CANCER SUPPORT COMMUNITY
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Unmet Needs, Caregiver Burden, and Quality of Life Among a Community Sample of Cancer Caregivers

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Background

- Caregivers to individuals with cancer can have many unmet needs; less is understood about the specific nature of these needs or how their needs are associated with caregiver burden, health-related quality of life, and cancer-related distress.

Aims

- The objectives of this study were to 1) identify the unmet needs of cancer caregivers, and 2) examine the relationships between unmet needs and caregiver burden, quality of life, and distress.

Methods

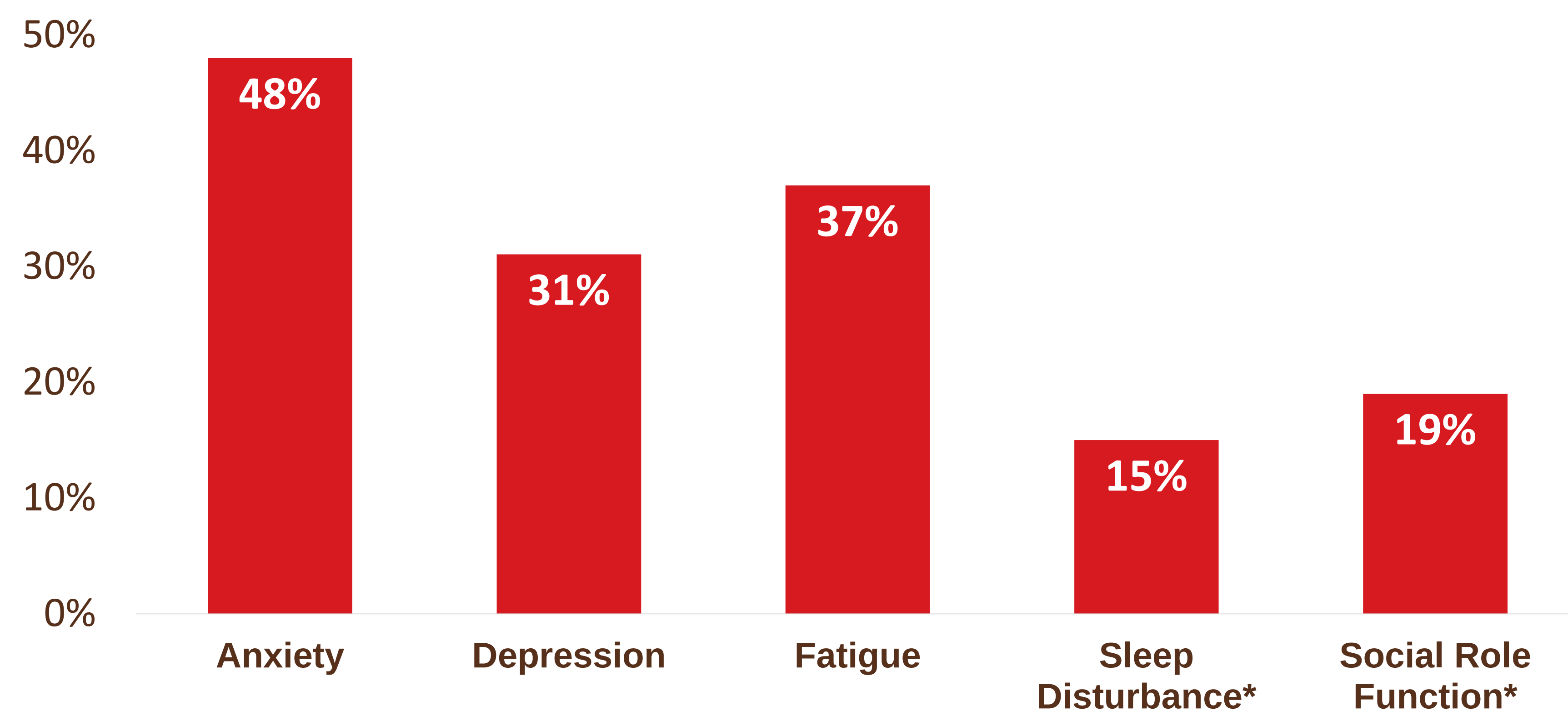
- 149 cancer caregivers, enrolled in the Cancer Support Community's online Cancer Experience Registry, answered questions assessing sociodemographic and caregiving history, patient's activities of daily living (ADLs; 5 items rated 0=*needs no help* to 2=*needs a lot of help* and summed), unmet needs (20 items rated 0=*none* to 4=*very much;* total unmet caregiver need calculated by averaging across all items), health-related quality of life (PROMIS-29), caregiver burden (Zarit Caregiver Burden Inventory), cancer-related distress (NCCN Distress Thermometer), sense of caregiving preparedness (Preparedness for Caregiving Scale), and perceived knowledge about the patient's cancer (0=*not at all* to 4=*very much*).
- Associations between unmet needs and sociodemographic and clinical characteristics were assessed with Pearson correlations to identify potential significant covariates.
- Associations between unmet needs and caregiver burden, perceived knowledge about the patient's care, sense of caregiving preparedness, and health-related quality of life were examined with Pearson correlations and multiple linear regression analysis.

