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Factors Promoting or Preventing Caregivers from Allowing Pediatric Participation in Research

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Introduction

In recent years, participation in clinical research has greatly influenced the prevention, prognosis, and treatment of many complex diseases. Although study purpose, protocol, and personal incentives influence enrollment in clinical studies, the greatest motivators for participation are the advancement of knowledge and the altruistic hope of finding an effective medical treatment.[1] Unfortunately, relatively low enrollment ranging from 3% to 20% has been reported for clinical trials for certain chronic conditions such as cancer.[2]

Although awareness of the benefits of and opportunities afforded by clinical trials has increased in the population, this awareness is far from ubiquitous and reflects poor inclusion of racial/ethnic minorities, women, and children.[3] Among racial/ethnic minorities, study designs, cultural differences, and linguistic barriers appear to limit participation, whereas the opportunity for medical treatment seems to increase willingness to engage in clinical studies.[2,4] Assuming that minorities will not participate in a clinical study has been shown to be a barrier for recruitment that lessens participation and representation of underserved individuals in clinical research.[5,6] Pediatric clinical research has improved during recent years, giving equal importance to common and uncommon diseases, designing studies to address potential differences across a spectrum of ages, and requiring participants' assent and parental consent.[7] The likelihood of a child participating in a clinical trial is mostly independent of the child's willingness to participate; children's lack of autonomy obliges parental involvement, which is concurrently conditional to parental understanding, trust, and endorsement of the research study. Given the trajectory of children's health into adulthood and the need to improve the health of the next generation, pediatric inclusion in the development of evidence-based medicine and therapies is paramount. From this perspective, this study identified potential predictors for allowing children to participate in clinical studies and evaluated whether motivators that promote or prevent parental support of children's participation differed according to racial/ethnic categorization.

Methods

Study Design and Participants

A sample of residents in South Florida's Miami-Dade, Broward, and Palm Beach counties was surveyed via landline or cell phone by Professional Research Consultants Inc. (PRC). For the telephone-administered survey, PRC assigned a caller ID number that was local to the area, made multiple attempts to reach respondents, and called at different times of the day on different days of the week. The sample was stratified by county to ensure adequate representation among all strata. At the time of the interview, for households with multiple children age 0–18, one child was selected at random based on which had the most recent birthday, and the survey questions were asked about that specific child. This produced a sample that is more representative by demographics of age and gender. The survey respondents were adults age 18 and older who had at least 1 child residing in the household for whom the respondent was the health care decision-maker (child's caregiver).

A sample of 1057 caregivers (the complete sample of the Community Health Needs Assessment, CHNA) were included in the study, and participants self-identified as Non-Hispanic White (n=406), Non-Hispanic Black (n=177), Hispanic (n=398), Non-Hispanic Asian (n=30), and others (n=18). Caregivers were 27.1% male (n=284) and 72.9% female (n=764). Data were de-identified prior to the investigator receiving the data, and an Institutional Review Board-exempt research protocol was approved for this study.

Survey Methods

The survey interview was constructed as part of a broader CHNA effort by a range of community stakeholders in child health in the South Florida region, including health care systems, city departments, health insurance companies, and school districts. For this research, we conducted a secondary analysis of CHNA data. Survey questions pertained to health care access, health insurance, chronic conditions, care utilization, demographics of the child of interest, and demographics of the respondent. To preserve generalizability of the responses, terms such as "clinical trial" were defined during the administration of the questionnaire. After nonresponse weights were taken into account, the data were post-stratified based on sample characteristics of age, gender, race, ethnicity, and poverty

status to further align the survey responses to known proportions in the population using U.S. Census Bureau population estimates. A statistical application package applied weighting variables that produced a sample. While the integrity of each individual's responses is maintained, 1 respondent's responses may contribute to the whole the same weight as, for example, 1.1 respondents. Another respondent, whose demographic characteristics may have been slightly oversampled, may contribute the same weight as 0.9 respondents.

