

Identifying Targets for Improving Mental Healthcare of Adolescents with Systemic Lupus Erythematosus: Perspectives from Pediatric Rheumatology Clinicians in the United States and Canada

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ABSTRACT. Objective. To identify targets for improving mental healthcare of adolescents with systemic lupus erythematosus (SLE) by assessing current practices and perceived barriers for mental health intervention by pediatric rheumatology clinicians.

Methods. Members of the Childhood Arthritis and Rheumatology Research Alliance (CARRA) completed a Web-based survey assessing current mental health practices, beliefs, and barriers. We examined associations between provider characteristics and the frequency of barriers to mental health screening and treatment using multivariable linear regression.

Results. Of the 375 eligible CARRA members, 130 responded (35%) and 119 completed the survey. Fifty-two percent described identification of depression/anxiety in adolescents with SLE at their practice as inadequate, and 45% described treatment as inadequate. Seventy-seven percent stated that routine screening for depression/anxiety in pediatric rheumatology should be conducted, but only 2% routinely used a standardized instrument. Limited staff resources and time were the most frequent barriers to screening. Respondents with formal postgraduate mental health training, experience treating young adults, and practicing at sites with very accessible mental health staff, in urban locations, and in Canada reported fewer barriers to screening. Long waitlists and limited availability of mental health providers were the most frequent barriers to treatment. Male clinicians and those practicing in the Midwest and Canada reported fewer barriers to treatment.

Conclusion. Pediatric rheumatology clinicians perceive a need for improved mental healthcare of adolescents with SLE. Potential strategies to overcome barriers include enhanced mental health training for pediatric rheumatologists, standardized rheumatology-based mental health practices, and better integration of medical and mental health services. (J Rheumatol First Release April 1 2016; doi:10.3899/jrheum.151228)

Key Indexing Terms:

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Systemic lupus erythematosus (SLE) is a chronic autoimmune condition associated with significant morbidity and mortality because of multiorgan damage as well as long-term immunosuppressive treatment¹. Mental health disorders such as depression and anxiety occur more frequently in adolescents with SLE than in healthy peers^{2,3}. This is likely to have multiple causes, including neuropsychiatric SLE, the psychological burden of chronic illness with onset during adolescence, the physical effect of SLE from disease damage, and treatment-related side effects, as well as other social, genetic, and environmental factors.

Depression and anxiety are underrecognized and undertreated among adolescents with SLE². Mental health intervention is important because depression and anxiety are associated with poor disease control, quality of life, school performance, and transition to adult care in other pediatric chronic disease^{4,5,6,7}, as well as poorer medication adherence, disease control, work productivity, and greater healthcare use in adults with SLE^{8,9,10,11,12}.

Adequate mental health intervention includes effective identification and treatment. The American Academy of Pediatrics (AAP) recommends yearly depression screening for all adolescents in primary care settings¹³, and studies indicate that collaborative mental and medical care models in primary care are effective in connecting patients to mental health services¹⁴. However, national data indicate that depression screening does not occur in primary care settings as currently recommended¹⁵, and adolescents with SLE who receive most of their healthcare through subspecialty clinics may benefit from mental health intervention in the pediatric rheumatology setting². Pediatric rheumatologists may therefore have a central role in facilitating mental health intervention for adolescents with SLE.

In our cross-sectional study of pediatric rheumatology clinicians in North America, we sought to identify inter-

vention targets for improving mental healthcare for adolescents with SLE by examining the current mental health environment in pediatric rheumatology. Specifically, we aimed to describe (1) current practices and beliefs for identifying and treating mental health disorders in adolescents with SLE, (2) the most frequent perceived barriers for identification and treatment of mental health disorders, and (3) provider and practice characteristics associated with these perceived barriers.

MATERIALS AND METHODS

Participants. We surveyed members of the Childhood Arthritis and Rheumatology Research Alliance (CARRA), a research network containing > 95% of practicing pediatric rheumatologists in the United States and Canada. Eligible participants included attending and fellow physicians, nurse practitioners, and physician assistants actively caring for children and adolescents with SLE. Non-clinician members of the CARRA were excluded. In May 2015, the CARRA included 439 total members (including board-eligible and board-certified pediatric rheumatologists, trainees, allied health professionals, and affiliated researchers), of whom 375 held medical or midlevel clinical degrees and were considered eligible for our study. The study was submitted but exempted from human subjects review by The Children's Hospital of Philadelphia Institutional Review Board.

