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Original Article

# A fetal diagnostic center's referral rate for perinatal palliative care

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**Background:** Fetal specialists support standardizing the practice of offering women palliative care for life limiting fetal diagnoses. However, there is little data available regarding what fetal specialists do in practice. Since 2003, our center has kept a database of all women referred for fetal complications.

**Methods:** Retrospective electronic chart review of pregnant women between 2006 and 2012 using UCSD's Fetal Care and Genetics Center referral database. Objectives were to determine: (I) how many high risk pregnancies referred to the University of California San Diego Medical Center (UCSD) over a 6-year period have potentially life limiting fetal diagnoses; (II) pregnancy outcome; and (III) referral rate to perinatal palliative care.

**Results:** Between July 2006 and July 2012, 1,144 women were referred to UCSD's Fetal Care and Genetics Center, a tertiary care center. Of that cohort, 332 women (29%) were diagnosed prenatally with a potentially life limiting fetal diagnosis. Most women were Hispanic or Latino, married, and had previous children. The median gestation at confirmed diagnosis was 19 weeks. Trisomy 13, Trisomy 18, and anencephaly comprised 21% of cases. The pregnancy outcome was determined in 95% cases: 56% therapeutic abortion, 16% intrauterine fetal demise, and 23% live birth. Only 11% of cases were referred to perinatal palliative care.

**Conclusions:** The vast majority of women with potentially life limiting fetal diagnoses are not referred to perinatal palliative care. Evaluation of how to integrate palliative care into high-risk obstetrics is needed.

**Keywords:** Antenatal; palliative care; perinatal; pregnancy; prenatal; referral

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## Introduction

Perinatal palliative care is specialized medical and emotional support for families who learn as a result of prenatal testing that their babies may die before or shortly after birth. There are about 212 perinatal palliative care programs in the United States: about half of these are hospital-based and only one quarter of hospital-based programs are part of a fetal diagnostic center (1). Most American programs have grown from hospices or pediatric palliative care programs that support delivery hospitals and fetal diagnostic centers.

Until 2013, the San Diego Hospice and Institute for Palliative Medicine (SDHIPM) was the sole provider for San Diego County's perinatal palliative care. Established in 1997, that team consisted of a hospice nurse, social worker, chaplain, and occasionally a hospice physician who visited families at their homes an average of three times prior to delivery (2). The palliative team's primary goal was to help families with the process of making choices about pregnancy management and medical decisions for the baby, by constructing a birth plan to incorporate personal and spiritual beliefs into the possible outcomes for their pregnancy and their child (3). The team provided support

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for anticipatory grief as families grappled with diverse potential outcomes of intrauterine fetal demise, neonatal death, and neonatal survival (4). Prior to delivery, the perinatal palliative care team disseminated the birth plan to the caregivers. Around the time of delivery, the home hospice team would go to the inpatient bedside to assist the family and hospital team in carrying out the birth plan. After a baby was born, the team continued to help family members by gathering keepsakes and assuring that they have time and space to be with their baby, create memories,

(III) To determine how many high risk pregnancies at UCSD with potentially life limiting fetal diagnoses were referred to perinatal palliative care at SDHIPM.

## Methods

This was a retrospective electronic chart review using a database of pregnant women with fetal anomalies referred to one of three high-risk perinatal centers in San Diego County over a 6-year period. The Institutional Review

and for some, say goodbye. The team also offered follow-up services that continued after the baby's death, including bereavement care and pediatric hospice if indicated.

At the time of this study, there were three high-risk fetal centers in San Diego County that referred to SDHIPM's Perinatal Palliative Care Program. The University of California San Diego (UCSD) Fetal Care and Genetics Center generated about 50% of SDHIPM's perinatal palliative care referrals. At UCSD's fetal diagnostic center, maternal-fetal medicine physicians, medical geneticists, genetic counselors, and radiologists provide concurrent prenatal and genetic counseling to patients and families in one office. Neonatology and other Pediatric subspecialty consults are scheduled separately at different locations. Since 2003, UCSD's Fetal Care and Genetics Center has kept a database of all women referred for fetal complications. There are over 5,500 entries with information including reason for referral, gestational age at referral, genetic testing, and pregnancy outcome. The purpose of this study is to review referrals to a single high-risk fetal diagnostic center over a 6-year period. The demographic, clinical, and outcome data will provide information on who is and who is not referred to perinatal palliative care in San Diego County, California. Our hypothesis is that a small proportion of women pregnant with a potentially life limiting fetal diagnosis, who could benefit from palliative care services, are referred to perinatal palliative care.

### *Objective*

(I) To determine how many high risk pregnancies referred to UCSD Medical Center have potentially life limiting fetal diagnoses;
(II) To determine the outcome for pregnancies with potentially life limiting fetal diagnoses: number of therapeutic abortions, intrauterine fetal demises, neonatal live born, and survival for live births;

Board for UCSD Human Research Protections Program approved the protocol for conduct of this study (Project number 131197). We reviewed the medical charts of subjects, entered the abstracted data into the database, and performed the analysis.

### *Setting/subjects*

Subjects were pregnant women between 2006 and 2012 with data entered in a UCSD Fetal Care and Genetics Center referral database. Cases were identified for further medical chart review using the electronic medical records system, EPIC Hyperspace, if the following potentially life limiting fetal diagnoses were identified:
(I) Trisomy 13, Trisomy 18, other potentially life limiting genetic disorders;
(II) Anencephaly, other neurologic anomalies (i.e., holoprosencephaly, severe hydrocephalus);
(III) Pulmonary hypoplasia (due to causes such as renal agenesis/dysplasia, fetal obstructive uropathy, severe oligo or anhydramnios, skeletal dysplasia, giant omphalocele);
(IV) Complex congenital heart defects;
(V) Hydrops, or;
(VI) Any anomalies for which therapeutic abortion was offered or elected.

### *Measurements*

The following variables were abstracted from the medical record for those pregnancies characterized as having a potentially life limiting fetal diagnosis:
(I) Demographic information (i.e., maternal age/ethnicity/spirituality, prior pregnancies and their outcomes, marital status, father of baby involvement, others in the home, fetal diagnoses, gestation at referral, presence of gestational diabetes/hypertension, extent of prenatal care,

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**Table 1** Demographic information for pregnant women with a potentially life limiting fetal diagnosis

### *Statistics*

Descriptive statistics and analyses were performed using