



Original Article

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Abstract

Background: Timely prenatal diagnosis of CHD allows families to participate in complex decisions and plan for the care of their child. This study sought to investigate whether timing of initial fetal echocardiogram and the characteristics of fetal counselling were impacted by parental socio-economic factors. **Methods:** Retrospective chart review of fetal cardiac patients from 1 January, 2017 to 31 December, 2018. We reviewed gestational age at first fetal echo, maternal age and ethnicity, zip code, rurality index, and hospital distance. Counselling was evaluated based on documentation regarding use of interpreter, time billed for counselling, and treatment option chosen. **Results:** Total of 139 maternal–fetal dyads were included, and 29 dyads had single-ventricle heart disease. There was no difference in income, hospital distance or rurality index, and first fetal echo timing. There was no significant difference between maternal ethnicity and maternal age, gestational age at initial visit, or follow-up. Patients in rural areas had increased counselling time ($p < .05$). There was no difference between socio-economic factors and ultimate parental choices (termination, palliative delivery, or cardiac interventions). **Conclusion:** Oregon comprises a heterogeneous population from a large geographical catchment. While prenatal counselling and family decision-making are multifaceted, we demonstrated that dyads were referred from across the state and received care in a uniformly timely manner, and once at our centre received consistent counselling despite differences in parental socio-economic factors.

CHD affect about 1% of live births in the United States every year and are the most common cause of death from a birth defect.^{1–3} With advances in imaging technology, CHD has increasingly been diagnosed in the prenatal period,^{4,5} with about 45% diagnosed in populations without known risk factors for CHD.⁶ Knowing about the diagnosis of CHD before birth allows for timely decision-making and medical transfer, if necessary, to tertiary medical centres equipped to manage these potentially complex infants. It also allows parents the opportunity to fully participate in those life-changing decisions. Qualitative studies that have explored the parental perspective point to the importance of early, factual information that centres on the preference of the parents.^{7–11} Parents may choose to terminate, continue the pregnancy, elect to have a palliative induction, or choose palliative care after birth.^{7–15} As such, the timing of the first cardiac fetal counselling visit is of great importance because it gives parents the information needed to make decisions regarding diagnosis, prognosis, management, and treatment options, and a glimpse into what their life may look like in different scenarios.^{12–15}

There has been significant research regarding the disparities in prenatal diagnosis and infant mortality. Prenatal diagnosis is less likely to occur if the mother lives in a rural area, has a lower socio-economic position, or does not have private insurance.^{16–18} Mortality rates in patients with CHD are also disparate.^{19,20} Infants born to non-Hispanic Black and Hispanic mothers are more likely to die from CHD than infants born to non-Hispanic White mothers.^{21–23} In children undergoing congenital heart surgery, Black children had a higher in-hospital mortality rate than White children, while Black and Hispanic children both had longer hospital stays than White children.²⁴ These racial and ethnic disparities in survival diminish when adjustments are made for insurance status and may also be decreasing in general.^{25,26} Furthermore, disadvantaged socio-economic position is associated with higher risk of infant mortality, though this association appears to be less significant in severe CHD.^{25,27} Given these findings, we sought to investigate whether the timing of the first fetal echocardiogram and characteristics of our institution's prenatal counselling were impacted by parental socio-economic characteristics. At our institution, we have a standardised prenatal counselling checklist which prompts providers to discuss all pregnancy options, anatomy of the cardiac lesion, delivery plan if pregnancy is continued, cardiac interventions that may be required, quality of life concerns, neuro-developmental outcomes, feeding issues, and the need for lifelong cardiology follow-up. In addition, we have fetal cardiology outreach clinics at sites around the state and a close relationship with the referring providers in these areas. Dyads seen at our fetal cardiology

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outreach sites are seen in person by one of our fetal cardiologists and have a fetal echocardiogram performed at that visit. The referring providers around the state are maternal–fetal medicine providers, obstetricians, family medicine providers, and midwives, all of whom can refer patients directly. We hypothesised that dyads from more rural environments or lower socio-economic positions would be referred for their first fetal echocardiogram at a later gestation due to inequalities in access to care.

