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### Mental Health and Experiences of Pregnancy Among Black Women and Birthing People with Type 1 Diabetes (T1D)

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**Mental Health and Experiences of Pregnancy Among Black Women and Birthing People  
with Type 1 Diabetes (T1D)**

A Clinical Dissertation Presented to

The University of San Francisco

School of Nursing and Health Professions

Department of Health Professions

Clinical Psychology PsyD Program

In partial fulfillment of the requirements for the degree of Doctor of Psychology in Clinical

Psychology

By

Madeleine E. Marcus

March 2023

**PsyD Clinical Dissertation Signature Page**

This Clinical Dissertation, written under the direction of the student's Clinical Dissertation Chair and Committee and approved by Members of the Committee, has been presented to and accepted by the faculty of the Clinical Psychology PsyD Program in partial fulfillment of the requirements for the degree of Doctor of Psychology. The content and research methodologies presented in this work represent the work of the student alone.

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### **Abstract**

This dissertation explored the potential effects of intersections of oppression (i.e., anti-Black racism, diabetes discrimination, and sexism) on mental health and pregnancy experiences among Black women and birthing people with Type 1 diabetes (T1D). Previous studies about pregnancy and T1D have included mainly white, cisgender women. Three participants qualified for inclusion in the present study and participated in semi-structured interviews, which the researcher analyzed using an interpretative phenomenological analysis (IPA) framework. Participants described feeling uncertain about whether aspects of their pregnancy experiences were related to obstetric and/or medical racism. Similarly, participants sometimes seemed uncertain about how racism may affect their ability to access online social support from other people with T1D, and they noted that they often felt online environments were unkind and predominately white. Participants identified instances of diabetes discrimination throughout their pregnancy experiences and voiced the need for ongoing exploration of how diabetes discrimination affects Black birthing people with T1D in medical settings. In particular, participants identified the need for more racial and T1D representation in research, medical resources, and online spaces. Participants cited their hopes to build representation of Black women with T1D as their primary reason for participating in the present study.

### **Introduction**

#### **Statement of the Problem**

Many medical professionals classify pregnancies of individuals with pre-existing diagnoses of Type 1 diabetes (T1D) as high risk, and people with diabetes (PWD) may experience intensive support from their healthcare team both prior to and during pregnancy in order to promote a successful and safe experience (Priya et al., 2018; Stenhouse et al., 2013).

White women with T1D, the majority participants in T1D pregnancy research, have described receiving intensive support within their pregnancy experiences (McGrath & Chrisler, 2017). For Black birthing people, the experience of pregnancy with T1D is likely complicated by medical racism,<sup>1</sup> as the healthcare system underserves Black<sup>2</sup> and African American PWD, thus increasing risk of negative health outcomes (Marshall et al., 2020).

Much of the existing literature documenting experiences of pregnancy with T1D includes white-identified, cisgender female participants of moderate to high socioeconomic status (SES) (McGrath & Chrisler, 2017; Rasmussen et al., 2013) despite comparable diagnosis rates<sup>3</sup> of T1D across Black and white racial groups (Spanakis & Golden, 2013). White diabetes research participants typically live in metropolitan areas and/or have live outside of the United States and have access to socialized healthcare (Edwards et al., 2016; Rasmussen et al., 2013; Singh et al., 2019). While valuable, data from these studies do not encapsulate the diverse experiences of PWT1D living in the United States during their pregnancies (Gatny & Axinn, 2012). Numerous studies document the impacts of systemic racism on Black and African American birthing people (e.g., Noursi et al., 2020; Yearby, 2020); yet, qualitative studies do not explore racial identity factors in research about pregnancy with T1D. Examples of systemic racism and other types of oppression that may impact pregnancy include bias in medicine, classism which leads to lack of financial access to care, discrimination based on physical condition, and geographical lack of available, trained specialists (Noursi et al., 2020). Furthermore, research on pregnancy is often

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<sup>1</sup> Medical racism is defined as biased perception, diagnosis, and/or treatment among medical professionals due to their patients' racial identities (Davis, 2019).

<sup>2</sup> Within this dissertation, the racial identity of people of the African diaspora, including African Americans, will be represented with the identity term 'Black' (Laws, 2020). Black is capitalized to represent a shared sense of community and experience (Laws, 2020). Use of the term 'white' to describe white racial identity will not be capitalized as a form of resistance against white supremacy (Laws, 2020).

<sup>3</sup> Rates of T1D diagnosis are 2.89 per 1,000 among white adolescents and 2.04 per 1,000 among Black adolescents (Spanakis & Golden, 2013).

focused on cisgender experiences and holds verbiage common to heterosexual couples, which does not consider the spectrum of gender and sexual identities (Olding & Li, 2020). Intersections of marginalization (Crenshaw, 1991) may therefore result in challenges to the pregnancy experience with T1D that are largely unaddressed in the current literature.

### **Purpose and Rationale of the Study**

In light of ongoing public health disparities regarding policy and access to care, it is important to consider how an inequitable system inherently creates greater risks and challenges for individuals with pre-existing conditions and marginalized identities. For example, Black PWD are at increased risk of hospitalization and serious health effects relative to other racial and ethnic groups if they contract COVID-19 (Ebekozi et al., 2020). T1D, in general, requires strict management of medical and lifestyle-related factors. Previous research has resulted in care-related guidelines about preventing diabetes-related complications via tight glucose control (e.g., American Diabetes Association, 2011; Vargas et al., 2010) without analyzing how tight control may not be feasible in marginalized communities due to medical racism, lack of insurance, and sociocultural determinants of health (Agarwal et al., 2020; Ekeke et al., 2020; Noursi et al., 2020). Birthing people with T1D, in particular, are asked to adhere to extremely regimented patterns of medical self-care, e.g., administering precise doses of insulin while their insulin needs change rapidly, and medical professionals may construe pregnancy challenges as the fault of birthing people for lack of compliance (Attanasio & Kozhimannil, 2015; Berg, 2005; Stenhouse et al., 2013).

The layers of identity within this target research population are complex, with PWD being more apt to experience health-related stigma during pregnancy relative to many other chronic health conditions (Attanasio & Kozhimannil, 2015). Incidence of health stigma increases



with Black racial identity (Attanasio & Kozhimannil, 2015) and among individuals who are cisgender female (Werner & Malterud, 2003), as well as transgender or gender nonconforming (Olding & Li, 2020). Consideration of health stigma as it relates to the intersection of oppressions is essential given that many medical and psychological practitioners hold privilege relative to the communities to which they provide service, ranging from privileged racial identity, socioeconomic status, gender, and/or ability status (Jetty, 2021). It is important to facilitate empathy and compassion within client care as well as increase understanding of challenges clients may face related to their layers of identity. Increased empathy and understanding may be possible through increased availability of qualitative data that describes pregnancy experiences among Black PWT1D.

This dissertation aimed to facilitate awareness of patient challenges and experiences so they may be better understood within the multidisciplinary healthcare community. The study explored coping strategies used by Black PWD and the role of the diabetes online community (DOC). This study sought to report pregnancy experiences among Black PWT1D in a way that is accessible to participants and responsive to their needs, thereby influencing the way Black birthing people with T1D are treated in the DOC, healthcare industry, and broader social context.

### **Research Questions and Hypotheses**

This study addressed two qualitative research questions: 1) What do Black PWT1D experience during pregnancy, and how is obstetric racism, medical racism, and/or diabetes-related discrimination related to their pregnancy experiences? 2) What is the role of online peer support in pregnancy experiences for Black PWT1D?

Given the role of medical racism in pregnancy experiences among Black women and disability discrimination among pregnant PWD, I hypothesized a likely cumulative effect of both

gendered racism and ableism on the pregnancy experiences of Black PWT1D. Additionally, I hypothesized that the primarily white DOC does not lend itself to inclusive support of Black PWT1D, and that there are perhaps supportive subgroups in which Black PWD may discuss their pregnancy experiences.

### **Definition of Terms and Language Acknowledgment**

As language can and will evolve, please adapt the verbiage of this dissertation to reflect future language around identity and culture that is most respectful of and accurate to the experiences of the target population. As mentioned above, this dissertation uses the identity term ‘Black’ to represent people of the African diaspora, including African Americans. Black is capitalized to represent a shared sense of community and experience (Laws, 2020). Use of the term ‘white’ to describe white racial identity will not be capitalized as a form of resistance against white supremacy (Laws, 2020).

**Birthing people:** gender-inclusive term to indicate people who are pregnant; not affiliated with gender identity.

**Diabetes distress:** a condition of emotional distress as a result of the challenges related to diabetes management.

**Diabetes online community (DOC):** a multi-platform online community of people with diabetes spanning social media websites including Facebook, Instagram, and Reddit.

**Gendered racism:** a term representing the intersectional experience of discrimination related to both race and gender, inclusive of gender-expansive identities; the experience of gendered racism among Black and African American women is also referred to as misogynoir (Bailey, 2018).

Iatrophobia: fear of medicine and/or medical providers related to history of involuntary, unethical, and non-therapeutic treatment of the Black community (Washington, 2008).

Interpretative Phenomenological Analysis (IPA): a qualitative research methodology for exploration of participant experiences.

Medical racism: “occurs when medical professionals’ perceptions, treatments, and/or diagnostic decisions” are influenced by patient race, thereby placing the patient at risk (Davis, 2019, p. 2).

Obstetric racism: medical racism that affects Black birthing people during pregnancy-related medical care.

Type 1 Diabetes (T1D): an autoimmune condition of unknown genetic and environmental etiology in which the immune system attacks and destroys insulin producing cells in the pancreas. People with T1D need continuous treatment with insulin to regulate their blood glucose levels.

Type 2 Diabetes (T2D): a metabolic condition of insulin resistance.

## **Literature Review**

### **History of Systemic Racism in Research**

Black-identified individuals are historically underrepresented in research and, if represented, have a history of being studied without consent and subjected to horrifically dangerous experimentation and maltreatment (Rajack-Talley et al., 2017; Warren et al., 2019; Washington, 2008, 2021). The violent and damaging research perpetrated throughout history has understandably contributed to distrust of researchers—both medical and psychological—in the Black community (Prather et al., 2018; Rajack-Talley et al., 2017; Warren et al., 2019; Washington, 2008). Medical ethicist and author Harriet Washington coined the term iatrophobia,

which she defined as “African American fears of medical professionals and institutions,” due to the long history of involuntary, unethical, and non-therapeutic treatment (2008, p. 420). Broadly known, twentieth century examples of harm inflicted by researchers include the US Public Health Service Syphilis Study at Tuskegee and the harvesting of Henrietta Lacks’s immortal cell line without her or her family’s consent (Turner, 2019; Wolinetz & Collins, 2020). Violent obstetric and gynecological research on Black women can be traced to the experimentation on and torture of enslaved African women conducted by J. Marion Sims, who is considered the ‘Father of Gynecology’ (Prather et al., 2018; Sartin, 2004; Washington, 2008). These infamous cases are only a few examples of the many ways science has harmed Black individuals and communities (Turner, 2019; Wolinetz & Collins, 2020; Washington, 2008).

### **The Role of Psychology in Upholding White Supremacy**

Mainstream psychology has been and continues to be rooted in white supremacist culture and suppositions of mental health (e.g. promoting individualism, self-determination, and lack of consideration of oppression). Examples of psychology engaging in anti-Black racism and enforcing racially hierarchical ideology include the origins of behavioral health and the racist applications of assessment to further impoverish and disenfranchise Black children and adults (Fernando, 2017). Disparate rates of diagnoses with psychiatric disorders are also prevalent in public health data: schizophrenia is more likely to be overdiagnosed in Black adults than among adults of other racial identities (Gara et al., 2019; Hampton, 2007), and ADHD and oppositional defiant disorder are more likely to be incorrectly diagnosed among Black children (Ballentine, 2019; Zablotsky & Alford, 2020).

The American Psychological Association (APA) published an ‘apology’ to people of color for its role in perpetuating racial hierarchy in 2021, claiming to reject and commit to

dismantling racism. The Association of Black Psychologists, Inc. (ABPsi) responded to the APA's message (2021), and they highlighted the lack of honesty and believability in the APA's 'apology' as well as the continued lack of consultation between the APA and ethnic psychological associations whose communities are continually directly harmed. ABPsi also noted the APA's apology served to absolve themselves of white guilt rather than own the reality of their historic and ongoing harm to the Black community. Similar conversations are ongoing within the American Academy of Pediatrics, American Medical Association, and American Psychiatric Association (Christopher et al., 2021) to emphasize the need to prioritize restorative justice rather than absolving guilt through white supremacist apologies.

### **Impacts of Anti-Black Bias in Healthcare**

Black cisgender women and gender expansive individuals are maltreated by medical systems in the United States, as demonstrated by studies of bias in health professionals, overall health outcomes, and mortality rates (Brown et al., 2020; Davis, 2019; Fiscella & Sanders, 2016; Noursi et al., 2020; Prather et al., 2018; Sutton et al., 2021). Provider response rates to Black women in critical condition are longer than those for women of other races, and providers are less likely to believe Black women who report experiencing pain (Hofacker et al., 2020; Hoffman et al., 2016). Due to this bias, medical professionals are less likely to support Black women and birthing people with life-saving treatments (Brown et al., 2020).

The prevalence of anti-Black bias is not sufficiently addressed in medical training, as surveys of medical students demonstrated that students continue to incorrectly believe that Black people have physically thicker skin and therefore feel less pain or need more forceful insertion of needles (Hoffman et al., 2016). Racist conceptualizations of pain differences originate in the torture of and experimentation on enslaved Africans, which white researchers and physicians

thought was justified due to racist mythology of biological differences, presumed low intelligence, and lessened experiences of pain due to having ‘primitive nervous systems’ (Washington, 2008, p. 793). White researchers’ and enslavers’ conceptualizations of racial difference enabled them to conduct experiments on enslaved Black people that would be considered inhumane if conducted on white people (Washington, 2008). Experimentation and racist mythology reinforced the rhetoric of how theorized high pain tolerance necessitated extremely vicious corporal punishment (Brown et al., 2020).

Examples of anti-Black racism that persist in today's medicine include how students are not trained to recognize disease in Black patients, particularly with regard to skin conditions (Louie & Wilkes, 2018). Despite evidence that many Black patients prefer to be treated by Black healthcare professionals due to cultural concordance and better health outcomes, continued underrepresentation of Black providers in medicine persists (Jetty, 2021). Systemic gendered racism therefore reinforces a medical system that is not attuned to the physical or emotional needs of Black birthing patients (Noursi et al., 2020).

Systemic mismanagement of health results in higher rates of chronic health conditions and complications among Black communities (Clements et al., 2020; Fiscella & Sanders, 2016). Research links rates of chronic illness to chronic stress associated with living in a society that constantly denigrates one’s identities—and living with intersections of oppression, such as anti-Black racism and misogyny, increases rates of disease development (Ekeke et al., 2020). Because diagnosis with T2D, a common chronic illness, is prevalent in Black communities, Black women with T1D may be misdiagnosed with T2D more frequently as compared to other racial and ethnic groups (Agarwal et al., 2020; Griffin, 2020; Lawrence, 2018). Black women with T1D are also likely to experience less support with diabetes management, as reflected by

disparate hemoglobin A1c<sup>4</sup> levels between Black and white PWD (Agarwal et al., 2020; Marshall et al., 2020; Spanakis & Golden, 2013).

The inequity evident in United States healthcare extends to perinatal medicine and is emphasized by statistics and social structures regarding pregnancy, birth, and postpartum health (Julian et al., 2020; Noursi et al., 2020; Yearby, 2020). Systemic misogynoir and gendered racism result in disparately high rates of Black women and birthing people living without access to comprehensive maternity care and insurance coverage (Noursi et al., 2020). Due to institutionalized racism, many Black individuals—even before becoming pregnant—have access to systematically fewer resources to prepare for a healthy pregnancy, including basic needs such as healthful nutrition, time and opportunity to exercise, and safe and supportive healthcare (Noursi et al., 2020). Moreover, pregnancy health disparities are not isolatable to other factors such as low SES, physical location, or educational attainment, as demonstrated by poor health outcomes among well-resourced Black women of high SES (Davis, 2019; Julian et al., 2020). Rather, multi-level challenges may interact with medical racism, but medical racism results in higher maternal mortality among Black women and birthing people across every other aspect of identity (Julian et al., 2020; Lemke & Brown, 2020; Noursi et al., 2020). Obstetric racism is medical racism specific to Black birthing people, and examples of obstetric racism include aggressive and violent intervention by OB/GYNs (e.g., obstetric rape), lack of appropriate medication, and lack of attention to patient concerns (Davis, 2019). Black women have advocated for and led the reproductive justice<sup>5</sup> movement in healthcare due to high incidence of

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<sup>4</sup> Hemoglobin A1c is a measure of glycosylated hemoglobin (e.g. how much sugar sticks to red blood cells). An A1c measurement is predictive of average blood glucose level over three months (Bashir et al., 2019; Yamamoto et al., 2019).

<sup>5</sup> Reproductive justice is “the human right to control our sexuality, our gender, our work, and our reproduction. That right can only be achieved when all women and girls have the complete economic, social, and political power and resources to make healthy decisions about our bodies, our families, and our communities in all areas of our lives” (In Our Own Voice: National Black Women’s Reproductive Justice Agenda, 2023).

obstetric racism (In Our Own Voice: National Black Women's Reproductive Justice Agenda, 2023; Julian et al., 2020; Noursi et al., 2020).

Anti-Black racism can significantly impact birthing people's preparation for conception as well as fetal development and delivery (Prather et al., 2018). Black women and birthing people are more likely to suffer medical negligence and resulting fatal complications during labor and delivery than other racial groups (Brown et al., 2020; Leonard et al., 2019). The severe maternal morbidity rates among Black patients are over twice as high as among white patients, and maternal mortality is three to four times as high as among Black patients (Leonard et al., 2019; Noursi et al., 2020; Owens & Fett, 2019).

Black birthing people may hold a collective awareness of risk not only to their own wellbeing, but also that of their babies (Davis, 2019). Black infant mortality<sup>6</sup> is higher than infant mortality among other racial groups (Ely & Driscoll, 2020; Vilda et al., 2021). Black infants are at particular risk in the United States due to the nation's elevated infant mortality rate in general when compared with other industrialized countries studied by the CDC (MacDorman et al., 2014). Anti-Black bias in healthcare therefore exists across the lifespan (Davis, 2019) and bears further investigation as to how it may affect the pregnancy experiences of Black birthing people with T1D.

### **Diabetes Discrimination: Pregnancy and T1D**

The physical experience of pregnancy with T1D is considered high risk in the medical community and broader society (Farley, 2019; Priya et al., 2018; Stenhouse et al., 2013).

Conceptualization of risk is due to the number of potential complications that can impact both the pregnant person and the fetus (Bashir et al., 2019). Pregnancy has the potential to cause

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<sup>6</sup> Infant mortality is defined as death within the first 12 months of life. Neonatal mortality is death within the first 28 days of life. Post-neonatal mortality is death of infants aged 28 days through 11 months (MacDorman et al., 2014).



vascular damage to individuals with T1D, which can manifest in kidney, eye, and heart diseases in addition to complications with gestation and labor (Vargas et al., 2010). Potential complications for fetuses of PWD include larger than average fetal weight and trouble regulating their blood glucose levels after birth, in addition to earlier impacts of parental elevated blood glucose preventing formation of typically healthy anatomy of the embryo or fetus (Bashir et al., 2019; Yamamoto et al., 2019).

