

Palliative Care
Matters | Building
National Consensus

L'importance des
soins palliatifs | Forger
un consensus national

Allison M. Williams, PhD

Professor & CIHR Chair in Gender, Work & Health
School of Geography & Earth Sciences
McMaster University

Educating, Training and Mentoring Caregivers

7 November 2016 – Ottawa, ON, Canada

1

Funding

- Canadian Institutes of Health (CIHR) Chair in Gender, Work & Health "Caregiver-Employees & Friendly Workplaces"
(Funding Reference Number: CG1 126585)

Palliative Care
Matters | Building
National Consensus

L'importance des
soins palliatifs | Forger
un consensus national

2

Acknowledgements

- Wendy Duggleby, Kelli Stadjuhar, both who provided feedback on the lay report;
- Chloe Ilagan, Research Assistant;
- Michelle Sims, and;
- All the caregivers who give generously every day.

What resources are required to ensure adequate education, training & mentorship for caregivers of Canadians experiencing a life-limiting illness?

Caregiver Readiness

Palliative Care
Matters

Building
National Consensus

L'importance des
soins palliatifs

Forger
un consensus national

5

Informal caregiving

Results from The Commonwealth Fund 2014 International Health Policy Survey of Older Adults (age 55+) show that Canadians generally spend more time as informal caregivers than people in other countries and don't always get the support they need.



1 in 5 older Canadians provided care to someone with an age-related problem at least once a week. That's about the same as the international average of 11 countries.



4 in 5 older Canadian caregivers provided care for their **family members**.



Almost half (47%) of older caregivers provided care for at least 10 hours a week, which is higher than the international average of 40%.



Canadian caregivers were more likely to experience **distress, anger or depression** if they provided 10 or more hours of informal care.



Almost one-quarter of Canadian caregivers needed help in the past year but didn't receive it.



The main reasons caregivers didn't get the help they needed were lack of services and not knowing where to go for help.

© 2015 Canadian Institute for Health Information

Palliative Care
Matters

Building
National Consensus

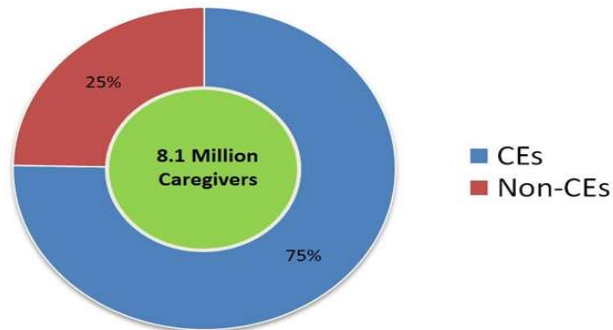
L'importance des
soins palliatifs

Forger
un consensus national

6

Who are Caregiver-Employees?

Caregiver Distribution Population in Canada



Palliative Care
Matters

Building
National Consensus

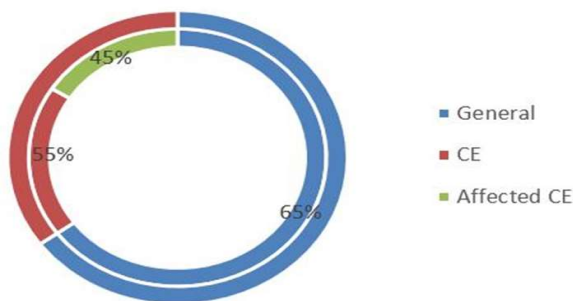
L'importance des
soins palliatifs

Forger
un consensus national

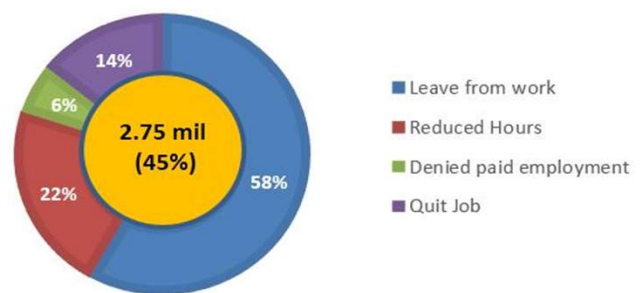
7

What is the Economic Impact?

