

Anencephaly: Concepts of Personhood, Ethical Questions, and Nursing Care

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Abstract

Anencephaly is a neural tube defect that severely limits the lifespan of affected infants. While these infants have no higher brain function, they are still persons, and should be given the same moral and ethical considerations as healthy infants. With this in mind, organ donation procedures should follow the same guidelines that apply to other donors. Because a large part of nursing care for anencephalic infants is palliative care, nurses need appropriate training to care effectively for both the infant and the family, providing for physical, emotional, psychological, and spiritual needs.

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Review of Pathology and Epidemiology

Anencephaly

Anencephaly is the congenital absence of the cranial vault, either with the cerebral hemispheres completely missing, or reduced to small masses (O'Toole, 2003). This condition is most likely the result of failure of the neural tissue to close completely at the cephalic end of the neural system, which usually occurs between the third and fourth week of pregnancy. The brain stem is intact, but the cerebral cortex is absent. The brain stem controls autonomic functions such as heart rate, respirations, blood pressure, salt and water balance, kidney function, and the function of other organs. The cerebral cortex controls functions such as consciousness, memories, emotions, and purposive actions (Foreman, 1999). Anencephalic infants who are born alive have a rudimentary brain stem, which can support reflex action such as breathing and some response to sound or touch (Cook, Erdman, Hevia, & Dickens, 2008). Around three-fourths of anencephalics are stillborn, and the remainder rarely survive beyond one week of age (Nakano, 1973). The consensus of international medical literature is that diagnosis of anencephaly indicates fetal non-viability, with the child dying within hours or days after birth (Diniz, 2007). However, there have been rare cases of anencephalic children living past the age of one, and one documented case where a female child lived up to the age of four (Foreman, 1999).

Physical Effects

There are numerous anatomical abnormalities that accompany this condition, which affects not just gross appearance, but also the function of the central nervous

system, the pituitary gland, adrenal gland, thyroid gland, kidneys, heart, liver, and spleen. Because the vault of the skull is absent, the eyes protrude and undeveloped brain presents as a mass of exposed tissue. Other associated anomalies that may be present include cyclopia (having only one eye), defects of the abdominal wall and diaphragm, and extra limbs. Central nervous system defects include absence of the cerebellum and absent or hypoplastic internal carotid arteries. The hypothalamus is usually absent, but the pituitary is present. The adrenal glands, and gonads are abnormally small, and the thyroid, kidneys, heart, liver, and spleen all have fewer cells than in unaffected infants (Nakano, 1973).

Epidemiology

Anencephaly typically affects females more than males, though the reason for this is unknown. One hypothesis to explain the greater incidence in females is that more affected male embryos are miscarried early in the pregnancy. The association between anencephaly and birth order can be described as U-shaped, with a high rate in first births, a low rate in second births, and an increasing risk with subsequent birth order thereafter. Anencephaly occurs six times more frequently in Caucasians than African-Americans. Women pregnant with their first child who live in poor social conditions have the greatest risk of having children with anencephaly or other neural tube defects. This is due primarily to poor prenatal care and less favorable nutrition (Nakano, 1973). Other environmental factors that can affect the occurrence of neural tube defects such as anencephaly include maternal diabetes mellitus, maternal obesity, use of anti-epileptic drugs during pregnancy, and hyperthermic situations such as febrile illness or hot tube use (Kondo, Kamihira, & Ozawa, 2009). Whether the cause of anencephaly is primarily

environmental or genetic is not known, though there have been studies alternately supporting both hypotheses (Detrait, et al., 2005). Most research concludes that the causative mechanisms are still poorly understood, and a combination of genetic, nutritional, and environmental factors plays a role (Kondo et al., 2009; McComb, 1997).

Moral and Ethical Questions

The moral and ethical questions surrounding anencephalics relate to their status as persons. Some would argue that these children are born without the capacity to function as persons, and therefore should not be considered persons. There are other questions to consider as well. Should the standard for brain death include neocortical death? If anencephalics are shown to be persons, what level of medical care should they receive? Do anencephalics feel pain? Is it morally acceptable to use anencephalics for organ donation? These are challenging questions, and answering them satisfactorily requires the definition of several terms, most notably personhood (Foreman, 1999).

Personhood

What is personhood? What are the necessary and sufficient qualifications to possess it? For clarification purposes, it must be noted that the terms *human* and *person* are not the same. Human is a biological or genetic concept speaking of a member of the human species as determined by DNA and a particular way of functioning. Human can also be used in the phrase *human being* to denote a combination of human organism and personhood. The term *person* is a nonphysical philosophical concept that cannot be determined solely by scientific study. Not all persons are necessarily human; examples of non-human persons would be God and angels (Foreman, 1999).

