

Why reinvent the wheel? Leveraging the lessons of HIV scale-up to confront non-communicable diseases

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The dramatic scale-up of HIV services in lower-income countries has led to the development of service delivery models reflecting the specific characteristics of HIV and its treatment as well as local contexts and cultures. Given the shared barriers and challenges faced by health programmes in lower-income countries, many of the implementation approaches developed for HIV programmes have the potential to contribute to the continuity care framework needed to address non-communicable diseases (NCDs) in resource-limited settings. HIV programmes are, in fact, the first large-scale chronic disease programmes in many countries, offering local and effective tools, models and approaches that can be replicated, adapted and expanded. As such, they might be used to ‘jumpstart’ the development of initiatives to provide prevention, care and treatment services for NCDs and other chronic conditions.

Keywords: HIV; chronic diseases; implementation; global health; diabetes

Introduction

Chronic non-communicable diseases (NCDs), including diabetes, cardiovascular disease, cancers and chronic respiratory illness, are now the world’s leading causes of mortality, with a significant and rapidly growing impact in low- and middle-income countries (LMIC) (Mathers and Loncar 2006, WHO 2008a). As the World Health Organization (WHO) has recognised, provision of chronic disease services is a primary care challenge for the twenty-first century (WHO 2008b), consistent with the Declaration of Alma Ata’s call for access to ‘appropriate treatment of common diseases’ (International Conference on Primary Health Care 1978). Although Millennium Development Goal 6 is focused on HIV, tuberculosis and malaria, its reference to ‘other major diseases’ might similarly be interpreted to include high-burden chronic diseases. Unfortunately, despite calls to action and rising awareness (Horton 2007, Beaglehole *et al.* 2008, Maher *et al.* 2009, Nabel *et al.* 2009), access to prevention, care and treatment for chronic conditions remains out of reach for most.

In recognition of these major gaps, advocacy for chronic disease services in LMIC has increased in recent years. Two years ago, WHO launched the *2008–2013 Action Plan for the Global Strategy for the Prevention and Control of Non-Communicable*

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Diseases (WHO 2008a). In 2009, leading research institutions founded the Global Alliance for Chronic Disease, and the NCD Alliance was formed by a partnership of the International Diabetes Federation, the World Heart Federation, the International Union Against Tuberculosis and Lung Disease and the International Union Against Cancer. In September 2011, the United Nations will convene a high-level meeting on NCDs where advocates will promote the inclusion of chronic disease indicators in the Millennium Development Goals (World Heart Federation 2009). Despite the current economic downturn, hopes are high that funding for NCDs will increase in the coming years.

As increasing attention is paid to the impact of NCDs on health and development, we note the contrast between emerging high-level policy and recommendations and the near-absence of practical guidance and experience delivering continuity care for NCDs within the weak health systems characteristic of resource-limited settings. Although there is increasing consensus about the 'upstream' population-level policies required to confront NCDs (e.g., primary prevention interventions such as tobacco control and salt reduction), the 'downstream' health systems strategies, programmes and implementation approaches required to deliver secondary prevention, care and treatment services to millions of people are less well developed.

One often overlooked fact is that many LMIC have *already* established examples of effective chronic disease programmes as they have scaled up HIV/AIDS services over the past decade. Although HIV and NCDs are often thought of as very different challenges – and administratively 'siloes' within most health agencies – HIV programmes are the first large-scale chronic disease initiatives in LMIC, offering local and effective models that can be emulated, adapted and expanded. Can the response to HIV, a chronic *communicable* disease, be leveraged to expand access to high-quality services for other chronic *non-communicable* conditions?

