**Factors Contributing to Uptake of Stillbirth Evaluations: A Qualitative Analysis**

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**Data Availability**

The data are not publicly available due to privacy or ethical restrictions.

**Abstract**

**Objective.** The purpose of this study was to explore individuals’ beliefs, values, and experiences surrounding stillbirth evaluation decisions.

**Design.** Qualitative research

**Setting.** University of Utah Health

**Population.** Parents who experienced a stillbirth in the past 5 years (n=19) were interviewed about their experiences and decision to consent or decline postmortem evaluations

**Methods.** Qualitative content analysis

**Main outcome measures**. Barriers and facilitators to parents’stillbirth postmortem decision-making.

**Results.** Participants communicated several facilitators and barriers that contributed to their stillbirth evaluation decision. Reasons for consenting to evaluations were belief in science, background in medicine, altruism, to inform future pregnancies, thinking about preventing another stillbirth, and how patients viewed the care of their stillborn by the medical team. Reasons for declining evaluations were receiving a diagnosis prior to being offered a postmortem evaluation, intent to avoid causing further harm to the baby, interest to spend more time with their baby, and cost of the evaluation.

**Conclusion.** Participants identified stillbirth as one of their most difficult experiences as a parent. Diagnostic and emotional barriers create further challenges to decision-making for stillbirth postmortem evaluations. Parents often rely on inadequate information and personal values and beliefs during this time-sensitive decision process. Decision support for stillbirth evaluations and training for medical providers could benefit parents, may increase stillbirth evaluation uptake, and potentially prevent decisional regret.

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**Key words.** stillbirth, fetal death, fetal autopsy, placental histology, genetic testing, shared decision-making

**Introduction**

Approximately two million stillbirths (> 28 weeks gestation) occur around the world each year.1 Determining stillbirth etiology is frequently done based on clinical history and observation, such as an external examination of the body. However, due to a lack of a single systematically applied protocol, clinical diagnostic approaches vary across institutions, and often do not include standardized evaluation metrics.2 This lack of uniformity can lead to a misdiagnosis based on preliminary clinical presentation. Undserstanding the cause of stillbirth is important not only to help researchers and physicians reduce incidence, but also help facilitate bereavement and decrease emotional duress.3

Fetal autopsy, placental histology, and genetic testing are the most useful evaluations for assessing stillbirth.4 Yet, despite strong recommendations from the American Congress of Obstetricians and Gynecologists (ACOG),2 only about one fifth of stillbirths in the U.S. undergo perinatal autopsy.5 Identifying factors contributing to a stillbirth not only helps focus care for subsequent pregnancies and target prevention strategies, it improves mental health.6–9

Stillbirth often leaves parents with increased anxiety, depression, and feelings of guilt or shame surrounding their loss.3,10 Parents are also at increased risk for experiencing anxiety during pregnancies that follow a loss.11–14 The RESPECT study,15 a large multi-country study, identified the most important factors in quality bereavement care. They stressed, “Make every effort to investigate and identify contributory factors, to provide an acceptable explanation to women and families for the death of their baby.” as one of the top priciples.15 Here we interviewed parents about their stillbirth experience and identified the barriers and facilitators to uptake of stillbirth evaluations.

**Materials and Methods**

This descriptive research used semi-structured interviews that were analyzed using content analysis to gather in-depth information about the stillbirth experience, as well as factors surrounding stillbirth evaluation decision. Part of the stillbirth experience is deciding whether to have any evaluations conducted to determine the cause of death, such as fetal autopsy, placental pathology, or genetic testing. A semi-structured interview guide was created based on published data and the clinical expertise of the research team (Supplemental Table 1).

Participants

Participants were identified through medical record abstraction within a national research consortium on stillbirth (SL). Ninety-four patients who met the following inclusion criteria were sent an invitation via email from the obstetrics clinic where they received care: 1) experienced a stillbirth within the last five years; 2) the stillbirth occurred at the University of Utah; 3) the patient had previously consented to being contacted for future research; 4) was at least 18 years old at the time of the interview; and 5) able to communicate in English. Two weeks after the email invitation was sent, patients were contacted by a member of the research team (SL) via telephone to determine their interest in the study if they had not already responded to the email invitation. Details about the study and its voluntary nature were reiterated over the phone prior to the interview. Enrollment for interviews concluded when data saturation 16 was reached (i.e., no new information was added from additional interviews).

