Gogo *Care and Protection of Vulnerable Children in Rural Malawi: Changing Responsibilities, Capacity to Provide, and Implications for well-being in the Era of HIV and AIDS*

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ORIGINAL ARTICLE

Gogo Care and Protection of Vulnerable Children in Rural Malawi: Changing Responsibilities, Capacity to Provide, and Implications for well-being in the Era of HIV and AIDS

Megan Littrell · Laura Murphy · Moses Kumwenda · Kate Macintyre

Abstract The role of older women in the care and protection of vulnerable children in sub-Saharan Africa may be changing given increasing rates of orphanhood due to AIDS. Concern regarding their capacity to provide for children and implications for their health and well-being dominate the literature. However, studies have not yet examined the situation of older caregivers in comparison to their younger counterparts over time. In this study, panel data on 1,219 caregivers in rural Malawi between 2007 and 2009 is complemented by in-depth interview (N=62) and group discussion (N=4) data. Caregiver responsibilities, capacity to care for children, and implications for well-being are examined. Chi-square tests examine differences in these measures between older foster caregivers and younger foster caregivers, parents of orphans, and parents of non-orphans. Older women, in comparison with younger counterparts, are more stable as primary caregivers for orphans. Care by older women is particularly valued when younger family stability is threatened by burdens of orphan care. Qualitative data reveal many challenges that older caregivers face, most notably provision of food. However, survey data suggest that the capacity to provide food, schooling and other basic needs is similar among older and younger caregivers. Self-reported health status is generally poorer among older caregivers, however levels of emotional distress and social capital are similar among older and younger caregivers. Providing care for children in old age appears to entail a number of benefits. Older women committed to providing care and protection for children are important assets, particularly in the context of threats to child well-being due to HIV and AIDS. Bolstering older caregivers with material and social support to help sustain their key roles in fostering is a promising avenue for maintaining extended family responses to HIV and AIDS.

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Introduction

Extended family systems of care have positioned sub-Saharan African families to protect the millions of children orphaned by AIDS and other causes of young adult mortality by ensuring family-based care even in the face of large-scale loss of young parents (Ankrah 1993; Madhavan 2004; Nyamukapa and Gregson 2005). Among key caregivers within the extended family system for foster care, grandmothers are playing a substantial role in providing care for children in AIDS-affected settings (Freeman and Nkomo 2006; Schatz and Ogunmefun 2007; Zimmer and Dayton 2005). There is evidence that in some contexts, the role of older women is changing. The reasoning is that increasing numbers of AIDS orphans place burdens on older women who would traditionally be cared for at this time in their life, rather than take responsibility for the care of others. Foster care appears to be less consensual than in the past (Ansell and van Blerk 2004; Cattell 2008; Foster 2000; Madhavan 2004; Nyambedha *et al.* 2003; Oleke *et al.* 2005; Williams 2003).

In the context of what appears to be increasing burdens, there is concern that older caregivers may be less capable of providing for children's basic needs, and that caretaking responsibilities can be detrimental to caregiver health and well-being (Nyambedha *et al.* 2007; Ssengonzi 2007; WHO 2002). This paper contributes to these debates around the relative burden of care, capacity to provide, and well-being of older caregivers compared to their younger counterparts. The study draws from a unique set of panel data on older and younger caregivers in rural Malawi over a two-year period enriched by qualitative interviews and group discussions with older caregivers and community members. Older caregivers are defined as children's caregivers that are age 50 and above. This paper refers to this type of caregiver as "*gogo*"—the Chichewa word for older adult or grandparent, or as "grandmother" given the role that gender plays in caring for children and a relatively short length of generations in rural Malawi. Women are typically responsible for the day-to-day care and supervision of children in this context, and most young women in Malawi have made the transition to motherhood by age 25 (NSO & ORC Macro 2005). By age 50, many women are therefore transitioning or have already completed a transition from primary caregiver to grandmother. This study places the experience of *gogos* providing foster care in the context of younger caregivers who either care for foster children; care for their own orphaned children; or care exclusively for their own non-orphaned children. These typologies among younger caregivers are important to consider given the diversity of caregiving responsibilities among younger caregivers with potential implications for capacity to provide and caregiver well-being (Littrell *et al.* 2011). Comparing older foster caregivers with these younger caregiver typologies contextualizes their experience in relation to the spectrum of circumstances faced by caregivers in rural Malawi.

The role of older adults in care and protection of children

In many sub-Saharan African settings, grandmothers have historically been choice foster parents and have played substantial roles in care and protection of children even when mothers are living in the household (Bledsoe and Brandon 1992; Goody 1982). Children in grandparent care often have parents living elsewhere, although it is also not uncommon for other adults to co-reside with grandparent(s) and their grandchildren (Hosegood and Timaeus 2005; Zimmer and Dayton 2005). Despite the presence of co-resident adults,

grandmothers often serve as the primary caregivers for children. They also make important financial contributions to the household when they can access pension funds or other cash transfers targeting seniors (Kimuna and Makiwane 2007; Schatz and Ogunmefun 2007). In times of crisis, including the death of a young parent, grandmothers are viewed as natural and reliable primary caregivers, even more so in the absence of the biological mother (Knodel *et al.* 2003; Schatz 2007; Williams 2003). Care for orphans in non-parental care is most often provided by grandparents (Beegle *et al.* 2010; Monasch and Boerma 2004).

According to simulation models, the role of grandmothers in providing foster care due to family crisis may continue to increase due to AIDS epidemics (Clark 2006; Merli and Palloni 2006). Due to rising numbers of orphans, fostering appears to increasingly entail assumption of full responsibility for children with fewer traditional supports (Ansell and van Blerk 2004; Nyambedha *et al.* 2003; Oleke *et al.* 2005; Williams 2003). As a result, older caregivers appear to be facing new and intensifying challenges.