PWD experience rapid changes to their insulin dosing needs during pregnancy and can find it challenging to manage their blood glucose levels (Magon & Chauhan, 2012). These changes can be generally described as an increased risk of hypoglycemia in the first trimester followed by a steady increase in insulin resistance throughout pregnancy and a reduction in insulin needs after labor and delivery (Egan et al., 2015). Despite this pattern of increasing insulin resistance, the volatility of blood glucose levels during pregnancy can result in episodes of hyperglycemia—harmful to fetal development and long term parental health if untreated—as well as hypoglycemia, which is imminently dangerous to birthing PWD due to risk of becoming unconscious, seizing, or dying from insufficient glucose in the bloodstream (Bashir et al., 2019; Vargas et al., 2010). Due to the physical and emotional challenges of pregnancy, PWD may experience an increase in stress, which can increase blood glucose levels and reduce insulin sensitivity in and of itself (Reynolds & Walker, 2002).

### ***Standards of Medical Care***

PWD experience discrimination from their social systems and healthcare providers on the basis of their diagnosis (Beverly et al., 2019), and this discrimination is compounded by becoming pregnant (Berg & Hotikasalo, 2000; Priya et al., 2018). Discrimination during pregnancy is more frequently reported among PWD and people with hypertension than many

other chronic illness groups (Attanasio & Kozhimannil, 2015). The rate of reported discrimination is higher among women of color relative to white women, with the strongest association between diabetes diagnosis and Black racial identity (Attanasio & Kozhimannil, 2015). Provider discrimination (e.g., not listening to patients of certain identities, not providing adequate information about conditions and/or treatment options, and blaming patients for their conditions due to bias) is associated with lower rates of preconception care despite encouragement for PWD to access pre-pregnancy planning and care services for improved health outcomes. PWD may simultaneously find that opportunities for inclusive care do not exist, particularly if they are BIPOC and/or experience low SES (Egan et al., 2015).

Pregnancy and reproductive health specialists often hold assumptions that PWT1D have gestational diabetes—a disorder of glucose intolerance which does not always necessitate insulin treatment and often resolves when pregnancy ends (American Diabetes Association, 2011; de Lusignan et al., 2012). Ninety percent of all diabetic pregnancies involve gestational diabetes, and the remaining ten percent include people with “pre-gestational diabetes,” either T1D or T2D (Magon & Chauhan, 2012). Due to the especially limited number of PWT1D amidst people with other forms of diabetes, the etiology of diabetes in pregnant PWT1D may be misunderstood, and these individuals may be criticized for needing to take insulin generally and during pregnancy and told to manage their condition with diet changes and increased exercise (Brown et al., 2017; Magon & Chauhan, 2012; Stenhouse et al., 2013). PWT1D may be undersupported in calculating new insulin dosages, which are necessary to keep their blood glucose in range as insulin resistance increases over the course of pregnancy (Berg & Sparud-Lundin, 2009; Feldman & Brown, 2016). The misunderstandings and bias on the part of healthcare providers can create a sense of impossibility around having a supportive medical team, and pregnant PWD often report

needing to “shop around” to find adequate specialty and basic care (Attanasio & Kozhimannil, 2015; Berg, 2005; Berg & Sparud-Lundin, 2009; Singh et al., 2019; Stenhouse et al., 2013). Additionally, PWD report issues in coordinated care during their pregnancy, with OB/GYN teams requesting a certain level of diabetes control and endocrinologists requesting another (Berg & Sparud-Lundin, 2009; Rasmussen et al., 2013; Sina et al., 2018; Stenhouse et al., 2013). Lack of integrated, attuned care places more responsibility on PWD to manage their condition during pregnancy, often without clear professional guidance (Berg & Sparud-Lundin, 2009; Egan et al., 2015; Stenhouse et al., 2013).

PWD may be assigned to maternal fetal medicine specialists in addition to their OB/GYN and endocrinology care teams to monitor their health and that of their fetus (Vargas et al., 2010). To prevent complications, providers often recommend patients maintain a reduced A1c leading up to and during pregnancy relative to non-pregnant PWD (Bashir et al., 2019; Yamamoto et al., 2019). Recommended A1c for pregnancy is below 6.0%, with many pregnant people with T1D striving for levels between 4.5 and 5.5% to reduce risk of complications (Feldman & Brown, 2016; Vargas et al., 2010). This range may seem impossible to PWD before they become pregnant, as previously mentioned standard recommendations for care of T1D encourage an A1c below 7.0% (Feldman & Brown, 2016; Vargas et al., 2010). The average A1c among young women with T1D is over 8.0% (Maiorino et al., 2018), and A1c levels are higher among Black PWT1D relative to other racial groups (Agarwal et al., 2020). The pregnancy-ready levels are possible with quality care from a dedicated endocrinology team and access to resources for PWD prior to and throughout pregnancy, but they take a considerable amount of mental and emotional work in addition to being expensive and time-consuming. PWD must regularly monitor their blood glucose levels and adjust their insulin dosages, and they may experience reductions in

insulin needs in the first trimester but need to take up to three times their normal, pre-pregnancy doses of insulin by the end of the third trimester (Magon & Chauhan, 2012; Vargas et al., 2010). Popular misconceptions of the infeasibility of pregnancy for PWD, often held by medical professionals and the public, may discourage PWD from trying to conceive (Attanasio & Kozhimannil, 2015; Berg & Sparud-Lundin, 2009; Beverly et al., 2019). Evidence suggests, however, that potential complications are overblown and unlikely to occur in PWD with well-controlled glucose levels (Magon & Chauhan, 2012; Vargas et al., 2010).

### ***Technology, Insurance, and Access***

Well-controlled glucose levels are more achievable than ever before with technological advancement in diabetes care (Farrington et al., 2018; Polsky et al., 2018). Consistent infusion of insulin, made possible by insulin pumps, enables pregnant PWD to give themselves sometimes incremental doses to prevent high and low blood glucose levels (Pozzilli et al., 2016). Continuous glucose monitors (CGMs), which enable interstitial monitoring of glucose in near-real-time, allow for prompt responses to deviations from euglycemia (Polsky et al., 2018; Murphy, 2019). CGM therapy can enable PWD to regularly view their glucose levels without needing to test their blood sugar via a fingerstick (Polsky et al., 2018; Murphy, 2019). The use of CGMs has been associated with increased time-in-range, a new measure of wellness with T1D that is considered to reduce risk of diabetes complications (Murphy, 2019). Linkage to CGM devices was approved by some insulin pump systems, rendering automated dosing possible and reducing the number of decisions PWD must make on a given day (Farrington et al., 2018; Murphy, 2019). Technological advances allow for increased control of blood glucose during pregnancy, which is a time of rapid changes to metabolism and insulin needs. PWD can experience safe and healthy pregnancies without access to insulin pumps or CGM technology

(Egan et al., 2015; Feig et al., 2018), but many choose to utilize diabetes technology to support their overall wellbeing (Polsky et al., 2018).

Equitable access to diabetes technology continues to be an issue, particularly as there are racial disparities in how information about the technology is shared in doctors' offices, in prescribing the technology, and in insurance coverage for the technology (DeSalvo et al., 2021; Kanbour et al., 2022). Black PWD tend to have less supportive insurance relative to white PWD (Odugbesan et al., 2022), and lack of representation of Black PWD using diabetes technology has been found to reinforce stigmatization of disability status (Mencher et al., 2022).

The expenses associated with pregnancy may factor into decisions to have children among PWD, and these expenses may be a particular burden to Black PWD due to underinsurance and the effects of financial inequality between Black and white Americans (Oliver & Shapiro, 2006). Regular care of T1D necessitates appointments with endocrinology health staff, and the number of appointments increases with pregnancy (Feldman & Brown, 2016). Even before conception, PWD who are considering becoming pregnant are instructed to meet with endocrinologists or other health professionals to determine whether their current level of glycemic control is suitable to being pregnant (Feldman & Brown, 2016). At these appointments, the current status of any of their diabetes-related health complications and propensity to develop complications with pregnancy will also be assessed (Feldman & Brown, 2016). Once pregnant and depending on their overall health and protocol of their healthcare teams, PWD may meet with their providers as often as weekly, particularly nearing delivery (Feldman & Brown, 2016).

Each medical visit may be associated with either a co-pay—if the patient is insured—or out-of-pocket payment if they are uninsured. These expenses can add up quickly, and, as

mentioned above, financial inequality may influence the ability for Black PWD to access appropriate care (Odugbesan et al., 2022). Moreover, the price of diabetes supplies, even at the most basic level, is exorbitantly expensive in the U.S. healthcare system (Jovanovič et al., 2015; Sussman et al., 2020). PWT1D incur a cost of pregnancy that is nearly double that of people without diabetes (Jovanovič et al., 2015). Care strategies to manage T1D during pregnancy, such as utilizing an insulin pump and CGM while pregnant, may incur additional cost if one's standard care utilized less expensive interventions such as syringes and fingerstick glucometers (Jovanovič et al., 2015). Many PWD have cited CGM technology to be a helpful if not essential aspect of their perinatal care, and even those who have not used CGMs previously may be prescribed CGMs during pregnancy to facilitate a tighter degree of glucose control (Farrington et al., 2018; Murphy et al., 2019; Polsky et al., 2018). CGM use may, in turn, reduce the overall potential cost of the pregnancy due to mitigating diabetes-related complications (Murphy et al., 2019). The recommendations for healthy nutrition, regular exercise, plenty of sleep, and reduced stress that are common to non-diabetic pregnancies are additionally important for PWD, as these aspects can help to minimize extreme swings in blood glucose and promote healthy fetal development (Feldman & Brown, 2016). These common guidelines are associated with additional expenses in terms of time, money, and emotional capacity.

### **Role of Online Community for Pregnant PWD**

Active social support and easy access to information have been demonstrated to be protective factors among pregnant PWD (Adolfsson & Jansson, 2012; Linden et al., 2018; McGrath & Chrisler, 2017), much of which can be found online (Litchman et al., 2019). The diabetes online community (DOC) is a multi-platform group of bloggers, organizations, and individuals affected by diabetes (Hilliard et al., 2015; Litchman et al., 2019). Content is

published and shared on platforms including Facebook, Instagram, Twitter, and diabetes-specific apps or web pages (Hilliard et al., 2015; Litchman et al., 2019). The T1D subset of the community allows for socialization and resource-sharing that can be difficult to accomplish offline due to wide geographic dispersion of PWD, different regional resources, and infrequency of finding “diabetics in the wild” (Hilliard et al., 2015; Litchman et al., 2019; Tenderich et al., 2019). Popular topics in the DOC include diabetes advocacy, sharing of information about personal health experiences or research findings, and coping through humor (Greene et al., 2010; Hilliard et al., 2015; Tenderich et al., 2019).

The DOC has increasingly focused on mental and emotional health, potentially due to the relationship between T1D and increased incidence of mood and anxiety disorders (van Duinkerken et al., 2020). Other underpinnings for posts about mental and emotional health may relate to the COVID-19 pandemic and sociocultural context of 2020, the U.S. political landscape, and the Black Lives Matter Movement (Chon & Park, 2020; Valdez et al., 2020). The DOC has grown exponentially in recent years due to the real-life isolation that PWD may experience by having a relatively uncommon and frequently misunderstood health condition (Greene et al., 2010; Hilliard et al., 2015). Much of the T1D-related content is generated by diabetes lifestyle bloggers, either in the context of supporting diabetes organizations or via an independent sharing of experiences. These bloggers include PWD who have been pregnant, with diabetes-specific organizations being created or developing small groups to connect this affinity-group. “Credentials” of these bloggers range from professional healthcare degrees to the experience of having gone through pregnancy themselves, sometimes in combination with paraprofessional roles such as life coach. In the pregnancy blogger realm, many PWD post with hashtags such as “#t1dpregnancy” to gain followers and connect with members of their community (Isip-Tan et

al., 2016). The lack of racial diversity in searches under this hashtag suggest that it may be more difficult to find and connect with Black or African American bloggers, potentially reinforced by racial bias in artificial intelligence recommendation features (Turner, 2018). Additionally, much of the research involving the DOC has documented the lack of racial diversity among users, calling into question whether BIPOC with T1D are welcome in DOC spaces (Litchman et al., 2019), and this research is supported by Black DOC members who discussed their experiences with racism in broader DOC spaces (Griffin, 2020; Lawrence, 2018).

A specific group for PWD experiencing pregnancy, Type 1 Diabetic Sugar Mommas, was created by women with diabetes who have experienced pregnancy (T1DSM, 2012). The objective of the organization is to be “a high-quality, informational resource for those who are in family planning, pregnant, or parenting with diabetes” (T1DSM, 2012). Social support and health promotion during pregnancy have been highlighted as protective factors for high-risk pregnancies, and PWD who are currently pregnant or considering becoming pregnant may benefit from the accumulated knowledge and experiences of this online community and others (McGrath & Chrisler, 2017; Sparud-Lundin et al., 2011). The Sugar Mommas social media and blog pages offer peer-sourced resources for pregnancy planning, pregnancy, and postpartum, and it is hosted with the support of medical professionals who specialize in T1D and pregnancy (T1DSM, 2012). Because the organization was founded in the Bay Area and the founder later moved to Spain, many of the group participants are living in the United States or Spain, though women from up to 25 countries have been represented (T1DSM, 2012). In anecdotal experience on the part of the researcher, posts appear to feature predominately white-passing PWD and guest speakers. Perceived whiteness in Sugar Mommas spaces is aligned with the general representation of PWD and care providers on social media, and it emphasizes the question of



whether these predominantly white spaces offer sufficient support to Black PWD who are pregnant (Litchman et al., 2019).

Diabetes organizations, as with all other organizations in United States healthcare and beyond, are imbued with systemic racism (Feagin & Bennefield, 2014). Examples of organizations prevalent in the diabetes community include the Juvenile Diabetes Research Foundation (JDRF) and Beyond Type 1, both of which contribute to research, advocacy, and representation-related discourse. Recent attempts by organizations such as JDRF to uplift Black PWD as a part of the Black Lives Matter movement have resulted in feedback from the DOC that organizations must engage in continued antiracist work in order to support Black PWD (Howe, 2020; Kowalski, 2020). Black PWD have been increasingly represented in JDRF advertisements and programming, but the organization has a history of not stepping in to moderate racist Instagram comments targeting Black guest bloggers (Howe, 2020).

White supremacy and implicit bias may influence the way posts are approved and bloggers are promoted (Benjamin, 2019; Turner, 2018), such as white bloggers becoming more popular, gaining more followers, and being shared more broadly, which reinforces their popularity and thereby perpetuates the invisibility of Black PWD. Similar lack of historic and current representation is reflected in other diabetes organizations, including Beyond Type 1 and the American Diabetes Association (Howe, 2020). Historically, the representation for Black PWD was elevated with regard to T2D rather than T1D, perhaps perpetuating the myth that Black-identified individuals are not likely to have T1D (Griffin, 2020; Lawrence, 2018). Organizations like Beyond Type 1 and the more research-focused T1D Exchange seem to be focusing on racial disparities more closely over the past few years, and both have posted to either

recruit BIPOC PWD for research or in support of improving access to diabetes technology among BIPOC PWD (e.g., Nesby, 2023; Vieira, 2022).

The amplification of the Black Lives Matter Movement in the summer of 2020 highlighted the inaccuracy of the myth that Black people do not have T1D (Agarwal et al., 2020), and a number of organizations began to feature Black PWD on social media platforms (Howe, 2020). The conversation around Black racial identity and T1D continues via these bloggers and activists, including collectives such as Dope Diabetic Girls, Diversity in Diabetes, and Diabaddie Organization (Appendix A). These individuals and groups highlight the role of anti-Blackness in the broader DOC, often without pay nor recognition from larger organizations, particularly given cyclical non-engagement with the BLM movement by white and non-Black people of color (Flynn, 2015). Many Black bloggers and influencers discuss issues within the DOC that are intertwined with race, including nutrition, exercise, pregnancy, insurance coverage, and access to diabetes technology (Appendix A).

Medical racism has been discussed by a number of online activists (Griffin, 2020; Lawrence, 2018) as having had a role in delaying their diagnosis and increasing risk of diabetes complications (Tuchman, 2020). Bloggers sharing their experiences may contribute to awareness of obstetric racism and/or iatrophobia within the DOC. As online sharing has been identified as a coping strategy for Black pregnant mothers without T1D who experienced stress during the COVID-19 pandemic (Wheeler et al., 2021), sharing experiences online may similarly support the mental health of pregnant Black PWT1D. Medical racism and its connection to incorrect or delayed diabetes diagnosis is reflected in the limited body of research about Black PWT1D (Agarwal et al., 2020; Mayer-Davis et al., 2009; Tuchman, 2020). The supportive networks that these bloggers created may enable systemic change as they continue to grow within the DOC;

however the larger diabetes organizations continually failed to center marginalized voices in their research and advocacy (Howe, 2020). Social media algorithms are also at fault for their inherent bias and what Ruha Benjamin has titled “The New Jim Code” (2019), as promotion and recommendation of posts has been linked to how well they fit the standards of white supremacy, either in terms of beauty norms, social and cultural uses of language, and which topics are flagged for being inappropriate for ‘community standards’ (Turner, 2018). Without connections to the Black and African American support system within the DOC, it may be difficult for Black PWT1D to find applicable and welcoming information about pregnancy from bloggers who share their racial identity.

### **Limitations of Previous Studies**

In studies on pregnancy and T1D in the United States, participant samples are generally composed of cisgender women who are connected to researchers via metropolitan health centers (McGrath & Chrisler, 2017) and are white-identified or not differentiated by race (Singh et al., 2019). Convenience or “snowball” sampling can provide increased contact with difficult-to-access populations; however, this process has likely resulted in the exclusion of BIPOC racial and ethnic groups<sup>7</sup> from diabetes research (McGrath & Chrisler, 2017; Morone, 2019; Woolley et al., 2015). The lack of racial and ethnic diversity in both research and community spaces, which is the result of years of racism and exclusion, may reinforce the idea that the majority of PWD have similar experiences (Morone, 2019). A narrow depiction of PWD then becomes the primary representation of T1D in research: mainly white, upper-middle to upper SES, highly educated, and living in metropolitan areas (Morone, 2019). Recruitment from

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<sup>7</sup> Systemic racism in diabetes health centers and advocacy groups excludes people who hold marginalized identities from accessing support from the diabetes community (Marshall et al., 2020; Spanakis & Golden, 2013; Valenzuela et al., 2020). BIPOC PWD are typically underrepresented at diabetes camp or adult networking opportunities (Valenzuela et al., 2020).

specific medical centers may also limit patient experiences to care from expert diabetes treatment teams (McGrath & Chrisler, 2017; Singh et al., 2019), and white racial identity may enable a greater level of care than is provided to PWD with other identities, who have not yet been centered in pregnancy and T1D research<sup>8</sup>.

The privileged racial and socioeconomic statuses of most participants in existing studies of pregnancy do not facilitate a body of research that represents a potentially diverse array of pregnancy experiences (Gatny & Axinn, 2012). Although pregnancy and T1D can be challenging for people of any identity, the way racism may impact pregnancy experiences among Black PWT1D is yet underexplored. As described above, Black-identified individuals are impacted by medical racism, which enacts disparate health outcomes as compared to other racial groups, thereby making exploration of their experiences with T1D and pregnancy all the more essential (Clements et al., 2020; Fiscella & Sanders, 2016).

