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Cancer Caregiving While Employed: Caregiving Roles, Employment Adjustments, Employer Assistance, and Preferences for Support

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Abstract

Cancer patients commonly require assistance from a relative or friend, and many of these "family caregivers" are navigating employment while caring. The purpose of this analysis was to understand the experience of employment while providing care to someone with cancer, including these caregivers' roles and burden, adjustments made to employment, assistance provided by employers, and preferences for employment and financial support. To further highlight this group of cancer caregivers, we compare it with (1) cancer caregivers who were not employed while caring; (2) caregivers for patients with a primary condition other than cancer who were employed while caring; and (3) caregivers for patients with a primary condition other than cancer who were not employed while caring. This secondary analysis is drawn from the National Alliance for Caregiving's (NAC)/AARP Caregiving in the US dataset of unpaid adult (i.e., age 18 and older) caregivers. Half of the cancer caregivers were employed while providing care, and these employed caregivers were significantly more likely to be younger than those non-employed while caring. The employed cancer caregivers provided significantly fewer hours of care per week on average than those non-employed (23.4 vs. 42.5 h/week) but provided a nearly equivalent number of ADLs on average. Nearly half (48%) of the employed cancer caregivers reported coming in late to work, leaving early, or taking off work to accommodate caregiving, while 24% cut back on hours at work or went from full-time to part-time employment and 11% retired early or quit work entirely. The employed cancer caregivers (excluding self-employed) indicated having access to flexible working hours (57%) or paid sick leave (48%), and most (73%) reported that their supervisor was aware of their caregiving role, which was significantly higher than employed non-cancer caregivers (55%). These findings suggest that balancing work and cancer caregiving is especially prevalent among younger caregivers, and that work adjustments are needed but that the cancer caregiving role might be more commonly discussed or shared with supervisors. These findings suggest the need to develop workplace educational resources for employees caring for a cancer patient but also for supervisors to enhance their understanding of caregiver strain, workload, and work-based strategies to assist cancer caregivers.

Keywords Cancer · Caregiving · Family care · Employment policy · Workforce

Introduction

Many Americans diagnosed with cancer—over 1.7 million expected in 2018 alone [1]—experience high physical and psychosocial strain [2, 3]. Thus, patients often rely on relatives and friends who provide medical or nursing-related care, monitor symptoms, and advocate for their needs in clinical care [4]. As a result of these tasks and others, these cancer caregivers provide many hours of care per week (33 on average), and, for some (32%), the time spent caring equates to a full-time job or more (41 or more hours) [4]. Hence, the ability to maintain employment or a career while providing care is likely difficult. We currently lack a full understanding of this experience of caring for a relative or friend with cancer while being employed, including how these caregivers might prefer

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to be supported for their own financial and psychosocial well-being.

A population-level analysis conducted in 2013 in the USA indicated that 8 million workers (including those working part-time) were providing family care, and the employed caregivers were less likely to be working full-time compared with the employed non-caregivers [5]. Furthermore, compared with the employed non-caregivers, the employed caregivers reported missing more work and had greater productivity impairment including presenteeism [5]. Similarly, non-population level findings in cancer and other specific contexts (e.g., older adult care) also suggest that caregiving can disrupt employment, including working fewer hours or retiring early [6, 7]. In studies conducted in the USA, providing high burden care—providing many hours of care per week, assistance with a high number of Activities of Daily Living (ADLs) or weekly care demands—is shown to be associated with disruption in employment in the form of retiring early or reducing hours of work [6, 8, 9]. Furthermore, a caregiver's education and income or overall wealth might affect whether a caregiver remains employed, but the direction of association is not fully clear. Namely, those with less flexible and lower paid employment may be more susceptible to experiencing difficulty in maintaining work; however, it has also been shown that caregivers with higher levels of education were more likely to report that caregiving interfered with their work [6]. It is also possible that those with higher education have greater job or managerial responsibilities and/or longer working hours and thus perceive caregiving to interfere with their work.

Other findings demonstrate that caregiving is particularly detrimental for women both in employment status and financially. For example, among workers in the UK between the ages of 50 and 75 years, women were more likely to leave the workforce and especially those caring for a spouse/partner [10]. Women have also been shown to be more likely than men to assume caregiving responsibilities and experience burden when working full-time [6, 11], while younger women who provide care are at heightened risk of financial strain later in life [12, 13]. Furthermore, in addition to financial risk, there might be mental health implications of employment disruption due to caregiving as at least one study noted that experiencing employment disruption while caring for an older adult was associated with heightened emotional strain [6].

