

Implementation of Meaningful Involvement of People Living with HIV/AIDS (MIPA) in HIV/AIDS Programmes in Matobo District of Zimbabwe

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Abstract • The HIV/AIDS pandemic is anti-development. It robs society of the resources that are akin to development. The MIPA is one of the programmes that have been put in place to help curb the pandemic in Zimbabwe. However, little appears to have been said about the effectiveness of the programme in Matobo District in Matebeleland South in Zimbabwe. This study evaluates the implementation of the programme. A mixed research design was used in the study. Semi-structured questionnaires were used in data collection. The theoretical framework of the study is a combination of the disclosure and the consequence theories of HIV/AIDS. The study concludes that implementation of the MIPA strategy in the district is not effective.

Keywords • People Living with HIV/ AIDS • HIV/AIDS Programmes • Zimbabwe

Introduction

The HIV/AIDS pandemic is one of the major development challenges for Zimbabwe, just as it is in many parts of the world. The pandemic robs of the economy of the skills and labour. The major problem with the pandemic is that it affects the productive and reproductive sector of the economy. With about 1.6 million people living with the HIV virus, Zimbabwe adopted various strategies to combat the spread of the pandemic. The National Behavioural Change Strategy (NBCS) is one of the strategies (Zimbabwe National HIV and AIDS Strategic Plan, 2006- 2010). The strategic issues of NBCS include full adherence to the principles of greater involvement of people with HIV/AIDS (GIPA), and meaningful involvement of people living with HIV (PLWHIV). The GIPA concept was adopted by the United Nations General Assembly Special Session on HIV

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and AIDS in 2001 and in 2003. Later PLWHIV lobbied for a new GIPA initiative called meaningful involvement of people with Aids (MIPA), which focuses more on the overall empowerment of PLWHIV. MIPA supports the integration of PLWHIV in the planning, implementation, monitoring and evaluation of interventions addressing HIV and AIDS issues.

According to the Asian Pacific Network of PLWHIV Report (January 2004), the concept is anchored on “Denver principles” of 1983 where HIV positive activists announced a set of principles destined to transform the way the world responded to the HIV epidemic (UNAIDS, 1999). The “Denver principles” set forth standards for human rights and self-empowerment of PLWHIV. The principles include; a refusal for people with HIV to be treated as victims, a plea against stigma and discrimination, and a request for support from all people. The Denver principles also call on all HIV-positive people to choose to be involved at all levels of decision making, to be included in HIV/AIDS fora and to be responsible for their own sexual health. Seemingly, little is known about the extent to which the GIPA principle is being applied in rural communities such as Matobo District.

Study Area

Matobo District lies on the Southern side of Bulawayo city. It shares its boundaries with Gwanda District on the South Eastern side and, Plumtree town to the West. The district has a total of 99396 inhabitants of which 52 294 are females and 47 102 are males (Zimbabwe HIV/AIDS District Atlas, 2006). HIV prevalence amongst pregnant women stands at 22%. (Matobo District Hospital ANC Statistics, June 2010). The district has 10 AIDS service organizations namely, Masiye Camp, Red Cross, Tshelanyemba AIDS Trust, Sikhethimpilo Centre, Word Vision Zimbabwe, Christian Care, Maranatha, Ministry of Health and Child Welfare, Matebeleland AIDS Council and Population services International and 116 support groups for PLWHIV (Matobo DA, 2010).

Statement of the Problem

The problem being addressed by the study is that people in Matobo District who are living with HIV have often been underutilised in HIV prevention despite the fact that they often understand each other's situation better than anyone else and are well placed to educate, counsel and advise one another and the affected community members. More so, there is scant information about the extent to which the MIPA principles is been applied in the district.

Assumption of the Study

The basic assumption of the study is that PLWHIV are not playing a central role in the direction and delivery of AIDS programmes in Matobo District; yet their involvement gives personal power and immediacy to AIDS efforts, improves the relevance of programmes and inspires others into action.

Justification of the study

Seemingly, the MIPA principle is central to the implementation of the Zimbabwe National Strategic Plan for HIV/AIDS. Analysing the operationalisation of the MIPA principle at community level helps in establishing the achievements and the challenges faced by

PLWHIV. Such information is likely to assist the organizations implementing the MIPA principle to improve their strategy against HIV/AIDS in the district. The effectiveness of MIPA helps create a better environment for the social and economic development of the nation.

