ETHICS IN PALLIATIVE CARE

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BIOETHICS IN PALLIATIVE CARE

- Ethical dilemmas at end of life are inevitable, complex, challenging
- Process of identifying the best course of action from available options
- Decision-making: built around guiding framework of moral principles
- Decisions may be complicated by lack of knowledge, reluctance to forego life-prolonging treatment

(Rushton, 2009)

ETHICAL PRINCIPLES

Justice:
- Goal: comprehensive, quality, equivalent end of life care
- Futile care
  Quality end of life care is not consistently available to all, especially children

(Grace, 2009)
(Goldman, 2001)

ETHICAL PRINCIPLES

Respect for persons:
- Autonomy: right of self-determination
- Privacy: confidentiality
- Veracity: truthfulness

(Grace, 2009)
ETHICAL PRINCIPLES

Nonmaleficence
• Do the least harm
• Remove any causes of harm

Beneficence
• Maximize benefit to patient
• Act in patient’s best interest

HOW DO WE IDENTIFY WHICH ACTION IS BEST?

• Quality of life measures are vital indicators of clinical benefit and are therefore important in measuring the value of treatment
• Patient/parent goals, wishes, values
• Patient’s best interest

DOUBLE EFFECT

The risk of a negative therapeutic outcome is acceptable if it fulfills four criteria:
1. The action, itself, must be morally good or neutral
2. The negative effect cannot be directly intended, even though it can be foreseen
3. The desired effect cannot be the direct result of the unintended, negative effect
4. The good effect must outweigh the negative effect that is permitted

(Rosenblum, 2005)
(Field & Behrman, 2004)
(Grace, 2009)
**RESEARCH**
- Informed consent
- Child’s assent
- Parental refusal to disclose information about terminal illness to child
  (Rosenblum, 2005)

**PHASE I TRIALS**
- Preliminary introduction of investigational drugs in children
- Identify right dose, assess for adverse reactions, toxicities
- Respect autonomy
- Values and goals should guide decisions
  (Haylett, 2009) (Horstmann, 2005)

**ETHICAL DILEMMAS SURROUNDING PHASE I TRIALS**
- Unknown effect on humans
- No guaranteed benefit or freedom from harm
- Side effects unknown
  (Haylett, 2009)
BENEFITS OF PHASE I TRIALS

- Source of hope
- Altruism
- Chance to develop more effective cancer therapies in the future
- Low risk of harm

(Horstmann, 2005)

WITHDRAWAL/WITHHOLDING TREATMENT

- Extraordinary means do not need to be utilized for support of life if the intervention is simply prolonging death
- Allows for disease to progress naturally
- Withdrawal/withholding treatment does not directly cause patient’s death
- Right of patient autonomy

(Lo, 2009) (Holmes, 2010)

DO-NOT-RESUSCITATE ORDERS

- Patient Self-Determination Act (1991)
- Public overestimates efficacy and outcomes of CPR
- Best interest of patient
- Reassure patient, family that comfort care will continue
- Repeat discussions as disease progresses to ensure adherence to patient/family wishes

(Lo, 2009) (Schroeder, 2002) (Mervat, 2008)
MANAGEMENT OF PAIN

• Lack of scientific knowledge about symptom management
• Concerns about side effects, addiction, hastening death
• Difficulty for child to communicate pain
• Assess for cultural/religious factors
  (Houlahan et al., 2006) (Ott, 2010)
  (von Gunten, 2005)

MANAGEMENT OF PAIN

• No research supports the claim that carefully titrated opioids hasten death
• Need for extraordinary pain control
• Intractable suffering as medical emergency
  (Thomas & Sykes, 2000)
  (Houlahan, 2006)

HOW DO NURSES BEST SUPPORT PARENTS OF CHILDREN AT END OF LIFE?

• Reflect on opinions, values, beliefs; know the standards of practice, code of ethics
• Provide information, education, anticipatory guidance
• Address physical, psychological, and spiritual needs of child and family
  (O’Brien, Duffy & O’Shea, 2010)
  (Rosenblum, 2005)
HOW DO NURSES BEST SUPPORT PARENTS OF CHILDREN AT END OF LIFE?

