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Community Participation in HIV/AIDS Programs

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1. Introduction

The advent of the human immunodeficiency virus (HIV) in the last few decades has presented considerable challenges to health systems throughout the world. Many countries developed measures to combat the spread of the virus and the trends are improving, mostly due to the introduction of potent new combinations of medications, the development of effective prevention strategies and increased community awareness. These improvements would not have been possible without the mobilisation of communities around the world, who, recognising their vulnerability, have taken collective action to curb the propagation of HIV. The subsequent pages discuss the origins, development and components of community participation with respect to HIV, including examples of strong community participation initiatives.

2. What is community participation?

In order to achieve the ambitious goal of Health for All, in 1978, World Health Organisation (WHO) and the United Nations Children's Fund (UNICEF) funded the International Conference on Primary Health Care (PHC) in Alma Atta, Kazakhstan. They pledged to provide basic health care for the entire world through the ingenious and comprehensive approach referred to as Primary Health Care (Werner & Sanders, 1997). The Alma Atta declaration emphasized the right and duty of communities to participate in the planning and implementation of their own health care. Apparently, strong community participation was a key element of the successful programs that led to the development of PHC principles. The previously existing but poorly recognised concept of community participation was recognised as the way forward for equitable health care.

The community participation model of health care is in many cases likened to "bottom-up" approaches and "grassroots" community action, in which the community is perceived as a third sector with the capacity to manage the more complex aspects of health care delivery historically handled poorly by the government (Botterill & Fisher, 2002). Most often, community initiatives precede the official national response to a problem.

Community participation in health can be defined along two fairly contrasting lines. It can be perceived as a movement in which the government and/or donors use community resources (i.e. land, labour, money) to meet the costs of providing health care. However, it can also be defined as a form of empowerment in which the community takes part in the decision-making process (Morgan, 1993).

The idea of community participation in health – also referred to as ‘community involvement’ or ‘community mobilisation’ – has inherited various meanings from different stakeholders who often use it for conflicting ends (Morgan, 1993; Olico-Okui, 2004). For the purposes of this book, community participation will be defined as all community contributions to prevent the spread of HIV and to improve the health care and quality of life of people living with HIV (PLHIV). The Joint United Nations Programme on HIV/AIDS (UNAIDS) recognises the following components as integral parts of community participation: raising awareness, prevention, policy and legal changes, alleviating impact, advocacy, care and support (UNAIDS, 1997).

3. Defining community participation in relation to HIV?

UNAIDS uses an all-encompassing definition of community, namely “a group of people who have something in common and will act together in their common interest” (UNAIDS, 1997). People who live together, work together or worship together belong to the same community. However, to better comprehend the need for a community to act together for their common good, it is imperative to consider exactly what the individuals have in common. In relation to HIV, it is the potential risk-factors affecting a community that determine its key characteristics. For example: people living in a village on a highway may be at higher risk for HIV due to unsafe sexual contact with truck drivers passing through. Sex workers are at a higher risk of contracting HIV by virtue of their profession. The practice of polygamy involves having multiple sexual partners, a known risk factor for HIV. Additionally, all these factors may be combined in one community, thus generating a complex situation for community medicine.

Under these circumstances, members of the community are affected, whether directly or indirectly, by the disease and should take part in deriving a solution. The way the community reacts to the disease is an important step toward developing prevention programs. Communities with high levels of stigma and discrimination create a challenging environment for initiating volunteer testing and counselling, care and support. On the other hand, in less judgmental communities it is easier to educate and empower community members and PLHIV. In other words, the community is the key to solving its own problems. A mobilized community is therefore one in which the members are aware of their vulnerability to HIV, are motivated to take action, have practical knowledge of their options to reduce their vulnerability, take action using personal resources, participate in decision-making and evaluation, all while assuming responsibility for successes and failures. Most importantly the community seeks external support when needed (UNAIDS, 1997).

4. HIV as a community illness

PLHIV are not islands off to themselves. They come from a community in which specific factors have exposed them to the virus. Children born to HIV-positive mothers represent

but a link in a long chain of people who have carried and passed on the illness. The presence of an HIV-positive child usually implies that either his/her parents have HIV and/or a third party from whom the infection was contracted. Upon the demise of the parents, family members normally step in to take care of the child.

