Outcomes of Patients with Trisomy 13 and 18 in a Center with a Dedicated Perinatal Palliative Care Program

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Abstract

Introduction:The objective of this study is to assess outcomes of pregnancies complicated by trisomy 13(T13) or trisomy 18(T18) and infants with T13 and T18, who were managed in a center with a perinatal palliative care program.

Methods:This is a single center retrospective cohort study of neonates with T13 or T18 and pregnancies complicated by T13 or T18 in which families opted to continue the pregnancy, that were followed at Columbia University Irving Medical Center(CUIMC) between 2008-2024.

Results:There were 109 pregnancies that resulted in 68 liveborn infants. Of those who met with the Neonatal Comfort Care Program(NCCP) prior to delivery, 69.9% opted for comfort care. There was no trend toward more intervention over a span of 17 years.

Discussion:Consistency of consulting practices by the NCCP at CUIMC is reflected in the lack of trend toward more intervention in patients with T13 and T18 which has been reported in other institutions.

Introduction

Trisomy 18 (T18), also known as Edwards syndrome, and Trisomy 13 (T13), or Patau's syndrome, are two of the most common autosomal trisomies in live births, with Trisomy 21 (T21), Down Syndrome, being the most prevalent.[1] T18 is more common than T13 with a prevalence of 4.08 per 10,000 births for T18 and 1.68 per 10,000 births for T13.[2] Unlike Trisomy 21, Trisomy 18 and 13 have traditionally been considered life-limiting genetic birth disorders with those who do survive facing profound neurologic impairment. Both Trisomy 18 and 13 are associated with a wide range of congenital malformations including congenital heart diseases, gastrointestinal disorders and other complications in major organ systems.[2,3] Historically surgical procedures have been withheld from this population, however like T21, as the medical community's understanding of these disease entities has evolved, the willingness to intervene has changed over time.[4,6]

Rates of surgical procedures such as tracheostomy and gastrostomy tube placement in patients with T18 increased throughout the country between 1997-2016.[5] This increase in surgical intervention may be due to providers willingness to offer intervention and families seeking intervention more frequently. Surgical intervention, specifically for complex congenital heart disease, had previously been withheld from this population as many physicians felt that the surgery itself would hasten death without leading to improved outcomes.[4] However, as centers began to publish improved survival data in patients who received cardiac surgery, the practice of withholding surgical intervention has gradually changed.[6,7] This change in practice prompted both the American Heart Association and the American Association for Thoracic Surgery to release practice recommendations for this population.[8,9] Both guidelines note that there is an increase in morbidity and mortality in this population as compared to the general population.

However when the patient is not mechanically ventilated prior to surgery the overall survival rates are seen as acceptable to these organizations, justifying surgical intervention.[8,9]

Though centers are becoming more comfortable with surgical intervention on patients with both T13 and T18, there remains significant variability when it comes to care choices that families make.[10] Counseling during and after pregnancy is vital to help inform families of all their options and support them to make decisions that align with their values. However, counseling practice varies widely with one study showing that less than half of families carrying a pregnancy with T13 or T18 received counseling from a neonatologist or palliative care doctor prior to delivery.[3] Those who do receive counseling report varied interactions with healthcare providers and many report that they felt judged for the decisions they were making for their child.[11,12]

The Neonatal Intensive Care Unit (NICU) at Morgan Stanley Children's Hospital at Columbia University Irving Medical Center (CUIMC) is a level IV NICU which offers a full range of medical and surgical interventions, including for the most complex congenital heart disease. A unique aspect of this NICU is the presence of the Neonatal Comfort Care Program (NCCP), a service of perinatal palliative care. The NCCP team meets with all families who have received a prenatal diagnosis of a life limiting condition and offers perinatal palliative care as an approach to care in addition to intensive medical therapy.

Previous research on T13 and T18 has demonstrated the varied medical management choices parents make for their infants in this population, from comfort care to full intervention. It's important to note that these are multicentered studies and thus, the counseling families received likely varies both within and across centers [2,14] Furthermore, the wraparound services that the NCCP team at CUIMC provides families is not yet the standard of care at other institutions. This is a single center retrospective cohort study of neonates with T13 or T18 and pregnancies complicated by T13 or T18 who opted to continue the pregnancy, over a 17-year period.

