Case Analysis

THE ETHICS WORKUP

Georgetown University Center for Clinical Bioethics

The ability to workup the ethical aspects of a case is an essential part of clinical reasoning. The emphasis in the ethics workup is on a sensible progression from the facts of the case to a morally sound decision. Using the five principal steps of the ethics workup, guardians and health professionals holding a variety of philosophical and religious positions regarding ethics can share a basic framework for thinking about and discussing morally troubling cases:

1. **WHAT ARE THE FACTS?** It is vitally important to clarify the facts of the case in order to anchor the decision. These facts are both medical and social. For example, both an estimate of prognosis and an understanding of the patient's home situation are often relevant to an ethical decision.
   - Persons involved (who?)
   - Diagnosis, prognosis, therapeutic options (what?)
   - Patient preferences, beliefs, values (what?)
   - Chronology of events, time constraints on decision (when?)
   - Medical setting (where?)
   - Reasons supporting claims, goals of current care (why?)

Nurses and social workers may be instrumental in ensuring that the patient/family and other nonmedical health professionals understand the medical facts and that the health care team understands pertinent nonmedical information about the patient and family.

2. **WHAT IS THE ISSUE?** Is there a conflict at the personal, interpersonal, institutional or societal level? Is there a question that arises either at the level of thought or feeling? Does the question have a moral or ethical component? Why? (e.g., does it raise issues of rights, moral character, etc.). The issue may not be ethical, but rather a diagnostic problem or a simple miscommunication.

3. **FRAME THE ISSUE:** Some guardians and health professionals will explore the issue using only one moral approach. Others will eclectically employ a variety of approaches. But no matter what one's underlying moral orientation, the ethical issue at stake in a given case can be framed in terms of several broad areas of concern, representing aspects of the case which may be in ethical conflict. It is therefore useful, if somewhat artificial, to dissect the case apart along the lines of the
following areas of concern:

a. Identify the appropriate Decision maker(s).
There are three rules of thumb for health care decision-making.
  - Patients with intact decision-making capacity make their own decisions. Decisionmaking capacity entails the ability to 1) understand the information necessary to make this particular decision (task specific), 2) reason in accord with relatively consistent values, and 3) communicate a preference.
  - Surrogates make health care decisions for incapacitated patients with a prior history of capacity by using the substituted judgment standard. To the extent that the patient’s values and preferences are known they should direct decision-making. The surrogate asks, “what would the patient choose if able to make and communicate a preference?” not “What would I choose if the choice were mine?”
  - Surrogates of patients who never possessed decision-making capacity: infants, small children and profoundly retarded adults, make decisions using the best interests standard. The surrogate asks, “Which option is most likely to benefit and to not harm the patient?” and considers relief of suffering, preservation and restoration of function, and the quality and extent of the life sustained

b. Apply the criteria to be used in reaching clinical decisions.
  1) The specific biomedical good of the patient: One should ask, what will advance the biomedical good of the patient? What are the medical options and likely outcomes?

  Determine the effectiveness of proposed interventions
  [A treatment is effective to the degree that it reverses or ameliorates the natural progression of the disease]. This is an objective medical determination to the degree that this is possible]

  2) The broader goods and interests of the patient: One should ask, what broader aspects of the patient’s good, i.e., the patient's dignity, religious faith, other valued beliefs, relationships, and the particular good of the patient’s choice, are pertinent to the decision at hand?

  Use a benefit-burden analysis to determine if the benefits of the proposed intervention outweigh the burdens. This is a subjective determination, which can only be made by the patient or by those who know the patient well.

  3) The goods and interests of other parties: Health professionals must also be attentive to the goods and interests of others, e.g., in the
distribution of resources. One should ask, what are the concerns of other parties (family, health care professionals, health care institution, law, society, etc.) and what differences do they make, morally, in the decisions that need to be made about this case? In deciding about an individual case, however, these concerns should generally not be given as much importance as that afforded the good of the individual patient whom health professionals have pledged to serve.

The physician explains the medical options to the patient/surrogates and if indicated makes a recommendation. The patient/surrogate makes an uncoerced, informed decision. Limits to patient/surrogate autonomy include the bounds of rational medicine/nursing/social work, the probability of direct harm to identifiable third parties, and violation of the consciences of involved health care professionals. In problematic cases the interdisciplinary team may meet to ensure consistency in their recommendations to the patient/surrogate(s).

c. Establish the health care professionals’ and guardian’s moral/professional obligations.
The primary object of all clinical decision making ought to be to secure the health, well-being or good dying of the patient and to do this while simultaneously respecting the integrity of the patient and all those involved in decision making and implementing the plan of care.

