Vulnerable Children and Youth Studies, 2014
Vol. 9, No. 3, 234–246, http://dx.doi.org/10.1080/17450128.2013.871379

Caregiver burden among adults caring for orphaned children in rural South Africa

Rachel Kidman[a]* and Tonya R. Thurman[b]

[a]*Global Health Systems and Development, Tulane University School of Public Health and Tropical Medicine, New Orleans, LA, USA;* [b]*Tulane University School of Social Work, New Orleans, LA, USA*

(*Received 16 July 2013; accepted 28 November 2013*)

The AIDS epidemic has created an unprecedented number of orphans. While largely absorbed by extended family, this additional responsibility can weigh heavily on their caregivers. The concept of caregiver burden captures multiple dimensions of well-being (e.g., physical, social and psychological). Measuring the extent and determinants of caregiving burden can inform the design of programmes to ease the negative consequences of caregiving. This study uses the baseline data from a study assessing interventions for orphans and vulnerable adolescents in the Eastern Cape, South Africa. Orphan caregivers (n = 726) completed an adapted version of the 12-item Zarit Burden Interview. In addition to basic caregiver and household demographics, the survey also collected information on AIDS-related illness and recent deaths. Descriptive data are presented, followed by multivariate Poisson regression models to explore factors associated with caregiver burden. Approximately 40% of caregivers reported high levels of orphan caregiving burden. Feelings of stress and inadequacy concerning their care responsibilities as well as anger towards the child were common. Household food insecurity was the most important predictor of orphan caregiving burden (marginal effect = 7.82; $p < 0.001$ for those reporting severe hunger); income was also a significant determinant. When other AIDS impacts were added to the model, only the AIDS-related illness of the caregiver was significantly associated with burden (marginal effect = 3.77; $p < 0.001$). This study suggests that caregivers with economic vulnerability and those struggling with their own AIDS-related illness feel most overburdened. These findings are particularly relevant to service providers who must identify caregivers in need of immediate assistance and allocate limited resources effectively. To alleviate caregiver burden, programmes must foster greater economic security (e.g., by facilitating access to social grants or directly providing cash transfers) and coordinate services with home-based care programmes serving the chronically ill.

Keywords: orphan; HIV/AIDS; caregiver burden; South Africa

Introduction

The AIDS epidemic has placed enormous pressure on extended families to provide informal care, both for people living with HIV and AIDS (PLWHA) as well as for

---

*Corresponding author. Email: rachelkidman@hotmail.com

This material is published by permission of United States Agency for International Development (USAID) Southern Africa under the President's Emergency Plan for AIDS Relief (PEPFAR) through Cooperative Agreement No. AID-674-A-12-00002 awarded to Tulane University. The United States Agency for International Development (USAID) Southern Africa retains for itself, and others acting on its behalf, a paid-up, non-exclusive, and irrevocable worldwide license in said article to reproduce, prepare derivative works, distribute copies to the public, and perform publicly and display publicly, by or on behalf of the Government.

children that may lose parents due to the disease. While a wealth of literature examines the impact of providing palliative care for PLWHA (Kipp, Matukala Nkosi, Laing, & Jhangri, 2006; Lee, Li, Jiraphongsa, & Rotheram-Borus, 2010; Lua & Mustapha, 2012; Orner, 2006; Pirraglia et al., 2005; Prachakul & Grant, 2003; Singh, Chaudoir, Escobar, & Kalichman, 2011), the field has been slower to recognize and document the unique challenges of caring for orphans.

As with caregiving for the chronically ill, the orphan caregiving role is born out of necessity (Raina et al., 2004). Parents pass away unexpectedly, and the vast majority of orphans (90%) are taken in by their extended family (Monasch & Boerma, 2004). Care for a dependent child encompasses a range of activities, including tending to their medical, financial and emotional needs. Importantly, orphans often have special needs that amplify demands on the caregiver: they are more likely to be HIV infected, to experience bereavement and AIDS-related stigma and to have emotional and behavioural problems (Cluver & Gardner, 2007; Cluver & Orkin, 2009; Govender, Penning, George, & Quinlan, 2011). Orphan caregivers also experience profound economic impacts, including heightened poverty and greater food insecurity (Heymann, Earle, Rajaraman, Miller, & Bogen, 2007; Kuo & Operario, 2010; Miller, Gruskin, Subramanian, Rajaraman, & Heymann, 2006). Extended family members have little to no formal training on how to deal with the additional challenges of caring for orphans and receive limited external support (Van Durme, Macq, Jeanmart, & Gobert, 2012). Some orphan caregivers are themselves HIV infected, adding additional strain to an already demanding role.