Outcomes of Interest

Participants were asked, "*In general, how likely would you be to allow your child to participate in a clinical research trial?*" with the answer options being "*Not at All Likely,*" "*Somewhat Likely,*" or "*Very Likely.*" This question was followed by either, "*What is the MAIN reason you would allow your child to participate in a clinical research trial?*" or "*What is the main reason you would NOT allow your child to participate in a clinical research trial?*" These questions were open ended, meaning that respondents were free to say whatever came to mind, and their verbatim responses were recorded. These responses were then grouped thematically for the analysis. For those not allowing participation, responses were classified into: "Fear or concern over study," "Need more information to decide," "Inconvenience," "Potential lack of health benefit," "Other," or "Don't know/Not sure." For those allowing participation, responses were classified as "Current health," "Future health," "Science," "Other," or "Unsure." These classifications were used to understand the motivators that promote or prevent allowing participation, whereas data from the other survey questions were used to identify predictors for allowing participation.

Analytic Approach

Initial data preparation required the evaluation of item-level nonresponse that, although limited for any one variable, could have been more substantial in multivariate models. A machine learning approach to variable multiple imputation was used to address item-level nonresponse utilizing random forest imputation[8,9]. This approach accommodates the wide number of potential interactions among covariates that may explain item-level nonresponse. Descriptive statistics were obtained for demographic variables through percentages and 95% confidence intervals (CI).[10] Unweighted and weighted responses for the question regarding the willingness of participation in a clinical research trial and reasons to

participate or not also were described in percentages and 95% CI for the weighted estimates. We also evaluated whether reasons for allowing and not allowing participation varied by race using weighted chi-square analyses.

Preliminary identification of predictors for pediatric research participation in clinical trials was achieved by performing exploratory unadjusted weighted multinomial association tests between the outcome of interest and a range of possibly related factors from the survey that may have influenced participation. An associated group of predictors were identified based on statistical associations at $p < .10$ and/or based on theoretical relevance. These predictors included the child's age, sex, race/ethnicity categorization, insurance status, survey items capturing whether the child had difficulties accessing health care, whether the child was reported to be limited in ability to engage in normal activities due to any condition, survey items capturing whether the child has ever had a chronic condition, whether the child has ever needed a specialist, whether the child needed special therapy or medication for any condition, the child's weight status (underweight, normal weight, overweight), household's poverty status, household language most predominantly used, and respondent's education level. Body mass index (BMI) was used to assess weight status, and the BMI number was plotted on the CDC BMI-for-age growth charts to obtain a percentile ranking. Percentiles were used to classify the weight status as: underweight $<5^{th}$ percentile, healthy weight $\geq 5^{th}$ and $<85^{th}$ percentile, overweight $\geq 85^{th}$ and $<95^{th}$ percentile, and obese $\geq 95^{th}$ percentile.

Preliminarily identified predictors were incorporated into a weighted multivariable multinomial logistic model (*full model*). Rather than including all identified covariates capturing information about access to care and child's health, 2 continuous sum score variables were derived. A "difficulties in access to care" score was constructed by summing difficulties experienced in the past 12 months (1=Yes, 0=No) among (a) difficulty finding a physician to care for the child, (b) difficulty finding an appointment for care, (c) difficulty finding available hours for care, (d) difficulty finding transportation for care, (e) difficulty paying for the cost of care, and (f) difficulty in the cost of medications. The reported chronic conditions sum score was constructed by summing the respondents' reports that the child had ever suffered from or been diagnosed with the following: (a) food allergies, (b) skin allergies, (c) respiratory allergies, (d) asthma, (e) a brain injury or concussion, (f) diabetes, (g) 3 or more ear infections, (h) epilepsy, (i) eye problems that could not be corrected with glasses or contact lenses, (j) hearing problems, (k) a learning disability, or (l) a migraine.

Because of the limits in sample size, the covariates included in the full model were further restricted into a reduced multivariable multinomial model containing only those that showed evidence of a statistically marginal or lower p-value ($p < .10$). All statistical analyses were performed using R 3.3 software.

Results

Table 1 shows weighted proportions and 95% CI for background demographic variables. Table 2 provides unweighted and weighted percentages according to how likely respondents were to allow a child to participate in a clinical research trial. About 2% of participants (n=18) reported they were unsure about participation or refused to provide an answer to the question. These responses were considered missing and imputed in weighted analyses to limit covariate categories with small frequencies included in models. Unweighted proportions were within the 95% CI of weighted proportions, suggesting limited extreme changes during sample weighting adjustments.

