# Prescribing for Children With Rheumatic Disease: Perceived Treatment Approaches Between Pediatric and Adult Rheumatologists

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Objective. To compare practice patterns and prescribing differences for juvenile idiopathic arthritis (JIA) between adult rheumatologists (ARs) and pediatric rheumatologists (PRs), the perceived educational needs, and factors that enhance or impede co-management.

Methods. Two parallel, cross-sectional surveys focusing on JIA were administered in 2009 to a random sample of 193 PRs and 500 ARs using the American College of Rheumatology membership file. Bivariate analysis was conducted for common items.

Results. The response rate was 62.1% for ARs (n = 306) and 72.3% for PRs (n = 138). Only 23% of responding ARs (n = 69) reported caring for children with JIA. Of these, 94% strongly agreed/agreed feeling comfortable diagnosing JIA; however, only 76% felt comfortable treating JIA. Clinical vignettes highlighted several prescribing differences. Forty-eight percent of ARs and 31% of PRs felt medications to treat JIA did not have clear dosing guidelines. Though PRs initiated disease-modifying antirheumatic drugs and biologic agents earlier, treatments were similar after 3 months. To enhance co-management, 74% of pediatric respondents endorsed shared medical records.

Conclusion. Nearly one-quarter of surveyed ARs care for children with JIA, with most limiting their practice to older children. There was more discomfort in treating JIA than diagnosing it, and there were significant prescribing differences. Both provider types identified the need for better dosing and treatment resources. Updated management guidelines along with exposure to pediatric rheumatology in fellowship could reduce treatment differences and enhance the care of children with JIA. Shared medical records and improvement in reimbursement may optimize co-management.

### INTRODUCTION

Rheumatologic diseases of childhood affect 300,000 children in the US and are associated with significant morbidity (1,2). For providers, pediatric rheumatology patients present unique challenges that are related to the rarity of these conditions and their variable presentation and disease course. Due to the national shortage of pediatric rheumatologists (PRs) (2), an estimated half of US children with rheumatologic disease are being cared for by adult rheumatologists (ARs) (2,3). Treatments for pediatric

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rheumatologic diseases have evolved substantially over the past few decades, resulting in decreased morbidity and mortality and also higher demands on providers for monitoring newer, higher-risk medications (4–7). However, many ARs (8) and primary care providers (9) who treat children report being uncomfortable caring for childhood rheumatologic disease patients and do not perceive themselves as up to date on the current pediatric treatments. It is not known how variations in treatment selection and dosing relate to subspecialty (pediatric versus adult rheumatology), fellowship training, and information resources.

To explore these issues, we conducted a national survey of ARs and PRs, with the following specific aims: 1) compare AR and PR current practice patterns for children with rheumatologic disease, including choice of medications, 2) compare the current and preferred resources used by ARs and PRs in caring for children with rheumatologic conditions, and 3) describe factors that enhance or impede effective co-management of pediatric rheumatology patients between ARs and PRs.

# MATERIALS AND METHODS

This cross-sectional, self-administered mail survey was conducted with a national sample of ARs and PRs in the

# Significance & Innovations

- To our knowledge, these results provide the first detailed national description of treatment choices among adult rheumatologists who report caring for children with juvenile idiopathic arthritis.
- The clinical vignettes used in this survey study highlight important differences in treatment patterns, both for initial and refractory cases, between pediatric and adult rheumatologists and demonstrate significant prescribing differences between adult rheumatologists with and without training from a pediatric rheumatologist.
- While the lack of pediatric rheumatologists is cited as a common reason for adult providers caring for children, this study suggests factors other than just distance to a pediatric provider may be impacting access to care.

US and was approved by the University of Michigan Institutional Review Board. This study was carried out in compliance with the Helsinki Declaration. From the American College of Rheumatology (ACR) membership file, we selected all 193 PRs and a random sample of 500 ARs with US addresses.

Survey instrument and administration. We developed and refined 2 parallel surveys, 1 for ARs and 1 for PRs, to reflect the different nature of their practices in regards to pediatric patients. The survey focused on juvenile idiopathic arthritis (JIA), the most common rheumatologic condition in children. Specific survey items were drawn from the published literature on treatments for JIA and the pediatric rheumatology workforce, as well as the principal investigator's (HVM) clinical practice.