Research Question

Two main questions underpin the study; (1) What are the perceptions of the people of Matobo District on the MIPA strategy? (2) How do PLWHIV in the district participate in MIPA?

Assumption

The study assumes that very few people do understand the MIPA principle. It is further assumed that personal benefits rather community benefits motivate the people in Matobo District to participate in the strategy.

Conceptual and Theoretical Framework

The study triangulates disclosure theories; namely, the disease progression theory and the consequences theory. Disclosure theories form the backbone of the MIPA principle as it takes individuals who would have experienced the consequences of living with HIV to make a difference in HIV/AIDS work. According to the disease progression theory, individuals disclose their HIV diagnosis as they become ill because when HIV progresses to AIDS they can no longer keep it a secret. Disease progression often results in hospitalizations and physical deterioration, which compels individuals to explain their illness (Babcock, 1998; Kalichman; 1995). Not only would hospitalization require explanation, but also if death is imminent. Delaying disclosure by the infected may be a way to normalize the life and protect others from pain. Marks and Bundek (1992: 300-3006) documented in a study of Hispanic men that as overall symptom severity increased, disclosure to others increased. By using a sample of symptomatic and asymptomatic men, Hays (1993), also found that asymptomatic men were less likely to disclose their HIV status than symptomatic men.

In a similar study, Mason (1995) purports that disease severity and time since testing for HIV have both been shown to be positively related to disclosure. Illness progression may heighten anxiety and need for social support, which may encourage disclosure to significant others such as friends and relatives. Studies of disease progression and disclosure of HIV status to sexual partners, however, have failed to find this same relationship. Perry et al (1994) did not find a relationship between severity of physical symptoms and disclosure to sex partners among 129 HIV-positive adults (UNAIDS, 1999). Thus, while disclosure to family may be influenced by disease progression, disclosure to sexual partners may not be.

The consequence theory of disclosure suggests that the relationship between disease progression and disclosure is moderated by the consequences one anticipates resulting from the disclosure. As the disease progresses, stresses accumulate which result in the need to evaluate the consequences of disclosure. Persons with HIV are likely to reveal to significant others and sexual partners once the rewards for disclosing outweigh the associated costs. According to Thibaut and Kelly (1959), individuals avoid costly

relationships and interactions and seek rewarding ones to maximize profits in their relationships or behaviours. More specifically, when individuals are faced with numerous choices they tend to make those which provide the most rewards with the least associated costs.

Rewards could be "pleasures, satisfactions, and gratifications a person enjoys." Costs are things of value that are relinquished in preference for an alternative reward that is of equal or greater value or something that would be punishing or distasteful that one would otherwise avoid. For persons with HIV, consequences of disclosing may be substantial. For instance, sharing an HIV-positive diagnosis can provoke feelings of anxiety and threats to personal well being (Bolund, 1990). Negative social consequences external to the HIV-positive individual, such as fear expressed by others, ostracism, and degradation may be experienced. Costs in terms of stressors within the individual's family network, such as denial, anger, guilt, and uncertainty are also associated with HIV. This might be especially true if the disclosure also leads to an admission of sexual behaviours that have not otherwise been acknowledged. Anderson (1989) asserts that, these physical, social, and emotional consequences can be confounded by fear of, or actual loss of, employment, insurance, housing, medical services, child custody, and the right to education.

Disclosing an HIV diagnosis can result in the acquisition of emotional, physical, and social resources such as assistance with home-related chores and errands, health and childcare, housing, medical attention, and the provision of medical information. Emotional benefits include the acquisition of social support and acceptance. Furthermore, disclosing one's sero-status frees the individual from hiding complicated medicine taking rituals from friends, family, and co-workers. Thus, indirectly, support for adhering to medical regimens is a positive consequence of disclosure. Each of these consequences may be important for the physical, emotional, and social functioning of the person. HIV theorists such as Derlega, Lovejoy and Winstead (1998) concluded that the process of reducing risks and increasing benefits of disclosure results in selectivity of disclosure. That is, HIV-positive individuals disclose to those who pose little risk while avoiding disclosing to those who could harm them thereby putting a human face to the HIV epidemic. It is through disclosure that the MIPA principle can be put into fruition.

