



THE UNIVERSITY *of* EDINBURGH

Edinburgh Research Explorer

Trends in informal care for disabled older Americans, 1982-2012

Citation for published version:

Janus, A & Doty, P 2018, 'Trends in informal care for disabled older Americans, 1982-2012', *The Gerontologist*, vol. 58, no. 5, pp. 863–871. <https://doi.org/10.1093/geront/gnx076>

Digital Object Identifier (DOI):

[10.1093/geront/gnx076](https://doi.org/10.1093/geront/gnx076)

Link:

[Link to publication record in Edinburgh Research Explorer](#)

Document Version:

Peer reviewed version

Published In:

The Gerontologist

General rights

Copyright for the publications made accessible via the Edinburgh Research Explorer is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy

The University of Edinburgh has made every reasonable effort to ensure that Edinburgh Research Explorer content complies with UK legislation. If you believe that the public display of this file breaches copyright please contact openaccess@ed.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.



Trends in Informal Care for Disabled Older Americans, 1982-2012

Word count (abstract, text, and references): 5.988

Dr. Alexander L. Janus, PhD
University of Edinburgh
School of Social and Political Science
Chrystal Macmillan Building
15a George Square
Edinburgh EH8 9LD
United Kingdom

alex.janus@ed.ac.uk

+44 7454 922590

Dr. Pamela Doty, PhD
US Department of Health & Human Services
Office of the Assistant Secretary for Planning and Evaluation
200 Independence Avenue, SW
Washington, DC 20201

Pamela.Doty@hhs.gov

(202) 690-7858

Acknowledgment

We would like to thank Brenda Spillman and Eric Stallard for very thorough comments on the analyses as well as Ruth Katz, Helen Lamont, and Bill Marton from the Office of the Assistant Secretary for Planning and Evaluation for very useful substantive and methodological comments. We would also like to thank participants in the quantitative methods workshop and the sociology seminar series at the University of Edinburgh for many insightful comments. Finally, extensive comments from three anonymous reviewers greatly contributed to the improvement of this manuscript. The contents of this paper are the responsibility of the authors and do not necessarily reflect the views or policies of the U.S. Department of Health and Human Services.

Conflict of Interest

We declare that we do not have any conflicts of interest.

Abstract

Purpose of the study. We examine trends in informal care from the perspective of both community-dwelling disabled older Americans and their caregivers from 1982 to 2012. We decompose hours of care received from spouses and children according to changes in: (a) the number of *potential* spousal and child caregivers (“family structure”), (b) the likelihood that existing spouses and children are caregivers (“caregiving propensity”), and (c) the amount of care provided by individual caregivers (“time burden”). *Design and Methods.* We examine two sets of time trends based on distinct samples of community-dwelling disabled older Americans from the 1982-2004 waves of the National Long-Term Care Survey (NLTC) and the 2000-2012 waves of the Health and Retirement Study (HRS). *Results.* Existing spouses’ and children’s decreasing likelihood of being caregivers led to fewer spousal and child caregivers per disabled older person in the 2004 NLTC than the 1982 NLTC. However, the NLTC and HRS time trends suggest that the amount of care provided by individual caregivers has been similar across the thirty years. *Implications.* Because individual caregivers’ time burden has remained fairly constant since the early 1980s, advocacy on behalf of policies that promote more and better support for caregivers is appropriate.

Key Words

HRS, NLTC, Caregiving – Informal, Demography, Intergenerational Relationships, Caregiver Stress

Introduction

Some advocates for older people and for family caregivers have suggested that the U.S. is in the midst of a growing long-term care and public health crisis (Centers for Disease Control and Prevention [CDC], 2017; Redfoot, Feinberg, & Houser, 2013; cf. Roth, Fredman, & Haley, 2015). They have pointed to various social trends such as decades of reduced fertility rates (Kirmeyer & Hamilton, 2011), lower marriage rates (Ruggles, 2015), higher divorce rates (Ruggles, 2015), the decline in parent-child co-residence (Ruggles, 2015), and the rise in women's labor force participation (U.S. Bureau of Labor Statistics [BLS], 2015) as having led to declines in the number of potential family caregivers or the availability of existing family members to provide care. At the same time, they recognize that informal caregiving is sometimes a stressful experience (CDC, 2017; Redfoot et al., 2013). Therefore, the “backbone” of the long-term care system—that is, family caregiving—is perceived to be reaching a breaking point (CDC, 2017; Redfoot et al., 2013).

If declines in informal care receipt have increased older people's unmet needs for human help, this would pose a public policy concern because of the high cost of replacing unpaid assistance from family with paid care (which Chari, Engberg, Ray, and Mehrotra (2015) estimated at \$221 billion, assuming paid, unlicensed personnel). Declines in informal care receipt would not necessarily point to a reduction in individual family caregivers' time burden. Quite the contrary, having fewer available family members to share caregiving responsibilities could actually lead to an increase in individual family caregivers' time burden. Although caregivers who report high stress are a minority (Roth et al., 2015), time burden is an important factor in explaining caregivers' health and subjective well-being (Pinquart & Sorensen, 2006).

If we take the standpoint of an older person situated within an informal support network, it is apparent that trends in informal care can be viewed from the perspective of the disabled

older person or their caregivers. Previous research has primarily focused on trends in older people's receipt of care using nationally representative surveys such as the National Long-Term Care Survey (NLTCS), the Medicare Current Beneficiary Survey (MCBS), and the Health and Retirement Study (HRS) that are designed to track changes in various dimensions of older people's health and functional status, health expenditures and services use, and caregiving resources that are relevant to older people's well-being.

Using the NLTCS, Spillman and Black (2005) found that receipt of any human help to manage disability declined from the 1980s into the late 1990s, as did Freedman, Agree, Martin, and Cornman (2006) in analyses of the MCBS. However, analysis of receipt of human assistance among HRS respondents aged 55 and older from 1998-2012 (Ankuda & Levine, 2016) found that receipt of any human help from paid and unpaid helpers other than friends increased. However, previous research from the perspective of the care recipient has presented less information on trends in number of caregivers and hours of care received.

Furthermore, despite a number of cross-sectional studies on caregiving practices and experiences (National Alliance for Caregiving [NAC] & AARP Public Policy Institute [AARP PPI], 2015), there is little systematic evidence on trends in informal caregivers' time burden, the likelihood that existing family members are caregivers, and related trends from the perspective of the caregiver. Using the NLTCS's caregiver surveys, Wolff and Kasper (2006) found that primary informal caregivers' time burden as well as the percentage of those reporting work conflict changed little from 1989 to 1999, but they also noted a striking decline in secondary caregivers. Estimates from Spillman and Black's (2005) study of the number of potential and active family caregivers suggest that the likelihood that spouses are caregivers decreased modestly from 1994 to 1999.

This study addresses these empirical gaps in the literature by examining trends in informal care from the perspective of both the disabled older person and their caregivers from

1982 to 2012. Our analysis is based on distinct samples of community-dwelling disabled older Americans from the NLTCs (1982 and waves every five years from 1984 through 2004) and the HRS (waves every two years from 2000 through 2012). In addition to information on care receipt, both the NLTCs and HRS contain data on care provision by individual caregivers. We decompose hours of care received from spouses and children according to changes in: (a) the number of *potential* spousal and child caregivers (“family structure”), (b) the likelihood that existing spouses and children are caregivers (“caregiving propensity”), and (c) the amount of care provided by individual spousal and child caregivers (“time burden”).

