McMaster University

McMaster
HEALTH FORUM

CITIZEN BRIEF

IMPROVING END-OF-LIFE COMMUNICATION AND DECISION-MAKING IN ONTARIO

30 NOVEMBER 2013

EVIDENCE >> INSIGHT >> ACTION

The McMaster Health Forum

For concerned citizens and influential thinkers and doers, the McMaster Health Forum strives to be a leading hub for improving health outcomes through collective problem solving. Operating at the regional/provincial level and at national levels, the Forum harnesses information, convenes stakeholders and prepares action-oriented leaders to meet a challenge creatively. The Forum acts as an agent of change by empowering stakeholders to set agendas, take well-considered actions and communicate the rationale for actions effectively.

About citizen panels

A citizen panel is an innovative way to seek public input on high-priority issues. Each panel brings together 10-14 citizens from all walks of life. Panel members share their ideas and experiences on an issue, and learn from the available research evidence and the views of others. The discussions of a citizen panel can reveal new understandings about an issue and spark insights about how it should be addressed.

About this brief

This brief was produced by the McMaster Health Forum to serve as the basis for discussions by the citizen panel on how to improve end-of-life communication and decision-making in Ontario. This brief includes information on this topic, including what is known about:

- the underlying problem;
- three possible options to address the problem; and
- potential barriers and facilitators to implementing these options.

This brief does not contain recommendations, which would have required the authors to make judgments based on their personal values and preferences.

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Less than 50% of Canadians had a discussion with a family member or friend about their healthcare treatment wishes if they were ill and unable to communicate.

The context:

Why is improving end-of-life communication and decision-making a high priority?

>> Despite the desire of many Ontarians to achieve greater control over decisions about end of life, most do not have any plan about end-of-life care.

Thousands of people must cope each year with the burden of end-of-life care decisions. In 2011-2012, more than 252,000 Canadians died (more than 96,000 of them in Ontario), and many more are affected by these deaths. It is estimated that each death affects the immediate well-being of approximately five other people, or more than 1.25 million Canadians each year.(20)

Despite the desire of many people to achieve greater control over decisions about end-of-life, most do not have a plan for end-of-life care. In fact, a national poll conducted in 2012 found that: (23)

- less than 50% of Canadians had a discussion with a family member or friend about their healthcare treatment wishes if they were ill and unable to communicate;
- only 9% had ever spoken to a healthcare provider about their wishes for end-of-life care;
- more than 80% do not have a written plan for end-of-life care; and
- only 46% have chosen a substitute decision-maker who could make decisions on their behalf if they were unable to communicate.

We will all be confronted with end-of-life care decisions at some point in our lives, either for ourselves or for a loved one. The number of people facing these complex decisions is likely to increase significantly in coming years because of three trends:

- the aging population;
- the growing number of patients with life-limiting chronic conditions and complex care needs; and
- new advances in healthcare that promise life-saving or life-prolonging possibilities.

Many organizations are working to improve end-of-life communication and decision-making in Ontario (and across Canada more generally). However, Ontario does not yet have a comprehensive end-of-life care strategy like other provinces, such as British Columbia and Quebec.(5;25)

In May 2013, the Ontario Medical Association (OMA) announced that it will play a leading role in promoting the development of a provincial strategy to improve care at the end of life.(26) The OMA represents more than 34,000 physicians, residents and medical students across the province. The OMA is seeking the views and experiences of Ontario citizens in order to guide its efforts.

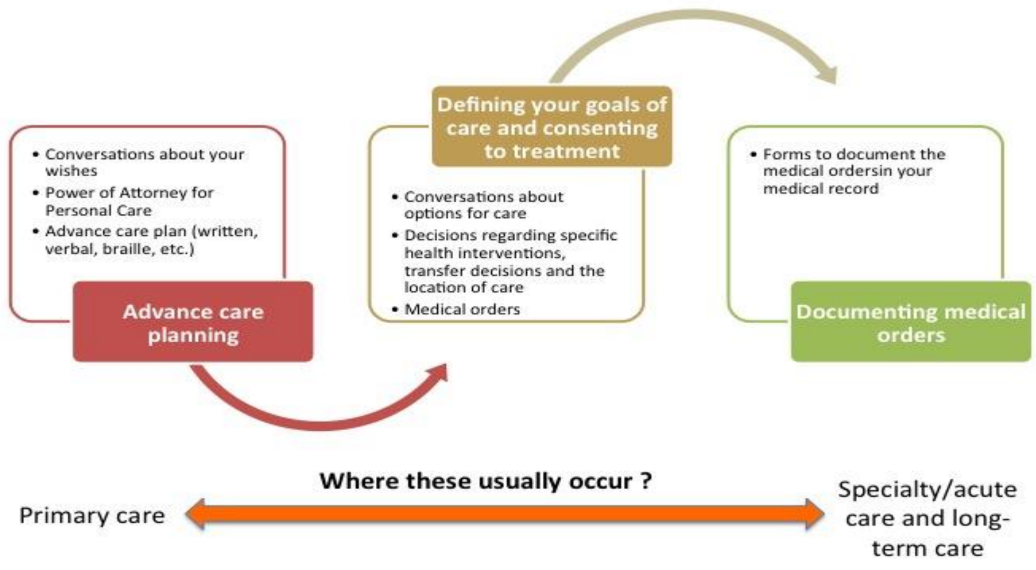
In this section of the brief, we define end-of-life communication and decision-making, explore the benefits of improved communication and decision-making, and review current laws in Ontario.

