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SHARED DECISION MAKING IN ADOLESCENCE: THE ROLE OF RACE AND HEALTH STATUS

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Abstract

Youth participation in Shared Decision Making (SDM) is still a novel clinical practice with unique considerations. Moreover, though SDM has been touted as an effective model for patient-centered care it has largely been underutilized and under-researched in Black and Latinx adolescent populations. The current study examined the association of health factors that may relate to Black and Latinx adolescents, their families, and HCPs engaging in SDM. Specifically, I examined within-group racial differences in relation to health conditions (i.e., pain, obesity, mental health status) and SDM during adolescence. Measures of adolescent chronic pain, BMI status (overweight/obese), mental health symptoms (depression/anxiety), SDM (caregiver-HCP SDM and inclusive SDM) were completed by caregivers. There were a total of 3,856 caregivers who completed the survey including 1,465 caregivers of Black adolescents and 2,391 caregivers of Latinx adolescents. Independent samples t-tests indicated Black youth who experienced chronic pain and/or mental health symptoms had lower scores of SDM. In addition, Latinx youth who experienced chronic pain, who were overweight/obese, or had mental health symptoms experienced lower scores of SDM than their peers. Results highlight a need for future research to focus on risk factors that negatively impact the inclusion of Black and Latinx youth in SDM.

Chapter 1. Introduction

Adolescence is a critical developmental period marked by rapid physical and psychological changes (Steinberg & Morris, 2001). These changes can occur simultaneously with the development of physical and mental health issues. Research has shown that many chronic health conditions in adulthood have their onset in adolescence—with three-fourths of mental health disorders having their first onset before the age of 24 (Kessler et. al 2007, NIMH, APA). The National Institute of Mental Health found that over the course of adolescence nearly half of adolescents in the United States are living with a mental health disorder—with only 20-50% of that population utilizing mental health care services. A national longitudinal survey found adolescent chronic and reoccurring pain prevalence rates for headaches, stomachaches, and backaches ranging from 13.5% to 31.88% (Stanford et al., 2008). The CDC reported that 21.2% of adolescents aged 12-19 are obese—with obesity rates being higher among certain ethnic minority populations. The prevalence of physical and mental health conditions among adolescents has steadily grown for the past three decades – much faster than the rates of healthcare utilization in this population.

The transition to adolescence is also marked by transitions in medical care. As teens gain more autonomy, they can communicate health concerns and advocate for medical interventions to their families and health care providers (HCPs). The American Academy of Pediatrics (AAP) encourages HCPs to include youth in the health care decision-making process (Adams & Levy, 2017). Shared decision-making (SDM) has been touted to improve communication during patient-provider interactions. A systematic review found that interventions to encourage SDM in pediatric settings significantly improve patient knowledge and reduce decisional conflict (Wyatt et al., 2015). However, SDM studies have largely focused on complex, debilitating pediatric conditions (e.g., cancer, JIA) and end-of-life treatment. There is a dearth of research on using SDM with youth who experience common mental health (i.e., depression or anxiety) and physical health (i.e., pain, overweight) symptoms. Furthermore, the research on SDM has largely focused on white inpatients with minimal data on Black and Latinx individuals.

Current research on adolescent health and SDM has also largely focused on applications of SDM. However, there is limited research on what factors are related to SDM in adolescent patients, specifically what factors can serve as facilitators or barriers to SDM engagement and/or access. The current study seeks to address gaps in understanding what factors are associated with SDM during adolescence with a focus on the presence of mental and physical conditions as well as race. The following sections will define SDM and discuss the unique components and challenges of SDM for adolescent populations. This is followed by a critical review of the literature on the relationships between SDM and health conditions, and SDM and race in adolescent populations. Then, I will review how health conditions and race may interact to influence SDM in adolescent populations and introduce the current study.

Chapter 2. Shared Decision Making

SDM is a patient-centered care model that engages patients and HCPs to partner to make medical decisions. In this model, patients, families, and HCPs collaboratively engage in all aspects of decision making and/or the creation of a treatment plan. The key features of SDM are that: (1) information flows in a bidirectional manner between patients and HCPs and any other stakeholders involved in the patient’s care, (2) HCPs and patients are educated on all available healthcare and treatment options, and (3) all parties share their values, preferences, and knowledge equally in the decision-making process (Elwyn et al., 2012; Kuo et al., 2012; Fiks & Noonan, 2013). Patients and HCPs share the process of decision-making to ensure patient preferences are properly respected, honored, and acknowledged; HCPs' expertise is communicated; risks, benefits, and probable outcomes are discussed; and patient advocacy is centered. Elwyn et al. (2012) suggest a 3-step process where deliberation is the largest component of SDM. Within deliberation, patients engage in choice talk, option talk, and decision talk, where patients communicate their initial preferences, receive decision support, and then make informed preferences. Findings from a systematic review suggest that SDM is associated with positive health behaviors; improved health-related quality of life and health status; and increased patient satisfaction, healthcare provider satisfaction, healthcare utilization, and healthcare engagement (Fiks, 2012; Hughes et al, 2018; Houtrow, 2019). These findings suggest that patient involvement in their health care decisions may have immediate and long-term effects on their overall health and wellness. The next section will explore the research on SDM in adolescence. Most SDM research focuses on adult populations and the next section will explore how SDM may operate with provider-patient interactions between HCPs, adolescents, and their caregivers.

Chapter 3. Shared Decision Making in Adolescence

Youth participation in SDM is still a novel clinical practice with unique considerations. Three contextual factors that make SDM in adolescence unique are (1) the inclusion of caregivers, (2) the need to prepare for the transition from pediatric to adult healthcare, and (3) developmental changes in adolescents' cognitive abilities to make informed decisions on treatment options and communicate their preferences. Understanding SDM in adolescent populations requires a clear understanding of the relationships and sets of interactions involved, which will be discussed below.

The literature on SDM in adolescents tends to focus on caregivers and HCPs relationships as a dyadic relationship in which HCPs still heavily guide all medical decision-making. Opel's (2018) 4-step framework for SDM in pediatrics suggests there are two kinds of SDM—parent-guided and physician-guided. It posits that SDM can only take place if the HCP determines there is more than one medical treatment option available and if medical benefits outweigh patient burdens. HCPs retain the majority of control when choosing treatment regimens and medications, while caregivers tend to be included later in the decision-making process for more minor decisions. Langer and Jensen Doss (2018) suggests six steps for SDM in youth:

(1) Discuss preferred roles in treatment planning
(2) Specify decisions to be made
(3) Present the available options for each decision
(4) Determine the pros and cons of each option
(5) Design a preliminary treatment plan.
(6) Implement progress monitoring.

However, this model still heavily relies on HCPs initiating SDM only if they deem more than one option is possible, rather than having SDM as a part of routine health care. With respect to adolescents, their caregivers' participation in SDM largely depends on what decisions the medical staff trusts them to make and have included in the provided decision aids. However, due to varying levels of trust and types of therapeutic relationships, the incorporation of decision aids varies based on HCP preference and clinical practice (O'Connor, Thomas & Flood, 2004). This occurrence highlights an unequal balance of power and input that may be prevalent in many caregiver-HCP SDM relationships.

Present SDM models also fail to incorporate youth into the SDM making process. Parent perspective has largely been used as the proxy to gauge the experience and preferences of teenagers. Less research has explicitly included adolescent preferences despite studies showing increased discordance between youth and their caregivers regarding treatment goals and presenting problems as youth mature from children into teenagers (Hawley, & Weisz, 2003; Makol et al., 2020). Specifically, adolescents report poorer emotional, social, and physical health than their caregivers' proxy reports indicate (Waters, Stewart-Brown & Fitzpatrick, 2003). This can be particularly problematic for children with a chronic illness and acute symptoms. Adolescents with and without special health needs should be empowered to be partners in their medical decision-making process. The interactions they have with HCPs during their teenage years are the foundation on which their health behaviors and future interactions with HCPs are built.

The National Institute of Minority Health and Health Disparities (NIMHD) has created a research framework to conceptualize the factors that impact health disparities experienced by minority populations. The research framework explicitly names caregiver-child interaction, family, patient-clinician relationship, and medical decision-making as key domains of influence that impact the health outcomes of individuals and the community. These factors align with the importance of the triadic (inclusive) and dyadic (caregiver-HCP) SDM relationships examined in this study and the recommendations for SDM implementation by the American Academy of Pediatrics.

Given the unique aforementioned factors, there is a need to implement an inclusive SDM model that explicitly includes adolescents as part of the decision-making process. Inclusive SDM is defined as a model that includes all individuals involved in a patient's medical decision-making process. Regardless of age or education all partners in a patient's medical care will be included in SDM as they will experience the benefits and consequences of the process. With regards to adolescence, an inclusive SDM model should include adolescents, caregivers, and HCPs. This has not previously been conceptualized in the literature. I am proposing a model (See Figure 1) to guide the discussion of communication patterns and contributor interactions to promote inclusive SDM for adolescent patients. The proposed model expands on previous dyadic models of SDM to indicate that the adolescent should be a primary partner in their healthcare decision-making process by listing the various relationships and interactions needed for an inclusive SDM model. I propose that SDM for adolescents encompasses four relationships/sets of interactions: adolescent and caregiver interactions, caregiver and HCP interactions, HCP and adolescent interactions, and the joint interactions of all three contributors. There are bi-directional communications between all three parties, and the interactions encompass communications focused on treatment options and clinical decision-making that honors and includes the values and preferences of each party.

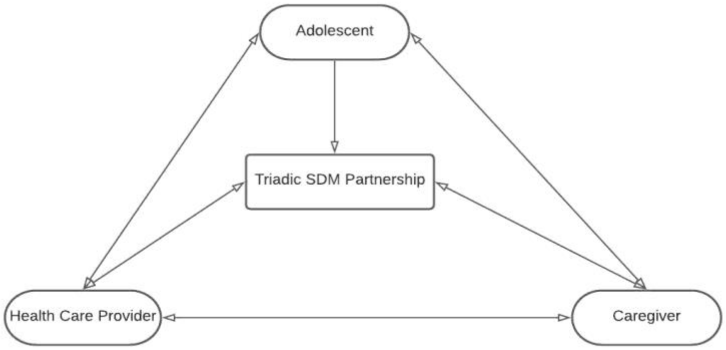

Figure 1. An Inclusive Triadic Model of Shared Decision Making in Adolescence

To date, there have not been any studies explicitly examining the triadic relationship between adolescents, caregivers, and HCPs in SDM and the involvement of adolescents in the healthcare settings. Studies have looked at the dyadic caregiver-HCP relationship and the caregiver-adolescent relationship. Triadic interactions should be examined to provide a clear picture of SDM for adolescent populations.

In conclusion, SDM is an important clinical model for promoting patient and caregiver inclusion, education, and preference. Previous research has failed to fully incorporate both caregivers and adolescents into the SDM process. We propose that to do so researchers and clinicians should work together to implement an inclusive SDM model that includes interactions between adolescents, caregivers, and HCPs. The next section provides a critical review of the literature on SDM within the context of managing physical health (pain and overweight) and mental health (depression and anxiety) conditions.

Chapter 4. Shared Decision Making and Health Conditions

In this chapter, I will discuss how health symptoms can potentially impact SDM for adolescent populations. The triadic model posits that each participant must equally participate in all aspects of decision-making for an inclusive SDM model of care to be implemented. However, chronic and debilitating conditions can affect how youth, their caregivers, and HCPs interact. For example, an adolescent's health condition may directly limit their decision-making capacity or lead to assumptions by their HCP or caregiver about the adolescent's decision-making capacity. Pain, being overweight/obese, and mental health conditions are three of the most common chronic health conditions affecting youth, but little is known about the degree to which these conditions relate to the SDM experiences of adolescents. Below is a critical review of the literature on these health conditions and their relationship to SDM with a focus on SDM during adolescence.

Pain. A review of chronic pain in adolescence reported chronic and reoccurring pain prevalence rates ranging from 26.2% to 31.8% for headaches, 13.5% to 22.2% for stomachaches, and 17.6% to 25.8% for backaches range from and respectively (Stanford et al., 2008). There is also a subgroup of adolescents who suffer more than one type of pain (i.e. headaches and stomachaches; Stanford et al., 2008). An international review of chronic pain referral patterns showed that U.S. youth experience longer pain durations (18 - 24 months) and delayed treatment initiation compared to their age-matched European counterparts (Cucchiaro et al, 2017). Reoccurring pain during adolescence can result in withdrawal from social activities, poor socio-emotional skills, smaller friend groups, peer victimization, isolation, and internalizing symptoms (King et al., 2011; Forgeron, Finley & Arnaout, 2006; Friedrichsdorf et al., 2016). The impact of chronic pain in the lives of adolescents is pervasive and interrupts the healthy development of later life outcomes. In addition, adolescents with reoccurring or chronic pain are more at risk to become adults who suffer from chronic pain (Murray et al., 2020, D. Brown et al., 2021). These negative consequences highlight the importance of developing effective strategies for working with youth and their families to ameliorate pain-related discomfort and develop life-long proper pain management strategies. Active communication between caregivers, children, and HCPs is paramount to optimizing pain management given that pain management can include medications, therapies, and/or behavioral modifications.

Recurrent pain may impact adolescent participation in SDM, as debilitating pain may weaken the adolescent-HCP relationship due to a desire to feel relief. When pain is debilitating, it can affect an individual's ability to think clearly and communicate; teenagers in pain may be less inclined to discuss best care options with their HCP due to their developmental stage and their desire to have their HCP make a unilateral decision that provides the quickest pain relief.

Research on SDM and pain management in adolescents is scarce so HCPs may not be equipped to properly treat youth with various treatment options or honor preferences. If youth are in pain, the HCP–caregiver relationship may strengthen as both parties may take the lead on pain relief options. Conversely, it is also possible that the HCP-caregiver relationship may worsen if a caregiver feels not enough is being done to alleviate their child's pain. A caregiver can lose faith in an HCP’s capability and may desire to independently do all they can to help their child without the input of an HCP. The adolescent-caregiver relationship may strengthen as parents may be teenagers' primary point of contact to communicate discomfort, and youth rely on parents to initiate health care. However, the adolescent-caregiver relationship may also worsen if an adolescent feels they are not being heard and/or the caregiver and the teenager's treatment goals differ. Managing adolescent pain requires HCPs to screen for adolescent pain and partner with caregivers and teenagers to identify and treat symptoms.

Published studies on SDM in youth pain populations are limited in the resources available to guide adolescents, parents, and caregivers on best practices. The literature on SDM in youth pain populations has largely focused on decision aid usage initiated by HCPs rather than a shared process between youth, parents, and HCPs (Crosby et al., 2015, Fiks et al., 2015, Brinkman et al., 2017, Sullivan et al., 2018). The issue of pain as a primary symptom is still largely missing and only referred to tangentially in qualitative data (Lipstein et al., 2013, Lipstein et al., 2014). To date, there is a dearth of research explicitly focused on SDM and pain management. Furthermore, there is no published research on SDM and pain management in the adolescent population; thus, additional research is needed.

Overweight, Obesity, and SDM. Overweight, a condition where an individual has a BMI of 25 to <30, and obesity, a condition where an individual has a body mass index (BMI) of

30 or greater, are the most common chronic health conditions in the United States. One in three children aged 2-19 years are overweight or obese (Skinner, Perrin & Skelton, 2016; Sahoo et al., 2015; CDC, 2021). Secondary risk factors associated with obesity include type 2 diabetes, high blood pressure, heart disease, and breathing problems. Thus, it is imperative that HCPs work with families to help children obtain and maintain a healthy weight. One factor associated with an adolescent being overweight that may impact the patient-provider relationship is weight stigmatization.

