# PEDIATRICS

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

# Conflicts Between Religious or Spiritual Beliefs and Pediatric Care: Informed Refusal, Exemptions, and Public Funding

COMMITTEE ON BIOETHICS

Pediatrics; originally published online October 28, 2013;
DOI: 10.1542/peds.2013-2716

The online version of this article, along with updated information and services, is located on the World Wide Web at:

http://pediatrics.aappublications.org/content/early/2013/10/23/peds.2013-2716

PEDIATRICS is the official journal of the American Academy of Pediatrics. A monthly publication, it has been published continuously since 1948. PEDIATRICS is owned, published, and trademarked by the American Academy of Pediatrics, 141 Northwest Point Boulevard, Elk Grove Village, Illinois, 60007. Copyright © 2013 by the American Academy of Pediatrics. All rights reserved. Print ISSN: 0031-4005. Online ISSN: 1098-4275.



# Conflicts Between Religious or Spiritual Beliefs and Pediatric Care: Informed Refusal, Exemptions, and Public Funding

COMMITTEE ON BIOETHICS

*Pediatrics*; originally published online October 28, 2013;

DOI: 10.1542/peds.2013-2716

**Updated Information &** including high resolution figures, can be found at:

Services http://pediatrics.aappublications.org/content/early/2013/10/23

/peds.2013-2716

**Permissions & Licensing** Information about reproducing this article in parts (figures,

tables) or in its entirety can be found online at:

http://pediatrics.aappublications.org/site/misc/Permissions.xh

tml

**Reprints** Information about ordering reprints can be found online:

http://pediatrics.aappublications.org/site/misc/reprints.xhtml

PEDIATRICS is the official journal of the American Academy of Pediatrics. A monthly publication, it has been published continuously since 1948. PEDIATRICS is owned, published, and trademarked by the American Academy of Pediatrics, 141 Northwest Point Boulevard, Elk Grove Village, Illinois, 60007. Copyright © 2013 by the American Academy of Pediatrics. All rights reserved. Print ISSN: 0031-4005. Online ISSN: 1098-4275.





### **POLICY STATEMENT**

# Conflicts Between Religious or Spiritual Beliefs and Pediatric Care: Informed Refusal, Exemptions, and Public Funding

### abstract



Although respect for parents' decision-making authority is an important principle, pediatricians should report suspected cases of medical neglect, and the state should, at times, intervene to require medical treatment of children. Some parents' reasons for refusing medical treatment are based on their religious or spiritual beliefs. In cases in which treatment is likely to prevent death or serious disability or relieve severe pain, children's health and future autonomy should be protected. Because religious exemptions to child abuse and neglect laws do not equally protect all children and may harm some children by causing confusion about the duty to provide medical treatment, these exemptions should be repealed. Furthermore, public health care funds should not cover alternative unproven religious or spiritual healing practices. Such payments may inappropriately legitimize these practices as appropriate medical treatment. *Pediatrics* 2013;132:962–965

### **INTRODUCTION**

Religion plays an important role in the lives of many individuals. Fiftyeight percent of respondents to a recent poll reported that religion is very important in their lives, and 23% reported that it is fairly important. The relationship between religion and medicine is complex. Some studies suggest "greater involvement in religion conveys more health-related benefits."2 There are, however, times when religion and medicine conflict. The current policy statement addresses 3 related issues: (1) parents' refusal of medical treatment of their children; (2) religious exemptions to child abuse and neglect laws; and (3) public funding of alternative unproven religious or spiritual healing practices. The statement situates religious refusals within the scope of parental authority and argues that children's future autonomy should be protected. Religious exemption statutes do not protect all children equally and create uncertainty and, to protect children's health, should be repealed. Public health care funding should focus on established, effective therapies, and paying for spiritual healing practices may inadvertently engender medical neglect. The discussion of these specific topics should not be interpreted as a broader criticism of the interaction between religion and medicine.

#### COMMITTEE ON BIOETHICS

#### **KEY WORDS**

exemption, informed refusal, medical neglect, pediatrics, religion

#### **ABBREVIATIONS**

AAP—American Academy of Pediatrics
HHS—US Department of Health and Human Services

This document is copyrighted and is the property of the American Academy of Pediatrics and its Board of Directors. All authors have filed conflict of interest statements with the American Academy of Pediatrics. Any conflicts have been resolved through a process approved by the Board of Directors. The American Academy of Pediatrics has neither solicited nor accepted any commercial involvement in the development of the content of this publication.