4. IDENTIFY AND WEIGH ALTERNATIVE COURSES OF ACTION AND THEN DECIDE: In clinical ethics, as in all other aspects of clinical care, a decision must be made. There is no simple formula. The answer will require clinical judgment, practical wisdom, and moral argument. Guardians should work closely with health care professionals to authorize a decision that secures the best interests of the patient: health, wellbeing, good dying. It is appropriate to ask clinicians for a recommendation based on their clinical expertise and experience. This should then be weighed with the guardian’s knowledge of the patient and estimate of best interests. Since we live in a morally pluralistic world, good people can reason differently about what ought to be done.

Ethically relevant considerations:
1) Balancing benefits and harms in the care of patients
2) Disclosure, informed consent, and shared decision making
3) The norms of family life
4) The relationships between clinicians and patients
5) The professional integrity of clinicians
6) Cost-effectiveness and allocation
7) Issues of cultural and religious variation
8) Considerations of power (Fletcher, Brody, Miller & Spencer)

Grounding and source of ethics: philosophical (based in reason), theological (based in faith), socio-cultural (based in custom)

5. CRITIQUE: It is important to be able to critique the decision that has been made by considering its major objections and then either responding adequately to them or changing one's decision. Some cases can even be taken to an ethics committee for further reflection.
Scenario #1

1. What are the Facts?

Mary Johns is a 50-year-old woman who has a profound level of intellectual disability and adaptive skills. She has the co-occurring disability of cerebral palsy and requires a custom-molded wheelchair for mobility, and 24-hour supports for eating, dressing, hygiene and to participate in her favorite community activities. Mary was institutionalized at an early age, and she has no family connections. You are her court appointed guardian, and you have worked with her for the past four years. You regularly participate in all interdisciplinary team meetings, and despite the ever-changing staff in her residence, you continue to be diligent in communicating with the staff so as to keep informed of Mary's needs. You also use staff to assist in communicating with Mary, since Mary does not seem to recognize you when you meet.

You receive a call from the hospital. It is the medical resident informing you that Mary has had a significant cerebral vascular accident/stroke (bleeding in the brain). While it is a bit premature to say with certainty, the extent of the bleed that is shown on the MRI would indicate that she would not likely recover her prior abilities (the resident does not seem to be familiar with her previous level of functioning, however). Because there was no indication of any advance directives when Mary presented at the emergency department, she was placed on a ventilator to maintain her breathing. The medical resident is asking you if you wish to execute a “do not resuscitate” order.

It is now a week later. Mary continues to require ventilator support, but she has not experienced any other crises. Today you are asked to consent for a gastric feeding tube to allow Mary to receive adequate nutrition. You have visited Mary 3 times in the hospital, but she doesn’t even open her eyes when you call her name and rub her arm. The staff from the group home tells you that they believe Mary will recover; she just needs time. The medical team at the hospital reports that the damage from the CVA is significant, and she is not likely to return to her former self.

2. What is the ethical issue?

*Should you consent to a “do not resuscitate” order in the event her heart stops or she stops breathing?*

*Should you consent to a gastric tube to provide her with nutrition?*
3. Frame the Issue
   
a. Identify the appropriate decision-maker
   
The facts as presented do not communicate sufficient information for a decision to be made about Mary Johns’ ability to meet the three criteria to demonstrate decision-making capacity: the ability to 1) understand her condition and treatment options, 2) deliberate in accordance with her own values and goals and to make an uncoerced decision among treatment options; and 3) communicate (verbally or nonverbally) this decision (Hastings Center Guidelines for Decisions on Life Sustaining Treatment and Care Near the End of Life). Her “profound level of intellectual disability” at the very least suggests that her ability to do the above is seriously compromised. To the extent that Mary’s caregivers can speak to what they believe her preferences are, these should be factored carefully into the decisions at hand. The guardian, however, is the primary decision-maker and needs to create a partnership and work closely with the professional team to make and authorize treatment decisions.

b. Apply the criteria to be used in reaching clinical decisions
   
   1) The specific biomedical good of the patient
   2) The broader goods and interests of the patient
   3) The goods and interests of other parties

Should you authorize attempts to resuscitate Mary if her heart stops or she stops breathing? The Hastings Center Guidelines for Decisions on Life-Sustaining Treatment and Care Near the End of Life ¹ read:

   In some circumstances, cardiopulmonary resuscitation (CPR) a term covering a range of interventions aimed at restoring heartbeat and breathing after cardiac arrest, is an effective treatment that can save lives. ...However, when a patient whose overall condition is deteriorating suffers cardiac arrest, the likelihood that CPR will meet its immediate goal of restoring heartbeat and breathing is lower, and the patient’s prognosis is likely to be poor no matter what interventions are subsequently attempted. There is a huge literature on the outcomes of CPR initiated in various settings and different patient populations.

