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Development and Initial Validation of a Measure of Parental Racial/Ethnic Discrimination in Pediatric Healthcare

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Abstract

Aim The aim of this study was to create a tool capable of measuring parents' experiences of discrimination when obtaining healthcare for their children, capturing their parental identities and perceptions of discrimination in the healthcare setting.
Background Discrimination experiences, including racial, ethnic, and healthcare discrimination, have negative health effects across the lifespan. Parents have an essential role in pediatric healthcare, which is distinct from the role of other caregivers in pediatric and non-pediatric healthcare settings. Though measures of discrimination in healthcare settings exist, few psychometrically valid tools evaluating parents' experiences of healthcare discrimination are readily available.
Methods A measure of parental racial/ethnic discrimination in healthcare was developed. Items were generated with theoretical and empirical literature followed by expert panel review. Items were tested among a population of US-based adult parents via online survey using exploratory factor analysis. Reliability, construct, and criterion validity were assessed.
Findings Item generation resulted in an acceptable pool of test items based on relevance and clarity (mean CVI = 0.94 and 0.70, respectively). Exploratory factor analysis resulted in a two-factor solution, one of which was related to discrimination experiences and demonstrated reliability (α α = 0.90) and construct and criterion validity ($r = 0.52$–0.74) with existing scales. The final six-item scale measuring parental discrimination experiences offers a way to better understand discrimination experiences unique to parents in the pediatric healthcare setting. Further validation with larger samples utilizing more traditional recruitment practices is recommended.

Keywords Parenting · Discrimination · Healthcare · Measurement

Introduction

Experiences of discrimination have well-documented negative effects on mental and physical health [1, 2] of minoritized and stigmatized groups [3–5] across the lifespan [6–9]. Discrimination is a person's experience of differential treatment from individuals and societal organizations on the basis of differences in race, sexual orientation, nativity, or other social identity [10]. Discrimination exists at individual, institutional, and cultural levels and is influenced by larger social forces and events (e.g., political, religious, cultural, historical) [11]. Individuals not identifying as members of a dominant (i.e., White, able-bodied, cisgendered, male) group report experiencing discrimination more often [12], with as many as 75% of minoritized adults in the USA reporting experiences of discrimination [13, 14]. The effects of discrimination are lifelong and multigenerational: Parental experiences of discrimination have a negative effect on child functioning [15], and repeated exposures to disadvantageous social conditions such as discrimination accelerate physical health declines, causing weathering effects which are inherited across generations [16, 17].

In the healthcare delivery setting, collaboration among patients and/or caregivers, physicians, nurses, social workers, and allied health professionals is essential for maintaining patient wellness and diagnosing and treating illness [18]. Such engagement is multi-tiered among caregivers, patients, and healthcare providers, with one participants' level of engagement (e.g., a provider demonstrating cultural

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humility) influencing the other participants' levels of engagement (e.g., a caregiver feels respected) via engendering therapeutic alliance, when providers and patients work together in mutuality toward an agreed-upon outcome [19]. Conversely, when patients experience discrimination, they may feel or express feelings of powerlessness, which leads to less engagement in healthcare process, thus weakening relationships between patients and healthcare providers [20]. Fear of discrimination may shape individuals' interactions with others, including those within the healthcare setting [21]. Of particular relevance is the effect discrimination can have on health seeking behaviors, healthy behaviors, and adherence to recommended health care treatments [22–24]. Based on a variety of measurement tools, more than 50% of adults identifying as members of a racially or ethnically minoritized group report experiencing discrimination in the healthcare setting [14, 25].

In the pediatric healthcare setting, relationships among parents, children, and healthcare providers are more salient given parents' paramount role in their child's comfort, care planning, medical decision making, and healthcare provision [26–28]. Such parental engagement in their child's care is strongly related to improved health outcomes for both parents and children [29–32]. Parental engagement is heavily influenced by interpersonal relationships with healthcare providers [20, 33–36]. Discrimination in pediatric healthcare settings affects pediatric patients as well as their parents and other familial caregivers [8, 15, 19, 37].

Parents who experience discrimination when obtaining healthcare for themselves experience altered relationships within healthcare settings [38] and may avoid future interactions with the healthcare setting for themselves or their children [39]. When parents avoid interactions with the healthcare setting as it relates to their children's healthcare, this may raise alarm with health care professionals working in systems requiring surveillance of parents. Given expectations that parents will obtain regular healthcare for their children, a parent avoiding care for their child may be met with clinician concern for child welfare issues associated with missed care [40, 41]. Therefore, scenarios in which parents avoid care due to experiences of discrimination can create situations of unnecessary systemic involvement in families and a misappropriation of institutional resources. Understanding parental discrimination in healthcare is necessary to enable family engagement and harm reduction among populations already alienated by marginalization.

Existing Measures

Several widely used tools measure general discrimination experiences and discrimination experiences in the healthcare setting (see Supplementary Materials: Appendix A, Table A1); however, none focus on the unique experience of parents. Interpretability and appropriateness of language in the existing measures are limited and do not reflect evolutions in our understanding of accurate and sensitive descriptive language, for example, the use of "Caucasian" instead of "White" in describing sample characteristics [42]. The Everyday Discrimination Scale (EDS) [43] has been widely utilized in a variety of populations for decades [44–46]. The EDS intends to capture general discrimination across many populations; recent work has called into question the utility of the EDS across socially diverse groups given the different ways discrimination manifests and is experienced across racial and other identity groups [47–49]. Further, the original intent of the EDS was to capture anti-Black sentiments in general settings and it may not be sensitive to other experiences of discrimination (i.e., discrimination as a result of 'model minority' stereotypes against Asian Americans) [49]. The EDS is sensitive to general discrimination events but is not specific to the healthcare setting, where discrimination combined with existing provider/patient power dynamics may challenge creation of therapeutic alliance [50]. Thus, the EDS has been adapted to be utilized in the healthcare setting [51] and validated in racially and ethnically diverse populations [51, 52].

