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Racial Disparities in the Diagnosis and Treatment of Type 1 Diabetes in Black American Youth

Kierra Mitchell
Scripps College

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**RACIAL DISPARITIES IN THE DIAGNOSIS AND TREATMENT
OF TYPE 1 DIABETES IN BLACK AMERICAN YOUTH**

A THESIS PRESENTED

BY

KIERRA R. MITCHELL

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Abstract

Introduction: Rates of childhood-onset type 1 diabetes (T1D) are steadily increasing among American youth, yet Black Americans are more likely to suffer from serious T1D-related complications caused by poor glycemic control. The aim of this thesis is to determine the external factors that are causing discrepancies in the development, diagnosis, treatment, and long-term management of T1D in Black youth.

Methods: Epidemiological studies were compiled from the American Diabetes Association, Center for Disease Control (CDC), International Diabetes Foundation (IDF), Kaiser Family Foundation (KFF), and the Claremont Colleges Library network to identify the sociocultural aspects that negatively affect long-term glycemic control in Black youth.

Results: Studies indicate that Black youth with T1D are more likely to face disadvantages in treatment regimen which are attributed to insurance coverage, socioeconomic status, education level, and implicit bias. Most studies demonstrate that these factors result in poor glycemic control, which subsequently leads to severe dysglycemia-related complications later in life.

Conclusion and Discussion: Many Black youth who suffer from T1D receive insufficient healthcare, which is often exacerbated by a lack of social and economic resources. As a result, they may not have the means to maintain consistent, healthy glycemic levels. System-level changes are necessary to change the morbidity and mortality of T1D in Black youth. Future research should include the analysis of other racial minority groups in order to uncover additional institutional disparities.

Introduction

In the United States, over 30 million people suffer from diabetes mellitus (DM). Of this population, the *Centers for Disease Control and Prevention* (CDC) estimates that 5% have been diagnosed with type 1 diabetes (T1D) — nearly 200,000 of whom are under 20 years old. The *American Diabetes Association* (ADA) defines T1D as a metabolic disease that negatively affects insulin production and prevents **glycemic control**.¹ By definition, the body is unable to produce insulin sufficiently, thereby causing elevated levels of glucose in the bloodstream. Before official diagnosis, a person suffering from T1D may experience symptoms of **dysglycemia** ranging from **polyuria** and **polydipsia** to sudden, rapid weight loss. These symptoms and the eventual diagnosis of T1D are more likely to occur during adolescence. When comparing racial statistics in the United States, White Americans are more likely to develop T1D than Black Americans (Dabelea *et al.*, 2014). Despite the smaller proportion of Blacks suffering from T1D compared to Whites, Black people are 2.4 times more likely to die from severe complications related to the disease (Spanakis and Golden, 2013). These statistics raise concerns regarding the contribution of external factors that may be causing disproportionately negative outcomes.

Long-term survivors of T1D are more likely to face severe complications such as kidney failure, lower-limb amputations, depression, and even death as a result of prolonged, poor glycemic control. However, in an epidemiological review of diabetes and diabetes-related complications led by Spanakis *et al.* (2013), the study revealed that outcomes are significantly worse for Black people in terms of cardiovascular health,

¹ All bolded terms are defined in the glossary

retinopathy, nephropathy, neuropathy, and end-stage renal disease (ESRD).

Interestingly, this trend also exists for the other racial minority groups, such as Mexican and Native Americans, that were included in this study. Given the severity of these complications, it is critical to identify and eliminate the genetic, racial, and socioeconomic obstacles that characterize this disease.

Unfortunately, there are few studies that focus specifically on T1D complications in Black children and adolescents. In general, there is very limited involvement of Black T1D patients in clinical trials, which negatively affects the representative nature of this research. In addition, in most of the studies that are currently available, data for Black T1D patients is often grouped with type 2 diabetes incidences. Therefore, this thesis seeks to compile current literature regarding how behavioral and socioeconomic disparities affect those who are diagnosed during childhood and lead to worse T1D complications over time. Specifically, the present study will focus on how implicit bias and disparities in treatment method, insurance coverage, education, and socioeconomic status correlate with extreme dysglycemia complications. With this information we can draw conclusions as to how we, as a society, can attempt to remedy these disparities. Understanding the source and cause of the increase in T1D-related incidences among the Black community will enable legislators, doctors, and researchers to develop effective policies that prevent or slow the rising prevalence of this disease.

