

# Infant and Child Nursing Ethics

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Heaven lies about us in our infancy.

—William Wordsworth, "Intimations of Immortality," 1807

# **OBJECTIVES**



After reading this chapter, the reader should be able to:

- 1. Discuss issues of vulnerability as they relate to the care of infants and children.
- 2. Understand ethical issues regarding the universal vaccination of children and the nurse's role.
- 3. Identify issues of social justice as they apply to infants and children.
- **4.** Evaluate ethical factors regarding refusing treatment for infants and children.
- 5. Discuss landmark cases in the ethical and legal care of infants and children.
- **6.** Understand the nurse's role as an advocate in the care of infants and children.

# **Mothering**

In the book *Ethics for the New Millennium*, the Dalai Lama (1999) emphasized the importance of the ethic of compassion. Empathy, which is one's "ability to enter into and, to some extent, share others' suffering" (p. 123), represents

compassion (nying je) at a basic level. The Dalai Lama stated that compassion can be developed, going beyond empathy to the extent that it arises without effort and "is unconditional, undifferentiated, and universal in scope" (p. 123). Compassion is a desire to separate another being from suffering. Compassion also is a sense of intimacy toward all feeling and perceiving beings (Dalai Lama, 1999). Persons with this well-developed level of compassion include in the scope of their compassion even those beings that may harm them. According to the Dalai Lama, this profound form of intimacy and compassion can be likened "to the love a mother has for her only child" (p. 123).

All animals are born into an initial condition of vulnerability and dependence. Human infants and children "arrive in the world in a condition of needy helplessness more or less unparalleled in any other animal species" (Nussbaum, 2001, p. 181). Historically, Western ethics generally has ignored human vulnerability and its resultant consequence of creating a need for humans to depend on one another (MacIntyre, 1999). However, some feminist philosophers, such as Virginia Held (1993) and Sara Ruddick (1995), have used the underlying premise of human dependence as the foundation for their views of ethics. In fact, feminist philosophers have proposed that the caring that occurs between a mother and her vulnerable and dependent child can be used as a model for all moral relationships. This model is similar to the model of compassion discussed by the Dalai Lama.

In considering how a feminist approach to ethics is relevant to the care of infants and children, nurses can think in terms of what Tong (1997) called a care-focused feminist ethics approach; this type of approach to ethics supports feminine values, such as "compassion, empathy, sympathy, nurturance, and kindness" (p. 38), that often have been marginalized in male-dominated societies. These values and virtues also are ones that are traditionally associated with good mothering.

There have been heated debates about the differences between the types of moral reasoning engaged in by males and females (see Care-Based Versus Justice-Based Reasoning in Chapter 1). However, Stimpson (1993) noted that "crucially, both women and men can be feminists" (p. viii). In accepting and using the feminine model of social relationships that exist between mothers and children, Stimpson stated "a moral agent, female or male, will be [what Held (1993) called] a 'mothering person" (p. viii).

Held (1993) proposed the concept of "mothering person" as a gender-neutral term used to describe the type of mothering that would occur in a society without male domination. Held stated that there are good reasons to believe that mothering should be a practice performed by both women and men. Ruddick (1995) defined a mother as one who is capable of doing maternal work and

a person who takes on responsibility for children's lives and for whom providing child care is a significant part of her or his working life. [She continued] I am suggesting that, whatever difference might exist between female and male mothers, there is no

reason to believe that one sex rather than the other is more capable of doing maternal work. (pp. 40–41)

When providing ethical care to infants and children, nurses support mothers and mothering persons, both females and males, who share in the unconditional compassion toward their children as described by the Dalai Lama.

# **Foundations of Trust**

A boy bathing in a river was in danger of being drowned. He called out to a passing traveler for help, but instead of holding out a helping hand, the man stood by unconcernedly and scolded the boy for his imprudence. "Oh sir!" cried the youth, "pray help me now and scold me afterwards."

—Aesop, Aesop's Fable

"Children are vulnerable, often frightened small people" (Ruddick, 1995, p. 119). An infant's development of basic trust

versus basic mistrust is the first of Erik Erikson's (1950/1985) eight stages of psychosocial development. According to Ruddick, it is the responsibility of mothers to establish the feeling of trust between themselves and their children, because children's trust ideally is founded on the nurturance and protectiveness of their mothers. Unless there are unusual circumstances, parents are entrusted with the autonomy to make decisions for their minor children. This autonomy is an endorsement of the trust that societies place in parents' ability and desire to provide care that is consistent with the best interests of their children. Although parents generally have autonomy privileges in decision making for their children, children have their own basic dignity as human beings. Kahlil Gibran (1923/2000) described an interesting perspective on the soul, or spirit, of children and parental rights (see Box 5.1).

Because most children depend on their mothering persons to be trustworthy, mothering persons often are wary when they are judging healthcare policies and choosing the people they entrust to meet their children's healthcare needs. Trust becomes an even greater issue when mothering people are not able to choose their children's healthcare providers, as is usually the case with nurses. Justified maternal wariness includes a cautious trust of nurses and other healthcare professionals who interact with and treat one's children. However, it is natural, and often a source of comfort, for parents to believe that healthcare professionals have a more complete grasp of the medical facts and probabilities related to their child's health care than they themselves have in many instances. Consequently, parents depend on and

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- Engage in a debate with your colleagues using the following positions: (1) mothering is an inherently female trait, and (2) mothering is not an inherently female trait.
- ➤ What can nurses do to include fathers in the "mothering" of children?
- ➤ Discuss the Dalai Lama's statement about compassion being similar "to the love a mother has for her only child." Why do you agree or disagree with this statement?