The demands of caregiving on employment are not fully understood among those who are assisting a relative or friend with cancer, including a lack of nationally representative data. Despite reporting of the population-level burden of caregiving among employed persons [5], as noted by de Moor and colleagues [7], most studies in oncology have been conducted using small, non-representative samples. Furthermore, given the intensity of cancer caregiving, it is necessary to explore not only the impact of caregiving on employment but also the experiences and perspectives of those who were employed while caring. In particular, to best inform and support caregivers in the workplace, we need analyses that seek to understand receipt of work-based support among caregivers and their preferences for support. Such findings will inform the development of workplace educational resources for employees and supervisors as well as public policy efforts related to employment and financial support.

In the USA, the Family Medical Leave Act (FMLA) remains the only federal law designed to ensure that caregivers who wish to temporarily leave work to provide care to a relative (i.e., a spouse, child, or parent only) with cancer can do so without being terminated. However, this policy is not universal for all workers (e.g., those working for small companies or not working full-time) and leaves states or employers to modify or supplement the policy to address shortcomings (e.g., unpaid leave) [14]. Support to address the employment and financial concerns of caregivers is evident. For example, in a qualitative study exploring areas of policy support among varied stakeholders, including caregivers, clinicians, researchers, and managers, work-based support was noted by all stakeholders as a high priority [15].

The purpose of this analysis was to understand the experience of being employed while providing care to someone with cancer, including these caregivers' roles and burden, adjustments made to employment, assistance received from employers, and preferences for employment and financial support. To further highlight this group of cancer caregivers, we compare it with (1) cancer caregivers who were not employed while caring; (2) caregivers for patients with a primary condition other than cancer who were employed while caring; and (3) caregivers for patients with a primary condition other than cancer who were not employed while caring. These findings will contribute to the development of policy and workplace resources (information, education, and support) for caregivers of cancer patients.

Methods

This study uses a cross-sectional nationally representative sample of adult family caregivers, age 18 or older, in the USA ("Caregiving in the U.S. 2015" report). The data were collected late 2014 using GfK's probability-based online KnowledgePanel®. Additional information about the Caregiving in the US 2015 study and methodology is available at http://www.caregiving.org/caregiving2015/. As a secondary analysis, this study was exempted by the Institutional Review Board at Arcadia University.

Sample

In order to qualify for the study, respondents must have self-identified as an unpaid caregiver of an adult either currently or at some point in the 12 months prior to the survey. Self-identified caregivers had to also report providing help with at least one Activity of Daily Living (ADL), Instrumental Activity of Daily Living (IADL), or medical/nursing task. This study examines the responses of 111 caregivers who indicated that cancer was the main problem or illness underlying why their family member or friend needed care, hereafter referred to as "cancer caregivers." Thus, the total sample includes 111 cancer caregivers and 1164 non-cancer caregivers. We compare these cancer caregivers with those of "non-cancer caregivers" or those who reported providing care to an adult family member or friend for a primary reason other than cancer. The top four primary reasons for providing care among the comparison (non-cancer caregiving) group were "old age"/aging/frailty (15%), Alzheimer's or dementia (9%), surgery/wounds (9%), and mobility problems (8%), while the remaining percentages are indicated in the original NAC cancer caregiving report. The sampling design and population weights applied have been previously described: http://www.caregiving.org/wp-content/uploads/2016/06/CancerCaregivingReport_FINAL_June-17-2016.pdf. For the purposes of this study, we also further stratified based on employment while providing care.

Measurement of Variables

The questionnaire that is the basis for this secondary analysis was designed by a team from NAC, the AARP Public Policy Institute, and Greenwald & Associates. Questions were designed to replicate questions from their 1997, 2004, and 2009 NAC/AARP Caregiving in the US studies, as well as to explore new areas. Variables and related questions are described below.

Employment Status To determine whether a caregiver was employed while providing care (yes or no), a single variable was developed based on two items (yes for either question equated to a yes for the variable): "Are you currently employed?" or "Have you been/Were you employed at any time in the last year while you were also helping your care recipient?" Employed caregivers were also asked if they were self-employed or owned their own business (yes or no).

Caregiver and Caregiving Characteristics Key caregiver characteristics (age at survey, race/ethnicity, gender, education, household income, rural residence) and care recipient characteristics (gender, age at survey) were collected. Caregiving characteristics included whether they were currently providing care or had provided care over the past 12 months but not currently providing care, whether they were the primary or secondary caregiver, proximity to the patient, and whether children/grandchildren were also in the home. These data are presented with respect to employment status and cancer caregiving status.

Roles Caregivers were asked "Do/Did you help your care recipient with any medical/nursing tasks (with list of examples)?" as well as to indicate whether they provided care for each of six Activities of Daily Living (ADL) and each of seven Instrumental Activities of Daily Living (IADL).

