Title: Design and distribution of a patient education tool to raise awareness of advance care planning among adult residents of Prince Edward Island

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Abstract

Background

Despite its numerous documented benefits, advance care planning has only been completed by a minority of Canadians. Although provincial and national resources on the topic exist, the problem remains that the public has limited knowledge of the purpose or process of engaging in advance care planning.

Methods

A review of local resources revealed that there was no short, easily mailed resource to introduce the concept of advance care planning. A pamphlet was designed as a concise manner to outline the key components of advance care planning in a visually appealing and easily comprehensible manner. The pamphlet was reviewed by the provincial leadership team. This educational tool could then be distributed across the province in virtual and physical format to patients, regardless of whether they have a primary care provider.

Results

The pamphlet was designed in both English and in French. It was approved by Health PEI. Distribution networks have been established to target residents of Prince Edward Island ages 50 and above.

Interpretation

The pamphlet serves to introduce and remind patients of the importance of advance care planning for preserving their autonomy when they are unable to speak for themselves. It does not rely on an

already overburdened medical system to implement. Future projects should consider other interventions and their impact for improving public uptake of advance care planning.

Introduction

Although advance care planning (ACP) provides several benefits, it remains an underutilized tool in preparing patients for their future medical needs. ACP refers to the process of thinking about and communicating one's wishes for future medical care so that family and care providers can follow those wishes even if one were not able to communicate. Family physicians and nurse practitioners are well positioned within the medical system to have these serious conversations before patients experience significant health complications or become incapacitated; they provide longitudinal care that allows for trust building and ongoing dialogue. ACP affords patients autonomy in their care and can improve coping and quality of life, which should be key goals for primary care providers as well. Unfortunately, these conversations are not the standard. Most patients age without ever undergoing formal ACP. As a result, they may receive medical interventions that are incongruent with their wishes. In our overburdened health care system, there are many missed opportunities to engage in preventative medicine. The goal of this project was to design and distribute a patient education tool to residents of Prince Edward Island (PEI) ages 50 and above to raise awareness of ACP in a manner that does not rely on overextended health care providers.

Background

ACP grants patients ongoing autonomy in their medical care, even when they can no longer communicate or provide informed consent. This process involves thinking about the medical treatments one would accept, telling loved ones about these wishes, writing down one's preferences in the form of a health care directive, and designating a substitute decision maker, also known as a health proxy.[1] Significant emotional benefits from ACP have been documented such as improved quality in life and in the dying process by foregoing often futile, aggressive interventions, reducing in-hospital deaths, and increasing use of palliative and hospice resources for optimal symptom management.[2-4] Serious medical complications and end-of-life are already difficult situations for support persons; the clear documentation of patient wishes can significantly alleviate pressure on these individuals so that they know the care provided is in keeping with what the patient wanted.[5]

There are numerous barriers to ACP for both patients and health care providers. From a patient's perspective, they may not know the purpose or way to engage in ACP;[6] they may prefer to defer decisions to their loved ones; they also may not be comfortable broaching this topic with their primary care provider, assuming they have one.[7] Health care providers have reported lack of time, poor accessibility to health care directives across settings, limited involvement in end-of-life care, low patient comprehension regarding the limitations of life-sustaining measures, and discomfort or lack of skills in having ACP discussions.[8] Some physicians have also expressed concerns about crushing hope or causing psychological distress by asking patients about ACP; however, research has shown that patients and their loved ones would like to have these discussions and derive emotional benefit from sharing their goals and wishes.[5]

Data on the completion of ACP in patient records varies widely. Health care directives are more commonly found among oncology patients than among those with non-oncological chronic diseases;[9] directives are often incomplete, excessively vague, and/or documented close to end-of-life. Unfortunately, there have not been robust analyses on the prevalence of ACP among Canadians. In 2018, the Canadian Family Physician published the results of a multisite cross-sectional survey.[10] A total of 810 patients ages 50 or older from 20 clinics in 3 provinces completed a questionnaire; this survey assessed their prior knowledge of ACP and whether they had thought about their wishes for future care, communicated those wishes to loved ones, completed a health care directive, or assigned a substitute decision maker. The authors reported that 58% of the study sample had no knowledge of ACP. While 68% had thought about their wishes for future medical care, only 32% had written down those wishes, 52.8% had conveyed those wishes to loved ones, and 50.4% had named a substitute decision maker. This study sample was small and only included individuals who had a primary care provider. Nonetheless, the results reflect that public knowledge of ACP is lacking.

