



Diversity, Equity, and Inclusion within Pediatric Adherence Science

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Abstract

Given the long-standing history of systemic racism in psychological science, diversity, equity, and inclusion (DEI) efforts are increasingly vital to the advancement and improvement of the field. This commentary extends the seminal work of the article *Upending Racism in Psychological Science: Strategies to Change How Our Science is Conducted, Reported, Reviewed, and Disseminated* (Buchanan et al., *Am Psychol*, <https://doi.org/10.31234/osf.io/6nk4x>, 2020) by providing tangible applications and recommendations to improve DEI integration into pediatric adherence science. Real-world adherence examples are discussed regarding the challenges faced in systematically integrating DEI principles, potential solutions to overcoming barriers, and the implications of these efforts on scientific advancement in an effort to address and dismantle research practices that perpetuate inequity and White supremacy. Specifically, we provide discourse and practical guidance related to the *conduct, reporting, reviewing, and dissemination* of pediatric adherence science to promote dialog and produce actionable change toward the promotion of health equity and social justice.

Keywords Self-management · Compliance · Systemic racism · Treatment · Communities of color

Introduction

Recent estimates in the United States suggest that approximately 19 percent of U.S. children and adolescents currently have at least one chronic health condition (Child and Adolescent Health Measurement Initiative, 2020) including highly prevalent medical or genetic conditions such as asthma, epilepsy, type 1 diabetes, cancer, and sickle cell disease. Treatments for these conditions comprise a variety of regimens which may include a combination of daily and rescue oral

and inhaled medications, injections, use of medical technology (e.g., blood glucose monitors, insulin pumps), infusion therapies, physical and occupational therapies, and/or lifestyle adaptations (e.g., diet, exercise, sleep hygiene, hydration; see Modi & Driscoll, 2020 for a comprehensive review of disease self-management among pediatric populations). Adherence as a construct has been defined as “...the extent to which a person’s behavior (in terms of taking medications, following diets, or executing lifestyle changes) coincides with medical or health advice” (Haynes et al., 1979). Despite the advent of new therapies and medical advancements, suboptimal adherence remains a prevalent concern among youth with chronic health conditions, significantly impacting health outcomes and symptoms (e.g., Schwartz et al., 2010; Walsh et al., 2014), treatment efficacy or escalation (e.g., Carmody et al., 2019), quality of life, and health care utilization and costs (e.g., Hommel et al., 2017; McGrady & Hommel, 2013). Further, developmental considerations add complexity to understanding adherence. For example, the level of caregiver involvement in a youth’s life, school environments, an increasing desire for independence during adolescence, and the transition to adult care all play a significant role in disease self-management, including adherence (e.g., Feldman et al., 2018; Gray et al., 2018; Gutiérrez-Colina

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et al., 2018; Schmidt et al., 2020). While these data demonstrate pediatric adherence to be a vitally important construct to address in clinical research, it is important to note that these studies have been conducted with predominately White samples that lack diversity. Additionally, health disparities exist across various conditions and racial and ethnic groups, as suboptimal levels of adherence are disproportionately observed in patients and families from underserved and historically marginalized communities (e.g., Centers for Disease Control & Prevention, 2013; McQuaid & Landier, 2018). While these data are unfortunately not unique to pediatrics, pediatric adherence science has a unique opportunity to integrate DEI into adherence promotion efforts early in life while health behaviors are being developed. Pediatrics is also well poised to help us better understand aspects of intersectionality and interactions with adherence behaviors. While our patients and families may experience inequities directly in the care and management of the child's chronic illness, families of these youth bring with them their personal life experiences, including experiences of racism and discrimination. These experiences of inequity and oppression in the larger context of families' lives may also impact the child's individual disease management. Further, within families, individual members may also have varied experiences, adding additional complexity to pediatric disease management. Examples may include differences in cultural beliefs, varied language proficiency, or exposure to systemic racism in healthcare settings between pediatric patients and their caregivers. Moreover, pediatric adherence science as a field of study is in need of increasing dedication to diversity, equity, and inclusion (DEI).

