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Examining COVID-19 hesitancies related to fertility and
pregnancy among Black and Latinx women

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An abstract of a thesis submitted to the Faculty of the Rollins School of Public Health of Emory University in partial fulfillment of the requirements for the degree of Master of Public Health in Global Health

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Abstract

Examining COVID-19 hesitancies related to fertility and pregnancy among Black and Latinx women

By: Belén Godínez-Santana

The COVID-19 pandemic has magnified inequalities that exist in the United States of America. Black, indigenous, and people of color (BIPOC) are disproportionately affected by the pandemic. Lack of trust in healthcare and government among BIPOC and under-resourced communities in the United States is a longstanding issue rooted in historical social injustices. The COVID-19 pandemic has further exacerbated the gap that exists in medical uptake among BIPOC communities and created an increased need for culturally, linguistically, and timely COVID-19 evidence-based information. The purpose of this thesis is to understand how the COVID-19 pandemic exacerbated health inequities among BIPOC communities and to assess the factors that play a role in COVID-19 vaccination uptake as it pertains to information mayhem regarding pregnancy and fertility for Black and Latinx women. To understand how information mayhem affects decisions related to pregnancy and fertility for Black and Latinx women, a secondary review of existing literature specifically related to hesitancy among Black and Latinx communities was conducted, and COVID design group data was analyzed. A qualitative approach was chosen to capture the variety and depth of participants' narratives. Findings were based on four themes that were generated: fear of vaccination based on past and present injustices on Black and Brown bodies, fear of vaccination due to hesitancies related to maternal and child health outcomes, general health fears related to COVID-19 vaccinations, and fears related to culture and religion. These themes ultimately suggested that information mayhem plays a significant role in the decisions Black and Latinx women make related to COVID-19 vaccines.

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Purpose

The purpose of this thesis is to understand how the COVID-19 pandemic exacerbated health inequities among BIPOC communities and to assess the factors that play a role in COVID-19 vaccination uptake as it pertains to information mayhem regarding pregnancy and fertility for Black and Latinx women.

Background

Importance of COVID-19 communication and vaccine uptake in BIPOC communities

The COVID-19 pandemic has magnified inequalities that exist in the United States of America. Black, indigenous, and people of color (BIPOC) are disproportionately affected by the pandemic. Not only have BIPOC communities borne the brunt of the COVID-19 pandemic in terms of negative health impacts (Iyanda et al., 2022), but complexities brought about by misinformation and historical social injustices have made effective dissemination of information difficult in already hard to reach communities (Sy et al., 2021). Lack of trust in healthcare and government among BIPOC and under-resourced communities in the United States is a longstanding issue rooted in historical social injustices. The COVID-19 pandemic has further exacerbated the gap that exists in medical uptake among BIPOC communities and created an increased need for culturally, linguistically, and timely COVID-19 evidence-based information.

Amid the rise of COVID-19 cases, deaths, and global spread of the disease, the World Health Organization (WHO) declared the COVID-19 outbreak a global pandemic on

March 11, 2020 (WHO, n.d.). Under such dire conditions, the public began searching for information and guidance online about the disease. In turn, there was a surfeit of information about the COVID-19 pandemic that spread quickly and widely. While some information was true, much of it was false. This resulted in misinformation spreading quickly throughout the country. Previous studies show that through social media, people share falsehoods more than evidence-based information (Lewandowsky et al., 2012). Knowing that true and evidence-based information is a necessary component to ensure the public is well-informed and can react effectively to a pandemic, effective communication strategies are needed to ensure important mitigation strategies. Considering that COVID-19 is just one of the many urgent health concerns that disproportionately affect low-income BIPOC communities, there is a need to provide them with increased access to vaccine evidence-based information to improve vaccination uptake.

Previous Relevant Work: COVIED Project

The Human Engagement Learning Platform (HELP) at Emory University contributed to the SARS-COV2 Vaccines Information Equity and Demand Creation (COVIED) Project by leading an effort to develop tailored public health messaging to encourage COVID-19 vaccination among populations that were at disproportionate risk for COVID-19 during the beginning of the project. HELP did this by leading a rapid formative ethnographic research project which was conducted in partnership with several key community organizations. The COVIED project was funded by the CDC and focused on the stories and narratives that participants were drawing on to explain and justify their COVID-19 vaccine hesitancy. Narratives were defined by COVIED as a set of events and related elements (e.g., rationales, motivations, and goals) that are linked to temporal and logical

sequence. They are recounted by a narrator for a specific purpose such as explaining or justifying an idea (HELP, 2022). HELP utilized narratives and counter-narratives to understand and help explain COVID-19 vaccine hesitancy among participants. These narratives were deduced from design groups. *Design groups*, a term coined by the HELP team to reflect their commitment to human-centered design principles and their commitment to leveraging participant' insights for the design of policies and interventions, were implemented to gather information from participants. This thesis is based on the data collected by the COVIED project through design group interviews, using the data to further understand narratives closely related to pregnancy and fertility for the participants.

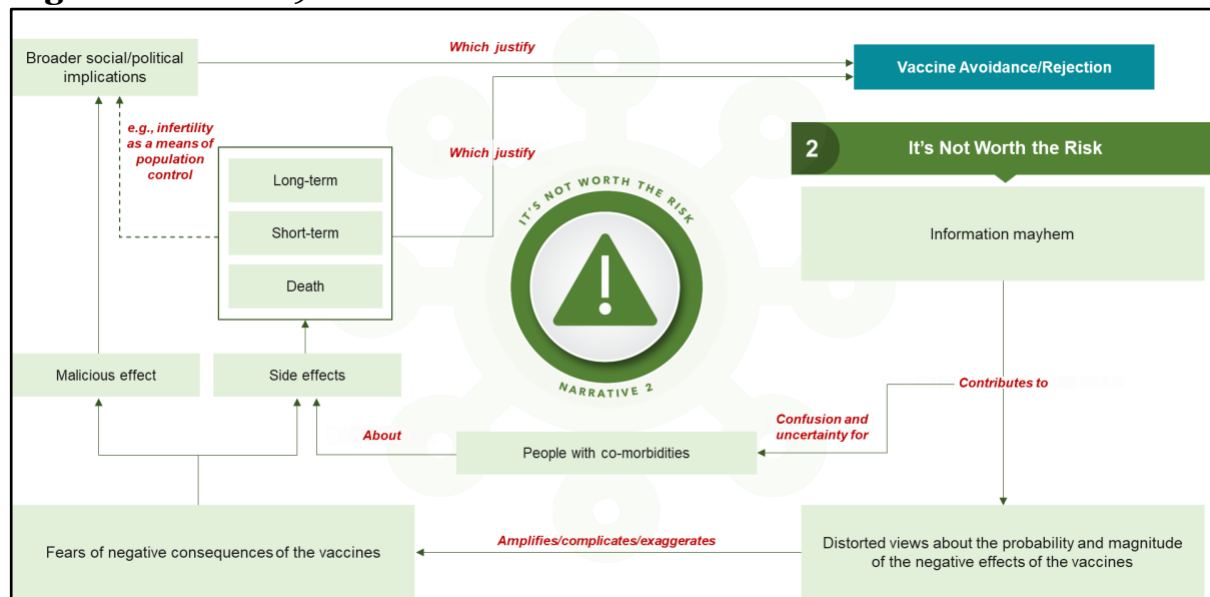
The COVIED study utilized narratives as the unit of analysis and identified narratives as stories that are told for a specific purpose, e.g., to make sense of, explain, or justify a set of events or actions. Narratives contain specific elements, including precipitating events or actions and their consequences linked in temporal and logical sequence. Narratives about “real” events are socially constructed. They are filtered and edited through repetition and refinement through social networks, social media, and mainstream media until they achieve a stable form (HELP, 2022). In the case of COVID-19 vaccination, narratives also reflect the efforts of individuals and organizations who are purposely spreading misinformation for their own political purposes. The narratives identified by the COVIED study were extremely common and stable across design groups and interviews. These narratives likely reflected unique aspects of the overall sample. The six major narratives identified in COVIED's analyses are the following:

1. The Big Push

2. Is it worth the risk?
3. It's about freedom
4. COVID vaccines are unnecessary
5. What's the point?
6. Waiting for more information

For this thesis, I chose to focus on the second narrative: It's Not Worth the Risk. This narrative is used to capture codes that mention anything related to the risks of vaccinations outweighing the risks of COVID-19 (see figure 1). Within this narrative, COVID captured the information mayhem code, which is further explored in this thesis to understand its effect on women's choices related to pregnancy and fertility.

