The health burden of caregivers.

Authors:

Gilbert Brenes-Camacho

Abstract

The population aging process has increased the relevance of caregivers. The article tries to investigate the health effects of this burden, especially the so-called caregivers' stress, among middle-aged Costa Ricans, using the new cohort of the CRELES study: respondents were born between 1945 and 1955 (aged 55 to 66 at baseline). People who take care of their parents are more likely to show higher points in Yesavage Geriatric Depression scale and report to be stressed due the health of relatives, unlike those that take care of their children, their parents-in-law, or others. However, there is no evidence of differentials in deleterious biomarker levels (cholesterol, HbA1C, C-reactive protein) associated with allostatic load among these caretakers compared to non-caretakers.

Introduction.

Due to population aging, there are a larger number of elderly people in need of care, even in the presence of morbidity compression. In developed countries, there is a mixture of formal and informal care giving. There has emerged an industry specialized in services to disabled elderly: elder homes, assisted-living communities, nurses and physicians visiting houses, etc. However, informal care provided by relatives is still prevalent. There is evidence of distress among both formal and informal caregivers; this is the so-called caregivers' stress (Amirkhanyan & Wolf, 2003; 2006). Caregivers' stress may worsen in the context of the sandwich generation: middle-aged adults –usually women (Remennick, 1999) who take care of parents or other older relatives and at the same time face the burden of working, taking care of children, or other domestic roles (Nichols & Junk, 1997; Rubin & White-Means, 2009)

In developing countries, like in Latin America (Brenes-Camacho, 2009; Silva-Ferreira & Rodriguez-Wong, 2008), care giving rests heavily on the availability of relatives that help with non-specialized assistance. Due to the speed of the aging process in these countries, a large proportion of people have reached old age having a relatively large number of children on whom to rely for care; besides, there is the assumption that these countries have a familistic tradition expressed in a larger proportion of the

population living in complex multi-generation living arrangements (). If the availability of kin and cultural behaviors determine the context of care giving, then caregivers' stress might appear differently in regions such as Latin America.

This analysis aims to explore caregivers' stress in a nationally representative sample of middle-aged persons in a developing country –Costa Rica– using data from the new cohort of the CRELES project: CRELES-2010. The article investigates whether there are differences in sources of stress between non-caregivers and caregivers, splitting the latter population according to who is the main recipient of care (parents, in-laws, spouses, others). The analysis also studies whether there are differences in allostatic load biomarkers across the care giving groups.

Literature Review

The quality of life of ill or disabled persons is associated with the quality of life of their caregivers, especially when the main source of caretaking is informal (Roth et al., 2009). The burden of care giving is multifaceted. It may affect physical and mental health, family dynamics, social life, and economic transfers (Brouwer, van Exel, van Gorp & Redekop, 2006). Most of the research has focused on caregivers' mental health. In nationally representative samples, some studies have found that caregivers –especially women, particularly those classified as part of a sandwich generation–report more stress or depression symptoms than non-caregivers (Amirkhanyan & Wolf, 2006; Rubin & White-Means, 2009). Other studies (Amirkhanyan & Wolf, 2003) show that non-caregivers who have relatives taking care of severely disabled people express emotional strains, even if the actual caregivers do not. Several studies have focused on people who provide assistance for particular populations. The mental health of caregivers of people with dementia is affected if they feel overloaded with the burden or if they have or lack family support (Arango-Lasprilla et al., 2009; Mitrani et al., 2006; Son et al., 2007).

In addition to mental health, other research projects have studied the burden of care giving in physical health. People who take care of dementia patients or who have been caregivers for a long time are in a higher risk of developing or having metabolic syndrome (Fredman et al., 2010). Care giving tasks are also related to functional limitations among middle-aged caregivers (Fredman et al., 2010; Roth et al., 2009). Taking care of disabled relatives may reduce social contacts with other people, too (Roth et al., 2009).