Across the field, the term “adherence” has grown in acceptance as compared to its predecessor, “compliance.” Following an important reconceptualization of the term and field more broadly, adherence was chosen to reduce blame (i.e., for suboptimal health outcomes) on patients and/or families and to better reflect the active and important role patients and families have in selecting, consenting to, and implementing treatment recommendations discussed with medical providers (Lutfey & Wishner, 1999; Modi & Driscoll, 2020). Still, adherence has its own negative connotations. For example, there is growing recognition in the type 1 diabetes literature highlighting how adherence may still imply engaging in behaviors that someone else (i.e., a medical provider/team) wants to occur (Dickinson et al., 2017; Modi & Driscoll, 2020).

Despite ongoing discussion around terminology, research efforts have demonstrated a growing appreciation for patients and families, including increasing emphasis and acceptance of shared decision making, wherein patient, caregiver(s), and clinicians arrive at a decision regarding medical care collaboratively (Barry & Edgman-Levitan, 2012). Given the focus on attending to patient and family rights and values,

shared decision making is currently considered best practice (National Quality Forum, 2018). However, the use of shared decision making across providers and clinical care environments remains variable. Further, inequitable use of shared decision making has been observed with patients from communities of color (e.g., Couët et al., 2015; Jolles et al., 2019).

The re-examination and adaptation of research practices and procedures with greater respect to diversity, equity, and inclusion (DEI) has become of utmost importance within the larger scientific literature. In psychological science in particular, recent articles such as Buchanan et al. (2020) have highlighted “epistemic oppression” (p. 3) within the field, including the systematic exclusion, underrepresentation, segregation, and overgeneralization of communities of color¹ in psychological research. Buchanan et al. (2020) share how these practices, which are widespread and over-relied upon in psychological science, beget research that is inherently inequitable and biased. As such, Buchanan et al. (2020) provide suggestions to eliminate such oppression and produce research that is more equitable, just, actively antiracist, and closer to being free of systemic biases.

While this work has generated conversation and movement in the field, more work is needed to apply these principles systematically and across domains of psychology, including adherence science. The purpose of this commentary is to extend the recommendations outlined by Buchanan et al. (2020) by applying their DEI principles, particularly around race and ethnicity, to pediatric adherence science. Application of these principles is particularly important in psychological science, which includes adherence science, given the history of medical injustices perpetrated against individuals and communities of color. In accordance with the topics delineated in their article, we will discuss potential methods for *conducting, reporting, reviewing, and disseminating* equitable and inclusive pediatric adherence and self-management research.

Conducting Adherence Science

Conceptualization

Accurately conceptualizing adherence and self-management require grounding research in a theoretical model that considers DEI. There are limited DEI theories specific to pediatric adherence science; however, the Pediatric

¹ “Communities of color” is used throughout this manuscript per recent inclusive language guidelines published by the American Psychological Association (2021). For more details, visit: <https://www.apa.org/about/apa/equity-diversity-inclusion/language-guidelines.pdf>.

Self-Management Model is one example that considers the relationship between race and ethnicity, social determinants of health, and adherence, and provides a framework for incorporating these variables into adherence research (Modi et al., 2012). When designing research studies guided by this model, it is recommended that researchers consider conceptualizing these constructs as mechanisms of change rather than demographic variables to control for (Modi et al., 2012). Research guided by this approach, for example, may assess racism as a potential moderator or mediator of adherence rather than simply including the patient or caregiver's race as a control covariate.

Despite its' strengths, the Pediatric Self-Management Model was developed using available research, which was conducted among samples composed of predominantly White individuals. Diversity Science approaches may be particularly informative as we continue to advance our theoretical models of adherence and increase population representativeness in our adherence research. For example, Minority Stress Theory considers how experiences of stigma, prejudice, heteronormativity, rejection, and internalized homophobia impact health outcomes and behaviors (Meyer, 2003). In adherence science, this theory has recently been applied to examine the use of pre-exposure prophylaxis (PrEP) among young men who have sex with men (Meanley et al., 2021). The Pediatric Self-Management Model could also be informed by this theory as experiences of minority stress can have implications on self-management behaviors across individual, family, community, and healthcare system domains. For example, while the present model discusses the importance of illness-related stigma, it could be expanded to include how internalized racial or ethnic stigma in the presence or absence of societal prejudice and experiences of systemic racism may contribute to underutilization of healthcare, suboptimal adherence, and/or feelings of mistrust towards healthcare providers and the healthcare system.

