Caregiver Education Needs Assessment

Pallium Canada

February 26-27, 2018

Ottawa, Ontario

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Executive Summary

Despite the existence of excellent caregiver educational resources available nationally and within some provinces in Canada, Pallium was receiving many requests to develop a caregiver offering that leveraged its Learning Essential Approaches to Palliative Care (LEAP) courseware.

To assess this opportunity, Pallium Canada convened a two-day workshop of caregiving experts and leaders from across Canada to explore:

- the current suite of primary caregiver educational offerings available to Canadians;
- potential gaps in educational primary caregiver offerings;
- the need for nationally available caregiver courseware; and,
- the role that Pallium could play if such an offering were required.

The workshop was attended by 16 participants from across Canada bringing experience and perspectives from: primary caregivers, organizations working with caregivers, research, and health care professionals (physician, RN, pharmacist, paramedic). The workshop was held in Ottawa on February 26-27, 2018.

Over the course of the discussions, the workshop participants arrived at the following findings related to the current state of caregiver educational offerings and opportunities for improvement or growth:

1. Significant, high-quality caregiver-facing resources already exist.
2. There is a need to improve the maintenance and renewal of caregiver resources to ensure that they are up-to-date and accurate for the Canadian care context.
3. Existing efforts to grow and renew caregiver resources should ensure the inclusion of emotional, spiritual, and social supports, beyond just the physical needs.
4. There is a need for new educational resources focused on empowering the caregiver and increasing their comfort level when talking with health care providers.
5. There is a need to increase access to, and awareness of, existing resources through local community support databases and awareness/education activities.
6. Proper and consistent referral to resources is needed. The community can play an important role in sharing the knowledge of resources.
7. There should be transparent, common, and consistent messaging and communication across the continuum of care providers, from physicians to volunteers, about the patient's care and the full-spectrum of resources available.
8. There is a need for a national policy focused on caregivers. This policy should not be disease or disability specific.

Collectively, the group did not see the value in Pallium developing a LEAP course for primary caregivers. Participants felt that the creation of a LEAP product for caregivers was not a valuable use of resources at this time and would not effectively address the existing gaps that were discussed during the workshop. Rather, participants felt that Pallium should look to integrate knowledge about community and caregiver support and resources into its existing LEAP courses for health care professionals. Pallium's work on Compassionate Communities was noted as an opportunity to integrate and support non-clinical needs of patients in the community setting and participants felt that Pallium is well positioned to contribute to building capacity among people that support caregivers.

One potential approach that the workshop participants identified where Pallium could add value is the development of an educational product that would support a cross-section of community members and support services (e.g., health care, police, workplace employees, faith communities, etc.) in their role(s) of providing support to caregivers. Participants recommended that the following topic areas should be included in a potential new product:

1. Impacts of being a Caregiver
2. Self-Reflection/contemplation
3. Dealing with logistics of end-of-life
4. Death literacy
5. Communication tools from a true “holistic” lens

Pallium appreciates the insight and advice that has been provided by the workshop participants on the current strengths and needs in caregiver education. Based on the findings of the workshop, Pallium will ensure any work it undertakes in this area does not duplicate or replicate what already exists but instead builds off existing tools and resources. Pallium will consider integrating information on existing community and caregiver supports into current LEAP courseware and Compassionate Community Toolkits. Pallium will also consider the development of an educational offering to address the educational needs of community members and service providers that support caregivers, including the priority topic areas identified above.

Workshop Proceedings

A two-day workshop was convened to explore: 1) the current primary caregiver educational resources available to Canadians; 2) potential gaps in educational primary caregiver offerings; 3) the need for a nationally available caregiver courseware, in particular for provinces and territories where caregiver support and education was not as readily available as in other areas; and, 4) the role that Pallium could play if such an offering were required. A *list of participants* can be found in (Appendix A). The *agenda* for the workshop can be found in (Appendix B).

The questions that were used to frame the workshop activities were:

1. What educational resources are currently available to caregivers to address their expressed needs?
2. What, if any, are the gaps in educational resources/offerings? How can these gaps be addressed?
3. What might a national Caregiver educational offering look like? What might Pallium's role be?
4. Do we want to collaborate on creating this offering?
5. If so, who else should/could be involved?
6. What resources does the group have to contribute to such a collaboration?

By the end of Day 1, participants did not see the value in Pallium developing a primary caregiver educational offering. Participants felt that the creation of a product for caregivers would not be an effective use of resources at this time and that it would not address the gaps discussed during the workshop. However, participants felt that Pallium is well positioned to contribute to building capacity among people that support caregivers and decided to focus the second day of discussions to consider the relevant topic areas that would be most beneficial if Pallium were to develop a product in this area ("LEAP Community Carers"). The report has been divided into two areas to reflect this outcome: Caregiver Education Needs Assessment and "LEAP Community Carers" Content Recommendations.

Caregiver Education Needs Assessment

To lay the foundation for group discussions, the first few activities of the workshop were focused on identifying the best resources available for primary caregivers. The full list of information generated from this work can be found in *Best Caregiver Educational Offering* (Appendix C) and *Current State of Educational Offerings* (Appendix D).

Participants were then asked to focus on the experiences of primary caregivers by creating an ideal picture of what this person would have wanted during their caregiving experience. See (Appendix E) for full details.

To clarify what role Pallium Canada might play in supporting caregivers through collaboration with provincial and Canadian groups working with caregivers, Kim Martens, Pallium's Interim Chief Operations Officer, identified suggestions and ideas Pallium had been exploring. The description of three potential areas of support can be found in *Pallium's Potential Role* (Appendix F). These descriptions were not meant to be exclusive but rather to set the stage for a discussion among small groups of participants. The results of the group discussions can be found in *Participant Perspectives* (Appendix G).

A summary of the results from the first three questions used to frame the workshop during Day 1 follows.

1. ***What educational resources are currently available to caregivers to address their expressed needs?***

Participants expressed difficulty finding resources to support caregivers' needs. Although numerous resources are available to caregivers, both provincially and Canada-wide, many participants were not aware of them. There is a need for strategies to make these resources known and available to all, thus increasing access to what already exists.

Canadian Virtual Hospice (CVH) was noted for having a variety of resources including videos, links to professionals, and psycho-social support. Pallium's LEAP products were also noted for having a national focus, which ensures everyone receives the same education Canada-wide. However, the LEAP curriculum is possibly too educationally specific for caregivers. Pallium partnering with CVH would be a great opportunity to span the availability to everyone.

There is a clear need to distinguish between *caregiver support* and *caregiver education*. As there is an increased desire from society for more people to be able to die at home, people will need more than physical resources to achieve this. There needs to be actual support from people when there is a crisis. There is a clear need to do better at physically being present. As much as tools and resources are important, these are not a replacement for physically being present and accessible.

In addition to finding ways to physically support the patient and caregiver there is also a need for emotional, spiritual, and social support. Physical resources and/or online support is helpful but is crucial to decrease the burden of isolation deeply felt by many primary caregivers.

What is missing systemically in Canada is that there are only three provincial caregiving associations (a fourth one is in development) and these associations are not getting referrals from health care professionals. More referrals to the provincial organizations are needed. There is also a need for local community support databases and increased awareness of location and availability. For example, 211 has local community resources but some felt it was incomplete.

