Delivering comprehensive home-based care programmes for HIV: a review of lessons learned and challenges ahead in the era of antiretroviral therapy

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Home-based care (HBC) programmes in low- and middle-income countries have evolved over the course of the past two decades in response to the HIV epidemic and wider availability of antiretroviral therapy (ART). Evidence is emerging from small-scale and well-resourced studies that ART delivery can be effectively incorporated within HBC programmes. However, before this approach can be expanded, it is necessary to consider the lessons learned from implementing routine HBC programmes and to assess what conditions are required for their roll-out in the context of ART provision.

In this paper, we review the literature on existing HBC programmes and consider the arguments for their expansion in the context of scaling up ART delivery. We develop a framework that draws on the underlying rationale for HBC and incorporates lessons learned from community health worker programmes. We then apply this framework to assess whether the necessary conditions are in place to effectively scale up HBC programmes in the ART era.

We show that the most effective HBC programmes incorporate ongoing support, training and remuneration for their workers; are integrated into existing health systems; and involve local communities from the outset in programme planning and delivery. Although considerable commitment has so far been demonstrated to delivering comprehensive HBC programmes, their effectiveness is often hindered by weak linkages with other HIV services. Top-down donor policies and a lack of sustainable and consistent funding strategies represent a formidable threat to these programmes in the long term.

The benefits of HBC programmes that incorporate ART care are unlikely to be replicated on a larger scale unless donors and policymakers address issues related to human resources, health service linkages and community preparedness. Innovative and sustainable funding policies are needed to support HBC programmes if they are to effectively complement national ART programmes in the long term.

Keywords Home-based care, HIV, community, community health workers
Background

The scale up of HIV programmes in low- and middle-income countries has been accompanied by a renewed interest among donors and policymakers in the role of lay community health workers (CHWs) to provide some of the range of services needed by people living with HIV (PLHIV) following their diagnosis. In particular, comprehensive home-based care (HBC) programmes are proving to be a popular strategy for ensuring a continuum of care and support to PLHIV outside the health facility environment. These programmes, which initially emerged as a response to civil society organizations (CSOs) to the needs of HIV-affected communities, are now increasingly being advocated as a cornerstone to the HIV response by international organizations and funding agencies (Lindsey 2002; USAID 2008). The progressive integration of HBC into national HIV policies in many low- and middle-income countries (National Department of Health, South Africa 2001; Lindsey 2002; Ministry of Health, Kenya 2002; Crouch 2004) has been accompanied by the development of extensive training packages, such as those recently released by the World Health Organization and the Red Cross to support large-scale preparation of community-based volunteers (IFRC 2008), and detailed guidelines on establishing national monitoring and evaluation strategies (Crouch 2004; Gilborn et al. 2004).

The renewed focus on HBC as a strategy for providing HIV care in the context of antiretroviral therapy (ART) provision has led to calls for evidence of its effectiveness (Jaffar et al. 2005; Korenromp and Kayondo 2008), and several epidemiological studies have recently been undertaken to investigate its impact on a variety of outcomes. Most recently, a cluster-randomized trial in Uganda has compared clinical outcomes, costs and adherence for home-based and health facility-based ART provision (Amuron et al. 2007). The results of the study concluded that the facility-based model was equivalent to the facility-based model in terms of virological response, mortality, CD4 count and adherence, while the costs of service provision were similar for both models and costs to the patient were lower when ART was provided through HBC (Jaffar et al. 2009). In another area of Uganda, the Home-Based AIDS Care project has demonstrated high levels of adherence to ART among a cohort of patients enrolled in the programme who receive their drugs and a range of care, prevention and support services at their homes (Weidle et al. 2006). The same project has also compared the social experiences of ART patients at baseline and after 3 months of receiving weekly HBC visits, and found that participants were more likely to report community support, family support and relationship strengthening at follow-up than at baseline, with 84% attributing these experiences to their participation in the HBC programme (Apondi et al. 2007). The effects of the home-based ART programme on mortality were also assessed by comparing death rates among the cohort participants before and after the start of ART and cotrimoxazole provision. The results showed that ART and cotrimoxazole were associated with a 93% (95% CI: 92–97%, P < 0.0001) reduction in mortality compared with the period in which no intervention was provided (Mermin et al. 2008).

These evaluations are important for providing evidence of the effectiveness of HBC interventions, and the well-publicized positive findings that have started to emerge are likely to play a key role in securing additional funding for increasing their coverage. Nevertheless, translating the achievements of these small-scale studies into national-level policies is likely to prove challenging without systematic assessments of the contextual and health systems factors that determine the successful implementation of routine HBC programmes, as well as critical debate over whether a largely volunteer workforce of HBC providers can, or should, be expected to play such a key role in providing HIV care. As noted by Walt (2005), epidemiological evaluations of CHW programmes are of limited value to policymakers, unless they are complemented by additional policy analyses that identify the factors that make one programme more effective than another, that assess the extent to which programmes can be transferred across settings or that identify the incentives needed to sustain these programmes over time.

