

Experiences of Black Pregnant People Offered Prenatal Diagnosis in the Setting of Fetal Anomalies: A Qualitative Study



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Background

- Disparities in access to and use of prenatal genetic diagnostic strategies are well documented for Black pregnant people.
- In addition, racism and its impact on disparate maternal-fetal outcomes is an increasingly important area of study and advocacy.
- There are few studies assessing the experiences of Black pregnant people when they are offered prenatal diagnostic testing in the setting of ultrasound detected fetal anomalies.

Objective

- The objective of this study is to describe the experiences of Black pregnant people who were offered prenatal diagnosis for ultrasound diagnosed fetal anomalies and identify healthcare processes to better support needs of this group.

Methods

- Interviews with Individuals with ultrasound detected fetal anomalies who were offered genetic counseling were eligible (IRB #20-3411).
- All interviews were performed by race-concordant interviewers.
- Interviews were based on the NIMHD Research Framework, focusing on healthcare system domains.
- We also explored domains relevant to a genetics and prenatal diagnosis context. Such domains included:
 - Perceptions of genetic counseling at time of diagnosis, including respect, compassion, trust, and quality of information.
 - Experience of being offered or undergoing prenatal diagnosis including safety, privacy, and return of results.
- A rapid qualitative analysis was performed on transcripts by AT, KSA, and ASD with formal analysis ongoing.

Results

- 15 individuals who self-identify as Black race and ethnicity were interviewed.
- Median age of participants was 28, IQR 20-37.
- 6 of 13 participants elected to proceed with prenatal diagnosis based on ultrasound findings.
- 12 of 13 participants were in the postpartum period during interview.
- 5 of 13 individuals experienced fetal or neonatal loss.

Figure 1. Emerging Themes & Example Quotations

"The care was respectful... the doctor and counselor in the clinic cared. It was just rushed."	Respected, but rushed
"I wasn't worried about those [privacy, genetic information] as much as the procedure [amniocentesis]."	Privacy and Data Handling
"I know for a fact that non-white women have different care, whether its conscious or unconscious... all of the [providers] there are White."	Representation in Healthcare
"First thing you do is go to google... what the doctor gives you is not clear. They use bigger words."	Seeking Clarifying Information
"I want to be able to advocate for myself, to say this is what I need... this is what I want."	Information as a route to Self Advocacy

Conclusions

Black pregnant people described experiences of racism in healthcare, rushed experience with diagnosis and decisions, and need for self advocacy. These issues likely contribute to disparities in use of prenatal genetic and genomic technologies and are central to improving access to this care.

National Institute on Minority Health and Health Disparities Research Framework

		Levels of Influence*			
		Individual	Interpersonal	Community	Societal
Domains of Influence (Over the Lifecourse)	Biological	Biological Vulnerability and Mechanisms	Caregiver-Child Interaction Family Microbiome	Community Illness Exposure Herd Immunity	Sanitation Immunization Pathogen Exposure
	Behavioral	Health Behaviors Coping Strategies	Family Functioning School/Work Functioning	Community Functioning	Policies and Laws
	Physical/Built Environment	Personal Environment	Household Environment School/Work Environment	Community Environment Community Resources	Societal Structure
	Sociocultural Environment	Sociodemographics Limited English Cultural Identity Response to Discrimination	Social Networks Family/Peer Norms Interpersonal Discrimination	Community Norms Local Structural Discrimination	Social Norms Societal Structural Discrimination
	Health Care System	Insurance Coverage Health Literacy Treatment Preferences	Patient-Clinician Relationship Medical Decision-Making	Availability of Services Safety Net Services	Quality of Care Health Care Policies
Health Outcomes		Individual Health	Family/ Organizational Health	Community Health	Population Health

National Institute of Minority Health and Health Disparities, 2018
 *Health Disparity Populations: Racial and Ethnic Minority Groups (defined by OMB Directive 15), People with Lower Socioeconomic Status, Underserved Rural Communities, Sexual and Gender Minority Groups, People with Disabilities
 Other Fundamental Characteristics: Sex and Gender, Disability, Geographic Region