Methods

We performed a retrospective chart review of all maternal–fetal cardiac patient dyads seen at Oregon Health and Science University (OHSU) outreach or main campus clinics from 1 January, 2017 to 31 December, 2018 who were diagnosed with CHD prenatally. All patients with a fetal cardiac diagnosis were included. Patients who had an isolated fetal arrhythmia were referred for second opinions or had previously met with a non-OHSU cardiologist were excluded. For those meeting inclusion criteria, we recorded the gestational age at the first fetal echocardiogram, age of mother, zip code of residence, number of follow-up fetal echocardiograms performed, median income, a calculated rural–urban index, and distance from OHSU. The median income was determined for the zip code of residence based on the Federal Information Processing Standards (FIPS) code data from 2017 from the US Department of Housing and Urban Development.²⁸ We evaluated rurality based on the Rural-Urban Continuum Codes (RUCC) from 2013 from the US Department of Agriculture Economic Research Service.²⁹ We noted maternal race/ethnicity as recorded in the chart. Similarly, we noted preferred maternal language as recorded in the chart. The fetal echocardiographic report was used to determine the CHD diagnosis at first fetal echocardiogram.

Counselling was evaluated based on documentation in the fetal echocardiographic report regarding use of interpreter, time billed for counselling, and treatment options discussed. Use of interpreter was recorded as phone interpreter, in-person interpreter, or ad hoc interpreter (family member or friend). Recommendations about the need for a cardiothoracic surgery or palliative care consult and whether these consults were completed either prenatally or postnatally were recorded. Treatment option ultimately chosen was documented as termination, palliative induction (defined as induction of pregnancy prior to 39 weeks gestational age leading to palliative care), palliative care after delivery, or continuation of pregnancy with plan for full postnatal intervention. Surgical cardiac intervention after birth was recorded when applicable. Statistical analysis was performed with GraphPad Prism 9.1.2. Two-tailed *t*-tests were used to compare continuous variables, and Chi-square tests were used to compare categorical variables. This study was approved by the local institutional review board.

Results

Within the group, 139 maternal–fetal dyads met inclusion criteria. There were 206 total fetal cardiology visits during the study period (139 initial fetal cardiology visits and 67 follow-up visits). Table 1 summarises the dyad and general fetal counselling characteristics. Average maternal age was 31 years, and average gestational age at first fetal echocardiogram was 24 weeks and 4 days (range 19 weeks and 2 days–39 weeks and 2 days). The median distance from maternal residence to our main centre was 51 miles

Table 1. Dyad and counselling characteristics (n= 139)

| | |
|---|------------------------|
| Maternal age (years) | 31 (17–45) |
| Gestational age at first FE (weeks) | 24.57 (16.86–39.29) |
| Median distance from cardiac centre (miles) | 51 (3.2–379.9) |
| Median income (\$) | 57,019 (42,624–83,695) |
| Interpreter use documented | 11 (8%) |
| Time billed for consult (mins) | 46 (15–80) |
| Single ventricle heart disease | 27 (19%) |
| Termination | 9 (6%) |
| Palliative induction (<39 weeks GA) | 6 (4%) |
| Palliative care after delivery | 4 (3%) |
| Continuation with full care postnatally | 120 (87%) |

FE = fetal echocardiogram; GA = gestational age.
Values shown are number (percent) or median (range).

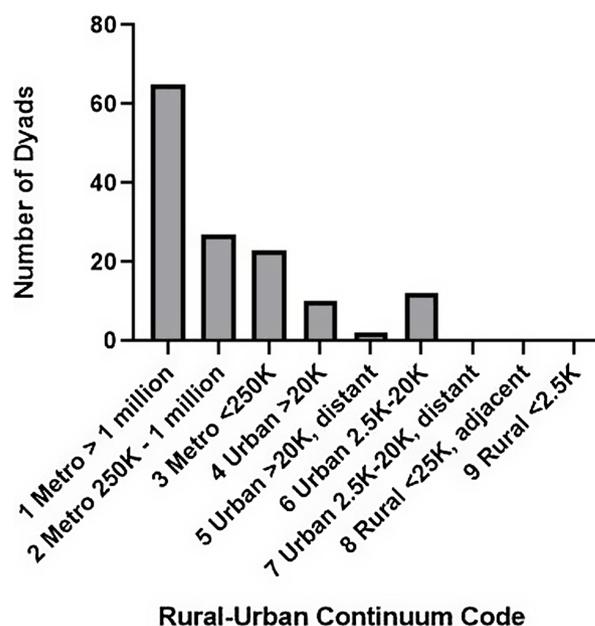


Figure 1. Maternal rurality. Number of dyads seen in each of the nine Rural-Urban Continuum code areas.