Survey instrument and administration. We administered an online survey to all CARRA members by e-mail listserv in May and June 2015. Eligibility for our study was determined by response to the first 2 items indicating eligible clinician type and active care of pediatric patients with SLE. Only eligible respondents were then administered the full 24-item survey assessing provider characteristics, current practices, beliefs, and barriers for mental healthcare of adolescents with SLE. Clinician characteristics included clinician type (attending or fellow physician, nurse practitioner, or physician assistant), sex, years in practice, level of formal mental health training, and upper age limit of patients with SLE treated. Practice characteristics included setting (university-affiliated, private practice, or other), location (urban, suburban, or rural), number of providers, SLE population size and insurance type (private, public, or other), presence of a specialized SLE clinic, involvement in SLE research, presence of on-site staff for assistance with management of mental health issues, and the level of accessibility (not very accessible, somewhat accessible, or very accessible) of these staff members. We elicited current mental healthcare practices for patients with depression or anxiety using branching logic to elucidate details about adequacy, settings, frequency, and methods for mental health screening, referrals, and treatment. We asked participants about their beliefs regarding the necessity of mental health screening, preferred resources and settings for screening and followup evaluation, and interest in receiving training for evaluation or pharmacologic treatment of mental health conditions. Participants rated the frequency of 27 potential barriers, 12 for routine screening and 15 for treatment of mental health problems, based on known correlates of unmet need for mental health services in children and adolescents^{16,17}. Participants used a 4-point Likert scale to rate the frequency of barriers as "never = 0," "sometimes = 1," "often = 2," or "very often = 3". Survey questions were drafted by 2 of the authors (AK and MV), and edited and pilot-tested by the CARRA Workgroup on SLE Mental Health. REDCap software¹⁸ was used to administer the surveys anonymously through an e-mail with a link to the Web-based survey. The survey link was available for 6 weeks and 3 reminder e-mails were sent.

Data analysis. After excluding ineligible responders and incomplete responses (those for whom survey was not submitted), we tabulated the responses and performed descriptive statistics for provider characteristics, current practices, and beliefs. For each potential barrier, we calculated the mean of Likert scores across respondents and ranked them by mean score (range 0–3). We then summed the Likert scores to calculate separate frequency scores for barriers to mental health screening (range 0–36) and to

treatment (range 0–45) for each respondent. We used these frequency scores as the outcome variable to examine associations of provider characteristics with the frequency of barriers in separate multivariable linear regression models for screening and treatment. To avoid overfitting, we included in the multivariable models only covariates with statistically significant pairwise associations ($p < 0.2$) with the outcome variable. Coefficients are reported with 95% CI and 2-sided p values. We performed all statistical analyses using Stata 13 (Stata Corp.).

RESULTS

Provider characteristics. Of the 375 eligible CARRA members, 130 (35%) responded. After excluding 11 incomplete responses, 119 were analyzed. Clinician and practice characteristics of the respondents are summarized in Table 1. Respondents included attending physicians (83%), fellows (14%), and nurse practitioners (3%). The majority of respon-

dents worked in university-affiliated (94%) and urban (82%) practices, with more than 5 providers (75%). Clinicians represented 30 US states (27% Northeast, 25% Midwest, 21% South, and 15% West) and 4 Canadian provinces (6%). These respondent demographics were comparable to the eligible CARRA membership, consisting of 72% attending physicians and 22% trainees, working primarily (79%) in large centers with 3 or more providers with regional representation from the US Northeast (23%), Midwest (26%), South (21%), West (19%), and Canada (9%).

Formal mental health training was reported by 91%, mostly occurring in medical or nursing school (70%). The majority of respondents reported the following staff to be present on-site, but the percentage reporting these staff to be “very accessible” for mental health issues was considerably

Table 1. Demographics of pediatric rheumatology clinicians (n = 119). Values are n (%) unless otherwise specified.

Characteristics	Values	Characteristics	Values
Clinician characteristics		Location*	
Type		Urban	97 (82)
Attending physician	98 (83)	Suburban	20 (17)
Fellow physician	17 (14)	Rural	1 (1)
Nurse practitioner	4 (3)	No. clinicians in practice*, median (IQR)	7 (5–11)
Physician assistant	0 (0)	Physicians	6 (4–10)
Sex*		Nurse practitioners	1 (0–1)
Female	86 (73)	Physician assistants	0 (0–0)
Male	32 (27)	Public insurance coverage of patients with SLE*	
Yrs in pediatric rheumatology practice		< 50%	34 (29)
< 5	31 (26)	≥ 50%	74 (62)
5–10	38 (32)	No. patients with SLE in practice*	
11–20	22 (18)	< 20	17 (14)
> 20	28 (24)	20–49	35 (30)
Level of formal mental health training		50–99	41 (34)
None	11 (9)	≥ 100	25 (21)
Medical school	80 (67)	Presence of specialized SLE clinic*	
Nursing school	3 (3)	Yes	31 (26)
Residency	14 (12)	Participation in SLE research	
Fellowship	9 (7)	Yes	83 (70)
Other	2 (2)	Presence of on-site staff to assist with mental health issues*	
Age of patient population treated		Social workers	109 (92)
Up to 19 yrs	39 (33)	Psychologists	93 (78)
Up to 24 yrs	75 (63)	Psychiatrists	97 (82)
Through adulthood	5 (4)	Child life specialists	106 (89)
Practice characteristics		Adolescent medicine practitioner	96 (81)
Type*		Very accessible on-site staff to assist with mental health issues*	
University-affiliated	112 (94)	Social workers	51 (43)
Private practice	3 (3)	Psychologists	10 (8)
Hospital-affiliated	3 (3)	Psychiatrists	7 (6)
Region		Child life specialists	37 (31)
United States	105 (88)	Adolescent medicine physicians	31 (26)
Northeast	32 (27)	Any very accessible on-site staff to assist with mental health issues*	
Midwest	30 (25)	Yes	77 (65)
South	25 (21)		
West	18 (15)		
Canada	7 (6)		
Atlantic	2 (2)		
Central	4 (3)		
Prairie	1 (1)		
West	0 (0)		
North	0 (0)		

* Percentages do not add to 100% because of missing observations (n) for the following variables: clinician sex (1), practice type (1), country (1), region (7), location (1), clinician number (2), SLE patient insurance (11), number (1), presence of SLE clinic (2), availability and accessibility of on-site staff to assist with mental health issues (4). IQR: interquartile range; SLE: systemic lupus erythematosus.

lower: social workers (92% vs 43%), psychologists (78% vs 8%), psychiatrists (82% vs 6%), child life specialists (89% vs 31%), and adolescent medicine practitioners (81% vs 26%). However, 65% of respondents indicated at least 1 of these on-site staff to be very accessible.

