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Ethical Challenges for the Nurse Caring for Neurologically Impaired Patients

A Case-Based Discussion

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Every day, nurses face difficult clinical situations. Neurologically impaired patients can be physically challenging patients by the nature of the illness; however, these patients can present unique ethical challenges as well. Nurses caring for neurologically impaired patients may experience a high burden of moral distress. This article seeks to briefly review the development of the Western medical ethical landscape and to highlight the unique ethical conflicts of nursing neurologically impaired patients.

KEY WORDS

ethics, nursing, neurologically impaired

At the heart of all nursing care is the desire to improve the well-being of the patient, family, and community. In the best of circumstances, health care decisions can be difficult. In the current health care environment of increasingly complex regulations, complicated treatment plans, and skyrocketing medical costs, nurses are challenged to see a clear path through these complexities. Ethical principles are a valuable tool for modern nurses. When charged with the care of the neurologically impaired patient, nurses carry a heavy burden to maintain solid ethical footing in an uncertain situation. At the same time, a 2008 Gallup survey of Americans ranked nurses as the top-rated profession for honesty and ethics.[1] In addition, the phenomenon of moral distress is emerging as a theme in nursing literature.

A BRIEF HISTORY OF MEDICAL AND NURSING ETHICS

Historians date the first code of medical ethics to the famous Hippocratic Oath. The oath requires physicians to pledge adherence to a number of ethical standards, broadly including patient confidentiality and nondiscriminatory care for all classes. The fifth century common era saw the Formula Comitis Archiatrorum, recorded by Cassiodorus, requiring physicians to work toward a deeper understanding[2] of disease and is the basis for modern-day medical consultation. Medical ethics also draws from the ninth century book *Practical Conduct of a Physician* by Ishaq ibn al-Ruhawi, documenting the first known medical peer-review and accountability process.[3]

Modern medical ethics practice is grounded in the 1794 pamphlet by Thomas Percival of England. This pamphlet led to the 1847 American Medical Association's first published code of medical ethics. In the aftermath of World War II, the world learned of the horrors of Nazi medical experimentation. Born out of the Nuremberg Trials, the Nuremberg Code explicitly mandated subject consent for conduction of human experiments. Following the Nuremberg Code, the Belmont Report was published in 1979 in the United States. The Belmont Report attempted to identify ethical principles to ensure the protection of human subjects in medical experiments—beneficence, justice, and respect for individuals. In modern medical practice, the main ethical principles have come to include autonomy, beneficence, nonmaleficence, justice, and respect for persons (Table 1).

Florence Nightingale brought nursing into the professional realm with the founding of the first formal nurses training program in 1860. Modern nursing and nursing ethics stand upon the shoulders of Nightingale. The Florence Nightingale Pledge was authored by Mrs Lystra E. Gretter and a Committee for the Farrand Training School for Nurses. The Pledge reads: "I solemnly pledge myself before God and in the presence of this assembly, to pass my life in purity and to practice my profession faithfully. I will abstain from whatever is deleterious and mischievous, and will not take or willingly administer any harmful drug. I will do all in my power to maintain and elevate the standard of my profession, and will hold in confidence all personal matters committed to my keeping and all family affairs coming to my knowledge in the practice of my calling. With loyalty will I endeavor to aid the physician in his work, and devote myself to the welfare of those committed to my care."[4]

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TABLE 1 Principles of Medical Ethics

Ethical Standard	Definition	In Practice
Autonomy (*voluntas aegroti suprema lex*)	Literally ''self-governance''	The right to chose or decline medical therapies
		Informed consent
		Shared decision making
Beneficence (*salus aegroti suprema lex*)	Act in the best interests of the patient	Assessment of risks and benefits of proposed medical intervention
Nonmaleficence (*primum non nocere*)	''Do no harm''	Assessment of detriment and benefits of proposed medical intervention
Justice	''What is deserved''	Allocation of limited medical resources, including expenditure of medical dollars and utilization of medical staff
Respect for persons		Right to treatment with dignity and honesty

By 1900, the first book of nursing ethics was published by American nursing pioneer Isabel Hampton Robb—*Nursing Ethics: For Hospital and Private Use*. By 1950, the American Nurses Association (ANA) published its first official code of ethics.[5] The current ANA code of ethics is listed in Table 2. The International Council of Nurses, Canadian Nurses Association, and the Royal College of Nurses have also published codes of ethics.[6-8]

