CARE AND SUPPORT

Care and support for people living with HIV/AIDS (PLHA) is increasingly recognized as integral and inseparable from efforts to prevent HIV. Organizations that set out to focus on prevention have been compelled to also address care and support as HIV/AIDS begins to affect their constituencies. The Horizons research strategy focuses on developing and assessing the impact of a variety of new care and support interventions that address the clinical, social, and economic needs of PLHA and their families. Horizons studies examine the role of various sectors in care and support, cost and sustainability, and the process of scaling up effective care and support programs. A prominent theme throughout the Horizons portfolio is the issue of stigma and discrimination and how they impede access to adequate care and support for PLHA.

Community Acceptance of Young People in Care and Support

Many young people are already providing care to sick family members, although few have the appropriate knowledge and skills to deal with the complex health needs and social issues associated with HIV/AIDS, such as stigmatization. One promising development in Zambia has been an intervention study conducted by Care International, Family Health Trust, and Horizons, to determine which care and support needs can be met by trained youth through anti-AIDS clubs.

Baseline findings revealed that 79 percent of young men and 73 percent of young women said they would be comfortable caring for PLHA, and 47 percent of males and 42 percent of females said they have provided care to a family member or other person who was chronically ill in the last six months. Despite overall support for assisting with caregiving, club members identified a number of concerns, including a lack of skills, training, and transport, and a fear that parents and church leaders might react negatively. Some club members also wondered about how confidentiality would be addressed and how older PLHA would feel about youth involvement.

Six months after training and distribution of kits containing such basic materials as aprons, soap, salt, disinfectant, gloves, cotton wool, and bandages, all clubs in the intervention arm of the study report that they are providing care for between four and twelve PLHA and that they are sharing their knowledge and skills with family members. Youth interaction with PLHA and their families is also lessening the rejection of PLHA by family members, who are showing a greater willingness to take part in caregiving. Critical to the involvement of young people in caregiving has been the support by club patrons, village leaders, and health professionals in order to establish links with households affected by HIV/AIDS and to give credibility to youth’s new role as caregivers.1
Scaling Up Patient-Centered Care and Support

The rapid growth of the HIV epidemic has intensified interest in learning more about the process, impact, and cost of scaling up care and support services. This has been the focus of a Horizons study on efforts to scale up a continuum of care and support services provided by YRG CARE, an NGO based in Chennai, India. With technical support from the International HIV/AIDS Alliance, YRG CARE has worked since January 2000 with scale-up partners to expand patient-centered services at four new sites in South India.

The study has identified a shift in priorities among all the scale-up partners, from an emphasis on adding or improving clinical services at baseline, to a recognition of the critical role and importance of counseling and psychosocial support by the end of the project. Clients also acknowledge the value of counseling; according to one PLHA service user:

*Counseling has been the most useful, and it has given a great sense of moral support to me, and given a new meaning to my life.*

The study also highlighted the importance of networking with other providers in order to develop referral systems, improve outreach to affected communities, and avoid duplicative services and competition among providers.

Increased visibility of care and support has resulted in greater community interest in prevention, leading to higher demand for prevention information and more targeted prevention activities with such key populations as sex workers, men who have sex with men, migrant laborers, prisoners, PLHA, and others. All scale-up partners reported increases in service utilization of prevention, care, and support services. To help meet this demand, an average of four full-time staff were added at the scale-up sites to support expanded care and support services, and volunteers increased dramatically from doubling at one site to a six-fold increase at another.²

Improving the Hospital Environment for PLHA

According to data from a Horizons study conducted in India with the NGO Sharan, concerns about stigma and discrimination in clinical settings is a major deterrent to care-seeking by PLHA, along with costs of care, hopelessness, and lack of information about available treatment. The study’s baseline survey revealed that health care workers harbor some negative attitudes about PLHA but also lack key information about HIV transmission and risk. These problem areas are exacerbated by poor infrastructure and lack of adequate infection control measures. Horizons and Sharan are conducting operations research to identify and address factors contributing to stigma and discrimination in clinical settings, including policies, staff attitudes and knowledge, training, and supplies.