Research Methodology

The research adopted a mixed research design. The methodology generated rich, detailed and valid data that contribute to an in-depth understanding of the problem at hand. The study gathered data from those involved in HIV prevention in Matobo District; namely, the AIDS Service Organizations, Ministry of Health Child and Welfare and the National AIDS Council officials were consulted through the course of the research. The PLWHIV support group members themselves were an important source of information as the problem at hand has a direct effect on them. By expressing their views, perceptions and aspirations they contributed usefully to the study by drawing on their experiences. The respondents were drawn from the community support groups of PLWHIV. The study involved 93 villages. Probabilistic and non- probabilistic sampling techniques were used to come up with 1116 participants were reached during the period of study, with 335 being males and 781 females. Data were analyzed using the frequency counts of the responses that were elicited. The demographic profiling of the respondents is shown in Table 1.

Table 1: Distribution of Respondents by Age Group

Ward	< 20	21-30	31-40	50
Kafusi	3	10	19	22
Dzembe	2	11	14	27
Gwezha	9	10	13	14
Makho	6	11	27	32
Beula	5	13	17	22
Sigangatsha	7	9	17	29
Malaba	5	8	15	16
Bidi	7	4	13	22
Bambanani	3	6	18	15
Makhasa	7	12	11	11
Mbembeswana	15	18	23	24
Sontala	12	9	13	21
Manyane	2	4	23	23
Madwaleni	8	7	15	27
Mkokha	5	12	21	45
Vulindlela	7	8	15	26
Dema	3	9	28	30
Mazhayimbe	7	6	18	37
Zamanyoni	0	12	12	22
ASOS focal persons	0	3	5	4
WAAC Focal persons	0	0	17	2
Total	113	182	354	467
Sample %	10%	16%	32%	42%

Findings

Majority of the respondents were not sure of the benefits of disclosing their HIV status (Figure 1).

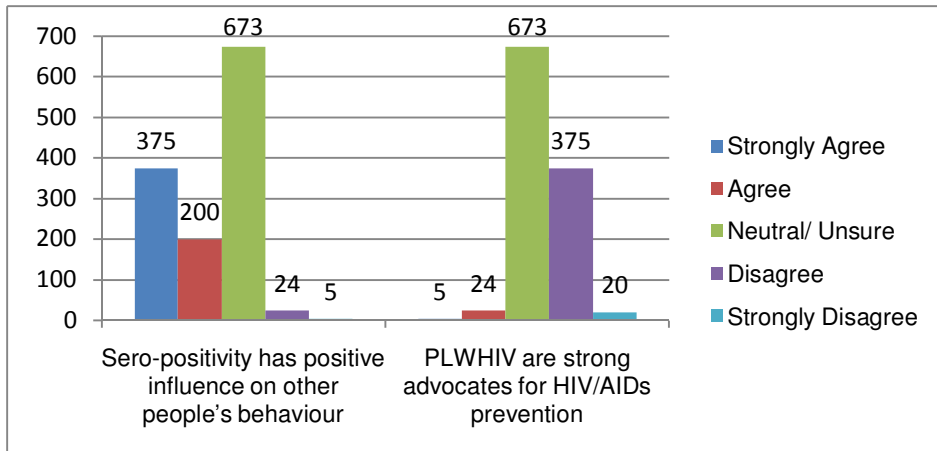


Figure 1: Impact of PLWHIV/ AIDS on Prevention of HIV

In the light of the results presented in Figure 1, the study notes that the majority of people in Matobo District do not know the benefits of coming out in the open about their HIV/AIDS status.

Majority of 61 % of the respondents proved to be unsure of their stance in advocacy for HIV prevention. A minority of 34% indicated that they had very little influence to the community on HIV prevention issues. Figure 2 provides a pictorial view of the findings. Therefore, the study concludes that most of the people in Matobo District are not sure of their stance in the advocacy for HIV/AIDS prevention.

Majority of the respondents were not aware of how they could use their status to transform the lives of other community members. One of the key informants disclosed that most PLWHIV view themselves as program beneficiaries rather than potential behaviour change agents.

