Maternal Health Experiences of Black Deaf and Hard of Hearing (DHH) Women in the United States

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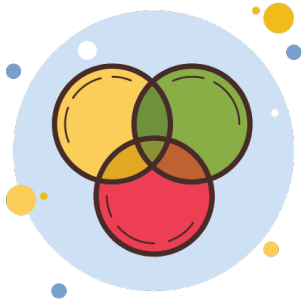
Introduction

- U.S. maternal outcomes have revealed alarming mortality rates.
  - Between 1990 and 2013, U.S. maternal mortality rates increased by 136% (WHO, 2014).
  - U.S. women face increased infant mortality rates—5.8 % in 2017—higher than many developed countries (e.g., 3.9% in the U.K.) (Organization for Economic Co-operation and Development, 2017).
- Women with disabilities face increased risks for inadequate prenatal care, antenatal and postnatal complications, delivery of low birthweight infants, and preterm births (Clements et al., 2020; Mitra et al., 2015; Mitra et al., 2015; Redshaw et al., 2013; Signore et al., 2011).

Introduction

- Black women historically experience disproportionate rates of adverse pregnancy outcomes and experiences.
  - Between 2011 and 2016, the pregnancy-related mortality rate for Black non-Hispanic women was over three times greater than white non-Hispanic women (Centers for Disease Control and Prevention, 2017).
  - There is a higher incidence of disability among Black Americans at 11.8% versus 5.6% for white Americans aged 22-44 years old (Alston & Turner, 1994).
    - A recent study found that pregnant DHH women are more likely to be Black (Mitra et al., 2020).
- **The compounded effects of these marginalized identities could result in adverse maternal health experiences and outcomes (Horner-Johnson et al., 2021).**

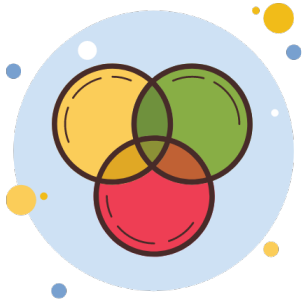
Methods: Intersectionality



Intersectionality: “analytical framework for understanding how aspects of a person's social and political identities combine to create different modes of discrimination and privilege” (coined by Kimberlé Crenshaw in 1989).

- Disparities in maternal health care cannot be attributed solely to disability or race but rather to their complex interplay.
- With intersectionality in mind, we aimed to ask new questions with an existing data set.

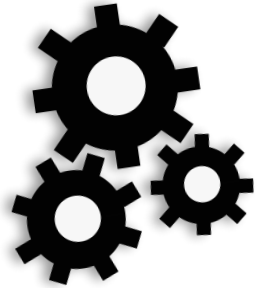
Objective



- Larger Qualitative Study: To examine the health care experiences and outcomes of DHH women in the United States

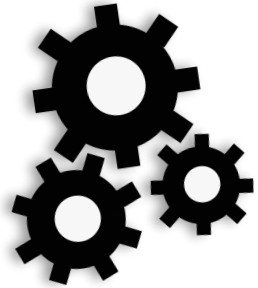
- Subgroup Analysis: To understand numerous unmet needs, barriers, and facilitators that Black DHH women face before, during, and after their pregnancy

Methods



- DHH Qualitative Interviews (n=67):
  - Women were recruited from research sites in Chicago, IL, & Rochester, NY, then online nationally
  - Eligibility Criteria:
    - DHH women, between 21 and 50 years old
    - Self-reported pregnancy/recent birth of a child within the past five years
  - 90-minute, open-ended, semi-structured interviews
    - Interview guide questions adapted from a study on pregnancy in women with physical disabilities (Mitra et al., 2016) and informed by a DHH advisory panel
- Subgroup Analysis (n=8):
  - Participants self-identified as Black or Bi-racial (one identity as Black)
    - Ages ranged from 23 to 43 years old (mean, 35)

