

VIEWPOINT

Improving Maternal Outcomes in Congenital Heart Disease



A National Call to Action

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The concerning surge in the U.S. maternal mortality rates has underscored the urgent need to improve maternal health. Between 2019 and 2021, maternal mortality rates increased from 20.1 to 32.9 deaths per 100,000 live births. Non-Hispanic Black pregnant individuals experienced more than double the risk of mortality during pregnancy compared to their White counterparts.¹ However, an estimated 84% of pregnancy-related deaths could have been prevented through improved maternal care.²

Mental health conditions emerge as the leading underlying cause of pregnancy-related deaths, significantly impacting Hispanic and White expectant individuals across 36 U.S. states from 2017 to 2019.² Cardiac conditions rank as the third leading cause of maternal mortality overall and particularly affecting Hispanic, Asian, and White individuals. However, among non-Hispanic Black individuals, cardiac conditions emerge as the primary underlying cause of maternal mortality.²

During the 1950s only about 15% of children with CHD survived until adulthood. Due to medical advancements, in 2010 approximately 1.4 million adults estimated to have CHD in the United States, resulting in a growing proportion of individuals with CHD who have reached childbearing age.³ This demographic shift underscores the importance of

addressing the unique health care needs and considerations of individuals with CHD during pregnancy and childbirth. Recent studies have shown the importance of improving mental health services during pregnancy and postnatally as a priority area for improved care for pregnant individuals with CHD.^{4,5} This emphasizes the importance of addressing both the physical and psychological aspects of maternal health.

Pregnant individuals with CHD face heightened risks of complications such as heart failure and arrhythmias, and some experience elevated mortality rates during pregnancy. Diverse cardiac anatomies and varying structural complexities inherent in CHD pose challenges in assessing maternal risk. Nonetheless, individuals with CHD can safely navigate pregnancy with careful risk stratification and comprehensive care plans facilitated by multidisciplinary teams trained in specialized care.⁶ When evaluating risk, providers must consider factors such as the type and repair status of the heart defect, the individual's overall health, disease progression, and access to specialized medical facilities.

While individuals with CHD experience an eight-fold increase in pregnancy complications compared to the general population, there has been limited research on both patient and provider priorities aimed at improving maternal outcomes within this expanding demographic. Incorporating the perspectives and needs of the CHD community is vital for mitigating the risks associated with pregnancy and enhancing overall maternal health outcomes.

INSIGHTS FROM THE COMMUNITY

Prior research has demonstrated that collaborating with patients during the early phase of project

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planning often leads to research priorities that closely align with what matters most to them.⁷

We embarked on an effort to define and prioritize strategies aimed at developing a roadmap for enhancing maternal care for individuals with CHD. To tackle this work, a diverse consortium was formed in 2022 comprising more than 90 adult patients, health care providers, researchers, health care administrators, and patient advocates. Through electronic surveys, breakout sessions, and focus groups, the coalition actively engaged with the broader CHD community to pinpoint key priorities for improving care for pregnant patients with CHD.

To ensure trust within the patient community that their voice was systematically incorporated into our analysis, we utilized qualitative thematic analysis techniques along with semiquantitative and quantitative methods.

Five main priority areas for improved maternal care emerged from this effort as voiced by patients with CHD, health care providers, researchers, and advocates: 1) improved communication between patients and providers to facilitate better understanding and shared decision-making; 2) enhanced care coordination among diverse health care teams to deliver comprehensive and integrated care; 3) expanded access to specialized health care services tailored to the unique requirements of patients with CHD; 4) increased education and awareness initiatives targeting both patients and providers to foster a deeper understanding of CHD management and treatment options; and 5) strengthened risk stratification and preconception counseling to empower informed decision-making concerning pregnancy and childbirth.

