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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.

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.

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

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, 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

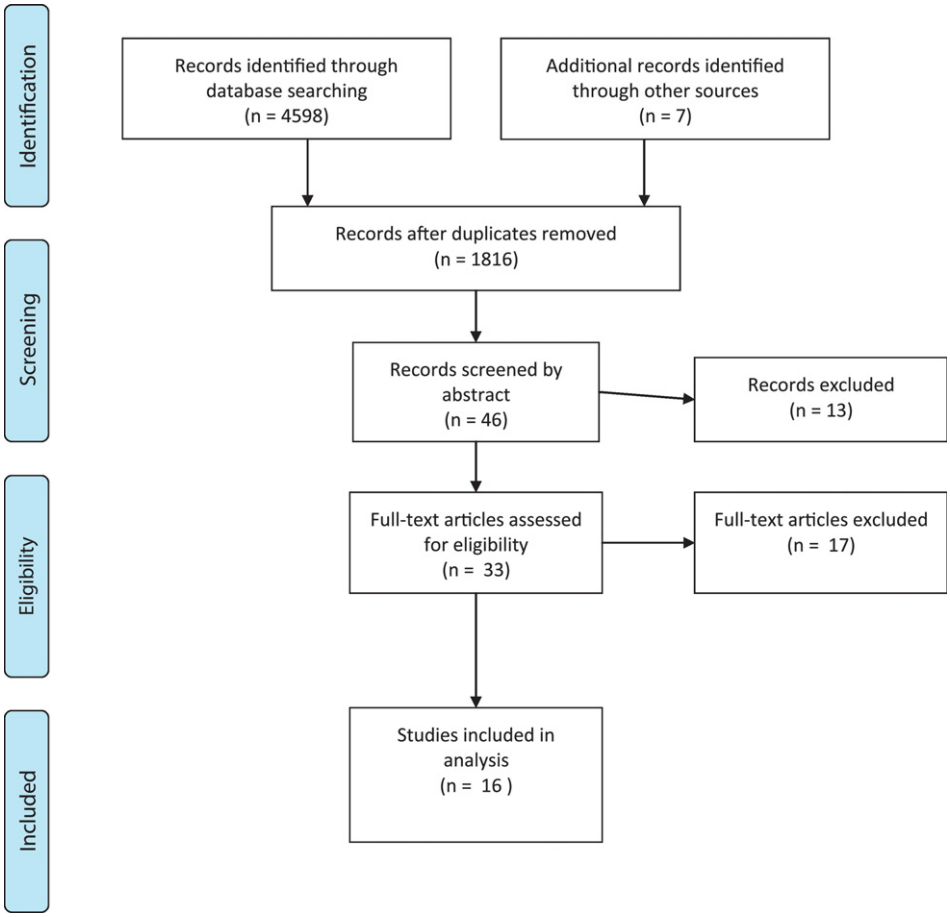

Fig. 1. PRISMA flow diagram.

(Cavallo et al., 2009; Toupin-April et al., 2009; Toupin-April, Cavallo, Ehrmann Feldman, & Ni, 2012). This sample (n = 182) was counted only once in the total calculations for this review. All patients and parents were recruited from one or more pediatric rheumatology clinics associated with a children's hospital, except for in one study in which participants were recruited from the community (Peterson, Mason, Nelson, O'Fallon, & Gabriel, 1997).

The findings from the articles based on the social determinants of health are described in the five categories described in Table 1: biology, individual behaviors, social environment, physical environment, and health services. In addition, findings about the effect of these variables on health outcomes (disease severity/disability, mental health, treatment adherence, use of alternative treatment options, and health-related quality of life) are integrated within the discussion.

Determinants of Health

Biology

The biological determinants of health extracted for this analysis were sex (male or female) and age of the person with JA at the time of the study. Other biological and genetic variables (i.e. specific genetic testing or family history) were beyond the scope of this review. The final sample of people with JA was 70.2% female (n = 1263). Only one study did not report the number of females versus males in the sample.

Ten of the studies in the final analysis included samples of children with JA. The weighted pooled mean age of children with JA at the time of the study was 9.92 ± 4.21. Two studies included samples of adults who had been diagnosed with JA prior to 16 years of age (Morse, 1972; Peterson et al., 1997). In the Morse (Morse, 1972) article, the majority of participants were age 12–18 (62%), but 38% were between the ages of 19–61 years. The sample in the Peterson et al. (Peterson et al., 1997) study was a mean age of 34 years at the time of the study.

