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## Racial and Ethnic Disparities in Communication Study Enrollment for Young People with Cancer: A Descriptive Analysis of the Literature

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### Abstract

**Objective:** We aimed to evaluate the racial and ethnic diversity of study participants in recent pediatric cancer communication literature.

**Methods:** We systematically searched for communication studies in pediatric oncology published between January 2018 and September 2020, limiting analysis to US studies. We considered race and ethnicity as separate categories in our analysis. Two authors screened studies and abstracted characteristics of race and ethnicity reporting and enrollment.

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Declaration of Competing Interests

The authors have no financial or professional competing interests or conflicts of interest relevant to the current article.

CREDIT statement

Sisk conceptualized the study, performed formal analysis, and wrote the original draft. Yaeger, Keenan, Mack, and DuBois conceptualized, reviewed and edited. Goodman and Servin participated in investigation, reviewing and editing.

**Results:** Of 98 articles included in this analysis, many studies failed to report participants' race (21/98) and ethnicity (40/98). Most studies ascertained race and ethnicity by self-report (51/98); 25 studies did not describe how they ascertained race and ethnicity. White participants were overrepresented in studies relative to the US population (median 80% in studies vs 72% in 2020 US census). Racial and ethnic minorities were underrepresented (Black: 7% vs 14%; Asian: 4% vs 7%; Pacific Islander: 0% vs 0.5%; Native American: 0.5% vs 3%; Hispanic 8% vs 19%).

**Conclusion:** Communication literature in pediatric oncology underrepresents all racial and ethnic minority populations and is inconsistent in the reporting of race and ethnicity.

**Practice Implications:** Future work should follow best practices to ensure this literature adequately represents the experiences of all families in pediatric oncology.

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## 1. Introduction

Communication between clinicians and patients or family members is central to delivering family-centered care in pediatric cancer.[1, 2] Effective communication fulfills multiple functions for families, such as making decisions, enabling self-management, providing validation, and supporting hope.[3] Fulfilling these functions can support parental peace of mind,[4, 5] hopefulness,[6] trust, [7] and feeling acknowledged[8] and comforted.[9] Conversely, communication failures can lead to inaccurate understanding of prognosis,[10–12] regret,[13] distress,[14] loss of trust,[15] and even medical harm.[14]

Recent literature suggests that families of racial or ethnic minority are at risk for suboptimal communication experiences. In a study of decision making, oncologists accurately recognized parental preferences for involvement in decision making for only 23% of Black parents and 27% of Hispanic parents, compared to 53% of White parents.[16] Furthermore, parents from underrepresented racial groups were more likely to report decisional regret, although this study was not designed to explain why these families reported greater regret. [13] Similar disparities have been described for prognostic disclosure. Although most parents overwhelmingly desired prognostic information regardless of race or ethnicity, physicians wrongly perceived that Black and Hispanic parents were less interested in prognostic details than White parents.[17] In a subsequent study of parents whose children had advanced cancer, racial minority parents were also less likely to recognize the child's poor prognosis, or that treatments were unlikely to offer a cure. Perhaps as a result, racial minority children were more likely to receive high-intensity medical care at the end of life. [18] Racial minority parents and parents with low income also received less communication from clinicians and demonstrated lower understanding of treatments in informed consent discussions.[19] In other areas of pediatrics, racial and ethnic minority parents were less satisfied with care and interpersonal communication during hospitalizations in pediatric hospitals.[20]

Racial and ethnic minority communities have historically and systemically been underrepresented in nearly all aspects of biomedical research, including cohort studies,[21] clinical trials,[22, 23] genomics,[24, 25] and biobanking research.[22] In our experience, many pediatric communication studies also lack diversity. This lack of representation could impede the ability to understand and explore communication experiences of racially diverse

families, which could affect the quality of communication and care these families receive. However, no prior studies have evaluated the racial and ethnic diversity of participants in studies of cancer communication with young people. In this study, we systematically searched for pediatric cancer communication studies from the last 3 years to characterize the reporting and enrollment related to race and ethnicity.