Our motivation for the decomposition is twofold. First, because different social trends are likely responsible for changes over time in family structure, caregiving propensity, and time burden, the decomposition is an important first step in gaining a better understanding of the social processes driving the overall trend in hours of care received. Second, as we discuss in the implications section, which components of the decomposition are driving the overall trend has public policy implications.

It is important to acknowledge that there is no one survey that, with consistent definitions and measures of functional disability, covers the entire 30-year period. Moreover, we think that there is unlikely ever to be such a survey, which creates problems to be sure in discerning long-term trends with the level of accuracy we would all prefer. The time lines of the NLTCs and the HRS do overlap, and they are the two most compatible surveys available. However, because of some differences in definitions and measures of functional disability, we cannot treat these two surveys as providing one continuous series of comparable data points. We can, however, legitimately ask whether the trends identifiable within each survey suggest that older people’s reliance on or family members’ provision of assistance with daily activities is increasing, decreasing or staying the same.

Theoretical Model and Hypotheses

Figure 1 presents our theoretical model and hypotheses regarding trends in the components of the decompositions for hours of care received from spouses and children. The dashed lines refer to pathways in the theoretical model that are not examined in the analysis, but that contribute to our hypotheses regarding trends in the components of the decompositions.

Social gerontologists and caregiving advocates have pointed to social trends such as decades of reduced fertility rates (Kirmeyer & Hamilton, 2011), lower marriage rates (Ruggles, 2015), and higher divorce rates (Ruggles, 2015) (Box A in Figure 1) as likely having contributed to declines in the number of potential spousal and child caregivers (H_{s1} and H_{c1} in Figure 1) (Seltzer & Bianchi, 2013). However, while family structure constitutes the “demographic scaffolding” of family relationships (Seltzer & Bianchi, 2013), the presence of a spouse, children or other family members does not necessarily imply that one is protected by a family safety net.

Drawing on rational choice theory and models of family decision making (Bryant & Zick, 2006), previous studies have pointed to both *personal commitment and costs* as well as *the availability of other family members* in explaining individual family members’ provision of care (Silverstein, Conroy, & Gans, 2008). Previous studies have also examined factors related to *older people’s needs for human help*, such as intrinsic disability, in explaining the size and composition of older people’s informal support networks (Li & Fries, 2005).

With regard to cost-related factors, studies of caregiver selection within sibling groups over the life course have found that children who live in closer geographic proximity to their parent (Leopold, Raab, & Engelhardt, 2014; Pillemer & Sutor, 2014) or who work fewer hours are more likely to transition to parent care (Leopold et al., 2014), although other studies

have not found the expected relationship between children's employment and parent care (Chesley & Poppie, 2009). Therefore, social trends such as the decline in parent-child co-residence (Ruggles, 2015) and the rise in women's labor force participation (BLS 2015) (Box B in Figure 1) have been identified as likely having contributed to declines in the availability of existing family members to provide care (Seltzer & Bianchi, 2013) (H_{s2} and H_{c2} in Figure 1).

A decrease in older people's intrinsic or unmet needs for human help (Box C in Figure 1) could also have contributed to declines in spouses' and adult children's propensity to give care (H_{s2} and H_{c2} in Figure 1). Christine Bishop (1999) was among the first long-term care researchers to call attention to the decline in nursing home use taking place and to examine possible explanations that included growth in alternative residential eldercare settings ("assisted living" broadly defined), increased access to Medicare-funded home care aide services during the 1990s that was likely to be reversed by home health payment reforms legislated in the Balanced Budget Act of 1997, and possible declines in intrinsic disability or at least in unmet need for human help to cope with disability among older Americans. All of the aforementioned social trends could also put downward pressures on spousal and adult child caregivers' time burden (H_{s3} and H_{c3} in Figure 1).

With regard to the availability of other family members, the hypothesized decline in the number of child caregivers, due to the hypothesized declines in number of children (H_{c1} in Figure 1) and children's propensity to give care (H_{c2} in Figure 1), could partly offset (H_{p2} in Figure 1) declines in individual child caregivers' time burden (or possibly even cause caregivers' time burden to increase) due to the negative within-cohort relationship between sibling availability and individual children's provision of care (Spitze, Ward, Deane, & Zhuo, 2012). Similarly, the hypothesized decline in number of children (H_{c1} in Figure 1) could partly offset (H_{p1} in Figure 1) declines in children's propensity to give care. Therefore, due to

the hypothesized negative trends in the number of potential spousal and child caregivers as well as the hypothesized (net) negative trends in caregiving propensity and time burden, we hypothesize that the hours of care received from spouses and children will have decreased overall.

Design and Methods

Secondary analysis of the NLTCs and the HRS was approved by the School of Social and Political Science Research Office at the University of Edinburgh. Samples from the NLTCs (1982 and waves every five years from 1984 through 2004) and the HRS (waves every two years from 2000 through 2012) are restricted to the community-dwelling older population 65 years and over who were chronically disabled (i.e., for at least 3 months) on at least one personal care task (“activity of daily living” [ADL]) or household management task (“instrumental activity of daily living” [IADL]), of which there were 24,115 such persons in the NLTCs and 22,523 such persons in the HRS. The units of analysis are, depending on the component of the decomposition examined, disabled older people, their spouses and children or their spousal and adult child caregivers (Table 1).

The analyses for both the NLTCs and the HRS are based on older people who meet broad criteria of limitations in ADL’s and IADL’s, using all available activities from each study. It is important to acknowledge that the NLTCs and the HRS rely on different definitions and measures of functional disability. For the NLTCs, an individual is regarded as having underlying difficulty in performing an ADL if (1) they did not do the task under consideration, (2) received active or standby help or (3) used special equipment. Underlying difficulty with an IADL is operationalized as not being able to perform the task because of disability or a health problem. For the HRS, IADL responses of “yes” (has “any difficulty”) and “can’t do” (“because of a health or memory problem”) and ADL responses of “yes” and

“can’t do” were considered limitations. Thus, the HRS’s definition of intrinsic disability is broader than the NLTCS’s definition in that it includes individuals who perform a task without human help or special equipment despite having some difficulty.

We also analyzed trends in number of caregivers and hours of care received based on older people who meet more restrictive criteria of activity limitations—namely, older people who received *any* human help (informal or formal). These more restrictive criteria limit these analyses to subsamples that may be more comparable across studies. Estimates of number of caregivers are similar between the NLTCS and the HRS in 1999/2000 and 2004 regardless of which samples are used. Estimates of hours of care received are generally higher in the HRS than the NLTCS regardless of which samples are used.

Both studies ask about limitations with the same 6 ADLs: dressing, bathing, eating, getting in or out of bed, using the toilet, and “get[ting] around inside” (NLTCS) or “walking across a room” (HRS). The HRS also asks about limitations with 5 IADLs: preparing meals, shopping for groceries, taking medicine, managing money, and making telephone calls. The NLTCS asks about limitations with these first 4 IADLs plus 5 additional tasks: doing “heavy work around the house,” doing “light work around the house,” doing laundry, “getting around outside,” and “going places beyond walking distance.”

In both the NLTCS and the HRS helpers are identified only if they provided assistance with an ADL or IADL. In the NLTCS respondents are asked, for the ADLs and the IADLs separately, what tasks each helper provided assistance with and how much time during the past week each helper spent helping with those tasks. In the HRS respondents are asked for the last month how many days each helper provided assistance (with ADLs and/or IADLs) and how many hours per day help was provided on the days the helper provided assistance. In both surveys the interview is conducted with a proxy informant if the respondent is unavailable.

