

**Erie St. Clair End-of-Life Care Network
Palliative Consultation Team**

Final Evaluation Report

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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**
Beth Lambie, Director

“We had one gentleman who wanted to die at home, and his wife did too, but he was having a lot of issues. So with the help of the team the nurse was able to keep him comfortable and keep him at home, and get in the supports they needed. They had someone on shift through the night and the expert knowledge available to make everyone comfortable, and he did have a good death at home.”

[Key stakeholder]

“We got a call from a community nurse that wanted to take the patient to the hospital. He was not feeling well, was short of breath, and all sorts of different complaints...The resource nurse went out to see the patient. He just needed his pain meds changed a bit, to do this and that. We did that and he never did go to the hospital.”

[PCT representative]

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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.
CAPCE	Comprehensive Advanced Palliative Care Education
CCAC	Community Care Access Centre
CHRIS	Client Health and Related Information System
COPD	Chronic Obstructive Pulmonary Disease
DNR	Do Not Resuscitate
ED/ ER	Emergency Department/ Emergency Room
EOLCN	End-of-life Care Network
ESAS	Edmonton System Assessment Scale
GPs	General Practitioners
LEAP	Learning Essential Approaches to Palliative and End of Life Care
LIHN	Local Integration Health Network
LRCC	London Regional Cancer Centre
LTC	Long-Term Care
MDs	Medical Doctors
OT	Occupational Therapy
PPS	Palliative Performance Scale
PPSMC	Palliative Pain and Symptom Management Consultant
SWO PPSMCP	Southwestern Ontario Palliative Pain and Symptom Management Consultation Program
PSW	Personal Support Worker
RN/ RPN	Registered Nurse/ Registered Practical Nurse

Executive Summary

INTRODUCTION

A Palliative Consultation Team (PCT) has been established in Sarnia-Lambton, Ontario as part of the Erie St. Clair End-of-Life Care Network (ESC EOLCN)'s vision for comprehensive, integrated, coordinated, and high quality hospice palliative/ end-of-life care services, available in a timely manner, irrespective of diagnosis or care setting for individuals living in the Erie St. Clair Local Health Integration Network (LHIN). The PCT is a multidisciplinary resource team for EOL care. The core team, consisting of a Palliative Care Physician, expert nurse/Nurse Practitioner, and administrative assistant, augmented with resource nurses from service provider agencies, serve to facilitate system integration and cross sector collaboration. An unfunded PCT is currently in place in Windsor Essex; as part of this current initiative a PCT was established in Sarnia Lambton in year one, with expansion to Chatham Kent and enhancements to the Windsor Essex team planned in years two and three of this three year initiative.

This document describes the methods and results of an evaluation of the PCT in Sarnia Lambton.

Evaluation Methods

Evaluation Focusing: An evaluation advisory committee was established; members acted as advisors to this evaluation, providing advice and feedback on the development and implementation of evaluation tools, facilitating identification of participants and data collection, and providing feedback on the final evaluation report.

Evaluation Objectives: The identified objectives of the evaluation were to:

- i) describe the population referred to the PCT and the services provided
- ii) identify impacts associated with the PCT
- iii) describe the process of developing and implementing the PCT.

Sources of Information: A combination of qualitative and quantitative methods were used to assess both process issues and outcomes:

- **Referral and Service Tracking** data were collected from January 1 to March 31, 2009.
- **Caregiver Satisfaction Interviews** were completed with 15 family caregivers of individuals receiving care from the PCT.
- **Key Stakeholder Survey** completed by 13 individuals representing the provider agencies (supervisors, frontline nursing staff), CCAC (Case Managers, frontline nursing staff), and primary care physicians.
- **Individual Interviews with Key Stakeholders** were conducted with 10 individuals to obtain in-depth information about the effectiveness and impacts of the PCT.
- **Focus Group and Individual Interviews with representatives of the PCT** were conducted with a total of 17 individuals order to obtain in-depth information about the development and implementation of the team.

This evaluation study was approved by the ethics Review Board for Health Sciences Research Involving Humans, University of Western Ontario.

RESULTS: Key Findings

OBJECTIVE 1: Describe the Population Referred to the Palliative Consultation Team and the Services Provided

Referrals: A total of 78 clients were referred to the PCT between December 18, 2008 and March 31, 2009. Referrals to the PCT have come primarily from the CCAC, family physicians, and specialists. The average age of clients was 68 years; the majority were men, lived in their own home and all but one had an available caregiver. Cancer was the most common diagnosis (78%), and pain the most frequent presenting problem (53%). The average PPS score at the time of the first assessment was 60%; roughly half of the clients had PPS scores of 60% or less.

Service Provision: Of the 78 clients referred to the team, 75 were seen by team members. A total of 68 clients received a comprehensive palliative assessment. Seventy-four percent of clients were seen within seven days of being referred to the team; almost half of all clients were seen on the same day that they were referred to the team. Clients were mostly assessed within the clinic (CCAC; 36%) or within their homes (28%). A shared care model of care was the most frequent (64%) model of care employed. The number of visits per client ranged from 1 – 7 with an average of 2 visits (+/- 1.4). Treatment recommendations were most frequently involved medications (new medications or changes/ adjustments to prescribed medications) and related to nursing visits, either to monitor the client or increase the number of visits. It was estimated that intervention by the team resulted in hospital avoidance at least 19 times. Referrals to other health professionals/ services were made for 9 (12%) clients. In these cases referrals were most frequently made to other physicians and to a social worker. A total of 26 clients (33%) referred to the PCT have died; 65% of these clients died at home. All of the remaining clients referred to the PCT continue to remain on service.

OBJECTIVE 2: Identify Impacts Associated with the Palliative Consultation Team

Across all of the sources of information (caregiver and key stakeholder surveys, interviews) the following impacts associated with the PCT were identified:

Client/ Caregiver Impacts

- Improved quality of palliative/ end-of-life care as evidenced by:
 - improved pain and symptom management
 - reduced caregiver burden
 - greater services/ supports provided at home
 - crisis and hospital avoidance
 - timely access to care
 - increased care provider capacity to provide palliative/ end-of-life care
 - improved communication with clients
- Increased trust/ confidence in home care
- Reduced potential for crises
- Enhanced support for caregivers
- Improved family caregiver capacity to provide care at home
- Increased client and caregiver satisfaction

Health Care Provider Impacts

- Increased access to resource support for community nurses
- Improved capacity for palliative care
- Increased job satisfaction for resource nurses

Health System Impacts

- Increased home deaths
- Hospital avoidance
- Emergency Department avoidance with direct hospital admissions
- Shorter hospital lengths of stay
- Increased and timely access to palliative care
- Improved communication among provider agencies
- Improved collaboration among provider agencies
- Increased use of standardized tools (PPS/ ESAS) among all care providers
- Increased perceptions of care at home as “safe”
- Integrated care

OBJECTIVE 3: Describe the Process of Developing and Implementing the Palliative Consultation Team

Selection of Resource Nurses:

CAPCE Training As a Requirement: Although CAPCE training was perceived to be a significant benefit and asset for the team resource nurses it was generally believed that it was not necessary as a mandatory requirement for team members. Passion for palliative care was considered an essential requirement for team members.

RN vs. RPN Requirements: Designation as a registered nurse was not viewed as a critical a mandatory requirement for team members; many registered practical nurses were described as effective palliative care nurses.

On-Call Responsibilities: To date there have been few issues around on-call responsibilities; team members have been able to meet these responsibilities. Challenges have been largely limited to financial issues (billing for visits to other agency clients, reimbursement to team members) and technological issues (failure of pagers to work across the area).

Development and Implementation of the PCT: Across all sources of information, the following issues related to the development and implementation of the PCT were identified:

Facilitating Factors:

- Palliative care champions (frontline and leadership levels)
- Key stakeholder support
- Availability and timing of LEAP education
- Easy access to team and palliative care physicians
- Frequent team meetings
- Effective team coordination
- Social work support

Challenges:**Implementation/ service delivery issues**

- Limited use of resource nurses
- Access to family physicians for updates on client status
- Limited family physician support
- Timely access to nursing support
- Establishing appropriate models of care
- Facilitating trust among provider agencies

Logistical issues

- Establishing effective communication vehicles
- Determining eligibility for the PCT
- Technological issues (pagers)
- Service delivery issues imposed by geographical boundaries
- Limited reimbursement for on-call time
- Billing issues associated with nurses visiting other-agency clients

Suggestions for improvements, sustainability and further development

- Improve/ increase communication within the team and among care providers
- Allow shared access to electronic documentation (CCAC, CHRIS)
- Secure ongoing funding
- Secure family physician support for the PCT
- Expand/ establish palliative care expert teams beyond Sarnia-Lambton
- Promote the PCT more widely
- Continue opportunities for education and team building
- Develop succession plans for the team physician
- Access to Hospice

General suggestions for improvements to palliative care

- Improve PSW service delivery (punctuality, availability, quality of care)
- Increase funding for shift nursing at end of life
- Increase opportunities for continuing palliative care education across disciplines and sectors
- Better home construction for home care
- Financial support for clients receiving care out of town

Resources/ supports needed for expansion:

- Designated team staff:
 - Team Assistant (full-time)
 - Team Coordinator
- Palliative care champions
- Family physician support
- Primary care nursing representation on the team
- Access to Interprofessional care
- Mentorship opportunities
- Continuing education and networking

CONCLUSIONS

Based on the findings of this evaluation, the following conclusions can be made about the Palliative Consultation Team:

- The PCT has achieved many of its objectives in a relatively short period of time. Further development, implementation, and expansion of the PCT has the potential to significantly impact the quality of hospice palliative/end-of-life care in this region. With continued success the PCT has the potential to be a model for other regions in the province. Lessons learned in developing and implementing the PCT in Sarnia-Lambton should be used to inform the development of PCTs in other areas.
- Although much of the evidence on health system impacts as a result of the PCT is anecdotal, there were suggestions that these impacts are also being demonstrated in statistics being maintained by various information systems (CCAC, hospital). Empirical/objective evidence based on hospital data related to Emergency Department visits for palliative/ end-of-life care issues, admissions, length of stay, and readmission rates as well as the number of home deaths would provide stronger evidence of the PCTs ability to manage care effectively within the community.
- There is much support for the PCT. It has been well received by caregivers and key stakeholders. Despite some implementation challenges, PCT members have been satisfied with their accomplishments. Some of the challenges experienced to date are inherent in the implementation of any new service. The team has an informal process in place for identifying challenges/issues and has worked towards resolving these to everyone's satisfaction.
- Currently, there is much support for the existing resource nurses on the team. They have been described as dedicated, highly knowledgeable, skilled and passionate about palliative care. There was general consensus that designation as a registered practical nurse is adequate for the role, dependent on candidates having the requisite knowledge and skills in palliative care. Although "passion" for palliative care has been identified as an important criterion, it should not supersede expertise and experience in importance, as passion alone does not guarantee competency. The published literature highlights the importance of expert competency as well as leadership skills and ability to work collaboratively, improve practice, and develop therapeutic relationships.¹
- One of the key elements of the PCT's success is that it builds upon existing capacity for palliative care within the community. Increased communication and collaboration among provider agencies is a significant outcome impacting the team's success. Suggestions made for improving and sustaining the team have the potential for further capacity building. In addition to resource supports (funding, shared information systems), opportunities for continuing education, team building, and better promotion/ marketing of the team will strengthen capacity to achieve its objectives.

¹ Tice, M.A. (2006). Nurse specialists in home health nursing: the certified hospice and palliative care nurse. *Home Healthcare Nurse*, 24(3):145-7.

Canning, D., Rosenberg, J.P., & Yates, P. (2007). Therapeutic relationships in specialist palliative care nursing practice. *International Journal of Palliative Nursing*, 13(5), 222-9.

- Lack of physician support for the work of the resource nurses poses a threat to the success of the team; suggestions related to continuing education and promotion of the team emphasizing the expertise of resource nurses, as well as opportunities for meaningful collaboration/ interactions between family physicians and team members could prove to be important strategies for securing physician support.
- One of the anticipated outcomes of the team was the provision of safer environments for patients and families requiring palliative care at home. Key stakeholder survey results indicated that the majority of those surveyed believed that safety within the home environment had not changed as a result of the team. This finding is somewhat inconsistent with the impacts identified throughout the evaluation. It is quite possible that the way in which the survey question was phased (How would you rate the current level of safety within home environments for end-of-life care? How does this compare with the level of safety within home environments prior to the inception of the Team?) was not a valid measure of this outcome. Future evaluations should ensure a more valid and reliable measuring changes to the provision of safe home environments, perhaps measuring the specific factors that ensure or define safety.

1.0 Background and Introduction

The Erie St. Clair End-of-Life Care Network (ESC EOLCN) has envisioned comprehensive, integrated, coordinated, and high quality hospice palliative/ end-of-life care services, available in a timely manner, irrespective of diagnosis or care setting for individuals living in the Erie St. Clair Local Health Integration Network (LHIN). An integrated Hospice Palliative Care system would serve to connect sectors, use common language tools, coordinate education across sectors and among disciplines, provide accountability and reporting infrastructures and encourage each health sector to be part of the integrated system of care. Goals for the integrated Hospice Palliative Care System are to provide enhancements to system integration, service integration, and service delivery and supports to consumers (palliative clients and caregivers). To this end, the ESC EOLCN has received funding from the ESC LHIN for several initiatives aimed at creating and supporting an integrated Hospice Palliative Care system in this region; this is a three year initiative. One of these initiatives is the development of a Palliative Consultation Team (PCT).

The PCT is a multidisciplinary resource team for EOL care. The core team, consisting of a physician specializing in palliative care (three 'back up' physicians are available when the team physician is away), a team coordinator (registered nurse), a social worker and a administrative assistant, augmented with nine resource nurses, three from each of the three service provider agencies contracted to provide nursing services to the CCAC²) who serve to facilitate system integration and cross sector collaboration in service delivery. The team aims to provide timely access to consultation support for primary care providers with the expectation that a shared care model of care will be developed. The PCT provides consultation support, including comprehensive assessment and care planning (considering all domains of care), consultation reports to Primary Care providers, client and family education and counselling, follow-up and direct care provision, as needed, across sectors. The team conducts regular clinical rounds to review care of clients on their caseload. The team is 'mobile', visiting clients wherever they reside or are receiving care (in their homes, hospital, long-term care or rest homes). A clinic operating out of the Community Care Access Centre (CCAC) is also part of this program. Consultation, support, and direct care are provided by the most appropriate member(s) of the team with support from other team members as needed. An overview of how the team functions is presented in Appendix A, including eligibility criteria and referral prioritization.

The main objectives (goals) of the Expert Palliative Care Team are to:

- improve access to effective palliative care for clients at the end of life, including expert pain and symptom management
- help shift care of the dying from acute care settings to appropriate alternate settings of individual preference (e.g. home, community living homes, residential hospices, retirement homes etc.)
- keep clients in their homes longer
- develop quick response capacity to prevent clients from going to the Emergency Department (ED) / being admitted
- facilitate earlier discharge from hospital

² These agencies are: Bayshore Health Care, VHA Home Health Care, and the VON.

- improve integration across the care continuum, thereby reducing duplication of services (enhancing efficiency)
- improve primary care providers' knowledge, skills and confidence in reducing the severity and distress associated with end of life symptoms through consultations and on-going, practice-based point of care education, thereby creating more clinical capacity in the community
- improve client/family and provider satisfaction with the palliative/ end-of-life care and quality of dying
- improve the overall standard and quality of care delivered to client/families at the end of life
- build an innovative model of care which synergistically leverages current provider systems and strengths and is robust and versatile enough to be maintained even with changes in personnel
- enhance concordance between clients' preference and place of death
- educate clients and families on how to manage end of life care in the home
- contribute to a more sustainable health care system.

Anticipated outcomes are summarized in the program logic model presented in Appendix B.

An unfunded PCT is currently in place in Windsor Essex; as part of this current initiative an PCT was established in Sarnia Lambton in year one, with expansion to Chatham Kent and enhancements to the Windsor Essex team planned in years two and three. The team commenced operation on January 1, 2009. This initiative is a collaboration between the North Lambton Community Health Centre and the CCAC; the EOLNC has assumed an advisory role for this initiative.

This document describes the methods and results of an evaluation of the PCT in Sarnia Lambton.

2.0 Evaluation Methods

2.1 Evaluation Focusing

The evaluation objectives and methods were initially developed with Beth Lambie, Director, ESC EOLCN. A small evaluation advisory committee was developed consisting of:

- Ann Brignell, Palliative Pain and Symptom Management Consultant
- Barb Frayne, Coordinator, Palliative Consultation Team
- Julie Johnston, Coordinator, Palliative Pain and Symptom Management Consultation Program
- Beth Lambie, Director, ESC EOLCN
- Glen Maddison, Palliative Care Physician, Palliative Consultation Team
- Shari Scarpelli, Administrative Support, Palliative Consultation Team
- Andrew Ward, Senior Manager, Client Services, ESC CCAC

Advisory committee members acted as advisors to this evaluation, providing advice and feedback on the development and implementation of evaluation tools, facilitating identification of participants and data collection, and providing feedback on the final evaluation report.

Key Stakeholders for this evaluation include: PCT members, consumers (clients, caregivers), CCAC and service provider agencies, Community Health Centres, (CHC), area hospitals, family physicians, and the ESC LHIN.

2.2 Evaluation Objectives

The identified objectives of the evaluation were to:

iv) describe the population referred to the PCT and the services provided:

- Who made up the PCT (numbers/ disciplines)?
- How many clients were referred to the PCT?
- How many initial visits were conducted?
- How many clients have been assessed?
- Who were the clients being assessed? (age, gender, place of residence, diagnosis, Palliative Performance Score, location/sector at time of assessment)
- What was the response time to referrals?
- What were the activities of the team (assessment, follow-up, direct care, other activities)?
- How many clients received follow-up?
- How many clients received direct care from team members?
- How much time did each visit take? (time per visit, time per client)
- How many members of the team were involved with each client?
- How long did clients remain on service?
- How many clinical rounds were held?
- How many referrals (calls) were received 'off hours'?
- What was the model of care employed with each client (shared care, primary care)?
- Who received the consultation report (primary care, client, Community Service Provider agency, CCAC, acute care)?
- Where did clients die (home/ hospital/ nursing home)?

v) identify impacts associated with the PCT:

Health System impacts:

- What impact does the PCT have on EOLC service within the community?
- What impact does the PCT have on the number of deaths that occur at home? In hospital?
- What impact did the team have on acute care LOS for clients requiring palliative care?
- What impact did the team have on admission to Emergency Department visits by clients requiring palliative care?

Client/ Caregiver-related impacts:

- What impact does the PCT have on client/ caregiver satisfaction with:

- access to assessment, care, and support services?
- pain and symptom management?
- timeliness of access to assessment, care, and support services?
- coordination of care across providers and sectors?
- communication with providers (response to their questions and concerns)?
- communication among providers (degree to which each provider involved is informed and aware of that clients' status and treatment plans)?
- Informed decision-making process (i.e., do they feel they have enough information with which to make treatment/care decisions)?
- preparation for death (EOL care, death management, post-death process).
- What impact does the PCT have on client/ caregiver satisfaction with assessment, follow-up, and care provided by the team (e.g., time spent with team members, explanations, results, overall perceptions of the assessment/ follow-up/ direct care provision)?
- What impact does the PCT have on meeting client/ caregiver preference for place of death (concordance between preference and actual place of death)?

