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Top Ten Tips Palliative Care Clinicians Should Know About Cognitive Impairment and Institutional Care

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Abstract

Most long-term care (LTC) residents are of age >65 years and have multiple chronic health conditions affecting their cognitive and physical functioning. Although some individuals in nursing homes return home after receiving therapy services, most will remain in a LTC facility until their deaths. This article seeks to provide guidance on how to assess and effectively select treatment for delirium, behavioral and psychological symptoms for patients with dementia, and address other common challenges such as advanced care planning, decision-making capacity, and artificial hydration at the end of life. To do so, we draw upon a team of physicians with training in various backgrounds such as geriatrics, palliative medicine, neurology, and psychiatry to shed light on those important topics in the following ''Top 10'' tips.

Keywords: advance care planning; delirium; dementia; palliative care; skilled nursing facility

Introduction

Moving to residential long-term care (LTC), often termed institutionalization, is a significant life event for an older person that is often portrayed with negativity.[1] Fewer than 0.5% of the total U.S. population (~1.5 million people)[2] resides in care homes, whereas ~4% of the U.K.'s population >65 years (~400,000 people) and ~20% of the population aged >85 years reside in care homes.[1] In the United States, approximately a fifth of all deaths occurs in nursing facilities. This proportion has remained relatively stable despite large increases in the share of deaths at home and in hospice.[3] Cognitive disorders such as dementia[4] and delirium are known to be associated with an increased risk of institutionalization. There is an urgent need for increased palliative care (PC) knowledge and skills around optimal treatment of common syndromes in nursing home residents such as delirium, behavioral disturbances in dementia, or nutrition and dehydration in end-of-life situations.

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Tip 1: Early Advance Care Planning with a Resulting Wishes Document Is Imperative to Provide Patient-Centered Care

As patients' health status changes, advance care planning (ACP) discussions and the resultant documents should be discussed and specified for anticipated health scenarios.[5] ACP for nursing home residents should aim to align the care and treatments received with the residents' expressed or presumed wishes and help residents and their surrogates feel both involved in planning future care and more confident that their future care will match the resident's wishes.[6] Indeed, structured ACP in LTC facilities has been noted to have additional positive benefits including strengthening the focus on patient-centered care.[7]

There are many barriers to conducting ACP in those with cognitive impairment living in LTC facilities including lack of previous discussions with family members or clinicians,[8] some nursing home physicians' lack of comfort with conducting ACP discussions with patients with dementia,[9] and patient characteristics such as life-threatening illness,[10] uncontrolled pain,[11] and neuropsychiatric symptoms.[10,12] Research is ongoing discussing methods by which ACP can be successfully conducted on a facility-wide scale to effect positive patient-level and nursing home-level outcomes.

A review of the implementation and research strategies of ACP in LTC facilities found that studies are limited and vary in their scope and implementation strategies. Key elements relate to the involvement and education of nurses, clinicians, and nursing home leaders.[11] After conducting a systematic review and ''Theory of Change'' workshop, Gilissen et al. identified 13 preconditions that must be in place to achieve consistent ACP in nursing home residents at a given facility.[6]

Finally, documentation of ACP discussions should be included in the patient's medical and nursing records in a consistent way.[13] In many countries, Physician Orders for Life-Sustaining Treatment (POLST) can both serve as the basis for ACP discussions and translate ACP discussions into emergency medical orders about cardiopulmonary resuscitation, scope of treatment, artificial nutrition and hydration, and use of antibiotics. Use of such forms has been shown to improve goal-concordant care of older adults in a variety of settings.[14]

Tip 2: For the Majority of Advanced Dementia Patients for Whom Comfort Is the Priority, Hospitalization Is Seldom Consistent with This Goal, with Rare Exceptions

As people with dementia move toward the end of their lives, the focus often shifts from hospitalization, invasive medical treatments, and sometimes harmful psychotropic drugs to the provision of a place of care that offers comfort and dignity.[15] Indeed, hospital care can be suboptimal for these patients due to the discontinuity of care, unfamiliar providers, and pressures for timely discharge. Decisions regarding hospital transfers should be guided by the primary goal of care (e.g., prolongation of life vs. comfort). Pneumonia, febrile episodes, and eating problems are associated with high six-month mortality rates and the most common reasons precipitating hospitalization in these patients.[15] These conditions, which are markers of disease progression, can usually be treated with equal efficacy in the nursing home or community, with less burden to the patient and fewer costs to the health care system.