Current practices. Responses about current practices regarding identification and treatment of mental health problems are summarized in Table 2. Fifty-two percent of respondents said that their practice did not adequately identify symptoms of depression/anxiety in adolescents with SLE and 45% said that they lacked adequate methods to connect symptomatic patients to mental health services. Almost all respondents (98%) reported informal screening for depression/anxiety; 55% did so routinely, 43% on a case-by-case basis, and 2% did not screen at all. Formal screening for depression/anxiety using a standardized instrument was reported by only 8% of respondents, routinely by 2%, and on a case-by-case basis by 6%. Most respondents reported 1–5 referrals to mental health professionals per month, of which

74% were on-site and 64% were off-site referrals. Thirteen percent of respondents reported prescribing medications for depression/anxiety.

Beliefs. Respondent beliefs about identifying and treating mental health problems are summarized in Table 2. Respondents said that attending physicians (66%), fellows (58%), nurse practitioners (51%), and nurses (53%) should be tasked with identifying patients with depression/anxiety. Most respondents indicated that routine screening for depression (85%) and anxiety (65%) should be performed, with the majority supporting screening every 3–6 months. The most preferred settings for routine screening were rheumatology clinics (77%) and primary care offices (56%). All respondents said that further evaluation of adolescents with positive screens should occur in a psychologist's or psychiatrist's office. Other preferred settings included primary care offices (34%), schools (25%), and rheumatology offices (18%). Ninety-one percent of respondents expressed interest in receiving training for the evaluation of

Table 2. Pediatric rheumatology clinician practices and beliefs regarding mental healthcare of adolescents with SLE (n = 119).

Variables	n (%)	Variables	n (%)
Current practices		Every 3–6	49 (49)
Adequate identification of patients with depression/anxiety symptoms		Every 6–12	31 (31)
Yes	57 (48)	Less than once a yr	6 (6)
Adequate connection of symptomatic patients to further mental health evaluation/treatment		Anxiety*, mos	77 (65)
Yes	65 (55)	Every 0–3	10 (13)
Informal depression/anxiety screening*		Every 3–6	36 (47)
Routinely in all patients	65 (55)	Every 6–12	26 (34)
Only in symptomatic patients	51 (43)	Less than once a yr	5 (6)
None	2 (2)	Preferred settings for depression/anxiety screening	
Formal depression/anxiety screening*		Rheumatology clinic	92 (77)
Routinely in all patients	2 (2)	Primary care office	67 (56)
Only in symptomatic patients	7 (6)	During hospitalizations	36 (30)
None	106 (89)	In the emergency room	21 (18)
No. on-site referrals to mental health professionals*		Preferred settings for evaluation of patients screening positive by a mental health professional	
0	28 (24)	Rheumatology office	22 (18)
1–5	87 (74)	Primary care office	41 (34)
> 5	3 (3)	Psychologist/psychiatrist office	119 (100)
No. off-site referrals to mental health professionals*		School	30 (25)
0	35 (31)	Other***	4 (3)
1–5	72 (64)	Level of interest in training for evaluation of adolescent mental health	
> 5	6 (5)	Not interested	11 (9)
No. respondents prescribing psychotropic medications for depression/anxiety	15 (13)	Somewhat interested	67 (56)
Beliefs		Very interested	41 (35)
Preferred rheumatology staff for identifying patients with depression/anxiety		Level of interest in training for pharmacologic treatment of adolescent mental health conditions	
Attending	78 (66)	Not interested	41 (34)
Fellow	69 (58)	Somewhat interested	56 (48)
Nurse practitioner	61 (51)	Very interested	21 (18)
Physician assistant	31 (26)		
Nurse	63 (53)		
Other**	9 (8)		
No. in support of routine screening for:			
Depression, mos	101 (85)		
Every 0–3	15 (15)		

* Observations were missing (n) as follows: informal depression/anxiety screening (1), formal depression/anxiety screening (4), routine screening for anxiety (11), number of on-site referrals (1), number of off-site referrals (6), high accessibility of on-site staff (4). ** Specific responses for “Other” were social worker (6), psychologist (2), and none (1). *** Specific responses for “Other” were emergency room (2), medical social worker (1), and home (1). SLE: systemic lupus erythematosus.

adolescent mental health, and 66% for pharmacologic treatment of mental health conditions.

Perceived barriers. The rankings of perceived barriers for mental health screening and treatment are summarized in Figure 1. The 5 most frequent barriers to screening were limited staff resources to screen, limited time during the encounter, limited availability of mental health providers, limited staff resources to follow up results of screening, and lack of institutional support. The 5 most frequent barriers to treatment were long waiting lists, limited locations of mental health providers, parent/patient uncertainty about where to obtain services, time burden for patients/families, and health insurance concerns.