In view of the above findings, the study notes that a majority of the people do not know how to apply the MIPA principle in preventing HIV/AIDS in the district (Figure 2).

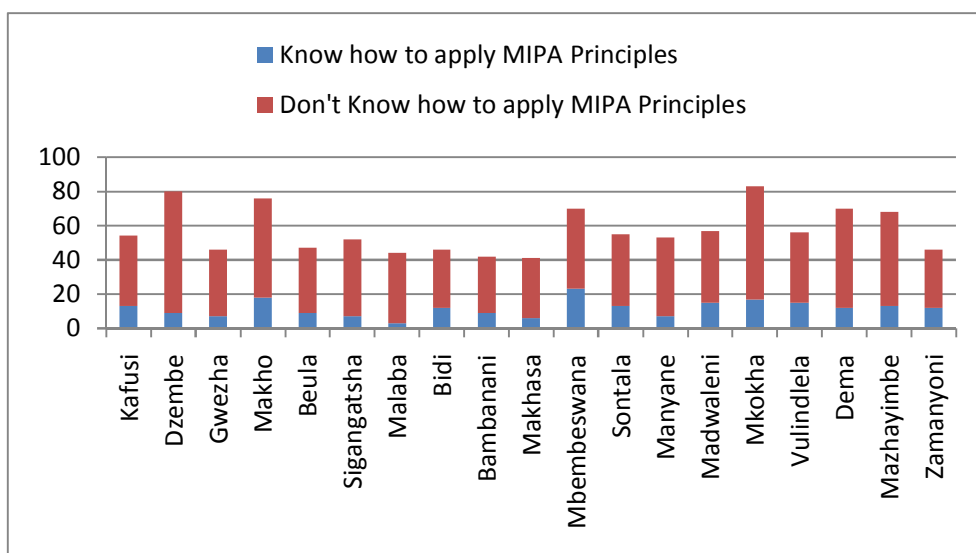


Figure 2: Place of Sero-positives in Anti-HIV/ AIDS Advocacy

Table 2 shows the roles PLWHIV play in accordance with the MIPA principle and strategy.

Table 2: Exposure to HIV/AIDS Prevention Training

Ward	Exposed		Not Exposed	
	Count	%	Count	%
Kafusi	13	24	41	76
Dzembe	9	11	71	89
Gwezha	7	0.1	39	99.9
Makho	18	22	58	78
Beula	9	19	38	81
Sigangatsha	7	13	45	87
Malaba	3	0.1	41	99.9
Bidi	12	26	34	74
Bambanani	9	21	33	79
Makhasa	6	0.1	35	99.9
Mbembeswana	23	0.4	47	99.6
Sontala	13	0.2	42	99.8
Manyane	7	13	46	87
Madwaleni	15	26	42	74
Mkokha	17	0.2	66	99.8
Vulindlela	14	27	41	73
Dema	12	17	58	83
Mazhayimbe	13	19	55	81
Zamanyoni	12	26	34	74
AIDS service Organizations Focal Persons	12	100	0	
Ward AIDS Action Committee Focal persons	19	100	0	
Total	250	22%	866	78%

From the statistics shown above, 22% (250) of the respondents were exposed to HIV prevention trainings. The above statistic shows that not much has been done to capacitate the PLWHIV in the district to play an active role in the prevention of HIV/AIDS in the district. Indeed, the study found that only 31 out of 1116 respondents had taken part in the development of at least one HIV prevention program.

Majority (97%) of the respondents felt that the MIPA of PLWHIV meant integrating PLWHIV in the planning, implementation, monitoring and evaluation of interventions addressing HIV issues. This shows that support group members are now aware of their stance in the ownership of programs designed for their communities.

A majority (97 %) or 1082 respondents understood the MIPA as a strategy that focuses on those infected with the HIV virus only. The respondents could not establish the role of their partners, spouses, children and parents in the MIPA strategy. One of the respondents note that MIPA was a strategy for the infected and that people should also come up with a strategy for those who are not infected by the virus.

A minority of 31 participants understood the meaning of HIV prevention advocacy. However, it was established that most of the respondents had not been exposed to HIV prevention trainings. This finding explains why the participants had a poor understanding of HIV prevention advocacy.