In 2001, Bird and Bogart published a measure of discrimination in healthcare [53], the Healthcare Discrimination Scale (HDS), which underwent multiple subsequent revisions by the original authors [54, 55] and adaptations by others, where it demonstrated good reliability and validity across multiple specific healthcare settings and populations [56]. A third tool, The Healthcare Discrimination Experience Scale (HDES) [57], was created to better assess healthcare discrimination experiences among adults of diverse racial identities with chronic medical conditions, a population who is likely to frequently interface with the healthcare environment and with healthcare providers [57].

All three of these tools and their adaptations measure healthcare experienced by the individual but not when the individual is present in the healthcare setting on behalf of someone else as a familial caregiver. Familial caregivers facilitate healthcare access by interacting with healthcare providers and healthcare settings alongside or on behalf of their family members [58]. Familial caregivers are recognized as having distinct relationships with those they care for as compared to paid or professional (i.e., non-familial) caregivers [59]. In this situation, racial or ethnic discrimination could be *directed* towards the caregiver, the patient, or both. But in the case of a young child or an adult with cognitive challenges, discrimination would be *perceived* primarily on the part of the caregiver. This distinctive circumstance necessitates a measurement specific to the experiences of discrimination for those acting as a caregiver.

Existing measures of familial caregiver experiences have primarily focused on the caregiver's feelings about providing care, including stress and strain (i.e., burden) in providing care [60], and positive aspects of caregiving [61]. Some measures capture the specific experience of caregivers in interacting with the healthcare team [62, 63], though these measures are largely focused on specific elements of this interaction such as communication and care planning [63], or perceived support for caregiver and patient [62].

While caregivers may be in familial relationships with those they care for (e.g., siblings, adult children), these relationships are fundamentally distinct from parent/child relationships, in which the need for a caregiver is expected and developmentally appropriate. Measurements of caregiving that relate specifically to parents are typically utilized in populations of parents caring for children with acute or chronic conditions (i.e., cancer, prematurity) [64–67]. Such measures do not tap into the construct of perceived discrimination, nor are they necessarily germane to the experiences of parents of children who primarily utilize healthcare services for typical developmental care and periodic illness care. Loo and colleagues adapted a measure of clinician's cultural sensitivity in pediatric primary care settings [68]. This measure demonstrated robust validity and reliability among parents of children aged 3–48 months, and the discrimination domain addresses parental perceptions of discrimination based on education level, race, and ethnicity in pediatric primary care settings. This tool primarily focuses on parents' interaction with physicians and medical office staff. Parents' interactions with non-physician healthcare providers such as nurses and the experiences of parents of children aged less than 3 or greater than 48 months were not assessed in the initial psychometric testing of this tool.

It is not possible to separate the multiple intersecting identities (e.g., racial or ethnic identity and identity as a parent) any one individual has, which affect health in interacting ways [69]. The degree to which individuals present specific elements of their identities, such as their language spoken or even word choice (e.g., "code switching"), may vary greatly based on setting, interpersonal dynamics, or myriad other factors [70]. Further, individuals may attribute their experiences of discrimination to one specific identity or identities [71].

Assessment of discrimination in any setting necessitates an intersectional view of individuals' identities[69, 72, 73] and health science researchers require measurement tools that acknowledge and account for this [47, 74]. Such measurement tools should evaluate discrimination experiences based on specified identities and in specific contexts to establish true representation of discrimination experiences, which are more interpretable and sensitive to differences among groups than existing measures [48, 49, 51]. Further, given the complexity of care and multidisciplinarity in pediatric healthcare settings, measurement tools, which are applicable to parents' interaction with a variety of healthcare providers, may better represent parents' overall experiences. The lack of an assessment tool capturing the intricacies of varying and intersecting forms of discrimination parents experience in the healthcare setting leaves a gap in the understanding of marginalized families' experiences. Such a gap continues to further health disparities in minoritized groups.

Theoretical Basis

This study was guided by a modification of Bronfenbrenner's ecological systems model, which offers a theoretical frame for understanding how individuals (e.g., a child, family, healthcare provider) are affected by multiple levels of the complex and inter-related environment around them [75]. This modification was additionally informed by the "Center for Latino Adolescent and Family Health framework of SDOH Mechanisms," which provides a mechanistic explanation for ways social determinants of health (SDOH) shape health inequities through key underlying elements such as social processes (e.g., discrimination) and health inequity outcomes [76]. This framework was adapted to the context of parental discrimination experiences in the pediatric healthcare setting (see Fig. 1). In pediatric healthcare experiences, a family (i.e., parent and child) interacts with a healthcare provider (e.g., doctor, nurse, social worker) in the healthcare setting (e.g., medical or dental clinic, emergency room, urgent care, same-day surgical center, inpatient hospital). This interaction is influenced by the intersecting identities of the participating individuals as well as systemic factors (e.g., paid family leave policies) and local factors (e.g., institutional implicit bias training for healthcare workers), which shape the environment of the interaction (e.g., micro level), and result in parental experiences of racial/ethnic healthcare discrimination.

