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 The Harkin Institute

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STILLBIRTH IN THE U.S REPORT

The Link Between Stillbirth & Maternal Mortality and Morbidity: Firsthand Accounts from American Women



CountTheKicks.org

Overview

America is seen as a leading developed country in almost all aspects, including our medical and technology sectors. Billions of dollars are spent each year on health care innovation; yet the rate of maternal morbidity is higher than other well-resourced developed countries¹ and stillbirth rates remain high compared to other developed countries.²

Some attention and effort is given to researching stillbirth trends and identifying strategies to change the stagnant reduction in stillbirth rates; however, less research and attention is given to maternal outcomes for expectant parents who experience a stillbirth.

According to one study, **more than 15% of maternal deaths within 42 days of delivery occur in women who experienced a stillbirth.**^{3,4,5}

This isn't surprising when examining the risk factors associated with stillbirth, the demographics of women who experience the highest rates of stillbirth, and the current approaches to preventing and treating expectant parents who experience or are at risk of experiencing stillbirth.

— **Author:**

Dr. Lyndi Buckingham-Schutt

— **Design & Layout**

Anh Nguyen

The Problem

Change in Fetal Movements: A red flag for stillbirth and adverse maternal outcomes

Women most at risk for severe maternal outcomes may also be at higher risk for stillbirth based on pre-existing or demographic characteristics and conditions related to their stillbirth. This includes: racism, parity (number of previous pregnancies), advanced maternal age, pre-existing diabetes and hypertension, gestational diabetes, preeclampsia, lack of private insurance, and less than a college education.^{6,7,8,9,10}

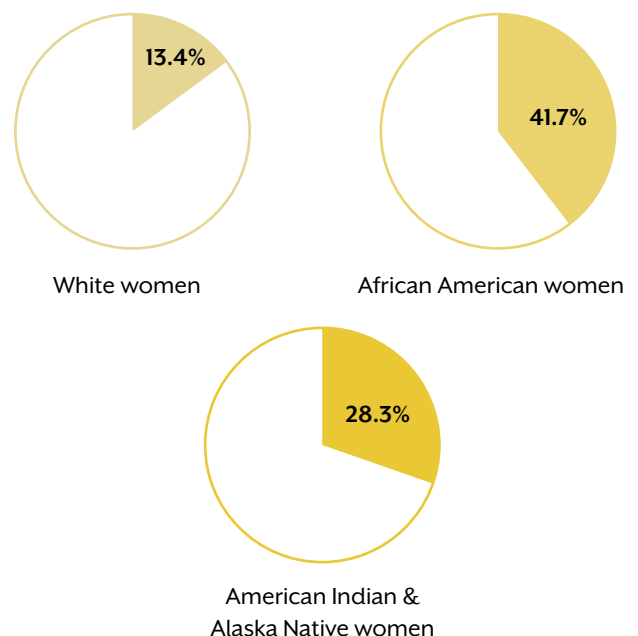
“Racial discrimination is a significant risk factor for adverse birth outcomes.”³⁶

According to the CDC, White women make up 13.4% of deaths due to pregnancy-related causes. African American women make up 41.7% of pregnancy-related deaths, which is similar to that of women in developing countries. American Indian and Alaska Native women follow at 28.3% of pregnancy-related deaths. Implicit bias is an immediate and large part of this systemic issue - and we must take immediate action to counteract it.³⁹

Factors such as advanced maternal age ≥ 35 years,^{11,12,13} parity,^{14,8,15,6,16} gestational age at birth,¹³ and nutrition and lifestyle factors (obesity, smoking, pre-existing maternal diabetes or hypertension^{8,10}) are all associated with increased risk of stillbirth and adverse pregnancy outcomes. Some of these factors

are modifiable, providing an opportunity to educate and increase awareness of stillbirth risk and methods of possible prevention among expectant people with these risk factors.

