MEDICAL PATERNALISM AND IGNORANCE OF STILLBIRTH

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"Stillbirth, the culprit that destroys more than one in every two hundred pregnancies in this country, was glaringly absent from these books that are specifically intended to guide couples through their pregnancies, to prepare them for every possible twist or turn."

- Alan Goldenbach, *Blindsided*, in They Were Still Born: Personal Stories About Stillbirth (Janel C. Atlas ed., 2010).

"Stillbirth is not something a pregnant woman or couple expects or prepares for. As one mother said, 'There was a 'stillbirth' chapter in one of my pregnancy books. I skipped it.' Many participants had believed that stillbirth is a very rare event. Several parents reported being surprised to learn the actual rates of stillbirth worldwide, or that stillbirth occurs much at all in high-income countries like the U.S. As one mother commented, 'You think this is something that only happens in third world countries, but not to us with our health care resources.'

Some couples in the study were pregnant for the first time and they were not considered 'high risk.' Others had had other healthy children and did not expect anything to go wrong with this pregnancy. Those who were considered to have high-risk pregnancies were concerned about delivering prematurely, not about stillbirth. As one participant commented, 'I was extremely high risk with all my pregnancies—and [stillbirth] was never something that came up. Nobody ever said anything.'

Good prenatal care was seen as providing protection against stillbirth: women who took good care of themselves and their babies would avoid problems with pregnancy and delivery."

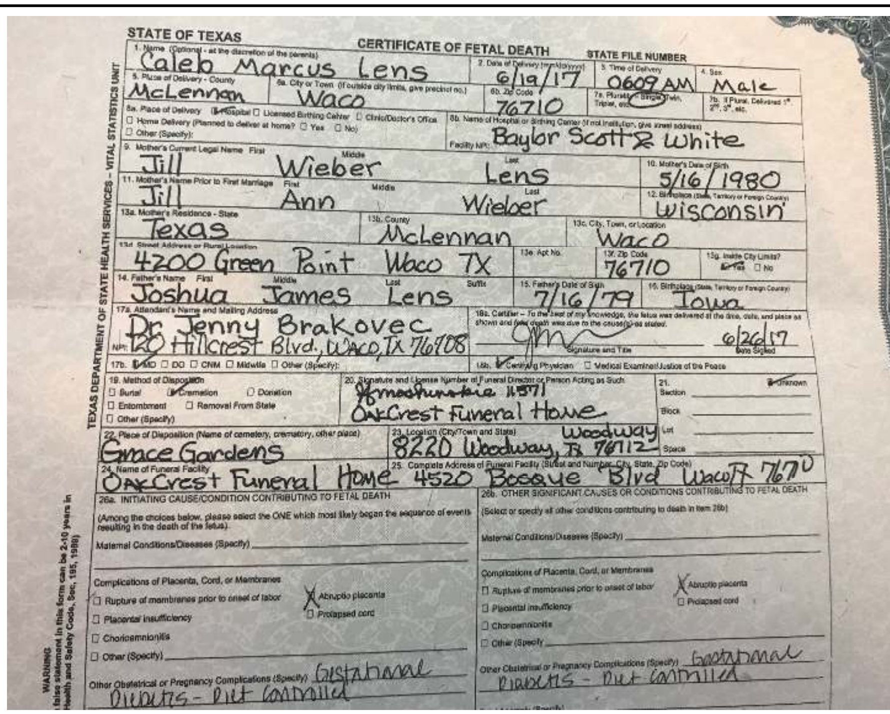
- Maureen C. Kelley & Susan B. Trinidad, *Silent Loss and the Clinical Encounter: Parents' and Physicians' Experiences of Stillbirth—a Qualitative Analysis*, BIOMED CENT. PREGNANCY & CHILDBIRTH, Nov. 27, 2012, at 13.

"[T]he silence surrounding stillbirth during pregnancy poses challenges for educating families. I would say it's probably the biggest hurdle that we face at the moment in regard to the issue. In the time that I've been with the Stillbirth Foundation, the very first thing that nine out of 10 families that come to us ask is, 'Why wasn't I ever told this was a possibility?' As was referred to before, we are told not to eat soft cheese and all of these different things, yet the issues arising from those particular behaviours are far less common than stillbirth. One in every 135 pregnancies in Australia will end in stillbirth. It's not spoken about. For nine out of 10 families to not even know that that is a possibility is astounding."

- Testimony of Ms Victoria Bowring, Chief Executive Officer, Stillbirth Foundation Australia, before governmental committee

"One parent said it best: 'If stillbirth really is ten times as common as cot death, we cannot be the only ones who had bought three sleep positioners but had never once considered the possibility of stillbirth.'"

- Gordon G.S. Smith, *A bonfire of the tape measures*, 377 Lancet 1307, 1307 (2011).