## 2. Materials and Methods

### 2.1 Inclusion and Exclusion Criteria

We systematically searched for communication studies in pediatric oncology published between January 2018 and September 2020. For inclusion, outcomes of the study needed to relate to “communication” in general or specific communication functions in pediatric oncology that we identified in past research: exchanging information, building relationships, enabling family self-management, making decisions, managing uncertainty, responding to emotions, providing validation, and supporting hope.[3] We limited our analysis to US studies to compare representativeness of race and ethnicity to the US population. We included studies that focused on pediatric and adolescent cancer, even if they also included adults with cancer.

### 2.2 Search Strategy

A medical librarian (LHY) searched for literature including the concepts of pediatric cancer/oncology and communication limiting to the years 2018-2020 and removing conference abstracts where possible. We limited to 3 years to ensure our search reflected current recruitment practices. LHY searched [Embase.com](https://www.embase.com/) 1947-, Ovid Medline 1946-, Scopus 1823-, Cochrane Database of Systematic Reviews (CDSR), Cochrane Central Register of Controlled Trials (CENTRAL), The Cumulative Index to Nursing and Allied Health Literature (CINAHL Plus) 1937-, and APA PsycINFO 1927-. A total of 11,219 results were found. 3,808 duplicate records were deleted after using the de-duplication processes described in “De-duplication of database search results for systematic reviews in EndNote,”[26] resulting in 7,411 unique citations. Fully reproducible search strategies are provided in Appendix A.

### 2.3 Data Abstraction and Analysis

We utilized Rayyan systematic review software for screening studies.[27] Two authors (BAS, MK) collaboratively screened studies for inclusion in two rounds. These authors excluded 7020 articles after reviewing title and abstract. The authors screened full text manuscripts for the remaining 391 articles. Single authors reviewed each article when screening by title abstract. Both authors reviewed each article when reviewing full text and agreed upon final inclusion/exclusion decisions. After exclusions, BAS and MK abstracted basic characteristics of studies into a spreadsheet, including citation, study design, population, and number of participants. BAS then abstracted characteristics of race and ethnicity reporting, including: which racial and ethnic categories were described, percentage of each reported race and ethnicity per study, whether ethnicity was reported as a racial category, and how race and ethnicity were ascertained. When studies included parents and children, we reported the race ethnicity of the child with cancer. When studies included

clinicians and parents or children, we abstracted the race and ethnicity of parents or children rather than the clinicians.

Several studies used combined racial categories, which made it difficult to abstract percent race and ethnicity proportions from each study. To determine proportions of each race and ethnicity in studies, we calculated the median percentages from all studies that provided this information, and we noted how many studies failed to report each race or ethnicity. We used median rather than mean due to a few small outlier studies. We also characterized how racial categories were combined. To compare percentages to the US population, we used data from the 2020 US Census ([www.census.gov](http://www.census.gov)). For simplicity, we will use “Black” to represent individuals who were reported as Black and/or African American. Also, we will use “Hispanic” to represent individuals who were reported as Hispanic and/or Latinx.

### 3. Results

Our initial search yielded 7,411 unique articles. (See Supplemental Figure 1 for screening flow chart) We excluded studies that did not focus on communication (n=6739), did not focus on pediatric or adolescent cancer (n=505), did not present original data (n=301), were performed outside US (n=127), and were not published in English (n=1). After exclusions, 98 articles were included in this analysis. Studies employed quantitative methods (i.e. surveys) (52, 53%), qualitative methods (33, 34%), mixed methods (6, 6%), intervention studies (6, 6%), and 1 case study. Sample sizes ranged from 2 to 1264 participants. Studies most commonly included pediatric, adolescent, and young adult patients with cancer (38, 39%) or parents (32, 33%). Fewer studies focused on clinicians (8, 8%), and 20% of studies included the perspectives of multiple participant groups. (Table 1) See Appendix B for a listing of included studies.

#### 3.1 Reporting of Race and Ethnicity

Most studies ascertained race and ethnicity by participant self-report (51, 52%), yet 26% of studies did not describe how they ascertained race and ethnicity. Many studies failed to report participants’ race (21, 21%) and ethnicity (40, 41%). Furthermore, many studies collapsed non-White races into aggregate categories: 14% of studies dichotomized White vs. non-White; 7% combined Asian and Pacific Islander; 5% combined Native American/Alaskan Native and “other” races. When reporting Hispanic ethnicity, 29% studies reported ethnicity as a racial category. These characteristics of reporting race and ethnicity were present across studies, regardless of study methodology. (Table 2)

