
Introduction to the Special Issue on Diversity and Health Disparities: Where Have We Been and Where Are We Going?

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Received February 16, 2016; revisions received February 23, 2016; accepted February 25, 2016

The Health Resources and Services Administration defines disparities as “the population-specific differences in the presence of disease, health outcomes, or access to care” (USDHHS, 2001). A substantial body of literature has documented that disparities in children’s health outcomes are widespread, persistent, and costly (Institute of Medicine, 2002). Ethnic and racial disparities are well-documented in several areas related to children’s health, such as nutrition/obesity; tobacco; prenatal, early childhood, and maternal health; flu vaccination; injuries; and asthma (American Academy of Pediatrics, 2009). Differences in mortality rates, access to care and use of services, prevention and population health, health status, adolescent health, chronic disease, and quality of care are specific areas in which racial and ethnic health disparities have been well-documented (American Academy of Pediatrics, 2010). This Special Section of the *Journal of Pediatric Psychology* on Diversity and Health Disparities was conceived to stimulate dissemination of high-quality reports of pediatric psychology research, including systematic or topical reviews of clinical issues relevant to health disparities in children, and empirical studies using a variety of methods including qualitative designs, clinical trials, and observational approaches. This Special Issue provides important information regarding understudied populations (Crosby et al., 2016; Loiselle et al., 2016; McQuaid, Farrow, Esteban, Jandasek, & Rudders, 2016), medication adherence in diverse groups (Kolmodin MacDonell, Jacques Tiura, A., Naar-King, S., & Fernandez, 2016;

Loiselle et al., 2016), sexual risk behavior (Karoly, Callahan, Schmiede, & Feldstein Ewing, 2016; Kolmodin MacDonell et al., 2016), cultural and demographic factors associated with weight and obesity (Banks, Berlin, Rybak, Kamody, & Cohen, 2016; Lim, Govey, Silverstein, Dumont-Driscoll, & Janicke, 2016), and cultural issues in patient care (Becker Herbst et al., 2016; Valenzuela and Smith, 2016; Welkom, Riekert, Rand, & Eakin, 2016).

The Special Issue begins with McQuaid and colleagues (2016), who outline several critical areas of research needed to truly understand the complex relationships between race/ethnicity and the understudied condition of food allergy in terms of diagnosis, management, and treatment access. True disparities in food allergy prevalence are difficult to estimate owing to the heterogeneity of how the condition is defined in epidemiological studies. Psychosocial research in cultural influences on food allergy management and outcomes is hampered owing to measurement limitations, as the majority of quality of life and adjustment measures specific to food allergy have been validated on largely white, higher socioeconomic status (SES) populations, even though it is clear from other chronic conditions such as asthma and diabetes that illness beliefs and disease management vary by culture and racial/ethnic background. The few reports that exist regarding access to food allergy medication, such as epinephrine, and availability of appropriate food document barriers for low-income families and those of racial/ethnic minority status (Huang, Chawla, Järvinen, &

Nowak-Węgrzyn, 2012; Savage & Johns, 2015), suggesting that ongoing work may reveal disparities in food allergy management and outcomes.

In a related vein, Crosby and colleagues (2016) also address issues related to appropriate measurement, arguing that psychosocial screening measures, when used in sickle-cell disease (SCD) populations, should have validity with that specific demographic group. They provide an initial examination of the internal consistency and predictive validity of the Psychosocial Assessment Tool – General (PAT-2.0 GEN AYA; Pai et al., 2008) in a sample of 45 adolescents and young adults with SCD, demonstrating validity among most of the scales. The authors suggest that clinicians could use items from this instrument as a way to elicit greater information and detail about psychosocial issues that may facilitate or interfere with family disease management in SCD, and ultimately improve management in this underserved population.

Loiselle and colleagues (2016) also focus on the important condition of pediatric SCD, and provide a systematic review and meta-analysis of studies involving medication adherence. Their comprehensive overview provides medication adherence rates by assessment method and medication type, and identifies important correlates for future research. SCD is disproportionately present in African-American and Latino children. Difficulties with medication adherence are widely observed, and can lead to additional disease complications and even death (Division of Blood Diseases and Resources, National Institutes of Health, 2002; Hassell, 2010). The authors indicate that, as SCD disproportionately affects individuals from diverse backgrounds, there are specific stressors such as discrimination and systemic factors (e.g., bias related to race and ethnicity that may affect providers' perceptions of adherence) that could uniquely contribute to adherence difficulties in these families. Given that these factors may ultimately result in lower quality of care, it is important to identify them to develop targeted interventions to enhance medication adherence in high-risk groups. Less than a third of studies reviewed by Loiselle and colleagues (2016) evaluated adherence in relation to demographic, medical, or psychosocial factors, indicating that the literature regarding correlates of this important component of disease management remains underdeveloped. Consistent with the theme of appropriate measurement strategies in diverse groups described in the first two papers (Crosby et al., 2016; McQuaid et al., 2016), the authors note that a more rigorous assessment of adherence, such as objective monitoring, may be necessary in future studies, and multilevel contributors to variations in adherence should also be evaluated.

