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## UNIVERSITY OF CALIFORNIA, IRVINE

# Evaluating Racial/Ethnic and Socioeconomic Differences from Child-Reporting of General Health Measures

## THESIS

submitted in partial satisfaction of the requirements for the degree of

## MASTER OF SCIENCE

in Biomedical and Translational Science

by

Arlene Ngor

Dissertation Committee: Professor Sherrie Kaplan, Chair Professor Sheldon Greenfield Professor Robert Wilson

 $\ensuremath{\mathbb{C}}$  2022 Arlene Ngor

## **TABLE OF CONTENTS**

		Page
LIST OF ABBREV	VIATIONS	iii
LIST OF APPEND	NICES	iv
LIST OF FIGURES	S	v
LIST OF TABLES		vi
ACKNOWLEDGE	MENTS	vii
ABSTRACT OF T	HE THESIS	viii
CHAPTER 1:	Introduction Child Health in the United States Quality of Life Health Measures Proxy-Reporting Assessment of Child HRQOL Intersection of Race/Ethnicity and Socioeconomic Status on Health Disparities Child Health Ratings Inventories (CHRIs) Implementation Study Objectives	1 1 2 3 4 5 6
CHAPTER 2:	Methods Study Source & Data Collection Study Instrument Key Study Variables Statistical Analysis	7 7 8 11 15
CHAPTER 3:	Results Study Cohort Baseline Characteristics Analytic Group According to Race/Ethnicity Analytic Group According to SES Analytics According to Annual Income Earnings Analytics According to SES CHRIs Health Measures Mean Value Differences Analyses	17 17 19 20 25 30 32 34
CHAPTER 4:	Discussion	40
CHAPTER 5:	Conclusion	46
REFERENCES		48
APPENDICES		54

## LIST OF ABBREVIATIONS

ASA	American Society of Anesthesiologists
CDPH	California Department of Public Health
CHRIs	Child Health Ratings Inventories
CI	Confidence Intervals
HRQOL	Health-Related Quality of Life
PCORI	Patient-Centered Outcomes Research Institute
PROs	Patient-Report Outcomes
Q	Quartile
QOL	Quality of Life
SES	Socioeconomic Status
STD	Standard Deviation
US (or USA)	United States (of America)

## LIST OF APPENDICES

## Page

Appendix A	Subset of Questions of the CHRIs Tool	54
Appendix B	CHRIs General Health Measures According to Reporter Perspective	57
Appendix C	Sample Survey Items for Each CHRIs General Health Subscale Measure	59

		Page
Figure 1	Static Illustration of Screen of Animated, Computer-Administered CHRIs Measure for Pediatric Patients.	8
Figure 2A	Quartile Distribution of Education and Income to Establish Socioeconomic Status Variable	13
Figure 2B	Quartile Distribution of Education and Income to Establish Socioeconomic Status Variable	14
Figure 3	Composite Variable of SES and Race/Ethnicity	15
Figure 4	CHRIs Project CONSORT Diagram	18
Figure 5	Distribution of Annual Income	23
Figure 5A	Distribution of Annual Income According Race/Ethnicity	27
Figure 5B	Distribution of Annual Income Amongst Hispanics	28
Figure 5C	Distribution of Annual Income Amongst Non-Hispanic Whites	28
Figure 5D	Distribution of Annual Income Amongst Others	29

## LIST OF FIGURES

		Page
Table 1	Descriptive Statistics of Study Cohort According to Race/Ethnicity	19
Table 2A	Descriptive Statistics of Hispanic and Non-Hispanic Racial/Ethnic Groups	22
Table 2B	Descriptive Statistics of Hispanic and Non-Hispanic White Racial/Ethnic Groups	23
Table 3	Descriptive Statistics of Low and High Socioeconomic Groups	24
Table 4A	Frequency Distribution of Annual Income According to Major Racial/Ethnic Groups	30
Table 4B	Frequency Distribution of Annual Income According to Hispanics and Non-Hispanics	30
Table 5A	Socioeconomic Status Distribution of Whole Analytic Group	31
Table 5B	Socioeconomic Status Distribution of Hispanics	31
Table 5C	Socioeconomic Status Distribution of Non-Hispanics	32
Table 6	Distribution of Race/Ethnicity and SES Composite Variable	32
Table 7	Mean Values of CHRIs Health Measures According to Race/Ethnicity	33
Table 8	Mean Values of CHRIs Health Measures According to Socioeconomic Status	34
Table 9	Comparison of Mean Values Between Low and High SES of CHRIs General Health Measures According to Race/Ethnicity	38
Table 10	Comparison of Mean Values Between Hispanics and Non-Hispanics of CHRIs General Health Measures According to Socioeconomic Status	39

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## **ABSTRACT OF THE THESIS**

## Evaluating Racial/Ethnic and Socioeconomic Differences from Child-Reporting of General Health Measures

By

Arlene Ngor

Master of Science in Biomedical and Translational Science University of California, Irvine, 2022 Professor Sherrie Kaplan, Chair

**Objective:** To study children's self-reporting health measures, as obtained from the Child Health Ratings Inventories (CHRIs) tool, according to race/ethnicity and/or socioeconomic status in order to understand and better improve the health quality of the pediatric patient population.

Patients and Methods: Longitudinal data was collected from a larger PCORI study developing and testing an animated computer survey, termed CHRIs, for the measurement of health amongst children. Pediatric surgical patients (4-12 years old) were surveyed with the CHRIs tool at three specific timepoints (pre-surgery, 2-days post, and 7-days post-surgery) to better understand their health status before and after their surgical procedure. The surveys inquired into the functional capacity or quality of life of the pediatric patients, who were read survey questions and then were able to select from survey responses represented as animations that illustrate the various possible health statuses. An aggregated dataset at the baseline timepoint, along with demographic information obtained from surveying of accompanying parents, were used for the analyses. The primary variables of education and annual income were used to create a composite variable that then was analyzed as a binary grouping variable called socioeconomic status (SES). The racial/ethnic profile of the pediatric population was examined in a binary manner as well -Hispanic or Non-Hispanic. From which, a composite variable examining both race/ethnicity and SES was developed and utilized in comprehending how children's self-reported health measures may vary based on such. **Results:** SES was distinguished as low or high depending on the respective education and income metrics reported from the pediatric patients' guardians. Race/ethnicity was differentiated as either Hispanic or Non-Hispanic, in which there were no identified confounding variables in choosing to group all racial/ethnic groups, excluding Hispanics, as a mixed categorical variable. In total, all racial/ethnic groups, other than Hispanics, represented a lower sample size as compared to the Hispanic only group, and no major differences were observed when comparing Non-Hispanic White only to the mixed grouping of Non-Hispanics, which was inclusive of Whites, Asians, and other minorities. To maintain the dataset with as much of the patient population captured, the holistic Non-Hispanic group was utilized for racial/ethnic comparisons against Hispanics. Overall, pediatric patients who identified as either Low SES or Hispanic were more likely to report lower CHRIs health measures scores, thus poorer health, than their High SES or Non-Hispanic counterparts. Further, pediatric patients, who were Low SES Non-Hispanic, tended to report the worst health as compared to those who were Low SES Non-Hispanic, High SES Hispanic, or High SES Non-Hispanic.

**Conclusions:** There is a demonstrated relationship between race/ethnicity and SES, in which the two variables intersect and impact one another. Trends suggest that being Low SES or Hispanic results in poorer health than the counterparts of being High SES or Non-Hispanic. When examining both SES and race/ethnicity together, being Hispanic and of Low SES suggests lower health reporting. The analyses of race/ethnicity and SES with regards to child's reporting of health demonstrates how considering the context and the demographic profile of patients through categorical variables, like race/ethnicity and SES, lend to better understanding of their health status. There is utility in self-reporting mechanisms, like the CHRIs tool, in which direct reporting from vulnerable populations, such as children, can allow for more targeted health diagnoses and better treatment plans.

## I. INTRODUCTION

## 1.1 Child Health in the United States

The study of health according to the child population is of particular interest, given that the children are a vulnerable population and represent a large portion of the United States' population. In 2019, the U.S. child population made up more than a quarter of the nation's population, with the majority being children of color [1]. Child health is best defined as "a state of physical, mental, intellectual, social and emotional well-being and not merely the absence of disease or infirmity. Healthy children live in families, environments, and communities that provide them with the opportunity to reach their fullest developmental potential" [2].

Further, the racial and ethnic disparities in healthcare have become more transparent within the field of child health. Poor childhood health can attribute to poorer health and socioeconomic outcomes as an adult [3, 4]. Working to ensure all children in the United States have access to physical and behavioral health is vital to our nation's future [1]. Thus, understanding disparities in child health is important to address health inequality and to predict potential disparities in adult health.

#### **1.2 Quality of Life Health Measures**

The study of health is often measured according to quality of life (QOL), which quantifies an overall satisfaction with life in terms of all aspects of well-being, including physical, social, economic, and psychological [5, 6]. This measure can be further examined according to an individual's satisfaction with health-related quality of life (HRQOL) that is a broad multi-dimensional concept that perceives physical, mental, and social functioning. On the

individual or group level, the evaluation of HRQOL can help determine life expectancy, burden of preventable chronic disease, and causes of death, while focusing on the impact of health status on quality of life [7].