Due to combined racial categories, proportions of specific races were absent from many articles: White race was reported in 78% of studies, Black in 63%, Asian in 37%, Pacific Islander/Native Hawaiian in 26%, Mixed race or multiracial in 19%, and Hispanic ethnicity in 59%. (Table 3) Reporting race/ethnicity was not feasible for 2 studies because they analyzed content of anonymous blog posts.[28, 29]

### 3.2 Inclusion of Children, Adolescents, and Caregivers of Racial and Ethnic Minorities in Studies

Twenty studies included both parents and patients, 32 studies included parents only, and 38 studies included patients only. In aggregate, White participants were overrepresented in studies relative to the US population (median 80% in studies vs 72% in 2020 US census). Racial and ethnic minorities were underrepresented (Black: 7% vs 14%; Asian: 4% vs 7%; Pacific Islander: 0% vs 0.5%; Native American: 0.5% vs 3%; Hispanic 8% vs 19%). This disparate representation was present across all study types. (Figure 1) Of the 57 studies that reported the proportion of Black participants, 82% (47/57) included a smaller proportion than the US national average, and 32% (18/57) included fewer than 5% Black participants. Of the 31 studies that reported the proportion of Asian participants, 90% (28/31) included a smaller proportion than the US national average, and 62% (19/31) included fewer than 5% Asian participants. Of 55 studies that reported the proportion of Hispanic participants, 85% (47/55) included a smaller proportion than US national average, and 18% (10/55) included fewer than 5% Hispanic participants.

Among studies that included parents, a median of 79% of parents were White, 7% Black, 2.5% Asian, 0% Pacific Islander, 0% Native American, and 7% Hispanic. Among studies that included patients, a median of 80% of patients were White, 6% Black, 4% Asian, 0% Pacific Islander, 0.5% Native American, and 11% Hispanic.

### 3.3 Inclusion of Clinicians of Racial and Ethnic Minorities in Studies

Race was reported in 4/8 studies of clinicians, and ethnicity was reported in 2/8 studies. Clinicians were predominantly White (median 96%) and non-Hispanic (99.5%). Fewer than 1% of clinicians were Black, 2% were Asian, and 2% were “other” race.

## 4. Discussion and Conclusion

### 4.1 Discussion

Communication values often reflect multiple aspects of personal, cultural, and community experiences. Therefore, it is critical to understand communication experiences within underrepresented populations in order to provide tailored, culturally appropriate communication. Our study demonstrates disparities in enrollment of participants from racial and ethnic minorities in studies of interpersonal communication between clinicians and families in pediatric oncology. For example, 82% of studies included a proportion of Black participants that was smaller than the proportion of Black individuals in the US population, and one-third of studies included fewer than 5% Black participants. We found similar trends for all other reported racial and ethnic minorities. Furthermore, we made these comparisons to the racial and ethnic distribution of the US population. Pediatric data from the US Surveillance, Epidemiology, and End Results (SEER) data suggest these disparities might be even greater. In the SEER database, 53% of childhood cancer patients are non-Hispanic White, 11% non-Hispanic Black, 7% Asian/Pacific Islander, 1% American Indian/Alaskan Native, and 29% Hispanic (any race).[30] Unfortunately, this dataset does not delineate which races constitute the Hispanic category, so we cannot make direct comparisons to our findings.

Additionally, our study identified several deficiencies in the reporting of race and ethnicity. First, 41% of studies did not report ethnicity and 21% did not report race. Some study types are not amenable to capturing demographic information. For example, 2 studies in this review analyzed anonymous illness blog posts.[28, 29] When feasible, researchers should make every effort to capture and report this data. Furthermore, many studies combined racial categories in demographic tables. While these categories might need to be combined in statistical analyses due to small numbers, these data should be transparently reported in the demographics table. If space limitations require the combination of categories or inclusion of an “other” category, the authors should list granular details in the table legend. Lastly, one-third of studies reported Hispanic ethnicity as a racial subcategory. This approach implies, for example, that an individual must be Black *or* Hispanic, rather than Black *and* Hispanic. This approach to collecting and reporting demographic data, which inadequately explores both race and Hispanic ethnicity, risks losing important details about participants. The American Medical Association recently published updated guidance on reporting race and ethnicity in medical journals, which we have summarized in Table 5.