Black Feminist Theory, as another example, highlights the intersections of racism, sexism, and classism and their influence on maternal and child health (Barlow & Johnson, 2021; Simmons, 2021). While the Pediatric Self-Management Model presently alludes to the influences of racism, particularly in acknowledging known health disparities, the model could be adapted to explicitly address racism, sexism, and classism and implications at each domain level. Relatedly, the Intersectionality Framework further highlights the intersection between socioeconomic position and race and ethnicity (Crenshaw, 1989) and can be applied to understanding health outcomes. The Pediatric Self-Management Model could benefit from additional information on how factors such as race and racism, sex and sexism, class and classism, as well as socioeconomic position, intersect and influence self-management and adherence outcomes. For example, this framework has recently been applied to

examine glycosylated hemoglobin (HbA1c) trajectories, a marker of self-management, among youth and young adults with type 1 diabetes (Liese et al., 2022). Moreover, incorporating these theories and intersecting constructs into existing models, such as the Pediatric Self-Management Model, may provide an improved and inclusive framework for understanding adherence challenges, thus, facilitating the development and selection of more equitable study designs.

Once a guiding theoretical model has been selected, representative stakeholders should be involved in defining and refining the research question (i.e., Phase I design) (Czajkowski et al., 2015). Community-based participatory research (CBPR) approaches may be particularly useful during this step. For example, community-advisory board approaches have demonstrated success in addressing disparities in health outcomes among adults (e.g., Cooper et al., 2016). At our own institution, we utilized a Stakeholder Advisory Council, wherein patients with sickle cell disease and their caregivers were involved in developing and implementing a shared decision-making self-management intervention (Hood et al., 2021). Ensuring that key stakeholders represent the racial and ethnic make-up of the patient population can maximize the likelihood that an engaging, inclusive study design, and/or adherence intervention is developed.

Recruiting & Training Researchers and Staff

Efforts should be made to enhance recruitment of study staff of color to support inclusive research and increase diversity within research teams (i.e., research assistants, students/volunteers, other research team members). Institutions and principal investigators should utilize equitable employee and volunteer recruitment methods within the community, rather than those restricted to academia and/or other internal processes. Efforts should also be made to engage high-school and undergraduate students from diverse backgrounds in adherence science, for example by offering summer training opportunities (e.g., <https://www.cincinnatichildrens.org/education/research/high-school/biomedical-research-internship-minority>) and courses that address pediatric adherence science (e.g., Introduction to Clinical Child/Pediatric Psychology offered at the University of Florida). Research teams should also obtain feedback from those hired and re-evaluate procedures routinely to promote more inclusive and equitable recruitment and retention of staff from diverse backgrounds over time.

Beyond research staff, institutions and research teams should also make efforts to enhance recruitment and retention of diverse investigators and collaborators. This may include promoting diversity cluster hires (Sgoutas-Emch et al., 2016) followed by strategic retention practices and diversity funding initiatives to demonstrate value and

Table 1 Resources for Training Research Staff

| Resource title | Organization | Website |
|--|------------------------------------|---|
| Good Clinical Practice eCourse | Society of Behavioral Medicine | https://www.sbm.org/training/good-clinical-practice-for-social-and-behavioral-research-elearning-course |
| Implicit Association Test | Project Implicit | https://implicit.harvard.edu/implicit/takeatest.html |
| Equity, Diversity, and Inclusion: Inclusive Language Guidelines | American Psychological Association | https://www.apa.org/about/apa/equity-diversity-inclusion/language-guidelines.pdf |
| Advancing Health Equity: A Guide to Language, Narrative and Concepts | American Medical Association | https://www.ama-assn.org/about/ama-center-health-equity/advancing-health-equity-guide-language-narrative-and-concepts-0 |

commitment to diverse scholars (e.g., Syed et al., 2018). Research has also suggested that efforts to support retention of diverse faculty and trainees may also be an effective path to increasing overall faculty diversity over time (e.g., Allen-Ramdial & Campbell, 2014). Additionally, training faculty search committees to improve diversity in hiring procedures (e.g., Cavanaugh & Green, 2020) and/or requesting that Human Resource departments give particular attention to diversity characteristics and provide a diverse applicant pool to be reviewed by search committees may be helpful. This is particularly important for adherence science as the biomedical literature suggests that diverse research teams publish more frequently, are cited more often, produce studies of higher quality and clinical significance, and are better equipped to address health disparities given complementary skill sets, greater variety in thought processes and experiences, and increased willingness to pursue innovative and creative ideas and solutions (e.g., Adams, 2013; Eckstrand et al., 2016; Freeman & Huang, 2014; Swartz et al., 2019).