Canada's Workforce



CE WORK IMPACT



1.3 billion lost per year

Palliative Care
Matters

Building
National Consensus

L'importance des
soins palliatifs

Forger
un consensus national

8

Daily Geographies

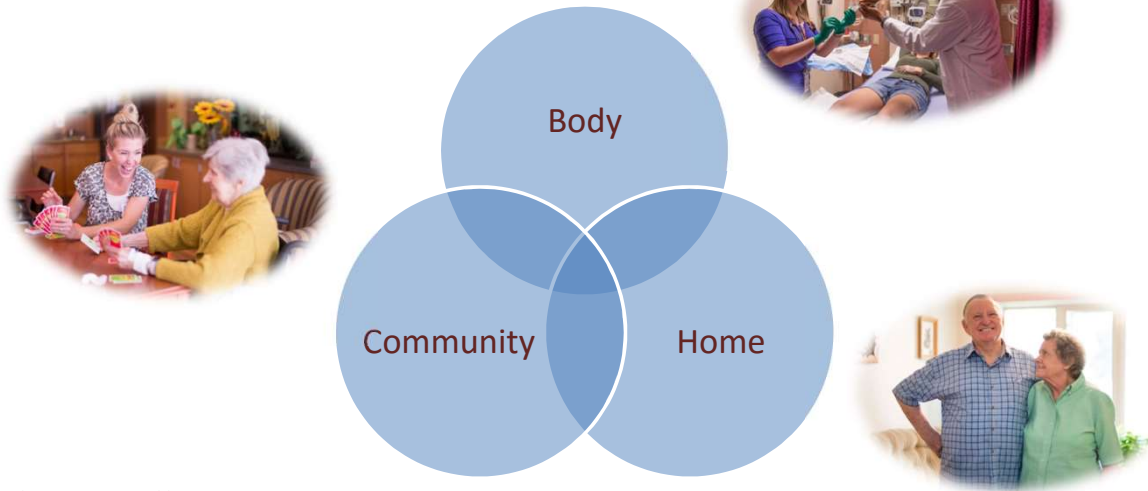


Photo Credits: Covenant Health

**Palliative Care
Matters**

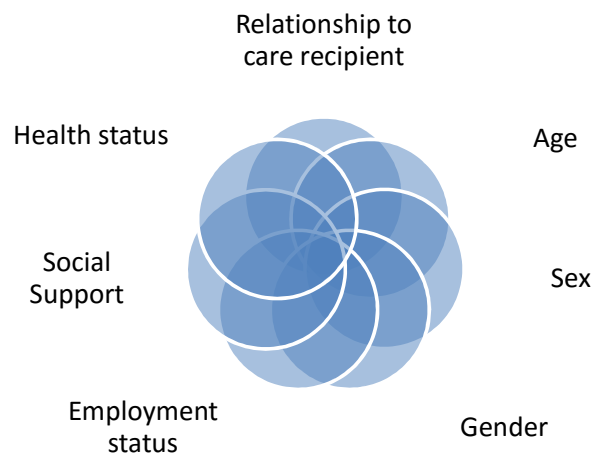
Building
National Consensus

**L'importance des
soins palliatifs**

Forger
un consensus national

9

Caregivers are **d****i****v****e****r****s****e**



**Palliative Care
Matters**

Building
National Consensus

**L'importance des
soins palliatifs**

Forger
un consensus national

10

Work-Family Balance OR Conflict?



Photo Credits: Covenant Health

**Palliative Care
Matters** | Building
National Consensus

**L'importance des
soins palliatifs** | Forger
un consensus national

11

Overview: What does the Research tell us?

**Palliative Care
Matters** | Building
National Consensus

**L'importance des
soins palliatifs** | Forger
un consensus national

12

What do we know?

The majority of palliative/end of life (EOL) caregivers are female, married, employed & living in a centre with 100,000 people or more.

