Canadian Hospice Palliative Care Association
Association canadienne de soins palliatifs

Strengthening a Palliative Approach
SPA LTC
in Long-Term Care

Comfort Care Rounds:

8 Learning Scenarios for Long-Term Care Staff

Instructions Page

Purpose of this resource: To increase the confidence and knowledge of staff caring for residents who are living and dying in Long-term Care.

Intended Audience: Staff who assist in the end-of-life decision-making within long-term care. Please encourage all staff (i.e., cleaning staff, recreation staff, etc.) to join. Encouraging an interdisciplinary team approach in learning strengthens teamwork, awareness, and overall quality of care for residents in LTC.

Teaching Plan:

1. Visual Aide: Distribute a copy of the Comfort Care Rounds booklet for everyone to have a visual learning guide (either electronically or a physical copy)
   [OR if this cannot be distributed] Display the Care Scenarios on a PowerPoint presentation or create a concept map of main points from the scenario on a board.
2. Introduction: Introduce the purpose of this resource to the audience and encourage optimism in learning.
3. Introduce the Scenario: Read each Resident scenario as a group (encourage the audience to participate in reading the scenarios).
4. Discussion/Facilitating questions: When facilitating questions note words of emphasis on a board (i.e., similar thoughts, outlying thoughts, etc.) to assist staff in recognizing learned experiences from the discussion.
5. Inform Practice: Review listed descriptions where opportunities to inform practice relating back to the specified scenario arise. Relate informed practice discussed during the comfort care round to current practices within the staff's scope of knowledge.
6. Roleplay: In this section, you will be practicing as if this scenario would arise in the practice setting. Encourage the group to openly collaborate and partake unitedly as the 'staff' that will help in the decision-making process within the specified scenario. You could also have one member of the group become the family or resident; in this way, they are able to feel how staff approach this situation.
7. Feedback: Provide feedback to the group throughout the Comfort Care Rounds. Both Constructive and positive feedback is beneficial for learning. Always encouraging ongoing learning and support among staff members.
8. Follow-up: At end of class follow up with any areas that group members would like to review. Ensure emotional support is provided through the rounds as this can be a sensitive topic for certain individuals.

Notes:

1. Encourage the group to openly discuss each scenario and not to worry if they are uncertain of what to say. Remind the group this is a learning experience.
2. Create an environment where the group members feel comfortable in expressing themselves. At times, members of the group may be uncertain of how to approach a question. The facilitator can encourage them optimistically by, stating phrases such as, “This is a great opportunity for growth and although you may not know the answer, you can begin to explore what you may already know or have felt in practice here, and within a safe, supportive group setting”.

References:

For additional learning and tips please visit the palliative alliance toolkit at:

https://www.palliativealliance.ca/

and review the following publication:

Wickson-Griffiths A., Kaasalainen S., Brazil K., McAiney C., Crawshaw D., Turner M., & Kelley, M. L. (2015). Comfort care rounds: A staff capacity-building initiative in long-term care homes. *Journal of Gerontological Nursing*, 41(1), 42-48.

Scenario 1

Section Type: Reflection and Education

Description of Resident Scenario

LB is an 80-year-old female. She lives with advanced dementia, and a history of breast cancer, hypertension, and diabetes. A Hoyer lift is used to help LB out of bed and into her wheelchair. Over the past few weeks, staff have noticed that LB has been verbally less engaged and wanting to spend most of her days in sleeping in bed. LB has lost a significant amount of weight over the past few weeks and is not interested in eating. LB is no longer able to make any decisions about her goals for end-of-life care. At this point, her substitute decision maker is insistent that LB receive all investigations and interventions to sustain life (i.e., blood tests, blood transfusion, IV fluids, etc.).

Purpose of Comfort Care Round

Assist substitute decision makers (often a family member) in learning about different options for goals of care for end-of-life care, including a palliative approach to care.

Questions for Facilitator to Start Discussion

- Does this scenario reflect the experiences of residents and family members that you currently care for?
    - What successes and/or challenges are you experiencing?
- What are the conflicts or tensions that are felt by staff in offering all interventions to sustain life?

Additional Discussion Questions

- What changes in the resident are staff noticing to prompt a discussion with the substitute decision maker about goals of care?

