



Information Brief

June 2004

Expanding the Care Continuum for HIV/AIDS: Bringing Carers into Focus

This bulletin highlights key findings from a longer paper written by the International Center for Research on Women, in partnership with the United Nations Development Fund for Women (UNIFEM), the International Labor Organization (ILO), and the Horizons Program. Our analysis suggests that (1) the international “care agenda” needs to incorporate an understanding of the care economy with a particular focus on the caregiver, and that (2) in so doing, national level health systems should work with other social development sectors to support household livelihoods and well-being. In addition, national governments must define specific public sector roles and responsibilities for the provision of care and provide guidance in shaping private and NGO sector inputs. Care, we argue, provides fundamental public goods and therefore needs appropriate remuneration and support.

“Who cares for the carers, and why is it taken for granted that women provide, and will continue to provide, care and support to family members and loved ones, with no sense of the cost and value of this work to society and the economy in general?” (Berman 2002).

This is not a rhetorical question for the majority of poor people affected by HIV and AIDS. When there is a sick or dying person in the house, someone quite literally has to care, whether out of love, duty, or simply a lack of options. It is generally recognized that women and girls are the principal caregivers in the vast majority of homes – a responsibility with substantially greater weight in homes affected by HIV and AIDS, although men and boys may be taking on more of this work as the epidemic progresses (e.g., Esu-Williams et al. 2003). It has also been observed that in carrying out

this largely unremunerated care work, women and girls are often forced to leave paid jobs, schooling and other opportunities, and that this care work displaces other health producing activities in the household and community (e.g., Steinberg et al. 2002).

The care work done in the household is referred to in economics literature as the “care economy” (Elson 2002). This work sustains families, allows children to go to school, and frees the time of other household members to generate income. The current public finance environment, which encourages governments to spend less on social development, has generated a “care gap” that women frequently subsidize with their own time, energy, and resources. Although care provides fundamental public goods, it is unaccounted for in government national income and product accounts.

Box 1

Women's activities in the care economy

- ▶ Collecting water and fuel
- ▶ Growing, storing, preparing, and serving food
- ▶ Cleaning and washing
- ▶ Bathing children and the sick
- ▶ Child care and socialization
- ▶ House maintenance
- ▶ Ministering to the sick
- ▶ Maintaining social relationships with family and neighbors
- ▶ Supplemental income generation

Both the burden of care work and the costs incurred are greatly exacerbated in the context of a mature HIV epidemic. Many indigenous social safety nets that underpinned the care economy in the pre-AIDS era are being eroded in highly affected communities. At the same time, development interventions that in the past had helped many poor families to manage, such as microcredit projects, are not necessarily appropriate for those affected by AIDS. And because few families ever obtain a formal diagnosis of the disease that is affecting them, they do not take advantage of health sector initiatives (such as home-based care programs and others) that could provide vital support.

While some efforts are being made to relieve the burden of AIDS care on household carers, much more needs to be done to enable individuals, families, and households to survive in a world shaken by AIDS.

The Care Economy in the Context of the AIDS Pandemic

Caring labor, always necessary to maintain families, has been stretched thin by the HIV/AIDS pandemic. Box 1 provides a partial listing of the unpaid activities undertaken by caregivers regardless of whether a family member is living with HIV and AIDS. Box 2 shows some of the additional work required in an AIDS-affected home. The precise activities will vary according to the circumstances of the family and stage of the illness.

Although few systematic studies have explored who provides care at the family level, it is widely acknowledged that women play a central role (e.g., Pizurki et al. 1987, cited in PANOS 1990) – elderly women in particular. It is important to note that men are also involved in caregiving, and that this involvement may indicate a renegotiation of gender norms in the context of this epidemic. For example, while reporting that men are almost never the primary carers in the home, a recent UNAIDS case study also notes that, in Uganda and South Africa at least, AIDS is beginning to challenge traditional attitudes and that men are increasingly willing to take a more active role in the physical care of sick spouses and family members (UNAIDS 2000).

Children are the least acknowledged carers in the home (UNAIDS 2000; Barnett and Whiteside 2002). Although it is not known how many children are currently acting as primary caregivers, their involvement will become increasingly common as the epidemic matures. Anecdotal evidence from various African countries suggests that these child carers are often very young, between 8 and 11 years old. Child carers are often forced to leave school to take on this caregiving work and also miss out on other opportunities such as sports, leisure, and socializing with peers. In addition, they are put in the position of having to watch their parents and elders sicken and die, to intimately handle their bodies and excreta, and to worry whether they are “doing it right” while at the same time dealing with their grief and facing an uncertain future.

