LEGAL MARGINALIZATION OF A WOMAN’S GRIEF AFTER STILLBIRTH

Stephanie Acosta Inks, JD
Georgetown University Law Center
Camille Josephine Gillott
Stillbirth: prediction, prevention and management
Edited by Catherine Y. Spong

CHAPTER 13
Psychosocial Care
Joanne Ciccirelli, PhD, FT, LMSW
Center for Loss and Trauma, Arizona State University, Phoenix, AZ, USA

ATTEND: toward a relationship-based, patient-centered model of psychosocial intervention

The image of a woman reaching down to bring her baby onto her breast at the moment of birth is a powerful one. She herselfs her baby, and every cell in her body knows and wants her strength. At the end of hours of pain and emotion, 5% more intensely than at any other time in life, she is exalted. To have the exhilaration, elation, and power that comes with the exultation and pain of giving birth is truly empowering [1].

Stillbirth: the collision of birth and death

Maggie just concluded her last visit with the obstetrician before the birth of her new baby. She has waited 10 long months for the baby’s arrival. The nursery is complete. Skippers are neatly stacked near the powder-scented wipes. Her tiny clothes sit patiently in the white dresser. The family purchased a boppy so that every morning they could listen to her heartbeat. For nearly 10 long months, Maggie had changed the way she talks, the way she dresses, her sleep patterns, and even the movies she watches and the music she listens to—she’s in preparation for their new child. She has parented this baby long before birth, nurturing her within the safety of her womb. The family has already named her ‘Grace’.

Grace’s brother and sister sit patiently in the waiting room anticipating the arrival of their new sister; their father already glowing. Any moment now they know that this new addition to their family will change their lives forever, and that she does. The nurse offers the whole family into a small room. “What is going on?” she asks. As he watches tears streaming down his sisters cheeks, Grace’s father bears those three most dreaded words as the nurse replies, “I’m so sorry...” And their nightmare begins.

Maggie endures 17 hours of grueling labor, and at the end of her 40-week journey through motherhood, she gives birth and death simultaneously to a beautiful 9-pound baby girl. Though she has not yet begun to process the trauma of this experience, her heart breaks, they leave the hospital without Grace, walking past a nursery of healthy newborns on her way. What was to be the happiest day of their lives, the month they would ordain every year, would become their worst nightmare.

Tomorrow Maggie’s dreams will be a jumbled mess, and she will wander the hallways of her home yearning to comfort herself, her arms literally burning to hold the baby. Primal maternal urges will drive her to the place where Grace is buried, and every time she walks into the nursery, she will question, morn, and often, blame herself. Maggie has a long, haunting road ahead.

Stillbirth is a traumatic experience that may incite long-term psychosocial problems that manifest the criteria for anxiety, depression, and posttraumatic stress disorder (PTSD). While no amount of compassion provider care can bring Grace back to her
“While all child deaths are widely accepted as painful and traumatic, stillbirth, due to its relative historic silence, is one of the few manners of death that has been least examined…” Pg. 204
“The larger sociopolitical system (macro system) shapes the attitudes, values, beliefs about a social problem through legislation, semantical structuring, and policy….this realm influences public policy administration, social service programming and delivery, management of care, research, agency formation related to a social problem...” Pg. 204
This presentation is:
• Not legal advice
• Reflects a work in progress
  • Planning for a Feb 2020 submission
• Welcome feedback whole heartily
  Sci2@law.georgetown.edu
Current state of my research where I see the sociopolitical structure/legal framework marginalizing stillbirth:

1. The way we conduct evaluations, particularly autopsies, following the death of the baby.
2. The way we handle the vital record of the baby’s life and death.
3. The way we provide leave time for women following the stillbirth of their baby, particularly with FMLA.
Ideas that are largely beyond the scope of this paper/scholarship are:

• Torts/Medical malpractice (Jill Weiber Lens has written about this)
• Fetal Protection Laws/Drug Abuse
• International Law, other than occasionally as a standard
• Abortion/Termination of Pregnancies
“Stillbirths occur 1 in every 160 deliveries in the United States. About 25,000 stillbirths at 20 weeks or greater gestation are reported every year.
Magnitude of the Stillbirth Women’s Public Health Problem

“Stillbirth rates have been consistently and significantly higher in Non-Hispanic black women at a rate of 11.25 per 1,000. The reason for this health care disparity is multifactorial and the subject of on-going research.”
“Giving birth to a dead baby is one of the most profound losses that a woman can suffer and has a wide variety of emotional, cognitive, psychological, spiritual, and physiological consequences.”
“Mothers experiencing stillbirth are recognized as disenfranchised. Dr. Doka defines disenfranchised grief as the grief persons experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned, or socially supported. For socially validated deaths, there is often community outpouring of sympathy and recognition of the deceased. However, individuals suffering from disenfranchised grief often do so in silence and may feel ashamed for their experiences, adding to the psychological complexity of their losses.”

