MATERNITY -2 HOUR

In 1 page, contrast the Infant Death Summary with the Family Interview #1638

1. What components are conflicting?
2. What is the overwhelming conclusion of the mother?
3. What information can you see might have created the disparity?

Case Summary EC1638: Infant Death

Cause of Death: Pulseless electrical activity **Death Year:** 2020

Background: Mother is a 35-year-old, married, African American in her third pregnancy. She had a set of twins in 2007 with one being a stillborn and had another baby in 2009. The twin pregnancy was complicated by preeclampsia, she reported no complications in 2009. Both were c-section deliveries. She is insured through Medicaid. She has an associate degree and is employed full time. She was arrested in 2017 for driving under a suspected license (suspended due to speeding). She is married to the father of the baby; he is a 29-year-old African American. There was no further history provided.

In 2016 the mother was involved with DCF due to inadequate supervision, that investigation was closed with no indicators. The children were removed in 2010 in another county due to a verified physical injury allegation on her daughter with the mother as the alleged perpetrator. There was another report prior to the removal in 2010 alleging inadequate supervision but it was closed with no indicators.

Mother's story was first told in Case Summary EC1595. This was a twin pregnancy where one passed away shortly after delivery in 2019 (EC1595) and the other one lived several months, into the new year.

Prenatal and Medical Summary:

At 14w2d, mother had an ultrasound visit, this was her first documented prenatal encounter. She was confirmed to be pregnant with a twin gestation. Due to historical concerns, the OB ordered an early glucose test, thrombocytopenia [abnormally low levels of platelets] workup, and an MFM referral. She was to return to be seen in two weeks.

Mother called the OB office at 15w6d, asking about "how long can I lay in certain positions?". She was advised to lay on left side and move around every 2 hours unless sleeping and to get support hose. Mother verbally agreed. She had a harmony test done at 16w5d.

At 17w1d, her OB visit was classified as a "new OB" appointment. Mother reported to be doing well but was vomiting every morning and having occasional abdominal pain. She had not completed 1st trimester labs and was encouraged to do so ASAP. She was given information on where to get TDap and flu vaccines. She was given a referral to WIC and a prenatal risk screen was completed. She scored a 15 for race (3), having a baby not born alive (3), having a baby more than 3 weeks before their due date (3), and having a low birth weight baby (3), a BMI over 35 [47.4 (2)], and beginning prenatal care in the 2nd trimester (1). She was referred to Healthy Start.

At 18w2d, she had her next OB visit. A pap smear and second ultrasound were done. She had her labs done and she was diagnosed with gestational diabetes after a failed glucose test. Her labs were also positive for THC but no visit notes indicated a discussion about this. She was noted to be sent home with diabetic supplies and prescribed Labetalol [anti-hypertensive]. Her thrombophilia evaluation was overall not concerning. Mother had stopped working for unknown reasons but wished to return to work and requested a letter consenting to do so. She was also referred to a diabetic education program. Mother verbally agreed. The diabetic education program noted to FIMR that mother had a visit scheduled but it was cancelled. They could not decipher who cancelled it or for what reason.

Connect reached out to mother at 18w5d. She discussed having a good support system with her pregnancy. Her car was in the shop, but she had good transportation to appointments. She was enrolled with WIC. She was concerned with getting baby supplies. Mother was educated on the importance of safe sleep and making sure twins were in separate bassinets. When discussing if the pregnancy was planned, mother reported she does not like taking birth control because it makes her body "shift" but she noted she and her husband get "tested" at DOH regularly (FIMR assumed to be for STIs). She was referred to services with Healthy Families. Healthy Families reached out within the week and scheduled an assessment, but mother was a no show, citing an emergency surgery (would turn out to be a cerclage placement). She ended up being closed as declined services two months later.

At 19w0d, she had her first appointment with MFM. An ultrasound was noted to be difficult due to mother's size. Some cervical funneling and a potential polyp were possible. Her blood sugar was noted to be high, she said she hadn't begun taking any of the medications prescribed. She was prescribed progesterone [thicken cervical lining] at this visit. A 24-hour urine test was collected. She was to follow up in one week to reassess cervical length and begin taking baby aspirin. Lovenox was put in place of labetalol. She was encouraged to keep a blood pressure and blood sugar log at home. She was given When you are overweight and Gestational Diabetes Care Instructions.

