RESEARCH UPDATE Research Update

Horizons

Programmatic Implications of a Cost Study of Home-based Care Programs in South Africa

The HIV/AIDS epidemic has meant that an increasing number of chronically ill people need ongoing assistance with care and support. Programs providing home-based care (HBC) services are a key component of the response to HIV/AIDS. However, few programs are using operations research, including cost studies, to decide what services to provide and how to structure their services.

In 2004, the Horizons Program undertook a study of six different HBC programs to provide key information to NGOs, government ministries, donors, and the programs themselves to inform decisions about service delivery. The study analyzed the cost of HBC services, the best use of resources, and how well programs are able to meet the needs of beneficiaries and their families.

Methodology

The researchers selected six home-based care programs from different South African provinces that provide formal services to clients. The sample represents programs that operate in rural areas and informal settlements, and includes two in Gauteng (HOPE *worldwide* Soweto and Hospice Soweto), two in KwaZulu Natal (Sinosizo and Medical Care Development International (MCDI) -Ndwedwe), and one each in Mpumalanga (Project Support Association Southern Africa (PSASA)) and the Eastern Cape (HOPE *worldwide* Port Elizabeth).

Data were collected from five sources for each of the six HBC programs: 1) a household survey of 374 clients (target sample size of 60 clients per program), 2) focus group discussions (FGD) involving 59 program beneficiaries (1 FGD per program), 3) focus group discussions with 53 formal caregivers (1 FGD per program), 4) financial records and service statistics, and 5) interviews with financial officers, and program managers and caregivers.

This summary focuses on the coverage, organization, volume, and costs of the services and focuses on the findings from the fourth and fifth methods of data collection. The researchers reviewed each program's financial records and service statistics to determine the scope of services offered and their cost. They also interviewed program staff to understand how resources are being used to provide services and the cost of the resources used.

The first step in the analysis was to identify the resources that are being used in the provision of services. Resources were classified as labor, supplies, or capital (investments expected to last for more than one year). Resource usage in the past 12 months was then estimated by reviewing administrative and financial records and by analyzing data from the caregivers. The service statistics from the organization were used to document the volume of home-based care services provided in the past 12 months.

Horizons is implemented by the Population Council with the International Center for Research on Women, the International HIV/AIDS Alliance, the Program for Appropriate Technology in Health, Tulane University, Family Health International, and Johns Hopkins University.

Description of the Programs

The two urban HOPE *worldwide* programs (H*WW* Soweto and H*WW* Port Elizabeth) grew from support groups that HOPE *worldwide* started in clinic settings in each community. As members of the support groups became too sick to attend the support group meetings, HOPE *worldwide* decided to expand its services by offering HBC. The Port Elizabeth program was the flagship program and relies heavily on skilled personnel to provide the HBC services. At the time of this study, the Soweto program was adding skilled personnel (a nurse) to the HBC program while relying on the support group coordinators to provide the HBC services.

Hospice Soweto, an urban program based in the township of Soweto, southwest of Johannesburg, evolved from a traditional hospice model serving terminally ill clients (primarily with cancer). As the prevalence of HIV/AIDS increased and the natural history of the disease took its course, the program increasingly found itself called in to assist with the care of people terminally ill with AIDS. Given its historical roots, the Hospice Soweto program relies heavily on trained health professionals for the delivery of HBC services.

The Sinosizo program is part of the Catholic Archdiocese of Durban. The program relies on a network of trained volunteers in two rural communities outside of Durban who are supported by a skilled nurse, a social worker, and a health educator at headquarters. The skilled personnel also make home care visits when client needs exceed the ability of the volunteers.

The MCDI HBC program is part of the organization's Ndwedwe Child Survival Project. The program works primarily through the provincial department of health in KwaZulu Natal, which has contracted with MCDI-Ndwedwe to provide training and supervision for community-based HBC volunteers as well as to manage the logistics of supplies distributed to HBC clients in the Ndwedwe district, a rural area in KwaZulu Natal province.

