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Introduction to the Special Issue: Addressing Health Disparities in Pediatric Psychology

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Received 14 July 2020; revisions received 14 July 2020; accepted 15 July 2020

Abstract

This introduction to the special issue on Addressing Health Disparities in Pediatric Psychology provides context for why this special issue is needed, reviews key findings of the accepted articles, and discusses future directions for advancing the field. This special issue, one of three on this topic area that has been put forth in the history of this journal, comes at a critical point in our world. This is a time when the COVID-19 pandemic is systematically infecting Black, Indigenous, and People of Color and when there has been increased attention to systemic racism and intersecting violence inherent in multiple systems, including the justice, health, and educational systems. Using Kilbourne et al. (2016) framework, this special issue focuses on Phase 2 and Phase 3 research. Rather than only identifying health disparities (Phase 1), this issue focuses on understanding mechanisms and translating such understanding into interventions and policy changes. The accepted articles span a wide gamut from obesity to autism to rural populations. Furthermore, the articles provide methods for advancing the field beyond simply noting that systematic differences exist toward strategies to address these inequities. We conclude this introduction by discussing next steps for future research, with hopes that it inspires the next generation to study issues of disparities and inequity in deeper, more meaningful, and impactful ways.

Key words: culture; disparities; professional and training issues; race/ethnicity.

Addressing disparities within pediatric populations and within the field of pediatric psychology has been a stated goal of the Society of Pediatric Psychology (SPP) for some time. This has resulted in previous special issues, statements, structural changes, and revisions to SPP's mission statement to reflect a focus on diversity, inclusion, health disparities, and promoting culturally responsive evidence-based practice. These efforts are particularly salient given the current context of the coronavirus disease 2019 (COVID-19) pandemic, which has exposed the underbelly of United

States-based health inequities, with systematic infection and death rates impacting Black, Indigenous, and People of Color (BIPOC) relative to white individuals (Centers for Disease Control and Prevention [CDC], 2020). Further, these disparities are occurring amid nationwide protests and a push for social justice reform addressing anti-Black systemic racism spurred by the disparate rates of police killings of Black community members. As pediatric psychologists, we must reckon with the realization that many of our patients, families, participants, trainees, and colleagues are disproportionately burdened by structural racism, discrimination, and disparate health outcomes. We must seek to ask the type of questions, provide the types of supports, and conduct the type of research that can ensure we are improving the health and well-being of *all* children.

In this introduction to the special issue, we are intentional in the language we are adopting. First, we unequivocally assert that race is a political and social construct that often serves as a proxy for the impact of systemic racist practices and structural inequality. Race is not a biological variable, and thus should always be examined with this premise in mind and with the intention of naming the driving forces behind any "racial differences." (Roberts, observed 2012: Smedley & Smedley, 2005). Second, we aim to model and encourage our field to move away from oppressive language toward Systems Centered Language (SCL). As defined by O'Reilly (2020), SCL is a "linguistic call to action that seeks to end the dehumanization of people that occurs while discussing how they are experiencing oppression." For example, instead of vulnerable populations, we use prohibited populations; instead of disproportionate, we use systematic. Such language shifts are necessary to move us away from using words that blame and shame individuals for intersectional, intergenerational, systemic racism, and discrimination that drive their experiences and health outcomes. Third, we assert the importance of labeling, studying, and intervening upon systemic racism as a specific cause of disease and as a distinct driver of racial health inequities (Boyd et al., 2020).

This special issue aims to push the discourse forward by moving our pediatric psychology profession from primarily documenting health disparities toward understanding mechanisms driving disparities; and developing and testing interventions, strategies, and solutions for eliminating the inequities. Ultimately, this special issue is about leveraging the power of research to promote and inform actions to address disparities and inequities in pediatric populations and in the practice of pediatric psychology. To move the health disparities research agenda forward, the Journal of Pediatric Psychology (JPP) has previously published special issues on economic, health, and mental health disparities among ethnic minority children and families (Willis, 2002); advancing research on the intersection of families, culture, and health outcomes (McQuaid & Barakat, 2012); and diversity and health disparities (Lescano et al., 2016); as well as a special JPP section on Diversity and Health Disparities (McQuaid, 2008). Each of these efforts has resulted in a broader array of publications focused on pediatric health disparities; but, now is the time to systematically advance the pediatric health disparities research agenda.

