

Comparing the Self-Reported Referral and Management Preferences of Pediatricians and Family Physicians for Children with Juvenile Rheumatoid Arthritis

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ABSTRACT. Objective. The symptoms of juvenile rheumatoid arthritis (JRA) are often first recognized by primary care physicians. Little is known about the determinants of the initial management and referral patterns of these physicians for children with JRA. We compared the self-reported preferences and practices of pediatricians (PD) and family physicians (FP) in the diagnosis and management of children with JRA.

Methods. Surveys were mailed to a national random sample of 700 PD and 867 FP. Questions included prior experience with JRA, usual patterns in the diagnosis and management of JRA, perception of the need for guidelines for referral and management of this condition, and physician demographic information. Data analysis included univariate and bivariate analysis.

Results. Response rates were 69% for PD and 49% for FP. Most respondents had seen very few JRA cases in the previous 5 years. Only 1% of respondents reported that they provided all diagnosis and management for patients with JRA. Forty-two percent of PD and 32% of FP refer all JRA diagnosis and management to subspecialists, while 46% of PD and 61% of FP refer only to confirm the diagnosis and guide initial therapy ($p = 0.011$). More PD than FP (PD 92% vs FP 76%; $p = 0.001$) referred patients with JRA to pediatric rheumatologists, while more FP than PD referred to general rheumatologists (PD 17% vs FP 37%; $p = 0.001$). The majority of FP reported feeling more comfortable managing rheumatologic disease in adults than children (82%). Few respondents felt that they were up to date on the latest advances in JRA treatment (PD 10% vs FP 4%; $p = 0.024$).

Conclusion. Multiple factors may contribute to physicians' referral practice, including a patient's clinical status and the physician's beliefs of inadequacy of training and inability to stay up to date. The pattern of care that children with JRA receive likely will be influenced by initial presentation to a PD or to a FP. (J Rheumatol 2003;30:2700-4)

Key Indexing Terms:

ARTHRITIS

PEDIATRICIAN

FAMILY PHYSICIAN

TREATMENT

Juvenile rheumatoid arthritis (JRA) is the most common rheumatic disease in children, with an incidence of 9-20 cases per 100,000¹⁻⁴. Early diagnosis and appropriate treatment of JRA is critical to minimize deformity and to maximize normal growth⁵.

Patients with chronic diseases are usually first brought to medical attention in the offices of their primary care physicians, who often refer them to subspecialists for subsequent care⁶⁻⁸. We examined the patterns of referral among primary

care pediatricians (PD) and family physicians (FP) for JRA. Prior studies have identified differences between PD and FP in terms of chronic disease management for conditions such as childhood depression^{9,10}. These differences have been described with respect to medication use and treatment strategies for children with mental health issues^{11,12}.

The most common reason for PD to refer their patients to subspecialists is for advice on diagnosis and management^{13,14}. While many studies have examined reasons for primary care physicians to refer to subspecialists¹⁵⁻¹⁷, few have delineated the similarities and differences between PD and FP regarding the referral process for their patients with specific chronic diseases, and none for JRA. Information in this area is important for determining the current and planning the future physician workforce necessary to care for children with a variety of chronic conditions, including rheumatologic disorders. Much work has been done comparing PD and FP with respect to outpatient management of immunizations¹⁸⁻²¹, pediatric emergencies^{22,23}, counseling²⁴⁻²⁶, antibiotic prescribing^{27,28}, and the manage-

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ment of a variety of clinical conditions^{29,30}. We examined the variation in perceptions among PD and FP concerning their ability to diagnose and care for children with JRA, and investigated potential differences in referral patterns among these primary care physicians.

MATERIALS AND METHODS

Physician study population and setting. A national random sample of 725 PD and 900 FP was drawn from the American Medical Association (AMA) Physician Masterfile, which includes both members and nonmembers of the AMA. General practitioners were not included in the family physician sample. The sample was provided by Medical Marketing Service, Inc. (MMS), a licensee of the AMA. Physicians age 70 and above were excluded.

Instrument. The 4-page questionnaire consisted of 23 questions that included items on physician attitudes, experiences, and demographic characteristics. Questions addressed referral choice and patterns of care provided to children with JRA. A Likert scale was used to rank the self-perceived comfort and competence of managing children with JRA and the ranking of determining factors for referral.

