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Antenatal Parallel Planning in Fetal Medicine: Hoping for the best but planning for the worst

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Objective

The British Association of Perinatal Medicine (BAPM) in partnership with Together for Short Lives charity proposes a framework of 4 groups of fetal / neonatal conditions that would benefit from paediatric palliative care input. These range from lethal conditions to extreme prematurity, severe growth restrictions or fetal conditions that may have a variable postnatal outcome. Good clinical practice entails early involvement of neonatal teams for a parallel plan (which may or may not be actioned) depending on the baby's condition at birth. The helps with better preparedness for both parents and the healthcare professionals involved at birth. However there is a variation around gestational thresholds for involving specialist teams, and also no consensus on specific eligible prenatal conditions. Late diagnosis, after third trimester scans, and not unusually hesitance around discussing "end of live care" by maternity teams who are taught to "save babies" can defer the antenatal parallel planning discussions. The purpose of this study was to evaluate the variation in practice in the UK in the offer and uptake of antenatal parallel planning for fetuses with poor long term prognosis, where the parents opt to continue the pregnancy.

Methods

Data was collected from two tertiary UK fetal medicine units (Evelina Women's and Children (London) and Liverpool Women's). Both units have access to paediatric palliative care, and are linked to neonatal hospices. Data collection included the conditions for which parallel planning was offered, gestation of discussion, teams involved, uptake of care plan after birth. The outcome data also included delivery and postnatal hospice stay details (where applicable). These data were then compared to establish a variation in practice.

Results

Data across the two units included 423 pregnancies. Data was collected from 2006 to 2022. In London (6000 annual births), there were 135 cases that were referred to paediatric palliative care - 70% singletons, and 30% multiple. The range of cases included severe (usually) cardiac abnormalities (75%), anhydramnios, anencephaly, lethal skeletal dysplasia to severe early onset growth restriction and extreme prematurity especially in multiple pregnancy. The average time of referral is between 32-36 weeks. In contrast, in Northwest Cheshire and Merseyside regions (9,000 annual births), there is a well-established referral pathway from as early as 20 weeks. Nearly 300 women were offered antenatal parallel planning between 2016-2022. Due to an earlier involvement of the subspecialist teams, there is a significant overlap between palliative and postnatal cases with stillbirth. Only a third need a formal palliative care assessment at birth. The case mix includes predominantly higher multiple pregnancy with discordant anomaly, skeletal dysplasia and renal / CNS abnormalities. There is also more flexibility around indications for end of life care in the hospice. A formal care plan allowed for lesser emergency plans, and better patient experience.

Conclusion

There is a disparity in conditions and timings of offering antenatal parallel planning by Fetal Medicine and neonatal (and / or paediatric palliative care teams) for babies with potentially short lives. There is an overlap in the accountability for care plans between Fetal Medicine and Neonatal teams. Although BAPM presents a range of conditions that would benefit from these discussions, many of these have variable course in pregnancy (in the era of prenatal exom sequencing). Parents' wishes, and limitations of medical interventions should be borne in mind, while offering the family the best fetal medicine care, preparing for the worst and hoping for the best.