Once hired, researchers and staff should be trained in DEI issues relevant to the patient population prior to study start-up. Historical mistrust of research and health care contexts (e.g., Jaiswal & Halkitis, 2019; LaVeist et al., 2009) may prohibit study enrollment (e.g., George et al., 2014; Stevens et al., 2016). Further, in adherence science specifically, personal and cultural beliefs about a chronic health condition and/or treatment regimens may also influence adherence behaviors (e.g., Shahin et al., 2019) and subsequently a patient and/or family's desire to participate in adherence-focused research. As such, an understanding of sociocultural influences on adherence is critical to treating participant families with empathy and understanding, rather than judgment, regardless of their adherence behaviors or willingness to participate in research.

Many institutions have embarked on training staff in DEI approaches broadly (e.g., Enders et al., 2021) and researchers could extend this training into their own labs. Training should emphasize how the historical trauma that research has imposed on individuals of color (e.g., the Tuskegee Syphilis Study) and the history of racism in medicine (e.g., forced sterilization of Indigenous

women) may impact adherence. For example, investigators and staff funded by the National Institutes of Health are now required to be trained in Good Clinical Practice. This e-course, available through the Society of Behavioral Medicine, may be particularly helpful for adherence scientists and research teams working with diverse participant populations. Researchers may also want to encourage their staff to take the Implicit Association Test, available through Project Implicit, to understand their own biases prior to working with research participants. Staff should also be trained on using equitable and inclusive language, for example, by becoming familiar with the American Psychological Association and American Medical Association's guidelines (see Table 1 for a list of resources described in this section). Ongoing conversations about language should consider perspectives on various terms utilized throughout the field and implications of each. This promotes more DEI-conscious conversation and scientific inquires among research teams (e.g., Atkin et al., 2022). Finally, staff should be aware of issues of equity, particularly in terms of collecting adherence data. For those conducting adherence research in type 1 and type 2 diabetes, for example, it is important that staff are aware of racial, ethnic, and socioeconomic inequities around access to diabetes-related technology (e.g., Addala et al., 2021; Akturk et al., 2021; Majidi et al., 2021). Such inequities necessitate that staff take extra care to ensure that interventions are delivered, and data are collected in equitable and inclusive manners. Sitting with a child and taking the time to go through the stored blood glucose levels in their meter may be necessary given that not all youth with diabetes have access to a continuous glucose monitor or software, internet, and a computer to upload their data.

In addition, training research staff to gently inquire about participation hesitations and declines during recruitment, as well as ensuring an understanding of all procedures through ample time for questions throughout the research process, may facilitate trust and confidence for prospective participants. Similarly, inclusion of testimonials of similar participants or word of mouth referrals from trusted community

partners could increase engagement and trust in the research process.

Sample Considerations

Efforts to enroll representative samples to accurately capture the voices of diverse participants are pertinent to a comprehensive understanding of adherence. While some chronic diseases occur in predominately White individuals (e.g., type 1 diabetes, inflammatory bowel disease, cystic fibrosis) relative to other racial and/or ethnic minority groups (e.g., LatinX, Black, Asian), adherence research in these diseases should not be relegated to only include White patients and families. Similarly, adherence research in sickle cell disease, a disease identified more predominately in Black individuals, should also include individuals and families from non-Black backgrounds. For example, Harry et al. (2019) conducted focus groups with adolescents and young adults with lupus, specifically ensuring the population included Black women, a group that is typically underrepresented in this area of research. Consistent with broad recommendations by Buchanan et al. (2020), it may also be beneficial to recruit samples exclusively comprised of individuals of color, in order to increase understanding and appreciation of adherence barriers and facilitators within diverse samples, rather than relying on comparisons between broadly defined racial and ethnic groups (Buchanan et al., 2020).

Enrolling representative samples often requires different recruitment and retention approaches to engage particular populations. For example, Ellis et al. (2021) reported the need for persistence in reaching out to some families of Black children with type 1 diabetes to make contact and recruit for clinical trials. Use of various contact approaches (e.g., mail, phone calls, texts, in-person) was critical in ensuring families were able to understand and participate in the research process; though in many cases, this persistence may not be common in the conduct of traditional research studies. This study, moreover, is a key example of the multimodal recruitment strategies that may be necessary to engage underrepresented communities of color in historically White-centered research.

