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Developing a Standard Approach to Examine Infant Mortality: Findings from the State Infant Mortality Collaborative (SIMC)

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Abstract

States can improve pregnancy outcomes by using a standard approach to assess infant mortality. The State Infant Mortality Collaborative (SIMC) developed a series of analyses to describe infant mortality in states, identify contributing factors to infant death, and develop the evidence base for implementing new or modifying existing programs and policies addressing infant mortality. The SIMC was conducted between 2004 and 2006 among five states: Delaware, Hawaii, Louisiana, Missouri, and North Carolina. States used analytic strategies in an iterative process to investigate contributors to infant mortality. Analyses were conducted within three domains: data reporting (quality, reporting, definitional criteria, and timeliness), cause and timing of infant death (classification of cause and fetal, neonatal, and postneonatal timing), and maturity and weight at birth/maturity and birth weight-specific mortality. All states identified the SIMC analyses as useful for examining infant mortality trends. In each of the three domains, SIMC results were used

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to identify important direct contributors to infant mortality including disparities, design or implement interventions to reduce infant death, and identify foci for additional analyses. While each state has unique structural, political, and programmatic circumstances, the SIMC model provides a systematic approach to investigating increasing or static infant mortality rates that can be easily replicated in all other states and allows for cross-state comparison of results.

Keywords

Infant mortality; Neonatal mortality; Postneonatal mortality; Fetal mortality; Perinatal mortality; Birth weight-specific mortality; Maternal and child health; Public health

Purpose

Infant mortality has historically served as a key indicator of population health and health care quality. While the United States has seen steady declines in the infant mortality rate (IMR) from the early 1900s to the early 1980s, racial/ethnic disparities have persisted: the IMR among African American infants was more than double the IMR of white infants in 2009 (12.6 infant deaths per 1,000 live births versus 5.3), a ratio that has changed little over several decades [1].

In response to concerns over the increase in the U.S. infant mortality rate in 2002 [2], the Centers for Disease Control and Prevention, in partnership with the Association of Maternal & Child Health Programs (AMCHP), the National March of Dimes Birth Defects Foundation, the Health Resources and Services Administration/Maternal and Child Health Bureau, the National Institute of Child Health and Human Development, CityMatCH, the National Association of County and City Health Officials, the University of Alabama at Birmingham, and the University of Illinois at Chicago, initiated the State Infant Mortality Collaborative (SIMC) in 2004. All partners contributed to the initial design, eligibility criteria, five-state selection process, and/or ongoing scientific and technical assistance. We examine the benefits of this standard approach for assessing infant mortality by: (1) describing the SIMC process, including a comparison of five state analyses on direct contributors to infant mortality; (2) defining the strategies identified for each analysis; and (3) summarizing application of analytic findings to modify existing policies or programs.

Description

Between 2004 and 2006, the SIMC was implemented to aid states in investigation of infant mortality through facilitated meetings with subject matter experts, review and recommendation of appropriate data sources, development of standard approaches for analyses of infant mortality causes and contributors, and interpretation of findings both consistent with the literature and useful for each participating state for programmatic and policy-making decisions.

Using available infant mortality data for all 50 states and the District of Columbia, eligibility for application to the collaborative was determined using information reflecting high or increasing burden of infant mortality. The following information was used to score state

eligibility: (1) three types of trend analyses, (2) the states' average IMR, and (3) states' race-adjusted IMR. Of 22 states which met the minimum scoring, the top 13 were determined to be eligible for the project; eight states applied and five were selected to participate, including Delaware, Hawaii, Louisiana, Missouri, and North Carolina. Each selected state provided a state summary of infant mortality that guided initial analyses (Table 1).

Multidisciplinary teams from all participating states met with infant mortality experts in 2004 to present their infant mortality data, share analytic approaches in one forum, and discuss ongoing state interventions. Teams consisted of at least one MCH program lead, one MCH data expert that could have either been a biostatistician or epidemiologist, one MCH policy expert, and one MCH subject matter expert from each state. Together, they generated hypotheses about potential contributors to fluctuations in IMRs [3]. As part of the collaborative process and the developed analytic strategies, states were guided in the conduct of a systematic assessment of direct contributors to infant mortality, subsequently referred to as the SIMC analyses.