What is end-of-life communication and decision-making?

End-of-life communication and decision-making can be broadly defined as the various conversations that take place and decisions that are made about death and dying. These conversations and decisions often involve three different processes: (1)

- advance care planning;
- defining the goals of care and consenting to treatment; and
- documenting medical orders.

Each process is described below in more detail.



Adapted from the Canadian Researchers at the End of Life Network (1)

Advance care planning

The first process is called "advance care planning." Advance care planning is a process of reflection and discussion about your wishes for end-of-life care. You can reflect and discuss with many people, including your family, your friends and your healthcare providers.

Advance care planning may result in two things. First, you can name a person who will provide consent for health or personal care if you become incapable of making your own decisions. This person is your substitute decision-maker. In Ontario, the only legal document that can authorize the appointment of a substitute decision-maker for healthcare decisions is the Power of Attorney for Personal Care. However, if you do not prepare a Power of Attorney for Personal Care and become incapable of making personal care decisions, the law has established a hierarchy of substitute decision-makers who can be authorized to act in this role:(9)

1. your spouse or common-law partner;
2. your child (if 16 or older) or parent;
3. your brother or sister;
4. any other relative by blood, marriage or adoption; and
5. the Office of the Public Guardian and Trustee (last resort).

A second possible outcome is the development of an advance care plan where you express your wishes for treatment and care at the end of life.(1) The advance care plan can provide direction to your substitute decision-maker (<u>not</u> to your healthcare providers) in order to help him/her feel confident in making future decisions on your behalf if you become incapable of making decisions yourself.(8;9)

Advance care planning is not just for the elderly or those diagnosed with life-limiting conditions and terminal illnesses. You can develop an advance care plan at any stage in your life, even

Glossary

Advance care planning

Advance care planning is a process of reflection and discussion about your wishes for end-of-life care.(1)

Capacity

Capacity refers to the ability to understand the information that is relevant to making a decision about a treatment and to appreciate the potential consequences of a decision (or lack of a decision).(4)

Chronic disease

Chronic diseases are "diseases of long duration and generally slow progression."(7) Examples of chronic diseases include cancer, chronic respiratory diseases, diabetes, heart disease and stroke.

End-of-life care

End-of-life care refers to care that is provided to help those with advanced, progressive and incurable illnesses (including advanced life-limiting chronic disease) to live as well as possible until they die. It supports the needs of patients, families and caregivers throughout the last phase of life and into grief and bereavement. End-of-life care also includes the management of pain and other symptoms, as well as the provision of psychological, emotional, social, spiritual and practical support.(18)

Glossary

Informed consent

Before consenting to (or refusing) a treatment, a person must receive information that a reasonable person in the same circumstances would want about:

- the nature and purpose of the proposed treatment;
- the risks and side effects of the treatment;
- alternative courses of action; and
- the consequences of not having the treatment.

A person must also receive additional information about these issues if requested.(4)

Life-limiting illness

Life-limiting illnesses are "illnesses that can be reasonably expected to cause the death of the individual within a foreseeable future."(5)

Substitute decision-maker

A substitute decision-maker is a person who is appointed to make decisions about health or personal care on behalf of someone who is incapable of making their own decisions.(10)

Terminal illness

A terminal illness is "an incurable medical condition caused by injury or disease. These are conditions that, even with life support, would end in death within weeks or months."(17)

if you are healthy.(27) Ideally, advance care planning is done in a primary care setting (such as your family doctor's office), which is typically your first point of contact with the healthcare system.

Defining goals of care and consenting to treatment

You may arrive at a point in your life where you are at high risk of dying within the next 12 months and you are receiving end-of-life care. This leads us to the second process, which is called here "defining goals of care and consenting to treatment."(1)

This process usually occurs in a setting where end-of-life care is provided (for example at home, in a hospice, or in a hospital). It involves a conversation with your healthcare providers about your prognosis (that means the likely outcome of your health conditions), the risks and expected outcomes of various treatment options, and your wishes for end-of-life care. This conversation will help you define clear and achievable goals of care (for example, avoiding a premature death, maintaining or improving functionality, prolonging life, relieving pain, staying in control, or supporting families and loved ones).

