Investigating Trends in Elder-Elder Caregiving in the United States: 1997 – 2014

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Abstract

Background: Caregiving is a difficult field to study due to the subjective nature of the data, and some of the research findings have been contradictory. Little research exists on the specific situation of elder-elder caregiving (where the caregiver is a person 64 years old and older caring for a care recipient who is also 64 years old and older.) Given the aging American population, this paper explores these elder relationships to better understand caregiving from their perspective.

Methods: ANOVA tests and a Pearson Correlation Matrix were performed in Prism 8 on publicly available data sets from the National Alliance for Caregiving. This survey data was from a random sample of caregivers collected via telephone and internet in 1997, 2004, 2009, and 2014.

Results: The ANOVA tests found a significant statistical difference ($p < 0.0001$) between the mean age of elder-elder caregivers. The post-hoc Games-Hollow test found statistically significant differences ($p < 0.0001$) for 1997 and 2009 when each was compared to 2014. No statistical difference was found between the mean age of elder-elder care recipients. No correlation was found between elder-elder caregiver age and level of burden experienced due to caregiving. The average length of time of caregiving for elder-elder caregivers was approximately 5 years for each year of survey administration.

Conclusion: The lack of prior investigation on the elder-elder caregiving population may be concealing the needs of this specific population. Further research could help society prioritize education and inform action plans that assist elder-elder caregivers, so that a) they may have a high quality of life near the end of life, and b) that their caregiving workload does not shift to stressed institutional health care systems.

Introduction

The term “caregiving” may not have much significance unless you have actually been or known a caregiver (CG) or care recipient (CR). However, there are over 44 million American CGs, and over 17 million of those CGs are caregiving for someone over the age of 64 (1, 2). Caregiving generally refers to the informal and unpaid work performed by a CG to assist a CR. In 2013, the economic value of caregiving in the United States was estimated to be $470 billion (3). Caregiving may include but is not limited to emotional support, physical assistance with personal care and household tasks, and more recently, financial support, home medical care and management, decision-making, and the navigation of complex medical systems such as hospitals and insurance companies (1, 2). The field of caregiving is a stark reminder for health professionals that they are not the main providers of patient care (3).

It is the eldest in society who are likely to have the most significant physical and cognitive limitations; and thus, be in need of caregiving (2). As the U.S. population ages, it is likely that the informal and unpaid work of caregiving will also increase. In 2010, there were 40.2 million people over the age of 65 living in the United States (4). The youngest of the Baby Boom Generation, composed of people born between 1946 and 1964, will be in their mid-60s by 2030 — that is roughly 20% of the country’s population that will be over the age of 64 (4,5).

By 2050, that number will more than double to 88.5 million (4). The eldest of the elders, those over 85 years old, will represent 2.3% of the population in 2030, and are projected to nearly double by 2050 (4). Although the baby boomers will also be facing mortality declines by and after 2050, their presence will be an unprecedented increase in the total number of elders within the U.S. population.

It is not only the CRs who are aging but also the CGs. This study explores the specific relationship of elder CGs who are 64 years old and older that care for elder CRs who are also 64 years old and older. This is referred to herein as elder-elder (E-E) caregiving.

Caregiving is a difficult field of study, largely because most of the research is opinion-based and completed through surveys. The collected data is self-reported and difficult to objectively verify. Similarly, unrelated surveys ask questions and record answers in slightly different ways, such as using a 1-to-5 scale versus a yes/no answer format. These discrepancies make comparing research problematic. Unsurprisingly, findings between studies sometimes seemed contradictory. For example, there is no clear consensus around the impact of CG burden amongst those caring for older CRs on mortality, depression, and mental stress (2,6,7). The current literature did underscore the clinical need and real-world application for this type of research given that people suffering with a chronic illness receive the majority of their care from lay caregivers at home (1).

The primary aim of this study was to investigate if the E-E caregiving population has also been aging from 1997 to 2014, given that the general population was and is aging? What is the sex of these CGs and their relationship to the CRs? And lastly, is there a correlation between E-E CGs age and level of burden experienced due to caregiving?

Methods

This paper used the National Alliance for Caregiving's open data sets (8,9). The following two data sets were explored: 1) Caregiving in the U.S. 2015 and 2) Caregiving in the U.S. 2009. The 2015 files contained surveys completed in 2014 and will here on out be referred to by that year. Advantageous for this project, the data set within Caregiving in the U.S. 2009 also included raw data from the years 1997 and 2004. Inclusion of these years were not indicated in the file title, and thus, not expected. The raw data was separated by year into separate files for statistical analysis.

