Ethics

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Welcome to this edition of the DNA Reporter, with a focus on ethics. In this issue, you’ll hear the voices of nurses from a variety of practice settings as they consider scenarios of decision-making that they encounter, from both ethical and legal perspectives. With each author’s contribution, I found myself not only more fully informed about the legal precedent for healthcare decisions, but also moved by the challenges that my nurse colleagues face as they advocate for patients and families.

Frequently in my career I’ve presented lectures on the topic of ethics in nursing and each time I prepare by returning to our profession’s source document: the American Nurses Association’s Code of Ethics for Nurses. I’ve come to appreciate how essential this document is to every professional nurse. Much like Robert Fulghum’s well known poem. All I Need to Know I Learned in Kindergarten, nursing’s code of ethics is truly the simplest and most profound statement on the art of nursing. It’s all there—compassion, respect, commitment, advocacy, professionalism, integrity, character, and competence in delivering quality care to individual patients, families, and society. Each day, professional nurses practice within this code, perhaps at times unaware of how often their daily acts of caring for patients is informed by our code of ethics.

Perhaps this issue will inspire each of us to review this seminal nursing document and to find all we need to know to practice as society’s most trusted professionals.

Happy Nurses Week! As we celebrate nursing in May and this year as DNA’s 100 years of supporting nurses, it is hard not to reflect back on where nursing was 100 years ago compared to where it is today. While there have been advances in nurse education, substantial increase in pay, and public respect and trust, there are still trends that have been threaded through the history of nursing and continue today.

In the 1980’s, some of the priorities of the Association were:
- Support measures designed to safeguard and protect the public in areas of health care
- Increase the public’s awareness of the nursing profession
- Actively respond to the interest and needs of nursing
- Enlarge nursing influence in determining health care policy through participation on health care planning

As we move forward with the work of DNA these priorities remain. DNA is currently addressing them through our legislative work with the BPA bill and the Future of Nursing in Delaware task force. Our activities, such as the Medicine Take Back...
events and the Mercury Thermometer Take Back, help to protect the public but also raise awareness about the nursing profession. Your suggestions and participation in supporting these priorities is not only appreciated but is essential to the work of DNA.

DNA is celebrating 100 years on April 18th. This centennial would not be possible without the initiative and support of its members. The partnership between the DNA and its members is vital to keeping the Association strong for the nursing profession in our state. Join your state nurses association today!

**Did you know?**

1932 – The public health movement grew from 3000 nurses in 1912 to over 20,000 in 1932.

1939 – Private duty nurse fee for an 8-hour shift was $5.

1943 – There were 84 nurses from DE in the armed forces.

1957 – The Delaware State Nurses Association was changed to Delaware Nurses Association.
President’s Message

Bonnie Osgood, MSN, RN-BC, NE-BC

Greetings Everyone,

Welcome to the May-June-July 2011 edition of the DNA Reporter.

HAPPY NATIONAL NURSE’S WEEK! National Nurse’s Week is celebrated May 6 through May 12.

National Nurse’s Day is May 6, 2011. The theme for this year’s National Nurse’s Week is: Nurses Trusted to Care. The value and contribution of nursing to our community is evident every day.

Did you know?

• For the 11th year, nurses were judged the most honest and ethical profession, according to a Gallup poll released December 2010. Eight out of 10 Americans judged nurses to have “high” or “very high” ethical standards.
• There are nearly 3.1 million registered nurses in the United States and 2.4 million of them are actively employed.
• The American Nurses Association was founded in 1896.
• The Delaware Nurses Association is celebrating 100 years this year.
• As of 3/6/11, there are nearly 14,500 registered nurses in Delaware, more than 1,100 advanced practice nurses, and 2,900 licensed practical nurses.

Thank you for all that you do. Happy Nurses Week!

The planning committee for the Excellence in Nursing Practice Awards has been busy planning this year’s event. Please nominate deserving nurses you feel represent excellence in nursing in Delaware. The Excellence in Nursing Practice Awards Ceremony will be in July, 2011. This event is a recognition and celebration of the excellence you bring to the profession. Nominations are submitted electronically. Nomination forms and detailed information regarding the event are available on the DNA website at www.demnurses.org.

The theme for this edition of the DNA Reporter is Ethics. We are all faced with ethical and moral decisions every day in our practice. We practice as advocates for our patient’s, families, and each other in whatever role or environment we serve.