Provider-related impacts:

- What impact does the PCT have on provider satisfaction with:
 - Care integration?
 - Communication regarding consultation results and care planning?
 - Care coordination and care planning for those requiring palliative care?
- What impact does the PCT have on primary care provider's capacity to manage palliative care/ EOL issues independently within their practice?
- What impact does the PCT have on physician confidence and comfort in their ability to manage palliative care/EOL issues independently in primary care?
- What impact does the PCT on building capacity for EOL among resource nurses (service provider agencies, CCAC)?

vi) describe the process of developing and implementing the PCT:

- What factors facilitated the development and implementation of the PCT?
- What were the challenges associated with implementation and what are the potential strategies to overcome these?
- What factors facilitated and challenged the development of the resource nurse team? How were individuals selected? Were they able to meet the on-call responsibilities (timeliness, quality of care)? Were their needs for capacity building met?
- What service delivery issues have arisen?
- What are the lessons learned in the development and implementation of the PCT?
- What are suggestions for improvement? For sustainability? For expansion to other counties?
- What are potential next steps for the PCT?

2.3 Design and Sources of Information

A comprehensive evaluation framework for the Sarnia Lambton PCT was developed based on the program logic model for this initiative. This evaluation framework is presented in Appendix C. The following sources of information were used to achieve the objectives of this evaluation; a combination of qualitative and quantitative methods were used to assess both process issues and outcomes.

2.3.1 Referral and Service Tracking

Referrals were tracked from the start of the project, January 01, 2009, to March 31, 2009. The PCT (administrative assistant) maintained records of the clients served (demographic information, service delivery and service outcomes). A list of data tracked is presented in Appendix D.

2.3.2 Caregiver Satisfaction Interview

Caregivers of clients served by the PCT were invited to participate in a brief telephone satisfaction interview. Caregivers acted as a representative/ proxy for clients, as it was anticipated that clients, many of whom were at end of life, would not be able to participate in the interviews. Caregivers were contacted a minimum of three weeks from their first contact with team members. The purpose of this interview was to obtain information related to:

- satisfaction with services received from the team (access, timeliness, care coordination, communication, informed decision making, preparation for death).
- for clients who have died – satisfaction with the management of death and location.
- suggestions for improvements to EOLC services.

The interview guide used for these interviews is presented in Appendix E.

Consistent with guidelines for the conduct of ethical research with consumers, caregivers were informed by a member of the PCT that an evaluation of the team was underway that involved the completion of a brief telephone interview; a letter of information was provided to them regarding the evaluation study. Caregivers who agreed to allow the team to share their contact information with the evaluation consultant, were contacted by the consultant to provide more information about the study, answer questions, to invite them to participate in the interview and obtain informed consent.

A total of 17 caregivers expressed an interest in participating in the interviews; 15 completed an interview (88% response rate; 2 caregivers were not interviewed because they could not be reached by telephone). The interviews ranged in length from 6 to 21 minutes (average = 13 minutes).

A high proportion of caregivers (40%) participating in the interviews were spouses of the care receivers; the remaining caregivers were children, siblings and parents of the care receivers. At the time of the interview the majority of the care receivers were at home; two care receivers had recently died (See Table 1).

Table 1: Caregiver Relationship to Care Receiver and Disposition (N = 15)

	Percentage (#)
Caregiver relationship to care receiver:	
Spouse/ partner	40.0% (6)
Child	26.7% (4)
Sibling	26.7% (4)
Parent	6.7% (1)
Care receiver disposition:	
At home	73.3% (11)
In hospital	13.3% (2)
Deceased	13.3% (2)

2.3.3 Key Stakeholder Survey

A survey was developed for key stakeholders including representatives from local service provider agencies (supervisors, frontline nursing staff), CCAC (Case Managers, frontline nursing staff), and primary care physicians who were involved with the team directly, or indirectly through the implementation of treatment plans/ recommendations developed by the team. Questions were asked related to their level of satisfaction with:

- their level of satisfaction with the work of the team (capacity building, consultation support, timeliness of access to assessment, care)
- satisfaction with the assessment and resulting treatment recommendations
- overall perceptions of the effectiveness of the team
- impacts (outcomes) of the team
- suggestions for improving EOL service delivery.

Outcomes were assessed using a post-pre methodology,³ in which respondents were asked to rate current (i.e., post-PCT involvement) outcomes (e.g., changes to care) and were then asked to rate the current outcome as compared to before the inception of this initiative. The key stakeholder survey is presented in Appendix F.

Potential respondents were identified by the evaluation Advisory Committee. The survey was administered on-line via Survey Monkey (www.surveymonkey.com). Consistent with the method of survey distribution recommended by Dillman,⁴ potential respondents were invited to complete the survey via e-mail and received follow-up reminders via e-mail to complete the survey. The survey was available for completion for a 2-week period from March 19 to April 2, 2009. A total of 18 invitations to complete the on-line survey were distributed (excluding 5 invitations that were undeliverable); 13 surveys were completed (72% response rate).

The majority of survey respondents (53%) were registered nurses. There was much variability in the amount of time that respondents have been employed in their current profession (range = 2

³Rockwell, S.K., & Kohn, H. (1989). Post-Then-Pre Evaluation. *Journal of Extension*, 27(2), 1-7.

⁴Dillman, D.A. (2000) *Main and internet surveys. The Tailored Design Method 2nd Ed.* New York: John Wiley and Sons.

- 38 years), with the average being 22 years. The majority of survey respondents (54%) have practices in which greater than 51% of their clients require palliative/ end-of-life care and the majority (77%) have worked with the PCT in regards to a least 6 and up to 20 clients in the past three months.

Table 2: Description of Survey Respondents (N=13)

Demographic Variable	Percentage (#)
<i>Discipline :</i>	
Physician	7.7% (1)
Registered Nurse	53.8% (7)
Case Manager	30.8% (4)
Agency nursing supervisor	7.7% (1)
<i>Number of years working in their field (N =12)</i>	
Average (+/-)	22 years (13)
Range	2 – 38 years
<i>Percentage of clients in practice requiring palliative/ end-of-life care</i>	
Not applicable	15.4% (4)
None	0
Less than 25%	15.4% (2)
26% - 50%	7.7% (1)
51% - 75%	30.8% (4)
Over 75%	23.1% (3)
<i>Contact with PCT in the past three months</i>	
In regards to more than 21 clients	0
11-20 clients	38.5% (5)
6 -10 clients	38.5% (5)
1-5 clients	23.1% (3)
Not at all	0

2.3.4 Individual Interviews with Key Stakeholders

Interviews were conducted with a purposeful sample of key stakeholders. The purpose of these interviews was to obtain in-depth information about the PCT, specifically:

- effectiveness in meeting objectives for clients/caregivers and care providers
- potential health system, provider, and client/ caregiver-related impacts
- identification of factors (enablers, barriers, challenges) impacting implementation/ use of the team
- identification of strategies to overcome barriers and challenges

- suggestions/ recommendations for enhancing EOL service delivery.

The interview guide for these interviews is presented in Appendix G.

These individual telephone interviews were conducted between March 24 and April 6, 2009. Key stakeholders were identified by the evaluation Advisory Committee. A total of 10 individuals participated in these interviews: one supervisor and one palliative care nurse representing each of the three service provider agencies and four CCAC Oncology Case Managers. Participants were given the interview questions in advance of the interview. The interviews ranged in length from 18 to 51 minutes (average = 28 minutes).

2.3.5 Interviews with the PCT Representatives

A focus group interview and individual interviews were conducted with members of the PCT and team organizers in order to obtain in-depth information about the development and implementation of the team, specifically:

- factors facilitating the development and implementation of the PCT
- challenges/ barriers to implementation and strategies to overcome these
- lessons learned
- suggestions for improvement, sustainability, further development and implementation of the team in this setting and as expanded to other counties, and
- potential impacts (client, physician, and system related).

The interview guide for this interview is presented in Appendix H.

A focus group interview was conducted on Tuesday March 31, 2009 in conjunction with a regularly scheduled team meeting. Fifteen individuals participated in this focus group interview; two individuals participated in individual telephone interviews. A total of 17 individuals participated in these interviews with representation from: three service provider agencies (N = 8), the PCT (N = 7; physician, nurse, Nurse Practitioner, administrative assistant, social worker, organizers), CCAC management (N = 1), and acute care (N = 1). The focus group interview was 60 minutes in length; individual interviews were approximately 20 minutes in length.

2.4 Data Collection and Analysis

Referral and service tracking data was compiled by the PCT (Administrative Assistant). The PCT distributed information sheets to caregivers and identified those interested in participating in an interview. The evaluation consultant distributed invitations to complete the key stakeholder survey. Survey data were analyzed using SPSS15.0.⁵ Descriptive statistics (frequencies, means, standard deviations) were generated for numeric variables. Content analyses were conducted on open-ended responses using an inductive analysis approach, in which common themes are identified and categorized.⁶ The evaluation consultant conducted all of the interviews. All of the interviews were tape-recorded and transcribed. Data analysis was consistent with recommended practices for qualitative data.⁷

⁵ SPSS 15.0. Chicago, IL: SPSS Inc., 2007.

⁶ Cavanagh, S. (1997). Content analysis: Concepts, methods, and applications. *Nurse Researcher*, 4, 5-16.

⁷ Patton, M.Q. (2002). *Qualitative Evaluation and Research*. Thousand Oaks, CA: Sage.

2.5 Ethics Review Board Approval

This evaluation study was approved by the ethics Review Board for Health Sciences Research Involving Humans, University of Western Ontario.

3.0 Results

The following is a summary of the highlights and main themes that have emerged from the evaluation. Detailed presentation of the results of the referral and service tracking is located in Appendix I; the results of the interviews with caregivers and key stakeholder survey are located in Appendices J and K, respectively.

3.1 **OBJECTIVE 1: Describe the Population Referred to the Palliative Consultation Team and the Services Provided**

KEY FINDINGS

Referrals: A total of 78 clients were referred to the PCT between December 18, 2008 and March 31, 2009. Referrals to the PCT have come primarily from the CCAC, family physicians, and specialists. The average age of clients was 68 years; the majority were men, lived in their own home and all but one had an available caregiver. Cancer was the most common diagnosis (78%), and pain the most frequent presenting problem (53%). The average PPS score at the time of the first assessment was 60%; roughly half of the clients had PPS scores of 60% or less.

Service Provision: Of the 78 clients referred to the team, 75 were seen by team members. A total of 68 clients received a comprehensive palliative assessment. Seventy-four percent of clients were seen within seven days of being referred to the team; almost half of all clients were seen on the same day that they were referred to the team. Clients were mostly assessed within the clinic (CCAC; 36%) or within their homes (28%). A shared care model of care was the most frequent (64%) model of care employed. The number of visits per client ranged from 1 – 7 with an average of 2 visits (+/- 1.4). Treatment recommendations were most frequently involved medications (new medications or changes/ adjustments to prescribed medications) and related to nursing visits, either to monitor the client or increase the number of visits. It was estimated that intervention by the team resulted in hospital avoidance at least 19 times. Referrals to other health professionals/ services were made for 9 (12%) clients. In these cases referrals were most frequently made to other physicians and to a social worker. A total of 26 clients (33%) referred to the PCT have died; 65% of these clients died at home. All of the remaining clients referred to the PCT continue to remain on service.

3.1.1 Referrals to the Palliative Consultation Team

A total of 78 clients were referred to the PCT between December 18, 2008⁸ and March 31, 2009. An average of 24 new clients were referred per month; number of referrals remained relatively the constant over the first three months that the team has been in place. Of the 78 clients referred to the team, 75 were seen by team members. Two were not seen by the team because they were admitted to hospital; one client died prior to the team visit. In total, the team has conducted 190 client consultations (home and clinic visits, case reviews at team rounds).

Table 3: Number of Clients Referred to the PCT between December 18, 2008* and March 31, 2009

	Number of Clients
Number of clients of referred: (December 18, 2008 – March 31, 2009)	78
Referrals per month:	
December 2008	5
January 2009	25
February 2009	21
March 2009	27
Number of clients seen by the team:	75
Number of clients assessed:	68
Total number of consults (home and clinic visits, case reviews at team rounds)	190

* Although the team officially commenced operation on January 1, 2009, some referrals were accepted in advance, starting on December 18, 2008.

Referrals to the PCT have come primarily from the CCAC, family physicians, and specialists (See Table 4).

Table 4: PCT Referral Sources (N = 78)

Referral Source	Percentage (#)
Community Care Access Centre	39.7% (31)
Family Physician	21.8% (17)

⁸ Although the team officially commenced operation on January 1, 2009, some referrals were accepted in advance, starting on December 18, 2008.

Referral Source	Percentage (#)
Specialist	19.2% (15)
Community Nurses	11.5% (9)
Hospital/ Emergency Department	5.1% (4)
London Regional Cancer Program	2.6% (2)

Table 5 presents demographic information on the clients referred to the PCT. The average age of clients was 68 years; the majority were men, lived in their own home and all but one had an available caregiver. Cancer was the most common diagnosis (86%), and pain the most frequent presenting problem (53%). The average PPS score at the time of the first assessment was 60%; roughly half of the clients had PPS scores of 60% or less.

Table 5: Demographic Information for Referred Clients (N = 78)

Demographic Information	Results
Age (years)	
Average (+/-)	67.5 (12.4)
Range	25* - 95
Gender	
Male	57.7% (45)
Female	42.3% (33)
Place of Residence	
Own home	100% (78)
Retirement Home/ Long-Term Care	0
Available Caregiver	98.7% (77)
Diagnosis (at time of assessment):	
Cancer**	85.9% (67)
Asbestosis/ COPD / Pneumonia	3.8% (3)
Congestive Heart Failure	2.6% (2)
Amyotrophic lateral sclerosis (ALS)	1.3% (1)
Unknown	6.4% (5)
Major Presenting Problems:	
Pain	52.8% (38)
Physical symptoms***	33.3% (26)
Psychological symptoms****	24.4% (19)
Maintenance visit	2.6% (2)

Demographic Information	Results
PPS Score (at time of first assessment): Average 60% or less	60% 50.6% (38)

Note: Percentages may not sum to 100% due to missing values.

* Only one client was <40 years of age; the majority (68%) were over 61 years of age (See Appendix E).

** Lung cancer: N = 20; 25.6%; GI (esophagus, stomach, bowel, rectum N = 8; 10.3%; Leukemia/ Lymphoma (Hodgkin's & Non –Hodgkin's): N = 6; 7.7%; all other types of cancer (breast, prostate, cervix, ovary, endometrial, brain, gall bladder, liver, kidney, palate, pancreas, pharynx) occurred in less than 5 (6.4%) clients per each type of cancer.

***Physical symptoms such as: cough, edema, nausea, bowel issues, chemotherapy side effects, shortness of breath.

****Psychological symptoms such as: anxiety, agitation, depression, confusion.

3.1.2 Service Provision

Of the 78 clients referred to the team, 75 were seen by team members (See Table 6). Two were not seen by the team because they were admitted to hospital; one client died prior to the team visit. A total of 68 clients received a comprehensive palliative assessment; consistent with expected targets (as outlined in the evaluation framework), over 90% of clients were assessed using standardized tools. Seventy-four percent of clients were seen within seven days of being referred to the team; almost half of all clients were seen on the same day that they were referred to the team. Clients were mostly assessed within the clinic (CCAC; 36%) or within their homes (28%). The amount of time required to complete an assessment ranged from 10 – 60 minutes, with the average being 39 minutes (+/- 20 minutes). In the majority of cases (62%), team reports were distributed within 5 days of the initial visit or assessment; 23% of reports were distributed on the same day of the initial visit or assessment. Reports were distributed to the CCAC (97%), service provider agency (48%) and physicians (family, specialists; 16%).

Table 6: Number of Clients Seen and Assessed by the PCT

	Percentage (#)
Number of clients seen by the team	96.2% (75)
Number of clients assessed	60.7% (68)
Time from Referral to First Contact (N = 61):	
Same day	47.5% (29)
1 – 7 days (1 week)	26.2% (16)
8 – 14 days (2 weeks)	11.5% (7)
15-31 days (3-4 weeks)	11.5% (7)
Greater than 1 month	3.3% (2)
Assessment Location:	
Clinic	36.0% (27)
Home	26.7% (20)
Emergency Department	1.3% (1)
Rounds	20.0% (15)

	Percentage (#)
Time required to complete assessment:	
Average (+/-)	38.5 (20.1) minutes
Range	10 - 60 minutes
Time from initial visit/ assessment to report distribution (N = 26):	
Same day	23.1% (6)
1 - 5 days	38.5% (12)
7 - 14 days	15.4% (4)
More than 20 days	15.4% (4)

Note: Percentages may not sum to 100% due to missing values.

Table 7 presents the health professionals involved in each case and the model of care employed. The team physician and resource nurses were involved in the majority of cases. A shared care model of care was the most frequent (64%) model of care employed.

Table 7: Percentage (number) of Health Professionals Involved and the Model of Care Employed

	Percentage (Number)
Health professionals involved in care:	
Team Physician	74.7%(56)
Team Coordinator	41.3% (31)
RN/ RPN	76.0% (57)
Social Worker	20.0 % (15)
Case Manager	30.7% (23)
Other Physicians	2.7% (2)
Model of Care employed:	
Shared Care	64.0% (48)
Primary Care	18.7% (14)

The number of visits per client ranged from 1 – 7 with an average of 2 visits (+/- 1.4; See Table 8). Treatment recommendations were most frequently related to medications (new medications or changes/ adjustments to prescribed medications) and related to nursing visits, either to monitor the client or increase the number of visits. It was estimated that intervention provided by the team resulted in hospital avoidance at least 19 times. Referrals to other health professionals/ services were made for 9 (12%) clients. In these cases referrals were most frequently made to other physicians and to a social worker. A total of 26 clients (33%) referred to the PCT have died; 65% of these clients died at home. All of the remaining clients referred to the PCT continue to remain on service.

Table 8: PCT Service Provision: Number of Visits, Treatment Recommendations, and Referrals to Other Professionals/ Services

	Percentage (Number)
<i>Total number of visits (assessment, follow-up, direct care) per client:</i>	
Average (+/-)	2.2 (1.4)
Range	1 – 7
<i>Treatment Recommendations:</i>	
Medication (new, change, adjustment)	40.0% (30)
Nursing – monitor, increase visits	16.0% (12)
Equipment-related*	6.7% (5)
Diagnostic testing (blood work/ x-rays)	4.0% (3)
Catheter/ Feeding tube	4.0% (3)
Symptom Response Kit	2.7% (2)
Other**	12.0% (9)
<i>Referrals to other health professionals/ services:</i>	
Referral to family (6) and palliative care physicians (2)	10.7% (8)
Referral to social worker	8.0% (6)
Occupational Therapist	1.3% (1)
Physiotherapist	2.7% (2)
Neighbourlink	1.3% (1)
<i>Number of clients discharged from service:</i>	0***
<i>Length of client stay on service (time from date of referral to discharge date):</i>	Not applicable
<i>Number clients that have died:</i>	33.3% (26)
<i>Place of death: (N = 26)</i>	
Home	65.4% (17)
Hospital	34.6% (9)

Note: Percentages do not sum to 100% due to missing data.

