

Review Article

Aging and HIV-Related Caregiving in Sub-Saharan Africa: A Social Ecological Approach

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Abstract

Background and Objectives: We reviewed the literature on older adults (OAs) who are caring for persons living with HIV/AIDS in sub-Saharan Africa (SSA), with the goal of adapting models of caregiver stress and coping to include culturally relevant and contextually appropriate factors specific to SSA, drawing on both life course and cultural capital theories.

Research Design and Methods: A systematic literature search found 81 articles published between 1975 and 2016 which were reviewed using a narrative approach. Primary sources of articles included electronic databases and relevant WHO websites.

Results: The main challenge of caregiving in SSA reflects significant financial constraints, specifically the lack of necessities such as food security, clean water, and access to health care. Caregiving is further complicated in SSA by serial bouts of caring for multiple individuals, including adult children and grandchildren, in the context of high levels of stigma associated with HIV. Factors promoting caregiver resilience included spirituality, bidirectional (reciprocal) caregiving, and collective coping strategies.

Discussion and Implications: The creation of a theoretical model of caregiving which focuses more broadly on the socio-cultural context of caregiving could lead to new ways of developing interventions in low-resources communities.

Keywords: Caregiving, International issues, Stress and coping

The confluence of population aging and the HIV/AIDS epidemic in sub-Saharan Africa (SSA) has resulted in a wide range of psychosocial and health impacts that are not fully understood (AVERT, 2015). SSA accounts for 70% of all cases of people living with HIV/AIDS (PLWHA), with prevalence ranging widely across the different countries in the region (UNAIDS, 2015). HIV/AIDS has eroded the working capacity of communities, and affected needed financial and material support to survive (Kang'ethe, 2012; Knodel, Watkins, & VanLandingham, 2002). Thus, many older adults (OAs; 50+) have been forced into primary caregiving

roles as younger adults, who would normally provide support to aging parents and their children, died from HIV/AIDS (Mathambo & Gibbs, 2009).

Given the contextual nature of older adult (OA) caregiving in SSA to PLWHA, it is important to understand the role of context (aging, HIV/AIDS, war, poverty) in the development of effective interventions. In SSA as elsewhere, care is shaped by the culture which informs the dimensions of “good” care, culture-specific approaches to symptoms and illness, and bereavement (Gysels, Pell, Straus, & Pool, 2011).

It is critical to address resource deficits for PLWHA and surviving orphans, including lack of basic infrastructure, food insecurity, and poor record keeping (Njororai & Njororai, 2013; Oppong, 2006). Unemployment and industrialization may also play a critical role in the recruitment of OA caregivers, as these forces often lead to urban migration and high prevalence of HIV/AIDS which, in turn, resulted in the creation of orphans and vulnerable children (OVC; Dolbin-MacNab & Yancura, 2017). Patriarchy and the marginalization of women exacerbates care deficits (Schatz & Seeley, 2015). Women, and increasingly OA women, provide most of the informal care in SSA. The emergence of male caregivers who provide both instrumental (financial) and nursing care is reflective of a larger demographic shift related to the feminization of labor in urban centers and the lack of employment for men (Block, 2016; Block, 2014).

The main goal of this review article is to extend sociocultural models of stress and coping to a true multilevel model which incorporates the impact of the larger historical context on social institutions, which in turn affect individual level stress and coping practices. We will do this through focusing on the impact of cultural resources on caregiver wellbeing in OAs providing care to persons with HIV/AIDS.

Sociocultural Models of Stress and Coping

Sociocultural values are important for the caregiving process (Pearlin, Mullan, Semple, & Skaff, 1990). Using Hispanic American caregivers as exemplars, Aranda and Knight (1997) defined culture in terms of a bipolar dimension of individualism and familism. They hypothesized that individuals adhering to individualism would report higher levels of

caregiving burden because the provision of care would interfere with the caregiver’s autonomy, whereas those adhering to familism would report lower levels. Surprisingly, this was not supported by their data. Knight and Sayegh (2010) recommended that additional research on ethnic differences in caregiving needed to explore a range of finer-grained dimensions of cultural values that are associated with both positive and negative effects on caregiver health outcomes. Aldwin (2007) suggested that cultural values influence coping resources, including social support and coping strategies, as well as the cognitive appraisal of burden, which might prove to be a fruitful avenue for expanding the model.

Following Knight and Sayegh’s (2010) recommendations, we expanded their stress and coping model (see Figure 1). (Knight and Sayegh’s original model is highlighted by a gray background.) The model consists of three levels: the sociohistorical, the intermediate, and the individual contexts. We drew on life course theory (Elder & George, 2016), which posits that individuals’ developmental paths are embedded in and transformed by local and global contexts and events that occur in the historical period and geographical location in which they live. In our model, the sociohistorical level is represented by the current confluence of population aging and the HIV epidemic. In SSA, the role of OA has been transformed in part because the HIV/AIDS epidemic has resulted in over a million deaths among working age adults (15–49), creating a “missing generation” (AVERT, 2015).

The second level of the expanded model in Figure 1 reflects Bourdieu’s theory of cultural capital or resources as the intermediary link between the larger sociohistorical context and immediate context of care (Bourdieu, 1986). Conceptually, culture can be understood to be a resource or

