Infant Mortality Reviews in the Aberdeen Area of the Indian Health Service: Strategies and Outcomes

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SYNOPSIS

Objective. To determine cause and manner of death for consecutive infant deaths in the Aberdeen Area of the Indian Health Service (AAIHS) from 1998 to 2002 and to identify risk markers for infant mortality.

Methods. Infant deaths in the AAIHS were identified from four data sources: death certificates from the four states in the AAIHS, deaths reported by local IHS Service Units, from obituaries in local and regional newspapers, and deaths reported by area hospitals. Each infant death is then sent to the local IHS service unit for review, where data from the infant and mother's chart is extracted and recorded. Local community factors, birth and death certificates, and autopsy reports are collected. The case is then reviewed at the Perinatal Infant Mortality Review (PIMR) meeting and a cause and manner of death is assigned. Summary data for the cohort was examined and then compared by mortality category and three age-at-death groups.

Results. Sudden infant death syndrome accounted for 33% of all infant deaths in the AAIHS. Prematurity was the second most prevalent cause-specific mortality category, accounting for 22% of all infant deaths. The authors found that infant mortality was surprisingly recurrent, with 32% of mothers of this infant having had a previous infant death.

Conclusions. The PIMR committee requires substantial resources to support a review committee with appropriate expertise and their travel. Participation of local IHS staff and tribal members provides an important cultural and community perspective for the review process. Quality improvement changes are currently being implemented. These include increasing data on substance use, mental health needs, and reviews of fetal deaths. The process of mortality review has been very helpful in public education in the AAIHS.

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Infant mortality rates (IMR) are a useful measure to compare the health of populations worldwide and within individual geographic areas or populations. In the developed world, IMR has decreased dramatically in the past 100 years. Much of this change has been due to clean water, sewer systems, and vaccination programs, which have resulted in very large reductions in infant and childhood mortality from infectious illness.

IMR is often increased in minority populations.[1] In the United States, rates are increased in both African Americans and Native Americans compared to the U.S. All Races rates.[1] Several previous reports have documented increased IMR among Native Americans.[2–19] For the period from 1996 to 1998, the U.S. All Races IMR was 7.2 and the All Indian Health Service (IHS) IMR for Indian infants was 8.9 after adjustment for racial misclassification on death certificates.[20]

The IHS is divided into twelve regional administrative units and the IMR rates vary widely by IHS area.[20] Of all IHS areas, the Aberdeen Area (AAIHS) has the highest IMR.[5,6,12,16] The Aberdeen IHS adjusted IMR was 12.5, a 74% increase when compared to the U.S. All Races rate of 7.2, and a 40% increase compared to the All IHS rate of 8.9.[20] Factors that account for the differences in the IMR rates in the U.S. and within the IHS are incompletely understood.

Rates of IMR also vary widely by infant age at death.[10,15] The IMR mortality rates per 1,000 live births are divided into three temporal periods: perinatal mortality, neonatal mortality, and post-neonatal mortality rates (see Figure).

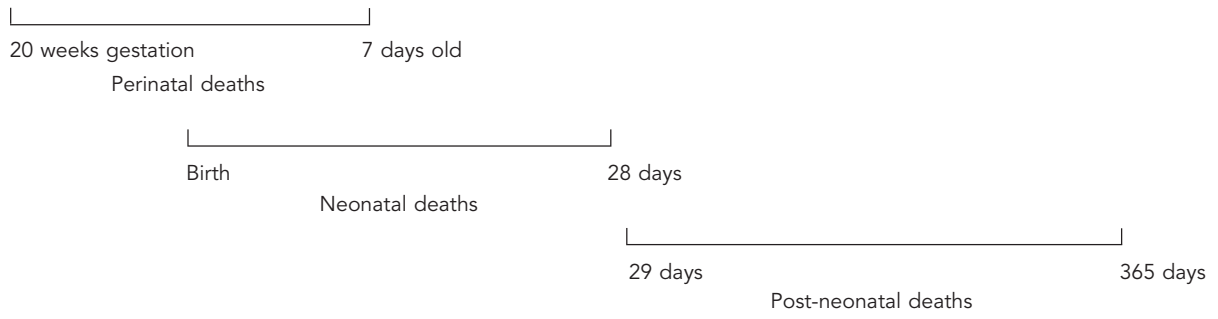
Deaths before the 28th day of life (neonatal mortality) are often related to factors occurring during pregnancy, labor, and delivery. For the period of 1996 to 1998, the U.S. All Races neonatal mortality rate was 4.8, the All IHS rate was 4.4, and the AAIHS rate was 5.6.[20] In the AAIHS, this represented an increase of 17% compared to the U.S. All Races rate of 4.8 and an increase of 27% compared to the All IHS rate of 4.4.