The ANA’s Code of Ethics (2001) establishes ethical standards of behavior for nurses relevant in all roles and practice settings. It provides guidelines for ethical analysis and the application of nurses’ professional skills and abilities into their everyday practice. There are nine provisions in the Code of Ethics for Nurses. The provisions are listed below. Interpretive statements are also included for each provision and are available on line and are an essential component in the understanding of the contextual meaning of the provisions of the Code. Please take the opportunity to review the full ANA’s Code of Ethics with interpretive statements available for review on line at no cost at www.nursingworld.org. The publication is also available for purchase on the ANA’s website.

I would like to take this opportunity to thank each of you for promoting excellence in the profession of nursing through the everyday application of our Code of Ethics. The challenges in our every day care of patients and families in crisis, pain and suffering are real and need to be acknowledged. Nurses’ consistent dedication to high standards in the promotion of health, education, advocacy in great part contribute to nursing being the most trusted profession. Thank you for all that you do.

Bonnie

Code of Ethics for Nurses

1. The nurse, in all professional relationships, practices with compassion and respect for the inherent dignity, worth, and uniqueness of every individual, unrestricted by considerations of social or economic status, personal attributes, or the nature of health problems.
Kelly Davis Appointed to ANA Reference Committee

Kelly Davis, a two-term DNA Delegate, has been appointed to the ANA Reference Committee for a two-year term. Kelly, a DNA member since 2002, has experience working with and interpreting references and bylaws. Her interest in this area stems from her student nurse days as a member of the Resolutions Committee for the National Student Nurses Association. She also participated on the DNA Bylaws Ad-Hoc Committee and is active on the DNA Legislative Committee.

The ANA Reference Committee receives, reviews and reports on proposals submitted for consideration by the House of Delegates.

Mark Your Calendars!

April 30th—National Medicine Take Back event
May 20th—Mercury Thermometer Exchange
September 23rd—Environmental Conference
October 28th—DNA Fall Conference

Information on these events can be found on the DNA website on the Events Calendar.

www.denurses.org
Resolving Medical Futility Disputes

Donna Casey, Thaddeus Pope

Conflicts over end-of-life treatment are common. One example of such conflict is the medical futility dispute. Typically, in the medical futility dispute the surrogate decision maker wants to continue aggressive treatment for a patient but healthcare providers determine that such treatment is inappropriate. In this article we discuss: (1) the types of medical futility, (2) how medical futility disputes can be prevented, and (3) how such disputes can be resolved.

Two Types of Medical Futility Disputes

There are two types of futility: physiologic futility and futility as understood as a lack of benefit. Physiologic futility refers to something that cannot achieve the intended goal. For example, in the treatment of a common cold, antibiotics would be physiologically futile. The common cold is caused by a virus, and antibiotics are ineffective against viruses. Therefore, antibiotics are futile in the treatment of the common cold. But while physiologic futility offers scientific certainty, it applies to few cases of treatment conflict.

The probability of a treatment's effectiveness is often higher than zero. Therefore, the more relevant type of futility is futility understood as a lack of benefit. There is some chance that the treatment might work to some degree. But, for critically ill patients, the likelihood is often very low. Is the treatment worthwhile? Is it indicated? Answering such questions requires a value laden, benefits vs. burdens judgment.

One more precise definition of futility identifies medical treatment that:

• has no realistic chance of providing a therapeutic benefit that the patient has the ability to perceive or appreciate, such as merely preserving the physiologic functions of a permanently unconscious patient;
• has no realistic chance of returning the patient to a level of health that permits survival without an acute level of care or hospital setting; or
• has no realistic chance of meeting the patient's own goals as evidenced by an advance directive or other clear and convincing evidence.

A Medical Futility Case Study

Clinical examples of medical futility that fit this definition can be found in Intensive Care Units (ICU) across the country. Here is a case in point. AH, 96 years old, is admitted to the medical floor where her health continues to deteriorate. She has been transferred to the intensive care unit where her decision maker refuses to allow a biopsy of the pleural fluid. Providers suspect that the effusion is malignant. AH had refused to have her breast cancer treated 20 years ago when it was first diagnosed, so the decision maker surmised that she would not want to have it treated now. AH had an advance directive that stated: “I want my life to be prolonged as long as possible within the limits of generally accepted health care standards.” Despite the apparent contradiction between refusing to treat the malignancy and wishing all medical interventions to preserve life, other treatments were aggressively pursued.