Continuity care: A key element of chronic disease management

The successful management of chronic diseases requires coordination of services for individuals over years and across disciplines and is dependent on strong national health systems and innovative, robustly supported service delivery models. As Nolte and McKee (2008) have noted, chronic conditions 'require a complex response over an extended time period that involves coordinated inputs from a wide range of health professionals and access to essential medicines and monitoring systems, all of which need to be optimally embedded within a system that promotes patient empowerment'. A comprehensive approach to chronic conditions includes a broad range of interventions, from primary prevention, to case finding, to community engagement and education, to the design, development, implementation and evaluation of care and treatment programmes. One key element of such programmes is successful *continuity of care* (Haggerty *et al.* 2003), which is critical to higher quality services for these conditions and associated with better health outcomes (van Servellen *et al.* 2006).

Naithani *et al.* (2006) describe four dimensions of experienced continuity from the patient's perspective:

...receiving regular reviews with clinical testing and provision of advice over time (longitudinal continuity); having a relationship with a usual care provider who knew and understood them, was concerned and interested, and took time to listen and explain (relational continuity); flexibility of service provision in response to changing needs or situations (flexible continuity); and consistency and co-ordination between different members of staff, and between hospital and...community settings (team and cross-boundary continuity).

Unfortunately, the constrained health systems in resource-limited settings are rarely able to provide continuity services of any kind. Despite the guidance provided by Wagner's Chronic Care Model (Wagner *et al.* 1999), WHO's Innovative Care for Chronic Conditions (WHO 2002) and other expert guidance, the fact is that health service delivery systems in LMIC typically provide only *episodic* care and are often designed for the relief of acute symptoms rather than the maintenance of well-being or the prevention and care of chronic conditions. In practice, continuity care may be unfamiliar to policy-makers and health workers, who lack effective local models to draw upon. From a practical perspective, marked shortages of appropriate space, staff, systems and infrastructure hinder the establishment of continuity services, and the expense and difficulty of accessing care leads patients to defer the routine visits so critical for the prevention, monitoring and treatment of chronic disease. The end result is the near-absence of large-scale service delivery models for chronic conditions in developing countries (De-Graft Aikins *et al.* 2010).

Health systems constraints

Many health facilities in LMIC lack key elements needed to provide continuity care – appointment systems; medical records; patient counselling and adherence support; linkages between clinical, laboratory and pharmacy services; longitudinal monitoring and evaluation systems; and outreach to communities for tracking and supportive services. Laboratory tests and medications for chronic diseases are rarely prioritised or affordable by national programmes, secured by strong procurement systems or subsidised at the point of service, making them expensive for patients and vulnerable to stock-outs. Health worker shortages and maldistribution prevent the development of the multi-disciplinary teams needed to provide comprehensive and effective continuity care responsive to the multitude of patient needs and preclude the stability of the patient/provider relationships so critical for good outcomes (Beaglehole *et al.* 2008). Rigid approaches to licensure, certification and professional scopes of work limit new professional cadres, innovation and task-sharing, while traditional professional hierarchies and attitudes undermine collaboration and multi-disciplinary partnerships (Dohrn *et al.* 2009).

Health systems in many LMIC reflect the impact of decades of underfunding and neglect. In sub-Saharan Africa, primary care systems were in a state of crisis prior to the onslaught of HIV/AIDS, which further strained systems and health workers to the breaking point (Joint Learning Initiative 2004). Despite these formidable barriers, HIV programmes have achieved remarkable success. HIV scale-up motivated the establishment of effective and innovative service delivery, aided by civil society involvement, the engagement of people living with HIV (PLWH), local leadership and ownership, multi-sectoral collaboration and unprecedented funding. The number of PLWH receiving antiretroviral treatment (ART) in LMIC

skyrocketed from 400,000 in 2003 to more than 5.2 million by 2009 (UNAIDS 2010). Although HIV scale-up remains a work in progress, with less than 50% of eligible patients worldwide receiving ART and insufficient retention in care within some programmes, the accomplishments have been substantial. Much has also been learned about the limitations of purely 'vertical' programmes and ways to mitigate the potential negative impacts of disease-specific initiatives on health systems (WHO Maximising Positive Synergies Collaborative Group 2009). Are there lessons that might inform – and perhaps accelerate – the development of NCD service delivery in LMIC?

