

# Student-Created 2 Week Aquifer Elective: End of Life Care and Difficult Conversations

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# Course: End of Life Care and Difficult Conversations

## Purpose:

Physicians often have the responsibility to disclose bad news to patients and help them navigate end of life care discussions. Although physicians, residents and students support that physicians' responsibilities include preparing patients for death and end of life care, few students and residents received training on end-of-life care during medical school.(1) Furthermore, students and residents have reported that they feel unprepared to engage in end of life conversations and to provide components of good care for the dying (1,2,3). Initiating difficult conversations with patients early helps them make informed decisions, decreases unnecessary costly medical interventions and improves their quality of life near the end of life.(2,3) However, conversations surrounding goals of care and end of life are not part of routine care, even for advanced cancer patients, and when these conversations do happen, they tend to occur late in the disease course (4). Given the importance of having difficult conversations with patients throughout their medical care, and the lack of training and preparedness to initiate these conversations felt by medical students and residents, we designed a virtual course about delivering difficult news and having end of life conversations with patients and their families. The course is geared towards 4th year medical students with the overall goal of enhancing medical training surrounding delivering difficult news and end of life care, and helping students be better prepared to approach these conversations as future residents.

## References:

1. Sullivan, Amy M et al. "The status of medical education in end-of-life care: a national report." *Journal of general internal medicine* vol. 18,9 (2003): 685-95. doi:10.1046/j.1525-1497.2003.21215.x
2. Sutherland, Ryan. "Dying Well-Informed: The Need for Better Clinical Education Surrounding Facilitating End-of-Life Conversations." *The Yale journal of biology and medicine* vol. 92,4 757-764. 20 Dec. 2019
3. MacKenzie, Amy and Lasota, Michelle. "Bringing Life to Death: The Need for Honest, Compassionate, and Effective End-of-Life Conversations". *American Society of Clinical Oncology Educational Book*.40:476-484 (2020). doi:10.1200/EDBK\_279767
4. Schulman-Green, Dena et al. "Oncologists' and Patients' Perceptions of Initial, Intermediate, and Final Goals of Care Conversations". *Journal of Pain and Symptom Management*. Vol 55,3: 890 - 896. March 2018. <https://doi.org/10.1016/j.jpainsymman.2017.09.024>

## Objectives:

By the end of the course students will be able to:

- Develop a general framework of how to approach delivering bad news to patients using the SPIKES model.
- Develop skills of eliciting perspectives and values of patients and families through reflective discussion practice
- Discuss approaches to difficult conversations and how they may vary depending on the patient population being addressed
- Develop a general framework to discuss end of life care options with patients
- List the requirements for and components of hospice, palliative care and advance directives.

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## Course Schedule Options

### **Suggestions for Implementing this Palliative news Course into your curriculum:**

We suggest that this curriculum be implemented over a two week period of time for 4th year medical students, as an online elective. Depending on the resources and availability of course directors at your institution, this course can take a number of forms.

Below we have two suggested schedules:

- 1) The first option includes a day-by-day schedule with specific daily cases and discussion assignments, that are best done in the order outlined. For each day, one Aquifer case will be paired with a number of outside, freely available online narrative content. We will offer alternative Aquifer cases that can be used, depending on what courses your institution subscribes to. We suggest using this layout if you have the capability of a discussion board, or faculty available to read and respond to written responses more immediately.
- 2) The second option requires less oversight and can be done in any order. Here, a list of relevant cases and outside materials will be provided to students at the outset. Students will complete the cases and read the outside material at their own pace, in whatever order they'd like, and they will be prompted at the end of the 2 week course with a quiz to assess the practical knowledge gained, as well as a number of essay prompts from which you can choose, or make your own, to request that students reflect on their experiences and lessons learned.

# Schedule Format #1- Day by Day Goals and Assignments

## Week 1-End of Life Care Options, Influencing Factors and Conversation Approaches

### DAY 1-Theme:Options available at EOL and the Physician's Role in the Conversation

- Cases: High Value Care 09
- Readings: ACP Ethics Manual Seventh Edition: Section on Care of Patients near the End of Life-  
[https://www.acpjournals.org/doi/10.7326/M18-2160?\\_ga=2.152452409.1618752071.1589204028-1409433073.1589204027&#208346044](https://www.acpjournals.org/doi/10.7326/M18-2160?_ga=2.152452409.1618752071.1589204028-1409433073.1589204027&#208346044)
- Podcast:Worster, B. *Hospice and Palliative Care: How to manage end of life symptoms*. The Curbsiders.  
<http://thecurbsiders.com/medical-education/s2-e16-hospice-palliative-care-manage-end-of-life-symptoms> (62 min)
- Interview: <https://www.sciencefriday.com/segments/atul-gawande-on-being-mortal/> (Assessing patient's priorities at EOL and quality of life) Simple conversations: What is your understanding of your health? What are your fears and worries for the future? What are your goals if your condition worsens? What are the outcomes that you'll find unacceptable? (27min)
- Questions:  
Content Check:  
What is hospice care? What is palliative care?  
What is the difference between hospice care and palliative care?  
What do patient's need to qualify for hospice care?What are the costs of hospice care for a patient enrolled in Medicare?

#### Reflection Questions:

Why do you think it is difficult to talk to patients' about end of life care?

How would you approach an end of life care conversation with a patient? What questions do you think would be important to address?

When do you think we should start having end of life care conversations with patients?

## DAY 2- Theme: Patient's perspectives on EOL care and what has value

- Cases: Geriatrics 21
- Readings: Gawande, A. *Letting go*. The New Yorker.  
<https://www.newyorker.com/magazine/2010/08/02/letting-go-2>

The Median Isn't the Message- Stephen Gould.

<https://people.umass.edu/biep540w/pdf/Stephen%20Jay%20Gould.pdf>

Yedidia, M. & MacGregor, B. "Confronting the prospect of dying: reports of terminally ill patients." *Journal of Pain and Symptom Management* (2001) 22.4: 807-819.

[https://doi.org/10.1016/S0885-3924\(01\)00325-6](https://doi.org/10.1016/S0885-3924(01)00325-6)

- Discussion Questions:
  - After going through Mrs. Kowalska's case, what is her main concern and fear if she were to die? Do you think these concerns are common for patients near the end of life?
  - Do you think it is important to ask patients about spirituality? Why or why not? How would you approach asking patients about their spirituality?
  - What do you think is the role of disclosing prognosis during end of life conversations?
  - How do you think patient characteristics affect their decisions to pursue medical treatments near the end of life? Compare Sarah Monopoli (recent first time mother with metastatic lung cancer) to Mrs. Kowalska. What kinds of pressures do patients have when facing these decisions?
  - Imagine you were a patient with terminal illness and had approximately 6 months to live. Your doctor tells you that you can try some treatments but the probability of them significantly prolonging your life is low. What would you be worried about? How would you want to spend your 6 months? What kinds of conversations would you like to have?

## DAY 3-Theme: End-of-Life Care from the Caregiver perspective and Family Conversations

- Cases: Geriatrics 14
- Readings:  
<https://theconversationproject.org/wp-content/uploads/2017/02/ConversationProject-ConversationStarterKit-English.pdf>  
<https://theconversationproject.org/wp-content/uploads/2017/03/ConversationProject-ProxyKit-English.pdf>
- Interview: Goodman, E. *How to start the Conversation with Ellen Goodman*. The Heart of Hospice.  
<https://www.stitcher.com/podcast/jerry-fenter/the-heart-of-hospice/e/62123067?autoplay=true>
- <https://danielleofri.com/one-last-visit-see-patient/>

- Discussion Questions:
  - What are Advance Directives? When should these documents ideally be filled out?
  - What does Full Code mean? What is the difference between Full Code and DNR?
  - What is a health care proxy or power of attorney?
  - What is the Conversation Project and why was it created?
  - Do you think it is important for family members to discuss end of life care preferences? Why or why not? How can you encourage families to have these conversations?
  - Imagine you have a patient with dementia who can no longer make decisions for herself who has reduced PO intake and been hospitalized frequently lately. Her main caregiver is her daughter, who was not able to discuss end of life care goals when her mother was able to make her own decisions. How would you go about determining the patient's goals of care? How would you approach this conversation with the daughter?
  - Think about having end of life care goal conversations with your parent or family member, do you think it would be difficult to initiate these conversations? Why or why not? What information would be important to gather?

