The experiences of caregivers of children living with HIV and AIDS in Uganda: a qualitative study

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Abstract

Background: Home-based care for HIV patients is popular in contexts severely affected by the epidemic and exacts a heavy toll on caregivers. This study aimed at understanding the experiences of caregivers and their survival strategies.

Methods: A total of 18 caregivers (3 males and 15 females) were interviewed using a semi-structured interview guide, and thematic analysis was used to analyse the data.

Results: Analysis suggests that the caregivers are burdened with insecure provisions for food and difficulties in accessing health care. They however survived these strains through managing their relationships, sharing burden with care-recipients, social networks and instrumental spirituality. These findings are discussed under two major themes: 1). Labour of caregiving and 2). Survivalism.

Conclusions: Home-based care presents huge opportunities for community response to the HIV/AIDS epidemic in African settings. It is however burdensome and thus should not be left for families alone to shoulder. There is therefore an urgent need for protecting home-based care for HIV children in Uganda. Implications for improving and strengthening social interventions in home-based care of HIV/AIDS in the Ugandan context are addressed.

Keywords: Experiences, Caregivers, Children with HIV, Uganda

Background

The HIV/AIDS epidemic in sub-Saharan Africa has had both direct and indirect effects on the population. Caregivers of HIV infected persons have been severely affected by the epidemic [1, 2]. The HIV epidemic has for a long time been one of the primary causes of both child and adult mortality in HIV endemic settings within Sub-Saharan Africa including Uganda [3]. This has placed an enormous care-giving burden on the extended family. This burden is particularly heavy on older persons who have a double burden of caring for their sick and dying adult children, as well as orphaned grandchildren [2]. Depending on the intensity of caregiving, such involvement has been observed to negatively affect their domestic economy, health, physical and psychological wellbeing of older caregivers and to lead to short-term weight loss, physical pain, and depression [1, 3–5]. An important part of the discourse is how the epidemic is affecting caregivers (affected) since in resource-poor settings family-centered approaches to HIV/AIDS care are being encouraged [6]. Such calls find relevance in Sub-Saharan Africa, where home-based care for HIV/AIDS patients plays a critically important role for millions of patients [7]. However, family-centered approach of caring for HIV and AIDS persons exacts a heavy burden on the caregivers [8]. Such burdens include physical health deterioration [9], burnout, emotional distress, family breakdown [10–13] and the destruction of household economies [14].

The impact of HIV/AIDS and how it has disrupted family structure and affected the roles of family members including elderly caregivers in Sub-Saharan Africa has been extensively examined [15]. For instance, an ethnographic study in two semi-rural communities in...