Challenges in providing care for children

Studies of older adult caregivers identify struggles in providing food and other basic household necessities for children (Muga and Onyango-Ouma 2009; Nyambedha *et al.* 2007; Schatz 2007; Ssengonzi 2007; Williams 2003). Older adult caregivers have trouble carrying out subsistence and income generating activities (i.e. farming) according to qualitative studies (Muga and Onyango-Ouma 2009; Nyambedha *et al.* 2007) and one quantitative study of time use and efficiency in production (Bock and Johnson 2008). Remittances from adult children are a key resource for older adults, and when these are lost due to adult child illness or death, challenges to providing for children are particularly strong (WHO 2002). Seeking social support from friends, neighbors and the church have been identified as coping strategies employed by grandmothers caring for children (Bohman *et al.* 2007; Oburu and Palmerus 2005). However, emerging evidence suggests that support for older caregivers from adult children and the wider social environment is inadequate (Cattell 2008; Nyambedha *et al.* 2007; Schatz 2007; Williams 2003a). Beyond family and community, government support is generally unavailable. However in countries with social pensions for older adults (South Africa, Namibia, Botswana, Mauritius and Lesotho), pensions are utilized by women to support other family members within their own households as well as non-residents (e.g. adult children that are unemployed) (Kimuna and Makiwane 2007; Schatz and Ogunmefun 2007).

Implications for caregiver well-being

Symptoms of emotional distress and poor self-reported health have been documented among older adults caring for ill adult children and/or orphans in Botswana (Thupayagale-Tshweneagae 2008); Uganda (Williams 2003; Ssengonzi 2007); Kenya (Oburu and Palmerus 2005; Nyambedha *et al.* 2007); Zimbabwe (Howard *et al.* 2006; WHO 2002); and Tanzania (Ainsworth and Dayton 2003). Distress seems to arise from anxiety over inability to provide a desired standard of care; burn-out and physical pressures of daily and parenting activities; a lack of adequate social support; and from sadness and/or grief over losing adult children to migration or to illness (Howard *et al.* 2006; Oburu and Palmerus 2005; Williams 2003). Poor self-reported physical health is reportedly linked with difficulty accessing medical care; poor nutrition, unhealthy environments and general aging; and to the burden of providing care for others (Ainsworth and Dayton 2003; Ice *et al.* 2008; Williams 2003).

Methods

Study setting

This study sheds light on caregivers in Malawi, a southern African country with an estimated adult HIV prevalence of 11.0 % and with an estimated 920,000 adults and children living with HIV in 2009 (UNAIDS 2010). Rates of orphanhood are increasing in Malawi (Beegle *et al.* 2010). The estimated number of orphans is over one million, half of whom were orphaned by AIDS (NAC 2008). Estimated numbers of orphans due to AIDS increased from 430,000 in 2001 to 650,000 in 2009 (UNAIDS 2010). Among all children under age 18, 12 % have lost their father, 6 % have lost their mother, and 4 % have lost both parents (NSO & ORC Macro 2005). National policy documents focus on the importance of older adults in providing care for children orphaned or made vulnerable by HIV and AIDS (MDPE 2008; MOGCCS 2005).

Design

This paper uses unique survey and interview data collected as part of an evaluation of the Orphan Support Africa (OSA) program in Malawi. Briefly, the OSA program provides support to community-based organizations (CBO) for activities to generate income to support orphans and vulnerable children. CBOs support families in a number of villages throughout a geographic region defined as a "group village" (see www.orphansupportafrica.org). Study districts include Nkhotakota, Dowa, Ntcheu and Mangochi located in the southern and central regions of the country. CBO catchment areas selected as study sites were randomly selected from among OSA-supported CBO catchment areas, so they represent the CBO catchment. Selected CBO catchment areas varied in size from six group villages in Nkhotakota and Mangochi to nine group villages in Ntcheu and 11 group villages in Dowa. Data to formally compare these CBO catchment areas with other communities in Malawi on key characteristics such as HIV and orphan prevalence are not available. However, observational data from field experience suggests that the CBO data are plausibly representative of much of rural Malawi. Nonetheless, the study sample cannot be considered nationally representative.

The longitudinal evaluation design followed a random selection of intervention households (slated for CBO support) and comparison households (not slated for CBO support) with at least one child under age 18. In each selected household, one primary caregiver completed a household roster, a household and caregiver well-being questionnaire, and a child well-being questionnaire. Of the 1,581 households that participated at baseline in 2007, 1,382 (87 %) were located and interviewed in 2009. Common reasons for loss to follow-up include: household dissolution (n=72); relocation (n=60); and household no longer contains children under age 18 (n=36). Household loss to follow up was not significantly more likely across baseline caregiver age (12 % of households with younger caregivers and 14 % of households with older caregivers were lost to follow-up) or orphan care (13 % of households without orphans and 12 % of household with orphans were lost to follow-up). Qualitative research activities were undertaken in 2008 to document program processes and program context, including exploration of orphan care and caregiver well-being with specific focus on older caregivers.

Participants

Among the 1,382 panel households, 1,219 interviewed in 2007 were re-interviewed in 2009 (88 %). Nearly all participants are female and 46 % were caring for orphans at

baseline. Baseline age ranges from 17 to 88 (mean=38; median=35). Qualitative study respondents included village headmen (n=20), CBO volunteers (n=29), CBO leaders (n=4) and female caregivers age 50 and older (n=9 IDI, n=31 participants in 4 group discussions). Discussion group respondents ranged in age from 52 to 90 (median=74) and were predominantly widowed or divorced (24 widowed, 2 divorced). All discussion group participants were caring for orphans. In depth interview participants ranged in age from 56 to 80 (median=73) and were predominantly widowed (n=7). The women were caring for orphans, and had one to nine children under the age of 18 in their care (median=3).

Procedures

Household survey At baseline in 2007, households in the intervention group were randomly sampled from a list of households slated by the four CBOs for support. The comparison group was randomly selected from households in the community that were not slated to receive CBO support. Household mapping and enumeration of approximately 15 households surrounding each selected intervention household was completed and a comparison household was randomly selected from these non-intervention households. All households selected for the comparison group were confirmed to be absent from CBO beneficiary lists before inclusion in the comparison group. Within each household, the primary caregiver of a randomly selected child under age 18 was interviewed. The household survey instrument included basic demographic information on household members and measures of well-being at household, caregiver and child levels. Data collection was completed during June, July and August, 2007. At follow-up, attempts were made to find all baseline households. Households included at follow-up contained member(s) listed on the baseline roster and at least one child under the age of 18. A primary caregiver of a newly selected child was interviewed. Data were collected during July, August and September, 2009. Data were double entered and validated using EpiData 3.1 (© EpiData Association, Odense Denmark).