In this context, we reviewed the HBC literature to examine how the concepts and definitions of HBC have evolved since the initial emergence of these programmes and to explore the rationale for their scale-up in the context of expanding ART provision. We also aimed to answer the following research questions: what conditions are required for expanding HBC programmes that incorporate ART care and to what extent are these conditions currently being met?

We approached our analysis by developing a framework based on the rationale for establishing and maintaining HBC and by drawing on the lessons learned from past experiences with CHW programmes, as described below. We then applied this framework to identify whether the necessary elements are in place to effectively scale up HBC programmes in the ART era in terms of available human resources, health systems, funding mechanisms and local communities. We conclude by reporting the policy recommendations that emerge from our findings and identifying further areas for research.

KEY MESSAGES

- The expansion of comprehensive home-based care (HBC) programmes in the context of antiretroviral therapy (ART) roll-out in low- and middle-income countries needs to be accompanied by analyses that identify the conditions necessary for effective and sustainable programme implementation.
- Factors influencing the effectiveness of HBC programmes include those that relate to human resources, health systems, funding mechanisms and adaptability to local contexts.
- The potential benefits of HBC in the context of ART provision are unlikely to be achieved or sustained as programmes are scaled up unless realistic policies are devised to promote staff retention and service integration within district health systems and to ensure sustainable sources of funding.
Methods

Search strategy

This review focuses on studies that have described or explored the factors that influence the implementation of community-led HBC programmes in low- and middle-income countries, and were published between 1990 and 2008. Articles were identified by searching the following electronic databases: PubMed, MEDLINE, Jstor, Popline, Eldis, Web of Knowledge and African Healthline. The search was restricted to articles written in English, and used combinations of the following search terms: community, home-based, care, home, HIV, AIDS, TB, tuberculosis, volunteer, health, worker, peer, expert patients and evaluation. Searches for misspellings and MeSH terms were automatically added in PubMed searches. We also followed up references in review articles, and hand-searched key journals including: AIDS Care, Evaluation and Program Planning, Health Policy, Health Policy and Planning, and Social Science and Medicine. Finally, we searched the ‘grey’ literature for additional studies relating to HBC programmes by searching websites of non-government organizations known to work in this field (including International HIV/AIDS Alliance, World Vision, Care International, Family Health International, MildMay, The AIDS Service Organization, Population Council and Health & Development Networks), as well as international organizations (WHO, UNAIDS, UNESCO, IFRC), groups involved in monitoring and evaluation activities of HIV programmes (Pathfinder, Measure Evaluations, Horizons, John Snow International), and by consulting experts working in HBC policy and planning.

Concepts and definitions of HBC

Definitions and concepts of HBC for HIV in low- and middle-income countries have evolved considerably over the course of the last two decades in response to the needs of those affected by HIV and greater access to care and treatment. Before the advent of ART provision in low- and middle-income countries, HBC often referred to care provided by informal care-givers or household members, with a specific focus on providing ‘care towards a dignified death’ (National Department of Health, South Africa 2001). Early programmes often incorporated care for tuberculosis (TB) patients including case detection, tracing, nursing, education and counseling to promote adherence, directly observed treatment and practical support (Blinkhoff et al. 1999; Nsutebu et al. 2001). In response to the growing burden of care that fell on family members, HBC programmes such as The AIDS Service Organization (TASO) in Uganda emerged with a focus on mobilizing volunteers to visit AIDS patients in their homes, provide counselling, assist with household chores and educate family members about the principals of palliative care.

More recently, comprehensive HBC programmes have emerged with an overarching aim of ensuring that PLHIV are linked with a comprehensive range of prevention, care, treatment and support services, in accordance with the notion of a ‘continuum of care’ approach which has been defined by WHO as ‘a network of resources and services that provide holistic and comprehensive support for the ill person and family caregivers’ (Lindsey 2002). Comprehensive HBC continues to be defined as any form of care given to sick people in their homes, but often identifies the role of a ‘service provider’, who is a community member trained in basic nursing, education and counselling skills (Littrell et al. 2007). In practice, most existing comprehensive HBC programmes usually include a combination of activities that include distribution of non-medical supplies and drugs for management of pain and opportunistic infections, HIV and ART education and counselling, assistance with domestic tasks, support for establishing peer groups for PLHIV and income-generation activities. As HIV treatment programmes have expanded, the focus of HBC activities in many settings has shifted to promoting access and adherence to ART (Cataldo et al. 2008).