The concept of caregiver burden has already been adopted in rhetoric from the palliative care field (e.g., Bachman DeSilva et al., 2008; Govender et al., 2011; Ice, Sadruddin, Vagedes, Yogo, & Juma, 2012) and is an ideal lens through which to assess the orphan caregiver experience. The concept itself arose in the 1960s (Deeken, Taylor, Mangan, Yabroff, & Ingham, 2003), with research first focused on significant burden created by mental illness (Grad & Sainsbury, 1963; Hoenig & Hamilton, 1966). Caregiver burden is usually referred to as the physical, emotional, social and financial hardship associated with caregiving for an ailing or an elderly family member (Zarit, Reever, & Bach-Peterson, 1980). Since its introduction, many variations on this concept have been introduced to capture distinct dimensions of burden; we leave discussion of competing conceptualizations and associated measurement to other reviews (e.g., Carretero, Garcés, Ródenas, & Sanjosé, 2009; Chou, 2000; Deeken et al., 2003; Platt, 1985; Schene, Tessler, & Gamache, 1996). In its general conceptualization, caregiver burden encompasses both objective and subjective components (Sales, 2003; Schulze & Rössler, 2005), a distinction first made by Hoenig and Hamilton (1966). Objective components include the observable effects of caregiving activities (e.g., financial or social consequences). The subjective component refers to how the caregiver perceives his or her new role. As such, it can include feelings of distress, guilt or shame (Awad & Voruganti, 2008; Sales, 2003). Caregivers who perceive a higher burden are at risk for declining physical and mental health, as are those under their care (e.g., Etters, Goodall, & Harrison, 2008). Importantly, individuals adopting similar caregiving responsibilities demonstrate wide variability in burden. Over the last three decades, researchers have used the concept of caregiving burden to isolate important determinants of physical and mental health and intervene on the palliative caregiver's behalf. Characteristics of the caregiver and the patient, the material and social resources available, and the competing priorities have all been linked to variation in caregiver burden and associated adverse outcomes (Awad & Voruganti, 2008; Schulze & Rössler, 2005).

A similar literature around orphan caregiving is lacking. While recent research highlights the potential physical, social and mental health consequences of orphan caregiving (Bachman DeSilva et al., 2008; Govender et al., 2011; Ice, Yogo, Heh, & Juma, 2010; Kruger, LekalakalaMokgela, & Wentzel-Viljoen, 2011; Kuo & Operario, 2010; Kuo, Fitzgerald, Operario, & Casale, 2012; Littrell, Boris, Brown, Hill, & Macintyre, 2011), the concept of caregiving burden has yet to be applied. Caregiver burden may be an important tool for identifying who is able to cope with the demands of orphan caregiving and who is in need of immediate targeted support. This study begins building this evidence base by measuring the extent and determinants of burden among orphan caregivers in rural South Africa. The burden of orphan care is particularly salient in this context: South Africa has an HIV prevalence of 17% among adults and is home to over 2 million AIDS orphans (UNAIDS, 2013). As such, many families fostering orphans simultaneously experience other AIDS impacts (Bachman DeSilva et al., 2008; Govender et al., 2011) and we hypothesized that these impacts might exacerbate the burden of orphan caregiving. The continued rise in the number of orphans, combined with the profound consequences for caregiver well-being, makes a deeper understanding of the orphan caregiver experience essential. It is our hope that this information can be used to identify caregivers at risk and to intervene more swiftly and effectively.

Methods

This is a descriptive study using cross-sectional baseline data drawn from an on-going longitudinal evaluation of interventions for orphans and vulnerable adolescents in the Eastern Cape province of South Africa. The research protocol and instruments were approved by the ethical review committees at Tulane University in United States and at the Human Sciences Research Council in South Africa.

Sample

World Vision operates the *Networks of Hope* programme for orphan and vulnerable children (OVC) in the Eastern Cape. Services are primarily provided during home visits by a local volunteer and include psychosocial support for both the child and the caregiver. Volunteers also help build economic security by assisting with school fee waivers, grant applications and emergency food parcels.

All adolescents aged 14–17 years who were currently enrolled in the programme and their caregivers were eligible for study participation. Primary caregivers were defined as the parent or guardian who is responsible for the pre-selected adolescent's welfare; specifically the person who prepares meals, seeks medical attention when the adolescent is ill and otherwise cares for the adolescent. A total of 876 caregivers participated in the baseline survey in January–March 2012, completing face-to-face interviews at their home in Sesotho or Xhosa. The majority of caregivers (83%; 726) were fostering an orphan and the current analysis uses this subset.

Measures

Caregiver burden

There are many tools available to measure caregiving burden (Van Durme et al., 2012). To our knowledge, none have yet been applied to orphan caregivers. This study employed the Zarit Burden Interview (ZBI) (Zarit et al., 1980). The original 29-item ZBI was developed over 30 years ago and has since become one of the most commonly used tools for measuring caregiving burden. A 2012 review found that the ZBI had been cited 1081 times in Medline and translated into 18 different languages (Van Durme et al., 2012). It has previously been used in South Africa to measure burden among caregivers for PLWHA (Singh et al., 2011). We use a 12-item short-form version that demonstrates good psychometric properties and has been previously validated under both cross-sectional and longitudinal conditions (Bédard et al., 2001; Higginson, Gao, Jackson, Murray, & Harding, 2010; Van Durme et al., 2012), albeit with very different populations and contexts. Prior research has typically applied the scale with caregivers of patients with advanced disease (e.g., dementia and cancer); however, we theorize that the concept and manifestations of burden remain relevant to orphan caregivers in South Africa.

