Since January 2020 Elsevier has created a COVID-19 resource centre with free information in English and Mandarin on the novel coronavirus COVID-19. The COVID-19 resource centre is hosted on Elsevier Connect, the company's public news and information website.

JAMDA 21 (2020) 2012–2013

JAMDA

journal homepage: www.jamda.com

Research Letter

Problems With Advance Care Planning Processes and Practices in Nursing Homes

To the Editor:

Serious concerns exist about advance care planning (ACP) and end-of-life (EOL) care in nursing homes (NHs). NH residents often experience a progressive burden of severe symptoms leading up to death. Aggressive medical care exposes them to iatrogenic complications and poor quality of EOL care,[1] concerns magnified by the severe acute respiratory syndrome coronavirus-2 (SARS-CoV-2) pandemic, wherein NH residents have taken the brunt of deaths.[2] In a prospective, observational study supported by research grants from the Canadian Frailty Network and Research Manitoba and approved by the Research Ethics Boards of all participating institutions, we assessed ACP processes and practices in 38 NHs in 3 Canadian provinces (10 Alberta, 10 Manitoba, 18 Ontario) recruited for the Better Targeting, Better Outcomes for Frail Elderly Patients (BABEL) study, an ongoing, randomized study of ACP in NHs. Public/private ownership of these NHs is 45%/55%. During 2017–2019, they completed a survey about prevalent ACP practices. Questions explored the frequency of practices on a 5-point Likert scale; for most reporting we grouped these responses into high (always, almost always, or usually), intermediate (about half the time), and low (never, almost never, or rarely).

ACP discussions occur in 92% of participating NHs at initial admission, and yearly thereafter in 97%. In 10%, they are not repeated with changes in residents' clinical status, which is problematic because EOL preferences can change.[3] Frequency of resident participation in ACP discussions is highly variable (Table 1); although this may reflect high prevalence of residents with dementia, the literature supports engaging cognitively impaired residents to the highest degree possible.[4] Nurses very frequently participate in ACP discussions. Physicians participate one-half of the time or less in 40% of the homes; such suboptimal involvement of physicians is recognized as being problematic.[5] Palliative care experts and spiritual advisors are rarely involved.

In over 80% of the NHs, resuscitation, comfort care, hospital/emergency department transfers, and use of antibiotics are always or almost always included in ACP discussions. Despite that most NH deaths are due to disorders that commonly cause cardiopulmonary arrest,[6] artificial life support is discussed one-half the time or less in 24% of homes. Feeding tubes and intravenous fluids are discussed even more rarely.

High participation by residents in decision-making during medical emergencies occurs in 50% of homes. In most, nurses and physicians have high participation in such discussions. Of note, in 63% of NHs, on-call physicians have high or intermediate frequency of being involved in such decision-making.

Regarding adherence in medical emergencies to prior ACP decisions, in 40% of NHs this occurs only "usually," and in another 8% it occurs one-half of the time or less. Possible contributors to such suboptimal performance may include substitute decision-makers being unprepared for crises, involvement of cross-covering physicians who lack familiarity with prior ACP decisions/wishes, and legally mandated "levels of care" documents. The latter identify 3 (to 5) levels, typically including no care limitations, comfort care only, and intermediate tier(s) such as allowing all care except for resuscitation. Unless personnel who participated in ACP discussions are involved at the time of crisis, nuance may be lost, and decisions may be inconsistent with what residents want.

In all 3 provinces, ACP documentation includes specific physician orders (eg, do not resuscitate) when applicable, and the "levels of care" document, which is maintained in a special section of the resident's medical chart in all of the participating NHs. Such documentation is reported to be always or almost always readily available to staff in 78% of the NHs.

Finally, NHs use various methods to communicate ACP information when residents are transferred to an emergency department or hospital. The most common are specific paper forms that go with the resident (95% of NHs) and verbal reports to transporting paramedics (in 65%). The most common forms are the "levels of care" document mentioned above, with their limitations. Relying on paramedics to transmit ACP information is limited by this same lack of nuance, and, additionally, if they hand off care to emergency department triage nurses rather than to clinicians who will be caring for the individual.

Our findings reinforce previously known problems in NH ACP, as well as identifying additional challenges that can contribute to care that is inconsistent with the wishes of these vulnerable individuals. As a report from 38 Canadian nursing homes, our findings may not be fully generalizable; however, the known deficiencies in EOL care and ACP in NHs are not particular to Canada and cross national borders.[7–10] These findings highlight the need to study ACP processes and practices in NHs, and devise and test approaches to improving them.