2. ***What, if any, are the gaps in educational resources/offerings? How can these gaps be addressed?***

Participants felt that whether the experience of the caregiver was good or bad, the caregiver was always left wanting something. Somehow, we need to get the individual caregiver to identify what they need and there is no single solution. We are a society of tasks, forms, and fix-it models—there is something to be said about bearing witness to suffering. There is always lots of people giving solutions and things, but no one is really listening. Some recurring themes were: social isolation and economic burden of caregiving, issues of recognizing/understanding consistent medical terminology, need for navigational support, and ideally a consolidation of local resources to one spot for easy access.

Participants found that while there are good resources and educational support for primary caregivers, there are still gaps in caregiver education needs as well as gaps in education needs for those who support the primary caregiver. Canadian Virtual Hospice was noted for having a variety of resources including videos, links to professionals, and psycho-social support. However, these resources do not address the need to decrease an acute sense of isolation through physical contact with the caregiver.

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Provincial Caregiver associations can provide the physical contact, however only three provinces have such associations and they are not fully leveraged by health care professionals.

The importance of being transparent with the primary caregiver and patient as to what is happening in terms of diagnosis, care, and care decisions, was seen as paramount. Nothing should be hidden from the caregiver and/or patient. There needs to be an element of empowerment to caregiver education so that the caregiver can be comfortable talking to health care providers. Many primary caregivers feel they are forgotten by health care workers and/or are not heard.

There are notable policy gaps beyond educational offerings for caregivers. There should be a national policy for caregivers and not just for disease specific trajectories (e.g.: Framework for Palliative Care). In supporting the caregiver, media outlets need to be more considerate and balanced in how they tell the story.

3. What might a national Caregiver educational offering look like? What might Pallium's role be?

The overwhelming recommendation for Pallium was to focus on education for health care professionals and citizens that help caregivers. The three most common recommendations are described in Table 1.

Table 1: Potential roles for Pallium

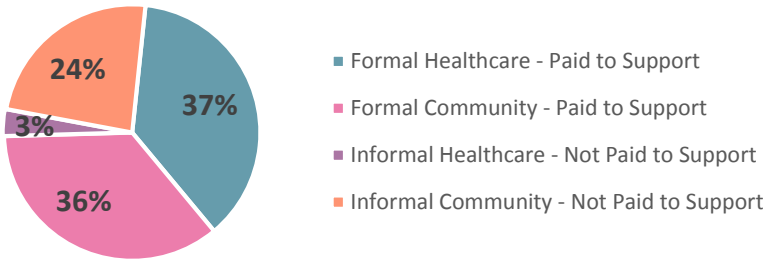
Role	Rational
Integrate caregiver education in current LEAPs	• This is a captive audience who are expanding their knowledge to support patients and caregivers dealing with the palliative care journey. • Share key resource points and awareness of the caregiver journey.
Community-facing toolkit designed to support the caregivers in their community	• Pallium is currently working to mobilize the community to build more compassion and support for those dealing with caregiving, dying, death, and grieving. Could a resource be created for this setting? • This could be a toolkit that is focused on supporting just the caregiver. • Or could we weave knowledge about the caregiving role and how to support them into community products?
New LEAP or other product	• This would be focused on those who are supporting/interacting with caregivers. • This could include health care professionals, emergency response professionals, and others who want to better support caregivers.

LEAP Community Courseware Content Recommendations

To set the stage for the discussion on topic areas for a LEAP Community Carers, participants were asked to reflect on what stood out for them from their work the previous day which is found in *Reflections from the Previous Day* (Appendix H). A key to the day's discussion was putting in place vocabulary, checklists and questions that are common for everyone and allowed everyone to engage in the dialogue.

The first activity of the day was to create an image of the typical circle of care for a primary caregiver and the person they are supporting. Participants were asked to show all the touch points a caregiver/patient might encounter while on their journey and how often they might interact with them. The more interactions, the closer the placement of the touchpoint identified. The results of this activity can be found in *Circle of Care* (Appendix I). Based on this activity, Pallium did a simple classification of roles (See Table 4 in Appendix I) and found that there are more contact points (60% versus 40%) that are not health care specific yet play a supportive role for the patient and caregiver.

Figure 1: Distribution of Formal and Informal Roles.



Participants recommended that Pallium could design a product that would support a cross-section of community members and support services including health care, police, workplace employees, and faith communities, to name a few. Key topic areas to be included in a new Pallium product could include:

1. Impacts of being a Caregiver
2. Self-Reflection/contemplation
3. Dealing with logistics of end-of-life
4. Death literacy
5. Communication tools from a true "holistic" lens

Overall, the participants highlighted the need to ensure that the interdisciplinary approach, which is promoted by Pallium and LEAP, is not exclusive to medical professionals and that everybody (including multi-sectoral and cross-sector carers from the community) is a part of the conversation. The participants felt that Pallium is well placed to contribute to build this connectivity and capacity among people that support caregivers.

Thank you!

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About Pallium

Pallium Canada is a national organization created to improve the quality of hospice and palliative care services through the development and dissemination of peer-reviewed education, resources, and clinical decision-making tools for inter-professional health care providers. Since 2001, Pallium Canada has been the sole national organization supporting continuing inter-professional palliative care education across Canada.

Pallium Canada's initiatives are all guided by a recognition of the need for an integrated approach to person-centered care for patients and their families living with a life-threatening illness. Pallium Canada aims to empower primary care and non-specialist providers in the delivery of high-quality palliative care through its educational programs, tools, and resources (including recently enhanced e-learning and multimedia formats). It is our hope that these tools may also act as a catalyst to improve the equity of access to palliative services for all Canadians and to help ensure their comfort and dignity throughout the illness journey.

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Appendix A: List of Participants

Attendees:

- Angus Campbell, Executive Director - Caregivers Nova Scotia/Caregiver – NS
- Anya Humphrey, Family Caregiver – ON
- Dr. Barbara Pesut, Professor/Canada Research Chair - Nav Care/UBC – BC
- Bonnie Tompkins, Compassionate Communities National Lead - Pallium Canada – ON
- Dr. David Henderson, Medical Director/President - Colchester East Hants Palliative Care Program and Canadian Society of Palliative Care Physicians – NS
- Dr. Elspeth MacEwan, Physician/Psychiatrist – ON
- Dr. Jasneet Parmar, Associate Professor/Medical Director CH Seniors Network/Medical Lead AHS Home Living and Transitions - Covenant Health and Alberta Health Services – AB
- Jodie McDonald, Provincial Program Consultant - Family Caregivers of British Columbia – BC
- Kim Fredricks, Regional Advisor and Project Manager - L'Appui – QC
- Kristen Watt, Community Pharmacist – ON
- Magalie Dumas, Regional Advisor and Caregiver Helpline Coordinator - L'Appui – QC
- Nahal Stoppels, Registered Nurse - Roger Neilson House/CHEO – ON
- Natalie Labelle, Clinical Coordinator - Regional Paramedic Program for Eastern Ontario – ON
- Pat Zakaib, Management and Organizational Consultant - Canadian Virtual Hospice (CVH) – ON
- Serena Lewis, Social Worker – NS
- Tim Stairs, Paramedic - Paramedic Association of Canada – NB

