The Grand Challenge of Data in Equitably Digitizing Black Maternal Health

Equitably Digitizing Black Maternal Health

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With nearly 700 child and maternal health deaths annually, the United States is the only developed country with steadily increasing maternal mortality rates (MMR). Black birthing people are nearly three times more likely to suffer a fatality in comparison to their white counterparts, and the disparity worsens with age and education. Artificial Intelligence (AI) has been identified as a promising strategy to identify high-risk birthing people to better monitor pregnancies towards better outcomes and reduce deaths and complications. As personalized technologies and AI become more widely used in pregnancy care, it is critical that it does not exacerbate existing disparities, for example by embedding racism into the algorithm with unfair weighting. The authors reviewed the current state of toolkits and digital technologies tailored to Black birthing people and found a low prevalence of AI created specifically with Black birthing people and their experiences in mind. This position paper presents three calls to action to aid in equitably digitizing maternal healthcare to reverse the trend of MMM in Black birthing people globally.

CCS CONCEPTS • Artificial Intelligence • Health Equity • Digital Technology • Maternal Health • Black/African American • Maternal Mortality • Digitization

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1. Motivation

While the maternal mortality ratios (MMR) have been declining globally over the past two decades, the United States remains the only industrialized country with rising MMR resulting in over 700 deaths per year [1]. Black birthing people experience nearly three times the rate of maternal mortality (41 deaths per 100,000 live births) compared to white women (13 deaths per 100,000 live births), and the rates only increase as they become more educated and grow older (four times more likely over the age of 30 and five times more likely with a college degree) [2].

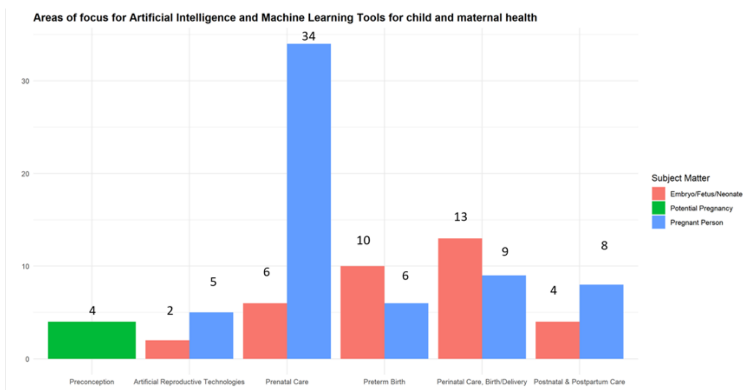
There is an increasing focus on the digitization of healthcare delivery for personalized and connected health, however further work is needed on tailoring and centering these personalized tools to specific cultural groups. Without equitable development, the underlying algorithms of these tools have been found to result in widening disparities [3].

The implementation of equitable, personalized health tools and Artificial Intelligence (AI) hold promising potential to close the gap in maternal health disparity through the creation of algorithms and analytics to improve outcome monitoring and care delivery at every stage of the maternal journey. AI has been used to build prediction models to improve risk and comorbidity monitoring during pregnancy as well as access to and frequency of routine pre- and post-natal care [4].

This work evaluates the current state of existing AI tools to assess the gaps in information delivery tailored specifically to Black birthing people. The authors give recommendations for improved data collection and algorithm considerations towards more culturally tailored tools.

2. Survey of Artificial Intelligence tools

To assemble a representative dataset of the artificial intelligence tools available to Black birthing people, we surveyed PubMed to identify systematic reviews published in the last three years using the Boolean search terms ("Pregnant" OR "Pregnancy") AND ("Artificial Intelligence" OR "Machine Learning" OR "Data Science"). Our search yielded 102 technologies designed for pregnancy described in **Figure 1.**



. Figure 1. Adapted from Davidson and Boland (2021) this figure illustrates the points of care where AI and ML have been applied at each stage of pregnancy (preconception, artificial reproductive technologies, prenatal care, preterm birth, perinatal care, birth/delivery, postnatal & postpartum care). We also include the distribution of studies by pregnancy phase to illustrate the stages of pregnancy with the most number for easy identification of gaps in the tools available.

