

**Erie St. Clair End-of-Life Care Network
Chatham Kent
Palliative Care Consultation Team (PCCT)**

Final Evaluation Report
Chatham Kent PCCT

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**For:
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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 Palliative Care Education Program
CCAC	Community Care Access Centre
CPR	Cardiopulmonary Resuscitation
ED/ ER	Emergency Department/ Emergency Room
EOL	End of Life
ESC EOLCN	Erie St. Clair End-of-Life Care Network
LEAP	Learning Essential Approaches to Palliative and End-of-Life Care
NP	Nurse Practitioner
OT	Occupational Therapist
PCCT	Palliative Care Consultation Team
PPSMC	Palliative Pain and Symptom Management Consultant
PT	Physiotherapist
RN/ RPN	Registered Nurse/ Registered Practical Nurse

INTRODUCTION

A PCCT was established in Sarnia Lambton in January 2009; in January 2010 a PCCT was launched in Chatham Kent. Although the general concept of the team is consistent across both counties, variation exists in terms of current levels of funded service provision, available expertise, and population and health service statistics (e.g., client demographics, health care utilization). The PCCT is a multidisciplinary resource team for palliative and end-of-life care. The core team (internal CCAC providers) consists of an expert Nurse Practitioner, Social Worker, spiritual care provider, administrative assistant, rehabilitation professional (OT or PT), as well as access to palliative care physician expertise, and is supported by secondary level experts (experienced palliative care nurses) from nursing service provider agencies (referred to as Resource Nurses, who have additional training in palliative care). The team provides access to specialist level hospice palliative care expertise. The local Palliative Pain and Symptom Management Consultant provides consultation support to the team. The team aims to provide integrated and coordinated end-of-life care and to provide enhanced palliative and end-of-life care in this region.

This report describes the methods and results of the second year evaluation of the Chatham Kent PCCT. The evaluation of the Sarnia Lambton PCCT is presented in a separate report.

EVALUATION METHODS

Evaluation Focusing: An evaluation advisory committee was established to support this evaluation; members acted as advisors, providing advice and feedback on the development and implementation of the evaluation.

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

- i) describe the services provided by the PCCT and the population served
- ii) identify impacts associated with the PCCT to date
- iii) describe the ongoing process of developing and implementing the PCCT.

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 March 1, 2010 to September 30, 2010.
- **Caregiver Satisfaction Interviews** were conducted with 11 family caregivers of individuals receiving care from the PCCT.
- **Key Stakeholder Survey** completed by 21 individuals representing the provider agencies, CCAC, hospice and hospital.
- **Key Stakeholders Interviews** were conducted with 7 individuals to obtain in-depth information about the effectiveness and impacts of the PCCT.
- **Focus Group and Individual Interviews with representatives of the PCCT** were conducted with a 15 individuals to obtain in-depth information about the development and implementation of the team.

This evaluation study was approved by the Research Ethics Board, University of Western Ontario.

RESULTS: Key Findings

Objective 1: Describe the services provided by the PCCT and the population served

Referrals: A total of 143 clients were referred to the PCCT between March 1, 2010 and September 30, 2010; 64 clients remained on the team's active caseload; 79% had been discharged from service, 66% of whom had died. The average length of stay on service was 42 days, with a range of 0 – 170 days. The number of referrals to the team per month ranged from 9 to 30, with an average of 20(+/-3.9) referrals per month; there has been a decline in the number of referrals to the team over the previous four months. The average age of clients was 69 years; there was an equal distribution of women and men referred to the team. Over half of the clients (58%) lived with their spouse or life partner. Cancer was the most common diagnosis (78%).

Service Provision: As would be expected, end-of-life care was the primary service category (78%) for clients at the time of referral to the team, followed by long-term support (10%). In total there were 699 client interactions with core team members, with 101 different clients; the average number of interactions per client was 7 (range = 1 – 45). Over half of these contacts were face-to-face visits (58%); 43% were telephone contacts. The highest percentage of interactions involved the Nurse Practitioner (33%) and Chaplain (28%). Over half of the interactions with a team member (51%) prevented an Emergency Department visit, that is, if the team had not been involved the client would have gone to the Emergency Department to access medical attention; this involved 36% (N = 51) of clients, with an average of four (+/- 3.6) Emergency Department diversion interactions per client.

Objective 2: Identify impacts associated with the PCCT to date

Across all of the sources of information for this evaluation, the following impacts associated with the PCCT were identified:

Client and Caregiver-Related Impacts:

- Client and caregiver satisfaction (timeliness, care coordination, the amount of information with which to make treatment or care decisions, and preparation for what will happen next).
- Client and caregiver satisfaction with the provision of emotional support, communication with the team, and coordination of care.
- Increased access to expert care
- Timely access to care
- Increased access to interprofessional care
- Increased opportunity to remain at home for care
- Increased support for dying in preferred location
- Reduced crises
- Increased client and caregiver satisfaction

Health Professional-Related Impacts

- Easier and timelier access to expert advice for primary nurses
- Increased opportunities for capacity building
- Increased job satisfaction
- Increased likelihood of nursing retention
- Increasing nursing confidence with ability to provide optimal palliative care

Health System Impacts

- Improved care coordination
- Improved quality of care
- Increased collaboration and congeniality among provider agencies
- Better use of existing resources
- Increased client access to support services
- Increase access to care for clients who do not have a family physician
- More timely response to palliative crises
- Increased number of home deaths (concordance between location of death and stated preference)
- Hospital avoidance/ reduced number of Emergency Department visits
- More appropriate use of Emergency Department and Palliative Care Unit
- Hospitalization delay
- Shorter length of hospital stay

Objective 3: Describe the process of developing and implementing the PCCT

Selection of Resource Nurses:

- **CAPCE Training a Mandatory Requirement:** There was general consensus among those interviewed that CAPCE training should be a mandatory requirement for Resources Nurses. It also suggested that the role be assumed by nurses with experience in palliative care, not novice nurses.
- **RN vs. RPN Requirements:** Although it was noted that RPNs are unable, due to the scope of their practice, to fulfill some direct care requirements, they have been nonetheless valued members of the team. It was suggested there be a balance of RNs and RPNs on the team.
- **On-call Responsibilities:** Generally it was noted that the Resource Nurses have been able to manage on-call responsibilities with minimal disruption to their regular workload.
- **Capacity Building:** Team rounds were identified as significant opportunity for capacity building; suggestions for further capacity building included opportunities to complete the LEAP training and education delivered via the Ontario Telemedicine Network, and to remain updated on new advances in pain and symptom management and alternative care strategies.

A number of factors were identified as **facilitating** the development and implementation of the PCCT:

- Capacity building for community nurses
- Biweekly team rounds
- Proactive approach to challenges
- Learnings from the Sarnia Lambton Team
- Collaboration among provider agencies

- Collaboration among partners
- Team fills a known gap in service
- Availability of the Nurse Practitioner
- Support from CCAC
- Management support from provider agencies
- Selection of appropriate people for the team

Challenges to the development and implementation of the PCCT included:

- Communication regarding on-call
- Communication with primary nurses
- Information sharing with acute care
- Limited access to Nurse Practitioner on weekends
- Gaps at intake level on weekends
- Inconsistent understanding of CCAC policy on provision of nursing support
- Potential for Resource Nurse burnout
- Resistance from some family physicians
- Lack of a residential hospice in Chatham Kent
- Limited palliative care beds in acute care
- Nursing shortages

Suggestions for improvements, sustainability and further development

- Increase access to Nurse Practitioners on weekends
- Secure sustainable funding support
- Use physician resources wisely
- Succession plan for Resource Nurses
- Increase educational opportunities for primary nurses
- Increase capacity building opportunities for family physicians
- Promote the team to family physicians
- Develop a central master calendar for each client
- Increase opportunities to interface with Regional Cancer Centres

General suggestions for improvements to palliative care

- Increase general public awareness of palliative care
- Establish a Residential Hospice in Chatham Kent
- Establish a palliative care resource/ link within acute care

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

- Within a relatively short period of time the PCCT has achieved many of its stated objectives, particularly those related to access to end-of-life care services (increased, enhanced, timeliness), client and caregiver satisfaction with care coordination, communication, and care provided at end of life. Generally, most of the benchmarks for the evaluation (90% of clients and stakeholders being satisfied with key aspects of the team) were attained. The exception to this being that less than 90% of care providers (62%) reported that they were now more capable of providing palliative and end-of-life care and only 38% of care providers reporting that safety in the home environment has improved as a result of the team. This is primarily a function of existing high level of safety within homes (average rating 4.0 out of 5)

and capability of care providers (average rating 4.5). Nonetheless, important care provider and health system impacts were identified. There is anecdotal evidence that the PCCT has had an impact on reducing the number of unnecessary Emergency Department visits and shortening the length of hospital stay for PCCT clients as the team is available to support the client within the community. Moreover, there is some anecdotal evidence that the transition of care between acute care and the community is better integrated and coordinated. The current model of care in which Resource Nurses are supplied by the community service provider agencies requires the willingness and commitment of community partners to put aside issues of territory and control to work cohesively as a group. There is evidence that the nurses and agencies involved with the team have been able to do this and in doing so have strengthened relationships and communication among the provider agencies. All of these early outcomes represent significant progress in filling palliative care service gaps that are well documented within the literature¹ and that prompted the development of the team in this region.

- A significant aspect of the team, as identified by caregivers and key informants, is the use of an interprofessional model of care to address all of the domains of palliative care and to impact quality of life. Caregivers were especially grateful for the opportunity to address their emotional and spiritual needs through access to a social worker, chaplain, and music therapist. Emotional and spiritual care were identified as significant value added, having significant impacts on quality of life for both caregivers and clients. Almost all of the caregivers interviewed spoke about how critical these services were to their ability to manage a home death, as evidenced by the number who noted they “*couldn’t have done it without*” these supports. Consistent with this, there is much support in the literature for an interprofessional approach to improve the quality of palliative care.²
- Although there has been some move towards improving integration and care coordination across sectors, there were suggestions that more could be done to facilitate the transition of clients from the community to hospital, with for example, the introduction of a specific palliative care resource person within the hospital to facilitate communication with team members at the time of admission regarding the clients current status and treatment plan. Other strategies of facilitating this type of communication should be investigated further. As an example, health passports or records, which summarize treatment goals and plans, including current medications and criteria for calling 911 (i.e., when emergent care is necessary) and which are maintained with clients and accompany them to hospital, have been used successfully in the management of chronic diseases as a cost effective method of facilitating communication across sectors.
- The team has been successful in meeting the end-of-life care needs of clients within the community; case examples provided by team members as well as the reports of caregivers provide evidence of practice improvements. Some of the challenges experienced to date

¹ 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.

² Bliss, J., Cowley, S., & White, A. (2000). Interprofessional working in palliative care in the community: a review of the literature. *Interprofessional Care*, 14 (3), 281-290.

Higginson, I.J., et al. (2003). Is there evidence that palliative care teams alter end-of-life experiences of patients and their caregivers? *Journal of Pain and Symptom Management*. 25 (2), 150-168.

with the implementation of the team are inherent in the implementation of any new service, particularly challenges related to communication and resistance among some care providers. Some of these identified challenges are currently being addressed by team leadership. Other identified challenges are not within the teams' scope to resolve (e.g., lack of a Residential Hospice, limited palliative care beds in acute care, nursing shortages), creative and innovative strategies will be required to minimize their impacts.

- One of the key elements of the Chatham Kent PCCT's success is that it builds upon the success and lessons learned by the Sarnia Lambton PCCT. As the Chatham Kent team progresses through the normal stages of program development, the Sarnia Lambton team can be a model for ongoing development and sustainability. Suggestions made for improving the team have the potential for further capacity building and sustainability. These suggestions are consistent with the published literature, which has identified the need for capacity building among primary care physicians³ as well as for interprofessional education in palliative care.⁴ Although "passion" for palliative care has been identified as an important criterion for selection of the Resource Nurses, it should not supersede expertise and experience in importance; 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.⁵ Continued support of palliative care and end-of-life education as provided through the Erie St. Clair End-of-Life Care Network Education Blueprint is one strategy for ongoing capacity building across sectors in this region. Further development, implementation, and expansion of the PCCT has the potential to significantly impact the quality of hospice palliative/ end-of-life care in this region. With continued success the PCCT has the potential to be a model for other regions in the province; lessons learned in developing and implementing the PCCT in Chatham Kent as well as Sarnia-Lambton can be used to inform the development of PCCTs in other areas of the province.

Limitations: Data related to impacts of the team on the health care system is largely anecdotal. Empirical evidence based on hospital data (e.g., ED readmission rates, reduced hospital admissions, reduced length of hospital stay) among PCCT clients and a comparison group (of clients not seen by PCCT) would provide stronger evidence of the PCCT's ability to manage care effectively within the community. It is acknowledged that availability of this data related specifically to palliative care is limited. Some of the data that was initially to be included as part of the description of the client population served by the team and the services provided by the team were not available either because they are not tracked and/or not easily accessible. Although the number of caregivers of PCCT clients recruited for this evaluation was lower than expected it is acknowledged that, by virtue of the end-of-life situation, this is a difficult population to access. However despite this, it was apparent that saturation was achieved (no or minimal new information was generated from the last interviews conducted) and consistent themes were identified across interview participants.

³ 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.

⁴ Koffman, J., & Higginson, I.J. (2005). Assessing the effectiveness and acceptability of interprofessional palliative care education. *Journal of Palliative Care*, 21 (4), 262-269.

McKee, N., Goodridge, D., Remillard, F., & D'Eon, M. (2010). Interprofessional palliative care problem-based learning: Evaluation of a pilot module as a teaching and learning method. *Journal of Interprofessional Care*, 24, 194.

⁵ 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.

1.0 Introduction

In February 2008, the Erie St. Clair End-of-Life Care Network (ESC EOLCN)⁶ submitted an application for funding from the Erie St. Clair (ESC) Local Health Integration Network (LHIN) through the Aging at Home Strategy to develop and implement a Palliative Care Consultation Team (PCCT). Notification of funding for year one (\$572,000) was received in July 2008. Year one funding was flowed through the North Lambton Community Health Centre; operationalization of the team was through CCAC. The ESC EOLCN was to serve in an advisory role. Year one funding was for a team in one county – Sarnia Lambton. In November 2009 the ESC LHIN approved the Consolidated Chatham-Kent/Sarnia Lambton Palliative Care Consultation Team project and provided annualized base funding of \$1,298,295.

This team was one of several initiatives aimed at creating and supporting an integrated Hospice Palliative Care system in this region. 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. This would serve to ensure that Ontarians have access to consistent, high quality end-of-life care that can relieve suffering and improve quality of life.

The PCCT is a multidisciplinary resource team for palliative and end-of-life care. The core team (internal CCAC providers) consists of an expert Nurse Practitioner, Social Workers, spiritual care providers, administrative assistant, rehabilitation professional (OT or PT), as well as a palliative care physician, (not funded through this initiative) and is supported by secondary level experts (experienced palliative care nurses) from nursing service provider agencies (referred to as Resource Nurses, who have additional training in palliative care). The local Palliative Pain and Symptom Management Consultant provides consultation support to the team. The team provides timely access to consultation support for primary care providers with the expectation that a shared care model of care will be developed. The PCCT provides comprehensive assessment and care planning, consultation reports to Primary Care providers, capacity building through mentoring, patient and family education and counselling (e.g., Advance Care Planning, processes involved in home deaths), and follow-up and direct care provision, as needed across sectors (clients are seen in their home, a clinic setting or health care settings as relevant). Additional services not currently provided by the home care system, such as in-home laboratory services, are provided by the team as needed. Other services, such as extra social work visits, and extended equipment rental augment service delivery currently provided by the home care system. Coordinated care planning and on-going education (capacity building) is facilitated by regular clinical rounds (bi-monthly). On-call access to the team is available 24/7, by accessing the Resource Nurses, who then access other team resources as needed.

⁶ The EOLCN serves in an advisory capacity and is not responsible for the day-to-day operations of the team; the ESC CCAC has operational responsibility for the team.

Clients referred to the team, are those who require specialist level expertise.⁷ Priority is given to clients in crisis, at risk of accessing acute system resources (e.g., hospital admission, emergency department visit), or needing more services than currently available.

The main objectives (goals) of the PCCT are to:

- increase access to specialized palliative care for clients in the community, including expertise in symptom management, disease progression/ prognosis, and all domains of issues associated with illnesses and bereavement.
- make it possible for clients to die with dignity at home, if that is their location of choice.
- decrease dependence on hospital through: emergency department avoidance, admission avoidance, reduced Alternative Level of Care (ALC) days, and reduced hospital length of stay.
- improve patient flow/ coordination/ integration across the care continuum.

An overview of the program and anticipated outcomes are summarized in the program logic model presented in Appendix A.

A PCCT was established in Sarnia Lambton in January 2009; in January 2010 a PCCT was launched in Chatham Kent. Although the general concept of the team is consistent across both counties, variation exists in terms of current levels of funded service provision, available expertise, and population and health service statistics (e.g., client demographics, health care utilization).

An evaluation of the initial development and implementation of the Sarnia Lambton PCCT was conducted in early 2009.⁸ The results of the evaluation indicated that the team was making significant headway in meeting its goals; the team was well received by clients and caregivers and early impacts on the use of health system resources were identified. Although the team built on existing capacity for palliative care within the community, it was suggested that additional supports and resources (continuing education, team building, promotion) could further support the efforts of the PCCT.

This report describes the methods and results of the evaluation of the Chatham Kent PCCT. The evaluation of the Sarnia Lambton PCCT is presented in a separate report.

2.0 Evaluation Methods

2.1 Evaluation Focusing

The evaluation objectives and methods were initially discussed in a meeting on April 7, 2010, with a number of key stakeholders: Beth Lambie, Director, ESC EOLCN; Andrew Ward, Senior Manager, Client Services, ESC CCAC; Cindy Stokes, Client Services Manager, ESC CCAC;

⁷ Three questions guide eligibility: Would you be surprised if this client died in the next six months? Does this client have symptoms and/or support needs? Do these symptoms and/or support needs require specialist level interventions?

⁸ Hillier, L.M. (April 30, 2009). Erie St. Clair End-of-Life Care Network Palliative Consultation Team. Final Evaluation Report. London, ON: Author.

Jennifer Allison, Client Services Manager, ESC CCAC; Vivianne DeWitt, Coordinator of Oncology, Palliative & Supportive Care, Chatham-Kent Health Alliance; Julie Johnston, Coordinator, Palliative Pain and Symptom Management Consultation Program; Lynn Chappel, Regional Vice President (Interim), Windsor Regional Cancer Centre; Paul Brown, Account Manager, ESC LHIN, Pete Crvenkovski, Manager, Quality and Utilization, ESC LHIN, and Jamie Lesparence, ESC LHIN.

To develop and implement the evaluation framework, an advisory committee was established consisting of the following members:

- Ann Brignell, Palliative Pain and Symptom Management Consultant, Kent and Lambton Counties
- Dr. Colin Bryan, Physician, Chatham Kent Palliative Care Consultation Team
- Vivianne DeWitte, Coordinator of Oncology, Palliative & Supportive Care, Chatham-Kent Health Alliance
- Barb Frayne, Registered Nurse, St. Joseph's Hospice, Sarnia
- Julie Johnston, Coordinator, Palliative Pain and Symptom Management Consultation Program
- Beth Lambie, Director, ESC EOLCN
- Dr. Glen Maddison, Physician, Sarnia Lambton Palliative Care Consultation Team
- Cindy Stokes, Client Services Manager, ESC Community Care Access Centre

Members of this advisory committee 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: PCCT members, consumers (clients, caregivers), Community Support Services (CSS) agencies, CCAC and Community Service Provider Agencies, Community Health Centres, (CHC), primary care providers, hospitals, cancer centers and the ESC LHIN.

