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Strengthening care and support services in the era of treatment: Symposium report

Horizons Program

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Symposium Report

22-23 November 2005
Johannesburg, South Africa

Horizons Program

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Horizons

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Acknowledgments

The following people were instrumental in conceptualizing and carrying out the symposium: Catherine Searle, Eka Williams, and Naomi Rutenberg of Horizons/Population Council; Ellen Weiss of Horizons/International Center for Research on Women; and Melinda Wilson of USAID.

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The Population Council is an international, non-profit, nongovernmental institution that seeks to improve the well-being and reproductive health of current and future generations around the world and to help achieve a humane, equitable, and sustainable balance between people and resources. The Council conducts biomedical, social science, and public health research and helps build research capacities in developing countries. Established in 1952, the Council is governed by an international board of trustees. Its New York headquarters supports a global network of country offices.

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Acknowledgments

Acronyms and Definitions

Acronyms and Definitions

AIDS	Acquired immune deficiency syndrome
ART	Antiretroviral therapy
ARV	Antiretrovirals
HCBC	Home- and community-based care
HCBC+	Home- and community-based care plus
HIV	Human immunodeficiency virus
Primary caregiver	An individual who provides most of the care to a person living with HIV, usually a relative living in the same residence.
Outside caregiver	An individual who provides care and support services to a person living with HIV and their household members who does not live in the same residence; can be a volunteer or a professional.
PMTCT	Prevention of mother-to-child transmission
VCT	Voluntary counseling and testing

Introduction

Sub-Saharan Africa has been devastated by the AIDS epidemic; current UNAIDS estimates show almost 26 million people infected with the disease in the region (UNAIDS and WHO 2005). As international attention continues to focus on sub-Saharan Africa as the region most affected by AIDS, hopeful signs have emerged, such as increased access to antiretroviral therapy (ART), which is allowing more people living with HIV to live healthier, longer, and more productive lives.

Although the availability of ART has greatly increased in South Africa, where HIV prevalence among adults is estimated to be around 25 percent (UNAIDS and WHO 2005), care and support services continue to play a critical role in the lives of people infected and affected by HIV. One reason is that treatment is not yet accessible or clinically appropriate for many people. Therefore, care and support services are still needed to help these individuals deal with the physical symptoms of HIV infection and with the psychosocial ramifications of being infected. Care and support services also benefit primary caregivers by providing them with respite care, and with material and emotional support to lessen their overall care burden. And for those eligible for treatment, care and support services can help them to learn more about ART, access treatment services, adhere to medication regimens, and cope with side effects as well as the psychosocial effects of being on treatment for the long term.

In response to a growing call from program managers and researchers in South Africa to engage in a dialogue with policymakers and donors about strengthening care and support services in the era of treatment, the Horizons Program organized a one-and-a-half day symposium on 22-23 November 2005 in Johannesburg. The symposium was designed to review current research and field experiences in order to identify ways to strengthen care and support programs, and to link them with treatment services. It also aimed to identify research, program, and policy gaps and priorities.

Over 70 representatives from more than 40 organizations attended the symposium (see Appendix B for a full list of participants). Julie Chitty from the Office of the Global AIDS Coordinator gave an overview presentation on care and support for people living with HIV/AIDS to begin the meeting, which was followed by presentations. Presenters included Horizons staff in South Africa; Horizons partners in South Africa, Rwanda, and Zambia; and other experts in treatment, care, and support working in South Africa (see Appendix A for the agenda). After each session, participants were asked to list the program, research, or policy concerns they felt to be priorities for the future. These were synthesized (Appendix C) and formed the basis of the second day of the symposium, during which a smaller group met to discuss and expand on them and the key issues raised.

This report focuses on key issues highlighted by symposium participants in their presentations[1] and priority lists, and during the discussions that followed, and is not meant to be a comprehensive analysis of all current care and support topics in the region. These key issues cluster around the following themes:

- Meeting the care, support, and treatment needs of different populations
- Strengthening the delivery of care and support services by outside caregivers
- Linking home- and community-based care with treatment and other services

The report also includes research, policy, and program recommendations that were formed in the small group discussion of the priority lists.

