Curr Rheumatol Rep (2012) 14:116–120
DOI 10.1007/s11926-012-0237-7

PEDIATRIC RHEUMATOLOGY (TJA LEHMAN, SECTION EDITOR)

The Clinical Spectrum of Juvenile Idiopathic Arthritis in a Large Urban Population

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Published online: 3 February 2012

Abstract Urban populations present particular challenges for medical providers. Patients are extremely diverse, with varied socioeconomic, cultural, and ethnic backgrounds. Physicians caring for children with juvenile idiopathic arthritis must be prepared to interact effectively with many types of families who bring with them varied experiences and expectations. Pediatric rheumatologists should be familiar with patient characteristics that can influence disease outcomes. Access to care is affected by place of residence, referral delays, parental education, and the child's insurance status. Patients of different ethnic backgrounds vary in their trust of physicians and health systems. Understanding of risk in medical decision making is influenced by ethnicity as well. Adherence also varies by ethnic group, with African American patients reporting lower adherence than Caucasian patients. Issues of doctor–patient communication and use of complementary and alternative medicine are also affected by cultural factors. Especially for physicians working in a large metropolitan area, an understanding of societal factors influencing patient behavior is essential to provide optimal care for children with juvenile idiopathic arthritis.

Keywords Juvenile idiopathic arthritis · Urban · Socioeconomic · Cultural · Ethnic · Access to care · Disparity · Clinical spectrum · Adherence

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Introduction

Juvenile idiopathic arthritis (JIA) describes a heterogeneous group of disorders characterized by joint inflammation, with a significant burden of long-term morbidity and disability. Prevalence estimates vary but may be as high as several hundred per 100,000 children [1]. New advances in therapy continue to improve the prognosis for children with JIA. However, medications alone do not dictate outcome. Broader societal trends also play a major role. Access to care, socioeconomic disparities, and ethnic and cultural differences can profoundly alter the prospects of a child diagnosed with JIA. Given the diversity of patients encountered in the urban setting, providers working in cities must be particularly aware of these influences on health.

Physicians are not independent actors, but rather exist within complex systems in which health care delivery and access to care play key roles. The urban health care provider must communicate with and care for patients and families of widely divergent social, cultural, and economic circumstances. To help understand how these varied influences impact upon the patient, the psychiatrist George Engel developed the biopsychosocial model of care. This model of care proposes a framework by which the care provider can incorporate this broad view of care into regular medical practice. The biopsychosocial model posits a hierarchy of systems, with the patient at the center. Within the patient are organs, tissues, molecules, and cells, the familiar building blocks of the biomedical understanding of disease. However, the patient exists within a family and community, all of which profoundly affect his or her ultimate outcome [2]. The patient may obtain medical care easily or with great difficulty, may interact with his or her physicians with trust or mistrust, and may or may not adhere to recommended therapies.

In this article, we apply the biopsychosocial model of care to understand the special characteristics and needs of urban children with juvenile arthritis. Children with JIA living in large metropolitan areas are affected by demographics, health care systems, socioeconomic factors, cultural factors, and ethnic factors. In this article, we review research relating to these factors as they apply to children with JIA.

Demographics of Large Urban Centers

In the United States, demographic characteristics of urban areas differ markedly from those of rural and suburban zones. In the 2010 US Census, 27.6% of respondents overall self-reported a race other than white—up from 24.9% in the 2000 Census [3]. A higher percentage of nonwhite Americans, compared with white Americans, live in metropolitan areas [4]. Although a majority of American citizens describe themselves as white, 89% of current US population growth is among racial and ethnic minorities, who reside primarily in urban areas. According to a Brookings Institute report, a majority of children in 31 large metropolitan areas—including New York, Chicago, Los Angeles, Miami, and Washington, DC—are from racial/ethnic minority groups [5].

Urban areas are also unique with regard to economic composition. Census data show that average incomes are higher inside than outside statistical metropolitan areas, which include cities and surrounding regions. Within metropolitan areas, incomes are lower inside the principal cities. Academic medical centers are frequently located within city centers, in closer proximity to lower-income populations. In the United States, city centers are relatively economically disadvantaged compared with surrounding areas. Households in city centers are also experiencing more rapid declines in real income during the current recession. From 2009 to 2010, median incomes of households within principal cities decreased by 3.4%, compared with a decline of 2.2% for all households in statistical metropolitan areas [6].