Data analysis

Interviews were conducted over the phone (SL, NR), audio-recorded (February to May 2021), professionally transcribed, and the transcripts were uploaded to the software Dedoose 9.0.17.17 Inductive content analysis was conducted by identifying codes from within the transcripts and systematically designating data segments that contain similar material or themes to the remaining transcripts. This coding methodology was based on prior work.18,19 One member of the research team (NR) generated the original codes (e.g., stillbirth evaluation uptake barriers). These codes were systematically applied to the remaining transcripts, with additional codes added as necessary. An independent coder (ER) reviewed data for accuracy. Discrepancies were resolved through discussion until a consensus was reached. Our study follows suggested Standards for Reporting Qualitative Research.20

**Results**

Nineteen parents were interviewed. The average age of participants at the time of their stillbirth was 31.1 years (Table 1). The number of children participants reported having, including losses, ranged from 1 to 13, with an average of 4.4 children. Participants tended to be well-educated, with 48.0% having a bachelor’s degree or higher, and at least 48.0% of participants had an income higher than the median annual Utah household income of $71.6k.21

Seventeen of the 19 participants were offered one or more stillbirth evaluations. Of those, 11 reported that they chose to undergo an autopsy, three, placenta histology, eight, genetic testing, three declined all examinations, and two were not offered any.

Themes related to the uptake of stillbirth evaluation(s):

1. Facilitators
2. Barriers
3. Satisfaction or regret in the decision

Facilitators to Stillbirth Evaluation

We asked participants why they did or did not consent to fetal autopsy, placental histology, and genetic testing. The most commonly reported reason was due to personal values and beliefs. For example, having a strong belief in science, wanting the information to inform future pregnancies, altruism, or they simply wanted to know why. The following are examples, with quotes from participant interviews, of the values and beliefs that contributed as facilitators to the stillbirth evaluation decision.

“*I really wanted the autopsy. For me that wasn’t weird, to be offered that, just because I have more of a medical based occupation. I have dissected cadavers, and I like knowing the reasons why. I was like, why did this happen?*” – Participant 4

“*I worked in medical field for almost 20 years, and my husband is very much into finding out as much weak information we could if we—for future pregnancies, so we definitely wanted to know what had gone wrong and answer some questions that we had in our own minds about what had gone wrong.*” – Participant 5

“*I remember that I pretty enthusiastically agreed because I believe in science, and having more information is helpful to me on a personal level. Also, HELLP syndrome in particular is still being researched.*” – Participant 6

Parents who chose placental histology or genetic testing but declined fetal autopsy also stated how they desired some understanding of the cause, yet felt protective of their baby.

“*Ultimately, me and my husband decided that we didn’t want an autopsy done on her and that, due to the genetic testing coming back with no real answers, that there would be no need to find out what was wrong with her.*” – Participant 13

The information parents received also contributed as a facilitator to consenting to stillbirth evaluation(s). When asked how evaluations were offered, responses ranged from not receiving any information to an in-depth conversation supplemented with educational reading material. Those who chose to have at least one of the stillbirth evaluations (n=14) remembered more about the evaluation options offered and how the information was presented to them. For example, three participants received an informational pamphlet and six were enrolled into a fetal autopsy study not related to this work.

The six participants who opted to get an autopsy as part of another study were presented with the most information and several expressed altruistic reasons for participating.

“*You know what? They had a clipboard, and they had some papers, and they pretty much talked me through the choices that I had. They explained to me about the study that they were doing and whether or not I wanted the autopsy.*” – Participant 7

Additionally, one of the participants saw medical providers treat their baby with respect, which was expressed as a facilitator for choosing autopsy.

“*We had the time that we needed. They treated him just like a baby, even though he was the size of my hand and was dead. That was really helpful. That made the choice to do the autopsy that much easier because it didn’t feel like oh yeah, okay, here; we’re just gonna treat this like we’re dissecting a frog in biology*.” – Participant 9

Barriers to Stillbirth Evaluation

Personal values and beliefs also were cited as the main reasons for declining evaluations, typically fetal autopsy. Participants said they declined one or more evaluation to: protect their baby from the harm they imagined was caused by the procedure; to spend more time with their baby; cost; or because they believed they already knew the cause of death prior to being offered the evaluations.

“*She's my angel looking after me. I didn't want to put her through that.*” – Participant 14

“*I needed to spend the time with him and have the keepsakes of him were taken care of, and I don’t think I needed anything outside of that*.” – Participant 17

“*They did offer it* [autopsy & genetic testing]*. They said it was not covered by my insurance.*” – Participant 15

“*It was my cervix, so I had that answer. I didn't want to disturb her little body, so we decided not to.*” – Participant 16

Medical providers were sometimes the barrier to obtaining a stillbirth evaluation. In several cases, the participant received a diagnosis before being offered any of the evaluations, which contributed to their decision to decline an evaluation. Additionally, some participants said their provider recommend against an evaluation, even if the participant asked for one. These participants also expressed lingering resentment towards their provider for not supporting their wishes.

