Educating Future Physicians in Palliative and End-of-Life Care

Former les futurs médecins dans les soins palliatifs et de fin de vie

Advance Care Planning: A Learning Module

Louise Hanvey BN MHA
Paul Daeninck MD MSc FRCPC
S. Lawrence Librach MD CCFP FCFP
for the EFFPEC project team

Objectives

- Define advance care planning & explain its importance
- Describe the steps of ACP
- Describe the role of patient, proxy, health care professionals
- Identify pitfalls & limitations in advance care planning

LH

Educating Future Physicians in Palliative and End-of-Life Care

Former les futurs médecins dans les soins palliatifs et de fin de vie

Objectives

- Discuss the process of development of the teaching module
- Identify the challenges in development
- Briefly review the content of module

Educating Future Physicians
in Palliative and End-of-Life Care

Former les futurs médecins dans
les soins palliatifs et de fin de vie

Context for Developing the Module: EFPPEC

EFPPEC is a national project aimed at facilitating the development of palliative & end-of-life care curriculum at Canada's 17 medical schools.

Educating Future Physicians
in Palliative and End-of-Life Care

Former les futurs médecins dans
les soins palliatifs et de fin de vie

EFPPEC Partners

- Association of Faculties of Medicine Canada (AFMC) principal partner/CHPCA co-partner
- Health Canada funding & close involvement of Canadian Strategy on Palliative/End of Life Care Working Group on Formal Caregiver Education
- Office is located at CHPCA in Ottawa

How does EFPPEC Work?

- Build on present state in medical schools by forming/facilitating local teams
- Identify common competencies in EOLC & examine to those competencies
- Assist in the development of curricula & clinical experiences
- Evaluation is a key component

Educating Future Physicians
in Palliative and End-of-Life Care

Former les futurs médecins dans
les soins palliatifs et de fin de vie

Case Description

Jennifer: 59 y o woman of Chinese descent

4 mo ago, developed lower thoracic back pain; Fam doc and orthopedic surgeon seen, but source of pain not apparent. Significant back pain using acetaminophen-oxycodone tablets 2 tabs qid without relief

1 wk ago, sudden severe thoracic back pain.

ER visit, x-ray showed T12 collapse.

Admitted, bone scan= bone mets at T 5, 6, 12, L 3, 4, & left acetabulum.

Abdominal MR= mass in head of pancreas, a 4 cm hepatic met and paraortic LNs.

Liver Bx= anaplastic adenoca

Dx: pancreatic adenocarcinoma

Surgeon feels she will need surgery to prevent duodenal obstruction

Medical Oncologist recommending chemotherapy with gemcitabine

LL

Case Description

Jennifer immigrated to Canada.

First marriage to an abusive Chinese man lasted only 2 y.

Second marriage x 29 y to Harold (Caucasian). She is a product manager for a generic pharmaceutical company. Her husband, 61 y, is on disability pension from municipal transit post-MVA. He has a back injury and needs cane to walk.

3 children: a married son, a daughter finishing her MA in psychology and a 14 y o daughter with Down's Syndrome.

They attend church infrequently.

Jennifer's mother is alive with mild dementia, lives in a residential home. Her father died 10 y ago with lung cancer. She has 2 siblings that she speaks to infrequently.

Jennifer and Harold sit down with medical team to discuss options for treatment.

Educating Future Physicians
in Palliative and End-of-Life Care

Former les futurs médecins dans
les soins palliatifs et de fin de vie

Educating Future Physicians
in Palliative and End-of-Life Care

Former les futurs médecins dans
les soins palliatifs et de fin de vie

ACP - Definition

A process whereby a capable (mentally competent) adult engages in a plan for making personal health care decisions in the event that he/she becomes incapable of personally directing his/her own health care

Educating Future Physicians in Palliative and End-of-Life Care

Former les futurs médecins dans les soins palliatifs et de fin de vie

ACP is a process

It is not defined by a written document only

"You're not supposed to write on your husband's chart, Mrs. Johnson!"

ACP - What is it?

- Process of planning & making choices for future medical care
- Values, preferences, wishes & goals are explored & documented
- Determines who is substitute decision maker (SDM)
- Professional & legal responsibility

Educating Future Physicians in Palliative and End-of-Life Care

Former les futurs médecins dans les soins palliatifs et de fin de vie

"And to my wife, Elizabeth, who hated my guts, I leave my large intestine."

ACP - What is it?