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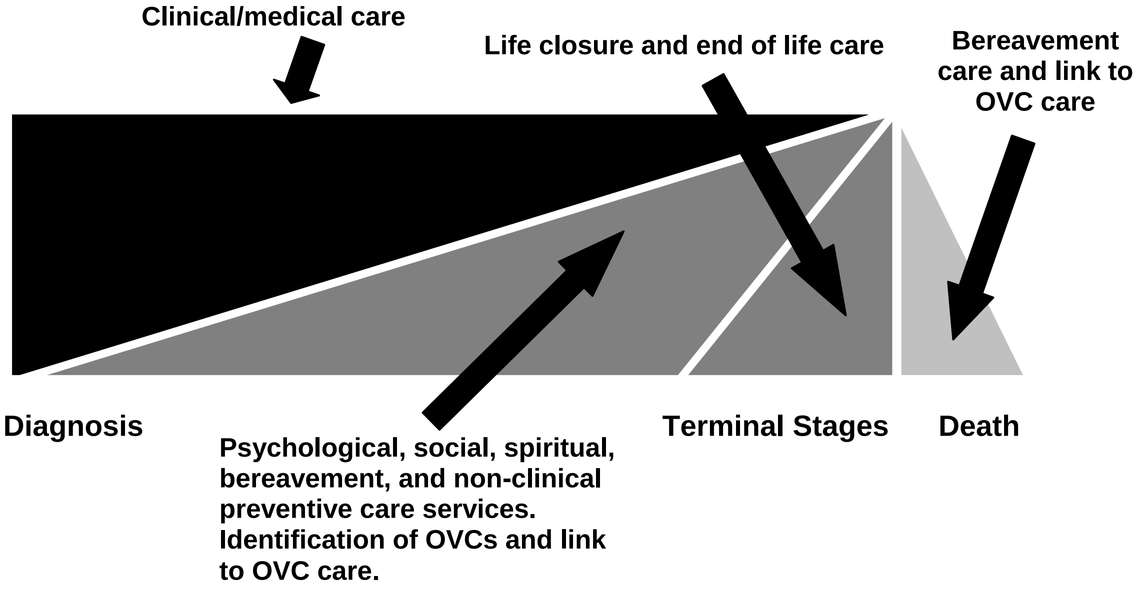
[1] The presentations can be found on the Horizons Program website by going to http://www.popcouncil.org/horizons/mtgs/cssasem05/summary.html

Key Findings

Programs providing care and support must be responsive to the changing needs of HIV-infected persons.

People living with HIV and their families have numerous care and support needs, which can vary depending on a myriad of factors, including the socioeconomic status of the household, the sex and age of infected individuals and dependents, their household roles and responsibilities, and the treatment regimens they follow to control the disease. The community and cultural context within which the family resides, including levels of AIDS-related stigma, also influence the extent and scope of their care and support needs. In addition, care and support needs are not static but fluctuate according to what stage the person with HIV is in (Box 1).

Box 1 The continuum of care needs of people living with HIV/AIDS



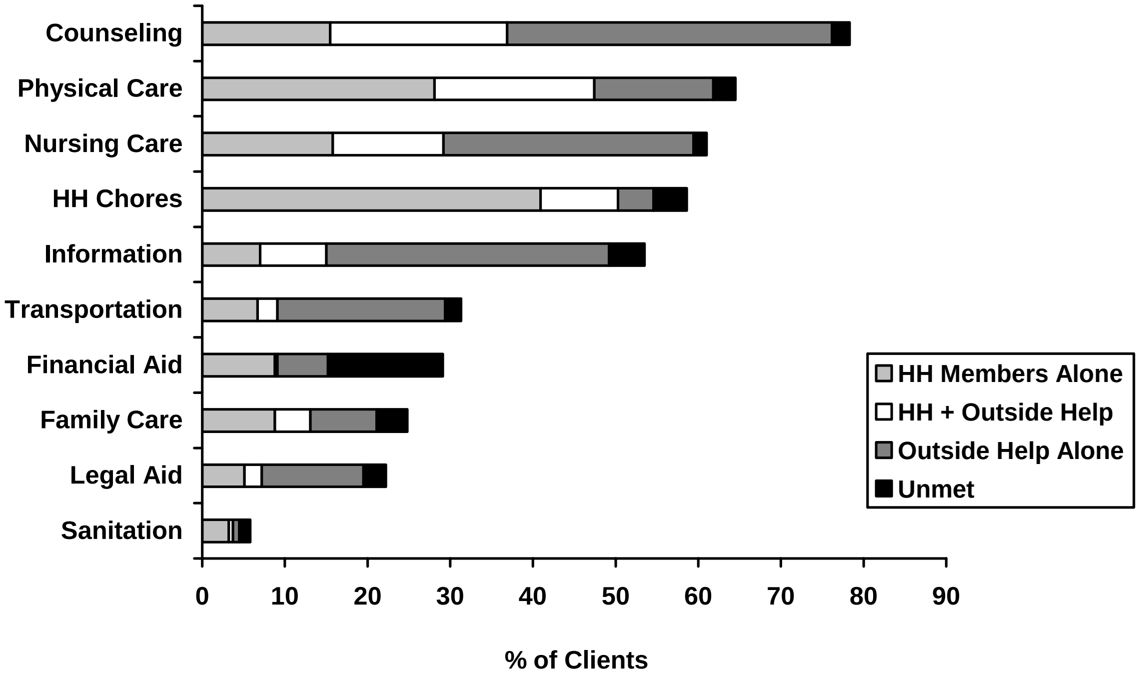
Source: Presentation by Julie Chitty, "Care and support for people living with HIV/AIDS: The President's Emergency Plan for AIDS Relief"

