

Title: The Psychological Impact on Health-related Quality of Life in Childhood-onset Lupus

Jordan T. Jones, Natoshia Cunningham, Jennifer Huggins, Susmita Kashikar-Zuck, and Hermine I. Brunner

Background/Purpose: Childhood-onset lupus (cSLE) is a chronic autoimmune disease and its effect on health-related quality of life (HRQoL) has not been fully established, but, disease activity alone does not solely account for the impact on HRQoL. Gaps in the literature exist around the impact of potentially modifiable factors (pain, sleep, fatigue, pain coping, mood, anxiety) in relation to HRQoL. Disease activity measures are often unrelated to psychological factors associated with cSLE. Chronic disease and its related psychological factors can impair participation in developmentally appropriate activities in adolescents, leading to chronically poor HRQoL. *Objectives* of this study were to evaluate psychological factors in patients with cSLE and the degree of HRQoL impairment in cSLE due to psychological factors commonly associated with chronic diseases.

Methods: As part of an ongoing study, a population-based cohort of cSLE patients (n= 20; 8 – 18 years) followed at Cincinnati Children’s Hospital were asked to complete brief measures of *pain* (Pain visual analog scale[Pain VAS]), *sleep* (Adolescent Sleep Wake Scale), *fatigue* (PedsQL Multidimensional Fatigue Scale), *pain coping* (Pain Coping Efficacy questionnaire, Pain Catastrophizing questionnaire), *mood* (Children’s Depression Inventory [CDI1]), *anxiety* (Screen for Child Anxiety Related Disorders [SCARED]), and *HRQoL* (PedsQL Generic Core scale and Rheumatology Module). Measures of disease activity (Systemic Lupus Erythematosus Disease Activity Index [SLEDAI], and physician completed visual analog scale of cSLE disease activity [MD Global, 0-10; 0=inactive]) were also obtained.

Results: Subjects were 90% female with mean age of 15.5 years (SD 1.5) and mean SLEDAI score of 7.8 (SD 6.1). Of the subjects, 60% had fatigue and more than minimal pain (Pain VAS ≥ 3), and 40% reported often feeling rested the next morning. Also, 25% had clinically significant anxiety symptoms (SCARED ≥ 25), and 30% had mild-to-moderate depressive symptoms (CDI1 ≥ 10). The average HRQoL score for cSLE patients was well below the reported healthy mean, and the presence of fatigue, anxiety, and decreased mood correlated highly with HRQoL (Pearson’s $r > 0.70$). Conversely, none of the HRQoL measures correlated with SLEDAI score or MD global ($r < 0.25$; see **Table 1**). Regression demonstrated HRQoL was most impacted by fatigue ($p < 0.05$) when evaluating all factors concurrently.

Conclusion: cSLE is often associated with decreased HRQoL, despite comprehensive treatment provided at a tertiary pediatric rheumatology center. Our data suggests that psychological aspects of health (pain, mood, fatigue and anxiety) contribute substantially to diminished HRQoL in cSLE patients, whereas, measures of cSLE activity are not related to HRQoL outcomes. Psychological factors, and especially fatigue, need to be addressed to achieve optimal health outcomes with cSLE.

Table 1: Pearson Correlation Coefficients

Pearson Correlations	HRQoL Measures		Psychological Variables						
	PedsQL GC	Peds QL RM	Fatigue	Anxiety	Mood	Sleep	Pain	Pain Coping	Pain Catastrophizing
PedsQL GC	1	0.89**	0.86**	-0.75**	-0.76**	0.65**	-0.51*	0.08	-0.56*
Peds QL RM	0.89**	1	0.86**	-0.71**	-0.78**	0.62**	-0.52*	0.01	-0.56*
Fatigue	0.86**	0.86**	1	-0.73**	-0.81**	0.62**	-0.55*	0.23	-0.63**
Anxiety	-0.75**	-0.71**	-0.73**	1	0.89**	-0.55*	0.36	0.09	0.54*
Mood	-0.76**	-0.78**	-0.81**	0.89**	1	-0.64**	0.32	0.06	0.52*
Sleep	0.65**	0.62**	0.62**	-0.55*	-0.64**	1	-0.15	-0.28	-0.35
Pain	-0.51*	-0.52*	-0.55*	0.36	0.32	-0.15	1	-0.21	0.34
Pain Coping	0.08	0.01	0.23	0.09	0.06	-0.28	-0.21	1	-0.27
Pain Catastrophizing	-0.56*	-0.56*	-0.63**	0.54*	0.52*	-0.35	0.34	-0.27	1
SLEDAI	0.06	0.14	-0.04	-0.04	-0.09	0.12	0.15	0.22	0.08
MD Global	-0.08	-0.06	-0.20	-0.04	0.11	-0.04	0.23	0.12	0.11

*Denotes p-value <0.05

** Denotes p-value < 0.01