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# Racial and Ethnic Differences in Parental Decision-Making Roles in Pediatric Oncology

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## Abstract

**Background:** Prior work in adult oncology suggests minority patients are less involved in decision making than preferred. However, few studies have explored decision-making experiences of minority parents in pediatric oncology.

**Objective:** To determine whether parental decision-making preferences and experiences vary by race/ethnicity.

**Design:** Questionnaire-based cohort study.

**Setting/Subjects:** Three hundred sixty five parents of children with cancer and their oncologists at two academic centers.

**Measurements:** Parents reported on preferred and actual decision-making roles. Associations between race/ethnicity and decision-making outcomes determined by chi-squared test.

**Results:** Most parents preferred shared decision making (235/368, 64%), whereas 23% (84/368) preferred parent-led decision making and 13% (49/368) preferred oncologist-led decision making. Parental decision-making preferences did not differ by race/ethnicity ( $p=0.38$ , chi-squared test). However, the actual role parents played in decision making differed by parental race/ethnicity, with 25% (71/290) of white parents reporting parent-led decision making, versus 37% (9/24) of black parents, 48% (13/27) of Hispanic parents, and 56% (15/27) of Asian/other parents ( $p=0.005$ , chi-squared test). Oncologists accurately predicted parental preferences for decision making 49% of the time ( $n=165/338$ ), but accuracy also differed by race and ethnicity. Oncologists accurately predicted parental preferences for 53% of white parents (140/266), 23% of black parents (5/22), 37% of Hispanic parents (10/27), and 43% of Asian/other race parents (10/23) ( $p=0.026$ , chi-squared test).

**Conclusions:** Minority parents held more active roles than white parents, and oncologists had more difficulty predicting decisional preferences for minority parents relative to white parents. These findings suggest that minority parents are at risk of inferior decision-making experiences.

**Keywords:** childhood cancer; communication; disparity; ethics; race; shared decision making

## Introduction

FOR PARENTS OF CHILDREN with cancer, making informed and appropriate decisions on behalf of their children is a core component of being a “good parent.”<sup>1–3</sup> However, parents can differ in the decision-making role they prefer or fulfill. While most parents of children with cancer prefer to engage in shared decision making with their child’s oncologist, more than one-third of parents prefer either oncologist-

led or parent-led roles.<sup>4</sup> When parents fulfill nonideal decision-making roles, they are more likely to experience regret regarding treatment decisions.<sup>4,5</sup> From past work, we know that minority parents are at greater risk of this decisional regret.<sup>5</sup> Yet, it is unknown whether or how the decision-making processes differ for parents of different races or ethnicities.

In adult oncology, non-white race/ethnicity has been associated with more unmet information needs,<sup>6</sup> lower

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ratings of communication effectiveness,<sup>7</sup> and a tendency to ask fewer questions,<sup>8</sup> especially in racially discordant interactions. In addition, studies in adult medicine have demonstrated that minority patients hold less active roles in decision making than white patients.<sup>9</sup> However, little has been published in the adult literature that specifically addresses racial or ethnic differences in preferences for decisional involvement. Furthermore, it is unclear whether adult findings will apply to pediatric oncology, where parents make decisions on behalf of their children.

In comparison, the pediatric literature on race/ethnicity and decision making is even sparser. A recent review article focusing on this topic found only 17 articles, of which 2 were related to pediatric oncology.<sup>10</sup> These oncology-related studies evaluated decisions made at the end of life, but not the decision-making process itself.<sup>11,12</sup> To better support minority parents in making decisions for their children with cancer, we need a deeper understanding of how experiences differ by race and ethnicity in pediatric oncology. In this study, our primary objective was to identify whether parental involvement in decision making varied by race/ethnicity, and secondarily to determine whether the accuracy of the oncologist's perception of parental preferences varied by race/ethnicity. Based on adult literature, we hypothesized that minority parents would fulfill a less active role than white parents.

## Methods

We surveyed parents of children with cancer and their oncologists at Dana-Farber Cancer Institute/Boston Children's Hospital (Massachusetts) and Children's Hospital of Philadelphia (Pennsylvania) between November 2008 and April 2014, as previously described.<sup>5</sup> Parents were eligible if able to read English or Spanish, their child was 18 years or younger, the first contact was 1–6 weeks from cancer diagnosis, and the child's oncologist permitted contact. We asked the parent with primary responsibility for decision making to participate in this study. If both parents equally shared decision-making roles, they were asked to choose which parent participated. Herein, we present a subset analysis of this larger study. The institutional review boards of both participating institutions approved this study.

