SA12- Why is Mom Dying? A Communication Method for Helping Families and Nursing Home Staff Cope with Natural Dying Process of Dementia Diagnoses

Saturday, March 24
2:30 PM- 3:30 PM

Session Description

In this session, participants will learn a practical approach to addressing the concerns that arise for families and staff members when a person with a dementia diagnoses stops eating or develops dysphagia. The presentation emphasizes an approach that alleviates guilt and grief of the caretakers, makes sense of the natural process occurring and allows informed decision making on options of alternate nutrition.

Learning Objectives

Review the science of aging/dementia and anorexia.
List the stepwise progression of anorexia that occurs in dementia diagnoses in a manner that makes sense.
Use communication techniques that alleviates guilt of caregivers.
Allow informed decision making in regards to potential alternate nutritional methods.

Presenter(s): Lauren Templeton, DO; Tommie Farrell, MD

Presenter(s) Disclosures: All speakers have reported they have no relevant financial relationships to disclose.
Why is Mom Dying? A Communication Method for Helping Families and Nursing Home Staff Cope with Natural Dying Process of Dementia Diagnoses

Tommie Farrell, MD
Pathways, Supportive and Palliative Care
Abilene TX

Lauren Templeton, DO
Medical Director
Hendrick Hospice
Abilene TX

Learning Objectives

By the end of the session, participants will be able to:

- Define the Science of Aging and Anorexia
- Identify Dementia as one of the key irreversible causes of anorexia
- Present information to families that allow them to make the most informed decisions about feeding in Dementia
- Demonstrate ongoing support to families through the natural process of Dementia

Explanatory Model

"An explanatory model is a useful description and explanation of why and how a thing works or an explanation of why a phenomenon is the way it is"

Think about how I answer this question?

Scenario

An 83-year-old male with history of Ischemic heart disease, BPH and dementia is admitted to hospice after a hospitalization for UTI. He has been living at home under the care of his daughter for the past two years. He has lost about 24 lbs. over the past year. He is bed to chair existence with maximum assist for transfers. He speaks a few words, “fine” and “no”.

Scenario Cont’d

He is requiring assistance for all ADLs including feeding which he requires a lot of cueing to keep eating and has to have soft foods – mainly puddings and soups. His other daughter is visiting from out of town when you make your initial visit to meet the patient and family.

One of the most pressing questions she asks is why is he dying? Why did he just stop eating?

Speaker Disclosures

Dr. Farrell has no financial relationships to disclose
Dr. Farrell is a member of the Governing Board for the Hospice Medical Director Certification - “The educational material I am presenting does not represent preparation for the HMDCB exam and this is not meant to be preparation for this exam.”
Dr. Lauren Templeton has no financial relationships to disclose
“To a man with an empty stomach, food is God”

- Mahatma Ghandi

Science of Aging and Anorexia

- Factors
  - Decreased physical activity and altered metabolism
  - Decreased hedonic (satisfaction) qualities of feeding (taste and smell alterations)
  - Altered hormones and neurotransmitters
  - Increase in satiating hormone cholecystokinin
  - Animal models show decrease in dynorphin, neuropeptide Y and nitric oxide

Science of Aging and Anorexia

- Leads to protein-energy malnutrition
  - Markers include SCALES
    - Sadness
    - low Cholesterol (<160 mg/dL)
    - low Albumin (<4 g/dL)
    - Loss of weight
    - Eating problems
    - Shopping problems or inability to prepare meal

Science of Aging and Anorexia

- Possible conditions associated with protein-energy malnutrition
  - Immune deficiency (helper T cells decreased)
  - Pressure ulcers
  - Anemia
  - Falls
  - Cognitive deficits
  - Osteopenia
  - Altered drug metabolism
  - Euthyroid sick syndrome
  - Decreased maximal breathing capacity

Science of Aging and Anorexia

- Potentially reversible causes
  - Social – poverty, social isolation, spousal loss, elder abuse or neglect
  - Psychologic – depression, bereavement, alcoholism, stressors/burdens
  - Iatrogenic – too many medicines, wrong combination of medications, side effects
  - Medical – hypercalcemia, gastritis (*Helicobacter*), gallstones, hyperthyroidism, chronic constipation
  - Other factors – dentures, dental loss/infection, food texture/type/temperature in facilities

Science of Aging and Anorexia

- Less likely to be reversed problems
  - Cancer
  - Parkinsonism
  - COPD and Cardiac disease
  - Paranoia
  - Dementia
  - Aging
Dementia and Anorexia

