Baby boomer caregiver and dementia caregiving: findings from the National Study of Caregiving

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Abstract

Background: previous studies have well documented the characteristics of baby boomers but less is known about the experiences of boomer caregivers (CGs) of people with dementia.
Objective: the purpose of this study was to compare the characteristics of boomer CGs of people with dementia with those of boomer CGs for people without dementia and to ascertain factors associated with outcomes.
Design: we selected baby boomer CGs from the National Study of Caregiving (NSOC) with 650 primary boomer CGs (138 CGs of people with dementia and 512 CGs of people without dementia).
Methods: the Stress Process Model (SPM) was used to examine the effects of resources (the use of paid help and informal support) and stressors (primary: level of CG care activities and interrupted sleep; secondary: strain of caregiving on work, other care and social activities) on CGs' down, depressed or hopeless feelings and self-perceived general health. *T*-tests and chi-square tests were used to compare SPM domain differences and ordinary least-square multiple regression analysis was used to investigate predictors of CGs' outcomes.
Results: high blood pressure and arthritis were the most prevalent chronic diseases in both groups. Boomer CGs of people with dementia reported providing more help with daily activities, higher level of caregiving and social activity conflict, experiencing more interrupted sleep and more down, depressed or hopeless feelings than CGs of people without dementia. Different factors predicted boomer CGs' outcomes.
Conclusion: the current results yield important information about the considerable differences between two baby boomer CG groups within the caregiving experiences. The findings highlight the need to provide tailored interventions to boomer CGs to help them cope with caregiving stress to improve their physical and mental health.

Keywords: caregiving, dementia, baby boomer, older people

Introduction

In 2012, over 15 million unpaid caregivers (CGs; e.g. family, relatives, friends) provided care for people with dementia at an estimated value of $216 billion [1]. As the estimated number of people with Alzheimer's disease and other dementias in the USA in 2013 is predicted to more than double by 2050 (13.8 million), more CG support for people with dementia will be needed. Caring for relatives with dementia creates various stressors for CGs—including care recipients' (CRs) memory and behaviour problems, communication problems, conflict and role strain—and can lead to deterioration in CGs' physical health, psychological well-being and social relations [2]. Caregivers of dementia patients in particular suffer more than other CGs–they tend to have

worse mental and physical health, less leisure time, more employment complications and more family conflict [2, 3].

Approximately one-fourth of the US population (78 million people) are baby boomers [4] (the generation born between 1946 and 1964). This generation influenced demographic trends and social structures [5], which may impact caring roles. For example, compared with the previous generation born before 1946, boomers are more likely to have lower rates of marriage, higher rates of separation and divorce, higher levels of education [6], fewer children [7], delayed childbearing [4] and larger number of siblings [8]. Boomers are also more likely to show a longer and more varied work history [9] and to stop working for pay in their late 60 s rather than at age 60 or 65 [10], which was true for the previous generation. Further, unlike the previous

generation, boomers can expect to provide personal care and financial assistance for their families for ∼40 years, first to their children, then simultaneously to young adult children and ageing parents for about 5 years on average; the remaining caregiving time is spent providing support to their parents [4], as well as to older siblings, spouses or their spouses' children, and themselves [8]. However, an increased life expectancy and longer periods of transition to adulthood for young adult children [11] might lengthen the period of providing care to parents, siblings and grown children, respectively. Thus, compared with the previous generation, baby boomers may experience higher levels of CG role strains, such as being responsible for multiple CG roles while they are working. Despite lack of studies on younger CGs, it is also possible that multiple caregiving roles may continue for younger CGs with the similar conditions such as smaller family, delayed child bearing and increased life expectancy [12].