Globally, studies of experiences of T1D during pregnancy have largely been completed in European countries and Australia (Edwards et al., 2016; Rasmussen et al., 2013; Woolley et al., 2015). Location of prior research may be related to high incidence of T1D diagnosis in these areas (Berg, 2005). The studies on pregnancy, often associated with major diabetes research centers (Dahlberg & Berg, 2020; Edwards et al., 2016), explore the experiences of populations with drastically different healthcare and sociopolitical contexts compared to the United States (Ridic et al., 2012). Prior research found that pregnant women with T1D benefitted from accessible professional and peer support, either in-person or online (Adolfsson & Jansson, 2012; Linden et al., 2018). The documented stresses of pregnancy with T1D impact perinatal mental

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<sup>8</sup> In COVID-19 research conducted on PWT1D, Black participants are more likely to have elevated hemoglobin A1c levels and serious health effects (Ebekozi et al., 2020). This finding prompted the research organization, T1D Exchange, to create a framework to recruit Black, Indigenous, and people of color (BIPOC) and LGBTQ+ communities more broadly (Vieira, 2021). Despite this new goal to enhance recruitment of Black PWD, the specific barriers to research participation among Black PWD have been largely unaddressed by most research studies.

health, particularly insofar as pregnant PWD mourned their lack of a ‘normal’ pregnancy experience but were willing to repeat the experience despite feeling overmedicalized (Dahlberg & Berg, 2020; Edwards et al., 2016). Similar results have been documented among white women in the United States (McGrath & Chrisler, 2017); however, these results may not translate readily to pregnancy experiences of PWD belonging to other racial and ethnic groups. Health disparities in these countries, while documented, may have different historical and social contexts relative to the United States (Bakhtiari et al., 2018; Bradby et al., 2019).

### **Clinical Psychology Implications**

While manageable, T1D and associated conditions are expensive in many senses of the word, with costs to time, money, and energy to maintain healthy and safe blood glucose levels (Dennick et al., 2017; Sussman et al., 2020; van Duinkerken et al., 2020). Diabetes distress, a condition of emotional distress as a result of the rigors of diabetes management, is well-documented across age cohorts (Dennick et al., 2017; Kelley et al., 2020). Diabetes distress is associated with poorer physical health outcomes (Schmitt et al., 2021) and may be additionally complicated by medical racism (Williams et al., 2020). Social stigma associated with diabetes is linked to elevated levels of depression and anxiety as well as diabetes distress, and these conditions are moderated by social support (Holmes-Truscott et al., 2020).

Diabetes distress is an important consideration during pregnancy, as pregnant PWD have described the emotional and mental load of making diabetes care decisions for not only oneself but also for a growing fetus as exceedingly stressful (Berg, 2005; Dahlberg & Berg, 2020; Singh et al., 2019). PWD may experience sexual dysfunction or infertility related to T1D, particularly if they were diagnosed less recently or if their A1c is chronically elevated (Sjöberg et al., 2013). Fertility and/or sexuality concerns can make conceiving and experiencing pregnancy additionally

physically, emotionally, and financially stressful (Wu et al., 2013). Additionally, PWD have an increased risk of pregnancy loss (Sjöberg et al., 2013). As Black women experience obstetric racism and higher rates of pregnancy loss relative to white women (Davis, 2019), differences in perceived and reported pregnancy-related stress among PWD of diverse racial identities bears further exploration. Risk of pregnancy loss and other pregnancy complications have been reported to increase stress during pregnancy and may increase incidence of mood disorders among PWD (Berg, 2005; Ventura et al., 2018).

Strict management of T1D during pregnancy may result in combined mental and physical fatigue, as tight management requires vigilance throughout the day and even during the night (Shivers et al., 2013). Alarm fatigue, when a PWD no longer responds to their CGM or insulin pump alarms, may be a consequence of strict glucose ranges (Shivers et al., 2013). T1D is linked to greater risk of stress and development of mood disorders in general, and the challenges that can accompany pregnancy can promote development of perinatal depression and anxiety (Kozhimannil et al., 2009). Diabetes distress may be more likely to occur in cases of prolonged stress in PWD, and it can be a particularly dangerous condition to develop during pregnancy due to reduced management behaviors and resulting pregnancy complications (Schmidt et al., 2019).

Exploration of mental health during pregnancy among Black PWT1D is essential. Perinatal depression (PPD) and anxiety (PPA) may cause issues with gestation, labor, and delivery as well as contribute to long term physical and mental health issues for the birthing person and fetus. Factors such as social stress and racial discrimination increase the likelihood of PPD among non-Hispanic Black women relative to women in all other racial and ethnic groups (Segre et al., 2006). During pregnancy, depression and anxiety are associated with malnutrition and risk of hypertension among birthing people (Gennaro et al., 2020). Similarly, health issues

for the birthing person may result in issues with fetal growth and development as well as premature or emergent delivery (Gennaro et al., 2020). In the postpartum period, PPD and PPA are associated with low birthweight, feeding issues, and slow growth for the infant as well as issues with sleeping (Gennaro et al., 2020). Among birthing people, PPD and PPA may be associated with trouble bonding with the new infant, sleep-related issues, dissatisfaction with parenthood, and increased risk of self-harm and/or suicide (Beck, 2006).

Emotional wellness among Black PWT1D may be especially at risk, as PWD are more likely than people without diabetes to experience mental health concerns, particularly depression, anxiety, and diabetes distress (Egan et al., 2017). PWD are likely to experience diabetes distress during pregnancy, as their experience with diabetes is particularly salient to fetal health and safety (Egan et al., 2017; Shefali et al., 2006). They may be more likely to experience diabetes-related discrimination due to their increased contact with medical providers who are not diabetes specialists, thereby increasing risk of developing mental health concerns related to diabetes stigma (Attanasio & Kozhimannil, 2015).

Black PWD are more likely to experience diabetes distress relative to white PWD (Williams et al., 2020). While there are no current studies of diabetes distress, PPD, or PPA among pregnant Black PWT1D, research of mental health conditions among Black birthing people demonstrates they have increased risk of developing mental health concerns relative to white women during pregnancy (Gennaro et al., 2020). In addition, Black birthing people are less likely to be provided adequate mental health treatment (Edge, 2010). Taken together, the intersections of racism, sexism, and ableism may amplify mental health concerns during pregnancy among Black PWT1D. Research of mental health during pregnancy among Black PWT1D is of importance to clinical psychology, as there is a lack of representation of Black

PWT1D in the mental health literature as well as a dearth of attuned clinical support for individuals in this population. This dissertation sought to examine experiences of pregnancy among Black PWT1D with a specific focus on mental and emotional wellbeing, care from medical teams, and social support. Additionally, the study sought to support the need to engage with anti-racist ethos while conducting psychological research.

### **Methodology**

Qualitative methodology was essential to this research in part due to historically limited exploration of experiences of pregnancy with T1D among Black birthing people (Smith et al., 2009). Black PWT1D are grossly underrepresented in studies about pregnancy, and qualitative research enabled more depthful exploration of participant experiences (Smith et al., 2009). Additionally, the narrative style of the resulting research may be more aligned with specific experiences of Black PWT1D.

### **Un/Trustworthiness and Reflexivity Statement**

Personal identity factors of the researcher, who is the filter through which IPA occurs, likely impacted participant experience as well as study findings (Smith et al., 2009). Differences in identity and lived experiences between participants and the researcher may have contributed to the researcher's untrustworthiness in this research process (Smith et al., 2009; Warren et al., 2019). Trustworthiness in qualitative research requires accountability and dependability on the part of the researcher to reflect the experiences of participants as closely, accurately, and ethically as possible. For these reasons, this research has been reflexive and conducted under the supervision of trusted dissertation committee members.

I am a white, middle class, cisgender female who was diagnosed with Type 1 diabetes in early childhood, and I have never been pregnant. My identities likely contributed to bias in my



data collection, analysis, and interpretation. As a woman with T1D, I am aware of and have experienced some of the burdens that impact people with T1D. I questioned whether some of my negative experiences with the medical system have been related to my female gender identity. At the same time, my racial privilege insulates me from and prevents understanding of the immense racism that impacts Black and brown communities in the United States medical system and beyond; and, my identities have largely granted me the privilege to access diabetes supplies safely and consistently enough that I have rarely been without essentials to care—namely, insulin, syringes, glucometer test strips, and most insulin pump supplies. Though I resonated with participants’ frustration with supply malfunction and doctor and support staff lack of knowledge about T1D, my socioeconomic and educational privilege, in combination with white privilege, may further insulate me from potential dangers of the healthcare system. My own lack of experience with pregnancy, which includes fears about pregnancy instilled by my own experiences with the medical system and broader society, means that I likely hold many biases about pregnancy and T1D.

Exploring the pregnancy experiences of Black individuals with T1D is important to me, and I recognize it has not been without risk. I was drawn to this work because Black women and gender expansive PWD need (and deserve) to have their experiences reflected in the literature on pregnancy, and I believed my position of power and privilege as a psychology trainee could influence how this topic is studied and prioritized within the academic system. The timing of the development of this study was in part reflective of my engagement with antiracism and unlearning of white supremacy in the context of the Black Lives Matter movement. The process of my own racial identity development has enabled me to engage in actions that emphasize the importance of Black lives, including this research project that centers Black and African

American experiences. I have worked to maintain awareness of how it can be complicated as a white researcher to study the experiences of Black people due to white saviorism and other negative behaviors that can arise due to presumed ‘allyship.’ Being a student within institutions—psychology and higher education—that have been and continue to be harmful to Black lives has made ongoing reflexivity all the more important. Ongoing supervision and dedication to both the outer and inner work of unlearning white supremacy have been essential aspects of this research.

Similarly to Participant 3, whose experiences will be further explored in the following results section, my early experiences with T1D led me to believe it was dangerous to become pregnant. I remember my mother being upset when I watched *Steel Magnolias* (Ross, 1989) during a childhood sleepover. Although I did not at the time grasp the impact of seeing a woman with T1D have a baby and then die of diabetes complications, this experience informed my sense of how pregnancy can be dangerous for people with diabetes. The danger of diabetes and pregnancy was in some ways reinforced by later interactions with other women with diabetes while in college, in which I found many of us felt pregnancy was impossible or unsafe.

My beliefs about pregnancy with T1D have shifted during the dissertation process through exposure to participants’ stories and the diabetes online community. I now believe in the feasibility of healthy and safe pregnancies with T1D, particularly with access to quality medical care and supportive diabetes technology. I appreciate the resilience and perseverance of online group members who model both the challenges and the successes of pregnancy. I am in many ways interested in this area of research because it helps me feel hopeful about the future of healthcare potentially becoming safer for bodies for whom it is historically and presently unsafe.

I tracked my emotional experiences throughout the research process, which ranged from feeling despair and sadness as participants shared negative experiences with their healthcare teams to feeling connected and uplifted by their messages of hope and care for their communities. I sometimes felt too close to participant experiences, and I felt a sense of vicarious trauma when proximity to my own experiences with T1D related to the participants' experiences. I also felt too far from participant experiences at times, and was concerned that my white racial identity may have created too unwelcoming a space for participants to reflect on the presence of racism in healthcare and/or the diabetes community.

Through the research process, I attuned to how participants shared traumatic experiences and noticed myself feeling concerned about how sharing their trauma could have impacted their wellbeing, and I thought of how, in a clinical space, best practices often call for slowing clients down during early sessions so they do not become overly flooded by trauma. At the same time, I wondered whether it was perhaps harder for me to hear traumatic experiences for the first time vs participants retelling them, and if I was, in some ways, falling into an overprotective, paternalistic, and white supremacist ideology by wanting to slow the rate of sharing. I noticed the duration for which some participants spoke and the rapidity of their speech, perhaps an unconscious coping strategy to share such traumatic information quickly and without many opportunities for questioning or shared reflection. This strategy may have promoted a sense of increased control for participants while recounting past situations in which they were unable to control their medically traumatic experiences. I also noticed my own perceptions of how the medical and birthing trauma could have been related to racism, which sometimes remained unnamed by participants, and how my bias continued to lead to inner questions about which aspects of oppression are or are not linked to participant experiences.

I found myself wondering how my stimulus value as a white woman interacted with the participants' stages of racial identity development (e.g., Participant 2 describing herself during the interview as a woman of color instead of a Black woman). I wondered if participants may not have named racism in their experiences due to racial identity processes. I also wondered how these interviews may have yielded different results with a Black woman or woman of color interviewer. I noticed that Participant 3 seemed to address race most directly of all participants, and I was also perhaps more active in asking her to expand when she mentioned race compared to how I engaged in earlier interviews. My increased level of questioning may have potentially been due to growing familiarity with the interview process, desire to get more information related to race and experiences of pregnancy, and how I perceived Participant 3's willingness to discuss race. I noticed myself feeling pulled to validate her musings about how previous medical and pregnancy experiences may have been due to racism.

I was also aware of the role of disability identity as another facet of identity development. I felt numerous shared "diabetes moments" throughout interviews, particularly when participants shared early diagnosis stories or stories about managing low blood glucose and/or issues with diabetes technology. I noticed myself feeling concerned for participants when they expressed having low blood glucose and even brain fog, and I felt grateful to be in a research environment where the shared experience of low blood glucose can contribute to empathy and a real intentionality behind encouraging participants to pause to care for themselves. I was aware of how sharing one aspect of identity (T1D) was helpful to the interview process while also noticing how our choices for our diabetes care were all distinct.

I have found myself feeling a lot of warmth and gratitude throughout interviews, during data analysis, and while reflecting on the research process. The moments of human

connectedness—from dogs barking to toddlers joining the Zoom call—were some of my favorite aspects of engaging in qualitative research. I continue to hope this research can be of support to the target population and can more broadly facilitate change within the diabetes online community (DOC), and this has felt more important not only through exposure to the richness of participant experiences but also through my efforts to collect data in online spaces that felt negative, judgmental, and rooted in white supremacy culture. I found myself feeling excited about and wishing I could participate in participants' ideas for program development and community building among Black women and other women of color with T1D. I continue to feel curious about whether participants connected with each other via the optional post-research network. I hope that they will continue forward from the research experience, however brief and however complicated by our shared and different identities, to experience safe, love-filled pregnancies/transitions to parenthood and feel held in their communities, whether with other people with T1D or in their significant existing support systems.

### **Context for Data Collection**

Data were collected via online individual interviews using securely encrypted video conferencing software (Zoom). These interviews were audio recorded and auto-transcribed via Zoom, Rev, and/or by the primary researcher and undergraduate research assistants for later analysis using ATLAS.ti. All interview recordings were numbered to remove personally identifiable information, and recordings were stored in a file protected with a unique password on a personal, password-protected laptop. De-identified files were backed up on a password-protected thumb drive, and recordings were not kept on an external cloud server.

### **Participant Inclusion and Exclusion Criteria**

Potential participants who identified as Black and/or African American, were pregnant up to the second trimester within the past 3 years, and were diagnosed with Type 1 Diabetes prior to their pregnancies were eligible for study inclusion. Criteria regarding length of pregnancy enabled inclusion of participants who experienced at least three months of pregnancy and developmental and/or diabetes-related changes but may have experienced pregnancy loss or still be experiencing pregnancy<sup>9</sup> at the time of data collection. Participants of any gender identity were welcome, and participants who were diagnosed with other forms of diabetes that cause insulin deficiency (such as LADA) could also participate. Participants were required to be 18 years old or older. Participants who identified as multiracial were also welcome, so long as being Black or African American was part of their racial/ethnic identity.

Potential participants were ineligible if they met any of the following exclusion criteria: 1) people who had their most recent pregnancy experience over 3 years ago; 2) people who were diagnosed with other forms of diabetes that did not result in global and lasting insulin deficiency, such as gestational diabetes, Type 2 diabetes, or diabetes insipidus; 3) people who were diagnosed with T1D after their most recent pregnancy experience; 4) people who did not experience pregnancy up to the second trimester (e.g., were currently pregnant and in the first trimester or had experienced pregnancy loss earlier in pregnancy, either group of whom therefore may not have experienced developmental changes associated with diabetes and pregnancy including insulin resistance). Recency of pregnancy was essential to the study in order to capture a sufficiently current experience of DOC groups, which have become more active in more recent years.

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<sup>9</sup> Although participants who were currently pregnant were ultimately eligible for the study, the Institutional Review Board was concerned about the potential for coercion due to the \$50 study incentive. The compensation protocol was therefore amended to support participant agency and offer a choice between receiving a virtual gift card or asking the researcher to send the equivalent amount of money to a diabetes and/or pregnancy non-profit of the participant's choice. The researcher wrote a letter advocating for pregnant participants to receive identical financial incentives to non-pregnant participants; this letter can be viewed in Appendix E.

### **Recruitment Procedures**

Participants were recruited through the diabetes online community (DOC) via the social media sites Facebook, Instagram, and Reddit. Recruitment messages were posted to The T1D Sugar Mommas pages and shared with BIPOC PWD Instagram collectives with T1D as well as posted to Reddit forums (see lists of influencers, pages, and forums in Appendix A). Incentives for participation were offered in the form of \$50 Visa virtual gift cards upon completion of the study. These gift cards were funded via the researcher's personal savings.

The study utilized purposive and snowball sampling to explore the online network of Black PWD who followed each other and perhaps engaged online to share information about their pregnancy experiences. This study aimed to utilize snowball sampling methods in a new way relative to previous studies of PWD and pregnancy, in the context of accessing the supportive subculture of Black PWD within and outside of diabetes organizations. Unfortunately, it proved challenging to contact online pages specific to T1D and pregnancy due to many having policies preventing researchers from posting studies. Even the admin and founder of Type 1 Diabetic Sugar Mommas (T1DSM), who had no such policy, shared reluctance to post the study due to perceiving it as “potentially racist and exclusionary.” While the flier was ultimately posted to the group after lengthy communication and advocacy with the admin, this process may have been indicative of the way whiteness shapes online acknowledgement—or lack thereof—of race.

Participant recruitment was limited, perhaps due to difficulty accessing the Black PWT1D population using social media sites. Data saturation was predicted within approximately six participant interviews based on IPA research, but only three participants were eligible for and participated in the study after six months of recruitment practices (Smith et al., 2009). Recruitment ceased after no new eligibility survey data were gathered for two months. More

details about the sample size and study process are available in the following sections. The number of interviews would have been adjusted if data saturation, the point at which no new information is gained with subsequent interviews, was reached prior to interviewing six participants (Fusch & Ness, 2015).

### **Data Collection Procedures**

Potential participants were invited to complete an eligibility survey via Qualtrics to screen for inclusion and exclusion criteria (Appendix B). If eligible to participate, they were contacted via email and/or text and invited to schedule individual interviews. Participants received copies of the informed consent document (Appendix D) and were asked to review the forms prior to the meeting and invited to ask questions via email or at the beginning of their interview if applicable. Participants signed the forms prior to or during the beginning of their individual, semi-structured interviews via secure video conferencing software (Zoom). These interviews lasted approximately one to one-and-a-half hours. The interviewees were asked a series of questions about their pregnancy experiences, and the interview was audio-recorded and stored on the researcher's personal, password-protected laptop with no personally identifiable information (Appendix C). The eligibility survey and semi-structured interview questions are available in Appendices B and C.