   Portrayals of CPR in popular media can prompt members of the public—including patients, surrogates, and loved ones—to form a misleading impression of the nature of this treatment and the

circumstances under which it is likely or unlikely to achieve its life-saving goal. In-hospital CPR involving advanced cardiac life support (ACLS) can be a highly invasive procedure that a patient may experience as burdensome.

Mary falls into the category of patients whose condition is deteriorating and the guardian is likely to get recommendation from clinicians to authorize a Do Not Attempt to Resuscitate (DNAR) or Do Not Resuscitate (DNR) order. It would be ethical to authorize such an order unless the guardian has reservations about the accuracy of the report of damage resulting from the cerebral bleed. In this situation asking for more time to evaluate the possibility of Mary’s return to her former level of functioning is appropriate. Many hospitals are now replacing DNAR/DNR terminology with Allow Natural Death (AND) Orders, which simply mean that in the event that one’s heart stops or one stops breathing, natural death is allowed and no interventions to restart heartbeat or breathing are attempted. An AND Order would similarly be ethically appropriate.

The decision about whether or not to insert a gastric feeding tube will turn on the degree of damage resulting from the stroke and Mary’s ability to return to her former self. Is the staff from the group home being unrealistic when they persist in believing that Mary will get better? Are they simply having difficulty accepting the medical team’s evaluation and prognosis? Alternatively, has the medical team allowed sufficient time to accurately describe the degree of damage secondary to the stroke and the probability that Mary will return to her former self? The guardian should press Mary’s physician for an answer to the latter question and if not satisfied with what is learned, seek a second opinion. It would be important to learn if it is probable that Mary will return to her former abilities, or if Mary can at least gain some capabilities that will allow her to enjoy some of the same things that previously gave her a good quality of life. If the guardian is confident that Mary’s damage is severe and that she will never return to her former self it would be appropriate to not insert the gastric tube and to transition to purely palliative goals. At this point, the ethical question becomes: Should the treatment change from stabilizing functioning to preparing for a comfortable and dignified death? If the later, a decision might be made to remove Mary’s ventilatory support.

Unless there are religious, cultural or other reasons to believe that Mary would value life lived under any circumstances it would be appropriate to transition to purely palliative goals at this point. Significant for the guardian is the fact that during the three visits with Mary, she doesn’t even open her
eyes when you call her name and rub her arm. This is a significant departure from baseline.

There are no immediate third parties to be considered when this decision is made except to be sensitive to the interests of the Mary’s caregivers.

c. Establish the health care professionals’ and guardian’s moral/professional obligations.
The primary object of all clinical decision making ought to be to secure the health, well-being or good dying of the patient and to do this while simultaneously respecting the integrity of the patient and all those involved in decision making and implementing the plan of care. If a decision is made to transition to purely palliative goals and to forego the feeding tube and or to remove ventilatory support, every effort should be made to prepare the patient for a comfortable, dignified death. All attention should be directed to the patient’s (and caregivers’) comfort and peace. A referral should then be made to hospice.

4. Identify and Weigh Alternative Courses of Action and Then Decide Ethically relevant considerations
   1) Balancing benefits and harms in the care of patients
   2) Disclosure, informed consent, and shared decision making
   3) The norms of family life
   4) The relationships between clinicians and patients
   5) The professional integrity of clinicians
   6) Cost-effectiveness and allocation
   7) Issues of cultural and religious variation
   8) Considerations of power

Basically there are two options to consider: 1) maintain the goal of stabilizing Mary’s functioning which entails treating complications as they arise, maintaining ventilatory support, inserting a feeding tube, resuscitation interventions if her heart or breathing stops, or 2) transition to purely palliative goals with the explicit goal being to prepare Mary, and her caregivers for a peaceful and dignified death.

In Mary’s case much will depend on the extent of damage related to bleeding into her brain and how this will affect her everyday functioning and ability to experience a meaningful life. To what degree will she be able to return to her pre-

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hospitalization baseline? And to the extent that this is impossible, would her resulting condition be acceptable to her—need to continue ventilatory support, be fed with a gastric tube, etc.? Are the burdens associated with these interventions proportionate to the benefits she derives? Unless her caregivers can make a case that it is reasonable to expect a return to previous functioning, then transitioning to purely palliative goals is ethically appropriate.

Given the obvious attachment Mary’s caregivers have to her, careful attention should be paid to supporting them and helping them to understand the decision being made. If the guardian, Ms. Johnson's caregivers, and health care professionals cannot agree on a course of action, referral to an ethics committee or consultant should be made.