The second widely used category of IMR is the post-neonatal mortality rate (deaths from 28 days to one year of age period). The U.S. All Races rates for post-neonatal mortality from 1996 to 1998 was 2.5, the All IHS rate was 4.4, and the AAIHS rate was 6.9.[20] In the AAIHS this rate was increased 176% compared to the U.S. All Races rate of 2.5, and 57% compared to the All IHS rate of 4.4.[20]

Much of the discrepancy in the post-neonatal rate of infant mortality in the AAIHS has been due to increased sudden infant death syndrome (SIDS) rates. From 1996 to 1998, the U.S. All Races SIDS rate was 10.7 per 1,000 live births, the All IHS rate was 18.1, and the Aberdeen Area rate was 27.6.[20] The SIDS rate was increased by 158% in the AAIHS compared to the U.S. All Races rate of 10.7, and by 52% when compared to the All IHS SIDS rate of 18.1.[20]

Increased IMR and SIDS rates for the AAIHS led to the development of the Aberdeen Area Perinatal and Infant Mortality Review (PIMR) in the late 1980s. The AAIHS PIMR is an expert panel that reviews all infant deaths in the AAIHS. The purpose of the PIMR is to improve the classification of the cause and manner of death, to identify preventable causes of infant death, and to report these to tribal leaders, IHS health care providers, and the AAIHS. The PIMR meets twice each year and is comprised of Indian Health Service physicians, nurses, staff, Tribal members, Tribal Healthy Start staff, and the AAIHS Women's Health Nurse Consultant who chairs the PIMR. Other members come from across the United States and include pathologists, epidemiologists, physicians, and nurses with expertise in SIDS. The PIMR meetings are held biannually, with the location rotating among the Tribal Nations in the AAIHS.

Figure. Infant mortality rates-temporal periods



METHODS

Much of the work of the Perinatal and Infant Mortality Review (PIMR) is completed prior to the actual case reviews. This effort involves identification of infant deaths, record location, and data extraction. Race is determined by birth certificate data or if one or both of the parents are enrolled members of a Tribal Nation. The four states in the AAIHS routinely send death certificates to the PIMR. When the infant was a resident birth, states also send the birth certificate for every Indian infant death they identify. Deaths are also identified by IHS service units and committee members, by reviewing obituaries from multiple regional newspapers, by reviews of death certificates by race, and by reports from regional referral centers. The PIMR has no system for determining the number of deaths that may be missed due to misclassification of race, deaths occurring in other states, or deaths simply not reported to the PIMR. We suspect the number of deaths not reported in the four states is low, since the PIMR has multiple overlapping ascertainment systems as noted above, and we review deaths even if they have occurred in the past one or two years when we become aware of them. The PIMR reviews deaths that occur both in and out of hospitals.

Notification of each Indian infant death is first sent to the local IHS Service Unit for a local review. The records requested are: (*1*) information on the death from local sources (i.e. obituary notices), (*2*) medical records for the mother and child, and (*3*) the results of the local service unit mortality review. The local review provides an opportunity for IHS staff to provide input into the review process about factors that may be relevant to the PIMR review, including information on living conditions and other family or community issues that would not otherwise be available to the PIMR. The results are then forwarded to the PIMR for review. If the birth or death certificates or autopsy report have not been attached to the file, they are added whenever they become available.

All members sign confidentiality statements at each PIMR meeting. The committee typically discusses about 25–30 deaths each meeting. The 25+ deaths can comprise 15–20 new deaths and 10–15 follow-up reviews from previous meetings that require additional information. Each complete case review takes about 30–45 minutes.

Whenever possible, the case review is presented to the committee by the local IHS service unit staff. The committee discusses each case to determine the cause and manner of death and potentially preventable risk factors. When preventable factors are identified, the PIMR makes recommendations to the local IHS service unit, health care providers (both IHS and non-IHS), and other appropriate agencies with suggestions for changes in care.