How parents' experiences of healthcare discrimination shape their decisions to obtain care for their children and how experiences of healthcare discrimination when obtaining healthcare for their children affect parents' own health and well-being are not well understood by healthcare providers in care settings. The aim of this study was to create a tool capable of capturing parents' experiences of discrimination when obtaining healthcare for their children, capturing their parental identities and perceptions of discrimination in the healthcare setting.

Methods Phase 1

Item Generation

Item generation was two-part. The first element utilized existing theoretical literature to identify salient elements

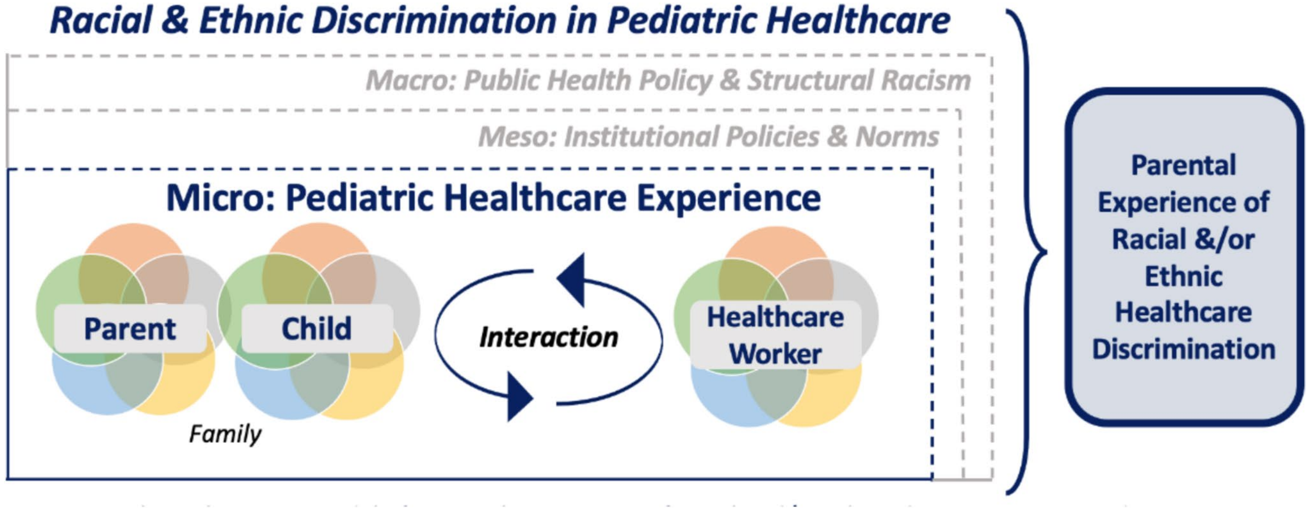

Fig. 1 Ecological systems model of parental experiences of racial and/or ethnic discrimination in pediatric healthcare. Individuals' intersecting identities shape the interaction between the family unit and pediatric healthcare workers

of the constructs of discrimination and parenting, including existing measures [50, 51]. Second, a literature search was conducted to ascertain qualitative accounts of the experiences of parents facing healthcare discrimination when seeking care for their children. Findings from each part contributed to item generation.

A literature review was conducted using Boolean operators of the search terms "qualitative," AND ("pediatric" OR "parental," OR "healthcare"/"health care") AND "discrimination." Retrieved articles included quantitative articles encompassing existing measures of everyday discrimination [43], discrimination in healthcare settings [51, 57], patient/provider therapeutic alliance [50], and clinician cultural sensitivity [68, 77]. Additionally, qualitative or mixed/multi-methods articles were retrieved and ranged in focus from detailing disparities in quality of care in the neonatal intensive care unit (NICU) [78] to experiences of discrimination in the peripartum period [79–81] and the influence of ethnic and language-based discrimination on sick-child visits for children of immigrant mothers [38]. The articles were carefully reviewed, and relevant themes of time spent, listening, assumptions, mistrust, and judgment were extracted and used to develop survey questions. The most compelling aspects of the literature reviewed were the first-hand accounts of discrimination that were described by the participants in their own words. For detailed examples, see Supplementary Materials: Appendix A, Table A2. Based on these themes, and informed by existing measures of discrimination, racial and ethnic discrimination, and discrimination in healthcare settings, 11 initial items were written and prepared for expert review.

Expert Panel

Obtaining expert feedback on item content, relevance, and clarity can help to establish content validity [82, 83]. Experts in the areas of healthcare, parent/child dyads, and/or discrimination were approached based on prior publications and statements of expertise available on public sites as well as snowball sampling to complete an online survey-based [84] assessment of the proposed items' relevance and clarity (see Supplementary Materials: Appendix A, Table A3). Respondents could also offer qualitative comment on included items.

Results: Expert Panel

Respondents ($n = 11$) represented broad academic and professional backgrounds in nursing, public health, medicine, population health, social work, and linguistic analysis. Experts had experience in relevant content areas of parenting/family, discrimination, structural inequalities, and healthcare delivery, and had a mean of 17.5 years of experience in their respective fields (see Supplementary Materials: Appendix A, Table A4). Additional information (i.e., institutional affiliation, age) was not obtained to protect participant confidentiality.