The care and support needs of HIV-infected individuals and their families are often too numerous and complex to be met by household members alone. Therefore, outside caregivers operating out of home-, community-, or health facility-based care programs aim to meet at least some of these needs.

It is important for HCBC programs to determine the needs of their target populations and the extent to which their services and activities respond to those needs.

The importance of home- and community-based care (HCBC) programs determining how well they are meeting the needs of their recipients was underscored by a presentation on findings from a 2004 study of six HCBC programs in South Africa conducted by the Horizons Program. The study found that outside caregivers are helping to meet important needs of households affected by HIV. Interviews with 374 clients of the six programs (approximately 60 per program) revealed that more than half needed help with counseling and support, physical care, nursing care, household chores, and information. When asked about how these needs were being met—whether with help from household members, HCBC programs, or a combination of the two—results showed that the programs were doing a good job helping to meet many of their clients' needs (Figure 1). However, the study also found that the programs could work more closely with household members to coordinate service delivery and to help meet unmet needs, such as for financial aid. (Homan and Searle 2005)

Figure 1 Need profile of all clients by source providing care



Source: Presentation by Catherine Searle, "Examining community needs and barriers to care treatment in South Africa"

HCBC programs are well positioned to be an entry point to other services, including treatment.

Symposium participants emphasized that HCBC programs are well positioned to be an entry point to other family and community services to help meet unmet needs, because they have already established a relationship with the household. Outside caregivers and HCBC programs can be key in establishing linkages between the households they visit and the services available in the community. If HCBC programs invest time and effort in determining the needs of their clients, they will be better able to prioritize what linkages to develop with other local services and programs, which will benefit recipients enormously. These services include treatment, prevention, VCT, PMTCT, programs for orphans and vulnerable children, and more.

A constant underlying issue for many HIV-affected households and communities is that of poverty, which makes it difficult for many households to pay for basic needs such as food and transportation. HCBC programs should aim to establish relationships between the households they care for and services addressing poverty reduction, such as organizations that set up income-generating activities and provide microcredit.

Establishing linkages with existing programs and services can help provide a holistic, comprehensive approach to caring for individuals and families infected and affected by HIV. Developing models of “HCBC+” in which HCBC programs are linked with other services is of critical importance, and should be a key focus of programs, researchers, and donors. The symposium featured presentations about the following programs, which illustrated various approaches for creating HCBC+ programs.

N’doro Model: The N’doro Model in South Africa, coordinated by Wits Palliative Care, is a good example of a successful palliative care service program based in the public sector, the first of its kind in the country. The N’doro Model is a hospital-based community outreach service that collaborates with local NGOs. It was first set up as a pilot program, which helped to identify a number of shortcomings, such as a weak referral system, a lack of patient trust in the formal health system, and a lack of mobility among service providers. These weaknesses were addressed in part by the creation of the Soweto Care Givers Network, a district-level network that brings together local organizations involved in HCBC, including both government and NGO entities. With assistance from various organizations in the Soweto Care Givers Network, the N’doro Model also conducts community empowerment activities through courses on care, support, and treatment for community members.

