Hospice Palliative Care in the MAiD Environment: Practically how do we co-exist in the new environment?

Friday, September 22, 2017

Presenters:

Dr J. David Henderson MD, CCFP(PC), President CSPCP
Maryse Bouvette, APN PC, Regional Palliative Consultation Team, Bruyere Continuing Care
Sarah Levesque, Canadian Hospice Palliative Care Association
Faculty / Presenter Disclosure

Presenter Names:
David Henderson, Maryse Bouvette, Sarah Levesque

Relationships with commercial interests:
• No relationship with commercial interests.
• No financial support or in-kind support received for this program.

Potential for Conflict(s) of Interest
• David Henderson, Maryse Bouvette and Sarah Levesque have not received payment for this presentation
• Products/programs discussed in the presentation have not made financial or in-kind contributions to this program
National Perspective
HPC and MAiD: National Context

CHPCA surveyed its membership between July 19 and August 16, 2017 to get feedback on what their experiences had been with MAiD to date.

WHY ASK?

So much of what we hear is through a national media lens, but we wanted to hear about what has been happening on the ground.
What did CHPCA want to know?

• What have been your lived experiences?
• What is your role and setting of care?
• What are your particular insights?

To what end?
• How can we remain focused on person-centered care within the Hospice Palliative Care community across Canada in light of this change?
THE DATA

Who responded?

• Almost 500 responses were received from all 12 provinces (no responses from any of the 3 territories).
Who responded?
Responses from many roles and all settings of care with nurses (36%), administrators (17%), volunteers (17%) and physicians (12%) with the highest rates of participation.
Respondents identified the following settings of care:

- Residential Hospice
- Home Care
- Acute Care Hospital
- Palliative Care Society
- Prison
- Shelter
- Long Term Care Facility
- Other
Current position on MAiD in these Settings of Care

- Our organization does not perform MAiD
- MAiD has been performed on site despite our recommending against it.
- Our organization allows an outside team/organization to perform MAiD on site.
- Our organization DOES NOT have a policy on MAiD yet.
- MAiD has been/can be performed on site.
Requests for MAiD

Has your organization received requests for MAiD?
Do you have a policy on MAiD.

...and has it been implemented?
Support for HPC and support for MAiD from provinces and health authorities

Have you received adequate support about MAiD?

Have you received adequate support for HPC?
Biggest challenges: Options

- Public and professional confusion about the difference between palliative care and MAiD
- Local public backlash against MAiD
- Local public backlash against our position not to allow MAiD to be performed
- Keeping person or patient-centered care at the center of our focus on Hospice Palliative Care.
- Lack of policy and process clarity
- Staffing to perform MAiD assessments
- Shortage of resources to perform MAiD
- Shortage of resources to maintain HPC standards
- Shortage of resources to deal with psychosocial aspects of care before during and after MAiD in all settings
- Emotional toll on health care professionals and volunteers
- Other
The biggest challenges...

All of them!
Insights from members: Key Messages

1. MAiD is here to stay: we need to figure out how to co-exist, keeping patient-centred care front of mind.
2. We need to promote universal access to HPC.
3. More funding is needed to expand HPC services and programs; we need to better articulate gaps in care.
4. There are gaps in education and training for both HPC and MAiD.
5. There are still limited policies around HPC and MAiD.
6. Canadians need better awareness of HPC and what it means.
A selection of comments

• "Il y a beaucoup de belles expériences spirituelles chez les patients et les familles qui vivent l'aide médicale à mourir. C'est mon expérience actuelle. Des départs dans l'amour et la dignité. Je déplore parfois les tensions entre ceux qui sont contre cette approche et ceux qui sont pour, cela n'aide pas le patient. Les soins palliatifs doivent marcher de concert avec cette option de soin de confort, telle que présenté dans la loi du Québec."

• "... there is a significant lack of economic support for the development of adequate palliative care resources, but in contrast to many of my colleagues I don't see this as contributing to the decision of patients to pursue MAID, and I have been involved in the majority of MAID cases in the province."
• “97% or more of individuals wish to live well until natural death. It is critical that more support is provided for effective and timely access to palliative care. Although goals of care discussions, pain and symptom management, and supports for patient and family are our job to do, also for individuals who chose MAiD, the procedure of MAiD is not. It is possible for a palliative care program to stay true to the WHO definition of palliative care during the first year and a half that MAiD has been legally available Canada.”

• “Grief for those left behind is different. There is an aspect of shame and a need to keep it "hidden", not to talk or tell.”

• “I believe Palliative Care should be kept a separate specialty from the performance of MAiD as the end goal of each is very different!”
“As a practitioner I wholly support a patient's autonomy and have no issue with MAID as an option. I am exceedingly disheartened that palliative care services have not been adequate to start with (pre-legislation), nor are they being increased, to prevent patients from choosing MAID simply because they did not have access to good, comprehensive palliative care. This is happening, I am seeing it my practice now regularly.”
What’s next?