Our objectives were to 1) Identify whether there are any factors that were associated with parental choice of comfort care versus intensive care, in an institution with a dedicated perinatal palliative care service; 2) Describe the evolution of care in our hospital to determine if more intervention has been sought over time; 3) Describe the outcomes of our patients. We hypothesized that more families would opt for comfort care at our center as compared to what had been reported in the literature, most likely due to the presence of the NCCP. We also hypothesized that over the period this cohort spans, more infants would have received medical and surgical interventions reflecting the overall trends reported nationally. We hope this research will bring a better understanding of patients with T13 and T18 and their course should they pursue comfort care or full intervention. We also hope to highlight how a perinatal palliative care team can impact the care of these patients. Ultimately this research aims to help improve how we counsel our families in the future.

Methods

This is a single center retrospective cohort study of neonates with T13 or T18 and of women whose pregnancy was complicated by T13 or T18 and who opted to continue the pregnancy. The study includes neonates born between 2008–2024 who were admitted to the NICU at CUIMC either inborn or outborn, with a diagnosis of T13 or T18. The study also includes pregnancies that were followed by the NCCP which ended in intrauterine fetal demise or stillbirth. Mothers who were seen at CUIMC but opted for termination were not included in the study. A detailed chart review of both the mothers' and neonates' medical records was performed to adequately capture the outcomes of each pregnancy.

This study was approved by the Institutional Review Board at CUIMC (IRB-AAAU0719). Due to the retrospective study design parental consent was not required.

The Neonatal Comfort Care Program (NCCP)

Candidates. At CUIMC, candidates for neonatal comfort care include fetuses and or neonates with a life limiting condition. This includes a broad range of diagnoses; renal anomalies such as renal agenesis and lower urinary tract obstruction, complex congenital heart disease, neurological anomalies such as holoprosencephaly and acrania as well as genetic conditions such as Trisomy 13 and 18.

NCCP Team. At CUIMC, the NCCP includes a core team of neonatologists, former NICU nurses and a midwife. The team partners closely with maternal-fetal medicine (MFM) physicians. The core team also works closely with other consulting professionals such as social workers, psychologists, child life professionals, speech pathologists, lactation consultants, and chaplains.

Prenatal Counseling and Birth Plans. When a prenatal diagnosis of a life-limiting condition is identified by the maternal-fetal medicine physician and the family chooses to continue the pregnancy, rather than terminate, a consultation with the core NCCP team is scheduled. The team first explores what the family has been told by other providers and what research they may have done already about the diagnosis. The neonatologist then clarifies the diagnosis, the potential wide range of prognoses, and answers any questions the family has. The team then presents care options to the family ranging from intensive care to comfort care. Reassurance is provided to the family that regardless of what care plan they pursue for their child, the NCCP team will be there with them to walk them through the prenatal and postnatal experience. Often a final plan of care for delivery is not made until multiple visits with the family are completed prenatally. This allows the family time to explore all options and gives the NCCP time to fully explore the family's values. Once a plan is established, the NCCP documents an interdisciplinary birth plan in the mother's electronic medical record. If a diagnosis is made postnatally or a patient is transferred into CUIMC from an outside hospital, the NCCP team will meet with the family upon admission and or diagnosis, to explore the family's understanding of their child's diagnosis and what care they would like their child to receive.

Postnatal Care. If the family opts to pursue comfort care, the NCCP team assures continuity of care by having the neonatologist who performed the initial consult act as the primary physician for the neonate. If the family chooses to pursue intensive care the NCCP team acts as a palliative care consultation team

while the infant is admitted in our NICU. NCCP guidelines for postnatal comfort/palliative care and for redirection of goals of care from intensive to palliative care have been published previously.[15,16]

Data Collection. Chart review of pregnant women and infants complicated by T13 or T18 was performed by study personnel from January 1, 2008 to December 31, 2024. Data was stored on an encrypted excel file and included a wide range of information. Maternal demographic information such as age, race, religion, marital status and insurance status were collected. Characteristics of the pregnancy were collected including maternal complications, number of gestations, number of consults with the NCCP team, plan of care for delivery, type of delivery and if monitoring was utilized during delivery. Neonatal outcomes such as length of life, care received, complications, surgical interventions and length of stay were collected for all pregnancies that resulted in a live birth.

Data Analysis Data are expressed as absolute numbers and mean or medians where appropriate based on normality of the data as determined by the Shapiro Wilk-test. Fisher's exact text was applied to see whether there's an association between two categorical variables with small cell counts. Log-rank test was run to compare survival distributions between comfort care and intervention groups. Kaplan-Meier survival curve was reported. We ran the logistic regression for binary outcome of the pregnancy and to test how the number of major anomalies affects the outcome. We also tested the Pearson correlation between birthweight and length of life for those who pursued comfort care. All the analysis was done using SAS 9.4.

