the problems, including volunteers. Its premise lies in the notion that it is necessary to initiate action to minimise or solve the problem, even if the problem seems too big and unsolvable. This perspective acts as a trigger to implement local actions collectively and to mobilise the communities to develop local social solutions (Dreyfus Health Foundation, 2002).

The experience described in this article is based on technical reports by CEDAPS and monitoring logbooks filled out by the community health leadership groups. These logbooks were developed specifically for this purpose. As mentioned by Akerman (2002), systematisation of the results of a social project is part of the intervention process and contributes to developing community leadership and grassroots organisations, and helping the community achieve better living and health conditions.

**Results**

All the communities involved in the AIDS struggle that are assisted by the COMUNICSE programme are members of a network called the Network of Communities in the Fight Against AIDS. Within each territory, inequities run the gamut from degraded housing conditions to geographic and political distance from productive sectors of the city, unemployment, low levels of education, difficult or non-existent access to public health services, and various kinds of violence—gender-based, structural, symbolic, and physical. Given this reality, the premise of CEDAPS is that each community has its own organisational past, power structure, and shared language codes and values.

Understanding and valuing this reality is vital when dealing with AIDS prevention and health promotion.

The community health leadership groups participating in the Network have in-depth knowledge of the socio-cultural context of the communities in which they live. They are, therefore, key actors in planning and developing actions capable of reaching the population. CEDAPS acts as a facilitator of these
actions by bridging the gap between popular and technical knowledge and strengthening, on a daily basis, its partnership with these grassroots community associations.

As part of the collective strategy, thirteen Community Prevention Centres (CPC) were set up. All were equipped with instruments, educational materials, and condoms. All requests for implementation and organisation came from the communities themselves after acknowledging the importance of the AIDS problem on their territories. The strategy was based on the idea that prevention should be implemented from within the community, an approach that attracted the interest of community health leadership groups. Between 1996 and 2004, condom distribution increased from 9,000 to 284,704, a clear indication of the success of the programme. While these numbers are not sufficient to meet the demand of vulnerable populations, the trend indicates that condoms are becoming part of the local culture and part of people’s daily lives in these communities. Individual and collective practices are being changed by access to information and condoms and by dialogue instituted by Community Prevention Agents based on the local culture.

In the remaining 42 communities where CPCs were not introduced, different kinds of initiatives were observed. The diversity of the local actions demonstrates that the AIDS epidemic is being tackled from different angles, using various themes, and targeting various population segments. Each of these communities initiated actions anchored within the community, an approach that attracted the interest of community health leadership groups. Between 1996 and 2004, condom distribution increased from 9,000 to 284,704, a clear indication of the success of the programme. While these numbers are not sufficient to meet the demand of vulnerable populations, the trend indicates that condoms are becoming part of the local culture and part of people’s daily lives in these communities. Individual and collective practices are being changed by access to information and condoms and by dialogue instituted by Community Prevention Agents based on the local culture.

Table 1 presents local initiatives designed and carried out by residents in different contexts, favouring the inclusion of the population and the social sustainability of the initiative. The culture must be understood and interpreted in order to draft a local plan that transcends the notion of educational intervention and that promotes the construction of a participatory response from the community. These are seed initiatives from which other initiatives emerge and develop in community movements for prevention and health.

<table>
<thead>
<tr>
<th>Title of Initiative</th>
<th>Objective</th>
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<tbody>
<tr>
<td>Sports for the love for life</td>
<td>To stimulate the practice of sports to promote love, life, self-esteem, and self-care</td>
</tr>
<tr>
<td>The D’Pre of prevention - Love - Dedication - Prevention – Hope</td>
<td>To disseminate information about prevention through music in concerts and on community radio stations</td>
</tr>
<tr>
<td>Walking and Prevention</td>
<td>To promote walks with adults and the elderly in the community and, during these trips, talk about AIDS and the importance of preventive practices</td>
</tr>
<tr>
<td>Safe sex has no age limit</td>
<td>To organise meetings among men and women who have been married for more than 20 years to discuss the importance of safe sex practices</td>
</tr>
<tr>
<td>Evangelic Women in Prevention</td>
<td>To stimulate discussion about prevention among women attending evangelic groups in the community, especially clergymen’s wives</td>
</tr>
<tr>
<td>Aware and Trained Teens</td>
<td>To trigger interest in and raise awareness of prevention among teens through play-based workshops</td>
</tr>
<tr>
<td>CINE- PREVE(NTION)</td>
<td>To disseminate information about prevention through the presentation of mainstream movies in the community, followed by educational movies and debates</td>
</tr>
<tr>
<td>Teaching acting: theatre as a weapon against AIDS</td>
<td>To create plays with the participation of community youth that stimulate reflection on subjects related to AIDS, such as information, condom use, prejudice, and discrimination</td>
</tr>
<tr>
<td>Family Education Prevention Project – PREDUF</td>
<td>To visit families of people living with HIV/AIDS in the community, provide answers to their questions about contamination and treatment, promote integration, and favour a better quality of life for the persons and families affected by this epidemic</td>
</tr>
</tbody>
</table>

Developing local action plans strengthens local movements for health and creates a sense of belonging to the community health leadership group. People involved not only participate in a social project, they also design, develop, and evaluate it. In addition, because local action plans are instrumental in identifying the problem they seek to solve, they provide a framework for defining results and process indicators. This, in turn, provides further opportunities for community health leadership groups to reflect on the lessons to be drawn from the experience.
The Network represents a form of political articulation. It holds monthly meetings where general aspects of community action are discussed and further developed. In addition, participants exchange experiences and practice political democracy, define their agenda, and provide mutual support. Establishing bonds that go beyond their involvement in social action, they build friendships and a solidarity network where learning is promoted. They participate in scientific and political events as participants and as speakers. They practice developing partnerships and social projects and seek to improve their professional careers by participating in courses and workshops. Participation in the Network transforms their lives and the lives of their communities.