Glannon (2002) held the view that persons are essentially human organisms, which begin to exist sometime after conception but before birth, and that persons do not begin to exist until they acquire the capacity for consciousness and mental life, and cease to exist when they permanently lose this capacity. He differentiated between two different views of death: psychological and biological. If individuals are persons, death occurs and existence ceases when individuals irreversibly lose the capacity for consciousness and other forms of mental life. If individuals are human organisms, death occurs and existence ceases when there is total and irreversible loss of the integrated functioning of bodily and brain processes. He personally held the view that the capacity for personhood develops only in the late stages of fetal life when brain structures develop. Anencephalic infants never develop a brain, thus he believed that they are not persons. By similar reasoning, he held that patients whose higher brain functions have been irreversibly damaged due to trauma or disease also fail to qualify as persons.

However, in contrast, Rae (2008) cautioned Christian ethicists to use care when considering any view that distinguishes between biological and biographical life. He said, "Biological life, far from being irrelevant to one's status, actually undergirds the notion of having a life" (p. 136). Consciousness/sentience is necessary to the experience of life, but is not necessary for one to be a person. He made specific mention of the patient in a persistent vegetative state, the anencephalic child, the severely demented, and the temporarily comatose as examples of persons with full rights to life, regardless of their level of cognitive function.

Many modern philosophers have adopted a functionalistic view of personhood, indicating that a person is one who presently functions in a certain way. Lists of

characteristics of personhood include such properties as consciousness of the external world, self-consciousness, self-determination, rational capacities, emotional expressions, willful direction, and communicative and social abilities. The idea behind a list such as this is that a human who does not possess any of these qualities is not a person (Foreman, 1999).

However, there is another way to view these characteristics, not as presently functioning, but as having the potential or capacity to function in this manner. If a person must always possess these characteristics, someone who is asleep, in a coma, or under sedation cannot logically be called a person. They are not conscious of the outside world or themselves, have no ability to make decisions, do not reason or have emotional expression, and do not communicate with anyone. It seems absurd to assert that because one is asleep means he is no longer a person. However, it may be argued that, because a sleeping person has the capacity to wake up and immediately begin functioning as a person, this point does not apply to persons such as those unborn or with fatal neural tube defects such as anencephaly, because they do not have this capacity. The issue with this argument is that the immediate capacity to function as a person can only be present if something even more basic is present (Foreman, 1999). This has been referred to as human nature, the soul, or the *basic inherent capacity*. Schwartz (1990) held the view that all humans, by nature, have this basic inherent capacity, whether or not the immediate capacities are ever actualized. Human beings in such unfortunate states as the severely retarded, those in a coma, or infants with anencephaly are still in possession of latent capacities, which are those capacities which are present, but inaccessible due to temporary or permanent damage, blockage, or underdevelopment. Abnormalities

represent a hindrance to the actualization of the capacity, rather than the absence of the capacity, as in a nonperson.

Bernstein (2002) commented that the same strong moral intuition which says that it is immoral to harm or kill a normal human infant is maintained in the case in which the infant lacks the potential to gain morally relevant characteristics. Regardless of the degree or extent of one's rationality, autonomy, language use, or moral agency, one's species is left intact. Genesis 1:26 says, "And God said: 'Let us make man in our image, in our likeness'" (NIV). The Scripture is clear that a person's status and rights are grounded in the image of God, setting human beings apart from animals and providing the essential basis for human dignity (Rae, 2008). Regardless of the extent of an infant's deficiencies, he or she is still human, created in the image of God. Having more rationality (autonomy, language use, moral agency, intelligence) does not make one's welfare more important (Bernstein, 2002).

Kittay (2005) argued against the view that intrinsic psychological capacities such as rationality and autonomy are requisites for claims of justice, a good quality of life, and the moral consideration of personhood. She said that to exclude those with severe cognitive disabilities from the moral consideration of persons would be as morally repugnant as earlier exclusions based on sex, race, and physical ability have been. After noting the high stakes involved in the definition of moral personhood, she said, "Personhood marks the moral threshold above which equal respect for the intrinsic value of an individual's life is required and the requirements of justice are operative and below which only relative interest has moral weight" (p. 101). She said that personhood is not the only basis for moral consideration, and that interests must be considered as well. The

incapacity of the infant and very young child to act according to their present or future interests does not mean that they are not persons. Rather, a morality of equal respect must prevail for all persons, regardless of their ability to act in their own interests.

Those who would argue that the severely cognitively impaired are not persons claim that only intrinsic psychological capacities are relevant for moral personhood, and that relational properties are generally not relevant. Relational properties such as social relations refer to a place in a matrix of relationships embedded in social practices through which the relations acquire meanings. Kittay (2005) argued that a social relation in this sense need not be dependent on ongoing interpersonal relationships between conscious individuals, and that biological relationships are neither necessary nor sufficient to define a social role. Social roles are defined by social practices. She said that an anencephalic infant is someone's child, and with that social relationship comes a series of appropriate emotional and moral responses, such as caring for the child for the child's own sake. "It is the practices that define parenthood, and not simply the intrinsic properties of the product of the pregnancy, that account for the epistemic reliability of a parent's grief at the birth of an anencephalic infant" (p.111). While not discounting rationality and autonomy, Kittay noted that whether or not an individual possesses any one set of intrinsic properties is not sufficient to determine whether or not the individual can have a moral life and be part of a moral community. Thus, possession of a set of intrinsic properties is not the basis on which to assign the individual a moral status.

