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Incidence and mortality trends in congenital diaphragmatic hernia in the United States

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Abstract

Objectives: The average incidence of congenital diaphragmatic hernia (CDH) in the United States (US) is 2.6 per 10,000 live births but it varies based on the population studied, the database used, and the study period. Further, previous studies suggest that pre-discharge mortality in CDH is declining but this may not capture the 'hidden mortality' and post-discharge mortality. We examined a population-based database to evaluate the trends in the incidence (2016–2023) and CDH-related infant mortality rate (CDH-IMR) [2007–2022] in the US.

Methods: We conducted a retrospective cross-sectional analysis of the CDC WONDER database. First, we queried the 2016–2023 natality dataset derived from birth certificates for live births with CDH (ICD-10 code Q79.0). We expressed CDH incidence as per 10,000 live births. Next, we queried the linked birth/infant death dataset from 2007 to 2022 for CDH-IMR through 1 year of age. CDH-IMR was expressed per 100,000 live births. Trends were evaluated with Joinpoint regression and reported using average annual percentage change (AAPC) with 95 % confidence intervals (CI).

Results: Among 29, 880, 509 live births between 2016 and 2023, 3,797 had CDH (1.3 per 10,000). Of these, 33.4 % were transferred within 24 h after birth. There was no significant change in the CDH incidence during the study period (AAPC 0.93 %; CI: −0.1, 2.0). The overall CDH-IMR (per 100,000) was 5.7, and it declined significantly from 6.3 in 2007 to 4.7 in 2022 (AAPC: −1.5 %; CI: −2.2, −0.8).

Conclusions: The CDH incidence, which was lower than previously reported and did not change from 2016 to 2023, requires validation. The downward trend in mortality needs ongoing surveillance to monitor the impact of new management strategies on mortality rates.

Keywords: congenital diaphragmatic hernia; incidence and infant mortality rate; CDH trends

Introduction

Congenital diaphragmatic hernia is a rare birth defect that is associated with significant morbidity and mortality. CDH is the costliest non-cardiac birth defect during the birth hospitalization [1]. The incidence of CDH varies depending on the population studied, the study period, and the data sources used. The incidence ranged from 1.8 per 10,000 in Florida from 1988 to 1992 to 3.6 per 10,000 in Minnesota between 1988 and 1990 [2]. Stallings et al. recently reported the incidence of CDH in the US to be 3.17 per 10,000 births on case-level data from 13 US population-based birth defect surveillance programs between 2016 and 2020 [3]. However, this study was fraught with incomplete ascertainment. For example, only data from 10 out of the 55 counties in California provided data for this study [3].

Furthermore, previous studies from the multicenter Congenital Diaphragmatic Hernia Study Group have demonstrated that the overall in-hospital, pre-discharge mortality decreased significantly from 30.7 to 26 % between 1995 and 2019 [4]. However, limiting the analysis to in-hospital outcomes at tertiary referral centers can result in selection bias because as many as 35 % of CDH do not survive to transport to tertiary centers, resulting in a 'hidden mortality' for CDH [5, 6]. Furthermore, focusing on survival to discharge or in-hospital mortality during the birth hospitalization without evaluating post-discharge mortality could also underestimate the mortality burden in CDH. Therefore, a population-based study is necessary to investigate the true mortality outcome of CDH, but few have been conducted in the US to date [7–10]. We conducted a population-based study to determine the trends in the incidence and mortality rate in infants with CDH through 1 year of age in the US from 2016 through 2023.

Prior presentation: This study was a poster presentation at the 2024 American Academy of Pediatrics National Conference and Exhibition on 27th September 2024 in Orlando, Florida.

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Methods

Data source

First, we performed a retrospective, repeated cross-sectional analysis of the Centers for Disease Control and Prevention's Wide-Ranging online Data for Epidemiologic Research (CDC WONDER) Natality dataset [11]. The natality dataset reports statistics for live births in the United States to US residents based on the 2003 revised birth certificate. All states in the US have been using the 2003 revised birth certificate since 2015. The data pertains to all live births (stillbirths excluded) and are available by a variety of demographic characteristics, such as the mother's race, and mother's age, and health and medical items, such as tobacco use, and method of delivery. The natality dataset is derived from birth certificates, and 99 % of all births in the US are registered with the CDC [12].