Table 3 shows unweighted and weighted descriptive information about reasons that caregivers reported would influence their decision to allow their children to participate in clinical research. Among the responders who were very likely to allow their child to participate in research, the majority chose "other" as their reason for participation, particularly if their child was in excellent health. Some of the reasons categorized by "other" were: "don't know/not sure," "purpose of research," "money," "safety," "if child would want to do it," "depends on how it is done," "availability of new medications," and "if appropriate for age." The most common responses for the selection "other" included "believe it is a good idea" and "depends on the purpose of the research." For responders who were unlikely to allow their child to participate in clinical research, the most common response was "fear/concern over study," while the least likely reason was "inconvenience." The classification "fear/concern over study" included specific responses such as "unknown side effects," "no trust," "child is too young," "unethical," "painful," "not FDA approved," "unhealthy," and "not going to use my child as guinea pig." Specific responses grouped under "inconvenience" included "scheduling" and "lack of time." Weighted chi-squared analyses show no differences by race/ethnicity for the reasons to allow participation [χ^2 (12) = 16.82, p=.41] or reasons not to allow participation [χ^2 (15) = 25.39, p=.19].

To identify potential predictors for allowing participation, the significant predictors of the full model were retained in a final reduced

multivariable multinomial model that fit the data more parsimoniously than the full exploratory model ($AIC_{Reduced}$=1,913.35 vs. AIC_{Full}=1,941.39; $BIC_{Reduced}$=2,002.68 vs. BIC_{Full}=2,199.47).

The independent variables in the reduced model included the child's race/ethnicity, the respondent's sex, whether the child was reported to be limited in ability to engage in normal activities due to any condition, child's weight, and the difficulties in accessing health care sum score. All results for the multinomial models are reported based on the reduced model.

Weighted odds ratios and 95% CIs of the contributions of the predictors from the reduced multivariate multinomial model to the willingness to participate in clinical research are represented in Figure 1. Using Non-Hispanic White (NHW) caregivers as the reference group, there were no differences in the likelihood to allow participation among Hispanic caregivers. Interestingly, in Non-Hispanic Black (NHB) caregivers, there was a statistical difference between "very likely" to allow participation relative to "somewhat likely" when compared with NHW caregivers. In respondents classified as another race/ethnicity, there was a statistical difference between "somewhat likely" to allow participation relative to "unlikely." Overall, males appeared to be more likely to allow participation than females. "Child health care access difficulties" in the past 12 months were consistently associated with a response of being "very likely" to allow participation and "somewhat likely" to allow participation. Similarly, "child's limited ability to do things due to a health condition" was associated with "very likely" and "somewhat likely" responses to allow participation. In general, respondents who reported that their child was underweight (vs. normal weight status) were more likely to allow clinical trial participation, whereas respondents of children who were overweight relative to normal weight did not differ in likelihood of allowing participation.

Figure 2 shows adjusted marginal probability estimates for the variables in the reduced final multinomial model. Even when adjusting for other factors, the marginal probability for most predictors was highest for being "Not at all likely" to allow participation (0.32 to 0.60). In contrast, across all predictors, the lowest adjusted probability was observed among the "Very likely to allow participation" respondents (0.07 to 0.23). Noteworthy is the observation that those respondents who reported their child had a health condition that limited the child's ability were also respondents who had a higher adjusted marginal probability of saying that they would be "Somewhat likely to allow participation" (0.42), which is higher than the adjusted marginal probability for being "Not at all likely" to allow participation (0.32) if the child had a health condition. In addition, the number of health care access difficulties reported by caregivers was related

to the likelihood of participation (Figure 3). The higher the number of health care access difficulties reported, the more likely the caregiver was to allow participation in clinical research.

Discussion

This study was designed to explore the role of different factors in promoting participation or preventing caregivers from allowing children to participate in clinical studies and to identify potential predictors for the willingness to participate. The results show that there are different reasons why caregivers will allow or reject their child's participation in clinical research, which include the sex of the participant, access to health care, race of the responder, and child's weight status. Our findings reflect the complex etiology underlying the participation of children in clinical research.

Aspects related to the design of the study, cultural differences, and linguistic barriers have been shown to limit participation of minorities in clinical investigations.[2] Our results suggest that the factors and motivators influencing caregiver decisions about allowing their child to participate in clinical research differ according to race/ethnic classification. NHB caregivers were more receptive to allowing participation, an observation contrary to previous reports of minorities' lack of willingness to participate in clinical research opportunities but in line with reports of minorities willing to but not asked to participate.[5,11,12] Although minority participation in clinical trials is complex, increased receptivity for participation may be a consequence of recent initiatives targeted to create awareness of the need for community networks to improve minority health, potentially combined with the altruistic commitment of minorities to find medical treatment for their communities.[13,14] From this perspective, recruitment efforts to increase minority participation might need to be strategically marketed as educational campaigns to create awareness of health as a social and collective responsibility.

