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THE POWER OF COLOR:
HOW DOES SHARED DECISION MAKING BETWEEN PHYSICIANS AND PATIENT
DIFFER BY RACE?

by

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B.A. University of Central Florida, 2018

A thesis submitted in partial fulfillment of the requirements
for the degree of Master of Arts
in the Department of Sociology
in the College of Sciences
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ABSTRACT

Objective: Shared Decision-Making (SDM) as a clinical approach allows patients and physicians to discuss the best treatment options for the patients' improved health outcomes. Over the past two decades, SDM has improved the quality of health by reassuring patients that they have a voice when considering treatment options. The objective of this study is threefold: to examine parents' perceptions of engaging in SDM with their physicians about their treatment options; to engage in the SDM process when their children's mental health conditions were the subject of SDM; and to assess the comfort level of parents engaging in SDM, based upon their highest levels of education. Specifically, the researcher was interested in how parents' racial demographics influenced their involvement in the SDM process.

Methods: The researcher reviewed in-depth the 2016-2017 National Survey of Children's Health (NSCH). In that study, interviewers asked parents of different races how they engaged in SDM with their physicians, when discussing their health and their children's mental health issues. The three questions dealt with parents' experiences with SDM and their physicians, parents' experiences with SDM when discussing their children's mental health conditions, and how parents' highest educational attainment might impact their comfort levels in engaging in SDM with their physicians. The researcher conducted a Univariate descriptive statistic, Cronbach Alpha Score, ANOVA, T-test and Tukey poc test to make valid conclusions in answering the question, "*How does shared decision-making between patient and physician differ by race?*"

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CHAPTER ONE: INTRODUCTION

Shared Decision-Making (SDM) is the process in which physicians and families interact to make decisions about health treatments (Elwyn, 2012). Numerous studies have shown that patients engaging in shared decision-making (SDM) with their physicians are more likely to experience better health outcomes (Politi, 2011; Elwyn, 2012). SDM has built trust between physicians and patients, and has increased patients' preventive care, self-reported health status, and diabetes control (Peek, 2012). SDM has been used as a model for patients and physicians for decades (Elwyn, 2012).

However, not all patients engage in SDM (Elwyn, 2012). Racial and ethnic minorities are less likely to engage in SDM, and are more likely to have the worst health outcomes in the U.S. (Williams, 2013). Studies have shown that a series of events such as medical mistrust and discrimination have impacted racial minorities' willingness to engage in SDM because they do not trust that their physicians are knowledgeable or sincere in their recommendations of the best treatment options (Washington, 2006).

Where physician-patient trust is present, SDM results in the most efficient and practical treatment recommendation. If trust were not an issue for African Americans, racial minorities could benefit from SDM (Boland, 2017). Health policymakers have attempted to revise SDM to incorporate racial and ethnic minorities' ability to engage in SDM without experiencing racism and stigmas (Boland, 2017; Williams, 2019). The research objective of this study is to examine the perceptions towards SDM from parents who see physicians to discuss their own treatment options and those related to their children who may have been diagnosed with a mental health condition.

In order to understand parents from all races engaging in SDM, the researcher used the 2016-2017 National Survey of Children Health (NSCH), which incorporated race, ethnicity, and parents' educational status in its research study. While the specific results of this report will be discussed later in this thesis, it should be noted here that of all the persons of color cited in the researcher's study, African-Americans had the greatest number of negative factors impeding the successful implementation of SDM between physicians and their patients.

CHAPTER TWO: LITERATURE REVIEW

Shared Decision Making (SDM): Pros and Cons

Shared Decision-Making (SDM) is defined as a clinical approach where patients and physicians discuss the best treatment options for the patient's best health outcomes (Elwyn, 2012). Elwyn et. al have stated that the importance of SDM is to educate patients on the knowledge of their health conditions and treatment options, and to allow patients to voice their opinions while engaging in the SDM process (Elwyn, 2012). When patients feel they are respected for voicing their concerns, they have better self-efficacy and will engage in preventive care by doing such things as engaging in good eating habits and regular exercises (Heisler, 2002; Hibbard, 2005, 2007). Patients who are given a clear understanding of the risks and benefits of their decisions are satisfied with the knowledge and the support that they receive from their physicians (Spatz, 2012).

Patel et. al found in their study that patients engaging in SDM reported having a better quality of life (Patel, 2008). For example, when physicians and patients are clear about the treatment necessary, patients recover in timely fashion, and can report that they are well and healthy afterwards (Patel, 2008). SDM is also effective when applied ethically to improve patient's health outcomes (O'Connor, 1998 Patel, 2008; Elywn, 2012) The benefits of SDM are that when patients feel that their physicians have heard their concerns, instead of feeling that they have no voice in their treatment options, they are more likely to agree with the treatment being given in the process (Spatz, 2012). When there are no conflicts between patients and physicians, the results of treatments are positive and SDM works (O'Connor, 1998; Elwyn, 2012).

At the same time, there are situations where the level of trust between patients and physicians is compromised by patients' prior experiences (Washington, 2006; Armstrong, 2007). Different racial groups have different past histories that cause them to be cautious of treatment recommendations by physicians (Washington, 2006; Scharff, 2015).

For example, some minority citizens have had bad experiences with physicians who offered either too little treatment options because patients were poor, or unnecessary treatment options because they had insurance (Lawrence and Kelecher, 2004). They felt victimized by their physicians, which directly impacted SDM (Lawrence and Kelecher, 2004). While many racial groups reported some distrust of their physicians in terms of SDM, African-Americans demonstrated significant problems with SDM, resulting in medical mistrust, lack of engaging in SDM and rejecting treatment recommendation because of the historical forms of structural racism, segregation and inequalities they had experienced during their day-to-day lives (Washington, 2006; Williams, 2013, 2019).