Qualitative study The orientation of the qualitative study component is in line with application of rapid ethnographic methods utilized in public health assessment and programmatic research (e.g. Needle *et al.* 2003; Scrimshaw and Hurtado 1987; Scrimshaw and Gleason 1992). As such, this study utilized predetermined sample sizes, and data were collected within a relatively short period of time (two weeks) in July, 2008. A random sample of CBO volunteers and village headmen were selected from the CBO catchment area. A sample of women age 50 or above who were caring for orphans were purposively identified by the CBO to participate in individual interviews and group discussions. Interview guides containing program context domains with respect to norms and conditions of care for orphans and vulnerable children were utilized with village headmen and CBO leaders and volunteers. Interview guides focused on older adult caregiver roles, challenges, strategies and well-being were utilized with older female caregivers, CBO leaders and volunteers. Interviews and group discussions conducted in Chichewa were digitally recorded, translated and transcribed by trained research assistants.

All research activities operate under the approval and oversight of Institutional Review Boards at Tulane University and the University of Malawi. A standard informed consent form was read to all participants and verbal consent obtained prior to all interviews and group discussions. Refusal rates for all rounds of data collection were less than 1 %.

Measurement and analysis

Quantitative analysis Survey data analysis focused on differences between older and younger caregivers. Older caregivers were defined as caregivers age 50 and above. This is consistent with previous studies focused on older caregivers (Ainsworth and Dayton 2003; Bock and Johnson 2008; Ssengonzi 2007) and conceptual pieces (Knodel *et al.* 2003) including the World Health Organization (WHO 2002). WHO (2002) notes that the age of 50 emerged as criteria for older adults after discussion of the chronological, cultural and functional categorization of people as old, and considering the relative disadvantage in poorer countries that leads to premature aging. Indeed, female life expectancy in Malawi in 2008 was 54 (World Bank 2010).

Caregivers were classified according to baseline caregiving status as one of four caregiver types: 1) older caregivers engaged in foster care; 2) younger caregivers engaged in foster care; 3) younger caregivers without foster children that are biological parents to maternal or paternal orphans; and 4) younger caregivers without foster children with biological non-orphaned children only (see Table 1). These categories were created using data on children residing in the household including their relationship to the caregiver and parental survival status. Children were categorized as orphans (one or both parents have died) or non-orphans (neither parent has died). Where survival status was unknown, parent survival was treated as living (Rutstein 2008). Foster children are defined as non-biological children and include orphans and non-orphans.

Caretaking responsibilities focus on orphan and foster care. Shifts in orphan care over time were measured by comparing the number of orphans on the household listing in 2007 with 2009. In addition to providing foster care, an ongoing relationship with foster children's parents was examined. This relationship was operationalized by assessing parental contact with foster children, ranging from "sometimes," "often," or "never."

Capacity to provide for children was examined with respect to socioeconomic status, food security and children's school attendance. Socioeconomic status was assessed for each respondent relative to other respondents in the sample using measures of housing, water, sanitation and household asset items modeled after the Malawi 2004 Demographic and Health Survey (DHS). Wealth index items were assigned a weight through principal components analysis and standardized in relation to a standard normal distribution. Each respondent was then characterized according to this score as low, middle or high wealth

Table 1 Caregiver definitions according to the types of children in care[1]

	Non-biological children	Biological children	
	Orphan or non-orphan	Orphan	Non-orphan
Older caregivers—age 50 and above			
• Foster parent	Yes	Yes or No	Yes or No
Younger caregivers—age 17–49			
• Foster parent	Yes	Yes or No	Yes or No
• Biological parent to orphans, not providing foster care	No	Yes[2]	Yes or No
• Biological parent to non-orphans, not providing foster care	No	No	Yes

1 Orphans are children with one or both parents deceased. Non-orphans are children with two living parents

2 Children with one deceased parent cared for by the surviving parent

(Rutstein and Johnson 2004). Baseline and follow-up wealth indices were created and shifts in relative wealth were assessed by comparing change in categorization over time. Six items from the Food and Nutrition Technical Assistance Project (FANTA) Household Food Insecurity Access Scale for measurement of food access were utilized to assess food security. Three dichotomous variables were created indicating if the household had experienced separate domains of food insecurity: anxiety and uncertainty about household food supply; insufficient quality; and insufficient food intake and its physical consequences (Coates *et al.* 2006). Shifts in food security were measured by comparing change in these domains over time (absence to presence of food insecurity and vice versa). Caregivers were categorized as having a child age six to 17 that was not currently attending school or as having all children of school age in school using assessment of each child's school attendance (currently attending or not) measured in the household roster.

Three measures of caregiver well-being are considered: self-reported health status, emotional distress and social capital. Responses to a single-item self-reported health status question were collapsed into fair/poor and good/very good. Emotional distress was measured with seven scale items from the positive and negative feelings subscale of the World Health Organization Quality of Life-100 (WHO 1995). The Cronbach's alpha for the baseline scale is 0.83 indicating good internal consistency, and the distribution of the additive scale has a favorable amount of variation with a range of 0–28, mean of 13 and median of 12. Dichotomous measures indicating higher distress relative to others in the sample (above median) were created using baseline and follow-up scores. Three measures of social capital were utilized: perceived trust, perceived support, and received support. The first three measures were assessed using single item statements with four-point response scales measuring degree of agreement. Responses were collapsed to indicate agreement or disagreement. Received support was measured by assessing specific types of support received from friends or neighbors in the past 6 months. Responses were collapsed to indicate receipt of any type of support.

All data analyses were performed using Stata 11.0 (© Stata Corporation, College Station, Texas). Chi-square tests examined differences in caretaking responsibilities, capacity to provide for children, and caregiver well-being at baseline and change over time across caregiver type.

Qualitative analysis Group discussion and in-depth interview transcripts were analyzed using qualitative directed content analysis whereby transcripts were interrogated for specific (e.g. responsibilities, challenges, well-being) and emergent (e.g. caregiving benefits) themes (Hsieh and Shannon 2005). Data were organized by theme and respondent type using Microsoft Excel—useful for its capabilities to organize qualitative data in meaningful ways and for its functions that aid in analysis (Meyer and Avery 2009). Specifically, transcripts were entered into an Excel file by transferring each codable unit to a separate cell on a line with additional cells containing identifying information for the unit of text. This process of data organization allowed the analyst to become familiar with the transcripts and to refine the coding scheme based on the data. Each unit of text was then assigned codes and sub-codes which were entered in cells corresponding to the data. Excel's Data functions including Filter and Sort were used to organize data according to theme, review data within each assigned code, and make adjustments to coding. When coding was complete, a synthesis of data within each code was drafted. Patterns among themes and across types of respondents were identified and interpreted in the context of existing literature on the AIDS epidemic in rural Malawi and on the situation of older caregivers in other sub-Saharan Africa contexts.

