Editorial

Comprehensive Care in Pediatric Rheumatic Diseases: A Multifaceted Challenge

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Behavior is the most influential predictor for developing a medical condition and subsequently accounts for 40% of premature deaths¹. Thus, simplistic approaches to complex health conditions are no longer viable or effective in producing optimal treatment outcomes. Successful psychological interventions have repeatedly demonstrated their profound effect on illness prevention, reduction of disease severity, and improved health-related quality of life². Examples include cognitive behavioral therapy and acceptance and commitment therapy for pain, behavioral interventions to increase healthy lifestyle habits to treat obesity, and self-management support to increase treatment adherence. Despite decades of research, clinical anecdotes, and the World Health Organization's biopsychosocial definition of health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity,"³ the lack of integrated care models across institutions perpetuates the dearth of behavioral healthcare, contributing to disease morbidity and mortality.

Although society is shifting toward biopsychosocial health-care approaches, the dualistic mind-body doctrine underlying the biomedical model remains ever-present⁴. The number of epidemics (e.g., obesity, diabetes, addiction) that continue to plague the United States, coupled with the generally lower level of US National Institutes of Health funding appropriated to mental health and pediatric institutes (e.g., National Institute of Mental Health, National Institute of Child Health and Human Development), are testaments to these systemic issues. It is of

the utmost importance that comprehensive care is provided to promote quality of life for patients and the individuals affected and/or involved in care, particularly in pediatric health conditions^{5,6,7}. However, despite dissemination of research, the translation and application into clinical care often lags behind, leaving many families with unmet needs.

Providing well-rounded treatment for health conditions must be multifaceted⁸, hence the recent trend for multidisciplinary clinics. Yet, what remains less well-integrated is the presence of psychosocial expertise within specialty clinics (e.g., pediatric rheumatology). The factors that contribute to illness prognosis, implementation of and barriers to pediatric self-management, vary across stages of development and involve different people (e.g., parents, teachers, coaches⁷). The Pediatric Self-Management Model provides a systematic approach to self-management and the roles of each person involved. This aspirational model further highlights the importance of proactive behavioral healthcare and the efforts needed to increase this initiative in our healthcare system⁷.

In this issue of *The Journal*, Rubinstein, *et al* sought to develop a prioritized research agenda on the mental health needs of youth diagnosed with rheumatic diseases⁹. The authors [members of the Childhood Arthritis and Rheumatology Research Alliance (CARRA) Mental Health Workgroup], used their previous work^{10,11} to highlight comorbid "mental health" areas in the extant pediatric rheumatology literature that warrant further attention and development. The study had several strengths including identification and prioritization of mental health gaps in the literature and an attempt to gain input from patients, parents, and providers on the "importance, feasibility, and actionability" for each mental health domain and domain items. The study also had several limitations, most notably the small sample size ($N = 59$). Patients and mental health providers were considerably underrepresented ($n = 4$ and $n = 3$, respectively). Unfortunately, the inadequate representation of mental health providers is not unique to this study, despite the growing number of pediatric psychologists in the medical field who focus on behavioral health care for chil-

This work was supported by a US National Institutes of Health grant (T32 HD068223).

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dren and families affected by chronic conditions and other health-related issues.

The study participants and findings address the disconnect between research promoting the importance of integrated care and the reality of what is being implemented and the resources available^{12,13}. For example, the authors call for disease-specific mental health screeners. Yet, there are several validated psychosocial screeners and measures of adjustment for pediatric chronic illness broadly, as well as for rheumatic diseases [e.g., Patient-Reported Outcomes Measurement Information System (PROMIS scales)¹⁴, Pediatric Quality of Life Inventory (PEDS-QL Rheumatology¹⁵)]. Generic behavioral assessments that can be used across chronic conditions are often appropriate, because despite the biological differences in specific illness conditions, the psychosocial experiences and effects are often similar. To the authors' point, indeed, rheumatic disease-specific measures have been beneficial in juvenile idiopathic arthritis and systemic lupus erythematosus, but there are also promising measures for rheumatic diseases collectively and other subgroups that exist¹⁶. Standardized care is vital to enhance the number of patients receiving quality health services, as is the importance of tailoring care to the needs of the individual. Thus, the concept of illness-specific mental health screeners is valuable, but may not be necessary in all cases, particularly when extant generic assessment tools can be applied appropriately.