The guidance in this statement does not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

All policy statements from the American Academy of Pediatrics automatically expire 5 years after publication unless reaffirmed, revised, or retired at or before that time.

www.pediatrics.org/cgi/doi/10.1542/peds.2013-2716 doi:10.1542/peds.2013-2716

PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).
Copyright © 2013 by the American Academy of Pediatrics

### RELIGIOUS OBJECTIONS TO MEDICAL CARE

Although parents have broad authority, they have less discretion in making medical decisions for their children than for themselves. On the basis of the ethical principles of autonomy and respect for persons, capacitated adults should have wide license in making medical decisions for themselves, including the refusal of potentially lifesaving medical treatment. Their liberty should only be limited in cases of direct harm to third parties, such as the risk of transmitting serious infectious diseases. Infants and children lack the ability to make autonomous medical decisions; therefore, the law generally authorizes their parents or guardians to make such decisions on their behalf. These decisions should primarily focus on the child's best interests.3,4 Clinicians should afford parents and guardians significant discretion in their interpretation of these interests and collaborate with them to develop treatment plans that promote their children's health. Although family autonomy and privacy are important social values, parents' choices may be limited when they rise to the level of abuse or neglect.5

Failure to provide children with essential medical care has been increasingly recognized as a form of neglect. In 1983, the US Department of Health and Human Services (HHS) amended its definition of negligent treatment to include failure to provide adequate medical care.6 A number of factors are relevant to the evaluation of suspected medical neglect, including likelihood and magnitude of the harm of foregoing medical treatment and the benefits, risks, and burdens of the proposed treatment.7-9 For example, the risk of an individual unimmunized child contracting a communicable vaccine-preventable disease may be low if immunization rates in the community are high and disease prevalence

is low.<sup>10</sup> Serious harms include death, severe disability, or severe pain. The American Academy of Pediatrics (AAP) Committee on Child Abuse and Neglect identifies a variety of factors that can lead to children not receiving appropriate medical care and corresponding graduated management options for pediatricians. For example, lack of awareness, knowledge, or skills can be addressed by counseling and education.7 Ethics consultation is an additional management option.7,11 If less-restrictive alternatives are not available or successful, pediatricians should refer families to child protective services agencies. In emergencies, providers may be ethically justified in administering treatment immediately necessary to preserve life, prevent serious disability, or treat severe pain. They should notify child protective services as soon as possible.

The basis for some parents' rejection of medical treatment is religious or spiritual. Traditions vary in the scope of medical treatments they refuse. For example, members of the Followers of Christ refuse all medical treatment in favor of prayer, anointing with oil, and the laying on of hands. 12 Christian Scientists may use dentists and physicians for "mechanical" procedures, such as setting bones or childbirth, but consider most illnesses to be the result of the individual's mental attitude and seek healing through spiritual means, such as prayer. They consider these healing practices incompatible with concurrent medical treatment.13 Other religious groups prohibit only specific medical interventions. On the basis of their interpretation of scripture, Jehovah's Witnesses only prohibit the use of blood and its major fractions.14 Understanding these differences is important in identifying whether there are mutually acceptable alternatives.

Some religious refusals have, tragically, led to children's deaths from readily

treatable conditions, such as pneumonia, appendicitis, or diabetes. 12,15 Although the free exercise of religion. including parents teaching their children their religious beliefs, is an important societal value, it must be balanced against other important societal values, such as protecting children from serious harm.<sup>16</sup> In some situations, the issue is primarily an empirical one —the relative efficacy of medical and spiritual interventions. Although systematic empirical evidence of the efficacy of religious interventions is often lacking, the courts can judge efficacy by using criteria generally accepted by both parents and health care providers. In other situations, the issue involves differing conceptions of benefit and harm. Parents and guardians should have significant discretion in weighing the risks and benefits of a proposed treatment. At times, the primary benefit of refusing medical treatment or seeking alternative nonmedical treatment is religious or spiritual, such as the implications of the treatment on the patient's eternal salvation. In such cases, the potential benefit cannot be evaluated by using generally accepted criteria. In such situations, the child's future ability to decide this contested issue for himself or herself should be protected.<sup>17</sup> Some adolescents may possess adequate decision-making capacity to comprehend and evaluate the risks and benefits of medical treatment. The possibility of coercion should also be considered in the evaluation of whether a capacitated adolescent's dissent is autonomous.18

The courts have consistently ordered life-saving medical treatment over parental religious objections.<sup>8,9</sup> In passages frequently quoted in subsequent rulings, the US Supreme Court famously stated, "The right to practice religion freely does not include liberty to expose the community or the child to communicable disease or the latter to

ill health or death" and "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 when they can make that choice for themselves."19 There is less unanimity in judicial decisions if the condition is not life-threatening, the treatment has significant adverse effects, or the treatment has limited efficacy.7-9 Courts may also consider the negative psychological effects of court-ordered treatment or medical foster care in their decisions.