In a related vein, Kolmodin MacDonell and colleagues (2016) acknowledge that racial and ethnic

minority (REM) youth with HIV are at particular risk of poor adherence to antiretroviral therapy and, consequently, having higher viral loads. Few studies of HIV among youth have focused on REM groups to identify the relevant contextual factors related to poor adherence. The authors test a conceptual model of adherence behavior focused on REM youth. Results indicated that youth with increased self-efficacy had better adherence, higher motivational readiness to take antiretroviral therapy, and greater self-reported social support. Additionally, youth with psychological symptoms and problem-level substance use had lower rates of adherence. The authors argue that interventions should aim to improve self-efficacy to improve adherence. They further note that the increased use of motivational interviewing would be helpful, particularly via field outreach for those youth who are unable to be reached in clinic settings. This paper also provides evidence for the resilience of sexual minority youth; specifically, sexual minority youth did not express more difficulties in these areas than heterosexual youth, despite literature that suggests that sexual minority youth often have poorer outcomes. The authors also note the applicability of their model to examine adherence among minority youth with other chronic illnesses.

Related to sexual health, Karoly and colleagues (2016) examine factors that may protect mainland U.S. Latino adolescents from elevated risk for negative outcomes related to risky sexual behavior. One unique feature of this paper is that it includes a focus on the Hispanic paradox for sexual behavior among this group, and considers the moderating role of parent monitoring. The Hispanic paradox is the name for a pattern of findings in the literature demonstrating that acculturated/assimilated children of Hispanic immigrants experience poorer developmental, educational, and health outcomes than those immigrant children who are less assimilated and tend to retain their cultural values, norms, and behaviors (Garcia Coll & Marks, 2012). In contrast, Karoly and colleagues' (2016) findings indicate that generational status was not directly associated with sexual behavior. However, the extent of parental monitoring of the teen's location appeared to have a protective role in decreasing the risk for sexual behaviors for certain youth. Specifically, greater monitoring of location was associated with less risky sexual behavior, but only for youth second generation and above. This study points to the importance of studying additional family and cultural factors related to sexuality, communication, and relationships (e.g., family connectedness), as well as immigration-related factors (such as time spent in the United States), to shed additional light on these findings, and the need to examine

whether these processes are unique to specific ethnic groups.

Ethnic factors are also a focus for [Lim and colleagues \(2016\)](#), who examined the relationship between depressive symptoms, ethnic identity, and health-related quality of life in overweight and obese children. They found that ethnic identity (specifically, the Affirmation and Belonging subscale of the Multigroup Ethnic Identity Measure; [Roberts et al., 1999](#)) moderated the relationship between depressive symptoms and health-related quality of life among minority youth. Ethnic identity is seen as an important variable to examine when looking at psychological and quality-of-life factors, as a strong sense of ethnic identity may be protective for minority youth, particularly with respect to disease management behaviors ([Koinis Mitchell et al., 2012](#)). Future research in this area would benefit from longitudinal designs to explore the causal and mechanistic impact of ethnic identity. The authors also recommend the inclusion of aspects of ethnic identity in pediatric weight management interventions, particularly as it relates to eating practices, food preferences, and physical activity patterns.

Continuing with the theme of obesity, [Banks and colleagues \(2016\)](#) challenge the notion that high SES may be beneficial for all children in regard to their risk for obesity owing to the assumption that higher SES may afford access to better nutrition, higher levels of parental education that may be more likely to have knowledge about the benefits of specific foods, access to more physical activities, safer communities for outside play, etc. In fact, the authors found that SES has a differential impact on adiposity for different demographic groups; higher SES predicted higher initial body mass index z -score (z BMI) for black males and lower initial z BMI and rate of change for white males. A nonlinear relation between SES and z BMI was found for white females. The next question that bears further examination in future studies is *why*? The timing of exposure to poverty across individual age trajectories is a strength and contribution, as it allows for timing and impact of exposure. The next important steps based on these findings appear to be to identify the multilevel processes that may explain these associations between SES, race, age, and obesity risk. Further, although the study included non-Latino white and African-American youth, examination of children from other ethnic groups and subgroups is necessary with respect to examination of trajectories of weight status over time.

