

Original Article

Cite this article: Kent EE, Mollica MA, Dionne-Odom JN, Ferrer RA, Jensen RE, Ornstein KA, Smith AW (2020). Effect of instrumental support on distress among family caregivers: Findings from a nationally representative study. *Palliative and Supportive Care* 18, 519–527. <https://doi.org/10.1017/S1478951520000036>

Received: 26 July 2019

Revised: 5 December 2019

Accepted: 11 January 2020



Key words:

Caregiving; Instrumental support; Patient-reported outcomes; Psychological distress

Author for correspondence:

Erin Kent, Department of Health Policy and Management, 1102-B McGavran-Greenberg Hall, CB # 7411, Gillings School of Global Public Health, University of North Carolina at Chapel Hill, Chapel Hill, NC 27599-7411. E-mail: erin.kent@unc.edu

Effect of instrumental support on distress among family caregivers: Findings from a nationally representative study

Erin E. Kent, PH.D., M.S.^{1,2,3} , Michelle A. Mollica, PH.D., M.P.H., R.N., O.C.N.², J. Nicholas Dionne-Odom, PH.D., A.P.R.N., A.C.H.P.N.⁴ , Rebecca A. Ferrer, PH.D.⁵, Roxanne E. Jensen, PH.D.², Katherine A. Ornstein, PH.D., M.P.H.⁶ and Ashley Wilder Smith, PH.D., M.P.H.²

¹Department of Health Policy and Management, Gillings School of Global Public Health, University of North Carolina at Chapel Hill, NC; ²Outcomes Research Branch, Healthcare Delivery Research Program, Division of Cancer Control and Population Sciences, National Cancer Institute, Bethesda, MD; ³ICF, Fairfax, VA; ⁴School of Nursing, University of Alabama at Birmingham, Birmingham, AL; ⁵Biobehavioral and Psychological Sciences Research Branch, Behavioral Research Program, Division of Cancer Control and Population Sciences, National Cancer Institute, Rockville, MD and ⁶Icahn School of Medicine at Mount Sinai, New York, NY

Abstract

Background and Objective. A priority focus on palliative and supportive care is helping the 43.5 million caregivers who care for individuals with serious illness. Lacking support may lead to caregiver distress and poorer care delivery to patients with serious illness. We examined the potential of instrumental support (assistance with material and task performance) to mitigate distress among caregivers.

Method. We analyzed data from the nationally representative Health Information National Trends Survey (HINTS V2, 2018). Informal/family caregivers were identified in HINTS V2 if they indicated they were caring for or making healthcare decisions for another adult with a health problem. We used the PROMIS® instrumental support four-item short-form *T*-scores and the Patient Health Questionnaire (PHQ-4) for distress. We examined multivariable linear regression models for associations between distress and instrumental support, adjusted for sampling weights, socio-demographics, and caregiving variables (care recipient health condition(s), years caregiving (≥ 2), relationship to care recipient, and caregiver burden). We examined interactions between burden and instrumental support on caregiver distress level.

Results. Our analyses included 311 caregivers (64.8% female, 64.9% non-Hispanic White). The unweighted mean instrumental support *T*-score was 50.4 (SD = 10.6, range = 29.3–63.3); weighted mean was 51.2 (SE = 1.00). Lower instrumental support ($p < 0.01$), younger caregiver age ($p < 0.04$), higher caregiving duration ($p = 0.008$), and caregiver unemployment ($p = 0.006$) were significantly associated with higher caregiver distress. Mean instrumental support scores by distress levels were 52.3 (within normal limits), 49.4 (mild), 48.9 (moderate), and 39.7 (severe). The association between instrumental support and distress did not differ by caregiver burden level.

Conclusions. Poor instrumental support is associated with high distress among caregivers, suggesting the need for palliative and supportive care interventions to help caregivers leverage instrumental support.

Introduction

A priority focus on palliative and supportive care is supporting the 43.5 million caregivers who care for individuals with serious illness. Increasing attention is being paid to the high demands placed on family caregivers, who provide an average of 24 h of unpaid support per week to relatives and friends with a serious health condition or disability (National Alliance for Caregiving and American Association for Retired Persons, 2015). For many caregivers, undertaking this role is burdensome and distressing, resulting in increased anxiety, depression, and poor quality of life (Ho et al., 2009; Nielsen et al., 2016; Geng et al., 2018). Other negative health effects and behaviors among caregivers have been documented, including increased cardiovascular events and decreased preventive health behaviors (Son et al., 2007; Reeves et al., 2012; Dionne-Odom et al., 2017), especially among women and spousal caregivers (Bom et al., 2018). Given the increasing number of patients with serious illness (Hughes and Smith, 2014), the burden on family caregivers is expected to increase, and it is important that palliative and supportive care teams better understand their unmet needs and provide optimal resources to minimize distress.

Optimizing social aspects of care for patients with serious illness and their families is a clinical practice guideline domain for quality palliative care (Ferrell et al., 2018). Social support is one resource that may be helpful to minimize distress and improve quality of life. Social support provides practical and emotional resources to help individuals to cope with stressful life events, particularly when this support is responsive to previously unmet needs (Collins and Feeney, 2000; Feeney and Collins, 2015). Research examining the link between social support and distress, including among caregivers, reveals a strong link between high perceived social support and lower levels of distress and burden (Adelman et al., 2014; Santini et al., 2015; Chang et al., 2016; Del-Pino-Casado et al., 2018). A recent meta-analysis found a moderate negative association between perceived social support and burden among caregivers of older adults (Del-Pino-Casado et al., 2018). Perceived social support can be differentiated as appraisal, instrumental support, emotional support, and informational support (LaRocco et al., 1980; House et al., 1988). *Instrumental support* refers to assistance with material and task performance for oneself, such as help with household chores and transportation to medical appointments (Seeman and Berkman, 1988), and its receipt is linked to better health outcomes (Berkman, 1984). Caregivers, in particular, need instrumental support, both related and unrelated to their caregiving activities, given the high demand placed on them to perform many tasks, often with little formal assistance or training.

