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Data Justice: MENA Women, Preterm Birth, and Discrimination

ABSTRACT

Maternal and infant health disparities are an important area of investigation in the field of public health. There is a lack of literature on the birth outcomes of Middle Eastern North African (MENA) women despite them being at risk of experiencing ethnic and/or religious discrimination. Furthermore, MENA women are often made 'invisible' when it comes to data collection due to the lack of an existing MENA racial category, presenting challenges when investigating health disparities that exist within this marginalized population. This concurrent mixed methods research project will utilize vital records and semi-structured interview data to investigate the adverse birth outcomes and discriminatory experiences of MENA women. Advancing knowledge on the adverse birth outcomes of MENA women will improve the current understanding of the maternal health status of this migrant population and make vital contributions to the fields of maternal health, migrant health, and health disparities.

PERSONAL STATEMENT

My own self-identification as a Middle Eastern-American has been a journey throughout my life. From a young age, I knew my identity made me different. I knew that my non-Caucasian name, dark curly hair, brown eyes, and deep olive complexion, made me unlike the other girls I interacted with daily. It wasn't so much that these were "bad" features, they just didn't mirror everyone else's. Although, I wasn't taught this distinction at a young age.

Despite the obvious physical differences and unspoken cultural divide, my classmates and I all still had to check the same box, "white". Every year when standardized test day came around I would look around, check off the box labeled "white" and let out a sigh. I felt frustrated, isolated, and confused. From the home-cooked lunches I would bring and get asked a million questions about, to the holidays I didn't get off to celebrate, society had made it very clear that I was different as if being a Middle Eastern American was something to be ashamed of. These realizations sparked the beginning of my exploration of ethnic/racial injustices and discrimination.

As a freshman at Elon University, I was introduced to the field of public health and have been intrigued ever since. Upon this introduction, I spent a significant amount of time exploring health inequities and was saddened, but not surprised, about the truths behind them: the most prominent stemming from racism. I took any chance I had to research this topic. In my freshman global seminar course and an English class, I was able to focus my final paper on health inequalities amongst communities of color. I couldn't

believe I went through my entire life not knowing about these disparities, even though I am part of a marginalized population myself. My new mission was to educate others on the knowledge I had been lacking for so long. Besides research papers, I have reflected on who I am and whom I identify as. My self-identification as a Middle Eastern American woman has shaped who I am today and is continuing to shape who I will become.

In the summer of 2021, I decided to take initiative on this passion for advocacy in relation to health inequalities and get involved in research. I reached out to Dr. Faustin and we created a plan that included me joining one of her existing projects focused on birth outcomes in foreign-born populations. I started working with Dr. Faustin this past fall and joined the Health Equity and Racism (H.E.R.) Lab – an organization committed to research, capacity building, and advocacy. Through these two experiences, my understanding of health inequities has evolved tremendously and motivated me to propose this independent research project.

The H.E.R. Lab has a team of visionary members who assist in the community-building and advocacy aspects of the lab. During my first meeting with the visionary members, I was honored to connect with Dr. Camara Phyllis Jones, who left us with this message, “Your voice is only as strong as you make it. If you wait till you have a platform, you’re never going to make a change. You are just as strong in this moment as you will be in ten years”. This has impacted me and led me to the realization that research isn’t just findings; it is what you do with them. There is no time left to wait for someone else to find results, the time is now. I plan to make my research known, and I plan to make my voice heard so that others can make theirs heard too.

PROJECT DESCRIPTION

FOCUS

Preterm birth (PTB) is one of the leading adverse health outcomes within the field of obstetrics. PTB is defined as being born prior to 37-weeks of gestation (CDC, 2021). Every year in the United States, around 380 million babies are born preterm; approximately one in every ten infants and the rate is rising (CDC, 2021). PTB can lead to various short-term complications such as respiratory distress, cardiovascular malfunctions, and long-term complications such as permanent brain injury, an increased risk of learning and development delays, and more (PTB - Symptoms and Causes, n.d.). These adverse outcomes that affect many in the U.S. are important to investigate, especially since PTB inequities have persisted for decades.

