Child Fatalities From Religion-motivated Medical Neglect

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ABSTRACT. *Objective.* **To evaluate deaths of children from families in which faith healing was practiced in lieu of medical care and to determine if such deaths were preventable.**

Design. **Cases of child fatality in faith-healing sects were reviewed. Probability of survival for each was then estimated based on expected survival rates for children with similar disorders who receive medical care.**

Participants. **One hundred seventy-two children who died between 1975 and 1995 and were identified by referral or record search. Criteria for inclusion were evidence that parents withheld medical care because of reliance on religious rituals and documentation sufficient to determine the cause of death.**

Results. **One hundred forty fatalities were from conditions for which survival rates with medical care would have exceeded 90%. Eighteen more had expected survival rates of >50%. All but 3 of the remainder would likely have had some benefit from clinical help.**

Conclusions. **When faith healing is used to the exclusion of medical treatment, the number of preventable child fatalities and the associated suffering are substantial and warrant public concern. Existing laws may be inadequate to protect children from this form of medical neglect.** ***Pediatrics*** **1998;101:625–629;** ***child abuse, child neglect, child fatality, Christian Science, faith healing, medical neglect, prayer, religion and medicine.***

Despite the great advances of scientifically based medicine, some individuals and groups continue to look primarily outside of modern medicine for remedial care.[1] Applied to minor or self-limited problems, many nonmedical practices are probably benign, but may lead to avoidable morbidity and mortality with more serious ailments.

Claims that prayer or religious beliefs have psychological or other benefits that contribute to illness recuperation are scientifically testable and perhaps supported by some evidence.[2,3] Although some churches have published testimonials claiming that organic and functional diseases are healed by soliciting divine power, this has not been confirmed by scientifically valid measures.[4] Death rates in graduates of a Christian Science college, a group whose central tenets deny the reality of disease and promote avoidance of medical services,[5] have been reported to be higher than graduates of a secular institution.[6]

Although legal precedents have established the right of an adult to refuse life sustaining treatment, they do not allow parents or guardians to deny children necessary medical care. The US Supreme Court stated this principle eloquently: "The right to practice religion freely does not include the liberty to expose the community or child to communicable disease, or the latter to ill health or death . . . Parents may be free to become martyrs themselves. But it does not follow they are free, in identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion. . . . "[7]

Despite this ruling, in late 1974 the US Department of Health, Education, and Welfare required states receiving federal child abuse prevention and treatment grants to have religious exemptions to child abuse and neglect charges.[8] With federal money at stake, states rapidly enacted exemptions for parents who relied on prayer rather than medical care when their children were sick or injured. A decade later nearly every state had these exemptions in the juvenile code, criminal code, or both.[9,10]

A few cases of children who died because of religion-motivated medical neglect have received national press coverage, but most get little or none. Reports in the medical literature are also rare. The American Academy of Pediatrics' first policy statement against religion-based medical neglect in 1988 cited press accounts rather than case reports.[11] Outbreaks of vaccine-preventable disease among groups with religious objections to immunization are reported frequently.[12–14] However, medical citations of fatalities are rare.[14,15] One study of perinatal events reported an Indiana sect that had a threefold increase in infant mortality and an 80-fold increase in maternal mortality compared with the general population.[16] The study reported here describes deaths that have occurred after the federal government required religious exemptions to child abuse and neglect laws.

METHODS

We compiled a list of child fatalities in the United States that occurred during the period from 1975 through 1995. Initial cases were from the files of Children's Healthcare Is a Legal Duty (CHILD), Inc, a nonprofit organization that gathers information on religion-based child abuse and neglect. These cases were collected from newspaper articles, trial records, personal communications, and public documents. With institutional review board approval, police records, coroners' files, and other confidential materials were examined for additional information. During this supplemental search, 4 additional candidates were identified.

Cases were included if the available information, including clinically descriptive histories and/or post mortem medical data, was sufficient to determine the cause of death with reasonable

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medical certainty, the standard for presentation of a medical opinion in most courts. This was assessed by one author (S.M.A.), a pediatrician who has qualified in court to examine records and present expert opinion in child fatality cases.