Figure 1. COVID-19 avoidance narrative: It's Not Worth the Risk



(HELP, 2022)

Narratives reflecting themes related to COVID-19 hesitancy among BIPOC communities

Three prominent themes that were identified by the COVIED study and that highlight the need for this thesis include: histories of discrimination and marginalization, suspicion of authorities, and information mayhem. These themes include the knowledge gaps that exist and contribute to COVID-19 hesitancy among BIPOC communities, especially for Black and Latinx women and influence the decisions they make related to vaccines. Ultimately, the narratives shaped the way people responded to COVID-19 vaccine information. The three themes identified are:

1. Histories of discrimination and marginalization (past)

The history of health and medicine in the United States has been marked by racial injustice and myriad forms of violence: unequal access to health care, the segregation of medical facilities, and the exclusion of African Americans from medical education being the most obvious examples (Nuriddin et al., 2020). Several recent research studies, especially those related to COVID-19 vaccines have drawn Americans' attention to the fact that racial and ethnic disparities exist in health care. It is clear that the U.S. health care system is not only flawed for many reasons, but it has been the cause of both injury and death for members of racial and ethnic minorities (Clark, 2009). In 2002, an Institute of Medicine (IOM) report requested by Congress, listed more than 100 studies documenting a wide range of disparities in the United States health care system. This report found that people belonging to racial and ethnic minorities often receive a lower quality of health care than people of European descent, even when their medical insurance coverage and income levels

are the same (Clark, 2009). Racial and ethnic disparities in health care continue to be documented. These past and present disparities are multiple and diverse, and present themselves as lingering mistrust of the medical community, especially among BIPOC communities.

2. Suspicion of authorities (political and economic motivations) (present)

The WHO defines vaccine hesitancy as a behavior influenced by several factors including issues of confidence (not trusting vaccine or provider), complacency (not perceiving a need for vaccination, not valuing the vaccine), and convenience (access). Such hesitancy for BIPOC communities is rooted in both the historical and contemporary contexts of systemic racism. A study with the objective of conducting a comprehensive and systematic national assessment of COVID-19 vaccine hesitancy in the American adult population revealed that in adjusted group comparisons, compared to their counterparts, vaccine hesitancy was highest among African Americans (34%), Hispanics (29%) and those who had children at home (25%) (Khubchandani et al., 2021). Antivax statements, conspiracy theories, myths, and questions about vaccine development have further exacerbated suspicion of authorities, especially those based on political and economic motivations.

3. Information mayhem (processing of information)

Information mayhem was defined by the COVIED team as information overload enabled by increasingly complex and interconnected sources including governments, companies, celebrities, influencers, and immediate social networks (HELP, 2022). This phenomenon has a dizzying effect on individuals as they struggle to make sense of the pandemic, usually with very little knowledge or understanding of COVID-19 or

COVID-19 vaccines. Social media outlets can be used for effective and rapid public health guidance dissemination, but they can also be used destructively to communicate misinformation at mass scale.

Much research has been conducted about COVID-19, causing a complementary infodemic, whereby various outlets and digital media portals share false information and unsourced recommendations about COVID-19 health (Mheidly & Fares, 2020). While media can often be harmful in the dissemination of false information, it also has the potential to contribute to health awareness and promotion. Media has proven to be a powerful avenue for the dissemination of wellness education and it plays a critical role in the public response to a pandemic, serving as a portal for communication between governments, health institutions, and communities (Mheidly & Fares, 2020).

Groups of focus: Black communities

In the United States, Black Americans are more likely to be diagnosed, be hospitalized, and die from COVID-19 (CDC, 2020). In comparison to White individuals, the death rate from COVID-19 has been reported to be 2-3 times higher for Black individuals (CDC, n.d.). COVID-19 outcome inequities affecting Black individuals are believed to stem from systemic racism. These have led to higher levels of social risk factors including unstable housing and homelessness, poverty, lower-wage, higher risk employment, and underlying health conditions, all of which are risk factors for severe COVID-19 disease and death. There is a need to focus on Black communities because these communities are at higher risk of being negatively impacted by COVID-19. Additionally, the media has reported that Black individuals do not trust the health care

system or government's responses to COVID-19. This medical and governmental mistrust among Black communities is a result of current and historical systemic racism and creates negative health outcomes for Black Americans.

Groups of focus: Latinx communities

Generations of systemic oppression and discrimination against Latinx communities in the United States have resulted in increased vulnerability to the impacts of the COVID-19 pandemic on these communities (Webb Hooper et al., 2020). Latinx families are disproportionately at risk of the economic repercussions of the pandemic due to a greater likelihood of experiencing poverty and low-wage work. Much of this is due to systemic institutional discrimination and the exponential increase in internal immigration reinforcement (Hibel et al., 20210107). Additionally, emerging evidence highlights disparities in contracting the virus as well as complications from the virus including higher rates of death. This can be linked to the fact that Latinx workers are more likely to work essential jobs which often preclude the recommended guidelines for social distancing to reduce transmission of the virus (Hibel et al., 20210107).

BIPOC are at higher risk of contracting and dying from COVID-19

When exploring the different reasons why is it important to understand the effects of low-vaccination rates on BIPOC communities, it is important to understand that BIPOC are at an increased risk of exposure to COVID-19, and often require a higher level of care at the time they test positive (Rubin-Miller et al., 2020). This thesis focuses specifically on the need for further research about the effects of COVID-19 vaccination uptake on Latinx and Black women.

Black and Latinx women and fears related to pregnancy/ fertility

Although COVID-19 vaccines are widely available in the United States, vaccination rates have been slow-moving, with many studies showing significant vaccine hesitancy in the country. An online survey to identify reasons for vaccine hesitancy among unvaccinated individuals found that 58% of unvaccinated respondents were worried about unknown long-term adverse effects (Diaz et al., n.d.). Of these, 41% percent believed that the COVID-19 vaccines can negatively impact reproductive health and/ or fertility, and 38% were unsure of the effects on fertility (Diaz et al., n.d.).

Summary

The COVID-19 pandemic has exposed and amplified the egregious health inequities that exist because of historical and modern-day instances of structural racism and health inequities for Black and Latinx women in the United States. Considering that marginalized communities have faced stark disproportionate rates of morbidity and mortality because of COVID-19, there is a need to continue to explore the direct effects that vaccine hesitancy has on these communities. Research suggests that Black and Latinx individuals are more hesitant than U.S. Whites to receive the COVID-19 vaccine. Additionally, Blacks are more likely to feel that the COVID-19 vaccine is not something they trust, a result that echoes prior research on reluctance for other vaccines, such as the HPV vaccine (Kricorian & Turner, 2021). Based on this research, Black and Latinx women living in the United States are more likely to believe that the COVID-19 vaccine is dangerous or not worth the risk.

This thesis will seek to expand understanding of the effects of information mayhem or the rapid spread of information on the decision-making of Black and Latinx women

about pregnancy and fertility. Based on this literature review, there is a need to further explore the effects of information mayhem on decisions related to pregnancy and fertility for BIPOC women.

