The University of Arizona Health Sciences

The CARES Toolkit

End-of-Life **Ca**ses and **Res**ources:

An Interprofessional Toolkit for Health Science Students

Facilitator Notes

Pharmacy: 35-Year-Old Native American Man Living with COVID-19 — Scenario 2

Case Title

Directions

1. Develop a series of questions and answers that address specific discussion points.

2. Develop 1-2 different scenarios (with questions and answers) that change or add discussion points.

3. Develop a list of needed community/healthcare resources and support services.

Possible Discussion Points (See Pages 10-12 for Example Questions):

- Difficult Conversations
- Ethical / Legal Considerations
- Patient Goals, Preferences and Values
- Medical Decision-Making Capacity
- Social Determinants of Health
- Advance Care Planning
- Community Resources/Access to Care
- Cognitive Impairment
- Health Literacy
- Sensory Deficits
- Ageism, Gender or Other Bias
- Cultural Humility / Diversity / Spiritual Considerations
- Family / Caregiver Concerns
- Limited English Proficiency
- Public Policy

Questions

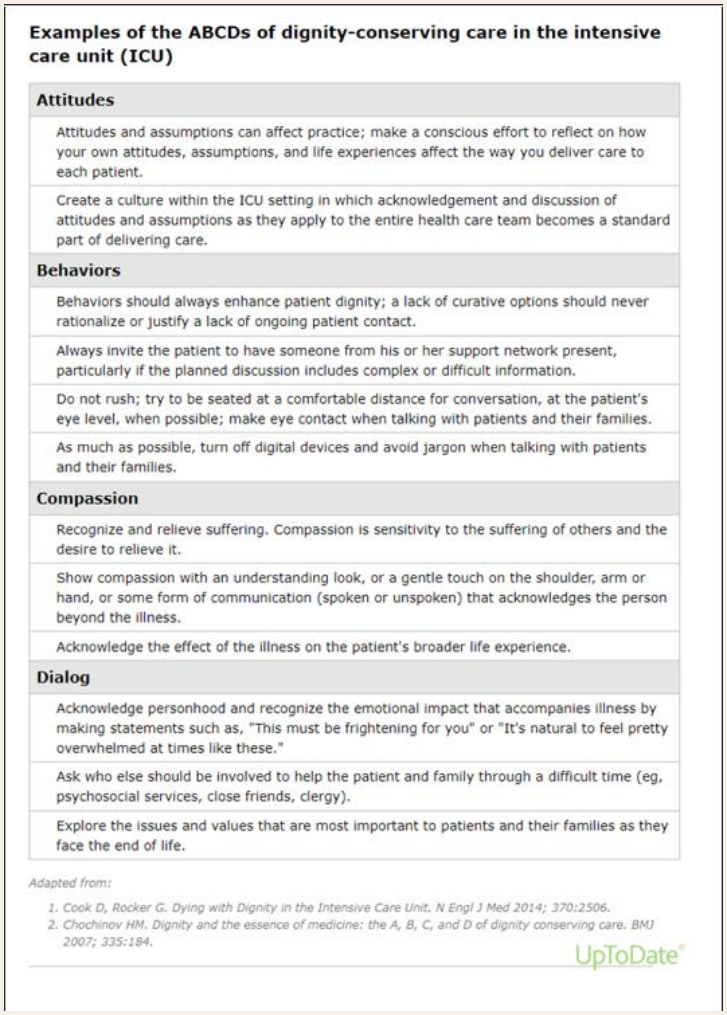
Develop a series of questions and answers that address specific discussion points.

Difficult Conversations & Cultural Humility

1. How should the difficult End-of-Life Care (EOLC) conversations be conducted to maintain cultural humility?

- The team should understand, be respectful of, and acknowledge the patient and family's cultural and religious beliefs and traditions. Patient and family's questions should be answered. Disease prognosis should be discussed by the team physician/provider. The effectiveness and risks versus benefits of the therapies should be clearly discussed. The benefits of advance care planning in making sure that the patient and family's wishes are adhered to.

- It is important to consider patient and family's religious beliefs and include chaplain in conversations based on those.