- How should staff start/approach the substitute decision maker with a conversation about goals of care?
- What questions might residents and/or substitute decision makers ask about goals of care?
    - How should staff respond? How have staff responded in the past?
- How can staff effectively communicate to the substitute decision maker the significance/implications of changing a goal of care (e.g., to align with a palliative approach to care)?
- How may the interdisciplinary team be involved in a goals of care discussion? (e.g., physician or nursing staff to speak to end-of-life prognosis or identifying specific signs; pharmacist to discuss deprescribing to medications that the resident may no longer benefit from).

Inform Practice – Centering the Resident in Goals of Care Discussion

Family members, in the role of substitute decision maker, need to make decisions based on what they believe are the resident's wishes. As health care providers we can ask questions to prompt their thinking, such as:

- "What is important to your [relative]…?"
- "What would [they] do or want in this circumstance …?"
- "Based on your [relative]'s current condition, we think she would benefit from a palliative approach to care…. how does this fit with your understanding of what your mother would want in this situation…?"

Inform Practice – Reflection Question

- How might you ask resident/patient-centered questions to explore wishes for care?

Inform Practice – Approaches to Care

It is important for substitute decision makers to understand approaches to care. Typically, residents (where able) and substitute decision makers (on the resident's behalf) are able express goals of care for treatment may focus on:

- **A palliative approach to care where interventions are directed at maximal comfort, symptom control and maintenance of quality of life**, which excludes attempted resuscitation. A palliative approach focuses on
  - treating symptoms
  - no investigations or limited to those that promote comfort
- **An approach to care that focuses on investigating causes and/or treating disease processes** where interventions are for care and control of the resident's condition. There is consensus that the resident may benefit from, and is accepting of, any appropriate investigations/interventions that can be offered. This approach may focus on
  - investigations and treatments such as blood transfusions, IV antibiotics, X-rays, blood tests
  - resuscitation (may or may not be offered)

Inform Practice – Resuscitation

- Many substitute decision makers do not know what is entailed when the resident's plan of care includes a resuscitation order.
- Substitute decision makers may believe that if CPR revives the resident, that they will return to their same level of function before the event requiring resuscitation.
  - In this specific scenario, LB is an 80-year-old resident, who is frail and has an extensive health history. The likelihood of LB or another resident in a similar circumstance returning to a similar quality of life is extremely unlikely after receiving CPR. Therefore, it is essential to educate substitute decision makers about the likely outcomes of CPR and discuss the goals of care and what they will mean for the resident's ongoing quality of life.

    - For example, “CPR involves pushing down into the chest, at least 2 inches deep, at a rate of 100 to 120 times per minute. Air is often forced into the lungs and an electric shock is often sent to the heart. Even if CPR is successful in reviving a resident in this circumstance, the resident would likely have significant physical trauma, including broken ribs, damage to the lungs and internal organs, internal bleeding, and brain damage due to oxygen deprivation.”

Inform Practice – Role Play

- How would you explain resuscitation procedures and likely outcomes to a resident or substitute decision maker? Practice!

References

CancerCare Manitoba. (2018). *Advance care planning and goals of care*. https://www.cancercare.mb.ca/export/sites/default/About-Us/.galleries/files/policy-files/patients/10.004-Advance-Care-Planning-and-Goals-of-Care_June-1-2018_final.pdf

Scenario 2

Section Type: Reflection and Action

Description of Resident Scenario

Last evening, EB, a 70-year-old male with end-stage cardiac disease and a history of depression and anxiety passed away. EB's Palliative Performance Scale score was PPS10% for the last 3 days of his life. The evening shift nurse reported that EB's breathing remained shallow but regular, and his family was at the bedside at the time of his passing. The nurse reported that EB appeared comfortable and was receiving 0.5mg of hydromorphone subcutaneously, every 4 hours.

Purpose of Comfort Care Round

Reflect on a recent 'good' resident death.

Questions for Facilitator to Start Discussion

- Does this scenario reflect the experiences of residents and family members that you currently cared for?
- What does a 'good death' or 'successful dying' look like in your practice?

Additional Discussion Questions

- What are the primary objectives for someone who is facing imminent death?
    - Change it up! Think about this question from the perspective of the resident, family, and staff
- What is your definition of a good death?
- How have you experienced a positive death (outside of work)?

- How comfortable do you feel in offering condolences or comforting family when they are present for the death?
    - Take the opportunity to explore your feelings of comfort or discomfort with peers (e.g., what leads to these feelings?)