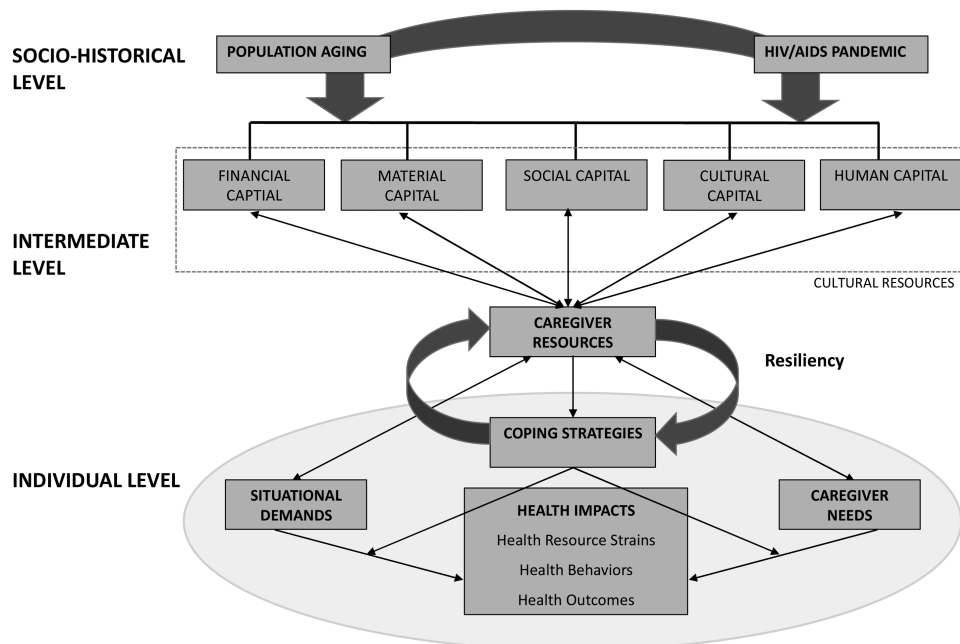


Figure 1. Sociocultural multileveled model of stress and coping. Sayegh and Knight’s model is highlighted in gray.

capital that can be spent, bartered, saved, discarded, created, or extinguished. Five types of cultural resources have been identified (Bourdieu, 1986; Heckman, 2007). *Material capital* includes the built environment, including hospitals, housing, transportation, food production, and sanitation systems (Lynch, Smith, Kaplan, & House, 2000; Ralston, 2017), and is a predictor of health and wellbeing among OAs (Ralston, 2017). *Financial capital* refers to access to tangible assets that can be used to purchase goods and services (Galama, 2015). *Cultural capital* refers to one's knowledge base, skill sets, assets, and social status (Bourdieu, 1986). *Social capital* refers to resources linked to social networks. The amount of social capital depends on the size of network connections and the resources possessed by network members. *Human capital* refers to an individual's genetic assets concerning appearance, intelligence, and talents, as well as their health status (Heckman, 2007). Note that culture also includes barriers to resources in these categories, such as some inequalities, health disparities, and social stigma.

The third level is the individual level and involves matching the situational demands of caregiving with the cultural resources needed to utilize or create coping strategies in response to these demands (see Aldwin, 2007). The double-headed arrows in the model suggest dynamic, transactional relationships among established cultural resources, caregiving situational demands, caregiver needs, and the resources available to caregivers. When the system is in a state of disequilibrium, caregivers may create new cultural resources to meet these demands. Caregiver resiliency is the ability of caregivers to adapt by using these cultural resources, and is illustrated by the movement from the intermediate level to the individual level (Aldwin & Igarashi, 2016).

Our expanded model differs from Knight and Sayegh's model in two distinct ways. First, we have expanded their definition of cultural values to refer to resources that can either be pre-existing or newly created to meet ongoing caregiving demands. Secondly, their model focuses on caregiving for patients with dementia, but we believe that this expanded conceptual model may be applicable to a wide range of illnesses and caregiving situations, including HIV-related caregiving. We will apply our conceptual model to the systematic review of the literature on OA caregivers to persons impacted by and/or living with HIV/AIDS in SSA.

Methods

Approach and Search Strategy

We searched both peer-reviewed and gray literature sources for articles published in English between January 1, 1975, and December 31, 2016, on OAs caring for HIV-positive family members in SSA in the following databases: MEDLINE, PsycINFO, Social Sciences Citation Index, CINAHL, Cochrane Library, Africa-Wide: NiPAD, and relevant WHO websites. Articles were included if they met the following inclusion criteria: conducted in SSA; sampled OA caregivers, aged 50 and older; used community samples;

and focused on HIV-related impacts. There were no restrictions on sample size or study design. Articles were excluded if they were not available in English. Identified articles from all sources were imported and duplicates removed. Titles and abstracts were read, and if deemed appropriate, the full article was obtained and coded.

Organizing the Information

Caregivers were defined as adult women or men aged 50+ who are providing care to PLWHA and/or children younger than 18 who may or may not be HIV-positive, but need care because of HIV. Most the articles included in this review had an aspect of caregiver stress/burden, orphan caregiving, or the impacts of caregiving on caregiver health, wellbeing, and finances in the title or abstract.

We used a narrative approach similar to Yee and Schultz's (2000) review of the empirical care giving literature. The diversity in measures used and the heavy reliance on qualitative research made a meta-analysis inadvisable. Several steps were used in organizing this review. Our first step involved summarizing the studies by constructing a table containing the country, sampling strategies, main topical domain, and the salient findings for each study). We considered organizing the articles by country, decade or other time variable (pre-and-post apartheid in South Africa), but there did not appear to be any substantive differences in the reported findings since the late 1990s when this topic first appears, and instead opted to organize it by country and publication date (see Table 1) for heuristic purposes.

We grouped these items into the categories defined by our theoretical model to illustrate the importance of cultural resources on informal caregiving. Finally, where appropriate, we noted examples of health outcomes across the three broad domains of health resource strains, health behaviors, and health outcomes.

Results

A total of 122 articles were identified from the databases, out of which a total of 81 met all the selection criteria and were used in the study. Articles were excluded because the topic did not include caregivers ($n = 17$), the caregiver was too young ($n = 9$), the study was not based in SSA ($n = 11$), or did not meet other criteria ($n = 3$). Out of the 81 reviewed articles, most were situated in South Africa ($n = 31$), followed by Kenya ($n = 16$), and Uganda ($n = 9$), Zimbabwe ($n = 7$), with the remaining studies in Botswana ($n = 5$), Ghana ($n = 2$), Lesotho ($n = 1$), Malawi ($n = 2$), Nigeria ($n = 1$), Tanzania ($n = 3$), and Togo ($n = 2$). Two cross-sectional studies on OA caregivers examined five or more countries at once. The articles described a variety of methods to collect data including, qualitative data collection (44%), cross-sectional and longitudinal quantitative studies (51%), and mixed-methods research studies (5%).

