Erie St. Clair End-of-Life Care Network
Hospice Palliative Care Education Blueprint

Year Two
Nursing Guidelines for End-of-Life Care in Long-Term Care

Evaluation Report

April 30, 2010

Prepared By:

Loretta M. Hillier, M.A.
Evaluation Consultant
London, Ontario
(519) 433-1174
lmhillier@rogers.com

For:

Erie St. Clair End-of-Life Care Network

Table of Contents

Section		Page
Education Blueprint Evaluation Executive Summary		i – vii
Nursing Guidelines for End-of-Life Care in Long-Term Care Settings		
Executive Summary		1
1.0 Introduction		2
2.0 Evaluation Objectives and Methods		2
3.0 Results		4
4.0 Conclusions		11
Acknowledgements		13
List of Appendices		14
A	Nursing Guidelines for End-of-Life Care in Long-Term Care Implementation Report Executive Summary (Author: Carole Gill)	15
B	Guide for the Interviews with Nursing Guidelines for End-of-Life Care Long-Term Care Representatives	16

Glossary of Terms

Average (+/-)	Average is calculated as the mean score; +/- = standard deviation, which is the average distance between individual scores from the overall average score.
AHCPE	Advance Hospice Palliative Care Education
CAPCE	Comprehensive Advanced Palliative Care Education
CCAC	Community Care Access Centre
COPD	Chronic Obstructive Pulmonary Disease
DNR	Do Not Resuscitate
ED/ ER	Emergency Department / Emergency Room
EOL/ EOLC	End of Life / End-of-Life Care
EOLCN	End-of-Life Care Network
ESC	Erie St. Clair
ESAS	Edmonton System Assessment Scale
HPC	Hospice Palliative Care
IT	Information Technology
LHIN	Local Health Integration Network
LTC	Long-Term Care
NP	Nurse Practitioner
OPQRSTU	Assessment acronym standing for onset, precipitating and alleviating factors, quality, region and radiation, severity, timing, affect of symptoms
OT	Occupational Therapy
OTN	Ontario Telemedicine Network
PCR	Palliative Care Resource
PON	Palliative Oncology Nurse
PPS	Palliative Performance Scale
PPSMC	Palliative Pain and Symptom Management Consultant
RT	Respiratory Therapist

SBAR	Communication tool acronym standing for: Situation, background, assessment, recommendation
SRK	Symptom Response Kit
SWO PPSMCP	Southwestern Ontario Palliative Pain and Symptom Management Consultation Program
PSW/HSW	Personal Support Worker/ Home Support Worker
PPI	Palliative Prognostic Indicator
RN/ RPN	Registered Nurse/ Registered Practical Nurse
VON	Victoria Order of Nurses – home care and community support provider agency
WHO	World Health Organization
WIFN	Walpole Island First Nation
WRCC	Windsor Regional Cancer Centre

Education Blueprint Year 2 Evaluation Executive Summary

Erie St. Clair End-of-Life Care Network Hospice Palliative Care Education Blueprint

INTRODUCTION

The Erie St. Clair End-of-Life Care Network (ESC EOLCN) has received funding from the Erie St. Clair Local Health Integration Network (LHIN)[1] to develop a LHIN-wide integrated and cross-sector hospice palliative care education program. An evaluation of the Year One initiatives of the Blueprint demonstrated that the stated objectives were largely met;[2] Year Two of the Blueprint builds on the initiatives of Year One and was informed by the evaluation. The following education initiatives make up the Year Two ESC HPC Education Blueprint:

1. **Skill Specific Education for Care Providers:** An education session (*Right Patient, Right Place, Right Time)* designed to enhance the knowledge, confidence, and skill of nurses with novice through to expert capability in hospice palliative and end-of-life care. Four identical sessions were conducted, two in Kent County and two in Lambton County. As part of this session, information was provided on available community resources to support HPC service recipients to receive care at home for as long as possible or as they wish and to reduce unnecessary use of acute care.

2. **Implementation of Nursing Guidelines for End-of-Life Care in Long-Term Care Settings:** Assessment of the implementation status of these guidelines and the identification of factors that facilitate and challenge implementation, which will inform the development for further supports to facilitate successful implementation and the development of a communications strategy to share and promote this initiative.

3. **Expansion of Video-Conferencing Capacity:** Ongoing support and education to video-conferencing (Ontario Telemedicine Network, OTN) at two sites (Windsor and Sarnia).

4. **Volunteer Education:** Building on Year One experiences, Year Two focused on: i) an environmental scan to describe the supply and demand for HPC volunteers in ESC, ii) continued promotion and support for the 'Share the Care™' model, and iii) standardization of volunteer education with the development/ sharing of one to two education sessions for HPC volunteers across Erie St. Clair.

5. **Cultural Education:** Year Two focused on continued engagement of this community to increase their awareness of available HPC support and services in ESC and provision of the Advanced Hospice Palliative Care Education (AHPCE) Program[3] (as developed by and

[1] The ESC LHIN consists of three counties: Windsor-Essex, Sarnia-Lambton, and Chatham-Kent.
[2] Hillier, L.M. (April 30, 2009). Erie St. Clair End-of-Life Care Network Hospice Palliative Care Education Blueprint. London, ON: Author.
[3] The AHPCE Program, along with the Fundamentals of Hospice Palliative Education Program and the Comprehensive Advanced Palliative Care Education Program (CAPCE), are palliative care education programs developed by the Southwestern Ontario Palliative Pain and Symptom Management Consultation Program that are widely delivered across the province. More information on these programs is available at: www.palliativecareswo.ca.

LORETTA M. HILLIER
Health Care Research and Evaluation
lmhillier@rogers.com

delivered through the Southwestern Ontario Palliative Pain and Symptom Management Consultation Program) and expanding First Nation Community relationships in ESC by introducing the Share the Care™ model to four First Nation communities in Southwestern Ontario.

6. **System Mapping and Integration:** This component of the Blueprint aimed at continued planning for this initiative, namely the development of: a planned approach to HPC education across ESC to ensure that the HPC system is fully supported by a sustainable education structure, a strategic approach to the use of OTN within the ESC EOLCN, and a communication strategy to promote the work of the Education Blueprint.

A comprehensive evaluation of this Education Blueprint was undertaken, examining both outcomes (summative evaluation) and development and implementation (formative evaluation). The evaluation report describes the methods and results of this evaluation.

