Using Pamphlets to Activate Advance Care Planning in Long-Term Care: Residents and Families’/Friends’ Views

SUMMARY

- Advance care planning (ACP) helps people with progressive, life-limiting illnesses communicate wishes and preferences for future end-of-life (EOL) care to family and health providers.
- Despite known benefits, ACP is rarely if ever activated in LTC settings.
- Addressing noted barriers to ACP in LTC, our team developed, implemented, and evaluated the effects of disease specific illness trajectory pamphlets for five life-limiting advanced clinical syndromes of high prevalence in LTC: dementia, heart failure, chronic obstructive pulmonary disease (COPD), renal failure, and frailty.

HOW WAS THIS STUDY DONE?

- This paper explores whether illness trajectory pamphlets for five conditions with high prevalence in long-term care (LTC), can support resident and family engagement in ACP.
- Our mixed methods study draws on 57 surveys responses and deliberations from seven focus groups with 56 LTC residents and families that explores; (a) reactions to the pamphlets, (b) if pamphlet use supports ACP engagement, and (c) when and how the pamphlets should be distributed.

KEY FINDINGS

- Survey results suggested that residents and families felt the pamphlets encouraged them to think about personal values and goals of care (48/57, 84%), clarified what to ask (40/57, 70%) and increased their comfort talking about EOL (36/57, 63%).
- Speaking about these issues regarding ACP with family members (32/57, 56%) or health providers (21/57, 37%) was less common.
- Our combined findings suggested that the pamphlets provided opportunities to prompt reflection about EOL issues for residents and families.
- It is further suggested that moving from reflection to activation could require staff follow up due to residents’ and families’...