RESEARCH BRIEF

Caregiver Burden and Workplace Productivity Among Hospice Cancer Caregivers

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OBJECTIVES: To examine the relationships among family caregiver burden and workplace productivity and activity impairment among home hospice family caregivers of individuals with cancer who worked while providing end-of-life caregiving.

SAMPLE & SETTING: Baseline data from a longitudinal study of communication between hospice providers and hospice family caregivers were used for this secondary analysis.

METHODS & VARIABLES: Working family caregivers with complete workplace productivity and activity impairment data were included in this analysis (N = 30). Demographic data, caregiver burden, and workplace productivity and activity impairment were examined with descriptive statistics, correlation analysis, and hierarchical linear regressions.

RESULTS: Hospice family caregivers were primarily White, female, married, and employed full-time. Caregiver burden levels were significantly positively associated with activity impairment, presenteeism, and work productivity loss. These relationships remained statistically significant when controlling for age.

IMPLICATIONS FOR NURSING: Hospice and oncology nurses can support working hospice family caregivers by assessing for burden and associated workplace challenges, as well as by providing referrals for respite and community resources.

KEYWORDS family caregiver; caregiver burden; workplace productivity; hospice; employment
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Family caregivers are key members of the cancer hospice care team who engage in an array of care activities, including activities of daily living, pain and symptom management, and nursing procedures such as medication administration and wound care (Parker Oliver et al., 2017). These contributions and associated burdens affect caregivers' own social, physical, emotional, financial, and occupational well-being (National Alliance for Caregiving and AARP Public Policy Institute, 2020; Parker Oliver et al., 2017).

The rates of working family caregivers are not fully understood because data are often only captured for individuals caring for adults; however, several national studies provide context. Hopps et al. (2017) reported that 18 million employed adults aged older than 18 years identify as family caregivers. Longacre et al. (2017) reported that more than half (52.9%) of caregivers aged between 18 and 64 years were employed either full- or part-time, and the National Alliance for Caregiving and AARP Public Policy Institute (2020) reported that in 2020, 61% of family caregivers worked.

Working caregivers reported more symptoms of depression (53% versus 32%) and insomnia (46% versus 37%), higher rates of healthcare utilization (4.1 versus 2.7 outpatient visits), and higher work productivity impairment (24% versus 14%) than noncaregivers (Hopps et al., 2017). Working family caregivers often report work interference with family caregiving (52.4%) and may have to reduce working hours or modify their schedule (Longacre et al., 2017). Some working family caregivers report leaving the workforce entirely because of caregiving responsibilities (39.8%) (Longacre et al., 2017). In later life, caregivers have lower incomes and lower net worth than noncaregivers (National Academies of Sciences, Engineering, and Medicine, 2016).

TABLE 1. Participant Demographics (N = 30)

Characteristic	$\bar{X}$	SD
Age (years)	51.87	12.76
Characteristic		**n**
Race[a]		
Asian		1
American Indian/Alaskan Native		1
Black or African American		2
White		24
Multiple races		2
Ethnicity[a]		
Hispanic/Latino		4
Non-Hispanic/Latino		31
Gender		
Female		19
Male		11
Relationship status		
Married		22
Separated or divorced		6
Committed relationship		1
Widowed		1
Education		
High school graduate or equivalent		4
Some college or vocational school		9
College graduate		8
Some graduate or professional school		2
Graduate or professional degree		7
Household income ($)		
10,000–24,999		2
25,000–39,999		3
40,000–49,999		4
50,000–74,999		6
75,000 or more		15
Employment status		
Full-time		22
Part-time		8
Relationship to care recipient		
Child		15
Spouse or partner		12
Sibling		2
Friend		1

[a] Participants could choose more than 1 response.

There is a significant research gap regarding the intersection of hospice cancer caregiving and occupational functioning among family caregivers. Therefore, the purpose of this exploratory analysis was to examine the relationships between family caregiver burden, workplace productivity, and activity impairment in unpaid work in working hospice family caregivers caring for individuals with cancer.

