




Comparing adult-child and spousal caregiver burden and potential contributors

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BACKGROUND: Adult-children caring for a parent with cancer comprise a significant segment of caregivers. Yet less is known about adult-child caregivers, their burden, or caregivers' and patients' gender's impact, which may differ from the well-studied spousal caregiver. This knowledge gap may hinder efforts to ameliorate adult-children's caregiver burden. **METHODS:** We analyzed caregiver surveys from the Cancer Care Outcomes Research and Surveillance Consortium, a multi-regional population-based study of patients with colorectal or lung cancer. Using t tests and multivariate regression models, we assessed whether adult-child and spousal caregivers' caregiving responsibilities and social/emotional and financial burdens differed and used structural equation models (SEMs) to examine mediating factors. **RESULTS:** Compared with spouses/partners (N = 1007), adult-children (N = 227) spent less time caregiving (14 vs 23 hours/week; $P < .001$), but experienced higher social/emotional burden ($P < .01$). In models adjusted for objective caregiving burden measures and demographics, adult-children's social/emotional ($P < .05$) and financial burdens ($P < .01$) were greater than spouses'. Poor communication quality was associated with greater social/emotional burden for both groups ($P < .05$). SEMs indicated that gender concordance between caregivers and patients (eg, daughters caring for mothers) and caregiver employment increased the difference between adult-child and spouses' social/emotional burden, whereas caregiver-patient relationship quality reduced it. **CONCLUSIONS:** Adult-children spend less time caregiving than spouses/partners, but have higher social/emotional and financial caregiving burdens, partially due to adult-children's employment, caregiver-patients' gender concordance, and relationship quality. Gender concordance's contribution to greater social/emotional burden adds important context to prior findings, indicating female caregivers experience the most burden. Interventions that improve caregiver-patient communication may reduce both adult-child and spousal caregiver burden. *Cancer* 2022;128:2015-2024. © 2022 American Cancer Society.

KEYWORDS: caregivers, caregiver preparedness, caregiving burden, communication, families, financial burden.

INTRODUCTION

Family caregivers are integral to the care of patients with cancer. They provide emotional support,¹ monitor patients' symptoms,² improve communication with medical teams,³ and aid medical decision-making.⁴ Such intensive physical, emotional, and time-consuming work adversely impacts caregivers, however. Studies indicate nearly half of cancer caregivers suffer from depression and/or anxiety⁵ and that caregiving negatively affects caregivers' financial and social well-being.^{6,7} Importantly, caregiver burden may also impact patients' mental and physical health.^{8,9}

Among an estimated 2.1 to 6.1 million family caregivers to adult patients with cancer,¹⁰ 44% of caregivers are adult-children, making them the largest caregiving population according to National Alliance for Caregiving's most recent national report on cancer caregivers.¹¹ Yet, few studies examine adult-child caregivers' needs and experiences compared with the well-studied population of spousal caregivers.¹² In the United States (US), studies find that adult-child caregivers report higher caregiving stress, psychological distress, and guilt compared with spouses, whereas others have explored the role reversal challenges of caring for one's parent, which differ from spouses' more reciprocal relationship.¹³⁻¹⁵ To date, few studies have investigated factors that shape these differences, hindering efforts to ameliorate adult-child caregiver burden. Amidst several legislative efforts (eg, Reforming American Immigration for Strong Employment [RAISE] Act to establish a national strategy to support family caregivers and President Biden's American Families Plan, which promotes paid family

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Additional supporting information may be found in the online version of this article.

DOI: 10.1002/cncr.34164, **Received:** August 30, 2021; **Revised:** November 30, 2021; **Accepted:** December 21, 2021, **Published online** May 14, 2022 in Wiley Online Library (wileyonlinelibrary.com)

leave), research on adult-child caregivers is necessary to ensure their needs are addressed.^{16,17}

Using Cancer Care Outcomes Research and Surveillance (CanCORS) Consortium data, this study compared US adult-child and spousal caregiving responsibilities, their social and emotional (social/emotional) and financial burdens, and factors shaping these burdens. Based on prior caregiving research,^{13,18,19} we hypothesized that adult-child caregivers would spend less time caregiving and perform fewer care activities than spouses, but experience greater social/emotional and financial burdens. We further hypothesized that caregivers' competing responsibilities, preparedness, relationship with the patient, and gender concordance (eg, daughters caring for mothers) would mediate differences in burdens.

MATERIALS AND METHODS

Data Set

We used CanCORS Caregiver Study data, a supplement survey to CanCORS, a longitudinal study of approximately 10,000 newly diagnosed patients with colorectal and lung cancer. Detailed information about CanCORS is published elsewhere.²⁰ CanCORS enrolled patients from 7 sites nationwide (5 cancer registries and 2 health care systems); participants were representative of patients with lung and colon cancer in US Surveillance, Epidemiology, and End Results Program regions.²¹ A subset of patients nominated a caregiver to participate during their baseline (n = 827) or follow-up (n = 821) interviews. Caregivers completed a mailed, self-administered survey a mean of 7.3 or 16.7 months after the patient's diagnosis, respectively. All participants were consented and participating sites' institutional review boards approved study protocols.

Outcome Variables

Social/emotional and financial burdens

We assessed social/emotional burden using a modified, 14-item version of the Zarit Burden Interview, which measures caregiving-related emotional, social, and relationship stress (Supporting Table 1).^{22,23} For example, caregivers rated their agreement with the statement "My care recipient asks for more help than he/she needs." Financial burden was assessed with 3 items measuring caregiving's impact on finances; eg, "Caring for my care recipient puts a financial strain on me." Responses were rated on a 5-point Likert scale from "disagree a lot" to "agree a lot." For both burden measures, we performed factor analysis with a polychoric correlation matrix to account for ordinal items and used first factors' loadings (Supporting Table 1). We rescaled both measures from 0

to 10 for interpretability. Higher scores indicate greater burden.