2.2 Evaluation Objectives

The identified objectives of the evaluation were to:

iv) describe the services provided by the PCCT and the population served to date⁹:

- Who made up the PCCT (numbers/ disciplines)?
- How many clients were referred to the PCCT?
- How many clients have been assessed?
- Who were the patients being assessed? (age, gender, place of residence, diagnosis, location/sector at time of assessment)
- What were the activities of the team (assessment, follow-up, direct care, other activities)?
- How many members of the team were involved with each client?
- Which team members were involved with each client?

⁹ Since inception of the team to September 30, 2010.

- How many visits did each professional (Nurse Practitioner, Social Worker, Chaplain, Occupational Therapist, Physicians and any other professionals) have with clients?
- How many individual clients are on each professionals' (Nurse Practitioner, Social Worker, Chaplain, Occupational Therapist, Physicians and any other professionals) case load? 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 with primary care, consultation only, consultation and follow-up)?
- Who received the consultation report (primary care, client, Community Service Provider agency, CCAC, acute care)?
- Where did clients die (home/ hospital/ long-term care home/ residential hospice)?

v) identify impacts associated with the PCCT to date:

Health System impacts:

- What impact does the PCCT have on EOLC service within the community: number of nursing visits, shift nursing hours, Personal Support Workers hours for EOLC, number of EOLC clients served in the home, number of visits to out-patient clinics (palliative care clinics)?
- What impact does the team have on increasing access to EOL health care services?
- What impact does the PCCT have on the number of deaths that occur at home? In hospital? In Residential Hospice?
- What impact does the PCCT have on acute care length of stay (LOS) and number of admissions for clients requiring palliative care?
- What impact did the team have on Emergency Department visits and hospital admissions by clients requiring palliative care?
- What impact did the team have on admission through the Emergency Department vs. direct admissions (for patients requiring admission to hospital)?

Client/ Caregiver-related impacts:

- What impact does the PCCT have on patient/ caregiver satisfaction with:
 - access to assessment, care, and support services?
 - pain and symptom management?
 - psychological/ social/ spiritual support?
 - timeliness of access to assessment, care, and support services?
 - coordination of care across providers and sectors?
 - communication with formal providers (response to their questions and concerns)?
 - communication among formal providers (degree to which each provider involved is informed and aware of that client's 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 PCCT 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 PCCT have on meeting patient/ caregiver preference for place of death (concordance between preference and actual place of death)?

Provider-related impacts:

- What impact does the PCCT have on provider satisfaction with:
 - care integration?
 - communication across providers and sectors?
 - care coordination and care planning for those requiring palliative care?
- What impact does the PCCT have on formal care provider's capacity to manage palliative care/ EOL issues within the community?
- What impact does the PCCT have on the increased use of standardized clinical assessment tools (ESAS, PPS) within the community?
- What impact does the PCCT have on response to assessment scores within targeted ranges?
- What impact does the PCCT have on care planning processes that appropriately respond to PPS and ESAS finding?

vi) describe the ongoing process of developing and implementing the PCCT:

- What factors facilitate the ongoing development and implementation of the PCCT?
- What were the challenges associated with implementation and what are the potential strategies to overcome these?
- What factors facilitate and challenge the role of the Resource Nurses (secondary expert team)?
- What resources are needed to support the work of the team? Are resource needs for capacity building being met?
- What service delivery issues have arisen?
- What are some of the key lessons learned in the ongoing development and implementation of the PCCT that can serve to inform the development and implementation of other PCCT teams?
- What are suggestions for improvement? For sustainability? For expansion to other counties?
- What are potential next steps/ goals for the PCCT?

2.3 Sources of Information

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

Referral and Service Tracking

Information describing the referrals received, services provided, and clients serviced by the PCCT were gathered from the CCAC Client Health and Related Information System (CHRIS),

which provides information on client demographics and service details. A list of information tracked is presented in Appendix C.

Caregiver Satisfaction Interview

Caregivers of clients served by the PCCT were invited to participate in a brief telephone interview. (Although the perspectives of clients are valued, it was anticipated that as many of the clients would be at end-of-life they would not be able to participate in the interviews; caregivers were the next best representative/proxy for clients). 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 of death.
- suggestions for improvements to EOLC services provided by the PCCT.

The guide for this interview is presented in Appendix D.

Caregivers eligible to participate in this interview were those on the current team caseload during the evaluation data collection time period (August – October 2010) and who had been involved with (seen by) the team on more than one occasion (caregivers whose loved one was waiting to be seen or who had only seen the team on one occasion were not eligible to participate). To participate in an interview, caregivers had to be the primary caregiver of someone who was served by the PCCT and needed to be able to read and speak English.

Caregivers were recruited to participate in the interviews over a 12-week period (mid-August to mid-October). In the interview, caregivers were reminded who the PCCT members were (by discipline) in order to differentiate PCCT members from the primary nurses visiting from the community service provider agencies.

Key Stakeholder Survey

Key stakeholders including representatives from local community service provider agencies (supervisors, frontline nursing staff), CCAC Case Managers, and other relevant key informants were invited to complete a brief survey asking them about their level of satisfaction with:

- the work of the team (capacity building, consultation support, timeliness of access to assessment, care),
- the assessment and resulting treatment recommendations,
- overall perceptions of the effectiveness of the team
- impacts (outcomes) of the team,
- suggestions for improving/ sustaining EOL services as provided by the PCCT.

Outcomes were assessed using a post-pre methodology,¹⁰ in which respondents were asked to rate current (i.e., post-PCCT involvement) outcomes (e.g., changes to care) and were then asked to rate the current outcome in comparison to prior to the inception of this initiative. This survey is presented in Appendix E.

To maximize response rate and ease burden of completion, this survey was administered on-line via Survey Monkey (www.surveymonkey.com). Consistent with the method of survey

¹⁰Rockwell, S.K., & Kohn, H. (1989). Post-Then-Pre Evaluation. *Journal of Extension*, 27(2), 1-7.

distribution described by Dillman,¹¹ 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 October 2 to 14, 2010.

Individual Interviews with Key Stakeholders

Individual telephone interviews were conducted with a purposeful sample of key stakeholders including representatives from three community service provider agencies, CCAC, and other relevant key informants. The purpose of these interviews was to obtain in-depth information about the PCCT, 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 guide for this interview is presented in Appendix F. These individual telephone interviews were conducted between September 18 and October 20, 2010. Participants were given the interview questions in advance. Key stakeholders were identified by the evaluation Advisory Committee.

Focus Group and Individual Interviews with the PCCT and Team Organizers

A focus group interview was conducted with members of the PCCT; individual interviews were proposed with team organizers/ leadership. The purpose of these interviews was to obtain in-depth information about the team, specifically:

- factors facilitating the ongoing development and implementation of the PCCT
- 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 (patient, care provider, and system related).

The guide for this interview is presented in Appendix G.

The focus group interview with the team was conducted on September 23, 2010 in conjunction with a regularly scheduled team meeting. Individual interviews were conducted via telephone.

2.4 Data Collection and Analysis

Referral and service tracking data was compiled by the PCCT/ CCAC CHRIS. Survey data was analyzed using SPSS15.0.¹² 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.¹³ All interviews were conducted by the evaluation consultant and were digitally-

¹¹ Dillman, D.A. (2000) *Main and internet surveys. The Tailored Design Method 2nd Ed.* New York: John Wiley and Sons.

¹² SPSS 15.0. Chicago, IL: SPSS Inc., 2007.

¹³ Cavanagh, S. (1997). Content analysis: Concepts, methods, and applications. *Nurse Researcher*, 4, 5-16.

recorded and transcribed. Interview analysis was consistent with recommended practices for qualitative data.¹⁴

2.5 Ethics Review Board Approval

This evaluation study was approved by the Research Ethics Board, University of Western Ontario.

3.0 Evaluation Results

The following is a summary of the highlights and main themes that emerged from the evaluation. Detailed presentations of the results of the referral and service tracking, caregiver satisfaction survey and key stakeholder survey are located in Appendices H - J, respectively.

3.1 Evaluation Response Rates

Table 1 presents the response rates for various components of the evaluation, which ranged from 78% – 100%.

Table 1: Response rates for evaluation components

Evaluation Component	Number completed/ Number invited (Response Rate)
Caregiver Satisfaction Interview	11/13 (84.6%)
Key Stakeholder Survey	21*/24 (87.5%)
Key Stakeholder Interviews	7/9 (77.8%)
Interviews with PCCT members PCCT leadership	13/ 13 (100%)** 2/2 (100%)

*As the same survey was being completed by key stakeholders associated with the Sarnia Lambton team, survey respondents were asked to indicate which team they were associated with (Sarnia Lambton, Chatham Kent, or both teams). Six individuals reported that they were involved with both team, and four individuals did not respond to this question. The data from these 10 individuals is included here.

** In total 24 individuals attended the focus group interview: 13 members of the PCCT (core team members and Resource Nurses), 5 representatives from the provider agencies (4 nursing managers, 1 volunteer coordinator), 2 CCAC Case Managers, 1 CCAC Nurse Practitioner, music therapist, and 2 students.

3.1.1 Caregiver Satisfaction Interviews

A total of 16 individuals expressed an interest in participating in the interviews; 3 were not eligible as they were the care recipients. Of the 13 caregivers invited to participate in an interview, 11 completed an interview (85% response rate); 2 caregivers were not interviewed

¹⁴ Patton, M.Q. (2002). *Qualitative Evaluation and Research*. Thousand Oaks, CA: Sage.

because they could not be reached by telephone. The interviews ranged in length from 15 to 29 minutes (average = 26 minutes).

The majority of caregivers (73%) participating in the interviews were spouses of the care receivers; the remaining caregivers were children of the care receivers. At the time of the interview the majority of the care receivers were at home (64%); the remaining care receivers had recently died (36%; See Table 2).

Table 2: Caregiver Relationship to Care Receiver and Disposition (N = 11)

	Percentage (#)
Caregiver relationship to care receiver:	
Spouse/ partner	72.7% (8)
Child	27.3% (48)
Care receiver disposition:	
At home	63.6% (7)
In hospital	0
In hospice	0
Deceased	36.4% (4)

3.1.2 Key Stakeholder Survey

A total of 24 invitations to complete the on-line survey were distributed via e-mail; all invitations were deliverable. Twenty-one surveys were completed (88% response rate), including six individuals who indicated that they were involved with both the Sarnia Lambton and Chatham Kent PCCTs and four individuals who did not indicate with which team they were associated.

The highest proportion of survey respondents were registered nurses (24%) and CCAC Case Managers (14%), otherwise there were a variety of disciplines represented (See Table 3). There was much variability in the amount of time that respondents have been employed in their current profession (range = 1 - 45 years), with the average being 15 years. The majority of survey respondents (62%) have practices in which greater than 51% of their clients require palliative/ end-of-life care and the almost half the respondents (48%) have worked with the PCCT in regards to more than 21 clients in the past three months.

Table 3: Description of Key Stakeholder Survey Respondents (N=21)

Demographic Variable	Percentage (#)
Discipline:	
Physician	9.5% (2)
Nurse Practitioner	4.8% (1)
Registered Nurse	23.8% (5)
CCAC Case Manager	14.3% (3)

Demographic Variable	Percentage (#)
Pastoral/spiritual care	4.8% (1)
Occupational Therapist	4.8% (1)
Social Worker	4.8% (1)
Other*	14.3% (3)
Practice Setting:	
Community based agency/ organization	66.7% (14)
Hospital	0
Private Practice	14.3% (3)
Long-Term Care	0
Other**	4.8% (1)
Number of years working in their field (N =12)	
Average (+/-)	15.1 years (11.6)
Range	1 - 45years
Percentage of clients in practice requiring palliative/ end-of-life care	
Not applicable	0
None	0
Less than 25%	9.5% (2)
26% - 50%	14.3% (3)
51% - 75%	14.3% (3)
Over 75%	47.6% (10)
Contact with PCCT in the past three months	
In regards to more than 21 clients	47.6% (10)
11-20 clients	19.0% (4)
6 -10 clients	19.0% (4)
1-5 clients	14.3% (31)
Not at all	0

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

* Other: Administration, Music Therapist, Volunteer Coordinator

** Other: Across all sectors

3.1.3 Interviews with Key Stakeholders

A total of 9 key stakeholders were invited to participate in an interview; 7 interviews were completed (two key stakeholder declined participation). Interviews were conducted with one nursing supervisor/ manager from each of the three community provider agencies, three CCAC Case Managers, one representative from Geranium House Day Hospice (volunteer services), and one representative from the Chatham Kent Health Alliance. The interviews ranged in length from 17 to 32 minutes (average = 28 minutes).

3.1.4 Interviews with PCCT Members and Leaders

A focus group interview was conducted on September 23, 2010 in conjunction with a regularly scheduled team meeting. Twenty four individuals participated in this focus group interview: 13 members of the PCCT (core team members and Resource Nurses), 5 representatives from the provider agencies (4 nursing managers, 1 volunteer coordinator), 2 CCAC Case Managers, 1 CCAC Nurse Practitioner, music therapist, and 2 students. The focus group interview was 73 minutes in length. Two interviews were conducted with individuals representing team leadership; these interviews were 42 and 84 minutes in length.

3.2 Objective 1: Describe the services provided by the PCCT and the population served

3.2.1 Team Membership

During the evaluation time period, the team consisted of 15 members: 5 CCAC internal providers: Nurse Practitioner, Social Worker, Occupational Therapist and Chaplain supported by an Administrative Assistant, Team leader, 8 Resource Nurses (although there are to be 3 Resource Nurses from each of the three provider agencies, one has staffing issues so is only able to provide one Resource Nurse; one of the agencies has provided four Resource Nurses) and two palliative care physicians. In addition, a music therapist is available.

3.2.2 Referrals to the Palliative Consultation Team

Data on referrals to the PCCT and services provided were collected from the inception of the team in March 1, 2010 to September 30, 2010. A detailed presentation of this data is located in Appendix H.

A total of 143 clients were referred to the PCCT between March 1 and September 30, 2010 (See Table 4). As of September 30, 2010, 64 clients remained on the team's active caseload; 79 had been discharged from service, 66% of whom had died (N = 52/79). The average length of stay on service was 42 days, with a range of 0 – 170 days.¹⁵ The highest percentage of clients were discharged from service due to death (52/79; 66%); more clients died at home (33/79; 42%) than in hospital (19/79; 24%).

Table 4: Number of Clients Referred to the PCCT between March 1, 2010 and September 30, 2010

	Number of Clients
Number of clients of referred (March 1 - September 30, 2010)	143
Number of clients on active caseload*	64 (44.8%)
Number of clients discharged	79 (55.2%)

¹⁵ Zero length of stay on service refers to clients who were only seen on one occasion by the team.

		Number of Clients
Length of stay on service (N = 79)		
Average (+/-) days		42.3 (40.2)
Range		0** – 170
Discharge Disposition (N = 79)		
Hospitalized (>14days)		25.3% (20)
Died at home		41.8% (33)
Died in hospital		24.1% (19)
Admitted to Long-Term care		1.3% (1)
Client preference***		2.5% (2)
Treatment complete		5.1% (4)
Service incomplete – change in service specialty		0
Other		0

* As of September 30, 2010.

** 0 length of stay = same day service and discharge

***Client has chosen to no longer receive service.

The number of referrals to the team per month ranged from 9 to 30, with an average of 20 (+/- 7.5) referrals per month (See Figure 1). Referrals to the team were highest in May 2010 (N = 30) after which referrals to the team have been declining.

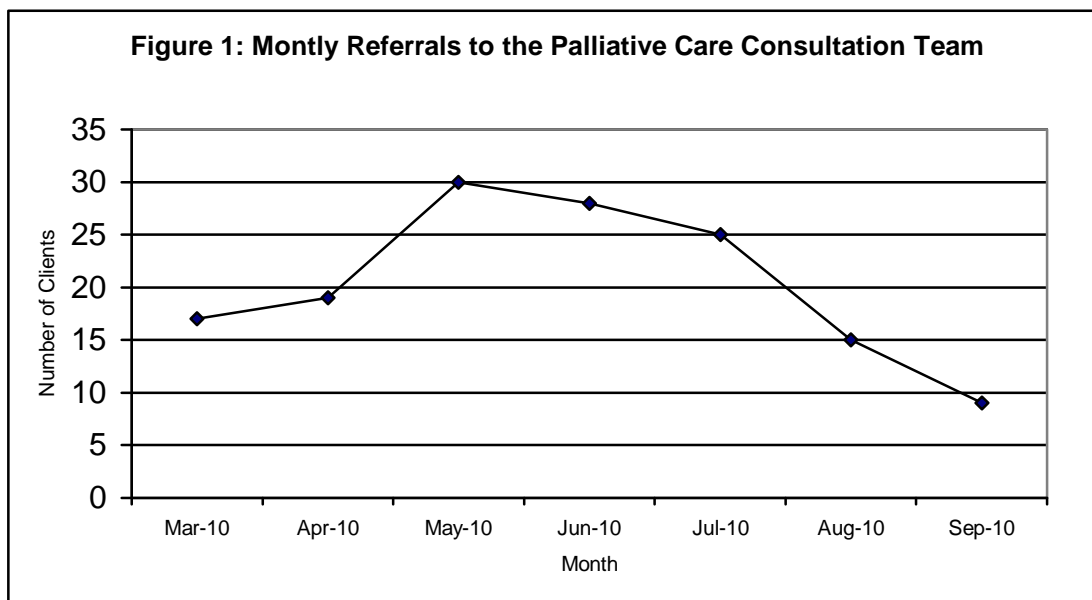


Table 5 presents demographic information on the clients referred to the PCCT. The average age of clients was 69 years; there was an equal distribution of women and men referred to the team. Over half (58%) of the clients lived with their spouse or life partner; 21% lived alone. Cancer was the most common diagnosis (78%).

Table 5: Demographic Information for Referred Clients (N = 143)

Demographic Information		Results
Age (years)	Average (+/-)	68.5 (13.0)
	Range	32* - 110
Gender	Female	50.3% (72)
	Male	49.7% (71)
Living Arrangements:		
	Alone	21.0% (30)
	Spouse/ Life partner	58.0% (839)
	With Spouse and family	8.4% (28)
	With family	5.6% (26)
	Non-private residence	0.7% (3)
	Other arrangement	3.5% (5)
Diagnosis (at time of assessment):		
	Cancer**	78.3% (112)
	Other conditions	21.7% (31)

* N= 31 (22%) clients were between 20 and 59 years of age; the majority (78%) were over 60 years of age (See Appendix H).

** Lung cancer: N = 30; 21.0%; GI (esophagus, bowel, intestines, colon): N = 29; 20.3%; Breast: N = 5, 3.5%; Prostrate: N = 7; 4.9%; Leukemia/ Lymphoma (Hodgkin's & Non-Hodgkin's): N = 6; 4.2%; All other types (cervix, ovary, endometrium, brain, gall bladder, liver, kidney, pancreas, occur in less than 4, 2.8%, clients each): N = 35, 24.5%.

3.2.2 Service Provision

As would be expected, end-of-life care was the primary service category (78%; See Table 6) for clients at the time of referral to the team, followed by long-term support (10%).