In this article, we report on the case reviews for 148 consecutive infant deaths from 1998 to 2002. We examined the data as summary data for the total group, by mortality category, and by three age-of-death categories. We used chi-square and one-way analyses of variance in the data analysis. This project was approved by the University of North Dakota Institutional Review Board and by the Aberdeen Area Institutional Review Board. We conclude with a discussion of the limitations of this process and the benefits of a systematic infant mortality review in communities with increased rates of infant mortality.

RESULTS

Summary data for the mortality cohort

Table 1 shows the prevalence of study variables for the 148 infant deaths. Nearly two-thirds of the deaths were males (ratio 1.8 to 1). The mean birthweight was 2,232 grams, and the mean gestation was 34 weeks. Sixty-five percent of the mothers began prenatal care in the first trimester and the mean number of prenatal visits was just under seven visits. The mean maternal age was 25 years. The average number of siblings was two. Mortality recurrence was surprisingly frequent; we found that nearly one-third of the infants (32%) had a previous sibling death.

The mean age at death was 67 days, with 41% of the deaths occurring within the first three weeks of life. For convenience and to facilitate analysis, the deaths were grouped into three categories of approximately equal size: (*1*) Prematurity, (*2*) SIDS, and (*3*) Other. The Other category is a combination group of deaths from causes other than SIDS or prematurity (e.g., congenital anomalies, homicide, or infection). None of the individual mortality categories in the Other mortality category was large enough to be used as a unique comparison group individually.

Birth certificates were located for 78% of the infants and death certificates were obtained for 88% of the infants. Local death reviews were completed for 62%, autopsies for 32%, and death scene investigations were completed for 15% of the cases. The PIMR attributed 22% of the deaths to prematurity and 33% to SIDS. Wednesday and Friday were the days of the week with the lowest prevalence of deaths (8% each), while Tuesdays had the highest prevalence at 20%. The proportion of deaths occurring in the months of August and December were increased at 12.7% for each month.

Table 1. Prevalence of variables for infant deaths in the Aberdeen Area of the Indian Health Service (n=148)

	n	*Percent*	n	*Mean*	*SD*
Year					
1998	38	25.68			
1999	25	16.89			
2000	28	18.92			
2001	28	18.92			
2002	29	19.59			
Gender					
Female	51	35.17			
Male	94	64.83			
Birthweight (grams)			137	2,232	1,254
Gestation (weeks)			140	33.7	6.63
Trimester prenatal care began					
First	92	64.79			
Second	34	23.94			
Third	16	11.27			
Number of prenatal visits			141	6.8	4.66
Mother's age (years)			144	24.5	5.80
Parity			143	2.2	2.26
Previous deaths					
None	96	67.61			
One	33	23.24			
Two	11	7.75			
Three	2	1.41			
Age at death in days					
1–21	59	41.26	143	67.5	80.86
22–90	39	27.27			
91–365	44	30.77			
Cause of death					
Prematurity	33	22.30			
SIDS	49	33.11			
Other	66	44.59			

	n	*Percent*
Day of death		
Sunday	19	17.27
Monday	17	15.45
Tuesday	22	20.00
Wednesday	9	8.18
Thursday	16	14.55
Friday	9	8.18
Saturday	18	16.36
Month of death		
January	10	9.09
February	8	7.27
March	7	6.36
April	7	6.36
May	5	4.55
June	6	5.45
July	10	9.09
August	14	12.73
September	12	10.91
October	10	9.09
November	7	6.36
December	14	12.73
Birth certificate	116	78.38
Death certificate	130	87.84
Local IMR done	92	62.16
Area IMR done	115	77.70
Autopsy	47	31.76
Death scene investigation	22	14.86
Recommendations	144	97.30

SD = standard deviation

The PIMR made recommendations for changes in care for 97% of the deaths, which fell into three broad categories. The first were routine recommendations for grief counseling for parents, families, and daycare providers where a death occurred. The second was recommendations for enhanced and early prenatal care, especially for women who had an infant death from prematurity or a previous death. The third was an increasing number of recommendations for genetic consultation after the birth of a child with congenital malformations.

We examined the data for effects from day of the week, proportion of deaths on weekends, or month of the year, or season of death by age at death. We did not find evidence of any significant effects for these time periods. This was a concern due to the extremely rural area of the AAIHS and concerns about access to care on weekends or holidays.