*Equipment-related recommendations included use of: CADD pump, oxygen, Spenco mattress pad

**Other recommendations included: education, emotional support, EOL care plan

*** Only those clients who have died are now considered “off service”; all other clients (N = 52) remain on service.

3.3 **OBJECTIVE 2: Identify impacts associated with the Palliative Consultation Team**

KEY FINDINGS

Client/ Caregiver Impacts

- Improved quality of palliative/ end-of-life care as evidenced by:
 - improved pain and symptom management
 - reduced caregiver burden
 - greater services/ supports provided a home
 - crisis and hospital avoidance
 - timely access to care
 - increased care provider capacity to provide palliative/ end-of-life care
 - improved communication with clients
- Increased trust/ confidence in home care
- Reduced potential for crises
- Enhanced support for caregivers
- Improved family caregiver capacity

Health Care Provider Impacts

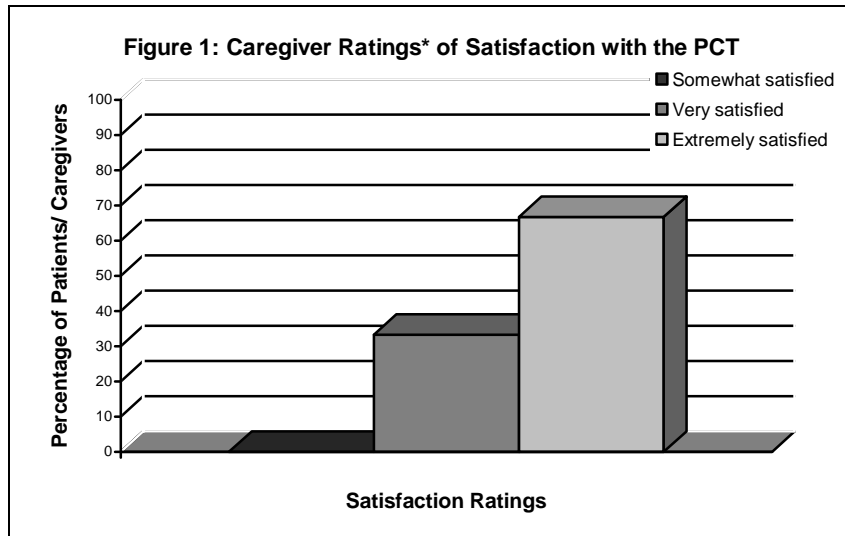
- Increased access to resource support for community nurses
- Improved capacity for palliative care
- Increased job satisfaction for resource nurses

Health System Impacts

- Increased home deaths
- Hospital avoidance
- Emergency Department avoidance with direct hospital admissions
- Shorter hospital lengths of stay
- Increased and timely access to palliative care
- Improved communication among provider agencies
- Improved collaboration among provider agencies
- Increased use of standardized tools (PPS/ ESAS) among all care providers
- Increased perceptions of care at home as “safe”
- Integrated care

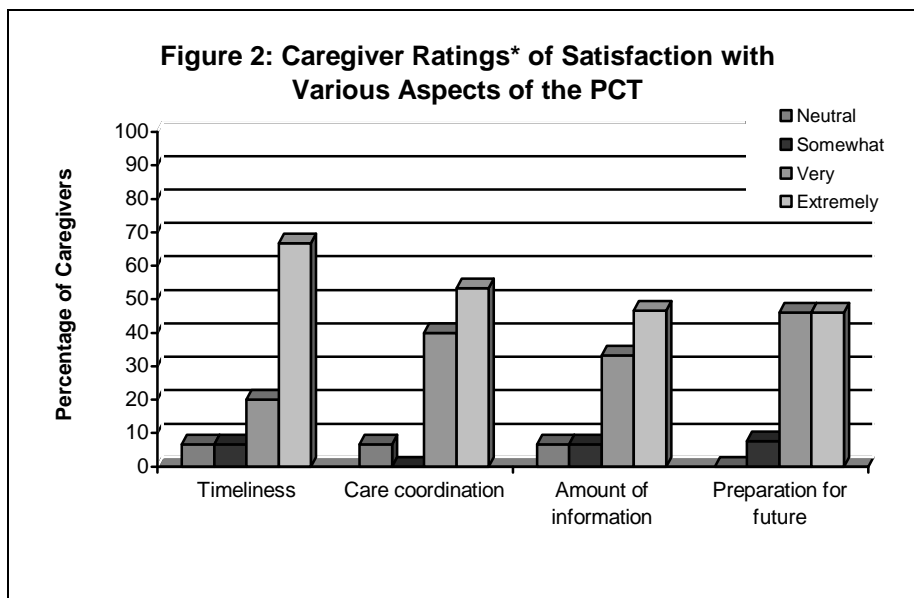
3.3.1 Client and Caregiver-Related Impacts

Caregiver Satisfaction: Figure 1 presents caregivers overall ratings of satisfaction with their first visit with the PCT. All of the caregivers reported that they were satisfied with the PCT, with the majority (67%) being “extremely” satisfied.



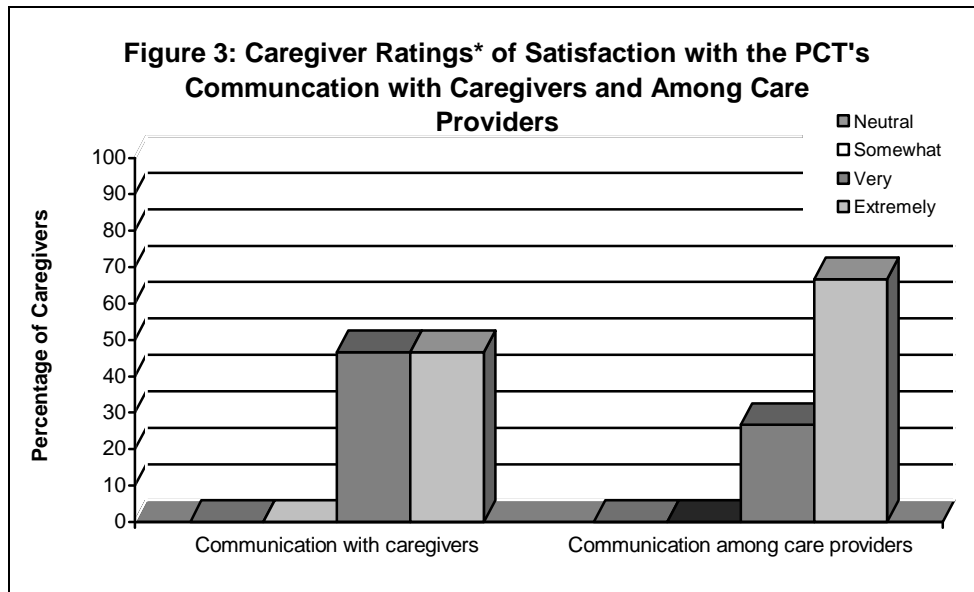
* 7-point rating scale: Extremely, very, somewhat dissatisfied/ Neither dissatisfied nor satisfied/ somewhat, very extremely satisfied. None of the caregivers provided ratings of dissatisfaction.

Caregivers' ratings of satisfaction with a number of aspects of the team: timeliness, care coordination, the amount of information with which to make treatment or care decisions, and preparation for what will happen next are presented in Figure 1. All of the caregivers reported being satisfied with these aspects with the majority providing ratings of "very" or "extremely" satisfied. Consistent with expected targets for caregiver satisfaction (outlined in the evaluation framework), greater than 90% of caregivers were satisfied with the PCT service.



* 7-point rating scale: Extremely, very, somewhat dissatisfied/ Neither dissatisfied nor satisfied/ somewhat, very extremely satisfied. None of the caregivers provided ratings of dissatisfaction.

All of the caregivers reported being satisfied with the way the team responded to their questions and concerns and the level of communication among all of the different care providers or services involved in their loved one’s care, with all of the caregivers providing ratings of “very” and “extremely” satisfied (See Figure 3).



* 7-point rating scale: Extremely, very, somewhat dissatisfied/ Neither dissatisfied nor satisfied/ somewhat, very extremely satisfied. None of the caregivers provided ratings of dissatisfaction.

Caregivers were asked to identify at least one thing that they really liked about the team and the service or care provided; these are summarized in Table 9. Caregivers indicated that they liked the quality care received, particularly in comparison to prior to the inception of the team/ other services involved, timeliness of access to care, the level of communication about the clients status and treatment, and the compassionate and caring nature of all team members.

Table 9: Things Caregivers Liked About the PCT and Service/ Care Provided

<p>Quality Care</p> <p><i>“They’ve been more helpful than any other doctors or services so far.”</i></p> <p><i>“Awesome care. The health system did not fail us. He was treated like a king and that’s what he deserved. It was perfect. I liked that [Team physician] came to the house. That’s a great idea.”</i></p> <p><i>“Second to none. [Team physician] has gone beyond the call of duty. [Team physician] has made my husband comfortable. Things had fallen through the cracks before we saw [Team physician] and he fixed things.”</i></p> <p>Timeliness of Access to Care</p> <p><i>“It has been first class. It was a Friday and our nurse came and was not at all happy with him, his symptoms. Within 4 hours a team member was at the house. They called [Team physician] and his medication was changed right away and this controlled his pain right away.”</i></p>

"It has been really helpful to me to deal with issues. I'm just a phone call away. I can call them and they are available right away."

"Accessibility - easy to access help when needed."

Good Communication

"They are good at sitting down and explaining things to me. What I should expect and what to do if something happens. What to look for, which is good because I'm not a nurse."

"Very informative, straightforward. They were upfront and honest."

Emotional support (compassionate, caring nature)

"They are very compassionate, honest and caring and have really helped us."

"We had a family meeting today with all my brothers and sisters there. They didn't make us feel rushed. There was so much compassion. You could tell they cared. I don't think we'd get this anywhere else. We are so lucky to have this in Sarnia."

"Friendliness"

When asked if there was anything about the team or the service/care they received that they did not like, the majority of caregivers (73%) indicated that they had no complaints to make about the care they have received from team members. Those that did have a complaint reported issues that were not directly related to the team, or within the team's control, such as the lack of consistency in the nurses/PSWs from the provider agencies that go into the home, PSW quality of care issues and lack of punctuality in attending appointments (*"We had some problems with the PSW from the [service provider agency], quality of care issues, she didn't show up on time and sometimes she didn't show up at all."*), and limited coordination of appointments between various nursing visits.

Additional interview comments made by caregivers reflected their satisfaction with the team and gratitude for the care they have received, as illustrated by the following comments:

"Care has been exceptional. They have been very honest with us, helping us to prepare. The whole experience has been wonderful."

"Long may it continue!"

"It's a wonderful service - we are grateful that the service is available."

"So far I have been very happy with the care. It's very unique that they have this service."

"Overall, we're very satisfied. Everything is going great. We have everything we need at this time."

Client and Caregiver Impacts as Identified by Key Stakeholders and PCT Representatives

Interviewed key stakeholders and PCT representatives identified a number of impacts for clients and caregivers associated with the PCT; these are summarized in Table 10.

Table 10: Summary of Client/ Caregiver-Related Impacts as Identified by Key Stakeholders and PCT Representatives

Client/ Caregiver Impacts

- Improved quality of care
 - Increased trust/ confidence in home care
 - Reduced potential for crises
 - Enhanced support for caregivers
 - Improved family caregiver capacity to provide care at home
-

- **Improved quality of care:** Overall, it was perceived that palliative/ end-of-life care has improved, particularly related to pain and symptom management. Improved care was attributed to the increased support available for primary community nurses. It was also noted that with the support of the resource nurses, primary nurses can continue to provide care to their regular clients thereby maintaining consistency in care.

“The quality of the palliative care that [clients] have received at end-of-life care has greatly increased, with better knowledge base, they’re getting advanced clinical assessments. I find now advanced pain and symptom management, their medication counselling is superb. I have great things to say about that. They acknowledge where pain medications can be improved or where medications related to bowels can be improved. They just go the extra mile, by looking at the whole picture.” [Key stakeholder]

“I know that at the end of life people are so scared to leave their home because they are so afraid they’ll never come back. So anything we do for them that allows them to stay in their home and if that means having one more resource person to problem solve or somebody else’s expertise to come along and facilitate the problem solving at home instead of having to make a trip to the emergency room, always a positive impact on clients.” [Key stakeholder]

- **Increased trust/ confidence in home care:** Improved quality of care has resulted in clients and caregivers trusting and having confidence in the care that is available in the community.

“They [clients] seem to be at peace with everything that’s happening. They don’t seem to be finding fault or anxious that something is being missed. So I think the fact that they know the nurse can get a hold of the doctor, and the doctor will make home visits, I think all that is really connected to make them feel trust in the system. “[Key stakeholder]

- **Reduced potential for crises:** Effective care planning and support from the team has reduced the potential of crises; these crises often result in an ED visit and/ or hospitalization.

“More players have input into developing the care plan... This has the potential to reduce crises because the plans are effective and well implemented.” [Key stakeholder]

- **Enhanced support for caregivers:** The specialized counselling and support provided by the team increases caregiver understanding of their loved one’s condition, assists them to make informed care decisions and reduces their distress.

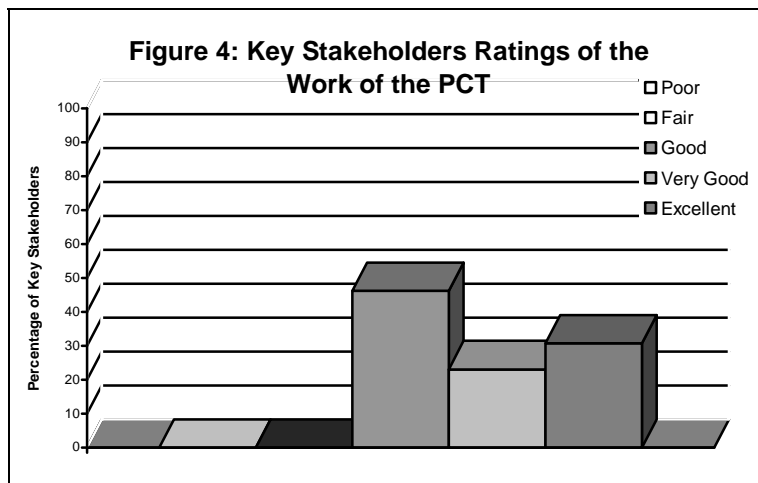
“I think that it helps the care givers by giving them additional counselling, you know and support during the difficult times with the end-of-life care, and regarding the management, like the physical and psychological changes. Just understanding them more and providing spiritual and related practical issues, and dealing with the whole picture.” [Key stakeholder]

- **Improved family caregiver capacity:** Improved pain and symptom management and support to families has resulted in family caregivers being better equipped and supported to care for their loved one at home without significant increases in requests for shift nursing. However, it was emphasized that shift nursing is a significant resource that allows clients to remain at home as long as possible or to die at home.

“Shift care hasn’t gone up. I think the family, families are accepting that and because of the quality of the nursing care I think maybe they’re able to manage a bit better... the night shifts especially are still important in their care, but I’m finding that a lot of them [caregivers] are doing it with only having shifts, say in the last few days or the last week of life as opposed to the last month, which his sometimes when things start to go downhill.” [Key stakeholder]

3.2.2 Health Professional-Related Impacts

Key Stakeholder Satisfaction: The majority (69%) of the key stakeholders survey respondents rated the work of the PCT as “good” (46%) or “very good” (23%); See Figure 4.



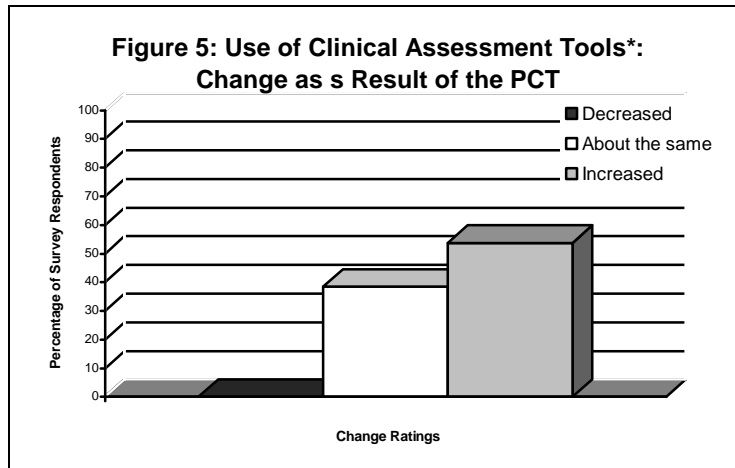
Using a 5- point scale (1 = not at all; 5 = extremely satisfied), survey respondents were asked to rate their level of satisfaction with a number of aspects of team functioning. Table 11 presents the rank ordering of their satisfaction with these aspects of team functioning based on average ratings. Generally, ratings ranged from moderate (3.3) to moderately high (4.3) levels of satisfaction. Survey respondents were most satisfied with treatment recommendations/ planning, availability of team members for consultation and the quality of assessment conducted. Key stakeholders were least, but still moderately satisfied with integration of care across health sectors. Consistent with expected targets (as outlined in the evaluation framework), over 90% of key stakeholders were satisfied with the PCT.

Table 11: Rank Ordering of Key Stakeholders Satisfaction with Various Aspects of Team Functioning (N = 12)

Ranking	Aspects of Team Functioning	Average (+/-)*	Range
1	Treatment recommendations/ planning	4.3 (.65)	3 – 5
2	Availability of team members for consult	4.3 (.65)	3 – 5
3	Quality of assessment	4.3 (.62)	3 – 5
4	Timeliness of access to assessment	4.2 (.72)	3 – 5
5	Follow-up	4.1 (.58)	3 – 5
6	Client/ family readiness for death	4.1 (.67)	3 – 5
7	Direct provision of care	4.1 (.79)	3 – 5
8	Communication	4.0 (.95)	3 – 5
9	Integration of care across care providers	3.8 (.72)	3 – 5
10	Care coordination	3.8 (.84)	3 – 5
11	Integration of care across health sectors	3.3 (.87)	3 – 5

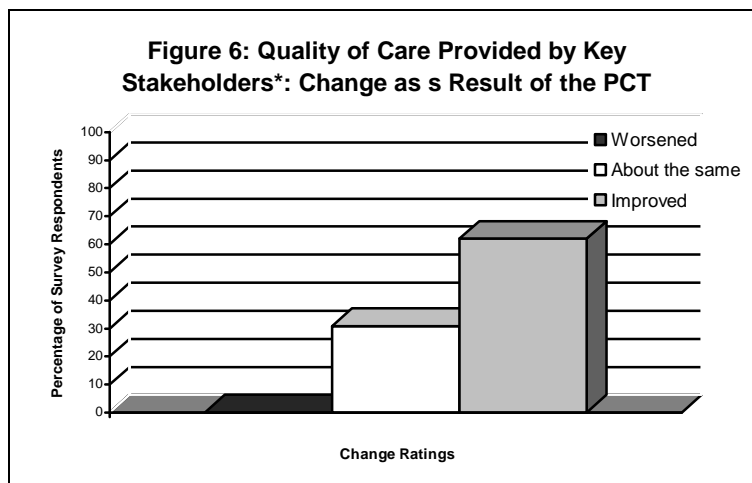
* As rated on a 5 point rating scale: 1 = not at all satisfied; 5 = extremely satisfied.

