ADVANCE DIRECTIVES AND HEALTH CARE COSTS AT THE END OF LIFE

Request: This TechNote was prepared in response to a request from the Chinook Health Region, Alberta about the published scientific evidence on the impact that the use of advance directives could have on health care costs near the end of life. The target population is represented by senior’s residents in long-term care facilities.

BACKGROUND

Demographic statistics

Canada has a rapidly growing aging population. Presently 12.5% of the Canadian population is 65 years or older, and this figure is expected to double by 2036. In Alberta, 9.8% of the population is over 65 years of age. This number is expected to increase to 14.5% by 2016, and by 2031, approximately one in four Albertans will be over the age of 65 years.

Approximately 4.2% of Albertan seniors were in 157 long-term care facilities in 1999. It is assumed that nursing homes will play an increasingly important role in the care of the dying. Of all deaths in the United States in 1993, 20% occurred in nursing homes, and that proportion is expected to grow to 40% by 2020.
Costs associated with treatment at the end of life

Medical care costs

Medical care costs have steadily increased in most Western countries and as a result there has been increasing pressure to allocate resources appropriately and to reduce the use of unnecessary or ineffective services. Health care is not consumed evenly across one’s lifespan. The most intensive use of services tends to be at the very end of life. That is why there are researchers who consider that health care costs are a function of the year of death rather than age. It is the high expenditures on health care just prior to death combined with the higher probability of death as we age that drives health care spending, not the age of the population.

There is much debate over what causes the rise in medical costs at the end of life. Among the factors that contribute to the higher costs associated with terminal care are: development and increasing use of complex technological interventions, heroic efforts at rescue, intensive utilization of cardiopulmonary resuscitation, and the use of different resources with little potential for benefit thereby increasing the length of stay in intensive care units.

In the United States it is estimated that approximately 30% of the annual Medicare budget is spent on 5.9% of Medicare enrollers who die within one year. An estimated 18% of lifetime medical cost expenditures are incurred during the last year of life, about 50% for care in the last 60 days, and about 40% goes for care given in the last 30 days of life. A large proportion of these costs result from treatments that have questionable efficacy and utility.

The National Leadership Commission on Health Care has estimated that the United States could save as much as $US 22 billion per year by eliminating inappropriate or ineffective care. Cost savings might result not from a few high-cost outliers but from many patients choosing to forgo common therapies, such as dialysis, antibiotics, or tube feeding. Moreover, many low-cost ancillary services will also be saved if patients’ choose to forgo treatment when there is little chance of survival.

A review of studies on cost savings at the end of life published in the United States, suggested that these savings are likely to be small, 10% or less during the last 12 months of life but it is possible to achieve huge medical savings near the end of life by reducing the use of medical tests and technology over many months before death. Also, the author suggested that in order to achieve important savings a radical transformation in the American culture and values has to occur, such as acceptance of death as a natural and inevitable part of life.
Medical care costs in nursing homes and outpatient facilities

There are authors who suggest that reducing care at the end of life may affect acute care and thus Medicare costs, but it is unlikely to decrease nursing home and other outpatient costs, and may even increase these costs. Even low-cost technology for care that is administered outside of hospitals is not cheap. The strategy of shifting patients from apparently high-cost to lower cost settings does not result in appreciable cost savings in the opinion of other authors. They considered that the apparent economic benefit of alternative care for dying critically ill patients represents cost shifting rather than cost saving when patients do not die but instead continue to receive care elsewhere. In an attempt to reduce health care costs in the United States, patient care was shifted from acute care hospitals to short stay surgical centres and nursing homes, between 1980 and 1995. This policy was associated with a decrease in inpatient acute care hospital stays by 40% during this period. However, instead of declining, overall hospital costs increased in part because a significant proportion of the anticipated savings were fixed costs. The authors presented the example of a county hospital in the United States where the fixed costs included capital expenditures, employee salaries and benefits, building maintenance, and utilities. Variable costs included salaries for health care professionals and patient care supplies, diagnostic and therapeutic supplies, and medications. In this example, the total hospital budget in 1993 was $US429 million of which 84% was represented by fixed and 16% by variable costs. In the case presented, the majority of costs in providing hospital services, including those in the intensive care unit were fixed and not amenable to cost savings through reducing length of stay unless beds were closed and personnel were released.