• CHPCA will be delving more deeply into the data following the conference and will be writing a full report on the survey results in the coming months.

• Once finished, the report will be available at www.chpca.net/projects-and-advocacy/maid

• Questions? Email us at info@chpca.net
Provincial Perspective
The intersection of MAiD and Palliative Care

National perspective
Provincial perspective
Local perspective
What do we do for these patients?

Vignette A
Mary
66 YO, advanced pancreatic cancer; liver mets and cachexia. Disease progression despite chemotherapy

Vignette B
Jack
73 YO man with advanced COPD; Lung fct 30% of normal Shortness of breath on mild exertion

Vignette C
Morris 53 YO man with recent diagnosis of Non-small cell lung Ca Shortness of breath on mild exertion. Requests MAiD
Canadian Society of Palliative Care Physicians

Survey
Statement
Current issues
Next steps

http://www.cspcp.ca
The majority of our members believe that this should not be provided by palliative care physicians. The SCC decision stated "While there are risks, to be sure, a carefully designed and managed system is capable of adequately addressing them".
Canadian Society of Palliative Care Physicians key recommendations on reducing harm:

Potential harm to patients who choose hastening their death because of inadequate support, including palliative care;
Potential harm to other individuals who may be negatively impacted, including physicians with strong moral opposition to any form of participation;
Potential harm to the specialty of palliative care, the medical profession and our allied health colleagues.

Respecting Palliative Care

For 40 years in Canada, Palliative Care providers and educators have been trying to correct the myth propagated by the public and health care providers that Palliative Care hastened death.

This fear has led to people waiting to access palliative care services and for health care providers to hesitate to refer to palliative care until very close to end of life.

Those of us working in Palliative Care Programs have all seen people who have struggled with uncontrolled symptoms for extended periods of time that have been brought under control very quickly once managed appropriately by clinicians who have had training in palliative care.

If Palliative Care Professionals now to start providing Maid or if it’s made available on palliative care units it undermines these 40 years of advocacy just when we are making progress.¹

¹ José Pereira, M.B.Ch.B., M.Sc., et al. Assisted Suicide and Euthanasia Should Not Be Practiced in Palliative Care Units. JOURNAL OF PALLIATIVE MEDICINE Volume 11, Number 8, 2008
Current Issues and Next steps

Request for comment on:

Advance Directives
Mature Minors
Mental Health as a primary diagnosis

Council of Canadian Academies (CCA), Expert Panel on Medical Assistance in Dying (MAID).

Re-survey membership to ensure we are speaking for the majority

- Develop a way to support members who are conscientious providers and conscientious objectors.
- Advocate for public and professional education
  - Death and dying
  - Palliative Care
  - Maid
Nova Scotia Health Authority

- Policy development
- Key factors (from a palliative care physicians perspective)
- Roll out
Local Planning.

- Work group development
- Team makeup
- Ideas
- Where we are today
- Where we may need to go
What we do with a persistent request. Operationalizing MAiD

Step 1: Attending MD contacts NSHA VP Medicine office (902 491-5892) and notifies Medical Site Lead and / or Administrative Site Lead of the request. Site Leads notifies the operational team.

Step 2: of Assessor 1 and 2 (Note: Assessor 1 does not need to be the attending MD)

Step 3: Assessors complete the comprehensive assessment form and determines if the patient meets eligibility.

- Inpatient / Community based patient requests MAiD
  - Assessors Determine Patient Meets MAID Criteria
    - Confirm Witness Complete (#3)
  - Assessors Determine Patient Does Not Meet MAID Criteria
    - Attending MD is notified
    - Patient may request MAID in the future
    - Patient requests MAID in the community (D/C planning initiated and patient transferred)
What we do with a persistent request.

Planning/Communication:

- Logistics team is notified MAID procedure will happen in hospital (operational site lead, medical site lead, pharmacy, spiritual care, palliative care (if involved in the care of the patient), attending MD, mentoring MDs, etc.
- When location, day and time have been identified: manager and staff will be notified.
- Local support team notified - SW & ambulatory patient care leader, spiritual care etc.
- Patient / Family: funeral arrangements made, seek input re: procedure (before the day of procedure)
- Automatic 10 day waiting period (may be waived in some situations – see NSHA MAID form)

Pre event: 24-48 hours prior

- Room prep, IV access established (1-2), family requests, funeral requests, transport, registration, PPO completed; identify support staff (RNs), Rx sent to pharmacy, notify security if necessary
- Procedure date and time confirmed with patient, family and Assessor #2
- Fax medication order to provider 2 (include patient identification label)

Post event:

- Support for family, time with patient, funeral arrangements
- Staff Support and Debrief – EAP/hospice, spiritual care
- Pharmacy or designate will return unused medication (2nd kit) to pharmacy
- Logistics Team Debrief and Reviews CEHHC Guidelines

*last updated March 29, 2017*
Empathic, patient-centered response

“I’m glad you asked me about this, but before I answer may I ask more about what led you to ask this question?”