Capacity Building: The majority of key stakeholder survey respondents (54%) reported that their use of assessment tools (ESAS, PPS) has increased as a result of the PCT (See Figure 5).



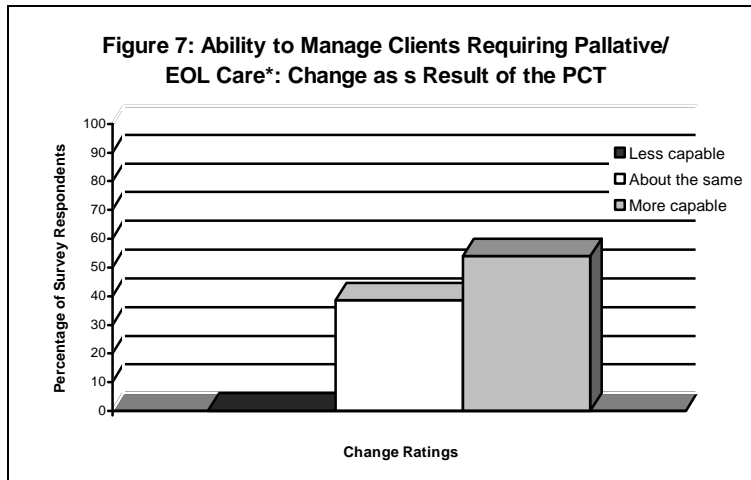
*5 point rating scale: Much increased, increased, neither increased nor decreased, decreased, much decreased. Increased use = sum of much increased/ increased ratings; Decreased use = sum of much decreased/ decreased ratings.
 Note: Percentages do not sum to 100% due to missing values.

Similarly, key stakeholder survey respondents were asked to rate the extent to which the quality of care they provide to clients requiring palliative/ end-of-life care has changed as a result of their involvement with the PCT. The majority of respondents (62%) reported that quality of care has improved, with equal percentages (31%) indicating that that care that “improved” or “much improved” (See Figure 6).



*5 point rating scale: Much improved, improved, neither improved nor worsened, worsened, much worsened. Improved = sum of much improved/ improved ratings; Worsened = sum of much worsened/ worsened ratings.
 Note: Percentages do not sum to 100% due to missing values.

The majority of key stakeholder survey respondents (54%) reported that as a result of the PCT they were now more capable of managing clients requiring palliative/ end-of-life care; 39% indicated that their ability to do so had not changed as result of the team (See Figure 7). These results are less than expected targets (as outlined in the evaluation framework; expected target – 90% of providers reporting increased capacity).



*5 point rating scale: 1 (less capable now), 2, 3 (about the same), 4, 5 (more capable now); Less capable now = sum of ratings of 1 and 2; More capable now = sum of ratings of 4 and 5.

Health Care Provider Impacts as Identified by Key Stakeholders and PCT Representatives

Interviewed key stakeholders and PCT representatives identified a number of impacts for health care providers associated with the PCT; these are summarized in Table 12.

Table 12: Summary of Health Care Provider-Related Impacts as Identified by Key Stakeholders and PCT Representatives

Health Care Provider Impacts

- Increased access to resource support for community nurses
 - Improved capacity for palliative care
 - Increased job satisfaction for resource nurses
-

- **Increased access to resource support for community nurses:** With 24/7 access to the team community nurses are better supported, particularly when dealing with complex cases and crisis situations as well as during nights and weekends when family doctors are not available.

“Just the fact that there’s 24/7 access to [resource nurses], which really makes a difference too, I mean that’s great for the nursing staff that are in the home. They know that they always have someone they can rely on.” [Key stakeholder]

“If we didn’t have the team and if we can’t contact the doctor on the team then there’s nothing we can do. Almost all the family doctors are not available after [hours]. Now some of them will give you a contact number for the evening, for what’s really close to end of life, but generally until they’re right at the end. Most family doctors, they’re gone out of their office at 3:00 and that’s that. All you could do is

you're best, and then send them to the ER if you can't do anything for them." [Key stakeholder]

Additional support provided by the team has resulted in increased comfort and confidence among community nurses, as illustrated in the following comment:

"I think it's just that there's a lot more, a better comfort level with any of the nurses knowing that they all have access to the team and all the different levels of expertise available any time." [Key stakeholder]

One key stakeholder noted that it may be too early to comment on whether the team has had an impact on community nurses, but that this will likely occur with time.

"As far as supporting their fellow health care providers, I think that in time the, the idea of this team will become more common place. I believe it's still new enough that people are still getting used to the fact that there is another resource out there for them to call upon." [Key stakeholder]

- **Improved capacity for palliative care:** It was noted that capacity among family physicians to provide palliative care has improved over the past year so that the team is better supported to provide optimal and timely care. As an example, it was noted that more physicians are willing prescribe medication to reduce pain, anxiety, and breathing issues. Consistent with this, it was noted that capacity for palliative care has increased among agency nurses as reflected in the following comments:

"The nurses who are involved in the team indirectly are getting education and feedback from the team nurses, so that would be then be enhancing their knowledge." [PCT representative]

"Well I think certainly that a primary nurse, once she accessed it [the PCT], I think she gets more experience and she's had back up and her confidence goes up. In the next situation she has a better idea of how to proceed, or feels more confident in her own judgment or certainly know the avenues for and when to access the extra support." [Key stakeholder]

- **Increased job satisfaction for resource nurses:** It was noted that the resource nurses serving on the team have enjoyed their role on the team and have experienced increased job satisfaction.

"I can tell you that the three nurses that work for this organization that serve on that team, have a higher level of job satisfaction because of their ability to contribute their expertise. And there's a sense of pride that goes with it. These three nurses work hard to gain the knowledge they have in palliative care and I think there is a higher sense of job satisfaction without a doubt." [Key stakeholder]

3.2.3 Health System-Related Impacts

Improved Quality of Palliative Care: Key stakeholder survey respondents identified a number of impacts/ outcomes associated with the PCT, many of which were reflected improved quality of care as evidenced by:

- improved pain and symptom management
- reduced caregiver burden
- greater services provided a home
- crisis and hospital avoidance
- timeliness of access to care
- increased care provider capacity to provide palliative/ end-of-life care
- improved communication with clients.

Use of Health System Resources: Key stakeholder survey respondents were asked to identify any key or most significant impacts associated with the PCT. The majority of identified outcomes were related to hospital avoidance (prevention and reduced visits to the ED). Similarly, it was noted that collaborative care among provider agencies and the PCT has optimized the use of existing resources. The impact of the team on health system resources is reflected in the following comments:

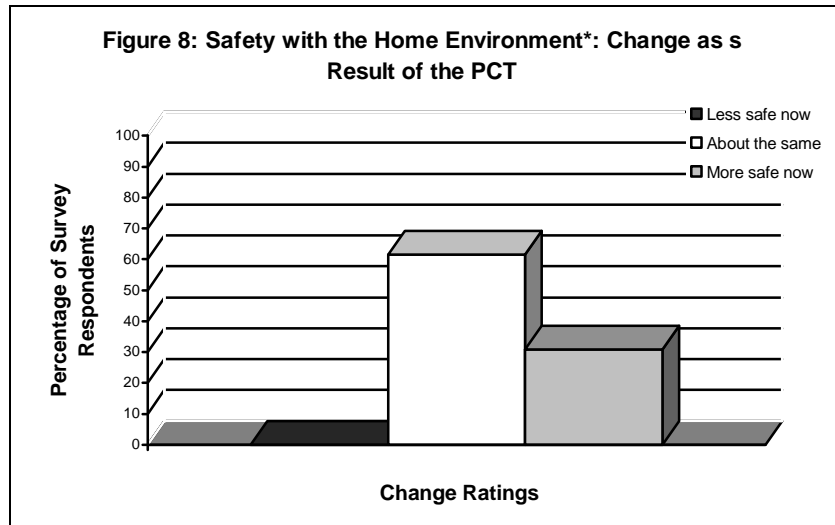
“Able to get direction, orders, visits by MD's after hours when normally GP's unavailable. This is a huge benefit to the client as well as the nurse. Avoids ER visits.”

“Information sharing, effective interdisciplinary communication, learning, care planning have all been enhanced.”

“The collaborative approach at the team meetings increases the resources for problem solving.”

“Decreased ER visits, decreased visits to Palliative Care Unit for symptom management.”

Safety within Home Environments: Key stakeholder survey respondents were asked to rate the current level of safety within home environments for palliative/ end-of-life care in comparison to prior to the inception of the PCT. Generally, the majority of respondents (62%) reported that the level of safety within home environments had not changed as a result of the team; 31% indicated that safety had improved (See Figure 8). These results are less than expected targets (as outlined in the evaluation framework; expected target – 90% of providers reporting safer home environments as a result of the team).



*5 point rating scale: 1 (less safe now), 2, 3 (about the same), 4, 5 (more safe now); Less safe now = sum of ratings of 1 and 2; More safe now = sum of ratings of 4 and 5.
 Note: Percentages do not sum to 100% due to missing responses.

Health System-Related Impacts as Identified by Key Stakeholders and PCT Representatives

Interviewed key stakeholders and PCT representatives identified a number of health system impacts associated with the PCT; these are summarized in Table 13.

Table 13: Summary of Health System-Related Impacts as Identified by Key Stakeholders and PCT Representatives

Health System Impacts

- Increased home deaths
- Hospital avoidance
- Emergency Department avoidance with direct hospital admissions
- Shorter hospital lengths of stay
- Increased and timely access to palliative care
- Improved communication among provider agencies
- Improved collaboration among provider agencies
- Improved care coordination
- Increased use of standardized tools (PPS/ ESAS) among all care providers
- Increased perceptions of care at home as “safe”
- Integrated care

- **Increased home deaths:** It was noted there has been an increase in the number of home deaths over the same time period last year, and there is greater concordance between client wishes and place of death. For example, it was noted that while many

clients/ family members may prefer a home death fears about limited support prevent them from doing so. Support provided by the team allows clients and caregivers to make informed decisions and care plans with the result that many choose to die at home.

“We’ve had a number of ‘good deaths’ at home that may not have happened without the team.” [PCT representative]

“There’s always going to be pain with cancer and they [clients] just have no idea that we would be able to manage that for the most part at home. They just kind of automatically think you have to go to the hospital. So when they find out, yea, they can be at home and as long as we can control the pain, and that’s very likely, then they’re usually that’s what they want to do.” [Key stakeholder]

“The increased supports and timeliness of access to care has resulted in the clients and caregivers being more comfortable about deciding to remain at home at end of life.” [Key stakeholder]

- **Hospital avoidance:** Access to care and supports in place to provide care at home was noted to prevent ED visits, particularly avoidable ED visits. In addition, with the formation of the team, the team physician as a palliative care specialist no longer requires a physician referral to see clients; therefore clients can be seen by the team physician as needed to prevent ED visits and potentially subsequent hospital admission. Consistent with this, it was noted that admissions from the community to the hospital palliative care unit have reduced since the inception of the team, reflecting a more appropriate use of hospital resources.

“The fact that very clearly the clients that would have went in to the ER at end of life if they became complex and did not have the team care, a large portion of those clients would have went to ER at end of life and they would have died in hospital, taking up a hospital bed. They would have been admitted to the hospital.” [PCT representative]

“Well I think one thing that I’m seeing too is less referrals to the palliative care unit. I think our out of town people, when the supports weren’t there, that was kind of their only option and then our palliative care unit was being utilized for pain and symptom management, and I see that that is decreasing somewhat, because we are able to do that in the community.” [Key stakeholder]

- **Emergency Department avoidance with direct hospital admissions:** Team support and collaboration with admitting physicians has allowed clients requiring hospitalization to be directly admitted to the hospital without having to be admitted to the ED first. This reduces stress on the ED system as well as stress and anxiety for clients and family members.

“Even when they [clients] do go to hospital, it’s having this team and being able to resource with the doctor, we can usually do direct admit as opposed to them going to emerg... So that in itself is pretty big. It takes that anxiety and even decreases the system and ER assessments.” [Key stakeholder]

- **Shorter hospital lengths of stay:** Supports available in the community through the team have allowed clients to return home sooner than previously. In addition, as the team is able to maintain clients at home for as long as possible, those who go to hospital are there for shorter lengths of stay.

“Even when people do get admitted it’s often for less time. They stay longer at home and then go in for 2- 3 days, then die. It’s too bad we couldn’t get them through those 2 days but in the past they might have spent 2 -3 weeks in the hospital. But we’re able to keep them at home until the very end.” [PCT representative]

“I think they [clients] build a better trust. They see the symptoms are being managed, so they’re not, keen to get into the hospital. And if they go in it just may be their last 24 hours as opposed to a week. So it may not totally prevent people from going to hospital, but it certainly I think decreases the amount of time people are spending in hospital.” [Key stakeholder]

- **Increased and timely access to palliative care:** The team has been able to respond quickly to new referrals, usually within 24 hours, and immediately to crisis situations. This response time prevents ED visits and emotional distress for clients and family members. Moreover, it was noted that the team is able to mobilize needed equipment, supplies, and home laboratory services in a timely manner.

“[The team] gets everyone on the same page quicker with biweekly rounds. Everyone is present therefore they get started on planning and implementation quicker.” [Key stakeholder]

“The assistance that they [PCT] provide helps to expedite testing and interventions that maybe they [clients] would have waited longer to see a specialist or all the services that are required for better symptom management are there.” [Key stakeholder]

- **Improved communication among provider agencies:** With the implementation of the team there is improved communication among provider agencies so that medical and social issues, particularly crises, are managed in a timely and efficient manner regardless of which provider agency the resource nurse team member and client are associated with.

“I think it’s also helpful, if somebody has a potential for crisis, are being brought forward so that those who are on call are made aware of it. So again the communication is broader because you’re using the different resources from the agencies on the team. So if the client is from point A, but your resource nurse is from point C, they still have an awareness of the client where they might not have before.” [PCT representative]

“Overall, effective communication throughout the whole system has certainly improved with the community, with all the stakeholders, with everybody involved with direct and indirect care, it’s much more visible and that impacts the flow and the outcomes.” [Key stakeholder]

- **Improved collaboration among provider agencies:** With the implementation of the team there is improved collaboration among provider agencies. Moreover, increased partnerships and networking among the nurses from different agencies has contributed to capacity building and increased resource support for nurses.

“I think there’s getting to be a build of trust too between the different providers.” [Key stakeholder]

“There is a cohesiveness, the team has really impacted the cohesiveness especially among organizations, which we needed desperately. So there was a real trust factor missing from organizations, so I think that’s really made a difference.” [Key stakeholder]

- **Improved care coordination:** All of the key health professionals/ services involved in a client’s care are now working together to identify needs and develop coordinated care plans in a more timely and efficient manner.

“It [PCT] has also helped with coordination, and for the case managers to know that the team is available, I believe it has definitely impacted at their end as well.” [Key stakeholder]

“All of the key players pull together for end-of-life care. It falls into place easily with the team because the key players are better partnered. There seems to be less push and pull at end of life to get clients what they need.” [Key stakeholders]

“It’s much easier to identify the needs of the client if everybody is at the table representing all of the services, care, and all of that information be included in the CHRIS and shared with everybody. It allows for a much better way of navigating the client, at end of life so that all their needs are identified. Everybody has the most up to date information and to act upon it... that’s something that hasn’t happened before. We’re now, instead of having one report from one individual care provider, about the service plan changes you have all care providers and you have social work as well, and the physicians who can all determine any given needs in that rounds and then determine how to move forward. Much more comprehensive and much more team focused.” [PCT representative]

- **Increased use of standardized tools (PPS/ ESAS) among all care providers:** Use of assessment tools has increasingly become common place as well as increasing frequency of updates on test scores (e.g., re-administration of the PPS as client condition changes). The use of these tools has resulted in a common language to describe and understand clients’ condition.

“I think it’s [ESAS] finally starting to be used more, there’s still a population of providers that don’t want to use the ESAS, they figure how they’ve been assessing is fine and that is true in some points. But between ESAS and PPS it just gives such a clear picture to everybody because we all understand what is being said. So yea, it is being understood the effectiveness of it, especially when the doctor is saying I really need this, so they are clicking in how important of a tool it is. We are seeing it used more. It’s still a slow process, but it is getting used.” [Key stakeholder]

- **Increased perceptions of care at home as “safe”:** While some key stakeholders were unable to comment on whether home environments were now safer because of the PCT, others commented that clients and family members may now be more aware that home settings can be a safe location to receive care because of supports available.

“I’m not sure safer, maybe there’s more realization that they’re safer. It may be in the fact that we’re getting more home visits by doctors, that that therefore maybe makes it safer, I definitely like the way our assessments are going by the nurses. But I don’t know that it wasn’t safe before. I think there still may be more of a trust thing that’s built within the system.” [Key stakeholder]

- **Integrated care:** The potential for integration of care will be enhanced with the tool that the team is currently developing for cross-sector communication to facilitate seamless client transfer across sectors (hospital, community, long-term care).

Case Illustrations: The following cases were described by PCT representatives and key stakeholders to illustrate the key benefits associated with the PCT.