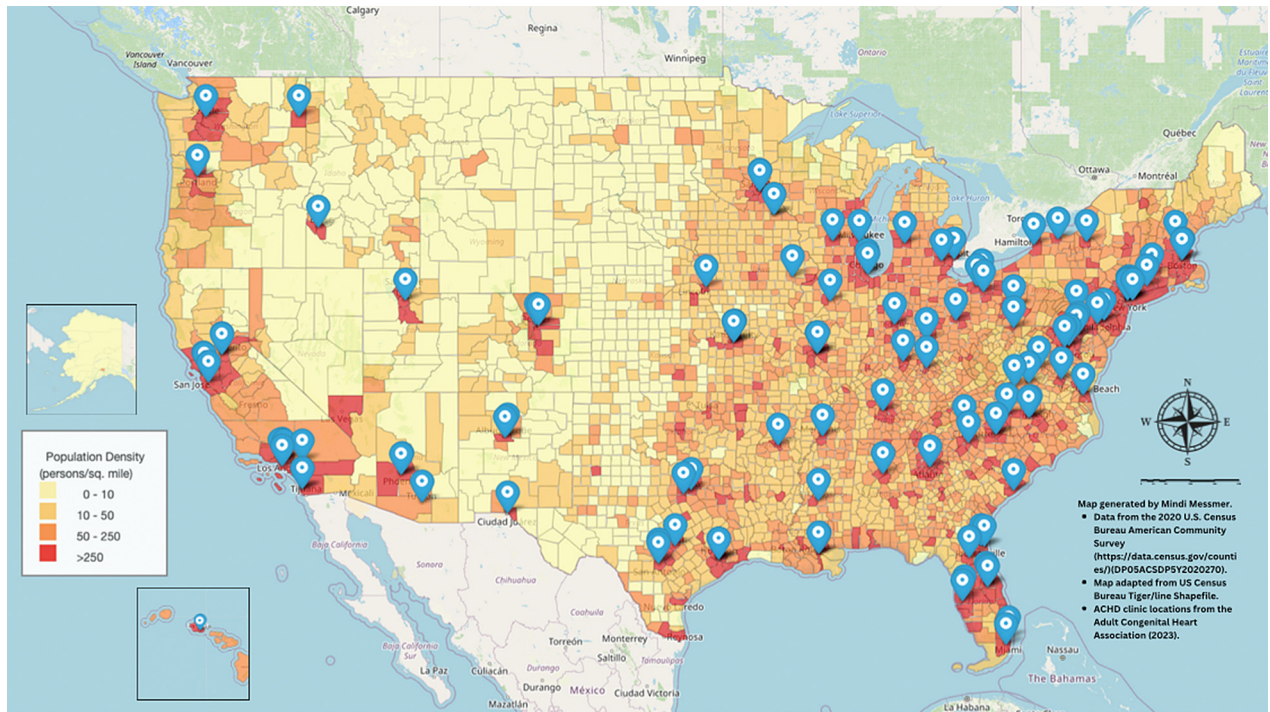
IMPROVED COMMUNICATION BETWEEN PROVIDERS AND PATIENTS. Both patients and providers highlighted the necessity for enhanced communication among patients and providers, among different health care professionals, and with the broader patient community to foster trust. Breakout session participants cited the need to improve engagement with communities to provide improved clinical care especially for marginalized and racially diverse groups to build trust in health care providers and the health care system. An example underscoring the need for enhanced communication is evident in our findings: despite the heightened risk associated with pregnancy for individuals with CHD, our survey revealed that only slightly more than half of patients reported receiving contraception counseling from their physicians.

IMPROVED CARE COORDINATION. Given challenges to accessing specialized care and the escalating maternal mortality rates, particularly among underserved populations, emphasize the pressing need to overcome siloed health care teams to provide comprehensive cardio-obstetrics care. The community emphasizes the necessity for well-coordinated teams, supported by comprehensive written management plans, as crucial elements to improve outcomes for pregnant patients with CHD. A patient-centric disease-specific plan is multifaceted and includes preconception counseling, assessment of maternal and fetal risks of pregnancy, review of medications and anticoagulation strategies, intrapartum monitoring, plan for anesthesia, delivery, and postpartum care. Successful implementation requires a coordinated, multidisciplinary health care team effort between adult congenital heart disease (ACHD) cardiologists, maternal-fetal medicine specialists, and obstetric anesthesiologists.