When examining health, single and composite measures can be selected as the main focus areas of study. Further, these measures can be organized or grouped according to domains or categories for a greater understanding of similar individual measures. Examples of grouped measures include physical and mental health, versus standalone measures, such as pain and energy [8]. Further, these domains can be further characterized as clinical versus nonclinical. Because the concept of health is so multidimensional, the breakdown of health according to domains would allow for better identification and assessment of individual factors or variables that affect one's overall health and wellness [9]. Additionally, each of these domains of health can be considered from the perspective of the reporter, such as self or proxy.

#### **1.3 Proxy-Reporting**

Observer or proxy-reporting has been utilized to support the study of vulnerable populations, such as the elderly, children, and people with intellectual disabilities, given their limited ability to best represent themselves and their health conditions. This reporting mechanism involves a third-party member who recalls, scores, or answers in the best interest of a respondent. Proxy-reporting may be used in place or in companion of self-reporting. Previous studies have shown that self-respondents tend to report a greater number of health problems than proxies do [10]. Many of these studies compare self- and proxy-reporting in order to understand discrepancies between the two reporting sources as well as evaluate the validity and reliability of

the instrument to collect such responses. These reported outcomes have been applied to Medicare beneficiaries, COPD patients, and those cognitively impaired [11-13].

#### **1.4 Assessment of Child HRQOL**

Improvement in care for chronically ill children has led to better quality of life in pediatric populations. The measures of HRQOL and QOL can be evaluated from questionnaires and surveys completed by patients and/or affiliates. These patient-report outcomes (PROs) are vital information that can be used to evaluate the prolonged impact of chronic illness on daily life. The Patient-Centered Outcomes Research Institute (PCORI), a government sponsored organization, focuses on healthcare providers and patients making better informed healthcare choices [14]. Several PCORI research projects highlight PROs, especially in the case of young children's health statues reported by themselves and their parents [15, 16]. The study of parent-child reporting is a growing field of research intended to comprehend how reporting leads to better understood health measures, from which the impact of disease and the treatment of care can be tailored and personalized to the patient. Many of these studies examine levels of discrepancies and agreement amongst children with anxiety, depression, headaches, aggression, and epilepsy [22-25].

The study of parents as proxy reports on child HRQOL has been examined for many pediatric populations - healthy, following traumatic injury or harm, with mental disorders, and diagnosed with chronic illnesses, such as cancer, ADHD, and juvenile idiopathic arthritis [22-28]. The child HRQOL for these studies has been measured with various instruments. These include the Pediatric Quality of Life Inventory (PedsQL), Child Health Questionnaire (CHQ), and Child Health and Illness Profile (CHIP) [5, 26]. These tools are generic health status

instruments with both parent and child questionnaires that assess children's HRQOL. Additionally, some instruments are tailored to be disease-specific and/or age group-designated. For example, the Cerebral Palsy Quality of Life Questionnaire for Children (CP QOL-Child) and the Impact of Pediatric Epilepsy on the Family Scale (IPES) are QOL-specific instruments [29-30].

#### 1.5 Intersection of Race/Ethnicity and Socioeconomic Status on Health Disparities

Health measures, such as QOL and HRQOL, are often examined against primary characteristic variables, like race/ethnicity and socioeconomic status (SES). The intersection of SES and race/ethnicity has been extensively reviewed in the literature. In particular, both low socioeconomic status and minority race/ethnicity are associated with poor health and shorten survival as seen through poor housing and nutrition, low educational and economic opportunities, and greater environmental risks [31]. SES, as best measured by education or income, relates to various standard measures of healthcare status, such as mammograms and childhood and influenza immunizations [31].

Further, being a member of a minority racial/ethnic group relates to less intensive and often lower quality of care. In particular, as compared to Whites, those of African American descendent are seen less often by specialists, receive less appropriate preventive care including mammography and influenza vaccinations, lower-quality hospital care, and fewer expensive, technological procedures. This follows with African Americans receiving less intensive healthcare services and treatments, including fewer kidney and bone marrow transplants, cesarean sections, and orthopedic procedures [31].

The study of race/ethnicity and SES closely intersects with health disparities. Thus, the collection of relevant and reliable data in this area would allow for future studies of health outcomes according to these agents. In 1997, the United States Department of Health and Human Services (DHHS) made strides in identifying racial and ethnic health disparities with the introduction of the Inclusion Policy that requires the collection of race and ethnicity in DHHS-funded and -sponsored projects [32].

There are various case studies that demonstrate targeted healthcare, according to race/ethnicity and SES, can lead to improve health quality. For example, older Black males are 8 times more at risk for hepatitis B than their White counterparts, from which an intervention amongst this at-risk group, via voucher incentives, case management, and at home calls and mail reminders, boosted hepatitis B vaccination [33-36]. As low-income women were better supported, rates of mammogram examination improved [37, 38]. The study of treatments and interventions according to race/ethnicity and SES allows for more targeted and thus personalized medicine in which specificity for the few can be focused versus generalizability for many.

## 1.6 Child Health Ratings Inventories (CHRIs) Implementation

Despite the growing number of studies that examine child HRQOL, there are limitations in understanding parent-child agreement levels. Some existing studies lack reliability reporting from either the parent or child, while others have reliability cut-offs that are too low [5,26]. The Child Health Ratings Inventories (CHRIs) instrument was developed using computer animation and specifically designed to reach the pediatric population that could not read or complete a health survey independently. The implementation of CHRIs allows for the removal of a facilitator, who administers the survey and records responses, and thus enables children to reliably self-report their own health measures [8, 15, 39].

In 1995, the CHRIs instrument was first conceived, validated, and tested for reliability by Dr. Sherrie H. Kaplan and colleagues at New England Medical Center. The instrument was designed using computer animation for self-reporting of health data amongst 5-12 year old children with chronic diseases [40]. The application of the CHRIs instrument has since extended to children with medical other conditions, such hematopoietic stem cell transplantation [39, 41].

CHRIs has been most recently utilized in a PCORI funded project (ME-1306-01715) for patient-centered outcomes research. In this study, CHRIS2.0 with added audible instructions and the reading of selection options was specifically developed for younger (4-12 year old) patients undergoing surgery [14, 15]. Using a subset of the PCORI study's data, this thesis examines how the self-reported health measures collected via CHRIS2.0 can be used to evaluate differences in general health measures according to race/ethnicity and to socioeconomic status. These variables may affect general health measures, like quality of life, and thus children's overall health quality.

## 1.7 Study Objectives

This thesis aims (1) to develop a composite variable examining the effects of both race/ethnicity and SES on general health measures, (2) to assess whether there were health measure differences amongst the proportions of the studied racial/ethnic (Hispanics versus non-Hispanics) and socioeconomic groups (Low versus High), and if so, to what extent, and lastly (3) to understand the magnitude of these differences according to the studied composite variable. By examining these objectives, additional insight would be provided regarding how race/ethnicity and/or socioeconomic status affects reported health measures amongst children.

#### **II. METHODS**

#### 2.1 Study Source & Data Collection

This thesis analyzes a specific subset of data originating from that collected and utilized for the PCORI project (ME-1306-01715) and its final report, entitled "Developing and Testing Animated Computer Surveys for Measuring Young Children's Health" [16]. This original PCORI study featured 725 families with children aged 4-12 years undergoing surgery at Children's Hospital of Orange County in California. The study cohort included surgical pediatric patients with American Society of Anesthesiologist (ASA) physical status scores from I to III. ASA I is considered "a normal healthy patient", ASA II "a patient with mild systemic disease", and ASA III "a patient with severe systemic disease that is not incapacitating" [42]. Participants had responses recorded according to three time points: pre-surgery, 2-days post-surgery, and 7days post-surgery.

For the analyses examined within this thesis, only pre-surgery responses completed by pediatric patients and their parents were evaluated. An aggregation of the data allowed for a focus of a subset of data according to the single time point of pre-surgery and highlighted the perspective of pediatric patients.

Participation in the study involved the guardians of pediatric patients self-reporting their own health and proxy-reporting their child's health either via the conventional method of paper copies of the survey or an online survey platform, Qualtrics. Questions from the survey were verbally read to pediatric patients for their own selection of choices/responses that were visually represented with a picture representing their functional capacity or quality of life on a computer or tablet (Figure 1). The CHRIs tool was designed to be user-friendly in which the reading level,

type size, and format of the questions were school-aged children appropriate, which allowed for the recruitment of younger surgical patients for the study [40]. This method of administration of the CHRIs tool allowed for children to participate directly and individually, without parent or proxy intervention. This survey was tested and validated against other measures, including the Pediatric Quality of Life Inventory (PedsQL), and found to produce reliable data. The content of the computer-animation for pediatric patients paralleled that of the traditional questionnaire completed by parents [8,15, 39].

Figure 1: Static Illustration of Screen of Animated, Computer-Administered CHRIs Measure for Pediatric Patients.



## 2.2 Study Instrument

The CHRIs tool was utilized similarly to previous reports, in which questions from the survey were animated and computer administered to gather direct pediatric patient-reported

outcomes regarding the various dimensions or subscales of health and well-being [8, 39]. For this particular study, the animated CHRIs tool administered to children consisted of 21 items (see Appendix A for a sample of questions used) over 8 constructs or dimensions of health, often referred to as health measures throughout this thesis: Physical Function, Role Function, Social Function, Cognitive Function, Energy, Pain, Mental Health, and Overall Quality of Life.