Table 6: Service Recipient Category* for Clients of the Palliative Care Consultation Team

Diagnosis and Service Category	Percentage (#)
Service Recipient Categories at Time of Referral:	
Acute	2.8% (4)
End of Life	78.3% (112)
Long Term Support	9.8% (14)
Maintenance	9.1% (13)
Rehabilitation	0

* Clients' overall service goals at the time of admission. *Acute*: to address the client's need for short term education, care or support as a result of illness, disability or injury; *End of Life*: to alleviate distressing symptoms to achieve the best quality of life by providing complex support in the last stages of their illness; *Long term support*: to delay institutionalization by providing supportive care, and relief of symptoms to preserve the client's level of function and autonomy, OR the client is in a Residential hospice setting. *Maintenance*: to maintain the client's independence by preventing/ minimizing the premature decline in health and/or functional status; *Rehabilitation*: to optimize the client's functional status within limits of their disability and to facilitate social integration and independence.

Type of client interactions and the service providers involved are presented in Table 7. There were 699 client interactions with 101 different clients; the average number of interactions per client was 7 (range = 1 – 45). More of these interactions were face-to-face visits (58%) than telephone contacts (43%). The highest percentage of interactions involved the Nurse Practitioner (33%) and the Chaplain (28%). The number of services involved with each client ranged from 1 – 5, with an average of 1.7 (+/- .84) services involved per client. Half of all clients (51%) had interactions with just one service; 32% had interactions with 2 services and 18% were involved with 3 or more services. CCAC internal providers were consulted 21 times regarding 38 different clients; the average number of consults was 4 (+/- 3.6) per client.

Table 7: Percentage (Number) and Type of Client Interactions and CCAC Internal Providers Involved (March1 – September 30, 2010)

	Percentage (#)
Number of Interactions:	699
Number of interactions per client:	
Average (+/-)	6.9 (8.2)
Range	1 – 45
Number of clients	101
Type of Interactions (N = 699)	
Face-to-face visit	57.5% (402)
Telephone call	42.5% (297)
Client Interactions with Core Team Members* (N = 699)	
Nurse Practitioner	32.6% (228)

	Percentage (#)
Occupational Therapist	21.3% (149)
Chaplain	28.3% (198)
Respiratory Therapist	0.6% (4)
Social Worker	17.2% (120)
<i>Number of Core Team Members Involved per Client (N = 101):</i>	
Average (+/-)	1.7 (.84)
Range	1 – 5
<i>Number of Consultations with Core Team Members*:</i>	
	21
<i>Number of consultations per client:</i>	
Average (+/-)	3.5 (3.6)
Range	1 – 19
Number of clients	38

* CCAC Internal Providers only (Core team members)

Over half (51%) of interactions with a team member prevented an Emergency Department visit, that is, if the team had not been involved the client would have gone to the Emergency Department to access medical attention; this involved 36% (N = 51) of clients, with an average of four (+/- 3.6) Emergency Department diversion interactions per client (See Table 8). Home Laboratory Services were ordered for seven clients since the service was made available in May 2010. There were 75 'on-call' interactions with clients. Two of the community service provider agencies responded to 87% of these calls. One agency responded to a small proportion of calls (13%); this was due to staffing shortages. The majority of these calls (N = 64) were managed with telephone contact. Few of these on-call interactions necessitated the involvement of a physician (17%) or nurse practitioner (9%).

Table 8: Emergency Department Diversions, Home Laboratory Services and On-Call Interactions with Clients

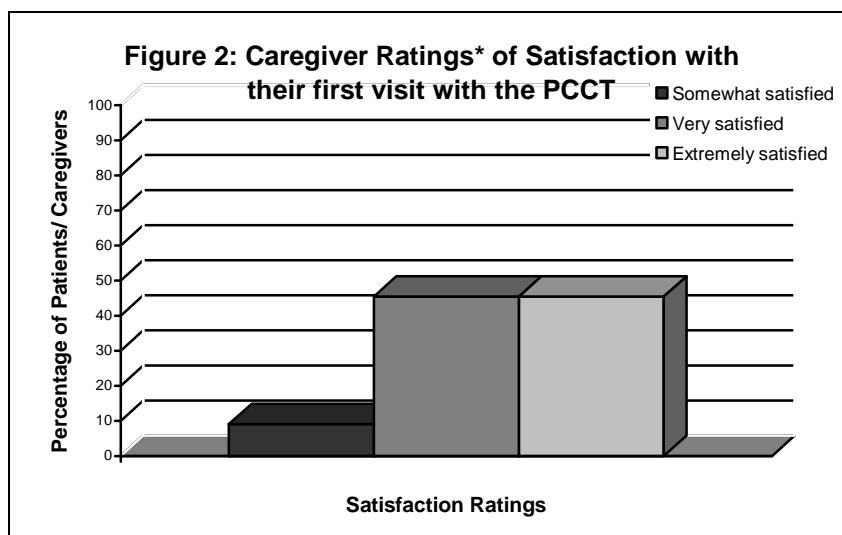
	Percentage (#)
Number of client interactions considered hospital avoidance/ diversion (N = 699)	358 (51.2%)
Number of clients with an interaction considered hospital avoidance/ diversion (N = 143)	35.7% (51)
Average number of interactions per client considered hospital avoidance/ diversion (N = 51)	
Average (+/-)	7.0 (7.3)
Range	1 – 36
Home Laboratory Services (May 1 – October 29, 2010)	7

	Percentage (#)
Number of 'On-Call' interactions	75
Number of 'On-Call' interactions per provider agency (N = 50)	
Provider A	13.3% (10)
Provider B	45.3% (34)
Provider C	41.3% (31)
Type of On-Call interaction (N = 58)	
Telephone consults	85.3% (64)
Face-to-face visits	14.7% (11)

3.4 Objective 2: Identify impacts associated with the PCCT to date

3.2.1 Client and Caregiver-Related Impacts

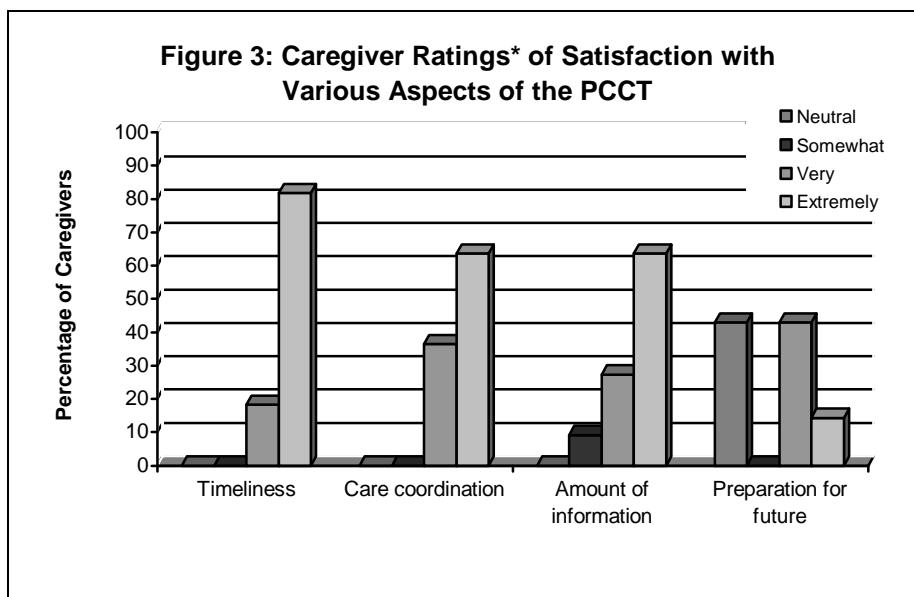
Caregiver Satisfaction: Figure 2 presents caregivers' overall ratings of satisfaction with their first visit with the PCCT. All of the caregivers reported that they were satisfied with the PCCT, with the majority (90%) being "very" or "extremely" satisfied (45% each).



* 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 (for those care receivers who had not died) are presented in Figure 3. All of the caregivers reported being satisfied with these aspects with the majority providing ratings of "very" or "extremely" satisfied; the exception being that 43% reported being neither satisfied nor dissatisfied with how they were prepared with what will happen next; 57%

reported being either “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 PCCT 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.

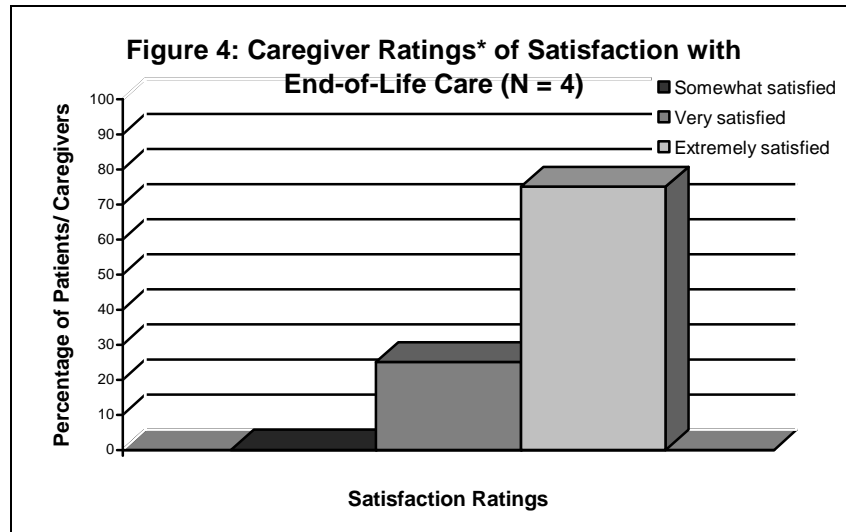
Satisfaction with end-of-life care: All of caregivers interviewed whose loved one had died reported that the death occurred at home consistent with their loved ones preferred location for death. Figure 4 presents caregivers’ overall ratings of satisfaction with the care that their loved one received at the end of life. All of the caregivers reported that they were satisfied with end-of-life care their loved one received from the PCCT, with all of them being “very” (25%) or “extremely” (75%) satisfied. Caregiver satisfaction with the end-of-life care provided by the team is reflected in the following comments”

“I asked him if he wanted to go to the hospital and he didn't. He said he just wanted to be here with me beside him. I was so happy to give this to him and that they could help me with this.”

“She was happier to be here and I wanted it too. The team was real good at helping me to make this happen for her.”

“They really helped me to do this [have father die at home]. They were an incredible support.”

“They were 100% helpful.”



* 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 were particularly appreciative of the emotional support and compassionate care that was provided by the team, the good communication, the ease with which they could access the team and that all care providers were coordinated in the provision of care.

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

Emotional support provided (compassionate care)

“Just that they’re here for support. When we went to the London clinic they didn’t offer us anything, no support at all.”

“The caring and concern of everyone involved. They arranged for respite for me because I have not family nearby and I’m the sole caregiver.”

“The way they care and give of themselves. There wasn’t anything they wouldn’t do for us. They bent over backwards for us. They still come to see me to make sure I’m doing okay.”

“They are just so compassionate. They each, the OT, nurses, were very compassionate and genuine with us and our family.”

“We loved the Chaplain. We felt extremely supported with him. He visited two times on the day that my father died. My dad wanted to make sure he had made good with God before he died and [Chaplain] helped him with this.”

Good communication

“They were always really good about telling me what will happen so there were no surprises. I understood what was going on all the time. They didn’t pull any punches or sugar coat it.”

“They are so easy to talk to - they take their time with you. The focus is on you and only you.”

“They make me feel comfortable. They are nice people.”

Easy to access

"They are so easy to contact if you have a question. They call back within the day."

Coordinated Care

"I'm nuts about the team. They're collaborating together. It eases suffering."

When asked if there was anything about the team or the service/care they received that they did not like, the majority of caregivers (82%; N = 9) 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 related to difficulty accessing a Resource Nurse or team physician, which in one instance resulted in a trip to the ED; their comments are as follows:

"Sometimes it's difficult to get a hold of a nurse on the weekend - on one occasion there was a mix up and nobody could come out to see her. I called on Friday night and again on Saturday morning. She had diarrhea and a fever and still no one called back so her fever when up to 101 and we had to go to the hospital and she was there for 10 days. We I got back from the hospital there was a message on the answering machine asking if I still needed someone to come out. I'm not sure what the mix up was."

"We had a problem one night getting the hold of the doctor for pain medication. It was a Saturday night and he was out to dinner and didn't want to be interrupted. It ended up taking a few hours to get the orders and then to get the medications. It created unnecessary suffering for my father."

One caregiver had a complaint not directly related to the team, or within the team's control but related to the schedule of the primary nurses from the provider agencies:

"Not knowing when the visiting nurses are coming in. It's unpredictable and sometimes they don't come when they say they're going to come."

Caregiver Support: All of the caregivers (100%) reported that the team gave them information or suggestions that helped them to better care for their loved one at home, as reflected in the following comments:

"I'm no nurse so they have really helped me figure things out."

"They provided diet and food suggestions, what to look for, what supplements to give her to help to stay strong. I followed their instructions and it must be good advice because she gained one pound in one week."

"They guided me on how to look after her and take care of her needs."

Emotional/ Spiritual Support: All of the caregivers (100%) reported that they were offered emotional or spiritual support. Of these, 91% accepted a visit from the team Chaplin or Social Worker. Figure 5 presents caregivers' ratings of satisfaction with the way their emotional/ spiritual needs were met. All of the caregivers reported that they were satisfied with the way the PCCT met their emotional/ spiritual needs, with the majority (55%) being "extremely" satisfied.

Satisfaction with the emotional and spiritual support received is reflected in the following comments:

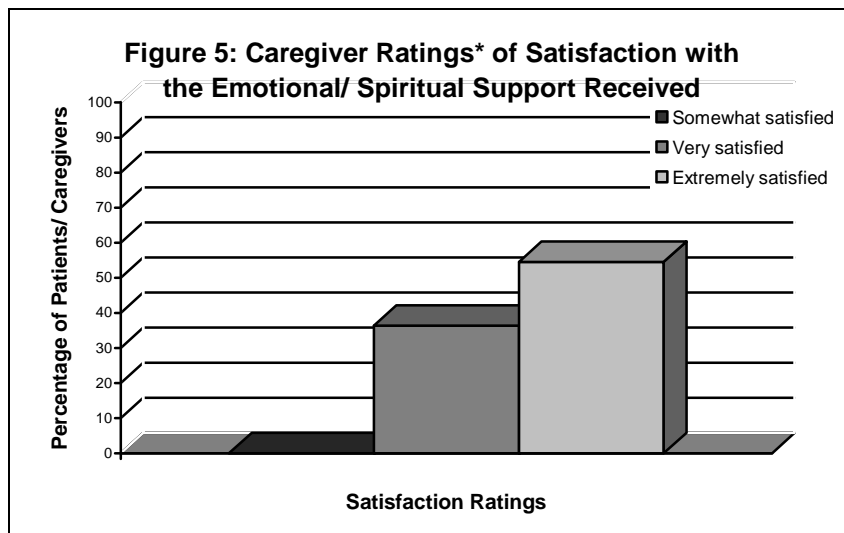
“They did a great job. I had never heard of these things before. I looked to lean on them and I could. They were there for me when I needed them.”

“They were kind and compassionate and encouraging. It was so nice for the chaplain to come to pray for us even though we had our own priest. It was good to have the social worker to talk to even just to know that I was doing all the right things.”

“The Chaplain and my husband have wonderful conversations, it’s been so good for him.”

“I’d do the same thing if I had to go through all over again. The same day that we talked about him getting baptized the Chaplain came and did it. It was wonderful.”

“They’ve been so helpful and caring. They’ve gone above and beyond what we expected.”



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

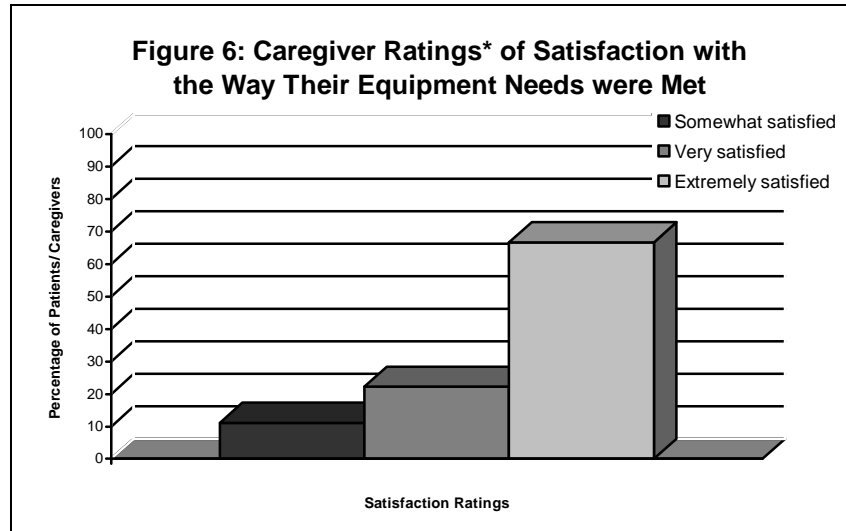
Provision of Special Equipment: The majority of caregivers (82%) reported that the team suggested or recommended special equipment for their home (e.g., walker or bathroom equipment such as shower grab bars, raised toilet seat, or shower bench); all of these caregivers (100%) accepted the recommendation for special equipment. Figure 1 presents caregivers’ ratings of satisfaction with the way their needs for special equipment were met by the team. The majority of caregivers (89%) provided ratings of “very” and “extremely” satisfied. Caregiver satisfaction with the provision of equipment is reflected in the following comments:

“They made suggestions for things in the bathroom that has made bathing much easier and safer. It gives him his dignity when he can do it on his own and he doesn’t need someone watching over him.”

“They wanted my wife to have a hospital bed. It was all arranged for me. I didn’t have to do a thing. I didn’t have to worry about making calls or delivery - they did it all.”

“They went above and beyond what we expected. Somebody heard that we needed a hospital bed and it was here.”

A caregiver who provided a rating of “somewhat” satisfied with way their equipment needs were met commented that a delay in accessing equipment occurred that was out of the control of the team.



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

Additional interview comments made by caregivers reflected their satisfaction with the team, as illustrated by the following comments:

“If someone is having the same troubles I would tell them about it [the team]. I would recommend this for them, for sure.”

“Just that they are well trained and excellent with the patient. I’ve been worried about how all of this was going to be because I’ve heard horror stories but it’s been nothing but good.”

“The team suggested respite so that I can go out - They arranged for someone from Geranium House to come over for a few hours every week so I can go out. I used to play a lot of golf but never got the chance most of the summer. This gives me some time to hit a few balls. I’ve really appreciated this.”

“They did a great job. They really got me through this.”

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

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

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

Client/ Caregiver Impacts

- Increased access to expert care
 - Timely access to care
 - Increased access to interprofessional care
 - Increased opportunity to remain at home for care
 - Increased support for dying in preferred location
 - Reduced crises
 - Increased client and caregiver satisfaction
-

- **Increased access to expert care:** The PCCT provides clients and caregivers with greater opportunities to access expert care and advice ranging from Resource Nurses who are contacted by primary visiting nurses to team rounds where difficult cases are reviewed and the expert advice of a range of health professionals is available. Clients also have greater access to a palliative care physician, which otherwise they might not access. In particular, it was noted that clients have access to better pain management as team members are up-to-date in their knowledge on optimal pain control.

“They’re [Team members] up to date, especially on the latest pain management and things like that and a lot of the family physicians, although it’s becoming more popular now, aren’t really up to date on pain management and dosages.” [PCCT]

- **Timely access to care:** It was noted that palliative problems and issues (e.g., pain, symptoms) are identified and managed in a timelier manner as a result of access to expert resources 24/7. This timely access to care has reduced client pain and suffering due to quicker access to medications.

