

Forum

Shifting Paradigms: Advance Care Planning for Pain Management in Older Adults With Dementia

Staja “Star” Booker, PhD(c), MS, RN^{1,*} and Rashida D. Booker, MOT, LOTR²

¹College of Nursing, The University of Iowa. ²LifeCare Hospitals of Shreveport, Louisiana.

*Address correspondence to: Staja “Star” Booker, PhD(c), MS, RN, The University of Iowa, 50 Newton Road, Iowa City, IA 52242.
E-mail: staja-booker@uiowa.edu

Received November 27, 2016; Editorial Decision Date February 8, 2017

Decision Editor: Rachel Pruchno, PhD

Abstract

Ensuring effective pain management is an important quality of life (and death) issue for older adults with dementia, particularly since they are more vulnerable to under-assessment and under-treatment of pain. Yet, pain management decisions are often made by health care providers and caregivers with little to no input on the older adult’s with dementia values for pain management. The Institute of Medicine (IOM) has recognized the revolutionary imperative to change the manner in which pain care is *planned* and coordinated. Implementing *advance care planning* (ACP) prior to advanced stages of dementia may assist in developing a person-centered pain management plan and improve pain care for this population throughout the dementia trajectory. This forum overviews the current state of pain management in dementia, discusses the significance of ACP in a pain management context, and offers practical solutions for common challenges in ACP. Dementia in this article is an umbrella term referring to the many forms of dementia that cause cognitive impairment.

Keywords: Advance care planning, Dementia, Pain management, Palliative care, Person-centered care

The [Institute of Medicine \(IOM, 2011\)](#) report on pain and the [National Pain Strategy \(2016\)](#) recognize an undeniable need to transform the perception, management, planning, and coordination of pain treatment across populations. Ultimately, a proactive system to pain management utilizing both prevention and palliation is needed. This paradigm shift, cultural transformation, and palliative turn attempts to improve the health of populations by “... infusing palliative care across whole health and social systems ...” and saturating health care providers’ training with palliative care and pain management education ([Morrissey, Herr, & Levine, 2015](#), p. 247; [IOM, 2011](#)). This shift emphasizes advance care planning (ACP), improved communication and education, collaboration, care coordination, and promotion of comfort through early intervention and individualized plans for relief and control of pain ([IOM, 2011](#); [Morrissey, Herr, & Levine, 2015](#); [Wilkie & Ezenwa, 2012](#)). This is especially relevant for high-risk

populations such as older adults with dementia, where gaps in pain management planning and coordination have contributed to treatment inadequacy. As chronic pain and dementia jointly become increasingly more prevalent in the context of rising life expectancy ([van Kooten et al., 2015](#); [Sosa-Ortiz, Acosta-Castillo, & Prince, 2012](#); [Corbett et al., 2014](#)), health promotion activities that involve planning and implementing patient-centered pain management are necessary in sustaining quality of life throughout the trajectory of dementia.

ACP is one practical solution to help mitigate the gaps in planning and coordinating management of pain in older adults with dementia. ACP entails recurrent conversations between patients, caregivers, and providers in which patients specify health care preferences in the event they are unable to make such decisions ([Lum, Sudore, & Bekelman, 2015](#)). ACP typically involves completion of an advance directive, a legal form which indicates preferences for

life-sustaining medical care, comfort care, and postmortem care. Recommendations suggest that advance care plans move beyond the vagueness of “comfort care,” and provide more specific directions to guide care of symptoms, such as pain (Unroe, Hickman, & Torke, (2016); AAHPM Research Committee Writing Group, 2016). Although ACP is an important component of geriatric pain management (Booker, Bartoszczyk, & Herr, 2016; Benton, 2006; Reuben et al., 2016; Mohanty et al., 2016), there is limited discourse on the implications of predetermining pain management preferences and needs in advance directives prior to cognitive incapacity. In this forum, we review the current state of pain management in dementia, discuss the significance of ACP in a pain management context, and offer practical solutions for challenges in ACP.

State of Pain Management in Older Adults With Dementia

Prevalence

Quality and adequate pain control is a fundamental human right no matter the stage of life or disease, but especially for older adults with dementia who are at greater risk for persistent (chronic) pain. Although dementia is not a source of persistent pain in itself, older adults with dementia often have multiple chronic conditions and injuries, such as arthritis and pressure ulcers, which cause pain (Molton & Terrill, 2014). The prevalence of persistent pain in older adults with dementia ranges from 30% to 68% (Hendriks, Smalbrugge, Galindo-Garre, Hertogh, & van der Steen, 2015; Corbett et al., 2012; McAuliffe, Brown, & Fetherstonhaugh, 2012). Among community-dwelling older adults with and without cognitive impairment, the prevalence of bothersome pain is estimated to be between 52%–64%, with 43% reporting activity limitations due to pain (Hunt et al., 2015; Patel et al., 2013). This trend is consistent in other studies as pain is one of the most frequently reported symptom by older adults with dementia and their caregivers alike (Murray, Sachs, Stocking, & Shega, 2012), and pain significantly increases during the last week of life (Hendriks et al., 2015).