## DAY 4-Theme: Culture and EOL care perspectives

- Cases: Geriatrics 26
- <https://www.youtube.com/watch?v=RofpAjqwMa8>
- Readings:
  - <https://www.newyorker.com/magazine/2020/04/06/chinas-struggles-with-hospice-care>
- Cain CL, Surbone A, Elk R, Kagawa-Singer M. Culture and Palliative Care: Preferences, Communication, Meaning, and Mutual Decision Making. *J Pain Symptom Manage*. 2018;55(5):1408-1419. [doi:10.1016/j.jpainsymman.2018.01.007](https://doi.org/10.1016/j.jpainsymman.2018.01.007)
- Podcast:
  - Crosscurrents. Racial disparities in end-of-life care: How mistrust keeps many African-Americans away from hospice. Mar Joann. <https://www.kalw.org/post/racial-disparities-end-life-care-how-mistrust-keeps-many-african-americans-away-hospice#stream/0> (14 minutes)
  - Crosscurrents. Challenges and cultural barriers faced by Asians and Latinos at the end of life. Mar, Joann. <https://www.kalw.org/post/challenges-and-cultural-barriers-faced-asians-and-latins-end-life> (14 minutes)
- Discussion Questions:
  - How would you have addressed Mr. Wang from the case when he came in for his follow up visit but did not fill his prescription or follow recommendations if you were his physician? What would have been your initial reaction?

- What is culture? What are some approaches in Western medicine that may differ from approaches in other cultures?
- What are some barriers that may affect the communication of end of life care preferences in people from different cultural backgrounds?
- What are some preferences about diagnosis disclosure that can vary among different patients?
- What are some ways you can approach asking patients about their beliefs and additional sociocultural factors?

## DAY 5-Theme: Putting it all together

Based on the cases and resources provided this week, for this day we have 2 reflection exercises that will help solidify the concepts discussed this week. In your reflections, you can include examples from personal experiences and/or examples from the resources of the week as well.

1. Watch this scene from the movie Wit (2001)  
[https://www.youtube.com/watch?v=NPoGXqNV\\_wc](https://www.youtube.com/watch?v=NPoGXqNV_wc)
    - Reflect on the conversation. How do you think it went? What assumptions were made? What options were given?
    - If you were the doctor disclosing the diagnosis in this case, how would you have approached the conversation? Rewrite the script.
    - If you were in the patient's position in this case, how would you feel about all the information being received and the way it was delivered? What pressures would you feel?
    - Was there any discussion about including family members in the conversation?
    - What assumptions from Western medicine were made in this case?
  
  2. Go back to Mrs. Kowalska's case (Geriatrics 21). Imagine that instead of meeting her in her home during a hospice care visit, you meet her and Tamara (her granddaughter) during a hospitalization for an acute COPD exacerbation. Mrs. Kowalska has had chronic end-stage COPD for 2 years and has been hospitalized more frequently for COPD exacerbations. You try to mention hospice care one day during your morning rounds. Tamara says she hasn't heard about hospice but wants her grandmother to receive the best possible care and doesn't want to give up on her. Mrs. Kowalska has full capacity to make her healthcare decisions.
    - How would you approach determining the goals of care for Mrs. Kowalska?
    - How would you inform her and her family about her options including continuing as she has been now vs. palliative and hospice care?
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## WEEK 2- Breaking Bad News and Having Difficult Conversations

### **DAY 1:** Theme: General Approach to Difficult Conversations: SPIKES

- **Primary case: Family Medicine 26**
- Alternative cases: Diagnostic Excellence 06 (Free Access), High Value Care 09 (Free Access)
  
- [Medical Lesson: Learning to Relate to Patients](#) (13 min)
- [A better way for doctors to break bad news](#)
- [A Poem for Those Lost and Confused After an ALS Diagnosis](#)
  
- Content Check:
  - What are the components of the SPIKES method for delivering “bad news”?
- Discussion Questions:
  - Why do you think it’s difficult for physicians to give bad news to patients?
  - Reflect on an experience you have had personally in receiving or delivering difficult news - what went well or poorly?
  - How do you feel the delivery of difficult news was portrayed in the case provided? What, if anything, did you learn, or what would you have done differently?
  - The three narrative pieces offer different perspectives on difficult medical conversations, did anything come up that was surprising or informative?

### **DAY 2:** Theme: Delivering difficult news to older patients and their family

- **Primary case: Geriatrics 15**
- Alternative cases: Internal Medicine 21, High Value Care 04 (Free Access)
  
- [Mom's Cancer – graphic novel by Brian Fies](#)  
Read the pages of the graphic novel embedded in the article
- [A Daughter Chronicles Her Parents' Final Months With Cancer : Shots - Health News](#)
- [Getting old should not mean losing control | Nicole Ruggiano | TEDxFIU](#) (15min)
  
- Discussion Questions:

What are some of the challenges associated with delivering bad news to older patients? What were some techniques employed by the physician in the Aquifer case in delivering bad news to Mr. Aiken?

What are some of the different ways that family members respond to the medical news or prognoses of loved ones, particularly their parents? What stood out about the ways that adult children respond to ailing parents in Mom’s Cancer, Nancy Borowick’s photo essay, and the stories in Nicole Ruggiano’s TED talk?

What legal, ethical, or moral responsibility do physicians have to the families of adult patients, if any?

In medical ethics, autonomy is often defined as the right of competent adults to make informed decisions about their health and medical care. In the Aquifer case listed above, the patient, his family, and his physicians were all on the same page, but what if they weren't? How might this case have gone differently if Mr. Aiken didn't want further workup but his son did? Or if Mr. Aiken wanted the physician to tell his son the results of his workup, but his son didn't know how to handle the news?

### DAY 3: Theme: Having difficult conversations in the pediatric population

- **Primary case: Medical Home 04 (Free Access)**
- Alternative cases: Pediatrics 29, Family Medicine 14
  
- [Medical Ethics 101](#)
- [Anything But "Sorry"](#) (2min)
- [On Keeping Bad Medical News from a Child Patient](#) (3min)
- [Imaginary Friends Society](#)
  - Watch one or two of the videos on the Imaginary Friends Society website (all under 5min)
  
- Discussion Questions:

What are some of the challenges provided with delivering bad news in the pediatric population? What are some techniques used by the creators of the Imaginary Friends Society to assist tough medical conversations?

Review the 4 tenets of medical ethics (autonomy, justice, beneficence and nonmaleficence). How might following medical ethics differ in the adult versus pediatric population when giving bad news and managing health care decisions?

Imagine if your child, sibling, cousin, or other child in your life were diagnosed with a terminal illness. What would you choose to tell them, or keep from them, and why? What if they were 3 years old versus 13 years old - both legally considered "incompetent"? What decisions would you let them make about their medical care?

In the Aquifer case, disclosing that their child has congenital anomalies is labeled as delivering "bad news." Does the "Anything But 'Sorry'" video change your perspective on how to approach these types of conversations with new parents?

Navigating parent guilt is a difficult part of giving bad news in the pediatric population. What were some tactics used in the Aquifer case to address parental guilt, and is there anything you might have done differently?

## DAY 4: Theme: Having difficult conversations about sexual and reproductive health

- **Primary case: Family Medicine 12**
- Alternative cases: Family Medicine 20, Diagnostic Excellence 03 (Free Access)
  
- [STIs aren't a consequence. They're inevitable. | Ella Dawson | TEDxConnecticutCollege](#) (17min)
- [Life After Miscarriage on Apple Podcasts](#)
  - Listen to 2 episodes of your choice (20-40mins each)
- [NEVER RARELY SOMETIMES ALWAYS - Official Trailer](#) (2min)
  
- Discussion Questions:

What are some of the challenges provided with delivering bad news regarding sexual or reproductive health? What role does stigma play in the conversations we have with patients, and the decisions patients must make?

On UpToDate, the “anxiety and disruption of personal relationships that can be associated with a positive test result” is cited as an additional reason why herpes screening tests with questionable sensitivity and specificity should not be used in asymptomatic individuals ([Epidemiology, clinical manifestations, and diagnosis of genital herpes simplex virus infection](#)). Taking into account Ella Dawson’s TED talk, what is the role of physicians when it comes to STIs and stigma?

What happens when our personal beliefs preemptively label news as “good” or “bad” as we deliver results to patients? Think about the two healthcare experiences the protagonist has during the Never Rarely Sometimes Always trailer - in what ways do they differ?

There were multiple episodes of delivery of sensitive news in this Aquifer case. How do you feel the delivery of this difficult news was portrayed in the case? What, if anything, did you learn, or what would you have done differently?

Patient shame and guilt often have to be addressed when delivering sensitive sexual or reproductive health news. Provide some examples from the Life After Miscarriages podcast where healthcare providers made things better or worse in these moments, and what takeaways you gathered for future patient care.

## DAY 5: Recap and Reflect

- Choose one example from below regarding delivering or receiving difficult health news, and rewrite the conversation in a way that you feel would have been more sensitive or productive:
  - Personal or professional experiences
  - Example from film, television, or provided narrative media for the week
  - One of the Aquifer cases for the week

- Watch this TED talk: [What happens when you have a disease doctors can't diagnose | Jennifer Brea](#) (17min)
    - We often think about giving bad news as synonymous with giving a diagnosis. But sometimes giving bad news means being unable to give a diagnosis. How does delivery of “no news” differ from delivering a bad diagnosis in how we, as providers feel, or how we might approach the conversation?
    - We often think about medicine as clear-cut and scientific, but as Ms. Brea states in her TED talk, “science and medicine are profoundly human endeavors.” How does history, human fallibility and bias play into our delivery of diagnoses? Do diagnostic errors affect certain populations more than others? Can you think of other examples of this type of error historically? Currently?
    - Is there anything that physicians or the medical community could/should do to avoid these types of diagnostic errors?
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## Guided Answer Sheet:

### **Week 1: End of Life Care Options, Influencing Factors and Conversation Approaches**

**DAY 1:** Theme: Options available at EOL and the Physician’s Role in the Conversation

Content Check:

- What is hospice care? What is palliative care?