Participants

N = 149	*M/n*	*SD/%*
Age (years)	54	12 *Range: 18 – 86*
Non-Hispanic White	128	86%
Female	113	76%
Caregiver relationship to patient		
Spouse	85	56%
Parent	32	22%
Hours of care provided weekly (*n*=146)		
≤20	56	38%
21-80	59	40%
>100	31	21%
Currently providing care	117	79%

Results

Percent of Caregivers Reporting Worse Quality of Life



*Note: Relative to PROMIS-29 US population norms, except where * denotes US population group balanced to include more people with chronic illness; worse denoted as +1SD for symptom scales and -1SD for function scale*

- Many caregivers report substantially worse quality of life than the national average for anxiety (48% of respondents), fatigue (37%), depression (31%), social functioning (19%), and sleep disturbance (15%).

Unmet Needs: Top Areas Where Caregivers Needed the Most Help

	Percent of Caregivers
Understanding the patient's medical condition, treatment, and prognosis	72%
Getting support for myself	64%
Learning about available emotional support resources	63%
Managing stress	62%
Managing feeling overwhelmed	62%
Learning about available financial resources	62%
Learning about available state and federal resources	61%
Taking better care of myself	59%
Providing emotional support for the patient	58%
Navigating the health care system	54%

Note: % indicating Somewhat to Very Much

- Caregivers desired support across a variety of physical, emotional, and practical aspects of life.
- In particular, understanding the patient's disease, self-care, quality of life, and financial matters were identified as areas of elevated need for support.
- Financial matters were a significant area of concern: 62% wished for at least some support understanding the resources available to them, and 61% wanted help understanding state and federal benefits.

Factors Associated with Total Unmet Caregiver Need

	Pearson *r*	*p*
Caregiver burden	.63	<.001
Cancer-related distress	.45	<.001
Depression	.49	<.001
Anxiety	.43	<.001
Fatigue	.38	<.001
Sleep disturbance	.30	<.001
Hours of care provided weekly	.29	<.001
Patient ADL assistance	.26	<.05
Social role functioning	-.43	<.001
Preparedness for providing care	-.43	<.001
Knowledge about patient's cancer	-.22	<.01

- Greater unmet caregiver need was associated with greater burden of care and distress, poorer caregiver quality of life, and lower sense of preparation and knowledge about care.

Caregiver Knowledge, Preparation, and Burden are Associated with Total Unmet Caregiver Need

Step and Predictor	Model *F*	ΔR^2	*β*	*t*	Part *r*
Step 1	7.76	.11			
Hours of care provided weekly			.18	2.00	.17*
Patient ADL assistance			.23	2.49	.21*
Step 2	10.42	.39			
Caregiver burden			.44	4.91	.32**
Preparedness for providing care			-.19	-2.36	-.16*
Knowledge about patient's cancer			-.15	-2.00	-.13*

Total R^2 = 0.50, p<.001 * p<.05, **p<.01

Note: All variables significantly associated with total unmet need at bivariate level were included in the model. Significant associations only are displayed. Covariates entered at first step were not significant in final model.

- Hierarchical regression demonstrated that greater caregiver burden and lower sense of preparation and knowledge about patient's cancer predicted total unmet caregiver need, after controlling for hours of care provided and patient ADLs assistance.

Implications and Conclusions

- Cancer caregivers experience an array of unmet practical and emotional needs, which are associated with worse caregiver burden, lack of knowledge about the patient's cancer, and poorer sense of preparation for the responsibilities and demands of caregiving.
- These results underscore the importance of assessment of unmet needs of caregivers by healthcare teams and highlight important topics to be addressed through education and support services, with a focus on enhancing understanding of the patient's illness and sense of caregiver preparation. These results also can inform policies that address the unmet needs of cancer caregivers.

Acknowledgments

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References

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CANCER EXPERIENCE REGISTRY
A PROGRAM *of the* CANCER SUPPORT COMMUNITY

The Cancer Experience Registry is an online research initiative that captures the immediate and ongoing or changing social and emotional experiences of cancer survivors and their caregivers.

- The Registry is for all cancer survivors and caregivers, but also includes 10 disease-specific surveys.
- Findings contribute toward advancing research, health care and policy.
- Over 12,000 cancer survivors and caregivers are registered in the Cancer Experience Registry.

Learn more or join the Registry at www.CancerExperienceRegistry.org

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