Caregiving Support Roles and Anxiety among Short- and Long-Term Family and Informal Cancer Caregivers

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Background

- Caregivers provide critical patient and family support before, during, and after cancer treatment.
- Caregiver distress and unmet needs can affect the quality of life and health of caregivers as well as patient well-being.
- While cancer caregiving is often characterized as an acute role, advances in cancer therapies have led to long-term role commitments for many caregivers.

Applebaum & Breitbart, 2013; O'Hara et al., 2010

Study Aims

1. To describe the support roles of family and informal caregivers across the cancer caregiving continuum

2. To examine the relationships between duration of caregiving, level of involvement in support roles, and anxiety among short- and long-term caregivers

Methods

- 428 caregivers enrolled in Cancer Support Community's online Cancer Experience Registry® and completed survey items including:
  - caregiving history (relationship to patient; # of years providing care)
  - level of involvement in 11 caregiving roles (0=*not at all* to 4=*very much*)
  - PROMIS-29 v2.0 anxiety subscale (4 items)

- Analysis:
  - Bivariate analysis (Pearson correlations, linear trends) comparing ordered levels of caregiving duration, level of involvement, and anxiety
  - Multivariate analysis (hierarchical multiple linear regression analysis) examining extent to which caregiving duration and level of involvement in caregiving roles predicted anxiety

Note: Analytic sample limited to current caregivers

Participant Socio-Demographic Characteristics

***N* = 428**	**Mean or *n***	***SD* or %**
Age (years; range 18-89)	53.8	12.6
Female Gender	351	82%
Race and Ethnicity		
Non-Hispanic White	366	86%
Non-Hispanic Black	14	3%
Hispanic	22	5%
Annual Income		
<$40K	97	23%
$40-59K	50	12%
$60-79K	52	12%
$80-99K	35	8%
$100K+	106	25%
Employment		
Full-time	209	49%
Part-time	46	11%
Retired	93	22%
Education		
College degree or higher	225	53%

Participant Caregiving History

***N* = 428**	***n***	**%**
Relationship to care recipient		
Caring for spouse	239	56%
Caring for parent	87	20%
Caring for child	39	9%
Caring for sibling	21	5%
Caring for friend	11	3%
Hours per week providing care		
<1-10 hours	98	23%
11-20 hours	87	20%
21-40 hours	61	14%
41+ hours	39	9%

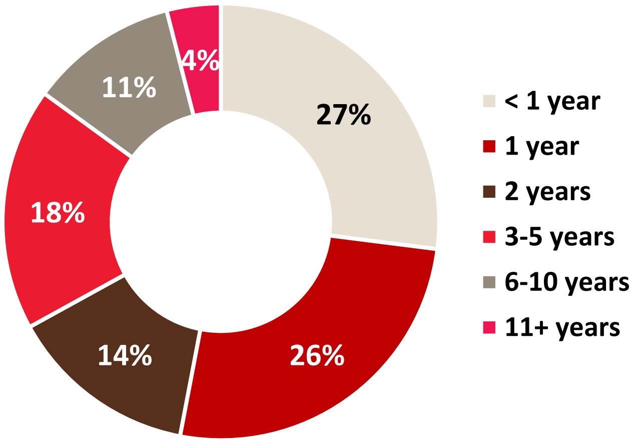
Care Recipient Characteristics

N = 428	Mean or *n*	*SD* or %
Years since diagnosis *(range: <1-27 years; n=392)*	3.0	4.0
<1 year	101	26%
1 year	104	27%
2 years	47	12%
3-5 years	70	18%
6-10 years	47	12%
11+ years	23	6%
Stage at diagnosis		
Stage 0-II	70	16%
Stage III	52	12%
Stage IV	197	46%
Cancer diagnosis		
Lung	60	14%
Breast	57	13%
Multiple Myeloma	32	7%
Colorectal	29	7%
Brain	27	6%
Prostate	19	5%

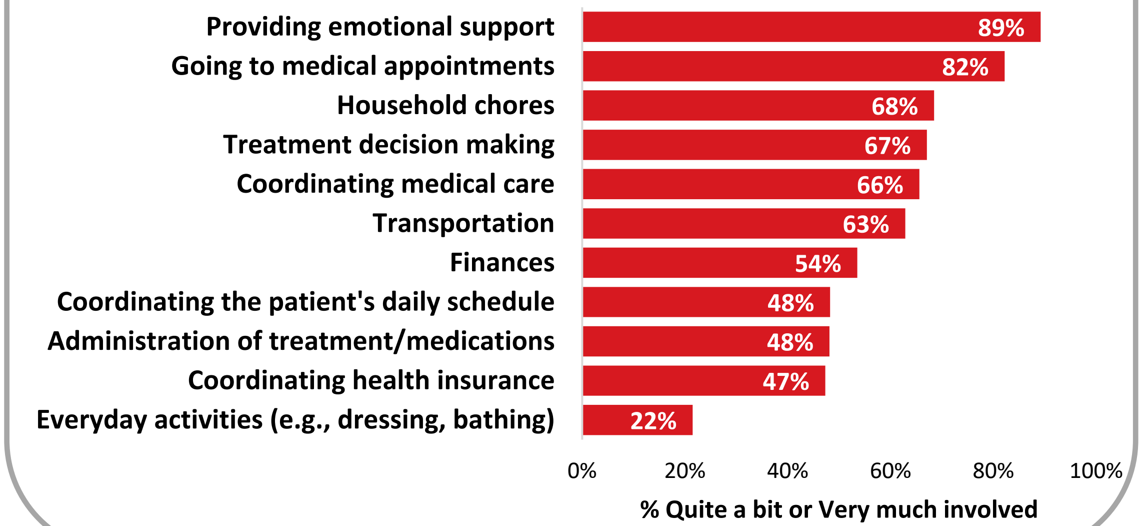
Note: Care recipient information provided by caregiver