The ANA anticipates publication of an updated code of ethics in 2015 in response to the changing health care environment, with an eye toward supporting nurses in all settings. The Executive Summary of the summit meeting for Nursing Ethics for the 21st Century provides this vision statement[10]: "Ethics is a critical part of everyday nursing practice. Nurses in all roles and settings must have the knowledge, skills and tools to uphold their professional values. We pledge

TABLE 2 American Nurses Association Code of Ethics[9]

Provision 1	The nurse, in all professional relationships, practices with compassion and respect for the inherent dignity, worth, and uniqueness of every individual, unrestricted by considerations of social or economic status, personal attributes, or the nature of health problems.
Provision 2	The nurse's primary commitment is to the patient, whether an individual, family, group, or community.
Provision 3	The nurse promotes, advocates for, and strives to protect the health, safety, and rights of the patient.
Provision 4	The nurse is responsible and accountable for individual nursing practice and determines the appropriate delegation of tasks consistent with the nurse's obligation to provide optimum patient care.
Provision 5	The nurse owes the same duties to self as to others, including the responsibility to preserve integrity and safety, to maintain competence, and to continue personal and professional growth.
Provision 6	The nurse participates in establishing, maintaining, and improving health care environments and conditions of employment conducive to the provision of quality health care and consistent with the values of the profession through individual and collective action.
Provision 7	The nurse participates in the advancement of the profession through contributions to practice, education, and knowledge environment.
Provision 8	The nurse collaborates with other health professionals and the public in promoting community, national, and international efforts to meet health needs.
Provision 9	The profession of nursing, as represented by associations and their members, is responsible for articulating nursing values, for maintaining the integrity of the profession and its practice, and for shaping social policy.

to work together to support and safeguard the professional values of nurses—and all health care professionals—and to strengthen a culture where they are able to practice ethically."

As the fields of medical and nursing ethics have advanced, the concept of moral distress has emerged. Originally coined by Andrew Jameton[11] in 1984 and defined as the experience of knowing the right thing to do but being unable to follow this course of action as a result of external constraints, the term *moral distress* has evolved. Webster and Baylis[12] describe it as the feeling that arises when an "error in judgement, or a personal failing, or some external and uncontrollable circumstance prevents an individual from doing the right thing." Although the definition of moral distress continues to evolve,[13] a growing body of international research has demonstrated that moral distress is clearly a distinct phenomenon. Importantly, moral distress looms large across health care disciplines.[14-20] Although ethical conflicts and moral distress are distinct phenomena, moral distress arises commonly among health care providers facing ethical conflicts. Moral distress acutely relates to adherence to professional and personal values, duties, and responsibilities.[17,21,22]

APPLYING ETHICAL PRINCIPLES TO THE NEUROLOGICALLY IMPAIRED PATIENT

Provision 3 of the ANA's code of nursing ethics perhaps speaks most to the challenges of nursing the neurologically impaired patient. The neurologically impaired patient is unique from the general medical population for a number of reasons—this serves only to heighten the ethical imperatives as well as the moral distress experienced by providers. Neurologically impaired patients may be deemed not competent to make medical decisions. The declaration of noncompetence heightens the patient's vulnerability and leaves him/her open to coercion, neglect, or frank abuse. In a severely impaired patient, the nurse carries great responsibility of maintaining the patient's safety. The disease trajectory may stretch for years or decades, as with Huntington disease or dementia. Alternatively, a sudden and neurologically devastating event such a head injury or intracranial hemorrhage may preclude an open dialogue with surrogate decision makers. With a severely debilitating disease such as muscular dystrophy, there is significant potential for disease-related suffering.

A number of other factors further complicate the landscape of neuroscience nursing. Significant neurologic impairment can occur across the ages—from the child with neural tube defects to the elder with vascular dementia. The moral burden of surrogate decision making can weigh heavily on the surrogates. Nurses are frequently witness to the significant burden of suffering of the patient, caregivers, and medical team. Nurses caring for neurologically impaired patients may experience moral suffering in the face of incurable illness, family and patient distress, and interfamily conflicts.