“Well from my experience is that I notice that the accessibility to care, particularly palliative care resource nurses, nurse practitioners, that has all been a lot quicker and more accessible which enables them to stay home instead of having them go to the ER for that expertise. I saw that primarily with resources nurses and the nurse practitioners that they were able to access them quickly when they needed it, especially for symptom management and I saw that and it enabled them to stay home.” [Key Stakeholder ID2]

“Better outcomes for the patients in terms of reduced pain and suffering because they’ve got quick access to the medications that they need... back in the olden days, I wouldn’t have had access to anyone, I would have been winging it, praying that that client didn’t pass through the night.” [Key Stakeholder ID4]

- **Increased access to interprofessional care:** The availability of physicians, Nurse Practitioners, a Social Worker, Chaplain, and Music Therapist on the team, increases clients' access to these services; without the team in place access to these expert services is limited. In particular it was noted that access to spiritual support and music therapy has contributed to clients well being and ability to cope with their illness.
- **Increased opportunity to remain at home for care:** The PCCT allows clients to remain at home to access care, including blood work and assessment of new or worsening symptoms or pain. Without the team in place many clients would use the hospital Emergency Department to access immediate care, which is often physically and emotionally distressing for them and their caregivers given the long waits for care and the need to repeat their medical history. Access to care at home prevents the distress often associated with visits to the hospital.

"I find the biggest support is the access to nurse practitioners and especially patients who aren't able to get out, who are very sick and terminally ill and you have that support that you can call them for advice and that allows for in home visits where family physicians aren't able to do that." [PCCT]

- **Increased support for dying in preferred location:** Clients are better supported to die in the location of their choice, particularly those wanting to die at home. The PCCT is able to support caregivers and family members and increase their capacity to manage a home death. It was noted that some clients and caregivers had initially wanted the death to occur in hospital because of fears of uncontrolled pain and symptoms with a home death, but changed their minds because their positive experiences with the team have increased their trust that a painless home death would be possible.
- **Reduced crises:** Proactive care planning has reduced the number crises for clients.

"I think it avoids crisis. We can discuss problems and or anticipate and get answers for things that might be pending and having things looked after during the day, so there's not a whole lot of calling in the middle of the night or in crisis because its just so well organized. Things are thought of in advance." [Key Stakeholder ID4]

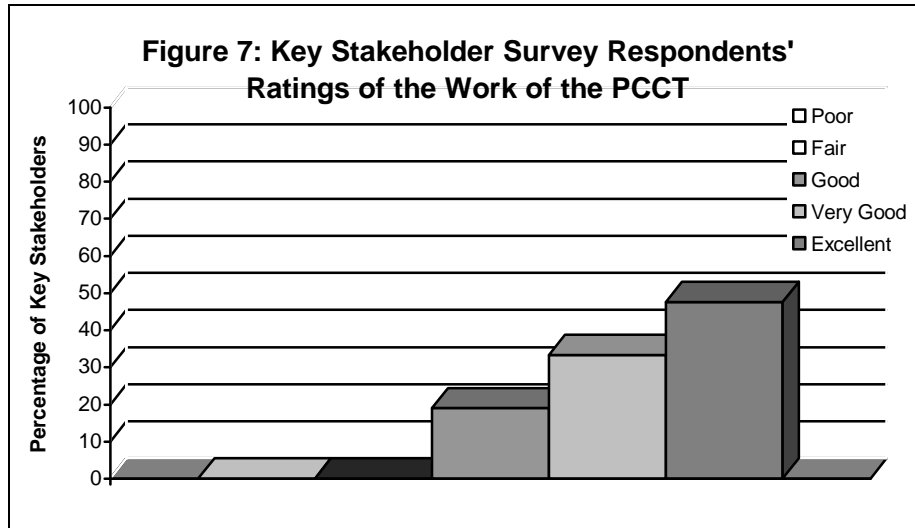
- **Increased client and caregiver satisfaction:** The PCCT has contributed to client and caregiver satisfaction with care provided in the community, particularly since many may have been skeptical the level of care that could be provided, or if they had prior negative experience.

"I've had some families come to me singing the praises of the team, especially children who may have had a parent or family member die a few years ago when this service wouldn't have been available. They all say they wish they had this back then, that it would have made a big difference. And because of those bad experiences some families don't want to stay at home because they think the help won't be there and they are grateful that it is now." [Key Stakeholder ID3]

3.2.2 Health Professional-Related Impacts

Care Provider Impacts as Identified by Key Stakeholder Survey Respondents

Key Stakeholder Satisfaction: The majority (88%) of the key stakeholders survey respondents rated the work of the PCCT as “very good” (33%) or “excellent” (48%); See Figure 7. Consistent with expected targets (as outlined in the evaluation framework), over 90% of key stakeholders were satisfied with the work of the PCCT.



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 moderately high (4.0) to high (4.6) levels of satisfaction. Survey respondents were most satisfied with the ability of the team to support clients to die in their preferred location, the quality of the assessment conducted, direct provision of care and treatment planning. Key stakeholders were least, but still moderately satisfied with integration of care across health sectors and care providers. Consistent with expected targets (as outlined in the evaluation framework), over 90% of key stakeholders were satisfied with the various aspects of the PCCT.

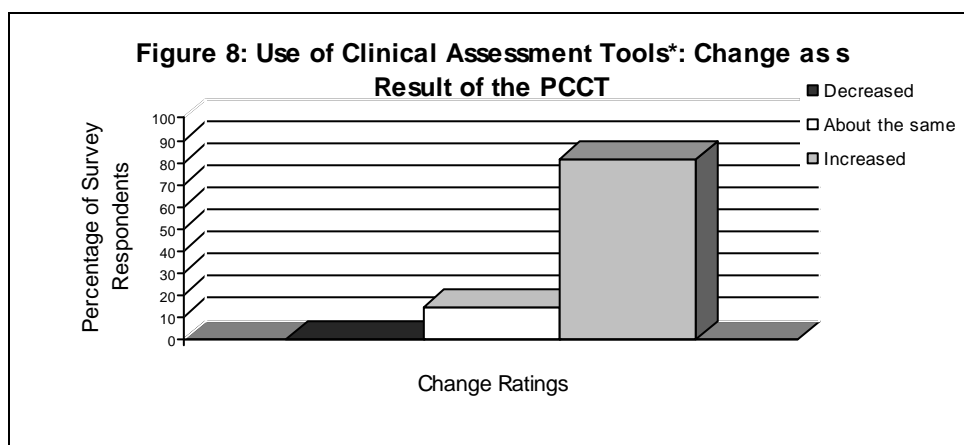
Table 11: Rank Ordering of Key Stakeholders Satisfaction with Various Aspects of Team Functioning (N = 19)

Ranking	Aspects of Team Functioning	Average (+/-)*	Range
1	Ability to support clients to die in their preferred location (N = 21)	4.62 (.59)	3 – 5
2	Quality of assessment (N = 20)	4.40 (.68)	3 – 5

Ranking	Aspects of Team Functioning	Average (+/-)*	Range
3	Direct provision of care (N = 21)	4.38 (.67)	3 – 5
4	Treatment recommendations/ planning (N = 21)	4.38 (.67)	3 – 5
5	Communication between the team and other care providers (N = 20)	4.35 (.75)	3 – 5
6	Patient/ family readiness for death (N = 21)	4.33 (.58)	3 – 5
7	Availability of team members for informal consultation (questions, follow-up) (N = 21)	4.33 (.73)	3 – 5
8	Follow-up (N = 21)	4.29 (.72)	3 – 5
9	Capacity building for end-of-life care (education/ resources) for team members, including Resource Nurses (N = 21)	4.24 (.83)	3 – 5
10	Timeliness of access to assessment (N = 21)	4.24 (.94)	2 – 5
11	Integration of care across care providers (N = 21)	4.19 (.68)	3 – 5
12	Care coordination (N = 21)	4.05 (.81)	3 – 5
13	Integration of care across health sectors (community – hospital) (N = 20)	3.95 (1.1)	2 – 5

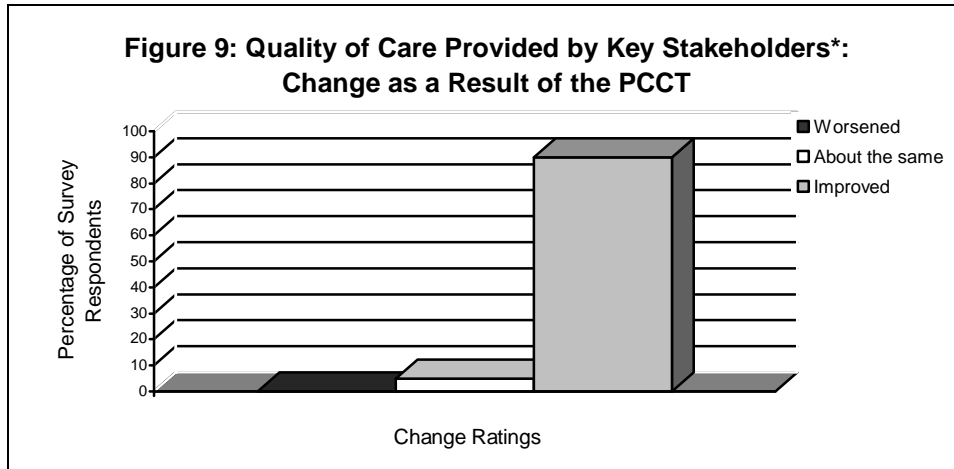
* As rated on a 5 point rating scale: 1 = not at all satisfied; 5 = extremely satisfied.

Capacity Building: The majority of key stakeholder survey respondents (81%) reported that their use of assessment tools (ESAS, PPS) has increased as a result of the PCCT (See Figure 8).



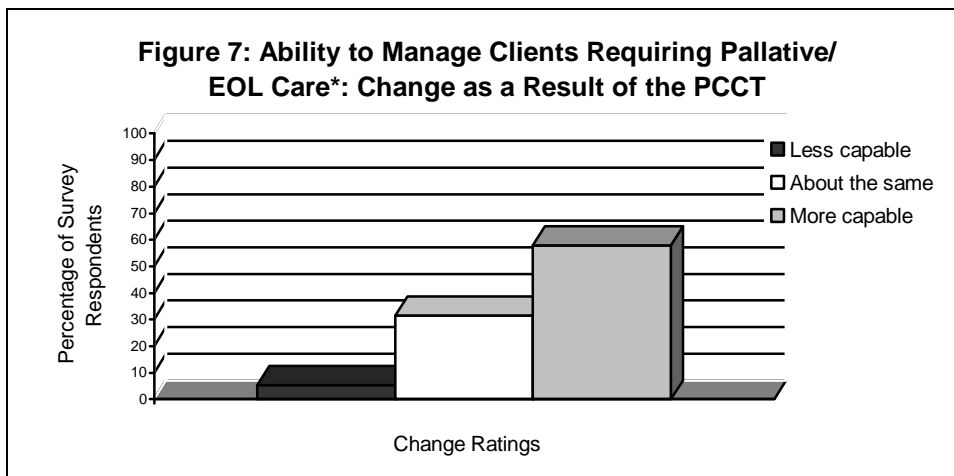
*5 point rating scale: Much increased, increased, neither increased nor decreased, decreased, much decreased. Increased use = sum of much increased/ increased ratings; Decreased use = sum of much decreased/ decreased ratings. Note: Percentages do not sum to 100% due to missing values.

Similarly, the majority of key stakeholder survey respondents (90%) reported that the quality of care they provide to clients requiring palliative/ end-of-life care has improved as a result of their involvement with the PCCT (See Figure 9).



*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 (62%) reported that as a result of the PCCT they were now more capable of managing clients requiring palliative/ end-of -life care in their own practice; 24% 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). Average ratings of current ability to manage clients requiring palliative care were quite high (4.5; +/- .61, as rated on a 5-point scale).



*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 PCCT Representatives

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

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

Health Care Provider Impacts

- Easier and timelier access to expert advice for primary nurses
 - Increased opportunities for capacity building
 - Increased job satisfaction
 - Increased likelihood of nursing retention
-

- **Easier and timelier access to expert advice:** With the PCCT in place, primary visiting nurses have easier and timelier access to expert advice. In contrast to prior to the inception of the team, primary nurses have a better sense of who to contact, how to contact them, and when to contact them.

“You don’t have to go through all the red tape. Its easier because you have specific people to go to, you know who’s on the team, they know the clients and it’s a lot easier and a lot quicker to get what we need for the family or for the client.” [Key Stakeholder ID1]

“I find the weekend access is totally key for me because I’ve been a nurse for 23 years and have had a heavy case load from day one, so the weekend access to the doctors that say they’re around but really are not, and say well just send them to emerge. So, it’s always been a struggle getting coverage on weekends.” [PCCT]

- **Increased opportunities for capacity building:** The PCCT has created more opportunities for palliative care education through formal education opportunities but also informal learning through the team rounds and ‘in the moment’ learning in the discussion of cases. It was noted that this capacity building has occurred not only for the Resources Nurses but also for the primary visiting nurses.

“[Resource Nurses] get more education, they get to work with the doctors more one on one, and they get to know the team members better I think as they have meetings every two weeks, and they have little education sessions at these meetings as well, and they learn from talking about other clients, from all the agencies, so it’s a good learning for them.” [Key Stakeholder ID1]

“I really like our rounds, I think that is really great. It’s a great opportunity to share ideas and get to know one another and I think its patient focused and we meet every two weeks and we discuss challenging cases. I’ve learned lots from other disciplines, because we have some real experts in the room and it’s so wonderful to share ideas and share knowledge.” [PCCT]

It was also noted that various opportunities for palliative care education within the region have served to support the work of the team as care providers become more knowledgeable about palliative care. As an example, it was noted that a family physician who participated in the LEAP (Learning Essential Approaches to Palliative and End-of-Life Care) training, had commented that she had always referred patients with restlessness to the Emergency Department because she believed that was the best place for them to get treatment. Following the LEAP training she better understood restlessness and supported team members' efforts to manage this symptom at home.

- **Increased job satisfaction:** It was noted that the opportunity to work in a 'team' and to interact with other professionals to resolve complex cases has reduced the sense of isolation that care providers feel when working in community settings and has increased their level of satisfaction with their work.

"I've actually been in a home where the nurse calls the nurse practitioner and so she had that available right then to her, at her fingertips and that seemed to take care of the issues more quickly instead of drawing out, it was dealt with more quickly. So, I think because I'm a nurse myself I can only imagine that would make you more satisfied in your job. To be able to actually make a difference and do it quickly and timely.... I've just heard so many times at our bi-weekly meetings how they feel supported by the team itself just knowing that you're alone in the job that you do in the community." [Key Stakeholder ID2]

- **Increased likelihood of nursing retention:** It was noted that the support provided to the Resources Nurses on the team will likely impact retention as they feel supported, valued, and enjoy their work. Emotional support provided by the team Social Worker contributes to retention by reducing the likelihood of burnout.

"If you feel supported and you have access to other nurses in the field and you are more likely to stay in that job. It can be a draining job dealing with dying people all the time. There's been tears shared at the meetings and the social worker has recently been addressing the care giver fatigue and care giver burn out at each meeting and giving an opportunity to share all that and that has been very effective and very therapeutic and I think it's the role of the social worker not only for clients, but now for us too, we feel cared for." [Key Stakeholder ID2]

3.2.3 Health System-Related Impacts

Health System-Related Impacts as Identified Clients and Caregivers

Use of Health System Resources: As part of the caregiver interviews, caregivers were asked to indicate whether the help that they received from the PCCT helped to keep their loved one out of the hospital or from visiting the Emergency Department. The majority of caregivers (81%) reported that the PCCT prevented visits to the hospital (See Table 13), with many providing specific examples of situations where intervention from the team prevented an ED visit. The one caregiver who reported that the team did not prevent ED visits reported that she was a nurse and therefore would not visit the ED unless absolutely necessary. ED prevention is reflected in the following examples:

“On the long weekend we ran out of dilaudid and our family doctor was on vacation. We called [NP] and she called and arranged it all within 20 minutes. Without that we would have gone to the hospital and God only knows how much time that would have taken. This team is just the most awesome. This is just so special.”

“Usually if we call them they come over right away to see what the problem is. If they didn't come, we'd have to go to the hospital, especially if she's really sick or has a fever. But when they come they solve what the problem is so we don't end up going to hospital after all.”

“We don't have a family doctor so if there's a problem we can call them [the team]. It's just so essential that we can get meds through the team and then see the doctor because we don't have one and before if we wanted to see one, we'd have to go to the hospital. We don't now though.”

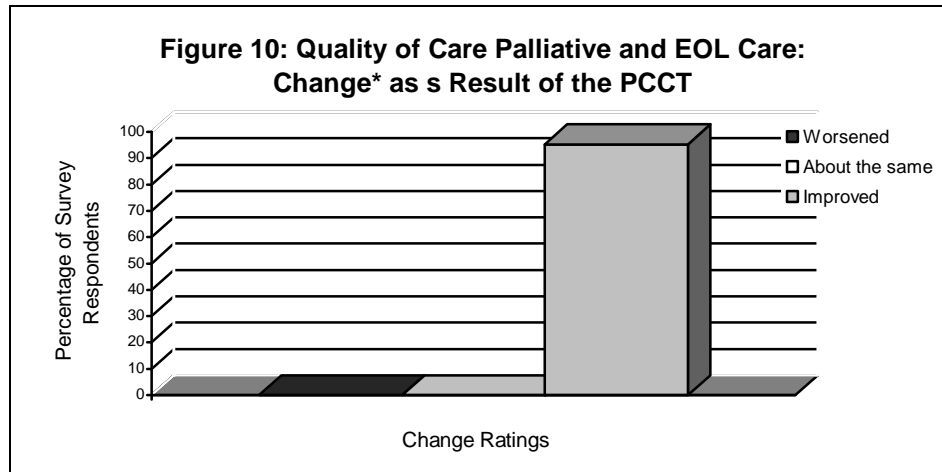
“They're [the team] better than our doctor. He's just so hard to get a hold of and he won't come here, so if we have any questions or problems we have someone to call.”

Table 13: Caregiver Reports of Hospital Avoidance as a Result of the Team

Do you think that the help that you've received from the team has helped to keep your loved one out of the hospital or from visiting the Emergency Department?	
Not sure	9.1% (1)
No	9.1% (1)
Yes	81.8% (9)

Health System-Related Impacts as Identified by Key Stakeholder Survey Respondents

Improved Quality of Palliative Care: Key stakeholder survey respondents were asked to rate the extent to which the overall quality of palliative and end-of-life care provided to clients has improved as a result of the PCCT (See Figure 10). All of the respondents (95%) that answered this question reported that quality of care has improved, with the majority of respondents (67%) indicating that care has “much improved”.



*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.

Key stakeholder survey respondents identified a number of impacts/ outcomes associated with the PCCT, many of which reflected improved quality of care as evidenced by:

- Increased collaboration among care providers and community partners to assist clients to meet their end-of-life care goals
- Emergency Department avoidance
- More appropriate use of Emergency Department and Palliative Care Unit
- Increased access to expert advice/ resources for primary nurses within the community
- Increased client access to support services (e.g., blood work at home, spiritual and social work support, occupational and music therapy)
- Capacity building for frontline nursing staff
- Increased nursing confidence with ability to provide optimal palliative care
- Access to care for clients who do not have a family physician
- More timely response to palliative crises
- Increased client chose in location of death (home deaths can be better supported)

These impacts are reflected in the following comments:

“More supports available to resource nursing staff, not only for client care, but for personal supports and reassurances. Hospital avoidance significant. More specialized holistic resources are available to a population who are unable to otherwise access some of the services which provide supports in care i.e. blood work at home, pastoral services.”

“Sharing of knowledge and tools such as ESAS and PPS to the front line nurses, caregivers and other professional staff so that there is a common language for developing care plans.”

“The availability of spiritual/consultative care has helped the clients feel more connected to the care pathways provided by the entire team.”

