

Preparedness for Care and Formal Training of Family Cancer Caregivers

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Background

- Caregivers to individuals with cancer frequently provide both instrumental and emotional support as part of their role as a caregiver. Prior CSC research has demonstrated that caregivers want more help in providing these types of care

Aims

- The objectives of this study were to 1) examine caregivers' preparedness to provide instrumental and emotional support, and 2) examine associations between preparedness, caregiver training, and psychological distress

Methods

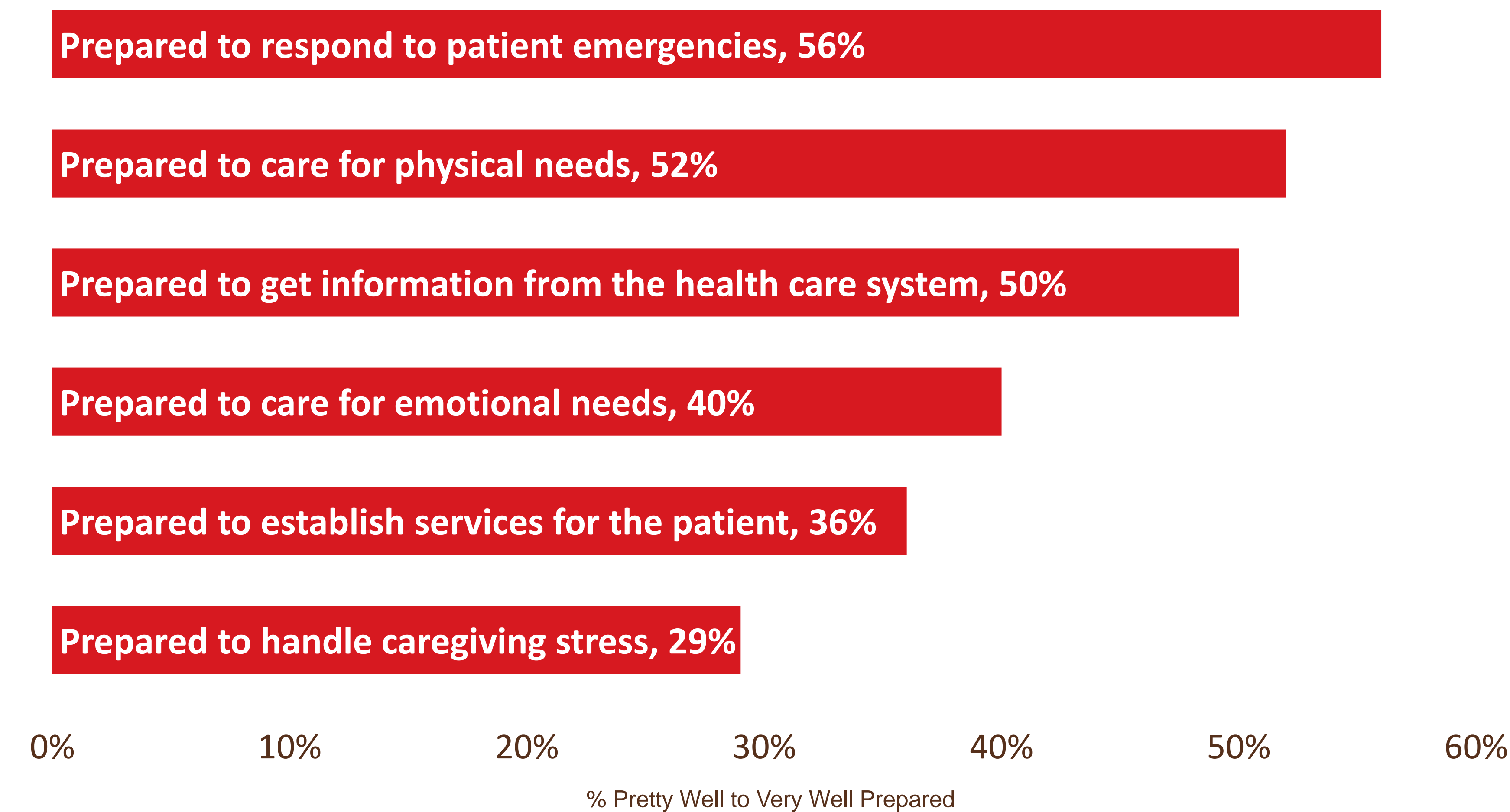
- 424 cancer caregivers enrolled in the Cancer Support Community's online Cancer Experience Registry and answered questions assessing sociodemographic and caregiving history, caregiver training experience, cancer-related psychological distress (PROMIS-29), and sense of caregiving preparedness (Preparedness for Caregiving Scale)
- Associations between training, distress, and care preparation were assessed with Pearson correlations to identify potential significant covariates
- Training history and variables correlated with physical and emotional care preparedness were entered into hierarchical multiple regression analyses