Patients’ preferences and medical care costs at the end of life

Patients’ preferences at the end of life vary and different surveys showed that many older adults would not want aggressive treatment if it was not likely to be helpful. One study showed that when people were asked to imagine themselves incompetent with a poor prognosis, they decided against life-sustaining treatments about 70% of the time. In another study, it was estimated that approximately 80% of patients would refuse life-sustaining therapy if they were in a persistent vegetative state.

Hospital and one-year costs were higher for patients who believed that they were receiving more aggressive care as reported in the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT). The difference in costs between patients receiving life-extending treatment and those receiving care focused on palliation was $US 40,000 per patient over one year. It appeared that physician awareness and adherence to treatment preferences was the critical determinant for this difference. Other researchers have shown that even if patients...
requested palliation instead of aggressive care, physicians seemed to poorly predict their patients’ preferences or worse, they were actively ignoring them. It was assumed by several researchers that advance directives (ADs) have the power to prevent unnecessary and unwanted treatments and may be effective in reducing some of the costs with terminal care. Also, it was hypothesized that if an intervention enhanced a person’s right to choose, dying persons would not opt for technological and costly medical care, physicians would honor that choice, alternative palliative care would be less costly, and an ethically defensible saving of wasted resources would result.

**Advance Directives**

An advance directive (AD) is a statement defining a patient’s legal rights and preferences to accept or refuse end-of-life medical treatment in case of incapacity. ADs were developed with the aim to increase patients’ autonomy, and informed decision and to provide high-quality care at the end of life. There are two major groups of ADs: instructional and proxy directives. Instructional directives are at times referred to as living wills (LWs), end of life instructions, or treatment directives. Proxy directives are at times referred to as durable power of attorney for health care (DPAHC), mandate for health care, appointment directives, and substitute decision maker for health care or personal directive agents.

The LW is a legal document that describes an individual’s specific instructions about their desire to have or not to have certain life sustaining procedures (such as cardiopulmonary resuscitation, mechanical ventilation, tube feedings, antibiotics treatment, etc.). It is administered for the purpose of prolonging life when the individual is permanently incapacitated and unable to voice those preferences.

The DPAHC, also called the “health care proxy”, specifies a proxy decision maker selected by the individual to make health care decisions on their behalf when they should become terminally ill or incapable of communicating personal wishes to be placed or not on life support.

Do Not Resuscitate (DNR) is a written order AD. It specifies a patient’s request not to receive cardiopulmonary resuscitation or intubation.

The majority of ADs used to instruct health care professionals to withdraw or withhold medical treatments are also used to request medical treatments. An AD only comes into effect when an individual is incompetent to make their own health care decisions.

There are many different ADs available in Canada. It has been recommended that a combined document which includes both a LW and a power of attorney for health care would provide the best assurance that critical care patients’ desires concerning medical treatment will be respected.
The Let Me Decide Health and Personal Care Directive was developed by Molloy and has been used in Ontario nursing homes. This document consists of both instructional and proxy components, providing a range of health care choices for life-threatening illnesses, cardiac arrest, and feeding. The same approach was used by the Vancouver Island Health Authority in British Columbia to educate and encourage people to document their choices for the type of medical care they want or do not want to receive should they become incapable of making those decisions themselves.

**LEGISLATION**

In the United States, the Patient Self-Determination Act (PSDA) became effective in 1991. It required all hospitals and other institutions/facilities certified by the Medicaid and Medicare programs to inform patients about the availability of ADs. Patients were also provided with written information about their options and were given the opportunity to complete a LW and/or a DPAHC. While ADs are available in Canada, there is no legislative pressure for hospitals to promote the concept of the ADs as that which exists under the PSDA in the United States. Both the Canadian Medical Association (1992) and the Canadian Nurses Association (1994) support the concept of ADs. Provinces such as Alberta, British Columbia, Ontario, Prince Edward Island, and Saskatchewan have more or less relevant legislation in this area. The Personal Directive Act became law in Alberta in December 1997 and covers broader aspects of personal matters than ADs that only focus on issues regarding health and medical treatments.

The percentage of Canadian patients that might use ADs and the costs that could be saved by the health care delivery system if an AD was used by a particular patient is information that is currently not collected.