More recently, a national online survey in 2020 was completed by 3,923 individuals ages 55 and over who were recruited via social media, email, and Facebook advertising.[11] Only 20.1% of female responders and 16.3% of male responders engaged in ACP. The evidence was of low quality and numerous biases may have been introduced as this was not a randomly generated sample. The survey relied on individuals who are comfortable and have a presence online. It is difficult to assess the vocabulary used and hence responders' comprehension of the specifics being asked. It is unknown what factors motivated some individuals to participate in ACP or whether they have a regular health care provider.

Several interventions have been studied with the goal of increasing the completion of ACP, each with varying levels of complexity and success. An electronic medical record (EMR) reminder has been tested, albeit over a short study follow-up period.[12] Those involved in the design and customization of the provincial EMR on PEI were not able to build a virtual tool during the timeframe of this project. Other interventions successfully trialed in other parts of the world unfortunately would not translate to the Canadian, or PEI-specific, health care system given different roles/responsibilities for health professionals and the current family physician crisis.[13,14] A quality improvement project in Ontario assessed primary care provider feedback on Serious Illness Care Program training sessions, which were designed to improve confidence and skills in ACP;[15] this study did not investigate for changes in the frequency of ACP discussions or documentation, and health care providers expressed numerous concerns. For example, there was lack of confidence in colleagues' ability to discuss ACP with patients or in patients' ability to engage in these conversations. Furthermore, concerns were expressed over prognostication uncertainty, time requirements in clinic for this topic, and ambiguity regarding those patients with whom ACP discussions should be initiated.

On PEI, both primary care providers and the public have access to a multitude of resources on ACP such as guidebooks, a wallet card, a workbook, and a health care directive form. These resources were developed for easy readability and lower grade level comprehension in both national languages by palliative care professionals, with input from allied health professionals and patient families. They are available on the Health PEI Staff Resource Centre for health care providers and on the Government of PEI website for the public. There are numerous national resources on ACP that are accessible online such as the Advance Care Planning Canada website[16] and the *Living Well, Planning Well* toolkit;[17] however, these resources rely on individuals to seek them out themselves and involve many pages of information to digest. In addition, there are province-specific requirements for health care directives to be legally recognized in a given jurisdiction.

A gap in the existing resources was identified. There are currently over 30,000 PEI residents on the patient registry waiting for a primary care provider. In addition, primary care across the country is over-extended, to the degree that it is described as a crisis. As such, it was deemed unrealistic to design an intervention for which the delivery would rely on primary care providers. An intervention rooted in primary care would also miss the large unaffiliated PEI population. The resources already appraised and approved by Health PEI are advanced in that multiple rely on patients already knowing about ACP; these workbooks and guides are also several pages long and so few are likely to read them in full.

This resident project sought to design and distribute a succinct yet comprehensive pamphlet on the key components of ACP. The target demographic for this patient education tool was any PEI resident ages 50 or above. The goal was to reach individuals irrespective of whether they have a primary care provider, so that they have improved awareness of ACP and are provided with sufficient information to undertake ACP on their own, if they so wish.

Methodology

The patient education tool, in the form of a pamphlet, was developed in collaboration with local palliative care physicians who have subject matter expertise in ACP and a strong understanding of local laws and regulations pertaining to actionable health care directives. The first draft was designed based on the most relevant information pulled from existing resources. Next, a diverse group of stakeholders informally reviewed the pamphlet for its content, visual appeal, and readability. Once refined based on feedback, the pamphlet was submitted to Health PEI for further refinement, approval, and translation. No funding was required for this project. Ethical approval was not required, as this project did not involve the collection or interpretation of sensitive information or the enrollment of human participants. Those who provided feedback on the tool design did so in a non-personal, informal manner.