She followed up at 20w0d with MFM. Her blood pressure continued to be elevated but she was not taking medication because she had not received the Labetalol. She reported to not have a blood pressure cuff either. She was encouraged to purchase one and monitor daily. She was also not taking her sugars due to not having a meter. An Rx was sent for a meter. She said she was taking her progesterone and at this visit, her cervix length was 1cm (down from 2 cm the week prior). Mother was counseled about the increased risk of spontaneous preterm birth due to the shortened cervix. Considering the progesterone seeming to not making a difference, she was counseled to have a cervical cerclage. Mother declined direct admission but agreed to return this evening for admission with the procedure occurring the next day.

Mother had the procedure done at the hospital the next day and it was without concern. However, her blood pressure increased to severe limits requiring multiple doses of IV labetalol and initiation of new antihypertensive. The decision was made to keep her overnight to assure good blood pressure control on new medication. She remained stable and was discharged the next day with a new prescription for Procardia.

She saw MFM again at 22w0d. She had good fetal movement. She was not checking sugars because she said she did not have her supplies yet. They were reordered. An ultrasound noted 29% growth discordance [significant difference between the two babies] and infant A had absent end flow in cord [indication of placental insufficiency] and poor growth. No intervention was recommended due to her gestational age and reassuring status of infant B. She understood the increased risk of the loss of baby A. Visits were to be weekly from this point on.

Her next appointment with her OB was at 22w1d. Mother admitted she was not checking her sugar levels. She had not filled the order for her glucose meter or other diabetes supplies. She was advised to monitor her glucose and blood pressure daily and keep a log. She was to also continue with her aspirin and progesterone but stop her Lovenox.

Her next appointment was at 23w0d with MFM. She had been monitoring her blood pressure and they were seen to be running high. She said she had not been taking her medication for reasons unknown. She was not checking her blood sugars at home. Baby A still had absent end diastolic flow in addition to oligohydramnios [limited amniotic fluid]. With her elevated blood pressure, the decision was made to admit her for closer monitoring. Delivery was recommended at 37 weeks.

Labor and Delivery Summary:

Mother presented at the hospital that evening (23w0d) for admission. She remained under constant monitoring for all conditions and remained relatively stable. Daily ultrasounds showed intermittent reversal flow. On 23w1d, MFM met with both parents and discussed viability at different gestational ages. They planned to give betamethasone later in the week.

At 23w4d Mother was counseled by MFM and neonatologist to discuss interventions. The likelihood of survival at this point was around 30%. Mother wished to consider her options overnight. If she desired neonatal resuscitation at 24 weeks, they would begin steroids tomorrow. Her husband was at bedside.

At 24w2d, mother met with a neonatologist again. With an estimated fetal weight of 390 g for baby A, the survival rate was low. She also understood the significant risk to both babies should she deliver within the next few days including the possibility of losing both babies. Ultimately, after discussion, she desired to continue forward to attempt close monitoring of both fetuses. The nurses noted mother was very upset. She said that she was sure her babies were fine and doesn't understand why the doctor was saying her babies are "very sick". She understood that the doppler flows were unchanged, but stated she was concerned because all the MDs seemed to look at the results differently. The nurse explained that all 4 doctors were concerned about her babies, and that sometimes differences in personalities may affect how information was delivered. Mother said she did not want the most recent doctor she spoke to to follow her case, but it was explained that they were covering the weekend and would be reviewing her monitoring strips and ultrasounds. She appeared more receptive of having them involved after discussing her feelings.

At 24w6d, a spontaneous fetal demise of Infant A was noted, and absent end flow was found with Infant B. Initially mother opted for expectant management with close fetal monitoring but soon, after attempting prolonged fetal monitoring, mother called them back into the room and stated she wished to be delivered. They discussed potential outcomes again and she opted for delivery. A delivery summary was not provided. The babies were born via C-section that afternoon with baby B weighing 730 grams (1 lb., 10 oz) with APGARS of 4 and 7.

Mother was discharged on day 2 postpartum.

Baby A passed away as detailed in EC 1595; baby B was taken to the NICU for care.

stpartum Summary:

Mother saw her OB for a postpartum visit on day 6. Her c-section was healing well without complication. There was no documented discussion about the loss. She was to return in a week. She missed that appointment and rescheduled for a week later due to car problems.

Her next visit was 3 weeks postpartum. Mother was struggling with depression and was referred for counseling. She declined antidepressants or any form of contraceptives. She was to return in 3 weeks.

At about one month postpartum, the OB's office attempted to contact mother after receiving a voicemail from her complaining of chest pains. The next day mother called again, complaining of an allergy flare up. She was called in a prescription for an albuterol inhaler and was recommended to follow up with her primary care for management.