Inclusion of diverse participants in studies is paramount, but researchers must be careful in how they operationalize race and ethnicity in analyses. Race is a social construct and often a proxy for things we cannot easily measure, such as racism, structural inequalities, and discrimination. The goal of including diverse participants must not be to attribute disparities to race alone or place blame on racial and ethnic minority participants. Instead, the goal should be to understand diverse communication experiences and perspectives to ensure that all families affected by pediatric cancer will benefit from tailored, sensitive communication. Furthermore, racial categories are reductionist and can wrongly imply that individuals within that racial category share similar beliefs, values, and experiences.

While this is the first study to analyze the diversity of enrollment in pediatric cancer communication studies, underrepresentation of racial and ethnic minorities is not unique to communication research. Racial and ethnic minority communities have historically and systemically been underrepresented in nearly all aspects of biomedical research.[21–25] In 2014, fewer than 2% of the National Cancer Institute’s (NCI) clinical trials focused on any racial or ethnic minority population.[31] Furthermore, fewer than 10% of participants in NCI-sponsored trials at that time were from racial or ethnic minority communities.[31] An analysis of *The Cancer Genome Atlas* found that only 3% of biospecimen samples were from Black participants.[32] These disparities in representation highlight the persistence of structural inequalities within medical research.

Different study types will require different proportions of racial and ethnic minority participants to characterize effectively these diverse experiences. In qualitative studies, one might strive for proportions of racial and ethnic minority participants that match the US census data if the goal is to ensure the study includes representative viewpoints. However, understanding experiences of communication for families within racial and ethnic minority groups might require larger numbers of participants. For quantitative studies, sample size estimates are more complex to calculate and must consider the test type and many other characteristics of the study sample and analysis plan. For demonstration purposes, a linear regression model powered to detect a moderate effect size would require approximately 100

participants from a racial or ethnic minority group, and 50 participants would be needed to detect a large effect size. Only 3 studies in our analysis included >50 Black participants and none included >100 Black participants. (See Appendix C for detailed sample size estimate.) Similarly, only 2 studies included >50 Hispanic participants.[32, 33] Participants from other races represented even smaller proportions of the total sample. This lack of racially diverse participants within pediatric communication literature indicates a gap in understanding the communication needs and values of racial and ethnic minority families and the need for more intentionally diverse sampling in studies.

Despite the importance of diverse sampling, researchers must also be careful in how they operationalize race and ethnicity in analyses. Race is a social construct and often a proxy for things we cannot easily measure, such as racism, structural inequalities, and discrimination. The goal of including diverse participants must not be to attribute disparities to race alone or place blame on racial and ethnic minority participants. Instead, the goal should be to understand diverse communication experiences and perspectives to ensure that all families affected by pediatric cancer will benefit from tailored, sensitive communication. Furthermore, racial categories are reductionist and can wrongly imply that individuals within that racial category share similar beliefs, values, and experiences.

Traditional institutions and mechanisms often used in research reinforce the exclusion of racially diverse cohorts of participants in studies. Research among adult cancer patients has indicated that barriers to enrollment of diverse participants exist at the individual, interpersonal, and systemic levels, such as potential participants' awareness of research opportunities, perceptions of the institution, and disparities in access to health centers. [33, 34] A growing body of research in pediatrics suggests the role of similar multilevel factors.[35] A systematic review, for example, identified that recruitment and retention of children in research was affected by multiple categories of factors: parent, child, family, and neighborhood characteristics.[36]

Multilevel interventions at each step of the research process are therefore necessary to address barriers to racially representative research. In other areas of biomedical research, community-engaged research has become a best practice for informing research designs and recruitment strategies.[37] Community-engaged research is defined as “the process of working collaboratively with groups of people affiliated by geographic proximity, special interests, or similar situations with respect to issues affecting their well-being.”[38] The goal of community engagement is to develop bi-directional trusting relationships that inform “all aspects of research from development, implementation, data analysis and interpretation, [and] dissemination.”[37] A Delphi process was used to reach consensus on 8 principles for engagement that could be adapted to communication research in pediatric oncology.[39] (Table 4)

In addition to these principles, researchers might engage with families of diverse racial and ethnic backgrounds to develop research questions that these families perceive to be important. Participants might be more likely to participate in studies that address issues they care about and answer questions they deem important. By building relationships with these families and co-developing ideas for meaningful research topics, researchers might



increase the relevance and significance of these projects. This engagement can take the form of advisory boards, qualitative interviews, or even informal conversations. Second, researchers should be equipped to conduct studies in multiple languages to reach potential participants who may not be able to engage in English. Lastly, researchers might partner with racial and ethnic minority families to create social network communities (or leverage existing communities) that can allow for engagement with non-geographic communities of racial and ethnic minority parents who share a specific interest in the rare disease. These and other approaches should be trialed to develop best practices that can convert good intentions into systemic improvements in the engagement of racial and ethnic minority communities in communication research.