Inform Practice – “Good” Death

How do we define a good death? This definition changes from person to person however, effective communication is key to ensure that residents (and substitute decision makers) are defining obtainable and meaningful goals related to end-of-life care.

The essence of what contributes to a ‘good death’ has not been well described in the literature. A study was conducted in which patients, caregivers, physicians, and nurses were asked to describe their experience of good deaths. A few common themes emerged from their ‘good death’ narratives:

- a death free from pain,
- a sense of a life well lived, and
- a sense of community (De Jong & Clarke, 2009)

According to an Institute of Medicine report (Meier et al., 2016), a good death is one that is “*free from avoidable distress and suffering for patient, family, and caregivers, in general accord with the patient’s and family’s wishes, and reasonably consistent with clinical, cultural, and ethical standards.”*

Many participants in the study spoke of a good death as telling stories of family, friends, and palliative care team members surrounding and supporting the dying person until their death. Participants described that the most important component of a good death was that the individual was not alone at the time of death. Many participants also spoke of good death narratives involving those who were free of pain and suffering and those who peacefully slipped away or died in their sleep (De Jong & Clarke, 2009).

Inform Practice – Reflection Questions

- How does this narrative “fit” with your experiences of good resident/family deaths?
- What is your comfort level in speaking to residents/families about goals related to end- of-life?
- Have you heard or experienced families reflecting on a “good death” because goals of care were met (e.g., resident was pain/anxiety free)? How did that make you feel?
- What challenges have you experienced in facilitating a “good death”? How (if you did) overcome these challenges overtime?
    - What strategies need to be in place to help you to facilitate a good death?

Inform Practice – Spiritual Care

It is important to consider that people may be spiritual beings and often desire to have religious or spiritual practices fulfilled. Spiritual care or clergy may be consulted to fulfill the resident’s needs.

Inform Practice – Reflection Questions

- What is your comfort level with spiritual care?
- What resources are available to you to support spiritual care in a palliative care approach?

References

De Jong, J. D., & Clarke, L. E. (2009). What is A Good Death? Stories from Palliative Care. *Journal of Palliative Care, 25*(1), *61–67*. doi:10.1177/082585970902500107

Meier, E. A., Gallegos, J. V., Thomas, L. P. M., Depp, C. A., Irwin, S. A., & Jeste, D. V. (2016). Defining a good death (successful dying): Literature review and a call for research and public dialogue. *The American Journal of Geriatric Psychiatry, 24*(4), *261–271*. doi:10.1016/j.jagp.2016.01.135

Scenario 3

Section Type: Reflection and Action

Description of Resident Scenario

Yesterday, BL, a 68-year-old male with Stage IV lung cancer and a history of high blood pressure passed away. BL's PPS for the past month has remained at PPS40%. He required assistance by one staff for transfers, and was alert, oriented, talkative, and very pleasant. BL had not complained of any pain and was not on any pain medication. Suddenly, the nurse heard BL gasping for air. BL had a severe inspiratory stridor (high pitched wheezing caused by blocked airflow), and was unable to talk, and wide eyed. While the nurse was on the phone calling the family to quickly come, BL passed away.

Purpose of Comfort Care Round

Reflect on a recent "bad" resident death.

Questions for Facilitator to Start Discussion

- Does this scenario reflect the experiences of residents and family members that you currently cared for?
- What does a "bad death" look like?
- Are sudden or unexpected deaths considered to be a "bad" death?

Additional Discussion Questions

- How do you cope with your feelings following a 'bad death'?
- Have you ever taken care of a resident who passed suddenly?
    - How did you feel about that experience?
    - Is there anything you wish could have gone differently?

- How do you view sudden or unexpected deaths?
- How do you work through sudden or unexpected deaths?
    - Can we categorically say these are “good” or “bad” deaths?

Inform Practice – “Bad” Death

Breaking the news of death is one of the most stressful and sensitive tasks that a health care provider can perform, especially if both staff and family were not expecting it. The essentials of what contributes to a ‘bad death’ have not been well described in the literature. A study was conducted where patients, caregivers, physicians, and nurses were asked to describe their experience of bad deaths. Common “bad death” themes included a painful death and a loss of control and independence. Most patients expressed their concerns about unexpected death as well as pain whether it be physical pain, spiritual distress, emotional upset or mental illness. Nurses described “bad deaths” as those where patients died in pain or with unrelieved symptoms. This experience also left nurses with a sense of guilt about not being able to relieve suffering. For example, a nurse shared that:

I wish we had done more in terms of giving sedation and pain relief. The family watched him die in agony. It was such a shame – surely we could have done more? He was in pain and we were not quick enough to respond – it was a really bad death. (Karen – Staff Nurse) (Costello, 2006).

