Religious beliefs and the use of complementary and alternative medicine can help or hinder health care and the well being of children, who are often unable to make informed decisions for themselves, but instead, depend on their parents or caregivers to make health care decisions for them. Tragically, this can sometimes result in prolonged suffering and death when parents or caregivers refuse treatment due to their own personal beliefs. This two-part article explores the case of Kara Neumann, an 11-year-old girl who died after her parents denied her medical care in lieu of prayer to cure her “spiritual attack,” and the role pediatric nurses can play in educating patients and their families.

Deciding Between Prayer or Medicine: The Case of Kara Neumann

On Easter Sunday (March 23, 2008), Madeline Kara Neumann of Weston, Wisconsin, died from diabetic ketoacidosis. Her parents said the 11-year-old had been ill for about a month (Glauber, 2008a). Her condition deteriorated rapidly in the 48 hours before she died (Glauber, 2008d). The day before she died, she was not able to eat, drink, walk, or use the toilet. She was unconscious for a few hours before she died. Relatives in California called 911, but Kara was pronounced dead after the emergency team brought her to a local hospital (Glauber, 2008a).

Her parents later stated they did not know Kara had diabetes (Glauber, 2008d). According to police documents, her father at first thought she was going through changes due to puberty. Relatives asked the parents to take Kara to a doctor, but they refused (Glauber, 2008c). They remained confident in the healing power of prayer. Her mother later told the police, “We just thought it was a spiritual attack, and we prayed for her” (Glauber, 2008d).

Given that they were not trained health care professionals, it is understandable that they did not recognize that Kara showed symptoms of diabetes or the seriousness of her condition. However, the evening before her death, her father sent an email to an online Christian ministry called AmericasLastDays.com. The email read, “Help, our daughter needs emergency prayer!” (Glauber, 2008d).

Five weeks later, the parents were charged with second-degree reckless homicide (Glauber, 2008d). According to the county District Attorney, “In our nation, we have a constitutional guarantee of freedom of religion. We also give parents leeway in matters of child rearing. However, neither is absolute. In this case, it was necessary to weigh freedom of religion andparenting rights against the state’s interests in protecting children” (Glauber, 2008d).

The Case of Kara Neumann: An Examination of the Ethical Principles

A recent situation in Wisconsin, as described by Dr. O'Mathuna, provides an excellent pediatric case study for a review of ethical principles. Pediatric nurses’ opinions about these types of public cases are valued and sought after because of the nursing profession's position of social trust and commitment to caring (Woods, 2001). Nurses maintain professional credibility when they participate in the discussion of ethics issues (McGrath, 1995). This article will provide a snapshot of the ethical principles as applied to Kara Neumann’s treatment, and hopefully, provide a basis for further discussion and debate among pediatric nurses and their colleagues.

Discussion

Kara Neumann’s story is a tragic one (see Figure 1). Her parents relied exclusively on prayer as the spiritual treatment for – what turned out to be – a medically treatable condition: diabetes. They have been charged with reckless homicide for Kara’s death from diabetic ketoacidosis. How would her situation have been reviewed in light of bioethical principles? Current Western philosophy considers four (sometimes six) principles to be central to ethics and health care: autonomy, beneficence, non-maleficence, justice, and sometimes fidelity and truth-telling. Each of these principles will be discussed as they might apply to Kara.

**Autonomy.** Autonomy is the ethical principle that recognizes and supports the capacity to decide for oneself (Beauchamp & Childress, 2001). Respect for autonomy promotes self-determination and protects bodily integrity.

**Figure 1. Media References**


As an ethicist who is also a Christian, I would like to be able to defend the parents. I cannot do that wholeheartedly for both ethical and theological reasons. However, a number of mitigating factors should be taken into account regarding the parents’ decisions. No matter how the Neumann’s fare in the eyes of the law, their situation is a terrible tragedy. They have suffered the loss of a child, which ranks as one of the most painful trials life can bring. Their decision not to treat Kara was determined by their beliefs. Given the origins of those beliefs, this discussion needs to include examination of relevant theological concepts.

Where the responsibility for Kara’s death is placed will have broad implications for others who make medical decisions influenced by religious and other beliefs. Similar ethical issues arise with decisions regarding complementary and alternative medicine (CAM). Parents may insist on treating their children with remedies and therapies that are not supported by the best available evidence. Studies of the popularity of CAM reveal that prayer is the most commonly used CAM therapy. A recent survey found that three of the top five “therapies” were different forms of prayer (Barnes, Powell-Griner, McFann, & Nahin, 2004). I have elaborated elsewhere on my objections to prayer being described as a “therapy,” but that is not the focus of this article (O’Mathnúa & Larimore, 2007). These studies reveal that prayer for healing is commonly practiced. Prayer is at the root of Christian faith as a way of relating with God, and is central to many other religions. Prayer itself is not what is problematic in the tragic death of Kara Neumann, but the parents’ rejection of medical treatment. Given the popularity of prayer for healing, it does not usually lead people to reject medical care.