PSASA, a rural HBC program, grew out of community-based, peer-education programs that operate in 44 communities throughout Mpumalanga province. These programs emphasize prevention messages conveyed by a trained peer educator to community members through a combination of group and one-on-one meetings. As the community-based peer education program progressed, it became clear that more than peer education was needed in the community, so PSASA trained their field staff to provide basic HBC services in addition to their continued involvement in peer education.

Each program in the study has evolved from a different historical background, has organized their resources in a different manner, provides a different package of HBC services, and serves a different mix of clients.

Key Findings

Coverage and intensity of services

As shown in Table 1, the number of clients served by each program ranges from just over 100 to over 12,000. Similarly, the number of client visits made by each program varies widely, ranging from just over 2,400 visits to over 300,000 visits annually. When the number of visits is calculated per client, each received between 19 and 61 visits per year, with MCDI-Ndwedwe and Hospice Soweto clients visited at least weekly, and clients from HWW's two programs and Sinosizo visited approximately once every two weeks. Each caregiver made between five and 10 visits per week and served between seven and 21 clients.

Table 1 highlights the large differences in coverage (number of clients served) and the intensity of services to clients (number of visits per client per year). The PSASA HBC program, which operates in 44 communities throughout Mpumalanga province, has the greatest number of clients and yearly client visits. The H*WW* peer education program, on the other hand, works in a small geographic area with only five caregivers. Despite these differences, both programs see their clients about once per fortnight.

Table 1 Scope and intensity of services

Program	# clients	# visits per year	# caregivers	"Performance" indicators		
				# visits per client per year	# visits per caregiver per week	# clients per caregiver
HWW Soweto	121	2,592	12	21.4	4.5	10.1
Hospice Soweto	500	27,515	57	55.0	10.1	8.8
PSASA	12,193	313,726	844	25.7	7.7	14.4
MCDI-Ndwedwe	858	51,960	121	60.6	8.9	7.1
Sinosizo	1,470	27,532	113	18.7	5.1	13.0
HWW Port Elizabeth	106	2,424	5	22.9	10.1	21.2

In contrast, MCDI-Ndwedwe and Hospice Soweto clients are seen on average more than once per week. These are the two programs with the fewest number of clients per caregiver and therefore, as might be expected, have more frequent client visits. The two programs with the fewest visits per client per year, H*WW* Soweto and Sinosizo, are also the two programs with the fewest visits per week by caregivers.

Staffing mix

HBC is very labor intensive. Therefore programs need to make choices on the level of training for their HBC caregivers, who can be program trained community members or academically trained professionals (e.g., nurses, social workers). The programs also need to determine the level of compensation for caregivers, who can range from pure volunteers, to volunteers that receive incentives, to stipend workers, to salaried workers. Table 2 shows how the different programs have organized their field staff.

Table 2 Field staff by type of training and compensation

Program	HBC field staff by type of training	HBC caregiver compensation
HWW Soweto	11 program trained + 1 nurse	Stipend workers + salaried worker
Hospice Soweto	48 program trained + 9 nurses/social workers	Stipend workers + salaried workers
PSASA	844 program trained	Stipend workers
MCDI-Ndwedwe	121 program trained	Pure volunteers
Sinosizo	111 program trained + 2 nurses/social workers	Incentive volunteers + salaried workers
HWW Port Elizabeth	4 program trained + 1 nurse	Stipend workers + salaried worker

Once again, there is variation from program to program. Sinosizo, Hospice Soweto, and the H*WW* programs supplement the services offered by the program trained HBC workers with the services of nurses and social workers, allowing for a broader range of services to be offered. For example, clients in these programs could receive a home visit by a nurse to treat an opportunistic infection. However, even MCDI-Ndwedwe and PSASA, with only program-trained staff, have academically trained professional supervisors who may provide some HBC services during their supervisory visits, although most caregiving is provided by program trained field staff.

To engage and retain academically trained workers, programs need to provide an adequate salary and benefits package. For program-trained personnel, the programs need to make decisions about whether to provide a stipend, offer an incentive package, or rely on pure volunteerism. These decisions have implications for who chooses to join the program and how long the program can expect to retain that worker.