Group comparisons by cause of death

When comparisons were made by mortality category, infants who died from prematurity had significantly ($p<0.001$) lower birthweights (812 grams), shorter gestation (24.5 weeks), and younger age at death (10.6 days) than the SIDS or other mortality categories (Table 2). The mothers of these infants also had significantly fewer prenatal visits ($p<0.001$).

In Table 3 we examine the other study variables by mortality category. The mothers of infants who died of SIDS were more likely to begin prenatal care after the first trimester ($p<0.001$). Autopsies were more likely to be completed in the SIDS group than in the Prematurity or Other mortality category ($p<0.001$). Death scene investigations were much more common in the SIDS group than in either the Prematurity or Other category ($p<0.001$). These two variables may represent a classification effect since a diagnosis of SIDS would not be made without a negative autopsy.

Group comparisons by age at death

In Table 4 we present comparisons of the means and ranges for the study variables by age at death category for the deaths. Birthweights were significantly lower and gestation significantly shorter for infants who died

Table 2. Mean values of risk factors for infant deaths in the Aberdeen Area of the Indian Health Service by mortality category

Mortality category	n	*Mean*	*SD*	*Minimum*	*Maximum*	p
Birthweight (grams)						
Premature	31	812.3	596.9	113	3,320	<0.001
SIDS	44	3,203.8	699.6	1,021	4,309	
Other	62	2,473.6	1,115.9	215	4,649	
Gestation (weeks)						
Premature	32	24.5	4.1	17	38	<0.001
SIDS	46	38.1	2.4	27	42	
Other	62	35.3	5.0	21	41	
Number of prenatal visits						
Premature	33	4.0	2.6	1	10	<0.001
SIDS	46	8.8	4.9	1	20	
Other	62	6.8	4.6	0	20	
Mother's age (years)						
Premature	33	24.8	5.2	17	36	0.228
SIDS	46	23.4	5.9	15	43	
Other	65	25.3	6.0	14	39	
Previous births						
Premature	33	2.5	2.3	0	9	0.652
SIDS	45	2.2	2.4	0	12	
Other	65	2.0	2.2	0	11	
Age at death (days)						
Premature	33	10.6	25.1	1	125	<0.001
SIDS	49	91.0	68.8	10	349	
Other	61	79.3	97.7	1	333	

SD = standard deviation

in the first three weeks of life ($p<0.001$). The mothers of these infants also had significantly fewer prenatal visits ($p=0.004$). We then examined the study variables for the three age-at-death categories. Only two variables were significant in this analysis. We found that autopsies ($p<0.001$) and death scene investigations were more likely to be completed for older infants ($p=0.010$).

DISCUSSION

In this article, we present data on five consecutive years of infant death reviews from the Aberdeen Area of the Indian Health Service Perinatal and Infant Mortality Review. The AAIHS has increased rates of infant mortality and especially high rates of post-neonatal infant mortality when compared to the U.S. All Races rate and to the All IHS rate. The male to female ratio was high, with males accounting for nearly two-thirds of the deaths. We found that 32% of the mothers of the current infant death had a previous infant or child death.

By examining the data by cause of and age at death, we found significant differences that may be useful to other groups who are considering development of an infant death review committee. As noted above, we found a pattern of recurrent mortality in same family. This finding supports the need for careful investigation of all infant deaths, enhanced prenatal care surveillance of these mothers during pregnancy, and increased attention to these babies after birth. In a previous study from the same population, home visiting by a nurse was associated with reduced risk for death from SIDS.[16] Population studies examining specific child care practices may also be useful in the identification of variables for risk reduction models.[21–23]

We found differences by age at death and mortality category. Deaths from prematurity were associated with short gestation, decreased prenatal visits, low birthweight, and early age at death. The mortality category of SIDS was associated with higher birthweight, increased number of prenatal visits, and older age at death. Smoking and alcohol use have both been reported to be important SIDS risk factors in this population.[5,6,12,16] This data suggest the need for enhanced access to substance abuse programs in the public health infrastructure in these remote settings. It is equally important to examine the programmatic efficacy and

Table 3. Variable prevalence for infant deaths in the Aberdeen Area of the Indian Health Service by mortality category