Examples of the ABCDs of dignity-conserving care in the intensive care unit (ICU)

Attitudes
Attitudes and assumptions can affect practice; make a conscious effort to reflect on how your own attitudes, assumptions, and life experiences affect the way you deliver care to each patient.
Create a culture within the ICU setting in which acknowledgement and discussion of attitudes and assumptions as they apply to the entire health care team becomes a standard part of delivering care.
Behaviors
Behaviors should always enhance patient dignity; a lack of curative options should never rationalize or justify a lack of ongoing patient contact.
Always invite the patient to have someone from his or her support network present, particularly if the planned discussion includes complex or difficult information.
Do not rush; try to be seated at a comfortable distance for conversation, at the patient's eye level, when possible; make eye contact when talking with patients and their families.
As much as possible, turn off digital devices and avoid jargon when talking with patients and their families.
Compassion
Recognize and relieve suffering. Compassion is sensitivity to the suffering of others and the desire to relieve it.
Show compassion with an understanding look, or a gentle touch on the shoulder, arm or hand, or some form of communication (spoken or unspoken) that acknowledges the person beyond the illness.
Acknowledge the effect of the illness on the patient's broader life experience.
Dialog
Acknowledge personhood and recognize the emotional impact that accompanies illness by making statements such as, "This must be frightening for you" or "It's natural to feel pretty overwhelmed at times like these."
Ask who else should be involved to help the patient and family through a difficult time (eg, psychosocial services, close friends, clergy).
Explore the issues and values that are most important to patients and their families as they face the end of life.

Adapted from:

1. *Cook D, Rocker G. Dying with Dignity in the Intensive Care Unit. N Engl J Med 2014; 370:2506.*
2. *Chochinov HM. Dignity and the essence of medicine: the A, B, C, and D of dignity conserving care. BMJ 2007; 335:184.*

Questions

Develop a series of questions and answers that address specific discussion points.

Family/Caregiver Concerns & Advance Care Planning

1. What are some of the concerns of patient's family with regards to decision on removal of mechanical ventilation/extubating the patient if his condition declines?

- The parents are concerned about their son suffering and feeling that is suffocating or being in pain. See answer to question 2 in this section.
- The parents are afraid that advance care planning means that they believe that their son is not going to survive. They do not want to abandon their child. It is important to discuss the advance care planning is beneficial and that:

"Advance care planning (ACP) is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care [1]. The goal of ACP is to help ensure that people receive medical care that is consistent with their values, goals, and preferences [1]. The timing and nature of ACP may vary depending on whether the person is healthy, has mild to moderate chronic illness, or has an advanced life-threatening illness and is thought likely to die within the next 12 months [2,3]. Regardless of the clinical scenario, ACP should be proactive, appropriately timed, and integrated into routine care. In addition, ACP should be revisited every time a person's medical condition changes [2-5].

ACP requires communication between patients, their family or other decision-makers, and their health care providers and is best done with consideration of the patient's relationships and culture, which will then drive specific medical treatment decisions that can be recorded in an advance directive (AD). ACP may include the completion of an AD, although this is not the primary intent of ACP discussions. Rather, the intent of ACP is to ensure that patients receive care that is aligned with their goals and values."
https://www-uptodate-com.ezproxy3.library.arizona.edu/contents/advance-care-planning-and-advance-directives?search=end%20of%20life%20comfort%20care&topicRef=14241&source=see_link
The team pharmacist is in the position of discussing the effectiveness and risks versus benefits of the medications that patient is receiving and answer the family's questions.

- Patient's family is concerned about not being with the patient at last days/hours of life as patient has COVID-19 and they cannot visit him. Ensure patient that they can do video calls with the patient with assistance of patient's nurse using their iPad. The team should be extremely compassionate in this discussion and facilitate what can be done based on hospital and CDC policies to have the family as close as possible.

Questions

Develop a series of questions and answers that address specific discussion points.

Family/Caregiver Concerns & Advance Care Planning (Continued)

2. What is end-of-life care/comfort care and how its discussion can assist with the family's decision making regarding advance care planning.

- End-of-life or comfort care contains medications to alleviate patient's pain and other symptoms that are associated with discomfort in last days/hours of life. Those medications include but are not limited to opioids for pain control, oxygen via nasal canula for dyspnea, anticholinergic medications for respiratory secretions, benzodiazepines for seizures and/or anxiety. Comfort care order sets to be identified and used accordingly.
https://www.cuanschutz.edu/docs/librariesprovider233/palliative-care/beacon/tab_1_comfort_care_order_set_implementation_introduction.pdf?sfvrsn=4a83f5ba_2

- It is important that patient's family understands the attempts that will be made to keep patient comfortable at end-of-life days/hours.
- The team pharmacist is in the prime position to discuss comfort care and its components with the family and answer their questions.

3. What conversations need to be conducted with patient's family regarding what happens at last hours of life?

Checklist for discussions with family about the last hours of life

Progressive unresponsiveness
Purposeless movements, facial expressions
Noisy breathing
Unlikely periods of awareness just before death
Possible acute events and action plan
Any other questions the family may have
Ask about previous deaths in the family (where, when, how)
Phone number (24 hours) for help
What to do after death

UpToDate

Questions

Develop a series of questions and answers that address specific discussion points.