Rae (2008) concluded that consciousness, sentience, and the ability to reflect the image of God are not determinants of what constitutes a person. Instead, those attributes are functions that result from being a person. All human beings are human persons

created in God's image with dignity, moral status, and rights to life. Ramsey (1978), a Christian ethicist, summed up this thought here:

Persons are not to be reducible for their potential. Patients are to be loved and cared for no matter who they are and no matter what their potential for higher values is, and certainly not on account of their responsiveness. Who they are, in Christian ethical perspective, is our neighbors. They do not become nearer neighbors because of any capacity they own, nor lesser neighbors because they lack some ability to prevail in their struggle for human achievement. (p. 226)

Implications for Anencephalics

Arguments over the personhood of anencephalics and other marginal cases will undoubtedly persist, given the wide range of worldviews influencing those who debate the subject. While the issue cannot be definitively determined, the status of anencephalics should still be approached with great caution. There is enough evidence to warrant the benefit of the doubt be given to the anencephalic child concerning personhood. While it may be possible that personhood is absent, there is not enough evidence available to give a valid conclusion. The benefit of the doubt should always go toward maintaining life if there is ever a reasonable question. With this thought in mind, it is now possible to delve into the questions aforementioned regarding standards for brain death, whether anencephalics feel pain and should be used for organ donation, and the kind of medical and nursing care they should receive from birth to death (Foreman, 1999).

Brain death. There are four different concepts used in the determination of death: failure of heart and lungs, separation of body and soul, whole brain death, and neocortical death. Failure of heart and lungs was the traditional defining factor for death, but with the

advent of modern life-extending technologies, this concept is no longer as decisive as it once was. Separation of body and soul is the definition of death formerly used by Aristotle and currently held by Christians. This theological truth is unobservable, and thus difficult to defend empirically. Whole brain death is when there is no spontaneous brain activity when measured by electroencephalogram, as well as no spontaneous respiratory function; this is the standard determination of death today (Foreman, 1999).

Neocortical death determines death to be when the neocortex, which is the outer layer of the brain covering the cerebrum, has irreversibly ceased to function. If the neocortex ceases to function, there is irreversible loss of consciousness and self-awareness, two qualities some believe to be the primary basis for personhood. Patients who are in a persistent vegetative state (PVS) fit this description and some would argue that anencephalics do as well. There remains much controversy over this determination of death, and to date no state or federal government agency has accepted this standard (Foreman, 1999). According to the President's Commission (1981), no one with spontaneous respiration meets current criteria for brain death (as cited in Baxter, 1996, p. 140).

Baines (2005) listed the Harvard guidelines developed in 1968 defining the appropriate steps in defining brain death. The first is that the patient should be deeply comatose, and that drugs, hypothermia, and metabolic disturbances be excluded as causes of the coma. The second is that there is a need for mechanical ventilation, and neuromuscular blocking agents have been excluded as a cause for respiratory failure. The third is that a condition that can lead to brain death has been diagnosed and the patient's condition is due to irremediable structural brain damage. Nathan and Greer (2006) added

three other conditions that must be met before determining brain death (adapted from the American Academy of Neurology in 2005): systolic blood pressure maintained above 90 mmHg; no evidence of drug intoxication, poisoning, or paralysis; and identification of the underlying cause by neuroimaging, computed tomography (CT), or lumbar puncture.

They also noted the three cardinal features of the clinical brain death examination: coma, absence of brainstem reflexes, and apnea.

Nathan and Greer also made note of the fact that the prevailing consensus of opinion is that brain death should be death of the brainstem as well as the cortical tissue. They did not agree with the theory that one must have some semblance of consciousness to be alive, and say that it is unacceptable that anencephalic infants, patients in a persistent vegetative state, and those in a coma following a traumatic brain injury should be considered dead. They argued that:

In patients continued on artificial ventilation following brain death, it has been observed that some brain functions persist, such as thermoregulation and hormone secretion (e.g., in response to organ retrieval, associated with a successful gestation of a fetus, or proportional growth, as in the case of a few children). Thus, it would seem that death ensues only when there is irreversible cessation of cardiopulmonary function, which would signal that truly *all* function has left the brain. This would exclude most if not all of the patients currently included in formal definitions of brain death. (p. 229)

They also pointed out that the determination of brain death is left up to the individual attending clinician or neurologist, and it is generally up to that physician's discretion

whether or not to perform any ancillary tests to investigate further the degree of brain death.

There are many legal, medical, and ethical questions surrounding the issue of brain death, which are not soon likely to be answered to the satisfaction of everyone interested in the issue. However, it seems only reasonable that when there is doubt, judgment should err on the side of preserving life (Foreman, 1999).