Program costs

Table 3 shows the total annual cost of the programs and the percent breakdown of annual program costs by category. The cost categories were selected to highlight the way in which programs are using their resources. The costs are measured for all resources involving transactions. For example, MCDI-Ndwedwe uses pure volunteers and therefore has no field staff costs in its program. On the other hand, even though the program does not pay for the supplies given to clients, there is a transaction associated with these items, so the cost of those supplies to the Provincial Department of Health is included as a pass-through.

Table 3 Annual HBC program cost by type of cost

Type of cost	HWW Soweto	Hospice Soweto	PSASA	MCDI-Ndwedwe	Sinosizo	HWW Port Elizabeth
Total annual cost (Rand)	232,538	2,727,279	7,069,973	430,376	1,370,496	563,415
Field staff (%)	46.9	43.1	32.7	0.0	12.8	20.4
Support staff (%)	32.3	11.1	5.9	12.1	23.4	14.5
Client supplies (%)	0.5	24.8	24.3	24.4	8.3	44.7
Caregiver supplies (%)	1.7	9.7	11.5	4.6	17.1	7.7
Supervision (%)	3.6	2.2	16.1	19.7	16.5	2.8
Training (%)	2.3	1.6	8.0	25.1	14.8	4.9
Equipment (%)	8.0	7.0	0.5	7.3	3.5	2.4
Infrastructure (%)	4.8	0.4	1.1	6.7	3.7	2.6

As expected, given the large differences across programs in terms of scope, there are large differences in the annual program costs across programs. Therefore, rather than focusing on Rand amounts, the analysis indicates the percentage breakdown in costs to highlight differences in how the programs structure their resources. The proportion of the budget spent on varying costs reflects the mix of staffing and the nature of services provided by each program.

Field staff

The two programs in Soweto allocate over 40 percent of their resources to field staff. These costs include the payments to HBC caregivers and the time other program staff spend providing home-based care services. As noted above, the MCDI-Ndwedwe program has no field staff costs because its field staff is comprised of pure volunteers. This does not imply that this resource does not have a value, and later in the analysis a value will be imputed on this time.

Support staff

Two programs (H*WW* Soweto and Sinosizo) devote over 20 percent of their resources to support staff. This includes the time of central office-based clinical personnel when they are not providing home-based care as well as administrative staff time.

Supplies
Client supplies represent the resources that are either given to the clients (food packets, medicines, personal hygiene supplies, etc.) or in the case of H*WW* Port Elizabeth, expenditures on the client's behalf (physician payments)—which account for the largest share of annual costs. Of note is the small (< 10 percent) share for client supplies in the H*WW* Soweto program and the Sinosizo program. The data from the H*WW* Soweto program were collected before a dedicated nurse joined the program, at which time the visits were primarily focused on psychological/emotional support. Therefore, little in the way of client supplies was used.

Caregiver supplies are comprised of the supplies given to the field staff to assist them in their work. This includes gloves, personal care supplies, uniforms, bags, etc. Because the Sinosizo program uses in-kind payments (incentives) for their field staff as opposed to stipends (e.g., PSASA), a higher share of program resources are noted in this category. In addition, the Sinosizo field staff has home-based care kits that they use as part of service delivery, so more costs appear in this category than in the client supplies category above.

Supervision and training
Supervision costs include the time of the supervisors and their transport. Not surprisingly, the two programs that rely heavily on volunteers (MCDI-Ndwedwe and Sinosizo) have more than 15 percent of their annual program costs in this category.

Training costs include the time of the trainers, transportation costs, venue fees, supplies, food, etc. associated with the training of the field staff. Once again the highest share of training costs are for programs that rely heavily on volunteers. As noted by program managers, some of this may be related to higher turnover among field staff, necessitating more frequent training.

Annual cost per client

In order to assess the relative cost of the programs, the annual cost per client and the percent share of resources that are of direct benefit were computed (Table 4). The annual cost per client controls for differences across programs in terms of the size of the client base. The percent share of client benefits indicates the portion of total program resources that the clients likely perceive as a direct benefit. These are the payments or in-kind gifts for field staff (the formal caregivers) and the supplies given to clients.