### **BOX 5.1** ETHICAL FORMATIONS: GIBRAN, "ON CHILDREN"

Your children are not your children. They are the sons and daughters of Life's longing for itself. They come through you but not from you, and though they are with you yet they belong not to you. You may give them your love but not your thoughts, for they have their own thoughts. You may house their bodies but not their souls, for their souls dwell in the house of tomorrow, which you cannot visit, not even in your dreams. You may strive to be like them, but seek not to make them like you. For life goes not backward nor tarries with yesterday. You are the bows from which your children as living arrows are sent forth. The archer sees the mark upon the path of the infinite, and He bends you with His might that His arrows may go swift and far. Let your bending in the archer's hand be for gladness; for even as He loves the arrow that flies so He loves also the bow that is stable. (pp. 17–18)

Source: Gibran, K. (2000). The prophet. New York, NY: Alfred A. Knopf. (Original work published 1923)

trust healthcare professionals to support or guide them in making difficult healthcare decisions for their children. Sometimes this trust is similar to the unavoidable trust that was discussed in Chapter 2.

# Universal Vaccination

Because of the grave threat of nonpreventable infectious diseases, people living before and during the early 1900s would have been delighted to have a wide array of available vaccines. However, due to successful public health advances in the 20th and 21st centuries, many people in the United States have not personally encountered some of the diseases that are now vaccine-preventable. Therefore, some people

> take for granted the benefits of available vaccines. According to the National Network for Immunization Information.

most parents today have not seen a child paralyzed by polio, or choking to death from diphtheria, or brain damaged by measles. Fear of vaccine-preventable diseases has diminished while concerns about vaccine safety have increased—even

though a number of the vaccines are even safer than decades ago as a result of medical research. (NNii, 2009, para. 3)

States vary in regard to mandatory childhood vaccination laws, sometimes called "school laws" (Centers for Disease Control [CDC], 2007). Every state allows vaccination exemptions for medical reasons, which are are based on documented medical information received from physicians, usually related to a child's allergy to vaccine components or an immune deficiency. If parents have sincere religious beliefs that are contrary to the acceptance of immunizations for their children, religious exemptions are allowed by all states except Mississippi and West Virginia (Institute for Vaccine Safety Johns Hopkins



# **Ethical Reflections**



With your colleagues, use the Socratic method discussed in Chapter 1 to analyze the concept of nurse-family trust. What factors and behaviors might influence mothering persons' trust of the nurses who care for their children? What factors and behaviors might influence nurses' trust of mothering persons? Discuss the different forms of paternalism (see Chapters 2 and 8) as they relate to the ethical care of children.

Bloomberg School of Public Health, 2011). Twenty states allow personal belief exemptions for parents' religious, philosophical, and other nonmedical objections to vaccines.

When exemptions are obtained, children can attend school without immunizations in most states, although parents or guardians may be judged liable in a civil case if, because of their child's lack of immunization, a vaccine-preventable communicable disease is transmitted to another person. Also, if parents follow the CDC's (2007) recommended guidelines to protect unvaccinated children, these unprotected children may miss months of school, as the CDC recommends that unvaccinated children remain at home during vaccine-preventable disease outbreaks, which may occur in waves spanning a number of weeks.

Some parents who are opposed to a program of universal vaccination seek ways to achieve natural immunity for their children. A popular method that is sometimes used to try to achieve natural immunity for children is having children attend "exposure parties." Groups of well and previously uninfected children are brought together with a child or children who are currently believed to be infectious with a specific vaccine-preventable disease, such as chicken pox, rubella, or measles (NNii, 2004a, 2004b, 2007). These parties are not without risks to children, including the most obvious result of having one's child endure sometimes dangerous and unnecessary illnesses (see Box 5.2).

The American Nurses Association (ANA)'s (2011) 1997 position statement about childhood immunization is still current:

The ANA recognizes the importance of immunizations to the health of individual children and the community as a whole, and of the pivotal roel [sic] nursing plays in assuring immunizations. The fulfillment of the immunization goal is a major undertaking that cannot be realized without the full endorsement of all professional nurses. For that reason, ANA will strive to attain the highest rate of immunization coverage in order to insure maximum protection overall for the general population. (ANA, 2011, para. 2)

In 2011, the ANA released a public service announcement (PSA) about nurses' roles in promoting immunizations. The theme for the campaign was nurses' power to protect people and to bring immunity to every community, which is a theme that is consistent with the role of nurses as trusted patient advocates. Box 5.3 contains nonconfrontational suggestions for healthcare professionals to use if parents resist immunizations for their children.

# **Children Underserved by Healthcare Systems**

Children are particularly vulnerable people because they must depend on others for their life-sustaining needs, including their health and well-being. Childhood vulnerability is heightened for some children because of conditions such as poverty and unfavorable social or family situations. Evidence suggests that healthcare professionals often do not adequately meet the nonmedical needs of vulnerable children

# BOX 5.2 ETHICAL FORMATIONS: RISKS OF MEASLES VERSUS RISKS OF THE MEASLES VACCINE

## **Risks of Measles**

Measles is a serious disease caused by a highly contagious virus that spreads when people touch or breathe in infectious droplets passed by coughing and sneezing.

Measles begins with fever, followed by cough, runny nose, and conjunctivitis ("pink eye").

Infection of the middle ear, pneumonia, croup, and diarrhea are common complications.

Measles encephalitis (an infection of the brain) occurs in 1 per 1,000 cases of natural measles, frequently resulting in permanent brain damage in survivors.

Approximately 5% of children (5 out of 100) with measles will develop pneumonia.

Of every 1,000 children who get measles in the United States, 1 to 2 die from the disease.

Death is more common in infants, in malnourished children, and among immunocompromised persons, including those with leukemia and HIV infection.

# Risks of the Vaccine

MMR is an attenuated (weakened) live virus vaccine. It prevents measles, mumps, and rubella. Nearly all (over 80%) children who get the MMR vaccine will have no side effects.

Most children who have a side effect will have only a mild reaction, such as soreness, redness, or swelling where the shot was given; mild rash; mild to moderate fever; swelling of the lymph glands; and temporary pain, stiffness, or swelling in the joints.