Organ donation from anencephalics. One of the major questions in the debate on the personhood of anencephalics is in regard to their potential use as organ donors. There is a great need for organs for infants, and those organs obviously need to come from other infants. Many believe that through organ donation, some good can come from the tragedy of having an anencephalic child (Glannon, 2002). The issue is that during the normal course of physical death, blood flow from the heart is reduced, providing inadequate perfusion to the various organ systems. As the organs suffer from the lack of oxygen, they begin to deteriorate into an unusable condition. This situation would be much the same if advanced life support measures like a ventilator were removed, but nutrition and fluids were being used to keep the infant alive. Once nutritive support is withdrawn, the heart and lungs will continue to function until they fail 10-12 days later because of inanition, electrolyte imbalance, or dehydration. This would leave the organs in very poor condition for transplantation. To obtain viable transplantable organs, death would have to be accelerated, which is illegal (Hoffenberg et al., 1997). If the anencephalic infant were placed on a ventilator, the organs would still receive adequate oxygen supply to keep them in a condition suitable for transplantation. However, it is also

illegal to excise organs from a living human being. Thus, the infant would need to be legally declared brain dead for this to happen (Foreman, 1999).

Hoffenberg et al. (1997) stated that there are obvious benefits to making a new source of organs available for transplantation. They first offer two arguments against the proposition of withholding life sustaining treatment from PVS patients. First, there is continuing uncertainty and controversy about the definition and diagnosis of PVS, higher brain death, and the recognition of residual consciousness. Errors can also be made during diagnosis that may result in a faulty prognosis. Second, some patients in PVS have evinced signs of recovery and improved function up to five years after the original injury.

The International Federation of Gynecology and Obstetrics (FIGO) Committee for the Ethical Aspects of Human Reproduction and Women's Health, chaired by J. Milliez, published a committee report in 2008 discussing aspects of anencephaly and organ transplantation. They recognized that the ethical principles of beneficence (providing organs to those in need) and protection of the vulnerable (taking advantage of the anencephalic infant) can conflict. They then proposed two guidelines regarding organ donation. First, "The purpose of organ donation constitutes an ethical ground for a woman to choose to maintain an anencephalic pregnancy" (p. 99). Second, "When an infant is born with signs of life but has no forebrain (anencephaly) and hence has no prospect of survival, with parental permission, the child may be placed on a ventilator for the purpose of organ donation following natural death" (p. 99). While these guidelines were undoubtedly developed carefully, there are a number of factors that may not have been considered.

Hoffenberg et al. (1997) offered three arguments against using the organs from a brain-dead patient for transplantation. First, the law distinguishes between passively allowing to die, and actively accelerating that death. While the former is allowed, the latter is not. Thus, it is unlawful to cause the death of a patient by removing his organs. Patients with brain stem function, such as anencephalic infants, cannot legally be considered dead, because, while they require nutrition and hydration, they do not require cardiopulmonary support. Their argument is stated clearly in two points: (1) if the healthcare team waits for a brain-dead patient to die after withdrawal of treatment, the organs are unusable. (2) If the healthcare team accelerates death, they are acting illegally. Thus, patients who have experienced neocortical death alone cannot really be suitable organ donors.

Second, once it is decided that a patient's life should be ended, how should it be done? It could be accomplished slowly, through the withdrawal of nutrition and hydration, or possibly more expeditiously, such as with the administration of a lethal drug. Because partially brain-dead patients are presumed to be non-sentient, they would not be able to suffer from hunger or thirst as they waste away. Lack of distress is a strong argument against advocacy of a more expeditious mode of death. Proponents of this view hold that if the infant would not feel any pain during a hastened death, the moral argument against euthanasia is weakened. Thus, a lethal drug that would cause pain in a sentient patient could be used in an anencephalic infant without moral distress on the part of the administering physician. However, while a more speedy death may reduce the misery of the family and nursing staff caused by a long and drawn-out death, it is still equivalent to active euthanasia, which is currently illegal.

Third, is it legally, morally, or practically possible to obtain organs from these patients? As mentioned above, since these patients are legally alive, their organs are unobtainable until death, at which point the organs are no longer viable for transplantation, due to the natural deterioration of organs during the dying process. This differs from a patient who, for example, was killed immediately in a car accident. The patient was healthy before the accident, with normal organ perfusion, and suffered acute fatal injuries, at which point undamaged organs could be salvaged. This is in contrast to the anencephalic infant whose organs are generally unviable at the time of death (Hoffenberg et al., 1997).

Morally, the decision is whether or not to terminate life. Hoffenberg et al. (1997) believe that there is no clear moral distinction between allowing to die by omission of treatment and more actively ending life, saying the outcome is the same. However, Meilaender (2005) promoted the ethic of “caring, but not killing,” (p. 32) saying that proper care of the anencephalic newborn does not entail useless attempts to sustain life. As long as these infants remain alive, ordinary care should be used to maintain their lives; however, aggressive care should be avoided. This method of care is based on the philosophy that there are limits to modern medicine, and there comes a time to recognize that there is nothing more that can be done (Foreman, 1999).