The model’s structure and innovative methods have resulted in expanded service coverage and increased patient trust. Patients now receive “Smart cards” that use the STAT system to track their medical history and medications, so they can go to any clinic or hospital in the system and are not tied to one place. Over 4,500 home visits have been conducted so far and the ARV program has been strengthened, all at a lower cost due to increased collaboration and reduced duplication of efforts.

ACER Project: The ARV Community Education and Referral, or ACER, Project in Zambia is implemented by the International HIV/AIDS Alliance and local NGOs, including networks of HIV-positive people and programs delivering HCBC and treatment services. ACER focuses on community education and referral for supporting ART adherence and prevention for people with HIV. The activities are primarily community-focused, yet provide a critical link to health centers where ART is provided, through the use of treatment support workers and treatment mobilizers. The intervention is producing tools and training materials to improve the communities’ health-seeking behaviors and increase their understanding of ART. Operations research is being conducted to determine the effects of the intervention activities on community members, and to document approaches for mobilizing and building on existing community structures.

HOPE *worldwide:* HOPE *worldwide* has established national programs in South Africa that focus on care and support for people living with HIV and for orphans and vulnerable children, HIV counseling and testing, and HIV prevention for youth and other groups. Their comprehensive HCBC programs work with various local partners to promote ART and to link with treatment services. For example, established support groups for people with HIV now focus on ARV literacy. Community Home Based Care Teams assist clients with the screening process to access ART. They also make regular visits to patients on ART to promote adherence and monitor for side effects, making referrals when necessary.

The N’doro Model and the ACER Project provide good examples of improved coordination and collaboration between health facilities and community-based services to ensure a continuum of care for people with HIV. They also highlight the importance of a strong, two-way referral system that links care and support programs with treatment and other services. HOPE *worldwide* activities illustrate the ways in which traditional care and support activities can be expanded to encompass treatment.

Children with HIV have distinct care, support, and treatment needs that merit greater attention.

Almost 2 million children under age 15 are estimated to be infected with HIV in sub-Saharan Africa (UNAIDS 2004). These children have very distinct care, support, and treatment needs, many of which are currently unmet by HCBC programs. Often programs are not prepared to help HIV-positive children and their households; by providing child-specific training for health care providers and adherence support for caregivers caring for an HIV-positive child, programs could become more sensitive to the different needs households face when they include an HIV-positive child.

A rapid situational analysis conducted by the Horizons Program in 2005 examined 16 sites in South Africa currently providing ARV services to children. Researchers determined that the majority of children were referred from primary care facilities or from in-patient wards at hospitals. Most children who were referred were already sick; very few healthy children were referred for ARVs. Service providers noted that if prevention of mother-to-child transmission (PMTCT), primary care, and voluntary counseling and testing (VCT) services were linked with HIV clinics to provide referrals, HIV-positive children could begin treatment before they became clinically unwell.

Medication adherence is an issue of particular importance for children on treatment. The Horizons study found that 15 percent of caregivers reported at least one missed dose in the preceding week. The responsibility of adherence, as well as care provision, falls heavily on women, as mothers and grandmothers tend to be the primary caregivers. Outside caregiving support is needed to help monitor adherence and provide emotional support to the primary caregivers. The role of outside caregivers is especially crucial for those children without responsible adults in their lives, such as youth who head their households (Michaels et al. 2006).

Symposium participants highlighted the need for disclosure support for families with HIV-positive children. Often children are brought to live with their grandparents because the parents are unwell and no longer able to care for their children, but grandparents are sometimes not told that the children themselves are sick. Hence disclosure becomes key to ensuring that HIV-positive children receive appropriate care, support, and treatment services.

Schools are well situated to be centers for care and support services.

With support from the Nelson Mandela Foundation, a school-based care and support program is being developed by Save the Children UK and other NGOs, and the Department of Education in Free State, South Africa. Schools are well placed to offer care and support services because they are in every community, they reach a large percentage of children, and they have a pre-established infrastructure with trained staff. The program will be implemented in five schools; each school will develop its own plan of action based on priority issues and available resources. A site-based support team, youth facilitators, and children’s groups will work together to implement this action plan, which will aim to help meet children’s physical, social, and emotional needs, and to foster life skills related to HIV prevention and care, substance abuse, parenting, etc.