Individual Behaviors

The individual factors found within the articles include physical activity/leisure, dietary modifications, psychosocial functioning, and vocational aspirations. Two studies evaluated leisure activities and physical activity (Cavallo, Majnemer, Duffy, & Feldman, 2015; Peterson et al., 1997). Despite equal interest in being active, the two studies concluded that children with JA have decreased capacity for physical activity and engaged in more sedentary leisure activities compared to healthy controls or siblings (Cavallo et al., 2015; Peterson et al., 1997). Children with JA were more likely to engage in spontaneous physical activities as opposed to planned, formal activities (Cavallo et al., 2015).

Three studies involved the effect of diet on JIA outcomes (Feldman et al., 2004; Shenoi, Shaffer, & Wallace, 2016; Zebracki et al., 2007). Neither exposure to cow's milk prior to one year of age nor breastfeeding were associated with the development of JIA (Shenoi et al., 2016). In two additional studies, dietary modifications were found in the context of complementary and alternative medicine (CAM) studies (Feldman et al., 2004; Zebracki et al., 2007). Specifically, participants who were in the majority ethnic group or who identified as natives of their country of residence (i.e. “Canadians”) had tried a dietary modification to treat JA, while the minority ethnic group participants or those who identified as immigrants did not report trying any dietary modifications as CAM (Feldman et al., 2004; Zebracki et al., 2007). Notably, the sample size for the study of Latino children was small (n = 36). The articles did not discuss any benefits or outcomes of the CAM dietary modifications.

Psychosocial functioning factors that were found in the final sample of articles included the child's self-efficacy (Seid, Huang, Niehaus,

Table 2
Study characteristics: sociocultural influences on juvenile arthritis outcomes.