Trust building patient/family & HCP
Reducing uncertainty
Helps to avoid confusion & conflict
Permits peace of mind

Educating Future Physicians in Palliative and End-of-Life Care

Former les futurs médecins dans les soins palliatifs et de fin de vie

Advance Directive (AD)

- A legal written document that outlines choices when someone is incompetent
- Many different formats dependent on jurisdiction
  - Living Will
  - Proxy directive (legal term to designate SDM)
  - Power of attorney for personal care

Educating Future Physicians in Palliative and End-of-Life Care

Former les futurs médecins dans les soins palliatifs et de fin de vie

Advance Directive

- Explains <u>who</u> makes health care decisions when the patient is unable incompetent & gives direction to that person
- It is not a consent

Educating Future Physicians in Palliative and End-of-Life Care

Former les futurs médecins dans les soins palliatifs et de fin de vie

"Ok, so you don't want CPR or tube feeds, but you'll take the fried rice & szechuan beef…"

Content – Initiating the Conversation

- Conversations about ACP best conducted before the end of life is near
- Best when individual has time & peace of mind to think about the goals of care, can talk openly about wishes & concerns with family or close friends & with HCPs who can provide information & support

PD

Educating Future Physicians in Palliative and End-of-Life Care

Former les futurs médecins dans les soins palliatifs et de fin de vie

5 Steps for AC Planning

1. Introduce the topic
2. Engage in structured discussions
3. Document patient preferences
4. Review, update
5. Apply directives when need arises

Educating Future Physicians
in Palliative and End-of-Life Care

Former les futurs médecins dans
les soins palliatifs et de fin de vie

Step 1: Introduce Topic

Be straightforward & routine

Determine patient familiarity

Explain the process

Determine comfort level

Determine SDM

Educating Future Physicians
in Palliative and End-of-Life Care

Former les futurs médecins dans
les soins palliatifs et de fin de vie

Step 2: Engage in Structured Discussions

- SDMs present
  - Pt may choose to have a conversation with you before speaking to SDM
- Describe scenarios, options for care
- Elicit patient's values, goals
- Use a worksheet
- Check for inconsistencies

Role of SDM

- Entrusted to speak for the patient
  - Should make decisions based on direction from person & not their own choices
- Involved in the discussions at some point
- Must be willing & able to take role

Patient & SDM Education

- Define key medical terms
- Explain benefits, burdens of treatments
  - Life support may only be short-term
  - Any intervention can be refused
  - Recovery cannot always be predicted

Educating Future Physicians in Palliative and End-of-Life Care

Former les futurs médecins dans les soins palliatifs et de fin de vie

Step 3: Document Preferences

- In the health record
  - Note any AD & review with team
- Sign the documentation
- Ensure portability across setting & provinces if possible

Educating Future Physicians in Palliative and End-of-Life Care

Former les futurs médecins dans les soins palliatifs et de fin de vie

Step 4: Review & Update

- Follow up periodically especially as condition changes
- Note major life/illness events
- Discuss & document changes
- Enter into the medical record
- Ensure portability

Educating Future Physicians
in Palliative and End-of-Life Care

Former les futurs médecins dans
les soins palliatifs et de fin de vie

Step 5: Apply the ACP

- AD only applies if the person is not capable
- Decisions about care must be discussed with the capable patient
  - Consent must be obtained

Educating Future Physicians in Palliative and End-of-Life Care

Former les futurs médecins dans les soins palliatifs et de fin de vie

Step 5: Apply the ACP

- Determine applicability
- Read & interpret the AD if there is one
- Consult with the SDM
- Carry out the treatment plan
- Expect disagreements & plan for resolution

Educating Future Physicians in Palliative and End-of-Life Care

Former les futurs médecins dans les soins palliatifs et de fin de vie

Benefits of ACP

- Symbol of HCPs commitment to patient empowerment
- Reminds us to value pts/families as partners in planning EOL care
- Encourages planning for death
  - concrete aid for overcoming aversions
  - face hard decisions about dying

Educating Future Physicians in Palliative and End-of-Life Care

Former les futurs médecins dans les soins palliatifs et de fin de vie

Benefits of ACP

- Reduces future difficulties; provides guidance for pt's wishes ("note in pocket")
- May reduce/resolve conflict & disagreement
- Can be completed at any time
  - Can be revised

Educating Future Physicians in Palliative and End-of-Life Care

Former les futurs médecins dans les soins palliatifs et de fin de vie

Common Pitfalls

- Failure to plan
- Unclear patient preferences
- Complete (& sign!) AD
- SDM absent for discussions
- SDM unwilling to follow wishes
- AD inaccessible

Educating Future Physicians
in Palliative and End-of-Life Care

Former les futurs médecins dans
les soins palliatifs et de fin de vie

"I think you misinterpreted the terms of my living will, dear."

