GUIDE FOR IMPROVEMENT OF FAMILY MEDICINE TRAINING (GIFT)
2017

The Importance of Training in Advance Care Planning in Family Medicine Residency Programs and Recommendations for an Advance Care Planning Curriculum

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WHAT IS ADVANCE CARE PLANNING AND WHY IS IT IMPORTANT?

Advance care planning (ACP), in general, is a process of reflection and communication of a person's values, beliefs, goals, and preferences, that allows the person to best prepare for the future, be it regarding medical care, finances, other personal matters.

When used in the medical context, ACP means helping patients, at any point in life, reflect about and communicate their values/beliefs/goals/preferences, so that health professionals and surrogate/substitute decision-makers (SDMs) can ensure that the medical care the patients receive is consistent with their values/beliefs/goals/preferences[1]. ACP helps prepare the patient for in-the-moment decision-making, and aids in decision-making (by healthcare professionals and SDMs) when the patient is incapable of making decisions for themselves. ACP can be used to make decisions about any and all medical care, including (but not limited to) end of life care. In addition, ACP is much more than a "decision tool" or "clinical prediction score". ACP is a *values*-based, discussion-provoking guide that helps physicians and SDMs make health care decisions that align with a person's values[2].

Medical decisions are context-dependent and they change depending on a patient's health status, mindset, and life situation. As such, ACP does not lead to one document that is static over time, or even necessarily to documents such as advance directives or "living wills". Rather, ACP is a dynamic conversation about planning for the *"what if"* situations that may occur across the entire lifespan. It is an ongoing process and should be revised at various life stages and in accordance with disease diagnosis and progression.

The designation of a SDM is a key element of ACP. Up to 76% of patients will be unable to participate in some or all of the decisions affecting their own healthcare at the end of life[3], and 50% of Canadians have not had a discussion with a family member or friend about what they would want or not want if they were ill and unable to communicate.[4] Without the direction provided by an ACP, families often feel burdened by directing medical care in crisis situations, and may feel ill-prepared to make decisions due to a lack of understanding on the patient's values and preferences. When no prior direction has been documented by the patient, physicians often resort to using full resuscitative and medical care. This can mean aggressive treatments that the patient might not have wanted, and may result in unnecessary suffering for both the patient and their family.

Previous research has highlighted numerous benefits of ACP including:

- Improved patient quality of life[5]
- Improved patient and family satisfaction with end-of-life care[6]
- Reduced stress and anxiety for patients and families[5]
- Improved communication with families[5]
- Reduced hospital admissions and length of stay[7]

- Increased hospice care[7]
- Reduced intensive care unit (ICU) days[8]

Despite these patient-centered benefits, and despite the fact that 60% of Canadians want their healthcare provider to give them information on ACP, participation in ACP is low.[9] In one national survey, only 9% of respondents indicated that they had discussed end-of-life care with their primary physicians.[10] Moreover, physicians lack confidence in this area. Only 26% of primary care physicians are comfortable leading ACP discussions with their patients and 67% feel they need more resources in order to do this.[9]

HOW IS ACP DIFFERENT FROM GOALS OF CARE/CODE STATUS?

The language around medical orders and decision-making can often be quite confusing, even amongst health care providers. A common misconception is that Goals of Care (GOC) or designating Code Status equates to ACP. While GOC and Code Status may be discussion points within the broader context of ACP discussions, they are distinct from ACP. The chart below outlines the distinctions between GOC/Code Status and ACP.

Table 1. The distinction between Goals of Care/Code Status and Advance Care Planning[11,12]

Goals of Care(GOC)/Code Status	Advance Care Planning (ACP)
Medical decision regarding treatment and resuscitation. (Usually, GOC or Code Status is an actual medical order, to be enacted by healthcare staff)	Does not necessarily pertain to a current medical decision Is NOT a medical order for enactment.
Medico-legal standardized document (often provincial) that identifies the focus of care and types of interventions that might be used or withheld.	Individualized discussions that are documented to identify patient values, wishes, and their choice of surrogate decision maker (SDM)
Guides *current* medical care decisions	Prepares a patient for making *future* medical decisions if they retain capacity. Guides the SDM (and clinicians) in making future care decisions if/when patient loses capacity
Conversations establishing GOC or Code Status tend to be performed when patients are sick	ACP is ideally performed when patients are "well" and able to competently participate in expressing their values and wishes
Narrow decision that can be incorporated into ACP	Broad conversation, includes non-medical as well as medical topics.