Thus, reducing vulnerability to HIV requires not only medical measures, but also social measures. For example, poor socio-economic status may reduce access to knowledge and barrier methods. Some cultural practices may limit women's ability to negotiate safer sex practices. The decimation of teachers in a community by HIV will affect the performance of students in that community. Lower levels of education will adversely affect the community. Likewise the loss of health workers to HIV or an increased burden of work due to care provided to PLHIV.

In some instances, PLHIV themselves are considered a community, and HIV activism usually stems from such communities. The control of HIV may require adapted methodologies to specific communities like commercial sex workers, men who have sex with men, medical personnel, etc.

It is becoming increasingly clear that HIV must be considered as a community problem, which needs to be solved using community-based solutions.

5. Community participation and HIV

Historically, health care projects with strong community involvement have been more successful, considering such bottom-up approaches often gain more acceptance by local populations than top-down, government-imposed solutions (Werner & Sanders, 1997). Generally speaking, and specifically in the case of HIV, countries most affected by the disease lack the financial and human resources needed to combat it. Not only did HIV decimate entire communities, creating a huge burden on the health system, it also wiped out health workers. Moreover, the spread of HIV is often linked to socio-cultural and behavioural factors that are particular to specific communities. The result is a problem that, in reality, can only be addressed within that community, by that community. Additionally, geo-political factors often slow the government response to HIV public health emergencies. The development and experimentation of new treatments and vaccines for HIV require community participation and, in many cases, community consent for necessary research.

Community participation in the response to HIV has been accepted as an essential element within health services and programs for a variety of reasons. First, HIV services have a much greater reach when stakeholder communities are involved in their design. Community contributions – in terms of money, material and manpower – can be mobilised to improve the lives of people both infected and affected by HIV. Reductions in vulnerability to HIV are achieved primarily through actions people take to protect themselves. Finally, the community has a right to be involved in decisions that affect their every-day lives (Morgan, 1993).

Community participation has played a central role in the fight against HIV since the onset of the epidemic. It has a positive effect on safer sex practices, social integration and identity (Ramirez-Valles, 2002).

6. Components of community participation in HIV

In this section, we will describe the various ways in which communities can participate in HIV programs. There are no hard lines between these components: communities of PLHIV

can be involved in providing care, while also being at the forefront of activism and peer education.

6.1 Care

The already thin-stretched human resources for health in the countries most affected by HIV have been further taxed by the influx of critically and terminally ill patients into hospitals. As a result, additional hands-on-deck are required to take care of HIV patients. In-hospital care is often provided by family members and consists mostly of providing food, ensuring basic hygiene, waste disposal, bed making and the purchase of necessary medicines. Such arrangements carry their own risks, serving as another means of spreading HIV as lay people are not typically trained in the management and disposal of biological waste. However, if trained by health personnel, their efforts are invaluable.

One of the key pillars of HIV management is home-based care. This approach began as an initiative to take medication to patients who were too sick to come to the hospital themselves. It quickly spread beyond the provision of medications to cover activities such as counselling and training of family members. This activity is carried out by trained lay people often called community relay agents or community health workers. Over the years, their scope of work has become broader, including within its mandate HIV prevention and counselling for community members; educating the community on the need for testing; distribution of condoms; and social mobilisation. These community health workers operate under the supervision of regional health personnel. As the need to integrate tuberculosis and HIV services began to grow, community health workers also took part in identifying community members likely to have tuberculosis, advising them to seek medical help.

Even in countries with better human resources for health, community volunteers often supplement hospital care.

6.2 Research

In order to achieve high levels of relevance and validity, research projects testing new approaches in the prevention and treatment of HIV must be carried out in the communities for which the given intervention is intended. Although often overlooked, community participation is a key component of HIV research. Clinical trials often require approval from regulatory bodies like Ethics Committees (EC); Data Safety and Monitoring Boards (DSMB); and Institutional Review Boards, all of which include community representatives. In countries with a more developed research agenda, Community Advisory Boards (CAB) also exist. CABs, which are made up entirely of community members, play a role in determining the relevance and safety of research proposals as they affect the community.