States approached examination of IMRs using two fundamental strategies: (1) examining inaccuracies and inconsistencies within the data that might alter the true magnitude of IMRs, and (2) examining various components of infant mortality and how rates are calculated, including cause of death, periods in which deaths occur relative to delivery (e.g., early neonatal, late neonatal, post-neonatal, etc.), and separating out excess mortality due to differences in the birth weight distribution from excess mortality attributable to differences in birth weight-specific mortality. In order to support comparisons among states, only universally available data sources (e.g., vital records data) were used. Findings were compiled from the national experts and the state teams following the SIMC, and included three distinct analytic domains: (1) data reporting, (2) cause and timing of death, and (3) maturity and weight at birth/maturity- and birth weight-specific mortality.

Assessment

Data Reporting: Definition and Methods

Variation in data quality, reporting, definitional criteria, and timeliness of vital records may have a profound impact on the utility of mortality rates to effectively guide programs and policies for reducing infant mortality. Incomplete reporting of live births less than 500 grams (g) and changes in state reporting rules for fetal deaths, resulting in more fetal deaths or fetal deaths being recorded as live births, may mask improvements in neonatal mortality despite clear reductions in birth-weight-specific mortality [4]. Timeliness of data availability affects the speed with which programs can detect changes in IMR and respond.

Studies documenting greater underreporting and misclassification of deaths at the extremes of birth weight and gestational age prompted states to focus on changes in reporting of extremely low birth weight deliveries of live-born infants and early fetal losses [5–8]. All states examined historic changes in definitions of fetal deaths based on birth weight and/or gestational age, along with changes in the completeness of reporting of fetal and infant deaths. All states also assessed the proportion of fetal deaths that occurred at 20–27 weeks gestation and the proportion of live births at <500 g. These proportions were compared with

a national estimate that 73 % of fetal deaths greater than 20 weeks gestation occur between 20–27 weeks [9], and a multi-state estimate that 0.3 % of live births weigh <500 g [10] to estimate underreporting of fetal deaths and live births in these categories and determine impacts on perinatal mortality and IMRs.

Data Reporting: Practical Application of State Findings

Delaware reported a substantial influence of inconsistent data reporting on changes in IMRs. Starting with data from the late 1990s, staff investigated data reporting issues by examining quality, completeness, and timeliness of hospital records. Those efforts resulted in clarification of definitions and reporting requirements of fetal death and improved communication with hospital staff. During the SIMC, a comparison of Delaware live birth and fetal death data showed that the reporting of live-born infants <500 g had steadily increased between 1993 and 2002. Additionally, just prior to Delaware's increase in the IMR (1992–1996), unexpectedly high proportions of <500 g deliveries had been classified incorrectly as surviving live births rather than infant deaths or fetal deaths, which resulted in an increased IMR (Table 2).

Delaware's corrections of underreporting of infant deaths accounted for a small but important proportion of the increase in infant mortality. Delaware continued efforts to improve quality control, including flagging records with missing or unknown birth weight, flagging records of infants <750 g for follow up to confirm live birth at the time of reporting, and subsequently conducting an audit of annual data files for all births <500 g, which included cross-referencing with additional data files such as newborn screening. Since its implementation, this process has facilitated near 100 % reporting of expected infant deaths, eliminating one source of IMR fluctuation.

In Louisiana, the IMR had decreased to a low of 8.9 per 1,000 live births in 2000, but then had returned to previous higher rates. The annual percentage of live births <500 g was stable at 0.3 % from 1998 to 2004. However, like Delaware, Louisiana investigators found underreporting of mortality among live births <500 g between 1998 and 2004 when compared with the expected number of deaths for this group, which resulted in implausibly low mortality rates within this high-risk birth weight category. These missing deaths artificially lowered IMRs during that time period. An adjustment to the IMR that added an estimate of the missing infant deaths increased the 2000 IMR from 8.9 to 9.8 per 1,000 live births, which smoothed fluctuations in the Louisiana IMR between 1998 and 2004.