It is worth noticing that the patterns described above have been observed in research carried out in developing countries or newly industrialized countries such as Colombia (Arango-Lasprilla, 2009), China (Wang et al., 2008), India (Dias et al., 2008), or Mexico City (Mendez-Luck, Kennedy & Wallace, 2008). However, none of these projects have studied care giving burden in a nationally representative sample

of caregivers who are not linked to a clinical setting. This article enhances the previous findings in developing countries by analyzing caregivers' stress in a sample of people selected randomly from the total population aged 55 to 65 and interviewed at home, in Costa Rica.

Data and methods

Data

The analysis uses the new cohort of the CRELES study: CRELES-2010. The acronym CRELES stands for "Costa Rica: Estudio de Longevidad y Envejecimiento Saludable": Costa Rican Study of Longevity and Healthy Aging. The study has been developed by researchers at the Central American Center for Population (CCP) and the University of California-Berkeley. The CRELES-2010 dataset is an on-going longitudinal study that targets the Costa Rican population born between 1945 and 1955, aged 55 to 65 at baseline, and residing in the country in 2010-2011. It has an expected sample size of 3000 main informants[1]. It also interviews co-resident spouses regardless of their year of birth; taking into account spouses, the project expects to have a total of 4500 interviews. The sample was drawn using a three-stage probabilistic sampling procedure selected with "probability proportional to size" (PPS). In the first stage, the primary sampling units (PSUs=Primary Sampling Units) are defined as pseudo-census tracts. Most of the pseudo-census tracts are pairs of census tracts, which were joined to have at least 15 houses with people born between 1945 and 1955. Two-hundred twenty two pseudo-census tracts were originally selected. Only two-hundred remained in the study because twenty two pseudo-census tracts are located in dangerous neighborhoods (because of crime) and hence were avoided because of safety concerns for the fieldworkers. For the second stage, the project selects all the houses with at least one person with the target age. For the third stage, the project randomly selects one person from the total persons living in the housing unit who were born between 1945 and 1955. The sampling frame used for the sampling design is the 2000 Costa Rican Population Census dataset, corrected with estimated survival ratios.

All field data are collected using Personal Digital Assistants (PDAs), with software applications developed by CCP for this study. All data and specimens in the study were collected at the participants' homes. In CRELES-2010, after finding the selected person, the fieldworker makes one visit for interview, anthropometric measurement, and collection of blood specimens. Participants have to sign the informed consent form at the beginning of the interview. Blood samples are collected by venipuncture:

---

[1] The first wave of CRELES-2010 will finish in December 2011.

1 EDTA purple top tube (for 3-4 ml. of whole blood) and 2 serum separating tubes (SST), with a clot activator (for 10-12 ml. of blood, to obtain 4-6 ml. of serum); however, participants do not need to be fasting given that the biomarkers analyzed by CRELES-2010 are not sensible to whether the person was fasting or not: total cholesterol, High Density Lipoprotein (HD), C-reactive protein (CRP), and glycated hemoglobin (Hb_{A1c}).   All biomarkers were processed by the Health Services Laboratory of the University of Costa Rica. This laboratory is accredited at the national and Inter-American level. Systolic and diastolic blood pressure are measured twice by interviewers during the interview process, using a standard digital blood pressure device.

Besides biomarkers, the other response variables are perceived stress according to several dimensions. Perceived stress is self-reported by interviewees from structured questions: "In today's society, some people feel stressed or anxious, but others do not. I will mention a few problems. For each, please tell me if it currently makes you feel stressed or anxious: own health, own financial status, family problems, and health of relatives and others. Does this make you feel stressed or anxious?" Another related dependent variable is depression, measured using Yesavage's Geriatric Depression Scale, based on the translation used in the SABE studies. We decided to use the scale as a discrete variable, reflecting the count of responses to the items.

The main independent variable is derived from answers to the following questions asked directly to respondents: "Do you (or your spouse) currently provide assistance to a relative or friend with any of the following personal tasks because they cannot do them by themselves: bathing, eating, dressing, walking across a room, etc? (Exclude any help with housing activites, transportation and running errands)". The wording of the question tries to operationalize giving care or assistance to persons with limitations in performing activities of daily living (ADL). After this question, respondents are asked to state who is the person that they help the most, classified in the following categories: spouse, mother, father, children, parents-in-law, and others. A dummy variable is created for each category in order to determine which recipient of help may produce a higher perceived burden.
The CRELES questionnaire also allows to measure from self-reports how many hours per week the person regularly spends in care giving, and how much time (classified in three categories: less than a year, between 1 and 5 years, and more than 5 years) has passed since the respondent started to help the person. To control for confounding effects, we analyze the following covariates: sex and age of respondent, and whether the interviewee dedicates time in supervising children.

