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: 30-Year-Old White Man Living with ALS — Scenario 1

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 12-14 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.

Patient Goals of Therapy, Preferences and Values

1. How should the goals of therapy be determined?

The goals of therapy should not be pre-defined and must be patient and disease specific. Goals of pharmacologic therapy should be determined based on (1) the pharmacist's conversation with the patient and caregivers determining patient's goals, (2) availability of pharmacologic agents for the symptoms/conditions, (3) patient's allergies and contraindications, (4) drug specific benefits, efficacy, adverse effects, and risks associated with use.

2. Should pharmacologic management only be considered for pain control?

Pharmacologic management should not be limited to pain control and needs to be individualized. Palliative and comfort care should include therapy for symptoms that impede on patient's quality of life and patient would like to be addressed.

Community Resources/Access to Care

1. How can community resources be identified?

There are disease specific websites that allow for identifying specialized clinics with multidisciplinary (interprofessional) care. Centers for Disease Control and Prevention (CDC) has information on various resources as well.

2. How can access to care be optimized for patients with ALS?

The resources noted in the previous response provide information on eligibility of the patient and family members for health insurances including Medicare and Medicaid. Drug manufacturers' assistance programs may offer assistance with the cost of the drugs or copays.

Questions

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

Family/Caregiver Concerns

1. What considerations should be made for caregivers?
Caregivers need support to have time to go to work, take care of matters of the house, exercise, shop, and rest. They need help with taking care of the patient when they cannot do their activities of daily living, lose ability to move, need to be picked up.

2. What family and caregiver concerns may worry the patient and what resources and support can assist in relieving those stressors?
Caregiver stress, financial needs, family health insurance, advance care planning, feeling of guilt for distressing the family members and anticipation of putting them in a position to make a difficult decision would worry patients. Resources to assist developing Advance Directives, financial assistance with medical needs, respite and hospice resources can assist relieve those stressors.

Scenario 1 and Questions

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

Dr. Jones wishes to only receive pain management and wants to let the disease take its rapid course.

1. What pharmacologic therapy do you recommend?

Student pharmacists need to provide long acting + short acting opioids to ensure adequate pain control. Medications should be provided to decrease risk of constipation with those medications in the setting of patient's lack of mobility.

Dr. Jones is very worried about Carol as she has to move him and assist him with all the activities of daily living. Also, Carol needs to go back to work as they cannot effort her losing her insurance and income.

2. What family and caregiver concerns may worry the patient and what resources and support can assist in relieving those stressors?

Student pharmacists need to identify that family and caregiver concerns are multilevel (emotional, financial, and workload related stressor). Providing mental health, family, and community support can assist with the emotional stressors. Helping the family / caregivers navigate the resources for financial and healthcare related support will assist with decreasing the current financial stressors. Respite care assists with reliving the caretakers' workload.

Scenario 2 and Questions

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

Dr. Jones wishes that in addition to pharmacologic management of pain, he receive medications for his muscle spasms. He also wants to know if there is anything to slow the progression of the disease.

1. What pharmacologic therapy do you recommend?

Student pharmacists to discuss pharmacologic options for patient's goals of therapy and evidence for use. Please note that the below list of the potential pharmacologic options is not comprehensive.

Decreasing the progression of the disease:

Riluzole - also has shown survival benefit
Formulations:
- Exservan oral film 50 mg - Place one film on tongue and let dissolve 1 hour before or 2 hours after a meal twice daily. (Preferred as per easier administration)

- Tiglutik Oral Suspension 50 mg/10 mL - 10 mL orally at least 1 hour before or 2 hours after a meal twice daily (Consider the large volume to be swallowed)
- Need to discuss if evidence support benefit in Dr. Jones as per as per his disease state and patient specific characteristics
- Significant drug-drug interactions and need for frequent dose adjustments to be discussed
- Adverse effects to be discussed
- High cost and available supports to be discussed

Edaravone (Radicava)
- Slows the decline of physical function
- IV infusion
- Student pharmacists should review the impact of IV infusion route of administration of this medication and frequency of use on its preferability.
- Adverse effects to be discussed
- Cost of medication and administration to be discussed

Scenario 2 and Questions

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

Pain control:
·Student pharmacists need to discuss the inadequate current management with as needed opioid.
· Need to discuss the need for long-acting opioid or one that releases throughout the day (e.g., Fentanyl patches) around the clock in addition to the needed morphine to avoid wearing off of the effect and chasing the pain
· Student pharmacists need to discuss the adverse effects of opioids and importance of having a bowel regimen to avoid or decrease risk of constipation

Muscle spasms / spasticity:
· Baclofen Oral tablets – 5 mg two to three times daily, may be increased every 3-7 days to a max dose of 80 to 120 mg per day.
· Student pharmacists need to discuss various options and their pros and cons, adverse effects, drug interactions

Dr. Jones does not think he can pay for his medications and medical needs. He still does not have insurance.