Results

Panel household survey results

Characteristics and dynamics of caregiving arrangements In 2007, 18 % of all children in the full baseline sample had a caregiver age 50 and above (see Fig. 1). Older caregivers were responsible for half of all foster children and nearly half of all double orphans (46 %), one-third of maternal orphans (36 %), and one-fifth of paternal orphans (21 %).

Table 2 describes orphan care in 2007, 2009 and change over time among caregivers who were classified as older foster caregivers, younger foster caregivers, younger biological parents to orphans, or younger biological parents to non-orphans in 2007. Levels of orphan care among older and younger foster caregivers in 2007 were similar (71 % versus 78 %). However, while this level of orphan care was largely maintained over time among older foster caregivers, orphan care dropped among younger foster caregivers. In 2009, 68 % of 2007 foster caregivers had orphans as compared with just 50 % of 2007 younger foster caregivers (χ^2=18.22, p<0.001). Within caregiver patterns of change show greater stability in the orphan caregiver role among older versus younger foster caregivers (χ^2=31.78, p<0.001). Specifically, one-third of 2007 younger foster caregivers had orphans in 2007 and were no longer engaged in orphan care in 2009, as compared with 12 % of older foster caregivers (see Table 2).

Among 2007 younger biological parents to orphans, 25 % were no longer caring for orphans in 2009, and 23 % had decreased the number of orphans in their care. About 8 % of younger caregivers without orphans in 2007 had orphans at follow-up in 2009 (see Table 2).

The burdens of providing foster care can be shared through remittances and other material support as well as emotional support received from foster children's parents. The potential for support—as measured through contact with foster children's parents—is presented in Table 3. Parental contact does not differ significantly between younger and older caregivers in 2007. Overall, a complete lack of contact with foster children's parents (due to death of the parent(s) or other reasons) was most commonly reported among both older (45 %) and younger (51 %) caregivers. In 2009, patterns of parental contact were significantly different among 2007-classified older versus younger foster caregivers (χ^2=82.70, p<0.001). This difference is largely driven by the fact that in 2009, 45 % of younger foster caregivers no longer had foster children in care as compared with 9 % of older foster caregivers. Similar to baseline, 47 % of older caregivers still had foster children in care with no parental contact as compared with just 26 % of younger foster caregivers (see Table 3).

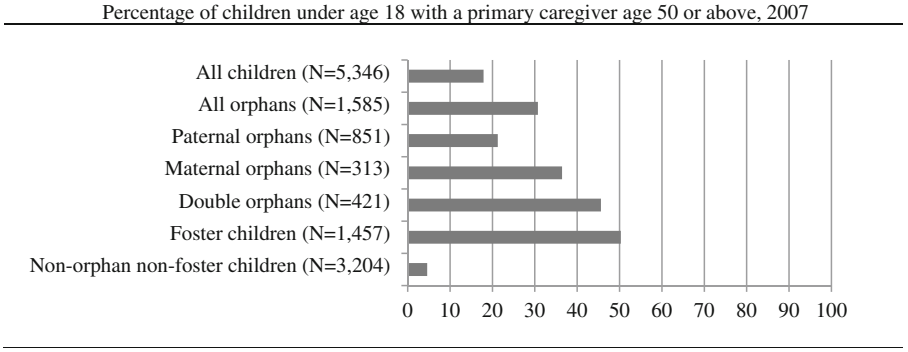

Fig. 1 Percentage of children under age 18 with a primary caregiver age 50 or above, 2007

Table 2 Baseline, follow-up and change in orphan care among older and younger caregivers with foster children, younger biological parents of orphans, and younger biological parents of non-orphans only, 2007–2009

	Older foster caregiver in 2007 (n=224)	Younger foster caregiver in 2007 (n=301)	χ^2	Younger biological parent of orphans in 2007 (n=147)	Younger biological parent of non-orphans in 2007 (n=521)
% Orphan care 2007	71.4	78.1	3.04	100.0	0.0
% Orphan care 2009	68.8	50.2	18.22***	75.5	8.1
Orphan care 2007–2009					
% Maintained	46.4	37.9		35.4	91.9
% Increased # orphans	13.4	9.6		17.0	0.0
% Decreased # orphans	18.8	15.3		23.1	0.0
% No longer caregiver	12.1	32.6		24.5	0.0
% Became caregiver	9.4	4.7	31.78***	0.0	8.1

* p<0.05 ** p<0.01 *** p<0.001

Capacity to provide among older versus younger caregivers Table 4 compares capacity to provide for children's basic needs among older foster caregivers, younger foster caregivers, younger biological parents to orphans, and younger biological parents to non-orphans (classified according to 2007 status). Relative household wealth differed significantly across baseline caregiver categories in 2007 (χ^2=30.47, p<0.001) (see Table 4). At baseline, half of younger parents to orphans were in the poorest wealth category at baseline as compared with 34 % of older foster caregivers; 30 % of younger foster caregivers; and 31 % of younger parents to non-orphans.

Table 3 Baseline and follow-up contact with foster children's parents among older and younger caregivers with foster children, 2007–2009

	Older foster caregiver in 2007	Younger foster caregiver in 2007	χ^2
2007 parental contact	(n=220)	(n=295)	
% Often	32.7	28.8	
% Sometimes	22.3	20.0	
% Never	45.0	51.2	1.94
2009 parental contact	(n=223)	(n=299)	
% Often	28.7	18.1	
% Sometimes	16.1	10.4	
% Never	46.6	26.4	
% No longer fostering	8.5	45.2	82.70***

* p<0.05 ** p<0.01 *** p<0.001

Table 4 Baseline and change over time in household wealth, food security and children's school attendance among older and younger caregivers with foster children, younger biological parents of orphans, and younger biological parents of non-orphans only, 2007–2009