Pamphlet Design

The review of literature and available resources on the topic of ACP identified a gap in the dissemination of information, which guided the development of this patient education tool. A pamphlet offers limited space for information and so careful consideration was undertaken to narrow down the most important aspects of ACP. The legal health care directive form on PEI specifies one's goals of care and health proxy(ies). As such, the educational tool was designed to include an overview of ACP and its relevance, in addition to a short explanation of goals of care options, considerations when choosing a health proxy, and the general steps in ACP with links to further resources to facilitate the process. A previous Health PEI-approved ACP resource, 5 Steps to Advance Care Planning, was modified to 6 steps to reinforce the fact that wishes change and so health care directives and proxy(ies) should be revised as needed.

Images were incorporated in the pamphlet for visual appeal. These photos were strategically chosen to be as inclusive as possible by reflecting diverse ethnicities and ages.

Although all adults could benefit from ACP, we chose to focus on those ages 50 and above to link this preventive health measure with the initiation of standard cancer screening programs. Patients with chronic significant comorbidities are also targeted via one of the organized distribution networks for the pamphlet.

The back of the pamphlet provides both a website and a phone number to access further resources vetted by Health PEI. The targeted demographic for this educational tool may be more comfortable accessing resources over the phone, rather than strictly online.

Once the first draft was completed, the pamphlet was circulated to the provincial leadership team for feedback. Those who critically assessed the tool included palliative care physicians, the palliative care coordinator, the palliative care director, family physicians, nurse practitioners, a geriatrician, a palliative care nurse, a social worker, and patient families. These individuals provided guidance regarding readability and comprehensiveness. The pamphlet was modified based on their suggestions and was subsequently submitted to Health PEI for approval.

The pamphlet was approved by Health PEI and the visual appeal was enhanced by the Creative Services department. A French version was created and revised.

Readability was informally assessed through the feedback solicited from the various stakeholders and was formally assessed using two different tools, depending on language. The English version, analyzed using the Flesch-Kincaid grade,[18] has a readability level of grade eight (score of 66). The French version was analyzed using Scolarius,[19] which identified a readability level of early high school (score of 91); this tool is not as specific in readability level as the well-established Flesch-Kincaid grade tool. The average reading level of the Canadian population is grade 8 and so the target readability level of patient educational tools should not exceed this grade level.[20]

The goal of the patient educational tool is to raise awareness on ACP among PEI residents. Due to time and resource constraints, there is no quantitative or qualitative research component to this project.

Pamphlet Distribution

An important consideration in this project was the plan for distribution of the patient educational tool. The PEI Colorectal Cancer Screening Program has agreed to distribute the pamphlet with its mail-out Fecal Immunochemical Test kits, which are sent out every two years to PEI residents ages 50 and above who are enrolled in the program. The cardiovascular and pulmonary rehabilitation programs have also agreed to distribute the educational tool to their client base, thereby targeting individuals with significant co-morbidities in whom timely ACP would be especially relevant. The

Cancer Treatment Centre already has resources and an onboarding session with its new patients about ACP and so this educational tool would not provide added value for oncology patients on PEI.

A province-wide announcement will be sent out to physicians and nurse practitioners to notify them of the pamphlet and its virtual format on the Staff Resource Centre. Physical pamphlets will be made available to display in the waiting rooms of patient medical homes. Access PEI will be contacted to negotiate the availability of the pamphlet in its locations across the province; this distribution network will improve access to physical copies of the pamphlet among unaffiliated patients.

Results

The final version of the pamphlet is attached in Appendix A in English, and Appendix B in French.