EVALUATION METHODS

Evaluation objectives across all of the components of the Blueprint were aimed at:
- i) Providing feedback on education sessions
- ii) Identifying impacts associated with education
- iii) Describing the development and implementation of initiatives
- iv) Describing progress to date

A mixed methods approach (quantitative and qualitative) was used to achieve the objectives of this evaluation. Sources of information included:
- ***Feedback surveys*** completed by education participants to obtain reactions to the sessions (Skill Specific Sessions, Share the Care™ information sessions); responses rates ranged from 80-90%.
- ***Follow-up surveys*** to assess impacts of the education delivered in Year One (Physical Skills, Hands on Care, Fundamentals Program); response rates ranged from 41 -100%.
- ***Environmental scan:*** Surveys and interviews with volunteer coordinators/ managers to assess the current state of volunteerism is ESC.
- ***Individual and group interviews*** with key stakeholders to gather in-depth information on impacts and to describe development and implementation of various initiatives (Skill Specific education, Share the Care™ with various First Nations communities, Nursing Guidelines for EOL Care in LTC, Story Telling Project); in total 30 individuals participated in the evaluation interviews.

KEY FINDINGS AND CONCLUSIONS

Skill Specific Education
- A total of 88% (N = 192) session participants completed reaction surveys. Across all sectors, participants viewed the program positively and perceived the session as very useful/ relevant to their work. Increases to knowledge, comfort and confidence were reported; it was anticipated that practice change was likely as a result of the session.
- Working group members (N = 11) participated individual interviews; factors that assisted with and that challenged the development and delivery of the education sessions were identified (none insurmountable), as well as suggestions for improvements/ sustainability.

These factors and strategies can inform the development and delivery of future sessions as well as provide a focus for improvements. Sessions offered in Year One and Year Two were noted to have an impact at an individual (increased access to information, increased trust in care), health provider (enhanced knowledge and skills, practice improvement), organizational (improved communication, development of policies and procedures to support palliative care), and health system levels (improved quality of care, potential for ED/ acute care diversion).

- Seventy individuals (41%) who participated in last year's Physical Skills sessions completed a follow-up survey. Changes to practice were identified as a result of last year's session, with associated client-related benefits including increased access to resources and supports, better pain and symptom management, and enhanced quality of care/ support. Some respondents identified increases in the amount of and access to palliative care services provided in the community and in the number of clients served at home and dying at home. Challenges exist associated with use of learned knowledge and skills including lack of support/ recognition, limited resources, and lack of integration and continuity of care across sectors. There was much support for ongoing education opportunities.

Conclusions: The Skill Specific education sessions were well received and described as a significant learning opportunity, relevant to practice, and likely to facilitate practice change. The significance of this learning opportunity is reflected in requests more palliative care related education and interest in formal palliative care programs. There is anecdotal evidence that this education program has had positive impacts on the system of care for individuals requiring palliative care. Most significantly, the sessions provided nurses with knowledge, skills, and resources to enhance palliative care within the community, thereby reducing the use of acute system resources and enhancing utilization of existing community resources. Challenges/ barriers to knowledge transfer were identified (e.g., limited physician and organizational support) - efforts aimed at reducing these will further enhance palliative care within the community; ongoing education is an important step toward addressing these challenges. Working group attention to evaluation feedback gathered at the Year One sessions served to resolve issues identified and to further develop education that is relevant and immediately applicable to practice. The structures created for this education initiative have the potential to ensure sustainability.

Nursing Guidelines for End-of-Life Care in Long-Term Care

- Five individuals, representing 5 LTC homes (2 that fully implemented the guidelines, and 3 that had limited implementation) were interviewed.
- A number of factors were identified as facilitating both full and limited implementation of the guidelines: Management support ('buy in' prior to the education session, selection of appropriate staff to attend training, support for in-house staff education); peer support (willingness to learn, willingness to discuss and review their EOL practice), support from CAPCE trained nurses and effective education and resources.
- Challenges to implementation focused primarily on competing priorities, namely the implementation of the MDS-RAI, upcoming changes to corporate palliative care policies and procedures, limited staff time and support because of the overwhelming changes currently occurring in LTC and limited management support. Although representatives from homes that were limited in their implementation of the guidelines expressed an interest in perhaps revisiting the guidelines, it was noted that current challenges would continue to hinder

implementation. Interest was expressed in perhaps considering the use of the guidelines to assist in care planning and to increase the use of the PPS.

- There was identified interest in opportunities for on-going education related to palliative and end-of-life care and refresher sessions to sustain implementation of the guidelines. Homes with limited implementation identified the need for more time and dedicated staff to facilitate implementation.
- Impacts associated with the nursing guidelines for EOL care were related primarily to improved resident care, increased staff capacity to manage EOL care and reduced need to transfer patients to hospital as family members are confident in the care that their loved one is receiving.

Conclusions: Although the uptake of the nursing guidelines for EOL care in LTC settings has been limited, there continues to be interest and support for this initiative. Representatives from homes in which there has been limited implementation have been challenged by competing priorities, but continue to hope that they will have an opportunity to implement the guidelines fully in the near future; there is perceived value in implementation of the guidelines for residents and family members as well as care providers. Ongoing management and staff support are most likely the critical factors that maintained implementation of the guidelines as a priority despite other competing initiatives. Securing this type of support in other homes is an important factor needed to facilitate implementation. Strategies that focus on 'baby steps' towards implementation including opportunities for capacity building (ongoing education/ training opportunities) may maintain interest and momentum towards full implementation and would most likely be welcome by front-line staff. The implementation of an education session targeted to nurses with CAPCE training, along with ongoing support from the PPSMC, represents a significant move towards addressing the support needs of homes interested in implementing the guidelines, particularly in terms of supporting in-house champions for this initiative.

