Analysis in Brief

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A Snapshot of Advance Directives in Long-Term Care: How Often Is “Do Not” Done?

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A Snapshot of Advance Directives in Long-Term Care: How Often Is “Do Not” Done?

A recent Supreme Court decision allowing physician-assisted death in Canada has ignited a broader national debate on end-of-life care, including the rights of individuals to determine what kinds of interventions they want or don’t want at the end of their lives. Many Canadian jurisdictions now encourage advance care planning to ensure a more person-centred approach to end-of-life care.

In long-term care, advance directives allow individuals and their families/legal guardians to communicate preferences for interventions and treatments in the event that these individuals are no longer able to make decisions for themselves. This study examines how often do-not-hospitalize (DNH) and do-not-resuscitate (DNR) directives were recorded for residents in 982 reporting Canadian long-term care facilities between 2009–2010 and 2011–2012 and, to the extent possible, whether these directives were followed in acute care settings. The findings of this study will shed light on how end-of-life preferences of long-term care residents are upheld and communicated across the continuum of care.

Key messages

- **Three-quarters of long-term care residents have a DNR directive.** These directives appear to be well followed across the continuum of care, with only about 1 in 2,500 residents receiving resuscitation in hospital despite having a directive not to resuscitate.
- **Fewer residents — 1 in 5 — have a DNH directive.** The study found that 1 in 14 (7%) residents with a directive not to be hospitalized was admitted to hospital. It is not possible to determine from the data what conversations were had with residents or their legal guardians at the time of a decision to hospitalize, and therefore whether the directive was appropriately followed. Those who were physically or mentally healthier were more likely to be transferred to hospital for care.
- **Close to half of hospitalizations among residents with a DNH directive were from potentially preventable causes.** Safety incidents, such as injuries from falls and infections, were among the most common reasons for hospital transfers. Overall, however, hospitalization rates for all long-term care residents declined significantly over the study period. Hospitalizations could be further reduced with the enhancement of palliative care services in long-term care settings.

About the data

Data used for this study is based on the assessments of almost 200,000 long-term care residents in 4 Canadian provinces and 1 territory. The data was submitted by participating long-term care facilities to the Continuing Care Reporting System (CCRS) — a data holding of the Canadian Institute for Health Information (CIHI) — between 2009–2010 and 2011–2012. Information for subsequent years is unavailable, as advance directive data elements were modified as of 2012–2013.

To follow the trajectory of long-term care residents in acute care, CCRS records were linked to those of CIHI’s Discharge Abstract Database (DAD). The DAD captures administrative, clinical and demographic information on hospital discharges (including deaths, sign-outs and transfers).

Coverage for this study is limited to jurisdictions that consistently recorded advance directives information over the study period:

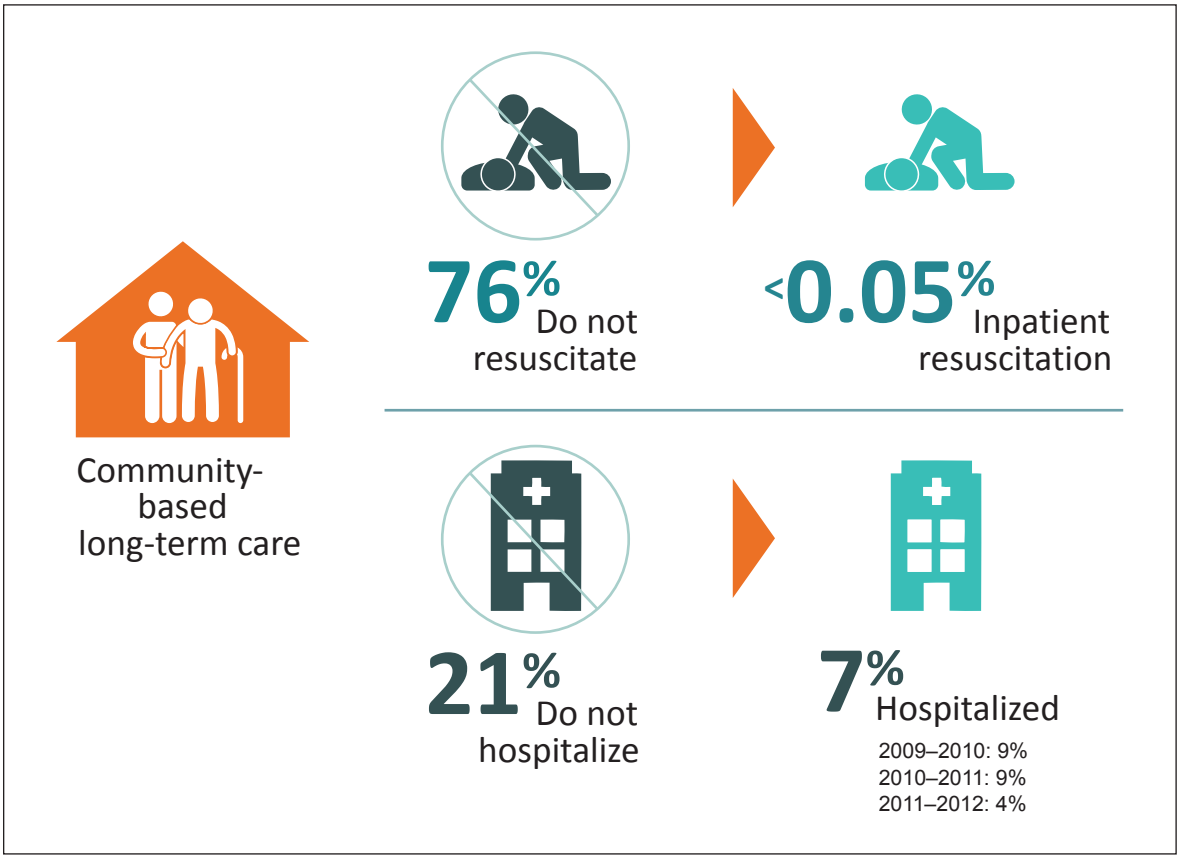
- Manitoba and Yukon: DNR reporting only; and
- Nova Scotia, Ontario and British Columbia: both DNH and DNR reporting.

Ontario and Yukon coverage includes most long-term care facilities that receive public funding, while data is limited to participating facilities in other provinces.

Data concerning the directives discussed in this study is drawn from the annual assessments of residents in reporting Canadian nursing and long-term care facilities.

Detailed results

Figure 1 Percentage of long-term care residents with a DNR or DNH directive and, of those, percentage of residents for whom resuscitation or hospitalization occurred



How often is a DNR directive followed?

- More than three-quarters of long-term care residents in the study had a directive to not resuscitate (Figure 1). A DNR directive states that no cardiopulmonary resuscitation (CPR) or other life-saving methods are to be used in the event of cardiac arrest or respiratory failure.
- Over the study period, less than 0.05% of residents with a DNR directive — or about 1 in 2,500 — received resuscitation in an acute care hospital after being transferred there for treatment. This suggests that do-not-resuscitate orders are well communicated between care facilities and well understood by care providers.

How often is a DNH directive followed?

- About 1 in 5 long-term care residents (21%) had a documented DNH directive. This type of directive states that the resident is not to be hospitalized even if he or she acquires a medical condition requiring hospital care. It is important to note that a DNH directive comes into effect only if the resident is unable to provide informed consent at the time of a decision to hospitalize or if a family member or legal guardian is unavailable to consult about treatment options.
- Almost 6,000 (n = 5,783) hospitalizations occurred among residents with a recorded DNH directive over the 3-year study period. This represents almost 7% (1 in 14) of long-term care residents with a DNH directive. More than half of these cases (3,331) involved residents who were moderately to severely cognitively impaired (or who likely could not make decisions for themselves).
- Residents with a DNH directive were about half as likely to be hospitalized as those without one. The hospitalization rate of residents without a DNH directive was 15%. However, hospitalization for both groups of residents declined by about half between 2009–2010 and 2011–2012. This coincides with a push in Ontario’s long-term care sector to reduce avoidable hospitalizations.

Why are residents with a DNH directive hospitalized?

The top 10 causes of hospital stays listed in **Table 1** were responsible for nearly 60% of all hospital admissions, including

- Trauma or injury, such as a broken hip sustained in a fall;
- End-of-life or palliative care;
- Infections such as pneumonia, urinary tract infections and sepsis (infection of the bloodstream); and
- Exacerbation of chronic conditions such as heart failure and chronic obstructive pulmonary disease (COPD).