Study	Purpose	Study design & outcome measures/instruments	Setting & sample	Relevant findings & conclusions
Athreya & McCormick (1987)	To determine the impact of childhood chronic illness (juvenile rheumatoid arthritis) on families	Design: cross-sectional Measures: Family Impact Scale; Sociodemographic Characteristics; Medical History; Rand Health Insurance Study Child Health Questionnaire to measure: Health Care Use, Limitations in Activities of Daily Living, & Parental Perception of Child Health; Healthcare Costs in Previous 30 Days	Pediatric Rheumatology Center n = 138 mothers marital status 81.9% married education level 11.6% < high school, 44.9% high school, 43.5% > high school income 13% < $10,000, 23.9% $10,000 to <$20,000, 21% $20,000 to <$30,000, 26.1% ≥ $30,000; child's limitations in activities of living 36.2% no limitations, 19.6% 4 + limitations	Limitations in activities of daily living had a greater family impact than the actual medical diagnosis. Families who were most vulnerable required health care in amounts that exceeded the family resources. 30% of parents perceived child's health as poor. Healthcare use was high - 27.5% of children hospitalized with 1.5 admissions per child hospitalized. The higher the number of health services used, the higher the family impact scores. Marital status of the mother, low educational attainment, and low income were predictors of high impact scores. Higher impact scores were associated with indicators of higher morbidity for all outcomes.
Brunner et al. (2006)	To determine the relationship between health insurance status and disease outcomes in children with juvenile arthritis.	Design: prospective, cross-sectional Measures: Current Disease Activity; Global Parent Rating of Patient Well-Being; Disability via CHAQ[a]; PedsQL for HRQOL[b]	Tertiary Pediatric Rheumatology Center n = 295 children mean age 12.6 ± 4.8 disease duration 5.3 ± 4.6 95% White, 3% Black, 1% Asian, 1% Multiracial n = 255 private insurance n = 40 Medicaid # females vs. males not stated	Medicaid was used sig. more often in non-white children and is associated with more disability and lower HRQOL. Children with Medicaid presented with severe disease features at onset more often. There was a sig. difference in patient disability between insurance groups. Proportion of children achieving normal physical function was lower in Medicaid group. No important differences between racial groups on other important outcome measures. Similar access to care services between groups. Children with Medicaid had fewer MRIs[c], were twice as likely to visit ED[d], and were seen more in ophthalmology.
Byczkowski et al. (2011)	To assess the use of Internet-based portals among families of children with chronic diseases and to describe characteristics of portal registrants and users.	Design: retrospective observational study Measures: % of families who obtained a portal account; % used the portal for the 1st time w/ in 3 months and again 3–6 months after registration; number of times logged in; session length	Children's Hospital n = 389 parents of children with juvenile arthritis; mean age of child 10.8 (SD not stated); 73.3% female; 87.4% white, 5.9% African American, 6.7% other; 15.8% Medicaid; 67% reside large urban area, 22.9% small urban area, 10.1% rural	There were disparities in accessing electronic health data by race and insurance status. Barriers to adopting these tools may exist for racial minorities and publicly insured families.
Cavallo et al. (2009)[p]	To describe coping in a cohort of parents of children with JIA; to determine whether HRQOL is associated with parental coping; to explore whether socio-demographic factors such as child's age, family SES[e] and family structure are associated with parental coping.	Design: cross-sectional postal survey measured 3 times over a 1-year period Measures: Quality of Life via JAQQ[f]; Coping Health Inventory for Parents; Parental Distress via Symptom Checklist 90-Revised; sociodemographic questionnaire	Two large Children's Hospital Rheumatology Clinics n = 182 parents caring for a child with JIA[g] returned questionnaires; mothers' mean age 39.6 yrs.; fathers' mean age 42.2 yrs.; Child mean age 10.2 ± 4.4, range 2–18; parents working 69.3%; parents with high psychological distress 15.7%; 2-parent family 73%; low SES 39.2%; child duration of disease mean 4.2 yrs.; pain score 16.9; active joint count 1.8; child sex 69.2% female	Consultation with healthcare professionals most useful for parents of children with more dysfunction; greater psychosocial dysfunction with JIA is associated with higher degree of parental psychological distress; coping by understanding the medical situation is most useful for parents of children with psychosocial difficulties but not those with systemic disease. Poorer child QOL = social support becomes less useful. Lower SES parents found Maintaining Family Integration and Understanding the Medical Situation most useful. No sig. association between parental coping and child's age or gender.
Cavallo et al. (2015)	To describe leisure activities of children and adolescents with JIA in terms of diversity, intensity, and enjoyment, and to identify potential determinants.	Design: cross-sectional Measures: Children's Assessment of Participation and Enjoyment (recreation, active physical, social, skill-based, and self-improvement leisure	Pediatric rheumatology clinic at a Children's hospital n = 107 children age 8–17 years w/ JIA and their families; mean age 12.8 ± 2.7 years; 75% girls; race/ethnicity not reported; family income ranged from CAN$ ~	Children with JIA participate in less physical activity than siblings w/o JIA. When compared with healthy Canadian population, both intensity and diversity in informal activities were lower in children with JIA. Children with JIA were more likely to engage in informal/spontaneous activities than

Table 2 (*continued*)