“We have a client who has been on service with us for a long time, probably well over a year. Her nurse sees her twice a week and her PPS is currently at 60%. She has had some real problematic symptoms but this nurse in her frustration basically gave up on a couple of the symptoms. She didn’t know what to do and she couldn’t get the help from the family physician that she wanted, and so she kind of gave up and just let the client and the family manage them the way they wanted to. It really wasn’t best practice, it really wasn’t what was good for the patient. A case manager went out to see the client and was actually kind of shocked and upset when she found out how the client was managing her pain and her bowels. She was actually very upset with this nurse. So she called her and the nurse explained her frustration and explained: ‘I can’t get anywhere with the family doctor, I have tried everything.’.... We sent one of the nurses in from the PCT to do an assessment and the palliative consultation nurse was able to give the primary nurse some real excellent suggestions that she hadn’t thought of, but then the other part was that [the team physician] was able to make some suggestions that the nurse also conveyed to the family doctor and the family doctor was more than happy to try these suggestions. So the client is getting better care. And is doing much better.” [Key stakeholder]

“We have one that we saw here in the clinic, she was a new patient for [Team physician] and she actually was with one of the agencies already. She had come in, was very ill, she was seen in the clinic about 3:00. Within 6 hours she had a symptom response kit in, a hospital bed, oxygen, IV antibiotics and a pain pump set up in the home, and the expected death plan completed before she left here. She died within 48 hours at home, which was her wish.” [PCT representative]

“A gentleman was having delirium at the end of life, and he had a family doctor that really didn’t understand the medications that were needed, and I was really becoming immensely frustrated. I actually came home and called the medical doctor on call who immediately gave me orders and the next day was out there to see the person. The delirium was controlled and he died peacefully at home. That was wonderful because there was no way that the family doctor was going to give me what he needed, and I had actually faxed to him that I needed this, because he didn’t do it when I phoned him, that I was going to be unable to provide the care if I didn’t get

these medications. So that didn't happen...without having the team or the physician 24/7 available that wouldn't have happened." [PCT representative]

"We had a patient that had heart problems, she did not have cancer. Most people don't think of palliative care in the non-malignant situation.... It was a nurse that checked to see if we would see this patient. She was a lady in her 90's and didn't want to go in the hospital. We kept her comfortable and she died in her own bed. That would not have probably happened if we didn't have a resource nurse who was knowledgeable enough to get involved even if she didn't have cancer. That's the future where palliative care should be getting more and more involved – in non-malignant cases." [PCT representative]

"I was able to contact the doctor on the team and get some pain meds ordered late at night for the client so he didn't have to go in to the ER, and then I could follow up with him easily several times over the next couple of days to do the best we could for the pain management. And then eventually we realized he'd have to go into hospital. By contacting the team doctor we were able to have him directly admitted straight to palliative care." [PCT representative]

3.4 **OBJECTIVE 3: Describe the process of developing and implementing the Palliative Consultation Team**

KEY FINDINGS

Selection of Resource Nurses

- **CAPCE Training As a Requirement:** Although CAPCE training was perceived to be a significant benefit and asset for team members it was generally believed that it was not necessary as a mandatory requirement for team members. Passion for palliative care was considered an essential requirement for team members.
- **RN vs. RPN Requirements:** Designation as a registered nurse was not viewed as a critical a mandatory requirement for team members; many registered practical nurses were described as effective palliative care nurses.
- **On-Call Responsibilities:** To date there have been few issues around on-call responsibilities; team members have been able to meet these responsibilities. Challenges have been largely limited to financial issues (billing for visits to other agency clients, reimbursement to team members) and technological issues (failure of pagers to work across the area).

Development and Implementation of the PCT: Across all sources of information, the following issues related to the development and implementation of the PCT were identified:

Facilitating Factors:

- Palliative care champions (frontline and leadership levels)
- Key stakeholder support
- Availability and timing of LEAP education
- Easy access to team and palliative care physicians
- Frequent team meetings
- Effective team coordination
- Social work support

Challenges:

Implementation/ service delivery issues

- Limited use of resource nurses
- Access to family physicians for updates on client status
- Limited family physician support
- Timely access to nursing support
- Establishing appropriate models of care
- Facilitating trust among provider agencies

Logistical issues

- Establishing effective communication vehicles
- Determining eligibility for the PCT
- Technological issues (pagers)
- Service delivery issues imposed by geographical boundaries
- Limited reimbursement for on-call time
- Billing issues associated with nurses visiting other-agency clients

Suggestions for improvements, sustainability and further development

- Improve/ increase communication within the team and among care providers
- Allow shared access to electronic documentation (CCAC – CHRIS)
- Secure ongoing funding
- Secure physician support for the PCT
- Expand/ establish palliative care expert teams beyond Sarnia-Lambton
- Promote the PCT more widely
- Continue opportunities for education and team building
- Develop succession plans for the team physician
- Access to Hospice

General suggestions for improvements to palliative care

- Improve PSW service delivery (punctuality, availability, quality of care)
- Increase funding for shift nursing at end of life
- Increase opportunities for continuing palliative care education across disciplines and sectors
- Better home construction for home care
- Financial support for clients receiving care out of town

Lessons Learned: Resources/ supports needed for expansion:

- Designated team staff:
 - Team Assistant (full-time)
 - Team Coordinator
- Palliative care champions
- Family physician support
- Primary care nursing representation on the team
- Access to Interprofessional care
- Mentorship opportunities
- Continuing education and networking

3.4.1 Selection of the Resource Nurses

Interviewed key stakeholders and PCT representatives were asked to comment on the selection of the resource nurses. All of those interviewed reported that the most appropriate individuals were selected for this team.

CAPCE Training As a Requirement: The majority of those interviewed noted that CAPCE training was a significant benefit for the resource nurses in that it enhances knowledge and assessment skills. However, many believed that it should not be a mandatory requirement because there are many experienced and excellent nurses with palliative care expertise who have not had CAPCE training. Consistent with this, many key stakeholders commented that having a “passion” for palliative care is an essential requirement for team members.

“I truly believe that a person who has invested the amount of time and energy into CAPCE, a nurse who has invested that amount of time and energy has a greater depth of knowledge and it doesn’t mean they have more experience in the field, but they bring some knowledge that other nurses don’t bring. Now having said that, do I believe that every CAPCE nurse is a great palliative care nurse? Absolutely not! I think that palliative care is a passion that runs in your veins and, and so there is an advantage to, a great advantage to having CAPCE trained nurses, I don’t believe it needs to be a requirement.” [Key stakeholder]

RN vs. RPN Requirements: All but one key stakeholder indicated that it was not necessary for team resource nurses to be registered nurses; many excellent palliative care nurses were reported to be registered practical nurses and many practice in partnership with registered nurses.

“My RPN is, man, she’s just one of the brightest and best and again, she is passionate about palliative care and her level of pain and symptom management far, far out exceeds some RNs that I know. So I do not think that that should ever be a deciding factor.” [Key stakeholder]

“I have some really keen RPNs who are quite comfortable in providing end of life care, and that being said, they’re not in there alone. They have resources around them, and so they partner together with an RN and it works out very well.” [Key stakeholder]

On-Call Responsibilities: All of the key stakeholders indicated that to date there have been no problems or challenges associated with the resource nurses maintaining their on-call responsibilities. Many of the issues arising during the on-call hours have been managed via telephone. Challenges have been largely been limited to financial issues that will be discussed in more detail later (Section 3.3.3 Challenges).

3.3.2 Facilitating Factors

Key stakeholders and PCT representatives identified a number of factors that have facilitated the development and implementation of the PCT; these factors are summarized in Table 14.

Table 14: Summary of the Factors Facilitating the Development and Implementation of the PCT

Facilitating Factors:

- Palliative care champions (frontline and leadership levels)
 - Key stakeholder support
 - Availability and timing of LEAP education
 - Easy access to team and palliative care physicians
 - Frequent team meetings
 - Effective team coordination
 - Social work support
-

- **Palliative care champions (frontline and leadership levels):** Team members who are passionate about palliative care and motivated to provide and advocate for optimal care were described as critical to the implementation of the team. Also identified as essential were individuals in leadership positions, particularly on the EOLCN, who were committed to improving palliative care service delivery in this region and had the vision to move this initiative forward.
- **Key stakeholder support:** Timely support from all key stakeholders/ provider agencies was viewed as instrumental to moving this initiative forward.

“All of the players, the agencies and everybody got on board quickly and got in and did all they could to make this thing work.” [PCT representative]

- **Availability and timing of LEAP education:** Prior to implementation of on-call rotation, the resource nurses attended the LEAP (Learning Essential Approaches to Palliative and End of Life Care) education program along with area family physicians. This provided them with an opportunity to increase their knowledge, skills, and confidence in palliative care, as well as an opportunity to establish relationships with local physicians and promote their competencies. In addition, useful resource material was provided to participants.

“I think [LEAP] helped facilitate trust between nurses, the nurses and physicians, but I also think it helped build capacity for them. [Key stakeholder]

“We had a full weekend seminar called LEAP and that I think was huge. That was really beneficial and we noticed with some of the family physicians there that they were obviously getting a lot out of it too ...they didn’t know how well the nurses are trained that are calling them and asking them things, and I think just getting their eyes open as to what we can do at home and what we are doing at home was a big, big issue.” [PCT Representative]

“The end of life package that we got is invaluable, because I went home and I studied that and I knew exactly what I was doing” [PCT representative]

- **Access to team and palliative care physicians:** Access to the team physician and other palliative care physicians, both face-to-face and via telephone has allowed team members to achieve their palliative care objectives and meet client needs in a timely manner.
- **Frequent team meetings:** Regularly scheduled team meetings provide an opportunity for all team members to become familiar with all of the active cases so that when they are on-call they have some familiarity with clients requiring care. The team meetings also provide an opportunity for team capacity building and problem-solving, as illustrated by the following comment:

“I think it’s a great opportunity to utilize their skills that someone else might not have encountered and what I can see their [Resource Nurses] sharing during rounds and being very helpful to one another.” [PCT representative]

- **Effective team coordination:** The team coordinator was perceived as knowledgeable and encouraging and vital to maintaining momentum and moving the team forward. This role was considered essential for effective and efficient team functioning.
- **Social work support:** The introduction of a social worker on a team provided an additional resource for nurses supporting clients with social issues.

“I think the inclusion of social work. I think that’s been very helpful with the nurses in the community, if they’re encountering some social issues within the family dynamics, it’s been an opportunity get them some help.” [PCT representative]

3.3.3 Challenges

A number of challenges were identified by key stakeholders and PCT representatives related to the implementation of the PCT and service delivery issues such as limited use of the resource nurses, limited access to and support from family physicians, timely access to nursing support, establishing appropriate models of care and facilitating trust among provider agencies. Logistical issues around the development of effective communication vehicles, eligibility criteria, use of pagers, geographical boundaries, and issues around billing and reimbursement to team members for on-call hours were also identified. Challenges are summarized in Table 15.

Table 15: Summary of the Factors Challenging the Implementation of the PCT

Implementation/ service delivery issues

- Limited use of the resource nurses
 - Access to family physicians for updates on client status
 - Limited family physician support
 - Timely access to nursing support
 - Establishing appropriate models of care
 - Facilitating trust among provider agencies
-

Logistical issues

- Establishing effective communication vehicles
 - Determining eligibility for the PCT
 - Technological issues (pagers)
 - Service delivery issues imposed by geographical boundaries
 - Limited payment for on-call time
 - Billing issues associated with nurses visiting other-agency clients
-

Implementation/ service delivery issues

- **Limited use of the resource nurses:** It was noted that within the provider agencies there are some community nurses that are not using team nurses to their full capacity. For example, the core team (the team physician in particular) is being called for issues that can efficiently be handled by the resource nurses. It was suggested that this may reduce over time as awareness of and experience with the expertise of the resource nurses increases.

“I think the biggest [challenge] in my mind is getting the nurses out in the community to buy in to utilizing this service and I think that just comes with time and again I think you have to prove yourself . Right? If they see that other people are going: ‘wow, you know, I plugged in to this team member with some really great outcomes.’ I think you’re going to get the buy in and it’s just really encouraging them to utilize it. And you know I think some of it is the mind set that you know: ‘I’m the primary nurse here and it’s going to look like I don’t know how to do my job’.” [Key stakeholder]

- **Access to family physicians for updates on client status:** The resource nurses are sometimes challenged to remain updated on clients’ status, and in particular what clients have been told about their condition. It was noted that the family physicians may need to work more closely/ collaboratively with team members to identify best methods for dealing with challenging cases and to understand their role/ expertise as team members.

“Another thing I found difficult is not knowing exactly what the patient has been told about the diagnosis and the fact that they come back from the family doctor and they are told there is no cancer. And they have lumps protruding from their abdomen that you are concerned about. So I, as a care giver, I’m left in the dark and it’s really hard to get a hold of some of these doctors. The phones are busy or they’re not taking messages, you can fax them, but you have to find that out. So that’s one of the things that’s a big issue for me is not knowing exactly where things stand.” [PCT representative]

“...It just I guess educating the doctors and saying we’re part of the team or I’m part of the team and I need to know what to do for this lady, how to handle her, what is the best approach?” [PCT representative]

- **Limited physician support:** Some family physicians have been described as reluctant to accept the resource nurses' assessments of patient status or care plan recommendations.
- **Timely access to nursing support:** When clients' status deteriorated quickly, the team has had challenges getting immediate shift nursing support; this has been particularly difficult on weekends.

“Trying to get help when you need it, for instance if the client is going downhill quickly and we need help overnight. Trying to get somebody in there, the shift nurse, in a timely fashion, weekends are notorious in trying to get anybody and that’s when it happens.” [PCT representative]

- **Establishing appropriate models of care:** There have been some cases in which resource nurses have perceived that clients have been referred to the team to take over care of the patient, when a consultation or shared care model of care would have been more appropriate. Improving capacity to assess and manage palliative care within primary care was identified as a strategy to overcome this issue.
- **Facilitating trust among provider agencies:** It was noted that one of the challenges of working in a team consisting of staff from different provider agencies has been facilitating trust among the agencies so that they are comfortable working together. This has been successful as collaboration among the agencies has been identified as a significant outcome associated with this initiative.

“The different providers working together and that communication tool and trusting each other, in a different provider, I think they each are a little weary of the other agency, because they’re another agency. And I think that’s one of the big, big challenges, but I think they’re learning as, as we’re doing more meetings, and the communication and the fact that they’re not being criticized. They’re there to help just give, lend another pair of eyes to what’s going on. I think, I think that’s slowly being overcome.” [Key stakeholder]

Logistical issues

- **Establishing effective communication vehicles:** Initially, there were some challenges related to:
 - getting client information to the resource nurses in a timely manner
 - identifying clients to be discussed at team rounds with enough notice to the resource nurses so that they could gather/ prepare an update on patients' status for presentation at the meeting
 - additional time needed to prepare for presentation at rounds particularly if the resource nurse was not the client's primary nurse. Reimbursement for the time spent preparing for rounds is not assumed by the PCT.

“...have to find out who the main nurse was and have them exchange information, and you know, that’s time consuming. It takes anywhere from a good 45 minutes to an hour to obtain information that they need to give this report on each client... its

three hours of extra work you know that they're not being paid for at all.... There's a lot of time being spent that's not being recognized." [Key stakeholder]

These challenges were identified early in the team's implementation and various process strategies are being explored and tested for resolving these issues.

- **Determining eligibility for the PCT:** The expectation that the client will die within 6 months as a criterion for referral to the PCT is often difficult to assess and is sometimes a "guess".
- **Technological issues (pagers):** There have been several occasions when the pagers used by the resource nurses have not worked because they were "out of range". This is an on-going issue in Lambton county and not specific to the team. Alternative options (e.g., designated team cell phones) are being explored further to ensure that team members are reached as needed.
- **Service delivery issues imposed by geographical boundaries:** At the onset, contractual issues arose regarding the geographical boundaries within which the resource nurses were available to work. This issue has since been resolved.
- **Limited reimbursement for on-call time:** This project had budgeted for \$4 per hour for the resource nurses to be on call but this did not factor in required deductions, so that in reality, unless agencies assume the financial burden of the deductions, the nurses are making much less for on-call hours. This issue is significant for unionized nurses. It is anticipated that this issue will be resolvable.
- **Billing issues associated with nurses visiting other-agency clients:** Billing issues arose when resource nurses, while on call, had visited clients that were not registered with their agency (i.e., the client is registered with one of the other provider agencies). Additional paperwork needed to be processed to admit and then discharge the client from their system in order to bill the CCAC for the one-time only visit. It is anticipated that an easier solution to this problem will be developed.

3.3.4 Suggestions for Improvements

Caregiver suggestions for improvements to care were primarily related to improving consistency in visiting nurses/PSWs, increasing nursing/PSW hours of care and improving punctuality in attending appointments. One caregiver commented that she was not clear on who to call regarding questions about the pain pump and that this type of information should be made explicit as when under such emotional stress it is difficult for caregivers to remember what they have been told:

"Needs to be clearer who to call when. For example, when to call the case manager and when to call the nurse directly. When we received the pain pump we weren't sure who to call about it. They may have told me but I'm under so much stress, so they may have told me what to do but it's so overwhelming."

It was also suggested that there needs to be better coordination between the London Regional Cancer Centre and local care providers – a caregiver reported that LRCC had suggested that

they go to the ED if they have any problems but the caregiver perceived this as not helpful advice.

Key stakeholders survey respondents identified a number of suggestions for improving the services provided to patients, caregivers and other care providers or how it could better support their efforts to assess and manage clients requiring palliative /end-of-life care; these were primarily related to improving/ increasing communication within the team and care providers external to the team, as reflected in the following comments:

“Increased communication in writing from all parties.”

“Primary nurses need to have reports on client condition, prognosis. We mostly try to do a great job working in the dark.”

“Community nurses are often left out of the loop when it comes to the exact diagnosis. This can make it difficult to plan strategically. Community nurses are the last to find out what is going on and the next steps. It would be nice if the nurses could have copies of transcription notes from doctors after an office visit. They do not need to be part of the in-home chart, but would give a more clear picture as to what may have been said in regards to the patient.”

Interviewed key stakeholder and PCT representatives identified a number of suggestions for improvements, sustainability and further development of the PCT; some of these suggestions address the challenges were identified earlier. Suggestions were also made regarding general improvements to palliative care service delivery in this region; these suggestions are summarized in Table 16.

Table 16: Summary of Suggestions for Improvements to the PCT and Palliative Care in General

Suggestions for improvements, sustainability and further development

- Allow shared access to electronic documentation (CCAC – CHRIS)
- Secure ongoing funding
- Secure physician support for the PCT
- Expand/ establish palliative care expert teams beyond Sarnia-Lambton
- Promote the PCT more widely
- Continue opportunities for education and team building
- Develop succession plans for the team physician
- Access to Hospice

General suggestions for improvements to palliative care

- Increase funding for shift nursing at end of life
 - Increase opportunities for continuing palliative care education across disciplines and sectors
 - Better home construction for home care
 - Financial support for clients receiving care out of town
-

- **Allow shared access to electronic documentation:** It was noted that resource nurses would benefit from having access to the CCAC's electronic documentation (Client Health and Related Information System, CHRIS) system. This would allow them to view charts and document while in clients' homes. This is currently not available, but it is hoped that in the near future shared access to the CHRIS will be available. In the meantime, the team physician has made his progress notes available to team members (usually within 24 hours of home visit, consult, or follow-up visit) so they can remain updated on clients' status.

"I think something we're planning is sharing the electronic documentation, here at CCAC with each of the agencies. I think that will be a benefit to being able to look and see what's in there.... the ability to the nursing community on the team, the opportunity to review the chart in the home and have some sort of electronic access so whether that be through a laptop or pilot or a Blackberry, so they could review the client's record while they're there and document." [PCT representative]

- **Secure ongoing funding:** It was noted that on-going (base) funding will be needed to sustain the PCT beyond this pilot project.
- **Secure family physician support for the PCT:** To increase the effectiveness of the team it was noted that it is important to have buy in / support from family physicians. A number of strategies for securing physician support were identified such as:
 - Having more family physicians complete the LEAP education program to increase their capacity for palliative care and to increase their awareness of the team's expertise.
 - Increasing awareness / promotion of team expertise via: regular updates to family physicians about the team and its progress, media coverage on the team (newspaper, television news stories).
- **Expand/ establish palliative care expert teams beyond Sarnia-Lambton:** It was noted that the decision to dedicate year one funding of this initiative to establish a PCT in Sarnia-Lambton was a strategic decision to enhance care in this region in light of recent palliative care bed closures in Sarnia. While this is understandable, it was hoped that enhancements to palliative care services in other counties (Windsor-Essex, Chatham-Kent) will follow in subsequent years.
- **Promote the PCT more widely:** To increase use of the resource nurses, it was suggested that there be more opportunities and vehicles for promoting the team, the expertise of its members, and services provided. Moreover, promoting the services provided by the PCT will better educate the general public about what options are available at end of life.