For supplies bought directly by the program, the costs were calculated from program expense records. For donated goods, the values noted by the donors were used (for example, the Department of Health donated 100,000 Rand worth of supplies to one program). The proportion that these supplies make up of total program expenses roughly equates the proportion of resources that are either going directly to program clients or to caregivers for the care of clients.

Table 4 Annual cost of HBC program per client and percent share for client benefits

Program	Annual cost per client (SAR)	% share client benefits
HWW Soweto	1,930	47
Hospice Soweto	5,455	68
PSASA	580	57
MCDI-Ndwedwe	502	24
Sinosizo	932	21
HWW Port Elizabeth	5,315	65

It would be misleading to conclude that the program with the lowest cost per client or the highest percentage

share of client benefits is necessarily the preferred model. Differences will exist across programs due to a number of factors: 1) programs with more professionally trained field staff are likely to have a higher total cost per client and a larger field staff costs percentage (Hospice Soweto and H*WW* Port Elizabeth), 2) programs that provide more supplies to clients will have higher total costs per client and a greater percentage share of client benefits (H*WW* Port Elizabeth), and 3) a program that uses pure volunteers will have a lower annual cost per client as well as a lower percent share of client benefits (MCDI-Ndwedwe). In fact, if a value were assigned to the caregiver time in the MCDI-Ndwedwe program equivalent to the stipends paid to the PSASA field staff, the annual cost per client for MCDI-Ndwedwe would rise to 925 Rand, and the percentage share of client benefits would increase from 24 percent to 59 percent.

The one program that stands out in this analysis is the Sinosizo program, which has a moderate cost per client but a low percent share of client benefits. During the data collection period, the program director noted that she expected such a result because they were in the process of shifting the support and supervisory personnel out to the field to take advantage of their clinical skills. When completed, this will increase the percent share of client benefits without making any major changes in the annual cost per client. In fact the annual cost per client may decrease if more clients can be served after this reorganization.

Cost per visit

Another performance measure that can be computed for HBC programs is the cost per visit. This measure needs to be seen in the context of the number of visits made to clients and the services provided at each contact. A program that provides more comprehensive care to its clients (Hospice Soweto and H*WW* Port Elizabeth) will have a higher cost per visit, while a program that has more frequent contact with its clients, such as MCDI-Ndwedwe, will have a lower cost per visit (Table 5).

Table 5 Cost per HBC visit by program

Program	Cost per visit (SAR)
HWW Soweto	90
Hospice Soweto	99
PSASA	23
MCDI-Ndwedwe	8
Sinosizo	50
HWW Port Elizabeth	232

As expected, the two more professionalized programs (Hospice Soweto and H*WW* Port Elizabeth) have the highest cost per visit, but there is a much larger difference between the two in this table than in the previous one (Table 4). This is because the H*WW* PE program is the only one that pays doctor fees and provides medicines to clients.

Based on Table 5, the two programs in Soweto look more similar than different. However, because of differences in the percent share of client benefits, the Hospice Soweto program uses 50 percent more resources for client benefits (67 Rand per visit) than the H*WW* Soweto program (43 Rand per visit). The PSASA and Sinosizo programs spend comparable amounts on resources for client visits (13 Rand per visit and 11 Rand per visit, respectively) despite costs per visit being twice as high for Sinosizo. If a cost is imputed for the MCDI-Ndwedwe volunteers, the cost per visit increases to 15 Rand of which 9 Rand would be of direct client benefit. As was seen earlier, there are great differences in the types of services delivered by the programs, so it should not be surprising to find large differences in the cost per visit.

Challenges faced by volunteer program caregivers

While the practice of using volunteer caregivers cuts program costs, there are serious issues that need to be addressed by policymakers and donors. Focus group discussions with volunteer program caregivers highlighted some of the challenges they face, as well as other program staff, in providing care to households.