Supplementary Data

Supplementary data related to this article can be found online at https://doi.org/10.1016/j.jamda.2020.07.010.

This work was supported by the Canadian Frailty Network (Grant#TG2015-15), and Research Manitoba.

https://doi.org/10.1016/j.jamda.2020.07.010

Table 1
Frequency of Processes and Practices of ACP

	Frequency (%)		
	Low (Never, Almost Never, or Rarely)	Intermediate (Almost One-Half the Time)	High (Always, Almost Always, or Usually)
Participation in ACP discussions			
Resident	32.4	29.7	37.9
Spouse	2.6	15.8	81.6
Children	0	15.8	84.1
Nurse	5.4	8.1	86.5
Physician	29.0	10.5	60.5
Social worker	42.9	17.1	40.0
Palliative care expert	71.4	11.4	13.2
Spiritual advisor	89.5	10.5	0
Medical topics discussed during ACP discussions			
Resuscitation	5.2	2.6	92.2
Comfort care	2.6	0	97.4
Hospital/emergency department transfer	7.9	0	92.1
Antibiotics	5.2	2.6	92.2
Artificial life support	18.4	5.3	76.3
Feeding tube	36.9	5.3	57.8
Intravenous fluids	28.9	10.5	60.6
Participation in urgent decision-making in residents' medical crises			
Resident	26.3	23.7	50.0
Resident's own nurse	0	0	100
Resident's own physician	0	10.5	89.5
On-call physician	36.8	26.3	36.9
Palliative care expert	75.7	8.1	16.2
Spiritual advisor	94.7	5.3	0

References

1. Caffrey C. Potentially preventable emergency department visits by nursing home residents: United States, 2004. NCHS Data Brief 2010;33:1–8.
2. Comas-Herrera A, Zalakaín J, Litwin C, et al. International Long Term Care Policy Network. Mortality associated with COVID-19 outbreaks in care homes: Early international evidence. Available at: https://ltccovid.org/wp-content/uploads/2020/05/Mortality-associated-with-COVID-21-May-7.pdf. Accessed June 5, 2020.
3. McParland E, Likourezos A, Chichin E, et al. Stability of preferences regarding life-sustaining treatment: A two-year prospective study of nursing home residents. Mt Sinai J Med 2013;70:85–92.
4. Harrison Dening K, Sampson EL, De Vries K. Advance care planning in dementia: Recommendations for healthcare professionals. Palliat Care 2019;12:1178224219826579.
5. Flo E, Husebo BS, Bruusgaard P, et al. A review of the implementation and research strategies of advance care planning in nursing homes. BMC Geriatr 2016;16:24.
6. Braggion M, Pellizzari M, Basso C, et al. Overall mortality and causes of death in newly admitted nursing home residents. Aging Clin Exp Res 2020;32:275–280.
7. Intrator O, Zinn J, Mor V. Nursing home characteristics and potentially preventable hospitalizations of long-stay residents. J Am Geriatr Soc 2004;52:1730–1736.
8. Allers K, Hoffmann F. Mortality and hospitalization at the end of life in newly admitted nursing home residents with and without dementia. Soc Psychiatry Psychiatr Epidemiol 2018;53:833–839.
9. Estabrooks CA, Hoben M, Poss JW, et al. Dying in a nursing home: Treatable symptom burden and its link to modifiable features of work context. J Am Med Dir Assoc 2015;16:515–520.
10. Wang HE, Shah MN, Allman RM, Kilgore M. Emergency department visits by nursing home residents in the United States. J Am Geriatr Soc 2011;59:1864–1872.

Nora Choi, MSc
Allan Garland, MD, MA
Clare Ramsey, MD
Jessica Steer, BA
University of Manitoba
Winnipeg, Manitoba, Canada

Heather Keller, PhD
George Heckman MD
Vanessa Vucea MSc
Ikdip Bains MSc
Brittany Kroetsch BSc
University of Waterloo
Waterloo, Ontario, Canada

Patrick Quail, MD
Seema King MSW
Tatiana Oshchepkova MSW
Tatiana Kalashnikova PhD
University of Calgary
Calgary, Alberta, Canada

Veronique Boscart, PhD
Michelle Heyer MSc
Conestoga College
Kitchener, Ontario, Canada