Box 2

Additional care activities in AIDS-affected home:

- ▶ Bathing the sick person and cleaning up after them
- ▶ Hand-feeding those too sick to feed themselves
- ▶ Escorting the sick person to and from the toilet
- ▶ General assistance in walking
- ▶ Emotional support
- ▶ Purchasing and administering drugs or remedies

HIV/AIDS Scenarios of Care

The figure on the next page outlines four different scenarios indicating a range of different forms of home-based care provision. Although most households will remain unlinked to any program (Situation 1), others will, over time, move in and out of the other situations pictured in the diagrams. It is crucial to note, however, that whether or not they receive program support, family members provide the bulk of care, and for the vast majority of AIDS-affected families, these caregivers are not linked to or supported by any formal HIV/AIDS care program. This is the “unlinked” system of care.

Challenges Faced By Unlinked Family Care Providers

The challenges facing unlinked carers range from burn-out and impoverishment to increased vulnerability to illness. Unlinked care providers receive no training, no support from formal programs, no concrete inputs such as gloves or medication, and generally little respite from their caregiving duties. They often lack information about the disease they are managing or what to expect over time. In addition, due to HIV/AIDS-related stigma, caregivers may be closed off from social support at the time they need it most. These challenges can result in the carer becoming exhausted and feeling out of options, sometimes neglecting the person in her care as a result. This can be devastating for all involved, not least the carer herself, who might otherwise derive satisfaction, self-esteem, and approbation from the community for being a “successful” carer.

Caring for someone living with AIDS also places a range of physical and emotional burdens on the caregiver – ranging from body aches, fatigue and muscle strain to emotional stress and feelings of despair and helplessness in the face of the care recipient’s imminent death (Akintola 2004).

These caregivers need education on the basic facts on HIV/AIDS and the ever-changing face of AIDS, physical support for respite, and psychosocial support. They also need to be aware of the various feelings they

can expect to go through and how to handle these. Most importantly, perhaps, they need resources such as gloves and water that will enable them to carry out their care work effectively, safely, and with dignity, as well as income support to sustain them throughout the illness.

Costs of Unlinked Care

The financial costs of home care have been greatly underestimated, not least because they do not, as a rule, take account of direct expenditures (medicines, transportation, labor time) and the opportunity cost of earnings sacrificed from paid work for time spent instead on unpaid care work. Households compensate for these costs in a number of ways, for instance by withdrawing savings, selling assets, withdrawing children from school, or depending on an extended family system and the community to support and help them (Desmond et al. 2000; Kongsin et al. 2000).

Health sector interventions alone are not sufficient to compensate for this burden on households: social protections are needed to help create safety nets to replace those no longer in place. These could come from a combination of state, private sector, and NGO programs.

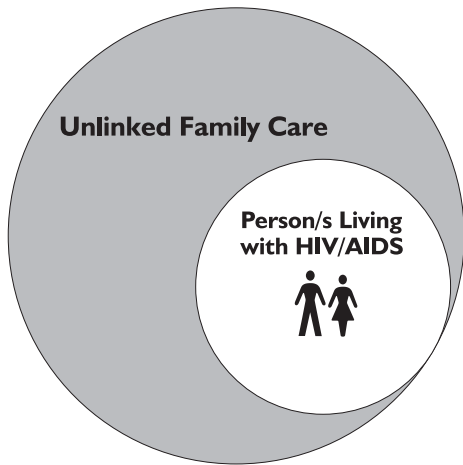
The Health Sector Response

The emphasis of HIV/AIDS policies and programs has, from the earliest days of the epidemic, been on *prevention*. Yet, awareness is slowly emerging of the importance of *care* and an international “care agenda.” However, the formal health care sectors of the most hard-hit countries have been unable to cope with the increased demands being placed on them by the epidemic. Therefore, the need for care has been keenly felt – and principally met – in the homes of those directly affected, usually without the benefit of external assistance.