PREGNANCY-RELATED MORTALITY RATIO
BY RACE/ETHNICITY
2014 - 2017



When examining non-modifiable characteristics such as race, the trends are alarming -- specifically among people from racial and ethnic minority groups that are already at higher risk of poor maternal outcomes. Overall, stillbirth rates among Black women in America are more than twice that of White women.¹⁷ Rates of stillbirth attributed to conditions unrelated to pregnancy, as well as maternal complications of pregnancy, were significantly higher among Black mothers compared to White mothers (**1.4 versus 0.4; 1.8 versus 0.6, respectively**). This is important when you consider not only fetal outcomes, but also outcomes for the mother and the risk factors that put women of color at greater risk for adverse pregnancy outcomes, including: structural and systemic racism and discrimination; social and economic factors; genetic conditions; and access to care and health insurance coverage.¹⁸

It is clear that there are conditions and additional characteristics that put expectant people at higher risk of experiencing a stillbirth. These factors not only put the fetus at risk, but also have significant impacts on maternal health as well. One large population-based cross-sectional study found the risk of severe maternal morbidityⁱ was **more than four times** higher among stillbirth deliveries compared with live births. In particular, the prevalence of major organ dysfunction or failure and hysterectomy were substantially higher among stillbirth deliveries.⁷ These findings are consistent with other literature that show hypertensive disorders and placental conditions (including previaⁱⁱ and accreteⁱⁱⁱ) had the highest prevalence of severe maternal morbidity.^{6,38}

One study that looked at data provided by the World Health Organization found that across countries, stillbirth and maternal mortalityⁱⁱⁱⁱ rates are strongly correlated, with about 5 stillbirths for each maternal death.^{37,38}

As mentioned previously, it is also important to note that maternal risk factors, whether acutely related to pregnancy or pre-existing, put certain expectant parents at higher risk for stillbirth and adverse pregnancy outcomes. Although special attention should be paid to specific populations, there is an overall need to identify ways to educate expectant parents about potential methods to prevent stillbirth and ensure the best outcomes for mom and baby. This includes:

- early intervention to improve outcomes for mom and baby;
- increasing awareness of factors that put expectant parents at risk for stillbirth and poor fetal and maternal outcomes;
- educating expectant parents on the importance of healthy behaviors such as fetal movement monitoring during pregnancy; and
- empowering expectant parents to seek out care when they are concerned.

Providers also play an important role in prevention and ensuring best outcomes, including:

- listening to expectant parents when they speak up;
- properly investigating concerns;
- educating expectant parents on the importance of fetal movement monitoring; and
- implementing a protocol in their practice or birthing hospital related to reduced fetal movement.

ⁱ Maternal morbidity describes any short- or long-term health problems that result from being pregnant and giving birth.

ⁱⁱ Placenta previa is a problem of pregnancy in which the placenta grows in the lowest part of the womb (uterus) and covers all or part of the opening to the cervix.

ⁱⁱⁱ Placenta accrete is a serious pregnancy condition that occurs when the placenta grows too deeply into the uterine wall.

ⁱⁱⁱⁱ Maternal mortality refers to the death of a woman from complications of pregnancy or childbirth that occur during the pregnancy or within the first year after birth.

One solution

Count the Kicks: How an app can help save the life of mom and baby

It is clear that stillbirth remains a significant public health crisis in the United States. Approximately 23,500 babies are stillborn in the United States each year.¹⁹ Identifying and providing appropriate interventions for pregnant people is critical to potentially improving the outcomes for their babies and also for themselves. Fetal movement monitoring is one evidence-based intervention that may lead to better outcomes.

23,500/year.
BABIES ARE STILLBORN IN THE U.S.

Research suggests that almost half of all pregnant women report being concerned about fetal movement change during pregnancy.²⁰ Although this would suggest it is a common concern, a similar percentage of women report they never received information about fetal movement monitoring from their healthcare provider.²¹

Of even more concern, women who have experienced a stillbirth report they were not told about the importance of fetal movement tracking, and as a result, were less likely to obtain prenatal health services that may have led to intervention.²² A growing body of evidence supports the use of fetal movement monitoring to improve perinatal outcomes, including stillbirth, by improving access to health information,^{23,24,25,26} increasing awareness of pregnancy-related risk factors, and empowering expectant parents to seek help from their healthcare provider.^{23,27} One such powerful and easily accessible tool is the *Count the Kicks* app.