AH remained a full code after progressing to complete renal failure requiring dialysis. She remained a full code even after progressing to long-term respiratory failure requiring mechanical ventilation including tracheostomy. AH was unresponsive to stimuli except deep pain and having severe generalized weeping edema with ubiquitous skin breakdown. Her cancerous breast had become a macerated open wound. She required artificial nutrition through a PEG tube, however she was unable to absorb the nutrition due to her poor health and suffered malabsorption diarrhea worsening her skin breakdown.

In short, there was no medical intervention that was going to be able to return her to her previous state of health. Medicine was not even able to prevent her imminent death. AH’s decision maker, however, insisted on continued aggressive care, ventilation, dialysis, antibiotics, tube feeds, dressing changes and attempted cardiac resuscitation.

Based on our working definition of futility, one might reasonably conclude that continuing aggressive treatment for AH is futile. No medication or treatment has any realistic chance of providing a therapeutic benefit that AH has the ability to perceive or appreciate, based on her vegetative neurologic condition. Medicine was indeed merely preserving the physiologic functions of an unconscious patient. Additionally, there was no realistic chance of returning AH to a level of health that would permit survival without an acute level of care (in her case, critical care).

One may wonder, however, if continued aggressive care would meet the patient’s own goals as evidenced by her advance directive. Even if it truly were AH's intent to continue futile care, is it appropriate to utilize extraordinarily expensive resources when no benefit can be realized? What can the bedside nurse who is dealing with an unreasonable family member do to advocate for her patient, whom she believes is suffering with every nursing intervention; turning, suctioning, dressing changes etc?

Resolving Futility Disputes through Consensus Building

Once on this road, it is indeed a very difficult journey. Like elsewhere in healthcare, prevention is the best alternative. We suggest utilizing the following strategies to prevent and/or informally resolve conflict with families and decision makers.

1. Develop Goals of Care. Collaborate with patients and families to develop goals of care upon admission. Once established, the patient and family should be kept abreast as to the progress towards these goals. When it is determined that patient will not be able to return to health or previous level of functioning, new goals of care should be developed in collaboration with the patient and family. Have one consistent professional be the primary communicator with the family. Teaching institutions with many residents and consultants contribute to conflicting messages and mistrust. When goals of care are agreed upon and it is clinically appropriate to do so, medically non-beneficial treatment may be limited or withdrawn.

2. Bring the Team Together to Communicate a Cohesive Message. If goals of care cannot be agreed upon, conduct an interdisciplinary meeting. Include: (1) key members of the health care team (medicine, nursing, respiratory therapy, other therapies as involved, nutrition, social work, etc.) (2) consulting physicians, (3) patient and/or decision maker, and (5) other family members and support persons as requested by the family. The purpose of the meeting is to facilitate open and productive communication so that all involved clearly understand the same information. The conference should be patient-centered and should cover the following:

• A discussion of patient and family values and goals, medical status and prognosis, treatment options, the goals of medical care and the definition and implications of CPR and a DNR order.
• A consultation to the Palliative Care Team may be helpful in managing these situations and should be considered.
• A second medical opinion may also be helpful. Sometimes, conflict is related to personality or misinformation. Transfer to another physician or health care facility may be appropriate.
• If the second physician concurs that the requested treatment is medically non-beneficial, that opinion should be communicated to the decision maker.

3. Consult the Ethics Committee. If the patient and/or decision maker continues to request...
resolving medical futility disputes continued from page 5

non-beneficial treatment and conflict persists, then consult the ethics committee. In an advisory capacity, the Ethics Committee should make every reasonable effort to hear all sides of the conflict, identify ethically acceptable options, and facilitate resolution of the conflict. When possible, it is preferable that the attending physician who participates in the ethics consultation should remain the attending of record until the conflict is resolved.

Resolving Futility Disputes through Unilateral Action

Fortunately, the vast majority of medical futility disputes are resolved through these measures. Providers and families almost always reach consensus. Still, in a small but significant subset of cases, conflict remains intractable. When these preventive efforts fail, an organization must assess whether it is willing to endure the possibility of legal action.