**ADs AND HEALTH CARE COSTS**

Sugarman et al. measured costs and benefits of the PSDA implementation in hospitals in the United States. The study showed that the incremental start-up cost for one institution’s response to the PSDA was estimated to be $US 49,304 ($US 1.31 per admission) and the total implementation cost of the program was $US 114,528. The national incremental start-up costs for hospitals to implement the PSDA was estimated to be between $US 43,625,114 and $US 101,569,922. The authors considered that many of the PSDA’s potential benefits and costs were intangible and therefore difficult or impossible to quantify. Examples of intangible benefits for patients and their families included enhancement of their autonomy and respect for their preferences, decreased suffering due to undesired care, and increased comfort in not being a burden. Intangible costs included the possibility of actual or perceived discrimination at the time of admission, increased bureaucratized medical decision making adding more
forms, and emotional difficulty experienced by the health care workers from frequent discussions about ADs.

Kessler and McClellan assessed the consequences of ADs on the medical care of elderly Medicare beneficiaries who died between 1985 and 1995 in the United States. In this study, the implementation of a law which enhanced incentives for compliance with ADs reduced the probability of dying in an acute care hospital in the last month of life but was not associated with any savings when compared to a law requiring delegation of treatment decisions in the absence of an AD, in the United States.

**Evidence From Studies on Costs Associated with ADs in Nursing Home Facilities**

No economic analysis was identified by the search strategy (Appendix A) that presented results on costs and consequences on patients who completed ADs. Only one RCT focused on how ADs used in nursing home facilities impacted health care costs (Table 1 Appendix B).

Molloy et al. pair-matched six nursing homes in Ontario, Canada, and randomized one of each pair to systematic implement an AD program (Let Me Decide [LMD]) or to continue with existing policies (Do Not Resuscitate [DNR] or another living wills directives, power of attorney, or no hospitalization), and measured satisfaction with care, costs associated with admission into hospital, and mortality, for all eligible residents in the homes. The authors collected prospective data for 18 months starting on the date the first LMD directive was completed and retrospective data for 12 months prior to that date. The study enrolled only homes with health care choices documented for less than 25% of their residents and by the end of the follow up 70% of residents in the intervention homes and 57% in the control homes had an AD. Compared to the retrospective period, when hospitalizations and hospital days were similar in the intervention and controlled homes, in the prospective period, the adjusted risk of hospitalization and the number of hospital days were statistically significant lower in the intervention home residents than controls (p = 0.001 and p = 0.01).

The total cost for each person was calculated based on health care use and unit costs of services for both the intervention and control homes. The cost difference between the intervention and control homes was consistent across all pairs of homes and was statistically significant. The hospital cost per resident (combined homes) was $Cdn 1,772 for intervention homes and $Cdn 3,869 for control homes (p = 0.003). The total health care costs (combined homes) were significantly lower for residents in the intervention homes $Cdn 3,490 vs. $Cdn 5,239 in the control homes (p = 0.01). Nursing home drug costs per resident (combined homes) were higher but not statistically significant in the intervention homes compared to control homes ($Cdn 1,606 vs. $Cdn 1,370, p = 0.149). The authors concluded that a systematic application of an LMD AD program in nursing homes would decrease overall health care services utilization.
by reducing hospitalizations without affecting satisfaction or mortality. Also, systematic application of ADs in a nursing home requires other resources such as training of nursing home personnel on ADs and palliative care and providing the nursing home with equipment for symptom relief and terminal care at the end of life. The authors did not provide details about the costs of these supplementary resources.

**DISCUSSION**

Coordinated care of dying patients has the potential to cut costs at different levels of the health care system in the view of many authors, however, there are authors who considered that a substantial savings may to be achieved through initiating major changes in the financing and delivering of health care in general rather than selectively on medical care at the end of life. There is a need for more research to document these points of view.

Measuring the impact of ADs on health care costs at the end of life seems to be a demanding process, due to some methodological aspects:

- Selection bias when choosing the study population. Patients who complete ADs are considered different from other patients. They prefer to avoid aggressive care and medical interventions at the end of life, and refuse care and interventions near death.

- The severity of disease may influence patients’ and physicians’ decisions.

- The time frame of assessment. Evaluating costs in shorter periods, prior to the patient’s death yields higher savings, while studies that assess costs over longer time periods, such as 6 to 12 months of life seem to report smaller savings.

