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ARTICLE

Prenatal counseling and parental decision-making following a fetal diagnosis of trisomy 13 or 18

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Abstract

Objectives To evaluate parental decisions following a prenatal diagnosis of trisomy 13 (T13) or trisomy 18 (T18), prenatal counseling received, and pregnancy outcomes.

Study design Single-center, retrospective cohort study of families with a prenatal diagnosis of T13 or T18 from 2000 to 2016.

Results Out of 152 pregnancies, 55% were terminated. Twenty percent chose induction with palliative care, 20% chose expectant management, 2% chose full interventions, and 3% were lost to follow-up. Counseling was based on initial parental goals, but most women were given options besides termination. Women who chose expectant management had a live birth in 50% of the cases. Women who chose neonatal interventions had a live birth in 100% of the cases, but there were no long-term survivors.

Conclusions The majority of women who continue their pregnancy after a fetal diagnosis of T13 or T18 desire expectant management with palliative care. A live birth can be expected at least half of the time.

Introduction

Trisomy 13 (T13) and 18 (T18) are chromosomal anomalies that have historically been considered lethal [1, 2]. Over the past 10 years, this has been called into question by physicians, ethicists, and families [3, 4]. The literature has focused on one of two areas: the commonly described negative parental experience of prenatal and neonatal counseling [5], and the extent of medical and surgical interventions that children with these conditions receive, their survival, and neurodevelopmental outcomes [6–15].

Importantly, the majority of pregnancies with T13 or T18 are terminated [16–18]. Data regarding parental goals and feelings when they choose termination of pregnancy, and factors such as gestational age at diagnosis, or presence of other anomalies that may affect that decision, are limited. Similarly, many families choose to pursue expectant management with the hopes of a live-born child and the opportunity to have some memories of their child, but may not want intensive medical interventions [5]. For families who are considering expectant management, there are limited data that health-care providers can use for counseling on the probability of having a live-born baby vs. the risks of stillbirth, fetal demise, or a preterm delivery [16, 17, 19].

In addition, the details about counseling information that is provided to families with these diagnoses at the prenatal visit is not well described, and is concentrated toward families who wanted more interventions [20], particularly in light of recent literature that informs that the outcomes for these infants are not uniformly lethal [14, 21–23]. Common messages are that there is better survival than historical data, and that the mortality rate may be a self-fulfilling medical prophecy [24, 25]. The argument is based on the premise that prenatal counseling may be limited, directive, biased, and therefore somewhat predetermined. Additionally, this argument might suggest that more parents may choose a different prenatal and neonatal course if offered all options including full neonatal intervention. While these viewpoints

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are important to hear, it must be acknowledged that they come with their own inherent bias, and there are limited data thus far looking at a prenatal cohort of patients and exploring their decision trajectories following the initial diagnosis.

Our objectives were to explore all T13/18 diagnosis at our center and: (1) describe parental goals following a prenatal diagnosis of T13 or 18, (2) describe aspects of prenatal counseling that were provided, (3) describe parental decisions made following counseling about the diagnosis, (4) explore trends over time in referrals, parental decisions made, and counseling options provided, and (5) describe perinatal outcomes for families who chose options other than termination of pregnancy.

Methods

We conducted a single-center retrospective cohort study of mothers who were seen at Froedtert Memorial Hospital (FMH) obstetric clinic or referred to the Fetal Concerns Center of Wisconsin (FCCW) following a prenatal diagnosis of T13 or T18 from 2000–2016. FMH is an academic medical center in affiliation with the Medical College of Wisconsin (MCW). The FCCW is a multi-disciplinary referral center for women whose pregnancies are complicated by concerns of fetal abnormalities. This study was approved by the Froedtert and Medical College of Wisconsin's institutional review board.

In order to include all pregnant women who received a prenatal diagnosis of T13 or T18 from 2000 to 2016, we used two data sources: (1) all women who had received a positive fetal karyotype for T13 or T18 from the Wisconsin Diagnostic Laboratory, a central laboratory for FMH (mosaic T13 or T18 were excluded), and (2) women who had a primary referral diagnosis of T13 or T18 in the clinical database maintained by the FCCW. There was some overlap between these two data sources, and all unique patients were retained in the subsequent data analysis.