(Psychological Effects of Stillbirth” by J. Cacciatore)
“abrupt cut off in the identity construction process and that denial of the baby’s existence was expressed both explicitly and implicitly. In a dramatic instant, there is an unraveling of a woman’s lived experience and rapid deconstruction of her motherhood at the hands of the person who was most intimately entrusted with her care for many months. The altered relationship can elicit negative immediate effects and poor long-term psychological outcomes for mothers and families.”

(Psychological Effects of Stillbirth by J. Cacciatore)
“Faced with bereaved parents, health professionals can further diminish the existence of the baby by referring to the baby who died as the fetus, even after birth. A disparity exists in the legitimization of grief responses after stillbirth versus the death of a live born child, and the stillbirth is generally minimized or treated as a non-event.”

Stillbirths 1

Stillbirths: why they matter

J Frederik Free, Joanne Cacioppo, Elizabeth M McClure, Oluwafemi Kuti, Abdul Hakeem Jakobo, Monir Islam, Jeremy Shiffman, for The Lancet’s Stillbirths Series steering committee

In this first paper of The Lancet’s Stillbirths Series we explore the present status of stillbirths in the world—from global health policy to a survey of community perceptions in 135 countries. Our findings highlight the need for a strong call for action. In times of global focus on motherhood, the mother’s own aspiration of a liveborn baby is not recognised on the world’s health agenda. Millions of deaths are not counted: stillbirths are not in the Global Burden of Disease, nor in disability-adjusted life-years lost, and they are not part of the UN Millennium Development Goals. The grief of mothers might be aggravated by social stigma, blame, and marginalization in regions where most deaths occur. Most stillborn babies are disposed of without any recognition or ritual, such as naming, funeral rites, or the mother holding or dressing the baby. Beliefs in the mother’s sins and evil spirits as causes of stillbirth are rife, and stillbirth is widely believed to be a natural selection of babies never meant to live. Stillbirth prevention is closely linked with prevention of maternal and neonatal deaths. Knowledge of causes and feasible solutions for prevention is key to health professionals’ priorities, to which this Stillbirths Series paper aims to contribute.

Why stillbirths matter

A mother gives birth to her baby after many months of pregnancy. But her baby is dead. Few words are needed to convey the tragedy of stillbirth. At the beginning of the third-trimester of pregnancy, the baby weighs about 1 kg, and most babies have the capacity to live outside the womb. At this stage of pregnancy, the risk of stillbirth is about 2%, and the risk of death at the very beginning of compared with the leading global causes of death in all age categories, all-cause stillbirths would rank fifth among the global health burndens—before diarrhoea, HIV/AIDS, tuberculosis, traffic accidents, and any form of cancer.11

This first paper of The Lancet’s Stillbirths Series will explore the present status of stillbirth in the world.
“Even though the bereaved parents may not want the information initially, health care providers should emphasize that results of the evaluation may be useful to the patient and her family in planning future pregnancies. If the family objects to a standard autopsy, they should be informed of the potential value of less invasive methods of evaluation, including the use of photographs....”

ACOG Practice Bulletin, p5
“The study of specific causes of stillbirth has been hampered by the lack of uniform protocols for evaluating and classifying stillbirths and by decreasing autopsy before a full postnatal investigation, and amended death certificates are rarely filed when additional information from the stillbirth evaluation emerges.”

ACOG Practice Bulletin, p4
“The most important tests in the evaluation of a stillbirth are fetal autopsy; examination of the placenta, cord, and membranes; and karyotype evaluation. An Algorithm for evaluation is given in Figure 1. Specific aspects of evaluation are outlined as follows and in table 3.”