Table 1. Summary of Sub-Saharan Africa Studies on Older Adults Caregiving for HIV/AIDS Family and Friends

Author	Sample and study design	Situational demand		Caregiver needs			Health impacts	
		Context/material capital	Coping	Financial capital	Social capital	Cultural and human capital	Health resource/strains	Health outcomes/behaviors
Multiple countries								
Lackey et al., 2011	Qualitative OA CGs and OVC (N = 256)	Inheritance challenge food security	Prevention training	Vulnerable	▼ Intergenerational relationships	▼ Intergenerational life skills	▲ Opportunity cost	▼ Physical and mental health
Zimmer & Dayton, 2005	Comparative cross-sectional	OAs in extended household		Vulnerable	▼ Support			
Botswana								
Shaibu, 2013	Qualitative OAs to OVC (N = 12)	Farm Distance	Spirituality & resilience	Vulnerable	▼ Support	Hard accept CG role	▲ Opportunity cost	▼ Physical & mental health
Bock & Johnson, 2008	Experimental Women age = 2.5–49 years (N = 22) & >50 years (N = 17)	OVC discipline		Vulnerable		▼ Intergenerational life skills	Produce ▼ food	
Thupayagale-Tshweneagae, 2008	Qualitative grandmothers to OVC (N = 25)	OVC discipline	Blame on witchcraft bad neighbors	Vulnerable	Stigma	Fail to protect family	Financial, physical & relational stress	Disenfranchised grief Sleep ^a
Alpasian & Mabutho, 2005	Qualitative (N = 7)			Vulnerable	▼ Support			▼ Physical & Mental health
Lindsey et al., 2003	Cross sectional (N = 35)	OAs are dislocated	Spirituality & resilience	Vulnerable	Stigma	Lack knowledge of HIV/AIDS	Financial, physical, & relational stress	▼ Mental health. Fasting of food
Drah, 2014	Qualitative (N = 49)	OAs have assets/lack mobility	Spirituality & resilience	Vulnerable multiple job			Financial, physical stress	▼ Physical ▲ Stress overworked ^a
Mwinituo & Mill, 2006	Qualitative (N = 15)	Disrespect by doctors		Vulnerable	▼ Support high stigma	Hide care work		▼ Physical & mental health
Kenya								
Chepngeno-Langat, 2014	Longitudinal (N = 1,322)	Number of OA CGs ▲ annually by 3%		Saving ▲ likelihood of CG		Age & health ▲ likelihood of CG	Serial CG	▼ Physical & mental health
Chepngeno-Langat & Evandrou, 2013	Longitudinal (N = 1,489)	Non-CGs older OAs Lack mobility				Age & health ▲ likelihood of CG	Serial CG	For non-CGs ▼ physical & mental health

Table 1. Continued

Author	Sample and study design	Situational demand		Caregiver needs			Health impacts	
		Context/material capital	Coping	Financial capital	Social capital	Cultural and human capital	Health resource/strains	Health outcomes/behaviors
Ice, Sadrudin, Vagedes, Yogo, & Juma, 2012	Cross sectional Luo CGs age = 60+ (N = 40)	Mostly female CGs				Women ▲ stress than men, Male CGs ▼ stress	Stress	For women, stress ▲ CG & CG intensity but not number of OVC
Ice et al., 2011	Longitudinal age 60+ (N = 689)	Food Security		Vulnerable	Social support → BMI	Age ▼ Nutrition	CG → anthropometric measures	Stress negative → anthropometric measures
Chepngeno-Langat, Madise, Evandrou, & Falkingham, 2011	Cross-sectional N = 1,529	HIV-CGs were younger		Vulnerable		Gender		Female AIDS CGs have ▲ disability & mobility, male CGs ▼ physical health than non-male CGs
Chepngeno-Langat & Falkingham, et al., 2010	Cross-sectional (N = 1,587)	Most CGs were male		HIV-CGs wealthier than non-CGs		HIV-CGs younger, ▼ schooling & married	Male CGs longer care than female CGs who provide critical care	
Skovdal, 2010	Qualitative OA guardians (N = 36), OVC (N = 69)	Bidirectional care between OA & OVC		Vulnerable		OVC are cared for & provide care for OA-CGs		
Muga & Onyango-Ouma, 2009	Qualitative/cross sectional (N = 115)	Climate change/increased dependency ratio		Vulnerable	▼ Support	Intergenerational relationships	Food security	
Wangui, 2009	Qualitative 60+ (N = 30)	▲ Nutritional status, increase land assets	Hired out or gave land to sons	OAs depend on remittances	▼ Support		▲ Nutritional OAs Cared for 2-3 OVC	Labor shortage and poor health limited land use
Ice, Zidron, & Juma, 2008	Cross-sectional mean age 73, (N = 287)			Vulnerable	Social support → pain	Age → SF-36 score and health	Grants → low pain, better mental health	Female CGs ▲ health than non-CGs, Male CGs ▼ than non-CG OA CGs ▲ stress than biological mothers, stress not → OVC adjustment
Oburu, 2005	Cross sectional mothers (N = 115) & OAs (N = 134)	Limited food crop				Age → OVC emotional adjustment score	▼ Energy, insufficient labor,	
Winters et al., 2005	Cross-sectional (N = 103)							No → blood glucose & depression