• Learn from the experts: children and families
• Establish a relationship of trust, respect, and compassion

“4 SQUARES” MODEL

• Bioethical tool: guides health care professionals through the decision-making process
• Four concepts are inherent to every clinical encounter: medical indications, patient preferences, contextual features, and quality of life

(Jonsen, Winslade, & Zieglle, 2006)

MEDICAL INDICATIONS

• Diagnosis
• Treatment options
• Risks
• Benefits
• Probable outcomes
PATIENT/PARENT VALUES AND PREFERENCES

• Goals
• Religious and cultural values
• Wishes
• Personal assessment of benefits and burdens

CONTEXTUAL FEATURES

• Social, legal, economic, and institutional circumstances that surround an individual case

QUALITY OF LIFE

• All interventions should improve or maintain the individual's quality of life
• Perspectives may vary between individuals regarding what constitutes a good quality of life
**THE ROLE OF HOPE IN DECISION MAKING**

- Hope is dynamic and interwoven with bereavement
- Hope for a miracle
- Hope the baby will live
- Hope the baby will be born alive
- Hope that the baby will not suffer
- Hope for a peaceful death

*(Feudtner, 2005)*
FEUDTNER’S PEARLS ON HOPE

• “Given what you are now up against, what are you hoping for?”
• “Do you mind telling me what else you might be hoping for?”

(Feudtner, 2009)

DYNAMIC NATURE OF HOPE

• Parents have hopes for their baby

• Hope for a miracle often exists simultaneously with hope for comfort

• Hopes can shift and change

(Côté-Arsenault & Denney-Koelsch, 2011)
COMMON ETHICAL ISSUES IN PALLIATIVE CARE

- Autonomy
- Euthanasia/Physician assisted suicide
- Withholding/withdrawing treatment
- Extraordinary measures
- Medical futility, powerlessness
- Professional adherence to standards
- Acceptable treatments and the questions related to suffering
- Truth telling

FACTORS INFLUENCING ETHICAL ISSUES IN END-OF-LIFE CARE

- Advances in technology
  - Can be victims of technology
  - Dying can be extended beyond what is reasonable
- Social/family systems
- Values/culture/religion
- Medical futility
- Fear of litigation
FACTORS (CONT.)

- Aging population
  - Possibility of physical decline
  - Possibility of mental decline
  - Fear of nursing home placement
- Lack of professional knowledge
- Legalization of assisted suicide
- Access to hospice
- Legal/bureaucratic obstacles

CASE STUDY

- 26 year old male
- Admitted for seizures → status epilepticus
- Anticonvulsants → hypotension → “dead gut”
- Consulted Saturday morning; met with surgeons, wife, pt’s parents, siblings
- Sunday—more colon removed
- Consulted for another meeting → wife only?

CASE STUDY (CONT.)

- Conflict: No HCPOA → no family consensus
- Wife: “He would never want to live this way”
- Family: “Hoping for the best”
- Recommended ethics consult
- Multiple family meetings
- Pt transferred to Palliative Care Unit on vent
- Extubated and died peacefully 10 days later
NURSING ROLE IN ADDRESSING ETHICAL ISSUES

- Values clarification
- Advocacy
- Member of interdisciplinary team
- Use of ethics resources

SHARED DECISION MAKING

- Balance of objective and subjective
- Balanced participation and authority
- Process oriented
- Narrative evolves over time
- Focuses on understanding
- Robust interpretation of informed consent

BALANCING BENEFIT AND BURDEN

<table>
<thead>
<tr>
<th>Benefit</th>
<th>Burden</th>
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<td>Isolation</td>
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<td>Immobility</td>
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ADVANCE CARE PLANNING
- Process of decision making and communicating
- Designation of surrogate/proxy
- Decision making is ongoing

ADVANCE DIRECTIVES
- Written means for communicating care choices
- Forms and laws differ by state
- Offer legal protection for patients