Appendix B indicates the number of questions designed for each health measure and composite subscale and which health measure was recorded per respondent. The number of survey items making up each general health measure varied from as few as 1 to as many as 4 questions. Specific word choices, such as "Not at all", "A little", "Some", "A lot", and "A whole lot", that the pediatric patients selected from were quantified on a Likert scale from 1 to 5. The Likert scale is a self-reporting mechanism used for qualitative analysis of health and well-being of the respondent [43, 44]. In this study, the Likert scale was used to correspond selected word choices to a certain level of agreement or frequency according to the patient's health, which can then be quantitatively converted to a numerical value for statistical analyses. The text-based responses were recoded and converted to a scale of 0 to 100 in the final analyses. A higher score indicated "better" health, and a lower score illustrated "worse" health. Specifically, the Likert score of 1 corresponded to a score of 0 in the final analysis, 2 corresponded to 25, 3 corresponded to 50, 4 corresponded to 75, and 5 corresponded to 100. Appendix C illustrates sample survey questions for each of the general health measures as well as how visual and read responses were provided via the CHRIs tool.

The total score for each of the individual health measures were the average of the number of questions prepared. For example, the Physical Function health measure constituted four questions and thus was the average of the score of these questions. Pain was the only measure

reliant on a single question and reversed coded for better health, or less pain, with a lower score. Three composite summary scores were derived from the grouping of the eight subscales: General Physical, General Mental, and Composite. The General Physical composite measure aggregated items from Physical, Role, Social, and Cognitive Functions and was calculated as the average of a simple algebraic sum of the scores of these 4 subscales.

$$\frac{Physical + Role + Social + Cognitive Functions}{4} = General Physical Health Composite$$

The General Mental composite measure aggregated items from Energy, Pain, Mental Health, and Overall Quality of Life and was also calculated as the average of the sums of the scores of 4 subscales.

$$\frac{Energy + Pain + Mental Health + Overall QOL}{4} = General Mental Health Composite$$

The overall composite score was calculated as the average of the General Physical and General Mental Health composite scores.

$$\frac{General Physical Health Composite + General Mental Health Composite}{2} = Composite$$

The CHRIs measures were reported according to three different unique perspectives: child's self-reporting, parent's proxy-reporting of child, and parent's self-reporting. For the purpose of this thesis, only the child's self-reported measures were examined. Additional filtering of data was conducted according to the grouping variable of either race/ethnicity or socioeconomic status (SES) or to a designed composite variable examining both race/ethnicity and SES, as to determine the relationship of these independent variables with respect to pediatric patient reported general health measures.

## 2.3 Key Study Variables

Mean values were assessed for each CHRIs general health at the baseline assessment, or initial visit at the hospital pre-surgery. CHRIs general health status measures include: Physical Function, Role Function, Social Function, Cognitive Function, Energy, Pain, Mental Health, Overall Quality of Life, General Physical, General Mental, and Composite. Each of these health measures represents a health-related functional status or a QOL state of being in day to day performance:

- Physical function ability to physically perform
- Role function ability to manage expected duties and expectations
- Social function ability to socialize and maintain interactions with friends and family
- Cognitive function ability to comprehend and critically think
- Energy capacity to perform
- Pain sensation of feeling unwell or uncomfortable
- Mental health management of emotional and psychological wellness
- Quality of life perceived satisfaction regarding position in life

The mean values of each of these health measures were then compared with the two grouping variables of race/ethnicity and of SES and then against the composite variable examining both race/ethnicity and SES in the form of mean differences.

The grouping variables were used for analyses of the mean values and mean differences according to race/ethnicity and to SES. First, SES was generated based on the quartiles (Q) of annual income and of education of the guardian; the multiplication of these quartiles (income\*education) resulted in a 4 x 4 distribution of the product, in which those valued within the top 37.5% of the calculated income education product were considered of High SES versus the remaining 62.5% representing Low SES.

The cutoffs used for each quartile design for income and education were thoughtfully considered relative to the specific variable itself. The designed quartile ranges for income relied upon values established by the state and federal governments concerning the federal poverty limit and reported annual income of state residents. Further, given the limited number of participants that shared their income in the CHRIs survey, a fair distribution of about a quarter of responses was aimed per quartile designation for a more even distribution for analysis. For annual income, quartiles ranges followed that of:

- Quartile 1 Less than \$20,000
- Quartile 2 Between \$20,000 and less than \$35,000
- Quartile 3 Between \$35,000 and less than \$80,000
- Quartile 4 Greater than \$80,000

First, quartile 1 reflected a cutoff that captured the federal poverty guideline of \$18,310 for a family of 2, according to the California Department of Public Health [45]. It was assumed that for a participant of this study, the smallest family size would be 2, reflective of the pediatric patient and their accompanying parent. Second, the range used for quartile 2 covered California's estimated per capita income of \$38,576 per year, as reported by the United States Census Bureau [46]. For quartile 3, an annual earning range that best resembled that for those of middle class

was designed. In particular, the minimum income indicated by the federal poverty guidelines was doubled to represent the necessary income means to live comfortably above the poverty line, which was a minimum of \$36,620 for a 2 person household [45]. The upper end of this quartile was determined according to the reported California median household income of \$78,672 [46]. Quartile 4 represented four times the upper limit of quartile 1. National values form the US Census Bureau were referenced if the California equivalence was not reported in the CDPH.

For education, the quartiles were established according to defined milestones for most educational journeys – receiving a high school diploma or college degree, and/or participating in secondary training in graduate or professional school. These achievements are usually captured at the following years of education that were then used for quartile design:

- Quartile 1 Some high school education with less than 12 years in total
- Quartile 2 Obtained a high school diploma, having completed 12 years in total
- Quartile 3 Some college education, having completed between 13 to 15 years in total
- Quartile 4 Obtained a college degree with a minimum of 16 years, or more if pursued additional secondary training in graduate or professional school

Further, it should be noted pre-kindergarten and kindergarten were not regarded as official years of education for these analyses.

# Figure 2A: Quartile Distribution of Education and Income to Establish Socioeconomic Status Variable

		Education (Years)			
		Q1	Q2	Q3	Q4
	Q1	1	2	3	4
Annual	Q2	2	4	6	8
Income	Q3	3	6	9	12
	Q4	4	8	12	16

Figure 2B: Quartile Distribution of Education and Income to Establish Socioeconomic Status Variable

		<b>Education (Years)</b>			
		<12	12	13-15	>16
Annual	<\$20K	Low	Low	Low	Low
Income	\$20K - \$34K	Low	Low	Low	High
(Dollars, in	\$35K - \$79K	Low	Low	High	High
thousands)	>\$80K	Low	High	High	High

According to Figures 2A and 2B, those of the numbered 8, 9, 12, and 16 positions (representative of 37.5% of all possibilities) were correspondingly deemed High SES, versus the numbered 1, 2, 3, 4, and 6 positions representing Low SES (the remaining 63.5% of all possibilities). Those of the red position were of higher SES standing as compared to those colored in blue, which represented individuals with fewer years of education and lower annual earnings. Overall, the SES variable was evaluated in a binary manner as either low or high, as driven by both annual income and education level.

Second, race/ethnicity was best distinguished relative to Hispanic origin. Those of Hispanic, Latino/a Spanish, Cuban, Puerto Rican, Mexican, Mexican American, and Chicano/a origins were recognized as a catch-all group termed Hispanic. Despite these ethnic differences, the group was still considered holistic given the Spanish background. Other racial/ethnic groups existed individually, but the total number of these participants was minimal and could not be best represented as a categorical variable on its own; thus, all other participating races were recategorized as Non-Hispanic, which came to represent Whites, Asian, African American/Black, Native American, and Other. It should be noted that Non-Hispanic included minority and nonminority groups. Minority groups include African American and Pacific Islander. Majority groups include Non-Hispanic Whites and Asian. The non-Hispanic grouping was not as

reflective of a uniform background as compared to the Hispanic group. However, this grouping as either Hispanics or Non-Hispanics was performed, given nearly 2/3 of the studied patient population who reported outcomes were Hispanic. Race/ethnicity was distinguished as a binary variable as either Hispanic or Non-Hispanic in order to understand how the Hispanic population reported health outcomes as compared to their Non-Hispanic counterpart.

Lastly, a composite variable examining the two binary variables of SES and race/ethnicity, discussed above, was designed. This composite variable allowed for the evaluation of differences between CHRIs general health measures according to the two different categorical variables of race/ethnicity and SES. This entailed a cross-analysis between each of the binary variables to examine four specific patient populations of the studied dataset: Low SES Hispanics, High SES Hispanics, Low SES Non-Hispanics, and High SES Non-Hispanics (Figure 5).