Table 1. Continued

Author	Sample and study design	Situational demand		Caregiver needs		Health impacts		
		Context/material capital	Coping	Financial capital	Social capital	Cultural and human capital	Health resource/strains	Health outcomes/behaviors
Juma et al., 2004	Qualitative (N = 84)	Food Security/poor housing, OVC Discipline	Small-scaled farming, pension, loans, spirituality	Vulnerable		Lack knowledge of HIV/AIDS & care skills	▲ Opportunity cost. Financial, emotional, and nursing care	▼ Physical & Mental health Satisfaction for care role
Oburu & Palmérus, 2003	Cross-sectional (N = 249)					Non-literate CGs use coercive discipline		OVCs age & assertive discipline → Total stress
Nyambetha et al., 2003	Qualitative households (N = 1,100)	OVC discipline, Inheritance rights	Used paid labor, small businesses	Vulnerable	▼ Social support, High social stigma	Tradition of care	▲ Opportunity cost	Skipped meals & missed sleep to nurse infants ^a
Lesotho								
Makoae, 2011	Qualitative CGs (N = 21)	High HIV prevalence do not know CR HIV statue				Maintain ritual of feeding		CR food intake linked to CG wellbeing
Littrell et al., 2012	Mixed methods (N = 1,281)			Vulnerable	▼ Social support	Aged CGs more stable than younger CGs	Must provide financial, emotional and nursing care	OA CGs ▼ Physical health & Mental health same for both
Malawi								
Sefasi, 2010	Qualitative (N = 116)	Resource depletion		Vulnerable		Knowledge of HIV/AIDS & care skills	Financial, emotional, & nursing care	
Nigeria								
Apata et al., 2010	Panel (N = 240)	21% of all OVC loss parents to AIDS	Selling assets	Vulnerable				▼ Mental health
South Africa								
Sidloyi & Bomela, 2016	Qualitative retired women 60+ (N = 15)	Premarital pregnancies, Crime	Loans, friendship based networks, small businesses	OAs Casual work, child labor	Social network			
Nyirenda et al., 2015	Cross-sectional CGs and non-CGs age 50+ (N = 422)			Vulnerable				Household wealth related to wellbeing
Dolbin-Magnab, Jarrott, O'Hora, Vrugt, & Erasmus, 2015	Qualitative OA women (N = 75)		Spirituality, loans, OVC grants Social network	OAs Access instrumental support	▲ Social network			▲ Alcohol use AIDS death related to OA poor physical health HIV+ OAs ▲ Health than HIV affected OAs

Table 1. Continued

Author	Sample and study design	Situational demand		Caregiver needs			Health impacts	
		Context/material capital	Coping	Financial capital	Social capital	Cultural and human capital	Health resource/strains	Health outcomes/behaviors
Chazan, 2014	Qualitative OA women (N = 100)				▼ Social Support Group			OAs enjoyed, & had hope for OVC
Kidman & Thurman, 2014	Longitudinal (N = 726)	Dependency ratio 1:6, Female CGs, Food insecurity		Vulnerable				▼ Physical & Mental health
Schatz & Gilbert, 2014	Qualitative Women, aged 60+, (N = 30)	Gendered work/roles			Stigma			CG-Burden
Bachman-DeSilva et al., 2013	Longitudinal (N = 4,030)	75% Households had grants, Food insecurity		Vulnerable				▼ Physical & Mental health
Casale & Wild, 2013	Qualitative	CGs care for average 2.7 OVC, OVC discipline & crime		Vulnerable	▼ Support			
Govender et al., 2012	Longitudinal (N = 616)			Vulnerable	▼ Support		HIV Wealth depletion	▼ Physical & Mental health
Schatz & Gilbert, 2012	Qualitative women age 60-75, (N = 30)	Lacking piped water, electricity, climate, OVC discipline	Spirituality, traditional medicines	Vulnerable				▼ Physical & Mental health
Petros, 2012	Cross-sectional OAs in South Africa, (N = 305)	Lacking piped water, electricity, Sanitation, bidirectional care		Vulnerable	Rely on informal support			CG-Fair wellbeing, untreated physical & mental illness
Tamasane & Head, 2012	Cross-sectional (N = 5,254)	1/3rd of children in Kopanong are OVC		Vulnerable	State gate keepers for child grant		Child grants are difficult	CG-rated health as Fair
Petros, 2011	Policy OAs	Lacked basic services		Vulnerable	CG stigma		Care under extreme deprivation	▼ Physical Health
Casale, 2011	Qualitative older adults		Adversity, hire resilience, hire out help	Vulnerable	▼ Support	Traditional healer	▲ Joy, focus & hope for OVC	
Kruger et al., 2011	Cross-sectional rural OAs (N = 134) & urban OAs age = 60+ (N = 196)	Pension main source of income				Age	Health of HIV affected OVC is compromised	Rural OAs had ▲ micronutrient & trace element intake, urban ▲ fat