### **Data Analysis**

This study utilizes and honors an intersectional approach as defined by Crenshaw (1991) and is informed by anti-racist, feminist, and pro-LGBTQ+ sentiments as established in the history of Black Feminism in *The Combahee River Collective Statement* (1977). A framework of disability justice (Bailey & Mobley, 2019; Berne et al., 2018) was incorporated into this intersectional approach, thereby hypothesizing that participants will experience the world based



on their collective, intersectional oppressions across race, gender, disability status, and any other potential marginalized identities, which are distinct from any one area of oppression considered individually. Rather, these aspects of identity are inseparable and result in a lived experience that is unique to these specific intersections and may also differ from person to person.

Data collected via qualitative interview was recorded and transcribed via Zoom cloud recording and/or Rev transcription service. These transcripts were de-identified, corrected, and cleaned by the researcher and undergraduate research assistants and saved for later analysis using ATLAS.ti, a data analytic software program that organizes, codes, and compares aspects of interviews. Data were processed using an IPA framework, which aims to interpret how participants make sense of their experiences through iterative and circular analysis (Smith et al., 2009). The process involved a multidirectional series of steps as outlined in *Interpretative Phenomenological Analysis: Theory, Method and Research* (Smith et al., 2009). Steps included line-by-line analysis, identification of emerging themes, and development of dialogue between researcher, data, and meanings (Smith et al., 2009). Other steps involved the development of a frame through which to illustrate relationships between themes and organization of material into a coherent process. Throughout the analysis, the researcher made use of supervision and collaboration to develop the plausibility of interpretations, create a full narrative, and reflect on the researcher's own processes. The analytic process occurred for each individual interview as well as when analyzing the interviews as a data set to bring forward common themes or distinct differences. The researcher became immersed in the data and continually engaged with each interview to promote depthful exposure to a piece of the participant's world (Smith et al., 2009).

***Step 1: Reading and re-reading***

Beginning with a single case, the researcher read the interview transcript three times. Each reading brought the researcher closer to the unique experience that the individual participant shared and centered the participant in the analysis, thereby making it more possible to access potential meanings of the participant's experiences (Smith et al., 2009). The first reading was coupled with the researcher listening to the synchronized audio recording of the interview and editing the transcript for accuracy. Any initial impressions were noted, but the primary purpose of this step was to become closely familiar with the data through active engagement with the interview text (Smith et al., 2009).

### ***Step 2: Initial noting***

The researcher uploaded the transcript to ATLAS.ti and listened to the audio recording while making notes. Following the methodology described by Smith et al. (2009), the researcher created codes in ATLAS.ti to note language and content in comprehensive detail. The initial noting process involved a series of descriptive, linguistic, or conceptual comments, whichever felt relevant to the data. Descriptive comments pertained to the content of the interview, in which details that were meaningful to the participant were elicited. Linguistic comments pertained to the use of language, or how content and meaning were presented by the participant, and included pacing, repetition, tone, and laughter. Conceptual comments pertained to interpretation of the data through wondering what beliefs underlied the participant's experiences. The noting process required self-reflexivity in order to examine how the researcher's own experiences and theoretical frame may have shaped responses and theories about the participant's experiences (Smith et al., 2009).

Areas of the transcript which felt 'important' to the researcher were annotated in order to make sense of why they felt important. The researcher kept a running log of thoughts prompted

by the data analytic process, and this log informed the researcher's reflexivity process.

Paragraphs of the transcript were read out of order to promote a closeness to the words rather than a skimming of the narrative. This process further distanced the researcher from the 'normative' way experiences are read and digested (Smith et al., 2009).

### ***Step 3: Developing emergent themes***

The researcher distilled the amount of detail from the transcript and notes into what Smith et al. (2009) terms a still-complex analysis. The process of distilling data involved notation of any patterns and relatedness between the first sets of notes and codes. Distilling the data required attention to portions of notes from certain areas of the transcript, which were then linked using similar codes within ATLAS.ti to search for meaning. Codes were condensed and restated in fewer and simpler words to get to the core ideas underlying sections of text. Simplified codes were printed and sorted into groups to support the development of emerging themes. These new themes reflected understandings of the text that are both conceptual and grounded. The theme development process related to the hermeneutic circle, in which the researcher analyzed parts of the interview rather than the whole and then recombined them into a new whole by entering resulting codes and themes into a Google Doc.

### ***Step 4: Searching for connections across emergent themes***

The researcher printed the themes from the Google Doc, cut them into pieces, and sorted them in order to chart relationships between themes into a structure that highlighted important topics and connections. To organize the data, the researcher followed guidelines by Smith et al. (2009) and moved themes that seemed related into clusters. These clusters were then titled with new names to describe the overarching themes. The researcher monitored the frequency with

which various themes arose and remained attuned to any meaningful pattern or potential relevance to emerging themes.

***Step 5: Moving to the next case***

After moving to each new case, steps 1-4 were repeated with the new source material. Each interview was honored for its individuality, and it was approached with as naive a research perspective as possible rather than seeking similar patterns from preceding interviews (Smith et al., 2009). Maintenance of relative naivety was attempted via pauses of at least a week in between the data analytic processes for each interview as well as reliance on the depthful reading and rereading processes described in Step 1. Review of the audio recording and reflection on the experience of the new interview also supported connectedness to the new material. The process of embedding oneself in the transcript data through repeated review was essential to this process.

***Step 6: Looking for patterns across cases***

Themes from each case were compared and connected via printing and sorting themes into clusters (Smith et al., 2009). Special attention was provided to themes that seemed particularly salient, and earlier themes were sometimes reordered or renamed based upon findings in this stage. The pattern-seeking process enabled attention to which themes were relatively unique to a specific case as well as which seemed to be shared. Findings were organized into a new table of themes to reflect overarching themes, subthemes, and unique themes for particular cases represented. This table (Table 1) is available for review in the following results section.

## **Results**

Given the role of medical racism in pregnancy experiences among Black women and disability discrimination among pregnant PWD, I hypothesized that there would be a likely

cumulative effect of both gendered racism and ableism on the pregnancy experiences of Black PWT1D. Additionally, I hypothesized that the primarily white Diabetes Online Community (DOC) does not lend itself to inclusive support of Black PWT1D, and that there are perhaps supportive subgroups in which Black PWD may discuss their pregnancy experiences.

### **Participants**

Forty-seven people<sup>10</sup> completed the eligibility survey following its dispersion to social media sites and medical contacts. Ten people met eligibility criteria and were invited to individual zoom interviews, and all scheduled to meet. Notably, seven people qualified for study inclusion based on the questionnaire; yet it became clear during the interview that they were unfamiliar with T1D nomenclature, standards of care, and medication requirements. Two of these individuals seemed to be the same person based on interview characteristics and vocal tone, though this was difficult to determine due to them keeping their cameras off. All seven would-be participants were informed of the researcher's ethical obligation to gather truthful and accurate data, and the interviews were terminated by the researcher due to significant suspicion that these would-be participants did not have T1D and were falsifying data in order to gain the monetary incentive associated with the study.

Three cisgender women were eligible for the study following the online eligibility questionnaire and preliminary conversation during their individual Zoom interviews. Of the three women who qualified for study inclusion, one was currently pregnant for the first time and was in the second trimester of pregnancy. The other two participants, one of whom had been pregnant multiple times, had one child each. All participants were over 18 and reported identifying as

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<sup>10</sup> While there were forty-seven separate eligibility survey entries, it is unclear whether some were completed by the same individuals. Many of the entries demonstrated that participants did not meet requirements, largely due to insufficient pregnancy duration and/or too much time since their most recent pregnancy. The researcher sent emails to individuals who did not qualify due to time constraints informing them that they were not currently eligible but would be contacted if study parameters changed.

Black or multiracial.<sup>11</sup> All three participants were currently living in the United States and had been in the United States during their pregnancies, and all had been diagnosed with T1D pre-pregnancy. One participant was diagnosed in childhood, another in emerging adulthood, and the third in early adulthood. Each participant lived in metropolitan areas with access to healthcare resources during their pregnancies, which had occurred within three years of data collection. The details of participant demographics (including ages of their children and geographic location) have been left intentionally vague in order to maintain confidentiality.

- Participant 1 (P1) was a Black woman in her 30s living in a city in the western United States. She was pregnant with her first child at the time of the interview, and was diagnosed with T1D in early adulthood.
- Participant 2 (P2) was a multiracial (Black and white) woman in her 30s living in a city in the midwestern United States. She had her first child within the past 3 years, had no other pregnancies, and she was diagnosed with T1D in emerging adulthood.
- Participant 3 (P3) was a Black woman in her 30s living in a city in the eastern United States. She had her first child within three years of the interview, and she was previously pregnant in her 20s, and she was diagnosed with T1D in childhood.

## Themes

Four major themes were identified across participants through the data analytic process, as can be reviewed in Table 1. The table includes nine subthemes related to the lived experiences of participants, who reported a range of internal experiences, physical experiences, experiences with healthcare, experiences with information-seeking, and experiences with lack of

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<sup>11</sup> One additional woman was eligible across all dimensions of identity and experience except for racial identity, as she identified primarily as Guyanese rather than Black and/or African American. This potential participant was not included in the study after consultation with the dissertation committee and consensus that Black identity was likely significant in perceptions and experiences of medical and gendered racism, especially when considering the implications of historical, genealogical enslavement and continued oppression of Black Americans within the United States.

representation and support both online and in-person. A detailed review of the interpretive analysis of participant data, including direct quotes, will follow in sections dedicated to each theme.

**Table 1**

*Themes and Subthemes Among Participants*

Themes and Subthemes
<ol style="list-style-type: none"> <li>1. Interplay of Psychological and Physical Experiences           <ol style="list-style-type: none"> <li>a. Influence of Pre-Pregnancy Experiences</li> <li>b. Cognitive-Emotional Experiences During Pregnancy</li> </ol> </li> </ol>
<ol style="list-style-type: none"> <li>2. Experiences with Healthcare System           <ol style="list-style-type: none"> <li>a. Mixed Experiences with Healthcare Providers</li> <li>b. Systemic Issues: Lack of Diabetes Expertise, Lack of Resources, and Racism</li> <li>c. Medical Trauma</li> </ol> </li> </ol>
<ol style="list-style-type: none"> <li>3. Coping: Strategies for Gathering Information, Seeking Support, and Fostering Mental/Emotional/Spiritual Well-Being           <ol style="list-style-type: none"> <li>a. Gathering Information: Researching About T1D and Pregnancy</li> <li>b. Seeking Support: Mixed Experiences with Online Peer Interactions</li> <li>c. Seeking Support: Benefits of Friend, Family, and Partner Support</li> <li>d. Strategies Supporting Well-Being</li> </ol> </li> </ol>
<ol style="list-style-type: none"> <li>4. Desire to Build More Representation and Inclusive Support</li> </ol>

**Theme 1: Interplay of Psychological and Physical Experiences**

All participants reported ways in which their cognitive and/or emotional experiences interacted with their physical experiences. The interplay of psychological and physical factors related to participants' internal experiences prior to and during pregnancy.

***Subtheme A: Influence of Pre-Pregnancy Experiences***

All participants reported that experiences with diabetes prior to pregnancy influenced their outlook leading up to and during their pregnancies. Below are quotes from all participants, who each endorsed themes related to past as present within their experiences.

Participant 1 expressed an omnipresent awareness of the risk associated with pregnancy as a person with T1D, stating, “I guess I just always knew it would be challenging. I just knew it was high risk.”

Participant 2 described a process of reading about diabetes management prior to pregnancy that did not coincide with her endocrinologist’s later recommendations, sharing:

[We were]...kind of talking about getting my A1C where it needed to be and...then breaking down that like stigma that like, no, it, it doesn't necessarily have to be there....this is what's ideal and what textbooks say, but also we need to look at real life and, you know, if you're doing...what we think is appropriate.

Participant 3 described the impact of being warned against pregnancy during her diagnosis in childhood:

I know all the horror stories about this. I'm going back to my past, and when I first got diagnosed, they told my parents that I probably wouldn't have children...I might have convinced myself at an early age, that I didn't want kids because of what I was told...For a large part of my life I used to tell people I probably wouldn't have kids...I guess that was my...kind of defense mechanism...to save myself the hurt.

### ***Subtheme B: Cognitive-Emotional Experiences During Pregnancy***

All of the participants noted their cognitive-emotional experiences as a major factor in their overall pregnancy experience, particularly as they overlapped with physical experiences of blood glucose changes and fetal development. They endorsed a variety of emotions, including



fear, excitement, frustration, and gratitude. They also described cognitive processes including concern, planning, uncertainty, and learning.

Participant 1 shared that, despite her strong coping skills and positive outlook:

I...have days where I'm...super depressed and like, stressed, or anxious, or worried...Just being pregnant and like knowing that...most pregnant people like after the first trimester...the likelihood of like a miscarriage or things like that, kind of the percentage falls, but then from a Type 1 pregnancy like there's the fear throughout the entire journey um and so just knowing that...and trying my best to...not worry too much about it.

Participant 2 similarly discussed recurrent experiences of anxiety related to pregnancy and diabetes:

There was definitely some...worry and anxiety there...like, am I doing this right? And what am I doing?...I mean, of course it's your first, so of course already, you're already like, ah, you know, I don't know what's going on. And every day is like, is this normal? Is this normal? Is that normal? You know, you're constantly asking, um, those questions.

Participant 2 also discussed the cognitive-emotional experience of burnout and her feelings of anxiety, frustration, and despair:

I have had...probably more than moments of frustration...feeling burnt out with just the constantness of, you know, managing this particular disease...with diabetes it's ever-present...especially with pregnancy, it was even more so that way...I was very, very worried, all the time...about my sugars and how my decisions were gonna impact my baby...[it was very] important to me to make sure that I was doing it all the best that I could...If my endocrinologist is telling me, 'you need to have your numbers here after meals and here when you wake up' and if I wasn't, it was devastating.

Participant 3 discussed the cognitive-emotional process of preventing herself from feeling excited or hopeful due to worry about her baby's health and chance of survival":

Each trimester I had the apps on my phone to watch as the pregnancy progressed. I would not allow myself to get excited for each milestone. I'm like 'Okay, well, this is supposed to be happening. Okay, and this is supposed to be happening.' I wouldn't allow myself to get excited.

Participant 3 described the way developmental changes affected her cognitive-emotional experience:

[my] first sign of optimism...was when I heard his heartbeat...Everybody just talked to me and everybody just kept saying, 'everything is going to be just fine, everything is okay,' and I'm still looking at these numbers. [laugh]...they're still fluctuating and I'm like 'what is happening with my baby, you know, is my baby going to be okay?'

All participants endorsed feeling unprepared for the changes to their usual experiences with T1D due to pregnancy, particularly related to insulin sensitivity in early pregnancy. They felt prepared for insulin resistance, which occurs later in pregnancy, but found themselves experiencing much lower blood glucose levels than expected in their first trimesters. Participants reported feeling surprised, frustrated, or afraid due to these changes.

Participant 1 noted her frustration related to insulin sensitivity:

First trimester I just was really frustrated with the sensitivity...nothing seemed to keep me [up]. I just was constantly eating gummy bears and drinking my juice...that was, like the biggest challenge of just the frustration of like I'm not even eating stuff that I want to be eating right now, it's just...trying my best to keep my sugar stable.

Participant 2 similarly described feeling shocked and afraid due to drastically lower blood glucose levels:

First trimester, I could not keep my blood sugars up to save my life, which was something that shocked me because I...was not prepared...it was scary. You know, I had a couple of times where...thank God my husband was with me, but I was like, my knees kept buckling underneath me and I couldn't walk. I had to...literally sit down on the sidewalk and he had to go home and get orange juice and come back [laugh]...I thought, oh, a 10 minute walk, like no big deal. I'm not gonna take my whole pack of crap with me, you know, for 10 minutes. Um, but after that happened, I never left home without my glucose tabs and fruit snacks.

Participant 3 also described feeling afraid, particularly due to low blood glucose levels at nighttime:

The lows used to scare the crap out of me, they would happen...almost every night. And regardless of what I did, regardless of the monitoring...I was talking to someone daily, daily we were making adjustments on my insulin pump...Why, why still these issues...why am I still having these lows? Why am I still having these high numbers? After reading a little bit more about pregnancy and seeing some other people's experiences, it's just the name of the game with type one diabetes the fluctuations and is the same in pregnancy, so I feel like I've kind of accepted that.

## **Theme 2: Experiences with Healthcare System**

All participants discussed healthcare as a primary factor in their pregnancy experiences. Participants ranged in their feelings toward their experiences with healthcare, often reporting the benefit of positive experiences, sometimes feeling ambivalent, and sometimes highlighting how

negative experiences with healthcare deeply impacted their mental and physical health during pregnancy. Participants reported systemic issues that they identified as related to lack of diabetes literacy and potential diabetes discrimination rather than overt racism, though some participants wondered whether racism could have been a factor in the way they were treated. Discrimination in any form was likely linked to systemic issues of medical providers receiving training that is ableist, racist, and sexist. Participants were aware of the study's potential intent to explore incidences of medical racism, and participants sometimes seemed almost apologetic for describing positive experiences. For instance, Participant 1 shared:

[It's been] totally positive, I haven't had any negative experiences. I know that...probably sure you're looking for other [experiences], (laughs) but so far in the process, I feel like i've been very lucky and...Every time my partner and I go to the hospital or the clinic, we're just super impressed with how well everyone has been treating us.

The researcher's white racial identity also likely impacted the level of participant's comfort with disclosing experiences of racism, as noted in the above section on untrustworthiness and reflexivity. These factors will be further described in the discussion section.

### ***Subtheme A: Mixed Experiences with Healthcare Providers***

All participants identified a mix of feeling supported and not supported by their healthcare providers prior to and during pregnancy. The first series of quotations illustrates participants' positive experiences and interactions with providers.

Participant 1 described feeling very supported in her current medical system, particularly due to support by specialists and experts in diabetes and pregnancy. She noted her concerns about not having one obstetrician assigned to her, but reflected feeling positive about having found such a supportive team:

I think it's so far it's been good, like everyone has been so welcoming and warm. I think the thing that I was a bit hesitant about is there's not one OB assigned to you. You're kind of seeing the whole group, and so that's the big...challenge...That probably was the biggest unknown, finding the right specialist team. And I just happened to be in the [Western United States metropolitan area] at one of the best hospitals...so I think all that coincidence and alignment was so helpful, but I think that that's probably the most important thing is making sure that you have a team that is specialized in OB as well, as you know, like specialists in high-risk, but then also specifically from a Type 1 diabetes perspective.

Participant 2 described her positive experiences with a new healthcare provider after ending services with an unsupportive doctor, and she reflected on how gender may have played a role in her experience of feeling supported:

I left and I looked for another physician...[I] told her what my experience was with my previous provider and how I was feeling very defeated...I needed that 'okay,' from a physician to say, 'we can do this, we can work with this. We can get you there.' And it wasn't like my A1Cs were like 12, right. They just weren't less than seven. They were like 7.5, 7.6, 7.4...[prior provider] was like 'Less than seven or don't even ask,' you know? And so [new provider was] like, 'You can drop your birth control today...we can do this right now. Like we don't need to wait if you're ready to get pregnant, let's do it.' So it was like a huge 180 turn...just a completely different vibe...sometimes I think a woman just listens better. I hate to say that, but, you know, that's my experience at least.