From the High Value Care 09 case, students can obtain these definitions.

“**End-of-life** care is a broad term that refers to both palliative and hospice care.”

“ **Palliative care** is defined by the World Health Organization as: "An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.””

From the Curbsiders podcast:

Palliative care=symptom management for anyone at any stage in their illness

Hospice care is more applicable for the later stages of illness. It is a medical benefit and entitlement of insurance for patients with a life expectancy of 6 months or less. Unlimited renewals are available if the patient lives more than 6 months. The philosophy of hospice care focuses on quality of life and comfort, as well as keeping patients out of the hospital during their final months of life.

- What is the difference between hospice care and palliative care?

Hospice vs. palliative care

	Hospice	Palliative
Location	Usually at home	Can be at home; most common at an institution such as hospital, extended care facility, or nursing home
Timing	Terminal or within six months of death	No time restrictions; at any state of illness, whether it be terminal or not
Payment	Insurance coverage for hospice can vary; many programs covered under Medicare	Likely covered by regular medical insurance
Treatment	Comfort-focused	No expectation that life-prolonging therapies will be avoided

\*\*Comparison from Aquifer High Value care 9 case.

- What do patient's need to qualify for hospice care? What are the costs of hospice care for a patient enrolled in Medicare?

From Aquifer Case High value care 09:

Although a physician must certify that a patient only has six months to live to receive hospice care, a physician can continue to certify for hospice care every 30 days, if a patient continues to live beyond six months.

Palliative care services for most patients on Medicare are primarily funded by [Medicare Part A](#). Most patients do not pay a premium for Medicare Part A.

Patients usually only receive bills for medications (\$5 copayment) and 5% of the Medicare-approved amount for inpatient respite care. Hospice covers a one-time consultation with a Hospice physician even if a patient decides against Hospice. Once enrolled in Hospice, all doctor and nurse visits are covered.

For full coverage, Medicare does require that all palliative care services be delivered as hospice care; therefore a physician must state that a patient would be expected to die within six months. However, if they continue to live past six months they can continue to receive hospice care as long as a physician continues to recertify every 30 days.

### Reflection Questions:

- Why do you think it is difficult to talk to patients' about end of life care?

Students can have different answers to this question. Some of the themes highlighted in the resources provided include that these conversations can be difficult to approach because with advancing medical technology there is always some treatment to offer even though it might not be curative or improve a patient's quality of life. Sometimes there is the perception that when physicians don't have a treatment option to offer "they have failed". Survival and safety is put as a priority for physicians, but these might not align with patient priorities near EOL. Patients may differ in their priorities and for this reason it is important to initiate conversations on patient priorities and expectations for EOL care.

- How would you approach an end of life care conversation with a patient? What questions do you think would be important to address?

Students may have different answers to this question and thoughts about how to approach the conversation. From the resources provided some of the questions suggested to initiate the conversation are:

From Aquifer High Value Care 09:

1. What is your understanding of your illness?
2. How do you like to get medical information?
3. What is important to you?
4. What are you hoping for?
5. Have you thought about a living will or advance care plan (if you were to get sicker)?

While there are no set guidelines on opening a conversation regarding end-of-life care, there have been a few templates proposed, such as the following:

1. Initiate discussion
2. Clarify prognosis
3. Identify end-of-life goals
4. Develop a treatment plan

From Dr. Gawande's interview *On Being Mortal*:

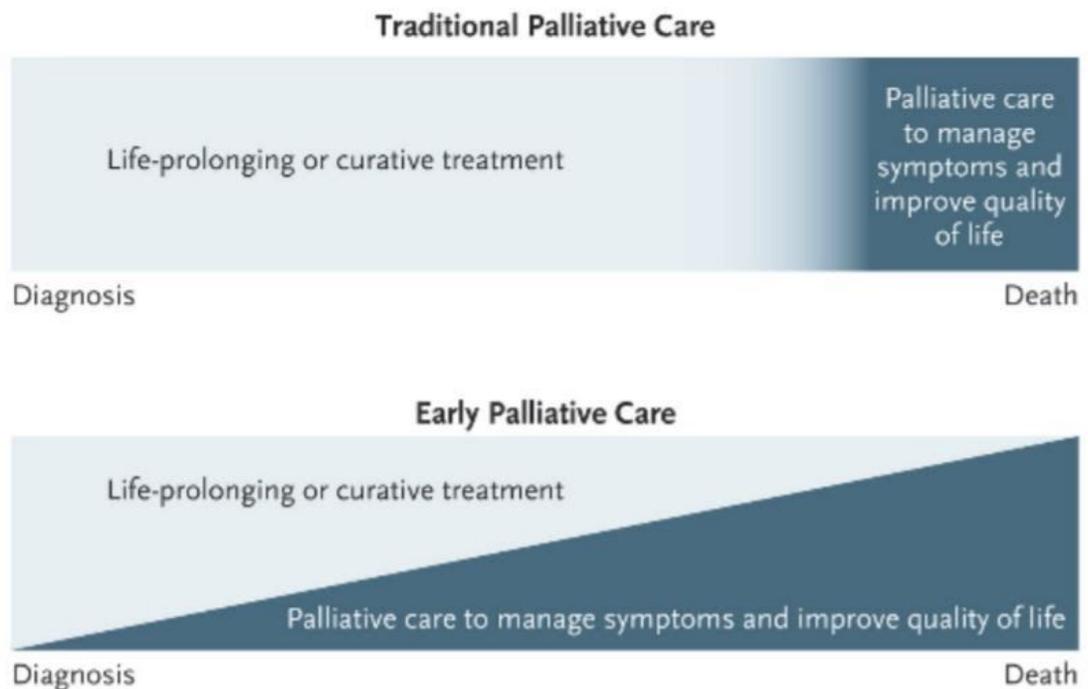
- Simple conversations: What is your understanding of your health? What are your fears and worries for the future? What are your goals if your condition worsens? What are the outcomes that you'll find unacceptable?

From Curbsiders Podcast:

- Scripts aka questions to ask a patient/family: What are you hoping for? What are you worried about? What is your understanding of this illness? If you had to guess, would mom or dad be happy with this quality of life?
- When do you think we should start having end of life care conversations with patients?

Students can have differing opinions on this question as well. In general it is recommended to start having end of life early with patients and having continuous discussions about their priorities throughout their care. Physicians and families don't need to wait until patients are acutely ill in the hospital to initiate conversations on EOL priorities. The emerging model of palliative care is a spectrum and even though hospice care requires patients to have a prognosis of less than 6 months to live, palliative care can be provided throughout different stages of illness and curative treatments do not need to be withdrawn to initiate palliative care.

Link from Aquifer High Value Care 09:



Parikh RB, Kirch RA, Smith TJ, Temel JS. Early specialty palliative care--translating data in oncology into practice. *The New England journal of medicine*. 2013;369(24):2347-2351

**DAY 2:** Theme: Patient's perspectives on EOL care and what has value

- After going through Mrs. Kowalska's case, what is her main concern and fear if she were to die? Do you think these concerns are common for patients near the end of life?

From Geriatrics 21:

One of Mrs. Kowalska's biggest concerns is her granddaughter's wellbeing. She has several bills piling up and is afraid her house will be taken away, which is the only thing she could leave her granddaughter. She is grateful for everything her granddaughter does but is afraid she is being a burden. Students can provide different opinions or reflections for the second part of the question but in general, it is common for patients to fear they will leave some things undone or leave behind a burden for their families to resolve.

From Geriatrics 21:

Patients with serious illness often have a strong awareness of their own mortality and fear what is unfinished or they won't be able to complete. This can result in an anticipatory grieving of the loss of their lives or clinical depression. They may not voluntarily share many of these thoughts of unfinished business if not directly asked. Some of the unfinished business may not be possible to complete; however, verbalization of their feelings and third-party discussion of alternatives to address their unfinished business may provide peace. This fear may also manifest as shortness of breath, pain, anorexia or insomnia. Addressing these spiritual/psychosocial emotions may alleviate or diminish physical symptoms.

From *Letting Go*:

"People have concerns besides simply prolonging their lives. Surveys of patients with terminal illness find that their top priorities include, in addition to avoiding suffering, being with family, having the touch of others, being mentally aware, and not becoming a burden to others." (Gawande, A)

- Do you think it is important to ask patients about spirituality? Why or why not? How would you approach asking patients about their spirituality?

As highlighted in the answer to the previous question, sometimes spiritual/psychosocial emotions can manifest as physical symptoms. Addressing fears, feelings and spirituality could help alleviate these physical symptoms. Additionally, asking patients about their spirituality could help identify potential needs that could improve their quality of life as they receive care.