The rarity of pediatric cancer also necessitates multi-institutional collaborations to ensure sufficient recruitment of underrepresented minority participants to develop meaningful and generalizable findings. To support these collaborations, funding agencies must provide sufficient financial resources to support subawards to multiple institutions to enhance diversity of recruitment. Without this investment, multi-institutional recruitment tends to rely on the goodwill of researchers who agree to recruit participants with limited or no financial support for their efforts. Additionally, site selection often requires tradeoffs between the availability of different racial and ethnic minority populations. For example, a hospital in the Southwest might have more Hispanic/Latinx patients but fewer Black/African American patients. A hospital in the South might have the opposite demographics. Researchers might create a communication-focused consortium of institutions, or leverage existing collaborative groups like Pediatric Palliative Care Research Network (PPCRN) or Palliative Care Research Cooperative Group (PCRC), to decrease barriers to developing multi-institutional communication studies.

This analysis of the literature should be interpreted in light of limitations. Many articles did not report granular details about race and/or ethnicity. Thus, we had to exclude many studies from the calculations of average percentages of race and ethnicity per study. This absence of data could have resulted in an under or over-estimation of the representation of racial and ethnic minority participants in these studies. Furthermore, we restricted our analysis to the last 3 years to ensure we were representing the current state of the literature, so we cannot comment on historic disparities. Likewise, our focus on racial and ethnic categories can give the impression that all members of a racial category share the same experiences. Additionally, searching for communication studies is difficult because of the many functions and definitions of communication. We utilized broad search terms and screened through more than 7000 articles, but our strategy might have missed pertinent articles. Lastly, this study focuses on race and ethnicity as an important variable of interest. However, we should note that race represents many complex and interacting domains, which includes the individual's sense of self and identity, cultural norms, societal structures, and biases. As such, "race" and "ethnicity" can only highlight areas where disparities exist and serve as a proxy for factors that are harder to measure (e.g. structural or interpersonal racism).

## 4.2 Conclusion

The current communication literature in pediatric oncology underrepresents all racial and ethnic minority populations and is inconsistent in the reporting of race and ethnicity. Communication is central to providing family-centered care in pediatric oncology, and a growing body of literature has identified racial and ethnic disparities in communication experiences.[13, 16–18, 20] As such, communication researchers, funding agencies, and journal editors must take steps to support more diverse recruitment and enrollment in communication studies. The rarity of pediatric cancer makes recruitment of diverse participants challenging, and future work should follow community-engagement best practices to ensure this literature adequately represents the experiences of all families affected by pediatric cancer.

