

AN ASSESSMENT OF HOME-BASED CARE PROGRAMS IN UGANDA: THEIR STRENGTHS AND WEAKNESSES

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ABSTRACT

Currently, lessons are being learnt from successful HIV/AIDS programs for policy decisions and program strengthening and implementation. This study assessed the Home-Based Care Programs in Uganda, highlighting their strengths and weaknesses, and relating these to their strategies. Using qualitative and quantitative methods, the following elements of care were assessed in seven Home-Based Care Programs: aims and objectives, provision and continuum of care, staffing, supplies and equipment, education, financing, costs of care, monitoring and evaluation, and impact. The findings were evaluated with the Best Practice criteria of relevance, sustainability, ethical soundness, effectiveness and efficiency. Comprehensiveness and delivery of AIDS care, integration with prevention and types of drugs were relevant to the family, community and national needs. Ethical principles of confidentiality and equity of access guided their approaches. Sustainability measures like networking, active community participation, including volunteer service were employed. Their periods of operation, 10-17 years, reflected medium term sustainability. Effectiveness was reflected in reported satisfaction with care and improvement in quality of life among high proportions of beneficiaries. Identified weaknesses include: weak management and financial controls; deficient records management; lack of defined outcome measures; heavy dependence on foreign funding; weak and informal health facilities linkage; a gap between the programs and the local political and administrative leaders; lack of national policy on AIDS home-based care. The facility outreach programs utilizing nursing personnel and large numbers of community volunteers for medical and enlarged psychosocial support appeared more efficient, from the large patient turnover and number of visits, low ratios of staff/patients and staff/visits conducted and lower average costs of care. There is a need for a national policy on home-based care, for standards and guidelines and internal funding. The home-based care programs require strengthening for enhanced efficiency and effectiveness with regards to management, and resource utilization.

Keywords: Home-Based Care Programs, Home-Based care, Best Practice criteria, relevance, sustainability, ethical soundness, effectiveness, efficiency, community-volunteers, Uganda, HIV/AIDS

INTRODUCTION

Home-based care, the program that offers health care services to support the care process in the home of the HIV infected person (WHO/GPA, 1989), has been a major care and support strategy since the inception of the epidemic in Uganda. This was against a background of scarce health care facilities, difficulty in accessing the available care facilities by the very ill, and the preference for terminal care and death in the home-setting (Kalluvya, 1997). Consistent with the comprehensive care strategy recommended for HIV/AIDS infected and affected individuals (Osborne et al., 1997:11B; Osborne 1996: 10), Home-Based Care Programs aim to alleviate human suffering and pain, and mitigate the impact of HIV/AIDS through comprehensive care package of nursing care, treatment of opportunistic infections including symptoms and pain; counseling and emotional support; assistance with essentials like food and soap; poverty alleviation measures like income generating activities; orphan care; legal aid including will-making; advocacy; prevention strategies of education and awareness programs for behaviour change and condom distribution. The extent of service depends on the Home-based care programs' objectives and strategies and available resources.

The documented successes and benefits of these programs include: enhancing the quality of life, easing of pressure on the few health facilities; alleviation of families' lack of essentials; stigma reduction and high risk behaviour change (Campbell 1988; WHO/GPA 1989; Chela et al 1995; Ndyabangi et al, 1995; Kaleeba et al., 1997; Family Health International, 1997, MacNeil and Anderson, 1998:12).

According to AfriCASO Directory of 2000, there were 39 registered home-based care programs in Uganda, a likely underestimate as many community-based organizations operate unregistered. Some home-based care programs are initiated and operate within the community (community-based organizations CBOs); some are faith-based organizations (FBO), operating as facility outreaches; some Non-governmental (NGOs), operating from facilities or within the communities; and a few are governmental (attached to government facilities). The FBOs and NGOs operate with varying degrees of community mobilization and participation. The facility based programs utilized medical personnel, mainly nurses while the CBOs utilize mainly volunteers.

An umbrella organization, the Joint Home Care, aims at promotion of experience sharing through networking among the Home-based care programs in Kampala. Each program is allocated a specific area to avoid overlapping of activities, duplication of efforts and a waste of resources (Rwomushana, 1997; Eriki et al., 1997).

