

# Demystifying HIV/AIDS research: a call for more community-based research in Botswana

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*We critically examine current HIV/AIDS research practices to argue for a reorientation toward participatory action research (PAR) for a more effective prevention of the HIV/AIDS epidemic in Botswana. This position is based on the fact that, there being no known cure for AIDS, prevention remains the most viable approach to the disease. Unlike traditional (academic) research which mainly aims to generate knowledge, often for knowledge sake, PAR integrates policy formulation and change as part of its agenda. Also, through its ability to draw community members to the total research process, the approach is capable of creating a sense of ownership of and responsibility over research knowledge and programmes of action emanating from it on the part of community members. These, in our view, are essential for the successful prevention of HIV/AIDS through changes in attitudes toward and in the practice of sex.*

## Introduction

One of the major challenges Africa today is the HIV/AIDS pandemic. Of the 34.3 million people estimated to be infected by the Human Immunodeficiency Virus (HIV) globally by 1999, about 24.5 million were found in sub-Saharan Africa (United Nations Programme on HIV/AIDS, 2000). About 83 % of the World's AIDS deaths are also said to have occurred in this region. Women are the most infected group. According to United Nations Programme on HIV/AIDS and the World Health Organization four out of five HIV positive women live in Sub-Saharan (UNAIDS & WHO, 1998). In some countries between 10-29 percent of pregnant women are HIV infected (Adepoju and Mbugua, 1997). In many African countries the pandemic now threatens not only the gains made in areas such as life expectancy, infant mortality and disease control but also compounds the challenges of providing health care services to the people. Furthermore, the spread of the pandemic in these countries has eroded the little that has been attained in terms of socio-economic development since independence, aggravating the levels of impoverishment.

The HIV/AIDS epidemic, however, is not evenly spread over the region. During the 1980s, for example, countries in Eastern Africa were most affected. Today the epidemic is most severe in Southern Africa. In Botswana, in particular, the first AIDS case was diagnosed in 1985 and since then the spread of the disease has been dramatic starting in urban and peri-urban areas and rapidly extending to rural localities. The 1995 Sentinel Survey estimated that about 23% of the adult population aged 15-49 years was HIV positive. The survey indicated that the number of people living with HIV had risen from 59,000 in 1992 to 180,000 by 1995 and was estimated to have reached 207,000 persons by 1997. This represented an increase of about 148,000 infected persons between 1992 and 1997. During the year 2000, the number of people with HIV was projected to be 332,000 (Botswana Government and UNDP, 1998).

The 1995 Sentinel Survey also indicated that the highest HIV infection rate was among youths aged 15 to 29 years. They accounted for about 56% of the reported cases of HIV related symptoms during the first quarter of 1996 and for about 79% of HIV positive expectant mothers (UNDP, 1998). However, females appeared to be more vulnerable than males and

constituted about 68% of those infected youths. The problem of HIV has also been found to be growing among children aged 0 to 4 years. Results from the latest Sentinel Surveillance survey reveal that the infection rate remains very high (Ministry of Health, 1997). The survey also revealed that the rural-urban differences in the rates of infection have almost disappeared and the virus is almost evenly distributed across the country.

Despite the threat posed by the HIV/AIDS pandemic to global populations, efforts to find a cure or vaccine against it have not produced tangible results and preventive measures remain the only viable approach to it. The effective prevention of the disease requires an all round understanding of the disease by both the vulnerable individuals, groups and/or communities and those crusading to stem down its spread. These parties must be knowledgeable about the ways the disease is spread (or contracted); its symptoms; ways of avoiding infection and the likely socio-economic and health consequences for the patients, the communities in which they reside and for the nation as a whole. In the developed world scientific research carried out in the medical, biological and natural sciences remains the leading source of such knowledge. But in the developing countries (such as Botswana) where medical, biological and natural scientific research is rather underdeveloped and for the most part hampered by the lack of funds, social science research remains the way forward. However, as will be demonstrated later, the current manner in which (social scientific) research takes place constitutes a constraint to the effective prevention of HIV/AIDS.