The 1996 Delaware Health Care Decisions Act (HCDA) provides that life-sustaining medical treatment may be withheld or withdrawn from incapacitated patients only with the consent of an authorized decision maker, except in three circumstances, when treatment is: (1) "medically ineffective," (2) "contrary to generally accepted health-care standards," and/or (2) contrary to the provider’s "conscience." But the statute defines these terms in such a narrow way that these exceptions do not apply to most futility disputes. Furthermore, even when these exceptions do apply, the statute requires providers to continue complying with treatment decisions unless or until the patient is transferred to another provider or facility. Since such transfers are almost never found, the statute effectively requires providers to comply with surrogate requests for aggressive curative treatment that they consider non-beneficial, burdensome, and even cruel.

Many providers feel that the HCDA does not sufficiently empower them to resist inappropriate treatment demands. Indeed, providers often feel as though they are torturing the patient. Still, they usually comply with surrogate decisions for such treatment due to fear of litigation. In short, the "decline to comply" provisions in HCDA do not provide an adequate mechanism for resolving intractable medical futility disputes.

Still, a separate HCDA provision is of some use. When a surrogate makes a treatment decision that clearly contradicts what the patient would have wanted, the provider need not comply with that decision. The HCDA provides that a surrogate must make treatment decisions "in accordance with the patient's individual instructions, if any, and other wishes to the extent known by the surrogate." If the surrogate is unable to determine what the patient would have done or intended under the circumstances, then the surrogate’s decision must "be made in the best interest of the patient." In other words, surrogates must make decisions that reflect the patient’s values, preferences, or best interests. Otherwise, they act outside the scope of their authority. Surrogates who are not faithful agents can and should be replaced.

While effective and functional in some cases, surrogate replacement is hardly a complete solution to medical futility disputes. Most patients have not completed any advance care planning. Of the roughly 35% of Delawareans who have completed advance directives, those directives are usually unavailable when needed. And even when available, those directives usually fail to speak clearly to the patient’s current clinical circumstances. In short, there is often no evidence of patient preferences. Consequently, it is impossible to demonstrate any contradiction between those preferences and surrogate decisions. While we know, statistically, that few would want to live in an extremely compromised condition, particularly if cognitively unaware, providers often do not know what any particular patient is willing to live with. In such cases, there are rarely grounds to replace a surrogate requesting treatment that providers determine is inappropriate.

Providers need to be able to "stand up" for their patients. The tough work is designing a dispute resolution mechanism that can act with the real-time speed these cases demand, yet include sufficient safeguards to ensure due process protections like neutral and unbiased adjudication.

References


The member’s only section is now active on the DNA website! To log in for the first time, click on ‘Forgot Password’ in the upper right hand corner and follow the prompts. You must click on ‘Forgot Password’ in the upper right section is now active on the DNA website! To log in for the first time, click on ‘Forgot Password’ in the upper right hand corner and follow the prompts. You must click on ‘Forgot Password’ in the upper right hand corner and follow the prompts. You must click on ‘Forgot Password’ in the upper right Click on ‘Forgot Password’ in the upper right hand corner and follow the prompts. You must click on ‘Forgot Password’ in the upper right hand corner and follow the prompts. You must click on ‘Forgot Password’ in the upper right hand corner and follow the prompts. You must click on ‘Forgot Password’ in the upper right hand corner and follow the prompts. You must click on ‘Forgot Password’ in the upper right hand corner and follow the prompts. You must click on ‘Forgot Password’ in the upper right hand corner and follow the prompts. You must click on ‘Forgot Password’ in the upper right hand corner and follow the prompts. You must
Hospice nurses often face ethical issues during their case management careers. The most obvious which come to mind are related to curtailing aggressive treatments, nutritional supplements, and parental feedings. However, experienced nurses often find that complying with family wishes, providing care to dying patients, and following federal guidelines often presents ethical issues. Addressing these issues may be challenging but relying on the support and counsel of the hospice social worker has improved my approach to difficult family situations.