Table 1. Continued

Author	Sample and study design	Situational demand			Caregiver needs			Health impacts	
		Context/material capital	Coping	Financial capital	Social capital	Cultural and human capital	Health resource/strains	Health outcomes/behaviors	
Ogunmefun et al., 2011	Qualitative 50–75 age (N = 60)		CG secrecy		Verbal & Social stigma		Marginal diets		
Schatz et al., 2011	Qualitative Women (N = 21)	Estrange/disconnected households		Vulnerable	▼ Social Support		▲ Social isolation		
Ardington et al., 2010	Panel data Age 60+, (N = 7,127)	No difference in expenditure pattern CG & non-CG		Pension mitigate consequences of HIV/AIDS	No impact of death of Adult child		Depression		
Boon, James, et al., 2010	Cross-sectional (N = 409)	Female care for average of 4.65 OVC		Income → negative attitude	Communicate with OVC		CG-Burden & CG-Stress		
Boon, Ruiters, et al., 2010	Longitudinal isiXhosa (N = 820)	21% of Adult children unemployed, 4.8% of the adult children are HIV+, OAs care for a average of 4.6 OVC		Vulnerable	▼ Social Support	Intervention	Expenditure had no impact on Mental & Physical Health	Program ▲ CG ability to relax	
Raniga & Simpson, 2010	Qualitative OA (N = 15)	Pension stabilized family	Spirituality		▲ Social supports		Adult death ▼ income	▼ Physical & Mental health	
Munthre & Maharaj, 2010	Mixed methods men & women (N = 974)	25% of CGs care > 3 OVC, Females are primary CGs		Vulnerable			Adult death ▼ income	CG-burden/exhaustion	
Boon et al., 2009	Cross-sectional isiXhosa speaking CGs (N=202)	50% of OAs have no income & care for 4.97 OVC		Vulnerable	Completion ▲ attitudes for PLWHA	Completion ▲ CG attitudes, norms & care		▼ Physical & Mental health	
Hlabayo & Ogunbanjo, 2009	Qualitative age 50+ (N = 9)	OVC discipline		Vulnerable	▼ Support social & services	CG painful		Mental & physical health/fear risk for HIV	
Nyasni, Srenberg, & Smith, 2009	Qualitative age 50+, (N = 45)	OVC discipline		Vulnerable	▼ Support social	Emotional support to OVC	Intergenerational Disharmony	CG burden/Physical health	
Hosegood, Preston, Busza, Moitse, & Timaeus, 2007	Qualitative CG age 50+ and OVC 15+ (N = 12)	OA men were more likely to be married/OA lived in extended families		Vulnerable	AIDS death 20% of household		Adult death ▼ income	Mental Health	
Schatz, 2007	Qualitative OAs age >59 (N = 30)	OA lived in extended families		Vulnerable	▼ Family support	Provide emotional support to OVC	Adult death ▼ income		

Table 1. Continued

Author	Sample and study design	Situational demand		Caregiver needs			Health impacts	
		Context/material capital	Coping	Financial capital	Social capital	Cultural and human capital	Health resource/strains	Health outcomes/behaviors
Hosegood, & Timaeus, 2006	Cross-sectional (N=10,612)	50% of household experience a death of prime-age adult		Vulnerable	Stigma & isolation	OA care expected	Adult death ▼ income	
Ogunmefun & Schatz, 2009	Cross-sectional female CGs (N = 60)	OA women are becoming CGs	Invested in insurance/credit	HIV households vulnerable	Extended family supported		OAs pay for all care to PLWHA	
Reddy, James, Esu-Williams, & Fisher, 2005	Qualitative (N = 89)	Pensions are used for household needs, OVC discipline		Vulnerable	Community social support		Must carry out multiple parenting roles	CG is emotionally & physically demanding
Tanzania de Klerk, 2011	Qualitative OA caregivers	Data collected before rollout of antiretroviral therapy			CRs are hidden to keep social support	Concealment means good parenting & loving care		▲ Mental health
Dayton & Ainsworth, 2004	Cross-sectional Age = 50+ (N = 757)	OA are not mobile in households		Healthy household 2x ▲ gainful activity rates,			42% of deaths were among prime-age adult	Prime-age adult death → ▲ BMI
Ainsworth & Dayton, 2003	Cross-sectional Age = 50+ (N = 1512)	56% of OAs have no durable assets, 67% of deaths attributed to AIDS		Vulnerable Adult death ▼ income		BMI ▲ women than men	42% of deaths were among prime-age adult	Household wealth ▲ BMI for OAs OVC in household ▼ → BMI
Togo Moore, 2007	Qualitative age = 50+, (N = 7)		Emotional coping, sought professional help	Adult death ▼ income	Adult death ▼ social support	OAs felt too old for CG	OAs pay for all care to PLWHA & OVC	Accepting death of adult child, CG burden for OVC
Moore & Henry, 2005	Mixed Method OAs (N = 50)		Condoms, stopping sexual activity, monogamy	Vulnerable Adult death ▼ income	▼ social support & isolation	Do not believe HIV care is risky	Need affordable drugs & foods	CG burden for OVC
Uganda Rutakumwa et al., 2015	Qualitative OAs (N = 40) dyads	Subsistence food production		Vulnerable	▼ Social support		Financial, physical & relational stress	▼ Physical & Mental health & bidirectional CG
Seruwagi, 2014	Qualitative (N = 129)	Bidirectional caregiving between CGs and OVC			OAs support early marriage		OAs provide instrumental support for education	▼ Physical & Mental health & bidirectional CG

Table 1. Continued

Author	Sample and study design	Situational demand		Caregiver needs			Health impacts	
		Context/material capital	Coping	Financial capital	Social capital	Cultural and human capital	Health resource/strains	Health outcomes/behaviors
Kasedde et al., 2014	Qualitative OA (N = 61)	Reciprocity Cultural intergenerational exchange	Preparing OVC for OA's death	Vulnerable	▼ social support & Stigma	Use of traditional medicine	Timing of CG Financial & relational stress	
Mugisha et al., 2013	Cross-sectional, (N = 510)		CG work → financial & physical support	CG work → financial & physical support	Women → financial support than men	Women care for OVC & provide → care than men		CG work, poverty, poor health HIV → CG burden
Kanya & Poindexter, 2009	Qualitative OA CGs (N = 11)	HIV/AIDS deaths, war and famine	Spirituality/inner resiliency	Vulnerable			Logistics of care & money	Stress, fear & poverty
Nankwango, Neema, & Phillips, 2009	Qualitative (N=215)	58% of population has lost someone to AIDS	Social support, professional help, faith		▼ social support & Stigma	Lack of education about HIV	Burden of OVC care is on rural OAs	
Ssegonzi, 2009	Qualitative (N = 27)		Food cultivation	PLWHA's finances → OA CG Vulnerable	▼ social support & Stigma	Women provide care mostly spouse		▼ Physical & Mental health
Ssegonzi, 2007	Qualitative N = 20,	Food insecurity		Vulnerable	▼ social support & Stigma	Women provide care mostly spouse	Financial, physical & relational stress	▼ Physical & Mental health
Kakooza & Kimuna, 2005	Cross-sectional OA, age 50+ (N = 300)			Vulnerable	▼ social support & Stigma		Financial, physical & relational stress	▼ Physical & Mental health Balance diet' health
Zvinavashe, Mukombwe, Mulikona, & Haruzivishe, 2015	Qualitative OVC-CGs (N = 30)	In adequate housing	Seek help from donations, sold surplus goods	Vulnerable	▼ social support			No physical & Mental health problems
Mhaka-Mutepe et al., 2015	Cross-sectional Mean = 62.4 (N = 327)	Most have access to care Material capital not → ASL ^b score			Social support → ASL score	Age → with resilience & ASL		Urban OAs, physical & Mental health → ASL
Skovdal et al., 2011	Qualitative Nurses (N = 25) OAs, (N = 8)	Food needs are being met via NGOs' Lack of transportation		Vulnerable	▼ social support	Poor health literacy	Financial, physical & care stress	▼ Physical & Mental health
Mudavanhu, Segalo, & Fourie, 2008	Qualitative Age = 50 + 6 (N = 12)	Climate instability Food insecurity	Seek help from donations, grants	Vulnerable			Financial, physical & care stress	▼ Physical & Mental health