Most (90%) of the participants indicated that they joined support groups during the time when the National AIDS Council was distributing food packs to those living with the virus. It was noted that PLWHIV join HIV/AIDS support groups to facilitate the flow of tangible benefits from donors and the government. One of the respondents said “In times of poverty, substantial donations tend to HIV victims encourage people to disclose seropositivity”. Ten percent of the respondents did not say anything on this question.

Majority of the respondents understood self-stigmatization to be avoidance of people and self-hatred. From the responses given, they were mostly aware of stigma instilled by external forces instead of stigma instilled by the self (Figure 3).

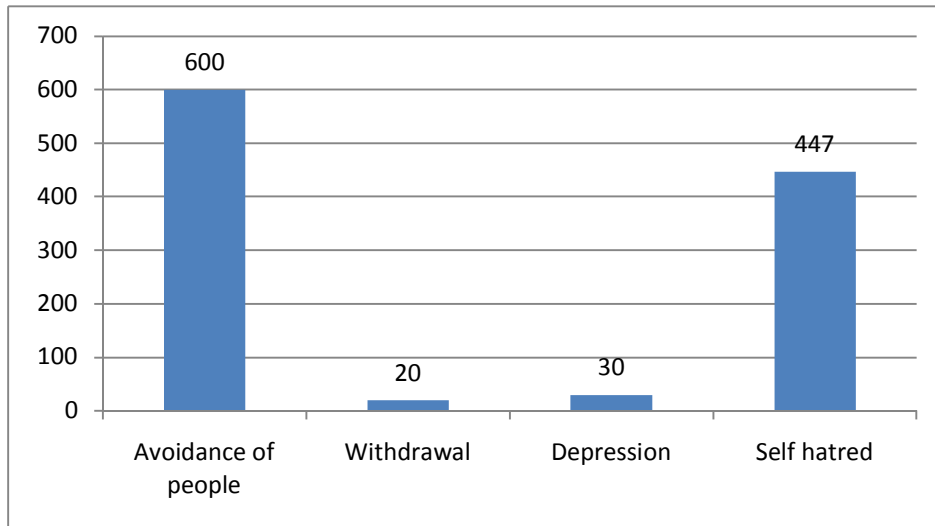


Figure 3: Participants' Understanding of Stigma

In view of the above data, the study concludes that avoidance of people and self-hatred are the main effects of HIV/AIDS stigmatization in Matobo District. The respondents indicated that status disclosure has become a common phenomenon since the inception of the Behaviour Change strategy in the district. This is now facilitating the acceptance of AIDS as a condition that does not deter the infected from taking part in development and self help programs. One of the respondents noted that “as more and more people talk about behaviour change, I feel comfortable to talk about my HIV status.”

Discussion

Understanding of the MIPA principle

The impact at community and individual level was not noticed amongst support group members. The respondents were no aware that by being involved they would psychologically benefit by sharing similar experiences and are part of a larger movement with the potential to shape and influence program design at local levels. The benefits of MIPA include the improvement of self-esteem, offering of a sense of personal empowerment, decrease of feelings of shame, stigma, isolation, or depression. By fear of speaking out in their communities, PLWHIV could not establish social relations and self-efficacy, improving psychological as well as physical health. Access to information about prevention, care and treatment was deficient in all areas covered. Active engagement of PLWHIV in strategic planning, implementation, monitoring and Evaluation, is lacking in all areas covered. Operationally, coordination of MIPA issues has been a serious drawback as organizations established by PLWHIV, or those organizations that are working with them have often failed to embrace all the actors and beneficiaries of MIPA. Additionally,

the capacity of PLWHIV networks often has limited their meaningful involvement in HIV and AIDS programming.

