

An Exploratory Model to Illustrate the Interrelationship Between HIV, Disability, and Caregiving in Southern Africa

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Increased caregiving burden and HIV-related disability have important implications for affected populations and health and social security systems in southern Africa. Based on a review of HIV, caregiving, and disability literature, and of existing disability models, the authors discuss the potential interrelationships between caregiving and disability in the context of HIV. They develop an exploratory model to illustrate these linkages. Co-existing experiences of disability and caregiving burden may lead to a vicious cycle of deteriorating well-being among affected households and place additional strain on social security systems. HIV may exacerbate this cycle at both a micro and a macro level. Research, policy, and practice should aim to provide more effective synergies between rehabilitation, HIV treatment, care and support, and household livelihood interventions. Particular attention should be paid to the ability of social systems to meet the specific needs of informal care providers with disability and their care recipients.

(Journal of the Association of Nurses in AIDS Care, 25, 351-363) Copyright © 2014 Association of Nurses in AIDS Care

Key words: Africa, caregiving, children, disability, HIV

The increase in the prevalence of disability among people living with HIV (PLWH) represents one of the most significant and underexplored secondary health-related impacts of the HIV epidemic in a post-antiretroviral therapy (ART) era (Nixon, Hanass-

Hancock, Whiteside, & Barnett, 2011). This is particularly true for southern Africa, which is the global region most highly affected by HIV. According to the 2011 World Health Organization (WHO) World Disability report, the prevalence of disability in southern Africa is estimated to be about 24.5%, far higher than the world average of 15% (World Health Organization [WHO], 2011). The report further explained that this phenomenon was related to the increase in chronic diseases, including HIV. The HIV epidemic has likely made a significant contribution to elevated disability prevalence in the southern African region, and its effects will increase with a growing number of people on ART (Meintjes et al., 2012; Nixon et al., 2011). The introduction of ART in the mid-2000s in resource-poor settings has increased the life expectancy of PLWH on treatment, thus decreasing HIV-related mortality (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2010) and transforming HIV into a chronic illness. However, scattered research from resource-poor settings such as Botswana, Brazil, Lesotho, South Africa, and Zimbabwe (Buyondo, Batamwita, Featherstone, & Mills, 2011; Hanass-Hancock, Regondi, van Egeraat, & Nixon, 2013; Myezwa, Buchalla, Jelsma, & Stewart, 2011), and data from resource rich settings such as Canada, the United

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Kingdom, and the United States (Hanass-Hancock & Nixon 2009; O'Brien, Davis, Strike, Young, & Bayoumi, 2009) have indicated that PLWH increasingly experience HIV-related disability and other adverse events. These challenges may result from living longer with HIV and its opportunistic infections, as well as from the side effects of treatment (Meintjes et al., 2012).

Simultaneously, the large number of adults and children in need of care and support, as a result of (mainly young) adult illness, disability, and mortality, has represented what is arguably the greatest social impact and public health challenge of the HIV epidemic (Barnett & Whiteside, 2006; Meintjes et al., 2012; Nixon et al., 2011). Recent estimates indicated that almost 90% of the approximately 17 million children in the world orphaned by HIV live in sub-Saharan Africa (UNAIDS, 2010). This statistic excluded the large number of children who were not orphaned but still needed care, such as children whose biological parents were absent or ill. The extended family, often described as the traditional social security system in Africa (Freeman & Nkomo, 2006), has, to date, absorbed the large majority of care for orphans and vulnerable children, people with HIV-related disability, and people who are ill (Kuo & Operario, 2009; UNAIDS, United Nations Population Fund, & United Nations Development Fund for Women, 2004). Reasons for this situation may include inadequate policies and health infrastructure as well as preferences of families and patients (Freeman & Nkomo, 2006; Kuo & Operario, 2009). Whatever the reasons, the costs, stresses, and health risks of caring are borne primarily by individuals and families (UNAIDS, 2010). In southern Africa, the burden of care also has had a clear social pattern with gender and age dimensions because caregiving activities are predominantly carried out by women, and increasingly, by older adults (Howard et al., 2006; Steinberg, Johnson, Schierhout, & Ndegwa, 2002; WHO, 2002).

The intersection of caregiving and disability in the context of HIV has the potential to be a double burden, leading to multiple challenges and health risks from the perspective of individuals and households at a micro level as well as public health and social systems at a macro level. However, little attention has been paid to the particular experiences and needs

of caregivers with disability in high HIV-prevalence settings in southern Africa. In this paper we discuss current evidence and understandings related to disability and caregiving linked to HIV. Drawing from existing literature and disability models, we proposed a conceptual framework-in-the-making to illustrate the potential interrelationships between caregiving and disability and to serve as a basis for future work in this area (Figure 1). The model illustrates how co-existing experiences of disability and caregiving responsibilities at an individual level can lead to a vicious cycle of poverty and increased caregiving and health challenges for individuals and households. We argue that, at a macro level, the dimension of these phenomena in HIV-endemic and resource-deprived settings will pose considerable challenges for already fragile health and social security systems. We discuss implications and priority areas for policy, research, and interventions in the region. To our knowledge, this is the first paper to explore inter-linkages between HIV, caregiving, and disability in southern Africa, and their consequences for broader health and social systems.

Background: Understanding Disability Dimensions in the Context of HIV

Disability is an often-misunderstood concept, traditionally dominated by medical terminology related to impairments. However, in recent years the social dimension of disability has become better understood and disability has been defined by the United Nations *Convention on the Rights of Persons with Disabilities* as an “evolving concept that results from the interaction between persons with impairments and attitudinal and environmental barriers, that hinders full and effective participation in society on an equal basis with others” (United Nations, 2006, p. 1). This definition emphasized not only the impairment itself, but also environmental conditions that contribute to the construct of disability. The WHO International Classification of Functioning, Disability, and Health (ICF) has provided a model to guide our understandings of disability in the context of various health conditions, including HIV. The ICF framework has been used by a number of researchers to describe and measure HIV-related disability and its potential

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