Davis (1988) noted that there are three theories that should be considered regarding the use of anencephalic bodies as donor banks: utilitarian, Kantian, and pro-life. The main aim of utilitarianism is to increase the sum total of pleasure in the world. Since anencephalics are regarded as incapable of experiencing pleasure, their only good comes from what they can offer others, namely, their organs. This viewpoint can actually

justify using anyone as a donor if someone of a higher status needed an organ to survive. It can also be used to justify the giving up of any commodity which might enhance the general good, as opposed to an individual good. Jeffreys (2001) noted that this theory of value is the Achilles' heel of utilitarianism, and that utilitarian calculations arbitrarily ignore spiritual goods. The issue Davis (1988) found with the Kantian view stems from the Kantian Categorical Imperative, which states that humanity should always be treated as an end and never as only a means. This view of rights and personhood demands a degree of rationality which anencephalics do not possess, having no higher brain function. Thus, according to the Kantian view, anencephalic infants have no better purpose than to be used as donors, and potentially better the lives of other infants in need of organs. In fact, according to the Kantian view, it is an obligation to take the infant's organs. Davis (1988) made the interesting point that even those who would abort the mentally handicapped and use anencephalic infants as donors still try to argue that they are treating them with respect. Koppelman (2003) echoed this by stating that the goodness of the end does not justify using any means to achieve that end, and potential donors should not be treated as mere means to the end of procuring organs. To do so would harm the donors in the name of utilitarian goals, as well as fail to treat them with respect. Ultimately, Davis (1988) believed that the pro-life view, where the right to life is given to all living human beings beginning at conception, is the most humane and logically consistent philosophy.

Transplants from those other than anencephalics are subject to very strict rules, and the donor must either consent or be physically dead. Anencephalics are not

physically dead, nor are they capable of consenting. The World Health Organization (2010) defined a livebirth as:

The expulsion or extraction from its mother of a product of conception irrespective of the duration of the pregnancy which after such a separation breathes, or shows any other evidence of life such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscle whether or not the umbilical cord has been cut or the placenta is attached. Each product of such a birth is considered liveborn. By this definition, anencephalics are alive, and by the time of natural death some organs, such as the heart, are useless for transplantation purposes. Davis (1988) said, “To overcome the problem of using the organs of such babies it seems that moral gymnastics are being performed by some doctors and ethicists to persuade us that while physically alive, such babies are ‘technically dead’” (p. 151). Anencephalic infants are persons too, and moral and ethical rules should be founded on the rights of the individual. If human rights are to be preserved against attacks from more powerful aggressors, logical consistency demands that those rights be extended to the less powerful in turn. If the severely handicapped may be sacrificed for the less handicapped, then one embarks on a slippery utilitarian slope. There should be great concern for deterioration of ethical decision making in the absence of sharp and precise boundaries. The slippery slope is a concept whereby permitting a specific course of action deemed to be ethical and appropriate might lead to other courses of action that are clearly unethical (Pinter, 2007). Davis (1988) pointed out that a statement such as “death is absolutely inevitable among babies born with anencephaly” (p. 152) is intended to justify taking organs while the infant is still alive. However, it fails to make mention of the fact that death is absolutely

inevitable for every person living. She concluded by stating that “the right to live one’s life from conception to natural death is a universal and basic freedom, not a commodity to be sold to the highest bidder or the strongest and most powerful” (p. 152).

The case against organ donation from anencephalics is strong both morally and ethically. There is really no way to obtain viable organs from anencephalics without accelerating the infant’s death, thus violating moral and ethical principles, as well as acting illegally (Davis, 1988).

The Role of the Nurse

The role of the nurse when caring for anencephalic children and their parents centers on providing for a variety of physical, emotional, psychological, and spiritual needs. The nurse should be informed on the basic ethics surrounding moral decisions that must be made by the parents, such as whether to implement life-sustaining medical treatments or allow their child’s body to be harvested for organs. As the child will most likely die within the first week of life, the nurse must be able to provide emotional support for the family as they begin the grieving process (Arnold, Gemma, & Cushman, 2005). It is important for the nurse to emphasize that, while there is no cure for anencephaly, the child is still unique and has great intrinsic value as a person. The nurse should strive to assist the family in providing the best quality of life for the child as long as it is alive, helping to make the situation bearable as well as provide lasting memories of treasured, though short, time with the baby, as well as an acceptable death (Craig & Goldman, 2003). Another important aspect of nursing care is emphasizing preconception counseling and prevention through nutrition, specifically folic acid supplementation (Carl & Hill, 2009; Folic acid, 2009; Lindsey, et al., 2007).

Moral and Ethical Education

The acquisition of moral characteristics is the proper business of nursing education and the exhibition of said characteristics is the true mark of professional behaviour. Florence Nightingale, pioneer of professional nursing in the 1900s, stipulated the following attributes are essential to the ideal nurse: truthfulness, obedience, punctuality, observation, sobriety, honesty, quietness, devotion, tact, loyalty, sympathy, and humility. Many of these traits are especially important for nurses working in pediatric palliative care, such as with anencephalic infants. In addition to developing these traits, it is important that nurses have the proper training to enable them to make informed ethical decisions when they are faced with difficult situations. Nursing education should include ethical theories, and in particular, their implications regarding end-of-life care (Sellman, 1997).