4 days later, the OB's office received a call from the NICU social work team. The social worker was concerned for mother's mental health. The OB explained that mother had been screened positive for postpartum depression and referred for mental health services. They checked in with the referral and the mental health provider said it had never been received. It was refaxed on this day. The next day, the mental health provider said it had still not been received. The OB attempted to contact mother and asked for her to call at her earliest convenience to discuss the referral.

Mother was a no show for her scheduled 6-week appointment. When staff called to check, mother said she was busy as she was going to the NICU every day to check on the baby. She would call back and reschedule. She was called in a prescription for Wellbutrin for her depression. The office checked on the status of the referral and confirmed the mental health provider was working on it and would be in touch with mother and the hospital social worker.

Infant Summary:

The baby was born via C-section at 24 weeks gestation weighing 730 grams (1 lb., 10 oz) with APGARS of 4 and 7. He was immediately intubated and required 4 rounds of curosurf [rescue treatment for respiratory distress syndrome].

The infant had a NICU stay of almost 10 months and the medical records had to be greatly summarized.

Medical conditions during his hospital stay included, but not limited to apnea, chronic lung disease, anemia of prematurity, pulmonary hypertension, alkalosis [excessive blood alkalinity], respiratory failure, constipation, sepsis, fungal infection, pneumonia, and retinopathy of prematurity. A hole in his heart was noted in the first month of life but resolved without intervention. Fentanyl, Morphine, and Ativan were all required at different times.

At 3 months and 8 days, it was noted there were no social concerns but significant stress in the family due to the loss of the first twin, a maternal uncle who had recently died, and a house fire involving the maternal grandmother.

At 5 months and 12 days, the family agreed for the baby to have a g-tube placed as they had been unable to wean him from a ventilator. 9 days after placement, the site around the g-tube developed an infection and split open, requiring antibiotics, a patch placement, and wound vac. It was ultimately removed 2 months later due to continued complications. He was being fed through a weighted feeding tube. A tracheostomy was done a week after the g-tube placement after several failed attempts at removing ventilation support. He required two enemas due to severe constipation related to the prolonged opioid usage.

When the infant was 6 months and 4 days, an incident was recorded by the RN. In the late evening, during shift hand-off the father asked nursing staff, "Can you take too many vitamins?" He stated that he had been snacking on them. It was also noted that he had earlier stated, " I have a lot on my plate, but I'm going to take care of it." The nurse asked father how he was feeling. They asked him if he wanted to go to the ED and he agreed. While being escorted, he commented on how the nurse was standing, "I stand like that when I'm a doctor." Once they got to the ED, he stated, "I thought that I could get more energy if I took more vitamins."

He came back the next day in the early hours of the morning and arrived wearing blue scrubs and not able to form full sentences. He said he was dealing with a lot of things and repeatedly apologized. He was reported to be acting erratic. Security was informed and he was seemingly taken to the ED (though not directly reported).

A couple days later, mother was noted to ask to help the nurse with suctioning the infant's trach. Mother was noted to express understanding and expressed excitement after successfully suctioning infant. The nurse encouraged her to become as active as possible with his care and discussed resources available for her.

In the coming days, father checked in frequently via phone. It was noted there was discussion of him checking into a mental health facility, but he had not due to "paperwork issues". It was not directly stated but inferred that he had been banned from the NICU at this time.

At 6 months and 10 days, father called to get updated on the baby. It was noted that he did not seem to listen when he was told that he was trespassed from the property when he asked about visiting. He said he didn't do anything wrong and that he had been sleep deprived. Staff later spoke with mother who said that he was now inpatient at a mental

health facility, having admitted himself several days ago. Father called again. When he was asked if he was in the hospital, he said yes but he was getting released soon. The father had his first visit back to the hospital less than a week later. A security guard, as well as the patient's mother were present. He father was in a good mood and asking appropriate questions.

At 6 months and 21 days, father was witnessed to be silencing the infant's saturation alarms multiple times, he was stopped and educated on why they were important and the reasoning behind them. After the third incidence, he verbalized he understood the reasoning. During this time, mother continued to visit actively and was noted to be hands on with trying to learn how to care for baby and discussing home healthcare options. She was noted to be happy with the support from the medical team. At 7 months and 4 days, a surgical tech found a large pocketknife in the crack of the couch in the infant's room. Security came to take possession of the knife.