Despite the challenges that boomers face, who will more likely care to multiple generations, the caregiving literature has not focused as much on baby boomer CGs—relatively little has been explored regarding baby boomer CGs of patients with different chronic conditions and even less is known abou the experiences of baby boomer CGs of family members with dementia and without, both of which are strongly related to advancing age. Further research on the baby boomer CGs of people without dementia is needed to provide a foundation for research into stressors of baby boomer CGs of people with dementia. Therefore, the purposes of this study were to (i) examine the characteristics of baby boomer CGs of people with dementia compared to those of baby boomer CGs of people without dementia and (ii) investigate the factors associated with subjective feelings of mood and self-perceived health status in baby boomer CGs.

Methods

Data source

We used data from the first wave of the National Study of Caregiving (NSOC). The NSOC is a sample of 2007 informal caregivers identified by the nearly 8,077 Medicare beneficiaries age 65 and older who were participants in the 2011 Round 1 Sample Person (SP) interview of the National Health and Aging Trends Study (NHATS), a nationally representative study that collects data from participants on an annual basis. The NSOC is intended to understand how the caregiver helps the older respondent in the NHATS with everyday activities and collects data on the assistance provided together with information on the caregiver's health, family employment and income [13]. Detailed data collection procedures and variable definitions are described in the NSOC User Guide [14]. Because this study focused on the baby boomer CGs of people with dementia and without dementia, we excluded those CGs who were not born between 1946 and 1964 (N = 996) and then those who did not provide a response to whether their NHATS study participant had dementia or not

(N = 361). The analyses in this study thus included only those caregivers (N = 650) who were baby boomers who did provide a response as to whether their SP had dementia. This submission was reviewed by the Office of Human Research Ethics at the University of North Carolina-Chapel Hill, which has determined that this submission does not constitute human subjects research as defined under federal regulations [45 code of federal regulations (CFR) 46.102 (d or f) and 21 CFR 56.102 (c)(e)(l)] and does not require institutional review board (IRB) approval.

Measures

Actual wordings of key measures (primary stressors, secondary stressors, resources and outcomes) used in the current study are presented in Table 1.

Primary stressors

The NSOC participants were asked about their care activities. In order to create a score for the level of care activities, the responses to these four questions were summed: helping with (i) chores, (ii) shopping, (iii) personal care (iv) getting around home. Response categories were from 1 = rarely to 4 = every day. Higher scores indicate higher level of involvement in helping with daily activities. Interrupted sleep was assessed by the question (1 = never to 5 = every night).

Secondary stressors

The strain of caregiving on work, child or other care and social activities was assessed by dichotomized responses (1 = yes, 0 = no). The responses to the four questions were summed. Higher scores indicate higher level of the conflict between caregiving and social activities.

Resources

The participants were asked about informal support in the three questions (1 = yes, 0 = no). The responses to the three questions were summed. Caregivers were also asked about using paid help. The questions used dichotomized responses (1 = yes, 0 = no).

Outcomes

The subjective feelings of mood were assessed using the question with a 4-level response from not at all (1) to nearly every day (4). The overall self-perceived physical health was assessed using the question with a 5-level response from poor (1) to excellent (5).

Background

The background characteristics included CGs' age, gender (0 = male, 1 = female), marital status (0 = not married including living with partner, never married, divorced/separated/widowed, 1 = married) and education (0 = high school or less, 1 = some college or more).