Burden Objective burden was measured using the Care Burden Index (an index combining hours of care and ADL and IADL tasks), which has been used consistently in National Alliance for Caregiving surveys [16–18]. To identify physical, emotional, and financial burden of caregiving, caregivers responded to the following questions: "How much of a physical strain would you say that caring for your care recipient is/was for you? How emotionally stressful would you say that caring for your care recipient is/was for you? How much of a financial strain would you say that caring for your care recipient is/was for you?" (Response options: 1: "not a strain at all"–5: "very much a strain; or 1: "not at all stressful"–5: "very stressful").

Employment Adjustments Caregivers were asked "As a result of caregiving, did you ever experience any of these things at work? (Went in late, left early, or took time off during the day to provide care; Took a leave of absence; Went from working full-time to part-time, or cut back your hours; Turned down a promotion; Lost any of your job benefits; Gave up working entirely; Retired early; Received a warning about your performance or attendance at work)". To determine awareness of one's caregiving role, caregivers were asked "Does/did your supervisor know that you are/were caring for your care recipient?"

Employer Assistance Caregivers indicated employer assistance by answering the following question, "For employees in your position, which of the following does/did your employer offer? (Flexible work hours; Paid sick days; Paid leave, where you could take paid time off from work for several weeks to care for a family member; Programs like information, referrals, counseling, or an employee assistance program, to help caregivers like yourself; Telecommuting or working from home)". Caregivers were also asked about preferences: "Below are some ways that people are proposing to help caregivers financially. Which one would you find/have found most helpful?" (An income tax credit to caregivers, to help offset the cost of care; A partially paid leave of absence from work, for caregivers who are employed; A program where caregivers could be paid for at least some of the hours they provide care; Not sure; Refused by not selecting an answer).

Analyses

The analyses are descriptive and include frequencies and bivariate comparisons. The bivariate comparisons included *t* tests for means with equal variances and independent *z*-tests for percentages (unpooled) were used. Comparison groups included cancer caregivers of patients who were employed (unweighted $n = 47$) and those not employed (unweighted $n = 64$) as well as non-cancer caregivers who were employed (unweighted $n = 684$) and those not employed (unweighted $n = 480$). All reported percentages and comparisons are based on weighted samples.

Results

The socio-demographics of the cancer caregivers and non-cancer caregivers as well as the care recipient characteristics were previously presented in a report available online at https://www.caregiving.org/wp-content/uploads/2016/06/CancerCaregivingReport_FINAL_June-17-2016.pdf [4]. Also indicated in the original report was the finding that groups did not differ significantly in terms of employment: they are employed at similar rates. Half (50%) of cancer caregivers indicated being employed while providing care, with 26% of employed cancer caregivers being self-employed.

In the current analyses, employed cancer caregivers were majority female (57%) and white (63%), but were not significantly different from the non-employed cancer caregivers with respect to gender or race/ethnicity (see Table 1). Employed cancer caregivers were significantly younger on average (46.4 years, s.d. = 11.8) than the non-employed cancer caregivers (59.8 years, s.d. = 15.0, $t = 4.39$, df = 109, $p < 0.01$; see Table 1). The patients of the employed cancer caregivers were 66.9 years of age on average (s.d. = 12.9) and in most cases were family members (87%) with the largest group caring for a parent or parent-in-law (49%). The median time of providing care for both the employed and non-employed cancer caregivers was 9 months. Table 1 provides additional characterization according to cancer caregiver status and employment status.

Roles and Burden

The employed cancer caregivers were very involved in supportive care related to health monitoring and management, including (1) Advocating with providers, community services, or government agencies (68%); (2) monitoring severity of symptoms (71%); (3) communicating with health care professionals (92%); and (4) performing medical/nursing tasks (69%), which is significantly higher than employed non-cancer caregivers for all roles except monitoring severity of symptoms (see Table 2). Furthermore, in terms of roles and tasks, the employed cancer caregivers assisted with 2.3 Activities of Daily Living (ADLs) on average (s.d. = 2.1), which was nearly equivalent to the 2.5 ADLs on average (s.d. = 2.1) for non-employed cancer caregivers. Table 2 highlights comparisons of ADLs according to employment status and cancer caregiving status. Employed cancer caregivers were significantly less likely to assist the patient in getting dressed than non-employed cancer caregivers (32% vs. 52%, $z = -1.96$, $p < 0.05$) but were significantly more likely than employed non-cancer caregivers to assist the patient in moving (to and from the toilet) (48% vs. 24%, $z = 3.09$, $p < 0.01$) and to assist with feeding (39% vs. 21%, $z = 2.26$, $p < 0.05$; see Table 2). Furthermore, IADLs also did not differ significantly according to employment status for the cancer caregivers (see Table 2). However, the employed cancer caregivers were significantly more likely than employed non-cancer caregivers to provide medicines, pills, or injections (61% vs. 43%, $z = 2.22$, $p < 0.05$) as well as arrange outside services (50% vs. 30%, $z = 2.45$, $p < 0.05$; see Table 2). Furthermore, in contrast to non-employed cancer caregivers, employed cancer caregivers were less likely to assist in housework (65% vs. 84%, $z = -2.07$, $p < 0.05$) or prepare meals (53% vs. 84%, $z = -3.27$, $p < 0.01$; see Table 2).