Of 565 eligible parents, 382 (68%) completed questionnaires. Ninety-five oncologists completed matched surveys for 361 patients (95%). Three hundred sixty eight parents completed all items on preferred and actual decision-making roles and race/ethnicity. Oncologist reports on perceived decisional preferences of parents were available for 338 parents.

## Data collection

Survey development has been described previously.<sup>5</sup> Parent and oncologist questionnaires included items from previously developed surveys<sup>13,14</sup> and select items from existing validated instruments. Questionnaires were available in English or Spanish, and in paper-and-pencil.

We assessed parents' preferred and actual decision-making roles with survey questions modified from those previously developed.<sup>15</sup> Specific phrasing was modified to be appropriate for pediatric rather than adult medicine.<sup>16</sup> Parents were asked, "Which statement best describes the role you

would prefer to play when decisions about treatment for your child's cancer are made?" Response options included, (1) I prefer to make the decisions about treatment with little or no input from my child's oncologist; (2) I prefer to make the decisions after considering my child's oncologist's opinion; (3) I prefer that my child's oncologist and I make the decisions together; (4) I prefer that my child's oncologist makes the decisions after considering my opinion; and (5) I prefer that my child's oncologist makes the decisions with little or no input from me. Parents were then asked "Which statement best describes the role you actually played when making decisions about treatment for your child's cancer?" with equivalent response options.

Oncologists were asked "Which statement best describes the role you believe this child's parent would prefer to play when decisions about treatment for the child's cancer are made?" with analogous response options.

## Parent and patient characteristics

Parents were asked in the survey to report their age, gender, race/ethnicity, highest level of education, and marital status, as well as their child's diagnosis, age at diagnosis, and gender. Race categories included white, black, Asian, or other. Ethnicity categories included Hispanic or non-Hispanic. We then combined racial and ethnic categories for analysis, with Hispanic ethnicity superseding race (i.e., Hispanic parents were categorized as Hispanic rather than an associated racial category such as white or black). For prognosis, oncologists were asked, "how likely you now think it is that this child will be cured of cancer," with response categories as follows: "extremely likely (more than 90% chance of cure)"; "very likely (75–90%)"; "moderately likely (50–74%)"; "somewhat likely (25–49%)"; "unlikely (10–24%)"; "very unlikely (less than 10%)"; or "no chance of cure."<sup>14</sup> The institutional review board of Dana-Farber Cancer Institute approved this study, and informed consent was obtained from all participants.

## Statistical analysis

For analysis, we combined the responses "I prefer to make the decisions about treatment with little or no input from my child's oncologist" and "I prefer to make the decisions after considering my child's oncologist's opinion" into a single category called "parent-led decision making." Similarly, we combined the responses "I prefer that my child's oncologist makes the decisions after considering my opinion" and "I prefer that my child's oncologist makes the decisions with little or no input from me" into a single category called "oncologist-led decision making." We collapsed response categories to be consistent with prior work and to eliminate small cell sizes, given the number of racial/ethnic categories being analyzed. In addition, we felt that these general categories (patient-led, shared, and oncologist-led decision making) were clinically meaningful for those in practice. Due to small numbers, "Asian" and "other" were combined into a single category.

We used chi-squared tests to evaluate associations between parent race/ethnicity and the following: parent's preferred role, parent's actual role, oncologist's perception, and accuracy of oncologist perception. We also utilized chi-squared tests to evaluate the association between the oncologist

TABLE 1. PARENT AND CHILD CHARACTERISTICS

|                                      | N (%)    |
|--------------------------------------|----------|
| Parent age                           |          |
| <30                                  | 38 (10)  |
| 30–39                                | 145 (40) |
| 40+                                  | 181 (50) |
| Parent gender                        |          |
| Female                               | 300 (82) |
| Male                                 | 68 (18)  |
| Parent race/ethnicity                |          |
| White                                | 290 (79) |
| Black                                | 24 (7)   |
| Hispanic                             | 27 (7)   |
| Asian/Other                          | 27 (7)   |
| Parent education                     |          |
| High school graduate or less         | 129 (36) |
| College graduate or technical school | 147 (40) |
| Graduate/professional school         | 88 (24)  |
| Parent marital status                |          |
| Married/living as married            | 303 (83) |
| Other                                | 62 (17)  |
| Child age at diagnosis               |          |
| 0–2                                  | 100 (27) |
| 3–6                                  | 74 (20)  |
| 7–12                                 | 99 (27)  |
| 13–18                                | 95 (26)  |
| Child gender                         |          |
| Male                                 | 203 (55) |
| Female                               | 164 (45) |
| Diagnosis                            |          |
| Hematologic malignancy               | 178 (48) |
| Solid tumor                          | 141 (38) |
| Brain tumor                          | 49 (13)  |
| Oncologist-rated prognosis           |          |
| >75% chance of cure                  | 209 (60) |
| 50–74%                               | 80 (23)  |
| <50%                                 | 61 (17)  |
| Site                                 |          |
| Boston                               | 268 (73) |
| Philadelphia                         | 100 (27) |