There appears to be a gender disparity regarding caregivers' willingness to allow their child to participate in clinical research. Male caregivers are more likely to allow participation (15%) compared to female caregivers (7%). The weight status of the child also appears to influence willingness to participate. Interestingly, probability estimates showed a greater disposition toward research participation among caregivers of children with underweight status and a greater aversion to participation among caregivers of children perceived to be within normal weight.

Our data indicate that respondents whose child had a health condition that limited his/her ability were more willing to participate in

research and less willing to refuse participation. Also, the adjusted marginal probability of those who are very or somewhat likely to participate increases as the number of health care access difficulties increases (Figure 3). Although research has shown that exposure to medical treatment or having the disease addressed by a clinical trial increases participation, our data suggest that parents might view a clinical study as a health care treatment option.[4,15] Parents tend to weigh risks and benefits when considering children's participation in clinical research and are motivated by the opportunity to access new treatments, healthcare professionals, and health information.[16] However, the observation that pediatric research participation is influenced by the health of the child raises concerns about the generalizability of the results of that research when health-biased samples are used to provide overall recommendations to the pediatric population.

It is noteworthy that no differences were observed in the motivators for clinical research participation between NHW and Hispanics. This finding is inconsistent with national estimates of Hispanic participation in clinical trials.[17,18] A potential explanation for this discrepancy may be related to regional variation of social structures and the role Hispanics play in the local communities.[19] In Miami-Dade County, Hispanics make up close to 70% of the population and are widely integrated into the social, political, and cultural fabric of the community. It is possible that this local environment contributes to the similarities noted between the responses of NHW and Hispanics in this study. These findings might inform future strategies directed toward reducing the gap in clinical research representation of minority populations, such as creating awareness among communities and considering health care access, race of the responder, and other variables. In addition, our findings underscore the need for future studies that account for the socioeconomic, political, and cultural diversity of Hispanic and other minority populations.

As in any population study, some limitations must be recognized. Foremost, the data utilized for this study was based on a survey whose original purpose was not directed toward understanding clinical research participation willingness, and the questions utilized in this survey were not designed to be used as a research tool for such. Consequently, the creation of categories capturing those potential motivators influencing clinical research was arbitrary and relied on the creativity, clinical experience, and consensual integrity of the investigators. The benefits of having a representative sample of the population of Miami-Dade, Broward, and Palm Beach counties were also clouded by the limitations of a sample size that became diluted when categorized by reasons for participation and racial/ethnic categories. The limited sample size, combined with the

laborious statistical approach, impaired the evaluation of potential interactions between and among predictors, including relationships between poverty levels and racial/ethnic categories. As a result, the exploration of such interactive terms was not included in the analyses. Even though this sample is representative, the self-selection of the caregivers to participate may limit the participation of those who are distrustful of research and who, in turn, are unlikely to allow their child to participate in a clinical trial. It is most important to state that, despite the limitations in the experimental design of the study, the importance of the results of this investigation cannot be minimized, particularly when understanding the need to increase pediatric participation in clinical research. The thoroughness of our statistical methodology and overall scientific approach to address our objective serve as evidence of the scientific rigor of our research team and our commitment to improve public health initiatives that can be inclusive of all.

From the perspective that clinically applied research will inform and improve health outcomes for all segments of the population, our findings raise awareness of the complex and multifactorial nature of engaging children of diverse backgrounds in clinical research participation and of the challenges faced by public health initiatives when trying to translate research findings into policies and treatments that might fail to be applicable to all.[20] Further research into the development of strategies for participatory research engagement of all sectors of the population seems paramount in order to implement preventive and treatment strategies that are culturally and biologically sensitive, fair, and equitable to all segments of the pediatric population.

Ethical Approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Conflict of interest: No authors report a conflict of interest.

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Table 1. Survey weighted estimates of background demographic characteristics of children in a sample of residents in South Florida, 2015.