Two worksheets were developed to facilitate the accurate collection of data for the completion of the revised 2003 standard birth certificate: the "Mother's Worksheet" (available at https://www.cdc.gov/nchs/data/dvs/moms-worksheet-2016.pdf) and the "Facility Worksheet" (available at https://www.cdc.gov/nchs/data/dvs/facility-worksheet-2016.pdf). In the Mother's Worksheet, data are directly obtained from the mother and include items such as race, Hispanic origin, and educational attainment. For the Facility Worksheet, data are obtained directly from the medical records of the mother and infant for items such as the date of the first prenatal care visit, pregnancy risk factors, and method of delivery [12]. On the Facility Worksheet, twelve congenital anomalies are separately identified in a checkbox format: 1) anencephaly; 2) meningomyelocele/spina bifida; 3) cyanotic congenital heart disease; 4) congenital diaphragmatic hernia; 5) omphalocele; 6) gastroschisis; 7) limb reduction defect; 8) cleft lip with or without cleft palate; 9) cleft palate alone; 10) Down syndrome; 11) suspected chromosomal disorder; and 12) hypospadias. This item allows for the reporting of more than one anomaly and includes a choice of "None of the above". If the item is not completed (i.e., none of the boxes are checked), it is classified as "Not stated". It is recommended that this information be collected directly from the medical record using the Facility Worksheet.

To examine the CDH-related infant mortality rate (CDH-IMR), we queried the linked birth/infant death dataset within CDC WONDER from 2007 to 2022 for CDH-IMR through 1 year of age. This database includes population-wide linked birth/infant death records, and more than 99 % of infant death records are linked to their corresponding birth certificates [13]. The purpose of the linkage is to use the many additional variables available from the birth certificate to conduct more detailed analyses of infant mortality patterns. The linked files include information from the birth certificate such as age, race, and Hispanic origin of the parents, birth weight, period of gestation, plurality, prenatal care usage, maternal education, live birth order, marital status, and maternal smoking, linked to information from the death certificate such as age at death and underlying and multiple cause of death [14]. The linked birth/infant death dataset has been used previously to examine the trends in cause-specific infant mortality in the US [15, 16]. This cross-sectional study did not require Institutional Review Board approval or patient informed consent because it used publicly available de-identified data per Common Rule 45 CFR § 46.

Study population, exposures, and outcomes

We queried the 2016–2023 natality dataset for live births with CDH (ICD-10 code Q79.0) for each year [17]. Next, we queried the linked birth/infant death records for infant deaths with CDH as the underlying cause of death. The World Health Organization defines the underlying cause of death as the disease or injury that initiates a sequence of events that leads directly to death. The exposure was the year of birth and the year of death, and the outcomes were the changes over time in the incidence of CDH and CDH-IMR. The incidence of CDH and CDH-IMR were further stratified by the mother's bridged race, gestational age, birth weight, geographic region, and sex. We used race data recorded on birth and death certificates, as captured in CDC WONDER. Race categories included Black or African American, White, Asian, American Indian or Alaskan Native, more than one race, Native Hawaiian, and others. Data on the mother's bridged race was available up to 2019. Except for non-Hispanic Black (NHB), non-Hispanic White (NHW), and Hispanic ethnicity, we did not study the other racial/ethnic categories due to suppression constraints (death counts fewer than 20) for most of the years of the study. Urbanization level was categorized into metropolitan and nonmetropolitan regions. Metropolitan regions included large central metropolitan regions, large fringe metropolitan regions, medium metropolitan regions, and small metropolitan regions. Nonmetropolitan regions included micropolitan regions and noncore nonmetropolitan regions. The incidence of CDH was calculated and expressed as per 10,000 live births. The CDH-IMR was calculated and expressed as per 100,000 live births.

Statistical analysis

We tabulated baseline demographic and perinatal characteristics of infants with CDH with frequencies and proportions. The Shapiro-Wilk and Kolmogorov-Smirnov tests were used to evaluate whether continuous data were

normally distributed. Continuous data with normal distribution were presented as means (SD) and were analyzed using the t-test. Continuous data with nonnormal distribution were presented as median with interquartile range (25th-75th quartile) and were analyzed using the Mann-Whitney *U* test for two groups. Differences among racial groups or geographic regions were ascertained using analysis of variance (ANOVA) with posthoc Tukey's Honestly Significant Difference (HSD) test. p-value <0.05 defined statistical significance.