Access to Care

Differences in access to care can markedly impact upon ultimate outcome for children with JIA. In the past several years, many studies have demonstrated decreased radiologic progression and better functional outcomes with early, aggressive treatment of adults with rheumatoid arthritis (RA) [7, 8]. Similarly, increasing evidence suggests that early treatment of JIA is necessary to optimize outcomes. A recent study in Finland evaluated treatment regimens for new-onset JIA. The study compared three treatment arms: methotrexate alone; combination disease-modifying antirheumatic drug (DMARD) therapy with methotrexate, sulfasalazine, and hydroxychloroquine; and treatment with infliximab plus methotrexate. The biologic arm was superior to combination DMARDs and remarkably superior to methotrexate monotherapy. All children in the biologic arm achieved American College of Rheumatology Pediatric 75% improvement (ACR-Pedi 75), compared with only half of those on methotrexate alone. Sixty-eight percent of children on infliximab plus methotrexate attained inactive disease, compared with 25% in the methotrexate-only arm [9]. The attainment of inactive disease, even temporarily, is likely associated with better long-term outcomes [10]. Although further long-term studies are needed, in the short to medium term, current data support early, aggressive therapy for polyarticular JIA.

Before starting treatment for JIA, however, a child with joint symptoms must be appropriately referred to a pediatric subspecialist. Access to pediatric rheumatology subspecialty care is a key variable determining onset of therapy. Over the past few years, multiple studies from several countries have been published demonstrating long delays between symptom onset and pediatric rheumatology evaluation for children with JIA. Delays of many months—even up to a year or more for some types of JIA in one study—are frequently seen [11, 12].

A 2010 article by Shiff et al. [13] reviewed the experience of more than 300 Canadian children eventually diagnosed with JIA. The authors obtained the information from a multicenter registry of all Canadian children diagnosed with JIA from January 2005 through June 2007. In this study, variables associated with decreased time to first pediatric rheumatology visit included higher parental educational attainment, limp, and fever. Higher parental education likely correlates with increased parental awareness of abnormal symptoms as well as greater ability to navigate the health care system as a child's advocate. Limp and fever were hypothesized to be alarming symptoms that were readily recognized as abnormal by parents and primary care providers alike. The presence of enthesitis or heel pain was associated with a longer delay prior to first pediatric rheumatology visit [13]. Possibly, these complaints are less well-known as symptoms of JIA.

In the United States, many children are uninsured or underinsured, with extremely limited access to subspecialty care. In 2010, 9.8% of all children, and 15.4% of children living in poverty were uninsured. Among ethnic groups studied, Hispanic children were most likely to be uninsured, at 16.3% [6]. Even among children with insurance, differential reimbursement by public (state-administered) and private insurance companies results in health disparities. A recent study used an innovative method to audit access to pediatric subspecialty care for children with public insurance compared with those with private insurance. Researchers posing as mothers of ill children

called an array of subspecialty clinics in the Chicago area representing seven different pediatric specialties. The callers requested an appointment for an urgent condition, utilizing a script that varied only by insurance type. Overall, nearly two thirds (66%) of publicly insured mock patients were denied an appointment, compared with 11% of privately insured patients. Insurance-based differences in wait time for appointments were also substantial. On average, publicly insured patients waited 22 days longer for a specialty appointment [14•]. This study did not specifically address pediatric rheumatology care. However, the economic forces that limit access to other subspecialties for publicly insured patients can be reasonably assumed to also act upon pediatric rheumatology centers.

Health Care Disparities: Access to Care

Pediatric rheumatology practice in a large urban population includes patients from diverse socioeconomic, cultural, and racial backgrounds. Literature specifically pertaining to sociocultural and ethnic influences on health in children with JIA is lacking. However, considerable scholarship exists examining these issues in adults with RA. In treating childhood arthritis, the child's parent has enormous influence over the treatment course chosen and over the child's adherence to treatment. Studies of adult attitudes regarding RA thus may be germane to pediatric rheumatology care. Clearly, more JIA-specific research examining disparities in treatment preferences, adherence, outcome, and arthritis-related health beliefs is needed, and previous findings in adult RA may assist to guide future studies in JIA.