Methods

The article initially compares means of biomarker levels and of the CES-D depression scale, and proportions of self-reported stress in different situations. We estimate Gaussian models for continuous dependent variables and logistic regressions for binary dependent variables. Given that we are analyzing the CES-D scale as a simple count of positive items, we use a negative binomial regression to assess the factors associated with depression. We add sex and age as control variables.

Preliminary Results

People who take care of their parents are more likely to show higher points in Yesavage Geriatric Depression scale and report to be stressed due the health of relatives, unlike those that take care of their children, their parents-in-law, or others. However, there is no evidence of differentials in deleterious biomarker levels (cholesterol, HbA1C, C-reactive protein) associated with allostatic load among these caretakers compared to non-caretakers.

(See Tables and Figures).

References

Amirkhanyan AA, Wolf DA (2003) "Caregiver Stress and Noncaregiver Stress: Exploring the Pathways of Psychiatric Morbidity". The Gerontologist 43: 817-827.

Amirkhanyan AA, Wolf DA (2006) "Parent Care and the Stress Process: Findings From Panel Data". Journals of Gerontology B-Psychological Sciences and Social Sciences 61: S248-S255.

Arango-Lasprilla JC, Moreno A, Rogers H, Francis K (2009). "The Effect of Dementia Patient's Physical, Cognitive, and Emotional/ Behavioral Problems on Caregiver Well-Being: Findings From a Spanish-Speaking Sample From Colombia, South America" American Journal of Alzheimer's disease and other dementias. 24: 384-395.

Brouwer WBF, van Exel NJA, van Gorp B, Redekop WK (2006). "The CarerQol instrument: A new instrument to measure care-related quality of life of informal caregivers for use in economic evaluations". Quality of Life Research 15:1005-1021.

Dias A, Dewey ME, D'Souza J, Dhume R, Motghare DD, Shaji KS, Menon R, Prince M, Pate V (2008) "The Effectiveness of a Home Care Program for Supporting Caregivers of Persons with Dementia in Developing Countries: A Randomised Controlled Trial from Goa, India". PLoS ONE 3(6): e2333.

doi: 10.1097/WAD.0b013e3181902334

Fredman L, Doros G, Cauley JA, Hillier TA, Hochberg MC (2010). "Caregiving, Metabolic Syndrome indicators, and 1-year Decline in Walking Speed: results of Caregiver-SOF". Journal of Gerontology A: Medical Sciences 65A:565–572.

Mendez-Luck C, Kennedy D, Wallace S (2008). "Concepts of Burden in Giving Care to Older Relatives: A Study of Female Caregivers in a Mexico City Neighborhood". Journal of Cross-Cultural Gerontology 23:265-282.

Mitrani VB, Lewis JE, Feaster DJ, Czaja SJ, Eisdorfer C, Shulz R, Szapocznik J (2006). "The Role of Family Functioning in the Stress Process of Dementia Caregivers: A Structural Family Framework". The Gerontologist 46: 97-105.

Nichols LS, Junk VW (1997). "The Sandwich Generation: Dependency, Proximity, and Task Assistance Needs of Parents". *Journal of Family and Economic Issues* 18:299-326.

Original Articles

Remennick LI (1999). "Women of the `Sandwich' Generation and Multiple Roles: The Case of Russian Immigrants of the 1990s in Israel". Sex Roles 40: 347-378.

Roth DL, Perkins M, Wadley VG, Temple EM, Haley WE (2009). "Family caregiving and emotional strain: associations with quality of life in a large national sample of middle-aged and older adults". Quality of Life Research 18:679–688.

Rubin R., White-Means S. (2009). "Informal Caregiving: Dilemmas of Sandwiched Caregivers". Journal of Family and Economic Issues 30: 252-257.

