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THE CHALLENGES OF COMMUNITY-BASED INTERVENTIONS FOR PEOPLE LIVING WITH HIV IN FOUR HIGH HIV PREVALENCE REGIONS IN GHANA: LESSONS FOR AFRICA

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ABSTRACT: *The 'HOPE' programme is a major community-based care and support programme for providing care for people living with HIV (PLHIV) in Ghana. This paper explores the challenges confronting the 'HOPE' programme and discusses them in the context of wider literature to provide lessons for Ghana and Africa. The study adopted a qualitative approach in which in-depth semi-structured interviews were carried out with 14 stakeholders and 8 focus group discussions were held with the programme beneficiaries. The data was analysed using thematic analysis. It was identified that only a few of the beneficiaries benefited from skills training leading to employment due to inadequate funding, slow cash flow and inadequate inter-sectoral collaborations. To compound these weaknesses, most reported that they preferred petty trading to the skills offered. Also, the long-term sustainability of the food supplementation once funding is discontinued was a major concern. However, the health education component could be sustained due to peer educators trained.*

KEYWORDS: HIV, Community-Based, Interventions, Care, Evaluation

INTRODUCTION

The number of people living with HIV (PLHIV) globally continues to increase as a consequence of population growth and the life-prolonging effect of antiretroviral therapy (UNAIDS, 2009). However, the infrastructures to support people living with HIV are limited in many poor countries affected by the pandemic (Gombe and Kimanzi, 2004). As a result, 56% and 15% PLHIV are not accessing relevant care and support services in Africa and Ghana respectively (Okine, 2010). A review of the literature on HIV in Africa carried out by the researcher revealed preponderances of evaluation into prevention strategies, level of behavioural changes (MacNeil, 1998) and clinical trials of therapy (Roger *et al.*, 1998). However, very little work has been carried out to examine the care and support component (Praag, 2006) provided by programmes which 'HOPE' (HIV/AIDS Orphans and Vulnerable Children and PLHIV Care, Support and Economic Enhancement Programme) is an example of one such programme.

A study conducted by Opportunity Industrialization Center International (OICI) in Ghana prior to the implementation of the 'HOPE' programme indicated that most of the resources available for HIV/AIDS by the Government of Ghana through the Ghana AIDS Commission, local and international NGOs were primarily focussed on prevention (OICI Ghana, 2003). In addition, technical and financial resources to build the capacity of health workers, caregivers

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and to provide care and support services for the PLHIV and Orphans and Vulnerable Children (OVC) were woefully inadequate. It is against this background that the 'HOPE' programme was instituted by OICI with support from the United States Agency for International Development (USAID). The goal was to provide and improve care, support and economic opportunities for the PLHIV and OVC in four high HIV/AIDS prevalence regions in Ghana (OICI Ghana, 2003). These are the Ashanti, Eastern, Greater-Accra and Western regions. The programme activities included food supplementation, health education and skills training. The interventions include the provision of monthly dry micro-nutrient dense food rations composed of Soy Fortified Sorghum Grits, Wheat Soy Blend and Vegetable Oil to the beneficiaries.

In addition, the programme seeks to build the capacity and create economic opportunities for the beneficiaries through monthly education, training workshops and skills training. The aim is to sustain livelihoods, promote behaviour change and communicate information. The intended outcomes are improved health, disease prevention and the alleviation of severe malnutrition (OICI Ghana, 2005).

The programme started in 2004 with 400 beneficiaries and now has over 1000 beneficiaries. The programme had two main target groups; the primary and the secondary target groups. The primary target groups which were the direct beneficiaries were the PLHIV and OVC. The secondary target groups were the community health nurses, traditional healers, the queen mothers, orphanage caregivers, and OICI counsellors.