One key element of the interventions being tested is a self-assessment checklist for a patient-friendly environment. Managers can use the checklist to identify and address institutional weaknesses with respect to care for PLHA. Use of the checklist has led to a number of actions with the potential to expand access to and improve the quality of care for PLHA, including:

- Engaging staff in participatory sensitization workshops that address PLHA needs and rights.
- Increasing the number of staff trained in HIV counseling and testing.
- Providing information and training on infection control, universal precautions, and post-exposure prophylaxis to increase staff safety, as well as allaying staff fears about treating HIV-positive patients.
- Developing and disseminating hospital-specific guidelines on care and management of PLHA in accordance with national policy.3

**Strengthening Home and Community Care and Support for PLHA**

A training program and manual, “Stay Fit and Feel Good,” is the focus of an intervention study being conducted in Thailand by Horizons, the Program for Appropriate Technology in Health (PATH), Lampang Provincial Health Office, and the Thai Ministry of Health. The researchers assessed the impact of the manual and training for family caregivers and village health volunteers (VHVs) on the quality of life for PLHA. Three rounds of data were collected using a structured questionnaire from 406 PLHA, 78 family members, and 120 VHVs. Quality of life was measured by 22 different questions divided among five domains: physical wellbeing, mental wellbeing, family and social relationships, life satisfaction, and economic wellbeing.

Findings show that PLHA who received care from trained family members or VHVs reported a decrease in the average duration of opportunistic infections in the last three months (from 27 days at baseline to 14 days at Round 3), compared with significant increases in the duration of physical sickness at the control sites. Improved physical and mental wellbeing was also reported, with the mean physical wellbeing score improving from 3.8 to 4.1 in the final round (maximum score = 5; p<.001), and the mean mental wellbeing score also improving from 31.6 to 33.2 (maximum score = 40; p<.01). There was no corresponding statistically significant improvement among PLHA in the control area.

Exposure to trained family caregivers in the intervention areas was related to improved PLHA physical wellbeing, while exposure to trained VHVs was associated with improvements in mental wellbeing of PLHA. This suggests that family caregivers were able to utilize knowledge from the manual and training to provide more appropriate medications, and that the VHVs strengthened their skills to perform home visits and were better equipped to handle the psychological problems of PLHA.4

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**Average duration of a physical sickness in the last 3 months among PLHA in the study**

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<tr>
<th></th>
<th>Baseline</th>
<th>Intermediate</th>
<th>Final</th>
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<tbody>
<tr>
<td>Days</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Intervention area</td>
<td>25</td>
<td>15</td>
<td>10</td>
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<tr>
<td>Control area</td>
<td>28</td>
<td>22</td>
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Women Living with HIV/AIDS Have Unique, Unmet Needs

Women living with HIV/AIDS in Burkina Faso and Ecuador report a gap between the information and care and support services they need and those that are available, according to a study of PLHA involvement in community-based organizations conducted by Horizons and the International HIV/AIDS Alliance. In Burkina Faso, HIV-positive women feel that they must continue to have children to fulfill gender role expectations and want information about how to do so safely. Yet they report that local professionals oppose their desire to become pregnant and withhold information about reducing the risk of transmission through pregnancy, delivery or breastfeeding. In both countries, women express a strong desire for additional health services for their children and for support in planning for their children’s future. NGOs providing services for PLHA in both countries were largely unaware of the particular needs of women living with HIV/AIDS but now aim to reorient their programs to meet gender-specific needs.5, 6

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1 Mobilizing Young People for the Care and Support of People Living with HIV/AIDS in Zambia. 2002. Horizons Research Update. *

*Available on the web at www.popcouncil.org/horizons.html; for a hard copy contact horizons@pcdc.org.