Educating Future Physicians in Palliative and End-of-Life Care

Former les futurs médecins dans les soins palliatifs et de fin de vie

Common Pitfalls

Focus too narrow

DNR does not encompass all of ACP

Poor understanding of medical interventions

Communicative patients are ignored

AD not read, not understood by HCPs

Preparation for the Final Days

- Advance planning
  - personal choices, caregivers, setting
- Loss, grief, coping strategies
- Educating / training patients, families & caregivers
  - communication, tasks of caring
  - what to expect
    - physiologic changes, events
    - symptom management

Educating Future Physicians in Palliative and End-of-Life Care

Former les futurs médecins dans les soins palliatifs et de fin de vie

Advance Planning

Practical Issues

Financial, legal affairs

Organ donation

Autopsy

Burial / cremation

Funeral / memorial services

Guardianship

Developing the Module

LH

Educating Future Physicians in Palliative and End-of-Life Care

Former les futurs médecins dans les soins palliatifs et de fin de vie

The Need for ACP Education

Health Canada's Secretariat on Palliative & EOLC hosted a meeting on ACP which highlighted the need for education for health professionals.

Working groups of the Canadian Strategy on Palliative & End-of-Life Care approached EFPPEC to develop a module for health professional education.

Educating Future Physicians in Palliative and End-of-Life Care

Former les futurs médecins dans les soins palliatifs et de fin de vie

Objectives

To produce a multifaceted, interprofessional education module on ACP for health professionals' undergraduate & postgraduate students.

Developed as an interprofessional approach to be used by physicians, nurses, social workers, spiritual advisors, & trained palliative care volunteers.

Educating Future Physicians
in Palliative and End-of-Life Care

Former les futurs médecins dans
les soins palliatifs et de fin de vie

Objectives

- **Topics include:**
  - **importance of advance care planning**
  - **incapacity to give informed consent**
  - **decision making process for EOLC**
  - **communication of end of life conditions & risks/benefits of possible treatment**
  - **appointment of a substitute decision-maker**
  - **models of advance directives**
- **Will not re-invent the wheel, but rather draw on existing Canadian resources.**

Educating Future Physicians in Palliative and End-of-Life Care

Former les futurs médecins dans les soins palliatifs et de fin de vie

Expert Working Group

- Physicians – family medicine, palliative medicine, critical care
- Social worker
- Nurse
- Lawyer
- Health Canada representative
- People with experience in developing ACP educational resources

Educating Future Physicians in Palliative and End-of-Life Care

Former les futurs médecins dans les soins palliatifs et de fin de vie

Editorial Review Group

- Members of a broad Editorial Review Group were identified to review the module
- Interprofessional with representation from across the country
- More than 50 people participated in the review representing all provs / territories

Educating Future Physicians in Palliative and End-of-Life Care

Former les futurs médecins dans les soins palliatifs et de fin de vie

Editorial Review Group

physicians, nurses

lawyers, social workers

chaplains, volunteers

bioethicists, educators

EFPPEC Local Leaders/

Teams

Editorial Review Group participated in a consensus building exercise to approve & modify the program

Needs Assessment

Gathered & synthesized existing resources in Advanced Care Planning Education

Pallium, Ontario Government/Alzheimer's Strategy, Fraser Valley Health Authority Calgary Health Authority, Ian Anderson Program, Dalhousie University, Gunderson Lutheran Medical Foundation Inc.

Educating Future Physicians in Palliative and End-of-Life Care

Former les futurs médecins dans les soins palliatifs et de fin de vie

Needs Assessment

- Searched provincial government websites to identify relevant material relating to advance care planning, health proxies, substitute decision makers; & advanced directives guidelines.
- Searched the national professional association & provincial Colleges of Physicians & Surgeons & Colleges of Nurses websites for ACP guidelines.