While many members of the family likely provide some elements of care and thus experience burden, it is important to create a sample that is homogeneous across salient domains (e.g., frequency and intimacy of contact and living in the same household), as recommended by Platt (1985). We focus on primary caregivers: the parent or guardian who is responsible for the pre-selected child's welfare; specifically the person who prepares meals, seeks medical attention when the child is ill and otherwise cares for the child. Thus, respondents were asked if they were the primary caregiver for any orphans, defined as a child that was not their biological child. Those who answered affirmatively were administered the short-form ZBI adapted to include references to orphan care rather than caring for chronically ill adults. The ZBI asks respondents to report how often care created a physical, social or psychological burden, and answers are recorded on a 5-point Likert scale ranging from never (0) to nearly always (4). Scores were summed to obtain a total score ranging from 0 to 48, with higher scores reflecting greater perceived burden. No formal threshold for the short-form ZBI exists to distinguish those experiencing high levels of burden. However, prior research suggested a threshold of 17 for the short-form ZBI might be appropriate (Bédard et al., 2001) and this approach is applied within our sample.

Potential determinants

Caregivers also reported on basic caregiver and household demographics, as well as specific measures of caregiver well-being. The choice of potential determinants was guided by a review of predictors of burden in other caregiving populations as well as conceptual consideration of unique challenges faced by orphan caregivers.

Caregiver demographic variables included age in years, gender, marital status (dichotomized living with a partner or not) and education level (coded as none, some primary and some secondary or higher). The survey also collected household demographics. Given the potential for the sheer volume of child dependents to overwhelm caregivers, the survey collected information on the household composition; two questions about the number of adult and child residents were then used to calculate a dependency ratio. Economic resources have been both shown to buffer the impact of caregiving and are a major challenge for the orphan caregiving population specifically. Monthly household income was measured in Rand (modelled per 1000R). Food security was measured using the 6-item Household Hunger Scale (Ballard, Coates, Swindale, & Deitchler, 2011). Based on the summed score, households were classified as having little to no hunger, moderate hunger or severe hunger. Neighbourhood type was dichotomized as rural village versus a rural township or commercial farm.

The survey also collected information on further AIDS impacts, as these may compound the challenges faced by orphan caregivers. Caregivers contending with their own AIDS-related illness may have fewer physical and emotional resources to devote to orphan care. Thus, caregivers indicating an illness of 3 months in a row or longer in the past 12 months were asked a series of dichotomous questions about AIDS-related signs and symptoms. This verbal autopsy was based on previous instruments (Cluver, Gardner, & Operario, 2007; Lopman, Barnabas, Boerma, Chawira, & Gaitskell, 2006) and asked whether or not the respondent had any of the following signs or symptoms that are common among patients with AIDS in the past 12 months: moderate or severe weight loss, chronic weakness, oedema of the legs, pale skin or rash, oral candidiasis, herpes zoster, respiratory tract infections, jaundice, chronic diarrhoea, sores and tuberculosis. Caregivers who reported three or more AIDS-related signs or symptoms were classified as AIDS-sick.

In high prevalence areas, caregiving for other family members with AIDS is also common and could compete with orphan caregiving responsibilities. Therefore, respondents were also asked whether any other family members had an illness of 3 months in a row or longer in the past 12 months. Finally, many orphan caregivers have recently lost adult children and other family members to AIDS, and their grief could influence how they perceive their caregiving role. To capture this potential determinant of burden, caregivers were asked to report whether there had been a death in the household during the past year.

Analyses

Data are described by calculating frequencies for categorical variables and means for continuous variables. Multivariate regression models were created to explore potential correlates of caregiver burden. The dependent variable (ZBI score) is count data with a Poisson distribution; thus, it was modelled using Poisson regression. Marginal effects, the amount of change in the original ZBI scale that would be predicted by the independent variable, are provided. Variables were entered in two stages: the first model includes only caregiver and household demographics and the second model adds likely AIDS impacts. Data were analysed using Stata version 10.1.

Results

Sample description

The demographic profile of orphan caregivers is provided in Table 1; we provide comparisons to the general population where possible below. Orphan caregivers had a mean age of 54.9 (SD 16.1) and were predominately female (92%). Most caregivers lived with a partner (72%), a substantially higher proportion than in the general population of the Eastern Cape (25%) (Statistics South Africa, 2012a). Most (91%) had at least some primary education, comparable to the provincial population (11%; EC census). On average, caregiver's households had 2.7 (SD 1.6) adults and 3.3 (SD 1.8) children, yielding a dependency ratio of 1.6 (SD 1.2) overall. Households were vulnerable, with almost a third (30%) experiencing moderate to severe hunger. While surveys of the general population have used different measures of food security, they similarly indicate hunger is widespread. For example, the 2012 General Household Survey found that 28% of households in the Eastern Cape had inadequate food access (Statistics South Africa, 2013). The average monthly income for our sample was R2565 (SD R2078); this

Table 1. Characteristics of orphan caregivers in Eastern Cape, South Africa (N = 726).