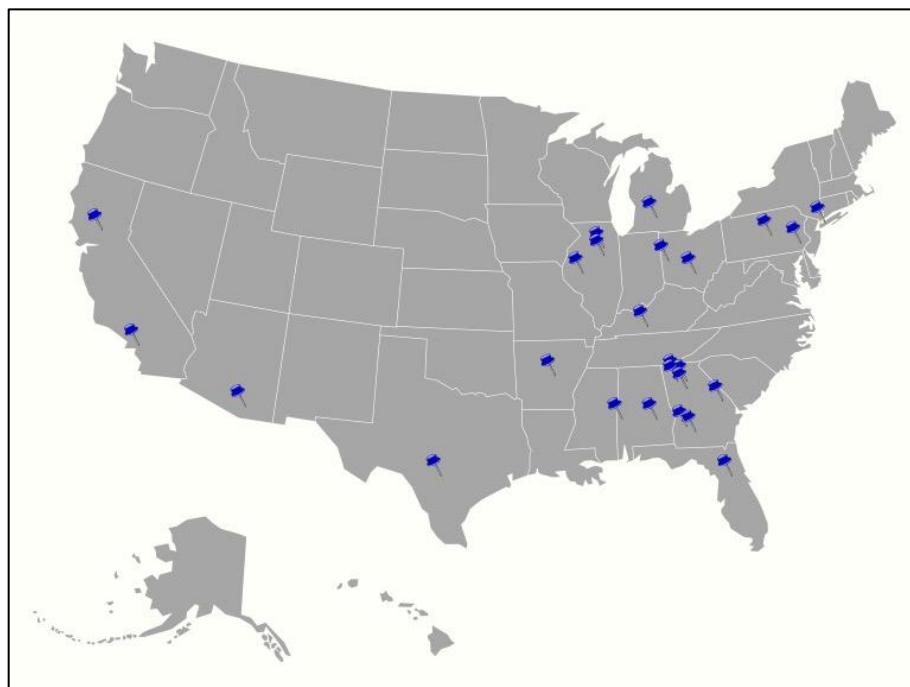
Significance

Assessing the factors that play a role in COVID-19 vaccination uptake for Black and Latinx women surrounding pregnancy and fertility is essential for public health entities to appropriately serve marginalized populations. Projects like COVIED help elicit insights about the rationales and influences that contribute to COVID-19 hesitancy in the same groups which include African American, Latinx, and Native American groups. The information gathered during design group interviews is critical for the road forward to developing tailored public health messaging to encourage COVID-19 vaccination among these populations. Although vaccine hesitancy is one of the primary concerns for the public health sector, it is important to understand the complexities that contribute to these anxieties, especially for populations that are most at risk for contracting and dying from COVID-19. In order to help inform effective public health interventions, it is imperative to gain a better understanding of how information mayhem affects the decision-making of Black and Latinx women. To do this, we must uplift the voices of marginalized populations by focusing resources and advocating for their priorities to ensure community agency.

Methods

Introduction

To understand how information mayhem affects decisions related to pregnancy and fertility for Black and Latinx women, several strategies were implemented to leverage the voices of community members in discussing their hesitancies surrounding fears of vaccination risks. Following a review of the literature specifically related to hesitancy among Black and Latinx communities to further understand the foundation of mistrust of government and healthcare, data was collected from COVID design groups to further understand COVID-19 vaccine hesitancy. During 53 design groups in 17 locations (see Figure 2 and Table 1), participants expressed their attitudes and expressions toward COVID-19 vaccinations. Audio recordings of design groups were transcribed verbatim, and transcripts were analyzed for the purpose of this study. Ultimately, a qualitative approach was chosen to capture the variety and depth of participants' narratives.

Figure 2. Map of design groups and interview locations**Table 1.** List of health center partners and location of design groups

Date	City	Health Center Name
2021-06-03	Albany, GA	Albany - all vaccinated
2021-06-18	Albany, GA	Albany - all vaccinated
2021-07-02	Albany, GA	Albany - all vaccinated
2021-07-13	Albany, GA	Albany - all vaccinated
2021-07-20	Albany, GA	Albany - unvaccinated
2021-08-22	Albany, GA	Albany area
2021-09-19	Albany, GA	Albany area
2021-04-16	Atlanta, GA	Our Lady of Guadalupe Catholic Mission
2021-05-14	Atlanta, GA	Carver High School
2021-05-21	Atlanta, GA	Kipp High School
2021-05-28	Atlanta, GA	Carver High School
2021-06-04	Atlanta, GA	Kipp High School
2021-06-24	Atlanta, GA	Family Health Center
2021-06-29	Atlanta, GA	Family Health Center
2021-10-05	Atlanta, GA	Family Health Center
2021-10-05	Atlanta, GA	Family Health Center
2021-08-17	Augusta, GA	100 Black Men
2021-09-09	Augusta, GA	100 Black Men
2021-06-23	Chicago, IL	Esperanza

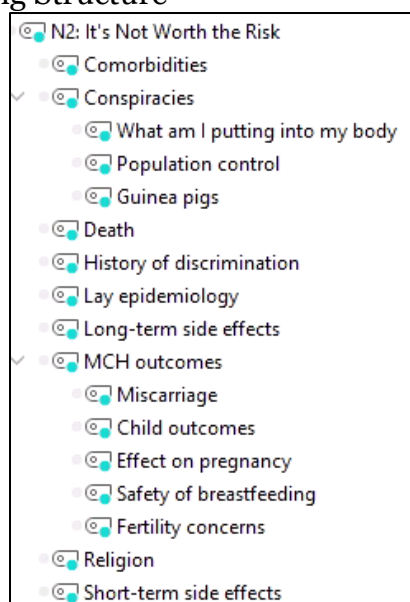
2021-07-01	Chicago, IL	Esperanza
2021-07-15	Chicago, IL	Esperanza
2021-07-21	Chicago, IL	Esperanza
2021-11-05	Chicago, IL	Individual Interview 2
2021-06-18	Columbus, OH	Heart of Ohio - Somali
2021-06-18	Columbus, OH	Heart of Ohio
2021-06-21	Columbus, OH	Heart of Ohio - Spanish
2021-07-14	Columbus, OH	Heart of Ohio - Spanish
2021-07-15	Columbus, OH	Heart of Ohio
2021-07-30	Columbus, OH	Heart of Ohio - Somali
2021-08-21	Eples, AL	Eples
2021-09-08	Eples, AL	Eples
2021-11-23	Florida	Individual Interview 4
2021-08-23	Flint, MI	PRC Network
2021-08-03	Harrisburg, PA	Hamilton Health
2021-10-05	Harrisburg, PA	Hamilton Health
2021-10-06	Harrisburg, PA	Hamilton Health
2021-08-09	Los Angeles, CA	Eisner Health
2021-08-12	Los Angeles, CA	Eisner Health
2021-08-26	Los Angeles, CA	Eisner Health
2021-08-31	Los Angeles, CA	Eisner Health
2021-06-17	Lima, OH	Health Partners of W. Ohio
2021-09-02	Little Rock, AR	Community Bible Church
2021-07-09	Marysville, CA	Harmony Health
2021-10-08	PHL	Spectrum
2021-10-15	PHL	Spectrum
2021-07-19	Queens/Bronx, NY	Urban Health
2021-07-29	Queens/Bronx, NY	Urban Health
2021-08-11	Queens/Bronx, NY	Urban Health
2021-10-04	Queens/Bronx, NY	Urban Health
2021-08-19	Russellville, KY	Logan County
2021-09-09	Russellville, KY	Logan County
2021-11-11	San Antonio, TX	Individual Interview 3
2021-11-05	Tucson, AZ	Individual Interview 1
2021-08-17	Tuskegee, AL	Tuskegee
2021-08-26	Tuskegee, AL	Tuskegee/Kentucky make up
2021-09-07	Tuskegee, AL	Tuskegee
2021-06-11	US-wide	Community Health Workers

Ethical Considerations

Design group audio recordings were transcribed and deidentified by the HELP team to maintain confidentiality of respondents.

Research Design

A secondary, code-based thematic analysis was used for this thesis (see Figure 3). A coding structure was developed based on recurring avoidance rationales related to not wanting to get vaccinated due to a number of fears. Codes that were developed during this thesis were reorganized to ensure that the purpose of the analysis was met. Nine meta-codes were identified: comorbidities, conspiracies, death, history of discrimination, lay epidemiology, long-term side effects, maternal and child health outcomes, religion, and short-term side effects. For the purpose of my analysis, I define meta-codes as codes that identify a “bigger picture” configuration, these are often referred to as parent codes in qualitative data analysis. Meta-codes pull together a wide range of material from the first cycle of coding and condense large amount of data into a smaller number of analytic units. Sub-codes, often know as daughter codes, provide a more concise view of the data. Meta-codes that include sub-codes are conspiracies and maternal and child health outcomes. Definitions of each meta-code and sub-codes are outlined in my codebook (see Figure 4). Each transcript was reviewed and coded in MAXQDA using the final coding structure. Primary themes were identified for the narrative “It’s Not Worth The Risk” that was identified by the COVIED study and a subset of codes was developed to better capture segments that would be useful to analyze.

Figure 3. Final Thesis Coding Structure**Figure 4.** Final Codebook

Meta-Codes & Sub-Codes	Simple Description	Full Definition	Detailed Inclusion Criteria	Detailed Exclusion Criteria	Example
Comorbidities	The simultaneous presence of two or more diseases or medical conditions in a person	Comorbidity is the presence of one or more additional conditions often co-occurring with a primary condition.	Use this code to describe when a person expresses a fear of vaccine interference with current medical conditions in the person. Captures discussions of potential effects of vaccines on issues like blood pressure, diabetes, etc. Includes mention of fear of vaccines based on race	Does not include mention of pregnancy	“Well, I have more underlying health conditions. So, I don’t want to have to take two shots, maybe three shots, because they are saying after the injections now, that later on you’re going to have something else. I have high blood pressure. I’m diabetic” (DG1 Carver 05.14.21 deidentified, Pos. 100).
Conspiracies - What am I putting into my body? - Population control - Guinea pigs	A secret plan by a group to do something unlawful or harmful	Conspiracies are attempts to explain harmful or tragic events as the result of the actions of a small powerful group. They increase prevalence in periods of widespread anxiety, uncertainty, or hardship	Includes discussions and arguments of conspiracy theories including foreign substances in vaccines (microchips, magnets, fetal tissue), population control, being guinea pigs for drug companies, vaccine ingredients	Does not include mention of experimentation on BIPOC bodies	“Just like they said later on, you’re going to have numbers on your arm or your bank card or something, or your ID is going to be scanned later on through your arm with the new technology. I don’t know” (PDG 1 Esperanza 07.01.21_deidentified, Pos. 104).