- The type of medical costs assessed. There are a variety of sources used to obtain financial data and different calculation methods. ADs may reduce direct medical costs by shifting these costs to the family.

There are authors who considered that completing directives in advance by competent patients who are not facing life or death decisions presents ethical dilemmas. It was supposed that such persons will not make the same decisions as in case of incapacity or incompetence with life-threatening illnesses. If directives completed in advance are not updated they may express wishes that are no longer valid. There are also questions about using or interrupting the use of technology and medical devices near the end of life, such as: is it ethical to sustain a patient’s life through the use of medical devices? or is it ethical to not keep a patient alive through the use of technology? Ongoing communication between patients and physicians is important to implement patients’ wishes.
CONCLUSIONS

ADs were developed with the aim to increase patients’ autonomy, decision making, and well-being at the end of life. Also, it was assumed that ADs may be effective in decreasing health care costs, if signed prior to incompetency by those completing ADs choosing less intensive interventions.

ADs are available in Canada but there is no legislative pressure for hospitals or other medical institutions to promote the concept as exists under the PSDA in the United States. The percentage of Canadians that might use ADs and the costs associated with ADs use is information that is currently not collected.

Authors of a Canadian study considered that if ADs are to be mandated by legislation in Canada, the subject would be politically controversial and might increase the debate around the legal and ethical aspects. However, the level of potential savings that may be obtained with the implementation of ADs seems to indicate a need to have the requisite debate about their introduction at the earliest possible opportunity in the opinion of the authors.

Economic analysis to provide information on cost-effectiveness, cost-benefit and/or cost-utility obtained with different types of ADs would be useful to confirm the accuracy of the hypothesis which assumes that ADs improve the quality of life, well-being, and autonomy of patients and also decrease the costs with health care.

The cost impact of the various types of ADs seems to be different and there is a need for more research to clarify these results and also to establish the right time for completion of these documents from the beneficial (patient and family), ethical, and economical perspectives.

Information was obtained from one RCT conducted in Ontario, Canada which focused on cost with care for seniors living in nursing homes. The authors of this RCT concluded that a systematic application of a LMD AD program can decrease the health care costs substantially by reducing hospitalizations without affecting satisfaction or mortality. This program provides a range of health care choices for life-threatening illness, cardiac arrest, and feeding. Interestingly, DNR orders and other documents (living wills, power of attorney) completed by residents in the comparative group were not associated with a reduction in the total costs for health care. The authors emphasized the need for other resources if LMD AD program is applied extensively in Canada which would involve training of nursing homes personnel on ADs and providing palliative care and equipping nursing homes with technologies for symptom relief and terminal care at the end of life. These costs were not taken into account in the present analysis.
Based on the results of one Canadian study the application of the LMD AD program in nursing homes would decrease resource use if there is compliance with the wishes of the nursing home resident. The projected savings estimated in this study is an over estimation since implementation and program operational costs were not included. As well, these types of studies need to measure other intangible costs/benefits such as the well being and autonomy of nursing home residents and the impact of an AD program on the family members.

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Alberta Heritage Foundation for Medical Research

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Technotes are brief reports, prepared on an urgent basis, which draw on limited reviews and analysis of relevant literature and on expert opinion and regulatory status where appropriate. They are not subject to an external review process.
APPENDIX A: SEARCH AND METHODOLOGY

Search

The literature search was conducted by the AHFMR Research Librarian (Ms. Liza Chan) between March 2 and 19, 2005. Major electronic databases used include: The Cochrane Library, NHS Centre for Reviews and Dissemination (CRD Databases: NHS EED, HTA, DARE), EMBASE, CINAHL, Web of Science and PubMed. In addition relevant library collections, web sites of practice guidelines, regulatory agencies and other HTA related agencies were searched. Internet search engines were also used to locate grey literature. Medical Subject Headings (MeSH) terms relevant to this topic were: advance directives; advance directive adherence; resuscitation orders; costs and cost analysis; living wills. Other keywords used were: personal directive(s); medical directive(s); health care directive(s); expenditure(s); healthcare directive(s); economic evaluation; health economics; economic aspects of illness; cost(s).