The most frequently mentioned challenge was households not having sufficient resources to cover the costs of caring for the sick person. The volunteer caregivers mentioned that they needed to provide their clients with supplies like diapers, gloves, disinfectant, and soap as well as medication for patients. Not all programs provide caregivers with these items. Program caregivers also reported that patients don't have access to medications, nor do they go to hospitals for services. If they go to the hospital, they are turned away because they cannot afford to pay the fees. In addition, program caregivers are blamed by hospital staff for sending patients with no money to the hospital. Patients often ask program caregivers to assist in paying hospital bills, and they also ask for help in paying for burial services. Caregivers commented that often they end up being personally involved by signing documents for clients, such as funeral benefit policies, and using their own resources to cover the cost of caring for the sick person. Many caregivers felt that they have to give money for transport, food, and washing soap to households that are extremely poor. According to a female caregiver from KZN, "P*eople always want more; if I bring bandages they ask where the food is."*

Discussions with program beneficiaries indicated that they too seemed aware of the conditions under which HBC volunteers work and acknowledged that caregivers sometimes provide assistance at their own expense by bringing food and paying for transport out of their own pockets. Some respondents argued that volunteers should be paid to provide services. As a female beneficiary from Mpumalanga noted, "*I would like volunteers to be hired full time and get paid for the good job that they are doing, because even our families are not helping us as much as they do."*

Volunteers also reported that some community health workers receive a stipend and care kits while many HBC volunteers do not receive any monetary or material support for their work or to carry out caregiving responsibilities at home. Some caregivers also felt that they are not empowered or acknowledged. For example, a female caregiver from KZN said, "*We really do work hard and people can't see that*." In a related complaint, it was argued that patients expect too much from caregivers, or that families rely on caregivers and stop providing care and want caregivers to do their washing and cleaning. A female caregiver from KZN said, "O*nce they know you are a volunteer, they think it is your responsibility to come every day to take care of their sick family member, even though you explained and taught them how to take care of the patient."*

Despite these challenges, the volunteer caregivers continue to provide services. When asked what motivates them, respondents spoke about wanting to assist their community, having aspirations to be a nurse, and caring about their patients. Some caregivers are HIV-positive or have HIV-positive family members and this has motivated them to care for other HIV-positive people. Caregivers also value the support from fellow caregivers.

Recommendations

A workshop was held to present data from the study to the six HBC programs and other stakeholders and to discuss the program and policy implications of the results. Some of the recommendations that emerged from the workshop are the following:

Programs need a standardized reporting system to collect data on HBC services.

Currently data collection in many of the HBC programs could be improved. One constraint to HBC programs is that little funding is available for the institutional development of programs. Without institutional development, programs may not have the skills or capacity to report properly and are less able to leverage funding. Competition between organizations was also mentioned as a stumbling block in terms of record keeping and reporting. Competition for clients, overlapping services, and clients using multiple

services were all raised as issues affecting data collection and reporting. It was recommended that HBC programs, in conjunction with government and donors, develop a standardized reporting system that responds to the needs of all parties.

Programs need to make strategic decisions about the services they can offer.
Programs must determine the mix of services and staff best suited to their capacity and budget. Service quality issues included optimum client to caregiver ratio, use of professional staff, and better monitoring and evaluation. Programs offering more comprehensive care generally are able to reach fewer clients and are more expensive. Policymakers and donors need to view HBC as a range of different types of services with varying costs.

Long term funding is needed for HBC programs.
Programs need long term funding if they are to provide good care for their communities. Clients will expect programs to deliver care for as long as they need it and there needs to be continuity in service provision. Longer term funding will allow HBC programs to plan for the future and strengthen their programs. Studies quantifying the contributions of HBC programs to the quality of life of clients may be useful in securing donor and other funding.

Initiatives to provide economic and emotional support to volunteer caregivers are needed.
Volunteer caregivers are often as poor as the households they are serving and need stipends if they are to deliver services. In addition, volunteers need assistance with emotional support and may have medical needs of their own, including access to treatment. Policymakers and donors need to consider these needs when drawing up policy and funding priorities.

Clarity is needed on training and payment for home-based caregivers.
There is little clarity from the government on training and payment for volunteers. The Department of Health does not currently recognize training programs run by other organizations, and it is difficult to register training programs with the local skills training body. Stipends also need to be standardized with donors and with the relevant government departments.

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