Weight stigmatization is defined as the social devaluation of an individual based on their physical appearance of being overweight or obese and appears to be a pervasive problem in healthcare (Sabin, Marini & Nosek, 2012). One study of 2,000 medical doctors found that the majority of doctors evidenced strong weight-based implicit bias and a preference for thin people (Pont et al., 2017; Sabin, Marini & Nosek, 2012). Findings from qualitative studies of HCPs indicate that many of them feel incompetent in dealing with obese youth, and report it is socially acceptable to use shame to motivate people to lose weight (Puhl & Brownell, 2001; Puhl & Heuer, 2009; Hatzenbuehler, Phelan & Link, 2013). In addition, findings also indicated HCPs tend to describe individuals who were obese as lazy, lacking self-control and being less intelligent (Pont et al., 2017, Sabin, Marini & Nosek, 2012; Puhl & King 2013; Huizinga et al., 2009; Hebl & Xu, 2001). Self-report surveys from HCPs found that they associated obesity with noncompliance, decreased medical adherence, hostility, dishonesty, and poor hygiene (Puhl & Brownell, 2006; Puhl, 2013; Pont et al. 2017, Huizinga et al, 2020; Puhl & King 2013; Huizinga et al., 2009; Hebl & Xu, 2001). The prejudice experienced in a clinical setting can simultaneously create barriers to health care utilization and erode the rapport between a patient and physician. National surveys have found that obese patients are less likely to utilize preventative health care, show up to follow-up appointments, and are at an increased likelihood of canceling appointments. One survey of caregivers with obese children reported that 34% of caregivers stated they would switch doctors if a physician referred to their child in a stigmatizing way, while one in four stated they would avoid future medical appointments for their child (Pont et al., 2017).

There is a dearth of research on the relationship between overweight status and SDM during adolescence. However, if an adolescent is overweight, it may lead to poorer interactions between the adolescent and their HCP as well as the adolescent's caregiver and the HCP due to weight stigmatization. The adolescent-caregiver relationship may also be impacted by a parent seeing their teens' overweight status as a direct result of their parenting. A parent may be defensive or feel guilty about their child's physical health status. Their subsequent behavior could be to shield their child from negative feedback, or conversely, be an advocate for their teenager. If an HCP exhibits weight stigmatizing behaviors, this can lead to changes in the caregiver-HCP relationship and negatively impact the way the HCP, caregiver, and adolescent interact. This would subsequently reduce the opportunity for adolescents to engage in SDM. Overall, research is needed to examine the possible association between the weight status of an adolescent and the SDM relationships.

Depression and Anxiety. Depression and anxiety are the most common mental health disorders among adolescents worldwide. Over the last decade, the number of youth diagnosed with depression and/or anxiety has increased from 5.4% to 10.1% in the United States (CDC, 2019; NSDUH, 2017; SAMSHA, 2017; DHHS, 2017). The number of American teenagers who have self-reported experiencing depression increased by 59% since 2007—with girls being three times more likely than boys to experience depression (NSDUH, 2017). The mental health of an adolescent may impact their decision-making capacity. Youth who suffer from depression and anxiety often exhibit changes in their mood and temperament (Garber & Weersing, 2010; Bradley, 2001). For youth who experience mental health symptoms, parents and HCPs may be more likely to limit youth input in decision-making if they believe their psychological capacity is compromised. Depression and anxiety can impact mood and emotion, which may impact a youth's ability to make clearly thought-out decisions Steinberg and Cauffman, 1996; Leykin, Roberts & Derubeis, 2011; Leahy, 2002). Youth experiencing depression or anxiety may also be struggling interpersonally, making it difficult to verbally articulate what and how they are feeling (Rudolph, 2009; Hammen, 2009). This symptomology would weaken both the adolescent-caregiver relationship and the HCP-adolescent relationship. There is a dearth of research on the relationship between mental health and SDM during adolescence.

In conclusion, pain, weight status, and mental health conditions may impact SDM in adolescence by reducing the likelihood of inclusive SDM taking place, worsening patient-HCP communication, and weakening the overall inclusive SDM model. There is limited information on how the health status of adolescents and other factors (e.g., race or ethnicity) impact their experiences of SDM in clinical settings. In the next chapter, I will discuss the present literature on how race relates to SDM.

Chapter 5. Race and SDM

A systematic review found that Black and Latinx patients are still largely underrepresented in SDM research (Jolles, Richmond, & Thomas, 2019). A national cross-sectional study on SDM, race, hyperlipidemia and hypertension in adults aged 40 and older (N= 1483) found that Black and Latinx patients had lower knowledge of their medication and their medical options and were more likely to report their physicians made the final decision for treatment (Ratanawongsa et al., 2010). A qualitative study of SDM in Black American adults with diabetes reported physician bias and/or cultural discordance as one of the main issues influencing negative patient-physician interactions (Peek et al., 2010). Black patients reported their HCPs were less likely to share relevant health information (e.g. test results) and were more likely to be paternalistic (i.e. domineering) during health care visits. Study participants also identified mistrust of white HCPs, negative HCPs attitudes, and internalized racism as factors that may influence access to SDM (Peek et al., 2010).

These findings are consistent with the large volume of research indicating Black and Latinx patients are more likely to experience barriers in patient-provider communication compared to their White counterparts (Borrell et al., 2006; Breland, 1998; Burgess et al, 2008; Benkert et al., 2006; Chen et al., 2005; LaVeist & Carroll, 2002; Townes, Chavez-Korell, & Cunningham, 2009). Black Americans are more likely to report physicians are less participatory and are more paternalistic during healthcare interactions compared to white counterparts when controlling for age, gender, and education (Cooper-Patrick et al., 1999). Quantitative and qualitative data have shown that Black and Latinx patients experience shorter clinic visits, less positive clinical encounters, and have reported less rapport with white physicians (Levinson, et al., 2008; Oliver et al., 2001). The racial differences in rapport with HCPs are partially due to structural racism within health care systems and medical prejudice and discrimination from HCPs. Research has shown that HCPs routinely underestimate the intelligence of Black and Latinx patients compared to White patients (Van Ryn, & Burke, 2000; Johnson, 2004). Assumptions about intelligence, likelihood to cooperate with medical adherence, ability to understand the components of a treatment regiment, and the ability to make complex medical decisions have negatively affected the health and wellness of Black and Latinx patients.

Structural and medical racism negatively impacts the quality of health care options available to patients. When HCPs are prejudice and/or discriminate against their patients based on the color of their skin, Black and Latinx patients inherently receive different medical treatment options and medical care (Blair et al., 2013; Fiscella et al., 2002). Of importance, previous research on Black adults and Black adolescents found that HCPs often do not screen Black patients for pain and are less likely to prescribe black patients narcotic medications to treat pain following surgery (Sabin & Greenwald, 2012; Hoffman et al., 2016). SDM requires that both parties' ideas, expertise, opinions, and experience are valued. If HCPs are less likely to value the ideas and/or offer comparable treatment to Black and Latinx patients—that their White peers are receiving, then Black and Latinx adolescents are inherently less likely to engage in inclusive SDM during routine medical visits.

Poor patient-provider communication is not a sudden phenomenon that starts in adulthood but is a continuation of previous healthcare interactions. A systematic review of adolescents and emerging adults with diabetes found Black and Latinx adolescents experience poorer patient-provider communication than their white peers (Monaghan, Hilliard, Sweenie & Riekert, 2013). Poor quality health communication may lead to poorer medical rapport, poorer healthcare quality, and less inclusive SDM for adolescence. Yet, there is a critical gap in the literature on patient-centered care in adolescence, and more specifically, SDM in adolescence. If preliminary research in adults suggests differences in Black and Latinx patients' healthcare experiences, it is paramount that we study race as an important factor influencing SDM for adolescents. This will allow us to intervene earlier and mitigate the likelihood of poor health outcomes. From an individual's first encounter with a healthcare system as a child with their caregiver(s), the communication—both explicit and non-verbal—of HCPs may influence whether they choose to sustain a patient-doctor relationship through adulthood or choose to sever a demeaning medical relationship that proves more harmful than healing.

Overall, there is a dearth of research on potential racial differences in SDM during adolescence. This is partially because SDM research has largely focused on White adult populations. Of note, previous research indicates Black and Latinx patients experience worse patient-provider relationships than their White counterparts (Nelson, 2002; Flower et al., 2017; Morales et al., 1999; Beach et al., 2011; Spooner et al., 2016). Given this information, there are likely racial differences in SDM during adolescence whereas the adolescent-HCP relationship is poor, the caregiver-HCP relationship is imbalanced, and the family is not a full partner in adolescent care. These racial differences are likely supported by structural racism and implicit racial bias on the part of the HCPs. The next section explores the possible interactions between health status and race, and how they may relate to SDM in adolescence.

Chapter 6: The Interactive Relationships between Health Status, Race, and SDM

One way race and health status may interact to relate to SDM during adolescence is if race acts as a moderator. Specifically, the race of the adolescent may exacerbate or mitigate the association between health status and inclusive SDM. This potential pathway is supported by the intersectionality framework. Intersectionality, a term first coined by Kimberlé Crenshaw, moves beyond identifying individual risk factors (i.e. race, gender, class) and focuses on how compounded factors create a unique experience for individuals with marginalized identities (Crenshaw, 1991). Studies of intersectionality have examined how various factors interact to impact the health and wellness of the population within different contexts. Intersectionality allows health researchers to understand the complex processes and unique lens needed to better understand how health-related outcomes differ. In the case of race and health, research has shown that health outcomes and patient-provider communication differ based on race among adults in the United States (Cooper- Patrick et al., 1999; Beach et al; 2011; Johnson et al., 2004). However, no studies have considered how the compounded risk of health status and race of adolescents' impacts patient-provider communication. Studies suggest adolescents with poor health statuses may experience poorer patient-provider communication, which may be further worsened if the adolescents are Black or Latinx (McCabe et al, 1999; Alegria, Vallas & Pumariega, 2010; Benkert et al., 2006)

Specifically, Black and Latinx adolescents with health issues may experience less inclusive SDM than their peers without health issues due to compounded risks. A longitudinal study examining racial/ethnic differences in treatment for adolescents with major depression found that Black (32%) and Latinx (31%) adolescents were significantly less likely than Whites (40%) to receive: (1) prescription medication for major depression, (2) treatment from a mental health HCPs, and (3) any outpatient mental health treatment regardless of family income and/or insurance status (Cummings & Druss, 2011). However, research has not examined within race or ethnicity differences in SDM for Black and Latinx adolescents.

Chapter 7. The Current Study

The purpose of this project was to examine how presence of specific health conditions (i.e., pain, obesity, and mental health status) may relate to within racial or ethnic group SDM experiences (i.e., Caregiver-HCP SDM and Inclusive/Triadic SDM) for Black and Latinx adolescents and their families. We will examine these relationships using three separate aims.

The first aim assessed whether recurrent pain is associated with SDM in Black and Latinx adolescents. I hypothesized (1a) that the presence of recurrent pain will be associated with lower levels of Caregiver-HCP and Inclusive SDM for Black adolescents; and I hypothesized (1b) that the presence of recurrent pain would be associated with lower levels of Caregiver-HCP and Inclusive SDM for Latinx adolescents.

The second aim of this proposal investigated whether being overweight or obese is associated with SDM in Black and Latinx adolescents. I hypothesized (2a) that being overweight or obese would be associated with lower levels of Caregiver-HCP and Inclusive SDM for Black adolescents, and I hypothesized (2b) that being overweight or obese would be associated with lower levels of Caregiver-HCP and Inclusive SDM for Latinx adolescents.

The third aim of this proposal is to examine whether mental health status is associated with SDM in Black and Latinx adolescents. I hypothesized (3a) that the presence of mental health symptoms (depression or anxiety) will be associated with lower levels of Caregiver-HCP and Inclusive SDM for Black adolescents, and I hypothesized (3b) that the presence of mental health symptoms (depression or anxiety) would be associated with lower levels of Caregiver-HCP and Inclusive SDM for Latinx adolescents.

Methods

Participants and Procedure

This study used a secondary dataset derived from the 2017 - 2018 National Survey of Children's Health (NSCH) that collected data in English and Spanish on the physical and emotional health of children 0 - 17 years old in the United States. To be eligible for the study, a household had to have at least one or more children under the age of 18. A guardian or parent was then asked to complete a questionnaire (see Appendixes F-I for information on questionnaire components used for the current study). Aspects of SDM were measured using 2 subscales of the questionnaire: the SDM scale and the family-centered care (FCC) scale. Households from all 50 states were randomly sampled and a total of 52,129 households were surveyed.

Inclusion criteria for the current study included being a Black or Latinx household with an adolescent aged 12-17 years. Approximately 7.40% (n = 3,856) of the total surveys meet these criteria (See Table 1). Of this sample, 38.0% identified as Black, and 62.0% identified as Latinx.

Table 1. Descriptive Statistics

	N (%)
Race/Ethnicity	
Black	1,465 (38.00)
Latinx	2,391 (62.00)

Measures

Demographics. Adolescent descriptive information, such as age, sex, race, and ethnicity, was collected. Caregivers were asked the sex of their adolescents (1 = male and 2 = female) and their child's age in years. To assess race and ethnicity, caregivers were first asked if their adolescent is of Hispanic, Latino, or Spanish origin. If they responded yes, regardless of reported race, the adolescents were identified as Latino. If a parent-reported no, then they were asked the race of their child. Race/ethnicities for the current study were coded as 1 = Latino, 2 = White, non-Latino, 3 = Black, non – Latino.

Health Insurance. This is a one-item measure that asked the current health insurance status of the adolescent at time of survey. Responses were 1 = currently insured or 2 = currently uninsured.

Parental Education. This is a one-item measure that asked the highest level of education among the adolescent's caregivers. Responses were 1 = less than high school, 2 = high school or GED, 3 = some college or technical school, 4 = College degree or higher.

Pain. Caregivers were asked "During the past 12 months, has your child had frequent or chronic difficulty with any of the following?" and a list of 7 conditions were probed. Pain was assessed by asking about "repeated or chronic physical pain, including headaches or other back or body pain'. Responses were 1= Yes and 2 = No.

Obesity. Caregivers reported their child's height, weight, and gender. This information was used to calculate body mass index using the Centers for Disease Control age and gender-based charts. The NSCH then sorted adolescents into 3 categories: 1 = Underweight less than 5th percentile, 2 = Children with a healthy weight (5th to 84th percentile), and 3 = Overweight children (85th to 94th percentile) or Obese children (95th percentile or above). Underweight children, who represented 5.6 percent of the 12 -17 population were excluded from the obesity analyses.

Depression and Anxiety. Caregivers were first asked “Has a doctor or other health care provider EVER told you that this child has…” and then presented with 6 conditions, two of which were “depression” and “anxiety problems”. Caregiver then responded yes or no to each condition. If they responded yes, the caregivers were asked to “does this child currently have the condition” and then responded yes or no. Responses were then coded 1 = Does not have condition, 2 = Ever told, but does not currently have the condition and 3 = currently has the condition. For the current study, responses were recoded as 1= Yes, if the child currently has the condition, and 2 = No, if the child does not currently have the condition or they have never had the condition. If caregivers answered yes to currently having either the depression or anxiety problems, their adolescent was considered to have a mental health symptoms.