Preterm Birth Inequities

Individuals of racial and ethnic groups experience PTB at a significantly high rate. For instance, a paper published in 2017 cited that non-Hispanic Black women experience PTB at a rate two times that of white women (Manuck, 2017). Racial and ethnic disparities within the healthcare field are not new. In a study conducted in 1999, researchers examined how the effects of perceived racism during one’s everyday life impacted PTB rates. The study showed that among individuals who gave birth preterm, a statistically significant amount indicated that they felt stress due to racial discrimination (Rosenberg et al., 2002). Although previous studies like these are important, most of them study U.S.-born populations leaving limited data on the health of migrant populations.

Patterns of adverse health for migrants can vary for a number of reasons such as migration selection, duration of U.S. residence, health status upon arrival, and many others. For many immigrant populations, oftentimes arrival to the U.S. may be their first exposure to discrimination. Studies have shown that when immigrants first arrive in the U.S. their health is typically better than that of US-born individuals of the same race/ethnicity (Teitler, 2012; Teitler, Martinson, & Reichman, 2015). Yet, this is not well documented and/or well understood for MENA populations in the U.S. While it's difficult to find data on MENA populations in particular, the U.S. census recorded that between 2000 and 2010 alone, there was a 72% increase in Arabic-speaking ancestry in the United States (Arab American Demographics Factsheet, 2018). Understanding this trend is important to shed light on the effects of ethnic discrimination on the maternal health of MENA populations, a population in the U.S. that is growing.

Discrimination

A larger amount of the research on discrimination and health in the US has focused on U.S.-born populations. Immigrants also experience discrimination and are an important group to understand as well. The stress resulting from discrimination has been documented as a contributing factor that can lead to an elevated rate of PTB (Dole, 2003). Following the tragic incidents of the September 11th attacks, MENA individuals have experienced a heightened rate of discrimination and stress (Padela & Heisler, 2010). This discrimination has translated into the medical field and within obstetric care based on "noteworthy" identifiers such as origin of name, traditional or religious dress, or non-Eurocentric facial features (Lauderdale, 2006). Previous research has documented stress as a contributing factor to adverse maternal/infant health outcomes (Dole, 2003). Yet this research predominantly focuses on U.S.-born individuals, not immigrants. Furthermore, stress due to discrimination based on one's racial or ethnic identity has also been shown to negatively impact overall health (Goforth et al., 2016). Less is known about how discriminatory stress influences the health outcomes of immigrants, and even less is known for MENA immigrants. This study will aim to contribute evidence towards the fact that MENA populations being categorized within the 'white' racial category is a false representation of a people and prevents us from being able to find out how this particular population is affected by discrimination when it comes to their health.

Data Justice

Middle Eastern Erasure/Invisibility:

The identity of MENA Americans has been disregarded for decades in both small and large ways (The Erasure of Middle Eastern and North African Immigrants from the American Narrative, n.d.). Identity categorization in the United States context first began during the separation of White and Black individuals: a social construction designed by people who believed that divisions were necessary in the hierarchy of life (Historical Foundations of Race, n.d.). On the U.S. Census when marking race, there is no place to identify Middle Eastern heritage. Unless one is included in the North African region of the Middle East, most individuals settle for 'white'. This lumping with the 'white' category makes it difficult to document adverse health outcomes more accurately within this population. There is a push for the Census category among activists and organizations from the MENA community (Awad et al 2022). Additionally, testing of the MENA category in the community indicated that if the option were there most MENA folks would use it. This provides further evidence for the need to disaggregate all ethnic populations when we collect data (Maghbouleh et al., 2022).

Lack of Literature

Although PTB has been studied extensively in White versus Black populations, there is limited data on how PTB impacts MENA women living in the U.S., resulting in gaps in the literature. Compared to other BIPOC (Black, Indigenous, People of Color) populations, there are significantly fewer collective resources due to data inequity in regard to data collection for this population. Due to most MENA individuals having to identify as white on official documents, it makes it more difficult to measure the rates of adverse health outcomes for this population, even with the use of a recently developed algorithm (Abuelezam et al., 2018).