Silva-Ferreira AR, Rodriguez-Wong L (2008). "Perspectivas da oferta de cuidadores informais da populaçao idosa: uma análise comparativa entre Brasil e Mexico", 2000-2015". In: Pélaez E (Org.) "Sociedad y Adulto Mayor en América Latina". Rio de Janeiro: ALAP Editor. Serie Investigaciones No. 5. Pp.183-204.

Son J, Erno A, Shea DG, Femia EE, Zarit SH, Stephens MAP (2007). "The Caregiver Stress Process and Health Outcomes". Journal of Aging and Health 19:871-887.

Wang G, Cheng Q, Wang Y, Deng YL, Ren RJ, Xu W, Zeng J, Bai L, Chen SD (2008). "The Metric Properties of Zarit Caregiver Burden Scale: Validation Study of a Chinese Version". Alzheimer Disease & Associated Disorders. 22: 321-326.

Tables and Figures.

Graph1. Costa Ricans aged 55 to 65: Proportion taking care of other persons, by sex, 2010/2011.
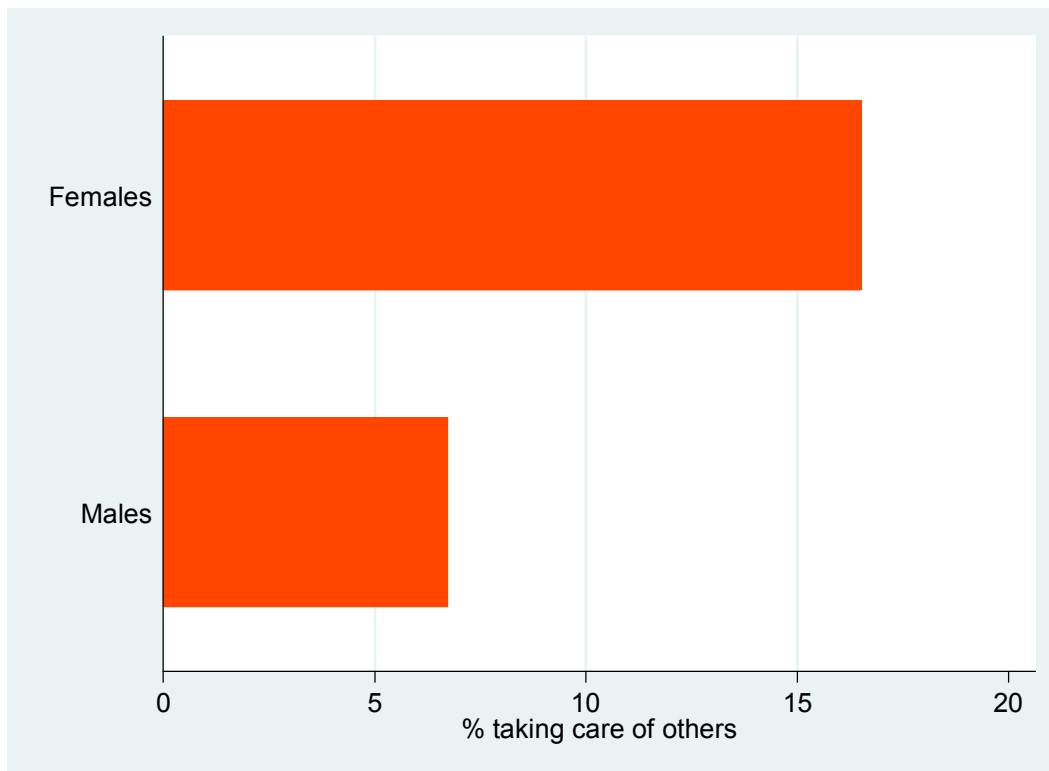
Source: CRELES-2010.