CASE-BASED EVALUATION OF ETHICAL CHALLENGES

Case 1—"Derrick"

Derrick was in graduate school and a rising mechanical engineer with 3 patents under his belt by age 24 years. He was the younger child in a family of 2 children. Derrick's mother was recently diagnosed with widely metastatic breast cancer. Derrick came to the attention of the hematology-oncology team when he presented to the emergency department with profound fatigue and shortness of breath. His hemoglobin level was 4.2 g/dL and peripheral blood smear reveals 20% circulating blasts. Derrick was diagnosed with acute myeloblastic leukemia (AML). Derrick underwent matched sibling stem cell transplantation. During the weeks that ensued, Derrick experienced delayed marrow engraftment followed by profound intestinal graft versus host disease (GVHD). He required intensive care for fluid and electrolyte management. After several weeks, Derrick's intestinal GVHD was controlled, but he began to experience other GVHD manifestations, including skin and hepatic GVHD.

Derrick had completed a durable power of attorney for health care naming his father (Franklin) but did not complete a living will. He had several conversations with his oncologist about his wishes, indicating that he wanted aggressive treatment "as long as there is a hope that I'll pull through this." Unfortunately, Derrick's platelet levels fell on posttransplantation day 73. He became obtunded after he experienced a large intraventricular hemorrhage. Derrick was transferred to the neurologic intensive care unit (ICU). The neurosurgeons remained hopeful that Derrick would recover neurologic function. After placement of a ventriculoperitoneal shunt, Derrick's cognition and level of consciousness improved. After 54 days in the neurosurgical unit and neurologic ICU, he was transferred back to the hematology-oncology ward for ongoing GVHD management. Ongoing bone marrow biopsies showed no evidence of leukemic cells.

Derrick ultimately was hospitalized for 14 months (including a 6-week stay for acute inpatient rehabilitation) before he was discharged home. Derrick remained at home for 3 days before he was readmitted with a profound recurrence of intestinal GVHD. Derrick developed a lower gastrointestinal bleed and was taken emergently to the operating room for an exploratory laparotomy on posttransplantation day 384. The surgeons removed 2 ft of diffusely hemorrhagic large bowel and created a colostomy. Derrick's parents and sister came to the ICU in tears—they understood the severity of the situation. Derrick's father, Franklin, however, fixated on the ongoing "cure" of Derrick's AML. Franklin became distressed during the consultation with the surgeons and abruptly ended the goals-of-care conversation. Derrick remained intubated in the ICU and on pressor support for 5 days before developing levophed-associated necrosis of the lips, toes, and fingertips. Derrick did not regain consciousness and died despite maximal medical therapy on posttransplantation day 389. By the end of Derrick's life, he had exceeded his insurance lifetime maximum, depleted his savings, and was provided financial assistance by the hospital.

After Derrick's death, the ICU nurses expressed tremendous anger and frustration over the manner of his death. Derrick's medical team had consulted the ethics team in his final week of life. Unfortunately, the ethics team was unavailable for consultation and family conference until Derrick's last day of life. The consultation was not held as Derrick was actively dying during the scheduled time.

A month after Derrick's death, the oncology social worker and chaplain held a debriefing conference. Nurses and physicians from each of the medical units involved in Derrick's care were invited. The ethics committee chair was available for the debriefing.

Case 1 Discussion

Several staff reactions emerged around the conflicts that presented during the prolonged course of his care. Staff were distressed—many expressed tremendous sadness, unease, and anger. They perceived that Derrick experienced prolonged suffering in a medically futile situation as a direct result of his father's decision to continue maximal medical therapy. One nurse commented, "we are here to save people who can be saved and to ease the transition to the next life for people who are beyond saving. This was an undignified way for a 24-year-old man to spend his last days." This is a classic example of moral distress—the nurses felt an obligation to ease Derrick's suffering in his final weeks. Because of his father's choices, Derrick was denied the ability to die a peaceful and natural death. The oncology social worker offered validation of the staff's distress.

After the initial processing, the ethics committee chair moved the discussion further. She highlighted the ethical themes emerging:

Veracity: there was a dearth of honest discussion with the patient and family about prognosis of the AML and GVHD. In part, this was a result of the fragmented care Derrick received across the organization. Multiple teams cared for Derrick, although the hematology-oncology team was the most consistent and was the team that discussed his wishes for medical care. Once Derrick became acutely ill during his last stay in the ICU, Derrick's father pulled aside the nurse and asked, "what are we really looking at here?" The nurse felt ill-equipped to discuss Derrick's true prognosis. With the medical intensive care unit team, Derrick's father expressed his concerns that Derrick's mother would stop treatment for her breast cancer if Derrick died. Derrick's father had repeatedly implored the team to hide Derrick's prognosis from his mother.