We manually reviewed all medical records for women with a fetal diagnosis of T13 or T18 and their infants (when applicable) using relevant electronic health records. We included all pregnant women seen at the FMH or the FCCW at least once even if delivery took place at another center. Pregnant women with a karyotype done at Wisconsin Diagnostic laboratory but who were never seen by a FMH doctor or the FCCW were excluded. For mothers, both outpatient and inpatient charts, physician and nursing notes including labor and delivery records, were reviewed as available. For infants, records from the newborn nursery and neonatal intensive care unit (NICU) were reviewed, depending on where the infant was admitted following birth.

The following data were extracted from the medical charts: maternal age, marital status, religious affiliation (if documented), gestational age at the time of diagnosis, method of diagnosis (maternal serum screening, amniocentesis, chorionic villus sampling, other); ultrasound findings; fetal gender, healthcare member who delivered the initial diagnosis, and perinatal outcome. If the pregnancy was not terminated, the mode of delivery and perinatal outcomes were obtained. For live born infants, birth weight, gestational age at birth, and discharge outcomes were extracted. For infants admitted to the NICU, an internal, NICU database was used for information regarding length of stay and discharge outcome. For infants admitted to another unit in the hospital (e.g., pediatric ICU or cardiac ICU), relevant records were reviewed. For infants discharged home, follow-up records were reviewed when available.

Finally, we manually reviewed all notes by FCCW nurse coordinators, genetic counselors, and physicians in order to understand perceived parental goals at the time of initial visit, counseling, and options provided to the family (e.g., termination of pregnancy vs. expectant management vs. full interventions), and final choice made by the family. The perceived initial goals were based on the initial intake assessment by an experienced fetal nurse coordinator. Due to the highly variable, open-ended nature of counseling, we created groups based on common themes. For example, counseling options were grouped into termination-focused, palliative-care focused, intervention-focused, expectant management-focused. All charts were reviewed by P.W. For families who chose options other than termination, charts were reviewed a second time by K.A. or S.L. in order to ensure consistency.

Continuous variables are presented as medians with interquartile range. Categorical variables are presented as proportions of total. Wilcoxon rank-sum test, Kruskal–Wallis test, or χ^2-tests were used for comparing differences between groups as appropriate. Mantel–Haenzscel tests were used to evaluate trends in proportion over time. Stata Statistical Software: Release 14. College Station, TX: StataCorp LP was used for data analyses.

Results

From 2000 to 2016, there were 152 pregnant mothers who received a prenatal diagnosis of T13 or T18 and were seen at the FMH. Of those, 88 patients (58%) were referred to the FCCW.

Demographic characteristics

Table 1 describes the characteristics of the patient population. There were 118 cases of T18, and 34 cases of T13. The median maternal age was 34. A majority of the mothers

Table 1 Demographic and clinical characteristics of pregnant mothers with a fetal diagnosis of T13 or T18

	T13 or T18 ($n = 152$)
T13	34
T18	118
Maternal age, median (IQR)	34.5 (29–38) years
Marital status	
% married	122 (79%)
Gestational age at diagnosis, *n* (%)	18 (15–21)[a] weeks
Fetal gender, n (%)	
Male	62 (41%)
Unknown	15 (10%)
Religion, n (%)	
Christian	86 (57%)
Non-Christian other (Hindu, Muslim, Mormon, Jehovah's witness)	7 (5%)
No religion	21 (14%)
Unknown or missing	38 (25%)
Gestation, n (%)	
Singleton gestation	145 (95%)
Twin gestation	1 (0.6%)
Triplet gestation	6 (4%)
Gravidity, n (%)	
Primigravid	32 (21%)
Number with one or more living children, *n* (%)	101 (66%)
Diagnostic tests done, n (%)	
Cell-free DNA	21 (15%)
Chorionic villus sampling	32 (21%)
Amniocentesis	104 (68%)
Ultrasound	129 (85%)
Quad screen	21 (14%)
At least one abnormality on ultrasound, n (%)	
Yes	150 (99%)
Unknown/not documented	2 (1%)
Additional complicating condition present[b]	97 (63%)

[a]Gestational age at diagnosis has six missing values

[b]An additional complicating condition was defined as a condition that would significantly impact neonatal survival or long-term prognosis in addition to the diagnosis of T13 or T18. The following were included: abdominal wall defect, complex heart defect, dandy-walker malformation, congenital diaphragmatic hernia, holoprosencephaly, hydrops fetalis, hypoplastic left heart syndrome, neural tube defect, microcephaly, tetralogy of fallot, pleural effusion, ascites, AV canal, Chiari malformation, cyclopia, bladder outlet obstruction, hydrocephalus, pulmonary stenosis, coarctation of aorta, esophageal atresia/TEF, pulmonary hypoplasia

were married (79%) and identified as Christian (57%). Most cases were singleton gestation (95%). An ultrasound abnormality was found in all but two cases. The majority of mothers had a confirmatory diagnostic test such as chorionic villus sampling or amniocentesis.