The responses from the 11 content experts were evaluated, and content validity indices (CVIs) were calculated for relevance and clarity of each individual item (I-CVI) and averaged to obtain a scale-level CVI (S-CVI; see Table 5) [87]. This method of calculating scale-level CVI has been criticized as being too lenient [87]; thus, the more stringent measure of scale-level CVI for universal agreement (S-CVI/

UA) was also calculated, which represents the proportion of experts in 100% agreement on the relevance and clarity of an item, or in other words, the percentage of items that received an item-CVI of 1.

To calculate item "CVI for relevance," responses of 3 ("quite relevant") and 4 ("highly relevant") were considered favorable and responses of 1 ("not relevant") or 2 ("somewhat relevant") were considered unfavorable. The number of favorable responses divided by the number of unfavorable responses represents the item CVI, or the percentage of experts in agreement with a favorable impression of the item. To calculate item CVI for "clarity," responses were submitted as either "no editing needed" or "yes editing needed" and, again, the number of favorable ("no editing needed") responses was divided by the number of total responses to represent item CVI for clarity. If an expert did not respond to a question, the CVI was calculated based on the number of responses received (i.e., divided by 10 rather than 11) [87].

For "relevance," I-CVIs ranged from 0.6 to 1, with a S-CVI (mean of all item CVIs) of 0.90, indicating 90% agreement on average among experts on the relevance of each item. The S-CVI/UA was 0.64, indicating that 64% of items achieved complete agreement among all experts by whom they were evaluated. For "clarity," there was less agreement among experts, with I-CVIs ranging from 0.5 to 1, an S-CVI of 0.70 and an S-CVI/UA of 0.18, meaning that there was 70% agreement on average among the experts on the clarity of each item, but only 18% of items achieved complete agreement among all experts. Based on these results, the original 11 items were modified, and some items were split into two questions, resulting in a 13-item scale, called the Parent Racial/Ethnic Healthcare Discrimination Scale (PREHDS). The original 11 items, I-CVIs, and 13 modified questions are presented in Supplementary Materials, Appendix A, Table A5 and more detailed item- and scale-level CVIs in Supplementary Materials, Appendix A, Table A6.

Methods Phase 2

Setting, Sample, and Recruitment

Participants were recruited through the CloudResearch Prime Panels platform, a third-party service which interfaces with Amazon Web Services' MTurk to assess MTurk workers' response quality, ensuring individual MTurk workers being recruited for the current study have already demonstrated acceptable to excellent performance on data quality checks (i.e., "approved workers") [88, 89]. CloudResearch Prime Panels have been found to produce respondents, which are more nationally representative than MTurk workers as a whole, based on demographic characteristics such as political affiliation, belief in God, and education level [88].

Eligibility criteria for participation by approved workers included participants' self-report of (1) being a parent to a child under age 18, (2) being over age 18 themselves, (3) having ever accompanied their child to a healthcare setting, and (4) fluency in English. Non-random stratified sampling was utilized to find eligible participants and to ensure oversampling of individuals identifying as members of minoritized racial groups [90].

Devills and Thorpe argue that there is no consensus among experts on the "right" sample size for factor analysis [91]. Existing studies evaluating measures of healthcare discrimination experiences have wide-ranging sample sizes, from 75 participants [51] to over 700 [57]. Tinsley and Tinsley's suggested ratio of five to 10 participants per item was considered when planning target recruitment for this study, with a minimum needed sample of 65–130 participants [92]. Using CloudResearch's MTurk Toolkit, two identical MTurk surveys were created. One instance aimed to recruit participants identifying as White up to a total of 75 participants, and the other instance aimed to recruit participants identifying as members of minoritized (i.e., non-White) racial groups, up to a total of 75 participants, for a total goal sample size of 150 participants.

Design

The 13-item Parent Racial/Ethnic Healthcare Discrimination Scale (see: "Methods Phase 1") was tested to determine reliability and validity. To assess concurrent validity, the Healthcare Discrimination Experience Scale (HDES)[48] was administered, and to assess convergent validity, the Medical Consultation Experiences Questionnaire (MCEQ), which consists of two subscales measuring feelings of alliance and confusion following a consultation with a healthcare provider [50, 93]. The MCEQ was used when developing the HDES, and it was found that higher levels of discrimination were associated with lower levels of alliance and higher levels of confusion [57]. Belief in a just world has also been found to be associated with perceptions of age-based discrimination, with higher levels of belief in a just world being associated with lower perceptions of discrimination [94]; thus, the Belief in a Just World (BJW) scale was also used to assess convergent validity and evaluate if BJW is associated with racial and ethnic discrimination as well [86, 93]. Discriminant validity was assessed using the "organization" subscale of the EMPATHIC-38-NICU-USA scale [85, 93]. The EMPATHIC-38-NICU-USA evaluates parents' satisfaction with their child's stay in a neonatal intensive care unit, and the "organization" subscale includes items related to the cleanliness, space, and efficiency within the neonatal intensive care environment. Satisfaction with pediatric health care is reflective of a parents' perceptions and experiences within a pediatric healthcare experience; however, these "organizational" elements of satisfaction should not be highly correlated with discrimination.

Data Collection and Management

Potential participants were screened utilizing CloudResearch Prime Panels to ensure MTurk workers with attributes reflecting (1) higher reliability and quality of responses and (2) applicability of worker demographics to current study. These criteria included (1) US-based respondent, 2) > 95% Human Intelligence Task (HIT) completion rate, and (3) workers over the age of 18 years. Interested potential participants completed a Qualtrics [84] survey, which began with a study information sheet containing study purpose, procedures, compensation, risks, benefits, and contact information for the institutional review board and primary investigators. Interested potential participants then selected "yes" to continue, indicating their consent to participate, or "no" to exit the survey.