Cases were excluded if documentation of the cause of death was inadequate or if the history did not indicate that failure to seek medical care was primarily based on a reliance on faith healing. Examples of the latter include children of some Amish communities where the barriers to care are more cultural than theological and children of Jehovah's Witnesses who were denied only blood products and were not expected to be healed by divine intervention.

After considering the underlying conditions and diagnoses that directly contributed to death, children were assigned a likely outcome with commonly available remedial or preventive medically supervised care (Table 1). Because medical advances altered expected mortality rates during the study period, comparisons were based on clinical experience and published statistics of the appropriate era. For chronic conditions (eg, tumors, diabetes) survival was compared with long-term survival rates published in journals or textbooks from the relevant field. For acute problems, such as infections and perinatal complications, the logical comparison was expected mortality during the acute process.

In most cases, the diagnosis permitted an assignment to an expected outcome based on a published statistic. For example, the mortality rate for treated cases of Rocky Mountain Spotted Fever in 1983 was 2%, less than one-third the rate for untreated cases.[17] Thus, a death during 1984 was considered to have an excellent probable outcome with medical treatment.

In other situations, a diagnostic group could be identified, but not a specific disorder. A child with acute lymphocytic leukemia presenting for medical attention in 1977 would have an expected 3-year survival of 74%[18] and 5-year survival >50%. Thus this child would be placed into the good outcome group. But a child with a nonspecified leukemia could only be assigned based on overall outcome for all types of the disease and was thus placed into the fair group.

In a few instances, judgment based on clinical experience had to be applied. For example, the data in all cases of renal failure were not adequate to determine an etiology for the end-stage disease. However, they were sufficient to exclude active processes such as Lupus or cancers. All of the teenagers in that group seemed to be good dialysis candidates, ensuring a >90% chance of long-term survival. Thus, the prognosis for their condition was considered excellent. In any situation in which the heterogeneity of clinical presentations made a simple, direct classification difficult, such as in the case of a foreign body aspiration, the most conservative classification that seemed reasonable was assigned.

Infants with fetal demise were placed in favorable prognostic groups only if adequate inspection or autopsy excluded major malformations. Although in utero demise can happen under obstetrical supervision, close monitoring improves detection and treatment of high-risk circumstances that lead to fetal loss. The expected outcome of a third trimester pregnancy is a live born, surviving infant, and thus, for the purpose of this review, expected outcome with care is excellent. Likewise, many of the preterm births might have been delayed with prenatal care or had successful neonatal supportive care. Thus, the expected outcome of preterm infants and stillborns was considered good.

Some of the infants studied were given the legal term stillborn on death certificates. In many cases, however, autopsy reports and witness statements indicated that death occurred during labor or delivery from causes that would have been easily prevented or treated with skilled assistance. Thus, for the purposes of this study, these perinatal deaths were listed in categories other than fetal demise.

TABLE 1. Classification of Expected Outcomes With Preventive or Remedial Medical Care

Classification	Criteria
Excellent	90% ≥expected survival
Good	50%–89% expected survival
Fair	10%–49% expected survival
Some benefit	<10% expected survival but expectation for pain and suffering reduction under medical care
No benefit	No significant improvement in outcome expected with medical care

RESULTS

Of 201 cases reviewed, 14 lacked sufficient information to be certain of the cause of death. In 15 cases, it could not be established that exclusive reliance on faith healing contributed to the demise. This left 172 children for evaluation.

Childhood Fatalities

The diagnoses of 113 children who died after their neonatal period are summarized in Table 2. Of the 98 children who did not have cancer, 92 would have had an excellent prognosis with commonly available medical and surgical care and 4 would have had a good outcome. Only 2 would not have clearly benefited from care. Many histories revealed that symptoms were obvious and prolonged. Parents were sufficiently concerned to seek outside assistance, asking for prayers and rituals from clergy, relatives, and other church members. For example, a 2-year-old child aspirated a bite of banana. Her parents frantically called other members of her religious circle for prayer during nearly an hour in which some signs of life were still present. In another case, a 6-week-old infant, weighing a pound less than at birth, died from pneumonia. The mother admitted giving the infant cardiopulmonary resuscitation several times during the 2 days before the infant's death. In one family 5 children died of pneumonia before the age of 20 months, 3 before the study period. Although this raises the possibility of genetic disorders such as cystic fibrosis, immune deficiency, or asthma, many such conditions have a good prognosis with treatment. Their mother was a nurse before joining a church with doctrinal objections to medical care.

