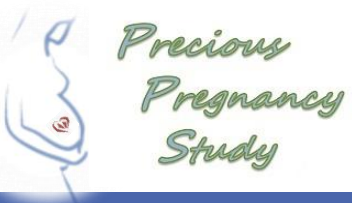


Parents' Reactions to Multi-disciplinary Perinatal Palliative Care During Pregnancy with a Lethal Fetal Diagnosis

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Background & Significance



- Prenatal testing is now routine
- 2% of fetuses diagnosed with life-limiting diagnoses
- 20-85% of mothers choose to continue with their pregnancy
- Learning of an LFD causes significant grief
- No prospective studies describe prenatal period with a known LFD
- No studies describe father's role or experience
- Few studies examine parents' needs from health care

Purpose

1. To describe parents' overall experiences of continuing pregnancy with a known lethal fetal diagnosis.
2. To describe the parents' experiences with and needs from health care providers.
3. To examine experiences with perinatal palliative care.

Methods

- Longitudinal, naturalistic design
- Inclusion criteria: 18 yo or older; single gestation; fetal prognosis < 2 mo.; continuing pregnancy; speak English; spouse/partner if willing
- 2 prenatal, 2 postnatal interviews (in person, telephone, Skype)
- Parents interviewed together and separately
- Transcripts, field notes & blogs



Data Analysis

- Began with data collection, through coding in Atlas.ti 7, writing
- Individual and team agreement
- Within case and cross case analysis
- Within gender and cross gender analysis
- Memos, codes
- Time periods, themes

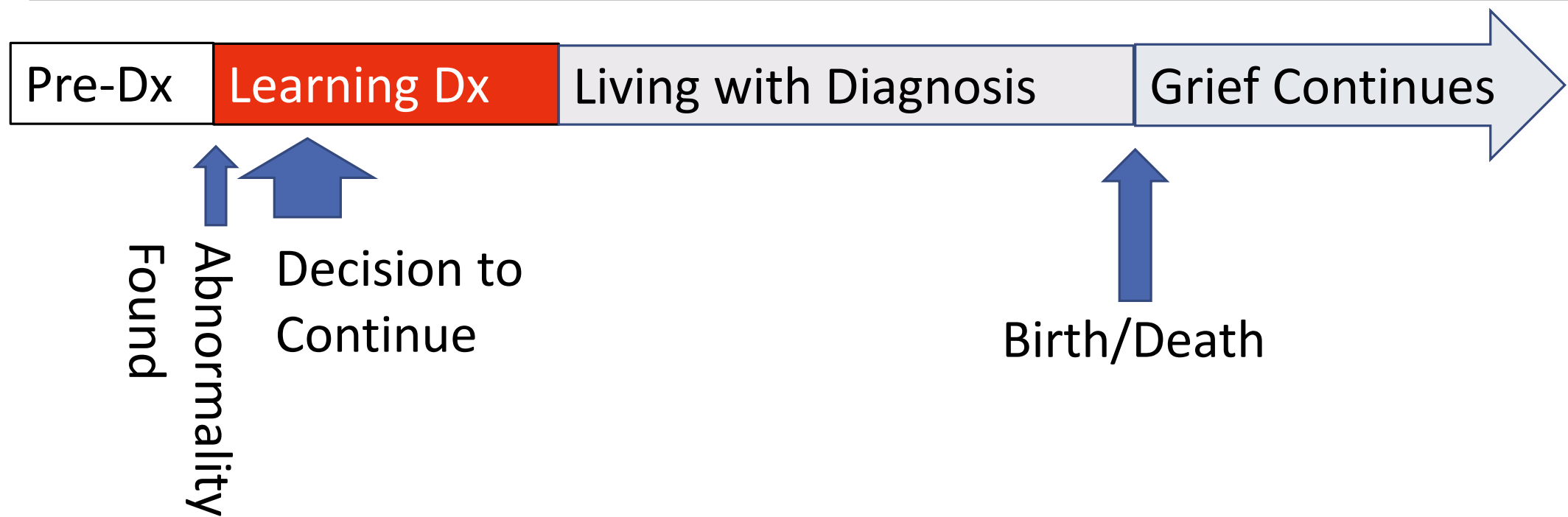
Results

Sample (N=30)

- Recruited through care providers; 6 centers, 4 states
- 16 mothers; 13 fathers, 1 female partner
- Diversity in race, income, education
- 6 first pregnancies; 9 with other children
- Diverse fetal diagnoses (trisomies; renal/low fluid; etc.)
- 90 interviews ranging 30 min-2 hrs.



Results: Time Periods of Pregnancy



Multi-disciplines

“I’ve seen more than 30 people in the last four months”

“I've lost track of how many doctors I've seen. The day is just a one big long string of nurses, doctors, consults, IV's, monitors.”

Sonographers

Social Workers

Obstetricians

Doulas

Nurses in OB office

Support Group

Genetics Counselors

Bereavement
Counselors

Maternal-Fetal-
Medicine Physicians

Hospice Nurses

Pediatric Cardiologists

Palliative Care Doctors

Neonatologists

OB inpatient nurses

Interactions with Care Providers

Helpful interactions:

- Honest, straight forward
- Reduce the power differential between provider & parents
- Understand needs & expectations of parents
- Write down information or give brochures
- Provide all options
- Avoid judgments

Taking their time

“He has always made us feel like we could ask as many questions as we want. We have never felt *rushed*.”