"It's just always making more people aware of what we can do to keep people in the home, there's a lot of speaking done when we start seeing the palliative patient and ask them about staying home or hospital at the end, and you know, a lot of them have no idea that we can do so much at home." [Key stakeholder]

- **Continue opportunities for education and team building:** Ongoing educational opportunities (e.g., LEAP) for team members and area family physicians were identified as important to team building and building capacity for palliative care on the team and in this region. Additional opportunities for team members to interact and problem solve common care issues were described as important to team building.

“And I think again it’s you know, trying to have events or you know learning sessions where everybody is there so you’re not a specific agency or the larger group and I think it’s just getting networking and getting comfortable with each other.” [Key stakeholder]

- **Develop succession plans for the team physician:** It was suggested that there be a plan in place to ensure that a trained physician would be available to replace the team physician if needed. A mentorship/ training plan was suggested as opportunity to identify and train potential future palliative care leaders.

“We have a physician who’s on board now, but should he ever decide to retire down the road, we need to have someone to follow in his footsteps so I don’t know, by mentorship, it could be incorporated into that too, to encourage other physicians who are coming from school or thinking of changing their practices to encourage them to take this on.” [PCT representative]

- **Access to Hospice:** It was noted that access to the new hospice in Sarnia will provide additional resources and options for clients.

“Having the Hospice will be an asset to draw on. Not everyone wants to go into Hospice, but for those who don’t want to die at home it is a very good alternative option.” [PCT representative]

General suggestions for improvements to palliative care

- **Increase funding for shift nursing at end of life:** It was suggested that greater resources need to be expended on supporting clients to die at home particularly the availability of shift nursing to support clients and families during the last days of life.

“Oh I think being able to have some funding for shift care closer to the end stage, and more providers available. We still have a problem with resources as far as home makers or nurses going in to provide care so I think if funding for increasing the service or to make it better even for home makers to provide, wanting to work with individuals who require end of life care.” [Key stakeholder]

- **Increased opportunities for continuing palliative care education:** Continuing education for all health care providers, across all sectors would assist to increase system-wide capacity for palliative/ end-of-life care.
- **Better home construction for home care:** Constructing homes that are ergonomically designed for home-based medical care (e.g., rooms capable of housing hospital beds, good air quality) and that are safe and healthy places for community nurses to work.

- **Financial support for clients receiving care out of town:** It was suggested that more financial support be available for clients receiving treatment or participating in intervention studies (e.g., studies at Princess Margaret hospital in Toronto) out of town to cover the cost of accommodations, food, travel and other needs (e.g., laptop computer to remain connected to family and friends).

3.3.5 Lessons Learned: Resources/ supports needed for expansion

The following resources and supports were identified as important for expansion/ creation of PCTs in other areas:

- **Designated team staff:**
 - **Team assistant:** Full time administrative support is needed to maintain client records and support team activities.
 - **Team Coordinator:** Full time coordinator to support the resource nurses and move the team forward.
- **Palliative care champions:** Physicians and nurses passionate about palliative care; a lead palliative care physician that is committed to palliative care and able to assume an education role is needed.
- **Family physician support:** “Buy in” from family physicians to support the efforts of team members. Team expertise and competency needs to be promoted to family physicians.
- **Primary care nursing:** representation of primary care nurses on the team.

“The team is made up of representatives from the front line of the primary nurses as well as nurse resources, palliative resources and the community service provider agencies so if we’re setting a model across the region, strong representation from the client advocacy point of view, many of the nurses are actually, some of them are there, they’re the primary nurse, they know that client well.” [PCT representative]

- **Access to Interprofessional care:** Team access to social workers, occupational therapists, and Chaplains to enhance support to clients.
- **Mentorship:** Opportunities for learning from established teams via one-on-one mentorship and shadowing opportunities.
- **Continuing education and networking:** Ongoing opportunities for continuing education and networking for both physicians and nurses is necessary to build their knowledge and confidence in palliative care.

4.0 Conclusions

Based on the findings of this evaluation, the following conclusions can be made about the Palliative Consultation Team:

- The PCT has achieved many of its objectives in a relatively short period of time. The shared care model of interprofessional service delivery represents a major move towards filling palliative care service gaps that are well documented within the literature.⁹ Although impacts to date have focused primarily on capacity building and care coordination within the community, given time and additional efforts to engage acute care stakeholders and facilitate cross sector communication, goals related to integration of care may be realized. Further development, implementation, and expansion of the PCT has the potential to significantly impact the quality of hospice palliative/ end-of-life care in this region. With continued success the PCT has the potential to be a model for other regions in the province. Lessons learned in developing and implementing the PCT in Sarnia-Lambton should be used to inform the development of PCTs in other areas.
- Although much of the evidence on health system impacts as a result of the PCT is anecdotal, there were suggestions that these impacts are also being demonstrated in statistics being maintained by various information systems (CCAC, hospital). Identified health care provider and health system impacts are consistent with published reports.¹⁰ Longer term impacts related to health system utilization were not evaluated in this evaluation but could now be included in future evaluation efforts. Empirical/ objective evidence based on hospital data related to Emergency Department visits for palliative/ end-of-life care issues, admissions, length of stay, and readmission rates as well as the number of home deaths¹¹ would provide stronger evidence of the PCTs ability to manage care effectively within the community.
- There is much support for the PCT, particularly for an interprofessional/ multidisciplinary approach to palliative care. It has been well received by caregivers and key stakeholders. Despite some implementation challenges, PCT members have been satisfied with their accomplishments. Some of the challenges experienced to date are inherent in the implementation of any new service. Key stakeholders clearly want the team to be successful and appear to be open to identifying and discussing problems/ issues and willing to work collaboratively to resolve these. The team has an informal process in place for identifying challenges/issues and has worked towards resolving these to everyone's satisfaction.

⁹ Grande, G.E., Barclay, S.I., Todd, C.J., (1997). Difficulty of symptom control and general practitioners' knowledge of patients' symptom. *Palliative Medicine*, 11(5), 399-406.

Groot, M.M., Vernooji-Sassen M.J., Crui, B.J., & Grol, R.P. (2006). General practitioners (GPs) and palliative care: perceived tasks and barriers in daily practice. *Palliative Medicine*, 2005; 19(2): 111-8.

Heyland, D.K., Lavery, J.V., Tranmer, J.E., Shortt, S.E., Taylor S.J. (2000). Dying in Canada: Is it an institutionalized, technologically supported experience? *Journal of Palliative Care*, 16(Suppl): S10-6.

¹⁰ Marshall, D., Howell, D., Brazil, K., Howard, M., & Taniguchi, A. (2008). Enhancing family physician capacity to deliver quality palliative home care. An end-of-life shared care model. *Canadian Family Physician*, 54, 1703e1-7.

¹¹ Although an increase in the number of home deaths is an important outcome associated with the team, caution is needed in making home deaths a quality indicator as there are many reasons for choosing to die in hospital that has nothing to do with the quality of care provided by the PCT in the community (e.g., survivors may not want to deal with the memory of a home death, clients do not want to burden or distress caregivers/ family members).

Although some challenges have not been resolved (e.g., appropriate reimbursement for on-call time, billing issues) it is anticipated that these are indeed resolvable.

- Currently, there is much support for the existing resource nurses on the team. They have been described as dedicated, highly knowledgeable, skilled and passionate about palliative care. There was general consensus that designation as a registered practical nurse is adequate for the role, dependent on candidates having the requisite knowledge and skills in palliative care. Although “passion” for palliative care has been identified as an important criterion, it should not supersede expertise and experience in importance, as passion alone does not guarantee competency. The published literature highlights the importance of expert competency as well as leadership skills and ability to work collaboratively, improve practice, and develop therapeutic relationships.¹²
- One of the key elements of the PCT’s success is that it builds upon existing capacity for palliative care within the community. Increased communication and collaboration among provider agencies is a significant outcome impacting the teams’ success. Suggestions made for improving and sustaining the team have the potential for further capacity building. In addition to resource supports (funding, shared information systems), opportunities for continuing education, team building, and better promotion/ marketing of the team will strengthen its ability to achieve its objectives. These strategies as well as those aimed at improving communication among team members have been identified a facilitating cooperation and team work within palliative care teams.¹³
- Lack of physician support for the work of the resource nurses poses a threat to the success of the team; suggestions related to continuing education and promotion of the team emphasizing the expertise of resource nurses, as well as opportunities for meaningful collaboration/ interactions between family physicians and team members could prove to be important strategies for securing physician support. Moreover, continuing education has been identified as a significant strategy for enhancing family physician capacity to deliver quality palliative care.²
- One of the anticipated outcomes of the team was the provision of safer environments for patients and families requiring palliative care at home. Key stakeholder survey results indicated that the majority of those surveyed believed that safety within the home environment had not changed as a result of the team. This finding is somewhat inconsistent with the impacts identified throughout the evaluation. It is quite possible that the way in which the survey question was phrased (How would you rate the current level of safety within home environments for end-of-life care? How does this compare with the level of safety within home environments prior to the inception of the Team?) was not a valid measure of this outcome. Future evaluations should ensure a more valid and reliable measuring changes to the provision of safe home environments, perhaps measuring the specific factors that ensure or define safety.

¹² Tice, M.A. (2006). Nurse specialists in home health nursing: the certified hospice and palliative care nurse. *Home Healthcare Nurse*, 24(3):145-7.

Canning, D., Rosenberg, J.P., & Yates, P. (2007). Therapeutic relationships in specialist palliative care nursing practice. *International Journal of Palliative Nursing*, 13(5), 222-9.

¹³ Junger, S., Pestinger, M., Elsner, F., Krumm, N., & Radbruch, L. (2007). Criteria for successful multiprofessional cooperation in palliative care teams. *Palliative Medicine*, 21(4), 347-54.

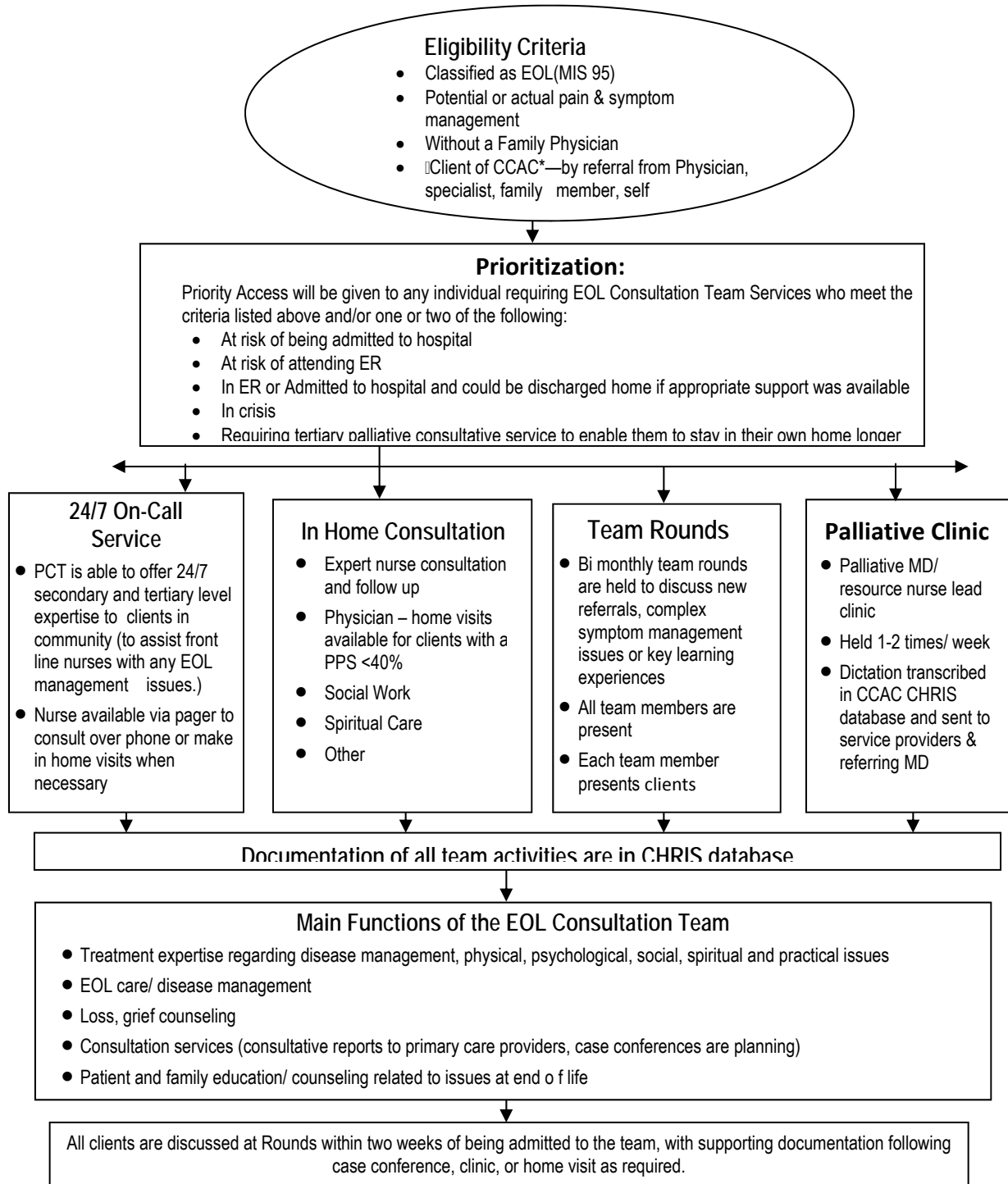
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Sarnia-Lambton Palliative Consultation Team - Overview



*Clients of CCAC – Patient may not be a pre-existing patient of CCAC, but upon admission to PCT patient is registered with CCAC.

Program Logic Model



**System- related
Outcomes**

-
- increase in EOLC service in the community (number of nursing visits, shift nursing hours, PSW hours for EOLC, out-patient visits)
 - enhanced and increased access to EOL health care services
 - increased number of EOLC clients served in the home.
 - decreased % of deaths in hospital
 - increased % of deaths in the home (expected deaths)
 - reduced number of palliative care-related visits to the ED*
 - reduced acute care costs for palliative care*
 - increased access to vital health care services at home
 - enhanced care path development and implementation*
 - improved population health*

Impact

Integrated and Coordinated EOL care
Enhanced palliative care and EOL care

EOL = End of life
EOLC – End-of-life care
ED = Emergency Department

* long-term outcomes that require >1 year for evidence of achievement

Evaluation Framework

Objective 1: describe the services provided by the Palliative Consultation Team and the population served

Outcomes	Indicators	Sources of Information	Design/ Timeline
Description of services provided by the expert time	<ul style="list-style-type: none"> • Number/type of professionals on the team • # of new referrals • Referral sources • # of initial visits • # of assessments conducted • # of follow-up visits • # of direct care visits • #of team rounds • Attendees at team rounds • #of calls in “off hours” (24/7 access) • # of shared care models of service delivery • # of primary care models of service delivery • # of consultation reports developed & distributed • Providers receiving a consultation report(primary care, client, service provider agency, CCAC, acute care) • # of clients referred to other services • time per visit, per client • # of team members involved per client • # of visits per client per team member • Length of client stay on service • Response time to referrals • Response time to consultation report distribution 	Service tracking records completed the team/administrative assistant	Service tracking from January 1 to March 31, 2009

Outcomes	Indicators	Sources of Information	Design/ Timeline
	<ul style="list-style-type: none"> Place of client death 		
Description of the client population served by the PCT	<ul style="list-style-type: none"> Age Gender Place of residence Available caregiver support Location at time of assessment Diagnosis Palliative Performance Score Place of death 	Service/client tracking records completed the team/administrative assistant	Service/client tracking from January 1 to March 31, 2009

Objective 2: Identify the impacts associated with the Palliative Consultation Team

Outcomes	Indicators	Target/Benchmark	Sources of Information	Design/ Timeline
<p><u>Client-related:</u></p> <ul style="list-style-type: none"> Concordance between preference and place of death. satisfaction with access to EOL care satisfaction with timeliness of access to EOL care satisfaction with care coordination satisfaction with communication regarding care satisfaction with 	Caregiver ratings of satisfaction	90% of clients/ caregivers satisfied with service	Caregiver Interview	Satisfaction interview (telephone) completed three weeks after initial visit with the team (January 1 to March 31, 2009)

Outcomes	Indicators	Target/Benchmark	Sources of Information	Design/ Timeline
informed decision-making <ul style="list-style-type: none"> • satisfaction with care provided • satisfaction with preparation for death 				
<ul style="list-style-type: none"> • provision of a safer environment for clients and families requiring palliative care at home 	Key stakeholder reports of safer home environments for EOL care as a result of the PCT	90% of providers reporting safer home environments for EOL care as a result of the PCT	Key stakeholder survey Key stakeholder interview	Key stakeholder surveys distributed in March 2009 Key stakeholder interviews conducted in March 2009
<p><u>Provider-related outcomes:</u></p> <ul style="list-style-type: none"> • satisfaction with care integration • satisfaction with communication across providers and sectors • satisfaction with care coordination • satisfaction with care planning • increased capacity for EOL care 	Provider ratings of satisfaction Provider ratings of increased capacity for EOLC as a result of the PCT	90% of providers satisfied with care integration, coordination, planning and communication 90% of providers reporting increased capacity for EOLC as a result of the PCT	Key stakeholder survey Key stakeholder interview	Key stakeholder surveys distributed in March 2009 Key stakeholder interviews conducted in March 2009

Outcomes	Indicators	Target/Benchmark	Sources of Information	Design/ Timeline
<ul style="list-style-type: none"> increased use of standardized clinical assessment tools – ESAS & PPS increased response to assessment scores within targeted ranges care planning processes which appropriately responded to PPS and ESAS findings. 	<p>Documented use of ESAS & PPS in client records (e.g., reports, assessments etc)</p>	<p>90% of clients screened for symptom severity using the ESAS</p> <p>90% of clients have functional status assessed using the PPS</p> <p>Scores used to inform care planning for 90% of clients</p>	<p>Service/client tracking records completed the team/administrative assistant</p>	<p>Service/client tracking from January 1 to March 31, 2009</p>
<p><u>System-related outcomes:</u></p> <ul style="list-style-type: none"> Increase in EOLC service in the community Enhanced and increased access to EOL health care services Increase in number of EOLC clients served in the home. 	<ul style="list-style-type: none"> increase number of nursing visits increase in shift nursing hours increase in PSW hours for EOLC increase in number of visits to outpatient clinic 	<p>2% increase in MIS 95 coded volumes in Q4 08/09 compared to Q4 07/08 in the following categories:</p> <ul style="list-style-type: none"> total number of clients total number of visits/hours-nursing/PSW/social work <p>2% increase in number of clinic visits Q4 08/09 compared to Q4 07/08</p>	<p>CCAC code 95</p>	<p>Retrospective analysis of submitted data</p>

Outcomes	Indicators	Target/Benchmark	Sources of Information	Design/ Timeline
Decrease in % of deaths in hospital* ¹⁴	Long-term outcome – unable to evaluate in the short time frame of this evaluation			
Increase in % of deaths in the home (expected deaths with EDITH protocols in place)	Proxy – location of death for clients in this program. Otherwise – unable Total number of expected home deaths between January 1 – March 31, 2009 Number of actual deaths at home between January 1 – March 31, 2009 Percent increase in home deaths compared to quarterly reports of the previous year.			
Reduction in number of palliative care-related visits to the ED*	Long-term outcome – unable to evaluate in the short time frame of this evaluation			
Reduced acute care costs for palliative care*	Long-term outcome – unable to evaluate in the short time frame of this evaluation			
Increased access to vital health care services at	Key stakeholder (Provider) reports of increased access	90% of providers reporting safer home	Key stakeholder survey Key stakeholder	Key stakeholder surveys distributed

* Although it is not possible provide evidence of these outcomes within the short-time frame of this evidence, qualitative data on potential impacts will be gathered as part of the focus group interviews with key stakeholders and the PCT/ team organizers.