As illustrated in the Geriatrics 21 case, sometimes asking patients open ended questions is enough to elicit some information about their spirituality. When more specific details are needed the FICA model could be a strategy to initiate a conversation on spirituality.

The FICA spiritual review is one formalized tool used to help assess a patient's spiritual history. It encourages the provider to ask the patient about:

F = Faith or beliefs (Do you consider yourself spiritual or religious?)

I = Importance (Is your faith important in your life?)

C = Community (Are you part of a spiritual community?)

A = Address care issues (How would you like me to help address these issues as we care for you?)

- What do you think is the role of disclosing prognosis during end of life conversations?

Students may reflect on the role of discussing prognosis based on the resources provided and come to different conclusions. Below are several prompts from the readings that could serve as points of discussion for the day.

From *Letting Go*:

"I asked Marcoux what he hopes to accomplish for terminal lung-cancer patients when they first come to see him. "I'm thinking, Can I get them a pretty good year or two out of this?" he said. "Those are *my* expectations. For me, the long tail for a patient like her is three to four years." But this is not what people want to hear. "They're thinking ten to twenty years. You hear that time and time again. And I'd be the same way if I were in their shoes."[...] A study led by the Harvard researcher Nicholas Christakis asked the doctors of almost five hundred terminally ill patients to estimate how long they thought their patient would survive, and then followed the patients. Sixty-three per cent of doctors overestimated survival time. Just seventeen per cent underestimated it. The average estimate was five hundred and thirty per cent too high. And, the better the doctors knew their patients, the more likely they were to err."(Gawande, A)

From *The Median Isn't the Message*:

"An hour later, surrounded by the latest literature on abdominal mesothelioma, I realized with a gulp why my doctor had offered that humane advice. The literature couldn't have been more brutally clear: mesothelioma is incurable, with a median mortality of only eight months after discovery. I sat stunned for about fifteen minutes, then smiled and said to myself: so that's why they didn't give me anything to read." (Gould, S)

"Hence the dilemma for humane doctors: since attitude matters so critically, should such a sombre conclusion be advertised, especially since few people have sufficient understanding of statistics to evaluate what the statements really mean? " (Gould, S)

"The distribution was indeed, strongly right skewed, with a long tail (however small) that extended for several years above the eight month median. I saw no reason why I shouldn't be in that small tail, and I breathed a very long sigh of relief. My technical

knowledge had helped. I had read the graph correctly. I had asked the right question and found the answers. I had obtained, in all probability, the most precious of all possible gifts in the circumstances - substantial time." (Gould, S)

- How do you think patient characteristics affect their decisions to pursue medical treatments near the end of life? Compare Sarah Monopoli (recent first time mother with metastatic lung cancer) to Mrs. Kowalska. What kinds of pressures do patients have when facing these decisions?

From *Geriatrics 21*, Mrs Kowalska is a 70 y/o female was experiencing symptomatic end-stage COPD for 2 years and was recommended by her doctor to consider hospice care. Given her age and having chronic illness for several years, the decision for her to opt for hospice care may have been expected. In this scenario she didn't experience pressure from family or her physician to continue treatments, but other individuals with a similar age group and chronic disease might face those pressures.

From *Letting go*, Mrs. Sarah Monopoli is a 34 y/o female who was diagnosed with metastatic lung cancer during her pregnancy with her first child at 39wks. She had never smoked and lived a healthy life otherwise. Given her age and lack of risk factors, the diagnosis of her terminal illness was unexpected. For these reasons, she probably faced additional pressures when approaching treatments and the thought of hospice or EOL care may have not crossed her mind. Additionally, her doctors may have been more hesitant to bring up EOL discussions given the unexpectedness of the diagnosis and her young age. Sarah may have felt pressure to keep receiving treatments with the hope that one would prolong her life and let her see her daughter grow, have more time with her husband and mother.

- Imagine you were a patient with terminal illness and had approximately 6 months to live. Your doctor tells you that you can try some treatments but the probability of them significantly prolonging your life is low. What would you be worried about? How would you want to spend your 6 months? What kinds of conversations would you like to have?

The goal of this question is to have students put themselves in a patient's shoes and think about what they would value in that situation and what conversations they would like to have. Some students may acknowledge that their decisions could vary depending on their age at the time of the diagnosis.

### **DAY 3**-Theme: End-of-Life Care from the Caregiver perspective and Family Conversations

- What are Advance Directives? When should these documents ideally be filled out?

From *Geriatrics 14*:

**Advance Directives** document a patient's wishes with regard to desired care near or at the end-of-life. Examples include forms that indicate the patient has appointed a durable power of attorney for health care decisions (health care proxy), or living wills (patient declaration of treatment wishes in various circumstances), or in some states, **Physician Orders for Life-Sustaining Treatment (POLST)** forms.

These documents often address whether the patient wishes to undergo cardiopulmonary resuscitation (CPR) or mechanical ventilation in the setting of cardiac or respiratory arrest or "incurable illness." They may also address whether the patient wishes to:

- have artificial fluids or nutrition if he or she can no longer eat;
- be treated with antibiotics; or even
- be hospitalized at all.

An advance directive is a valuable tool to assist medical professionals and family in decision-making by providing concrete evidence of a patient's wishes, obtained when the individual was cognizant and able to participate in decision-making.

Individual patients should be encouraged to have these documents filled out when they still have decision-making capacity, ideally in an outpatient setting under the guidance of a primary care provider, in an effort to plan for the future.

- What does Full Code mean? What is the difference between Full Code and DNR?

From Geriatrics 14:

**Full code** refers to an order that indicates that, in the case of respiratory or cardiac arrest, the patient would want full resuscitation efforts including CPR, medications and intubation/mechanical ventilation. Generally, if not otherwise specified, "full code" is considered the default. DNR stands for "do not resuscitate." This option refers to a patient's wishes not to be resuscitated in the event of a respiratory or cardiac arrest. It does not extend to any other treatment decisions and should not prevent other types of care.

- What is a health care proxy or power of attorney?

From Geriatrics 14:

A **health care proxy or power-of-attorney (PoA)** is someone who has been assigned, by the patient, the authority (via a written document) to make decisions upon someone's behalf if they are unable to do it themselves. Individuals may also have a power of attorney for financial affairs.

Designating a decision-maker in cases where there is no power of attorney can be complicated, and can differ from jurisdiction to jurisdiction. The convention is to usually have the next of kin or close friends serve as decision-maker. These individuals are usually chosen in the following order (although the exact order may change from state to state):

- Spouse
  - Adult child
  - Parent
  - Sibling
  - Other first-degree relatives, such as nieces, nephews, aunts, uncles, cousins, etc.
  - Close friends or acquaintances can be called upon to assist if none of the above are available.
- What is the Conversation Project and why was it created?

The conversation project is a public engagement initiative with the main goal of having every person's wishes for end of life care expressed and respected. They develop tools and resources to begin talking to loved ones about their wishes for end of life care. The nonprofit was founded by writer Ellen Goodman after she had served as a caregiver for her mother with Alzheimer's for many years and realized caring for her mother and making her health care decisions would have been much easier if they had conversed about her preferences for EOL care.

- Do you think it is important for family members to discuss end of life care preferences? Why or why not? How can you encourage families to have these conversations?

Students may have different opinions regarding the importance of EOL care conversations with family members. In general, it is recommended that family members discuss end of life care preferences early to ensure the loved one's wishes are respected in a scenario where they can no longer make decisions for themselves and need a healthcare proxy. In general, physicians could initiate starting these conversations in the outpatient setting asking what is your understanding of your illness? What are your fears and worries for the future? What are your goals if your condition worsens? What outcomes would be unacceptable for you?.

The conversation project also has many resources and conversation starter kits on their website for families to initiate end of life care preferences conversations with their loved ones. Physicians could refer patients to this resource or have patients and families fill a starter kit out before a follow up visit. Below is an example page from one of the conversation starter kit tools.

How involved do you want your loved ones to be?

1     2     3     4     5

I want my loved ones to do exactly what I've said, even if it makes them a little uncomfortable

I want my loved ones to do what brings them peace, even if it goes against what I've said

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When it comes to your privacy...

1     2     3     4     5

- Imagine you have a patient with dementia who can no longer make decisions for herself who has reduced PO intake and been hospitalized frequently lately. Her main caregiver is her daughter, who was not able to discuss end of life care goals when her mother was able to make her own decisions. How would you go about determining the patient's goals of care? How would you approach this conversation with the daughter?

The goal of this question is to have students think about having the conversation about end of life care when patients themselves are not able to participate in the decision making process. In the absence of patient participation, it is important to determine what the patient's goals of care would have been in each scenario. To approach this conversation with a family member of a patient:

From Geriatrics 14:

- Discuss and understand what the patient's wishes might have been had she been able to make the decision
    - Example questions: What is your understanding of your loved one's illness? If your loved one were able to participate, what do you think they would have preferred? If you were to guess, what would be the most important things for your loved one if their health were to decline? What outcomes do you think they would consider unacceptable? What are your fears and concerns for the future?
  - Understand, by listening and then verbalizing, what the worries of the family might be.
  - Convey information about the risks and benefits of the procedure
  - State or restate the patient's goals of care
  - Make a recommendation to the patient's decision-maker based on all of the above
- Think about having end of life care goal conversations with your parent or family member, do you think it would be difficult to initiate these conversations? Why or why not? What information would be important to gather?