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<td>The Cochrane Library</td>
<td><a href="http://www.thecochranelibrary.com">http://www.thecochranelibrary.com</a></td>
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2 exp Living Wills/  
3 "medical directive$".mp.  
4 "advance directive$".mp.  
5 "personal directive$".mp.  
6 "health care directive$".mp.  
7 "healthcare directive$".mp.  
8 exp "costs and cost analysis"/  
9 "economic aspects of illness"/  
10 exp Health Resource Allocation/  
11 cost.mp.  
12 costs.mp.  
13 costing$.mp.  
14 Budgets/  
15 1 or 2 or 3 or 4 or 5 or 6 or 7  
16 8 or 9 or 10 or 11 or 12 or 13 or 14  
17 15 and 16 |
| EconLit   | EBSCO    | 2005-03-09 | (cost OR costs OR costing* OR expenditure*  
OR econom* OR budget* OR financ*) AND  
("advance directive" OR "living will" OR "medical directive" OR "personal directives" OR "power of attorney" OR "resuscitation order") |
| ABI Inform | Proquest | 2005-03-09 | ((cost OR costs OR costing* OR expenditure*  
OR econom*) AND ("advance directive" OR "living will" OR "medical directive" OR "resuscitation order") |
| EBM Reviews - ACP Journal Club | Ovid | <1991 to January/February 2005> | 1 "medical directive$.mp.  
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5 "healthcare directive$.mp.  
6 living will$.mp.  
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9 costing$.mp.  
10 economic$.mp.  
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14 12 and 13 |
| Web of Science SSCI & SCI | ISI | 2005-03-12 | TS=((cost OR costs OR costing* OR expenditure* OR econom* OR budget* OR financ*) AND (advance directive* OR personal directive* OR medical directive* OR living will*)) |

**Library Catalogues**

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OR econom$ OR budget$ OR financ$) AND  
("advance directive" OR "living will" OR  
"medical directive$" OR "personal directive$" OR  
"power of attorney" OR "resuscitation order$") |
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**Guidelines**

**Clinical Trials**

| Clinicaltrials.gov (US) | Clinicaltrials.gov | 2005-03-07 | (“advance directive”* or “personal directive”* or “living will”*) AND (cost* OR economics) |

**Agencies**

| Health Canada              | http://www.hc-sc.gc.ca/english                | 2005-03-12 | Phrase search: advance directive* ; personal directive* |
| US Food and Drug Administration | www.fda.gov                                  | 2005-03-08 | “advance directive”; “personal directive” |
| Aetna Clinical Policy Bulletins | http://www.aetna.com/about/cov_det_policies.html | 2005-03-03 | [browse the publication list] |
| CCOHTA                      | www.ccohta.ca                                | 2005-03-08 | Advance directive; personal directive |
| ECRI                        | www.ecri.org                                 | 2005-03-09 | Advance directive* AND cost* ; personal directive* AND cost* |
| AETMIS                      | http://www.aetmis.go.uv.qc.ca                | 2005-03-09 | [browse the publication list] |
| Ontario Medical Advisory Secretariat | http://www.health.gov.on.ca/english/providers/program/mas/mas_mn.html | 2005-03-09 | [browse the publication list] |
| McGill HTA unit             | http://www.mcgill.ca/tau/                    | 2005-03-09 | [browse the publication list] |
| US National Cancer Institute | www.cancer.gov                              | 2005-03-12 | Advance directive cost |
| Cabot                       | http://cahspr.ca/cabot/                      | 2005-03-12 | Database not available |

**Web Search Engines**

| Google                       | http://www.google.com                        | 2005-03-09 | “advance directive”* “economic analysis”; “advance directive” *cost analysis”; “personal directive” *economic analysis” *personal directive” *cost analysis” |
| Althetweb                    | www.alltheweb.com                            | 2005-03-09 | “advance directive” *economic analysis”; “advance directive” *cost analysis”; “personal directive” *economic analysis” “personal directive” *cost analysis” |

**Note:** † **“*”, “#”, and “?” are truncation characters that retrieve all possible suffix variations of the root word e.g. surg* retrieves surgery, surgical, surgeon, etc. Semicolons “;” are used when terms are entered separately.
Methodology
The studies identified by the search strategy were retrieved, reviewed, and assessed to determine the relevancy of each study. Studies were included if they met the following criteria:

Study design: systematic review, randomized controlled trial, prospective or retrospective comparative study that provided a quantitative measure of costs associated with completion of advance directives, or that compared cost with advance directives with cost with no intervention;

Intervention: advance directive (Living Will, Durable Power of Attorney for Health Care, Let Me Decide order, Do Not Resuscitate order);

Study population: seniors 55 years of age and older, residents in a long term care facility;

Setting: non-acute health care settings (such as nursing homes and senior centres);

Outcome measurements: costs and (if available) consequences associated with completion of an advance directive;

Publication limits: studies published from 1990 onwards;

Language: English;

Abstract of the study: available.