Study	Purpose	Study design & outcome measures/instruments	Setting & sample	Relevant findings & conclusions
		activities); disease characteristics; sociodemographic factors	32,000–107,000	formal, structured activities. There is equal interest in being active, but children with JIA engage in more sedentary behaviors on a daily basis than healthy controls. Higher family income = greater diversity in informal leisure activities.
Feldman et al. (2004)	To describe the frequency of CAM[h] use in patients with JIA and to explore whether CAM was associated with patient-specific characteristics, parent-specific characteristics, and medical management factors.	Design: cross-sectional Measures: CAM "ever use" and use in the past 3 months; Psychological distress with SCL-90-R; Adherence to treatment via PARQ; caregiver's coping with child illness via CHIP[n]; clinical information; demographics	Pedi Rheumatology clinics from 2 large pediatric university-based teaching hospitals n = 118 children enrolled; 67% female; mean age 10.4 ± 3.9; family income CAD$: 21% < $45,000, 34% $45,000–75,000, 46% > $75,000; ethnicity - 32% French Canadian, 45% English Canadian, 24% Other	44% of families encountered problems w/ management of their child's JIA. Ever use of CAM was 34%; use of CAM is common among patients with JIA. Ever use of CAM was higher in patients whose parents used CAM and among those who considered themselves French Canadian as opposed to belonging to a specific ethnic group. Other ethnic groups used CAM rarely (many were recent immigrants with fewer resources to expend on CAM). Parent reported adherence was high for medications and lower for exercises and splints. There was a non-statistically-significant trend to lower CAM use in families with lower family income (CAM is not covered by Canada's universal healthcare). CAM use was not related to decrease in adherence to conventional medical treatment.
Hill & Walters (1969)	To report the medical and social differences between patients w/ JRA[i] who were Indian and those who were not Indian.	Design: cross-sectional design, comparative analysis Measures: Functional classification modified from Steinbrocker, Traeger and Batterman's adult criteria; Social Questionnaire from Canadian Arthritis and Rheumatism Society Medical History; Scholastic Function based on letter grade	Children's Arthritis Center at a Children's Medical Hospital n = 70 subjects with JRA; 18.6% Indian; sample included 17 non-Indian boys, 40 non-Indian girls, 5 Indian boys, and 8 Indian girls; 68.6% female	The Indians were below average in school performance while non-Indians were above average. Children from large families suffered more from severe arthritis. All Indian families were large (≥4 children). Indian children came from smaller, overcrowded homes, more broken homes, less educated parents; 75% of families had marginal incomes and majority of fathers had irregular or no employment. Over half had ≥1 slow or mentally impaired child. 61% of Indian children were severely limited in functional capacity. No arthritis in siblings of Indian children with JIA, suggesting poor environment more likely predicts outcomes than genetics.
Morse (1972)	To determine the educational and vocational experience of patients with JRA.	Design: qualitative analysis w/ a semi-structured interview Measures: Aspiration and Achievement Questionnaire; Patient Perception of Guidance Counselors Questionnaire	Juvenile Arthritis Center at a Children's Hospital n = 100 patients with JRA; mean age of the sample not stated; 78 females, 22 males; 62% age 12–18, 10% 19–22, 13% 23–27, 15% 28–61; 95% financially independent or supported by families; 97% white, 3% black; 87% single	High level of educational and vocational aspiration and achievement; school guidance and state rehabilitation centers helpful to some people but there is room for improvement. Hospital social work was a bridge to community services.
Peterson et al. (1997)	To evaluate physical and psychosocial impact of JRA among a population-based cohort of adults who had the disease during childhood, compared with a control cohort of subjects w/ no history of JRA.	Design: population-based epidemiological research Measures: Disability assessed via HAQ[j]; demographics; health history	Residents of Rochester, Minnesota w/ JRA n = 44 responded (31 female) and n = 102 controls (68 female); mean age 34 years for both cases and controls; 96% white	HAQ worse, higher rate of unemployment, less ability for physical exercise among cases compared to controls. No difference in % completing high school, annual income among wage earners, health insurance status, and pregnancy rates or outcomes. Cases were advised against pregnancy more often than controls.
Rapoff et al. (2005)	To describe patterns of adherence to NSAIDs[k] in newly diagnosed patients with JRA, and examine demographic and disease-related variables as potential predictors of adherence.	Design: cross-sectional cohort study of 28 days Measures: Primary NSAID medication adherence monitored by an electronic bottle cap; demographics;	University Medical Center n = 48 participants; mean age 8.6 ± 4.0; 71% female; 90% white	Adherent group had a higher concentration of white patients, mothers had more education, were of higher socioeconomic status, and had a higher active joint count. Did not differ on age, sex, mother's or father's marital status, father's education, participant's JRA subtype, duration of morning stiffness,

(*continued on next page*)

Table 2 (*continued*)

