

Background: Mental health conditions are common in youth with rheumatologic disease, yet intervention strategies for pediatric subspecialty patients is understudied. Patient-engaged research, involving patients and families on the research team, is a valuable technique for examining sensitive topics such as mental health. We used a patient-engaged approach to investigate mental health needs of youth with rheumatologic disease.

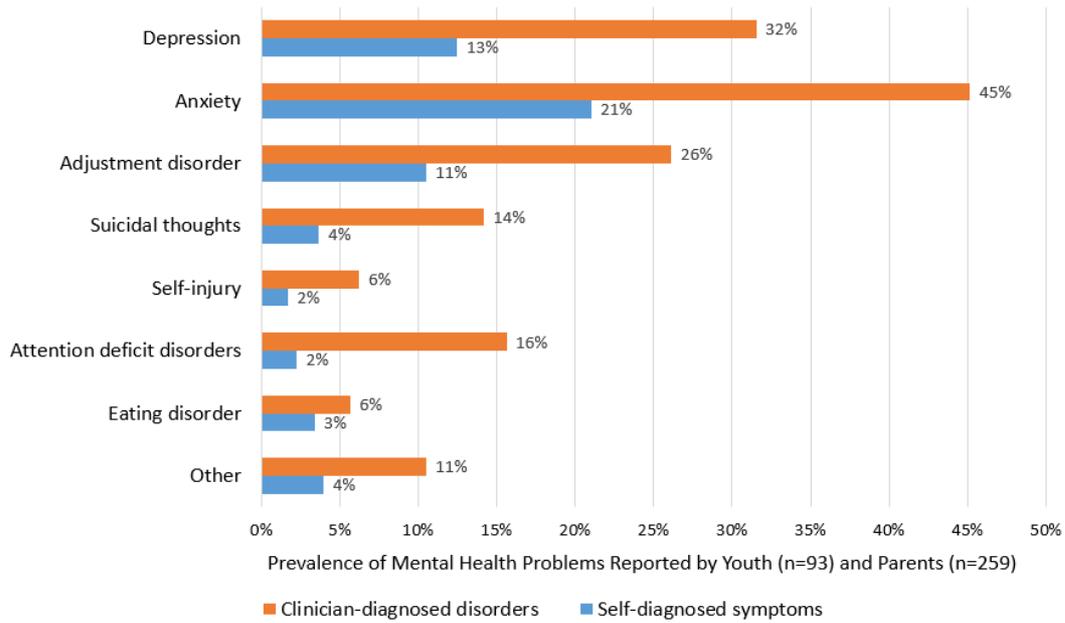
Methods: An online survey examined beliefs and experiences with mental health for patients with juvenile arthritis, juvenile dermatomyositis, or systemic lupus erythematosus. Youth ages 14-24 years and parents of youth 8-24 years were eligible to participate. The survey was developed in collaboration with patient and parent advisors, the Childhood Arthritis & Rheumatology Research Alliance (CARRA), and the Patients, Advocates, and Rheumatology Teams Network for Research and Service (PARTNERS). Participants were recruited through the Arthritis Foundation, Lupus Foundation of America, and Cure JM Foundation. We compared youth and parent responses using regression models (adjusted for demographic and disease covariates) to examine the prevalence of mental health problems, and Likert ratings for the impact of disease aspects on mental health, and comfort level with potential mental health providers.

Results: 352 respondents included 93 youth (26%) and 259 (74%) parents. Mental health problems were highly prevalent, with clinician-diagnosed anxiety reported by 45%, depression 32%, and adjustment disorders 26% (Figure 1); another 13%, 21% and 11% reported self-diagnosed symptoms of these disorders, respectively. Mean Likert scores indicated that disease aspects most impacting mental health (0=low, 4=high) were physical limitation at 2.7 (SD 1.1), taking medications at 2.6 (1.2), and dealing with disease flares at 2.5 (1.2). Adjusted models showed no difference between youth and parents for reported mental health problems or impacting factors. Youth were significantly less comfortable interacting with all potential mental health providers than parents, particularly social workers and school counselors (Figure 2); both groups felt most comfortable with rheumatologists and primary care providers.