Framework for identifying conditions for effective scale-up of HBC

Our framework for identifying and assessing the conditions for expanding HBC in the context of ART provision incorporates four main themes, namely human resources, health systems, financing and local community factors, as shown in Figure 1. These elements incorporate the essential components of HBC as outlined in the WHO framework for establishing and maintaining HBC programmes in low- and middle-income countries (Lindsey 2002), and reflect the underlying rationale for expanding these programmes, as well as the lessons learned from past CHW programmes, as described in the following sections.

Rationale for scaling up HBC

The rationale behind the current expansion of HBC programmes in low- and middle-income countries partly reflects a pragmatic response to the lack of human resources that are required to provide HIV care for diagnosed persons, and that currently poses a major barrier to the successful roll-out of ART programmes (Marchal et al. 2004; Van Damme et al. 2006). The provision of HBC services can help to reduce the burden on health facilities by shifting certain tasks to patients’ homes, and it has been suggested that they may prove more sustainable than providing alternative clinic-based services using formally trained health care workers (Jaffar et al. 2005). Furthermore, providing care within the household can overcome some of the identified barriers to accessing HIV care, including those that relate to the economic and opportunity costs incurred by patients if they have to travel to attend health facilities (Posse et al. 2008). Finally, by promoting the involvement and engagement of local communities in HIV care, HBC has the potential to reduce the pervasive stigma that surrounds the illness, thus improving uptake of HIV testing, and access to care and support for those diagnosed with HIV (Blinkhoff et al. 1999; Waterman et al. 2007; Roura et al. 2009). Community-based HBC workers may also be the best placed to provide education and emotional support to patients and household members of people living with HIV, improving quality of care in the home and adherence to drug regimens, including ART, as well as the social experiences of PLHIV (Weidle et al. 2006; Apondi et al. 2007).
Lessons learned from CHW programmes

The concept of using community members to deliver health services in low- and middle-income countries is not a new one, and many insights into the potential challenges faced by HBC programmes can be gained from past experience with CHW programmes. The idea of using CHWs first gained popularity three decades ago, when community members were viewed as an alternative resource that could be mobilized to deliver equitable and sustainable primary health care (PHC) in low-income settings, as envisaged by the Alma Ata Declaration (Hall and Taylor 2003). The parallels between the contextual factors that encouraged the emergence of the PHC paradigm in the 1970s and those facilitating the expansion of community-led HBC programmes include growing concerns over the inadequacy of existing health systems in reaching poor, largely rural populations, and an awareness that a reliance on doctor-driven health services delivered at facility level is insufficient to promote a holistic or ‘continuum of care’ approach to health.

The decline in enthusiasm for widespread CHW programmes during the 1980s and 1990s has been attributed to multiple factors categorized broadly by Standing and Chowdury (2008) as those that are extrinsically structural and economic in nature, and those that represent institutional constraints. In particular, the global economic recession and the accompanying neo-liberal economic policies that shaped funding availability during the 1980s have often been cited as key factors that triggered a shift towards a preference for vertical health programmes during this period (Berman et al. 1987; Standing and Chowdhury 2008). In addition to economic factors, challenges emerged in relation to the ambiguous situation of CHWs between the health system and their communities, leading to tensions in their relationships with professional health care workers (Walt 1988). Furthermore, the lack of remuneration for CHWs, and a paucity of training, management, supervision and logistical support, created an environment that was less than conducive to the successful scale-up of these programmes (Walt 1988).

The extent to which community-led HBC programmes are likely to succumb to similar challenges in the context of providing support to ART delivery has not been systematically addressed in the literature, despite the current trend for expanding the scale of these initiatives in low- and middle-income countries. If HBC programmes are to be effective and sustainable when coverage is expanded, they will need to address and overcome the myriad of challenges that may occur during their implementation, and to consider what lessons can be learned from settings where they have been implemented.

Results

Human resources for HBC programmes

One of the key issues in understanding whether the effectiveness of ART delivery through HBC is likely to be replicable in larger, routine programmes concerns the recruitment and retention of staff to deliver the services. For example, in the cluster-randomized trial in Uganda, the ‘lay workers’ who visited patients in their homes, carried out assessments, delivered drugs and gave adherence support were qualified to degree level or were studying part-time for a degree whilst working. As well as receiving 4 weeks of intensive training, on-the-job support and supervision, staff were provided with a mobile phone so that they could consult a physician for advice during home visits if necessary. Lay workers visiting patients in their homes were also paid a salary, and the organization that employed them had transparent policies on recruitment, training and career development (Jaffar et al. 2009).

In contrast, although routine HBC programmes usually include professional managerial staff, most HBC workers are volunteers
or receive small stipends or material items in exchange for their work. In most programmes, HBC workers are usually considered as a sub-group of CHWs, who have previously been defined by WHO as being members of the community where they work, selected by and answerable to the local community (WHO 1989). Although CHWs are generally expected to be supported by the health system, they are not necessarily a part of its organization, and usually have a much shorter training than professional health care workers and require minimal qualifications to be eligible for selection.

