
Parents' Experiences of Continuing Pregnancy with a Lethal Fetal Diagnosis: Goal, Stages, Tasks of Pregnancy

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Learner Objectives:

- 1) State the research design and method used in this study
- 2) Explain the relationship between the identified stages of pregnancy and the revised tasks of pregnancy



Background

- Prenatal testing is now routine; anatomy scan usually done 18-20 weeks gestation
- 3% of fetuses diagnosed with congenital anomalies (WHO, 2014)
- Approximately 2% Life-threatening (CDC, 2015)
- 20-85% choose to continue with their pregnancy (ACOG, 2009)
- Learning of an lethal fetal diagnosis (LFD) causes significant grief
- Little is known about parents' pregnancy experience with a known LFD



Pregnancy as Developmental Process

- Not just biophysical but also psycho-social process for the mother (Côté-Arsenault, Brody & Dombeck, 2009; Rubin, 1984).
- Involves a series of predictive tasks to be mastered in order to accomplish goals and achieve parent roles (Rubin (1975), Cranley (1979), Müller (1992))
- Holistic Care -> recognizes the developmental nature of pregnancy for both parents, and addresses all needs

Study Purpose

1. To describe parents' overall experiences of continuing pregnancy with a known LFD.
2. To understand how the developmental tasks of pregnancy are altered in an LFD



Inclusion Criteria

1. Women pregnant with a fetus with lethal diagnosis (prognosis \leq 2 mos) + spouse/partner if willing
2. Recruitment as close to fetal diagnosis as possible
3. Single gestation
4. English speaking



Methods: Qualitative Interview



- Longitudinal, naturalistic
 - 2 prenatal interviews
 - 2 post birth/death interviews
- Audio recorded
- Professional transcription
- Verification of transcripts
- Data managed in Atlas.ti

Methods: Qualitative Analysis

- 2 or more cycles coding
(Miles, Huberman & Saldña, 2014)
- Weekly research team meetings
- Descriptive and category codes
- Iterative process of coding
- Theme identification
- Within and cross-case analysis



Sample ($N=30$)

- Recruited through MFM centers, genetic counselors, bereavement counselors, word-of-mouth
- 5 centers, 4 states
- 16 mothers
- 14 partners (13 fathers, 1 female partner)
- Diverse couple race, income, education
- 90 interviews; ranging 30 min-2 hrs.

Obstetrical History of Mothers

Number of pregnancies			
Range	M(SD)	1-8	2.6 (2.0)
History of Infertility (N)			3
History of miscarriage (N)			3
Number of living children			
Range	M(SD)	0-7	1.5(1.9)

Demographics of Sample

		Mothers		Fathers/Partners	
Age Range	M(SD)	22-42	32.9(5.5)	21-49	33.64 (7.2)
Race	N(%)				
	Caucasian	11	(68.8%)	10	(62.5%)
	African-American	3	(18.8%)	2	(12.5%)
	Hispanic	1	(6.3%)	2	(12.5%)
	Asian/Pacific Islander	1	(6.3%)	0	
Education in years					
Range	M(SD)	12-21	15.1(2.8)	10-19	13.9 (2.9)
Family Income					
	Range (median)	0 - > 120,000		(\$60-80,000)	



Results: Overall Impression

- Diagnosis of an LFD is a crisis
- Parent goals, expectations, & needs changed over time
 - Stages of Continuing Pregnancy identified
 - Developmental Tasks of Pregnancy are altered from typical pregnancy
 - Overall Goal of parents identified



STAGES OF PREGNANCY

PRE-DIAGNOSIS

LEARNING DIAGNOSIS

LIVING WITH DIAGNOSIS

BIRTH & DEATH

POST DEATH

DEVELOPMENTAL TASKS

Navigating Relationships

Comprehending
Implications of
the Condition

Revising Goals
of Pregnancy

Preparing
for Birth and
Inevitable
Death

Making the Most
of Time with Baby

Advocating for Baby
with Integrity

Adjusting to
Life in Absence
of Baby

OVERALL GOAL

No Regrets

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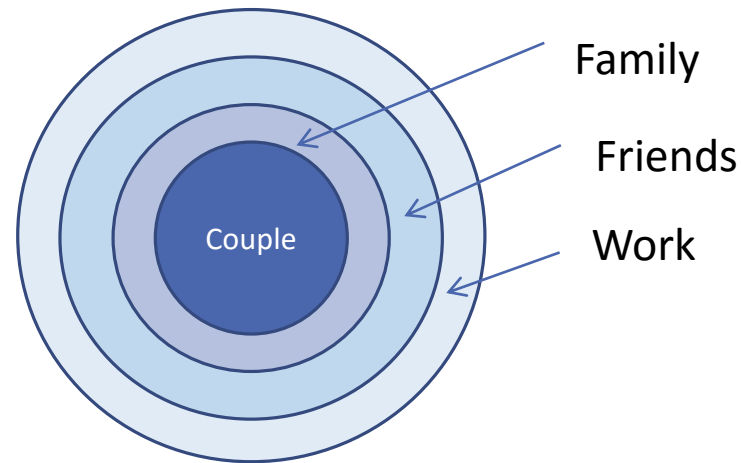
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OVERALL GOAL