However, adequate care at the patient's place of residence depends on the availability of integrated clinical pathways including active treatments (e.g., availability of oral antimicrobials, portable chest radiographs, oxygen saturation monitoring, and rehydration for pneumonia), high-quality PC, and staff skilled in the care of people with dementia.[16] Finally, the desire to avoid hospitalization should be formalized with relatives before the onset of an acute illness within an ACP process or advance directives. Patients with surrogates who have an understanding of the prognosis and clinical course are more likely to receive less aggressive care near the end of life.[17]

Tip 3: Alterations in Behavior and Mental Status Require a Careful Evaluation for Delirium

Delirium and dementia are the most common causes for cognitive impairment.[18] The risk for both increases with age and disease progression. Dementia is a risk factor for delirium and vice versa.[18] Dementia is commonly characterized by a chronic progressive course; delirium in contrast has an acute onset. Consciousness and awareness are fluctuating in delirium and speech can be incoherent and distractible.[19] There are hyperactive and hypoactive forms of delirium. In delirium, it is essential to search for reversible underlying causes (see discussion in Tip 7).[18] If these reversible causes are detected, they should be treated either in delirium or in dementia, because they cause suffering in both conditions. Nonpharmacological measures such as visual reminders of time of day and hearing aids for patients with these are helpful for patients with either condition. Aides for orientation or cognitive simulation and sleep hygiene are helpful in both conditions.[20] Delirium is common at the end of life, but end-of-life dreams and visions should be considered separately because they are often not a burden but often a resource for dying patients.[21]

Tip 4: Since Delirium Is Common in Patients Who Are Institutionalized and Hypoactive Delirium Is Especially Hard to Recognize, Delirium Screening Should Be Performed at Least Weekly

The prevalence of delirium in residents of LTC facilities ranges from 32% to 70% and varies significantly based on the diagnostic tools used for measurement.[22,23] Delirium is associated with multiple negative consequences including cognitive and functional decline, family distress, increased burden on nursing staff, increased health care costs, and increased morbidity and mortality.[24–26] Furthermore, both licensed nurses and nursing assistants have poor recognition of delirium, especially hypoactive delirium.[27] Therefore, evidence-based delirium guidelines recommend that delirium screening (which is more common in acute care settings) continues in postacute care settings.[28] Multiple assessment tools, both observational instruments and cognitive tests, exist for detecting delirium.[28] The selection of one or more instruments (RADAR tool has been studied[9]) to utilize as part of a delirium screening program at a nursing facility will need to be highly tailored depending on the goal of the screening, the frequency with which it will

be performed, and the staff available to perform the screening. The inclusion of regular and frequent delirium screening is key to the ongoing physical and mental health of your residents.

Tip 5: Nonpharmacological Measures Are the Preferred Treatment for Both Delirium and Dementia, and Antipsychotics Should Be Particularly Avoided in Hypoactive Delirium

Behavioral and psychological symptoms (BPS), such as agitation or anxiety, are frequent in both dementia and delirium. Since they are associated with individual suffering, interfere with care, and may impose a burden on other residents, they often become the focus for urgent intervention.

Several treatment algorithms have been proposed for BPS in dementia that prioritize nonpharmacological measures.[29,30] For agitation, person-centered care, communication skills training, adapted dementia care mapping, activities, music therapy, and sensory intervention are effective, whereas aromatherapy and light therapy are not.[31] Pharmacologically, there is evidence that intensified pain treatment decreases agitation in nursing home residents with dementia.[32] Although several antipsychotics have shown efficacy against agitation in dementia, they increase mortality and are associated with a substantial side effect burden.[33] Consequently, their use in LTC for dementia has decreased in recent years.[34] Treatment effects have to be monitored, tapering should be attempted within four months of initiation of antipsychotics, and haloperidol should not be used as first-line treatment.[35]

Importantly, there is only a very limited evidence base for the treatment of BPS in delirium, in particular for this patient population. The available data are mostly limited to postoperative delirium and not to delirium in LTC. Based on these data, the use of antipsychotics in delirium is generally not thought to improve delirium duration or severity.[36] Still, antipsychotics can be used to control agitation in hyperactive delirium on a case-by-case basis but there is no rationale for their use in hypoactive delirium. For terminal delirium, some pieces of evidence suggest that the use of risperidone or haloperidol increases symptom load for those with mild-to-moderate delirium.[37] For BPS in both dementia and delirium, educating caregivers and involving family members are of crucial importance.