		Socioeconomic Status		
		Low	High	
	Uispanias	Low SES	High SES	
	nispanies	Hispanics	Hispanics	
Race/Ethnicity	Non- Hispanics	Low SES	High SES	
		Non-	nigli SES	
		Hispanics	non-mispanics	

#### Figure 3. Composite Variable of SES and Race/Ethnicity

## 2.4 Statistical Analysis

Data analysis occurred using the SPSS software [47]. All variables were normally distributed via visual assessment of histograms, and thus were summarized with frequencies and proportions using Fisher's Exact Test and means and standard deviations using the independent samples t-test. Descriptive statistics (mean, standard deviation, and mean difference with 95%

confidence intervals) were calculated for child-reported measures. Comparisons of mean differences were made according to the grouping variable of either race/ethnicity or SES. For analysis of means within each studied patient population, independent samples t-tests were performed in the comparison of Hispanics versus Non-Hispanics, low versus High SES, and Hispanic/Non-Hispanics versus low/High SES. These group analyses can best be summarized by the following:

- Hispanics versus Non-Hispanics (Table 7)
- Low SES versus High SES (Table 8)
- Low SES Hispanics versus High SES Hispanics (Table 9)
- Low SES Non-Hispanics versus High SES Non-Hispanics (Table 9)
- Low SES Hispanics versus Low SES Non-Hispanics (Table 10)
- High SES Hispanics versus High SES Non-Hispanics (Table 10)

### **III. RESULTS**

## 3.1 Study Cohort

Of the original PCORI project, a total number of 2,254 patients were originally screened, from which 1,517 were eligible. This was reduced to 902, due to many cancellations of hospital appointments and no opportunity to approach families to obtain consent for study participation before surgery. Of the families approached, only 725 were initially recruited, with only a fraction participating at each of the three observed time points. Figure 2 depicts a CONSORT diagram of the participating patients and their families. The original patient recruitment, as discussed in the final PCORI report, is highlighted in blue. For this thesis, the orange and green highlights indicate the subset of data used for all results discussed further.

Of those who completed the initial baseline CHRIs survey at the pre-surgery time point, illustrated in orange in Figure 2, only the pediatric patient respondents were analyzed for subsequent sub-studies and according to the grouping variables of either race/ethnicity or SES. These two categorical variables of race/ethnicity and SES were then recapitulated as a composite variable evaluating the effects of both race/ethnicity and SES. Specifically, the composite variable compared between low and high socioeconomic statuses and between Hispanics and Non-Hispanics. These grouping and composite variables, highlighted in green in Figure 2, were the analytic groups studied for this thesis.

Specifically, 273 pediatric self-reported responses that included race/ethnicity and 550 pediatric self-reported survey responses that included socioeconomic status (Figure 4) were studied for SES. There were specific cases in which respondent data was not used for the thesis analysis: (1) if more than 5% of the questionnaire was missing data, (2) if either income or

education level of the parent was not indicated, and (3) if race or ethnicity of the parent or child was not indicated.



## Figure 4: CHRIs Project CONSORT Diagram

## **3.2 Baseline Characteristics**

The pediatric patients were majority (59.8%) male, with an average age of 7.4 years. Parents were predominantly (84.4%) female, with an average age of 36.6 years.. Children averaged 2.2 years of education, while parents completed a mean of 12.8 years. The racial/ethnic profile of the participating children was 67.3% Hispanic, 24.0% Non-Hispanic White, and 7.5% identifying as Asian, African-American, or other. This mirrored that of the accompanying parents, who were 67.2% Hispanic, 24.4% Non-Hispanic White, and about 8.5% constituting Asian, African-American, or other races/ethnicities. Table 1 captures the descriptive statistics of the study population.

Characteristics	Children (n=657)	Parents (n=644)		
Age (years)	7.4	36.6		
Female (%)	40.2	84.4		
Education (years)	2.2	12.8		
Race/ethnicity (%)				
Hispanic	67.3	67.2		
Non-Hispanic White	24.0	24.4		
Asian <sup>b</sup>	5.7	6.4		
Other <sup>c</sup>	1.8	2.1		

Table 1. Descriptive Statistics of Study Cohort<sup>a</sup>

<sup>a</sup>Table entries are means.

<sup>b</sup>Inclusive of Chinese, Filipino, Japanese, Korean, Vietnamese, and Indian <sup>c</sup>Inclusive of African-American, American Indian/Alaskan Native, Native American, Guamanian, Chamorro, Samoan, and other Pacific Islander

## 3.3 Analytic Group According to Race/Ethnicity

The racial/ethnic profile of the participating children observed at the baseline pre-surgery

time point is shown in Table 2. Tables 2A and 2B show group comparisons of Hispanic versus

Non-Hispanic (Table 2A) and Hispanic versus Non-Hispanic White (Table 2B).

For Table 2A, no significant differences were noted for age or education between

Hispanic and Non-Hispanic children. On average, the two groups were majority male, 7.5 years

of age, and had completed 2.2 years of education. There was a significantly higher percentage of males in the Non-Hispanic group than in the Hispanic group.

In comparing between these two tables (2A and 2B), here we see no major differences in characteristic statistics if we chose to encompass non-Hispanic inclusive of all racial/ethnic groups, other than Hispanic, versus just that of non-Hispanic Whites by itself. No clear confounding variable was exhibited in the descriptive statistics between these two groups – Non-Hispanics versus Non-Hispanic Whites. This suggested that the Non-Hispanic group, for the analyses here, were reflective or pretty similar to the Non-Hispanic White group on its own.

Further, there were notable differences in education and annual income between Hispanic and Non-Hispanic parents. Non-Hispanic parents had an average of ~3 more years of education than Hispanic parents, who on average had a high school education level (~12 years in total). Non-Hispanics had significantly higher income (~2.5 times that of Hispanics). For these studied racial/ethnic groups, the accompanying parent was often a female and married. It was statistically observed that there were more married Hispanic than married Non-Hispanic parents present with the pediatric patient. The Non-Hispanic parent group was about 4 years older than the Hispanic group, averaging about 35 years of age.

## 3.4 Analytic Group According to Socioeconomic Status

Table 3 shows the demographic characteristics of the participating children in the Low SES and High SES groups. On average, both SES groups were majority male, a little over 7 years of age, and had completed about 2 years of education. The Low SES group had a significantly higher percentage of males than the High SES group.

Investigation of differences between Low SES and High SES parents exhibited significant differences across all studied characteristics– gender, age, marriage status, education, and annual income. On average, Low SES parents were female and married, younger by 5 years, had 5 fewer years of education, and made nearly a third of the income of their High SES counterparts, who were estimated to also be female and married, nearly 40 years of age, obtained a college degree (16 years of education), and earned nearly \$130,000 annually.

		Hispanic (n=442)	Non-Hispanic (n=219)			
		Mean [SD]	Mean [SD]	N	Aean Difference <sup>b</sup> (± 95% CI)	p-value
	Age (years)	7.4 [2.5]	7.2 [2.5]	0.2		0.297
Child	Female (%)	44.1	35.5	-	-	
	<b>Education (years)</b>	2.2 [2.6]	2.1 [2.6]	0.1		0.542
	Age (years)	35.1 [6.9]	40.2 [6.3]	-5.1***		< 0.001
	Female (%)	87.9	77.7	-	-	
Parent	Married (%)	59.6	52.2	-	-	
	<b>Education (years)</b>	11.8 [3.1]	15.2 [3.4]	-3.4***		< 0.001
	Annual Income (\$)	61,409.18 [52,314.44]	117,366.13 [139,767.62]	-55,956.95		0.058

Table 2A: Descriptive Statistics of Hispanic and Non-Hispanic Racial/Ethnic Groups<sup>a</sup> (n=646)

<sup>a</sup>Table entries are means with standard deviations in brackets. <sup>b</sup>Mean differences are reported as Hispanic minus Non-Hispanic, with 95% confidence intervals.

		Hispanic (n=442)	Non-Hispanic White (n=158)			
		Mean [SD]	Mean [SD]	Ν	/lean Difference <sup>b</sup> (± 95% CI)	p- value
	Age (years)	7.4 [2.5]	7.2 [2.5]	0.2		0.392
Child	Female (%)	44.1	35.5	-	-	
	Education (years)	2.2 [2.6]	2.1 [2.6]	0.1		0.473
	Age (years)	35.1 [6.9]	40.1 [6.5]	-5.0***		< 0.001
	Female (%)	87.9	77.7	-	-	
Parent	Married (%)	59.6	52.2	-	-	
	Education (years)	11.8 [3.1]	15.2 [3.2]	-3.4***		< 0.001
	Annual Income (\$)	61,409.18 [52,314.44]	123,225.95 [134,723.10]	-61,816.77		0.067

*Table 2B: Descriptive Statistics of Hispanic and Non-Hispanic White Racial/Ethnic Groups<sup>a</sup> (n=600)* 

<sup>a</sup>Table entries are means with standard deviations in brackets.

<sup>b</sup>Mean differences are reported as Hispanic minus Non-Hispanic White, with 95% confidence intervals.

	•	Low SES (n=341)	High SES (n=209)			
		Mean [SD]	Mean [SD]	Mean Difference <sup>b</sup> (± 95% CI) v		p- value
	Age (years)	7.4 [2.5]	7.3 [2.6]	0.1	(-0.4, 0.5)	0.812
Child	Female (%)	35.5	44.1	-	-	0.014
	<b>Education (years)</b>	2.2 [2.5]	2.0 [2.6]	0.1	(-0.3, 0.6)	0.136
	Age (years)	34.6 [6.8]	39.6 [6.4]	-5.0***	(-6.1,-3.9)	< 0.001
	Female (%)	88.3	78.4	-	-	0.002
Parent	Married (%)	53.8	85.5	-	-	< 0.001
	Education (years)	11.0 [2.7]	16.0 [2.2]	-5.0***	(-5.5, -4.65)	< 0.001
	Annual Income (\$)	45,566.53 [387,536.19]	129,239.75 [12,329.68]	-83.673.22***	(-127,328.46, -40,017.97)	< 0.001

Table 3: Descriptive Statistics of Low and High Socioeconomic Groups<sup>a</sup> (n=550)

<sup>a</sup>Table entries are means with standard deviations in brackets. <sup>b</sup>Mean differences are reported as Low SES minus High SES, with 95% confidence intervals.