Distressed individuals have better health outcomes in general when they receive support (Girme et al., 2013). Caregivers specifically report lower distress when they receive higher instrumental support (Jarrott et al., 2005). However, some studies report conflicting findings. A replication analysis of studies examining social support and distress among caregivers found that higher instrumental support was associated with lower distress in only one out of four datasets examined, indicating the need to further study the role that instrumental support plays in alleviating caregiver distress (Miller et al., 2001). Theoretically, instrumental support to help caregivers directly as well as with caregiving tasks may bolster caregiver coping (Miller et al., 2001; Nishio et al., 2017). However, population-based studies of instrumental support provided to family caregivers are limited. The objective of the current study was to identify relationships between instrumental support and caregiver distress in a national sample of U.S. family caregivers of adults with serious health problems. We hypothesized that higher instrumental support would be associated with lower caregiver distress. We also hypothesized that the association between support and distress would differ by the level of caregiving burden.

Methods

Data source

We analyzed data from the 2018 Health Information National Trends Survey (HINTS), Version V, Cycle 2. Briefly, HINTS is an annual nationally representative survey about the American public's use of health information, health behaviors, and health communication patterns (Hesse et al., 2017). We chose this HINTS cycle because it contained a module on caregiving and a validated instrumental support measure.

Participants

We defined informal/family caregivers in the current study as those positively endorsing the item "currently caring for or

making healthcare decisions for someone with a medical, behavioral, disability, or other condition" ($n = 474$). We excluded those who indicated that they were caregiving solely for a child or children ($n = 122$), given the variation in cultural conceptions about illness across the life course and differences in the way healthcare delivery is organized between adults and children. We also excluded caregivers who reported that they were paid for any part of the care they provided ($n = 41$) to avoid including home healthcare aids and to focus on unpaid family caregivers, leaving a total of $n = 311$ informal caregivers of adults.

Measures

We measured psychological distress by using a combination of depressive and anxiety symptoms from the Patient Health Questionnaire (PHQ-4) (Kroenke et al., 2009; Ellis et al., 2015), as done in previous caregiving studies (Denno et al., 2013; Haun et al., 2014; Chang et al., 2016). Anxiety symptoms were measured using two items: (1) "being bothered by feeling nervous, anxious, or on edge" and (2) "not being able to stop or control worrying" (range: 0–6; $r = 0.70$). Depressive symptoms were measured by two items: (1) "being bothered by feeling down, depressed, or hopeless" and (2) "having little interest or pleasure in doing things" (range: 0–6; $r = 0.74$). All four items were summed to create a measure of psychological distress (range: 0–12). High scores indicate high distress. We categorized the PHQ-4 according to established clinical ranges of distress [within normal limits (WNL): 0–2, mild: 3–5, moderate: 6–8, severe: 9–12] (Kroenke et al., 2009).

We used the four-item Patient-Reported Outcomes Measurement Information System® (PROMIS®) Short-Form (SF) v2.0 Instrumental Support 4a measure to assess instrumental support reported to be received by caregivers (Hahn et al., 2014). Note that the PROMIS instrumental support measure is not specific to caregiving; items refer to support for oneself generally. Items assessed whether caregivers have "someone to prepare meals if unable to do themselves," "someone to take them to the doctor if needed," "someone to help with daily chores if they are sick," and "someone to run errands if needed." All responses use a 5-point Likert scale ranging from "never" to "always." PROMIS measures are reported on a T -score metric; 50 is considered average in the US general population, and 10 points equates to one standard deviation. For the current study, Cronbach's α for PROMIS instrumental support was 0.90. Guidelines for interpretation of PROMIS scores suggest that 3–5 points indicate a meaningful difference in outcome (Northwestern University, 2019). Details on the performance of the PROMIS instrumental support measure for the HINTS caregiving sample are provided in Supplementary Appendix 1.

Socio-demographic covariates included age at survey (categorical: 18–34, 35–49, 50–64, 65–74, 75+), gender (dichotomized: male or female), race/ethnicity (categorical: Non-Hispanic White, Non-Hispanic Black, Hispanic, and Non-Hispanic Other), household income (dichotomized: \pm \$75 K), educational attainment (categorical: high school graduate or less, some college or technical school, or college graduate or above), employment (categorical: employed/student, not working or in school, retired), geographic density based on residence at survey (dichotomized: urban vs. rural, based on 2003 US Department of Agriculture Rural/Urban Commuting Area (RUCA) Codes: urban = 1–3, rural = 4–9) (Weaver et al., 2013). Additionally, we included caregiving-specific variables. We stratified caregiving duration at

± 2 years (National Alliance for Caregiving and American Association for Retired Persons, 2015). We captured caregiving burden as a composite variable comprised of the following weighted measures using an approach detailed by the National Alliance for Caregiving 2015 Caregiving in the USA: (1) hours of caregiving per week, (2) assistance with activities of daily living (ADLs, including bathing, dressing, toileting, incontinence assistance, feeding, and transfers from bed and chairs), and with (3) instrumental activities of daily living (IADLs, including meal preparation, assistance with finances, shopping, housework, and transportation) (National Alliance for Caregiving and American Association for Retired Persons, 2015). We assigned caregiving hours per week the following points: 0–8 h = 1 point; 9–20 h = 2 points, 21–40 h = 3 points, and 41+ h = 4 points. Both ADL and IADL assistance were summed according to tasks: 0 ADLs, 1 IADL = 1 point; 0 ADLs, 2+ ADLs = 2 points, 1 ADL, any IADLs = 3 points; 2+ ADLs, any IADLs = 4 points. We categorized the sum of both hours per week and ADL/IADL assistance points as low (2–4 points), medium (5 points), and high (6–8 points) (National Alliance for Caregiving, 2015).