While most of the literature suggests that most HBC workers belong to the geographical area in which they work, and receive a short period of training, there is little evidence that they are usually either selected by the community or accountable to them. For example, in a descriptive study of HBC programmes in Kenya, Johnson and Khanna (2004) noted that volunteers were selected during weekly meetings run by the local community leader, but the extent to which the leader represented the views of local residents was less clear. Few other studies describe recruitment procedures for HBC workers, or detail well-functioning processes through which the community can monitor HBC volunteers. Parallels with past experiences of recruiting CHWs suggest that few advances have been made in this area over the last decade (Walt 1988; WHO 1989).

Understanding the reasons why community members become involved with, and remain committed to, HBC programmes is important for ensuring that realistic human resource policies are in place to promote the long-term sustainability of these programmes. Motivations for becoming involved in HBC work appear similar across settings, with lay persons often driven by a desire to help their community to cope with the burden of HIV, although religious beliefs and opportunities to receive training or income also appear to play important roles in attracting volunteers (Uys 2002; Johnson and Khanna 2004; de Saxe Zerden et al. 2006; Schneider et al. 2008). Reports from programmes in Zambia, Ecuador, Burkina Faso and South Africa, where PLHIV are involved in the delivery of HBC services, suggest that enhanced access to peer support, as well as an opportunity to overcome self-stigma also motivate participation (Blinkhoff et al. 1999; Cornu and Attawell 2003).

In contrast to the apparent ease in attracting volunteers to join HBC programmes, poor retention of HBC workers is frequently cited as a major challenge to maintaining programmes, and has often been attributed to high levels of emotional stress, a lack of training and supervision, and low levels of remuneration. Several studies have noted that the emotional burden on HBC volunteers is particularly high in programmes where the focus is on providing end of life care (Uys 2002; de Saxe Zerden et al. 2006). Furthermore, HBC programmes recruiting volunteers living with HIV are often affected by losing staff to the disease, resulting in a loss of skills and expertise, as well as demoralization among other team members (Cornu and Attawell 2003; de Cenival et al. 2004; Waterman et al. 2006). Two Kenyan studies have also noted that some HBC workers living with HIV have been negatively affected by seeing a physical decline among their own clients (Cornu and Attawell 2003; Amuyunzu-Nyamongo et al. 2007).

The frustration associated with being ill-equipped to address seemingly overwhelming problems of poverty, isolation and stigma can also have a detrimental effect on HBC workers’ morale and retention (Uys 2002; Esu-Williams et al. 2003; de Saxe Zerden et al. 2006; O’Grady et al. 2008). Indeed, HBC workers frequently report feeling powerless to meet the high expectations of their clients in terms of providing access to material support or additional income (Esu-Williams et al. 2003; de Saxe Zerden et al. 2006; Amuyunzu-Nyamongo et al. 2007). In a Kenyan study, HBC workers reported that beneficiaries became less receptive to psychosocial support services when basic services such as food or transportation were limited (Amuyunzu-Nyamongo et al. 2007). The emotional burden of providing care has been compounded in settings where ART supplies have been rationed, and HBC workers have found themselves on the frontline of managing the disappointment of those who have not been selected for treatment (de Cenival et al. 2004; Amuyunzu-Nyamongo et al. 2007).

The availability and range of training opportunities has also been closely associated with sustained motivation among HBC workers, as well as with their ability to respond appropriately to their clients’ needs (O’Grady et al. 2008). In particular, adequate and ongoing training and support is perceived to be essential for establishing credibility and legitimacy for HBC workers within their community, or within the context of the health care system when collaborating with health care professionals (Hadley and Maher 2000; Uys 2002). Furthermore, equipping HBC workers with adequate skills to address their clients’ needs has been particularly problematic in programmes that lack capacity to provide ongoing training. As a result, some HBC workers have found themselves unprepared to provide counseling or palliative care, while others have reported an inability to respond to the specific needs of orphans, vulnerable children and adolescents (de Saxe Zerden et al. 2006). In a South African study, Uys (2002) noted that HBC workers were often inadequately trained to cope with the mental health problems of their clients, including those relating to alcohol abuse, depression and other mental health problems, with similar issues reported from a programme in Kenya (Amuyunzu-Nyamongo et al. 2007).

Furthermore, training needs have not always evolved adequately to deal with ART (Waterman et al. 2006; Cataldo et al. 2008), resulting in reports of adverse impacts on clients, including inaccurate information being conveyed during adherence counselling (Cornu and Attawell 2003; Nganda 2006), discriminatory attitudes or breaches of confidentiality (Ncama 2005). In a Zambian study, researchers found that as caregivers became progressively integrated in the formal delivery and support of ART programmes, their roles became increasingly medicalized. In turn, caregivers would use their new ‘status’ to gradually impose a range of moral expectations on their clients, including pressure to comply with ‘lifestyle’ advice through coercive and controlling forms of exchange. Both observations highlight the need for additional training of HBC providers as their roles evolve to incorporate greater support to ART programmes (Cataldo 2009).