Structural Racism and Medical Mistrust

Structural racism is defined as macro-level social forces and institutional ideologies that coordinate and generate inequities in the lives of racial and ethnic groups (Bonilla-Silvia, 1997; Williams, 2013). Structural racism is the outcome of many different factors, such as institutional, historical, and cultural practices that routinely advantage one social or ethnic group while creating disadvantages for other racial group in the areas of housing, occupation, credit markets, education, criminal justice, economics, and health care (Reskin, 2012; Williams, 2013; Phelan and Link, 2015). In other words, this happens by design, not coincidence or accident (Williams,2013;2019).

It is the most pervasive form of racism, most often attributed to privileging White Americans and oppressing African-Americans, Latinos, Asians, Pacific Islanders, Native Americans and other people of color (Lawrence, 2004; Williams, 2013, 2019). In the history of the United States, the acts of Jim Crow laws, Black Codes, and segregation had prohibited people of color from experiencing equal opportunities, and this inequality also became evident in health care (Washington, 2006; Williams, 2013, 2019). In particular, African-Americans seeking quality health care and finding predominantly White physicians to care for them carried feelings of oppression and distrust into examination rooms, making shared decision making difficult or non-existent (Washington, 2006; Lee, 2018). Without the bond of trust that is common in shared decision making between patient and physician, treatment options may not be thoroughly or comfortably explored (Armstrong, 2007).

Racism and health inequities became even more problematic in the U.S., given the fact that minority racial groups have higher rates of chronic conditions such as diabetes, cancer, PTSD, and hypertension than their White peers (Gee, 2011). Comparing data from several racial groups, persons of color are likely to have higher rates of morbidity and mortality, which negatively impact their life expectancy rate and the quality of life while they are alive (Gee, 2011).

Regardless of whether or not persons of color, more specifically African-Americans, know and understand the long-term problem associated with not seeing a physician for regular checkups and follow up treatment, they often refuse to schedule appointments with physicians concerning their health status (Armstrong, 2007; Williams, 2013, 2019). Evidence suggests that cultural and language barriers lead to medical

mistrust when it comes to shared decision making (Peek,2008,2011;2012). They may feel that physicians are “talking down to them,” or that whatever the physician recommends is insincere and not in the best interest of their patients (Peek,2011). These are important reasons why certain racial groups find discussing their health conditions and treatment options with physicians difficult or impossible (Williams, 2013, 2019). Armstrong and colleagues found in their study that African-Americans and Hispanics distrusted physicians in health institutions when discussing treatments options recommended by their physicians (Armstrong, 2007).

There is a significant amount of literature that has shown that when studying racial differences and patients’ distrust of their physicians, a large focus is on African-American communities (Durso, 1997; Gamble, 1999; Hoover, 1999; Washington, 2006; Armstrong, 2007). African-American communities have high levels of patients distrusting physicians because of the stigmas they experience when attempting to discuss treatment recommendations (Armstrong, 2007; Washington, 2006).

A review of slavery from the historical perspective reveals that African-American communities were the involuntary and unwilling participants of countless medical experimentations at the hands of cruel physicians who did not consider them to be human (Washington, 2006). Author Harriet Washington’s book *Medical Apartheid* (2006) describes the full account of the history of African-Americans’ dehumanized mistreatment as unwitting participants in medical experiments (Washington, 2006).

Scholars today are aware of controversial topics such as the *Tuskegee Experiment* (1932-1972), in which African Americans with Syphilis were denied treatment in order to see the effects of no treatment on the spread of the disease. Predictably, African-

Americans died at alarming rates, which is no surprise to scholars or to average citizens of color learning about the *Tuskegee Experiment* today (Jones, 1981, Washington, 2006; Reverby, 2009).

It is true that many African Americans currently are not aware of specific historical mistreatments like the ones described above, but they have an inherent distrust of doctors who don't look like them making medical decisions for them (Lee, 2018). Serious forms of racial discrimination like this have negatively impacted the relationship between White physicians and African American patients in terms of their attitude towards SDM to achieve the best treatment options modern medicine has to offer (Washington, 2006). African Americans today are likely to deliberately seek out African American physicians, even if they have to travel greater distances to meet them (Torres, 2018).

Deep distrust that is generational in the African American community has been at the root of keeping them from seeking medical attention and information regarding their health conditions (Washington, 2006). Monica Peek and colleagues found in their study that African- Americans are less likely to engage in SDM with physicians, and to disregard any medical information being told to them as the "best" treatment (Peek, 2011). While SDM has been proven to be effective when patients are engaging in the process with physicians whom they trust, African American patients have often raised their concerns about the effectiveness of the model of SDM (Peek, 2011, 2012). They have not put trust in White physicians when they are in positions to discuss health and medicine treatment options with them (Cooper-Patrick, 1999; Levinson, 2008; Peek, 2008; Nathan, 2016).

Not only does this generational mistrust cause African American patients not to engage in SDM with their physicians, but also this mistrust affects their children not having the opportunity to receive the treatments regarding their health status (Washington, 2006). Parents make decisions in every area of their children's lives and dealing with health and SDM is no exception (Chavira, 2017). Racism and medical mistrust have influenced stigmas in the minority communities. As a result, some children do not receive the proper diagnoses or treatments for their physical and mental health conditions (Washington, 2006; Reverby, 2009).

Children's Mental Health Conditions

A mental health disorder is a behavioral pattern or mental pattern that causes significant distress or impairment of personal functioning (Brooks, 2008; Cockerham, 2016). Mental health disorders could become persistent or could occur as a single episode (Brooks, 2008). The causes of mental health disorders are often inconsistent because it is usually defined by how a person behaves, feels, thinks, and perceives (Cockerham, 2016).