ACOG Practice Bulletin, p4
“An autopsy is important in giving additional insight into the conditions that lead to death. This additional information is particularly important in arriving at the immediate and underlying causes when the cause is not immediately clear.” p.41
“Perinatal autopsy plays an invaluable role in the overall management of the unsuccessful pregnancy. In addition to the accurate identification of malformations, inherited disorders and acquired diseases, it also allows the exclusion of such diagnoses. Positive and negative findings are equally important in the counselling of parents.”

(Prognostic Role of the Perinatal Postmortem; Rushton; Abstract).
“Evaluating all perinatal deaths, they found that in 26% of cases the autopsy was the only means of establishing a cause of death. Furthermore, in nearly 50% of these cases, the autopsy alone suggested the need for additional genetics testing and genetic counseling...”

(Stillbirth: A Review, p 89).
Autopsies reduced the unexplained fetal deaths by an additional 30%... One study found that of all testing, a placental evaluation and autopsy were the most valuable.”

(Stillbirth: A Review)
Studies have found “significant discrepancies between the clinically reported cause of death and data found at autopsy”...

Moreover, “Fetal death certificates are not reliable to provide accurate assessments of the underlying cause of fetal deaths and one study showed that when autopsies were performed after the fetal death certificate was complete, the autopsy changed the diagnosis in almost 50% of cases.”

(Stillbirth: A Review, p 89).
In spite of ACOG stating that a ‘carefully performed autopsy is the single most useful step in identifying the cause of fetal death’, only a portion of fetal deaths are evaluated by a pathologist.”

(Stillbirth: A Review).
Decision influences and aftermath: parents, stillbirth and autopsy

Dell Horey PhD,* ** Vicki Flenady PhD,†** Liz Conway,† Emma McLeod BPharm(Hons)§ and Teck Yee Khong MD††**

*Research Fellow, Research Education and Development Unit, La Trobe University, Melbourne, Vic., †Associate Professor, Mater Medical Research Institute, University of Queensland, Brisbane, Qld, †State Coordinator, SANDS Queensland, Brisbane, Qld, §Founder and Director, Stillbirth Foundation Australia, Sydney, NSW, ¶Consultant, SA Pathology at Women's and Children's Hospital, University of Adelaide, Adelaide, SA and **Member, Australian and New Zealand Stillbirth Alliance (ANZSA), Woolloongabba, Qld, Australia

Abstract

Background Stillbirth, among the most distressing experiences an adult may face, is also a time when parents must decide whether an
Investigating perinatal death: a review of the options when autopsy consent is refused

C Wright, B J E Lee

Autopsy remains the best method of investigating perinatal deaths. Recent years have, however, seen a decline in autopsy rates. This review looks at some of the options available for investigating perinatal deaths when the family decline to give consent for standard autopsy.

T

he information provided by perinatal autopsy is important both for patient care and for the maintenance and understanding of care. The value of the standard autopsy, however, can only be recognized if there is understanding of the patient, the family, and the autopsy procedure itself. In this article, the author describes the benefits and limitations of the autopsy, and the factors that influence the decision to perform an autopsy. He also discusses the ethical and legal aspects of autopsy, and the potential benefits of alternative methods of investigation. Although the standard autopsy may be the best method of investigation, it is not always appropriate or possible. Alternative methods of investigation, such as postmortem imaging and non-invasive testing, may be more appropriate in certain cases.

EXTERNAL EXAMINATION

Many non-invasive methods are an extension of the autopsy. Although the standard autopsy relies on the examination of the body, it is not always possible to perform a complete examination. Instead, the body may be examined in a non-invasive manner, such as postmortem imaging. This allows for the identification of abnormalities, which can be used to inform the diagnosis and management of the patient.

PLACENTAL AND UMBILICAL CORD

Pathology and Radiology: These are the primary tools for the investigation of perinatal death. Pathology provides information on the cause of death, while radiology can be used to identify abnormalities in the umbilical cord and placenta. However, these methods are limited by the availability of specimens and the expertise of the specialists involved.

Availability of less invasive prenatal, perinatal and paediatric autopsy will improve uptake rates: a mixed-methods study with bereaved parents


Aims: To investigate whether less invasive methods of autopsy would be acceptable to bereaved parents and likely to increase uptake rates.

Design: Mixed-methods study.

Setting: Bereaved parents received prospectively across women's hospitals in England and subsequently through the national network of neonatal perinatal service.

Sample: High-fidelity and real-time surveys and 28 interviews with bereaved parents.

Methods: Cross-sectional survey and qualitative semi-structured telephone interviews.