Research indicates that youth with chronic health conditions are at risk for poor psychosocial adjustment; in pediatric rheumatic conditions, anxiety and depressive symptoms appear to be the most common¹⁷. Thus it is not unusual for screeners of depressive and anxiety symptoms and/or disorders to be non-illness-specific because they are assessing symptoms of mental health that do not discriminate by condition. It is more important that information on psychosocial contributors to pediatric rheumatic conditions and use of developmentally appropriate measures be incorporated into rheumatology clinics, than ensuring that they are disease- and subtype-specific. Additional inquiries can be made based on items endorsed as necessary. Further, there are many free self- and proxy-report psychosocial screeners that can be given to caregivers and patients (e.g., Patient Health Questionnaire 9-item scale¹⁸, Psychosocial Assessment Tool¹⁹, PEDS-QL generic and Rheumatology¹⁵, PROMIS;¹⁴ see Thabrew, *et al*²⁰ for a comprehensive review). Given the downstream effect parental adjustment typically has on child adjustment, it is equally as important to screen caregivers of patients²¹. In sum, there are developmentally appropriate assessment tools readily accessible, a number of which are validated cross-culturally and available in multiple languages and conditions.

Understandably, priorities of care remain heavily focused on medical provision, but often neglect behavioral healthcare provision. Hopefully, as we progress so will the incorporation of psychosocial education and screeners into standard care as a requirement for all hospitals and clinics. Unfortunately, the number of medical professionals who are well versed in the

psychosocial literature supporting these initiatives is limited. This underscores the importance of multidisciplinary team members when providing care to a patient.

Two related factors relevant to improving behavioral healthcare in subspecialty clinics are board certification and training. The American Board of Pediatrics Specialty Board Examination for Rheumatologists dedicates only 2% of the examination to competency on psychosocial, developmental, and educational issues²². This is reflective of the training focus and indicative of the inherent challenge that exists within pediatric rheumatology (as well as other subspecialty care). Efforts needed to provide better multidisciplinary care include direct behavioral healthcare provision, enhanced training on behavioral healthcare issues so medical providers feel equipped to assess and refer to psychologists or other mental health providers as necessary, and additional institutional resources to allow this shift in care to be made.

Incorporating biopsychosocial models of illness across training and subspecialties would further improve quality of care. For example, well-known models of adjustment including Thompson and Gustafson's Transactional Stress and Coping Model²³ and the Pediatric Psychosocial Preventative Health Model²⁴ provide biopsychosocial conceptualizations of adjustment to chronic conditions from a systems perspective. These models should not only be taught to professionals but also provided to patients to assist in their psychoeducation and empowerment. Thankfully, attempts to address training deficits have begun, most notably in primary care physicians receiving intensive tutelage in integrated health²⁵. Additionally, medical schools are beginning to incorporate formal training in these areas, which should have longterm positive effects on patient care. The goal of training is primarily to raise awareness and improve care through recognition of problems. However, integrated care should remain the goal to which all providers aspire because it offers the best and most comprehensive level of care provision.

The specific mental health areas that Rubinstein, *et al*'s study highlighted as the most important, actionable, and feasible were (1) determining prevalence and incidence rates of mental health disorders in pediatric rheumatic diseases, (2) determining which are most important to screen for, (3) determining the validity of pediatric rheumatological screeners, and (4) identifying the barriers and facilitators to incorporating mental health screening into pediatric rheumatology settings⁹. We offer the following additional components as recommended priorities: (1) behavioral health training on the interaction between behavioral and medical health, (2) increasing opportunities for patients and families to receive integrated care, (3) administering psychosocial screeners to caregivers and patients that target internalizing symptoms and disorders using existing validated mental health screeners representing both pediatric rheumatology-specific and generic assessment tools, (4) addressing subclinical psychological symptoms as a means of preventive and proactive care, and (5) a system to facilitate referrals to appropriate behavioral

health providers if a pediatric psychologist cannot be integrated with the specialty care team.

This editorial is not intended to offer an all-inclusive overview of issues related to providing comprehensive care, but rather to highlight barriers and recent progress, and provide resources to readers invested in improving the quality of life for youth with rheumatic conditions and their families. Rubinstein and colleagues provide valuable insight into much larger systematic issues and initial calls for action⁹. The authors displayed great initiative by highlighting the importance of multidisciplinary care for pediatric rheumatic diseases, quantifying specific areas that should be prioritized, and providing next steps for researchers and clinicians to address these gaps moving forward. It is our hope that these additional recommendations are also considered.

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