Health professionals and psychiatrists are mainly the ones who diagnose patients with disorders, and who presumably take into consideration their cultural and religious beliefs when making a diagnosis (APA, 2013). Mental disorders affect the lives and wellbeing of millions of children, adolescents and adults each year (Cockerham, 2016; NAMI, 2019). The National Alliance on Mental Health reported in 2016 that 7.7 million U.S. children between the ages of six and seventeen were diagnosed with a mental health condition by a physician or a psychiatrist (NAMI, 2019). Perou et al. found in their study

that children being diagnosed with a mental health disorder experienced changes in their learning ability, behavior and social interactions with their peers (Perou, 2013).

The Center for Disease Control and Prevention (CDC) reports that among the mental disorders that are diagnosed among children, approximately 16.9 million children as young as three years old and up to seventeen years old experience Attention-Deficit Hyperactivity Disorder (ADHD), behavioral problems, anxiety and depression most often (CDC, 2019).

Children diagnosed with one of the four prevalent disorders tend to experience differences in health services due to the dynamic of their racial and ethnic backgrounds (Howell, 2008). Marrast et al. found in their study that African-American and Latino children made 37% and 49% fewer visits to psychiatrists, respectively, than their White counterparts. Also, these two minority groups of children had respectively 47% and 58% fewer visits to any mental health professional, compared to White children (Marrast, 2016).

Marrast's study went on to address the fact that, despite the above disparity, African American and White children had similar rates of mental health problems and similar rates of severe episodes that result in emergency visits for care (Marrast, 2016). However, African American children had lower rates of uses of mental health services than their counterparts (Marrast, 2016).

Access to mental health treatments for minority children has become problematic because of their parents' or family members' lack of understanding about the need for treatment, and their negative attitudes towards treatment (Algeria, 2011). There is evidence that racial and cultural differences between patients and physicians have resulted

in fewer discussions about treatment options, along with fewer opportunities for shared decision-making (Richardson, 2001; Hansen, 2006).

One study showed that one-third of African-Americans have reported that racism was a major issue in their desire to seek mental health care for their children, and they reported that they have experienced multiple levels of institutional, societal, and individual racism in seeking out mental health services for their children (Hansen, 2006). The role of stigma has been frequently cited in the African-American communities because of the lack of medical information given to them by mostly White physicians (NAMI, 2019).

Many African-Americans struggle with the knowledge of their children having mental disorders, but nevertheless they have become reluctant to seek treatment or advice from physicians (NAMI, 2019). The impact of stigma influences labeling, stereotyping, separation and discrimination among adults and children from all racial groups who are diagnosed with a mental health disorder (Link & Phelan, 2001; Costello, Egger & Angold, 2005; Hale, Raaijmakers, Muris, Hoof & Meeus, 2008; Merikangas, 2005; Polanczyk, Salum, Sugaya, Caye, & Rohde, 2015). Additionally, parents' perceptions of adult and child mental disorders and related mental health services have likely influenced the role they play in securing appropriate treatments for their children's health conditions (Chavira, 2017).

Children rely on their parents' opinions about their mental health conditions, so they trust their parents' decisions in seeking or not seeking medical service to improve their health status (Puustinen, Lyyra, Metsäpelto, & Pulkkinen, 2008; Sayal, 2006; Shanley, Reid, & Evans, 2008). Therefore, children's ability to receive medical attention

is determined by their parents' attitudes towards the mental health symptoms displayed by their children, and their knowledge of treatment options in SDM with physicians in health institutions (McKay & Bannon, 2004; Stiffman, et al., 2004; Chavira, 2017).

CHAPTER THREE: THEORETICAL FRAMEWORK

There are two theories that can be applied as the theoretical orientations of this research: Jo C. Phelan and Bruce G. Link's theory on fundamental causes, and Erving Goffman's theory of stigma. Both theories provide two similar perspectives on SDM, health inequalities, discrimination and medical mistrust.

Phelan and Link's fundamental causes theory explains the association between socioeconomic status and health disparities creating health inequalities that impact dramatic changes in risk factors and health interventions associated with diseases (Phelan & Link, 1995, 2010). Phelan and Link state that the fundamental causes theory has four important components: (1) The cause influences multiple disease outcome; (2) The cause affects disease outcomes through multiple risk factors; (3) The cause involves access to resources, such as money, power, knowledge, prestige, and social connections that can assist in avoiding health risks or minimizing the spread of diseases once they occur; and (4) The cause involves association between a fundamental cause and health that is reproduced over time via the replacement of intervening mechanisms (Phelan & Link, 2010). The impact that fundamental causes have on individuals' health status can influence stigma among individuals having less knowledge about health conditions and treatments (Phelan & Link, 2010).

Fundamental causes and health outcomes align perfectly with Goffman's theory of stigma. Goffman defines stigma as an attribute, behavior, or reputation which is socially discrediting in many ways (Goffman, 1963,1997; Hatzenbuehler,2013). Stigma is when society marks someone for disgrace because of something that person did, has, or is. For example,

people with mental health are stigmatized and negatively sanctioned in society (Goffman,1963;1997). Stigma is something people also feel shame over (Goffman,1963;1997). Those who are stigmatized, or likely to be stigmatized for some reason, are less likely to approach anyone for help, lest their stigma become known (Goffman,1963;1997). Therefore, people who have mental health conditions, which are considered socially stigmatized conditions, may not readily talk about mental health with physicians (Goffman,1963;1997). And mental health is more stigmatized in African-American families than in White families (Snowden, 2007). Paired with medical mistrust, stigma can help us understand why African Americans are less likely to use SDM with their physicians when discussing mental health conditions (Snowden, 2007).