One of the most common and oftentimes most difficult ethical dilemmas encountered is related to the “H word”. After receiving a referral from a doctor (oncologist, primary, cardiac, etc.), the nurse arrives at the patient’s home armed with information detailing the benefits of hospice care and the desire to help yet another patient and family. He/she is often greeted at the door with the comforting words “don’t mention hospice”, “Dad doesn’t know he is dying”, “If you say you are from hospice, Mom will give up hope,” The dilemma is clear. Upon entering the home, a nurse quickly assesses that this 70 year old patient with metastatic cancer is clearly uncomfortable, chair bound and in need of extensive comfort interventions. Several family members may be present and they are all looking for palliation for their loved one. The nurse (or in some instances supportive team member) must quickly determine the best way to explain hospice services, which are noticeably needed, while attempting to comply with the family’s wishes.

All hospice personnel must follow strict guidelines called “Conditions of Participation” which clearly outline the ruling that the patient must be involved in the informed consent. It is further stipulated that if a person is alert and oriented he/she must sign this informed consent or assign someone to sign if physical condition prohibits completing the task. A detailed explanation must accompany this alternate signature. Prior to being introduced to the patient, the nurse may explain to the primary caregiver that if the patient asks directly if she/he represents hospice or if they are dying a truthful answer must be given. It is vitally important that hospice personnel recognize and are sensitive to cultures, family dynamics, anxiety and fear during the assessment process. However, a detailed explanation of services may be given without overemphasizing the dreaded “hospice” word. The admissions nurse may start by chatting with the patient and the group about what has been going on over the past few weeks related to the patient’s physical condition. Then while explaining the services, open ended questions such as “have you thought about further hospitalization?” “do you have a living will?”, etc. are woven into the conversation and generally a comfort level is reached.

A common situation may occur where a family requests that we do not mention hospice to their dying loved one. The patient is alert and oriented to self and family members, but extremely lethargic. The initialadmissions informational includes a thorough discussion of no hospitalizations, do not resuscitate. Although the patient is extremely fatigued, he clearly understands that he will be cared for in the home setting and there will be no aggressive treatment or hospitalizations. The patient requests that his wife sign the paperwork. During the admissions process the extended family requests that staff members not introduce themselves as being from hospice. Often within hours of admission to hospice services, an innate extended family member calls into the office complaining that the nurse arrived at the home with a hospice designated bag and a name tag. It is clear that the family is most afraid of the dying process and issues related to end of life. While complying with the family’s initial wishes not to explicitly or continually mention hospice, the request not to wear identification, etc may be viewed as overly hiding the hospice identity. The hospice team should be involved in ongoing discussions with the family in order to achieve a comfort level and understanding of all aspects of end of life care. The struggle between autonomy, family values and achieving desired comfort levels remains a continuing process.

Another common ethical issue involves working with an active participant in patient care (sometimes a relative) who is not in total agreement with the hospice plan of care. Although the patient has consented to hospice comfort measures, the hospice team may be confronted by a caregiver who refuses to follow the pain and symptom management regimen. This caregiver wants the patient to be alert, awake and able to interact. Yet, the case manager encounters a patient with significant signs and symptoms of pain. The patient may have an elevated heart rate, grimacing and moaning upon movement. Although oriented, the patient may close his/her eyes when asked “are you in pain”, allowing the caregiver to answer. This family member may be the primary caregiver during the day and continues to discourage the use of pain medications. The caregiver may openly voice opposition to the hospice plan of care and the initial decision of patient and immediate family in electing hospice. Although the hospice interdisciplinary team attempts to treat the patient/family as a unit, it may be best to request that the caregiver leave the room while a member of the team is assessing and visiting with the patient. The team must effectively treat the patient’s symptoms while recognizing a strong family bond. Again, the most utilized approach is a family meeting to review the contractual understanding between the patient, family and hospice. As a hospice nurse I have been fortunate enough to work with interdisciplinary teams whose social work staff has assisted with family dynamics raising ethical dilemmas. Most importantly, I have been able to learn varied approaches to difficult situations wherein my education was social worker driven.
In many ways adolescence is a period of “in between.” Teenagers may feel they are not quite adults, but no longer children. Parents, healthcare professionals, and other adults may question when to start regarding teens as adults as far as expectations, decision-making, and personal choices. Cultures vary in what is meant by adolescence and the proposed behaviors, variables inherent in the study of ethics. For some ethical dilemmas, morals or laws provide clear guidance with regard to teenagers. In other ethical issues solutions are by no means clear.