Kilbourne et al. (2006) provide a useful framework for guiding health disparities research progression by organizing the process into three phases: detecting, understanding, and reduction. According to the framework, health disparities research should progress sequentially by first identifying our most prohibited populations and documenting existing health disparities (Phase 1, detection); then identifying mechanisms driving health disparities (Phase 2, understanding); and ultimately, translating that work into interventions and policy changes (Phase 3, reducing/eliminating). Through previous efforts, the field of pediatric psychology has built up a solid literature base focused on detection of disparities in pediatric populations. However, less work is being focused on understanding, reducing, and eliminating these disparities. For example, in the 2016 JPP special issue on Diversity and Health Disparities (Lescano et al., 2016), the majority of the articles focused on documenting pediatric health disparities, highlighting the most prohibited populations, and showcasing measurement issues in pediatric health disparities work; but few articles focused on how factors linked to cultural and socioeconomic differences (e.g., systemic racism, ethnic identity, health literacy) impacted pediatric health, and no articles investigated interventions to address health disparities. A brief search of articles published in *JPP* since the 2016 special issue using the search terms "diversity" and "health disparities" identified only 12 articles, the majority of which focused on documenting pediatric health disparities. Building on the foundation of these Phase 1 studies, this special issue aims to inspire the field to push closer to elimination by promoting research focused on Phase 2, (i.e., understanding mechanisms that drive and ameliorate disparities in pediatric populations and pediatric psychology practice) and Phase 3 (i.e., reducing and eliminating health disparities within pediatric populations via interventions, translation and dissemination research, and policy change).

To engage in shared understanding, we begin by defining health disparities and health equity. While a "disparity" simply refers to difference, health disparities refer to specific kinds of health differences among various groups. Guided by Kilbourne et al. (2006, p. 2114) definition, we define health disparities as: "observed clinically and statistically significant differences in health outcomes and health care use between socially distinct" prohibited and less prohibited populations. Prohibited populations are defined as: "groups that have faced discrimination because of underlying differences in social status." This definition is inclusive of BIPOC communities, gender and sexual minorities, immigrants and refugees, individuals experiencing low socioeconomic status, individuals with disabilities, and other groups who have, or currently experience,

systemic racism and discrimination that lead to unequal health. Additively, health equity is the principle underlying the commitment to reduce and eliminate health disparities. It is actuated by seeking the highest possible standard of health for all while focusing on the needs of those exposed to the additional harms of poor health, based on their social conditions and identity (Braveman, 2014).

Consistent with our call for papers, the 13 articles selected for inclusion in this special issue focus on Phase 2 and Phase 3 investigations of Kilbourne et al. (2006) model. They include a commentary, a narrative review, qualitative, quantitative, and mixed methods studies.

Commentaries and Conceptual Reviews to Inform Future Health Disparities Research

A commentary (Valenzuela et al., 2020) was invited to remark on the specific contributions of both the COVID-19 and racism pandemics on pediatric psychology health disparities. Authors not only discuss these contemporary issues and their specific impact on BIPOC patients, families, and trainees but also highlight specific opportunities where pediatric psychologists can focus in order to begin to tackle these inequities. A topical review by Delozier et al. (2020) applies the minority stress framework to discuss and make suggestions for researching health disparities in transgender and gender expansive (TGE) adolescents. Their work both highlights the lack of research on TGE adolescents and highlights a promising framework for moving that research area forward.