Our analysis of this experience indicates that community involvement in a concrete health-related cause, when coupled with technical assistance, provides an opportunity for democratic and participatory management that strengthens community leadership, giving collective meaning to local action. Community actions implemented by the communities themselves can generate health promotion movements that take action on illness prevention and the structural inequities in health systems. Life in the favelas and suburbs of Rio de Janeiro is harsh. It is characterised by constant political fighting and survival strategies. Low-income communities participating in the Network of Communities are an example of direct action by the communities in the fight against various social problems. The mobilisation resulting from this type of organisation strengthens the capacity of communities to become healthier and better able to fight vulnerabilities to the various illnesses to which they are exposed, including AIDS.

**Discussion**

The popular movement for AIDS prevention in Rio slum communities demonstrates the potential for community capacity building through the support of local community health leadership groups to develop local responses to locally identified problems. Inspired by the Brazilian social movement against AIDS, community associations created a network that encourages collective problem-solving and places the problem of AIDS in a political and social context, thereby influencing the dynamics of social movements fighting for better living conditions.

Strengthening the capacity of civil society to find direct solutions to health problems is a basic premise of health promotion. Actions by community health leadership groups directly address the conceptual and practical aspects of health promotion. The Network of Communities strengthens the ability of local communities to fight the political battles in countries like Brazil that are part of the daily struggle to transform the structural determinants of health. In practice, this transcends the idea of medicating problems that often prevents them from becoming part of the social arena (Paiva, 2003). The approach exemplified in this article acts directly on the structural determinants of health, generating empowerment and promoting health.

The power acquired by communities through participation in this social movement contributes to changing the ways individuals perceive and act upon social problems that are at the root of vulnerability. It does so through an educational approach that values the creation of public spaces (discussion groups, councils, managers, networks, centres) that promote individual and collective participation in the identification and critical analysis of their problems and the development of strategies for action based on health education as a “practice of freedom” (Freire, 1997). Some of the labels associated with this approach that seeks to replace educational methodologies based on “power over others” include “empowerment education”, “popular education”, and “education for emancipation.”

**References**


The notion of “power over others” is replaced with methods that value debate and discussion of ideas, opinions, and concepts aimed at solving problems (power shared with others). This perspective permeates the interventions that CEDAPS develops in partnership with the members of the Network.

“Empowerment education” contributes to emancipation by developing critical thinking and stimulating actions aimed at overcoming the institutional and ideological structures of oppression. This process is triggered by local actions implemented by community health leadership groups, with AIDS as the main focus. The daily work of prevention leads community health agents to think about their own happiness projects based on and developed using their personal life experiences and a collective, shared meaning. The sharing of meanings and goals is transformed into a factor of HIV/AIDS prevention, strengthening self-care at the individual and collective levels (Ayres 2002; Paiva, 2003).

When combined with empowerment and health promotion, the social practice perspective contributes to the development of healthy citizens who are aware of their rights and who possess the right to have rights (Carvalho 2004). It is a battlefield of social causes in which the empowerment of individuals, groups, and communities is essential. Many communities are not yet engaged in the fight for social justice. They are deprived of prevention actions and are thus still vulnerable due to the persistence of social inequities and illnesses, including AIDS, that spread through the crevices and faults created by oppression, prejudice, and social and economic discrimination (Parker, 2000). We still have much to learn from the practices implemented by community health leadership groups in favelas and have yet to realistically identify the potential for transformation through public education and health promotion.

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Résumé : Un réseau communautaire dans la lutte contre le SIDA : des actions locales pour faire face aux inégalités de santé et promouvoir la santé à Rio de Janeiro, Brésil.

Au Brésil, lorsqu’elle s’insère dans un contexte de grandes inégalités sociales, l’épidémie du SIDA devient bien plus complexe et nécessite des interventions efficaces et basées sur la participation communautaire. Cet article décrit l’expérience d’une organisation de la société civile, le Centre pour la Promotion de la Santé (CEDAPS), dans les communautés des bidonvilles (favelas) de Rio de Janeiro, au Brésil. Utilisant une approche basée sur la participation communautaire, 55 organismes communautaires ont été mobilisés pour développer des actions locales afin de lutter contre la vulnérabilité sociale croissante de ces populations face au VIH/SIDA. Cela a été fait grâce à des initiatives de prévention déjà en place, basées sur la culture locale et développées par un réseau communautaire, le Network of Communities in the Fight Against AIDS. Ce mouvement a amené les différentes communautés à « s’approprier » les actions sociales mises en œuvre. La lutte contre le SIDA a été un facteur de mobilisation pour ces communautés qui se sont ainsi engagées et organisées et a contribué à sensibiliser la population aux droits à la santé. Au travers des actions locales, on a également ciblé les déterminants de la vulnérabilité locale, comme l’ont suggéré les professionnels de la promotion de la santé.