Tip 6: Behavioral Symptoms of Dementia Are Difficult to Manage: Attention to Routine and Circadian Rhythm, Facilitation of a Safe Environment for Wandering, and Consideration of Reversible Causes for Agitation Are All Important to Managing Symptoms

The presence of dementia increases the risk of delirium by 5–10 times. Diagnosis of delirium superimposed on dementia is a clinical challenge and validated tools such as 4AT or the Confusion Assessment Method may help.[38–40] When caregivers note a sudden change in behavior or mental status in the person with dementia, clinicians should be concerned and think about possible reversible causes of dementia.[41] Delirium superimposed on dementia is often multifactorial in nature. A combination of low-impact etiologies may cause an acute brain failure. Possible precipitating stressors vary from constipation to inappropriate use of psychoactive medications.[42] The mnemonic ''PINCH ME'' (Pain, INfection, Constipation, deHydration, Medication, Environment) can help identify potential underlying causes of delirium superimposed on dementia.[43]

As patients with dementia lose the ability to communicate their needs verbally, a trial-and-error approach by caregivers is often needed to learn what the behavior might be representing.[42] There is not a single antipsychotic drug that has shown to be effective in the treatment of delirium superimposed on dementia. In PC patients with dementia, symptoms of delirium might even worsen by using antipsychotics.[44] There are studies suggesting that empiric treatment of pain can reduce agitation in residents of nursing homes with moderate-to-severe dementia.[32] This finding reinforces the importance of assessing and treating pain as a part of the overall treatment to prevent agitation and aggression in patients with dementia. Successful interventions are multifactorial and include early identification of delirium, treating underlying precipitants, and nonpharmacological approaches such as orientation strategies and mobilization.[45]

Tip 7: People with Dementia Living in Care Homes Should Have Chronic Disease Targets Adjusted to Avoid Iatrogenic Side Effects and Systematic Deprescribing, Including of Dementia Medications in Late Disease, Should Occur

Tight pharmacological control of chronic diseases (e.g., hypertension, hypothyroidism, diabetes, and hyperlipidemia) has been shown in multiple studies to potentially worsen functional outcomes and increase mortality for frail older adults living in care homes. Given these concerns, clinical targets should shift to become more liberalized depending on their age and functional status. Professional society guidelines reflect this ''happy medium'' principle.

Systematic deprescribing can improve outcomes and has been shown to be both feasible and safe for older adults living in care homes. Evidence shows increased risk of adverse events, such as falls, orthostasis, and mortality, with intensive treatment of hypertension (goal systolic blood pressure [SBP] <140 mmHg) in frail institutionalized older adults. The Society for Post-Acute and Long-Term Care Medicine recommends a higher SBP goal of <150 mmHg, even in those at high risk of cardiovascular disease and strokes. For dependent nonambulatory individuals, elevated blood pressure may be protective against cognitive decline and mortality.[46,47]

Professional guidelines recommend a higher thyroid-stimulating hormone threshold of 4–6 in the treatment of hypothyroidism for adults of age >70 years due to overall improved outcomes in this population with a higher clinical target.[48] Recent findings also do not support routine treatment with levothyroxine for subclinical hypothyroidism in adults aged 80 years and older.[49]

Similarly, expert guidelines outline different hemoglobin-A1C target ranges for older adults with diabetes based on health and functional status to avoid the adverse outcomes of both hyper- and hypoglycemia (the latter being more devastating for patients in poor health). A joint diabetes/geriatrics guideline recommends a target hemoglobin-A1C goal of <8.5% (7.5%–8.5%) for people living in care homes or for those with moderate-to-severe cognitive impairment.[50]

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Lipid-reducing medications for prevention of cardiovascular disease in advanced dementia and/or in the case of limited life expectancy have not been shown to improve outcomes, and stopping these medications has been shown to improve quality of life. It is, therefore, reasonable to stop these medications and not check lipid levels in older adults with advanced dementia living in care homes.

Experts recommend trying to discontinue antidementia medication if there is any sign of adverse effects, such as gastrointestinal upset, and in end stages of disease.[51] Once people have progressed to becoming fully dependent for all activities of daily living, the likelihood of continued benefit (i.e., preservation of cognitive and functional status) is likely outweighed by potential side effects and drug–drug interactions. In this population, discontinuation of antidementia medications has been shown to be safe and well tolerated.[52]

Tip 8: The Likelihood of Diminished Capacity Is Related to the Severity of Cognitive Impairment: Brief Measures of Overall Cognition Such as the Mini-Mental State Examination Are Not a Substitute for an Assessment of Capacity, Which Must Be Assessed Clinically Based on the Decision to Be Made

In the health care context, decision-making capacity means the ability of individual patients to make autonomous decisions about their health care. According to the widely acknowledged model of Appelbaum and Grisso, capacity is constituted of four necessary sequentially operational abilities: (1) the ability to understand decision-related information presented in an appropriate manner, (2) the ability to appreciate this information and apply it to one's own situation, (3) the ability to reason and balance the consequences and implications of various alternative options, and (4) the ability to make and express a choice based on the three previous processes.[53]