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Navigating Relationships

- Parents have family and friends awaiting news
- Relationships are important and necessary during pregnancy
- Parents intentionally expand or restrict their social circles



Navigating Relationships

RESTRICTION

[Day of diagnosis] “The rest of that evening, it was very hard to tell our families. They wanted to be here right away. I guess we just kind of—we didn’t want anybody here. There was no way we were going to begin to deal with our own emotions if we have to deal with other people’s emotions as well.”



EXPANSION

“I went from being very private to like singing it to the rooftops like, ‘Who wants to see my photos? Let me just tell you the whole day.’ I’ve really sparsed down how much I share sometimes because it does, it opens up a lot of emotion.”



Comprehending Implications of the Condition

“I didn't understand why, why do babies with this condition not survive? I did not understand, like if her heart is not in that bad shape, and if it's fluid in her brain, I know that's bad, but they can do things about that. I did not understand why can't she survive? (sigh)

After explanation about lung prematurity:

“That was so helpful. It was *so* helpful. Because I finally understood what it was that meant life or death...*I want to know, I want to understand it.*”

“I wanted to know what was next. You're still pregnant and still have this beautiful baby that you're expecting and now you have to know where to go from here.”

Revising Goals of Pregnancy

- Previous goals & expectations for a healthy baby no longer possible
- What can be hoped for?
- Parenting must happen now
- Treasure baby now



“We kind of have a motto, ‘Five minutes at a time,’ but we do have a lot of comfort knowing that we’re doing the right thing and we’re going to get to see her and meet her. We just pray that she’s with us for a short time and how she can feel our touch and hear our voice.”

Making the Most of Time with Baby

“We started reading. A couple of weeks ago, we decided we’d start reading a book each night before we go to bed...For me personally, I think that makes me feel more connected to [her].”



- Acceptance of baby in actual condition
- Making the most of the time they have
- Concentrated or accelerated parenting

Preparing for Birth & Inevitable Death

- Medical Decision-Making
- Writing a birth plan
 - Provided parents a sense of control
- Other children
- Planning rituals/memory making
- Preparations cut short in preterm birth

“Meanwhile we were making this birth plan and talking about a C-section date...I don't know that we would have been able to say this at the time, but it felt like we had a little bit of control over how this was going to happen. And, and we could kind of think about what it was going to look like.”



Advocating for Baby with Integrity

- Making decisions that seem best to them
- Following through with their plans
- Not giving up
- Being a “good parent” starts during pregnancy
- Honoring personhood of the baby

“At least I’ll be able to look in her face and tell her I love her, hold her, and let her know that I did try all I could.”

“We couldn’t just, NOT!..but we had to try—I mean [we] put up a hell of a battle for these last months. Why can’t we fight a little more for her now, that we have some control? I think we...did what was right for her.”

Adjusting to Life in Absence of Baby

“Yes, we have his hand and foot ink prints in our bedroom... We got his candle that has a picture of him that we had for his funeral and a picture of each of us in the family holding him. It’s kind of like a big family grouping.”

- Grief and Bereavement
- Honoring the Life of Baby
- Rituals
- Weaving baby’s memory into fabric of family

“I just want him to be significant to the world, not just me (choked up). I think of our memories of him. We’re really excited to get our pictures. We’re really glad that some of our family got to meet him because it just makes him part of their lives too... I think just memorializing him now is important to us.”



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OVERALL GOAL

No Regrets

Overall Goal: Have No Regrets

“Our resounding theme in all this is we feel like we made the right choice.”

“I don’t think we regret our decision ever. I mean I don’t think we’ll ever look back and say it was too hard; we wish we hadn’t done it because even though we lost [Baby], this has been the most miraculous time of our lives.



Conclusion

- Parents in this study were guided by their overall goal to “Have No Regrets” afterwards
- Newly identified tasks of pregnancy for parents continuing pregnancy with LFD can guide and improve care
- Fathers contributed a great deal and appreciated being in the study
- Prognostic certainty impacted movement through revised tasks
- These parents were inspiring by their commitment to their babies.



QUESTIONS?



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