## 4.3 Practice Implications

Guidance for communication practices in pediatric cancer derive from literature that systematically underrepresents all racial and ethnic minority communities. To ensure that communication meets the needs of all families in pediatric oncology, it is imperative that future studies include the perspectives of racially and ethnically diverse participants.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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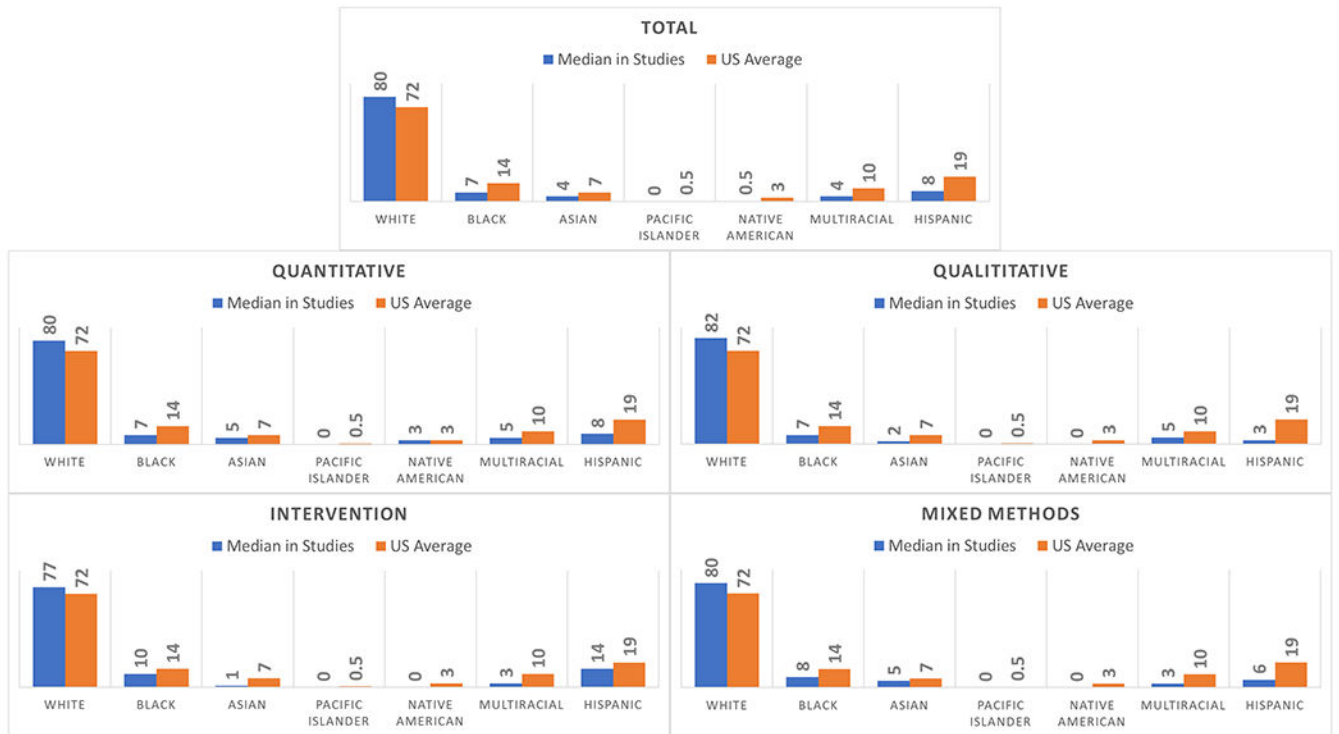
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### Highlights

- 20% of studies failed to report ethnicity; 40% failed to report Hispanic ethnicity.
- 25% of studies did not report how race or ethnicity were ascertained.
- Racial and ethnic minority participants were underrepresented in studies.
- 32% of studies included fewer than 5% Black participants.



**Figure 1. Enrollment of Racial and Ethnic Minorities in Studies**  
 Each column represents the median percentage of participants from each race and ethnicity in a given study type. US proportions were taken from 2020 census at [www.census.gov](http://www.census.gov).

**Table 1.**

## Characteristics of Studies

<b>Variable</b>	<b>Number of studies (%)</b>
<i>Study Design</i>	
<i>Qualitative</i>	33 (34)
<i>Quantitative</i>	52 (53)
<i>Mixed Methods</i>	6 (6)
<i>Intervention</i>	6 (6)
<i>Case Study</i>	1 (1)
<i>Number of Participants, Median (IQR)*</i>	
<i>Qualitative</i>	25 (14 to 37)
<i>Quantitative</i>	164 (100 to 229)
<i>Mixed Methods</i>	34 (17 to 34)
<i>Intervention</i>	66 (38 to 84)
<i>Case Study</i>	2 (N/A)
<i>Types of Participants</i>	
<i>Parents</i>	32 (33)
<i>Children, Adolescents, and Young Adults</i>	38 (39)
<i>Clinicians</i>	8 (8)
<i>Multiple</i>	20 (20)
<i>How Race and Ethnicity Were Ascertained</i>	
<i>Self-Report</i>	51 (52)
<i>Chart Review</i>	1 (1)
<i>Not Described</i>	25 (26)
<i>N/A (Race and Ethnicity Not Reported)</i>	21 (21)