We used Joinpoint regression version 5.0.2 (National Cancer Institute, Bethesda, Maryland, USA) to examine trends in the incidence of CDH (2016 through 2023) and CDH-IMR (2007 through 2022) [18]. Joinpoint is statistical software for the analysis of trends using joinpoint models, where several different lines are connected at the inflection points or "joinpoints." The software takes trend data and fits the simplest joinpoint model that the data allow, starting with the minimum number of joinpoints (for example, zero joinpoints is a straight line), and tests whether more joinpoints are statistically significant and must be added to the model, up to the maximum number of joinpoints the data allow. The models may incorporate estimated variation for each point (e.g., when the responses are age-adjusted rates) or use a Poisson model of variation. In addition, the models may also be linear on the log of the response (e.g., for calculating annual percentage rate change). Trends were reported using average annual percentage change (AAPC) with 95 % confidence intervals (CI). The trend was considered significant if the 95 % CI did not include zero. Because the study objective was to examine the temporal trends (rather than the causal relationship between calendar years and outcomes), we did not adjust for covariates [19]. Further, to avoid any trends and racial differences from being masked, we did not perform an adjusted analysis [7]. The analysis for this manuscript was completed between 1st to 7th February 2025.

Results

Incidence of CDH

Among 29, 880, 509 live births between 2016 and 2023, 3,797 had the presence of CDH (1.3 per 10,000) indicated on their birth certificates. Of these, 57.2 % were male, 59.3 % were Non-Hispanic White (NHW), 11 % were Non-Hispanic Black (NHB), and 82.1 % were in metropolitan areas. Furthermore, the average gestational age and birthweight were 37 weeks and 2,852 gm, respectively, and 33.4 % were transferred within 24 h after birth (Table 1).

As shown in Table 2, the incidence of CDH was more likely to be significantly higher in preterm and low birth weight infants, males, rural areas, NHW infants, and in the Midwest census region. There was no significant change in the CDH incidence during the study period (remained stable at 1.2 to 1.3 per 10,000; AAPC 0.93 %; CI: −0.1, 2.0).

Infant mortality rate attributable to CDH

From 2007 through 2022, 3,564 infants out of a total livebirth population of 62.8 million had CDH listed as the underlying cause of death through 1 year of age (overall CDH-IMR of 5.66 ± 0.49 per 100,000). Of all the deaths attributed to CDH, 7.4 , 27.6, 18.95, 24.45, and 21.7 % died within<1 h, 1–23 h, 1–6 days, 7–27 days, and 28–364 days of life, respectively. Thus, the majority of deaths from CDH occurred within the first 7 days of life (53.9 %). The CDH-IMR declined significantly from 6.32 in 2007 to 4.72 in 2022 (APC: −1.5 %; CI: −2.2 to −0.8 %) [Figure 1].

As shown in Table 3, the CDH-IMR was significantly higher in males (6.11 ± 0.77 vs. 5.19 ± 0.41 in females; p<0.001), but there was no significant difference between NHW and NHB (6.29 ± 0.76 vs. 6.05 ± 0.66; p=0.79). However, the CDH-IMR was significantly lower in Hispanic infants (5.40 ± 0.52) when compared to NHB infants (p=0.009) but not significantly lower than NHW infants (p=0.08). The CDH-IMR did not change in NHB infants (APC 0.03 %; CI: −2.9 to 3.7 %), males (AAPC: - 0.3 %; CI: −1.3, 0.7), and females (AAPC: −0.3 %; CI: −1.3, 0.7). For NHW, the CDH-IMR decreased significantly from 6.54 to 4.61 per 100,000 live births from 2007 to 2019 (APC: −1.8 %; CI: −3.2 to −0.4 %).

Discussion

Based on birth certificate data obtained from the CDC WONDER natality dataset, the incidence of CDH was much lower than those reported in previous studies, and there was no significant change in the incidence rate between 2016 and 2023. Of the infants with CDH, approximately one-third were transferred within 24 h of birth. Additionally, while the CDH-IMR decreased in NHW infants in tandem with the overall decrease in CDH-IMR, there was no significant change in NHB infants. These findings add to the existing literature and extend the data on CHD-related mortality beyond the birth hospitalization up to 1 year of age.

The CDH incidence of 1.3 per 10,000 live births in the present study is substantially lower than the reported incidence of 2.3–3.8 per 10,000 live births reported from various states in the US [3, 20–25], Canada [26], England [27], Sweden

Table 1: Demographic and perinatal characteristics of livebirths with congenital diaphragmatic hernia in the United States from 2016 – 2023.

