

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

Krishelle L. Marc-Aurele<sup>1</sup>, Andrew D. Hull<sup>2,3</sup>, Marilyn C. Jones<sup>1,3</sup>, Dolores H. Pretorius<sup>3,4</sup>

<sup>1</sup>Department of Pediatrics, UC San Diego/Rady Children's Hospitals, UC San Diego, CA, USA; <sup>2</sup>Department of Reproductive Medicine, UC San Diego, CA, USA; <sup>3</sup>UCSD Maternal-Fetal Care and Genetics, CA, USA; <sup>4</sup>Department of Radiology, UC San Diego, CA, USA

*Contributions:* (I) Conception and design: KL Marc-Aurele; (II) Administrative support: None; (III) Provision of study materials or patients: AD Hull, MC Jones, DH Pretorius; (IV) Collection and assembly of data: AD Hull, MC Jones, DH Pretorius; (V) Data analysis and interpretation: KL Marc-Aurele; (VI) Manuscript writing: All authors; (VII) Final approval of manuscript: All authors

*Correspondence to:* Krishelle L. Marc-Aurele, MD. UC San Diego, 9300 Campus Point Drive MC#7774, La Jolla, CA 92037, USA. Email: kmaurele@ucsd.edu.

**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

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, 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;
- (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 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,

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

Pregnant mothers	N=332	%
<b>Age</b>		
<35 years	241	73
≥35 years	91	27
<b>Ethnicity</b>		
Hispanic/Latino	140	42
Non-Hispanic	114	34
Asian	35	11
Multiracial	26	8
Black	9	3
Unknown	8	2
<b>Spirituality</b>		
Not Specified	145	44
Christian/catholic	117	35
“None”	56	17
Other	14	4
<b>Marital Status</b>		
Married	205	62
Single	117	35
Divorced/separated	10	3
<b>Gravida</b>		
1	92	28
2	89	27
Greater than 2	123	37
Unknown	28	8
<b>Previous children</b>		
Yes	175	53
No	129	39
Unknown	28	8

results from quadruple screen/amniocentesis/prenatal ultrasounds, medications, drug use);

- (II) Pregnancy outcomes [i.e., referral to perinatal palliative care, therapeutic abortion, intrauterine fetal demise, presence of resuscitation at delivery, neonatal death, admission to neonatal intensive care unit (NICU), neonatal survival].

## Statistics

Descriptive statistics and analyses were performed using Wizard software Version 1.7.20 (Miller, L. Chicago, IL, USA). To compare demographic data by pregnancy outcome, *t*-test and ANOVA were used when the continuous variables were normally distributed and Kruskal-Wallis was used when the data was not. Categorical variables were analyzed with the Chi square test. A logistic regression model was used to examine the influence of variables on the pregnancy outcome of therapeutic abortion and the outcome of referral to perinatal palliative care. A significance level of  $P < 0.05$  was used.