Since no changes in fetal death reporting requirements (weight of 350 g or 20 weeks of gestation) had occurred in Louisiana, strategies to address underreporting focused on training. Louisiana worked to create a generalized approach to data reporting and an analytic plan that could be adapted by other states. One strategy to address underreporting required hospital chart abstraction of 5–10 % of deliveries, but necessitated hospital permissions and personnel time. Other strategies included using the Fetal Infant Mortality Review (FIMR) model [11] to sample from the larger obstetric population for reviewing pregnancies that have reached at least 20 weeks gestation, and using a billing record review to match fetal deaths with insurance and Medicaid records.

Cause and Timing of Infant Death: Definition and Methods

Changes in causes of infant deaths over time, such as increases in preterm-related causes of death or congenital anomalies, may increase overall IMR, while improvement in cause-specific mortality may be unevenly distributed by racial/ethnic groups [12]. Improvements in medical care may shift etiologically-related deaths from the fetal to neonatal or postneonatal periods. Investigation of cause- and timing-specific mortality includes assessing trends in causes of death and changes in classification of death; comparing death rates among fetal, neonatal, and postneonatal periods over time; and assessing changes in cause and timing within categories of infant maturity. Definitions selected for use in a classification system for infant deaths and reliability of data for classification may also affect proportionate mortality [13–23].

While several systems of classification of perinatal death exist [23–28], no single system has been adopted as a standard. Standardized systems exist including the International Statistical Classification of Diseases (ICD; series 9 and 10) codes, however, these classification systems are often cumbersome and complex. SIMC states were encouraged to use the modified Dollfus classification because it has only nine cause of death categories, has good comparability between ICD-9 and ICD-10 codes, and is etiology-based with a focus on prevention [27, 28]. Analyses included calculation of cause-specific mortality rates stratified by birth weight, plurality, and maternal demographic characteristics (e.g. age, race/ethnicity, and socioeconomic status). States assessed changes in specific causes of death and the classification of the causes and the timing of death within birth weight and gestational age categories.

Cause and Timing of Infant Death: Practical Application of State Findings

In Missouri, cause-specific mortality attributable to Sudden Infant Death Syndrome (SIDS) increased from 0.8 per 100,000 live births in 2001 to 0.9 per 100,000 live births in 2002. In 2002, African American infants had higher SIDS mortality than white infants (1.9 versus 0.8 per 100,000 live births, respectively). Based on these findings, focus groups were convened to explore infant care practices. Two programs were implemented to address focus group findings related to SIDS: (1) “Back to Sleep” training for infant health care providers, and (2) a “safe sleep” outreach campaign for the public in the St. Louis area [29] (Table 2).

North Carolina examined cause and timing of death in 2001–2003. Infants born to African American women were at 2.5 times the risk of dying compared with those born to white women. Prematurity and related causes was the leading cause of death, and African Americans experienced 3.6 times the infant deaths due to prematurity and related causes compared with white infants. Compared with the US, North Carolina had higher IMRs from 2001 to 2003, but the distribution of causes was similar. Mortality decreased across the fetal, neonatal, and postneonatal periods, suggesting that improvements seen in North Carolina's IMRs were related to improved survival rather than postponement of death. The only increase observed was in the percentage of infant deaths occurring in the first hour of life, which increased from 26 to 29 % from 1989–1993 to 1999–2002, respectively.

Delaware's investigation into changes in the timing of infant death found an increase in the proportion of infant deaths in the early neonatal period (0–6 days) relative to the late neonatal and post-neonatal periods between 1994–1996 and 1998–2000, with a disproportionate increase in deaths on the first day of life. These findings indicated focused examination was necessary since cause of death analysis in the early neonatal period did not yield detailed information on the risk factors for infant death. To better inform the public, the Delaware Division of Public Health began to provide infant death data to the public online and through statistical micro-reports, which led to data use by public health partners for their own reports and analytic requests to support new programs and policy development. The state implemented a Fetal and Infant Mortality Review process to better understand all fetal and early neonatal infant deaths.

Maturity and Weight at Birth/Maturity- and Birth Weight-specific Mortality: Definition and Methods

Maturity at birth (gestational age) and weight at birth are strong predictors of infant survival [30–35]. Changes in the proportion of high-risk infants (i.e. relatively more infants were born early or small) and mortality risk within high-risk birth weight and gestational age categories (i.e. relatively more infant deaths among those born early or small) may impact overall IMRs. States examined the stability of trends in maturity at birth and looked for associations with changing IMRs. The Perinatal Periods of Risk (PPOR) approach [36–38] and Kitagawa analyses [39] were used to determine the impact of maturity at birth on infant mortality rates.