To capture differences found in caregiving burden between spousal and non-spousal caregivers (Davis et al., 2011; Li et al., 2013; Reblin et al., 2016), we classified care recipient relationship as spouse/partner vs. non-spouse/partner (dichotomous). We categorized care recipient condition as having had Alzheimer's/dementia, chronic conditions including cancer, other (orthopedic/musculoskeletal issues, mental health/behavioral/substance abuse issues, neurological/developmental issues, acute conditions, aging/aging-related conditions not listed, and other), or multiple conditions (categorical). We handled missing data using hot-deck imputation for selected socio-demographic variables (i.e., age [$n = 5$], gender [$n = 2$], race/ethnicity [$n = 17$], education [$n = 4$], and marital status [$n = 4$]). For household income, we included a missing category. We used listwise deletion for missing data on remaining variables.

Statistical analysis

We adjusted the multivariable linear regression models of instrumental support and distress for socio-demographics and caregiving variables. Given a known significant association between caregiving strain and caregiver distress (Bevans and Sternberg, 2012; Beinart et al., 2012; Applebaum and Breitbart, 2013; Evangelista et al., 2016) and that instrumental support can ameliorate burden (Badr and Krebs, 2013; Chi and Demiris, 2015; Ferrell and Wittenberg, 2017), we tested an interaction between caregiving burden level and instrumental support on distress. We reported adjusted mean instrumental support scores according to distress categories (Kroenke et al., 2009). All models incorporated survey weights to account for complex sampling design and parameters were tested for significance at $p < 0.05$. We conducted statistical analyses using SAS version 9.4 (SAS Institute, Cary, NC) and SAS-callable SUDAAN version 11.0.0 (RTI International, Research Triangle Park, NC).

Results

A total of 474 respondents indicated that they were serving as an informal/family caregiver, representing 14.9% of the US adult population. Of those, 352 reported caring for an adult. Finally, of those individuals, 41 were excluded if they reported receiving payment for any part of that care. The final analytic subset

included 311 individuals representing 23,452,665 (10.2% of the US adult population).

Caregiver characteristics are provided in Table 1. The majority of caregivers were female (64.8%), non-Hispanic White (64.9%), and married or partnered (70.7%). Many caregivers reported having attended some college or technical school (45.7%), and with household incomes at $\leq \$75$ K (52.2%). Most caregivers reported working or studying (65.5%) and living in an urban environment (83.8%). Caregivers were most likely to report caring for a parent (42%), attending to a care recipient with multiple health problems (65.5%), and caring for more than 2 years (61.7%). More than half of caregivers reported low/no levels of burden (57.6%), with 29.3% reporting high burden, and 13.1% reporting medium burden.

Instrumental support

The distribution of instrumental support received was negatively skewed, with 31% of respondents indicating the highest level of support (T -score: 63.3; Figure 1). The mean unweighted instrumental support T -score was 50.4 (SD = 10.6, range = 29.3–63.3). The mean weighted instrumental support T -score was 51.22 (SE = 1.00).

Instrumental support and psychological distress

Table 2 shows the adjusted parameter estimates of the multivariable models regressing psychological distress on instrumental support, socio-demographic factors, and caregiving variables. Higher instrumental support was significantly associated with lower distress in both the unadjusted and adjusted models, ($\text{adj}\beta = -0.09$, SE = 0.03, $p = 0.003$). Other variables significantly associated with distress in the adjusted model included younger age, employment status, and caregiving duration. Individuals ages 65+ at survey reported lower distress ($\text{adj}\beta = -2.31$, SE = 0.92, $p = 0.02$) than those ages 18–49. Being employed/student/homemaker associated with lower distress than being unemployed/disabled ($\text{adj}\beta = -3.38$, SE = 1.17, $p = 0.006$) and caring for ≥ 2 years compared to < 2 years was associated with greater distress ($\text{adj}\beta = 1.44$, SE = 0.52, $p = 0.008$). Neither caregiving burden ($p = 0.73$) nor the interaction term between caregiving burden and instrumental support was significant ($p = 0.71$); thus, the final model shown contains no interaction term.

Figure 2 shows the average level of instrumental support at clinical thresholds for distress: WNL: 52.3, mild: 49.4, moderate: 48.9, and severe: 39.7, demonstrating decreasing levels of instrumental support at each threshold of distress.

Discussion

In this population-based study of U.S. caregivers, we demonstrated a significant inverse association between instrumental support and psychological distress, after adjusting for key socio-demographic and caregiving variables. This supports our hypothesis that higher instrumental support is associated with lower distress. Our findings suggest that palliative and supportive clinicians should recognize social aspects of care in meeting patients and families' needs.

