

Caregivers and healthy ageing with HIV in low-income and middle-income countries



The success of the HIV response has created a compelling necessity for health-care systems to support people living with HIV as they age. *The Lancet HIV Commission on Ageing and HIV: a global perspective* has carefully outlined the clinical, social, and system-level changes that are needed to meet this need, recognising the crucial role of local and digital communities.¹ Yet one essential role, that of the personal caregiver, requires future development.

In low-income and middle-income countries (LMICs), where health systems are often overstretched and long-term care remains insufficient, the everyday work of supporting a person with HIV typically falls to individual family members, peers, or other lay members of the community.^{2,3} Previously, adults older than 50 years, especially grandmothers, were primarily seen as caregivers to children affected by HIV. Now, older people living with HIV require care. This development marks a new phase of the epidemic within health-care systems, where caregiving outside of a clinical setting has historically been under-recognised and poorly supported.

Across LMICs, growing numbers of people living with HIV are reaching older age and also living with chronic comorbid conditions, frailty, depression, chronic pain, and other functional limitations.⁴ These realities make care at home and in the community more complex than support for medication adherence alone. Many older adults require help navigating multiple appointments, organising treatment across several health conditions, taking multiple medications, recognising side-effects, maintaining mobility, monitoring their symptoms, and communicating effectively with health-care providers. Older adults might also need help negotiating transport barriers, food insecurity, social isolation, and interruptions in access to medicines for non-communicable diseases. In practice, much of this work occurs in homes and communities rather than clinics. However, the people who provide this care have little or no formal preparation to undertake these roles.

This omission reflects a broader failure to treat caregiving as part of health-care system capacity. WHO has highlighted major deficiencies in long-term care

systems globally, including inadequate support for informal caregivers in low-income settings.⁵ For older people ageing with HIV, the consequences of these deficiencies are magnified. Caregiving is layered onto the persistent burdens of stigma, poverty, transport barriers, and fragmented service delivery.⁶ Reviews from sub-Saharan Africa show that HIV-related caregiving has long been embedded in families and communities, and that these caregivers experience burden, stress, and inadequate support themselves.⁷ In practice, the caregiver in LMIC settings often becomes an interpreter, navigator, adherence supporter, advocate, and emotional anchor all at once. Without recognising these roles explicitly, health-care systems risk assuming that essential elements of long-term care and support for healthy ageing will somehow be absorbed within households at no cost to caregivers themselves.

Building capacity for caregivers of people ageing with HIV needs to be carefully crafted and defined. Firstly, in addition to other formal and informal health-care providers, personal caregivers need a basic understanding of what ageing with HIV entails, including multimorbidity, polypharmacy, mental health challenges, cognitive changes, frailty, and common geriatric syndromes. Secondly, caregivers need training in health-related practical skills, such as how to organise medications, support clinic attendance, identify warning signs requiring urgent clinical review, assist with simple home-based monitoring (blood pressure or glucose) where appropriate, and knowing when, where, and how to get help when needed. Thirdly, caregivers need communication skills that are grounded in dignity and confidentiality, especially when addressing adherence difficulties, mood symptoms, memory loss, declining function, or disclosure concerns. Fourthly, caregivers need training in person-centred care on how to support autonomy, respect preferences, establish goals of care, and avoid reducing older people with HIV to a set of diseases. These are not advanced specialist competencies, but foundational requirements for safe and humane care.

Existing global frameworks offer a starting point, but these require adaptation. WHO's Integrated Care

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for Older People guidance provides a useful platform for community-level support for declines in intrinsic capacity.⁸ However, in LMICs, education for all people who care for older adults living with HIV needs to go further to explicitly address HIV-related stigma, chronic disease co-management, treatment burden, and the realities of caregiving in under-resourced households. Personal caregivers need simple, accessible, and culturally appropriate education that can be delivered through clinics, community groups, home visits, and mobile technologies. Emerging evidence suggests such low-cost approaches are feasible. In rural Malawi, a WhatsApp audio intervention co-developed with informal caregivers of people with HIV improved caregiver wellbeing and showed how practical and context-sensitive educational support can be delivered beyond facilities.³

Training alone will not ensure healthy ageing for people with HIV. Educational efforts need to be integrated into a functioning system or else this training will only shift even more responsibility onto already burdened households. Personal caregivers cannot be expected to monitor, support, and refer effectively without clear care pathways, responsive clinics, and essential medicines. Caregivers also require support themselves. Burnout, financial strain, and psychosocial distress among caregivers can undermine the outcomes that these programmes seek to improve.⁹ Educational interventions should therefore be paired with policies that acknowledge personal caregivers as part of the continuum of care rather than as an invisible workforce.

The *Lancet HIV* Commission's call for healthy ageing with HIV will remain incomplete unless the question on who delivers care beyond the clinical setting, at home, and across fragmented systems is addressed. In LMICs, caregivers are not peripheral to care, but an essential part of the care system.¹⁰ Their educational needs should, therefore, be explicitly incorporated into HIV and ageing policies, integrated care models, and implementation

research. Minimum caregiver competencies should be defined, training packages should be adapted and tested, and caregiver outcomes should be measured alongside patient outcomes. Healthy ageing with HIV will not only depend on what health-care systems know, but also whether caregivers are recognised, prepared, and supported as essential partners in care. Failing to do so will leave one of the most important pillars of healthy ageing with HIV unplanned, under-resourced, and invisible.

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