“Clients have access to more timely med changes, new prescriptions etc. As well, they receive visits from a NP and have access to a social worker, OT, Chaplain and Music Therapist, again in a much more timely manner than before.”

Similarly, key stakeholder survey respondents were also asked to indicate whether they thought the work of the PCCT has helped to keep clients out of the hospital or from visiting the Emergency Department. The majority of key stakeholders (62%) reported that the team has kept clients out of hospital (See Table 14). Comments associated with this were related to the team’s ability to do this because of increased capacity for assessment and management within the home, more timely access to physicians for medication orders, especially after hours and on weekends, primary nurse access to the Nurse Practitioner and Resource Nurses for assistance with complex issues, and education for clients and family member regarding end-of-life advance planning and decision making.

Table 14: Key Stakeholder Survey Respondents Reports of Hospital Avoidance as a Result of the Team

Do you think that the work of the Team has helped to keep clients out of the hospital or from visiting the Emergency Department?	
Not sure	19.0% (4)
No	0
Yes	61.9% (13)

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

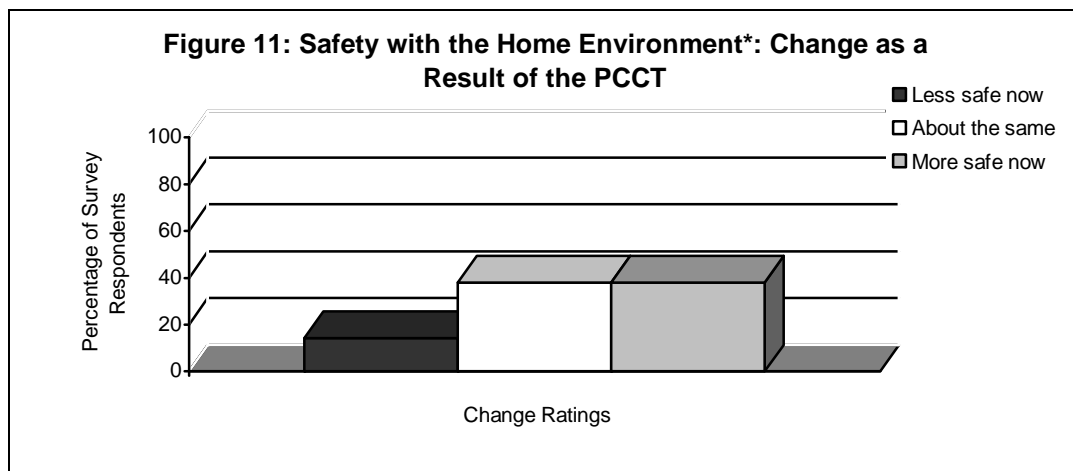
As a result of the PCCT, the majority of key stakeholders reported that client’s length of hospital stay (71%) and the number of clients dying in hospital (67%) has decreased, and that access to vital health care services at home has increased (67%, See Table 15). Less than 19% of respondents indicated that there were no changes to these indicators.

Table 15: Health System Impacts as a Result of the PCCT

As a result of the work of the Team has...	Increased	Stayed the Same	Decreased
client’s length of hospital stay...	0	14.3% (3)	71.4% (15)
the number of clients dying in hospital....	0	19.0% (4)	66.7% (14)
access to vital health care services at home....	86.7% (18)	10.5% (2)	0

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 PCCT. An equal proportion of respondents (38%) reported that the level of safety within home environments has improved since the inception of the team or

had not changed as a result of the team (See Figure 11). 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). However, the average rating of the current level of safety within the home environment was moderately high (4.0, +/- .64; as rated on a 5 point scale: 1 = not at all safe; 5 = extremely safe).



*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 PCCT Representatives

Interviewed key stakeholders and PCCT representatives identified a number of health system impacts associated with the PCCT; these are summarized in Table 16.

Table 16: Summary of Health System-Related Impacts as Identified by Key Stakeholders and PCCT Representatives

Health System Impacts

- Improved care coordination
- Improved quality of care
- Increased collaboration and congeniality among provider agencies
- Better use of existing resources
- Increased number of home deaths
- Reduced number of Emergency Department visits
- Hospitalization delay
- Shorter length of hospital stay

- **Improved care coordination:** Care between various health providers is better coordinated with transitions between providers being “smoother”. Similarly, coordination between services has improved as the team provides a mechanism for linking appropriate services.

“I’ve seen it to be more smooth, primarily between the nurse, the resource nurse and the nurse practitioner and the two physicians that they have.” [Key Stakeholder ID2]

“It’s much more streamlined. It’s like one-stop shopping. One person goes in and links to all the key services.” [Key Stakeholder ID5]

Coordination between sectors has also improved. A hospital representative attends the PCCT rounds and as a consequence is informed of clients on the team’s active caseload so that when they are admitted to hospital staff can be apprised of the persons’ care plan and wishes, as reflected in the following comment:

“Actually, what is nice is that when I sit at the table, when we’re doing our every two weeks rounds is that I get an idea of where those people are, where they’re at, when they tell us about the PPS. I have an idea that a) where they are in the trajectory, b) what their goal is. Is it to stay home or are they okay with coming in to hospital? And that gives me at least an opportunity to know where they’re at in the event they do unexpectedly come into hospital, and go from there.” [Key stakeholder ID7]

Improved care coordination is reflected in the following case example:

“I just had an example of where my client was at home and her wish was to die at the hospital, and I kept her at home. She was transferred to the hospital and died 6 days later, peacefully at the hospital with her family at the bedside, and it went very smoothly. I contacted [PCCT representative] at the hospital because I had that available to me. I wouldn’t have even known she existed if it wasn’t for this team. So I was able to contact her, contact the CCAC case manager that’s at the hospital so that everybody knows she’s coming, where she’s at, what we had done, and the communication was just fabulous and everything went smoothly, she went into a palliative care bed and died peacefully.” [PCCT]

- **Improved quality of care:** It was noted that access to interprofessional care, better care planning, and improved care coordination has improved the quality of palliative care in this region. It was also noted that the use of standardized tools has created a common language that has contributed to improved quality of care.

“There is no doubt in my mind that the quality of care that people get, the palliative care that they get in the community has improved three-fold. The care planning is better because of all the people in the room. It’s better coordinated.” [Key Stakeholder ID3]

“It’s more focused care because they’re using their standardized tools for the numeric pain scale, as well as the ESAS. I think that provides some consistency so everybody knows the language and everybody gets very familiar with knowing what that person’s status is. That I think is a great benefit.” [Key Stakeholder ID7]

“Definitely the quality of care for the clients is improved. Services are more seamless, there’s less wait times and if you run into problems usually you can access the nurse practitioner right away instead of sometimes it used to take days,

and now it could take hours before changes in the service plan are implemented.
[PCCT]

- **Increased collaboration and congeniality among provider agencies:** The PCCT was credited with providing an opportunity for the local community service provider agencies to work together in a collaborative, non-competitive manner. Communication between the agencies has increased.

“Agencies can work together with each other. With this whole RFP process and everything, it’s kind of pulled agencies apart and this way it’s [the PCCT] bringing the agencies together so they can discuss on a level playing ground without any of worries. There are no territory worries, they’re in there as a team together to talk about clients to make it better for them and I think its bringing the agencies kind of back together. I can see that.” [Key Stakeholder ID1]

- **Better use of existing resources:** It was noted that there has been an increase in the use of the existing services/ resources in palliative care as a result of the team. As an example, there is greater use of volunteers through the community support service agencies as needs for support are better identified and as awareness of existing services to support clients receiving palliative care is increased, as reflected in the following comment made by a volunteer coordinator:

“We can fill in some gaps, like I coordinate volunteers to sit with clients, sometimes if there’s gaps where they’re not able to put in professional nursing services or PSW services, but a volunteer might be a great way to help and they’re able to contact me. Now they know about me, where some of them didn’t know before, so I have some referrals coming from nurses that I didn’t before.” [Key Stakeholder]

- **Increased number of home deaths:** A greater number of clients are choosing to die at home because of the support and resources available through the PCCT.

“I think there’s a definite impact at the hospital, for sure, because they [clients] have the support system there so the patient and their families are more confident to have them at home because they have access to us, they have access to the resources to die at home.” [Key Stakeholder ID5]

- **Reduced number of Emergency Department visits:** With the availability of the PCCT, clients are able to access timely care in their home thus avoiding the need to go to the Emergency Department to access care. Proactive care planning was credited with preventing the crises that often result in a 911 call and an Emergency Department visit. Similarly, access to the team physician can prevent an Emergency Department visit when a family physician cannot be reached or the client does not have a family physician.

“I have seen families call the nurse who accesses their resource nurse and the issue at hand gets dealt with before they make it to the ER. Well I know it’s averted ER visits, so I think definitely system impact because you don’t end up in the hospital or ER, so that’s cost saving and I think also ultimately you have client satisfaction, which is huge.” [Key Stakeholder ID2]

“[The team] is able to keep people at home even in a crisis....That’s the goal of all of this is to think ahead. That patient might not be able to swallow on Friday at 4:00, well let’s have things in the house, let’s have a back-up plan. I think that’s why we do so well in this area, we have a good team that does think ahead and plan ahead so things are in place. So we don’t want to burn out the doctors and the client doesn’t have to go to the hospital.” [Key Stakeholder ID4]

“Having access to the physician is critical because family docs aren’t always able to respond in a crisis situation and there’s the clients that don’t even a family doctor.” [Key Stakeholder ID6]

- **Hospitalization delay:** For those clients who die in hospital, the PCCT allows them to remain at home for as long as possible, thus reducing the length of time they are in hospital.

“It’s been my own experience that they tend to stay home longer. I think that because they feel supported and because the resources are there to support them in caring for their family members, I think they stay home longer. And if they aren’t able to manage those symptoms in the home and if it becomes a stressful, frightening experience and its exhausting and if they don’t have the support they need, and they tend to go sooner. ” [Key Stakeholder ID2]

- **Shorter length of hospital stay:** A hospital representative noted PCCT clients tend to be admitted less frequently to hospital and to have shorter lengths of hospital stay, though there are currently no statistics to confirm this.

“But generally speaking, people that come in from the community that are on the PCCT team, we don’t see them as often, and if we do its for shorter days and now I don’t have any numbers to verify that, but I just know by, who we see that from the community’s perspective. There has been a decrease in the amount of or the frequency.” [Key Stakeholder]

Case Illustrations¹⁶: The following case studies describe actual clinical interactions between PCCT members and their clients. These cases illustrate the impacts associated with the team, namely, timely access to care, crisis management, care coordination and continuity of care between sectors and care providers, provision of emotional and spiritual support, and support for clients to die in their preferred location.

Case #1

A client with terminal restlessness was discharged from hospital to home, with family members wanting to follow on her wish to die at home. Prescribed medication was not effective and the restlessness continued. The client was unable to get comfortable in her hospital bed, was constantly taking her clothes off and constantly getting out of bed. Given her frail state, the family was concerned about the potential for a serious fall. The clients’ primary caregiver, her daughter, was becoming extremely distressed fearing that she would not be able to have her

¹⁶ Some of the details have been modified in order to protect the confidentiality of the client.

mother die at home; she was at her “breaking point”. The Resource Nurse contacted the Nurse Practitioner by telephone, and she was able to suggest some medications. The nurses provided some education around the restlessness and use of medication and provided some suggestions for management. The medication arrived shortly thereafter and was effective at managing the restlessness. A volunteer was put in place to provide respite for the caregiver, whose ability to keep her mother at home was enhanced. The client died peacefully at home.

In this instance, the PCCT:

- ★ effectively managed a crisis situation
- ★ effectively managed an end-of-life symptom
- ★ averted an Emergency Department visit and potential hospital admission
- ★ provided emotional support to a distressed caregiver
- ★ supported the client and family’s wishes to die at home
- ★ improved the quality of the client’s life and death

Case #2

A woman recently diagnosed with lung cancer was discharged from hospital on a long weekend to die at home according to her wishes. She was discharged home rapidly as she wanted to see her grandchild perform in a community parade. As a new referral to the team, the Resource Nurse met with the family at home soon after they arrived home to provide teaching on the IV and catheter. As there was no consent for treatment for CPR in place, the nurse discussed this with the family and completed the necessary forms. A home pronouncement plan was completed. The palliative care physician was contacted and within half an hour all of the necessary medication orders were in place. All of this occurred on a statutory holiday. The woman was able to see her grandchild perform in the parade from her front porch. She died peacefully at home within 3 days.

In this instance, the PCCT:

- ★ provided timely access to care during “off hours”
- ★ facilitated a seamless transition from hospital to the community
- ★ supported a clients’ preference for location of death
- ★ improved the quality of the client’s life and death

Case#3

A woman was admitted to hospital in the middle night for a complication that could only be managed in hospital. Although not admitted to the palliative care unit because there no beds available in the unit, unit nurses were familiar with her and became involved to ensure that her medical needs were managed so that she could go home to die according to her wishes. The hospital staff worked with team members to ensure the caregiver was adequately prepared for the return home and that all the necessary medications and equipment were available at home before the discharge. Without the team in place, it was noted that the patient would have remained in hospital longer, with the potential of dying in hospital, which was not what she had wanted.

In this instance, the PCCT:

- ★ facilitated an appropriate hospital admission
- ★ facilitated continuity of care with hospital partners
- ★ facilitated care coordination among various providers
- ★ shortened the patients' length of hospital stay
- ★ facilitated a seamless transition from hospital to the community
- ★ supported a clients' preference for location of death

Case #4

A middle aged man with a debilitating chronic disease had expressed an interest to die at home, however he lived alone and had minimal family supports. In consultation with the team, he was discharged from hospital to die at home. The primary nurse, PCCT Resource Nurse, Nurse Practitioner, CCAC Case Manager, and several other health care providers met at the clients home when he arrived to develop a coordinated care plan for his death. As he was quite ill and speaking was difficult for him, he was able to provide his input to all the relevant care providers at one time, so he did not have to repeat himself several times. Feeling concerned that he might be overwhelmed by the number of people present, he was asked outright if he was feeling overwhelmed. In contrary, he replied that he felt very loved, very cared for, and was confident that his needs were going to be met. Volunteers were put in place provide some informal care giving. By the end of the day a care plan, all the necessary medication and equipment, and supports were put in place. The chaplain became involved to offer spiritual support and provided a service in the clients' home before he passed away.

In this instance, the PCCT:

- ★ provided timely access to end-of-life care
- ★ provided interprofessional care
- ★ facilitated care coordination among various providers
- ★ met the clients' needs for spiritual care
- ★ supported a clients' preference for location of death

3.4 Objective 3: Describe the process of developing and implementing the PCCT

3.4.1 Secondary Level Expert Team

Although one of the community service provider agencies has had difficulty recruiting Resources Nurses because of staffing shortages, another agency has been able to provide one extra Resource Nurse. All of those interviewed reported that the most appropriate individuals have been selected as Resources Nurses for this team.

CAPCE Training as a Requirement: Given the high level of assessment and management required of the Resource Nurses, as well as their role in building capacity among primary nurses, it was believed that CAPCE training should be a mandatory requirement for the position. Moreover it was noted that this role is best staffed by nurses with experience in palliative care,

not new nurses. It was also suggested that the Resource Nurses complete LEAP training (Learning Essential Approaches to Palliative and End-of-Life Care) once in the role.

“The resource nurse should be a seasoned nurse in my opinion. I don’t think you should have brand new ones on that team, that would be my opinion. If I were a palliative patient and you’re telling me this is a resource nurse, I would expect that they’ve have some experience in order to be a resource nurse and I would expect that if you’re going to be called a resource nurse that you would have CAPCE.” [Key Stakeholder ID2]

RN vs. RPN Requirements: Although the majority of those interviewed indicated that knowledge base and passion for palliative care are essential for the Resource Nurse role, noting that both Registered Nurses and Registered Practical Nurses can both be quite capable, it was noted that there are direct care requirements that are not within the RPN scope of practice (e.g., provide the starting dose in a CADD pump or increase the dose of a narcotic). It was also noted that RNs, by virtue of their extended training, may be better able at critical thinking. As such, it was suggested that there be a balance in the number of RNs and RPNs in the Resource Nurse role. It was cautioned that the most knowledgeable, skilled and experienced RPNs should be selected for the Resource Nurse Role.

“I don’t think it should really matter whether they’re RNs or RPNs.... its that passion for palliative care and the twinkle in their eye and their eagerness to learn and absorb.” [Key Stakeholder ID4]

“I have a few RPNs that are CAPCE trained and they are just as good as the RNs. Its only some of the technical skills, like they can’t really work the central lines...so it would only be some of the technical skills that RNs can do that RPNs can’t...But they’re just as knowledgeable and capable of doing palliative care.” [Key Stakeholder ID1]

“I think that RN, RPNs are both very, very capable of doing so [palliative care] however, I’m not sure if the RPNs are able to at the same level as the RNs when it comes to that higher level intervention of critical thinking.” [Key Stakeholder ID6]

“If you would have asked me before this program started I would have said I wanted RNs. But there’s been a couple of RPNs that have been phenomenal, so I think it’s having the right RPN or, and/or RN.” [PCCT ID9]

On-Call Responsibilities: It was noted that the biggest issue related to on-call responsibility was that the expectation that Resource Nurses maintain their regular caseload. As this was quite burdensome, the provider agencies assumed responsibility for the weekday on-call. This has helped to reduce some of the burden experienced by the Resource Nurses and is believed to help reduce the potential for burn-out. Generally, it was noted that the on-call responsibilities have not been onerous, primarily because of the proactive approach to care.

“It [on-call] hasn’t been too bad at all, because I think we do such a great job of anticipating and discussing at rounds and getting those problems out there, I don’t think there’s a lot of after hour calls and the ones they have had, have been appropriate calls.” [Key Stakeholder ID4]

Similar to challenges experienced by the Sarnia Lambton PCCT, there are issues with pagers not being within range in some areas of the county, so that Resource Nurses may miss a call.

“I live out in a dead zone. So I’m always worried whether I’ve missed a page.” [PCCT]

Capacity Building: It was noted that team rounds provide a good learning opportunity for the resource nurses. Suggestions for capacity building among the Resource Nurses included providing them the opportunity to complete the LEAP training, to access education opportunities available through the Ontario Telemedicine Network, and to remain updated on new advances in pain and symptom management and alternative care strategies.

3.4.2 Facilitating Factors

Key stakeholders and PCCT representatives identified a number of factors that have facilitated the development and implementation of the PCCT; these factors are summarized in Table 17.

Table 17: Summary of the Factors Facilitating the Development and Implementation of the PCCT

Facilitating Factors:

- Capacity building for community nurses
 - Biweekly team rounds
 - Proactive approach to challenges
 - Learnings from the Sarnia Lambton Team
 - Collaboration among provider agencies
 - Collaboration among partners
 - Team fills a known gap in service
 - Availability of the Nurse Practitioner
 - Support from CCAC
 - Management support from provider agencies
 - Selection of appropriate people for the team
-

Facilitating Factors:

- **Capacity building for community nurses:** Opportunities for additional education, both formal and informal, for the Resource Nurses have helped to increase their confidence and to support their role as palliative care resources. Similarly, it was noted that education and mentorship of primary nurses has been important to assisting them to identify the palliative issues that require a referral or contact with the PCCT.

“Education of the primary nurse of when to contact those resources. Those resources can’t be everywhere, so the eyes and the ears of that primary nurse is important. They’ve done some education there, and I think that’s the key to accessing that kind of expertise.” [Key Stakeholder ID7].