Defining your goals of care will help to guide your decisions (or the decisions made by your substitute decision-maker if you are incapable of making your own decisions) regarding the type of care you receive (e.g., medication, surgery) and where you receive it (e.g., home or hospital). These decisions will eventually get summarized in (or become enacted through) a medical order. A medical order is a type of document that lets other healthcare providers know what the patients' decisions are that may guide current care (e.g., give primary focus to comfort measures) or future care (e.g., use cardiopulmonary resuscitation in the event of a heart attack).

It is important to know that this process does not assume that your advance care plan is automatically accepted as medical orders. Your advance care plan is an expression of your wishes for end-of-life care. They are not legally-binding instructions. Your healthcare providers must always seek your consent (or the consent of your substitute decision-maker if you are incapable of making your own decisions) before providing specific treatment or care.(1)

Documenting medical orders

The third process is documenting the medical orders resulting from previous planning and decisions. Various forms and checklists are commonly used by healthcare providers to document medical orders or the 'level of care' that you should receive at the end of life.(1)

What are the benefits of improved communication and decision-making?

There are many benefits of improving end-of-life communication and decision-making. For example, advance care planning can prepare you to make the best possible decisions for end-of-life care.(28) A guide developed by the government of Ontario also highlights that advance care planning can be beneficial to everyone concerned: "[it is] easier for you, because you'll have the confidence that your wishes are known; easier for those close to you, because it can reduce their stress in making tough decisions on your behalf; and easier for your care providers, because they'll be able to act in keeping with your wishes in an emergency."(22)

Recent studies conducted in Canada and around the world also suggest that improved communication and decision-making at the end of life could:

- improve end-of-life care in general;(29)
- improve patient and family satisfaction (e.g., avoiding the use of unwanted intrusive medical interventions when there is little hope for a meaningful recovery, feeling at peace,

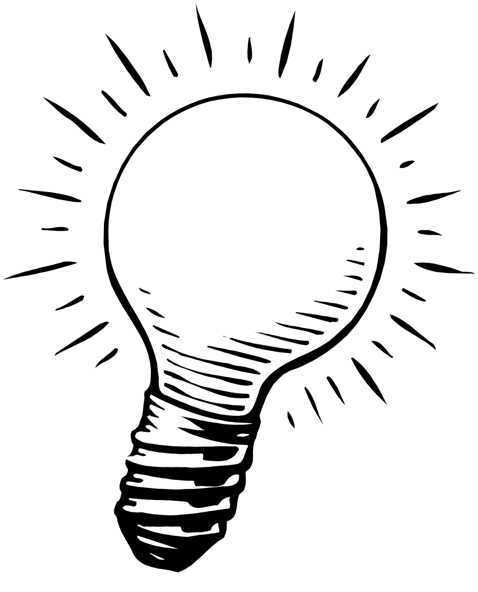
feeling that providers took a personal interest in them, and receiving timely information about their condition);(29-31)

- reduce stress, anxiety and depression in surviving relatives;(29)
- ensure that the patients' preferences for care at the end of life match the documentation of those preferences in their medical records;(32) and
- help to develop individualized approaches for end-of-life care that are aligned with the wishes and needs of each patient.(31)

What are the laws related to end-of-life communication and decision-making in Ontario?

Laws governing end-of-life communication and decision-making vary across Canada. In Ontario, the two most important laws are the Health Care Consent Act (4) and the Substitute Decisions Act.(10) These laws govern consent and capacity to make healthcare decisions. The following box highlights 10 things to keep in mind that are specific to the laws in Ontario.

An administrative tribunal, called the Consent and Capacity Board, also has the authority to hold hearings dealing with the two Ontario laws. For example, if someone has been declared incapable to make health and personal care decisions, this person can appeal before the Consent and Capacity Board.



>> Ten things to keep in mind about current laws in Ontario

- A person has the right to consent to (or refuse) a treatment, admission to a healthcare facility or personal assistance services, if they have the mental capacity to do so.
- Completing an advance care plan is voluntary.
- Completing an 'advance care planning' form or 'levels of care' form cannot be a requirement for the admission into a healthcare facility.
- Nobody can make an advance care plan on your behalf.
- An advance care plan can take many valid forms in Ontario: written, verbal, braille, video and any other means that you may use to communicate.
- An advance care plan, no matter how specific, is an expression of your wishes and it cannot replace informed consent regarding healthcare decisions, which must be sought by healthcare providers from you or your substitute decision-maker if you become incapable.
- An advance care plan provides direction to your substitute decision-maker, not the healthcare providers (with the exception of an emergency).
- Healthcare providers are only allowed to provide treatment without obtaining consent in case of an emergency, but they are required to follow any known wishes that are applicable to the circumstances.
- Your substitute decision-maker is required to follow your wishes when giving or refusing consent, but also must determine if your wishes are applicable and relevant to the treatment decisions to be made, and must interpret what you intended and meant by your wishes.
- The only legal document that can authorize the appointment of a substitute decision-maker for healthcare decisions is the Power of Attorney for Personal Care.

