Caring for the Caregivers of Patients Choosing MAID

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Faculty/Presenter Disclosure

Faculty:
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Patents: None / None / None
Other: Employee of Alberta Health Services / Alberta Health Services / N/A
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None
Mitigating Potential Bias
Objectives

1. Recognize the unique challenges associated with supporting caregivers of patients choosing MAID

2. Identify the social and emotional supports currently available

3. Review results and recommendations of South Zone MAID family feedback questionnaire
If you have a device (iPhone, Android, tablet, or computer), please go to the website

www.menti.com

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Leona’s Story
Leona’s Thoughts

- Patient-centred v. Family-centred support
- Professional Responsibility v. Personal Belief
- Patient/Caregiver v. Health System
- Social/emotional support for the caregiver
  - Including respect for their information needs
- Understanding the role of hospice care
- Continuity of MAiD support
- Pre/Post MAiD grief counselling
Provincial Approach to MAiD
Annual Palliative Education and Research Days

June-Dec 2016: 63
2017: 205
2018: 305
2019: 239*

*(as of Aug 31/19)

<table>
<thead>
<tr>
<th>Zone</th>
<th>Total</th>
<th>Facility</th>
<th>Community</th>
</tr>
</thead>
<tbody>
<tr>
<td>South</td>
<td>90</td>
<td>65</td>
<td>25</td>
</tr>
<tr>
<td>Calgary</td>
<td>298</td>
<td>191</td>
<td>107</td>
</tr>
<tr>
<td>Central</td>
<td>79</td>
<td>55</td>
<td>24</td>
</tr>
<tr>
<td>Edmonton</td>
<td>294</td>
<td>180</td>
<td>114</td>
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<tr>
<td>North</td>
<td>51</td>
<td>29</td>
<td>22</td>
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<tr>
<td><strong>TOTAL</strong></td>
<td>812</td>
<td>520</td>
<td>292</td>
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</tbody>
</table>

*data is cumulative beginning June 17, 2016
As of Aug 31/19
Annual Palliative Education and Research Days

Patient and Family Process

1. Inquiry
2. Meet with Care Coordination Service (CCS)
3. Assessment 1
4. Provision of MAID
5. Follow up with Family

*Min. 10 Days

- Formal Request
- Ongoing dialogue with CCS, planning

Assessment 1 Assessment 2
Family Feedback

- Semi-Structured Interviews
- Family focus group
- Questionnaire

n = 38
Family Survey (n=14)

<table>
<thead>
<tr>
<th></th>
<th>Rate 4/5</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall Satisfaction</td>
<td>92%</td>
<td>4.6</td>
</tr>
<tr>
<td>Satisfaction with the way they were treated</td>
<td>92%</td>
<td>4.5</td>
</tr>
<tr>
<td>Finding info on MAID</td>
<td>80%</td>
<td>4.3</td>
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</table>
## Family Survey

<table>
<thead>
<tr>
<th></th>
<th>Response Rate</th>
<th>Rating</th>
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</thead>
<tbody>
<tr>
<td>Timely response</td>
<td>86%</td>
<td>4.8</td>
</tr>
<tr>
<td>Adequate info – patient</td>
<td>71%</td>
<td>4.5</td>
</tr>
<tr>
<td>Info – self</td>
<td>79%</td>
<td>4.6</td>
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</tbody>
</table>
### Family Survey – Emotional support

<table>
<thead>
<tr>
<th></th>
<th>Prior to Death</th>
<th>Day of Death</th>
<th>After Death</th>
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</thead>
<tbody>
<tr>
<td><strong>Patient</strong></td>
<td>69% (4.0)</td>
<td>85% (4.2)</td>
<td></td>
</tr>
<tr>
<td><strong>Family</strong></td>
<td>69% (3.7)</td>
<td>77% (4.2)</td>
<td>62% (3.6)</td>
</tr>
</tbody>
</table>

“Would be nice if there was a community support group for families after”

“There is no help for men and we are just supposed to suck it up and get on with life. There is no compassion in your system for men…”
### Social Work

<table>
<thead>
<tr>
<th></th>
<th>Pre</th>
<th>MAID</th>
<th>Post</th>
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<tbody>
<tr>
<td>AHS:</td>
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<td></td>
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<tr>
<td>Inpatients / Facility</td>
<td>X*</td>
<td>X*</td>
<td></td>
</tr>
<tr>
<td>Palliative Care</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Home Care</td>
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<td>X*</td>
<td></td>
</tr>
<tr>
<td>Covenant Health:</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Inpatients / Facility</td>
<td>X</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Supportive care, not counselling
Back to Menti

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What does the research say?
Caregivers of individuals who seek MAiD vary little from other caregivers

- Hard to engage in research because they are already stretched thin.
- System that emphasizes patient-centered care and individual autonomy.
- Difficult to define, given “the multiple meaningful and differing relationships patients may have” (Goldberg et al., 2019, p. 1)
- Need better access to early and ongoing psychosocial intervention
Canadian Hospice Palliative Care Association *Fact Sheet: Hospice Palliative Care in Canada* (2017)

- Less than half of Caregivers say the support and information they need is often available
  - one fifth say it is always available
- Canadians who provided care for those at end of life:
  - negative effect on mental health (41%)
  - negative effect on physical health (38%)
Factors that complicate the caregiver role in MAiD include:

• Additional tasks associated with accessing MAiD
• Personal dilemmas with MAiD
• Relational strain
• Risk of emotional difficulties tied to stigmatization following MAiD
Survey of next of kin July 2016 - July 2017
Hales et al. 2019

• Lack of clarity regarding process; unnecessary complexity and anxiety.
• Distress related to time: reflection period and scheduling the provision.
• Burden associated with keeping MAiD decision private increases complexity of death, grief, and healing process.
• Perception of change in approach from the patient’s care team once an inquiry for MAiD had occurred.
• Limited access, nature, and timing of bereavement support.
Literature review: *Impact of (MAiD) on family caregivers* (Goldberg et al 2019)

- Research on post-MAiD caregiver outcomes is scant
- “(w)hether or not the patient went through with assisted death did not influence grief or mental health outcomes for family members”.
- Secrecy, stigmatization, and relational strain contributed to increased negative outcomes in the absence of caregiver support.
- Advocate for implementation of support services and psychosocial interventions with Caregivers prior to and post MAID
Canadian Association of Psychosocial Oncology (2017)

“(p)sychosocial oncology considers the family as the unit of care and recognizes that family members may also require support when a loved one requests MAID. Psychosocial oncology services should remain involved with patients and families who are undergoing the MAID process, including throughout the steps of MAID assessment, the waiting period (anticipatory grief support), and in the time after MAID is provided. Bereavement services or grief counseling for family members should be offered”
“After patients themselves, (caregivers) are the most impacted by the MAiD process, and yet there is relatively little clinical attention or resources allocated to them”
Emotional support

AHS / Covenant Social Work

Connect Family Members

Local Counsellors

Volunteers

Dying with Dignity Canada

Bridge C14

Patient Family Advisor

Annual Palliative Education and Research Days
Take Home Message

1. Be a **Safe** person to talk to about MAID: *Communicate* this Clearly
2. **Actively Connect** (*nudge*) to resources, don’t just offer “if needed”. Provide written information
3. *Establish Networks* of family members who have had a loved one choose MAID
4. **Continuity** along the journey
References