One RCT met the inclusion criteria. The study compared health care costs for the treatment of patients who were included in the Let Me Decide advance directive program with costs for the treatment of patients who did not receive the intervention program.
APPENDIX B. TABLE 1 COSTS WITH ADs IN NURSING HOMES

<table>
<thead>
<tr>
<th>Study</th>
<th>Study Population Intervention</th>
<th>Source of Financial Data</th>
<th>Results, Authors’ Conclusions</th>
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<tr>
<td>Molloy et al. 24</td>
<td></td>
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<td>Mean costs per resident participating in the prospective study:</td>
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<td>2000, Canada RCT</td>
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<tr>
<td>June 1, 1994 - August 31, 1998</td>
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<td><strong>Study population:</strong></td>
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<td>N = 1292 residents in 6 Ontario nursing homes (≥ 100 residents each), only n = 818 completed ADs.</td>
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<td><strong>Intervention group:</strong></td>
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<tr>
<td>Three intervention homes (N₁ = 444): n₁ = 395 LMD* n₂ = 27 DNR n₃ = 22 Other¶ Mean age (range): 79.40 to 83.63 years</td>
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<tr>
<td><strong>Control group:</strong></td>
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<tr>
<td>Three control homes (N₂ = 374) n₁ = 0 LMD* n₂ = 266 DNR n₃ = 108 Other¶ Mean age (range): 83.44 to 84.80 years</td>
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<td>*LMD AD program provided by registered nurses (education of staff in local hospitals and nursing homes, residents, and families about ADs; offer ADs for life-threatening illness, cardiac arrest, and nutrition)</td>
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<td>¶Living wills, power of attorney, no hospitalization</td>
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<td>Prospective data for 18 months on the date the first LMD directive was completed. Information from a hospital participating in the Ontario Case Costing Project: unit cost of hospital tests, procedures, emergency department visits, and patient days in a hospital by type of ward and type of diagnosis; The Ontario provincial fee schedule for services: cost estimates for physician consultations and assessments, daily hospital visits, diagnostic procedures, and surgical operations The Ontario Ministry of Health price list: stock medications cost The Ontario Drug Benefit formulary non-stock prescription medication costs Local pharmacies survey nonprescription non-stock drug prices</td>
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<tr>
<td>Hospitalization costs§</td>
<td>3,869</td>
<td>1,772</td>
<td></td>
</tr>
<tr>
<td>Nursing home drug costs¶</td>
<td>1,370</td>
<td>1,606</td>
<td></td>
</tr>
<tr>
<td>Total costs‡</td>
<td>5,239</td>
<td>3,490</td>
<td></td>
</tr>
</tbody>
</table>

*Combined results from homes (all three pairs)

§p=0.003, ¶p=0.149, ‡p=0.013

The cost difference between intervention and control homes was consistent across all pairs of homes.

Systematic implementation of comprehensive and specific directives may reduce costs in institutions with a high rate of non-specific directives. The authors anticipated that systematic application of LMD would decrease overall resource utilization because staff would follow the wishes of acutely ill residents and their families and allow these residents to remain in the home.

AD – advance directive; DNR - Do Not Resuscitate; LMD - Let Me Decide; N, n – number of participants; RCT – randomized controlled trial.
APPENDIX C: ABBREVIATIONS

AD - advance directive
CI - confidence interval
DNR - Do Not Resuscitate
DPAHC - Durable Power of Attorney for Health Care
LMD - Let Me Decide
LW - Living Will
PSDA - Patient Self-Determination Act
RCT - randomized controlled trial
SR - systematic review
SUPPORT - the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments
TISS - Therapeutic Intensity Scale Score
REFERENCES