For more information about the legal context: (8;9)

Box 1

86% of Canadians have never heard of advance care planning.

The problem:

Why is improving end-of-life communication and decision-making challenging?

>> Improving end-of-life communication and decision-making is challenging because it deals with issues that involve the law, medicine and social values.

Taking action to improve end-of-life communication and decision-making in Ontario is challenging since it deals with many issues. In the section below, we highlight some factors that contribute to the problem and that require careful consideration.

Few people engage in end-of-life conversations with their families and friends

Few people engage in end-of-life conversation with their families and friends. Several reasons could explain this situation. One reason could be that we are a society that tries to avoid and sometimes even 'deny' death. In a report about palliative and end-of-life care, Canadian Senator Sharon Carstairs, said: "In Canada, we are a death-denying society. We avoid thinking or talking about death."(33) A 'death-denying' society implies that we individually and collectively are attempting to ignore the subject of death and behave as if death does not exist. A recent national poll conducted in 2013 suggests that the notion of a 'death-denying society' may not fully capture what Canadians are thinking about this topic.(34) This poll showed that more than 80% of Canadians say that they are comfortable discussing issues related to end-of-life care. However, the vast majority admitted that they have not made any end-of-life care plans. Among the top reasons for not making a plan are:

- 43% of respondents said that they "haven't really thought about it;" and
- 35% of all respondents, and 16% of respondents over the age of 70, said that it is not applicable yet because they are too young and healthy.

A second reason could be that people are simply not aware that there is such a thing as "advance care planning." This seems consistent with the results of another national poll conducted in 2012 that found that 86% of Canadians have never heard of advance care planning.(23)

Few people engage in end-of-life conversations with their healthcare providers

Not only do people not engage in end-of-life conversations with their families and friends, but they also do not engage in these conversations with their healthcare providers. This is an important challenge since a recent poll showed that 57% of people would like to ask their doctors for advice and information about end-of-life care.(34) Another recent poll showed that very few people had ever spoken to a healthcare provider about their wishes for care.(23)

>> First-generation immigrants

First-generation immigrants may face important challenges in engaging in end-of-life communication and decision-making. Ontario is a multicultural society with a large and vibrant immigrant population, mostly concentrated in large urban areas.(2) It is estimated that 6.5% of all immigrants (and 15.6% of immigrants who are 65 years and older) in Ontario are unable to carry on a conversation in English or French.(2)

These immigrants are likely to face significant challenges when engaging in conversations about end-of-life care with healthcare providers who are not proficient in the immigrants' mother tongues.(11)

Beyond language, culture (and religion) may shape the values and norms regarding various dimensions of end-of-life care, including the patient's and family's perspective on: health, suffering, death and dying; the use of Western medicine; the role of informal/family caregiving; providing information about the likely outcome of the illness; and the role of the patient and family in the decision-making process.(13-16) The multicultural makeup of Ontario suggests the need for culturally-sensitive end-of-life communication and decision-making to meet the needs and expectations of a growing immigrant population.

Box 2

This situation could be explained, in part, by the fact that many people do not have access to a regular physician. It is estimated that 9.2% of Ontarians do not have access to a regular physician.(35) In addition, 3.2% of sicker adults in the province do not have a regular physician or place to go for medical care.(36) This lack of access poses a significant challenge for those most in need of engaging in end-of-life conversations with a healthcare provider.

Another reason could be that many healthcare providers may not fully understand how patients make decisions.(37) Many may also lack the skills to communicate about sensitive end-of-life issues with their patients, to involve their patients in decision about the various treatment options, and to engage effectively with patients of different cultures and socio-economic backgrounds.(37)

In addition, there may be confusion among healthcare providers about who is best positioned to have advance care planning discussions with patients, who can interpret patients' wishes, who can provide consent if patients are incapable of making their own decisions, how we should collectively ensure that patients and families are in a better state to make decisions about end-of-life care, and when and how this should be done.(37)

End-of-life care issues are complex

End-of-life care issues are quite complex, as they deal with issues involving the law, medicine and social values. For example, achieving meaningful end-of-life communication and decision-making requires some degree of awareness and knowledge of current laws governing healthcare decisions. It requires knowledge of the likely progression of illness and a patient's prognosis, of life-sustaining technologies, and of the meanings of various medical orders. It also requires healthcare providers and a health system that are culturally sensitive and hence able to meet the needs and expectations of a multicultural population.

A recent national poll showed the complexity of end-of-life care issues from the public's perspective,(34) for example:

- there is no clear understanding of how end-of-life care is delivered (especially at home) and who pays for it; and
- there is confusion about various terms related to end-of-life care.

