Understanding the effect of caregiving to children and adults on older adult's perceived quality of life in Uganda

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Abstract: This paper explores the relationship between perceived quality of life, gender and among older adults in Uganda. Perceived quality of life is not only a concern in high-income countries but also in low income countries as older adults in these areas face a unique set of challenges that impact their ability to "age well." A focus on perceived quality of life has the potential to highlight the positive impacts of caregiving may have on older adults' lives. In a country impacted by HIV, social roles associated with caregiving to young children may differentially impact wellbeing compared to those associated with caregiving to adults. This paper will make use of cross-sectional and unique longitudinal data from the Study on global AGEing and adult health (SAGE) Wellbeing of Older People Study (WOPS) collected in collaboration between the Medical Research Council Uganda Research Unit on AIDS/Uganda Virus research Institute (UVRI) and the World Health Organization (WHO). Our aim is to provide a more complex picture of how caregiving influences personal wellbeing in later life.

Extended Abstract

Introduction

Perceived quality of life is an important indicator of societal wellbeing (Stiglitz, Sen, and Fitoussi 2009), particularly for older populations who will inevitably experience physical decline. Older adults play a central role as caregivers in Uganda (Mugisha et al. 2013). Due to the lack of formal care infrastructure and cultural tradition, most care is done in the household and by older women (Apt 2012; Thrush and Hyder 2014). The majority of research on older adults' relationship to children in low and middle income countries (LMICs) has focused on the negative outcomes associated with caregiving (Casale 2011). Casale calls for research on older caregivers to move "beyond a focus on how HIV breaks down households and relationships to afford greater attention to the resulting families and bonds created" (2011:1284). It is important to understand how caregiving to young children may differently impact older adults quality of life compared to caregiving to older adults.

Past research has suggested that caregiving impacts older adults though the possible pathways of economic stressors, physical health stressors and/or psychological stressors (Ice et al. 2010; Nyirenda et al. 2015). It can be argued caregiving to children may present a different impact of stressors on older adults lives than caregiving to adults. It may also be argued caregiving may also positively impact older adults feelings of wellbeing. Caregiving may give the older adult a sense of purpose, strengthen family ties or build networks of exchange. Old adults providing care work may intern be repaid with assistance with daily tasks (Schatz and Ogunmefun 2007). In a larger study of caregiving responsibilities, Mugisha and colleagues (2013) found caregiving to be associated with better health and wellbeing for older Ugandans. However, Mugisha and colleagues (2013) did not differentiate between caregiving to children from caregiving to adults. Evidence from South Africa suggests that caregiving to adults has a greater negative impact on older adults wellbeing than caregiving to children (Nyirenda et al. 2015). Nyirenda and colleagues (2015) suggest caregiving to adults may be more finically burdensome. Limited studies have been able to examine the influence of caregiving on wellbeing over time in Africa. One longitudinal study from Kenya found grandparents who preformed care for children did not find negative effects for physical health but did have negative impacts on mental health (Ice et al. 2010). More analysis using longitudinal data is needed to better understand the associations between caregiving and wellbeing.

Using a gendered lens is important when investigating the impact of care work on perceived quality of life. Care work is more likely to be done by women in the household (Schatz and Seeley 2015). There is evidence from Uganda that men also participate in care work; however it is typical lower intensity than the work preformed by women (Mugisha et al. 2013). Men are most likely to provide financial assistance (Mugisha et al. 2013). There is also evidence that women may take a greater emotional burden from their care work than men (Schatz & Gilbert, 2012). In additoin to gender, HIV status (infected or affected) is also likely to impact older adults' caregiving responiblities and subsenquently impact their quality of life.

This paper will build on the work of Mugisha and colleagues (2013, 2015) by addressing the following research questions:

1) Does caregiving to children have a different impact on older adults' quality of life than caregiving to adults?
2) Does the health status of the older adult mediate the relationship between caregiving and quality of life?
3) Do these associations change over time?

Data and Methods

We use data from the Study on global AGEing and adult health (SAGE)- Wellbeing of Older People Study (WOPS) conducted in Uganda in collaboration between the Medical Research Council Uganda Research Unit on AIDS/Uganda Virus Research Institute (UVRI) and the World Health Organization (WHO) SAGE. The aim of the study is to provide data on the effects of HIV/AIDS on older adults in Uganda (Kowal et al. 2012). The survey collects information on health and wellbeing status, healthcare utilization, and caregiving and receiving among adults aged 50 and older. The survey is a shortened version of the WHO SAGE instrument. Three rounds of data have been collected with Wave 1 in 2010, Wave 2 in 2013 and Wave 3 in 2016. Replacements due to losses were added at each additional wave. Stratified random sampling was used to select participants into five strata base on if the respondent was HIV infected, affected, or neither.

Variables

The dependent variable is a WHO constructed composite measure of perceived quality of life (WHO-QoL). The measure is based on eight question (each on a 5-point likert scale) referring to the four broad domains of quality of life, including satisfaction with one's physical, psychological, social and environmental circumstances (Schmidt, Mühlan, and Power 2006). The individual questions investigated whether the respondent felt they had enough energy for daily life, enough money to meet needs, their satisfaction with health and self, ability to perform daily activities, personal relationships, condition of living space, and overall quality of life. The measure is converted to a 0-100 scale with a higher score indicating a higher reported quality of life.