QUESTION
The percentage of patients diagnosed with terminal cancer who have advance directives is:
- Almost 90%
- About 50%
- Less than 30%
- Less than 10%
ANSWER

- The percentage of patients diagnosed with terminal cancer who have advance directives is:
  - Almost 90%
  - About 50%
  - **Less than 30% (Kish, Martin, and Price; 2000)**
  - Less than 10%

INTERVENTIONS DEPEND ON GOALS OF CARE

- Curative intent
- Acute therapeutic treatment
- Life sustaining treatments:
  - Resuscitation
  - Other therapies (Medically provided hydration/nutrition, ventilation, dialysis)
  - Withholding/withdrawing treatments
- Palliative treatments:
  - Antibiotics
  - Blood transfusions

NURSING IMPERATIVE TO PROVIDE PALLIATIVE CARE

- Nurses have an ethical obligation to assess and respond to patient’s pain, symptoms, and suffering
- Nurses must respond to patients in an ethical and legal manner
- Interdisciplinary collaboration is essential
MEDICAL FUTILITY

- Interventions that will not achieve the intended result
- Conflicts re: benefit/burden of treatment
- Often involve communication failures
- Limits of usefulness of prognostic data and policies

ISSUES OF JUSTICE IN END-OF-LIFE CARE

- Inequity of care delivery
- Nurses must be involved in system changes to improve care
- Responsibility to families after death

COSTS OF END-OF-LIFE CARE

- Palliative Care/Hospice as a cost effective option
- Inappropriate or unwanted care is costly
- Current systems can create severe family burden
  - Reimbursement systems limit access & coverage for services
RESEARCH AT THE END-OF-LIFE

- Need for appropriate research
- Sense of obligation may exist
- Issues of non-maleficence, autonomy

FACILITATING ETHICAL AND LEGAL PRACTICE

- Nurses have an obligation to be knowledgeable about the ethical/legal dimensions of professional practice
- Ethical dilemmas are inevitable

STANDARDS OF PROFESSIONAL NURSING PRACTICE

- ANA “Code for Nurses”
- The Nurse Practice Act
- Hospice and Palliative Nurses Association
- ANA Standards of Practice
- NHPCO Standards and Guidelines for Nurses
WHEN ETHICAL DILEMMAS OCCUR

• Nurse as advocate to insure understanding of options, clarification of preferences/values, communication with care team
• Formal case analysis: useful when usual care planning can’t resolve dilemmas
  - Apply decision making models
  - Ethics Committee involvement

MORAL DISTRESS: DEFINITION

• You know the ethically appropriate action to take, but you are unable to act upon it.
• You act in a manner contrary to your personal and professional values, which undermines your integrity and authenticity.

(Jameton, 1993)

MORAL DISTRESS ISSUES AT END-OF-LIFE

• Terminally ill pts not allowed to die with dignity
• Critically ill pts resuscitated without a clear understanding of their circumstances
• Pts die with inadequate symptom management
• Dying pts kept on life support until death
• Poor communication
• Lack of trust
• Lack of collaboration across disciplines
BARRIERS TO OVERCOMING MORAL DISTRESS

• Internal:
  • Lack of awareness
  • Insufficient skills
  • Lack of confidence
  • Fear

• External
  • Institutionalized obstacles (Ex.: time, support, policy, power imbalances)

THE 4A’S TO RISE ABOVE MORAL DISTRESS

• ASK:
  You may be unaware of the exact nature of the problem but are feeling distressed.
  GOAL: You become aware that moral distress is present

• AFFIRM:
  Affirm your distress and your commitment to take care of yourself.
  GOAL: You make a commitment to address moral distress

• ASSESS:
  Identify your source of distress—personal/environment.
  GOAL: You are ready to make an action plan

• ACT:
  Prepare personally and professionally to take action
  GOAL: You preserve your integrity and authenticity

AACN, 2009

CONCLUSION

• Nurses’ involvement
• Application of ethical principles
• Seek balance
• Nurses as advocates
• Interdisciplinary involvement
• Be aware
CASE STUDY: 7YO WITH BRAIN STEM GLIOMA