Independent Variable

Caregiver-patient relation

We categorized caregivers as spouse/partner or child; all other relations (parent; sibling; friend; other) (N = 354) or missing (n = 15) were excluded. Excluded relations differed from adult-child and spousal caregivers on several demographic characteristics but completed similar levels of caregiving (Supporting Tables 2-4). Like prior non-cancer research, other relations reported less subjective burden compared with adult-child caregivers.^{24,25}

Mediating Covariates

To investigate factors that might mediate differences in burden between adult-child and spousal caregivers, we drew on Pearlin's stress process model (Fig. 1).²⁶ The model proposes that caregivers' reactions to stress are shaped by stressors (eg, caregiving demands, employment, child-care), background factors (eg, age, gender, education), and resources (eg, caregiving preparedness, support).

Stressors

Stressors included whether caregivers were primarily responsible for children under 18 years old and whether they had paid employment. We hypothesized that child-care and career responsibilities would mediate differences between adult-children and spouses' burdens because, compared with spouses, adult-children are more likely to be employed, more junior in their careers, and have younger children.¹⁹

Background factors

We included caregivers' gender (male vs female) and gender concordance between caregiver and patient (discordant vs concordant). Research indicates that daughters are more likely to care for parents than sons, and that women suffer greater caregiving burden.^{27,28} Additionally, with caregiving's feminization,²⁹ we theorized that gender concordant dyads would struggle to navigate their relationships more than discordant dyads because mothers and daughters might both expect more of a daughter than a male caregiver.^{30,31} In contrast, fathers and sons might struggle due to their lack of socialization into receiving help and caregiving.^{32,33}

Resources

Similar to other studies,³⁴⁻³⁶ we included caregivers' preparedness for caregiving as a resource, hypothesizing adult-children would be less prepared due to their lifephase. We included communication and relationship quality, which

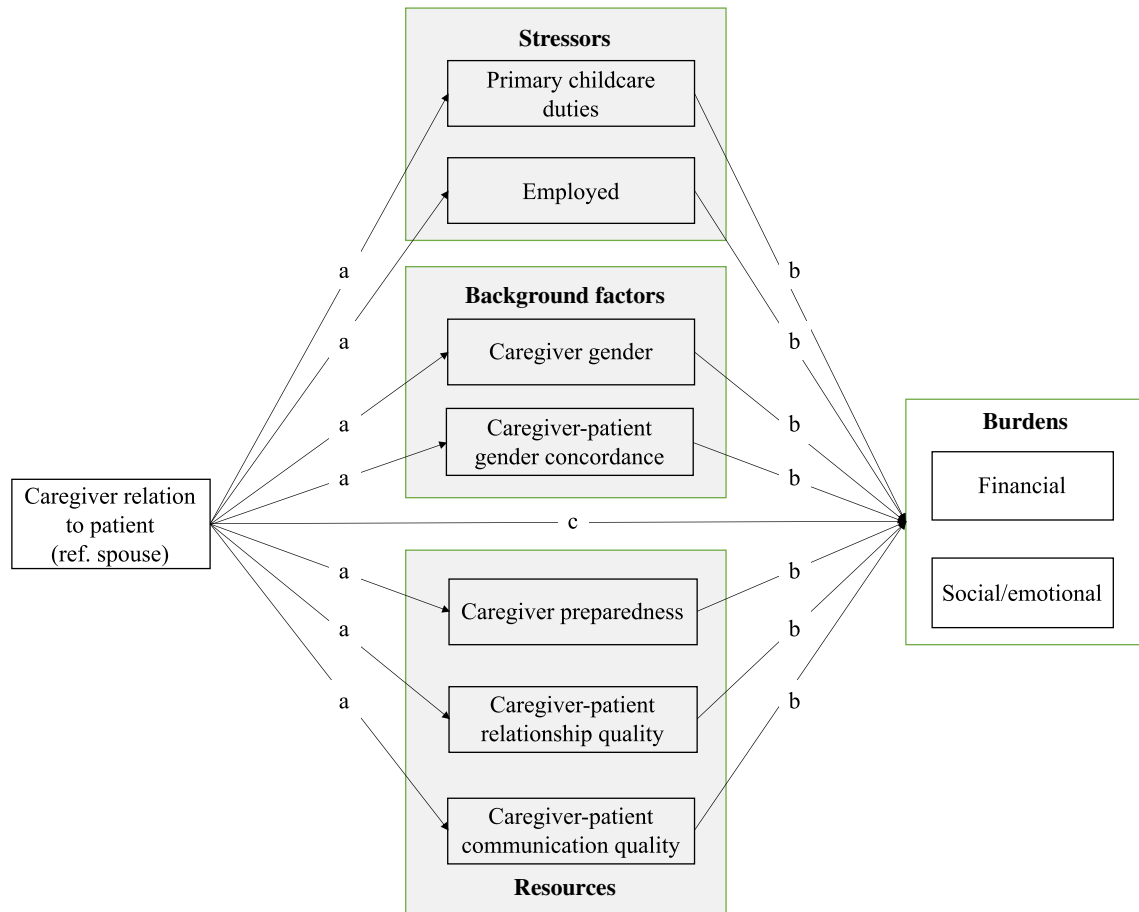


Figure 1. Generalized structural equation model: mediators of caregiver-patient relation’s association with burden.

are associated with reduced burden,^{37,38} hypothesizing that these qualities could mitigate the stress, communication, and relational difficulties often intrinsic to the role reversal of a child caring for a parent. Caregiving preparedness was assessed with the 4-item subscale of the Family Caregiving Inventory, which measures caregivers’ confidence caring for their loved one’s emotional and physical needs, finding services, and coping with caregiving’s stress.³⁹ Responses were on a 5-point Likert scale from “not at all confident” to “extremely confident.” Factor analysis with a polychoric matrix was used to create a component score (Supporting Table 5). Relationship quality was based on responses to the questions, “Generally how well do you and your care recipient get along together right now?” and “Taking everything into consideration, how close do you feel your relationship is between you and your care recipient right now?” Responses were on a 4-point Likert scale from “not at all close/well” to “very close/well.” We performed factor analysis with a polychoric correlation matrix to create a measure. Higher scores indicated better

quality. Communication quality was measured as caregivers’ responses to “How is communication between you and your care recipient these days? In other words, how well can you exchange ideas or talk about things that really concern you right now?” Caregivers responded on a 4-point Likert scale from “not at all well” to “very well.”

