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"Have no regrets:" Parents' experiences and developmental tasks in pregnancy with a lethal fetal diagnosis

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ABSTRACT

Significance: Lethal fetal diagnoses are made in 2% of all pregnancies. The pregnancy experience is certainly changed for the parents who choose to continue the pregnancy with a known fetal diagnosis but little is known about how the psychological and developmental processes are altered.
Methods: This longitudinal phenomenological study of 16 mothers and 14 fathers/partners sought to learn the experiences and developmental needs of parents who continue their pregnancy despite the lethal diagnosis. The study was guided by Merleau-Ponty's philosophic view of embodiment. Interviews ($N = 90$) were conducted with mothers and fathers over time, from mid-pregnancy until 2–3 months post birth. Data analysis was iterative, through a minimum of two cycles of coding, theme identification, within- and cross-case analysis, and the writing of results.
Results: Despite individual differences, parents were quite consistent in sharing that their overall goal was to "Have no regrets" when all was said and done. Five stages of pregnancy were identified: Pre-diagnosis, Learning Diagnosis, Living with Diagnosis, Birth & Death, and Post Death. Developmental tasks of pregnancy that emerged were 1) Navigating Relationships, 2) Comprehending Implication of the Condition, 3) Revising Goals of Pregnancy, 4) Making the Most of Time with Baby, 5) Preparing for Birth and Inevitable Death, 6) Advocating for Baby with Integrity, and 7) Adjusting to Life in Absence of Baby. Prognostic certainty was found to be highly influential in parents' progression through developmental tasks.
Conclusion: The framework of parents' pregnancy experiences with lethal fetal diagnosis that emerged can serve as a useful guide for providers who care for families, especially in perinatal palliative care. Providing patient-centered care that is matched to the stage and developmental tasks of these families may lead to improved care and greater parent satisfaction.

The majority of couples embark upon pregnancy, assuming that they will have a healthy child. Parents expect prenatal tests to confirm that everything is going normally with their pregnancy. Hence, those who are told of a lethal fetal diagnosis (LFD) experience intense grief and shock when their expectations are shattered (Côté-Arsenault and Denney-Koelsch, 2011; Lalor et al., 2009; Sandelowski and Barroso, 2005). In 3% of fetuses, conditions exist that are life-limiting and 2% are considered lethal (Coleman, 2015). Under these circumstances, 20–60% of parents choose not to intervene, and continue their pregnancies (Breeze et al., 2007; Leuthner and Jones, 2007; Walker et al., 2008). Factors influencing parent choices include their views on abortion, prognostic certainty of fetal condition, concern for what is best for the affected baby, and personal choices of the effect on one's family and relationships having an impaired child to care for (Sandelowski and Barroso, 2005). This study focused on those parents who continued their pregnancies with a LFD.

1. Conceptual framework: pregnancy as a developmental process

Viewing pregnancy as a developmental process provides a normative approach to an anticipated human development event. A developmental task is a psychosocial process that is undertaken to continue growth or change, sometimes undertaken simultaneously or, more often, the completion of one makes way for

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another to begin. Developmental theories, such as those of cognition or learning, vary in their assumptions regarding whether stages or tasks are discontinuous or continuous, and whether everyone goes through them in exactly the same way (i.e. multifinality) (Cicchetti and Rogosch, 1996; Kail and Cavanaugh, 2010). While pregnancy developmental theories are not as refined as child developmental theories they can serve as a general guide to care providers to assess parent's focus and motivations across pregnancy and parenting. In the instance of pregnancy the developmental tasks move an individual as they move from not-parent to parent-to-this-child.

As many scholars have noted, pregnancy is a time to prepare for parenthood for both mothers and fathers. Mothers undergo physical, psychological and social processes to achieve their maternal identity (Flagler and Nicoll, 1990; Nelson, 2003; Rubin, 1976, 1984). Rubin (1984) described four tasks in pregnancy to achieve maternal identity 1) ensuring safe passage for mother and child, 2) ensuring acceptance of the child, 3) binding-in, and 4) giving of oneself. Less is known about fathers' development during pregnancy, but they appear to undergo a similar psychological and emotional transition (Valentine, 1982). In a meta-synthesis of 13 studies, Kowlessar et al. (2015) found that fathers' experiences moved from feeling distant from the pregnancy in the first trimester, to reaching acceptance and becoming emotionally invested in the second trimester, when they can feel the baby move. In the third trimester, fathers redefined themselves as a father and left their old self behind (Kowlessar et al., 2015). It is clear that pregnancy is life-changing for both mothers and fathers.

