The Illness Experience of Youth with Lupus/Mixed Connective Tissue Disease: A Mixed Methods Analysis of Patient and Parent Perspectives

Date:

Apr 2016
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OBJECTIVE: We aimed to develop a model of the illness experience for youth with systemic lupus erythematosus (SLE)/mixed connective tissue disease (MCTD).

METHODS: We conducted 32 semi-structured interviews with 16 outpatient youth with SLE/MCTD, age 11 to 22 years, and their parents. We qualitatively defined key features of illness for families and distinguished profiles of youth adapting well vs poorly to SLE/MCTD. We then related these profiles to features of illness, patient-level attributes and outcomes.

RESULTS: Experiences with SLE/MCTD grouped into five themes: managing disease, limitations, stigma, illness uncertainty and psychological coping. Youth adapting well experienced minimal challenges in these areas. Youth adapting poorly (4/16) experienced significant challenges in >1 thematic area, and were older with lower socioeconomic status, quality of life and psychosocial functioning, and increased disease-related morbidity. They also described suboptimal treatment adherence, healthcare utilization and transition to adult care. These findings support a dynamic model in which illness adaptation and outcomes are shaped by patient characteristics and five central illness-related challenges.

CONCLUSION: Further testing of our model of illness experience may help guide comprehensive and personalized care of youth with SLE/MCTD, with targeted supports for youth at risk for negative adaptation to illness and poor outcomes.

Journal:

Lupus
Authors:

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