#### **3.5 Analytics According to Annual Income Earnings**

Descriptive statistics demonstrated that annual income of Hispanics versus Non-Hispanics and Low SES versus High SES displayed statistical significance, with the Non-Hispanic and High SES groups scoring on the higher end. Thus, a deeper evaluation of income was examined across multiple fronts, including according to quartile ranges and race/ethnicity.

Figure 5 depicts the frequency distribution of annual income from parents of participating patients. Reported salaries ranged from as low as a few thousand dollars to those in the hundred-thousand-dollar range. The bar graph is color coded according to income quartile range to illustrate the density per quartile.





Figure 5A examines the various income groupings to see the spread amongst racial/ethnic groups. In particular, it examines of the number of individuals identified per income bracket, what percent of them are Hispanic, Non-Hispanic White, and Other. Overwhelmingly, Hispanics make up a majority of the percentage of those of the lower income spectrum, as compared to non-Hispanic Whites representing nearly all of the percentages for income on the higher end. The distribution of annual income earnings are further displayed in Figures 5B-5D, in which each figure displays the frequency of individuals according to income bracket and race/ethnicity.

Figure 5B shows that a large number of individuals sampled for analyses are Hispanic, whom are spreading amongst the lower income spectrum. According to the distribution spread, a majority of Hispanics are earning below \$40,000 per year. The distribution tail shows very few Hispanics earning in the fourth quartile range.

Figure 5C shows a wide distribution of Non-Hispanic Whites that have annual earnings across nearly all income brackets. There is no clear majority of which income bracket Non-Hispanic Whites occupy, but it is evident that the average annual income of this group is much higher than that of Hispanics.

Figure 5D notes the annual income of individuals who identify as Other. While a much lower number of folks were identified in this racial/ethnic group, the overall spread is much more wide with a majority of Other individuals producing annual incomes that are between \$60,000-\$139,000.



Figure 5A: Distribution of Annual Income According Race/Ethnicity (n=559)

Figure 5B: Distribution of Annual Income Amongst Hispanics (n=395)



Figure 5C: Distribution of Annual Income Amongst Non-Hispanic Whites (n=125)



Figure 5D: Distribution of Annual Income Amongst Others (n=41)



Furthermore, Tables 4A and 4B are heat maps illustrating the distribution of income according to the observed quartile ranges that also highlight income distribution within each observed racial/ethnic group. Specifically, the red color indicates a larger number of individuals within that defined income range, as compared to the blue color, which represents fewer individuals. The Non-Hispanic White, Asian, and Other groups in Table 4A were later collapsed into a single category, Non-Hispanic, given their low numbers. This binary representation of race/ethnicity, seen in Table 4B, illustrates that Hispanics represent nearly 67% of respondent data used for this analysis.

Table 4A: Frequency Distribution of Annual Income According to Major Racial/Ethnic Groups<sup>a</sup> (n=572)

	Q1	Q2	Q3	Q4
	<\$20K	\$20K - \$34K	\$35K - \$79K	> \$80K
Hispanics	119 (20.8)	125 (21.9)	93 (16.3)	50 (8.7)
Non-Hispanic Whites	16 (2.8)	14 (2.5)	36 (6.3)	76 (13.3)
Asians	5 (0.9)	3 (0.5)	9 (1.6)	15 (2.6)
Other	2 (0.4)	2 (0.4)	4 (0.7)	3 (0.5)

<sup>a</sup>Entries are frequency counts with percent relative to total in bracket.

Table 4B: Frequency Distribution of Annual Income According to Hispanics and Non-Hispanics<sup>a</sup> (n=572)

	Q1 <\$20K	Q2 \$20K - \$34K	Q3 \$35K - \$79K	Q4 > \$80K
Hispanics	119 (20.8)	125 (21.9)	93 (16.3)	50 (8.7)
Non-Hispanics	23 (4.0)	19 (3.3)	49 (8.6)	94 (16.4)

<sup>a</sup>Entries are frequency counts with percent relative to total in bracket.

Close examination of annual income according to Hispanics and Non-Hispanics, in Table 4B, further validates the statistical differences originally noted in the descriptive statistics of Table 2. Both Tables 4A and 4B show a reverse trend in earnings between Hispanics and other racial/ethnic groups. Specifically, Hispanics tend to be the majority and earn less income than their Non-Hispanic counterparts, which include Whites, Asians, African-Americans, and other racial/ethnic groups.

## **3.6 Analytics According to Socioeconomic Status**

Initial analyses surrounding annual income, seen with Tables 4A and 4B, demonstrate perceivable income differences between the Hispanic and Non-Hispanic study groups. Thus,

further evaluation examining socioeconomic status, a composite variable driven by both income and education, was conducted.

Tables 5A, 5B, and 5C are heat maps that display the spread of annual income versus the level of education according to the SES composite variable. The first heat map, Table 5A, captures the whole analytic group of both Hispanics and Non-Hispanics in which the observed trend suggests that with fewer years of education, lower annual earnings are expected.

When the analytic group is parsed according to the grouping variable of either Hispanics or Non-Hispanics, there is a more striking difference in SES distribution. In particular, Table 5B shows that a majority of Hispanics are less educated and are earning less annually. This contrasts to Table 5C, in which a majority of Non-Hispanics tend to perform better in annual earnings and longer in terms of education.

Table 5A: Socioeconomic Status Distribution of Whole Analytic Group (n=472)

		Education (Years)							
		<12	<12 12 13-15 >16						
Annual	<\$20K	64	49	20	9				
Income	\$20K <b>-</b> \$34K	45	56	33	10				
(Dollars, in	\$35K - \$79K	23	50	34	36				
thousands)	> \$80K	3	10	37	93				

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Table 5B: Socioeconomic Status Distribution of Hispanics (n=384)

		Education (Years)						
		<12	<12 12 13-15 >16					
Annual	<\$20K	60	42	13	4			
Income	\$20K - \$34K	42	50	29	4			
(Dollars, in	\$35K - \$79K	21	36	20	14			
thousands)	> \$80K	2	5	17	25			

## Table 5C: Socioeconomic Status Distribution of Non-Hispanics (n=188)

		<b>Education (Years)</b>						
		<12 12 13-15 >16						
Annual	<\$20K	4	7	7	5			
Income	\$20K - \$34K	3	6	4	6			
(Dollars, in	\$35K - \$79K	2	14	14	22			
thousands)	> \$80K	1	5	20	68			

This cross-analysis between Hispanics and Non-Hispanics examining income and education shows a major divide in the SES of these groups. Table 6 highlights the SES spread between Hispanics and Non-Hispanics. Over 50% of all participants in the analytic group are Low SES and Hispanic, as compared to nearly a quarter being High SES and Non-Hispanic.

## Table 6. Distribution of Race/Ethnicity and SES Composite Variable<sup>a</sup> (n=573)

		Socioeconomic Status			
		Low	High		
Race/Ethnicity	Hispanics	300 (52.4)	85 (14.8)		
	Non-Hispanics	53 (9.3)	135 (23.6)		

<sup>a</sup>Entries are frequency counts with percent relative to total in bracket.

## 3.7 CHRIs Health Measures According to Grouping and Composite Variables

Independent analyses of the independent variables of race/ethnicity, annual income, education, and SES with regards to each other were followed by evaluation of these variables relative to the dependent variable of CHRIs health measures. Tables 7 and 8 present the mean, standard deviation, and mean differences, with the 95% confidence intervals of CHRIs health measures according to either the grouping variable of race/ethnicity or SES or the composite variable of race/ethnicity and SES. Tables 9 and 10 further evaluate the mean values of CHRIs health measures with consideration of race/ethnicity amongst low and High SES and of SES amongst Hispanics and Non-Hispanics.

## 3.7A Mean Differences Analysis According to Race/Ethnicity

The ten individual CHRIs health measures were first evaluated according to the grouping variable of Hispanic and Non-Hispanic, based on children's self-reported scores (Table 7). Hispanic patients generally self-reported being less healthy than Non-Hispanic counterparts across all CHRIs health measures. Of the 10, six of them demonstrated significant differences in how Hispanics and Non-Hispanic children reported their own health. The General Physical Health composite construct (composed of the Physical, Role, Social, and Social Functions measures) was significantly different amongst the reporting from Hispanic and Non-Hispanic children, as observed for the Energy health measure. Overall, Hispanic children tended to report their health status about five points significantly lower than Non-Hispanic counterparts.

CHRIs Health Measures	Hispanic	Non-Hispanic	Mea	an Difference <sup>b</sup> (± 95% CI)
Physical Function	60.8 [24.6]	66.5 [24.7]	-5.8	(-10.6, -0.9)*
Role Function	65.1 [25.0]	72.0 [22.9]	-6.9	(-11.7, -2.2)*
Social Function	72.0 [20.8]	78.4 [19.0]	-6.5	(-10.4, -2.5)***
Cognitive Function	66.0 [26.7]	71.8 [26.1]	-5.8	(-11.1, -0.6)*
Energy	69.4 [23.2]	76.4 [22.0]	-7.0	(-11.5, -2.5)*
Pain	73.9 [28.5]	75.3 [28.3]	-1.4	(-7.0, 4.2)
Mental Health	73.2 [26.4]	76.3 [23.4]	-3.1	(-8.0, 1.9)
Overall Quality of Life	82.4 [20.1]	83.3 [20.6]	-0.9	(-5.0, 3.1)
General Physical Health	65.9 [18.9]	72.2 [18.4]	-6.3	(-10, -2.6)***
General Mental Health	74.7 [17.7]	77.8 [18.9]	-3.1	(-6.7, 0.5)
Composite	70.3 [16.1]	75.0 [16.9]	-4.7	$(-7.9, -1.4)^*$

Table 7. Mean Values of CHRIs Health Measures According to Race/Ethnicity<sup>a</sup> (n=400)

\*denotes p<0.05

\*\*\*\*denotes p<0.001

<sup>a</sup>Table entries are means with standard deviations in brackets.