Learning from HIV scale-up

While the overall impact of HIV scale-up on health systems has been heterogeneous and deeply contextual (Oomman *et al.* 2008, Biesma *et al.* 2009, Rabkin *et al.* 2009, WHO Maximising Positive Synergies Collaborative Group 2009), there are clearly areas in which the lessons learned from HIV programmes can enhance the framework for prevention, care and treatment of other chronic conditions, such as diabetes, cardiovascular disease, chronic lung disease, mental illness and some cancers. It is important to note that specific characteristics of HIV/AIDS have dictated the design of HIV programmes and mandated a continuity approach to service delivery. HIV infection is distinguished by asymptomatic periods interspersed with illness, necessitating attention to health maintenance as well as disease management. Treatment entails the need for meticulous lifelong adherence to ART and long-term behaviour changes for prevention of HIV transmission, requiring HIV programmes to ensure effective drug supplies, proficient counselling and ongoing support for adherence and retention. HIV-related stigma requires the provision of sensitive demand generation among at-risk individuals and those living with HIV, psychosocial support and community engagement. Strong programme managers are needed to ensure appropriate infrastructure, supplies, staffing and data management and to initiate models of care bridging health facilities and communities (Abrams and El-Sadr 2009).

As noted in Table 1, these problems are not unique to HIV programmes; many barriers faced in the implementation of HIV services are similar to those faced by other health programmes in resource-limited settings. Similarly, the conceptual framework of continuity care is not specific to HIV, or to low-income settings. It is the *response* – the portfolio of local and practical implementation solutions developed to address these challenges – that should be of interest to other chronic disease initiatives. Models of care have been developed in a wide range of countries and contexts, transforming and strengthening HIV service delivery (see Table 2).

Key differences

While there are conceptual similarities between HIV service delivery and programmes providing care and treatment for other chronic conditions, there are also some key differences. ART is often more expensive than interventions for hypertension or diabetes, although several studies have demonstrated the cost-effectiveness of ART for HIV disease in resource-limited settings (Loubiere *et al.* 2010). For those with advanced HIV/AIDS, effective care and initiation of ART can

Table 1. Shared barriers and challenges.^a

Barriers/ Challenges	HIV/AIDS	Diabetes	Cardiovascular disease	Chronic lung disease	Mental health
Demand-side barriers	✓	✓	✓	✓	✓
Inequitable availability	✓	✓	✓	✓	✓
Human resources	✓	✓	✓	✓	✓
Lack of adherence support	✓	✓	✓	✓	✓
Infrastructure and equipment	✓	✓	✓	✓	✓
Programme management	✓	✓	✓	✓	✓
Drug supply/ procurement	✓	✓	✓	✓	✓
Referrals and linkages	✓	✓	✓	✓	✓
Community involvement	✓	✓	✓	✓	✓

^aAdapted from Travis *et al.* (2004).

have a rapid and profound impact on recovery and resumption of well-being (Badri *et al.* 2004, Nash *et al.* 2008). This ‘Lazarus effect’ makes it easy to see the benefits of treatment and may make it more difficult for policy-makers to argue against HIV scale-up, despite early concerns about feasibility and cost. In contrast, advocacy for largely asymptomatic chronic conditions such as hypertension may be more challenging.

Table 2. Illustrative HIV/AIDS programme innovations.