The premise for this secondary analysis stems from the conservation of resources theory. The conservation of resources theory posits that resources (valued objects, characteristics, or conditions) may have a protective effect for caregivers with stressful caregiving situations (Hobfoll, 1989). Working family caregivers may struggle to recover lost resources of time, energy, or mental focus from caregiving to sustain work performance. Increased caregiver burden may result in greater resource loss, thus negatively affecting caregiver work outcomes (work productivity, activity impairment) (Hobfoll, 1989).

Methods

This is an exploratory secondary data analysis of baseline family caregiver data from a longitudinal prospective study among family caregivers of individuals with cancer who were receiving hospice care (Tay et al., 2020). Data were collected from 2017 to 2020 from four home hospice agencies in Utah, Massachusetts, Florida, and Ohio. Ethics approval was obtained from the University of Utah Institutional Review Board, and participants provided informed consent.

Sample

Participants (N = 102) were family caregivers (family, friends, and neighbors) identified through patient records from participating home hospice agencies. Eligible caregivers were contacted by telephone for recruitment. Research staff scheduled home visits to provide education about the study and obtain study consent. Following consent, caregivers completed baseline surveys using a tablet device or pen and paper. Caregivers were adults (aged 18 years or older) who were able to speak and understand English, caring for an adult with a primary diagnosis of cancer and prognosis of two weeks or more to live, and caring for the patient in the home (Tay et al., 2020). For the current analysis, family caregivers who were working full- or part-time and had complete data for all Workplace Productivity and Activity Impairment questionnaire (WPAI) subscales were included (N = 30).

Measures

Demographic characteristics: The authors measured age, race and ethnicity, gender, relationship status, education, household income, relationship to care recipient, and full- or part-time employment.

Zarit Burden Interview short form: The Zarit Burden Interview short form is a 12-item scale that measures perceived burden related to caregiving. Items are scored on a five-point Likert-type scale. Scores range from 0 to 48, with higher scores indicating greater caregiver burden. Reliability has consistently been reported to be greater than α = 0.7, with a clinical cutoff ranging from 12 to 17, indicating detection of high burden (Bédard et al., 2001; O'Rourke & Tuokko, 2003; van Durme et al., 2012; Yu et al., 2018).

WPAI questionnaire: The WPAI questionnaire is a six-item quantitative measure of health-related work productivity loss for workers that assesses missed work (absenteeism); impairment at work and reduced on-the-job effectiveness (presenteeism); the combination of work impairment, absenteeism, and presenteeism (workplace productivity loss); and activity impairment (caregiving affecting regular activities). WPAI outcomes are calculated as impairment percentages, with higher percentages indicating greater impairment and lower productivity, and with differing equations for each dimension. The WPAI has been found to be valid and reliable across multiple disease conditions and with family caregivers (Giovannetti et al., 2009).

KNOWLEDGE TRANSLATION

- Working caregivers of individuals with cancer who are in hospice experience caregiver burden that may affect their occupational well-being.
- Findings suggest a significant relationship between caregiver burden and workplace productivity loss, but not absenteeism; caregivers with higher burden in this sample experienced more disruptions to productivity at work but were not missing work.
- Oncology and hospice nurses can address family caregiver burden through holistic assessment and referrals to community resources, which may also support family caregiver productivity in the workplace.

Analysis

Working family caregiver baseline data were analyzed using IBM SPSS Statistics, version 28.0, for frequencies and descriptive statistics, and correlation analysis (Pearson's r) identified significant relationships among perceived caregiver burden, workplace productivity, activity impairment. Hierarchical linear regression was used, with age as a covariate, caregiver burden as the independent variable, and dimensions of workplace productivity and activity impairment as outcome variables. A dummy variable was created based on a mean split of the data for age (0 = aged 51 years or younger, 1 = aged 52 years or older).

