



HIV Orphanhood Research and the Representation of Older Orphans in Sub-Saharan Africa: A Literature Review

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One impact of incurable HIV infection is the large number of orphans and vulnerable children (OVC) who are affected by HIV. The age-based criteria used to determine support eligibility for HIV orphans, however, exclude older orphans (≥ 18 years of age) from support. We conducted a literature survey in order to explore possible inclusion of older orphans (ages 18–24 years) in HIV orphanhood research. We found 17 studies conducted in eight countries that met the review inclusion criteria. Findings from the review revealed that older HIV orphans are underrepresented in the OVC literature. The emerging, but limited, evidence suggests that older orphans are at risk for poorer psychosocial and reproductive outcomes. We recommend increasing inclusion of older orphans in HIV orphan research because of their complex physical, reproductive, and psychosocial needs. This inclusion is necessary to allow their experiences and needs to become clearer.

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Sub-Saharan Africa is regarded as the epicenter of the HIV epidemic. In 2012, approximately 23.5 million people in Sub-Saharan Africa were infected with HIV. This figure represented 69% of the people living with HIV worldwide (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2012). Despite advances in the treatment options available

for people living with HIV, the disease still remains the world's leading infectious killer (World Health Organization, 2013). Casualties of the HIV epidemic include not only the infected but also the affected. HIV mostly affects people in their productive and reproductive years (Ferreira, Pessôa, & Dos Santos, 2011), and the epidemic has resulted in millions of orphans and vulnerable children (OVC) worldwide. In 2011, 17.3 million children younger than 18 years of age lost one or both parents to HIV-related illnesses (United Nations International Children's Emergency Funds [UNICEF], 2010), and it was estimated that 90% of these children were living in Sub-Saharan Africa (President's Emergency Plan for AIDS Relief, 2012).

The death of a parent, regardless of the cause, places children under heightened risk. This includes problems such as depression, anxiety, and loss of opportunities. There is also a pervasive influence of stigma and discrimination attached to HIV-related mortality (Doku, 2009). Scholars (Kain, 1996; Sikkema et al., 2000; Wild, 2001) have concluded that HIV-related stigma complicates coping and adjustment while also challenging historical models of bereavement.

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Literature is replete with the experiences and needs of HIV orphans younger than 18 years of age, and this has given rise to interventions such as poverty reduction programs. Some of these programs have included cash transfers (Adato & Bassett, 2009), education support (Lewin & Sabates, 2012), home visiting/mentoring support (Mikton & Butchart, 2009), and various forms of counseling and psychotherapy (Rotheram-Borus, Weiss, Alber, & Lester, 2005; Thupayagale-Tshweneagae, Susan, & Hoffmann, 2010). However, the needs of older orphans and their experiences have been neglected secondary to those of orphans younger than 18 (Evans, 2010). The limited availability of funds may be cited for the exclusion of older orphans in support planning. It does not necessarily follow, however, that the deleterious effects of HIV orphanhood get better when children turn 18 or that they have stopped being orphans.

Young people between the ages of 18 and 24 years have often been referred to as youth (Kurz, 2012). They represent a unique category of OVC because they have different needs from those of children and adults. These needs are more complex than the needs of younger orphans because of physical and psychological development during puberty, and the steps needed to move toward independence and adulthood (Ruland et al., 2005). For instance, Balk (1996) explained that bereaved early adolescents (12–14 years) were likely to think that only their peers would understand them. However, in later adolescence to early adulthood (18–24 years), belonging in another person's life was seen as giving a purpose to life (Balk, 1996).

Several factors render youth-specific programs important. Youth is characterized as a period with the heightened threat of chronic illness, drug and alcohol abuse, poor scholastic performance, and risk-taking behaviors (Barnes, Hoffman, Welte, Farrell, & Dintcheff, 2006). Losing a parent to a highly stigmatized disease such as HIV can have a negative impact on a young person's development and can predict poorer health outcomes. In an HIV endemic region such as Sub-Saharan Africa, health care practitioners will find information about orphans who are older than 18 years of age to be very important. The aim of our literature review, therefore, was to explore the inclusion of HIV orphans older than

18 years of age in research studies in order to report on their experiences and needs.

Method

Inclusion Criteria

Studies that met the following inclusion criteria were included in the review: (a) participants of interest were HIV orphans, (b) phenomena of interest in the study were HIV orphan experiences and needs, (c) publication was an original research article, (d) publication was in peer-reviewed journals, (e) publication was written in English, and (f) study was conducted in a Sub-Saharan Africa country. An HIV orphan was defined as an individual who had lost at least one parent to HIV infection in all included studies.

Literature Search Strategy

Electronic searches of EBSCOHOST, which consisted of the Cumulative Index to Nursing and Allied Health, Academic Search Complete, Medline, PINFO, and Health source databases, were carried out. There were no restrictions related to date because the authors wanted as many studies as possible. Literature search was conducted using selected key words: *orphans*, *HIV*, *AIDS*, *experience*, and *needs*. The authors independently carried out a critical appraisal of located studies and reached consensus on studies to be included. The data we extracted included specific details about the ages of the HIV orphans, study designs, data collection methods, analyses, and findings.

Result of the Literature Search

The key words *orphans*, *HIV*, and *AIDS* produced 1,253 articles; when combined with *experience* and *needs*, the articles were reduced to 880 articles. Following the removal of 87 duplicate titles, the titles and abstracts of the remaining 793 articles were reviewed against the review inclusion criteria. During this process, 714 studies were excluded, leaving 79 articles, which were retrieved for full text examination. After review of the full text, 17 studies that

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