At 7 months and 18 days, father was present throughout the overnight shift but never slept. When the nurse asked him when he slept, he stated "I do not need sleep at all, I just meditate..." During this time, he was noted to repeatedly clean the room with medical grade wipes. He was asked not to use the wipes more than once. Additionally, he continuously used a personal thermometer to check infant's temperature against the request by the nurse. He also made statements such as, "I can help you draw labs; I am trained in this." "I would give the Ativan now." "I am going to observe you so that I can perform the procedure next time." Department of Children and Family was called in to assess the social situation. DCF believed that the "father was showing signs of mental health issues. The mother stated that she felt safe at the home with the father. It was observed that the father loved the newborn very much". The report was screened out with no concerns. They had no further involvement.

At 7 months and 21 days, a child life specialist provided support to mother at the infant's bedside, providing support for bonding with the baby and how to help her two children at home. Mother was also provided keepsake footprint activity. Mother verbally engaged in discussion and expressed gratitude for information and bonding activity.

At 8 months and 4 days, nursing received a phone call from the father asking for details of the care of the G-tube site, to ensure he and mother knew how to take care of the baby. He said he was learning to be a doctor and needed to be there to "give permission for things". He was noted to speak very quickly and increased tone of voice, reporting that he did not think the situation was fair. The nurse let father speak and reassured him with all updates that she could.

At 8 months and 30 days, child life was noted to provide grief resources to mother to help support her children following the death of their grandmother.

When he was 9 months and 8 days, the family had a meeting with medical staff and social work to discuss the infant's worsening health as he had begun to decline in the last few days. At this time the infant was ordered DNAR [do not attempt resuscitation] and the family was considering end of life plans. The next day, child life followed up with the family. Mother verbalized that "I don't know about taking him off the ventilator and to hospice" and that the baby "doesn't do well when I'm not here and improves when I'm here". Mother was noted to only engage in conversation when asked questions and eventually stopped speaking.

Terminal Event

At 9 months and 12 days, the staff updating the parents on his continued worsening status. They planned to continue care without escalation. He was minimally responsive but did not seem to be in pain. The parents were noted to be grieving the anticipated natural death. Spiritual support was place for both parents. The next day, he was noted to be mostly unresponsive. His heart rate was elevated into the 180s and he was given morphine in response. Family was called to come to the hospital. He then had bradycardia and desaturations. His heartrate then dropped into the 50s and continued to slow down as nursing staff held him, parents were not present at the final moments. He passed away.

When they arrived, mother was noted to be in a hysterical state and accused the nurse holding the baby as "killing her baby", asking why he had been given morphine. The nurse explained the events with his heart rate and that she did not feel comfortable not treating it as best she could as he was showing signs of pain. Mom told the nurse to "get out of the room and give me my baby". She handed infant to Mom and left the room. The parents were given alone time with the infant. The doctor went to speak with them, but mother said, "there is nothing else you can do for him" and shut the door on him. She later did let one nurse enter the room. Mother was noted to be initially upset, but then thanked her for taking care of her baby. She then began crying and screaming for the baby to wake up. She was left alone with the baby with spiritual support and security close by. After parents had been in the room for quite some time, Mother told the nurse that she was going to have the father drive her home to be with the other children and that she would be back this morning. She said he was going to come back to hold their son during the night. When he came back, he declined any bereavement support such as pictures or footprints. Parents were requesting an autopsy and the medical staff agreed to better evaluate cause of death.

The day after he passed, medical records noted they spoke with the father of the baby to discuss funeral arrangements. Mother mentioned having the baby go to the morgue for an autopsy and it was noted that this provider's understanding was that they had declined the autopsy. Mother responded she had never declined it. [there were no notes of any discussion outside the two already documented here]. The provider spoke with a charge nurse who said mother had declined the autopsy and was given all the information about the autopsy prior to her decision. Ultimately, there was no autopsy done. Child life mailed bereavement resources to the family.

The cause of death was pulseless electrical activity due to severe metabolic/respiratory acidosis due to severe pulmonary hypertension due to bronchopulmonary dysplasia/respiratory failure. Extreme prematurity was listed as a significant condition contributing to death.

A family interview was done by FIMR 5 months after the infant loss. Mother was provided guidance to mental health providers, support groups, and a memory box. The transcript is below. Mother felt very strongly about her experiences and was grateful for the opportunity for someone to listen to her perspective.