There is no government policy and direct participation in Home-based Care. Therefore there are no guidelines or standards to regulate their activities. The cost of home-based care is borne by the private sector, often religious or charity, with funds largely from external donors. However some CBO programs receive insufficient funds from the District Sexually Transmitted Infections (STI) Program (Mulogo, 1998).

As other countries seek to learn from the Uganda experience and success in reducing the HIV prevalence from about 30% to 5% (Mbutaiteye et al, 2002), Home-Based care will be one of the strategies focused on. Furthermore, with the current recognized inadequacy of prevention alone in HIV/AIDS epidemic control, and the new thrust on care and support, including treatment for opportunistic infections and anti-retroviral therapy, there is a need for strengthening and expanding the existing Home-Based Care Programs. This would position them for participation in this new thrust. A need therefore arises for an overview of the existing programs regarding the care offered and strengths and weaknesses, with the overall aim of improving the quality of care, and drawing out lessons for other AIDS programs and policy both nationally and internationally.

It was against this background that this assessment of Home-Based Care Programs in Uganda was conducted. The aim was to improve the quality of home-based care provided for the people living with HIV/AIDS and terminal cancers. This was to be achieved through the following objectives: assessing the components and practices of home-based care by programs of different strategies, including the cost of care; identifying the factors necessary for providing quality home-based care; and identifying the strengths and weaknesses in the delivery of home-based care by the programs using the UNAIDS Best Practice criteria for AIDS Home-Care.

Best Practice, defined by UNAIDS as the continuous process of learning, feedback, reflection and analysis of what works or does not work (**UNAIDS 1999**), identifies effective programs based on research and evaluation. Such programs present lessons in strengths and weakness, and information useful for programs and policies. The UNAIDS recommended the following criteria for identifying Best Practice programs we home-based care programs:

- Relevance
- Ethical Soundness
- Sustainability
- Effectiveness
- Efficiency

A relevant program is in alignment with identified local and national needs, taking into consideration, in its planning and implementation, factors such as leadership structure,

community educational and economic status, and local cultural practices and norms especially with regards to women and children's situation.

Ethical soundness is the degree to which the program planning and implementation are guided by appropriate professional and social conducts. These include equity, access to care, distributive justice with no discrimination, confidentiality, informed consent, autonomy in care, respect for human rights and dignity of the beneficiaries. The workers need to demonstrate compassion, solidarity, tolerance and responsibility.

Sustainability refers to the capacity of a Home-based care program to continue to function with some degree of autonomy in the mid- or long-term. A sustainable program partners with local authority and power structure, networks with community organizations, links with pre-existing institutions, and builds local capacity. Sources and reliability of funding are critical to program stability and longevity. Flexibility and adaptability of programs allow for response to resource availability fluctuations.

Efficiency is the ability of a Home-Based Care Program to produce its desired outcome with minimum resource expenditure, in terms of time, money and labor. This is critical in AIDS work in communities with limited resources despite many and complex needs. It includes issues of resource (financial, human and material) management; records and information management; monitoring and evaluation with defined indicators; and cost-benefit analysis using measures like cost/treatment, and staff person hours/visit.

The effectiveness of a program/practice is the extent to which it produces the defined outcomes and meets its objectives. Effectiveness of a program is demonstrated by: a clear link between its activities and the effects; a quantifiable change in the situation that is being addressed, demonstrated through quantitative data or interview of the beneficiaries; outcomes (medium-term results) and overall impacts (long-term results).

METHODS

The characteristics of the convenient sample of 7 home-based care programs in terms of geographic and urban/periurban/rural coverage were as shown on Table 1. Selection was done to include the programs representing geographic, urban/periurban/rural coverage, and the strategies (community-based, faith-based facility outreaches, NGOs and governmental programs).

Using qualitative and quantitative methods, data were collected from multiple sources with appropriate instruments. For each Home-Based Care Program, Focus Group Discussions (FGDs) were conducted among the program caregivers (1 group of 8-10 participants), family caregivers (2 groups of 8-10 participants per group) and community volunteers (1-2 groups of 8-10 participants per group) using guidelines on their training, roles, motivation and remuneration, the impact of their work on the recipients, and their concerns and constraints. Program managers were interviewed with schedules on their roles; program coverage, activities and impact; sources of funding; and concerns and constraints. Community leaders (civil, political and religious) were interviewed with schedules on their awareness of and relationship with and participation in the program activities, and the benefits/impacts of the programs.