SDM – Caregiver and HCP Focus. The SDM scale is a 3-item measure that focuses on the caregiver-HCP relationship. Caregivers were first asked in 2017 “During the past 12 months, were any decisions needed about this child’s health care services or treatment, such as whether to start or stop a prescription or therapy services, get a referral to a specialist, or have a medical procedure?” In 2018, caregivers were asked “During the past 12 months, did this child need any decisions to be made regarding his or her health care, such as whether to get prescriptions, referrals, or procedures?” If they responded yes, caregivers were asked how often did this child’s doctors or other health care providers: 1) discuss with you the range of options to consider for their child's health care or treatment; 2) makes it easy to raise concerns or disagree with recommendations for the child's health, and 3) works together to decide which health care and treatment choices would be best for the child. Responses were recorded as 1 = Always, 2 = Usually, 3 = Sometimes, 4 = Never. Each item was reverse coded on a 4-point Likert scale 1 = Never, 2 = Sometimes, 3 = Usually, 4 = Always. The researcher created a composite SDM score by adding each score and dividing it by three. If any items were missing, the composite score was not calculated. The Cronbach's alpha for SDM in the current study was .90.

SDM – Inclusive of Caregiver, HCP, and Child. FCC scale is a 5-item measure that was chosen as a measure to reflect a more inclusive version of SDM, as it focuses on interactions between the caregiver, child, and HCP. It uses five experience-of-care questions: (1) spends enough time with the child, (2) listens carefully to you (3) sensitive to family values/customs, (4) gives needed information, and (5) family feels like a partner. Each item was reverse coded on a 4-point Likert scale 1 = Never, 2 = Sometimes, 3 = Usually 4 = Always. The researcher created a composite score by adding each score and dividing by the number of responses. The composite FCC measure is only considered missing if all components are missing. Of note, the instructions indicated "Answer the following questions only if this child had a health care visit in the past 12 months. Otherwise skip…".   The Cronbach's alpha for FCC in the current study was .92.

Data Analysis Plan

Descriptive Statistics

Prior to running the main analyses, descriptive statistics were conducted, and the data were assessed for normality, outliers, and linearity. Normality of the data was assessed by examining skewness and kurtosis statistics (See Table 2). The SDM scale and the FCC scale were normally distributed based on absolute skewness values and absolute kurtosis values (See Table 2).

Table 2. Skewness and Kurtosis

	Black				Latinx			
	Skewness		Kurtosis		Skewness		Kurtosis	
	Statistic	S.E.	Statistic	S.E.	Statistic	S.E.	Statistic	S.E.
Age	-.16	.06	-1.26	.12	-.07	.05	-1.24	.10
FCC	-1.64	.14	1.72	.29	-1.28	.11	3.03	.22
SDM	-1.96	.07	4.14	.15	-1.65	.11	.50	.22
Note. FCC = Family Centered Care; SDM = Shared Decision-Making Scale								

All statistical analyses were completed using SPSS ® software, Version 26 for MAC (SPSS, 2019), and were run separately for the Black and Latinx subsamples. Descriptive statistics were reported for predictor and outcome variables (see Table 3). Specifically, age, SDM and FCC scores were described with means, standard deviations, and ranges. Categorical variables (i.e., sex, health insurance status, parent education) were described with frequencies and percentages.

Independent sample t-tests were used to assess for differences in SDM and FCC scores based on pain, obesity and mental health status. If the independent sample t-test was significant ($p < .05$), a subsequent hierarchical regression was conducted. The hierarchical regressions were used to predict SDM and FCC scores from health status (pain, obesity, and mental health status) controlling for age, sex, parental education, and health insurance. Missing data was handled using pairwise deletion.

Results

Preliminary Analyses

Descriptive statistics were run for demographics to determine the characteristics of each racial subgroup (see Table 3). A total of 1,465 participants identified as Black adolescents. Approximately 48% of Black adolescent participants were female, with an average age of 14.70 years. Also, 15% of Black adolescent participants experienced chronic pain in the past year, 38% percent of Black adolescents were obese or overweight, and roughly 13% presently had at least one mental health issue. About 92% of Black adolescent participants were insured at the time of the survey and 73% had at least one caregiver with more than a High School diploma. Nearly 71% of Black adolescents and their families completed the inclusive SDM subscale versus 20% who completed the caregiver-HCP SDM subscale. The average SDM score for Black adolescents was 3.65 (SD = .55), which suggests a high frequency of caregiver-HCP SDM. The average FCC score for Black adolescents was 3.66 (SD = .54), which suggest a high frequency of inclusive SDM.

A total of 2,391 participants identified as Latinx adolescents. Approximately, 48% of the Latinx participants identified as female with an average age of 14.68 years. Roughly, 30% of participants reported that English was not the primary household language, suggesting differences in health experiences and access. In addition, 14% of Latinx adolescents experienced difficulty with physical pain in the last 12 months, 35% of Latinx adolescents were overweight and/or obese, and 19% had at least one mental issue. About 91% of Latinx participants were insured at the time of the survey and 66.70% had at least one parent with more than a High School diploma. The average SDM score for Latinx adolescents was 3.58 (SD = .60), which suggests high frequency of caregiver-HCP SDM. The average FCC score for Latinx adolescents was 3.56 (SD = .58), which suggest a high frequency of inclusive SDM.

Table 3. Means Scores, Standard Deviation and Ranges

	Black (n = 1,465)			Latinx (n = 2,391)		
	M	**SD**	**Range**	**M**	**SD**	**Range**
Age	14.75	1.70	12-17	14.60	1.67	12-17
SDM	3.67	.55	1 - 4	3.58	.60	1 - 4
FCC	3.66	.54	1- 4	3.56	.54	1 - 4
	n	**%**	**N**	**n**	**%**	**N**
Pain Last 12 months	187	13.14%	1,453	330	13.80%	2,380
Overweight/Obese	508	38.80%	1,309	750	35.01%	2,142
Mental Health Symptoms	143	9.85%	1,452	329	13.95%	2,358
Female	707	48.30%	1,465	1,141	47.70%	2,391
Currently Insured	1355	92.50%	1,411	2,191	91.60%	2,380
Parent Education						
< High School	85	5.80%	1,465	265	11.10%	2,391
High School	298	20.30%	1,465	531	22.20%	2,391
> High School	1,082	73.90%	1,465	1,585	66.70%	2,391
Note. FCC = Family Centered Care Scale; SDM = Shared Decision Making						

Table 4. Percentages of Doc Visit/Decision, SDM, and FCC Data Available for Analyses

	Black (n = 1,465)			Latinx (n = 2,391)		
	n	%	N	n	%	N
Decision Making	291	19.96%	1,465	478	19.99%	2,391
SDM	291	19.96%	1,465	475	19.87%	2,391
FCC	1044	71.26%	1,465	1642	68.67%	2,391
Note. Decision Making = Yes responses to the 2017 or 2018 SDM gateway question; FCC = Family Centered Care Scale; SDM = Shared Decision Making						

The current study's missing data from the SDM and FCC survey data are shown in Table 4. The SDM measure had a gateway question that asked caregivers if their child had a medical visit that required decision-making in the past 12 months (see Measures section). If the caregiver answered yes, they completed the SDM questions; if they answered no, they did not complete the SDM questions. This may explain the low response rates with approximately 20% of Black and Latinx caregivers completing the SDM measure. The FCC measure did not have a gateway question, but instructions said "Answer the following questions only if this child had a health care visit in the past 12 months. Otherwise skip…". This resulted in 71% of Black caregivers completing the FCC questions and 69% of Latinx caregivers completing the FCC questions.

Aim 1- Chronic Pain and SDM

For Black Adolescents. Independent samples t-tests were run to determine if there were differences in SDM and FCC scores among Black adolescents who experienced chronic pain and those who did not (see Table 4). For the SDM score analyses, due to the assumption of homogeneity of variances being violated, a Satterthwaite approximation—which uses a more rigorous degrees of freedom value—was used to assess for differences. The SDM scores were not statistically different, (t(120) = -1.54, p = .13). For the FCC score analyses, due to the assumption of homogeneity of variances being violated, a Satterthwaite approximation was used. The FCC scores were lower for Black adolescents who experienced chronic pain (M= 3.52, SD = .60) than Black adolescents who did not experience chronic pain (M= 3.68, SD = .52; t(200)= -3.23, p = .00). A subsequent hierarchical multiple regression was run to determine if pain improved the prediction of FCC scores in Black adolescents over and above demographic factors and health status. The full model was statistically significant (R^2 = .01, F(5, 1,038) = 2.40, p < .05). In Step 1, age, sex, parental education, and health insurance status were statistically significant and explained 1% of the variance in FCC scores (R^2 = .01, F(4, 1039) = 3.01, p < .05). In Step 2, pain was added to the model and did not significantly improve the prediction. See Appendix A.

Table 5. Independent Sample t-test of Pain and SDM

	Yes			No					
	M	SD	n	M	SD	n	t	df	p
Black SDM	3.58	.59	76	3.70	.53	212	-1.54	121	.10
Black FCC	3.52	.60	157	3.68	.52	878	-3.24†	200	00**
Latinx SDM	3.44	.66	130	3.64	.57	344	-3.04†	204	.00**
Latinx FCC	3.45	.59	258	3.58	.59	1375	-3.34	360	.00**
*p < .05, **p < .01. | † Satterthwaite Approximation									

For Latinx Adolescents. Independent samples t-tests were run to determine if there were differences in SDM and FCC scores between Latinx adolescents who experienced chronic pain and those who did not (see Table 4). For the SDM scores, due to the assumption of homogeneity of variances being violated, a Satterthwaite approximation was used. SDM scores were lower for Latinx adolescents who experienced pain (M= 3.44, SD = .66) than Latinx adolescents who did not experience chronic pain (M= 3.64, SD = .57), (t(204)= -3.04., p = .00). A subsequent hierarchical multiple regression was run to determine if pain improved the prediction of SDM scores in Latinx adolescents over and above demographic factors and health status. The full model was also not statistically significant (R^2 = .01, F(5, 469) = 1.81, p = .11). The FCC scores were lower for Latinx adolescents who experienced pain (M= 3.45, SD = .59) than Black adolescents who did not experience chronic pain (M= 3.58, SD = .59; t(1631)= -3.33, p < .01). A subsequent hierarchical multiple regression was run to determine if pain improved the prediction of FCC scores in Latinx adolescents over and above demographic factors and health status. The full model was statistically significant (R^2 = .01, F(5, 1,636) = 3.26, p < .05). In Step 1, age, sex, parental education, and health insurance status were statistically significant and explained 1% of the variance in FCC scores (R^2 = .01, F(4, 1637) = 3.69, p < .05). In Step 2, pain was added to the model but did not significantly improve the prediction. See Appendix B.

Aim 2 – Obesity and SDM

For Black Adolescents. Independent samples t-tests were run to determine if there were differences in SDM and FCC scores between Black adolescents who were in the obese/overweight range and adolescents who were in the normal weight range (see Table 5). There were no statistically significant differences in SDM scores among Black adolescents based on weight status (t(262) = -.88, p = .38). There were also no statistically significant differences in FCC scores among Black adolescents based on weight status (t(942) = -.30, p = .76).

Table 6. Independent Sample T-tests of SDM, FCC, and Obesity

	Yes			No					
	M	SD	n	M	SD	n	t	df	p
Black SDM	3.65	.57	155	3.71	.52	109	-0.88	262	.38
Black FCC	3.66	.53	579	3.67	.53	365	-0.30	942	.76
Latinx SDM	3.62	.58	289	3.50	.62	145	2.11	432	.04*
Latinx FCC	3.60	.56	985	3.50	.62	505	3.31†	918	.00**
*p < .05, **p < .01. | † Satterthwaite Approximation									

For Latinx Adolescents. Independent samples t-tests were run to determine if there were differences in SDM and FCC scores between Latinx adolescents who were in the obese/overweight range and adolescents who were normal weight range. There were statistically significant differences in SDM scores based on weight status, such that Latinx adolescents who were in the overweight/obese range had lower SDM scores (M = 3.62, SD = .59) than Latinx adolescents in the normal range for weight (M = 3.50, SD = .63). A subsequent hierarchical multiple regression was run to determine if overweight/obese BMI categorization improved the prediction of SDM scores in Latinx adolescents over and above demographic factors and health status. The full model was also not statistically significant (R^2 = .01, F(5, 469) = 1.82, p =.11). See Appendix C. For the FCC scores, due to the assumption of homogeneity of variances being violated a Satterthwaite approximation was used. The FCC scores were lower for Latinx adolescents who were in the obese/overweight range (M = 3.65, SD = .63) than Latinx adolescents who were in the normal weight range (M= 3.61, SD = .56; t(919)= 3.31, p < .01). A subsequent hierarchical multiple regression was run to determine if overweight/obese BMI categorization improved the prediction of FCC scores in Latinx adolescents over and above demographic factors and health status. The full model was statistically significant ($R^2 = .01$, $F(5, 1636) = 3.26$, $p <.01$). In Step 1, age, sex, parental education, and health insurance status were statistically and explained 1% of the variance in FCC scores ($R^2 = .01$, $F(4, 1637) = 3.69$, $p <.01$). In step two, obesity was added to the model and did not significantly improve the prediction. See Appendix C.

Aim 3 – Mental Health Symptoms and SDM

For Black Adolescents. Independent samples t-tests were run to determine if there were differences in SDM and FCC scores between Black adolescents who had mental health symptoms (depression or anxiety) and those who did not (see Table 7). There were no statistically significant differences in SDM scores among Black adolescents based on mental health status ($t(284) = 1.17$, $p = .24$). There were statistically significant differences in FCC scores among Black adolescents based on mental health status, with Black adolescents with mental health symptoms having lower FCC scores ($M = 3.53$, $SD = .58$) than Black adolescents who did not have mental health symptoms ($M= 3.67$, $SD = .53$), ($t(1,024) = 2.86$, $p = .01$). A subsequent hierarchical multiple regression was run to determine if mental health status improved the prediction of SDM scores in Black adolescents over and above demographic factors and health status. The full model was statistically significant ($R^2 = .01$, $F(4, 1,021) = 2.53$, $p < .05$). In Step 1, age, sex, parental education, and health insurance status were statistically significant and explained 1% of the variance in FCC scores. In Step 2, mental health was added to the model and did not significantly improve the prediction ($R^2 = .01$, $F(1, 1020) = 3.71$, $p < .05$). See Appendix D.