The results of the multivariable regression analyses for associations of pediatric rheumatologist characteristics with frequency of perceived barriers to mental health screening and treatment are presented in Table 3. Provider characteristics associated with fewer perceived barriers to mental health screening were formal postgraduate mental health training, experience treating young adults up to 24 years of age and older adults, practice location in urban settings and in Canada, and very accessible mental health staff. Provider characteristics associated with decreased frequency of perceived barriers to mental health treatment were male sex and practice location in the Midwest and in Canada.

DISCUSSION

Our cross-sectional survey provides insight into the state of mental healthcare for adolescents with SLE from the

perspective of pediatric rheumatology clinicians in North America. About half of the pediatric rheumatologists in our study perceived an unmet need for better identification and treatment of mental health problems in their practices. Given that adolescents with SLE and concurrent mental health problems are at high risk for poor disease control resulting in end-organ damage, as well as other poor outcomes as they transition into young adulthood¹⁹, our results highlight a critical need for more timely and effective mental health intervention in this population. Through examination of current practices, beliefs, perceived barriers, and associated provider characteristics, we advance our understanding of factors affecting mental healthcare for adolescents with SLE and identify potential intervention targets at the provider, practice, institution/organization, and healthcare system levels.

Effective mental healthcare relies on early identification of mental health symptoms for further evaluation and treatment. For adolescents with SLE, pediatric rheumatologists are often the most frequently seen providers and therefore an important contact point for identification². As recognized in the 2014 AAP recommendations¹³, routine depression screening is best achieved with standardized screening tools; however, only 2% of pediatric rheumatology clinicians reported routine use of a standardized instrument. This is a worrisome finding given the potential for provider, patient, and family factors to adversely influence informal identification methods. For example, patient/caregiver and provider discomfort with mental health may lead to failure

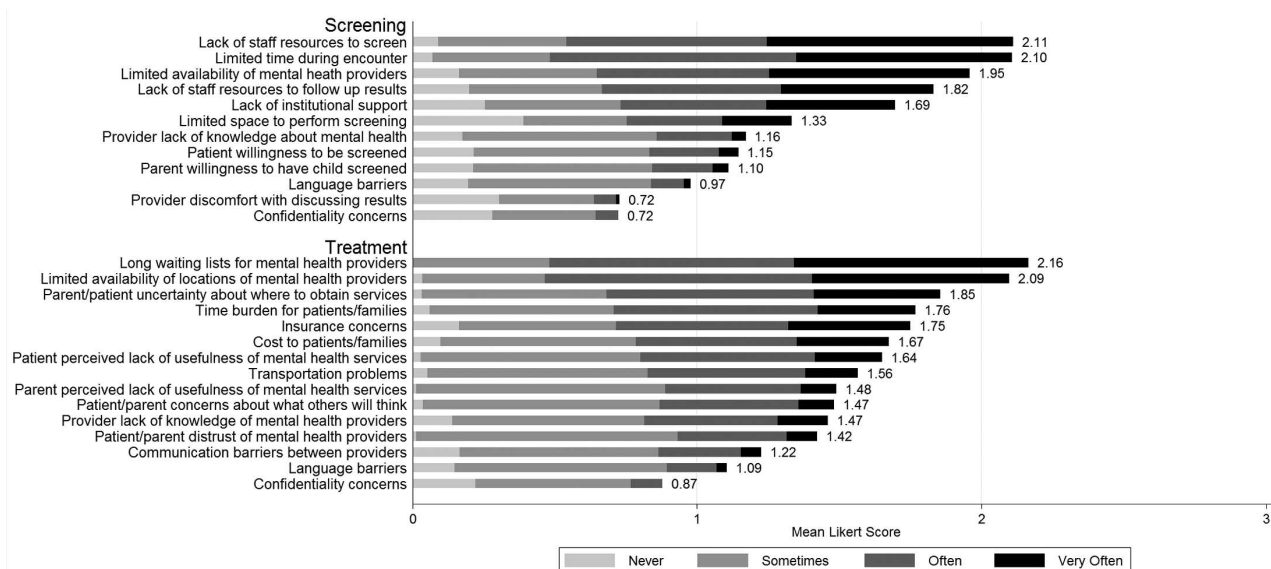


Figure 1. Barriers to mental health screening and treatment as perceived by pediatric rheumatology clinicians. Shown are perceived barriers to mental health screening and treatment ranked by mean Likert score for frequency (range 0–3), as well as the proportion of responses for each frequency rating (0 = never, 1 = sometimes, 2 = often, 3 = very often). Missing observations (n) for screening barriers include confidentiality concerns (1), lack of staff resources/time to screen (2), and patient willingness to be screened (2). Missing observations for treatment barriers include long waiting lists (1), limited availability (1), time burden (1), insurance concerns (1), cost (1), patient perceived lack of usefulness (1), patient/parent concerns about what others will think (1), provider lack of knowledge (1), patient/parent distrust (1), communication barriers between providers (1), and confidentiality concerns (1).

Table 3. Associations of pediatric rheumatologist characteristics with higher frequency of perceived barriers to mental health screening and treatment in adolescents with SLE. Shown are the coefficients with 95% CI for respondent characteristics included in the multivariable regression models for frequency of barriers to mental health screening and treatment. Reference groups are denoted by “—”.

