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2019

## Ethical Patient Care Overview for Doctoral Nursing Students

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## CHAPTER 3

### Ethical Guidelines Particular to Practice

#### COURTNEY REINISCH

Clinical care is guided by knowledge, competency, and the maintenance of ethical standards. Maintenance of ethical standards is necessary by all care providers across disciplines. Attention should be paid to the following ethical tenets: autonomy, beneficence, non-maleficence, justice, veracity, and confidentiality. Avoiding paternalism is a goal for providers to optimize outcomes for individuals and families. Providers who demonstrate a thorough understanding of ethical principles best serve individuals, communities, and populations by strengthening trust with adherence to ethical standards.

#### 3.1. AUTONOMY

Autonomy allows an individual to make decisions in their own perceived best interest: free from deceit, duress, constraint or coercion. Individuals are to be informed participants in the decision-making process. Autonomy respects personal freedom for the individual, family, and community in receipt of care. Respect for autonomy enhances the professional relationship between provider and humans engaged in a clinical encounter.

Inherent to the principle of autonomy is the concept of informed consent. Individuals have the right to be properly informed of their state of health, be it illness or wellness. Risks and benefits of any procedures that will be used to assess and treat a human should be clearly described. This facilitates the individual, family, or community's decision-making regarding care. Discussions regarding treatment options, risks, and benefits are necessary to educate recipients of care. This allows the individual to provide informed consent.

When discussing risk and benefits of treatment, the APRN should speak in a manner which is understandable to the individual. This may present a challenge when an individual or family's native languages is different from the APRN. The use of professional translation services is necessary to ensure the humans involved understand the implications of the discussion. It is not acceptable to put the burden of translation on individuals who are not trained professionals. Interpretation services must be employed to confirm consent is truly informed.

Individuals and families with limited literacy pose a significant challenge in the process of risk, benefit discussions. APRNs need to proceed with caution when dealing with individuals or populations with low literacy levels. It is imperative to minimize risk for coercion when dealing with vulnerable populations.

When providing written information to individuals, forms must be written at an appropriate literacy level. The Joint Commission recommends patient educational materials be written at or below a fifth grade reading level (TJC, 2010). In cases of low literacy, information should be read to the individual to ensure comprehension. Health information and forms for consent should be available in the individual's native language to ensure understanding.

Health literacy includes the reading and math skills which allow an individual to function in the health care environment. Limited health literacy can increase risk for hospitalization, and in-adherence with medications and treatment plans. The APRN needs to deliver necessary health education in clear, concise, and understandable terminology when speaking with humans. Older adults are at greater risk for limited health literacy skills as they deal with declines in cognition and senses.

The APRN who respects the principle of autonomy respects the individual's freedom to make their own decisions. For example, an 89 year old female presents to her internist as she is preparing to travel with her family. The individual lives in the community with an aide due to Alzheimer's dementia. She is forgetful at times regarding appointments, keys, and pots on the stove. She no longer drives or cooks, as these tasks are completed by the assistant. At the time of consultation, the individual is oriented to person, place, and time. She knows the names of all her family members.

The individual advises the provider she will be traveling with her daughter's family to a location at 5000 feet elevation. The APRN understands the concern for the effects of altitude and possible anxiety associated with air travel. However, the APRN respects the individual's autonomy. She asks the individual, "Do you want to go on this trip?" The 89 year old individual confirms that she wants to travel with her family. Although this individual has Alzheimer's dementia, she is able to articulate her desires. Understanding the risks, the APRN develops a plan to support the individual's health so she may travel with her family.

### 3.2. BENEFICENCE

Beneficence is defined as the principle of doing "good". It involves doing as much good as possible in order to benefit another. It may consist of a positive action which removes or prevents the individual's problem. Beneficence strives to promote the very best.

Doing "good" sounds like a reasonable charge; however, this may be a challenge for the practicing APRN. When evaluating a 69 year old obese male individual for right leg pain who presents to the emergency department due to a fall, the APRN determines that the individual has no fractures or thrombosis. The individual has a history of chronic back pain, and recurrent lower extremity cellulitis. This individual is unable to ambulate during this ED admission. The APRN calls the individual's primary care provider to discuss the case. The APRN believes this patient may require a 23 hour observation or admission to the hospital for physical therapy evaluation and potential sub-acute placement. In the APRN's opinion, it is not safe to discharge this individual to home as he lives alone and is unable to care for himself. The APRN is acting utilizing the principle of beneficence.

The APRN respects the individual's autonomy and discusses the proposed plan with the individual. The individual verbalizes understanding of the issues and the reasons for admission. He agrees that this seems like a reasonable plan. However, when the APRN speaks to the individual's primary care physician, she is met with resistance. The PCP suggests to the APRN the individual is not telling the truth, and that the individual could walk if he so chose. The APRN advocates for the individual and the ultimately individual was admitted for observation and PT evaluation. Although doing "good" seems a reasonable goal for the APRN, it may be a challenge.

### 3.3. NONMALEFICENCE

Nonmaleficence is defined as “do no harm nor inflict damage to another”. Nonmaleficence is embodied in the principle of Primum Non Nocere. It is reflected in the Hippocratic Oath as “physician—do no harm”. Treatment for a particular individual’s diagnosis may not balance the risks associated with the treatment when a risk-benefit analysis is considered. Ergo, a provider may choose to not perform a procedure or intervention if there is an increased risk of doing harm.