STATE OF TEXAS
CERTIFICATE OF FETAL DEATH
STATE FILE NUMBER

TEXAS DEPARTMENT OF STATE HEALTH SERVICES – VITAL STATISTICS UNIT

1. Name (Optional - at the discretion of the parents): Caleb Marcus Lens
2. Date of Delivery (mm/dd/yyyy): 6/19/17
3. Time of Delivery: 0609 AM
4. Sex: Male
5. Place of Delivery - County: McLennan
6a. City or Town (If outside city limits, give precinct no.): Waco
6b. Zip Code: 76710
7a. Plurality - Single, Twin, Triplet, etc.: Single
7b. If Plural, Delivered 1st, 2nd, 3rd, etc.
8a. Place of Delivery: Hospital ☐ Licensed Birthing Center ☐ Clinic/Doctor's Office ☐ Home Delivery (Planned to deliver at home? ☐ Yes ☐ No) ☐ Other (Specify):
8b. Name of Hospital or Birthing Center (If not institution, give street address): Facility NPI: Baylor Scott & White
9. Mother's Current Legal Name: First: Jill; Middle: Wieber; Last: Lens
10. Mother's Date of Birth: 5/16/1980
11. Mother's Name Prior to First Marriage: First: Jill; Middle: Ann; Last: Wieber
12. Birthplace (State, Territory or Foreign Country): Wisconsin
13a. Mother's Residence - State: Texas
13b. County: McLennan
13c. City, Town, or Location: Waco
13d. Street Address or Rural Location: 4200 Green Point Waco TX
13e. Apt No.
13f. Zip Code: 76710
13g. Inside City Limits? Yes ☐ No
14. Father's Name: First: Joshua; Middle: James; Last: Lens; Suffix
15. Father's Date of Birth: 7/16/79
16. Birthplace (State, Territory or Foreign Country): Iowa
17a. Attendant's Name and Mailing Address: Dr Jenny Brakovec; NPI: 120 Hillcrest Blvd., Waco, TX 76708
17b. MD ☐ DO ☐ CNM ☐ Midwife ☐ Other (Specify):
18a. Certifier – To the best of my knowledge, the fetus was delivered at the time, date, and place as shown and fetal death was due to the cause(s) as stated. Signature and Title; Date Signed: 6/26/17
18b. Certifying Physician ☐ Medical Examiner/Justice of the Peace
19. Method of Disposition: ☐ Burial; Cremation; ☐ Donation; ☐ Entombment; ☐ Removal From State; ☐ Other (Specify)
20. Signature and License Number of Funeral Director or Person Acting as Such: 11571 OakCrest Funeral Home
21. Unknown; Section; Block; Lot; Space
22. Place of Disposition (Name of cemetery, crematory, other place): Grace Gardens
23. Location (City/Town and State): 8220 Woodway, Tx 76712 Woodway
24. Name of Funeral Facility: OakCrest Funeral Home
25. Complete Address of Funeral Facility (Street and Number, City, State, Zip Code): 4520 Bosque Blvd Waco TX 76710
26a. INITIATING CAUSE/CONDITION CONTRIBUTING TO FETAL DEATH
(Among the choices below, please select the ONE which most likely began the sequence of events resulting in the death of the fetus.)
Maternal Conditions/Diseases (Specify)
Complications of Placenta, Cord, or Membranes
☐ Rupture of membranes prior to onset of labor; X Abruptio placenta; ☐ Placental insufficiency; ☐ Prolapsed cord; ☐ Chorioamnionitis; ☐ Other (Specify)
Other Obstetrical or Pregnancy Complications (Specify): Gestational Diabetes - Diet controlled
26b. OTHER SIGNIFICANT CAUSES OR CONDITIONS CONTRIBUTING TO FETAL DEATH
(Select or specify all other conditions contributing to death in item 26b)
Maternal Conditions/Diseases (Specify)
Complications of Placenta, Cord, or Membranes
☐ Rupture of membranes prior to onset of labor; X Abruptio placenta; ☐ Prolapsed cord; ☐ Placental insufficiency; ☐ Chorioamnionitis; ☐ Other (Specify)
Other Obstetrical or Pregnancy Complications (Specify): Gestational Diabetes - Diet controlled

WARNING: false statement in this form can be 2-10 years in ... Health and Safety Code, Sec. 195, 1988)

Tort Law

- Civil Action for personal injury
- Includes medical malpractice claims
- Stillbirth usually a wrongful death claim

Informed Consent Malpractice Claim

- Medical malpractice claim based on doctor's failure to disclose a risk
- Disclosure Standards:
  - *Traditional "Doctor Knows Best" Standard*
  - *Modern Materiality Standard – Must Disclose all Facts that a Reasonable Patient would want to know*