This study calls for a reorientation of HIV/AIDS research to make it more effective as a tool for the prevention of the spread of HIV. More specifically, it advocates for an approach that demystifies research by making it not only more community based but also participatory and action oriented and hence the term 'participatory action research' (PAR). The study underlines the importance and necessity of intensive community participation in the total HIV/AIDS research process based on the fact that the disease can neither be treated nor prevented through biomedical means. The only effective way to deal with it is through community-based prevention in the form of changes in the social lives of vulnerable individuals, groups and communities. As will be demonstrated shortly, injecting a participatory and action orientation to research would raise the levels of community involvement, awareness and understanding of the HIV/AIDS epidemic.

### **What is participatory action research?**

The concept of participatory action research has two parts; *participation* and *action*. The notion of "action research" can be traced back to Kurt Lewin's (1946) proposal that the best way to study something was by trying to change it. Elden and Levin (1991:127) define an action research as a "strategy for using scientific methods to solve practical problems in a way that contribute(s) general social science theory and knowledge" and to make practice more effective. Action research, it is assumed, brings researchers closer to the client's world while at the same time drawing the client closer to the research process (Kondrat and Juliá, 1997). It demands that social scientists and the community are equal partners in the planning and implementation of a project, and that each brings valuable resources to the project. The fundamental aim of action research is to improve practice rather than to produce knowledge. The production and utilisation of knowledge is conditional to this fundamental aim. Action and research take place alternately in an ongoing learning process for everyone involved. Because of this dynamic process between researcher and community and between research and action, there is no general formula for conducting action research. Ideally the initiative for an action research project comes from members of a community who find themselves facing serious problems be it health or otherwise. The initiative should not come from social researchers who believe (rightly or wrongly) that they know what is best for a particular community.

The concept of 'participatory' introduces a new dimension to the concept of action research. It represents the notion that the beneficiaries of social and economic development should take part in identifying solutions to the problems that afflict them. That is, those to be affected by proposed change should participate in defining needs and isolating appropriate actions (Kondrat, 1994; UNDP, 1990; McTaggart, 1989). According to McTaggart (1989:3), participation "means sharing in the way research is conceptualised, practiced, and brought to bear in the life-world. It means ownership-responsible agency in the production of knowledge and the improvement of practice." Participation is a pointer that the researcher respects "the needs, intelligence and dignity of the people" (Park, 1992:32) whom he/she is supposed to benefit. In the words of Hall (1992:15), it places "the less powerful at the center of the knowledge creation process" and limits the authority of those in power to speak for the wants of others. Like action research, participatory action research is committed to improving social conditions and emphasises the utility of knowledge (Kondrat & Juliá, 1997). It aims to emancipate by transforming social structures and challenging unjust social practices. As a technique for collection and dissemination of data participatory research "first came into international recognition with Freire's philosophy of conscientisation, epitomising a strategy for the liberation of the oppressed people" (Bramor, 1995:117). The approach has for sometime now been popularised in the field of social and economic development (see e.g., David, 1991; Durst, 1992; Rahman, 1993; Haq, 1995; Kondrat, 1994).

Based on the specifications of the participatory and action components of PAR provided above, it can be concluded that participatory action research is a process of building knowledge socially with change oriented strategies. It incorporates grass root initiatives in the accumulation of knowledge by allowing for social groups to collectively analyse their social, economic and political experiences for the purpose of their own advancement (Kondrat and Juliá, 1997). PAR is a process that commences with a general recognition of the need for some improvement or change. This could be done by the community members themselves or with the help of an outsider as a catalyst. Next, members of the group—at least some (Whyte, 1991)—participate in the identification of the problem and the ways in which it affects them. Thereafter, the people together decide what additional information is required. Here outside expertise may be useful in designing methodologies for information gathering. The data collection process pays very close attention to "popular wisdom, experiential knowledge, and cultural know-how (Kondrat & Juliá, 1997: 42). The focus of the data always remains the clarification of social conditions and informing appropriate action.