What do we know?

Palliative/EOL caregiving is the most intense type of caregiving, potentially causing the greatest caregiver burden.

What do we know?

These caregivers also experience complex transitions in their roles/relationships, environment, & physical/mental health, decreasing their quality of life.

[The caregiver experience & the need for self-care](#)

What do we know?

Family caregivers often do not see themselves as legitimate recipients of support. Therefore, their requirements, while really important, need to be done in the context of the patient.

What do we know?

Caregivers learn through trial & error, actively seek information & guidance & reflect on their current experiences. They prefer to have person-to-person learning complimented by secondary or tertiary resources, such as those on-line, via telephone, or in hard copy formats.

What do we know?

The idea of a palliative navigator has been suggested by a number of scholars & practitioners. The role of the navigator would be to work side by side with families, providing a single access point & assisting in care coordination.

Findings

What did Ipsos (2016) determine?

(1) Moderate Confidence

Canadians polled feel that confidence in palliative/EOL caregiving is moderate.

What did Ipsos (2016) determine?

(2) Health Care Facilities Responsible

- Canadians feel that hospitals or health care facilities in which the palliative care is being provided (46%) should be responsible for providing information & training for caregivers.
- Just more than three-in-ten Canadians place such responsibility on:
 - family doctors (32%) & nurses (31%), followed by;
 - provincial (29%) & federal (21%) governments.

What did Ipsos (2016) determine?

(3) Training by Professionals

Canadians prefer to be trained by those in the health system - by hospital health care providers, such as physicians & nurses.

What did Ipsos (2016) determine?

(4) Priority Information Needs

- If Canadians were caring for a close friend or family member who was dealing with a life-threatening illness, priority information needs involve:
 - who to call in an emergency (73%);
 - how to use machines (72%);
 - what to do when a patient dies at home (72%)
 - how to give medication (71%), &;
 - information about dedicated care providers (70%).

What did Ipsos (2016) determine?

(4) Priority Information Needs

- If Canadians were caring for a close friend or family member who was dealing with a life-threatening illness, priority information needs would also seek information about options for:
 - financial support (68%);
 - the patient's diet (67%), &;
 - what supplies are needed (64%), among other topics.

What did Ipsos (2016) determine?

(5) Elements of a Palliative HC Program

- A strong majority of Canadians agree that all 15 elements of a potential palliative home care program should be included. The strongest agreement is found for having:
 - 24/7 access to a nurse (91%);
 - daily assistance with caregiving (91%);
 - access to equipment as needed (91%);
 - panic alerts/buttons for patients when left alone (91%);
 - **education & information for caregivers (91%);**
 - someone in the system to coordinate care (91%), &;
 - a single access point (i.e. one number to call) for help (90%).

What did Ipsos (2016) determine?

(5) Elements of a Palliative HC Program

- The lowest agreement expressed (albeit still strong at 80%) is found for renovation funding (i.e. bathroom bars, ramps, vehicles).

What did Ipsos (2016) determine?

(6) Overall Confident in Care Role

- Almost one-quarter (24%) of Canadians have been (20%) or are currently (4%) caregiving for someone important to them who was or is dealing with a life-threatening illness, & among this subgroup, 77% are confident in providing the necessary care.

Implications

What does this mean for caregivers? *Education, Training and Mentorship*

The provision of education, training & mentorship require much the same support & strategies, although they each represent different aspects of the information & support required by caregivers.

Rationale for training of and attention to caregivers

Education

- **Education** encompasses how to access:
 - help (health care, community supports, transportation, caregiver-friendly programs in the workplace, living wills, advanced care planning, etc.)¹⁷, as well as;
 - general information about the patient's disease(s) & what to expect.^{24, 53}

Education

- Information preferences vary & often depend upon being able to comprehend and/or accept the terminal diagnosis.[32](#)
- Disease-specific education needs to take place throughout the illness trajectory.[4](#), [6](#),
- Two additional educational needs identified are:
 - financial planning/budgeting, &;
 - effective communication, especially as it relates to information sharing needed between health care providers, caregiver & patient.