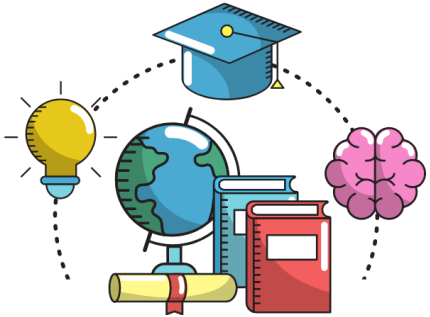
Methods



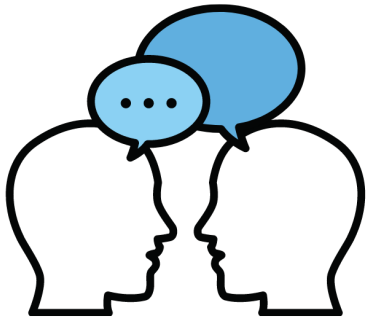
- Author and Interviewer Positionality:
  - Interviewers' self identified as a white Deaf woman and a non-Deaf, ASL-fluent, female interpreter of Puerto Rican descent.
  - Writing team included individuals with a wide range of identities (including two hearing women of color and a Deaf man).
- Qualitative Analysis:
  - Dedoose Version 8.3.35 (a cloud-based software)
  - Deductive coding based on previously developed codebook
  - Emergent inductive codes were added to reflect answers unique to the Black DHH maternal health experience
  - Two authors collaboratively coded transcript after calibration

Major Themes

Familial & Cultural Support



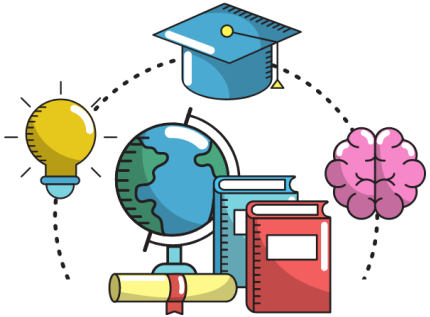
Knowledge & Educational Opportunities



Communication Accessibility

Major Themes

Familial & Cultural Support



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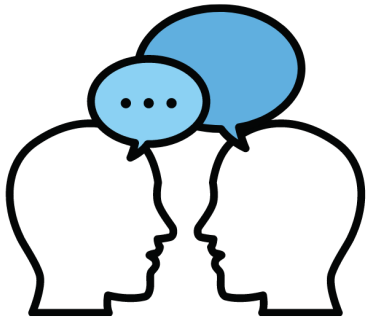


Communication Accessibility

Results: Familial & Cultural Support

- Unmet Needs and Barriers:
  - Participants commented on wanting more health care providers and interpreters who shared their racial backgrounds,
    - *". . . culture, understanding, empathy. I need my people [of color] for support when I am in pain and emotional"* (P2).

  - One participant identified a potential provider belief that Black patients tolerate more pain leading to her issues being ignored,
    - *"Our concerns are not being taken seriously or [providers] think we are being dramatic."*
    - *"[It] is hard for me to talk about a part [of myself/my identities] without including another part they all are connected to me"* (P3).

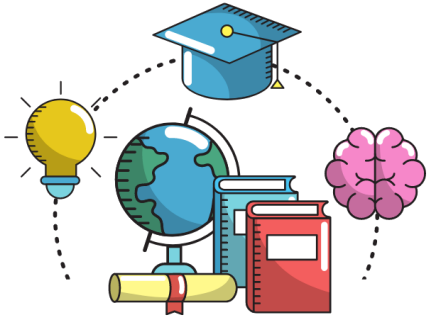
Results: Familial & Cultural Support

- Facilitators:
  - Family members who help:
    - when interpreters were not available
    - assist in advocating for communication accommodations
    - provide emotional support

  - Providers who were either POC or aware of how to communicate with DHH women effectively,
    - *"One POC nurse was very sweet and helpful when I was struggling to breastfeed … she was very caring and tried her best to communicate with me writing and [going] close up to me"* (P2).

Major Themes

Familial & Cultural Support



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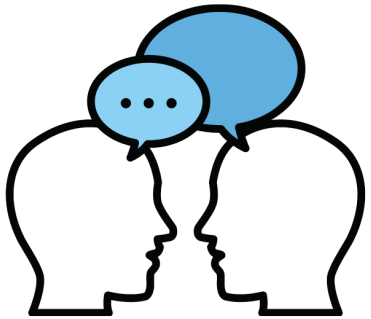

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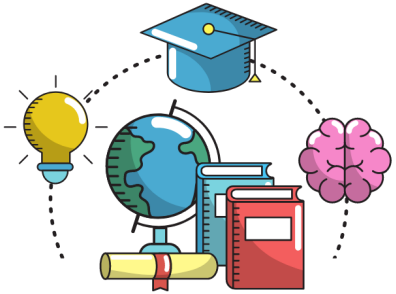
Results: Knowledge & Educational Opportunities



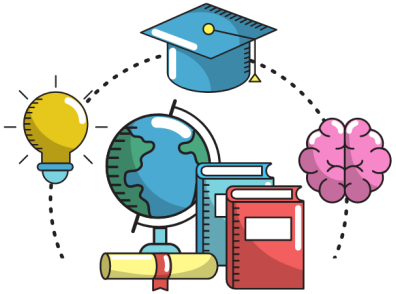
- Unmet Needs and Barriers:
  - One participant's newborn died due to complications from a uterine infection. She stated,

"I wish the OB/GYN had told me I had a uterine infection but she didn't know because I only told her I had been having a little cramping and she said it was probably from stress"

  - When she tried to make sense of what happened, her doctor failed to provide an adequate explanation,

"All he said was that he didn't know why and he didn't understand" (P1).