2. What resources are available for patient's medication coverage?
· Student pharmacists to discuss patient assistance resources including ALS specific national and state resources, medication assistance programs through the drug companies, eligibility criteria for Medicaid/AHCCCS (see resources).

Scenario 2 and Questions

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

Dr. Jones is worried about Carol's stress.

3. What resources are available to help patient at home and relieve Carol?

- Student pharmacists to discuss:
· Respite care support resources
· Financial support resources and family insurance support resources. (Carol will need longer leave and may need to take a leave without pay that also will affect her ability to maintain and pay for health insurance.)
· How those resources can be navigated and are there organizations to help with that
· Dr. Jones likely has educational loans as well. Discuss resources to pay that off
· Durable Medical equipment support to assist Carol and patient with patient's activities of daily living including speaking as this function declines.

Resources and Support Services for the Patient / Family

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

Organizations that support ALS patients and caregivers
https://www.cdc.gov/als/OrganizationsthatSupportPALS.html

National ALS Registry Partners:
· ALS Association:external icon the largest, national non-profit organization dedicated to ALS by providing assistance for people with ALS through a nationwide network of chapters, coordinating multidisciplinary care through certified clinical care centers.
· MDA ALS:external icon supports muscular dystrophy and related life-threatening diseases such as ALS through its national network of clinics.
· Les Turner ALS Foundation:external icon provides comprehensive ALS care and support services in the Chicagoland area and at Northwestern Medicine.
· Northeast Amyotrophic Lateral Sclerosis Consortium (NEALS):external icon supports ALS research and clinical trials through its network of ALS partners.
· National Institutes of Health (NIH):external icon National Institute of Aging (NIA) partners with the Registry to provide research support in the area of genetic analyses of specimens from the National ALS Biorepository.
· CReATe:external icon goal of the Clinical Research in ALS and Related Disorders for Therapeutic Development (CReATe) Consortium is to advance therapeutic development for sporadic and familial forms of amyotrophic lateral sclerosis (ALS).
ALS Informational Sites:
· ALS Clinical Trials:external icon find ALS clinical trials approved by the Food and Drug Administration (FDA).
· I AM ALS:external icon patient-led community that provides critical support and resources to patients, caregivers and loved ones.

Financial and Medication Assistance for ALS:
https://www.needymeds.org/copay_diseases.taf?_function=summary&disease_id=151&disease_eng=Amyotrophic%20Lateral%20Sclerosis%20%28ALS%29&dx=18&drp=als

Resources and Support Services for the Patient / Family

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

National Resources

ALS Foundation For Life- Provides grants to ALS patients in financial need to assist with respite costs, travel costs related to ALS clinics or research, generators, durable medical equipment repairs and personal emergency response systems. Services provided include: Durable Medical Equipment; Respite Care/Expenses; Transportation Services.

Assistance Fund, Inc. - Amyotrophic Lateral Sclerosis (ALS) Financial Assistance Program- Provides financial assistance for patients who have been diagnosed with Amyotrphic Lateral Sclerosis (ALS). Services provided include: Financial Assistance.

Canine Partners for Life - Service Dog Program- Provides service dogs to people with a disability or medical condition covered by the program. Services provided include Service Animals.

Edward T. Strauss Memorial Fund - "With Eddie's Help", Inc.- Provides financial assistance for medical equipment and/or supplies to individuals who have, or to families where an individual has Amyotrophic Lateral Sclerosis(ALS). Services provided include Medical Expenses; Medical Supplies/Expenses.

HARK - Financial Assistance Program-Provides assistance to alleviate the financial burdens faced by families battling ALS. Services provided include Child Care/Child Care Expenses; Durable Medical Equipment; Home/Vehicle - Repairs/Modifications; Living Expenses/Household Expenses; Travel Expenses/Gas Cards; Financial Assistance.

HealthWell Foundation - Amyotrophic Lateral Sclerosis Fund- Provides financial assistance for insurance co-payments and premium. Services provided include Insurance Co-Payments; Insurance Premiums; Financial Assistance.

Muscular Dystrophy Association Equipment Assistance- Program provides assistance in locating prescribed medical equipment through referrals to community resources for individuals with neuromuscular diseases. Services provided include Equipment Loan Program; Information & Referral/Counseling Services/Case Management.

Project Main Street- Helping those who are experiencing financial challenges as a direct result of ALS. Services include financial assistance.

Team Gleason- Helps financially with respite care, communication devices and adventure travel. Services include Durable Medical Equipment; Respite Care/Expenses; Wish Grants/Gift Baskets/Trips/Parties.

Resources and Support Services for the Patient / Family

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

Arizona Resources

ALS Association Arizona Chapter - Medical Equipment Loan Closet- Loans durable medical equipment to individuals who have ALS. Services provided include Durable Medical Equipment; Equipment Loan Program.

ALS Association Arizona Chapter - Respite Care Program- Provides respite care to caretakers of individuals who have ALS. Services provided include Respite Care/Expenses.

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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