\* IQR = Interquartile Range

**Table 2.**

## Characteristics of Race and Ethnicity Reporting

	<b>Total n (%)<sup>*</sup></b>	<b>Quantitative n (%)</b>	<b>Qualitative n (%)</b>	<b>Intervention n (%)</b>	<b>Mixed Methods n (%)</b>
Ethnicity not reported	40 (41)	16 (31)	21 (64)	1 (17)	2 (33)
Race not reported	21 (21)	8 (15)	10 (30)	1 (17)	2 (33)
White/Non-White Dichotomy	14 (14)	8 (15)	6 (18)	0	0
Black/Non-Black Dichotomy	1 (1)	0	1 (3)	0	0
Black/White/Other	2 (2)	1 (2)	1 (3)	0	0
Hispanic reported as racial subcategory	28 (29)	22 (42)	3 (9)	1 (17)	2 (33)
Asian and Pacific Islander combined	7 (7)	6 (12)	1 (3)	0	0
Native American/Alaskan Native and Other combined	5 (5)	5 (10)	0	0	0
Other and Multiple Races combined	1 (1)	0	0	1 (17)	0

\* Percentages use total number of study type as denominator, as follows: quantitative (n=52), qualitative (n=33), intervention (n=6), mixed methods (n=6), and case study (n=1). The case study was excluded from this table, and it reported race but not ethnicity.

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**Table 3.**

## Number of Studies Reporting Race and Ethnicity

	<b>Total n (%)<sup>*</sup></b>	<b>Quantitative n (%)</b>	<b>Qualitative n (%)</b>	<b>Intervention n (%)</b>	<b>Mixed Methods n (%)</b>
Asian	36 (37)	16 (31)	12 (36)	5 (83)	2 (33)
Black	62 (63)	37 (71)	16 (48)	5 (83)	3 (50)
Hispanic	58 (59)	36 (69)	12 (36)	5 (83)	4 (67)
Mixed Race/Multiracial	19 (19)	5 (10)	8 (24)	3 (50)	2 (33)
Native American/Native Alaskan	24 (24)	9 (17)	10 (30)	3 (50)	1 (17)
Pacific Islander/Native Hawaiian	25 (26)	9 (17)	9 (27)	5 (83)	1 (17)
White	76 (78)	44 (85)	23 (70)	5 (83)	4 (67)

\* Percentages use total number of study type as denominator, as follows: quantitative (n=52), qualitative (n=33), intervention (n=6), mixed methods (n=6), and case study (n=1). The case study was excluded from this table, and it reported race but not ethnicity. Thus, the sum of studies listing each race and ethnicity is 1 fewer than the total number of studies listed in the first column.

**Table 4.**

Adapting Community Engagement Principles to Communication Research (Adapted from Goodman, et al.)

<b>Adapting Community Engagement Principles to Communication Research (Adapted from Goodman, et al. 2020[39])</b>
Focus on community perspectives related to communication and care, especially relate to systemic barriers and institutional inequalities
Encourage and respond to partner input during all phases of research
Build sustainable partnerships to meet mutually agreed-upon goals and objectives
Foster co-learning and co-benefit for all partners
Build on strengths and resources within the community or patient population
Facilitate collaborative, equitable, and culturally sensitive partnerships
Involve partners in dissemination process, including publications and education
Build and maintain trust between researchers and community partners

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**Table 5.**

## Guidance for Reporting Race and Ethnicity

<b>Guidance for Reporting Race and Ethnicity (adapted from Flanagin et al. [40])</b>
Used standard racial and ethnic categories as described by federal standards (American Indian or Alaskan Native, Asian, Black or African American, Hispanic or Latino, Native Hawaiian or Other Pacific Islander, White).[41]
Recognize that race and ethnicity are social constructs that lack scientific or biological meaning.
In methods section, describe how the researchers ascertained race and ethnicity (e.g. self-report, chart review, investigator observed, etc.).
Use specific race and ethnicity categories rather than collective terms (i.e. avoid combining racial and ethnic categories for convenience).
Avoid using “other” race or ethnicity categories as a “convenience” grouping, unless this category was prespecified in a database or instrument protocol.
List categories in alphabetical order in text and tables.
Report race and ethnicity categories of participants in the results section.
Avoid using the term “minorities” without a descriptor. For example, use “racial and ethnic minority groups” or “racial and ethnic minority individuals” rather than “minorities.”
Report “race and ethnicity” rather than “race/ethnicity”, to acknowledge that there are many subcategories within race and ethnicity.
Avoid using racial and ethnic terms in noun form (i.e. use “Black participants” rather than “Blacks”).

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