Measuring Adherence

Research teams should also be trained in how the history of racism in medicine may impact the perception of tracking adherence via electronic monitoring devices (e.g., MEMS® pill bottles), a common adherence measurement strategy. For example, some patients and/or caregivers may express reservations about health data being collected via adherence monitoring devices and have concerns about who will have access to their data and what those individuals will be able to see (Ramsey et al., 2018). Research

teams should be trained in how to assess for, be sensitive to, and respond to these concerns during open, honest, and empathetic conversations (e.g., “I hear you have concerns about providing this information to our team. Can you tell me more about that?”; “How can we make your family feel more comfortable?”)

Despite the reconceptualization from compliance to adherence science, adherence research, by nature, assumes that patients and families are following medical recommendations that are decided upon by a medical expert. This can perpetuate a power differential between families and providers. While shared decision-making efforts have grown in acceptance and are designed to help mitigate these effects (Barry & Edgman-Levitan, 2012), the opinions of patients and families about their medications or proposed adherence regimens are not always included in the final regimen decisions. A lack of acknowledgment of a patient or family’s health beliefs, particularly if differing, may lead to patients and families to engage in adherence behaviors which are discrepant from prescribed regimens (e.g., Conn et al., 2007; Elliott et al., 2001). Thus, acknowledging the power differential between physicians and patients (e.g., Durand et al., 2014; Frosch et al., 2012), adherence researchers may wish to assess and address patient and caregiver understanding of, and agreement with, their prescribed regimen prior to measuring adherence and interpreting adherence data.

Discrepancies between patients and providers regarding treatment recommendations may also be related to issues of health literacy (e.g., difficulty calculating insulin ratios as part of diabetes management), access (e.g., patient splits time between households but was only prescribed one inhaler), or experiences of racism and discrimination (e.g., differences in prescribing practices, inequitable use of shared decision making). Further, to maximize the likelihood of obtaining an accurate estimate of adherence, research teams should recognize that the level of responsibility a youth has in managing their chronic condition changes across development and may vary across racial, ethnic, and sociocultural backgrounds (Yinusa-Nyahkoon et al., 2010). Research teams are encouraged to acknowledge and normalize that adherence is difficult every day and that all families and/or patients have things that get in the way of doing treatments. Such conversations open the dialog between researchers and patients and may allow for patients/families to accurately describe their adherence and barriers (Modi et al., 2009; Ramsey et al., 2018). We recommend multi-method assessment of adherence and adherence barriers, inclusive of qualitative descriptors (e.g., interviews, focus groups, written feedback), medical chart review, and quantitative data collection (e.g., electronic monitoring, Medical Adherence Measure, Barriers to Adherence Tool; Varnell et al., 2017; Zelikovsky & Schast, 2008) for a richer understanding of adherence-related concerns.

Finally, we acknowledge that many of the available measures of adherence were validated among samples described as predominantly White and that self-reported measures may only be available in English and/or be written at advanced reading levels. Further, analyses typically rely on normative data approaches and are conducted by comparing group differences, which may lose nuances in adherence when samples contain small numbers of participants of color. Given these limitations, adherence researchers should also strive to validate existing measures among samples of color and develop new measures and approaches to measurement and analysis as needed.

Reporting Adherence Science

Use System-Centered Language

When preparing study findings for publication, language selection is critical as the words we use can blame a person's identity rather than the inequities inflicted upon that group. We recommend selecting language that does not perpetuate negative stereotypes of communities of color and adequately describes the researcher's conceptualization and definition of race and ethnicity. Specifically, to describe the relationship between race and adherence, researchers could choose to say, "children with asthma who identify as Black or African American are exposed to additional harms that drive suboptimal adherence" instead of "Black or African American children with asthma are at-risk for non-adherence." To provide readers with a broader understanding of this conceptualization, we recommend that researchers then elaborate on the "additional harms" that they believe may be associated with suboptimal adherence. For example, additional harms might include experiences of discrimination and racism in the medical system or broader red-lining practices that contribute to sub-standard living environments for individuals of color that can make adherence more difficult (e.g., exposure to environmental hazards, limited access to healthy food or social services). These recommendations align with guidelines for inclusive language recently published by the American Psychological Association (American Psychological Association, 2019, 2021) suggesting the importance of selecting language that reflects person-first and identity-first perspectives; denounces White-centeredness, hierarchies among populations, and historical patterns of epistemic racism; and communicates topics related to racial and ethnic identity with honor, inclusivity and respect.