Characteristics	Coefficient (95% CI)	
	Screening	Treatment
Sex		
Female	—	—
Male	-2.0 (-4.4 to 0.3)	-3.6 (-6.6 to -0.6)*
Level of mental health training		
None	—	—
Medical	-1.5 (-5.2 to 2.1)	2.3 (-2.4 to 6.9)
Nursing or physician assistant school	-5.4 (-12.0 to 1.3)	-5.3 (-13.8 to 3.2)
Medical residency/fellowship or other graduate level	-4.4 (-8.5 to -0.2)*	-1.3 (-6.5 to 3.9)
Age of patient population treated		
Up to 19 yrs	—	—
Up to 24 yrs	-3.3 (-5.7 to -0.9)**	-2.6 (-5.7 to 0.4)
Through adulthood	-7.8 (-14.1 to -1.6)*	-6.9 (-14.8 to 1.04)
Practice type		
University-affiliated	—	—
Private practice/hospital-affiliated	0.1 (-6.1 to 6.4)	2.4 (-5.7 to 10.6)
Practice region		
Northeast US	—	—
Midwest US	-2.7 (-5.6 to 0.2)	-3.9 (-7.6 to -0.1)*
South US	-1.4 (-4.3 to 1.4)	-0.6 (-4.2 to 3.0)
West US	-2.7 (-6.0 to 0.6)	-3.5 (-7.6 to 0.7)
Canada	-6.3 (-11.4 to -1.2)*	-9.2 (-15.5 to -2.8)**
Location		
Rural	—	—
Urban	-3.3 (-6.3 to -0.4)*	—
No. patients with SLE in practice		
< 20	—	—
20–99	3.2 (-0.3 to 6.6)	3.5 (-0.9 to 7.8)
≥ 100	2.1 (-1.6 to 5.8)	0.7 (-4.8 to 6.2)
Presence of very accessible mental health staff		
No	—	—
Yes	-3.3 (-5.5 to -1.0)**	-1.1 (-3.9 to 1.8)
No. providers	—	-0.08 (-0.5 to 0.3)

* $p < 0.05$. ** $p < 0.01$. *** $p < 0.001$. Covariates included in the screening model (number of observations = 100) were clinician sex; level of mental health training; age of patient population treated; practice type, region, and location; number of patients with SLE; and accessibility of mental health staff. Covariates included in the treatment model (number of observations = 98) were clinician sex, level of mental health training, age of patient population treated, practice type and region, number of patients with SLE, accessibility of mental health staff, and number of providers. Missing observations were dropped from the analysis. SLE: systemic lupus erythematosus.

to recognize symptoms in informal discussion. Additionally, patient/caregiver and provider cultural biases may contribute to racial/ethnic disparities in mental healthcare^{20,21}, which is of particular importance to adolescents with SLE who predominantly represent racial/ethnic minorities.

It is also notable that the frequency ratings for barriers to treatment were generally higher than those to screening. While more than 75% of clinicians indicated the presence of various on-site staff to assist with mental health issues, less than 30% indicated high accessibility of on-site psychologists, psychiatrists, and adolescent medicine providers. As recommended by the US Preventive Services Task Force, mental health screening for adolescents should be accompanied by systems to ensure accurate diagnosis, psycho-

therapy, and followup²². However, rheumatology clinicians in our sample indicated limited availability of mental health providers as a key barrier to mental health screening, as well as considerable inadequacy and variability of mental health treatment options and adolescent medicine providers. Additionally, with 64% of referrals occurring to off-site mental health providers, the highly ranked challenges of limited locations, long waiting lists, and time and cost burdens to patients/families are highly pertinent. Thus, availability and accessibility of mental health services must be improved to adequately meet the high mental health needs of this population.

Addressing both medical and mental health needs lies at the heart of providing effective, comprehensive, and

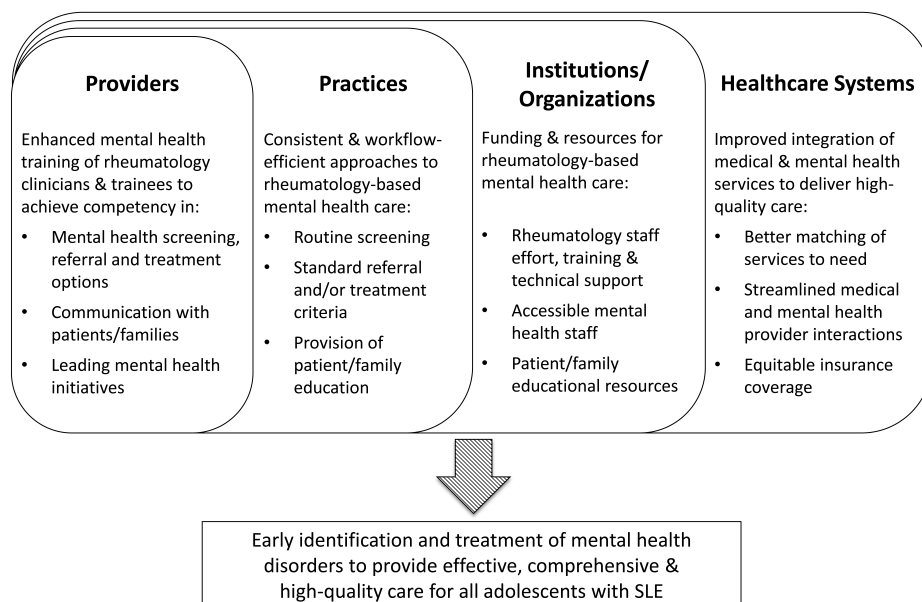


Figure 2. Potential targets for improving mental healthcare for adolescents with SLE. SLE: systemic lupus erythematosus.

high-quality care to adolescents with SLE. We combined frequency rankings and provider characteristics associated with perceived barriers to examine additional factors influencing mental healthcare for adolescents with SLE. Our analyses identify potential intervention targets at the levels of the individual provider, practice, institution/organization, and healthcare system (Figure 2).