Findings: A quarter (25%) of parents reported that they would consider a less invasive method of autopsy (e.g. non-invasive placental and umbilical cord imaging). There was a significant difference in the likelihood of parents choosing a less invasive method of autopsy, with 75% of parents choosing a traditional method versus 25% choosing a less invasive method (p < 0.01). The parents also expressed a desire for more information about the different methods available.

Conclusions: Less invasive methods of autopsy are acceptable alternatives for bereaved parents, and it is likely to increase uptake rates and improve patient experience. Further research on the ethical, medical, and policy implications of less invasive methods of autopsy is recommended.

Keywords: Autopsy, parents, consent, perinatal and pediatric autopsy, bereavement, patient experience.
“Minimally invasive autopsy has accuracy similar to that of conventional autopsy for detection of cause of death or major pathological abnormality after death in fetuses, newborns, and infants, but was less accurate in older children. If undertaken jointly by pathologists and radiologists, minimally invasive autopsy could be an acceptable alternative to conventional autopsy in selected cases.”

(The Lancet Series; Post Mortem MRI vs. Conventional Autopsy in Fetuses)
Death Scene Investigation and Autopsy Practices in Sudden Unexpected Infant Deaths

Alexa B. Eck Lambert, MPH\textsuperscript{1}, Sharyn E. Parks, PhD, MPH\textsuperscript{2}, Lena Camperleno, DrPH, RN\textsuperscript{2}, Carri Cottengim, MA\textsuperscript{2}, Rebecca L. Anderson, MPH\textsuperscript{2}, Theresa M. Covington, MPH\textsuperscript{3}, and Carrie K. Snapiro-Mendoza, PhD, MPH\textsuperscript{2}

\textsuperscript{1}DB Consulting Group, Inc, Silver Spring, MD
\textsuperscript{2}Division of Reproductive Health, Centers for Disease Control and Prevention, Atlanta, GA
\textsuperscript{3}National Center for the Review and Prevention of Child Death, Michigan Public Health Institute, Okemos, MI
Conclusion: The discrepancy between the KNOWN value of autopsies or other reliable tools of death evaluation for stillborn babies and the GOVERNMENT’s demonstrated interest in ensuring they are accomplished for the stillborn infant (as the government has with SIDS) is a legal marginalization of a mother’s grief that not only hampers the individual woman’s recovery both short and long term but also the public health law of maternal fetal medicine.
Point II: Vital Records for Stillborn Babies

“Improving systems for reporting births and neonatal deaths is a matter of human rights and a prerequisite for reducing stillbirths and neonatal mortality. By counting the number of stillbirths and neonatal deaths, gathering information on where and why these deaths occurred and also by trying to understand the underlying contributing causes and avoidable factors, health-care providers, programme managers, administrators and policy-makers can help to prevent future deaths and grief for patients, and improve the quality of care provided throughout the health system.”

(WHO “Making Every Baby Count”)
Counting the numbers more accurately, and gaining a better understanding of the causes of death are key to tackling the burden of 27 million neonatal deaths and 26 million stillbirths that are estimated to occur each year.”

(WHO “Making Every Baby Count Surveillance Guide”)
“A mortality audit is the process of capturing information on the number and causes of stillbirths and neonatal deaths, and then identifying specific cases for systematic, critical analysis of the quality of care received, in a no-blame, interdisciplinary setting, with a view to improving the care provided to all mothers and babies. It is an established mechanism to examine the circumstances surrounding each death including any breakdowns in care that may have been preventable. Applying the audit cycle to the circumstance surrounding deaths is an established quality improvement strategy that can highlight breakdowns in clinical care at the local level as well as breakdowns in processes at the district or national level, and ultimately improve the civil registration and vital statistics (CVRS) system and quality of care overall.”