The study by [Welkom and colleagues \(2016\)](#) goes beyond investigating the relationship between simple SES indicators and health behavior by examining the associations between caregiver health literacy and smoking-related outcome expectancies,

implementation of home/car smoking bans, and child secondhand smoke exposure. Caregivers with low health literacy had higher levels of home air nicotine and child salivary cotinine. Ten percent of the primarily African-American sample had low health literacy, consistent with national samples (14%), but better than what is typically found in other African-American (24%) and low-income (27%) groups, but the measurement of health literacy has been consistently variable. Further, this study points to the double-edged sword of the challenge of measuring of health literacy among people who may not be health-literate enough to complete such a questionnaire. The authors provide suggestions for increasing health literacy, such as utilizing simplified language and teach-back techniques and supplementing verbal information with pictures and/or videos, along with prioritizing and isolating essential material and presenting numerical data in a tabular format.

Consistent with [Welkom's focus on the importance of communication](#), [Valenzuela and Smith \(2016\)](#) provide a topical review that examined provider–patient interactions (PPI) in the context of racial/ethnic disparities. In adults, racial/ethnic minorities experience poorer PPI, which may be associated with poorer health outcomes. Emerging literature in the pediatric arena suggests that PPI can be targeted to help with health outcomes, including key factors such as information exchange, shared decision-making, and patient-centered communication. Methodological challenges in this research include the measurement of triadic (patient–caregiver–provider) interactions that are culturally and developmentally sensitive. Much research (a large portion of it from the asthma literature) has shown that parents and children don't ask questions of their providers ([Sleath et al., 2014](#)). Research with REMs shows that they feel less understood by health care providers (HCPs), spend less time with them, and have less adequate explanations about key issues such as consent and treatment course ([Sleath et al., 2014](#)). Studies consistently find that improved communication relates to better adherence and that increased shared decision-making is associated with decreases in hospitalizations, emergency visits, and office visits. Limited English proficiency is a major factor that can lead to poor health outcomes and is often complicated by the use of ad hoc interpreters. Motivational interviewing is relevant and can assist in the training of HCPs as well as its ease of use in reaching populations “where they're at.” Current measures of PPI don't take into account issues that are inherent to REM relationship with HCPs. Welkom et al. also discuss the importance of recruiting minorities into the health professions and improving HCP education on cultural issues.

Finally, [Becker Herbst and colleagues \(2016\)](#) indicate that the integration of behavioral health into primary care remains an important area of opportunity and growth for pediatric psychologists. Patient-centered medical homes with integrated behavioral health approaches hold promise for addressing health disparities, given their focus on treating patients in their communities and providing coordinated care. The article poses the interesting question of what disparities may persist when behavioral health consultation is integrated into a primary care medical home setting. Findings from their evaluation of a coordinated system providing care to a multilingual population indicate some key disparities among language groups in presenting concerns, medical record documentation, and referral to behavioral health services. Interestingly, analysis of medical records revealed less documentation of behavioral health or psychosocial issues among families with limited English proficiency, and limited discussion of family strengths and resources. This finding may suggest that provider and/or interpreter language limitations may have resulted in “missed opportunities” to fully explore family behavioral health needs and resources, which may be important for culturally tailored recommendations. As with the manuscript by [Valenzuela and Smith \(2016\)](#), these findings illustrate the importance of continuing to consider language as an important factor that may compound health disparities among culturally diverse populations.

Conclusions and Future Directions

In 2012, *JPP* published a related Special Section on Families, Culture, and Health Outcomes ([McQuaid & Barakat, 2012](#)). Strengths of published research at that time included an increased focus on cultural factors not only as a risk factor for health disparities but also as a protective factor for health promotion. A number of articles also provided examples of effective methods and strategies for recruitment and retention of diverse groups to facilitate our ongoing investigations in health disparities. Despite these encouraging trends, [McQuaid and Barakat \(2012\)](#) suggested a number of important agendas for promoting high-quality research in cultural issues and health outcomes. These recommendations included increased emphasis on cultural groups less typically studied, including vulnerable populations such as refugees, immigrants from the Middle East, and understudied populations within the United States and Canada, such as Native American and First Nations (aboriginal) families. Increased rigor regarding the definition and measurement of complex concepts such as acculturation, cultural identity, and cultural values was also deemed necessary. Finally, efforts to expand our training

approaches to include qualitative and mixed-methods research to assist in theory development and adaptation of evidence-based approaches for culturally diverse groups were recommended ([McQuaid & Barakat, 2012](#)).