Health systems elements	Examples of innovations from HIV programmes
Stewardship	Transparent target-setting, ‘Three Ones’ principles, support for decentralisation and others
Financing and payments	Performance-based financing, elimination of user fees and innovative insurance schemes
Human resources	Training, mentoring, task-shifting, task-sharing and engagement of PLWH
Infrastructure	Renovations and repairs of clinical, counselling, laboratory and pharmacy space
Commodities/supply chain	Development and strengthening of procurement systems
Information/data	On-site medical records, electronic medical records and ‘Three Ones’ approach
Clinical services	Family-focused care, adherence support and comprehensive primary care for PLWH
Behaviours of providers and patients	Multidisciplinary teams, prominent use of counsellors and peer educators, increased focus on adherence and psychosocial support and enhanced demand/uptake of services

Programmatic lessons

The historic response to the HIV/AIDS epidemic spanned many sectors and services; we focus here on the programmatic response which enabled the rapid delivery of complex clinical services to millions. We note, however, that these lessons will be of limited impact without an ‘NCD movement’ analogous to that seen for HIV – that is, activism, country leadership, donor funding, community engagement and health worker empowerment. In some cases, the programmatic strategies described below represent innovations and new ideas; others are newly invigorated, appropriately resourced and successfully implemented approaches first developed decades ago. Given the common barriers and challenges faced by health programmes in LMIC, each of these approaches has the potential to contribute concrete lessons, tools and/or approaches to continuity care in resource-limited settings:

- *Multi-disciplinary teams.* HIV/AIDS care requires more than the clinical services offered by doctors and nurses. In order to provide effective comprehensive HIV care, programmes have established multi-disciplinary teams and added new health worker cadres, enhancing counselling, adherence support, patient education and community outreach. This approach has transformed professional hierarchies, strengthened patient–provider relationships and facilitated the task-shifting and task-sharing described below (El-Sadr and Abrams 2007); it could easily be adapted to the care of mental illness, diabetes, cardiovascular disease and other chronic conditions.
- *Family-focused care.* Co-located, co-scheduled appointments for family members, coordination among adult and paediatric providers serving the same household, linkage of family medical records and outreach to family members not yet engaged in care are some examples of the family-focused service model. In developing countries, many of these strategies have been initiated for the first time in the context of HIV programmes (Tonwe-Gold *et al.* 2009) but would serve equally well for households affected by diabetes and other chronic conditions affecting families.
- *Support for adherence and retention.* Systems to assess and support retention in care and adherence to medication are the sine qua non of HIV programmes. At many facilities, HIV programmes have introduced the first-ever appointment systems and on-site medical records, enhanced pharmacy systems and documentation, instituted patient support groups and defaulter tracking, and engaged PLWH to provide peer education. This represents a marked shift from the episodic care model and can be leveraged to support a wide range of chronic diseases. The importance of adherence with medications for diabetes, hypertension and hypercholesterolaemia is well recognised, for example, and the challenges implicit in achieving adherence with antidepressants and antipsychotic medications in individuals with mental health conditions must be carefully addressed.
- *Engagement of people living with HIV, civil society and stakeholders.* Stakeholder engagement is not specific to HIV/AIDS, but the extent to which PLWH and civil society have led efforts to expand access to HIV programmes and to support their implementation may be unprecedented (UNAIDS 2007). This involvement has generated broad-based support for HIV services, as well as

new resources to tackle health threats. Like HIV/AIDS, mental illnesses are often stigmatised, and mental health programmes benefit greatly from community mobilisation, demand generation, engagement of civil society and establishment of peer educators or supporters.