5. Critique

Whatever alternative is selected, once it is implemented the guardian should carefully follow the outcomes to see what can be learned that would be helpful in a similar situation in the future.
Scenario #2

1. What are the Facts?
Robert Perkins is a 45-year-old man with Down syndrome. You have been his guardian since he was 18 years old and exited the child welfare system. Despite his profound level of intellectual disability, you have come to appreciate his sense of humor over the years, and you know about his favorite food (pizza), past times (walking to the ice cream store up the street from his home) and favorite clothes to wear (anything made of sweat shirt fabric).

After two years have passed, staff reports new behavioral problems that include agitation after returning from his afternoon job, refusals to take a shower, and wanting to eat dinner right after he already had dinner. Robert is eventually diagnosed with dementia. Although placed on a drug that was supposed to slow the rate of dementia-related problems, Robert has developed a seizure disorder, has had to quit his job, and recently has been having choking episodes when eating.

Robert’s swallowing study shows that there is no physical obstruction in his esophagus, but the speech therapist and the occupational therapist relate his eating problems to the fact that he is forgetting how to eat and can no longer swallow easily.

You participate in an interdisciplinary team meeting. The caregiving staff who know Robert well are in favor of using a gastric tube for nutrition. The primary care physician is not in favor of the gastric tube because of the presence of dementia, the rapidity with which he is declining, and the futility of a nutritional intervention to his eventual outcome.

2. What is the ethical issue?
Should the guardian consent to a gastric tube to provide Mr. Perkins with nutrition? How can the conflict between the caregiving staff and primary care physician be mediated?

3. Frame the Issue
a. Identify the appropriate decision-maker
At an earlier age Mr. Perkins was capable of making and executing some simple decisions (food preferences, clothing) but at the present time dementia is robbing him of the ability to meet the three criteria to demonstrate decision-making capacity: the ability to 1) understand his condition and treatment options, 2) deliberate in accordance with his own values and goals and to make an uncoerced decision among treatment options; and 3) communicate (verbally or nonverbally) this decision
(Hastings Center Guidelines for Decisions on Life Sustaining Treatment and Care Near the End of Life). The guardian is the primary decision-maker and needs to create a partnership and work closely with the professional team to make and authorize treatment decisions.

b. Apply the criteria to be used in reaching clinical decisions
   1) The specific biomedical good of the patient
   2) The broader goods and interests of the patient
   3) The goods and interests of other parties

While a gastric tube may “solve the problem” of impaired nutrition and reduce the likelihood of choking, there is general medical consensus that in end-stage dementia the goals of care should be transitioned to purely palliative goals. The preponderance of evidence does not support the use of feeding tubes for adults with advanced dementia.³ A nasogastric tube will not cure or ameliorate his dementia and rapid decline. It would be appropriate and necessary for the guardian to ask the primary care physician if all treatable causes of Mr. Perkin’s rapid decline have been ruled out given the fact of Mr. Perkin’s young age (45) and extremely rapid decline.

The burden of proof would be on the caregiving staff to provide a rationale for why the nasogastric tube should be inserted. Are there religious or cultural beliefs or values that would dictate insertion of the nasogastric tube? What if the burdens associated with a feeding tube outweigh the anticipated benefits? There do not seem to be third party interests at stake in this decision.

c. Establish the health care professionals’ and guardian’s moral/professional obligations.

The primary object of all clinical decision making ought to be to secure the health, well-being or good dying of the patient and to do this while simultaneously respecting the integrity of the patient and all those involved in decision making and implementing the plan of care. If a decision is made to transition to purely palliative goals and to forego the feeding tube every effort should be made to prepare the patient for a comfortable, dignified death. All attention should be directed to the patient (and family’s) comfort and peace. A referral should then be made to hospice.

4. Identify and Weigh Alternative Courses of Action and Then Decide

Ethically relevant considerations

1) Balancing benefits and harms in the care of patients
2) Disclosure, informed consent, and shared decision making
3) The norms of family life
4) The relationships between clinicians and patients
5) The professional integrity of clinicians
6) Cost-effectiveness and allocation
7) Issues of cultural and religious variation
8) Considerations of power

Basically there are two options to consider: 1) insertion of a feeding tube with the primary treatment goal being to stabilize his functioning—even with the rapid decline and dementia progression or 2) transitioning to purely palliative goals with the explicit goal being to prepare him, his family, caregivers and house mates (assuming he is in a group home) for a peaceful and dignified death. In Mr. Perkin’s case, evidence-based practice and the disproportionate burden-benefit ratio associated with feeding tubes for someone in his condition recommend transitioning to palliative goals. Some believe that every patient should be fed—even when this entails medical nutrition and hydration-- and that failure to do so constitutes gross neglect. Research has, however, now countered this view. Given the obvious attachment Mr. Perkin’s caregivers have to him, careful attention should be paid to supporting them and helping them to understand the decision being made. If the guardian, Mr. Perkin’s caregivers, and health care professionals cannot agree on a course of action, referral to an ethics committee or consultant should be made.