At the provider level, our findings indicate a role for formal mental health training of pediatric rheumatology clinicians to improve competency and leadership in implementing practices for identification and referral/treatment of patients with mental health symptoms. Respondents with higher levels of formal mental health training and more experience with treating adults perceived a lower frequency of barriers to screening. Yet, two-thirds of our sample had received formal mental health training only in medical school and almost 10% reported no training at all. Interestingly, we also found that male clinician sex was associated with lower frequency of barriers to treatment. This may represent a previously described complex relationship specific to men whereby higher perceived self-competency mediates minimization of the involvement of mental health professionals, which may be modified by formal mental health training²³. Postgraduate mental health training for clinicians and ongoing experience is likely to facilitate communication between patients, families, and clinicians about mental health issues, thereby increasing clinician awareness and identification of mental health needs for adolescents with SLE, as well as enhancing knowledge and skill in using available mental health resources²⁴. Given the considerable interest in further mental health training from 91% of our sample, devel-

opment of such programs should be an educational and quality improvement priority.

At the practice level, our results call for a consistent and workflow-friendly approach to pediatric rheumatology-based mental health screening and referral/treatment. Several free, brief, validated, and standardized instruments are available for depression and anxiety screening of adolescents by pediatric rheumatologists. The AAP recommends the Patient Health Questionnaire for depression, the Kutcher Adolescent Depression Scale, and the Screen for Child Anxiety Related Emotional Disorders²⁵. Additionally, validated pediatric depression and anxiety assessment tools are publicly available through the Patient Reported Outcomes Measurement Information System²⁶. Although yearly adolescent depression screening is recommended by the AAP, screening at least every 6–12 months may be suitable for adolescents with SLE, as indicated by our survey results and by studies showing a higher frequency of depression symptoms in adolescents with SLE compared with healthy peers^{2,3}. This screening interval also parallels that recommended for adolescents with Type 1 diabetes²⁷ who have a similar depression prevalence to those with SLE²⁸.

Our respondents recognized physicians, nurse practitioners, and nurses as appropriate staff for identifying mental health problems in adolescents with SLE. Although limited staff resources and time were selected as the most frequently perceived barriers to screening, paralleling known problems of high patient load and limited workforce for pediatric rheumatology clinicians²⁹, these challenges are not insurmountable because routine depression screening has been successfully implemented in other pediatric subspecialty

settings. Drawing on a successful model for depression screening in outpatient adolescents with Type 1 diabetes³⁰, key components of pediatric rheumatology-based mental health intervention would include (1) integration of consistent screening processes into the clinic work flow and electronic health record, (2) effective communication among families, clinic staff, and providers to promote awareness and acceptance of mental health screening, and (3) ensuring adequate social work and psychology referral resources.

Integrating mental healthcare in pediatric rheumatology practices could help ensure availability of adequate mental health resources. Evidence supports the efficacy and cost-effectiveness of collaborative care models for improving mental health treatment rates and outcomes in outpatient primary and specialty care settings^{14,31}. Although most of our sample did not prefer the rheumatology clinic for mental health treatment, this may reflect the current lack of accessible on-site mental health professionals, and access to these additional personnel may become particularly relevant if mental health referrals increase because of improved detection of mental health problems. Using existing resources by involving on-site medical social workers, adolescent medicine clinicians, and child life specialists in the management of mental health issues may make collaborative care more acceptable and attainable in pediatric rheumatology. Further, the use of innovative modes of mental health treatment delivery such as Web-based cognitive behavioral therapy programs for adolescent depression and anxiety may also improve accessibility and decrease cost of mental health interventions^{32,33}. More research is therefore needed to determine the optimal models for pediatric rheumatology.

At the institution/organization level, implementation of pediatric rheumatology-based mental health intervention may be facilitated by funding and resources from healthcare institutions as well as organizations for clinicians and patients/families. Institutional support from hospital administrators may enable rheumatology staff effort and provide accessible mental health staff. Organizations may provide training and technical support for mental health intervention, and educational resources for patients and families. The American Board of Pediatrics provides a Web-based depression screening performance improvement module, available to pediatric rheumatologists as part of its maintenance of certification program. The AAP also offers Web-based resources for tools and implementation strategies to support improvement in behavioral health screening. The Lupus Foundation of America also has Web-based resources for patient education on mental health. Further, collaborative research and quality improvement efforts through the CARRA, the Pediatric Rheumatology Care and Outcomes Improvement Network, the Patients, Advocates, and Rheumatology Teams Network for Research and Service, and the American College of Rheumatology may provide national platforms for development and implementation of

standard pediatric rheumatology-based mental health intervention.