Inform Practice – Reflection Questions

- How do these themes about a “bad” death resonate with you?
    - Unrelieved resident pain or distressing symptoms
    - Residents experiencing spiritual distress of emotional upset
- Have you had a similar impression to Karen - “surely we could have done more”?
- Have you felt guilt or prolonged upset about a death? What happened?
- Are there topics that you need to learn more about to facilitate a “good death”?

Inform Practice – Communication

A “bad death” was described as limited control over the events leading up to and including the death event (Costello, 2006). During a “bad death event” nurses did not feel well prepared and sometimes felt like there was not enough time to get to know the families. A “bad death” also meant nurses not being able to help to coordinate religious rites for patients (i.e. sacrament of the sick). These events may lead to poor communication with families as the following statements illustrate:

- *Joe died too quickly. We were not ready at all. It was a very bad death for him, us and the family.*
- *Joe’s family should have been better informed. They said they didn’t know he was dying, but we were of the opinion that they knew. The relatives made us feel so guilty – it was very poor communication really.*
- *Talk about getting to know your patients. David came in at 4.00 p.m. and died five hours later. We hardly had time to complete the documentation. Most of the staff had not even said ‘Hello’.*
- *We had no idea that (Dennis) was going to die – otherwise we would have planned things, like asking the priest to call and speaking to the family in an effort to prepare them.*

Inform Practice – Reflection Questions

- How do these experiences resonate with you?
- What strategies can be used to facilitate effective communication/relationship building with families?
- How do you ensure that the resident and family are prepared for the eventually of death?

Inform Practice – Tips for Communicating with Grieving Family

1. **Acknowledge that you can’t imagine how they are feeling.**
2. **Ask about their loved one.** Don’t push this. Only if it feels natural.
3. **Ask them what they need.** It also may be appropriate to give them some suggestions like: “Can I call more family for you?” or simply “I can give you some time?”

4. **Ask if they want to speak with a doctor about any questions if available.**
5. **Ask if they would like you to page the Social Worker or Pastoral Care if available.**
6. **Answer their questions about what happens next.** When families are in shock, it is difficult for them to make decisions. Go over funeral home information (number, when to call etc.). Explain whether they will stay at the morgue or go straight to the funeral home.
7. **Acknowledge that you don't know what to say.** If you are having a difficult time with knowing what to say, just be honest. Families know that there is nothing you could say to possibly 'fix' the situation.
8. **Give them space and time if they need it.**
9. **Don't judge.** Everyone handles death differently. Some families cry, some laugh or joke, or some may not show any emotion at all. Some family members may not want to enter the room or even come in to say goodbye. Understanding from all nurses is needed as families grieve in the best way that works for them (Williams, 2014).

Inform Practice – Reflection Questions

- How do you communicate with grieving families?
- How do the suggestions fit into your practice?
- Have you had difficulty in communicating with a grieving family?
    - What has worked?
    - What strategies have not gone well?

References

Costello, J. (2006). Dying well: Nurses' experiences of 'good and bad' deaths in hospital. *Issues and Innovations in Nursing Practice*. 594-601. http://www.brown.uk.com/palliative/costello.pdf

Williams, L. (2014, March 31). *Supporting grieving families: tips for RNs and others on the front line.* What's your grief? https://whatsyourgrief.com/supporting-grieving-families-tips-rns-nurses/

Scenario 4

Section Type: Debriefing

For Facilitators

For additional support in conducting peer-led debriefing, access *Reflective debriefing: Supporting people and practice in long-term care* video https://www.youtube.com/watch?v=Du0orYXX8MI&t=2s

Purpose of Comfort Care Round

A peer-led debriefing session on coping mechanisms while working with dying residents and their families.

Questions for Facilitator to Start Discussion

- How did the experience of your resident's death influence your feelings about death?
- Did you find any meaning in being able to make your resident comfortable in their last few days or moments?
- Did you feel any gratitude or inspiration because of going through this death?
- Have you been impacted by multiple or more frequency of death during a COVID-19 or other outbreak? How has that experience different from other loss?