Mediational Factors Driving Pediatric Health Disparities

A study by Avalos et al. (2020) examined the relationship between familism and self-esteem in the quality of life of Latinx adolescents with obesity. Their findings inform clinical providers about how increased familism and self-esteem can protect against poor weight -specific quality of life. A study by Mougianis et al. (2020) investigated the complex relationships between perceived racism, social support, depressive symptoms, and health-related quality of life in adolescents with sickle cell disease. Findings highlight the impact of racism on youth faced with dual challenges of managing a chronic illness while Black-identified in the United States. A study by Daniel et al. (2020) investigated mediators of parenting skills and child sleep in young Black- and Latinx-identified children. The findings emphasized the direct and indirect effects of household chaos, caregiver sleep knowledge, and caregiver sleep in understanding children's sleep; highlighting these factors as intervention targets for designing future interventions.

Modifying Interventions to Address Health Disparities

A qualitative study by Gordillo et al. (2020) examined how Latina-identified and non-Latina mothers of children diagnosed with Autism Spectrum Disorder make service decisions. Findings highlight how intervention programs focused on Latina mothers of children with autism should be designed to address their informational needs and cultural concerns. A mixed methods study by Jernigan (2020) focused on developing recommendations for healthy lifestyle interventions to address obesity in Black-identified girls. Findings highlight the lens through which Black-identified adolescent girls define health and the socioecological factors that influence their health attitudes, beliefs, and behaviors, with implications for enhancing program retention and sustaining intervention engagement in order to address disparities in obesity prevalence. A mixed method study by Everhart et al. (2020) gathered perspectives of school nurses to develop recommendations for school-based interventions that can address pediatric asthma disparities in an urban community. Findings highlighted strategies for coordination among researchers, medical providers, and schools to effectively address structural barriers to intervention implementation. A study by Fehr et al. (2020) focused on investigating factors that influence rural parents' treatment seeking behaviors and service delivery preferences. These findings highlight the value of integrating behavioral health services into primary care as a way to address rural pediatric health disparities.

Factors Impacting Implementation of Interventions to Address Disparities in Care Access

A series of studies identified factors related to implementing programs for racially and ethnically diverse populations and populations exposed to additional harm. A qualitative study by Patel et al. (2020) examined the experiences of Spanish-speaking families of children with leukemia to identify parent barriers to participation in a parent training intervention. By understanding barriers, the authors were able to pilot a well-received intervention for these patients. A qualitative study (Williamson et al., 2020) of caregivers and clinicians focused on identifying ways to adapt and implement evidence-based interventions for primarily Black-identified toddlers and preschoolers presenting with sleep issues in an urban environment relegated for people experiencing low socioeconomic status. The findings highlight the common and unique concerns of caregivers and clinicians living and working in these environments; thus, emphasizing the value of attaining both perspectives when designing and

preparing to implement interventions in settings relegated to have fewer resources. Another qualitative study (Butler et al., 2020) focused on parents of Blackand Latinx-identified children with Type 1 diabetes to identify barriers and facilitators to parental involvement in diabetes management. Their findings highlight the range of individual, social, and environmental factors that influence decision making for these parents, including their own distress, religious/spiritual coping, and access to diabetes technology. A longitudinal study by Vaz et al. (2020) examined which social risk factors predict future health complications among pediatric inpatients. Findings highlight the value of obtaining caregiver report of social risk in conjunction with medical chart information in determining risk for experiencing health disparities, and thus, families most in need of intervention.

Conclusions and Future Directions

The articles in this special issue start the process of moving pediatric health disparities research beyond documenting disparities and inequities to identifying factors and mechanisms driving and ameliorating disparities in health and health care delivery. However, there are still numerous gaps in complete coverage of these issues in this issue. The special issue has no studies using randomized clinical trials focused on interventions to address pediatric health disparities; studies applying concepts of diversity science, intersectionality of social identities, implicit bias, and cultural humility to understanding and reducing health disparities; and studies addressing the role of diversity and cultural humility in pediatric psychology training. It is our hope that this special issue will stimulate high quality research in all of these areas, which is critical for moving the pediatric health disparities research agenda forward. Though this special issue marks a solid step and our hope for a continued push to inspire the field forward, below are additional areas in need of focus and recommendations to advance pediatric health disparities research.