	Premature		*SIDS*		*Other*		
Mortality category	n	*Percent*	n	*Percent*	n	*Percent*	p
Gender							
Female	12	37.5	20	40.8	19	29.7	0.448
Male	20	62.5	29	59.2	45	70.3	
Trimester care began							
First	21	63.6	22	47.8	49	77.8	<0.001
Second	12	36.4	16	34.8	6	9.5	
Third	0		8	17.4	8	12.7	
Previous deaths							
None	20	60.6	33	75.0	43	66.2	0.746
One	9	27.3	8	18.2	16	24.6	
Two	4	12.1	2	4.6	5	7.7	
Three	0		1	2.3	1	1.5	
Age at death days							
1–21	29	87.9	4	8.2	26	42.6	<0.001
22–90	3	9.1	22	44.9	14	23.0	
91–620	1	3.0	23	46.9	21	34.4	
Day of death							
Sunday	1	5.0	6	16.7	12	22.2	0.170
Monday	5	25.0	7	19.4	5	9.3	
Tuesday	2	10.0	8	22.2	12	22.2	
Wednesday	5	25.0	2	5.6	2	3.7	
Thursday	2	10.0	4	11.1	10	18.5	
Friday	2	10.0	3	8.3	4	7.4	
Saturday	3	15.0	6	16.7	9	16.7	
Month of death							
January	3	15.0	2	5.6	5	9.3	0.413
February	4	20.0	1	2.8	3	5.6	
March	1	5.0	0		6	11.1	
April	1	5.0	4	11.1	2	3.7	
May	1	5.0	2	5.6	2	3.7	
June	1	5.0	2	5.6	3	5.6	
July	0		6	16.7	4	7.4	
August	1	5.0	5	13.9	8	14.8	
September	4	20.0	3	8.3	5	9.3	
October	1	5.0	4	11.1	5	9.3	
November	2	10.0	2	5.6	3	5.6	
December	1	5.0	5	13.9	8	14.8	
Birth certificate	28	84.9	38	77.6	50	75.8	0.576
Death certificate	29	87.9	46	93.9	55	83.3	0.232
Local IMR done	18	54.6	34	87.2	40	60.6	0.585
Area IMR done	23	69.7	37	75.5	55	83.3	0.419
Autopsy	4	12.1	29	59.2	14	21.2	<0.001
Death scene investigation	0		18	36.7	4	6.1	<0.001
Recommendations	32	97.0	48	98.0	64	97.0	0.189

to identify the service or intervention models for substance abuse (smoking and alcohol use) best fitted for these diverse rural communities.

SIDS rates have been elevated in the AAIHS for many years and the reasons for this are not clear. The proportion of deaths classified as SIDS remains high, accounting for nearly one-third of all infant deaths. The SIDS cases had the lowest rate of previous infant deaths and the lowest rate of early prenatal care (48%) of the three mortality categories ($p<0.001$) (Tables 2 and 3). One of the goals of the PIMR was to improve the database available to examine risk and causal factors

Table 4. Means and ranges of variable values for infant deaths in the Aberdeen Area of the Indian Health Service by age at death in days

Age at death (days)	n	*Mean*	*SD*	*Minimum*	*Maximum*	p
Birthweight (grams)						
1–21	55	1,399	1,053	113	4,649	<0.001
22–90	35	2,899	851	557	4,026	
91–-365	44	3,002	1,060	369	4,564	
Gestation (weeks)						
1–21	56	29.1	7.2	17	40	<0.001
22–90	36	37.1	3.9	24	42	
91–365	44	36.8	3.7	27	41	
Number of prenatal visits						
1–21	57	5.4	3.7	1	20	0.004
22–90	37	8.2	4.0	1	17	
91–365	43	7.7	5.5	0	20	
Mother's age (years)						
1–21	58	24.7	5.3	15	36	0.747
22–90	37	24.0	5.8	15	39	
91–365	44	25.0	6.5	16	43	
Previous births						
1–21	58	2.2	2.3	0	9	0.865
22–90	37	2.1	1.6	0	5	
91–365	43	2.4	2.8	0	12	

SD = standard deviation

for SIDS and to examine the process of classification of infant deaths, especially SIDS. In this task the PIMR has made important improvements, as demonstrated in this article.