Using checklists, program co-ordinators, administrators, and financial personnel were interviewed and records reviewed for data on infrastructure; administration including personnel and financial management; costs of care; records (including patients' records) collection, management and utilization; inputs such as drugs and non-drug supplies, home-care kits types and contents, traditional remedies and transportation.

Through interview of caregivers and non-participant observations of home/community care visits (total of 30 visits) by experienced home-care nurses on the research teams, data were collected with checklists on the following aspects of care: composition and roles of care teams' roles and composition; preparation of home-care kits for home/community care visits; care approach, types and contents; medication; utilization of universal precaution; record-keeping and referrals.

For each program, randomly selected patients (75) and family caregivers (75), and all the team caregivers were interviewed with semi-structured questionnaires.

The indicators in the instruments (questionnaires, focus group discussion guides, interview guidelines, and checklists) were developed by a team of specialists in the field. Some key indicators of home-based care by WHO (Lindsey, 2001) were also incorporated. The instruments were compiled into a data collection tool (booklet) for each Home-Based Care Program.

A team of 4 research assistants, proficient in the local language, assessed each Program. The team members received a 3day training on issues of HIV/AIDS, peculiarities of AIDS patients, interview techniques and administration of the instruments. A pilot test was carried out in a comparable Home-Based Care Program, and necessary alterations made. Each program was assessed over a period of 2 weeks.

The entry, cleaning, and verification of the collected data were done with EPI-INFO 6 software and data analysis with EPI-2000. Proportions were calculated for quantitative data and analysis of the FGDs done.

Concerning ethics, necessary permission was obtained from the MOHU, District Authority, and the studied Home-Based Care Programs. The programs were visited to understudy their schedules, work routines and other peculiarities, which were considered in the research planning. Informed consent was obtained from the patients, families and communities. Due attention was given to the human dignity and rights of the patients and their families during data collection. The questionnaires were anonymous to ensure confidentiality.

Sample size Determination

The sample size for patients' and family caregivers' interviews was calculated with EPI-Info software, using the formula below:

$$n/(1-(n/\text{population}))$$

$$n = z^2(P(1-P)/D^2)$$

z = area under the normal distribution curve

P = proportion at risk

D = error rate

At a precision of 95%, the sample size for each of the patients and family caregivers' interviews was 384. The number was fitted into the seven selected home-based care programs.

RESULTS

The characteristics of the seven Home-Based Care Programs assessed were as shown on Table 1.

Administration/Management

All the Home-Based Care Programs had a common mission of reducing HIV/AIDS associated suffering in the patients, families and communities. They had written objectives stating services, target population and coverage areas, though there were no outcome measures for impact assessment. With written policies on services, personnel, job description, salaries and benefits, they had organizational structures and plans/charts, though these were available in only MHC, MPK, and KMHC. Various management activities were in place. They had administrative heads of programs with different appellations.

Staffing

The composition of care-teams and the other types of staff utilized by the home-based care programs were as shown on Tables 2 and 3. Though all the programs had doctors, the nurses constituted the core of care-teams, except in MPKLA that utilized only PLHA volunteers and volunteer visiting doctors. The community volunteers worked under the supervision of nurses in NHC, KMHC, AHAP, and TASOM, and under volunteer visiting doctors in MPKLA. HUK and MHM utilized the volunteered services of professionals, some of whom gave patient care while others engaged in other duties. The non-caregiving staff included administrative and financial staff and general duty staff.

The programs had policies and procedures in place for recruitment, working hours, benefits, staff promotion, discipline and firing. AHAP was run by the hospital, and had no defined policy and procedures.