Survey administration. Once the physician sample was received from MMS, several deletions were made to conform with eligibility criteria (e.g., physicians in training, age > 69 yrs), resulting in a final mailing sample of 700 PD and 867 FP. The family physician and pediatric surveys were sent with a specialty-appropriate cover letter explaining the study and the importance of physician feedback, along with a reply envelope. Up to 3 survey mailings to nonrespondents were conducted. The mailing dates were in March and April 1999.

Because the response rate in both physician groups after the 3 initial mailings was less than 50%, physician directories were used to verify the physician addresses for accuracy. A fourth mailing was sent to FP in February 2000, and to PD in May 2000. The original survey was sent to physicians for whom a new address was verified, and an abbreviated form of each survey was sent to the nonrespondents whose addresses had not changed. The abbreviated surveys were a single page and included questions about patterns of care, pattern of referral of patients with JRA, and physician demographic information.

Analysis. Initially, general frequency distributions of all survey responses were performed. For both survey versions (PD and FP), responses to identical questions were both compared and combined. Bivariate analyses using chi-square statistics were conducted to examine associations between primary care providers' usual pattern of JRA care and potential relevant factors, such as specialty, previous JRA training, and comfort level in diagnosis and treatment of this condition. Analyses were performed using SAS (Version 6.12, SAS Institute, Cary, NC, USA).

The study was approved by the institutional review boards at the University of Michigan and the University of North Carolina-Chapel Hill.

RESULTS

Response rate. Of the 700 PD and 867 FP in our national random sample, some were excluded from the sample because surveys were undeliverable ($n = 34$ for PD, $n = 29$ for FP). Of the remaining 666 PD, response rate was 69% ($n = 458$). Of the remaining 838 FP, response rate was 49% ($n = 412$). Some respondents were excluded from analysis because they did not currently see children (109 PD, 135 FP) or were retired or deceased (7 PD, 5 FP). Data analysis was performed on the remaining 342 PD and 272 FP eligible surveys.

Characteristics of physicians surveyed. Characteristics of

respondents (Table 1) are consistent with national demographic patterns for these 2 specialties and did not differ significantly from nonrespondents. Only 16% of PD and 9% of FP reported that a rheumatologist was on site in their practice. Most respondents had seen few JRA cases in the past 5 years prior to the survey (Table 2). FP were more likely than PD to not have seen a single patient with JRA in that time period.

Table 3 shows how PD and FP characterized their usual patterns of care for children with JRA. More than 90% of both PD and FP refer patients with JRA for specialty care. However, PD were more likely than FP to report that referred patients receive all JRA care from specialists. In contrast, FP were more likely than PD to refer to a specialist to confirm the diagnosis and establish an initial treatment plan, but they provided longterm management for the patient themselves.

With regard to previous training, whether or not a physician had completed a pediatric rheumatology rotation during residency had no significant effect on JRA referral patterns. Further, there was no significant difference in the reported usual pattern of care based on provider age, or whether they had specifically learned about JRA during their continuity clinic experience.

While physicians of both specialties usually referred suspected JRA cases, Table 4 illustrates the factors physicians reported "important" in the decision to refer. The most important factors noted by both PD and FP were a patient's refractory clinical course, severity of symptoms, and parental request. More FP than PD felt that patient age was an important factor in the referral decision. The child's insurance status was reported by both PD and FP least frequently as an important factor determining referral of patients with JRA.

Table 5 shows the referral destinations for patients with JRA. PD were most likely to refer their patients to a pediatric rheumatologist, while FP would frequently refer to a general rheumatologist. Referral of JRA patients to an orthopedist was reported to be uncommon by both PD and FP.

Referral choice of primary care physicians was also dependent upon factors other than physician specialty. The specialist's professional reputation was the leading determinant of referral choice for both PD and FP (92% vs 87%; $p = \text{nonsignificant}$). Appointment availability was also important (72% PD, 80% FP; $p = \text{NS}$). Distance to the referral site was a lower priority for PD, but cited by more than half of FP (38% PD, 53% FP; $p = 0.002$).