Within adherence science, the term "adherence" has largely replaced the term "non-compliance," as non-compliance carries with it connotations of blame. However, terms like "non-adherent" or "non-compliant" are often still ascribed to diverse populations and using either of these

terms to describe specific populations can link negative and blaming language to those individuals rather than to systemic adherence barriers. Dickinson et al. (2017) have provided recommendations specifically around the use of language in diabetes care and education, suggesting the use of neutral, non-judgmental, person-first, and strengths-based language. In this consensus report, Dickinson et al. (2017) also discuss how adherence may be a less preferred term when communicating directly with patients and families and recommends consideration of alternative language such as engagement, participation, involvement, or medication taking (i.e., "They take their medication whenever their family is able to afford it.")

Define Race and Culture Contextually

Researchers must be aware that race is socially and politically constructed, and that race and ethnicity are separate constructs (Braveman et al., 2017, 2022). When race, ethnicity, or other sociodemographic or cultural factors are included in statistical models, researchers should clearly describe why these variables were included and how these variables were collected and reported. To assist in these efforts, Palermo et al., (2021) provide instructions for reporting race and ethnicity in the *Journal of Pediatric Psychology*, a prominent journal for pediatric adherence science research. Specific attention is to be paid to terminology, sources used to identify race and ethnicity, reporting of race and ethnicity in sample description, and interpretation of race and ethnicity findings with explicit recognition of limitations (see Palermo et al., 2021).

In adherence science, the implications of not defining race and ethnicity contextually can lead to inaccurate generalizations about adherence among populations of color. For example, asthma prevalence and morbidity are higher among youth of color, and this discrepancy likely reflects that these youth face greater barriers to adherence than White youth due to systemic and structural factors (Asthma & Allergy Foundation of America, 2020). It is insufficient to say that youth of color experience "worse" adherence without acknowledging the existence of these adherence barriers. If adherence rates are consistently lower among communities of color, authors should discuss why this might be the case and propose hypotheses regarding the role of systemic racism on adherence behaviors (e.g., inequitable use of shared decision making) and in the broader field of science (e.g., measurement biases). A recent example examining adherence barriers in two racial groups (White and Black) found that Black children and caregivers experienced more healthcare system and community barriers that influenced seizure outcomes compared to White children who experienced more individual and family level barriers (Gutierrez-Colina et al., 2022). Authors discuss how systemic racism

influences racial differences in adherence barriers and recommendations to reduce health disparities that affect Black children with epilepsy are highlighted.

Report Sample Heterogeneity

Race and ethnicity are often examined as predictors of adherence by comparing adherence among communities of color to White samples. Adherence researchers should consider whether such categorization and comparisons are appropriate or necessary for their work. As discussed by Buchanan et al. (2020), an alternative, more equitable approach is to report sample heterogeneity, particularly within samples or subsamples of communities of color, and to discuss differences in adherence across groups, rather than singling out a specific race or ethnicity and presuming that all participants come from similar backgrounds.

Reviewing Adherence Science

Recommendations for reviewing adherence science within a DEI framework are broadly applicable to all types of health and pediatric research. The review of research occurs at many stages of the research process, from inception to dissemination, but is often incumbent on grant reviewing agencies, institutional review boards, journal reviewers, associate editors, and editors to ensure the application of best practices around DEI. Standards around reviewing should be established by journals to include review of systems centered and bias free language, with checks and balances built into the review process by authors, reviewers, and editors. Further, standards around reporting race and ethnicity (more than 4–5 categories) and gender (male, female, transgender, etc.) would benefit psychological science broadly (Boyd et al., 2020). For example, Buchanan et al. (2020) highlight a problematic double standard that studies conducted among predominantly White samples do not typically identify their sample demographics in the paper title, whereas studies conducted among predominantly individuals of color are often required to indicate and provide rationale for doing so. Until journals and granting agencies require specific, equitable attention to DEI throughout the research process, scientists are less likely to be intrinsically motivated to ensure representation in their research (Burlaw et al., 2019; Roberts et al., 2020).