Provision of care

All the programs cared for HIV/AIDS patients, and all, except MPKLA and TASOM, included terminal cancer patients in home-care. The bulk of the services of HUK and MHM were terminal cancer home-care. All the Programs provided comprehensive care including nursing and medical care, psychosocial support including counseling, material assistance – school fees provision and Income Generating Activities, orphan care, and spiritual care. The type and extent of care depended on the thrusts, objectives and resource availability of the program. MPKLA, the community-based program, gave mainly psychosocial support and physical care, with first aid

medical care. The Faith-Based Organizations (NHC and KMHC), being facility outreaches, gave more medical care with a lot of psychosocial support, while the HUK and MHM gave more medical care, including pain control, and less social care.

The teams provided home/community care as shown on Table 2. Home-care is care in the home of the patient while community care is care in a designated place in the community where the less ill patients congregated. Three programs (HUK, MPKLA, and AHAP) conducted only home-visits. Four programs (NHC, KMHC, MHM and TASOM) conducted community-care visits and home-visits. The numbers of patients cared for, and home-visits conducted annually by each program were as shown on Table 3.

Access to comprehensive care continuum by PLHA was promoted through free treatment, waiver of co-payment for the very poor, and appropriate referrals. There was no formal linkage with health facilities and other community-care resources, each program worked out its own referral modalities.

Patients Records

All the programs, except MPKLA, had patients' care records' folders, from which records were entered into a Master-book. MPKLA kept only a Master-book of patients' names. The records were incomplete in many cases in the programs, with prescriptions and recording often illegible, and the folders irregularly stacked in locked cupboards and bags, making information retrieval difficult. Protocols on confidentiality of status, through secured record keeping, were followed. Other records' tools were referral forms, medicine chart, prescription books and registers. Computerization of data was in infancy. The records were used for report writing, accountability, planning, progress assessment, budget, research and seeking funds.

Supplies and Equipment

These included drugs, non-drug supplies, home-care kits and transport. All the programs, except MPKLA and AHAP, stocked simple and cheap basic drugs drawn from the National Essential Drugs List for Primary Care. These included analgesics, antibiotics, gut motility drugs, antimalarials, antifungals, antiparasitics, haematinics, and oral rehydration salts. Oral Morphine was also available in HUK, MHM, NHC, KMHC, and AHAP. Program HUK was the government's technical partner in capacity building for oral morphine utilization in the health facilities. The MPKLA stocked only few basic drugs for first aid. The government Program, AHAP, had no drugs supplied for home-visits. Most drugs used in the programs were oral and topical, with injections little used.

Non-drug supplies, like bandages, swabs, gloves, and disinfectants were inadequate in all the programs. Food items such as sugar, maize flour and oil for material assistance were part of non-drug supplies in NHC, MPKLA, and KHMC. All the programs had steps and procedures for ensuring the quality and regularity of their drug supplies. Traditional remedies, though recommended, were not stocked routinely. KMHC had its own local skin cream prepared from local materials.

Each program defined and stocked its home-based care kit, except AHAP, which had none. Three types of kits were identified: team caregivers', family caregivers', and community volunteers'. Only the team caregivers' kit was well defined, available and actively used.

The transportation for home/community visits included: motor vehicles, motorcycles, bicycles, and foot when necessary. The main transportation in all the programs was the motor vehicle, usually a petrol or diesel 4-wheel drive. The vehicle number varied with the number of teams, ranging from 1-6. Seventy-five percent (75.0%) of the vehicles were donated old by individuals, agencies and corporate bodies. All the Programs had procedures in place for fueling, maintenance and monitoring of vehicle movements. A major concern in all the programs was the high running and maintenance costs of the aging vehicles. KMHC had 600 bicycles for the community volunteers' movement in the communities.

Education

All the programs had appropriate home-based care education programs for the team and family caregivers and community volunteers. Training included counseling to obviate the need for or reduce the number of full counselors needed.

Five programs (HUK, NHC, KMHC, MHM and TASO) engaged in training of other programs' caregivers, health workers and non-professionals, including traditional healers and other groups in the community. All the programs utilized appropriate training curricula, delivery methods, and languages, and evaluated their training programs.

Community education programs for HIV awareness and prevention, behavior change and stigma reduction, were organized for churches, schools, and the public through talks, drama, songs, and community radio.