Table 1 Top 10 causes of hospital stays among long-term care residents with a DNH directive

Most responsible diagnosis*	Number of cases	Percentage of total cases
Total DNH hospital stays	**5,783**	
Pelvic/hip/femur trauma/repair	909	15.7%
Viral/bacterial/unspecified pneumonia	460	8.0%
Palliative care	350	6.1%
Urinary tract infections	300	5.2%
Gastrointestinal hemorrhage/obstruction	270	4.7%
Chronic obstructive pulmonary disease	258	4.5%
Other trauma/injury/complication	225	3.9%
Sepsis	219	3.8%
Aspiration pneumonia	218	3.8%
Heart failure without intervention	216	3.7%

Note
* Based on modified CIHI Case Mix Groups.
Source
Discharge Abstract Database, 2009–2010 to 2011–2012, Canadian Institute for Health Information.

Further comparison of these cases (**Table 2**) shows that

- Nearly half (47%) of hospitalizations for residents with a DNH directive were potentially avoidable;[2] this is about the same proportion (46%) as for residents who were hospitalized without advance directives on hospital care. Hospitalizations are considered potentially avoidable if
  - The reason for hospitalization can be prevented from occurring (e.g., falls, infections, aspiration pneumonia, a lung infection caused by feeding problems); or
  - The condition responsible for the hospital visit could potentially be managed in the long-term care setting (e.g., chronic condition such as COPD or heart failure).
- The proportion of hospital stays for injuries was about twice as high (19%) for residents with a DNH directive as for those without one (10%). Hospitalization for injuries such as fractures is often considered necessary, as treatment may require surgery and fractures are typically very painful. Under these circumstances, families may be more likely to reconsider a decision not to hospitalize, and long-term care staff may be less willing to abide by a DNH if a family member/legal guardian can’t be reached in a timely fashion and a resident is unable to provide consent.
- The proportion of palliative care hospitalizations was slightly higher for residents with a DNH directive, and overall it tripled for both groups of residents over the 3-year study period — increasing from 3% of total hospitalizations among long-term care residents

in 2009–2010 to 9% in 2011–2012. While palliative care is not included in the definition of avoidable hospitalizations used in this analysis, good palliative care programs in community settings or outside of hospitals can improve the quality of life of residents who are terminally ill, and potentially reduce the need for transfers to hospital.[1, 2]

- Both groups of hospitalized residents were equally likely to die in hospital, with about 1 in 5 not surviving his or her hospital stay.

Table 2 Comparison of hospitalization cases among residents with and without a DNH directive

		Residents with a DNH directive	Residents without a DNH directive
Total hospitalization episodes		**5,783**	**44,114**
Potentially avoidable hospitalizations*	Number	2,676	19,946
Potentially avoidable hospitalizations*	Percentage of hospitalizations	46.3%	45.2%
Injury case	Number	1,110	4,672
Injury case	Percentage of hospitalizations	19.2%	10.6%
Palliative care†	Number	350	2,084
Palliative care†	Percentage of hospitalizations	6.1%	4.7%
Death in hospital	Number	1,230	9,570
Death in hospital	Percentage of hospitalizations	21.3%	21.7%

Notes
* See Walker et al.[3]
† CMG code 810 — Palliative Care.
Categories are not mutually exclusive, and a single stay may fit into several categories.
Source
Discharge Abstract Database, 2009–2010 to 2011–2012, Canadian Institute for Health Information.

Who is most likely to be hospitalized with a DNH directive?

Table 3 identifies the types of residents and long-term care facilities most closely associated with transfers to acute care hospitals:

- Individuals who were relatively young (younger than 90), more independent and more stable in health were more likely to be admitted to hospital. For example, residents who had low or moderate dependencies for activities of daily living (e.g., eating, bathing, walking) were over 60% more likely to be admitted to hospital than their highly dependent peers, after adjusting for other factors. This finding is consistent with other research on long-term care transitions to hospital.[4]

- Residents who were of sound mind (or with little or no cognitive impairment) with a DNH directive were over 40% more likely to be admitted to hospital. These residents would have been able to decide whether or not they wanted to be cared for in hospital — overriding any reliance on the advance directive.
- Male residents with DNH directives were 34% more likely to be hospitalized than their female counterparts, after adjusting for other factors.
- Individuals with diabetes were also 34% more likely to end up in hospital. This may be due to the fact that diabetes can make other illnesses (e.g., infections) more severe and more difficult to treat.

