Alzheimer's Advance Care Planning

Caregivers

Disclosure Statement

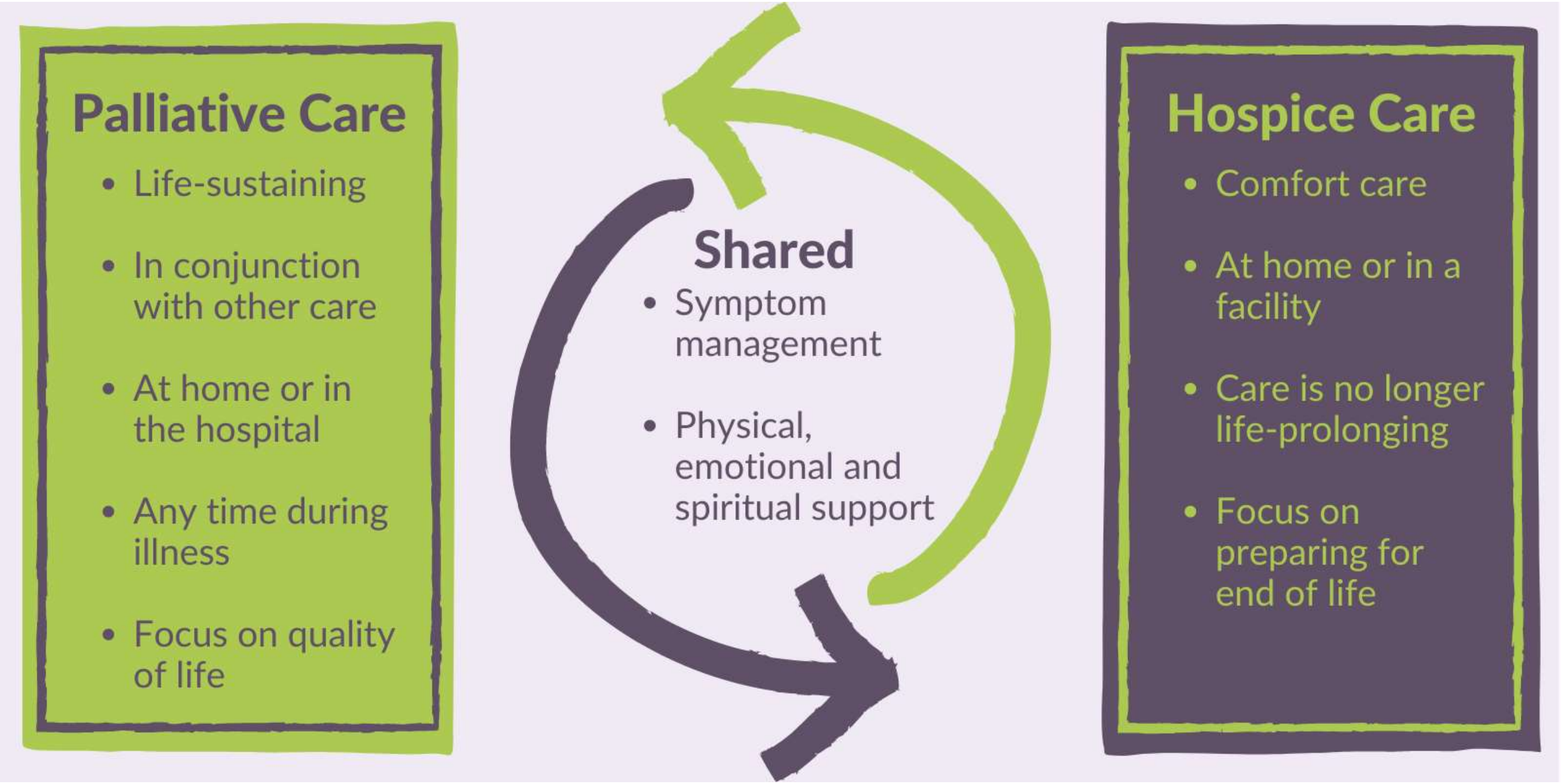
I have no financial interest or affiliation concerning material discussed in this presentation.

Advance Care Planning

- This is an interactive discussion:
- I will present information you can use to:
  - Guide you to early discussions with your loved ones about advance care planning
  - Use the advance care plan to guide you and the family through the difficult decisions that will lay before you over the coming years.
  - Understand the stages of disease management: active treatment, palliative care and hospice care and how each are different

Palliative Care

should be a normal and expected part of management of most progressive, advanced, and serious diseases, initiated at the onset of diagnosis.