Participant 2 noted the benefits of having an endocrinology team who supported her agency and helped reduce her pressure to be perfect during pregnancy:

My endo team has always been and was throughout, you know, my whole pregnancy, very supportive, and wanting me to be driving the bus as much as possible... they kind of said 'this does not have to be perfection,' you know? And they reminded me of that several times... And it's still not perfect, [even with a] perfectly great meal. And my blood sugar's 300 and then I'm freaking out because, oh my gosh, what's that doing to my baby? And so they would try to like, 'it's gonna be okay, you know, if it's high for two minutes, you know, and it's already coming back down, like, that's okay. Like you're gonna be fine. The baby will be fine. Like all of these things are gonna be okay.' So that was very helpful, very supportive.

Two participants also reported negative experiences with healthcare providers, which they identified as significantly impactful to their wellbeing. Both participants who reported negative experiences with healthcare providers noted feeling like their doctors were making the decisions rather than being collaborative or promoting patient agency.

Participant 2 discussed complex experiences and feelings related to health providers only listening to her to a certain extent:

I feel like mostly I had a good team... they listened to an extent, you know, to what I was wanting. Um, but I think because I was high risk, it was almost like that was a reason to kind of trump anything else. So it was like, whatever's specifically going to make sure that the outcome is the best, which, I mean, I can't fault them for wanting that. I want that too, you know?

Participant 2 also discussed negative preconception experiences with an endocrinologist with T1D who was not supportive of her desire to become pregnant:

This doctor, he had Type 1, you know, he was very pump savvy. He seemed pretty open

minded and you know, I liked his bedside manner for the most part, pretty much straightforward. Um, but he was very, um, very stringent on, you know, your A1C must be this for six months before I would even talk to you about pregnancy. And you know, I'm kind of continuing to ask him like, Hey, I'd like to, you know, think about this. I'd like to be in, you know, pursuing this soon. And he just wouldn't budge at all. And it was very difficult because at that time I felt like I was doing everything above and beyond, you know, what should have been asked of somebody as a diabetic, as a Type 1, as a female trying to conceive. And my A1C just wasn't playing well. He wasn't being very nice, you know, and I was just having a lot of trouble getting my numbers where he wanted them to be for long enough for him to say, yep, you can get pregnant...I kind of got to the point where I felt like he wasn't listening to me anymore and just was not really encouraging me to be a part of the care. And so I left and I looked for another physician.

Participant 3 shared her negative experiences with healthcare providers' strong reactions related to her prior pregnancies:

I don't recall what my A1C was, however, I was convinced by medical staff I should not go through with the pregnancies. Just like 'Oh no oh my God!' and 'This is not going to be okay, this is not going to be successful, and you should terminate.'

***Subtheme B: Systemic Issues: Lack of Diabetes Expertise, Lack of Resources, and Racism***

All participants noted how the medical system can be complicated and has the potential to impact their health. All participants reported systemic lack of expertise about T1D and pregnancy, feeling shuffled around, and ultimately feeling as if their healthcare providers utilized a teamwork approach, though some had better experiences with healthcare teamwork than others. Participants also discussed their desire for more T1D-informed resources within the healthcare

system, whether those resources are broadly for T1D and pregnancy, related to race and representation, or complementary to western medicine, such as acupuncture, lactation consultation, and midwifery. Two participants, P2 and P3, described events that seemed potentially linked to medical racism (and will be further discussed at the end of this section and/or in the following section on medical trauma), but they expressed uncertainty about whether racism impacted their experiences.

Participant 1 described systemic issues with healthcare providers who were ill-equipped to support PWT1D who become pregnant:

So there's so many layers of like care right...I had an endocrinologist that I worked with prior to pregnancy, but as soon as I got pregnant, I had to find a new doctor...she wasn't as connected to...the OB community and didn't necessarily have like the resources...a lot of...medical care professionals do not want to be responsible for the care of type one diabetics and pregnancy because it is so high-risk and...it's such a specialty...they tend to want to defer...to the experts in the field.

Participant 2 noted systemic issues with feeling like there was less relational support due to not having an assigned obstetrician:

I felt [less supported by] the OB team...I think it was because of how they did their practice, where you had a doctor, but you see everybody in the practice because anybody could be delivering you, which is nice. I understand why they do that. But I think it also creates for some patients like me, less of a feeling of support or like continuity of care or like establishing a relationship...what's funny about this whole thing too, I think is, you know, even though they had me meet everybody under the sun, the one surgeon that did my C-section? Never met him before in my life. Never saw him before he came in.



When discussing their experiences with the healthcare system, participants 1 and 2 noted their access to good insurance as a main resource in accessing good care within the health system. Participant 1 shared, “I’ve also been super blessed too, just having really good insurance. That, I think, has made it also not as much of a burden that I feel like a lot of other folks probably might experience too.”

Participants 1 and 3 shared some of their wishes for more healthcare resources that fit their values. Participant 1, for example, discussed her desire for T1D-inclusive complementary care that is typically not accessible to PWT1D during pregnancy:

There's like the strong community of doulas...I asked some friends, I was like does anyone have doulas that are specialized in Type 1 and all of that, and...that's not really a thing...I think I even messaged a doula...I just don't think there is like the expertise of managing that and then I think it just goes back to how, even from a traditional medicine perspective, how folks feel uncomfortable with...us higher risk, you know situations.

Participant 3 described systemic lack of access to certain aspects of birth plans due to her T1D:

I had asked about the possibility of delivering in a squatting position...It was kind of dismissed. Basically squatting wasn't really an option...I feel like I won't be because of my condition I am excluded from experiencing an at-home birth or water birth...I am interested, but I understand my condition...I understand the need for insulin or whatever other medications it is that you know they provide...I guess, because this is what I know when ...and it's what I'm more familiar with, I won't fight it.

Participant 2 shared her experiences with health providers making unilateral decisions that evoked examples of obstetric racism discussed by Davis (2019). The medical providers’ lack

of attention and attunement to her and her baby's needs—a systemic issue that affects Black birthing people—resulted in medical trauma, as apparent in the below quote and in the following subtheme:

I don't know if he really needed to come out yet, but that was their decision. I didn't really feel like I had any sort of say in that...because it was my first and I...maybe didn't educate myself enough about what that would mean. If I decided to say 'No, I don't think he's that big yet. And he can stay in.' He wasn't ready to come out...we did every induction method under the sun...I was in labor for close to three days...from the start of induction until C-section, it was almost 72 full hours...lots of uncomfortableness in general...Cytotec, every single round that they could give me, they maxed out all the softening agents. They did the balloon dilation, broke my water, all that stuff. [They checked my cervix] all the time, which was almost worse than the contractions. The checking was horrendous. That was my whole experience with pregnancy, not great, you know?...[the C-section] was like somebody was ripping something out of me cuz he wouldn't come out.

### ***Subtheme C: Medical Trauma***

Two participants endorsed having experienced some form of trauma due to pregnancy-related medical treatment. Experiences included trauma due to feeling over-medicalized related to having T1D, not being able to make choices about their healthcare, and/or experiencing trauma during the birthing process.

As referenced in the prior section, Participant 2 described experiencing medical trauma related to diabetes management throughout labor and delivery:

It was a fairly traumatic experience from start to finish...just the blood sugar checking and, you know, the, the insulin drip and the glucagon and all of that on top of just the regular trauma of what happened during that time frame, you know, it just definitely just added another layer of challenge [laugh].

Participant 2 also reported medical trauma specifically due to providers forcing an induction and subsequent C-section:

[Baby] was starting to get kind of in distress. Like his heart rate was dropping, his temperature. My temperature was elevating. So they're like, Nope, we've gotta take him out now. So they...did the C-section and that was even quite traumatic...they couldn't get [baby] out. They were using forceps and suction several different times. And they said afterwards, '[Baby] just kept kind of spinning around in your uterus and not wanting to come out.' And so this is why I'm saying I don't think [baby] was ready. I don't think [baby] needed to come out at 38 weeks because I was high risk. They made the call and I wasn't really in a position to feel like I could fight that...maybe I can't, I don't know.

Participant 3 was thoughtful about how past traumatic experiences of coerced termination of pregnancies may have been avoidable:

I do wonder if there was any possibility that my two prior pregnancies could have been successful...I do wonder, after...still experiencing fluctuations with this pregnancy, yeah my baby is fine...so I do wonder about that...I can't remember what my A1C was back then. This pregnancy my A1C was where it needed to be. Six-point-whatever it's supposed to be [laugh]. I imagine it's possible I probably could have been 11 or 12 A1C back then...And maybe that could have made all the difference...I don't know if I really want to do the research to find out because I don't know if I want to know the truth.

### **Theme 3: Coping: Strategies for Gathering Information, Seeking Support, and Fostering Mental/Emotional/Spiritual Well-Being**

All participants described a desire to find community support and information about T1D and pregnancy that would reinforce their health and the health of their babies. Often, this required doing their own research and determining which aspects of others' experiences—whether online or in real life—felt both transferable and applicable without becoming overwhelmed. All participants discussed the importance of peer, family, and online support as main coping factors during pregnancy. Participants found online support in different ways, using different platforms, and described conflicting feelings about online groups. Participants were intentional about developing coping strategies that served their mental, emotional, spiritual, and community needs. Participants were also reflective about their desires to support others through their participation in the present study. This theme is composed of four subthemes: Gathering Information: Researching About T1D and Pregnancy,' 'Seeking Support: Mixed Experiences with Online Peer Interactions,' and 'Strategies Supporting Well-Being.'

#### ***Subtheme A: Gathering Information: Researching About T1D and Pregnancy***

All participants described researching information about T1D and pregnancy, sometimes very intensely, using Google, books, or social media sites. Participants often cited the lack of clear information that was easily available about T1D and pregnancy—whether in their medical systems or online—and the need to pursue specialized information. The intensity with which they researched was sometimes described as “obsessing,” by participants.

Participant 1 discussed her use of online searches and Reddit forum participation as primary ways she gathered information, and she acknowledged the sometimes obsessive nature of researching:

I could be in a Google trap, one day, you know and then someone on the Reddit forum said something because someone was like freaking out, and I screenshotted it, but she basically said, like ‘I’m pretty sure like,’—and this is probably not PC but—‘a pregnant person on drugs versus us with Type 1, I’m pretty sure that we’re doing...everything we possibly can to bring a healthy baby in this world, and like that is enough,’ you know...just like a good refreshing thing of like we’re *obsessing* you know and...we can have a different perspective on it yeah.

Participant 2 discussed her feelings of having read and researched perhaps too much, but how this connected to her deep care for her child:

I really devoured [laugh] a lot of things...I tried to read whatever I could that was from reputable child rearing or birthing, um, websites, or, you know, through certified individuals through social media...I feel like I did an overabundance of reading, like maybe even borderline too much reading [laugh]...on like everything that could happen [laugh] right...but [laugh], you know, when it comes to like caring for my child who I’ve been wishing for and praying for, for years, I wanna make sure that I have all the resources that I can to do this job to the best of my ability...I just wanna be educated on...what’s recommended and then make my own decisions about what’s best.

***Subtheme B: Seeking Support: Mixed Experiences with Online Peer Interactions***

All participants utilized some form of online peer-supported platform for information gathering, including Facebook pages, Instagram posts, YouTube videos, and anonymous Reddit forums. Participants used these spaces to read others’ experiences with T1D and pregnancy as well as ask questions and/or solicit perspectives about their own experiences. Participants discussed positive and negative experiences related to online groups. All participants reported

feeling troubled by unsupportive content and lack of sensitivity online as it related to experiences with medical complications, diabetes management, and T1D and pregnancy. Though participants did not report overt racist incidents in the online communities, they noted that lack of racial representation across spaces made them feel more different from other PWD and less like they could engage.

Participant 1 felt she found sufficient support online through an anonymous Reddit forum:

I just kind of found [r/bumperswhobolus] and I was like ‘oh I’m getting the information that I am looking for,’ and...I haven't really looked for other forums...it was like the right information that I needed and support too...it's like the questions to ask, the things to think about, all of that...I get the questions I need, we all are just pregnant people who are navigating this.” She also noted that she liked spaces in which she could maintain anonymity due to online racism, “I like the anonymous nature of Reddit, and I'm not in an environment [where it is obviously] predominantly white women and just like that's not always the most welcoming communities so...I feel like oftentimes folks don't even acknowledge [race] outside, you know, so like it's probably something that they're not even thinking about.

Participant 2 discussed her experience of online groups as both helpful and potentially triggering when considering potential medical complications:

The Type 1 pregnancy Facebook page was very helpful. Um, but also to an extent, like you have to be kind of careful, like how much you click on that stuff and like what you're reading, um, because there's a lot of triggering things on there too, of ...things that [are] always kind of in the back of your mind...and don't wanna really acknowledge as being a

reality for some people. Um, so yeah, that, um, certainly kind of is a double-edged sword with social media groups.” She noted that, though she did not experience overt racism, she was aware of unkind attitudes online, “I haven't, thankfully within those communities, haven't seen a lot of like specifically racist remarks, but more just unkind remarks in general and a lot of judgment surrounding what people were doing, you know, in terms of managing their diabetes or perhaps maybe not managing it all that well...And being shamed for doing that.

Participant 3 described feeling happy to connect with other women with diabetes, particularly when discussing pregnancy:

I'm really happy to be in this space [the interview], to be here with you, having this conversation...for so long I've looked for people like myself to identify with and talk to...so happy to have found that space...I never wanted to talk about my diabetes [before]...It might have been the sparking of that idea about me reaching out to other women like myself and talking about our pregnancies.

### ***Subtheme C: Seeking Support: Benefits of Friend, Family, and Partner Support***

All participants reported that non-T1 friends, family, and partners were the most present and supportive relationships during their pregnancies. None of the participants reported close personal relationships with anyone else with T1D among their friends or families, however, friend and family relationships were responsible for most of their social support.

Participant 1 described the experience of being supported by her partner during her pregnancy:

I feel like [my partner]'s been my primary support you know, through the process...I had COVID first trimester too, and so I joke and say my dog would have been rehomed if I

didn't have him because it was just that exhausting [laugh] and like did not have the capacity to care for the dog. So he's been super supportive and in it with me the whole time.

Participant 2 discussed the benefits of being connected to friends, family, and her husband, and being able to talk to them about her experiences. She reflected on the significance of having the support of other women who were pregnant, whether at the same time or previously, during her own pregnancy:

My sister was a huge source of support. She actually was pregnant at the same time...So that was so huge to be able to go through that with her...my mom was also a huge source of support...my husband, of course...and my friends, my girlfriend actually was six weeks behind me...we could kind of be like, okay, this is happening to me. Has this happened to you yet?...Something that you wouldn't necessarily wanna ask your doctor about or like a random person on a Facebook page...I feel comfortable asking my sister, my best friend, like, is this normal? Are you having this too? So that was huge...just being able to feel like I was going through this experience with other people that were close to me...helped me feel supported...I think that talking is important...being able to talk about my experiences with my husband and him...asking about it and, you know, being as supportive as he could within doctor's appointments and...all of that.

Participant 3 discussed the role of family support and noted how they encouraged her even when they may have been worried themselves:

I'm very close to my parents...mom it's like she's excited but...she might have been nervous too, for me, you know now that I think about it...But she still kept encouraging. Dad kept encouraging, but she wasn't as excited as you would expect mom to be...she



might have been concerned, like me, but I know she was praying, praying very hard for me.

### ***Subtheme D: Strategies Supporting Well-Being***

All participants endorsed utilizing coping strategies as strong supports for their mental health throughout pregnancy, including mindfulness, religion/spirituality, positivity, and talking to others.

Participant 1 described her use of mindfulness, adaptation, and coping tools:

We get the cards we're dealt, and we have to learn how to adapt and make the best of it...there's good days, there's bad days, but do the best you can with what you have...I guess I think of it as tools, right, so it's just a way of focusing on the things that I can control and the things that I can't.

Participant 2 discussed the role of spirituality and faith as it related to her coping:

I think to a degree, my faith, my relationship with God allowed me to cope in ways that I don't know if I would have otherwise...kind of trusting his plan for whatever was to come...did kind of give me a level of peace, although most of the time my brain got the better of me with worrying and anxiety, even though it's like, I know in my heart that this is gonna be okay, whatever ends up happening. Um, but yeah, I think that was a huge part of my coping.

Participant 3 described a number of coping strategies linked to religious practices and social support, "...praying, a lot of praying. And talking, talking to family and friends. Praying and talking to family and friends. I was seeking out Black women like me who had pregnancy."

### **Theme 4: Desire to Build More Representation and Inclusive Support**

All participants noted the lack of racial representation in the sources of information they found during their research and peer-support process—white women dominated the narratives as peers with T1D as well as many of the health professionals writing about diabetes and pregnancy. Participants described a lack of Black women and other women of color in online T1D pregnancy spaces, and they therefore had to seek “safe enough” platforms on which to engage and find support from other Black women without T1D in the real world. Participants reported feeling different from other (often white) PWD due to often being the only people of color in online spaces, and all participants cited their desire to share their experiences and promote representation of Black women with T1D as main motivating factors for participation in the present study. All participants strongly desired to share their experiences and knowledge in order to support their communities and increase representation in research for people who share their identities. Participants discussed wanting to share hopefulness and encouragement to other Black women with T1D who are considering becoming pregnant.

Participant 2 reflected on the lack of representation of women of color on social media: I'm kind of thinking back and like, gosh, like everyone I follow on Instagram...they're all white people, you know, like there, there are not very many people that come from, you know, other places, you know, other cultures, other races, you know, that, that discuss how to raise children, you know, and, and even in my support group online through Facebook, same kind of thing, it was mostly white people, you know, white women...not really did I see many women of color on there discussing their problems.

Participant 2 also discussed the potential benefits of connecting with other people of color with T1D, who may share more of her experiences:

I think it would've helped me to talk to other people of color...that had Type 1. I know plenty of other people that have Type 1, none of them are anything like me, they're all white [laugh]...to an extent like, yeah, we have a lot to talk about [related] to diabetes itself. Yeah. But, you know, there's a layer there that is just not gonna be transferred, you know, when you're not of, of that other, you know?...and now have this other layer on top of that, of like I'm other and I'm other...and are there any other people like that out there?...it did feel very much isolating at times with that...knowledge that it's kind of me...and not a whole lot of other people in my area, um, that I could talk to that were specifically type one and a person of color and pregnant, or had recently been pregnant or, you know, are now a mom, you know?"

Participant 3 also discussed the way racial identity can shape experience:

There's a lot of people on YouTube, a lot of women, discussing Type 1 and pregnancy, but they were all white...I was going on YouTube and like I said I just couldn't find anyone Black, not even Hispanic, and not Indian you know. And it's fine, I still listen to some of the stories. But I don't know, I guess, I wanted a little bit more identification or representation...it's unfortunate that our experiences are determined by our race.

When discussing her reasons for participating in the present study, Participant 1 shared, "I know that there's so few Black women with Type 1 diabetes, so I was just...wanting to support and...whatever small piece of my contribution that will help the broader community and maybe how people think about things differently."

Participant 2 expressed her hopes for the research and for WOC with T1D to feel empowered and held in community through hearing participant stories:

I do hope that if this [research] is shared, you know, to women of color, that they feel empowered...that they feel more supported or that they can find support...even if it's a small group of us, um, there's power in small numbers, [laugh]...if it helps another person help themselves make a decision about whether or not pregnancy with Type 1 or motherhood in Type 1 is for them, you know, um, if it helps to make that decision more educated, you know, then I think that would be great, you know? Yeah. Anytime you can hear other people's experiences, even if they're even a tiny bit like you, I think that that really does help...I hope that this is helpful in giving them that feeling...that they're the same, you know, as other people and that they are not alone.