ACOG – Informed Consent

- "[M]akes possible the patients active involvement in her medical planning and care."
- "[E]xpresses respect for the patient as a person," particularly by "respect[ing] a patients' moral right to bodily integrity, [and] to self-determination …."
- "[M]akes possible the patient's active involvement in her medical planning and care."
- "[I]ncludes the patient's awareness and understanding of her situation and possibilities."
- Highlights importance of patient's "active participation in decisions about the management of one's medical care."
- "Consent in this sense requires not only external freedom and freedom from inner compulsion, but also … freedom from *ignorance*."
- ACOG Committee Opinion, Informed Consent, No. 439, Aug. 2009 (reaffirmed 2015)

The Reasons Doctors Don't Disclose the Risk of Stillbirth

- The Low Risk
- The Anxiety Myth
- The Fatalism Myth

The Low Risk

Physicians "reported some discomfort in bringing up the topic of stillbirth with a mother or couple before it happens, often because it is typically a clinically unexpected and sudden event."

- Maureen C. Kelley & Susan B. Trinidad, *Silent Loss and the Clinical Encounter: Parents' and Physicians' Experiences of Stillbirth—a Qualitative Analysis*, BIOMED CENT. PREGNANCY & CHILDBIRTH, Nov. 27, 2012

The Anxiety Myth

One doctor explained why he does not mention stillbirth before it happens "out of concern that it may frighten the patient unnecessarily." Specifically, he doesn't "use the actual word" stillbirth because "[i]t scares people."

- Maureen C. Kelley & Susan B. Trinidad, *Silent Loss and the Clinical Encounter: Parents' and Physicians' Experiences of Stillbirth—a Qualitative Analysis*, BIOMED CENT. PREGNANCY & CHILDBIRTH, Nov. 27, 2012

The Fatalism Myth

Instructions without Warnings

Doctor explained, that despite his "extensive experience in the area of stillbirth prevention," he "tended to avoid directly mentioning stillbirth to his patients." When he discusses the important of fetal movements, he will "refer in bleak terms to it being safer for the baby."

- Testimony of Dr. Michael Gannon before Australian governmental committee

Doctor explained that he talks about stillbirth only "indirectly" by "talk[ing] about warning signs." For instance, he tells women to come in if the baby is moving less, but, in his words, "I don't say the word 'stillbirth,' but what I mean is, if things are not going well and you are not noticing the baby moving well, I want you to come in and get evaluated in the hope of picking up something early so that you potentially prevent a stillbirth, but I don't use the actual word."

- Maureen C. Kelley & Susan B. Trinidad, *Silent Loss and the Clinical Encounter: Parents' and Physicians' Experiences of Stillbirth—a Qualitative Analysis*, BioMed Cent. Pregnancy & Childbirth, Nov. 27, 2012

Fatalism and Proof of Causation in Tort Law

- "Preponderance of Evidence" Burden of Proof
- Plain language: More likely than Not

Public Health Benefits

- Preventing Stillbirths
- Reducing the Shock after Stillbirth
- Reducing the Stigma and Taboo of Stillbirth
- Reducing Blame and Malpractice Liability

Reducing the Shock After

"How bad, sad, or difficult information is received depends on many factors, including expectations, previous experiences, and general personality disposition."

- Lesley Fallowfield & Valerie Jenkins, Communicating sad, bad, and difficult news in Medicine, 363:9405 The Lancet 312, 313 (2004).

Specific to parents of sick children, "[n]o families want[] to be protected from bad news."

Something as simple as a "warning shot," providing a heads-up that bad news is possible, is helpful and empowering for parents.

- Charles J. Schubert & Patricia Chambers, *Delivering Bad News*, 6: Clin. Ped. Emerg. Med. 165, 168 (2005)

Parents "wanted advice about what to expect, believing with hindsight that having been forewarned of the symptoms had helped them cope with the unknown future."

- H. Woolley, A. Stein, GC Forrest, & JD Baum, *Imparting the Diagnosis of Life Threatening Illness in Children*, 298 BMJ 1624 (1989)

Malpractice Liability

Patients sue because of "poor communication and lack of trust," because they are "frustrated with brief, rushed appointments and who believe their physicians show insufficient attention," and if they "perceive their physicians to be patronizing them by providing insufficient detail or glossing over medical explanations."

- Elizabeth Kukura, Obstetric Violence, 106 Geo. L. J. 721, 772 (2018).

[A]n approach which results in patients being aware that the outcome of treatment is uncertain and potentially dangerous, and in their taking responsibility for the ultimate choice to undergo that treatment, may be less likely to encourage recriminations and litigation, in the event of an adverse outcome, than an approach which requires patients to rely on their doctors to determine whether a risk inherent in a particular form of treatment should be incurred.

- Montgomery v. Lanarkshire Health Board (Scotland), UK Supreme Court (2015).

THANK YOU.

Comments and questions please.