5. Critique

Whatever alternative is selected, once it is implemented the guardian should carefully follow the outcomes to see what can be learned that would be helpful in a similar situation in the future.

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Scenario #3

1. What are the Facts?
Louise Parker is a 65 year old woman with profound intellectual disability. Her older sister has always served as her surrogate decision-maker, but she was recently diagnosed with advanced dementia, and you have been appointed by the court to serve as Ms. Parker’s guardian.

You review the medical record and discover that Ms. Parker has always been very active and enjoyed relatively good health with the exception of high blood pressure that has been difficult to control over the years. Her primary care physician recently referred her to a renal specialist because her glomerular filtration rate is 17, which indicates that Ms. Parker will need to consider beginning kidney dialysis. Ms. Parker’s staff tells you that they have no idea how that will be accomplished because she requires sedation for routine dental exams and for blood draws for routine tests. You check with another guardian who tells you not to worry because she represents several people who are given heavy sedatives three times a week when they receive dialysis.

2. What is the ethical issue?
Should you consent to renal dialysis?

3. Frame the Issue
   a. Identify the appropriate decision-maker
   Ms. Parker has never been capable of meeting the three criteria to demonstrate decision-making capacity: the ability to 1) understand her condition and treatment options, 2) deliberate in accordance with her own values and goals and to make an uncoerced decision among treatment options; and 3) communicate (verbally or nonverbally) this decision (Hastings Center Guidelines for Decisions on Life Sustaining Treatment and Care Near the End of Life). Since the older sister who served as her surrogate decision maker now has advanced dementia, the court appointed guardian is the primary decision-maker and needs to create a partnership and work closely with the professional team to make and authorize treatment decisions.

   b. Apply the criteria to be used in reaching clinical decisions
      1) The specific biomedical good of the patient
      2) The broader goods and interests of the patient
      3) The goods and interests of other parties

   Hemodialysis is a therapy that compensates for a period of time for the failure of an organ system necessary for life. Clearly renal dialysis is
indicated for Ms. Parker if we are just looking to address her failing renal (kidney) function. Many and probably most 65 year olds with a comparable glomerular filtration rate of 17 but without the complicating variables of Ms. Parker’s profound intellectual disability would opt to begin dialysis. These individuals with decision-making capacity would make decisions about initiating and continuing dialysis after thoughtfully reflecting on the anticipated benefits of treatment versus the burdens of treatment. Decision-making about dialysis requires clear communication about diagnosis, prognosis, the patient’s preferences and treatment options, including the option to forgo life-sustaining treatment.5

The critical question in Ms. Parker’s situation is whether or not and how the need to sedate her for each dialysis treatment should influence the treatment decision. The growing trend is to discourage initiating treatments that routinely involve sedation—as opposed to dental work, which might require one episode of sedation annually. In Ms. Parker’s case if dialysis with sedation returns her to her usual active state of good health and the three times weekly experiences of sedation do begin to compromise her general health, it could be warranted. The only way to know this would be to authorize a trial by therapy and to carefully monitor what happens. Ideally, if Ms. Parker becomes acclimated to the dialysis experience, she may eventually need less and less sedation while experiencing all the benefits of dialysis. In the event this does not happen and the burdens of sedation and dialysis become disproportionate to the benefit of improved renal function, dialysis should be discontinued. It is always ethically permissible to withdraw a treatment once started, which proves to be ineffective or disproportionately burdensome.

As always, central to making treatment decisions is reflection about what not only “fixes” a discrete medical problem, in this case impaired renal function, but also what promotes the well-being of the whole person.

Third party interests at stake in this decision involve the caregivers who will be responsible for transportation and assistance on the days the Ms. Parker is receiving treatment.

**c. Establish the health care professionals’ and guardian’s moral/professional obligations.**

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The primary object of all clinical decision making ought to be to secure the health, well-being or good dying of the patient and to do this while simultaneously respecting the integrity of the patient and all those involved in decision making and implementing the plan of care. Ms. Parker’s guardian and health care professionals need to reflect carefully on what it is reasonable to expect if dialysis with sedation is initiated. If a decision is made at present or eventually to transition to purely palliative goals and to forego the dialysis, every effort should be made to prepare the patient for a comfortable, dignified death. All attention should be directed to the patient (and family’s and caregiver’s) comfort and peace. A referral should then be made to hospice.