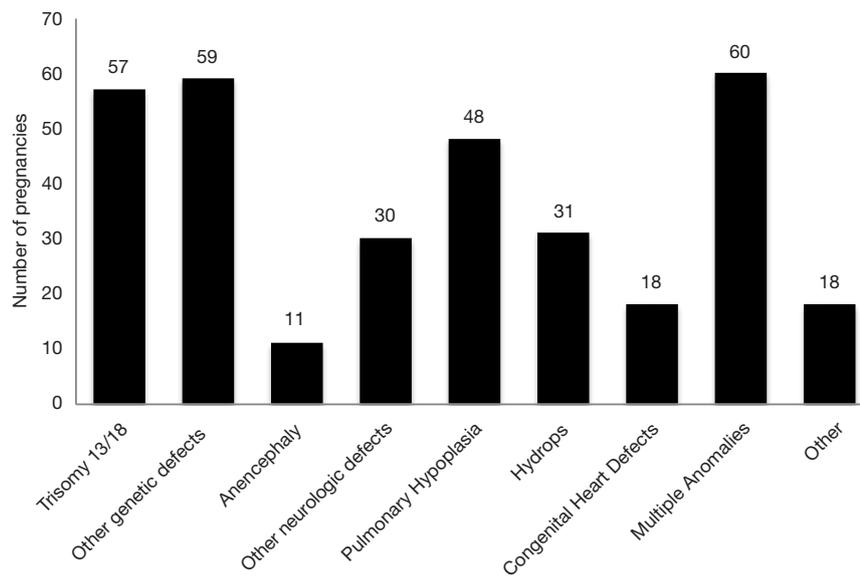
## Results

Between July 2006 and July 2012, 1,144 women were referred to UC San Diego's Fetal Care and Genetics Center for fetal anomalies. Of that cohort, 332 women (29%) were diagnosed prenatally with a potentially life limiting fetal diagnosis. The average maternal age was 30 (SD 7), ranging from 14 to 46 years old (see *Table 1*). The median maternal age was 31 years old. Most women were Hispanic or Latino, married, and had previous children.

Thirty five percent (116/332) of pregnancies had a potentially life limiting genetic disorder (see *Figure 1*). Trisomy 13, Trisomy 18, and anencephaly comprised 21% (68/332) of cases. The median gestation at confirmed diagnosis was 19 (17–21 interquartile range) weeks (*Table 2*). The median gestation at the time of pregnancy outcome was 22 (19–33 interquartile range) weeks. The median number of days from fetal diagnostic center consultation to pregnancy outcome was 18 days (8–55 interquartile range).

The pregnancy outcome was determined by chart review in 95% (315/332) of cases (*Figure 2*). Of the total 332 cases, 56% (186/332) resulted in therapeutic abortion, 16% (53/332) resulted in intrauterine fetal demise, and 23% (76/332) resulted in a live birth. Only 11% of the total 332 cases were referred to perinatal palliative care and only 26 of the 36 women referred actually received perinatal palliative care. For pregnancies with fetal diagnoses of Trisomy 13, Trisomy 18, and anencephaly, 47% (32/68) resulted in therapeutic abortion, 24% (16/68) resulted in an intrauterine fetal demise, and 16% (11/68) resulted in a live birth (*Figure 3*). Only 19% (13/68) of these pregnancies were referred to perinatal palliative care before delivery.

There were statistically significant differences between the women who had expectant management, or plans to continue the pregnancy (i.e., live born or



**Figure 1** Life limiting pregnancy diagnoses. Together, Trisomy 13, Trisomy 18, and anencephaly made up 68 of the 332 cases. Other Genetic Defects included Trisomy 21 often with another anomaly such as encephalocele, hydrops, or congenital heart defect (N=19), Other Trisomies (N=4), Turners syndrome (N=18), Chromosomal deletions (N=9), Triploidy (N=7), and Tetraploidy (N=2). Other Neurologic Defects included Holoprosencephaly (N=10), Neural Tube Defects (N=9), Ventriculomegaly (N=7), Encephalocele (N=1), Ex vacuo brain loss (N=1), Intracranial teratoma (N=1), and Rhombencephalosynapsis (N=1). Pulmonary Hypoplasia included Skeletal Dysplasia (N=19), Renal agenesis (N=9), Fetal Obstructive Uropathy (N=5), Giant Omphalocele (N=4), Echogenic/Cystic kidneys plus oligo- or anhydramnios (N=4), Anhydramnios (N=3), Pena Shokeir (N=1), Congenital Diaphragmatic Hernia (N=1), and suspected Meckel Gruber (N=2). Hydrops was in the absence of known cardiac or genetic defects (N=31). Congenital Heart Disease included Single Ventricle physiology (N=10), Truncus Arteriosus (N=2), Severe Aortic Stenosis with Heart Failure (N=1), Unbalanced AV Canal (N=1), Ebstein's Anomaly (N=1), Complex Cardiac Defect (N=1), Echogenic heart (N=1), and Cardiac Teratoma (N=1). Multiple Anomalies included more than one malformation (i.e. Limb-Body-Wall defects, Congenital Diaphragmatic Hernia plus Hypoplastic Left Heart Syndrome, Larsen Syndrome, Pentology of Cantrell, Caudal regression, etc). Other included Conjoined twins (N=3), Twin-to-twin-transfusion syndrome (N=3), Teratoma (N=4), acardiac twin (N=3), CCAM (N=1), Intrauterine CMV (N=1), Nasopharyngeal teratoma (N=1), Absent fetal mandible (N=1), and Situs Inversus with Heterotaxy (N=1).