In about 5 to 15% of children given MMR, a fever in excess of 103°F may occur—usually beginning about 7 to 12 days after they receive the vaccine.

About 15% of women who receive MMR will develop acute arthritis or swelling of the joints. This condition is usually very short lived.

In rare cases (about 3 children out of 10,000 given MMR, or 0.03% of recipients), a moderate reaction such as seizure related to high fever may occur.

In rare cases (about 1 child out of 30,000 given MMR), a child may develop temporary low platelet count, which can cause bleeding.

In extremely rare cases (less than 1 child out of 1,000,000 given MMR), children have a serious reaction, such as lowered consciousness, coma, or hypersensitivity (anaphylaxis)—swelling inside the mouth, difficulty breathing, low blood pressure, and rarely, shock.

Source: National Network for Immunization Information. (2004a). Measles parties. Retrieved from http://www.immunizationinfo.org/issues/exposure-parties/measles-parties

(Barreto, Perez, & Halfon, 2007). Providers fail to inquire about family conditions such as homelessness, social problems, substance abuse, and poverty because they are unsure about resources that are available or believe that they have no way to help families solve these problematic issues. By failing to provide interventions to improve serious nonmedical problems during childhood, healthcare providers unintentionally may compound these problems, such as contributing to an increased risk of developmental delays, substance and physical abuse, and emotional disorders among children and their families.

### **BOX 5.3** ETHICAL FORMATIONS: OVERCOMING VACCINATION RESISTANCE

Ascertain exactly what is bothering the parent about vaccinations.

Clearly state your recommendation and rationale.

Voice your respect for the parent's views.

Develop a mutually acceptable plan.

If possible, administer vaccines that protect against the diseases for which the child is most at risk, based on the child's age and immunization history, and the prevalence of the disease in your community.

Be sure to repeat your recommendations when you subsequently see the child and parent; parents may reconsider their decisions.

Source: Adapted from Dias, M., & Marcuse, E. K. (2000, July). When parents resist immunization. Contemporary Pediatrics. Retrieved from http://www.dshs.state.tx.us/immunize/forms/resist.pdf

More than 8 million children in the United States are uninsured (childrensdefense.org, 2011; State Health Access Data Assistance Center [SHADAC] & Urban Institute, 2005), though most of these children are eligible for Medicaid or State Children's Health Insurance Program (SCHIP) services (SHADAC & Urban Center, 2005). Healthcare providers need to screen underserved children who are particularly vulnerable to "the 'double jeopardy' of childhood poverty" (Barreto et al., 2007, p. 174). A two-pronged assessment should be conducted that focuses on "the types and impacts of higher levels of exposure to risk factors as well as assessing available levels of resources and health services (protective and health-promoting factors)" (p. 174) for children affected by poverty. Ethical practice in the nursing care of children includes nurses' willingness to address social problems that often are very difficult to solve, such as immigration, homelessness, and poverty, that continue to have a major impact on the health of children in the United States.

# **Children of Immigrant Families**

The 2010 census revealed that children of immigrants represent one in four people under the age of 18, and that these children "are now the fastest-growing segment of the nation's youth, an indication that both legal and illegal immigrants as well as minority births are lifting the nation's population" (Yen, 2011, para. 3). According to the Center for Health and Health Care in Schools (2005), "the poverty rate of children in

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- ➤ Do you believe that exposure parties are unethical? Defend vour answer.
- Review the ethical theories and approaches in Chapters 1 and 2. Which theories and approaches are particularly relevant to ethics and immunization issues and laws?
- Research some of the reasons that parents refuse immunizations for their children and gather specific information about exposure parties. Imagine that you are a public health nurse working at a county health department. A mother brings her newborn in for a well-baby checkup. The baby's mother tells you that she has heard that exposure parties are a good way to immunize children. How would you respond to the mother's comment?

immigrant families is 21%" (para. 2). Because of welfare law changes in 1996, during their first 5 years in the United States, immigrants are not eligible to receive assistance from the Temporary Assistance to Needy Families (TANF) and Medicaid programs that serve the poor (Borjas, 2011; Center for Health and Health Care in Schools, 2005); however, eligibility for these programs has been opened in some states through state-funded programs. Food stamp access is also restricted among immigrant families.

Children born in the United States to non-U.S. citizen immigrant mothers automatically are granted U.S. citizenship at birth; however, some governmental officials are critics of readily providing healthcare benefits to these so-called anchor babies (babies that provide a reason for noncitizen parents to remain in the United States) (Globe Editorial, 2006). These critics have created federal policies that involve lengthy bureaucratic red tape that often prevents these infants from rapidly receiving Medicaid coverage for health care. Although these children are "known to" the Medicaid program because the program pays the hospital bills generated from their births, the government requires additional paperwork for continued Medicaid coverage. This additional paperwork often frightens parents who fear deportation.

Consequently, many of these so-called anchor babies, who are U.S. citizens and thus eligible for healthcare programs, do not receive immunizations and other primary and secondary preventive services. Ironically, creating barriers to early health care for these children often causes more taxpayer expense because money subsequently must be spent to treat preventable diseases. The American Academy of Pediatrics (1997) proposed 10 recommendations for pediatricians to help children of immigrant families. These recommendations, which also are useful for nurses, are shown in Box 5.4.

# Global Problems of Poverty and Infectious Diseases

Statistical data regarding the unmet needs of infants, children, and adolescents worldwide should concern all compassionate people, but especially nurses. Of special significance is the fact that about two-thirds of the deaths accounted for in these statistics are the result of conditions for which there are low-cost prevention measures or treatment. Data taken directly from the World Health Organization (WHO, 2008) website include the following:

Nearly 10 million children under the age of 5 die each year—more than 1,000 every hour—but most could survive threats and thrive with access to simple, affordable interventions.

The risk of death is highest in the first month of life. Preterm birth, birth asphyxia, and infections cause most newborn deaths.