When considering any treatment, the prudent APRN will consider both the risks and the benefits to the individual. For example, a 23 year old individual with end-stage leukemia requests to enroll in a clinical trial to appease her parents’ request for her to not resign herself to hospice or palliative care. In the parents’ view, accepting hospice care would be “giving up.” The APRN must balance the individual’s desire to please her parents with the chance of futility from treatment. The risks associated with the clinical trial include side effects of the medications, additional complications, and no benefit from treatment to slow or stop the progression of the individual’s disease. The risk of death is inherent in the case, as the individual is extremely debilitated from her cancer. The possible benefits for the individual could be an improvement in her condition and eradication of her disease.

When considering care for this individual the concepts of autonomy, veracity, and beneficence must be considered in this type of decision making. The APRN wants to respect the autonomy of the 23 year old individual with leukemia to make her own decisions. The APRN is truthful about the risks and benefits of the treatment being considered.

Evidence-based treatment guidelines need to be employed when considering a risk benefit analysis. Treatment within guidelines provides benefit to the majority of the individuals with a syndrome or disease. Providers use guidelines to provide benefit to most individuals. Consideration for cultural and family preferences need to be included in decision making processes.

### 3.4. JUSTICE

Justice includes the concepts of fairness and entitlement. Fairness encompasses the distribution of goods and services as well as equitability amongst a society. Fairness evaluates who receives benefits and to what degree. Individuals deserve to be treated in a fair and equal manner regardless of ethnicity, social status, religious beliefs, sexual orientation, or any other social or personal uniqueness.

The APRN may serve justice in the system by utilizing evidence-based guidelines which have been shown to provide positive individual outcomes. By following guideline-based care for individuals with diabetes, the APRN may optimize the individual’s glucose levels. This may then prevent future, costly complications to the individual and the health care system at large.

The APRN who respects health care resources as limited and valuable understands distributive justice. Distributive justice is important when considering health care services as a right for all or when

considering a social system of health care services. The APRN who is able to deliver high quality care at an affordable price will be a key player in restricting healthcare costs for the future.

### 3.5. VERACITY

Veracity refers to truth telling. It involves comprehensive, accurate and objective communication of information between the practitioner and individual. The obligation of veracity is closely linked with fidelity. Fidelity requires an agreement and kept promise. Veracity and fidelity prohibit deceit. These ethical tenets protect trust. Individuals cannot be expected to trust a care provider if they are not provided the truth. Truth telling is at the core of the patient-provider relationship and is required for the establishment of a trusting relationship.

Developing a strong patient-provider relationship may be difficult due to today's practice environment. Productivity demands reduce time spent with each individual and family. Individuals who receive care in large multi-provider practices may see a different provider at each visit. Health care consumers are savvy today as they have more access to health related information knowledge via the internet. This has positive benefits of an educated consumer; however, it may result in individuals demanding expensive tests or treatments the provider does not believe are in the individual's best interest.

Truth telling seems straight forward and desirable. Delivering news of a difficult diagnosis needs to be handled with sensitivity. The APRN must be straightforward in the effort to deliver the unfortunate news. Culture may influence truth telling. In certain cultures and religions, it is not acceptable to plan for end of life. The APRN may also be asked by family members to not tell the truth to an individual with a terminal diagnosis. The APRN may have to speak to an individual without family present in order to have an honest discussion.

There are times when the APRN may be instructed not to tell an individual the truth. An example is when a nurse advises the APRN that she will need to repeat a phlebotomy procedure due to improper labeling of the tubes. The nurse wants to tell the individual that the specimen inadequate and this is the reason for the additional procedure. This is not the truth. The nurse does not intend harm to the individual, and the procedure needs to be performed. What does the APRN do in this situation?

An attending physician may instruct an APRN not to advise an individual about a mass seen on a chest radiograph. Rather, the physician may advise the APRN to tell the individual that an admission is required due to an abnormality seen on the radiograph. The plan is to advise the individual of the mass after further imaging studies are complete. This is not exactly lying, but the truth is withheld until a later time. The APRN may be uncomfortable with the process of withholding the truth.

### 3.6. CONFIDENTIALITY

Confidentiality protects individual's privileged information and guards a care provider's trustworthiness. Individuals surrender some privacy by divulging privileged information to a health care provider. Confidentiality obligates the provider to not share privileged information without permission from the

individual. Trust is weakened if the individual fears unauthorized disclosure. This may impede the provider's ability to care for the individual.

Federal guidelines have been enacted to protect individual confidentiality. The Health Insurance Portability and Accountability Act (HIPAA) is a federal law intended to protect individual privacy by limiting identifiable data and establishing how this information may be used. Information includes anything related to the past, present or future of that individual's physical or mental health where there is an identifiable piece. Since the Health Information Technology for Economic and Clinical Health (HITECH) Act was passed in 2009, the scope of Health Insurance and Portability and Accountability Act's (HIPAA) privacy and security protections has expanded to notifying individuals of privacy breaches (Fisher & Clayton, 2012).

The consequences of violating HIPAA may result in both civil and criminal penalties, including fines and possible jail time. A health care provider may be individually sued for defamation, invasion of privacy or harassment and face personal liability. APRNs must use caution to protect individual confidentiality and avoid HIPAA violations.