Parental goals, counseling, and final decisions made

Table 2 outlines parental goals at the initial visit, specialists seen by families, documented options offered during counseling, and final choices made regarding continuation vs. termination of pregnancy. Many women (41%) came in wanting to terminate the pregnancy and may have met providers at the FCCW for clarification or support, such as a FCC nurse or other specialist. Counseling was tailored to initial parent goals: when women came in wanting to terminate, counseling was focused on termination options, but other options were discussed a third of the time when initial goals were seen as unclear. When women were unsure (32%) or wanted to continue the pregnancy with palliative care (23%) or all interventions (3%), they were more likely to be referred to the FCCW, and to meet with a FCC nurse and a neonatologist. Counseling then was more inclusive of the range of available options. Women who came in wanting to terminate the pregnancy chose that option almost all the time. Women who came in unsure usually chose termination or early induction of labor, with a third choosing expectant management, but none chose interventions. Women who hoped to continue the pregnancy as far as possible were more likely to choose expectant management, but a third chose not to continue the pregnancy following counseling, and none chose interventions. Women who presented wanting everything done often chose all interventions after counseling. Of note, no family chose full intervention unless they came with that motivation.

Counseling provided

Supplemental Information 1 shows information that was documented as being included in counseling. Obstetricians usually documented only survival information regarding pregnancy outcomes. Maternal–fetal medicine specialist (M.F.M.) documented survival, adding the contributions of the comorbid ultrasound findings and maternal risks. Neonatologists and genetic counselors usually documented information about survival, neurodevelopmental outcomes, and burdens or quality of life for survivors, often in light of the comorbid conditions. Most health-care professionals documented the term "lethal" when referring to neonatal outcomes. When statistics were documented, they were not consistent between providers. For example, some obstetricians cited a 0–10% live birth rate, whereas other providers documented anywhere from a 50–90% chance of children dying before the first year of life. Documentation about neurodevelopmental outcomes included information such as children with these diagnoses would not be

Table 2 Parental goals, counseling options offered, and choices made following a prenatal diagnosis of trisomy 13 or 18 ($n = 152$)

Parent goals at initial visit	Specialists seen	*N* (%)	Options offered	*N* (%)	Choices made	*N* (%)
Terminate pregnancy	OB/perinatologist	62 (100%)	Termination/early induction	40 (65%)	Termination	38 (95%)
62 (41%)	FCC nurse	25 (40%)			Induction with palliative care	2 (5%)
	Genetic counselor	19 (31%)				
	Neonatologist	3 (5%)	All options offered	19 (31%)	Termination	14 (74%)
					Induction with palliative care	3 (16%)
					Expectant management with palliative care	2 (11%)
			Unknown/not documented	3 (5%)	Termination	3 (100%)
Unsure	OB/perinatologist	47 (96%)	All options offered	32 (65%)	Induction with palliative care	13 (41%)
49 (32%)	FCC nurse	26 (53%)			Termination	11 (34%)
	Genetic counselor	21 (43%)			Expectant management with palliative care	7 (22%)
	Neonatologist	18 (37%)				
	Other specialists	1 (2%)			Unknown	1 (3%)
			Termination	13 (27%)	Termination	12 (92%)
					Expectant management with palliative care	1 (8%)
			Palliative-care focused	2 (4%)	Expectant management with palliative care	1 (50%)
					Unknown	1 (50%)
			Unknown/not documented	2 (4%)	Termination	1 (50%)
					Unknown	1 (50%)
Continue pregnancy as long as	OB/perinatologist	24 (77%)	All options offered	28 (90%)	Expectant management with palliative care	17 (61%)
possible	FCC nurse	27 (87%)				
31 (20%)	Genetic counselor	13 (42%)			Induction with palliative care	9 (32%)
	Neonatologist	23 (74%)			Termination	1 (4%)
	Other specialists	7 (22%)			Unknown	1 (4%)
			Palliative-care focused	2 (7%)	Expectant management with palliative care	2 (100%)
			Intervention-focused	1 (3%)	Expectant management with palliative care	1 (100%)
Induce with palliative care	OB/perinatologist	5 (100%)	All options offered	4 (80%)	Induction with palliative care	3 (75%)
5 (3%)	FCC nurse	5 (100%)				
	Genetic counselor	2 (40%)				
	Neonatologist	4 (80%)				
					Termination	1 (25%)
			Termination	1 (20%)	Induction with palliative care	1 (100%)
Want everything done	OB/perinatologist	5 (100%)	All options offered	3 (60%)	All interventions	2 (67%)
5 (3%)	FCC nurse	5 (100%)			Induction with palliative care	1 (33%)
	Genetic counselor	3 (60%)	Intervention-focused	2 (40%)	All interventions	2 (100%)
	Neonatologist	5 (100%)				
	Other specialists	3 (60%)				