4. Identify and Weigh Alternative Courses of Action and Then Decide Ethically relevant considerations
   1) Balancing benefits and harms in the care of patients
   2) Disclosure, informed consent, and shared decision making
   3) The norms of family life
   4) The relationships between clinicians and patients
   5) The professional integrity of clinicians
   6) Cost-effectiveness and allocation
   7) Issues of cultural and religious variation
   8) Considerations of power

Basically there are three options to consider.
1) Commit to renal dialysis with sedation and accept as the overall goal to stabilize her functioning, treating each new condition or complication as it arises.
2) Attempt a trial by therapy to determine if her need for sedation can be met without disproportionately compromising her well-being. The goal in this instance would be to eventually decrease her need for sedation as she becomes acclimated to the experience of dialysis. Here also the overall goal is to stabilize her functioning. If the burdens associated with sedation and dialysis become disproportionate to the benefits of improved renal function, dialysis can be stopped and Ms. Parker transitioned to purely palliative goals.
3) Make a decision that evidence supports not attempting a trial by therapy and transition immediately to the goal of allowing the compromised renal function to continue and preparing Ms. Parker for a comfortable and dignified death. In this instance a referral to hospice is imperative.

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In this instance we would recommend the trial by therapy unless the experience of involved health care professionals in numerous similar situations convinces them that the cumulative burdens of the ongoing need for sedation and dialysis are bound to outweigh the benefits of improved renal health. Those who know Ms. Parker best are best situated to assess the likelihood that her need for sedation will decrease as she becomes acclimatized to the experience of dialysis.

If the guardian, Ms. Parker’s caregivers, and health care professionals cannot agree on a course of action, referral to an ethics committee or consultant should be made.

5. Critique

Whatever alternative is selected, once it is implemented the guardian should carefully follow the outcomes to see what can be learned that would be helpful in a similar situation in the future.
Scenario #4

1. What are the Facts?

John Rosario is an 85-year-old man with profound intellectual disability. You have been his guardian for the past 5 years, since his only brother, who had been his health care decision-maker, died suddenly. You know that when John was a child, he was placed in the state institution, where he learned to enjoy cigarette smoking. He continued smoking a half a pack a day until he was 60 years old. John was recently diagnosed with Stage 4 lung cancer. You elected to not seek chemotherapy or radiation treatment based on your interpretation of the medical recommendations given to you.

When you visit John, he actually does not appear much different to you from before the cancer diagnosis. He likes to watch TV, still enjoys eating his favorite foods, but has recently stopped going to church because he gets too tired. You are notified that John has been admitted to the hospital with pneumonia. The doctor in the emergency department calls you to receive consent to treat the pneumonia. You are surprised that you are being given the alternative not to treat the pneumonia.

2. What is the ethical issue?

Should you consent to the antibiotic treatment?

3. Frame the Issue

a. Identify the appropriate decision-maker

Mr. Rosario has never been capable of meeting the three criteria to demonstrate decision-making capacity: the ability to 1) understand her condition and treatment options, 2) deliberate in accordance with her own values and goals and to make an uncoerced decision among treatment options; and 3) communicate (verbally or nonverbally) this decision (Hastings Center Guidelines for Decisions on Life Sustaining Treatment and Care Near the End of Life). Since the death of his brother who served as his surrogate decision maker, the court appointed guardian is the primary decision-maker and needs to create a partnership and work closely with the professional team to make and authorize treatment decisions.

b. Apply the criteria to be used in reaching clinical decisions

1) The specific biomedical good of the patient
2) The broader goods and interests of the patient
3) The goods and interests of other parties
Treatment for pneumonia involves curing the infection and preventing any complications. Specific treatments depend on the type and severity of the pneumonia, and the patient’s age and overall health. The options include:

- **Antibiotics**, to treat bacterial pneumonia. It may take time to identify the type of bacteria causing the pneumonia and to choose the best antibiotic to treat it. Symptoms often improve within three days, although improvement usually takes twice as long in smokers. If the patient’s symptoms don't improve, the doctor may recommend a different antibiotic.

- **Antiviral medications**, to treat viral pneumonia. Symptoms generally improve in one to three weeks.

- **Fever reducers**, such as aspirin or ibuprofen.

- **Cough medicine**, to calm the patient’s cough so he/she can rest. Because coughing helps loosen and move fluid from your lungs, it’s a good idea not to eliminate the cough completely.

**Hospitalization**

The patient may need to be hospitalized if:

- He/she is older than age 65
- He/she becomes confused about time, people or places (as a result of the infection)
- His/her nausea and vomiting prevent the patient from keeping down oral antibiotics
- His/her blood pressure drops
- His/her breathing is rapid
- He/she needs breathing assistance
- His/her temperature is below normal

If the patient needs to be placed on a ventilator or the symptoms are severe, the patient may need to be admitted to an intensive care unit.