Count the Kicks (CTK) is a free smart device app that was created in response to the research on fetal movement tracking and stillbirth outcomes. The app helps expectant parents track fetal movements using a mobile phone app. Although the effects of the app on fetal and maternal outcomes are still being studied, there is evidence that shows the app increases knowledge about fetal movements, reduces anxiety, and influences their interaction with health care providers, including the need for prompt reporting of a change in fetal movement and timely interventions to prevent stillbirth.^{28,29} Use of a fetal tracking app is essential considering that many expectant parents report they receive inadequate information about fetal movement from their care providers.^{20,30}

There is good reason to encourage use of the CTK app among those at higher risk of stillbirth and adverse perinatal outcomes, specifically related to the literature that shows certain conditions and characteristics are associated with higher prevalence of poor outcomes.

Self-submitted birth stories from expectant parents that used CTK provide context to research linking a change in fetal movement to adverse perinatal outcomes such as hemorrhage, emergency delivery, umbilical cord complications, placental dysfunction, low birth weight and fetal growth restriction.^{31,32,33} The next section includes selected stories from expectant parents that used CTK during their pregnancy, experienced an adverse perinatal outcome related to a significant change in fetal movement, and their reflection of what the use of the fetal movement tracking app meant for them and their baby.

For some expectant parents, using the CTK app was empowering, increasing their understanding of adverse pregnancy experiences, increasing awareness, and empowering them to seek immediate care.²³ Multiple expectant parents that used CTK report the information provided in the app and baby save stories shared on the app gave them the push necessary to *seek out care and in turn, save their life and their baby's life.*



was extremely tight. At the same time the doc was assessing me and said my placenta was on the verge of abruption. *My doctor told me he was proud of me and said, 'you did what you are supposed to do. You listened to your body, came in when you were nervous and because of that you are alive and your baby is alive. It could have been a completely different story had you waited.'*”

“Unbeknownst to me, I had developed severe preeclampsia in just a matter of days and the symptoms I was feeling had nothing to do with a cold or general pregnancy discomfort, but rather with a much more serious condition that had suddenly started to compromise both my health and the health of the baby. After only 2 hours of monitoring my blood pressure at the hospital, the doctors determined that the baby needed to be delivered right away, and 45 minutes later he arrived via emergency C-section. My sky high blood pressure and failing liver and kidney function would not have supported his vitals much longer. *Thank God for this app and for the bravery of all of the women who shared their stories so generously. Had it not been for that, I don't even want to think about what might have happened.*”



“One day I noticed our son was not moving as much as he normally did. I called my doctor and they told me to go to the hospital for tests. After the tests, the doctor came in and said something is not right – we need to get him out. Within 25 minutes, I delivered our son. As soon as they got him out I heard the doctor say – ‘oh wow that’s tight.’ [My son] had the cord wrapped around him 3 times, and I guess it

“... I was 37 weeks and a few days, I noticed a very significant decrease in [my daughter’s] movements which brought a great amount of anxiety and concern for me. I called my OB and she had me come in for monitoring and get a NST. ***I still had not felt any movement and I very clearly voiced my concern and I knew something was very off about her movements due to my consistent tracking with the Count the Kicks app. I ended up being induced that day after my NST since she hadn’t kicked and didn’t pass the non-stress test.*** When we started the induction process we noticed some concerns with the baby’s heart rate in line with the intensity of my contractions; every time I contracted her heart rate dipped a significant amount which worried the OB, nurses and myself. The baby was extremely stressed with my contractions and I wasn’t progressing with my dilation, which resulted in an emergency C-section. Had I not been able to monitor my kicks with the app, even my OB said could have been dangerous for the baby and myself. After I delivered and went home I was told my placenta had also had an infection which could have been deadly for [my daughter] and myself, so I endlessly thank the team that helped me deliver, my OB for acknowledging my concerns and doing what was best for my baby and myself and most importantly the app, it saved [my daughter’s] life as we don’t know what could have happened had I not seen the significant decrease in her movements and had her delivered that very day.”