Discussion & Limitations

The patient educational tool is one strategy towards improving public awareness of and engagement in ACP. Its purpose is to reach as many PEI residents as possible, particularly those ages 50 and above, and/or those with chronic cardiovascular or respiratory conditions. The scant, low quality evidence regarding knowledge of and engagement in ACP reflects that this is a national problem. Our population is aging and yet few are prepared with their goals of care clearly outlined and substitute decision makers identified. Future initiatives should strive to address barriers faced by both patients and health care providers. For example, renumeration in the form of new billings codes could incentivize primary care providers to take the time to discuss ACP with their patients. EMR tools could help remind practitioners that this is an area of preventive medicine to address with a given patient. Training on the ACP process could help to reiterate its importance and build competence among care providers in broaching these difficult conversations. Initial conversations on this subject matter do not necessarily need to be provided by primary care providers; it may be beneficial to consider training allied health professionals such as home care nurses and family practice nurses to help distribute the responsibility and time required. ACP should become part of routine practice and so formal curriculum at the medical school and residency levels should be explored. Larger public awareness campaigns in a variety of media formats could facilitate knowledge translation to the public.

For each initiative, it is important to incorporate key performance indicators for ongoing assessment and improvement. Future research could explore PEI-specific data regarding knowledge of and engagement in ACP. Pre- and post-intervention surveys could assess the impact of the pamphlet distribution/mailing campaign on raising awareness of ACP. Focus groups could formally investigate how the pamphlet information is received by members of the public to ensure the acceptability of the wording and content.

This project had its limitations. Although we did not have focus groups to assess the patient's emotional response to the pamphlet, we engaged a variety of stakeholders informally for feedback on wording and visual appeal. Due to time and resource constraints, we were unable to include evaluation of the effectiveness of the pamphlet in raising awareness of ACP on PEI. Thankfully, the patient education tool was affordable and simple to produce and disburse given pre-existing printing and delivery capacities within Health PEI. Nonetheless, metrics on efficacy would be invaluable for ensuring that the tool is useful, worth funding, and acceptable to the public. Distribution of the tool through the Colorectal Cancer Screening Program and cardio-pulmonary rehabilitation programs limits the number of adult PEI residents that may be reached, despite the tool being designed and appropriate for all adults; we hoped to also capture more of the public by displaying the pamphlet in waiting rooms within medical clinics and Access PEI sites. While patients may read the pamphlet, it by itself may be insufficient to motivate most individuals to engage in ACP; we emphasized the importance of completing a health care directive while one is well, but the topic of ACP may remain emotionally difficult to broach amongst loved ones.

Conclusion

Significant barriers among patients and primary care providers impede the broad uptake of ACP on PEI and across Canada. The pamphlet should provide a method for educating the public in a manner that does not rely on practitioners as the first source of information. While challenging, ACP is a worthwhile topic to discuss with loved ones and with one's primary care provider to improve quality in life and in death. Our health care system requires sustained efforts through multiple avenues to encourage ACP among the general population.

Appendix A – Pamphlet (English)

Appendix B – Pamphlet (French)

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Who will speak for you if you cannot speak for yourself?

Health care proxy(ies)

- Your health care proxy is DIFFERENT from Power of Attorney; Power of Attorney authorizes someone of your choosing to make **financial** decisions for you.
- Choose the person(s) you trust most to make health care decisions on your behalf based on **your wishes.**
- You can choose one or more proxy(ies). A proxy can be a family member, friend, or anyone you choose who knows about your health and wishes and who is at least 16 years old.
- They must agree to be your health care proxy and sign your **Health Care Directive.**
- If you do not have a health care proxy, you will be appointed a substitute decision-maker following PEI legislation.

Six Steps to Advance Care Planning...