Table 7. for Independent Samples T-test for FCC, SDM and Mental health

	Yes			No					
	M	SD	n	M	SD	n	t	df	p
Black SDM	3.61	.52	73	3.70	.54	213	1.17	284	.24
Black FCC	3.53	.58	120	3.67	.53	906	2.65	145	.01
Latinx SDM	3.48	.66	151	3.63	.57	313	2.42	261	.02
Latinx FCC	3.49	.58	266	3.58	.59	1349	2.27	1613	.02
*p < .05, **p < .01. | † Satterthwaite Approximation									

For Latinx Adolescents. Independent samples t-tests were run to determine if there were differences in SDM and FCC scores between Latinx adolescents who had a mental health symptoms and those who did not. There were statistically significant differences in SDM scores among Latinx adolescents based on mental health status, with Latinx adolescents with mental health symptoms having lower SDM scores (M = 3.48, SD = .66) than Latinx adolescents who did not have mental health symptoms (M= 3.63, SD = .57), *t*(261) = 2.41, p = .02). A subsequent hierarchical multiple regression was run to determine if mental health status improved the prediction of SDM scores in Latinx adolescents over and above demographic factors. The full model was also not statistically significant (R^2 = .02, F(4, 470) = 2.22, p =.06). See Appendix E. There were statistically significant differences in FCC scores among Latinx adolescents based on mental health status, with Latinx adolescents with mental health symptoms having lower FCC scores (M = 3.49, SD = .58) than Latinx adolescents who did not have a mental health status (M= 3.58, SD = .59), *t*(1613) = 2.73, p = .02). A subsequent hierarchical multiple regression was run to determine if mental health status improved the prediction of SDM scores in Latinx adolescents over and above demographic factors. The full model was statistically significant ($R^2 = .01$, $F(4, 1637) = 3.69$, $p =.01$). In Step 1, age, sex, parental education, and health insurance status were statistically significant and explained 1% of the variance in FCC scores. In Step 2, mental health status was added to the model and did not significantly improve the prediction ($R^2 = .00$, $F(1, 1636) = 3.26$, $p < .05$). See Appendix E.

Discussion

The current study explored the relationships between health factors and SDM for Black and Latinx adolescents, with a focus on caregiver-HCP SDM and inclusive SDM. Most SDM research has focused on White adult populations; leading to limited research examining the SDM experiences of Black and Latinx adolescent populations. The racialized nature of interactions between Black and Latinx adolescents, their families, and HCPs may contribute to differences in the SDM experiences of Black and Latinx adolescents and their families. Despite health disparities for Black and Latinx youth regarding pain prevalence, weight status, and mental health status – Black and Latinx adolescents and their families receive less time with their HCPs. In addition, structural racism creates multi-level barriers in receiving quality care for these populations, such as reducing their access to quality healthcare facilities and HCPs and having their healthcare experiences being shaped by implicit bias of HCPs (Gee & Ford, 2011). Black and Latinx adolescents and their families are more likely to have a physician who is of a different race and or ethnicity, which previous research suggests can negatively impact patient-provider interactions (Johnson et al et al., 2017; Hall et al., 2015; Staton et al., 2007). Experiences in health care shape future health behaviors and may determine whether a patient returns for follow-up care. The overall goal of the current study was to examine caregiver-HCP SDM and inclusive SDM experiences of Black and Latinx adolescents and their families, and to examine how pain, obesity, and mental health status of the adolescents relate to the SDM experiences of these populations.

Black Adolescents and SDM

Caregivers of Black adolescents generally reported high caregiver-HCP SDM and high inclusive SDM. Approximately 13% of Black adolescents in the current study experienced chronic pain in the past year, which is within range of 2007 data estimating 13% to 32% adolescents experience chronic and recurring pain (Stanford et al., 2008). Black adolescents' overweight/obese prevalence rate in this study was 39%, which is higher than other national estimates using data from 2016 of Black adolescents of about 23%, but in line with data indicating that ethnic minority populations have higher BMI rates than white counterparts (CDC, 2021). The prevalence rates for mental health diagnoses among Black adolescents in the current study were roughly 9%, which is similar to other national prevalence estimates using data from 2019 for Black adolescents of 10.3% (CDC, 2021).

Chronic Pain. Consistent with my hypotheses, Black adolescents who experienced chronic pain experienced lower levels of inclusive SDM than their peers who did not experience chronic pain. However, inconsistent with my hypothesis, chronic pain status did not affect caregiver-HCP SDM, suggesting adolescent participation in SDM is the significant feature of the triadic relationship that is being negated. These findings suggest Black adolescents who are experiencing chronic pain are less likely to be included or participate in their healthcare. It may be that Black adolescents experiencing chronic pain may be communicating their needs for pain management, but their caregivers and HCPs are not incorporating their preferences or including them in the decision-making process. Previous studies have found that pain reported by Black adults is often ignored during medical visits (Hoffman et al., 2016; Reyes-Giddy et al., 2007; Anderson, Green & Payne et al., 2009). Alternatively, these findings could mean that Black adolescents are experiencing high pain intensity or pain duration, and this pain has led to them choosing not to participate in the decision-making process; thus, they are capitulating control over their pain management to caregivers and HCPs. Further research is needed to determine whether Black adolescents with pain are choosing or not choosing to participate in the SDM.

Regardless, if Black adolescents who experience chronic or repetitive pain experiences are less likely to be included in the SDM process, it may result in them experiencing higher pain severity or longer duration of undermanaged or undertreated pain. They may also be less likely to adhere to a treatment plan as it does not include their preferences. Future research is needed to determine how SDM relates to pain and other health outcomes for Black adolescents who experience pain.

Overweight/Obese Status. Contrary to my hypothesis, there were no differences in inclusive and caregiver-HCP SDM between overweight/obese Black adolescents and their peers. This suggests that regardless of BMI status, Black adolescents and their caregivers are experiencing similar levels of access to SDM as their Black adolescent counterparts. This is contrary to previous literature that indicates that despite higher healthcare utilization in overweight/obese individuals, HCPs spend less time, build less rapport, explain less things to Black adult overweight/obese patients, and include them less in medical decision making compared to their white counterparts (Wiesenthal et al, 2016; Wong, et al., 2015; Mold & Forbes, 2013; Gudzune et al., 2013). Prior studies demonstrate that HCPs hold negative stereotypes about overweight/obese patients – with physicians reporting that they have less respect for overweight/obese patients, labeling overweight/obese patients as noncompliant, lazy, and a waste of their time (Puhl & King 2013; Huizinga et al., 2009; Hebl & Xu, 2001). Our study findings suggest that the weight status of Black adolescents does not relate to their SDM experiences. Thus, there is strong evidence of weight status affecting the healthcare experience of Black adults, but study results suggest Black overweight/obese adolescents experiences may vary. Additional research is needed.

Differences in type of HCPs may contribute to varying experiences between Black adolescents and adults. Adults visit primary care physicians (PCPs) independently, so their SDM relationship is a dyad (patient-HCP) versus adolescents who visit a pediatrician with their caregiver – a triadic SDM relationship (adolescent-caregiver-HCP), with two adults communicating and sharing the responsibility of responding to symptoms, molding health behaviors and responding based on developmental needs of the adolescent. Future research may need to focus on how the transition to adulthood and different health care providers may impact how SDM relates to weight status in Black youth.

Mental Health Status. Consistent with my hypothesis, Black adolescents who experienced mental health symptoms experienced lower levels of inclusive SDM than their peers who did not experience mental health symptoms. However, inconsistent with my hypothesis, mental health symptoms did not affect caregiver-HCP SDM, suggesting adolescent participation in SDM is the significant feature of the triadic relationship that is being negated. These findings suggest Black adolescents who are experiencing depression or anxiety symptoms are less likely to be included or participate in their healthcare. Previous studies have found racial disparities for Black youth in comparison to their White counterparts in pediatric mental health care, specifically in access and quality of mental health services (Alegria et al, 2010). This is consistent with a study of depression in Black adults that found chronicity of depression was higher amongst Black individuals compared to their White counterparts and fewer than half of Black adults sought professional treatment for depression despite self-reporting their condition as being severe or debilitating (Bailey, Mokonogho & Kumar, 2019; Williams et al., 2007). These findings may suggest that Black adolescents are communicating their mental health needs to their HCPs and caregivers, however, those needs are not being heard or addressed. Alternatively, it may be that Black adolescents are communicating their needs, but the national shortage of mental health professionals is negatively affecting Black individuals' abilities to receive comprehensive mental health services. Future research should further investigate the relationship between mental health and SDM among Black adolescents and their families.

Of note, research on depression and anxiety assessment tools has found that Black youth are more likely to express their depressed feelings by reporting physical pains or interpersonal conflicts, which widely used depression screeners and assessment tools do not account for (Lu et al, 2017). That research suggests the screening and assessment tools do not comprehensively address and account for the physical and psychological symptoms of depression and anxiety experienced by Black youth. Stigma coupled with insufficient screening may lead to depression and anxiety in Black adolescents being under-diagnosed, and under treated which may have impacted the current study's findings. Future research is needed that examines mental health symptoms of Black adolescents using measures that include somatic and physiological symptoms related to depression and anxiety.

Latinx Adolescents and SDM

Caregivers of Latinx adolescents generally reported high caregiver-HCP SDM and high inclusive SDM. Approximately, 14% of Latinx adolescents in the current study experienced chronic pain in the past year, which is within the range of previous 2007 national prevalence rates for adolescent youth of about 13% to 32% (Stanford et al., 2008). In this study, Latinx adolescents' overweight/obese prevalence rate was roughly 35%, which is higher than 2019 national averages that report about 18% of Latinx youth tend to be overweight/obese (CDC, 2021). The current study's prevalence rates for mental health diagnoses among Latinx adolescents were roughly 12% for anxiety and 7% for depression, which is slightly lower than

2019 national prevalence estimates of 7.1% for anxiety and 22% depression for Latinx adolescents (CDC, 2021).

Chronic Pain. Consistent with my hypothesis, Latinx adolescents who experienced chronic pain experienced lower levels of inclusive SDM and caregiver-HCP SDM. These findings suggest Latinx youth who experience chronic pain and their caregivers are less likely to be included or participate in SDM. Similar to Black adolescents who experience pain, this may lead to adolescents disengaging or ignoring pain management advice due to their lack of participation in the SDM process. Further, this could contribute to higher pain severity, longer unmanaged pain, and/or poorer pain management. Lower parent participation in SDM for this population may suggest parents do not feel empowered to share information with their HCPs or feel like they are a partner in their child's health care. Low caregiver participation in SDM may lead to dissatisfaction with their child's HCPs, which could subsequently lead to disengagement from healthcare utilization. This could exacerbate pain disparities in Latinx adolescents as caregivers would not seek out resources or referrals and would not follow up with their child's HCPs. Although the literature is limited, one qualitative study in adult Latinx populations found adult patients reported perceiving HCPs did not believe, care, and/or disregarded their reports of pain. Another study found some Latinx adults have a cultural stigma toward strong pain medication due to fear of addiction (Hollingshead et al., 2016). This may cause poor treatment adherence and mistrust of HCPs if patients feel physicians are not honoring their preferences. This may also lead to a mismatch where HCPs are prescribing medications, but patients are choosing not to take them because of the cultural stigma; therefore, leading to what looks like poor treatment adherence but what is a cultural divide.

Studies have also shown that HCPs bias against Latinx adult patients has contributed to disparities in access to pain management treatment (Hollingshead et al., 2016; Maina et al., 2018, Blair et al., 2014). These findings could mean that there is a misalignment (imbalance) in the triadic relationship between Latinx youth, their parents, and HCPs. If physicians are taking a more paternalistic approach in their interactions with Latinx youth and their families—in addition to not openly discussing or being knowledgeable of culturally reflexive practices and patient preferences —care could be negatively impacted. Alternatively, Latinx youth and their caregivers may not sufficiently be communicating their needs, which may be due to patient-provider power differentials or feeling their desires will not be heard or honored by HCPs. Further research is needed to determine whether Latinx adolescents with pain and their caregivers are choosing not to participate in SDM and/or are being left out of the triadic relationship due to HCP behaviors and attitudes.

Overweight/Obese Status. Consistent with my hypothesis, Latinx adolescents who were overweight/obese experienced lower levels of inclusive SDM and caregiver-HCP SDM compared to Latinx adolescents who were not overweight/obese, suggesting adolescent and caregiver participation in SDM are significantly affected by weight status. These findings suggest Latinx adolescents who are overweight/obese and their caregivers are less likely to be included or participate in their healthcare. It may be that Latinx youth and their caregivers are communicating challenges with being overweight/obese and their need for weight management support, but their preferences are being disregarded by their HCPs. Previous studies have found HCPs report low self-efficacy in managing overweight/obesity in primary care settings. Additionally, HCPs have reported a lack of confidence in preventing and managing the BMI status of overweight/obese children (Fowler-Brown & Kahwati, 2004; Perrin, Flower, Garrett, &

Ammerman, 2005; Colindres, Vu & Davis, 2009). This suggests the breakdown in the triadic relationship may be due to physicians' discomfort, lack of training, or a combination of both factors. Weight stigma may also threaten the physical health of obese Latinx adolescents and impede the implementation of effective SDM efforts to manage and/ or prevent obesity. This may further exacerbate present health disparities in overweight/obesity rates of Latinx youth. If caregivers are bringing their children to HCPs to assist in the improvement of youths' physical health, but HCPs are not equipped to treat adolescents then SDM would not be occur as the transfer of skills, resources and knowledge would be unequal.

Further, these findings could suggest that the health care needs of Latinx adolescents who are overweight/obese are not being sufficiently addressed and treated. If Latinx adolescents who are overweight/obese and their caregivers are less likely to be included in the SDM process, it may result in them experiencing increased health complications and undertreated weight management. Alternatively, these finding could mean Latinx adolescents and their caregivers are not communicating their concerns with HCPs possibly due to power differentials either between the patient-provider relationship or caregiver-provider relationship. Previous research has also found that BMI scales fail to capture body composition information – specifically in regard to fat distribution. More specifically studies have found BMI differs by race, especially among women (Rahman et al., 2009). Thus, Latinx adolescents who are overweight/obese on the BMI scale can be healthy and culturally their weight and physique are not of alarm to them or their caregivers. Nevertheless, they may experience medical bias as weight is still largely used as a health risk indicator among adolescents despite higher BMI independently not being a sole direct link to health complications (Kuk et al., 2018). Future research on weight should expand to collect body fat and body composition data and determine how the weight and body composition of Latinx adolescents relates to their experiences with SDM and subsequent health outcomes.

Mental Health Status. Consistent with my hypothesis, Latinx adolescents with mental health symptoms experienced lower levels of inclusive SDM and caregiver-HCP SDM compared to Latinx adolescents without mental health symptoms, suggesting adolescent and caregiver participation in SDM is affected by adolescents' depression and anxiety symptoms. It may be that Latinx youth and their caregivers retain stigma surrounding seeking mental health treatment or communicating the need for mental health treatment. Conversely, it could be that teenagers and their caregivers are communicating their needs, but the national shortage of mental health professionals, which disproportionately affects Latinx communities ability to receive care (Goldston et al., 2008). Our current findings are consistent with previous research that found Latinx parents and youth reported they frequently do not have any choice in mental health treatment options (Liverpool et al., 2021; Jordan et al., 2018). Previous studies on mood disorders, such as depression and anxiety, have found Latinx youth express depressed or anxious feelings ("nervios") through reporting physical symptoms. (Carpenter-Song et al., 2010). This suggests that questionnaires used by HCPs to measure mental health symptoms may not fully capture youth experiences or symptomology. Future research is needed to further examine the relationship between mental health symptoms and SDM among Latinx adolescents and their families.