Volunteer Education

- Surveys were completed by 13 individuals representing various organizations across sectors and counties; 7 individuals completed more in-depth interviews regarding HPC volunteerism. Although the response rate for the environmental scan survey and interviews was low, there was representation across sectors and some consistent themes. There are currently unmet needs for hospice palliative care volunteers. The environmental scan generated ideas for improving the recruitment, training and education, and retention of volunteers. Many of the issues raised regarding volunteerism were consistent across sectors; partnerships within and across sectors were identified as opportunities for resolving challenges related to volunteer training and education.
- Six individuals that participated in last year's Hand on Care Training completed a follow-up survey. Over half of those surveyed had delivered the training (19 sessions) or had sessions scheduled. At least 35 individuals have been trained to date; sessions have been well received. The initial train-the-trainer session and available resources prepared trainers to deliver this training, though they were challenged by the long length of the program, limited volunteer interest in extended training and limited organizational support; suggestions for overcoming these challenges were identified.
- Two individuals participated in interviews regarding the Story Telling Project. It was noted that the tool kit binders, provided through funding from the Education Blueprint, were essential to the delivery of this project and to increase accessibility, as many clients were not able to pay for the binders independently. Benefits associated with this project included

the opportunity to leave a "legacy' for their family, to refocus their attention away from their health challenges to something positive and of interest to them, and to provide social interaction with others.
- Eighty percent (N = 38) participants of the Share the Care*™* session completed a session reaction survey.The information session was well received. Respondents valued the case presentations ("stories") illustrating use of and success with the model, resource materials, and the opportunity to share ideas with others. Great value was seen in this informal model of caregiving as an opportunity to reduce stress for primary caregivers/ family members, provide greater options for care, enhance ability to provide care at home/ remain at home, and improve quality of life for all involved.

Conclusions: Generally there is a need for more HPC volunteers, necessitating optimization of recruitment, training, and retention efforts. Strategies and opportunities for enhancing these efforts have been identified; there is much interest in cross-organization partnerships. Train-the-trainer models (e.g., Hands on Care) and promotion of initiatives that expand the volunteer pool (e.g., Share the Care*™*) provide significant opportunities for capacity building in hospice palliative care within the community.

<u>Cultural (First Nation) Education</u>

- All of the participants of the Fundamentals Program delivered in Year One of the Education Blueprint on Walpole Island completed a follow-up survey. The program was well received by respondents and rated as very useful to their work. The majority of respondents indicated that as a result of the Fundamentals Program they now engage more often in various practice activities (consistent with the performance objectives for this program), and are more knowledgeable and more confident and comfortable in providing palliative care. Generally, it was reported that practice improvements had occurred as a result of the program and there is a strong desire for ongoing opportunities for education and performance improvement.
- A session feedback survey was completed by 90% (N = 17) of participants who attended a Share the Care™ information session, and interviews were conducted with 2 session organizers and representatives from 3 of the 4 First Nation communities in attendance. The Share the Care*™* information session was well received and there is much interest in implementing the model within First Nation communities. Implementation of the session was facilitated by leadership support from the First Nation communities, support from the Share the Care*™* Coordinator from the South West End-of-Life Care Network, the previous relationship between the Walpole Island First Nation communities and the ESC EOLCN and consistency of the model with the First Nation culture. Key lessons learned in the implementation of the session highlighted important things to consider when introducing the model to First Nation communities. Potential impacts associated with the use of this model within First Nation communities included: capacity building and increased resources for EOL care, improved palliative and EOL care, increased support for home deaths and strengthened relationships within the community. Dedicated leadership support and advocacy, resource support, strategies for caregiver self-care (to prevent burnout) and ongoing opportunities for palliative and EOL education and bereavement and grief support were identified as important for moving the model forward.

Conclusions: Over the past year, this initiative has gone a long way toward building the relationships with the Walpole Island First Nation community needed to introduce palliative and

EOL care supports and resources for both formal and informal caregivers. The success of the Share the Care™ information session with participants from four First Nation communities suggests the potential for future events in a similar format. Education provided to date has had a positive impact with participants reporting practice improvements and wanting more opportunities for capacity building (more education, more supportive resources). The lessons learned from the development and implementation of the Share the Care™ session, as well as other education programs with the Walpole Island First Nation community, can be used to inform the implementation of other education initiatives, particularly initiatives with other First Nation communities within the province.

System Mapping and Integration

- The evaluation objectives for this component of the Education Blueprint were to: i) to develop a plan to describe the current state of HPC related education for care providers in ESC (across sectors and disciplines), ii) to assess key stakeholders' perceptions of the potential success of communication methods outlined within a communication strategy, developed in Year Two, for HPC education in this region, and iii) describe the progress in implementing the ESC EOLCN Education Blueprint and the number of individuals participating in the various initiatives.
- A survey has been developed with input from key stakeholders in the field to assess the current state of HPC related education for care providers in ESC. This survey will be administered in Year Three of the Education Blueprint. Similarly, a survey has been developed with input from key stakeholders in the field to explore opportunities for enhancing communications about HPC education. This survey will be administered in Year Three of the Education Blueprint.

- **Conclusions:** Across all of the components of the Education Blueprint, 396 individuals participated in education or information sessions. Year Two objectives were mostly completed or in-progress towards completion.). Year Three plans for further supports to HPC education and communication will be informed, in part, by a consultation process (survey-based) with key stakeholders. Video-conferencing technology is fully operational in two sites; there is much support for the use of the technology and leveraging learnings to date. Opportunities/ strategies to maximize use of the technology for education and meetings will further support the efforts to increase access to palliative care education in this region.

FINAL CONCLUSIONS

Based on the results of the evaluation of the Year Two initiatives of the Erie St. Clair End-of-Life Care Network Education Blueprint the following conclusions can be made:

- The Year Two objectives of the Education Blueprint were mostly all achieved; some are still in progress. Education initiatives delivered in Year Two were well received and support overall efforts to enhance hospice palliative care across sectors in this region.

- Challenges to initiatives as identified in the Year One evaluation were attended to in Year Two and mostly resolved, demonstrating the interest of initiative organizers to reflect on feedback and resolve identified issues. Continued attention to key stakeholder feedback will serve to inform and maximize planning and education efforts for Year Three. Similarly,

identified factors facilitating and hindering implementation of Blueprint initiatives and key lessons learned can serve to inform not only other initiative developed by the Blueprint, but also the application of this Blueprint to other regions of the province.

- Evaluation efforts focused on the identification of impacts associated with education, resources and supports provided to date by the Education Blueprint. Although mostly self-report and anecdotal there are consistent benefits identified across sectors, counties, and key stakeholders. These benefits are namely related to enhanced client and caregiver access to quality of palliative and EOL care within the community, capacity building among care providers (enhanced knowledge, assessment and management skills, confidence), volunteers (increased access to training and supports), organizations (improved communication, development of policies and procedures to support hospice palliative care), with the potential for health system enhancements (improved quality of care, emergency department/ acute care diversion, improved/ more appropriate use of existing system resources). Although it would be difficult to attribute specific outcomes to specific Education Blueprint efforts, it is most likely that combined efforts to provide a coordinated and integrated approach to hospice palliative ad EOL care interact with other palliative care system enhancements (e.g., Hospice programs, expert consultation teams) to affect improvements to care. Plans to develop a more structured and standardized approach to volunteer and care provider education as well as efforts to develop a communication strategy to promote the hospice palliative care education will further support capacity building in this region.