The goal of this question is for students to think about how they would approach these conversations with their own family members from the perspective of a caregiver instead of a physician. Students can have different opinions and approaches to these conversations. They can also use the starter kits from the conversation project to help them think through how to approach these conversations.

The information that would be important to gather during these conversations will vary depending on the family member and his or her conditions but in general:

- What would be most important for your loved one in the end?

- How much information would they like to know about their conditions and treatments?
- How involved would they like to be in their treatment decision process?
- Who do they want to make health care decisions for them if they are no longer able to?
- How much medical treatment they would like to receive? What conditions would they consider unacceptable? (Resuscitation if your heart stops, breathing tube, feeding tube)
- Where would they prefer to spend their last days? (at home, at a hospital?)
- Are there any unresolved issues they fear or are worried about?
- When would it be okay to shift from a curative care focus to a comfort care focus?

#### **DAY 4**-Theme: Culture and EOL care perspectives

- How would you have addressed Mr. Wang from the case when he came in for his follow up visit but did not fill his prescription or follow recommendations if you were his physician? What would have been your initial reaction?

From Aquifer Case Geriatrics 26:

Mr. Wang, a 78 y/o Mandarin speaking male, comes in with his family for a follow up visit after being diagnosed with Alzheimer's dementia, but he did not fill out his prescription or follow the physician's recommendation because they read about the disease and didn't think he had it.

Students can have differing answers on how to approach this situation. Some may say that they would explain the illness again and their thought process as to why they think Mr. Wang has a diagnosis of Alzheimer's disease. Others may say they would feel frustrated initially if a patient comes in for a follow-up visit and doesn't follow the physicians recommendations or if a patient's family has differing opinions about a diagnosis.

The recommended approach to a situation like the one in the case is to ask the patient about his beliefs regarding his illness or health status in general. From Geriatrics 26: "Once you understand where the patient is coming from, you can identify discrepancies, address any misunderstandings, and negotiate a treatment plan acceptable to both parties. A good strategy for eliciting the patient's perspective is found in Kleinman's explanatory model of illness."

Students could also mention Kleiman's explanatory model of illness as an approach to the conversation with Mr. Wang. Some of the questions recommended in this model are:

- What do you think caused your problem?

- Why do you think it started when it did?
- What do you think your sickness does to you? How does it work?
- How severe is your sickness? Will it have a short or a long course?
- What kind of treatment do you think you should receive?
- What are the most important results you hope to receive from this treatment?
- What are the chief problems your illness has caused for you?
- What do you fear most about your illness?

A discussion on how physician or patient biases can affect perception of disease or need for treatment could be initiated here.

- What is culture? What are some approaches in Western medicine that may differ from approaches in other cultures?

From Aquifer Geriatrics 26:

'Culture' refers to integrated patterns of human behavior that include the language, thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social groups.

Culture impacts an individual's interactions with the healthcare system in many different ways. Some may be readily identified, such as the language the patient speaks, while others may be less obvious, such as the patient's understanding of causative factors in disease or concept of death.

Some examples of how Western Medicine may differ from other approaches is also included in Geriatrics 26. These include:

- A reductionist and mechanistic view of the human body. Disease is understood to be a malfunction in the machine which needs to be localized and corrected. Contrast this with other cultural beliefs of balances of forces or humors (yin/yang, hot/cold), or supernatural causes of illness.
- As a logical result of the above, western medicine tends to focus on disease, or specific pathophysiological processes, some of which may even be asymptomatic, such as hypertension. The focus is not on illness-which can be thought of as the subjective experience of being unwell, and which may not have an identifiable pathophysiology, such as irritable bowel syndrome. The goals of care thus tend to revolve around "cure", or correction of the pathology, rather than on "healing", or easing of the psychological experience. The focus, in other words, is more on the disease than on what the patient is experiencing.
- In American medicine more than other western countries, providers have tended to favor more dramatic and aggressive treatments in the pursuit of cure (e.g.,

experimental chemotherapy, higher frequency preventative tests such as mammograms).

Students may also have additional examples based on their personal experiences.

- What are some barriers that may affect the communication of end of life care preferences in people from different cultural backgrounds?

From Cain CL, Surbone A, Elk R, Kagawa-Singer M. Culture and Palliative Care: Preferences, Communication, Meaning, and Mutual Decision Making. *J Pain Symptom Manage*. 2018;55(5):1408-1419. [doi:10.1016/j.jpainsymman.2018.01.007](https://doi.org/10.1016/j.jpainsymman.2018.01.007)

Preference for care can be influenced by complex social, historical and political factors, as well as economic conditions, insurance status, and structural features of neighborhoods. Studies on end of life outcomes have shown differences between patients belonging to different racial/ethnic groups. For example, “ Studies with African Americans (AAs) and Latinos often conclude that they prefer high-intensity treatment measures at the end of life compared to whites.” This could be due to a variety of factors, including differences in preference for communication of EOL care priorities, mistrust in medical care, historic patterns of racism and research abuses, differences in faith practices. Access to care for services and pharmacies in different neighborhoods is also a significant barrier limiting options available to patients and could also influence the patient’s decisions regarding EOL care.

- What are some preferences about diagnosis disclosure that can vary among different patients?

Some patients may want to know every detail about their diagnosis and what to expect, while others prefer to know less or not discuss at all. In some cultures, talking about death is taboo or thought to hasten the whole process and is not openly addressed. It is important to ask all patients how much they already know about their illness and how much they would like to know about their illness. Although preferences may vary in different cultures, the culture of the patient should not be assumed. Even if a patient belongs to a culture where certain preferences are common, the patient should always be asked his/her diagnosis disclosure preferences.

- What are some ways you can approach asking patients about their beliefs and additional sociocultural factors?

Students can have different approaches to this question based on the resources provided from the week and/or personal experiences.

From Cain CL, Surbone A, Elk R, Kagawa-Singer M. Culture and Palliative Care: Preferences, Communication, Meaning, and Mutual Decision Making. *J Pain Symptom Manage*. 2018;55(5):1408-1419. [doi:10.1016/j.jpainsymman.2018.01.007](https://doi.org/10.1016/j.jpainsymman.2018.01.007)

The ABCDE model to ascertain level of cultural influence can be helpful to elicit additional information from patients. It is outlined in Table 2 of the article but in summary:

Attitudes- What does the disease mean to the patient or the patient's family?

Beliefs- What is important for us to know as a healthcare team about your faith or spiritual needs? How can we support your needs and practices? Where do you find the strength to make sense of these experiences?

Context- Where were you born and raised? How has your life changed? What were other important times in your life and how might these experiences help us understand your situation?

Decision-making style- Some patients may prefer to make their own healthcare decisions, while others may rely heavily on family members or prefer to make the decision as a group. It is important to ask patients about their decision making preferences.

Environment- assess the need for translators, potential organizations within the patient's community, the influence of chaplains or family members.

## **DAY 5: Theme: Putting it all together**

For both reflection exercises, students or the course director could decide whether they want the students to write an essay where they address all the question prompts or answer each question individually. The goal of these reflections is to reinforce concepts from the week and have students recreate conversations based on what they have learned.

1. Watch this scene from the movie *Wit* (2001)  
[https://www.youtube.com/watch?v=NPoGXqNV\\_wc](https://www.youtube.com/watch?v=NPoGXqNV_wc)

From watching this scene, students should be able to identify that this is not a good way to disclose a diagnosis of terminal illness. The patient was given no alternative options to proceeding and she barely asked about her feelings regarding the diagnosis. It was assumed that she would proceed with experimental treatments (maybe because she was a professor). She was not given the opportunity to express her preferences and the doctor disclosed every detail about her diagnosis without asking how much she would like to know.

When rewriting the conversation script, students can have a variety of approaches but the overall goal is for them to include the patient in the conversation, find out what the patient knows and how much they would like to know, and not jump into disclosing the diagnosis right away. Additionally, they should find what the patients priorities and preferences are for care and given all the options and risks and benefits of each. Additionally, some students may want to include a more thorough conversation about spirituality and social history as part of their script. Some questions students could use as part of their script could be:

- What is your understanding about your condition?
- How much would you like to know regarding your diagnosis?
- What are your priorities for your care? What is important to you?
- What are you hoping for?
- What are your fears and concerns for the future?
- What kinds of things would you like to be able to do even if your condition worsens? What conditions would you find unacceptable?

Patients should be given the time to respond and process the information. It is likely that not all of the questions and information would be disclosed in a single meeting.

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## Week 2: Breaking Bad News and Having Difficult Conversations

### DAY 1:

- What are the components of the SPIKES method for delivering bad news?