Research has addressed the fact that African Americans ignore the signs of mental health disorders such as ADHD, and are most likely to mistrust schoolteachers' and staff members' opinions of their children's medical condition if the diagnosis is ADHD (Pescosolido, 2007). Researchers have also highlighted the fact that African Americans who are diagnosed with ADHD have limited available resources such as health care insurance, which increases their out- of-pocket payments on prescription drugs and medical treatment (Bailey, 2005). Statistics show that for families without adequate health insurance, regular doctor visits, with or without the added dimension of SDM, are prohibitive (Bailey, 2005). That economic fact, coupled with what we know about persistent racial discrimination, is likely to influence African Americans to be unwilling to seek medical care for their medical issues (Burgess, 2008). In addition, other components such as poverty, limited knowledge about ADHD and cultural attitudes can contribute to minorities in general having access to health care (Bailey, 2005).

Lastly, language barriers can be often misunderstood between doctors and minority patients, especially African American and Latino patients who are seeking the proper medical assistance and treatments (Snowden, 2007).

CHAPTER FOUR: METHODOLOGY

The researcher's study aims to explore parents engaging in SDM with physicians, whether discussing their own health issues or their children's mental health issues. SDM is an approach to medical treatments where physicians and parents discuss treatment options to improve their or their children's health conditions. Examining the impacts of how SDM differs by the child's race/ethnicity, mental health conditions, and parents' educational status will provide evidence on how effective SDM is as a process to ensure that patients accept and receive the best treatment options. The purpose of this research is to understand the reasons different racial groups successfully or unsuccessfully engage in SDM with physicians, when parents have to make difficult treatment decisions about their health and the mental health of their children.

Data

The data used for the researcher's thesis come from the 2016-2017 National Survey of Children's Health (NSCH). The NSCH is sponsored by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB), and is conducted by the United States Census Bureau. The 2016 NSCH was conducted from June 2016 through February 2017. The 2017 survey was conducted from August 2017 to February 2018 (The Child and Adolescent Health Measurement Initiative [CAHMI], 2017). A total of 71,811 surveys were completed nationally by parents/caregivers of children under the age of 17 for the 2016-2017 combined NSCH.

The NSCH questionnaires were completed by mail and online (CAHMI, 2017).

Households received a mailed invitation asking an adult who is familiar with the child's health and health care in the household (usually the parent) to complete a short screener questionnaire (via web or paper). The screener questionnaire asked participants to identify all children ages 0-17 living in the household (CAHMI, 2017). If a child (or children) lived in the household, the participants who chose to respond online were immediately directed to a more detailed, age-specific topical questionnaire (CAHMI, 2017).

Only one child per household was randomly selected to be the subject of the detailed topical questionnaire. Participants could also request a paper copy of the screener and topical questionnaire if they did not wish to complete it online. All non-responding households received a reminder in the mail (CAHMI, 2017). A mailed paper screener was provided if the household did not respond to the first two web-survey invitations (CAHMI, 2017).

Sample Size:

The test sample consisted only of parents and children who visited a physician within the last twelve months, which totaled 15,553 respondents.

Dependent Variable

Shared Decision-Making. In the 2016-2017 NSCH, SDM was a dependent variable. In the data, parents answered prescribed questions about a doctor's visit with their children within the past twelve months where a treatment option needed to be selected. The questions included these: (1) How often do physicians engage in SDM and offer treatment options to parents whose children had a mental health condition? (2) How often do physicians makes SDM

comfortable among parents, thus allowing them to ask important questions or firmly disagree with treatment recommendations? (3) How often do parents and their physicians collaborate to decide the best treatment choices for their children's mental health conditions? All three SDM items were coded for easy participant responses, using "always," "usually," "sometimes," or "never" as choices.

The researcher decided to reverse code all four answers, and an SDM scale was created by adding the responses of respondents from the three SDM items above. In developing this scale, the researcher ran a Cronbach Alpha to examine the internal consistency of the three questions.

Independent Variables

Child's Race. The NSCH data used seven racial/ethnic categories. The original coding for all races was (1) White, (2) African Americans (3) Native American, (4) Asian, (5) Hawaiian/Pacific Islander, (6) Other Races and (7) Two or more races. Because Hawaiian, Asian and other or two or more race numbers were too small in the data set, I decided to recode children's race into four categories for this study: 1=1 White, 2=2 Black, 3=3 Hawaiian plus Asian and 4=4 Some plus other. I combined both Hawaiian and/Pacific Islanders into the broader groups of Asian based on the general coding of race. Finally, I dropped two or more races and Other races due to insufficient numbers in the analysis leaving me with four categories of race.

Ethnicity. Ethnicity was coded (0) Hispanic and (1) non-Hispanic.

Mental health conditions. Mental health conditions are the most common health conditions in the United States (cdc.gov). Eleven percent (6.4 million) of children ages 6-17

are frequently diagnosed by physicians with prevalent disorders such as attention deficit hyperactivity disorder (ADHD), depression, anxiety and behavioral problems (Hamed, 2015;CDC,2019). Since mental health conditions were applied as an independent variable, the researcher used the International Statistical Classification of Diseases and Related Health Problems (ICD-10), which is a medical classification system used by physicians to assist when diagnosing a child or an adolescent with a mental health condition (ICD-10, 2018). Below is a list of the most prevalent mental health conditions being used in this study to understand parental attitudes towards SDM when they spoke with their physicians. The ICD-10 provides the definition and the codes of how ADHD, Depression, Anxiety and Behavioral problem are applied ethically in the medical field by physicians when diagnosing a patient with a mental health condition.