The ethical principles of autonomy, beneficence, nonmaleficence and justice apply to all persons, but because infants are incapable of making their own decisions, that task falls to surrogates, generally parents. One of the most difficult issues encountered by health care professionals working in pediatric palliative care is conflicts between parents and the health care team over goals of care. If not properly addressed, ethical conflict can develop into moral distress among staff. The way the health care team handles difficult situations such as end-of-life care profoundly influences the experience of the infant, family, and caregivers (Klein, 2009).

Suffering

One common concern of staff regarding care of infants is the suffering of their patient. Staff may view life-prolonging procedures and equipment as causing more harm

than benefit to their patient. However, parents may have different views of what constitutes beneficence and of how to assess the suffering of their own child. These issues can be addressed by sincere and well-informed discussion regarding goals of care, and by emphasizing key aspects of the child's care while acknowledging the family unit. In this way, the basis for the parent's choices for their child can be elicited, and the staff can evaluate whether those choices are compatible with the infant's best interests.

Baby Doe regulations are in place to help define legal parameters in which medical care is provided to infants. These regulations are designed to ensure that infants receive appropriate medical care regardless of their mental capacities. These regulations are sometimes misinterpreted to mean that care should never be withheld from infants with disabilities; however, the regulations do not require that non-beneficial care be delivered to disabled infants. Nursing staff need to be aware of these regulations to help them during the decision-making process.

If nurses are aware of both legal and ethical considerations regarding life-prolonging care and end-of-life care, conflicts between staff and parents can be resolved more easily, with less moral distress for both parents and staff. In particularly difficult cases, an organizational ethics committee can provide clarity and structure to decision making, and help elucidate the objective best interests of the infant, as well as subjective or contextual issues (Klein, 2009).

Home Management

In some situations, like many involving anencephalics, intensive aggressive medical therapy is a futile exercise only prolonging a short life of suffering. When faced with situations like this, health care providers sometimes feel hopeless, having exhausted

the benefits of potentially helpful medical treatments. However, instead of focusing on the failure to cure the infant, health care providers should focus on the opportunity to provide loving care to the infant as well as the family during this time of grief, stress, and transition. In most cases, palliative care is appropriate, and in some cases, even home care can be beneficial for these families (Craig & Goldman, 2003).

Home care can be considered for infants in the following categories: infants for whom aggressive intervention offers only a short life with significant suffering, infants who have suffered perinatal asphyxia leading to profound brain damage, infants with overwhelming illness with no prospect of long term survival, and infants extremely unlikely to survive infancy due to lethal birth defects such as anencephaly.

Withdrawing intensive support does not equate to withdrawal of care. The 1995 statement *Ethical Aspects of the Management of Severely Malformed Newborn Infants* recognized that when parents and physicians agree that it is in the best interests of such infants, they should be allowed to die with dignity, without inappropriate or futile medical intervention (Cook, et al., 2008). Instead of aggressive medical care, the infants and family should receive palliative care. Palliative care involves active treatment designed to provide care for these infants in a comfortable environment, free from pain and distressing symptoms, with practical and emotional support for their caregivers. Palliative care involves care not only as long as the infant is alive, whether that is for hours, days, weeks, or months, but also support for the family after death and during the bereavement process.

The family and health care team should make decisions about continued interventions together. While some questions will be appropriate only for a doctor to

answer, the nurse should be prepared to give the family information within her scope of practice. This can include topics such as what is likely to happen if intensive care is withdrawn or withheld and what palliative care for their infant will involve. Parents and families need adequate time to discuss and understand their child's prognosis. Other helpful resources that can be suggested by the nurse include talking to other parents who have gone through similar situations, referrals to support organizations or religious organizations, and obtaining a second opinion from an outside consultant.

While it is more typical for infants to be cared for in the hospital, this can sometimes be an added stressor on parents who are trying to spend time with their dying infant, care for other children at home, continue to provide income for their family, and cope with their own grief. Well organized home-centered care can be ideal for some families (Craig & Goldman, 2003). Additionally, the long-term psychological outcome for parents may be better when their child dies at home (Lauer, Mulhern, Schell, & Camitta, 1989). Typically, there are no medical reasons that prevent a family from taking their dying infant home, as long as there are appropriate local resources.

When information is given to parents considering home care, it should include an idea of what to expect as the baby deteriorates, including symptoms and symptom management, as well as a realistic picture of the level of support that can be provided. Regardless of the decision the parents and family make, their decision should be respected and supported. The family should also be given the option and freedom of reviewing or changing their decision at any time.

Because caring for a dying child is understandably exhausting, both physically and emotionally, there should be at least two main caregivers. This is usually the mother

and father, but can also include another close relative or friend. Professionals that must be involved include a designated pediatrician, the pediatric home care nursing team, a general practitioner, and a health visitor.