Outcomes	Indicators	Target/Benchmark	Sources of Information	Design/ Timeline
home		environments for EOL care as a result of the PCT	interview	in March 2009 Key stakeholder interviews conducted in March 2009
Enhanced care path development and implementation*	Long-term outcome – unable to evaluate in the short time frame of this evaluation			
Improved population health*	Long-term outcome – unable to evaluate in the short time frame of this evaluation			

Objective 3: Describe the development and implementation of the Palliative Consultation Team

Outcomes	Indicators	Sources of Information	Design/ Timeline
Description of the development and implementation of the PCT	<ul style="list-style-type: none"> • Factors that facilitated or enabled the development and implementation of the PCT • Challenges, or barriers, to role development and implementation • Service delivery issues • Key lessons learned • Suggestions for improvement? For sustainability? For expansion to other counties? • Next steps for the PCT? 	<p>Key stakeholder interview</p> <p>Focus Group interviews with PCT and key stakeholders (EOLC Network)</p>	<p>Individual key stakeholder interviews conducted in March 2009</p> <p>Focus group conducted in early April 2009</p>

Appendix D

Referral and Service Tracking

Data	Definition
Date of referral	Day/month/year
Referral source	Family Physician, Specialist, CCAC, agencies, other (specify)
Other referral	Specify "other" referral source
Age at time of referral	2008 minus year of birth
Gender	Male/female
Place of residence	Home, long-term care, retirement home, other (specify)
Other residence	Specify "other" residence
Availability of an informal caregiver (family/friend)	Yes/no
Date of initial visit	Day/month/year
Date of assessment (even if the same as initial visit)	Day/month/year
If a referred client was not seen by team, what was the reason?	List reason
If an assessment was not conducted, what was the reason?	List reason
Length of time to complete the assessment	Minutes/hours
Location at time of assessment	Home, hospital, clinic, other
Other location	Specify other location of assessment
Team members involved in assessment	Physician, nurse, NP, Social worker, other (specify)
Other member	Specify "other" member involved
Diagnosis at time of assessment	List

Data	Definition
PPS score at time of assessment	Provide score
Date report distributed	Day/month/year
If a report was not generated, what was the reason?	List reason
Individuals (services) that received a copy of the report	Primary care MD
Individuals (services) that received a copy of the report	Client
Individuals (services) that received a copy of the report	Service provider agency
Individuals (services) that received a copy of the report	CCAC
Individuals (services) that received a copy of the report	Hospital
Individuals (services) that received a copy of the report	Specify other
Major presenting problems	List presenting problems (e.g., pain, symptoms, emotional distress)
Treatment recommendations	List recommendations as presented in report
Referrals to other health professional or service	List to whom client was referred
Number of follow-up visits	Number
Number of direct care visits	Number
Total number of visits (assessment, follow-up, direct care)	Number
Model of care	Shared care (primary care physician and team working together to provide care) Primary care (team made recommendations that were implemented by the family physician) Other

Data	Definition
Discharge from service date	Day/month/year
Has client died?	Yes/No/ Don't know
Date of death	Day/month/year
Place of death	Home/Hospital/ Hospice/Other/ unknown

Interview Guide for the Interviews with Caregivers

1. Interview with:

- the caregiver of a client? What is your relationship to the client?
- Spouse/partner
 - Child
 - Extended family member
 - Friend
 - Other, please specify: _____

Is your care receiver still at home? Yes No

Care receiver is in hospital: Yes No

Care receiver has died:¹⁵ Yes No

2. I'd like to ask you about how satisfied you were with various aspects of the Team.

Overall, how satisfied were you with your first visit with the team? I'm going to read out some words that describe different levels of satisfaction and I'd like you to select the one that best describes how satisfied you were with your first visit with the Team.

Extremely dissatisfied	Very dissatisfied	Somewhat dissatisfied	Not satisfied nor dissatisfied	Somewhat satisfied	Very satisfied	Extremely satisfied
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3. How satisfied were you with the amount of time that you waited to see the team, that is, the timeliness in which you saw them?

Extremely dissatisfied	Very dissatisfied	Somewhat dissatisfied	Not satisfied nor dissatisfied	Somewhat satisfied	Very satisfied	Extremely satisfied
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4. How satisfied were you with the way your loved one's care was coordinated with all the other health professionals that were involved, such as your family physician, visiting nurses, or the hospital? (Prompt: For example, all the other services and supports outlined in the care plan were in place, for example, the pharmacy was informed of drug changes, the visiting nurse provided necessary equipment)

Extremely dissatisfied	Very dissatisfied	Somewhat dissatisfied	Not satisfied nor dissatisfied	Somewhat satisfied	Very satisfied	Extremely satisfied
---------------------------	----------------------	--------------------------	--------------------------------------	-----------------------	-------------------	------------------------

¹⁵ This is not an interview question, but will be discerned from the conversation with the care giver.

5. How satisfied were you with the way the team responded to your questions and concerns?

Extremely dissatisfied Very dissatisfied Somewhat dissatisfied Not satisfied nor dissatisfied Somewhat satisfied Very satisfied Extremely satisfied

6. How satisfied were you the level of communication among all of the different care providers or services involved in your loved one's care? (Prompt: did everyone know what they needed to do as part of the care plan that was in place?)

Extremely dissatisfied Very dissatisfied Somewhat dissatisfied Not satisfied nor dissatisfied Somewhat satisfied Very satisfied Extremely satisfied

7. How satisfied are you that you have had enough information with which to make treatment or care decisions?

Extremely dissatisfied Very dissatisfied Somewhat Dissatisfied Not satisfied nor dissatisfied Somewhat satisfied Very satisfied Extremely satisfied

8. In the event that clients have died:

Did your loved one die at home? in hospital? in long-term care? hospice?

8.1 Was this the plan?

Yes No Not sure

8.2 Do you have any comments you'd like to make about this? (Prompts: What did you think about this? Was this the location you wanted?)

8.3 How satisfied were you with the way in which your loved one's care was managed at the end of his/her life?

Extremely dissatisfied Very dissatisfied Somewhat dissatisfied Not satisfied nor dissatisfied Somewhat satisfied Very satisfied Extremely satisfied

8. For clients who have not died:

How satisfied are you with the way that you and your loved one have been prepared for what will happen next?

Extremely dissatisfied Very dissatisfied Somewhat dissatisfied Not satisfied nor dissatisfied Somewhat satisfied Very satisfied Extremely satisfied

9. Could you please tell me about at least one thing that you really liked about the team and service or care they provided?
10. Was there anything that you didn't like about the team and the service or care they provided?
11. Do you have any suggestions for improving the services or care provided by the team or for improving palliative care/ end-of-life care in general?
12. We are at the end of the interview now, do you have any final or additional comments that you'd like to make about the team or the care you have received?

Key Stakeholder Survey

1. In the past three months, how much contact have you had with members of the team in regards to clients you are dealing with who require palliative care?

- In regards to more than 21 clients
- In regards to 11 – 20 clients
- In regards to 6 – 10 clients
- In regards to 1 – 5 clients
- Not at all

2. Overall, how would rate the work of the Team?

Poor
fair
good
very good
excellent

3. How satisfied are you with the following elements of the team?

	Not at all satisfied 1	2	3	4	Extremely satisfied 5
Timeliness of access to assessment	1	2	3	4	5
Follow-up	1	2	3	4	5
Direct provision of care	1	2	3	4	5
Quality of assessment	1	2	3	4	5
Treatment recommendations/ planning	1	2	3	4	5
Availability of team members for informal consultation (questions, follow-up)	1	2	3	4	5
Communication between the team and other care providers	1	2	3	4	5
Integration of care across care providers	1	2	3	4	5
Integration of care across health sectors (community – hospital)	1	2	3	4	5
Care coordination	1	2	3	4	5

8 a. Overall, how would you rate **your current ability to manage** clients requiring palliative care (within your scope of practice)?

n/a	1	2	3	4	5
Not my role	Not at all capable				Extremely Capable

b. How does this compare with your ability to manage clients requiring palliative care (within your scope of practice) prior to the inception of the Team?

1	2	3	4	5
I am now less capable		About the same		I am now more capable

9. As a result of your involvement with the Team, do you think that the quality of care you provide to clients requiring palliative/end-of-life care has:

- Much improved
- Improved
- Neither improved or worsened
- Worsened
- Much worsened

10. Are you able to identify any key, or most significant, impacts/ outcomes associated with the Team? These impacts can be client/caregiver, health professional, or health system-related.

- No
- Yes, please describe:

Additional Comments

Do you have any additional comments you would like to make about the Team or the provision of palliative/end-of-life care in this region?

Demographic Information

The following information will be used to analyse the results and will be reported as group information only. It will NOT be used in an attempt to identify you.

Tell us about yourself:

Which of the following best describes your discipline/profession?

- Physician
- Registered Nurse
- Registered Practical Nurse
- Personal Support Worker
- Nurse Practitioner

- Case Manager
- Agency nursing supervisor
- Pharmacist
- Volunteer coordinator
- Pastoral/spiritual care
- Other, please specify: _____

How many years have you been employed in your current profession? _____ years

What percentage of the clients that you work with require palliative / end-of-life care?

- Not applicable
- None
- Less than 25%
- 26% - 50%
- 51% - 75%
- Over 75%

You have come to the end of the survey. Thank you for completing this survey.

Interview Guide for Interviews with Key Stakeholders

Potential Impacts

1. How effective do you think the team has been at meeting the needs of clients/ caregivers at end of life?

1.1 What are some of the client-related impacts or positive outcomes associated with the Team?

Prompts:

Client-related outcomes:

- Concordance between preference and place of death.
- satisfaction with access to EOL care
- satisfaction with timeliness of access to EOL care
- satisfaction with care coordination
- satisfaction with communication regarding care
- satisfaction with informed decision-making
- satisfaction with care provided
- provision of a safer environment for clients and families requiring palliative care at home
- satisfaction with preparation for death

2. How effective do you think the team has been at meeting the needs of care providers who are providing palliative/ end-of-life care?

2.1 What are some of the care provider-related impacts or positive outcomes associated with the Team?

Provider-related outcomes:

- satisfaction with care integration
- satisfaction with communication across providers and sectors
- satisfaction with care coordination
- satisfaction with care planning
- increased capacity for EOL care
- increased use of standardized clinical assessment tools – ESAS & PPS
- increased response to assessment scores within targeted ranges
- enhanced care planning processes that appropriately respond to PPS and ESAS findings

3. How effective do you think the team has been at optimising the use of system resources for palliative/ end-of-life care (e.g., hospital avoidance, keeping clients at home longer)?

3.1 What are some of the health system-related impacts or positive outcomes associated with the Team?

System-related outcomes:

- increase in EOLC service in the community (number of nursing visits, shift nursing hours, PSW hours for EOLC, out-patient visits)
- enhanced and increased access to EOL health care services
- increased number of EOLC clients served in the home.
- decreased % of deaths in hospital
- increased % of deaths in the home (expected deaths)
- increased access to vital health care services at home

4. Can you provide an example based on your experience to illustrate a key impact of the Team? Can you share with me any cases that stand out in your mind as being particularly illustrative of the benefits associated with the Team?

Development and Implementation of the Palliative Consultation Team

I'd like to discuss the development and implementation of the Palliative Consultation Team, but also the resources nurses from the service provider agencies. Let's start with the resource nurses.

5. What are your thoughts on the selection of the resource nurses? Were the most appropriate individuals selected? Were these individuals CAPCE trained?
- 5.1 Is there value in having CAPCE trained nurses as part of the team?
 - 5.2 Does it matter if they are Registered Nurses or Registered Practical Nurses?
 - 5.3 To what extent were they able to manage their on-call responsibilities (timeliness, quality of care)?
 - 5.4 What suggestions for further education/ capacity building do you have for the resource nurses?
 - 5.5 Do you have any other comments to make about the resource nurse (facilitating factors, challenges, suggestions for improvement)?

I'd like to now focus on the development and implementation of the Palliative Consultation Team.

6. What has worked well with the development and implementation of the Team? What are some of the things that facilitated its development and implementation (e.g., needs, support)?
7. What are some of the challenges that have been experienced to date with the team? What some of the factors that hindered optimal implementation (barriers at individual, project, system levels)?
8. Do you have any suggestions for overcoming these challenges/ barriers?
9. What suggestions do you have for improvement, sustainability or further development and implementation of the Team?

10. Do you have any general suggestions for enhancing palliative /end-of-life care service delivery in this region?

Additional Comments

Do you have any additional/final comments you'd like to make about the Team?

Interview Guide for Interview with the PCT and Team Organizers

Development and Implementation of the Palliative Consultation Team

11. What has worked well with the development and implementation of the Team? What are some of the things that facilitated its development and implementation (e.g., needs, support)?
12. What are some of the challenges that have been experienced to date with the team? What are some of the factors that hindered optimal implementation (barriers at individual, project, system levels)?
13. Do you have any suggestions for overcoming these challenges/ barriers?
14. Are there any service delivery issues that have not already been identified that threaten the effectiveness of the team or palliative/ end-of-care service delivery in this region?
15. What do you think are some of the key lessons learned in the development and implementation of the Team?
16. What suggestions do you have for improvement, sustainability or further development and implementation of the Team in this setting?

Expansion to other counties

17. What do you think needs to be in place in order for the expansion of this initiative to other counties? What resources/ supports are needed for expansion to be successful?
18. Do you have any general suggestions for enhancing palliative/ end-of-life care service delivery in this region?

Potential Impacts

19. What are some of the client-related impacts or positive outcomes associated with the Team?

Prompts:

Client-related outcomes:

- Concordance between preference and place of death
- satisfaction with access to EOL care
- satisfaction with timeliness of access to EOL care
- satisfaction with care coordination
- satisfaction with communication regarding care
- satisfaction with informed decision-making
- satisfaction with care provided

- provision of a safer environment for clients and families requiring palliative care at home
- satisfaction with preparation for death

Provider-related outcomes:

- satisfaction with care integration
- satisfaction with communication across providers and sectors
- satisfaction with care coordination
- satisfaction with care planning
- increased capacity for EOL care
- increased use of standardized clinical assessment tools – ESAS & PPS
- increased response to assessment scores within targeted ranges
- enhanced care planning processes that appropriately respond to PPS and ESAS findings

System-related outcomes:

- increase in EOLC service in the community (number of nursing visits, shift nursing hours, PSW hours for EOLC, out-patient visits)
- enhanced and increased access to EOL health care services
- increased number of EOLC clients served in the home.
- decreased % of deaths in hospital
- increased % of deaths in the home (expected deaths)
- increased access to vital health care services at home

20. Can you provide an example based on your experience to illustrate a key impact of the Team? Can you share with me any cases that stand out in your mind as being particularly illustrative of the benefits associated with the Team?

Additional Comments

Do you have any additional/final comments you'd like to make about the Team?

Results of the Referral and Service Tracking

Note: Percentages may not sum to 100% due to missing data.

REFERRALS	Number
Number of clients of referred: (December 18, 2008 – March 31, 2009)	78
Referrals per month:	
December 2008	5
January 2009	25
February 2009	21
March 2009	27
Number of clients seen by the team:	75
Number of clients assessed:	68
Reasons why clients were not seen by the team/ assessed:	
<ul style="list-style-type: none"> • Client died prior to visit (1) • Client was admitted to hospital (2) 	
Number of Client consults: (Home visits, clinic visits, case reviews at team rounds)	190

REFERRAL SOURCES (N=78)	Percentage (#)
Community Care Access Centre	39.7% (31)
Family Physician	21.8% (17)
Specialist	19.2% (15)
Community Nurses	11.5% (9)
Hospital/ Emergency Department	5.1% (4)
London Regional Cancer Program	2.6% (2)

CLIENT POPULATION (N = 78)	Total (N= 78)
Age (at time of referral):	
Under 40 years	1.3% (1)
41-60 years	28.2% (22)
61-70 years	25.6 % (20)
71-80 years	32.1% (25)
Over 81 years	10.6% (9)
Average (+/-)	67.5 (12.4) years
Range	25 – 95 years
Gender:	
Female	42.3% (33)
Male	57.7% (45)
Place of Residence:	
Own home	100% (78)
Long-term care/ retirement home	0
Availability of a Caregiver:	
Yes	98.7% (77)
No	1.3% (1)
Diagnosis (at time of assessment):	
Cancer ¹⁶	85.9% (671)
Asbestosis/ Chronic Obstructive Pulmonary Disorder/ Pneumonia	3.8% (3)
Congestive Heart Failure	2.6% (2)
Amyotrophic lateral sclerosis	1.3% (1)
Unknown	6.4% (5)
Major Presenting problems:	
Pain	52.8% (38)
Physical symptoms (cough, edema, nausea, bowel issues, chemo side effects, shortness of breath)	33.3% (26)
Psychological symptoms (anxiety, agitation, depression, confusion)	24.4% (19)
Maintenance visit	2.6% (2)
PPS Score (at time of first assessment):	
Average	60%
PPS Scores: 10%	1.3% (1)

¹⁶ Lung cancer: N = 20; 25.6%; GI (esophagus, stomach, bowel, rectum N = 8; 10.3%; Leukemia/ Lymphoma (Hodgkin's & Non-Hodgkin's): N = 6, 7.7%; all others types of cancer (breast, prostate, cervix, ovary, endometrium, brain, gall bladder, liver, kidney, palate, pancreas, pharynx) occur in less than 5 (6.4%) clients each.