Mental Disorders

<u>List of this disorder</u>	<u>Diagnose Definition</u>	<u>Codes</u>
ADHD (Attention Deficit Hyperactivity Disorder)	Behavioral and emotional disorder with onset usually occurring in childhood and adolescence	F90-F98
Depression	Mood (affective) disorder	F30-F39
Behavioral Disorder	Behavioral and emotional disorder with onset usually occurring in childhood and adolescence	F90-F98
Anxiety	Dissociative, stress related, somatoform and other nonpsychotic mental disorders	F40-F48

All four conditions were in the NSCH. Parents answered either “yes” or “no” to specific questions relative to the four categories above. If parents had no responses, the answer was coded “no response.” Once again, the researcher decided to recode all variables in all four mental health categories so that 1=1 “yes” and 2=0 “no,” eliminating the “no response” answers for purposes of this study.

Parents’ educational status. The last independent variable the researcher used in this study was the parents’ educational status. The reason was to understand whether there were differences in racial groups engaging in the SDM process with their physicians, attributed to the highest education of the parents. The original coding was (1) less than high school diploma, (2) high school diploma, (3) some college or associate’s degree, and (4) college degree or higher and. Lastly, the researcher decided to merge the first two categories (high school or less) and the latter two categories (at least some college) and remove invalid responses.

Research Questions and Hypotheses

There were two research questions which formed the basis for this thesis: “Do responses from parents engaging in SDM with their physicians about health and treatment options differ based upon race, ethnicity and the highest education of the parents?” Also, “Does the quality of SDM engagement differ among families, based upon their children having or not having mental health disorders?” For this, the researcher developed four hypotheses: (1) White families are more likely than African-Americans and other races of color to engage in SDM with their physicians ; (2) Non-Hispanic families are more likely than Hispanic families to engage in SDM with their physicians when discussing treatment options; (3) Parents’ highest

educational achievement directly impacts their engagement in SDM with physicians offering treatment options for medical issues; and (4) SDM engagement will vary across races of parents of children with mental health conditions.

Analytic Strategy

The goal of this research was to examine different races of parents, as they successfully or unsuccessfully engaged in SDM with their physicians. They would be sharing information about their own illnesses, in terms of accepting and following through on treatment options presented by those physicians. The parents would also address their ability to engage in SDM with physicians, when the topic was whether or not their children had a mental condition. To accomplish this goal, the independent variables (the child's race/ethnicity, mental health disorders, and parents' highest educational status) were tested to discover their relationship to the dependent variables (SDM). To test whether SDM scales differ according to parents' and their children's race the researcher ran an Independent Two Sample T-test. The Independent Two Sample T-test examined whether the difference in the mean score average among Whites, African Americans, Hawaiians, Native Americans and some other races differed in terms of parents engaging in SDM.

Next, it was important to test whether SDM scales differed according to the race/ethnicity of the children whose parents used the SDM process to discuss their children's mental health issues. The researcher ran an ANOVA test. The ANOVA test examined whether the difference in mean score averages between Non-Hispanic and Hispanic families differed in their level of SDM engagement with physicians.

To test whether SDM scale differed for parents whose children were diagnosed with at least one of four mental health disorders (ADHD, Depression, Anxiety and Behavioral problems), the researcher ran an Independent Two Sample T-test. The Independent Two Sample T-test examined differences in mean score averages in the following categories: (1) parents of children who were or were not diagnosed with ADHD; (2) parents of children who were or were not diagnosed with Depression; (3) parents of children who were or were not diagnosed with Anxiety; and (4) parents of children who were or were not diagnosed with Behavioral problems . The Dependent Variable was also the level of parent engagement in the SDM process with their physicians.

In terms of measuring the effects of the parents' highest levels of education on the SDM process, the researcher used an Independent Two Sample T-test. The Independent Two Sample T-test examined the difference in mean score averages for parents having a high school diploma or less schooling, and parents having some college or a college degree.

Lastly, all analyses were conducted using STATA 15.1 (StataCorp, 2017) and the National Survey of Children Health (NSCH) 2016-2017 combined data sets.

and Black ((Mcfarlane, Campbell, Sharps & Watson, 2002; PRAMS, 2018). With that in mind, a study on pregnancy violence is likely to garner a higher percentage of women in the reproductive age than a study on abused women of all characteristics and statuses. Thus, age may or may not be as significant as it appears. However, a troubling finding is that victims and perpetrators were more likely to be black, even though black people only account for 16.9% of Florida's population (U.S. Census Bureau, 2018).

CHAPTER FIVE: FINDINGS

Table 1 displays the univariate descriptive statistic of the socio-demographics of race, ethnicity and the educational attainments of parents who engaged in the SDM process with their physicians. In this study, 15,553 parents answered the question regarding their race. Parents who identified their children as White totaled 12,598 (81%), while parents who identified their children as African-American totaled 802 (5%). Additionally, 528 (3%) parents stated that their children were Asian/Hawaiian and Pacific Islander, while 1,625 (10%) parents claimed their children's races were other than those listed in the data.

Table 1: Univariate Descriptive Statistics

Demographics	N	%
Race	15,553	100
Caucasians	12,598	81.00
African Americans	802	0.051
Asian/Hawaiian/Pacific Islander	528	0.033
Other races	1,625	0.104
Ethnicity	15,553	100
Hispanic	1,452	9.34
Non-Hispanic	1,4101	90.66
Education	15,403	100
HS/less	1,517	9.85
At least some college	13,886	90.15

Moreover, of the 15,553 parents who considered their families to be White, 14,101 (90%) said their children were Non-Hispanic, while 1,452 (9%) said their children were Hispanic.

Lastly, a total of 15,403 parents answered the question regarding their highest educational status, with 13,886 (90%) acknowledging that they had at least some college education, and 1,517 (9%) admitting they had less than a high school diploma or a high school diploma.