Variable	Level	N*	Proportion (95% CI)
Child age (y)	4/Under	352	33.33% (29.79% - 36.87%)
	5 to 12	409	38.72% (35.42% - 42.02%)
	13 to 17	295	27.94% (25.08% - 30.80%)
Child sex	Male	540	51.13% (47.67% - 54.59%)
	Female	516	48.87% (45.41% - 52.33%)
Child Race/ethnicity	Non-Hispanic White (NHW)	286	27.08% (24.44% - 29.72%)
	Hispanic	445	42.18% (38.74% - 45.62%)
	Non-Hispanic Black (NHB)	253	23.98% (20.69% - 27.27%)
	Other race/ethnicity	71	6.76% (4.94% - 8.58%)
Child insurance status	Private health insurance	496	46.95% (43.55% - 50.35%)
	Medicaid or Medicare	396	37.49% (33.92% - 41.06%)
	Uninsured	85	8.05% (6.08% - 10.02%)
	Other	79	7.50% (5.59% - 9.41%)
Child has usual source of care	Yes	869	82.28% (79.49% - 85.07%)
	No	187	17.72% (14.93% - 20.51%)
HHS poverty status	200% of poverty or higher	600	56.77% (53.16% - 60.38%)
	100% to 199% of poverty	238	22.56% (19.69% - 25.43%)
	Below poverty	218	20.67% (17.00% - 24.34%)
Household language	English	855	80.90% (78.01% - 83.79%)
	Spanish	140	13.25% (10.69% - 15.81%)
	Other	61	5.85% (4.19% - 7.51%)
Caregiver education level	Postgraduate	184	17.43% (15.11% - 19.75%)
	College graduate	323	30.59% (27.54% - 33.64%)
	Some college/technical school	347	32.88% (29.53% - 36.23%)
	High school or less	201	19.10% (16.08% - 22.12%)
Child's weight status	About the right weight	767	72.61% (69.52% - 75.70%)
	Overweight	147	13.98% (11.60% - 16.36%)
	Underweight	141	13.41% (11.03% - 15.79%)

*N values are based on the rounded weighted estimates after imputation

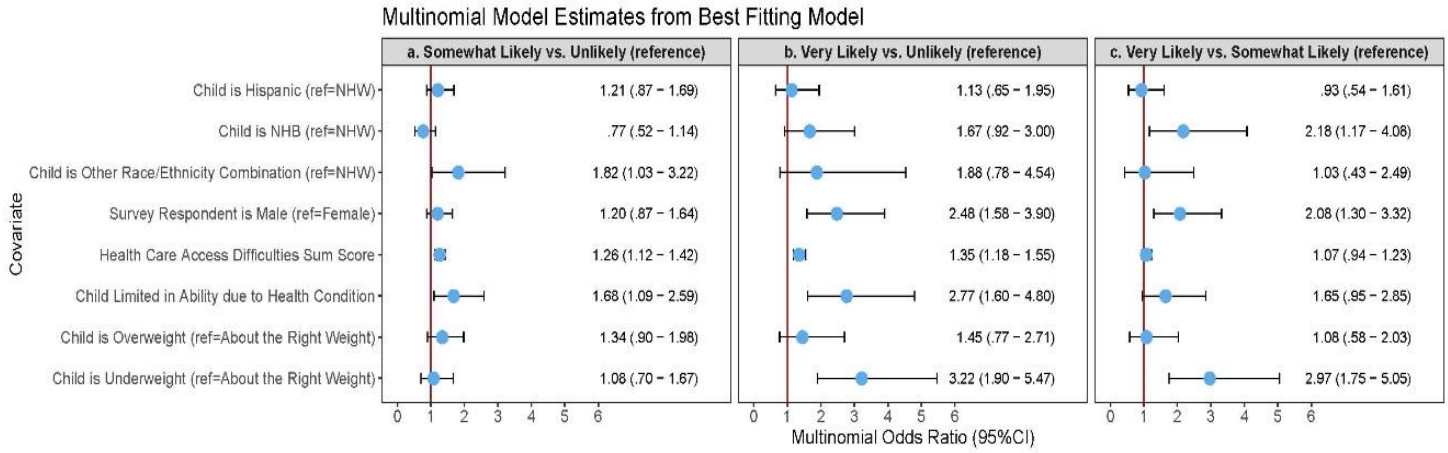
Table 2. Responses to the question "In general, how likely would you be to allow your child to participate in a clinical research trial?" Answers are provided for unweighted and weighted estimates in a sample of residents in South Florida, 2015.