(range 3.2–379.9 miles). The majority of maternal–fetal dyads (83%) lived in RUCC codes 1–3 (classified as metro areas), and none lived in RUCC codes 7–9 (the most rural classifications) (Fig. 1). Median income by home zip code was \$57,019 (range \$42,624–\$83,695).

The majority of mothers identified as non-Hispanic White (66%) (Fig. 2). Approximately 19% of mothers identified as Hispanic, with the majority of those identifying as Hispanic White. This was similar to the 2020 US Census Bureau tally that estimated the racial makeup of Oregon to be 75% non-Hispanic White, 13.4% Hispanic or Latino, 4.9% Asian, 2.2% Black or African American, 1.8% American Indian and Alaska Native, and 0.5% Native Hawaiian and Other Pacific Islander. Spanish was the second most common preferred language after English. Interpreter use was documented in 11 of the initial counselling appointments. Six used in-person interpreters, three phone interpreters, and two ad hoc interpreters – in both cases with family members acting as interpreters.

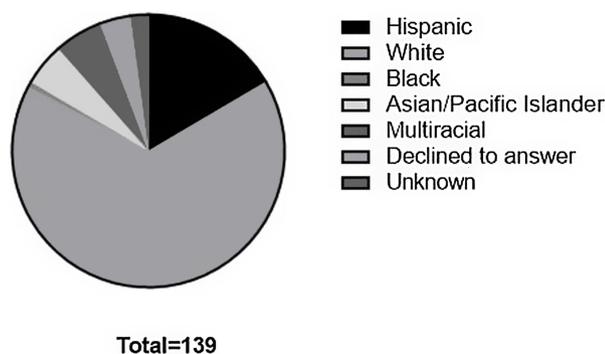


Figure 2. Maternal self-identified ethnicity. Breakdown of self-identified ethnicity of 139 pregnant patients.

The average time documented for a fetal cardiology consult was 46 minutes. CHD diagnoses ranged from mild disease (small ventricular level shunt) to complex disease with heterotaxy and single-ventricle physiology. Seventeen per cent of fetal patients were diagnosed with single-ventricle heart disease. Most pregnancies were continued without intervention. Six per cent of pregnancies resulted in termination, 4% in palliative induction, and 3% in palliative care after delivery. Recommendations for a fetal palliative care consult were not infrequent and were documented in approximately 22% of the initial fetal counselling visits. The palliative care team wrote at least one consult note on 26% of the maternal–fetal dyads. The majority of these consultations occurred during the prenatal period.

As shown in Table 2, there was no significant difference between maternal race/ethnicity and gestational age at initial fetal echocardiogram, or maternal age, or time billed for the consult. In addition, there was no significant difference in insurance type and timing of initial fetal echocardiogram or time billed for the consult. Interestingly the non-Hispanic White group was more likely to be more rural, with lower median household incomes, and at a greater distance from the cardiac centre. Also of note, use of interpreter did not result in longer counselling time being billed. Additionally, there was no statistically significant difference between maternal race/ethnicity and ultimate pregnancy outcomes, including termination and palliative care. Furthermore, there was no significant difference between gestational age of first fetal echocardiogram at less than 24 weeks or after 24 weeks and income, maternal age, time counselled or distance from OHSU, or rurality (Table 3). For dyads with a first fetal echocardiogram prior to 24 weeks gestational age, there was a statistically significant difference between continuation with full cardiac care postnatally and termination/palliative care.

Not surprisingly, diagnosis and distance did impact length of counselling. Dyads with single-ventricle heart disease had longer counselling times ($p = 0.002$) compared to other CHD diagnoses. Farther distance from our surgical centre also correlated with longer length of counselling ($p < 0.05$).