Community Resources/Access to Care

1. What health insurance resources available?

- Based on the patient's income he may be eligible for AHCCCS.
https://www.azahcccs.gov/Members/Downloads/EligibilityRequirements.pdf
Social worker can assist in obtaining coverage. The coverage may retrospectively pay for patient's hospital care.

- Additional benefits are available for American Indians and obtaining additional health insurance does not affect their ability to use Indian health services.

- Patient and family can also receive health insurance vial Market Place, Medicaid, and Children's Health Insurance Program (CHIP) without losing Indian Health Services (IHS) benefits.

Scenario 1 and Questions

Develop 1-2 different scenarios (with questions and answers) that change or add discussion points.

Patient recovers and is ready to be discharged.

1. What is an important step to be taken?

- Student pharmacists need to identify follow-up needs, discharge canceling and transition of care needs.

- Student pharmacists need to identify the need for reviewing vaccination needs and preventative care needs with the patient and the family.

- Student pharmacists need to identify the need for the patient to complete Advance Care

Plan/Advanced Directive and how this can be facilitated as part of transition of care.

- Student pharmacists need to identify the need for the patient and the family to obtain health insurance and to seek medical attention when needed.

Scenario 2 and Questions

Develop 1-2 different scenarios (with questions and answers) that change or add discussion points.

Patient declines and the family is very distressed, and the decision is made to withdraw mechanical ventilation.

1. What support should be provided to patient and his family?

- Student pharmacists should identify the need for comfort care based on patients' symptoms and how the team can obtain information on related order sets.

- Student pharmacists should identify the need for the team collaborating with palliative care based on hospital policy.

- Student pharmacists should express the need for pharmacists to provide the needed support for the team in terms of medication dosing and available alternate routes of administrations of comfort care medications.

Resources and Support Services for the Patient / Family

Develop a list of needed community/healthcare resources and support services.

• National Institute of Health (NIH)
Therapeutic Management of Hospitalized Adults With COVID-19
https://www.covid19treatmentguidelines.nih.gov/management/clinical-management/hospitalized-adults--therapeutic-management/#:~:text=The%20Panel%20recommends%20remdesivir%20(without,of%20the%20disease%20(BIIa

• Indian Health Service (IHS)
https://www.ihs.gov/aboutihs/

• IHS Health Care
https://www.ihs.gov/findhealthcare/

Example Questions for Discussion Points

Difficult Conversations

- What is the specific communication/conversation skill(s) that is needed for this case? (e.g., Best Case/Worse Case framework; Serious Illness Conversation)
- How would you begin the conversation?

Ethical / Legal Considerations

- Are there any ethical/legal considerations that need our attention?
- Do they have a medical power of attorney?

Patient Goals, Preferences and Values

- How do you ensure you know/understand the patient's care preferences and values?
- What strategies would you use to assess the patient's goals, preferences, and values?

Medical Decision-Making Capacity

- Decision-Making capacity is always related to a specific medical decision. Capable patients have the legal and ethical right to make their own treatment decisions.
- Does the patient have decisional capacity? What more would you need to know?

Community Resources / Access to Care

- What community or healthcare resources or services would help the patient and/or family?

Social Determinants of Health (SDH)

- How would you address any known SDH issues? (food, housing or transportation insecurities; childcare, utility, legal, or education needs; financial resources; employment instability).

Advance Care Planning

- What do you see as the important decisions that the patient/family are facing?
- What specific knowledge is needed to provide the best of care? (e.g., definition of palliative care vs. hospice benefits).

Cognitive Impairment

- Does the patient have any cognitive impairment?

Health Literacy

- Can the patient understand and navigate health-related issues? Note: health literacy is different from general literacy.

Sensory Deficits

- Does the patient have any sensory impairment (hearing, vision)?

Ageism, Gender or Other Bias

- Can you identify any overarching bias?
- Can you identify any possible assumptions one might make about this patient? Note: Ageism occurs for people of ALL ages.

Cultural Humility / Diversity / Spiritual Considerations

- How does the patient's culture influence our approach to care?
- What terms may be misunderstood because of cultural definitions?

Family / Caregiver Concerns

- Does the patient have a caregiver?
- What is their relationship?
- Does the patient live with the caregiver?
- If not, does the caregiver live close-by or are they a long-distance caregiver?
- How is caregiver handling the stress of being a caregiver?
- Do they need support/resources?

Limited English Proficiency

- How do you identify if someone has limited English proficiency?
- When do you know you should bring a translator into the conversation?
- How do you access a translator?

Public Policy

- What information about this patient might inform public policy or regulatory action?

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