IMPROVED ACCESS TO SPECIALIZED CARE. Access limitations can exacerbate stress for those choosing to proceed with a pregnancy experience due to the complex factors associated with their diagnosis, both before and during pregnancy, and postpartum. Patients have reported that lack of access to specialized reproductive health care intensifies stress during decision-making processes. This is particularly troubling considering that approximately 30% to 40% of patients with CHD surveyed report mental health diagnoses. Access limitations likely contribute to a loss of critical care follow-up particularly during the high-risk postdelivery 1-year period. According to the Adult Congenital Heart Association, there are 120 ACHD clinics in the United States, all of which are in or near urban areas (Figure 1). The concentration of these clinics in urban areas creates health care deserts and disparities in access to specialized pregnancy-related care for individuals with CHD. Approximately 54% of the U.S. population lives within a 1-hour drive catchment and 40% live within an estimated 1-to-4-hour drive to 56 of the mid- and high-volume ACHD clinics in the continental United States.⁸

Additionally, financial constraints and gaps in insurance coverage can exacerbate stress especially when additional tests are required for informed decision-making regarding pregnancy. Barriers to care are likely to be exacerbated among individuals of lower socioeconomic status and educational attainment.

FIGURE 1 Population Density and Locations of Adult Congenital Heart Disease Clinic Locations in the United States Supplied by the Adult Congenital Heart Disease Association



Population density of U.S. counties obtained from the U.S. Census Bureau American Community Survey for 2020. Adult Congenital Heart Disease Association clinic locations as of 2023 are indicated by blue location markers (n = 120). ACHD = adult congenital heart disease.

Patients and providers underscore that individuals with CHD would greatly benefit from prenatal psychotherapeutic intervention. Such interventions could effectively reduce stress and equip patients with coping mechanisms to address concerns about their own and their baby's future. However, patients have reported that financial constraints pose a significant barrier, making access to necessary care unattainable for many, even for those with some level of insurance coverage. Moreover, the national shortage of specialized health care providers, including mental health care professionals, coupled with limited access to specialized cardiac care centers, further exacerbates disparities in prenatal, natal, and postpartum care for patients with CHD.⁸

IMPROVED PATIENT AND PROVIDER EDUCATION.

Our research highlights the need for health care professional education to focus on providing general guidelines or recommendations for care, such

as contraceptive options for people with CHD and medication classes to recommend or avoid during pregnancy. Patients express concerns about potential genetic transmission of their condition to their offspring, and maternal health risks during pregnancy. In addition, they may grapple with their risk tolerance, trying to navigate decisions about treatment options and lifestyle choices. Addressing these concerns through comprehensive education and support is essential for individuals with CHD navigating pregnancy-related decisions.

There are notable knowledge gaps in the transition of care, particularly during the crucial period for discussions about contraception and counseling on pregnancy risks. With less than 500 board-certified ACHD cardiologists in the United States, there is a significant shortage of these specialists.

Patients consistently emphasized the importance of health care professionals being trained in emotional intelligence and sensitivity when

addressing CHD and reproductive health. As 1 health care professional noted responsibilities like managing contraception might fall outside their usual scope:

“I would not be typically managing or prescribing contraception in vascular or preventative cardiology clinics.”

This highlights the importance of appropriate training and collaboration among health care providers to address the unique needs of patients with CHD.

The significance of this issue is further emphasized by the fact that 83% of individuals with CHD aged 18 to 45 years attending an ACHD clinic in the United States reported being sexually active and 45% reported having an unintended pregnancy. When they were asked about contraception use, 36% used a tier I contraception method and 24% did not use any contraception at all.⁹

IMPROVED RISK STRATIFICATION AND PRECONCEPTION COUNSELING. During pregnancy, the frequency and type of cardiovascular follow-up for patients with CHD depend on underlying conditions and their severity.¹⁰ Access to specialized heart care is key to risk stratification, identifying how to mitigate risk before conception and how to effectively recommend contraception if pregnancy is prohibitive. Given challenges in access to care, improving communication between different team members—especially if they are located within different institutions with different electronic medical records—is of

critical importance in improving care and outcomes during preconception, intrapartum, delivery, and postpartum.

FUTURE DIRECTIONS

Our collaborative efforts centered on setting short-, medium-, and long-term priorities spanning 1, 3, and 5 years to improve care and reduce maternal mortality for pregnant individuals with CHD. These priorities revolve around 4 core areas: education, research, clinical care, addressing disparities, and mental health. We anticipate synthesizing and finalizing our collective efforts culminating in a roadmap for improved care for pregnant individuals with CHD in the third quarter of 2024. We hope that the consortium’s efforts will drive impactful change that leads to improved maternal outcomes that may also extend beyond the CHD community.

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