From Family Medicine 26:

- **Setting up the interview:** Arrange a private room where you can sit face to face with the patient. Encourage the patient to bring family members for support. Make eye contact during the interview.
- **Perception:** Use the rule, "before you tell, ask." Find out what is the patient's understanding of the situation before launching into an explanation. This allows you to dispel misinformation and identify denial.
- **Invitation:** Because a minority of patients do not want to learn about bad news, ask how the patient would like you to explain the information about the diagnosis.
- **Give Knowledge and information to the patient:** Expressing your own emotions about the bad news can lessen the shock of the news (e.g. "It makes me very sad to have to tell you that..."). Make sure to use non-technical words and avoid being overly blunt.
- **Address the patient's Emotions with empathic responses:** First, identify the emotion the patient is expressing and identify the reason for it (usually this is related to the bad news). Then let the patient know that you understand their emotion (e.g. "I can tell you weren't expecting to hear this." "I imagine this isn't what you wanted to hear.").

- **Strategy and Summary:** Laying out a plan for what will happen next, including how the patient can contact you and when you will see them again, can relieve anxiety and uncertainty for the patient. Summarizing the information and checking for understanding can prevent misunderstandings and avoid either an overly optimistic or pessimistic response by the patient.
- Why do you think it's difficult for physicians to give bad news to patients?

Sample responses could include that physicians are taught to “heal” and “save” and often giving bad news feels like a failure. We also might not have gotten as much experience or practice with difficult conversations during training or school as we have, say, learning about the science and medicine behind diseases, so it's harder to do things we don't have as much practice in.

- Reflect on an experience you have had personally in receiving or delivering difficult news - what went well or poorly?

Responses will vary depending on the individual.

- How do you feel the delivery of difficult news was portrayed in the case provided? What, if anything, did you learn, or what would you have done differently?

Potential responses include that it was good that the physician asked the patient if he was okay for information to be given in front of family before delivering it, assessing the level of patient understanding prior to delivering a diagnosis, giving the family and patient time to process and cry before speaking again, offering the option of further information or not, that it's good the case gave a variety of sample answers to a tough question, etc. Things that could have been better would be an explicit conversation about goals of care, preferences about how information is given, assessing (or at least informing at a later date) the importance of advance directives and discussions with family about what's important, referral for social or spiritual support etc.

- The three narrative pieces offer different perspectives on difficult medical conversations, did anything come up that was surprising or informative?

Responses will vary, but could include that it's interesting to see a physician's perspective on these conversations, once he's on the patient side of the equation, or that it's interesting to see how a patient might process an ALS diagnosis and express it in poem form - many ways to deal with diagnoses, or how it would be beneficial for your school to host check in meetings like the one in the podcast etc. The poem might make people realize that while giving bad news is a conversation that ends in the room for us, it's a life-long set of questions for patients, etc.

## **DAY 2**

What are some of the challenges associated with delivering bad news to older patients?

Responses could include difficulties with negotiating independence in older patients, cognitive impairment and dementia, financial and benefits issues, inadequate social support, feelings of depression and isolation, family members trying to assert their wishes, physician discomfort with asking goals of care questions, etc.

What were some techniques employed by the physician in the Aquifer case in delivering bad news to Mr. Aiken?

Sample responses could include, making sure the patient was okay with having the son present for the conversation, first asking the patient about his baseline understanding, assessing what kind of information he would like to know prior to delivering it, waiting to proceed while the patient and his family member processed, acknowledging the patient's fear and sadness, etc.

What are some of the different ways that family members respond to the medical news or prognoses of loved ones, particularly their parents? What stood out about the ways that adult children respond to ailing parents in Mom's Cancer, Nancy Borowick's photo essay, and the stories in Nicole Ruggiano's TED talk?

Some family members have difficulty separating their wishes for their parents or loved ones, from the wishes of the loved ones themselves. Some adult children take on authority roles, delegating and managing the care of their loved ones, others struggle with the changing dynamics that now exist. Some family members get frustrated at their loved ones, as is seen in Mom's Cancer, when the patient is unable to recognize the severity of her illness. In the photo essay, this daughter sought to capture the beauty and humor in a devastating moment, for there wasn't anything else she felt she could do. In Nicole Ruggiano's TED talk, she discusses how family members often supersede or ignore the wishes of older patients, as if they have lost their autonomy and independence completely, forgetting that older adults are not different from younger ones in their basic desires and needs.

What legal, ethical, or moral responsibility do physicians have to the families of adult patients, if any?

Of course if a patient is deemed incompetent and their loved ones have legal power of attorney or health care proxy status, then legally we must turn to them for guidance on their loved one's care. However, if an adult patient retains their competence, our duty (legally, ethically and morally) is to assess the patient's wishes and abide by them, regardless of the wishes of their family members. This of course is difficult to do, and may cause strain in the relationships between family members and providers. Palliative care teams and family meetings are often good ways to address the concerns of family while laying out the care plan that is in accordance to the patient's wishes. Of course, our role is to always be compassionate and respectful to all members involved, even when tensions are high.

In medical ethics, autonomy is often defined as the right of competent adults to make informed decisions about their health and medical care. In the Aquifer case listed above, the patient, his family, and his physicians were all on the same page, but what if they weren't? How might this case have gone differently if Mr. Aiken didn't want further workup but his son did? Or if Mr. Aiken wanted the physician to tell his son the results of his workup, but his son didn't know how to handle the news?

Although the patient's son is legally the health care proxy for the patient, the patient retains competence and as such his wishes should be respected. Of course, more information can be given to assess the patient's understanding of the risks and benefits involved, in order to establish that he is well enough informed to decline treatment. If the patient wanted the information to be given first to his son, then the physician would help that son process the information, always assessing what and how much information the patient wanted to know, and what his goals of care were, so that the son could adequately make decisions.

### **DAY 3**

What are some of the challenges provided with delivering bad news in the pediatric population? What are some techniques used by the creators of the Imaginary Friends Society to assist tough medical conversations?

Responses could include that children are not considered legally "competent," however the ability of children to understand and make informed decisions varies on a case-by-case basis and isn't always directly linked with age. Responses could also include tricky family dynamics, when parents' actions or beliefs might not be in the direct medical best interest of the patient, or managing the guilt and fear of parents, along with the child patient, etc. It's also oftentimes emotionally harder for providers to give bad news to children, especially if it's a terminal diagnosis.

Review the 4 tenets of medical ethics (autonomy, justice, beneficence and nonmaleficence). How might following medical ethics differ in the adult versus pediatric population when it comes to giving bad news and managing health care decisions?

For the most part, children cannot have autonomy under the law, as they are not deemed competent to make decisions on their own behalf. So other people have to make decisions for the child, but it might get complicated to separate the interests of the parents from those of the child. For example if the parents have a religious belief that alters management for the child, or if they don't want their child vaccinated etc. This is where beneficence and non-maleficence come into play, and where the job of pediatricians and the state might have to be asserted. But in some cases, families might choose not to tell their child of a terminal diagnosis when there is nothing that can be done (as in the NPR piece), and depending on the age of the child, this might be a difficult thing for providers to do. These are all considerations that can make giving bad news in the pediatric population more tricky than in adults.

Imagine if your child, sibling, cousin, or other child in your life were diagnosed with a terminal illness. What would you choose to tell them, or keep from them, and why? What if they were 3 years old versus 13 years old - both legally considered "incompetent"? What decisions would you let them make about their medical care?

Responses will vary

In the Aquifer case, disclosing that their child has congenital anomalies is labeled as delivering "bad news." Does the "Anything But 'Sorry'" video change your perspective on how to approach these types of conversations with new parents?

Although the conversations within the case are very non-judgmental and informative, it is true that the sections are labeled "bad news." It is common for us to label deviations from the norm as "bad" because they might bring challenges to a child or their family that they might not have been expecting. It's a hard balance - on the one hand, providers should acknowledge the emotional response of the parent and not try to steer them to feeling differently - this is not what they were expecting and they are allowed to grieve for losing that plan. However, negative emotions should never be offered first by the physician by leading with "I'm sorry", as was expressed in the "Anything But 'Sorry'" video. It is important in these conversations to choose your words carefully and intentionally, without implying how the patient *should* feel, and that's often difficult!

Navigating parent guilt is a difficult part of giving bad news in the pediatric population. What were some tactics used in the Aquifer case to address parental guilt, and is there anything you might have done differently?

In the case, the physician acknowledges the mother's emotion of guilt, normalizes it, and asks more about how she's feeling. The physician then explains that although things are not fully understood at the moment, it is unlikely that there was anything she did or could have done to prevent or cause her baby's symptoms. Some things that students might think could be improved would be acknowledgement that not all patients will want to be touched when they're upset, or maybe giving the couple some time alone to process the news before diving into a family history.

#### **DAY 4**

What are some of the challenges provided with delivering bad news regarding sexual or reproductive health? What role does stigma play in the conversations we have with patients, and the decisions patients must make?