Regrets:

- Emma Gofton, Family Caregiver – ON

Facilitator:

- Kim Martens, Interim COO - Pallium Canada – ON

Facilitation Support:

- David Elliot, Program Improvement and Sustainability Lead - Pallium Canada – ON
- Kirsten Efremov, Compassionate Communities Assistant - Pallium Canada – ON

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Appendix B: Workshop Agenda

Caregiver Education Needs Assessment

Day 1: February 26, 2018

Time	Topic
8:30	Welcome & Meeting logistics
9:00	Best Caregiver Educational Offerings
9:25	Sharing Our Stories and Personal Resources
10:00	Current State of Educational Offerings
10:45	Break
11:00	Plenary Reflection
11:10	The Primary Caregiver perspective
12:30	Lunch
1:30	Pallium's potential role
2:15	Participant Perspectives on Pallium's Role
3:00	Break
3:15	Recommendations to Pallium on its role
4:30	Conclusion of Needs Assessment/ Request for help on LEAP Community
4:45	End of Day 1

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LEAP Community Courseware Content Recommendations

Day2: February 27, 2018

Time	Topic
8:30	Welcome & Reflections from Day 1
9:00	Circle of Care
10:15	Break
10:30	What might a LEAP Community Carers Look like?
11:45	Additional topics for consideration
12:15	Final thoughts
12:30	End of Day 2

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Appendix C: Best Caregiver Educational Offerings

Activity: Participants were asked to find someone they did not know, introduce themselves and then describe the best caregiver education offering/resource they were aware of.

Results: During this activity, the best resources discussed were:

- What to expect offering in hospice (Coach the caregiver at every point in the process)
- What to expect on Admission to Long-term Care – family resource tool
- What to expect in the last hours/days of life
- LEAP Paramedic
  - http://pallium.ca/leap-courses/leap-paramedic/
- Hospice Booklet – Develop Curriculum Communication with Caregivers (Nova Scotia Workplace Education)
- L'Appui Web Portal
  - https://www.lappui.org/en
- Canadian Virtual Hospice "Ask a Doc
  - http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Support/Support/Ask+a+Professional.aspx
- Canadian Virtual Hospice – resources that are always available specifically my grief
  - http://www.mygrief.ca/
- E-Learning and Webinars through Family Caregivers of BC
  - https://www.familycaregiversbc.ca/events/webinars/
- 211 / hipinfo.ca – resources online, over the phone or in person
  - http://211.ca/ (national number)
  - http://www.hipinfo.ca/ (Halton Community Services Database – each community should have their own database. At this specific local level you can call, go online or go into any library and receive assistance from any librarian)
- 3-hour caregiver Workshop
  - http://caregiversns.org/
- CHPCA and Order of Lazarus Caregiver Handbook (Green Caregiver Book)
  - https://www.stlazarus.ca/docs/publications/caregivers_guide_2015_en.pdf
- Faith-based Communities
- Caregiver Coaching

Other Resources:

- Medscheck in Ontario
  - https://www.opatoday.com/professional/resources/for-pharmacists/programs/medscheck
- Double Duty – health work force that is providing care in the health care system and to caregivers.

Participant reflections as part of the activity:

There may be numerous resources available to caregivers in each province and Canada-wide but many of us have not heard about resources presented today.

In a hospice/hospital setting, there is a captured audience, so we can facilitate a lot of the conversation that is happening. How do we get tools/information out there and are they as an effective tool as having the right people out there having the conversations with caregivers? How can we create tools that work like those tools available in the hospice (right information, right time, for the right person, in the right format)?

There is not just one way we can support caregivers. There are multiple modes we are going to have to use in order to meet the needs of all caregivers.

There are different supports that are in different geographical areas and how do we get that inventory going for the people in those specific areas. Strategies on how to make these resources available.

As there is more pressure from society for more people to die at home, people need more than physical resources. There needs to be actual support from people when there is a crisis. We need to do better at physically being there. As much as we need to use and share the tools and resources, we also need to realize and remember these aren't replacement for physically being present and accessible.

There is a clear need to distinguish between *caregiver support* and *caregiver education*.

Information isn't what people always need. Many popular topics seen by Family Caregivers of BC is those on support and how to feel more supported and how to support yourself emotionally. The moment we take our support resource and turn it into a webinar, booklet, pamphlet or workshop then it becomes education. That education can be very supportive in ways if you have that connection but then there becomes a moment when the education no longer meets the need.

Workshops developed specifically for caregivers in mind. Nova Scotia Caregivers developed a course to teach ACP to caregivers because caregivers need to know to do to an ACP for someone who is dying.

Canadian Virtual Hospice (CVH) has a team of professional doctors who are available to communicate with a person with specific problems if the caregiver does not have time to go to a seminar. CVH has tools that are always available 24 hours a day.

Caregivers still don't feel supported. Huge opportunity for health care providers to provide caregiver support at the time it's needed, at the point of care, in a timely manner and to make those resources available to our family caregivers. Trying to educate health care professional about family caregivers and the resources that are available in that geographic area.

Who do we educate? How much time do we spend educating caregivers? Or do we need to make sure all our home care agencies etc. have this education?

Looking at other LEAP products that Pallium has done, they bring together a national focus and because of this you know you are going to get the same education Canada wide. This brings together a focused best practices collection of information that makes it easy for everyone across the country to not have

to search for this information. Can we consolidate these tools and bring best practice tools together and make that available widely? It would not solve all the issues, but it would be a great start.

Huge breakdown in communication from the system and the patient and the caregivers are in the middle. The breakdown seems to come from what the system wants and what the caregiver needs. How can we build education for the system to communicate and raise awareness to the caregivers and patients, almost forming a loop so that the system can improve for the caregivers? Perhaps instead of creating education we look at a communication strategy for communicating these existing resources.

What do we think of education? Often when it is related to education we create competencies and curriculum then we deliver and evaluate. So, we probably need 2 strategies because often times what the caregiver needs is always in the moment and it's always in the context of support. Marco strategy in that we do have some curriculum and best practices available then an in the moment strategy support and having 2 different target audiences for each group.

LEAP curriculum possibly too educationally specific for caregivers. Instructing people without making them feel like its education. Partnering with CVH would be a great opportunity to span the availability to everyone. Then providing occasional workshop settings to allow caregivers to meet would be a great secondary offering.

What is missing systemically in Canada is that we only have 3 provincial caregiving associations (4th one in the works) and the caregiving associations don't get the referrals from health care professionals. The number one thing Caregivers Nova Scotia hears is that "we had no idea you existed" and "I am so glad I am able to talk to somebody". Systemically, we need to have more referrals to the provincial organizations.

Also, there are 10 provinces and 3 territories in Canada, yet we only have 3 (soon to be 4) caregiving associations.

Many psychosocial gaps and how do we help health care providers be more comfortable in those situations. There can be a level of empowerment in helping health care providers become more comfortable talking about uncomfortable topics. Which could have a much broader impact than trying to gear it to all the caregivers with diverse needs across Canada.

Take the audience and teach/educate them on how to ask those health care professionals how to slow down, for example. Maybe with these courses we need to empower the caregiver to talk directly to health care professional.