- Brain stem gliomas account for 15-20% of pediatric brain tumors
- Carry worst prognosis, with median survival less than one year; 10-20% alive at 2 years
- Surgical resection not indicated due to diffusely infiltrative nature
- Therapeutic options: observation, RT, investigational approaches

CASE STUDY: 7YO WITH BRAIN STEM GLIOMA

- “Honeymoon” phase during treatment
- Relapse typically occurs in 3-9 months
- Symptoms: worsened cranial neuropathies, deteriorating ambulation, dramatic neurologic deterioration, “locked in” syndrome

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Brain Stem Glioma: Two Case Studies
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Brain Stem Glioma: Two Case Studies

Ruth K. Rosenblum, MS, RN, CPNP

The paths taken by each family in coming to terms with the dismal prognosis associated with brain stem glioma can be quite different. The case studies of 2 school-age girls diagnosed with a brain stem glioma within weeks of each other are presented. The multidisciplinary team response to each family was individualized at each stage of diagnosis, treatment, and end-of-life care, as expected. The ultimate chronologic union of these 2 families as each child neared death was somewhat uncanny. The experience of each family, and their relationship with the team through this process, was an intense challenge and learning experience.

Key words: neuro-oncology, brain stem glioma, ethics

JB

JB, a 7 year-old-girl, was diagnosed with a brain stem mass in November 2002 after experiencing a 2-week history of headache, fatigue, difficulty with balance, changes with eye movements, double vision, and head tilt. She was the youngest in the family, with 2 older brothers, ages 12 and 16. She was the “darling” of the family and was often described as the glue that held the family together. Her diagnosis of a brain stem glioma was devastating to her parents and extended family, as expected.

Soon after diagnosis, JB’s parents were informed about the dismal nature of this disease and given the opportunity to participate in a clinical trial involving gadolinium-texaphyrin given simultaneously with radiation therapy. The family eagerly agreed to this treatment, and JB tolerated it well with few side effects. By February 2003, the size of the tumor had decreased when compared with prior assessments.

At each visit, JB’s father, an attorney, had a multitude of questions and research to discuss with the team. In fact, at one point, he tried to hire an undergraduate student to work for him in exchange for room and board, whose sole responsibility would be to research brain stem gliomas and their treatment. Also, the father made it clear that JB was not to know the nature of her diagnosis or the prognosis. After each physical examination was completed, a volunteer was enlisted to take JB to the hospital gift shop or elsewhere for the duration of the appointment. Further in-depth discussions took place about research, prognosis, and so forth after JB had left the room. The team vehemently stated that there were “no secrets” kept from JB, and all questions that she asked were answered.

Throughout this time, JB did well. Her condition was stable, she was attending school, and the family took a trip to Hawaii in the spring. But by late June 2003, the tumor progressed with interval enlargement and accompanying symptoms of ataxia.

JB’s father expressed an interest to explore other therapeutic options and alternative approaches. She was taken to multiple centers throughout the United States for further assessment, and finally she started on Can-cell, an alternative treatment. Conventional treatments including thalidomide and etoposide, as well as temozolomide, were offered. More important, a long discussion took place regarding JB’s understanding of

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her tumor progression. She understood pieces of the picture but had never been shown the picture in its entirety.

In August 2003, a ventriculoperitoneal shunt procedure was done at an outside hospital due to obstructive hydrocephalus. By early September, her symptoms recurred with a vengeance. She experienced increasing ataxia, dysphagia, urinary retention, and respiratory congestion. Later that month, she became apneic after taking her medication. Paramedics were called, and she was intubated and subsequently transferred to our facility. Throughout this episode, the family maintained hope for a full recovery.