“*It seemed like we had to push and pry to get testing done. ‘Well, if you guys are really worried about it, we could do an autopsy, but it’s gonna cost money.’ It’s like, well, how much? It’s like $100. It’s like, you kidding me? In the grand scheme of medical expenses, that’s nothing*.” – Participant 12

The last barrier identified was not recieving information about the evaluations. Two participants were not offered evaluation options. Nonetheless, they expressed that they would have liked to have been told about their options.

“*I think any knowledge, any option is good because a lot of times you could go to a doctor if you have any questions, like now, would you want to know? I don’t know unless I’m offered*.” – Participant 19

Satisfaction or Regret in Stillbirth Evaluation(s) Decision:

Sixteen of the 19 participants expressed satisfaction about their stillbirth evaluation decision regardless of their choice. The main reasons most participants gave for being satisfied with their decision was knowledge about the cause or because they felt they did everything they could. Several also expressed that the results helped them cope with the loss or that they felt relief from the results.

Represetative quotes from participants who opted for one or more evaluation:

“*Absolutely, yeah. Yeah, definitely. I’m now pregnant again and I think it is helpful to have that information*.” – Participant 1

“*I feel like that one, we handled it the best. We did everything we could*.” – Participant 3

“*I would have regretted not having had that information*.” – Participant 6

Represetative quote from a participant who declined evaluations:

“*Just because we already knew her condition and what she was diagnosed with. I truly just believed it was just a very rare situation. …I didn't want to put her through that.*” – Participant 14

Most participants did not regret their stillbirth evaluation decision.

“*I guess me, personally, I don’t see the downside of the autopsy. It didn’t seem like there was much of any noticeable expense to it. I wish I could say that, yeah, we got all this useful information from it. I don’t know that we did, but at least I can look back on it and say, “You know what? At least we tried,” or at least if there was something super obvious as to what happened, we would have found out*.” – Participant 12

The only regret that was expressed was from one participant whose decision was not realized and from the two participants who did not receive information about their stillbirth options.

“*It definitely was [frustrating] to leave the hospital and not really have a definite answer on why it happened and how it could happen if I happen to get pregnant again.”* – Participant 15

“*I think at least—I would have like to know about the histology of the placenta. Even the genetic testing, I think that—I don’t know if that would be able to tell me more or not, or the doctors more or not. We don’t know unless we find out, unless we look.*” – Participant 19

**Discussion**

Main Findings

The stillbirth evaluation decision comes at a time when parents are grieving the loss of their baby, maternal physical exhaustion from the birth, or maternal impairment from anesthesia or opioid medications for pain. This level of distress decreases one’s ability to make decisions22 at a time when numerous other decisions must also be made, such as funeral arrangements and when and how to tell to friends and family of the loss. Conflicting desires and needs (e.g., wanting to spend time with the stillborn, not wanting to harm the baby, wanting answers to causes) further complicates decision making. Among participants in this study, this decision-making aligned with the knowledge, values, and existing parental beliefs prior to the event. Unfortunately, misconceptions about medical evaluation contributed to declining one or more evaluations, most often fetal autopsy.

Decision-making for stillbirth evaluations is often impacted by emotions and parental readiness.23 In the present study, the reasons expressed for consenting to an evaluation varied by type of examination. Parents who consented to fetal autopsy wanted to understand why their baby passed away. They approached their decision with more deductive reasoning than emotions and were more likely to point to how their science or medical background made them feel comfortable with their decision. Those who chose placental histology or genetic testing over fetal autopsy often didn’t want to harm their baby, but desired information about the cause of their stillbirth. Other reasons for consenting to one or more of the stillbirth evaluations were a desire to understand whether they were to blame, to inform possible future pregnancies, and the respect shown by the medical team towards the stillborn and parents. Those who choose one or more of the evaluations often expressed a desire to contribute to the scientific knowledge about preventing future stillbirths and to help others who may have suffered a loss.

Limitations

Patients were recruited from a single hospital, were more likely to be non-Hispanic White, well educated, wealthier, and at least 40% belonged to The Church of Jesus Christ of Latter-Day Saints. Our cohort may not represent the general population and it is well understood that stillbirth occurs at higher rates among minoritized and socioeconomically disadvantaged groups.24,25 However, our participants’ shared experiences were similar to two other research cohorts from around the world.23,26 Additionally, recall bias and the highly distressing nature of a stillbirth may have also contributed to some of the participants not remembering the details about their experience.