“The LEAP training was sort of the period at the end of the sentence. Most of us had had CAPCE and had been doing palliative care, and the common language tools. I walked away from there thinking: ‘Give me more of this.’ When you’re speaking with physicians that aren’t familiar, because you’ve got the language tools and you can report more accurately, and you say: ‘I’m from this new team’, and it gets you farther with the physician that you’re trying to get what the client needs, with confidence.”
[PCCT]

Presentations to all community service provider agency staff provided an opportunity for primary nurses to learn about the team in terms of its members and services provided, eligibility criteria, how to access the team. This helped to facilitate a common, consistent understanding of the team. Consistent with this, the information brochure about the team has helped to facilitate client and family member understanding of who makes up the team and what the team does.

- **Biweekly team rounds:** PCCT rounds were perceived as a significant opportunity for supporting team members. In specific the rounds were identified as an opportunity for team building, capacity building and for early identification and resolution of issues related to the implementation of the team. It was noted that rounds are lead by an effective chairperson, who was described as a good leader and meeting facilitator, and who values the contribution of all members of team. Good communication between team members has helped to support their work.

“I would say primarily the biweekly meetings have been really important for ironing out things that have come up. I think that was key, had it gone longer I think you would have developed frustrations around the process, but it was tweaked and dealt with early. So that any concerns or things that needed to be dealt with were dealt with in a very timely manner and very appropriately, really respectful...It really has been great communication, biweekly meetings and a real acceptance of all the team members. Each time we meet there’s been opportunity for everyone to speak, like a roundtable, so its just real supportive and opportunities to learn. That’s great. You come there and everyone is sharing and if they have a situation they’re not sure what to do with. Every week you’re learning something new, so its very fresh every time. It hasn’t become stagnant.” [Key Stakeholder ID2]

- **Proactive approach to challenges:** Team leadership was described as being proactive in responding to issues and concerns that arise, and as responding in a supportive manner to challenges. As an example, it was noted that team has acknowledged the potential for burn out for the one Resource Nurse that is the sole representative from her provider agency; her on-call time has been reduced to better support her until more Resource Nurses are recruited from her agency.
- **Learnings from the Sarnia Lambton Team:** It was noted that the Chatham Kent PCCT learned from the experiences of the Sarnia Lambton PCCT and modeled their processes and structure after that team.

[Chatham Kent PCCT] *didn’t get off the ground with as many glitches.* [Sarnia Lambton PCCT] *worked through all the glitches. They’ve been there before, so we saw the problems and one of those problems was the on-call and so that got*

corrected for us so we didn't have to go through that. Anything that they've learned along the way over the last few years has been put into place here so that's helped us." [Key Stakeholder ID1]

"Certainly the development of the team was a continued process, but it was nice that we had Sarnia Lambton as a stepping stone and then we could just build on those, so that certainly made it much easier." [PCCTID9]

- **Collaboration among provider agencies:** Relationships and communication between the community service provider agencies have increased and improved with the team as nurses work together to meet the needs of clients.

"This has really fostered communication and support. We're all nurses doing the same thing, its not about who we work for at this meeting. It's been wonderful. I just feel like I can communicate with the nurses from each agency, there's no competition, no 'this is my patient'. There's definitely a team approach." [Key Stakeholder ID2]

- **Collaborative relationships among partners:** The willingness of partners from across sectors to work collaboratively to improve palliative care in this region was identified as important to the development of the team.

"I think the fact that in both communities the CCAC who took the lead in implementation was very careful about including all the partners, and then of course I think the second part of that is that the partners were willing to come to the table, and there could have been some staking out of: 'This is our area', and there wasn't. People were very willing to look at a new project and see how that would fit and enhance it from what we've had over the years, so I think that has worked well." [PCCT ID4]

- **Team fills a known gap in service:** It was noted that the success of the team is in part a function of the fact that it fills a much needed gap in palliative care service in this region.

"I think one reason the team has been successful is that it was really needed in this area. There were huge gaps in service and this has definitely gone a long way to filling those gaps. Before there was nothing like this." [Key Stakeholder ID3]

- **Availability of the Nurse Practitioner:** The availability of a Nurse Practitioner was identified as a significant factor facilitating the work of the team, particularly in terms of having a higher level of expertise to access and being able to access care in a timely manner without necessarily needing to contact a physician, which was viewed as sometimes being a challenge.
- **Support from CCAC:** The CCAC was credited for organizing biweekly team rounds and ensuring that the Resources Nurses have opportunities to access education needed to support their role. Moreover, the team processes were described as very clear, in terms of the role of the team and policies and procedures in place.

- **Management support from provider agencies:** High support and commitment from the management/ leadership of the community service provider agencies was credited with the success of agency Resource Nurses in this model of care. Management has supported their attendance at educational sessions and team meetings and has also been involved by attending rounds.

“The managers are very aware of it. It was actually my manager that wanted me to join the team. She was very supportive of it because of the need for palliative care in the community.” [Key Stakeholder ID5]

- **Selection of appropriate people for the team:** It was noted that those selected to be on the team, particularly the Resources Nurses, were the right people for the role as they have a passion for palliative care and are committed to making the team be successful.

3.4.3 Challenges

A number of challenges were identified by key stakeholders and PCCT representatives related to the implementation of the PCCT, such as communication issues, limited access to a Nurse Practitioner on weekends and resistance from some family physicians, and service delivery issues such as the lack of a Residential Hospice, limited number of palliative care beds in acute care and nursing shortages. Challenges are summarized in Table 18.

Table 18: Summary of the Factors Challenging the Implementation of the PCCT

Challenges:

- Communication regarding on-call
 - Communication with primary nurses
 - Information sharing with acute care
 - Limited access to Nurse Practitioner on weekends
 - Gaps at intake level on weekends
 - Inconsistent understanding of CCAC policy on provision of nursing support
 - Potential for Resource Nurse burnout
 - Resistance from some family physicians
 - Lack of a Residential Hospice in Chatham Kent
 - Limited palliative care beds in acute care
 - Nursing shortages
-

Challenges

- **Communication regarding on-call:** Although it was noted that communication within the team is generally very good, there have been some issues regarding lack of awareness of which physician is on-call.

“Not always knowing who’s on call, which doctor you should call because nurses never really like bothering doctors if they can help it and so that might be something they could work at.” [Key Stakeholder ID2]

- **Communication with primary nurses:** Generally, it was noted that more effort needs to be made to inform primary nurses of changes to the clients care plan.

“I think the one part of communication that we could improve on is remembering to get that information back to the primary nurses. Sometimes our brains are filled with all of this information and ideas, but to make it seamless, it has to get transferred back to the primary nurse, and sometimes that’s not perfect but it is still new, because I’ve often had some of the primary nurses say: ‘Well, nobody told me that.’” [Key Stakeholder ID4]

- **Information sharing with acute care:** Ensuring that PCCT clients are identified when they enter the hospital (Emergency Department or palliative care unit) so that hospital staff can be updated on their status has been a challenge.

“I think one of the challenges is making sure that when our patients do enter hospital and they’re on the PCCT team that [palliative care coordinator] can get right involved and we can update her.” [PCCT]

- **Limited access to Nurse Practitioner on weekends:** It noted that limited access to the Nurse Practitioner and team physician on weekends can pose a problem when complex or crisis situations arise.

“It’s not because these nurse practitioners don’t want to be on call, its funding. And so that’s just makes you nervous, because there was a long weekend in July where both doctors were away and you wouldn’t have had anyone to call.” [PCCT]

- **Gaps at intake level on weekends:** It was noted that PCCT clients are not always readily identified when the nursing agencies are contacted on weekends, so advice that may be appropriate for clients in general, may not be appropriate for PCCT clients, as for example, when suggestions are made for the client to go the Emergency Department, as reflected in the following example:

“On a Sunday night, it was a client, the son called in to our on call and said his father was having difficulty breathing. In the computer, the coordinator’s at home on a laptop, is privy to only so much info. The diagnosis in the computer was COPD...she paged the nurse that was on call and what do you think her response was, if somebody’s in distress and having difficulty breathing? So we recognized definitely that we have to have a flag in this computer system ... if you have any client that has a DNR, has a home pronouncement plan, is seen by the PCC team, we actually hi-lite their name red and put in a comment so that that coordinator in a quick click, she can say to the nurse, is it a PCCT client. That makes a big difference to how the nurse getting this call would react, so they may not have to call 9-1-1. These are some of the glitches that we’re working out.” [Key Stakeholder ID4]

- **Inconsistent understanding of CCAC policy on provision of nursing support:** It was noted that in some situations clients have been informed that they would have access to 24 hour nursing, however, this was not possible.

“In one case the client had been told they could get all the nursing care they needed. The client thought there would be 24 hour nursing care but I had to tell them this wasn’t possible. They [PCCT] can’t promise what we can’t follow through on.” [Key Stakeholder ID3]

- **Potential for Resource Nurse burnout:** Concern was expressed that the Resource Nurses may be at high risk for burnout or compassion fatigue because they are extremely passionate about palliative care and tend to over extend themselves in caring for their clients. Similarly, workload issues related to assuming Resource Nurse duties on top of their regular caseload was identified as placing them at risk for burn out.
- **Resistance from some family physicians:** Limited family physician awareness of the team and their expertise was identified as contributing to the resistance to team recommendations experienced with some physicians. It was suggested that this resistance will decrease over time as physicians become more familiar with the team and the benefits associated with having their clients on the team caseload.

“We haven’t had our name to the family physician group and there’s been some barriers...making them aware of this expert team and the resource nurses in the community because it is an expert team, so I think that that is a challenge that we still need to resolve, with the medical community. [PCCT]

- **Lack of a Residential Hospice in Chatham Kent:** No Residential Hospice in Chatham Kent was identified as limiting the options that clients have for end-of-life care.

“Well I think the fact that we don’t have a hospice in Chatham Kent is a challenge, because that’s considered home and it’s a great resource for some people that live alone and don’t want to go to the hospital and could really benefit from being allowed in to a hospice. There is that resource for Sarnia and Windsor, and a lot of people don’t like to leave their family, so to me that’s a huge loss... Some care givers don’t want to do the end of life at home, and then they end up putting them in the hospital or respite in a nursing home, so I think that hospice is a great idea.” [PCCT]

- **Limited palliative care beds in acute care:** The limited number of palliative care beds at the Chatham Kent Health Alliance poses a problem when clients at end of life remain home as long as possible before going to hospital, only to find there are no beds, leaving the Emergency Department as their only option. This situation has been extremely distressing for family members.

“There’s not enough palliative beds at the hospital.... So this option is being given to the client and family, but then when it happens, the time comes, they have to wait for the direct admit because there’s no palliative beds. And the only option is the emergency room.... I’ve seen where you have them waiting and the family just becomes completely exhausted, stressed out, and if you get the spin off from that,

the health issues that they experience and unable to cope, and then you're dealing with not just the client, you're dealing with a whole other bunch of problems these people face and it's just unnecessary.” PCCT]

- **Nursing shortages:** It was noted that one of the provider agencies was experiencing staffing issues related a shortage of community nurses; turnover in nurses poses a problem to continuity of care. In general, there was concern that nursing shortages in general could pose a problem for the sustainability of the team in the future.

3.3.4 Suggestions for Improvements

Interviewed key stakeholder and PCCT representatives identified a number of suggestions for improvements, sustainability and further development of the PCT; some of these suggestions address the challenges identified earlier. Suggestions were also made regarding general improvements to palliative care service delivery in this region; these suggestions are summarized in Table 19.

Table 19: Summary of Suggestions for Improvements to the PCCT and Palliative Care in General

Suggestions for improvements, sustainability and further development

- Increase access to Nurse Practitioners on weekends
- Secure sustainable funding support
- Use physician resources wisely
- Succession plan for Resource Nurses
- Increase educational opportunities for primary nurses
- Increase capacity building opportunities for family physicians.
- Promote the team to family physicians
- Develop a central master calendar for each client
- Increase opportunities to interface with Regional Cancer Centres

General suggestions for improvements to palliative care

- Increase general public awareness of palliative care
 - Establish a hospice in Chatham Kent
 - Establish a palliative care resource/ link within acute care
-

Suggestions for improvements, sustainability and further development

- ***Increase access to Nurse Practitioners on weekends:*** To ensure access to a higher level of expertise and to be able to facilitate timely changes to medication orders, it was suggested that there be access to Nurse Practitioners on weekends.

“The nurse practitioners can only do so many hours so they weren’t being around on the weekends, and the doctors of course aren’t always available. So there’s been weekends where we’ve had nobody and I know they’re working on maybe working on nurse practitioners after hours being a little bit different, because we need to have

somebody that the nurses can call, a nurse practitioner or a doctor, that they can call no matter what because the point of the team is to have people available.” [Key Stakeholder ID1]

- **Secure sustainable funding support:** As there is much support for the work of the team, it was suggested that financial support and commitment for the team be secured to ensure its sustainability in the long run.

“Probably the biggest thing is making sure that there is a commitment to financial resources so that it doesn’t fall apart. It’s a great idea but if in 2, or 3 or 4 years the resources aren’t there, then what? So that’s really important that they’re capturing data to support what we do and hopefully that data will be what they need to realize that it’s worth putting money in to.” [Key Stakeholder ID2]

- **Use physician resources wisely:** It was suggested that with the availability and expertise of the Nurse Practitioner, it is not necessary for physicians to be present for the entire time of the team rounds. Physicians’ time should be focused more on consultation for complex issues rather than some the practical nursing issues that arise during the rounds.

“It’s important that they [physicians] be there, but I think it’s only for those cases where the discussion about patients is the trouble shooting they can do. A lot of times the NPs have the answers and the doctor doesn’t necessarily have to be there for the whole thing... They need to be able to use their time well, and I think the NPs have that capacity, to really keep those sessions more meaningful and with [Pain and Symptom Management Consultant] coming to these, I think we’ve got a huge knowledge base there to help and then tap the doc on the shoulder when we do have some questions.” [Key Stakeholder ID7]

- **Succession plan for Resource Nurses:** Plans need to be in place to ensure that there are nurses trained (CAPCE) and available should Resource Nurses burn out or retire.
- **Increase educational opportunities for primary nurses:** As more clients opt to die at home with the support of the PCCT, there is a need for greater capacity among primary nurses to provide palliative and end-of-life care; there should be more opportunities for primary nurses to complete available palliative care courses and as well as to take advantage of other courses and workshops that become available.
- **Increase capacity building opportunities for family physicians:** To better support the work of the team and to improve quality and continuity of care, it was suggested that family physicians have greater access to educational opportunities such the LEAP education.
- **Promote the team to family physicians:** As many physicians are not familiar with the team, thus hindering the efficiency of the team when attempting to make recommendations, it was suggested that work of the team be promoted. It was noted that a dinner meeting is in the planning process as an opportunity to promote and share information about the team with physicians in the region.

“Getting the word out to the physicians, that’s one piece that we do have to do. And I think the plan is to have an annual dinner and we’ll invite physicians but just getting the word out. There’s a couple of things we’re working on. We’re working on a letter that we’ll provide to any family physicians that the PCCT team has seen.” [PCCTID9]

- **Develop a central master calendar for each client:** It was suggested that a central master calendar be developed for each client that details when providers will be the visiting the client. This would reduce the unnecessary overlaps in visits, thus reducing client anxiety over the number of providers in the home at the same time, and would facilitate combined visits when appropriate (i.e., primary and Resource Nurse visits at the same time).
- **Increase opportunities to interface with Regional Cancer Centres:** It was noted that although many of the PCCT clients are treated at the Regional Cancer Centres in Windsor and London, PCCT members have very few interactions with the professionals there, have never visited the centers, and have little understanding of the care and services offered to clients. It was suggested that PCCT members have an opportunity to visit the centres as an opportunity to better understand the experiences of their clients.

General suggestions for improvements to palliative care

- **Increase general public awareness of palliative care:** There is a general need to increase awareness of palliative care, specifically what it is and what services are available.

“October is you breast cancer month and I know that palliative care has in May a week, but I think we need to bump up that profile in the public eye. People shy away from palliative care. There needs to be some work done around what that language means to the public. It is generally supportive care, and palliation is a speciality when it’s necessary. I think increasing public awareness that this is available.” [Key Stakeholder ID7]

- **Establish a Residential Hospice in Chatham Kent:** The establishment of a hospice in Chatham Kent would increase options for palliative and end-of-life care.
- **Establish a palliative care resource/ link within acute care:** It was noted at PCCT clients who go to the Emergency Department may not be identified as requiring palliative care or as a PCCT client so the intervention they receive may not be consistent with the care plan that has been implemented. It was suggested that there be a specific resource within the Emergency Department who can link with the PCCT care plan to the treatment the presenting problem and return the client back to the community to be followed by the PCCT.

“Having a person in the hospital, who can be a triage person and work to getting people back home, supported to go back home and having them managed by the PCCT team. When someone arrives in a crisis in the ER, they need someone to help diffuse that, and if you don’t have the skills and you don’t have the time and you really don’t know what’s going on because you’re not aware of the issues at end of life, then nothing is diffused, and I think that would really be helpful.” [PCCT ID4]

3.3.5 Lessons Learned: Resources/ supports needed for expansion

The following key lessons learned in the development and implementation of the Chatham Kent PCCT, as well as needed resources and supports were identified as important for expansion/ creation of PCCTs in other areas:

- **Dedicated funding for the PCCT**, as this level of service cannot be provided within existing resources.
- **Good management support and commitment** at the community service provider agency level as well as the CCAC level; support for the concept and provision of resources to sustain the team.
- **Family physician support** will ensure timely response to requests for medication orders/ changes to the treatment plan.
- **Development of an interprofessional model of care**, particularly the inclusion of a Social Worker and Chaplain to provide emotional and spiritual support consistent with a holistic model of palliative care; a nurse practitioner role is essential to support the work of the team.
- **Efficient and clear referral and communication processes/ procedures** should be in place at the start to ensure smooth implementation of the team.
- **Ongoing opportunities for education/ capacity building** among primary visiting nurses, Resource Nurses, and primary care physicians are essential to support the work of the team.
- **Promotion and marketing of the PCCT**, so that the general public and health professionals across sectors are aware of who the team is and what they do.

4.0 Conclusions

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

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

- Within a relatively short period of time the PCCT has achieved many of its stated objectives, particularly those related to access to end-of-life care services (increased, enhanced, timeliness), client and caregiver satisfaction with care coordination, communication, and care provided at end-of-life. Generally, most of the benchmarks for the evaluation (90% of clients and stakeholders being satisfied with key aspects of the team) were attained. The exception to this being that less than 90% of care providers (62%) reported that they were

now more capable of providing palliative and end-of-life care and only 38% of care providers reporting that safety in the home environment has improved as a result of the team. This is primarily a function of existing high level of safety within homes (average rating 4.0 out of 5) and capability of care providers (average rating 4.5). Nonetheless, important care provider and health system impacts were identified. There is anecdotal evidence that team has had an impact on reducing the number of unnecessary Emergency Department visits and shortening the length of hospital stay for PCCT clients as the team is available to support the client within the community. Moreover, there is some anecdotal evidence that the transition of care between acute care and the community is better integrated and coordinated. The current model of care in which Resource Nurses are supplied by the community service provider agencies requires the willingness and commitment of community partners to put aside issues of territory and control to work cohesively as a group; there is evidence that the nurses and agencies involved with the team have been able to do this and in doing so have strengthened relationships and communication among the provider agencies. All of these early outcomes represent significant progress in filling palliative care service gaps that are well documented within the literature¹⁷ and that prompted the development of the team in this region.