ACP does not equal end of life medical care

ACP should be done when a person is well, and not simply to plan for end of life medical care. ACP can be a form of end of life planning (i.e. planning for what treatments etc you would wish to be done, if you are incapable of speaking for yourself), but it also includes non-medical subject matter such as estate planning, wills, and power of attorney.

WHY IS ACP IMPORTANT IN FAMILY MEDICINE?

Family physicians have long-standing relationships with their patients. They are the health care professionals that best know their patient's health status, personal priorities and social context. Furthermore, they have the advantage of being able to engage in the process of ACP over several visits. For these reasons, family physicians are best positioned to conduct these sensitive conversations with their patients.[5]

The nature of disease and causes of death in Canada also contribute to the importance of early ACP. An estimated 62% of all deaths each year in Canada are due to one of the following chronic diseases: heart disease, cancer, stroke, chronic obstructive pulmonary disease (COPD), and diabetes.[13] 38.4% of Canadians live with at least one of the ten main chronic diseases (heart disease, stroke, cancer, asthma, COPD, diabetes, arthritis, Alzheimer's or other dementia, mood disorder, anxiety)[14], and many patients live with their chronic disease(s) for years, even decades, before death. However, as their disease progresses, their life expectancy and quality of life may change, which can impact their wishes for future care. Because of the dynamic nature of ACP, and because family physicians provide the vast majority of chronic disease management, family physicians should be doing ACP and incorporating it as a routine part of chronic disease care (Figure 1).

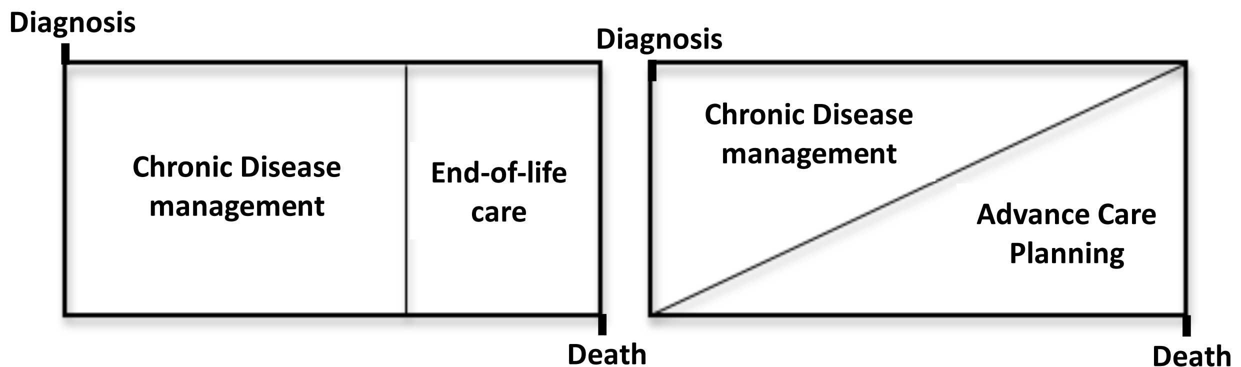

Figure 1. Chronic Disease Management and Advance Care Planning[15]
The historic model of end-of-life care (left) involved end-of-life care as a distinctly separate period of care with a foreseeable end-point to the patient's life, without any aspect of advance care planning during the illness period when the patient was still "healthy" or functional.
The new standard of chronic disease management (right) involves performing Advance Care Planning concurrently with chronic disease management in order to prioritize patient values and incorporate palliative care elements as the disease progresses and treatment priorities change. Note that this new model can also be depicted in a "bow-tie" shape, so references to the "bow-tie" model may exist in certain regions of Canada.

