

From Counting Outputs to Assessing Outcomes: A Shift in Measuring the Impact of Palliative Care Services

April 29, 2013
HPCO Conference
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Learning Objectives

1. To share the comprehensive evidence based Framework for Evaluation to apply to palliative care programs.
2. To demonstrate applicability of the Framework to palliative care services/programs.
3. To assist attendees in applying the framework to their own setting.



Background

Outcomes versus Outputs

In the past, health service providers were required to report on their **outputs** - how many clients did they see, for how many hours. Now, the LHIN instead asks them to report on their **outcomes** - how are clients healthier as a result of the program.



- Ministry support of the Integrated Client Care Project (ICCP) – Palliative Care. A partnership with Institute for Clinical and Evaluative Sciences (ICES) and the Ontario Association of Community Care Access Centres (OACCAC)
- ICCP-PC involves 6 CCACs and their contracted Service Provider Organization (SPOs) in testing innovations in palliative care that will improve the quality of services provided to the client
- Impact Assessment (IA) Team for ICCP-PC is tasked with determining how to measure the impact of ICCP-PC



Development of the Framework

- Based on a comprehensive review of indicators from around the world
- Includes quantitative and qualitative analysis
- Presents methods for using cost, processes and client/caregiver experiences to evaluate outcomes of care
- Participating ICCP-PC sites provided input during the development of the Framework



Measuring Palliative Care in Ontario

Many moving parts to consider for coordinated measurement!

LHIN Co-Leads for Provincial PC - Data & Performance Working Group

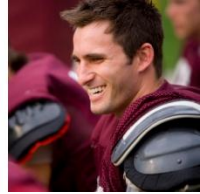
Provincial Declaration

LHIN Wide Palliative Care Planning

Outcomes Based Pathways/Reimbursement: All CCACs and SPOs

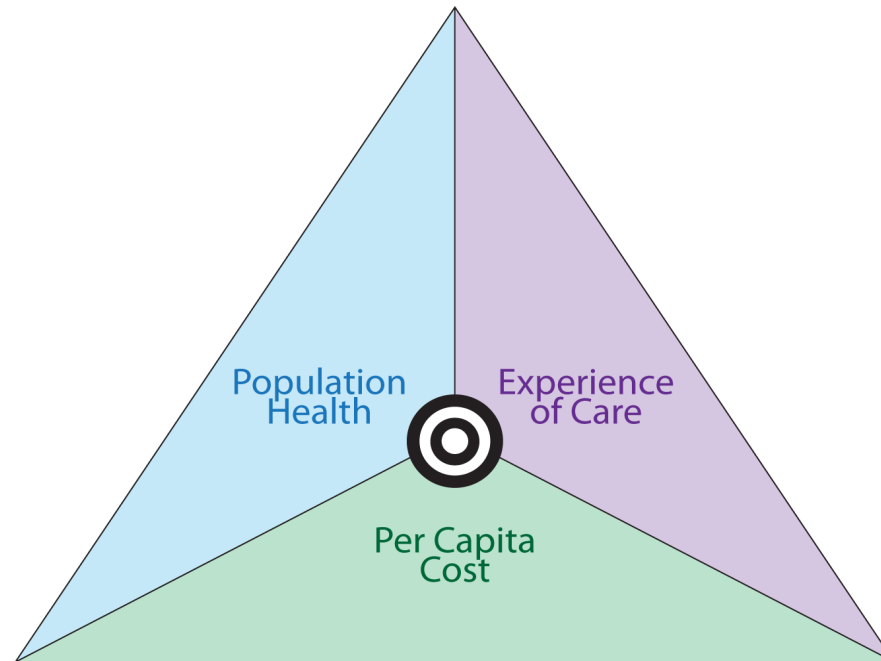
Nurse Practitioners

ICCP-PC: Select CCACs and SPOs



Triple Aim

Balancing the Triple Aim* helps to develop balanced measures



*Adapted from: The Institute for Healthcare Improvement

Overview of the IA Team's Approach to Evaluation

ICCP FRAMEWORK FOR EVALUATION

IA Team Goal: Demonstrate “effectiveness”/impact of the ICC teams’ interventions.

Specific Goals:

1. Clients and families should receive **clinical best practices** based on their needs.
2. Clients and families experience **seamless transitions** across care settings.
3. Clients and families are **active participants** in care planning decisions.
4. Clients who wish to be **cared for or die at home** are supported to do so.
5. Client care is paid for based on quality and outcomes.

Cost

Use ICES admin data up to **March 31, 2013**

- Compares enhanced care vs. usual care
- Use propensity score matching to simulate a Randomized Control Trial (RCT)

Compare rates of:

- Emergency department (ED) visits
- Hospitalizations
- Length of stay (LOS)
- Death in hospital
- Difference in overall costs
- CCAC/home care use

Process

Provider Experience Tool

- Compares enhanced care vs. usual care

- *Tools to be determined*

Qualitative Analysis of Sites

- Compares enhanced care vs. usual care

- *What did the team do?*
- *What is the intervention?*

Outcomes Based Pathways/Reimbursement (OBP/R)

Client/Family Experience

Online surveys using validated tools

- Compares enhanced care vs. usual care

Key dimensions of care important to client/family. Examples include:

- *Communication*
- *Shared decision-making*
- *Symptom management*
- *Spiritual support*
- *Skill of care team*
- *Access to care team 24/7*
- *Etc.*

Client Interviews (client stories and videos)

- Compares enhanced care vs. usual care

In collaboration with Sites & OA

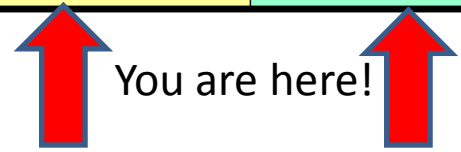


“Real World” Applicability

Understand why you're measuring...

