

## EXPLORING THE ROLE OF FAMILY CAREGIVERS AND HOME-BASED CARE PROGRAMS IN MEETING THE NEEDS OF PEOPLE LIVING WITH HIV/AIDS

As more households in South Africa are affected by HIV/AIDS, there is a growing need for assistance with care and support. Increasingly households are faced with coping with the needs of sick members, including assistance with daily living, treatment, and palliative care. Given the limited availability of formal, inpatient programs, households rely upon informal caregivers (e.g., household or family members, friends, community members, or voluntary organizations) and home-based care (HBC) programs for assistance. Households may use one or more of these sources of support in order to cope with caring for sick members.

In 2004, the Horizons Program undertook a study of six different HBC programs on 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.

This summary documents the roles played by household and HBC program caregivers in meeting the needs of the chronically ill. It also identifies those needs that are not being met by household and HBC program caregivers. A better understanding of the roles played by the different caregivers and of the unmet needs of the chronically ill can assist program managers, policy makers, and donors in strengthening interventions to mitigate the impact of HIV/AIDS on households.

### 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 (PSA-SA)), 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.

### Description of the Programs

The two urban HOPE *worldwide* programs (HWW Soweto and HWW 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 upon 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 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

### **Most study households do not have a working member.**

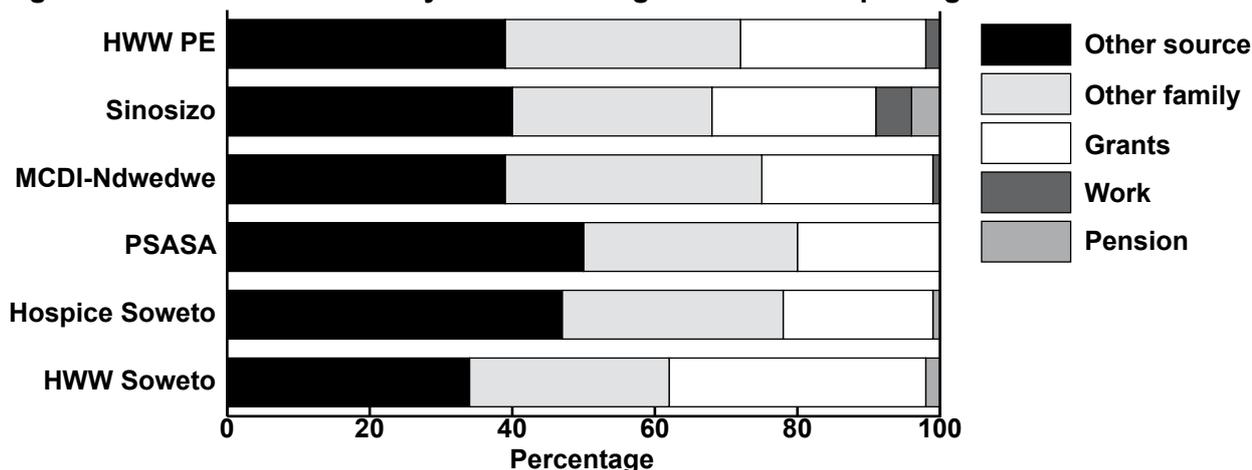
The households in the survey sample typically include 5-6 persons, of which one person is sick. In over half of the households there is no one who is working, and in two-thirds to three-quarters of the households, depending on the study site, at least one person is in school.

### **A large proportion of household income is from pensions or social grants.**

The reported monthly household income from all persons in the household ranges from a low of ~750 Rand among Hospice Soweto clients to around 1080 Rand for MCDI-Ndwedwe clients (though they have, on average, larger households). The poverty line for a household of 4 people is approximately 1200 Rand per month, indicating that many of the households surveyed survive on very limited resources. Overall, six percent of households report no source of income, although this varies by program from a low of 6 percent of the PSASA sample to a high of 16 percent of the HWW Soweto sample.

Figure 1 shows the mean proportion of household income by income source for each HBC program sample in the study. Of interest is that 34 - 50 percent of the household income is in the form of pensions. Work provides 28 - 36 percent of household income, followed by grants, which provide 20 - 36 percent of household income. These include childcare grants, foster care grants, child dependency grants, and disability grants. Other family members very rarely remit money to the household.