*n* = 368 parents who completed questions at baseline on decision-making preferences and roles. Missing data: Parent age (*n* = 4), parent education (*n* = 4), parent marital status (*n* = 3), child gender (*n* = 1), and prognosis (*n* = 18).

accurately knowing the parental preference and the parent fulfilling the ideal decision-making role. We defined “ideal decision-making role” as an exact match between the oncologist’s and parent’s report of parental preferences. Analyses were conducted by using SAS statistical package v9.4.

## Results

Parents reported race/ethnicity as follows: 79% white, 7% black, 7% Hispanic, and 7% Asian/other. Participating parents were predominantly female (82%) and well educated (Table 1). Most children had hematologic malignancies (48%), with the remainder having solid tumors (38%) and brain tumors (13%). Patients generally had good oncologist-reported prognosis, with 60% of patients having at least 75% chance of cure at baseline.

### Decision-making preferences and actual roles

Most parents preferred shared decision making (235/368, 64%), whereas 23% (84/368) preferred parent-led decision making and 13% (49/368) preferred oncologist-led decision making. Parental preferences for decision-making role did not significantly differ by race/ethnicity ( $p = 0.38$  by chi-squared test, Table 2). However, the actual role parents played in decision making did differ by parental race/ethnicity, with 25% (71/290) of white parents reporting parent-led decision making versus 37% (9/24) of black parents, 48% (13/27) of Hispanic parents, and 56% (15/27) of Asian/other parents ( $p = 0.005$  by chi-squared test, Table 3).

### Oncologist perceptions

Overall, oncologists perceived that 29% (97/338) of parents preferred parent-led decision making, 56% (191/338) preferred shared decision making, and 15% (50/338) preferred oncologist-led decision making. The oncologist’s perception of parental decision-making preferences was not associated with race/ethnicity ( $p = 0.43$  by chi-squared test, Table 4). However, oncologist accuracy in understanding decision-making preferences differed by race/ethnicity. Although oncologists accurately predicted parental preferences for decision making 49% of the time ( $n = 165/338$ ), oncologists’ predictions of preferred parental roles were accurate for 53% of white parents (140/266), 23% of black parents (5/22), 37% of Hispanic parents (10/27), and 43% of Asian/other race parents (10/23) ( $p = 0.026$  by chi-squared test, Fig. 1). We then evaluated whether the oncologist’s accurate knowledge of parental preferences was associated with the parent fulfilling their ideal decision-making role, but did not find a significant association ( $p = 0.24$  by chi-squared test).

## Discussion

Parents of children with cancer can have a variety of preferences for their role in decision making. In previous work, we found that the majority of parents desired a shared role in decision making, although more than one-third of parents preferred either oncologist-led or parent-led decision

TABLE 2. ASSOCIATION OF RACE/ETHNICITY WITH PARENT’S PREFERRED DECISION-MAKING ROLE

|             | Parent-led decision making | Shared decision making | Oncologist-led decision making | Total      |
|-------------|----------------------------|------------------------|--------------------------------|------------|
| White       | 59/290 (20%)               | 191/290 (66%)          | 40/290 (14%)                   | 290        |
| Black       | 6/24 (25%)                 | 15/24 (63%)            | 3/24 (12%)                     | 24         |
| Hispanic    | 9/27 (33%)                 | 14/27 (52%)            | 4/27 (15%)                     | 27         |
| Asian/Other | 10/27 (37%)                | 15/27 (56%)            | 2/27 (7%)                      | 27         |
| Total       | 84                         | 235                    | 49                             | $p = 0.38$ |

*n* = 368. *p* value represents chi-squared test.