- A significant aspect of the team, as identified by caregivers and key informants, is the use of an interprofessional model of care to address all of the domains of palliative care and to impact quality of life. Caregivers were especially grateful for the opportunity to address their emotional and spiritual needs through access to a Social Worker, Chaplain, and Music Therapist. Emotional and spiritual care were identified as significant value added, having significant impacts on quality of life for both caregivers and clients. Almost all of the caregivers interviewed spoke about how critical these services were to their ability to manage a home death, as evidenced by the number who noted they *“couldn’t have done it without”* without these supports. Consistent with this, there is much support in the literature for an interprofessional approach to improve the quality of palliative care.¹⁸
- Although there has been some move towards improving integration and care coordination across sectors, there were suggestions that more could be done to facilitate the transition of clients from the community to hospital, with for example, the introduction of a specific palliative care resource person within the hospital to facilitate communication with team members at the time of admission regarding the clients current status and treatment plan. Other strategies of facilitating this type of communication should be investigated further. As an example, health passports or records, which summarize treatment goals and plans, including current medications and criteria for calling 911 (i.e., when emergent care is necessary) and which are maintained with clients and accompany them to hospital, have been used successfully in the management of chronic diseases as a cost effective method of facilitating communication across sectors.

¹⁷ 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.

¹⁸ Bliss, J., Cowley, S, & White, A. (2000). Interprofessional working in palliative care in the community: a review of the literature. *Interprofessional Care*, 14 (3), 281-290.

Higginson, I.J., et al. (2003). Is there evidence that palliative care teams alter end-of-life experiences of patients and their caregivers? *Journal of Pain and Symptom Management*. 25 (2), 150-168.

- The team has been successful in meeting the end-of-life care needs of clients within the community; case examples provided by team members as well as the reports of caregivers provide evidence of practice improvements. Some of the challenges experienced to date with the implementation of the team are inherent in the implementation of any new service, particularly challenges related to communication and resistance among some care providers. Some of these identified challenges are currently being addressed by team leadership. Other identified challenges are not within the teams' scope to resolve (e.g., lack of a hospice, limited palliative care beds in acute care, nursing shortages), creative and innovative strategies will be required to minimize their impacts.
- One of the key elements of the Chatham Kent PCCT's success is that it builds upon the success and lessons learned by the Sarnia Lambton PCCT. As the Chatham Kent team progresses through the normal stages of program development, the Sarnia Lambton team can be a model for ongoing development and sustainability. Suggestions made for improving the team have the potential for further capacity building and sustainability. Ongoing capacity building among primary visiting nurses, Resource Nurses, and family physicians was identified as important to supporting the work of the team. These suggestions are consistent with the published literature, which has identified the need for capacity building among primary care physicians¹⁹ as well as for interprofessional education in palliative care.²⁰ Although "passion" for palliative care has been identified as an important criterion for selection of the Resource Nurses, it should not supersede expertise and experience in importance; 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.²¹ Continued support of palliative care and end-of-life education as provided through the Erie St. Clair End-of-Life Care Network Education Blueprint is one strategy for ongoing capacity building across sectors in this region. Further development, implementation, and expansion of the PCCT has the potential to significantly impact the quality of hospice palliative/ end-of-life care in this region. With continued success the PCCT has the potential to be a model for other regions in the province; lessons learned in developing and implementing the PCCT in Chatham Kent as well as Sarnia-Lambton can be used to inform the development of PCCTs in other areas of the province.

Limitations: There are several limitations to this evaluation. Data related to impacts of the team on the health care system is largely anecdotal. Empirical evidence based on hospital data (e.g., ED readmission rates, reduced hospital admissions, reduced length of hospital stay) among PCCT clients and a comparison group (of clients not seen by PCCT) would provide stronger evidence of the PCCT's ability to manage care effectively within the community. It is acknowledged that availability of this data related specifically to palliative care is limited. Some of the data that was initially to be included as part of the description of the client population

¹⁹ 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.

²⁰ Koffman, J., & Higginson, I.J. (2005). Assessing the effectiveness and acceptability of interprofessional palliative care education. *Journal of Palliative Care*, 21 (4), 262-269.

McKee, N., Goodridge, D., Remillard, F., & D'Eon, M. (2010). Interprofessional palliative care problem-based learning: Evaluation of a pilot module as a teaching and learning method. *Journal of Interprofessional Care*, 24, 194.

²¹ 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.

served by the team and the services provided by the team were not available either because they are tracked or not easily accessible. For example, PPS scores are recorded on clients individual consultation reports, but these are not entered into an information system, the palliative care physicians' visits are not tracked as this position on the team is not internal to the CCAC (thus not tracked in CHRIS), and date of referral to the team is not tracked in the CHRIS so it is not possible to calculate timeliness of access to service once referred (e.g., referral date minus the date of first contact with the team²²). Similarly, length of PCCT visits and referral source are not recorded so this information is not available. Although the number of caregivers of PCCT clients recruited for this evaluation was lower than expected it is acknowledged that, by virtue of the end-of-life situation, this is a difficult population to access. However despite this, it was apparent that saturation was achieved (no or minimal new information was generated from the last interviews conducted) and consistent themes were identified across interview participants.

²² Date of referral was recently added to the CHRIS, so this information may be available in the future.

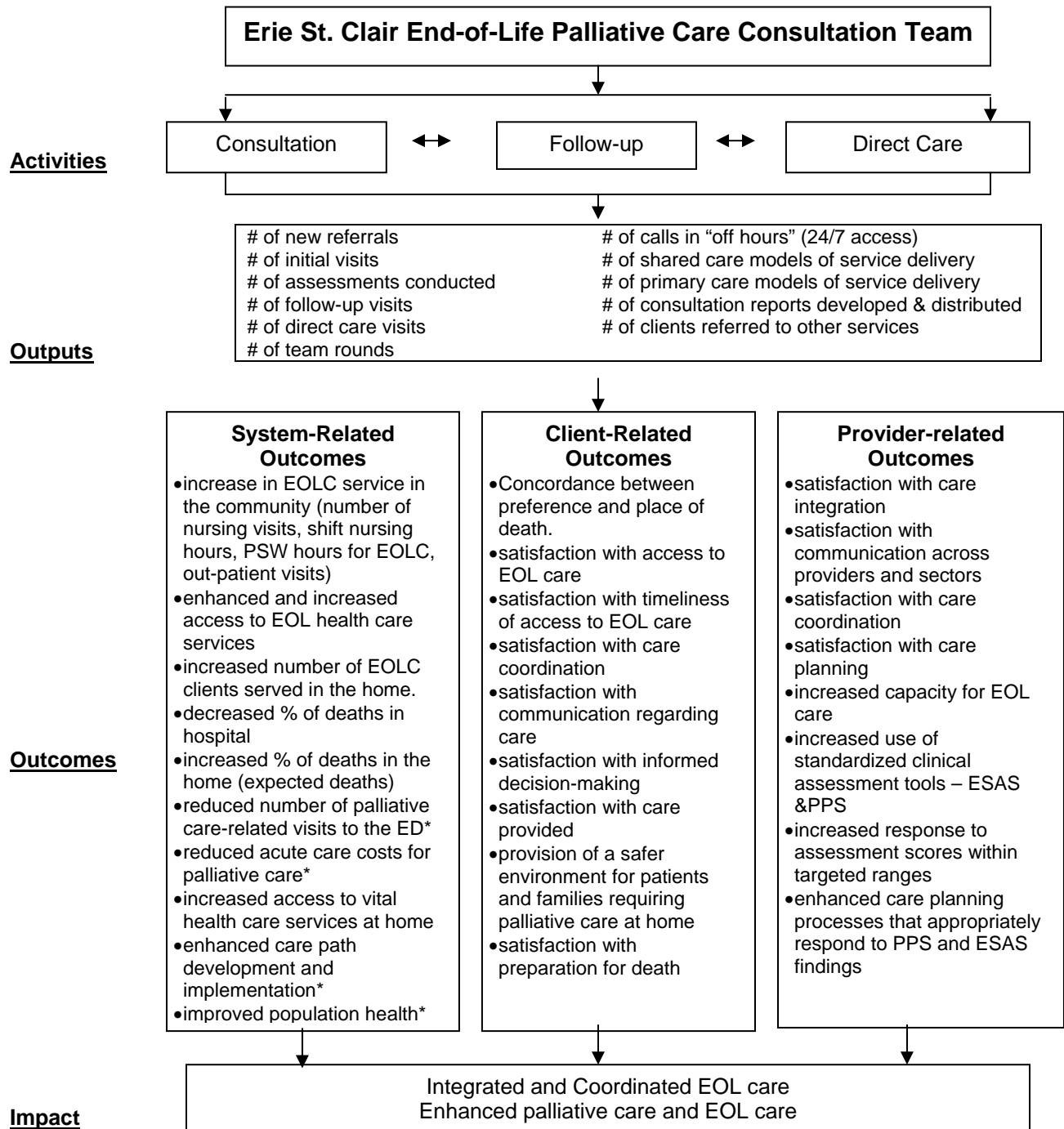
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Program Logic Model



EOL = End-of-life; EOLC – End-of-life care; ED = Emergency Department
 * long-term outcomes that require >2-3 years 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 PCCT	<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 calls in “off hours” (24/7 access) • # of each type of model of service delivery (shared care with primary care, consultation only, consultation and follow-up) • # of consultation reports developed & distributed • Providers receiving a consultation report (primary care, client, Community Support Service agency, CCAC, acute care) • # of clients referred to other services • time per visit, per client • # of team members involved per client • Disciplines of team members involved per client • # of visits per client per team member (NP, SW, Chaplain, OT, MD, others) • # of clients on each team members’ case load. • # of clients seen by Physician. • Location of service (home/ clinic/ other location) 	CHRIS; additional information generated by team /administrative assistant as needed	Sarnia Lambton: Service tracking from January 1, 2009 to September 30, 2010. Chatham Kent: January 2010 – September 2010

Outcomes	Indicators	Sources of Information	Design/ Timeline
	<ul style="list-style-type: none"> • Length of client stay on service • Response time to referrals • Response time to consultation report distribution • Place of client death 		
Description of the patient population served by the PCCT	<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 	CHRIS; additional information generated by team /administrative assistant as needed	Sarnia Lambton: Service tracking from January 1, 2009 to September 30, 2010. Chatham Kent: January 2010 – September 2010

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 informed decision-making • satisfaction with care provided • satisfaction with preparation for death 	Caregiver ratings of satisfaction	90% of patients/ caregivers satisfied with service	CHRIS; additional information generated by team /administrative assistant as needed Caregiver Interviews	Satisfaction interviews (telephone) conducted with caregivers of clients on the PCCTs current caseload; to be conducted in August-September 2010
<ul style="list-style-type: none"> • provision of a safer environment for patients and families requiring palliative care at home 	Key stakeholder reports of safer home environments for EOL care as a result of the PCCT	90% of providers reporting safer home environments for EOL care as a result of the PCCT	Key stakeholder survey Key stakeholder interviews	Key stakeholder survey distributed in September 2010 Key stakeholder interviews conducted in Sept/ October 2010

Outcomes	Indicators	Target/Benchmark	Sources of Information	Design/ Timeline
<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 	<p>Provider ratings of satisfaction</p> <p>Provider ratings of increased capacity for EOLC as a result of the PCCT</p>	<p>90% of providers satisfied with care integration, coordination, planning and communication</p> <p>90% of providers reporting increased capacity for EOLC as a result of the PCCT</p>	<p>Key stakeholder survey</p> <p>Key stakeholder interviews</p>	<p>Key stakeholder surveys distributed in September 2010</p> <p>Key stakeholder interviews conducted in September/ October 2010</p>
<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>CHRIS – potential information on use of PPS – to be explored further</p> <p>Provider agencies – potential information on use of ESAS – to be explored further</p>	<p>Sarnia Lambton: Service tracking from January 1, 2009 to September 30, 2010.</p> <p>Chatham Kent: January 2010 – September 2010</p>

Outcomes	Indicators	Target/Benchmark	Sources of Information	Design/ Timeline
<p><u>System-related outcomes:</u>²³</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 2009/2010 compared to 2007/2008 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 in 2009/2010 compared to 2007/2008</p>	CHRIS: CCAC code 95	Retrospective analysis of submitted data
Decrease in % of deaths in hospital	<p>Key stakeholder/ PCCT perceptions of impact of the team on the % of deaths in hospital</p> <p>Number of palliative care related deaths in hospital</p>	<p>Perceptions of reduced % of deaths in hospital</p> <p>Reduced number of palliative care related deaths over time</p>	<p>Key stakeholder survey</p> <p>Key stakeholder and PCCT interviews</p> <p>Hospital data (Chatham-Kent Health)</p>	<p>Key stakeholder survey distributed in September 2010</p> <p>Key stakeholder interviews conducted in</p>

²³ Note: Data on many of the system related outcomes are not available to due to how information systems code and record data. For example, it is not possible to identify the number of palliative care related visits to the Emergency Department because “palliative care” is not a code used to track ED visits; presenting problems are coded according to symptom (e.g., abdominal pain, shortness of breath) so that it is not possible to indentify palliative care related visits by presenting problem.

Outcomes	Indicators	Target/Benchmark	Sources of Information	Design/ Timeline
			Alliance) – Z51.5 codes for palliative deaths in hospital	September/ October 2010 Quarterly reports of palliative care related deaths in hospital
Increase in % of deaths in the home (expected deaths with EDITH protocols in place)	Percent increase in home deaths in 2009/2010 compared to quarterly reports in 2007/2008.		CHRIS (potentially – to be explored further)	
Reduced hospital length of stay	Key stakeholder/ PCCT perceptions of impact of the team on the hospital length of stay	Perceptions of reduced hospital length of stay	Key stakeholder survey Key stakeholder and PCCT interviews	Key stakeholder survey distributed in September 2010 Key stakeholder interviews conducted in September/ October 2010
Reduction in number of palliative care-related visits to the ED	Key stakeholder/ PCCT perceptions of impact of the team on ED use	Perceptions of reduced ED visits	Key stakeholder survey Key stakeholder and PCCT interviews	Key stakeholder survey distributed in September 2010 Key stakeholder interviews conducted in September/ October 2010

Outcomes	Indicators	Target/Benchmark	Sources of Information	Design/ Timeline
	Caregiver reports of ED visits in previous 30days; perceptions of impact of the team on ED use	Perceptions of reduced ED visits	Caregiver Interviews	Satisfaction interviews (telephone) conducted with caregivers of clients on the PCCTs current caseload; to be conducted in August-September 2010
	ED avoidance (change in service status)	Increase in number of ED avoidances over time	CHRIS	Service tracking from January 1, 2009 to date.
	ED diversions (intervention prevents ED visit)	Increase in number of ED diversions over time	CHRIS	Service tracking from January 1, 2009 to date.
Reduced hospital admissions	Caregiver reports of hospital discharge in previous 7 days, and number of hospital admissions in previous 90 days Reduction in palliative care related hospital admissions over time.	Perceptions of reduced hospital admissions Number of palliative care related hospital admissions	Caregiver Interviews Discharge Abstract Database (DAD) ²⁴ – number of admissions related to palliative care.	Satisfaction interviews (telephone) conducted with caregivers of clients on the PCCTs current caseload; to be conducted in August-September 2010

²⁴ DAD is a database maintained by the Canadian Institute for Health Information (CIHI) that maintains information on hospital admissions and discharges. This data will be accessed for the Chatham-Kent Health Alliance.

Outcomes	Indicators	Target/Benchmark	Sources of Information	Design/ Timeline
				DAD data for 2009 and 2010
Reduced acute care costs for palliative care	Long-term outcome – unable to evaluate in the short time frame of this evaluation			
Reduced hospital admissions through the Emergency Department vs Direct admissions (for patients requiring admission to hospital).	Key stakeholder reports	Increase in direct admissions to palliative care bed	Key stakeholder interviews	Key stakeholder interviews conducted in September/ October 2010
Increased access to vital health care services at home	Key stakeholder (Provider) reports of increased access	90% of providers reporting safer home environments for EOL care as a result of the PCCT	Key stakeholder survey Key stakeholder interviews	Key stakeholder survey distributed in September 2010 Key stakeholder interviews conducted in September/ October 2010
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
<p>Description of the development and implementation of the PCCT (ongoing development and implementation for Sarnia Lambton; initial development and implementation for Chatham Kent)</p>	<ul style="list-style-type: none"> • Factors that facilitated or enabled the ongoing development and implementation of the PCCT • Challenges, or barriers, to role development and implementation • Resolution of challenges identified in the initial evaluation of the Sarnia Lambton PCCT • Service delivery issues • Key lessons learned in ongoing implementation • Suggestions for improvement? For sustainability? For expansion to other counties? • Next steps/ goals for the PCCT? 	<p>Key stakeholder interviews</p>	<p>Key stakeholder interviews conducted in September/ October 2010</p>

Referral and Service Tracking: List of Information Tracked

Referrals/ Services:

- # of referrals to team
- # of referrals per month
- # of clients on active caseload
- # of clients discharged from service
- # of clients that have died
- Length of stay on service (measured in days)
- # of “on call” contacts calls
 - # of contacts with core team members as a result of “on call” contact
- Discharge disposition
 - # of clients that died at home
 - # of clients that died in hospital
- Service recipient categories at time of referral
- # of home laboratory service orders
- # of team members involved per client
- Discipline of team members involved per clients
- # of visits per client per team member
- # of client interactions considered Emergency Department avoidance/ diversion
 - # of clients with an interaction considered ED avoidance/ diversion

Client demographics:

- Age
- Gender
- Living arrangements
- Diagnosis at time of assessment

Caregiver Satisfaction Interview Guide

1. Interview with:

- the caregiver of a patient? What is your relationship to the patient?
 - 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 is in hospice: Yes No
 Care receiver has died:²⁵ 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
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²⁵ This was not an interview question, but was 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. Do you think that the Team helped you to be a better caregiver, that is, did they give you information or suggestions that helped you to better care for your loved one at home?

- Yes
- No
- Not sure

9. Did the team offer you with emotional or spiritual support?,

- Yes No

If yes, did you accept a visit from the team Chaplain or Social Worker?

- Yes No

If yes, how satisfied are you with the way your needs for emotional or spiritual support were met?

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

Do you have any comments you would like to make about this?

13. Do you think that the help that you've received from the team has helped to keep your loved one out of the hospital or from visiting the Emergency Department?
- Not sure
 - No
 - Yes – in what ways (how) has the team done this?
14. Could you please tell me about at least one thing that you really liked about the team and service or care they provided?
15. Was there anything that you didn't like about the team and the service or care they provided?
16. Do you have any suggestions for improving the services or care provided by the team or for improving palliative care or end-of-life care in general?
17. 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

you for taking the time to complete this survey. Your opinions are important to us. **This survey is anonymous and confidential – you do not need to give your name and we will not collect any information that will tell us who you are.**

Please note that this survey is not intended to evaluate the performance of any particular Palliative Care Consultation Team member, but is intended as an evaluation of the role of the team in palliative care service delivery.

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

- In regards to more than 21 patients
- In regards to 11 – 20 patients
- In regards to 6 – 10 patients
- In regards to 1 – 5 patients
- 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
Provision of multidisciplinary/ interprofessional care	1	2	3	4	5
Availability of team members for informal consultation (questions, follow-up)	1	2	3	4	5

11. Do you think that the work of the Team has helped to keep clients out of the hospital or from visiting the Emergency Department?

- Not sure
- No
- Yes – in what ways (how) has the Team done this?

12. What impact do you think the Team has had on the following uses of the health care system.

As a result of the work of the Team has...	Increased	Stayed the Same	Decreased
client’s length of hospital stay...	Increased	Stayed the Same	Decreased
the number of clients dying in hospital....	Increased	Stayed the Same	Decreased
access to vital health care services at home....	Increased	Stayed the Same	Decreased

Additional Comments

Do you have any additional comments you would like to make about the Team or the provision of palliative and 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: _____

Which of the following best describes your practice setting?

- Community-based agency/ organization
- Hospital
- Private Practice
- Long-term care
- Other, please specify:

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

What percentage of the patients that you work with require palliative or end-of-life care?