Educating Future Physicians in Palliative and End-of-Life Care

Former les futurs médecins dans les soins palliatifs et de fin de vie

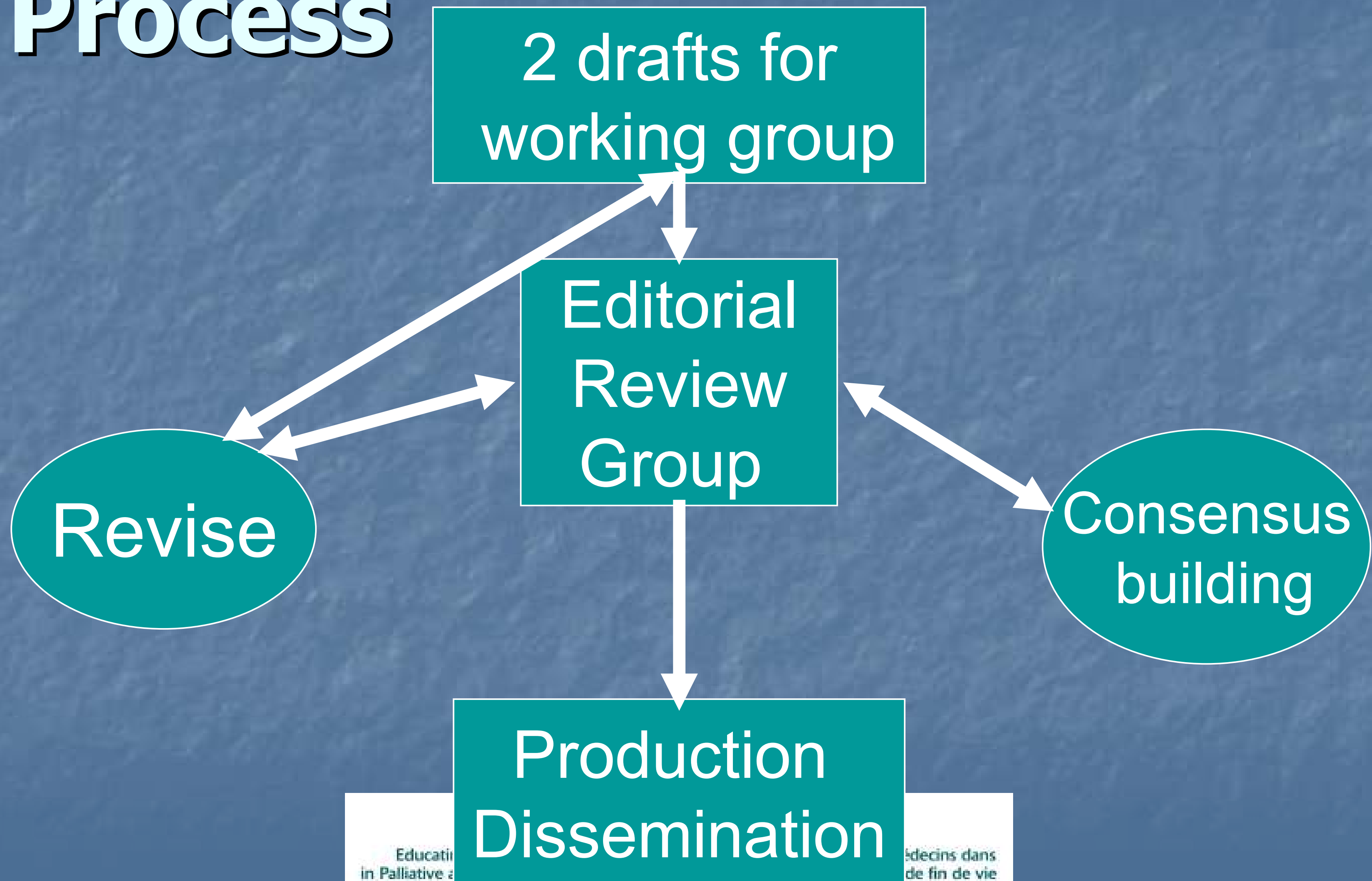
Needs Assessment

Advised the EFPPEC Local Leaders of the initiative, & ask them to identify learning resources that they have developed or would recommend.

Educating Future Physicians in Palliative and End-of-Life Care

Former les futurs médecins dans les soins palliatifs et de fin de vie

Process



Process

- Overwhelming support for the module.
- All found content relevant – wanted to add content rather than remove.
- Constructive recommendations for additions/modifications.