For youth-headed households, material support must be complemented by emotional support and a connection to the community.

The symposium featured a presentation about an intervention in Rwanda that builds on a material support program for youth-headed households by providing psychosocial support via trained adult mentors. The mentorship model was developed by World Vision Rwanda and is being implemented and evaluated in collaboration with the Rwanda School of Public Health, Tulane School of Public Health, and the Horizons Program. The model consists of trained adult volunteer mentors who are paired with youth-headed households in order to provide them with emotional support and a connection to the community—aspects that they lacked, as revealed from formative research. A key feature of the project is the active involvement of the community in program design, including the involvement of youth in identifying potential adult mentors. Within a period of a year, 156 mentors were trained and had made more than 17,000 visits to 442 youth-headed households. The retention rate of mentors was excellent; only two dropped out during this period (Brown, Thurman, and Snider 2005). The impact of the program on the youth and the mentors is being assessed and results are expected in late 2006.

HCBC programs must also address the needs of primary caregivers, who are often women and the elderly.

Primary caregivers provide invaluable help to the individuals they care for, and the presentations and discussion emphasized that it is crucial for programs not to forget them when identifying and responding to the care and support needs of the household. Often these primary caregivers are female; therefore HCBC programs have a role to play in fostering greater involvement of men and boys in order to better distribute the caregiving burden within the household.

As a group, the elderly frequently assume a lot of the caregiving within households. Many grandparents are forced to care for their grandchildren after their children become too sick to do so themselves. A study conducted in South Africa in 2004 by the Medical Research Council and Horizons, and presented at the symposium, investigated the scope of care provided by the elderly, and the economic and psychosocial factors affecting elderly caregivers. The study found that elderly caregivers have a multitude of responsibilities, including parenting; ensuring the education of children in the household; doing household chores; and providing nursing care, emotional support, and financial assistance. Focus group discussions, in-depth interviews, and quantitative interviews conducted with elderly caregivers revealed that these responsibilities take their toll on them, because they are often already in poor health and have inadequate economic resources.

In this study, elderly caregivers noted that they receive little external support, which increases their emotional burden. As their children die, they are often unable to properly grieve, as they are too busy caring for their orphaned grandchildren and have few outside support mechanisms. The study concluded that support groups and mentorship programs for elderly caregivers may alleviate some of their emotional burden. Such programs could also provide information on treatment, which may be relevant to children and grandchildren under their care.

Elderly caregivers also mentioned a lack of support and cooperation from their dependents, which not only causes extra stress, but also raises concerns about the continuity of the household. In many households the middle generation is dying of AIDS, leaving only grandparents and grandchildren. Without strong intergenerational communication between elderly caregivers and their dependents, the household structure may weaken and its survival may be threatened. Another problem faced by the elderly is difficulty accessing government grants that can provide financial assistance to themselves and their households (Reddy et al. 2005).

Challenges and needs of elderly caregivers

“ We never thought that it is going to be like that, we never even thought that there will be even those children, we raised ours now we have to raise the grandchildren…. I am starting at the beginning where I was supposed to be resting and the children are looking after me.”

“We are really struggling with these children. You are raising them, but they come and go…. as much as we are trying as parents, they are just out of control.”

“And there is a need for the support group and these groups do pray a lot, that is the thing that I like about them, and I like them a lot because they support each other.”

Source: Reddy et al. 2005

HCBC programs must not forget the needs of their staff and volunteers.

HCBC programs rely on a range of people—from pure volunteers who receive no money and minimal training, to salaried, skilled professionals—to provide a wide range of services. Symposium participants emphasized that although these outside caregivers may vary in terms of their training and remuneration, programs must not overlook their particular needs, such as for psychosocial support due to personal and occupational-related emotional stress. Support groups or mentorship programs should be considered for outside caregivers as well. In addition, programs need to pay more attention to issues that affect outside caregivers’ job satisfaction and performance, such as the availability and replenishment of care kits, incentives, and training.

The contents of the kits used by home- and community-based caregivers vary widely, often dependent on the funder’s priorities or donations received. An assessment conducted in South Africa in 2004 by the Reproductive Health Research Unit and PATH, and presented at the symposium, highlighted the many discrepancies of care kits. While the Department of Health has established guidelines for the kits, provinces modify them to their specific situations, resulting in a wide variety of contents. Many programs reported a lack of funds to provide enough kits, or to fill them with items commonly used by caregivers, such as gauze, antiseptic, gloves, and cotton wool. The costs of the kits also vary greatly, depending on the contents.