Decomposition of Hours of Care Received

We decompose mean hours of care received into three parts: “family structure,” “the propensity to give care,” and “caregiving intensity.” The three-part decomposition for the mean hours of care received from children is:

$$\bar{C} = \mu_f P_c \mu_h,$$

where μ_f is the mean number of children (i.e., family structure), P_c is the proportion of children who are caregivers (i.e., the propensity to give care), and μ_h is the mean hours of care provided by child caregivers (i.e., caregiving intensity). The decomposition for care received from spouses is:

$$\bar{S} = P_f P_c \mu_h,$$

where P_f is the proportion of older people who are married, P_c is the proportion of spouses who are caregivers, and μ_h is the mean hours of care provided by spousal caregivers. Furthermore, the product of the first two quantities in the child decomposition ($\mu_f P_c$) gives us the mean number of child caregivers, while the first two quantities in the spousal decomposition ($P_f P_c$) gives us the proportion of older people with spousal caregivers.

We adjust estimates of spouses’ and adult children’s propensity to give care and caregiving intensity for differences in older people’s age and limitations with ADL’s and IADL’s. Furthermore, because children’s propensity to give care may be negatively related to the availability of siblings, we adjust these estimates for sibship size. Similarly, we adjust estimates of children’s caregiving intensity for number of siblings who are caregivers. To control for other factors, we use generalized linear models with robust standard errors to take into account the clustering of children within measurement occasions (for the child models only) and the clustering of measurement occasions within older persons. All analyses were weighted using appropriate respondent-level weights.

Results

Controlling for age and limitations with daily activities, estimates from the NLTCs indicate that the number of adult child caregivers ($-.14, p < .01$), other family caregivers ($-.32, p < .01$), and other informal caregivers ($-.10, p < .01$) per disabled older person (including those without a caregiver) decreased from 1982 to 2004 (Figure 1). The proportion of disabled older people with a caregiving spouse also decreased from .32 to .25 ($p < .01$). By contrast, from 2000 to 2012 estimates from the HRS indicate that the number of adult child caregivers ($.05, p < .05$) and other family caregivers ($.08, p < .01$) per disabled older person increased. The HRS estimates also suggest that from 2000 to 2012 the proportion of disabled older people with a caregiving spouse increased from .24 to .28 ($p < .01$).

Estimates from the NLTCs indicate that average hours of care received from adult children during the previous week per disabled older person (including those not receiving any care) declined from 8.2 hours in 1982 to 3.9 hours in 1999 ($p < .01$) (Figure 2). Average hours of care received from spouses declined from 8.3 hours in 1982 to 4.6 hours in 1999 ($p < .01$). Average hours of care received from other family caregivers ($p < .01$) and other informal caregivers ($p < .05$) also declined during this period. Since 2000, according to the HRS estimates, average hours of care received from all informal sources have stayed fairly constant.

With regard to the family structure component of the decompositions (Table 2), the NLTCs estimates suggest that from 1982 to 2004 the percentage of disabled older people who are married decreased from 43.7 percent to 37.5 percent ($p < .05$), while the mean number of children increased from 2.4 children in 1982 to 2.9 children in 2004. By contrast, the HRS estimates suggest that both the percentage of married disabled older people and the mean number of children have stayed fairly constant from 2000 to 2012. Therefore, the

results were largely inconsistent with our expectations regarding trends in family structure (H_{s1} and H_{c1} in Figure 1) except for the decrease in the percentage of married disabled older people between the 1982 and 2004 NLTCS surveys.

Consistent with our expectations (H_{s2} in Figure 1), the NLTCS estimates indicate that, among married disabled older people, the probability of having a spousal caregiver decreased from .83 in 1982 to .59 in 2004 ($p < .01$) (Figure 4). By contrast, the HRS estimates suggest that spouses' caregiving propensity has risen modestly from .54 in 2000 to .59 in 2012 ($p < .05$). Consistent with our expectations (H_{c2} in Figure 1), children's propensity to give care decreased from .22 in 1982 to .14 in 2004 ($p < .01$) (Figure 4). By contrast, children's probability of being a caregiver stayed fairly constant from 2000 to 2012. Despite the negative relationship between number of siblings and children's caregiving propensity in the pooled NLTCS and HRS waves (see Supplementary Table C), the estimates from the models with controls for number of children suggest that even if the family structure component of the decompositions had remained constant the NLTCS and HRS trends in children's caregiving propensity would have been little changed (Figure 4).

Contrary to our expectations (H_{s3} and H_{c3} in Figure 1), the NLTCS estimates indicate that there was no statistically significant difference between 1989 and 2004 in hours of care provided by spousal or adult child caregivers during the previous week ($p \geq .05$) (Figure 5). According to the HRS estimates, the hours of care provided by spousal caregivers rose by 6.0 hours from 2000 to 2008 ($p < .05$) and then declined by 11.1 hours from 2008 to 2012 ($p < .01$), resulting in statistically insignificant net change between 2000 and 2012 ($p \geq .05$). The estimates from the models with controls for number of child caregivers suggest that if number of child caregivers had remained constant the estimated decrease in individual child caregivers' time burden from 1989 to 1999 would have been 16 percent greater, although this decrease would have remained statistically insignificant ($p \geq .05$) (Figure 5, see

Supplementary Table D for the complete model estimates). Therefore, consistent with our expectations (H_{p2} in Figure 1), our estimates suggest that the decline in number of child caregivers has put modest upward pressure on individual child caregivers' time burden.

Discussion

The NLTCs estimates suggest that, controlling for older people's age and limitations with daily activities, the number of spousal and adult child caregivers decreased from 1982 to 2004. However, contrary to our expectations (H_{c1} and H_{p1} in Figure), changes over time in number of children were modest (and sometimes not in the expected direction) and had little effect on the trend in children's propensity to give care. One reason that decreasing cohort total fertility rates starting with the 1932 birth cohort (Kirmeyer & Hamilton, 2011) may have not been manifest in our estimates is greater "family blending" and an increase in the number of step-kin that could have offset declines in the number of biological children (Wachter, 1997).

Consistent with our expectations (H_{s2} and H_{c2} in Figure 1), the NLTCs estimates suggest that spouses' and children's propensity to give care declined from 1982 to 2004. The decline in caregiving propensity could be explained by the declining availability of these close relatives to provide care, greater reliance on paid services, and/or a decrease in older people's needs for human help (that are not captured by the covariates in the present analysis). However, substantial declines in parent-child co-residence (Ruggles, 2015) as well as modest declines in geographic mobility among the older population (Wolf & Longino, 2005) occurred before the time period covered by this study. The opportunity costs of taking up a caregiver role may have increased due to the rise in women's labor force participation during the 1980's and 1990's (BLS 2015). Men's opportunity costs may also be greater now

due to increases in their contributions to domestic tasks during the same time period (Bianchi, 2011).

If disabled older people's unmet needs grew during the 1980's and 1990's due to the declining availability of family caregivers, we might suppose that the percentage of older people receiving paid home care and/or living in residential care settings would have increased. In the NLTCs the percentage of disabled older people living at home who received any paid care rose between 1989 and 1999 and then declined to almost 1982 levels, as Medicare home health benefit-financed aide services increased in response to coverage liberalizations then decreased dramatically following the home health payment reforms legislated in the Balanced Budget Act of 1997 (Wolff & Kasper, 2006). However, between 2002 and 2014 in the HRS receipt of any paid home care rose 25 percent among all older Americans and about 17 percent among those with severe disabilities (Johnson, 2017).