CLIENT POPULATION (N = 78)	Total (N= 78)
20%	1.3% (1)
30%	2.6% (2)
40%	10.3% (8)
50%	16.7% (13)
60%	19.2% (15)
70%	19.2% (15)
80%	15.4% (12)
90%	2.6% (2)
100%	1.3% (1)

Service/ Care Provision	Total (N = 75)
Time from Referral to First Contact (N = 61):	
Same day	47.5% (29)
1 – 7 days (1 week)	26.2% (16)
8 – 14 days (2 weeks)	11.5% (7)
15-31 days (3-4 weeks)	11.5% (7)
Greater than 1 month	3.3% (2)
Time required to complete assessment:	
10 minutes	20.0% (15)
30 minutes	26.7% (17)
45 minutes	2.6% (2)
60 minutes	20.0% (26)
Average (+/-)	38.5 (20.1) minutes
Range	10 - 60 minutes
Assessment Location:	
Clinic	36.0% (27)
Home	26.7% (20)
Emergency Department	1.3% (1)
Rounds	20.0% (15)
Health professionals involved in case:	
Team Physician	74.7%(56)
Team Coordinator	41.3% (31)
RN/ RPN	76.0% (57)
Social Worker	20.0 % (15)
Case Manager	30.7% (23)
Other Physicians	2.7% (2)
Model of Care employed:	
Shared Care	64.0% (48)
Primary Care	18.7% (14)
Other	4.0% (3)
	40.0% (30)

Service/ Care Provision	Total (N = 75)
Treatment Recommendations:	
Medication (new, change, adjustment)	
Nursing – monitor, increase visits	16.0% (12)
Equipment-related (CADD pump, oxygen, Spenco mattress pad)	6.7% (5)
Diagnostic testing (blood work/ x-rays)	4.0% (3)
Catheter/ Feeding tube	4.0% (3)
Symptom Response Kit	2.7% (2)
Other (education, emotional support, EOL care plan)	12.0% (9)
Referrals to other health professionals/ services:	
Referral to family (6) and palliative care physicians (2)	10.7% (8)
Referral to social worker	8.0% (6)
Occupational Therapist	1.3% (1)
Physiotherapist	2.7% (2)
Neighbourlink	1.3% (1)
ER Avoidance (Intervention that avoided an ER visit):	25% (19)
Number of follow-up visits per client:	
Number of clients with more than one visit	41.3% (31)
Average (+/-) number of follow-up visits	2.2 (1.2)
Range	0 - 7
Number of direct care visits per client:	
Number of clients with a direct care visit (all had one visit)	5.3% (4)
Total number of visits (assessment, follow-up, direct care) per client:	
Average (+/-)	2.2 (1.4)
Range	1 - 7
Number of 'Pages' to Core Team Members	19
Time from initial visit/ assessment to report distribution (N = 26):	
Same day	23.1% (6)
1 - 5 days	38.5% (12)
7 – 14 days	15.4% (4)
More than 20 days	15.4% (4)
Report distributed to:	
Physician	14.7% (11)
Client	0
Service Provider Agency	48.0% (36)
CCAC	97.3% (73)
Specialist	1.3% (1)

Service/ Care Provision	Total (N = 75)
Number of clients discharged from service:	0 ¹⁷
Length of client stay on service (time from date of referral to discharge date):	Not applicable
Number clients that have died:	33.3% (26)
Place of death: (N = 26)	
Home	65.4% (17)
Hospital	34.6% (9)

¹⁷ Only those clients who have died are now considered “off service”; all other clients (N = 52) remain on service.

Results of the Interviews with Caregivers

N = 15

What is your relationship to the client?

40.0% (6)	Spouse/partner
26.7% (4)	Child
26.7% (4)	Sibling
6.7% (1)	Parent

Status:

Yes responses	
73.3% (11)	Is your care receiver still at home?
13.3% (2)	Care receiver is in hospital
13.3% (2)	Care receiver has died

Overall, how satisfied were you with your first visit with the team? I'm going to read out some words that describe different levels of satisfaction and I'd like you to select the one that best describes how satisfied you were with your first visit with the Team.

Extremely dissatisfied	Very dissatisfied	Somewhat dissatisfied	Not satisfied nor dissatisfied	Somewhat satisfied	Very satisfied	Extremely satisfied
0	0	0	0	0	33.3% (5)	66.7% (10)

How satisfied were you with the amount of time that you waited to see the team, that is, the timeliness in which you saw them?

Extremely dissatisfied	Very dissatisfied	Somewhat dissatisfied	Not satisfied nor dissatisfied	Somewhat satisfied	Very satisfied	Extremely satisfied
0	0	0	6.7% (1)	6.7% (1)	20.0% (3)	66.7% (10)

How satisfied were you with the way your loved one's care was coordinated with all the other health professionals that were involved, such as your family physician, visiting nurses, or the hospital? (Prompt: For example, all the other services and supports outlined in the care plan were in place, for example, the pharmacy was informed of drug changes, the visiting nurse provided necessary equipment)

Extremely dissatisfied	Very dissatisfied	Somewhat dissatisfied	Not satisfied nor dissatisfied	Somewhat satisfied	Very satisfied	Extremely satisfied
0	0	0	6.7% (1)	0	40.0% (6)	53.3% (8)

How satisfied were you with the way the team responded to your questions and concerns?

Extremely dissatisfied	Very dissatisfied	Somewhat dissatisfied	Not satisfied nor dissatisfied	Somewhat satisfied	Very satisfied	Extremely satisfied
0	0	0	0	0	46.7% (7)	46.7% (7)

Note: Percentages do not sum to 100% due to missing responses.

How satisfied were you the level of communication among all of the different care providers or services involved in your loved one's care? (Prompt: did everyone know what they needed to do as part of the care plan that was in place?)

Extremely dissatisfied	Very dissatisfied	Somewhat dissatisfied	Not satisfied nor dissatisfied	Somewhat satisfied	Very satisfied	Extremely satisfied
0	0	0	0	0	26.7% (4)	66.7% (10)

Note: Percentages do not sum to 100% due to missing responses.

How satisfied are you that you have had enough information with which to make treatment or care decisions?

Extremely dissatisfied	Very dissatisfied	Somewhat dissatisfied	Not satisfied nor dissatisfied	Somewhat satisfied	Very satisfied	Extremely satisfied
0	0	0	6.7% (1)	6.7% (1)	33.3% (5)	46.7% (7)

Note: Percentages do not sum to 100% due to missing responses.

FOR CLIENTS WHO HAVE DIED: (N=2)

Did your loved one die:

50.0% (1)	at home?
50.0% (1)	in hospital?
0	in long-term care?
0	hospice?

Was this the plan?

100% (2)	Yes
0	No
0	Not sure

Do you have any comments you'd like to make about this? (Prompts: What did you think about this? Was this the location you wanted?)

- *This was her wish. We were given the assistance we needed so we could keep her at home as comfortable as possible.*
- *This was what we all wanted. It was perfect. He died peacefully.*

How satisfied were you with the way in which your loved one's care was managed at the end of his/her life?

Extremely dissatisfied	Very dissatisfied	Somewhat dissatisfied	Not satisfied nor dissatisfied	Somewhat satisfied	Very satisfied	Extremely satisfied
0	0	0	0	0	0	100% (2)

FOR CLIENTS WHO HAVE NOT DIED:

How satisfied are you with the way that you and your loved one have been prepared for what will happen next? (N= 13)

Extremely dissatisfied	Very dissatisfied	Somewhat dissatisfied	Not satisfied nor dissatisfied	Somewhat satisfied	Very satisfied	Extremely satisfied
0	0	0	0	7.6% (1)	46.1% (6)	46.1% (6)

Could you please tell me about at least one thing that you really liked about the team and service or care they provided?

- *They are very compassionate, honest and caring and have really helped us.*
- *It has been first class. It was a Friday and our nurse came and was not at all happy with him, his symptoms. Within 4 hours a team member was at the house. They called [Team physician] and his medication was changed right away and this controlled his pain right away.*
- *We see [Team physician] once a week and the nurse comes in weekly. That's our team.*
- *I'm really satisfied with the doctor.*
- *They are good at sitting down and explaining things to me. What I should expect and what to do if something happens. What to look for, which is good because I'm not a nurse.*
- *They've been more helpful than any other doctors or services so far.*
- *Awesome care. The health system did not fail us. He was treated like a king and that's what he deserved. It was perfect. I liked that [Team physician] came to the house. That's a great idea.*
- *It has been really helpful to me to deal with issues. I'm just a phone call away. I can call them and they are available right away.*
- *We had a family meeting today with all my brothers and sisters there. They didn't make us feel rushed. There was so much compassion. You could tell they cared. I don't think we'd get this anywhere else. We are so lucky to have this in Sarnia.*
- *Accessibility - easy to access help when needed.*
- *Very informative, straightforward. They were upfront and honest.*
- *Second to none. [Team physician] has gone beyond the call of duty. [Team physician] has made my husband comfortable. Things had fallen through the cracks before we saw [Team physician] and he fixed things.*
- *Surprising to me that it works so well. I'm from [another country] and they have anything as comprehensive as this.*
- *No complaints everything has been wonderful.*
- *Friendliness*

Was there anything that you didn't like about the team and the service or care they provided?

- *There are various nurses that come in and there is no consistency in who comes in. It would benefit the patient if the same nurse who was familiar with the patient came in all the time.*
- *The visiting nurses did not come on time. They were always late. My father is the kind of person that wouldn't do anything until they go there. He wouldn't eat or go to the bathroom.*
- *We had some problems with the PSW from [service provider agency] - quality of care issues, she didn't show up on time and sometimes she didn't show up at all.*
- *Coordinate the visits better. I don't live with my [sibling], so I try to come over when people are here to take care of him and sometimes they call and say they'll be here at 10am and others call to say they'll be here at 2pm. Well I can't always be there. I have a home of my own to look after and he really needs me because he doesn't always comprehend what they're saying.*

Do you have any suggestions for improving the services or care provided by the team or for improving palliative care/ end-of-life care in general?

- *I would like to see consistency in the nurses coming in. And additional support for my mother - More than 4 hours a week is needed.*
- *None*
- *The health system is in a real mess. [Care receiver] drives 130 miles to London, they spend 3 minutes with him and aren't very helpful.*
- *The visiting nurses should come on time.*
- *Needs to be clearer who to call when. For example, when to call the case manager and when to call the nurse directly. When we received the pain pump we weren't sure who to call about it. They may have told me but I'm under so much stress, so they may have told me what to do but it's so overwhelming. There needs to be better communication between LRCC and local care providers. They say if we run into a problem to go to Emerg but that's not always helpful.*
- *Coordinate the visits better so that everyone that comes on that day comes around the same time.*

Do you have any final or additional comments that you'd like to make about the team or the care you have received?

- *Care has been exceptional. They have been very honest with us, helping us to prepare. The whole experience has been wonderful.*
- *Long may it continue! When somebody says they'll get back to me, they do it and they do it in short order.*
- *It's a wonderful service - we are grateful that the service is available. [Team physician] is very informed about pain management and that's what we're after.*
- *[Team physician] has been awesome. He has really listened to us.*
- *All are really good to [care receiver]. They've told me call if I have any questions so it's nice and comforting for me to have the number. I know if I called them anyone of them would come out here.*
- *So far I have been very happy with the care. It's very unique that they have this service.*
- *Everything is working well with us.*
- *If everyone has just a bit of the compassion that [Team physician] has, the world would be a better place. There hasn't been anyone hasn't been wonderful and gone beyond the call of duty.*
- *I really liked the way they worked.*
- *The nurses are all good.*
- *Overall, we're very satisfied. Everything is going great. We have everything we need at this time.*

Results of the Key Stakeholder Survey

N = 13

In the past three months, how much contact have you had with members of the team in regards to clients you are dealing with who require palliative care?

0	In regards to more than 21 clients
38.5% (5)	In regards to 11 – 20 clients
38.5% (5)	In regards to 6 – 10 clients
23.1% (3)	In regards to 1 – 5 clients
0	Not at all

Overall, how would rate the work of the Team?

poor	fair	good	very good	excellent
0	0	46.2% (6)	23.1% (3)	30.8% (4)

How satisfied are you with the following elements of the team? (5-point rating scale: 1 = not all satisfied; 5 = extremely satisfied)

N =12	Avg (+/-)	Range
Timeliness of access to assessment	4.2 (.72)	3 – 5
Follow-up	4.1 (.58)	3 – 5
Direct provision of care	4.1 (.79)	3 – 5
Quality of assessment	4.3 (.62)	3 – 5
Treatment recommendations/ planning	4.3 (.65)	3 – 5
Availability of team members for informal consultation (questions, follow-up)	4.3 (.65)	3 – 5
Communication between the team and other care providers	4.0 (.95)	3 – 5
Integration of care across care providers	3.8 (.72)	3 – 5
Integration of care across health sectors (community – hospital)	3.3 (.87)	3 – 5
Care coordination	3.8 (.84)	3 – 5
Client/ family readiness for death	4.1 (.67)	3 – 5

Do you have any suggestions for how the team can improve the services it provides to clients, caregivers, and other care providers or how it can better support your efforts to assess and manage clients requiring palliative/ end-of-life care?

- *Need to get names of patients to be discussed as soon as possible to get up to date info on them. I know this is being addressed.*
- *Increased communication in writing from all parties.*
- *I believe the team will continue to evolve as we increase our knowledge and comfort providing the service. Also other service providers will increase their referrals to the team. 5. It is too soon to evaluate the results as the number of clients/families remain small. However I used the medical team for one client and was very satisfied.*
- *Primary nurses need to have reports on client condition, prognosis. We mostly try to do a great job working in the dark.*
- *have already decrease # of trans to ER's for assess. Continue to educate and f/u with providers in home*
- *Hospital representation on the team. Electronic record Resource nurses sharing with other community nurses Environments and ergonomics appropriate for nurses. Wage parity for community nurses with hospital nurses Increased Physician education to support nurses request for orders to alleviate suffering Team conferences for clients returning to the community*
- *When clients are referred to the team-the primary nurse should do the presenting. At present the resource nurse is expected to gather info and present. Often will have never met patient or if so only once.*
- *Community nurses are often left out of the loop when it comes to the exact diagnosis. This can make it difficult to plan strategically. Community nurses are the last to find out what is going on and the next steps. It would be nice if the nurses could have copies of transcription notes from doctors after an office visit. They do not need to be part of the in-home chart, but would give a more clear picture as to what may have been said in regards to the patient. The community may need to change is entry into practice with palliative clients to a base line of CAPCE for nurses. Each agency will have to develop its own policy for this. Patients are generally more comfortable with a knowledgeable nurse who can also show confidence in practice.*

Impacts

As a result of the team, do you think that the overall quality of palliative/ end-of-life care provided to clients has:

30.8% (4)	Much improved
30.8% (4)	Improved
30.8% (4)	Neither improved nor worsened
0	Worsened
0	Much worsened

Note: Percentages do not sum to 100% due to missing responses.

How would you rate the current level of safety within home environments for palliative/end-of-life care? (5 point rating scale: 1 = not at all safe; 5 = extremely safe) (N = 12)

3.8 (.84)	Average (+/-)
2 – 5	Range

How does this compare with the level of safety within home environments prior to the inception of the Team?

Less safe now 1	2	About the same 3	4	More safe now 5
0	0	61.5% (8)	23.1% (3)	7.7% (1)

Note: Percentages do not sum to 100% due to missing responses.

As a result of the Team, do you think that your use of standardized clinical assessment tools (e.g., ESAS, PPS) has:

0	Much increased
53.8% (7)	Increased
38.5% (5)	Neither increased nor decreased
0	Decreased
0	Much decreased

Note: Percentages do not sum to 100% due to missing responses.

Overall, how would you rate your current ability to manage clients requiring palliative care (within your scope of practice)? (5-point rating scale: 1 = not at all capable; 5 = extremely capable) (N=12)

0	Not applicable
4.4 (.52)	Average (+/-)
4 – 5	Range

How does this compare with your ability to manage clients requiring palliative care (within your scope of practice) prior to the inception of the Team?

I am now less capable 1	2	About the same 3	4	I am now more capable 5
0	0	38.5% (5)	15.4% (2)	38.5% (5)

Note: Percentages do not sum to 100% due to missing responses.

As a result of your involvement with the Team, do you think that the quality of care you provide to clients requiring palliative/ end-of-life care has:

30.8% (4)	Much improved
30.8% (4)	Improved
30.8% (4)	Neither improved nor worsened
0	Worsened
0	Much worsened

Note: Percentages do not sum to 100% due to missing responses.

Are you able to identify any key, or most significant, impacts/ outcomes associated with the Team? These impacts can be client/caregiver, health professional, or health system-related.

7.7% (1)	No
84.6% (11)	<p>Yes, please describe:</p> <ul style="list-style-type: none"> • <i>Prevention of trips to Emerg plus decreasing the emotional burden on families i.e., avoiding and anticipating a crisis well before it happens if possible.</i> • <i>More scope for end of life care at home.</i> • <i>My client was not receiving expert medical recommendations so I called [physician] and she gave me medical orders immediately which we implemented with the result that my client died peacefully at home. The next day she visited the home providing reassurance that they had access to medical staff.</i> • <i>Able to get direction, orders, visits by MD's after hours when normally GP's unavailable. This is a huge benefit to the client as well as the nurse. Avoids ER visits.</i> • <i>decrease in ER assessments, better update to Dr's</i> • <i>The LEAP program seems to have increased nurses' confidence in providing care. The participants of LEAP feel special and have a better understanding of why in the past they were not able to get the orders to support Clients from Physicians. The lead at CCAC advocates for what nurses need to do their job. Each agency has an oxymeter for assessment of patients by the resource team. The collaborative approach at the team meetings increases the resources for problem solving.</i> • <i>Information sharing, effective interdisciplinary communication, learning , care planning have all been enhanced</i> • <i>Decreased ER visits, decreased visits to Palliative Care Unit for Symptom management.</i> • <i>increased education of the health professional</i> • <i>I was able to assist with communication of a client need, for a primary nurse, with a doctor to get what was needed. The primary nurse's scope of practice also increased as a result of the education received through this experience and consultation with the team member.</i> • <i>Better medication management. Better pain and symptom management Decreased emergency room visits.</i>

Note: Percentages do not sum to 100% due to missing responses.

Additional Comments

Do you have any additional comments you would like to make about the Team or the provision of palliative/ end-of-life care in this region?

- *Appreciate very much having 24 access to a palliative Dr. if needed., also a team of specially trained nurses gives the confidence that the assessment of a situation, when needed, will be thorough and consistent.*
- *No as it is early days at this point. I have one concern as I hope that the pager will be active in all areas that I work as my [service provider agency] pager is not and when it doesn't work I have no knowledge that it rang and the sender has no way to know I did not receive the page.*
- *Think this is enormous for allowing clients to die at home in comfort with support.*
- *I believe templates for physician orders would help close the learning curve for physicians as well as give the nurses what they need to provide care to their clients. I think that community nurses should work in the palliative unit or hospice to hone skills and confidence.*
- *Political will and commitment will be a large factor in maintaining and growing the improvements to palliative care that have been achieved from the introduction of the PCT*
- *Thanks to the team-a patient was able to access a palliative doctor-so I realized that end-of-life care has certainly improved with the formation and implementation of the team.*
- *I would love to see the team continued.*
- *Excellent Resource! We now provide a higher standard of care to palliative and end of life clients and their caregivers.*

Demographic Information

Which of the following best describes your discipline/profession?

7.7% (1)	Physician
53.8% (7)	Registered Nurse
0	Registered Practical Nurse
0	Personal Support Worker
0	Nurse Practitioner
30.8% (4)	Case Manager
7.7% (1)	Agency nursing supervisor
0	Pharmacist
0	Volunteer coordinator
0	Pastoral/spiritual care

How many years have you been in employed in your current profession? (N = 12)

21.9 (13.4) years	Average (+/-)
2 – 38 years	Range

What percentage of the clients that you work with require palliative/end-of-life care?

15.4% (2)	Not applicable
0	None
15.4% (2)	Less than 25%
7.7% (1)	26% - 50%
30.8% (4)	51% - 75%
23.1% (3)	Over 75%