### BOX 5.4 ETHICAL FORMATIONS: RECOMMENDATIONS FOR CHILDREN OF **IMMIGRANT FAMILIES**

- 1. Oppose denying needed services to any child residing within the borders of the United States.
- 2. Take advantage of educational opportunities and resources to achieve a better understanding of immigrant cultures and the healthcare needs of immigrant children and families.
- 3. Tolerate and respect cultural differences in attitudes and approaches to child-rearing.
- 4. Be aware of the special health problems for which immigrant children are at risk, such as vaccine-preventable diseases, tuberculosis, syphilis, and parasitic diseases; poor nutritional status; delayed growth and development; poor dental health; poor mental health; and school problems.
- 5. Be educated about the unique stresses that immigration may place on children and families and about resources that provide services in the family's language.
- 6. With the approval of the child's parent or legal quardian, recognize and support the extended family in healthcare activities.
- 7. Follow up with continuing health supervision, mental health, and social services for any screening received by immigrants and refugees before they entered the United States.
- 8. Develop linguistically and culturally appropriate services in concert with public health, social services, and school systems in local communities.
- **9.** Define the healthcare needs of immigrant children.
- 10. Support and participate in locally developed, community-based activities that increase access to health care for immigrant children (pp. 155–156).

Source: Adapted from American Academy of Pediatrics Committee on Community Health Services. (1997). Health care for children of immigrant families. Pediatrics, 100, 153-156.

Pneumonia is the prime cause of death in children under 5 years of age. Nearly three-quarters of all cases occur in just 15 countries. Addressing the major risk factors—including malnutrition and indoor air pollution—is essential to preventing pneumonia, as are vaccination and breastfeeding. Antibiotics and oxygen are vital tools for effectively managing the illness. Diarrheal diseases are a leading cause of sickness and death among children in developing countries. Breastfeeding helps prevent diarrhea among young children.

Treatment for sick children with Oral Rehydration Salts (ORS), combined with zinc supplements, is safe, cost-effective, and saves lives.

One African child dies every 30 seconds from malaria. Insecticide-treated nets prevent transmission and increase child survival.

Over 90% of children with HIV are infected through mother-to-child transmission, which can be prevented with antiretrovirals, as well as safer delivery and feeding practices.

About 20 million children under 5 worldwide are severely malnourished, which leaves them more vulnerable to illness and early death.





# **Ethical Reflections**

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What is social justice? (see Chapters 1 and 11) Consider the problems of global poverty and infectious diseases as they affect children and relate them to social justice. What can nurses do to improve social justice for the world's population of children? Do you believe that many members of the world population avert their eyes from the healthcare plight of innocent children? Support your answer. Review critical theory in Chapter 1. Read additional literature, as needed. How can critical theory be applied to the worldwide healthcare disparities involving children? What other ethical theories and approaches discussed in Chapters 1 and 2 apply to the worldwide disparities in health care for children? Explain.

# **Abused Children**

Child abuse, which includes physical, sexual, and emotional abuse, as well as neglect, is a form of family violence (Ramsey, 2006). Family violence is an "action by a family member with the intent to cause harm to or control another family member" (Allender & Spradley, 2005, p. 908). The most common form of child abuse falls under the category of neglect (Ramsey, 2006). Although all states have mandatory child abuse reporting laws, it is believed that abuse is significantly underreported.

The ethical responsibility of nurses in the care of children includes the responsibility to be alert to the signs of abuse and to report abuse appropriately. Nurses, along with all other healthcare professionals, are considered mandatory reporters of possible abuse (Ramsey, 2006). Situations that signal possible abuse include:

- Conflict between the explanation of how an incident occurred and the physical findings, such as poorly explained bruises or fractures
- Age-inappropriate behaviors or behaviors that signify poor social adjustment, such as "aggressive behavior, social withdrawal, depression, lying, stealing, thumb sucking" (Ramsey, 2006, p. 59), and risk-taking (sexual promiscuity, reckless driving, etc.)
- Alcohol and other drug abuse
- Problems in school
- Suicidal ideation

The usual responsibility of handling a patient's treatment confidentially is waived in the instance of suspected child abuse, even when the person reporting the abuse is the patient (Ramsey, 2006). Abuse does not need to be confirmed as factual in order to be reportable. The identification of suspected abuse should be promptly reported to the agency designated by each state. There is legal protection in most states for professionals, including nurses, who are reporting suspected abuse in good faith, though healthcare professionals may be exposed to legal sanctions if they fail to report suspected abuse to the appropriate agencies.

# **Surrogate Decision Making**

Children are legally incompetent individuals who, in most cases, must have surrogate decision makers for important life decisions, including healthcare decisions. Ethicists have established standards that are accepted as being ethically appropriate

for guiding healthcare decisions made on behalf of infants and children. The most commonly accepted ethical standard that underlies surrogate decision making for children is based on a standard of best interest. When using the best interest standard, surrogate decision makers base their decisions on what they believe will provide the most benefits and the least burdens for the child. The best interest standard is a quality-of-life assessment, and when using it a surrogate decision maker must determine the highest net benefit among the available options, assigning different weights to interest the patient has in each option and discounting or subtracting inherent risks or costs. The best interest standard protects another's well-being by requiring surrogates to assess the risks and benefits of various treatments and alternatives to treatment, making it inescapably a quality-of-life criterion (Beauchamp & Childress, 2009, p. 138).

The standard of best interest is similar to the standard of substituted judgment, but the two standards are distinctly different. The aim of the standard of substituted judgment is for a surrogate to make decisions that abide by the previously known (either verbalized or inferred) treatment preferences that persons had when they were able to express those preferences (i.e., when they were competent) at a time when persons are no longer able to express treatment preferences (i.e., when they are no longer competent). Thus, some ethicists argue that only a standard of best interest is appropriate when decisions are made for children because decisions are being made for persons who have never been legally competent; consequently, there is no history of known preferences from children based on their competent thinking.