Reviewing boards, whether for the National Institutes of Health or a specific journal, should have diverse representation, both from who the reviewer is demographically, to their areas of expertise and the types of research methodologies they conduct (Roberts et al., 2020). For example, community-engaged research (e.g., CBPR), qualitative

and mixed-methods research (e.g., focus groups, in-depth interviews, usability testing), and dissemination-implementation science expertise should be represented among reviewer groups. These methods allow for diverse scientific thinking and a deeper understanding of the socio-cultural influences on adherence science, leading to more thorough and inclusive review of adherence research. Consequently, attention to these considerations on review boards and panels incentivizes researchers to draw specific attention to these methodologies and other key DEI principles in submitted work, thereby advancing science bi-directionally.

Adherence science is conducted across a wide array of pediatric chronic conditions, which impact children from all walks of life. As reviewers, we should strongly critique research in which efforts were not made to reflect the true diversity of the population and which do not address the limitations of the study sample. To use clinical trials as an example, adherence science is substantially hindered when we develop and test interventions for the majority instead of incorporating the diverse and underrepresented perspectives of the full disease community.

Journal reviewers and editors should also consider the complexity of intersectionality as it influences adherence and self-management behaviors and encourage examination of data with this lens (Boyd et al., 2020; Raque et al., 2021). Further, journals should encourage authors to discuss the influence of social determinants of health and systemic racism on their findings (Boyd et al., 2020). However, for this level of reviewing to be possible, adherence researchers will need to measure and report on multiple constructs to ensure that race and ethnicity are not confounded with socioeconomic status (and other social determinants) or vice versa, and for both researchers and reviewers to evaluate factors predicting adherence through the lens of inclusion and intersectionality.

Finally, editors should be primed to review for inclusivity in publication practices to ensure an increasing trend in highlighting the work of individuals from diverse backgrounds. Given the gross underrepresentation and systematic exclusion of communities of color in the scientific literature, including in pediatric adherence science, Buchanan et al. (2020) encourages recommending and prioritizing the citation and publication of articles and grants with representative samples, as well as works spearheaded by authors from communities of color. Editors and reviewers should note when citations do not appear representative of the diversity within the field and/or the particular area of research focus. Editors should also make efforts to collect demographic information inclusively and track outcomes over time to identify and systematically address any inequities in their publication or award practices.

Disseminating Adherence Science

Engaging communities of color in all phases of research is strongly recommended; however, it is particularly vital to the dissemination process. Traditionally, researchers develop dissemination plans without the input of the population served, limiting their reach and effectiveness. Consequently, messages about research findings may lack cultural relevance and dissemination strategies may fail to “meet communities where they are” (Bodison et al., 2015). Individuals and organizations within communities of color can help research teams leverage natural sources of dissemination (e.g., barber shops, churches, health collaboratives), craft culturally meaningful messages, and recommend the most relevant technology platforms (e.g., social media, blogs) for community dissemination. For example, while churches and related religious organizations may be a culturally relevant dissemination source, recruitment efforts in these locations without stakeholder input and support, particularly for psychological research, may be detrimental to community relationship building, stigmatizing, or even harmful, despite well-intended actions (e.g., McDade et al., 2021).

It is essential that adherence research findings and related interventions are disseminated to key stakeholders in the lives of children from communities of color, such as extended family members, teachers, school nurses, coaches, and other community organizations (e.g., faith-based youth groups, recreational centers). Stakeholders can be instrumental in (1) preventing suboptimal adherence (e.g., school nurses who can administer medications during school; Salazar et al., 2018), (2) mitigating adherence barriers (e.g., community health workers building trust with families to understand cultural beliefs around medications and support discussions with medical providers; Segal et al., 2020), and/or (3) sustaining ongoing adherence behaviors and health promotion behaviors (e.g., community pediatricians, coaches, or salient community stakeholders can encourage youth to continue to take their medications; Nieuwlaat et al., 2014; Spray & Hunleth, 2022). While recent examples suggest a growing desire to integrate stakeholders into dissemination plans, these groups have not been historically or universally included in dissemination plans. Barriers exist to implementation (e.g., time, experience, skill) and there is a need for more systematic guidance, training, and tools for successful use of strategies (e.g., Byrnes et al., 2019). In fact, recent research has suggested that even scientists with expertise in dissemination and implementation science, which not all adherence scientists may have, report varied and inconsistent use of strategies for including stakeholders as well as understanding which strategies are most effective and sustainable over time (e.g., Knoepke et al., 2019).