Healthcare facilities and providers are also grappling with the most effective way to accurately document goals of care and treatment decisions to align with Ontario's laws. For example, some healthcare facilities are requiring patients or their substitute decision-makers to complete advance care planning forms or 'levels of care' forms before being admitted to their facilities.(9) This practice is illegal since advance care planning must be voluntary. It cannot be a requirement for the admission into a healthcare facility, and patients have the right to express their wishes in any way they prefer.(9) In addition, these forms are often not clearly worded, and they are completed when the patients do not have all the information about the likely progression of their health conditions and the likely consequences of various care options.(9) Healthcare providers often refer to these forms when deciding on specific treatment and care, without engaging in a conversation with (and seeking informed consent from) competent patients or their substitute decision-makers. Seeking consent is a legal requirement in Ontario.(9;38)

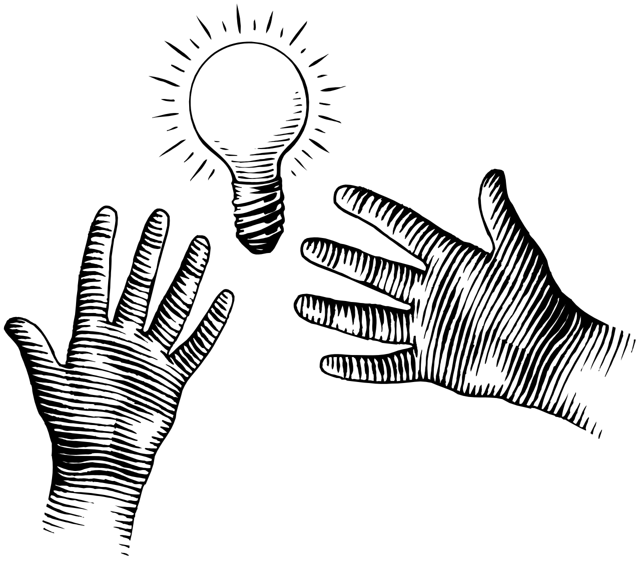
Advance care plans and expressed wishes aren’t ‘there’ when they are needed

Another challenge is the lack of availability (or knowledge) of established advance care plans and expressed wishes for end-of-life care. One reason could be that those who have completed advance care plans often do not provide clear directions to their substitute decision-maker, or they have appointed a substitute decision-maker who is unlikely to know their wishes.(39)

A fragmented health system also contributes to this problem. Most patients end up dying in a hospital setting while being cared for by healthcare providers who had no pre-existing relationship with them.(40) These healthcare providers are often unaware that a patient previously prepared an advance care plan or appointed a substitute decision-maker.(38)

Bringing about change takes time, resources and commitment from many players

There have been some promising steps taken by governments at all levels, as well as by researchers, to improve end-of-life communication and decision-making in Ontario and across Canada. These efforts aim to improve, for example, public awareness about advance care planning, education and training for healthcare providers, and standards of practice. However, efforts of this kind take time, resources and commitment from many players to bring about change. Box three provides a list of a few recent initiatives.



>> A few recent initiatives

Federal/Pan-Canadian Initiatives

- The Advance Care Planning National Framework Task Group (with support from the Canadian Hospice Palliative Care Association and other stakeholders) released a national framework for advance care planning with the aim to guide activities, programs and standards of practice across the country.(3)
- Several public awareness campaigns – Speak Up, Speak Up Ontario! and National Advance Care Planning Day (April 16th) – are underway [www.advancecareplanning.ca].
- The Canadian Researchers at the End of Life Network (CARENET) released a conversation guide to help physicians talk with patients and families about end-of-life care.(6)
- The ACCEPT study conducted by CARENET researchers is an initiative to audit the availability (or knowledge) of prior advance care plans and expressed wishes.(12)

Provincial Initiatives

- "Time to Talk about the End of Life" public education forums are organized by the Consent and Capacity Board.(19)
- Educational sessions for the public and healthcare providers about advance care planning in relation to healthcare consent are organized by the Health Care Consent and Advance Care Planning Community of Practice.(21)
- The government of Ontario produced the Guide for Advance Care Planning and a wallet card that people can carry with important information and contacts.(22)

Regional Initiatives

- A coalition of Ontario hospitals developed a quick guide for patients and healthcare providers offering information about advance care planning in relation to informed consent.(24)

Box 3

We have selected three options (among many) for which we are seeking public input.

Options:

How can we address the problem?

>> To promote discussion about the pros and cons of potential solutions, we have selected three options for improving end-of-life communication and decision-making in Ontario.

Many options could be selected as a starting point for discussion. We have selected three options (among many) for which we are seeking public input:

1. improving public awareness about end-of-life care;
2. engaging citizens in a province-wide dialogue to encourage open discussions about end-of-life care; and
3. providing citizens with the tools and information they need to engage in advance care planning.