In using the best interest standard, parents must sacrifice their personal goals for their child in favor of the child's needs and interests. Parents are put in a difficult situation when they must be uncompromising in trying to attend to one child's best interest when it may conflict with the best interest of another child or children within the same family (Ross, 1998).

# Refusal of Treatment

Parents sometimes refuse treatment for their children, and children themselves may, in some cases, be deemed to have decisional capacity to refuse treatment based on religious beliefs or other reasons. In general, religious and cultural beliefs are given respect in healthcare matters and are protected through liberties granted by the U.S. Constitution (Jonsen, Siegler, & Winslade, 2006, 2010). Serious consideration must be given to the wishes of maturing children who are judged to have good insight about the benefits and burdens of their healthcare treatment. The following factors should be taken into consideration and carefully weighed when evaluating the extent of autonomy to be granted to minor children in refusing health care, keeping in mind, however, that efforts need to be made not to undermine the relationship between children and their mothering person(s) (Jonsen et al., 2006):

The support for the child's request by the child's mothering person(s)

The severity of the child's condition, such as a child with a terminal and irreversible condition who refuses additional painful treatment versus a situation, such as meningitis, in which the child's condition is acute and reversible The consequence of direct harm to the child that potentially could result from the child's decision and the child's realistic understanding of the possible consequences

Fear, distress, or parental pressure as a motivation for the child's decision

Parental autonomy with regard to a child's healthcare treatment is usually given wide latitude (Jonsen et al., 2006, 2010; Ross, 1998); however, some parental refusals are considered to be abusive or neglectful. State laws protect children from parental healthcare decisions based on religious or other beliefs that can result in serious risk or harm to the child (Jonsen et al., 2006). Nevertheless, many states do not prosecute parents for abuse or neglect if they try to refuse treatment based on religious beliefs. In general, the following principles are followed in overriding parental autonomy in the treatment of children:

The parent or parents are not given the right of parental autonomy if they are deemed to be incapacitated or incompetent because of factors such as substance abuse, certain psychiatric disorders, minimal ability to comprehend the best interest of the child, or habitual physical abuse.

As is done when considering respect for the autonomy of a child, the severity of the child's condition and the direct harm to the child that could result from nontreatment should be evaluated. The child should be treated even against the wishes of the parents to prevent or cure serious disease or disability.

Blood transfusions should be given to a child of a Jehovah's Witness when transfusions are needed to protect the child from the serious complications of disease or injury. Court authority need not be sought in an emergency situation, as legal precedent protects the safety of the child (see Box 5.5).

When analyzing the ethical path to take in regard to refusals of treatment for children, consultation may need to be sought from mental health practitioners or an ethics committee.

# Impaired and Critically III Children

When neonatal intensive care units (NICUs) were developed in the 1960s, the goal was to increase the likelihood that premature babies would survive. Many medical and technological advances followed, and researchers are still making strides in neonatology today. NICUs are often complicated and scary places for parents who are grappling with the trauma of having a severely impaired or terminally ill neonate. Parents frequently must make life-and-death decisions about their infants

### **BOX 5.5** ETHICAL FORMATIONS: PROTECTION OF VULNERABLE CHILDREN

In the words of a Supreme Court decision about the authority of a Jehovah's Witness parent, "Parents may be free to become martyrs themselves, but it does not follow that they are free . . . to make martyrs of their children" (Prince v. Massachusetts, 1944).

Source: Jonsen, A. R., Siegler, M., & Winslade, W. J. (2006). Clinical ethics: A practical approach to ethical decisions in clinical medicine (6th ed.). New York, NY: McGraw-Hill, p. 98.

within a context that would be highly stressful even in the best of circumstances. NICUs are often emotionally charged places for nurses, too, as they watch the miracles of life play out before them while they also share in the experience of a family's deepest suffering.

# Quality of Life

In considering quality-of-life determinations for newborns and children, it is important to refer back to the ethical foundation involved with surrogate decision making for children that is, the standard of best interest. There are at least two differences between how quality-of-life decisions are judged for infants and children as opposed to how they are judged for adults (Jonsen et al., 2010). Adults are either able to verbalize preferences that reflect their personal evaluations about the quality of their lives or other people have a general idea of those preferences when an adult becomes incapacitated. In contrast, "[i]n pediatrics, the life whose quality is being assessed is almost entirely in the future, and no expression of preferences is available" (Jonsen et al., p. 158).

Healthcare professionals must be aware of any tendencies they may have to judge the quality of life of pediatric patients as lower than the children, to the best of their ability, or their mothering person(s) would judge it. Nurses are not in a position to make major, ethics-laden treatment decisions in the care of infants and children; even advanced-practice nurses, such as nurse practitioners who work in NICUs, work in collaboration with other healthcare professionals. However, all nurses who work with children are potentially very influential in the healthcare decisions made by parents and other healthcare providers. Practical wisdom, in the tradition of Socrates, Plato, and Aristotle, and the good character of nurses are essential elements in the compassionate care of children.

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- ➤ Identify specific issues of social justice related to the hightechnology health care provided to premature infants. For example, should healthcare professionals consider "How small is too small?" when planning and providing care for a fetus or neonate?
- ➤ What information and approaches can be used to analyze the ethics of decision making about age-based distribution of healthcare resources?
- ➣ How should scarce healthcare resources be used? For technologically advanced intensive care services for the very young? For technologically advanced intensive care services for the very old? For prevention and health promotion? Support your position(s).
- ➤ Who should decide about how scarce healthcare resources should be distributed? Why?





# **Ethical Reflections**

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Discuss criteria and methods that healthcare providers can use to evaluate the motives, requests, and behaviors of mothering persons in regard to making quality-of-life decisions for their seriously impaired children. Use the story of Ashley in Box 5.6 as a case study. Ashley's parents asked physicians to stunt her growth so that her small size would make it easier for them to physically care for her.

Apply ethical theories, approaches, and decision-making models in analyzing this case. Do you agree or disagree with the child receiving hormones to stop her growth? Support your answer.

