

# **A Survey of Prenatal Genetic Counselors' Knowledge, Experience, and Role in Perinatal Hospice**

**Jennifer Dick, Katie Krepkovich, Lisa Demers, MaryAnn Whalen Campion**

Boston University School of Medicine, Boston, Massachusetts

Perinatal hospice entails palliative care and services provided for infants affected with a lethal condition and their families. Prenatal genetic counselors are often in the position of giving a lethal fetal diagnosis to the patient or counseling families shortly after receiving a lethal fetal diagnosis. Patients wishing to continue their pregnancies or those who are undecided regarding how to proceed should be made aware of the availability of perinatal hospice services. Therefore, genetic counselors have the opportunity to play an important role as a perinatal hospice informant and resource link for the patient. This study sought to elucidate genetic counselors' current level of involvement in perinatal hospice by surveying counselors regarding their knowledge, experiences, and role. After analyzing survey responses from 251 genetic counselors with at least 6 months prenatal work experience, we found that 88.4% indicated familiarity with the principles of perinatal hospice, and most (82.2%) described perinatal hospice as a "very important" option to routinely offer patients given a lethal fetal diagnosis. Of those counselors with prior experiences involving perinatal hospice, the vast majority (94.1%) expressed that their experiences were somewhat or very positive. However, when compared to termination and continuation options, continuation with perinatal hospice was presented to patients significantly less frequently ( $p < 0.001$ ). Further analyses indicated that perinatal hospice familiarity and the frequency of offering such services varied significantly across geographic regions and levels of prenatal counseling experience. These findings represent an overall disparity in the number of counselors who recognize the positive utility of perinatal hospice and the frequency with which it is offered to patients. Our data suggests the need for better perinatal hospice training and education so that counselors feel competent and comfortable incorporating it into their practices, as perinatal hospice should represent a philosophy of care, rather than a formalized program or facility.