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Building a Viable Telemedicine Presence in Pediatric Rheumatology

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Pediatric rheumatology access; Telemedicine in pediatric rheumatology; Clinical examination telemedicine

In pediatric rheumatology, patient access to certified providers is a troubling issue. The Arthritis Foundation estimates that approximately 300,000 children in the United States have juvenile idiopathic arthritis (JIA), but notes that there are fewer than 400 board-certified and practicing pediatric rheumatologists.¹ There are presently 9 states (including Alaska, Idaho, Montana, New Hampshire, Oklahoma, South Dakota, Wyoming and West Virginia) that are without any full-time pediatric rheumatology providers (Fig. 1).^{2,3} The American Academy of Pediatrics Division of Workforce and Medical Education Policy notes that most pediatric subspecialists are working in urban areas, at academic centers, with median wait times that may exceed 2 weeks for some specialties.⁴ In pediatric rheumatology, this means that patients are traveling an average of 92 km (57 miles)⁵ to see their provider, compared with 40 km (25 miles) for patients followed in other pediatric subspecialties, and up to a quarter of adult rheumatologists care for pediatric patients with rheumatologic needs.⁶ This finding represents a considerable gap in access because most pediatric rheumatic diseases are chronic cyclic conditions. With respect to patient adoption of telemedicine, another study in pediatric rheumatology reported that, even though 28% of clinic patients traveled greater than 3 hours to see their pediatric rheumatology providers, most (95%) patients reported preference for in-person clinical visits rather than telemedicine visits. However, patient familiarity with telemedicine as a clinical tool did increase the preference for telemedicine visits.⁷ Before telemedicine practices can be adopted as a routine part of pediatric rheumatology care, providers and patients need to clearly understand its strengths and limitations as a tool for health care. For providers, this includes research that results in standardization of telemedicine practices, including (1) specification of patients appropriate for telemedicine follow-up, and (2) clinical guidelines for conducting appropriate and complete video examinations. For patients and their families, this may include education

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around telemedicine and planning for incorporating telemedicine as part of their routine chronic disease management.

Standardizing telemedicine clinical practice in pediatric rheumatology still needs to be done to ensure appropriate and comprehensive care is given to patients with chronic disease, as well as providing standardized workflows that can support governmental initiatives and policies surrounding telehealth. In order to address the provider-specific issues related to telemedicine, the key issues that have limited its adoption as a part of pediatric chronic disease management have begun to be unpacked.

The pediatric rheumatology group at Stanford Children's has already begun to study this problem and is in the first part of a multiphase pilot study that addresses the clinical gaps involved in pediatric rheumatology provider-patient video visits. Based on expert input, we have identified barriers to adoption of telemedicine that surround the components of the in-person clinic visit experience, including but not limited to (1) the rheumatologic physical examination, (2) the vital signs, (3) modes of communication between provider and patient, (4) the need for immediate laboratory work or imaging, and (5) the need for nursing or social work support. The first phase of the study used expert clinical opinion with modified Delphi methodology⁸ to establish what is standard of practice and essential to clinical practice in routine, follow-up, in-person appointments for patients with either JIA or systemic lupus erythematosus (SLE). The reason for selection for patients with these diagnoses is that (1) they are the most commonly treated diagnoses in pediatric rheumatology clinical practice, and (2) they differ in terms of clinical assessment of disease activity. For example, in SLE, a patient may not have overt clinical symptoms of active disease but may have laboratory features that suggest otherwise, whereas a patient with JIA may have completely normal laboratory tests but a large swollen knee. This process included independent ratings of a 16-item survey on present clinical practices by a panel of 4 attending pediatric rheumatologists at Stanford Children's Health, followed by a face-to-face meeting to reach consensus regarding those survey items that did not reach at least 75% consensus (per item) in the written survey. Each item that had not reached consensus in the initial written survey was reviewed and discussed, and consensus for all survey items was reached in the first round of discussion. As shown in Box 1, immediate access to clinic resources such as laboratory, social work, nursing, and imaging is convenient to have but not necessary for most of our follow-up patients with JIA or SLE. Furthermore, the essential examination components that help determine disease activity, disease progression, or medication side effects vary depending on the diagnosis and characteristics of the individual patient's disease. For example, a patient with known JIA and uveitis needs regular eye examinations. The slit-lamp examination is critical for monitoring uveitis activity; however, it is within routine practice for rheumatologists to conduct a basic ophthalmologic examination because chronic changes may be visible without slit-lamp. The essential components for a rheumatologic clinical examination are featured in Box 1.

The next steps of this study are to use the clinical framework outlined in Box 1 and develop a checklist, that will be used to directly compare follow-up video visits and follow-up in-person visits in the Stanford Children's pediatric rheumatology clinics. We hypothesize that 75% of the essential clinical standard practice (including examination) will be completed

in the telemedicine visits. Ultimately, we will be able to measure these differences and understand the specific limitations of patient-provider video visits, such as effectiveness for urgent problems that come up unexpectedly. Understanding the differences between both types of clinical visits will (1) help determine solutions toward potential examination limitations, (2) provide a framework that can be used to standardize video visits, (3) understand the necessary education for patients around video visits, (4) improve provider clinical support and education regarding telemedicine visits, and (5) further governmental policy or insurance practices regarding telemedicine reimbursement.

If pediatric rheumatologists can better understand what is essential and nonessential in an in-person clinic visit, they can better understand the potential limitations in the use of telemedicine for chronic disease management and work toward solutions that continue to increase access and improve medical decision making in telemedicine.