### **Characteristics of existing HIV/AIDS research**

HIV/AIDS research can be classified under the domain of health research. This type of research as a whole mainly falls into three categories: research commissioned by health authorities, research undertaken by health workers, and research initiated and conducted by outsiders who are either non-health researchers or first researchers. A broad examination of the existing HIV/AIDS research reveals several aspects of the same that undermine its capacity to effectively further the prevention of the pandemic. First, more often than not HIV/AIDS has been viewed solely as a health problem (Jackson, 1996) and research on the subject is primarily based within health institutions. This has prevailed despite the fact that HIV/AIDS is more than a health problem. It is also a behavioural problem whose solution is not only a matter for the scientists but also for the whole community. As a result, research has excessively focused on the health and demographic characteristics (such as age and sex) of those infected with the disease at the expense of other features (such as the

socioeconomic status of the infected and societal barriers to prevention) that are central to bringing about the behavioural change necessary to arrest its spread.

Research is carried out for two purposes; to increase knowledge and for its applied utility. Virtually all existing HIV/AIDS research appears to have been driven by the former than the latter purpose. That is, it has been academic rather than action oriented. Since the driving force behind most academic research is the generation of theoretical rather than applied knowledge, the action part of most HIV/AIDS research has either been relegated to a subsidiary level or totally ignored in the past. The dissemination of (academic) research findings is usually through the write up of papers in (academic) journals which service providers and community groups may never gain access to. What the research may choose to emphasise in his/her report may be determined by the focus of the target journal rather than by the burning issues affecting the community studied. In addition, the language and styles of presentation utilised in constructing research findings may be beyond the reach of the community members who should be the primary beneficiaries of the same. Academics and other intellectuals are also driven by personal motivations and ambitions (Henshel, 1990) that may stand opposed to the needs of the people. In sum, what should be available to all ends up becoming the monopoly of a small privileged social group. Yet as Kondrat and Juliá (1997: 35) state, "knowledge about people's real life experiences and social and political realities under which they live belongs to the people who actually live those realities. If not to them, then to whom?"

The tendency to treat HIV/AIDS mainly as a health problem coupled with the adoption of an academic approach to research on the subject has also resulted in a clear cut division between researchers (both medical and academic) and the users who include communities, community organizations and NGOs. This makes it practically difficult to bring the two together. In addition, individual success is measured by academic prominence over others rather than demonstrable gains in the community resulting from research. This breeds the type of competitiveness among researchers themselves that makes it difficult for researchers from various research areas to work across disciplines.

The approach that has been used to carry out HIV/AIDS research in the past has been disempowering to the communities or groups that are studied in terms of its design and application. Those who advocate for participatory action research generally concur that "one of the characteristics of traditional research is the remarkably skewed power distribution between the researcher and the so-called subjects" (Fernandes & Tandon, 1981:4). Even where application has been a major objective, more often than not, those involved in making the decisions guided by the research findings are quite removed from the communities/groups that were researched. The traditional method of doing HIV/AIDS research has also been alienating, marginalising and exploitative (Kondrat & Juliá, 1997) to those who should be the primary beneficiaries of research knowledge generated from the research process. It reduces them to mere "objects" of study (Kondrat, 1994). The development of the research agenda has been the pre-occupation of the researchers who are not directly linked to the community. These tend to utilise a top-down approach in their research that does not take into consideration the expertise of the community members with respect to the total research process. PAR would reduce the marginalisation and exploitation of vulnerable groups.

Another characteristic of HIV/AIDS research that may undermine its utility in the prevention of the disease is that, more often than not, the agenda for research may be dictated by the political economy since the research is usually funded by external agencies rather than by the researchers themselves. It is not uncharacteristic for those funding the research to dictate its direction. HIV/AIDS (medical) research, for example, is essentially an industry dominated by pharmaceutical corporations (Altman, 1995) with firms

concentrated in countries like the United States of America, Japan and a few European countries. These firms are mainly interested in the development of a bio-medical cure for AIDS. As such, they rarely, if ever at all, incorporate behavioural change in their research agenda.