Subjects of clinical research are an enormous community contribution to the advancement of science. Large numbers of people are recruited every day into HIV trials. These participants contribute to the development of rapid tests, vaccines, medication and behavioural interventions. Community involvement in HIV vaccine research is necessary for success, as it promotes better enrolment and retention in trials (ICASO, 2007).

6.3 Activism

HIV activists are community members who may or may not be infected with HIV and who promote equal rights and opportunities for PLHIV. They seek to empower PLHIV and decry

situations and people that jeopardize their rights and dignity. They fight for the legal rights of PLHIV; availability and accessibility of testing and treatment services; and discourage risky behaviour among vulnerable groups (Senterfitt, 1998). Activists play an important role in changing legislation and policy that work to the disadvantage of PLHIV and vulnerable populations. Through activism and workshops with the medical community, they are able to negotiate for better and specially tailored services. They also contribute to the mitigation of stigma and discrimination by educating journalists to use more appropriate terminology when reporting on HIV-related issues. In many countries, stigma and discrimination against PLHIV are the key reasons that people give for refusing testing, medication and other HIV services. Activism may take the form of education, mass media campaigns, law suits and public demonstrations.

HIV activists made a significant contribution to the development of effective preventive and treatment strategies for HIV by mounting pressure for accelerated research and contributing to the development of clinical guidelines. Many deaths have been prevented thanks to such activism (Harrington, 2009).

A small proportion of activists resort to dramatic demonstrations and sometimes violence. These few should not be used as examples to undermine the positive achievements obtained by community activism.

6.4 Role models

Role models play an important role in catalysing behaviour change. Reducing individual and community vulnerability to HIV relies heavily on bringing about positive behaviour changes. Depending on the context, celebrities, football players, artists and politicians can use their status to encourage positive practices by setting examples for the community. Many people worldwide were moved when United States President Barack Obama publicly did an HIV test. Some role models take part in advertisements and mass media campaigns encouraging abstinence, condom use and testing. Role models can also act as peer educators.

6.5 Peer educators

Peer educators are usually community members with social characteristics similar to a target group. Their function is to transmit a desired health message to achieve positive behaviour changes by speaking in a language and cultural context that their community is more apt to receive. The most common example is the use of students to conduct education among their peers to raise awareness about safe sex. Peer leaders are generally identified within the community they are to work with. They are then trained to educate and encourage positive behaviours that reduce vulnerability to HIV. At the onset of the HIV epidemic in the 1980s, peer education was used to access difficult populations like men who have sex with men, commercial sex workers and injecting drug users. Over time, it has gained momentum and it is now used to reach adolescents worldwide (Ward et al., 1997).

6.6 Associations of PLHIV

PLHIV can play a major role in encouraging testing and disclosure, reducing stigma, providing credible information and raising funds by openly disclosing their status. Depending on legislation, associations of PLHIV can be comprised entirely or partially of HIV-positive persons. Other groups that might participate can include people affected by HIV, such as those living with or related to someone who is HIV-positive. Associations

of PLHIV give a face to the disease, while providing comfort and support to persons already living with the disease. These associations are also the ideal forum for PLHIV to focus on their rights and health and demand an adequate response from their governments.

6.7 Community-Based Organisations (CBOs)

Community based organisations (CBOs) represent a more organised effort to combat HIV. These organisations are created by community members, have their headquarters in the community and collaborate with the local health authorities to achieve prevention, treatment, care and support goals. Their range of activities depends on their individual mission statements, but they may be involved in home-based care, voluntary counselling and testing, patient identification and referral, subsidy of health-related costs, research, data collection and local health area decision-making. They are particularly in tune with community needs and have an active presence within their respective communities. For instance, there are CBOs that focus on prevention and treatment efforts among specific vulnerable groups, such as sex workers to injecting drug users. Often the staff of such organisations include members of vulnerable groups (e.g. current/former sex workers or drug users). Their intimate connection to their respective communities provides an essential and invaluable link between service providers and target populations. These CBOs conduct outreach work distributing condoms and/or needles directly to target groups and providing valuable informational materials, counselling and case management to disenfranchised populations.