Discussion

With clear inequity in the provision of health care across the nation, evaluating the approach towards parents of unborn children with CHD at high risk for poor outcomes serves as an effective barometer for how equitably we are providing initial care in the field of paediatric–fetal cardiology. This study sought to investigate whether the timing and the characteristics of the

initial fetal counselling visit for maternal–fetal dyads diagnosed with CHD in the prenatal period were impacted by parental demographic and socio-economic factors. Race, ethnicity, socio-economic, or geographic factors did not impact the timing of the initial fetal echocardiogram appointment and counselling visit. Dyads were referred from across the state and received care in a uniformly timely manner irrespective of distance from referral centre, rurality, or income. This uniform timeliness of referrals from across the state is in part due to the outreach efforts of the fetal cardiology group at our institution. We found that in addition to discussing diagnosis and postnatal management options, parents were counselled on a variety of pregnancy and treatment options, ranging from potential surgical cardiac intervention to palliative care. Furthermore, we demonstrated that maternal–fetal dyads received consistent length of counselling with or without use of an interpreter. Finally, while numbers were small, we also saw that there was no significant difference in the choices those families made (termination, palliative care, or surgery) based on race, ethnicity, or geographic factors.

Interestingly use of an interpreter did not result in a longer length of time being billed. This may be due to documentation about interpreter use being incompletely recorded in the chart or demonstrates that using time billed as a surrogate for time counselled may not accurately reflect the actual provider time spent with families.

Dyads who lived farther away from our institution or were diagnosed with single-ventricle heart disease had significantly longer initial counselling visits. This finding seems to demonstrate an appropriate tailoring of counselling depending on specific parental needs, in this case, complex cardiac diagnosis or potential difficulty with accessing care. Palliative consult recommendations were not infrequent and recommended in the initial fetal counselling visit in about one in five maternal–fetal dyads. This finding emphasises the broader importance of the initial fetal counselling visit in connecting patients to helpful resources and a multidisciplinary team approach to the care of fetal cardiac patients.

Prior studies have previously demonstrated a lack of standardisation in counselling³⁰ and have also shown that parents and paediatric cardiologists differ in what they consider important for parents of children with CHD to know in the prenatal and neonatal period.³¹ This study did not evaluate the granular details of each encounter and how individual parental or physician factors impacted the discussion (as this level of detail was not included in the clinical documentation).

Additionally, it is very clear that inequitable delivery of care goes far beyond length of counselling time documented and consistent referral for additional services. The intimate and nuanced conversation that occurs during a fetal diagnosis counselling session is dependent on characteristics of the individuals involved. Within these interactions, beliefs, behaviours, practices, and expressions reflecting different individual or cultural values are revealed, and families may feel exposed or at risk. Psychological concepts like uncertainty avoidance, where individuals differ on the amount of tolerance they have of unpredictability, or collectivism where shared familial decision-making is an important determinant of behaviour, take on significantly greater meaning when discussing the fate of a pregnancy complicated by single-ventricle heart disease. However, the unique and dynamic nature of every counselling session is also what makes it particularly challenging to study. Direct qualitative analysis of the content of these initial fetal counselling visits with the inclusion of provider and patient perspective is essential. Detailed

Table 2. Maternal race/ethnicity and dyad-counselling characteristics

| | Non-Hispanic white (95) | Hispanic, Black, multiracial, Pacific-Islander, non-Hispanic Asian (44) | p-Value |
|---|-------------------------|---|---------|
| Maternal age (years) | 31 (17–45) | 28 (19–44) | NS |
| Gestational age at first FE (weeks) | 24.86 (16.86–37.71) | 25 (18–39.29) | NS |
| Median distance from cardiac centre (miles) | 67.1 (3.2–379.9) | 19.5 (5.3–379.9) | <0.001 |
| RUCC | 2 (1–6) | 1 (1–6) | <0.005 |
| Median income (\$) | 56,408 (42,624–81,061) | 72,367 (42,624–82,819) | <0.0001 |
| Time billed for consult (mins) | | 40 (20–80) | NS |
| Single-ventricle heart disease | 15 (16%) | 12 (27%) | NS |
| Termination | 8 (8%) | 1 (2%) | NS* |
| Palliative induction (< 39 weeks GA) | 4 (4%) | 2 (5%) | |
| Palliative care after delivery | 2 (2%) | 2 (5%) | |
| Continuation with full care postnatally | 81 (85%) | 39 (89%) | NS* |

RUCC = rural-urban continuum code; FE = fetal echocardiogram; GA = gestational age.