Another parent-child ethics case that has been widely debated in the media is the case of Terri Schiavo. Research the specific events of this case. Because Terri was an adult rather than a legally incompetent child, compare and contrast relevant

quality-of-life determinations. Evaluate the ethics-related parent-child issues involved with this case. What type of decisionmaking standard were Terri's parents using?

What is the standard that is most accepted by ethicists in a case like Terri's? Why?

# Withholding and Withdrawing Treatment

A comprehensive discussion of end-of-life issues is provided in Chapter 9. This discussion generally can be used as a basis for considering decisions about withholding and withdrawing treatment for children; infants, however, fall into a special class of persons in regard to withholding and withdrawing treatment.

Anyone seriously interested in the study of nursing and healthcare ethics realizes that it is difficult to separate ethics from related laws, governmental regulations, and public policies. In evaluating the ethical care of infants in terms of withholding and withdrawing treatment, it is helpful to understand the history and circumstances involved with several landmark cases. Some of these cases help to summarize and clarify the usual actions that are expected to be taken with regard to the treatment of infants, although conclusions about the ethical directions provided by these cases are by no means without dispute. The following discussion is based on public information about these cases and a history provided by Pence (2004).

# 1971: Johns Hopkins Cases

In the 1970s, two infants with Down syndrome were "allowed to die" at Johns Hopkins Hospital, based on what some people believe were the selfish motives of the parents (Pence, 2004). A third infant with Down syndrome was referred to Johns Hopkins shortly thereafter because of the hospital's reputation for allowing the other two infants to die. However, at this point the hospital staff presented a more balanced view of the infant's prognosis that resulted in a different outcome: the third baby was treated and lived.

# 1984: Child Abuse Prevention and Treatment Act Amendments (Baby Doe Rules)

The 1984 Child Abuse Prevention and Treatment Act Amendments, also referred to as the Baby Doe rules, are based on the case of Infant Doe, who was born in Indiana in 1982. "Baby Doe' cases arise when parents of impaired neonates or physicians charged with the care of these neonates question whether continued treatment is worthwhile and consider forgoing treatment in order to hasten death" (Pence, 2004, p. 216).

Many of the events in the short life of Infant Doe greatly influenced the precedent that has set the direction for the treat-

ment of impaired newborns. Infant Doe was born on April 9, 1982, and died 6 days

### **BOX 5.6** ETHICAL FORMATIONS: "PILLOW ANGEL"

The father's plea was heartfelt and most unusual. Stop the physical growth of my developmentally disabled little girl [with static encephalopathy], he asked a panel of doctors, so that we may be better able to care for her as years go by.

Strapped in a wheelchair, the daughter, a charming dark-haired 6-year-old named Ashley . . . "There's no question this little girl's world is her family," says a doctor who attended that session. "Any concerns were put to rest by watching [the parents and the child]." Which is one reason the medical staff at Seattle's Children's Hospital agreed to the father's 2004 request, deciding that it was ethical to remove Ashley's uterus and breast buds and begin hormone treatments to stop her growth.

Today Ashley is a 9-year-old girl with the mind of a baby, who will never grow into a fully developed woman. Her family . . . initially kept their decision private. But an article published in a medical journal [in October 2006] brought an outcry of public criticism about their choice.... For doctors, stopping Ashley's growth presented two issues: Would the novel treatment improve her life? And would it cause harm?

[As cited by Morehouse, Ashley's parents shared the following statements on their website:]

We call [Ashley] our Pillow Angel since she is so sweet and stays right where we place her—usually on a pillow . . .

Source: Morehouse, M. (2007, January). Girl, interrupted. People, 69-70.

later (Pence, 2004). The controversy surrounding the care of Infant Doe was based on disagreements about whether treatment should be withheld because the infant had Down syndrome and a tracheo-esophageal fistula. The obstetrician who delivered Infant Doe discouraged the parents from seeking surgical correction of the fistula and indicated that the baby might become a "mere blob." Based on the obstetrician's recommendations and their own beliefs, the parents refused care for their infant. Hospital staff and administrators disagreed with this decision and appealed the decision to a county judge. No guardian ad litem was appointed for the baby, and an unrecorded, middle-of-the-night hearing was conducted by the judge at the hospital. The meeting resulted in the judge's support of the parents' decision. The hospital staff appealed the decision unsuccessfully all the way to the Indiana Supreme Court. They were in the process of taking the case to the U.S. Supreme Court when Infant Doe died.

The specific details of what followed these events are interesting but are beyond the scope of this chapter. However, the ultimate outcome was that the media attention given to the Infant Doe case precipitated action by the Reagan administration, specifically the U.S. Justice Department and the U.S. Department of Health and Human Services (DHHS) (Pence, 2004). Baby Doe rules were published by the federal government and became effective on February 12, 1984. The rules were based on Section 504 of the Rehabilitation Act of 1973, which forbids discrimination based entirely on a person's handicaps. The Baby Doe rules provide for a curtailment of federal funds to institutions that violate the regulations.

# **BOX 5.7** ETHICAL FORMATIONS: THE CASE OF INFANT DOE

The U.S. Civil Rights Commission reviewed the Infant Doe case in 1989, along with other Baby Doe cases, and "the commission concluded that [the obstetrician's] evaluation was 'strikingly out of touch with the contemporary evidence on the capabilities of people with Down syndrome."

Source: U.S. Commission on Civil Rights, as cited by Pence, G. (2004). Classic cases in medical ethics. Boston, MA: McGraw-Hill, p. 220.

According to Pence (2004), "this interpretation by the Justice Department created a new conceptual synthesis: imperiled newborns were said to be handicapped citizens who could suffer discrimination against their civil rights" (p. 221; see Box 5.7) It is noteworthy that the federal Second Circuit Court of Appeals issued a ruling within 10 days of the Baby Doe rules that made the new rules essentially unenforceable. This ruling was based on the case of Baby Jane Doe.