Graph 2. Relative distribution of people whom are taken care of by Costa Ricans aged 55 to 65, 2010/2011.
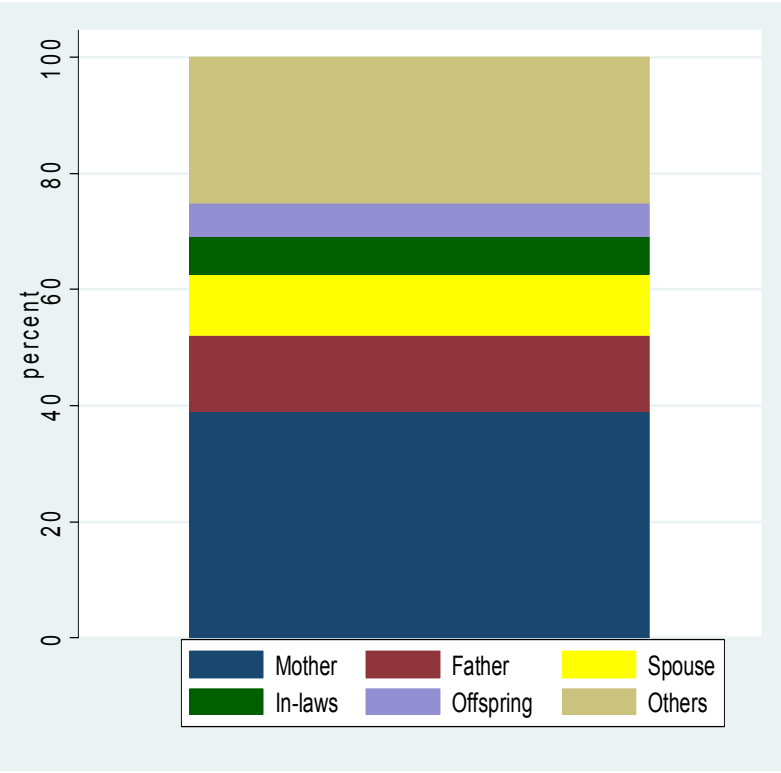
Table 1. Costa Ricans caretakers aged 55/65: Distribution of time since start of caretaking and mean weekly hours of caretaking, by relation to care receivers, 2010/2011.

Care receivers		Time since start of caretaking				Weekly hours of caretaking	
	Total	< 1 year	1 to 5 y	>5 years		Mean	sd
Mother	100.0	30.2	31.1	38.7		6.2	10.2
Father	100.0	38.9	33.3	27.8		4.5	6.7
Spouse	100.0	48.3	41.4	10.3		7.9	13.4
Offspring	100.0	37.5	6.3	56.2		7.8	13.3
In-laws	100.0	58.8	41.2	0.0		2.1	3.3
Others	100.0	41.2	27.9	30.9		5.2	11.6
Total	100.0	38.2	30.9	30.9		5.7	10.5

Source: CRELES-2010.

Table 2. Costa Ricans aged 55/65: Mean levels of health biomarkers, mean depression scale level, and proportion reporting types of stress, by caretaker condition, 2010/2011.

Health marker		Caretaker		sig[1]
	Total	Yes	No	
(n)	2457	275	2182	
Mean systolic blood pressure (mm/Hg)	139.4 (20.4)	139.1 (19.2)	139.4 (20.5)	
Mean diastolic blood pressure (mm/Hg)	81.2 (11.1)	81.8 (11.1)	81.1 (11.1)	
Glycated Hemoglobin HbA1C (%)	6.2 (1.1)	6.2 (1.1)	6.2 (1.1)	
Total cholesterol (mg/dl)	207.4 (41.7)	209.0 (43.3)	207.2 (41.5)	
C-reactive protein (mg/dl)	4.8 (7.7)	5.0 (5.6)	4.8 (7.9)	
Depression scale (count of affirmative answers in CES-D items)	3.3 (3.4)	3.7 (3.2)	3.3 (3.4)	
%Reporting stress with:				
-Own health	43.9	47.6	43.4	
-Own financial status	46.4	51.3	45.8	
-Family problems	27.7	30.2	27.4	
-Health of relatives and others	49.9	65.5	48.0	*
Note:	1/ Likelihood-ratio tests for differences of proportions, t-test for differences of means. 2/ *: p<0.05			

Source: CRELES-2010.

Table 3. Costa Rican caretakers age 55-65: Negative binomial regression coefficients of CES-D depression scale (count of items) on caretaking and relative-oriented caretaking, controlling for other covariates.