- Many of the relationships (e.g., across sectors, with the Walpole Island First Nation community) and structures (e.g., working groups, committees) developed as result of the Education Blueprint have the potential to ensure sustainability. There is much support for more education regarding palliative and end-of-life care. The Blueprint has stimulated interest in and raised the “bar” for practice improvements; this can be sustained through exploration of strategies and opportunities to support ongoing HPC education.

Evaluation Limitations: Response rates for some of the evaluation components (environmental scan on volunteerism, interviews on the implementation of the EOL nursing guidelines in LTC) were very low. Identified reasons for the poor response rates and potential solutions can inform the implementation of the Year Three evaluation in order maximize key stakeholder involvement, as for example in the survey of key stakeholders to inform the development of a sustainable education structure and communication strategy for education. Identified impacts associated with the initiatives that make up the Education Blueprint were largely self-reported and anecdotal. Although difficult to develop, objective measures of impacts (e.g., increase in inquiries/ registration in formal palliative care education programs, ED diversions/ reduction in crisis visits to ED, increase in deaths in preferred location) would provide further support for the work of the Education Blueprint.

Executive Summary: Implementation of Nursing Guidelines of End-of-Life Care in Long-Term Care Settings

Introduction: Year Two activities for this initiative focussed on the assessment of the implementation status of these guidelines and the identification of factors that facilitate and challenge implementation, and the development of a communications strategy to share and promote this initiative.

Evaluation Methods: The objectives of the evaluation were to: i) describe implementation of the nursing guidelines and ii) promote this initiative through the publication of evaluation findings in a peer-reviewed scientific journal. Interviews were conducted with LTC representatives that participated in the Year One training sessions .

Key Findings:
Facilitating Factors; A number of factors were identified as facilitating both full and limited implementation of the guidelines: Management support ('buy in' prior to the education session, selection of appropriate staff to attend training, support for in-house staff education); peer support (willingness to learn, willingness to discuss and review their EOL practice), support from CAPCE trained nurses and effective education and resources.

Challenges to implementation focused primarily on competing priorities, namely the implementation of the MDS-RAI, upcoming changes to corporate palliative care policies and procedures, limited staff time and support because of the overwhelming changes currently occurring in LTC and limited management support. Although representatives from homes that were limited in their implementation of the guidelines expressed an interest in perhaps revisiting the guidelines, it was noted that current challenges would continue to hinder implementation. Interest was expressed in perhaps considering the use of the guidelines to assist in care planning and to increase the use of the PPS.

Needed resources: There was identified interest in opportunities for on-going education related to palliative and end-of-life care and refresher sessions to sustain implementation of the guidelines. Homes with limited implementation identified the need for more time and dedicated staff to facilitate implementation.

Impacts associated with the nursing guidelines for EOL care were related primarily to improved resident care, increased staff capacity to manage EOL care and reduced need to transfer patients to hospital as family members are confident in the care that their loved one is receiving.

Conclusions: Although the uptake of the nursing guidelines for EOL care in LTC settings has been limited, there continues to be interest and support for this initiative. Representatives from homes in which there has been limited implementation have been challenged by competing priorities, but continue to hope that they will have an opportunity to implement the guidelines fully in the near future; there is perceived value in implementation of the guidelines for residents and family members as well as care providers. Ongoing management and staff support are most likely the critical factors that maintained implementation of the guidelines as a priority despite other competing initiatives. Securing this type of support in other homes is an important factor needed to facilitate implementation. Strategies that focus on 'baby steps' towards implementation including opportunities for capacity building (ongoing education/ training opportunities) may maintain interest and momentum towards full implementation and would most likely be welcome by front-line staff.

LORETTA M. HILLIER
Health Care Research and Evaluation
lmhillier@rogers.com

1.0 Introduction

In Year One of the Education Blueprint training was delivered to support the implementation of nursing guidelines for EOL care across all ESC Long-Term Care (LTC) Homes. Year Two activities focussed on: i) assessment of the implementation status of these guidelines and the identification of factors that facilitate and challenge implementation, which will inform the development for further supports to facilitate successful implementation, ii) the development and delivery of further support to facilitate successful implementation of the guidelines as informed by the assessment (i), and iii) the development of a communications strategy to share and promote this initiative.

A preliminary assessment of the implementation status of the guidelines was conducted by Carole Gill, Palliative Pain and Symptom Management Consultant (PPSMC) for Windsor and Essex County. (The executive summary for this assessment is presented in Appendix A). Of the 35 long-term care homes in ESC, 33 participated in this Education Blueprint initiative. The guidelines have been fully implemented in 6 (18%) homes and partially implemented in pilot units in 7 (21%) homes. In total, 79% of homes have committed to the implementation of the guidelines, 13 (39%) homes have already either fully or partially implemented the guidelines and an additional 13 (39%) homes have plans to implement in the guidelines in the future. It was concluded that although most of the LTC homes hold the guidelines in high regard and are interested in implementation, they are challenged by competing priorities, primarily the implementation of the MD-RAI assessment tool and new computer software, which has been laboursome and time-consuming for homes. Consistent with this, implementation of the guidelines has been hindered by the turnover of staff championing the guidelines and requirements to follow corporate policies for end-of-life care.

In response to the findings of the preliminary assessment of the implementation status of the guidelines (described above), an education session was developed and delivered by Carole Gill, PPSMC for Windsor and Essex County. This session was targeted to homes interested in implementing the guidelines, and specifically to nurses who had completed the Comprehensive Advanced Palliative Care Education Program (CAPCE). Six CAPCE trained nurses participated in this session, representing five LTC homes. The purpose of this session was to increase the capacity/ provide support to these individuals as champions for this initiative by brainstorming and developing an action plan for the implementation of the guidelines within their respective homes, including the identification of potential implementation challenges and strategies to overcome these challenges. The PPSMC will remain an active resource to this champion group as they move forward with the implementation of the guidelines.