HOW ARE WE DOING NOW AT TRAINING RESIDENTS IN ACP?

At the September 2016 College of Family Physicians of Canada's (CFPC) Section of Resident's (SoR) Council meeting, ACP was identified as a topic of importance to residents across the nation. After much discussion amongst SoR Council members, it became evident that the level of knowledge and training on ACP was highly variable across residency programs.

In order to obtain a broader resident perspective on current training in ACP, the CFPC SoR performed a national online survey of current Family Medicine residents in the fall of 2016. The survey received participation from ~10% of current Family Medicine residents, representing each of the 17 national programs. Key findings from the data is summarized in Table 2. A detailed breakdown of the responses received are included in Appendix 1. The survey questions, and the raw data from respondents, are included in Appendix 2.

Table 2. Summary of Major Survey Findings

Summary of Major Survey Findings
Only 33% of residents report having received either didactic or clinical teaching on ACP during their residency training.
Over 75% of residents report wanting to have more didactic and clinical teaching on ACP during residency. Most report wanting 1-4 more hours of both didactic and clinical teaching.
Residents specifically requested more training on the **practical aspects** of performing ACP, including developing an approach to ACP discussions and providing guidance on appropriate language for these discussions. Respondents also stated they wished to have **practice performing** ACP in a safe environment (SIM, standardized patients).
A majority (60%) of residents responded that they were not aware of any distinction between ACP and Goals of Care (GOC) discussions*****.
The most common location that residents reported performing ACP was in the Emergency Room (48%)*****.
Only 40% of residents indicate that they believe they will feel prepared to guide patients in ACP discussions following their residency.
80% of residents indicated that they would find a clinical aid / "How-to-Guide" helpful or very helpful in performing ACP

*Given that GOC and Code Status discussions are likely to be much more common and appropriate in the Emergency Room setting than ACP discussions, the authors infer that these respondents did not clearly understand the definition of ACP (as distinct from other types of end-of-life care discussions).

HOW CAN WE BETTER TRAIN RESIDENTS IN ACP?

Our committee performed an extensive literature review to determine established best practices in teaching ACP to Family Medicine residents. We contacted librarians at both the University of Alberta and the University of British Columbia to develop a search strategy using keyword searches encompassing three concepts (Advance Care Planning, Education, Family Medicine). We used this search strategy in the Medline and Embase databases. Despite this, we were unable to find published evidence-based best practices on ACP training for Family Medicine residents.

Given the feedback from our survey and common themes from various ACP resources, we have developed teaching recommendations designed to address the gap that residents have identified in their training.

We encourage a two-part approach to ACP education: didactic teaching and clinical teaching.

Didactic Teaching

While most residents have identified that they currently receive 1-2 hours of didactic teaching on ACP, the majority stated that they would like an additional 1-3 hours of exposure to didactic teaching during their residency. It would be valuable to incorporate teaching on ACP throughout the academic year, through multiple formal and informal sessions, to increase resident knowledge retention. Teaching sessions may be dedicated to the topic of ACP, but can also be easily incorporated into existing teaching sessions on related topics, including Palliative Care, Ethics, the Periodic Health Exam, etc. Such sessions may take the form of academic half-days, site-based teaching, large-group/small group teaching, or online modules - we found no evidence to recommend specific methods of teaching over others. Rather, each program should deliver these training sessions in ways it deems most appropriate given its own unique context.