	Proportion of newborns with CDH, n (%)
Average age of mother, years	29.2
Average gestational age by OE, weeks	37.0
Average gestational age by LMP, weeks	37.2
Birthweight	
<2.5 kg	975 (25.7)
≥2.5 kg	2,758 (72.6)
Not stated or unknown	64 (1.7)
Gestational age	
Preterm (≤36 weeks)	1.022 (26.9)
Term (≥37 weeks)	2,744 (73.1)
Mode of delivery	
Vaginal	2,131 (56.1)
Cesarean delivery	1,666 (43.9)
Gender	
Male	2,172 (57.2)
Female	1,625 (42.8)
Plurality	
Singleton	3,657 (96.3)
Twin/triplets or higher	110 (2.9)
Unknown/not stated	30 (0.8)
Expected payer, %	
Medicaid	1,596 (42)
Private insurance	1,853 (48.8)
Self-pay	158 (3.2)
Other/unknown	190 (6)
Mother's race and ethnicity[a]	
Non-hispanic black or african american	421 (11.1)
Non-hispanic white	2,251 (59.3)
Non-hispanic asian	164 (4.3)
More than one race (non-hispanic) and native Hawaiian	86 (2.2)
American indian/Alaskan native (non-hispanic)	44 (1.2)
Hispanic	770 (20.3)
Unknown/not reported hispanic ethnicity	61 (2.2)
Urbanization	
Metropolitan	3,118 (82.1)
Non-metropolitan or rural	679 (17.8)
Transferred within 24 h of birth	
Yes	1,269 (33.4)
No	2,506 (66.0)
Not stated or unknown	22 (0.6)

[a]Based on self-reported maternal race and ethnicity on birth certificates from 2007 to 2019.

Table 2: Demographic and perinatal characteristics of infants with congenital diaphragmatic hernia listed as the underlying cause of death from 2007 through 2022.

	Infants with CDH as the underlying cause of death n (%)	CDH-IMR per 100,000 live births (95 % confidence interval)	p-Value
Birthweight			<0.001
<2.5 kg	1,426 (40.0)	27.6 (25.8, 28.8)	
≥2.5 kg	2,136 (59.9)	3.7 (3.2, 4.0)	
Not stated or unknown	***		
Gestational age			
Preterm (≤36 weeks)	1,338 (37.5)	18.1 (16.6, 17.7)	<0.001
Term (≥37 weeks)	2,209 (62.0)	4 (3.7, 4.4)	
Unknown/Not stated	***		
Gender			
Male	1,972 (55.3)	6.1 (5.7, 6.5)	0.001
Female	1,592 (44.7)	5.2 (4.8, 5.5)	
Plurality			
Singleton	3,422 (96.0)	5.6 (5.4, 5.9)	
Twin/triplets or higher	110 (4.0)	6.7***	
Mother's bridged race/ethnicity[a,b]			<0.001
Non-hispanic black or african american	487 (16.1)	6.3 (5.7, 6.5)	
Non-hispanic white	1,683 (55.6)	6.1 (5.7, 6.2)	
Hispanic or latino	658 (21.7)	5.4 (5.0, 5.7)	
Non-hispanic other races	158 (5.2)	4.2 (4.0, 4.6)	
Origin unknown or not stated	40 (1.3)	9.8	
Census region[c]			<0.001
Northeast (NE)	429 (12.0)	4.3 (3.9, 4.5)	
Midwest (MW)	865 (24.2)	6.6 (5.9, 7.2)	
South (S)	1,507 (42.3)	6.2 (5.7, 6.6)	
West (W)	763 (21.4)	5.0 (4.5, 5.3)	

[a]Race/ethnicity data were available up to 2019. Thus, a total of 3,206 deaths from CDH, was used as the denominator for calculating the proportions for each race/ethnic group. [b]Pairwise comparisons with posthoc Tukey's HSD: NHB, vs. NHW (p=0.8); NHW, vs. Hispanic, p=0.8. All other comparisons showed statistically significant difference. [c]Pairwise comparisons with posthoc Tukey's HSD: CDH-IMR, significantly higher in the Midwest and South census regions (p<0.001). The difference between the Midwest and South was not significant (p=0.7). ***Data not available due to in the CDC WONDER, database.