Community and non-profit can bring in psychological, mental, emotional and social support and when health care professionals are stressed out or have poor resources they can only focus on the physical wedge of the pie. So, when community and not for profit can come in and say I can help with the caregiver, I can go for coffee with them and/or go to where they are then the health care professionals feel more relieved. When education focuses only on the intellectual pie it is not sufficient care. Educational efforts are more important when they are meeting ALL dimensions of health.

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Appendix D: Current State Caregiver Educational Offering

Activity: Participants were asked to individually write down five of their organization's greatest resources or the five greatest resources that they had used as a Caregiver. Of these five resources, participants were then asked to choose the top two. These resources were grouped according to their use within group settings, for individual support or resources that could be used in either setting (both). (See Table 1: Top Caregiver Resources). The other three resources were captured in Table 2: as Additional Resources.

Discussion Summary:

There is clearly a wealth of resources available to Canadian caregivers but with such small projects in place it can be hard and unclear as to where to direct a person. There could be a need to develop education about what is already existing rather than evidence-based criteria on what we could develop, as we have just scratched the surface. However, we also need to be mindful of how things change, what is still relevant and valid, and what is considered useful and helpful information for caregivers. The caregiving journey can greatly differ from person to person. It can be sudden and quick or chronic and slow and ever changing. Thus, education would have to be mindful of these different trajectories. Maybe developing or supporting a national policy for family caregivers is the key, as we are already moving towards patient and family centered care. Often in policies/bills the term used is family and not family caregivers this leave a gap. Most recently a National policy for palliative care was established and it is the hope that caregivers will be a part of this. But do we need to shine a light on family caregivers under each strategy/policy/bill or advocate for a national framework focusing solely on family caregivers regardless of disease/disability? Finally, half of family caregivers often already work 30 plus hours a week in addition to taking care of patient. Employers and workplaces need to be given the correct education and tools to know how to manage the situations appropriately.

Table 2: Top Caregiver Resources

Group
• Advance Care planning for Caregivers • Alzheimer's Society AB and NWT "Seeds of Hope Program" • Caregivers Alberta (Caregivers Canada) – Navigator (HCPs) and Compass (7CGs) • TeamStepps (app and curriculum and implementation plan) • Roger Neilson House – Parent Support Group (Facilitated and peer directed option) Caregiver Tele-Connect

Both Individual and Group
• Video: Jim Mulcahy – A Story of Care? • KidsGrief Webinars – CVH • Community Map of resources/agencies/people/places • Lotsahelpinghands.com – Create a care community • "Circles of Support: Strengthening Personal Networks" (Model and Training) – Cowichan Family Caregivers Support Society • Resource Template – Community based for NAVcare • Hipinfo.ca (palliative care/grief tab) • Family caregivers of BC/TCN – Webinar: "Non-violent Communication for Difficult Conversations". • Choosing wisely guidelines for palliative care • Next step in care – 7C4s and HCPs Working together PATH program – medication de-prescribing guidelines

Individual
• Symptom Response Kit • Chat/Phone Programs with Peers (ex: Cancer Society – Volunteers are matched with caregivers through a platform – needs, similar experience)/Peer Support • Caregiver helpline or website service to accompany and support in real time • CVH – Ask a professional/How to videos • Guide about their options, rights and choices – Be aware = Be prepared – Empowerment • 24/7 on call palliative care MD and RN for Support and/or troubleshooting • A guide with all the acronyms used by the health and social services workers • Care for a loved one at home – decision guide (Robinson et. al.) • Changes Toolkit from U of A (Duggleby et. al.) • CHPCA Compassionate Care Brochure • A workbook/care log for caregiver/anyone to fill in their person's story, likes/dislikes/memories/care journey • "Staying Healthy while Caregiving" – Family Caregivers of BC eLearning Course • EAP • A caregiver's Guide • How to deal with EoL or geriatric issues in the emergency room • My Ear "actively listening" – Nothing about me without me

Table 3: Additional Resources

- Demand a plan – senior awareness
- 211 – National Database
- Choosing wisely guidelines for LTC
- LHIN Palliative Pain and symptom Management Outreach Nurse
- An invitation to a social meeting with other caregivers and a professional of health care system
- A list of helpful websites (e.g.: Canadian Virtual Hospice, caringbridge.org)
- Caregiver supports and resources (www.seniorsnetworkcovenany.ca)
- The change foundation (www.changefoundation.ca)
- University of Texas (SA) PL (www.uthscsa.edu) – People Living with Dementia
- Saint Elizabeth
- Family Caregivers of BC/TCN: Webinar – "Self-Compassion"
- "Navigating the Healthcare system" – Webinar Family Caregivers of BC/TCN
- "Are you Aging Well?" Resource Card (Based on Dr. Rockwood's Frailty Scale – Eldercare Project in Cowichan)
- Speak up Tool ACP - advancecareplanning.ca
- Training Programs Web and Nurses (ex: Stress Management, Devenir aidant, ça s'apprend ("Learning How to become/to be a caregiver")
- Huddol – web platform/social network; artificial intelligence that directs the caregiver to the group/web community to answer their needs
- Ted Talks: Brene Brown and Susan David (Vulnerability, shame, emotional agility)
- What to Expect Booklet – Colchester East Hants Hospice
- BC Nurse Line
- Intervention to be used with FCG by CHN – CSNAT (Stajduhar, Sawatzky et. al.)
- FCG at Home – Evidence Based Review (Funk, Stajduhar et. al. – only for a particular population)
- For those Grappling with MAiD – Quebec Document for Healthcare Providers
- Special Patient Program
- Preparing for Death and Dying
- How to sleep when overwhelmed? How to ask for the kind of support that will help the caregiver be able to relax.
- Meals on Wheels or any organization cooking for you when no time
- The FCG needs assessment – Evidence-based needs and self-rated degree being met (Dumont et al.)
- Grief support that is provided in a way that enhances the peoples' support network (e.g.: group program that aims towards ongoing peer support)

Appendix E: Caregiver Perspective

Activity: Participants were split into two groups. Half of the participants within each group were asked to represent the "caregiver voice". Creative presentations were developed to highlight "what resources would I as a primary caregiver have needed/wanted battling through my caregiver journey?"

Questions considered were:

1. What would you change?
2. How would you strengthen what is already out there?
3. What else may be needed?
4. What would my ideal educational caregiver education look like?