The study described earlier and preliminary data show the need for additional research in telemedicine in pediatric rheumatology care. Only by understanding how to optimally use technologic tools can clinicians improve the delivery of medical care for patients with chronic disease. Telemedicine in pediatric rheumatology care can serve as a model for other pediatric subspecialties requiring chronic disease management. Studies could be conducted in other subspecialties, because the necessary clinical components for successful follow-up visits may vary widely. Telemedicine has the potential to be a critical component in pediatric chronic care, and it is the responsibility of clinicians to understand how best to use it for their patients.

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KEY POINTS

- This article describes issues in patient access to pediatric rheumatologic care and the potential use of telemedicine in pediatric rheumatology. It also describes the necessary components of clinical exams in pediatric rheumatology.

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Box 1**Necessary clinical components for pediatric rheumatology visits***Essential components for SLE follow-up visit*

Vitals: temperature, blood pressure, weight

Examination:

Focused ear, nose, and throat examination

Lung examination

Cardiac examination

Abdominal examination

Skin examination

MSK/joint examination: general upper extremities and lower extremities

Laboratory tests:

Laboratory tests are necessary to determine level of disease activity

Laboratory tests are not necessary at the time of the clinical visit but are needed for that encounter

Imaging

Imaging is not required at time of the visit in greater than 50% of patients with SLE

Essential components for JIA^a follow-up visit

Vitals: weight

Examination

Lung examination

Cardiac examination

Abdominal examination

MSK/joint examination including:

Temporomandibular joint

Spine/sacroiliac joints

Upper extremities

Lower extremities

Leg length

Gait

Ophthalmologic examination^b

Laboratory tests:

Laboratory tests are not necessary to determine level of disease activity

Laboratory tests are not necessary at the time of the clinical visit, but may be needed for that encounter (ie, drug toxicity monitoring)

Imaging

Imaging is not required at the time of the visit in more than 50% of patients with SLE

Abbreviation: MSK, musculoskeletal.

^aIf systemic JIA, need blood pressure, temperature, and weight.

^bFor known iritis, need documentation from ophthalmologist within last 3 months.

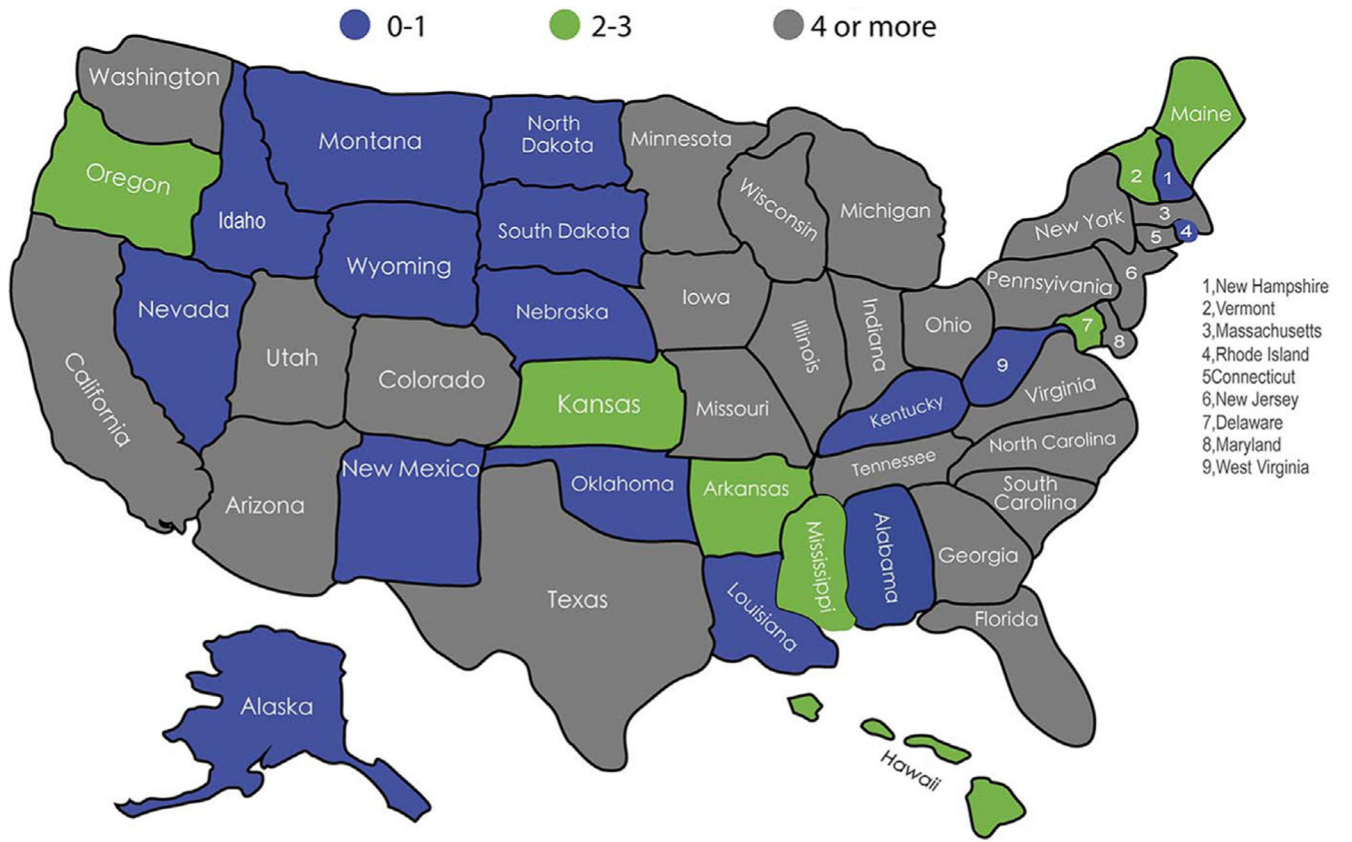


Fig. 1.
Number of pediatric rheumatologists by state.