

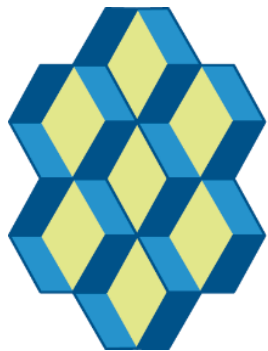


SPA- LTC Project:

Strengthening A Palliative Approach in Long-Term Care

3rd Annual TVN Conference

September 29th, Sheraton Centre Hotel, Toronto, ON



Technology
Evaluation
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SPA-LTC Project: TVN-Funded Strategic Impact Grant

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Advisory Board

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 - Louise Harvey/Canadian Hospice Palliative Care Association



Background

- As the population continues to age, more people will die in long term care (LTC) homes
- These people represent one of society's most frail and marginalized populations who often struggle with managing multiple chronic conditions and social isolation
- Palliative care is complicated for residents who suffer with dementia due to the gradual loss of their cognitive abilities
 - decision-making related to care needs often rests with family members or health care professionals



Palliative Approach in LTC

- Begins when residents are admitted into LTC, most have chronic, life-limiting conditions
- Based on symptom management and residents needs, not prognosis
- Interdisciplinary approach to care within a holistic perspective, resident-focused
- Focus on preparation and care planning
- Need for family education and support



5 Year Project (2009-2014)

- Goal of the Community University Research Alliance funded by the Social Sciences and Humanities Research Council (SSHRC) entitled ***Improving the Quality of Life of People Dying in Long Term Care Homes*** was to improve quality of life for people who are dying in LTC homes through developing palliative care programs using a process of community capacity development (PI: ML Kelley)
- Developed toolkit for other LTC homes to access:
 - www.palliativealliance.ca
- SPA-LTC builds on this work by implementing and evaluating some of these tools



SPA-LTC Project: An Overview



SPA-LTC Project Methods

- Participatory Action Research Study
 - Champion Team
 - Advisory Board
 - Program Components Shift with feedback and evaluation
- Mixed methods
 - Focus group data
 - Surveys
 - Chart data
- Multiple Case Study Design
 - 4 LTC sties

LONG TERM CARE HOME



SPA-LTC Core Components

Care Conferences

- occurs: 6 weeks post admission
- goals of care discussed with family/resident and IP team

Develop PC Champion Team

- opinion leaders
- meet bimonthly

Implement PPS

- weekly if <30%
- monthly if > 30%

Bereavement Follow-up

- occurs 1 month post-death
- LTC staff calls family to provide support and referral if needed

Hold Comfort Care Rounds

- meet bimonthly
- PC consultant to attend
- education and reflection

EOL Family Care Conferences

- occurs if PPS<30%
- family completes questionnaire before FCC
- family meets with IP team

Research Team

Advisory Board: Partners & Decision Makers

Community Palliative Care Consultants



Preliminary findings from our pre-implementation focus groups



Focus Group Purpose

- Develop an understanding on different stakeholders' perspectives of what palliative care means
- Engage knowledge users at the front end of the research
- Examine perspectives and reactions to proposed study interventions



Focus Group Participants

A total of 20 focus groups were conducted in all four participating homes with 124 participants:

- 24 residents
- 14 family members
- 33 personal support workers (PSWs)
- 25 nurses
- 21 support staff
- 4 volunteers
- 3 Other



Focus Group Analysis

- Three step process of analysis informed by grounded theory approach
 - Open coding
 - Axial coding
 - Selective coding

- Coding structure developed with resident data and refined with analysis of other stakeholder groups



Findings –Main Themes

- **Overarching sense of passivity amongst residents**
 - Did not see themselves as agents of their own care
- **Conceptualizations of palliative care trajectory limited**
 - Residents focused on post mortem
 - Staff focused on final days of life
- **Public nature of death and dying impacted residents' and families**
 - Highlighted for residents what they felt to be 'good' vs 'bad' end of life care
 - Made families worried about feeling abandoned when residents died
 - Fears not expressed to staff

Implications Adaptations to Intervention



- Development of illness trajectory pamphlets
 - Meet informational needs expressed by families
 - Help to activate early identification and discussion
- Development Methods
 - Material from 5 on-line sites
 - Reviewed by specialists in palliative care (PC) (n= 2) and Alzheimer's and dementia (n=1), LTC staff (n= 34) and residents (n=1)
 - Assessed for readability

An Illness Trajectory Resource for Dementia Caregivers



A Palliative Approach to Care

A Palliative Approach to Care refers to:

- Symptom management
- Supportive care
- Advanced care planning
- Open communication
- Social and spiritual support

The focus of care shifts from prolonging life to maintaining quality of life. It does not require a palliative care referral. A palliative approach applies to both chronic (e.g. dementia) and reversible (e.g. infections) conditions.

