



Disease and Medication Beliefs and their Relationship to Adherence and Functional Outcomes in Pediatric Systemic Lupus Erythematosus

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Background

- Pediatric onset systemic lupus erythematosus (pSLE) is a multi-organ connective tissue disease associated with significant morbidity and mortality.
- Although adult data suggests that beliefs about medications and illness may be modifiable moderators of adherence, little research has explored the relationship between these factors and adherence or disease outcome in pediatric patients.
- Our study examines both parent and child beliefs about medication and illness and assess whether these beliefs impact medication adherence and functional outcomes in pediatric lupus.

Methods

- Adolescents aged 12 to 18 with pSLE and the parent accompanying them to the clinic visit were eligible to participate.
- Through self-administered surveys given at regular clinic visits and chart review, we obtained the following from parents and adolescents:
 - Childhood Health Assessment Questionnaire, Visual Analogue Scale (VASCHAQ)
 - Single Item Medication Adherence Scale
 - Beliefs about Medicines Questionnaire (BMQ)-
 - Brief Illness Perception Questionnaire (BIPQ)-
 - Demographic data
 - Disease onset, organ systems involved, and medication list
 - Systemic Lupus Erythematosus Disease Activity Index 2000 (SLEDAI-2K)- from the medical record

Primary Hypotheses

Adherence

- Parents of adolescent lupus patients and adolescents with lupus **who endorse beliefs that medications are harmful** will report **lower adolescent medication adherence**

- Parents of adolescent lupus patients and adolescents with lupus **who endorse beliefs that medications are necessary** will report **higher adolescent medication adherence**
- Parents of adolescent lupus patients and adolescents with lupus **who perceive that the adolescent has a low level of control over lupus** will report **increased adolescent functional disability**
- Parents of adolescent lupus patients and adolescents with lupus **who report that the adolescent is highly emotionally affected by lupus** will report **increased adolescent functional disability**

Results

Table 1: Demographics

Parents (n=15)	
Age, mean (range)	44 years (33-59)
Gender	Female: 86.7% (n=13) Male 13.3% (n=2)
Race/Ethnicity (respondents were allowed to check more than one answer)	African American: 13.3% (n=2) Asian: 13.3% (n=2) Hispanic/Latino: 80% (n=9) Non-Hispanic White: 13.3% (n=2) Other: 6.7% (n=1)
Highest level of formal education completed	Some high school: 6.7% (n=1) High School Diploma: 26.7% (n=4) Some College: 26.7% (n=4) College Degree: 26.7% (n=4) Graduate/Professional 13.3%(n=2)
Compliant with medications in the last 14 days?*	73.3%
Adolescents (n=17)	
Age, mean (range)	15.1 years (12-18)
Gender	Female: 82.4% (n=14) Male: 17.6% (n=3)
Race/Ethnicity (respondents were allowed to check more than one answer)	African American: 11.8% (n=2) Asian 11.8% (n=2) Hispanic/Latino: 70.15% (n=12) Non-Hispanic White: 11.8% (n=2) Other: 5.9% (n=1)
Renal involvement (ever)	65% (N=11)
SLEDAI Score mean (SD)	4.65 (4.12)
Compliant with medications in the last 14 days?*	70%

*Defined as missing 1 or fewer doses

Table 2: BMQ Scores (Harm and Necessity Domains) vs Medication Adherence- Correlation Coefficients**

	Child-Reported Missed Doses	Parent-Reported Missed Doses	Missed Doses Agreement Score*
Parent-BMQ Harm Score	0.0988	0.0727	0.17771
Child-BMQ Harm Score	0.009468	0.1000399	0.006338
Parent-BMQ Necessity Score	0.011079	0.000387	2.47E-05
Child- BMQ Necessity Score	0.150842	0.000768	0.121667

*The agreement score was calculated try taking the absolute value of parent score-child score.

**Only 14 parent-child pairs are included in the analysis, as others had incomplete data

Table 3: BIPQ Scores (Control domain and Emotional domain) vs Functional Disability- Correlation Coefficients**

	Child VASCHAQ Score	Parent VASCHAQ Score	VASCHAQ Agreement score*
Parent-BIPQ Control Score	0.017	0.002231	0.033109
Child-BIPQ Control Score	0.0972	0.003018	0.417
Parent-BIPQ Emotional Score	0.022957	0.008	0.063677
Child- BIPQ Emotional Score	0.043163	0.26974	7.875E-07

*The agreement score was calculated try taking the absolute value of parent score-child score.

**Only 14 parent-child pairs are included in the analysis, as others had incomplete data

Discussion

Contrary to what was expected, neither parent harm score nor child total harm score correlated with missed doses as reported by parent or child.

Parental and patient beliefs about medication harm and necessity do not appear to influence medication compliance in this sample

Contrary to what was expected, neither parent control score nor child control score correlated with functional disability score.

We did find a modest correlation between the child control score and the VASCHAQ agreement score, suggesting that as the adolescent's perception of control over disesae increased, agreement between parent and child regarding level of functional disability improved.

Interestingly, as the degree to which a child was emotionally affected by lupus increased, there was a weak correlation with decreased functional disability as reported by parents.

Further analysis is planned to explore the relationship between other domains of the BMQ and BIPQ and functional disability and medication adherence

Limitations

- Small sample size
- Our sample was disproportionately Hispanic, so generalizability to non-Hispanic populations may not be appropriate
- Parents in our sample were predominantly mothers, limiting generalizability to fathers

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