Participant 3 described feeling hopeful that the present study could support other Black women with T1D to feel more confident in the feasibility of pregnancy:

For anyone else, like me, hopefully they see this, and they feel encouraged, inspired, you know, to proceed and know that it's not all bad. Levels will fluctuate just like they do...without being pregnant, it will be the same during pregnancy...I would really like to encourage someone else who probably had the same experiences I did or even if they didn't have that same experience...just to say, 'It's not impossible.' It's not that it can't happen, it can happen, and it can be successful...just take care of yourself.

Participants also reflected on things they learned during their pregnancies and hoped to share with other Black women and birthing PWT1D who were considering pregnancy and who maybe, like them, had been discouraged by the healthcare system.

Participant 1, who was in the second trimester of her pregnancy during the interview, reflected:

At this point in time, right, being [in the second trimester] there isn't anything in particular from my experience, thus far, that I feel like was a massive gap, and also my endocrinologist because we were prepping...I feel like I knew what I needed to know. Participant 2 described wishing she could go back and encourage herself during challenging moments of her pregnancy by saying something like:

'Hey, this is temporary. This is the season of your pregnancy. This is what happens. And once you're done, it'll go back to normal and it will be okay.'...we'll take whatever happens. It will be fine. Like we'll work our way through it, you know?

## **Discussion**

### **Discussion of Themes**

In the following section, the major themes and subthemes identified through the present study will be discussed as they support or contrast existing literature in related topic areas.

### **Discussion of Theme 1: Interplay of Psychological and Physical Experiences**

Internal psychological experiences, such as perception and integration of the external world, are correlated with mental and physical health in numerous ways (e.g., Behan et al., 2015). In the present study, cognitive and/or emotional experiences were associated with physical experiences, such as low blood glucose and/or pregnancy development. Additionally, the interplay of psychological and physical experiences seemed to be closely associated with participants' wellbeing. All participants identified ways in which their experiences were shaped by external and other internal factors, including past experiences, personality characteristics, and temperament. This theme included the following subthemes: 'Influence of Pre-Pregnancy Experiences' and 'Cognitive-Emotional Experiences During Pregnancy.'

#### ***Subtheme A: Influence of Pre-Pregnancy Experiences***

“Past is present,” a psychoanalytic term originating in early psychology to describe how one’s past echoes into their future experiences (Jacobs, 2012), was apparent in each participant’s interview. Past experiences of having been told of the dangers of diabetes and pregnancy seemed to be particularly salient, evoking the *Steel Magnolias*<sup>12</sup> bias of pregnancy being risky and irresponsible (Farley, 2019). Participant 3 also drew attention to the historical and present impact of being one of few BIPOC children at diabetes camps, where children were racist, as well as the only child with diabetes at school, where children were ableist. She also noted the impact of her doctors telling her family at her diagnosis, which occurred in childhood, that she should never become pregnant. Her earlier experiences with lack of racial diversity at camp (Valenzuela et al., 2020) lived on into the present, as she struggled to connect with BIPOC DOC members about pregnancy. The ableism she experienced in school paralleled the ableism she experienced in adulthood when her doctors insisted she terminate her earlier pregnancies. Her experiences prior to pregnancy thereby influenced her inner world leading up to and during her pregnancy, as noted below with respect to cognitive-emotional experiences. Similarly, both other participants described a pre-knowingness of the challenges associated with T1D and pregnancy, and this reflects research findings that social and medical messages about one’s condition often influence future cognition, emotion, and behavior (Dunn, 2015).

### ***Subtheme B: Cognitive-Emotional Experiences During Pregnancy***

All participants described having thoughts and feelings related to their pregnancies and T1D, and managing these cognitions and emotions was a major part of their wellness. Cognitive processes such as anxiety are associated with diabetes distress (Dennick et al., 2017; Kelley et

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<sup>12</sup> *Steel Magnolias* is a 1989 film and play. It prominently features the pregnancy experience of a woman with T1D, who conceives against medical recommendations and then dies due to kidney-related complications when her child is an infant. Although it is based in part on the screenwriter’s experience of losing his sister, it has been criticized as having eugenicist undertones and promoting fear about people with disabilities having children (Farley, 2019).

al., 2020), which may be more likely to occur during pregnancy due to high-pressure diabetes management and experiences of gendered racism and ableism in their healthcare and social ‘support’ spaces (Egan et al., 2017; Williams et al., 2020). Similarly, depression as a cognitive-emotional patterning is associated with diabetes distress (Egan et al., 2017). Cognitive processes like avoidance may have been at play during participants’ pregnancies and even during the interviews, as participants seemed to orient toward positivity—evoking prior research on resilience among Black women—even while describing challenging content (Abrams et al., 2014). Avoidance and/or compartmentalization are documented means by which Black Americans may cope with trauma across certain stages of racial identity development, particularly in environments in which white supremacy culture prevents authentic emotional disclosure (Lipscomb & Ashley, 2020). White supremacy culture preventing disclosure is a particular consideration due to sociocultural pressures to be a ‘Strong Black Woman,’ which may result in less expression of vulnerability, particularly with my stimulus value as a white researcher (Abrams et al., 2014; Mizock et al., 2011). My whiteness likely affected the filtering of information through the participants and then through myself as the recipient of information (Mizock et al., 2011). Even so, participants shared depthful cognitive and emotional experiences expressing levels of anxiety, stress, and depression that were certainly impactful to their wellbeing and are similar to cognitive-emotional experiences of pregnancy reported by white women with T1D (e.g., Berg & Sparud-Lundin, 2009). In the present study as well as prior literature, pregnant women with T1D endorsed worry about their A1C levels, the chance of medical complications, and insulin resistance and/or sensitivity (Berg & Sparud-Lundin, 2009).

In prior studies of pregnancy in white women with T1D, qualitative research participants have reported surprise at both how much insulin sensitivity affected them in early pregnancy and

how insulin resistance affected them in their third trimesters (Woolley et al., 2015). Though pregnancy guidelines for PWT1D caution about the increase in insulin sensitivity and increased risk of hypoglycemia in early pregnancy (Magon & Chauhan, 2012), there is relatively less emphasis on insulin sensitivity in conversations about diabetes and pregnancy, whether among medical professionals and patients or in online discourse (García-Patterson et al., 2010; Woolley et al., 2015). Participants in the present study endorsed feeling unprepared for and disturbed by insulin sensitivity but prepared for insulin resistance later in pregnancy, supporting findings in prior studies that pregnant PWT1D need more preparation for and support around early metabolic changes.

The physical and emotional impact of intensely low blood glucose is dangerous for pregnant people and their fetuses (Vargas et al., 2010), and recurrent, stubborn hypoglycemia caused participants in the current study to feel surprised, frustrated, or afraid. Experiences with low blood glucose therefore caused considerable stress to participants in early pregnancy and, as stress can affect blood glucose and overall well-being (Edwards et al., 2016), protective measures for pregnant people with T1D should be further explored. Additionally, studies examining police brutality have documented the risk of having hypoglycemia and other health conditions when interacting with ‘helping’ and justice professions, even paramedics, due to racist bias and coding of hypoglycemic symptoms as substance use and/or behavioral misconduct rather than physical health issues needing immediate attention and support (Herd, 2020). Black PWD are less likely to receive support in emergency situations and are more likely to be restrained or even killed during episodes of hypoglycemia (Herd, 2020), thus intensifying the dangers of surprising, intense low blood glucose during pregnancy.

## **Discussion of Theme 2: Experiences with Healthcare System**



Theme 2 encapsulates the many healthcare experiences, both positive and negative, that participants reported throughout the study. Quality of healthcare is associated with patient wellbeing, and frequent contact with the health system increases need for compassionate, supportive, and informed care (Geyer, 2021). The frequency with which pregnant PWT1D are exposed to the healthcare system has been described as both overwhelming and supportive in prior studies (e.g., Edwards et al., 2016; Rasmussen et al., 2013), thus demonstrating the range of lived experiences as they relate to context, quality of care, perception, and interpretation. All three participants in the present study discussed healthcare as a primary factor in their wellbeing throughout their pregnancy experiences. The experiences with healthcare theme includes three subthemes: ‘Mixed Experiences with Healthcare Providers,’ ‘Systemic Issues: Lack of Diabetes Expertise, Lack of Resources, and Racism,’ and ‘Medical Trauma.’

#### ***Subtheme A: Mixed Experiences with Healthcare Providers***

Supportive relationships with healthcare providers are an important resource for people with health concerns (Riedl & Schübler, 2017), as supported by all participants in the present study. Supportive relationships with healthcare providers reduce patient stress and increase patient resilience (Náfrádi et al., 2018) as well as protect against medical trauma and development of stress-related mental health conditions (Hall & Hall, 2017). All participants in the present study identified their healthcare providers as a source of support at least part of the time, though they also reported negative experiences including reductions in their own agency. Participant 2, for example, reported a number of mixed experiences with her healthcare providers, including feeling unsupported by her first endocrinologist but moving to another, very supportive endocrinology care team. She also reported feeling both supported and not supported

during various interactions with her obstetric care providers: she described receiving adequate care but was also aware of providers making decisions that minimized her agency.

Autonomy in healthcare is associated with improved physical wellbeing, sense of self, and mental health (Yeom & Lee, 2022). Diagnosis with T1D is associated with perceptions of reduced autonomy and increases in diabetes distress as PWD adjust to their new lifestyle inclusive of often demanding diabetes management (Mohn et al., 2015). Reduced autonomy can become more likely when T1D intersects with other health conditions, including pregnancy, due to providers' desires to reduce risk of T1D-related complications (Mohn et al., 2015; Singh et al., 2019). Birthing people may not be able to experience pregnancy as they may have wished or follow their ideal birth plan due to medical necessity (Fischer et al., 2020; Singh et al., 2019). It is therefore essential to continue to promote agency as much as possible among birthing people with T1D in order to support their mental health along with their physical health, as indicated by participants in the present study who had negative experiences and felt they did not have choices in their care.

Supportive relationships with care providers who center the importance of the Black experience are even more essential when Black Americans interact with the healthcare system due to the historic and ongoing effects of systemic racism (Baratta et al., 2022). Participants in the present study did not report instances of overt racism in interactions with their healthcare providers, which may be an artifact of stimulus value of the white researcher and/or related to participants' own racial identity development or meaning-making of their experiences. Participants not reporting racialized experiences is in contradiction with numerous existing studies about the broad impacts of racism in medicine, such as reduced attention to pain management (Hofacker et al., 2020; Hoffman et al., 2016), disparate birthing person and fetal

health outcomes (Brown et al., 2020; Leonard et al., 2019), and inequity in acquisition of diabetes care technology across racial groups (Agarwal et al., 2020). An additional factor to consider as potentially related to the lack of reporting of experiences is that the participants—particularly Participant 1—may have had fewer or even no instances of racism to report, perhaps due to her care being located within a metropolitan research hospital with racially diverse providers. Lack of experiences of racism could be related to participants receiving care from racially-concordant providers or providers of color in multiculturally-aware health systems (Shen et. al, 2018). As the current study did not prompt participants to report their healthcare providers' identities, the role of provider identity on Black PWT1D's pregnancy experiences is an important area of consideration for future research.

Medical racism is associated with reduced attunement and sensitivity to patient need (Davis, 2019), and, in the present study, participants' negative healthcare experiences may have been related to their healthcare providers' implicit biases. It may have been difficult for participants to communicate experiences of biased treatment due to internal questioning of whether what occurred was linked to racism, particularly if it was implicit rather than explicit. The oft-repeated process of white people denying racism and/or not believing racism plays a role in Black people's experiences could likely also have impacted the perceived level of safety (or lack thereof) to report experiences of racism in the context of the study (Williams & Etkins, 2021). The role of systemic racism and bias and the potential to further reduce autonomy among Black birthing parents with T1D therefore bears further exploration, especially as many medical and psychological practitioners hold privilege over the communities to which they provide services, and Black healthcare providers continue to be underrepresented in psychology and medicine (Jetty, 2021; Washington, 2008).

***Subtheme B: Systemic Issues: Lack of Diabetes Expertise, Lack of Resources, and Racism***

This subtheme reflects the systemic issues participants reported during their pregnancy experiences. All participants noted how the complexity of navigating the medical system affected their experiences, especially given the pervasive lack of expertise about T1D among providers. Participant experiences reflect findings in the literature about providers seeming to not have expertise treating pregnant patients with T1D (e.g., de Lusignan et al., 2012) as well as a strong push to refer patients to specialists which, while supportive of medical needs, may intensify patient perceptions of and worry about being ‘high-risk’ (Attanasio & Kozhimannil, 2015; Berg & Sparud-Lundin, 2009; Beverly et al., 2019). Other system issues, like inadequate insurance, further complicate patient experiences with healthcare, particularly with conditions like T1D and the increased need for frequent specialist appointments and medical supplies due to insulin resistance during pregnancy (Feldman & Brown, 2016; Jovanović et al., 2015; Sussman et al., 2020). Lack of sufficient insurance coverage among Black Americans, while not endorsed by participants in the present study, is linked to systemic and institutional racism and financial inequity (Odugbesan et al., 2022).

Participants were vocal about the need for more T1D-informed resources within the healthcare system, both broadly related to T1D and specific to T1D and pregnancy, which coincides with studies demonstrating the paucity of T1D interventions within healthcare (Zafra-Tanaka et al., 2022). Participants also addressed the need for resources that are more representative of racial diversity and experiences with T1D and pregnancy as Black women, which highlights the need for organizations that integrate disability and race in addition to disability- and race-specific organizations like T1DSM or Black Mamas Matter Alliance (2022), which provides resources that speak to pregnancy experiences among Black women and birthing

people. Non-medicalized resources that reflect complimentary care were also of interest to participants, such as acupuncture, lactation consultation, and midwifery, which coincides with prior research on patient desire for and the relative scarcity of culturally-responsive and diverse care practices within the western medical system (Frenkel et al., 2008).

Participants 2 and 3 also addressed feeling unsure about how medical racism may have impacted their experiences, as they did not report experiencing overt racism but felt provider and system bias may have resulted in lack of support of participant agency to make health decisions (e.g. coercion to terminate earlier pregnancies, avoid becoming pregnant, and induce labor and delivery without clear cause). The link between racism and control of fertility/conception and means of reproduction is supported by literature that documents the longstanding abuse and control of Black women's bodies (Davis, 2019; Washington, 2008). Participant 2, who described her traumatic experiences with labor and delivery, may have experienced systemic pressures to induce and then proceed to C-section not only due to her high-risk status related to T1D, but also due to the disparately high maternal mortality rates among Black women, which result in higher likelihood of being forced into C-sections (Bryant et al., 2009).

Participants' experiences may speak to the different levels at which racism can operate and influence mental health (Williams & Etkins, 2021)—while they did not report experiencing racism at an interpersonal level (e.g., from providers), systemic racism may have been involved in the way the healthcare system provided (or did not provide) care. Systemic issues of bias and discrimination can lead to anxiety, depression, and emotional fatigue among Black people, as they often have to exert energy to make meaning of their experiences and/or process whether they were linked to oppression (Carter & Kirkinis, 2021). Further exploration of the role of

implicit and/or systemic racism is indicated, particularly as medical and/or obstetric racism may be linked to present participants' experiences of medical trauma.

### ***Subtheme C: Medical Trauma***

Medical trauma in PWD has been linked to diagnosis, emergency care treatment, and development of diabetes distress in addition to the breadth of literature on medical trauma related to diabetes complications (e.g., D'Alberty et al., 2012). Medical trauma among PWD can result from cumulative experiences like the additive burden of changing insulin pump or continuous glucose monitor equipment and/or intense physical and psychological experiences associated with complications such as neuropathy, kidney failure, retinopathy, amputation, or even dementia in late life (Feldman & Brown, 2016). Birthing people are also prone to being exposed to obstetric trauma, particularly when they have other disabilities and health needs (Lipson & Rogers, 2000), and Black birthing people experience obstetric trauma more frequently than do most other racial groups (Davis, 2019).

Medical staff making decisions unilaterally, thereby reducing sense of autonomy among patients, increases risk of medical trauma (Mohn et al., 2015; Yeom & Lee, 2022), as was discussed by participants 2 and 3 in the present study. Gendered racist and ableist biases in the medical system are strongly linked to reduction in patients' health agency and trauma-related outcomes (Davis, 2019). While every pregnancy and delivery is different, Black birthing PWT1D are thus more likely to experience medical trauma (e.g. coerced pregnancy terminations, forced labor inductions, and violent delivery practices endorsed by participants, as reported by current participants). Black PWD are also less likely to receive support for trauma within the medical or psychological healthcare system due to systemic racism (Matthew, 2018).

### **Discussion of Theme 3: Coping: Strategies for Gathering Information, Seeking Support,**

**and Fostering Mental/Emotional/Spiritual Well-Being**

Participants described a process of seeking information, social support, and coping strategies for overall well-being that aligns with prior qualitative research about T1D and pregnancy (Sparud-Lundin et al., 2011). Accurate, helpful information, social support, and strong coping skills may be even more crucial among Black birthing PWT1D due to the higher rates of maternal and infant mortality among Black birthing people (Julian et al., 2020; Lemke & Brown, 2020; Noursi et al., 2020) and statistically higher incidence of elevated blood glucose and medical complications among Black American PWD (Agarwal et al., 2020). This population's potential to have increased stress associated with diabetes management and maintaining a healthy, safe pregnancy bears further exploration.

Participants of the present study described having the desire to find information about T1D and pregnancy that was supportive of their health and the health of their babies. Often, this required doing their own research online and determining which aspects of others' experiences felt both transferable and applicable without becoming overwhelmed, which involves a similar filtering process described by white birthing PWT1D (Sparud-Lundin et al., 2011) but has the additional layer of needing to filter by racial experiences. Similarly, participants needed to access social support, both online and in their communities, with the consideration of finding spaces that were supportive of their racial identities. Participants were also intentional about developing coping strategies that fit their needs both along with and separate from contacting their social support resources. This theme consists of four subthemes: 'Gathering Information: Researching about T1D and Pregnancy,' 'Seeking Support: Mixed Experiences with Online Peer Interactions,' 'Seeking Support: Benefits of Friend, Family, and Partner Support,' and 'Strategies Supporting Well-Being.'

***Subtheme A: Gathering Information: Researching about T1D and Pregnancy***

PWT1D initiating a process of intense research has been associated with pre-conception and perinatal periods in other qualitative studies (Sparud-Lundin et al., 2011). Pressure to research is likely linked to the sociocultural portrayal of the dangers of pregnancy with T1D and resultant anxiety about high-risk pregnancy and potential complications to the health of the birthing person and fetus (Schmidt et al., 2019). Similar to other studies exploring pregnancy experiences among PWT1D, all participants described researching information about T1D and pregnancy using Google, books, or social media sites. Scholars commonly cited these resources as integral sources of knowledge that can help birthing PWT1D prepare to manage their health more strictly compared to how they may practice diabetes management while they are not pregnant, particularly with regard to meal planning, dosing insulin, and other strategies to minimize stress (Adolfsson & Jansson, 2012). Participants in the present study and in other studies have identified their need to pursue specialized information in addition to information shared by their medical providers (Sparud-Lundin et al., 2011). Participants in the present study described an intense or even obsessive quality to their research, perhaps signifying an even bigger press to gain supportive information relative to white PWT1D in other studies, who ranged in their use of web-based research (Sparud-Lundin et al., 2011).