Social media is a growing technology with potential for unintentional HIPAA violations. Misconduct on social media websites may raise liability under state or federal regulations focused on preventing individual abuse or exploitation. If the health care provider's conduct violates the policies of the employer, the provider may face employment consequences, including termination. The reputation of the health care organization may be at stake when a HIPAA violation occurs (National Council of State Boards of Nursing, 2011).

APRNs now face new challenges in protecting individual confidentiality. The majority of individuals, family, and providers use smart phones in their daily lives. These phones have Internet capability at the touch of the fingertip. An individual in the care of an APRN may seek to post information on a social media site during the visit. The individual may wish to photograph a procedure being performed by the APRN. The individual being an autonomous human may choose to do this. The APRN must avoid posting any personal identifying information on any social media website. This includes, but is not limited to names, dates of birth, and photographs which may pose risk of identification.

When consulting a specialist, the APRN may wish to share information with the other provider. Sharing information with another provider involved in the care of individual is not a violation of privacy. The APRN must use a secure or encrypted method to share information with another provider involved in a case. APRNs need to use caution when sharing information with other providers to avoid HIPAA and institutional violations.

### 3.7. PATERNALISM

Paternalism permits health care professionals to act on behalf of humans if an individual is not able to choose or act for him or herself. Paternalism, when utilized in conjunction with autonomy and veracity, allows the practitioner to assist the individual in care related decisions. The provider must act in the fiduciary relationship, placing the needs of the individual above their own personal needs, and the needs

of others. This may prove challenging when there are opposing views on the particular treatment of an individual or family.

Paternalistic decisions may occur in the emergency or surgical setting. The APRN in anesthesia may make a decision to provide additional pain relief during a surgical procedure based on vital sign changes. The individual under anesthesia care is unable to verbalize the need for additional pain relief, but the provider will make that decision based on objective findings.

If any of these seven ethical tenets—autonomy, beneficence, non-maleficence, justice, veracity, and paternalism—are challenged, a provider will face an ethical dilemma. Understanding these tenets will guide the provider to resolve the dilemma. This may still prove difficult and result in moral uncertainty and distress.

### 3.8. MORAL UNCERTAINTY, DILEMMAS, DISTRESS, FATIGUE—JUSTICE

Moral certainty is achieved with a very high level of certainty for an action. Moral uncertainty lacks certainty or probability, and makes action questionable. When the resolution is not transparent, it is difficult for the health care provider to act. There may be a sense of constraint from the institution which does not allow the nurse the sense of ability to act (Fourie, 2016).

Moral distress has been defined as the negative feeling associated with a sense of responsibility and a sense of powerlessness (Landry, 2017). Dealing with moral distress is one of the hazards of a career in health care. Moral distress arises when a person or nurse believes they know the right thing to do, but are unable to act due to institutional or other outside constraints (Fourie, 2017). This results in negative self-directed emotions in response to one's perceived involvement in morally undesirable situation (Campbell, Ulrich & Grady, 2016).

Moral distress influences the well-being of nurses, quality of care, and workplace attrition rates (Kelly, 1998; Corley et al., 2001; Corley, 2002; Hamric & Blackhall 2007; Hamric, Borchers, & Epstein, 2012; Whitehead et al. 2015). Moral distress differs from other types of work place dissatisfaction in that it causes individuals to feel morally compromised in some way.

Nurses are challenged to maintain professionalism and responsibility in their everyday practice. Nurses commonly encounter clinical situations that contain ethical conflicts. Examples include administering futile care to an end of life individual against their expressed wishes because the family insists. A nurse may be involved in administering CPR to an elderly individual with terminal cancer whose family has just rescinded the do not resuscitate order. Unresolved conflicts may cause feelings of frustration and powerlessness, especially when nurses are faced with circumstances associated with moral uncertainty or distress.

The discomfort associated with moral distress can be associated with compassion fatigue. Compassion fatigue was identified in association with burnout and is known as secondary traumatic stress disorder (Coetzee & Klopper, 2010). If compassion fatigue is not addressed in the early stages, nurses' ability to

continue to deliver optimal care may be compromised. A lack of resources, inadequate positive feedback, and the nurse's response to personal distress can place nurses at risk for compassion fatigue. Addressing the factors which place nurses at risk for compassion fatigue can result in improved workplace retention of caring nurses (Coetzee & Laschinger, 2017).

APRNs face similar challenges in their practice. Additional education in biomedical ethics provided in doctoral level education assists these providers in resolving complex situations and potentially minimizes job dissatisfaction. APRNs, due to the nature of their practices, have more autonomy than nurses. Nurses by scope of practice often work based on the orders of a physician or face employment loss or punishment by an institution for the act of insubordination. APRNs educate individuals, families, and engage in the practice of shared decision making to help to resolve ethical conflicts in their practice. The APRN may consult the institution's bioethics team when a distressing conflict arises.

Justice is the principle of fair and equal treatment for all in research and practice. Due reward and honor are shared by all members of a provider or research team. In research, justice also includes equitable distribution of benefits and burdens of research. Justice represents treating people without prejudice. The APRN must apply the principle of justice to any role in which they act: researcher, educator, clinician, and scholar.