Mr. Rosario’s guardian seems surprised to be asked to consent to his ward receiving antibiotics because oral medications seem a simple solution to a potentially life-threatening infection. What the guardian may not realize is first, treatment may

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7 The Mayo Clinic. Available at: http://www.mayoclinic.com/health/pneumonia/DS00135/DSECTION=treatments-and-drugs
involve parenteral medications (medications delivered outside the digestive tract) and rehydration therapy and even transfer to an intensive care unit for ventilatory support, and second, there is an active debate in the literature about pneumonia being the old person’s friend, for those believe that there are things worse than death and who prefer to die sooner rather than later. Like any other proposed medical treatment, antibiotics may be refused if a judgment is reached that they are medically ineffective or if the associated burdens are judged to outweigh the anticipated benefits.

At the time of the guardian’s last visit with Mr. Rosario, John was perceived as not being much different than before his stage four lung cancer was diagnosed. If this is therefore a treatable pneumonia with the benefits of treatment outweighing related burdens, the decision to consent to antibiotics seem simple. Unless the guardian has reason to believe that Mr. Rosario would prefer death from a treatable pneumonia to living the life he has left with his stage four lung cancer—or that treatment would not secure his best interests, treatment is indicated. If you begin treatment and the pneumonia advances requiring further interventions and/or his cancer progresses with new and problematic complications, the decision to treat the pneumonia can be revisited. It is always ethically permissive to withdraw a treatment once started, which proves to be ineffective or disproportionately burdensome.

As always, central to making treatment decisions is reflection about what not only “fixes” a discrete medical problem, in this case impaired bacterial pneumonia, but also what promotes the well-being of the whole person.

There do not seem to be third party interests at stake in this decision.

c. Establish the health care professionals’ and guardian’s moral/professional obligations.
The primary object of all clinical decision making ought to be to secure the health, well-being or good dying of the patient and to do this while simultaneously respecting the integrity of the patient and all those involved in decision making and implementing the plan of care. Mr. Rosario’s guardian and health care professionals need to reflect carefully on what it is reasonable to expect if antibiotics or other medical treatments for pneumonia are initiated. If a decision is made at present or eventually to transition to purely palliative goals and to forego the antibiotics, every effort

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should be made to prepare the patient for a comfortable, dignified death. All attention should be directed to the patient (and family's and caregiver's) comfort and peace. A referral should then be made to hospice.

4. Identify and Weigh Alternative Courses of Action and Then Decide

Ethically relevant considerations

1) Balancing benefits and harms in the care of patients
2) Disclosure, informed consent, and shared decision making
3) The norms of family life
4) The relationships between clinicians and patients
5) The professional integrity of clinicians
6) Cost-effectiveness and allocation
7) Issues of cultural and religious variation
8) Considerations of power

Basically there are three options to consider.
1) Consent to the use of antibiotics and accept as the overall goal to stabilize his functioning, treating each new condition or complication as it arises.
2) Attempt a trial by therapy to determine if his pneumonia can be successfully treated without further complications and disproportionately compromising his well-being. Here also the overall goal is to stabilize his functioning. If the burdens associated with treating the pneumonia or worsening cancer symptoms become disproportionate to the benefits associated with treatment, antibiotic therapy and other treatments can be stopped and Mr. Rosario transitioned to purely palliative goals.
3) Make a decision that Mr. Rosario's interests and well-being are best served by not attempting a trial by therapy and transitioning immediately to the goal of preparation for comfortable and dignified death. In this instance a referral to hospice is imperative.

Unless than is any reason to believe that Mr. Rosario welcomes pneumonia as the “old person’s friend” and would choose to die sooner rather than later (and it is difficult to imagine how anyone would know this) a trial by therapy should be commenced and antibiotics started.

If the guardian, Mr. Rosario's caregivers, and health care professionals cannot agree on a course of action, referral to an ethics committee or consultant should be made.

5. Critique

Whatever alternative is selected, once it is implemented the guardian should carefully follow the outcomes to see what can be learned that would be helpful in a similar situation in the future.
Scenario #5

1. What are the Facts?

Denise Miller is a 62-year-old nonverbal female diagnosed with profound intellectual disability (ID). You are her court-appointed guardian. Her medical diagnoses include seizure disorder, Crohn’s disease, diverticulitis, and reflux esophagitis. In 1954 she had a craniotomy for a subdural effusion. She was recently hospitalized after developing cellulitis in her left leg with notable swelling in the shin area. She is on a low fat, chopped diet and has had a history of gastrointestinal (GI) concerns. Admitting diagnosis is osteomyelitis of the left leg (previous rod insertion from a broken leg). She was hospitalized for two months and at some point during her hospitalization she developed a GI bleed and aspirated and had to be transferred to a long term acute care (LTAC) hospital for IV antibiotic treatment of her osteomyelitis and aspiration pneumonia. During her LTAC stay, she stopped eating, had a seizure lasting more than 5 minutes, and was transferred back to the hospital emergency room for further evaluation. While she is at the hospital for treatment of the seizure, you are approached and asked to consent to the placement of a feeding tube because of her decreased appetite and weight loss.