Other Covariates

Caregiving responsibilities

To gauge caregiving responsibilities, we included caregiver-reported hours/week caregiving, primary caregiver status (≥50% of care), and tasks performed over the past 2 weeks. Tasks were categorized into activities of daily living (ADLs) (eg, bathing and dressing), instrumental activities of daily living (IADLs) (eg, making phone calls and driving to appointments), and clinical care tasks (eg, monitoring side effects and giving medications) (Supporting Table 6). We created 3 measures for each category: 1) number of tasks performed; 2) if the patient did not need help; and 3) the proportion of tasks

caregivers performed (eg, number of ADLs a caregiver performed/total number of ADLs needed).

Patient clinical factors

Clinical factors included patient age, cancer type, stage (I/II or III/IV), and comorbidity level (none to grade 3) at the patient's baseline interview. Treatment information was excluded because it was collected at baseline and likely changed before caregivers' survey and did not differentiate between intravenous and oral therapies that could differentially affect caregiver burden.

Caregiver demographics

Self-reported gender, race/ethnicity, education, household poverty status (150% of 2005 federal poverty level adjusted for household size), and survey timing (ie, baseline or follow-up) were captured. We did not adjust for caregivers residing with patients or for caregiver age since nearly all spouses lived with the patient and caregivers' and patients' ages were highly correlated.

Statistical Analysis

To assess potential differences between adult-child and spousal caregivers, we performed t-tests for all covariates. To investigate factors associated with caregiving burden, we fit cross-sectional ordinary least squares regressions for burden measures with study site random effects. In baseline models, we adjusted for caregiver-patient relation (adult-child vs spouse), patient clinical factors, caregiver demographics, caregiving responsibilities, site of care, and survey wave. The full model added all mediating covariates. To assess whether the proposed mediators mediated associations between caregiver-patient relationship and burden measures, we used Mplus 8 to estimate a generalized structural equation model with confidence intervals using bootstrapping techniques ($b = 500$) with Monte Carlo simulation to adjust for missingness.⁴⁰ Two-sided P values $< .05$ were considered statistically significant.

Because missing data ranged from 1% to 11%, we used Stata 16's "mi" multiple imputation procedure to impute 20 data sets. Logistic regression models estimating variable missingness suggested no systematic nonresponse. We excluded 26 observations missing both burden measures. All adjusted analyses used imputed data except the generalized structural equation model, which accounts for missingness.⁴⁰ Because gender concordance was low among spousal caregivers (2%) (Table 1), we conducted a power analysis to determine the sample size needed to estimate differences in

mean burden measures by gender concordance, which indicated our sample size was sufficiently powered at 0.80. In sensitivity analyses, we fit models without imputed outcomes and estimated ordinal logit regressions with burdens measured as the sum of burden items' responses. Results were not substantively different (not shown).

RESULTS

Among 1234 adult-child and spousal caregivers, 18% were adult-children ($N = 227$) (Table 1). Compared with spouses, adult-children disproportionately identified as a person of color (29% vs 22%; $P = .04$), female (81% vs 73%; $P = .01$), had more education (76% vs 61% some college or higher; $P < .001$), lower poverty rates (13% vs 19%; $P = .04$), and cared for older patients (69 vs 61-years-old; $P < .001$). Adult-child caregivers were disproportionately employed (76% vs 43%; $P < .001$) and responsible for childcare (32% vs 11%; $P < .001$). Relatively more adult-children cared for female patients (61% vs 26%; $P < .001$). Adult-children were less prepared for caregiving than spouses (3.7 vs 3.9; $P < .001$), but there were no statistically significant differences by communication or relationship quality.

Caregiving responsibilities

Spouses spent significantly more time caregiving than adult-children (23.3 vs 14.3 hours/week; $P < .001$) (Table 2) and disproportionately served as the primary caregiver (93% vs 71%; $P < .001$). There were no statistically significant differences in caregiving levels or types of tasks performed (ADLs, IADLs, or clinical care tasks).

Caregiver Burden

On average, adult-child caregivers experienced higher social/emotional burden than spouses (3.1 vs 2.6; $P < .01$) (Table 3). Adult-children's financial burden was higher than spouses, but not statistically different (3.7 vs 3.4; $P = .20$).

In baseline models that controlled for patient clinical factors, caregiving responsibilities, and caregiver demographics, adult-child caregivers experienced statistically higher social/emotional burden (β , 0.34; 95% confidence interval [CI], 0.02, 0.65) (Table 4) and financial burden (β , 0.58; 95% CI, 0.15, 1.00), compared with spouses.