[28], Europe [8], and other countries [29]. This clearly suggests that the collection of data on CDH with birth certificates underestimates the true incidence of the condition. This is most likely due to the restriction of the CDC Natality dataset to only live births in the US. Most of the previous studies included stillbirths, fetal deaths, and termination of pregnancies, which were not included in the present study. Previous studies have shown that elective termination of pregnancies complicated by CDH ranges from 10 to 73 %,

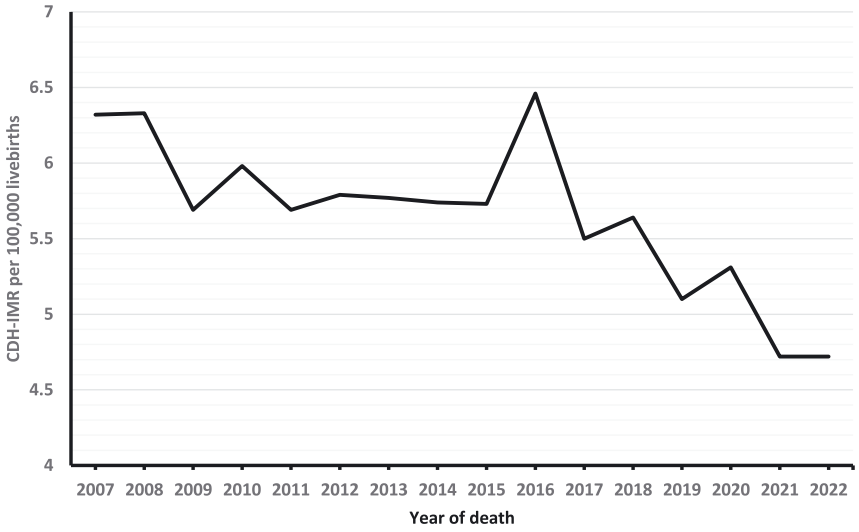

Figure 1: Changes in the CDH-IMR over time in the United States from 2007 through 2022.

depending on the absence or presence of other major congenital anomalies [30–34]. As it stands now, birth certificate data cannot be used to estimate the incidence of CDH in the US based on the CDC Natality dataset. Additionally, despite changes over time in some of the risk factors for CDH, the present study did not demonstrate any significant changes over time in the incidence of CDH, and this accords with the findings of previous reports from Minnesota, Michigan, and Canada [24, 26, 35]. Advanced maternal age>40 years has been cited as a risk factor for CDH, but the birth rate among women aged 40–44 years has increased by 318 % between 2001 and 2020 [36, 37]. Similarly, smoking during pregnancy is another risk factor which has declined significantly between 2016 and 2021 [38]. Pregestational diabetes in pregnancy has also increased significantly in the US between 2016 and 2021 [38]. Taken together, it is unclear why the incidence of CDH has not significantly changed in the face of changes in some of the risk factors for CDH. This is an area that requires further study.

Another notable finding from this study is the observation that 33.4 % of newborns with CDH were transferred within the first 24 h. This is lower than the reported transfer rate of 62 % reported by Carmichael et al. [39] from California and 48 % for the US reported by Aly et al. [40]. The differences likely stem from the different databases used for the various studies. Although the reasons for transfer are not provided in the CDC Natality dataset, there are several potential reasons for this. First, some of these newborns with CDH could have been diagnosed postnatally at centers not equipped to care for them. Second, more than a quarter of newborns with CDH in the present study were born preterm. Thus, it is possible that even if delivery had been planned at tertiary centers, the onset of pregnancy complications such as preterm labor could have led to some of these babies being delivered at centers without level III neonatal intensive care units to care for them. Third, those transferred had complicated CDH with advanced medical care requirements that exceeded the capabilities of their birth hospitals. That notwithstanding, these transfer rates are high and suggest that there are opportunities for improvement in prenatal care and delivery planning at tertiary centers with the capabilities and resources to care for these high-risk infants.

The present study found that the majority of deaths attributable to CHD occurred in the first week of life, and this confirms the results of the population-based study from California, US, in which half of all deaths from CDH occurred in the first week of life [39]. Within the first week of life, we found that 35 % of all the deaths attributed to CDH occurred within the first 24 h of life. While the circumstances of these deaths are unknown, this proportion is very high, and further studies are needed to understand the circumstances and the contributing causes of death. This will be helpful in the development of strategies to improve outcomes and decrease mortality for these high-risk infants. Additionally, the present study found that CDH-IMR decreased significantly between 2007 and 2022. This is consistent with previously published reports [29, 41]. This can be attributed to increased prenatal diagnosis of CDH and proper planning for the perinatal management of infants with CDH [42]. Other reasons include advances in obstetric care and fetal surgery [43], perinatal and neonatal management including the use of high frequency mechanical ventilation, vasodilators, and extracorporeal membrane oxygenation for severe pulmonary hypertension, and advances in surgical and anesthetic care.