No less than any other part of society, Christians have been exposed to recent cultural and philosophical changes. The critique of authority and promotion of individualism have impacted how people approach their Christian faith. Certainly, some authorities have abused their position and influence, victimizing others. That must be denounced vigorously, whether those authorities were theological, medical, political, or anything else. However, in response to past abuses, some have become suspicious of any authority. In our postmodern world, isolation and individualism have become dominant, along with slogans to “reject all authority.” When taken to the extreme, situations like that of the Neumann family can result. They had become isolated from others who could have helped them understand their situation as something other than as a spiritual attack. Postmodern thinking makes it difficult to humbly accept when medical authorities might have good evidence and a child’s best interests on their side.

The extreme position on medical care taken by the Neumanns is not unique. A week after Kara’s death, an Oregon couple was charged with manslaughter and criminal mistreatment in the death of their 15-month-old daughter (Anonymous, 2008). According to the state medical examiner, the child could have been treated with antibiotics. The parents belong to the Followers of Christ Church, which preaches against using medical treatment. A review of similar situations found that between 1975 and 1995, 140 U.S. children died after parents withheld treatment for religious reasons when survival rates with medical treatment exceeded 90% (Asser & Swain, 1998).

While the Neumann family did not belong to any particular church, they were influenced by the teachings of David Eells, founder of Unleavened Bread Ministries and the AmericasLastDays.com Web site. A few days after Kara’s death, Eells revealed that he had prayed on the phone with the parents the night before Kara died and while she was being taken by ambulance to the hospital where she was pronounced dead (Glauber, 2008b). Eells apparently did not encourage the Neumanns to seek medical attention but prayed for them. He now claims that the Neumanns are undergoing “persecution by the world” (Eells, 2008).

Eells and his ministry are part of a group of Christian (Beauchamp & Childress, 2001). This principle is the basis for informed consent and is usually only afforded to adults. Autonomy for children or minors has been limited because they do not have the capacity and legal power to give informed consent (Bartholome, 1989). However, state laws do provide for minors to consent in some circumstances. For example, Wisconsin state law allows for a 12-year-old to consent to bone marrow donation for her or his sibling if certain conditions are met (WI Stat §146.34(4)). In recent years, there has been an increase in attention to a child’s participation in health care decision making, and obtaining assent from a child or minor patient is seen as a significant factor in caring for children (American Academy of Pediatrics Committee on Bioethics, 1995; Bartholome 1989). Carnevale (2004) promotes recognizing children’s moral viewpoints on their own merits. The concept of “assent” requests health care providers to allow children to participate in their medical decision making to the extent they are able or are capable (Bartholome 1989).

A child’s refusal, or “dissent,” should be taken very seriously. Dissent may be overridden in certain circumstances, such as where the intervention is essential to a child’s welfare and cannot be deferred without substantial risk (American Academy of Pediatrics Committee on Bioethics, 1995). An apology should be given to a child whenever treatment is given over a child’s refusal (Bartholome, 1989).

• As an 11-year-old, it is likely that Kara would have had the ability to understand her condition and offer her viewpoint on whether she should receive treatment or not. Further, given the severity of her symptoms, it is also likely that Kara would have wanted treatment that, at the very least, would have provided symptom relief.

• If, after receiving information about her medical condition and the recommended treatment, Kara had refused treatment (and agreed with her parents), this would present an ethical difficulty. However, since Kara’s life or health was seriously endangered, ethically her dissent could have been overridden.

Beneficence. Beneficence is the ethical principle that promotes our doing good and “refers to a moral action to act for the benefit of others” (Beauchamp & Childress, 2001, p. 166). In cases where the patient is unable to act autonomously and his or her wishes cannot be determined, decisions are to be made that are a benefit to the patient. This may be referred to as a “best interests standard.” “The best interests standard protects another’s well being by assessing risks and benefits of various treatments and alternatives to treatments, by considering pain and suffering, and by evaluating restoration or loss of functioning” (Beauchamp & Chambers, 2001, p. 102). With few statutory exceptions, unless minors are emancipated, the laws do not afford them the opportunity to make their own healthcare decisions. A parent is usually the most appropriate person to make a decision for what treatment is in the best interests of a child (pediatric nurses are sure to have noted exceptions to this general rule). When reviewing Kara’s situation, the following factors should have been weighed in determining her best interests:

• The benefits of relying exclusively on spiritual treatment remain primarily with Kara’s parents. The parents were able to act in accord with their personal faith beliefs. (There are many unknowns about this faith practice, which does not appear to have any widely-recognized tenets.) Kara may have received an indirect benefit as a family member, such as affection from her parents, for complying with their faith beliefs.
churches and organizations that reject the use of medical treatment and pharmaceutical drugs. A number of books and CDs promoting this perspective were found at the Neumann’s house (Glauber, 2008c), including a book by Eells (2006). The book gives anecdotal reports of people ceasing to use medicine and drugs, and instead, trusting in faith and prayer. Many of the accounts imply that people’s symptoms were the side effects of drugs they had been taking. Other Christian groups have similar views, which I have critiqued elsewhere (O’Mathúna & Larimore, 2007).

While much of Eells’ material encourages the rejection of medicine, he does state that, “I am not condemning those who use doctors or medicine” (Eells, 2006, p. 272). He also gives his theological reasons for his position. He claims that God uses non-physical (spiritual) means to eliminate the physical curses of the world, such as sickness, pain, and poverty. He claims that this was how Jesus and his disciples lived, and Christians should do likewise (Eells, 2006). He refers regularly to the underlying principle that God’s power is revealed in humanity’s weakness. But when humans use physical means to relieve physical problems (“like sickness, torment, poverty, and such”), these means will be ineffective and lead to further problems (Eells, 2006, p. 273). The practical application for Eells is that Christians should pray for healing and not resort to the physical methods of doctors and drugs.

These views fall within a tradition of teachings (Christian and otherwise) that dichotomise the world into its physical and spiritual realms. This contrasts dramatically with the New Testament and much Christian literature, which promotes an integrated view of the physical and spiritual worlds. The New Testament encourages those who get sick to pray, but also to be anointed with oil, or use a little wine for their stomachs; money was to be collected to relieve poverty; taxes were to be paid to promote security; preachers were to be paid a salary; the weak and vulnerable were to be helped practically. The picture presented is holistic, not dichotomised. Working for a living is not in conflict with thanking God for his provisions (through talents, education, or a strong economy).

In the same way, most Christian interpreters see no conflict with praying for healing while calling the doctor or going to a pharmacist. The ancient Jewish book, also found in the Old Testament Apocrypha, puts it this way – All healing is from God, but since He also made the world’s medicines and physicians, all approaches should be used when sick, along with prayer (Ecclesiasticus 38:1-15). The substances and knowledge of modern health care are part of the created world that God has given to humanity to use ethically. There is nothing inherently unspiritual in using the material world to meet our needs.

While the Neumann parents were undoubtedly sincere in their religious beliefs, they accepted a minority and highly questioned interpretation of the Christian faith. This therefore raises challenging questions about the ethical responsibilities of those who provide information to help people make decisions. The teachings of Mr. Eells and others are leading people to neglect their own physical health and that of their children. They are also culpable in these situations and guilty of misinforming and misleading parents like the Neumanns.

Questioning the validity of anyone’s religious teachings or beliefs is a contentious issue. Yet situations such as David Koresh in Waco, Texas, or Jim Jones in Jonestown, Guyana, show that religious teaching can become destructive. Some limits must be set on people’s freedom to practice their religious beliefs. Freedom of religion is an important value, but it cannot be absolute. To take an extreme example, infant sacrifice has been practiced as part of several religions. I hope it would be difficult to find anyone who would defend this practice in the name of religious freedom. In that case, we need ethical guidelines on how to determine when religious freedoms should be

- The burdens of spiritual treatment in this case (and with hindsight) are heartbreaking: continuation of her symptoms, the unknown of whether prayers would cure Kara, and death.
- The benefits of medical treatment include a proven effective treatment (insulin) that would have allowed Kara the ability to live and develop into a cognitively and physically intact adult. With treatment, Kara could have continued her education, maintained relationships with loved ones, and looked forward to living independently one day. Also, depending upon her condition, the long-term effects of living with diabetes might have been mitigated depending upon the severity or stability of her diabetes and prescribed medical treatment regime.
- The burdens of medical treatment for diabetes include daily finger sticks and insulin injections, injection-site pain and bruising, emotional effects (such as anxiety, feeling different from her friends and family), and other effects of living with a chronic disease. Long-term burdens would also encompass all those associated with diabetes. Lastly, one cannot underestimate the emotional harm of acting against one’s beliefs and the effect this may have on the entire family, including attitudes toward Kara.