(WHO “Making Every Baby Count Surveillance Guide”)
“This process is already being used in many countries in the form of maternal death surveillance and response (MDSR). This is a key strategy to collect accurate information linked to routine health systems recording how many maternal deaths occurred, where the women died, why they died, and what could be done differently to prevent similar deaths in the future. The process of routine identification and timely notification of deaths is a continuous action cycle linking quality improvement from the local to the national level. Although women and their babies share the same period of highest risk, often with the same health workers present, less information has been captured for stillbirths and neonatal deaths than for maternal deaths. Even basic information about each birth and death is limited, and the practice of reviewing selected deaths is not widespread (WHO “Making Every Baby Count”).
“A Death Certificate is a permanent record and is the source for government statistics and is used to determine which Medical conditions receive research and development funding, to set public health goals, and to measure health status at various levels….”
“Mortality data are valuable to physicians indirectly by influencing funding that supports medical and health research that may alter clinical practice and directly as a research tool. Research topics include identifying disease etiology, evaluating diagnostic and therapeutic techniques….” Pg. 2
“Because statistical data derived from death certificates can be no more accurate than the information on the certificate, it is very important that all persons concerned with the registration of deaths strive not only for complete registrations, but also for accuracy and promptness in reporting these events.” Pg. 3
“Stillbirths need to count. They constitute the majority of the world’s perinatal deaths and yet, they are largely invisible. Simply counting stillbirths is only the first step in analysis and prevention. From a public health perspective, there is a need for information on timing and circumstances of death, associated conditions and underlying causes, and availability and quality of care. This information will guide efforts to prevent stillbirths and improve quality of care... The need for better data is a pressing issue in stillbirth prevention, where there is a significant gap in translating knowledge into proven strategies to reduce fetal mortality.”

(“Making Stillbirths Count, Making Numbers Talk”)
“Each state in the US develops its own definition, reporting criteria, and fetal death certificate, which can produce variability in reporting across states. Additionally, previous studies suggest that fetal death certificate data are limited in utility as a source for national stillbirth surveillance due to under- or over-reporting and the completeness and quality of recorded data.”

The Stillbirth Surveillance Consortium
Patient’s Worksheet for the Report of Fetal Death

We are truly sorry about the loss you have experienced. We understand this is a difficult time for you and your loved ones. We want to make sure you have as much information as possible about the fetal death that occurred.

The information that follows is not intended to provide legal advice. It is provided to help you understand the process of reporting a fetal death. This information is based on the International Society for Gynecological Endocrinology (ISGE) guidelines and should be verified with your healthcare provider.

PLEASE PRINT CLEARLY

1. Would you like to move the child? (This is entirely optional.)
   - Yes
   - No
   - Don’t know

2. What is your name?
   - First Name
   - Middle Name
   - Last Name
   - Suffix (e.g., Jr., Sr., etc.)

3. What is your married or legal name?
   - First Name
   - Middle Name
   - Last Name
   - Suffix (e.g., Jr., Sr., etc.)

4. Where do you usually live?
   - City, Town, or Location
   - State
   - Zip Code
   - (If not United States, enter country name)

5. In this household, is there someone who is an adult who has a disability or a mental illness?
   - Yes
   - No
   - Don’t know

6. In this household, are there children under the age of 18 years who live here?
   - Yes
   - No
   - Don’t know

FACILITY WORKSHEET FOR THE REPORT OF FETAL DEATH

Complete this worksheet for prompt and accurate reporting of fetal death. The Medicaid and/or State and Local Regulations require the following information of each fetal death.

The completion of this worksheet will be helpful to the hospital or other facility involved in the care of the mother and fetus, and to the medical examiner who may be involved in the investigation of the fetal death.

1. Facility name:
   - [Facility Name]

2. Facility ID:
   - [Facility ID]

3. City, Town, or Location of delivery:
   - [City/Town/Location]
   - [Zip Code]

4. County of delivery:
   - [County]

5. Place of delivery:
   - [Hospital]
   - [Out-of-Hospital Delivery]
   - [Other (Specify, e.g., in home, on or off site)]

6. Cause of fetal death:
   - [Cause]

Preventive care:
- Pregnancy care record, prenatal care record, birth and delivery record

Information for the following items should be obtained from the patient’s prenatal care record and from other medical reports in the patient's chart. If the patient’s prenatal care record is not in the hospital chart, please contact the prenatal care provider to obtain the record, or a copy of the prenatal care information. Preferred and acceptable sources are given before each section. Please do not provide information from sources other than those listed.

[Signatures and Dates]
Seeking Answers to Stop Another Stillbirth

By JANE E. BRODY  APRIL 1, 2008

Victoria Tapia, then 19, was having a “perfect pregnancy” at 29 weeks until one morning she no longer felt the fetus moving. An ultrasound confirmed that it had died in utero.

“I was devastated,” Ms. Tapia said in an interview. “They couldn’t give me a reason why Gracie had died. The autopsy was inconclusive. They told me it was a fluke and unlikely to happen again.”