OB obstetrician, *FCC* Fetal Concerns Center

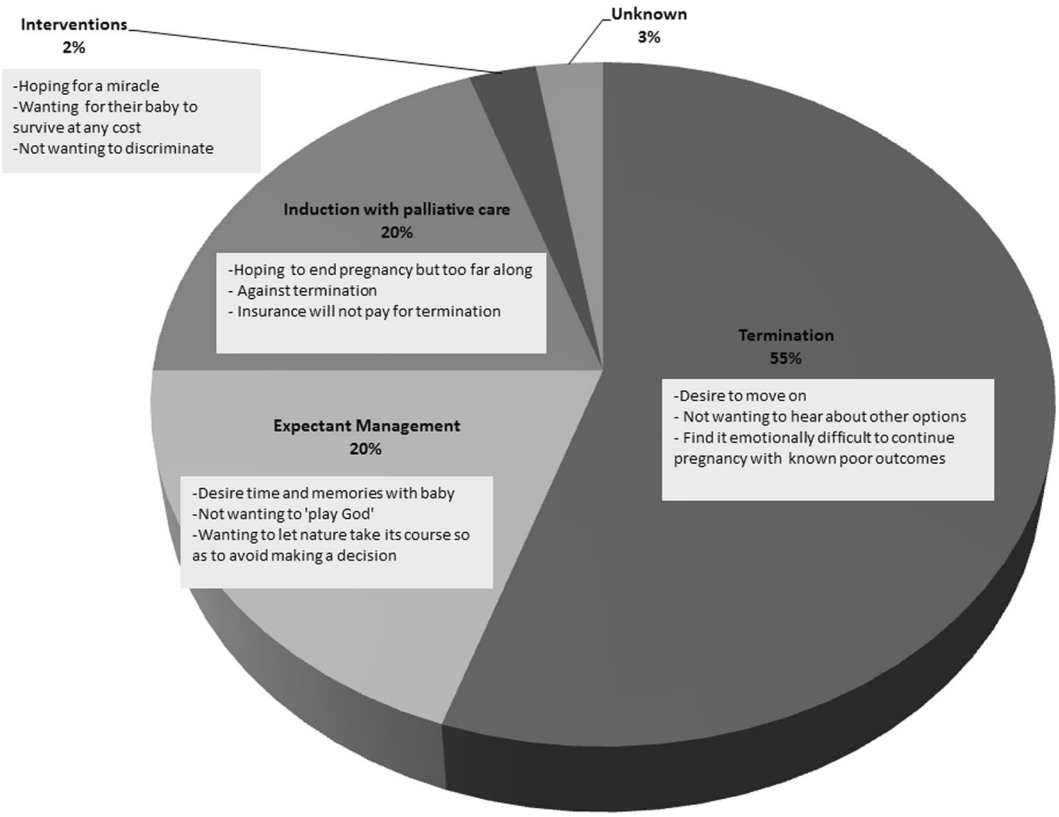

Fig. 1 Final parental decisions after a prenatal diagnosis of trisomy 13 or 18 ($n = 152$)

expected to develop beyond a 6–12-month-old stage, but that they would respond to touch and would know their own family members, and that walking and talking were usually limited to children who were mosaic. Documentation about comorbid health conditions included information about additional ultrasound findings and how these might contribute to the prognosis of the child. These conversations were primarily with neonatologists and MFMs. Content included the possibilities for interventions with specific anomalies such as cardiac surgery for heart malformations or shunt placement for hydrocephalus, but mostly, these were used as further evidence of the poor prognosis of the fetus. Discussions about the impact on families focused mainly on risk of recurrence of T13 or T18 with a future pregnancy, risk to the mother's future pregnancies in the case of a C-section, and the kind of financial and emotional support the family might need regardless of the choices they made.