The employed cancer caregivers provided 23.4 hours of care per week on average (s.d. = 28.4), which was significantly lower than the number of hours of care provided by the non-employed cancer caregivers (42.5 h/week, s.d. = 31.2, $t = 2.98$, df = 109, $p < 0.01$). Most of the employed cancer caregivers (70%) provided ≤ 20 h of care, which was a significantly higher percentage than those who were not employed (40%, $z = 3.10$, $p < 0.01$); yet, 17% of the employed cancer caregivers provided 41 h or more of care.

For the employed cancer caregivers, the mean burden level (i.e., Care Burden Index) was 3.0 (range 1: low—5: high) and is determined based on hours of care per week and ADLs/IADLs. This level (3.0, s.d. = 1.5) was significantly lower than that for non-employed cancer caregivers (3.7, s.d. = 1.3, $t = 2.44$, df = 109, $p < 0.05$; see Table 3). Half (50%) of employed cancer caregivers experienced a high level (level 4 or 5) of burden, which was significantly lower than non-employed cancer caregivers (74%, $z = -2.44$, $p < 0.05$). Furthermore, 22% employed cancer caregivers indicated high (i.e., level 4 or 5) physical strain, 49% indicated high emotional strain, and 32% indicated high financial strain, all of which were not significantly different than non-employed cancer caregiver (20%, 50%, and 18%, respectively). However, this percentage of employed cancer caregivers (32%) indicating high financial strain (level 4 or 5) is significantly higher than employed non-cancer caregivers indicating such strain (17%, $z = 2.12$, $p < 0.05$; see Table 3).

Table 1 Caregiver and caregiving characteristics by cancer and employment status

	Cancer caregiving		Non-cancer caregiving	
	Employed	Not employed	Employed	Not employed
Weighted *n* (unweighted)	56 (47)	55 (64)	680 (684)	445 (480)
Age—mean, in years	*46.4*	*59.8****	45.1	*55.0****
Standard deviation	11.8	15.0	14.4	17.9
t value (degrees of freedom)		4.39 (109)	0.61 (729)	3.28 (525)
18–49	*60%*	*26%****	55%	*36%****
z-score		3.57	0.58	2.90
50 or over	*40%*	*74%****	45%	*64%****
z-score		− 3.57	− 0.58	− 2.90
Gender—female	57%	59%	55%	67%
z-score		− 0.20	0.22	− 1.25
Race/ethnicity				
White	63%	68%	58%	67%
z-score		− 0.58	0.63	− 0.58
Black	7%	15%	13%	13%
z-score		− 1.21	− 1.33	− 1.25
Asian/Pacific Islander	12%	5%	7%	5%
z-score		0.94	0.74	1.05
Hispanic	19%	12%	19%	14%
z-score		0.89	− 0.09	0.84
Education—college degree or more	*49%*	*31%**	39%	*26%****
z-score		*1.68*	*1.14*	*2.75*
Household income under $50,000	*39%*	53%	41%	*55%***
z-score		− 1.30	− 0.25	− 1.97
Lives in rural area	*11%*	19%	13%	*19%**
z-score		− 1.17	− 0.51	− 1.66
Current caregiver	*45%*	*27%**	*59%**	54%
z-score		1.73	− 1.80	− 1.20
Distance from patient				
Lives with patient	36%	43%	31%	39%
z-score		− 0.68	0.66	− 0.35
Lives within 20 min of patient	37%	32%	42%	38%
z-score		0.50	− 0.61	− 0.17
Care status				
Primary caregiver—sole	*28%*	35%	*45%***	*52%****

Table 1 (continued)

	Cancer caregiving		Non-cancer caregiving	
	Employed	Not employed	Employed	Not employed
z-score		− 0.73	− 2.38	− 3.34
Primary caregiver—leads among others	11%	20%	17%	15%
z-score		− 1.20	− 1.17	− 0.79
Secondary—shared equally with others	*27%*	18%	*12%***	*10%***
z-score		0.97	1.97	2.27
Secondary—others provide more care	*34%*	27%	26%	*21%**
z-score		0.78	1.11	1.72
Children/grandchildren in the household	27%	26%	32%	23%
z-score		0.12	− 0.75	0.47
Patient female gender	63%	76%	66%	63%
z-score		− 1.26	− 0.37	0.02
Patient lives in rural area	22%	20%	27%	30%
z-score		0.27	− 0.78	− 1.11
Patient age—mean, in years	66.9	69.1	68.2	71.3
Standard deviation	12.9	12.7	18.2	17.7
t value (degrees of freedom)		0.82 (109)	0.47 (729)	1.60 (523)
18–49	15%	9%	15%	12%
z-score		0.92	0.02	0.61
50–74	50%	58%	38%	37%
z-score		− 0.72	1.45	1.62
75 or over	*35%*	33%	46%	*51%***
z-score		0.14	− 1.50	− 2.01
Patient is				
Parent or parent-in law	49%	39%	55%	40%
z-score		1.04	0.80	1.19
Spouse or partner	11%	22%	8%	18%
z-score		− 1.40	0.48	− 1.38
Other relative	27%	27%	24%	23%
z-score		0.13	0.57	0.73
Non-relative	13%	12%	13%	19%
z-score		0.06	− 0.04	− 1.02