The percentage of older people 65 years and over living in residential care settings increased from 5.3 percent in 1992 to 6.5 percent in 2002 (Spillman & Black, 2006; Spillman, Liu, & McGilliard, 2002). The growth in residential eldercare masks two contradictory trends: (1) the substantial decline in nursing home use and (2) the dramatic growth in the percentage of older people living in alternative residential care settings (Freedman & Spillman, 2014; Grabowski, Stevenson, & Cornell, 2012). Compared to nursing homes, these alternative settings encompass a broader range of accommodations, often offering a higher level of privacy and independence (Freedman & Spillman, 2014). The growth in alternative residential care settings may be partially explained by the decline in the availability of family caregivers. At the same time, these settings may also be more attractive to disabled elders and their families because they are more compatible with elders' and their adult children's preferences for independent living and also offer disabled elders more opportunities to socialize with peers. Also, based on longitudinal analyses of the HRS,

Johnson (2017) found that assisted living is more affordable than home care to older Americans who have income or savings above Medicaid allowable limits unless they are admitted to a nursing home and spend down to Medicaid eligibility. This is because assisted living costs are all-inclusive (of food, housing, and other basic living expenses as well as services). Thus, older adults with disabilities can apply a much greater share of their income, savings and their major asset (home equity) toward the cost of assisted living than they could toward the cost of home care.

At the same time, older people's needs have likely changed due to the declines in disability (Schoeni, Freedman, & Martin, 2008) and cognitive impairment (Larson, Yaffe, & Langa, 2013) as well as the growth in reliance on assistive technologies (Freedman et al., 2006). Most notably, Freedman et al. (2006) found, using a decomposition technique, that shifts toward reliance on technology accounted for half the decline in numbers of older people dependent on human helpers. Schoeni et al. (2008) note that decline in "disability" due to improvements in health status and physical and cognitive functioning can be difficult to differentiate from decreased need for human help due to assistive devices and environmental modifications. They concluded that substantial reductions in old-age disability between the early 1980s and early 2000s are likely also attributable to advances in medical care and socio-economic changes.

The HRS estimates suggest that children's probability of being a caregiver stayed fairly constant while spouses' caregiving propensity rose modestly between 2000 and 2012. Trends in disability (Federal Interagency Forum on Aging-Related Statistics, 2016) as well as changes possibly related to the availability of family caregivers (Ruggles, 2015) were similarly stagnant during this period. Between 2002 and 2014, in the HRS, nursing home use among all older Americans decreased by 25% (17% among those with severe disabilities);

use of alternative residential care settings among all older Americans remained constant but doubled among those with severe disabilities (Johnson, 2017).

However, while there has been a decline in spouses' and children's propensity to give care, the NLTCs and HRS estimates suggest that, contrary to our expectations (H_{s3} and H_{c3} in Figure 1), individual spousal and child caregivers' time burden has remained fairly constant over the 30-year period covered by this study. Furthermore, consistent with our expectations (H_{p2} in Figure), our estimates suggest that the decline in number of child caregivers has put modest upward pressure on individual child caregivers' time burden. We suspect that time burden has not risen because of a decrease in older people's needs over time, but that it has not decreased because of the decline in the number of child caregivers.

Implications

Individual caregivers' time burden is not only consequential from the standpoint of caregiver stress and well-being, but from the perspective of the older person receiving care and public long-term care expenditures. Caregiver stress is a powerful predictor that disabled older people will stop receiving care "at home" where they prefer to be and move into nursing homes (Spillman, 2014). Minimizing nursing home use is a public policy goal because nursing home care is costly and transitioning from community to nursing home care increases the likelihood that financial help from Medicaid will be required.

Our trend analyses provide little evidence that the U.S. is currently in the midst of a growing public health crisis because the time burden on spouses and adult children who provide care to disabled older people has increased. Nevertheless, the fact that individual caregivers' time burden has remained fairly constant over the study period suggests that advocacy on behalf of policies that promote more and better support for caregivers is appropriate. Caregiver advocacy groups such as AARP and the Family Caregiver Alliance

favor requiring formal assessment of the needs of family caregivers when the care needs of applicants for Medicaid-funded long-term services and supports are assessed (Kelly, Wolfe, Gibson, & Feinberg, 2013). A U.S. Department of Labor (2016) report argued that paid family leave for employed caregivers of older people is critical and noted that California, New Jersey, and Rhode Island had already established such programs. When family caregivers have been asked what kinds of assistance they thought would be most helpful, the most frequently mentioned types of assistance have included a tax break or a monetary subsidy and respite services (Doty & Spillman, 2015; NAC & AARP PPI, 2015). In the meantime, unless or until any new caregiver support policies are adopted, government support for caregivers will remain limited to the National Family Caregiver Support Program (NFCSP), funded through the Older Americans Act, and indirect support available to family caregivers of Medicaid home and community-based services recipients (Doty & Spillman, 2015).

Our findings are relevant to broader discussions regarding past trends and future prospects in the practical importance of intergenerational relationships (Swartz, 2009). While our 2012 results are certainly consonant with findings from a number of studies suggesting that families remain the “mainstay” or “backbone” of the long-term care system, the trend analyses suggest that the role of families in the provision of assistance with daily activities is less prominent than before. However, the trends documented in this study do not necessarily imply that intergenerational relationships are decreasing in importance. While arguments emphasizing the resilience and resurgence of intergenerational relationships have highlighted the prevalence of affective ties (Swartz, 2009), there are few systematic comparisons of intergenerational interaction over time. Social gerontologists could better utilize existing data sources, such as the American Time Use Survey, to gain a more complete picture of broader trends in older people’s social connectedness and informal support resources, and the original

decomposition approach presented in this paper could help to significantly advance this research agenda.