Level	Unweighted		Weighted	
	N	Percent	N	Percent (CI)
Not at All Likely	584	55.25%	570	53.94% (50.47% - 57.41%)
Somewhat Likely	350	33.11%	367	34.73% (31.41% - 38.05%)
Very Likely	105	9.93%	119	11.32% (9.02% - 13.62%)

Table 3. Unweighted and weighted percent estimates of identified reasons to participate or not participate among respondents in a sample of residents in South Florida, 2015.

	Level	Unweighted		Weighted	
		N	Percent	N	Percent
Reasons Not to Participate	Fear or concern over study	477	51.40%	466	50.84% (47.15% - 54.54%)
	Need more information to decide	139	14.98%	128	13.93% (11.51% - 16.36%)
	Inconvenience	50	5.39%	43	4.69% (3.20% - 6.18%)
	Potential lack of health benefit	56	6.03%	54	5.87% (4.19% - 7.56%)
	Other	106	11.42%	111	12.03% (9.57% - 14.49%)
	Don't know/Not sure	100	10.78%	116	12.63% (9.96% - 15.29%)
Reasons to Participate	Child current health	88	11.13%	88	10.87% (8.45% - 13.29%)
	Child future health	52	6.57%	51	6.30% (4.41% - 8.18%)
	Science	157	19.85%	146	18.10% (15.13% - 21.06%)
	Other	404	51.07%	408	50.60% (46.59% - 54.60%)
	Unsure	90	11.38%	115	14.14% (11.04% - 17.23%)

Figure 1. Multinomial model estimates according to race/ethnicity, sex, child limited ability due to health condition, and child weight status in a sample of residents in South Florida, 2015.



Multinomial odds ratios (circles) and 95% CIs (black error bars) show the magnitude of effects of each covariate in the final model. 95% CI bars that do not cross the red line at 1.00 can quickly be identified as statistically significant. The OR and associated 95% CI for each multinomial outcome contrast are also listed to the right of the visual effects.

Figure 2. Adjusted marginal probability estimates and 95% CI according to child's race/ethnicity, sex, limited ability due to health condition, and weight status in a sample of residents in South Florida, 2015.

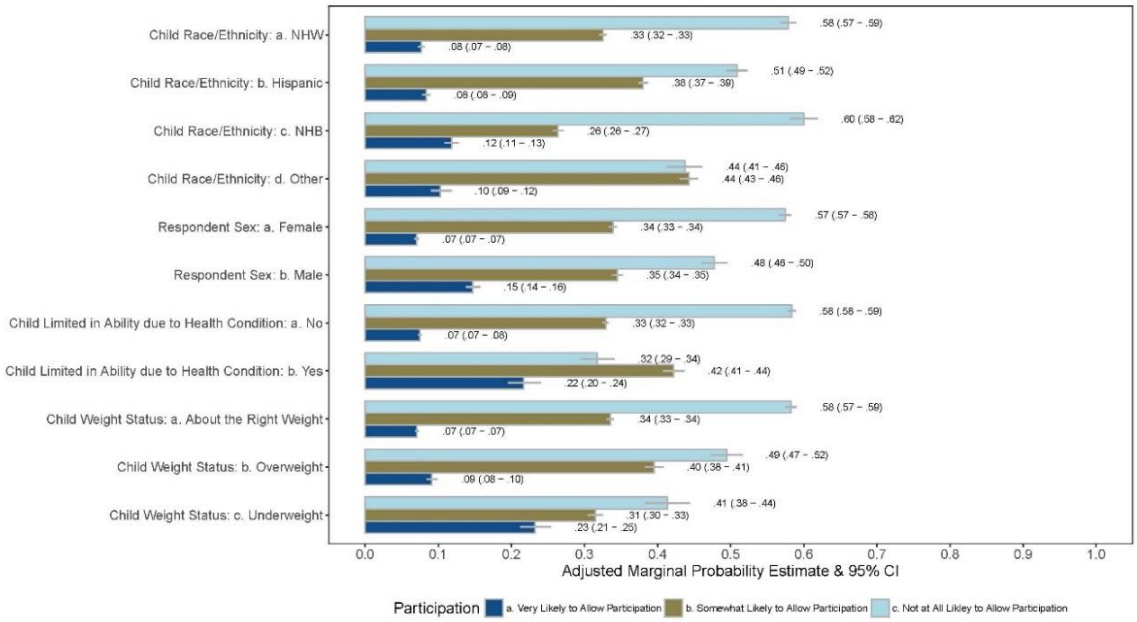


Figure 3. Health care access difficulties and participation in a sample of residents in South Florida, 2015.