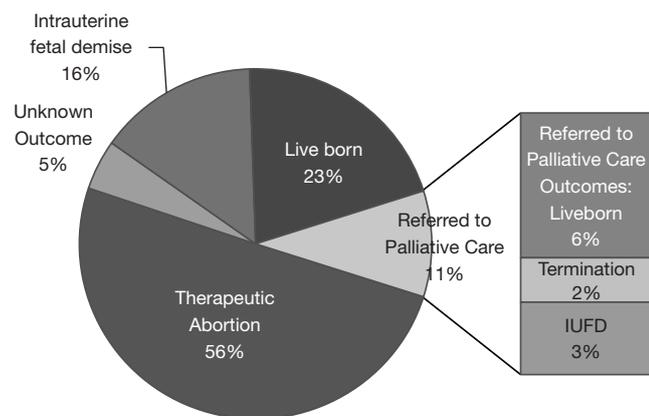
**Table 2** Gestation at confirmed diagnosis, pregnancy outcome, and time from consult to pregnancy outcome

Pregnancy (N=332)	Mean [SD]	Range
Gestation at confirmed diagnosis (weeks)	20 [5]	[9–38]
Gestation at time of pregnancy outcome (weeks)	25 [8]	[12–42]
Time from fetal diagnostic center consult to pregnancy outcome (days)	38 [43]	[0–199]

fetal demise outcomes), compared with the women who had a therapeutic abortion (Table 3). Women who had a therapeutic abortion were more likely to be a few years older and Non-Hispanic, and less likely to be Christian or Catholic. The only predictor in a logistic regression model of therapeutic abortion was maternal age with an OR =1.2

(95% CI, 1.026–1.115).

Similarly, there were some differences between women who were referred to perinatal palliative care compared with those who were not. In a logistic regression model, women who were referred to perinatal palliative care before delivery were more likely to have a later gestational age at



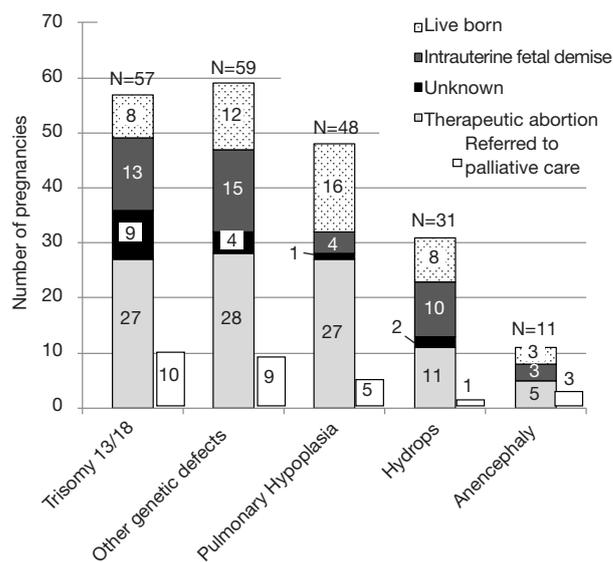
**Figure 2** Outcomes for pregnancies with potentially life limiting fetal diagnoses.

the time of diagnosis ( $22 \pm 2.1$  vs.  $19 \pm 0.6$  weeks,  $P=0.014$ ), an abnormal genetic test during pregnancy ( $53\%$  vs.  $32\%$ ,  $P=0.015$ ), and were less likely to have had a therapeutic abortion ( $17\%$  vs.  $64\%$ ,  $P<0.001$ ). There were no significant differences in age, ethnicity, spirituality, marital status, or parity between these two groups.

The median gestational ages at the time of pregnancy outcome were statistically different by outcome with therapeutic abortions occurring at 20 weeks, intrauterine fetal demise at 28 weeks, and live born birth at 37 weeks ( $P<0.001$ ). There were 76 live born infants (Figure 4). The average birth weight was 2,479 grams. The longest surviving infant lived at least 8 years, alive at the time of data collection. Live born infant survival was skewed to the left with the median at 8 days and the average at 112 days. Of the fetal Trisomy 13 and 18 pregnancies, only 4 survived past 24 hours. Pregnancies with fetal pulmonary hypoplasia or fetal congenital heart defects had higher survival rates with 33% or 28% live born, respectively, and more infants surviving past one year, 13% or 17%, respectively.