Results:

Group 1:

- Themes discovered during their conversations
    - Liable
    - Society/education
    - Impacts on career/unsupportive employers
    - Social life/social isolation
    - Economic condition and social classes impact
    - Pre-existing relations
    - Possibilities of abuse
    - Issues of recognizing terminologies
    - Raising awareness
    - Recognizing of chosen families
    - "I am more than a caregiver, I am a human being"
    - "Being a caregiver is a part of my life, not all my life"
    - North American Cultural

        - Changing the climate or cultural and how
        - Good will without the cliché
- Stories "How would I rewrite my story?"
    - Caregivers are bringing emotion to conversation that don't have emotion
        - Story 1 – Young Caregiver
            - Friends supporting the caregiver – removing social isolation
            - Extended family listening and support – removing judgment and fear
            - Teachers recognized impact on life – make changes to assignments
            - School administration lack of communication – direct person to resources
    - Story 2 – Single Parent Caregiver
        - Rural communities challenge to find support – less rigid support services
        - Child care support – for when you need to be away from your children
        - Tangibles – doing the grocery shopping
        - Finding people who are child centered to explain things to your children
        - Who will take care of my children when/if I die
    - Story 3 – Isolated Caregiver
        - LGBTQ+ discrimination from health care and family
        - Lack of support and resources – referring to caregiver organizations
        - Bedside care for caregivers

Group 2:

- Drama
    - Blaming the caregiver for:
        - lack of organization
        - lack of transportation
        - not knowing detail of patient illness
        - not trying to push alternative medicines
- Flip Chart – Questions for Caregivers
    - 1. What would I want for someone experiencing the caregiver journey?
        - Want someone there. Don't want to be alone
        - Want someone to listen not preach – ask me what "I" need!
        - Ask (more) questions
        - Advocate for yourself and family
        - Being able to express concern, that they are uncomfortable and to stop
        - Difficult Honesty
    - 2. What would strengthen what is there for caregivers?
        - 24 hour a day phone number for support/help/assistance
        - Care team need to ask "how are things" and be present routinely
        - Someone to be present during the dying process
        - Secondary options for a back-up plan
        - More education for health care providers – screening for empathy
    - 3. What else might we need?
        - Better post death support
        - Navigational support

    - Money
    - Mapping care/caregiver needs
    - Medical terminology into lay language
- 4. What would ideal educational caregiver offering look like?
    - Accessible to all caregivers (no matter the setting Ex: Rural)
    - Based on what they need in the moment
    - Consistent messaging – same terminology is being used everywhere
    - Combination of tools – Online, in person, on the phone
    - Consolidation of local resources to one spot for easy access

Participant Reflections:

- Calls of distress – Not knowing where to go or where to turn, no one is listening.
- Sense of abandonment.
- What to do about it: Be Human! The tools would all be good, but it's the heart that is needed.
- Consequences of caregiving.
- Whether the experience was good or bad, the caregiver was always left wanting something.
- Extent of caregiving, scope of what is needed.
- Similar stories in us across the world and there is a great capacity towards compassionate communities.
- We are a society of tasks, forms and fix it models – something to be said about bearing witness to suffering. There is always lots of people giving solutions and things, but no one is really listening.
- Being supported allows the caregiver to bear that unbearable suffering.

- In the realm of mystery/darkness – not able to fix.
- Are there limits to resilience – caregivers continue to care despite all odds.
    - How far can you go, how long can you last, how much can you do?
    - Everyone comes in with a different capacity without judgement
- Demographic in the room – All the caregivers in this room have made it to a certain point but what about the ones that won't or can't make it to this point, not having the strength left to speak
    - Socioeconomic, trauma, addictions, etc. – sometimes we don't see these people are caregivers because the other "labels" take priority
- Media coverage of caregivers always seems to be negative or poor
    - Sometimes caregivers end up "abandoning" the patient in the ED and the caregiver gets deemed bad but it really should be looked at from a different lens. More along the lines of what did the health care system do poorly that we could not get to those people sooner to prevent this from happening?
    - Media needs to present a more balanced view.
- If we can provide what caregivers are looking for maybe that resilience can be fostered.
    - Need to start delivering on what caregivers are asking for.
- Giving caregivers more empowerment is great but then if things don't work out there is greater grief because they carried more of the responsibility.
- Becoming a mini-nurse: complexity of nursing care that is provided. How much energy have we provided into teaching those who need it, basic nursing care? The reason we don't do this is because then we would have to admit we have very limited nursing resources for the caregiver in the home.
- Change the language as to not invoke more shame on people.
- Change the home care services in Canada – we don't know what we need, so stop trying to hide the resources that are available.
- Somehow, we need to get the individual caregiver to identify what they need.
- No one single solution.

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Appendix F: Pallium's Potential Role

Presentation:
To clarify what role Pallium Canada might play in supporting caregivers through collaboration with provincial and Canadian groups working with caregivers, Kim Martens removed her facilitator hat and spoke as Pallium's Interim Chief Operations Officer about suggestions and ideas Pallium had been exploring. These descriptions were not meant to be exclusive but rather to set the stage for a discussion among small groups of participants.

Potential Support Areas:

- LEAP Model
  - Pallium Canada's Learning Essential Approaches to Palliative Care (LEAP) courses are generalist level inter-professional palliative care education designed for nurses, physicians, pharmacists, social workers, paramedics, care aides and community carers. LEAP Courses are tailored to various settings of care to ensure Canadians have access to the right care, at the right time, in the right place.
- Toolkit Model
  - Provide the necessary and related information, tools and resources, in a specific order, for people to guide them in designing a plan, to organize an event or to accomplish a goal.
- Airbus Model – Palliative Approach to Care
  - Each person provides a piece (wing, tire, door, and window) of the puzzle (or Airbus) and maintain intellectual property rights. Everything together builds a product that supports the greater good rather and building it individually.

Discussion:
Canadian Virtual Hospice (CVH) gets approximately 1.6 million hits per year. It has countless resources available for those who need it. However, CVH cannot cover it all. Some participants expressed that CVH offers too many tools and thus it makes it harder for those to find what is valuable to them versus what is not. In addition, participants noted that CVH is missing the interaction with the community or train the trainer concept, some caregivers want to physically talk to people rather than accessing everything online. Many caregivers, when searching online, end up with American resources which triggers them to ask "is there one available to Canadians?" We also need to look at some attention shifting to those non-cancer caregivers and focus more on the palliative care approach foundational message. Do we need to do a better job at educating health care professionals about available resources that are available to caregivers (i.e.: referral to caregiver associations) or do they not have the time or capacity to support caregivers and we should move this to a grass roots level to journey with the caregiver?
We also need to look at cost. Three billion went into home care but only 600 thousand has been spent and there needs to be caution when spending the health accord dollars. We have the time and the money to help family caregivers, yet they still are being let down and not included in essential conversations. We must look at changing the culture in our health care system to be more inclusive of difficult terminology and referrals to support services.