For pediatric adherence science, applying an ecological model, like the Pediatric Self-Management Model (Modi et al., 2012), to dissemination planning helps ensure that research findings and interventions will be disseminated beyond the family to the larger community stakeholders who could greatly benefit from findings. For example, researchers could plan to disseminate findings to the community via postcards summarizing best practices that could be hung in school clinics or recreation centers. For pediatric adherence science, specifically, lay summaries around general adherence outcomes (e.g., known barriers and facilitators of adherence behaviors) and/or effective behavioral intervention strategies (e.g., pill swallowing, environmental restructuring, use of reminders) can be provided to school nurses to assist with self-management in that environment. Further, school nurses may also be utilized as a key stakeholder to help provide important feedback on how to build upon or disseminate behavioral interventions more broadly into school environments beyond a specific clinical trial or to establish an effective sustainability plan at the end of a given study.

To promote broader use of research and intervention findings in the community, the research team could participate in a community dissemination conference where community stakeholders not involved in the research (e.g., agencies with after-school programs) are invited to consider how the findings might be applied in their setting (Khodyakov et al., 2014). This can provide critical information on not only the utility of our work, but also address perceived need in the community. Further, insights provided by community members who join can be vital to understanding potential barriers and facilitators to community dissemination and problem solving around issues raised. Finally, stakeholder voices, especially those with influence in the community (e.g., pastors, community leaders) can collaborate with researchers through this platform to inform, review, and modify existing dissemination plans as well help design future research efforts around effectiveness and translatability.

Adherence research findings often fail to reach policy makers and healthcare organizations who develop healthcare and adherence-related reimbursement guidelines. Incorporating policy and public health-focused strategies (e.g., policy briefs, storytelling/patient narratives) can facilitate dissemination to these groups. This is especially important when the research is conducted with communities of color, as existing policies and practices may have been developed using data from predominantly White populations and may not adequately address social determinants experienced by communities of color (e.g., access to care). Thus, we encourage researchers to disseminate research findings (e.g., adherence preferences, what works best for whom) through policy briefs and op-eds as a means for advocating for equitable practices to optimize

adherence. More information on how to write these documents has been published by the American Psychological Association (Lee, 2018; Wong et al., 2017).

Conclusion

DEI efforts are gaining increasing momentum within academic medical centers and have the potential to dramatically change pediatric psychology clinical practice and research. Recent world events, including the COVID-19 pandemic and public racial injustices against communities of color, have resulted in critical action steps that will hopefully result in a necessary paradigm shift. Buchanan et al. (2020) is one such example in which detailed guidance is provided for dismantling racism and White supremacy in psychological science, including pediatric psychology.

Adherence science, as an overarching topic that affects almost all pediatric populations, presents unique considerations relevant to DEI, including the known relations between suboptimal adherence and disparate health and psychological outcomes for communities of color (e.g., Schwartz et al., 2010; Walsh et al., 2014). Systemic barriers further contribute to variability in adherence behaviors across race, ethnicity, sex, socioeconomic advantage/disadvantage, and more (e.g., Gregerson et al., 2019; Lee et al., 2019; Majidi et al., 2021; Redmond et al., 2021), which may subsequently contribute to health inequities. Despite these known truths, we have not systematically integrated DEI strategies into pediatric adherence research. One driver of this gap may be a lack of practical guidance on how to optimally integrate DEI into adherence science; the purpose of this manuscript was to begin to address this need.

There remains a vital need for psychological science, including adherence science, to take meaningful action toward the application and practice of DEI in all aspects of our work. However, the road to accomplishing these goals is neither linear nor without complications. Adherence scientists will undoubtedly continue to face the challenges of adapting to and implementing DEI principles into practice over time, and well-intended action may not always produce desired equitable effects. In anticipation of these challenges and the likelihood that we will be most successful in DEI efforts if we can learn from the experiences of our colleagues, the current commentary described several challenges or barriers faced by our adherence science colleagues and offers potential, practical solutions to overcome them based on this experience. Doing so will better equip our scientists and practitioners to deliver equitable science and care.

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