Consenting participants first completed three screening questions to verify they met eligibility criteria. If the participant was not found to be eligible, the survey was terminated, and no compensation was provided. Eligible, consenting participants completed the following questionnaires in the survey: (1) five demographic questions, including location of pediatric healthcare experience (e.g., hospital, dental office, urgent care), gender identity, ethnicity, age, and education level; (2) 13-item Parent Racial/Ethnic Healthcare Discrimination Scale (PREHDS); (3) 12-item Medical Consultation Experience Questionnaire (MCEQ); (4) 6-item Healthcare Discrimination Experience Scale (HDES); (5) 4-item EMPATHIC-38-NICU-USA satisfaction with care Organization subscale; (6) 8-item Belief in a Just World (BJW) Scale; (7) two randomly placed attention check questions; (8) one reCAPTCHA question to reduce risk of survey completion by non-human respondents (i.e., AI Bots); and (9) one optional open-ended item for additional comments. Each response was reviewed by a study team member before payment was approved. Participants were paid $1.85 for a completed survey. All survey questions, including each of the scales of interest and variables generated, are detailed in the data dictionary in Supplementary Materials, Appendix B.

Survey data were exported from Qualtrics [84] in.csv format and imported into SAS v9.4 (SAS Institute, Inc., 2016), which was used for these analyses (see Supplementary Materials: Appendix B: data dictionary).

Fraudulent Response Analysis

Utilizing online survey platforms for recruitment introduces unique validity challenges in identifying inattentive, nefarious, or non-human respondents to surveys [95]. A study-specific fraudulence assessment scoring algorithm was created based on and applied to all records in the sample (see Supplementary Materials, Appendix C: Fraud Detection Algorithm) [95, 96]. Of the 447 participants screened, 139 participants met inclusion criteria and were assessed for fraud. Sixty interpretable qualitative responses were received and included as part of the fraudulent response analysis. Any response scoring one or more of three possible points was considered suspicious and was not analyzed. Differences among pre- and post-fraud detection samples are detailed in Supplementary Materials Appendix C: Sample Characteristic Changes. The remaining responses were utilized in this analysis ($n = 58$). Descriptive statistics were generated for variables of interest and evaluated for central tendency, skewness, and kurtosis.

Reflexivity

Reflexivity is a critical element in the study of social phenomenon such as discrimination experiences to make more explicit power dynamics between researchers and participants and address how social position and personal experiences of researchers inform research work. All the authors have an academic and social interest in better measuring and understanding healthcare discrimination experiences of minoritized populations. Further, all authors have expertise in fields related to measurement of parents' discrimination experiences in the healthcare setting.

The authorship team includes individuals who identify as cis-gender male, cis-gender female, non-Hispanic, Asian, Black, White, and as parents, healthcare providers, allied health professionals, and multi-method healthcare researchers. The expert panel participants who aided in item generation may share many of these lived experiences, but this information was not obtained to protect expert participant privacy. Our authorship team was aware of the potential for harm in creating a measurement tool, which does not accurately reflect or capture minoritized individuals' experiences. Our team increased our attentiveness to reflexivity through team reflection to reduce the risk of bias negatively impacting our analysis or presentation of findings.

Results

Sample Characteristics

The final sample consisted of 58 participants, and demographics and sample characteristics are presented in Table 1. The sample was primarily White (61%) and Black (25%) with smaller representation of other racial groups. The

Table 1 Sample characteristics ($N = 58$)

Characteristic	*n* (%)
Race	
White	36 (61)
Black	15 (25)
Asian	6 (10)
Native America/American Indian	1 (2)
Multi-racial/another race	0
Native Hawaiian, Alaskan, or Pacific Islander	1 (2)
Ethnicity	
Non-Hispanic	53 (91)
Hispanic	5 (9)
Gender	
Male	30 (52)
Female	28 (48)
Age	
18–35	22 (38)
36–55	35 (60)
56–75	1 (2)
Education	
High school	1 (2)
Associate degree	11 (19)
Bachelor's degree	11 (19)
Graduate degree	24 (41)
Healthcare location	
Doctor's office or clinic	36 (62)
Dentist office	6 (10)
Urgent care	9 (16)
Emergency room	7 (12)

sample (9%) endorsed Hispanic ethnicity. Participants were primarily male (52%) and between the ages of 18 and 55, consistent with the requirement of being a parent of a child under 18 years old. The sample was highly educated, with most participants (62%) holding at least a bachelor's degree. Most healthcare encounters occurred in a doctor's office or clinic (62%), but there was representation of experiences in the dentist's office, urgent care clinic, and emergency room as well.

Construct and Criterion Validity

Distributional Properties of the PREHDS and Factor Analysis

A correlation matrix was generated, and it was determined that some correlations in the matrix exceeded 0.30, indicating factorability (see Supplementary Materials, Appendix D). The average intra-item correlation was 0.11, likely low due to the directionality of the item scores. Exploratory factor analysis was conducted using iterated principal factor analysis, and although a three-factor model was initially considered, Factor 3 consisted of a single item (item 12), which, based on theory, was not distinct enough from other items to warrant representing a third factor. A forced two-factor model was generated, and item 12 still performed quite poorly and, thus, was removed from subsequent analysis. Therefore, the final two-factor model included items 1–11 and 13. Objective measures were used to assess factor structure (i.e., Eigenvalues, Scree plots, parallel analysis, optimal coordinates, and acceleration factor). The cumulative variance explained by the two-factor model was 0.69 (Appendix D). Sampling adequacy was assessed using the Kaiser–Meyer–Olkin (KMO) test, with an overall MSA of 0.806, indicating that a significant portion of the variability in the correlation matrix can be accounted for by the factor model [97].