Items included on both the pediatric and adult surveys were study eligibility (i.e., provision of care for children age <18 years with JIA), number of pediatric rheumatology patients seen in the outpatient and inpatient settings, practice patterns related to the treatment of various subtypes of JIA (explored via 4 case vignettes), resources utilized when making treatment decisions, practice setting, and year of residency completion.

Items included only on the adult survey were limitations in outpatient practice by patient age or diagnosis; attitudes related to comfort in diagnosing and treating JIA, factors influencing decisions to treat children, and adequacy of resources to treat children with JIA; information needs related to caring for children with JIA; patterns for referral of JIA patients to PRs; and extent of pediatric training during rheumatology fellowship. Items included only on the pediatric survey were attitudes related to appropriateness of JIA referrals and barriers to treatment and practice patterns and preferences related to co-management of JIA patients with ARs.

Survey questions encompassed a variety of formats, including Likert scales, fixed-choice response items, and open-response items; formats were tailored to question

type and content. Questions were pilot tested with a convenience sample of physicians to assess clarity and ease of administration, and revisions were made based on pilot test feedback. The survey instruments are provided in Supplementary Appendix A (available on the *Arthritis Care & Research* web site at http://onlinelibrary.wiley.com/doi/10.1002/acr.23273/abstract).

The survey mailings included a personalized cover letter inviting participation, and a postage-paid reply envelope. The initial mailing was sent in March 2009 and included a \$2 cash incentive. After 5 weeks, a second mailing was sent to nonrespondents.

Data analysis. Survey responses were coded, entered, and verified. Only those respondents who reported providing care to children ages 0–17 years with JIA were eligible for further analysis. For this group, we generated frequency distributions and conducted bivariate analysis using a likelihood chi-square test; *P* values less than 0.05 were considered statistically significant. For items common to both surveys, bivariate analyses compared ARs and PRs. Analysis of the clinical vignettes included only those ARs who reported caring for children in the age range described in the vignette, as our intention was to report the treatment choices of those who actually provide care in the case described. Additional bivariate analyses were conducted for items specific to adult and to pediatric surveys. All analyses were conducted using SAS, version 9.1.

#### **RESULTS**

Of the 693 surveys mailed, 444 were returned, while 9 were undeliverable, for a 64.9% response rate; the response rate was 62.1% for ARs (n = 306) and 72.3% for PRs (n = 138). Only 23% of responding ARs (n = 69), but 93% of PRs (n = 128), reported that they provide direct patient care for children ages 0–17 years with JIA and were eligible for subsequent analyses.

Characteristics of eligible respondents. Table 1 presents characteristics of the 197 eligible respondents. With respect to practice setting, PRs were concentrated in academic medical centers, while more ARs practiced in private clinics. The majority of ARs (64%) limited their practice based on patient age; in addition, 4% limited their practice by diagnosis, excluding children with systemic lupus erythematosus/connective tissue disease. Of those who limit their practice by patient age, 58% only treat children ages >10 years (Table 1), with a very small minority seeing children ages <6 years. Just under half of adult respondents (49%) were listed with a pediatric designation in the ACR membership directory. ARs practicing more than 50 miles from a PR were more likely to not place age limits for their pediatric practice compared to those within 50 miles (68% versus 32%; P = 0.001).

Attitudes of ARs about JIA care. Of ARs who reported caring for pediatric patients with JIA, 94% strongly agreed/agreed that they are comfortable diagnosing JIA in children. However, only 76% report being comfortable treating JIA, and 72% felt they were up to date on the

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	Adult rheumatologists $(n = 69)$	Pediatric rheumatologists (n = 128)
Practice setting, %		
Academic center, general hospital	20	9
Academic center, children's hospital	3	85
Community hospital	23	4
Private clinic	62	11
Other	12	2
Pediatric outpatients seen/week, mean (range)	2 (0–12)	29 (3–145)
Pediatric inpatients seen/month, mean (range)	2 (0–20)	11 (0–185)
Age limitation on pediatric outpatients, %		NA
No limits	36	
No patients <3 years	6	
No patients <6 years	22	
No patients <11 years	26	
No patients <16 years	10	
Distance from pediatric rheumatologist, %		NA
≤50 miles	60	
>50 miles	40	
Pediatric experience in fellowship, %		NA
Adult rheumatologist preceptor	48	
Pediatric rheumatologist preceptor	52	
Year residency completed, mean (range)	1981 (1967–1985)	1993 (1967–2008)

latest advances in JIA treatment. While 75% felt there were adequate resources to assist them in treating JIA, only 51% agreed that medications to treat JIA have clear dosing guidelines. Over half (55%) agreed "lack of pediatric rheumatologists leads me to treat children with JIA myself."