Cost of Care

The annual number of patients and visits by the programs were as shown on Table 3, which also shows the average cost/patient visit and patient's co-payment. Treatment was free in MPKLA, AHAP and TASOM. Table 4 shows the breakdown of the recurrent expenditure by

amount and proportions of cost categories in HUK & MHM, NHC and KMHC. The spending on direct care of patients (medicine and welfare) in HUK and MHM together, KMHC and NHC were 15.4%, 20.7% and 29.5% of their total expenditure respectively.

Financing and Financial Management

The home-based care programs, except AHAP, were heavily dependent on external funding mainly from charity organizations in the western countries. Two of the studied programs (HUK and MHM) were affiliates of a western NGO that regularly fund-raised in the home country. Internal funding, from corporate bodies, community organizations and individuals, was low. There was no direct government funding. The running fund for AHAP was included in the hospital budget. HUK and MHM set a target of raising 20% of running costs from local sources, and through regular fund-raising drives, reached 13% mark. Four of the programs (HUK, NHC, KMHC and MHM) charged minimal co-payment and had provision for waivers.

Annual budgets were drawn up in all the programs, except AHAP. They had accounting personnel ranging from accountant to accounts clerk, and cashier. Funds were disbursed in cash and cheques. Accounts monitoring and payrolls systems were in place. Financial and accountability reports were prepared regularly. Audited accounts were available in all the Home-Based Care Programs except AHAP, which did not handle its own funds. However access to details of accounts was limited.

Support

Table 5 shows the sources and types of support for the Home-Based Care Programs. These included financial and material donations (drugs, vehicles, land, and house), volunteer services, technical support and capacity building. Three Programs (NHC, KMHC and AHAP) received donated anti-TB, fluconazole and condom from government programs. All, except AHAP, received motor vehicle donations. TASOM received land for building its facility from the government, KMHC received land and water for building of a farm school for AIDS orphans while HUK received a building donated by the family of a beneficiary. All the programs were beneficiaries of the government and donor agencies' technical/capacity building programs.

Monitoring and Evaluation

There were no guidelines and standards for home-based care. The programs utilized some guidelines such as the National Essential Drugs List for Primary Health Care.

Only TASOM had a Quality Assurance framework, defined by its umbrella organization. Quality assurance steps undertaken by all the programs included: setting goals and objectives, defining team members' roles, and ensuring drugs' adequacy, regularity and quality. Five programs (HUK, NHC, KMHC, AHAP and MHM) that utilized oral morphine had guidelines for pain control. The programs had no defined performance standards and outcome measures. All the programs carried out monitoring and supervision irregularly, though they had no tools. Though periodic evaluation was included in the work-plan of all the programs, only NHC, AHAP and TASOM had previous internal evaluation. All the programs had been externally evaluated, with reports available in only HUK, MPKLA and KMHC.

Perception of home-care by patients, caregivers, community volunteers and leaders

Table 6 shows the proportions of patients satisfied with improvement in some Quality of Life dimensions, and proportions of caregivers satisfied with aspects of care received by the family and ill relatives.

Seventy eight percent (78.3%) of team caregivers were satisfied with the adequacy of their working, 77.6% of them were satisfied with the orientation and on-the-job training received. The issue of inadequacy of health and safety measures at work featured prominently in the focus group discussions with the caregivers expressing concern about exposure to diseases like tuberculosis without necessary protection.

The community volunteers in the Focus Groups acknowledged the quality and contents of their training and their impact on the HIV/AIDS situations in their communities. Specifically they had been active in the areas of community education/ awareness program for behaviour change, stigma reduction and condom distribution. Their concerns included: insufficient working materials like gloves, umbrella, gum boots, and bicycles for transportation; lack of material benefits such as salaries, and lack of protection from communicable diseases.

The religious and civil leaders were actively involved in the promotion of HIV/AIDS awareness, facilitating programs' activities, and in one instance contributed land and water to the program for building of a farm school for AIDS orphans. The political leaders, though acclaiming the work done by the programs, had no working relationship with them, and felt that home-based care was an area for the Health officials only. In the coverage area by one of the programs, the grass-root political leaders desired involvement and participation in the program activities, as they felt that only the elite leaders were currently involved.