Both data sets included codebooks explaining the data's nomenclature. The 2009 files included the final survey questions in English and Spanish, and a report of their methodology. All 4 years of data were gathered from a random sample of CGs via telephone and online surveys, and over 200 variables were collected through the survey questions. Variables analyzed in this report included age and sex for both CG and CR; the length of time the CG had been caregiving; the relationship of the CR to the CG as defined by the CG; the CG's health status; and the level of burden experienced by the CG due to caregiving.

Data exclusion criteria included any incomplete surveys. Additionally, the survey responses were further whittled to the population of interest to include only CGs aged 64 and over who care for CRs aged 64 and over. Survey respondents who withheld or did not know their own age or the age of their care recipient were also excluded. This resulted in an E-E caregiving sample of n = 147, 115, 282, and 445 for years 1997, 2004, 2009, and 2014.

Data analysis

IBM's SPSS Statistics Version 26 was used to organize the data and Prism 8 to run the statistical tests and create the figures. Summary statistics for age, sex, length of time caregiving, relationship of CG to CR, and health status of CG were calculated for each data set by year. ANOVA tests was performed to compare the mean age of CG and CR respectively in 1997, 2004, 2009 and 2014.

The one-way Brown-Forsythe and Welch ANOVA tests compared the mean elder-elder CG ages from the four specified years (alpha=0.05). These versions of the test were chosen because the standard deviation for each group were unequal. The post-hoc test for significance was the Games-Hollow multiple comparison test (alpha=0.05), which was chosen because the sample sizes were over 50.

A one-tail Pearson Correlation matrix was performed to see if there was an association between caregiver age and the level of burden experienced during any one year.

Results

The median, minimum, and maximum ages of E-E CGs and CRs from 1997 to 2014 is shown in Figure 1. The main variation in CG age occurred from 2004 to 2014, increasing from 69 years old to 75 years old. However, the median age of CRs showed minimal variation during the 17-year time frame. In 2004, the maximum age for CGs (99 years) was older than the maximum age for CRs (97 years). The two 99-year-old CGs in 2004 were outliers, as no other year saw CG ages above 90 years old. The maximum age of CRs (107 years old) occurred in 2014, the most recent year of data collection, and is another outlier, as no other year saw CR ages above 99 years old.

Both the Brown-Forsythe ANOVA ($F(3,541.1) = 16.69$, $p < 0.0001$) and Welch ANOVA ($F(3, 350.7) = 18.05$, $p < 0.0001$) tests found a significant statistical difference in the mean age of E-E CGs between the 4 specified years. The post-hoc test found statistically significant differences for the mean age of E-E CGs for each year when compared to 2014 (Table 1). The most significant difference in mean age was found between 1997 and 2014. The ANOVA tests found no statistical difference between the mean age of E-E CRs; thus, no follow-up testing was done on that group.

The sex breakdown among those involved in E-E caregiving is shown in Table 2. The majority of CGs each year were female, with an uptick in male CGs in 2014. CR sex is also predominantly female with the most equal sex division being in 2004. The relationship between the E-E CG and the CR as defined by the CG is shown in Figure 2. The identifier shown