Adult patients are presumed to have full decision-making capacity unless proven otherwise. A recent systematic review, however, has found the average prevalence of decision-making incapacity to be 34% in the medical setting and 48% in the psychiatric setting.[54] The assessment of decision-making capacity is a complex medical judgment that requires face-to-face communication with the patient about a specific decision. Any cultural or communication barriers should be identified and removed before assessing capacity.[55]

Since the mentioned four abilities depend on cognitive processes, broadly understood diminished capacity is generally related to cognitive impairment. Yet, common measures of cognitive impairment can only serve as rough estimates of capacity: the Mini-Mental State Examination, for example, is only correlated with capacity in the very high (>24) and the very low (<16) ranges.[56] Diagnostic categories in and of themselves usually do not permit a conclusive inference on capacity. There are specific instruments to assess decision-making capacity, but so far, no gold standard exists. The choice of the instrument should be tailored to the kind of cognitive impairment, its cultural and personal context, and its use should only be added to an independent clinical judgment based on a structured interview.[56,57] As capacity is always decision-specific and health care decisions vary based on their complexity (e.g., information difficult to understand, alternative options close to each other, and long-reaching consequences for existential life domains), an individual patient may at the same time retain capacity for certain decisions but not for others.

Tip 9: People with Advanced-Stage Dementia with Neurodegenerative Dysphagia Do Not Benefit from Artificial Nutrition and Hydration

Weight loss is frequent in advanced dementia and may be caused by either reduced food intake (e.g., due to behavioral symptoms or dysphagia), increased energy expenditure (due to agitation), or both. The subsequent cachexia is a common cause of death in advanced dementia. Since careful hand feeding is labor intensive and may only be partly compensatory, gastric tube feeding has been used widely in the past to guarantee sufficient caloric intake. Tube feeding was also thought to decrease risk for aspiration pneumonia in patients with dysphagia. However, there is no evidence supporting increased survival or better nutritional status,[58,59] and tube feeding may even be associated with an increased risk for pressure ulcers.[60]

In contrast, forgoing artificial nutrition and hydration in patients with severe dementia who scarcely ate or drank anymore in general appeared not to be associated with high levels of discomfort.[61] Consequently, the use of gastric tube feeding in nursing home residents with advanced dementia has decreased[62] and professional organizations such as the American Geriatrics Society[63] and the European Association of Palliative Care[64] now advise against it.

The benefits of short-term forms of artificial hydration (intravenous or subcutaneous infusions) in advanced dementia have not been determined. Clinically, artificial hydration may be used on a case-by-case basis, for example, to treat suspected delirium due to dehydration. In conclusion, careful feeding by hand (termed ''comfort feeding'' when discussing with families),[65] mouth care, and other palliative measures to alleviate symptom burden are the mainstay of care when nutritional intake becomes insufficient in advanced dementia.

Tip 10: The Quality of End-of-Life Care for Nursing Home Residents Is Improved by the Presence of Hospice Services for Both the Residents Receiving Hospice and Those Not Enrolled

Residents in an LTC facility, whether they are there for skilled care such as physical therapy or for residential/custodial care, are, by definition, receiving PC (i.e., care that is provided to the whole person including physical and psychosocial aspects). For those residents who are approaching the end of their lives, formal hospice services may better meet their needs. Hospice care in the LTC setting has been shown to reduce transitions to acute care in the last days of life.

Hospice care in facilities has been shown to help evaluate and manage symptoms such as pain. Compared with residents not receiving hospice care, residents in hospice are less likely to have burdensome interventions such as feeding tubes or drug injections. Residents enrolled in hospice are more likely to have completed an advance directive.[66,67] Finally, hospice care includes bereavement support for the resident's family as well as the facility staff who grieving their death.[68]

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It has been found that the hospice philosophy of care can diffuse or spill over to the care of residents who are not enrolled in hospice.[68–70] This spillover is caused by the presence of hospice providers who demonstrate or teach excellent end-of-life skills, but does not necessarily correlate with the number of hospice providers.[69] The presence of hospice in a facility has been shown at the facility level to reduce hospitalizations and to increase ACP and evaluation and treatment of symptoms such as pain.[66,70]

Conclusions

Cognitive disorders such as dementia and delirium are common in nursing home residents. A better understanding of these conditions enables optimal PC delivery to those living in nursing facilities. A thorough understanding of these conditions will assist PC clinicians in effectively collaborating with other health care providers in nursing home facilities to improve care for patients and their families.

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