Training

- **Training** includes the practical aspects of care, including:
 - ✓ personal & physical care;
 - ✓ technological tasks, &;
 - ✓ management of symptoms, pain & medication.[17](#), [25](#), [33](#), [49-53](#)
- Further, it encompasses the psycho-social aspects of care, including the social, psychological & needs of the patient.

Training

- Competent training ensures caregivers have access to health care providers, services and/or equipment that are:
 - ✓ Adequate;
 - ✓ Competent;
 - ✓ Flexible;
 - ✓ Coordinated;
 - ✓ Organized;
 - ✓ Continuous/consistent, &;
 - ✓ Communicative.



Photo Credit: Covenant Health

Palliative Care
Matters | Building
National Consensus

L'importance des
soins palliatifs | Forger
un consensus national

35

Mentorship

- **Mentorship** is central to empowerment & sustainability in the caregiving role, given that caregivers are ambivalent about their own needs being met. [22](#), [1](#), [35](#), [54](#), [57](#), [81](#)
- At a minimum, mentorship is needed to address the following critical areas:
 - ✓ Navigating the health care system; caregiver health & wellness (self-care, minimizing social isolation);
 - ✓ Family dynamics;
 - ✓ Communication & assertiveness skills;
 - ✓ Sharing the care, &;
 - ✓ Bereavement.

Palliative Care
Matters | Building
National Consensus

L'importance des
soins palliatifs | Forger
un consensus national

36

Mentorship

- Caregivers who are also employed may also need to be mentored in making use of caregiver-friendly workplace policies, such as:
 - flexible work, or;
 - unpaid leave.
- As with the education and training needs outlined above, there is no one best communication medium or program to ensure this mentorship, but, rather, needs to be **tailored to each caregiver & caregiving situation.**

Challenges for family caregivers

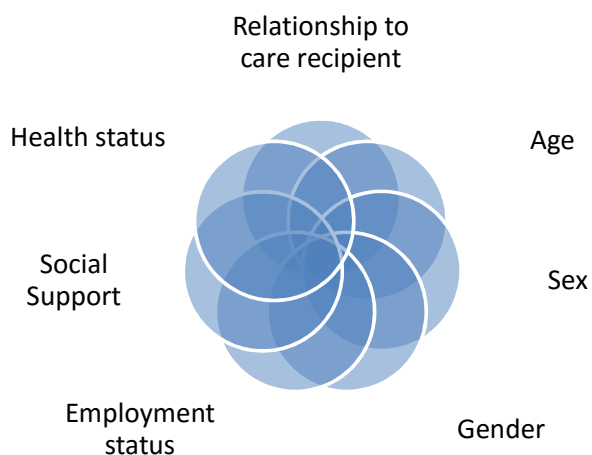
Palliative Navigator

- Similar to the midwifery model, the idea of a ***palliative navigator*** has been suggested by a number of scholars & practitioners.[20](#), [66](#)
- The role of the navigator would be to work side by side with families, providing a single access point & assisting in care coordination.

Palliative Navigator

- ✓ Caregivers prefer to have ***person-to-person*** learning,
- ✓ complimented by secondary or tertiary resources, (i.e. available on-line, via telephone, or in hard copy).
- ✓ A ***palliative navigator*** would fill this role in providing effective, individualized training, while
- ✓ Being able to address the demographic variations & affiliations of any individual caregiver.

Caregivers are **d** **i** **V** **e** **r** **S** **e**



Alternatives

- If Palliative Navigators are unavailable, trained individuals associated with one of a number of existing programs and services available in geographically proximate community-based organizations would suffice:
 - i.e., disease-specific organizations, such as the Canadian Cancer Society or the Alzheimer's Society of Canada.

Alternatives

- ✓ These individuals ideally are health care professionals trained in palliative care.
- ✓ They should be competent in providing face-to-face education, training & mentorship, as well as being able to direct caregivers to other educational resources such as on-line platforms, videos, & hard-copy formats.

Caregiver Education Questions