Results

In this sample of working family caregivers (N = 30), the mean age was 51.87 years (SD = 12.76). Most of the working caregivers were White (n = 24), female (n = 19), married (n = 22), and employed full-time (n = 22). Most caregivers reported having at least some college education (n = 26) and a household income of $50,000 or more (n = 21). Half (n = 15) reported being a child of the hospice care recipient, followed by being a spouse or partner (n = 12) (see Table 1). Based on the clinical cutoff for burden, participants experienced

TABLE 2. WPAI Means and Bivariate Correlations (N = 30)

Variable	$\bar{X}$	SD	1	2	3	4	5
ZBI-12	17.93	8.51	1	–	–	–	–
WPAI activity impairment	47.1	30.29	0.46*	1	–	–	–
WPAI presenteeism	66.62	34.52	0.45*	0.65**	1	–	–
WPAI work productivity	39	30.61	0.54**	0.73**	0.93**	1	–
WPAI absenteeism	29.66	29.33	0.26	0.48**	0.88**	0.76**	1

*$p < 0.05$; **$p < 0.01$

WPAI—Work Productivity and Activity Impairment questionnaire; ZBI-12—Zarit Burden Interview short form

Note. For the ZBI-12, scores range from 0 to 48, with higher scores indicating greater caregiver burden. The WPAI assesses 4 dimensions, and WPAI outcomes are calculated as impairment percentages, with higher percentages indicating greater impairment and lower productivity, and with differing equations for each dimension.

TABLE 3. Linear Models of WPAI Activity Impairment, Presenteeism, Work Impairment, and Absenteeism (N = 30)

	Activity Impairment[a]			Presenteeism[b]		
Variable	**β**	**95% CI**	**p**	**β**	**95% CI**	**p**
Step 1						
Age	0.12	[–16.15, 30.08]	0.54	–0.09	[–32.29, 20.54]	0.65
Step 2						
Age	0.15	[–11.9, 29.84]	0.39	–0.05	[–27.88, 20.48]	0.76
Burden	0.47	[0.43, 2.9]	0.01*	0.45	[0.38, 3.24]	0.02*
	Work Productivity[c]			**Absenteeism[d]**		
Variable	**β**	**95% CI**	**p**	**β**	**95% CI**	**p**
Step 1						
Age	–0.16	[–33.11, 13.29]	0.39	0.02	[–21.25, 23.8]	0.91
Step 2						
Age	–0.13	[–27.6, 12.39]	0.44	0.04	[–19.83, 24.58]	0.83
Burden	0.53	[0.73, 3.1]	0.003**	0.27	[–0.4, 2.23]	0.16

* $p < 0.05$; ** $p < 0.01$
[a] $R^2 = 0.01$ for step 1; $\Delta R^2 = 0.22$ for step 2 ($p < 0.05$)
[b] $R^2 = 0.007$ for step 1; $\Delta R^2 = 0.20$ for step 2 ($p < 0.05$)
[c] $R^2 = 0.03$ for step 1; $\Delta R^2 = 0.28$ for step 2 ($p < 0.01$)
[d] $R^2 = 0$ for step 1; $\Delta R^2 = 0.07$ for step 2 ($p = 0.16$)
CI—confidence interval; WPAI—Work Productivity and Activity Impairment questionnaire
Note. The continuous independent variable was the Zarit Burden Interview short form.
Note. Covariates were age (0 = individuals aged 51 years or younger, and 1 = individuals aged 52 years or older) and preparation for caregiving.

high levels of burden, with a mean score of 17.93 (SD = 8.51). WPAI mean percentages included 47.1% (SD = 30.29) for activity impairment, 66.62% (SD = 34.52) for presenteeism, 39% (SD = 30.61) for work productivity, and 29.66% (SD = 29.33) for absenteeism (see Table 2).