Death	The action of dying or being killed	The act of dying; the end of life of a person or organism; the total and permanent cessation of all the vital functions of an organism	Includes discussions of fearing COVID-19 vaccination due to the fear of immediate or future death due to vaccine ingredients. Includes mention of long-term fears that eventually result in death	Does not include mention of short-term or long-term side effects that do not result in death	"I had a cousin text me all the way from Arkansas... Screenshotted me a picture of the news saying over a hundred people have died from the Johnson & Johnson, and over 150 or something like that have died from the other type of vaccine" (OppFlintMI 08.23.21_deidentified, Pos. 90).
History of Discrimination	The intended of accomplished differential treatment of persons or social groups for reason of certain generalized traits	The historical unjust or prejudicial treatment of different categories of people, especially on the grounds of race, age, or sex	Captures mentions of medical experimentation on Black and Brown bodies and/or ethical transgressions (e.g. Tuskegee explicit or implicit). Includes mention of current mistreatment that stems from historical marginalization. Includes mention of documentation status/ fear of deportation	Does not include mention of differential treatment of persons for reasons other than race, age, or sex	"You have to realize that black bodies have been through a lot of abuse. They've been through exploitation, they've been through experimentation. Black women have been sterilized because of different vaccines. It's just the black community has a lot of apprehensions for a lot of reasons" (DG1 Kipp 05.21.21 deidentified, Pos. 73).
Lay epidemiology	The processes through which health risks are understood or interpreted by laypeople	Drawing conclusions based on limited observations, usually/ always available in your own life (e.g. I know someone who knows someone who died from the COVID vaccine). Inference does not follow the observation	Captures mention of fear of COVID-19 vaccine based on what happened to someone in the participants' social network	Does not have to be a personal connection to respondent	"Her best friend's mother passed away with complications with the injection. In talking to people, I've heard many people say that they know people who have passed away after getting the injection. My son's friend passed away, and her brother-in-law, after getting the injection" (DG1 Carver 05.14.21 deidentified, Pos. 50).
Long-term side effects	A problem that is caused by a disease and may continue for months or years	The continuation of symptoms lasting longer than the initial recovery	Includes discussions and arguments of plausible and implausible long-term side effects and general safety concerns. Includes mention of "long haulers syndrome". Includes mentions of blood clots, myocarditis/ pericarditis, physical deformities, weakened immune system	Does not include mention of fears related to fertility, general maternal health, child health concerns, or death	"So those doctors and nurses and people that work in the medical field saying that people develop heart problems and blood clots and all kinds of stuff that was happening to healthy people after they had been vaccinated. And even before that, they were just saying there were too many unknowns. I love my life the way it is and I just don't want to be some guinea pig for the CDC" (1KI110521 deidentified, Pos. 95).
MCH outcomes - Miscarriage - Child outcomes - Effect on pregnancy - Safety of breastfeeding	Outcomes related to the health of mothers and children	Maternal outcomes include pregnancy complications. Child health outcomes include the healthy development of children	Includes discussions of infertility, and references to pregnant and breastfeeding mothers. Includes all mentions of hesitations related to fertility issues	Does not include mention of fear unrelated to MCH outcomes	"Some of my patients have said that they've heard that it will make them infertile or give them problems with fertility. That's one big one" (SDG1 UrbanHlthPln 07.19.21 deidentified, Pos. 61).

- Fertility concerns			and/ or motherhood. Includes all mentions of fears of vaccination children. Includes mention of autism		
Religion	The belief in and worship of a superhuman controlling power, especially a personal God or gods	A personal set or institutionalized system of religious attitudes, beliefs, and practices. The service and worship of God or the supernatural	Includes discussions and arguments of religion and religiosity. Includes mentions of not wanting to get vaccinated for fear of the devil	Does not include mention of fears unrelated to religiosity	“So from a religious standpoint, am I losing faith in God by getting this shot/. Am I saying that God doesn’t got me, and this shot is becoming my God now? This COVID-19 is my Lord and savior. The government is Jesus, now, and this is the holy water. So I’m just trying to be open-minded, but very aware and mindful of what’s being said, and who’s saying what, and who’s it coming from?” (RSIGrp2EpesAL 09.08.21_deidentified, Pos. 275).
Short-term side effects	Problems that are caused by a disease but usually go away after a few days and up to a month	Side effects occurring over or involving a relatively short period of time	Includes mention of body aches, muscle spasms, and fear of needles	Does not include mention of side effects lasting longer than one month	“What happened to me was that my blood pressure spiked. My blood pressure had been regulated before I received the vaccination, and a week and a half after I received the vaccination, my blood pressure spiked to numbers I haven’t seen in years... I had to hold off on the second shot” (DG1 Carver 05.14.21 deidentified, Pos. 75).

Following the process of coding segments in data into codes and sub-codes, the dataset was analyzed in MAXQDA. The final dataset includes 9 meta-codes and 413 coded segments of transcripts. The final coding structure is presented in Table 2.

Table 2. Final coding structure

Code System	Frequency (n=413)
Narrative: It's Not Worth the Risk	458
Comorbidities*	39
Conspiracies*	17
What am I putting into my body	32
Population control	17
Guinea pigs	8
Death*	30
History of discrimination*	25
Lay epidemiology*	24
Long-term side effects*	92
MCH Outcomes*	
Miscarriage	1
Child Outcomes	3
Effect of pregnancy	10
Safety of breastfeeding	3
Fertility concerns	16
Religion*	17
Short-term side effects*	79

*meta-code

Population and Sample

For the COVIED project, there was a focus on sub-populations in the United States with the highest risk of acquiring COVID-19, and of experiencing severe illness and death: African American, Latinx, and Native American groups. In total, 53 design groups in 17 locations and a total of 10 states were conducted. Thirty-four of the design groups consisted solely of African American participants, three consisted solely of Latinx participants, two consisted solely of Somali participants, and 14 groups were a mix of African American, Caucasian, and Native American participants. In total, there were over 360 participants in all groups with approximately 69% of them identifying as female. The age range of participants was 20-84, with the average age estimated at around 45-55. Approximately 95% of the people interviewed were not vaccinated at the time of the interview. All interviews were utilized for the analysis of this thesis.

Procedures and Instruments

For this thesis, a total of 53 design group transcripts were imported into MAXQDA for a code-based analysis. Transcripts were reviewed, coded, and integrated into the narrative “It’s Not Worth the Risk.”