Conclusion: Youth with rheumatologic disease have high rates of diagnosed and undiagnosed mental health problems, which are impacted by their disease. Mental health intervention strategies are needed, focusing on both primary care and subspecialty care settings to provide mental health education, screening and treatment for these youth.

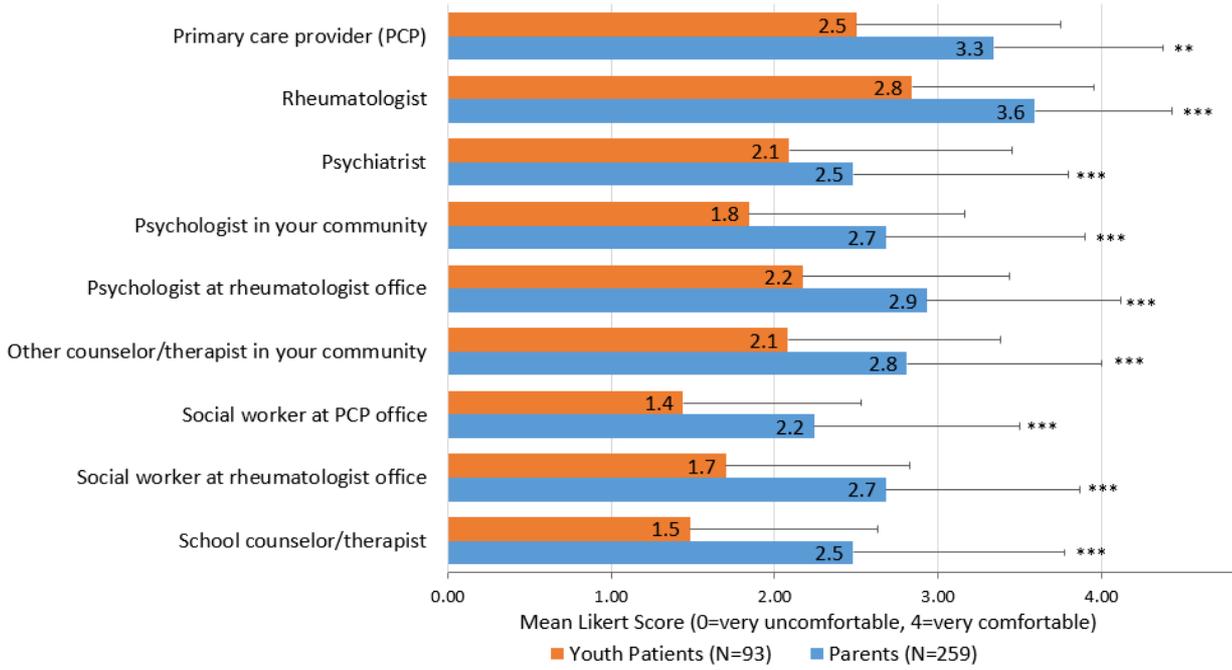
Institutional Review Board (IRB) Approval: The study was approved by the Children's Hospital of Philadelphia IRB, Duke University Health System IRB, and Lupus Foundation of America IRB.

Figure 1. Prevalence of Mental Health Problems for Youth with Rheumatologic Disease: Clinician-diagnosed vs Self-diagnosed



Results are shown for logistic regression models adjusted for patient age, gender, disease duration and patient/parent-reported visual assessment score for disease-related health.

Figure 2. Comparison of Level of Comfort with Potential Mental Health Providers Among Youth Patients and Parents



Results are shown for logistic regression models comparing Likert scores among youth patients and parents, adjusted for patient age, gender, disease duration and patient/parent-reported visual assessment score for disease-related health. **= $p < 0.01$, ***= $p < 0.001$