Issues/Discrepancies:

Limited Records (prenatal and hospital)

Case# 1638: Family Interview

Interview conducted over a secure skype connection with mother.
Consent to record the interview share information verbalized on a recorded line with full disclosure regarding usage of information.
Questions are not necessarily in the order they were asked

Life Course/Social background

MOTHER'S INFORMATION

- Born and raised in Pensacola. Oldest of 12 children. Hold a certificate as a combo welder, and 35 years old. "Always had a big responsibility in my life"
- Total of 5 children but only 2 currently alive and 3 deceased. In 2007, had a set of twins, the boy passed away, but the girl survived. In 2009 had a boy. In 2009 met husband and married in 2010.
- Was working at the beach and was laid off due to Hurricane Sally. Currently a treat maker and works on making candied apples, and pretzels. Their home had little damage from the Hurricane but not bad.

FATHER'S INFORMATION

- Military brat and works traveling construction.
- Not the father of any of her living children. "I gave him his first children; it came out of nowhere".

Financial

Did you work during your pregnancy? Yes

Please describe what you did at your job: Cook out at the beach

Did you consider your job to be physically hard? No

Did your job make you tense?
"No, but I was on my feet a lot during this job though the doctor didn't want me to, and I was on bed rest due to blood pressure concerns which was hard"

Did FOB work during your pregnancy? Yes, construction.

What were the sources of your family income during the past 12 months_x_Wages or pay from a job

Would you be willing to share the total annual household income range?

$0-40,999

Payment for Care

What was the payer source for your:

I.Prenatal care: Medicaid
II.Hospital care: Medicaid

Social

How did you feel about your living situation during pregnancy? Stable living condition and were fine.

Did you had a stable phone number during your pregnancy? Yes

During your pregnancy, did you worry about not having enough money from one month to the next? No

Were you exposed to any chemicals just prior to or during pregnancy? No

Were you required to take any precautions? If so, please describe: Bedrest

Were you exposed to second hand smoke just prior to your pregnancy or during your pregnancy? No

Did you own your own car or depend on others for rides? Had my own car

Life Course

As a child, did you experience any of the following?

__ Housing inadequate/homeless

X Food insecurity

__ Treated violently.

__ Parent or caregiver with substance abuse/drinking/mental health problems

__ Parental separation

__ Incarcerated household member

Tell me about your family, friends, and other support systems.

"Mostly just my husband, but also my family, especially mom when she was alive"

Was your partner/ father of the baby supportive during your pregnancy? Yes

Overall, how would you describe your relationship with the father of the baby now? Excellent

Medical History

Medical/Mental Health History

20. Have you ever had any of the following:

1. __allergies
2. __ anemia
3. __cancer
4. __ chronic or acute
5. __respiratory
6. __ dental/gum
7. __diabetes
8. __ gastrointestinal
9. __genetic disorders
10. __ gyno problems
11. __heart disease
12. ***X hypertension***
13. ***X mental health***
14. __ musculoskeletal
15. __neurological
16. __ thyroid conditions
17. __sickle cell disease
18. __ urinary tract
19. __autoimmune

X: **Bronchitis

was born with bronchitis and has small breathing problems.

- Has always had issues with blood pressure during pregnancy.
- Feels that her body can't carry twins since she has only been able to successfully carry singletons.

Mother was offered mental health counseling by lakeview after the loss of her daughter in 2019 (first twin); she was diagnosed with severe post-traumatic stress disorder after all of this happened. Chose not to go through it and didn't feel that any counselor would be able to help her. "No therapist on earth that could help me with what I'm going through". Within 10 months she had lost 4 immediate family members. July: lost daughter. Brother died in October, mother died 6 months later, one month after than mother buried her son.

Currently smokes marijuana as her coping mechanism. Tried anti-depressants before but ended up falling after a shower. "Vowed to never take any pills again". "I just deal with it on my own"

Have you had any other pregnancies? Yes

How many times have you been pregnant prior to this most recent pregnancy? Twice

1. **Date of Birth** 2007, female

   Conditions during pregnancy: Incarcerated at the time of birth, twin pregnancy.