Parental values and final pregnancy decision

Figure 1 shows final parental decision following counseling, and recurring themes that emerged for each decision category. Parents who terminated their pregnancy cited reasons such as poor outcomes, inability to carry a fetus with a low chance of survival and hoping to try again. Documented reasons why parents chose early induction and palliative care was that they either would have terminated if they had found out the diagnosis earlier, because of insurance delays or refusals, or that they were against termination, but psychologically found it difficult to continue toward a term pregnancy with a baby they recognized might die inside them. One parent described the decision-making as "being on a death penalty jury". Parents who chose expectant management cited being against termination of pregnancy and not wanting to make that decision, yet appreciating not wanting their baby to suffer, or live with a burdensome or poor quality of life. Additionally, they cited the hopes of meeting their baby alive. Parents who wanted full interventions cited reasons such as not wanting to discriminate against their baby, wanting to give their baby any possible chance of survival, and/or their belief in the possibility of a miracle, even appreciating and describing this chance as a "parting of the Red Sea."

Trends over time

Supplemental Information 2 shows the number of women with a fetal diagnosis of T13 or T18 who were referred to the FCCW ($n = 88$ out of total 152) as a proportion of total

Table 3 Outcomes of pregnancies following a fetal diagnosis of T13 or T18 ($n = 148$)

	Termination ($n = 81$)	Induction with palliative care ($n = 32$)	Expectant management with palliative care ($n = 31$)	Intervention ($n = 4$)	P value
Gestational age at diagnosis (median (IQR)	17 (13–19)	20 (18–230) weeks	20 (15–23) weeks	21 (14–21) weeks	0.0001
Maternal age, median (IQR)	35 (29–38) years	33 (26–39) years	35 (29–39) years	35 (29–38)	0.700
Presence of an additional complicating condition[a]	40 (49%)	27 (84%)	24 (77%)	3 (75%)	0.001
Primigravid mother	11 (14%)	12 (37%)	7 (23%)	1 (25%)	0.045
Other living children present	55 (68%)	18 (56%)	23 (74%)	2 (50%)	0.411
Married	64 (79%)	21 (66%)	29 (94%)	4 (100%)	0.346
Religious affiliation identified	40 (49%)	21 (65%)	24 (77%)	2 (50%)	0.097
No religious affiliation	15 (18%)	2 (6%)	3 (10%)	0 (0%)	
Pregnancy outcome ($n = 62$)					
Live born		17/31 (55%)	12/27 (44%)	4/4 (100%)[b]	
Stillborn (death during labor)		13/31 (42%)	6/27 (22%)	—	
IUFD (death before onset of labor)		1/31 (3%)	9/27 (33%)	—	
For live born infants					
Gestational age at birth		29 (25–35) weeks	37 (36–38) weeks	33 (30–37) weeks	
Of those delivered vaginally, % live born		15/28 (54%)	5/10 (50%)	1/1 (100%)	

[a]An additional complicating condition was defined as a condition that would significantly impact neonatal survival or long-term prognosis in addition to the diagnosis of T13 or T18. The following were included: abdominal wall defect, complex heart defect, dandy-walker malformation, congenital diaphragmatic hernia, holoprosencephaly, hydrops fetalis, hypoplastic left heart syndrome, neural tube defect, microcephaly, tetralogy of fallot, pleural effusion, ascites, AV canal, Chiari malformation, cyclopia, bladder outlet obstruction, hydrocephalus, pulmonary stenosis, coarctation of aorta, esophageal atresia/TEF, pulmonary hypoplasia

[b]All infants who received interventions have subsequently died (age at death ranged from 1 day to 14 months)

referrals to the FCCW during the same time period. There was an increase in the number of patients seen with a fetal diagnosis of T13 or T18 and a corresponding increase in the total number of referrals to FCCW over time, with 40% of patients being seen in the last 5 years of the study period (2012–2016). However, the proportion of T13 or T18 referrals was not different over time. Trends over time for each parental decision category (e.g., interventions vs. termination vs. expectant management) were not statistically significant nor were counseling options offered to families, however all families who wanted interventions were seen within the last 2 years of the study period. Forty-five percent of the families who chose expectant management were seen within the last 4 years of the study period. Fewer families (18% vs. 36%) chose induction of labor with palliative care in 2012–2016 compared to 2000–2005, which may reflect changes in state abortion laws that impact options [26].