Shifting Clinical Care to the Home and Community

As the HIV epidemic continued unabated into the mid-to late 1990s, programmers and policymakers began to consider ways to formally shift the locus of clinical

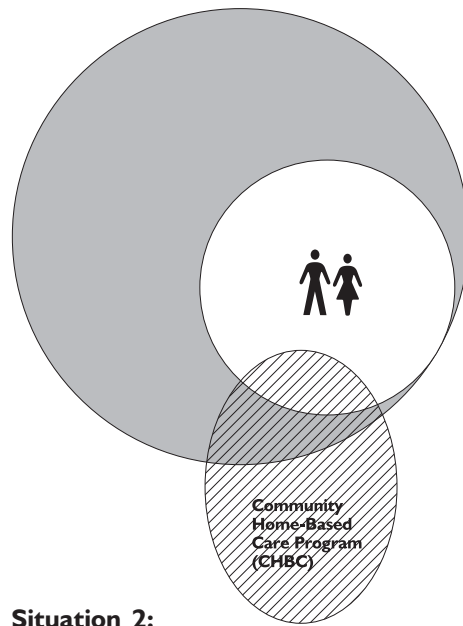
Figure 1



Situation 1:

This diagram depicts the situation prevailing in the vast majority of AIDS-affected households. The large shaded circle represents care provided by family members within the household, while the smaller circle represents the household care economy that is devoted to the care of those living with HIV and AIDS.

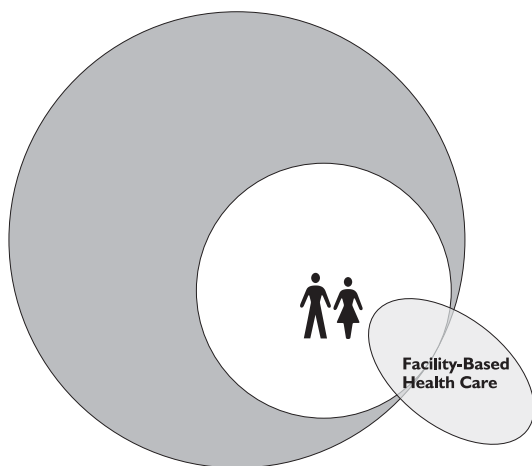
This household type is unlinked to any formal care program and has little access to health care facilities. Those who are ill are not likely to have obtained a formal HIV diagnosis. Although the carer may be obtaining medicines and various remedies for symptoms from traditional healers and local pharmacies, the family in this situation does not have the time or money to access formal health care services regularly.



Situation 2:

CHBC program provides support to PLHA, alleviating some of the family's care burden. Although they may be getting some clinical care from the CHBC program, they may not be accessing formal facility-based health services. Services provided by CHBC programs in this scenario may include:

- ▶ Spiritual and emotional support;
- ▶ Help with custodial tasks such as washing bedsheets and clothes of PLHA;
- ▶ Help with hand-feeding;
- ▶ Help bathing the PLHA and other minor nursing duties;
- ▶ Provision of some medications and treatment for symptoms and uncomplicated opportunistic infections.

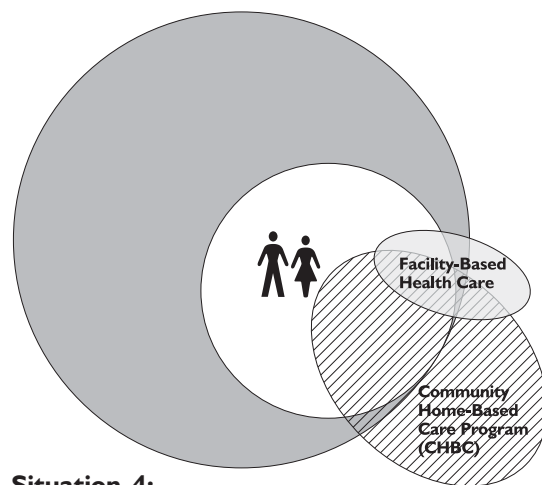


Situation 3:

The PLHA is obtaining access to facility-based health care (represented by the light gray oval). The household is not directly benefiting from this care (the light gray area does not overlap with the shaded circle). In fact, the overall household burden has grown somewhat due to the costs of formal health care.