Table 6 delineates survey respondents' self-perceptions of their ability and comfort in managing JRA in the primary care setting. While PD were more likely than FP to be comfortable in the diagnosis of JRA, less than half responded in that manner. Concerns regarding time-consuming management of patients with JRA was not a common reason for referral cited by PD or FP. FP reported

Table 1. Respondent characteristics.

| | Pediatricians, n = 342, % | Family Physicians, n = 272, % | p |
|----------------------------|---------------------------|-------------------------------|-------|
| Male | 56 | 72 | 0.001 |
| White, non-Hispanic | 87 | 85 | NS |
| Less than 55 years old | 81 | 90 | 0.001 |
| Board certified | 90 | 81 | 0.001 |
| Practice setting | | | |
| 1–2 physician practice | 22 | 38 | 0.001 |
| Group practice (3+) | 62 | 49 | |
| Academic or hospital based | 13 | 9 | |
| Public | 4 | 4 | |

Table 2. Number of patients with JRA in past 5 years.

| | Pediatricians, n = 342, % | Family Physicians, n = 272, % |
|---------------------------------|---------------------------|-------------------------------|
| No JRA suspected or diagnosed | 11 | 38 |
| 1–2 patients | 41 | 42 |
| 3–10 patients | 40 | 18 |
| > 10 patients | 3 | 1 |
| Suspected JRA cases, but unsure | 4 | 2 |

p = 0.001 for comparisons between pediatricians and family physicians.

Table 3. Management and referral of patients with JRA: “the usual pattern of care for children with JRA.”

| | Pediatricians, n = 342, % | Family Physicians, n = 272, % |
|---|---------------------------|-------------------------------|
| Refer for all JRA diagnosis and care | 42 | 32 |
| Refer to confirm diagnosis, guide initial treatment | 46 | 61 |
| Refer if disease worsens after my treatment | 6 | 4 |
| Diagnose, treat, manage myself | 1 | 1 |

p = 0.011 for comparisons between pediatricians and family physicians.

Table 4. Factors important in JRA patient referrals (percentage responding “Important” or “Very important”).

| | Pediatricians, n = 342, % | Family Physicians, n = 272, % | p |
|----------------------------|---------------------------|-------------------------------|-------|
| Refractory clinical course | 73 | 85 | 0.004 |
| Severity of symptoms | 71 | 87 | 0.001 |
| Parental request | 71 | 84 | 0.004 |
| Type of JRA at onset | 58 | 69 | 0.04 |
| Age of patient | 46 | 65 | 0.001 |
| Compliance with therapy | 53 | 59 | NS |
| Insurance status | 16 | 26 | 0.016 |

Table 5. Referral destinations for patients with JRA; respondents were allowed to select more than one choice for referral destinations.

| | Pediatricians, n = 342, % | Family Physicians, n = 272, % | p |
|--------------------------|---------------------------|-------------------------------|-------|
| Pediatric rheumatologist | 92 | 76 | 0.001 |
| General rheumatologist | 17 | 37 | 0.001 |
| Orthopedist | 2 | 4 | NS |
| Pediatrician | 1 | 14 | 0.001 |

Table 6. Self-reported knowledge, attitudes, and practices regarding JRA care: percentage responding “Agree” or “Strongly agree.”

| Statement on Survey | Pediatricians, n = 304, % | Family Physicians, n = 170, % | p |
|---|---------------------------|-------------------------------|-------|
| I am comfortable diagnosing JRA. | 42 | 19 | 0.001 |
| Managing JRA is so time-consuming that I usually refer these patients. | 19 | 22 | NS |
| I am adequately trained in diagnosing/managing JRA. | 18 | 12 | 0.038 |
| I am up to date on the latest advances in JRA treatment. | 10 | 4 | 0.024 |
| Lack of referral physicians leads me to treat JRA patients myself. | 5 | 5 | NS |
| I am more comfortable managing rheumatologic disease in adults than children. | NA | 82 | — |

a much greater comfort level with adult rheumatologic patients than with children.

DISCUSSION

Despite being the most common rheumatic disease in children, JRA is seen infrequently in the offices of primary care physicians. That the overwhelming majority of PD and FP reported having seen no patients with JRA in the past 5 years may explain the overwhelming tendency for primary care physicians to refer to specialists when encountering a child with symptoms of JRA. Our study confirms the finding of previous work that a high rate of referral follows initial presentation of a health problem, suggesting that PD may not feel adequately trained to handle particular issues¹³. Another possibility is that PD have been socialized during residency training to refer children with complex chronic conditions to specialists to ensure they receive the most comprehensive and up-to-date therapy available.