Other factors to consider when assessing best interests include a child and family’s culture, educational background, social support system, and any financial or economic concerns. Whenever parents refuse effective medical treatment for their child, questions to explore include the parents’ reasons for choosing spiritual treatment over medical treatment, whether they are emotionally stable, and whether the parents are being unduly influenced by outside factors. (Dr. O’Mathuna suggests this happened with the Neumanns.)

Non-maleficence. The principle of non-maleficence implores us to do no harm. As nurses, we may readily see the parents’ not seeking medical treatment as the “harm” in Kara’s situation. However, as Catlin (1996) recognized, for the parent, acting against one’s conscience or religious belief is a more serious harm than death. But parental religious/cultural decision making does not hold the highest weight in the U.S., and U.S. Courts have placed the sanctity of a child’s life above a patient’s sense of religious belief. “Parents may be free to become martyrs themselves. But it does not follow they are free…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” (Prince v. Massachusetts, p. 170).

Social justice. The principle of social justice usually includes a discussion about allocation of resources. The American Academy of Pediatrics Committee on Bioethics (1997) cites justice concerns if children are not uniformly protected by law. The AAP also asserts that refusing to seek medical care for children should not be tolerated by the law, even if for religious reasons (American Academy of Pediatrics Committee on Bioethics, 1997).

- In Kara’s case, the use of insulin for diabetes, a recognized, effective treatment, would have been an appropriate use of this widely available resource. It is unclear whether poverty or lack of access to health care or lack of insurance contributed to her parents’ decision to forego medical treatment.

Other principles. The principles of fidelity and truth-telling generally refer to health care providers’ obligations to the patient. Fidelity refers to the keeping of promises and maintaining confidentiality; truth-telling refers to honesty about the patient’s treatment or condition (Schroeter, Derse, Junkerman, & Schiedermayer, 2002). These prin-
restricted. The physical well being of children would be an obvi-
ous candidate. We also need public and private dialogue and
debate over the validity of religious teachings, especially when
they claim to fall within a specific religious tradition.
When competent adults decide for themselves to ignore
symptoms or refuse medical care, we must allow them the free-
dom to do so. That includes using only prayer for healing. We
may view their decisions as unethical, unwiseful, or ignorant. We
may discuss, debate, or argue with them about the reasons for
their decisions. But in the end, we must allow adults to choose
for themselves as part of respecting them as people. God gives
all of us that freedom.

The situation is different when those decisions directly
impact others, especially children. The Bible repeatedly calls on
Christians to help provide for the physical needs of others, as
well as their spiritual, emotional, and relational needs. When
parents refuse to meet the physical needs of their children, for
whatever reason, intervention is necessary to protect the chil-
dren. They deserve the opportunity to reach the age at which
they can make informed decisions for themselves.

This tragic situation also points to the importance of teach-
ing people to critically evaluate everything they are told.
Educators and many others have an ethical responsibility to
provide children and adults the skills to critically evaluate what
they are being exposed to on the Internet, in their popular enter-
tainment, and in their religious teaching. The New Testament
itself lauds the Jewish people of Berea after hearing the
Apostle Paul’s Christian teachings, they eagerly examined their
Scriptures to see “if what Paul said was true” (Acts 17:11).
That sort of inquiry into anything we are told or taught might
help avoid some of the tragedies like that of the Neumann fam-
ily.

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Principles are difficult to apply to Kara’s case because her par-
ents’ perception of the truth was that her symptoms were
the result of a spiritual crisis that could be cured through
prayer alone. If the Neumanns had sought medical care in
addition to spiritual treatment, nurses would have been
obligated to uphold these principles while caring for Kara.

Closing
Pediatric nurses are natural advocates for children, and
their profession calls upon them to do so (American Nurses Association, 2001).
In caring for children, nurses frequently encounter situations where they must evaluate
whether a particular treatment plan serves the child’s best
interests. While nurses must respect the different value
systems presented by their patients and patients’ families,
they must also weigh the potential for harm against the
potential for benefit when evaluating various treatment
options, including the option of no treatment. It is impor-
tant for nurses to raise considerations of value differences
on behalf of their patients whenever treatment options are
discussed. Nurses should also raise the possibility of insti-
tutional or majority culture bias against certain values,
especially as against a particular culture or religious belief.

Pediatric nurses should carefully consider the implications
of parents’ use of spiritual treatment to the exclusion of
effective medical treatment for children and help to pro-
mote a balanced public policy that advances the physical,
emotional, and spiritual well being of all children.

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