Clinical care in facilities might include:

- ▶ Treatment for opportunistic infections
- ▶ Treatment for sexually transmitted diseases
- ▶ Pain relief
- ▶ HIV counseling and testing



Situation 4:

This household is linked to a community home-based care program (striped oval), and the PLHA is receiving some clinical care from facility-based health services (light gray oval). The CHBC program in this scenario is also linked to formal health sector facilities, so may be better able to provide clinical inputs. However, the program lacks a family support component. The PLHA is getting the benefit of improved care, but the household and its carers are not benefiting as much as they might be if the CHBC program and the formal health sector services were purposively addressing their needs.

care from the health services to the community. Initial efforts revolved around a principle of hospital-based outreach, whereby hospital staff traveled directly to patients' homes to provide care. Not surprisingly, however, these programs were found to be time-consuming and expensive, especially in rural areas (Hansen et al. 1994; Chela 1995).

Meanwhile families, households and communities had already begun to respond to the crisis. The core of this response was and remains within affected households themselves – the domain of “unlinked” care. In addition, a range of new programs emerged, mostly led by faith- and community-based organizations, to support people living with HIV and AIDS and their families, under the rubric of Community Home-Based Care (CHBC). Yet many of these community initiatives struggled, their networks and strategies often only able to reach a small segment of the affected population, especially in high prevalence countries. In response to the need to coordinate these many ongoing responses, the WHO developed the “care continuum” framework (WHO 2000), which includes a range of comprehensive services, with provision of care extending from the individual/home to the hospital (Osborne 1996).

The “care continuum” represents an important advance in the development of an agenda for the provision of care. Viewed through the “care economy” lens, and taking into account the prevalence of unlinked care, however, a number of important areas for further development emerge. For example, although “home care” and “community care” feature in the continuum, the focus remains on formal health sector interventions, without adequate attention to creating mechanisms that can effectively link the ongoing home and community responses to the formal health care programs. The formal health care sector focus of the care continuum also fails to account for the challenges posed to access, such as poverty, stigma and gender. To be truly comprehensive, and to truly facilitate the movement of those affected by HIV/AIDS into care, the continuum needs to encompass a wider breadth of response.

Recent Developments in the Health Sector Response: Anti-Retroviral Treatment

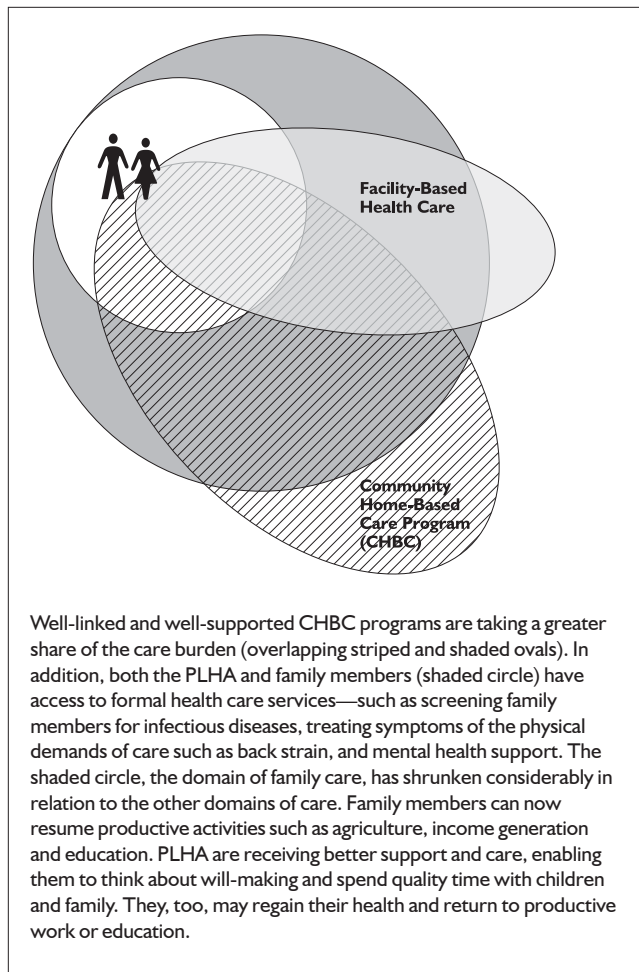
Many current initiatives are attempting to increase the availability of anti-retroviral treatment (ART) in poor, highly affected countries. While these efforts are urgently necessary and to be welcomed, a concern is that they have not incorporated a gender analysis into their design, and so may not be taking adequate account of the ongoing importance and prevalence of “unlinked care.” More troubling is the possibility that the full force of attention being applied to this one domain of AIDS care (clinical) may cause the issue of home care to once again drop off the international (and therefore national) HIV/AIDS agenda and so undermine the preliminary and partial gains made toward mobilizing advocacy and action for meeting the full range of care needs of those living with HIV and AIDS, as well as the needs of unlinked family carers.