Our study indicates that although PD and FP refer most patients with JRA for specialty care, FP were more likely than PD to seek specialty care only for confirmation of diagnosis and guidance for initial treatment. More FP than PD were likely to participate in co-managing patients with JRA by participating in followup care with the subspecialists. In contrast, PD were more likely than FP to refer children with JRA to specialists for all JRA diagnosis and management. This was surprising, given that more PD than FP rated themselves as being comfortable in diagnosing JRA. This difference may be explained by the possibility that PD have more comfort in JRA diagnosis but do not feel adequately trained in management. Another possible explanation is that PD may place greater value on the role of the specialist in ensuring the most current strategies for management of the patient with JRA after the initial diagnosis.

Workforce distribution also may be a primary contributing factor for referral patterns that differentiate PD from FP. For example, more FP than PD refer pediatric patients with suspected JRA to internist rheumatologists. This likely occurs because FP have developed a relationship with general rheumatologists who provide care to their adult patients with more common rheumatic diseases such as osteoarthritis. Additionally, our data show that FP are more likely to consider distance to the referral site as an important consideration in deciding whom to refer. FP are more likely to practice in rural areas, which tend to have limited access to pediatric subspecialists. This may also account for the tendency for FP to rely on specialists only to guide initial treatment, with the expectation that subsequent care would be co-managed or fully managed by the FP. Of note, 14% of FP refer JRA patients to a pediatrician. Based on our findings, it is likely that such patients would then be referred again to a specialist. This may indicate inefficiencies in the referral process that might be eliminated if the FP were to refer directly to a subspecialist, thus minimizing inconve-

nience and cost to the patients, who might be making unnecessary physician visits.

The tendency for more PD than FP to refer pediatric patients with suspected rheumatologic diseases to subspecialists can be attributed to more than workforce distribution, but also to different practice styles and different training experiences. Due to the nature of their practice, FP may be more accustomed than PD to managing a panoply of patient issues, including surgical procedures, obstetrical cases, and psychiatric issues. PD are trained to be generalists for children, but generally do not care for these patients once they reach adulthood. Their training experiences usually expose them to a heightened awareness of the role pediatric subspecialists may adopt in caring for children with chronic disease. Our data show that more PD than FP had prior training experiences affording exposure to children with JRA, such as having had completed a pediatric rheumatology rotation. While these training experiences did not appear to influence PD taking a more active role in the longterm management of children with JRA, they may account for more PD than FP feeling competent in the initial diagnosis of this condition.

Our study also revealed that most primary care physicians would refer their pediatric patients with suspected JRA to a rheumatologist, either a pediatric rheumatologist or a general rheumatologist. This was in contrast to an earlier retrospective chart review study by Cuesta and colleagues indicating that most children with pauciarticular JRA were referred first to orthopedic surgeons prior to referral for pediatric rheumatology care³¹. This difference perhaps reflects a practice pattern at the particular institution where that study was performed. In contrast, our study population was nationwide and likely more reflective of routine practice patterns.

Our study sought to illustrate potential differences and similarities between PD and FP in managing children with JRA, and has raised several questions. Future studies are needed to address the catalysts for subspecialty referral, "usual patterns of care" for PD and FP, and the implications for clinical outcome and costs based on these differing management and referral styles.

Our ability to generalize pediatrician and family physician practices with respect to the overall specialty referral process is limited by our research design. First, the study concentrated on the referral and management processes of primary care physicians specifically caring for children with JRA. As JRA is a well defined sign/symptom complex, it is not certain whether this may serve as a proxy for other chronic disease management. Second, the study was a self-reported survey with no verification of the referral patterns reported. Third, although characteristics of the respondents were consistent with national demographic patterns for these 2 specialties, the limited response rate, especially among FP, may limit generalizability. Fourth, rheumatologic

diseases are relatively rare in children. Thus, recall regarding the assessment and treatment of such children may be biased.

In caring for children with JRA, PD and FP seek subspecialty input. Only a small proportion of primary care physicians report adequate training in diagnosis and management of patients with JRA. The degree of subspecialty involvement after the initial diagnosis is made is usually different for PD and FP. Future inquiries should examine patient and parent preferences in defining the relationship between the primary care physician and the subspecialist, and also examine the clinical and cost outcomes for children whose chronic diseases are managed to a greater or lesser degree by their primary care physicians.

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