After admission to the pediatric intensive care unit (PICU) for this episode, JB remained intubated and ventilated for approximately 2 weeks. During her PICU stay, her father relentlessly requested that she receive a gastrostomy tube for feeding purposes and also a tracheotomy. It was these requests that eventually prompted Ethics Committee consultation. Throughout this time, her father never made it clear to JB that her condition was terminal. The team remained concerned about the ominous nature of the tumor and JB’s dramatic deterioration. The team also strongly opposed invasive procedures such as the gastrostomy tube and tracheotomy in a patient with a brain stem glioma. The ethical questions that remained were, Would JB ever be extubated? Would her father agree to terminate treatment at any point while on the ventilator? Would JB ever be told that she was dying? Do-not-resuscitate (DNR) status was discussed but never implemented. While on the ventilator, JB was awake, alert, and even playful at times. She and her dad would frequently give each other the “thumbs-up” sign.

After 2 weeks of ventilation and 1 to 2 unsuccessful extubations, JB was finally extubated and able to return home with her family. She and the family received nursing support and hospice care; a DNR order was never obtained. What would happen if another apneic event occurred was unclear. Her care was transferred from the neuro-oncologist to her primary care provider, in part due to differences in opinion regarding end-of-life care. Ultimately, she expired in October 2003.

SG

SG was an 8-year-old girl who presented to the clinic in October 2003 with a 4-week history of eye drooping, facial palsy, and ataxia. She was the only child of the marriage, with 3 older siblings from her mother’s previous marriage. The family was Mexican American with many paternal relatives in Mexico. She was loved and cherished as the only child of the union of these 2 individuals and the father’s only child. As with JB, SG’s parents were informed about the nature of this tumor. They, too, were given the opportunity to participate in the gadolinium-texaphyrin clinical trial, which they declined. SG went on to receive conventional radiation therapy, which she tolerated well.

The next several months were uneventful, with fairly minimal treatment effects from radiation therapy. By March 2003, SG had developed a 3-cm cyst arising from the back of the brain stem glioma. The cyst was surgically decompressed, and the hydrocephalus resolved shortly after procedure. SG’s condition had been severely compromised by the time she went to surgery, as evidenced by increasing headaches, nausea, vomiting, and somnolence. After the cyst fenestration, her condition dramatically improved.

SG spent the following months with her family, attending school intermittently, and visiting relatives in Mexico. By September 2003, SG returned to the clinic with indications of tumor progression including weakness, difficulty swallowing, drooling, and sensory loss. Hospice care was initiated. By mid-October, SG was neurologically “locked in” with no motor control of extremities, face, or oropharynx. Her only communication was via eye blinking. The hospice nurse placed a nasogastric (NG) tube for nutritional support and hydration, and a Foley catheter was placed for treatment of urinary retention. The use of morphine, lorazepam, and other comfort measures was initiated. A DNR order was agreed to by SG’s parents and initiated.

One morning in late October 2003, her parents noticed her breathing was labored, and she began to moan, possibly indicating abdominal pain. Her abdomen was distended, and her urine output was decreased. By the next day, she was breathing heavily, was pale and cyanotic, and exhibited decerebrate posturing. The next day, she was admitted to the hospital for palliative care. Her hospital course was prolonged. She received morphine and other pain and agitation medications and was started on NG feeds at the time of admission. Other routine inpatient care was initiated.

By early December 2003, NG feeds were discontinued, and eventually intravenous (IV) fluids were
also discontinued. The only fluid received was through the morphine basal patient-controlled analgesia. It was unclear to providers how she remained alive for weeks with minimal fluid intake via IV. The DNR order continued throughout the hospitalization, and she only had 1 episode of apnea and desaturation, which did not require intervention. Throughout the hospitalization until her death, end-of-life issues were constantly reviewed and revisited with her parents. She expired at the end of December 2003.

This family was under great stress, as expected. SG’s father had taken time off from his job just after SG’s diagnosis, and by this time had no remaining time. SG was in the terminal stage of illness for 2 months, throughout which time her father’s employer continually threatened to dismiss him from his job. Hospital social workers and other personnel intervened on his behalf. Eventually, a local newspaper was notified and published an article about the family and their situation.

By a strange twist of fate and circumstances, JB’s father saw the newspaper article explaining SG’s condition and the difficulties her father was having with work. He offered to help in any way he could, up to and including paying the father’s salary for a period of time. The neuro-oncology team was impressed that Mr B could see through his own grief to reach out to another father in an equally dismal situation. JB’s father remembered meeting Mr G while both girls were undergoing radiation therapy the year before, just after diagnosis. Although the 2 families had minimal, if any, contact in the intervening months, they now were somewhat connected again through their daughters’ terminal illnesses.