Table 3 Top characteristics associated with hospitalization among long-term care residents with a DNH directive*

Long-term care resident assessment characteristics	Point estimate	Confidence limits†
More medically stable: CHESS Scale score 0–3 (vs. medically unstable)	1.63	1.41–1.88
Lower dependence for activities of daily living: ADL Short Form score <9 (vs. more dependent)	1.61	1.52–1.71
Cognitively intact: CPS Scale score <2 (vs. cognitive impairment)	1.42	1.32–1.52
Male (vs. female/other)	1.34	1.27–1.42
Diabetes (vs. no diabetes)	1.34	1.25–1.42
Younger: Age <90 years (vs. 90+ years)	1.29	1.22–1.37
Congestive heart failure (vs. no congestive heart failure)	1.28	1.19–1.38
Private–for-profit long-term care facility (vs. public)	1.25	1.17–1.34
Daily pain: Pain Scale score 2–3 (vs. no daily pain)	1.25	1.17–1.33

Notes
* See companion data tables for full regression model results.
† p <0.001, Wald upper and lower confidence limits.
CHESS Scale: Changes in Health, End-Stage Disease and Signs and Symptoms Scale.
ADL Short Form: Activities of Daily Living Short Form Scale.
CPS: Cognitive Performance Scale.
Model concordance = 0.631, C = 0.635.
Source
Continuing Care Reporting System, 2009–2010 to 2011–2012, Canadian Institute for Health Information.

Conclusions and discussion

Advance care planning or advance directives are associated with better patient experience[4] and lower costs for the health system.[5] While long-term care facilities in Canada typically discuss care goals with residents, little information is currently available to understand what kind of directives are in place, and whether documented patient preferences are being followed in clinical practice and across the continuum of care. This snapshot analysis helps to shed light on the use of do-not-hospitalize and do-not-resuscitate directives in long-term care, based on the largest sample of any Canadian study on the topic.

Key findings from this analysis raise the following points for discussion:

- **There is an opportunity to raise awareness with residents and families about advance care planning.** Fewer long-term care residents had DNH directives (21%), compared with those with DNR documentation (76%). Research shows that a decision to transfer a resident to hospital despite the person’s advance wishes is often made by family members.[4] This suggests an opportunity to raise awareness with residents and their families to better assess the health benefits and risks of hospital stays. For frail and vulnerable residents, for example, research shows that the stress of a hospital transfer and potential risk of infection can often outweigh the perceived benefits of treatment.[6, 7] Sometimes, serious infections such as pneumonia can be treated in long-term care facilities, often with better outcomes for these patients.[8, 9] That said, it is up to residents and their families to decide on the best course of action.
- **While a lot of progress has been made, potentially avoidable hospitalizations can be further reduced in long-term care settings.** Safety initiatives (e.g., falls prevention and infection control strategies) and better management of chronic conditions in long-term care facilities can help reduce many of the incidents that send residents to hospital despite their advance directives.

  Initiatives to improve the quality of long-term care and avoid unnecessary hospitalizations, such as Ontario’s Residents First initiative,[10] appear to be bearing fruit; hospitalizations among all long-term care residents dropped significantly — by about 50% — over the 3 years of this study period.
- **Palliative care services can be enhanced in long-term care.** Palliative care is one of the top 3 causes of hospital stays among long-term care residents with a directive to not hospitalize, and one of the few areas that did not experience a decline in hospitalization over the study period. While many jurisdictions in Canada have initiatives under way to improve end-of-life services out of hospital, few nursing homes have formal palliative care programs.[1, 11]

- **More data is required in order to follow trends over time.** While this analysis provides good baseline information on the use of DNR and DNH directives, data about these directives is no longer captured and reported to CIHI. Long-term care facilities are striving to offer better-quality care that is more focused on individual preferences for end-of-life care, so measuring progress in this area is useful.

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