2.0 Evaluation Objectives and Methods

The identified objectives of the evaluation of the implementation of nursing guidelines for end-of-life care in long-term care settings component of the Education Blueprint were:

i) to describe implementation of the of nursing guidelines for EOL in LTC care settings[4]:
   - What factors facilitated the successful implementation of the guidelines?

[4] Note: Although some of these issues were addressed in Carole Gill's preliminary assessment, it was decided that a more in-depth consultation with LTC home representatives conducted by an objective, external party may elucidate further the issues challenging the implementation of the guidelines.

- What challenges or barriers to implementation hindered implementation?
- What additional supports (e.g., resources, materials, education) are needed to facilitate implementation of the guidelines?
- What suggestions did interview participants have for improving this initiative?
- What ongoing goals did LTC homes have for this initiative over the next year?

ii) to promote the Nursing Guidelines for End-of-Life Care in LTC Settings initiative through the publication of previously reported[5] and current evaluation findings in a peer-reviewed scientific journal.

Sources of Information

To meet the above stated evaluation objectives the following methods were employed:

Focus group interviews with LTC representatives

A purposeful sample of representatives from the LTC homes that participated in the Year One training sessions for this initiative were invited to participate in interviews regarding the implementation of the nursing guidelines. Separate focus group interviews were held for representatives from those homes identified (in the preliminary assessment) as having successfully implemented the guidelines, and for representatives from those homes identified as not having implemented the guidelines. The guide for these interviews is presented in Appendix B.

All 62 individuals that participated in the Year One initiative were sent an invitation to participate in these interviews via e-mail; four invitations were returned 'undeliverable', one individual indicated that she was no longer employed in long-term care. The response rate for the interview request was quite low: 10 individuals (18%; 10/57) expressed an interest in participating in the interviews. Four individuals did not respond to subsequent requests to schedule an interview, four individuals scheduled an individual telephone, two of which were completed, and two of which cancelled and did not reschedule and 2 individuals completed the interview in a group format, and one individual provided written responses to the interview questions. These interviews ranged in length from 20 to 32 minutes (average 25 minutes).

In total, five individuals (9%; 5/57) contributed to these interviews; three from homes that did not fully implement the guidelines or that discontinued use of the guidelines and two from homes that have fully implemented the guidelines.

Publication of Evaluation Findings

Evaluation findings to date (previously reported and current) will be summarized in a manuscript for submission to a peer-reviewed scientific journal. Potential journals (nursing, nursing/long-term care home, administration, palliative care) will be explored to identify the most appropriate target audience. The evaluation consultant will work with those involved in the development and

[5] An evaluation of the nursing guidelines was completed in 2007: Hillier, L.M. (Mary 27, 2007). Nursing Guidelines for End-of-Life Care in Long-Term Care Settings. London ON: Author.

implementation[6] of these guidelines to select a journal and prepare a manuscript for submission. The publication manuscript is not included in this evaluation report but when available can be requested from the evaluation consultant or initiative organizers.

Data Collection and Analysis

Invitations to participate in the evaluation interviews were distributed by the evaluation consultant and all interviews were scheduled and conducted by the evaluation consultant. Interviews were digitally recorded and transcribed. Interview data analysis was consistent with recommended practices for qualitative data.[7]

3.0 Results

The following is a summary of the highlights and main themes that have emerged from the evaluation of the Nursing Guidelines for End-of-Life Care in LTC initiative.

3.1 Objective 1: To describe implementation of the nursing guidelines for EOL care in LTC care settings

Implementation of the Guidelines

Table 1 presents a summary of the factors facilitating implementation of the guidelines, challenges, and goals for further implementation as identified by representatives from homes that were successful in their implementation of the guidelines and representatives from homes that were limited in their implementation of the guidelines.

Table 1: Implementation of the nursing guidelines for EOL care in long-term care

Successful Implementation	**Limited/ Discontinued Implementation**

Facilitating Factors:
• Management support
  o 'buy in' prior to the education session
  o selection of appropriate staff to attend training
  o support for in-house staff education
• Peer support
  o willingness to learn
  o willingness to discuss and review their EOL practice
	Facilitating Factors (partial implementation):
	• Management support
	  o Support for initial attempts to implement ("stalled" by challenges)
	• Support from CAPCE trained nurses
	  o Conducted in-services
	  o Drafted letters of support for physicians

[6] Including: Carole Gill, Palliative Pain and Symptom Consultant for Windsor Essex, Jacqueline Crandall, Project Coordinator; Kelly Froese, RPN, Sun Parlour Home for Senior Citizens, Leamington, ON.
[7] Patton, M.Q. (2002). *Qualitative Evaluation and Research.* Thousand Oaks, CA: Sage.

Successful Implementation	Limited/ Discontinued Implementation
• Education session was effective; resources provided were useful	

Challenges:
• Ensuring all staff, across all shifts, attending the in-house training sessions
• Ensuring staff regularly assess residents using the PPS
• Ensuring consistency in ratings so residents get consistent care
	Challenges:
	• Competing priorities (implementation of MDS-RAI)
	• Upcoming changes to corporate palliative care policies and procedures
	• Limited staff time and support
	  o staff overwhelmed by new changes
	  o laboursome and time consuming nature of MDS-RAI implementation left staff disinterested and too busy to implement new guidelines
	• Duplication of tools used in the MDS-RAI and guidelines (use of ESAS)
	• Limited management and IT support for implementation

Goals for the Next Year: • Improve communication with physicians regarding assessment results • Deliver refresher education sessions	***Goals for the Next Year:*** • Consider use of the guidelines to assist with care planning • Increase use of the PPS
Needed Resources: • Opportunities for on-going education related to palliative and end-of-life care • Opportunities for refresher sessions	***Needed Resources:*** • Time to implement guidelines • Dedicated staff member to facilitate implementation

Progress to Date and Facilitating Factors:

Successful Implementation: Representatives from the two homes that had successfully implemented the guidelines reported that following their participation in last year's education program, they returned to their homes and immediately began implementation. Both homes are conducting assessments with all residents on a quarterly basis and following the guidelines when residents' conditions are declining. They identified support from their Director of Care/ Manager of Care as well as support from their peers as critical to their ability to apply what they had learned in the session to their home. One participant indicated that she believes that the management team in her home had supported this initiative prior to the education session and had selected staff to attend that would be able to move this initiative forward, as reflected in the following comment:

"I think that it really helped that there was 'buy in' even before we got to the session. They [leadership] *told us they wanted us to do this and we were to go and learn what we needed to do, what needed to be done. So, I think they picked me and the other person because they knew that we could do it. And we did."*

It was also noted that management support was reflected in *"freedom to educate and teach"* long-term staff on how to use the guidelines to improve end-of-life care. Moreover, it was noted that support from peers in terms of being open to learning about the guidelines and open to discussions and reviews regarding how to manage end-of-life care helped to facilitate the implementation of the guidelines.