Table 1. Continued

Author	Sample and study design	Situational demand		Caregiver needs			Health impacts	
		Context/material capital	Coping	Financial capital	Social capital	Cultural and human capital	Health resource/ strains	Health outcomes/ behaviors
Agyarko et al., 2002		Food insecurity, Community violence		Vulnerable	Stigma	Fear of contracting HIV	Financial, physical & care stress	▼ Physical & Mental health
Bindura-Mutangandira, (N = 20) 2001	Qualitative mean 50+		Resource reallocation join burial societies	Adult child death ▼ Vulnerable	Adult child death ▼ social support		Financial, physical & care stress	▼ Physical & Mental health
Mupedziswa, 1997	Policy study	Climate instability Food Insecurity Foreign debt	Use pension	Vulnerable	Adult child death ▼ social support		Need for healthcare, food, and shelter	

Note: BMI = Body mass index; CG = caregiver; CR = care-recipient; OA = older adult(s); OVC = orphan and vulnerable children; PLWHA = person(s) living with HIV/AIDS.
^aHealth behavior. ^bAcceptance of self and life events. ^cNongovernmental organization.

Situational Demands

The deaths of prime-age adults have altered household composition and access to resources (Adamchak, Wilson, Nyanguru, & Hampson, 1991; Agyarko, Madzingira, Mupedziswa, Mujuru, & Kanyowa, 2002; Ainsworth & Dayton, 2003; Cohen & Menken, 2006). The articles detailed the poor infrastructure, such as the lack hospitals, medications, access to land, irrigation and modern farming techniques, food distribution, and transportation, as well as widespread unemployment, food insecurity, and climate change. This impacts OA caregivers' ability to provide safe and effective care to PLWHA and to OVC (Ainsworth & Dayton, 2003; Juma, Okeyo, & Kidenda, 2004; Muga & Onyango-Ouma, 2009). For example, in Tanzania, early publications reported that social safety nets were compromised (Kaijage, 1997), hospitals were overwhelmed (Uys & Cameron, 2003), and food insecurity was commonplace (United Republic of Tanzania, 2006). Recent reports from Tanzania suggest that little has changed. HIV-related stigma and discrimination, stress, and care burden continue to challenge resources for caregiving (de Klerk, 2011; Pallangyo & Mayers, 2009).

AIDS-related deaths have resulted in the creation of 12-million orphans who have largely been absorbed into extended family networks comprised of OAs (Hlabyago & Ogunbanjo, 2009). In most countries in SSA, the extended family, primarily grandparents, care for a large number of OVC (HelpAge International, 2008; Monasch & Boerma, 2004). In national household surveys conducted in 40 countries, only 13 of the countries included information on OA caregivers (Monasch & Boerma, 2004). In those 13 countries, between 24% and 64% of OAs were fostering OVC affected by HIV/AIDS. In Malawi, OAs cared for nearly half (46%) of orphans who have lost both parents. Despite the relatively low prevalence of HIV/AIDS in Kenya, the percentage of OAs providing care increased from 11% in 2006 to 14% by 2014 (Chepngeno-Langat, 2014). In Namibia, the proportion of orphans being cared for by grandparents rose from 44% in 1992 to 61% in 2000 (UNICEF, 2003). In Zimbabwe, South Africa, and Namibia, 60% of AIDS orphans lived with OA caregivers (Zimmer & Dayton, 2005).

Caregiving for OVC has some positive aspects. In Kenya, OVC in the household was associated with better health outcomes for men (Ice, Juma, & Yogo, 2008). In Botswana, a country with the second highest prevalence of HIV/AIDS in the world (17.6%), both children and OAs provide bidirectional care (Lindsey, Hirschfeld, Tiou, & Neube, 2003). Similar patterns of bidirectional care were reported in Kenya and South Africa (Petros, 2011, 2012; Skovdal, 2010). Often, OAs are receiving care for non-HIV or HIV-related health issues or personal care (Nyirenda, Evandrou, Mutevedzi, Hosegood, & Falkingham, 2015). In SSA, OVC often do necessary chores, such as hauling water, tending animals, and so on, which helps both to fill in the labor gap caused by parental death and helps the grandparent's

household economy (Sidloyi & Bomela, 2016; Skovdal, 2010). This care work by OVC is not purely instrumental. In Uganda, the care work for OA caregivers was described as compassionate, highly desired, and loving (Rutakumwa et al. 2015; Seruwagi 2014).