6.8 The Municipal Council

Over time, the institution known as the Municipal Council has acquired a variety of meanings. For the purposes of this chapter, this term will refer to a small, democratically elected governmental body operating in small communities, the leader of which is often the mayor. This is a formal body representing the community in all areas including health. In some legislations, the mayor or a representative of the council is also a member of the health district management committee. The municipal council determines the community agenda for health and provides estimates of how much of their budget can be allocated for health. These finances can be used to boost community efforts to fight HIV by providing compensation for social mobilisers and community health workers.

6.9 Community health appraisal

Planning health care services requires appraisal and 'community diagnosis', both of which require the direct involvement of community members. Community representatives may be responsible for providing information as well as collecting and analysing collected and existing data. The involvement of community members in validating data collected, both empowers the community and ensures that the data does in fact reflect the given community (Rifkin, 1992). HIV programs require in-depth appraisal of community problems before interventions can be developed. The community's knowledge, attitudes, practices and behaviours must be adequately assessed. Additionally, there must be a thorough study and understanding of local cultures and traditions, including dates and locations of social events, traditional calendars and local means of communication. It is equally important to investigate

community demographics, use of services and literacy rates. It is only then, for example, that program managers can determine not only how many condoms are needed, but how to best disseminate them so that the community will receive them. It will also determine when and where to have health talks; what is the best medium for communication; and what kind of language and messaging needs to be used in order to effectively deliver important health messages. The community, therefore, plays an important role in the decision-making process by providing, collecting and validating information pertinent to the development of HIV programs.

7. Challenges to community participation

Community participation in HIV activities is often hampered by a lack of adequate leadership and poor credibility owing to the fact that community members usually have no formal training either in health or community action. For example, without appropriate training, community workers visiting households of PLHIV may disclose patients' status in the community. Support groups are not only difficult to establish and sustain, but retention rates are low due to fear of stigma and status disclosure (Population Council and Health Systems Trust, 2006). Community advisory bodies are also difficult to initiate and sustain (UNAIDS, 2007).

In some countries, community mobilisation may be perceived as opposition to the government and constructive initiatives may be stopped or delayed. In fact, such initiatives can be dangerous for those involved. Political, religious and cultural factors can impede community efforts that appear to contradict accepted social standards, such as the distribution of essential prevention materials (i.e. condoms, needles) and important educational information. Additionally, the governments of many countries are reluctant to fund such initiatives, resulting in fierce competition among CBOs for international funds from the same pool of donors: this often creates an environment that fosters competition rather than collaboration. Further, community participation often ignites power struggles within the community, as members are far from homogenous and can be in bitter disagreement among themselves. All these factors make community participation a highly dynamic and complex process (Olico-Okui, 2004).

Additional challenges to community participation include ensuring that the community takes ownership of the initiative. Rushed programs using community participation as an objective rather than a process are more likely to hamper the long-term success of the initiative. Also, community participation often requires external support. Consistent provision of supplies that cannot be generated from the community is crucial to ensure continuity. Finally, it is also necessary to ensure adequate leadership and representation from community members by retaining their interest in the project, reserving seats for them at important meetings and making them know that their input is valuable.

The integration of health care services is not making community participation any easier. Community volunteers who initially focused on HIV activities now find themselves providing services for tuberculosis and, at times, general reproductive health. There is a need for the development of better conceptual frameworks to determine the extent and scope of community participation in specific projects. Finally, there may be too few examples of success community initiatives to follow from.

8. Examples of community participation in HIV programs

8.1 CBOs and vaccine development in Brazil

In August 1991, the WHO selected Brazil as a preferred site for vaccine trials. Brazilian authorities were less than welcoming to foreign-initiated research and decried the use of Brazilians as “guinea pigs”. HIV activists understood the need to be involved in vaccine research and used the opportunity to discuss the development of trial capacity and infrastructure in Brazil, while insisting on the highest standards for research processes and ethics. They even negotiated access to vaccines in the future (ICASO, 2006).