In the role of the researcher, the APRN applies ethical guidelines to authorship. Authorship is defined as having substantial participation in the conception and design of the research study or intervention, or in the analysis and interpretation of data or results. Authorship must include substantial participation in the drafting or editing of the manuscript. The author provides final approval of the version of the manuscript to be published. The author has the ability to explain and defend the study or intervention in scholarly settings (International Committee of Medical Journal Editors (ICMJE, 2017)).

The APRN participating in research will likely be a member of a team. In these cases, the order of authorship is determined by the output from each of the contributing authors. The researcher who makes the largest contribution is entitled to appear as the lead author, or may choose to assume any other position of his or her choice. The lead author should generate the original concept of the work, perform the actual research study, and be identified as the Primary Investigator. The lead author analyzes and interprets the data, and the writing of all or most of the manuscript. In cases where two or more authors equally meet the above requirements, the authors should resolve the dilemma in a collegial manner. The designation of lead author should be assigned to the person who either played the more significant role in the implementation of the research study or wrote the largest portion of the manuscript text (ICMJE, 2017).

Most institutions will have set guidelines for the ethical conduct of research and this will be discussed in another chapter in this book. The purpose of these guidelines is to avoid research misconduct. Research misconduct is defined as deliberate fabrication, falsification, or plagiarism in reporting research results (American Psychological Association (APA, 2012)). It does not include honest error or differences of opinion. The APRN engaged in research wants to avoid research misconduct as this may result in



sanctions from employers, professional associations, and by agencies funding research. The APRN should consult the institutional guidelines to be certain to engage in ethical research.

### 3.9. INFORMED CONSENT—SURROGACY

Health care providers aim to obtain informed consent from individuals who can make well informed decisions about care (AMA, N.D.) Impairments to reasoning and judgment may make it impossible for an individual to give informed consent. Intellectual or emotional immaturity, high levels of stress, mental retardation, severe mental illness, intoxication, severe sleep deprivation, Alzheimer's disease, or unconsciousness are examples of conditions in which an individual may not be able to provide informed consent. Providers must find other acceptable sources including family members, surrogates, or legal guardians to provide consent in the aforementioned cases.

Individuals may not fully understand the meaning of a procedure or treatment as described by a provider. Informed consent requires a clear appreciation and understanding of the facts, implications, and future consequences of an action. To give informed consent, the individual must have adequate reasoning faculties and have all relevant facts before consent can be given.

The APRN must consider the notion of competency when seeking consent. Questioning if an individual competent to provide consent is necessary. What is competence? A legal definition of competence is provided in another chapter of this text.

The state of an individual's competency can vary based on health status. Healthcare providers must be aware that individuals may be competent to perform a task at one point in time and not be competent at a later time. In some cases, the APRN must evaluate an individual's capacity to make a decision if the individual experiences periods of confusion requiring admission to the hospital. The APRN would need to assess the individual's orientation to person, place, and time when determining capacity for decision making. The APRN may have to return at a later time to reassess the individual's condition and ability to make decisions, if the initial evaluation revealed a level of confusion. Any discussion requires documentation.

In other cases, an individual may have the capacity for judgment except in the reference to their health state. An example would be an individual who has become accustomed to using opioids to treat chronic pain. Because of the effects of these medications on cognition, this individual may lack the capacity to consider other options. The APRN must always completely and accurately document the individual's state when discussing options for care.

Laws regarding competence were created to protect property rather than individuals (Beauchamp & Childress, 2013, p. 114). Unfortunately, the law does not aid the APRN, as laws regarding competence are not well suited for medical decision making. As competence may vary depending on context, it is not appropriate to globally judge competence. An individual may not have the capacity to make a decision while suffering through an acute migraine headache or a transient ischemic attack, but this does not mean the individual is globally incompetent. The APRN must document any discussion with individuals and note if they are pain free and oriented at the time of the discussion.

A lack of informed consent makes it legally impossible to act. When an individual is unable to give informed consent, another person may be authorized to give consent on his behalf. In the case of minors, parents or legal guardians may give consent. Caregivers for the mentally ill may give consent. In cases of individuals who are critically injured or unconscious, physicians and other members of the healthcare team will administer life-saving treatment. They will act with implied, emergent consent.

If an unconscious or incapacitated individual cannot express consent, the law assumes that the individual consented to treatment for the emergency situation. Implied legal consent is based on two principles: (1) Duty to obtain informed consent is excused if death or irreparable harm may result if the physician delays providing treatment. (2) The law presumes that a reasonable, competent, lucid adult would consent to lifesaving treatment (*Canterberry v Spence*, 1972).

Courts differ on the definition of a “true emergency.” Courts generally will allow the doctrine to protect physicians who act in good faith in caring for an individual with a perceived emergency condition (*Thomson v Sun City Community Hospital*, 1984). The law works on the assumption of reasonable behavior. It assumes a reasonable individual would want medical care in the event of an emergency (*Moore, Moffet, Fider, & Moore*, 2014).

Laws support the right of a physician to act in an emergency without expressed consent. It is clear there is protection for physicians’ decisions in an emergency situation. Nurses are judged based on doing what another prudent nurse would do in that situation. APRNs are held to similar standards.

In circumstances where an individual is unable to provide consent, a surrogate may be appointed to act on the behalf of an individual. The surrogate has the power to act on behalf of the individual, as long as there is reason to believe that the surrogate is making decisions based on the individual’s wishes, values, or interests. Whenever possible, the APRN must keep in mind that all individuals have a right to decide and their choices must be considered even when a surrogate has been assigned. The APRN must assess that the surrogate is indeed acting in the individual’s best interest and is respecting the individual’s autonomy.