In the situation of a LFD, the developmental processes of pregnancy are likely changed when it is known that there will be no healthy baby to parent. O'Leary (2009) identified revised tasks in pregnancy subsequent to perinatal loss due to the parents' grief and fear of another perinatal loss. While no literature was found that specifically addressed altered tasks of pregnancy in the case of LFD there is evidence that the social aspects of pregnancy are altered after a fetal diagnosis. Sandelowski and Barroso noted that women with a prenatal diagnosis sought “stigma management” when they experienced fear of what others may think of them post diagnosis (2005, p. 315). In the prior work of the authors of this current study and that of others, parents reported feeling “utterly alone” and disconnected from family and friends after sharing their baby's diagnosis (Côté-Arsenault and Denney-Koelsch, 2011, p. 5) and mothers have said that they feel like public property surrounded by expectations of a healthy baby (Smith et al., 2013). Because a pregnancy removes usual social barriers in public places, all of these mothers reported that their social interactions were often awkward and isolating.

Prenatal attachment, or binding-in to baby, is a complex process under the most routine circumstances (Rubin, 1984). Parental withholding of emotional attachment has been noted in some pregnancies when the future with the baby was uncertain (Côté-Arsenault and Donato, 2011; Rothman, 1986; Laxton-Kane and Slade, 2002). Our prior work has shown that parents felt attached to their babies with LFD, valued them as a person, and took measures to care for themselves in an effort to improve fetal outcomes (Côté-Arsenault and Denney-Koelsch, 2011; Côté-Arsenault et al., 2015).

2. Pregnancy loss

Pregnancy loss, at any gestation or in the neonatal period, is known to cause intense grief for many from a deep sense of loss for a wished-for child but also for one's sense of self, their role as a parent, their ability to be a biological woman, and a sense of safety in the world (Côté-Arsenault, 2011; Côté-Arsenault and Mahlangu, 1999; Garstang et al., 2014; Hill et al., 2008). Prior pregnancy loss may also negatively impact subsequent pregnancy experiences, parenting, and child outcomes due to fear of another loss, anxiety during pregnancy and hypervigilance of living children (Blackmore et al., 2011; Côté-Arsenault, 2007; O'Leary and Warland, 2012; Theut et al., 1992).

2.1. Fetal diagnosis

A fetal diagnosis infers that the fetus has a condition, syndrome, or abnormality that is pathological. Life-limiting fetal diagnosis implies that the condition will shorten the life of the baby; lethal fetal diagnosis is defined here as a condition will lead to death at any time up to 2–3 months after birth.

Amidst the grief and anticipated loss with a LFD, parents can also experience some positive outcomes. Personal growth after LFD was identified in 18 out of 25 parents by Black and Sandelowski (2010). Lalor, Begley and Galavan also found that women had “re-casted hope” as a result of their coping and adaptation to fetal diagnoses (2008, p. 462). Lalor and colleagues (Lalor et al., 2009) described women's adaptation to fetal diagnosis in the Republic of Ireland, where termination of pregnancy is not legal. Their resulting theory depicts, across the women's pregnancy experiences, their pre-ultrasound *Assume Normal* stance of their pregnancy through the *Shock*, *Gaining Meaning*, and *Rebuilding* processes of coping and decision-making regarding continuing or terminating the pregnancy. Two different information seeking styles—high information seekers and information avoiders— were also identified (Lalor et al., 2008) suggesting that care providers should match their approach to women's preferred style.

Beyond the prospective research of Lalor and team (2008; 2009), the body of knowledge of parent experiences of continuing pregnancy with a known life limiting fetal diagnosis is sparse. A limited number of studies focused on a single fetal diagnosis, and others provided retrospective accounts. Two additional prospective studies described parents as being shocked, finding the pregnancy intensely difficult, but nonetheless, loving their baby as a person (Côté-Arsenault and Denney-Koelsch, 2011; Smith et al., 2012).

Normal pregnancy is a time-limited, nine month gestational process, often divided into three 13 week trimesters, or more recently, as 40 weeks of gestation for fetal development (Jorgensen, 2010). However, Sandelowski and Barroso (2005) describe pregnancies as being experienced as two halves since the advent of routine prenatal testing: pre- and post-testing. Indeed, the issue of the marking of time in pregnancy is a common finding in the studies on response to fetal diagnosis. Smith, Dietsch, and Bonner (2012) reported that time was distorted for parents who continued their pregnancy with a serious or lethal fetal diagnosis as they took in the reality of their baby's diagnosis and mindfully enjoyed their time with baby. Across all prospective studies the dimensions of the pregnancy experience varied from being a process of adaptation, or an experience of time distortion. Seeking to make sense of time during pregnancy seems to be inherent in the experience.

All studies indicate that learning of a life-limiting fetal diagnosis dramatically changes the experience of pregnancy (Côté-Arsenault and Denney-Koelsch, 2011; Lalor et al., 2009; Smith et al., 2012). Notable gaps in the literature include father's perspective and details of the developmental process after choosing to continue the pregnancy. This study was designed to address both of these gaps. Therefore, the broad purpose of this investigation was to prospectively describe parents' lived experience of continuing pregnancy with a lethal fetal diagnosis (LFD). Within this broad goal was a secondary aim to investigate the developmental tasks of pregnancy