ProMax (oblique) rotation was used due to high correlation between factors 1 and 2 (0.429). After rotation, factor loadings supported a two-factor model, with items 1–6 loading on Factor 2: Parent/Provider Relationship (hereafter "Relationship") and items 7–11 and 13 loading on factor 1: "Discrimination" (Table 2). Correlations and semi-partial correlations tables are shown in Supplementary Materials, Appendix A. All items have communalities > 0.4. Means, standard deviation, skewness, and kurtosis for all items and factor total scores are presented in Table 3.

Comparisons with Existing Scales

We hypothesized a priori that PREHDS scores would have high correlations with HDES and MCEQ scores (indicating greater discrimination experiences, which are associated with lower levels of alliance and higher levels of confusion), low correlations with BJW scale (indicating lower belief in a just world in those who experience greater discrimination), and no correlation with EMPATHIC organization subscale (indicating no relationship between discrimination experiences and satisfaction with the clinical environment). Correlations were calculated between the mean score on each PREHDS Factor and the mean scores on the HDES, MCEQ alliance subscale, MCEQ confusion subscale, Empathic organizational subscale, and BJW scale. Moderate-to-strong correlations were found between both PREHDS Factors and the HDES scale, indicating good concurrent validity with the existing health care discrimination scale [93]. There were also moderate-to-strong correlations between both PREHDS Factors and the MCEQ alliance and confusion subscales, indicating convergent validity [93]. However, the BJW scale was not predictive of PREHDS scores as it did not correlate well with either of the PREHDS Factors, and there was an unexpected moderate correlation of both PREHDS Factors and the EMPATHIC organization subscale (Table 4). Properties of each scale tested are detailed in Supplementary Materials: Appendix D.

Table 2 Final factor structure (correlations)

	Item #	Discrimination	Relationship
1	When getting health care for your child, doctors and health care workers take the time to meet your child's needs	−0.189	**0.761**
2	When getting health care for your child, doctors and health care workers give you enough information to meet your child's needs	−0.415	**0.760**
3	When getting health care for your child, doctors and health care workers believe what you tell them	−0.409	**0.820**
4	When getting health care for your child, doctors and health care workers take your concerns about your child's health seriously	−0.343	**0.800**
5	When getting health care for your child, doctors and health care providers act like you are a good parent	−0.475	**0.706**
6	When getting health care for your child, doctors and health care workers really listen to you	−0.378	**0.857**
7	When getting health care for your child, doctors and health care workers assume things about YOU based on your race or ethnic group	**0.802**	−0.358
8	When getting health care for your child, doctors and health care workers assume things about YOUR CHILD based on their race or ethnic group	**0.737**	−0.271
9	When getting health care for your child, doctors and health care workers act like you are being "difficult" because of your race or ethnic group	**0.888**	−0.356
10	Doctors and health care workers look down on your parenting practices due to your race or ethnic group	**0.952**	−0.411
11	Doctors and health care workers act like you are not honest about your child's health	**0.636**	−0.418
13	Doctors and health care workers would be more supportive of your parenting choices if you were part of a different race or ethnic group	**0.689**	−0.329

Bolded values indicate factor loadings ≥ |0.50|

Table 3 Factor properties

Factor/item #	Mean	SD	Skew	Kurtosis	Eigenvalue (total = 12)
Relationship (Factor 2)	4.264	0.708	−1.017	0.750	2.33
1	4.310	0.863	−1.337	1.397	
2	4.172	0.920	−1.335	1.967	
3	4.345	0.785	−1.154	1.074	
4	4.345	0.785	−1.154	1.074	
5	4.207	0.833	−0.788	−0.064	
6	4.207	0.969	−1.273	1.322	
Discrimination (Factor 1)	2.227	1.124	0.608	−0.953	5.92
7	2.397	1.363	0.484	−1.048	
8	2.448	1.353	0.399	−1.221	
9	1.948	1.262	1.238	0.411	
10	2.138	1.492	0.839	−0.927	
11	1.983	1.192	1.129	0.351	
13	2.448	1.512	0.544	−1.193	

Reliability

Essentially tau-equivalent assumptions were met, with very similar means and variances for each item, indicating all PREHDS items are measuring the underlying constructs with roughly equal precision. Cronbach's = 0.90 was calculated for each Factor's items to estimate internal consistency. Internal consistency was high, with alpha = 0.90 for each factor.

Final Scale Construction

The items for each factor were evaluated for content, and it was determined that Factor 1 ("Discrimination") represented perceptions of explicit parental racial/ethnic discrimination in healthcare, including negative assumptions, provider distrust, provider indifference, and provider disapproval. Meanwhile, items loading onto Factor 2 ("Relationship") represented perceptions of the parent/provider relationship, including time spent, mutual information exchange, provider trust in the parent, and provider empathy. These two factors are related, but represent distinct constructs, with Factor 1 more closely reflecting the construct of discrimination, while Factor 2 aligns better with more general perceptions of the parent/provider relationship. Thus, it was concluded that our final PREHDS scale would best represent our construct of interest through the Discrimination factor alone and the final scale consisted of six items (Table 5).