Perception

High rates of persistent pain in older adults with dementia are not surprising given recent research that suggests these individuals may actually experience greater pain (DeFrin et al., 2015). Heightened sensations to pain and noxious stimuli combined with potentially lower pain thresholds may be due to neuropathological changes in the brain associated with various types of dementia. In fact, some evidence reveals that older adults with dementia have higher pain intensity ratings than those without cognitive impairment (Monroe et al., 2014; Scherder et al., 2015). In spite of this, older adults with dementia are perceived to be less sensitive to pain and painful stimuli (McAuliffe,

Brown, & Fetherstonhaugh, 2012). This ominous misconception often results in delayed recognition, assessment, and treatment of pain by health care providers (Corbett et al., 2012).

Assessment

Obtaining self-report is the accepted and current standard of practice for assessment of pain. Self-report capacity is defined as the ability to recognize and reliably report pain through verbal or purposeful nonverbal self-disclosure to a provider or caregiver. Older adults with dementia progressively lose cognitive capacity in the areas of memory, judgment, language, mood, and ability to make decisions (Cunningham, McGuinness, Herron, & Passmore, 2015), and this limits verbal communication of their pain and need for treatment. Although pain memory may be affected by dementia (Álvaro González, 2015), research shows that severity of dementia does not always limit self-reporting of pain (Lee, McConnell, Knafl, & Algase, 2015; Chen & Lin, 2015). In fact, older adults with dementia who score low on cognitive screenings have been able to reliably report pain (Hadjistavropoulos et al., 2014). Thus, health care providers should not simply rely on mental status exam scores or other cognitive screenings to discount older adults' with dementia ability to report pain, but should also use their clinical judgment as well as other techniques to determine an older adult's reliability to report pain (see Booker & Herr, 2016). When the older adult is unable to self-report pain, providers should refer to evidence-based strategies to assess pain (Hadjistavropoulos et al., 2014).

Treatment

Despite the prevalence of pain, it is generally under-treated in older adults with dementia (IOM, 2011; Monroe et al., 2014; Tan et al., 2015). Under-treatment is magnified in this population because they are sometimes unable to self-report pain to providers, but even more so when there is no advance directive to guide care. Under-treatment of pain can take the form of having no routine or as needed orders for analgesic medications, inappropriate analgesic medications, or no multimodal pain management plan (i.e., plan for integrative use of pharmacological and nonpharmacological strategies). Studies show the use of analgesic medications for pain among older adults across health care settings can be as low as nearly 40% but as high as 70% (Tan et al., 2015); whereas approximately 20%–70% of older adults with dementia used no analgesics (Hunt et al., 2015; Pimentel et al., 2015).

Pain that is un-/under-treated in older adults is a form of elder abuse, which has resulted in legal litigation under the auspice of undue pain and suffering (Morrissey, Herr, & Levine, 2015). But also concerning are the deleterious consequences that occur when older adults with dementia are inadequately treated for pain—falls and

compromised mobility, decreased immune response, mental health disorders, decreased or lost ability to engage in social interactions, impaired sleep, and even worsening cognition function (Molton & Terrill, 2014; van der Leeuw et al., 2016). Managing pain adequately can also reduce behavioral and psychological symptoms of dementia (BPSD; Husebo et al., 2014; Tosato et al., 2012). In fact, systematic, individualized pain management can significantly lower agitation levels in older adults with dementia (Sandvik et al., 2014). In return, psychotropic medications used to treat BPSD are significantly reduced and adverse effects are lessened, which are relevant outcomes supporting best practice initiatives to reduce antipsychotic medication use in older adults.

Significance of ACP in a Pain Management Context

Sampson and colleagues (2011) contend, "Advance care planning is, in theory, a necessary intervention for people with severe dementia..." given the prevalence of pain in this population (p. 197). The high rates of pain treatment disparity resulting in decreased quality of life and functional and cognitive decline (Kolanowski et al., 2015) further indicate a practical need for clear and identifiable directives for pain management, particularly since many with dementia reside in nursing homes (NHs) where pain management remains less than optimal (Hallenbeck, 2015). The role of ACP, as asserted in this article, is to empower and prepare the older adult with dementia and proxy decision-maker to develop a value-based pain management plan throughout the course of dementia. ACP discussions can equip patients and proxy decision-makers with education and skills on the "how to's" and "if-then's" of evidence-based pain management in older adults with dementia (see Table 1).

Older adults with dementia progressively lose ability to verbalize their wishes for pain care; therefore, it is recommended that ACP is initiated early in the dementia trajectory (Bollig, Gjengedal, & Rosland, 2016; Robinson et al., 2012). However, discussions about management of pain and other discomforting symptoms often occurs during end-of-life conversations about comfort care, with minimal detail about the scope of pain management options available. This can result in nonindividualized pain care and potential undertreatment and inappropriate treatment. New standards for ACP discussions, mainly provider reimbursement, recently approved by Centers for Medicare and Medicaid Services may facilitate earlier conversations with patients and families (<https://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2015-Fact-sheets-items/2015-10-30-2.html>).