Pregnancy outcomes

Table 3 compares pregnancy characteristics among those who chose termination vs. other options, as well as outcomes of pregnancies that were not terminated. The cohort that chose termination was diagnosed at a younger gestational age (17 weeks vs. 20 weeks). Maternal age, marital status and religious affiliation were not significantly different among groups. For families who chose expectant management, an in utero fetal demise occurred in 33% of cases. For those who delivered vaginally, a live birth occurred in at least 50% of the cases. For those who had a C-section, a live birth occurred in 87% of the cases. For the infants born alive after expectant management, 5 out of 12 infants died on the same day, and the remainder survived for 1–8 days after birth. Families who chose neonatal interventions were more likely to deliver via C-section, and all children were born alive and admitted to the NICU. Three out of 4 babies died while in the hospital on days 1, 6, and 205, respectively. One infant was discharged home but subsequently died at 14 months of age. All 4 infants received mechanical ventilation; the two infants who survived beyond a week received a G-tube. The infant who died on day 6 had a CDH repair on day 2. The infant who died on day 205 had cardiac surgery and a tracheostomy. The infant who died at 14 months of age received respiratory support as any late preterm infant might, had no major structural anomalies and required no surgical interventions other than the G-Tube, yet had many hospital admissions throughout her life.

Discussion

This is the first study to represent a large cohort of women with a prenatal diagnosis of T13 or T18, and describes their initial goals following the diagnosis, prenatal counseling received, and final decisions and pregnancy outcomes. Our major conclusions are as follows:

1. The majority of women with a prenatal diagnosis of T13 or T18 come in to a regional perinatal center knowing how they would like to proceed with the pregnancy, with termination being the most common choice. The next largest group is those that choose expectant management with the hopes of a live born child yet choosing palliative care as the neonatal treatment.
2. Documentation of prenatal counseling usually includes all options, but often focuses on information about survival, with neonatologists documenting more data on the life of those that survive.
3. For those who choose expectant management with palliative care, we provide some data on the chances of having a live born baby with different modes of delivery. For women who choose this option, our data show that a live birth can be expected in 50% of cases during a vaginal delivery and an 87% chance if a C-section is performed.
4. Neonatal interventions are chosen by a small minority of women, and typically their choice is clear prior to team counseling.

In a high-risk perinatal clinic, a majority of women with a prenatal diagnosis of T13 or T18 arrive knowing how they want to proceed with the pregnancy. Based on our cohort and similar to prior studies, over half of these women choose termination of pregnancy, especially when the diagnosis was made before 20 weeks of pregnancy [27–29]. Common documented reasons reported by women who choose to terminate the pregnancy were the psychological burden of carrying a pregnancy with known poor outcomes and the hopes for a healthy child in the future. Another one-fifth of women in our cohort chose early induction with palliative care. These women were often diagnosed at or after 20 weeks' gestation when termination may be harder to obtain, and were more likely seen prior to 2015, after which there was a change in abortion laws that limit this option in the state of Wisconsin [26]. Families must now choose early termination (<22 weeks) in-state, termination out-of-state (if >22 weeks), or expectant management. Some women who chose early induction hoped to see and hold their baby. Importantly, while some women desired opportunities for memory making, not all wanted mementos. Many stated that continuation of the pregnancy would be too hard emotionally. Women who wanted to continue the pregnancy commonly chose expectant management. All of these women had hopes of meeting their baby alive. While some took on maternal risks of a C-section, all wanted palliative care as the main neonatal intervention.