**Brain Stem Glioma**

Tumors of the central nervous system represent the second most common pediatric cancer diagnosed in the United States each year. Brain stem tumors account for 15% to 20% of all pediatric brain tumors and are the group of tumors that carry the worst prognosis for long-term survival (Broniscer & Gajjar, 2004). The median age of occurrence for all brain stem gliomas is 6 to 7 years. Children present with a short history of multiple cranial nerve problems and hemiparesis. Common presenting symptoms include abnormal eye movements, diplopia, facial weakness, facial sensory loss, dysphagia, and dysarthria. Many times, the symptoms are attributed to the flu or another process until they become more obvious. Diffusely infiltrative brain stem gliomas are the classic brain tumor having a poor prognosis. Most arise in the pons, then infiltrate to other parts of the posterior fossa. Histologically, abnormal glial cells invade the brain stem and infiltrate between normal neural structures. This occurs in a diffuse, irregular pattern. Occasionally, disseminated neuraxis spread occurs. Diagnosis is confirmed by neuroimaging studies and clinical findings. Magnetic resonance imaging (MRI) can delineate the size and extent of tumor as well as the presence of vasogenic edema (Jallo, Biser-Rohrbaugh, & Freed, 2004).

**Prognosis**

Median survival for a diffusely infiltrative glioma is less than 1 year. Survival rates at 2 years are less than 10% to 20%. Other types of focal brain stem tumors have a much better prognosis and are amenable to surgery and/or radiotherapy. Patients with neurofibromatosis type 1 generally display a more indolent course when diagnosed with a brain stem glioma. Survival rates are up to 90% over 5 years (Guillamo et al., 2003).

**Treatment**

Once the diagnosis of brain stem glioma has been made by MRI and clinical findings, treatment options are discussed. Surgical resection is generally not indicated due to the diffuse intrinsic nature of these tumors. Biopsies are not necessary because, in the context of typical clinical presentation and characteristic MRI findings, histology results do not influence treatment (Jallo et al., 2004).

Therapeutic options include observation, radiotherapy, or investigational approaches. Radiotherapy remains the mainstay of treatment for most children with diffusely infiltrative brain stem gliomas. Radiotherapy will help to resolve the cranial neuropathies and ataxia temporarily, within 5 to 6 weeks after starting. The “honeymoon” phase of treatment, after radiotherapy, can be a time when the child exhibits minimal symptoms and is able to return to school. Many families use this...
time for travel or other meaningful time spent together. Relapse occurs in 3 to 9 months, with symptoms including worsening cranial neuropathies and their sequelae, deteriorating ambulation, and sometimes dramatic neurologic deterioration, including “locked-in” syndrome.

Investigational treatment approaches currently include the use of gadolinium texaphyrin used as a radiosensitizer. A radiosensitizer is a drug that makes tumor cells more sensitive to radiation therapy. Unfortunately, these efforts have been largely unsuccessful in achieving prolonged survival from this tumor.

Locked-in Syndrome

Toward the end of her life, SG became neurologically locked in. Locked-in syndrome is a disorder characterized by complete paralysis of voluntary muscles in all body parts except those that control eye movement. This is usually caused by a stroke. Individuals who are locked in are conscious and can think and reason, but they cannot speak or move. Sometimes communication can occur with eye blinking. There is no cure for this syndrome. Prognosis for individuals with this syndrome is poor, particularly when it is caused by a brain stem glioma. SG never awoke or communicated after becoming locked in.