The strengths of this study include the use of a population-based database covering the entire US. Over 99 % of infant deaths are registered and linked with their

Table 3: Incidence of congenital diaphragmatic hernia in the United States from 2016 to 2023 according to perinatal and demographic characteristics.

	Incidence of CDH per 10,000 live births ± standard deviation	p-Value
Birthweight		<0.001
<2.5 kg	4 ± 0.5	
≥2.5 kg	1.0 ± 0.08	
Gestational age		<0.001
Preterm (≤36 weeks)	3.4 ± 0.1	
Term (≥37 weeks)	1.0 ± 0.05	
Gender		<0.001
Male	1.4 ± 0.09	
Female	1.1 ± 0.04	
Mother's race and ethnicity[a]		<0.001
Non-hispanic black or african american	1.0 ± 0.09	
Non-hispanic white	1.5 ± 0.07	
Non-hispanic asian	0.9 ± 0.3	
More than one race (non-hispanic) and native Hawaiian	1.1b	
American indian/Alaskan native (non-hispanic)	2.0b	
Hispanic or latino	1.1 ± 0.1	
Unknown/not reported hispanic ethnicity		
Urbanization		<0.001
Metropolitan	1.2 ± 0.06	
Non-metropolitan or rural	1.7 ± 0.2	
Census region[c]		<0.001
Northeast	1.6 ± 0.2	
Midwest	1.8 ± 0.1	
South	1.1 ± 0.07	
West, median, IQR	1.0 (0.9, 1.05)	

[a]Pairwise comparisons with Tukey's HSD, showed that the CDH, incidence was highest in Non-Hispanic White newborns with p=0.001. All other comparisons not significant. Due to the small number for each year, the data for more than one race, Alaskan Native, Native Hawaiian, and those of unknown Hispanic origin, were not included in the analysis of variance. [b]Standard deviation not calculated due to limited data points. [c]The CDH, incidence was significantly higher in the Northeast and the Midwest (p=0.001) compared to the South and West. However, the difference between the Northeast and the Midwest were not significant just like the difference between the South and West regions (p=0.7).

corresponding death certificates. Thus, the findings on the CDH-IMR from this study are nationally representative. Second, we evaluated all infant deaths attributed to CDH within the first year of life over 16 years, and this provides more information on the mortality trends within the first year as opposed to in-hospital mortality reported by previous studies. However, there are several limitations to this study. As previously stated, the natality dataset used for this study excluded pregnancy terminations, fetal deaths, and still births; thus, the incidence of CDH based on birth certificate data is most likely an underestimate of the actual value. The linked birth/infant death dataset is devoid of granular clinical details. For example, there is no information on which infants with CDH were prenatally diagnosed, had fetal surgery, had postnatal surgical repair, and their timing, nor was there information on the laterality of the defect, size of the defect, presence of other major congenital anomalies, use of ECMO, etc. Therefore, further analyses based on these variables were not possible. All these and any changes over time could have impacted the mortality trends observed in this study.

Conclusions

The CDH incidence based on national birth certificate data was lower than previously reported and did not significantly change from 2016 to 2023. The transfer of a third of CDH births post-delivery indicates that opportunities for improved prenatal care and delivery planning at tertiary perinatal centers should be given priority. The downward trend in mortality needs ongoing surveillance to monitor the impact of new management strategies on mortality rates.

Research ethics: Not applicable. This cross-sectional study did not require Institutional Review Board approval or patient informed consent because it used publicly available de-identified data in accordance with Common Rule 45 CFR § 46.
Informed consent: Not applicable.
Author contributions: Nihal Shah: Methodology, Investigation, Data curation, Statistical analysis, Writing- Original draft preparation. Fredrick Dapaah-Siakwan: conceptualization, methodology, statistical analysis, Investigation, Supervision, Validation, and Writing- Reviewing and Editing. All authors have accepted responsibility for the entire contents of this manuscript and approved its submissions.
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Conflict of interest: The authors state no conflict of interest.
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Data availability: Data availability statement: all data used for this study are publicly available from the Natality dataset of the CDC WONDER website (https://wonder.cdc.gov/natality.html).

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