Inform Practice – Grief

Grief is a natural healthy response to death. Especially in long term care, staff build strong family-like relationships with residents and their families. After a resident has passed away, staff members can be expected to carry on with their work without acknowledging their emotions and feelings about the loss. Each staff member may have a different reaction to grief as each grieving experience is unique.

Inform Practice – Peer-Led Debriefing “How To”

What is Peer-Led Debriefing?

A debriefing session provides individuals the opportunity to take a step back from an emotionally stressful event. Through a guided process involving specific questions and discussions, individuals may share their experiences and feelings.

Why Engage in this Process?

This **Peer Led Debriefing** intervention is intended to be incorporated in long term care. Debriefing has been shown to be effective in improving overall workplace wellness, decrease staff stress, and decrease absenteeism.

Debriefing allows staff members to voice and share their experiences in a safe and supportive small group setting. Debriefing is therapeutic in nature and allows staff to acknowledge their grief and loss in their own unique way.

Getting Started

Use “INNPUT,” a peer-led debriefing model to initiate discussion:

I - Introduction

N - Need to say

N - Need to do

P - Plan

U - Understand Impact

T - Thank you

Introduction

Discuss the experience.

Example: “I just want to let you know that I realize that (…’s) death might be difficult for you, and even though you might have strong feelings about her death, you also have to continue on today and finish your shift caring for others.”

Need to say

Ask what the staff members need to say.

In this section, it is important for staff members to discuss the resident and the resident's death. A peer-led debriefer may ask questions to facilitate discussion among the group:

- "I am wondering if anyone would like to share some memories or thoughts about the resident"
- "Does anyone have any unanswered questions about her death or the events leading up

to her death?"

Need to do

Ask what the staff members need individually or as a group to continue working through their shift:

- "Would it be okay if I go around the room to check in to see what you might need to help you manage through the rest of the shift and for the next 24 hours before you come back to work?"
- "When you care for someone who dies, it is completely normal to feel numerous emotions. The most important thing to do is to care for yourself over the next few days."

Plan

This section may seem repetitive; however, it is important to identify plans and actions for self-care.

- "Some of you may need or want to go back in (…) room and spend a few minutes saying your goodbyes. Others may want to keep to themselves for the rest of the shift, while others will want to spend time with others while on their break."

This may be a time to ask others how they like to cope with the passing of a resident. If someone does not feel comfortable sharing, that is okay!

Understand Impact

Assist staff members to formulate a care plan and normalize reactions:

- "Just to be clear, here are some of the things you are going to do to take care of yourself for the rest of the shift today and over the next few days." (repeat examples given)

- “The grief that you experience today is normal given your relationship with so and so.”
- “I hope you remember how you were supported today by your colleagues and the great examples each of you have provided with how to provide self-care.”

Thank you

Example: “I want to thank you all for your time. We all know that ending this shift will be difficult but you all have mentioned some good ideas to help you get through it.”

Strategies that may help staff cope with the death of a resident:

- Practice self-care: Grief affects the body physically and therefore, it is important to take care of yourself by getting enough sleep, exercise and eating healthy.
- Let yourself grieve: It is okay to show your emotions and feelings whether that be by yourself, with your co-workers or with family and friends. If you do not allow yourself to go through the grieving process, it may impact your ability to relate to other patients.
- Talk with your colleagues: Whether it be in a formal discussion such as in a debriefing session or informal discussion such as after work, only those who work in the medical field can understand the pain of a patient’s death. It is therapeutic to talk about what you are going through with those who have gone through the same or similar experiences.
- Heal however you can: Every situation is unique and there is no one approach to dealing with death. In our own way, each one of us must take the time to reflect and process our individual experience. Research shows that health care workers who care for dying patients often find meaning and satisfaction in their work.

References

Quality Palliative Care in Long Term Care Alliance. (2013). *Peer led debriefing toolkit: Guidelines for promoting effective grief support among front line staff.* http://www.palliativealliance.ca/assets/files/Alliance_Reources/Org_Change/Peer_Led_Debriefing-_Final.pdf

Scenario 5

Section Type: Reflection and Education

Description of Resident Scenario

AM is a 60-year-old female and has a history of multiple sclerosis, diabetes, and chronic wound infections. AM is bed bound and has limited function of her upper extremities. Due to lack of proper nutrition and circulation, AM has a wound on her coccyx that has not healed over the past 6 months. She must be transferred to the hospital to receive IV antibiotics. She describes her quality of life as poor and often expresses that she wants to die. AM has decided that she no longer would like to be transferred out to the hospital and would like to stop all condition- related treatment, including oral antibiotics.