Table 2 presents the attitudes of ARs, stratified by the limits they place on their pediatric patient population. Consistently, ARs who limited their pediatric practice to older adolescents expressed the most hesitancy about JIA care.

ARs reporting 0–1 outpatient pediatric visits per week were more likely than those with  $\geq$ 2 pediatric visits per week to report being uncomfortable diagnosing JIA (11% versus 0%; P=0.04) and treating JIA (39% versus 4%; P<0.001), and were less likely to feel they were up to date on JIA treatments (42% versus 8%; P=0.002). Those with training from a PR during fellowship were more likely to report adequate resources to assist them (91% versus 62%; P=0.007), but otherwise they did not report more comfort diagnosing or treating JIA.

	Strongly disagree/disagree, %	Strongly agree/agree, %	P
I am comfortable diagnosing JIA in children			
No age limits	0	100	0.03
No patients age <3 years	0	100	
No patients age <11 years	14	86	
I am comfortable treating children with JIA			
No age limits	4	96	< 0.00
No patients age <3 years	7	93	
No patients age <11 years	50	50	
I am up to date on the latest advances in JIA treatment			
No age limits	12	88	< 0.00
No patients age <3 years	14	86	
No patients age <11 years	48	52	
Medications to treat JIA have clear dosing guidelines			
No age limits	40	60	0.34
No patients age <3 years	43	5 <i>7</i>	
No patients age <11 years	59	41	

Impact of specialty on medication preference. Four clinical vignettes were presented to survey respondents, representing a range of JIA subtypes. For each vignette, respondents selected the treatment(s) they would recommend as initial therapy, and whether the patient was refractory after 3 months of the initial treatment. The vignettes presented were 1) a 2-year-old with oligoarticular JIA, 2) a 6-year-old with systemic onset JIA, 3) a 9-year-old with polyarticular JIA without rheumatoid factor (RF), and 4) a 14-year-old with RF-positive polyarticular JIA. Full descriptions of the vignettes are located in Supplementary Appendix B (available on the *Arthritis Care & Research* web site at http://onlinelibrary.wiley.com/doi/10.1002/acr.23273/abstract).

The clinical vignettes revealed several important prescribing differences (Table 3). For the 2-year-old with oligoarticular JIA, ARs were more likely to initiate methotrexate treatment (12% versus 2%; P=0.02); conversely, for the 9-year-old with RF-negative polyarticular JIA, PRs were more likely to initiate methotrexate treatment (74% versus 44%; P=0.0005) and to treat with a tumor necrosis factor (TNF) inhibitor (79% versus 54%; P=0.003). PRs were more likely to treat the 6-year-old with refractory systemic JIA with anakinra (58% versus 38%; P=0.04), and to initiate a TNF inhibitor for the 14-year-old with RF-positive polyarticular JIA (21% versus 7%; P<0.01).

Association of rheumatology training and practice setting on treatment selection. ARs with training from a PR differed in their prescribing patterns compared to

those with pediatric training from ARs. Those with training from a PR were more likely to treat RF-positive JIA with steroid injections (25% versus 7%; P = 0.05) and were less likely to refer to a PR at the initial visit (0% versus 10%; P = 0.03). There was also a trend toward higher rates of initial methotrexate use by those with training from a PR (90% versus 72%; P = 0.06). The most significant results, however, were seen in the treatment of polyarticular JIA, where ARs with training from a PR were more likely to select methotrexate for initial treatment (44% versus 21%; P = 0.05) and TNF inhibitors for refractory disease (58% versus 32%; P = 0.04), and less likely to select oral steroids (0% versus 11%; P = 0.03). ARs practicing in academic centers were less likely to select TNF inhibitors (0% versus 19%) and initial intraarticular injections (0% versus 20%; P = 0.02) for the treatment of oligoarticular JIA. The only significant difference among pediatric respondents based on training was in the selection of TNF inhibitors for polyarticular JIA, with those who trained after 1995 being more likely to select a TNF inhibitor than those who trained prior to 1995 (87% versus 71%; P = 0.03).