Adjustment for mediators eliminated adult-child caregivers' statistically significant association with both

TABLE 1. Caregiver and Patient Characteristics by Caregiver Relation to Patient

Measure	Missing	Overall (N = 1234)		Adult-Child (N = 227)		Spouse/Partner (N = 1007)		P
		N	%	N	%	N	%	
Caregiver characteristics								
Age, mean, (SD)	25	58	(13)	45	(12)	61	(12)	<.001
Race/ethnicity								
Non-Hispanic White	18	930	76	161	71	769	78	.04
Black		148	12	33	15	115	12	
Hispanic		62	5	15	7	47	5	
Asian		39	3	9	4	30	3	
American Indian		24	2	6	3	18	2	
Native Hawaiian/other Pacific Islander		7	1	2	1	5	1	
Other		6	0	0	0	6	1	
Educational attainment								
High school degree or less	11	440	36	53	24	387	39	<.001
Some college or higher		783	64	172	76	611	61	
Household federal poverty threshold								
Below 150%	0	217	18	29	13	188	19	.04
At least 150%		1017	82	198	87	819	81	
Caregiver stressors								
Employment status								
No paid work	66	589	50	53	24	536	57	<.001
Part-time/full-time		579	50	169	76	410	43	
Responsible for children under 18 years old								
Yes	0	188	15	73	32	115	11	<.001
No		1046	85	154	68	892	89	
Patient cancer characteristics								
Gender								
Female	0	405	33	139	61	266	26	<.001
Male		829	67	88	39	741	74	
Age at patient survey, mean (SD)								
	0	62	(17)	69	(17)	61	(17)	<.001
Cancer type								
Lung	0	570	46	118	52	452	45	.05
Colon		664	54	109	48	555	55	
Stage at diagnosis								
Stage I/II	47	584	49	103	48	481	50	.60
Stage III/IV		603	51	113	52	490	50	
Comorbidity level								
None	140	283	26	50	25	233	26	.57
Grade 1, mild		416	38	70	35	346	39	
Grade 2, moderate		209	19	44	22	165	18	
Grade 3, severe		186	17	35	18	151	17	
Background factors								
Caregiver gender								
Female	24	898	74	183	81	715	73	.01
Male		312	26	43	19	269	27	
Gender concordance								
Yes	24	153	13	130	58	23	2	<.001
No		1057	87	96	42	961	98	
Resources								
Caregiving preparedness, mean (SD)	38	3.9	0.8	3.7	0.8	3.9	0.8	<.001
Caregiver-patient relationship quality, mean (SD)	33	3.5	0.5	3.5	0.5	3.5	0.6	.32
Caregiver-patient communication quality								
Not well at all	14	54	4	6	3	48	5	.58
A little well		134	11	37	16	97	10	
Somewhat well		369	30	65	29	304	30	
Very well		665	54	120	53	545	54	

Abbreviation: SD, standard deviation. Values based on t tests conducted with imputed data.

burdens (Table 4). Caregivers' employment was positively associated with social/emotional burden (β , 0.24; 95% CI, 0.01, 0.48). Female caregivers had higher social/emotional (β , 0.56; 95% CI, 0.32, 0.80) and financial (β , 0.69; 95%

CI, 0.31, 1.07) burdens than males. Caregiver-patient gender concordance was also associated with higher social/emotional burden (β , 0.45; 95% CI, 0.05, 0.85) than gender discordant relationships. Caregiving preparedness

TABLE 2. Differences in Caregiving Responsibilities by Caregiver Relationship to Patient

Measure	Missing	Adult-Child (n = 227)		Spouse/Partner (n = 1007)		P
		Mean	95% CI	Mean	95% CI	
Hours spent caregiving per week	76	13.9	10.2-17.5	23.0	21.2-24.7	<.001
Percent primary caregiver (≥50% of care)	58	71.3%	67.3-75.4	93.0%	91.1-94.9	<.001
ADLs						
No. of tasks performed	22	1.4	1.1-1.6	1.2	1.0-1.3	.17
Percent of needed tasks performed	22	49.4%	42.2-56.7	53.1%	49.5-56.7	.38
No help needed	22	44.8%	38.3-51.4	50.1%	47.0-53.3	.15
IADLs						
No. of tasks performed	21	3.4	3.1-3.7	3.1	3.0-3.3	.14
Percent of needed tasks performed	21	73.0%	68.6-77.5	70.1%	67.9-72.3	.25
No help needed	21	50.2%	43.7-56.7	51.3%	48.2-54.4	.76
Clinical care tasks						
No. of tasks performed	18	2.6	2.3-2.9	2.7	2.6-2.8	.44
Percent of needed tasks performed	18	57.8%	52.9-62.6	63.2%	60.9-65.4	.05
No help needed	18	56.8%	50.4-63.3	57.9%	54.8-61.0	.77

Abbreviations: ADLs, activities of daily living; CI, confidence interval; IADLs, instrumental activities of daily living. Analyses estimated with imputed data.

TABLE 3. Differences in Caregiving Burden by Caregiver Relationship to Patient

Burden	Missing	Adult-Child (n = 227)		Spouse/Partner (n = 1007)		P
		Mean	95% CI	Mean	95% CI	
Social/emotional	57	3.1	2.8-3.4	2.6	2.5-2.7	<.01
Financial	77	3.7	3.3-4.1	3.4	3.2-3.6	.20

Abbreviation: CI, confidence interval. Unadjusted analyses estimated with imputed data.

(β , -0.62 ; 95% CI, -0.75 , -0.48), relationship quality (β , -0.68 ; 95% CI, -0.95 , -0.40), and communication quality (β , -0.76 ; 95% CI, -1.39 , -0.13) were statistically significantly associated with lower social/emotional burden. Preparedness was statistically significantly associated with lower financial burden (β , -0.38 ; 95% CI, -0.58 , -0.17).