Beneficence: Derrick's father's conflict between decision making for his dying son and caring for a terminally ill wife, each of them "fighting for the other." In an ideal situation, the surrogate would be able to think purely of the patient's best interests. Unfortunately, Derrick's father was in conflict. He wanted for both his wife and his son to live. Derrick's father had been asked to make a decision to withdraw life support or to change his code status to do not resuscitate.

The nurses and medical teams questioned the decision for aggressive and ultimately futile care. This was in direct conflict with Derrick's expressed wishes. When Derrick entered the hospital the last time, it became clear that Derrick was dying. To the medical team, there was no reasonable hope for recovery. In the team's opinion, the ongoing intubation and pressor support were not beneficent care.

Justice: The surgeon that operated on Derrick's bowel questioned how much money the hospital lost on Derrick's care. It seemed to the surgeon that Derrick's care was a tremendous injustice. The surgeon had spent time volunteering on medical missions in foreign countries and had trained in the local county hospital. He was saddened by the iniquity of care and access to care across countries and even across institutions. The ethicist acknowledged that Derrick's care was emblematic of the unfair distribution of limited medical resources.

Ultimately, there was no opportunity to resolve these ethical conflicts. The debriefing session offered the nursing and medical staff the opportunity to share lessons learned and to processes the deep conflicts of Derrick's care.

Case 2—"Tracy"

Tracy was a 68-year-old mother of 3 grown men. Tracy was diagnosed with a malignant brain tumor after experiencing a seizure at church. Tracy's second husband, Rich, accompanied her to every neuro-oncology appointment. Tracy's first husband was the father of her sons and had died 10 years before in an industrial accident. Rich was clearly a strong presence in Tracy's life, often dictating her medical choices. With each successive tumor recurrence, Tracy became cognitively impaired and her aphasia worsened. Tracy largely deferred to Rich as her surrogate decision maker. However, during 1 chemotherapy infusion, Tracy's son Ezekiel mentioned to the nurse that he worried about Rich's intentions. Ezekiel felt Rich wanted to keep Tracy alive to continue collecting her disability benefits.

Eventually, all treatment options were exhausted. After receiving 2 courses of Food and Drug Administration–approved chemotherapy, Tracy completed a clinical trial. When her tumor recurred a fourth time, the neuro-oncologist recommended hospice care. Rich was adamantly against the recommendation. Rich lobbied the neuro-oncologist to prescribe an older chemotherapy regimen. After much discussion of the potential risks and likelihood of disease stability, Tracy received this regimen. Tracy was completely aphasic and dependent for all transfers and mobility. Rich professed profound faith and a strong belief that "G-d would heal" Tracy's tumor.

After Tracy's next magnetic resonance imaging (MRI) scan again demonstrated tumor growth, the neuro-oncologist refused to prescribe further chemotherapy. Rich was not accepting of the neuro-oncologist's recommendation for hospice care. Rich insisted on continuing to search for a treatment center that would accept Tracy for a clinical trial. Arrangements were made for Tracy to remain at home with home health and monthly in-home palliative care consultations as Rich continued his search. At this juncture, Ezekiel and his brothers consulted with an attorney. They shared with the neuro-oncology team that they were pursuing legal guardianship over Tracy's care and finances. Ezekiel and his brothers asked for documentation from the neuro-oncologist to bolster their legal standing. The neuro-oncologist, after consulting with the hospital attorney, declined to get involved in the family dynamic but directed them to the medical records department for a copy of her medical record. The neuro-oncologist did, however, phone the state's Department of Health and Human Services. He reported to the state's caseworker his concern for financial exploitation of Tracy by her husband and documented this in the medical record.

The home health nurse remained in regular contact with the neuro-oncology team. Rich began administering Tracy an oil derived from marijuana in the belief that it was an antitumor therapy.