Study	Purpose	Study design & outcome measures/instruments	Setting & sample	Relevant findings & conclusions
		disease-related variables		or complexity of NSAID regimen. Overall adherence rate was 52%. The most robust predictor of adherence to NSAIDs was SES.
Seid et al. (2014)	To examine the degree to which nonmedical factors explain additional variance in parent proxy report and child self-report of health-related quality of life among newly diagnosed children w/ JIA after accounting for medical factors.	Design: cross-sectional Measures: Medical factors; nonmedical factors; HRQOL measured via Pediatric Quality of Life Inventory Generic Core Scales; Physician-rated global assessment of disease activity; active joint count; select laboratory tests	Children's Hospital Medical Center n = 230 parents of children age 2–16 years; n = 180 patients >5 years (mean age 9.42 ± 4.49); 69.1% female; 92.6% White; 50.7% report problems w/ cost of care; 71% private insurance, 20.7% public insurance	Nonmedical factors, including self-efficacy, coping w/ pain, barriers to adherence, social support, and parental distress, are associated with HRQOL total, physical functioning, and psychosocial functioning scales. Parental distress associated w/ parent proxy-reported HRQOL. Child self-efficacy and social support were associated w/ self-report HRQOL.
Shenoi et al. (2016)	To investigate the association of selected environmental and early-life risk factors w/ the development of JIA.	Design: case-control study Measures: Questionnaire about early life exposures and environmental exposures	Pediatric Rheumatology Outpatient Clinic at a large Children's Hospital n = 225 cases (70.7% female, 84.9% white, mean age 11.1 ± 4.1) n = 138 controls (56.5% female, 79.7% white, mean age 10.7 ± 4.1)	Preterm delivery was associated with JIA. No association between household smoking or maternal parental smoking, breastfeeding, hospitalization w/ infection in the first year of life, daycare attendance before 6 years of age, household pets, or residential area prior to onset of JIA.
Shiff et al. (2010)	To explore factors associated w/ longer time from symptom onset to the first visit to a pediatric rheumatologist, and w/ longer time from first visit to a diagnosis of JIA.	Design: prospective cohort study (part of larger ReACCh[l] Out cohort study) Measures: Demographics; clinical data; JRA core set measures; JAQQ; Quality of My Life Questionnaire; SES via Parental Education	16 Pediatric Rheumatology Centers n = 319 newly diagnosed patients; 65% female; median age at baseline 8.0; ethnicity - aboriginal 7%, Chinese, Korean, or Japanese 7%, South Asian 7%, and European 67%; maximum level of parent education - elementary or secondary 19%, some postsecondary 33%, university or postgraduate 48%	Having a fever, any part of South Asian ethnicity, highly educated parents, and limp were significantly associated with shorter time from symptom onset to first pediatric rheumatologist assessment. Heel pain or enthesitis were associated with longer time to first pediatric rheumatology visit. South Asian children may have a more severe presentation of JA, parents may seek care earlier, may reside in urban or suburban areas making it easier to obtain care. Distance to pediatric rheumatology clinic did not influence time to first visit, despite 21% of patients living >150 km from a clinic and median distance was 38.2 km. Accessibility is not impeded by travel for the patients included in this study, but patients who were not referred were not included.
Toupin-April et al. (2009)[p]	To determine the frequency of use of different types of complementary and alternative health care in children w/ JIA, to evaluate their effectiveness from the parents' point of view, and to explore factors associated w/ utilization and w/ continued use.	Design: prospective cohort study, questionnaires completed every 3 months for 1 year Measures: JAQQ; CAHC[m] questionnaire; general information; Parent Adherence Report Questionnaire; Economic Hardship Questionnaire	Pedi Rheumatology clinics from 2 large pediatric university-based teaching hospitals caregivers of n = 182 children with JIA age 2–18; mean age 10.2 ± 4.4; 70% female; 76.3% Canadian cultural background	Neither children's demographic and socioeconomic characteristics nor disease status were associated with CHAC use. Lower parents' perceived helpfulness of medications and previous use of CAHC are associated w/ a longer use of CAHC by their child.
Toupin-April et al. (2012)[p]	To examine the associations among caregiver perceived economic hardship, psychological distress, children's disease activity, and HRQOL	Design: prospective cohort, measured at baseline, 6 months, and 12 months Measures: HRQOL	Pedi Rheumatology clinics from 2 large pediatric university-based teaching hospitals caregivers of n = 182 children with JIA age 2–18; mean age 10.2 ± 4.4; 70% female	Higher caregiver perceived economic hardship, psychological distress, and higher children's disease activity were associated with worse children's HRQOL.
Zebracki et al. (2007)	To describe the use of CAM and its relationship to symptoms of anxiety, depression, and dysthymia in Latino children w/ JIA or arthralgia.	Design: cross-sectional design Measures: Demographic and clinical Questionnaires; CAM questionnaire; CHAQ; Acculturation Rating Scale for Mexican Americans-II; Child and Adolescent Symptoms	Pediatric Rheumatology Clinic at a Children's Hospital n = 36 Latino children (n = 17 with JIA); mean age 12.29 ± 2.59; 70.6% female; Mexican 65% and 18% Puerto Rican; 41% income <$25,000; 65% primary caregiver high school graduate/GED[o] or higher education	The majority of families (56%) used at least one CAM therapy. Most common for Latino families was prayer, massage, meditation, skin creams, aromatherapy, touch therapy, and herbal medicine. CAM was used to manage pain or improve overall well-being. Parents considered CAM to be somewhat helpful. Level of acculturation was not associated with CAM use. Children's

Table 2 (*continued*)

Study	Purpose	Study design & outcome measures/instruments	Setting & sample	Relevant findings & conclusions
		Inventories-4		anxiety and depression were within normal limits. CAM use was not associated with psychological functioning in this group.