Black and Latinx SDM

There were shared and unique experiences of SDM for Black and Latinx adolescents and their families. Overall findings showed both Black and Latinx youth who experienced chronic pain had lower levels of triadic SDM. Historically in the United States, research has shown that

HCPs have neglected the pain of Black and Latinx adults in part due to medical racism and false assumptions about pain tolerance and predisposition to drug abuse (Anderson, Green & Payne, 2009; Reyes- Gibby et al., 2007; Hoffman, Trawalter, Axt, & Oliver, 2016). These findings suggest Black and Latinx adolescents experience disparities in pain treatment precedes adulthood. Findings also showed that caregivers of Latinx adolescents who experienced chronic pain reported less caregiver-HCP SDM, but not caregivers of Black adolescents. Further research is needed to identify what may be leading to Latinx caregivers' issues with SDM when their adolescents are experiencing pain.

Overweight/obese Latinx youth and their caregivers experienced lower levels of triadic and dyadic SDM, while overweight/obese Black youth and their caregivers did not. These differences in findings may in part be due to Latinx families navigating health care settings that does not account for their unique bilingual and sociocultural experience. If families do not feel their traditions or culture are being honored, it can impact their SDM experience. Further there may be generational differences in relation to the acceptance of pharmacological versus non-pharmacological interventions to treat obesity. Further research is needed to examine what may be leading to overweight/obese Latinx adolescents and their caregivers' differential experiences with SDM.

For both Black and Latinx adolescents and their caregivers, mental health status was related to Inclusive SDM. For Latinx youth is was also related to caregiver-HCP SDM Of note, national data has shown Black youth remain misdiagnosed, underdiagnosed, and have limited access to mental health treatment (Liang et al., 2016; Rose, Joe, & Lindsey, 2010). The National Healthcare Disparities Report by the Agency for Healthcare Research and Quality suggests that nationally there are gaps in accurate data collection detailing rates of depression and anxiety among Black adolescents and healthcare utilization (National Healthcare Quality and Disparities Reports, AHRQ, 2021). For Latinx individuals, a qualitative study of Latinx adults reported that their HCPs do not understand their experiences and frequently experience cross-cultural communication challenges (Lightfoot et al., 2019). The Latinx adults in the study reported time spent with their HCPs, accessibility to treatment, and appropriateness of treatment plan options as factors impacting their access to healthcare and improvement in their patient-provider relationships. Previous research has also found disparities in the healthcare experiences of non-Spanish speaking, bilingual, and Spanish speaking Latinx adults in patient-provider communication – specifically in regards to language and cultural needs (Abraído-Lanza, Céspedes, Daya, Flórez & White, 2011; Murray-García, Selby, Schmittdiel, Grumbach, & Quesenberry, (2000). The lack of culturally and linguistically appropriate mental health services in conjunction with mental health stigma within the Latinx community creates barriers to sufficient care.

Biased estimates in conjunction with the stigma associated with the discussion and treatment of mental health symptoms in Black and Latinx populations further contribute to mental health disparities in Black and Latinx youth (Avenevoli et al., 2013; Goldston et al., 2008). It is also plausible that mental health stigma impacted the survey collection related to the mental health data. Mental health stigma may impact an individual or a caregiver’s decision to disclose mental health symptomology in addition to negatively impacting health-seeking behaviors (Masuda, Anderson, & Edmonds, 2012). In Black and Latinx communities’, stigma and cultural beliefs remain large barriers to receiving mental health treatment (Sanders Thompson, Bazile, & Akbar, 2004; Comas-Diaz, 2006).

Overall, researchers need to take a multifaceted approach to assessing mental health symptoms in Black and Latinx youth to increase their reach – including but not limited to culturally relevant engagement strategies, psychoeducational material for families to improve knowledge on mental health and SDM, direct engagement of youth, culturally tailored public health campaigns and interventions, and continuing medical education and training for all pediatric HCPs. Ideally, future research will include nuanced and tailored interventions to the specific needs of Black and Latinx adolescents.

Limitations

The current study is not without limitations. This study was a cross-sectional, secondary data analysis that allowed researchers to gauge observational data from 2017 and 2018. This limited the measures available to assess the factors of interest, and did not allow for the examination of temporal relationships between variables. For example, the mental health measure assessed whether an HCP ever told the caregivers if their children currently had or previously had depression or anxiety problems. This did not give an accurate description of the severity of depression and anxiety symptomology being experienced by the child. Also, caregivers may have underreported mental health symptoms of their child out of fear of labeling or shame. Previous studies have suggested a generational shift in how mental health is viewed, with younger generations being more open to treatment and health care utilization (Ward & Mengesha, 2013). Future research will need to be part of culturally curated public health campaigns focused on mental health that address multiple generations to reach caregivers and youth. In addition, future research on SDM in mental health settings should ask caregivers their perception of their child’s mental health symptoms and ask adolescents to self-report their mental health symptoms.

Another key limitation is that the current study relied on caregiver self-report for SDM experiences without external observation of the caregiver-adolescent-HCP encounter. It is important to consider how attuned caregivers are to their adolescents and how their experience in a healthcare setting would affect their perception of their and their adolescents' interactions with HCPs. Because very few studies have examined SDM in adolescence, future research should examine caregiver-child concordance on SDM, adolescent perception of SDM, and adolescent-caregiver-HCP concordance on SDM. Future studies should also include pain reports from adolescents directly and not parent proxies about their symptoms.

Caregivers were also asked to report their adolescent's race and ethnicity; however, the survey did not include questions to capture racialized experiences. Scales that assess racialized experiences may measure structural racism, personally experienced discrimination, and other health inequities rather than just collecting demographic data. Research has shown that racism (interpersonal and structural) and discrimination negatively affect Black and Latinx communities' access to high-quality medical care, access to comprehensive health resources, and clinical preventive services, which in turn prolongs and exacerbates health disparities (Williams, & Mohammed, 2009; Williams, Lawrence & Davis, 2019). Simply collecting demographic data on an individual's race and ethnicity does not capture their racialized experience in healthcare settings. Given the intersection of health, race, and SDM, future research on SDM should examine potential differences in the level of satisfaction and inclusion based on perceived experiences of discrimination and include both adolescent and caregiver reports (Peek et al., 2011; Armstrong et al., 2013).

Lastly, the SDM survey's gateway question first asked parents if their child needed any decisions to be made regarding his or her health care in the past 12 months. If the answer was no, then caregivers did not complete the SDM questions. This led to approximately 80% of the Black and Latinx caregivers not completing the SDM scale because they answered no to the screening question. Future surveys should not screen participants out based on recent health care visits requiring decisions and should instead ask all participants to complete SDM questions to ensure generalizability for the range of Black and Latinx youth experiences.

Future Directions and Clinical Implications

There are several important research and clinical implications of the current study. The study findings address major research gaps in the understanding of within-group racial ethnic differences in SDM and how SDM relates to adolescent health conditions (i.e., pain, obesity, mental health status). The varied SDM experiences, specifically in regards to pain, obesity and mental health, suggest disparate health care experiences for Black and Latinx youth. There remains underutilization and a lack of consensus on SDM implementation in pediatric clinical settings. In addition, there is a lack of resources offered to train HCPs and educate caregivers and their children on SDM. Presently, there is Opel's 4-step framework and Langer & Jensen Doss's step-by-step guide for pediatric SDM; however, it has not been tailored to Black and Latinx families.

The present study examined Black and Latinx adolescents' experiences with SDM based on their physical and mental health. For both Black and Latinx adolescents, pain and mental health were risk factors that impacted their experiences with SDM. However, there remains limited data on pain prevalence, mental health prevalence rates, physical and mental health outcomes, pain management, and health care utilization for Black and Latinx youth. Researchers should possibly partner with schools and youth-serving institutions to collect comprehensive data on the Black and Latinx experiences of pain that include symptom duration, access to services, health utilization, and offer tailored services to Black and Latinx youth. Additionally, future research should consider the comorbidity of pain, obesity, and mental health conditions in Black and Latinx adolescents. Previous research has found that mental health is associated with worse physical health problems in youth and vice versa. (Cohen et al., 1998; Anderson, Cohen, Naumova & Must, 2006; Aarons et al., 2008). Studies have also found that co-morbid mental and physical health conditions followed youth into adulthood and contributed low quality of life (Chen, Cohen, Kasen & Johnson, 2006).

Adolescence is a period of rapid physical and mental growth, development of health behaviors, and transition into emerging adulthood. This pivotal period presents an opportunity for HCPs and caregivers to partner with adolescents to increase health literacy, autonomy, communication of preferences, and address physical and mental health risks. In previous studies, physicians reported factors such as insufficient information, limited time, and patient assertiveness as impacting the SDM process (Shepherd, Tattersall & Butow, 2008; Lown, Hanson & Clark, 2009; Zeuner, Frosch, Kuzemchak, & Politi, 2015). HCPs are an essential part of the healthcare experience and need to be better equipped to identify the risks and underlying mechanisms that lead to the health disparities plaguing Black and Latinx youth. If HCPs are not properly trained on how to screen for certain physical and mental health conditions. and how to properly utilize SDM in Black and Latinx adolescent populations – Black and Latinx communities will remain undertreated, underserved, and vulnerable.

Taken together, risks factors, such as living in health care shortage areas, lack of access to quality health care and poorer patient-provider interactions, may further exacerbate health disparities. Interventions, training, workshops, and psychoeducation resources are needed to foster skills development, increase engagement, and communication for each part of the triad (adolescents, caregivers, and HCPs), and support adolescents' health and wellness. Future research needs to address a wide scope of descriptive information to fill in the present gap in adolescent SDM experiences. Future research should study whether physical and mental health symptoms influence SDM for younger children, such as 8-12-year olds. In addition, there are differences in how individuals with different sexual and gender identities experience mental health symptoms and physical development. Of note, this caregiver population was also highly insured and highly educated, which is not representative of a great percentage of families and youth living in the United States of America. Future research should strive to be more inclusive of the varied health insurance status and educational differences among caregivers. It is necessary we examine these important contextual factors to better help us understand trends in SDM among Black and Latinx youth and their families.

Future studies and research should include also incorporate self-reports from each part of the SDM triadic. Additionally, there is a need for continuing medical education and interventions to effectively train HCPs in the delivery of culturally informed shared decision-making that encourages the participation of adolescents and their families. There is also a strong need for bilingual and bicultural HCPs to support and work in Latinx communities to empower youth and their families to comfortably communicate their health needs. Increased access to decision aids, patient advocacy and educational information on SDM would serve to equip caregivers and adolescents with resources to increase knowledge.

Conclusion

This study attempts to highlight the unique and varied SDM experiences faced by Black and Latinx adolescents and their caregivers. It proposes a triadic (inclusive) model of SDM and also attempts to bridge an important gap in our knowledge of the relationships between mental and physical health conditions and the differing types of SDM experiences of Black and Latinx adolescents and their families. Our findings suggest Black and Latinx adolescents who experience chronic pain and their families experience lower levels of SDM, and overweight/obese Latinx youth and their families experience lower levels of SDM. It is important to identify and examine other variables that relate to differential SDM experiences of Black and Latinx adolescents, including barriers and facilitators that inclusive SDM. The study's results have implications for the creation of SDM intervention studies, such as targeting increasing HCP usage of SDM as a patient-centered care model and SDM psychoeducation resources for Black and Latinx pediatric families. Interventions offering SDM support and culturally relevant resources to Black and Latinx families may begin to target and reduce health care disparities. As such, the present findings support the importance of prioritizing the inclusion of Black and Latinx adolescents in SDM interventions based on the adolescent's chronic pain and weight status.

References

Aarons, G. A., Monn, A. R., Leslie, L. K., Garland, A. F., Lugo, L., Hough, R. L., & Brown, S. A. (2008). Association between mental and physical health problems in high-risk adolescents: A longitudinal study. Journal of Adolescent Health, 43(3), 260-267.

Abu-Saad, H. H., & Hamers, J. P. H. (1997). Decision-making and paediatric pain: A review. Journal of Advanced Nursing, 26(5), 946–952. https://doi.org/10.1046/j.1365-2648.1997.00416.x

Adams, R. C., & Levy, S. E. (2017). Shared decision-making and children with disabilities: Pathways to consensus. Pediatrics, 139(6). https://doi.org/10.1542/peds.2017-0956

Alegria, M., Vallas, M., & Pumariega, A. (2010). Racial and Ethnic Disparities in Pediatric Mental Health. Child and Adolescent Psychiatric Clinics of North America, 19(4), 759–774. https://doi.org/10.1016/j.chc.2010.07.001.Racial

Allen-Meares, P. (1987). Depression in childhood and adolescence. Social Work (United States), 32(6), 512–516. https://doi.org/10.1093/sw/32.6.512

Ambresin, A. E., Bennett, K., Patton, G. C., Sanci, L. A., & Sawyer, S. M. (2013). Assessment of youth-friendly health care: A systematic review of indicators drawn from young people's perspectives. Journal of Adolescent Health, 52(6), 670–681. https://doi.org/10.1016/j.jadohealth.2012.12.014

Anderson, K. O., Green, C. R., & Payne, R. (2009). Racial and ethnic disparities in pain: causes and consequences of unequal care. The Journal of Pain, 10(12), 1187-1204.

Anderson, S. E., Cohen, P., Naumova, E. N., & Must, A. (2006). Association of depression and anxiety disorders with weight change in a prospective community-based study of children followed up into adulthood. Archives of pediatrics & adolescent medicine, 160(3), 285-291.

Armstrong, K., Putt, M., Halbert, C. H., Grande, D., Schwartz, J. S., Liao, K., Marcus, N., Demeter, M. B., & Shea, J. A. (2013). Prior experiences of racial discrimination and racial differences in health care system distrust. Medical care, 51(2), 144–150. https://doi.org/10.1097/MLR.0b013e31827310a1

Assari, S., Gibbons, F. X., & Simons, R. (2018). Depression among Black Youth; Interaction of Class and Place. Brain sciences, 8(6), 108. https://doi.org/10.3390/brainsci8060108

Arroyo, C. G., & Zigler, E. (2014). Racial identity, academic achievement, and the psychological well-being of economically disadvantaged adolescents. By Arroyo, Carmen G.; Zigler, Edward, 69(c), 9998.

Armstrong, K., Putt, M., Halbert, C. H., Grande, D., Schwartz, J. S., Liao, K., Marcus, N., Demeter, M. B., & Shea, J. A. (2013). Prior experiences of racial discrimination and racial differences in health care system distrust. Medical care, 51(2), 144–150. https://doi.org/10.1097/MLR.0b013e31827310a1

Assari, S., Gibbons, F. X., & Simons, R. (2018). Depression among black youth; interaction of class and place. Brain Sciences, 8(6), 1–17. https://doi.org/10.3390/brainsci8060108

Avenevoli, S., Baio, J., Bitsko, R. H., Blumberg, S. J., Brody, D. J., Crosby, A., ... & Visser, S. N. (2013). Mental health surveillance among children--United States, 2005-2011.