Our primary explanatory variables are related to caregiving to a child or an adult. "Caregiver to an adult" is a dichotomist variable coded 1 if the respondent reported being the primary caregiver to any adult inside or outside of the household. "Caregiver to a child" is a dichotomist variable coded 1 if the respondent reported being the primary caregiver to any child within the household.

We include a measure of the respondents HIV status including the categories of infected, affected, or neither. "Infected" are older adults with the disease themselves. "Affected" are older adults with an adult child who died of AIDS-related illness or who currently have an adult child living with HIV. "Neither" are respondents who have no children with HIV/AIDS and are not themselves infected with HIV.

We include two measures of physical health to evaluate the possible mediating relationship of health on caregiving influence on perceived quality of life. First, a dichotomist variable indicating the respondent's self report of the presence of the following conditions: diabetes, stroke, angina, hypertension, asthma, and chronic obstructive pulmonary disease. Second, we used the World Health Organization Disability Assessment Schedule II (WHODAS II) as a measure of physical limitations. The WHODAS II scale assesses day-to-day functioning using twelve questions, covering the domains of cognition, cognition, mobility, self-care, getting along, life activities, and participation to assess individuals' difficulty performing certain activities during the past 30 days.

We also include a number of controls including age, education, material status, residence (urban or rural), and a proxy for household socioeconomic status.

Preliminary analysis

We present primary descriptive statistics from Wave 3 of SAGE WOPS. Because of known differences by gender in caregiving and wellbeing, we examine these relationships separately for men and women. We then present descriptive statistics of caregiving status and perceived quality of life by HIV status.

Preliminary Findings

Table 1 shows descriptive statistics for our sample of adults age 50 and older. Overall, 62 percent report being the primary caregiver to at least one child in the household. Fifty-seven percent of the sample report being the primary caregiver to an adult. The mean quality of life score is approximately 55 with a standard deviation of 17.9. Overall the sample is majority female (58%). More women than men report being a caregiver to a child; however, a much higher percent of men report being a primary care giver to an adult (67% vs. 50%). Women report a slightly lower perceived quality of life compared to men.

Table 2 shows selected characteristics by HIV status. Interestingly those who are HIV infected report the highest perceived quality of life score of 60, while those HIV affected report the lowest quality of life score of 48. Those HIV infected report the highest percentage of being the primary caregiver to a child.

Future Directions

The paper will develop in two ways. First, using the cross-sectional data from Wave 3, we will use regression analysis to assess the relationship between quality of life and caregiving while controlling for important individual characteristics including physical health. We will also explore in more detail the types of care the older adults report giving. We will investigate separately giving of personal care (bathing, eating, dressing, moving about, toileting, taking medicines), physical assistance (buying food, cooking, fetching water, agricultural work), and financial assistance. We will investigate how different types of care may differently impact perceived quality of life. Also how health status may mediate the relationship between caregiving and perceived quality of life.

Second, future iterations of this paper will use fixed effect models run with the longitudinal data to evaluate the relationship between caregiving and perceived quality of life. The longitudinal sample consists of individuals' age 50-plus in 2010 that were surveyed in Wave 1, Wave 2, and Wave 3, with a total sample size of 282 individuals. Analysis using the longitudinal data will allow for investigation of trends over time. Importantly, the longitudinal data will also allow for assessing and controlling for possible endogeneity between quality of life and caregiving with this subsample. We will use caution in interpreting our findings because we will have likely not fully addressed possible selection. Individuals who have higher perceived quality of life scores may be more likely to seek caregiving roles or to be asked to take on such roles. Overall this work will strengthen the research around the influence of caregiving on older adults' perceived quality of life with the use of longitudinal.

In line with other scholars we hope to turn the conversation from blanket assumptions of negative effects caregiving to understanding how caregiving may have a positive impact on older adults lives, and how policy might further support caregivers. If current trends in caregiving continue, as Uganda's older population increases in number and percentage of the population, older adults generally, and older women specifically, are likely to take on more caregiving roles. Having a more complete picture of how caregiving influences older adults lives is vital for creating sound policy.

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Table 1. Percent or mean (S.D.) by sex, Wave 3 (2016) SAGE-WOPS MRC/UVRI

	Men	Women	Overall
Caregiving			
Caregiver to child	60	64	62
Caregiver to adult	67	50	57
Health and wellbeing			
Perceived quality of life	59.4 (18.6)	52.7 (16.8)	55.4 (17.9)
Physical functioning	26.4 (23.2)	29.3 (23.14)	34.2 (24.0)
Presence of chronic disease	43	53	49
HIV status			
Infected	60	51	54
Affected	18	31	26
Neither	22	18	20
Demographics			
Age			
50to 59	33	29	31
60to 69	33	38	36
70 to 79	18	22	21
80plus	16	11	12
Residence			
Rural	56	48	51
Urban	44	52	49
Marital status			
Married or cohabiting	68	14	36
Divorced/ separated Widowed/ never	32	86	64
Education			
None	9	24	18
Less than primary	46	49	47
Primary or higher	45	27	34
Household has a main source of income			
Yes	57	43	49
No	43	57	51
N	224	344	596

Table 2. Selected characteristics by HIV status, Wave 3 (2016) SAGE-WOPS MRC/UVRI

	HIV affected	HIV infected	Neither
Caregiver to a child	57	66	56
Caregiver to an adult	60	60	45
Perceived quality of life	48.7 (18.1)	60.2 (17.2)	52.3 (16.4)
N	150	318	119