<sup>b</sup>Mean differences are reported as Hispanic minus Non-Hispanic, with 95% confidence intervals.

## 3.7B Mean Differences Analysis According to Socioeconomic Status

Following such an analysis according to race/ethnicity, the ten individual CHRIs health measures were then evaluated according to the grouping variable of low and High SES based on children's self-reported scores (Table 8). Children of Low SES tended to self-report health measures that were lower than their High SES counterparts, across all of the general health measures assessed. The mean differences between low and High SES groups were significant for Role Function, overall QOL, General Physical Health composite, General Mental Health composite, and Composite, but exceptionally noted for Social Function with 7 points greater for those of High SES. Overall, children of Low SES reported poorer health than those of High SES.

CHRIs Health Measures	Low SES	High SES	Mea (	an Difference <sup>b</sup> (± 95% CI)
Physical Function	61.3 [23.5]	64.2 [26.8]	-2.9	(-8.5, 2.8)
Role Function	64.7 [24.8]	71.2 [24.7]	-6.5	(-12.1, -0.9)*
Social Function	71.1 [21.5]	78.3 [16.8]	-7.2	(-11.7, -2.8)***
Cognitive Function	67.2 [27.2]	68.3 [27.0]	-1.1	(-7.2, 5.0)
Energy	69.5 [23.6]	74.4 [22.5]	-4.8	(-10.1, 0.4)
Pain	72.4 [28.5]	77.5 [27.9]	-5.1	(-11.5, 1.3)
Mental Health	73.7 [26.3]	75.7 [23.6]	-2.0	(-7.7, 3.7)
Overall Quality of Life	80.1 [21.3]	86.4 [17.3]	-6.3	(-10.6, -2.0)*
General Physical Health	66.1 [18.5]	70.5 [19.0]	-4.4	(-8.7, -0.2)*
General Mental Health	73.9 [18.3]	78.5 [17.4]	-4.6	(-8.6, -0.5)*
Composite	70.0 [16.5]	74.5 [15.9]	-4.5	(-8.2, -0.8)*

Table 8: Mean Values of CHRIs Health Measures According to Socioeconomic Status<sup>a</sup> (n=311)

\*denotes p<0.05

\*\*\*\*denotes p<0.001

<sup>a</sup>Table entries are means with standard deviations in brackets.

<sup>b</sup>Mean differences are reported as Low SES minus High SES, with 95% confidence intervals.

## **3.8 Mean Value Differences Analyses**

Examination of the variables of race/ethnicity and SES, seen in Tables 7 and 8, showed

poorer health reporting if Hispanic or of Low SES. This led to the investigation of CHRIs health

measure reporting according to the cross of race/ethnicity and SES patient populations,

specifically those that identified as Low SES Hispanic, High SES Hispanic, Low SES Non-

Hispanic, and High SES Non-Hispanic. These additional analyses were conducted to determine how:

- SES differs amongst Hispanics (Table 9 left panel)
- SES differs amongst Non-Hispanics (Table 9 right panel)
- Race/ethnicity differs within Low SES (Table 10 left panel)
- Race/ethnicity differs within High SES (Table 10 right panel)

## 3.8A Comparison of Mean Value Differences According to Race/Ethnicity

The evaluation of mean differences according to race/ethnicity entailed the examination of differences driven by SES amongst Hispanics (left panel of Table 9) and amongst Non-Hispanics (right panel of Table 9). These analyses specifically examined:

- Low SES Hispanics versus High SES Hispanics
- Low SES Non-Hispanics versus High SES Non-Hispanics

## Hispanics analysis - Low SES Hispanics versus High SES Hispanics

Within the Hispanic group, those of Low SES generally reported poorer health as compared to their High SES counterparts, which was observed for the health measures of Physical Function, Role Function, Social Function, Cognitive Function, Energy, Pain, overall QOL, General Physical Health composite, General Mental Health composite, Composite. Only for the Mental Health measure did High SES Hispanic children rate themselves slightly better in health than Low SES Hispanics. Interestingly, the overall QOL measure was the only measure to demonstrate statistical significance between Low SES Hispanics and High SES Hispanics, in which those of Low SES scored themselves 7 points lower than their High SES counterpart.

#### Non-Hispanics analysis - <u>Low SES</u> Non-Hispanics versus <u>High SES</u> Non-Hispanics

The observed trend of poorer health reporting amongst those Hispanic, regardless of SES, was also observed for those Non-Hispanic. Within the Non-Hispanic group, Low SES patients scored themselves lower than their High SES counterparts for the measures of Role Function, Social Function, Energy, Pain, Mental Health, overall QOL, General Physical Health composite, General Mental Health composite, and Composite. The only statistically significant differences lied in the scoring of pain and social function between the different socioeconomic classes of Non-Hispanics, as those of High SES reported more pain (8 points greater) and better management of duties/expectations (20 points greater) than their Low SES counterpart.

#### 3.8B Comparison of Mean Value Differences According to Socioeconomic Status

The evaluation of mean differences according to SES entailed the examination of differences driven by race/ethnicity amongst the low socioeconomic group (left panel of Table 10) and amongst the high socioeconomic group (right panel of Table 10). These analyses specifically examined:

- Low SES Hispanics versus Low SES Non-Hispanics
- High SES Hispanics versus High SES Non-Hispanics

## Low SES analysis - Low SES Hispanics versus Low SES Non-Hispanics

Within the low socioeconomic group, Hispanics generally reported themselves in worse health than their Non-Hispanic counterparts, which was observed for the health measures of Role Function, Social Function, Cognitive Function, Energy, Pain, Mental Health, General Physical Health composite, General Mental Health composite, and Composite. The only measure that exhibited statistical significance was Social Function, which was ~8 points higher for Low SES Non-Hispanics than for Low SES Hispanics. The Physical Function and overall QOL measures were reported more negatively by Low SES Non-Hispanics than their Low SES Hispanic counterparts.

## High SES analysis - High SES Hispanics versus High SES Non-Hispanics

The observed trend of poorer health reporting amongst the low socioeconomic group, regardless of race/ethnicity, was also observed within the high socioeconomic group. Within the high socioeconomic group, Hispanic patients scored themselves lower than their Non-Hispanic counterparts for all of the CHRIs health measures, except for overall QOL and General Mental Health composite. However, no statistically significant differences between the Hispanic and Non-Hispanic groups were observed for CHRIs health measures amongst the high socioeconomic group.

		<u>Hispan</u>	ics		<u>Non-Hispanics</u>				
CHRIs Health Measures	Low SES	High SES	Meat (H	n Difference <sup>b</sup> ± 95% CI)	Low SES	Low SES High SES M		ean Difference <sup>b</sup> (± 95% CI)	
Physical Function	59.4 [24.9]	64.5 [26.4]	-5.1	[-12.0, 1.9]	67.2 [19.9]	63.0 [27.0]	4.2	[-5.9, 14.3]	
Role Function	64.6 [24.8]	68.0 [27.8]	-3.4	[-10.6, 3.8]	67.2 [27.6]	70.7 [24.6]	-3.5	[-13.7, 6.7]	
Social Function	70.4 [22.9]	71.8 [18.2]	-1.4	[-8.1, 5.2]	72.0 [17.3]	80.0 [18.1]	-8.0*	[-15.4, 0.6]	
Cognitive Function	65.8 [27.0]	66.5 [28.2]	-0.7	[-8.9, 7.5]	69.9 [29.1]	68.7 [27.1]	1.2	[-10.1, 12.6]	
Energy	68.7 [24.4]	70.7 [24.5]	-2.0	[-9.2, 5.2]	73.2 [23.2]	76.2 [22.9]	-3.0	[-12.3, 6.3]	
Pain	72.9 [28.5]	74.5 [30.2]	-1.6	[-10.5, 7.2]	67.7 [30.4]	80.0 [26.9]	-12.3*	[23.9, 0.7]	
Mental Health	72.8 [27.1]	72.6 [24.4]	0.2	[-8.1, 8.6]	75.4 [23.8]	77.3 [23.6]	-1.9	[-11.8, 8.0]	
Overall Quality of Life	80.5 [20.8]	87.7 [17.2]	-7.3*	[13.7, 0.9]	78.3 [23.7]	85.5 [17.4]	-7.1	[-15.3, 1.0]	
General Physical Health	64.6 [19.3]	67.4 [20.4]	-2.8	[-8.8, 3.2]	68.5 [18.2]	71.0 [19.3]	-2.5	[-10.4, 5.4]	
General Mental Health	74.0 [17.8]	76.7 [16.4]	-2.6	[-8.2, 2.9]	73.9 [20.9]	79.6 [18.0]	-5.8	[-13.7, 2.2]	
Composite	69.7 [16.4]	72.6 [14.4]	-2.9	[-8.0, 2.2]	71.7 [17.0]	75.7 [16.8]	-4.0	[-11.2, 3.1]	

 Table 9: Comparison of Mean Values Between Low and High SES of CHRIs General Health Measures According to

 Race/Ethnicity<sup>a</sup>

\*denotes p<0.05

<sup>a</sup>Table entries are means with standard deviations in brackets.

