Sociocultural Considerations in Juvenile Arthritis: A Review

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ABSTRACT

Problem: Juvenile Arthritis (JA) is one of the most common autoimmune diseases in children. A variety of sociocultural factors that influence health outcomes in children with JA have been examined in previous research. However, clinical guidelines to guide the care of these children lack support because this research has not been systematically examined and synthesized.
Eligibility Criteria: Primary research articles from five internet databases were included if they were peer-reviewed articles in English of studies conducted in the U.S. or Canada and referenced one or more determinants of health, quality of life, socioeconomic status, or health disparities in children with JA.
Sample: The final sample included 16 articles representing 2139 children and 939 parents.
Results: Topics covered in the studies included medication compliance, electronic medical records, environmental risk factors, economic hardship, parental coping, leisure activities, and their effects on patient outcomes including disability and quality of life. Patients with Medicaid experienced more severe outcomes than patients with private insurance despite equivalent levels of healthcare utilization. Other important topics, such as effects of the physical environment and alcohol use, were missing from the literature.
Conclusions: Five categories of health determinants were found to influence outcomes: biology, individual behaviors, social environment, physical environment, and health services. Disparities continue to exist for racial and ethnic minority children with JA and those of low socioeconomic status.
Implications: Sociocultural factors should be taken into consideration when developing care plans, research studies, and policies in order to remove barriers and promote the best outcomes for this vulnerable population.

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Introduction

Juvenile Arthritis (JA) refers to a collection of inflammatory joint diseases with symptom onset prior to age 16 years. JA is one of the most common autoimmune diseases in children (Sacks, Helmick, Luo, Ilowite, & Bowyer, 2007). The prevalence of JA is 0.6–1.5 per 10,000 in the general population in the United States (Sacks et al., 2007). Pediatric rheumatologic disease accounts for 827,000 health care visits each year, including 83,000 emergency department visits (Sacks et al., 2007).

A variety of factors influence outcomes in children with chronic conditions in general and JA in particular. Outcomes of interest for patients with JA include disease severity, health related quality of life, pain, fatigue, and disability (Bromberg, Connelly, Anthony, Gil, & Schanberg, 2014; Schanberg, Anthony, Gil, & Maurin, 2003). Children are experiencing pain on approximately 70% of days, with up to one-fourth reporting pain in the highest range of the pain scales (Bromberg et al., 2014; Schanberg et al., 2003). Pain and fatigue are influenced by the inflammatory disease process, but are further exacerbated by medications, limited range of motion, sedentary lifestyle, self-consciousness and social isolation, and emotional states (Pelajo, Lopez-Benitez, & Miller, 2012). It is also known that one-fifth of children with JA are obese, which can also develop as a side effect of medications or a sedentary lifestyle (Pelajo et al., 2012). These rates are consistent with the general population, but in children with JA, obesity complicates pain and limits mobility, and can also lead to other serious health outcomes (Pelajo et al., 2012). Since children are not yet independent, the family is an integral part of disease management that cannot be separated. For example, food options and meal patterns related to obesity are affected by the family's social context, education level, lifestyle preferences, cultural identification, etc. (Solar & Irwin, 2010).

Several U.S. government agencies, including the Institute of Medicine, the Agency for Healthcare Research & Quality (AHRQ), and the Office of Disease Prevention and Health Promotion (ODPHP), have published reports about the necessity of considering the sociocultural factors that

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influence health outcomes and the importance of reducing health disparities (Agency for Healthcare Research and Quality, 2009; Institute of Medicine, 2003; U.S. Department of Health and Human Services, 2016). The ODPHP's Healthy People 2020 report defines these sociocultural factors that influence health status as the social determinants of health (Secretary's Advisory Committee on Health Promotion and Disease Prevention Objectives for 2020, 2010; U.S. Department of Health and Human Services, 2016). Social determinants of health are "the conditions in which people are born, grow, live, work, and age, and the wider set of forces and systems shaping the conditions of daily life" ((Solar & Irwin, 2010), p. 79). One goal of Healthy People 2020 is to reduce school absenteeism among adolescents due to illness or injury (Secretary's Advisory Committee on Health Promotion and Disease Prevention Objectives for 2020, 2010; U.S. Department of Health and Human Services, 2016). In order to accomplish this goal for children with a chronic condition like JA, it is important to first understand the holistic spectrum of sociocultural factors that influence outcomes.