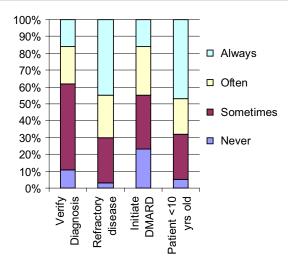
Information and education needs for JIA. While ARs report higher rates of disagreement with the statement "medications to treat JIA have clear dosing guidelines" at 48%, almost one-third of PRs also disagree with this statement (31%). ARs who felt there were not clear dosing guidelines were more likely to refer patients age <10 years to a PR, with 86% often or always referring these children.

Table 3. Treatment selection by JIA subtype based on clinical vignettes*								
	2-year-old: oJIA		6-year-old: soJIA		9-year-old: pJIA		14-year-old: RF+: рЛА	
	Adult (n = 25)	Ped. (n = 128)	Adult (n = 33)	Ped. (n = 128)	Adult (n = 39)	Ped. (n = 128)	Adult (n = 59)	Ped. (n = 127)
NSAID	80	89	73	88†	90	95	79	93‡
MTX Initial	10	2†	20		4.4	74+	0.4	0.0
	12		39	55 27	44	74‡	81 14	89
Refractory	32	52	38		46	24†		9
Total TNFi	44	54	77	82	90	98	95	98
Initial	0	0	3	1	0	5	7	21‡
Refractory	16	9	19	32	54‡	79‡	77	74
Oral steroids Steroid inj.			64	69	23	25	38	42
Initial	48	63			23	17	17	9
Refractory	28	28						
ANK								
Initial			12	10				
Refractory			38	56†				
ABT							0	0
Initial							3	12
Refractory								

<sup>\*</sup> Values are percentages. The sample size (n) for adult rheumatologist varies, as only those respondents who reported seeing children of each age were included in analyses. Sulfasalazine, hydroxychloroquine, and leflunomide were selected by fewer than 10% of respondents; results not shown. JIA = juvenile idiopathic arthritis; oJIA = oligoarticular JIA; soJIA = systemic onset JIA; pJIA = polyarticular JIA; RF = rheumatoid factor; NSAID = nonsteroidal antirheumatic drug; MTX = methotrexate; TNFi = tumor necrosis factor inhibitor; inj. = injection; ANK = anakinra; ABT = abatacept.

<sup>†</sup> P < 0.05. ‡ P < 0.01.

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**Figure 1.** Frequency of referral from adult to pediatric rheumatologist. Sample size varies in each category by number of respondents; total number of respondents = 69. DMARD = disease-modifying antirheumatic drug.

The most common information and education needs of ARs were updates on diagnostic and therapeutic advances in JIA (63%) and pediatric dosing guidelines by age/weight (53%). While over half of respondents felt dosing guidelines were needed, only 32% selected needing guidelines/algorithms to assist in choosing medications. Only 7% of respondents indicated they had no informational or educational needs in caring for pediatric JIA patients.

**Referral of pediatric JIA patients.** The majority of ARs caring for pediatric JIA patients (n=69) refer their patients to PRs in refractory cases and for children age <10 years (Figure 1). Conversely, ARs seemed comfortable with initiation of disease-modifying antirheumatic drugs, referring less often for that reason.

PRs expressed a different view of referral. Of 115 PRs surveyed, almost half reported they did not feel ARs referred JIA patients to them at an appropriate time in the child's disease course. The vast majority of PRs report taking over all rheumatologic care for most or all patients referred from ARs. Co-management of the patient, or returning the patient back to the AR, is reported to be uncommon.

Co-management of patients. To enhance co-management, 74% of pediatric respondents endorsed shared medical records. Most pediatric respondents also cited reimbursement (63%) and treatment guidelines (53%) as ways to facilitate co-management. Only 27% felt telemedicine would enhance co-management. Of the 18% who selected "other," the most common response was that they did not co-manage patients and/or they did not feel ARs should care for pediatric patients.

#### **DISCUSSION**

This national survey of ARs and PRs was conducted to provide insights into the characteristics and prescribing practices for juvenile arthritis by ARs and PRs, the resources utilized to make treatment decisions, and the interactions between adult and pediatric providers.

Consistent with previous reports, we found that while most ARs report being comfortable diagnosing JIA, nearly one-quarter feel uncomfortable treating these children. Our survey indicates that only 23% of ARs provide care for pediatric patients with JIA, and many of these limit their practice to older children (ages >10 years). Not surprisingly, we found that ARs who reported feeling uncomfortable treating JIA were more likely to limit the age of children they see and to refer their JIA patients to PRs.