### RELIGIOUS EXEMPTIONS TO CHILD ABUSE AND NEGLECT LAWS

Most states have "religious exemptions" to their child abuse and neglect laws. These exemptions proliferated in response to the Child Abuse Prevention and Treatment Act of 1974. The act stated, "Provided, however, that a parent or guardian legitimately practicing his religious beliefs who thereby does not provide specified medical treatment for a child, for that reason alone shall not be considered a negligent parent or guardian."20 Enacting exemptions was a condition for states to receive federal child abuse grants. More than 40 states adopted exemptions, which vary in their location within each state's code and wording.8 Some apply to child protective services agencies' ability to intervene, and others apply to parents' criminal liability. The HHS revised its position, taking a neutral stance, when the act was reauthorized in 1983: "Nothing in this part should be construed as requiring or prohibiting a finding of negligent treatment or maltreatment when a parent practicing his or her religious beliefs does not, for that reason alone, provide medical treatment for a child."21 After reauthorization of the act in 1987, HHS clarified that reports of medical neglect should

only be made if there is harm or a substantial risk of harm, and religious exemptions should be a matter of state discretion rather than federal imposition. A number of states subsequently amended or repealed their religious exemption statutes. Most recently, after the deaths of 2 children, Oregon repealed its exemption.

The AAP believes that religious exemptions to state child abuse and neglect laws should be repealed. These exemptions fail to provide an equivalent level of protection to children whose parents practice spiritual healing and children whose parents do not.16 In addition, they may create confusion that results in harm to children; parents may be unclear about their duty to provide medical treatment, child protective services agencies may falsely believe that they cannot intervene until after a child suffers serious injury or dies, and prosecutors and courts may be uncertain whether parents are subject to criminal liability if their child dies of medical neglect.5,16 Although the exemptions could be revised to make it explicit that seeking medical care is required when a child is seriously ill,5,8 repeal is preferable because it provides greater clarity. 16 For example, parents and spiritual healers who are members of groups that refuse all medical treatment may not be able to differentiate moderate from severe illnesses and. therefore, fail to seek medical attention in a timely manner. 14,16

# PUBLIC FUNDING OF SPIRITUAL HEALING PRACTICES

In addition to efforts to create religious exemptions, some churches and legislators have sought to provide public funds to pay for religious or spiritual healing practices. For example, Medicare and Medicaid cover care provided at Christian Science sanatoria and other religious nonmedical health care institutions and exempt these institutions

from medical oversight requirements.<sup>23</sup> In addition, there were unsuccessful efforts to include coverage of Christian Science practitioners in the 2009 federal health care reform bills<sup>24</sup> and ongoing efforts to include their services in the essential health benefits package. These efforts should be distinguished from both health care services provided by religious organizations, such as Roman Catholic and Seventh-day Adventist hospitals, and pastoral care provided as a bundled service.

Coverage for unproven care by unlicensed practitioners is poor public policy for several reasons. Fundamentally, public funds should be spent on established, effective therapies.25 In addition, religious nonmedical health care institutions provide custodial rather than skilled nursing care, a benefit not covered in other institutions. Given patients' exemptions from undergoing medical examinations, it is not possible to determine whether patients of religious nonmedical health care institutions would otherwise qualify for benefits.<sup>23,26</sup> Because providing public funding for unproven alternative spiritual healing practices may be perceived as legitimating these services, parents may not believe that they have an obligation to seek medical treatment. Although the AAP recognizes the importance of addressing children's spiritual needs as part of the comprehensive care of children, it opposes public funding of religious or spiritual healing practices.

### **RECOMMENDATIONS**

- Pediatricians, pediatric medical subspecialists, and pediatric surgical specialists should respect families and their religious or spiritual beliefs and collaborate with them to develop treatment plans to promote their children's health.
- 2. Pediatricians, pediatric medical subspecialists, and pediatric surgical specialists should report

suspected cases of medical neglect to state child protective services agencies, regardless of whether the parents' decision is based on religious beliefs.

 Pediatricians, pediatric medical subspecialists, pediatric surgical specialists, and the AAP and its chapters should work to repeal religious exemptions to child abuse and neglect laws and to prevent public payment for religious or spiritual healing practices.

#### **LEAD AUTHORS**

Armand H. Matheny Antommaria, MD, PhD Kathryn L. Weise, MD

### COMMITTEE ON BIOETHICS, 2011–2012

Mary E. Fallat, MD Aviva L. Katz, MD Mark R. Mercurio, MD Margaret R. Moon, MD Alexander L. Okun, MD Sally A. Webb, MD Kathryn L. Weise, MD

#### **CONSULTANT**

Jessica W. Berg, JD, MPH

### PAST CONTRIBUTING COMMITTEE MEMBERS

Armand H. Matheny Antommaria, MD, PhD lan R. Holzman, MD Lainie Friedman Ross, MD, PhD