Table 1. Exact wordings of key variables

Measures	Exact wordings
Primary stressors	
Help with daily activities	In the last month, how often did you help {SP} with laundry, cleaning or making hot meals or do these chores? Would you say every day, most days, some days, rarely or never?
	In the last month, how often did you shop with {SP} for groceries or personal items or do {his/her} shopping for {him/her}? Would you say every day, most days, some days, rarely or never?
	In the last month, how often did you help {SP} with personal care such as eating, showering or bathing, dressing or grooming or using the toilet? Would you say every day, most days, some days, rarely or never?
	In the last month, how often did you help {SP} get around, that is, getting in and out of bed, getting around inside {his/her} home or leaving {his/her} home to go outside? Would you say every day, most days, some days, rarely or never?
Interrupted sleep	In the last month, how often did helping {SP} cause your sleep to be interrupted? [Would you say every day, most days, some days, rarely or never?]
Secondary stressors	
Caregiving—other family care conflict	In the last month, did helping {SP} ever keep you from doing this (caring for a child or other adult)?
Caregiving—work conflict	In the last month, did helping {SP} ever keep you from doing this (working for pay)?
Caregiving—social activity conflict	In the last month, did helping {SP} ever keep you from doing this (participating in club meetings or group activities {other than religious services})? IF NEEDED: These could be any ongoing group activity including dinner or bridge clubs, neighbourhood or political organisations, knitting, or regular exercise groups.
Resources	
Informal support	Do you have friends or family that you talk to about important things in your life?
	Do you have friends or family that help you with your daily activities, such as running errands, or helping you with things around the house?
	Do you have friends or family that help you care for {SP}?
Paid help	In the last year, have you helped {SP} find a paid helper to do household chores or personal care?
Outcomes	
Subjective feeling of mood	Over the last month, how often have you felt down, depressed or hopeless?
Overall self-perceived physical health	Would you say that in general, your health is excellent, very good, good, fair or poor?

Analysis

Pearson correlation coefficients assessed multicollinearity between predictors (i.e. $r > 0.70$) [15]. The bivariate correlations indicated no multicollinearity, and the highest correlations were between being married and the level of informal support ($r = 0.455$). Two-tailed independent t-tests and chi-square tests were used to assess the differences in characteristics between baby boomer CGs of people with dementia and without dementia. Lastly, four ordinary least-squares multiple regression analyses with simultaneous entry of predictors were used to investigate factors associated with the outcomes of interest.

Results

Sample description

Table 2 presents descriptive information on demographic characteristics of baby boomer CGs of people with dementia and without dementia. The average age of baby boomer CGs of people with dementia and without dementia was 57.41 (range: 47–65) and 57.23 years (range: 47–65), respectively. More than two-fifths of both groups were married. More than two-thirds of baby boomer CGs were children of the CR and the majority were daughters of the recipient. More than one-quarter of the two groups had a college degree or higher. Baby boomer CGs of people with dementia reported:

providing more help with daily activities, t (648) = 6.937, $P < 0.001$; a higher level of caregiving and social activity conflict, t (648) = 5.273, $P < 0.001$; more interrupted sleep, t (648) = 4.372, $P < 0.001$; and were more likely to feel depressed, t (648) = 2.298, $P = 0.022$. Although there was no significant difference between the two groups in prevalence of chronic illness, high blood pressure and arthritis were the top two prevalent diseases in both baby boomer CGs of people with dementia and without dementia. The two groups did not experience significant differences in perceived general health due to caregiving. A chi-square test, however, revealed significant differences between the groups in: having paid help, χ^2 (1, $N = 650$) = 20.86, $P = 0.000$; experiencing higher caregiving–work conflict, χ^2 (1, $N = 650$) = 9.635, $P = 0.002$; and higher caregiving–other family care conflict, χ^2 (1, $N = 650$) = 4.536, $P = 0.033$.

Regression analysis

As shown in Table 3, four models are explained between 9 and 29% of the variance. The results of the regression analysis are given in Table 3; attention is drawn to different findings of the four models in the next two paragraphs.