Background Information

Genetic Factors

In order to understand the varying effects that T1D has on Blacks in comparison to other racial groups, it is important to have a thorough understanding of the disease itself. To begin, the development of T1D starts at the genetic level. Although family history is often considered a major indicator of T1D susceptibility, surprisingly, only 20% of people diagnosed with T1D have a known family history of the disease (CDC, 2018; Tao *et al.*, 2010). Thus, familial relationships do not necessarily indicate the likelihood of developing T1D. Rather, as proven by genome-wide association study (GWAS) meta-analyses, it is the presence of specific genetic markers that determine T1D progression. In a study completed by Robertson *et al.* (2009), 41 distinct loci were found in the *Type 1 Diabetes Genetics Consortium* (T1DGC) and associated with T1D risk. While the exact impact of each locus is still being examined, research suggests that the presence of islet autoimmunity also serves as an indicator of T1D susceptibility. Further, the amount of islet autoantibodies positively correlates with the likelihood of disease development. According to Jacobsen *et al.* (2018), the progression of T1D occurs in three stages determined by the level of beta-cell destruction in the pancreas: *Stage one* is characterized by the presence of two or more islet autoantibodies with **normoglycemia**, followed by progression to dysglycemia in *stage two*, and the eventual adherence to diabetes criteria set forth by the ADA in *stage three*. In short, early manifestations of T1D have little to no symptoms until substantial loss of beta-cell mass occurs during stage 3. At this point, the pancreas no longer produces a sufficient

amount of insulin to maintain glucose homeostasis, resulting in **diabetic ketoacidosis (DKA)** (Robertson and Rich, 2018). In summary, genetic factors such as autoimmune pancreatic islets and genetic markers are thought to be involved in each stage of the development of T1D at varying levels. The presence of these factors thereby determine the rate of progression and subsequent occurrence of diabetic complications.

Prevention

At this point in time, there are no known methods that can fully prevent the development of T1D. Due to the lack of obvious symptoms as defined by stage one, type 1 diabetics may not recognize disease onset until dysglycemia is severe. Currently, the only way to predict and potentially improve later symptoms of DKA is to enact autoantibody screening programs (Jacobsen *et al.*, 2018). This method is particularly effective among children and adolescents due to their young age. In support of this solution, Deylami *et al.* (2018) found that public awareness campaigns for earlier screening of T1D leads to earlier diagnosis. Thereby, earlier screening decreases levels of DKA at onset relative to those who are diagnosed later. Currently, researchers are looking to identify other methods of pre-T1D management such as diet, exercise, and glutamic acid decarboxylase (GAD) therapy that can be used to prevent the loss of beta-cell function in newly diagnosed patients (Shalitin and Chase, 2013). Above all, a better understanding of the causes of islet autoimmunity is needed before an official prevention method can be developed.

Treatment Options

After diagnosis, physicians suggest management care in the form intensive insulin therapy in the form of daily insulin injections (MDI) or the use of a continuous subcutaneous insulin infusion (CSII) (Boland *et al.*, 2000). While both products aim to regulate blood glucose levels, MDI requires insulin to be injected via syringe multiple times daily, whereas CSII provides continuous delivery of short-acting insulin directly into the bloodstream. Both methods require the patient to be educated on how to match insulin dosage with food intake, blood glucose levels, and anticipated physical activity (Cummins *et al.*, 2010). In general, CSII allows for more flexibility in regards to food intake and physical activity because it simulates physiologic insulin response better than MDI. This significantly impacts youth with T1D because they are more likely to be active and possess inconsistent eating patterns, such as snacking and higher levels of carb intake (Shalitin and Chase, 2013). The Diabetes Control and Complications Trial (DCCT) of 1987 showed that consistent, intensive insulin therapy plays an important role in improving glycemic control and T1D outcomes. To accomplish this, the DCCT examined the physiological and psychological responses to CSII and MDI in adolescents with T1D. The study spanned 12 months and the results were used to determine the most effective treatment regimen for adolescents. Participants using CSII exhibited better glycemic control and experienced 50% less dysglycemia incidents than participants using MDI. Although self-reports completed by the participants indicated overall improvements in self-efficacy and depression with both treatment methods, patients reported that CSII-treatments made it easier to cope with diabetes which improved their overall

quality of life (Boland *et al.*, 2000). Thus, while both MDI and CSII have been proven to be effective glycemic regulators, CSII includes added personal-ease benefits, especially for young people with T1D.