Challenges and Practical Solutions

Challenge 1: Determining Decision-Making Capacity

An older adult with dementia who is able to self-report pain may or may not have capacity to make treatment decisions alone. Decision-making capacity refers to a patient's ability to provide informed consent for treatment or to refuse treatment (Chettih, 2012). A finding of incapacity to self-report pain should not always preclude engagement in pain management planning. Treatment decision-making capacity requires high executive functioning, and that older adults with dementia understand and differentiate the treatment options, weigh the benefits and risks, use judgment to make safe decisions, and can articulate their decisions in their own words. Although older adults with dementia are presumed to have the capacity to make health care decisions unless proven otherwise, there is no consensus for determining decision-making capacity (Wilkins, 2015).

Table 1. Components to Consider in a Pain Management Advance Care Plan

1. Goals for care: guided by patient preferences, develop an overall goal and a specific comfort-function-mood goal; this is critical in determining pathway to pain treatment.
2. Procedures: specify procedures that should be avoided or minimized (e.g., intravenous therapy if at risk for venous complications). It is important to minimize procedures that may cause additional pain and risk for suffering (e.g., cardiopulmonary resuscitation, intubation), even if the pain is temporary.
3. Risk/benefit: determine appropriateness of and when to use basic and/or advanced therapies and time-limited analgesic trials. Treatments should be based on patient health status, any health or cultural contraindications, and risks and benefits of each treatment.
4. Type of treatment: nonpharmacological (i.e., environmental, complementary, alternative, and integrative therapies) and/or pharmacological treatments, or no treatments.
5. Frequency of treatments: around-the-clock and/or as needed.
6. Route/mode of treatment: determine best treatment method based on patient's current health status and preference (e.g., oral, intravenous, etc.).
7. Medication titration: establish procedure for de-/escalation of pain medication dose
8. Social support: determine the individual(s) who will assist the older adult with dementia implement and adhere to a pain (self) management regimen or will ensure pain management plan is honored in acute or long-term care settings.
9. Research: identify if participation in pain research at any point is acceptable and feasible.

Solution 1: Optimize Decision-Making and Agency

In the context of pain management, several strategies can optimize decision-making capacity of the older adult with dementia:

1. Designate and document one person as the proxy decision-maker and/or medical power of attorney (i.e., family, trusted friend, caregiver) to consistently attend health appointments and provide decision support for the older adult with dementia. The roles of the older adult with dementia, proxy decision-maker, and each interdisciplinary team member should be clearly delineated.
2. Introduce conversations with older adults when they are not experiencing moderate or severe pain or under the influence of pain medication in order to improve their capacity to make informed decisions (American Nurses Association [ANA], 2010).
3. Initiate discussions (a) early in the dementia trajectory and (b) during times when the older adult is more lucid and cognitive ability is most reliable, as evidenced by a brief cognitive assessment and clinical judgment.
4. Provide modest amounts of information at any given time.
5. Use a culturally sensitive approach, respecting cultural values related to pain and utilizing interpreter services when needed.

Challenge 2: Identifying Patient Goals, Preferences, and Values

Fundamental to ACP is establishing patient values and setting clear goals and expectations for pain management. It may be difficult for patients and families to complete advance directives for future, unknown situations; this process may in actuality increase indecisiveness and temporary stress. For many patients with progressive and terminal conditions, such as dementia, and their families, pain and symptom management or freedom from pain are key goals (Kwak, Wallendal, Fritsch, Leo, & Hyde, 2014; Meghani & Hinds, 2015). Although nearly 50% of older adults reported they would rather die than suffer from considerable pain (McCarthy et al., 2008), in most situations, there has been no ACP or expression of their wishes to providers or caregivers (Bollig et al., 2016). In one ACP study, 80% of older adults indicated pain relief and comfort as their goal of care, but only 41% of older adults had both a health care proxy and living will (McCarthy et al., 2008). Some argue that “broad values statements, such as wanting to maintain dignity or be free from pain, are often too general to inform individual treatment decisions” (Sudore & Fried, 2010, p. 256); however, knowing patient values and preferences can inform treatment decisions and aid “in-the-moment” decision-making.

Solution 2: Provide Example Scenarios

Using past health events experienced by the older adult with dementia can guide conversations about pain care.

Another method is to provide example scenarios of realistic situations necessitating pain and palliative care treatment. A study presenting hypothetical situations to health care proxies of older adults with dementia found that 68% opted for the goal of comfort care only, whereas over 70% favored pain and symptom control as the only desired treatment interventions (Kwak, De Larwelle, Valuch, & Kesler, 2016). Families of older adults with dementia were more satisfied with end-of-life care in NHs when a comfort goal was explicitly developed (van Soest-Poortvliet et al., 2015).