Most people in long-term care homes benefit from a palliative approach to care because they are living with conditions for which no cure exists. Many people can live in comfort in long term care homes for months or years with such conditions.

For more information regarding the Palliative Approach to Care, please visit <http://www.virtualhospice.ca/>.

Advanced Care Planning

This pamphlet has been created to help people with AD and their families plan ahead by learning about the associated signs and symptoms, and disease progression. Considering resident preferences, values and beliefs for end-of-life care early on can help persons with AD, caregivers and staff make care decisions that respect resident dignity and promote quality of life.

For more information on Advanced Care Planning, please visit <http://www.advancencareplanning.ca/>

Resources

1) Alzheimer Society of Canada: education materials about what to expect at each AD stage, coping strategies, and personal stories/advice.

• Types of dementias/ symptoms/ treatment:
<http://www.alzheimer.ca/en/About-dementia>

• AD Stages & Caregiver Information:
<http://www.alzheimer.ca/en/We-can-help/Resources/Alzheimer-Society-brochures-and-publications>

• All About Me toolkit (record of individuals' information)
http://www.alzheimer.ca/-/media/Files/national/Core-lit-brochures/all_about_me_booklet_e.pdf

2) Alzheimer's Association (American Organization): living with AD, interactive tour of inside the brain in multiple languages, common myths of AD & what to expect at each stage.

http://www.alz.org/alzheimers_disease_publications.asp

3) Comfort Care at the End-of-Life for Persons with Alzheimer's Disease or other degenerate disease of the brain : 13 page booklet with information for caregivers on what to expect and how to support an individual with AD in long term care.

http://www.expertise-sante.com/modules/AxialRealisation/img_repository/files/documents/guide_eng.pdf

The Palliative Approach for Alzheimer's Disease in Long-Term Care

Version 2

A Resource for Residents, Family and Informal Caregivers



What is Dementia?

Dementia describes a group of progressive brain disorders. Progressive means the symptoms will worsen over time. Dementia affects a person's cognitive function (e.g. thinking, problem-solving, language, mood) and behaviour, and reduces one's ability to perform normal daily activities.

Alzheimer's disease (AD) is the most common form and occurs in 60 to 80% of cases of dementia. It is the result of the build up of plaques in the brain and degeneration of brain cells. The average person with AD lives 4 to 6 years after the initial diagnosis. A person with AD can be described as being at the early, middle, late, and end-of-life stage. This pamphlet will discuss the late and end-of-life stages.

Common Experiences for Caregivers

Caregivers need to be mindful of their own health and well-being while caring for persons with AD. Symptoms of depression and anxiety may be experienced by caregivers. Long term stress may weaken your immune system and may make you prone to infections. Stress may also cause wounds to take a longer time to heal.

If you are feeling caregiver stress, remember that you are not alone. Support services are available in the pamphlet resource section. You can access each organization's contact information through the web links. These can provide educational resources, support and counseling programs.

Living with AD

The progression of AD cannot be reversed and there is no current cure. Being well informed about AD will help caregivers to know what to expect and to make decisions for end-of-life. Persons with AD will have a new type of 'normal'. Caregivers should try to meet their abilities where possible.

Late Stage

Persons with AD will experience :

- Severe memory loss (e.g. names, events) affecting daily activities
- Loss of concept of time and space
- Difficulty producing speech
- Loss of ability to eat and recognize food
- Loss of ability to use the toilet (e.g. stool and urine incontinence), bathe, and walk without assistance
- Difficulty swallowing (increased risk for pneumonia and fever)
- Weight loss
- Decreased interest in engaging in activities

Tips for Caregivers:

- Consider nonverbal forms of communication (e.g. play music, show pictures, use of aromas) that may be comforting to the resident
- Ask staff how resident typically expresses feelings through his or her behaviour
- Explore eating options if resident can no longer swallow food
- Explore options for activity (e.g. social, physical) that may improve quality of life

End-of-Life Stage

Persons with AD will experience:

- Emotions, but they may not be obvious from facial expressions and behaviours
- Changes in circulation (e.g. cold hands/feet, skin breakdown/pressure sores)
- Gradual organ failure
- Decreased interest in eating and drinking
- Possible pain, shortness of breath and agitation

Tips for Caregivers:

- Ask health care provider about medications to manage pain, shortness of breath, and agitation
- Continue to reminisce with resident by playing music and telling comforting stories
- Always consider residents' values and preferences at end-of-life, and reflect on previous discussions
- Discuss strategies with staff to maintain resident's dignity
- Remember that appetite and weight loss are normal for persons at the end-of-life, although it may be distressing to you

Questions to Ask Your Health Care Provider

- What kinds of changes can I expect during the late and end-of-life stage?
- How long can someone be in the later stages of this illness?
- What types of care decisions may I be faced with when end of life is near?