Results

Pregnancy Characteristics:

As seen in Table 1a. a total of 109 pregnancies with either T13 or T18 were identified. Of those, 19 were complicated by T13 and 90 by T18. In most cases (88.1%) fetal ultrasound features images suggested the diagnosis, and 66.7% of the women underwent invasive prenatal testing for confirmation.

Of the 93 pregnancies followed at CUIMC, 55.9% resulted in a liveborn infant, 31.2% resulted in an IUFD and 12.9% ended in a stillbirth. (Figure 1a) The number of major anomalies noted prenatally did not correlate to the outcome of the pregnancy.

Delivery characteristics of the 80 mothers who delivered stillborn or liveborn infants at CUIMC are detailed in Table 1b. Of the 24 women who underwent cesarean delivery, 14 were indicated for fetal wellbeing and 10 were due to maternal indications. Full demographic data of all mothers in this cohort can be found in Table 2.

Perinatal plan of Care at CUIMC:

All families with a prenatal diagnosis of T13 or T18 and followed at CUIMC had at least one prenatal encounter with the NCCP team, however average number of encounters for each pregnancy was 2.5

(with a range of 1-10). Most mothers (69.9%) opted to pursue a plan of comfort care at the time of delivery, 23.7% opted for some level of intervention, and 6.5% were undecided. (Figure 1a) As detailed in Figure 1b., the NCCP met 16 infants and families postnatally including 8 inborn postnatal diagnoses and 8 who were transferred into CUIMC for higher level of care. At the time of the initial postnatal encounter all infants had a plan of full intervention. The average number of encounters offered by the NCCP team to each family was 5.5 (with a range of 1-15).

Figure 2 shows the care decisions made by families who met with the NCCP team over 17 years. Families did not opt for more intervention in more recent years as compared to earlier in the cohort. There was no trend in care decisions identified. Religion was not associated with care preferences nor ethnicity.

Neonatal Outcomes:

Characteristics of all infants (inborn and outborn) are shown in Table 3.

The survival curves for infants treated with comfort care and for those treated with full intervention are seen in Figure 3. Among 31 infants who received comfort care (Figure 3a) 63.3% passed within the first 24 hours of life and 76.7% within the first week of life. Only 13% percent survived the first month and no survival was seen by 3 months. Birthweight did not correlate to length of life for those treated with comfort care.

Thirty-seven infants were initially treated with full intervention (Figure 1a,b), however more than half of their families (54.1%) ultimately chose to redirect their goals of care and the infants subsequently passed. Of the remaining cases, 9 infants died while receiving full intervention efforts and 8 infants are still living at the time of this publication (ages: 12, 9, 7, 5, 5, 4, 3, 2). Of the 37 infants who initially received full intervention, 8.1% of the infants passed within the first 24 hours of life, 16.2% within the first week of life, while 70% survived the first month of life (Figure 3b). Other infants' characteristics in terms of surgical procedures and length of stay are shown in Table 3.

Discussion

This single center retrospective cohort study highlights the role a dedicated perinatal palliative care team plays in the care of patients with T13 and T18. This review unexpectedly demonstrates that there was not an increase in the number of families who chose medical or surgical intervention since the inception of the perinatal palliative care program at CUIMC, despite the national trend toward intensive care intervention. Families counseled and followed by the NCCP continued to choose comfort care management at a consistent rate. This study provides an overview of prenatal, perinatal and postnatal outcomes of fetuses and infants with T13 and T18.

Unlike other studies that include all pregnancies complicated with T13 and T18 in their analysis, this cohort focuses on only those pregnancies where the family opted to continue the pregnancy despite the

diagnosis of T13 or T18.[2,10] Within our cohort the majority of pregnancies resulted in a livebirth, though rates of both IUFD and stillbirth are higher in this cohort as compared to pregnancies with healthy fetuses, which is consistent with other reports in the literature.[2] The number of major fetal anomalies present was not associated with the outcome of pregnancy, therefore providers should be cautious when speculating about the outcome of pregnancies and prepare families they are counseling that it is likely they will meet their child alive.