Baby boomer CGs of people with dementia

Caregiving–social activity conflict was directly and significantly related to feeling down, depressed or hopeless

Table 2. Sample characteristics

Characteristic	Total (n = 650)	Baby boomer CGs of people with dementia (n = 138) %	Baby boomer CGs of people without dementia (n = 512) %	P value[a]
Age (in years) (*Mean* (*SD*))	57.28 (5.42)	57.41 (5.6)	57.23 (5.37)	NS
Gender (Female)	69.5	72.5	68.8	NS
Proxy race/ethnicity[b]				
Non-Hispanic White	57.1	55.8	57.4	NS
Non-Hispanic Black	33.2	33.3	33.2	
Hispanic	7.2	10.1	6.4	
All others/don't know/refused	2.4	0.7	2.7	
Marital status				
Married	43.2	44.2	44.2	NS
Living with partner	4.6	5.1	5.2	
Never married	17.2	15.9	14.5	
Divorced/separated	18.3	21.8	13.5	
Widowed	6.3	8.0	5.4	
Relationship to CR				
Spouse	9.7	5.1	10.9	NS
Daughter	51.2	59.4	49	
Son	24.3	22.5	24.8	
Child-in-law	3.5	2.9	3	
Sibling	2.0	1.4	2	
Grandchildren	0.8	0	1.0	
Niece or nephew	3.4	4.4	3.1	
Friends	0.2	0.7	1.8	
Other relatives	1.2	0.7	0.8	
Others	4.9	2.9	6.1	
Education				
Less than high school/don't know/refused	18.5	15.2	19.3	NS
High school diploma/General educational development	28.5	28.3	28.6	
Some college or associate degree	24.9	31.9	24	
Bachelor's degree or higher	27.4	24.6	29.1	
Income, median ($)	10,000	13,500	9,300	NS
CG's chronic illness				
Heart attack	3.5	3.6	3.5	NS
Heart disease	7.2	5.1	7.8	
High blood pressure	44.8	47.8	43.9	
Arthritis	40	39.1	40.2	
Osteoporosis	12.3	10.9	12.7	
Diabetes	17.2	16.7	17.4	
Lung disease	14.3	13	14.6	
Cancer	8.5	11.6	7.6	
Serious difficulty seeing	6	7.2	5.3	
Serious difficulty hearing	5.5	5.1	5.3	
Score for help with daily activities (*Mean* (*SD*))	12.16 (4.3)	14.3 (4.96)	11.57 (4.07)	<0.001
Paid help (yes)	20.5	34.1	17.5	<0.001
Informal support	2.18 (1.78)	2.42 (1.04)	2.11 (1.95)	<0.05
Caregiving role strains				
Caregiving–other family care conflict	5.7	9.4	4.7	<0.05
Caregiving–work conflict	17.2	26.1	14.8	<0.01
Caregiving–activities/leisure conflict (*Mean,* (*SD*))	0.62 (1.3)	1.1 (1.39)	0.48 (1.24)	<0.001
Interrupted sleep	1.95 (1.13)	2.28 (1.27)	1.83 (1.05)	<0.01
Feeling down, depressed or hopeless	1.48 (1)	1.65 (0.83)	1.43 (1.04)	<0.05
Physical health	3.32 (1.12)	3.34 (1.03)	3.32(1.15)	

[a]P values denote differences between baby boomer CGs of people with dementia and baby boomer CGs of people without dementia based on chi-square tests or independent samples *t*-tests.
[b]CR's race was used, because CG's race was not available.

condition of baby boomer CGs of people with dementia. A higher level of informal support was negatively associated with depressive feeling. Caregiving–other family care conflict was negatively linked with scores on the boomer CG's general health. Older baby boomer CGs of people with dementia reported significantly lower levels of general health than younger baby boomer CGs of people with dementia. Married baby boomer CGs of people with dementia reported better general health compared with unmarried baby boomer CGs of people with dementia.