# Baby Jane Doe: Kerri-Lynn

Baby Jane Doe, Kerri-Lynn A., was born in 1983 at St. Charles Hospital in Long Island, New York. She was transferred to the NICU at the University Hospital of the State University of New York (SUNY) at Stony Brook because of her complicated condition at birth. Kerri-Lynn was born with spina bifida, hydrocephalus, an impaired kidney, and microcephaly (Pence, 2004). Her parents were lower middle-class people who had been married for only 4 months when Kerri-Lynn was conceived. After Kerri-Lynn was born, there was disagreement among the medical staff and other people about whether she should be treated or provided with comfort measures (food, hydration, and antibiotics) and allowed to die. The parents decided in favor of withholding aggressive treatment.

The controversy resulted in legal proceedings that eventually included the involvement of the Justice Department and the DHHS. Leaders within these agencies wanted to send representatives to review Kerri-Lynn's medical records to ascertain whether the Baby Doe rules were being violated. However, the parents and the hospital objected to allowing the government representatives to review the records. Ultimately, a federal appeals court, and then the U.S. Supreme Court, ruled in favor of the parents and the hospital in the case of *Bowen v. American Hospital Association et al.* in 1986 (Pence, 2004).

This ruling essentially removed the enforcement potential from the Baby Doe rules. The rules cannot be enforced if the government has no authority to review the individual medical records of infants to determine if the rules are being violated. The Supreme Court explained that because the parents do not receive federal funds for the provision of medical care, their decisions are not bound by Section 504 of the Rehabilitation Act (Pence, 2004). Baby Jane Doe's parents later allowed the recommended surgery to be performed (see Box 5.8). The attorney who represented her parents reported in 1998 that Kerri-Lynn was 15 years old and living with her parents.

### **BOX 5.8** ETHICAL FORMATIONS: THE CASE OF KERRI-LYNN

In 1994, B. D. Colen was a lecturer in social medicine at Harvard University. He provided an update on Kerri-Lynn:

Now a 10-year-old . . . Baby Jane Doe is not only a self-aware little girl, who experiences and returns the love of her parents; she also attends a school for developmentally disabled children once again proving that medicine is an art, not a science, and clinical decision making is best left in the clinic, to those who will have to live with the decision being made.

Source: Pence, G. (2004). Classic cases in medical ethics. Boston, MA: McGraw-Hill, p. 226.

Although "in reality [the Baby Doe regulation] does not apply directly to physicians, nurses, or parents, it does get the attention of many" (Carter & Leuthner, 2003, p. 484). The 1984 Child Abuse Prevention and Treatment Act (Baby Doe rules) generally provides three reasons to withhold treatment from newborns; confusion remains, however, about whether the rules are an attempt to mandate nutrition, hydration, and medications for all neonates. This confusion, in addition to the compassion that most people feel toward a dying or severely impaired child, is one reason that healthcare professionals experience moral uncertainty in relation to decisions about withholding and withdrawing treatment from neonates. The 1984 act states:

The term "withholding of medically indicated treatment" does not include the failure to provide treatment (other than appropriate nutrition, hydration, or medication) to an infant when, in the treating physician's . . . reasonable medical judgment:

- 1. the infant is chronically and irreversibly comatose,
- 2. the provision of such treatment would
  - a. merely prolong dying,
  - b. not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or
  - c. otherwise be futile in terms of the survival of the infant, or
- 3. the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane. (U.S. Child Protection and Treatment Act of 1984 as cited by Carter & Leuthner, 2003, p. 484)

According to Carter and Leuthner (2003), the language in these rules that addresses situations in which aggressive treatment of infants is not required can be interpreted to mean two different things with regard to nutrition: "(1) every infant should always be provided with medical means of nutrition [or] (2) every infant should receive nutrition appropriate for his/her medical situation" (p. 484).

Carter and Leuthner proposed that the Baby Doe rules should not be interpreted to restrict or prevent the withdrawal of nutrition. However, interpretations of the

rules with regard to withholding and withdrawing nutrition, hydration, and medications vary among healthcare providers and institutions, and, as mentioned previously, healthcare providers experience moral uncertainty regarding these rules. When situations arise that precipitate discussions about withholding and withdrawing nutrition and hydration from newborns, the involvement of an ethics committee is recommended. It also may be helpful for healthcare professionals serving on an ethics committee to obtain consultation from ethicists who specialize in pediatric care.

# 1993: In the Matter of Baby K.

Although the Baby Doe rules provided a basis for the right of parents to refuse treatment for their severely disabled newborns, the ruling left the unanswered question of whether parents also have the right to insist on treatment for their newborns when medical staff believe the treatment would be futile or useless. The landmark case that provided a precedent for this type of situation involved Baby K., born with an encephaly in 1992. Baby K.'s mother insisted that a hospital provide maximum treatment for her child, including ventilator support. Hospital physicians disagreed with the mother's wishes and proposed that warmth, nutrition, and hydration were all that should be required in Baby K.'s care. The case was taken to the legal system for resolution. In reviewing this case, judges noted that medical assessments indicated that Baby K. was not being subjected to care requested by her mother that would cause the baby pain or suffering. Judges serving on the U.S. Court of Appeals for the Fourth Circuit ruled in favor of the mother and ordered the hospital to provide the level of care that Baby K.'s mother requested (In the Matter of Baby K, 1993).

# The Influence of Nurses: Character

Those who stand for nothing, fall for anything.

—ALEXANDER HAMILTON

The good character or virtuous behavior of nurses, other healthcare professionals, and parents is not the only character that is relevant to the well-being of children. A child's own character development is important, too. School nurses are in a special position to help with this, and any nurse who works with children would do well to keep in mind the importance of influencing the development of a child's good character and educating others about this development. Ryan and Bohlin (1999) suggested that children need to be engaged in "heart, mind, and head" to know "who [they] are" and "what [they] stand for" (pp. xvi-xvii).