<sup>b</sup>Mean differences are reported as Low SES minus High SES, with 95% confidence intervals.

	Low Socioeconomic Status				High Socioeconomic Status				
CHRIs Health Measures	Hispanic	Non-Hispanic	Mean (±	Difference <sup>b</sup> 95% CI)	Hispanic	Non-Hispanic	Mean (±	Mean Difference <sup>b</sup> (± 95% CI)	
Physical Function	64.5 [26.4]	63.0 [27.0]	1.4	[-7.0, 9.8]	59.4 [24.9]	67.2 [19.9]	-7.8	[-16.8, 1.1]	
<b>Role Function</b>	68.0 [27.8]	70.7 [24.6]	-2.8	[-11.2, 5.6]	64.6 [24.8]	67.2 [27.6]	-2.7	[-12.0, 6.6]	
Social Function	71.8 [18.2]	80.0 [18.1]	-8.2*	[-14.4, -2.0]	70.3 [22.9]	72.0 [17.3]	-1.7	[-10.2, 6.8]	
Cognitive Function	66.5 [28.2]	68.7 [27.1]	-2.2	[-11.5, 7.2]	65.8 [27.0]	69.9 [29.1]	-4.1	[-14.4, 6.2]	
Energy	70.7 [24.5]	76.2 [22.9]	-5.5	[-13.4, 2.3]	68.7 [24.4]	73.2 [23.2]	-4.5	[-13.5, 4.4]	
Pain	74.5 [30.2]	80.0 [26.9]	-5.5	[-15.1, 4.2]	72.9 [28.5]	67.7 [30.4]	5.2	[-5.9, 16.3]	
Mental Health	72.6 [24.4]	77.3 [23.6]	-4.7	[-13.1, 3.7]	72.8 [27.1]	75.4 [23.8]	-2.6	[-12.9, 7.7]	
Overall Quality of Life	87.7 [17.2]	85.5 [17.4]	2.3	[-3.9, 8.4]	80.5 [20.8]	78.3 [23.7]	2.1	[-6.3, 10.5]	
General Physical Health	67.4 [20.4]	71.0 [19.3]	-3.6	[-10.3, 3.2]	64.6 [19.3]	68.5 [18.2]	-3.8	[-11.2, 3.5]	
General Mental Health	76.7 [16.4]	79.6 [18.0]	-2.9	[-9.1, 3.2]	74.0 [17.8]	73.9 [20.9]	0.2	[-7.0, 7.4]	
Composite	72.6 [14.4]	75.7 [16.8]	-3.1	[-8.8, 2.5]	69.7 [16.4]	71.7 [17.0]	-2.0	[-8.5, 4.5]	

Table 10: Comparison of Mean Values Between Hispanics and Non-Hispanics of CHRIs General Health Measures According to Socioeconomic Status<sup>a</sup>

<sup>a</sup>Table entries are means with standard deviations in brackets.

<sup>b</sup>Mean differences are reported as Hispanic minus Non-Hispanic, with 95% confidence intervals.

#### **IV. DISCUSSION**

Patient-reported outcomes are essential to determining diagnoses and appropriate care. Thus, the study of HRQOL and other health-related measures is important, especially when examined through the lens of a self or proxy-reporter. The capture of general health measures, like HRQOL, using the CHRIs instrument, allows for better comprehension of a pediatric patient's health and well-being according to the child's own self-reporting as well as from the parent's reporting of their own health and child's health.

This thesis study demonstrates the utility of child-reporting in which health outcomes originating from the pediatric patients can be beneficially applied toward understanding their health and wellness in the context of race/ethnicity and SES. Patient-reported health outcomes, when coupled with descriptive data like demographics, annual income earning, level of education, and zip code of parents and proxy, can be used to better understand pediatric patients' health prognoses and then recommend appropriate health treatments and interventions.

Within child health, much of the existing literature surrounding parent-child reporting evaluates health measures, like HRQOL. Often, these studies examine the parent-child relationship from a specific lens, such as the patient's health condition, or according to multiple scales or measures, like HRQOL. These studies aid in understanding how the diagnosis and treatment of a certain illness can be viewed according to patent and child. For example, moderate to good accordance with regards to QOL has been previously observed amongst pediatric patients with heart disease [48, 49]. Such was similarly noticed amongst children with rheumatoid conditions, in which parent and child agreed for all but one of the measures [50].

Studies on children with cancer have demonstrated varied levels of agreement between parent and child, ranging from poor to good [51].

Parent-child reporting studies have examined levels of agreement between the two reporting sources and provided a foundation for which self-reported outcomes from pediatric patients can be used for insight about the specific patient population. However, heavy reliance on proxy reporting alone can be limiting and misrepresentative of a child's actual health status. For example, a 2001 system review examined that parents are more likely to perceive illness as compared their children. There exists more concordance between parents and chronically sick patients as compared to parents and healthy children [27]. Additionally, a 2008 review studying parent-child agreement of nineteen HRQOL instruments noted that parents of healthier children tend to undermeasure their children's HRQOL [5]. Additionally, discrepancies between the informants may result depending on the age of the pediatric patient and if a chronically sick child is surveyed versus a healthy individual [52].

Thus, this thesis solely examined how pediatric patients' reported data, obtained via the CHRIs survey, may be used for understanding their health status according to their perspective, with some additional context from their parents. Further, the characterization of these patients according to race/ethnicity and their SES suggest a trend in children's health that mirrors that in adults.

While the current understanding of child HRQOL relative to race and ethnicity and/or SES is limited due to little research on the topic, there is an understood direct relationship with race/ethnicity and SES per the literature studying the intersection of these variables to health [53-56]. The few studies that examine child HRQOL do so in the context of multiple variables. One study examining income noted that those ranked the lowest produced poorer child HRQOL

measurements as compared to ranked higher. [57] Parents facing food insecurity reported low child HRQOL, where in fact Black male parents, reported lower physical function and lower total HRQOL measurements [53].

Thus, the designed composite variable of race/ethnicity and SES allowed for the evaluation of multiple attributes affecting reported health outcomes. As past studies have suggested, there is an observed relationship between race/ethnicity and SES in which Hispanics report worse health, as experienced by those of the Low SES group [54, 55]. This is consistent with the study results of this thesis in which those Hispanics and those of Low SES reported poorer health, which is further supported when Low SES Hispanics scored worse health than High SES Hispanics.

Further, certain minority groups are marked for greater risk of health conditions, such as: African Africans with asthma and skin allergies; Native Americans with hearing or vision problems; Latinos with dental conditions [59]. More intensive studies have examined the impact of parental education and income with regards to children's health, noting that African Americans, Native Americans, and Hispanics are the poorest, least healthy, and with the least well-educated parents. These differences do persist following adjustment for family income and parental education, illustrating that such racial/ethnic and socioeconomic differences contribute to the disparities faced by these non-White groups [60]. Additional studies of the racial/ethnic disparities with regards to SES and other contextual variables are to be studied in order to better determine their influence on child HRQOL.

The capture of general health measures, like HRQOL, using the CHRIs instrument allows for better comprehension of a pediatric patient's health and well-being according to the child's own self-reporting as well as from the parent's reporting of their own health and child's health.

Thus, this thesis assessed the relationship between race/ethnicity and socioeconomic status amongst pediatric patients as means of understanding whether they are mediators of health measures, like HRQOL, assessed by pediatric patients.

#### 4.1 Study Limitations

The mentioned work was conducted at a single medical center, and thus a greater number of participating sites would diversify the sample to evaluate the generalizability of findings. The site for this study is located in a predominantly White community with the admission of patients based exclusively on authorized insurance [61, 62]. Considering this, the partial patient population captured in this study may not be well representative of whole racial/ethnic group in the larger area. A single site of study limits the extrapolation of the study, as it is difficult to conclude if the conclusions drawn are geographically based to this community versus a trend observed throughout the whole United States. Further, given that the medical site used for the study requires insurance authorization, it may be limiting the breadth of patients who can best be reached.

The results of this study are based on a sample of pediatric patients who are literate and have access to a computer for the animated, computer-administered survey. Thus, the results reported here are limited to these patients and may not apply to those less literate and lacking technology. Further, the CHRIs survey that was modified for computer administration was previously noted for having poor to good agreement for the subscales examined. Compared to the PedsQL tool, CHRIs and a few other child-reporting instruments used less frequently [5].

The pediatric patients pooled were those associated with forthcoming surgery operations with plastic surgery, urology, and ENT (ear, nose, and throat). The health burden and overall

health statuses experienced by this type of patient population may be different than patients of cardiology or neurology. Surveying amongst a wider range of surgical types as well as amongst healthy patients would allow for the generalizability of findings to all types of patients.