Works Cited

- Bianchi, S. M. (2011). Family change and time allocation in american families. *The Annals of the American Academy of Political and Social Science*, **638**, 21-44.
doi:10.1177/0002716211413731
- Bishop, C. E. (1999). Where are the missing elders? The decline in nursing home use, 1985 and 1995. *Health Affairs*, **18**, 146-155. doi:10.1377/hlthaff.18.4.146
- Bryant, W. K., & Zick, C. D. (2006). *The economic organization of the household*. New York: Cambridge University Press.
- Centers for Disease Control and Prevention. (2017). *Caregiving: A public health priority*. Retrieved from <http://www.cdc.gov/aging/caregiving>
- Chari, A. V., Engberg, J., Ray, K., & Mehrotra, A. (2015). The opportunity costs of informal elder-care in the united states. *Health Services Research*, **50**, 871-882.
doi:10.1111/1475-6773.12238
- Chesley, N., & Poppie, K. (2009). Assisting parents and in-laws: Gender, type of assistance, and couples' employment. *Journal of Marriage and Family*, **71**, 247-262.
doi:10.1111/j.1741-3737.2009.00597.x
- Doty, P., & Spillman, B. (2015). Help for family caregivers available from government programs and policies. In J. E. Gaugler & R. L. Kane (Eds.), *Family caregiving in the new normal* (pp. 153-192). New York: Elsevier.
- Federal Interagency Forum on Aging-Related Statistics. (2016). *Older americans 2016: Key indicators of well-being*. Retrieved from <https://agingstats.gov/docs/LatestReport/Older-Americans-2016-Key-Indicators-of-WellBeing.pdf>
- Freedman, V. A., Agree, E. M., Martin, L. G., & Cornman, J. C. (2006). Trends in the use of assistive technology and personal care for late-life disability, 1992-2001. *The Gerontologist*, **46**, 124-127. doi:10.1093/geront/46.1.124
- Freedman, V. A., & Spillman, B. C. (2014). The residential continuum from home to nursing home: Size, characteristics and unmet needs of older adults. *Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, **69**, S42-S50.
doi:10.1093/geronb/gbu120
- Grabowski, D. C., Stevenson, D. G., & Cornell, P. Y. (2012). Assisted living expansion and the market for nursing home care. *Health Services Research*, **47**, 2296-2315.
doi:10.1111/j.1475-6773.2012.01425.x
- Johnson, R. W. (2017). *The lifetime risk of receiving long-term services and supports*. Retrieved from Department of Health and Human Services, Assistant Secretary for Planning and Evaluation: forthcoming
- Kelly, K., Wolfe, N., Gibson, M. J., & Feinberg, L. (2013). *Listening to family caregivers: The need to include family caregiver assessment in medicaid home- and community-based service waiver programs*. Retrieved from AARP Public Policy Institute: http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2013/the-need-to-include-family-caregiver-assessment-medicaid-hcbs-waiver-programs-report-AARP-ppi-ltc.pdf
- Kirmeyer, S. E., & Hamilton, B. E. (2011). *Childbearing differences among three generations of u.S. Women* (NCHS Data Brief No. 68). Retrieved from Centers for Disease Control and Prevention: <https://www.cdc.gov/nchs/data/databriefs/db68.pdf>
- Larson, E. B., Yaffe, K., & Langa, K. M. (2013). New insights into the dementia epidemic. *New England Journal of Medicine*, **369**, 2275-2277. doi:10.1056/NEJMp1311405

- Leopold, T., Raab, M., & Engelhardt, H. (2014). The transition to parent care: Costs, commitments, and caregiver selection among children. *Journal of Marriage and Family*, **76**, 300-318. doi:10.1111/jomf.12099
- Li, L. W., & Fries, B. E. (2005). Elder disability as an explanation for racial differences in informal home care. *The Gerontologist*, **45**, 206-215. doi:10.1093/geront/45.2.206
- National Alliance for Caregiving, & AARP Public Policy Institute. (2015). *Caregiving in the united states 2015*. Retrieved from <http://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf>
- Pillemer, K., & Suitor, J. J. (2014). Who provides care? A prospective study of caregiving among adult siblings. *The Gerontologist*, **54**, 589-598. doi:10.1093/geront/gnt066
- Pinquart, M., & Sorensen, S. (2006). Gender differences in caregiver stressors, social resources, and health: An updated meta-analysis. *Journal of Gerontology: PSYCHOLOGICAL SCIENCES*, **61B**, P33-P45. doi:https://doi.org/10.1093/geronb/61.1.P33
- Redfoot, D., Feinberg, L., & Houser, A. (2013). *The aging of the baby boom and the growing care gap: A look at future declines in the availability of family caregivers* (Insight on the Issues 85). Retrieved from AARP Public Policy Institute: http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2013/baby-boom-and-the-growing-care-gap-insight-AARP-ppi-ltc.pdf
- Roth, D. L., Fredman, L., & Haley, W. E. (2015). Informal caregiving and its impact on health: A reappraisal from population-based studies. *The Gerontologist*, **55**, 309-319. doi:10.1093/geront/gnu177
- Ruggles, S. (2015). Patriarchy, power, and pay: The transformation of american families, 1800-2015. *Demography*, **52**, 1797-1823. doi:10.1007/s13524-015-0440-z
- Schoeni, R. F., Freedman, V. A., & Martin, L. G. (2008). Why is late-life disability declining? *Milbank Quarterly*, **86**, 47-89. doi:10.1111/j.1468-0009.2007.00513.x
- Seltzer, J. A., & Bianchi, S. M. (2013). Demographic change and parent-child relationships in adulthood. *Annual Review of Sociology*, **39**, 275-290. doi:10.1146/annurev-soc-071312-145602
- Silverstein, M., Conroy, S. J., & Gans, D. (2008). Commitment to caring: Filial responsibility and the allocation of support by adult children to older mothers. In M. E. Szinovacz & A. Davey (Eds.), *Caregiving contexts: Cultural, familial, and societal implications* (pp. 71-91). New York: Springer.
- Spillman, B. C. (2014). *Why do elders receiving informal home care transition to long stay nursing home residency?* Department of Health and Human Services, Assistant Secretary for Planning and Evaluation.
- Spillman, B. C., & Black, K. J. (2005). *Staying the course: Trends in family caregiving* (No. 2005-17). Retrieved from AARP Public Policy Institute: http://assets.aarp.org/rgcenter/il/2005_17_caregiving.pdf
- Spillman, B. C., & Black, K. J. (2006). *The size and characteristics of the residential care population: Evidence from three national surveys*. Retrieved from Department of Health and Human Services, Assistant Secretary for Planning and Evaluation: <https://aspe.hhs.gov/system/files/pdf/74581/3natlsur.pdf>
- Spillman, B. C., Liu, K., & McGilliard, C. (2002). *Trends in residential long-term care: Use of nursing homes and assisted living and characteristics of facilities and residents*. Retrieved from Department of Health and Human Services, Assistant Secretary for Planning and Evaluation: <https://aspe.hhs.gov/system/files/pdf/72746/rltct.pdf>

- Spitze, G., Ward, R., Deane, G., & Zhuo, Y. (2012). Cross-siblings effects in parent-adult child exchanges of socioemotional support. *Research on Aging*, **34**, 197-221. doi:10.1177/0164027511420170
- Swartz, T. T. (2009). Intergenerational family relations in adulthood: Patterns, variations, and implications in the contemporary united states. *Annual Review of Sociology*, **35**, 191-212. doi:10.1146/annurev.soc.34.040507.134615
- U.S. Bureau of Labor Statistics. (2015). *Women in the labor force: A databook* (Report 1059). Retrieved from <https://www.bls.gov/opub/reports/womens-databook/archive/women-in-the-labor-force-a-databook-2015.pdf>
- U.S. Department of Labor. (2016). *Leaving it to the family: The effects of paid leave on adult child caregivers*. Retrieved from https://www.dol.gov/asp/evaluation/WorkerLeaveStudy/files/Paid_Leave_Leaving_it_to_the_family_Report.pdf
- Wachter, K. W. (1997). Kinship resources for the elderly. *Philosophical Transactions B*, **352**, 1811-1817. doi:10.1098/rstb.1997.0166
- Wolf, D. A., & Longino, J., Charles F. (2005). Our "increasingly mobile society?" The curious persistence of a false belief. *The Gerontologist*, **45**, 5-11. doi:10.1093/geront/45.1.5
- Wolff, J. L., & Kasper, J. D. (2006). Caregivers of frail elders: Updating a national profile. *The Gerontologist*, **46**, 344-356. doi:10.1093/geront/46.3.344

Tables and Figures

Figure 1. Theoretical Model and Hypotheses Regarding Trends in the Three Components of the Decompositions