Caregiver level		
	N	%
Female	666	91.7
Married/partnered	520	71.7
Education		
No education	63	8.7
Some primary	370	51.0
Some secondary or higher	293	40.4
Food security		
Little to no hunger	510	70.3
Moderate hunger	173	23.9
Severe hunger	42	5.8
Potential AIDS-related illness	102	14.1
	Mean	SD
Age in years	54.9	16.1
Household level		
	N	%
Other adult chronic illness in household	135	18.6
Household death in past year	110	15.2
Rural village	683	94.1
	Mean	SD
Dependency ratio	1.6	1.2
Monthly income in Rand	2565.3	2077.6

compares to the provincial average of R5379 (Statistics South Africa, 2012a). The majority of households in our sample lived in a rural village, with only 6% living in townships or on a commercial farm.

In addition to fostering orphans, caregivers faced further challenges that were potentially related to the AIDS epidemic. First, illness was common among orphan caregivers, with 23% reporting a chronic illness for 3 months or longer in the past year. While province-specific statistics are not available, comparable national data indicate that 8% of the population reports suffering from a chronic illness (7% of men and 10% of women) (Statistics South Africa, 2012b); thus, this suggests a greater burden of illness among our caregiver population. While only 24 (3%) of caregivers self-reported as HIV-positive, 14% endorsed at least three signs or symptoms associated with AIDS-related illness. Second, many orphan caregivers had taken on dual caregiving responsibilities: 19% reported a chronically ill family member living in their home, most commonly an adult child or parent. Finally, 15% had experienced a household death in the last year; deaths were mostly among their children (33%), parents (20%) and siblings (14%).

The extent of caregiver burden

Orphan caregivers reported high levels of burden (mean 16.1, SD 8.4, and range 0–48). Using 17 as a cut-off for the ZBI, 40% of orphan caregivers can be classified as experiencing a high level of caregiving burden. Endorsement of specific items is described in Table 2. Feelings of inadequacy dominated: the majority of caregivers (79%) reported that they quite frequently or nearly always felt they should be doing

Table 2. Endorsement of caregiving burden scale items.

Orphan caregiving, N = 724, alpha = 0.82	Never/ rarely	Sometimes	Quite frequently/ nearly always
How often do you feel:	%	%	%
…that because of the time you spend with the orphaned child(ren) that you don't have enough time for yourself?	72	16	14
…stressed between caring for the orphaned child(ren) and trying to meet other responsibilities for your family or work?	57	20	23
…angry when you are around the orphaned child(ren)?	60	25	15
…that your care for the orphaned child(ren) currently affects your relationships with other family members or friends in a negative way?	77	14	9
…strained when caring for the orphaned child(ren)?	66	20	14
…your health has suffered because of your involvement with the orphaned child(ren)?	65	18	17
…that you don't have as much privacy as you would like because of the orphaned child(ren)?	79	10	11
…that your social life has suffered because you are caring for the orphaned child(ren)?	72	15	14
…you have lost control of your life since you began caring for the orphaned child(ren)?	74	14	12
…uncertain about what to do about the orphaned child(ren)?	78	13	9
….you should be doing more for the orphaned child(ren)?	11	10	79
….you could do a better job in caring for the orphaned child(ren)?	7	10	83

more for the orphaned child(ren) and 83% felt that they could do a better job in caring for the orphaned child(ren). The next most commonly endorsed ZBI item pertained to the stress that orphan care created around meeting other family/work responsibilities; 23% reported experiencing this quite frequently or nearly always and another 20% reported experiencing this sometimes. Feelings of anger towards the orphaned child were equally common. Results also highlight the potential impacts of orphan caregiving on their well-being: about a third reported that their physical health had suffered and nearly a quarter confirmed negative effects on their personal relationships and social life.

Factors associated with caregiver burden

In the multivariate regression controlling for basic caregiver and household demographics (see Model 1, Table 3), food insecurity was the most important predictor of orphan caregiving burden. Respondents reporting moderate hunger scored an average of 2.70 points higher ($p < 0.001$) on the orphan caregiving burden scale when compared with those reporting little to no hunger after adjustment for other factors; respondents reporting severe hunger scored 7.82 points higher ($p < 0.001$). Monthly household income was also a significant determinant: a gain of 1000R was associated with an increase of approximately half a point on the caregiver burden scale ($\beta = 0.44$, $p < 0.01$). No other caregiver (i.e., gender, age, partnership type and education) or household demographic factor (i.e., dependency ratio and neighbourhood type) was significantly associated with caregiver

Table 3. Marginal effects of caregiver and household factors regressed onto ZBI scores.