The three options do not have to be considered separately. They could be pursued together or in sequence. New options could also emerge during the discussions.

In the following sections, we examine what is known about the pros and cons for each option, by summarizing the findings of systematic reviews of the research literature. A systematic review is a summary of all the studies addressing a clearly formulated question. The authors use systematic and explicit methods to identify, select and evaluate the quality of the studies, and to summarize the findings from the included studies.

Not all systematic reviews are of high quality. We present the findings from systematic reviews along with an appraisal of the quality of each review:

- low-quality reviews: conclusions drawn from these reviews can be applied with a low degree of confidence;
- medium-quality reviews: conclusions drawn from these reviews can be applied with a medium degree of confidence; and
- high-quality reviews: conclusions drawn from these reviews can be applied with a high degree of confidence.

Option 1 – Improving public awareness about end-of-life care

The first option aims to improve public awareness about end-of-life care in general. More specifically, it could help raise awareness about the current gaps in end-of-life services, build commitment for addressing these gaps, and empower the public to advocate for change (for example, advocating for the development of a provincial strategy).

One way to improve awareness could be to launch a social marketing campaign to raise public awareness about end-of-life care. Social marketing campaigns use communication strategies to change behaviour or beliefs relating to the acceptability of an idea by a target group in the population. Social marketing campaigns are often used to change health-related behaviours, such as quitting smoking or becoming aware of breast cancer.

We found two systematic reviews (both of medium quality) that examined the effectiveness of social marketing campaigns. The reviews found that social marketing campaigns can be effective in:

- encouraging voluntary health behaviour change;(41;42) and
- bringing about changes in the environment in which we live and in public policies.(42)

We also found that shorter interventions generally achieved larger impacts.(41) In addition, online social marketing campaigns have similar effects to sophisticated print campaigns, but online campaigns have the advantages of reaching more people and lower costs. (41)

Option 2 – Engaging citizens in a province-wide dialogue to encourage open discussions about end-of-life care

The second option aims to engage citizens in a province-wide dialogue to encourage open discussions about end-of-life care. This option could address the challenges associated with a 'death-denying' society that avoids thinking and talking about death. More specifically, it could help to raise awareness about end-of-life care issues, increase public understanding of end-of-life care issues, and ultimately make people feel comfortable talking about it.

Large public dialogues on sensitive issues, like end of life, are not common in Canada. One recent example is the Dying with Dignity consultation launched by the government of Quebec in 2010. The public was invited to discuss and provide feedback about end-of-life care in various ways: submitting written comments, participating in regional public hearings, and completing an online survey.(43) Another recent example of a large public dialogue on a sensitive issue is the consultation led by the Mental Health Commission of Canada in 2009. The Commission engaged the public in regional dialogues, online surveys, roundtables and focus groups across the country to discuss mental health issues and ultimately guide the development of a mental health strategy for Canada. This initiative wanted to overcome "the stigma that has kept discussion of mental health issues out of the public arena for far too long."(44)

We found nine systematic reviews examining different strategies to engage the public. Three reviews found that methods allowing informed discussion among citizens (instead of more traditional methods like surveys and focus groups) can enhance their awareness and understanding about an issue, and also increase their competence for future public-engagement activities.(45-47)

A recent and medium-quality review found benefits for the use of public deliberation methods (e.g., citizen panels and juries, consensus conferences, planning cells) in better understanding the public's values, improving understanding of complex issues (particularly ethical and social dilemmas), and enhancing civic-mindedness.(48)

Four of the reviews found limited evidence about the effectiveness of different types of methods to engage the public in developing healthcare policies,(45;49;50) in defining priorities and in allocating resources.(51)

Lastly, another recent and medium-quality review concluded that the implementation of a public-engagement process can be influenced by many factors. Two key factors are the degree of commitment of the organization putting the process in place, and the types of issues that will be discussed (for instance, some issues are more complex or contentious than others).(47)

Option 3 – Providing citizens with the tools and information they need to engage in advance care planning

The third option aims to provide citizens with the tools and information they need to engage in advance care planning. More specifically, it could inform citizens about the legal aspects of advance care planning that are specific to Ontario (e.g., who can speak on their behalf when they are no longer capable to do so, and the link between advance care planning and consent to treatment). It could also provide citizens with simple tools to help them communicate and document their wishes for end-of-life care.

One way that these tools and information could be provided is through the mass media (e.g., television, radio, newspapers and internet). We found an old but high-quality review that examined the effects of using mass media on the utilization of health services.(52) The authors found benefits for planned mass media campaigns and unplanned mass media coverage on the utilization of health services. However, the authors found limited evidence about the characteristics of successful mass media campaigns, and notably about how messages should be framed.