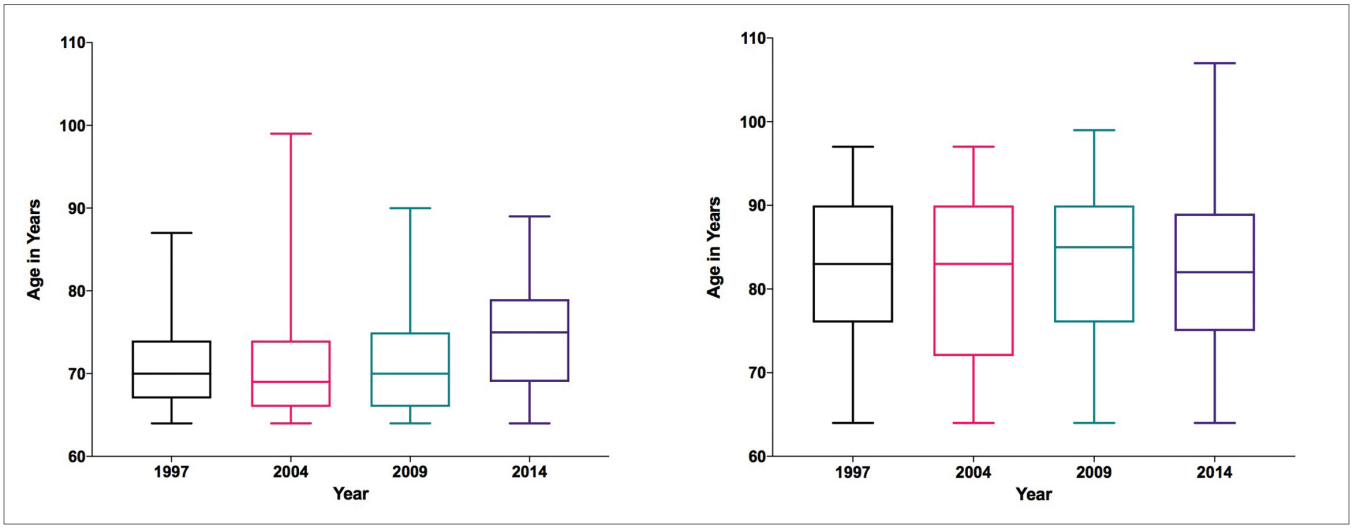

Figure 1. Summary information for E-E CGs (left) and E-E CRs (right) including median and min-max ages in 1997, 2004, 2009, and 2014.

	Mean Difference	Summary	Adjusted P value
1997 v. 2014	**3.237**	****	**<0.0001**
2004 v. 2014	**2.732**	**	**0.0017**
2009 v. 2014	**2.679**	****	**<0.0001**
1997 v. 2004	0.5042	ns	0.9228
1997 v. 2009	0.5576	ns	0.7652
2004 v. 2009	0.05338	ns	0.9999

Table 1. Results of the Games-Howell multiple comparison test comparing mean ages in 1997, 2004, 2009, and 2014. The asterisk indicates a statistically significant p-value.

(e.g. mother) refers to the CR. The relationship of spouse, mother, or friend/non-relative/neighbor dominated the top three spots, accounting for at least 65% of the relationships in any given year. Within the catchall percentage of "other" are CRs who are children and grandchildren of the CG. These CRs of the next generation accounted for 0.13% in 2017, 5.7% in 2004, 7.6% in 2009, and 6.0% in 2014.

The average length of time for E-E caregiving is approximately 5 years with a standard deviation ranging approximately from 5 to 10 years in any given year (Figure 3). The Pearson Correlation matrix found no correlation found between E-E CG age and the level of burden experienced, with r = 0.04, 0.112, 0.014, and 0.022 for 1997, 2004, 2009, and 2014 respectively. Relatedly, when asked, "How has caregiving affected your health status?" most E-E CGs responded that caregiving had not affected their health (Figure 4).

	CG Sex	CR Sex
1997	M: 24% F: 76%	M: 25% F: 36% UK: 38%
2004	M: 37% F: 63%	M: 40% F: 55% DK: 5%
2009	M: 32% F: 68%	M: 33% F: 67%
2014	M: 43% F: 57%	M: 35% F: 65%

Table 2. Breakdown of E-E CG and CR Sexes in 1997, 2004, 2009, and 2014. Note: M = Male, F = Female, UK = Unknown, DK = Don't know.

Discussion

The results thus far support the idea that the E-E caregiving population is aging, reflecting U.S population trends, with the median age of caregivers increasing from 69 to 75 years old; although, the median age of care recipients did not significantly change. While the traditional view of E-E caregiving might be of two 70 y/o spouses caring for each other or a 70-year-old child taking care of her 95-year-old mother, those are not the only relationships present in E-E caregiving. The percentage of CGs caring for a family member of the next generation (i.e. child, grandchild) rose to a high of 7.6% in 2009.

Another interesting trend is the decrease in caregiving of non-relative friends (29.9% to 18.4%) with the increase in spousal caregiving (22.5% to 38.9%) from 1997 to 2014. It is possible that this shift in relationship between E-E CGs and CRs may be partly due to a more accepting cultural shift, where non-heterosexual partners were more comfortable labeling their partner as spouse instead of non-relative friend.