Palliative Care
• Life-sustaining
• In conjunction with other care
• At home or in the hospital
• Any time during illness
• Focus on quality of life
Shared
• Symptom management
• Physical, emotional and spiritual support
Hospice Care
• Comfort care
• At home or in a facility
• Care is no longer life-prolonging
• Focus on preparing for end of life

Palliative Care

- Can begin when a person has a diagnosis of a serious life limiting disease
- Generally, a person accepts a palliative plan of care when
  - They acknowledge that treatment will slow the disease but not cure it
  - Their primary concern is limiting symptoms of the disease and quality of life
- Over the course of an Alzheimer's diagnosis how a person selects treatment, defines symptoms of concern and define quality of life will vary.
- Family, culture, spiritual beliefs and their own values will frame those decisions.

The person with Alzheimer's Disease

- Preparing for End of Life starts at the time of diagnosis
- Dementia complicates a person's health because at some point the person can't make decisions for themselves
- Their ability to care for themselves progressively declines slowly over the years.
- Family members may not be readily available to assist with care for a variety of reasons.
- Absolute worse situation for everyone is to be at a point of decision and be aware decision making will be a challenge
- To avoid these situations; have discussions early and frequently with the patient and family.; involve as many members of the family as possible

Advanced Care Planning

- A meaningful discussion about Advanced Care Planning or Advanced Directive requires several components.
  - Everyone (patient and family) understands the disease and the implications of the illness at the point and going forward.
  - Patient and family need to be ready to have the conversation.
  - The discussion must be relevant for the moment... if the patient is still working, performing chores and selfcare the discussion will be much different than if the patient has lost one or more ADLs
- Many times a person is admitted to the hospital or ER, their PCP is unaware and thus unable to share the person's wishes. The Family becomes the source of that information.
- If the family is uninformed or unaware of decisions made, can and do make decisions inconsistent with the person's wishes.

Patient Preferences About Serious Illness

- Two Nurse Practitioners, Whitehead and Carter have documented the PASI Model for a guided discussion with patients.
- The model is used in collaboration with Texas MOST/POLST (Medical Orders for Scope of Treatment) and the Five Wishes
- It is a model to normalize the conversation around preferences as the person moves through their illness, because those preference can and will change as the person's illness progresses.
- We are going to do an exercise