The search for the meaning of life overshadows almost all human endeavors in people young and old. In the fast-paced world of the 21st century, parents are busy trying to provide their families with necessities and physical comforts, and children are often busy playing video games and watching television—there is scarcely time

to ponder the greater mysteries of life. Ryan and Bohlin (1999) proposed that "detached from a conception of the purpose of life, virtues become merely nice ideals, empty of meaning" (p. 39). They suggested that adults should not fear stimulating children to ponder the age-old question about why they were born. Many children, but particularly children who are ill, think about the meaning of life even when they do not know how to articulate their feelings. Nurses can provide these children with a kind hand and a warm heart during frightening times.

Almost any time is a good time to take the opportunity to educate children in the development of moral and intellectual virtues; as the old saying goes, "It is never too early." Stenson (1999) proposed that there are three ways to help children internalize virtuous habits and strengths of character when they are on their journey from infancy to adulthood. Those three means of internalization, and the order in which they occur, are:

- 1. By example: Children learn from what they witness in the lives of parents and other adults they respect (and thus unconsciously imitate).
- 2. Through directed practice: Children learn from what they are repeatedly led to do or are made to do by parents and other respected adults.
- 3. From words: Children learn from what they hear from parents and other respected adults as explanations for what they witness and are led to do. (Stenson, 1999, p. 207)

# www Ethical Reflections



- ➤ Box 5.9 contains examples from the ANA's (2001) Code of Ethics for Nurses with Interpretive Statements. How are these examples relevant to nursing ethics in the care of infants and children?
- What other provisions and statements in the ANA's Code of Ethics for Nurses are particularly pertinent to the nursing care of infants and children? (See Appendix A) Discuss these provisions and provide examples of how they apply to nursing practice.

### **BOX 5.9** ETHICAL FORMATIONS: CODE OF ETHICS FOR NURSES

Nursing care is directed toward meeting the comprehensive needs of patients and their families across the continuum of care (1.3, p. 7).

Prior to implementation, all research should be approved by a qualified review board to ensure patient protection and the ethical integrity of the research (3.3, p. 13).

Nurses have the duty to question and, if necessary, to report and to refuse to participate in research they deem morally objectionable (3.3, p. 13).

Nurses are faced with decisions in the context of the increased complexity and changing patterns in the delivery of health care (4.1, p. 16).

The nurse has responsibility to be aware not only of specific health needs of individual patients but also of broader health concerns such as world hunger, environmental pollution, lack of access to health care, violation of human rights, and inequitable distribution of nursing and healthcare resources (8.1, p. 23).

Nurses are patient advocates, but they also are role models. Nurses may never know when the example that they show to children and their mothering person(s) may influence the future of a child or may influence the future of nursing.

# CASE STUDY: TO FEED OR NOT TO FEED?



aby S. is a neonate admitted to the NICU at the county hospital where you work as the nurse manager. Mrs. S. had an amniotic fluid embolus during her delivery, and Baby S. experienced anoxia. Consequently, Baby S. had an Apgar score of 0 at birth. The baby was "successfully" resuscitated but remains unconscious. All of the baby's organs experienced hypoxic insult. Baby S. was placed on a ventilator and parenteral nutrition was later initiated. Mrs. S. is physically very weak and experiencing grief, along with her husband, over the condition of their infant. They have two other young children, ages 2 and 5 years old. Baby S. has been weaned from the ventilator but has remained unresponsive. Mr. and Mrs. S. have requested that the hospital staff discontinue their infant's nutrition and hydration. The NICU medical, nursing, and social work staff have not previously experienced a situation quite like the one that is occurring with the S. family.

# **Case Study Questions**

- 1. You are meeting with the neonatologists, the NICU charge nurse, the infant's primary nurse, the hospital chaplain, and the social worker in the NICU. What do you contribute to the group's discussion with regard to how you believe the staff should proceed in providing the best care for Baby S. and her family?
- 2. How do the Baby Doe rules affect this case?

- **3.** One of the staff RNs comments, "I think the mother and father are being selfish about their request to withdraw nutrition from Baby S. I think it is because they don't want to be bothered with taking care of her at home." How do you address these comments?
- 4. What surrogate decision-making standard should be used in this case? What influence should the interests of Baby S.'s siblings have in decision making in this case?
- 5. Caring for Baby S. and interacting with her family has caused a great deal of emotional and moral suffering for the NICU nursing staff (see Moral Suffering in Chapter 2). What behaviors might you expect to observe among the nursing staff? What do you do as the nurse manager to address this situation?
- **6.** As would be expected, Mr. and Mrs. S. also are experiencing a great deal of moral suffering and grief. How would you handle your personal interactions with Mr. and Mrs. S., and what would you do to help educate your staff in working with families in a situation such as this one? What do you know or what information can you locate about the grief that parents experience when their infant is extremely impaired or dies? How would you try to help Mr. and Mrs. S.?

# **KEY POINTS**

The words *mother* and *mothering person* can be gender neutral.

The best-interest standard is generally the ethical approach used in making difficult decisions about the healthcare treatment of children.

Children and other people may be harmed when children are not immunized. Nurses must understand the best ways to interact with parents who refuse to have their children immunized.

Ethical practice in the nursing care of children needs to include nurses' willingness to address social problems, such as those resulting from immigration, homelessness, and poverty, that often are very difficult to solve. Globally, many children become sick annually and die from preventable diseases and conditions.

Nurses are "mandatory reporters" of child abuse. There is legal protection in most states for nurses who are reporting suspected child abuse in good faith. The ethics of allowing children themselves or their parents to refuse healthcare treatments is based on a number of factors. These factors include the severity of the potential harm to the child that may result from the refusal.

The Child Abuse Amendments of 1984 are frequently referred to as the Baby Doe rules. Although these rules lack power in actual enforcement, they are influential in decisions regarding the withholding and withdrawing of supportive care involving infants.

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