Findings

Introduction

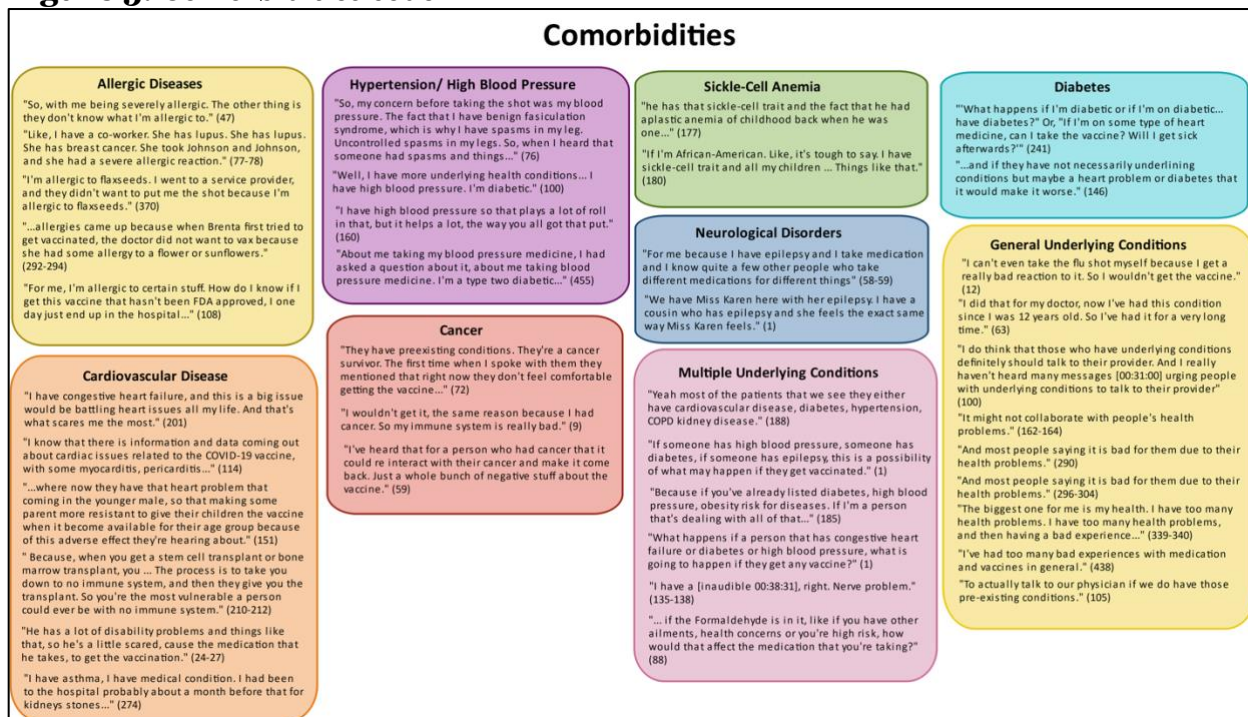
In this section, I will present the findings that emerged upon analysis of the data. The presented results for this thesis focus on codes that arose from an analysis of the four themes that will be discussed in the Discussions section. The findings contain nine sections, for the nine codes that I identified while analyzing the 53 design interviews about COVID-19 hesitations: Comorbidities, Conspiracies, Death, History of Discrimination, Lay Epidemiology, Long-term Side Effects, Maternal and Child Health Outcomes, Religion, and Short-term Side Effects. Some of these concepts have discernable sub-categories which were broken down into what I refer to as sub-codes. To simplify the presentation of the analysis, quotes were pulled directly from design group interviews to provide readers with a more comprehensive understanding of examples of the different sections. The following analysis is an examination of each of these sections and common elements across design group interviews.

Comorbidities

I define the comorbidities meta-code as the simultaneous presence of two or more diseases or medical conditions in a person. This describes when a person expresses a fear of vaccine interference with current medical conditions. It captures discussions of potential effects of vaccines on health issues like blood pressure, diabetes, etc.

Additionally, this code also includes mention of fear of vaccines based on racial factors including identifying as African American and being hesitant of the ways in which vaccinations may affect people of different races differently.

The comorbidities code includes all diseases and illnesses mentioned by participants to explain their reasoning behind COVID-19 hesitancy. Illnesses most frequently mentioned included allergic disease, cardiovascular disease, hypertension/ high blood pressure, cancer, sickle-cell anemia, neurological disorders, and diabetes. These are presented with quotes in Figure 5. Participants also mentioned multiple underlying conditions in specific segments, with no direct explanation as to which of these conditions played the greatest role in their vaccination hesitancy. Additionally, some participants referenced general underlying conditions, failing to identify any one specific comorbidity that contributed to their hesitancy. These were categorized under “General Underlying Conditions.”

Figure 5. Comorbidities code

Conspiracies

The conspiracies meta-code includes three sub-codes: What am I Putting into my Body, Population Control, and Guinea Pigs. For this thesis, I have defined conspiracies as attempts to explain harmful or tragic events as the result of the actions of a small powerful group. They increase in prevalence in periods of widespread anxiety, uncertainty, or hardship. In the case of COVID-19 vaccines, conspiracies about COVID-19 have increased in parallel with COVID-19 persistence worldwide. This meta-code includes discussions and arguments about conspiracy theories, including foreign substances in vaccines (microchips, magnets, fetal tissues, etc.), population control, being guinea pigs for vaccine companies, and questioning of vaccine ingredients.

In Figure 6, conspiracies were broken down into four sections: General Conspiracies, What am I Putting into my Body, Population Control, and Guinea Pigs. In the sub-code What am I Putting into my Body participants mentioned fears regarding the ingredients in the COVID-19 vaccine, sometimes mentioning that they looked up the ingredients on the CDC website and were skeptical about them. For Population Control, people expressed hesitancy based on historical injustices or just general observations and their mistrust of the government, suggesting that the government was trying to depopulate certain races. Lastly, people expressed concern about the COVID-19 vaccine being developed too quickly and expressed that they did not want to be part of a CDC experiment.

Figure 6. Conspiracies code

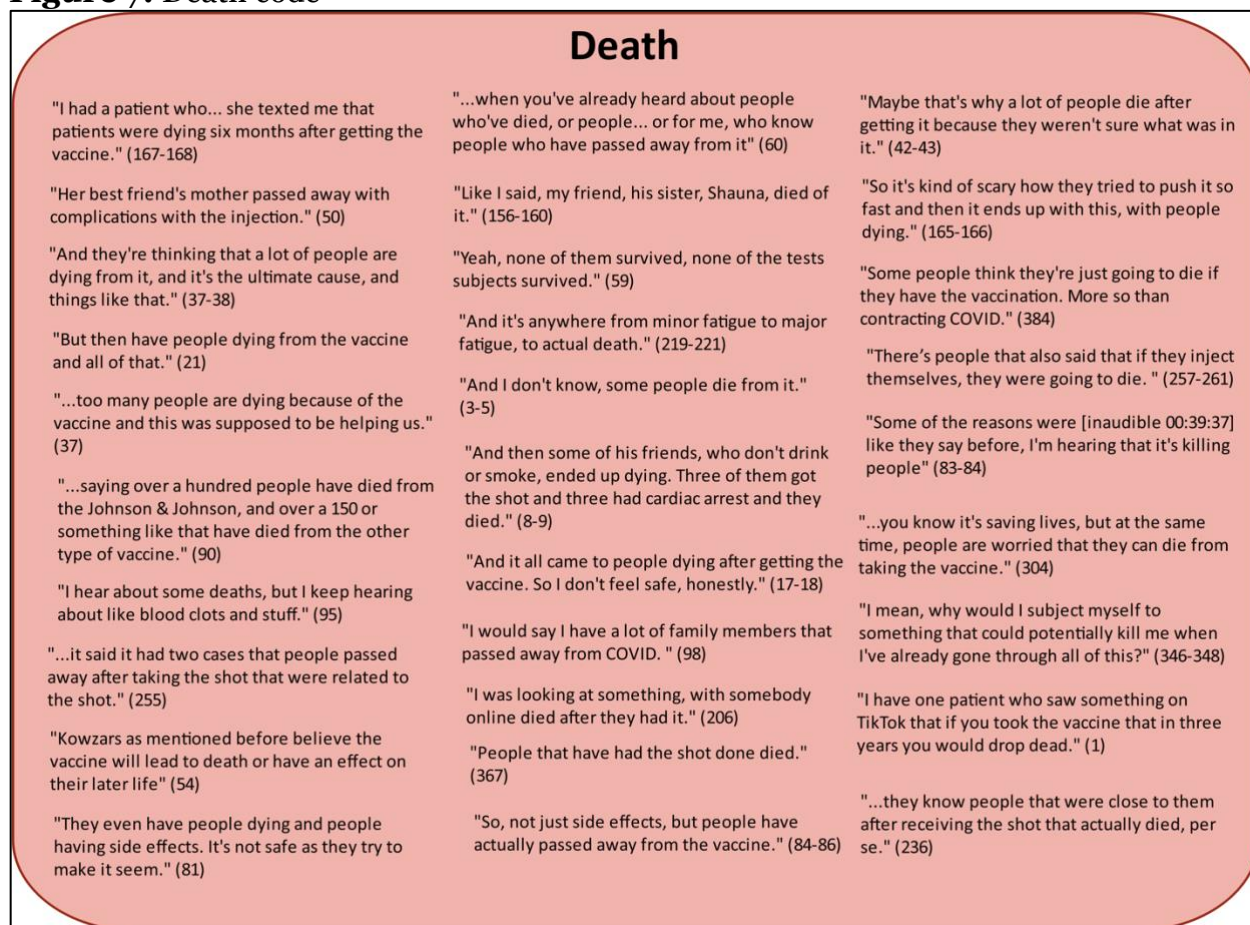


Death

Death is defined as the act of dying, the end of life as a person, and the total and permanent cessation of all the vital functions of an organism (Merriam-Webster). This meta-code includes discussions of fearing that the COVID-19 vaccine components will lead to immediate or future death. This code also includes mention of long-term effects that may result in eventual death.

