



# Caregiver Burden and Quality of Life Factors Affecting Caregivers Caring for Patients with CTCL

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### BACKGROUND

Caregivers play a critical role for cutaneous t-cell lymphoma (CTCL) patients but the willingness to assist with care, ability, and reaction differs among caregivers.<sup>1</sup> The health of caregivers may become compromised during illness episodes<sup>2</sup> leading to depression, anxiety, sleep disorders, social isolation. Caregiving is a multi-dimensional concept that includes both role and personal strain.<sup>3</sup> Specific to CTCL, the QOL and impact on caregivers caring for patients with CTCL has not been studied.<sup>4</sup>

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### HYPOTHESIS

A unique caregiver burden and quality of life for the caregivers of CTCL patients exists, and as such, there may be unidentified, and thus unmet, caregiver needs.

### SPECIFIC AIMS

- Determine if there are unidentified and unmet needs of caregiver stressors and gaps in awareness, knowledge and services that may be of benefit to CTCL caregivers.
- Describe the demographics, unique caregiver burden and quality of life issues in those caring for patients with cutaneous t-cell lymphoma.
- Determine the difference in caregiver burden dependent upon the severity of the loved one's disease severity as perceived by the caregiver.
- Determine if caregivers perceive that their needs are being met by health care providers

### METHODS

- Cross sectional design (N = 42)
- 3 questionnaires at point of contact-anonymous
  - Zarit Burden Interview: 22 items assess personal and role strain
  - Caregiver QOL – Cancer: 35-items; assess overall wellbeing
  - Quality of Life Demographic tool – 16 item, researcher-developed
    - Assessment of disease severity, impact of scratching, skin shedding, appearance, public reaction, and skin care demands on time & effort
    - Factors causing most caregiver stress (skin symptoms vs. other medical)
  - Co-morbidities
  - Assessment of healthcare provider’s recognition and support of caregiving burden

### SAMPLE CHARACTERISTICS

	N	%
Males	10	24
Females	32	76

	N	%
Spouse	27	64
Daughter	5	12
Son	2	5
Significant other	3	7
Other	5	12

### SAMPLE CHARACTERISTICS

	MEAN	RANGE	SD
Age	61	29-87	14.36
Years caring for loved one	9.28	1-57	9.63
Years loved one had skin symptoms	8.7	1-71	11.71

### CO-MORBIDITIES OF PATIENTS

MORBIDITY	N	%	MORBIDITY	N	%
Mobility	16	38	Chronic pain	7	17
CAD	14	33	Stroke	1	2
Lung disease	4	10	Diabetes	5	12
Circulatory issues	5	12	Mental disorder	7	17
Chronic wounds	4	10	Other*	8	19

\*Other: Dizziness, loss of appetite, sleep apnea, prostate CA, eczema, glaucoma, MS, hearing loss

### SCORES ON QUALITY OF LIFE TOOLS

SEVERITY OF DISEASE ASSESSMENT	MEAN SCORES	
	CAREGIVER – QOL TOOL	ZARIT BURDEN INTERVIEW
	Range 0-4*	Range (0-4)*
Minor	1.044	0.5957
Moderate	1.2482	0.8379
Severe	1.9591 + p 0.0307	1.7386 + p 0.0063

\*0 = none (never), 1 = a little bit (rarely); 2 = somewhat (sometimes); 3 = quite a bit (quite frequently); 4 = very much (nearly always)  
+ ANOVA

### DEMOGRAPHIC QUESTIONNAIRE: ASSESSMENT OF UNIQUE BURDEN OF CTCL CAREGIVERS

Caregiver very much bothered by:	Minor n=14 (%)	Moderate n = 23 (%)	Severe n = 4 (%)	P value* (p < 0.05)
				*Mantel-Haenszel Chi-Square test
Scratching	1 (7)	2 (9)	3 (75)	0.0154
Shedding	0 (0)	4 (17)	1 (25)	0.0524

\*Also asked if bothered by appearance, public reaction, time/effort to care for skin, and if HCP is sensitive to needs of caregiver.

### DEMOGRAPHIC QUESTIONNAIRE: ATTRIBUTION ASSESSMENT OF BURDEN

Majority of burden caused by:	Minor	Moderate/Severe (categories collapsed for analysis) (%)	P value* (p < 0.05)
			*Mantel-Haenszel Chi-Square test
Skin symptoms	10 (71)	18 (67)	p 0.0499
Medical problems	0	8 (30)	

### CONCLUSION

- Trends, rather than significance of data, were identified to support hypothesis.
- Moderate & severe disease assessment correlated with being more bothered by itching & scratching behaviors while skin symptoms, rather than other medical issues, contribute to the majority of caregiver burden.
- Higher scores on Burden Interview and Cancer QOL correlate positively with increased severity.

### LIMITATIONS

- Small, heterogeneous sample size
- Wide variation of N within the mild, moderate, and severely assessed disease groups
- Demographic tool requires further testing, refinement, and improved clarity of items

### RECOMMENDATIONS

- Replicate study with larger sample size and control group size for better cross section
- Revise, assess reliability/validity and pilot test demographic questionnaire
- Repeat study concentrating on moderate and severe disease

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