	Older foster caregiver in 2007 (n=224)	Younger foster caregiver in 2007 (n=301)	Younger biological parent of orphans in 2007 (n=147)	Younger biological parent of non-orphans in 2007 (n=521)	χ^2
Wealth 2007					
% Poor	33.93	30.23	50.34	30.90	
% Middle	29.02	31.23	25.17	38.20	
% High	37.05	38.54	24.49	30.90	30.47***
Wealth 2007–09					
%Maintain	61.61	55.81	66.67	55.66	
% Richer	16.52	23.92	19.73	21.50	
% Poorer	21.88	20.27	13.61	22.84	11.52
% Insufficient food quality 2007	78.57	76.74	78.91	71.98	5.75
Food quality 2007–09					
% Maintain	64.73	66.11	70.07	64.30	
% Became insecure	11.16	12.62	9.52	13.82	
% Became secure	24.11	21.26	20.41	21.88	3.41
% Insufficient food quantity 2007	60.27	56.81	58.50	51.44	6.27
Food quantity 2007–09					
%Maintain	60.27	67.77	59.86	60.08	
% Became insecure	17.86	17.28	19.05	22.07	
% Became secure	21.88	14.95	21.09	17.85	9.05
% Child out of school 2007	33.04	36.21	30.61	23.42	17.27**
Child out of school 2007–09					
% Maintain	67.86	66.11	65.31	70.83	
% Gained	14.73	16.28	17.69	17.27	
% No longer	17.41	17.61	17.01	11.90	7.59

* p<0.05 ** p<0.01 *** p<0.001

More than half of all caregivers maintained their relative socioeconomic status over time and there are no significant differences in shifts in socioeconomic status across caregiver groups. There are no significant differences in food security measures of insufficient food quality and quantity across baseline caregiver categories in 2007, 2009, or in patterns of change over time. Frequency of having a school-age child that is not attending school is significantly different across baseline caregiver categories in 2007 (χ^2=17.27, p<0.01), but not with respect to change over time. In 2007, 23 % of caregivers of non-orphan biological children had a child age six to 17 that was not

attending school as compared with 33 % of older foster caregivers, 36 % of younger foster caregivers and 31 % of younger parents of orphans (see Table 4).

Caregiver well-being: emotional, physical and social health Table 5 compares measures of well-being among older foster caregivers, younger foster caregivers, younger biological parents to orphans and younger biological parents to non-orphans (according to baseline status). Frequency of poor self-reported health was significantly different across caregiver groups at baseline (χ^2=89.94, p<0.001) and with respect to change over time (χ^2=19.91, p<0.01) (see Table 5). Older foster caregivers had highest levels of poor health in 2007 (47 %) as compared with younger foster caregivers (28 %), younger parents to orphans (20 % and younger parents to non-orphans (15 %). Over

Table 5 Baseline and change over time in well-being among older and younger caregivers with foster children, younger biological parents of orphans, and younger biological parents of non-orphans only, 2007–2009

	Older foster caregiver in 2007 (n=224)	Younger foster caregiver in 2007 (n=301)	Younger biological parent of orphans in 2007 (n=147)	Younger biological parent of non-orphans in 2007 (n=521)	χ^2
% Poor health 2007	47.77	27.91	20.41	15.38	89.94***
Health 2007–2009					
%Maintained	64.73	67.77	75.51	76.73	
% Poorer	17.86	16.61	10.20	14.23	
%Better	17.41	15.61	14.29	9.04	19.91**
% Higher distress 2007	56.70	53.82	50.34	41.27	20.55***
Distress 2007–09					
% Maintained	63.84	52.82	58.50	60.65	
% Higher	17.86	21.93	22.45	20.54	
% Lower	18.30	25.25	19.05	18.81	9.14
% Trust 2007	84.38	83.06	75.34	77.88	7.89*
Trust 2007–09					
% Maintained	74.55	68.11	65.07	65.96	
% Gained	11.16	8.64	17.12	13.65	
% Lost	14.29	23.26	17.81	20.38	14.61*
% Perceived support 2007	72.77	69.44	71.92	77.31	6.67
Perceived support 2007–09					
% Maintained	65.63	51.83	59.59	57.31	
% Gained	12.50	15.95	17.81	11.54	
% Lost	21.88	32.23	22.60	31.15	17.22**
% Received support 2007	71.88	63.79	71.43	67.18	4.89
Received support 2007–09					
% Maintained	45.09	46.84	46.94	47.60	
% Gained	11.61	11.63	6.80	8.64	
% Lost	43.30	41.53	46.26	43.76	4.61

* p<0.05 ** p<0.01 *** p<0.001

time, older and younger foster caregivers are less likely to maintain health status (65 % and 68 % respectively) as compared with younger parents to orphans (76 %) and younger parents to non-orphans (77 %). However, a consistent pattern of declining or improving health is not evident: 18 % of older foster caregivers shift from good to poor health and 17 % from poor to good health; and 17 % of younger foster caregivers shift from good to poor health and 16 % from poor to good health (see Table 5).

Frequency of higher emotional distress was significantly different across caregiver groups in 2007 (χ^2=20.55, p<0.001) but not with respect to change over time. In 2007, younger parents to non-orphans had lowest levels of relatively high emotional distress (41 %) as compared with younger parents to orphans (50 %); younger foster caregivers (54 %); and older foster caregivers (57 %). Between 53 % (younger foster) and 64 % (older foster) of caregivers maintained distress levels over time, and there is lack of a consistent pattern of increasing or decreasing stress across caregiver groups (see Table 5).

Caregivers in rural Malawi generally report high levels of perceived and received support, and there is no significant difference in these measures of social capital across caregiver groups at baseline. While a loss of a sense of perceived support over time was common among younger foster caregivers, it was less common among older caregivers. Over time, 32 % of younger foster caregivers lost a sense of perceived support while 16 % gained, and similarly 31 % of parents of non-orphans experienced a loss and 12 % a gain. These levels are higher in comparison with older foster caregivers (22 % loss, 13 % gain) and younger parents to orphans (23 % loss, 18 % gain) In 2007, perceived trust was highest among older (84 %) and younger (83 %) foster caregivers in comparison with 75 % of parents to orphans and 78 % of parents to non-orphans. However, younger foster caregivers were less likely to maintain this sense of trust over time (68 % maintain, 23 % loss, 9 % gain) in relation to older caregivers (75 % maintain, 14 % loss, 11 % gain) (see Table 5).