	Model (1)		Model (2)	
Independent variables	Marginal Effect	SE	Marginal Effect	SE
Caregiver and household demographics				
Female	−0.036	(1.10)	−0.14	(1.06)
Age in years	0.027	(0.024)	0.022	(0.025)
Married/partnered	0.16	(0.73)	0.12	(0.71)
Education				
None (ref)				
Some primary	1.51	(1.24)	1.91*	(1.16)
Some secondary or higher	1.47	(1.31)	1.81	(1.23)
Dependency ratio	0.23	(0.23)	0.21	(0.23)
Food insecurity				
Little to no hunger (ref)				
Moderate hunger	2.70***	(0.78)	2.26***	(0.78)
Severe hunger	7.82***	(1.25)	6.78***	(1.20)
Household income (per 1000 Rand)	0.44**	(0.18)	0.45***	(0.17)
Neighbourhood type				
Rural village (ref)				
Rural township/commercial farm	0.63	(2.04)	0.66	(1.98)
Potential AIDS-related impacts				
Caregiver AIDS-related illness			3.77***	(0.83)
Other adult chronic illness in household			0.65	(0.68)
Household death in past year			0.69	(0.83)
Observations	716		715	

Notes: Robust standard errors (SEs) in parentheses.
$^{***}p < 0.01$, $^{**}p < 0.05$, $^{*}p < 0.1$.

burden in Model 1; however, the positive association between caregiver education and high burden did reach significance in Model 2.

When other AIDS impacts were added to the model (see Model 2, Table 3), only the AIDS-related illness of the caregiver was significantly associated with burden ($\beta = 3.77$, $p < 0.001$); neither chronic illness among other family members nor a recent death in the household demonstrated a significant association.

Discussion

In the context of the AIDS epidemic, millions of orphans have been absorbed into extended families. While most families take on this role willingly, recent research suggests it comes with substantial adverse consequences for the primary caregiver, including higher perceived stress and depression, more chronic illness, worse nutrition and greater health declines over time (Bachman DeSilva et al., 2008; Govender et al., 2011; Ice et al., 2010; Kruger et al., 2011; Kuo & Operario, 2010; Kuo et al., 2012; Littrell et al., 2011). This study used a standardized measure of caregiving burden, adopted from the chronic illness literature, to capture how orphan caregivers perceive their new role and its impact across diverse areas of their lives. Results illuminate some of the challenges facing orphan caregivers, the stress that it brings to their lives and the potential detriments to their physical, mental and social well-being.

Overall, approximately 40% of our sample perceived a high burden associated with orphan caregiving. More specifically, caregivers in our sample reported feeling inadequate and angry when around orphaned children; this finding merits further investigation in light of the higher rates of physical and emotional abuse reported among orphans in South Africa (Cluver, Orkin, Boyes, Gardner, & Meinck, 2011; Gray et al., 2006). In the meantime, caregivers reporting feelings of inadequacy and anger towards the child may benefit from interventions focused on emotional support and parenting skills.

The determinants of caregiver burden are particularly relevant to service providers who must identify caregivers in need of immediate assistance and allocate limited resources effectively. Our findings suggest that households experiencing food insecurity and other economic stressors represent one high-risk group. Controlling for other caregiver and household factors, severe hunger was associated with an 8-point rise on the burden scale, almost a full standard deviation. Household income was also significantly associated with burden, though to a lesser degree. This is consistent with other studies reporting an association between economic vulnerability and heightened distress among orphan caregivers (Littrell et al., 2011).

It is important to note that this study took place in South Africa, which is unique in offering a range of social grants, and thus caregivers may have greater economic resources than those in neighbouring countries. Within South Africa, however, grant access is not universal: children who are orphaned, living in poverty or living in the Eastern Cape are most likely to be excluded (Bachman DeSilva et al., 2008; Case, Hosegood, & Lund, 2005; Sanfilippo, Neubourg, & Martorano, 2012). Programmes need to better facilitate grant access by providing information on eligibility, accompanying caregivers to court and social services, and advocating for administrative changes. Moreover, in countries where state social protection programmes are lacking, serious consideration should be given towards the adoption of direct cash transfers and emergency food aid.

The AIDS-related illness of the primary caregiver was also associated with heightened burden; neither chronic illness among other family members nor a recent death in the household demonstrated a similar association. Currently, palliative care and orphan care are usually served by different funding circles and thus operate as separate programmes. There have been repeated calls for better linkages between orphan care and palliative care programmes (Heymann & Kidman, 2009; Irwin, Adams, & Winter, 2009), and these findings reinforce this message. Early intervention should be targeted at dually affected caregivers and include both medical and psychosocial services, in an effort to alleviate burden. For more recommendations on how to reduce the caregiving burden associated with HIV/AIDS more generally, the authors refer programmers to a previous publication by UNAIDS (2008).

Attempts to alleviate burden within the orphan caregiving population are in their infancy. While the above recommendations are based on our empirical findings, the existing literature on caregiver burden in other populations also lends important lessons for future programming. Intervention research has highlighted both overall approaches and specific types of interventions that ease burden among palliative caregivers. For example, a meta-analysis of 24 interventions for dementia caregivers found that multicomponent interventions, rather than those with a single target, were more effective at reducing caregiver burden (Acton & Kang, 2001). Other proven interventions that may have relevance to orphan caregivers include training to increase knowledge and coping skills, increasing social contact and expanding links to social assistance programmes (Cooke, McNally, Mulligan, Harrison, & Newman, 2001; Schulze & Rössler, 2005). While most studies originate from the chronic disease literature in the western world, they none-the-less increase our general understanding of the caregiving process, its determinants and – most importantly – potential ways of mitigating burden.