Interpretation

The reasons for declining stillbirth evaluations are varied and complex. Previous research identified several reasons for declining evaluations including complexity of the consent, emotional stress of the situation, lack of information for families and providers, mistrust, and belief that no new information will be found.23,27 Among participants in this study, the most common reason stated for declining a stillbirth evaluation was that they had already received a probable cause of the stillbirth before any of the examinations were offered. They believed that no new information would be found with further testing. However, fetal autopsy is known to correct major errors in the clinically determined cause of stillbirth 24.3% of the time.28 Participants in this study expressed that even in the case of inconclusive results, actively doing something for their baby or confirming that they were not responsible for the death is valuable to parents and their healing process, consistent with findings of others.6,8,29

Our participants were more often misinformed about fetal autopsy than other tests. Several participants expressed a desire to protect their baby from the harm inflicted by an autopsy without knowing what the procedure entails or the other evaluation options. Meaney et. al. indicated that parents’ misperceptions about the invasiveness of autopsies were based on the dramatization seen on television.23 However, the autopsy exam may be done at varying levels of invasiveness, with targeted options that assess part of the body or radiographic-only exams, which do not require any incisions.30,31 Even with a full fetal autopsy, the incisions are created similar to a surgery and stitched afterward.32 Clothing and a cap can be used to cover the incisions if the patient desires an open casket funeral.

These misconceptions could have been addressed through better communication or educational materials. Decision aids are tools that support informed decision making in medical situations where there is often no “best” option.33 A decision aid for stillbirth evaluations could explain the level of invasiveness of each examination, and for parents who are uncomfortable with a full fetal autopsy, a decision aid can present alternatives, such as partial autopsy, computed tomography, ultrasonography, or magnetic resonance imaging.31,34 The creation and utilization of this decision aid would provide unbiased information, increase capacity for shared decision making between patients and their providers, and reduce decisional conflict of those faced with uncertainty.

Hospital-level factors contributing to stillbirth evaluation decision-making include the necessity to make many other decisions concerning the stillbirth, a lack of provider training, and limited time available for medical providers to communicate with bereaved parents.35 The limited time providers have to inform and answer questions about stillbirth evaluation options and procedures, leave many parents making a decision based on the information they come into the hospital with. Participants in our study unveiled several examples of how they were misinformed. For instance, some parents chose to decline evaluations because they erroneously thought that it precluded them from spending time with their baby. In another case, they declined an autopsy because they said they couldn’t afford it. However, the hospital where they received their stillbirth care covers the cost of fetal autopsies.

Another key area that could facilitate the decision to consent to stillbirth evaluations, is educating clinicians and hospital staff on best practices for interacting with grieving parents.35 Within our cohort, some women shared gratitude about the care they received in the hospital despite their shock of discovering their baby had passed. Yet others expressed frustration concerning interactions with providers, which lingered in the months to years after the stillbirth. Physician communication training programs have been successfully created in other medical fields, such as primary care.36,37 By giving clinicians the skills they need to communicate with patients about difficult topics, the patient is more likely to receive care that supports their values and needs.

Finally, in addition to the emotional trauma of stillbirth, there are numerous decisions that must be made within a small timeframe for which the parents, and sometimes hospital personnel, are not adequately prepared to deal with. Parents in this cohort who were not offered stillbirth evaluations or had their requests denied expressed dissatisfaction with the medical system. Negative experiences like these color the stillbirth experience for the parents for years afterwards but could be minimized through provider training and educational materials that facilitate shared decision-making.

**Conclusions**

Stillbirth evaluations improve etiological understanding for parents, and the care providers and researchers trying to identify risk factors to prevent stillbirth. We identified patient barriers to choosing autopsy among parents who had experienced a stillbirth. Two major barriers to autopsy consent were a misconception regarding prohibited time spent with the baby and that no new information would be identified from an evaluation. Providers could potentially improve uptake by educating and offereing stillbirth evaluations, supporting parents’ wishes, and treating their baby with respect.

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**Contribution**

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Naomi Riches: formal analysis (lead), writing – original draft (lead); writing – review and editing (equal)

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**Ethics Approval Statement**

Ethical approval for this study was granted by the University of Utah Institutional Review Board (IRB\_00133359).

**Supplemenatary Materials**

Supplementary Table 1 – Semi-structured interview guide

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