AM has just revised her goals of care to align with a palliative approach to care. Staff believe this approach will hasten AM's death and do not agree with her decision.

Purpose of Comfort Care Round

Discuss a palliative approach to care in situations where resident and staff values are in conflict.

Questions for Facilitator to Start Discussion

- Does this scenario reflect the experiences of residents and family members that you currently care for?
    - What challenges are you experiencing?
- How do you feel about AM's (or a current resident's) decision to stop treatment?

Additional Discussion Questions

- Do you think that AM is giving up hope?
    - How might you explore this further with AM?
- Do you feel like there is something more you could do for AM to change her mind?

    - Would this action be appropriate? Note: Whether we agree or disagree, we should respect her wishes in this case, and be available to her should she want to explore her feelings and choices further.
- How can we as health care provider's support AM's decision to stop treatment?
    - Does choosing a palliative approach, mean choosing death?

Inform Practice – A Palliative Approach

Sometimes health care staff, patients or family members will refuse a palliative approach to care because they think it means "giving up" or that there is no longer hope. Palliative care neither hastens nor postpones dying. The goal of a palliative approach to care is to improve the quality of life. In some circumstances, a palliative approach to care can even extend life, be alleviating treatable symptoms.

In this scenario, AM is likely exhausted from being cared for by unfamiliar faces during numerous hospital visits, being away from the comfort of her long-term care home, and continually receiving antibiotics. Whether it be a condition, disease or infection, a time may come when residents no longer benefit from medical treatment. However, treating the symptoms (i.e., pain) becomes the primary focus of care. In this scenario, AM has little control over how the infection is taking over her body due to her past medical history, however, she does have control over stopping medical treatment and living out the rest of her days as comfortable and as pain free as possible. If a resident is continuously undergoing uncomfortable and painful curative treatment for an incurable illness, they may experience more of a benefit by having their symptoms treated.

Inform Practice – Reflection Questions

- What are your thoughts regarding the following statement: Perhaps AM is not making the decision to stop all treatment and instead, the infection has made this decision for her?
- What additional supports or human resources may help the resident in making this decision?
- How should the interdisciplinary team respond given the new goals of care?
    - Perhaps think about care planning, medications needed to support end-of-life care, psychosocial/spiritual supports, family supports, etc.

Scenario 6

Section Type: Reflection and Action

Description of Resident Scenario

BL is a 75-year-old woman with a history of end stage cardiac disease. She is often short of breath, has a chronic cough and has significant edema in her lower limbs. BL has noticed that her condition has been progressing and her symptoms have been getting worse over the past few weeks. BL is alert and oriented and is aware that she does not have much longer to live. At her palliative care conference, she has expressed to the interprofessional team that she wants to live out the rest of her days as comfortable and as pain free as possible. The team acknowledged her desire for a palliative approach to care.

BL has one son and one daughter who have a history of not getting along. When BL voiced her wishes regarding a palliative approach to care, her son was upset. Her son wants BL to be transferred out to the hospital so that the doctors can "fix" her. He shouted at staff, "Are you just going to let her die?" BL's son is not interested in having conversations with staff members and states that he has "lost all trust in the health care team because of their support for BL's decision."

BL's daughter is supportive of a palliative approach for her mother and has seen her suffer enough. Staff members often overhear yelling between the son and daughter in terms of what is best for their mother. BL has privately expressed to many staff members how upset this conflict is making her. She only wishes that her family could get along so that everyone can enjoy the remaining time she has left.

Purpose of Comfort Care Round

Explore the impact of challenging family dynamics as residents approach the end of their life.

Questions for Facilitator to Start Discussion

- Does this scenario reflect the experiences of residents and family members that you currently care for?
    - What successes and/or challenges are you experiencing?

Inform Practice – Navigating Challenging Family Dynamics

It is not uncommon for family members to have different opinions on what they believe is best for the resident. Some family members believe that their relative should be pursuing aggressive treatments to prolong their life, while others understand and believe these treatments do not offer enough benefits to promote quality of life.