Participants

	M/n	SD/%
Age (years)	52.5	13.3
	Range: 21 - 88	
Female	338	82%
White	349	85%
Not Hispanic, Latino, or Spanish	364	89%
Caregiver relationship to patient		
Spouse	178	53%
Adult child	88	26%
Parent	29	9%
Hours of care provided weekly		
≤10	67	20%
11-20	75	22%
21-40	60	18%
41-100	69	20%
>100	69	20%
Currently providing care	253	73%
Received formal caregiver training	55	17%

Results

Caregiver Preparedness



- About half of caregivers felt pretty well or very well prepared to respond to patient emergencies (56%), care for physical needs (52%), and get information from the health care system (50%)
- Only 40% felt prepared to care for emotional needs, 36% to establish services for the patient, and 29% to handle caregiving stress

Caregiver Training



- 17% of caregivers reported having received formal caregiver training
- 44% of those trained received ≤1 hour of training; 49% wanted additional training
- Training was most often provided by a nurse (51%), other healthcare professional (14%), physician (11%), or social worker (7%), or because they received medical training as part of a career in healthcare

Associations with Formal Training

	r	p
Prepared to care for physical needs	.20	<.001
Prepared to get information	.15	<.05
Prepared to manage emergencies	.12	<.05

Significant associations only displayed

- Training was associated with greater preparedness in caring for physical needs, getting information, and managing emergencies
- Training was not associated with preparedness to provide emotional support, handle caregiving stress, or establish patient services ($r_s = .06-.09$)

Associations Between Feeling Prepared and Psychological Distress

	r	p
Prepared to care for physical needs		
Anxiety	-.13	<.05
Depression	-.18	<.005
Prepared to care for emotional needs		
Anxiety	-.27	<.001
Depression	-.29	<.001

- Lower preparedness to care for physical and emotional needs were each associated with greater psychological distress

Physical Care Preparedness Remains Associated with Formal Training

Step and Predictor	Model F	ΔR^2	β	t	Part r
Step 1					
	5.49	.04			
Depression			-.24	-2.4	-.14*
Anxiety			-.07	-.68	-.04
Step 2					
	8.0	.04			
Depression			-.07	-.70	-.04
Anxiety			-.23	-2.4	-.14*
Formal training			.21	3.5	.21**
Total $R^2 = .29, p < .001$					* $p < .05$, ** $p < .001$

- Training was associated with greater physical care preparedness after controlling for anxiety and depression
- Training was not associated with emotional support preparedness ($p = .20$)

Implications and Conclusions

- Formal caregiver training is associated with greater preparedness for providing instrumental support, but not providing emotional support
- Prior CSC research has shown that over half (58%) of caregivers want more help providing emotional support for the patient; innovative programs are needed to train and support caregivers, with focus on both instrumental and emotional care provision
- Advocacy organizations and oncology care systems can play an integrative role in developing and testing new approaches to train caregivers

Acknowledgments

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References

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- 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