Overall, high levels of instrumental support were reported among caregivers. While there are limited validation studies of the PROMIS instrumental support measure, in our study, the mean T -score was lower than reported in a study of adults receiving

Table 1. Socio-demographic and caregiving characteristics, HINTS 5 Cycle 2 Caregiving-Instrumental Support Study, $n=311$ informal caregivers of adult recipients

	<i>n</i>	Weighted %	95%CI
Age at survey			
18–49	69	38.2	(30.5, 46.5)
50–64	128	38.6	(31.2, 46.4)
65+	114	23.3	(17.8, 29.8)
Gender			
Male	100	35.2	(27.3, 44.1)
Female	211	64.8	(56.0, 72.7)
Race/ethnicity			
Hispanic/Latino	43	14.9	(9.5, 22.7)
NH White	196	64.9	(56.7, 72.4)
NH African American	45	11.7	(7.6, 17.6)
NH Other	27	8.5	(5.0, 14.2)
Education			
High school graduate or less	63	24.7	(18.5, 32.1)
Some college/Technical school	104	45.7	(37.3, 54.4)
College graduate or more	144	29.6	(22.8, 37.5)
Marital status			
Married/Living as Married	205	70.7	(63.8, 76.7)
Divorced/Widowed/Separated/Single — Never Married	106	29.3	(23.3, 36.2)
Household income			
Less than \$75K	166	52.2	(44.1, 60.2)
\$75K or more	114	38.8	(31.3, 47.0)
Missing	31	9.0	(5.2, 15.2)
Employment status			
Missing, $n=11$			
Employed/Student/Homemaker	172	65.5	(57.9, 72.3)
Unemployed/Disabled/Other/Missing	32	11.3	(7.4, 17.0)
Retired	96	23.2	(17.6, 29.9)
Urban/Rural			
Urban	256	83.8	(77.0, 88.9)
Rural	55	16.2	(11.1, 23.0)
Caregiving relationship			
Spouse/partner	80	22.3	(17.5, 27.9)
Parent	123	42.0	(34.3, 50.0)
Friend/other relative	66	21.5	(16.5, 27.4)
Multiple care recipients	42	14.3	(9.1, 21.9)
Caregiving condition summary			
Multiple conditions	197	65.5	(57.2, 73.0)
Alzheimer's/Dementia	27	8.5	(5.2, 13.5)

(Continued)

Table 1. (Continued.)

	<i>n</i>	Weighted %	95%CI
Chronic conditions/cancer	26	7.7	(4.9, 11.9)
Other single conditions/DK	61	18.3	(12.8, 25.4)
Caregiving burden			
Missing, $n=51$			
Low/No burden	141	57.6	(49.0, 65.9)
Medium burden	40	13.1	(8.1, 20.5)
High burden	79	29.3	(22.7, 36.9)
Caregiving duration			
Missing, $n=17$			
Less than 2 years	111	38.3	(31.1, 46.1)
2 years or greater	183	61.7	(53.9, 68.9)

outpatient surgery (mean = 55, SD = 8.8) (Nota et al., 2016) and higher than for patients with both a chronic illness and comorbid depression (mean = 47.2, SD = 10) (Hong et al., 2019). However, caregivers who reported any level of distress had significantly lower instrumental support than caregivers who reported no distress. This effect was largest for caregivers who reported “severe” distress and who indicated a level of instrumental support far lower than all other caregivers and others within the general population. This finding suggests that caregivers facing severe distress may be lacking in sufficient instrumental support.

Though not the primary association investigated in our study, it was surprising that caregiver burden was not significantly related to overall distress and did not modify the observed association between support and distress. However, consistent with the stress and coping model of caregiving (Fletcher et al., 2012), greater duration of caregiving was associated with distress. Unemployment was also associated with caregiver distress, consistent with other findings in the caregiving literature (Longacre et al., 2017). Being unemployed could lead to distress in caregivers for many reasons, including financial distress from loss of income (de Moor et al., 2016) and loss of identity associated with work (Kim et al., 2006), as well as one component of role theory, role enhancement, which suggests that employment can buffer stress through social support and respite (Gonzales et al., 2017). Other factors such as caregiver–care recipient relationship and care recipient health condition were not significantly associated with distress. Contextual, psychosocial factors related to relationship quality might be more important in predicting both burden and benefit-finding than relationship type or care recipient health condition in predicting distress (Reblin et al., 2016); however, we could not determine this in the current study.

While there are many aspects of social support, perceived support (including instrumental, emotional, informational, and other forms of perceived social support) may be of particular importance when examining distress and other caregiving outcomes (Collins and Feeney, 2000; Gleason et al., 2008; Feeney and Collins, 2015). Perceived support is distinct from and may have a greater impact on caregiver experience than support, otherwise assumed or observed (Gleason et al., 2008; Uchino, 2009; Del-Pino-Casado et al., 2018). Assessing perceptions of support directly from caregivers, as was done in the current study, may