The rate of cesarian delivery in our cohort is much lower than other cohorts[2]. The overall rate in the CUIMC population was 30% with just over half of cesarian deliveries being performed for fetal indications (Table 1b). This is very similar to the rate of cesarian delivery in the general population.[18] Fetal intolerance of labor in those with T13 and T18 has been noted in the literature and indicated as the primary reason for the high rate of cesarian delivery (64-80%).[19,20] Possible reasons for our lower rate of cesarian delivery are the high rate of families being consulted prior to delivery who opted for comfort care at delivery as well as mothers who opted to labor without monitoring regardless of the plan of care after birth. 37.5% of mothers in this cohort opted to have fetal monitoring during labor. Some mothers opted for monitoring even when they had a plan of comfort care as they valued meeting their child alive and opted for cesarian delivery should there be fetal distress. Other mothers wanted monitoring but did not consent for a cesarian delivery even in the case of fetal intolerance of labor. In these scenarios mothers often indicated that hearing the baby's heart rate during labor was important to them and they wanted to be prepared if their infant passed during the labor process. Despite having a significantly lower rate of cesarian section in our cohort as compared to other reports in the literature, our livebirth rate is equivalent or higher than other cohorts.[2,20] This is a significant finding as it may suggest that those undergoing cesarian delivery for fetal distress in other centers may have resulted in a livebirth if vaginal delivery was allowed to proceed.

Unique to this cohort is that 100% of those with a prenatal diagnosis of T13 or T18 were seen at least once by the NCCP team. This consult rate sets this cohort apart from others published in the literature who report a consult rate with neonatology or a specialized team between 50-60%.[2,10] All infants that the NCCP team met postnatally had either been diagnosed after birth or transferred from an outside hospital. At the time of the initial encounter all of these infants were on a plan of full intervention. The NCCP team met with most families more than once, demonstrating the continuity of care that is provided by the team.

Given the overall increase in surgical intervention noted over time across the country for this patient population, we hypothesized that CUIMC families would opt for more intervention over time, however, no such trend was identified.[5,6] The trend toward less intervention may be due to the consistent counseling practices utilized at CUIMC. Since the inception of the program in 2008, the standard of care has been for the NCCP team to work in close contact with the MFM team to offer a full range of options to our families. Thus, the majority of the families in this cohort received consistent counseling regardless of the year of presentation. Similar to other reports in the literature, religious practice and ethnicity did not

correlate to care preferences between those who chose comfort care vs. intervention.[16] Within this cohort, 69.9% of families who the NCCP team met with prenatally opted to pursue comfort care at the time of delivery, much higher than what has been reported in the literature. Cortezzo et. al report 47% of the patients within their cohort were treated with comfort care, and even more striking, a group from Alabama reports that 92.6% of their T18 population was admitted to the NICU.[2,26] We speculate that the NCCP team presence at CUIMC may itself result in the higher rate of families pursuing comfort care. One reason could be that families perceive that the plan of comfort/palliative care, as offered by the NCCP, is a valid medical treatment option alternative to intensive care. Moreover, we speculate that having a primary medical and interdisciplinary team follow the family both prenatally and postnatally, allows the family to develop a bond with the team and not worry that they will be abandoned to care for their dying child alone. This hypothesis has been supported in the literature by families of patients with T18 who report their desire for providers who will not judge them but support them through this difficult journey, recognizing the love they have for their child.[23,24] Given that this current research cannot detail motivations behind care decisions, we hope to further explore this in a forthcoming qualitative study.

As seen in the survival curves in Figure 3, there is a clear difference in length of life between those who pursued full intervention (3b) versus those who were treated with a plan of comfort care (3a). However, there are infants who were treated with comfort care that survived past hospital discharge and received hospice care, whether at home or at a rehab facility. It is incredibly important that providers who counsel the families of patients with T13 or T18 are aware that even with minimal interventions these infants can live past the first week of life. Prenatal counseling should include the possibility of survival even though most infants with T13 and T18 who are treated with comfort care pass soon after birth, some will live past maternal hospital discharge. Providers need to be prepared to help families decide where they want to have their child receive care should they live longer than expected. In these cases, one area that families may need help navigating is how best to feed their child. Feeding infants who live past the initial 24 hours is an important component of providing comfort to the child. It is our practice to work with families to find the best feeding strategy given most infants with T13 and T18 have difficulty with feeding. (21) If the baby's latch continues to be a challenge despite working with a speech and language pathologist and utilizing special nipples, our team will work with families so that they are comfortable placing a NG tube. During the initial hospitalization at birth we usually recommend against placing a gastrostomy tube in these patients as we want to minimize time spent in the hospital and maximize time with family. However, if a family is uncomfortable managing NG tube feedings at home and the estimated length of life is longer than a month or two, we will work with our general surgical colleagues to expedite gastrostomy tube placement as soon as possible.