Food insecurity, reported in most of the reviewed articles, is perhaps one of the most unanticipated effects of the HIV/AIDS epidemic. This stems in part from the loss of working age adults, access to land, inheritance laws, and an overall loss of productivity due to poverty (Agyarko et al., 2002; Mwanyangala, Mayombana, & Urassa, 2010; Pallangyo & Mayers, 2009), time spent caregiving, lack of knowledge of modern farming techniques, increased household size, aging, and chronic health problems (Nyirenda et al., 2015; Oburu, 2005; Wangui, 2009). OAs who cared for very young children seem to be particularly burdened (Shaibu, 2013).

In summary, the HIV/AIDS literature has largely focused on the impacts of caring for OVC rather than OAs caring for both adult children and grandchildren. Research is needed on the influence of HIV-related caregiving responsibilities versus other types of informal care and how care recipients are affected when an established caregiver experiences a decline in health or functional status.

Caregiver Needs

Caregiver needs reflect the range of resources required for support. Included is the availability of resources that directly impact caregiver performance in assistance with activities of daily living (ADL), and instrumental activities of daily living (IADL), such as the access to financial capital, social support (social capital), and caregiving know how (cultural capital).

Financial Capital

The main source of income for caregivers varied by country. In South Africa, the majority of OAs depend on the old-age pensions and cottage industries, e.g., selling fruit, milling grain, or providing other nondurable goods and services (Bachman-DeSilva et al., 2013). The impact of public transfers are considerable; a Cape Town study found no differences in expenditure patterns between households with orphans, AIDS-related deaths, and other OA households (Ardington et al., 2010). Household subsidies did initially promote stabilization of households in SSA (Raniga & Simpson, 2010). However, the subsidies were not enough and subsequent studies reported that OAs were financially worse off after providing care to a family member with HIV (Bachman-DeSilva et al., 2013; Casale, 2015; Casale & Wild, 2013; Cohen et al., 2015; Kidman & Thurman, 2014).

Many SSA countries do not have broad pension coverage, and poverty consistently impinges on cultural resources throughout the region. Reasons for economic insecurity center around six recurring themes. First, caregiving

duties prevented engaging in income-generating activities (Chazan, 2008; Juma et al., 2004; Shaibu, 2013), and second, there were fewer family members available to farm and tend cattle (Lindsey et al., 2003; Wangui, 2009). Third, repeated bouts of caregiving depleted household resources (Chepngeno-Langat, 2014), often resulting in the fourth problem, poor health. Fifth, what few government grants exist are often inconsistent, insufficient, and nonaccessible (Bachanas et al., 2001; Hlabyago & Ogunbanjo, 2009; Petros, 2012; Tamasane & Head, 2012). Finally, HIV-related caregiving resulted in a lack of support from surviving sons and daughters, as well as inheritance inequalities among male and female family relatives. Thus, there are multiple pathways to poverty among older caregivers.

Social Capital

Despite the large literature on caregiving and PLWHA in high-income countries (HICs; Prachkul & Grant, 2003), most studies only examined instrumental social support and stigma. Several SSA studies reported that OA caregivers continue to experience a shortage of informal supports from family, friends, or neighbors (Alpasian & Mabutho, 2005; Boon, Ruiter, et al., 2010; Nyambedha, 2007; Nyambedha, Wandibba, & Aagaard-Hansen, 2003). Most OAs in South Africa (86%) reported that they were solely responsible for providing basic need for dependents (Boon, Ruiter, et al., 2010). In Malawi, only 31% of OAs were dependent on adult children for help (Sefasi, 2010). In Kenya, social support was linked to increased pain and higher BMI scores (Ice, Heh, Yogo, & Juma, 2011; Ice et al., 2008; Wangui, 2009).

Instrumental support from nonfamily sources was equally strained. Several studies reported that OA caregivers were not treated with respect by governmental official and by hospital staff, including doctors (Hlabyago & Ogunbanjo, 2009; Mwinituo & Mill, 2006; Tamasane & Head, 2012).

OA caregivers experienced many forms of stigma. In Botswana, OAs reported a sense of loneliness and isolation and that stigma was experienced by both caregivers for PLWHA and other chronic diseases (Lindsey et al., 2003). Caregivers in South Africa reported verbal, voyeuristic, and physical stigma (Hosegood & Timaeus, 2006; Lindsey et al., 2003; Ogunmefun, Gilbert, & Schatz, 2011). In Ghana, OA caregivers go to great lengths to hide the HIV status of care recipients as well as their caregiving activities, resulting in isolation of both the PLWHA and the caregiver (Mwinituo & Mill, 2006).

Coping Strategies

Studies of coping mainly addressed financial strategies and religious/spiritual strategies. OA caregivers coped with financial strain by using their knowledge and social networks to access old-age and foster-care grants, as well as their saving accounts (Ardington et al., 2010). In Kenya,

OA caregivers engaged in small-scale farming and the selling of assets to meet the ongoing care needs of PLWHA and funeral costs (Wangui, 2009). There is some evidence that OAs in South Africa use a revolving pool of microcredit as a source of income (Lackey, Clacherty, Martin, & Hillier, 2011; Ogunmefun & Schatz, 2009; Schatz & Ogunmefun, 2007). Additional coping strategies included: applying for food grants, carefully managing income, investing in funeral insurance and credit programs, and creating associations to form social support networks (Casale, 2011; Chazan, 2008, 2014; Juma et al., 2004).

Several studies reported the use of spirituality as a coping mechanism (Drah, 2014; Shaibu, 2013). In South Africa, caregivers reported talking to their pastor, congregants, and praying to God (Chazan, 2008). Alternately, silence and concealment of AIDS illness was a coping mechanism identified in South Africa to protect and honor individuals affected by HIV/AIDS (de Klerk, 2011).

Health Impacts

Health Resource Strains

There are several unusual characteristics of HIV-related caregiving in SSA. The first is serial caregiving—many OAs care for one adult child, and then another—either concurrently or sequentially, as well as their offspring. In Kenya, 10% of noncaregiving OAs in a household transitioned into caregiving and 50% of these caregivers were providing care transitioned to noncaregiving status (Chepngeno-Langat & Evandrou, 2013). A second feature is the number of care-recipients, which are generally not analyzed with regard to caregiver health outcomes or asset dissolution. Caregiving is associated with high opportunity costs where OAs must forgo gainful opportunities to provide care (Nyambedha, Wandibba, & Aagaard-Hansen, 2001).