In a paper published this past year, the authors evaluated how the lack of data on this entire population takes away from the world's knowledge on health disparities. In their findings, they emphasized that the only way to fix this issue of data injustice is to call into question the politics that circle racial and ethnic categories. The lack of a relatable category on census documents and standardized forms, masks the issues facing a growing number of individuals who are a part of this population (Awad et al., 2022).

Despite all that is known, data on this increasing population is not represented in population health research. This proposed study will aim to explore the identity of MENA women: how they freely identify, how they self-identify within given boundaries, and how despite the lack of identity on forms, they can be very visible and identifiable based on “noteworthy characteristics” within the healthcare field (Lauderdale, 2006). Furthermore, it will explore the relationship between perceived discrimination and adverse maternal health outcomes.

SCHOLARLY PROCESS

The proposed research will use a concurrent mixed methods approach to conduct an analysis of ethnic discrimination and PTB inequities for MENA birthing persons living in the U.S. This relationship between discrimination and adverse maternal/infant health outcomes is well-documented in other communities of color. The objective of this study is to examine PTB inequities and provide further insight into the ways discrimination may play a role in the health of MENA women. The concurrent design will allow for the analysis of the quantitative and qualitative data to occur at the same time.

The quantitative strand will consist of analyzing birth records. The New York City vital records dataset is one of the few that collects data on country of origin and ancestry for all birthing populations. The dataset is from years 2008 - 2016 and contains over 900,000 births and include all live singleton births to MENA women ages 18 - 50. The resulting analytic dataset will be examined to estimate the prevalence and risk of preterm birth for MENA women. STATA will be employed to manage and analyze the data. These quantitative findings will provide an insight into the adverse birth outcomes of MENA women.

The qualitative strand will consist of semi-structured interviews that will explore the lived experiences of MENA American women. Participants will be asked about their experiences with perceived discrimination during their pregnancy and labor/delivery. Participants will need to be between the ages of 18 - 50, identify as MENA, and have birthed a child in the U.S. These interviews will be recorded and transcribed. I will use NVivo, a qualitative analysis software, to help organize, code, and analyze the data. Throughout the data collection process, we will review transcripts and continue data collection until saturation is reached, which will likely result in 20-25 interviews. The findings will be analyzed using the Sort, Sift, Think and Shift method (Maietta, 2006), allowing for increased familiarization with the data. These qualitative findings will provide insight into how perceived discrimination impacts the maternal health of MENA American birthing persons, an extremely understudied population.

PROPOSED PRODUCTS

Research dissemination is an essential part of the research process. I plan to share my findings in the following ways: (1) Prepare and submit an abstract to present at SURF, NCUR, and the American Public Health Association conference. (2) Prepare and submit a peer-reviewed manuscript to the Social Science and Medicine Journal, a strong fit due to the intersectionality of my proposed project. (3) Share my findings on the projects page of the Health Equity and Racism (H.E.R.) Lab website, as I am a member of the H.E.R. Lab. Disseminating this research has the potential to inform future research on MENA birthing populations.

FEASIBILITY

The insider status I have as a MENA American woman born of first-generation parents results in a deep-rooted connection to this community and gives me a cultural understanding that outside individuals don't have. Additionally, this can help create trust and build the rapport needed to effectively conduct individual interviews.

Despite my positionality, I understand that I am not an expert in this field and therefore I am also networking and connecting with experts at Elon such as, Dr. Elgamal who is my minor advisor, and Dr. Green, an incoming Elon public health studies faculty member who researches health inequities in MENA populations and has already provided some insight on this project. This will increase my capacity and understanding of my target population, which is essential for my proposed research project.

My research mentor, Dr. Faustin, is experienced with health equity research in populations that are often underrepresented in datasets and has access to NYC vital data records with a large sample size of births, including births from those of MENA origin and ancestry. Dr. Faustin will be able to provide me with the conceptual and methodological training I will need to complete this project, as she is a mixed-methods researcher who applies interdisciplinary frameworks towards her research on the impact of racial stress on maternal health outcomes.