DISCUSSION

The findings on Home-based care are discussed in the light of the UNAIDS Home-Based Care Best Practice criteria of relevance, ethical soundness, sustainability, efficiency and effectiveness, highlighting the strengths and weaknesses of the programs of different strategies.

The longevity of the studied Home-Based Care Programs is a measure of their relevance, effectiveness and sustainability. Through different strategies, the comprehensive care and activities for the PLHA, their families and community, addressed various HIV/AIDS associated issues such as lack of access to health care, poverty, and cultural preference for care and dying at home for the very ill (Kalluvya, 1997). The Essential Drugs, other supplies such as traditional remedies, and materials like food and soap were tailored to the served population's needs. Reaching out initially into the community through home-visits, with care and support and prevention strategies, they demonstrated their responsiveness and relevance to the community's changing needs by later including community care, and palliative terminal cancer care by some.

The government's recognition and involvement of some programs in its activities is an index of their community and national relevance and effectiveness. However, a formal political commitment and policy framework for home-based care with regards to guidelines, standards and formal health facility linkage, including appropriate referral system, would enhance their relevance and enable them pull down resources from central and district levels for community care. Moreover the capacity of selected home-based care programs, based on their effectiveness, efficiency and impact, could be further strengthened and supervised to deliver drugs, especially anti-retrovirals, to patients or complement the formal system to do this, making them more relevant to the patients' health needs. Such community-based approaches have been found feasible in the extending Anti-retroviral treatment to the AIDS patients in resource poor settings (Farmer et al., 2001).

Though the survival of the programs for periods of 10 – 17 years reflects their sustainability in the medium term, their dependence on foreign funding, highlighted in this study, has been cited as a major sustainability problem of programs in the developing countries (Chela et al, 1994). However all the programs were cognizant of this status, and engaged in sustainability measures such as community involvement, local networking to utilize other community resources, capacity building through training of different cadres of caregivers, including community volunteers. The NGO program has gone further in setting a target and actively soliciting for internal funds. It is noteworthy that the ready availability of donor funds in Uganda may not be readily duplicated in other settings.

All the Home-based care programs adhered to the ethical principles involved in HIV/AIDS care: aiming at improving the patients' quality of life; promoting the patients' human dignity and the right to informed choices; promoting confidentiality in status and personal affairs though encouraging openness for stigma reduction; and maximizing resources to promote access to care. Equity was ensured through free treatment and low co-payment with waivers for the poor, though this varied with programs. There was no discrimination on the basis of religion, or inability to pay.

Though the programs lacked defined outcome measures, their effectiveness is reflected in: the numbers of new and old patients cared for; the yearly home visits conducted; high levels of beneficiaries' satisfaction with services; and improvement in quality of life. This is more so when viewed against their aim of alleviating suffering and pain. Their impact is attested to by the increased community awareness of HIV/AIDS and its transmission, high-risk sexual behaviour change and stigma reduction. The continued donors' support over the years could be taken as a measure of the confidence of donors in their effectiveness.

The efficiency measures the programs employed increase the number of patients and reduce cost included: use of appropriate staff equipped with multiple skills; utilization of volunteer service and community care visits; and putting in place management, resource and financial controls to maximize resources and avoid wastage. However the strengths of these varied with programs, with the CBO program weaker in management, resource and financial controls.

Only very few programs, the two NGO programs and one FBO, had indicators of efficiency such as cost of care per visit, and cost of care per patient per year. Necessary data for calculating such indicators were not easily available, as records' (patients, administrative and financial) collection, organization and management were deficient. However, the available data on transportation and personnel expenditures in the programs indicated a degree of efficiency in resource use for care. The average costs per visit (\$3-6) were much lower than for Zimbabwe (US \$16-42 per visit in 1995) and Zambia (US\$14-38 per visit in 1994) (Chela et al 1994; Woelk et al 1997 unpubl). However the studied Home-Based Care Program might not have considered all the costs involved in their home-visits. Breakdown of their expenditure on patient care showed that the proportions consumed by transport (16-25%) were much below 44% recorded in the Zambian study (Chela et al 1994). It is possible that these programs had learnt lessons in cost-containment from the findings of these earlier studies. Their concern about running and maintenance costs of their old fleet of vehicles is an indication that transport maintenance could consume less.