Several points are striking when looking at the outcome data of those infants who received full intervention. As seen in Figure 3b there were several infants who lived for several years. This longer than expected life of several of our patients, has been reported in the literature in both case reports and retrospective studies.[25,26] As seen in Table 3, the length of stay for infants who received full intervention is wide ranging. Parents need to be prepared that pursuing full intervention for their child with T13 or T18

will likely come with a long hospitalization. Furthermore, as seen in Table 3, those who underwent surgical procedures had longer lengths of stay in the hospital and almost a third of the infants passed despite surgical intervention. Over half of families who initially pursued full intervention opted to redirect care. This suggests the importance of the continued presence of a palliative care team in the care of these patients. To our knowledge this manuscript is the first to report rates of redirection in this population that was followed since birth. It is vital that those counseling families of children with T13 and T18 are able to help walk parents through what a care plan of full intervention may look like. It is impossible to anticipate all the complications that may come up during the course of an infant's hospitalization, therefore the continued presence of the palliative care team is vital to providing well rounded care.

Though this study uniquely shows the impact of a perinatal palliative care team on the care of infants with T13 and T18, there are some limitations. First, this is a retrospective study, however given the low frequency of cases of T13 and T18, a prospective study that follows this population would have to span several years in order to collect enough data to make meaningful conclusions. Second, this is a single center study performed in an academic institution, thus our population, although quite diverse, maybe not be representative of populations in local community or rural hospitals. Third, a potential bias could be related to population differences in ethnicity and religion; however, our data showed that neither religion nor ethnicity were associated with care preferences. Lastly, to fully elucidate motivations behind care decisions, further research is warranted. For this reason, we are engaging in a qualitative study to better understand the role the NCCP team plays in helping families navigate the type of care they want their child to receive.

The data from this patient population as compared to other reports in the literature suggest the essential role of a perinatal palliative program in providing informed options and accompanying families as they pursue their preferred goal of care for neonates affected by T13 and T18. It is our hope that this work displays the importance of continuity of care throughout the perinatal journey when caring for complex patients and families.

Declarations

Data Availability- The datasets generated during and/or analyzed during the current study are available from the corresponding author on reasonable request.

Conflict of Interest- The authors have no conflict of interest to declare.

Contributors' Statement Page

Drs Brady and Parravicini conceptualized and designed the study, led the multidisciplinary team, analyzed data, drafted the initial manuscript, and reviewed and revised the manuscript.

Brynn McNamee-Tweed helped design the study and reviewed and revised the manuscript.

Dr. Zhgan helped inform the study design, helped draft sections of the manuscript and performed data analysis

Nikolas Blenitsky helped with data collection and reviewed final data.

All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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Ethics Statement-

This study was approved by the Institutional Review Board at CUIMC (IRB-AAAU0719). Due to the retrospective study design parental consent was not required.

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Tables

Table 1a. Pregnancy Characteristics, Entire Cohort of patients both inborn and outborn (n=109)

Pregnancies with T18/T13	109
T18	90 (82.6%)
T13	19 (17.4%)
Prenatal Diagnostics	
Abnormalities seen on Ultrasound	96 (88.1%)
Noninvasive Prenatal Testing	54 (49.5%)
Chorionic Villus Sampling	13 (11.7%)
Amniocentesis	60 (55.0%)

Table 1b. Delivery characteristics (n=80)

Monitoring During Delivery	30 (37.5%)
Mode of delivery	
C-section	24 (30.0%)
Vaginal	56 (70.0%)

Table 2. Entire Cohort of patients both inborn and outborn (n=109)

Maternal Characteristics	
Maternal Age*	37 (8.0)
Marital Status	
Married/ Long Term relationship	90 (82.7%)
Single	19 (17.3%)
Gravida*	4 (5.0)
Maternal Race	
Asian	3 (2.8%)
Black	15 (13.8%)
Caucasian	61 (56.0%)
Hispanic	30 (27.5%)
Preferred Language	
English	90 (83.5%)
Spanish	17 (15.6%)
Other	2 (1.8%)
Religion	
Christian	54 (49.5%)
Jewish	30 (27.5%)
Muslim	3 (2.8%)
Not religious	6 (5.5%)
Not reported	16 (14.7%)
Insurance Status	
Private	52 (47.7%)
Medicaid	57 (52.3%)

*Median (IQR)