This Special Issue on Diversity and Health Disparities addresses, to some extent, the further directions proposed by [McQuaid and Barakat in 2012](#); the current studies provide an increased emphasis on understudied populations, although there is a greater need for work on more vulnerable groups such as refugees. Additionally, while there is some evidence of greater emphasis on cultural identity ([Lim and colleagues, 2016](#)), more work is needed that incorporates multiple elements of this construct and experiences/processes that may be associated with it, including racial/ethnic identity, as well as immigration and acculturation related-factors such as nativity, generational status, and cultural stress.

Importantly, the studies presented in the current special issue provide a greater emphasis on the nuances of patient–provider interactions when culturally diverse families seek care within traditional health care systems ([Becker Herbst et al., 2016](#); [Valenzuela and Smith, 2016](#)). Investigations such as these will continue to grow in importance as the demographics of the United States and Canada become increasingly diverse; for example, population projections from the U.S. Census indicate that by 2060, the proportion of the current majority group (non-Hispanic white) will have decreased from 62.2% of the population to only 43.6% of the population ([Colby & Ortman, 2014](#)). The importance of increasing the diversity of the health care and public health workforce, as well as the need for cultural competence training for all health care professionals, will only grow in importance over the next few decades ([USDHHS, 2011](#)).

It is also clear from the work presented in this issue that there continues to be a need to build on our current understanding of the multilevel contributors to disparities in health outcomes that go beyond ethnic or racial background or SES. Although there is some growth in this area with respect to cultural and immigration-related factors, several helpful models in the literature with respect to specific chronic illnesses and health behaviors suggest that disparities are multiterminated and involve processes along the individual, family/cultural, environmental, and health care system levels ([Boergers & Koinis Mitchell, 2010](#); [Canino et al., 2006](#)). There is a need to expand upon our examination of processes within each of these possible determinants of disparities to better inform our intervention approaches with specific groups. For example, within the family/cultural domain, there is a need to identify specific cultural beliefs, values, and experiences that may guide health behaviors. Similarly,

biological processes that may be related to health outcomes such as immune function and other biomarkers of health status that may vary by race and ethnicity are important areas for future investigation in studies evaluating the multilevel factors that contribute to disparities.

Clearly, increased conceptual and methodological rigor will be important to enhance our understanding of cultural issues and health care disparities in pediatric chronic conditions. How we define “cultural diversity” is critically important. Some studies continue to dichotomize samples into minority and nonminority groups owing to limited representation in some racial and ethnic categories, potentially masking important cultural differences between disparate groups (e.g. Hawaiian/Pacific Islanders, Mexican Americans, African-Americans). Larger samples are needed to allow for finer distinctions among racial and ethnic groups that differ on numerous demographic, familial, and cultural characteristics. Sample representativeness overall continues to be an ongoing concern; limiting samples to only participants who speak English or those from higher SES backgrounds will, by definition, bias the conclusions we draw from our work. Measurement development and validation studies using largely middle-class, non-Hispanic White participants may ultimately bias not only our study findings, but the theoretical models we propose to understand and improve children and families’ health behavior practices.

Additionally, as recently proposed by [Lescano \(2015\)](#), more sophisticated analyses of ethnographic data in our ongoing intervention research will be necessary to ensure methodological rigor. This includes techniques such as the examination of whether randomization was equal by race/ethnicity across treatment groups, the assessment of differential attrition by race/ethnicity, the use of the race/ethnicity variable as a covariate in the analyses when appropriate, and the analysis of outcomes by racial/ethnic group (i.e., moderation analyses; [Mak, Law, Alvidrez, & Perez-Stable, 2007](#)). Further, more sensitive understanding of the multiple stresses families face versus a focus on a specific stressor using cumulative risk approaches may more sensitively capture the reality of those families with children who are at a higher risk for poor health outcomes ([Koinis Mitchell et al., 2007](#)).

In summary, the papers included in this special issue bring us closer to addressing the future directions for research described in the 2012 Culture and Health *JPP* issue. The ultimate goal of this area of health disparity research is to conduct sound research that will yield findings to better inform interventions that are effective for specific groups and, ultimately, will assist in decreasing the existing disparities in health outcomes in children across specific disease conditions.

Conflicts of interest: None declared.

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