We considered the limited geographic distribution of PRs as a likely contributor to the need for ARs caring for children (10). In our study, 55% of ARs treating children agreed that the lack of PRs leads them to treat children themselves, despite the majority of them practicing within 50 miles of a PR. While we consider distance to be an important factor that affects access to care, we do not have information from patients or their primary care providers regarding what is considered a reasonable distance to travel for subspecialty care. Furthermore, the contribution of other factors such as long weight times, insurance limitations, or family circumstances is unknown. Given the ongoing workforce limitations in pediatric rheumatology, further characterizing these limitations will be important to ultimately improve access to care.

The clinical vignettes used in this survey study highlight important differences in treatment patterns, both initial and for refractory cases, between PRs and ARs. Treatment with intraarticular corticosteroids in oligoarticular disease among PRs was similar to a previous study (11,12); the lower utilization of intraarticular corticosteroids by ARs may reflect inexperience with injections in young children, or the lack of services for pediatric sedation. Compared to ARs, PRs were more likely to use methotrexate or biologic agents at the initial evaluation, and were more likely to select TNF inhibitors in the treatment of polyarticular JIA. This suggests that pediatric training may offer a different perspective on the treatment of JIA and the importance of early and aggressive therapy (13,14). Additionally, we found significant prescribing differences between ARs with and without training from a PR; this supports the importance of exposing adult rheumatology fellows to PRs during their training. From our results, it appears ARs are limiting the care they provide to mainly adolescents, and that after 3 months into treatment, they are treating children similarly.

The lack of clear dosing guidelines for JIA treatments was endorsed by half of adult rheumatology respondents, but also by almost one-third of PRs. While review of the literature was reported as the most common mechanism for obtaining dosing regimens by both ARs and PRs, informal consultations with colleagues and information from national meetings were also commonly used. Further investigation into the nature of the information needed may help in developing resources to provide both PRs and ARs with easily accessible information. Simple dosing questions may be best presented in an

electronic format. However, if the questions arising reflect more nuanced concerns or patient-specific issues, developing systems to improve access to a PR or experts may be more useful.

ARs frequently refer pediatric patients to PRs for consultation, but it appears that few PRs participate in co-management with adult providers, and even fewer refer the child back to the adult provider for all ongoing care. The motivation for adult providers to refer to PRs was not clearly delineated in our study, and we cannot differentiate if the intention was for a consultation versus a transfer of care. However, the fact that over one-third of ARs reported referring often or always to "verify diagnosis and guide therapy" suggests at least a portion of adult providers may be seeking input only to confirm optimal treatment, but not to transfer all care. It is less clear how interested PRs were in comanaging or consulting on children with JIA, as almost half felt internist rheumatologists did not refer JIA patients at an appropriate time in their disease course. Many PRs commented that they did not see a role of adult providers caring for children, which may reflect either their personal opinion, or those of families that specifically request a consulting PR to take over their child's care.

Given the current workforce limitations, it is not feasible for PRs to care for all children with rheumatologic disease. To increase access to care for pediatric patients, it is likely that several changes within health care will be necessary. One method may include optimizing care for children with JIA treated by adult providers through 1) encouraging co-management relationships, 2) dissemination of evidence-based guidelines for the diagnosis and treatment of pediatric rheumatic disease, and 3) increased emphasis on pediatric training during adult fellowship training. This is particularly advantageous, as a 2002 survey suggested that, compared to PRs alone, an additional 40% of the pediatric population lives within 50 miles of an internist rheumatologist who treats children (10). Alternatively, there may be an increasing role for physician extenders working directly with PRs; a 2004 survey indicated that almost half of PRs use physician extenders (2). Although varying models exist, incorporating physician extenders may result in increasing the number of patients who can be seen (and therefore reducing wait times). These providers may be particularly helpful in increasing access in urban areas where they can work directly with PRs in a clinical setting. However, rural areas or states that do not have a PR may also benefit from physician extenders who have dedicated pediatric musculoskeletal training and experience. In these areas, telemedicine and expanding outreach clinics could greatly improve access in both rural and urban settings.

Additional efforts to improve the pediatric rheumatology workforce are reviewed elsewhere (2) and include recommendations to increase the supply of PRs, increased education and reliance on general pediatricians, and use of telemedicine. Telemedicine may improve access, particularly in underserved areas where general pediatricians and physician extenders can facilitate medication

monitoring, routine followups of patients with JIA who are responding well to treatment, and early recognition of a new patient with suspected JIA. However, a local provider with experience performing a musculoskeletal examination is essential for this modality. In our survey, few respondents felt telemedicine would enhance co-management. However, with the expansion of electronic medical records (EMRs) and increased comfort with technology in the medical community, we would expect some of these attitudes to change, especially if issues around reimbursement are addressed.