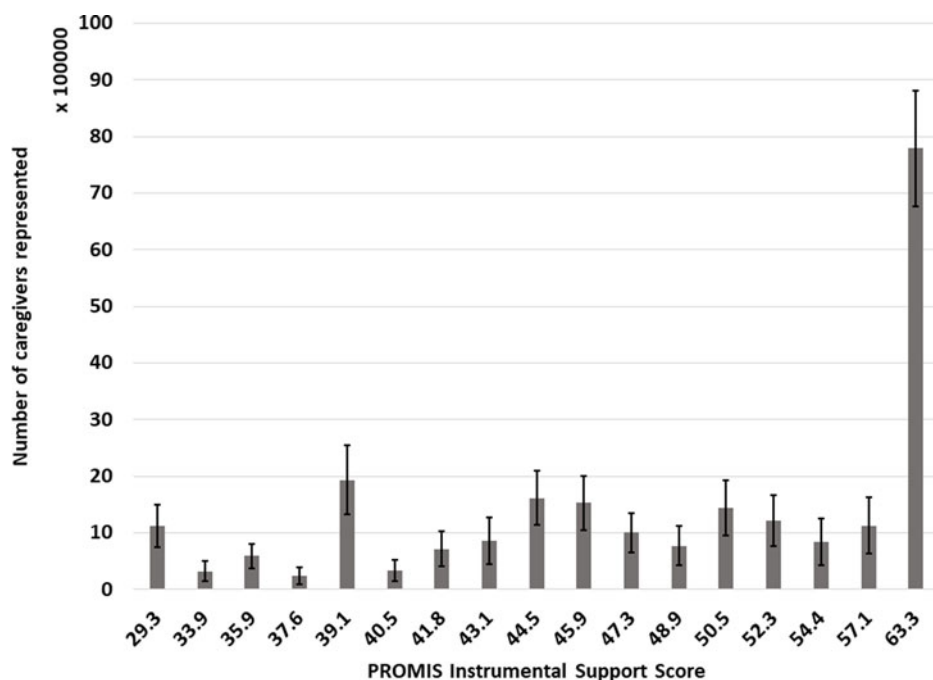


Fig. 1. Distribution of instrumental support reported by caregivers ($n = 311$, weighted $n = 23,452,665$). Error bars represent the standard error of the estimated population size.

be critical for palliative care clinicians trying to understand the actual impact of support on caregiver distress (Gleason et al., 2008). In addition, social support may act as an effect modifier as well as a predictor, and its role should be examined in longitudinal datasets to provide further insight into the causality of social support and distress among caregivers.

These results point to the need for palliative and supportive care interventions that bolster perceived instrumental support among caregivers. There are several reviews of psychosocial interventions to support caregivers of adults with serious health problems, including heart failure (Evangelista et al., 2016), cancer (Ferrell and Wittenberg, 2017), and Alzheimer's disease (Beinart et al., 2012), with interventions building upon different coping strategies. Problem-focused coping, which focuses on the individual's ability to adapt to and manage environmental stressors (Baker and Berenbaum, 2007), may be particularly appropriate for enabling caregivers to harness instrumental support from their networks (Dionne-Odom et al., 2018; Kent and Dionne-Odom, 2019). Interventions designed with self-management principles and based on the Caregiver Stress Model (Pearlin et al., 1990) and other similar theories can help caregivers identify and map out their sources of support by type (hands-on, informational, communication, financial, emotional, and self-care). This, in turn, provides caregivers with a way to tailor the support they receive (Reblin et al., 2017). Strategies like these can help caregivers and their network recognize and activate specific types of social support, like instrumental, which in turn may lead to lower burden and distress. Furthermore, as emphasized by the National Consensus Project Clinical Practice Guidelines on Quality Palliative Care, interdisciplinary palliative care teams should include professional social workers (Ferrell et al., 2018). Social workers may be best positioned to address both patient and family social factors, including helping family caregivers leverage the instrumental support they need. Finally, system-level interventions are needed, including those delivered to healthcare providers and other clinical staff to help raise awareness about support needs for caregivers and connect them to resources

through the healthcare system and in the community. State-level policies to encourage, and in some cases require, hospitals to identify, prepare, and communicate with caregivers are being implemented (Ahern Gould, 2018). Whether these policies will reduce caregiver distress remains to be seen.

One limitation of the present study was the lack of available data on other dimensions of social support, including emotional support (Feeney, 2004). Instrumental support may interact with emotional support receipt and provision (Morelli et al., 2015). Assessing additional dimensions of social support is important for future study. The PROMIS measure is not specific to caregiving tasks; however, the goal of the current study was to elucidate caregivers' views on the availability of help and support for themselves. Controlling for caregiving burden controlled for some confounding of the burden on distress; however, this variable had a moderate amount of missing data ($n = 51$). A sensitivity analysis removing the burden from the model yielded no change to the parameter estimate for instrumental support on distress; thus, the support and distress association appears to be robust. Additional caveats included limited sample size to examine differences by specific care recipient condition, which is critical for informing practice and future study, and some heterogeneity in our sample of caregivers who cared for individuals with diverse health problems. In addition, given that this study excluded paid caregivers, it is possible that some caregivers who received compensation for the care they provided, through Medicaid, the VA, or another payor, were excluded from the analysis. Finally, these data are cross-sectional; thus, associations do not imply causality. Strengths of the study include its population-based sampling, an uncommon opportunity in studies of caregivers. In addition, detailed questions on caregiving experience available through the caregiving module in HINTS V2 allowed for assessment of constructs germane to the caregiving experience. Finally, using two validated measures, the PROMIS instrumental support short form and the PHQ-4, allowed a more rigorous ascertainment of constructs of support and distress, superior to other studies reliant on single-item and more generic measures.

Table 2. Adjusted^a parameter estimates for linear regression on psychological distress (PHQ-4)

	β	SE	p	Wald p -value
Intercept	2.49	1.97	0.2112	
PROMIS instrumental support	-0.09	0.03	0.0032	0.0032
Age at survey				
18-49	Ref	-	-	0.0393
50-64	-1.18	0.61	0.0575	
65+	-2.31	0.92	0.0155	
Gender				
Female	Ref	-	-	0.4755
Male	-0.38	0.53	0.4755	
Race/ethnicity				
NH White	Ref	-	-	0.7402
Hispanic/Latino	-0.42	0.82	0.6108	
NH African American	-0.11	0.74	0.8816	
NH Other	0.63	0.87	0.473	
Educational attainment				
High school graduate or less	Ref	-	-	0.7889
Some college/Technical school	-0.24	0.57	0.6713	
College graduate or more	0.13	0.65	0.8405	
Marital status				
Married/Living as Married	Ref	-	-	0.6011
Divorced/Widowed/Separated/Single-Never Married	0.38	0.72	0.6011	
Household income				
\$75K or more	Ref	-	-	0.5668
Less than \$75K	0.37	0.53	0.4886	
Missing	0.72	0.76	0.3514	
Employment status				
Unemployed/Disabled/Other	Ref	-	-	0.0094
Employed/Student/Homemaker	-3.38	1.17	0.0059	
Retired	-1.84	1.31	0.1638	
Urban/Rural status				
Rural	Ref	-	-	0.6773
Urban	-0.29	0.7	0.6773	
Care recipient-caregiver relationship				
Spouse/partner	Ref	-	-	0.1945
Parent	-0.13	0.79	0.8739	
Other relationship/DK	0.25	0.94	0.7889	
Multiple care recipients	-1.39	0.97	0.1564	
Care recipient health condition(s)				
Other single conditions	Ref	-	-	0.2126
Alzheimer's/Dementia	-1.39	0.86	0.1132	
Chronic conditions including cancer	0.15	0.91	0.8737	
Multiple conditions	0.13	0.81	0.871	
Caregiving burden index ^b				