In Figure 7, I have included quotes that demonstrate different death-related fears expressed by design group participants.

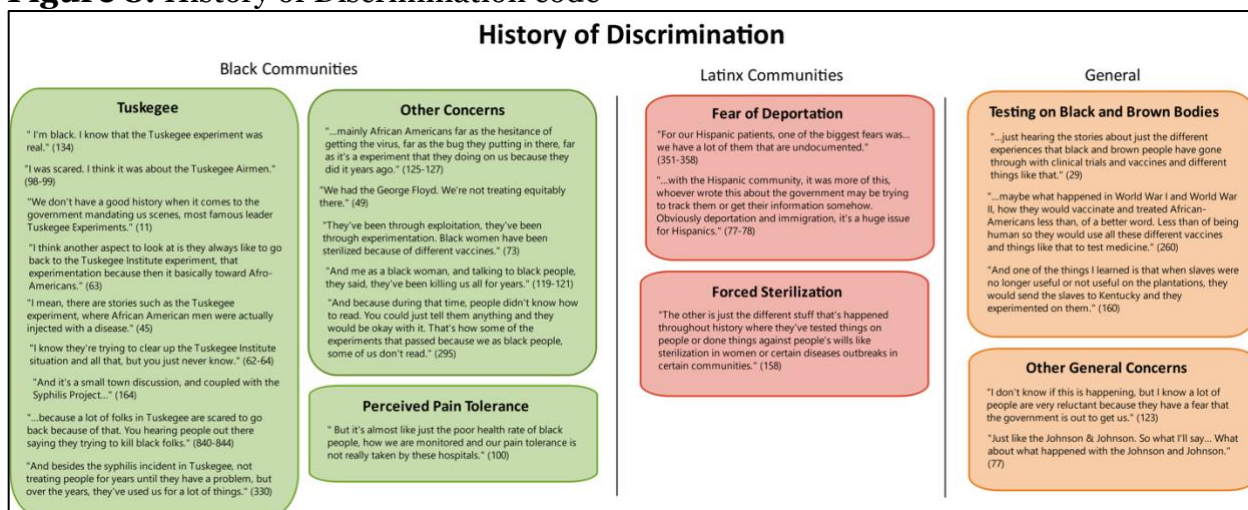
Figure 7. Death code



History of Discrimination

The history of discrimination meta-code includes all mentions of prejudicial treatment based on grounds of race. For this thesis, I define history of discrimination as the intended or accomplished differential treatment of persons or social groups on the basis of certain generalized traits. This code captures all mentions of medical experimentation on Black and Brown bodies and/or ethical transgressions, for example explicit and implicit mentions of the Tuskegee Syphilis Study. The Tuskegee Syphilis Study was a trial conducted by the U.S. Public Health Service in which hundreds of low-income Black men in Alabama were used as test subjects with no informed consent. They were enticed with offerings such as free meals, health care, and burial stipends, and were followed to document the natural progression of untreated syphilis, even after penicillin became available (Attia, 2021). This code also includes mention of current mistreatment that stems from historical marginalization including mention of immigration status and fear of deportation.

In figure 8, I included quotes from participants where they referenced histories of discrimination to justify their reasoning for vaccine hesitancy. These were broken up into three categories: history of discrimination among Black communities, Latinx communities, and other general mentions. The most frequently mentioned was the Tuskegee Syphilis Study, with participants mentioning that due to this historical injustice, they do not trust COVID-19 vaccines.

Figure 8. History of Discrimination code

Lay Epidemiology

For this thesis, lay epidemiology is defined as drawing conclusions based on limited observations available in one's own life. For example, "I know someone who knows someone who died from the COVID vaccines". In lay epidemiology, health risks are understood or interpreted by laypeople and assume them to be true without any scrutiny. This meta-code captures mention of fear of COVID-19 vaccine based on what happened to someone in participant's social networks, or what they hear might have happened to someone. These people do not necessarily need to have a personal connection to the participants.

Long-Term Side Effects

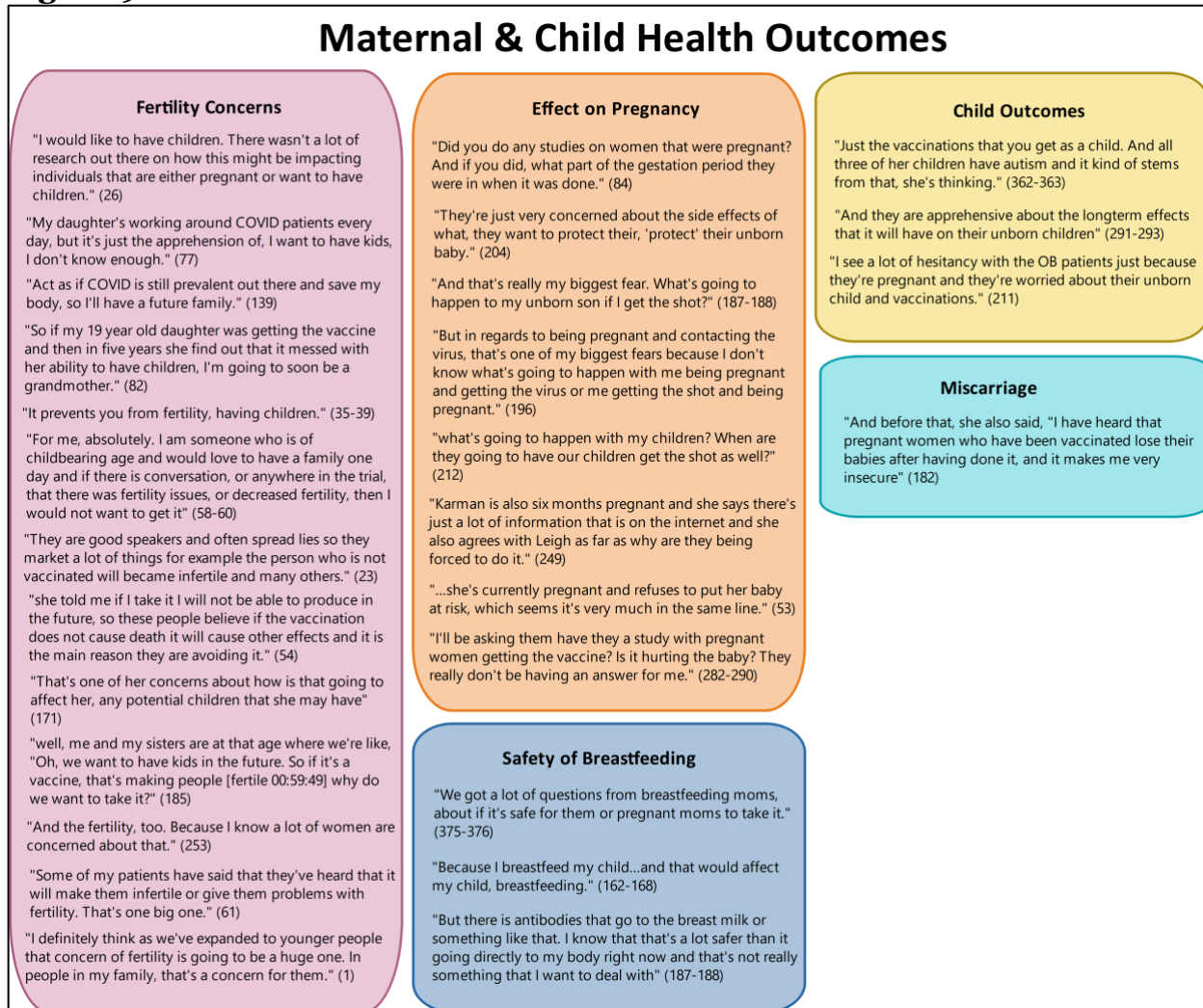
For the purpose of this thesis, long-term side effects are problems that are caused by a disease, in this case COVID-19, and may continue for months or years. Long-term side effects last longer than the initial recovery and are often referred to as "long hauler syndrome" in the context of the COVID-19 pandemic. This meta-code includes discussions and arguments of plausible and implausible long-term side effects and

general safety concerns. It also includes mention of blood clots, myocarditis/pericarditis, physical deformities, and a weakened immune system. For this thesis, I did not include mentions related to fertility, maternal health, child health, or death as these mentions are all captured in other meta-codes.