In Botswana the situation has not been that much different. Here, like elsewhere, judged by the continued high rates of HIV infection, social science research appears not to be serving its preventive function effectively. Although the scarcity of resources prevented the commencement of intensive HIV/AIDS research in Botswana until 1992, considerable research has been undertaken since then and the stock of available information has increased tremendously. However, a closer look at the existing research reveals that it suffers from most of the shortcomings listed earlier. Most of the research has been spear headed by the National AIDS Control Programme in the Ministry of Health. The programme conducts annual HIV Sentinel Surveillance surveys amongst pregnant women who attend ante-natal clinic with a view to providing information about the levels and trends in the AIDS epidemic; that is, the number of people who are infected and the rate of infection. Recently, the Sentinel Surveillance studies have been extended to include men presenting symptoms of a sexually transmitted disease (STD) at selected health facilities. The problem with Sentinel Surveillance Surveys is that they provide information about the spread of the virus (or the rate of infection and the age and sex of those infected with the virus) without presenting an in-depth understanding of the HIV/AIDS epidemic. Such an understanding would, for instance, offer reasons behind the spread of the disease, allowing for an insight into the behaviour of the respondents or documenting their socioeconomic status. This shortcoming has acted to limit the practical effectiveness of the research since it is those factors that are overlooked that are important in bringing about the behavioural change that would prevent the spread of the disease.

There exist other studies that have been conducted by academics (e.g., Macdonald, 1996; Ubomba-Jaswa, 1992; Ingstad, 1990) and various NGOs. While these studies can be ruled to be community based, virtually all of them have been neither participatory nor action oriented in the manner spelled out earlier. They have been initiated by experts from outside the communities studied rather than by the community members themselves. These tend to dominate the research process and community members only serve the role of informants (or study objects). Although studies conducted by NGOs are usually change driven, these have been oriented toward the broader policy framework of the Ministry of Health rather than toward changing the life situation of the affected groups or communities. Studies conducted by academics, on the other hand, suffer from the same shortcomings that were identified earlier with regard to academic oriented research. Such studies, nevertheless, could constitute an important take off point for PAR.

### **Utility of PAR in the context of HIV/AIDS**

Participatory action research has an effective role to play in the fight against HIV/AIDS. The approach has certain qualities that make it particularly suitable for the generation of knowledge that would inform the prevention of the HIV/AIDS pandemic. First, participatory action research is collaborative research between the researcher (social scientist) and (some of) the community members (Kondrat & Juliá, 1997; Whyte, 1991). It eliminates the clear distinctions between the researcher and the objects of research (Kondrat and Juliá, 1997) by making the researcher who is the outsider to become a co-learner and co-investigator (Maguire, 1987). To underline its emphasis on the generation of knowledge from the perspective of both the researchers and the researched, the technique draws community members into the analysis of their own reality. It builds respect in professional groups for their insights and knowledge about the problems people are faced with while at

the same time listening to local people so as to avoid mistakes and to develop programme that take into account the specific situation and conditions which will influence the outcome of programmes. Ideally each party does what he/she does best and this maximises their respective strengths (Kortein cited in Monu, 1995). PAR acknowledges the expertise of the people by treating them as the experts on their own life situation and thus involving them, either individually or collectively, in the formulation of research design, the collection of data and the analysis of findings for their implications for social change. However, for the approach to work it requires social scientists to remove their ideological and disciplinary blinders, become familiar with the operations of the community and to continuously learn how they could become relevant to the needs of the group. They must also demystify social science to make it every person's tool. This way they are able to turn both agency personnel and in some instances the villagers themselves into more effective action researchers (Kortein cited in Monu, 1995).

By intensifying community participation, PAR draws community members closer to the total research process. By working alongside researchers, the people come to understand better what they already know and experience and on the basis of this understanding they are able to take informed action to alter their lives and circumstances (Freire, 1990). In other words, PAR allows the people to take ownership of issues and "restores the place of ordinary people as the creator of knowledge" (Park, 1992:32). It democratises knowledge and allows community members access to the arenas where decisions are made.

Participatory action research is change-oriented research. Unlike in orthodox research where in most cases you merely make up explicit intention of collectively investigating reality in order to transform it, it uses a three-part process of social investigation, education and action. The approach demands that researchers give as much, if not more, weight to the usefulness of knowledge for social action as to the advancement of a formal (theoretical) body of knowledge generated through the research (Kondrat & Juliá, 1997). According to Kondrat & Juliá (1997:43), knowledge should be "generated *in use*, and the boundary between knowledge and action" should become very fluid. The research should aim to develop critical consciousness, to improve the lives of those involved in the research process and to transform fundamental societal structures and relationships. It should inform some kind of action, which the research-action partners can undertake together. Thereafter the results of the action are to be assessed and, depending upon the results of the assessment research, it may be necessary to develop or completely redesign the original action undertaken. In this way action and research continue as alternate processes in the solution of the community's problems. Because in PAR the community members are the prime movers of the change it strives to bring about, the research is designed so as to be relevant to the community and the findings are used immediately to develop interventions. It should identify local needs and priorities, place issues in the context of people's lives and give direction to programme development and service provision.