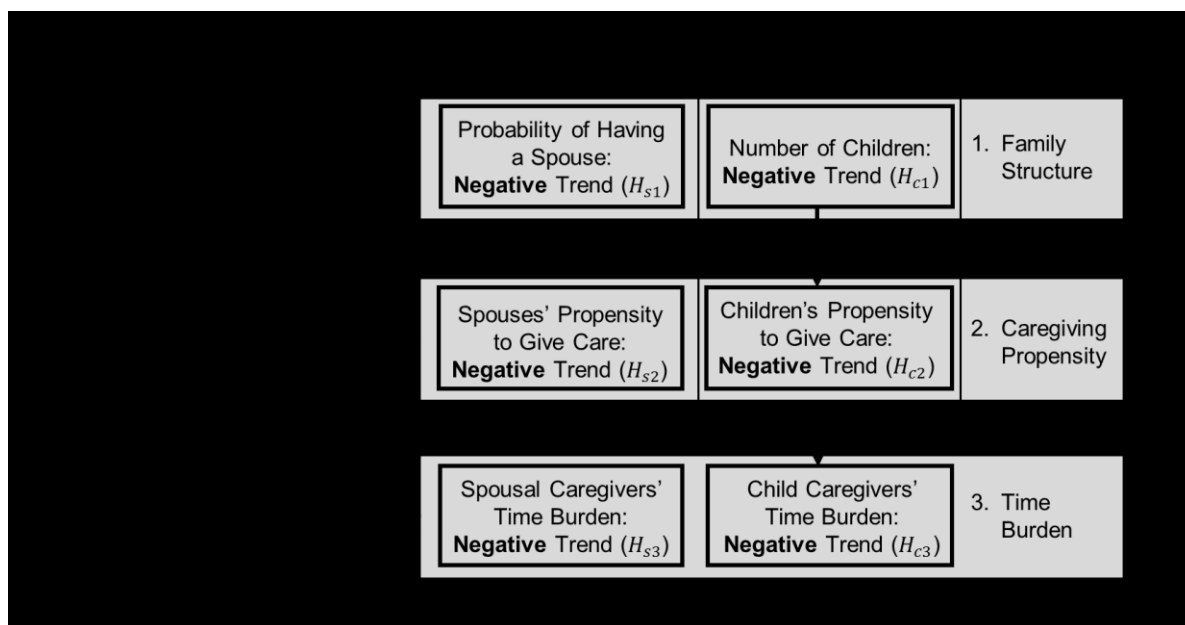


Table 1. Number of Observations at Each Level of Analysis

	NLTCs		HRS		Component of Decomposition
	Number	Percent	Number	Percent	
Disabled older people	24,115		22,523		1st
...who are married	9,338	39	9,729	43	2nd (spousal)
...who have a spouse caregiver	7,384	79	5,431	56	3rd (spousal)
Children	62,525		75,779		2nd (child)
...who are caregivers	13,742	22	10,050	13	3rd (child)

Figure 2. Number of Informal Caregivers by Source, 1982-2012 (Solid markers are the NLTC estimates, empty markers are the HRS estimates)

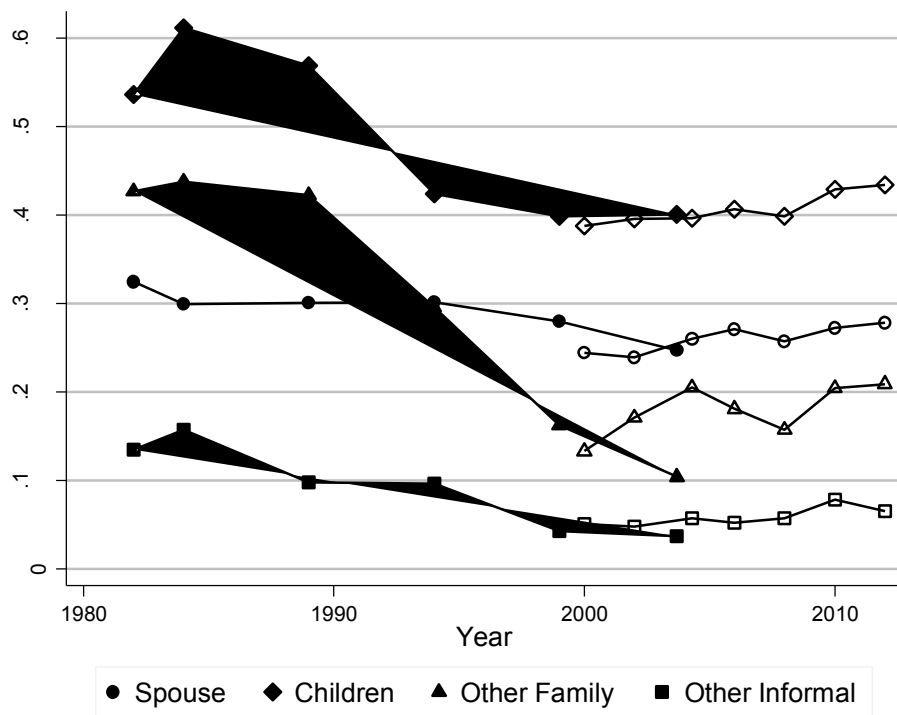


Figure 3. Hours of Informal Care Received During Past Week by Source, 1989-2012 (Solid markers are the NLTC estimates, empty markers are the HRS estimates)

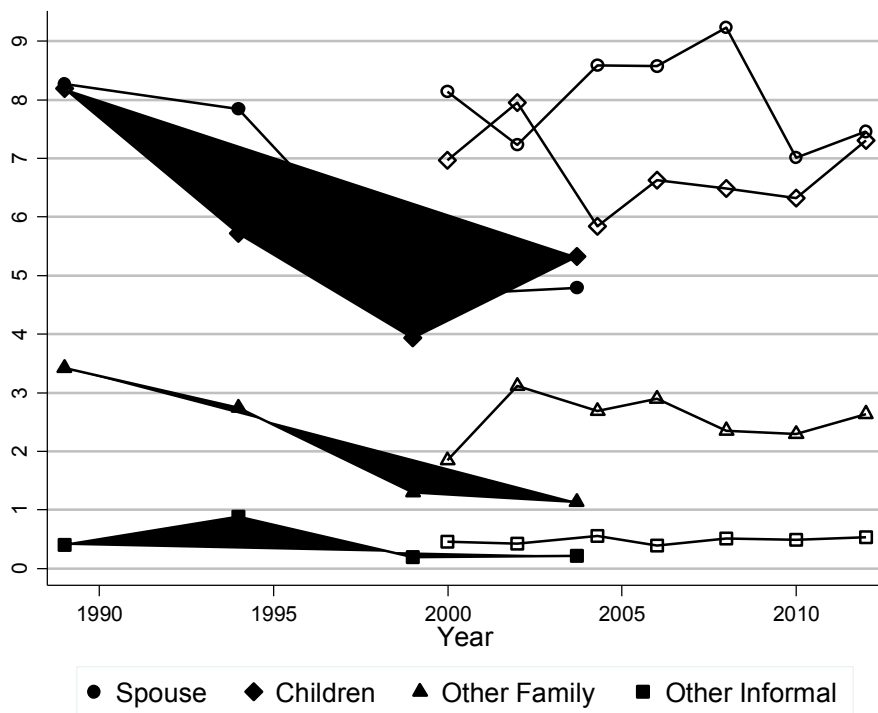


Table 2. Older People’s Marital Status and Number of Living Children by Year and Survey

	Percentage Married			Number of Children		
	Mean	95% CI		Mean	95% CI	
		LB	UB		LB	UB
NLTCS^a						
1982	44	40	48	2.4	2.2	2.5
1984	41	37	46	2.4	2.2	2.6
1989	42	38	46	2.6	2.4	2.8
1994	40	35	45	2.7	2.5	2.9
1999	40	36	44	2.6	2.5	2.8
2004	37	34	41	2.9	2.8	3.1
HRS^b						
2000	44	42	46	3.2	3.1	3.3
2002	42	40	44	3.3	3.2	3.4
2004	47	45	49	3.3	3.2	3.4
2006	47	45	49	3.3	3.2	3.4
2008	44	42	47	3.3	3.2	3.4
2010	43	41	45	3.3	3.2	3.4
2012	44	42	46	3.3	3.2	3.4

Notes: ^aN=24,115. ^bN=22,523.