- Enhancement of the normal processes of anhedonia of eating and physical inactivity
- Inflammatory cytokines elevated during the dementia process
- Feeding Apraxia
  - Forget how to chew or swallow
  - Like a small child not learned to eat solids

Dementia and Anorexia

- Abnormal eating behaviors
  - Perhaps from destruction (plaques and tangles) of the:
    - hippocampus (behavior)
    - hypothalamus (appetite regulation)
  - Or interpretation of Feeding Apraxia as a behavior problem
  - Inverse relationship between behavior problems and weight maintenance

Dementia and Aging

- Studies show weight gain and/or weight maintenance is associated with reduced risk of mortality
- But, poor evidence that much helps when it comes to appetite stimulants
- May be some benefit with high-calorie supplements

BUT, Back to the Point

- Most patients and families do not care about the science listed above
- They want answers
- Let’s assume we will all do due diligence at working on reversible causes
- Reality is that many/most of Dementia/Parkinson’s patients will have progressive anorexia
- What do we say?

Goals of my explanatory model

- Make sense and kept simple
- Does not completely throw out the science
- Help alleviate suffering and guilt of the family
- Follows the natural course of the disease (so explains future steps)
- Allows autonomy of choices with good information of the typical disease trajectory

Sample of the conversation

Family – “Why did he just stop eating?”

Me – "First let me just state how much I can’t imagine how difficult it is to watch this happening…” [make sure they really know we get that this is hard]
- “This is a very common dilemma/situation seen in almost all of our patients with this disease…” [normalize the situation]
Sample of the conversation

- "Actually if you think about it this hasn’t just happened. It has been going on for a while and we see some steps that almost always happen in order…” [intro to use of the explanatory model]
- “I like to think about there being 6 steps of feeding…” (I actually hold up 6 fingers)

Sample conversation

- [the explanatory model unfolded] “First, we have to realize we are hungry. How long has it been that someone else has been reminding your dad it is time to eat?..”
- the family will likely start remembering a time months / years ago
- I periodically re-ask that same question in regards to the following steps

Sample conversation

“Then, we have to obtain or make that food.” (second step)

Sample conversation

“Then, we have to bring that food up to our mouth to eat. How long has someone been helping feed your dad?” (step 3)

Sample Conversation

• “When it appears that a person is full need to think about what it feels like to push more food on them when we are the hand providing the food…” “Think about Thanksgiving day when you are stuffed and someone trying to get you to take another piece of Pumpkin pie.”

Sample conversation

“We then have to chew the food. How long have we been softening up his food?” (step 4)
Sample conversation

“Now all of those first steps can be replaced by others… You have been loving surrogates for your dad for the past year… You have reminded him to eat, made his meals, placed it to his mouth, made it soft… (or in case of nursing home) You have made sure he was where someone could feed him…”
[statement to start helping in alleviating guilt and reassuring family they have done all they could]

Sample conversation

“The next two steps are hard in that no matter as much as you would like you can’t naturally replace them… the next step is swallowing… as much as you like you can’t do this for him…” (step 5)

Sample conversation

“Now this is the time that some decide since they can’t naturally replace this step they will go ahead and artificially replace it with a feeding tube, but…”
[informed consent statement – this lecture not meant to go over the to feed or not to feed data / conversation]

Sample conversation

“And even with the feeding tube, there is a last step that still eventually shuts down and has already been started in your dad. That is the step of the colon digesting the food correctly… When I look at your dad I see how little muscle and fat he has under his skin…” (step 6)

End of the conversation

- At this point I usually make more empathetic statements of the difficulty of this situation
- I ask if what I explained makes sense and ask what questions do they have for me

End of the conversation

- We discuss what care we can still continue during this natural process
- A lot of the end of the conversation is based off watching the emotional cues as the explanatory model is rolled out
- Are they getting it? / Is more information needed? / Do they need the tube feeding conversation?
End of Conversation

- Other concerns addressed
  - “Starvation”
  - When a person is hungry and we don’t give them food that is “starving” them. Allowing them to not eat when not hungry is different.
  - Anorexia produces an increase in levels of endorphins the same natural comforting medicines we get when we exercise

Response

- That is the 6-step explanatory model of why parents and spouses with dementia stop eating
- Most families seem to appreciate this model
- Less ambiguous than stating “how complicated” it really is
- More information than stating “this just happens in dementia”

Expert Responses

- That’s you guys
- Thoughts and tips from my colleagues who I consider the experts

References