At the healthcare system level, improved integration of medical and mental health services is likely to result in a higher quality of care for adolescents with complex medical conditions such as SLE. We observed that respondents practicing in urban locations, the midwestern United States, and Canada perceived fewer barriers to mental healthcare, possibly reflecting better systems for matching need to services in these areas. Recent national data indicate that compared with states in other US regions, midwestern states have some of the highest ratios of access to need for mental health services, as well as higher rates of youth with health insurance coverage³⁴. Regarding differences between the United States and Canada, physician-provided mental healthcare is universally covered in Canada and patients at hospital-based subspecialties, such as pediatric rheumatology, also receive coverage for non-physician mental healthcare providers in these settings³⁵. This contrasts with the highly fragmented system of mental health coverage in the United States, which may lead to greater mismatches of need and access to care. Although there were no associations of barriers with patient insurance type, the survey did not identify the complexities of medical and mental health coverage from our data. Achieving change in regional services availability and insurance coverage within healthcare systems is challenging, but improving communication and collaboration between pediatric rheumatologists and mental healthcare providers is a reasonable initial step.

There are several limitations to our study. First, our results may have limited generalizability because of the 35% survey response rate. However, our respondent demographics closely parallel those of the CARRA membership, and their experiences are likely representative of the current mental health environment of pediatric rheumatology in North America. Second, self-selection bias may have led to skewing of our results if respondents perceive mental healthcare as more important compared to nonrespondents. Third, information bias may exist because of social desirability if respondents provided expected responses rather than their true perceptions, although this was likely minimized by the anonymous design of the survey. Fourth, the predetermined survey response options may not represent the breadth of respondent views; further mixed methods investigation may yield additional information. Finally, our study is limited to the perspectives of pediatric rheumatologists. Other perspectives from patients and families, nurses, social workers, behavioral health professionals, primary care providers, administrators, and insurers are needed to develop interventional strategies to improve mental healthcare for adolescents with SLE; these studies are currently under development.

The results of our study illustrate the challenges encountered by pediatric rheumatologists in caring for the mental health needs of adolescents with SLE. Potential strategies to

overcome multilevel barriers include enhanced mental health training for pediatric rheumatologists, standardized pediatric rheumatology-based mental health practices, and better integration of medical and mental health services. There is a need for collaborative efforts by pediatric rheumatologists through national organizations such as the CARRA to develop standard practices for mental health intervention toward achieving the goal of effective, comprehensive, and quality care for all adolescents with SLE.

APPENDIX 1.

List of study collaborators. The following are members of the Childhood Arthritis and Rheumatology Research Alliance (CARRA) Systemic Lupus Erythematosus Mental Health Workgroup: Rina Mina, Kasha Wiley, Amit Thakral, Martha Rodriguez, Janet Orrock, Sarah Hoffman, Norman Ilowite, Jessica Neely, Judyann Olson, A. Martyniuk, Aimee Hersh, Judith Barlin, and Tracey Wright.

