
1. Introduction

'He was in the same clothes in a corner bed [of the hospital], no sheets nothing. The food that they had taken for him was lying there. He was blind, crippled and not talking.' – L, unpaid carer, Jamaica

'When we started getting the basket people use to laugh at us saying we are eating AIDS food....' – Lillian, unpaid carer, Botswana

'Right before she was brought to the hospital she was found lying in her own vomit with rotting food in her cell, cigarette butts everywhere and fruit flies all over.' – Cynthia, unpaid carer, Canada

'There is nobody on earth who can really stand beside me. Today I cannot do any work properly due to my HIV infection because people rebuke me or neglect me.' – Hamida, unpaid carer, Bangladesh

'The most difficult is that you have to stay indoors, you don't go out. Since she don't walk you have to stay indoors. She needs drinking water, she wants to go to the toilet, you have to carry her.' – Amira, unpaid carer, Nigeria

'My anger was with my own family because they would not come and visit us or bring food for her like what is normally done when someone is sick. It was like I had no family.' – Ruth, unpaid carer, Papua New Guinea

These voices are those of unpaid carers living without human rights, living without dignity, living without protection, living without freedom and equality. They live with fear, live with want, live in servitude.

At the centre of the HIV and AIDS response are the estimated 34 million people living with HIV. Of the 12 million people who urgently require access to treatment, care and support, 9 million do not have access to treatment and will die of AIDS (UNAIDS 2011). In these cases, where the bodies of people living with HIV have begun to break down as the virus takes control over their ability to function, carers are essential providers of physical, social and psychological support. They walk hand in hand with those they love and those for whom they care, especially in resource-poor settings. Yet, as the voices of these carers of people struggling with AIDS-related illnesses reveal, they are often as invisible as they are taken for granted by the system that depends on them.

This study is about the millions of carers of people living with AIDS – carers who form no part of the global strategic policy frameworks that are supposed to deliver effective and efficient outcomes in the global response to HIV and AIDS.

The impact of the international public debt crisis on HIV programming has resulted in an increased focus on efficiency of

resource use. Reaching or even maintaining treatment targets has therefore become a priority. The missing factor in the treatment equation is those who care for the 9 million who require treatment but cannot access it. Evaluation criteria to assess HIV programmes focus on reduction of the national burden of HIV and AIDS without acknowledging where that burden falls. AIDS is a crisis that hits hardest at the household level.

Public debt, HIV funding and households in crisis

The current public debt crisis that developed countries are facing will have serious consequences for funding global HIV programmes. The impact of the economic downturn on national budgets and the resultant reduction in public spending will lower household capacity to access HIV and AIDS-related services that are already under severe pressure due to cuts in external aid. Consequently, unpaid carers in the household will be required to shoulder even more burden as they effectively subsidise public health provision. Of particular concern therefore is the non-acknowledgement of budgetary targets for education, health, agriculture and water at a regional 2010 meeting of African ministers of finance, planning and economic development (AFRO-NETS 2010). This would have serious implications for the realisation of the Millennium Development Goals (MDGs) and confronting the AIDS crisis – especially for young women in sub-Saharan Africa, given that 4 out of 5 million HIV-positive young women live in that region (UNAIDS 2011).

Measures that reduce the burden on the household receive the least financial and implementation support. But it is the household – and, by and large, the women of the household – who subsidise HIV care. However, in many cases, gay, bisexual and transgender people also care for their partners. The impact on families is also rarely recognised, such as a lack of access to basic necessities due to stigma and discrimination. These and other direct and indirect effects cannot be easily measured in monetary terms.

To date, the main focus of AIDS care has been on treatment, yet this focus fails to acknowledge the vital contribution made by unpaid carers in the household. Undoubtedly cutbacks, including the lack of maintaining international and national commitments on health expenditures, will have a severe impact on institutional and cross-sectoral aspects of health care. As a result, HIV-related advocacy, human

rights protection and civil society activism towards the achievement of gender equality and the empowerment of women and men will be disadvantaged, under-resourced and compromised.

Rights, resources and the invisible care burden

The invisibility of 'who cares' underscores core inadequacies of the global AIDS response, exacerbated by the failure to apply a human rights framework to the implementation and delivery of care and support programmes. Retention of a definition of work that excludes unpaid care work is a fundamental breach of a basic human right. In those rare instances where home-based care is compensated as part of care and support programmes, it is based on outmoded notions of the family¹ and household. Part of the reason for this is the predominant focus on hyper-endemic contexts in Africa. This ignores not only the diversity of households, families and support systems in Africa itself but also the families and support systems providing critical care work in countries around the world experiencing concentrated epidemics among sex workers, drug users, gay and bisexual men and migrant populations, among others. The diversity of care and support systems is invisible or ignored in the AIDS response where the experience of social exclusion and indignities may be even more extreme. If we are to reach universal access goals and the MDGs, this fractured understanding is untenable.