For *t* value and *z*-scores, $^{*}p < 0.10$; $^{**}p < 0.05$; $^{***}p < 0.01$. Significant characteristics are italicized and all are comparisons with employed cancer caregivers. Means and percentages are based on weighted samples

Table 2 Care tasks ("yes") by cancer and employment status

	Cancer caregiving		Non-cancer caregiving	
	Employed	Not employed	Employed	Not employed
Weighted *n* (unweighted)	56 (47)	55 (64)	680 (684)	445 (480)
ADL—mean, in number of ADLs	_2.3_	2.5	_1.5_***	_1.8_*
Standard deviation	2.1	2.1	1.8	1.9
t value (degrees of freedom)		.43 (109)	2.71 (729)	1.79 (525)
Get in and out of beds and chairs	54%	61%	41%	45%
z-score		− 0.68	1.62	1.13
Get dressed	_32%_	_52%_**	28%	35%
z-score		− 1.96	0.49	− 0.40
Get to and from the toilet	_48%_	44%	_24%_***	_29%_**
z-score		0.39	3.09	2.40
Bathe or shower	35%	34%	25%	26%
z-score		0.07	1.29	1.14
By dealing with incontinence or diapers	_25%_	22%	_14%_*	19%
z-score		0.36	1.65	0.85
By feeding him or her	_39%_	40%	_21%_**	_24%_*
z-score		− 0.02	2.26	1.91
IADL—mean, in number of IADLs	4.3	4.8	4.1	4.3
Standard deviation	1.8	1.6	1.9	1.9
t value (degrees of freedom)		.41 (109)	0.82 (729)	0.14 (525)
Giving medicines, pills, or injections for his/her condition	_61%_	61%	_43%_**	48%
z-score		− 0.06	2.22	1.53
Managing finances, such as paying bills, or filling out insurance claims	63%	56%	55%	51%
z-score		0.74	1.04	1.53
Assisting with grocery or other shopping	_64%_	77%	74%	_80%_**
z-score		− 1.37	− 1.34	−2.11
Assisting with housework, such as doing dishes, laundry or straightening up	_65%_	_84%_**	71%	74%
z-score		− 2.07	− 0.84	− 1.19
Preparing meals	_53%_	_84%_***	56%	_67%_*
z-score		− 3.27	− 0.44	− 1.79
Transportation, either by driving him/her, or helping your care recipient get transportation	77%	86%	78%	77%
z-score		− 1.11	− 0.07	0.03
Arranging outside services, such as nurses, home care aides, or meals on wheels	_50%_	37%	_30%_**	_31%_**
z-score		1.27	2.45	2.37
Advocating for him/her with health care providers, community services, or government agencies	_68%_	56%	_51%_**	_46%_***
z-score		1.18	2.32	2.85
Monitoring the severity of his/her condition so that you can adjust care accordingly	71%	81%	67%	64%
z-score		− 1.02	0.67	1.04
Communicating with health care professionals like doctors, nurses, or social workers about his/her care	_92%_	_71%_***	_63%_***	_61%_***
z-score		2.82	6.27	6.32
Performing medical/nursing tasks	_69%_	75%	_53%_**	61%
z-score		− 0.59	2.25	1.17

For *t* value and *z*-scores, $*p < 0.10$; $**p < 0.05$; $***p < 0.01$. Significant characteristics are italicized and all are comparisons with employed cancer caregivers. Means and percentages are based on weighted samples

Table 3 Care Burden Index and physical, emotional, and financial strain by cancer and employment status