The education session held last year was described as extremely useful in terms of providing the homes with the information and resources they needed to implement the guidelines independently.

"[The PPSMC] *was awesome. She told us how we should do it and what doesn't work and what she found to be helpful. That was helpful because she gave us all the information we needed, like the handouts, the tools and we got a pamphlet for the families that we still give out to everyone."*

Limited Implementation: Representatives from the three homes that have had limited implementation of the guidelines noted that they implemented only certain components of the guidelines (e.g., use of PPS or ESAS, education on EOL care, or distribution of the EOL pamphlet for family members). All three participants noted that while they had the support of their Administrator, Director of Care, and regional Nurse Clinicians, challenges (described below) "*stalled"* further implementation. It was noted by one participant that her home was able to start the process of planning for implementation, conducting in-services, and draft information/ support letters to physicians and residents' council because they had several CAPCE trained nurses who could support the implementation process; implementation of the guidelines did not occur beyond planning.

One participant noted that although her home has not implemented the guidelines, the corporation is proactive about EOL care and has policies and procedures in place that are consistent with Ontario Ministry of Health and Long-term Care guidelines.

Challenges:

Challenges to implementation were experienced by both homes that were successful in implementing the guidelines and those that were limited with their implementation.

Successful Implementation: Despite the fact that these homes had good staff support for the implementation of the guidelines, it was noted that it required much prompting to ensure that all staff across all shifts attended the initial training sessions on the use of the guidelines and staff required reminders to regularly assess using the PPS, particularly at times when the resident appeared stable, as reflected in the following comment:

"Staff were not always assessing residents regularly with the PPS. Especially if they had done it several times and it was, say the resident was at 40% and they were supposed to

assess until they were stable. They needed reminders about this….They got so focused on the care that they forgot."

It was also noted that initially it was necessary to make sure that all staff were using the PPS consistently in terms of the ratings that they were providing, so that residents received consistent care.

Limited Implementation: Although participants noted that they attempted to implement the guidelines soon after the education session they were hindered by other initiatives that became a greater priority, such as the implementation of the MDS-RAI (Minimum Data Set – Resident Assessment Instrument), new documentation protocols (e.g., computerized systems) and corporate changes to palliative care policies and procedures.

"We're part of a corporation and our corporate office is currently looking at developing a new palliative care program as well, we're thinking, to include both the ESAS and the PPS scales and a whole new way of looking at things so we're kind of in limbo."

It was noted that despite there being support for the use of the guidelines, the implementation of the MDS-RAI was extremely challenging and laboursome, leaving minimal time or interest in developing anything new,

"I mean everybody was very supportive. Some of the staff have the: 'oh my gosh, not a change' – but for the most part everybody was excited. ...It's [EOL guidelines] *another piece of paperwork you know, which it always is, and that's really hard on a lot of our staff, especially now with the MDS and everything. I mean their time has just been literally dissected into a hundred different things that they can't possibly do in an eight hour shift, so that has become an issue."*

Moreover, it was noted that there is some duplication between the guidelines and MDS-RAI, as the ESAS is included in the MDS-RAI assessment so staff felt that they were already implementing part of the guidelines and were not interested in doing extra work that is already captured in the current assessment.

"I had people telling me: 'We're already doing the ESAS'. So they didn't want to do anything else. In some ways they were doing more than they actually thought, but it's much like the MDS."

The home that had discontinued use of the guidelines did so at the time that a new computerized system was introduced – the guidelines were not added to the on-line documentation system, as described in the following comment:

"But as we transferred more and more info into 'computer only' work, the guidelines were among many assessments that did not make it to the computer assessments. Our IT manager was approached several times about the importance of the Nursing Guidelines for EOL Care but each time refused to add it, saying that the MDS had its own system for palliative care.… The IT department is headed by an RN who was not part of the initial process and so doesn't feel it is a necessary addition to the RAI."

Key Lessons Learned:

Successful implementation: Representatives from homes that were able to implement the guidelines noted that management support in terms of providing time to prepare and conduct in-services was important as was ensuring that all staff attended the initial training sessions and that they completely understand how to use the tools and then use the information to develop appropriate care plans.

> *"You really need to make sure that the initial education reaches everybody, on every shift and make sure that they all get it, that they understand what it is they're supposed be doing."*

Intentions for Further Implementation:

Successful implementation: Representatives from homes that were able to implement the guidelines noted several goals related to the guidelines that they would like to achieve in the next year. These included:

- **Improving communication among staff:** It was noted communication between staff conducting the assessments and physicians could be improved. For example, there are some physicians who are not familiar with the PPS, so staff need to better communicate with them the results of assessment in a way that physicians can understand.

  "The physicians don't typically use the PPS, so telling them it's 30% where as it used to be 60% doesn't mean anything to them."

- **Refresher education sessions:** There is interest in having refresher sessions to remind staff of the guidelines, review challenging cases and as a way of ensuring that all new staff have training on the guidelines. One participant considered having the local PPSMC attend as a guest speaker.

Limited implementation: Although representatives from homes that were limited in their implementation of guidelines expressed an interest in perhaps revisiting the guidelines, it was noted that current challenges would continue to hinder implementation. Interest was expressed in perhaps considering the use of the guidelines to assist in care planning and to increase the use of the PPS.

Resources and Supports

Successful implementation: Representatives from homes that were able to implement the guidelines noted that as they are currently implementing guidelines, there are few resources or supports needed. It was noted that they could benefit from ongoing opportunities for palliative and end-of-life care, and refresher sessions as mentioned earlier (review, case study review, problem-solving complex cases).

Limited implementation: Representatives from homes that were limited in their implementation of the guidelines noted that a key challenge to the implementation of the guidelines is lack of

time, mostly due to the burdensome nature of the MDS-RAI implementation, as reflected in the following comment:

> *"Time. What we need is time. If you could take away the MDS than we could probably do this."*

One participant noted that if her home was to commit to full implementation it would be helpful to have dedicated staff member who would be responsible for ensuring that everyone was trained, all the resources needed were available (hand outs, tools, care plans etc), and that all staff are assessing residents and implementing the guidelines as outlined.