Maternal and Child Health Outcomes

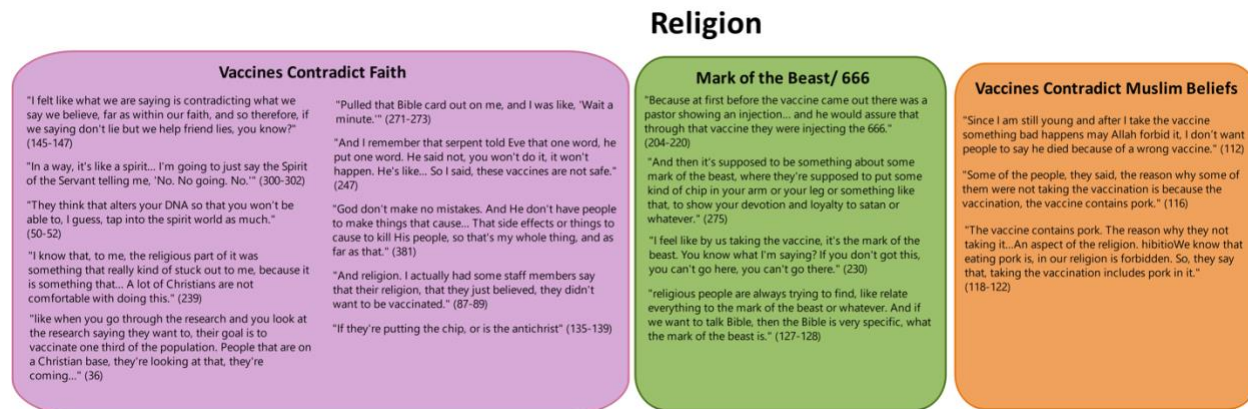
The maternal and child health outcomes meta-code describes outcomes related to the health of mothers and children. This code includes discussions of infertility, and references to pregnant and breastfeeding mothers. Additionally, it includes all mentions of hesitations related to fertility issues and/ or pregnancy. This meta-code includes fears related to vaccinating children for any reason related to their health outcomes including the fear that vaccines cause autism.

In figure 9 I have organized quotes related to maternal and child health into five categories: fertility concerns, effect on pregnancy, safety of breastfeeding, child outcomes, and miscarriage. These sub-codes were all mentioned by participants as reasons why they were hesitant about receiving the COVID-19 vaccine or having their children receive the vaccine.

Figure 9. Maternal and Child Health Outcomes code

Religion

The religion meta-code includes mentions of the belief in the worship of a superhuman controlling power, especially a personal God or Gods. This meta-code includes discussions and arguments about religion and religiosity. Additionally, mentions of not wanting to get vaccinated for fear of the devil are also included. For example, some participants mentioned that COVID-19 vaccinations produce physical vaccine scars and that these are viewed as the "mark of the beast".

Figure 10. Religion code

Short-Term Side Effects

In this thesis, short-term side effects are problems that are caused by a disease (COVID-19) but usually go away after a few days and up to a month. This code includes mention of body aches, muscle spasms, and fear of needles.

Codes Summary

The key findings that emerged from these results include specific fears that contribute to COVID-19 hesitancy among Black and Latinx communities including fear of vaccine interaction with existing health concerns, components of the COVID-19 vaccine, historical instances of discrimination, religious beliefs, short and long-term side effects, and concerns current and prospective mothers have about their and their children's health. Emerging themes based on the nine codes identified include: fear of vaccination based on past and present injustices on Black and Brown bodies, fear of vaccination due to hesitancies related to maternal and child health outcomes, general health fears related to COVID-19 vaccinations, and fears related to culture and religion. These four overarching themes will be discussed in the discussion section of this thesis.

Themes

Based on the initial meta-codes and sub-codes, I distilled four major themes that help understand and transform the data into explanatory concepts. The four themes are:

1. Fear of vaccination based on past and present injustices on Black and Brown bodies
2. Fear of vaccination due to hesitancies related to maternal and child health outcomes
3. General health fears related to COVID-19 vaccinations
4. Fears related to culture and religion

These four themes demonstrate the complexities that play a role in decision-making for BIPOC women.

Theme 1, fear of vaccination based on past and present injustices on Black and Brown bodies includes the codes History of Discrimination and Conspiracies. This theme includes the complexities that surround reasoning behind not wanting to get vaccinated due to historical and present instances of discrimination of Black and Brown people. Additionally, this theme consists of all reasoning related to conspiracy theories, questioning of vaccine ingredients and fear of population control and testing on BIPOC communities. The most notable finding for this theme was that the concern most frequently mentioned by participants related to instances of present and historical discrimination was the Tuskegee Syphilis Study.

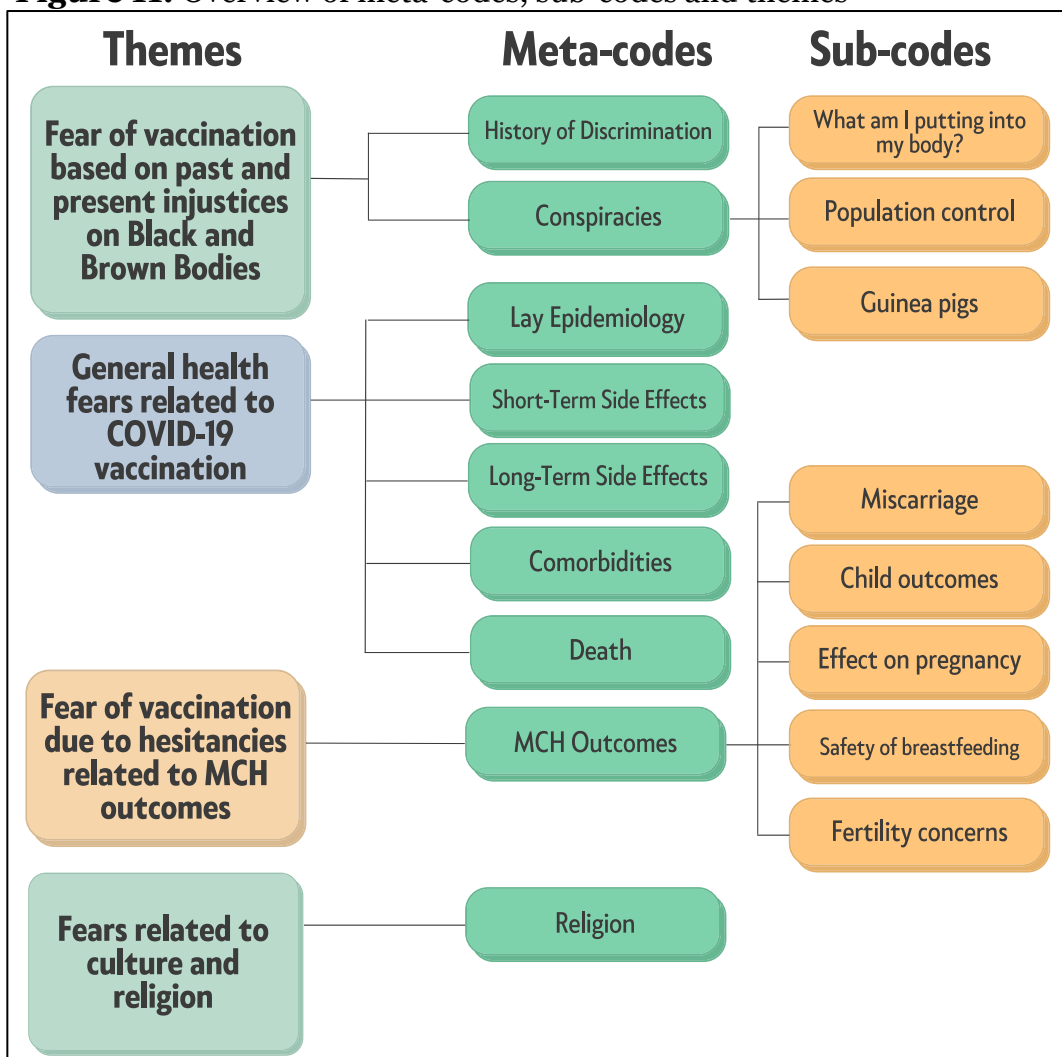
Theme 2, fear of vaccination due to hesitancies related to maternal and child health outcomes includes all mention of MCH related fears surrounding pregnancy and

possible negative effects of vaccines on fetuses. For this theme, the most significant finding was that the biggest maternal and child health concern for participants were issues related to fertility. Participants mentioned fear of vaccination due to possible effects on fertility with more frequency than mentions of other topics including effects on pregnancy, safety of breastfeeding, child outcomes, and miscarriage.