Several expectant parents share that use of the CTK app gave them the push to go to the hospital for immediate care. Identifying a concern related to a significant change in fetal movement is not uncommon among pregnant women^{20,31}; however, research suggests that mixed messaging and lack of awareness of potential complications (fetal or maternal) may keep women from seeking care in a timely manner.^{34,35} The CTK app provides a platform for expectant parents to track normal movement patterns for their baby and

consistent messaging to expectant people that are experiencing a significant change in fetal movement. The app encourages expectant parents to contact their healthcare provider and seek out care if their baby’s movement is irregular.

“I got there [hospital] and they took a urine sample right away. I had protein and blood in my urine with a really high blood pressure. They monitored the baby for about an hour and had me drink cold water. She still wasn’t moving, although she had a strong heartbeat. They did an ultrasound and said baby was not responding and I had low fluid. My doctor called me 10 minutes later and let me know I had developed preeclampsia, my liver was shutting down, and the only cure was to deliver. He informed me that I was not dilated and with my high blood pressure and baby not moving we wouldn’t be able to handle the labor process. So he ordered a C-section. I was very scared what would happen and wanted my little girl to be healthy! I’m extremely happy that I followed my mommy instinct and went in. It not only saved my baby girl’s life, but also mine!”

“I’m extremely happy that I followed my mommy instinct and went in. It not only saved my baby girl’s life, but also mine!”



“On the day I turned 38 weeks pregnant, I woke up feeling ‘off.’ I couldn’t put my finger on it, but just didn’t feel well. I chalked it up to being very pregnant in the summer and went about my day. I had a prenatal massage scheduled that afternoon, and at the end of what should have been a relaxing time, it hit me that I hadn’t felt the baby move the entire time. I went home, had a sugary snack, and sat down to count. ***It took me 50 minutes to reach 10 kicks, which I knew was different than my normal thanks to the app.*** I still thought I was probably making too big of a deal out of it, but my husband encouraged me to call my midwives to get their input. When I let her know about the change in his movement, the midwife on call told me to head in to triage immediately for monitoring. ***At triage, we discovered that my blood pressure (which had been totally normal up to this point) was sky high, and it worsened over the next 2 hours. I was induced immediately, and the next afternoon gave birth to our healthy, perfect baby boy.***”

Improving awareness of a significant change in fetal movement and seeking care for a concern

about a significant change in fetal movement are essential elements of the app and may result in emergency intervention. Immediate intervention is not always necessary but in critical situations and under specific conditions, emergency action improves maternal and fetal outcomes.

“That night I did my kick count and could not get the babies to move much. I drank cold water, I moved around, I even tried some caffeine to try to get them to move. I decided that I was not going to sleep at all that night. I stayed up and kept trying over and over to get my kick count up. At 3 a.m. I could not take it anymore and we rushed to the hospital. When we got there we went directly to the OB area and they took me back immediately. When they tried to locate the heart rates they could not get either one of them to read over 60. ***They started prepping me for immediate emergency surgery again.*** They flipped me to my side and for some reason I decided to lift my stomach to relieve some pressure I felt. Instantly the heart rates jumped into the 120s. ***When we got back to the OR they were able to keep both babies’ heart rates stable***”

When they did the Cesarean they found that baby A had the cord wrapped around her neck. Baby B had a bad infection in the amniotic sac. The placenta had fused and also was beginning to clot again (the same thing that happened with my son). If I had not used *Count the Kicks* and stayed up that night I would have lost my twins as well.”