Impacts

Impacts associated with the nursing guidelines for EOL care are presented in Table 2. Representatives from homes that have successfully implemented the guidelines identified a number of impacts associated with the implementation of the EOL guidelines in LTC, namely as related to improved resident care, increased staff capacity to manage EOL care and reduced need to transfer patients to hospital as family members are confident in the care that their loved one is receiving.

Table 2: Summary of impacts associated with the nursing guidelines for end-of-life care in long-term care

Resident-related impacts:
- Improved resident care at end-of-life
- Improved documentation
- Improved level of communication with staff

Care provider-related impacts:
- Improved communication among staff
- Enhanced capacity for EOL care
- Enhanced staff confidence regarding EOL care

Health system-related impacts:
- Fewer family requests for transfers to hospital at end-of-life
- More appropriate transfers to hospital at end-of-life

- **Improved resident care:** It was noted the guidelines ensure that residents' who are declining are identified and plans are put in place to manage their care. The guidelines ensure that all residents receive consistent care.

  "An RPN went with me [to education session]. *She feels sometimes that staff are so busy looking after physical aspects that they forget about emotional aspects. Reading over the guidelines is helpful to review all of the important issues and to remember what*

you need to discuss with family. Gives us way[a] to refocus on the whole person and holistic care."

The representative from the home that has discontinued the use of the guidelines, noted that despite this, staff continue to maintain the goals of EOL care, as described in the following comment:

"There are still some staff who use the reference EOL red books when they have questions. We use the EOL booklets as information for our residents/families. We have 2 palliative care carts with a CD player, a touch light with soft light, blankets and pillow for families. Several of our lounges have places for families to stretch out/relax, use the phone and gather together for vigils. The staff have not lost their commitment to ease these residents and their families in their time of need."

It was noted that family members have been satisfied with the EOL care provided in LTC, as reflected in the following comment:

"When we were doing the guidelines we sent out surveys to families that had members that deceased at [LTC home]. *Most families felt that they were treated well, their loved one was nursed with care, love and knowledge."*

- **Improved documentation:** Use of the PPS, ESAS and standard care plan forms have improved documentation regarding residents' needs at end-of-life and ensures that "*all staff are on the same page about what the resident needs."*

- **Improved level of communication with family members:** It was noted that the assessment and guidelines provide staff with prompts of what they need to talk to family members about and what they need to prepare them for.

- **Improved level of communication among staff:** Similarly, the assessment tools and guidelines have created a common language for discussing residents' condition and for managing EOL care.

  "I think it's really opened up discussion of how we manage end-of-life care, especially at the different levels and percentages and it gives us ideas of what to talk to the family about."

- **Enhanced staff capacity for EOL care:** The training received related to the guidelines, and the use of the assessment tools and guidelines were credited with enhancing staff knowledge and competency regarding EOL care.

  "People are coming forward with more questions. It's increased discussion of how we can do better."

- **Enhanced staff confidence regarding EOL care:** It was noted the guidelines have contributed to increased staff confidence in providing EOL care.

"Staff gained confidence in their knowledge of EOL issues and what could be offered to residents/families."

- **Reduced requests for transfers to hospital:** As staff become more competent in managing EOL and discussing EOL issues with family members, there have been fewer requests by family members to have their loved ones transferred to hospital for end-of-life care. It was suggested that family members are more confident in the care provided in LTC and thus do not feel that there is a need for their loved ones to go to hospital.

  "We don't have a lot of transfer to hospital anyway, but I think that fewer families are asking for this. Sometimes they panic because they think they need to be in the hospital, that somehow it's going to be better there. But I think they can see that it will be just as good here."

- **More appropriate transfers to hospital:** It was noted that with the use of the guidelines and improved end-of-life care in LTC, those residents that are transferred to hospital at end-of-life are appropriate for acute care. The guidelines assist staff to discuss their goals for end-of-life care and various options, so that informed decisions are made.

  "I think that when residents have to go to hospital, there are improved transfers. It [the guidelines] *helps staff be more aware of the what the goals are, so they know what to do, what the best thing is."*

Limited Implementation: It is important to note that representatives from homes with limited implementation anticipate potential benefits associated with the use of the guidelines, including enhanced resident care, increased family satisfaction with care and enhanced staff capacity to manage EOL care, as reflected in the following comment:

> *"I really think that it would be good for residents if we could use the guidelines as we were shown at that the education day and I think it would help the families too understand better what we we're doing and why…. I think people here, the RPNs and PSWs would learn a lot more too."*

Case Illustration: The following case was provided to illustrate the benefits associated with the Nursing Guidelines for end-of-life care: identification of decline, improved pain management and initiation of EOL care planning.

"Recently we had a resident who had been at about 30-40% for a really long time, months and months. He had stopped eating and drinking. The doctor discontinued his medications. Then the RPN did the quarterly PPS and it had gone down to 20%. She reported the decline to the RN, that it had gone down since the last quarter and she felt we needed to be doing more for this resident. The RN spoke with the doctor and told him about it, not the PPS, but that the resident was declining, and we were able to get him medication to better manage his pain."

4.0 Conclusions

Based on the results of these interviews the following conclusions can be made:

- Although the uptake of the nursing guidelines for EOL care in LTC settings has been limited, there continues to be interest and support for this initiative. Representatives from homes in which there has been limited implementation have been challenged by competing priorities, but continue to hope that they will have an opportunity to implement the guidelines fully in the near future. Despite the fact that there are some perceptions of overlap with the MDS-RAI assessment and documentation, there is perceived value in the full implementation of the guidelines for residents and family members as well as care providers.

- It is clear that the homes that have fully implemented the guidelines have experienced some benefits, with positive impacts identified related to residents and family members, care providers and the health system.

- Although all homes in the region have been challenged by the implementation of MDS-RAI and new documentation systems, some homes have been nonetheless able to implement the guidelines. Ongoing management and staff support are most likely the critical factors that maintained the guidelines as a priority despite other competing initiatives. Securing this type of support in other homes is an important factor needed to facilitate implementation.