Bailey, R. K., Mokonogho, J., & Kumar, A. (2019). Racial and ethnic differences in depression: current perspectives. Neuropsychiatric disease and treatment, 15, 603–609. https://doi.org/10.2147/NDT.S128584

Bellizzi, K. M., Aziz, N. M., Rowland, J. H., Weaver, K., Arora, N. K., Hamilton, A. S., … Keel, G. (2012). Double jeopardy? Age, race, and HRQOL in older adults with cancer. Journal of Cancer Epidemiology, 2012. https://doi.org/10.1155/2012/478642

Beach, M. C., Saha, S., Korthuis, P. T., Sharp, V., Cohn, J., Wilson, I. B., Eggly, S., Cooper, L. A., Roter, D., Sankar, A., & Moore, R. (2011). Patient-provider communication differs for black compared to white HIV-infected patients. AIDS and behavior, 15(4), 805–811. https://doi.org/10.1007/s10461-009-9664-5

Benard, S., & Correll, S. J. (2015). Normative discrimination and the motherhood penalty. Working in America: Continuity, Conflict, and Change in a New Economic Era, 1989(1), 271–282. https://doi.org/10.4324/9781315631011-38

Bentley, T. G. K., Palta, M., Paulsen, A. J., Cherepanov, D., Dunham, N. C., Feeny, D., … Fryback, D. G. (2011). Race and gender associations between obesity and nine health-related quality-of-life measures. Quality of Life Research, 20(5), 665–674. https://doi.org/10.1007/s11136-011-9878-7

Bitsko, R. H., Holbrook, J. R., Ghandour, R. M., Blumberg, S. J., Visser, S. N., Perou, R., & John, W. (2019). Epidemiology and Impact of Health Care Provider–Diagnosed Anxiety and Depression Among US Children. Journal of Developmental and Behavioral Pediatrics, 39(5), 395–403. https://doi.org/10.1097/DBP.0000000000000571.Epidemiology

Blair, I. V., Steiner, J. F., Fairclough, D. L., Hanratty, R., Price, D. W., Hirsh, H. K., ... & Havranek, E. P. (2013). Clinicians’ implicit ethnic/racial bias and perceptions of care among Black and Latino patients. The Annals of Family Medicine, 11(1), 43-52.

Boland, L., Graham, I. D., Légaré, F., Lewis, K., Jull, J., Shephard, A., … Stacey, D. (2019). Barriers and facilitators of pediatric shared decision-making: A systematic review. Implementation Science, 14(1). https://doi.org/10.1186/s13012-018-0851-5

Bostwick, W. B., Meyer, I., Aranda, F., Russell, S., Hughes, T., Birkett, M., & Mustanski, B. (2014). Mental health and suicidality among racially/ethnically diverse sexual minority youths. American Journal of Public Health, 104(6), 1129–1136. https://doi.org/10.2105/AJPH.2013.301749

Bradley S. J. (2001). Anxiety and mood disorders in children and adolescents: A practice update. Paediatrics & child health, 6(7), 459–463. https://doi.org/10.1093/pch/6.7.459

Byrd, A. S., Toth, A. T., & Stanford, F. C. (2018). Racial Disparities in Obesity Treatment. Current Obesity Report, 7(2), 130–138. https://doi.org/10.1007/s13679-018-0301-3.Racial

Brown, D., Schenk, S., Genent, D., Zernikow, B., & Wager, J. (2021). A scoping review of chronic pain in emerging adults. Pain reports, 6(1), e920. https://doi.org/10.1097/PR9.0000000000000920

Carpenter-Song, E., Chu, E., Drake, R. E., Ritsema, M., Smith, B., & Alverson, H. (2010). Ethno-cultural variations in the experience and meaning of mental illness and treatment: implications for access and utilization. Transcultural psychiatry, 47(2), 224–251. https://doi.org/10.1177/1363461510368906

CDC. (2021). Data and Statistics on Children' s Mental Health.

Chen, H., Cohen, P., Kasen, S., & Johnson, J. G. (2006). Adolescent Axis I and personality disorders predict quality of life during young adulthood. Journal of Adolescent Health, 39(1), 14-19.

Child and Adolescent Health Measurement Initiative (CAHMI) (2019). 2017-2018 National Survey of Children's Health (2 Years Combined Data Set): SPSS Data Set. Data Resource Center for Child and Adolescent Health supported by Cooperative Agreement U59MC27866 from the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [04/20/21] from childhealthdata.org

Colindres, M., Vu, M. B., & Davis, L. P. (2009). Latino caregiver's insight into childhood overweight management and relationships with their health care providers. Hispanic Health Care International, 7(1).

Clayman, M. L. (2018). Shared decision making's adolescence and transition into adulthood. Patient Education and Counseling, 101(10), 1723–1724. https://doi.org/10.1016/j.pec.2018.08.010

Cohen, P., Pine, D. S., Must, A., Kasen, S., & Brook, J. (1998). Prospective associations between somatic illness and mental illness from childhood to adulthood. American journal of epidemiology, 147(3), 232-239.

Como, D. H., Duker, L. I. S., Polido, J. C., & Cermak, S. A. (2019). The persistence of oral health disparities for african american children: A scoping review. International Journal of Environmental Research and Public Health, 16(5). https://doi.org/10.3390/ijerph16050710

Cook, M. N., Peterson, J., & Sheldon, C. (2009). Adolescent depression: An update and guide to clinical decision-making. Psychiatry, 6(9), 17–31.

Cooper-Patrick, L., Gallo, J. J., Gonzales, J. J., Vu, H. T., Powe, N. R., Nelson, C., & Ford, D. E. (1999). Race, gender, and partnership in the patient-physician relationship. JAMA, 282(6), 583–589. https://doi.org/10.1001/jama.282.6.583

Coyne, I., Amory, A., Kiernan, G., & Gibson, F. (2014). Children's participation in shared decision-making: Children, adolescents, parents and healthcare professionals' perspectives and experiences. European Journal of Oncology Nursing, 18(3), 273–280. https://doi.org/10.1016/j.ejon.2014.01.006

Coyne, I., & Harder, M. (2011). Children’s participation in decision-making: Balancing protection with shared decision-making using a situational perspective. Journal of Child Health Care, 15(4), 312–319. https://doi.org/10.1177/1367493511406570

Cummings, J. R., & Druss, B. G. (2011). Racial/ethnic differences in mental health service use among adolescents with major depression. Journal of the American Academy of Child and Adolescent Psychiatry, 50(2), 160–170. https://doi.org/10.1016/j.jaac.2010.11.004

Derrington, S. F., Paquette, E., & Johnson, K. A. (2018). Cross-cultural interactions and shared decision-making. Pediatrics, 142(November 2018), S187–S192. https://doi.org/10.1542/peds.2018-0516J

Devine, K. A., Monaghan, M., & Schwartz, L. A. (2017). Introduction to the Special Issue on Adolescent and Young Adult Health: Why We Care, How Far We Have Come, and Where We Are Going. Journal of Pediatric Psychology, 42(9), 903–909. https://doi.org/10.1093/jpepsy/jsx101

Drotar, D., & Rohan, J. M. (2013). Pediatric Adherence and Health Behavior Change. The Oxford Handbook of Health Communication, Behavior Change, and Treatment Adherence, (July 2019), 387.

Edbrooke-Childs, J., Jacob, J., Argent, R., Patalay, P., Deighton, J., & Wolpert, M. (2016). The relationship between child- and parent-reported shared decision making and child-, parent-, and clinician-reported treatment outcome in routinely collected child mental health services data. Clinical Child Psychology and Psychiatry, 21(2), 324–338. https://doi.org/10.1177/1359104515591226

Eichner, J. M., Johnson, B. H., Betts, J. M., Chitkara, M. B., Jewell, J. A., Lye, P. S., … Shelton, T. (2012). Patient- and family-centered care and the pediatrician’s role. Pediatrics, 129(2), 394–404. https://doi.org/10.1542/peds.2011-3084

Eligibility, N. I. S. (2019). National Survey of Children ’ s Health CATI Instrument. Health Care, 1(0607), 1–8.

Elwyn, G., Dehlendorf, C., Epstein, R. M., Marrin, K., White, J., & Frosch, D. L. (2014). Shared decision making and motivational interviewing: Achieving patient-centered care across the spectrum of health care problems. Annals of Family Medicine, 12(3), 270–275. https://doi.org/10.1370/afm.1615

Erickson, P. (2004). A health outcomes framework for assessing health status and quality of life: enhanced data for decision making. Journal of the National Cancer Institute. Monographs, 16803(33), 168–177. https://doi.org/10.1093/jncimonographs/lgh006

Feiss, R., & Pangelinan, M. M. (2021). Relationships between physical and mental health in adolescents from low-income, rural communities: Univariate and multivariate analyses. International Journal of Environmental Research and Public Health, 18(4), 1–16. https://doi.org/10.3390/ijerph18041372

Federal Interagency Forum on Child and Family Statistics. America’s children: Key national indicators of well-being, 2021. U.S. Government Printing Office.

Fiscella, K., Franks, P., Doescher, M. P., & Saver, B. G. (2002). Disparities in health care by race, ethnicity, and language among the insured: findings from a national sample. Medical care, 52-59.

Flower, K. B., Skinner, A. C., Yin, H. S., Rothman, R. L., Sanders, L. M., Delamater, A., & Perrin, E. M. (2017). Satisfaction With Communication in Primary Care for Spanish-Speaking and English-Speaking Parents. Academic pediatrics, 17(4), 416–423. https://doi.org/10.1016/j.acap.2017.01.005

Foster, G. D., Wadden, T. A., Makris, A. P., Davidson, D., Sanderson, R. S., Allison, D. B., & Kessler, A. (2003). Primary care physicians' attitudes about obesity and its treatment. Obesity Research, 11(10), 1168–1177. https://doi.org/10.1038/oby.2003.161

Frederick, C. B., Snellman, K., & Putnam, R. D. (2014). Increasing socioeconomic disparities in adolescent obesity. Proceedings of the National Academy of Sciences of the United States of America, 111(4), 1338–1342. https://doi.org/10.1073/pnas.1321355110

Fiks, A. G., & Noonan, K. G. (2013). Shared decision-making in pediatrics. Health Affairs, 32(4), 822. https://doi.org/10.1377/hlthaff.2013.0201

Garcia, C., Skay, C., Sieving, R., Naughton, S., & Bearinger, L. H. (2008). Family and racial factors associated with suicide and emotional distress among Latino students. Journal of School Health, 78(9), 487-495

Garber, J., & Weersing, V. R. (2010). Comorbidity of Anxiety and Depression in Youth: Implications for Treatment and Prevention. Clinical psychology: a publication of the

Division of Clinical Psychology of the American Psychological Association, 17(4), 293–306. https://doi.org/10.1111/j.1468-2850.2010.01221.x

Gee, G. C., & Ford, C. L. (2011). STRUCTURAL RACISM AND HEALTH INEQUITIES: Old Issues, New Directions. Du Bois review : social science research on race, 8(1), 115–132. https://doi.org/10.1017/S1742058X11000130

Goldston, D. B., Molock, S. D., Whitbeck, L. B., Murakami, J. L., Zayas, L. H., & Hall, G. C. N. (2008). Cultural considerations in adolescent suicide prevention and psychosocial treatment. American Psychologist, 63(1), 14.

Gudzune, K. A., Beach, M. C., Roter, D. L., & Cooper, L. A. (2013). Physicians build less rapport with obese patients. Obesity, 21(10), 2146-2152.

Hall, W. J., Chapman, M. V., Lee, K. M., Merino, Y. M., Thomas, T. W., Payne, B. K., Eng, E. Day, S. H., & Coyne-Beasley, T. (2015). Implicit Racial/Ethnic Bias Among Health Care Professionals and Its Influence on Health Care Outcomes: A Systematic Review. American journal of public health, 105(12), e60–e76. https://doi.org/10.2105/AJPH.2015.302903

Hale, K. L., Wallace, D. D., Blanco-Durán, D., Annis, I. E., Guzman, L. E., García, S. J., Pérez Jolles, M., Sleath, B. L., Elwyn, G., Stein, G. L., & Thomas, K. C. (2020). Conversations between Latina mothers and their child's mental health provider: An observational study of shared decision-making regarding pediatric patient mental health needs. Patient education and counseling, 103(1), 96–102. https://doi.org/10.1016/j.pec.2019.08.013

Hamann, J., Mendel, R., Bühner, M., Kissling, W., Cohen, R., Knipfer, E., & Eckstein, H. H. (2012). How should patients behave to facilitate shared decision making–the doctors' view. Health Expectations, 15(4), 360-366.

Hammen, C. (2009). Adolescent depression: Stressful interpersonal contexts and risk for recurrence. Current directions in psychological science, 18(4), 200-204.

Hatzenbuehler, M. L., Phelan, J. C., & Link, B. G. (2013). Stigma as a fundamental cause of population health inequalities. American journal of public health, 103(5), 813-821.

Hebl, M. R., & Xu, J. (2001). Weighing the care: physicians' reactions to the size of a patient. International journal of obesity, 25(8), 1246-1252.

Huizinga, M. M., Cooper, L. A., Bleich, S. N., Clark, J. M., & Beach, M. C. (2009). Physician respect for patients with obesity. Journal of general internal medicine, 24(11), 1236-1239.

Hoffman, K. M., Trawalter, S., Axt, J. R., & Oliver, M. N. (2016). Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites. Proceedings of the National Academy of Sciences of the United States of America, 113(16), 4296–4301. https://doi.org/10.1073/pnas.1516047113

Hollingshead, N. A., Ashburn-Nardo, L., Stewart, J. C., & Hirsh, A. T. (2016). The Pain Experience of Hispanic Americans: A Critical Literature Review and Conceptual Model. The journal of pain, 17(5), 513–528. https://doi.org/10.1016/j.jpain.2015.10.022

Hughes, T. M., Merath, K., Chen, Q., Sun, S., Palmer, E., Idrees, J. J., … Pawlik, T. M. (2018). Association of shared decision-making on patient-reported health outcomes and healthcare utilization. American Journal of Surgery, 216(1), 7–12. https://doi.org/10.1016/j.amjsurg.2018.01.011

Jordan, A., Wood, F., Edwards, A., Shepherd, V., & Joseph-Williams, N. (2018). What adolescents living with long-term conditions say about being involved in decision-making about their healthcare: a systematic review and narrative synthesis of preferences and experiences. Patient Education and Counseling, 101(10), 1725-1735.

Jordan, A., Joseph-Williams, N., Edwards, A., Holland-Hart, D., & Wood, F. (2019). “I’d Like to Have More of a Say Because It’s My Body”: Adolescents’ Perceptions Around Barriers and Facilitators to Shared Decision-Making. Journal of Adolescent Health, 65(5), 633–642. https://doi.org/10.1016/j.jadohealth.2019.05.024

Johnson, R. L., Roter, D., Powe, N. R., & Cooper, L. A. (2004). Patient race/ethnicity and quality of patient–physician communication during medical visits. American journal of public health, 94(12), 2084-2090.