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

Which of the teams have you been involved with?

- Sarnia Lambton
- Chatham Kent
- Both teams

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

Guide for the Interview with Key Stakeholders

Potential Impacts

We're interested in learning more about the impacts associated with the team.

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

Prompts:

Patient-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
- satisfaction with the provision of multidisciplinary/ interprofessional care
- satisfaction with the provision of emotional and spiritual support
- satisfaction with provision of equipment (assistive devices, equipment for home safety)
- provision of a safer environment for patients and families requiring palliative care at home
- satisfaction with preparation for death

2. 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 – access to EOL education/ resources
- 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. What are some of the health system-related impacts or positive outcomes associated with the Team?

System-related outcomes:

- care planning that's responsive to PPS and ESAS findings
 - 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 visits to ED/ hospitalizations
 - decreased % of deaths in hospital
 - increased % of deaths in the home (expected deaths with the home pronouncement plan in place)
 - 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 Care Consultation Team

I'd like to discuss the development and implementation of the Palliative Care Consultation Team.

I'd like to start by talking about the secondary expert team from the service provider agencies (Resource Nurses).

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

I'd like to now focus on the development and implementation of the Palliative Care 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. What suggestions do you have for improvement, sustainability or further development and implementation of the Team?
9. Do you have any general suggestions for enhancing palliative or 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?

Guide for the Interview with PCCT Members and Leaders

Development and Implementation of the Palliative Consultation Team

We're interested in learning more about the implementation of the team over the past year.

1. What has worked well with the (Sarnia Lambton: ongoing) development and implementation of the Team? What are some of the things that has facilitated its ongoing development and implementation (e.g., needs, support)?
2. 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)?
3. Do you have any suggestions for overcoming these challenges/ barriers?
4. 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?
5. What do you think are some of the key lessons learned in the development and implementation of the Team?
6. What suggestions do you have for improvement, sustainability or further development and implementation of the Team in this setting?

Expansion to other counties

7. 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?
8. Do you have any general suggestions for enhancing palliative or end-of-life care service delivery in this region?

Potential Impacts

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

Prompts:

Patient-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
- satisfaction with the provision of multidisciplinary/ interprofessional care
- satisfaction with the provision of emotional and spiritual support
- satisfaction with provision of equipment (assistive devices, equipment for home safety)
- provision of a safer environment for patients 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 – access to EOL education/ resources
- 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:

- care planning that's responsive to PPS and ESAS findings
- 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 visits to ED/ hospitalizations
- decreased % of deaths in hospital
- increased % of deaths in the home (expected deaths with home pronouncement plans in place)
- increased access to vital health care services at home

10. 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: ²⁶ (April 1, 2009 – September 30, 2010)	143
Referrals per month:	
March 2010	17
April 2010	19
May 2010	30
June 2010	28
July 2010	25
August 2010	15
September 2010	9
Average per month (+/-)	20.4 (7.5)
Range	9 – 30
Number of months	7
Number of clients on active caseload:	44.8% (64)
Number of discharges from service:	55.2% (79)
Number of clients that have died	52/79 (65.8%)
Length of stay on service (N = 79):	
Average (+/-) days	42.3 (40.2)
Range	0 ²⁷ – 170
Number of clients	260
Discharge Disposition (N = 79):	
Hospitalized (>14days)	25.3% (20)
Died (while under CCAC care)	41.8% (33)
Died in hospital (< 14 days) ²⁸	24.1% (19)
Admitted to Long-Term care	1.3% (1)
Client preference ²⁹	2.5% (2)
Treatment complete	5.1% (4)

²⁶ For seven clients, the team (Sarnia Lambton or Chatham Kent) to which they were referred is not known. This may be due to a number of reasons: the referral is pending or the client was originally registered with the Patient Master Index, the information system used by the CCAC prior to the use of the CHRIS, so that this information was not recorded. These seven clients are not included in the total number of clients referred to the Sarnia Lambton PCCT.

²⁷ 0 Length of stay = service and discharge on same day

²⁸ This represents the number of clients that have died at home.

²⁹ Client has chosen to no longer receive service.

CLIENT POPULATION		Percentage (#) N = 143
Age (at time of referral):		
	< 19 years	0
	20 – 49 years	7.0% (10)
	50 – 59 years	14.7% (21)
	60 – 69 years	30.8% (44)
	70 – 79 years	28.7% (41)
	80 – 89 years	15.4% (22)
	> 90 years	3.5% (5)
Age (years)	Average (+/-) Range	68.5 (13.0) 32 – 110
Gender:		
	Female	50.3% (72)
	Male	49.7% (71)
Living Arrangements:		
	Alone	21.0% (30)
	Spouse/ Life partner	58.0% (83)
	With Spouse and family	8.4% (12)
	With family	5.6% (8)
	Non-private residence	0.7% (1)
	Other arrangement	3.5% (5)
Diagnosis (at time of assessment):		
	Cancer ³⁰	78.3% (112)
	Other conditions	21.7% (31)

³⁰ Lung cancer: N = 30; 21.0%; GI (esophagus, bowel, intestines, colon): N = 29; 20.3%; Breast: N = 5, 3.5%; Prostrate: N = 7; 4.9%; Leukemia/ Lymphoma (Hodgkin's & Non-Hodgkins): N =6; 4.2%; All other types (cervix, ovary, endometrium, brain, gall bladder, liver, kidney, pancreas, occur in less than 4, 2.8%, clients each): N = 35, 24.5%.

Service/ Care Provision	Percentage (#)
Service Recipient Categories at Time of Referral (N = 143):³¹	
Acute	2.8% (4)
End of Life	78.3% (112)
Long Term Supportive	9.8% (14)
Maintenance	9.1% (13)
Rehabilitation	0
Number of Interactions with CCAC Internal Providers:	699
Number of interactions per client:	
Average (+/-)	6.9 (8.2)
Range	1 – 45
Number of clients	101
CCAC internal providers involved per interaction (N = 699):	
Nurse Practitioner	32.6% (228)
Occupational Therapist	21.3% (149)
Chaplain	28.3% (198)
Respiratory Therapist	0.6% (4)
Social Worker	17.2% (120)
Average number of CCAC internal providers involved per client (N = 101)	
Average (+/-)	1.7 (.84)
Range	1 – 5
1 service involved	50.5% (51)
2 services involved	31.7% (32)
3 services involved	15.8% (16)
4 services involved	1.0% (1)
5 services involved	1.0% (1)
Type of Interactions (N = 699):	
Face-to-face visit	57.5% (402)
Telephone call	42.5% (297)

³¹ * Clients' overall service goals at the time of admission. *Acute*: to address the client's need for short term education, care or support as a result of illness, disability or injury; *End of Life*: to alleviate distressing symptoms to achieve the best quality of life by providing complex support in the last stages of their illness; *Long term support*: to delay institutionalization by providing supportive care, and relief of symptoms to preserve the client's level of function and autonomy, OR the client is in a Residential hospice setting. *Maintenance*: to maintain the client's independence by preventing/ minimizing the premature decline in health and/or functional status; *Rehabilitation*: to optimize the client's functional status within limits of their disability and to facilitate social integration and independence.

Service/ Care Provision	Percentage (#)
Home Laboratory Services (May 1 – October 29, 2010)	7
Number of Consultations with CCAC Internal Providers (Core Team Members):	21
Number of consultations per client:	
Average (+/-)	3.5 (3.6)
Range	1 – 19
Number of clients	38
Number of client interactions considered hospital avoidance/ diversion	358
Number of clients with an interaction considered hospital avoidance/ diversion (N = 143)	35.7% (51)
Average number of interactions per client considered hospital avoidance/ diversion (N = 51)	
Average (+/-)	7.0 (7.3)
Range	1 - 36
Number of ‘On-Call’ interactions	75
Number of ‘On-Call’ interactions per provider agency (N = 50)	
Provider A	13.3% (10)
Provider B	45.3% (34)
Provider C	41.3% (31)
Type of On-Call interaction (N = 58)	
Telephone consults	85.3% (64)
Face-to-face visits	14.7% (11)
On-Call telephone consults - discipline involved (N = 64)	
Resource Nurse	73.4% (64)
Physician ³²	17.2% (11)
Nurse Practitioner ³³	9.4% (6)
On-Call face-to-face consults – discipline involved (N = 11)	
Resource Nurse ³⁴	100% (11)

³² This indicates the number of times a Resource Nurse contacted a physician as a result of an “on-call” telephone contact with a client.

³³ This indicates the number of times a Resource Nurse contacted a Nurse Practitioner as a result of an “on-call” contact with a client.

Results of the Key Stakeholder Survey

N = 21 (87.5% response rate)

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

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

47.6% (10)	In regards to more than 21 patients
19.0% (4)	In regards to 11 – 20 patients
19.0% (4)	In regards to 6 – 10 patients
14.3% (3)	In regards to 1 – 5 patients
0	Not at all

Overall, how would rate the work of the Team?

poor	fair	good	very good	excellent
0	0	19.0% (4)	33.3% (7)	47.6% (10)

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

	Avg (+/-)	Range
Timeliness of access to assessment (N = 21)	4.24 (.94)	2 – 5
Follow-up (N = 21)	4.29 (.72)	3 – 5
Direct provision of care (N = 21)	4.38 (.67)	3 – 5
Quality of assessment (N = 20)	4.40 (.68)	3 – 5
Treatment recommendations/ planning (N = 21)	4.38 (.67)	3 – 5
Availability of team members for informal consultation (questions, follow-up) (N = 21)	4.33 (.73)	3 – 5
Communication between the team and other care providers (N = 20)	4.35 (.75)	3 – 5
Integration of care across care providers (N = 21)	4.19 (.68)	3 – 5

³⁴ No other team members were contacted by a Resource Nurse as a result of an “on-call” face-to-face contact with a client.

	Avg (+/-)	Range
Integration of care across health sectors (community – hospital) (N = 20)	3.95 (1.1)	2 – 5
Care coordination (N = 21)	4.05 (.81)	3 – 5
Patient/ family readiness for death (N = 21)	4.33 (.58)	3 – 5
Capacity building for end of life care (education/ resources) for team members, including Resource Nurses (N = 21)	4.24 (.83)	3 – 5
Ability to support clients to die in their preferred location (N = 21)	4.62 (.59)	3 – 5

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

- *Maintenance of calendar for scheduled visits from team members, so that one provider aware when another is scheduled to visit and can either schedule for same time with client consent, or re-schedule for another time/day if too overwhelming for client.*
- *I think that the PCCT should try to advertise themselves so that the medical community is more aware of this new expert team trying to help patients stay home with expert symptom and pain control. Family physicians are not really aware of the team and what their role is.*
- *More verbal referral and interaction with team, due to sudden changes in clients referred to the PCCT there is not always the time for electronic processing. If NP is a way or not available there needs to be an approach that considers the client's needs.*
- *I think having NP coverage on weekends would help with improving quality of care.*
- *Enhanced communication between hospital and home especially during an ER visit. Also educate local physicians about the PCCT and what it offers thereby enhancing communication between family physician, client and PCCT.*
- *I am in a supportive capacity for the team and do not provide direct care. My answers may skew this survey. One way to continue to improve individual team members performance is for one to one mentoring.*
- *Intentional mentoring of each PCCT team nurse.*
- *More NP, expertly trained nurses and physicians. It is the physician and nurses who are making the difference with clients staying at home for as long as possible or preventing unnecessary ED assessments. There needs to be increased education also for OT if that role continues (I do not feel it impacts client ability to stay at home or manage better at home, assess also not taking into account clients condition, inability to operate suggested equip). Also, team members - SW, OT only available Mon - Fri, NP works compressed work week, and also unavailable due to # of meetings etc. One other thing is team is set up in "consultative role" not hands on role, which also increased the # of providers having to see clients*
- *develop symptom control kit for palliative care patients especially on weekends when pharmacy may not be readily available*
- *Better team education would assist in providing enhanced expert care.*

Impacts

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

66.7% (14)	Much improved
28.6% (6)	Improved
0	Neither improved nor worsened
0	Worsened
0	Much worsened

How would you rate the current level of safety within home environments for end-of-life care? (5 point rating scale: 1 = not at all safe; 5 = extremely safe) (N = 20)

4.10 (.64)	Average (+/-)
3 – 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	14.3% (3)	38.1% (8)	14.3% (3)	23.8% (5)

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

38.1% (8)	Much increased
42.9% (9)	Increased
14.3% (3)	Neither increased nor decreased
0	Decreased
0	Much decreased

Overall, how would you rate your current ability to manage patients 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
4.50 (.61)	Average (+/-)
3 – 5	Range

How does this compare with your ability to manage patients 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	4.8% (1)	23.8% (5)	23.8% (5)	38.1% (8)

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

47.6% (1)	Much improved
42.9% (9)	Improved
4.8% (1)	Neither improved nor worsened
0	Worsened
0	Much worsened

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

19.0% (4)	No
61.9% (13)	Yes, please describe: •

- *PCCT/Oncology Team collaboration and involvement with all engaged community partners and those in the circle of care to ultimately assist/enable the Client to reach their end of life goals, i.e., to pass away at home or the local Hospice.*
- *More supports available to resource nursing staff, not only for client care, but for personal supports and reassurances. Hospital avoidance significant. More specialized holistic resources are available to a population who are unable to otherwise access some of the services which provide supports in care i.e. blood work at home, pastoral services.*
- *Sharing of knowledge and tools such as ESAS and PPS to the front line nurses, caregivers and other professional staff so that their is a common language for developing care plans. Improved access to care. The NP availability as well as*
- *people are wanting to stay at home the team makes it possible*
- *The availability of spiritual/consultative care has helped the clients feel more connected to the care pathways provided by the entire team.*
- *palliative clients who have had no family physician now have access to PCCT physicians, quicker response time for pain crisis, easier access for support from team members i.e.,: advice from fellow team members, increased confidence in nurses*
- *More accessibility to Dr. /N.P. for orders for the patients. Better services available more readily for the clients.*
- *Clients/ family feel more supported as well as the nursing staff within the homes.*
- *Clients have access to more timely med changes, new prescriptions etc. As well, they receive visits from a NP and have access to s social worker, OT, Chaplain and Music Therapist, again in a much more timely manner than before. Palliative*

- *Patients now have a choice to stay at home with adequate support and symptom management and education regarding the issues they face. More focused and appropriate use of the ED and hospital PCU. Health grief follows a "good death".*
- *increased knowledge of nurses when assessing clients symptoms to prevent ED assess (if physician available to call - works best with Dr Maddison/ Dostaler/ Kolano and a couple of GP's)*
- *better assess for palliative care patients to nursing staff familiar with palliative care problems*
- *I am finding that we have been able to keep more patients at home (by their choice) when they have very complex issues/concerns. As opposed to before the team, these patients would have been sent to hospital.*

Do you think that the work of the Team has helped to keep clients out of the hospital or from visiting the Emergency Department?

19.0% (4)	Not sure
0	No
61.9% (13)	Yes – in what ways (how) has the Team done this?

- Averting hospital/ER admissions/visits by managing the Client in their home, through the professional expertise and compassion of all Team members to create a comfortable and safe home environment, enabling the Client to best achieve their end of life goals.
- we now can access a physician more easily after hours as well as on the weekends
- Increased number of resources but mostly due to NP access for home assessments.
- By having direct, immediate access to Nursing, nurse practitioners and physician this has definitely impacted the patient's ability to remain in their home for treatment instead of the Emergency departments. Access to immediate care is important to patients and their families.
- -Absolutely!! Arranging for hydration in the home through NP rather than ER visit, assessing and treating simple infections at home such as a UTI avoids ER visits. The Team assisting patients and their families at home to manage delirium and terminal restlessness has kept clients out of ER and hospital. Managing pain crises through the team (NP, Physician consultant) when the MRP is not available avoids ER visits.
- Sometimes it is simply pain control, nursing care, emotional and spiritual care now we come to them.
- Orders can be given without the clients having to attend the ER and home examinations for the clients by the Dr./NP on the team
- When symptom are managed in a more timely fashion...this enables clients to stay home instead of presenting to ER for assessment.
- Symptoms are managed by timely medication changes and prescriptions because front line nurses have access to resource nurses, PCCT NP's and PCCT Physicians thereby averting an ER visit. This is especially true in crisis pain and symptoms situations.
- Education for pt and family support in decision-making management of issues at EOL timely response and support in EOL crises.
- Usually - due to speaking with physicians post assess of client to manage symptoms in the home. Still further education needs to be done
- better care at home, improved symptom control, better support for family

- Better able to provide care in the home (through collaboration b/w doctor, NP's, nurses, SW, and OT...). Through education and communication, people are collaborating with one another to solve the complex concerns as opposed to before the automatic response to any of the concerns would have been "You need to go to the hospital/ER".

What impact do you think the Team has had on the following uses of the health care system.

As a result of the work of the Team has...	Increased	Stayed the Same	Decreased
client's length of hospital stay...	0	14.3% (3)	71.4% (15)
the number of clients dying in hospital....	0	19.0% (4)	66.7% (14)
access to vital health care services at home....	85.7% (18)	0	0

Additional Comments

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

- *The Team is composed of individuals who have a passion for palliative and end-of-life care. The individuals I have had the opportunity to work with have consistently demonstrated Client centered practice and their commitment to providing the best service(s) to end of life Client's in Lambton and Chatham County.*
- *I think we have a great system working here in this region. We are very lucky and blessed to have great care providers that other communities do not have available yet. We are inspiring other communities to provide the same quality of care we have and we are definitely leading the way for quality patient care in this province.*
- *I think the addition of a residential hospice would enhance palliative care in our community. For those patients who wish to remain at home but may not have the supports to do so (caregiver) could move over to a hospice for care if necessary and avoid hospitals.*
- *I believe from a chaplaincy perspective that society is learning how to die with dignity and in the presence of family familiar surroundings*
- *Really like the comradery amongst the team the boundary lines or competition lines have disappeared.*
- *I have heard from clients that they feel more supported and their anxiety levels decreased knowing that if they need the help it is available to them. I have also noticed that clients and their families are able to manage at home longer before going to hospital to die if the hospital is their preferred place to die.*
- *The team is an excellent role model for other areas. Using experienced nurses and supporting them with NP and physician and pastoral care and social to provide holistic care in the home. On-going education is happening with interdisciplinary rounds twice a week. One on one mentoring would also enhance their practice.*

- Importance of education for more nurses for quality assessments and more resources for shift care to maintain client in their home, rather than admit to hospice

Demographic Information

Which of the following best describes your discipline/profession?

9.5% (2)	Physician
23.8% (5)	Registered Nurse
0	Registered Practical Nurse
0	Personal Support Worker
4.8% (1)	Nurse Practitioner
4.8% (1)	Respiratory Therapist
4.8% (1)	Social Worker
4.8% (1)	Occupational Therapist
14.3% (3)	Case Manager
% ()	Agency nursing supervisor
% ()	Pharmacist
4.8% (1)	Volunteer coordinator
4.8% (1)	Pastoral/spiritual care
9.5% (2)	Other, please describe: <ul style="list-style-type: none"> • Clinic Administration • Music Therapist

Which of the following best describes your practice setting?

66.7% (14)	Community-based agency/ organization
0	Hospital
14.3% (3)	Private Practice
0	Long-term care
4.8% (1)	Other, please specify: <ul style="list-style-type: none"> • Across all sectors

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

15.13 (11.6)	Average (+/-)
1 – 45	Range

What percentage of the patients that you work with require palliative or end-of-life care?

0	Not applicable
0	None
9.5% (2)	Less than 25%
14.3% (3)	26% - 50%
14.3% (3)	51% - 75%
47.6% (10)	Over 75%