Figure 4. Spouses’ and Adult Children’s Propensity to Give Care, 1982-2012 (1982-2004 trends are the NLTCS estimates, 2000-2012 trends are the HRS estimates)

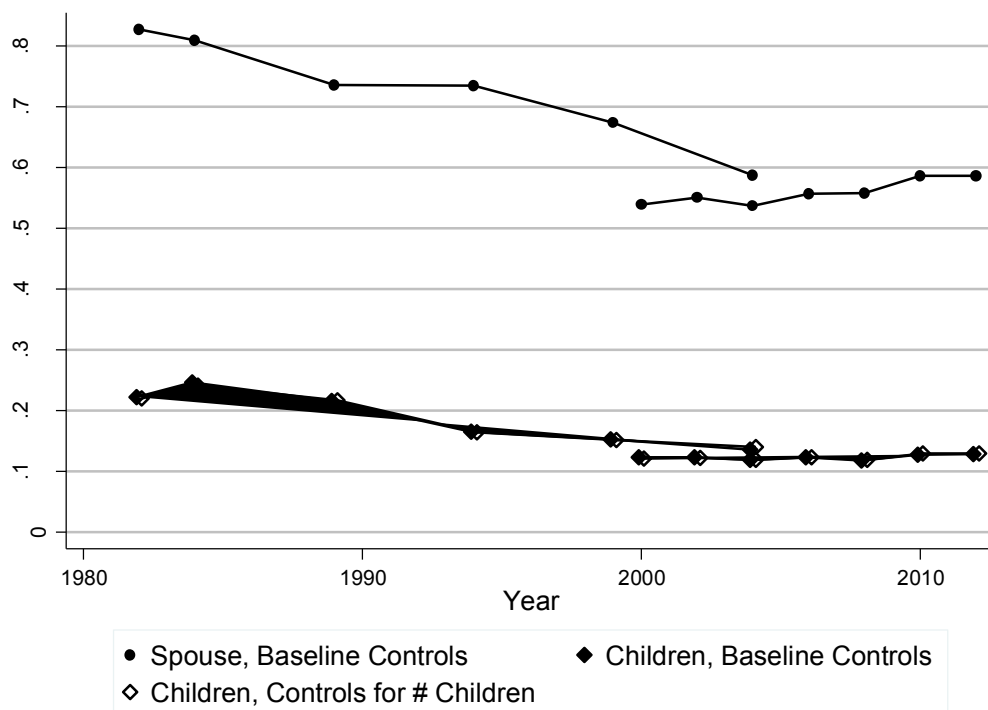
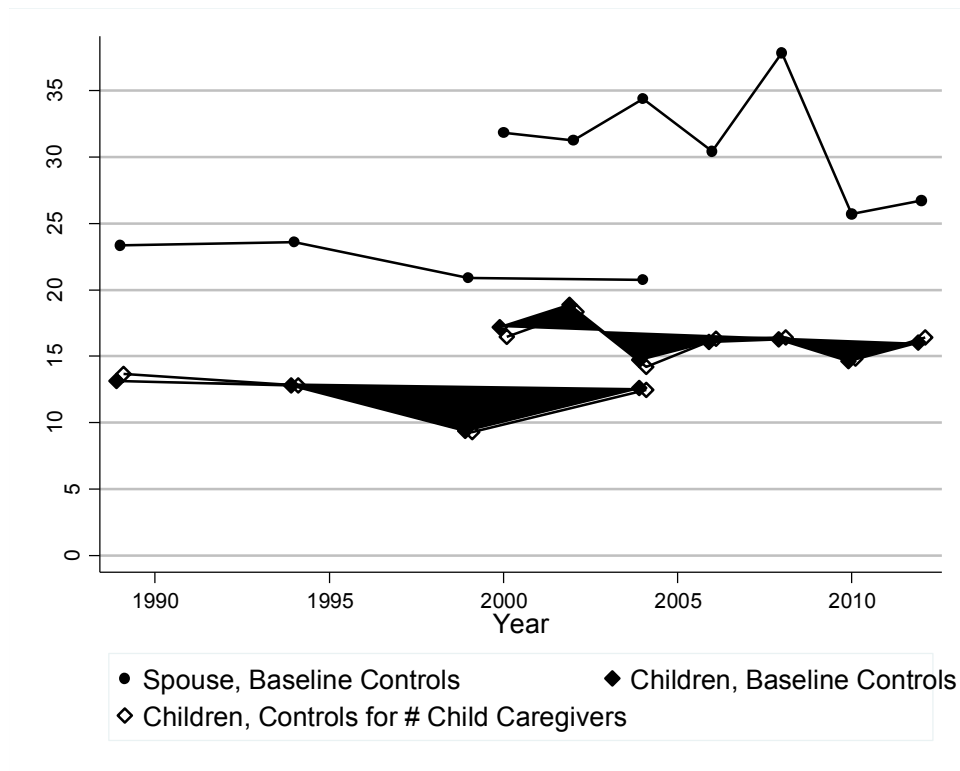


Figure 5. Hours of Care Given During Past Week by Spousal and Adult Child Caregivers (1982-2004 trends are the NLTCS estimates, 2000-2012 trends are the HRS estimates)



Supplementary Tables

Table A. Coefficients from Generalized Linear Regression Models Explaining Number of Informal Caregivers

	NLTCS ^a				HRS ^b			
	Spouses	Children	Other family	Other informal	Spouses	Children	Other family	Other informal
Year (NLTCS) (omitted: 1982)								
1984	-.13	.13	.02	.15	-	-	-	-
1989	-.12	.06	-.01	-.32	-	-	-	-
1994	-.12	-.23 **	-.37 **	-.34 *	-	-	-	-
1999	-.23	-.30 **	-.97 **	-1.16 **	-	-	-	-
2004	-.41 **	-.29 **	-1.41 **	-1.29 **	-	-	-	-
Year (HRS) (omitted: 2000)								
2002	-	-	-	-	-.03	.02	.25 **	-.06
2004	-	-	-	-	.09	.02	.43 **	.12
2006	-	-	-	-	.15 *	.05	.31 **	.03
2008	-	-	-	-	.07	.03	.17	.12
2010	-	-	-	-	.16 *	.10 *	.43 **	.44 **
2012	-	-	-	-	.19 **	.11 *	.45 **	.25
Age (omitted: 65-69)								
70-74	-.42 **	.01	.06	.16	-.04	.22 **	.05	-.19
75-79	-.70 **	.15	.11	.62 **	-.05	.36 **	.17	-.10
80-84	-1.02 **	.34 **	.23	.59 **	-.27 **	.65 **	.31 **	-.10
85-89	-1.67 **	.52 **	.59 **	.71 **	-.77 **	.81 **	.68 **	.17
90-94	-2.13 **	.52 **	.78 **	.44	-1.36 **	.93 **	.74 **	.36 *
95+	-2.95 **	.51 **	.92 **	-.12	-1.91 **	.94 **	1.05 **	.14
Functional limitations (omitted: IADL only)								
1 ADL	-.34 **	.08	.21	.14	-1.03 **	-.61 **	-.45 **	-.44 **
2 ADL's	-.18	.38 **	.18	.23	-.38 **	-.09 *	.09	.00
3 ADL's	.01	.49 **	.56 **	.48 *	-.13	.19 **	.46 **	.26
4 ADL's	.39 *	.52 **	.64 **	.78 *	.05	.47 **	.61 **	.28
5 ADL's	.85 **	.74 **	.65 **	.31	.02	.60 **	.84 **	.82 **
6 ADL's	.76 **	.80 **	.61 **	.08	.37 **	.70 **	1.01 **	.50 **