TABLE 3. ASSOCIATION OF RACE/ETHNICITY WITH PARENTS' ACTUAL DECISION-MAKING ROLES

|             | <i>Parent-led decision making</i> | <i>Shared decision making</i> | <i>Oncologist-led decision making</i> | <i>Total</i> |
|-------------|-----------------------------------|-------------------------------|---------------------------------------|--------------|
| White       | 71/290 (25%)                      | 134/290 (46%)                 | 85/290 (29%)                          | 290          |
| Black       | 9/24 (37%)                        | 9/24 (37%)                    | 6/24 (26%)                            | 24           |
| Hispanic    | 13/27 (48%)                       | 7/27 (26%)                    | 7/27 (26%)                            | 27           |
| Asian/Other | 15/27 (56%)                       | 9/27 (33%)                    | 3/27 (11%)                            | 27           |
| Total       | 108                               | 159                           | 101                                   | $p = 0.005$  |

$n = 368$ .  $p$  value represents chi-squared test.

making.<sup>4</sup> While there are many factors that might influence a parent's decision-making preference, this study suggests that race/ethnicity is not one of these factors. Instead, most parents, regardless of race or ethnicity, prefer to share decision making with the oncologist.

However, the actual roles parents fulfilled in this study did vary by race/ethnicity, with minority parents more likely to hold a more active decision-making role, and more active than they desired. This finding contrasts with prior studies in adult medicine that found less decision-making involvement of minority patients relative to whites.<sup>9</sup> It is unclear why this finding in pediatrics differed from studies in adults. While this shift toward more active decision-making roles could be viewed as an improvement over past adult studies, holding a larger role in decision making can be just as difficult for parents as being less involved than desired.<sup>4</sup>

We know from prior work that minority parents are at an increased risk of decisional regret,<sup>4,5</sup> and it is possible that holding more responsibility for decisions than desired is a contributor. Holding nonideal roles might also impede minority parents' abilities to fulfill their perceived "good parent" role, especially if they feel they made poor decisions on behalf of their child. Fulfilling this "good parent" role is central to the identity of most parents,<sup>1,2</sup> and failing to support this role might affect the ability of parents to care for their children or themselves. The impact of decision making on parents in pediatric oncology, especially minority parents, requires further study.

This increased parental responsibility for decision making among minority parents could indicate that some oncologists find it more challenging to offer clear treatment recommendations and engage in supportive partnerships in decision-making interactions with minority parents. Whether these types of interactions are beneficial or harmful depends on the context of individual parent-oncologist relationships, but our findings raise the concern that minority parents are less effectively supported in decision making, and are instead asked to carry greater decisional burden. Racial and ethnic

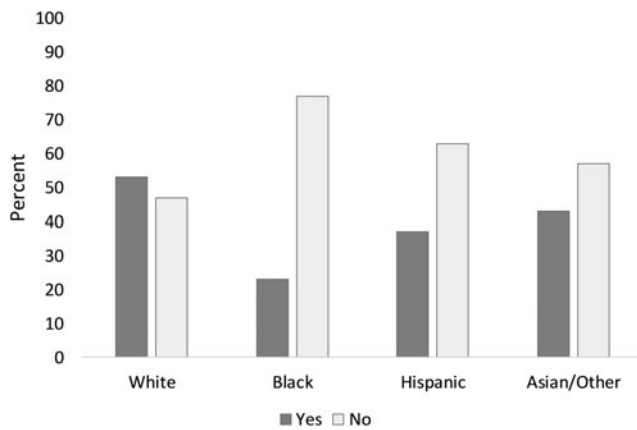
differences in decisional roles might be explained, in part, by the oncologist's poor ability to accurately understand parental decision-making preferences. In considering all parents, regardless of race/ethnicity, oncologists only had an accurate perception of the parent's preferred role 49% of the time. Yet, accuracy was even worse with minority parents. For example, clinicians accurately judged black parents' decision-making preferences only 23% of the time. This finding is similar to previous work showing that oncologists' perceptions of parental preferences for prognostic information differed by race, with oncologists tending to assume minority parents wanted less information.<sup>17</sup> Yet, while oncologists may provide less information to minority parents, our findings suggest that they also ask minority parents to carry greater weight in decision making relative to white parents. Taken together, the two issues may compound minority parents' challenges when it comes to making the best decisions for their children.