***Subtheme B: Seeking Support: Mixed Experiences with Online Peer Interactions***

Across research on the benefits of social support with PWD, support from fellow PWT1D has been associated with emotional wellbeing, coping, and positive health behaviors (e.g. Hilliard et al., 2015; McGrath & Chrisler, 2017; Rasmussen et al., 2013; Sparud-Lundin et al., 2011). PWT1D are often found to benefit from peer connection and to have diminished diabetes distress and burnout, perhaps due to feeling understood in the context of their shared conditions



(Hilliard et al., 2015; Holmes-Truscott et al., 2020; Rasmussen et al., 2013). Although it is not yet reflected in the present data, the anecdotal experience of the researcher posits that PWT1D also risk feeling inferior to their peers when engaging online, particularly if their networks are vocal about comparing their A1c values, blood glucose time-in-range, and other numerical data such as insulin to carbohydrate ratios. The negative effects of online engagement bear further research, especially as participants of the present study endorsed negative experiences with online peers.

The impact of internalized ableism, as well as other kinds of bias, exists within the diabetes online community (DOC) as with face-to-face relationships, and online behaviors can often be more overtly biased due to feelings of anonymity and disconnection (Christopherson, 2007). Participants in the present study described bias in the DOC as overwhelming, though prior studies have focused more closely on the benefits of online peer support (e.g., Hilliard et al., 2015; McGrath & Chrisler, 2017). Online peer-support platforms can be a positive, validating space in which PWT1D can share and gather information and process their experiences, but online groups in general can also foster negative, scientifically-unfounded, and damaging perceptions about health-related topics and/or community members (Collier, 2018). Insular online groups can also create unwelcoming atmospheres in which racism, classism, and other forms of discriminatory attitudes are displayed, whether overtly or covertly, through the way group members engage on each other's posts (Burns, 2017).

All participants in the present study reported feeling troubled by unsupportive content and lack of sensitivity as it related to their own and others' experiences with medical complications, diabetes management, and T1D and pregnancy. While participants did not report overt incidences of racism in these groups, they described their awareness of how the spaces

were dominated by white women, coinciding with prior research demonstrating the lack of representation of people of color in the DOC (Litchman et al., 2019). Participants also noted an awareness of how spaces with white women are unwelcoming and often do not acknowledge race, which links to literature about white-dominated online spaces (Ortiz, 2021). As white supremacy in online spaces is associated with reduced social support for BIPOC individuals (Keum & Li, 2022), more attention to the effects of white supremacy in online diabetes spaces, as well as continued racial justice work in online spaces, is necessary. Participants noted that online peer support would be more helpful if it was more representative of their experiences, particularly with regard to race, and they sought other coping strategies and forms of social support that were often experienced as better suited to their needs.

***Subtheme C: Seeking Support: Benefits of Friend, Family, and Partner Support***

In-person social support during pregnancy has been associated with overall health for birthing PWT1D, who benefit from strong relationships with their family, friends, and healthcare team (e.g. Rasmussen et al., 2013; Singh et al., 2019). Among Black Americans, social support during pregnancy may include biological and chosen family networks as well as relationships with close others in neighborhoods and/or church communities (Sagrestano et al., 1999). All participants in the present study identified their friends, family, and partners as the most present and supportive relationships during their pregnancies. Significantly, none of the people in close relationship with participants had T1D, perhaps suggesting the importance of quality social support over similar disability experience, which seems to be distinct from other literature that speaks to the benefits of T1 social support among white women (McGrath & Chrisler, 2017; Rasmussen et al., 2013; Sparud-Lundin et al., 2011). For example, Participant 1, when asked

about whether she wished she could have a community of Black women with T1D who were pregnant, answered:

Honestly, not really. It hasn't really been something that I've thought about...Us marginalized communities we don't often think about that, like 'Oh, what if I had that?' or 'Why isn't it like this?'...It's like you work with what you have, and I'm grateful that I have my sister who's been pregnant, I have other women that have been pregnant and, you know, have been supportive in that way.

Perceptions of social support among Black PWT1D, particularly as it may relate to non-T1 support within the Black community, necessitates further exploration.

Participants expressed benefitting from being in community with fellow Black women who were currently or had previously been pregnant, which coincides with research that has documented the necessity of shared cultural connection among Black birthing people as an important protective factor (Liese et al., 2022). Participants in the present study did not report close personal relationships with anyone else with T1D, with all identifying the lack of availability of such relationships and, more specifically, the lack of pregnant women of color with T1D in their communities. Participants may have therefore found sufficient, racially-representative social support within relationships with their non-T1 networks and have gone outside of those connections only to seek specific information about T1D and pregnancy.

#### ***Subtheme D: Strategies Supporting Well-Being***

Coping strategies were a majorly impactful theme across all participant interviews. All participants identified forms of religious and spiritual coping, which coincides with literature on the protectiveness of spiritual coping among Black Americans (Graham, 2016). Coping through spirituality and trusting in a higher power is associated with enhanced wellness in challenging

and traumatic situations (Graham, 2016). Mindfulness, another significant coping strategy and emerging frontrunner in trauma-focused psychology (Wagner & Caceres-Melillo, 2023), was also utilized by participants. Participants also expressed a realistic recognition of difficulty and concurrent orientation toward positivity as a protective coping strategy, which coincides with findings from Utsey et al. (2008) on the benefits of optimism in promoting mental wellbeing among Black individuals. Openness to talking to others and seeking resources were two other coping strategies that participants utilized to promote mental wellbeing and support all of the above forms of coping. Talking to others and seeking resources link to social and community support, which is well-documented as a significant coping strategy among Black Americans (Daley et al., 1995).

#### **Discussion of Theme 4: Desire to Build More Representation and Inclusive Support**

Lack of representation has been a focus of racial justice and inclusivity work within the DOC since the wider resurgence of the Black Lives Matter movement following the deaths of George Floyd, Breonna Taylor, and other Black Americans due to police brutality in Spring 2020 (e.g. Vieira, 2022). Police brutality has persisted since early colonial United States history and has been ongoing despite the Black Lives Matter movement, which began in 2013 after the murder of Trayvon Martin (Lebron, 2023). The attention of white and non-Black POC to the necessity of racial justice work specifically focused on addressing anti-Black racism ebbs and flows, often becoming obscured due to processes of white supremacy and recurrent abandonment of the work (Flynn, 2015). From the researcher's perspective, some organizations within the DOC seem to be promoting attention to health disparities and lack of BIPOC representation (e.g. Beyond Type 1; T1D Exchange). Other DOC groups and organizations are undergoing a "forgetting" and "ignoring" process that coincides with abandonment of racial justice work, and

many groups never seemed to attempt to build representation or promote white accountability in the first place (e.g. The Diabetes Link).

Prior research has documented that lack of representation and/or exclusionary online environments are painful to Black Americans, though even Black Americans who participate in Black-led online spaces may experience symptoms of depression and anxiety (Stanton et al., 2017). In the present study, all participants noted the lack of representation of Black PWT1D in online peer connections as well as among pregnancy-focused healthcare professionals who published information about diabetes and pregnancy. Participants described seeking “safe enough” platforms on which to engage, similar to findings in previous studies discussing the combined benefits and challenges of being able to protect oneself from online racism by using anonymous forums (Burns, 2017; Ortiz, 2021).

Feeling different from other PWD was highly salient to participants in the current study, and all participants cited their desire to build representation and share their experiences as main motivating factors for participation in the present study. They were particularly attuned to wanting to share with others the kind of support they wished they could have received and positive messaging around the feasibility of pregnancy with T1D, thus demonstrating a care for community and reinforcing findings of prior research demonstrating the benefits of in-group support among Black birthing people (Adams & Thomas, 2018). The community transmission of hope and encouragement, which contrasts and protects against burnout and despair (Adams & Thomas, 2018), is likely as important among Black birthing PWT1D as it is among Black birthing people without chronic health conditions. As white PWT1D have been found to benefit from positive messages of hopefulness about diabetes and pregnancy (McGrath & Chrisler, 2017; Rasmussen et al., 2013), there may exist an additive effect of the intersection of Black

racial identity and T1D status that results in even more protection and promotion of wellbeing among Black birthing PWT1D who receive messages of hope from people who share their identities and experiences.

Notably, all participants in the present study opted into the post-research network, which linked participants via email. After they were connected, one of the participants responded to the researcher directly to express her gratitude. While it is unknown whether participants have contacted each other and how their relationships may have evolved, it is the hope of the researcher that they have found mutual support and resonance of shared experiences through being connected.

### **Clinical Implications**

This dissertation reported some of the mental and physical health experiences of Black birthing PWT1D, and the findings speak to systemic lack of support for this population across health professions and peer support spaces. Participants clearly voiced instances of diabetes distress, anxiety, and depression throughout their pregnancies. Participants who had already experienced delivery reported medical trauma and how their experiences related to uncertainty about whether they wanted to become pregnant again, though they were certain they wanted more children. Participants' experiences highlighted the need for healthcare providers—including mental health providers—to dedicate themselves to dismantling oppression in healthcare. Combating systemic oppression is an ongoing process, and providers must continually re-orient to social justice practices while working within hegemonic structures. White supremacy culture, patriarchy, and ableism are embedded in health professions, and, as demonstrated by participants in the present study, working with clinicians with concordant identities does not necessarily prevent racism, sexism, and/or ableism. Clinicians must maintain

reflexivity about their individual identities as well as their role in systemic oppression as providers in systems that historically and currently harm marginalized groups. Training and research that engage with anti-racist ethos are paramount, as are ongoing clinical policies to engage with cultural humility and client-directed care.

The importance of patient agency and autonomy were significant clinical implications in the present study, as participants noted their awareness of who was “driving the bus,” (e.g., the providers or the participants themselves) and how that impacted their mental and physical health experiences. Reduced sense of agency among participants was linked to their experiences of medical trauma, as is supported by prior findings about models of clinician-patient interaction (Wang et al., 2020). Participants in the present study seemed to experience better physical and mental health outcomes when their healthcare providers followed mutual participation and/or guidance-cooperation models of care (Wang et al., 2020). Continued attention to the benefits of these models, as opposed to the paternalistic activity-passivity model in which providers are the experts (Wang et al., 2020), is a significant clinical implication for providers who support Black birthing PWT1D, in particular, due to the historic and ongoing effects of oppression and trauma. Patient-led forms of communication and care support patient sense of wellbeing and overall health, and this dissertation supports the need to continue to shift dominant discourses of pregnancy and T1D medical care toward honoring patient knowledge rather than only provider expertise. The community health worker model is another means by which more trauma-informed care can begin to support patients prior to and during birthing, as communal support has been associated with improved wellbeing, particularly among Black birthing people who are supported by midwives (Muse et al., 2018). Such shifts in the discourse and culture surrounding pregnancy-related care could thereby have a huge impact on the mental health and

experiences of Black birthing PWT1D during pregnancy, especially when it comes to making care more trauma-informed and reducing risk of unnecessary C-sections. More emphasis on patient agency may also reduce feelings of iatrophobia, which, as discussed in the literature review, are common among Black Americans (Washington, 2008).

Participants voiced a clear need for increased knowledge of T1D among health providers, and they recognized the benefits of being cared for by medical providers who had higher levels of competency and confidence regarding T1D and pregnancy. The clinical implications of more integration of knowledge about T1D and pregnancy among endocrinologists may destigmatize the pregnancy process for Black Americans, who already experience stigma and barriers to pregnancy due to reproductive injustice and medical racism (Davis, 2019). Special attention to T1D-specific information must be considered due to the relatively higher incidence of T2D among Black Americans (Spanakis & Golden, 2013) and resulting bias and inattention to T1D among both members of the Black community themselves and health professionals who treat the Black community. This includes mental health clinicians, who are often undereducated about the mental health implications of diabetes in general and, in particular, at the intersection of T1D and pregnancy.

In addition to the above findings, the present study focused on the need for more representation of Black birthing people in T1D pregnancy communities as well as T1D online communities more broadly. Participants' experiences of lack of representation increased their feelings of isolation and being unlike other PWT1D, which contrasts literature demonstrating the association between representation and feelings of support and belonging among white PWT1D (e.g. Rasmussen et al., 2013). As incidence of depression, anxiety, and diabetes distress can be mediated by social support (Holmes-Truscott et al., 2020), increased representation has the



potential to hugely benefit mental health among Black birthing PWT1D. The already bolstering and protective effects of social support by family and friends without T1D, demonstrated by participant reports in the present study, should also not be underestimated. Non-T1D, in-person social support may also be highlighted as a main strength among social support resources that may already be available to Black birthing people with T1D and can perhaps be further promoted by health provider acknowledgement and encouragement of social support in pregnancy.

Clinical implications for the present study also include the potential for participants' words to directly influence the pregnancy experiences of other Black birthing people with T1D who are considering pregnancy. The messages of hope, conveyed by participants both as messaging they wish they had received and that they wanted to share with others, likely have a protective and wellness-promoting effect for both the participants and the people who read their messages. In-group mentoring and advocacy have been associated with increased reflection, sense of confidence, and feelings of connectedness to one's community (Hagerty et al., 1992), thereby having a potential for direct impact on participants' wellbeing. Prior research also reflects how people of color navigate social media and challenge biases through reconstructing identity and finding space for joy (Lee, 2017), which may be a further supportive strategy accessed by participants in relationship to each other and future supportive online spaces.

### **Limitations**

Limitations to the study included narrow inclusion criteria, small sample size, potential implications of racial identity of the researcher and participants, and the pressured context of the research being part of a dissertation. The narrow inclusion criteria and difficulty in accessing the participant population resulted in a small sample size and, though the sample size met criteria for an IPA study, limited data. All participants lived in metropolitan areas during their pregnancies

and received care through large medical centers. Participants who signed up for the study also described a particular interest in building representation in research which is both very valuable and may signify an openness to participating in white supremacist, hegemonic, research systems and not reflect the experiences of people who may have fit criteria but elected not to participate for a variety of reasons, including things like burnout and racial trauma. Participants' own racial identities and racial experiences may have also affected the salience of racism and white supremacy in their pregnancy experiences.

The individuality of experience and identity also complicates the potential for generalizability of the study, particularly due to the small sample size and nature of qualitative research as representations of individual experiences. Lack of generalizability is also affected by differences in pregnancy status among participants in the present study, e.g., whether participants were previously pregnant or currently pregnant. Unfamiliarity with the late stages of pregnancy and labor and delivery may have resulted in different mental health experiences, emotional and cognitive processes, and trauma-related forms of coping among the participant who was currently pregnant compared to participants who had completed their pregnancies and reflected on their experiences while knowing their babies—and they themselves—had endured trauma and survived. If this study were replicated, the researcher may consider recruiting more participants who are currently pregnant and doing a longitudinal study of the participants' experiences at different stages of pregnancy and parenthood. If that is not possible, one may also consider the benefits of doing a cross-sectional study (with pregnant birthing Black PWT1D and Black PWT1D who were previously pregnant) to compare mental health experiences in different stages of the pregnancy and birthing process. As this would necessitate more detailed recruitment, the

researcher may benefit from recruiting within a reproductive health department in a medical research center that serves Black PWT1D.

My stimulus value as a white researcher may have affected recruitment and likely influenced the transparency with which participants could discuss the effects of white supremacy and racism on their pregnancies and mental health. Although participants shared reflectively about racism and were aware of the purpose of the study, replicating this study with a researcher of color—particularly if they share Black racial identity—may allow for more direct discussions and could yield different results. The sociocultural pressure to be a Strong Black Woman is an example of a dynamic that may have influenced participant sharing in a space with a non-Black researcher (Hall et al., 2021). My biases, including how personal racial and disability identities shape my perceptions and interpretations, must also be considered due to the reflective nature of IPA methodology (Smith et al., 2009), as was discussed above in the methods section.

### **Suggestions for Future Research**

More exploration of pregnancy and mental health among Black birthing people with T1D is needed, both with respect to qualitative experiences and quantitative data. The field of diabetes and pregnancy research requires ongoing integration of the experiences of Black birthing people, particularly with T1D, and continued consideration of how intersections of oppression can affect wellness. Building robustness and inclusivity among future studies is necessary, as is expanding studies to include pregnancy experiences of other BIPOC individuals with T1D and to more closely analyze other intersections of identity such as socioeconomic class, education, and location. This research must be biopsychosocial and utilized across health professions as well as accessible to research populations, who desire more representation and data that supports their lived experiences.

In the present study, participants who had already experienced the birthing process demonstrated a clear attunement to the process of transitioning to parenthood, and they sometimes began to answer questions about their current experiences of parenting toddlers rather than their pregnancy experiences. The importance of examining mental health and wellbeing during the transition to parenthood for Black birthing people with T1D cannot be ignored, as prior research includes, again, majority white women.

The present study also indicates the need for interventional research about white supremacy, ableism, and other forms of bias in online diabetes social support groups. These groups are often a main point of information seeking and sharing during pregnancy, and exploration of group dynamics may highlight biases that remain unaddressed by many online groups. The development of groups specific to people of color who are considering pregnancy with T1D, as well as how to share information about such groups to make them accessible, may also be considered.

## **Conclusion**

In developing this study and analyzing the data, I sought to explore: 1) What do Black PWT1D experience during pregnancy, and how is obstetric racism, medical racism, and/or diabetes-related discrimination related to their pregnancy experiences? And 2) What is the role of online peer support in pregnancy experiences for Black PWT1D? The pregnancy experiences of Black birthing people with T1D are as diverse and individual as pregnancy experiences among any other group, and, through the study, participants shared their individual experiences as well as some common experiences and hopes.

Given the role of medical racism in pregnancy experiences among Black women and disability discrimination among pregnant PWD, I hypothesized that there would be a likely

cumulative effect of both gendered racism and ableism on the pregnancy experiences of Black PWT1D. Additionally, I hypothesized that the primarily white DOC does not lend itself to inclusive support of Black PWT1D, and that there are perhaps supportive subgroups in which Black PWD may discuss their pregnancy experiences. One of the participants reported she did not experience gendered racism and ableism during her pregnancy, perhaps due to her location in a metropolitan area and her healthcare within an esteemed academic center for diabetes and pregnancy. The other two participants endorsed experiences that were suggestive of medical racism and diabetes discrimination, particularly as they were advised against pregnancy and not included in decisions about their healthcare. All participants noted the lack of knowledge among providers with respect to pregnancy and T1D, emphasizing the need for more integration of knowledge about pregnancy among endocrinologists and knowledge about T1D among gynecologists and obstetricians in order to challenge bias and potential for pregnancy and/or diabetes discrimination. When asked about online peer support, participants noted the lack of representation in online spaces, which reflects prior research about whiteness in diabetes networking spaces (Valenzuela et al., 2020). The inhospitable nature of non-representative online groups diminished the participants' access to online social support, which can be a significant protective factor during pregnancy with T1D. The relative lack of ability to safely access online support spaces speaks to the need for ongoing racial justice work in the diabetes online community, which will hopefully promote more representation and support of Black birthing people with T1D.

This study adds to the current body of research by exploring the experiences of a group which is commonly not reflected in qualitative studies of T1D and pregnancy. The analysis of participant experience while considering overlapping systems of oppression (Crenshaw, 1991)

may support awareness of the complexity of pregnancy for Black birthing people with T1D among multidisciplinary health providers. The study also explored coping strategies used by Black PWT1D and how coping was or was not associated with use of the diabetes online community (DOC), especially as participants identified more social support in their family and friend networks rather than predominantly white DOC spaces. This study sought to report pregnancy experiences among Black PWT1D in an accessible and responsive way, and it may be used in the DOC, healthcare industry, and broader social context to promote racial justice, further research of participant experiences, and overall well-being of Black birthing people with T1D.