-OR-

“I am honoured that you felt comfortable enough to talk to me about this, can you tell me what is leading you to ask about this?”

-OR-

“Thank you for trusting me enough to ask that question, It seems very important to you, can you tell me more?”

-OR-

“Thank you for trusting me enough to ask that question, It seems very important to you, can I finish …… and come back so we have more time to talk about this?”
Exploring Requests for MAID
Accepting this role takes courage

To succeed, you enter into the patient/family story. (Values/goals)
• You become a part of the story.
• You become vulnerable as another human sharing the mystery, pain, suffering, joy and wonder of mortality.

To do this, we need to engage into deep personal reflection, and learn to balance personal integrity and non-abandonment. Use your perspective teams as a sounding board to support you.
Challenges

Non-abandonment
Supporting the patient
Supporting families
  • Supportive families
  • Non-supportive families
  • Bereavement support
Challenges

Supporting staff

Conscientious providers
Education
Confident referrals
What assessments will be done?
Emotional support
Additional study of the effects of providing MAiD on providers
Conscientious objectors
Effects on Physicians/Nurse Practitioners

Research shows that the emotional and psychological effects on the provider can be substantial. Feeling powerless and isolated and being taken aback by the “suddenness” of the death.

Effects continued

The rest of the team and even conscientious objectors fielding requests can be affected as well.

Mona Gupta Psychiatrist/Bioethics researcher
Centre Hospitalier de l’Universite de Montreal

One suggestion is to have formal briefings for health care team to talk with ethicists, spiritual care providers or psychologists.

“We need to help health care providers develop communication skills and the ability to personally reflect on assisted death”

Dr Eric Wasylenko Palliative Care Physician/Clinical Ethicist Univ. of Alberta
Supporting our colleagues safely

One male physician in Ontario commented “I don’t feel comfortable showing emotion in front of the team, in front of my colleagues.” “I once revealed my feelings, and showed emotion in front of my colleagues. They treated me differently after that– I was no longer part of the herd, no longer seen as reliable. It felt a lot like being shunned.”

V. Milne et al. Healthy Debate, June 2, 2016
Still much to learn!
Local Perspective
Objectives

• Better understand one's own the philosophy of Palliative Care (PC) is distinct from the Medical Assistance in Dying (MAiD)’s one
• Name Advance Care Planning as key element
• Review a framework for ethical dialogue
• Discuss clinical situations reinforcing the reality of the co-existence of PC and MAID
Palliative Care aims to relieve suffering and improve the quality of living and dying in those patients diagnosed with a progressive, incurable illness.

- Palliative care applies to all ages
- Palliative care addresses:
  - Physical, psychological, social, and spiritual needs
  - Loss, grief and bereavement
  - Preparation for, and management of, self-determined life closure and the dying process
- It may complement and enhance disease-modifying therapy or it may become the total focus of care
Aspects/Domains of Holistic Care

Adapted from: “Domains of Issues Associated with Illness and Bereavement” in A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice. CHPCA, March 2013,
Palliative Care

Affirms life and regards dying

...as normal

Intends neither to hasten nor postpone death
What do patients and families want?

- Achieving adequate pain and symptom management
- Avoiding inappropriate prolongation of dying
- Achieving a sense of control
- Relieving burden
- Strengthening family relationships

Quality of life

How does the reality of MAID unfold in our daily Palliative Care clinical work?
An “ethical grid” to assist in decision making

<table>
<thead>
<tr>
<th><strong>Medical Considerations</strong></th>
<th><strong>Patient (and Family) Factors and Preferences</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Facts of the medical history</td>
<td>Patient/family understanding of illness</td>
</tr>
<tr>
<td>Prognosis</td>
<td>Patient capacity to make decisions</td>
</tr>
<tr>
<td>Treatment options, risks vs. benefits</td>
<td>Patient goals</td>
</tr>
<tr>
<td>Are treatments being considered consistent with</td>
<td></td>
</tr>
<tr>
<td>goals of care?</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Quality of Life Issues</strong></th>
<th><strong>Contextual Considerations</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>What does quality of life mean for the patient</td>
<td>Whose interests are affected?</td>
</tr>
<tr>
<td>(and family)?</td>
<td>What are societal norms and expectations?</td>
</tr>
<tr>
<td>What gives meaning and brings dignity to their</td>
<td>What are the thoughts of the caregivers?</td>
</tr>
<tr>
<td>life?</td>
<td></td>
</tr>
</tbody>
</table>