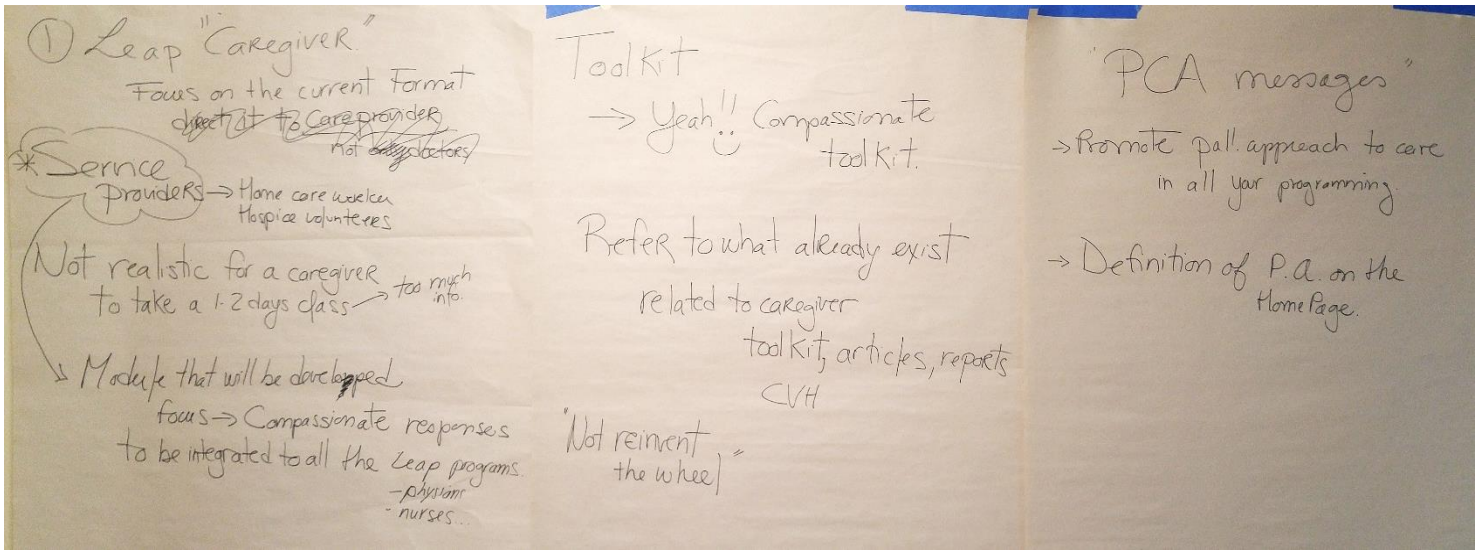
Appendix G: Participant Perspectives

Activity: Based on the description of the LEAP, Toolkit and Airbus Models, participants were asked to work in groups of three and propose what role they see for Pallium

Results:

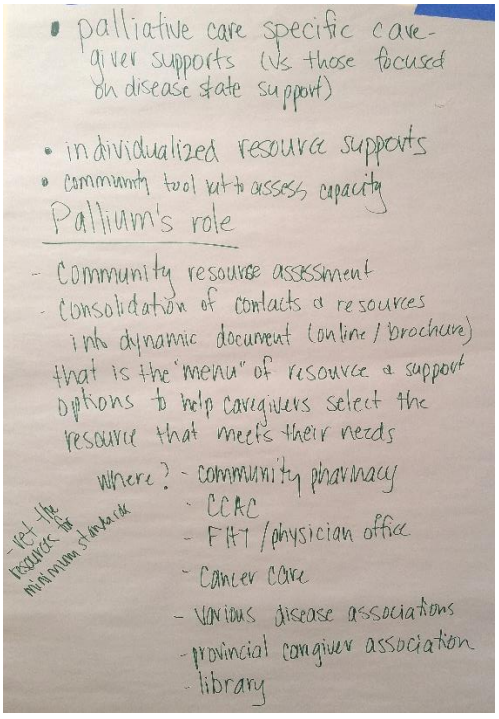
Group 1

- Potential to develop a LEAP for service people
- Unrealistic for a caregiver to take a 1-2 day class
- Toolkit – yet another tool for the caregiver, refer to what already exists
- Palliative Care Approach (PCA) messages/definition of what it is on home page so that the general population will understand palliative doesn't mean death



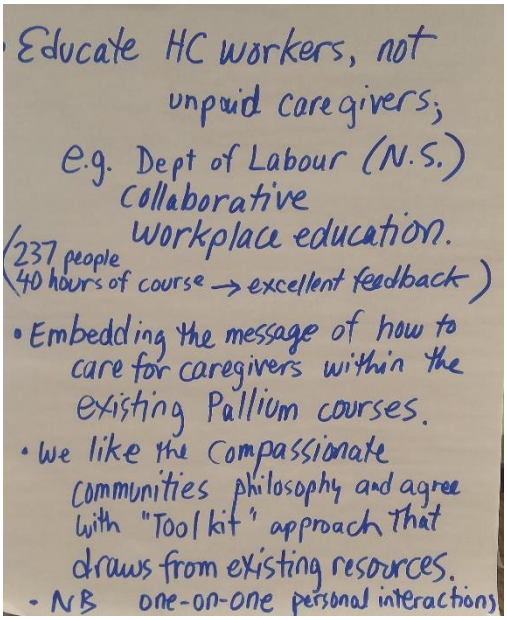
Group 2

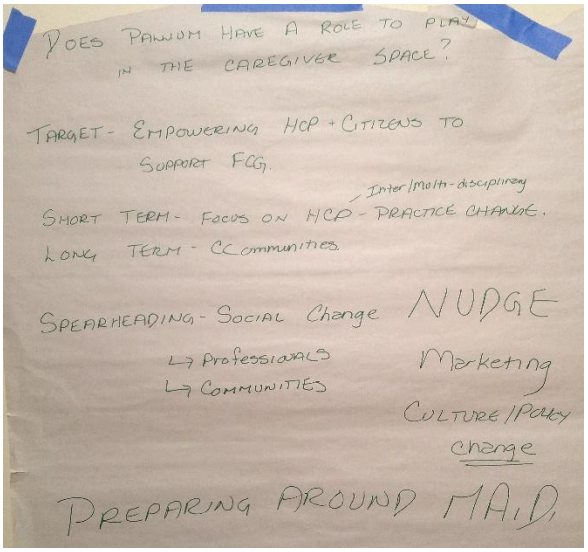
- Palliative specific supports
- Community toolkit to assess the capacity of the community to support caregivers
- Community resources assessment
- Online and in print resources for resources that meet their needs - available everywhere



Group 3

- Don't want to be educating caregivers – lack of attention span
- Want to educate front line workers
- Ministry of Labour could provide education of front line workers to have conversations with caregivers
- Embedding the message on how to care for caregivers in the course you already have; personal one on one conversations between professional and unpaid caregivers



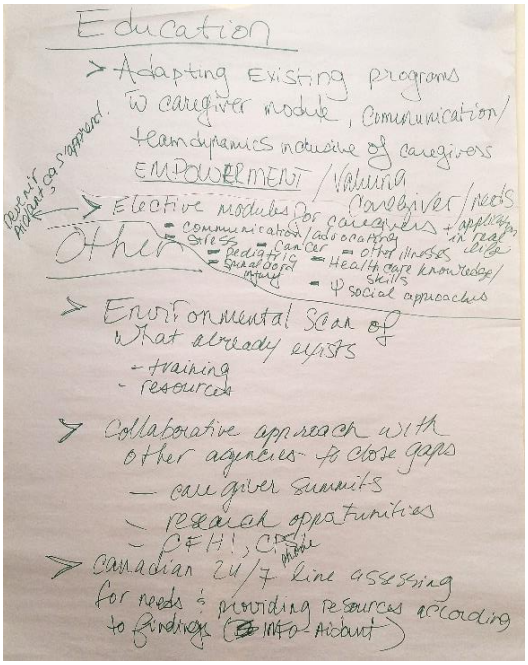


Group 4

- Target empowering Healthcare professionals and citizen to help caregivers
- Set the bar as to know what is expected - the nudge
- Family caregiver issues around MAID

Group 5

- Education - adapting existing programs – communication, team dynamics
- Elective modules
- Environmental scan
- Quebec site looking at their frame work and adapting



Participant Discussion:

Participants discussed the need to not take away the responsibility that each province can hold when creating caregiver support. There was talk about a grant to put together an inventory of services and resources for caregivers but the challenge with this is who will keep it updated and ensure the sources are still relevant. In Quebec, they have developed, and artificial intelligence called Huddol where the caregiver can type in resources they need and through algorithms, Huddol can provide them with answers.