Significant takeaways of this study include a call to action for healthcare and diabetes online communities to engage with racial justice work, which is often—if not always—abandoned by individuals and institutions who benefit from white supremacy. Furthermore, increased attunement to mental health and experiences of pregnancy among Black birthing people with T1D is necessary due to the often complex effects of white supremacy and ableism in the U.S. medical model of care, and pregnancy and mental health outcomes may be improved with more clinician training, awareness of the need to prioritize patient-led care, and attention to the role of identity, oppression, and trauma in medical systems and beyond. Healthcare professionals, including clinical psychologists, must become more accountable in navigating social justice-informed training and practice, and they must actively work to address systemic and institutional racism and the implications of social determinants of health.

It is also essential to maintain awareness of how pregnancy experiences among Black PWT1D are as diverse as they are across groups with any other shared demographic factor. It is impossible to encapsulate the entirety of peoples' experiences with one qualitative study, and continued explorations of this group's experiences with pregnancy are essential in order to

promote social justice in research, representation in data, and change within racist healthcare and social systems. It is my hope that this dissertation will promote continued attention to the importance of considering intersectionality within diabetes-focused spaces, which tend to be monolithic, and, as participants in the present study identified, unwelcoming.

Perhaps most importantly, this study uplifts messages of hopefulness and encouragement shared by participants, who wish to build community and provide their experiences as examples of how Black birthing people with T1D can and do have healthy pregnancies. This study demonstrates how Black birthing people with T1D may seek and find support that meets their physical, spiritual, community, family, and mental health needs even while experiencing challenging and traumatic pregnancy and pre-pregnancy experiences. Continued research, clinical practice, and community engagement with anti-racist and other anti-oppressive action may continue to support Black birthing PWT1D as they experience pregnancy and grow their families.

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## Appendix A

### Instagram Handles, Subreddits, and Facebook Pages

Table listing DOC-related social media pages contacted for study recruitment:

Social Media Type	Facebook	Instagram	Reddit
Handle/Page	T1DSM - Private Group (T1D Women/Mom Group)	@beyondtype1daily	r/BumpersWhoBolus
	Type 1 Diabetes and Pregnancy	@diabaddieorg	r/Type1Diabetes
	Type 1 Diabetes and pregnancy <sup>13</sup>	@diversityindiabetes	
	DIY Looping and Pregnancy	@dopediabeticgirls	
		@t1dexchange	
		@t1dsugarmommas	
		@wocdiabetes	

<sup>13</sup> Pages with similar names were contacted via Facebook (e.g., Type 1 Diabetes and Pregnancy and Type 1 Diabetes and pregnancy).

**Appendix B****Recruitment Flier**

## **RESEARCH OPPORTUNITY:**

Have you been pregnant?  
Do you have Type 1 diabetes?  
Do you identify as Black  
and/or African American?

***PLEASE JOIN US FOR A RESEARCH  
STUDY TO SHARE YOUR EXPERIENCES***

Interviewees will receive a **\$50 Visa gift card**

Please sign up at the **LINK**

## Appendix C

### Eligibility Survey

Thank you for clicking the link to learn more about this study. The goal of this research is to interview Black birthing people with Type 1 diabetes (T1D), who have historically been excluded from most pregnancy research.

Before you decide if you are interested, I would like to share a bit about myself as the person who would be interviewing you:

I am a young, white woman with T1D (diagnosed in early childhood) who has never been pregnant. I am interested in interviewing Black birthing people with T1D because many studies of T1D and pregnancy only include white women. I have studied pregnancy and parenting experiences throughout my training as a doctoral student at the University of San Francisco, and seeing members of the Diabetes Online Community (DOC) experience pregnancy solidified my interest in studying pregnancy and T1D.

Throughout this process, I will work to be a responsible and ethical researcher by being in close contact with my dissertation committee. Please contact me, Madi Marcus, at [memarcus@dons.usfca.edu](mailto:memarcus@dons.usfca.edu) or my dissertation chair, Dr. Michelle Montagno, at [mjmontagno@usfca.edu](mailto:mjmontagno@usfca.edu) with any questions.

I invite you to answer the questions below. I am looking to interview Black birthing people with T1D or LADA who have been pregnant within the past 3 years, are over 18, and live in the United States (or did during pregnancy).

I look forward to connecting further if you are eligible for and interested in participating in this study.

1. How did you find this research study?

- a. Facebook
  - b. Instagram
  - c. Reddit
  - d. Other (please list)
2. Are you currently 18 years old or older?
  3. Do you identify as Black and/or African American?
    - a. Yes, I identify as Black and/or African American
    - b. I identify as multiracial
    - c. I would like to provide another answer (please list below)
  4. Have you been diagnosed with Type 1 diabetes?
    - a. Yes
    - b. No
    - c. I'm not sure
    - d. I've been diagnosed with another type of diabetes (please list below)
  5. How many times have you been pregnant within the past 3 years?
  6. How many children did you have within the past 3 years?
  7. Have you been pregnant up to the second trimester within the past 3 years?
    - a. Yes
    - b. No, I have experienced pregnancy loss before the second trimester
    - c. No, it has been longer than 3 years since I've been pregnant (please list how long ago below)
    - d. I am currently pregnant (please list which trimester below)
  8. Were you diagnosed with Type 1 diabetes before becoming pregnant?

- a. Yes
  - b. No, I was diagnosed during pregnancy
  - c. No, I was diagnosed after pregnancy
  - d. No, I was diagnosed with another type of diabetes (please list below)
9. Do you live in the United States?
- a. Yes
  - b. No
  - c. No, but I lived there while I was pregnant
10. Would you be willing to participate in an individual interview to share more about your experiences during pregnancy?
- a. If you say yes, you will be asked to provide your contact information so we can schedule a time to meet on Zoom at your convenience. Interviews will occur sometime between October and December 2021. If you complete an individual interview, you will be compensated with a \$50 virtual Visa gift card.
11. What is the best email address at which to contact you?
12. What is the best phone number at which to contact you?
13. Do you prefer to be contacted by email, phone call, or text to schedule an interview?
- Please select all that apply.
- a. Email
  - b. Phone call
  - c. Text
14. If you prefer to be contacted by phone call, what are some times that work well for you?
- Please include your time zone.

15. Do you have any questions for me?

Thank you for completing this survey. I will reach out to you via your preferred means of contact within the next week to notify you whether or not we will be able to have an interview together.

If you are able to participate in this study, I will invite you to schedule a time to meet with me for an individual interview. These interviews will occur sometime over the next 3 months (January to March 2022). I look forward to hopefully connecting more to learn about your pregnancy experiences!

Gratefully,

Madi Marcus [memarcus@dons.usfca.edu](mailto:memarcus@dons.usfca.edu)



## Appendix D

### Consent Form



### CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Below is a description of the research procedures and an explanation of your rights as a research participant. You should read this information carefully. If you agree to participate, you will sign in the space provided to indicate that you have read and understand the information on this consent form. You are entitled to and will receive a copy of this form.

You have been asked to participate in a research study conducted by Madeleine (Madi) Marcus, a graduate student in the Clinical Psychology PsyD Program within the School of Nursing and Health Professions at University of San Francisco. The faculty supervisor for this study is Dr. Michelle Montagno, PsyD, a professor in the Clinical Psychology PsyD Program.

#### WHAT THE STUDY IS ABOUT:

The purpose of this research study is to learn about experiences of pregnancy among Black and/or African American birthing people\* with Type 1 diabetes (T1D). Specifically, this study aims to explore the way Black birthing people with T1D are supported (or not supported) by their medical care teams and online social support platforms.

\*Birthing people: a gender-inclusive term for people who have been pregnant. This may include cisgender, transgender, and gender non-binary individuals.

#### WHAT WE WILL ASK YOU TO DO:

During this study, the following will happen: we will arrange a time to meet online using Zoom teleconferencing software. I will ask to change your name on Zoom to protect your privacy, and I will record the interview. At this meeting, I will ask you questions about your experiences during pregnancy.

#### AUDIO RECORDINGS:

Our interview will be recorded to the cloud by Zoom, auto-transcribed, and password-protected. These recordings are needed for data analysis, in which I will look for common themes between your interview and other participants' interviews. Research assistants will listen to the audio recording to clean/edit the transcription. Your real name will not be associated with these recordings or transcriptions, and any data linking your real name to your study name will be kept in a password-protected file stored on a password-protected computer. The recordings and records of the pseudonyms will be deleted following completion of the study.

**DURATION AND LOCATION OF THE STUDY:**

Your participation in this study will involve one individual interview session that will last approximately one hour. The study will take place over Zoom with audio and video enabled.

**POTENTIAL RISKS AND DISCOMFORTS:**

The research procedures described above may involve the following risks and/or discomforts: you will be asked questions about your pregnancy, your diabetes, your support system, and your relationships with your medical care providers. These questions may feel personal and may cause uncomfortable memories. While it is your choice what you share over the course of the interview, you may experience negative feelings or memories as a result of the interview process. If that occurs, support resources may be available to you (see Resources Page). Serious risks are unlikely over the course of this study. If you wish, you may choose to withdraw your consent and discontinue your participation at any time during the study without penalty.

Recordings that are kept online, while password-protected, will be transcribed by Zoom's automatic transcription service and edited by undergraduate research assistants. There is minimal risk of this data being accessed by unauthorized individuals, and your real name will not be associated with your recording.

**BENEFITS:**

The possible benefits of participating in this study are your optional invitation to join a post-research network with other participants. Those who opt-in will be connected with each other and may provide each other with increased social support. Additionally, this study may provide possible benefits to others in the diabetes community, which includes access to the de-identified, collective wisdom of study participants.

**CONFIDENTIALITY:**

Any data you provide in this study will be kept confidential unless disclosure is required by law.\*\* In any report we publish, we will not include information that will make it possible to identify you or any individual participant. Specifically, we will change your name prior to beginning recording, so research assistants will not have access to your real name. Records linking your real name to your pseudonym will be kept separate from your recording in a password-protected file viewable by only the principal investigator. We will delete these records following completion of the study. This informed consent record will be kept in a secure file for 3 years and then destroyed.

\*\*Mandated reporting must occur in the event of disclosed child abuse, dependant/older adult abuse, grave and imminent threats to others, and/or active threats to self.

**COMPENSATION/PAYMENT FOR PARTICIPATION:**

You will receive one (1) Visa virtual gift card totaling \$50 for your participation in this study. If you would prefer to instead donate this amount of money, you can ask the researcher to donate the equivalent amount (\$50) to the American Diabetes Association or another diabetes non-profit of your choice. If you choose to withdraw before completing the study, you will not receive any compensation.

**VOLUNTARY NATURE OF THE STUDY:**

Your participation is voluntary and you may refuse to participate without penalty or loss of benefits. Furthermore, you may skip any questions or tasks that make you uncomfortable and may discontinue

your participation at any time without penalty. In addition, the researcher has the right to withdraw you from participation in the study at any time.

**OFFER TO ANSWER QUESTIONS:**

Please ask any questions you have now. If you have questions later, you should contact the principal investigator: Madi Marcus, at [memarcus@dons.usfca.edu](mailto:memarcus@dons.usfca.edu). You may also contact the dissertation chair, Michelle Montagno, PsyD, at [mjmontagno@usfca.edu](mailto:mjmontagno@usfca.edu). If you have questions or concerns about your rights as a participant in this study, you may contact the University of San Francisco Institutional Review Board at [IRBPHS@usfca.edu](mailto:IRBPHS@usfca.edu).

**I HAVE READ THE ABOVE INFORMATION. ANY QUESTIONS I HAVE ASKED HAVE BEEN ANSWERED. I AGREE TO PARTICIPATE IN THIS RESEARCH PROJECT AND I WILL RECEIVE A COPY OF THIS CONSENT FORM.**

\_\_\_\_\_ *PARTICIPANT'S SIGNATURE*

\_\_\_\_\_ *DATE*

**Resources Page**

If you find you would like to access supportive therapy following this experience, please visit the below resources to see if there is a therapist in your area:

Therapy For Black Girls

<https://therapyforblackgirls.com/>

Black Female Therapists

<https://www.blackfemaletherapists.com/>

If you find yourself in need of more immediate support, please use the below crisis hotlines/warm-lines:

**Bay Area Postpartum Depression Stress Line (7 days/week)**

Phone: 1-800-773-7090 (9am-9pm); 1-800-773-6667 (after 9pm)

**Talk Line Support Center (free 24/7 parenting hotline)**

Website: [www.sfkids.org](http://www.sfkids.org)

**Postpartum Support International (specializes in prenatal and postnatal well-being)**

Website: <http://www.postpartum.net/learn-more/pregnancy-postpartum-mental-health/>

Phone: **1-800-994-4PPD**

**San Francisco Suicide Prevention** (24/7 crisis hotline and also has a chat option from 11am – 11pm

Mon-Fri)

Website: [www.sfsuicide.org](http://www.sfsuicide.org)

Phone: **415-781-0500**

**National Suicide Prevention Lifeline**

Website: [www.suicidepreventionlifeline.org](http://www.suicidepreventionlifeline.org)

Phone: **1-800-273-8255**

Please contact Madi at [memarcus@dons.usfca.edu](mailto:memarcus@dons.usfca.edu) with any questions about this resources page.

## Appendix E

### Letter to IRB Advocating for Proposed Incentives

Dear Dr. Hitti and IRB Committee,

Thank you for your consideration of potential coercion in your review of my proposed study incentives as they may affect pregnant women. I have consulted with my dissertation chair and committee members, and I will include our collective thoughts below. Please let me know your thoughts and impressions.

Given the history of abuse of Black people by scientific research, it is necessary to offer compensation for participants' time. The time and energy people may have to extend to participate in these interviews makes offering compensation to both pregnant and non-pregnant people all the more essential. It is also essential to compensate for their time due to all participants likely having an increased burden of frequent medical appointments due to diabetes in general and, additionally, pregnancy. This proposed study is distinct from studies offering financial incentives for behavior change, as it is a one-time interview that is designed to be a supportive way for participants to share their narrative around pregnancy experiences, and questions are designed to be similar to what participants may have already considered internally or discussed with their peers, medical providers, or family. As pregnant participants are presumably equally competent to consent to talk interviews as previously-pregnant participants, it is appropriate to offer equal incentives for their participation.

In collaboration with my dissertation committee, another aspect to support participant agency has been added: if participants so choose, they may instead ask the researcher to donate the equivalent amount of money (\$50) to the American Diabetes Association or a similar diabetes and/or pregnancy non-profit of their choice. This may align with altruistic motivations of research participation, whether in sharing knowledge to benefit their peers or providing financial donations to research and advocacy organizations (Garg et al., 2017).

If the committee finds the \$50 amount to cause undue influence, perhaps we could reduce the amount to \$40 (or even \$35) per participant. I am drawn to maintaining the proposed \$50 incentive due to historic--and ongoing--physical, emotional, and financial exploitation of these groups (Black people and pregnant people), but remain open to your feedback in this area. Similarly, I am open to altering the inclusion criteria to include only people who are not currently pregnant, but would like to include these potential participants if possible due to the potential significance of their present experiences.

I welcome your thoughts, and I look forward to making this study as equitable and inclusive as possible with your support.

Thank you,

Madi Marcus

Doctoral Candidate

Clinical Psychology PsyD Program

School of Nursing and Health Professions | University of San Francisco

#### References

- Garg, N., Round, T. P., Daker, W. G., Bower, P., & Griffiths, C. J. (2017). Attitudes to participating in a birth cohort study, views from a multiethnic population: A qualitative study using focus groups. *Health Expectations: An International Journal of Public Participation in Health Care & Health Policy*, 20(1), 146–158. <https://doi.org/10.1111/hex.12445>

## Appendix F

### Interview Guide

Thank you so much for your generosity in participating in this interview. I am looking forward to learning more about you and your story.<sup>14</sup> Do you have any questions about the informed consent document?<sup>15</sup>

Before we begin, I wanted to briefly recall what you may have read in the survey about my identities so you know a bit about who is interviewing you today. I am a white, cisgender woman, I was diagnosed with T1D when I was 3 years old, and I have never been pregnant. I have been interested in diabetes related-research for a long time, and I became interested in pregnancy and diabetes through my work at the University of San Francisco and through seeing people in the diabetes online community experience pregnancy. The purpose of this study is to center experiences of Black women and birthing people with T1D, as research on diabetes and pregnancy often only focuses on white cisgender women. You are welcome to share anything in this space, with mindfulness of how it may or may not be difficult to share certain things with me due to similarities or differences in our identities and experiences. We can also take a break at any time, if you would like. With all of that in mind, do you have any questions for me before we begin?

To do this research, we will be recording our conversation today. Is that okay with you?

1. Would you mind telling me a bit about yourself? Could you tell me more about your general experience with T1D?

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<sup>14</sup> If the participant's camera was off, I also said: I wanted to check with you: are you aware your camera is currently off? Are you in a place where you can turn it on? Video is typically required as part of this study.

<sup>15</sup> If the participant had not yet submitted the informed consent document and/or if they kept their camera off, I asked a series of questions to screen for whether they truly had T1D. These questions are available in Appendix G.

Thank you for sharing a bit about yourself so far. As we keep talking, these questions will be about your most recent pregnancy experience.

2. Before you became pregnant, what did you think being pregnant with T1D would be like?
3. What was it like for you to prepare for pregnancy? What was your 1st/2nd/3rd trimester like? How did you manage your diabetes?
4. How was your experience with your medical team? What sort of healthcare providers did you have? Did you expect/want anything different? Were you able to access the care you needed/wanted?
  - a. How did your experiences with your medical team make you feel? Did you feel supported? Did you feel heard? Did you ever feel afraid?
  - b. How did that impact your wellness? Did you notice anything changing in your physical wellbeing? What about your emotional wellbeing?
5. Who supported you in your pregnancy? What did that support look like?
6. How did you cope with all that we've talked about so far?
7. I remember you found me from FB/IG/Reddit (*recall how they found me*). Sometimes people have turned to online communities for support during pregnancy. Did you use the diabetes online community (DOC) such as T1D Sugar Mommas or other social media pages? How was that for you?
  - a. What other resources might have been useful? How did you find/connect to the DOC?
8. What do you wish you had known prior to your experience, or what would you want to pass along to other Black PWT1D considering pregnancy?



- a. Would you repeat the experience?
9. Why did you choose to participate in this research project? What are your hopes?
10. How would you like to see findings from this research shared?
11. Is there anything else you would like to share that we didn't get a chance to discuss?

Thank you for all that you have shared and for spending this time with me today. I will be available via email or phone if you have any questions for me after the interview. I will go ahead and stop recording now.

As I had mentioned in that initial survey, there is an opportunity to join the post-research network with other participants. Do you have questions about this, and would you like to be included?

I will be sending you a virtual Visa gift card in gratitude for your participation in this study. You are welcome to choose whether you would prefer to receive the gift card directly or donate it to a diabetes or pregnancy non-profit of your choice. What is the best way for me to get that to you? (Card or donation; text or email?)

## **Appendix G**

### **T1D Screening Questions**

Before you send in the informed consent, I would like to ask you a few screening questions to make sure you are eligible for this study. Your answers to these questions will not be included in the research.

1. What type of diabetes do you have? When were you diagnosed?
2. What is your current diabetes management like? What was it like during pregnancy?
3. What medications are you taking? How often?
4. What was your most recent a1C?