Studies in adult RA demonstrate worse functional outcomes in minority patients compared with white patients. A large, cross-sectional, exploratory study utilized data from multiple RA databanks. Patient-reported outcomes were assessed via recorded Stanford Health Assessment Questionnaire scores. The cohort included 4,731 patients. Although the proportions of minority patients were low (the cohort was 91% white), the high absolute numbers of patients included powered the study adequately to demonstrate differences between ethnic groups. The Caucasian subgroup was older, with a longer disease duration, but Hispanic and African American patients reported more pain and worse global health status. Disability scores were also worse among Hispanic and African American patients, but this difference was not statistically significant. The cross-sectional study design did not allow for evaluation of causes of these disparities. Of interest, DMARDs were used slightly more frequently by Caucasian patients [15].

Differential access to advanced therapies is one hypothesized cause of the observed disparities in outcome. A study of 1,879 adult RA patients from throughout the United States found no significant ethnicity-based differences in time to first DMARD or first biologic. In this study, the majority (86%) of participants were white, and the vast majority (>95%) were insured [16]. The relatively small number of nonwhite participants in this study decreases the power of this investigation to identify small differences in treatment among various racial groups. Also, the absence of uninsured patients potentially masks important overall trends in disease course and management among ethnic minorities, as African Americans and Hispanic Americans are much more likely to be uninsured than white Americans. Despite these caveats, this study is encouraging in its conclusion that with adequate insurance, aggressive treatment may be prescribed as frequently to minority patients as to white patients.

Insurance status is likely a proxy for multiple socioeconomic factors, including income and education. Children with JIA with Medicaid were found to have significantly worse disease outcomes than privately insured children, despite similar health resource utilization. A study of 294 children with JIA showed significantly higher disability and worse quality-of-life assessment scores among children with Medicaid compared with those with private insurance, despite the fact that they were treated by the same physicians. Disparities in disability and quality of life persisted even after correcting for race, JIA onset and course, and disease duration [17]. Discrepancies in health literacy may account for some of these observations. Health literacy refers to an individual's ability to obtain, process, and understand health information. In a 2009 study, health literacy skills were assessed in 68 children with JIA and their parents. Health literacy was strongly associated with insurance type. Patients and parents with adequate health literacy were far more likely to have private insurance than those with limited literacy [18]. Among families with Medicaid, almost 30% demonstrated limited literacy.

Health Care Disparities: Social and Cultural Factors

The urban practitioner must be prepared to treat patients who bring a wide assortment of backgrounds and opinions to the examination room. A patient's cultural and social milieu may dramatically affect his or her medical decision making. For example, complementary and alternative medicine (CAM) modalities are frequently used by families of children with juvenile arthritis. The effect of ethnicity on CAM use is unclear. In a Canadian study of CAM for JIA, members of ethnic minorities were less likely to use CAM [19]. However, CAM use is extremely frequent in certain groups. For example, more than 80% of RA patients in India and Korea utilize CAM [20, 21]. In some circumstances CAM may have a beneficial effect on outcomes. A Chicago-based

survey evaluated CAM use by Latino children with musculoskeletal complaints. The majority of participants used at least one form of CAM, most frequently prayer or massage. Only 45% reported that their physician was aware of CAM use. In this study, anxiety and dysthymia were decreased among children with arthralgias who utilized CAM [22]. Pediatric rheumatologists working in urban areas may benefit from familiarizing themselves with health beliefs of local populations, especially in areas in which there are large communities of people from a particular cultural background.