If death is expected within a few hours of going home, the parents may feel reassured if a member of the nursing team can stay with them. If the parents are told that someone will stay with them until their child dies, there must be a rotation of caregivers available however long is necessary. Parents need to be sufficiently well informed that they can be in control of any situation that may arise, and have access to support resources at all times. This includes correct information about any medications their infant is on, and how to prepare and administer them. Parents will have life-long memories of their child's short life, and to keep those memories bearable, they should be informed on how to provide rapid symptom relief as symptoms occur. Topics that should be discussed with parents include drug administration, feeding, respiratory distress, pain, constipation, vomiting, secretions, and seizures (Craig & Goldman, 2003).

Mementoes of the baby are very important, especially when life has been very short. The nurse should encourage the parents to take pictures of their child and perhaps save hand and footprints. Other meaningful keepsakes can include a lock of hair or maternity unit name bands (Craig & Goldman, 2003).

Family Support

Nursing support for the family is essential throughout the infant's entire lifetime, from conception to death. Giving birth to a child who will die in infancy is devastating for the family. Most parents experience denial, anger, guilt, desperation, and acute grief. Not only are these parents losing their child, they are also losing dreams and hopes, as

well as their role as parents. Thus, parents need opportunities to acknowledge and express their feelings. Offering these opportunities is as much a part of palliative care as providing care to the dying infant (Craig & Goldman, 2003). Nurses should pay particular attention to parents with depressive symptoms, as there are many resources available to help them, including their infant's palliative care program (Knapp, Madden, Curtis, Sloyer, & Shenkman, 2010).

Siblings need care as well, as they often feel isolated and neglected because their parents are so focused on their dying brother or sister. While parents often have little energy or emotion to invest in siblings, they should still be encouraged to talk to their other children about the situation. Siblings need to be included in the life of their brother or sister, and be prepared for and included in the death. It is important for adults to emphasize to the other children that it is not their fault.

Grandparents also need opportunities to talk about their feelings, as they are coping not only with their own grief, but also that of their children and grandchildren. Often they feel a sense of injustice that the youngest, instead of the oldest, member of the family has died. If possible, they should be included in the decision making process and be given opportunities to spend time with their newest grandchild while he or she is still alive.

Home care of a dying infant requires a holistic approach that addresses the needs of the infant as well as the family. Essential to this process is a well coordinated multidisciplinary team that acknowledges the central role of parents. The entire family, including siblings and grandparents should be supported through the life, death, and

grieving process, leaving them with memories of a bearable death and treasured time with their infant (Craig & Goldman, 2003).

There are many resources for nurses who are involved in end-of-life care. One resource that is specific to care of dying infants and their families is Resolve Through Sharing (RTS). This is a perinatal bereavement education program designed to help nurses care for families who have experienced early pregnancy loss, stillbirth, or newborn death. RTS training teaches nurses how to understand grief, attachment, and loss, as well communication skills, conflict resolution, and how to help families create memories. Resources like this produce skilled and competent nurses that can provide care and support to dying infants and grieving families (Bereavement Services, 2010).

Nursing Goals

Ultimately, caring for the sick is competently and compassionately sharing knowledge and experience with the purpose of helping another human being at a time of great need (Kane, 2006). Much of the nursing care provided for anencephalic infants and their families falls into the realm of palliative care. Pediatric palliative care can be both stressful and rewarding, and requires coping skills, confidence, knowledge, and skills to comfort grieving parents (Morgan, 2009).

Issues in Palliative Nursing

Nurses caring for dying children often have many unmet needs that impact the way they care for the patients, their job satisfaction, and ultimately, hospital retention rate. When a child dies in the hospital, after extensive measures have been taken to save their life, health care workers often perceive the death of the child as a triple failure. The first sense of failure is that they did not have the means, skills, or abilities to save a life.

The second is that in their social roles as adults they were unable to protect the child from harm. The third is that they betrayed parents who trusted them with the most valuable being in their life. This sense of failure increases grief and intensifies feelings of helplessness, guilt, anger, and sadness. As the nurses' awareness of their own losses and vulnerabilities increases, feelings of anxiety and stress increase as well (Papadatou, 1997). Major issues in pediatric palliative care include moral and ethical distress, personal pain, lack of support and collaboration, burnout, and lack of professional collaboration and education.

Moral and ethical distress. Moral and ethical distress occurs when nurses are asked to act in a manner that is contrary to their beliefs. When nurses' personal and professional values are disregarded, their integrity is undermined. Nurses then struggle with the dilemma between their obligation to follow physicians' orders and their duty to provide a comfortable death for the infant. Both external and internal barriers may occur when health care providers are prevented from acting according to personal values and professional standards. External barriers occur when a nurse's opinion is neither sought nor valued in the workplace. Internal barriers result when a nurse has poor communication skills or lacks the knowledge and skill to appropriately provide palliative care. If these barriers are not resolved, job satisfaction and appropriate patient care will not be maintained (Morgan, 2009).