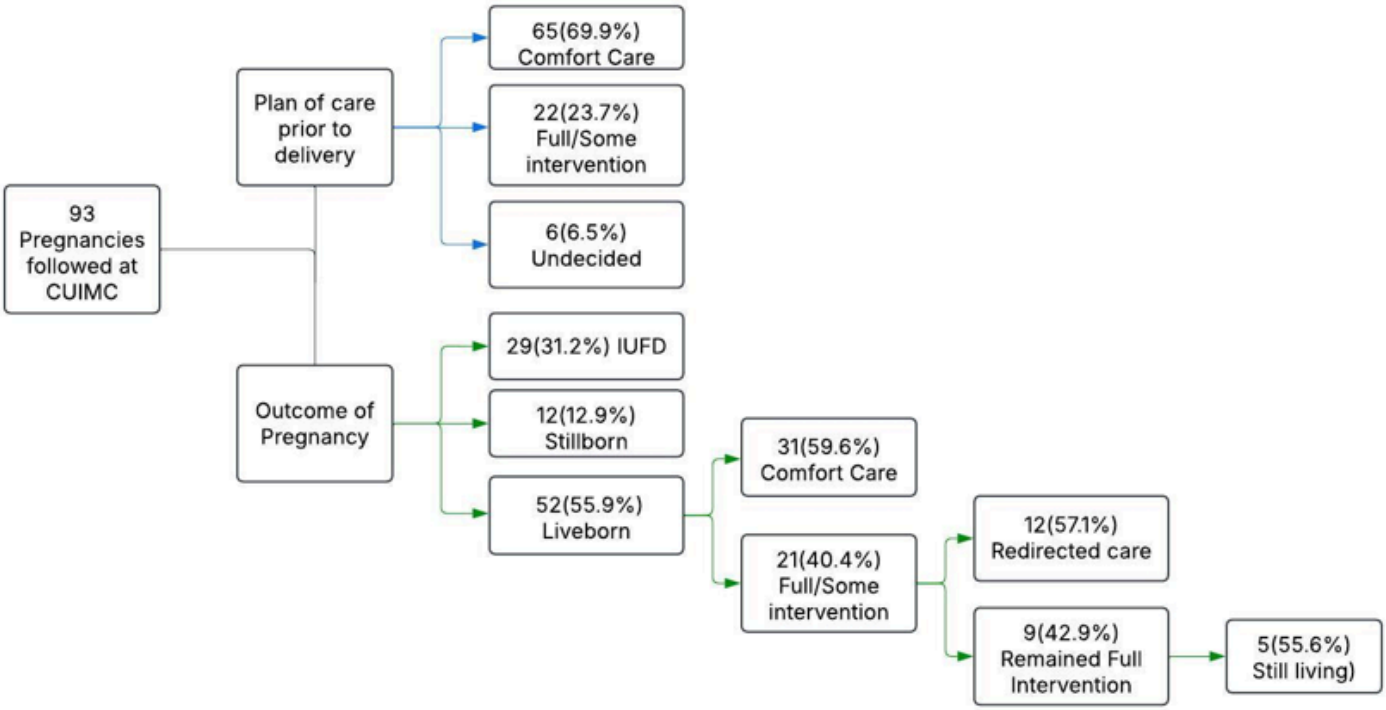
Table 3. Outcomes of all infants followed at CUIMC

General Infant characteristics (n=68)	
Birthweight*	1,845 grams (757.5)
Gestational Age at Birth*	37 Weeks (5.0)
Major Organ Involvement*^	2 (2.0)
Full Intervention Infant Care (n=37)	
Underwent Surgical Procedures	20 (54.1%)
Gastrostomy tube	11
Other GI Surgery (Esophageal Atresia, Hernia, Omphalocele, ect.)	6
Tracheostomy	2
Cardiac	9
Died despite surgical interventions	10
Length of Stay*	60 Days (71.5)
Length of stay who underwent Surgical Procedures*	90 Days (83.0)

*Median; ^ Major organ involvement indicates abnormalities noted on prenatal or postnatal imaging of major organ systems such as Cardiac, Neurologic, Renal, Pulmonary and Gastrointestinal

Figures

Figure 1a.



1b.