An “ethical grid” to assist in decision making

<table>
<thead>
<tr>
<th>Medical Considerations</th>
<th>Patient (and Family) Factors and Preferences</th>
</tr>
</thead>
<tbody>
<tr>
<td>Facts of the medical history</td>
<td>Patient/family understanding of illness</td>
</tr>
<tr>
<td>Prognosis</td>
<td>Patient capacity to make decisions</td>
</tr>
<tr>
<td>Treatment options, risks vs. benefits</td>
<td>Patient goals</td>
</tr>
<tr>
<td>Are treatments being considered consistent with goals of care?</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Quality of Life Issues</th>
<th>Contextual Considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>What does quality of life mean for the patient (and family)?</td>
<td>Whose interests are affected?</td>
</tr>
<tr>
<td>What gives meaning and brings dignity to their life?</td>
<td>What are societal norms and expectations?</td>
</tr>
<tr>
<td></td>
<td>What are the thoughts of the caregivers?</td>
</tr>
</tbody>
</table>

Mrs Rose

- 84 year old woman
- Hx of COPD, closely followed by respirologist
- Recurrent pneumonia
- Arthritis
- Angina
Mrs Rose

Living in LTC
X 2 years

84 yo

13yo
Mrs Rose

Problem:

Mrs Rose has decided that her quality of life was so poor that she was now determined to be transferred to the PCU to die.

Note: MAID not available at that time
The problem???

My point of view

The other`s point of view
Slow Decline from Chronic Disease

- e.g. CHF, COPD

The EPEC Project
My point of view
Common point of view
Common ground
Dialogue
The other`s point of view

Latimer 1998
Increasing her awareness about her options
The impact of Palliative Care

From Victim to Decision-maker

Her journey…
Clinical Situation: Mr Ian Fection

• 39 year old man

• Progressive multiple sclerosis

• Living in complex continuing care setting X 9 years

• Requiring complete care

• Experiencing recurrent pulmonary and urinary infections

• Developing difficulty swallowing
Clinical Situation: Mr Ian Fection

Problems:

• Mr Fection is frequently sharing with the nurses how he finds it hard to live.

• He has been offered psycho-social spiritual support

• He has been assessed by psychiatry to rule out depression
My point of view

The other's point of view

Common point of view

Common ground

Dialogue

Latimer 1998
Problem Solving

- Clarify the problem
  - Patient
  - Family
  - Team

Factors influencing the decision
- Cultural Context
- Patient as person
- Patient/ family Experience
- Disease
- Team

Latimer, 2005
What are the GOAL and OBJECTIVES?

For each decision:
What are the advantages/disadvantages?
What are the patient’s wishes?
Are they congruent with the goal and objectives?
The impact of Palliative Care

It is about Control!
Advance Care Planning

Speak Up

Start the conversation about end-of-life care.
Time!

...a therapeutic option

Dr Jose Pereira, 2008
Mr. Too Slow

- 74 year old man
- Diagnosed with metastatic oesophageal cancer
- No more oncology treatment
- Very poor prognosis
- PPS 40%
-
Mr. Too Slow

- Living at home with his wife.
- Good support from sons and their families

5 grand children
Mr. Too Slow

Medical assistance in living

Versus

Medical assistance in dying
The problem???

Mr. Time

Mrs Time

Palliative Care assisted in clarifying the issue
Got a Severe Case of Ostrich Syndrome?
Major areas of difficulty:

- Facts
- Methods
- Goals & Objectives
- Values

Level of difficulty
EOL Key Factors:

- Family dynamics
- Belief systems (societal, local, personal…)
- Health care system/information (as a person)
- Cultural factors
- Technology
So, can Palliative Care and MAiD CO-EXIST?
Yes, Palliative Care and MAID can co-exist.
Palliative Care is **NOT** about **OUTCOME** but about helping a human being through his journey towards death, based on:

- His values
- His peers/family support
- His past and present journey and related suffering
- His choice
Our society needs to improve the access to PALLIATIVE CARE in order to see DEATH as a reality in its search for meaning.

Palliative Care can **make a difference!**

It is about relationship and being present = **good care**
“Man is not destroyed by suffering, he is destroyed by suffering without meaning”.

Viktor E. Frankl 1959
Questions
Comments!
References

• Canadian Hospice Palliative Care Association, National Normes, 2002 (Web site).

• Canadian Hospice Palliative Care Association, Advance Care Planning (Web site)

• Hall, Pippa; Bouvette, Maryse; Heilmann-Stille, Kirsten; and Weaver, Lynda. Interprofessional collaborative practice in palliative care in Palliative Medicine, A Case-based Manual, Oxford, UK, 2012.


• Pallium Pocket Book, 2013