Surrogate decision makers must uphold three standards. The substituted judgment standard requires the surrogate decision maker to make the decision the incompetent individual would have made if competent (*Beauchamp & Childress*, 2013, p. 69). The pure autonomy standard respects prior autonomous judgments regardless of the existence of a formal advance directive (*Beauchamp & Childress*, 2013, p. 227-8). Without written advance directives, a surrogate decision maker may make decisions based on their own values and selectively consider events from the individual’s life which may not be relevant to the decision at hand.

The final standard is the “best interest” standard, which holds that a surrogate decision maker must weigh options and maximize benefit through a comparative assessment of options—while discounting inherent risks or cost (*Beauchamp & Childress*, 2013, p. 228). The best interest standard is open to interpretation and is dependent upon who is making the decision. Parents may choose to volunteer a child to donate an organ for a sibling, although the child refuses. The best interest of the individual may

override the desire of the donor. The prudent APRN would consider an ethics committee evaluation in such a case.

If there is no advance directive that designates a proxy, the individual's family should become the surrogate decision maker (AMA, 2018). Although the term family is not exact, it includes persons with whom the individual is closely associated. Typically the individual's closest family member is the first choice as surrogate. Family may include partners, spouses, and very close friends.

In cases where there is no one closely associated with the individual, but there are persons who both care about the individual and have sufficient relevant knowledge of the individual, such persons may be appropriate surrogates. APRNs must familiarize themselves with specific state and institutional rules and regulations regarding surrogates. The APRN must be sensitive to possible multiple conflicting views of family members in these circumstances. In the case of a comatose married woman, her husband became her surrogate. However, conflict arose when the individual's mother wanted care withdrawn. The individual's mother petitioned the courts and lost. In this situation, the husband's status as closest family member won out.

### 3.10. WITHDRAWING AND WITHHOLDING TREATMENT

End of life decisions are viewed as complex and instilled with uncertainty. Each person experiences health decision-making uniquely. In the context of end of life situations, both individuals and their families are challenged with complex decision-making. These situations involve questioning, and uncertainty intersects with a struggle to do the right thing. Families and care providers also struggle with the possibilities of failing to do the right thing according to the expectations of self and others (Milton, 2010).

Withholding and withdrawal of life support is a process through which various medical interventions are either not given to individuals or removed from them with the expectation that the individuals will die from their underlying illnesses. The withholding and withdrawal of life support is legally justified primarily by the principles of informed consent and informed refusal, both of which have strong roots in the common law. The principles hold that treatment may not be initiated without the approval of individuals or their surrogates except in emergency situations, and that individuals or surrogates may refuse any or all therapies.

End of life decisions are often made using a shared decision-making model. Shared decision making is a collaborative process involving care providers, individuals or surrogates the opportunity to engage in health care decision making incorporating best evidence with the individual's values, goals, and preferences (Kon, Davidson, Morrison, Danis & White, 2017). Using this model, clinicians attempt to clarify an individual's values and reach consensus about treatment plans consistent with individual preferences. Critically ill individuals are impaired in their decision making ability, leaving family members and other surrogates to make end-of-life decisions, in accordance with a substituted judgment standard. Health care providers often make decisions for individuals who lack families or other surrogates and have no advance directives, based on a best interest standard.

What may seem the right thing to do to one individual may seem cruel and unjustified to another. Individuals and families may elect to withhold feeding and hydration, and allow death to occur “naturally.” However, as the individual is dying, a family member may question if they are causing death by not feeding or hydrating the individual. The goal of non-maleficence is at the forefront when questions arise. It may be reasonable for the family to provide a dying individual a small amount of water as this is not likely to neither cause harm nor change the outcome. Providing pain relief may be acceptable for the same reason.

Just as some health care providers may have mixed motives in caring for dying individuals, some family members may want to ease their loved ones’ pain while possibly hastening death. Family members may disagree on the chosen approach and may try to alter the plan by having the individual treated emergently in an acute care facility. They may be challenged to respect the individual’s autonomy and decision to withhold treatment. APRNs may provide education and support to individuals and family members when the decision to withhold further treatment is made in an attempt to ensure the individual is spared additional, unwanted medical intervention.

APRNs are often key members of a palliative care team. Palliative care improves the quality of life for individuals and families dealing with life threatening illness through the prevention or treatment of suffering. This includes assessment and management of pain and other physical, psychosocial and spiritual problems in terminally ill individuals (WHO, N.D.). The withholding and withdrawal of life support and the administration of palliative care usually involve a multidisciplinary approach, and all involved parties, including the APRN, should participate in planning how such care is realized. The APRN may work to achieve the goal of palliative care, which is to provide comfort. Measures that do not relieve suffering but merely hasten death should be avoided.

End of life care includes difficult decisions. Dying in America is often complicated by discordant treatment teams, insufficient treatment of discomfort, transitions of care settings, and care responsibilities assumed by family members (National Academy of Medicine, 2015). To minimize conflict, the goal of palliative care and the means of achieving that goal should be clearly spelled out in the health record.