	Cancer caregiving		Non-cancer c	
Weighted n (unweighted)	Employed 56 (47)	Not employed 55 (64)	Employed 680 (684)	Not employed 445 (480)
Care Burden Index—mean	_3.0_	_3.7_**	2.7	3.1
Standard deviation	1.5	1.3	1.4	1.4
t value (degrees of freedom)		2.44 (109)	1.44 (726)	0.37 (522)
Net: low (1–2)	_32%_	21%	_47%_**	34%
z-score		1.18	-2.06	− 0.28
Net: high (4–5)	_50%_	_74%_**	_33%_**	46%
z-score		− 2.44	2.09	0.44
Physical strain—mean	2.4	2.5	2.3	2.6
Standard deviation	1.3	1.2	1.2	1.3
t value (degrees of freedom)		0.41 (109)	0.59 (726)	0.86 (524)
Net: low (1–2)	52%	60%	57%	50%
z-score		− 0.80	− 0.70	0.24
Net: high (4–5)	22%	20%	16%	25%
z-score		0.31	0.97	− 0.36
Emotionally stressful—mean	_3.4_	3.3	_3.0_**	3.1
Standard deviation	1.2	1.2	1.3	1.3
t value (degrees of freedom)		0.29 (108)	2.09 (726)	1.53 (519)
Net: low (1–2)	_22%_	29%	_38%_**	_34%_*
z-score		− 0.86	− 2.40	− 1.81
Net: high (4–5)	49%	50%	37%	38%
z-score		− 0.03	1.59	1.36
Financial strain—mean	_2.6_	2.2	2.3	_2.2_**
Standard deviation	1.4	1.5	1.3	1.3
t value (degrees of freedom)		1.39 (108)	1.58 (726)	2.16 (523)
Net: low (1–2)	_48%_	64%	59%	_66%_**
z-score		− 1.54	− 1.37	− 2.16
Net: high (4–5)	_32%_	_18%_*	_17%_**	_18%_*
z-score		1.66	2.12	1.94

For t value and z-scores, *$p < 0.10$; **$p < 0.05$; ***$p < 0.01$. Significant characteristics are italicized and all are comparisons with employed cancer caregivers. Means and percentages are based on weighted samples

Table 4 Employment adjustments, assistance, and preferences by cancer and employment status

Weighted *n* (unweighted)	Cancer caregiving		Non-cancer caregiving	
	Employed 56 (47)	Not employed 55 (64)	Employed 680 (684)	Not employed 445 (480)
Employment adjustments				
Went in late, left early, or took time off to provide care	48%	--	49%	--
z-score			− 0.15	
Took a leave of absence	19%	--	15%	--
z-score			0.62	
Went from working full-time to part-time, or cut back hours	24%	--	13%	--
z-score			1.62	
Turned down a promotion	*0%*	--	_6%***_	--
z-score			− 5.91	
Lost any job benefits	*0%*	--	_3%***_	--
z-score			− 4.48	
Gave up working entirely	7%	--	6%	--
z-score			0.15	
Retired early	4%	--	4%	--
z-score			0.00	
Received a warning about your performance or attendance at work	5%	--	7%	--
z-score			− 0.51	
Employer assistance offered[i]				
Flexible work hours	57%	--	52%	--
z-score			0.47	
Paid sick days	48%	--	52%	--
z-score			− 0.45	
Paid leave, where you could take paid time off from work for several weeks to care for a family member	33%	--	32%	--
z-score			0.12	
Programs like information, referrals, counseling, or an employee assistance program to help caregivers	23%	--	24%	--
z-score			− 0.04	
Telecommuting or work from home	25%	--	22%	--
z-score			0.37	
Employer knows about caregiving[i]	*73%*	--	_55%**_	--
z-score			2.27	
Helpful proposals for caregivers				
An income tax credit to caregivers, to help offset the cost of care	26%	17%	36%	21%
z-score		0.94	− 1.52	0.63

Table 4 (continued)

Weighted *n* (unweighted)	Cancer caregiving Employed 56 (47)	 Not employed 55 (64)	Non-cancer caregiving Employed 680 (684)	 Not employed 445 (480)
A partially paid leave of absence from work	17%	17%	14%	7%
z-score		0.00	0.53	1.55
A program where caregivers could be paid at least some of the hours they provide care	29%	28%	26%	37%
z-score		0.09	0.39	− 1.14
Not sure	29%	38%	24%	34%
z-score		− 0.94	0.66	− 0.71
Support banning workplace discrimination against workers who have caregiving responsibilities	83%	*66%**	*68%***	*65%****
z-score		1.86	2.34	2.62

For *t* value and *z*-scores, *$p < 0.10$; **$p < 0.05$; ***$p < 0.01$. Significant characteristics are italicized and all are comparisons with employed cancer caregivers.. Means and percentages are based on weighted samples

[i] For those not self-employed only; weighted $n = 41$ (35 unweighted) for cancer caregivers and weighted $n = 560$ (557 unweighted) for non-cancer caregivers

Employment Adjustments to Accommodate Caregiving

As a result of caregiving, employed caregivers did the following: (1) Went in late, left early, or took time off to provide care (48%); (2) went from working full-time to part-time, or cut back hours (24%); (3) took a leave of absence (19%); (4) gave up work entirely (7%); (5) received a warning about performance (5%); or (6) retired early (4%). Of the employed cancer caregivers who were not self-employed (unweighted $n = 35$), 73% (weighted) indicated that their supervisor knew they were providing care and this was significantly higher than the employed (but not self-employed) non-cancer caregivers (unweighted $n = 557$; 55% weighted, $z = 2.27$, $p < 0.05$; see Table 4).