   Pregnancy Outcome: Live Birth *Current Status:* Living

2. **Date of Birth:** 2007, male

   Conditions during pregnancy: Incarcerated at the time of birth, twin pregnancy

   Pregnancy Outcome: Still Birth *Current Status:* Deceased, did not disclose cause of death

3. **Date of Birth:** 2009, male

   Conditions during pregnancy: none

   Pregnancy Outcome: Live Birth *Current Status:* Living

4. **Date of Birth:** 2019, female

   Conditions during pregnancy: twin pregnancy

   Pregnancy Outcome: Still Birth *Status:* Deceased, Newborn affected by maternal hypertensive disorder

Have any of your children been placed in foster care or adopted? *Temporarily*

Daughter was taken away 10 years ago. "NAME was getting her hair braided and I was getting frustrated, so I whooped her, spanked her [on her lower backside] ...but what had happened was, I didn't know it at the time, but her adenoids were swollen. When I whooped her, it caused her nose to bleed. I never, not one time, put my hands on my daughters face to make her nose bleed, ever.... My brother was drunk and called the police on me....and DCF got involved."

Due to the incident, went to jail for 3 months. *DCF records were not pulled for this incident as they were not local so mom's recollection could not be corroborated. No arrest records were found locally related to this incident.

Pregnancy

Was your pregnancy planned? No but had tried for children before, so it was a good surprise.

Were you on any birth control prior to pregnancy? No and not on it currently

Do you expect to have more children? Yes

Are you currently using birth control? If not, why? No

X I want to get pregnant __I don't believe in birth control

__I am not having sex __My partner does not want me to use birth control

__I can't afford birth control __I don't know where to find information

__I had my tubes tied __Other *(specify)* _____

Most women have mixed feeling about being pregnant, how did you feel?

X I wanted to be pregnant sooner

__I didn't want to be pregnant then or at any time in the future

__I wanted to be pregnant later

__I wanted to be pregnant then/positive

__Mixed-I didn't want it at first, accepted it later

How many weeks pregnant were you when you were sure you were pregnant? 8 weeks

How many weeks or months pregnant were you on your first visit? 12 weeks

Tell me about your prenatal care.

Great relationship with OB. Had no issues and made it to all appointments.

Began going to high risk once when the OB told her to go due to her age (over 35) and history with twins.

Were there any barriers that made it difficult for you to get prenatal care? None

Did you have to change your prenatal care provider during this pregnancy? No

Did you ever visit the emergency room or L&D triage during your pregnancy? No

How satisfied were you with the prenatal care you received?

Very satisfied with primary OB/GYN "I wish they could have handled everything during my pregnancy."

"Felt I was being deceived about a few things looking back with what I know now."

"I felt they were not being honest with me."

"Felt like preemie babies are treated as abortion babies" [referring to the way gestational age can influence resuscitation efforts]

Did you ever feel you were treated differently or unfairly in getting services?

If so, for what reason?

X Race ***X Cultural/ethnic background***

__Type of insurance ***X Ability to pay (on Medicaid)***

X Marital status __ Other

There was a family they became friends with while in the hospital, mother reports the children had similar conditions, but they did not push the other family to get the same surgeries they were "pushing" her to do (g-tube, trach) "all at once" and reports that baby is still alive and has not had either surgery. To mother, this had to do with race and insurance "they didn't want to continue to pay for his stay".

was not listened to. "My husband would have sold every last possession to make sure NAME had what he needed. If it had about insurance, we would have dropped everything to get private insurance. I just wish they would have been straightforward"

By him being a preemie.... His skin was not fully developed to support that g-tube. That's what I was trying to tell the doctors and nurses. My husband was already against it, but I was willing to do whatever they wanted to get my son home". Reports they were threatened with child services if parents didn't consent to the g-tube surgery due to it being medically necessary. Mother was too scared to say no because of her history with DCF despite not being comfortable with the surgery at his age. "Trusted them" since they were "medical professionals". "Just like I thought, he had that surgery, and everything went downhill". Reports no report was actually filed with DCF.

Reports father got "kicked out" of the hospital for praying and rituals over the child. "thats how we meditate, how we pray". Reports they didn't let him come back for months and was not given an answer about what he was doing wrong. Does not believe the hospital documented it "He wasn't doing no crazy stuff, like talking in tongues or anything. You know how we raise our voices sometimes though? It's meditation"

Which of the following educational topics did you prenatal care provider, nurse, case manager or other healthcare provider review with you during your pregnancy?

__Avoidance of drugs/alcohol

__Complications/danger signs

__Environmental Hazards

__Car seat safety

__Exercise

__STD's

X Signs/symptoms of labor

X Signs/symptoms of pregnancy- induced hypertension

X Postpartum visits

X Postpartum depression

X Breast and bottle feeding

X Fetal movement

__HIV counseling

__Nutrition

__Pregnancy weight gain

X Safe infant sleep

X Signs/symptoms of preterm labor

__Vaccination history

__ Risk factors

__ Family Planning

Did you have Healthy Start or Healthy Families services during your pregnancy? Yes, referred by primary OB but couldn't engage.