Theme 3, general health fears related to COVID-19 vaccinations includes the following codes: comorbidities, death, long-term side effects, short-term side effects, and lay epidemiology. For theme 3, the most noteworthy finding was that the comorbidity most frequently mentioned by participants was cardiovascular disease. Cardiovascular disease was mentioned more than other comorbidities including allergic diseases, sickle-cell anemia, neurological disorders, and diabetes.

Theme 4, fears related to culture and religion includes the religion code. The most significant finding for theme 4 was that most participants who brought up religion as explanation for their COVID-19 vaccine hesitancies explained that vaccines contradicted their faith. These themes are outlined in figure 11.

Figure 11. Overview of meta-codes, sub-codes and themes



Information Mayhem and Pregnancy/ Fertility Concerns

Vaccine hesitancy is complex and varies across communities. It includes factors such as complacency, convenience, and confidence (European Union, 2020). The likelihood of vaccine hesitancy is dependent on many factors including histories of discrimination and marginalization, suspicion of authorities, and information mayhem. The distilled themes in this results section suggest that information mayhem plays a role in increasing fears and hesitancies for participants.

Discussion

Finding 1: Tuskegee Syphilis Study

Mention of fear of vaccination based on past and present injustices on Black and Brown bodies was repeatedly mentioned in many design group interviews. A notable finding that emerged from this theme was that the most frequently cited instance of historical discrimination was the Tuskegee Syphilis Study. This injustice was mentioned more often than other instances of discrimination across all participating racial groups. Although most mentions of past and present instances of discrimination were very general, in other words, people mentioned discrimination in a general sense, there were many segments that specifically referred to the Tuskegee Syphilis Study explicitly. One participant stated, “I think another aspect to look at is they always like to go back to the Tuskegee Institute experiment, that experimentation because then it basically toward Afro-Americans” (PDG1Albany_06.18.21, 63). Here, the participant explicitly mentions that this study was specific to Black Americans, who were essentially the victims of this experiment. The participant in this design group interview references the Tuskegee Syphilis Study as a reason for not trusting the U.S. healthcare system and ultimately for not wanting to receive the COVID-19 vaccine. Similarly, another participant in a different design group stated, “And besides the syphilis incident in Tuskegee, not treating people for years until they have a problem, but over the years, they’ve used us for a lot of things” (RSIGrp2Albany_09.19.20, 330). This participant mentions experimentation on Black communities in the United States as a reason for not wanting to get vaccinated. Other concerns in this theme that were not as frequently mentioned

were: perceived pain tolerance, fear of deportation, forced sterilization, and testing on Black and Brown bodies.

Finding 2: Issues Related to Fertility

When it comes to maternal and child health outcomes, the most frequently mentioned concerns were issues related to fertility. This finding is noteworthy as there was a total of five categories identified for this code including fertility concerns, effects on pregnancy, safety of breastfeeding, child outcomes, and miscarriage. Participants in design group interviews expressed concerns related to fertility more often than the four other topics. One participant explained, “I would like to have children. There wasn’t a lot of research out there on how this might be impacting individuals that are either pregnant or want to have children” (DG1Kipp_05.21.21), 26). Here, the participant expresses concern about there not being enough existing research related to maternal and child health outcomes. Additionally, some participants expressed concern about their daughters not being able to have children in the future, stating that they hoped to one day be grandmothers: “So if my 19-year-old daughter was getting the vaccine and then in five years she finds out that it messed with her ability to have children, I’m going to soon be a grandmother” (SDG1HamiltonHlth_8.3.2021). This finding closely relates to information mayhem and the effects of a lack of accessibility of reputable and evidence-based information available for BIPOC communities. In multiple instances, participants expressed concerns about there not being enough information or research related to fertility. The processing of information plays a role in participants’ understanding of the safety of vaccines.

Finding 3: Cardiovascular Disease

Participants frequently mentioned comorbidities as a reason for their COVID-19 vaccine hesitancy. A noteworthy finding was that the most frequently mentioned comorbidity was cardiovascular disease. Cardiovascular disease was mentioned more often than other comorbidities including allergic diseases, sickle-cell anemia, neurological disorders, and diabetes. Mentions of cardiovascular disease include fears of vaccine interaction with existing comorbidities as well as the fear of developing cardiovascular issues including myocarditis and pericarditis. One participant stated, “I have congestive heart failure, and this is a big issue would be battling heart issues all my life. And that’s what scares me the most. Because like you said, you had it and they came out with something the next day that scared you to death” (SDG1HamiltonHlth_8.3.2021).

Myocarditis is inflammation of the heart muscle, and pericarditis is inflammation of the outer lining of the heart. In both cases, the body’s immune system causes inflammation in response to an infection or some other trigger (CDC, 2021). This finding is significant because some participants mentioned a fear of developing myocarditis or pericarditis based on information they had consumed either through social networks or based on data that they had seen online. One participant stated, “I am someone who’s not been vaccinated. I will say and at this time, I’m opting not to be vaccinated until I just get more data and more research, and more data comes out. Specifically, I know that there is information and data coming out about cardiac issues related to the COVID-19 vaccine, with some myocarditis, pericarditis, and I recently had an uncle who experienced a heart attack after getting the vaccine” (PDG1AlbanyAreaUnvacc7.20.2021). This quote encompasses multiple topics including mention of comorbidities as well as mention of lay epidemiology. Information mayhem

plays a role in this participant's decision-making because they are basing not wanting to get vaccinated on both data they have seen related to cardiovascular disease as well as not enough information about the effect vaccines have.

Finding 4: Contradiction of Faith

The fourth and final finding was that most participants who mentioned religion as an explanation for their COVID-19 vaccine hesitations brought up vaccines contradicting their faith, often referencing the Bible. Other less discussed topics included the “mark of the beast” and vaccines contradicting Muslim beliefs. Participants discussed that COVID-19 vaccines contradicted what they believed in, mentioning things like, “I felt like what we are saying is contradicting what we say we believe, far as within our faith” (4KII_112321, 145). This specific participant discussed that the church wants people to look out for one another as their “brother's keeper” while claiming God's love, and they conclude that vaccines contradict the church's teachings. Through analysis of vaccine reluctance to COVID-19 in terms of religious beliefs, the results show that a contradiction of faith was the top reason for participants not wanting to get vaccinated.

Limitations

The largest limitation of this thesis itself is in information available from initial data collection. Although the thesis focuses solely on Latinx and Black communities, participant demographic information was not completely clear based on the data collected by the COVIED team. It was challenging to read design group interviews without detailed demographic knowledge about participants including age, sex, and race. Additionally, because some of this information was not readily available,

assessment of the data based on race and ethnicity was limited. This limitation created room for error during data analysis.

Another limitation was that this thesis project was completed by a single researcher and so it lacks the transdisciplinary approach that is necessary for intercoder reliability and for validating codes and themes.

Though there are logistical challenges with presenting this preliminary report, I feel confident that the coding organization and collection criteria is significant to inform future research related to the role information mayhem plays in COVID-19 vaccination uptake in BIPOC communities.

Conclusions

This thesis set out to increase understanding of the health inequities that have disproportionately impacted BIPOC in the United States. The literature review helps capture research that would lay a foundation for the reader to understand COVID-19 vaccine hesitancy broadly. In this thesis, I aimed to demonstrate that information mayhem plays a significant role in the decision-making of Latinx and Black women related to COVID-19 vaccination uptake. More specifically, I explored and assessed the different topics that play a role in their decision-making, including developing specific codes and themes that would help inform the results of this thesis. I delved into the four different themes that arose from the data, connecting them back to the purpose of this thesis. My analysis brought me to the conclusion that information mayhem plays a significant role in the decisions Black and Latinx women make related to COVID-19

vaccines. These decisions are influenced by information mayhem which further exacerbates hesitancies among these groups.

Without proper vaccine uptake data of the participants in the COVIED design group interviews, as well as follow-up about changes in opinions about COVID-19 vaccines, it is difficult to truly measure the effect of information mayhem on participants. However, given the information that was collected by the COVIED team, it may be reasonable to presume information mayhem has at least a minimal impact on decision-making.

While the nature of the pandemic may continue to vary in its path, it is imperative to leverage the voices of marginalized communities to further understand their health needs. Future public health advocacy efforts should remain focused on creating more equitable strategies to improve health outcomes for all communities, but especially for those who have been ignored for far too long.

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