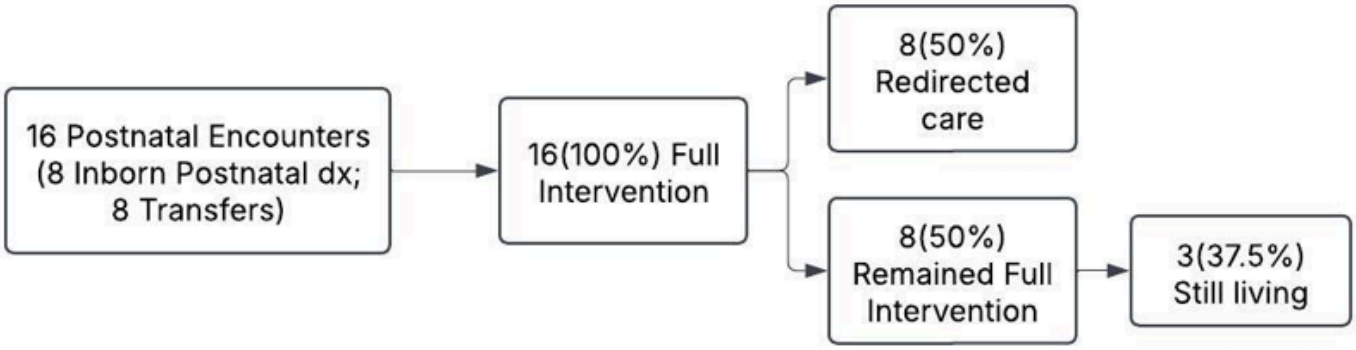


Figure 1

Legend not included with this version

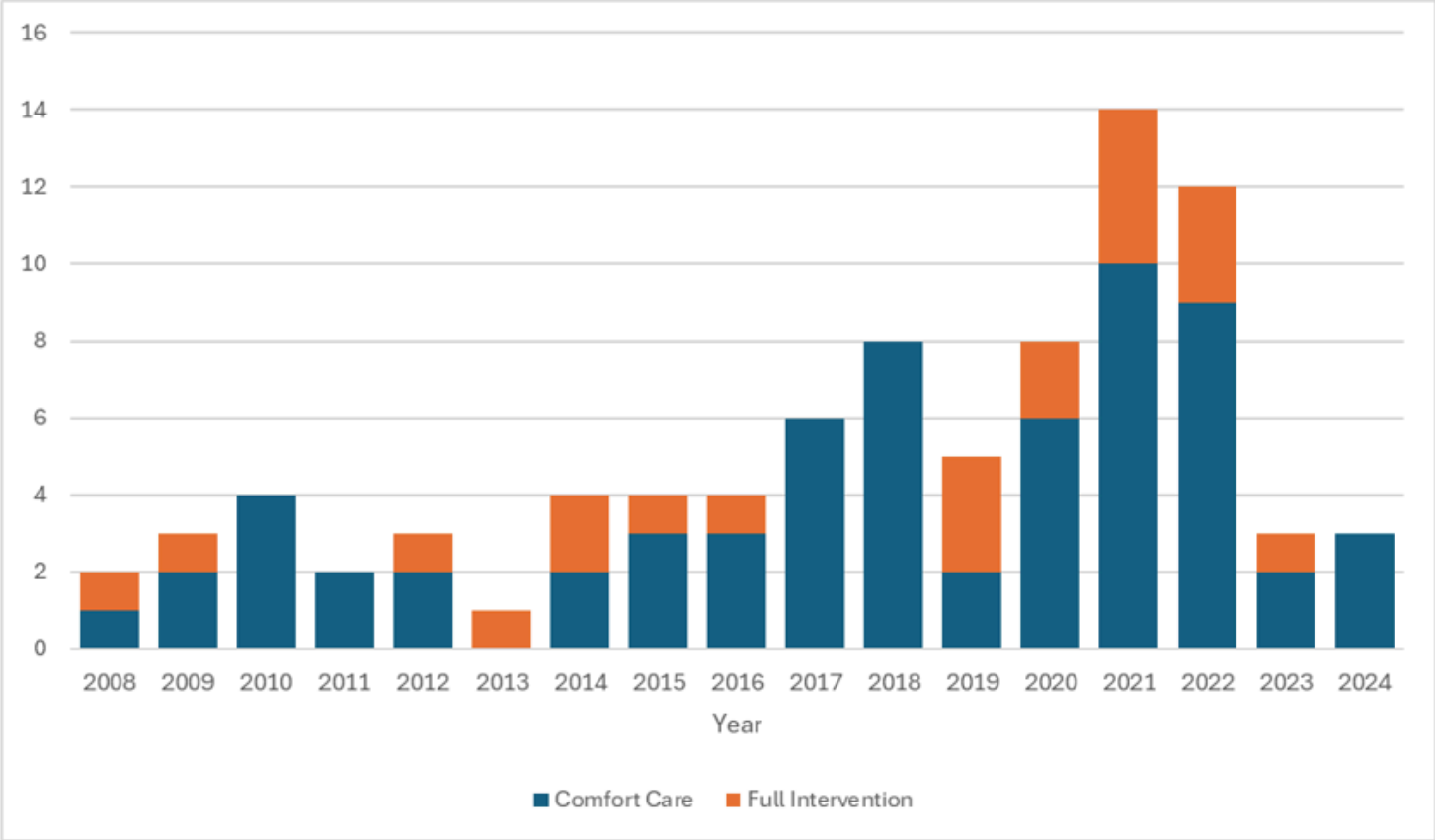


Figure 2

* Prenatal plan of care for families, counseled by NCCP team. N=93, of note 6 families did not make a care decision prior to delivery.