Another way to do this could be through mailing information to citizens about advance care planning. We found a recent overview of systematic reviews examining the effectiveness of different types of interventions to increase the completion rate of legal documents that allow people to express their wishes for end-of-life care.(53) The authors found that the most effective way to increase the completion rates was combining information material provided to patients (e.g., mailing pamphlets and forms about the Power of Attorney for Personal Care) and repeated conversations with healthcare providers during clinical visits. The passive dissemination of information material alone does not significantly increase the completion rates.

Summarizing what we know about the three options

In the following table we summarize what we know about each of the three options.

Option 1 – Improving public awareness about end-of-life care

Summary of what is known about social marketing campaigns

- Social marketing campaigns can be effective to:
    - encourage voluntary health behaviour change;(41;42) and
    - bring about changes in the environment in which we live and in public policies.(42)
- Shorter social marketing campaigns generally achieved larger impacts.(41)
- Online social marketing campaigns have similar effects to sophisticated print campaigns, but have the advantages of reaching more people and lower costs.(41)
- No systematic review identified negative consequences of social marketing campaigns.

Option 2 – Engaging citizens in a province-wide dialogue to encourage open discussions about end-of-life care

Summary of what is known about public dialogues

- Methods allowing informed discussion among citizens (in contrast with more traditional methods like surveys and focus groups) can:
    - enhance their awareness and understanding about an issue;(45-47) and
    - increase their competence for future public engagement activities.(45-47)
- There is limited evidence about the effectiveness of different types of methods to engage the public in developing healthcare policies,(45;49;50) in defining priorities and in allocating resources.(51)
- No systematic review identified negative consequences of public engagement.

Option 3 – Providing citizens with the tools and information they need to engage in advance care planning

Summary of what is known about strategies to inform and educate the public

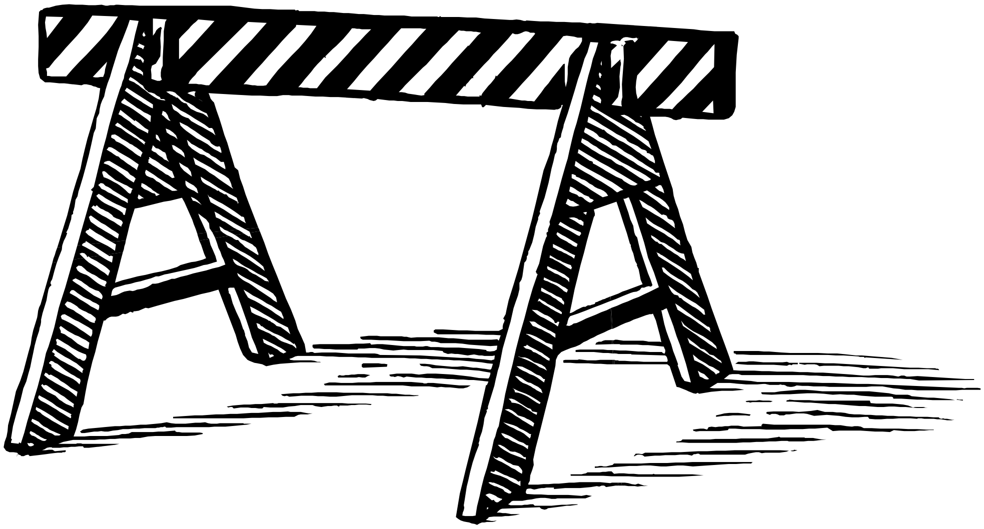
- Mass media campaigns
    - An old but high-quality review that examined the effects of using mass media on the utilization of health services found benefits for planned mass media campaigns and unplanned mass media coverage on the utilization of health services.(52)
    - However, the authors found limited evidence about the characteristics of successful mass media campaigns, and notably about how messages should be framed.(52)
- Mailing information to citizens
    - A recent overview of systematic reviews examining the effectiveness of different types of interventions to increase the completion rate of legal documents that allow people to express their wishes for end-of-life care found that:
        - the most effective way to increase the completion rates was combining information material (for example, mailing pamphlets and forms about the Power of Attorney for Personal Care) and repeated conversations with healthcare providers during clinical visits;(53) and
        - the use of passive information material alone does not significantly increase the completion rates.(53)
- No systematic review identified negative consequences of public information and education.

Implementation considerations

It is important to consider what barriers we may face if we implement the proposed options. These barriers may affect different groups (e.g., patients, citizens, healthcare providers), different healthcare organizations or the health system. While some barriers could be overcome, others could be so substantial that they force us to re-evaluate whether we should pursue that option.

The implementation of each of the three options could also be influenced by the ability to take advantage of potential windows of opportunity. A window of opportunity could be, for example, a recent event that was highly publicized in the media, a crisis, a change in public opinion, or an upcoming election. A window of opportunity can facilitate the implementation of an option.