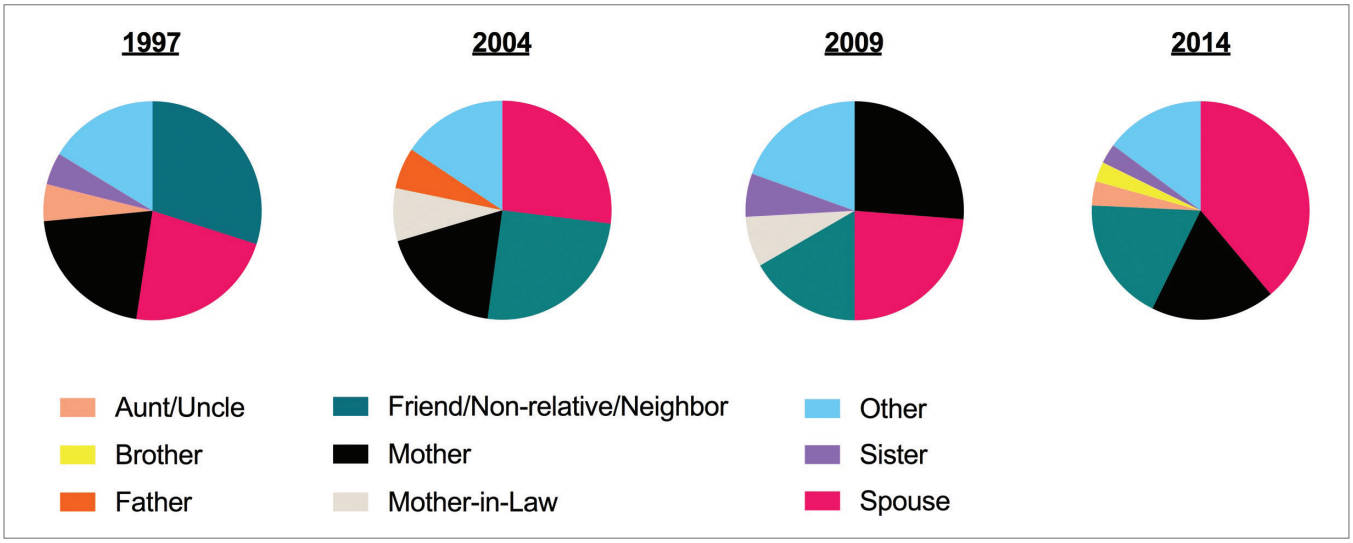

Figure 2. Relationships of E-E CGs to their CRs for 1997, 2004, 2009, and 2014. The identifying relationship is of the CR. In 2014, six relationships are shown as Brother and Sister were tied for fifth place at 3%.

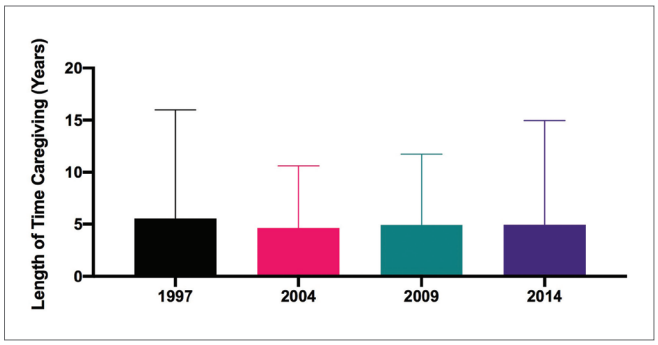

Figure 3. Mean Length of Time in years (with standard deviation) that E-E CGs report caregiving in 1997, 2004, 2009, and 2014.

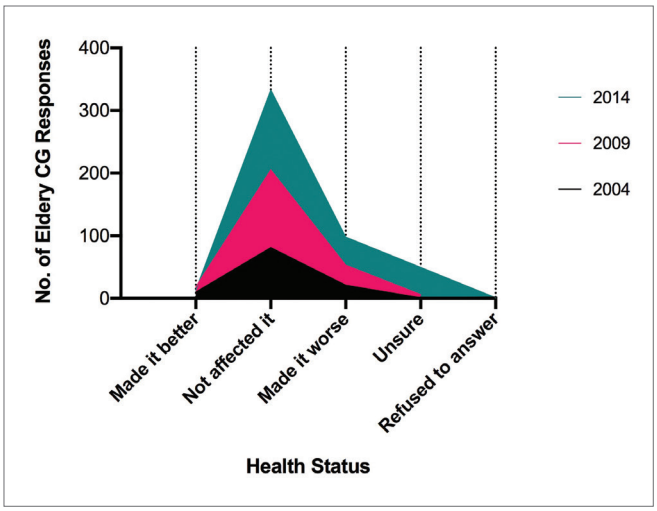

Figure 4. Histogram of E-E CG responses on impact of caregiving on self-reported Health Status for 1997, 2004, 2009, and 2014.

