

Disability and caretakers at the end of life.

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*Abstract*

*Disability and the role and need of elderly caretakers increase with age, especially during the time immediately before death. We consider information of deceased persons at the second wave of two Latin American longitudinal studies, to study how this information sheds light on the relationship between aging, disability and living arrangements among the elderly. A greater increase in dependence on performing Activities of Daily Living (ADL) is observed among decedents than among respondents alive at second wave. Incidence of dependence is more than 50% higher and the association between chronic disease and disability is stronger if decedents are taken into account for computation. The most important change in living arrangements among disabled elderly is the arrival of other non-relatives in the household. Results from Costa Rica suggest that elderly's main helpers are family members, but during the end-of-life period, new household members arrive to help in care taking chores.*

**Introduction**

An important trait of the biological process of aging is that disability status increases with age. Disability at old age develops from mental and physical impairments that arise as a consequence of multiple chronic and degenerative illnesses that are more prevalent among the elderly; it is also a consequence of senescence: the aging body accumulates a series of insults that progressively limit the functional ability of the elderly. The vulnerability that an older person faces due to disability and morbidities associated to it are the main reason why the older person needs other people to look after him. Geriatric research has studied how disability status triggers

other events in the life of older persons: institutionalization, spatial mobility, and changes in living arrangements (Speare, Avery and Lawton, 1991; Worobey and Angel, 1990; De Jong et al. , 1995; Silverstein and Zablotski, 1996; Hays, Pieper, and Purser, 2003; Miller and Weissert, 2000; Waite and Hughes, 1999).

Disability status generally worsens in the time immediately before death, especially when terminal illnesses have made an advance into the health of the elderly. Given that the average time of exposure to disability among terminally ill patients is relatively short, cross-sectional data may hide the impact of disability on demographic dynamics, such as changes in living arrangements. Other longitudinal studies keep track of only alive persons, disregarding the relevance of losses to follow up due to death on the topic that is being studied. This paper explores how adding second-wave decedents sheds light on the relationship between disability and changes in living arrangements in two Latin American countries: Mexico and Costa Rica. The importance of analyzing these two countries is that Latin America is a region where elderly institutionalization is not very prevalent (Perez-Amador and Brenes-Camacho, 2007), a “familistic” perspective on living arrangements is apparent (Bongarts and Zimmer, 2002), and the population aging process is still starting given that the age-dependency ratio is temporarily decreasing.

## **Literature review**

The articles by Speare, Avery, and Lawton (1991) and Worobey and Angel (1990) showed that becoming disabled induced institutionalization or a change of the living arrangements of elderly people: the living arrangement becomes more complex. However, both studies showed that most of the elderly stayed in the same living arrangement in which they were during the first wave. Functional limitation is positively associated with moving into retirement communities or institutions (DeJong et al, 1995; Silverstein and Zablotski, 1996, Miller and Weissert, 2000). Hays, Pieper and Purser (2003) –using hazard models where functional limitation was the main independent variable– studied institutionalization and household expansion as competing risks. This means that when elderly people become more disabled, they face different options in order to deal with disability: moving into a nursing facility, moving to

another house seeking for assistance, modifying their living arrangements to find such assistance, or a sequence of all these events.

In Latin America, prevalence of institutionalization is lower than in industrialized countries because there is less demand for such services, which are typically expensive for the living standards of the region's elderly (Pereira, Angel & Angel, 2007; Brenes-Camacho, 2009). Changes in living arrangements are more likely to occur when Latin American elderly people face health problems. Bongarts and Zimmer (2002) consider that the distribution of types of elderly households is very similar across countries because these countries face similar cultural traits. The Latin American culture is considered to be "familistic": it gives emphasis to informal support networks within families. On the contrary, Perez-Amador and Brenes-Camacho (2007) describe cross-country differences in the motives behind living arrangement changes. The differences were related to the stage of the Demographic Transition in which each analyzed country was. Simple types of households (only couples, living alone, etc.) were more frequent in countries with an earlier onset of fertility decline (Argentina, Uruguay, Cuba). Such differences suggest that elderly living arrangements –and probably caretaking, too– are determined more by availability of kin, rather than by a "familistic" culture.