The qualities of PAR discussed above make it particularly suited for the generation of knowledge to inform the prevention of HIV/AIDS. For instance, community identification with the total research process (research problem, methodologies, results and general knowledge generated), creates a sense of ownership of the research process and its outcomes and circumvents the possibilities of community alienation from the same. Where the community members are alienated from the research and its findings, they are likely to disregard them and this undermines the policy component of research. That is, the community members' failure to identify with the research outcomes will affect in a negative way their commitment to the implementation of any change oriented policies emanating from the research results. In addition, by improving the level of community participation in the total research process, PAR raises the level of awareness about a

problematic condition such as HIV/AIDS. A heightened level of awareness is a necessary ingredient in the effective prevention of HIV/AIDS. It allows vulnerable groups to come to terms with the reality and paves the way for the quest of solutions to their affliction.

Given that PAR is driven more by the desire to use research in social action than with publishing knowledge generated through the research, a shift to this approach would enhance the prevention of HIV/AIDS in Botswana. Although Kondrat and Juliá (1997: 45) see "no inherent conflict between an emphasis on social action, on the one hand, and published documentation and dissemination of process and outcomes, on the other," past trends in HIV/AIDS research point to an emphasis on the latter at the expense of the former. A participatory action research approach would reverse this situation and create conditions that favour greater integration of community members in both the generation of knowledge about HIV/AIDS and the utilisation of that knowledge for the prevention of the spread of the disease itself.

PAR provides a people-oriented approach to the study of HIV/AIDS. Being people centred, the approach would minimise the mystery that has surrounded HIV/AIDS research (thereby undermining its practical utility) and reduce the stigma still associated with the disease. The approach encourages self-reliance in the generation of knowledge and collective action to alter an undesirable condition (Kondrat & Juliá, 1997), in this case HIV/AIDS. It develops critical consciousness and capacity building among community members thus encouraging community members to become the prime movers of change. Adopting a participatory approach to HIV/AIDS control, therefore, is tantamount to incorporating vulnerable groups in the total process from the beginning to the end. This would intensify their involvement in both the research process and in the action to bring about change. Rather than just serve as mere objects of research, as has been the case in the past where community members have mainly participated as informants, participatory action research would guarantee community members participation in a variety of areas that would span the identification of problem of interest, the management of the research process, processing and dissemination of the research information, and the actual consumption of the knowledge generated. A PAR approach would facilitate dialogue, discussion and bonding between researchers and community members; create considerable trust among researchers and community members; enable the community members to be aware of the nature of their problem and needs and to identify with the condition (problem) being researched; and circumvent the hesitant response from community members that arises from misconceptualisations caused by their alienation from the processes through which knowledge is developed and from the subsequent policies fashioned from that knowledge. In sum, PAR would give HIV/AIDS research a more humane face. It would empower communities to take charge of their destinies by creating a sense of ownership of (and obligation toward) the research activity, the information generated by it, and in the change agenda evolving from it. This would, in turn, boost the adoption rate of knowledge generated through research.

Finally, the utility of PAR has been demonstrated and the approach has been found to work within different cultural contexts. In the developing countries, it has been advocated by practitioners and researchers in diverse fields such as economics, sociology, anthropology, education, agriculture and public health (Finn, 1994). Past experience indicates that participatory action research readily precipitates questioning and taking charge on the part of community members. Indeed, there are researches that have enlisted community participation in different ways. In Nigeria, Brazil and South Africa, for example, researchers involved members of the community in designing the data collection instruments, discussing the findings and planning interventions (Weiss & Gupta, 1993).