[a] CHAQ, childhood health assessment questionnaire.
[b] HRQOL, health related quality of life.
[c] MRI, magnetic resonance imaging.
[d] ED, emergency department.
[e] SES, socioeconomic status.
[f] JAQQ, juvenile arthritis quality of life questionnaire.
[g] JIA, juvenile idiopathic arthritis.
[h] CAM, complementary and alternative medicine
[i] JRA, juvenile rheumatoid arthritis.
[j] PARQ, parent adherence report questionnaire
[k] NSAID, non-steroidal anti-inflammatory drug.
[l] ReACCh out, research on arthritis in canadian children emphasizing outcomes.
[m] CAHC, complementary and alternative health care.
[n] CHIP, coping health inventory for parents.
[o] GED, general education diploma.
[p] Studies represent different aspects of the same sample of caregivers. The sample of n = 182 caregivers was counted only once in total sample size for the review.

Brunner, & Lovell, 2014), child coping with pain (Seid et al., 2014), and psychosocial functioning ((Cavallo et al., 2009; Seid et al., 2014; Toupin-April et al., 2009); Zebracki et al., 2007). Psychosocial functioning is defined as depression, anxiety, frustration, interacting poorly with siblings, feeling sad, or arguing often (Shaw, Southwood, Duffy, & McDonagh, 2006).

Reports of high educational and vocational aspiration were found in two articles (Morse, 1972; Peterson et al., 1997). Those in high school expressed an intent to pursue a variety of vocational roles. Working adults with JA had equivalent salaries, but overall there were higher rates of unemployment in those with JA as compared to controls. They also completed high school and intended to pursue higher education in comparable numbers to control groups.

Social Environment

Social environment factors found in the articles included race/ethnicity, psychosocial functioning, education level of the parent, education level of the patients, and socioeconomic status (SES)/income. Race and/or ethnicity were reported in all but three of the articles (Cavallo et al., 2009; Cavallo et al., 2015; Toupin-April et al., 2012). Of the studies with race or ethnicity data, 83.1% of the combined sample was white. Seven of these studies grouped all non-white racial or ethnic groups into a nonspecific "other" category ((Byczkowski, Munafo, & Britto, 2011); Feldman et al., 2004; (Hill & Walters, 1969; Peterson et al., 1997; Rapoff, Belmont, Lindsley, & Olson, 2005; Seid et al., 2014; Shenoi et al., 2016; Toupin-April et al., 2009)). Three studies investigated the needs of a particular minority group: Asian children (Shiff et al., 2010), Indian children (Hill & Walters, 1969) and Latino children (Zebracki et al., 2007). They concluded that health disparities exist among these groups in terms of disease outcomes, range of treatment options, and rate to first rheumatology visit.

Parental coping and caregiver psychological distress were measured in three studies ((Cavallo et al., 2009); Feldman et al., 2004; (Seid et al., 2014)). High levels of parental distress were reported at rates of 11–25%. High parental distress was associated with a lower child health-related quality of life in one study but was not associated with total HRQOL in another. CAM use was not associated with parental distress or coping with their child's illness (Cavallo et al., 2009). The two studies used different scales to measure health related quality of life and parental distress, but both found more parental distress with lower levels of child psychosocial functioning.

The education level of the parent or caregiver was reported in five studies (Feldman et al., 2004; (Hill & Walters, 1969; Rapoff et al., 2005); Shiff et al., 2010; Zebracki et al., 2007). Three of them found that a higher education level of the parent or caregiver was associated with better outcomes (Hill & Walters, 1969), shorter time to first rheumatology visit (Shiff et al., 2010), and increased medication adherence (Rapoff et al., 2005). The other two studies did not report any relationship between parental education level and outcomes (Feldman et al., 2004; Zebracki et al., 2007).