## **Data and methods**

For Costa Rica, we will use the dataset from CRELES, the Costa Rican Study on Longevity and Healthy Aging. It is an on-going longitudinal study of a nationally representative sample of 2,827 adults born in 1945 or before (ages 60 and over at the first interview) and residing in Costa Rica by the year 2000, with over-sampling of the older old. For this analysis we use the data for the first wave of interviews, conducted from November 2004 through September 2006, and the second wave, conducted between November 2006 and June 2008. This sample size was obtained from a two-step procedure. First, an original sample of 9,600 individuals was randomly selected from the 2000 census database with stratification by 5-year age groups. Sampling fractions ranged from 1.1% among those born in 1941-45 to 100% for those born before 1905. Next, for the in-depth longitudinal study we are analyzing here, a sub-sample of 60 "health areas" (out of

102 for the whole country) was taken with probability proportional to the population ages 60 and over. This sub-sample included near 5,300 individuals. The sub-sample, which covers 59% of Costa Rican territory, yielded the following non-response rates: 19% deceased by the contact date; 18% non-found in the field; 2% moved to other addresses; 2% rejected the interview; 2% pendant interviews after several visits (likely rejections). From those interviewed: 95% provided blood sample; 91% had anthropometric measures; 24% required a proxy to answer the questionnaire. All field data were collected using Personal Digital Assistants (PDAs), also known as palm computers, with software applications developed by CCP for this study.

For Mexico, we will use Mexican Health and Aging Study (MHAS). Its target population comprises Mexicans born before 1951 and their spouses and partners, and it is representative to the non-institutionalized population aged 50 and over in 2001. The first wave data collection was finished in 2001 and is based in a stratified multi-stage sampling design, selected from a master sample of the Mexican Employment Survey. The second wave was conducted in 2003. The total number of respondents during the first wave was 15,230 persons for an overall response rate of 92% (Palloni and Soldo 2002, Wong and Espinoza 2003). We use only people originally selected in the sample, but not their spouses, if any. Besides, we deleted all the records corresponding to respondents age 50 to 59, in order to have a sample comparable to the other two.

We use descriptive statistics to introduce the characteristics of the population and the Welfare State in these three countries. The time at exposure of becoming disabled was computed as the time that passed between two waves, or the time between the first interview and the time of death.

### **Preliminary Results.**

In Costa Rica, from the 2,828 persons interviewed in 2002-2004, 269 were found deceased at the second wave (Table 1). If we only consider those that were alive in both waves, 92% remained with no ADL limitations and 3% became disabled by wave 2; 3% were found disabled in both waves, while almost 2% recovered from disability. However, among those reported as deceased in second wave, 40% transit into disability from wave 1 and wave 2 and 29% remained with no

disability between waves. If decedents' information is considered, disability incidence rates are a higher than if they were not considered; differences are more noticeable before age 80 (Figure 1). This means that, if decedents are not taken into account for incidence computations, the subsample of respondents who were alive at wave 2 is a selected subsample from the total population; this selection bias underestimates disability incidence.

If this selection bias were not affecting the way disability evolves over time, the distribution of status at wave 2 according to morbidity subgroups should show similar disability structures (help vs. no help, in Table 2) among those alive and those dead at wave 2. According to wave 2, being functionally dependent was more common among those people that died than among respondents alive in wave 2, in every morbidity group that could be defined. In the general subsample of decedents, there were a little bit more than 2 disabled persons for every non-disabled one. Among people with cancer, this ratio grows up to 6 among cancer patients, up to 5 among stroke patients, and up to 10 among people with osteoporosis (Table 2). There are no significant differences in the distribution of status at wave 2 across socio-demographic variables (Table 3).

Such diseases, like cancer, stroke, and osteoporosis, are typically disabling, thus patients require assistance from others. If these diseases were relatively common among respondents that were disabled and deceased at wave 2, therefore, we might observe a greater need of help in wave 2 if we analyze both people that were alive and people that died before wave 2. There are no significant differences in the distributions of helper's relationship with the respondent, across vitality status in wave 2, although the data show an increase in helpers who are classify as "Others inside household" (Table 4).

In terms of changes in living arrangements, according to Table 5, slightly more than half of households experienced no change from wave 1 to wave 2, and the most common changes involve children or other relatives. Besides, one in four respondents experienced the departure of a household member. However, there are no significant differences across wave 2 status, except in additional non-relatives and additional domestic service. The arrival of additional domestic service person is more common among disabled people who were alive at wave 2, while the arrival of non-relative household members seems to be significantly more common in

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households of disabled decedent people. These people are probably paid workers hired to help disabled elderly at the end of life.