Limitations

This study is largely descriptive in nature and draws exclusively on cross-sectional data. While it is important to be cognizant of the potential for reverse causality with AIDS-related factors, we expect this to be rare (e.g., it is unlikely that the burden of orphan caregiving leads to AIDS-related illness in caregivers). Another major limitation is the lack of generalizability. Specifically, caregivers were drawn from a rural population with access to both a comprehensive orphan care programme and South Africa's social assistance programmes; other orphan caregiving populations may differ substantially.

Finally, while the measurement of caregiving burden has been widely adopted in the chronic disease literature, this is its first appearance in the orphan caregiving field. The measure used, the ZBI, was originally developed for dementia caregivers and was not tailored to the specific challenges of orphan care in sub-Saharan Africa. Similarly, the threshold applied in the study was also established for use with a very different caregiving population and may require adjustment to better distinguish orphan caregivers at significant risk. While the internal consistency of the scale measured by cronbach's alpha was high (0.82) and comparable to that found in original validation study for the short-form ZBI (0.88) (Bédard et al., 2001), further assessments of the scale's validity in this context are warranted. Use by other researchers will help establish the instrument's potential utility in the field of orphan caregiving and highlight areas for refinement. A common, standardized measure of caregiver burden will enable comparisons across studies and may serve as an important determinant of well-being for both caregivers and the children under their care. The measure may also be a particularly useful tool for assessing intervention impact. We envision that the concept and measurement of caregiving burden could be applied to assess multifaceted interventions that seek to change a wide variety of factors (e.g., home visiting programmes that offer diffuse support across emotional, financial and social domains); other instruments might be better suited to evaluate interventions targeting a specific outcome (e.g., depression).

Conclusion

The orphan caregiver role can be challenging, identifying those individuals at high risk for adverse outcomes provides an opportunity for early intervention and support. The caregiving burden concept can help to define the scope of the challenge, highlight the modifiable risk factors and give practitioners useful direction for intervention design. Specifically, the current study suggests that caregivers with economic vulnerability and those grappling with their own illness feel most overburdened and should be targeted for immediate assistance.

Acknowledgements

Support for this project was provided by the United States Agency for International Development (USAID) Southern Africa under the President's Emergency Plan for AIDS Relief (PEPFAR) through Cooperative Agreement No. AID-674-A-12-00002 awarded to Tulane University. The views expressed in this document do not necessarily reflect those of USAID or the United States Government.

References

Acton, G.J., & Kang, J. (2001). Interventions to reduce the burden of caregiving for an adult with dementia: A meta-analysis. *Research in Nursing & Health, 24*(5), 349–360. doi:10.1002/nur.1036

Awad, A.G., & Voruganti, L.N.P. (2008). The burden of schizophrenia on caregivers: A review. *PharmacoEconomics, 26*(2), 149–162.

Bachman DeSilva, M., Beard, J., Cakwe, M., McCoy, K., Nkosi, B., Parikh, A., … Simon, J. (2008). Vulnerability of orphan caregivers vs. non-orphan caregivers in KwaZulu-Natal. *Vulnerable Children and Youth Studies, 3*(2), 102–111. doi:10.1080/17450120701868411

Ballard, T., Coates, J., Swindale, A., & Deitchler, M. (2011). *Household Hunger scale: Indicator definition and measurement guide*. Washington, DC: Food and Nutrition Technical Assistance II Project, FHI 360.

Bédard, M., Molloy, D.W., Squire, L., Dubois, S., Lever, J.A., & O'Donnell, M. (2001). The Zarit Burden interview: A new short version and screening version. *The Gerontologist, 41*(5), 652–657. doi:10.1093/geront/41.5.652

Carretero, S., Garcés, J., Ródenas, F., & Sanjosé, V. (2009). The informal caregiver's burden of dependent people: Theory and empirical review. *Archives of gerontology and geriatrics, 49*(1), 74–79. doi:10.1016/j.archger.2008.05.004

Case, A., Hosegood, V., & Lund, F. (2005). The reach and impact of child support grants: Evidence from KwaZulu-Natal. *Development Southern Africa, 22*(4), 467–482.

Chou, K.-R. (2000). Caregiver burden: A concept analysis. *Journal of Pediatric Nursing, 15*(6), 398–407. doi:10.1053/jpdn.2000.16709

Cluver, L., & Gardner, F. (2007). The mental health of children orphaned by AIDS: A review of international and southern African research. *Journal of Child and Adolescent Mental Health, 19*(1), 1–17.

Cluver, L., Gardner, F., & Operario, D. (2007). Psychological distress amongst AIDS-orphaned children in urban South Africa. *Journal of Child Psychology and Psychiatry, 48*(8), 755–763.