Perinatal Periods of Risk (PPOR) Approach

The PPOR approach categorizes fetal and infant deaths by timing of death (fetal: 24 weeks or more gestation, neonatal: birth to 28 days, and post-neonatal: 1–11 months) and birth weight (500–1,499 and $\geq 1,500$ g), dividing mortality into four periods of risk linked to primary prevention strategies (Fig. 1) [38]. Excess mortality among 500–1,499 g births and fetal deaths are attributed to factors associated with Maternal Health and Prematurity. Deaths at higher birth weights are segmented by period of death (fetal, neonatal, or post-neonatal) and subsequently attributed to factors associated with Maternal Care, Newborn Care, or Infant Care, respectively. Excess mortality, which is calculated as the difference between mortality rates of the population of interest compared with a reference population, is calculated for each period, and corresponds with suggested interventions for reduction of mortality. Periods with substantial excess mortality are investigated to determine likely causes, and to prioritize among known risk and preventive factors related to those causes. Interventions to address Maternal Health and Prematurity typically focus on preconception health, health behaviors, and perinatal care. Maternal Care interventions typically focus on prenatal care, referral systems, or high risk obstetric care interventions. Newborn Care interventions focus on neonatal management, perinatal systems, and pediatric surgery. Finally, Infant Health interventions address sleep position, breastfeeding practices, and injury prevention.

Kitagawa Analyses

Causes of death for fetal deaths and infants born very low birth weight are multifactorial, and related to complications of both pregnancy and fetal development limiting the utility of the cause and timing of death analyses described previously. Rather, the relative contribution of birth weight distribution and birth weight-specific mortality, which can be determined using Kitagawa analyses, is more relevant for understanding the dynamics of IMRs. In general, Kitagawa analyses examine the relative contributions of factors that change a rate over time [39]. When applied to infant mortality, Kitagawa analyses examine whether excess mortality is due to increasing numbers of infants born at very low birth weight (birth weight distribution), or to increased mortality among very low birth weight infants (birth weight-specific mortality) (Fig. 2). Using this method, comparison of the target population to another, such as a national reference population (e.g. US non-Hispanic white mothers aged 20 years and older with 13 years or more of education), or comparison of a population at two time points, indicates whether one population has a birth weight advantage and/or a survival advantage. The risk factors, causes, and interventions for mortality attributed to birth weight distribution relate to behavioral, social, health, and economic disparities experienced by mothers that may ultimately result in the delivery of a very low birth weight infant, while those associated with birth weight-specific mortality relate to perinatal or medical care provided to mother and infant before, during, and after delivery, resulting in decreased infant survival [40].

Maturity and Weight at Birth/Maturity- and Birth Weight-Specific Mortality: Practical Application of State Findings

Hawaii used the PPOR approach for data from 1996–2000 [3] and found that 69 % of excess mortality was attributable to maternal health/prematurity. Analysis by maternal age showed a larger relative excess in maternal health/prematurity among births to women <20 years of age. Earlier analyses of Pregnancy Risk Assessment Monitoring System (PRAMS) [41] data had shown that Hawaiian resident women <20 years of age were at increased odds of low birth weight delivery [42]. Kitagawa analysis revealed that the majority (93 %) of excess fetoinfant mortality was attributable to birth weight distribution, and was predominantly explained by increases in births 500–749 g. Small numbers of infant deaths and a diverse array of ethnic sub-populations led Hawaii to explore additional methods of analysis for understanding infant mortality. For example, Hawaii's finding of excess infant mortality in the maternal health/prematurity group among women <20 years of age led to a chart review of all infant deaths among women <20 years of age regardless of birth weight, timing of death, or cause of death (Table 2).