Mediating Adult-Child Caregiver Association With Burden

Results from generalized structural equation models suggest that the gap in social/emotional burden between adult-children and spousal caregivers was mediated by several factors whereas financial burden had no mediating pathways (Table 5). Caregiver employment was a statistically significant mediator of social/emotional burden (effect, 0.14; 95% CI, 0.08, 0.15), as was caregiver-patient gender concordance (effect, 0.32; 95% CI, 0.21, 0.57). Relationship quality was protective because it was associated with a decreased gap in social/emotional burden (effect, -0.08 ; 95% CI, -0.15 , -0.02).

DISCUSSION

Our study's findings indicate that, although adult-child caregivers spend less time caring for a parent with cancer than spousal caregivers and receive more help from others, they experience greater caregiving burden. These differences persisted even after accounting for patients' clinical factors, caregiving time and responsibilities, and caregivers' demographic factors. This suggests that caregivers find it more emotionally, socially, and financially difficult to care for a parent than a spouse.

Although the National Alliance for Caregiving's most recent national report on cancer caregivers shows that adult-children are the largest caregiver population,¹¹ few studies have investigated how adult-children's burden differ from the relatively well-studied spousal caregivers.¹² Our findings reinforce prior research that adult-child caregivers experience greater emotional burden than spouses.^{13,14} We also build on past research by 1) demonstrating that adult-children experience more financial burden than spousal caregivers and 2) identifying factors that contribute to burden differences between adult-children and spouses. Results from mediation models indicate that adult-children's employment contributed to the difference in social/emotional burden, adding context to our finding that adult-children caregivers spend less time caregiving but feel more burdened. Spousal caregivers are more likely to be retired than adult-children and may thus have more time for caregiving, whereas adult-children may struggle to balance caregiving and career responsibilities, leaving less time for friends, family, and self-care.

Our findings about gender differences add important nuance to existing knowledge. Although studies have long

TABLE 4. Associations With Caregiver Social/Emotional and Financial Burdens (N = 1234)

	Social/Emotional		Financial	
	Baseline	Full	Baseline	Full
	β (95% CI)	β (95% CI)	β (95% CI)	β (95% CI)
Family relation (ref = spouse)				
Adult-child	0.34* (0.02, 0.65)	-0.06 (-0.44, 0.32)	0.58** (0.15, 1.00)	0.51 (-0.05, 1.08)
Caregiver competing responsibilities				
Primarily responsible for children <18 years old		0.12 (-0.18, 0.42)		0.36 (-0.09, 0.82)
Caregiver employment (ref = not employed)				
Part-time/full-time		0.24* (0.01, 0.48)		0.16 (-0.20, 0.51)
Caregiver-patient relationship characteristics				
Caregiver gender (ref = male)				
Female		0.56*** (0.32, 0.80)		0.69*** (0.31, 1.07)
Caregiver-patient gender concordance (ref = discordant)				
Aligned		0.45* (0.05, 0.85)		-0.29 (-0.88, 0.31)
Caregiver preparedness		-0.62*** (-0.75, -0.48)		-0.38*** (-0.58, -0.17)
Caregiver-patient relationship quality		-0.68*** (-0.95, -0.40)		-0.10 (-0.51, 0.30)
Caregiver-patient communication quality (ref = not well at all)				
A little well		0.07 (-0.52, 0.67)		0.00 (-0.91, 0.91)
Somewhat well		-0.16 (-0.75, 0.43)		-0.02 (-0.91, 0.86)
Very well		-0.76*** (-1.39, -0.13)		-0.34 (-1.29, 0.61)

Abbreviation: CI, confidence interval.

Models estimated with imputed data.

Models adjusted for patient clinical characteristics (age, cancer type, and stage at diagnosis), caregiving characteristics (hours/weeks and levels of activities of daily living, instrumental activities of daily living, and clinical care tasks), caregiver demographics (race/ethnicity, household income, and educational attainment), site of care, and survey wave.

* $P < .05$

** $P < .01$

*** $P < .001$.

found that female caregivers experience greater burden than males,²⁸ few considered whether gender concordance between caregivers and patients influenced burden. Our results indicate that gender and gender concordance have independent effects on social/emotional burden. This suggests that daughters caring for mothers experience the highest burden, followed by sons and daughters caring for fathers, while sons caring for mothers are the least burdened. This pattern may be shaped by several factors including daughters feeling more obligated to their mother than their father³⁰ while finding caring for their mother more difficult than sons do because of gendered expectations about emotional support.³¹ In contrast, support and caregiving skill deficits may increase burden for sons caring for fathers (eg, sons may seek and/or receive less support from their parent-patient and their social network compared with daughters and spouses).^{32,33} Additionally, women are socialized early on to be caregivers.⁴¹ These factors can exacerbate burden for female caregivers, but also foster less demanding female patients⁴² who may help with their own care more than male patients.

Like others,^{34,38} we found evidence that caregiver-patient relationship quality and caregiver preparedness reduced burden. We also found that relationship quality reduced the social/emotional burden gap between adult-children and spouses. Although less research explores

mechanisms that link relationship quality and burden, prior studies indicate that relationship quality benefits caregivers' self-esteem and communication, and that positive views of caregiving⁴³ may help adult-children struggling with the role reversal of caring for a parent.