In addition, Tracy demonstrated diminishing interest in food. Rich struggled to accept this observation and continued to make home-made pureed soups. Rich spoon-fed Tracy for 3 months before Tracy ultimately succumbed to her tumor. After her death, Rich phoned the clinic and asked for a postmortem MRI to demonstrate how efficacious the marijuana oil was in "curing" Tracy's tumor. The physician declined to order an MRI.

Case 2 Discussion

Autonomy: Tracy's default deference to Rich as her decision maker was problematic. In part, Tracy seemed to demure to her dominating husband, and in part, she had seemed to the treating team to truly share some of Rich's ideas about faith and health. The neuro-oncologist was ultimately torn between the family in this complex situation and used the available legal resources to navigate the situation. He did not, however, consult with the medical ethics team. The physician expressed a feeling of having done "due diligence" in referring the case to the state's Department of Health and Human Services. The physician also felt that Tracy's deference to Rich for medical decision making from early in her treatment course was de facto consent of medical surrogacy.

The clinic nurse working with the physician felt that for Tracy to be truly exercising autonomy, she would have been making decisions without controlling outside forces (ie, Rich's influence). However, the nurse allowed, "Even from day 1, Tracy looked to Rich when she elected for treatments. I guess she really did want his help." This case highlights the difficulty of allowing patients to elect choices that we as nurses may disagree with personally and professionally.

Balancing beneficence and nonmaleficence: Rich's dominance over Tracy's care may have resulted in more aggressive therapy than most patients receive. The neuro-oncology clinic referred most patients to hospice care for the final weeks and days of life. Tracy did not benefit from this and instead received rather aggressive oral feeding, even when she was losing the ability to safely swallow. Certainly, all providers struggle with the risk-benefit balance of aggressive treatment in palliative care scenarios.

Tracy's case highlights the struggle between "doing good" and "doing no harm" in several ways. First, Tracy received aggressive chemotherapy at the fourth recurrence of her tumor. Tracy was no longer able to provide verbal feedback to her team about her discomfort, and the clinical assessments were made based in part on Rich's sense of how Tracy was doing. This information was open to significant bias as a result. The neuro-oncologist felt that the fourth line of treatment was potentially efficacious based on published data and his experience. Her quality of life was arguably impacted by this treatment.

Second was Rich's behavior of aggressive feeding and oral hydration in Tracy's final weeks. The palliative care team and home health nurse had both counseled Rich on the expected phases of dying. The home health nurse informed Rich that as Tracy withdrew from life-sustaining behavior such as eating and drinking, it was signaling a more imminent demise. Tracy's stomach bloated with the excess food and liquid despite a bowel regimen to prevent constipation. Rich seemed to be unable to process this information but agreed to stop feeding Tracy when she was no longer swallowing or responding to her surroundings. The home health nurse reported a deep sense of relief when this happened. The home health nurse also described a sense of accomplishment at navigating both complex family dynamics and a difficult ethical situation.

Lastly, the use of (federally) illegal and unregulated substances without Tracy's explicit consent is ethically problematic. The argument could be made that Rich was conducting a medical experiment. However, in the state where Rich and Tracy lived, the legislative body has passed a law permitting use of medical marijuana. Although Rich was using the marijuana oil to try to control her tumor, it may have served to alleviate pain. Tracy seemed to bear no ill effects by the report of the home health nurse and Tracy's sons.

Lessons Learned

The situations described above are conglomerations of experiences I have had over time as a practicing nurse and nurse practitioner. In the course of writing this article, I found myself reliving the ethical struggles and my personal sense of discomfort. It occurs to me that as nurses, we are continually traumatized and retraumatized by both loss and ethically muddy situations. This work is both physically and emotionally/spiritually taxing. How do we prevent burnout? How do we draw young people to this profession knowing the difficulties they will face? The answer for this nurse lies in taking a hard look at how I first provide care to myself.

In working through a difficult ethical situation, I have found that the first step is to unite the care team—bring the patient, family, and providers to a mutual understanding of the perceived problem. If this does not "resolve" the conflict, seek outside assistance from available resources. In many hospitals, ethics committees are now available. Then, share the experience so that others can learn from the experience. Lastly, as nurses and the frontline of health care, we owe it to ourselves to understand our own cultural and individual biases. We strive to refine nursing both in the practice of our profession and in the ethical underpinnings of our actions. As these definitions evolve, nurses must continue to share their experiences. Future patients and future generations of nurses will look to the ethical precedents we set.

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