Seven months later, Ms. Tapia was pregnant again. The genetic tests were normal, the pregnancy was closely monitored and everything was going well until the 36th week. She went into early labor, and when she arrived at the hospital, there was no heartbeat.

Again, no reason for the stillbirth could be found. “It was really brutal,” she said. “I felt like damaged goods, and I didn’t want to attempt another pregnancy.” But she did. and this time at 26 weeks delivered A.J., now 3. A.J.’s very premature birth followed separation of the placenta from the uterus, leading doctors to suspect that this might have caused the earlier deaths.
<table>
<thead>
<tr>
<th>U.S. State Government Certificates of Birth Resulting in StillBirth</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alaska Certificates of Birth Resulting in StillBirth (2009)</td>
</tr>
<tr>
<td>Arizona Certificates of Birth Resulting in StillBirth (2001)</td>
</tr>
<tr>
<td>Arkansas Certificates of Birth Resulting in StillBirth (2007)</td>
</tr>
<tr>
<td>California Certificates of Birth Resulting in StillBirth (2008)</td>
</tr>
<tr>
<td>Florida Certificates of Birth Resulting in StillBirth (2006)</td>
</tr>
<tr>
<td>Georgia Certificates of Birth Resulting in StillBirth (2008)</td>
</tr>
<tr>
<td>Indiana Certificates of Birth Resulting in StillBirth (2002)</td>
</tr>
<tr>
<td>Louisiana Certificates of Birth Resulting in StillBirth (2003)</td>
</tr>
<tr>
<td>Maine Certificates of Birth Resulting in StillBirth (2009)</td>
</tr>
<tr>
<td>Maryland Certificates of Birth Resulting in StillBirth (2003)</td>
</tr>
<tr>
<td>Massachusetts Certificates of Birth Resulting in StillBirth (2002)</td>
</tr>
<tr>
<td>Minnesota Certificates of Birth Resulting in StillBirth (2005)</td>
</tr>
<tr>
<td>Mississippi Certificates of Birth Resulting in StillBirth (2007)</td>
</tr>
<tr>
<td>Missouri Certificates of Birth Resulting in StillBirth (2004)</td>
</tr>
<tr>
<td>Montana Certificates of Birth Resulting in StillBirth (2008)</td>
</tr>
<tr>
<td>Nebraska Certificates of Birth Resulting in StillBirth (2008)</td>
</tr>
<tr>
<td>New Hampshire Certificates of Birth Resulting in StillBirth (2008)</td>
</tr>
<tr>
<td>New Jersey Certificates of Birth Resulting in StillBirth (2004)</td>
</tr>
<tr>
<td>North Dakota Certificates of Birth Resulting in StillBirth (2008)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>State</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oklahoma Certificates of Birth Resulting in StillBirth (2008)</td>
</tr>
<tr>
<td>Rhode Island Certificates of Birth Resulting in StillBirth (2007)</td>
</tr>
<tr>
<td>South Carolina Certificates of Birth Resulting in StillBirth (2006)</td>
</tr>
<tr>
<td>South Dakota Certificates of Birth Resulting in StillBirth (2007)</td>
</tr>
<tr>
<td>Tennessee Certificates of Birth Resulting in StillBirth (2010)</td>
</tr>
<tr>
<td>Texas Certificates of Birth Resulting in StillBirth (2005)</td>
</tr>
<tr>
<td>Utah Certificates of Birth Resulting in StillBirth (2002)</td>
</tr>
<tr>
<td>Virginia Certificates of Birth Resulting in StillBirth (2003)</td>
</tr>
<tr>
<td>U.S. States That Issue Certificates of StillBirth</td>
</tr>
<tr>
<td>Colorado (2004)</td>
</tr>
<tr>
<td>Delaware (2004)</td>
</tr>
<tr>
<td>Idaho</td>
</tr>
<tr>
<td>Illinois</td>
</tr>
<tr>
<td>Iowa</td>
</tr>
<tr>
<td>Kentucky</td>
</tr>
<tr>
<td>Michigan (2002)</td>
</tr>
<tr>
<td>Ohio</td>
</tr>
<tr>
<td>Oregon (2006)</td>
</tr>
<tr>
<td>Pennsylvania Certificate of StillBirth</td>
</tr>
<tr>
<td>Foreign Government Sites Certificates of Fetal Still Birth or Death</td>
</tr>
<tr>
<td>Ireland — How Parents Can Register a StillBirth</td>
</tr>
<tr>
<td>U.K. Registration of Still Birth</td>
</tr>
<tr>
<td>Scotland General Register — Registering a StillBirth</td>
</tr>
<tr>
<td>Canada Stillbirth Database</td>
</tr>
</tbody>
</table>
“Dissatisfied with the issuance of a stillborn death certificate, bereaved parents of stillborn babies have successfully lobbied state legislatures nationwide to issue stillborn birth certificates under newly enacted “Missing Angels Acts.” These Acts raise a perplexing set of questions. While acknowledging the desire of grieving parents to have some form of recognition for their children, it is important to think carefully about just what is being certified in the name of the larger community. How has issuing birth certificates to babies who never lived come to seem a reasonable rather than eccentric legislative gesture? And importantly, do stillborn birth certificates have implications for other areas of law involving prenatal death, particularly regulation of abortion?” (Carol Sanger, “The Birth of Death: Stillborn Birth Certificates and the Problem for the Law”)
A BILL