## Discussion

Our study shows a low referral rate to a well established home based perinatal palliative care program from an academic fetal diagnostic center in San Diego, California. For pregnancies in this study with fetal Trisomy 13, Trisomy 18, and anencephaly, conditions often diagnosed early and most commonly in the literature considered for perinatal palliative care, only 19% of women were referred to perinatal palliative care before delivery. Similar



**Figure 3** Pregnancy outcome by diagnosis. Some diagnoses are not displayed. For all fetal diagnoses, therapeutic abortion was the most frequent outcome. The perinatal palliative care referral rate ranged from 0–27%, with anencephaly having the highest referral rate. Outcomes for pregnancies with Multiple Fetal Anomalies included 41 therapeutic abortions (TAB), 4 intrauterine fetal demises (IUFD), 15 live born, and 2 referred to perinatal palliative care (PPC). For pregnancies with Other Neurologic Defects, there were 20 TAB, 2 IUFD, 7 live born, 1 unknown outcome, and 5 referred to PPC. Outcomes for pregnancies with Congenital Heart Defects included 12 TAB, 1 IUFD, and 5 live born. No pregnant women in this group were referred to PPC. In pregnancies categorized as Other, there were 13 TAB, 3 IUFD, 2 live born, and 1 referred to PPC. Of the 10 pregnancies with fetal single ventricle physiology, there were 4 TAB, 1 IUFD, 5 live born, and none referred to PPC. Four of the live born infants underwent surgical intervention. Outcomes for 10 pregnancies with fetal Holoprosencephaly included 4 TAB, 1 IUFD, 5 live born, and 3 referred to PPC. Of the 19 pregnancies with fetal skeletal dysplasia, there were 11 TAB, 8 live born, and 2 referred to PPC.

findings have been reported from the Fetal Concerns program in Wisconsin; Leuthner *et al.* reported that only 14% of women (185/1,354) received palliative care during pregnancy (5). Our study's low palliative care referral rate is likely related to a greater proportion of women who underwent therapeutic abortion.

In San Diego County, therapeutic abortion is available to women at 23 weeks gestation in the pregnancy or earlier. The average ages at confirmed fetal diagnosis and

**Table 3** Demographics by pregnancy outcome. The intrauterine fetal demise outcome was categorized under expectant management along with a live born outcome because the gestational age at which intrauterine fetal demise occurred was well past the age at which therapeutic abortion is offered in San Diego County