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Tables and Figures.

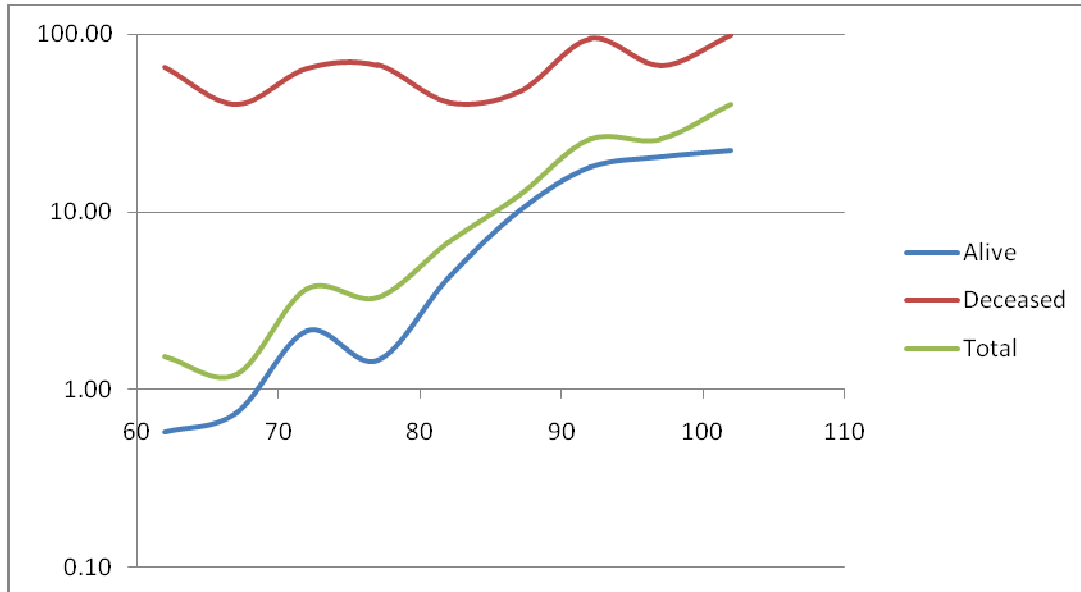
Table 1. People age 60 and over: Inter-wave changes in the proportion receiving help in at least one limitation in Activities of Daily Living (ADL), controlling by whether people were alive or deceased in second wave, for Costa Rica (CRELES) and Mexico (MHAS).

ADL limitation wave 1	ADL limitation wave 2	Alive in wave 2	Receiving help Deceased by wave 2 1/	Total
Costa Rica				
(n=)		2,559	269	2,828
Yes	Yes	3.2	29.2	4.5
	No	1.6	1.4	1.6
No	Yes	2.8	40.4	4.7
	No	92.4	29.0	89.2
Total		100.0	100.0	100.0
Mexico				
(n=)				
Yes	Yes			
	No			
No	Yes			
	No			
Total				

Source: CRELES for Costa Rica, MHAS for Mexico

Figure 1. Incidence rates of ADL dependence by 5-year age groups, according to whether decedents are included in computations, in Costa Rica and Mexico.

Costa Rica



Source: CRELES for Costa Rica, MHAS for Mexico.

Table 2. ADL dependence and decedent status by wave 2, by comorbidities in wave 1, standardized by age groups, in Costa Rica and Mexico.