The programme has achieved successes on the implementation of the programme activities as revealed in the detailed research carried out by the researcher. However, there are challenges associated with the implementation of these activities especially the skills training component. Given the challenges confronting care and support programmes for PLHIV in Ghana and Africa, it became prudent to learn more about those challenges. The paper therefore focussed on the views of the patients and stakeholders on the programme activities to unravel those challenges and discussed them in the context of wider literature to provide lessons for Ghana and Africa.

METHODOLOGY

Study population

The study population were People Living with HIV belonging to 21 support groups which had been enrolled into the 'HOPE' programme for a minimum of twelve months and stakeholders directly involved in the programme implementation.

Data collection technique

The 8 focus groups were sampled from the 21 support groups using a simple random technique. Each group had eight PLHIV as these were randomly selected again using a paper ballot. The focus group discussions were held at the support groups meeting room as a convenient place agreed upon by the participants. The questions were asked about the supports they received from OICI and its contribution to their health, wellbeing, home and lifestyle, challenges and recommendations. Additional questions were asked to gain a deeper understanding of individual circumstances.

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The 14 stakeholders were contacted and interviewed. These were eight support group coordinators, all the four OICI regional coordinators, the OICI Monitoring and Evaluation Officer and the National HIV/AIDS Director of OICI Ghana 'HOPE' programme. The support group coordinators selected were those in-charges of the support groups selected for focus discussions to reconcile any emerging issues from the focus group discussions. Interviews with the stakeholders gathered information on the structure of the programme, the core activities, how well the programme has progressed in accordance with the goals and the objectives of the programme, challenges and recommendations for the future. All the focus group discussions and the interviews were audio recorded and additional notes were taken where necessary. The audio recordings of focus group discussions and semi-structured interviews were transcribed verbatim.

Data coding and analysis

The data were analysed using thematic analysis (Braun and Clarke, 2006), facilitated by software (ATLAS Ti). Initial codes were applied to the transcripts, refined and subsequently sorted into potential themes. These were then grouped into broad categorical headings which map onto the questions asked. These are: beneficiaries and stakeholders' views on the skills offered (Benefits and constraints), beneficiaries and stakeholders' views on the food supplementation (Benefits and constraints), beneficiaries and stakeholders' views on the health education (Benefits and constraints), level of programme involvement, suggested policies and broader changes and level of confidence for programme sustainability. However, three themes which highlighted enormous challenges were selected for this paper to provide lesson learning. These are the beneficiaries and stakeholders' views on the skills offered, food supplementation and health education.

RESULTS

Beneficiaries and stakeholders view on the skills offered

The qualitative studies demonstrated that the programme was perceived as beneficial to health, nutrition, social and the psychological status:

> *Before they came to help us the disease was killing us massively, we were dying of the disease, but since they came in, the rate has reduced (4th speaker, FG 2).*

However, most of the beneficiaries self reported being unemployed. According to them, some lost their jobs whilst others resigned from their job because of their HIV status. This was as a result of stigmatisation and discrimination against PLHIV at workplaces. They indicated that only a few of them benefited from skills training leading to employment. This is because of inadequate funds as a result of under budgeting in the initial programme proposal, slow cash flow from their donor and lack of inter-professional collaboration in the proposal development:

> *I think for every programme, before you can run a detail programme you need money. I think one weakness of our programme is that we under budgeted for most of our programmes so we're finding it difficult to meet most of our needs (Stakeholder 11).*

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> *I think, the budget is still a challenge and coming up with a programme, there is a need for the finance persons to get technical HIV/AIDS persons who can give them details on what the activities are so they can base the budget on, so that in running the programme you don't get hot up along the way that you do not have funds to continue because these are vulnerable groups you are dealing with (Stakeholder 7).*

However, beneficiaries identified participation and cooperation as being key prerequisites for success to address the challenge of inadequate funds but they also identified important weaknesses in 'HOPE' with respect to these criteria. This is because, participants indicated receiving support from the organisations such as the World Vision, National AIDS control programme (NACP), ESTHER, Adventist Relief Agency (ADRA), and the Ghana AIDS Commission (GAC). The support included financial support for skills training, medication, monthly meetings and educational programmes to build their capacity. However, there were no collaborations with these organisations with the exception of the GAC which provided little financial support for OVC skills training tools.