Preliminary findings from our staff surveys



Staff Survey Purpose

- Gather base line data on overall state of staff knowledge and comfort with palliative care
- Examine possible differences between registered, staff, support staff and PSWs on knowledge and comfort
 - Tools selected were Not discipline specific
- Guide implementation by site specific areas requiring attention
 - Trends in knowledge gaps



Staff Surveys

- Training, Experience and Role
 - education, occupation, hrs per week
- Inter-professional Collaboration for Palliative Care
 - attending rounds, reviewing charts, attending care conferences
 - Intensity of Professional Collaboration Survey (Sicotte et al., 2002)
 - 17 items, 5 point likert scale
- Comfort and Knowledge Related to End-of-Life Care
 - End-of-Life Professional Caregiver Survey (Lazenby et al., 2012)
 - 28 item, 5 point likert scale

Summary of Staff Survey Participants



A total of 296 staff surveys were collected in all four participating homes (42% response rate, overall). The total amount of surveys collected among staff are as follows:

- 119 PSWs (40% of total responses)
 - 44% PT & 56% FT; 66% between the ages of 35-54
- 66 Nurses (22% of total responses)
 - 30% PT & 70% FT; 63% between the ages of 35-54
- 103 support staff (35% of total responses)
- 8 Allied Health Professionals (3% of total responses)

Preliminary Between Groups Analysis



- Descriptive statistics were compiled for items related to nurse and PSW roles and responsibilities within a palliative care context
- Specific survey items were also evaluated for differences between nurses and PSWs in responses across end-of-life care knowledge and practices (*t-tests*)
- Between groups ANOVAs were also performed to explore differences between nurses, PSWs and support staff on items related to staff and peer support resources

Findings Descriptive Analysis PSWs & Nurses



- Nurses more integrated in care planning than PSWs
 - 85% of PSWs say they have contributed to the development of care plans compared to 97% of nurses
 - 63% of PSWs say they have attended care conferences compared to 83% of nurses

Findings – PSWs & Nurses End of Life Caregiver Survey



Item	Nurses		PSW		T-test
	M	SD	M	SD	
I am knowledgeable about cultural factors influencing end-of-life care	2.75	1.03	2.24	1.36	6.66*
I am comfortable dealing with patients' and families religious and cultural perspectives	3.16	0.88	2.82	1.36	3.17
I can recognize when patients are appropriate for referral to hospice	2.91	0.92	2.21	1.34	13.54**
I am familiar with palliative care principles and national guidelines	3.08	1.09	2.80	0.93	2.89

*p<.05

**p<.001

Findings – PSW, Nurses & Support Staff End of Life Care Caregiver Survey

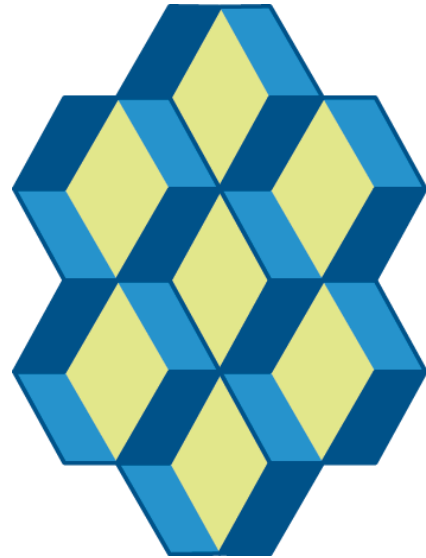


Item	Support Staff		Nurses		PSW		F-test
	M	SD	M	SD	M	SD	
I have personal resources to help meet my needs when working with dying patients and their families	1.69	1.30	2.88	1.13	2.43	1.35	16.11**
I feel that my workplace provides resources to support staff who care for dying patients	2.39	1.49	2.97	1.03	2.93	1.38	5.92*

*p<.05

**p<.001

Post hoc bonferroni tests found no significant differences between nurses and PSWs on these survey items. However, compared to both nurses and PSWs, support staff were significantly less likely to indicate they had access to resources to support their work with this population.



Technology Evaluation **IN THE ELDERLY™**

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