Values shown are number (percent), median (range).

*Chi-square performed on non-intervention (termination/palliative induction/palliative care) versus continuation of full care postnatally.

Table 3. Timing of first fetal echocardiogram and dyad characteristics

| | First fetal echocardiogram <24 weeks gestational age (63) | First fetal echocardiogram >24 weeks gestational age (76) | p-Value |
|---|---|---|----------|
| Maternal age (years) | 31 (17–44) | 29.5 (18–45) | NS |
| Median distance from cardiac centre (miles) | 48 (3.2–280.1) | 42.9(5.3–379.9) | NS |
| RUCC | 2 (1–6) | 2 (1–6) | NS |
| Median income (\$) | 61,776 (45,374–82,819) | 62,557 (42,624–82,819) | NS |
| Time billed for consult (mins) | | 40 (15–80) | NS |
| Single ventricle heart disease | 12 (19%) | 15 (20%) | NS |
| Termination | 9 (14%) | 0 | |
| Palliative induction (< 39 weeks GA) | 6 (19%) | 0 | |
| Palliative care after delivery | 2 (3%) | 2 (3%) | |
| Continuation with full care postnatally | 46 (73%) | 74 (97%) | <0.0001* |

RUCC = rural-urban continuum code; GA = gestational age.

Values shown are number (percent), median (range).

* Chi-square performed on non-intervention (termination/palliative induction/palliative care) versus continuation of full care postnatally.

analysis of the substance, pace, intensity, emotional response, and level of engagement of both providers and patients with various backgrounds should be our next investigation to better understand what effective counselling for fetal CHD really means.

There are a number of limitations to this study. The retrospective nature of the study limited our review of the counselling content to what was documented, which as described above, was variable. Additionally, this study was based on a single-referral centre, which limits the generalisability of the results. The analysis of differences in timeliness and length of visits by race and ethnicity was also limited by small group size for individual race and ethnicity groups, as well as use of race and ethnicity categories provided by the electronic medical record. The limited number of patients from the most rural areas of the state reflects that those areas have small populations but makes it hard to comment on the equity

of care for those families. Similarly, due to the small number of visits that documented interpreter use, further analysis of visit length by interpreter type was limited. In future studies, a larger pool of maternal–fetal dyads across multiple centres would be useful to confirm the findings of this study. Finally, this study examined the dyads that made it into our care prenatally. During this time period, there were nine patients who required neonatal surgery who did not have a prenatal diagnosis (CHD diagnoses consisted of three transpositions of the great arteries, three total anomalous pulmonary venous connections, and one interrupted aortic arch, and two aortic arch hypoplasia with ventricular septal defects), no patients with single-ventricle heart disease were missed. We do not have full prenatal dyad information and characteristics on these postnatal diagnosis patients, but all nine were captured by pre-discharge critical CHD pulse oximetry screening.

In conclusion, while prenatal counselling and family decision-making are multifaceted, we demonstrated that despite differences in geographic and socio-economic backgrounds, maternal–fetal dyads from across the state were referred and received care in a uniformly timely manner. Once the dyad was seen at our centre, they received consistent counselling regarding all pregnancy and postnatal options. Due to the nature of the field, and the variability in CHD, uniformity in approach to families is crucial for providing effective and targeted information regarding diagnosis, prognosis, and treatment options. In a nation beset by healthcare inequities, this study should only be the first step in evaluating how to most effectively and consistently approach this challenge.

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Competing interests. None.

Ethical standards. The authors assert that all procedures contributing to this work comply with the ethical standards with the relevant national guidelines on human experimentation (United States of America) and with the Helsinki Declaration of 1975 as revised in 2008 and have been approved by the institutional committee at OHSU IRB.

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