Nevertheless, disparities in disease outcome are likely complex and multifactorial, with multiple interrelated, contributing factors. Adherence to therapy is critical to maximize treatment efficacy. A 2008 Texas study of 102 rheumatology patients (70 with RA, 32 with systemic lupus erythematosus) showed significantly decreased self-reported adherence among African American and Hispanic patients as compared with white patients. African American and Hispanic patients were more likely to forget to take medications and to self-discontinue medications due to adverse effects or lack of efficacy. Among all groups, the five most common causes of medication nonadherence were feeling the drug was harmful, sleeping at dose time, feeling unwell, feeling depressed/overwhelmed, and having difficulty with scheduled times. African Americans and Hispanic patients endorsed all these reasons significantly more frequently than white patients [23].

The aforementioned study did not formally evaluate causes of differential adherence by patients of different ethnicities. However, the physician–patient relationship, in particular patient trust in physicians, likely has significant influence. A study of 102 ethnically diverse English- or Spanish-speaking Texas patients with RA or systemic lupus erythematosus evaluated patient trust in physicians and in the US health care system using validated instruments. Elements of physician communication style were also evaluated. Latino and African American patients reported lower trust in physicians than did white patients. Nonwhite males reported lower trust in physicians than nonwhite females. Correlates of trust in the US health care system differed from predictors of trust in physicians. Interestingly, Spanish-speaking patients displayed higher levels of trust in the US health care system than did English-speaking or bilingual patients. Trust in the US health care system was inversely correlated with patients' educational attainments. Less-educated patients reported more trust in the health care system compared with patients with some post-high school education. Particular physician communication styles, including patient centeredness, informativeness, and sensitivity to patient concerns, promoted trust. Finally, increased disease activity independently predicted increased trust in physicians [24]. Pediatric rheumatology providers should be aware that multiple nonmodifiable factors related to patient ethnicity and socioeconomic status affect patient trust in physicians. Modifying physician communication style may mitigate some of the factors that decrease trust, thus improving the physician–patient relationship. Research specifically evaluating the relationship between physician communication styles and patient trust in the realm of pediatric rheumatology is needed.

Cultural differences also influence patients' acceptance of recommended therapies. An innovative 2009 study evaluated treatment preferences of 136 RA patients (67 African American, 69 white) from two geographically distant medical centers. The study utilized a computerized, iterative, decision-making model known as *conjoint analysis*. The program presented treatment options in terms of specific risks and benefits, Mathematical concepts such as percent risks were visually represented in an easily comprehensible manner. Aggressive therapy was portrayed using a description of the risks, benefits, and methods of administration of biologic DMARDs, but without medication names to avoid confounding by brand recognition. African American patients were strikingly less likely to favor aggressive therapy. Fifty-one percent of white patients preferred aggressive therapy, compared with only 16% of African Americans. Married patients and more highly educated patients were also more likely to prefer aggressive therapy. Age, disease duration, and functional status had no significant effect on treatment preference. After controlling for all other covariates using logistic regression, race remained the single strongest predictor of treatment preference. Among individuals without a college education, 32% of whites and only 3% of African American patients preferred aggressive treatment [25•]. African Americans were far more risk averse than whites. White participants were most influenced by likelihood of disease remission or progression, whereas African Americans were most influenced by the theoretical risk of cancer [26]. Patient treatment preferences likely have a strong effect on patient adherence to medication regimens, thereby contributing to health care disparities. These findings suggest that providers' sensitivity to patients' culturally mediated assessment of risk may be helpful in the clinical setting, although this has not been tested empirically.

Conclusions

For pediatric rheumatologists to most effectively treat children with JIA living in large urban areas, it is not enough to prescribe the right medication for the child's condition. To optimize therapeutic outcomes, the practitioner must have an understanding of cultural, economic, and social forces that act to enable or prevent ready access to care, and are major determinants of a parent's willingness to adhere to recommended treatment plans. A multidisciplinary approach involving the services of social workers, therapists, translators/interpreters, and others may yield the most success. Physician

communication styles appear to be key as well, especially with regard to improving patient trust in physicians. We must hope that future research will further clarify modifiable factors that can promote improved access to care and better patient–physician relationships, thereby optimizing outcomes for children with JIA.

Disclosure Dr. Onel has had travel/accommodations expenses/ covered reimbursed by CARRA (Childhood Arthritis and Rheumatology Research Alliance).

Dr. Tesher reported no potential conflicts of interest relevant to this article.

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