Discriminant Validity

Mean PREHDS score for non-Hispanic, White participants was 2.1, and the mean for participants who are members of minoritized groups was 2.5, with a standard deviation of 1.3. This difference was not statistically significant ($p = 0.174$), but this may be the result of our small sample size. Demonstrated effect size ($d = 0.31$) was small to medium.

Table 4 Scale correlations for criterion, convergent, and divergent validity

	Relationship (F2)	Discrimination (F1)	HDES	EMPATHIC	BJW	Alliance[86]	Confusion[86]
Relationship (F2)	1						
Discrimination (F1)	−0.445*	1					
HDES	−0.545*	0.739*	1				
EMPATHIC	0.592*	−0.414*	−0.463*	1			
BJW	0.430*	0.142	−0.032	0.276*	1		
Alliance	0.695*	−0.521*	−0.588*	0.603*	0.205	1	
Confusion	−0.417*	0.560*	0.613*	−0.565*	−0.169	−0.602*	1

*Statistically significant $p < 0.05$; *F*2: factor two, "Relationship"; F1: factor one, "Discrimination"; HDES: Healthcare Discrimination Experience Scale [74]; EMPATHIC: EMPATHIC-38-NICU-USA [85]; BJW: Belief in a Just World [86]

Table 5 Parental Racial and Ethnic Healthcare Discrimination Scale (PREHDS)—Final Version

1	When getting health care for your child, doctors and health care workers assume things about YOU based on your race or ethnic group
2	When getting health care for your child, doctors and health care workers assume things about YOUR CHILD based on their race or ethnic group
3	When getting health care for your child, doctors and health care workers act like you are being "difficult" because of your race or ethnic group
4	When getting health care for your child, doctors and health care workers look down on your parenting practices because of your race or ethnic group
5	Doctors and health care workers act like you are not honest about your child's health
6	Doctors and health care workers would be more supportive of your parenting choices if you were part of a different race or ethnic group

Discussion

Discrimination experiences of parents and their children are intertwined and affect both members of the parent/child dyad [34, 55]. By acknowledging the unique relationship between parents and children and the potential effects of discrimination on parents in the healthcare setting, this scale provides a better lens through which to understand parents' experiences in obtaining their child's healthcare.

We anticipated one factor a priori; however, analysis of the initial PREHDS items revealed a two-dimensional construct. We surmised that the two factors would relate to parenting experiences and discrimination experiences but were surprised to find the factors represented explicit discrimination experiences and parent/provider relationships. Items that hung on Factor 1 seemed more explicitly related to the experience of racial/ethnic discrimination, reflecting parents' perceptions of negative assumptions, distrust of parents, indifference, and disapproval on the part of the medical provider; hence, we refer to Factor 1 as "Discrimination" factor. Items that hung on the Relationship factor, however, were more related to the parent and provider's relationship, reflecting parents' perceptions of time spent, mutual information exchange, provider trust in parents, and provider empathy; hence, we refer to Factor 2 as the "Relationship" factor. Though communication and relationships are an integral part of the healthcare interaction, and although parent/provider communication and relationships are influenced by some of the same constructs, which influence discrimination (i.e., racism), they are distinct from discrimination and thus were removed from the final scale.

Some inter-item correlations were unexpected, notably those between items relating to trust, PREHDS3 ("When getting health care for your child, doctors and health care workers believe what you tell them") and PREHDS11 ("Doctors and health care workers act like you are not honest about your child's health"). Given both items reflect trust/distrust, we anticipated high correlations between them; however, we found these items to not be particularly correlated (correlation coefficient = −0.294). Perhaps this indicates these items represent two distinct components of trust within the latent construct of parental discrimination in healthcare. One item, PREHDS12 ("Doctors and health care workers act like you are not honest about how you parent.") was rated as having low clarity in the item generation phase and was subsequently edited. Despite this editing, PREHDS12 did not perform very well in our testing, demonstrating low correlation with Discrimination and Relationship factors, and was subsequently dropped from the final PREHDS measure. The reasons for this poor performance remain unclear given the editing completed based on expert panel feedback. We hypothesize that this item may have been referencing experiences too nonspecific to the healthcare setting (i.e., referencing parenting practices in general); it could be confusingly phrased, or could be irrelevant to parents. Further exploration of this item with parents may help to illuminate the meanings parents derive from the item as currently phrased.

Several other measures were included in our survey, including the HDES, MCEQ, and BJW scales to assess concurrent and convergent validity, and the EMPATHIC-38-NICU-USA satisfaction with care "Organization" subscale to assess divergent validity. Hypothesized and actual relationships between scales are shown in Supplementary Materials Appendix E, Table E1. The majority of the correlations were not surprising; however, we had hypothesized some correlation with BJW and found no relationship with the Discrimination factor, but a moderate positive relationship with the Relationship factor. This could be attributed to the fact that this measure, while it has demonstrated convergent validity with age-based discrimination in the past, it has not been measured in relation to racial and ethnic discrimination [61].

Likewise, where we did not hypothesize a relationship between our PREHDS scale and the EMPATHIC "Organization" subscale, we found a moderate correlation. This could be explained if parents' experiences of discrimination in the healthcare environment influence their overall perceptions of healthcare facilities, or if they perceive poor facility organization to be an indicator of discrimination (e.g., if poor attention to the environment is a result of staff discrimination or indifference towards a patient/family). It is also possible that a dissatisfying healthcare experience could negatively influence parents' perceptions of the overall experience, including discrimination and facility organization, without respect to the specific source of the dissatisfaction.