Documentation reflects the goal of palliative care to avoid ethical and legal conflict. Opportunity exists for APRNs to assist in the process of shared decision making regarding end of life planning, withholding, and withdrawing of treatment. APRNs in community settings can assist the process by engaging in meaningful discussion with individuals and families long before they are critically ill. According to the National Academy of Medicine (2015), conversations for advance directives do not occur because neither family members nor providers start the dialogue. Both are waiting for the other to initiate the conversation. The APRN works with individuals and families to clarify end of life desires in advance, utilizing clearly written advance directives which could minimize the need for surrogates.

### 3.11. ORDINARY vs. EXTRAORDINARY TREATMENT

Individuals may be eligible for medical treatment, regardless of whether the treatment is viewed as extraordinary or ordinary. The term ordinary is not equivalent to usual or customary. Ordinary care

implies any treatment modality which offers reasonable hope of benefit, and can be used without excessive expense, pain or other inconvenience for the individual (Beauchamp & Childress, 2013, p. 162).

Extraordinary care, if used, would not offer a reasonable hope of benefit. Any treatment which is excessively expensive, excessively painful, or is inconvenient may be considered extraordinary (Beauchamp & Childress, 2013, p. 162). Employing this definition of care would imply that any treatment which offers no reasonable hope or benefit should be avoided, as this would be considered harmful to the individual.

The notion of ordinary and extraordinary care is replaced with the concept of optional management. The following example illustrates this distinction. Treating pneumonia in an elderly community residing female is usual and prudent care. In the case of an 88 year old female with advanced Alzheimer's, COPD, and alcoholism, the family and primary care provider agreed to forego treating this individual's acute pneumonia. Instead, this individual was provided comfort measures in her home where she died within 48 hours of diagnosis.

Opting not to treat the individual's pneumonia seems reasonable utilizing a shared decision making model. Treating the individual's pneumonia could ultimately have prolonged her life; however, the question of benefit should be examined. Treatment in this case would require an inpatient admission, as the individual was not lucid. She would have required ventilator support and invasive management in an intensive care setting. This would make the treatment of pneumonia in this case extraordinary care as it would be expensive, painful, and inconvenient. The APRN well versed in shared decision making can assist individuals and families in choosing the best options for care.

Health care providers may make sound moral judgments by examining the type of treatment to be used. Consideration must be given to the degree of complexity or risk, the cost and availability of the treatment. Payment should not influence treatment decisions of the moral provider. By comparing the risks of a particular treatment with the potential for benefit, and accounting for individual's base line health status and the current acuity of the situation, prudent decisions regarding care can be made.

When deciding to employ an extraordinary treatment, a health care provider must consider the individual's desires, condition, the likelihood of survival and the cost. Employing a costly and limitedly available therapy may be appropriate if there is significant long term benefit. The availability of organs for transplantation can be scarce. This modality is therefore not readily available to all individuals. Teams are typically involved in the decision making for who should obtain this limited resource. APRNs may be members of these teams.

APRNs encourage individuals to accept those treatments which they believe are reasonable and beneficial, while considering the burdens of a particular treatment. This will vary from person to person. Ultimately the APRN respects it is the individual's responsibility to accept or decline treatments. The APRN exercises best judgment in cases in which an individual's motives may be unclear.

### 3.12. MEDICAL NUTRITION

Medical nutrition refers to nutritional procedures including assessment and interventions in the treatment of an illness, injury or disease condition. A specially tailored diet is planned based upon the individual's medical, psychosocial history, physical examination, and dietary history. Medical nutrition may reduce the risk of developing complications in conditions such as diabetes, or it may ameliorate the effects of conditions such as hyperlipidemia. Many medical conditions may either develop or worsen due to improper or lack of nutrition.

Invasive interventions such as feeding tubes may be employed to improve an individual's nutritional status when an individual is unable to eat or swallow. The use of feeding tubes in nursing home residents with advanced dementia is a well-known example. In this individual population, the nutritional need is evident. However, providing forced nutrition will not reverse the individual's dementia and the disease will progress.

Nurses play a vital role in providing information and guiding family members through difficult nutrition decisions. Investigators found that nurses believe family members would benefit from guidance in decisions regarding the placement of feeding tubes (Lopez, Amella, Mitchell, & Strumpf (2010)). However, their findings indicate that nurses were reluctant to become involved in these difficult decisions. For nurses to guide family members about the use of feeding tubes, they require education about the rationale for doing so utilizing evidence-based research. APRNs are key members of the health care team able to support the education of individuals, staff nurses and families to reach decisions which are beneficial and optimize quality of life.

Feeding tubes have associated risks and complications, including obstruction and site infection. They require daily maintenance. The demands of this therapy may be more than a family can provide and this in turn may infringe upon the individual and family's quality of life. APRNs must weigh the benefits of nutritional therapy with the associated risks when considering this option for an individual. APRNs may provide recommendations for nasal gastric feeding tube placement on an as needed basis as opposed to a more invasive procedure.

When an individual requires more nutritional support, the APRN can request a consultation with a gastroenterologist for placement of a percutaneous feeding tube. The APRN engages in the process of shared decision making with the family and other members of the health care team. The APRN should support the individual's wishes in the process of determining what the best nutritional therapy is for the individual.