A few who benefited could not use their newly acquired skills because of lack of capital to start a business:

> *The soap making, when we were trained, we did not have any money to start the project, so the soap making activity slowed down (5th speaker, FG 2).*

To compound these weaknesses, most reported that they preferred petty trading to the skills offered:

> *I feel that if they get money, everybody should be supported to do whatever he/she is doing in a very small way so that the interest of me selling my salt will still be there, the interest of selling my paper in the market will still be there but not the idea of the support group having soap and I am not interested and I have to come and cope with that situation (Stakeholder 9).*

Beneficiaries and stakeholders view on the food supplementation

Findings from the interviews and focus group discussions, demonstrated that the food supplementation was perceived as beneficial to health and nutritional status:

> *[…] the food helps us a lot. It gives us strength and when we check our body weight, we observe that we have gained some weight (2nd speaker, FG 4).*

They reported that the anti-retroviral drugs were making them hungry and the food has contributed tremendously to alleviate that effect:

> *When you are put on ARV it is another thing all together. You get hungry, you need to eat and you need to take your drugs. How do you take your drug when you don't have food? It is a challenge, so most people were not adhering. They tell us that, I am not taking my drugs because when I take my drug I get hungry and I don't have money to buy food. So adherence to ARV has increased rather than decreased* (*Stakeholder 7).*

Additionally, they reported that support groups have been sustained, membership had increased and most of the PLHIV attended meetings because of the food:

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> *You realise that food, although is phasing out but it has always been able to always bring these people together so that if you have any other thing that you want to tell them, you can tell them but without the food normally you see that they do not even attend their monthly meetings, so if you go there for education, no matter the kind of education you coming with, all they are interested is the food (Stakeholder 9).*

Nonetheless, there were challenges that hampered the smooth implementation of the programme. Beneficiaries reported that the quantity of food received was reduced in the course of programme implementation to give equal quantities to all groups receiving support from the USAID in order to control participants moving from one support group to another.

In addition, some indicated that food should be varied for them since they were fed up eating one type of meal. Also, the long term sustainability of the food supplementation once funding is discontinued was a concern:

> *Most of them depend on the food to take their drugs and I don't know where some of them their daily bread will come from when the programme ends since most of them cannot afford to sustain the food (Stakeholder 14).*

Finally, they mentioned selling some of the food to earn money to buy other types of food and to pay for their medications:

> *The situation is, eating the food is very helpful but due to financial difficulties some of us sell the food. The reasons we do that is that, sometimes we need to buy the drugs meanwhile you are financially handicap, so you are forced to do so even though that is not desired (3rd speaker, FG 3).*

Beneficiaries and stakeholders view on the health education

The qualitative research suggests that there was not much feeling of programme involvement in aspects of the programme activities from either stakeholders or beneficiaries:

> *Sometimes some people do not like the food they supply. It can happen that they collect and go and sell to buy whatever they like. So if they had seen us we are going to bring you food, do you like it. Most of them like the tombrown this is what I have seen. So if they had consulted us instead of ordering for wheat, bring tombrown* (*Stakeholder 14).*

However, there was suggestion of beneficiaries and stakeholders involvement in the educational aspects of the programme:

> *The peer educators trained in the support groups, if we are not there they would continue with their education (Stakeholder 7).*

Also, the secondary target groups were trained to support the PLHIV in their catchment areas:

> *OICI intervention is not about helping the PLHIV alone but also training the nurses on psychosocial counselling and home based care. Training caregivers and educating caregivers during monthly meetings. We also train traditional healers so that they begin doing the right thing (Stakeholder 11).*

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However, beneficiaries expressed concerns about the criteria for selecting participants for training workshops. These required that participants could write, respond and contribute to discussions:

> *There are people who are not good speakers in public, some cannot write, they cannot respond to questions. Those who are able to respond and contribute to the discussions are selected to attend the workshops (4th speaker, FG 3).*

DISCUSSION

Inadequate funding is becoming a major constraint to most of the community-based interventions that proved to be effective in Africa (Florentino, 2003). This is evident in the 'HOPE' programme where a few were trained on a skill due to inadequate funding. This is probably because of inefficient use of resources for community-based interventions in Africa. This happens when collaboration among organisations with similar vision and operating common catchment areas are not explored to pull resources together for a common intervention. Simply because most of these organisations want sole recognition to their interventions as an effective approach to improve the life of the beneficiaries in order to maintain support from their donors. This is evident in the 'HOPE' programme where there were inadequate formal collaborations with other NGOs and public organisations implementing similar interventions in their catchment areas with the exception of the Ghana AIDS Commission which provided little financial support for OVC tools (as indicated in the interviews). Yet, some support groups under the 'HOPE' programme were receiving similar support from these organisations. The supports from these organisations were not controlled to help attribute outcomes to the interventions. From the point of view of this evaluation, it is impossible to know what outcomes are attributable to 'HOPE' and what may have resulted from inputs from other NGOs. However, inter-sectoral collaboration by developing common guidelines that is applicable for local settings have proved to be successfully and ensures effective and efficient use of resources (WHO, 2001). This approach was adopted by UNICEF in 2002 in 100 districts within 11 countries in West Africa during the implementation of the programme called Accelerated Child Survival and Development (ACSD). The programme involved all key partners such as the World Bank, numerous NGOs, government and community leaders, WHO and others. The programme brought 20% reduction in child deaths across 16 districts where it was fully implemented and 10% across districts where it was implemented partially after three years (Veneman, 2005). It is possible that the collaboration of the 'HOPE' programme with these organisations could have saved the programme from some financial burdens if arrangements had been formalised and economies of scale utilised.

Problems associated with proposal development are increasingly becoming a concern. In most instances, either the proposal excludes the key needs of the beneficiaries or most of the activities are under budgeted. This was evident in the 'HOPE' programme where the budgets for most of the programme activities were underestimated as indicated in the interviews. Also, among those who had been previously trained on a skill prior to the programme, 72% attributed non-use of skills to lack of initial capital (OICI Ghana, 2003). This should have been addressed in the initial proposal. However, the same concern has been raised, where beneficiaries attributed non-use of skills to lack of initial capital. The suggestion from the interviews is that these failures arose because the consultants who worked on the proposal did

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not collaborate adequately with the technical team. This problem has been identified with many other proposals submitted for funding from developing countries: there is a tendency to exclude key needs of the intended beneficiaries either because they have not been adequately involved in developing proposals or important inter-professional collaborations have to been established. For instance, a study conducted by the Global Funds as a result of funds earmarked for AIDS, Malaria and Tuberculosis in developing countries revealed these very weaknesses and further commented that most of the agencies that benefited had weak initial evaluation proposal in terms of their ability to meet the key needs of intended beneficiaries (Radelet and Siddiqi, 2007).

Finally, the nature of food provided by the programme brought benefits to the beneficiaries but the sustainability of the food component beyond the programme period remains a major concern. This is not surprising given that the members of the support groups were recruited into the 'HOPE' programme because of difficulties in maintaining normal life – a circumstance that can lead to depression and loss of hope (Williams *et al.*, 2005). It seems logical to suggest that the programme should have invested in local production through community farming which would have resulted in beneficiaries being able to enjoy the produce during and, crucially, after implementation of the programme.

CONCLUSIONS

The study identified inadequate funding, perceived lack of cooperation, weak programme design, weak initial proposal, inadequate inter-professional collaboration and the long term sustainability of the intervention as challenges confronting the programme. However, greater participation by members of the community, local produce and more inter-sectoral cooperation were seen as important criteria to minimise these challenges but as key weaknesses of the current intervention.

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