One father had a medical degree and had completed a year of residency before joining a church opposed to medical care. After 4 days of fever, his 5-month-old son began having apneic episodes. The father told the coroner that with each spell he "rebuked the spirit of death" and the infant "perked right back up and started breathing." The infant died the next day from bacterial meningitis.

For the children with tumors, available medical care would have given them a reasonable chance for long-term survival and reduction of pain and suffering. A 2-year-old boy with Wilms' tumor had a primary that weighed 2.5 kg, approximately one sixth of his body mass. A 12-year-old girl was kept out of school for 7 months while the primary osteogenic sarcoma on her leg grew to a circumference of 41 inches and her parents relied solely on prayer. A timely diagnosis would have allowed at least a modest chance for survival.

Prenatal and Perinatal Fatalities

Table 3 lists the principal causes of 59 prenatal and perinatal deaths. All but 1 of the newborns would have had a good to excellent expected outcome with

TABLE 2. Child Fatalities Associated With Religion-motivated Medical Neglect

Diagnoses	N	Ages (Years Unless Specified)	Expected Outcome
General or miscellaneous:			
Cachexia, gastric aspiration	1	9	Excellent
Dehydration	6	4 mo, 5 mo, 1, 5, 8, 12	Excellent
Diabetes, type 1	12	3, 7, 10, 10, 11, 12, 12, 13, 13, 15, 15, 16	Excellent
Epilepsy, withheld medications	1	17	Excellent
Burns, 50% total burn surface area	1	1	Good
Hydrocephaly, myelomeningocoele	1	2 mo	Excellent
Foreign body aspiration	1	2	Good
Renal failure	3	15, 15, 15	Excellent
Trauma, motor vehicle accident	1	2	No benefit
Infections:			
Diphtheria	3	3, 4, 9	Excellent
Laryngotracheobronchitis	1	18 mo	Excellent
Measles (with complications)	7	1, 5, 9, 9, 13, 14, 16	Excellent
Meningitis, *H influenzae*	9	4 mo, 1 (7), 4	Excellent
Meningitis, *S pneumoniae*	4	2 mo, 5 mo, 1, 7	Excellent
Meningitis, bacterial, nonspecified	1	1	Excellent
Meningitis, posttraumatic	1	15	Excellent
Pericarditis, *S pneumoniae*	1	1	Excellent
Pertussis	1	1 mo	Excellent
Pneumonia (varying etiologies)	22	1 mo to 2 y	Excellent
Pneumonia/myocarditis	1	1	Good
Rocky Mountain spotted fever	1	4	Excellent
Toxic shock syndrome, staphylococcus	1	17	Excellent
Abdominal surgical disorders:			
Intussuception	3	8 mo, 9 mo, 14	Excellent
Appendicitis, ruptured	7	5 to 14	Excellent
Small bowel obstruction	1	6	Excellent
Strangulated hernia	1	6	Excellent
Volvulus	2	9 days, 26 mo	Excellent
Congenital heart lesions:			
Common atrioventricular canal	1	7 mo	Good
Double outlet right ventricle	1	12	No benefit
Ventricular septal defect, pneumonia	2	9 mo, 10 mo	Excellent
Tumors:			
Ewing's sarcoma	1	13	Good
Leukemia, acute lymphocytic	3	4, 5, 7	Good
Leukemia, nonspecified	1	2	Fair
Lymphoma, Burkitt's	1	13	Good
Lymphoma, non-Hodgkins	1	3	Good
Neuroblastoma	1	1	Fair
Osteogenic sarcoma	3	6, 12, 14	Fair
Posterior fossa, nonspecified	1	2	Fair
Rhabdomyosarcoma	2	4 and 5	Fair
Wilms' tumor	1	2	Good
Total	113		

medical care. The mothers generally declined prenatal care and the deliveries were either unassisted or attended by nonlicensed midwives. Two mothers had prior cesarean sections and had been advised against home delivery. Siblings of 2 deceased newborns had previously received court-ordered medical care for illness or injury. In one case, a relative of an infant with respiratory difficulty called for medical assistance, but a church elder turned the responding emergency crew away saying that with prayer the infant was breathing better. The infant died within a few hours. One infant was asphyxiated because of intrapulmonary bleeding, which might have been prevented with a routine vitamin K injection.