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Appendix H: Reflections from the Previous Day

Activity: Participants were asked to reflect on what was talked about the previous day and to share any insights, a-ha moments or ideas that could contribute to today's discussion.

Results:

- There is a need for intersection of personal and professional (knowledge, resources, information)
- There are many resources available, however, there is still a gap in getting the knowledge to the right people. There is one way to fill the gap and that is through marketing but a lot of the organizations who have the resources/information don't get the money for advertising and promotion or commit people to the resources. The question then becomes how can we do better to market those resources?
- There were lots of ideas. Now it is about everyone going back to their environment and trying to implement some of the information discussed.
- There needs to be an increase in awareness across Canada and we need to try to get Public Health (units) involved as well.
- Special patient program (SPP) in Nova Scotia, allows people to register as special populations so when paramedics are called they are aware of the situation and can help rather than just taking them to the hospital. In one example, the paramedics were called and when they arrived made tea for the person and chatted. The paramedics in Nova Scotia and PEI all receive the LEAP paramedic training so they can be better aware of the sensitive issues that are taking place.
- Many emergency service professionals are beginning to have mental health issues because they do not know how to provide the proper services to those in distress.
- In Edmonton Alberta, the have evolved EMS for Long Term Care and home care. They have created a circle of care around patients who are palliative so that when EMS comes to the home the information also gets send to the patient's family doctors. This has resulted in positive outcomes for those in palliative and end-of-life care.
- We need to start looking at that wrap around effect. What needs to be put in place, so everyone can connect? Developing vocabulary, checklists and questions that are common for everyone.
- We need to ensure that the interdisciplinary approach is not exclusive and that everybody is a part of the conversation including multi-sectoral and cross sectors.
- Tools can often be misleading. We can use them but then nothing ever gets done with the tools and the situations and problems never get addressed. We need to have skilled people to deliver and interpret the tools for their actual use.
- We also lack consistency around knowledge, tools and skills. People end up falling through the cracks because there is a lack of, little or no communication between people. We need to work on both the art and science of palliative care.

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Appendix I: Circle of Care

Activity: Participants were tasked with creating an image of a typical circle of care for a primary caregiver and the person they are supporting. Individually they brainstormed touch points a caregiver/patient might encounter while on their journey and how often they might interact with them. The more interactions, the closer the placement of the touchpoint identified. Individuals then worked in groups and then the two groups came together in plenary to crate the image for the circle of care (Image 1 below).

Participant Discussion:

- There is a dyad of caregivers and the interaction that happens between both people needs to be considered. This simply shows the connections not necessarily anything about their capabilities.
- Sometimes a single touch point can change the care trajectory.
- Think of these points of contact as opportunities. Opportunities, to make these moments and experiences better by becoming more sensitive to the caregiver issues.
- Everybody needs to learn about compassionate care. How can we reduce the touch points? Can we limit to a single point for communication purposes or when we are doing the work can we infuse compassionate care into regular practice?
- What does the context of dying mean in 2018 and beyond? There needs to be a consistency in death and grief literacy, but we also need to remain diverse in these conversations.
- We all have different roles to play in health care. The physician and volunteer play/have very different responsibilities but if they both echo the same thing the impact can be huge.

Pallium Analysis: Based on this activity, Pallium did a simple classification of formal and informal roles and found that there are more contact points (60% versus 40%) that are not health care specific yet play a supportive role for the patient and caregiver.

Image 1: Circle of Care Activity

Table 4: Classification of Supportive Roles found within Circle of Care Activity

Formal (paid to support**)**		**Informal (**not paid to support**)**	
Health Care: Education	**Community:** Education	**Health Care:** Education	**Community:** Education
Health Care Providers	Law Community	Volunteer (e.g.: Hospital, Hospice, Nursing Home)	Community Social Supports
Administrative Assistant	Policy Makers/Governments	Community Social Supports	Volunteer (e.g.: Faith Community, School, community)
Media	Media		Family
Alternative Health Practitioners	Administrative Assistant		Friends
Health Organizations/Community Service Organizations (i.e.: Alzheimer's Society)	IT Staff		Outside Home Supports (yard/snow)
Funeral Directors	Financial Advisors/Bankers		Faith Community - members
Personal Support Worker (PSW)/Home Care Aide (HCA)	Educators		Housekeeping
Pharmacist	Health Organizations/Community Service Organizations (i.e.: United Way)		Pastoral Care
Educators	Transportation Staff		Faith Community
Paramedic	Housekeeping		Employers
Registered Nurse (RN)/Registered Practical Nurse (RPN)/Licensed Practical Nurse (LPN)	Policy Makers/Government		Coworkers
Social Work	Porters		Neighbours
Naturopathic Doctor (ND)	IT Staff		Local Business Owners
Physiotherapy (PT)	Financial Advisors/Bankers		Clergy
Transportation Staff (Hospital)	Dietary Aide		
Pastoral Care	Community Housing Workers		
Medical Doctor (MD)	Transportation Staff (i.e.: Taxi, bus)		
Registered Dietician (RD)	Funeral Staff		
Mental Health Supports	Coroner Staff\transport		
Coroner	Law Community		
Occupational Therapy (OT)	Funeral Planners		
Emergency Medical Technician			

Appendix J: What might a LEAP Community Carers Look like?

Activity: Participants were asked to write their 5 key curriculum nuggets/topics that should be included in a potential LEAP Community Carers. Participants were then asked to merge into pairs, then groups of 4, groups of 8 and finally all 16 came together to produce the top recommendations. The group was then asked to create what could be the 5 Main modules of a LEAP for community Carers. Each time groups merged they were only allowed to keep their top 5 topics. The photos below show the resources that were not included in the top five after each merger. Among these ideas are numerous resources that could also be part of a LEAP for community Carers.

Results: An overarching title for the modules was: **Palliative Approach (Compassionate Care, Focus on Family Caregivers, Death Literacy).** Potential modules could include:

1. Impacts of being a Caregiver
2. Self-Reflection/Contemplation
3. Dealing with Logistics of end-of-life
4. Death Literacy
5. Communication Tools from a true "holistic" lens

During the last merge of ideas, several concepts were discussed.