Challenge 3: Aligning Patient Values With Treatment Benefit

It is critical to align pain care with the older adult’s values. For example, in cases of intractable pain, advanced treatments such as medical marijuana or palliative sedation may be averse to the older adult’s values of what constitutes moral and safe pain control. The balance between adequate analgesia and risk is important for all older adults, but especially for those with dementia who are more vulnerable to suffering from pain and/or adverse health events. “Patients asking for assistance in dying—or assisted suicide—may, in reality, be voicing their desire for autonomy, pain relief...” (ANA, 2010, p. 17). Therefore, it is vital to clarify the difference between “aggressive pain treatment” and “aggressive” pain treatment. The first refers to one’s due diligence to provide the most effective relief from pain, whereas the latter refers to advanced or invasive treatments and delivery systems that in itself may cause additional side effects, pain, and suffering. According to the ANA (1992), nurses should assess the “appropriateness of providing high-tech curative medical care to those who simply require comfort, relief from pain...” (p. 17). Thus, older adults with dementia and their families should consider the impact of life-sustaining interventions on prolongation of life, quality of life, and subsequent pain and suffering. Holley (2012) makes a good point about the use of life-sustaining measures, such as cardiopulmonary resuscitation, and its impact in causing pain and suffering in frail older adults who are especially vulnerable to rib and sternal fractures during chest compressions. Nonetheless, providers should reassure older adults with dementia that regardless of their decisions about life-sustaining interventions, pain and symptom relief will be provided.

Although the decision to refuse pain treatments may conflict with bioethical principles and negate the moral imperative to improve pain care in older adults with dementia, such decisions should be respected. For example, some cultures may decline the use of medications, such as opioids, at the end-of-life due to cultural and religious beliefs (Coolen, 2012; Ehman, 2012). Withholding treatment is controversial, and a conversation between all invested parties about implications of under-treatment of pain, suffering, and distress may be necessary. It should be clearly documented in an advance directive when pain relief interventions are unwanted.

Older adults and proxy decision-makers might also consider preferences regarding participation in pain research during the advanced stages of dementia. Pain research with older adults with various types of dementia is needed, and while there are benefits, risks, and biases for participation, few rarely consider this in an advance directive. Recommendations regarding ethical participation of older adults with dementia in pain research are available (Monroe, Herr, Mion, & Cowan, 2013).

Solution 3: Discuss the Spectrum of Pain Management Options

Multimodal treatment is recommended for management of pain, and the discussion about the scope of options can become overwhelming. It is necessary to identify and remedy discordance between what patients and families need and prefer, the services which they can receive (e.g., covered by Medicare/insurance), and the timeframe for initiating, withholding, and/or withdrawing treatments. Many caregivers lack the knowledge and skills to effectively initiate, adapt, and support pain management for their loved ones, which is why it is encouraged that providers assess caregivers' and proxy decision-makers' capacity to support implementation of a pain management plan (Booker, Bartoszczyk, & Herr, 2016).

To help patients and proxies understand the range of pain management options, offer a pain menu (examples can be Googled) and/or checklist of commonly used pharmacological and nonpharmacological options (see Table 2). During conversations with the health care provider, have the patient and the proxy decision-maker simultaneously check the options that are most appealing. Several observations can be gleaned from the checklist: options requiring more targeted discussion, options the older adult and proxy agree/disagree on, and an indication of the older adult's values. In addition to a checklist, it may prove useful to provide pertinent sample questions that older patients should ask of health care providers (see Table 3) as well as an example of an evidence-based protocol for assessment and treatment of pain in dementia (Sandvik et al., 2014).

Challenge 4: Maintaining Continuity of Pain Care Communication

Pain is a common reason why older adults are transferred from NHs and skilled nursing facilities (SNFs) to acute care settings (Ashcraft & Owen, 2014; Simmons et al., 2016). However, during transitions between settings and/or providers, key pain assessment and management information are not communicated at these critical points in

Table 2. Sample Patient Checklist of Pain Management Options

Goal for Pain Symptom Management:

Priorities for Pain Management:

Expectations for Treatments:

Acceptable pain intensity rating:

PAIN VALUES RATING

Please rate the following in order of most important to least important

_____ Total relief of pain (no pain)

_____ To be comfortable

_____ Control over pain (some pain is tolerable as long as can I remain functional)

TREATMENT OPTIONS

MEDICATIONS^a

- Acetaminophen
- Select Non-steroidal Anti-inflammatory drugs
- Opioids
- Local anesthetic
- Adjunct medications
 - Corticosteroids
 - Biologics
- Adjuvant medications
 - Anticonvulsants
 - Antidepressants
- Advanced therapies (e.g., radiation therapy, spinal cord stimulation, palliative sedation)
- Experimental pain medication