In Botswana a shift toward more participatory and action-oriented HIV/AIDS research would not be extremely challenging to attain given the already existent community based structures for health care provision. Although there exists no trace of truly participatory action oriented research, elements of community participation are evident in the field of health care delivery. Community participation is one of the pillars of the Primary Health Care (PHC) strategy that was adopted by the government in its efforts to attain the goal of "Health for All" (Maganu, 1994, 1997; Ministry of Health, 1984). Through a decentralised system for the delivery PHC, the government has been able to cultivate the involvement of the communities and local authorities in policy determination, planning, implementation and evaluation of health care. This has occurred through the establishment of Village Development Committees, Village Extension Teams and Village Health Committees, to name a few. Through these structures seminars, in which ideas flow from the bottom up and vice versa, are organized for the community leaders, youths and teachers, among others. The health workers introduce a topic and the consequences of the problems and then allow the participants to assess whether it constitutes one of the problems facing the community and to come up with suggestions as to how to deal with the problem. This is not very different from what PAR entails.

Community structures created by NGOs such as the Botswana Red Cross and the Young Women's Christian Association (YWCA) may also serve a similar purpose. These, however, remain comparatively weak (UNICEF, 1990) compared to their equivalents in other developing countries. Not to forget the traditional *kgotla* approach in solving problems that is well rooted in Tswana society. The *kgotla* is a local public consultative assembly (Molutsi, 1998; Somolekae & Lekorwe, 1998) comprising the chief, tribal councilors, village development committee members, headmen and community members. It deliberates over matters affecting the community and makes important decisions. Being a community based democratic system, it would provide a bedrock on which PAR for the prevention of HIV/AIDS can thrive.

## Conclusion

The major thesis of this paper is that the notion of participatory action research should be extended to HIV/AIDS research in Botswana and elsewhere in the developing countries. It challenges the manner in which HIV/AIDS research has been carried out in the past on two grounds. That is, most of the knowledge generated through research grounded on traditional methods has been academic rather than action-oriented and, in terms of its design and application, the research has been both disempowering, alienating (or marginalising) and exploitative to the communities it is supposed to benefit. As such, it has failed to further the goal of curtailing the spread of HIV/AIDS. Based on these facts, it is argued that the prevention of the spread of the HIV virus could benefit immensely from both a participatory and action oriented approach to research. The approach would give such research a new orientation that would recognise that the community members who are to be affected by the programmes and policies based on research findings do genuinely have significant contributions to make to the entire (research) process. It would engage them constructively in both the research project and in the formulation and execution policies and programmes emanating from within the community and based on local realities and experience. This, in turn, would empower individuals and their communities and persuade them to take responsibility for their own wellbeing building on the strengths of local knowledge and values.

The importance of a participatory action oriented approach to HIV/AIDS research is underlined by the fact that, in the absence of a known cure or vaccine for the disease, prevention still remains the dominant mode of intervention. Prevention is in itself a process



of bringing about change in the society at large and in communities and vulnerable groups. In Botswana, after well over a decade of government mounted HIV/AIDS campaigns utilising messages fashioned from knowledge about the pandemic by both local and international intellectuals and experts applying traditional methods of research, the rate of infection has not slowed down. Today the country is rated among the countries with the highest infection rates in the world. This suggests that vulnerable individuals, groups and communities have not embraced the change (review of attitudes toward and practice of sex) advocated by preventive messages. Because of its very nature, participatory action research would enhance this goal tremendously. It would integrate groups and communities into the planning, execution and management of that change. This would create a sense of ownership of, responsibility over, and commitment to the whole process.

To conclude, an emphasis on participatory action research as a better approach to the prevention of HIV/AIDS neither suggests that the approach is perfect nor that it is appropriate for all kinds of problematic conditions. The approach does have some disadvantages that may undermine its utility. For instance, the close relationship between researcher and subjects makes it quite difficult for the researcher to be objective and the research is, therefore, vulnerable to all kinds of experimenter and subject effects (Bailey, 1994). Also, the narrow focus of research (to a particular community with a particular difficulty) prevents the social scientist from generalising research findings to other communities. Yet, it is often the case that different communities/groups can be experiencing similar problematic conditions. The focus condition of this paper--HIV/AIDS --is a good case in point.

#### Note

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