What Are Ways to Help Establish a Likely Cause of Perinatal Mortality?

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Background

Parents requesting assistance or guidance from Group B Strep International (GBSI) desired recommendations for a reliable means to diagnose group B strep (GBS) as the proximate cause of adverse pregnancy outcomes to find the answer or “missing piece of the puzzle” to help bring them closure and provide information for subsequent pregnancies.

Objective

Review and analyze evidence or research-based means to “provably” establish GBS or other potentially preventable perinatal infections as the likely cause of perinatal morbidity and mortality.
Methods

• We did Medline, PubMed and Google searches in the English language focusing on fetal, perinatal, and neonatal morbidities and mortalities and associated terms.
• We examined specialized perinatal and pediatric pathology published monographs/guidelines for determining causes of perinatal death.

Results

1) We found no research-based or “evidence-based” protocols or clinical pathways demonstrating improved patient or provider understanding of proximate causes of adverse pregnancy outcomes possibly caused by infection.
2) We found few studies evaluating infection/inflammation related protocols.
3) We found testimonial suggestions and innovative approaches including “visual” or “virtual” autopsy of fetuses or neonates as well as fetal membranes, placentas, and umbilical cords.
4) We found no protocols aimed at proving microbial causes of death.
5) We found multiple factors impairing findings of high quality evidence for determining causes of perinatal death. These factors included societal, parental, provider, administrative, payor, and public health resource ignorance or indifference regarding direct causes of perinatal death.

“Both parents and staff identified needs for improved training and development of evidence-based protocols (to guide care of families suffering perinatal mortality)”
Suggested Ways to Help Establish a Likely Cause of Perinatal Mortality:

- Communicating with parents about perinatal autopsy
- Autopsy and placental examination
- Investigation of fetal deaths
- Examination of babies who die in the perinatal period
- Institutional perinatal mortality audit and classification
- Psychological and social aspects of perinatal bereavement

Informed Choices

“We unfortunately did not do an autopsy, we found that very invasive, but we felt we lacked information and direction hence our choice.”

- Mother of stillborn son Shaddai whose cause of death is still under investigation 11 months later

Offer Options

“Complete diagnostic autopsy (CDA) is considered the gold standard methodology to inform on cause of death (CoD).”


Verbal autopsy (VA) is a systematic approach for determining causes of death without routine medical certification.

Leitao J. Global Health Action 2013; 6. 21518.
Observation

“In my experience, severe chorioamnionitis sometimes gives the surface of the placenta the granular appearance of melted sugar.”
James A. McGregor, MD, CM

Procedural Communication

“My beautiful boy was stillborn on October 5th, and was 10 pounds, 9.5 ounces (4804 grams) and 22.44 inches long (57 cm). I was 10 days overdue.

I had given permission to take several tests from my baby such as swabs from his throat, nose and ears, a babygram, and a muscle biopsy which were not performed. The gynaecologist told me that he forgot to do this, but in my medical file he wrote down that he thought the patient did not want this.

The only test that was performed on my baby was the inspection by the pediatrician.

Also, another gynaecologist told me she wrote in my medical file to do the listeria test, but then the absence of listeria was not mentioned by the microbiologist. The microbiologist also forgot to mention the absence of GBS from my vaginal swab, and said that he does not think it was that although the results from the vaginal swab were positive for gram positive cocci, gram negative rods and bacterial vaginosis.

All is still being investigated, so until the investigation is finished and the specialist concludes and confirms the cause of death based on the tests that they did perform, I will have to wait.”

-Mother of stillborn son Shaddai whose cause of death is still under investigation 11 months later

Suggested Ways to Establish a Likely Cause of Perinatal Mortality:

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“We spoke to 3 midwives and a consultant about an autopsy and while they told us the decision was ours, they advised us that having an autopsy would most likely not determine the cause of our baby's death and would give us no answers. The common theory was that these things just happen and in most cases an answer is never found. We therefore decided to only have the placenta and cord sent off for testing.”

-GBS mother of baby girl stillborn due to unexplained reasons

Autopsy results showed chorioamnionitis and pneumonia due to group B strep. However, three of my four ob-gyns advised us to not have an autopsy done as it would most likely not determine the cause of Rose's stillbirth. Thanks to the other ob-gyn and a supportive pathologist, we decided to at least have a tissue sampling of Rose's heart and lungs cultured.

“A case was defined by the isolation of group B streptococci from a normally sterile site (e.g., blood or cerebrospinal fluid) in a resident within a surveillance area; cases identified on the basis of isolation of group B streptococci from amniotic fluid, placenta, or urine alone were not included.”

GBS-specific Ways to Establish a Likely Cause of Perinatal Mortality:

Provider knowledge regarding GBS pathogenesis

“…GBS can cross intact amniotic membranes.” CDC 2010 MMWR

“...I was told as my baby was dead before she was born, this would not in any way have caused her death.”
- Mother of stillborn daughter

“My doctor, nor any doctors in her practice, knew that GBS could pass like this.”
- GBS mother of daughter who was born extremely sick via C-section and lived six days

Gap in medical training?

GBS-specific Ways to Establish a Likely Cause of Perinatal Mortality:

Develop and justify epidemiologic, clinically graded (“Proven,” “Likely,” “Possible,” or “Atypical”) case definitions of previously unclassified invasive perinatal-onset group B streptococcal (POGBS) invasive disease in order to inform research, advocacy, public policy, clinical care, and social support.

(available as a handout)

Universal Classification

The World Health Organization is working to universally categorize the causes of perinatal death to provide continuity in reporting amongst countries - an important step to better inform research!

The World Health Organization (WHO) (Classifying the causes of perinatal death.

Classification systems for causes of stillbirth and neonatal death, 2009-2014: an assessment of alignment with characteristics for an effective global system.
Fetal Death Records

We also found that, even in high income countries, fetal death records aren't being routinely updated once the final diagnosis is in so even if a reasonable cause of death is found the cause isn't included to be able to accurately assess the burden of any particular disease. Fetal death records need to be universally updated with final diagnosis to show burden of disease to inform research.

Conclusion

We found NO reliable clinical practices directed at improving knowledge regarding causes of perinatal death and systematic improvements of care in future pregnancies. We suggest that parental and other advocacy groups or other granting agencies mount strategies to societal, professional, legal, and public health entities to improve systematic care of preconception, pregnancy, and early life health care which include perinatal services dedicated to improve counseling of afflicted families and communities.

Conclusion

We suggest that:

1) Providers be given adequate training to sensitively offer pathology testing options to parents.
2) Procedures are implemented to ensure that parent's pathology testing requests are honored.
3) Parents be informed to consider pathology testing options available to possibly find a cause, for closure, to better manage subsequent pregnancies, to guide research, and to be more accurately able to determine the burden of causes of fetal death.
4) Perinatal provider medical training should include key concepts related to group B strep.
5) Fetal death records should be updated with the final diagnosis to more accurately assess the causes of fetal death and the burden of group B strep disease.