- It is difficult to identify next steps for this initiative; homes overwhelmed with other priorities are not yet in a position to support implementation, even if resources or supports were made available to do so. Strategies that focus on 'baby steps' towards implementation including opportunities for capacity building (ongoing education/ training opportunities, mentorship support from CAPCE trained nurses) may maintain interest and momentum towards full implementation and would most likely be welcome by front-line staff. The implementation of an education session targeted to nurses with CAPCE training, along with ongoing support from the PPSMC, represents a significant move towards addressing the support needs of homes interested in implementing the guidelines, particularly in terms of supporting in-house champions for this initiative.

Limitations: The response rate for the evaluation interviews was low, so that the information gathered may not be representative of all homes (though findings of this evaluation were consistent with those of the preliminary assessment, which captured all of the homes in the region). Some of the same factors that challenged homes to implement the guidelines may also explain the lack of interest in contributing to this evaluation. The representatives from the LTC homes that participated in the evaluation interviews were front-line staff who were selected to participate in the education session and implement the guidelines. While it is possible that their perspectives differ from those of management/ senior leadership, the findings of this evaluation were consistent with those obtained in the preliminary assessment in which management/ senior leadership were the primary sources of information. The evidence of impacts associated with the guidelines are primarily self-reported and anecdotal. If there is interest in obtaining more objective outcome measures there may be opportunities for comparing outcomes related to EOL care between homes that have implemented and those that have not implemented the guidelines (e.g., staff confidence, transfers to acute care at end-of-life), though homes with limited implementation may not be willing or able to participate in this type of evaluation.

Acknowledgements

The feedback and advice of the ESC Education Committee is gratefully acknowledged. The consultant is especially grateful to Julie Johnston, Maura Purdon, Carole Gill and Ann Brignell for their assistance in facilitating the implementation of the evaluation across the many projects. The contribution of those who participated in this evaluation by completing a survey or participating in interviews is especially appreciated. Their contribution of time and insight reflects their commitment to building capacity for quality palliative / end-of-life care across this region.

List of Appendices

Appendix A	Nursing Guidelines for End-of-Life Care in Long-Term Care Implementation Report Executive Summary (Author: Carole Gill)
Appendix B	Guide for the Interviews with Nursing Guidelines for End-of-Life Care Long-Term Care Representatives

Appendix A

Nursing Guidelines for End-of-Life Care in Long-Term Care Implementation Report Executive Summary (Author: Carole Gill)

Implementation Executive Summary January 2010

Background
The implementation of the *"Nursing Guidelines for End-of-life Care in Long Term Care Settings"* is an initiative of the Erie St. Clair Blueprint for Hospice Palliative Care Education. Education focuses on the Palliative Performance Scale (PPS), the Edmonton Symptom Assessment System (ESAS), and the Nursing Guidelines for end-of-life care in long term care settings.

There are thirty five Long Term Care Homes operating in Erie St. Clair (ESC). Two homes, the Sun Parlor Home for Seniors and the Leamington Nursing Home now Franklin Gardens were part of a Change Foundation funded initiative to develop nursing guidelines for end-of-life care in long term care settings (2005). Two homes, Riverview Gardens and Tilbury Manor, did not participate in the ESC Blueprint education initiative.

Implementation
The guidelines are fully implemented in 6 long term care homes in Erie St. Clair. Partial implementation on a pilot unit is reported in 7 homes. No implementation is reported in 20 homes. Of note is the Malden Park Home in Essex which will close December 2010.

Challenges to implementation
The challenge theme to the implementation of the guidelines is the concurrent implementation of the MDS-RAI tool in all long term care homes. A report of other challenges includes change in human resources championing the initiative, the implementation of new computer soft ware, and the mandatory use of corporate policies for end-of-life care residents.

Education of staff
Staff education is dependent on the goal of the implementation plan. All staff is formerly educated when full implementation is planned. Targeted pilot unit staff is educated when a unit is identified to participate in the initial project.

Future plans to implement
Thirteen homes plan to implement the guidelines in the future.

Resources to facilitate future implementation
Palliative care education is the main resource identified. CAPCE Resource Nurses are enhancing the educational opportunities in individual homes. Select homes request a new start with the previous education being offered again to new senior managers and champion staff.

Appendix B

Guide for the Interviews with Nursing Guidelines for End-of-Life Care Long-Term Care Representatives

Development and Implementation

I'd like to start the interview by talking about the development and implementation of the EOL care nursing guidelines.

1.0 Tell me about where you are at with the implementation of the guidelines.

2.0 What has worked well with the implementation of the guidelines, or with efforts to begin the implementation of the guidelines?

3.0 What are some of the challenges that you've experienced with the implementation of the guidelines?

- 3.1 Are staff/ your peers experiencing any challenges as they learn about and use the guidelines?
- 3.2 What challenges do you anticipate as you begin to/ continue to implement these guidelines?
- 3.3 What strategies can be used to overcome these challenges?

4.0 What are some of the key lessons learned in implementing the guidelines? If you had to give advice to someone who was interested in implementing the guidelines in their home, what would it be?

5.0 As you move forward with these guidelines, do you/ your home have any goals that you wish to achieve in the next year?

Resources and Supports

6.0 Do you need any additional resources or supports (e.g., resource materials, time, space, education) to facilitate, or help you with the implementation of the guidelines?

7.0 What suggestions do you have for improving this initiative, or for supporting homes as they implement the guidelines?

For homes that have implemented/ begun to implement the guidelines:

8.0 How long have you been using the guidelines?

- 8.1 How often have the guidelines been used (with some/ most/ all residents at end-of-life)? If infrequently: why do you think it wasn't used more frequently?

9.0 In what ways do you think the guidelines have changed clinical practice related to end-of-life care in your home?

Prompts for impacts not generated spontaneously – what impact have the guidelines had on:

9.1 Staff knowledge regarding EOL care?
9.2 Staff competence in providing optimal EOL care?
9.3 Staff confidence in their ability to provide EOL care?
9.4 Patient and family satisfaction with the care they receive? Has this changed from prior to the initiative?
9.5 Transfers to hospitals? Has this project resulted in fewer, or more appropriate transfers to hospital? Have more residents remained in the home for end-of-life care?

10.0 Does anyone have any case examples or stories they would like to share that illustrate the benefits associated with the guidelines?

11.0 Were there any changes related to EOL care that you had expected to occur as a result of the guidelines, but did not occur?

11.1 Why do you think this didn't happen? Do not think we need this question

Additional Comments

12.0 Do you have any additional comments you'd like to make regarding this initiative or the implementation of the guidelines?