In Louisiana, PPOR analyses of 2000–2002 data [43] showed a concentration of excess mortality in the Maternal Health/Prematurity Group. Analysis stratified by race revealed a mortality excess of 8.8 among African Americans, 52 % of which was attributable to Maternal Health/Prematurity. Louisiana used period-linked birth/infant death files from 1991–2002 to conduct Kitagawa analyses by race. In nearly every year, African American infant mortality was at least twice that of white infants, and 80 % of excess mortality was attributable to changes in birth weight distribution. Birth weight-specific mortality significantly declined among all groups, indicating overall excess mortality was attributable

to a shift in birth weight distribution. Using findings from PPOR, Louisiana prioritized maternal health/prematurity as an area for intervention. Louisiana FIMR began conducting PPOR in each of its nine regions and comparing results with the state overall as part of a Perinatal Needs Assessment Template. The combined findings of FIMR, PPOR, and PRAMS indicated that substance abuse during pregnancy was an important issue to address in reducing excess infant mortality, and the Screening Brief Intervention Referral and Treatment (SBIRT) model [44], an approach to screening and early intervention for substance abuse disorders, was adopted for pregnant and postpartum women.

In North Carolina, Kitagawa analyses revealed a steady increase in the proportion of low birth weight live births and static mortality rates in each birth weight category, pointing to a greater contribution of birth weight distribution to infant mortality. The percent increase of low birth weight by weight category ranged from 8 to 67 % from 1990 to 2005, with the greatest increase in the <500 g birth weight category. During the period from 1989–1993, 15 % of post-neonatal deaths were to infants born weighing <1,500 g; by 1999–2003, this figure increased to 22 %, indicating that survival of very low birth weight infants past the neonatal period may have slowed the decline in overall post-neonatal mortality. Subsequently, North Carolina examined factors associated with maternal health and birth outcomes by race/ethnicity and age, and found disparities in all outcomes (obesity, general health status, hypertension). These findings led to a focus on reduction of health disparities, and included strategies such as use of focus groups to understand attitudes and practices regarding women's health and inclusion of health disparities as part of the scope of work for the Child Fatality Task Force, a legislative study commission which makes recommendations to the General Assembly and Governor based on data and research [45]. Task Force activities led to funding of two SIMC recommendations: one to reduce preterm births using 17 alpha hydroxyprogesterone caproate (17p) among low income pregnant women with a history of preterm birth (\$250,000 from the General Assembly), and a second to form a statewide perinatal quality care collaborative, which collected data from 26 neonatal intensive care units (NICUs) and set quality benchmarks (\$50,000 from the General Assembly).

Summary of SIMC Analyses and Lessons Learned

SIMC analyses provided a systematic strategy for approaching state infant mortality, and the collaborative process allowed states to conduct initial analyses with guidance from national experts and follow-up with other states to compare results. States performed SIMC analyses to investigate infant mortality trends and translated these findings into recommendations for action. A major goal of the SIMC was to examine data quality before conducting subsequent analyses, and this was particularly helpful for states with small populations, where small numbers of underreported cases translated into large rate changes and affected later attempts to examine IMR components. Despite technological advances in electronic vital statistics systems, states emphasized the need for ongoing training of hospital records staff to ensure data quality by preventing errors at the point of reporting. States noted that some causes of death, such as SIDS, were more amenable to intervention than others, which made findings related to these causes of death easier to translate to program and policy staff. After examining maturity at birth and maturity-specific mortality, states found variations in their

PPOR and Kitagawa findings by race or regional geography that enabled them to target interventions for reducing disparities in excess infant mortality.

Limitations

Although the SIMC promoted the use of a set of analytic tools for examining infant mortality, these tools were not without limitations. In general, SIMC analyses were limited in their ability to explain the ultimate causes of infant mortality and the broader risk factors that led to increased infant mortality within categories of identified direct contributors. For example, misclassification of live births and still births for extremely small infants on the edge of viability remain a challenge in defining infant mortality rates, and fetal deaths and early infant deaths may be misclassified. Using perinatal mortality as a measure may remove some of this bias, but does not account for later infant deaths. Kitagawa analyses could attribute mortality to increasing numbers of premature births rather than increased mortality among premature births, but the method could not explain why prematurity was increasing. Instead, SIMC findings directed hypotheses and subsequent analyses toward identification of strategies that further focused intervention efforts. The utility of some analytic methods was limited by the relatively small numbers of infant deaths in some states; states encountered small sample sizes for some categories when they attempted to stratify causes of death by other variables. States found some methods, such as Kitagawa analyses, difficult to translate into action for policy makers, particularly because of conceptual distinctions that can be difficult to explain concisely.