Several studies have noted that supervision of HBC workers has been limited, with insufficient time and resources allocated to establishing regular meetings and consultations with supervisors (Uys 2002; O’Grady et al. 2008). The need for opportunities to share experiences and to foster a sense of support
and community among HBC workers is often cited as an important strategy for continuous learning and skill development, as well as a means to diffuse tensions in situations where HBC workers perceive themselves to be undervalued by health professionals, or need to refer difficult cases to supervisors (Uys et al. 2002; Waterman et al. 2006). Some studies have also identified a need for additional access to psychosocial support for HBC workers, or specific counselling skills to enable them to better manage the most challenging cases (Waterman et al. 2006). Regular meetings for HBC workers to share their experiences have been identified as an important coping strategy to reduce emotional burnout (de Saxe Zerden et al. 2006).

A lack of adequate remuneration for HBC workers also emerges as an impediment to the successful implementation of programme activities (Uys 2001; Cornu and Attawell 2003; Waterman et al. 2006; O’Grady et al. 2008). Research from South Africa has suggested that low levels of remuneration leave HBC workers feeling exploited, particularly where they perceive themselves to be in need of the services that they provide to their clients (Ncama 2005; Schneider et al. 2008). Similar reports have emerged from programmes where volunteers have found it necessary to use their own resources to provide food or money for their clients (de Saxe Zerden et al. 2006), or to care for clients’ children (de Saxe Zerden et al. 2006; Waterman et al. 2006). In other cases, HBC volunteers have perceived themselves as a part of a strategy adopted to absolve the government of taking on their responsibilities to provide ‘professional’ care to those who are sick (Schneider et al. 2008). This anticipated role for volunteers may reflect pragmatism in the face of widespread health worker shortages and the need to provide care for a growing number of HIV-infected persons. Nevertheless, the hope that HBC volunteers can replace a higher cadre of health worker is likely to lead to tensions between stakeholders involved in HBC, and may ultimately prove unsustainable. For example, expectations of substantial input into programme activities in return for limited payments can contribute to a high turnover of HBC workers, which creates its own problems in terms of identifying and training new volunteers or providing continuous counselling services to existing programme beneficiaries (Health & Development Networks and SAAIDS 2008). Furthermore, in the absence of adequate remuneration, some HBC workers view participation in HBC programmes as a stepping stone towards recruitment into paid positions elsewhere, further undermining the long-term stability and development of HBC activities (Waterman et al. 2006; O’Grady et al. 2008; Schneider et al. 2008).

Effective referral systems—lessons for the integration of HBC into health systems?

Any scale-up of HBC programmes that incorporates ART delivery or care for ART patients will require collaboration between different stakeholders involved in health service provision. As their name suggests, the effectiveness of comprehensive HBC programmes depends partly on their ability to create well-functioning partnerships between organizations providing a range of care, treatment, prevention and support services. Nevertheless, progress in this area has lagged, and although WHO policy documents and some national HIV strategic frameworks have acknowledged the importance of developing links and referral systems between HIV service providers (National AIDS Coordinating Agency 2003; WHO 2003), guidance on how to establish these mechanisms in practice has only recently started to emerge (Stuart et al. 2005).

The need for greater emphasis on building partnerships, linkages and referral mechanisms in order to create effective local contexts for providing HBC has been extensively reviewed by Campbell and Foulis (2004), who note that there has been a lack of systematic research into the types of relationships and partnerships that can promote effective exchanges between those involved in supporting HBC initiatives. As a result, although the objectives of many HBC programmes include networking, partnership formation, establishment of referral systems and creation of links with other non-government or government bodies, the implementation of these activities lacks an evidence base and consequently can be difficult to implement in practice.

In a Botswanan study documenting the experiences of HIV-focused civil society groups, Kiley and Hovoroka (2006) note that difficulties in establishing effective partnerships between HIV service providers were frequently attributed to a shortage of time and money for establishing collaborative partnerships, or for travelling to meet representatives from different organizations, as well as lack of awareness about other service providers in the area. Additional barriers to collaboration between HBC programmes and district health services have been reported from a Zambian study that highlighted a perceived lack of interest in HBC activities among health centre staff, and an absence of policies concerning patient referrals or formalized partnerships (Bond et al. 2005). Conversely, in a Tanzanian study that documented the implementation of a referral mechanism linking a HBC programme and government-run Voluntary Counseling and Testing and HIV clinics, the involvement of key stakeholders throughout the design and implementation process was identified as a key factor in achieving high levels of acceptance and satisfaction with the system (Nsigaye et al. 2009).