For example, adolescents may participate in research. As part of the study of ethics, for some ethical dilemmas, solutions are by no means clear. For example, adolescents may participate in research. As part of the study of ethics, some researchers will believe that the teen brain continues to grow and develop throughout the teen years. Despite the adolescent’s often adult-like physical appearance, proliferation, pruning, and myelination of the teen brain is a “work in progress.” These maturational processes have great bearing on a teen’s abilities to set priorities, practice empathy, organize their thoughts, understand consequences, appraise risks, and engage in behaviors. The maturing of the executive portion of the brain or the prefrontal cortex, also known as the “area of sober second thought,” may dictate how society views ethical dilemmas, adults’ conceptualization of the role of the teen, and how society views teens in general and on an individual basis. Teens’ abilities to reason, deliberate multiple factors, and make sound decisions in an ethical conflict are significantly influenced by brain development.

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An adolescent’s abilities to consent to health care, participate in research, access written health information, and other areas confronted within the healthcare environment are largely dictated by state laws or policies and are designed to protect the adolescent. These protections, though, may reflect how society views teens. Many states consider 18 year the age of majority, though four states required 17 and one state required 16. To differentiate age of majority from the age of consent, individuals less than this age are considered minors and are considered to have different legal responsibilities than those of parents, marriage, or graduation from high school. Some states differentiate mature minors, emancipated minors, and stipulations associated with emergency care. Mature minors, according to state law, may be granted more rights than a child but less than an adult. In order to afford youth additional rights, minors may be considered emancipated based on their participation in the military, parenting a child, documented self-sufficiency and living independent of parents, marriage, or graduation from high school. Many states use a legal, court directed process of emancipation known as the Judicial Bypass Mechanism. The state of Delaware does not have a minor or emancipation stipulations or laws so each case must be addressed by the courts on an individual basis.

Consent for health treatment, choices about refusal of treatment, and areas of consent in which parent/guardians and teens differ in opinion may offer confusion or conflict to others. Refusal to participate in research. Adolescent participation in experimental therapies, solicitation of mental health services, and adherence to a plan of care may offer ethical dilemmas with regard to the care of teens. Some practitioners caution that teens may not seek out health care for sensitive or private health issues due to the need to solicit parental consent for treatment. All states allow for adolescents to consent for routine treatments without parental consent but the limitations and specific of these policies vary from state to state. These policies may reflect local beliefs regarding adolescent cognitive development and on adult perceptions of the health needs of youth. The confidentiality offered this care may be a factor upon federal and state laws and also dependent upon these states’ laws such as the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule, in addition to other state laws.

Access to information related to prevention education has also been identified as an area of health care that need to gain knowledge related to such high-risk behaviors as drugs, alcohol, sexual health, and other means to attain and maintain health may be compromised if confidential health information is shared. Condom distribution and sexually transmitted disease prevention, and abstinence-only versus comprehensive sexuality education that provide examples of potential areas of discord when providing education to teens.

Research is an important area in which teens are offered a level of protection and nurses may need to provide advocacy for patients. Dependent upon the level of risk associated with the research and the effects of the research, those involved in the research may have an obligation to parents in order to participate in research and must provide parental consent in order to participate in research. In some instances, the reluctance to place children and adolescents at risk has limited the depth of research and findings available. Informed consent is important as adolescents have been found to benefit from greater involvement in the consent process to enhance autonomy and decision-making. The use of age focused permission processes may marginalize teens.

The most debated ethical dilemmas related to youth are the laws, policies, and issues associated with reproductive health. Age of consensual sexual relations, ability to have access to contraceptives, and abortion are an issue with the state laws indicating that adults must report circumstances where it is believed that teens are involved in: child abuse, neglect, dependency, unlawful sexual contact, and threat to harm to self or others. Referral to the media, social marketing, and changes in parenting laws indicate that adults must report circumstances where it is believed that teens are involved in: child abuse, neglect, dependency, unlawful sexual contact, and threat to harm to self or others. Referral to the Delaware laws (10 DELCode Sec. 901; http://delcode.delaware.gov) may provide clarity for these policies.

The nurse is in a pivotal role to protect teens and their rights to autonomy, informed consent, access to care, and personal safety. Ongoing research, discussion, and clarification of federal and state laws, agency policies, and nursing roles are important ways for nurses to advocate for teens. Nurses should ensure that adolescents have a voice in their health and health care, are protected during that care, and are treated as autonomous individuals with the associated rights and responsibilities.