Qualitative study results

This section presents qualitative results beginning with findings related to the roles and responsibilities of grandmothers in rural Malawi followed by challenges that they reportedly face and benefits that come with the primary caregiver role.

"Go to the gogo and try some care there" In the Chichewa language, older men and women are referred to and refer to themselves as *gogo*; qualitative data confirm that the term typically refers to people age 50 and above. Respondents characterized the role of female *gogo* as one of protecting children from harm; narratives on how and why older women came to be caring for children highlighted the social problems that put children at risk and the role that these women are expected to play in protecting children in such circumstances. Older women described a sense of peace knowing that children in their care are not at risk for abuse or neglect at the hands of others including parents or foster caregivers. As a CBO volunteer explained, "If the children are suffering in the family, we think they should go to the *gogo* and try some care there [sic]" (Nkhotakota volunteer IDI 1). Grandmothers protect children from the neglect that they may experience when mothers remarry husbands that are unwilling to provide adequately for stepchildren, or when children are placed with younger aunts and uncles who are already struggling to provide for their own children.

"I cannot raise another man's child" Children are at risk of maltreatment for a number of reasons; most commonly discussed were divorce and parental death. In the event of divorce

or death of one parent, remarriage is highly likely, yet children from previous marriages are often unwelcome in the new home. The role of grandmothers in cases of remarriage is to protect children by serving in the primary caregiver role. An Nkhotakota caregiver explained, "If my daughter remarries after her husband has died, she cannot go there with her children because her new husband will not take care of them. This is why we insist to take the children. Those children are neglected when they go there because the new husband says 'I cannot raise another man's child'" (Nkhotakota GD 4). A vibrant discussion ensued around this topic during the group discussion in Ntcheu District. One respondent put forth, "It is very difficult for men to take care of another man's children. To go to the market and buy his meat then see many people eating on the same plate. It cannot happen. The marriage can end because of this… Should I be buying meat and you should be feeding your children instead of me?" (R2). Respondents chimed in, "Mine should die of hunger while yours are eating my meat?! All these children of yours, should I be the one to feed them? You will see that the family has ended" (R8). Another respondent confirmed, "In order for you to prevent the family from ending, you just say 'I should just take care of these children" (R3, Ntcheu, GD).

"It is the gogo who provides care when children are sick" The role that older women typically play in caring for children can serve as a conduit for material support from relatives, particularly adult children. Material support provided by adult children and other relatives can be a key to survival and capacity to provide for children in cases where older adults lack physical strength to cultivate or engage in manual labor, or when they lack adequate land and/or farm inputs. Where support from the parents of children in care is not possible due to death, divorce or other family crises, support may come from other adult children that are aunts and uncles to children in grandmother's care. In fact, while these aunts and uncles may be hesitant to take nieces and nephews into their homes due to existing strain on household resources, they may find it feasible to support the children and their grandmother as a unit. The CBO leader in Dowa explained this delineation of different support roles: "When the uncles help their parents, the orphans are also helped at the same time. But it is the *gogo* who provides care when children are sick or need a bath."

"You don't find a gogo here living alone." Older women in rural Malawi are expected to be residing with children. Many respondents did not know of older women living alone, and others said that an older woman living alone would be viewed with suspicion; could be accused of bewitching relatives; could have experienced rejection by children or grandchildren; or is selfish or too harsh with children. As an Nkhotakota volunteer explained, "The *gogo* is sometimes condemned, but it's a general trend here to expect that *gogos* should have children. You don't find a *gogo* here living alone, she is supposed to help children." Since it is not good for older women to live alone, they might be sent a child from a healthy intact household. As a volunteer in Dowa explained, "Sometimes the *gogo* can go to one of her daughters or sons to ask for a grandchild because maybe she is weak and unable to farm. It is the responsibility of those parents to provide some support in terms of giving a daughter or a son."

"How can I go on feeding the children?" Faced with the task of providing for children's basic needs, older women are often described and self-identify as weak or small in a context where physical labor is required for subsistence farming and casual labor. The challenge of providing food was most commonly discussed. Caregivers repeatedly voiced anxiety and sadness over not being able to adequately feed children. One Mangochi caregiver explained,

"What I worry of is how I can go on feeding the children" (Mangochi caregiver IDI 2). While lack of physical strength is a barrier to food production, more often the prohibitive cost of fertilizer is lamented, as in this group discussion in Ntcheu. The interviewer posted the question: How does the worry come with regard to food?

> R4: It comes because of the inadequacy of the food… [due to] lack of fertilizer. R8: Nowadays farming requires medicine. In the past we were just farming without fertilizer. R2: But now, without fertilizer, when you plant crops you will harvest very little. This makes you worry about what you will do to feed the children (Ntcheu FGD).

Inadequate yields mean that other strategies are necessary for earning food, income and other necessities, especially given the small plots of land left to older caregivers after land redistribution to adult children. Some rely on *ganyu*—informal work undertaken to earn food and/or cash for survival, ranging from work on agricultural estates to short term exchanges of labor for food or wages (Whiteside 2000). Although many people in Malawi engage in *ganyu*, it is to some extent shameful as it is an admission of poverty and sign that the household does not have any food (Whiteside 2000). Short term agricultural work is often in exchange for small portions of maize flour. An Ntcheu caregiver explained taking on *ganyu* to meet basic needs for that particular day.

> Sometimes we do *ganyu* in the gardens of some people. When you do that, they can give you a plate of maize flour. You come with it to cook for the children. You will see that they are leaving to play, the following day you do the same (Ntcheu GD 2).

Caregiving in the era of HIV and AIDS Respondents were asked to comment on how life for older women is different today than it was in the past (in the time of their grandmothers). Today, more grandmothers face the death of their adult children, and older women are finding themselves caring for larger numbers of orphans. As one caregiver explained, "One daughter will leave you and while you are thinking of taking some of her children to care, you will see that another one is also leaving. Leaving all their responsibilities to us at a time when we don't have the energy" (Ntcheu GD 3).

Fostering orphaned children—in particular those that have lost both parents—is particularly stressful for older women, and is a situation that is increasing due to AIDS. The stress of orphan care arises primarily from lack of support from children's parents. For fostering grandmothers, the child's parents are a key source of material and emotional support. When parents pass away, older women face all responsibilities alone. Grandmothers that had lost children who were previously key supports expressed feeling overwhelmed and alone. A caregiver in Nkhotakota explained, "Everything is a problem when one is taking care of orphans because you can't look up to someone when you have problems" (Nkhotakhota caregiver IDI 2). Even when a surviving parent may not provide support on a regular basis, the fact that he or she is still alive and can be petitioned for help as needed is important.