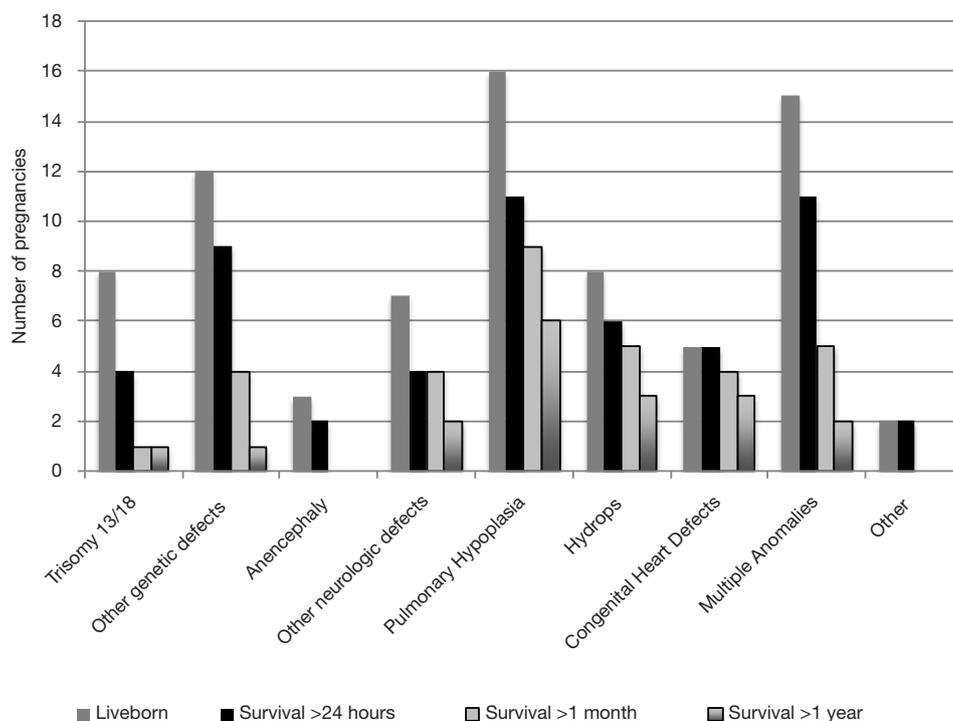
Patient characteristics	Expectant management (Live born or Fetal Demise) (N=130)	Therapeutic abortion (N=185)	Unknown (N=17)	P
Maternal age				0.03 <sup>†</sup>
Median	28	31	33	
1 <sup>st</sup> / 3 <sup>rd</sup> quartile	24/34	27/36	28/36	
Ethnicity				0.01 <sup>†</sup>
Hispanic/Latino	54%	37%	18%	
Non-Hispanic	25%	38%	64%	
Multiracial	8%	8%	6%	
Asian	7%	13%	12%	
Black	5%	2%	0%	
Unknown	1%	2%	0%	
Spirituality				0.004 <sup>‡</sup>
Christian/catholic	46%	29%	24%	
Not specified	32%	50%	71%	
“None”	18%	16%	5%	
Other	4%	5%	0%	
Gravida				0.02 <sup>†</sup>
Median	2	2	3	
1 <sup>st</sup> / 3 <sup>rd</sup> quartile	1/4	1/3	3/5	
Marital status				0.59 <sup>†</sup>
Married	55%	64%	82%	
Single	42%	32%	18%	
Divorced/separated	3%	4%	0%	

<sup>†</sup>, Kruskal-Wallis; <sup>‡</sup>, Chi-square.

therapeutic abortion in this study suggest that the chance to provide a palliative care consult before women elect to undergo therapeutic abortion is within only a few days. At the time of this study, perinatal palliative care required a referral from an obstetrician and time to set up an in-home consult. Based on our previous work, the average time from diagnosis to referral for palliative care was seven weeks and then the average time from referral to first perinatal palliative care visit was 14 days (2). In a survey of fetal specialists, more than 90% supported standardizing the practice of offering women the option of palliative care for life limiting fetal diagnoses, however, achieving this goal

for families with time constraints requires a palliative team member to be available everyday (6). We wonder whether having a palliative care representative in the fetal diagnostic center might increase referral rates. The palliative team member could help to educate families as well as the fetal diagnostic team to clear up misperceptions regarding the intent of palliative care, and explain the differences between palliative care and hospice (7). Furthermore, the palliative team member might close the gap in time between diagnosis and perinatal palliative care provision.

Because of the small number of women referred to perinatal palliative care in this study, we found only a few



**Figure 4** Length of survival by diagnosis. Eighteen infants survived past 1 year of life. At the time of data collection, their diagnoses (ages) were Trisomy 13 (5 years old), Chromosomal deletion (2 years old), Holoprosencephaly (2 years old), intracranial teratoma (8 years old), Skeletal dysplasia (three 4-year and one 7-year-old), Echogenic/Cystic kidneys plus oligo- or anhydramnios (1 years old), Posterior Urethral Valves (5 years old), Immune Hydrops (18 months and 3 years old), Unknown Etiology Hydrops (2 years old), Hypoplastic Left Heart Syndrome (ages 1, 2, and 5 years), Facio-auriculo-vertebral sequence (4 years old), and VACTERL (vertebral defects, anal atresia, cardiac defects, tracheo-esophageal fistula, renal anomalies, and limb abnormalities) association (2 years old). Fourteen infants survived beyond 1 month but died before turning 1 years old. Three infants with Other Genetic Defects: Turner Syndrome, Chromosomal deletion, and Trisomy. Two infants with Other Neurologic Defects: both Holoprosencephaly. Three infants with Pulmonary Hypoplasia: Skeletal Dysplasia (N=2) and Echogenic/Cystic kidneys plus oligo- or anhydramnios (N=1). Two infants with hydrops: postnatal diagnosis of bilateral chylothorax and unknown etiology. One infant with Hypoplastic Left Heart Syndrome. Three infants with Multiple Anomalies: Larsen syndrome, Caudal regression, and unknown syndrome.