Discussion

Brain stem glioma is a diagnosis that demands a multidisciplinary approach (Shiminski-Maher, 1995). The multidisciplinary team consists of a nurse practitioner, occupational therapist, school specialist, neuropsychologist, child life social worker, dietician, chaplain, palliative care, hospice, and primary attending physician and was available to both of these families at each juncture of their respective illnesses. Other specialties were consulted as needed. The demands on these 2 families, as they each entered the world of brain stem gliomas, were immense. The intensity of a diagnosis of a brain stem tumor and the predicted length of survival and poor prognosis challenges even the most highly functioning families. Assistance with mobilization of resources is a key function of team members, entering and exiting aspects of care as appropriate. Emotional support for the parents and siblings at diagnosis and beyond is also important as the family witnesses their child’s decline.

Several ethical issues arose over the months JB and SG received treatment. JB’s father made it clear that his daughter was never to know the nature of her diagnosis or prognosis. All discussions about treatment options, MRI results, and so on took place with JB out of the room. She knew she had a “tumor” or “bump” in her head and that the treatments that she received were trying to make it go away. All questions that were asked by JB were answered honestly by the team. Even as she was admitted to the PICU and ventilated, late in the course of her disease, she was never told about the nature of the disease. Did she know she would ultimately die of her disease? Are there things she might have done or said if she truly knew her time was limited? There is no way to know. Several team members felt uncomfortable with the lack of age appropriate knowledge being provided to her. Did our assent to allow JB to be taken from the room during treatment and prognosis discussions inhibit her right to know? The team struggled continually to keep JB’s best interest in the forefront of her care.

SG was in the hospital for the last 8 weeks of her life. Initially, she received hydration and NG feeding. Eventually, as time wore on and she became neurologically “locked in,” the NG feedings were stopped. Intravenous fluids were given in only very small amounts. Yet she stayed alive for close to 6 weeks after NG feedings were discontinued. Urine output was also more than expected, given the amount of IV fluids ordered. The team was puzzled. One theory was that SG’s father was surreptitiously giving her extra IV fluid. Although he was well aware of the diagnosis and prognosis and SG was no longer able to communicate with him, it might possibly have been that he could not bear to let her die.

Ethical Issues

Five recognized ethical principles are commonly used in medical practice. These include respect for persons, beneficence, nonmaleficence, proportionality, and justice. In the 2 case studies described here, respect for persons, beneficence, and nonmaleficence were principles that certainly came into play. There are more questions than answers.
Respect for persons is defined as the duty to respect the self-determination and choices of a person, as well as to protect persons with diminished autonomy, such as young children. Typically, children who are of the age of these 2 girls are included in discussions about their disease in a developmentally appropriate manner. Parental autonomy in disclosing information to a child can be difficult to determine. Many children, learning about their diagnosis years later, feel betrayed that they were not told earlier. Other children say they “knew” the diagnosis even if not directly told. In the case of the child with brain stem glioma, the prognosis is so poor and time is so short that determination of what the child knew, and when this occurred, is often never known.

Beneficence is the obligation to secure the well-being of persons by acting positively on their behalf and to maximize benefits that can be attained. In JB’s case, her father's beneficence and his goal to maximize the “good” in her short life were admirable. However, when her body started failing and decisions about tracheotomies and gastrostomy tubes were taking place, caregivers and team members questioned the benefit to her. Likewise, nonmaleficence, the obligation to minimize harm and remove causes of harm wherever possible, was also in question. Many involved thought that experimental therapeutics and increased talk of invasive procedures went against this basic ethical principle. SG’s parents chose to continue NG feeds and fluids for a time after she became neurologically locked in. Is this considered beneficence or nonmaleficence in the context of an inoperable brain tumor with average survival of 1 year or less?

Conclusion

The experience of caring for these 2 children and their families made a profound impact on the multidisciplinary team. The juxtaposition of their similar yet different situations created much discussion and the need for debriefing after each girl’s death occurred. The nursing role at each stage of their disease was important. In all phases, we provided education, information, physical care, and comfort and support (Shiminski-Maher, 1995). Providing these services in parallel to these 2 families was an emotional challenge for all involved throughout the 14 months that they were treated. One year after their deaths, the intense emotions regarding the ethical issues outlined in this essay have dimmed somewhat. However, this author and the team still occasionally reflect on our experiences with these 2 families and what we have learned from them that will help us to care for other children and families in the future.

References