Health Behaviors

Health behaviors were only examined by two studies. In the first, OA caregivers reported foregoing meals, restricting their food intake, or working extra jobs to purchase the care-recipient's preferred food (Kruger, Lekalakalomogela, & Wentzel-Viljoen, 2011). The second study found that alcohol abuse was problematic for OA caregivers in South Africa (Sidloyi & Bomela, 2016).

Health Outcomes

Grandparents are grieving both for their adult children and report stress in caregiving for grandchildren. In Botswana, OAs had “disenfranchised” grief: they had to hide their own pain of losing adult children because they had to serve as a source of strength to the surviving grandchildren (Thupayagale-Tshweneagae, 2008). Grandmother caregivers in Botswana, Togo, and Uganda reported that they felt depressed and isolated, with a loss of control when grandchildren were unruly and disrespectful (Kamya & Poindexter, 2009; Moore, 2007; Thupayagale-Tshweneagae, 2008).

Over half (57%) of Kenyan caregivers reported a poor quality of life and 74% reported that caregiving had a large impact on their lives (Lindsey et al., 2003). Kenyan caregivers of HIV-positive kin had poorer self-reported health compared to other types of caregivers. Men reported worse health than women and new caregivers were more likely to report having a major health problem compared with those who had never provided care (Chepngeno-Langat, 2014). Thus, the majority of the studies find impaired mental and physical health among caregivers, perhaps due to their greater poverty and age.

Discussion

The literature on OA caregiving in SSA is fragmented across several disciplines. Despite the more robust literature on HIV-related caregiving in HICs, much less is known about OA caregivers providing HIV-related care to adult children and grandchildren in SSA. This is important because, in many ways, the situation in SSA presages a dilemma that HICs will be facing in the next few decades—namely, many OAs will be requiring care and there will be too few caregivers (AARP, 2013a, 2013b).

We found that OA caregivers in SSA face a range of challenges that can be framed by the sociohistorical context of population aging and AIDS. Further, our adapted cultural resources model emphasizes the collective nature of both the stressors and adaptive strategies. Most of the articles reviewed focused on material and economic resources, with comparatively fewer about psychosocial resources such as nonfinancial social support and coping in the SSA context. Although access to “public goods” is critical to caregiver wellbeing, it does little to address contextual factors such as, inheritance rights, intergenerational conflict, HIV-stigma, and rising dependency ratios (Lackey et al., 2011; Ralston, 2017). Another topic not addressed in the reviewed literature was related to the development of post-colonial migrant labor patterns (Camlin et al., 2010). However, the relationship between migration and AIDS is complex, and most individuals move to urban centers for economic benefits. Whether this applies to OA caregivers is unknown.

Our multileveled model allows for the capturing of the social-cultural context of caregiving in SSA (population aging and HIV/AIDS pandemic). Studies reviewed consistently reported resource constraints that framed the situational demands of care including: lack of material capital (safe housing, roads, and transportation); lack of inheritance rights; and lack of food security (Ice et al., 2011; Lackey et al., 2011). These stressors were further augmented by the necessity of needing to care for multiple family members, either serially or at the same time (Chepngeno-Langat, 2014; Zimmer et al., 2005).

A significant finding was that the bidirectionality of caregiving was often emphasized. Grandchildren were not only the recipients of care, but they also provided much needed

household and farm labor which enhanced their grandparents' ability to provide care (Kasedde et al., 2014; Petros, 2012; Skovdal, 2010). The care by OVC was not purely instrumental (e.g., running chores). OAs draw strength from their OVC and attach a great deal of importance to the quality of their relationships (Seruwagi, 2014).

Third, at the individual level, the use of cultural resources was linked to a range of coping strategies, such as religious/spiritual coping, which is a very important resource. However, the collective nature of some of the coping strategies allowed for leveraging in resource-poor environments. Villagers reported communal strategies for financial and nutritional shortfalls, as well as for accessing often-distant medical care and meet cultural demand of funeral costs (Njororai & Njororai, 2013).

The relationship between caregiving and caregiver physical wellbeing was more complex. Several studies reported poor health outcomes, but a few studies reporting positive health outcomes. Some of this may be due reverse causality—younger and healthier individuals may take up caregiving duties. However, there is some evidence that having a purpose in life may prove beneficial for older caregiver's health (Casale, 2015). The SSA grandparents are often literally the only factor preventing complete destitution of their households, which provides a powerful incentive for maintaining functional health.

Despite the resource-poor environment in SSA, many OA caregivers nonetheless exhibited resilience. They drew on their religious/spirituality, their sense of purpose, and their embeddedness in the communities. Despite social stigma, they often utilized collective strategies. Finally, this review emphasized the importance of OAs—in holding together their families and cultures in the face of an overwhelming pandemic and economic pressures.

Conclusion and Future Directions

The current body of evidence uncovered in this literature review partially supports our adapted conceptual model. This model allows for an integrated understanding of the stress and coping processes stemming from the wider cultural context. By identifying cultural resources and the collective nature of coping and adaptation in a resource-poor environment, our model provides a framework for caregiver intervention that is not solely focused on the individual, but recognizes the importance of targeting community-level efforts in interventions.

Bidirectional caregiving is emerging as an important construct (Nagpal, Heid, Zarit, & Whitlatch, 2015). We need more research understanding the dynamic transactions between family members, friends, and the larger community to understand the resources that can be both drawn on and created during stressful situations. Next steps for research in this field should include the identification of processes that fortify existing cultural resources or the development of cultural resources that influence caregiver resilience.

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Conflict of Interest

None reported.

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