Covariates	Model 1			Model 2	
	Coef	p-value		Coef	p-value
Being caretaker	0.126	0.416			
Taking care of:					
-Spouse				0.193	0.435
-Mother				0.336	0.050
-Father				0.316	0.151
-Offspring				-0.021	0.948
-Parents-in-law				-0.353	0.218
Others				-0.093	0.627
Males	-0.177	0.000		-0.170	0.000
Age	-0.007	0.318		-0.008	0.280
Weekly hours of care	0.004	0.569		0.003	0.688
Years of care (ordinal variable)	-0.076	0.311		-0.100	0.196
Taking care of children	-0.038	0.481		-0.032	0.555

Note: 1/ Likelihood ratio test of negative binomial parameter=0: p-value=0.000

Table 4. Costa Rican caretakers age 55-65: Logit regression coefficients of being stressed due to own's health on caretaking and relative-oriented caretaking, controlling for other covariates.

Covariates	Model 1			Model 2	
	Coef	p-value		Coef	p-value
Being caretaker	0.026	0.873			
Taking care of:					
-Spouse				-0.220	0.629
-Mother				0.373	0.112
-Father				0.287	0.443
-Offspring				-0.033	0.953
-Parents-in-law				-0.584	0.299
Others				-0.402	0.293
Males	-0.427	0.000		-0.413	0.000
Age	-0.022	0.140		-0.023	0.015
Weekly hours of care	0.007	0.612		0.005	0.013
Years of care (ordinal variable)	-	-		-	-
Taking care of children	0.107	0.353		0.116	0.316

Note: 1/ Likelihood ratio test of negative binomial parameter=0: p-value=0.000

Table 5. Costa Rican caretakers age 55-65: Logit regression coefficients of being stressed due to own's financial situation on caretaking and relative-oriented caretaking, controlling for other covariates.

Covariates	Model 1			Model 2	
	Coef	p-value		Coef	p-value
Being caretaker	0.101	0.542			
Taking care of:					
-Spouse				-0.449	0.336
-Mother				0.131	0.577
-Father				0.518	0.179
-Offspring				0.979	0.120
-Parents-in-law				0.483	0.376
Others				-0.226	0.434
Males	-0.383	0.000		-0.381	0.000
Age	-0.088	0.000		-0.089	0.000
Weekly hours of care	-0.003	0.814		-0.004	0.790
Years of care (ordinal variable)					
Taking care of children	0.032	0.782		0.034	0.116

Note: 1/ Likelihood ratio test of negative binomial parameter=0: p-value=0.000

Table 6. Costa Rican caretakers age 55-65: Logit regression coefficients of being stressed due to family problems or issues on caretaking and relative-oriented caretaking, controlling for other covariates.

Covariates	Model 1			Model 2	
	Coef	p-value		Coef	p-value
Being caretaker	-0.057	0.751			
Taking care of:					
-Spouse				-0.341	0.521
-Mother				0.227	0.351
-Father				0.351	0.363
-Offspring				-1.018	0.195
-Parents-in-law				0.128	0.822
Others				-0.665	0.060
Males	-0.516	0.000		-0.511	0.000
Age	-0.050	0.003		-0.051	0.002
Weekly hours of care	-0.005	0.731		-0.004	0.802
Years of care (ordinal variable)					
Taking care of children	0.227	0.063		0.231	0.059

Note: 1/ Likelihood ratio test of negative binomial parameter=0: p-value=0.000

Table 7. Costa Rican caretakers age 55-65: Logit regression coefficients of being stressed due to relatives' health problems on caretaking and relative-oriented caretaking, controlling for other covariates.

Covariates	Model 1			Model 2	
	Coef	p-value		Coef	p-value
Being caretaker	0.639	0.000			
Taking care of:					
-Spouse				1.020	0.041
-Mother				0.660	0.007
-Father				1.234	0.005
-Offspring				0.083	0.883
-Parents-in-law				0.740	0.184
Others				0.286	0.321
Males	-0.229	0.027		-0.233	0.024
Age	0.013	0.380		0.012	0.429
Weekly hours of care	-0.008	0.546		-0.008	0.527
Years of care (ordinal variable)					
Taking care of children	0.004	0.970		0.007	0.950

Note: 1/ Likelihood ratio test of negative binomial parameter=0: p-value=0.000