Regardless of the treatment method, both require periodic measurements of blood glucose levels. Daily self-monitoring of blood glucose (SMBG) provides an intermittent representation of glucose levels, while the use of a Continuous Glucose Monitor (CGM) illustrates glucose variability over a 24 hour period (Shalitin *et al.*, 2012). Accurate and consistent measurements of blood glucose ensure that the current treatment method is working, which helps prevent instances of dysglycemia. As demonstrated, long-term diabetes complications can be prevented with close monitoring and well-managed glycemic control.

Cost

Considering patients with T1D typically suffer from the disease for a longer period of time due to earlier diagnoses, treatment represents a significant lifelong cost and time commitment (Jacobsen *et al.*, 2018). As required, regulating T1D requires daily insulin and constant monitoring for survival. Since 2002, the average price of insulin has increased steadily from roughly \$40 a vial to \$130. Although the amount of insulin needed varies per person, one vial typically lasts 1.5 weeks before the prescription must be refilled (Hua, *et al.*, 2016). In total, average yearly medical expenditures for families with children diagnosed with T1D is approximately \$12,000 for children aged 3 to 18 (Tao *et al.*, 2010). The same study also found that young patients with T1D who stay at least one night in the hospital spend an average total of \$23,137 per year. It is important to note, however, that in the

United States, the shared medical costs for each family depends on their insurance coverage— a topic that will be discussed later. Nevertheless, studies have shown that the T1D has a substantial economic impact, making socioeconomic status a crucial component of understanding the full extent of the disease (Tao *et al.*, 2010).

Given the background information presented on T1D prevention, diagnosis, and management care, next I will use previous literature to examine the effects of external factors such as socioeconomic status, insurance status, implicit bias, and education levels on T1D outcomes in Black youth.

Literature Review

Given the multidisciplinary nature of this topic, a relevant literature review spans the fields of economics, public health, social psychology, and public policy. The majority of health-related studies regarding T1D do not differentiate between race or age, which neglects the underlying differences that exist. Therefore, more research is needed in the realm of how demographic factors, especially those of White and Black people, may impact health outcomes.

Proposed contributors to the disparities faced by Black youth

I. Treatment method

Amongst epidemiological findings, Paull *et al.* (2015) observed a large population of childhood type 1 diabetics in order to examine how their treatment regimen affected glycemic control. In this study, diabetes management and clinical outcomes were compared among 8841 White and 697 Black participants under 18 years old who had been diagnosed with T1D for over a year. Results showed that CSII-treatment was significantly higher in White participants than in Black participants across all levels of socioeconomic and insurance status. In addition, Black participants experienced poorer glycemic control than White participants, which resulted in more DKA/hyperglycemia and severe hypoglycemic events. Given the added benefits of CSII-treatment in terms of glycemic control, ease, and personal satisfaction as discussed by the DCCT study group, this leads us to question why more children are not using insulin-pump therapy. Of course it is important to acknowledge

that pump treatment is a large investment, however, the wide range of participants of various income levels in this study indicates that disparities in treatment method transcend socioeconomic class. Unfortunately, Paull *et al.* fails to mention how each participant chose their treatment regimen (i.e. financial factors, experience and comfort level) making the source of this disparity unclear. Certainly, circumstances can only be determined on a case-by-case basis. Regardless, whether the discrepancy exists due to cost or lack of information, given the results of this study, it is clear that marked disparities in insulin therapy methods and outcomes exist between Black and White people. As demonstrated, barriers to CSII-treatment and optimal glycemic control exist beyond socioeconomic status and should be explored across all ethnic groups.

II. Insurance coverage and socioeconomic status

Access to health care includes the access to medical professionals and facilities as well as the ability to receive services and afford the associated fees. Regulating T1D has an annual cost of \$14.4 billion in the United States in terms of medical expenditures and lost income (Tao *et al.*, 2010). Individual costs for patients and their families may vary depending on many factors including, but not limited to, insurance coverage and treatment plan. In the United States, there are severe gaps in health coverage among the Black population—especially among children. Statistically, 6% of Black children are uninsured, 41% are insured through private coverage, and 54% receive Medicaid or other public assistance. In comparison, 4% of White children are uninsured, 66% receive private coverage, and 30% receive Medicaid or other public assistance (KFF, 2018). While the rate of uninsured Black

children has greatly decreased since the enactment of the Affordable Care Act, Blacks are still more likely than Whites and other higher socioeconomic status groups to be uninsured (Cohen, *et al.* 2016).