Prior research found that 70% of CGs who are caring for an older adult do so for 2 to 7 years (2). My data supports the notion that CG is not a short-term responsibility—the average length of time a CG is caregiving was 5 years, which was unchanged from 1997 to 2014 — even when the CGs themselves are elderly. The larger standard deviations in 1997 (10.4 years) and 2014 (10.0 years) compared to the other two years may be due to the survey's limitations. When CGs were asked how long they had been caregiving, some CGs may have responded by stating, the CR's whole life. In such cases, interviewers had been instructed to enter the CR's age as the answer; thus, potentially resulting in skewed data.

The primary limitation on this research stems from the method of data collection: surveys. Although the surveys were thorough (over 200 variables), allowed for some open-ended answers, and gave interviewers cues on how to "probe" a respondent, the fact remains that subjective survey data can often have less than optimal accuracy. The original study design did not include any additional follow-up or verification of the information.

The Level of Burden score used in the correlation test was a *consolidated* score meaning the study makers asked multiple questions regarding hours of care and number of daily activities performed in the survey, assigned values to those answers, and then consolidated a respondent's answers into a Level of Burden scale (9). More interesting results could come from performing correlation tests between the specific variables asked (regarding financial, emotional and physical stress) and an E-E CGs age.

Conclusion

As CGs are as group get older, it is imperative that health care professionals ensure the needs of CGs are being sufficiently addressed. The lack of thorough investigation on the E-E caregiving population may be concealing the needs of this specific population. Follow-up studies should explore caregiving subset populations such as generation spanning E-E caregiving, particularly when the CG is the older participant, or non-relative social E-E caregiving, because such relationships likely have interpersonal dynamics and complexities that are not being addressed elsewhere.

Similarly, additional research should investigate how best to shorten the average length of time that E-E CGs undergo such responsibilities. Likewise, with no clear consensus in the field of caregiving on the positive and negative impacts of caregiving on CGs, particularly E-E CGs, new studies need to explore potential benefits and burdens. Such research could help society prioritize education and inform action plans to assist caregivers, ensuring that a) they have a high quality of life near the end of life, and b) that their workload does not shift to stressed institutional health care systems.

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Disclosures

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References

1. Wittenberg E, Prosser LA. Health as a family affair. *N Engl J of Med*. 2016; 374(19):1804–6.
2. National Academies of Sciences, Engineering, and Medicine. Families caring for an aging America. 2016. DOI: https://doi.org/10.17226/23606.
3. Boyle DA. The caregiving quandary. *Clin J Oncol Nurs*. 2017; 21(2):139.
4. Vincent GK, Velkoff VA. The next four decades: The older population in the United States: 2010 to 2050: US Department of Commerce. Economics and Statistics Administration, US Census Bureau. 2010; 25-1138
5. Colby SL, Ortman JM. The baby boom cohort in the United States: 2012 to 2060. Current Population Reports. U.S. Census Bureau. 2014; 25-1141.
6. Schulz R, Beach SR. Caregiving as a risk factor for mortality: The caregiver health effects study. *JAMA*. 1999; 282(23):2215-9.

7. Anderson LA, Edwards VJ, Pearson WS, Talley RC, McGuire LC, Andresen EM. Adult caregivers in the United States: Characteristics and differences in well-being, by caregiver age and caregiving status. *Prev Chronic Dis*. 2013; 10:130090. DOI: http://dx.doi.org/10.5888/pcd10.130090
8. National Alliance for Caregiving. Caregiving in the US 2015. NAC and the AARP Public Institute. Washington DC: Greenwald & Associates. 2015. https://www.caregiving.org/research/open-data/
9. National Alliance for Caregiving. Caregiving in the US 2009. NAC and the AARP Public Institute. Washington DC: Greenwald & Associates. 2009. https://www.caregiving.org/research/open-data/