3a.

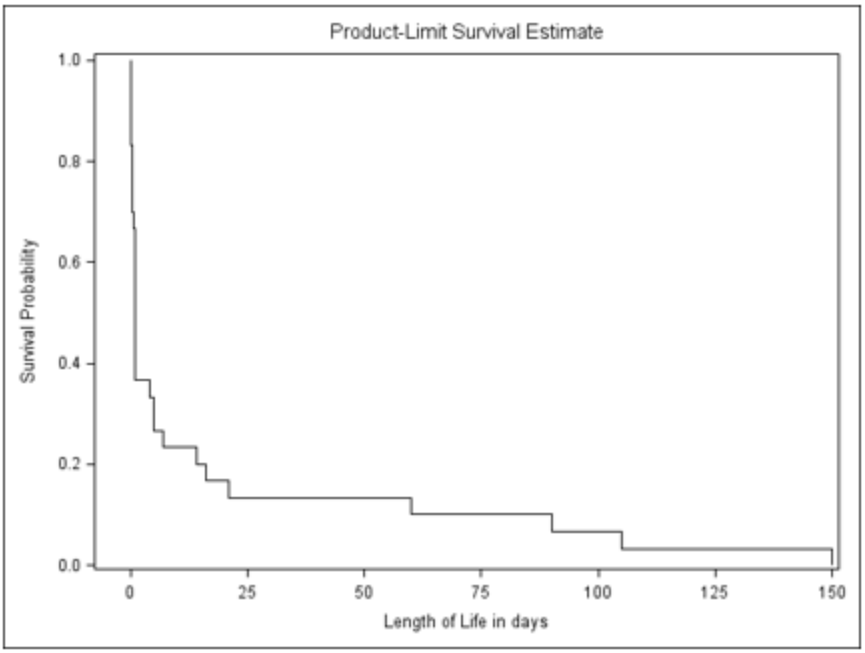


Figure 3b.

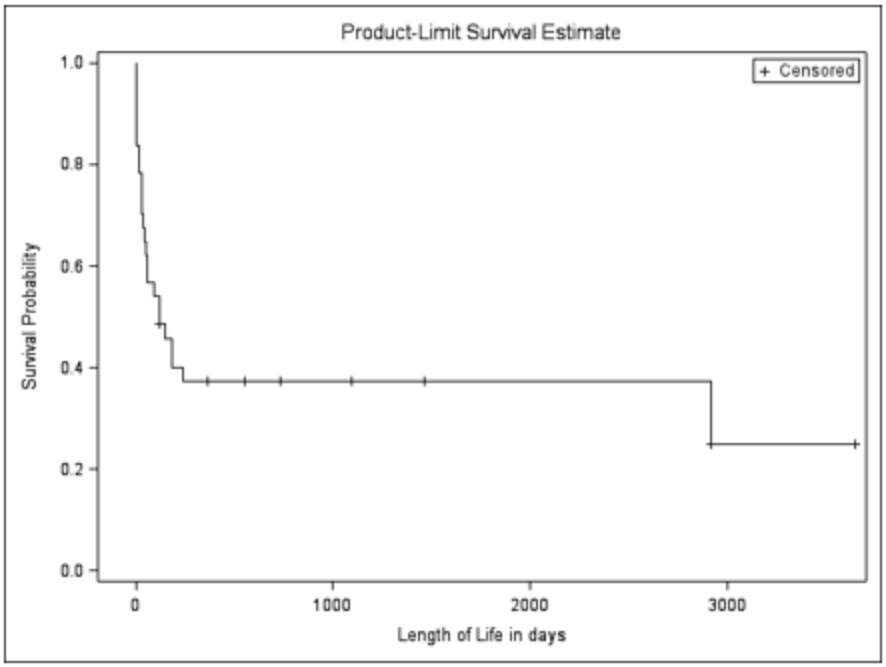


Figure 3

3a. Kaplan Myer Survival Curve of those infants treated with Comfort Care

3b. Kaplan Myer Survival Curve of those infants treated with ICU intervention.