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REFERENCES

- Cassidy JT. Textbook of pediatric rheumatology, 6th ed. Philadelphia: Saunders/Elsevier; 2011.
- Knight A, Weiss P, Morales K, Gerdes M, Gutstein A, Vickery M, et al. Depression and anxiety and their association with healthcare utilization in pediatric lupus and mixed connective tissue disease patients: a cross-sectional study. *Pediatr Rheumatol Online J* 2014;12:42.
- Jones JT, Cunningham N, Kashikar-Zuck S, Brunner HI. Pain, fatigue and psychological impact on health-related quality of life in childhood-onset lupus. *Arthritis Care Res* 2016;68:73-80.
- Bernstein CM, Stockwell MS, Gallagher MP, Rosenthal SL, Soren K. Mental health issues in adolescents and young adults with type 1 diabetes: prevalence and impact on glycemic control. *Clin Pediatr* 2013;52:10-5.
- Bitsko MJ, Everhart RS, Rubin BK. The adolescent with asthma. *Paediatr Respir Rev* 2014;15:146-53.
- Calsbeek H, Rijken M, Bekkers MJ, Dekker J, van Berge Henegouwen GP. School and leisure activities in adolescents and young adults with chronic digestive disorders: impact of burden of disease. *Int J Behav Med* 2006;13:121-30.
- Reigada LC, Bruzzese JM, Benkov KJ, Levy J, Waxman AR, Petkova E, et al. Illness-specific anxiety: implications for functioning and utilization of medical services in adolescents with inflammatory bowel disease. *J Spec Pediatr Nurs* 2011;16:207-15.
- Julian LJ, Yelin E, Yazdany J, Panopalis P, Trupin L, Criswell LA, et al. Depression, medication adherence, and service utilization in systemic lupus erythematosus. *Arthritis Rheum* 2009;61:240-6.
- Nery FG, Borba EF, Hatch JP, Soares JC, Bonfa E, Neto FL. Major depressive disorder and disease activity in systemic lupus erythematosus. *Compr Psychiatry* 2007;48:14-9.
- Bachen EA, Chesney MA, Criswell LA. Prevalence of mood and anxiety disorders in women with systemic lupus erythematosus. *Arthritis Rheum* 2009;61:822-9.
- Panopalis P, Yazdany J, Gillis JZ, Julian L, Trupin L, Hersh AO, et al. Health care costs and costs associated with changes in work productivity among persons with systemic lupus erythematosus. *Arthritis Rheum* 2008;59:1788-95.
- Panopalis P, Gillis JZ, Yazdany J, Trupin L, Hersh A, Julian L, et al. Frequent use of the emergency department among persons with systemic lupus erythematosus. *Arthritis Care Res* 2010;62:401-8.
- American Academy of Pediatrics. Recommendations for preventive pediatric health care. [Internet. Accessed February 19, 2016.] Available from: www.aap.org/en-us/professional-resources/practice-support/Periodicity/Periodicity%20Schedule_FINAL.pdf
- Kolko DJ, Campo J, Kilbourne AM, Hart J, Sakolsky D, Wisniewski S. Collaborative care outcomes for pediatric behavioral health problems: a cluster randomized trial. *Pediatrics* 2014;133:e981-92.
- Zenlea IS, Milliren CE, Mednick L, Rhodes ET. Depression screening in adolescents in the United States: a national study of ambulatory office-based practice. *Acad Pediatr* 2014;14:186-91.
- Flisher AJ, Kramer RA, Grosser RC, Alegria M, Bird HR, Bourdon KH, et al. Correlates of unmet need for mental health services by children and adolescents. *Psychol Med* 1997;27:1145-54.
- Gunn WB Jr, Blount A. Primary care mental health: a new frontier for psychology. *J Clin Psychol* 2009;65:235-52.
- Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)—a metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform* 2009;42:377-81.
- Felsenstein S, Reiff AO, Ramanathan A. Transition of care and health-related outcomes in pediatric-onset systemic lupus erythematosus. *Arthritis Care Res* 2015;67:1521-8.
- Meyer OL, Saw A, Cho YI, Fancher TL. Disparities in assessment, treatment, and recommendations for specialty mental health care: patient reports of medical provider behavior. *Health Serv Res* 2015;50:750-67.
- Alegria M, Vallas M, Pumariega AJ. Racial and ethnic disparities in pediatric mental health. *Child Adolesc Psychiatr Clin N Am* 2010;19:759-74.
- US Preventive Services Task Force. Screening and treatment for major depressive disorder in children and adolescents: US Preventive Services Task Force Recommendation Statement. *Pediatrics* 2009;123:1223-8.
- Graham RD, Rudd MD, Bryan CJ. Primary care providers' views regarding assessing and treating suicidal patients. *Suicide Life Threat Behav* 2011;41:614-23.
- Garcia-Ortega I, Kadlec H, Kutcher S, Hollander M, Kallstrom L, Mazowita G. Program evaluation of a child and youth mental health training program for family physicians in British Columbia. *J Can Acad Child Adolesc Psychiatry* 2013;22:296-302.
- American Academy of Pediatrics. Mental health screening and assessment tools for primary care. [Internet. Accessed February 19, 2016.] Available from: www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Mental-Health/Documents/MH_ScreeningChart.pdf
- PROMIS. PROMIS for clinicians. [Internet. Accessed February 19, 2016.] Available from: www.nihpromis.org/Clinicians/InClinicians
- Chiang JL, Kirkman MS, Laffel LM, Peters AL; Type 1 Diabetes Sourcebook Authors. Type 1 diabetes through the life span: a position statement of the American Diabetes Association. *Diabetes Care* 2014;37:2034-54.
- Knight A, Weiss P, Morales K, Gerdes M, Reardon M, Vickery M, et al. Identifying differences in risk factors for depression and anxiety in pediatric chronic disease: a matched cross-sectional study of youth with lupus/mixed connective tissue disease and their peers with diabetes. *J Pediatr* 2015;167:1397-403.e1.
- Althouse LA, Stockman JA 3rd. Pediatric workforce: a look at pediatric rheumatology data from the American Board of Pediatrics. *J Pediatr* 2006;149:869-70.
- Corathers SD, Kichler J, Jones NH, Houchen A, Jolly M, Morwessel N, et al. Improving depression screening for adolescents with type 1 diabetes. *Pediatrics* 2013;132:e1395-402.
- Woltmann E, Grogan-Kaylor A, Perron B, Georges H, Kilbourne

- AM, Bauer MS. Comparative effectiveness of collaborative chronic care models for mental health conditions across primary, specialty, and behavioral health care settings: systematic review and meta-analysis. *Am J Psychiatry* 2012;169:790-804.
32. Brown RT, Shaftman SR, Tilley BC, Anthony KK, Kral MC, Maxson B, et al. The health education for lupus study: a randomized controlled cognitive-behavioral intervention targeting psychosocial adjustment and quality of life in adolescent females with systemic lupus erythematosus. *Am J Med Sci* 2012;344:274-82.
33. Clarke AM, Kuosmanen T, Barry MM. A systematic review of online youth mental health promotion and prevention interventions. *J Youth Adolesc* 2015;44:90-113.
34. Mental Health America. Parity or disparity: the state of mental health in America 2015. [Internet. Accessed February 19, 2016.] Available from: [www.mentalhealthamerica.net/sites/default/files/Parity or Disparity Report FINAL.pdf](http://www.mentalhealthamerica.net/sites/default/files/Parity%20or%20Disparity%20Report%20FINAL.pdf)
35. The Commonwealth Fund. 2014 international profiles of health care systems. [Internet. Accessed February 19, 2016.] Available from: www.commonwealthfund.org/~media/files/publications/fund-report/2015/jan/1802_mossialos_intl_profiles_2014_v7.pdf