The availability of ART does not obviate the importance of a caring household. Firstly, people on treatment may need support for treatment-taking. Because the regimes are complex and quite toxic, the carer may need to keep records of the specific medications and doses the patient is taking, how they should be taken, and potential side effects. Secondly, although more research is needed on the interrelationships between ART and household well-being, close family relationships may actually enhance the physical effects of treatment (Kim et al. 2004).

Social Protection and Economic Interventions

The previous sections have highlighted some of the challenges facing carers in AIDS-affected households, how these challenges have been exacerbated by health service weaknesses, and how the CHBC movement has sought to mitigate these effects. Also touched upon were the potential contributions and limitations of new initiatives emerging onto the international HIV/AIDS agenda – the increased availability of anti-retroviral treatment. It is clear from the literature that whole household systems are affected by HIV/AIDS – that household well-being is undermined by the long-term,

Figure 2: An improved situation



systemic effects of providing care for terminally ill, severely debilitated adults who would otherwise have been making substantive contributions to the household economy. Although individual households will do their best to mitigate these effects, the choices they are forced to make may further undermine their long-term viability and ability to withstand shocks.

Donohue (1998) illustrates that the overall effect of HIV/AIDS on the economic well-being of affected households depends on the availability and size of household financial safety nets. Yet, many household safety nets are being eroded by the effects of the pandemic, and where conditions do not exist for households to cope, they need to be created. Health

sector interventions are not well-placed to facilitate this kind of resource development, which is why researchers, policy makers, and programmers are looking for ways to strengthen the economic foundations of households through the provision of social protections, effectively creating new safety nets. These interventions include state-sponsored social protection programs, such as pension schemes, disability grants and social insurance; private sector schemes such as insurance programs; and NGO programs that offer savings and other asset accumulation services. By strengthening the economic resilience of households affected by AIDS, these programs have the potential to support both those living with HIV and AIDS and their carers.

An Integrated Management Approach

Mitigating the impact of the pandemic on poor households in highly affected countries will be too much for any single sector or single type of intervention to undertake alone. “Community-based care” has often been perceived as *the* solution to the crisis of care, resulting in a retreat of the public sector and increased dependence on non-governmental organizations to establish programs. Meanwhile, many communities and households in high prevalence areas are themselves increasingly unable to cope. Although it would be ill-advised to become overly dependent on NGOs for CBHC, CHBC does have a fundamentally important role to play in mitigating the impacts of caring for those living with HIV and AIDS: “The issue in question is not whether to choose either state-based interventions or community-based solutions, but how to combine both sets of actions” (Quinlan and Desmond 2002:36). This implies providing care and support using limited resources to their maximum advantage, for example, by coordinating non-governmental initiatives with state-sponsored efforts.

Figure 2 represents an application of the “best-case” scenario in which home-based carers are linked to integrated NGO and state services.

Conclusion

It is clear that the “care agenda” is advancing. There are an increasing number of voices from the community calling for more and better attention to the needs of those caring for people living with HIV/AIDS in their homes and the importance of facilitating and enabling this care, not taking it for granted. It will be vital for these voices to be heard at national and international policy levels, and that action on expanding the “care agenda” proceed immediately. Downloading responsibility for care onto women, families, and communities can simply no longer be an appropriate or sustainable response.

Recommendations for Further Research

- 1) Although there have been a few studies on the impact of caring for someone living with HIV/AIDS, very few have attempted to quantify this impact. Such studies would need to explore the differential impacts of caregiving on women and men; impacts across different age groups; and implications of shifts in time-use for the individuals and households involved.
- 2) In the unlinked system of care, there is an urgent need to study who the care providers are, the forms of care they are providing, the costs and benefits of this care provision for the various household members, and how the unlinked “system” of care interrelates with the formal system of CHBC.
- 3) Research on the ways gender roles and expectations are shifting in the context of the epidemic could help identify ways to support adolescent and adult men to assume a greater role in caregiving.
- 4) There is a need for studies exploring the impact of antiretroviral therapy (ART) on households: How are household members involved in the treatment process, and what are the implications of this involvement for their own well-being, the well-being of the person on treatment, and the well-being of the broader household? How is the increased policy and programming focus on treatment affecting individuals and households *not* receiving ART? And to what extent do international and national level policies on ART integrate gender concerns?

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