statistically significant differences between those who were referred and those who were not referred. One apparent difference was that women referred to palliative care were more likely to have had an abnormal genetic test during pregnancy. This may reflect a perceived need by health care providers for diagnostic certainty in order to consult palliative care and is supported by surveyed maternal fetal medicine specialists and pediatric subspecialists for whom the degree of diagnostic certainty was the most influencing factor in discussing perinatal palliative care (6). Tosello and colleagues argue that “*professionals cannot avoid the uncertainty*” and “*this uncertainty must be incorporated by the perinatal professionals*” to share with families so that they can plan. Interviews of bereaved parents highlight the

importance of continuity of care and memory making (8). During the grieving process, some parents regret how they spent time with their baby (9). Parents want parenting activities, such as bathing, dressing, and holding as memories to reflect upon during bereavement (8,10). Parents who felt involved tended to be more inclined to trust providers and were better able to consider limiting treatment (11). Receiving a palliative consult has been shown to result in fewer days in intensive care units and fewer medical procedures including cardiopulmonary resuscitation for infants, and more frequent referrals for support services for families (12). In particular, families with uncertain but suspected life-limiting fetal diagnoses need perinatal palliative care support to process the diagnosis

and what it means for their baby and pregnancy in order to make thoughtful choices ahead (13).

Retrospective studies of perinatal palliative care report infant survival from hours to months (2,13,14-16). The infant survival in our population ranged from hours to years, with 18 infants surviving past 1 year of life. This likely reflects the limitation of accurate prognostication based on prenatal data. Not surprisingly, we also have difficulty predicting death and neurodevelopmental impairment with postnatal information (17-19). Our reality is that we have imperfect means of predicting outcomes. Recommendations for physicians facing considerable prognostic uncertainty are to begin conversations using language that is open to multiple possible outcomes: to “hope for the best and prepare for the worst (20,21)”. This guidance, although intended for conversations with adult patients who face a life limiting prognosis, may also serve as a framework for situations in which a fetus’ outcome is uncertain.

For many women, their decision-making about carrying a pregnancy with a potentially life limiting fetal diagnosis to term is based on their faith (2). About 40% of pregnancies in this study were managed expectantly. This is consistent with three other smaller studies that report between 40–85% of women with probable life limiting fetal diagnoses will chose to continue the pregnancy (5,22,23). If we limit the provision of perinatal palliative care to those who choose expectant management, then we might aim our referral rates to be closer to 40% of pregnancies.

Limitations of this study were due to its retrospective nature. For example, information regarding spirituality and ethnicity were derived from data entered by the medical staff into the electronic medical record fields and may not have been accurate because of the limited choices available in drop down menus. Similarly, the medical record charting frequently did not provide enough information to delineate between spontaneous versus therapeutic abortions for prior pregnancies. These patient characteristics often impact decision-making and would have been useful to evaluate. Furthermore, the study is from a single institution with a population that may not be generalizable to other centers.

## Conclusions

Our study shows a low referral rate to a well established home based perinatal palliative care program from an academic fetal diagnostic center in San Diego, California. Just over half of the mothers in this cohort elected for therapeutic abortion, narrowing the chance to provide

palliative care to within days. Only one in ten women were referred to palliative care, leaving the majority of women that elect to continue the pregnancy unprepared for the potentially short time they have with their baby. We wonder whether integrating a palliative care representative in the fetal diagnostic center might provide better quality of care and outcomes for families with potentially life limiting fetal diagnoses.

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## Footnote

*Conflicts of Interest:* The authors have no conflicts of interest to declare.

*Ethical Statement:* The Institutional Review Board for UCSD Human Research Protections Program approved the protocol for conduct of this study (Project number 131197).

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