For many, particularly those of middle-class status, health insurance stands as an institutional barrier to preventive healthcare access regardless of race. In a recent study conducted at Yale University, Herkert *et al.* (2018) suspects that healthcare is unaffordable for middle-class patients with an income between \$25,000 and \$100,000 due to the fact that they are simultaneously ineligible for Medicaid, unable to afford private health insurance, and cannot afford unsubsidized costs. Further, the study shows that T1D patients within this income range are more likely to reduce necessary insulin usage, despite necessity, as a way to save money. Consequently, these patients are prone to poor glycemic control. As expected, supporting research suggests that the uninsured have overall worse health outcomes than the insured (Institute of Medicine, 2009). Many communities have attempted to remedy healthcare inaccessibility with the installment of free clinics and community health centers, however, in reality, many of these facilities lack specialty services. In terms of T1D, specialty services may be necessary to address serious optical, endocrine, and dermatology issues that may arise as a consequence of poor glycemic control (American Diabetes Association, 2012). Thus, those without insurance are more likely to suffer from these complications.

Considering the uninsured population constitutes a relatively small percentage of Black children, it is also important to critically view the outcomes of those with health insurance— particularly through government-assistance programs. Unfortunately, studies

have shown that disparities exist among those using public assistance such as Medicaid in comparison to those with private insurance, further proving the inaccessibility of healthcare. According to the RAND study of 1984 which was conducted by the U.S. Department of Health and Human Services, government-run health insurance plans do not ensure better care nor a better quality of life despite subsidized costs, which suggests that disparities exist outside of health insurance. Across the country, there are a limited number of health facilities that accept Medicaid, which may make it difficult for people to find physicians and specialists depending on their geographic location. Moreover, facility limitations lead to overcrowded emergency rooms and clinics, which results in longer wait times for all patients before they can be treated. For many lower-middle class families with less flexible work obligations, the time commitment associated with a doctor's visit may deter them from seeking regular medical treatment. The work culture in the U.S. does not easily allow for low-income individuals to take time off of work to schedule and attend doctors appointments. Considering most children cannot be treated without an adult present at their appointments, it may be difficult for them to receive regular medical care and/or specialized help until dysglycemia complications are severe. In many cases, parents taking time off of work may also result in their inability to afford life-saving medication such as insulin, for their children. In relating T1D in children to socioeconomic status, there are significant relationships between race, low-income, and poor glycemetic control. In short, households that do not have disposable income for treatment often underutilize effective services pertaining to preventative health services and early detection, which may cause otherwise easily-solved complications to worsen drastically over time (Adepoju, 2015). In a study conducted by

researchers at the Journal of the American Medical Association in 1992, physicians were interviewed regarding the occurrences of avoidable hospitalizations they have encountered with Medicaid or uninsured patients in comparison to those with private insurance. Together, the physicians revealed that there is an overall higher rate of hospitalization for conditions that would have benefitted from preventative or aggressive treatments. Again, this study suggests that Medicaid recipients do not have access to higher quality care, despite having health insurance. In short, insurance coverage does not necessarily correlate to better health.

The precise impact of socioeconomic status on Black youth with T1D is difficult to establish due to the limited participation of high-income Black families in epidemiological studies. Therefore it is difficult to disentangle the effects of race and income on healthcare access and treatment options.

III. Education

Education level is not only a major indicator of socioeconomic status but in terms of medical care, it encompasses the ability to process information, engage with medical professionals, and make informed decisions on how to handle diagnoses. In addition, higher education levels often lead to a better understanding of the importance of exercise and a healthy diet, both of which aid in glycemic control in type 1 diabetics. In the U.S., 14% of Blacks have less than a high school diploma (KFF, 2018). For children of parents with low education levels, they are often at a disadvantage due to the fact that their parents may be unable to understand clinical terms in the doctor's office. Because family support can translate to better quality of care, it is important that a child has a trusted adult who

understands the severity of their diagnosis and is able to teach them how to regulate their own glucose levels.