Table 2 displays a univariate descriptive statistic of parents answering whether their children were clinically diagnosed with ADHD, Depression, Anxiety or Behavioral problems. In this case, 15,475 answered whether or not their children were diagnosed with ADHD. Data showed that 12,332 (79%) maintained that their children did not have ADHD, while 3,243 (21%) agreed that their children had ADHD. For Depression, 15,523 parents answered whether or not their children were diagnosed, and 13,663 (88%) stated that their children did not have Depression, while 1,860 (11%) answered that their children had or were experiencing Depression. For Anxiety, 15,514 parents addressed whether or not they felt their child was diagnosed with Anxiety. Of that number, 12,061 (77%) answered that their children did not have Anxiety, while 3,453 (22%) responded that their children did suffer from Anxiety. Finally, 13,233 parents answered whether their children had been diagnosed with having a Behavioral problem. Eighty-two percent, or 10,898 answered that their children had no Behavioral problems, while 2,335 (17%) answered that their children had a Behavioral problem.

Table 2: Univariate Descriptive Statistics

Conditions	N	%
ADHD	15,475	100
Yes	3,143	20.31
No	12,332	79.68
Depression	15,523	100
Yes	1,860	11.98
No	13,663	88.01
Anxiety	15,514	
Yes	3,453	22.25
No	12,061	77.74
Behavioral Problems	13,233	100
Yes	2,335	17.64
No	10,898	82.35

Table 3 displays the univariate Shared Decision Making (SDM) table. The following three questions were given to parents: (1) How often do physicians discuss SDM and treatment options regarding their children’s mental health conditions? (2) How often do physicians make the SDM process comfortable, so that parents are willing to ask important questions and to firmly disagree with treatment recommendations? (3) How often do physicians and parents collaborate to decide the best treatment options for their children’s mental health conditions?

Parents answering the questions were given a choice of saying, (1) always, (2) usually, (3) sometimes, and (4) never. The following questions were asked only if the children had an

appointment with the physician within the past 12 months, and whether or not decisions about treatment options were required.

Table 3: Shared Decision-Making (SDM)

Shared Decision Making (SDM)	Answer	%
Discuss SDM for their child’s health care or treatment	(1) Always	73.18
	(2) Usually	19.21
	(3) Sometimes	6.02
	(4) Never	1.59
Make it easy to raise concerns or disagree with recommendations for child’s health	(1) Always	72.13
	(2) Usually	19.85
	(3) Sometimes	6.18
	(4) Never	1.83
Work together to decide health care and treatment choices would be best for child	(1) Always	74.29
	(2) Usually	19.11
	(3) Sometimes	5.21
	(4) Never	1.39

The researcher created a table with the following three questions, in order to understand the parents’ opinions while engaging in SDM with their physicians. Question One was SDM for their children’s health care or treatment. Approximately 73% of the parents answered “always,” follow by 19% answering “usually,” 6% answering “sometimes,” and 1% answering “never.”

The second question asked parents if SDM made it easy to raise concern or disagree with recommendations made for their children’s treatment? Approximately 72% of the parents

answered “always,” follow by 19% answering “usually,” 6% answering “sometimes” and 1% answering “never.”

Lastly, parents were asked a third question on whether working together with physicians to decide health care and treatment choices would be best for their children? Again, approximately 74% of the parents answered “always,” follow by 19% answering “usually,” 5% answering “sometimes” and 1% answering “never.”

Shared Decision Making (SDM) Score

The researcher decided to run a reliability test (Cronbach Alpha) to examine if the questions used to create the SDM scale were consistent in measuring parents’ attitudes towards SDM.

Table 4: Shared Decision Making (SDM) Score

Item	Obs	Sign	correlation	Correlation	Covariance	Alpha
SDM 1	15658		0.8979	0.7694	.3495112	0.8857
SDM 2	15654		0.9134	0.7968	.3256618	0.8634
SDM3	15696		0.9308	0.8448	.3200936	.08234
Test Scale				.331767	0.9003	

Table 4 displays the results of the Cronbach Alpha test. The Cronbach alpha value is a measure of internal consistency on how closely related a set items are as a group, noting that a reliability coefficient of .80 or higher is considered acceptable in the field of social science. The researcher’s overall Cronbach value was .90, indicating that the individual questions are sufficiently related.

The individual Cronbach Alpha value for each question indicates the reliability of the scale if that question were removed. While the Cronbach Alpha value would still be at least .80 if any one question were removed, the overall Cronbach alpha value would still be less than if all the questions were retained. Therefore, the scale reliability would not be improved by removing any of the three questions.

Table 5: Shared Decision Making (SDM) scale differences by race

All Races	Mean	N
Caucasians	10.96	15,553
African American	10.78	
Hawaiian plus Asian	10.78	
Some/other races	10.68	

*F 9.45 *P<.01

Table 5 displays the result of a one-way ANOVA analysis comparing mean SDM scale average between racial groups (Whites, African-Americans, Asian/Pacific Islander and Other racial groups). The researcher was curious about knowing whether SDM scale averages differed across racial groups, or are differences just due to normal sampling variation? The ANOVA is an inferential test used to determine if there is a significant difference between the means of three groups.

Prior to conducting the ANOVA analysis, we established the null and alternative hypotheses: White families' mean SDM score was 10.96, compared to a mean SDM score of 10.78 for African-Americans families. For Asian/Pacific Islander, the mean SDM score was 10.68, and for other races mean SDM score of 10.78. Ho: Mean one does equal to mean two: The

mean SDM score does not differ significantly for Whites, African-American, Asians/Pacific Islanders and parents of other racial groups.

Ha: Mean one does not equal to mean two: The mean Shared Decision-Making score does differ among Whites, African Americans, Asians/Pacific Islanders and parents of other racial groups.

The results of the one-way ANOVA indicate one SDM score significantly differs across racial groups ($P < .01$); therefore, we can reject the null hypothesis which tells us that Whites have higher means scores of SDM than African-Americans, Hawaiians, Asians, and other races. In order to determine which racial group's means differed, the researcher conducted an additional Tukey test. A Tukey test is a post hoc single-step multiple comparison procedural and statistical test. This can be used to find means that are significantly different from each other.