There are several potential limitations to our study. As our data were collected in 2009, changes to the health care system may impact access to care, provider beliefs, and current practices. The use of EMRs may increase the ability to co-manage patients; however, there is significant heterogeneity in available EMR systems and many do not have the ability to share data. In addition, our survey suggests that provider beliefs were a significant barrier to co-management and are unlikely to be influenced by EMR availability. While insurance rates have improved with the passing of the Affordable Care Act (ACA), it is unclear what impact this has had on access to pediatric specialist care. There were far fewer children affected by the ACA, with the number of uninsured children decreasing by only 1 million, compared to 16 million non-elderly adults between 2013 and 2016 (15) (despite children making up almost one-quarter of the population). In addition, compared to other specialties, a 2015 study found that rheumatology was more commonly excluded from insurance plans purchased through open enrollment in the federal marketplace (16). The significance of our study remains relevant due to 1) the continued limitations in the pediatric workforce, and 2) limited change in the distribution of PRs nationally, both for clinical care demands and for educational exposure in academic centers. For example, there are still 8 states with no PRs and several with fewer than 2 (17). Consistent with the results of our study, most PRs continue to be concentrated in academic centers in large populated cities, with most continuing to split their time between research and educational responsibilities (17). It is therefore unlikely that exposure to a PR has significantly changed.

Our study has additional limitations. Data are selfreported practices and perceptions of physicians; practice patterns were not independently validated through medical records or other means. Second, while randomization typically serves to reduce sampling bias, the survey methodology is prone to self-selection bias and exclusion/nonresponse bias, especially for rheumatologists not listed in the ACR membership directory. It is possible that the ACR membership directory overrepresents certain practitioner demographics (such as academic clinicians). It is reassuring that other surveys that have combined the ACR membership directory and the American Medical Association Physician Masterfile found a similar proportion of adult and PRs in academic practice seen in our survey (18). Although a random sample was requested, responses were received only from ARs who completed residency in or before 1985; 274 Van Mater et al

thus, results do not reflect ARs who completed residency training in the last 20 years. It is not clear if the age discrepancy between adult and pediatric respondents is solely from the random sample of physicians provided, or if older rheumatologists were more likely to complete the survey. Other provider surveys also demonstrated a low response rate for younger rheumatologists (18). Despite the limitations inherent with surveys, the response rate for this study is excellent and higher than other rheumatology physician surveys (18), which may minimize the impact of bias.

Nearly a quarter of surveyed ARs care for children with JIA, with most limiting their practice to older children. Due to workforce limitations, finding ways to facilitate optimal care for children with JIA treated by adult providers, rather than absorbing them into the pediatric practice, may provide greater access and improve care. In general, we found there was more discomfort in treating JIA than in diagnosing it, with a lack of clear dosing guidelines for treatments being endorsed by half of adult rheumatology respondents, as well as almost a third of PRs. Since our initial survey, the ACR has worked to address these concerns by publishing guidelines for the treatment of JIA (19). Our data support the importance of continuing to develop treatment guidelines for children with rheumatic diseases, and future directives should also focus on the best ways to update and disseminate this information to adult providers who may be caring for children.

Finally, our survey indicated significant prescribing differences between ARs with and without training from a PR. The prescribing differences highlight that pediatric-specific education for ARs is critical to improve comfort in diagnosis and managing childhood rheumatic disease. Educational efforts may capitalize on a multifaceted approach that includes 1) expanded courses and workshops in pediatric rheumatology at national meetings, 2) continued development and dissemination of ACR guidelines for pediatric rheumatic diseases, and "toolkits" for diagnosis and management of JIA designed for ARs, and 3) implementation of standardized learning modules for providers and practicing clinicians. It is hoped that fostering these educational activities will improve access to care and interactions between adult and pediatric providers.