The sociocultural perspective on health outcomes combines traditional medicine with psychology and sociology (Horwitz, 2017). The sociocultural perspective states that biology, disease states, and the social environment are inextricably related and that the interaction influences health outcomes (Horwitz, 2017). For the purpose of this paper, the sociocultural factors influencing health are defined as the social determinants of health, which fall into five categories: biology, individual behaviors, social environment, physical environment, and health services (U.S. Department of Health and Human Services, 2016). Specific definitions of each of the categories are summarized in Table 1.

Previous reviews of the research on health outcomes in persons with arthritis did not exclusively focus on people diagnosed with JA prior to 16 years of age; reviewers commonly supplemented their review scope with articles about adults with rheumatoid arthritis, or studies about adults or children in general. Further, they included studies of children outside the U.S. and Canada, which would reflect very different health care systems and cultural influences (Tesher & Onel, 2012). The purpose of this review is to analyze all primary research studies that are specific to people diagnosed with any type of JA in childhood and that were conducted in the U.S. and/or Canada to: (1) identify the sociocultural factors and determinants of health studied in this population to date; and (2) describe how those sociocultural factors and determinants of health influence JA health outcomes.

Methods

Five internet literature databases (PubMed, CINAHL, JSTOR, Web of Science, and PsyINFO) were searched using different combinations of the terms *health disparity*, *poverty or poor*, *socioeconomic status*, *minority or minorities*, *race or ethnicity*, *underserved*, *determinants of health*, and *juvenile arthritis*. Ancestry searches were also conducted by reviewing the references of selected articles. The search strategy is described in Fig. 1. After removing duplicates, the search resulted in 46 articles screened by title and abstract and an additional 7 articles retrieved from ancestry searches. Thirty-three of these articles were retrieved for full text screening. Primary research articles were included if they referenced one or more social determinants of health, quality of life, socioeconomic status, or health disparities in people of any age who were diagnosed with any type of JA prior to 16 years of age. Because the social and political context in which the child resides is inextricably related to disease outcomes, articles were limited to studies conducted in the U.S. and Canada for this analysis. Studies were excluded if the studies were conducted outside of the U.S. or Canada. After applying inclusion and exclusion criteria, a total of 16 articles remained in the final sample.

Data Analysis

Data were extracted from the articles on the five categories of determinants of health: biology, individual behaviors, social environment,

Table 1
Determinants of health categories used for data extraction as defined by the U.S. Department of Health and Human Services.

Determinant of health	Definition
Biology	Age
	Sex
Individual behaviors	Physical activity
	Diet
	Psychosocial functioning/behaviors
	Alcohol use
	Cigarette use
	Other drug use
Social environment	Availability of resources to meet daily needs such as:
	Education level (parent and/or child)
	Employment
	Income
	Race/ethnicity/culture
	Socioeconomic status
	Social support and social interactions
	Exposure to mass media & emerging technologies
	Transportation options
	Residential segregation
	Parental characteristics, behaviors, or psychosocial functioning
Physical environment	Natural environment
	Built environment
	Worksites
	Schools
	Recreational settings
	Housing
	Homes
	Neighborhoods
	Pollution or exposure to toxic substances and other physical hazards,
	Physical barriers
	Aesthetic elements
Health services	Lack of access or limited access to health services, including:
	Lack of insurance
	Limited language access
	High cost
	Lack of availability of healthcare

physical environment, and health services (U.S. Department of Health and Human Services, 2016). The definitions of each of the categories are summarized in Table 1. Data were analyzed by grouping the findings according to the definitions of the social determinants of health.

In addition, to consider potential risk of bias in the primary studies that comprised this review, data were extracted about the instruments used to measure the outcomes in each study, including reliability and validity considerations. Further, each included article was assessed using the Johns Hopkins Hospital Evidence Appraisal Model that involves an evidence strength rating (Levels 1–3) and a quality rating of A, B, or C (Dearholt & Dang, 2012). A Level 1 rating is considered to be the highest quality evidence, and is assigned to randomized controlled trials or meta-analyses of randomized controlled trials (Dearholt & Dang, 2012). Level 2 is assigned to a quasi-experimental study, and Level 3 is assigned to non-experimental, qualitative, or meta-syntheses of qualitative studies (Dearholt & Dang, 2012). A quality grade of A is defined as high quality, B is good quality, and C is low quality or major flaws (Dearholt & Dang, 2012). The quality ratings are based on a risk of bias assessment that considers adequacy of the sample size, randomization, presence of a control group, equal treatment of groups, description of the data collection methods, and study limitations (Dearholt & Dang, 2012).

Findings

The 16 articles included in the final sample are summarized in Table 2. The findings represent a total sample across the studies of n = 1880 people with JA, n = 939 parents, and n = 259 child controls. Three of the 16 articles reported on various aspects of the same sample