The consequences of poor linkages and referral systems include missed opportunities to provide identified patients with complementary care services, to promote greater access to treatments (Uys 2001), and to ensure that ART adherence support and defaulter tracing systems are able to function effectively (Nsigaye et al. 2009). In the case of HIV and TB, inefficient or absent linkages can render control efforts for each disease less effective. Research from South Africa has shown that a lack of collaboration between HBC programmes and government-run TB services resulted in lost opportunities for HBC workers to provide adherence support to their clients as they were unaware of their TB treatment status (Uys 2002). A Zambian study suggested high levels of unmet need for HIV testing and prevention services among HBC clients receiving TB care (Bond et al. 2005).

Funding policies and their implications for sustainability

The scope and sustainability of any future scale-up of HBC programmes will be determined by the provision and accessibility of funding. Despite the increased availability of bilateral and international funding for HBC programmes over the past decade, there are frequent reports of dissatisfaction among
programme managers in relation to the influence of donors in defining programme activities and the implications of these relationships for the effectiveness and sustainability of their activities. In a Botswanan study that surveyed CSOs involved in delivering HIV-related interventions, Kiley and Hovorka (2006) note that development ‘partners’ are often perceived as ‘calling the shots’ with respect to funding policies that reflect international agendas, and that are not necessarily shared or welcomed at grassroots or district level. In another survey of CSOs working in HIV and AIDS in three South African communities, Birdsall and Kelly (2005) conclude that although the local response to the epidemic has been ‘widespread and effective in identifying and addressing needs on the ground’, these efforts have been ‘overlooked and marginalized’ by donors in favour of ‘emphasis on large-scale centralized approaches to HIV/AIDS prevention, care and treatment’.

Furthermore, funding channels available to organizations providing HBC are frequently perceived to be inherently complicated, long-winded, highly competitive, vague and often only comprehensible to those involved in administering the funds (Kiley and Hovorka 2006). The specific skills needed for writing successful funding proposals also tend to be missing among local organizations even when the skills required for delivering effective and locally relevant HBC programmes are available (Birdsall and Kelly 2005).

Shifting trends in donor policies towards HBC programmes have also served to undermine the effectiveness of the activities that are being delivered on the ground. In a Kenyan study, Waterman et al. (2006) examined the contextual factors that facilitated or hindered the process of implementing effective and sustainable HBC programmes, and noted that local organizations have a tendency to ‘change activities at a whim’ in response to what donors will fund. The consequences of such a shift can include a loss of acquired expertise in areas where funding availability is reduced, confusion among the community as to which organizations provide which services, a lack of confidence among potential service users in relation to the proficiency or durability of organizations in providing HBC activities, and a dearth of activities for issues other than HIV-related care and treatment (Nduna 2007).

Similar problems have emerged in South Africa and Botswana where HBC programmes are largely funded through government grants that originate from bilateral donor policies. As noted by Russel and Schneider (2000), attempts have been made by local governments to accelerate and support the development of HBC programme activities, but the flow of funding is often restricted by bottlenecks that impact on programme implementation. In particular, increasing demands in donor-driven reporting procedures can result in long delays in funds reaching programmes, undermining the possibility to deliver activities continuously over a defined reporting period. In some instances, funding has arrived so late that several months of activities have to be condensed into an unrealistically short time-frame in order for the money to be spent.

Sufficient capacity to implement monitoring activities or operational research has been identified in some HBC programme evaluations as an essential factor to promote consistency between local needs, programme content and funding resources. Furthermore, calls for increasing research training have focused on the need for practical monitoring and evaluation (M&E) techniques that are easy to implement to replace existing systems that are often designed to fulfil donor-driven reporting requirements (Birdsall and Kelly 2005). Even programmes funded by major international donors who have participated in the formulation of extensive M&E guidelines have reported insufficient resources to implement reporting systems effectively, such that in some cases even simple indicators such as the number of beneficiaries receiving assistance have been difficult to determine (O’Grady et al. 2008).

Although many HBC organizations rate problems with funding among their most important concerns, some programmes cite success in building funding partnerships (Birdsall and Kelly 2005), particularly where opportunities have been available to acquire sufficient expertise in management skills and fundraising, with some organizations reporting that they had been able to provide training for other community-led HBC groups in these areas (de Cenival and Prunier-Duparge 2005).

Community contexts of HBC programmes
Lessons from existing HBC programmes suggest that the degree of wider community support emerges across settings as a key factor to their success, and one that needs to be acknowledged as programmes expand and incorporate care for ART patients. However, while the need to observe and engage with community protocols in order to gain community acceptance has been noted by many HBC providers, it often fails to be adequately factored into programme activities (Nsutebu et al. 2001), partly because involving community stakeholders in planning and evaluation activities is perceived as a time-consuming and complex process, but also due to a failure to understand its importance to a programme’s success.