References


Debra Kirsch, MJ, BSN, RN, CCRN, PHRN

Debra Kirsch, MJ, BSN, RN, CCRN, PHRN earned her BSN from Temple University and her Master’s in Science from Widener School of Law (with honors). Deb is certified in pediatric critical care nursing and as a pre-hospital registered nurse. An enthusiastic learner, Deb’s 22 year pediatric nursing career has spanned a very diverse background, including: acute/critical care, emergency transport, cardiac and neonatal intensive care and emergency nursing. Deb is currently working at Nemours/A.I. DuPont Hospital for Children in the pediatric intensive care unit. Deb serves on the hospital based Ethics, Nursing Practice and the Nursing Shared Governance committees. Deb also works independently as a Legal Nurse Consultant. Deb can be reached at: dkirsch@nemours.org or deb.m.kirsch@gmail.com.

Pediatric healthcare providers routinely encounter a multitude of social issues when caring for mentally or physically challenged infants and children. Today, nurses are more accustomed to cultural diversity when caring for these children. However, when parents’ religious beliefs are in conflict with proposed medical intervention, an ethical issue quickly ensues. Often the issue is centered on spiritual healing through prayer in lieu of medical intervention. In some instances, ethics consultants are called upon to educate and/or negotiate with parents on the potential outcomes to refusing necessary medical care. In some instances, an Ethics consult may resolve the differences between healthcare provider and parent. In others, the courts are called in to determine the best interests of the child.

The U.S. Constitution’s Free Exercise Clause of the First Amendment guarantees all Americans the freedom to practice one’s religion without government interference (U.S. Const., amend. 1). The Fourteenth Amendment guarantees parents the fundamental right to make health care decisions regarding their children (Meyer v. Nebraska, 262 U.S. 390, 399 (1923)). Inevitably, there are circumstances where these two rights are in conflict with each other, where a child, in need of medical treatment will be denied medical intervention based on parental autonomy to raise their children, while being guided by their spiritual beliefs. This article will bring into the legal consciousness of the rights to autonomy, in raising a child in need of medical treatment, under the auspices of their religious faith and the state’s interest in protecting that child and the public from harm. Ordinarily, this is legally accomplished by appointment of a special guardian or a guardian ad litem, a court-appointed individual to act on the child’s behalf and in his/her best interest, but with special or limited powers (Black’s Law Dictionary, 2005). This issue will continue to be a hot topic area as long as children in need of medical care are caught between their parents’ religious beliefs and/or their own religious beliefs and the state’s compelling interest to protect them and the public.

Many minority religions in the United States oppose all or specific medical treatments. Parents following these religious principles believe their children will be spiritually harmed by medical intervention(s) (Lederman, 1995). Christian Scientists rely on God for healing. Their faith teaches them that illness and disease can be treated through the concentration of faith and prayer, accomplished without the use of drugs, physicians or surgery (Albanese, 1995). Jehovah’s Witnesses oppose blood transfusions, including reinforcement of their own blood after it has been removed from their bodies. The tenet of their religious belief is that it violates their fundamental biblical teachings, their bodies. The tenet of their religious belief is that it violates their fundamental biblical teachings, prohibiting the ingestion of blood (Anderson, 1983). The court may exercise its state power to protect the interests of a child by compelling medical treatment despite parental religious objections, considered to be unrealistic when the child is confronted with a life-threatening injury to life or limb and provided harm to the child can be shown by the refusal of the medical treatment (People v. Pierson, 1903).

In September of 1990, The Delaware Division of Protective Services petitioned the Family Court for temporary custody of Colin, a three year old diagnosed with Burkitt’s lymphoma, an aggressive and terminal form of pediatric cancer. The Family Court was faced with determining the best interests of Colin, despite his Christian Science parents’ belief in spiritual healing through prayer. The parents claimed a violation of their First Amendment right to exercise religious freedom and relying on the Delaware statutes 10 Del. C. § 901(11) & 16 Del. C. § 907 which exempt parents from abuse and neglect who rely solely on spiritual means as treatment for their children’s ailments. The Family Court rejected both arguments and awarded DCPS custody of Colin. The trial court, however, issue proposing to granting the parents the ability to file an immediate appeal to the Supreme Court of Delaware.

