

Palliative Care

Spinal CSF Leak: Bridging the Gap Conference

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Dr. Katherine Morrison MD

- Associate Professor CUSOM
- University of Colorado Palliative Medicine, Anschutz Campus
- Co-Director Community Based Hospice and Palliative Medicine Fellowship
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Contact:
Katherine.2.morrison@cuanschutz.edu



Learning Objectives

01

Define palliative care

02

Discuss how palliative care may benefit those with neurological conditions such as CSF leaks

03

Discuss importance of decision maker and advance directives

Palliative care: What is it?

Medical care focused on improving quality of life for people living with *serious illness*

- “a condition that carries a high risk of mortality, negatively impacts quality of life and daily function, and/or is burdensome in symptoms, treatments or caregiver stress.”

To live *as well as possible, as long as possible*

Palliative Care is...

- Skilled communication about what to expect in the future in order to ensure that care is matched to the goals and priorities of the patient and the family
 - **Goals of care**
- Intensive family meetings and patient/family counseling
- Management of complex/refractory physical and emotional symptoms
- Medical decision-making in the context of the neurologic condition
- Coordination and communication of care plans among all providers and across all settings
- Consultation/completion of advance care planning

The IDT & Psych-Social-Spiritual Assessment

Who is this person?

Who is this person in relation to others?



Uncertainty Diagnostic and Prognostic

Ubiquitous within many neurological illnesses

Uncertainty about what the future holds can deprive patients/families of a **sense of control**
→ stress and emotional turmoil

Estimating outcome in neurologic illness is more challenging than in the oncology population

Best case, worst case and most likely case scenarios

CSF leaks can have profound impact on Quality of Life

- 95 completed questionnaires (59 confirmed+36 suspected)
- Predominately female (69.5%) and white (91.6 %)
- Average age 51.5 yrs
- Physical Health
 - 74.5% scored headache in most severe category
- Mental Health
 - half of patients with moderate or severe depression
 - 25.4% with moderate to severe anxiety
 - 64.2% endorsed a wish to be dead
 - 22.4% had demonstrated suicidal behavior
- Patients who were symptom free (n-22) scored significantly better than symptomatic patients, comparable to general population

Unmet Palliative Care Needs in Typical Neurology Models of Care

Poor communication and inadequate psychosocial support at time of diagnosis for most conditions

Under-recognition and under-treatment of symptoms

Low rates of advance care planning discussions and completion of advance directives

Lack of standardized approach to goals of care discussions

Lack of systematic approaches to care partner support, psychosocial issues, or spiritual wellbeing

Low rates of hospice use (4-20% for most disorders) and high rates of hospital deaths (~50%)

Usual Neurologic Chronic Care -vs- Palliative Care

Usual Care	Palliative Care
Focuses on disease-related medical symptoms	Focuses on <i>total pain</i> of serious illness (physical, psychosocial, spiritual, practical challenges)
Focuses on improving physical health	Focuses on improving overall well-being and reducing suffering
Seeks to prolong life	Affirms and values life, while planning for possibility of decline and end of life
Focuses on patient	Focuses on patient and family/care partners
Focuses on enhancing <u>quantity</u> of life	Focuses on enhancing <u>quality</u> of life

Hope for the Best. Prepare for Just in Case.

Appoint	Have	Have	Complete
Decision maker	A goals of care conversation with your decision maker	A goals of care conversation with your neurologist, palliative care or primary care physician	Advance Directives MDPOA

Decision Maker

Not necessarily who loves you best or whom you love best

Should be someone who knows your wishes well

Use tools to help you talk about decisions (the conversation project, the five wishes, etc.)

Protect your choices with a legal document: MDPOA

Value Based Goals of Care

What brings you happiness/joy/meaning/satisfaction?

Given what you know, what is most important now?

What are your core values and priorities? (these may change)

Are there any non-negotiables/lines-in-the-sand?

Revisit whenever there is a major change or at least once a year

Examples of Value Based Goals of Care

- Connection
 - I want to continue to be able to communicate clearly with my family and friends.
- Family
 - I do not want to burden my husband with my health care needs and would like to be placed in skilled nursing if unable to take care of myself
 - I value any and all time with my children even if not able to communicate with them.
- Independence
 - I do not want to be kept alive on machines if there is any uncertainty that I will not be able to take care of myself at home
- Quality of Life
 - If the choice is between prolonging my life vs. decreasing pain, please treat my pain

Where is palliative care delivered

Primary palliative care

- Primary care physician/APP
- Social workers/RNs/chaplains
- Primary neurologists

Specialty palliative care

- Inpatient hospital
- Outpatient clinic
- Community palliative care
- Neuropalliative care clinic
- Hospice

Resources

- The Conversation Project:
<https://theconversationproject.org/nhdd/advance-care-planning/>
- The 5 wishes: <https://www.fivewishes.org>
- Primary Care
 - Colorado MOST
 - DNR
 - MDPOA