Employment-Related Assistance and Caregivers' Preferences for Financial or Employment-Related Support

The employed (excluding self-employed) caregivers indicated the following support via their employer: Flexible working hours (57%); paid sick days (48%); paid leave to care for a family member (33%); telecommuting or work from home (25%); or programs like information, referrals, counseling, or an employee assistance program (23%) (see Table 4). Most (83%) of the employed cancer caregivers indicated supporting banning workplace discrimination against workers who have caregiving responsibilities, which was significantly higher than employed non-cancer caregivers (68%, $z = 2.34$, $p < 0.05$). The employed cancer caregivers indicated that the following would have been most helpful for them: A program where caregivers could be paid for at least some of the hours they provide care (29%); an income tax credit to caregivers, to help offset the cost of care (26%); a partially paid leave of absence from work, for caregivers who are employed (17%); and 29% answered Not sure (see Table 4).

Discussion

These findings indicate that although cancer caregivers are employed at similar rates than non-cancer caregivers, both groups have a high percentage of employed caregivers including half of the cancer caregivers being employed while providing care. Employed cancer caregivers were significantly more likely to be younger than non-employed cancer caregivers, but there was no significant difference with respect to gender, educational status, or other demographics.

Most employed cancer caregivers were "secondary" caregivers, meaning that they shared this role equally with a relative or friend or another individual was the primary caregiver. This high percentage of caregivers serving as a secondary caregiver might be related to the demands of balancing employment while caring. Yet, a sizeable percentage of employed cancer caregivers were serving as the primary caregiver for the patient, including being the sole caregiver. Going forward, it will be important to explore the demands of employed primary, sole caregivers as well as caregivers who are part of a caregiving team to identify how each subpopulation can best be supported. For example, it is possible that those who are providing care alone while balancing employment might need financial support to supplement paid formal assistance. Furthermore, education materials should be developed to inform these caregivers about accessing formal care resources to sustain employment if desired. In contrast, caregivers providing care as part of a care team might benefit from materials or resources that address topics such as sharing caregiving roles as well as how to communicate needs and barriers related to work-caregiving balance. Indeed, employed cancer caregivers were also shown to be more likely (than both employed non-cancer caregivers and non-employed cancer caregivers) to arrange outside services and coordinate care and might need resources to do so effectively.

Assisting patients with ADLs and IADLs was similar on average for employed and non-employed cancer caregivers. However, with respect to specific tasks, compared with employed non-cancer caregivers, employed cancer caregivers were more likely to assist with feeding and toileting. This might suggest more debilitating and poorer physical capacity among the care recipients due to cancer. Moreover, most of the employed cancer caregivers indicated that they advocated for the patient, monitored patient symptoms, communicated with health professionals, and performed medical/nursing tasks (68% or higher in all areas). These findings suggest the need for education materials and communication skills training related to a caregiver's active and engaged role in clinical care, but such resources must be accessible to caregivers who are employed. Strategies to ensure access might involve the development of materials and trainings that are web-based, independent-learning modules. Furthermore, to help caregivers manage employment responsibilities and be engaged in clinical care, virtual or telemedicine-related approaches could be explored via research in terms of allowing a caregiver to be engaged in a patient's clinical appointment if their employment limits them from being present onsite.

Half of the employed caregivers were in high burden caregiving situations (based on hours of care and IADLs/ADLs). This percentage was significantly lower than non-employed cancer caregivers, which might stem from the reduced hours of care employed caregivers are able to provide more than the type of assistance provided. Possibly due to the demands of working, employed cancer caregivers provided significantly fewer hours of care per week on average than non-employed. However, nearly 2 in 10 provided the equivalent of a full-time job or more (≥ 41 h) in caregiving hours, in addition to employment. In other research involving a small sample of caregivers for persons with advanced cancer, greater work productivity loss was associated with greater number of caregiving hours [19].

In addition to the objective burden of caregiving, approximately half of employed cancer caregivers expressed that caregiving was highly stressful. Moreover, approximately 3 in 10 indicated high financial strain. However, the percentage indicating high financial strain was higher (non-significantly) than the non-employed cancer caregivers and significantly higher than the employed non-cancer caregivers. This finding is supportive of previous literature indicating that cancer patients and their families experience financial burden [20, 21]. In this sample, this finding could be due to the fact that the employed cancer caregivers were younger than those not employed and thus were potentially in mid-career when their relative or friend was diagnosed with cancer. This supports an earlier finding exploring employment rates among caregivers for those with brain cancer which reported that those who were employed were younger in age [22]. Future work should continue to explore factors that may contribute to caregiving being financially burdensome to employed cancer caregivers, including how much they are contributing to the patient's medical bills. Importantly, employers should ensure that employees have access to education and resources specific to managing emotional stress and financial strain of cancer caregiving. Employers can utilize existing materials developed specifically for caregivers, such as the American Cancer Society's Caregiver Support Videos (available at https://www.cancer.org/caregivers.html).