Johnson, T. J., Winger, D. G., Hickey, R. W., Switzer, G. E., Miller, E., Nguyen, M. B., Saladino, R. A., & Hausmann, L. R. (2017). Comparison of Physician Implicit Racial Bias Toward Adults Versus Children. Academic pediatrics, 17(2), 120–126. https://doi.org/10.1016/j.acap.2016.08.010

Kane, L., & Ashbaugh, A. R. (2017). Simple and parallel mediation: {A} tutorial exploring anxiety sensitivity, sensation seeking, and gender. The Quantitative Methods for Psychology, 13(3), 148–165. https://doi.org/10.20982/tqmp.13.3.p148

Kaplan, R. M., & Frosch, D. L. (2005). Decision making in medicine and health care. Annual Review of Clinical Psychology, 1, 525–556. https://doi.org/10.1146/annurev.clinpsy.1.102803.144118

Kessler, R., Amminger, G., Aguilar-Gaxiola, S., Alonso, J., Lee, S., & Üstün, T. B. (2007). Age of onset of mental disorders: A review of recent literature. Current Opinion in Psychiatry, 20(4), 359–364. https://doi.org/10.1097/YCO.0b013e32816ebc8c

Kotecki, J. A., Gennuso, K. P., Givens, M. L., & Kindig, D. A. (2019). Separate and Sick: Residential Segregation and the Health of Children and Youth in Metropolitan Statistical Areas. Journal of Urban Health, 96(2), 149–158. https://doi.org/10.1007/s11524-018-00330-4

Krockow, E. M., Riviere, E., & Frosch, C. A. (2019). Improving shared health decision making for children and adolescents with chronic illness: A narrative literature review. Patient Education and Counseling, 102(4), 623–630. https://doi.org/10.1016/j.pec.2018.11.017

Kuhlthau, K. A., Bloom, S., Van Cleave, J., Knapp, A. A., Romm, D., Klatka, K., … Perrin, J. M. (2011). Evidence for family-centered care for children with special health care needs: A systematic review. Academic Pediatrics, 11(2), 136-143.e8. https://doi.org/10.1016/j.acap.2010.12.014

Kuk, J. L., Rotondi, M., Sui, X., Blair, S. N., & Ardern, C. I. (2018). Individuals with obesity but no other metabolic risk factors are not at significantly elevated all-cause mortality risk in men and women. *Clinical obesity*, *8*(5), 305-312.

Kuppermann, M., & Sawaya, G. (2015). Shared Decision-Making: Easy to Evoke, Challenging to Implement Miriam. JAMA, 175(2), 167–168. https://doi.org/10.1001/jamainternmed.2014.4606.Shared

Kuo, D. Z., Houtrow, A. J., Arango, P., Kuhlthau, K. A., Simmons, J. M., & Neff, J. M. (2012). Family-centered care: Current applications and future directions in pediatric health care. Maternal and Child Health Journal, 16(2), 297–305. https://doi.org/10.1007/s10995-011-0751-7

Landi, G., Pakenham, K. I., Benassi, M., Giovagnoli, S., Tossani, E., & Grandi, S. (2021). A model of the effects of parental illness on youth adjustment and family functioning: The moderating effects of psychological flexibility on youth caregiving and stress. International Journal of Environmental Research and Public Health, 18(9). https://doi.org/10.3390/ijerph18094902

Langer, D., & Jensen-Doss, A. (2018). Shared Decision-Making in Youth Mental Health Care: Using the Evidence to Plan Treatments Collaboratively. Journal of Clinical Child Adolescent Psychology, 47(5), 100–106. https://doi.org/10.1080/15374416.2016.1247358.Shared

Langer, D. A., & Jensen-Doss, A. (2018). Shared Decision-Making in Youth Mental Health Care: Using the Evidence to Plan Treatments Collaboratively. Journal of Clinical Child and Adolescent Psychology. https://doi.org/10.1080/15374416.2016.1247358

Larson, K., Cull, W. L., Racine, A. D., & Olson, L. M. (2016). Trends in access to health care services for US children: 2000-2014. Pediatrics, 138(6). https://doi.org/10.1542/peds.2016-2176

Lau, M., Lin, H., & Flores, G. (2012). Racial/ethnic disparities in health and health care among U.S. adolescents. Health Services Research, 47(5), 2031–2059. https://doi.org/10.1111/j.1475-6773.2012.01394.x

Leahy, R. L. (2002). Decision making and personality disorders. Journal of Cognitive Psychotherapy, 16(2), 209-225.

Leykin, Y., Roberts, C. S., & Derubeis, R. J. (2011). Decision-Making and Depressive Symptomatology. Cognitive therapy and research, 35(4), 333–341. https://doi.org/10.1007/s10608-010-9308-0

Lichstein, J. C., Ghandour, R. M., & Mann, M. Y. (2018). Access to the medical home among children with and without special health care needs. Pediatrics, 142(6). https://doi.org/10.1542/peds.2018-1795

Lim, C. S., Welkom, J. S., Cohen, L. L., & Osunkwo, I. (2012). Evaluating the protective role of racial identity in children with sickle cell disease. Journal of Pediatric Psychology, 37(8), 832–842. https://doi.org/10.1093/jpepsy/jss059

Lim, C. S., Gowey, M. A., Silverstein, J., Dumont-Driscoll, M., & Janicke, D. M. (2016). Depressive Symptoms, Ethnic Identity, and Health-Related Quality of Life in Obese Youth. Journal of Pediatric Psychology, 41(4), 441–452. https://doi.org/10.1093/jpepsy/jsv014

Lindsey, M. A., Sheftall, A. H., Xiao, Y., & Joe, S. (2019). Trends of Suicidal Behaviors Among High School Students in the United States: 1991–2017. Pediatrics, 144(5), e20191187. https://doi.org/10.1542/peds.2019-1187

Liverpool, S., Pereira, B., Hayes, D., Wolpert, M., & Edbrooke-Childs, J. (2021). A scoping review and assessment of essential elements of shared decision-making of parent-involved interventions in child and adolescent mental health. European Child & Adolescent Psychiatry, 30(9), 1319-1338.

Lown, B. A., Hanson, J. L., & Clark, W. D. (2009). Mutual influence in shared decision making: a collaborative study of patients and physicians. Health Expectations, 12(2), 160-174.

Lubetkin, E. I., Jia, H., Franks, P., & Gold, M. R. (2005). Relationship among sociodemographic factors, clinical conditions, and health-related quality of life: Examining the EQ-5D in the U.S. general population. Quality of Life Research, 14(10), 2187–2196. https://doi.org/10.1007/s11136-005-8028-5

Maina, I. W., Belton, T. D., Ginzberg, S., Singh, A., & Johnson, T. J. (2018). A decade of studying implicit racial/ethnic bias in healthcare providers using the implicit association test. Social science & medicine (1982), 199, 219–229. https://doi.org/10.1016/j.socscimed.2017.05.009

Makol, B. A., Youngstrom, E. A., Racz, S. J., Qasmieh, N., Glenn, L. E., & De Los Reyes, A. (2020). Integrating multiple informants' reports: How conceptual and measurement models may address long-standing problems in clinical decision-making. Clinical Psychological Science, 8(6), 953-970.

Makoul, G., & Clayman, M. L. (2006). An integrative model of shared decision making in medical encounters. Patient Education and Counseling, 60(3), 301–312. https://doi.org/10.1016/j.pec.2005.06.010

Marrast, L., Himmelstein, D. U., & Woolhandler, S. (2016). Racial and Ethnic Disparities in Mental Health Care for Children and Young Adults: A National Study. International Journal of Health Services, 46(4), 810–824. https://doi.org/10.1177/0020731416662736

Martin-Gutierrez, G., Wallander, J. L., Yang, Y. (June), Depaoli, S., Elliott, M. N., Coker, T. R., & Schuster, M. A. (2021). Racial/Ethnic Differences in the Relationship Between Stressful Life Events and Quality of Life in Adolescents. Journal of Adolescent Health, 68(2), 292–299. https://doi.org/10.1016/j.jadohealth.2020.05.055

Martinez, R. O., & Dukes, R. L. (1997). The effects of ethnic identity, ethnicity, and gender on adolescent well-being. Journal of Youth and Adolescence, 26(5), 503–516. https://doi.org/10.1023/A:1024525821078

McDermott, E. R., Umaña-Taylor, A. J., & Martinez-Fuentes, S. (2018). Family ethnic socialization predicts better academic outcomes via proactive coping with discrimination and increased self-efficacy. Journal of Adolescence, 65(November 2017), 189–195. https://doi.org/10.1016/j.adolescence.2018.03.011

Meghani, S. H., Brooks, J. M., Gipson-Jones, T., Waite, R., Whitfield-Harris, L., & Deatrick, J. A. (2009). Patient-provider race-concordance: Does it matter in improving minority patients' health outcomes? Ethnicity and Health, 14(1), 107–130. https://doi.org/10.1080/13557850802227031

Meredith, L. S., Stein, B. D., Paddock, S. M., Jaycox, L. H., Quinn, V. P., Chandra, A., & Burnam, A. (2009). Perceived barriers to treatment for adolescent depression. Medical Care, 677-685

Merikangas, K. R., Calkins, M. E., Burstein, M., He, J. P., Chiavacci, R., Lateef, T., Ruparel, K., Gur, R. C., Lehner, T., Hakonarson, H., & Gur, R. E. (2015). Comorbidity of physical and mental disorders in the neurodevelopmental genomics cohort study. Pediatrics, 135(4), e927–e938. https://doi.org/10.1542/peds.2014-1444

Michael R. Bronsert, William G. Henderson, Robert Valuck, Patrick Hosokawa, and K. H. (2008). NIH Public Access. Bone, 23(1), 1–7. https://doi.org/10.1007/s10461-009-9664-5.Patient

Miller, D. B. (1999). Racial socialization and racial identity: Can they promote resiliency for African American adolescents? Adolescence, 34(135), 493–501.

Mold, F., & Forbes, A. (2013). Patients' and professionals' experiences and perspectives of obesity in health-care settings: a synthesis of current research. Health expectations : an international journal of public participation in health care and health policy, 16(2), 119–142. https://doi.org/10.1111/j.1369-7625.2011.00699.x

Monahan, K. C., Oesterle, S., & Hawkins, J. D. (2016). Alcohol Use in Adolescence, 42(5), 621–638. https://doi.org/10.1002/jcop.21642.The

Moreno Villares, J. M. (2018). Stigma experienced by children and adolescents with obesity. Acta Pediatrica Espanola, 76(3–4), 63.

Morales, L. S., Cunningham, W. E., Brown, J. A., Liu, H., & Hays, R. D. (1999). Are Latinos less satisfied with communication by health care providers?. Journal of general internal medicine, 14(7), 409- 417.

Munford, M. B. (1994). Relationship of Gender, Self-Esteem, Social Class, and Racial Identity to Depression in Blacks. Journal of Black Psychology. https://doi.org/10.1177/00957984940202005

Murray, C. B., Groenewald, C. B., de la Vega, R., & Palermo, T. M. (2020). Long-term impact of adolescent chronic pain on young adult educational, vocational, and social outcomes. Pain, 161(2), 439–445. https://doi.org/10.1097/j.pain.0000000000001732

Negri, V., & Odiot, T. (1990). Protection et conservation des parcellaires antiques dans le paysage actuel. Revue Archéologique Du Centre de La France, 29(2), 117–130. https://doi.org/10.3406/racf.1990.2625

Nelson, A. (2002). Unequal treatment: confronting racial and ethnic disparities in health care. Journal of the national medical association, 94(8), 666

Ngadimon, I. W., Islahudin, F., Mohamed Shah, N., Md. Hatah, E., & Makmor-Bakry, M. (2017). Improving shared decision-making in adolescents through antibiotic education.

International Journal of Clinical Pharmacy, 39(1), 120–125. https://doi.org/10.1007/s11096-016-0407-1

Oberg, C., Colianni, S., & King-Schultz, L. (2016). Child Health Disparities in the 21st Century. Current Problems in Pediatric and Adolescent Health Care, 46(9), 291–312. https://doi.org/10.1016/j.cppeds.2016.07.001

Ogden, C. L., Fryar, C. D., Martin, C. B., Freedman, D. S., Carroll, M. D., Gu, Q., & Hales, C. M. (2020). Trends in obesity prevalence by race and hispanic origin - 1999-2000 to 2017-2018. JAMA - Journal of the American Medical Association, 324(12), 1208–1210. https://doi.org/10.1001/jama.2020.14590

Paradies, Y., Ben, J., Denson, N., Elias, A., Priest, N., Pieterse, A., … Gee, G. (2015). Racism as a determinant of health: A systematic review and meta-analysis. PLoS ONE, 10(9), 1–48. https://doi.org/10.1371/journal.pone.0138511

Peek, M. E., Odoms-Young, A., Quinn, M. T., Gorawara-Bhat, R., Wilson, S. C., & Chin, M. H. (2010). Details for Manuscript Number: SSM-D-08-01910 R2; Race and Shared Decision-Making: Perspectives of African-Americans with Diabetes; Soc Sci Med, 71(1), 1–9. https://doi.org/10.1016/j.socscimed.2010.03.014.

Peek, M. E., Nunez-Smith, M., Drum, M., & Lewis, T. T. (2011). Adapting the everyday discrimination scale to medical settings: reliability and validity testing in a sample of African American patients. Ethnicity & disease, 21(4), 502–509.

Peek, M. E., Lopez, F. Y., Williams, H. S., Xu, L. J., McNulty, M. C., Acree, M. E., & Schneider, J. A. (2016). Development of a Conceptual Framework for Understanding Shared Decision making Among African-American LGBT Patients and their Clinicians. Journal of General Internal Medicine, 31(6), 677–687. https://doi.org/10.1007/s11606-016-3616-3

Pereira, C., Palta, M., Mullahy, J., & Fryback, D. (2011). Race and preference-based health-related quality of life measures in the United States. Quality of Life Research, 20(6), 969–978. https://doi.org/10.1007/s11136-010-9813-3.Race

Puhl, R. M., & Brownell, K. D. (2006). Confronting and coping with weight stigma: An investigation of overweight and obese adults. Obesity, 14(10), 1802–1815. https://doi.org/10.1038/oby.2006.208

Puhl, R. M., & Heuer, C. A. (2009). The stigma of obesity: a review and update. Obesity, 17(5), 941.

Puhl, R. M., & King, K. M. (2013). Weight discrimination and bullying. Best practice & research Clinical endocrinology & metabolism, 27(2), 117-127.

Rahman, M., Temple, J. R., Breitkopf, C. R., & Berenson, A. B. (2009). Racial differences in body fat distribution among reproductive-aged women. Metabolism: clinical and experimental, 58(9), 1329–1337. https://doi.org/10.1016/j.metabol.2009.04.017

Ratanawongsa, N., Zikmund-Fisher, B. J., Couper, M. P., Van Hoewyk, J., & Powe, N. R. (2010). Race, ethnicity, and shared decision making for hyperlipidemia and hypertension treatment: The DECISIONS survey. Medical Decision Making, 30(5). https://doi.org/10.1177/0272989X10378699

Reyes-Gibby, C. C., Aday, L. A., Todd, K. H., Cleeland, C. S., & Anderson, K. O. (2007). Pain in aging community-dwelling adults in the United States: non-Hispanic whites, non-Hispanic blacks, and Hispanics. The Journal of Pain, 8(1), 75-84.

Rigby, D. (2015). Shared decision making. Australian Journal of Pharmacy, 96(1144), 64–67. https://doi.org/10.1055/s-0039-1677417

Rossen, L. M., & Talih, M. (2014). Social determinants of disparities in weight among US children and adolescents. Annals of Epidemiology, 24(10), 705-713.e2. https://doi.org/10.1016/j.annepidem.2014.07.010

Rudolph, K. D. (2009). The interpersonal context of adolescent depression.