1. **THINK:** What are your values and wishes about your care and treatment? What would you want and not want in an emergency? Do you want to be an organ and tissue donor?
2. **LEARN:** Learn about different medical procedures and what they can and can't do.
3. **DECIDE:** Choose your health care proxy(ies).
4. **TALK:** Communicate your wishes with your health care proxy(ies).
5. **RECORD:** Write down your ideas. Fill out the Health Care Directive form available from the Health PEI website below. Share it with your health care team and keep a copy in a safe place your proxy(ies) can easily access.
6. **UPDATE:** Update your Health Care Directive and/or proxy(ies) as needed

Get started today!

Access healthpei.ca/advancecareplanning to explore resources for creating your advance care plan:

- Guide to Advance Care Planning
- Health Care Directive Form
- Advance Care Planning Workbook
- Advance Care Planning Wallet Card

For further information, contact the Provincial Palliative Care Centre: 902.368.4781

Health PEI

Advance Care Planning

Communicating your wishes for future medical care

Advance Care Planning

What is it?

Advance Care Planning is the process of thinking and communicating about your health, goals, and wishes so that your future health care team knows what you would want if you are unable to communicate. The written documentation of your Advance Care Plan is called a **Health Care Directive.**

It also involves identifying those you want to speak on your behalf if you are unable to do so. The person(s) you choose will be your health care proxy(ies) and will make decisions based on your wishes.

Why is it important?

Your health care team wants to provide you with the best care possible based on what you would want for yourself. You may not be able to express your wishes during a medical situation, so your Health Care Directive and health care proxy(ies) will inform your team of what you would want.

You do not need a health care provider to do Advance Care Planning or to complete a Health Care Directive.

Goals of Care

A goals of care discussion is completed between yourself and your doctor/nurse practitioner to provide a general focus for your care, especially if you are admitted to the hospital.

Some patients wish to have all treatments, including resuscitation (see CPR section), done to preserve their life. This may involve wanting some or all the procedures outlined in the CPR section.

Others wish to have medical treatment, excluding resuscitation. This option offers treatment for potentially reversible conditions in addition to symptom control.

Other patients wish to be made comfortable. The focus of their medical care is on the management of symptoms without life-preserving or life-extending treatments.

Cardiopulmonary Resuscitation (CPR)

If your heart stops beating and/or you stop breathing, CPR may be started, which could involve the following procedures:

- Chest compressions: pushing hard and fast on the chest to try to pump blood to the rest of the body
- Defibrillation: the delivery of electric shock(s) to the chest to try to restart the normal heart rate and rhythm
- Intubation and ventilation: the process of inserting a tube into the airway to try to deliver oxygen and simulate breathing
- Medications for jumpstarting the heart
- Intensive Care Unit (ICU)/Critical Care Unit (CCU) admission to maintain adequate breathing and heart function if CPR is successful

Consider whether you would want these procedures done. Unlike what you may see on TV, CPR has risks and is often unsuccessful. Very few CPR survivors will return to their previous way of life.

You can change your **Health Care Directive** at any time!

Health PEI

Qui parlera pour vous si vous êtes incapable de le faire?

Mandataires pour les soins de santé

- Un mandataire pour les soins de santé est DIFFÉRENT d'une procuration, qui autorise la personne de votre choix à prendre des décisions financières en votre nom.
- Choisissez quelqu'un en qui vous avez confiance pour prendre des décisions concernant vos soins de santé en respectant vos souhaits.
- Vous pouvez choisir plus d'un mandataire. Il peut s'agir d'un membre de la famille, d'un ami, ou de toute autre personne qui connaît votre état de santé et vos souhaits, tant qu'elle ait 16 ans ou plus.
- Toute personne choisie doit accepter d'être votre mandataire et signer votre directive en matière de soins de santé.
- Si vous n'avez pas de mandataire pour vos soins de santé, un mandataire spécial vous sera affecté conformément aux lois de l'Île.