Furthermore, a specific financial strain for caregivers can be the modifications made to employment in terms of hours worked or work status, and thus, public policy must be expanded at state and federal levels to better support caregivers—including those who wish to sustain employment while caring or take a leave and return to work following caregiving. Common work adjustments for the employed cancer caregivers included coming in late, leaving early, or taking off work, while fewer, cut back on hours at work or went from full-time to part-time employment or retired early or quit work entirely. These findings are similar to the literature showing work interference among caregivers caring for older adults (52.4% indicated caregiving interfered with their employment) [6]. Furthermore, 25% from the Medical Expenditure Panel survey (ECSS) and 29% from a related LIVESTRONG survey of cancer survivors reported that their caregivers made extended employment changes [7]. Specifically, among those in the ECSS survey who reported taking paid time off, most (74.1%) took leave lasting 2 to < 6 months, which is more but close to the average duration of care from this study (9.6 months). In the MEPS/LIVESTRONG study, findings also suggested that although early retirement was rare (4%) among caregivers, those that did choose to retire early did so as a result of cancer caregiving [7]. Another 7% of survivors reported their caregiver quit work altogether. Future research should consider a study of those who retire early or quit work entirely and perceptions of ability to return to work after caregiving.

Absent from the literature is if and how caregivers are assisted while employed and their preferences. Employment assistance was available for some but not all employed (excluding self-employed) cancer caregivers. Assistance was most consistently in the form of flexible working hours or paid sick leave, but still only available for half or less (57% and 48%, respectively). Importantly, one-quarter had the option to telecommute, while fewer (23%) had access to support services including counseling. Communication within the workplace about cancer and the caregiving might be occurring more readily in the context of cancer, given that more cancer caregivers than non-cancer caregivers reported their supervisor was aware of their caregiving role. This might suggest cancer is more readily discussed in the work place, possibly due to the less long-term nature of the caregiving role and the often acute or immediate needs of the patient. Previous qualitative interview findings are consistent with our results and showed that cancer caregivers that indicated that most felt supported by their co-workers [23]. Not surprisingly, most employed cancer caregivers were in favor of banning discrimination in the workplace for caregivers. This reinforces the importance of asking caregivers their preferences with respect to decreasing financial concerns while caring [24]. An important role for the cancer education field could be to develop trainings and materials specifically for human resource (HR) departments to aid in understanding the needs of employees who are caring for a relative or friend with cancer and how to support the employees via organizational policy so that employment can be sustained. Moreover, HR departments could then provide materials and training to supervisors so that the needs of cancer caregivers are even more openly discussed and addressed.

Limitations

Certain limitations of the current study warrant mention. Data for the study are from a cross-sectional survey of caregivers; thus, any associations found cannot be considered causal. Furthermore, this cross-sectional study design allows for understanding of potential associations but the design is weaker than a prospective, longitudinal design. Future research should seek to follow caregivers longitudinally to explore impact on work, financial stability, and well-being. Caregivers were also asked to recall their caregiving experiences over a 12-month period; thus, findings may be prone to recall bias. Few details are obtained about the specifics of the care recipient's health condition; thus, findings with respect to cancer site, stage at diagnosis, and treatment history cannot be determined. Despite these limitations, caregiving in the US is a unique data source in that it collects survey data directly from caregivers, relies on a probability-based sample, and provides comprehensive characteristics of the caregiving experience.

Conclusions

These findings contribute to the literature by assisting in our overall understanding of the experiences of employed cancer caregivers compared with those non-employed as well as caregivers of other conditions (employed and non-employed). Employed cancer caregivers, despite providing fewer hours of care per week, are still highly engaged in care by assisting with ADLs/IADLs as well communicating and advocating for the patient. The caregivers experience work disruption, most prevalent in the form of reducing or modifying work hours, while few quit or retire as a result of caregiving. This suggests a need to consider how to support caregivers while assisting a patient with cancer. Many, but not all, employed cancer caregivers reported having access to paid sick leave or flexible hours. Going forward, providing comprehensive employment support to employees who are caregivers is needed. This might include policy approaches to ensure financial support to pay for formal care for those who are a primary, sole caregiver as well as organizational approaches toward informing and training human resource departments and supervisors to understand and meet the needs of their employees.

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Compliance with Ethical Standards

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