Common sources of family conflict include:

- Thinking that another family member is providing inadequate help or care
- Disagreement (between family members, the patient and family members, health care providers and family) regarding the patient’s illness and prognosis, the treatment, or the plan of care
- When multiple family members become involved in clinical decision-making
- When certain family members only provide limited amount of care or not always available to help with the resident’s care
- Lack of trust within the health care system, or health care providers
- Longstanding family issues unrelated to the resident’s condition that are intensified due to the nature of the situation
- Different grief trajectories: Some family members being more accepting and others less so of the approaching death or other potential negative outcomes

Inform Practice – Discussion Questions

- Have you ever experienced any of these situations in your practice?
    - If so, how did you approach the situation?
- What are some strategies to best approach BL’s son?
- How would this situation differ if BL did not have decision making capacity?

Inform Practice – Communication with Families

The following considerations are recommended when there are disagreements between family members and/or the health care team:

- It is important to recognize your own feelings of anger, fear, or frustrations so that these emotions do not influence your communication with family members.
- When it comes to discussing the withdrawal of life-sustaining treatments, explore the family members' feelings. Family members often struggle with guilt or remorse when making difficult decisions for their loved one. For example, if a family member says, "Even though I know my father would not want this, I just cannot let him go" or "I can't be the one making a decision that results in his death," the health care provider can respond by saying, "I cannot begin to imagine how difficult it is to make these kinds of decisions at end of life. This isn't just your decision, it is a shared decision, just as it would be if your father were here to have this discussion with us."
- Staff members can explore the relationship of the patient to the family member (i.e., "Tell me about your mother...". When family members of the patient are experiencing distress, it is appropriate to allow them to show their emotions.
- Aim for consistency regarding expectations and treatment to build and maintain a trusting relationship.
- It is important for care providers to be sensitive to the different experiences and backgrounds of patients and their families.

References

Rosenstein, D.L., & Park, E. (2020). *Challenging interactions with patients and families in palliative care.* https://www.uptodate.com/contents/challenging-interactions-with-patients-and-families-in-palliative-care#H2870945119

Scenario 7

Section Type: Reflection and Education

Description of Resident Scenario

KM is a 71-year-old man with a diagnosis of end stage COPD (chronic obstructive pulmonary disease) and mild to moderate dementia. KM's COPD requires him to use more energy just to breathe than people without COPD. KM has lost a significant amount of weight and muscle mass over the past 2 months. KM is finding it difficult to eat as he often feels short of breath or needs to cough. He states that he is "not hungry" and often drinks one Ensure at every meal. KM's daughter is concerned that the staff are "starving her father to death" and wants to explore the option of a feeding tube.

Purpose of Comfort Care Round

Explore nutrition-related needs within a palliative approach to care.

Questions for Facilitator to Start Discussion

- Does this scenario reflect the experiences of residents and family members that you currently care for?
    - What successes and/or challenges are you experiencing?

Additional Discussion Questions

- How would you support KM's nutritional needs?
    - What members of the interdisciplinary team should be involved in care planning around nutritional needs?
- Is KM really "starving"?
- How would you respond to KM's daughter?

- What are some of the risks associated with placing a feeding tube in KM?
    - How can we educate residents and family members on this topic for them to make an informed decision?
- With a change in intake, do the goals of care need to be revisited?

Inform Practice – Nutrition at End-of-Life

The use of artificial nutrition through feeding tubes appears to be valuable in patients with chronic illnesses such as amyotrophic lateral sclerosis (ALS), where life can be extended by months or years. However, there is a lack of evidence to support that feeding tubes provide benefit to those who have a terminal illness with a foreseen death within 6 months (Danis, 2021). When family members notice that a relative slows/stops eating and/or drinking, it can be difficult for them to bear. Food is one of the most basic human needs and family members often think that their relative will “starve to death” if they no longer have the desire to eat or drink (Canadian Virtual Hospice, n.d.). Food is often associated with families, happiness, love, and memories. When a resident slows/stops eating, family members can have negative feelings or reactions (Hospice of Huntington, n.d.). It is important to educate families on digestive process changes at end-of life to help families make informed decisions regarding what is best for their relative (Hospice of Huntington, n.d.).

Inform Practice – Discussion Question

How would you explain changes in the digestive process at end-of-life?