Although we found no evidence that caregiver-patient communication mediated differences in adult-child and spousal caregiver burden, our results do indicate that communication is associated with caregiver burden, consistent with prior research.^{37,44} In fully adjusted models, caregivers with high quality communication experienced a third less social/emotional burden than caregivers with low quality communication. Based on standardized regression coefficients, communication quality had the largest effect size. Our findings extend prior research by suggesting that adult-child and spousal caregivers similarly benefit from communication quality. This is promising since little is known about strategies to reduce adult-children's burden,¹² and because prior interventions targeting caregiver-patient communication have benefited caregivers.⁴⁵

Our study identifies challenges and resources for addressing adult-children's increased burden. Specifically, our findings suggest interventions need to target adult-children's difficulties balancing work and caregiving

TABLE 5. Bootstrapped Indirect and Direct Effects for Patient-Caregiver Relation's Association With Social/Emotional and Financial Burdens by Mediation

Effects	Social/Emotional Burden					Financial Burden				
	a	b	Effect	95% CI	P	a	b	Effect	95% CI	P
Stressors (indirect)										
Employment	+	+	0.14	0.08, 0.15	<.001	+	+	0.12	-0.03, 0.14	.10
Childcare	+	+	0.07	-0.02, 0.15	.22	+	+	0.17	0.03, 0.36	.10
Background factors (indirect)										
Caregiver gender	+	+	0.02	0.00, 0.06	.24	+	+	0.03	0.00, 0.07	.23
Caregiver-patient gender concordance	+	+	0.32	0.21, 0.57	.04	+	-	-0.17	-0.52, -0.14	.29
Resources (indirect)										
Caregiver preparedness	-	-	0.03	-0.06, 0.13	.47	-	-	0.02	-0.06, 0.11	.52
Relationship quality	+	-	-0.08	-0.15, -0.02	.03	+	+	0.00	-0.05, 0.07	.95
Communication quality	+	-	-0.04	-0.11, 0.02	.25	+	-	0.00	-0.04, 0.04	.87
Caregiver-patient relation (direct)			-0.13	-0.45, 0.28	.58			0.47	-0.05, 1.02	.16

Abbreviation: CI, confidence interval.

Models adjusted for patient clinical characteristics (age, cancer type, and stage at diagnosis), caregiving characteristics (hours/weeks and levels of activities of daily living, instrumental activities of daily living, and clinical care tasks), caregiver demographics (race/ethnicity, household income, and educational attainment), site of care, and survey wave.

"a" and "b" columns report coefficient sign for indirect pathway. "a" represents pathway X → M and "b" represents pathway M → Y.

We do not report proportion of total effect, which would be uninformative due to the competitive or inconsistent mediations (effects with opposite signs). CIs are asymmetric to account for non-normal distribution.

responsibilities and identify novel engagement strategies because adult-child caregivers may need more resources, but have less time, especially in-person. Similarly, our finding that gender concordance exacerbates burden suggests that communication interventions should be adapted for adult-children caring for parents of the same gender. Communication varies by communication-partners' gender and social role⁴⁶ thus strategies that help opposite-sex spouses communicate may not benefit children interacting with parents or, for instance, sons engaging with fathers. Importantly, future studies should assess whether interventions that benefit spouses should be modified for adult-child caregivers. Studies should also identify mechanisms that explain financial burden differences between adult-children and spouses and processes that link caregiver-patient gender-concordance and communication quality to caregiver burden.

Employment's exacerbating effect on burden suggests the need for more flexible workplaces, an often intransigent issue due to cost. At a policy level, our findings support President Biden's American Families Plan to expand access to paid family leave.¹⁶ This plan does not address caregivers needs' explicitly, however, and our results suggest that adult-child caregivers need additional supports. Therefore, it is important that caregiver needs assessments—an intrinsic component to the RAISE Act,¹⁷ which does target caregivers—consider caregivers' relation to the patient, as well as caregivers' gender and patient-caregiver gender concordance.

There are several important limitations to this study, including survey timing issues. Because caregivers completed surveys several months after patients, we could not control for clinical factors when caregivers completed surveys that could influence burden (eg, use of intravenous chemotherapy). To mitigate this potential bias, we adjusted for when caregivers completed surveys, patients' cancer stage, and whether caregivers recently attended oncology appointments (presumably more frequent while patients undergo treatment). Selection effects may also have biased results because the most burdened caregivers may not have participated. Additionally, although adult-children were disproportionately from a minority racial/ethnic background compared to spouses, our sample was only large enough to control for non-Hispanic White versus all else. Because CanCORS only sampled patients with lung and colorectal cancer (approximately one-fifth of new cancer cases),⁴⁷ our findings likely represent the experiences of caregivers with moderate to extensive burden. In other studies, colorectal cancer caregivers report average levels of caregiving time and costs, comparable to caregivers of patients with prostate and breast cancer, whereas lung cancer caregivers suffer the largest burden levels.⁴⁸ Finally, although these data were collected from 2005 to 2008, CanCORS is one of the few, multiregional surveys with wide-ranging caregiving measures and a sufficiently large sample to study adult-child cancer caregivers. Relatedly, our results likely underestimate the present gap in financial burden between adult-child and spousal caregivers because

millennials' age-adjusted growth is substantially behind earlier generations due to the Great Recession.⁴⁹

In conclusion, this study demonstrates that, although adult-child caregivers spend less time caregiving than spouses, they experience more social/emotional and financial burdens. Our findings indicate that caregiver-patient relationship quality reduces the social/emotional burden gap whereas adult-children's career and gender concordance increase the gap. The finding that gender concordance is associated with burden adds important context to research indicating that female caregivers experience the greatest caregiver burden, suggesting that the dyad's gender makeup also matters. We also found evidence that spousal and adult-child caregivers who report high-quality communication with the patient have lower social/emotional burden, suggesting communication interventions may benefit both groups. Additional research is needed to ensure efforts to reduce caregiving burden can address adult-children's particular caregiving challenges.

FUNDING SUPPORT

Anny T. H. R. Fenton is supported by the National Cancer Institute (NCI) (5T32CA092203). The Cancer Care Outcomes Research and Surveillance study was supported by the NCI via grants to the Statistical Coordinating Center (U01 CA093344), Dana-Farber Cancer Institute/Cancer Research Network through the NCI-supported Primary Data Collection and Research Centers (U01 CA 093332), Harvard Medical School/Northern California Cancer Center (U01 CA093324), RAND/University of California, Los Angeles (U01 CA093348), University of Alabama at Birmingham (U01 CA093329), University of Iowa (U01 CA01013), and University of North Carolina U01 CA093339. Cancer Care Outcomes Research and Surveillance study was also supported by the Department of Veterans Affairs through a grant to the Durham Veterans Affairs Medical Center (CRS 02-164).