> It is very difficult for a *gogo* to look after an orphan that lost both parents. If one parent is alive, that parent may at times remember to bring some items to the child. Although that may be here or there, they can still bring a little bit of help. While one that has no parent, the *gogo* has to do everything alone. If a sickness comes, food shortage comes, any challenge has to be solved by the *gogo*. While if there is a parent, a message can be sent that the child needs help and they can at times help them (Nkhotakota volunteer IDI 2).

"Every day is full of worries" Older caregivers described stress in the form of "thinking too much" about inability to provide for children, particularly being able to provide food but also providing school fees and materials; blankets and clothing; and soap for bathing and cleaning clothes. A Mangochi caregiver explained, "Every day is full of worries because we think of what children are going to eat or how they are going to be taken care of" (Mangochi GD 8). An inability to provide for children's basic needs can lead to feelings of defeat. As an Ntcheu caregiver said, "I don't have the energy to take care of these children. I fail to provide everything that these children need. I fail to do that and sometimes you feel that your heart is already dead" (Ntcheu caregiver IDI 1). Another source of distress is the memory of an adult child that has passed away. A volunteer in Mangochi, explained "If the *gogo* is living with an orphan, those orphans always remind the *gogo* of their child. She will keep remembering and thinking 'if only I had my child, they could come help me care for these grandchildren."

Physical health impacts were more often described as "reduced power" or weakness rather than as specific health problems. Most commonly, implications of the caregiving role for physical health were attributed to caregiver stress about being able to provide for children. However, some respondents spoke of change in physical health that arises from physical burdens of work to provide for the children including maintaining the household (e.g. fetching water, cooking, bathing children) as well as engaging in labor to feed and support the children. For example, one CBO leader explained health deterioration that occurs when several children come to stay in the household, "Because at first she [*gogo*] was doing, I can say, a small job, but when the family is big, she has a big job. So power [health] can reduce" (Ntcheu CBO leader IDI). The link to reduced physical health was also made through caregiver sacrifice of her own food intake to feed the children.

"I am doing a good job" Despite the hardships and struggles, caring for older children provides benefits for older caregivers. Grandmothers describe the joy and pride that comes with managing to support children and nurture their development. Caring for children can provide a sense of purpose. A CBO volunteer in Dowa who is also a grandmother caring for grandchildren expressed a sense of purpose when she said, "We ask God to please give us a long life because if we die, these children will have nowhere to go. I am given a long life so I can care for these children (Dowa volunteer IDI 1)" An Ntcheu caregiver explained, "When they [children] go out to play with their friends and come back, they find that I am here. When I go to the garden, I find that they have fetched the water and they are growing up while they are with me. This makes me satisfied that I am doing a good job" (Ntcheu caregiver IDI 1).

Discussion

Roles and responsibilities of older caregivers

Contemporary concern with grandmothers' role in the context of HIV and AIDS has lead to the assertion in some contexts that older women are caregivers of "last resort" who surrender a peaceful retirement for the burdens of childcare (see review by Foster 2000). Results from this study suggest that older women are perhaps the best solution in difficult circumstances to ensure protection of children at risk for neglect or abuse. Where family crises including parental death, divorce and remarriage threaten children's well-being, grandmothers are viewed as important resources (Knodel *et al.* 2003; Schatz 2007; Williams 2003).

Panel data from this study suggest that in comparison with younger foster caregivers, older caregivers are more stable in the role as primary caregiver to orphaned and foster children over a two-year period. Younger caregivers appear to be more likely to serve in relatively temporary roles both as foster caregivers as well as primary caregivers to their own orphaned children. Most commonly, orphaned children in Malawi have lost their father but not their mother (NSO & ORC Macro 2005), and panel data from this study show that young widows often send all orphans to another household over time or reduce the number of orphans in care. Previous studies have documented the financial struggle that families face in providing for orphans (Deininger *et al.* 2003; Howard *et al.* 2006; Miller *et al.* 2006). Respondents in this study echoed these struggles, suggesting that the reason for more temporary foster and orphan care among younger families is because of difficulties faced in taking on such responsibilities. Taking on care for foster children is difficult when many young families face challenges in meeting the basic needs of their own children. Additionally, when young widows remarry, stepfathers may be reluctant to take on responsibility for providing and caring for stepchildren. Older caregivers play a particularly important role in care for double and maternal orphans. Results suggest that nearly half of all double and over a third of all maternal orphans are cared for by older caregivers. Similar to studies in other AIDS-affected settings, older caregivers reported that AIDS appears to be increasing the number of orphans that need grandparent care, and that providing for children without living parent(s) to petition for support is particularly difficult (Ansell and van Blerk 2004; Nyambedha *et al.* 2003, 2007; Williams 2003). This study finds that both older and younger foster caregivers take up the most challenging foster roles; at baseline about half of foster caregivers were providing for children lacking any sort of relationship with biological parents. However, it is older caregivers who endure such challenging roles over time. They maintain care for children cut off from parental support over time whereas younger foster caregivers are more likely to discontinue providing for such children.

Capacity to provide

Qualitative results highlight many of challenges in providing for children's basic needs that have been identified in studies of older caregivers in other settings (Bock and Johnson 2008; Muga and Onyango-Ouma 2009; Nyambedha *et al.* 2007; Schatz 2007; Ssengonzi 2007; WHO 2002; Williams 2003). However, whereas previous studies did not include comparison of challenges faced by older versus younger caregivers, survey data from this study allowed for such comparison. Results suggest that the capacity of older foster caregivers to provide for children's basic needs including food and schooling does not differ significantly from the capacity of younger caregivers—including those with foster children, orphans, or simply their own biological children. With respect to relative socioeconomic status, evidence suggests that it is younger parents to orphans that struggle in relation to older caregivers and other younger caregivers. Furthermore, results over time suggest that older caregivers do not face particularly higher frequency of declines in relative socioeconomic status or food security relative to younger caregivers.