Cluver, L., & Orkin, M. (2009). Cumulative risk and AIDS-orphanhood: Interactions of stigma, bullying and poverty on child mental health in South Africa. *Social Science & Medicine, 69*(8), 1186–1193.

Cluver, L.P., Orkin, M.P., Boyes, M.P., Gardner, F.P., & Meinck, F.M. (2011). Transactional sex amongst AIDS-orphaned and AIDS-affected adolescents predicted by abuse and extreme poverty. *Journal of Acquired Immune Deficiency Syndrome, 58*(3), 334–343.

Cooke, D.D., McNally, L., Mulligan, K.T., Harrison, M.J.G., & Newman, S.P. (2001). Psychosocial interventions for caregivers of people with dementia: A systematic review. *Aging & Mental Health, 5*(2), 120–135. doi:10.1080/713650019

Deeken, J.F., Taylor, K.L., Mangan, P., Yabroff, K.R., & Ingham, J.M. (2003). Care for the caregivers: A review of self-report instruments developed to measure the burden, needs, and quality of life of informal caregivers. *Journal of Pain and Symptom Management, 26*(4), 922–953. doi:10.1016/S0885-3924(03)00327-0

Etters, L., Goodall, D., & Harrison, B.E. (2008). Caregiver burden among dementia patient caregivers: A review of the literature. *Journal of the American Academy of Nurse Practitioners, 20*(8), 423–428. doi:10.1111/j.1745-7599.2008.00342.x

Govender, K., Penning, S., George, G., & Quinlan, T. (2011). Weighing up the burden of care on caregivers of orphan children: The Amajuba district child health and wellbeing project, South Africa. *AIDS Care,* 1–10. doi:10.1080/09540121.2011.630455

Grad, J., & Sainsbury, P. (1963). Mental illness and the family. *The Lancet, 281*(7280), 544–547. doi:10.1016/S0140-6736(63)91339-4

Gray, G., Van Niekerk, R., Struthers, H., Violari, A., Martinson, N., McIntyre, J., & Naidu, V. (2006). The effects of adult morbidity and mortality on household welfare and the well-being of children in Soweto. *Vulnerable Children & Youth Studies, 1*(1), 15–28. doi:10.1080/17450120600659051

Heymann, J., Earle, A., Rajaraman, D., Miller, C., & Bogen, K. (2007). Extended family caring for children orphaned by AIDS: Balancing essential work and caregiving in a high HIV prevalence nations. *AIDS Care, 19*(3), 337–345.

Heymann, J., & Kidman, R. (2009). HIV/AIDS, declining family resources and the community safety net. *AIDS Care, 21*(sup1), 34–42. doi:10.1080/09540120902927593

Higginson, I.J., Gao, W., Jackson, D., Murray, J., & Harding, R. (2010). Short-form Zarit caregiver burden interviews were valid in advanced conditions. *Journal of Clinical Epidemiology, 63*(5), 535–542. doi:10.1016/j.jclinepi.2009.06.014

Hoenig, J., & Hamilton, M.W. (1966). The schizophrenic patient in the community and his effect on the household. *International Journal of Social Psychiatry, 12*(3), 165–176. doi:10.1177/002076406601200301

Ice, G.H., Sadruddin, A.F.A., Vagedes, A., Yogo, J., & Juma, E. (2012). Stress associated with caregiving: An examination of the stress process model among Kenyan Luo elders. *Social Science & Medicine, 74*(12), 2020–2027. doi:10.1016/j.socscimed.2012.02.018

Ice, G.H., Yogo, J., Heh, V., & Juma, E. (2010). The impact of caregiving on the health and well-being of Kenyan Luo grandparents. *Research on Aging, 32*(1), 40–66. doi:10.1177/0164027509348128

Irwin, A., Adams, A., & Winter, A. (2009). *Home truths: facing the facts on children, AIDS, and poverty: Joint learning initiative on children and HIV/AIDS*. Retrieved from http://www.ssrc.org/publications/view/home-truths-facing-the-facts-on-children-aids-and-poverty/.

Kipp, W., Matukala Nkosi, T., Laing, L., & Jhangri, G.S. (2006). Care burden and self-reported health status of informal women caregivers of HIV/AIDS patients in Kinshasa, Democratic Republic of Congo. *AIDS Care, 18*(7), 694–697. doi:10.1080/13548500500294401

Kruger, A., LekalakalaMokgela, S.E., & Wentzel-Viljoen, E. (2011). Rural and urban older African caregivers coping with HIV/AIDS are nutritionally compromised. *Journal of Nutrition in Gerontology and Geriatrics, 30*(3), 274–290. doi:10.1080/01639366.2010.528333

Kuo, C., Fitzgerald, J., Operario, D., & Casale, M. (2012). Social support disparities for caregivers o AIDS-orphaned children in South Africa. *Journal of Community Psychology, 40*(6), 631–644. doi:10.1002/jcop.20521

Kuo, C., & Operario, D. (2010). Caring for AIDS-orphaned children: An exploratory study of challenges faced by carers in KwaZulu-Natal, South Africa. *Vulnerable Children and Youth Studies, 5*(4), 344–352. doi:10.1080/17450128.2010.516372