Currently home- and community-based caregivers in South Africa include both unpaid volunteers and paid volunteers, who receive a stipend for their work. The stipend amount varies and is often dependent on the funding source of the program. Within South Africa, the Departments of Health, Education, and Social Welfare pay their volunteers different amounts; when various international and local organizations and donors are considered, the size of stipends varies immensely, which can cause tension between outside caregivers. Symposium participants noted that it is difficult for people to dedicate themselves to home- and community-based caregiving in lieu of a formal career when stipends provided are insufficient to support their families. This can also lead to tension between caregivers and their recipients, as caregivers may be tasked with delivering food parcels to recipients, while at the same time not having enough to feed their own families.

Caregiver comments about care kits

"We only have one kit bag"
"We would appreciate having a full kit"
"We have no funds to buy kits"
"Our request has been made but we have not received kits yet"
"Our HBC program does not have the care packs…we are begging that the process of giving HBC kits be fast…"

Source: Presentation by Zonke Mabude, "An assessment of the home-based care kit situation in South Africa."

Similar to incentive schemes, the length and content of training for outside caregivers vary, and subsequently so does the quality of the services offered. Although there is a minimum requirement in South Africa of a 59-day, 13-module training program for home- and community-based caregivers, this often does not translate into practice. A lack of oversight combined with an urgent need for services results in many programs providing much shorter training periods, sometimes as little as five days. Training is particularly important in the era of treatment, as the knowledge and skills necessary to become a successful caregiver are expanded to include components such as adherence support, knowledge of referral networks, and fostering disclosure.

Knowing what HCBC programs costs can help determine what services to provide and how services should be structured.

The symposium included a presentation that described a cost evaluation that has been undertaken of HCBC services in three provinces in South Africa by the Health Economics Research Office (HERO) and the Joint Economics AIDS and Poverty Programme (JEAPP). The results will include the per-unit, annual, and marginal costs of specific care services, which will help programs, governments, and donors determine their budgets. In addition, measurable process indicators will be identified, such as the length of home care visits and the number of caregivers trained.

Symposium participants emphasized the importance of not only determining the costs of a program, but also ensuring that programs are of sufficient quality. By developing and using indicators to measure quality and then determining the cost of a quality service, programs can ensure that their services are of high quality and are cost-effective.

Conclusions and Recommendations

The symposium reinforced the importance of HCBC programs in the era of treatment. The presentations and discussions highlighted that these programs can take on a number of important roles to improve uptake of treatment by HIV-infected individuals and help ensure positive clinical and virological outcomes. For example, care and support programs can identify and refer individuals for ART and help them with the screening process to access treatment services. Outside caregivers can provide needed support to HIV-infected individuals to facilitate disclosure to at least one person, which is a requirement for accessing treatment in South Africa. They can also increase treatment literacy, help with the management of side effects, and support adherence. But, regardless of the availability of treatment in the community, HCBC programs continue to play an important role in the continuum of care that individuals with HIV need over time.

The symposium highlighted the following key programmatic, policy, and research gaps and priorities that need attention by government, NGOs, researchers, and donors to foster quality and sustainable care and support programs in the era of treatment.

Programmatic and Policy Issues

- **Referral systems** need to be examined and strengthened, as referrals between clinic-based services and HCBC programs are often weak or non-existent. Referrals that do occur tend to be one-way referrals, with home- and community-based caregivers referring patients to clinics and services without receiving feedback or updates from the clinics. Linkages should be strengthened such that clinics refer patients back to the HCBC programs. Training workshops or other activities that bring together home- and community-based caregivers with clinic- and hospital-based service providers could be key for cementing solid linkages between the two types of programs to foster referrals.

- **Early identification of children** for treatment is a priority. If HCBC programs created stronger linkages with PMTCT programs and immunization programs, children ages 0 to 5 years who are eligible for treatment could be identified before they become very sick.

- **Family-centered approaches** to care and treatment are needed**.** This would make receiving care and treatment more convenient for households, as well as help identify HIV-infected children and their caretakers who need treatment. Although participants cited some hospitals in South Africa where a health provider could refer a child's caretaker for services in the same hospital on the same day as the child's appointment, they felt that this was far from the norm.