Patient with Serious Illness Model

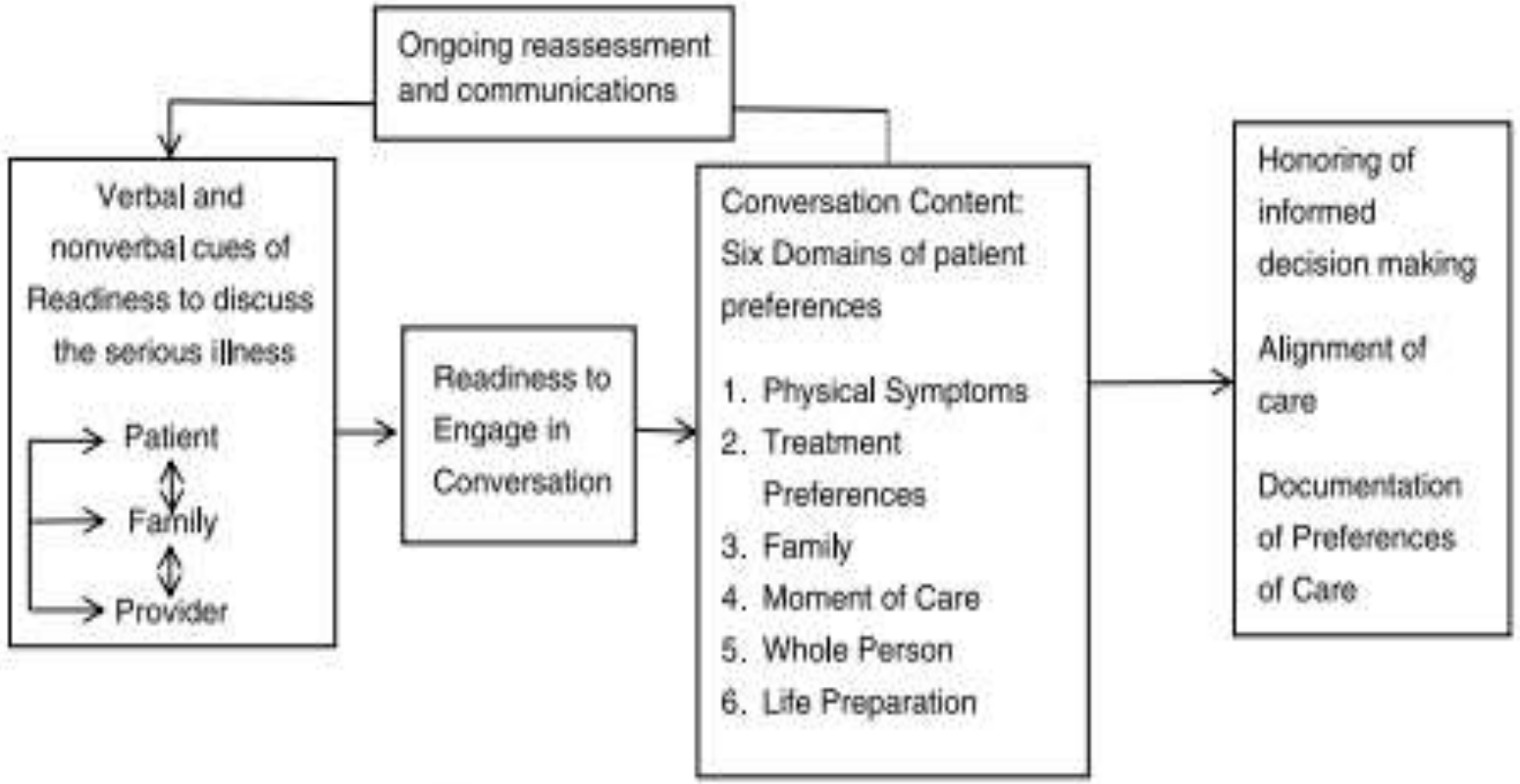


FIGURE. Model of meaningful conversation in serious illness.

Domains: What is important Right Now?

- Symptoms review - the tool has a list of symptoms
  - How important is it to you to have your symptoms under control?
  - Which of these symptoms are your top 3 concerns?
  - Are your symptoms being addressed or managed?
- Treatment Preferences
  - Having a serious illness, you may need to make decisions about treatment preferences. If you were to need any of these treatments today, would you want them? Breathing machine, dialysis machine, antibiotics, feeding tube, CPR, artificial hydration, intensive care.
- Family
  - How important is it to you to spend time with the following members of your family? Review a list of family members

Domains: What is important Right Now?

- Whole Person - Elicit core values and needs
    - How important is it for you to:
        - Laugh and smile
        - Keep your dignity and self-respect
        - Find meaning and purpose in your life
        - Be touched or hugged by your loved ones

Domains: What is important Right Now?

- Life Preparation - Spiritual, financial, and medical coverage concerns
  - How important it is to you to have a visit from a religious or spiritual advisor? If so, who?
  - How important is it to you to avoid strain on your loved ones? How so?
  - How important are the following to you?
    - Have personal medical leave?
    - Your family have medical leave?
    - Manage your health care cost?
    - Other?
  - How important is it to you to feel at peace with what lies ahead?

Domains: What is important Right Now?

- Moment of Care - from whom and where would you like to receive personal care
  - If unable to care for yourself, where would you like to have your care given: home, assisted living, nursing home etc
  - Whom would you like to help with your care if this occurs?

Patient Preferences About Serious Illness

- Complete this tool soon after diagnosis
- After evidence of decline or a medical event
- Allows the PCP to discuss physical changes as they occur and the treatment
  - Change in weight, difficult swallowing
  - Ability to perform Activities of Daily Living
  - Update the treatment preferences related to the changes in condition
- When the PCP needs to have the conversation regarding EOL, the family isn't caught unawares

So... Best Case Scenerio

- Review this information with your loved ones
- As the disease progresses, your answers to these questions change and guide you to the next steps
- You can us this information to update your wishes in a document like Texas POLST/MOST, Five Wishes or just inform your physician.
- Most important, through this process, your loved one's doctor keeps you informed and you have a chance to make decisions based on the changes in their condition. If you must go to an ER or Hospital, you can discuss those wishes with the ER Physician or Hospitalist.

Decisions

- Palliative Care
- Stay the Course
- Hospice Care

Decisions: Palliative Care Option

- Palliative Care is paid by Medicare and some insurances as a fee for service. It is not paid as a complete program, i.e. Hospice
- There are good palliative care options in El Paso
  - Physicians with palliative care private practices, provide consultative services in the office, home and hospitals and collaborative with the PCP
  - Clinics like WellMed that offer palliative care services for the UnitedHealthcare and WellMed community
  - Consulting services, i.e., Aspire, which offer SW and APN consultations and collaborate with primary care physicians
- Excellent for managing complex medical challenges, family issues
- Excellent for reviewing medications as the patient declines and adjusting based on the decline
  - This is a good time to reduce the number of meds especially those that won't have an impact on the person's health
- Home visits by nursing and social services

Decisions: Stay the Course

- Maintain communication with the doctor and out of town family members
- Hopefully have a way to do home visits to continue to track the patient's decline
- Options if you can't take your loved one to the doctor for follow-ups

Decision: Hospice Care

- Medicare defines Hospice Care as reserved for the individual who has a prognosis of 6 months or less, if the disease ran its normal course.
- A person with Alzheimer's may be in Late Stage for a few years before they are appropriate for Hospice Care.
- Criteria for Hospice admission is very specific..
- The Hospice Team needs specific information from the Primary Care Practitioner to justify the admission.
- The information collected over the course of the person's illness will help you communicate the person's need for hospice and help keep the person on hospice for the duration of their illness.