Pseudoscience was sometimes offered along with prayer. During 1 birth, a 3-day ordeal that included difficult labor and maternal convulsions, the founding elder of the sect told the mother her copious green vaginal discharge was "a good thing," a sign that she had peritonitis and poisons were being expelled thanks to the prayers of the group. It is likely that her discharge was meconium, a sign of fetal distress.

Deliveries attended by unlicensed midwives had tragic results. In one case, a 23-year-old woman presented to an emergency room after 56 hours of active labor with the infant's head at the vaginal opening for >16 hours. The dead fetus was delivered via emergency cesarean, and was in an advanced state of decomposition. The mother died within hours after delivery from sepsis because of the retained uterine contents. The medical examiner noted that the corpse of the infant was so foul smelling that it was inconceivable anyone attending the delivery could not have noticed.

Five additional mothers of perinatal infants died from complications of delivery. A few mothers eventually were treated in emergency departments for vaginal lacerations and retained placentas. In 2 cases, dead newborns had twin siblings who survived after being taken to hospitals.

Other Findings

A total of 23 denominations from 34 states were represented in this study. Five groups accounted for

TABLE 3. Perinatal Fatalities Associated With Religion-motivated Medical Neglect

Diagnoses	N	Comments	Expected Outcome
Fetal demise			
Preterm	3	26-, 32-, 34-week gestations	Good
Term	6	Large infants, some postterm	Excellent
Hydrops faetalis	1	Blood group incompatibility	Excellent
Preterm infants		(All over 30 weeks unless noted)	
Apnea, respiratory arrest	1		Excellent
Asphyxia	1	Nuchal cord, breech	Excellent
Intraventricular hemorrhage	1	34-week gestations	Good
Prematurity, severe	1	600 g, 1 month maternal bleeding	Good
Respiratory distress syndrome	5	30- to 34-week gestations	Excellent
Respiratory failure, unspecified	3	Several lived more than a day at home	Excellent
Septicemia, strep	1		Excellent
Traumatic delivery	1	Subarachnoid hemorrhage	Excellent
Term infants			
Anencephaly, myelomeningocoele	1		No benefit
Asphyxia			
nonspecified	5	Several failed unskilled resuscitations	Excellent
breech	6		Excellent
maternal shock	1		Excellent
nuchal cord	2		Excellent
prolonged labor	6	From 2 to 4 days	Excellent
uncleared secretions	2		Excellent
Birth trauma	5	Internal and external head injuries	Excellent
Hemorrhagic disease of newborn	1	Pulmonary hemorrhage, lived 4 days	Excellent
Hypothermia, shock	1		Excellent
Meconium aspiration	2		Excellent
Respiratory failure	3		Excellent
Total	59		

83% of the total fatalities (Table 4). Several states had totals disproportionate to population. There were 50 from Indiana, home of the Faith Assembly. Pennsylvania had 16 fatalities, including 14 from the Faith Tabernacle. The Church of the First Born accounted for the majority of 15 deaths in neighboring Oklahoma and Colorado. In South Dakota there were 5 deaths from the End Time Ministries. Nationwide, the Christian Science church had 28 deaths in the study.

Contacts with public agencies and mandated reporters of suspected child neglect were not unusual among the children. Believing they were powerless in the face of the parents' wishes, some teachers ignored obvious symptoms and sent lessons home to bedridden children. Some social workers and law enforcement officers allowed parents to decline examinations of children reported to be ill. Public officials did not investigate the deaths of some children.

One teenager asked teachers for help getting medical care for fainting spells, which she had been refused at home. She ran away from home, but law enforcement returned her to the custody of her father. She died 3 days later from a ruptured appendix.

