Family Members Recommendations for Advance Care Planning in Two Long-Term Care Homes: A Qualitative Study

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**Background**

- A sub study of a larger five year project “Improving Quality of Life for People Who Are Dying in Long-term Care Homes.”
- Project is dedicated to the development and delivery of palliative care programs through the creation of palliative care resource teams
- Advance care planning (ACP) and care planning (CP) is the essential component to providing holistic palliative care
- Knowing the wishes (ACP) of a resident and continued communication of individual care needs can ensure that a resident receives quality resident centered care and quality palliative care at end-of-life (EOL)

**Objectives**

- This study explores the research question of “What are family members and substitute decision makers (SDM’s) views and perspectives on ACP and CP in LTC?”
- This research can contribute to LTC policy by providing insight and recommendations from the family member’s and SDM’s perspective
- Having ACP and CP discussions can assure a resident’s DIGNITY throughout their care in LTC homes

**Results**

**Education:**
- LTC homes need to ensure that residents and family members are educated on their choices to meet their individual care needs
  - “cause I didn’t realize…I just didn’t know the system…so when you are asked for that decision, you are thinking the hospital is the best place…hospice is better because it’s in a hospital…I didn’t realize that they do everything here that they do in the hospital” (family member)

**Timing:**
- LTC homes need to assess, collaborate and consult with residents and family members in an organized manner on ACP and CP, this will ensure consistency while respecting a residents dignity
  - “what might be helpful is to provide some education or some background to family members on admission about, you know, planting the seed…then getting back to that person, you know, a couple of weeks later, have you had a chance to review that material?…what do you think? Can we set something up to discuss this? Someone might say can you give me more time? You know, then, [staff] can just keep following it, following up…there is so much happening [when someone is moving into LTC]” (family member)

**Communication:**
- LTC homes can facilitate ACP and CP conversations by having strong connections and continual communication between LTC staff and family members
  - “the people on the floor are very much part of Mom’s life …and they’re all just nuts about her and it would be very unfair to leave them out of the process…So how that could be facilitated I don’t know it could be part of the planning process.” (family member)

**Knowing the Resident:**
- LTC staff need to know residents wishes for spiritual, physical, social and psychological care needs in order to provide “resident” centered care
  - “I think… a staff should really know the person, as a person before coming into long term care…capturing the past into the present I think, I think it’s important” (family member)

**Conclusion**

- With advances in medicine and life expectancy increasing, there will be an increase of residents transitioning into LTC homes within the next twenty years in need of holistic palliative care
- ACP and CP is essential to guiding health care providers and family members in providing holistic palliative care and insuring quality end of life for residents of LTC
- Families and SDM’s are receptive and open to conversations and discussions about ACP and CP, however, the timing of these conversations need to be carefully considered and not left till EOL
- All disciplines that work in LTC should be comfortable having conversations about ACP and CP with residents and their family members