Though the studied home-based care programs were mainly the well-established one, and the community-based programs underrepresented in this study, a comparison of the performance of the programs regarding the criteria could be made. From the available data, KMHC was the largest of the programs and seemed more efficient in the areas of staff/ patients ratio and staff/home and community visits ration than the other programs with similar staff strength. It has also been able to run at a cheaper average cost than other programs with lower annual turnover of patients and patient visits. This might be due to its heavy utilization of free service of a large number of community volunteers, and community care which increases patient coverage, though this was not the case with other programs that utilized community care.

The effectiveness of AHAP, the government program, which is run by the hospital centrally, is questionable. It had no budget of its own and no home-care kit with home-care visit almost entirely psychosocial, and with very low caregivers' satisfaction. The government needs to institute proper policy empowering the home-care programs to function synergistically with the health facilities for patients' benefit.

The psychosocial and medical components of care were more balanced in KMHC and NHC, faith-based facility outreaches, compared with HUK and MHM where care was mainly medical, and MPKLA where care was mainly psychosocial. Although this may have to do with their starting objectives, lack of appropriate personnel and inputs such as drugs may account for skewdness towards psychosocial care (Mulogo 1998). However, to remain relevant to the needs of the PLHA and their families which are both medical and psychosocial (Kikule, 2000; Kikule 2001), a balance of the various aspects of care offered, becomes imperative. Strengthening the linkage of the programs with other available community resources for care and support would go a long way to redress any unavoidable imbalance.

However the tenuous relationship between the programs and political leaders, and lack of formal linkage with health facilities were other sustainability problems. Other programs also need to emulate HUK and MHM in actively seeking to increase local input through local fund raising.

Lack of available data and absence of outcome measures in the programs rendered economic evaluation, needed to guide resource allocation and justification, problematic. However, Home-based Care Programs' cost per visit of \$3-\$6, available in three programs, seems very high, compared with the national health per capital of \$12, as an AIDS patient would need more than a single visit in a year or in the course of an illness episode. Although user-fees have been abolished in Uganda, where the drugs at the Primary Health Facilities are provided free, the contribution of co-payment may still be cheaper from the home-care patient's perspective, than attending hospital for free care because of transportation and other opportunity costs attached to

hospital care. The issue of which is cheaper between home-care and hospital care from different perspectives remains unsolved. A prospective cost- effectiveness study, considering costs from different perspectives will be necessary to resolve this issue.

CONCLUSION

The studied Home-Based care programs demonstrated that they were Best Practice, and have met the needs of the AIDS patients, families and communities. While showing strengths in the areas of relevance and ethical soundness, there were identified weaknesses in aspects of sustainability, efficiency and effectiveness that need attention. However, the faith-based facility outreaches appear more efficient and effective with regards to resource utilization, outputs in terms of patient load, lower costs of care.

The relevance of the programs to the community and national needs recommends them for policy recognition and inclusion, so as to increase internal funding and further strengthen their capacity to improve on their sustainability, efficiency and effectiveness.

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Table 1: Characteristics of the studied Home-Based Care Program

Home-Based Care Program	Region	Years of Operation	Characteristics
HUK	Central	9	NGO; mainly urban with some periurban coverage
NHC	Central	15	FBO; Mainly urban with periurban coverage
MPKLA	Central	10	CBO; urban coverage only
KMHC	Southern	15	FBO/NGO; urban-based with rural coverage
AHAP	Northern	12	Government; urban-based, with mainly rural coverage
MHM	Western	4	NGO; urban-based, with urban & rural coverage
TASOM	Eastern	12	NGO; urban and rural coverage

NGO - non-governmental organization
 CBO - community-based organization
 FBO - faith-based organization