Bivariate correlations showed that hospice family caregiver burden levels were significantly positively associated with activity impairment ($r = 0.46$, $p < 0.05$), presenteeism ($r = 0.45$, $p < 0.05$), and work productivity loss ($r = 0.54$, $p < 0.01$). When hospice family caregivers had high burden levels, they had correspondingly higher rates of activity impairment, presenteeism, and work productivity loss. After controlling for age in the regression analysis, these relationships remained statistically significant (see Table 3). There was no significant relationship between caregiver burden and absenteeism.

Discussion

The number of working family caregivers is rapidly increasing in response to the aging U.S. population (National Academies of Sciences, Engineering, and Medicine, 2016), yet very little is known about the relationship among hospice cancer caregiving burden and work performance. To the authors' knowledge, this is the first study to examine this relationship. The identified associations between perceived caregiver burden and activity impairment, presenteeism, and work productivity loss align with the conservation of resources model: Caregivers who were burdened had fewer resources to contribute to their workplace (Hobfoll, 1989). This article's exploratory and preliminary findings suggest that further research is needed to understand the intersection of caregiver burden, absenteeism, and workplace impairment among hospice cancer caregivers. Caregiver burden was associated with presenteeism and work productivity loss, indicating that when burdened family caregivers are at work, they may not be as productive or effective. The authors' findings align with research that suggests working family caregivers with high burden may not be as productive while at work, even if they are not missing work (Wang et al., 2020).

The absence of a significant relationship of burden with workplace absenteeism is interesting, possibly indicating that the level of burden may not correspond to a greater number of missed workdays. Although less effective in their roles, caregivers may be going to work because of income needs and employer leave policies. For example, in the United States, a limited number of family caregivers have access to paid leave or alternative avenues for insurance, which may result in family caregivers working even if they are overwhelmed with burden (National Academies of Sciences, Engineering, and Medicine, 2016). Further research is needed to determine the influence of the conditions of employment (wage or salary) and availability of paid family leave on the relationship between absenteeism and caregiver burden.

Limitations

This secondary analysis is underpowered, with 30 participants. However, the authors' findings provide a basis for further examination of the relationship between caregiver burden and work productivity, particularly in the unstudied area of hospice cancer caregiving. Future research on larger samples can provide firmer evidence and expand on these findings. Additional avenues for research may include examining employment conditions and income levels, as well as the influence of other family caregiver characteristics such as gender identity, race, ethnicity, workplace culture, and access to paid leave.

Implications for Nursing

Implications for the relationships among work productivity, activity impairment, and employment in working hospice caregivers are multifaceted and complex, encompassing U.S. health and economic policy, employers, nurses and the hospice care team. Employers can implement family caregiving–friendly policies and connect caregivers to employee assistance plans that may provide child care, older adult care support, mental health counseling, transportation services, meal delivery, grief support, and legal assistance (Boumans & Dorant, 2021). Employers may benefit from this support through reductions in working family caregiver presenteeism (work impairment or reduced effectiveness), loss of institutional knowledge, and cost of hiring and training replacements (Longacre et al., 2017). Some working family caregivers do not have access to employee assistance plans; therefore, hospice and oncology nurses and social workers can support these caregivers with community resource referrals, including respite care, 211, and the Area Agencies on Aging (Family Caregiver Alliance, n.d.). In addition, hospice and oncology nurses can identify and respond to family caregiver burden early so that the employment and health consequences of caregiver burden may be mitigated (Becqué et al., 2019). Finally, policy initiatives to address robust paid family leave in the United States may promote greater equity in resource allocation and support for working family caregivers of patients in hospice (Gardiner et al., 2020).

Conclusion

This study's findings suggest a significant relationship among hospice caregiver burden and activity impairment, presenteeism, and work productivity loss, but no relationship between caregiver burden and absence from work. Further research with a larger, more diverse sample is needed to fully understand these relationships. Oncology and hospice nurses supporting these family caregivers can recognize the effect of family caregiving on employment and provide referrals for community resources.

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