**Figure 1 Household income by source among households reporting income**



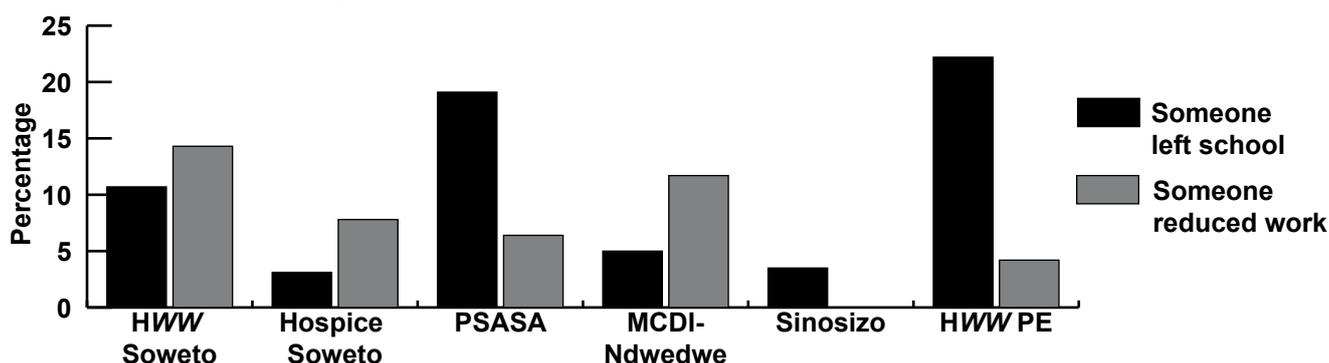
**Coping strategies to assist with caregiving include seeking outside assistance, taking someone out of school, and reducing work hours.**

The researchers asked the survey respondents to report on strategies used by the household to cope with having a sick member. As shown in Figure 2, in addition to seeking outside assistance from a HBC program, approximately 20 percent of households receiving services from PSASA and HWW Port Elizabeth took someone out of school. This response can reduce household expenses and can increase the available time of household members to provide assistance to the sick person. Only for clients of HWW Soweto and the MCDI-Ndwedwe program did more than 10 percent of respondents report that a family member reduced working hours or left work. This response reduces household income but increases the available time for household members to provide assistance. The low use of this strategy may be influenced by high unemployment among these households, as indicated by the substantial proportion of study households that do not have a working member.

**The majority of program beneficiaries in the sample are female and between the ages of 26 and 45 years old.**

Overall more than two-thirds of the HBC program clients in the survey sample are female (range 62 percent for MCDI-Ndwedwe to 70 percent for HWW Port Elizabeth). When examined by age, 15 percent are less than 26 years old (7 percent less than 16 years old), 30 percent are 26 to 35 years old, and 24 percent are 36 to 45 years old, with the remaining 30 percent almost evenly divided between those 46 to 55 years old (15 percent) and those greater than 55 years old (16 percent). Over half are in the prime productive 20-year interval of 26 to 45 years old. This is what would be expected given the natural history of HIV/AIDS and the state of the pandemic in South Africa.

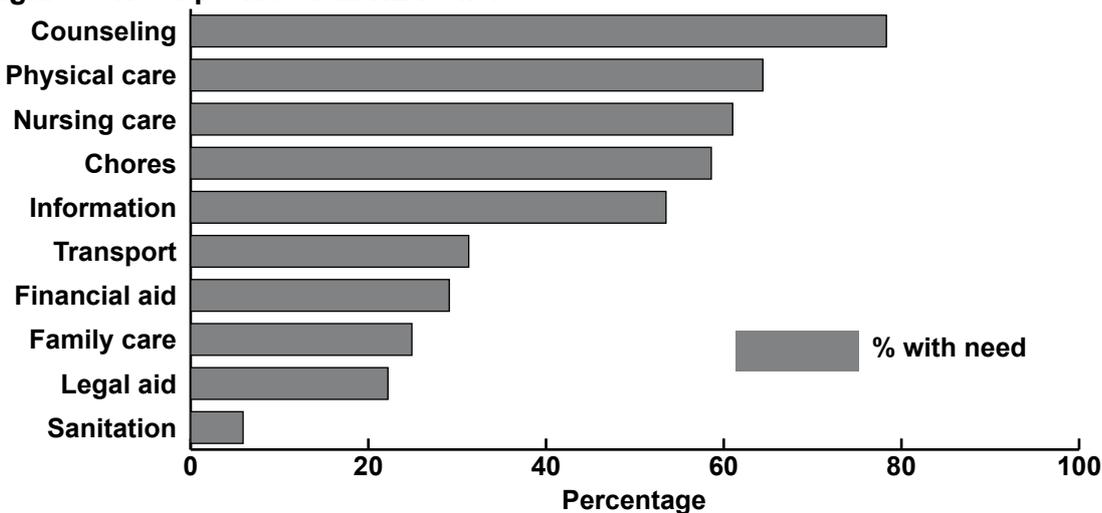
**Figure 2 Household coping strategy by program**



### The most common needs reported are for physical care and nursing care.

The overall distribution of type of need across all clients is shown in Figure 3. The most common need was someone to provide emotional/spiritual support (counseling). This was followed by someone to assist with physical care (e.g., bathing, eating, dressing, using the toilet) and nursing care (e.g., pain management, treating wounds, taking medication). A need for assistance with household chores such as cleaning, cooking, shopping, running errands, or gardening and someone to provide information on HIV/AIDS and caregiving were cited by more than half of the respondents. The remaining needs (transport, financial assistance, care for other family members, legal aid, and shelter/sanitation) were cited by less than a third of the households.