Comments

NON-MEDICATIONS^b

- Environmental adjustments
- Aromatherapy
- Massage
- Warm/cool compresses
- Distraction using individualized, therapeutic activities (e.g., music therapy)
- Acupressure
- Physical therapy
- Spiritual support
- Range of motion
- Transcutaneous electrical nerve stimulation (TENS)
- Pain management consult

Comments

^aThe medications should also be tailored to type of pain (nociceptive, neuropathic, mixed, and cancer) and to pain severity (mild, moderate, severe). This list can be expanded to be more specific for each category of medications. ^bCertain types of non-medications, particularly those requiring higher cognitive function (e.g., cognitive-behavioral therapy, guided imagery, breathing techniques, biofeedback) or those that may frighten or be uncomfortable (e.g., acupuncture, TENS), may be inappropriate for older adult with dementia. This list can be expanded to include other individualized nonmedication treatments.

Table 3. Questions to Ask Health Care Providers

1. What types of pain medications can be safely used given my health status?
2. What side effects might I experience from various pain treatments?
3. What types of non-medications are available and which can be safely and easily implemented?
4. Can any of my current pain-relieving medications be used in future events?
5. How will pain medications impact my dementia?
6. Will any pain medications hasten death at the end-of-life?
7. What resources on pain management are available to me and my family or caregiver?
8. How will the approach to pain management affect my family or caregiver's quality of life?
9. What is the process for updating my preferences for pain treatment in my advance directive?

time, almost defeating the purpose for acute care transfer (Simmons et al., 2016). "If the results of a pain assessment are not communicated to other staff members (e.g., documented in the older patient's medical chart), valuable information on pain in seniors may be lost (e.g., the timing, intensity, and correlates of pain)" (Martin et al., 2005, p. 152).

Solution 4: Document Patient Preferences

In response to this issue, Simmons and colleagues (2016) recommend implementing a "specific, planned process between hospital and SNF" for pain assessment and management across care transitions (p. 1138), in which preferences for hospitalization for new onset pain is clearly and specifically documented in the medical record (Unroe et al., 2016). When there are no documented directives or verbal consensus, disagreement among older adults with dementia, proxy decision-makers, and health care providers regarding the best approach to pain management may occur, causing undue suffering for the older adult. Utilize an interdisciplinary ethics committee and legal mediation when compromising problems develop.

Challenge 5: Planning for the Future

As dementia progresses, an older adult's care preference may not remain stable; that is, past preferences for care may not align with the preferences of the present or future self (Wilkins, 2015). Moreover, the present and future self may have difficulty articulating these new wishes. A change in treatment preference may manifest as the older adult with dementia verbally (e.g., saying "no") and physically (e.g., not opening mouth) refusing treatment. These behaviors could contrarily be interpreted as automatic or unconscious behaviors or BPSD. Moreover, as novel treatments become available, initiation of such must be guided

by treatment benefit and safety along with patient's documented preferences.

Solution 5: Initiate Ongoing ACP Discussions

As the older adult's clinical condition advances, reviewing and updating care preferences to reflect their current wishes is essential and highly recommended (Unroe et al., 2016). An interdisciplinary conference with the older adult and proxy decision-maker should be held at critical decision points to re-evaluate care, especially when behaviors change and the older adult with dementia becomes more incapable to articulate their continuing preferences. The frequency of ACP conversations will depend on the progression of dementia and chronic pain, but a generic time frame for updating the advance directive should be established and communicated to all parties involved. Some suggest updating preferences at least annually and when the individual's health condition changes (Unroe et al., 2016).

Conclusion

ACP is essential in guiding care when the older adult with dementia loses decisional and communication capacity. ACP anticipates needs and defines wishes, maintains continuity in care, improves quality of care, reduces caregiver or surrogate decision-maker burden, and supports meaningful use of health care by older adults with dementia, families, and society as a whole. Conversely, advance directives are not absolute, and ambiguities and dilemmas may still arise as health status changes. Thus, decisions and preferences should be re-evaluated throughout the dementia trajectory. We hope our perspective helps older adults with dementia, caregivers, and providers prepare for future pain decisions because ACP can Advance the Care of Pain.

Funding

This work was supported by the National Institute of Nursing Research of the National Institutes of Health under award number [T32 NR011147—PIs: Drs. Keela A. Herr and Ann M. McCarthy; Pre-doctoral fellow S. Booker].

Acknowledgments

The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. The authors declare no financial or commercial conflicts of interests. The authors send thanks to Dr. Lois Marshall for her review of an early version of this article.