Table 3. Results of simultaneous ordinary least-squares multiple regression predicting subjective feelings of mood and self-perceived general health of baby boomer CGs of people with dementia and people without dementia

Variable	Baby boomer CGs of people with dementia			Baby boomer CGs of people without dementia		
	b	SE_b	β	b	SE_b	β
Outcome: subjective feelings of mood						
CG context						
Gender (1 = female)	−0.088	0.150	−0.048	0.073	0.90	0.035
Marital status (1 = married)	−0.171	0.126	−0.121	0.020	0.056	0.017
Age	−0.008	0.012	−0.048	−0.007	0.008	−0.037
Education (1 = some college or more)	−0.192	0.143	−0.116	−0.056	0.090	−0.029*
Primary stressors						
Help with daily activities	−0.011	0.019	−0.061	−0.008	0.012	−0.034
Interrupted sleep	−0.031	0.042	−0.070	0.065	0.032	0.107*
Secondary stressors						
Caregiving–other family care conflict	−0.057	0.255	−0.02	0.645	0.212	0.143**
Caregiving–work conflict	0.282	0.172	0.151	0.076	0.129	0.028
Caregiving–social activity conflict	0.160	0.065	0.270**	0.097	0.043	0.115*
Resource						
Informal support	−0.200	0.072	−0.228*	−0.131	0.044	−0.134**
Paid help (1 = yes)	−0.018	0.138	0.010	−0.081	0.112	−0.032
R^2		0.221				0.091
F	(11,126)	3.254***		(11,498)		4.556***
Outcome: perceived general health						
CG Context						
Gender (1 = female)	0.304	0.179	0.132	0.162	0.108	0.066
Marital status (1 = married)	0.314	0.150	0.187*	0.059	0.067	0.043
Age	−0.039	0.014	−0.211**	0.001	0.009	0.003
Education (1 = some college or more)	0.328	0.170	0.162	0.269	0.109	0.117*
Primary stressors						
Help with daily activities	0.022	0.023	0.097	0.027	0.015	−0.043
Interrupted sleep	−0.077	0.049	−0.142	−0.053	0.039	−0.073
Secondary stressors						
Caregiving–other family care conflict	−0.851	0.304	−0.242**	−0.239	0.255	−0.044
Caregiving–work conflict	−0.245	0.205	−0.105	−0.030	0.155	−0.009
Caregiving–social activity conflict	−0.112	0.077	−0.153	−0.163	0.052	−0.161**
Resource						
Informal support	0.039	0.086	0.035	0.027	0.053	0.023
Paid help (1 = yes)	−0.119	0.164	−0.055	−0.053	0.135	−0.022
R^2		0.292				0.086
F	(11,126)	4.734***		(10,496)		4.266***

*$P \leq 0.05$.
**$P \leq 0.01$.
***$P \leq 0.001$.

Baby boomer CGs of people without dementia

Caregivers who reported higher levels of interrupted sleep, caregiving–family social activity conflict, caregiving–social activity conflict and lower level of informal support were more likely to feel depressed. Caregiving–social activity conflict was negatively associated with CG's general health. Caregivers with higher-level education reported significantly lower level of feeling depressed and better perceived general health.

Discussion

Our study provides a comprehensive understanding of demographics, prevalence of chronic illness and caregiving experience of baby boomer CGs of people with dementia compared with baby boomer CGs of people without dementia. The

findings from this study contribute to the body of caregiving research in several ways. They address the gap in the literature that does not focus on baby boomer CG specifically and potential differences in the caregiving experience between baby boomer CGs of people with and without dementia.

More than two-fifths of baby boomer CGs in our study reported having high blood pressure or arthritis. These findings clearly show the potential for physical health risks for boomer caregivers. Research shows that chronic stress, particularly the non-adaptive response to stress, is the more likely cause of sustained elevation of blood pressure [16]. Given that dementia caregiving is associated with chronic stress, the caregivers in this study are at risk for sustained elevation of blood pressure, which is associated with a cascade of life-threatening diseases that can affect the heart, brain and kidneys [17]. Further, as the boomer CGs get older, their

current arthritis condition may result in minor-to-severe disability and lead to consequences for physical (the eyes, lungs, skin, heart and blood vessels and other organs), social and psychological functioning [18]. Other studies have shown that arthritis is associated with becoming disabling with stress, work and lack of time for self-care [19, 20].