I also plan to attend the Qualitative Research Summer Intensive held by Research talk and the Odum Institute's free STATA course to increase my skills in qualitative and quantitative methods. Additionally, my methodological approach of using zoom/skype and phone/audio options for primary data collection will increase accessibility during recruitment and data collection. Lastly, I am in the process of completing my CITI training in preparation to submit an IRB application.

My positionally, my intellectual curiosity and drive, my planned additional training and Dr. Faustin's expertise and data access make this project feasible.

BUDGET

Data Collection and Analysis Materials
- Sony ICD-UX570 Digital Voice Recorder: $72.00
- STATA license: $425.00
- Nvivo – Qualitative Software: $85.00
- Temi - Transcription Service ($0.25/minute): $300.00
- Participant Incentives ($40.00/person): $800.00

Total: $1,682.00

Professional Development
- NCUR 2023 - Eau Claire, Wisconsin
    - Registration: $100.00
    - Travel: $530.00
    - Hotel ($150.00/night): $450.00
    - Meals: $100.00
- APHA 2023 – Atlanta, GA
    - Registration (student): $247.00
    - Travel: $503.00
    - Hotel ($175.000/night): $525.000
    - Meals: $100.00
    - Membership Dues: $85.00
- Phase 1: Racial Equity Workshop Greensboro, NC
    - Registration: $375.00
    - Meals: $65.00
- Measuring Racial Equity: A Groundwater Approach- Greensboro, NC
    - Registration: $89
    - Meals: $50

Total: $3219.00

Academic Development
- Qualitative Research Summer Intensive
    - Fundamentals of Qualitative Research (July 25-26): $530
    - Conducting Qualitative Interviews (July 27): $265
    - Coding and Analyzing Qualitative Data (July 28 - 29): $530
- J-Term Abroad: $4,500
- Tuition: $9,274.00

Total: $15,099

Grand Total: $20,000.00

PROPOSED EXPERIENCES and PRODUCTS

	Experiences	Products
Summer 2022	Quantitative Strand: Literature review Qualitative Strand: Literature review Training and Development: Attend 19th Annual Qualitative Research Summer Intensive	- IRB application and approval
Fall 2022	Quantitative Strand: - Data management - Descriptive analysis - Create tables for descriptive results Qualitative Strand: - Develop interview questions - Refine Recruitment materials Training and Development: Apply to SURE	- Submitted SURE application
Winter 2023	Quantitative Strand: n/a Qualitative Strand: - Begin recruitment - Refine interview guide Training and Development: n/a	- Completed interview guide
Spring 2023	Quantitative Strand: - Comparative analysis - Create tables for comparative results Qualitative Strand: - Start conducting interviews - Begin analysis Training and Development: Apply to APHA	- Prepare APHA abstract
Summer 2023	Quantitative Strand: - Complete quant analysis - Begin drafting quant portion of results section Qualitative Strand: - Continue interviews - Continue analysis Training and Development: - Begin drafting background and	- Participate in SURE and present SURE poster presentation

	methods of manuscript - REI training	
Fall 2023	Quantitative Strand: n/a Qualitative Strand: Begin drafting qualitative portion of results section Training and Development: - Apply to NCUR - Prepare abstract and attend NCUR abstract workshop	- Attend and present at APHA
Winter 2024	Quantitative Strand: Create data visuals to be used for research dissemination page Qualitative Strand: Create data visuals to be used for research dissemination page Training and Development: Continue writing manuscript	- Begin creating the projects page for this project to be posted on HER Lab website
Spring 2024	Quantitative Strand: n/a Qualitative Strand: n/a Training and Development: - Apply to SURF - Prepare NCUR and SURF presentations - Attend SURF workshop	- Present at SURF - Present at NCUR - Complete projects page for HER Lab website - Submit manuscript to Social Science and Medicine

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