A list of potential barriers and windows of opportunity for implementing the three options is provided on the following page. This table is provided to spur reflection about some of the considerations that may influence choices about an optimal way forward. We have identified the barriers and windows of opportunity from a range of sources (not just the research literature) and we have not rank ordered them in any way.



Option 1 – Improving public awareness about end-of-life care

Barriers	Windows of opportunity
• It may be difficult to develop social marketing campaigns that are tailored to the various ethno-cultural communities in the province. • It may be difficult to ensure that a social marketing campaign reaches all those who could benefit, including hard-to-reach groups (e.g., people with limited reading skills or with limited access to mass media).	• There is an opportunity to build on past and ongoing initiatives, such as: o Speak Up and Speak Up Ontario! aim to raise awareness about advance care planning and the need to start the conversation about end-of-life-care [www.advancecareplanning.ca].(27)

Option 2 – Engaging citizens in a province-wide dialogue to encourage open discussions about end-of-life care

Barriers	Windows of opportunity
• Some citizens may be frustrated by past citizen-engagement efforts that have not meaningfully influenced policies, programs and services. • Some individuals and organizations may try to broaden the issue to contentious moral and legal issues (e.g., assisted suicide, euthanasia), or to frame it as a way to deny access to care, or as a cost-reduction strategy that may accelerate end of life (e.g., death panels).	• 'Death cafés' are becoming popular places where people gather to talk about death, and they could provide a venue for promoting end-of-life conversations [deathcafe.com].(54) • In June 2013, Ontario Premier Kathleen Wynne stated that it was time to have a provincial discussion about end-of-life care. The two opposition parties agreed with the need to take action and proposed the creation of a legislative committee to examine the issue.(55)

Option 3 – Providing citizens with the tools and information they need to engage in advance care planning

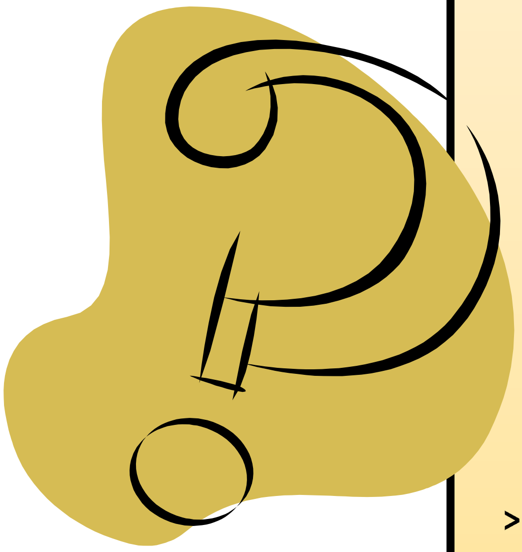
Barriers	Windows of opportunity
• 42% of adult Canadians have low literacy skills and they have difficulties reading, understanding and acting on health information.(56) • Many people may not be aware or understand current laws in Ontario (e.g., issues pertaining to consent and capacity, expressed wishes versus consent, who can interpret wishes, and who can provide consent).(8) • Some healthcare providers may not have sufficient time and resources to engage in conversations about advance care planning, especially with healthy patients.	• There is an opportunity to build on past and ongoing initiatives, such as: o the public education forums organized by the Consent and Capacity Board;(19) o the educational sessions for the public and healthcare providers about advance care planning organized by the Health Care Consent and Advance Care Planning Community of Practice;(21) and o the Guide for Advance Care Planning produced by the government of Ontario.(22)

Questions for the citizen panel

>> We want to hear your views about the problem, the three options for addressing it, and how we can move forward.

This brief was prepared to stimulate the discussion during the citizen panel. The views, experiences and knowledge of citizens can make a great contribution in finding viable solutions to the problem.

More specifically, the panel will provide an opportunity to explore the questions outlined in the box on the right. Although we will be looking for common ground during these discussions, the goal of the panel is not to reach consensus, but to gather a range of perspectives on this topic.



>> What are the most important challenges faced for improving end-of-life communication and decision-making in the province?

>> What are your views about the three proposed options?

Option 1 – What are the prospects for, and likely outcomes of, efforts to raise public awareness about end-of-life care?

Option 2 – What would it take to shift our society to a point where we are comfortable talking openly about end-of-life care?

Option 3 – What tangible supports are needed by citizens to engage in advance care planning?

>> What are potential barriers and windows of opportunity to implement these three options?

Box 4

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Conflict of interest

The authors declare that they have no professional or commercial interests relevant to the citizen brief. The funder played no role in the identification, selection, assessment, synthesis or presentation of the research evidence profiled in the citizen brief.

Merit review

The citizen brief was reviewed by a small number of citizens, other stakeholders, policymakers and researchers in order to ensure its relevance and rigour.

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