IV. Implicit bias among medical professionals

To ensure accessibility for all patients, medical professionals are responsible for fostering an objective and impartial environment. In general, a patient's comfort level with their physician affects their willingness to ask important questions and seek help, which thereby affects their ability to manage their disease. Unfortunately, a considerable amount of evidence suggests that a patient's sociodemographic characteristics have an impact on their interactions with physicians— regardless of intentionality (Van Ryn and Burke, 2000; Johnson *et al.*, 2017). This concept is best defined by *implicit bias*; a psychological concept that describes the unconscious attribution of stereotypes to a particular social group. Unconscious discrimination among health professionals raises concerns about how a physician's judgment of their patients influences the diagnosis, treatment recommendations, and quality of care they provide. In a study completed by Van Ryn and Burke (2000), survey data was used to examine the degree to which a patient's race and socioeconomic status affects a physicians' perception of their patient. Results of the study indicate that physicians tend to perceive Blacks, especially those of lower and middle class, more negatively than Whites in terms of the risk of noncompliance to medical advice, intelligence, and personality. In a similar study, Johnson *et al.* (2017) measured implicit racial bias of resident physicians using the Adult and Child Race Implicit Association Tests (IATs). They found that the residents exhibited moderate pro-White and anti-Black bias towards both adults and children.

Of note, resident demographic and specialty characteristics were not controlled, which suggests that pediatric residents are just as susceptible to implicit bias as physicians in other fields. In terms of T1D, implicit bias may impact the extent to which a physician explains a diagnosis to their patient as well as the treatment regimens that are suggested. In the event that the explanations are insufficient, patients are undoubtedly more prone to experience poor glycemic control and develop complications over time.

Conclusion, Discussion & Future Research

The aim of this thesis is to address the increase in T1D diagnoses and how insufficient social and economic resources negatively affects the morbidity and mortality of Black youth with this disease. Research suggests that external factors such as wealth, insurance status, education level, and implicit bias from medical professionals affects a patient's ability to maintain consistent, healthy glycemic levels. As discussed, prolonged, poor glycemic control leads to severe complications over time. Although some may argue that it is the parent's responsibility to care for and manage the overall health of their child, studies show that the disparities in the diagnosis and management of T1D transcend circumstances beyond parental control. Thus, I propose that system-level changes are necessary to reduce the morbidity and mortality of T1D in Black youth.

With regards to disparities in treatment method, it is critical that patients of all backgrounds feel comfortable in medical spaces. Thus, physicians should be required to periodically take courses and assessments on implicit bias over the course of their career. Being in a position of power, it is a physician's responsibility to be equipped with psychological tools to address their own unconscious bias and uphold their hippocratic oath. This will ensure that each patient receives adequate information about their diagnosis and treatment options regardless of race, socioeconomic status, or education level. In addition, according to the implicit bias studies completed by Johnson *et al.* (2017), Black doctors showed less bias towards their patients overall. Thus, increasing the representation of Black

medical professionals is expected to have a positive impact on physician-patient interactions and the outcomes of Black patients.

Due to the limitations of epidemiological studies that focus specifically on T1D complications in Black youth, future research should include Black patients of diverse socioeconomic and educational backgrounds as well as analysis of the issues faced by members of other racial and ethnic minority groups. In doing so, connections between institutional factors that contribute to health disparities can be better evaluated. Such studies should push policymakers to address and reduce these inequities.

Glossary²

Diabetic ketoacidosis	an abnormal condition of reduced alkalinity of the blood and tissues that is marked by sickly sweet breath, headache, nausea and vomiting, and visual disturbances that is a result of excessive acid production resulting from increased levels of ketones in the blood
Dysglycemia	the presence of a normal concentration of glucose in the blood
End-stage renal disease (ESRD)	the final stage of kidney failure (as that resulting from diabetes, chronic hypertension, or glomerulonephritis) that is marked by the complete or nearly complete irreversible loss of renal function
Glycemic control	control of the presence of glucose in the blood
Nephropathy	an abnormal state of the kidney
Neuropathy	damage, disease, or dysfunction of one or more nerves especially of the peripheral nervous system that is typically marked by burning or shooting pain, numbness, tingling, or muscle weakness or atrophy, is often degenerative, and is usually caused by injury, infection, disease, drugs, toxins, or vitamin deficiency
Normoglycemia	the presence of a normal concentration of glucose in the blood
Polydipsia	excessive or abnormal thirst
Polyuria	excessive secretion of urine
Retinopathy	any of various noninflammatory disorders of the retina including some that cause blindness

² All definitions were sourced from the Merriam-Webster Medical Dictionary

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