We found that baby boomer CGs of people with dementia as compared with their counterparts caring for those without dementia reported significantly higher levels of stressors with daily activities, level of interrupted sleep, caregiving–work conflict, caregiving—other family care conflict, caregiving–social activity and more depressed or hopeless feelings. These results support the findings in previous studies [21, 22] that CGs of people with dementia experience greater burden and strain from dementia caregiving compared to CGs of people without dementia.

Our another findings that corroborate previous results show that reduced social activity participation due to caregiving was associated with feeling down or depressed for both groups, as well as with self-perceived general health of boomer CGs of people without dementia. Previous studies have noted that maintaining an active life through leisure and social activities is related to increased well-being [23–25]. It is possible that caregiving demands may reduce opportunities to enjoy leisure and social time for the boomer CGs and therefore may be more likely to experience conflicts between caregiving and reduced leisure and social time. Both CG groups experienced lower level of feeling down or depressed when provided with informal support from family or friends. This result is consistent with previous studies that have identified the positive effects of family social support on CGs' emotional well-being [26, 27].

By comparing baby boomer CGs of people with dementia to baby boomers CGs of people without dementia, this study increases our understanding of the caregiving experience for the baby boomer cohort of CGs, even when the results may not be intuitively obvious. For example, caregiving conflict–care for other family such as children or other elderly appears as a significantly negative predictor of perceived general health for baby boomer CGs of people with dementia and of the depressive feelings of baby boomer CGs of people without dementia. This may be because most of the baby boomer CGs of people with dementia in this study were women who, in addition to providing care, could also be expected to take the primary responsibility for maintaining their own households as well as being employed. The demands of these multiple roles might cause baby boomer CGs of people with dementia to experience worse general health as compared with their counterparts. Similarly, baby boomer CGs of people without dementia might find it stressful to meet dual care demands, which could lead to worse depressed feelings.

There are several weaknesses in this study. Interpretation of the results is limited by the cross-sectional nature of the study. Because dementia is a progressive disease, the relationship between the predictor variables and general health or subjective feeling of mood might change over time. Thus, longitudinal research is needed to understand more fully the effects of the potential changes on the relationships. Another limitation is that this study used CG's proxy report on CR's dementia not based on a formal diagnosis. Thus, inferences from these results should not be directed at all baby boomer CGs of people with dementia, but rather baby boomer CGs of people with dementia who perceive that they provide dementia caregiving. Finally, the current study used a single item measure of the down/depressed/hopeless feeling. Although a single question might be useful to understand CG's feeling of down, depressed or hopeless, a more comprehensive measure of depressive symptomatology is necessary to identify clinically depressed boomer CGs and how potential factors may impact boomer CGs' levels of depressive symptoms.

However, given the aforementioned limitations, our results not only corroborate previous work but also draw attention to associations not previously reported. Our findings highlight the need to provide tailored interventions, which take into account the conditions for which care is being provided to boomer CGs to help them cope and deal with caregiving stress. Health professionals should emphasise the importance of self-care and health promotion among baby boomer CGs. In order to alleviate stress from caregiving, boomer CGs should be encouraged to maintain relationships with their friends, families or neighbours through phone calls or family reunions. Service providers might use our findings to inform service implementation and help baby boomer CGs create time to continue to engage in at least minimum levels of leisure activity. Such efforts might reduce stress levels and also reduce emotional and physical distress in both boomer CG groups. Health professionals might be also able to offer various support programmes that reflect the unique characteristics of each CG' needs in order to help CGs create a healthier balance between caregiving and their own lives, which for boomers include playing multiple roles as caregivers and remaining in the workforce longer than the previous generation.

Key points

- High blood pressure and arthritis were the most prevalent chronic diseases in both groups.
- Significant differences between boomer CGs of people with dementia and CG of people without dementia were found.
- Different factors predicted boomer CGs of people with dementia and without dementia depression and physical health.

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Conflicts of interest

None declared.

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