Results: Knowledge & Educational Opportunities

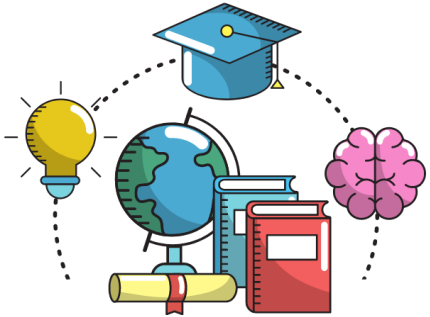


- One participant expressed a desire for providers to have cultural sensitivity training:
  - *"Take cultural sensitivity training class, some for POC and some for deaf"* (P2). This participant stated that the resources they share should also be *"culturally sensitive or friendly."*

- Facilitators:
  - Taking birthing classes with an ASL interpreter
  - Addressing information gaps by finding community with other mothers; for example, using a social media group for Deaf moms

Major Themes

Familial & Cultural Support



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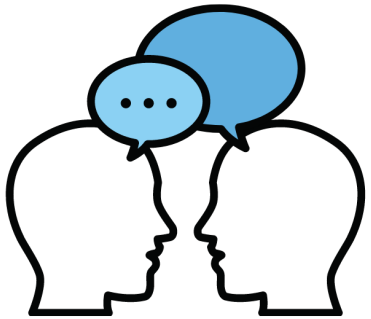

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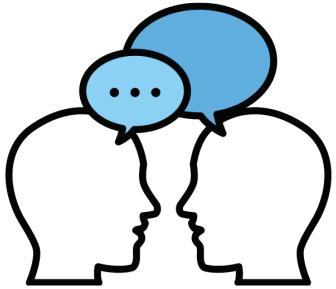
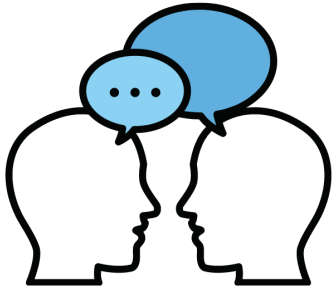


- Unmet Needs and Barriers:
  - One study participant described how a lack of consistent communication meant they
    - *"couldn't understand everything."* This woman stated, *"I didn't have [an] interpreter at birth"* (P1).
  - Another participant stated,
    - *"Sometimes I do not understand [terminology used by hearing people] and am embarrassed to ask what it means. Looking back, I wish I spoke out more and talked to someone and found a group. I could have developed that group with deaf and POC [mothers]"* (P2).

Results: Communication Accessibility



- Facilitators
  - Sign language-fluent providers and/or interpreters ensured language accessibility met participants' communication needs.
    - *"[My provider] SimComs which was perfect"* (P6).
    - *"I never had any issues with communicating with the doctors because an interpreter was there. Since the interpreter was there, communication was fine. If there wasn't an interpreter, then communication would've been lost…"* (P8).

Discussion

- Project Findings:
  - Black DHH women experience many of the same issues as their white DHH counterparts.
    - Unique to Black DHH mothers is the support needed aligned with/ aware of their intersecting racial and deaf experiences
  - Responses demonstrated the importance of familial/cultural support & accessible communication for a healthy pregnancy

- Limitations:
  - Limited sample of Black DHH women
  - Subgroup analysis with no interview questions specific to racial identity
  - Lack of racial concordance between interviewers and interviewees

Conclusion

- Major Take-aways:
  - To improve communication accessibility, health care providers must ensure that DHH women are provided with communication accommodations, accessible information, and emotional support/compassionate care throughout their pregnancy and birth.
  - Cultural awareness is important to fully acknowledge the maternal experiences of Black DHH women
- Plans for Future Research:
  - A study designed with race/ethnicity in mind would allow for a more in-depth analysis of Black DHH maternal health experiences.
  - Researchers should utilize other demographics to fully demonstrate compounding effects of identity (income, class, race, gender, disability).

Acknowledgments & Contact Info

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