Recommendations

SIMC states made several recommendations for examining infant mortality trends in the future. These recommendations were to (1) examine the extremes of infant size and age, which may contribute significantly to overall IMR; (2) use analyses for identifying the nature of disparities in IMR by race and ethnicity; (3) utilize both qualitative and quantitative data to describe findings; (4) analyze data longitudinally by linking data sets in innovative ways (e.g., linking birth/death certificates with educational data, etc.); (5) partner with other states and institutions to validate analyses and methods; and (6) think strategically about how findings from each analysis contribute to the practical application of interventions.

Conclusion

SIMC analyses may lead to changes in the focus of interventions, even without further analyses of risk factors, because the components of the IMR help identify causes and contributors that may be targeted for appropriate intervention. SIMC findings can be used to facilitate decisions about allocation and reallocation of resources to maximize reductions in infant mortality. These efforts can be helpful in guiding other states interested in a similar examination of IMR. Ultimately, the SIMC provides a useful framework for states that are ready to examine infant mortality trends, and the analyses provide a basis for translation of findings to modify or implement changes to interventions, programs, and policies aimed at addressing infant mortality.

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Appendix

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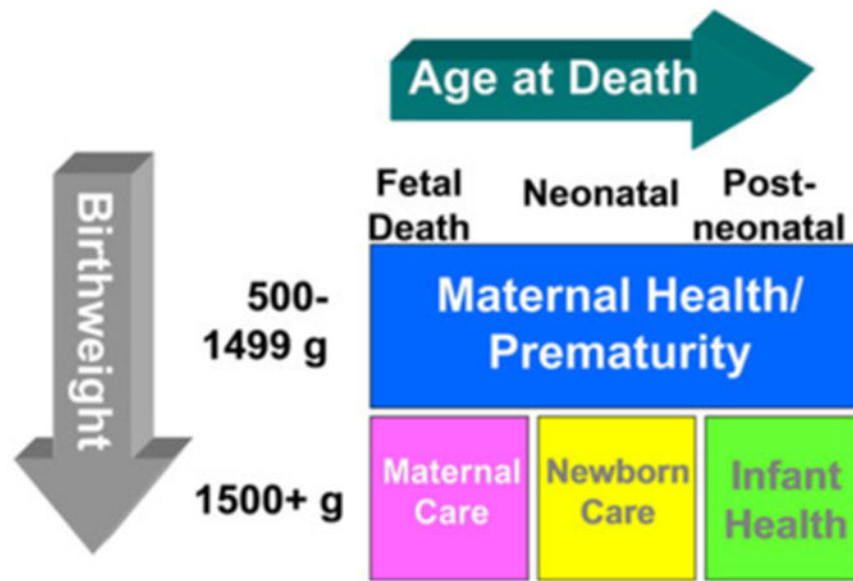


Fig. 1. Perinatal periods of risk (PPOR) classification of infant deaths. Used with permission, www.citymatch.org/ppor_index.php [46]