Given our use of CloudResearch Prime Panels to reach approved MTurk workers, we anticipated fewer concerns with response fidelity. To our knowledge, this is the first study around discrimination experiences to closely scrutinize risk for interference by bots or inattentive respondents, though we acknowledge the proliferation of bots in online survey–based research has evolved over recent years [89, 96, 98]. The risk of fraudulent responses or bot interference is likely increasing over time relative to risks present when prior measures of discrimination experiences were created and validated using online survey-based platforms.

Theoretical and statistical analyses of the 13 PREHDS items helped to determine which items truly represented the latent construct of parental racial discrimination experiences in pediatric healthcare, resulting in six items, which aim to evaluate parents' experiences of healthcare discrimination when obtaining healthcare for their child.

Limitations

Given the exploratory nature of this work, these preliminary validation results should be interpreted accordingly. Replication studies for further validation performed in larger samples would enable use of confirmatory factor analysis to further examine factor structure.

Discrimination is a latent construct based on multiple complex and interacting factors at the interpersonal level, which are not readily observable; thus, this tool and other tools may not fully capture the complex and varied experience discrimination, which are faced by minoritized individuals in the healthcare setting. This scale specifically intends to capture racial and/or ethnic discrimination but does not attempt to capture other forms of discrimination parents may experience in the pediatric healthcare setting (e.g., gender- or weight-based discrimination [99]). Participant responses may vary by presence, level, and type of internalized racism within an individual parent and may be complicated by stereotype threat, with participants potentially displaying apprehension about confirming negative stereotypes about themselves or their racial, ethnic, cultural, or other identity-based group [100].

This discrimination measure may need rewording. The current phrasing may inadvertently invoke blame on the individual through their non-dominant identity (e.g., "because of your race or ethnicity") rather than on discrimination itself (e.g., "because of racism") [49]. Additionally, our authorship team's perspectives are limited; thus, we utilized subject matter experts and the participants themselves to provide perspectives we could not speak to. Further expert review focused on the perspectives of parents who are members of minoritized racial groups is warranted. The order of instruments was not randomized, which could have introduced context effects in responses [91].

The applicability and interpretation of this study are limited using the CloudResearch platform for participant recruitment. First, though Prime Panel participants are considered to mirror nationally representative samples [88], this study's participants may not be representative of parents who accompany their children into healthcare settings. Participants in this study may be more technologically literate than the general population given their ability to access and use Prime Panel. Most research on parents in the medical setting to date has disproportionally represented the perspectives of highly formally educated, White, married women [101–104]. Our sample, which skewed slightly more male ($n = 30$, 52%), may either uncover perspectives, which have henceforth been lacking (i.e., those of fathers or male-identifying parental figures) or may not be a truly representative sample.

Due to the nature of the interaction with potential participants, the risk of reaching an inappropriate or misaligned participant pool exists. Despite including attention checks and taking additional steps in survey design and administration to reduce non-human responses (i.e., use of ReCAPTCHA and automatic bot checks built into the CloudResearch platform), some responses raise concerns that human respondents may not have answered truthfully and/or attentively. As technology evolves the possibility exists that a more sophisticated "bot" (i.e., a code to automatically complete online surveys) may behave in ways not detected by our fraud detection algorithm criteria and submitted responses which were inadvertently included [96].

Future Recommendations for Scale Refinement

Given that initial exploratory factor analysis resulted in a two-factor solution, contrary to expectations, the final six-item PREHDS scale should be further explored with confirmatory factor analysis in a larger sample to ensure a single-factor solution representing parents' experiences of discrimination. Replication in other samples of parents would strengthen generalizability as well as providing a broader assessment of reliability and validity. Review of items with parents in pediatric healthcare settings acting as expert panel members could add dimension to the construct validity established in the initial expert panel. Further, comparing responses between parents of "well" children in non-acute healthcare settings (e.g., pediatrician's office, dental visit) with parents of ill children in non-acute or acute healthcare settings (e.g., inpatient setting, emergency department) should be undertaken to assess the differences, given the specific ways parents of ill children actualize their parental role [105, 106]. Further, comparing responses by item based on intersecting identities (e.g., a combination of gender identity, race, and ethnicity) might illuminate additional sources of discrimination, which may not have revealed themselves in our analysis. Future analysis should include measurement of internalized racism to enable a closer examination of discrimination experiences in relation to internalized racism [107]. Variations in response patterns may be indicative of how parents in disparate parenting contexts construct their parental role identity. Further validity testing is planned for additional scale refinement utilizing alternative recruiting strategies. Future validity testing should include randomization of instrument order to minimize the risk of context effects [91].

When patients and healthcare providers establish a relationship based on therapeutic alliance, they move away from the traditionally patriarchal and authoritarian provider-as-authority dynamic into an "effective partnership in the pursuit of health goals" [108]. For parents and children, such effective partnerships can have positive health outcomes for children and their parents across the lifespan. Identifying and addressing local and systemic discrimination in the pediatric healthcare setting begin with a more nuanced understanding of parents' experiences of discrimination.

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Data Availability Not applicable.

Declarations

Disclaimer The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Ethical Approval This is an observational study. The Duke University Health System Institutional Review Board approved this study (Pro00113139).

Consent to Participate This study was approved as exempt and as such written informed consent was not sought. Participants were provided a study overview, including risks and benefits of participation, and indicated their willingness to participate (i.e., "verbal consent") by agreeing to proceed with the online survey materials.

Conflict of Interests The authors declare no competing interests.

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