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

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Abstract

Advance directives allow individuals and their families or 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. It found that three-quarters of long-term care residents had a directive not to resuscitate and that these directives appeared to be well followed across the continuum; only 1 in 2,500 residents with a DNR received resuscitation in hospital. Fewer residents - 1 in 5 - had a directive not to hospitalize, and about 1 in 14 (7%) of these residents was admitted to hospital. The data are unable to determine whether patients or their families provided consent for these hospitalizations at the time of a decision to transfer. Close to half of hospitalizations among residents with a DNH directive were from potentially preventable causes, such as injuries or infections. Although hospital transfers from long-term care decreased 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 are based on the assessments of almost 200,000 long-term care residents in four Canadian provinces and one territory. The data were 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 acute care Discharge Abstract Database. Coverage for this study is limited to the following jurisdictions:

- Manitoba and Yukon: do-not-resuscitate (DNR) reporting only.
- Nova Scotia, Ontario and British Columbia: both do-nothospitalize (DNH) and DNR reporting.

Ontario and Yukon coverage includes most long-term care facilities that receive public funding, whereas data are limited to participating facilities in other provinces, resulting in predominantly Ontario-based reporting.

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 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 DNR 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 (N = 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.

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



Why are residents with a DNH directive hospitalized?

The top 10 causes of hospital stays were responsible for nearly 60% of all hospital admissions, including:

infections such as pneumonia, urinary tract infections and sepsis (infection of the bloodstream) – 21%;

- trauma or injury, such as a broken hip sustained in a fall 20%;
- exacerbation of chronic conditions such as heart failure and chronic obstructive pulmonary disease - 9%; and
- end-of-life or palliative care 6%.

Nearly half (47%) of the hospitalizations for residents with a DNH directive were potentially avoidable (Walker et al. 2009). As outlined in Table 1, 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%). 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.

TABLE 1. 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*, $n(\%)$	2,676 (46.3)	19,946 (45.2)
Injury case, n(%)	1,110 (19.2)	4,672 (10.6)
Palliative care§, n(%)	350 (6.1)	2,084 (4.7)
Death in hospital, n(%)	1,230 (21.3)	9,570 (21.7)

^{*}See Walker et al. (2009).

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.

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

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

The factors that were associated with transfers to acute care hospitals for residents with a DNH directive were similar to those of other studies on the hospital transfer of long-term care residents (Biola et al. 2010). Individuals who were relatively young (younger than 90), more independent and more stable in health were more likely to be admitted to hospital.

Conclusions and discussion

There is an opportunity to raise awareness with residents and families about advance care planning. Research shows that

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a decision to transfer a resident to hospital despite the person's advance wishes is often made by family members (Biola et al. 2010). The stress of a hospital transfer and potential risk of infection can often outweigh the perceived benefits of treatment (Konetzka et al. 2008; Ouslander and Maslow 2012). Sometimes, serious infections such as pneumonia can be treated in long-term care facilities, often with better outcomes for these patients (Fried et al. 1997; Thompson et al. 1997). That being said, it is up to residents and their families to decide on the best course of action.

Although a lot of progress has been made, potentially avoidable hospitalizations can be further reduced in long-term care settings. Initiatives to improve the quality of long-term care and avoid unnecessary hospitalizations, such as Ontario's Residents First initiative (Health Quality Ontario, n.d.), 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.

Results also suggest that palliative care services can be enhanced in long-term care. Palliative care is one of the few areas that did not experience a decline in hospital transfers over the study period. Although 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 (Quality Hospice Palliative Care Coalition of Ontario 2010; Williams et al. 2010).

These findings and others, as well as more information on data and methods, are described in detail in a recent CIHI publication, A snapshot of advance directives in long-term care: How often is do not done? This report is available free of charge at: https://secure.cihi.ca/free_products/advance_directive_ often_do_not_done_en.pdf>. HQ

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