In a Kenyan study, researchers noted that a failure to include community members in discussions relating to the implementation of HBC programmes resulted in a local campaign against the organization to prevent potential beneficiaries from participating in programme activities (Waterman et al. 2006). The effective delivery of HBC services may also be compromised when set against a backdrop of high levels of stigma surrounding HIV infection. In a review of the contextual factors that influence the delivery of HBC programmes, Campbell and Foulis (2004) provide several examples of how HBC workers’ tasks may be undermined by negative community attitudes towards HIV, including inadvertent disclosure of their clients’ HIV status by visiting certain households on a regular basis. Other researchers have rejected romanticized notions of ‘unswerving community support’ from HBC initiatives, describing attitudes of community members towards HIV-infected persons by members of the community as ranging from ‘ambivalence to outright rejection’ (Olenja 1999).

Furthermore, in the context of extreme poverty in many settings where HBC programmes are being implemented, feelings of jealousy have been reported from some community members who are averse to the idea that PLHIV deserve the apparently privileged levels of support that they receive from these initiatives (Roura et al. 2008). Evaluations of HBC programmes in Burkina Faso and Zambia cite examples of community members accusing PLHIV of pretending to be HIV-positive in order to obtain money from donors (Cornu and
Attawell 2003). Similarly, in Ecuador and Zambia, some PLHIV have reported personal experiences of stigma and discrimination because of their visible involvement in delivering services or working with an NGO providing HBC services (Cornu and Attawell 2003).

An extension of ‘sensitization’ and ‘mobilization’ activities has often been identified as a strategy to overcome the apparent lack of community ownership for HBC activities in some settings. However, few researchers, with the exception of Campbell and Foulis (2004), have conceptualized the relationship between community involvement, participation and ownership in the context of providing HBC programmes.

Ensuring the local relevance of programme activities also emerges from the literature as an essential factor for engaging the interest of the local community, and enabling project activities to be sustained over the long term. Income-generation activities (IGAs) are often viewed as a sustainable and ‘local’ solution to providing PLHIV with financial security and, in some HBC programmes, as a means to achieve a secure funding source to either complement donor funding or to accompany a phasing out of external inputs. However, these initiatives have had mixed success, with some IGAs proving to be limited in scope and ultimately unsuccessful, largely due to the costs of initiating and sustaining activities, or difficulties in identifying existing local markets (Littrell et al. 2007). Other examples from South Africa have demonstrated that IGAs are frequently unprofitable in practice and serve only to frustrate and demoralize programme participants, with ‘false expectations and a lack of technical support as to how to develop successful business plans’ (Russel and Schneider 2000).

Such lessons indicate that IGAs are only likely to be successful and sustainable if they correspond to the interests and skills of local people, are designed with their input, include a choice of different activities and result in a product for which there is local demand (Littrell et al. 2007). The implementation of IGAs in communities that are inexperienced with managing activities to be sustained over the long term. Income-generation activities (IGAs) are often viewed as a sustainable and ‘local’ solution to providing PLHIV with financial security and, in some HBC programmes, as a means to achieve a secure funding source to either complement donor funding or to accompany a phasing out of external inputs. However, these initiatives have had mixed success, with some IGAs proving to be limited in scope and ultimately unsuccessful, largely due to the costs of initiating and sustaining activities, or difficulties in identifying existing local markets (Littrell et al. 2007). Other examples from South Africa have demonstrated that IGAs are frequently unprofitable in practice and serve only to frustrate and demoralize programme participants, with ‘false expectations and a lack of technical support as to how to develop successful business plans’ (Russel and Schneider 2000).

Such lessons indicate that IGAs are only likely to be successful and sustainable if they correspond to the interests and skills of local people, are designed with their input, include a choice of different activities and result in a product for which there is local demand (Littrell et al. 2007). The implementation of IGAs in communities that are inexperienced with managing such projects will not serve as a panacea to realistic long-term funding strategies for ensuring the financial sustainability of HBC programmes.

**Conclusion**

In the context of multiple initiatives for scaling up access to HIV prevention, care, treatment and support services in low- and middle-income countries, there has been substantial enthusiasm among international policymakers and funding agencies for expanding the provision of comprehensive HBC services. This commitment, along with emerging findings of their impact on mortality reduction, adherence and improved social outcomes, has created policy environments conducive to the development of national-level policies for expanding HBC programmes that support ART delivery in many low- and middle-income countries.