**Figure 3 Need profile of all HBC clients**



### Most household caregivers are female family members.

The vast majority of survey respondents reported that their household caregiver was a woman (78 percent). The burden of care falls on caregivers of all ages. Nearly 40 percent of caregivers are 46 years or older, with 20 percent of these caregivers over 55 years of age. Forty-three percent of caregivers are in the 26 to 45 year age range, which corresponds to the most productive period of a person's life. This suggests high opportunity costs to households associated with the care of sick persons. Eighteen percent of the household caregivers are less than 26 years old (4 percent less than 16 years old).

When looking at the relationship between the sick person and the household caregiver, the bulk (82 percent) of the household caregiving is provided by immediate family members. Of interest is that 25 percent is provided by someone a generation younger than the sick person (e.g., son, daughter, nephew, niece, etc) and 33 percent is provided by someone a generation older (e.g., mother, grandmother, aunt, etc). The remaining caregivers are from the same generation (35 percent). This highlights the transgenerational nature of caregiving in many households.

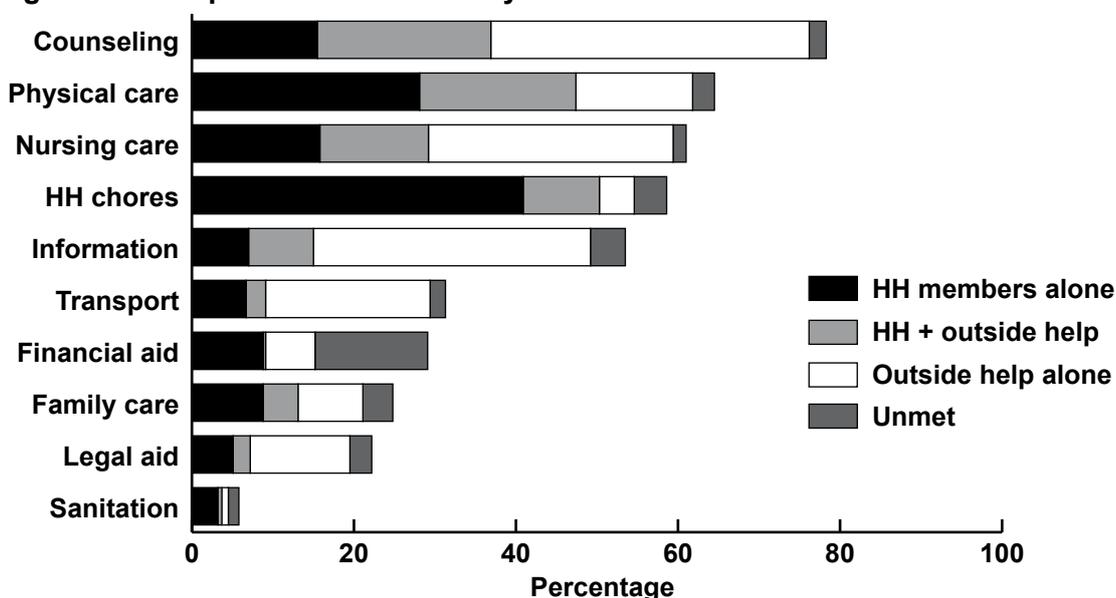
Qualitative data from focus group discussions with beneficiaries similarly reveal that caregivers within the family tend to be female. Beneficiaries report that it is mainly their mothers and in some cases their sisters or daughters who assist with providing care. Respondents feel that fathers and brothers do not provide support (in some cases these household members are absent or dead). According to a female respondent from Mpumalanga, "Fathers can't take care of the sick; they only help out with money once in a while." Similarly, a woman from KZN comments, "A man can't take care of a sick person. It is obvious the woman or mother is the one who takes care of the sick one." A female respondent KZN notes, "You know males they are not that sensitive. Mothers can take care of so many things. Most males don't like taking care of sick people... women are patient and caring. Men can't be like that."

## Despite the assistance of HBC programs, households report unmet needs.

As might be expected, not all needs are addressed by the outside caregivers. The extent to which the program fulfills a client's needs is influenced by the skills of the outside caregivers as well as the ability of the household members to contribute towards addressing needs. Figure 4 shows the need profile with each bar split into four sections based on the percentage of clients whose needs are being addressed by: only household members, household members with assistance from the outside caregivers, outside caregivers only, and those whose needs remain unmet despite access to the outside caregivers.