A premature girl was delivered successfully at a hospital after her twin brother died during a home birth. Her mild respiratory distress syndrome resolved after 4 days of oxygen and other minimally invasive support. She then developed progressively severe apneic spells. The medical staff acquiesced to the parents' request not to transfer the child to a higher level unit, despite an expected good prognosis. She died 2 days later when she could not be resuscitated after a respiratory arrest.

TABLE 4. Religious Groups With Core Beliefs of Medical Care Avoidance

Organization Name	Deaths
Church of the First Born	23
End Time Ministries	12
Faith Assembly	64
Faith Tabernacle	16
First Church of Christ, Scientist (Christian Science)	28
Other denominations (N = 18), or unaffiliated	29
Total	172

DISCUSSION

Calculations of overall incidence and mortality rates are not possible in this study as the number of children in the groups sampled is not available and the cases were collected in a nonrigorous manner. However, we think that the comparison with outcomes expected in ordinary medical settings is a valid indicator that death and/or suffering were preventable in virtually all of these children. These fatalities were not from esoteric entities but ordinary ailments seen and treated routinely in community medical centers. Deaths from dehydration, appendicitis, labor complications, antibiotic-sensitive bacterial infections, vaccine-preventable disorders, or hemorrhagic disease of the newborn have a very low frequency in the United States.

We suspect that many more fatalities have occurred during the study period than the cases reported here. Deaths of children in faith-healing sects are often recorded as attributable to natural causes and the contribution of neglect minimized or not investigated. During the course of requesting documents for this study, we were told of deaths of children because of religion-motivated medical neglect that were not previously known to us from public records, newspapers, or other sources.

In many jurisdictions the classification of stillborn for an infant who has not taken a breath preempted

investigation of individuals involved in unattended deliveries, including unlicensed midwives.

The legal requirements for care of infants who have begun breathing are also inadequate in some states. One Indiana jury acquitted parents who let their 9-hour-old, preterm infant die without medical help. The judge instructed the jury that state law did not require the parents to obtain hospitalization until the infant had stopped breathing. Because survival after out-of-hospital cardiopulmonary arrest of infants is generally poor, such a law effectively obviates a duty to provide care.

In 1983, the federal government removed religious exemptions from federal mandate, allowing states to repeal them. The well-organized lobbying of exemption supporters, however, has defeated most repeal efforts. Today only five states, Massachusetts, Maryland, Nebraska, North Carolina, and Hawaii, have no exemptions either to civil abuse and neglect charges or criminal charges. The law and politics of this issue are discussed extensively elsewhere.[9,10,19–21]

Twenty-six percent of the deaths in this study have occurred since 1988, when the American Academy of Pediatrics first called for elimination of religious exemption laws[11] and several years after the federal government began allowing repeal. Excluding the Faith Assembly in which high reported maternal and child death rates declined after some prosecutions[22] and the death of its charismatic leader, 35% of the fatalities in this sample occurred from 1988 to 1995, 38% of the study period. Thus, it seems that this form of preventable child mortality continues unchecked.

From our observation, religious exemption laws promote the assumption that parents have the right to withhold necessary medical care from their children on religious grounds. Mandated reporters have been discouraged from contacting authorities or are unaware of their obligations and of means for state intervention. State agencies have sometimes hesitated to act on reports they do receive. Whereas Christian Science church leaders advise members in Britain and Canada to obey laws requiring medical care of sick children,[23,24] they have advised US members that the laws allow them to withhold medical care.[25,26] Several Pentecostal clergy and parents have also claimed that exemption laws confer the right to deny medical care to children.[27]

The American Academy of Pediatrics, American Medical Association, National District Attorneys Association, and National Committee for the Prevention of Child Abuse, among others, have adopted policy statements calling for the complete repeal of religious exemptions in child abuse and neglect and criminal statutes.[28–31] The children of members of faith-healing sects deserve the same protections under the law as other children have. We believe that the repeal of exemption laws is a necessary step toward assuring such protection and should be accomplished before hundreds more children suffer needlessly and die prematurely.

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