Not only are sexual and reproductive health highly personal, they are also often the topic of social, religious and political discourse. People are given different levels of education on these topics, depending on what school they attended, and in what state, and families approach educating their children on these topics differently. American society has different norms on

what is “acceptable” sexual and reproductive behavior which is different across gender and sexual orientation lines, and has a definite impact on children, adolescents and adults. Regardless of these contextual factors, sexual and reproductive health are by definition intimate, and thus often carry an emotional weight to them. As practitioners, we are not immune to these same emotions and it is often difficult for us to discuss these topics openly and calmly with patients of all ages, gender identities and sexual orientations. Stigma impacts if/how patients broach these topics with providers or loved ones, and also how providers and loved ones react in return.

On UpToDate, the “anxiety and disruption of personal relationships that can be associated with a positive test result” is cited as an additional reason why herpes screening tests with questionable sensitivity and specificity should not be used in asymptomatic individuals ([Epidemiology, clinical manifestations, and diagnosis of genital herpes simplex virus infection](#)). Taking into account Ella Dawson’s TED talk, what is the role of physicians when it comes to STIs and stigma?

The fact that there’s a statement about “anxiety and disruption of personal relationships” on an objective medical website highlights that stigma surrounding STDs is real and pervasive, and perhaps includes those in the medical field itself. That being said, however, in Ella Dawson’s TED talk, she suggests that it is inappropriate that physicians NOT screen people who are asymptomatic for herpes, given the prevalence of the virus in society. Physicians should follow the guidelines set out by the evidence, but should have open and honest conversations with patients about prevalence and actively work to destigmatize STDs, particularly chronic and common ones like Herpes, to better allow patients to have informed conversations with partners moving forward, and live their lives without shame and guilt.

What happens when our personal beliefs preemptively label news as “good” or “bad” as we deliver results to patients? Think about the two healthcare experiences the protagonist has during the Never Rarely Sometimes Always trailer - in what ways do they differ?

Sometimes, “you’re pregnant” isn’t good news, and shouldn’t be followed by “congratulations!” In the youtube clip, the health practitioner who confirms that the protagonist is pregnant does so by saying “this is the most magical sound you’ll ever hear” and is oblivious of the pained, tearful look on the protagonist’s face. The health practitioner at the end of the clip, however, acknowledges that the situation is hard, and doesn’t place her own “spin” on the situation. It is hard for practitioners to separate their own feelings in these moments, but it’s the right thing to do for patients. We should never assume a patient feels the same way we would in their shoes.

There were multiple episodes of delivery of sensitive news in this Aquifer case. How do you feel the delivery of this difficult news was portrayed in the case? What, if anything, did you learn, or what would you have done differently?

Responses will vary but could include good things like establishing confidentiality, screening for sexual assault, asking about birth control preferences, giving options about pregnancy, adoption and termination, walking the patient through a pelvic exam prior to the examination, asking patient's mother to step outside, checking in with the patient emotionally, assessing level of support, asking the patient if she would like to know what's seen on ultrasound, checking in with the patient emotionally after hearing the heartbeat, giving encouragement and reinforcing patient strength, leaving the room when the patient requested space. Something that's always tricky is deciding what words to use - for example, the patient used the word "baby" but when the provider informed the patient of her inevitable abortion, the provider used the word "fetus." There's no right answer here, but it's important to use language that the patient is comfortable with and not to overly medicalize an emotional and personal experience like pregnancy loss.

Patient shame and guilt often have to be addressed when delivering sensitive sexual or reproductive health news. Provide some examples from the Life After Miscarriages podcast where healthcare providers made things better or worse in these moments, and what takeaways you gathered for future patient care.

Responses will vary depending on the podcasts listened to, but could include providers who were emotionally attentive, versus those who were cold, etc.

## DAY 5

- Choose one example from below regarding delivering or receiving difficult health news, and rewrite the conversation in a way that you feel would have been more sensitive or productive:
  - Personal or professional experiences
  - Example from film, television, or provided narrative media for the week
  - One of the Aquifer cases for the week

Responses will vary

- Watch this TED talk: [What happens when you have a disease doctors can't diagnose | Jennifer Brea](#) (17min)
  - We often think about giving bad news as synonymous with giving a diagnosis. But sometimes giving bad news means being unable to give a diagnosis. How does delivery of "no news" differ from delivering a bad diagnosis in how we, as providers feel, or how we might approach the conversation?

Responses might include provider discomfort with not "knowing" or with getting things wrong. We spend years learning so that we can know what is wrong with a patient when they present, but we often don't know, or it often takes years to figure it out. We need to be humble in our conversations with patients, and acknowledge that we don't know but that we will work with the patient to find the answer. It is a balance, but providers don't always acknowledge that patients are the experts in their bodies, even though we've studied physiology and pathology for years.

- We often think about medicine as clear-cut and scientific, but as Ms. Brea states in her TED talk, “science and medicine are profoundly human endeavors.” How does history, human fallibility and bias play into our delivery of diagnoses? Do diagnostic errors affect certain populations more than others? Can you think of other examples of this type of error historically? Currently?

Responses will vary but historic examples can include studies on head measurements to establish mental inferiority of women and black people, eugenics, medical experimentation on people of color including obstetrics and gynecology (Dr. Sims) and the Tuskegee syphilis experiments, Nazi experimentation on Jewish people, pathologizing homosexuality and trans identities etc. Currently we see reports of black individuals receiving less pain control, and black women and children dying at much higher rates than their white counterparts during childbirth, to name a few.

- Is there anything that physicians or the medical community could/should do to avoid these types of diagnostic errors?

Responses will vary. But learn. Learn about the unpleasant and often inhumane history of the medical field. And ask. Don't make assumptions about a patient's experiences, motives or wishes.

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## **Schedule Format #2- Comprehensive Cases and Assignments**

### Cases and Resources

#### **Aquifer Cases:**

- High Value Care 09
- Geriatrics 14
- Geriatrics 21
- Geriatrics 26
- Family Medicine 12
- Medical Home 04
- Geriatrics 15
- Family Medicine 26

#### **Alternate Cases:**

- Family Medicine 20
- Diagnostic Excellence 03

- Pediatrics 29
- Family Medicine 14
- Internal Medicine 21
- High Value Care 04
- Diagnostic Excellence 06 (Free Access)

### External Resources/Readings:

- Podcast:Worster, B. *Hospice and Palliative Care: How to manage end of life symptoms*. The Curbsiders.  
<http://thecurbsiders.com/medical-education/s2-e16-hospice-palliative-care-manage-end-of-life-symptoms> (62 min)
- Interview: Gawande, A. *On Being Mortal*.  
<https://www.sciencefriday.com/segments/atul-gawande-on-being-mortal/> (27min)
- Readings: Gawande, A. *Letting go*. The New Yorker.  
<https://www.newyorker.com/magazine/2010/08/02/letting-go-2>
- Interview: Goodman, E. *How to start the Conversation with Ellen Goodman*. The Heart of Hospice.  
<https://www.stitcher.com/podcast/jerry-fenter/the-heart-of-hospice/e/62123067?autoplay=true>
- <https://danielleofri.com/one-last-visit-see-patient/>
- Cain CL, Surbone A, Elk R, Kagawa-Singer M. Culture and Palliative Care: Preferences, Communication, Meaning, and Mutual Decision Making. *J Pain Symptom Manage*. 2018;55(5):1408-1419. [doi:10.1016/j.jpainsymman.2018.01.007](https://doi.org/10.1016/j.jpainsymman.2018.01.007)
- [A better way for doctors to break bad news](#)
- [Medical Ethics 101](#)
- [On Keeping Bad Medical News from a Child Patient](#) (3min)
- [Mom's Cancer – graphic novel by Brian Fies](#)
  - Read the pages of the graphic novel embedded in the article
- [STIs aren't a consequence. They're inevitable. | Ella Dawson | TEDxConnecticutCollege](#) (17min)

### Assignments:

#### Short Essay Questions:

- How would you approach an end of life care conversation with a patient? What questions do you think would be important to address?
- Imagine you were a patient with terminal illness and had approximately 6 months to live. Your doctor tells you that you can try some treatments but the probability of them significantly prolonging your life is low. What would you be worried about? How would you want to spend your 6 months? What kinds of conversations would you like to have?
- Imagine you have a patient with dementia who can no longer make decisions for herself who has reduced PO intake and been hospitalized frequently lately. Her main caregiver

is her daughter, who was not able to discuss end of life care goals when her mother was able to make her own decisions. How would you go about determining the patient's goals of care? How would you approach this conversation with the daughter?

- What are some barriers that may affect the communication of end of life care preferences in people from different cultural backgrounds?
- Why do you think it's difficult for physicians to give bad news to patients?
- What are some of the different ways that family members respond to the medical news or prognoses of loved ones, particularly their parents? What stands out about the ways that the adult children in "Mom's Cancer" respond to the patient's illness?
- Review the 4 tenets of medical ethics (autonomy, justice, beneficence and nonmaleficence). How might following medical ethics differ in the adult versus pediatric population when giving bad news and managing health care decisions?
- What are some of the challenges provided with delivering bad news regarding sexual or reproductive health? What role does stigma play in the conversations we have with patients, and the decisions patients must make?