“The guy kind of—the doctor that did that and everything seemed like he just didn’t give a shit basically. He just wanted to hurry up and just get us moving along and that was it.”

Interactions with Care Providers

Interactions that added to parents' burden:

- Withholding information
- Wait times; waiting rooms
- Rules

Neutral: neither helpful or non-helpful

- OK- no harm done

Waiting Times

“I realized that like it was torture. It was terrible because I really think that we—I don’t think I slept any. I think we lived in hell that whole time period. It was terrible. It was terrible.”

Knows the Situation

“Like going to the OB, it doesn’t seem like any of the nurses know our situation. When we go in there, it’s kind of like, they always ask me, “Oh, so are you ready for the baby?” like it’s a normal pregnancy. That’s kind of hard, but all the doctors seem to know what’s going on.”

Lack of Caring

“I felt like nobody really cared. I was like, “What am I, Supposed to just have her and let her die? Are you all not going to take any methods of trying to save her life? What is going to happen?”

Lack of Caring

“I had one “nurse” come in and tell me they have check B-n’s hearing... and I quote “He has Trisomy 13, he is not going to hear” and NEVER checked him!!!! This was the thing that killed me!!... If there is anything from this study that I can help change- make sure the nurses that are in this situation are ones that really care; not ones that “fake caring”. As a parent in this situation, the last thing you need is a nurse to make things more difficult than they already are.”

Honesty

“Just be compassionate but be upfront, be honest.”

“I do appreciate that it was just upfront and said, ‘Listen, this is what it is.’ I appreciate the fact that they didn’t beat around the bush.”

“They didn’t want to tell me that she passed away. I would get very upset with them, but I was really delirious—They were trying to protect me from being hurt, but I’m like **I’m going to be hurt regardless.**”

Guiding Principles for Providers

- Know the Story
- Recognize their Journey
- Encourage their Parenting
 - Promote Understanding
 - Provide Options
 - Facilitate Decision-Making
 - Nonjudgmental Guidance
- Be Sensitive to Unique Needs
 - Caring
 - Reframing Hope
 - Reduce Burden
 - Read the Mood
- Respect Personhood of Baby



*Precious
Pregnancy
Study*

Know the Story

“I'd never met her before. Um, and I was already a mess just because this was all still so new and I was just scared to death about what was going to happen...She came in and..started the ultrasound. And after a few minutes, her first question was, um, have you had a fetal MRI? (sigh) And I realized that she didn't know anything.”

Providing Options

“That’s when the lady was just telling her, you know, “You have this option and it’s not looking good. You should basically choose to do this.” **I was very upset because I felt like that was the only option they were giving her.** You weren’t really sure that’s what was wrong at that point so I felt that like it was just—they were pushing her and she was very upset and vulnerable. I just wanted to leave. I was upset. Eventually, we just ended up leaving and deciding on our own at home away from the people that were there because they were very negative.”

Maintain Hope

- “We know all the bad things. We kind of wanted to see the good things.”
- “Even though I know what the outcome may be, just the fact that she just gave me that little bit of hope and she made it clear that I’m not trying to lead you in any way, but this is what we have to do as doctors...Her tone...the doctor that came and talked with me and my son, he had like—he was nice about it, but it just was so all just so downhill-like and it just was so depressing to talk to him.”

Respect Personhood of Baby

- “The doctor even asked us if we had a name picked out for the baby before he told us the results. That tiny gesture right there skyrocketed my respect for him.”
- “Just treat him like a normal baby.”

Interactions with Sonographers

- Had profound impact on parents- positive & negative
- Sonographers had the power to access the fetus for the parents
- Sonographers need to ask parents their expectations
- Treat baby as a person; call by name
- Help parents be parents.

Time with Baby



- “If our baby, our prognosis is terminal, the only time we will get to see her active and moving is during the times that we get to see her on ultrasound.”
- “I don’t know that it really changes much, but I think it’s really wonderful.. This may be the only opportunity that we actually have to meet her in all her life.”

Engaged Interactions Preferred

“We had a great ultrasound technician, wonderful guy. He was just—He was very straightforward. There was no silence...He spoke to us through everything and just made M feel, ‘Listen you guys, I’m with you through it.’ He’s told us everything.”

Provider Continuity

“Especially now, since I’m so far along, I’d rather to be seen by the same people...I don’t want you asking me...what’s been going on...That way I won’t have to keep explaining myself to those people.”

Palliative care access

Prenatal Palliative Care Consultation:

“[Things were] not very clear and these guys explained everything right to a T, helped you understand, helped you to know all the options you’d have and just said they were there a hundred percent no matter what you decided... they would go with what you did decide and they would take you through it and guide you through it. I just thought they were exceptional in what they do.”

Perinatal Palliative Care

- “I asked about the comfort care, you know, did N provide it and everything. I kind of got the idea from my doctor that– like I don’t think he does this and everything...I was like, ‘Well, what could be done for the baby, you know, oxygen, morphine?’ He’s like, ‘We’ll just let you hold him.’ That’s what he told me comfort care was.”
- Perinatal Hospice RN
 - Went to appointments with them
 - Attended delivery
 - Hand-picked floor nurses

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Future of Perinatal Palliative Care

- Requires multi-disciplinary team approach
- Remove power differential whenever possible
- Have a care coordinator; nurse is ideal
- Need standards of care
- Research needed on models of care