References

- Álvaro González, L. C. (2015). The neurologist facing pain in dementia. *Neurología (Barcelona, Spain)*, 30(9), 574–585. doi:10.1016/j.nrl.2012.02.001

- American Nurses Association (ANA). (2010). *Position statement: Registered nurses' roles and responsibilities in providing expert care and counseling at the end of life*. Silver Spring, MD: ANA.
- American Nurses Association (ANA). (1992). *Position Statement: Assisted Suicide (retired)*. Silver Spring, MD: ANA.
- Ashcraft, A. S., & Owen, D. C. (2014). From nursing home to acute care: Signs, symptoms, and strategies used to prevent transfer. *Geriatric Nursing (New York, N.Y.)*, 35(4), 316–320. doi:10.1016/j.gerinurse.2014.06.007
- Benton, T. J. (2006). Pain management is part of advance directives discussion. *American Family Physician*, 73(8), 1331–1332.
- Bollig, G., Gjengedal, E., & Rosland, J. H. (2016). They know! Do they? A qualitative study of residents and relatives views on advance care planning, end-of-life care, and decision-making in nursing homes. *Palliative Medicine*, 30(5), 456–470. doi:10.1177/0269216315605753
- Booker, S.S., Bartoszczyk, D.A., & Herr, K.A. (2016). Managing pain in frail elders. *American Nurse Today*, 11, 1–9. Retrieved November 1, 2016, from <https://www.americannursetoday.com/managing-pain-frail-elders/>.
- Booker, S. Q., & Herr, K. A. (2016). Assessment and measurement of pain in adults in later life. *Clinics in Geriatric Medicine*, 32(4), 677–692. doi:10.1016/j.cger.2016.06.012
- Chen, Y. -H., & Lin, L. -C. (2015). The credibility of self-reported pain among institutional older people with different cognitive function in Taiwan. *Pain Management Nursing*, 16(3), 163–172. doi:http://dx.doi.org/10.1016/j.pmn.2014.05.010
- Chettih, M. (2012). Turning the lens inward: Cultural competence and providers' values in health care decision making. *The Gerontologist*, 52(6), 739–747. doi:10.1093/geront/gns008
- Coolen, P. R. (2012). Cultural relevance in end-of-life care. Retrieved January 16, 2017, from <http://ethnomed.org/clinical/end-of-life/cultural-relevance-in-end-of-life-care>.
- Corbett, A., Husebo, B. S., Achterberg, W. P., Aarsland, D., Erdal, A., & Flo, E. (2014). The importance of pain management in older people with dementia. *British Medical Bulletin*, 111(1), 139–148. doi:10.1093/bmb/ldu023
- Corbett, A., Husebo, B., Malcangio, M., Staniland, A., Cohen-Mansfield, J., Aarsland, D., & Ballard, C. (2012). Assessment and treatment of pain in people with dementia. *Nature Reviews. Neurology*, 8(5), 264–274. doi:10.1038/nrneuro.2012.53
- Cunningham, E. L., McGuinness, B., Herron, B., & Passmore, A. P. (2015). Dementia. *The Ulster Medical Journal*, 84(2), 79–87.
- Defrin, R., Amanzio, M., de Tommaso, M., Dimova, V., Filipovic, S., Finn, D. P., ... Kunz, M. (2015). Experimental pain processing in individuals with cognitive impairment: Current state of the science. *Pain*, 156(8), 1396–1408. doi:10.1097/j.pain.0000000000000195
- Ehman, J. (2012). Religious diversity: Practical points for health care providers. Retrieved January 16, 2017, from http://www.uphs.upenn.edu/pastoral/resed/diversity_points.html.
- Hadjistavropoulos, T., Herr, K., Prkachin, K. M., Craig, K. D., Gibson, S. J., Lukas, A., & Smith, J. H. (2014). Pain assessment in elderly adults with dementia. *The Lancet. Neurology*, 13(12), 1216–1227. doi:10.1016/S1474-4422(14)70103-6
- Hallenbeck, J. (2015). Pain management in American nursing homes—a long way to go. *Journal of the American Geriatrics Society*, 63(4), 642–643. doi:10.1111/jgs.13342