Except for household chores, financial aid, and sanitation, the outside caregivers are involved in helping the household with the majority of situations where a client has a given need. The outside caregivers provide the bulk of counseling, nursing care, information, transportation, and legal aid, working alone rather than in tandem with household members. This heavy reliance upon the outside caregivers may create situations of dependency by the household on the outside caregivers. In terms of needs that remain unmet despite the availability of outside caregiver services, the one need that has a significant gap is financial assistance. This need remains unmet in 48 percent of households who identify financial assistance as a need.

**Figure 4 Need profile of all clients by source of care**



Even in the cases where the outside caregivers are involved in the provision of services, on average, the household caregivers spend more time per week assisting the sick person than the outside caregivers. Time is not a perfect measure of intensity since it may be that a trained caregiver is more efficient. Also, given high unemployment rates, there is less pressure on the household caregiver to limit the time spent with the sick person. Nevertheless, this suggests that the outside caregivers serve more as a complement to the household caregivers than a substitute.

However, in some cases, the outside caregiver cannot be replaced by a household member. For those services that are being provided by outside caregivers, the researchers asked if there is someone in the household who could provide that service if the outside caregiver is not available. Figure 5 shows the expected source of care for client needs if the outside caregiver is not available. While the majority of households feel someone in the household could substitute for the outside caregiver, for four of the top five needs (counseling, physical care, nursing care, and information) more than 10 percent of clients say those needs would remain unmet if not for the availability of outside caregivers.



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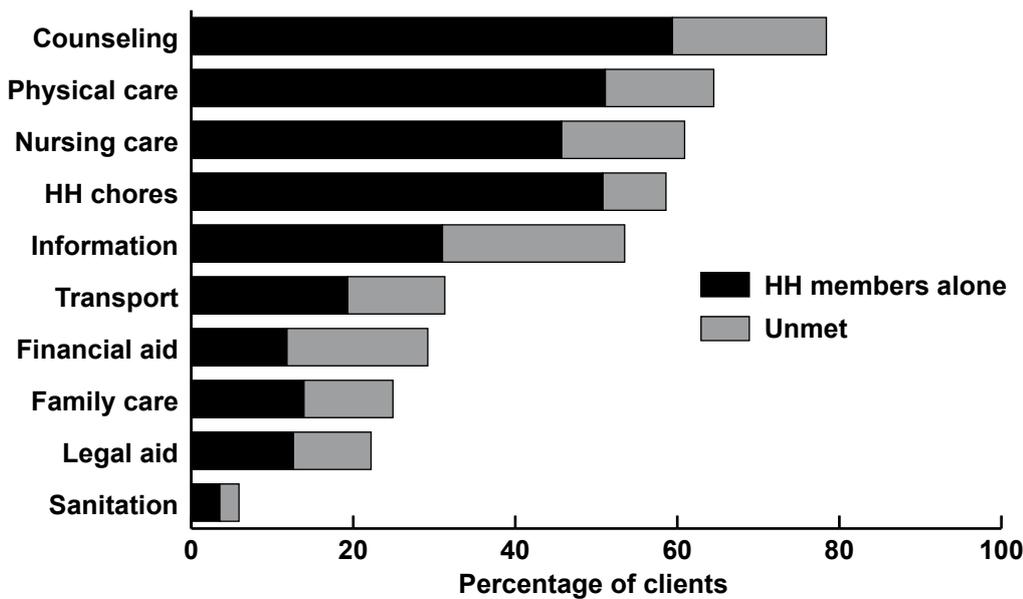
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Figure 5 Household ability to replace outside caregiver by service



Similarly, findings from the qualitative research indicate that despite the important role beneficiaries feel the programs play in their lives, they also have many needs that are not being met. Respondents identified financial needs, needs relating to access to medical care, and emotional needs in particular as being insufficiently met.

## Conclusions and Recommendations

This research documents the differences in types of care provided by informal and formal caregivers. The findings suggest that:

**Formal caregivers serve more as a complement to the household caregivers than as a substitute.** Even where formal caregivers are providing HBC services, the household caregivers, on average, spend more time per week assisting the sick person than the formal caregivers.

**There is a need for HBC programs to work more closely with household members.** Interventions to educate families on caregiving are needed as household caregivers may lack the necessary skills for caregiving. This is evidenced by the substantial proportion of caregivers who wish to receive more information and education on caring for people living with HIV/AIDS.

**HBC programs need to explore ways to assist households with income generation.** Many of the households served by HBC programs are very poor and linking HBC programs with income generation activities may alleviate some of the financial burdens they face.

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