### 3.13. MEDICAL FUTILITY

Futile medical care exists when there is no hope for improvement in an incapacitating condition. Futile care fails to offer benefit (Jecker, 2014). Quantitative futility is defined as existing when the possibility a treatment will benefit a patient is exceedingly poor. Qualitative futility refers to the quality of benefit of a treatment will be exceedingly poor. Both types of futility indicate the benefit will not have a positive effect on the individual.

Futile care has no possibility of achieving a good outcome and serves only to prolong life. There is no known physical or spiritual benefit derived from such care. Futile care may prolong grieving and give false hope. Caregivers may see themselves as forced to act against the best interests of their individual in cases of futile medical treatment.

In a setting of limited resources, futile care involves the expenditure of resources that could be used by other individuals who have a likelihood of achieving a positive outcome. The utilitarian will argue that a just society should spend and ration its resources sensibly in order to save as many lives as possible. A grim prognosis does not justify an end to care, but a truly futile prognosis requires further consideration by the APRN and members of the healthcare team.

For example, Baby K was born anencephalic with only the brainstem having developed during pregnancy (Ascension Health, 2012). The baby's mother had been notified of her condition following ultrasound and had been advised to terminate the pregnancy by her obstetrician and neonatologist. The mother chose to carry the child to term because of her religious beliefs. The mother and the hospital in which she delivered had opposing views on care for this child.

The hospital physicians strongly advised a Do Not Resuscitate (DNR) order for the child, which the mother refused. Baby K remained on ventilator support for six weeks while a search for another hospital was done. No other facility would accept Baby K. Finally, the child was transferred to a long term care nursing facility after being weaned from a ventilator, but the baby returned to the hospital many times for respiratory problems. Many critics of this case insist that the medical expenses used to keep Baby K on life support for over two years could have been better spent on awareness and prevention efforts of her condition (Ascension Health, 2012).

Some argue that futile clinical care should be a market commodity able to be purchased (Appeal, 2009). If the purchaser of the clinical services has the necessary funds, and as long as other individuals are not being denied access to clinical resources as a result, it may be reasonable to utilize this commodity. In this scenario, Baby K would be able to receive ICU care until funding vanished.

The issues of equity often arise in treatment of end-stage cancer (Khatcheressian, Harrington, Lyckholm, & Smith, 2008). Researchers report lack of provider-individual communication regarding prognosis, goals of therapy, and benefits of aggressive symptom management contribute to the delivery of futile chemotherapy. APRNs engage in open communications to avoid subjecting individuals to futile care.

The purchasing of care is an option in need of examination. If the goal of nursing practice is to do no harm and to benefit an individual, is futile care providing the individual benefit? If the individual or family has the resources to provide the necessary care to keep an individual alive and not tax the system at large, is it reasonable to allow for this type of care?

When caring for an infant who survives an anoxic brain injury and requires home ventilator support, this question is a difficult one. These children require expensive, daily multidisciplinary therapies, including speech therapy, physical therapy, occupational therapy, and nursing care. They require care from primary pediatric services, as well as sub-specialty services, such as pulmonary medicine. The parents

require education and support in caring for a technology dependent child. As these children grow, they will continue to require services and durable medical equipment.

Resuscitating infants who suffer anoxic brain injuries at birth may result in lifelong care. It is a difficult decision for health care providers and parents to allow a neonate to die without intervention. The parents may choose to have every intervention done to save their infant even after being given a poor prognosis. It may be satisfying to the parent to have the baby in their care regardless of the outcome. Truly informed consent is necessary in these circumstances because of the high level of emotions involved.

APRNs communicate openly with parents in these challenging situations. The APRN thoroughly explains the process of resuscitation and that successful resuscitation does not negate brain injury. The dilemma is who is obtaining benefit from care in this situation—the parent or the child. Ethics committees in the setting of limited resources may determine if some individuals are beyond medical hope and if care would be futile.

### 3.14. ETHICS COMMITTEES

Ethics committees typically include members from diverse backgrounds who support health care institutions with three major functions: providing ethics consultation, developing and/or revising select policies pertaining to clinical ethics, and facilitating education about topical issues in clinical ethics (University of Washington Department of Bioethics & Humanities, 2010). These committees may assist with interpreting advance directives, withholding and withdrawing life-sustaining treatments, informed consent, and decisions surrounding organ procurement.

Ethics committee members may represent major clinical services and other stakeholders in health care delivery such as clinicians from medicine, surgery, psychiatry, nursing, social work, a chaplain, and a community representative. APRNs may serve as committee members. These committees often include a quality improvement manager, an educator employed by the facility, a lawyer, and at least one individual with advanced training in ethics. The individual with advanced training in ethics may come from philosophy, law, medicine, theology, or anthropology.

A clinician faced with an ethical dilemma requests an ethics consultation when two conditions are met: there is an ethical problem in the care of an individual, and the resolution does not occur after bringing this to the attention of the team responsible for the care of the individual (University of Washington Department of Bioethics & Humanities, 2010). A true ethical dilemma occurs because there is a conflict between principles of autonomy, beneficence, and justice, or between principles and outcomes.

Clinical ethics consultations are interventions by trained members of a bioethics advisory committee to help resolve an ethical dilemma or answer an ethical question that arises in the course of individual care. The consultation is purely advisory. Bioethics committee members and consultants have no authority to make individual care decisions. Individuals and their insurers are typically not charged for ethics consultations.