- Hendriks, S. A., Smalbrugge, M., Galindo-Garre, F., Hertogh, C. M., & van der Steen, J. T. (2015). From admission to death: Prevalence and course of pain, agitation, and shortness of breath, and treatment of these symptoms in nursing home residents with dementia. *Journal of the American Medical Directors Association*, 16(6), 475–481. doi:10.1016/j.jamda.2014.12.016
- Holley, J. L. (2012). Advance care planning in CKD/ESRD: An evolving process. *Clinical Journal of the American Society of Nephrology*, 7(6), 1033–1038. doi:10.2215/CJN.00580112
- Hunt, L. J., Covinsky, K. E., Yaffe, K., Stephens, C. E., Miao, Y., Boscardin, W. J., & Smith, A. K. (2015). Pain in community-dwelling older adults with dementia: Results from the National Health and Aging Trends Study. *Journal of the American Geriatrics Society*, 63(8), 1503–1511. doi:10.1111/jgs.13536
- Husebo, B. S., Ballard, C., Cohen-Mansfield, J., Seifert, R., & Aarsland, D. (2014). The response of agitated behavior to pain management in persons with dementia. *The American Journal of Geriatric Psychiatry*, 22(7), 708–717. doi:10.1016/j.jagp.2012.12.006
- Institute of Medicine. (2011). *Relieving pain in America: A blueprint for transforming prevention, care, education, and research*. Washington, DC: National Academies Press.
- Interagency Pain Research Coordinating Committee. (2016). National pain strategy: A comprehensive population health-level strategy for pain. Retrieved November 20, 2016, from https://iprcc.nih.gov/docs/HHSNational_Pain_Strategy.pdf.
- Kolanowski, A., Mogle, J., Fick, D. M., Hill, N., Mulhall, P., Nadler, J., ... Behrens, L. (2015). Pain, delirium, and physical function in skilled nursing home patients with dementia. *Journal of the American Medical Directors Association*, 16(1), 37–40. doi:10.1016/j.jamda.2014.07.002
- Kwak, J., De Larwelle, J. A., Valuch, K. O., & Kesler, T. (2016). Role of advance care planning in proxy decision making among individuals with dementia and their family caregivers. *Research in Gerontological Nursing*, 9(2), 72–80. doi:10.3928/19404921-20150522-06
- Kwak, J., Wallendal, M. S., Fritsch, T., Leo, G., & Hyde, T. (2014). Advance care planning and proxy decision making for patients with advanced Parkinson disease. *Southern Medical Journal*, 107(3), 178–185. doi:10.1097/SMJ.0000000000000075
- Lee, K. H., McConnell, E. S., Knafel, G. J., & Algase, D. L. (2015). Pain and psychological well-being among people with dementia in long-term care. *Pain Medicine*, 16(6), 1083–1089. doi:10.1111/pme.12739
- Lum, H. D., Sudore, R. L., & Bekelman, D. B. (2015). Advance care planning in the elderly. *The Medical Clinics of North America*, 99(2), 391–403. doi:10.1016/j.mcna.2014.11.010
- Martin, R., Williams, J., Hadjistavropoulos, T., Hadjistavropoulos, H. D., & MacLean, M. (2005). A qualitative investigation of seniors' and caregivers' views on pain assessment and management. *The Canadian Journal of Nursing Research*, 37(2), 142–164.
- McAuliffe, L., Brown, D., & Fetherstonhaugh, D. (2012). Pain and dementia: An overview of the literature. *International Journal of Older People Nursing*, 7(3), 219–226. doi:10.1111/j.1748-3743.2012.00331.x
- McCarthy, E. P., Pencina, M. J., Kelly-Hayes, M., Evans, J. C., Oberacker, E. J., D'Agostino, R. B. Sr., ... Murabito, J. M. (2008). Advance care planning and health care preferences of community-dwelling elders: The Framingham Heart Study. *The Journals*