Nevertheless, despite the positive political and economic climate that has served to place comprehensive HBC programmes squarely on the HIV policy agenda, the emerging evidence suggests that current plans to expand HBC coverage have given insufficient attention to addressing the challenges that have been documented by those implementing small-scale but routine programmes. In particular, well-meaning objectives in relation to providing a ‘continuum of care’ are unlikely to translate into workable practices on the ground in the absence of more innovative thinking about how effective links between different service providers or organizations work in practice. As well as a need for further research to explore how to integrate HBC services within the overall context of HIV and other health care provision, it is necessary for programme planners and donors to factor in the time and costs that are required for HBC programmes to conduct essential networking and partnership-building activities.

Furthermore, the assumption that comprehensive HBC programmes represent either a low-cost or sustainable strategy for providing the range of services required by PLHIV has not been demonstrated by experiences on the ground. Despite some efforts to cost HBC interventions in Zimbabwe, Rwanda and Uganda (Hansen et al. 1998; Chandler et al. 2004; Jaffar et al. 2009), there has been little work on exploring the relative costs or cost-effectiveness of different HBC strategies across settings. Further research is needed in this field. Indeed, HBC programmes may only be low-cost when insufficient funding is available to deliver or maintain planned activities, such as the provision of nutritional support or non-food items to households affected by HIV. These issues become essential in the context of expanding ART provision, where the ability of HBC programmes to assist with transportation of patients to attend hospital appointments, or supplement their nutritional intake can impact on PLHIV’s ability to adhere to their treatment.

There is consistent evidence throughout the HBC literature of the enormous commitment among lay persons to providing HBC to persons affected by HIV. Furthermore, the development of extensive training packages by WHO and the Red Cross to support large-scale preparation of volunteers to support HIV-positive persons, including those on ART (IFRC 2008), is to be lauded as an important step in responding to a frequently identified need for skill development among those delivering HBC services. Nevertheless, one of the greatest threats to the effective mobilization of lay health workers is the failure to acknowledge key lessons from previous experience with CHW programmes; namely that unless lay workers receive adequate support and remuneration, they are unlikely to remain committed to contributing to community health programmes in the long term. The consistency with which the retention of HBC workers emerges as a barrier to the successful implementation of HBC programmes should serve as a wake-up call to the need for more realistic policies to systematically acknowledge and adequately compensate the input given by community workers.

Indeed, one of the most important policy recommendations in relation to the scale-up of HBC programmes that effectively support ART provision concerns the recruitment and retention of those delivering the services. Human resources policies need to be developed that translate into realistic expectations of lay workers’ skills and that correspond to the amount of training and level of access to supervisory support they receive. These policies should also include measures to promote long-term retention of lay health workers once they are trained, including remuneration packages or equivalent schemes that recognize...
and reward the contribution they have made. Nationally recognized certification of trained lay health workers that demonstrates adherence to minimum standards laid out in common frameworks should also be considered as a policy to clarify the potentially ambiguous position of HBC workers between health facilities and the community, and to contribute to wider strengthening of health systems. Funding agencies also need to recognize the benefits of investing in appropriate training and remuneration policies for staff in the programmes they support, as initial outlays in these areas are likely to result in cost savings in the longer term if turnover rates are reduced.

Many of the current challenges faced by HBC programmes in low- and middle-income countries mirror those documented over 20 years ago by the WHO study group on CHWs, which included minimal policy and organizational interest, poorly defined functions, poor selection, deficiencies in training and continual education, lack of support and supervision, uncertain working conditions, undetermined cost and sources of finance, and a lack of monitoring and evaluation (WHO 1989). In the context of the current financial crisis, which provides further parallels with this period, it is even more important that policy-makers address these challenges as HBC programmes continue to evolve, if they are to weather the global economic storm.

Within the context of this review, we have not attempted to describe the broader social benefits of HBC to programme participants, which have been reviewed elsewhere in the literature (Russel and Schneider 2000; de Cenival and Prunier-Duparge 2005), but rather focus on the lessons learned through the process of implementing these programmes in a variety of low- and middle-income country settings. We conclude that the commitment and financial resources channelled into providing ART drugs for millions across the developing world need to be met with a similar level of dedication to (1) ensuring that the necessary conditions are in place for providing effective long-term care and support for PLHIV, and (2) addressing identified barriers to the implementation of HBC programmes. This requires that funding agencies take heed of the concerns raised by those responsible for implementing programmes, particularly in relation to greater flexibility in defining and developing activities that are relevant to different contexts and incorporate genuine participation by local communities. Unrealistic expectations that a ‘one-size fits all’ approach will suffice when defining HBC programme activities only serve to erode their credibility and legitimacy among the communities that they intend to benefit. While it may take more time and money to tailor HBC interventions to the specificities of different local contexts, this approach is essential for ensuring that programmes remain relevant to the persons they are expected to benefit. A failure to meet this challenge will undermine existing efforts to increase the provision of promising HBC interventions and will result in disillusionment among those who have given their time to help affected members of their community, and among those who these programmes are intended to serve.

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