The Delaware Supreme Court considering the statutes, recognized the spiritual treatment exemptions may be a violation of the First Amendment ban against the government establishment of an official State religion in the language chosen, “practices of a recognized church or religious denomination by a duly accredited practitioner thereof” were intended to benefit one religion over another, particularly, Christian Scientists (Newmark v. Williams/DCPS, 1993). This in turn violates the Lemon test of government “excessive entanglement” (Lemon v. Kurtzman, 1971). The court opted to leave this question unanswered for a future date, but found that the religious world “balancing test” to be: the effectiveness of the proposed treatment (Newmark v. Williams/DCPS, 1993).

The Delaware Supreme Court determined the “balancing test” to be: the effectiveness of proposed chemotherapy treatment, Colin’s chance of survival with or without medical treatment and the effect the aggressive chemotherapy regimen would have on Colin, should the treatment be administered. Ultimately, the court held that the state’s interest in protecting the child did not outweigh the parents’ authority to make medical decisions, in the best interest of their child. The state did not meet the burden of a compelling interest in demanding medical treatment over parental objections, considering Colin’s treatment would be highly invasive and risky, possibly leading to his death with a low chance of attaining a successful cure. The court held that Colin’s best interests would better be served by remaining in the care of his loving and nurturing parents, who were free to reject the treatment proposed by the medical staff involved (Newmark v. Williams/DCPS, 1993). Nurses have a duty to preserve self-integrity. Ethical issues such as the one raised may invoke feelings that violate the nurse’s moral code. Consistent objections are appropriate, in so far as the objection is not related to personal preference, prejudice, convenience, or arbitrariness. In order to prevent the potential for patient abandonment, the nurse is bound to ensure patient safety and in doing so is obligated to provide adequate notice of his/her objection, so that the necessary measures may be taken to provide the appropriate level of care for the child (American Nurses Association, 2001).

The controversy surrounding court ordered medical intervention for an ailing child over the religious objections of the parents is a complicated matrix of fundamental rights to religious freedom, authority of parents to make decisions regarding the rearing of their children and the state’s compelling interest in the protection, health and well-being of the child involved. A careful balancing act is imperative to ensure fundamental rights are not violated, while determining the appropriate course of action in the child’s best interest. When appropriate, courts will consider the child’s input on the matter, but only if the child is mature and intelligent enough to comprehend the benefits and risks of the involved treatment. There are no easy answers to the dilemma facing the courts when deciding to accept or reject parental religious objections to necessary medical treatment. Until more neutral laws are enacted, the risk of spiritual treatment being imposed on parents from a different faith only seem to muddy already murky waters.

References
Ethics is described as a set of moral principles and judgments to guide human conduct. Ethics involves values, standards, sense of rightness/wrongness, consideration, and debate. Nursing and related disciplines encounter situations that mandate, require, indicate, and suggest the use of those principles. Thus, nurses must seek resources to guide their ethical thoughts and deliberations and actions. This column contains examples of professional organizations, publications, practice settings, case studies, and evidence-based practice resources.

**ORGANIZATIONS**

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**JOURNALS**

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**PRACTICE SETTINGS** – Search by inserting the name of your practice setting into this phrase: "ethics in ______ nursing" [for example, ethics in oncology nursing]. Other settings might be: pediatric, maternal child, rehab, emergency, perioperative, long term care, home health, medical surgical, cardiovascular, public health, school, executive, nursing education, informatics, occupational, research, forensic, etc.

**CASE STUDIES** – Fry, Veatch, & Taylor (2011); Pasci (2008); Yoo, Moorhouse, Khan, & Rodney (2010); Camden (2009); Butts & Rich (2008); Crigger (2011)

**EVIDENCE-BASED PRACTICE** – Philbrick (2009); Snyder & Gauthier (2008); Manson (2008); Townsend, Cox, & Yi (2010); Murray & Huchsmann (2009); University of Minnesota Bio-medical Library (2010)

Search National Guidelines Clearinghouse; Cochrane Library, Joanna Briggs
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- Much more!
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- Save 10% on personal accounting fees
- Discounts to personal insurance such as life, disability, job loss
- Email alerts
- Online networking: DNA Facebook page
- Publishing opportunities and discounts
- State leadership opportunities
- Much more!

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