Covariates		Status wave 2				Total
		Alive, no help	Alive, help	Deceased, no help	Deceased, help	
Costa Rica	2827	89.24	5.59	1.57	3.59	100.00
Cancer						
-without information wave 2	190	80.03	9.51	1.54	8.93	100.0
-with information wave 2	238	73.73	8.70	2.62	14.96	100.00
Heart attack						
-without information wave 2	148	68.92	13.51	4.73	12.84	100.00
-with information wave 2	223	64.01	9.37	9.76	16.86	100.00
Stroke						
-without information wave 2	156	58.91	26.94	2.24	11.90	100.00
-with information wave 2	197	56.38	25.25	2.18	16.19	100.00
Lung disease						
-without information wave 2	502	85.35	7.80	2.19	4.65	100.00
-with information wave 2	645	79.39	8.27	3.05	9.29	100.00
Geriatric fall and bone fracture						
-without information wave 2	1092	85.14	8.17	1.81	4.88	100.00
-with information wave 2	1518	86.89	7.76	1.48	3.87	100.00
Hypertension	1378	87.72	6.33	1.96	3.99	100.00
Hypercholesterolemia	975	90.84	5.07	1.02	3.06	100.00
Diabetes	542	86.33	5.76	2.05	5.86	100.00
Arthritis	464	86.42	7.60	1.54	4.44	100.00
Osteoporosis	264	86.81	8.40	0.43	4.37	100.00
Mexico						
Cancer						
-without information wave 1						
-with information wave 1						
Heart attack						
-without information wave 1						
-with information wave 1						
Stroke						
-without information wave 1						
-with information wave 1						
Lung disease						
-without information wave 1						
-with information wave 1						
Geriatric fall and bone fracture						
-without information wave 1						
-with information wave 1						
Hypertension						
Hypercholesterolemia						
Diabetes						
Arthritis						
Osteoporosis						

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Source: CRELES for Costa Rica, MHAS for Mexico.

Table 3. ADL dependence and decedent status by wave 2, by socio-demographic covariates in wave 1, standardized by age groups, in Costa Rica and Mexico.

Covariates		Status wave 2				Total
		Alive, no help	Alive, help	Deceased, no help	Deceased, help	
Costa Rica	2827	89.24	5.59	1.57	3.59	100.00
Sex						
-Men	1293	90.65	4.25	1.73	3.36	100.00
-Women	1534	87.96	6.81	1.42	3.81	100.00
Marital status						
-Married/Cohabiting	1403	92.38	3.98	1.31	2.32	100.00
-Not in union	1425	84.46	8.04	1.96	5.54	100.00
Education						
-Less than 6 years	1968	86.07	7.34	2.18	4.41	100.00
-6 years or more	859	92.54	3.78	0.94	2.75	100.00
Household size						
-1	348	89.69	5.37	1.63	3.31	100.00
-2 to 4	1815	89.49	5.52	1.54	3.46	100.00
-5 or more	660	88.47	5.90	1.58	4.05	100.00
Mexico						
Sex						
-Men						
-Women						
Marital status						
-Married/Cohabiting						
-Not in union						
Education						
-Less than 6 years						
-6 years or more						
Household size						
-1						
-2 to 4						
-5 or more						

Source: CRELES for Costa Rica, MHAS for Mexico.

Table 4. Helpers' relationship to people aged 60 and over with ADL limitation, by status in wave 1 and wave 2, in Costa Rica and Mexico.

	Wave 1	Total	Wave 2 Alive	Deceased
Costa Rica				
(n=)				
-Spouse	24.1	16.9	16.8	17.0
-Children inside HH	40.0	27.3	26.9	28.0
-Children outside HH	8.5	10.4	9.8	11.2
-Others inside HH	14.9	27.7	28.7	26.2
-Other outside HH	24.1	17.8	17.9	17.6
Total	100.0	100.0	100.0	100.0
Mexico				
(n=)				
-Spouse				
-Children inside HH				
-Children outside HH				
-Other relative				
-Other				
Total				

Table 5. Relative distribution (%) of changes in living arrangements of people aged 60 and over, by type of change, according to status in wave 2, Costa Rica and Mexico.

Covariates	Status wave 2				Total	adjusted Pearson $\chi^2$ test p-value
	Alive, no help	Alive, help	Deceased, no help	Deceased, help		
Costa Rica						
(n=)	2250	307	67	199	2813	
Total (%)	100.0	100.0	100.0	100.0	100.0	
No changes	53.1	57.7	53.9	45.1	53.1	
Additional child	15.8	11.6	13.2	13.4	15.5	
Additional child-in-law or grandchild	8.2	8.1	8.8	9.3	8.2	
Other additional relative	11.9	13.7	15.8	15.1	12.2	
Additional non-relative	2.6	7.2	2.0	10.3	3.0	***
Additional domestic service	0.1	4.0	0.3	1.4	0.4	***
Departure of hh members	26.9	25.5	28.3	29.8	26.9	
Total						
Mexico						
(n=)						
Total (%)						
No changes						
Additional child						
Additional child-in-law or grandchild						
Other additional relative						
Additional non-relative						
Additional domestic service						
Departure of hh members						
Total						

Note: Percentages do not add up to one because categories are not mutually exclusive.