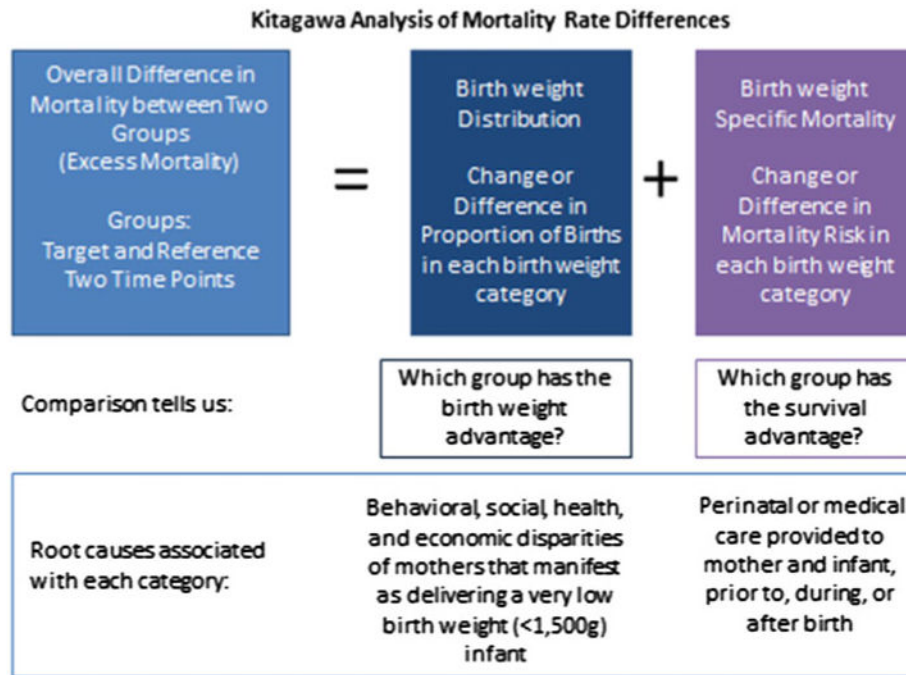


Fig. 2. Kitagawa analysis: conceptual calculation and definition. Created from the perinatal periods of risk (PPOR) phase II analysis protocol for this publication [46]

Table 1
Infant mortality prior to participation in the State Infant Mortality Collaborative for participating states: Delaware, Hawaii, Louisiana, Missouri, and North Carolina, data ranging from 1990 to 2005

State	Status of infant mortality rate	Perinatal circumstances
Delaware	Increasing 7.1 ^a in 1994–1996 to 8.8 in 1999–2001	Increase in low and very low birth weight Increase in deaths in first day of life Decrease in deaths in the late neonatal and post-neonatal periods
Hawaii	Increasing 5.3 in 1997 to 7.6 in 2000	Ethnic disparities in infant mortality Increase in post-neonatal mortality
Louisiana	Increasing 9.1 in 1998 to 10.2 in 2002	Persistent racial disparities despite proportionately larger increases in IMR among whites 49th in US for IMR in 2004
Missouri	Stagnant then increasing 7.1 in the 1990s to 8.5 in 2002	IMR among African Americans nearly double the state rate High maternal smoking rates High rates of low birth weight Low levels of prenatal care
North Carolina	Decreasing then stagnant 10.6 in 1990 to 8.6 in 2000, stable at 8.8 in 2004 and 2005	Despite improvements, IMR was still among the highest in the US in 2004–2005

^aInfant Mortality Rate (IMR) expressed as infant deaths per 1,000 live births

Table 2
Summary of State Infant Mortality Collaborative findings by analytic domain and sub-domain

State	Data reporting		Cause & timing	Maturity and weight at birth and maturity- and birth weight-specific mortality
	Fetal death requirements	State findings		
Delaware	1987–1990: Weight of 400 g or 20 weeks gestation	Changing definitions of fetal death Increased reporting of infant deaths	Increases in death on the first day of life	Increases in infant mortality rate attributable to excess deaths among very low birth weight infants
	1990: Weight of 350 g or more or 20 weeks of gestation or more	Shift from classification of fetal deaths <500 g to live births, resulting in a slight increase in infant mortality		
Hawaii	All products of human conception	Data quality was sufficient to continue with analyses	N/A	<p>Excess mortality among Maternal Health/Prematurity period</p> <p>Disparities in excess mortality by race and geography</p> <p>Excess mortality attributable to birth weight distribution or birth weight specific mortality differs by race</p> <p>Excess mortality attributable to birth weight distribution</p> <p>Explained by increase in 500–749 g births</p>
Louisiana	Weight of 350 g or more or 20 weeks of gestation or more	Underreporting of infant deaths due to uncounted deaths among infants weighing less than 500 g	Survival differential by level of Neonatal Intensive Care Unit care for very low birthweight infants	Excess mortality among African American infants attributable to birth weight distribution
Missouri	Weight of 350 g or more or 20 weeks of gestation or more	N/A	Race differences in cause-specific mortality	Birth weight-specific mortality decreased in all groups
North Carolina	20 weeks gestation or more	N/A	Disparities by race for preterm birth	Excess mortality attributable to birth weight distribution