We recommend reviewing the following components in didactic instruction:

- What is ACP and why is it important
    - ACP is much more than just another “decision tool” or “decision score” - ACP is a dynamic series of conversations, with the patient and their SDM, about planning for the *“what if”* situations that may occur across the entire lifespan (not just at the end of life).
- Clarify the terminology used in discussions involving ACP:
    - i.e. The fact that ACP includes all aspects of planning for the future, both medical and non-medical: medical being personal directives/advance directives and Goals of Care/Code Status, non-medical being Power of Attorney, Enduring Power of Attorney, wills, etc)

- Specify that patients should perform the medical aspects of ACP with a physician (or other clinical allied health professional, such as a social worker); not just with a lawyer or family members
- Educate learners on province/region specific regulations that apply to ACP. For example, some regions specify in law the precedence of who will be a patient's SDM, unless otherwise documented in advance by the patient
- Emphasize the longitudinal nature of ACP and the importance of its integration in chronic disease management[2]
    - Conversations must be revisited over the course of the patient's illness experience and over the course of their life
    - At each conversation, the physician should provide specific and tailored guidance around prognosis and outcomes to allow patients to make informed *plans* (not necessarily *decisions*) about their future care
    - Patient preferences may necessarily change over time - the physician should expect this and adapt accordingly
- Utilize the ID3 Framework for carrying out an ACP conversation (see below)
- Review the key things to document in an advance care plan
    - Designating a Surrogate Decision Maker (SDM)
    - Personal preferences, including:
        - Important spiritual or religious beliefs which may impact care
        - Body/organ donation requests
        - Wishes for burial/cremation etc.
    - Values assessment, to inform future healthcare decisions by SDM
    - Tradeoffs that the patient is willing to accept, between furthering life-span and additional intervention:
        - What quality of life is acceptable; what is unacceptable
        - Treatments/interventions which would be acceptable or unacceptable based on the patient's values and desired quality of life
    - GOC or Code Status, if/when it has been determined

Clinical Teaching

While most residents have identified that they currently receive 1-2 hours of clinical teaching on ACP, the majority stated that they would like an additional 1-3 hours of exposure to clinical teaching during their residency program. Just as with didactic teaching, there is value in distributing clinical teaching on ACP over multiple sessions, so that residents may continually develop and enhance their ACP discussion skills throughout residency.

Our recommendations for clinical teaching involve providing opportunities for residents to conduct observed ACP discussions via simulation, standardized patients or role play. If those options are unavailable, another option could be to have residents practice ACP discussions

with real patients who have consented to participate in a learning exercise for training physicians. This would allow residents to practice the ID3 framework and adjust it to their individual style prior to engaging in these sensitive discussions with real patients outside of a formal learning environment. It would also give the opportunity for residents to receive feedback from an observer. The 'observer' could be a physician with experience in ACP, or it could be the resident themselves (i.e. videotape the encounter and have the resident watch the recording afterwards). We recommend providing at least two opportunities for this clinical practice in order to more realistically simulate the ongoing process of ACP.

Importantly, the value of implicit learning through role-modelling good preceptor practices must not be discounted. Currently, only 26% of practicing family physicians feel comfortable in leading patients in ACP discussions.[9] Increasing the capability and confidence of family physician preceptors to conduct effective ACP conversations would likely improve learning and uptake by resident learners.

Lastly, we also recommend that residents be directed to existing provincial resources on ACP, as well as the national *Speak Up!* campaign (in particular, the *Just Ask* resources for physicians). Please refer to Appendix 3 for a resource list. Many of the resources listed have links to patient handouts that can be left in clinic waiting rooms.

HOW CAN WE GUIDE RESIDENTS IN ACP DISCUSSION?

After reviewing the literature and existing resources on ACP, we have devised a simple framework for ACP discussions – ID3 (Figure 2). This framework does not replace formal ACP instruction and education, but rather is meant to provide structure for ACP discussions. It has also been summarized in a point-of-care clinical tool which clinicians can refer to easily during clinical encounters (see Appendix 4).