### Final Essay:

- Option 1: Watch this TED talk: [What happens when you have a disease doctors can't diagnose | Jennifer Brea](#) (17min)
  - We often think about giving bad news as synonymous with giving a diagnosis. But sometimes giving bad news means being unable to give a diagnosis. How does delivery of "no news" differ from delivering a bad diagnosis in how we, as providers feel, or how we might approach the conversation?
- Option 2: Watch this scene from the movie Wit (2001) [https://www.youtube.com/watch?v=NPoGXqNV\\_wc](https://www.youtube.com/watch?v=NPoGXqNV_wc)
  - If you were the doctor disclosing the diagnosis in this case, how would you have approached the conversation? Rewrite the script and explain why you decided to approach the conversation this way.

### Final Quiz (From questions found in these Aquifer cases):

1. What is hospice care?
  - a. Hospice care is a medical benefit and entitlement of insurance only for patients that have a life expectancy of less than 1 month. Unlimited renewals are available if the patient lives more than 6 months. The philosophy of hospice care focuses on quality of life and comfort.
  - b. Hospice care is a medical benefit and entitlement of insurance for patients with a life expectancy of 6 months or less. Unlimited renewals are available if the patient lives more than 6 months. The philosophy of hospice care focuses on quality of life and comfort.**
  - c. Hospice care is a medical benefit and entitlement of insurance for patients with a life expectancy of 6 months of less. Renewals are not available if a patient lives

more than 6 months. The philosophy of hospice care focuses on quality of life and comfort.

- d. Hospice care is a medical benefit and entitlement of insurance only for patients who have terminal cancer with a life expectancy of 6 months or less. Unlimited renewals are available if the patient lives more than 6 months. The philosophy of hospice care focuses on quality of life and comfort.

2. What is palliative care?

- a. Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of treatment of pain. It can only be offered during late stages of illness.
- b. Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of treatment of pain. It can be offered at any stage of illness.
- c. **Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. It can be offered at any stage of illness.**
- d. Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. It can only be offered during late stages of illness.

3. What is needed to qualify for hospice care for a Medicare patient?

- a. **For full coverage, Medicare does require that all palliative care services be delivered as hospice care; therefore a physician must state that a patient would be expected to die within six months. However, if they continue to live past six months they can continue to receive hospice care as long as a physician continues to recertify every 30 days.**
- b. For full coverage, Medicare does not require that all palliative care services be delivered as hospice care; therefore a physician does not need to certify a life expectancy for a patient.
- c. For full coverage, Medicare does require that all palliative care services be delivered as hospice care; therefore a physician must state that a patient would be expected to die within six months. However, if they continue to live past six months they cannot continue to receive hospice care.
- d. For full coverage, Medicare does require that all palliative care services be delivered as hospice care; therefore a physician must state that a patient would

be expected to die within one month. However, if they continue to live past one month they can continue to receive hospice care as long as a physician continues to recertify every 30 days.

4. What are Advance Directives and when should these documents ideally be filled out?
  - a. Advance directives document a patient's wishes with regard to desired care near or at the end-of-life. Examples include forms that indicate the patient has appointed a durable power of attorney for health care decisions (health care proxy), or living wills (patient declaration of treatment wishes in various circumstances). These documents should ideally be filled out before a patient gets ill and patients must agree to be DNR.
  - b. Advance directives document a patient's wishes with regard to desired care near or at the end-of-life. Examples include forms that indicate the patient has appointed a durable power of attorney for health care decisions (health care proxy), or living wills (patient declaration of treatment wishes in various circumstances). These documents should ideally be filled out before a patient gets ill but patient's cannot make changes to the document afterwards.
  - c. Advance directives document a patient's wishes with regard to desired care near or at the end-of-life. Examples include forms that indicate the patient has appointed a durable power of attorney for health care decisions (health care proxy), or living wills (patient declaration of treatment wishes in various circumstances). These documents can only be filled out when patients are at advanced stages of illness.
  - d. **Advance Directives document a patient's wishes with regard to desired care near or at the end-of-life. Examples include forms that indicate the patient has appointed a durable power of attorney for health care decisions (health care proxy), or living wills (patient declaration of treatment wishes in various circumstances). These documents should ideally be filled out before the patient gets ill.**
  
5. What does Full Code mean?
  - a. Full code refers to an order that indicates that, in the case of respiratory or cardiac arrest the patient would want full resuscitation efforts including CPR, medications, but not intubation/mechanical ventilation. Generally, if not otherwise specified, "full code" is considered the default.
  - b. **Full code refers to an order that indicates that, in the case of respiratory or cardiac arrest, the patient would want full resuscitation efforts including CPR, medications and intubation/mechanical ventilation. Generally, if not otherwise specified, "full code" is considered the default.**
  - c. Full code refers to an order that indicates that, in the case of respiratory or cardiac arrest, the patient would want full resuscitation efforts including CPR, medications and intubation/mechanical ventilation. Generally, patients must certify they are full code before receiving any intervention.

- d. Full code refers to an order that indicates that, in the case of respiratory or cardiac arrest, the patient would want full resuscitation efforts including CPR, medications but not intubation/mechanical ventilation. Generally, patients must certify they are full code before receiving intervention.
6. What is the difference between Full Code and DNR?
- a. Full code refers to an order that indicates that, in the case of respiratory or cardiac arrest, the patient would want full resuscitation efforts. DNR stands for "do not resuscitate." This option refers to a patient's wishes not to be resuscitated in any event. It indicates the patient would not want to receive any medical intervention other than pain management.
  - b. Full code refers to an order that indicates that, in the case of respiratory or cardiac arrest, the patient would want full resuscitation efforts. DNR stands for "do not resuscitate." This option refers to a patient's wishes not to be resuscitated in the event of a respiratory arrest but not cardiac arrest and DNR patients can still receive CPR. It does not extend to any other treatment decisions and should not prevent other types of care.
  - c. **Full code refers to an order that indicates that, in the case of respiratory or cardiac arrest, the patient would want full resuscitation efforts. DNR stands for "do not resuscitate." This option refers to a patient's wishes not to be resuscitated in the event of a respiratory or cardiac arrest. It does not extend to any other treatment decisions and should not prevent other types of care.**
  - d. Full code refers to an order that indicates that, in the case of respiratory or cardiac arrest, the patient would want full resuscitation efforts. DNR stands for "do not resuscitate." This option refers to a patient's wishes not to be resuscitated in the event of a cardiac arrest but patients can still be intubated in the event of a respiratory arrest. It does not extend to any other treatment decisions and should not prevent other types of care.
7. What is a health care proxy or power of attorney?
- a. **Someone who has been assigned by the patient, the authority (via a written document) to make decisions upon someone's behalf if they are unable to do it themselves.**
  - b. Someone who has been assigned by the patient's family to have the authority to make decisions upon the patient's behalf
  - c. Someone who has been assigned by the patient the authority to make decisions upon the patient's behalf only in the event the patient becomes unconscious
  - d. Someone who has been assigned by the patient the authority to make decisions upon the patient's behalf and is always a spouse or family member.
8. What are some approaches in Western medicine that may differ from approaches in other cultures?

- a. Western medicine focuses on healing and easing the psychological experience of illness rather than finding a cure for a disease.
  - b. Western medicine focuses more on what the patient is experiencing rather than focusing on a specific disease
  - c. Western medicine does not tend to favor more dramatic and aggressive treatments in the pursuit of cure (e.g., experimental chemotherapy, higher frequency preventative tests such as mammograms).
  - d. **Western medicine tends to focus on disease, or specific pathophysiological processes, some of which may even be asymptomatic, such as hypertension.**
9. What are the components of the SPIKES method for delivering bad news?
- a. **SPIKES stands for: Setting up the interview, Perception, Invitation, Knowledge, addressing Emotions, Strategy and Summary**
  - b. SPIKES stands for: Setting up the interview, Perception, Initiating with diagnosis, Knowledge, addressing Expectations, Strategy and Summary
  - c. SPIKES stands for: Setting up the interview, Physician leader, Invitation, Kindness, addressing Emotions, Strategy and Summary
  - d. SPIKES stands for: Setting up the interview, Providing answers, Invitation, Knowledge, addressing Expectations, Strategy and Summary
10. What are some ways you can set up the interview when anticipating having a difficult conversation with a patient?
- a. Arrange a private room where you can sit face to face with the patient. Do not encourage the patient to bring family members as they may interfere with the conversation. Make eye contact during the interview. Have tissues in the room
  - b. **Arrange a private room where you can sit face to face with the patient. Encourage the patient to bring family members for support. Make eye contact during the interview. Have tissues in the room.**
  - c. Do not pre-arrange a meeting area as it can make the patient suspect the conversation will involve bad news. Encourage the patient to bring family members for support. Make eye contact during the interview. Have tissues in the room.
  - d. Do not pre-arrange a meeting area as it can make the patient suspect the conversation will involve bad news. Do not encourage the patient to bring family members as they may interfere with the conversation. Make eye contact during the interview. Have tissues in the room.