- of Gerontology. Series A, Biological Sciences and Medical Sciences, 63(9), 951–959.
- Meghani, S.H., & Hinds, P.S. (2015). Policy brief: The Institute of Medicine report Dying in America: Improving quality and honoring individual preferences near the end of life. *Nursing Outlook*, 63, 51–59. doi:http://dx.doi.org/10.1016/j.outlook.2014.11.007
- Mohanty, S., Rosenthal, R. A., Russell, M. M., Neuman, M. D., Ko, C. Y., & Esnaola, N. F. (2016). Optimal perioperative management of the geriatric patient: A Best Practices Guideline from the American College of Surgeons NSQIP and the American Geriatrics Society. *Journal of the American College of Surgeons*, 222(5), 930–947. doi:10.1016/j.jamcollsurg.2015.12.026
- Molton, I. R., & Terrill, A. L. (2014). Overview of persistent pain in older adults. *The American Psychologist*, 69(2), 197–207. doi:10.1037/a0035794
- Monroe, T. B., Herr, K. A., Mion, L. C., & Cowan, R. L. (2013). Ethical and legal issues in pain research in cognitively impaired older adults. *International Journal of Nursing Studies*, 50(9), 1283–1287. doi:10.1016/j.ijnurstu.2012.11.023
- Monroe, T. B., Misra, S. K., Habermann, R. C., Dietrich, M. S., Cowan, R. L., & Simmons, S. F. (2014). Pain reports and pain medication treatment in nursing home residents with and without dementia. *Geriatrics and Gerontology International*, 14(3), 541–548. doi:10.1111/ggi.12130
- Morrissey, M. B., Herr, K., & Levine, C. (2015). Public health imperative of the 21st century: Innovations in palliative care systems, services, and supports to improve health and well-being of older Americans. *The Gerontologist*, 55(2), 245–251. doi:10.1093/geront/gnu178
- Murray, T. M., Sachs, G. A., Stocking, C., & Shega, J. W. (2012). The symptom experience of community-dwelling persons with dementia: Self and caregiver report and comparison with standardized symptom assessment measures. *The American Journal of Geriatric Psychiatry*, 20(4), 298–305. doi:10.1097/JGP.0b013e318235b758
- Patel, K. V., Guralnik, J. M., Dansie, E. J., & Turk, D. C. (2013). Prevalence and impact of pain among older adults in the United States: Findings from the 2011 National Health and Aging Trends Study. *Pain*, 154(12), 2649–2657. doi:10.1016/j.pain.2013.07.029
- Reuben, D.B., Herr, K.A., Pacala, J.T., Pollock, B.G., Potter, J.F., & Semla, T.P. (2016). *Geriatrics at your fingertips 2016*. New York: American Geriatrics Society.
- Robinson, L., Dickinson, C., Rousseau, N., Beyer, F., Clark, A., Hughes, J., ... Exley, C. (2012). A systematic review of the effectiveness of advance care planning interventions for people with cognitive impairment and dementia. *Age and Ageing*, 41(2), 263–269. doi:10.1093/ageing/afr148
- Sampson, E. L., Jones, L., Thuné-Boyle, I. C., Kukkastenvemas, R., King, M., Leurent, B., ... Blanchard, M. R. (2011). Palliative assessment and advance care planning in severe dementia: An exploratory randomized controlled trial of a complex intervention. *Palliative Medicine*, 25(3), 197–209. doi:10.1177/0269216310391691
- Sandvik, R. K., Selbaek, G., Seifert, R., Aarsland, D., Ballard, C., Corbett, A., & Husebo, B. S. (2014). Impact of a stepwise protocol for treating pain on pain intensity in nursing home patients with dementia: A cluster randomized trial. *European Journal of Pain (London, England)*, 18(10), 1490–1500. doi:10.1002/ejp.523
- Simmons, S. F., Schnelle, J. F., Saraf, A. A., Simon Coelho, C., Jacobsen, J. M., Kripalani, S., ... Vasilevskis, E. E. (2016). Pain and satisfaction with pain management among older patients during the transition from acute to skilled nursing care. *The Gerontologist*, 56(6), 1138–1145. doi:10.1093/geront/gnv058
- Sosa-Ortiz, A. L., Acosta-Castillo, I., & Prince, M. J. (2012). Epidemiology of dementias and Alzheimer's disease. *Archives of Medical Research*, 43(8), 600–608. doi:10.1016/j.arcmed.2012.11.003
- Sudore, R. L., & Fried, T. R. (2010). Redefining the “planning” in advance care planning: preparing for end-of-life decision making. *Annals of Internal Medicine*, 153(4), 256–261. doi:10.7326/0003-4819-153-4-201008170-00008
- Tan, E. C., Jakanovic, N., Koponen, M. P., Thomas, D., Hilmer, S. N., & Bell, J. S. (2015). Prevalence of analgesic use and pain in people with and without dementia or cognitive impairment in aged care facilities: A systematic review and meta-analysis. *Current Clinical Pharmacology*, 10(3), 194–203.
- Tosato, M., Lukas, A., van der Roest, H. G., Danese, P., Antocicco, M., Finne-Soveri, H., ... Onder, G. (2012). Association of pain with behavioral and psychiatric symptoms among nursing home residents with cognitive impairment: Results from the SHELTER study. *Pain*, 153(2), 305–310. doi:10.1016/j.pain.2011.10.007
- Unroe, K. T., Hickman, S. E., & Torke, A. M.; AAHPM Research Committee Writing Group. (2016). Care consistency with documented care preferences: Methodologic considerations for implementing the “Measuring What Matters” quality indicator. *Journal of Pain and Symptom Management*, 52(4), 453–458. doi:10.1016/j.jpainsymman.2016.04.015
- van der Leeuw, G., Eggermont, L. H., Shi, L., Milberg, W. P., Gross, A. L., Hausdorff, J. M., ... Leveille, S. G. (2016). Pain and cognitive function among older adults living in the community. *The Journals of Gerontology. Series A, Biological Sciences and Medical Sciences*, 71(3), 398–405. doi:10.1093/gerona/gle166
- van Kooten, J., Delwel, S., Binnekade, T. T., Smalbrugge, M., van der Wouden, J. C., Perez, R. S., ... Scherder, E. J. (2015). Pain in dementia: Prevalence and associated factors: protocol of a multidisciplinary study. *BMC Geriatrics*, 15, 29. doi:10.1186/s12877-015-0025-0
- van Soest-Poortvliet, M. C., van der Steen, J. T., de Vet, H. C., Hertogh, C. M., Deliëns, L., & Onwuteaka-Philipsen, B. D. (2015). Comfort goal of care and end-of-life outcomes in dementia: A prospective study. *Palliative Medicine*, 29(6), 538–546. doi:10.1177/0269216315570409
- Wilkie, D. J., & Ezenwa, M. O. (2012). Pain and symptom management in palliative care and at end of life. *Nursing Outlook*, 60(6), 357–364. doi:10.1016/j.outlook.2012.08.002
- Wilkins, J. M. (2015). More than capacity: Alternatives for sexual decision making for individuals with dementia. *The Gerontologist*, 55(5), 716–723. doi:10.1093/geront/gnv098