Preparation:

1. Triage the discussion according the patient's health status (Table 3)

Table 3. Triaging ACP Discussions[16]

Health Status	Acuity	Actions
Well adult	Non-urgent	Encourage the patient to choose a SDM; talk about what's important to them in their life and functioning. Conversation about ACP may be triggered by life events (i.e. marriage, pregnancy, new job, etc)
Sick patient, or patient with chronic disease	Semi-urgent	Engage in full ACP conversation (see "ID3 Framework" below); conversation may be triggered by medical events (i.e. new diagnosis, discharge from hospital, etc) If living with chronic disease, discuss disease course and potential decision points that may arise in the future as disease progresses Ensure SDM is aware of discussion and any decisions made. GOC and/or Code Status may also be discussed at this stage.
Acute deterioration in health	Urgent - Decision needed now	Conduct ACP conversation with the patient if not already done. GOC and/or Code Status must be discussed with the patient or SDM at this stage, if not already done; physician may recommend best treatment based on the patient's goals, fears, values and their specific illness context

2. Check for and review previous ACP conversations
3. Plan for a serious discussion in an appropriate setting that will take time
4. Ensure family/SDM is present if desired by patient (initial discussions may be done individually with the patient, but as the process unfolds, it will be important to involve family/SDMs)

Conversation:

After completing the adequate preparation, the framework below can guide the conversation. The framework can be conveniently packaged into the mnemonic *ID3* (Figure 2).

<table>
<tr><th colspan="5">Framework for ACP Discussions (ID3)</th></tr>
<tr><td>Introduce/ Inform[17]</td><td colspan="4">What is ACP and why is it important? Describe the process.
Introduce the idea: “I’m hoping we can talk about where things are with your illness/health, and where things might be going…”
Seek permission: “...Is this ok?”
An option may be to provide the patient with take-home information after an initial introduction to ACP, and have the patient return for a dedicated appointment to work through the rest of the process.</td></tr>
<tr><td rowspan="2">Discuss[17]*</td><td>Understanding</td><td>Goals</td><td>Fears</td><td>Trade-offs</td></tr>
<tr><td>“How much do you (or your family) know about your illness? What information would you like from me?”</td><td>“What are the most important things you still want to do in life?
What are some abilities in life you can’t do without?”</td><td>“What are your biggest fears and worries about your health? About life in general?”</td><td>“If you get sicker, what kind of extra healthcare services are you willing to endure to gain more time?”</td></tr>
<tr><td>Decide</td><td colspan="4">Decide on an SDM: “If you are unable to speak for yourself about medical decisions, who do you want to speak for you?”
“Have you talked to your SDM (or anyone else) about your wishes or preferences for health care that may arise?”
Decide, from the details that the patient told you, what they value in their lives, and help them articulate these values (i.e. family, friendships, love, purpose, etc)
Decide what principles of medical care align best with the values that were discussed.
Note: It may not be appropriate for decisions to be made in the initial conversation(s)</td></tr>
<tr><td>Document</td><td colspan="4">Document the designated SDM. The patient should ensure that their SDM is aware of their role, and informed about the patient’s priorities and wishes.
Document your discussion and any decisions that may have been made.
Encourage your patients to record their wishes (i.e. SDM, values, etc) into a formal Personal Directive document.</td></tr>
</table>

Figure 2. *ID3* Framework for ACP Discussions.
NOTE: The ID3 framework is meant to serve as an approach for clinicians in conducting ACP discussion. Although not exhaustive, it provides a roadmap for the discussions as well as conversation prompts taken from the Serious Illness Conversation Guide (SICG)[17] to engage patients in the process of ACP.
Also note that for brevity/conciseness reasons, the original wording of the questions/phrases suggested by the SICG have been modified/shortened. The essence of the questions is maintained, however the current wording is no longer “evidence-based”. For the original phrasing of these questions, refer to source #17 (the SICG document).

Specific mention must be made of the “Goals” component of the ID3 discussion. We suggest specifically asking patients what their *goals* are, as opposed to what their *values* are, simply because people realistically are better able to articulate their goals than their values. From their goals, the clinician ideally can then infer the patient’s values and help the patient articulate them. Thinking about the patient must be emphasized, because the ID3 framework is not meant to be another checklist that allows practitioners to turn off their brains. Rather, it is meant to stimulate thought and consideration for one’s patients.