Access to treatment, care and support are the pillars of the global response to HIV and AIDS. Governments and the international community are focused on preserving treatment enrolment targets and ensuring prevention dollars are invested according to epidemiological profiles. Most national plans are driven by considerations of available donor resources and convenient implementation arrangements. In most countries with concentrated epidemics, efficiency is equated with achieving targets for prevention coverage of high-risk groups and for antiretroviral treatment (ART). The effectiveness of the programmes is judged by whether these interventions have been able to reduce the burden of HIV and AIDS in the long run. Yet the evaluation criteria do not consider where that burden falls. There is a disjuncture between the burden of HIV at a national level and the burden of HIV that falls on the household. Home is the primary site of care for those living with AIDS.

Measures that reduce the burden on the household such as care and support programmes are the ones that get the least amount of finances and implementation support. Concerns about creating entitlements through the continued scaling up of treatment have already begun to impact donor funds made available for access to ART. This is resulting in proposed and actual caps on enrolment in treatment programmes. We therefore face a crisis in the rights to life and to the highest attainable standard of health for people living with HIV. We also face the hidden crises experienced by those who care for them, especially in resource-poor settings most vulnerable to decreases in donor support for treatment. Securing the rights of the carer in these scenarios is essential if the household is not to collapse under the burden of lost life years that could have been saved.

Focusing on the carer is therefore an efficient and effective response to reduce the burden of AIDS on the economy. It is at the household level that the most important decisions about the allocation of resources are made. Over time, different policy provisions – for example nutrition programmes aimed at children or the payment of child benefit support as in the OVC² programme in Botswana supported by the Global Fund – have targeted carers for delivery. AIDS Free World, a non-governmental organisation (NGO), also has a small project where they pay home-based carers. However, focusing on carers is not generally the case in AIDS care provision programmes around the world.

The household experiences greater costs related to caring. Financial costs include increased costs of food, medications and commodities needed for caring. Opportunity costs include loss of income, loss of subsistence production and loss of children's education. Invisible costs include the deteriorating physical and mental health of the carer, plummeting nutrition levels of the household, deteriorating worsening living conditions and sometimes complete loss of shelter, loss of educational opportunities and loss of community participation and personal safety. Barnett and Whiteside (2003) have observed that HIV has been the fastest way for a family to move from relative wealth to relative poverty. This disconnect between the realisation of human rights and the 'efficiency' approach in AIDS programming is evidenced by the state of carers.

Listening to carers' voices

Employing a gender-responsive human rights lens to reconcile a cost benefit analysis of HIV and AIDS with a political economy

approach, this research listened to the voices of unpaid HIV carers in the household. This approach enabled an assessment of 'dignity' and 'rights' in unpaid care and helped to make the case for placing unpaid HIV care-work in the household at the centre of policy formulation for care and treatment as it makes financial sense and leads to social justice.

Eleven Commonwealth countries were identified based on their particular epidemic profiles and the fact that their unpaid care experience and burden would resonate with other countries in the Commonwealth. The study acknowledges that the unpaid care experience would be exacerbated by factors such as disability and disadvantage stemming from situations including unemployment, lack of education, social class, caste and age. In addition discrimination based on factors such as sex, colour and sexual orientation would make the unpaid care experience more onerous.

Within the conceptual framework that is elaborated in the next chapter, key aspects of the unpaid carer's work, life choices and perceptions of rights and responsibilities were examined against particular articles of international human rights instruments to identify how, when and why the unpaid carer's rights were compromised and their dignity eroded. The research process advanced the analytical framework as it led to the examination of the concepts of dignity and servitude in a new way.

The unpaid carers' voices were situated within the analytical contexts of (1) capability servitude in the household – access to and experience of basic freedoms and rights; (2) experiences and perceptions of stigma and discrimination; (3) access to and experience of health services in a public hospital setting; (4) experiences of prisoners living with HIV; and (5) experiences of gender-based violence.

The literature review made it obvious that the research focus in the field would be most usefully situated within a rights-based framework and in particular focused on the dignity of the caregiver in a capability approach analysis. It highlighted different impacts on carers by age, cultural expectations, religion, sexual orientation and gender, and most of this was overlaid with stigma. The second phase of the research involved primary qualitative research with women, men and girls from households affected by HIV as well as with those involved in caring for family members or partners living with HIV or with a clinical diagnosis of AIDS. This phase consisted of key informant interviews. The methodology outlined in the Annex details the theoretical underpinnings and research approach that shaped the study.

The research findings not only lay the groundwork for more conceptual work towards bringing together economic, social, political and human rights strands in examining HIV and AIDS but also embed the layered analysis in the different contexts in which unpaid carers live and experience the epidemic. The findings call into question States' and donors' obligations to the standards agreed in key human rights conventions. By demonstrating that putting carers at the centre increases the efficiency and effectiveness of investments in responses to AIDS, the research asserts that respecting the rights of caregivers contributes to the achievement of universal access targets and the MDGs.

Notes

1. See the section on 'Diversity of family structure and composition' in the ICPD Programme of Action (United Nations 1994), which recognises the process of rapid demographic and socioeconomic change throughout the world that has influenced patterns of family formation and family life and altered family composition and structure.
2. Orphans and vulnerable children.