- **Improved access to economic resources** is necessary. **Microfinance schemes**, in which small loans are made to individuals in order to start a sustainable, income-generating activity, are becoming more common; however, government policy around microfinance is still needed in order to ensure the system is structured appropriately and continues to meet the needs of the communities it is designed to serve. In addition, the elderly are often left out of microfinance and other schemes, such as *stokvels* (rotating credit schemes); operations research is needed to determine how to involve the elderly in such schemes and whether this helps to reduce poverty. Assisting households to apply for government **grants** would also be invaluable, to decrease the financial strain many elderly caregivers and households face.

- To address the psychosocial needs of **elderly caregivers**, HCBC programs should develop strategies to target them directly with outside support, including emotional support in the form of support groups or mentorship programs. Programs could also provide information about treatment, including how to access ART, and provide adherence support. Interventions to improve intergenerational communication between elderly caregivers and their dependents could help strengthen family ties and ensure the continuity of the household after elderly caregivers pass away.

- Stakeholders and donors must establish clear, formal guidelines for volunteer compensation, since standardizing **incentive schemes** will reduce tension between programs. Providing fair compensation will also attract more people to the programs, allowing for broader care services.

- Clearer guidelines on the required length and content of the curricula must be established for **training** outside caregivers. Once these are established, the training itself must also be monitored to ensure compliance, consistency, and quality. A reference database of trainings and curricula could be created in an attempt to be sure that organizations are not duplicating efforts.

- To provide HCBC services, programs must determine what is absolutely necessary for their caregivers to have access to and provide these bare essentials in **care kits**. This includes ensuring that a sufficient number of kits are properly filled, stored, and accessible. To do so, budgets for procurement of supplies and bags should be centralized at a higher government level to increase buying power and ensure kits are available to smaller organizations unable to afford them. By streamlining expansion and standardizing production and supply, care kits can become a more powerful tool.

- More attention needs to be focused on providing **quality services**. However, determining how best to ensure quality can be difficult, and the word “quality” is often used without supporting evidence. To ensure that the services provided by HCBC programs are of the highest quality, performance objectives, supervision and mentoring, and monitoring of programs and caregivers is crucial. Tools and instruments for measuring quality must be created so that programs can be confident about the services and training they provide.

Research

- **Situational analysis studies** of HCBC programs are needed to look at the scope, content, and quality of services offered in different communities. This would allow programs to determine if they are currently meeting the needs of their clients and highlight gaps in service delivery. For example, many programs currently focus almost solely on counseling; if care recipients were surveyed, results might show that there is more than enough counseling available in the community, but not enough treatment literacy, help with household chores, or other services.

- The effects of HCBC programs must be better **documented**, especially in terms of their value added in the era of treatment. To conduct evaluation studies that determine effectiveness, quality, and cost, data collection **instruments** will need to be developed. Instrument development and implementation of evaluation studies will require collaboration on the part of programmers, researchers, government, and other donors, and care and support recipients and their communities

- **Stigma** remains an issue, even in the era of treatment. Studies should be conducted on the relationship between the availability of HCBC programs and treatment services, and their effect on stigma in a community.

- **Children** living with or affected by AIDS are also important to address in research. Future studies should focus on the issue of disclosure among children, as well as the role of HCBC programs in helping children and their families deal with AIDS-related stigma.

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Appendix A: Symposium Agenda

The following presentations were given at the "Repositioning Care and Support in the Era of Treatment" symposium, 22-23 November 2005, Johannesburg, South Africa.

Opening comments

- *Care and support for people living with HIV/AIDS: The President's Emergency Plan for AIDS Relief*
  Julie Chitty, Regional Palliative Care Technical Advisor, Office of the Global AIDS Coordinator

Theme 1: Meeting the care and support needs of different populations

- *Examining community needs and barriers to care treatment in South Africa*
  Catherine Searle, Horizons/Population Council, Johannesburg

- *Meeting the needs of children with HIV*
  Lewis Ndhlovu, Horizons/Population Council, Johannesburg

- *Trapped in a difficult situation: The role of the elderly in the care of OVC and the sick in the Eastern Cape*
  Priscilla Reddy, Medical Research Council, Cape Town