“Recognizing decreased fetal movement was certainly a part of the medical decision to intervene and deliver [my daughter] early, at 36 weeks, 2 days. I was diagnosed with mild preeclampsia nearly two weeks prior and had started to record kick counts. After a failed attempt to turn the baby out of the breech position, a recorded heart rate deceleration and poor fetal heart rate variability on NST after the procedure alerted me to the need to monitor her movement more closely. I had previously clocked her movements as about 10 in 10-15 minutes and had not really had any concerns prior to week 34. Just before the external cephalic version attempt, however, I noticed she seemed to take closer to 20 minutes to get to 10 movements. ***And after the version, using the Count the Kicks App daily, I objectively was able to record that she started to take nearly 30 or even 45 minutes to reach that.*** At my follow-up appointment, two days after the version attempt, [my daughter] did have a reassuring NST, but after I mentioned the decreased movement in combination with my increased blood pressure, I was upgraded to preeclampsia with severe features and my medical team and I decided it best to have a C-section that afternoon just to be safe. As it turned out, it was good we did! Even though her non-stress test had looked OK, her decreased movements were a harbinger of fetal distress. She was found to have a tight nuchal cord x2, which was preventing her from turning out of breech lie and would have likely led to fetal distress had we delayed the delivery much longer. Additionally, my placenta had to be removed in several pieces as it was so calcified; this also would have likely contributed to worsening fetal hypoxia had I

remained pregnant for even just a few more days. As it was, her APGARs were six and eight; just barely avoiding a NICU stay, [my daughter] is now home and doing well. ***Using the Count the Kicks App was definitely a good choice. The App was an important part of my final days of pregnancy and contributed to the overall picture of needing to deliver her early for both her health and mine.”***



"At my 28 week appointment, I was told about the *Count the Kicks* program. ... By the following Monday, I noticed he wasn't moving much. I thought he was just being stubborn and sleepy. A few days later, on that Wednesday morning, my motherly instincts told me something wasn't right. ***I remembered the Count the Kicks advice I was told about exactly a week before. I called my doctor and was told to come in.*** There was no fetal movement on the ultrasound, and a very, very faint heartbeat. Within minutes, doctors literally ran me in for an emergency C-section. ***I can't thank you enough for this program. The doctors told us if I had waited another few hours, both my son and I would not be here to share our story.*** We found out that I had Factor V Leiden after [my son] was born. [My son] is also a carrier. A blood clot in my placenta caused [my son] to be born prematurely. ***This unknown clot condition put the both of us at risk for severe complications during pregnancy, including death.*** [My son] also had a blood clot at birth, and I ended up with a Deep vein thrombosis (DVT) 4 weeks after he was born."

"I am passionate about sharing *Count the Kicks* because it empowers mothers to speak up about concerns they have regarding their baby's health and because it is a positive tool used to both address and reduce stillbirth outcomes. I believe if I had more knowledge about my movement my stillborn son may have survived pregnancy. It is because of him that I continue to share *Count the Kicks* message. While he was born at 28 weeks, I did express concern about his movements early on and was never given definitive information, or any really, about movement. It was never really addressed. And because of his death, I very nearly lost my life due to a hemorrhage while having my placenta surgically removed."

These stories represent a small percentage of women that have experienced adverse outcomes related to their pregnancy and significant change in fetal movement. They provide an important opportunity to contextualize the data on the association between adverse perinatal outcomes and a change in fetal movement and the benefits of Interventions such as CTK. Although the research on kick counting is ongoing, CTK is supported by a number of providers and health experts.



"There is no doubt that *Count the Kicks* was critically important in reducing the stillbirth rate here in Iowa and I am sure it's going to do the same across the country and around the world."

–Dr. Neil Mandsager, Medical Director, MercyOne Perinatal Center

Conclusion

More research, resources, and education need to be invested in addressing the risk factors associated with stillbirth, care and interventions for women who experience the highest rates of stillbirth, and the current approaches to preventing and treating expectant parents who experience or are at risk of experiencing stillbirth. CTK is an example of an intervention that is addressing these needs and is well-received by expectant parents and providers alike. It is imperative that providers are proactively discussing stillbirth prevention (or risk factors) with their patients and providing evidence-based solutions like *Count the Kicks* to every patient they work with. Building awareness of the problem and directing patients, providers, and the public to a solution is one giant step towards preventing stillbirth and maternal morbidity and mortality so we can improve birth outcomes for parents and babies.

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