8.2 The AIDS Support Organisation (TASO) in Uganda

In 1987, groups of PLHIV and their families started forming spontaneously throughout Uganda. They came together to share information, comfort one another and cope with the burdens of stigma and discrimination. The new larger group grew rapidly as news spread of their activities. They then sought out external financial and logistic assistance for training volunteers in prevention and care. It is now one of the biggest HIV care organisations in Africa with 150 staff members and 200 volunteers (UNAIDS, 1997).

8.3 The CIHR Canadian HIV Trials Network (CTN) Community Advisory Committee (CAC)

Before the initiation of the CAC for the CTN, very few volunteers participated in the review of HIV clinical trials in Canada. In the late 1980s, PLHIV demanded a bigger role in the decision-making process. In response, scientists and drug companies began adding PLHIV to existing committees. In 1993, the CTN added another level of review by a newly created CAC to reinforce the work of other community members in other CTN committees. The CAC’s advice is essential in determining if trials will be attractive to participants. Based on the CAC’s recommendations, specific changes can be made without the study losing its scientific value. Now, pharmaceutical companies regularly ask for community input in the development of protocols and informed consent forms. The CAC’s activities include ensuring that the proposed research is relevant and of interest to the HIV community; that the research is ethical and protects trial volunteers from unnecessary risk; and that informed consent is clear and understandable. They also provide a forum for the discussion of trials and improve communication between community representatives and researchers (CTN, 2010).

8.4 The Lawyers’ Collective, Bombay, India

The Lawyers’ Collective is an Indian NGO that devotes considerable resources to the legal needs of PLHIV. It is mostly self-financed, but has fought many legal cases and worked towards changing laws that discriminate against PLHIV. In 1989, they took on the case of Dominic D’Souza, arrested because he was found to be HIV-positive after donating blood. He was considered a ‘public threat’ under the Goa Public Health Act and was subsequently incarcerated. D’Souza’s case reached the High Court, and, with the help of the Collective, he was released and amendments were made to the Public Health Act (UNAIDS, 1997).

8.5 HIV Vaccine Division (HAVD), South Africa

The HAVD developed an extensive and comprehensive community education program in the Soweto community of South Africa. They began teaching community members about

HIV vaccine trials a full year before the onset of the trials. This 'no rush' policy gave the community ample time to absorb the information and make informed decisions about whether they wanted to take part in the trials or not. Their understanding is assessed before they are included in the trials. They also have a representative community advisory board that advises the researchers on community norms and concerns. The board members are democratically elected by their constituents.

9. Conclusion

Community participation has played a fundamental role in the fight against HIV. It has a positive effect on prevention strategies, uptake and availability of treatment and use of services. It has also initiated and guided the research agenda for HIV prevention and treatment. The scope of community participation is much broader than often reported and should not be overlooked. Communities with high burdens of HIV are encouraged to mobilise and participate in a collaborative response to the epidemic.

10. Acknowledgment

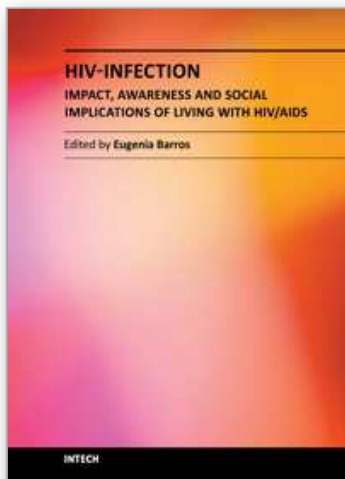
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The past few decades have seen the escalation of HIV-infections and the 'frantic' search for new drugs to treat the millions of people that live with HIV-AIDS. However because HIV-AIDS cannot be cured, but only controlled with drugs, and the Antiretroviral (ARV) treatment itself results in some undesirable conditions, it is important to generate wider awareness of the plight of people living with this condition. This book attempts to provide information of the initiatives that have been used, successfully or unsuccessfully, to both prevent and combat this 'pandemic' taking into consideration the social, economic, cultural and educational aspects that involve individuals, communities and the countries affected.

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