In rural Malawi, as in other sub-Saharan Africa contexts, there are many challenges to providing for the needs of children and families. Food insecurity is a chronic and widespread problem in Malawi (Conroy *et al.* 2006; Mandala 2005). Triangulation of data suggest that the challenges in providing for children that emerged from the qualitative data, most salient of which was providing food, afflict many caregivers in rural Malawi. Inadequate yields due to subsistence farming on very small plots of land and declines in soil fertility requiring expensive fertilizers are challenges faced by much of the rural population (Conroy *et al.*

2006; UNICEF 2001). While the physical demands of cultivation may be more intense for older caregivers, their capacity to provide food for children appears similar to that of younger caregivers. Evidently, additional mechanisms are in place to support older people. For example, Whiteside (2000) writes that while they have limited physical capacity, older people in Malawi may be given *ganyu* (informal work) in exchange for food on relatively easy terms out of kindness. Direct support from friends and family may also be an important mechanism for some older caregivers, although this type of received support is reportedly equally common among younger caregivers.

Implications for caregiver well-being

Older caregivers often report suffering poor health. This is to be expected given medical problems due to aging and a poor diet that is common among elders in sub-Saharan Africa (Kimokoti and Hamer 2008). Older caregivers experience a frequency of emotional distress that is similar to younger foster caregivers and to younger parents of orphans, but all of these have higher frequency of high distress than younger parents to non-orphans. Previous studies focused on older caregivers highlight their distress and isolation (Nyambedha *et al.* 2007; Oburu and Palmerus 2005; Ssengonzi 2007; Thupayagale-Tshweneagae 2008). This study finds no significant difference in changing distress levels over time and caregiver age. These results support the notion that older caregivers do not necessarily suffer more distress and isolation than younger caregivers, including those younger caregivers facing similar fostering circumstances and those caring for their own orphaned or non-orphaned children. In fact, older caregivers experienced relatively high levels of perceived trust that were maintained over time. High levels of perceived and received support were common across caregiver groups at baseline, however older caregivers maintained the perception of support over time to a greater extent than their younger foster caregiver counterparts.

Researchers and policy makers suspect that status, kinship support and living conditions among elderly in sub-Saharan Africa are declining due to modernization, migration, economic conditions and HIV and AIDS (Cattell 2008; Cohen and Menken 2006; Kazeze 2008; Kimokoti and Hamer 2008; MDPE 2008). This study provides evidence that the primary caregiver role may buffer these declines. Life in rural Malawi is arduous and social and economic conditions insecure. Serving as a caregiver may provide tangible and intangible support, status and a sense of purpose that can buffer older adults from declines in mental and social health over time. Further studies that expand the older adult sample to include those that do not serve in the primary caregiver role are needed to better understand caregiving and aging in context. Absence of children in the home of a Malawian grandmother appears to be indication that something has gone wrong in the woman's relationships with others; socially and culturally, caring for children in some capacity is important. Children are a source of companionship, and they provide a lifeline to assistance in the case of emergencies. They provide a sense of purpose, joy and pride, helping caregivers cope with the challenges of rural life and caregiving. Taking responsibility for orphaned children when one's own adult children are lost can help grandmothers cope with their loss (Schatz 2007; WHO 2002). Grandmothers often express hope that grandchildren will support *gogo* in the future.

Study limitations and recommendations for future research

The key strengths of this study are the use of both qualitative data and longitudinal quantitative data, and inclusion of older and younger caregivers. This unique mix of data

allows for triangulation of qualitative and quantitative findings, and comparisons between older caregivers and younger caregivers across the spectrum of caregiving circumstances including foster care and care for their own orphaned and non-orphaned children. Results from this study can guide programmers and researchers in devoting more attention to older caregivers in other settings. However, the social context of rural southern and central Malawi may differ from other HIV-affected areas. In addition, this study utilized program evaluation data that are not representative of the general population in rural Malawi. The household survey was conducted among a sample of intervention and comparison households that does not necessarily reflect the distribution of vulnerable children and households in the study communities. The risk of this design is an oversampling of households with orphans and vulnerable children, although the extent to which the sample over-represents households with orphans and vulnerable children is not known. Results should therefore be interpreted with caution until confirmed by nationally-representative studies. The qualitative study was implemented using rapid ethnographic methods, and therefore "saturation" in response themes was not necessarily achieved. The rich narratives that emerged call for continued ethnographic research to explore the situation of older caregivers.

Global demographic trends have recently stimulated research initiatives on older adults in sub-Saharan Africa and elsewhere. Population-based studies on older adults can contribute to better understanding their roles, responsibilities and well-being. Research concerned with caregiving among older adults should aim to place the caregiving role in context of the aging experience by including non-caregiving older adults (e.g. Ice *et al.* 2010). Additionally, study results highlight the need to appreciate the common, cross-generational demands of providing for children in rural Malawi today. Future studies on caregiving should span the generations so as to avoid attributing all aspects of poverty and hardship characteristic of rural Africa today to age alone or to HIV and AIDS.

Providing care for children in old age appears to entail benefits including but not limited to material and social support from extended family. Future research should refrain from assuming that child care provision is a burden on older adults and remain open to exploration of the benefits that caregivers experience. The benefits that may come with caring for children are particularly important to consider given changing social and economic conditions that influence support, status and opportunity among older adults.

Conclusion

Grandmothers have long played a role in ensuring child health and well-being in Malawi and elsewhere in sub-Saharan Africa. This fact is often overlooked in child-focused interventions targeting orphans and vulnerable children in the current era of HIV and AIDS. Older women are committed to providing care and protection for the children of their children. Although they struggle, grandmothers should not be viewed as passive victims. They are important assets in Malawian communities, and should be recognized, respected and supported. Bolstering grandmothers with material and social support to help sustain their key roles in fostering is a promising avenue for maintaining extended family responses to HIV and AIDS.

Social protection for older adults would not only benefit elders themselves but also the children in their care (Kimuna and Makiwane 2007; Schatz and Ogunmefun 2007). Social protection in the form of social pensions for older adults is available in a few southern African countries (Kimuna and Makiwane 2007). A more targeted approach to reaching the very poorest older caregivers is through cash transfer schemes. Cash transfer approaches

have recently gained visibility for success in improving the situation of the very poor (Hanlon *et al.* 2010), including recent programs focused specifically on those caring for orphans and vulnerable children (Adato and Basset 2008; Bryant 2009). Results from this study suggest that social pension programs and/or more targeted cash transfer schemes could be used to bolster older caregivers in the critical roles that they play in caring for family members.

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