Theme 2: Models and cost of community-based care and support

- *An assessment of the home-based care kit situation in South Africa*
  Zonke Mabude, RHRU, Durban

- *Cost evaluations of home-/community-based care*
  Veni Naidu, JEAPP, Johannesburg

- *Mentorship program to provide psychosocial support to child-headed households in Gikongoro: Lessons learned to date*
  Edward Kalisa, World Vision International, Kigali

- *Schools as centers for care and support*
  Lynette Mudekunye, Save the Children UK, Pretoria

Theme 3: Care and support priorities in the era of ART

- *Lessons learnt from the N'doro model*
  Natalya Dinat, Wits Palliative Care, Johannesburg

- *The* HOPE *worldwide South Africa experience*
  Karolien Van der Watt, HOPE *worldwide*, Port Elizabeth

- *Community education and referral: Supporting adherence to antiretroviral treatment and prevention for people with HIV in Zambia*
  Phillimon Ndubani, Institute of Economic and Social Research, Lusaka

Appendix B: Participant List

Name	Organization
Phyllis Jones-Changa	AED
Ndilikazi Buhlungu	Africare
Ragis Govendor	Age-In-Action
Renee Saunders	American Solidarity Center
Zola Madikizela	Atlantic Philanthropies
Mpefe Ketlhapile	Boston University of Health Economics Research Unit
Karen Birdsall	CADRE
Kalie Naidoo	CARE
Zonke Mabude	Care & Support RHRU
Portia Marks	CBR/Population Council
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Thembi Maleka	Wits Health/Right To Care
Natalya Dinat	Wits Palliative Care
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Appendix C: Priority List

Each participant was asked to identify their top priorities for each of the three themes covered in the symposium. Priorities could relate to program, research, or policy concerns. Below is a list of some of the key identified priorities, according to theme.

Priorities from Theme 1: Meeting the Care and Support Needs of Different Populations

1. Formalizing referral networks among HCBC programs and treatment.
2. Standardizing training of primary caregivers and community members on ARVs and on care and support, including supervision and quality control.
3. Increasing community involvement, including developing strategies for community mobilization.
4. Developing and testing child-centered models of care and support.
5. Ensuring effective incentive schemes to properly recruit and retain community caregivers, including training, food, professional growth, transportation, HCBC kits, etc.
6. VCT and disclosure for children, to lead to earlier identification and treatment, as well as access to basic health care.
7. Researching the care and support services available for HIV-positive children.
8. Addressing issues of stigma and disclosure and their relationship to ARV access.
9. Meeting the needs of elderly caregivers and youth-headed households.
10. Investigating care and support needs of men.

Priorities from Theme 2: Models and Cost of Home- and Community-based Care and Support

1. Establishing minimum standards for palliative care.
2. Supporting caregivers in resource-poor settings.
3. Evaluating HCBC services, costs, and outcomes to inform cost of quality care services.
4. Linking HCBC to government and NGO treatment facilities, including framework and policy guidelines for the provision of care.
5. Providing a useful and economical home- and community-based care kit for every caregiver.
6. Monitoring and evaluating HCBC programs.
7. Creating more standards to guide costing and pricing principles for all sectoral programs, including HCBC programs, caring for children who are affected by HIV, ART and VCT programs, etc.

Priorities from Theme 3: Care and Support Priorities in the Era of ART

1. Supporting families with several members that are HIV-infected.
2. Examining the role of gender in caregiver relationships.
3. Exploring the relationship between adherence/knowledge/use of ART and the different HCBC models to determine if HCBC programs make ART programs more effective.
4. Providing continuous grants for all those on ARV treatment.
5. Integrating preventive strategies.
6. Strengthening community education and ensuring a uniform referral system.
7. Developing institutions or organizations to coordinate care and support and ART programs.
8. Encouraging donor harmonization toward ART program support and cost-effectiveness.

Horizons

Horizons is a global operations research program designed to:

- Identify and test strategies to improve HIV/AIDS prevention, treatment, and care programs and services.

- Disseminate best practices and promote research utilization with a view toward scaling up successful interventions.

Population Council

Horizons is implemented by the Population Council in collaboration with
- International Center for Research on Women (ICRW)
- International HIV/AIDS Alliance
- Program for Appropriate Technology in Health (PATH)
- Tulane University
- Family Health International (FHI)
- Johns Hopkins University

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