Lee, S.-J., Li, L., Jiraphongsa, C., & Rotheram-Borus, M.J. (2010). Caregiver burden of family members of persons living with HIV in Thailand. *International Journal of Nursing Practice, 16*(1), 57–63. doi:10.1111/j.1440-172X.2009.01812.x

Littrell, M., Boris, N.W., Brown, L., Hill, M., & Macintyre, K. (2011). The influence of orphan care and other household shocks on health status over time: A longitudinal study of children's caregivers in rural Malawi. *AIDS Care, 23*(12), 1551–1561. doi:10.1080/09540121.2011.582079

Lopman, B.A., Barnabas, R.V., Boerma, J.T., Chawira, G., Gaitskell, K., Harrop, T., … Gregson, S. (2006). Creating and validating an algorithm to measure AIDS mortality in the adult population using verbal autopsy. *PLoS Medicine, 3*(8), e312.

Lua, P.L., & Mustapha, N. (2012). Mental health-related experiences and challenges of informal HIV/AIDS caregivers: A brief review and analysis. *ASEAN Journal of Psychiatry, 13*(2), 197–217.

Miller, C., Gruskin, S., Subramanian, S., Rajaraman, D., & Heymann, J. (2006). Orphan care in Botswana's working households: Growing responsibilities in the absence of adequate support. *American Journal of Public Health, 96*(8), 1429–1435.

Monasch, R., & Boerma, J. (2004). Orphanhood and childcare patterns in sub-Saharan Africa: An analysis of national surveys from 40 countries. *AIDS, 18*(Suppl2), S55–S65.

Orner, P. (2006). Psychosocial impacts on caregivers of people living with AIDS. *AIDS Care, 18*(3), 236–240. doi:10.1080/09540120500456565

Pirraglia, P.A., Bishop, D., Herman, D.S., Trisvan, E., Lopez, R.A., Torgersen, C.S., … Stein, M.D. (2005). Caregiver burden and depression among informal caregivers of HIV-infected individuals. *Journal of General Internal Medicine, 20*(6), 510–514. doi:10.1111/j.1525-1497.2005.0073.x

Platt, S. (1985). Measuring the burden of psychiatric illness on the family: An evaluation of some rating scales. *Psychological medicine, 15*(02), 383–393. doi:10.1017/S0033291700023680

Prachakul, W., & Grant, J.S. (2003). Informal caregivers of persons with HIV/AIDS: A review and analysis. *Journal of the Association of Nurses in AIDS Care, 14*(3), 55–71. doi:10.1177/1055329003014003005

Raina, P., O'Donnell, M., Schwellnus, H., Rosenbaum, P., King, G., Brehaut, J., … Wood, E. (2004). Caregiving process and caregiver burden: Conceptual models to guide research and practice. *BMC Pediatrics, 4*(1), 1.

Sales, E. (2003). Family burden and quality of life. *Quality of Life Research, 12*, 33.

Sanfilippo, M., Neubourg, C.D., & Martorano, B. (2012). *The impact of social protection on children: A review of the literature* (Working Paper 2012-06). Florence: UNICEF Office of Research.

Schene, A., Tessler, R., & Gamache, G. (1996). Instruments measuring family or caregiver burden in severe mental illness. In G. Thornicroft & M. Tansella (Eds.), *Mental health outcome measures* (pp. 53–73). Berlin: Springer.

Schulze, B., & Rössler, W. (2005). Caregiver burden in mental illness: Review of measurement, findings and interventions in 2004–2005. *Current Opinion in Psychiatry, 18*(6), 684–691.

Singh, D., Chaudoir, S.R., Escobar, M.C., & Kalichman, S. (2011). Stigma, burden, social support, and willingness to care among caregivers of PLWHA in home-based care in South Africa. *AIDS Care, 23*(7), 839–845. doi:10.1080/09540121.2010.542122

Statistics South Africa. (2012a). Census 2011 Municipal report – Eastern Cape. Pretoria: Author.

Statistics South Africa. (2012b). *Poverty profile of South Africa: Application of the poverty lines on the LCS 2008/2009*. Pretoria: Author.

Statistics South Africa. (2013). *General household survey*. Pretoria: Author.

UNAIDS. J. U. N. P. o. H. A. (2008). *Caregiving in the context of HIV/AIDS*. New York, NY: United Nations, Division for the Advancement of Women.

UNAIDS. (2013). *South Africa: HIV and AIDS estimates (2011)*. Retrieved March 1, 2013, from http://www.unaids.org/en/regionscountries/countries/southafrica/#1

Van Durme, T., Macq, J., Jeanmart, C., & Gobert, M. (2012). Tools for measuring the impact of informal caregiving of the elderly: A literature review. *International Journal of Nursing Studies, 49*(4), 490–504. doi:10.1016/j.ijnurstu.2011.10.011

Zarit, S.H., Reever, K.E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *The Gerontologist, 20*(6), 649–655. doi:10.1093/geront/20.6.649