- **Know, Be, Do –** What do you have to know? How you are to be? What should you be doing?
- **Palliative Approach**: Beyond that of those with cancer, upstream, cross context (Healthcare context – Kelly Stajduhar)
- **Compassionate therapy** – Shane Sinclair
- **Dignity Therapy –** Harvey Chochinov

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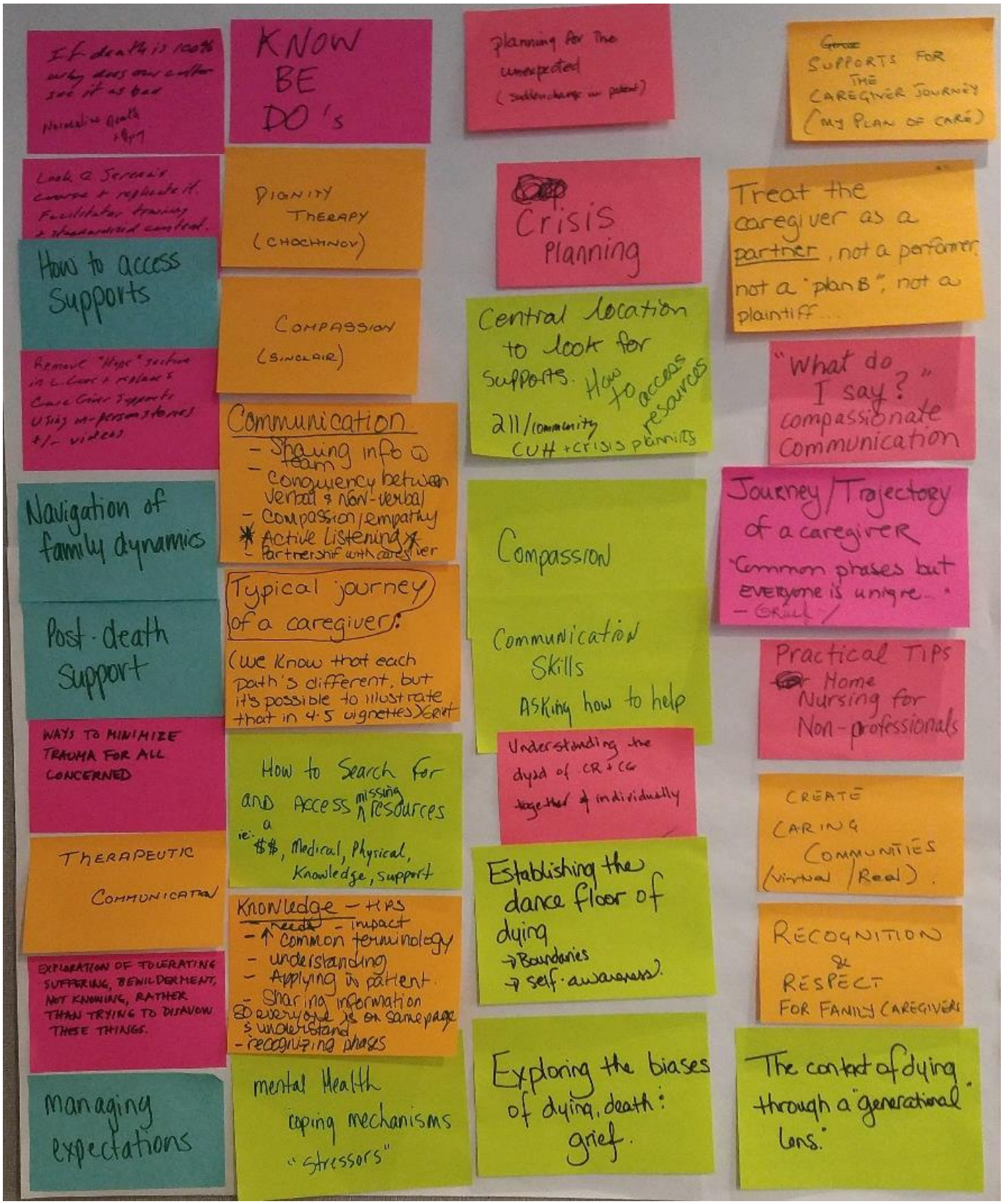
Additional Topic ideas:



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Appendix K: Final Thoughts

Activity: Participants were asked to take their ideas that did not make the final cut and place them under the five identified modules as potential topics that could be part of that module.

Results:

Palliative Approach (Compassionate Care, Focus on Family Caregivers, Death Literacy)

1. **Impacts of being a Caregiver**
    a. Care caring communities (virtual/real)
    b. Understanding the "caregiving family" (dyad of patient and caregiver)
    c. Enhancing and respecting skills and contributors across sectors
    d. Learn how to ask or prompt caregiver/care receiver on how you can help
    e. Video or in-person stories from caregivers
    f. Impacts of a caregiver Journey
2. **Self-Reflection/Contemplation**
    a. Just Be! Comfortability in the moment
    b. Exploring the biases of dying, death and grief
    c. Boundaried Practice (e.g.: Silence, when/how to hold space)
3. **Dealing with Logistics of end-of-life**
    a. Post-death Support
    b. How to access Supports
    c. Crisis planning
    d. The circle of care/ Creating a mixed circle of support
    e. Support for the caregiver journey
    f. Managing the vast see of information
    g. What to expect as death approaches
    h. The context of dying through a generational lens
4. **Death Literacy**
    a. Definition/Common Terminology
    b. The different needs of caregivers
    c. Compassionate
    d. Spectrum of Grief (caregiver and patient)
    e. Caregiver Journey
    f. How to treat a caregiver (treat as a partner, not a performer, a plan B or plaintiff)
    g. Trauma minimization
    h. Normalizing death and dying
5. **Communication Tools from a true "holistic" lens**
    a. Managing Expectations
    b. "What do I say?" Compassionate Communication/Active Listening/Verbal vs. Non-verbal
        i. What to say and not say (Ex: abuse of clichés, being too insensitive or sensitive)

    ii. Teaching caregiver how to say stop when something is not right (Assertion)

c. Ask First – Get an understanding of the situation
d. Planning for the unexpected (sudden change in patient)
e. Recognition and Respect for Family Caregivers
f. Basic Questions to assess the social status of the unit (ex: meals, sleep, housing)
g. Expectations of honesty from doctors and nurses – “Clear Language”
h. Awareness/Monitoring (advocating change)

A Caregiver's Lament

(poem shared by a participant at the end of

My hands are dry and cracked from endless cleaning
dishes, toilets, vomit pails

My feet and ankles ache from trips with trays
up and down stairs
All day and all night

My mind is weary with multitasking
constant interruptions telephone doorbell
schedules appointments constant change
people and pills
symptoms and suggestions

Some people cannot understand this.
They tell me their war stories
They chat cheerfully
They pepper spray me with questions
They say they know how I feel
How can they know when I don't even have
time to notice myself?

Like a bird alone on a rooftop
I lie awake
Listening to freezing rain
Thinking about tomorrow
Scraping the car windows
Getting breakfast
Morning medications
Another trip to the hospital
Between phone calls and emails

Like a bird alone on a rooftop
I lie awake
listening to laboured breath, wheezing,
my beloved sleeping
my fears creeping

O my beloved
Your bones grow weak
Your skin is dry and cracked
Your ankles swell
your mind muddled

O my beloved
I long to remember the fullness of our lives
together
Our hearts open
Our spirits strong
Love deepening

Like a bird alone on a rooftop
I wait in the dark
empty space
I wait for morning to come
for a new time
A new song?

Gazing up through the skylight
I hear the stars;
far away the moon glows
a gentle light
Mother God sings me her lullaby
and under her sheltering wings, I sleep
a deep rest
I sink into comfort.

Morning comes
I rise slowly;
A sparrow sings.
My hands are warm and soft
my feet strong and steady
my mind is clear
my heart open
to this new day.