To amend the Family and Medical Leave Act of 1993 to provide leave because of the death of a son or daughter.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the “Parental Bereavement Act of 2017” or the “Sarah Grace-Farley-Kluger Act”.

SEC. 2. FAMILY LEAVE BECAUSE OF THE DEATH OF A SON OR DAUGHTER.

(b) FAMILY LEAVE.—
Conclusion: The “HOW” and the “WHY” of counting and certifying stillborn babies matters from both from an individual/women’s rights and from a public health standpoint.
“It would make scant sense to provide job-protected leave to a woman to care for a newborn, but not for recovery from delivery, a miscarriage, or the birth of a stillborn baby.” (Justice Ginsburg, Coleman v. Court of Appeals of Maryland Et Al).

Point III: Minimum Federal Maternity leave After Birth Regardless of Newborn Care
The Employer's Guide to

The Family and Medical Leave Act
“the birth of a child and to care to care for the newborn child, because of the of the placement of a child with the employee for adoption or foster care?”
“because the employees own serious health condition makes the employee unable to perform the functions of his or her own job,”
“An illness, injury, impairment, or physical or mental condition that involves (A) inpatient care in a hospital, hospice, or residential medical care facility; or (B) continuing treatment by a health care provider.”
The House and Senate Committee Reports list the types of illnesses and conditions that would likely qualify as serious health conditions: “Examples include but are not limited to heart attacks, heart conditions requiring heart bypass or valve operations, most cancers... ongoing pregnancy, miscarriages, complications or illnesses related to pregnancy, such as severe morning sickness, the need for prenatal care, childbirth and recovery from childbirth.”

“All of these conditions meet the general test that either the underlying health condition or the treatment for it requires that the employee be absent from work on a recurring basis or for more than a few days for treatment or recovery.”
“Tragically, Szabo’s child was stillborn, but this means that she was not entitled to maternity leave under the Act, since such leave is only required under the Act in order to care for a son or daughter. Nor did Szabo demonstrate a ‘serious health condition that makes the employee unable to perform the functions of the position of such employee’ an alternative basis for leave under the Act. Her own doctor wrote a letter saying that she was able to return to work ‘as she is recovering so well.’ Dr. Olson also testified that recovery times vary and that he would not have written the letter if Szabo was unable to return to work, and that Szabo did not tell him that her employer was pressuring her to return to work…. True, Szabo claims that she prevailed upon her doctor to write the note because she was afraid BU would fire her if she did not return to work, but she points to no evidence showing that upon her return to work she was ‘unable to perform the functions of the position of such employee.’”
Effect of Leave: “I found that returning to work within 12 weeks of giving birth was associated with worse mental health. Additionally, early return to work was associated with a higher likelihood of major depressive disorder.” “Returning to work within 12 weeks had a substantial negative impact.” (“The Effect of Paid Leave on Maternal Mental Health” by Bidisha Mandal in Maternal and Child Health Journal)
Stillborn mothers are not covered under the birth of a child/newborn care provision but rather under the self care provision and I think this results in inequitable treatment.
Current state of my research where I see the sociopolitical structure/legal framework marginalizing stillbirth:

1. The way we conduct evaluations, particularly autopsies, following the death of the baby.
2. The way we handle the vital record of the baby’s life and death.
3. The way we provide leave time for women following the stillbirth of their baby, particularly with FMLA.
Camille Josephine Gillott & Her Mother Rachel Gillott
Thank you