Another important point in the Discussion portion of ID3 is the consideration of *tradeoffs*. Tradeoff discussions need to be quite specific and tailored to the patient context. A simple *“Do you want cardiopulmonary resuscitation (CPR) or intubation?”* does not suffice. The amount and degree of interventions that a patient may be willing to tolerate can be general (i.e. resuscitative discussions pertaining to CPR, intubation, ICU admission, etc.) or disease-specific (i.e. lung rehab for patients with COPD). In other words, the expected clinical outcomes with or without various interventions (i.e. change in prognosis/duration of life, functional impairment, location of care) should be discussed first, before specific interventions and the tradeoffs around them can be discussed. The family physician must guide patients through various health scenarios that may arise, in order to address possible future health outcomes. For example, for a patient with COPD, the tradeoff discussion may involve something like this: *“Your lung function is getting worse, but you may prolong lung function for another few months if you do these exercises. These exercises will require time and dedication and physical work. Would you be willing to work harder and spend time on these rehab classes to be able to live a bit longer?”* This is just one example of disease-specific interventions that should be discussed during ACP for patients whose disease trajectory warrants anticipating future treatment options[18].

Please note that all aspects of this framework may not be reached in one visit, and multiple visits may be required in order to reach the Decide and Document stages. Once a decision has been reached and documented, the Advance Care Plan should be followed up on and revisited as the patient’s health and social circumstances change. Allow room for questions at all stages, as well as clarification of terminology.

One caveat of this framework is that it assumes capacity and competence for the patient to engage in ACP discussions.[19] The purpose of this document is not to address capacity assessment, but we will make the point that capacity (i.e. the ability of the patient to understand what ACP is and is not, as well as appreciate the consequences of ACP discussions and decisions) is an essential prerequisite for ACP.

SUMMARY

ACP is becoming an increasingly important topic in primary care as more patients with multiple comorbidities and chronic diseases are living longer due to advances in medical treatment. ACP allows patients to assert their values and priorities for care throughout their disease course and throughout their lifecycle, so that when potentially unexpected situations arise and the patient is unable to make treatment decisions, physicians and family can direct care in a manner that is in keeping with the patient's wishes. In doing so, ACP not only improves the quality of patient care, but also may help direct constrained healthcare resources to areas of greater need, increasing health system efficiency. Family physicians are well-positioned to guide ACP discussions given the longitudinal care they provide, yet many physicians, including resident physicians, feel uncomfortable in directing these conversations. ACP training should be incorporated into Family Medicine residency training across the country using both didactic and clinical teaching methods. We have provided a point-of-care resource to help provide structure to the ACP process and encourage resident physicians to use the provided framework in their ACP conversations with patients.

RECOMMENDATIONS TO PROGRAM DIRECTORS

1. Incorporate a minimum of 3 – 5 hours of both didactic and clinical teaching specifically on ACP in your residency curriculum. This time should ideally be divided across multiple teaching and clinical sessions throughout residency.
2. Provide residents with opportunities to practice ACP in a supervised and safe environment (i.e. SIM, standardized patients).
3. Distribute our point-of-care clinical tool, and direct your residents to your province-specific ACP resources as well as the national *Speak Up!* campaign's *Just Ask* resource guides for physician-directed ACP discussions.
4. Consider supporting research on ACP teaching in residency, specifically examining effective methods of teaching as well as resident-preparedness for ACP discussions and if this translates into patient-centered outcomes.
5. Invest in faculty development on ACP, so that effective skills and practices are modelled by preceptors in both didactic and clinical teaching environments.

ACKNOWLEDGEMENTS

Special thanks to the many experts on Advance Care Planning in Canada, who we consulted for feedback during the creation of this document, including:

- Dr J Simon
- Dr S Cunningham
- Dr E Gimon
- Dr J Ko
- Dr M Howard
- Dr J Shaw
- Dr M Glettner
- The CFPC Palliative Care Team:
    - A Girouard
    - Dr M Lecours
    - Dr A Grill
    - Dr S Connidis
    - Dr C Johnson
    - Dr GCM Ma

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