CONFLICT OF INTEREST DISCLOSURES

Alexi A. Wright received contracts or grants from the National Cancer Institute, National Institute of Nursing Research, the Agency for Healthcare Research and Quality, National Comprehensive Cancer Network/Astra-Zeneca, and PackHealth and consulting fees from Glaxo-Smith Kline. Nancy Keating received grants or contracts to the institution from Centers for Medicare & Medicaid Services, the National Cancer Institute, Arnold Ventures, and Commonwealth Fund and consulting fees from Research Triangle. The other authors made no disclosures.

AUTHOR CONTRIBUTIONS

Anny T.H.R. Fenton: Conceptualization, analysis, methodology, investigation, and writing—original draft. **Nancy L. Keating:** Investigation, data curation, and funding acquisition. **Katherine A. Ornstein:** Methodology and investigation. **Alexi A. Wright:** Conceptualization and investigation. All authors were responsible for reviewing and editing.

REFERENCES

- Lund L, Ross L, Petersen MA, Groenvold M. Cancer caregiving tasks and consequences and their associations with caregiver status and the caregiver's relationship to the patient: a survey. *BMC Cancer*. 2014;14:1-13. doi:10.1186/1471-2407-14-541
- van Ryn M, Sanders S, Kahn K, et al. Objective burden, resources, and other stressors among informal cancer caregivers: a hidden quality issue? *Psychooncology*. 2011;20:44-52. doi:10.1002/pon.1703
- Isenberg SR, Aslakson RA, Dionne-Odom JN, et al. Family companions' involvement during pre-surgical consent visits for major cancer surgery and its relationship to visit communication and satisfaction. *Patient Educ Couns*. 2018;101:1066-1074. doi:10.1016/j.pec.2018.01.011
- Shin DW, Cho J, Roter DL, et al. Preferences for and experiences of family involvement in cancer treatment decision-making: patient-caregiver dyads study. *Psychooncology*. 2013;22:2624-2631. doi:10.1002/pon.3339
- Geng H-M, Chuang D-M, Yang F, et al. Prevalence and determinants of depression in caregivers of cancer patients: a systematic review and meta-analysis. *Medicine (Baltimore)*. 2018;97:e11863. doi:10.1097/MD.00000000000011863
- Stenberg U, Ruland CM, Miaskowski C. Review of the literature on the effects of caring for a patient with cancer. *Psychooncology*. 2010;19:1013-1025. doi:10.1002/pon.1670
- Girgis A, Lambert S, Johnson C, Waller A, Currow D. Physical, psychosocial, relationship, and economic burden of caring for people with cancer: a review. *J Oncol Pract*. 2013;9:197-202. doi:10.1200/JOP.2012.000690
- Litzelman K, Green PA, Yabroff KR. Cancer and quality of life in spousal dyads: spillover in couples with and without cancer-related health problems. *Support Care Cancer*. 2016;24:763-771. doi:10.1007/s00520-015-2840-4
- Kim Y, Kashy DA, Wellisch DK, Spillers RL, Kaw CK, Smith TG. Quality of life of couples dealing with cancer: dyadic and individual adjustment among breast and prostate cancer survivors and their spousal caregivers. *Ann Behav Med*. 2008;35:230-238. doi:10.1007/s12160-008-9026-y
- Kent EE, Dionne-Odom JN. Population-based profile of mental health and support service need among family caregivers of adults with cancer. *J Oncol Pract*. 2019;15:e122-e131. doi:10.1200/jop.18.00522
- National Alliance For Caregiving. Cancer Caregiving in the US: An Intense, Episodic, and Challenging Care Experience; 2016.
- Kent EE, Rowland JH, Northouse L, et al. Caring for caregivers and patients: research and clinical priorities for informal cancer caregiving. *Cancer*. 2016;122:1987-1995. doi:10.1002/cncr.29939
- Kim Y, Baker F, Spillers RL. Cancer caregivers' quality of life: effects of gender, relationship, and appraisal. *J Pain Symptom Manage*. 2007;34:294-304. doi:10.1016/j.jpainsymman.2006.11.012
- Spillers RL, Wellisch DK, Kim Y, Matthews BA, Baker F. Family caregivers and guilt in the context of cancer care. *Psychosomatics*. 2008;49:511-519. doi:10.1176/appi.psy.49.6.511
- Puterman J, Cadell S. Timing is everything: the experience of parental cancer for young adult daughters—a pilot study. *J Psychosoc Oncol*. 2008;26:103-121. doi:10.1300/J077v26n02_07
- The White House. Fact Sheet: The American Families Plan. Published April 28, 2021. Accessed June 2, 2021. <https://www.whitehouse.gov/briefing-room/statements-releases/2021/04/28/fact-sheet-the-american-families-plan/>
- RAISE Family Caregiving Advisory Council. ACL Administration for Community Living. Accessed June 2, 2021. <https://acl.gov/programs/support-caregivers/raise-family-caregiving-advisory-council>
- Chappell NL, Dujela C, Smith A. Spouse and adult child differences in caregiving burden. *Can J Aging*. 2014;33:462-472. doi:10.1017/S0714980814000336
- Litzelman K. The unique experience of caregivers based on their life stage and relationship to the patient. In: Applebaum AJ, ed. *Cancer Caregivers*. Oxford University Press; 2019:34-50.
- Ayanian JZ, Chrischilles EA, Wallace RB, et al. Understanding cancer treatment and outcomes: the cancer care outcomes research and surveillance consortium. *J Clin Oncol*. 2004;22:2992-2996.
- Catalano PJ, Ayanian JZ, Weeks JC, et al. Representativeness of participants in the cancer care outcomes research and surveillance consortium relative to the surveillance, epidemiology, and end results program. *Med Care*. 2013;51:1-14. doi:10.1097/MLR.0b013e318222a711
- Mollica MA, Litzelman K, Rowland JH, Kent EE. The role of medical/nursing skills training in caregiver confidence and burden: a CanCORS study. *Cancer*. 2017;123:4481-4487. doi:10.1002/cncr.30875

23. Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist*. 1980;20:649-655.
24. Marino VR, Badana ANS, Haley WE. Care demands and well-being of primary and secondary non-spousal caregivers of aging adults. *Clin Gerontol*. 2020;43:558-571. doi:10.1080/07317115.2020.1759748
25. Neal MB, Ingersoll-Dayton B, Starrels ME. Gender and relationship differences in caregiving patterns and consequences among employed caregivers. *Gerontologist*. 1997;37:804-816.
26. Pearlin LI, Mullan JT, Semple SJ, Skaff MM. Caregiving and the stress process: an overview of concepts and their measures. *Gerontologist*. 1990;30:583-594.
27. Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS. Caregiver burden: a clinical review. *J Am Med Assoc*. 2014;311:1052-1059. doi:10.1001/jama.2014.304
28. Allen SM. Gender differences in spousal caregiving and unmet need for care. *J Gerontol*. 1994;49:S187-S195.
29. Aronson J. Dutiful daughters and undemanding mothers: constraining images of giving and receiving care in middle and later life. In: Baines CT, Evans PM, Neysmith SN, eds. *Women's Caring: Feminist Perspectives on Social Welfare*. McClelland & Stewart; 1991:138-168.
30. Finley NJ, Roberts MD, Banahan III BF. Motivators and inhibitors of attitudes of filial obligation toward aging parents. *Gerontologist*. 1988;28:73-78.
31. Horowitz A. Sons and daughters as caregivers to older parents: differences in role performance and consequences. *Gerontologist*. 1985;25:612-617.
32. Lin I, Fee HR, Wu H. Negative and positive caregiving experiences: a closer look at the intersection of gender and relationship. *Fam Relat*. 2012;61:343-358.
33. Neufeld A, Kushner KE. Men family caregivers' experience of nonsupportive interactions: context and expectations. *J Fam Nurs*. 2009;15:171-197.
34. Schumacher KL, Stewart BJ, Archbold PG. Mutuality and preparedness moderate the effects of caregiving demand on cancer family caregiver outcomes. *Nurs Res*. 2007;56:425-433. doi:10.1097/01.NNR.0000299852.75300.03
35. Fujinami R, Sun V, Zachariah F, Uman G, Grant M, Ferrell B. Family caregivers' distress levels related to quality of life, burden, and preparedness. *Psychooncology*. 2015;24:54-62. doi:10.1002/pon.3562
36. Henriksson A, Arestedt K. Exploring factors and caregiver outcomes associated with feelings of preparedness for caregiving in family caregivers in palliative care: a correlational, cross-sectional study. *Palliat Med*. 2013;27. doi:10.1177/0269216313486954
37. Otto AK, Ketcher D, Heyman RE, Vadaparampil ST, Ellington L, Reblin M. Communication between advanced cancer patients and their family caregivers: relationship with caregiver burden and preparedness for caregiving. *Health Commun*. 2021;36:714-721. doi:10.1080/10410236.2020.1712039
38. Reblin M, Donaldson G, Ellington L, Mooney K, Caserta M, Lund D. Spouse cancer caregivers' burden and distress at entry to home hospice: the role of relationship quality. *J Soc Pers Relat*. 2016;33:666-686. doi:10.1177/0265407515588220
39. Schumacher KL, Stewart BJ, Archbold PG. Conceptualization and measurement of doing family caregiving well. *Image J Nurs Sch*. 1998;30:63-70. doi:10.1111/j.1547-5069.1998.tb01238.x
40. MacKinnon DP, Dwyer JH. Estimating mediated effects in prevention studies. *Eval Rev*. 1993;17:144-158.
41. Hochschild A, Machung A. *The Second Shift: Working Parents and the Revolution at Home*. Viking; 1989.
42. Litzelman K, Kent EE, Rowland JH. Social factors in informal cancer caregivers: the interrelationships among social stressors, relationship quality, and family functioning in the CanCORS data set. *Cancer*. 2016;122:278-286. doi:10.1002/cncr.29741
43. Snyder JR. Impact of caregiver-receiver relationship quality on burden and satisfaction. *J Women Aging*. 2000;12:147-167. doi:10.1300/J074v12n01_10
44. Fried TR, Bradley EH, O'Leary JR, Byers AL. Unmet desire for caregiver-patient communication and increased caregiver burden. *J Am Geriatr Soc*. 2005;53:59-65.
45. Applebaum AJ, Breitbart W. Care for the cancer caregiver: a systematic review. *Palliat Support Care*. 2013;11:231-252. doi:10.1016/j.physb.2017.03.040
46. Coates J. *Women, Men and Language: A Sociolinguistic Account of Gender Differences in Language*. Routledge; 2015.
47. American Cancer Society. *Cancer Facts & Figures 2021*. Accessed October 12, 2021. <https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2021/cancer-facts-and-figures-2021.pdf>
48. Yabroff KR, Kim Y. Time costs associated with informal caregiving for cancer survivors. *Cancer*. 2009;115:4362-4373. doi:10.1002/cncr.24588
49. Gale W, Gelfond H, Fichtner J, Harris B. *The Wealth of Generations, With Special Attention to the Millennials*. National Bureau of Economic Research; 2020:w27123. doi:10.3386/w27123