Russell, L. (2017). Chronic Illness and Disability. Sociology for Health Professionals, 122–139. https://doi.org/10.4135/9781526401922.n9

Sabin, J. A., & Greenwald, A. G. (2012). The influence of implicit bias on treatment recommendations for 4 common pediatric conditions: pain, urinary tract infection, attention deficit hyperactivity disorder, and asthma. American journal of public health, 102(5), 988–995. https://doi.org/10.2105/AJPH.2011.300621

Sabin, J. A., Marini, M., & Nosek, B. A. (2012). Implicit and Explicit Anti-Fat Bias among a Large Sample of Medical Doctors by BMI, Race/Ethnicity and Gender. PLoS ONE, 7(11), 1–7. https://doi.org/10.1371/journal.pone.0048448

Saha, S., Arbelaez, J. J., & Cooper, L. A. (2003). Patient-Physician Relationships and Racial Disparities in the Quality of Health Care. American Journal of Public Health, 93(10), 1713–1719. https://doi.org/10.2105/AJPH.93.10.1713

Sambasivarao, S. V. (2013). Where is the evidence? A systematic review of shared decision making and patient outcomes. Journal of the Society for Medical Decision Making, 18(9), 1199–1216. https://doi.org/10.1177/0272989X14551638.Where

Sellers, R. M., Caldwell, C. H., Schmeelk-Cone, K. H., & Zimmerman, M. A. (2003). Racial identity, racial discrimination, perceived stress, and psychological distress among African American young adults. Journal of Health and Social behavior, 302-317

Sellers, R. M., & Shelton, J. N. (2003). The Role of Racial Identity in Perceived Racial Discrimination. Journal of Personality and Social Psychology, 84(5), 1079–1092. https://doi.org/10.1037/0022-3514.84.5.1079

Serván-Mori, E., Gonzalez-Robledo, L. M., Nigenda, G., Quezada, A. D., González-Robledo, M. C., & Rodríguez-Cuevas, F. G. (2021). Prevalence of Depression and Generalized Anxiety Disorder Among Mexican Indigenous Adolescents and Young Adults: Challenges for Healthcare. Child Psychiatry and Human Development, 52(1), 179–189. https://doi.org/10.1007/s10578-020-01001-9

Shepherd, H. L., Tattersall, M. H., & Butow, P. N. (2008). Physician-identified factors affecting patient participation in reaching treatment decisions. Journal of Clinical Oncology, 26(10), 1724-1731.

Shonkoff, J. P., Garner, A. S., Siegel, B. S., Dobbins, M. I., Earls, M. F., McGuinn, L., … Wegner, L. M. (2012). The lifelong effects of early childhood adversity and toxic stress. Pediatrics, 129(1). https://doi.org/10.1542/peds.2011-2663

Spooner, K. K., Salemi, J. L., Salihu, H. M., & Zoorob, R. J. (2016). Disparities in perceived patient-provider communication quality in the United States: Trends and correlates. Patient Education and Counseling, 99(5), 844–854. https://doi.org/10.1016/j.pec.2015.12.007

Staton, L. J., Panda, M., Chen, I., Genao, I., Kurz, J., Pasanen, M., ... & Cykert, S. (2007). When race matters: disagreement in pain perception between patients and their physicians in primary care. Journal of the National Medical Association, 99(5), 532.

Stanford, E. A., Chambers, C. T., Biesanz, J. C., & Chen, E. (2008). The frequency, trajectories and predictors of adolescent recurrent pain: a population-based approach. *Pain*, *138*(1), 11–21. https://doi.org/10.1016/j.pain.2007.10.032

Steinberg, L., & Morris, A. S. (2001). Adolescent development. Annual Review of Psychology, 52, 83–110. https://doi.org/10.1146/annurev.psych.52.1.83

Stiggelbout, A. M., Van Der Weijden, T., De Wit, M. P. T., Frosch, D., Légaré, F., Montori, V. M., Elwyn, G. (2012). Shared decision making: Really putting patients at the centre of healthcare. BMJ (Online), 344(7842), 1–6. https://doi.org/10.1136/bmj.e256

Story, M., French, S. A., Resnick, M. D., & Blum, R. W. (1995). Ethnic/racial and socioeconomic differences in dieting behaviors and body image perceptions in adolescents. International Journal of Eating Disorders, 18(2), 173-179.

Ströhle, A., Höfler, M., Pfister, H., Müller, A. G., Hoyer, J., Wittchen, H. U., & Lieb, R. (2007). Physical activity and prevalence and incidence of mental disorders in adolescents and young adults. Psychological medicine, 37(11), 1657-1666

Tait, R. C., & Chibnall, J. T. (2014). Racial/ethnic disparities in the assessment and treatment of pain. American Psychologist, 69(2), 131–141. https://doi.org/10.1037/a0035204

Tom, D. M., Aquino, C., Arredondo, A. R., & Foster, B. A. (2017). Parent Preferences for Shared Decision-making in Acute Versus Chronic Illness. Hospital Pediatrics, 7(10), 602–609. https://doi.org/10.1542/hpeds.2017-0049

Trent, M., Dooley, D. G., Dougé, J., Trent, M. E., Cavanaugh, R. M., Lacroix, A. E., … Wallace, S. B. (2019). The impact of racism on child and adolescent health. Pediatrics, 144(2). https://doi.org/10.1542/peds.2019-1765

Turner, J. C., & Oakes, P. J. (1986). Reference To Individualism , Interactionism and Social Influence. British Journal of Social Psychology, 25, 237–252.

Umaña-Taylor, A. J., & Updegraff, K. A. (2007). Latino adolescents’ mental health: Exploring the interrelations among discrimination, ethnic identity, cultural orientation, self-esteem, and depressive symptoms. Journal of Adolescence, 30(4), 549–567. https://doi.org/10.1016/j.adolescence.2006.08.002

Vo, D. X., & Park, J. M. (2008). Racial/Ethnic disparities and culturally competent health care among youth and young men. American Journal of Men's Health, 2(2), 192–205. https://doi.org/10.1177/1557988308317758

Waters, E., Stewart-Brown, S., & Fitzpatrick, R. (2003). Agreement between adolescent self-report and parent reports of health and well-being: Results of an epidemiological study. Child: Care, Health and Development, 29(6), 501–509. https://doi.org/10.1046/j.1365-2214.2003.00370.x

Weiss, E. M., Clark, J. D., Heike, C. L., Rosenberg, A. R., Shah, S. K., Wilfond, B. S., & Opel, D. J. (2019). Gaps in the implementation of shared decision-making: illustrative cases. Pediatrics, 143(3). https://doi.org/10.1542/peds.2018-3055

Whitley, R. (2009). The implications of race and ethnicity for shared decision-making. Psychiatric Rehabilitation Journal, 32(3), 227–230. https://doi.org/10.2975/32.3.2009.227.230

Whitley, R. (2009). The implications of race and ethnicity for shared decision-making. Psychiatric Rehabilitation Journal, 32(3), 227–230. https://doi.org/10.2975/32.3.2009.227.230

Wigfall, L., & Tanner, A. (2018). Health literacy and healthcare engagement as predictors of shared decision making among adult information seekers in the United States: a secondary data analysis of the Health Information. Journal of Cancer Education, 33(1), 67–73. https://doi.org/10.1007/s13187-016-1052-z.Health

Williams, D. R., Yu, Y., Jackson, J. S., & Anderson, N. B. (1997). Racial differences in physical and mental health. Socio-economic status, stress and discrimination. Journal of Health Psychology, 2(3), 335–351. https://doi.org/10.1177/135910539700200305

Williams, D. R., Gonzalez, H. M., Neighbors, H., Nesse, R., Abelson, J. M., Sweetman, J., & Jackson, J. S. (2007). Prevalence and distribution of major depressive disorder in African Americans, Caribbean blacks, and non-Hispanic whites: results from the National Survey of American Life. Archives of general psychiatry, 64(3), 305-315.

Williams, D. R., Lawrence, J. A., & Davis, B. A. (2019). Racism and health: evidence and needed research. *Annual review of public health*, *40*, 105-125

Williams, D. R., & Mohammed, S. A. (2009). Discrimination and racial disparities in health: Evidence and needed research. Journal of Behavioral Medicine, 32(1), 20–47. https://doi.org/10.1007/s10865-008-9185-0

Wyatt, K. D., List, B., Brinkman, W. B., Prutsky Lopez, G., Asi, N., Erwin, P., … LeBlanc, A. (2015). Shared Decision Making in Pediatrics: A Systematic Review and Meta-analysis. Academic Pediatrics, 15(6), 573–583. https://doi.org/10.1016/j.acap.2015.03.011

Zafari, Z., Keyes, K. M., Jiao, B., Williams, S. Z., & Muennig, P. A. (2020). Differences between blacks and whites in well-being, beliefs, emotional states, behaviors and survival, 1978-2014. PloS One, 15(9), e0238919. https://doi.org/10.1371/journal.pone.0238919

Zeuner, R., Frosch, D. L., Kuzemchak, M. D., & Politi, M. C. (2015). Physicians' perceptions of shared decision-making behaviours: a qualitative study demonstrating the continued chasm between aspirations and clinical practice. Health Expectations, 18(6), 2465-2476.

Appendix A
Hierarchical Regression for FCC and Pain in Black Adolescents

Black FCC							
Regression coefficients							
Step 1	Controls	B^1	SE^2	β^3	ΔR^2	t	p
	Age	-.00	.01	-.00	.01	-.16	.88
	Sex	-.00	.03	-.01		-.24	.81
	Health Insurance	-.00	.00	-.01		-.44	.66
	Parental Education	.11	.03	.11		3.39	.00**
Step 2		B^1	SE^2	β^3	ΔR^2	t	p
	Pain	-.00	.00	-.01	.01	-.04	.96

Appendix B

Hierarchical Regression for FCC and Pain in Latinx Adolescents

Latinx FCC								Latinx SDM						
Regression coefficients														
Step 1	Controls	B[1]	SE[2]	β[3]	ΔR^2	t	p	Controls	B[1]	SE[2]	β[3]	ΔR^2	t	p
	Age	-.02	.01	-.04	.01	-1.75	.08	Age	-.00	.02	-.02	.01	-.40	.69
	Sex	.03	.03	.02		.92	.35	Sex	.05	.06	.04		.85	.40
	Health Insurance	.00	.00	.02		.72	.47	Health Insurance	.04	.16	.01		.27	.79
	Parental Education	.08	.02	.08		3.23	.00	Parental Education	.15	.05	.13		2.86	.00**
Step 2		B[1]	SE[2]	β[3]	ΔR^2	t	p		B[1]	SE[2]	β[3]	ΔR^2	t	p
	Pain	.00	.00	.03	.01	1.24	.23	Pain	-.00	.01	-.02	.01	-.46	.64

Appendix C
Hierarchical Regression for FCC, SDM, and Obesity in Latinx Adolescents

Latinx FCC							Latinx SDM						
Regression coefficients													
Step 1	Controls	B^1	SE^2	β^3	ΔR^2	t	p	Controls	B^1	SE^2	β^3	ΔR^2	t	p
	Age	-.02	.01	-.05	.01	-2.10	.04*	Age	-.01	.02	-.02	.01	-.43	.67
	Sex	.02	.03	.02		.71	.48	Sex	.03	.06	.02		.50	.62
	Health Insurance	.00	.01	.02		.58	.56	Health Insurance	.11	.16	.03		.70	.49
	Parental Education	.06	.03	.07		2.56	.01*	Parental Education	.14	.06	.13		2.59	.01*
Step 2		B^1	SE^2	β^3	ΔR^2	t	p		B^1	SE^2	β^3	ΔR^2	t	p
	Obesity	-.00	.02	-.02	.02	-.46	.00**	Obesity	-.11	.06	-.09	.01	-1.83	.07

Appendix D
Hierarchical Regression for FCC and Mental in Black Adolescents

Black FCC							
Regression coefficients							
Step 1	Controls	B[1]	SE[2]	β[3]	ΔR²	t	p
	Age	-.00	.01	-.01	.01	-.18	.86
	Sex	-.01	.03	-.01		-.40	.68
	Health Insurance	-.00	.00	-.01		-.45	.65
	Parental Education	.10	.03	.10		3.09	.00
Step 2		B[1]	SE[2]	β[3]	ΔR²	t	p
	Mental Health	-.15	.05	-.09	.01	-2.90	.02

Appendix E
Hierarchical Regression for FCC, SDM and Mental Health in Latinx Adolescents

Latinx FCC							Latinx SDM						
Regression coefficients													
Step 1	Controls	B^1	SE^2	β^3	ΔR^2	t	p	Controls	B^1	SE^2	β^3	ΔR^2	t	p
	Age	-.01	.01	-.04	.00	-1.58	.11	Age	-.00	.02	-.01	.01	-.30	.76
	Sex	.03	.03	.02		.99	.32	Sex	-.06	.06	-.05		-1.05	.30
	Health Insurance	.00	.00	.02		.70	.48	Health Insurance	.04	.16	.01		-.27	.79
	Parental Education	.07	.02	.08		3.08	.00	Parental Education	.15	.05	.13		2.75	.01*
Step 2		B^1	SE^2	β^3	ΔR^2	t	p		B^1	SE^2	β^3	ΔR^2	t	p
	Mental Health	-.09	.04	-.06	.00	-2.32	.02	Pain	-.15	.06	-.12	.01	-2.51	.01

Appendix F
Physical Health Questions

Pain	**During the past 12 months, has this child had frequent or chronic difficulty with any of the following?** d. Repeated or chronic physical pain, including headaches or other back or body pain → Yes or No
Obesity	Assessment of body mass index (BMI) in children and teenagers is approached differently than for adults. Because growth patterns differ, BMI in youth is age and gender-specific. In the NSCH, BMI is based on parents' recollection of the selected child's height and weight.

Appendix G
Mental Health Questions

Anxiety	**Has a doctor or other health care provider EVER told you that this child has…** A19) Anxiety Problems? Yes or No ➔ If Yes, does this child CURRENTLY have the condition? Yes or No
Depression	Has a doctor or other health care provider EVER told you that this child has… A20) Depression? Yes or No ➔ If Yes, does this child CURRENTLY have the condition? Yes or No

Appendix H
Family-Centered Care Scale

Instructions: Answer the following questions only if this child had a health care visit in the past 12 months.

During the past 12 months, how often did this child's doctor or other health care providers…

1	2	3	4
Never	Sometimes	Usually	Always
a. Spend enough time with this child?			
b. Listen carefully to you?			
c. Show sensitivity to your family's values and customs?			
d. Provide the specific information you needed concerning this child?			
f. Help you feel like a partner in this child's care?			

Appendix I
Shared Decision-Making Scale

2017: DURING THE PAST 12 MONTHS, were any decisions needed about this child’s health care services or treatment, such as whether to start or stop a prescription or therapy services, get a referral to a specialist, or have a medical procedure?

2018: DURING THE PAST 12 MONTHS, did this child need any decisions to be made regarding his or her health care, such as whether to get prescriptions, referrals, or procedures? Yes or No

If yes, During the past 12 months, how often did this child’s doctors or other health care providers …

1	2	3	4
Never	Sometimes	Usually	Always
a. Discuss with you the range of options to consider for his or her health care or treatment?			
b. Make it easy for you to raise concerns or disagree with recommendations for this child’s health care?			
c. Work with you to decide together which health care and treatment choices would be best for this child?			

Vita

Mona Quarless was born on September 26th, 1990 in Woodbridge, England. She graduated from Marymount School of New York in Manhattan, New York in 2008. Mona received her Bachelor of the Arts from Middlebury College in Middlebury, Vermont in 2012. She received her Master of Education from Vanderbilt University in Nashville, TN in 2016. She subsequently received her Master of Science in Health Psychology from Virginia Commonwealth University in 2019. Throughout Mona’s graduate career her research has broadly focused on the social determinants of health—specifically social context, physical environment, and health care resources. Her current research interests include the physical and mental health of children and adolescents and the implementation of shared decision-making.