Table 6: Tukey Test: Comparing racial disparities

Comparison	Mean diff.	T
African Americans vs Caucasians	-.178	-.269*
Some Other Vs Caucasians	-.174	-.363**
Hawaiian plus Asian Vs Caucasians	-.275	-.340**
Some Other Vs African American	.004	0.05
Hawaiian plus Asian Vs African Americans	-.096	-.095
Hawaiian plus Asian Vs Some Other	-.100	.091

*P<.05; **P<.01

According to the results of the Tukey Test, there were statistically significant differences between SDM mean scores of African Americans, compared to Whites (P<.05) and other races (P<.01), and for Whites versus Asians/Pacific Islanders (P<.01).

Table 7: Shared Decision Making (SDM) scale by Hispanics and Non-Hispanics

Ethnicity	Mean	T	N
Hispanics	10.69	-5.04*	15,553
Non-Hispanics	10.94		

*P<.01

Tables 7 displays the results of the T-test comparing mean scores towards Shared Decision-Making scale averages between Hispanics and non-Hispanics. The researcher was curious to know whether SDM scale averages differed between non-Hispanic and Hispanic families, or whether the differences were just due to normal sampling variation. The T-test is an inferential test used to determine if there is a significant difference between the means of two groups.

Prior to conducting the T-test, the researcher established the null and alternative hypotheses: Ho: The mean Shared Decision Making (SDM) score for Hispanic families (10.69) was the same as the mean Shared Decision Making (SDM) score for Non-Hispanic families (10.94). Ha: Mean one does not equal to mean two: The mean Shared Decision Making (SDM) score for Hispanics families (10.69) was not the same as the mean Shared Decision Making (SDM) score for Non-Hispanics families (10.94).

The T-test indicated a mean difference in the Shared Decision Making (SDM) score for Hispanics versus Non-Hispanics (P<.01). Thus, the researcher could reject the null hypothesis indicating that Non-Hispanic families had higher mean scores of SDM than Hispanic families.

Table 8: Shared Decision Making (SDM) scale by Children's mental health

ADHD	Mean	T	N
<i>Yes</i>	10.74	6.52*	15,475
<i>No</i>	10.97		
Depression			
<i>Yes</i>	10.50	10.6*	15,523
<i>No</i>	10.98		
Anxiety			
<i>Yes</i>	10.64	10.5*	15,514
<i>No</i>	11.00		
Behavioral Problem			
<i>Yes</i>	10.43	13.9*	13,233
<i>No</i>	11.01		

*P-value <.01

Table 8 displayed the results of T-tests comparing mean scores towards Shared Decision-Making scale scores among (1) parents of children with ADHD versus without ADHD, (2) parents of children with Depression versus without Depression, (3) parents of children with Anxiety versus without Anxiety and, (4) parents of children with Behavioral problems versus without Behavioral problems. The researcher was curious to know whether Shared Decision Making (SDM) scale scores differed between each group (with ADHD versus without, and so forth), or whether the differences were just due to normal sampling variation. Prior to conducting the T-test, the researcher established the null and alternative hypotheses: Parents of children with ADHD had a mean SDM score of 10.74, compared to parents of children without ADHD with a mean of 10.97. The difference is not statistically significant, however.

Shared Decision Making (SDM) scale by ADHD

Ho: Mean one does equal to mean two: The mean SDM score for parents of children with ADHD did not differ from the mean SDM score for parents of children without ADHD. Ha: The mean SDM score for parents of children with ADHD differed from the mean SDM score for parents of children without ADHD. The results of the T-test indicated that there is a significant difference in the mean SDM score for parents of children with ADHD versus those without ($P < .01$).

Shared Decision Making (SDM) scale by Depression

Parents of children with Depression had a mean SDM score of 10.50, compared to parents of children without Depression with a mean of 10.98. Prior to conducting the T-test, the researcher established the null and alternative hypotheses: Ho: Mean one does equal to mean two: The means SDM score for parents of children with Depression did not differ from the mean SDM score for parents of children without Depression. Ha: The means SDM score for parents of children with Depression differed from the mean SDM score for parents of children without Depression.

The results of the T-test indicated that there was a significant difference in the mean SDM score for parents of children with Depression versus those without Depression ($P < .01$).

Shared Decision Making (SDM) scale by Anxiety

Parents of children with Anxiety had a mean SDM score of 10.64, compared to parents of children without Anxiety whose mean score was 11.00. Prior to conducting the T-test, the researcher established the null and alternative hypotheses: Ho: Mean one does equal to mean

two: The mean SDM score for parents of children with Anxiety did not differ from the mean SDM score for parents of children without Anxiety. Ha: The mean SDM score for parents of children with Anxiety differed from the mean SDM score for parents of children without Anxiety.

The results of the T-test indicated that there was a significant difference in the mean SDM score for parents of children with Anxiety versus those without Anxiety ($P < .01$).

Shared Decision Making (SDM) by Behavioral Problem

Parents of children with Behavioral problems had a mean SDM score of 10.43, compared to parents of children without Behavioral problem who had a mean score of 11.01. Prior to conducting the T-test, the researcher established the null and alternative hypotheses: Ho: Mean one does equal to mean two: The mean SDM score for parents of children with Behavioral problem did not differ from the mean SDM score for parents of children without Behavioral problems.

Ha: The mean SDM score for parents of children with Behavioral problem differed from the mean SDM score for parents of children without Behavioral problems. The results of the T-test indicated that there was a significant difference in the mean SDM score for parents of children with Behavioral problem versus those without Behavioral problems ($P < .01$).