(Continued)

Table 2. (Continued.)

	β	SE	p	Wald p -value
Low burden	Ref	–		0.7494
Medium burden	0.53	0.75	0.4891	
High burden	0.37	0.64	0.5689	
Caregiving duration				
Less than 2 years	Ref			0.0079
2 years or greater	1.44	0.52	0.0079	

^aAdjusted for all factors in the model, $n = 282$, $r^2 = 0.33$.

^bCaregiving burden index from caregiving in the US survey, the composite score of assistance with activities of daily living, instrumental activities of daily living, and hours per week providing care.

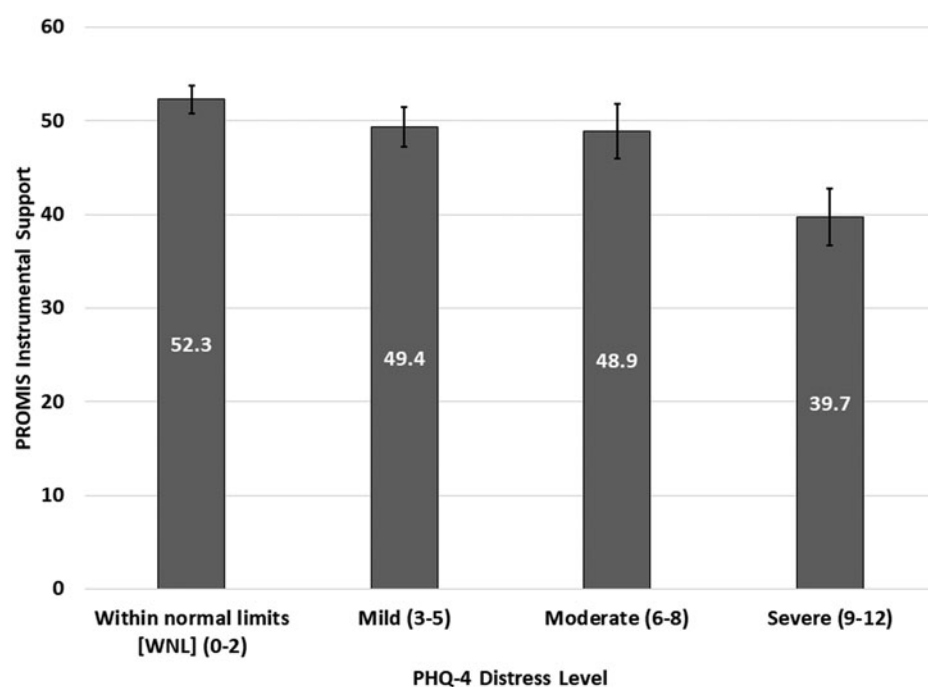


Fig. 2. Adjusted least-squared means of Instrumental Support by PHQ-4 distress level (WNL: $n = 210$, Mild: $n = 57$, Moderate: $n = 19$, Severe: $n = 21$, Missing: $n = 4$), $r^2 = 0.28$. Error bars represent 95% confidence intervals.

Conclusions

In this population-based, nationally representative study, we found that instrumental support has an inverse association with distress in informal caregivers of adults with serious health problems. Future work should use longitudinal data collection to determine the trajectory of support provision and the receipt of multiple dimensions of social support. In addition, palliative and supportive care interventions should focus on improving support for caregivers as a means of reducing distress. Instrumental support may buffer against poor health outcomes among caregivers. Findings from this study suggest that increasing access to and use of instrumental support could be an effective target for caregiver-focused interventions.

Supplementary material. The supplementary material for this article can be found at <https://doi.org/10.1017/S1478951520000036>.

Funding. Dr. Dionne-Odom is funded by the National Institute of Nursing Research (R00NR015903) and the National Cancer Institute (R01CA229197). Dr. Ornstein is funded by the National Institute on Aging (K01AG047923, R01AG060967) and the National Palliative Care Research Center.

Disclaimer. The findings and interpretations in this manuscript are those of the authors and do not necessarily represent those of the National Cancer Institute or National Institutes of Health.

References

- Adelman RD, Tmanova LL, Delgado D, *et al.* (2014) Caregiver burden: A clinical review. *JAMA* 311(10), 1052–1060.
- Ahern Gould K (2018) The CARE Act: Identifying and supporting family caregivers from hospitals to home. *Dimensions of Critical Care Nursing* 37(2), 59–61.
- Applebaum AJ and Breitbart W (2013) Care for the cancer caregiver: A systematic review. *Palliative Supportive Care* 11(3), 231–252.
- Badr H and Krebs P (2013) A systematic review and meta-analysis of psychosocial interventions for couples coping with cancer. *Psycho-Oncology* 22(8), 1688–1704.
- Baker JP and Berenbaum H (2007) Emotional approach and problem-focused coping: A comparison of potentially adaptive strategies. *Cognition and Emotion* 21(1), 95–118.
- Beinart N, Weinman J, Wade D, *et al.* (2012) Caregiver burden and psycho-educational interventions in Alzheimer's disease: A review. *Dementia and Geriatric Cognitive Disorders Extra* 2(1), 638–648.