Challenges in Developing the Module

Challenges

- ACP laws across Canada are not harmonized, leading to different requirements under the various provincial statutes.
- Laws include federal legislation (criminal law); provincial legislation (Advance Directive & Health Care Consent Legislation) & Common Law

Educating Future Physicians in Palliative and End-of-Life Care

Former les futurs médecins dans les soins palliatifs et de fin de vie

Challenges

Terminology is not consistently used or understood

- e.g., proxy, substitute decision-maker, advanced directive, proxy directive, living will

Educating Future Physicians in Palliative and End-of-Life Care

Former les futurs médecins dans les soins palliatifs et de fin de vie

Challenges

- Understanding of the concepts of consent to treatment & their relationship to the process of advance care planning is not clear

Educating Future Physicians in Palliative and End-of-Life Care

Former les futurs médecins dans les soins palliatifs et de fin de vie

Content of the Education Module

Educating Future Physicians
in Palliative and End-of-Life Care

Former les futurs médecins dans
les soins palliatifs et de fin de vie

Content Overview

- Overview
- ACP & Consent & Capacity
- How to Initiate the Conversation
- Having the Conversation
- Explaining Life-Sustaining Therapy

Content Overview

- Advance Care Planning & the Values & Experiences of Health Care Providers
- Conflict: Prevention & Management
- Building Organizational Capacity for ACP
- Educational Resources
- Teacher's Guide

Educating Future Physicians in Palliative and End-of-Life Care

Former les futurs médecins dans les soins palliatifs et de fin de vie

Content – Legal Framework

Over the past 15 to 20 years, legislation has been enacted in almost all provinces & territories across Canada to codify the right to make arrangements about personal choices for future health care. Provinces & territories provide legal recognition for different forms of advance directives. ACP laws across Canada are not harmonized, leading to different requirements under the various provincial statutes.

Educating Future Physicians
in Palliative and End-of-Life Care

Former les futurs médecins dans
les soins palliatifs et de fin de vie

Content – Legal Framework

It is the health care provider's responsibility to know what the law says in their province/territory

What form of AD is recognized?

Is there a definition of capacity or competence? What is it?

Does the law specify an age below which one cannot make an AD? What is it?

Does the law enable a person to appoint a substitute decision-maker?

Does it allow you, as a HCP, to take instructions from an advance directive or must you speak with a substitute decision-maker before providing (or not providing) treatment?

If there is no substitute decision-maker appointed, to whom does the health care provider turn? Does the law specify a hierarchy of people who can make treatment decisions for an incapable person?

"In some respects, this century's scientific & medical advances have made living easier & dying harder."

Approaching Death: Improving Care at the End of Life

The Institute of Medicine, Washington, D.C., 1997

Educating Future Physicians in Palliative and End-of-Life Care

Former les futurs médecins dans les soins palliatifs et de fin de vie

Summary

- Advanced directives require open & direct communication
- ADs ensure patient's wishes known & honoured
- ADs can guide health professionals
- EFPPEC module valuable teaching tool for advanced care planning

"No, the advanced directive doesn't allow you to forbid your husband from marrying again!"

Educating Future Physicians in Palliative and End-of-Life Care

Former les futurs médecins dans les soins palliatifs et de fin de vie

Questions?
Comments?

Educating Future Physicians in Palliative and End-of-Life Care

Former les futurs médecins dans les soins palliatifs et de fin de vie

Content – The Role of Health Professionals

Health care providers can & should be a support & resource to individuals doing advance care planning. Health care providers should know how to assist an individual to complete an advance care plan.

Educating Future Physicians
in Palliative and End-of-Life Care

Former les futurs médecins dans
les soins palliatifs et de fin de vie

Content – Ethical Obligations

While the provincial/territorial legal framework is not uniform across the country, there is a legal & professional ethic that crosses provincial/territorial lines. This ethical obligation is expressed by a number of Canadian professional bodies – obliges professionals to honour a person's advance care choices wherever possible.

Educating Future Physicians in Palliative and End-of-Life Care

Former les futurs médecins dans les soins palliatifs et de fin de vie

Content – Role of Health Professionals

The CMA Code of Ethics advises:

- Ascertain wherever possible & recognize your patient's wishes about the initiation, continuation or cessation of life-sustaining treatment.
- Respect the intentions of an incompetent patient as they were expressed (e.g., through a valid advance directive or proxy designation) before the patient became incompetent.

Content – Role of Health Professionals

The Code of Ethics for Registered Nurses (Canadian Nurses Association) states that:

Nurses must respect a person's advance directives about present & future health care choices that have been given or written by a person prior to loss of decisional capacity.

When a person lacks decisional capacity, nurses must obtain consent for nursing care from a substitute decision-maker, subject to the laws in their jurisdiction.

Educating Future Physicians in Palliative and End-of-Life Care

Former les futurs médecins dans les soins palliatifs et de fin de vie

Content – Having the Conversation

- The module focuses on the human side of advance care planning – the conversations health care professionals have with the person & his or her family, how to prepare, what to talk about & what to look out for.
- Provides many examples of how to initiate & have the conversation.