During your pregnancy, did you have any illness, injury or other health problems? Yes

Specify: High blood pressure became a concern. Went on baby aspirin and bed rest. ".I think the only thing I did once they told me they didn't want me on my feet, I just kept going back forth to the bathroom. That was the only thing other than that I did".

Often during pregnancy, women are expected to take special precautions to prevent pre-term or early labor. During this pregnancy, did your doctor instruct you to do anything to prevent premature labor? Yes

If yes, which of the following did you do to prevent premature or early delivery? *(Check all that apply)*

__Took medicine to prevent labor

__Stopped or limited sex

X Doctor sewed the cervix closed

X Was hospitalized

__Reduced housework

__Got hormone shots

__Used condoms to prevent infection

X Had bed rest for one or more weeks

__Reduced work hours or stopped working earlier than expected

Was it difficult to follow professional advice? No

"I was so happy once they told me to go on bedrest. I was trying to be superwoman, but it was kind of beating me up a little

During your pregnancy, did you see a dentist? No

Do you or have you ever smoked? Yes "When I found out I was pregnant, I completely stopped" "Marijuana, no cigarettes."

Did you change the amount of tobacco you used during this pregnancy? Yes

If yes, what influenced you to change? *(Check all that apply)*

__I was urged by my doctor or nurse __Smoking tasted or smelled bad to me

__I was urged by my friends or family __Smoking made me feel sick

__I lost the desire to smoke X ***Other: (Specify) stopped all together for the safety of baby***

During your pregnancy, how many alcoholic drinks did you have in an average week if any?

None

Did you use any medications, drugs, or other substances during pregnancy?

X OTC medications (baby aspirin)

__ Allergy medications __Antibiotics

__Anti-flu/antivirals medications __Anti-depressants/anti-anxiety/anti-psychotics

__Anti-epileptic medications __Anti-hypertensives medications

__Anti-hypothyroidism medications __Arthritis medications

__Diabetes medications __Asthma medications

__ Nasuea/vomiting medications __Cholesterol medications

__Sleeping pills __Medications to treat preterm labor

__Cocaine __Heroin

__ Marijuana __Methamphetamine

__Medications to treat drug addictions __Opiates

X Other : "medication for cerclage"

Labor and Delivery

Can you tell me about what happened?

The baby was doing well when he was 4 months old, began getting worse in month 5 and in month 6 they said that the baby needed a trach. At first, was in agreement with whatever they said they needed to do "When I say I was kissing their butt...whatever they wanted. I was buying them lunches..i was cooking for them. I just wanted my baby home, I didn't care."

Began to have concerns when it came to the g-tube, felt it was too many surgeries at one time. "And I was still worried about his little skin. I knew deep down in my heart. I knew that he wasn't ready for that. And here's the thing. I went to school for nursing. I got turned down because I'm a convicted felon. So it's a lot of things that I know that they don't know that I know. You know what I'm saying? So, I knew I had common sense to know that I knew that his skin was not ready for this surgery" Went through with surgery due to feeling threatened by DCF.

After the g-tube surgery, family was told that there needed to be a correction surgery for the g-tube since there was something wrong. Total of 3 surgeries in one month.

the home inspection less than 3 weeks before he passed away. "I do him a celebration on the DATE of every month, he had ed 9 months girl, we had chocolate cake, he ate chocolate cake and everything. And we had the balloons and had a celebration, d he had on blue shoes and stuff."

7 days before he passed, he had 2 blood transfusion that were not successful to "turn his blood around".

5 days before, the hospital told the parents that he wasn't going to make it and wanted them to place the baby is hospice.

"My husband was totally against it. And these were his words, NAME, if you put my son in hospice, I swear to God, I'm leaving you. And that's how serious he was, like he really did not want nothing to happen to our son. And I wasn't with it. I'm his mom, and I want him to live too."