Three studies reported on the education level of the patients with juvenile rheumatoid arthritis (JRA). Two studies evaluated the education of patients with JRA as they age (Morse, 1972; Peterson et al., 1997), while a third looked at school performance of children with JRA of Indian descent compared to non-Indians with JRA (Hill & Walters, 1969). The two studies of the adults with JRA found high levels of educational achievement, and no difference between high school graduation rates of children with JRA and those without. However, these two studies included samples of 96–97% white children. In contrast, Morse (Morse, 1972) found that the Indian children were below average in school performance, while the non-Indians were above average.

SES and income influenced outcomes in the studies. Parents of low SES reported that maintaining family integration (completing activities with family members) and understanding the medical situation (asking doctors and other health professionals about their child's condition and care plan) were useful in managing their child's care at higher rates than those of higher SES. Yet these families were also less likely to access an electronic patient portal where they could obtain information autonomously. Racial and ethnic minorities were more likely to be of low SES and exhibit more disability, worse HRQOL, perform poorly in school, and have severely limited functional capacity. Among children with JA who reached adulthood, those who were employed had no difference in annual income among wage earners compared to controls, but they experienced more unemployment than controls. Even families of middle to high SES reported problems with the high costs of their child's medical care. As a result, higher caregiver perceived economic hardship at any SES level was associated with poor HRQOL in the child. In addition, SES was the most robust predictor of medication adherence.

Physical Environment

Two studies evaluated the physical environment's effects on the development of juvenile idiopathic arthritis (JIA) (Hill & Walters, 1969; Shenoi et al., 2016). The ethnic minority groups came from smaller, overcrowded homes and were more likely to be severely limited in functional capacity (Hill & Walters, 1969). One study found no association between the residential area, secondhand smoking in the household or maternal smoking, daycare attendance before six years of age, household pets, or hospitalization with infection in the first year of life

prior to onset of JIA (Shenoi et al., 2016). Notably, no other studies were found that evaluated the effect of pollution or other environmental toxins on outcome measures.

Health Services

Health insurance status was mentioned in six of the studies (Brunner et al., 2006; Byczkowski et al., 2011; Hill & Walters, 1969; Peterson et al., 1997; Seid et al., 2014; Toupin-April et al., 2009). The rate of Medicaid (government-funded insurance) coverage ranged from 15.5–20.7% of the samples. Those with Medicaid were more likely to be minorities, to have more severe outcomes, to have more significant disability, to have fewer diagnostic MRIs, were less likely to use CAM, more likely to visit an emergency department, and to have lower HRQOL. Outcomes were significantly different for those with public insurance versus private insurance in all studies except for one, in which no difference was found between those with JA and controls based on insurance type (Peterson et al., 1997); however, it is possible that the public insurance coverage has deteriorated in the time since the article was published. The healthcare utilization was reportedly equivalent between types of insurance groups, meaning that access to care and frequency of care were not limited by Medicaid.

Risk of Bias

Based on the Johns Hopkins evidence level and quality rating analysis, all studies were rated at evidence level 3 because they were non-experimental observational studies or qualitative studies. Two studies received a quality rating of B (good quality) and 13 received a quality rating of C (low quality or major flaws). Most studies were cross-sectional designs and lacked a control group, but a majority of the study groups were of sufficient sample size. Due to the paucity of research in this area, this is the most substantial available evidence from which to draw conclusions.

Instruments

The instruments used to measure variable outcomes were disparate across the studies. Four instruments were used to measure quality of life in these studies: PedsQL, Pediatric Quality of Life Inventory Generic Core Scales, JA Quality of Life Questionnaire, and the Quality of My Life Questionnaire. The Child Health Assessment Questionnaire was used to measure disability and physical limitations in three studies. SES was approximated with a variety of methods, including using parent education level, average income of geographic areas, actual income, or type of health insurance. There is a need for standardized measures of instruments in these studies.

Recommendations and Conclusions

Findings from this analysis indicate that health outcomes for children with JA are influenced by biology, individual behaviors, the social environment, the physical environment, and health services. This review expands upon previous literature because it clarifies the nature of these factors with evidence specifically obtained from patients with JA. It also categorizes findings within the framework used most often by the IOM and other major government agencies.