- *Monitoring, evaluation and programme design.* HIV programmes have been conceptualised, designed and monitored in ground-breaking ways. Establishing explicit targets and publically reporting results (and shortcomings) maximizes accountability, enabling stakeholders to assess performance and to compare facilities and partners. The UNAIDS ‘Three Ones’ principles mandate one HIV/AIDS national framework, one national AIDS coordinating authority and one country-level monitoring and evaluation (M&E) system (UNAIDS 2004). HIV programmes have introduced new data collection systems and cadres (such as data clerks), as well as innovative approaches to using data to enhance quality at the facility level, rather than simply sending it ‘up the chain’ to the district or national levels. Even the simplest HIV/AIDS M&E system must track cohort retention rates, interim outcomes (including the results of clinical and laboratory monitoring) and end points such as loss to follow-up, transfer to another facility or death. These indicators inform programme design and implementation in addition to M&E; they are equally applicable to other chronic disease programmes (Harries *et al.* 2009).
- *Task-shifting.* While task-shifting is far from a new concept, the realisation that HIV scale-up would be impossible without it has catalysed renewed interest, energy and resources (WHO 2007). Randomised trials have demonstrated the non-inferiority of nurse-managed ART compared to physician-managed ART (Sanne *et al.* 2010), further supporting task-shifting and task-sharing. HIV programmes have added new health worker cadres, such as the counsellors, peer educators and data clerks described above. They have also leveraged the skills of existing cadres by redefining scopes of practice, enabling nurses (Chang *et al.* 2009) and medical officers (Sher *et al.* 2009) to prescribe antiretroviral medications, for example, or training laypeople to support adherence and retention (Torpey *et al.* 2008).
- *Community-based and home-based care.* The need for adherence and self-care, in the home and in the community, is one of the hallmarks of chronic disease. The fact that lifelong treatment is more effectively supported at the community level has been complemented by the need to decentralise and disseminate HIV/AIDS services in order to provide widespread access. Many HIV programmes support a continuum of care, from the hospital, to the health centre, to community-based resources, to home-based care and support. Community-based organisations have been engaged to provide counselling and care services, laypeople have been trained to support adherence and outreach, and PLWH associations play an increasingly important role in community and patient involvement. While community-based care is not a novelty and lessons from earlier community health worker programmes can and should inform HIV/AIDS programmes (Hermann *et al.* 2009), early data suggest that even complex continuity services can be effectively supported at the community level (Jaffar *et al.* 2009).
- *Health systems strengthening.* The rapid scale-up of HIV programmes in the context of fragile health systems has highlighted a decades-long debate about

the advantages and disadvantages of ‘vertical’ or disease-specific programming. Critics lament the ‘stove-piped’ nature of HIV funding and programming and the risk of unintended consequences for health systems (Garrett 2007, Shakarishvili *et al.* 2010). Others point to the potential of HIV programmes to strengthen the health systems of which they are a part (El-Sadr and Abrams 2007). As noted, evidence of the impact of HIV scale-up on health systems is varied and contextual, but there is burgeoning interest in utilising the lessons from retrospective studies to craft prospective trials of ‘diagonal’ programmes – disease-specific interventions designed to minimise untoward impact on other health programmes and/or to deliberately support health systems more broadly. These lessons may also inform the design of other chronic disease programmes.

The way forward

Ministries of health, international donors and global health programmes – including the US President’s Emergency Plan for AIDS Relief, the World Bank, the Global Fund for AIDS, Tuberculosis, and Malaria, and the Obama administration’s Global Health Initiative – have increasingly emphasised the importance of strengthening health systems. The lessons learned from HIV programmes can profoundly shape our response to this challenge, and one way in which HIV scale-up might be leveraged to strengthen health systems is in the domain of chronic diseases. Tools and approaches developed to address HIV/AIDS – from service delivery models, support for health system stewardship, adherence support systems and community engagement to appointment books, enrolment forms, medical records and M&E strategies – can be adapted for other chronic conditions and as components of comprehensive preventive and primary care services. HIV programmes can expand to provide services for other chronic diseases (Janssens *et al.* 2007) and/or serve as models to inform the development of continuity care systems. Indeed, many ‘episodic’ illnesses, such as malaria and diarrhoea, can be conceptualised as recurring manifestations of repeated or chronic exposures, requiring a continuity care approach to remediation. Similarly, interventions to support healthy behaviours, from safer sex to tobacco cessation, require the ongoing – chronic – engagement of individuals and communities. We can build on the lessons learned by HIV programmes, as well as their existing resources and partnerships, to systematically enhance the provision of continuity care in resource-limited settings. Operations research is needed to inform the design and implementation of chronic disease programmes, to answer key questions about the applicability of HIV models to NCD programmes and to identify what works, why and why not. The time has come for action on chronic diseases – action which can and should be catalysed by the practical successes of HIV scale-up.

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