Notes: Weighted. ^aN=24,115. ^bN=22,523. * $p < .05$, ** $p < .01$.

Table B. Coefficients from Generalized Linear Regression Models with Log Link Explaining Hours of Informal Care Received

	NLTCS ^a				HRS ^b			
	Spouses	Children	Other family	Other informal	Spouses	Children	Other family	Other informal
Year (NLTCS) (omitted: 1989)								
1994	-.05	-.36 *	-.22	.78 *	-	-	-	-
1999	-.58 **	-.73 **	-.97 **	-.70 *	-	-	-	-
2004	-.55 **	-.43 **	-1.10 **	-.62 *	-	-	-	-
Year (HRS) (omitted: 2000)								
2002	-	-	-	-	-.12	.13	.52 **	-.09
2004	-	-	-	-	.05	-.17	.38 *	.18
2006	-	-	-	-	.05	-.05	.45 *	-.17
2008	-	-	-	-	.13	-.07	.24	.10
2010	-	-	-	-	-.15	-.10	.22	.05
2012	-	-	-	-	-.09	.05	.36	.16
Age (omitted: 65-69)								
70-74	-.18	-.29	-.53 *	-.63	.12	.35 **	.14	-.15
75-79	-.31 *	-.18	-.43	.15	.26 **	.70 **	.48 **	-.24
80-84	-.41 **	.19	-.42	.16	.19	.98 **	.64 **	-.11
85-89	-1.12 **	.78 **	.26	.44	-.01	1.24 **	1.23 **	.29
90-94	-1.34 **	.59 **	-.04	-.17	-.48 *	1.41 **	1.17 **	.42
95+	-1.30 *	.77 **	.49	-.45	-1.00 **	1.78 **	1.78 **	.71
Functional limitations (omitted: IADL only)								
1 ADL	-.28	.27	.37	.65	-.80 **	-.49 **	-.33 *	-1.08 **
2 ADL's	.32	1.10 **	.23	-.50	.12	.18	.39 *	.09
3 ADL's	1.06 **	1.38 **	1.30 **	.76 *	.45 **	.64 **	.92 **	.40
4 ADL's	1.50 **	1.39 **	1.52 **	.48	.86 **	1.12 **	1.26 **	.34
5 ADL's	2.02 **	2.05 **	1.72 **	1.43 **	.94 **	1.41 **	1.56 **	1.14 **
6 ADL's	2.31 **	2.61 **	1.91 **	2.02 **	1.49 **	1.84 **	2.15 **	1.41 **

Notes: Weighted. ^aN=13,506. ^bN=22,523. *p < .05, **p < .01.

Table C. Odds Ratios from Logistic Regression Models Explaining Spouses' and Adult Children's Propensity to Give Care

	NLTCS		HRS	
	Spouses ^a	Children ^b	Spouses ^c	Children ^d
Year (NLTCS) (omitted: 1982)				
1984	.88	1.13	-	-
1989	.57 *	.98	-	-
1994	.57 *	.67 **	-	-
1999	.41 **	.61 **	-	-
2004	.28 **	.56 **	-	-
Year (HRS) (omitted: 2000)				
2002	-	-	1.05	1.01
2004	-	-	.99	.98
2006	-	-	1.09	1.02
2008	-	-	1.09	.98
2010	-	-	1.25 *	1.09
2012	-	-	1.25 *	1.09
Age (omitted: 65-69)				
70-74	.51 **	1.08	.99	1.24 **
75-79	.49 **	1.28 *	1.23 *	1.50 **
80-84	.53 **	1.64 **	1.36 **	2.12 **
85-89	.42 **	2.41 **	1.19	2.79 **
90-94	.41 **	2.63 **	1.26	3.60 **
95+	.30 *	2.59 **	1.46	3.72 **
Functional limitations (omitted: IADL only)				
1 ADL	.87	1.09	.26 **	.52 **
2 ADL's	1.58 *	1.58 **	.75 **	.91
3 ADL's	2.81 **	1.86 **	1.35 **	1.27 **
4 ADL's	2.89 **	1.80 **	2.11 **	1.74 **
5 ADL's	8.25 **	2.27 **	3.37 **	2.18 **
6 ADL's	3.94 **	2.66 **	3.03 **	2.36 **
Number of Children (omitted: 0)				
2	-	.45 **	-	.49 **
3	-	.40 **	-	.36 **
4	-	.36 **	-	.32 **
5+	-	.24 **	-	.21 **

Notes: Weighted. ^aN=9,338. ^bN=62,525. ^cN=9,729. ^dN=75,779. * $p < .05$, ** $p < .01$.

Table D. Coefficients from Generalized Linear Regression Models with Log Link Explaining Hours of Care Given by Spousal and Adult Child Caregivers

	NLTCS		HRS	
	Spouses ^a	Children ^b	Spouses ^c	Children ^d
Year (NLTCS) (omitted: 1989)				
1994	.01	-.07	-	-
1999	-.11	-.38 **	-	-
2004	-.12	-.09	-	-
Year (HRS) (omitted: 2000)				
2002	-	-	-.02	.11
2004	-	-	.08	-.15
2006	-	-	-.05	-.01
2008	-	-	.17 *	.00
2010	-	-	-.21 *	-.11
2012	-	-	-.17	.00
Age (omitted: 65-69)				
70-74	.09	-.21	.06	.17
75-79	.24	-.29 *	.07	.34 **
80-84	.22	-.12	.14	.34 **
85-89	-.26	.26	.36 **	.43 **
90-94	.61 *	.05	.22	.44 **
95+	1.13 **	.36 *	.04	.69 **
Functional limitations (omitted: IADL only)				
1 ADL	-.07	.17	-.06	.16 *
2 ADL's	.38 *	.77 **	.34 **	.32 **
3 ADL's	.95 **	.84 **	.55 **	.49 **
4 ADL's	1.07 **	.84 **	.83 **	.76 **
5 ADL's	1.27 **	1.29 **	.96 **	.89 **
6 ADL's	1.75 **	1.78 **	1.28 **	1.19 **
Number of Child Caregivers (omitted: 1)				
2	-	-.58 **	-	-.39 **
3+	-	-.38 **	-	-.54 **

Notes: Weighted. ^aN=7,384. ^bN=13,742. ^cN=5,431. ^dN=10,050. * $p < .05$, ** $p < .01$.