The articles included in the review are detailed in the appendix. In the process of completing our search, we identified three observations consistent with other literature on the Black maternal health crisis [5]. (1) When searching for Black maternal health technologies on academic databases, there is a lack of pre-established keywords to find tools specifically for Black birthing people. The inclusion of ((“African Continental Ancestry Group” OR “Black” OR “African American”) in our search strategy dramatically reduced the number of articles available on PubMed including articles that described useful tools for Black pregnant people. (2) Our search included studies from multiple countries where the concept of race differs from the United States. We encourage researchers who are doing work focused in the United States to include a population representative of the national population. In studies that reported race, the representation of Black birthing people was equal to or greater than the representation for the general population. This needs to be the gold standard of personalizing AI for birthing people. (3) AI tools primarily focused on improving the quality of prenatal care by predicting the risk of adverse outcomes for the pregnant person.

3. Prescription

The conversation around personalized health and AI for cultural minorities often focuses on the effects of racism and widening disparities. We encourage an expanded focus to include the positive potential of personal informatics and AI when tailored to the cultural needs of Black birthing people. Improved data collection and culturally sensitive tools can lead to early detection of potential adverse outcomes significantly decreasing the chance of mortality. Many of the tools are targeted to the provider, but the birthing person will benefit from tools they can personalize to their desires. We therefore prescribe three calls to action for the AI community based on our observations: (1) transparent and easily accessible reporting of racial representation in the datasets used to develop AI tools, (2) the establishment and inclusion of standardized race-related key terms for easier identification of tools relevant to Black pregnant people, and (3) the expansion of AI tools to include the full breadth of pregnancy with particular attention to phases before and after prenatal care.

Our initial finding that the inclusion of race-related terms eliminated a significant number of results is indicative of the significant lack of data transparency for Black mothers in tools that affect them at every stage of pregnancy; particularly prenatal care, where indications of life-threatening complications are mostly likely to arise. Therefore, a major component in addressing the maternal health crisis is ensuring transparent and easily located demographic data in datasets, and accessibility of tools by Black mothers once developed for when they need it most. We argue that this transparency can be achieved by urging authors of datasets and tools to include culturally appropriate keywords indicative of the composition of the datasets used for development.

We encourage AI tool developers to not only continue reporting racial demographics, but more importantly utilize datasets with equal representation for all races to design AI tools for pregnancy. We believe the studies that did not report race could benefit from transparently reporting the racial representation. In doing so, authors allow Black birthing people to assess the applicability of the tool. This not only eases the process of finding relevant information but also has the potential to build confidence and trustworthiness within the Black community. Therefore, moving forward, we ask all authors of AI tools to include a racial breakdown of the dataset used to design their tool.

Most of the AI tools surveyed focused on the prenatal period, but the tools developed should adequately represent each stage of pregnancy from preconception to the first year of infancy. Black birthing people are more likely to have lower success with IVF and fertilization and can benefit from tools during this stage.

To develop the culturally tailored, personalized tools Black Mothers need, it is important to collect and structure data that promotes understanding of the increased risks and care needs specifically for Black women's needs, at all phases of maternal health care, and how those would translate through digitization.

4. Conclusion

Increased risk for maternal mortality and morbidity is well-defined for Black birthing people. The authors call for three advancements in AI tools that will enable Black birthing people to get more personalized insights and the right resources in accessible and usable ways. Personal Health Informatics and AI researchers should dedicate research and data practices towards the racial pregnancy disparity and provide Black birthing people with inclusive tools needed at every stage to ensure a healthy pregnancy and successful birth of their children.

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A APPENDICES

A.1 References from systematic review of AI tools used in maternal care

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