This disconnect between oncologists' perceptions and parental preferences could also indicate that oncologists lack familiarity with minority parents and families. This lack of familiarity could be exacerbated by the fact that most oncologists are not black or Hispanic, and the vast majority of minority patients will have racially discordant interactions with doctors,<sup>18</sup> especially in oncology.<sup>19</sup> As much work on implicit racial bias has shown, these biases can affect clinicians' conscious and subconscious thought processes.<sup>20-22</sup> For example, one study found that implicit racial biases and stereotypes of pediatricians affected treatment decisions, leading to fewer postoperative narcotic prescriptions for African American children.<sup>23</sup> This same implicit bias might contribute to communication disparities observed in this and previous studies. Alternatively, our findings could indicate that doctors and parents define decision-making roles differently, especially for minority parents. However, parents in this study did not differ in their decision-making preferences based on race/ethnicity; rather, it was only the oncologist's perception of their preferences that varied based on the parent's race/ethnicity.

TABLE 4. ASSOCIATION OF RACE/ETHNICITY WITH ONCOLOGIST'S PERCEPTION OF PARENTS' PREFERRED DECISION-MAKING ROLE

|             | <i>Parent-led decision making</i> | <i>Shared decision making</i> | <i>Oncologist-led decision making</i> | <i>Total</i> |
|-------------|-----------------------------------|-------------------------------|---------------------------------------|--------------|
| White       | 77/266 (29%)                      | 153/266 (57%)                 | 36/266 (14%)                          | 266          |
| Black       | 8/22 (36%)                        | 10/22 (45%)                   | 4/22 (18%)                            | 22           |
| Hispanic    | 4/27 (15%)                        | 16/27 (59%)                   | 7/27 (26%)                            | 27           |
| Asian/Other | 8/23 (35%)                        | 12/23 (52%)                   | 3/23 (13%)                            | 23           |
| Total       | 97                                | 191                           | 50                                    | $p = 0.43$   |

$n = 338$ .  $p$  value represents chi-squared test.



**FIG. 1.** Effect of Race/Ethnicity on Oncologist's Accurate Understanding of Parent's Preferred Decision-Making Role,  $p=0.026$  by chi-squared test.

Beyond decisional regret, it seems probable that such communication disparities impact other areas of health, but there is a dearth of literature focusing on the role of race/ethnicity in communication in pediatric oncology, and there are even fewer publications on race/ethnicity and decision making.<sup>10</sup> While the current small body of pediatric communication literature identifies racial disparities in decision making,<sup>5,10</sup> unmet information needs,<sup>17,24</sup> and satisfaction with care,<sup>25</sup> our current understanding of these disparities is superficial, which makes intervention more difficult. Future studies should take steps to develop larger samples of minority parents and patients to better understand the barriers and facilitators of effective communication for these parents. Future work should also focus on determining the best practices for assessing parental decision-making preferences. This process will almost certainly require more than asking, "What role do you want to play in this decision?" Instead, this process will likely require value elicitation, information exchange, and relationship building, but specific recommendations require further study. This work is needed to provide minority families with better care, and to provide clinicians with better guidance and training.

These results should be interpreted in light of this study's limitations. First, minority parents were underrepresented in the study sample, thus decreasing our ability to explore communication disparities in more detailed analyses. Parents of children with brain tumors and less-educated parents were also underrepresented. In addition, we combined "Asian" with other underrepresented race/ethnicities for statistical purposes, which created a heterogeneous group. Furthermore, this study occurred at two highly specialized pediatric cancer centers. Combined, these factors might affect generalizability of our results. Beyond study sample limitations, this study was also limited by the questions we used to assess the decision-making process. Decision making is more complex than simply the roles we fulfill, and these questions did not account for other contextual factors, such as the different people in the room and their preferences (e.g., the child and the other parent) or the perceived significance of the decisions. Furthermore, we do not know how many consults involved both parents versus only one parent, a factor that could have affected decision making. Finally our questionnaire did

not ascertain the race/ethnicity of the oncologists, so we are unable to determine whether interactions were racially discordant or concordant, although the majority of oncologists at these institutions were not black or Hispanic. Despite these limitations, our findings add important insights to a sparse body of literature.

In this study, we found that parents did not differ in their decision-making preferences by race/ethnicity, but their actual roles did vary. Furthermore, oncologists had difficulty identifying preferences for decisional engagement among all parents, but especially among minorities. These findings suggest that parents in pediatric oncology are being communicated with differently based on their race/ethnicity, whether intentionally or not. These discrepancies matter because holding nonideal decision-making roles can impair the ability of parents to fulfill their definition of a "good parent," and these parents can experience regret. These findings add to the small body of communication literature in pediatric oncology that addresses the role of race/ethnicity. Further dedicated study is needed to ensure we are providing equitable care to all patients and parents.

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