2. What is the ethical issue?

Should you consent to a gastric tube to provide her with nutrition?

3. Frame the Issue

a. Identify the appropriate decision-maker

The facts as presented demonstrate that Ms. Miller is unable to meet the three criteria to demonstrate decision-making capacity: the ability to 1) understand her condition and treatment options, 2) deliberate in accordance with her own values and goals and to make an un-coerced decision among treatment options; and 3) communicate (verbally or nonverbally) this decision (Hastings Center Guidelines for Decisions on Life Sustaining Treatment and Care Near the End of Life). The guardian is the primary decision-maker and needs to create a partnership and work closely with the professional team to make and authorize treatment decisions.
b. Apply the criteria to be used in reaching clinical decisions
   1) The specific biomedical good of the patient
   2) The broader goods and interests of the patient
   3) The goods and interests of other parties

The decision about whether or not to insert a gastric feeding tube will turn on a judgment about Ms. Miller’s ability to ingest and swallow food safely in the future. The guardian should not authorize placement of the gastric tube until (s)he learns why Ms. Miller stopped eating in the LTAC and suffered weight loss. It is sadly not uncommon in new settings for food trays to be placed in front of patients with disabilities without anyone first determining the degree of assistance needed to bring food to the mouth. Since Ms. Miller has always required assistance with feeding – it should be no surprise that many food trays went back to the kitchen untouched if no assistance was offered her in the LTAC. The guardian should request that a trial of offering assistance at meals time be attempted and that Ms. Miller’s usual care attendants be consulted about her food preferences and any mealtime protocols that are followed to facilitate her eating.

Alternatively, it may be the case that Ms. Miller’s worsening medical condition aggravated by the osteomyelitis and gastrointestinal bleeding and new seizure activity have weakened her to the degree that her return to her pre-hospitalization baseline is no longer possible. In this event, her loss of appetite may signal the body’s beginning to slow down. If this is the case, there are three options. The guardian might authorize a trial of artificial nutrition to see if improved nutrition strengthens her to the point that she resumes the desire and ability to take foods by mouth—in which case the artificial nutrition would be stopped. Alternatively, the gastric tube may simply be placed and artificial feedings continued until the body can no longer receive them. The third option would be to transition to purely palliative goals, attempt hand-feeding, but if it is unsuccessful, make no effort to initiate artificial feedings—an option that seems premature at this point. As in all situations decisions about artificial feeding entail making judgments about whether or not such feeding is consistent with the overall treatment goal (stabilize functioning or prepare for a comfortable and dignified death) and whether or not the anticipated benefits outweigh the burdens associated with artificial feeding. It is important to remember that for individuals like Ms. Miller meal times may be one of the most enjoyable times of the day if the caregiver uses offering assistance with feeding to demonstrate compassionate and warm human presence. Having someone come to your room to drop a can of feeding solution into a bag in no way compares to the experience of being handfed.
Stopping to question what influence, if any, Ms. Miller’s intellectual disability has on decision-making, the guardian should be confident that (s)he is making the same decision for Ms. Miller that would be made for a person in a similar medical condition who did not have an intellectual disability.

There are no immediate third parties to be considered when this decision is made.

c. Establish the health care professionals’ and guardian’s moral/professional obligations.
The primary object of all clinical decision making ought to be to secure the health, well-being or good dying of the patient and to do this while simultaneously respecting the integrity of the patient and all those involved in decision making and implementing the plan of care. The guardian and professional caregivers should work together to develop a plan for feeding Ms. Miller that promotes her overall well-being—not one that merely solves the immediate “problem” of weight loss.

4. Identify and Weigh Alternative Courses of Action and Then Decide Ethically relevant considerations
   1) Balancing benefits and harms in the care of patients
   2) Disclosure, informed consent, and shared decision making
   3) The norms of family life
   4) The relationships between clinicians and patients
   5) The professional integrity of clinicians
   6) Cost-effectiveness and allocation
   7) Issues of cultural and religious variation
   8) Considerations of power

This case scenario is interesting because we basically have professional caregivers wanting to benefit Ms. Miller—but making decisions with an inadequate database. Good clinical decisions cannot be made without good data. We also see in this case the culture of medicine prioritizing the treatment of medical conditions (osteomyelitis, gastrointestinal bleed, seizures) while simultaneously failing to pay attention to the whole person—and her/his need for assistance with the simple activities of every day living—in this case, eating. It underscores the need for the

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guardian to have established a close relationship with the daily caregivers who know Ms. Miller best and to be confident in relaying their experience and expertise to professional caregivers in the hospital.

5. Critique

Whatever alternative is selected, once it is implemented the guardian should carefully follow the outcomes to see what can be learned that would be helpful in a similar situation in the future.

THE END