First, authors studying pediatric health disparities should center their work in the current literature for that population based on the appropriate Kilbourne et al. (2006) phase. For example, if researchers are working with a population that has emerging health disparities, key Phase 1 questions might include: "have disparities been well documented?" and "have measurement issues related to disparities in the population been addressed?" For populations where disparities have been well established, researchers should determine if their work is designed to progress the field to a place of understanding about the mechanistic drivers for the identified disparities or if previous work is being used to develop interventions and plan successful implementation of interventions. The Kilbourne and colleagues' phases can also be used to craft recommendations for future directions and clinical recommendations.

Second, a recent blog published "On racism: A new standard for publishing on racial health inequities" (Boyd et al., 2020) provides helpful recommendations for authors designing, conducting, and reporting on health disparities research; and for reviewers and editors evaluating manuscripts in this area. It is strongly suggested that researchers review these recommendations, but we highlight a few below. One recommendation for authors includes clearly defining race during the research design phase in a way that clearly references the sociopolitical nature of the concept-a self-report variable with particular social and identity related implications-and never offering genetic interpretations of race. Other recommendations include soliciting patient input to ensure the research is grounded in the priorities of the population being studied; identifying the policy and clinical implications of the research; and citing BIPOC experts whose work have been the basis for a large body of scholarship on systemic racism and health disparities. For reviewers and editors, recommendations include "being critical of work that reifies biological race"; "reviewing the citations" to ensure the submission reflects the range of data on race and racism; and "consulting experts," which may also mean acknowledging gaps in one's expertise to review certain aspects of papers. The blog post focuses exclusively on racial health inequity research; however, the recommendations can be expanded to other intersectional identities and their relevant sources of health disparities. For example, researchers should: (a) be clear about defining their key social identity concepts in their disparities work (e.g., race, ethnicity, language, socioeconomic status, disability, rurality); (b) be intentional about the positive and negative implications of the work; (c) seek community input from conception of the research project to distribution of findings; and (d) clearly cite the experts for work that has preceded the described project, with a particular focus on BIPOC who have been building the literature base.

In this spirit, it is important that we acknowledge that this special issue builds off the excellent work accomplished in previous special issues that highlighted these and other topics related to diversity and health disparities. We want to highlight a number of recommendations generated by the 2016 JPP special issue on diversity and health disparities (Lescano et al., 2016) that still need to be addressed to keep advancing the field of pediatric psychology health disparities. One such area highlighted for future work was addressing the needs of our most prohibited populations, including refugees. Given that 2019 marked a period with over 70,000 children being referred to the Unaccompanied Alien Child program of the U.S. Department of Health and Human Services (Administration for Children and Families, 2020), this focus is particularly timely and salient for pediatric psychologists. Other areas that remain unaddressed include research on cultural factors, such as cultural identity; increasing diversity and inclusion in the public health workforce; more cultural competence/humility training for all health care professionals; and increasing the "conceptual and methodological rigor" of pediatric health disparities research (Lescano et al., 2016, p. 389).

Last, diversity, inclusion, and health disparities topics should be acknowledged and discussed in the majority of pediatric psychology research regardless of whether these studies intentionally set out to examine pediatric health disparities or not. Issues of systematic health differences-whether related to race, ethnicity, gender, sexual orientation, socioeconomic status, or region-impact all of the factors, processes, and interventions we investigate. We, as pediatric psychologists, cannot ignore how these contextual factors shape us and the work that we do. This includes who we study, teach, and provide services to; how we study, teach, and serve them; how we interpret research results and patients' behaviors; and how we translate what we learn into recommendations and action. We must push ourselves to ask key questions early and often as we design, execute, interpret, translate, and implement our work. Our patients, students, participants, colleagues, and field depend on it.

Conflicts of interest: None declared.

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