The AAIHS has made improvements in the number of deaths investigated, the number of infants with autopsies, and the number of death scene investigations. This effort has been gradual, in part due to the geography of the AAIHS, where infant deaths may occur 100 miles from a health care facility with expertise in infant mortality or pediatric services. The majority of the 19 Tribal Nations in the AAIHS are in rural or frontier settings. The autopsies are often completed 200 or 300 miles from the site of the death. Severe winter weather is a very important factor for at least five months of the year in the AAIHS.

Limitations

The data presented here have been difficult to obtain. The birth and death certificates must be obtained from four different states, each with unique issues about data sharing. The local reviews involve multiple IHS facilities and 19 Tribal Nations. The autopsies are completed in more than eight locations. We are unable to estimate how our classification of deaths by the PIMR may influence these findings. The effect of the classification of death by the PIMR would likely be most important for SIDS, since this is the mortality category with the most problematic criteria to apply in the context of an infant death.

For some infant deaths, multiple law enforcement agencies are involved. These include tribal police and coroners, state law enforcement agencies, county coroners and sheriffs, and federal agencies. Thus, the procedures for timely data sharing can be problematic. The committee often does not have access to adequate data on alcohol or drug use during pregnancy or at the time of the death. As noted above, these are data elements that the PIMR is adding to the review process.

Outcomes from the PIMR

The PIMR has several unique strengths that have evolved over the years. These include contact with the law enforcement agencies listed above, the involvement of local IHS service units, and ongoing contact with the multiple Tribal Nations regional referral centers where some deaths occur. The 19 individual Tribal Nations represent different cultures with widely differing belief systems about infant deaths. The committee works diligently to respect these beliefs. The PIMR also works to connect parents, child care personnel, and others with grief support services. This has been one of the important accomplishments of the PIMR and the cooperating agencies.

The systematic review of each infant death has produced several positive benefits in the AAIHS. The

number of deaths that are reviewed at the local level has risen steadily. The completeness of the death reviews at the local level has also improved. These two important developments may improve the ability of local providers to identify and respond to preventable factors for infant deaths.[11,21–23] We feel that the inclusion of personnel from the local service unit increases the potential for recommendations from the PIMR to be considered and utilized in care plans for future pregnancies. The strategy of alternating the PIMR meetings at different Tribal Nations or IHS service units has been challenging; however, the rotation of meeting sites appears to have been useful to acquaint PIMR members with local resources and challenges confronting the IHS. One of the most common is the geographic isolation of many Tribal Nations and the people in those communities.

The process of reviewing infant deaths over the past 12 years has also been helpful in the development of a pool of knowledgeable personnel on the reservations in the AAIHS service units. This has resulted in numerous presentations on infant mortality to tribal elders and tribal leaders, high risk communities, and to several state and national provider organizations. In the AAIHS, infant death review is now an expectation and the results are being used in the development of prevention strategies. The data from this effort have been helpful is attracting additional funding and researchers for prevention and services for high risk infants, families, and communities. Many local community providers are aware of risk factors for infant mortality as a result of the work of the AAIHS PIMR.

Additional research is urgently needed to determine why the rate of SIDS remains high in the AAIHS. The high rate of previous deaths to children of the mothers of these infants raises important questions about why the recurrent mortality risk is high in these mothers and their children. Some Northern Plains Tribes are currently participating in several projects to improve understanding of risk factors for mortality, especially SIDS, and to develop population-specific prevention programs. Smoking and alcohol use also remain high, and greatly improved prevention and treatment programs are needed in the AAIHS.

The data from the AAIHS-PIMR will likely grow in value as the number of cases reviewed increases. Case control studies using linked existing data sets may also be a useful and inexpensive next step to improve the identification of risk factors and the magnitude of risk from these factors. The PIMR is also expanding the reviews to include fetal deaths after 20 weeks of gestation.

The process of development of a death review committee is expensive and time-consuming, and relies on donated time from many of the members. An important outcome of the PIMR has been the routine examination of infant deaths and the realization that patterns of risk factors are present. Each infant death is now not just an isolated tragedy, but rather an event requiring careful examination of what happened and an opportunity to improve care for the next infants in these communities. It does help to keep in mind an important fact: Each one of these deaths has a story to tell. Each story has a lesson. While we still have much to learn, the tragedy of each infant death furthers our education. This knowledge is necessary to give each future baby the opportunity for life.

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