“I Walk with Her Every Day”: Parents’ Experiences of Pregnancy with a Lethal Fetal Diagnosis (TH316)

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Objectives
- Explain the gap in the literature that is filled by the Precious Pregnancy Study.
- State the three time periods of parent experiences with a lethal fetal diagnosis.
- Describe two key aspects of parent experiences with a lethal fetal diagnosis.

Perinatal palliative care is a growing field, although there is sparse literature about parents’ needs to inform care of families with lethal fetal diagnoses (LFD). In this session we will present the results and implications of the Precious Pregnancy Study, which significantly increases our knowledge about parents’ needs when continuing pregnancy with an LFD.

In an NINR-funded, qualitative, naturalistic study of 16 couples with LFDs, we interviewed mothers and their partners twice during pregnancy and twice after the birth and death of their baby, for a total of 60 interviews. Our aims were to understand their overall personal experiences with continuing pregnancy after an LFD and their experiences with and needs from healthcare providers.

Learning of a lethal condition during pregnancy causes a crisis in parents’ lives, with intense grief reactions, followed by a series of healthcare interactions, during which they learn and understand the diagnosis and plan and prepare for birth and death. Three time periods of pregnancy were identified: prediagnosis, learning the diagnosis, and living with the diagnosis. We will discuss how the parents’ experiences and needs changed through these three time periods.

We will describe their varied interactions with healthcare providers, and what they found helpful or unhelpful. Parents described the profound impact of ultrasounds, as a treasured moment with their baby and a conduit to understanding and making sense of the diagnosis. We will describe the ways they treasured their time with their baby, hoped for the best, parented their baby, and negotiated interactions with their family and social group.

Finally, we will present the implications of this study for healthcare providers, with practical suggestions for improving care.