Barriers and Facilitators for Mental Healthcare in Pediatric Lupus and Mixed Connective Tissue Disease: A Qualitative Study of Youth and Parent Perspectives

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BACKGROUND: Untreated mental health problems may result in poor outcomes for youth with systemic lupus erythematosus (SLE) and mixed connective tissue disease (MCTD). We investigated perceptions, barriers and facilitators for mental healthcare of these youth.

METHODS: We conducted 32 semi-structured interviews with 16 outpatient youth with SLE/MCTD, ages 11–22 years, and their parents. We used purposive sampling to deliberately obtain the experiences of youth screened during a previous study for depression and anxiety with the Patient Health Questionnaire 9 and the Screen for Childhood Anxiety and Related Disorders, respectively. We recruited 6 youth with previous positive screens and 10 with negative screens. We assessed interim mental health history, and qualitatively examined perceptions, barriers and facilitators for mental healthcare.

RESULTS: Youth with a mental health history increased from 6 (38 %) at initial screening to 9 (56 %) at interview (mean follow-up = 2.1 years). Youth receiving mental health treatment increased from 33 to 67 %. Youth and parents identified rheumatologists as primary physicians and found mental health screening in rheumatology acceptable. Barriers to mental healthcare included: stigma; fear; uncertainty about getting help; parental emotional burden; minimization by doctors; and limited mental healthcare access. Facilitators included: strong clinician relationships; clinician initiative, sincerity and normalization in discussing mental health; and increased patient/family awareness of mental health issues in SLE/MCTD.

CONCLUSION: Youth with SLE/MCTD and their parents perceive pediatric rheumatologists as a preferred source for mental health screening, guidance and referral. Interventions addressing barriers and enhancing facilitators may improve mental healthcare for youth with SLE/MCTD.

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Authors: Knight A, Vickery M, Fiks A, Barg F

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