Table 9: Shared Decision Making (SDM) scale by Parent's educational status

Educational Attainment	Mean	T	N
Less or high school	10.69	-5.38*	15,383
Some or high school	10.95		

*P<.01

Tables 9 displayed the results of the T-test comparing mean scores towards the Shared Decision-Making scale average between parents with a high school diploma or less, and parents with at least some level college education or a college degree. The researcher was curious to know whether Shared Decision Making (SDM) scale averages differed between parents with high school or less education and parents with some level of college education or a college degree.

The T-test is an inferential test used to determine if there is a significant difference between the means of two groups. Prior to conducting the T-test, the researcher established the null and alternative hypotheses: Parents with a high school diploma or less had a mean average score of 10.69, compared to parents with at least some level of college, and a mean score of 10.95. Ho: Mean one does equal to mean two: The mean SDM score for parents with a high school diploma or less did not differ from the mean SDM score for parents with a least some level of college education.

Ha: Mean one does not equal to mean two: The mean SDM score for parents with a high school diploma or less differed from the mean SDM score for parents with a least some level of college education. The results of the T-test indicated that there was a significant difference in the

mean SDM score for parents with a high school diploma or less, compared to parents with at least some level of college education or a college degree.

CHAPTER SIX: DISCUSSION

This study used a quantitative method to explore how parents engaged in the SDM process with their physicians about their health concerns, and about their children's mental health issues. Parents engaging in SDM with physicians regarding their children's mental health conditions were the researcher's primary concerns. Additionally, it was important to also discuss parents' perceptions of their physicians' credibility in recommending treatment options, particularly when the parents were African American.

Literature and previous quantitative studies have explained that parent's perceptions of physicians, especially when physicians were White and patients were persons of color. Also, because young children's diagnoses of mental disorders have increased more for children of color than for White children, their parents often viewed physician's treatment recommendations as negative when they were seeking special services for their children (Pescosolido, 2007; Snowden, 2007; Chavira, 2017).

Limitations of This Study

Since the researcher performed tests and drew conclusions based upon an existing, comprehensive national study, results are limited to the findings from the researcher's additional tests performed on those data. Another researcher might want to use these data as baseline information from which to conduct surveys of parents engaging in SDM with their physicians today. They would not necessarily need a sample size as big as the one in the national study the researcher used, but they would need to ensure that the survey sample

represented a cross-section of parents from different age, racial/ethnic and socioeconomic groups of individuals.

Also, the researcher did not seek information relative to the parents' social factors, levels of income, accessibility to health insurance, or accessibility to physicians within a reasonable distance from where the parents lived. The researcher did mention that many African-American parents were willing to travel farther distances to bring themselves and their children to physicians of color.

Another researcher might want to conduct seminars or disseminate literature on the benefits of SDM between patients and physicians before engaging in a research project like this one. Would a better informed population be more inclined to positively engage in SDM, or would additional information have no effect on the perceptions of parents towards their physicians?

At the same time, another researcher might communicate with physicians in hopes of having them make conscious efforts to educate parents on the benefits of SDM before they make diagnoses and recommend treatment options. While difficult to measure quantifiably, the idea of building trust in relationships between patients and physicians is most important. White physicians may need to have consultation meetings with potential patients of color, acknowledging the inherent distrust that came from systemic racism. After that, these physicians may achieve better results when engaging in the SDM process with patients of color.

Conclusions

The researcher's data supports the current literature that deepens our understanding of parents' SDM engagement with their physicians, but adds the dimension of systemic racism affecting the perceptions of patients of color, with African-Americans being the most strongly impacted. Additionally, the researcher valued parents' views on mental health disorders when they did or did not use the SDM process to discuss treatment options for their children with physicians. Again, it was important to note the differences in perceptions among racial groups of color, versus those of Whites. Finally, regardless of race, there were data to support the fact that the highest educational attainment of the parents impacted their receptiveness to physicians' diagnoses and recommended treatment options.

Indeed, our data reminds us that parents engaging in SDM are less likely to report their children not being diagnosed with mental health disorders. The interest in our finding indicates that White families (Non-Hispanics) are more likely to engage in SDM with their physicians, compared to African-Americans, Hawaiians, Asians, and other races. Research supports the view that racism, historical medical mistrust, stigma and discrimination are key factors in African-Americans and other persons of color having less engagement in SDM with physicians than Whites (Armstrong, 2007; Williams, 2013, 2019).

**APPENDIX:
IRB APPROVAL**



UNIVERSITY OF CENTRAL FLORIDA

Institutional Review Board

FWA00000351
IRB00001138, IRB00012110
Office of Research
12201 Research Parkway
Orlando, FL 32826-3246

NOT HUMAN RESEARCH DETERMINATION

May 15, 2020

Dear [Vernon Headley](#):

On 5/15/2020, the IRB reviewed the following protocol:

Type of Review:	Initial Study
Title of Study:	The power of color:How does shared decision making between physicians and patients differ by race
Investigator:	Vernon Headley
IRB ID:	STUDY00001827
Funding:	None
Grant ID:	None
Documents Reviewed:	<ul style="list-style-type: none"> • Vernon Headley, Category: Faculty Research Approval; • Vernon Headley, Category: IRB Protocol; • Vernon Headley, Category: Test Instruments;

The IRB determined that the proposed activity is not research involving human subjects as defined by DHHS and FDA regulations.

IRB review and approval by this organization is not required. This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these activities are research involving human in which the organization is engaged, please submit a new request to the IRB for a determination. You can create a modification by clicking **Create Modification / CR** within the study.

If you have any questions, please contact the UCF IRB at 407-823-2901 or irb@ucf.edu. Please include your project title and IRB number in all correspondence with this office.

Sincerely,

Kamille Birkbeck
Designated Reviewer

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