Hospice Criteria

- A prognosis of 6 months or less - if the disease runs its natural course
- FAST Scale of 7+
- Co-Morbid conditions that may have an impact on the course of the patient's illness
  - Heart disease, kidney disease or other neurological illness
  - Noting the structural/functional impairments together with any limitations in activity
    - i.e., person with end stage heart disease

FAST Scale

Stage 1-6

Stage #1: No difficulty, either subjectively or objectively Stage #2: Complains of forgettiStage #1: No difficulty, either subjectively or objectively

Stage #2: Complains of forgetting location of objects; subjective work difficulties

Stage #3: Decreased job functioning evident to coworkers; difficulty in traveling to new locations

Stage #4: Decreased ability to perform complex tasks (e.g., planning dinner for guests; handling finances)

Stage #5: Requires assistance in choosing proper clothing

Stage #6: Decreased ability to dress, bathe, and toilet independently:

- · Sub-stage 6a: Difficulty putting clothing on properly
- · Sub-stage 6b: Unable to bathe properly; may develop fear of bathing
- · Sub-stage 6c: Inability to handle mechanics of toileting (i.e., forgets to flush, does not wipe properly)
- · Sub-stage 6d: Urinary incontinence
- · Sub-stage 6e: Fecal incontinence

Stage 7

Stage #7: Loss of speech, locomotion, and consciousness:

- · Sub-stage 7a: Ability to speak limited (1 to 5 words a day)
- · Sub-stage 7b: All intelligible vocabulary lost
- · Sub-stage 7c: Non-ambulatory
- · Sub-stage 7d: Unable to sit up independently
- · Sub-stage 7e: Unable to smile
- · Sub-stage 7f: Unable to hold head up.

Co-Morbid Conditions

- The presence of a co-morbid condition isn't enough.
- How does the co-morbid condition impact the life expectancy of the patient. Using heart disease as an example.
  - Heart failure? Stage of Heart Failure? EGF?
  - Medications? Do the medications manage the symptoms of heart failure?
  - Functional Impairments? Has SOB at rest? Requires Oxygen?
- The same is for the history of Cancer., Kidney Ds or Neurological disorders.

Hospice Criteria

- Secondary conditions:
  - Weight loss
  - Difficulty swallowing - pocketing food
  - Bedsores
  - Delirium
  - Recent infections, i.e, pneumonia in the last 6 months, UTI
  - Hospitalizations and ER Visits.

Decisions: Hospice Care

- Review the patient's decline over the past year - I would ask family to consider how their loved one was at Christmas the prior year.
  - Weight and ability to take in food without assistance
  - Ability to speak - complete sentence,? few words,?
  - Ambulation
  - Admissions to the hospital and why,
  - Loss of ADLs (bath, dress, eat, transfer/walk, continence, toileting) after the admission or since last visit
  - Change in any of the Co-Morbid Conditions
    - Worsen of the condition,
    - Unable to take medications that managed the condition
    - Increase in SOB, having to use Oxygen at rest
  - New Secondary Conditions
    - Pneumonia
    - Skin breakdown
    - Inability to swallow and increase risk of aspiration
- I suggest you keep a journal

Hospice

- The Hospice uses all this information to determine if your loved one is appropriate for Hospice Care
- Why elect Hospice Care?
  - A hospice team develops a plan of care based on your wishes.
  - A hospice nurse will see and evaluate your loved one at least every 2 weeks, in most cases once a week.
  - You will call the nurse when something new happens, the nurse communicates with the physician.
    - This prevents doctor visits and hospitalizations.
  - There is a team that includes a social worker and a chaplain.
  - Death and Dying are their area of expertise. It is their superpower. They know your concerns, what makes you scared at night, the most common symptoms and how to manage them.

There are no wrong decisions

Our job is that the family is informed and can make decisions based on their family values and the wishes of the patient.

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- Holland, Diane E, PhD, RN et al, "Nurse Led Patient-Centered Advanced Care Planning in Primary Care.. A Pilot Study". Journal of Hospice and Palliative Nursing. 2017 19(4), 368-375
- www.medicare.gov
  - You can review the services covered by Medicare: Hospice, Home Care and Palliative Care
  - Select specific agencies and review the agencies quality scores

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