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#### **AUTHOR CONTRIBUTIONS**

All authors were involved in drafting the article or revising it critically for important intellectual content, and all authors approved the final version to be submitted for publication. Dr. Van Mater had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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# REFERENCES

- Sacks JJ, Helmick CG, Luo YH, Ilowite NT, Bowyer S. Prevalence of and annual ambulatory health care visits for pediatric arthritis and other rheumatologic conditions in the United States in 2001–2004. Arthritis Rheum 2007;57:1439–45.
- Duke EM. US Department of Health and Human Resources: report to Congress. The pediatric rheumatology workforce: a study of the supply and demand for pediatric rheumatologists. URL: https://pdfs.semanticscholar.org/4f1d/41eec3b2ec be7e529efb169cdb0d82c0a951.pdf.
- Mayer ML, Sandborg CI, Mellins ED. Role of pediatric and internist rheumatologists in treating children with rheumatic diseases. Pediatrics 2004;113:173–81.
- DeWitt EM, Sherry DD, Cron RQ. Pediatric rheumatology for the adult rheumatologist. I: therapy and dosing for pediatric rheumatic disorders. J Clin Rheumatol 2005;11:21–33.
- Milojevic DS, Ilowite NT. Treatment of rheumatic diseases in children: special considerations. Rheum Dis Clin North Am 2002;28:461–82.
- Singer NG, Scalzi LV. Remittive agents in pediatric rheumatology. Curr Opin Rheumatol 2004;16:571–6.
- Chira P, Sandborg CI. Novel therapies in pediatric rheumatic diseases. Curr Opin Pediatr 2003;15:579–85.
- Sherry DD, Wallace CA, Kahn S. Pediatric rheumatology in adult rheumatology practices in Washington State. Arthritis Rheum 1996;39:1218–21.
- Freed GL, Jee S, Stein L, Spera L, Clark SJ. Comparing the self-reported referral and management preferences of pediatricians and family physicians for children with juvenile rheumatoid arthritis. J Rheumatol 2003;30:2700

  –4.
- Mayer ML, Mellins ED, Sandborg CI. Access to pediatric rheumatologic care in the United States. Arthritis Rheum 2003;49:759-65.
- Beukelman T, Guevara JP, Albert DA, Sherry DD, Burnham JM. Variation in the initial treatment of knee monoarthritis in juvenile idiopathic arthritis: a survey of pediatric rheumatologists in the United States and Canada. J Rheumatol 2007;34:1918–24.
- 12. Beukelman T, Guevara JP, Albert DA, Sherry DD, Burnham JM. Usage of intra-articular corticosteroid injections for the treatment of juvenile idiopathic arthritis: a survey of pediatric rheumatologists in the United States and Canada. Clin Exp Rheumatol 2008;26:700–3.
- 13. Tynjala P, Vahasalo P, Tarkiainen M, Kroger L, Aalto K, Malin M, et al. Aggressive combination drug therapy in very early polyarticular juvenile idiopathic arthritis (ACUTE-JIA): a multicentre randomised open-label clinical trial. Ann Rheum Dis 2011;70:1605–12.
- Wallace CA, Giannini EH, Spalding SJ, Hashkes PJ, O'Neil KM, Zeft AS, et al. Trial of early aggressive therapy in polyarticular juvenile idiopathic arthritis. Arthritis Rheum 2012;64:2012–21.
- 15. Garfield RT, Mjerol M, Damico A, Foutz J. The Henry J. Kaiser Family Foundation. The uninsured: a primer. 2016. URL: http://files.kff.org/attachment/Report-The-Uninsured-A%20Primer-Key-Facts-about-Health-Insurance-and-the-Unisured-in-America-in-the-Era-of-Health-Reform.
- Dorner SC, Jacobs DB, Sommers BD. Adequacy of outpatient specialty care access in marketplace plans under the Affordable Care Act [letter]. JAMA 2015;314:1749–50.
- Kolonko K. Pediatric rheumatologists increasing in number but still rare. In: The Rheumatologist. 2012. URL: http:// www.the-rheumatologist.org/article/pediatric-rheumatologistsincreasing-in-number-but-still-rare/.
- Hogan P, Bouchery E, for the Lewin Group. Rheumatologist survey overview. 2006. URL: http://www.rheumatology.org/ Portals/0/Files/Lewin%20Study%20Overview.pdf.
- 19. Beukelman T, Patkar NM, Saag KG, Tolleson-Rinehart S, Cron RQ, DeWitt EM, et al. American College of Rheumatology recommendations for the treatment of juvenile idiopathic arthritis: initiation and safety monitoring of therapeutic agents for the treatment of arthritis and systemic features. Arthritis Care Res (Hoboken) 2011;63:465–82.