### **LIAISONS**

Douglas S. Diekema, MD, MPH – *American Board of Pediatrics* 

Kevin W. Coughlin, MD – Canadian Pediatric Society

Steven J. Ralston,  $MD-\mathit{American}\ \mathit{College}\ \mathit{of}\ \mathit{Obstetricians}\ \mathit{and}\ \mathit{Gynecologists}$ 

#### **STAFF**

Alison Baker, MS

### **REFERENCES**

- Gallup. Religion. Available at: www.gallup. com/poll/1690/religion.aspx. Accessed April 21, 2013
- Krause N. Religion and health: making sense of a disheveled literature. J Relig Health. 2011;50(1):20–35
- American Academy of Pediatrics, Committee on Bioethics. Informed consent, parental permission, and assent in pediatric practice. *Pediatrics*. 1995;95(2):314–317
- 4. Ross LF. Children, Families, and Health Care Decision Making. Oxford, UK: Clarendon Press; 1998
- Gathings JT Jr. When rights clash: the conflict between a parent's right to free exercise of religion versus his child's right to life. *Cumberland Law Rev.* 1988–1989;19 (3):585–616
- 6. Child Abuse and Neglect Prevention and Treatment, 45 CFR § 1340.2(d)(2)(i) (1983)
- Jenny C; Committee on Child Abuse and Neglect, American Academy of Pediatrics. Recognizing and responding to medical neglect. *Pediatrics*. 2007;120(6):1385–1389
- Malecha WF. Faith healing exemptions to child protection laws: keeping the faith versus medical care for children. *J Legis*. 1985;12(2):243–263
- Trahan J. Constitutional law: parental denial of a child's medical treatment for religious reasons. *Annu Surv Am Law.* 1989; 1989(1):307–341
- 10. Diekema DS; American Academy of Pediatrics Committee on Bioethics. Responding to

- parental refusals of immunization of children. *Pediatrics*. 2005;115(5):1428–1431
- American Academy of Pediatrics. Committee on Bioethics. Institutional ethics committees. *Pediatrics*. 2001;107(1):205–209
- Mayes S. Another Followers of Christ couple indicted in death of a child. The Oregonian. July 31, 2010. Available at: www.oregonlive.com/oregon-city/index.ssf/2010/07/another\_followers\_of\_christ\_couple\_indicted\_in\_death\_of\_a\_child.html. Accessed August 15, 2012
- Talbot NA. The position of the Christian Science church. N Engl J Med. 1983;309(26): 1641–1644
- Dixon JL, Smalley MG. Jehovah's Witnesses. The surgical/ethical challenge. *JAMA*. 1981; 246(21):2471–2472
- Asser SM, Swan R. Child fatalities from religion-motivated medical neglect. *Pediat*rics. 1998;101(4 pt 1):625–629
- 16. Monopoli PA. Allocating the costs of parental free exercise: striking a new balance between sincere religious belief and a child's right to medical treatment. Pepperdine Law Rev. 1991;18(2):319–352
- Sheldon M. Ethical issues in the forced transfusion of Jehovah's Witness children. J Emerg Med. 1996;14(2):251–257
- Guichon J, Mitchell I. Medical emergencies in children of orthodox Jehovah's Witness families: three recent legal cases, ethical issues and proposals for management.

- Paediatr Child Health (Oxford). 2006;11(10): 655–658
- 19. *Prince v Massachusetts*, 321 US 158, 170 (1944)
- 20. Child Abuse and Neglect Prevention and Treatment Act, 45 CFR § 1340.1-2(b) (1975)
- 21. Child Abuse and Neglect Prevention and Treatment Act, 45 CFR § 1340.2(d) (2) (ii) (1983)
- 22. Mayes S. Kitzhaber signs bill to eliminate religious defense for faith-healing parents. The Oregonian. June 16, 2011. Available at: www.oregonlive.com/oregon-city/index.ssf/ 2011/06/kitzhaber\_signs\_bill\_to\_eliminate\_ religious\_defense\_for\_faith-healing\_parents. html. Accessed August 15, 2012
- Harris BR. Veiled in textual neutrality: is that enough? A candid reexamination of the constitutionality of Section 4454 of the Balanced Budget Act of 1997. Alabama Law Rev. 2010;61(2):393–423
- Wan W. 'Spiritual health care' raises church-state concerns. The Washington Post. November 23, 2009. Available at: www. washingtonpost.com/wp-dyn/content/article/ 2009/11/22/AR2009112202216.html. Accessed August 15, 2012
- Libby R; Committee on Child Health Financing American Academy of Pediatrics. Principles of health care financing. *Pediatrics*. 2010;126 (5):1018–1021
- Children's Health Care Is a Legal Duty Inc v Min de Parle, 212 F.3d 1084 (8th Cir. 2000), cert. denied, 532 US 957 (2001)