For this study, race and ethnicity was examined according to the perspective of Hispanic and Non-Hispanic, thereby only analyzing one major racial/ethnic group versus a mixed group of other racial/ethnic groups. The Hispanic group was most holistic of a similar background versus the Non-Hispanic represented a mixed group, not necessarily prolific of everyone of that group. A comparison of Hispanic versus Non-Hispanic Whites would also have been of interest, but due to the low number of Non-Hispanic White respondents that proved to be not as different as the Non-Hispanic group as a whole, the Non-Hispanic mixed categorical variable was utilized for analyses. Similarly, analyses examining the effects amongst minorities, such as Hispanics versus Asian or African American, would be of greater value to see if reported outcomes are the same or different amongst different races/ethnicities. For this study, additional lens according to African Americans or Asians were not evaluated, given the low number of study participants of that respective racial/ethnic group. Recruitment of more diverse or a large number of study participants would enable statistical analyses that examine greater racial/ethnical differences. Determination of ideal sample size via power analysis could be done in the future to provide greater analytic strength for evaluating strictly between Hispanics and Non-Hispanic Whites, between minority groups, or amongst other comparisons.

Furthermore, race/ethnicity and SES composite variable was dependent on the designed race/ethnicity and SES grouping variables. The race/ethnicity variable was designed as binary, Hispanic and Non-Hispanic, while the SES variable was dependent on having values for both education and annual income, should either of these metrics be missing, then SES could not be

determined and thus paired with race/ethnicity for composite variable analyses. The SES composite variable was not imputed should education or annual income be missing, and some reported CHRIs health measures were not included in the analyses, given the missing context of SES. The stringency of SES needing both education and annual income resulted in the loss of data for greater sample size evaluation. Thus, the consideration of imputation of annual income or education could allow for additional context of SES for individuals amongst all of the race/ethnic groups studied.

## V. CONCLUSION

The work presented herein demonstrates the value of understanding the relationship of child and parent reporting of general health measures and the utility of each of these respondent's reported outcomes. All sources of patient-reported outcomes can be used to better understand the patient in terms of diagnosis and treatment plan.

For this thesis, the study evaluated different grouping variables, Hispanic versus Non-Hispanic and Low SES versus High SES, which provided insight into how these distinguishing characteristic impact the reporting of health measures. In particular, it is noted those who are Hispanic and those who are of Low SES tended to score lower health scales than those of their counterparts, Non-Hispanic and High SES. Children who are Hispanic and of Low SES, are observed as being lower scorers as compared to children who are Non-Hispanic and of Low SES, are Non-Hispanic and of High SES, and are Hispanic and High SES.

The evaluation of the four studied populations (Low SES Hispanics, High SES Hispanics, Low SES Non-Hispanics, and High SES Non-Hispanics) revealed how race/ethnicity and SES are indeed driving differences in self-reported CHRIs health measures from children. Specifically, when evaluating according to race/ethnicity (Hispanics versus Non-Hispanics), those of Low SES are reporting poorer health than their High SES equivalent. According to SES (low versus high), Hispanics are worse in health than their Non-Hispanic counterparts. Therefore, this suggests that those who are Hispanic and of the low socioeconomic group are more likely to be reporting more negative health measures than those Non-Hispanic and of higher socioeconomic standing.

Future research investigating child-reporting amongst specific pediatric populations will provide greater insight to how certain characteristics, like race/ethnicity or SES, or a health condition, such as diabetes, may influence general health measures, like HRQOL. Therefore, additional work investigating self-reported health measures from children according to race/ethnicity and SES would be of great interest to the child health field.

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## **VII. APPENDICES**

## Appendix A: Subset of questions used to evaluate CHRIs studied measures.

PRC1	How much does not feeling well get in the way when you want to play hard? 1=Not at all 2=A little 3=Some 4=A lot 5=A whole lot
PRC2	How much does not feeling well get in the way when you want to play ball? 1=Not at all 2=A little 3=Some 4=A lot 5=A whole lot
PRC3	How much does not feeling well get in the way when you want to do things like swing or walk a few blocks? 1=Not at all 2=A little 3=Some 4=A lot 5=A whole lot
PRC4	How much does not feeling well get in the way when you want to climb? (like on the crossbars, on the jungle gym, up a slide) 1=Not at all 2=A little 3=Some 4=A lot 5=A whole lot
PRC5	How often do you have to miss school because you aren't feeling well? 1=Never 2=Not very often 3=Sometimes 4=A lot 5=A whole lot
PRC6	How much does not feeling well get in the way of your classroom activities? 1=Not at all 2=A little 3=Some 4=A lot

		5=A whole lot				
PRC7	How much does not fe	eeling well get in the way when you do your schoolwork? 1=Not at all 2=A little 3=Some 4=A lot				
		5=A whole lot				
PRC8	How much does not fe house?	eeling well get in the way when you do work around the				
		1=Not at all				
		2=A little				
		3=Some				
		4=A lot				
		5=A whole lot				
PRC9	How much does not for family?	eeling well get in the way of enjoying time with your				
	5	1=Not at all				
		2=A little				
		3=Some				
		4=A lot				
		5=A whole lot				
PRC10	How much energy hav	How much energy have you had for playing lately?				
	0,	1=A whole lot				
		2 = A lot				
		3= Some				
		4=A little				
		5=Very little				
PRC11	How much energy have you had after school?					
11011	nov much chergy nuv	1=A whole lot				
		2=A lot				
		3=Some				
		4=A little				
		5=Very little				
PRC12	How often do you nee	How often do you need to take time out to rest during the day?				
		1=Never				
		2=Not Very Often				
		3=Sometimes				
		4=A lot of the time				
		5=A whole lot of the time				

PRC13	How much does not feeling well make it hard to pay attention? 1=Not at all 2=A little 3=Some 4=A lot 5=A whole lot
PRC14	How much does not feeling well get in the way when you want to concentrate? 1=Not at all 2=A little 3=Some 4=A lot 5=A whole lot
PRC15	How much does not feeling well keep you from wanting to talk to or spend time with your friends? 1=Not at all 2=A little 3=Some 4=A lot 5=A whole lot
PRC16	How much help do you get from your family and friends when you aren't feeling well? 1=A whole lot 2=A lot 3=Some 4=A little 5=None at all
PRC17	How much pain have you had lately? 1=None at all 2=A little 3=Some 4=A lot 5=A whole lot
PRC18	How nervous, worried, or fidgety have you felt lately? 1=Not at all 2=A little 3=Some 4=A lot 5=A whole lot
PRC19	How happy or sad have you been lately? 1=Really happy

	2=Pretty happy 3=Happy 4=A little sad				
	5=Sad				
PRC20	How have you been doing lately?				
	1=Great				
	2=Good				
	3=Okay				
	4=Not great				
	5=Pretty bad				
PRC21	How much fun have you been having lately?				
	1=A Whole Lot				
	2=A Lot				
	3=Some				
	4=A Little				
	5=None at all				

<u>CHRIs</u> <u>General</u> <u>Health</u> <u>Measure</u>	<u># of</u> <u>Items</u>	<u>Child Self-</u> <u>Reported</u> <u>Assessment</u>	<u>Parent Proxy-</u> <u>Reported</u> <u>Assessment</u>	<u>Parent Self-</u> <u>Reported</u> <u>Assessment*</u>		
Physical Function	4	Included	Included	Included		
<b>Role Function</b>	4	Included	Included	Included		
Social Function	3	Included	Included	Included		
Cognitive Function2		Included	Included	Included		
Energy	Energy 3 Included Included		Included	Included		
Pain	1	Included	Included	Excluded*		
Mental Health	2	Included	Included	Included		
Overall Quality of Life	2	Included	Included	Included		
General Physical Health Composite	12	Physical Function + Role Function + Social Function + Cognitive Function	Physical Function + Role Function + Social Function + Cognitive Function	Physical Function + Role Function + Social Function + Cognitive Function		
General Mental Health	8	Energy + Pain + Mental Health + Overall Quality of Life	Energy + Pain + Mental Health + Overall Quality of Life	Energy + Mental Health + Overall Quality of Life		
Composite	20	General Physical Health Composite + General Mental Health Composite	General Physical Health Composite + General Mental Health Composite	General Physical Health Composite + General Mental Health Composite		

## Appendix B: CHRIs General Health Measures According to Reporting Source

\*Exclusion of this construct, as the accompanying parent of the pediatric patient is considered to be of general good or decent health and well-being, and any discomfort or pain of the guardian is anticipated not to interfere with the proxy-reporting of the child.

General Health Subscale Measures	General Health Measures	Sample Survey Question	Visualized and Read Response Options				
	Physical Function	"How much does not feeling well get in the way when you want to play hard (like run fast, bike hard, play tag?)"	Not At All       A Little       Some       A Lot       A Whole Lot				
General Physical	Role Function	"How much do you have to miss school because you weren't feeling well?"	Not At All       A Little       Some       A Lot       A Whole Lot				
Health Composite	Social Function	"How much does not feeling well keep you from wanting to talk or spend time with friends?"	Not At All A Little Some A Lot A Whole Lot				
	Cognitive Function	"How much does not feeling well make it hard to pay attention (like when you read, write or have to follow directions)?"	Not At All A Little Some A Lot A Whole Lot				

# Appendix C: Sample Survey Items for Each CHRIs General Health Subscale Measure

	Energy	"How much energy have you had for playing lately (like on the playground, in your neighborhood)?"	A Whole Lot	ALot	Gome	A Little	Very Little
General Mental	Pain	"How much pain have you had lately?"	None at All	ALittle	Some	ALot	A Whole Lot
Health Composite	Mental Health	"How happy or sad have you been lately?"	Really Happy	Pretty Happy	Нарру	A Little Sad	Sad
	Overall Quality of Life	"How have you been doing lately?"	Great	Good	Ok	Not Great	Pretty Bad