La planification préalable des soins en six étapes

1. **RÉFLEXION :** Quelles sont vos valeurs et volontés en matière de soins et de traitement? Que voudriez-vous faire ou éviter en cas d'urgence? Souhaitez-vous devenir donneur d'organes et de tissus?
2. **INFORMATION :** Assurez-vous de comprendre les différentes interventions médicales et leurs possibilités.
3. **DÉCISION :** Choisissez un ou plusieurs mandataires pour les soins de santé.
4. **DISCUSSION :** Communiquez vos souhaits à vos mandataires.
5. **DOCUMENT :** Notez vos idées. Créez votre directive en matière de soins de santé (voir le site Web de Santé Î.-P.-É. plus bas). Donnez-la à votre équipe de soins et gardez-en une copie dans un endroit sûr et facile d'accès pour vos mandataires.
6. **MISE À JOUR :** Modifiez votre directive en matière de soins de santé et vos mandataires au besoin.

Commencez dès aujourd'hui!

Visitez **healthpei.ca/planificationpreal-abledessoins** pour consulter les ressources sur la planification préalable des soins :

- Guide sur la planification préalable des soins
- Directive en matière de soins de santé
- Manuel sur la planification préalable des soins
- Carte de planification préalable des soins

Information supplémentaire Centre provincial de soins palliatifs : 902-368-4781

Santé Î.-P.-É.

Planification préalable des soins

Comment communiquer vos souhaits en matière de futurs soins de santé

Planification préalable des soins

Qu'est-ce que c'est?

Il s'agit d'un processus de réflexion et de communication sur votre santé, vos objectifs et vos souhaits afin que votre future équipe de soins sache comment vous souhaitez procéder si vous êtes incapable de communiquer. Vous pouvez préparer un plan sous forme de directive en matière de soins de santé.

Vous devez aussi identifier une ou plusieurs personnes qui parleront en votre nom et prendront des décisions en fonction de vos souhaits, au besoin. Ce sont les mandataires de vos soins de santé.

Pourquoi est-ce important?

Votre équipe soignante veut vous fournir les meilleurs soins possibles en fonction de vos souhaits. Si vous n'êtes pas en mesure de vous exprimer lors d'une situation médicale, votre directive relative aux soins de santé et vos mandataires informeront votre équipe soignante de vos souhaits.

Il n'est pas nécessaire d'avoir un MD pour planifier ses soins futurs ou établir une directive en matière de soins de santé.

Objectifs des soins

Vous aurez une discussion avec votre médecin ou infirmière praticienne sur les objectifs de vos soins pour donner une orientation générale à vos soins, surtout si on vous admet à l'hôpital.

Certaines personnes approuvent tous les traitements, y compris la réanimation, pouvant préserver leur vie. Il peut s'agir de certaines ou de toutes les procédures décrites dans la section sur la RCP.

D'autres optent pour un traitement médical à l'exclusion de la réanimation. Cette option permet de traiter des affections possiblement réversibles, en plus de contrôler les symptômes.

D'autres encore souhaitent tout simplement être à l'aise. Les soins sont alors axés sur la gestion des symptômes, sans traitement visant à préserver ou à prolonger la vie.

Réanimation cardio-pulmonaire (RCP)

La RCP entre en jeu si votre cœur s'arrête ou si vous cessez de respirer. Les procédures suivantes sont alors possibles.

- Compressions thoraciques : pression forte et rapide sur la poitrine pour essayer de pomper le sang vers le reste du corps.
- Défibrillation : administration d'une ou de plusieurs décharges électriques à la poitrine pour tenter de rétablir le rythme cardiaque
- Intubation et ventilation : insertion d'un tube dans les voies respiratoires pour tenter d'administrer de l'oxygène et de simuler la respiration
- Médicaments pour relancer le cœur
- Admission à l'unité des soins intensifs ou critiques pour maintenir une respiration et une fonction cardiaque adéquates si la RCP réussit

Décidez si vous souhaiteriez qu'on effectue ces procédures. Contrairement à ce qu'on voit à la télévision, la RCP comporte des risques et échoue souvent. Très peu de survivants à la RCP retrouvent leur mode de vie antérieur.

Vous pouvez modifier votre directive en matière de soins de santé n'importe quand!

Santé Î.-P.-É.