Day before he passed away, mother had started a new job "I was trying to get up the money to move into a bigger house, so he can have his own room"

"I was looking back at medical records, that was the day he was given 3 doses of morphine within 3 hours" "I guess that was supposed to have killed him, but it didn't. So, the next day, we had came in there. We hung out all day that day. And he was like, his health was like really declining then. And we hung out that day and I was you know getting kind of exhausted...So we stepped out, to go get something to eat. And we got the phone call. And she was like, 'Well, you know, his heart rate was going up. And you know, I told you that we would call you if anything happened'. So, she said, 'Well, I'm going to give him another dose of morphine. I'm going to give him another dose of morphine'. So, I didn't think about it. Then she turned around and call back 15 minutes later and said she thought we needed to get there. So, I don't have no driver's license. I'm going down STREET, running red lights here. I don't care what the hell's going on. I'm panicking. So, this time when we get out there to the NICU, they don't make us wash our hands or nothing, they just said you need to go to the back, go to the back. So, I get to the back and the room is like a vacant hotel. As if he had just moved in there. He was connected to no medicine, nothing. And she was holding my baby the nurse that had kicked him out. She was holding him. And I was angry. I was enraged because I felt I missed it. You know, I missed I missed it. I missed the celebration, what's going on? And um, I asked her I said, 'put my baby down'. And I asked her I said, 'why did you give my son morphine, knowing that it would further constrict his breathing'. She told me because his heart rate was going up. That made no sense to me. And it still does not make sense to me to this day. There were doctors in there. There were nurses in there. Neither one of them could stand up for their colleagues."

Mother felt that the entire issue came back to 5 months prior when he had the 3 surgeries. Felt that he became constipated, and the hospital staff was not listening to her concerns about what she believed was needed for him to have a bowel movement. She believes this led to him turning septic which added difficulty to the chronic lung disease he already had.".

Mother feels that the g-tube should have been later when the baby was bigger, "fatter" and he would still be here. Says that he seemed to be progressing well and gaining weight his first 6 months. Has no idea why he became sick and began to decline. Wonders if they brought something in when they visited him but tries to avoid thinking they could have been to blame.

How was the baby's death explained?

"They said it was only the ventilator was pretty much keeping him alive. At that point NAME was already dead, I don't' want to say it like that, but I mean he was blinking his eyes and holding his hand out for me to hold him...but I don't know..."

"Death certificate says pulmonary cardiac arrest. And what caused him to go into pulmonary cardiac arrest was when the nurse gave him that morphine."

Has not talked to anyone at the hospital since his death "I don't trust anyone."

"I do want some closure; I want someone to tell me...I don't know."

"They did the family meeting [when Hospice was discussed] and no had talked to me since his death".

"There was nothing they could tell me. I had already knew."

"A mother knows a child's body more than a doctor or a nurse."

Feels very strongly she knew her child and that he was not "ready to go" on his own

Bereavement

Were you offered any mementos, grief counseling, or a referral to community resources?

"The nurses did what they could. Some of the nurses stayed in touch with me after I lost him."

Who has helped you the most through this difficult time?

'I don't have a support system for real' "I have a family, but nobody is feeling sorry for nobody right now"

"Everything she [her mom] had been dealing with, it's all on me now. It's been a pattern since I was small...I have 3 brothers incarcerated. Instead of my mom taking care of them, I have to take care of it now."

Thinking back on the entire experience, what do you think would have made things better for you?

Feels people were not straightforward with her about what was going on

Still does not believe she has closure.

Believes the home inspection "was a cover up" since he died so shortly after. "I told the whole world my son was coming home. I just knew he was coming home."

Did Covid-19 at all affect how you grieved or were able to work through things?

COVID did not affect anything. Funeral was able to happen without any COVID issues.

Postpartum

Tell me about your postpartum period after you left the hospital. Did you have a postpartum visit?

Went back to her OB for postpartum as scheduled.

She had just started a new job right before the baby dies, she had not worked while he was in the NICU. Had to keep working to maintain the job.

How are you taking care of yourself?

"I had just started a job the day before he died. So right now, I got laid off on that job with the hurricane. But I had been working to keep busy after he died".

Future Plans

Tell me about your plans now.

Mother and Husband are interested in having another kid that can be biologically related to her husband. Her other kids are from pervious partners. Children are doing well with everything that has happened but want to go live with their biological fathers (still local). "They're alone because their siblings are all on their dad's side". "I don't want them to be alone but at the same time I don't' want to be alone. I feel bad."

Feels "so so bad" for her husband. "I gave him a boy and a girl just to have them taken away from him. He worked so hard all these years". Compared it to the viral video of the two sisters where the birthday girl had her candles blown out by her sister "He didn't get to blow out his own candles"

"I feel empty. I feel alone. I feel so bad. I got kids, but I feel bad for my husband."

Is there anything else you want to share with me today?

"Parents are the kid's voices and don't let the doctors and nurses take that away. Act on the feeling of something not being right. I think my baby would still be here if I stood up against the g-tube."

"You are your children's voice"