- Berkman LF** (1984) Assessing the physical health effects of social networks and social support. *Annual Review of Public Health* 5, 413–432.
- Bevans M and Sternberg EM** (2012) Caregiving burden, stress, and health effects among family caregivers of adult cancer patients. *JAMA* 307(4), 398–403.
- Bom J, Bakx P, Schut F, et al.** (2018) The impact of informal caregiving for older adults on the health of various types of caregivers: A systematic review. *Gerontologist* 59(5), e629–e642.
- Chang SS, Zhang Y, Jevagurunathan A, et al.** (2016) Providing care to relatives with mental illness: Reactions and distress among primary informal caregivers. *BMC Psychiatry* 16, 1–9.
- Chi NC and Demiris G** (2015) A systematic review of telehealth tools and interventions to support family caregivers. *Journal of Telemedicine and Telecare* 21(1), 37–44.
- Collins NL and Feeney BC** (2000) A safe haven: An attachment theory perspective on support seeking and caregiving in intimate relationships. *Journal of Personality and Social Psychology* 78(6), 1053–1073.
- Davis LL, Gilliss CL, Deshefy-Longhi T, et al.** (2011) The nature and scope of stressful spousal caregiving relationships. *Journal of Family Nursing* 17(2), 224–240.
- Del-Pino-Casado R, Frias-Osuna A, Palomino-Moral PA, et al.** (2018) Social support and subjective burden in caregivers of adults and older adults: A meta-analysis. *PLoS ONE* 13(1), e0189874.
- de Moor JS, Dowling EC, Ekwueme DU, et al.** (2016) Employment implications of informal cancer caregiving. *Journal of Cancer Survivorship* 11(1), 48–57.
- Denno MS, Gillard PJ, Graham GD, et al.** (2013) Anxiety and depression associated with caregiver burden in caregivers of stroke survivors with spasticity. *Archives of Physical Medicine and Rehabilitation* 94(9), 1731–1736.
- Dionne-Odom JN, Demark-Wahnefried W, Taylor RA, et al.** (2017) The self-care practices of family caregivers of persons with poor prognosis cancer: Differences by varying levels of caregiver well-being and preparedness. *Supportive Care in Cancer* 25(8), 2437–2444.
- Dionne-Odom JN, Applebaum AJ, Ornstein KA, et al.** (2018) Participation and interest in support services among family caregivers of older adults with cancer. *Psycho-Oncology* 27(3), 969–976.
- Ellis EM, Orom H, Giovino GA, et al.** (2015) Relations between negative affect and health behaviors by race/ethnicity: Differential effects for symptoms of depression and anxiety. *Health Psychology* 34(9), 966–969.
- Evangelista LS, Stromberg A and Dionne-Odom JN** (2016) An integrated review of interventions to improve psychological outcomes in caregivers of patients with heart failure. *Current Opinion in Supportive and Palliative Care* 10(1), 24–31.
- Feeney BC** (2004) A secure base: Responsive support of goal strivings and exploration in adult intimate relationships. *Journal of Personality and Social Psychology* 87(5), 631–648.
- Feeney BC and Collins NL** (2015) A new look at social support: A theoretical perspective on thriving through relationships. *Personality and Social Psychology Review* 19(2), 113–147.
- Ferrell B and Wittenberg E** (2017) A review of family caregiving intervention trials in oncology. *CA: A Cancer Journal for Clinicians* 67(4), 318–325.
- Ferrell BR, Twaddle ML, Melnick A, et al.** (2018) National consensus project clinical practice guidelines for quality palliative care guidelines, 4th edition. *Journal of Palliative Medicine* 21(12), 1684–1690.
- Fletcher BS, Miaskowski C, Given B, et al.** (2012) The cancer family caregiving experience: An updated and expanded conceptual model. *European Journal of Oncology Nursing* 16(4), 387–398.
- Geng HM, Chuang DM, Yang F, et al.** (2018) Prevalence and determinants of depression in caregivers of cancer patients: A systematic review and meta-analysis. *Medicine* 97(39), e11863.
- Girme YU, Overall NC and Simpson JA** (2013) When visibility matters: Short-term versus long-term costs and benefits of visible and invisible support. *Personality and Social Psychology Bulletin* 39(11), 1441–1454.
- Gleason ME, Iida M, Shrout PE, et al.** (2008) Receiving support as a mixed blessing: Evidence for dual effects of support on psychological outcomes. *Journal of Personality and Social Psychology* 94(5), 824–838.
- Gonzales E, Lee Y and Brown C** (2017) Back to work? Not everyone. Examining the longitudinal relationships between informal caregiving and paid work after formal retirement. *Journals of Gerontology, Series B: Psychological Sciences and Social Sciences* 72(3), 532–539.
- Hahn EA, DeWalt DA, Bode RK, et al.** (2014) New English and Spanish social health measures will facilitate evaluating health determinants. *Health Psychology* 33(5), 490–499.
- Haun MW, Sklenarova H, Brechtel A, et al.** (2014) Distress in cancer patients and their caregivers and association with the caregivers' perception of dyadic communication. *Oncology Research and Treatment* 37, 384–388.
- Hesse BW, Greenberg AJ, Peterson EB, et al.** (2017) The health information national trends survey (HINTS): A resource for consumer engagement and health communication research. *Studies in Health Technology and Informatics* 240, 330–346.
- Ho SC, Chan A, Woo J, et al.** (2009) Impact of caregiving on health and quality of life: A comparative population-based study of caregivers for elderly persons and noncaregivers. *Journals of Gerontology, Series A: Biological Sciences and Medical Sciences* 64(8), 873–879.
- Hong J, Aspey L, Bao G, et al.** (2019) Chronic cutaneous lupus erythematosus: Depression burden and associated factors. *American Journal of Clinical Dermatology* 20(3), 465–475.
- House JS, Umberson D and Landis KR** (1988) Structures and processes of social support. *Annual Review of Sociology* 14(1), 293–318.
- Hughes MT and Smith TJ** (2014) The growth of palliative care in the United States. *Annual Review of Public Health* 35, 459–475.
- Jarrott SE, Zarit SH, Stephens MA, et al.** (2005) Instrumental help and caregivers' distress: Effects of change in informal and formal help. *American Journal of Alzheimer's Disease & Other Dementias* 20(3), 181–190.
- Kent EE and Dionne-Odom JN** (2019) Population-based profile of mental health and support service need among family caregivers of adults with cancer. *Journal of Oncology Practice* 15(2), e122–e131.
- Kim Y, Baker F, Spillers RL, et al.** (2006) Psychological adjustment of cancer caregivers with multiple roles. *Psycho-Oncology* 15(9), 795–804.
- Kroenke K, Spitzer RL, Williams JB, et al.** (2009) An ultra-brief screening scale for anxiety and depression: The PHQ-4. *Psychosomatics* 50(6), 613–621.
- LaRocco JM, House JS and French Jr. JR** (1980) Social support, occupational stress, and health. *Journal of Health and Social Behavior* 21(3), 202–218.
- Li QP, Mak YW and Loke AY** (2013) Spouses' experience of caregiving for cancer patients: A literature review. *International Nursing Review* 60(2), 178–187.
- Longacre ML, Valdmanis VG, Handorf EA, et al.** (2017) Work impact and emotional stress among informal caregivers for older adults. *Journals of Gerontology, Series B: Psychological Sciences and Social Sciences* 72(3), 522–531.
- Miller B, Townsend A, Carpenter E, et al.** (2001) Social support and caregiver distress: A replication analysis. *Journals of Gerontology, Series B: Psychological Sciences and Social Sciences* 56(4), S249–256.
- Morelli SA, Lee IA, Arnn ME, et al.** (2015) Emotional and instrumental support provision interact to predict well-being. *Emotion* 15(4), 484–493.
- National Alliance for Caregiving** (2015) *Caregiving in the U.S. 2015 – Appendix B: Detailed Methodology*. <https://www.caregiving.org/wp-content/uploads/2015/05/CGV016-Main-Report-Appendix-B-Detailed-Methodology-5.21.15.pdf> (Accessed 26 July 2019).
- National Alliance for Caregiving and American Association for Retired Persons** (2015) *Caregiving in the U.S.* https://www.caregiving.org/wp-content/uploads/2015/05/2015_CaregivingintheUS_Final-Report-June-4_WEB.pdf (Accessed 26 July 2019).
- Nielsen MK, Neergaard MA, Jensen AB, et al.** (2016) Psychological distress, health, and socio-economic factors in caregivers of terminally ill patients: A nationwide population-based cohort study. *Supportive Care in Cancer* 24(7), 3057–3067.
- Nishio M, Kimura H, Ogomori K, et al.** (2017) Emotional and instrumental support influencing male caregivers for people with dementia living at home. *Journal of Rural Medicine* 12(1), 20–27.
- Northwestern University** (2019) *Health measures*, Vol. 2019. Northwestern University.
- Nota SP, Spit SA, Oosterhoff TC, et al.** (2016) Is social support associated with upper extremity disability? *Clinical Orthopaedics and Related Research* 474(8), 1830–1836.