Care Duration and Caregiving Roles

Years providing care



Level of involvement in patient's care



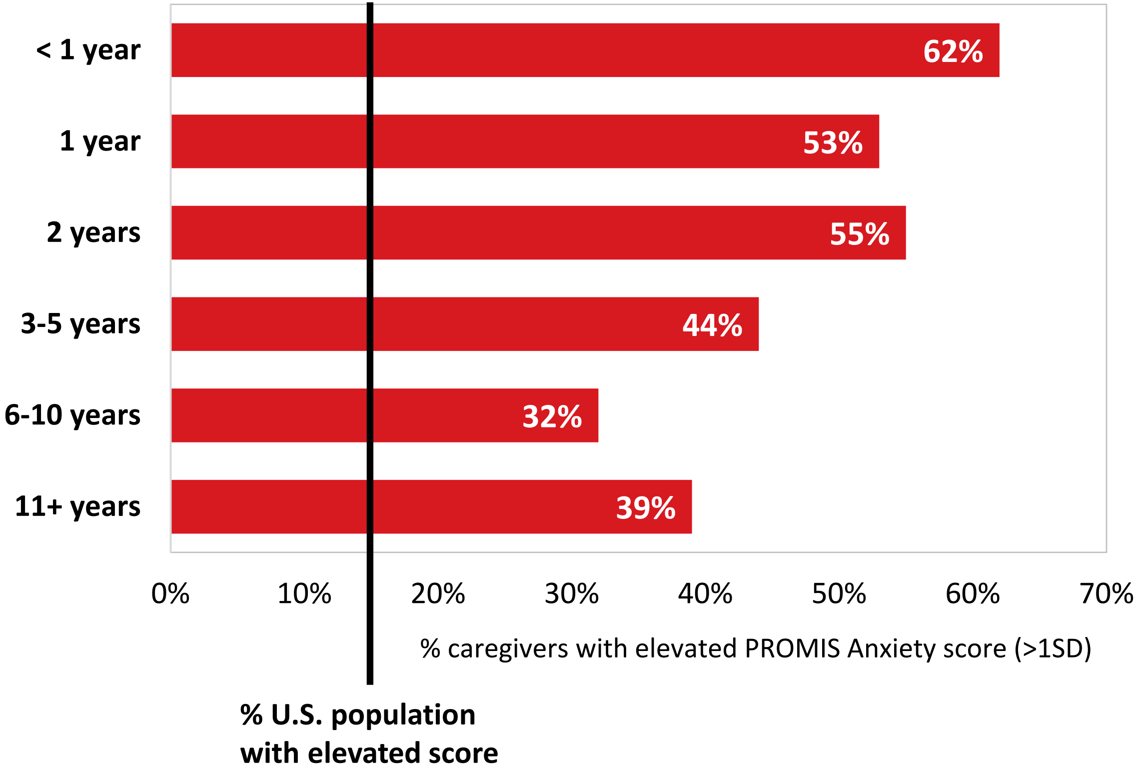
Shorter caregiving duration was associated with greater involvement in:

- **medical care coordination** (χ^2 for trend = 9.27, $p < .01$)
- **providing transportation** (χ^2 for trend = 6.08, $p < .05$)
- **administering treatment/medications** (χ^2 for trend = 9.04, $p < .01$)

Caregiver Anxiety and Care Duration

Anxiety was greater among shorter-term caregivers than longer-term caregivers (χ^2 for trend = 13.25, $p < .001$)

Across all caregiving durations, rates of elevated anxiety were substantially higher than the general US population



Caregiver Anxiety and Caregiving Roles

Anxiety was correlated with level of involvement across all caregiving support roles (*ps* < .05), although effect sizes were small

	Pearson *r*
Going to medical appointments	.24
Coordinating medical care	.23
Household chores	.22
Treatment decision-making	.21
Transportation	.19
Coordinating the patient’s daily schedule	.18
Providing emotional support	.17
Coordinating health insurance	.17
Finances	.17
Everyday activities (e.g., dressing, bathing)	.12
Administration of treatment/medications	.12

Regression Analysis Predicting Anxiety

	Model Statistics at Final Step			
Predictor Variables (ΔR^2)	Model R^2	Significant Predictors	Parameter Estimate	Semipartial *r*
Step 1: Age; Gender (0.04**)	**.12****	**Age***	-0.09	-.11
Step 2: Duration providing care; level of involvement in medical appointments; practical tasks; finances and insurance; emotional support (0.08**)		**Duration providing care***	-0.78	-.12
		Level of involvement in medical appointments*	1.45	.10

Level of involvement in medical appointments is a composite variable comprised of: going to medical appointments, coordinating medical care, & treatment decision-making

n = 396; *p<.05; **p<.01

Conclusions and Implications

- Caregivers provide high levels of emotional, medical, and practical support across the cancer caregiving continuum.
- Shorter duration of caregiving and greater involvement in medical visits were associated with greater levels of caregiver anxiety.
- Many cancer caregivers experience elevated levels of anxiety, at rates much higher than the general populace, regardless of care duration.
- Short- and long-term caregivers may benefit from supportive care and resources to reduce anxiety, address unmet need, and enhance well-being.
- Future work will continue to prioritize engaging diverse caregiver populations and evaluate the role of caregiver distress screening, referral, and follow-up in identifying and improving caregiver anxiety and quality of life.