Lack of technical capacity is further aggravated by the existence of negative social attitude to PLWHIV (stigma and discrimination) by the greater society including some community gatekeepers. Further, the representatives of PLWHIV sometimes represent their own individual interests as opposed to the collective interests of PLWHIV. In such a case the representatives cease to be accountable to the broader constituency of PLWHIV and contributing positively to reducing HIV transmission. PLWHIV have thus continued to be involved more as programme beneficiaries than as partners in the design and implementation of HIV and AIDS programmes. It also emerged that stigma and discrimination against risk groups such as those infected with HIV/AIDS persists in the communities. Consequently, people who suspect they might be infected with HIV are afraid to be tested for HIV. It would be very difficult for anyone to disclose his/her HIV status soon after testing positive because of the realistic fear of experiencing social death. The death comes many years before sickness and actual biological death. The above view shows that social discrimination is an important factor in the fight against HIV/AIDS. Put differently, social discrimination and stigmatization of HIV victims reverse the global efforts that are being made in promoting the universal access of HIV prevention services to communities.

MIPA Advocacy

The study established that there challenges to MIPA advocacy. These challenges include: weak management, low skill levels, funding constraints, difficulties in representing the diversity of people living with HIV, a lack of documentation of their histories of self-empowerment and a lack of evaluation of successes and failures. In fact one of the respondents noted that much energy is spent on basic survival, including fighting for access to treatment for HIV and opportunistic infections, care and support. It also emerged that financial constrain is also a barrier to the participation of PLWHIV in the fight against the pandemic in their respective communities. The respondents reported the need to be capacitated on advocacy skills so that they are capable of identifying problems related to HIV work and coming up with strategies to address them at their levels.

The study also established that focal persons for PLWHIV in Ward AIDS Action Committees (WAAC) have also failed to represent the needs of people living with the virus despite the fact that they were strategically designed to address the gaps identified in program development. The National AIDS council created these structures so that the voices of people living with HIV could be heard from the grassroots.

It was also established that funding has been a huge problem in carrying out advocacy activities in the community as there has been a shortage in the provision of information and communication material to facilitate the dissemination of various HIV messages and to save as identification material for those interested in helping out communities in HIV prevention. Representatives from the Zimbabwe Network of People Living with HIV indicated that they were made to form groups but no follow-ups have been made in strengthening the activities that are being carried out. It also emerged that the District AIDS Action committee monitoring and evaluation subcommittee in Matobo District has not been active in evaluating the successes and failures of the implementation of the MIPA principle despite its rollout as an important HIV prevention advocacy strategy.

Motivation for PLWHIV to Carry out MIPA Activities

The current MIPA principle calling for greater involvement of PLWHIV in HIV/AIDS programmes cannot take root without financial investment in individuals. Investment in PLWHIV is fundamental to establishing social practices, and demonstrating commitment to improving the lives of PLWHIV and contributing to HIV prevention in their catchment areas. It emerged that PLWHIV in Matobo District have not been getting sufficient promotional material for their activities in their catchment areas; and yet the PLWHIV programme requires skills training to ensure that group members are effective champions in their roles within their communities. In fact, literacy in the basic science of HIV is also essential. PLWHIV need up-to-date training in areas, such as prevention, care, and treatment; HIV counselling and testing; prevention of mother-to-child transmission; and human rights, stigma, and discrimination, if they are to understand their own HIV status, communicate effectively with providers, and advocate for high-quality care and treatment. Adequate financial investment is needed so that PLWHIV can support themselves and their families while participating in programmatic and policy initiatives.

Conclusions

The study concludes that the MIPA principle is not being applied in Matobo District as expected by the disclosure and consequence theory. HIV/AIDS organizations in the district need to develop proper PLWHIV-centred not system-centred thinking around the fight against the pandemic. In a bid to improve the work of PLWHIV in rolling out the MIPA principle support, there is need to build from community responses, provide a principled and grounded approach to HIV interventions, which recognize that community expertise, and experience is critical to success. In addition to contributing critical work in our communities, people with HIV should be encouraged to participate in decision-making roles. The study also concludes that the PLWHIV in Matobo District attach the benefits of MIPA to the infected persons only. The finding confirms the view that personal benefits rather community benefits motivate the PLWHIV in the district to participate in the MIPA strategy. The study further concludes that the people in the district are ill-prepared to participate fully in MIPA. Training and re-training programmes are required to capacitate the PLWHIV to take up a meaningful role in the fight against the HIV/AIDS pandemic. The expansion of health and education services at the centre of all community development initiatives. This will empower the district if communities are to be able to respond adequately to issues of HIV and AIDS.

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