- Pearlin LI, Mullan JT, Semple SJ, et al.** (1990) Caregiving and the stress process: An overview of concepts and their measures. *Gerontologist* **30**(5), 583–594.
- Reblin M, Donaldson G, Ellington L, et al.** (2016) Spouse cancer caregivers' burden and distress at entry to home hospice: The role of relationship quality. *Journal of Social and Personal Relationships* **33**(5), 666–686.
- Reblin M, Wu YP, Pok J, et al.** (2017) Development of the electronic social network assessment program using the center for eHealth and wellbeing research roadmap. *JMIR Human Factors* **4**(3), e23.
- Reeves KW, Bacon K and Fredman L** (2012) Caregiving associated with selected cancer risk behaviors and screening utilization among women: Cross-sectional results of the 2009 BRFSS. *BMC Public Health* **12**, 685.
- Santini ZI, Koyanagi A, Tyrovolas S, et al.** (2015) The association between social relationships and depression: A systematic review. *Journal of Affective Disorders* **175**, 53–65.
- Seeman TE and Berkman LF** (1988) Structural characteristics of social networks and their relationship with social support in the elderly: Who provides support. *Social Science and Medicine* **26**(7), 737–749.
- Son J, Erno A, Shea DG, et al.** (2007) The caregiver stress process and health outcomes. *Journal of Aging and Health* **19**(6), 871–887.
- Uchino BN** (2009) Understanding the links between social support and physical health: A life-span perspective with emphasis on the separability of perceived and received support. *Perspectives on Psychological Science* **4**(3), 236–255.
- Weaver KE, Geiger AM, Lu L, et al.** (2013) Rural-urban disparities in health status among US cancer survivors. *Cancer* **119**(5), 1050–1057.