Table 2: Home-Based Care Programs' Teams and Types of Outreach

Home-based Care Program	No of team	Teams' Composition	Type of Visits	Frequency of Visits
HUK	3	Nurse/clinical officer/doctor + driver	Home-care	Daily
NHC	2	Nurse + driver + community Volunteer	Home-care Community-care	Thrice/week
MPKLA	8	Community volunteer (PLHA) + driver	Home-care	Daily
KMHC	3	2 nurses + driver + community volunteer	Community-care Home-care	Daily
AHAP	1	2 nurses +driver + community volunteer	Home-care	Thrice/week
MHM	1	2 nurses/doctor + driver	Home-care Community-care	Daily Weekly
TASOM	1	2 nurses/counselor + doctor + driver + community volunteer	Home-care Community care	Thrice/week

Table 3: Staff distribution, Annual service output, costs of care and co-payment in the home-based care programs

Home-based care program	HUK	NHC	MPKLA	KMHC	AHAP	MHM	TASOM
Number of Staff							
Caregiving staff	22	20	4	26	18	6	19
Volunteers	15	50	14 ⁺	720	3	1	-
Non-caregiving staff	32	3	10	12	6	6	19
Service Output							
Visits per year	4771	1573	4102	18190	878	700	1052
Patients per year (old \$ new)	800	776	610	3150	206	380	287
Cost of care /home-visit (\$)	6.0	*	*	3.0	*	6.0	*
Co-payment/patient visit (\$)	2.5	0.6	-	0.3	-	2.5	-

- No co-payment
 * Data not available
 + main caregivers in MPKLA

US \$1 = 1750/- UgSh

Table 4: Proportions (%) of Annual Expenditure for 2000/2001 by Recurrent cost category by Home-Based Care Program

Home-Based Care Program	Personnel	Transport	Medicine	Patients Social Welfare	Administration	Depreciation	Total in US \$
HUK & MHM	43.0	16.3	12.5	3.1	15.0	10.1	100,304.1
NHC	42.1	20.0	18.0	11.5	8.4		171,600
*MPKLA							
KMHC	38.4	25.6	8.2	12.5	7.5	7.8	74,548.9
*AHAP							
*TASOM							

* Data not available

Source of data on expenditure in HUK and MHM was a common financial report

Source of data on expenditure for KMHC were from audited accounts

1 US\$ = 1750/= Ushs in the period 2000/2001

Table 5: Sources and Types of support for studied Home-based care programs

Home-based care program	HUK	NHC	MPKLA	KMHC	AHAP	MHM	TASOM
<i>External</i>							
Charity Organizations							
Financial	+	+	+	+	-	+	+
Volunteered Services	+	-	+	-	-	+	-
Supplies	-	-	-	+	-	-	-
Bilateral and Multilateral Organizations							
Financial	+	-	-	+	-	+	-
Technical	+	+	+	+	-	+	+
Individuals							
Financial	+	-	+	-	-	+	-
Volunteered services	+	-	+	-	-	+	-
<i>Internal</i>							
Government (central & district)							
Capacity – building	+	+	+	+	+	+	+
Supplies	-	+	+	+	+	+	+
Corporate/community Organizations							
Financial	+	-	-	-	-	+	-
Material	+	+	+	+	-	+	-
Individuals							
Financial	+	-	+	-	-	+	-
Materials	+	+	+	-	-	+	-
Volunteered services	+	+	+	+	+	+	+

+ Yes

- No

Table 6: Proportions of patients and family caregivers satisfied with dimensions of home-care by Home-Based Care program (%)

	HUK	NHC	MPKLA	KMHC	AHAP	MHM	TASOM
% patients satisfied with improvement in:							
Overall wellbeing	100.0	93.1	94.5	96.9	94.9	76.7	95.6
Suffering from symptoms	98.8	87.9	95.8	94.8	100.0	78.6	96.3
Ability to work	84.7	68.8	93.4	88.0	89.7	52.0	84.3
Outlook to life	100.0	88.6	94.1	100.0	94.6	70.8	86.7
Feeling of negative emotions (e.g fear, anger)	95.2	91.7	93.6	91.7	94.7	70.4	97.8
% of family caregivers satisfied with:							
Frequency of home/ Community visits	98.7	82.6	94.7	95.3	82.9	93.8	88.0
Overall care	96.7	98.5	92.6	89.3	93.8	88.9	94.6
Material assistance Information on HIV/AIDS	92.0	97.1	94.1	96.9	95.2	75.7	96.0