The process of an ethics consultation consists of several steps. Consultants review medical records and interview the individual, physicians, nurses, family members, surrogate decision makers, and other relevant parties. The consultants provide an analysis of the ethical issue and suggest means to resolve it. This may include a face-to-face meeting with all parties. The case may be presented to a full bioethics advisory committee meeting and discussed. Follow-up is often performed.

The most common issues prompting clinical ethics consultations are conflicts between the medical and nursing staffs over the best care of the individual. Other reasons may include a conflict between the medical-nursing staff and the family over an individual's plan of care. Evidence that the medical staff is not following the wishes of the individual or surrogate results in conflict. Evidence that the family or surrogate decision maker is making a decision that is not in the individual's best interest can also result in an ethical dilemma.

### 3.15. CASE STUDIES

The APRN may face multiple ethical challenges while engaging in clinical practice. The following scenarios are examples of situations that may arise.

#### 3.15.1. Case One

A nineteen year old female individual presents to the urgent care center with her mother and with a 10 day history of right lower quadrant pain. Both are feeling frustrated due to lack of a diagnosis. The individual was seen 10 days ago in an emergency department and discharged being told she had a hernia which would require evaluation in an ambulatory setting. She then saw her family physician three days later and was referred to a surgeon who would be seeing her in two weeks. She presents this evening due to continuation of the pain and her mother's pressuring her to "find out what is wrong." The individual denies any loss of appetite, nausea, vomiting or diarrhea. She reports dysuria with frequency. She denies that movement or lifting increases her pain. She also denies any bulges to her abdominal wall, just a small "bump" to the right lower abdominal region that is not painful. It is difficult to obtain a history directly from the individual because her mother continually interrupts and answers the questions for the individual.

On further questioning, the individual admits to a vaginal discharge, burning with urination, and sexual activity without barrier protection. She had a boyfriend for the past year with whom she recently ended the relationship. She is uncertain as to whether he had other sexual partners. She reports that he had been her only partner. Her last gynecologic visit was one year ago. She denies a history of previous sexually transmitted infections (STI). Her last menstrual period was two weeks prior and was normal.

After examination, the individual was diagnosed with a sexually transmitted disease. She did not wish to share this information with her mother. The individual's mother pressured the provider for answers and a diagnosis. The provider was challenged to maintain the individual's confidentiality. What ethical principle would guide this provider's decision making? How should she handle the missed diagnosis by the family physician? Are there legal ramifications? What if the individual loses fertility because of the

delay in diagnosis? If the mother of the individual was paying for the individual's medical bills, would that change what information she should be given?

### 3.15.2. Case Two

A 78 year old male individual was admitted to the hospital with a brain injury after a fall. He has a history of diabetes mellitus, hypertension, anemia and dementia. He presented with areas of ecchymosis to his forehead. His computerized tomography (CT) scan showed hemorrhagic contusions of the bilateral frontal lobes, left temporal lobe, and small subdural hematomas on the frontal lobes. During his hospitalization he was oriented to person, place, and time and dates for a portion of his stay. The nursing staff reports the individual suffers from occasional confusion, mild short term memory loss, and intermittent agitation. At times he was aggressive to the nursing staff and often refused medications, including insulin and antihypertensive prescription drugs. The APRN managing this individual's care is faced with a dilemma. Can this individual with a documented brain injury and history of dementia refuse his medical therapy? Can he be forced to take his medications? How should the practitioner proceed? Is an ethics committee consult necessary?

### 3.15.3. Case Three

An 82 year old female is admitted from the nursing home for an acute exacerbation of heart failure (HF) and hypernatremia. The individual suffers from advanced Alzheimer's dementia. The individual required diuresis with intravenous furosemide (Lasix) and over the next four days, the HF symptoms and sodium levels improved. Two days later, the sodium levels decreased and a nephrology consultation was obtained. The individual was started on tolvaptan (Samsca) to treat the hypernatremia. This improved the sodium levels, but the individual became hypokalemic, requiring treatment for the elevated potassium. The individual then experienced an episode of syncope resulting in a fall, from which she recovered. The following day, she had an episode of staring off into space which was suspected to be a seizure. The individual was evaluated for a cerebral vascular accident (CVA) and no acute bleeding was identified. The individual continued to experience a complicated hospitalization and worsening of her dementia.

How does the APRN approach an elderly frail individual with multiple complex conditions? Was admission for the HF and resulting complications worth the risk of worsening the individual's dementia? How could this situation be avoided? When is palliative care appropriate for this individual?

### 3.15.4. Case Four

A thirteen year old female comes to the office with her mother for an annual physical examination. During the exam, when she is alone with the practitioner, the individual advises the APRN that she has been sexually active for the past year. The APRN completes the examination and during the follow-up office time, recommends the vaccination for human papilloma virus (HPV). The individual's mother refuses this vaccination as she states her daughter is not sexually active. The individual's mother is

concerned that by vaccinating her daughter, she is encouraging early sexual debut. The individual is not vaccinated on this visit and the APRN recommends a follow up visit in two weeks. At the next visit, the individual arrives without her mother and she requests the HPV vaccination. How does the APRN advise this individual? What ethical principles are guiding the APRN's decision to vaccinate this individual? Are there legal issues involved? Does the provider have a duty to tell the individual's mother? Is the provider obligated to counsel the individual to tell her mother?

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