Inform Practice – ‘Food for Thought’

‘Food’ for thought: ‘Starving people want food, dying people do not.’

Near end of life, the body is preparing for death and residents generally do not feel hungry. Those who do feel hungry, only require a small amount of food to feel satisfied. The body saves energy for other major bodily functions, rather than focusing on energy spent for eating and drinking (which in this scenario, takes up a lot of energy for KM). It is important to explain to residents and families that the use of a feeding tube at end of life does not reverse or cure an illness. It is important for residents and family members to know that dehydration and starvation are not painful at end of life (Hospice of Huntington, n.d.). When people, including KM are near end of life, their metabolism changes and their organ function slows down. This results in elevated ketone levels (water-soluble molecules produced by the liver), which produces a mild sense of euphoria or happiness (Brown, 2007). When patients nearing end of life no longer have the desire to eat or drink, it is usually their way of saying, “it is time for me to rest.” (Hospice of Huntington, n.d.).

In this scenario, KM also has dementia. It may be difficult for KM to understand why a tube has been placed in his abdomen and there is a risk that he may pull it out. One study showed that those with severe dementia who received feeding tubes may in fact increase the death rate, increase the number of new medical conditions, and reduce quality of life. Another study of nursing home residents with dementia showed that feeding tubes did not increase survival rates. In addition, those with feeding tubes did not improve weight status nor did the feeding tube placement lower the risk of aspiration pneumonia or pressure ulcer healing.

Important Take Away

No one should ever be forced to eat or drink, especially if they are not able to make the decision for themselves. If KM is hungry or thirsty, comfort foods and beverages should be provided. To alleviate symptoms of dry mouth and thirst, mouth care should always be provided (oral cleaning, ice chips, the use of artificial saliva, lip moisturizers etc.).

The number one question that family members need to consider when making decisions about tube feed placement or any other medical treatment decisions is… what does/would the resident want?

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Scenario 8

Section Type: Reflection

Purpose of Comfort Care Round

Explore challenges to the delivery of quality end-of-life care in long term care facilities.

Discussion Questions

- What do you think are some common barriers surrounding end-of-life care?
- What are some ways we can improve end-of-life care in nursing homes?
- What are some challenges that residents in long term care facilities face when it comes to end-of-life?

Inform Practice – State of Palliative Care

A recent Canadian report from 2018 revealed that 6% of residents in long term care facilities have a record of receiving palliative care in their last year of life. Many residents die with untreated symptoms, often after multiple hospitalizations and prolonged treatments. There are many barriers when it comes to delivering quality end-of-life in nursing homes. Some include:

- A high turnover in staff members
- Limited human resources: a nurse who is caring for a dying resident may also be caring for 30 other residents during a day shift or even up to 80 residents on a night shift
- Many attending physicians are often only available in person on a weekly or even monthly basis
- Nurses and doctors in long term care facilities are not always specially trained on how to best manage a patient's symptoms near end of life (i.e. breathlessness, pain, agitation, delirium). Even if medical professionals are trained in palliative care, they may not have the time or resources to help

What can we do to make a difference for residents nearing end-of-life?

- Culture change: Palliative care is often associated with strictly end-of-life care. However, "21st century" palliative care is intended to focus on quality of life, treat symptoms in a timely manner, and maintain one's wellbeing for as long as possible. Education sessions (such as these 'comfort care rounds') are one strategy for long term care staff to learn about and reflect on a palliative approach to care.
- Education: You may be surprised to learn that many medical professionals have not received formal training in palliative care and yet, may be working in geriatrics. It is important for the interprofessional team to receive education and updates on current palliative trends such as medications and treatments, to advocate for their residents. For example, Comfort Care Rounds held a few times a month may help increase staff knowledge of evidence-based strategies for palliative care issues.
- Advocate for more staff: Staffing ratios in long term care facilities must improve to help monitor symptoms closely and deliver appropriate treatment.

Awareness and education are key factors when it comes to providing strong end-of-life care for our residents. It starts with close monitoring of pain and symptoms, advance care planning and goals of care planning as well as looking after the psychological and emotional needs of residents and their families. It is important to advocate for your residents, whether it be for adequate pain relief or relaying your resident's wishes to the medical staff or their family members. Residents deserve to have the best palliative care we know how to deliver. Therefore, education is so important so that we can integrate palliative care into long term care facilities so that residents can live with the least amount of suffering until the very end.

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