As expected, the majority of JA patients in this study were female. Since individual behaviors vary based on sex, and the social environment affects boys and girls differently, it is recommended that studies continue to evaluate the specific needs of girls versus boys with JA. This includes consideration of the role of the parents and caregivers and how their interactions may differ among males versus females with JA.

The sample was predominantly school-age children spanning from pre-K to junior high. There are gaps in the literature about very young children with JA and those children with JA who have become adults. Future research should focus on how developmental dependencies and communication challenges of the very young child with JA relate to the sociocultural health determinants and influence outcomes. In addition, the two studies addressing outcomes of children with JA in adulthood are outdated and in need of updating. Particularly, are the needs of children with JA who have grown into adults the same as adults with rheumatoid arthritis, or are there special considerations?

Individual behaviors found in the JA literature include physical activity, diet, and psychosocial functioning/behaviors. Interventions should focus on helping those with JA remain physically active by capitalizing on spontaneous physical activity opportunities as opposed to formal planned activities. Additional studies are needed about the effects of culturally appropriate, accessible, and financially reasonable dietary modifications on health outcomes, particularly because of the current popularity of gluten-free diets among caregivers of children with JA. The value of other CAM interventions among minority and low SES populations should be explored to provide the greatest variety of options for those patients who experience the most severe problems. Interventions are needed to improve or preserve the self-efficacy of children with JA, and also to promote coping skills in both children and parents. No articles were found about alcohol use, cigarette use, and other drug use.

There is a paucity of literature about racial and ethnic minority children with JA and those children of low SES. Many of the samples were composed of 85% or more white children. Minority groups continue to be underrepresented in the research and are more likely to experience more severe outcomes of their JA. Since racial and ethnic minority groups are also more likely to be of low socioeconomic status and have lower education rates, it is imperative that special consideration should be paid to the needs of these groups to eliminate health disparities. More extensive support should be provided to parents so that they are able to financially, emotionally, and physically care for their children with appropriate levels of health literacy developed through quality education.

Families of low SES experience more severe disease outcomes, are less likely to adhere to medication regimens, and the children are more likely to have a poor HRQOL. They are more likely to find it helpful to obtain medical information directly from their caregivers, and yet they are less likely to independently access this information through an electronic portal. In the rush to adapt to technological advances, it is essential that providers continue to connect with patients and families to prevent health disparities.

The effects of the physical environment are understudied in this population. More research is warranted, particularly because power plants with high pollution emissions are linked to inflammatory health conditions (Brender, Maantay, & Chakraborty, 2011). Also, power plants with high pollution emissions are more likely to be located close to low SES neighborhoods and they disproportionately affect racial and ethnic minorities. For example, 2 out of 5 Latinos live within 30 miles of a power plant (Centers for Disease Control and Prevention (CDC), 2011; Rocha, 2016). Also, Latinos are 165% more likely than non-Latino whites to live in the counties with the highest levels of harmful pollution (Centers for Disease Control and Prevention (CDC), 2011; Rocha, 2016). These same neighborhoods are more likely to have contaminated water and be lacking safe outdoor spaces to play (Brender et al., 2011; Centers for Disease Control and Prevention (CDC), 2011; Rocha, 2016). More research is needed in these areas to improve outcomes but also to assist policy makers with informed decisions.

Findings from this analysis indicate that those with Medicaid insurance are more likely to experience severe outcomes even though healthcare utilization was equivalent in these studies. Possible causes should be explored in more depth and policy analysts should look closely at how care for those with Medicaid can be improved. The effects of language barriers and acculturation are also missing from this literature and warrant further investigation.

There are limitations of the conclusions of this review. The studies were all of lower quality evidence due to the nature of the cross-sectional study design. Also, the small sample size of findings from some of the determinants of health indicates that more research is warranted. However, because there is a limited amount of evidence for JA, these studies

are of extreme importance and the best currently available indicator of the phenomenon.

In conclusion, outcomes in children with JA are affected by all five categories of the determinants of health. Findings from this review expand upon previous work that concluded that demographics, health care systems, socioeconomic factors, cultural factors, and ethnic factors affect children with JA (Tesher & Onel, 2012). Specifically, this analysis clarifies the nature of these factors with evidence from children with JA instead of drawing conclusions from literature about adult populations or children in general. These factors should be taken into consideration when developing care plans, research studies, and policies in order to promote the best outcomes for this vulnerable population.

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