When nurses feel they can no longer help the terminally ill recover, they begin to experience a deep sense of helplessness, sadness, and ambivalence. There is uncertainty regarding the dilemma between palliative and curative care (Yam, Rossiter & Cheung, 2001). Performing aggressive treatments is difficult when the infant is actively dying, and

when nurse input is ignored, nurses may become angry, frustrated, and resentful about the patient care being provided. Aggressive or painful measures which are futile take up precious time that the family could use to prepare for the child's death. Both adults and children need time to say goodbyes and find closure (Morgan, 2009).

Personal pain. Many nurses report feeling extreme sadness when dealing with the death of children. This can be compounded when a nurse is caring for a child around the same age as a child of her own. Nurses also suffer emotionally at the termination of established relationships with patients and families. One protective mechanism that nurses sometimes use is keeping themselves busy with physical care, and minimizing interactions with families as much as possible in an effort to avoid distress (Yam et al., 2001).

Lack of support and collaboration. Many nurses report feeling a lack of support from peers, administrative personnel, and other members of the health care team. This lack of support can cause a great deal of stress for nurses, and made a significant impact on the quality of care they were able to provide to the infant and family. Collaborators such as clinical nurse specialists, social workers, child life personnel, and chaplains can help provide much needed services to families, explaining procedures, providing meal assistance for families, and providing spiritual guidance. When these collaborators are not present, the nurse must fulfill the responsibility of meeting these needs.

Burnout. Because of these issues (moral and ethical distress, personal pain, and lack of support), employee turnover rates are often negatively affected. High levels of stress and ethical dilemmas are the biggest contributors to high turnover rates. Lack of

control and frustration lead many nurses to seek less stressful work environments (Morgan, 2009).

Jading is a term specific to burnout related to prolonged stays by a sick child, numerous readmissions, and continued aggressive care that may seem futile. This effect can be compounded by dealing with families who have different expectations than the health care team of the child's situation and medical prognosis. Jading is a hazard when the health care team, expected to provide morally responsive care, can no longer extend themselves fully. It can be minimized by "finding meaning in the case, finding an opportunity to learn, modifying one's goals and expectations and an involved multidisciplinary team" (Jones et al., 2007, p. 45).

Lack of professional collaboration and education. Health care professionals are increasingly exposed to death and the dying process with little prior education to help deal with the needs of the patient, and minimal preparation in recognizing and handling their own personal reactions in the face of death. Areas of inexperience reported by staff members included communicating with patients and families about end-of-life issues, transition of patients into palliative or hospice care, do-not-resuscitate orders, and pain management issues. Insufficient training in these areas can exacerbate stress and affect quality of care. Both nurses and physicians struggle with feelings of inexperience in managing end-of-life symptoms (Contro, Larson, Scofield, Sourkes, & Cohen, 2004). Nurses also report having inadequate knowledge, expertise, and skills to comfort grieving parents. Many feel uncomfortable when parents cry, and fear saying something that would be inappropriate and offensive to parents (Yam et al., 2001). Having a palliative care network, attending palliative care rounds, patient care conferences, and bereavement

debriefing sessions are all useful strategies in increasing knowledge and comfort with palliative care, facilitating effective communication with staff and families, and increasing knowledge of coping strategies (Jones et al., 2007).

Conclusions

There will always be legal, medical, and ethical questions regarding the status of anencephalic infants. However, as stated previously, it seems only reasonable that when there is doubt, judgment should err on the side of preserving life (Foreman, 1999). Anencephalic infants should be respected and cared for as persons, with a right to medical treatment and palliative care. Their bodies should be treated with utmost care, like those of any seriously ill patient, and their death should not be hastened in an attempt to gain organs for donation (Davis, 1988).

Health care professionals will provide better care and support to seriously ill infants and their families when they feel supported personally and professionally. Thus, there must be a willingness by the health care system to invest in the greatest palliative care asset: the health care professionals. When attending to the suffering of a dying patient, the process of caring is just as important as the attainment of palliative care outcomes. Parents identify as care priorities the need for honest and complete information, ready access to staff, smoothly coordinated care, emotional expression and support by staff, preservation of the integrity of the parent-child relationship, and spiritual support. Increased training in practical, psychosocial, medical and spiritual aspects of pediatric palliative care for all health care professionals is critical to success (Jones et al., 2007).

Kane (2006) suggested that the palliative care mandate for health care professionals should be to “improve access to evidence-based, quality supportive care services provided by empathic, compassionate and competent health care providers who can attend to the child and family’s multiple physical, emotional, and spiritual needs throughout the illness trajectory and across the hospital, clinic, and home care settings” (p. 849). Nurses can find meaning in their profession by addressing the needs of the individual as a whole person, and as a community of caring professionals, delving into the mysteries of the suffering and dying of the most vulnerable patients, and learning from the richness of their experiences (Kane, 2006). While a child’s death may seem like a long and difficult road, nurses have the power to create a brighter journey for both patients and families (Morgan, 2009).

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