At our institution, we found that prenatal counseling often included all options but was also tailored to parent goals. If a family arrived knowing they wanted to terminate the pregnancy, they were not actively counseled on options for interventions or expectant management. Conversely, if a family initially stated that termination was not an option, they were counseled on different alternatives. The content on survival, disease or organ specific outcomes, and neurodevelopmental outcome had some variation. Whether this was patient or provider-driven based on the meeting, and what impact it had on decision-making cannot be determined from this study. Indeed, an area of practice improvement for physicians is providing accurate counseling information to families in an empathetic and balanced way [30]. For example, women carrying a fetus with a diagnosis of T13 or T18 are often told that their child will die in utero or during the birthing process [5, 31]. Our data suggests that this is not accurate in at least half of the cases of pregnancy continuation. When physicians do not know the data or fail to honestly acknowledge to families that a range of outcomes is possible, they either create distrust in any providers' ability to predict outcome or set up the patient to consider their child as being outside the norm, either of which may have other far-reaching consequences. On the other hand, some families may come in already having set their minds on one option (usually termination and rarely, interventions), and may not be interested in hearing about other options. An important area of future research would be to understand the families' perspectives on the information they received at counseling, and how or whether it affected their decision-making.

For families whose common goal is expectant management and a live born child, there are limited previously published data on the outcomes of continuation of pregnancy and the chances of live birth vs. the risks of stillbirth or fetal demise [16, 17, 19]. Our study fills an important gap in knowledge about these pregnancies that can help guide prenatal counseling. If the family goal is a live born baby, this is achieved at least half of the time in women who choose expectant management, with two-thirds of the pregnancies being carried to full-term. In one-third of the cases of expectant management there is in utero fetal demise, and in 20% of cases there is a stillbirth during labor. Yet this is very different data than the 0–10% chance of live birth that some parents note as a common obstetric counseling statistic. Once the pregnant woman reaches term, there is a 50% chance of a live birth with vaginal delivery, and for women who undergo a C-section delivery, this rate is higher still, albeit with more risks to the mother and

potential risk to future pregnancies. When early induction with palliative care is chosen, a live birth can be expected over half of the time, but the risk of stillbirth in labor is greater, perhaps due to fetal intolerance of labor at a younger gestational age. While decisions are not straightforward for families, these numbers may be helpful in setting realistic expectations for the pregnancy. They can also be valuable in not overstating the need for a C-section in order to have a live birth.

Recent literature has focused largely on the outcomes of infants with T13 or 18 who receive medical and surgical interventions during the neonatal period and beyond [6–14, 22, 32]. These studies answer important questions for all families who do not choose termination. For the small minority that might choose life-sustaining measures for their children, it provides them the best information for the most informed choice [33]. For those families who are considering expectant management and palliative care, it provides them the information to make a choice based on burdens of known outcomes. In our cohort, there were women who choose either termination or palliative care once knowing this information. Whether this helps in the longer-term grief process is also an area of future research. As the debate surrounding provision of interventions for children with T13 or T18 continues, we must acknowledge that this debate addresses the fewer than 5% of families who choose interventions, and we raise caution that the pendulum ought not to swing from limiting parental choice because of lethality to parents losing their voice in the direction of mandated care.

In conclusion, the majority of families choose termination of pregnancy after a fetal diagnosis of T13 or T18, however many others continue the pregnancy with goals of a live born child but not necessarily medical interventions, while few request full intervention. Prenatal counseling is tailored to parental goals, and thus may not always include all possible outcomes. At the same time, families are offered multiple options a majority of the time, which seems to contradict the literature that surveys parents alone. Physicians should be sensitive to the difficult decisions that all families with this diagnosis face and individualize counseling information to support families in alignment with families' goals and values.

Limitations

Data presented in this study should be interpreted in light of several limitations. We studied women who were referred to a large, tertiary, maternal–fetal center, and this sample does not include women who may have been only cared for by community obstetricians. Thus, our population may overestimate the percentage of families who wanted to continue a pregnancy. At the same time, we do not know the accuracy of what families are counseled by their community obstetricians, thus questioning fully informed decision-making. This was a retrospective study which relied on interpretation of medical documentation in order to assess perceived parental goals and information provided at counseling. Although multiple notes (besides physician documentation) were assessed to collect accurate data, medical documentation may not be completely reflective of what was said at counseling, or what the parents perceived they were told.

In spite of these limitations, this is the first study that presents data from a large number of women with a prenatal fetal diagnosis of T13 or T18 and explores the range of decisions made by women with such pregnancies, which in our opinion, presents a more balanced view of the contemporary scenario. Importantly, it provides perinatal outcome data of pregnancies for women who chose expectant management with palliative care, thus providing at least some expectations of obstetrical outcome that can be available for counseling purposes. Our next steps will be to conduct follow-up qualitative interviews of a proportion of these families to obtain first-hand accounts of the parental perception of counseling information provided, and how we can improve counseling for families who are faced with these diagnoses.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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