The Three Faces of Performance Measurement

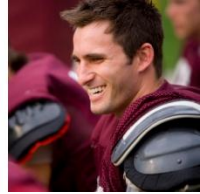
Aspect	Improvement	Accountability	Research
<u>Aim</u>	Improvement of care	Comparison, choice, reassurance, spur for change	New knowledge
<u>Methods:</u> • Test Observability	Test observable	No test, evaluate current performance	Test blinded or controlled
• Bias	Accept consistent bias	Measure and adjust to reduce bias	Design to eliminate bias
• Sample Size	“Just enough” data, small sequential samples	Obtain 100% of available, relevant data	“Just in case” data
• Flexibility of Hypothesis	Hypothesis flexible, changes as learning takes place	No hypothesis	Fixed hypothesis
• Testing Strategy	Sequential tests	No tests	One large test
• Determining if a change is an improvement	Run charts or Shewhart control charts	No change focus	Hypothesis, statistical tests (t-test, F-test, chi square), p-values
• Confidentiality of the data	Data used only by those involved with improvement	Data available for public consumption and review	Research subjects' identities protected





Lessons Learned and Applicability

- Know why you're measuring...for improvement, accountability or research
- Much work is happening to develop measures..don't lose sight of how your program measures fit in the system
- Focus on outcomes not just outputs
- Data is important but don't forget about the quality and experience of care



Thank You!

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Caregiver Experience Survey

This survey is about the care and services received by you and your family member/friend in the last months of his/her life. The information you give will help us improve care for people who are dying, and for their family and friends. Your views are, therefore, important to us. We realize this questionnaire may bring back strong memories.

We are interested in finding out the experiences of all people who have died whether suddenly, after a short illness, or after a long illness. Some of the questions may not be relevant to you. Please fill in as much of the survey as you can, or if you would rather not answer one of the questions, please go on to the next one.

Instructions: As you go through the survey, please follow the instructions and answer the questions by ticking the most appropriate box or boxes, like this . Tick only one answer to each question unless the question states otherwise.

The survey takes about 20 minutes to complete.

This survey is anonymous and completion is voluntary.

Please complete the survey at your earliest convenience and return the completed survey in the stamped, self-addressed envelope provided.

This study is being managed by a research team at McMaster University, Hamilton, Ontario on behalf of the Ontario Ministry of Health, Ontario Community Care Access Centres, and service providers.

Contact information is provided on the last page of this survey form.

This survey contains questions from the following questionnaires:

FAMCARE Scale (Kristjanson L.J. Validity and reliability testing of the FAMCARE Scale: measuring family satisfaction with advanced cancer care. Soc Sci Med 1993; 36: 693–701.)

VOICES questionnaire (Hunt, K.J., Shlomo, N., Richardson, A., Addington-Hall J.M. (2011) VOICES Redesign and Testing to Inform a National End of Life Care Survey. Southampton: University of Southampton)

PART A: Family Member/Friend Information

The first set of questions asks some general information about the family member/friend you cared for.

1. What was the gender of this person? Male Female
2. How old was he/she when he/she died?
- | | | |
|--------------------------------|--------------------------------|-------------------------------------|
| <input type="checkbox"/> 18-19 | <input type="checkbox"/> 40-49 | <input type="checkbox"/> 70-79 |
| <input type="checkbox"/> 20-29 | <input type="checkbox"/> 50-59 | <input type="checkbox"/> 80-89 |
| <input type="checkbox"/> 30-39 | <input type="checkbox"/> 60-69 | <input type="checkbox"/> 90+ |
| | | <input type="checkbox"/> Don't know |
- 3 What was his/her diagnosis? _____ Don't know
4. Where in Ontario did he/she receive most of his/her care in the last three months of life?
- | | |
|--|---|
| <input type="checkbox"/> Bolton, Brampton, Caledon, Dufferin County, Malton, Orangeville, Rexdale, Shelburne, Woodbridge | <input type="checkbox"/> South Etobicoke, Mississauga, Halton Hills, Oakville, Milton |
| <input type="checkbox"/> Brant, Burlington, Haldimand, Hamilton, Niagara, Norfolk | <input type="checkbox"/> Waterloo Wellington |
| <input type="checkbox"/> Central Toronto | |
| <input type="checkbox"/> United Counties of Leeds & Grenville, Lanark County | <input type="checkbox"/> Other (specify) _____
_____ |
5. Which ethnic group did he/she belong to? *Tick one only*
- | | |
|---|---|
| <input type="checkbox"/> South Asian | <input type="checkbox"/> European |
| <input type="checkbox"/> Chinese | <input type="checkbox"/> Middle Eastern |
| <input type="checkbox"/> Black | <input type="checkbox"/> Aboriginal |
| <input type="checkbox"/> Filipino | <input type="checkbox"/> Don't know |
| <input type="checkbox"/> Latin American | <input type="checkbox"/> Other group (specify): _____ |
6. What was his/her religion? *Tick one only*
- | | |
|--|--|
| <input type="checkbox"/> No religion | <input type="checkbox"/> Muslim |
| <input type="checkbox"/> Christian (all denominations) | <input type="checkbox"/> Sikh |
| <input type="checkbox"/> Buddhist | <input type="checkbox"/> Don't know |
| <input type="checkbox"/> Hindu | <input type="checkbox"/> Other religion (specify): _____ |
| <input type="checkbox"/> Jewish | |

PART B: General Satisfaction with Aspects of Care

For these next questions think about the actions of the homecare providers (nurses, personal support workers, social workers, etc.) that were involved in the care of your family member/friend in the last three months of life.

Please answer the questions below indicating the extent to which you were satisfied with the following:

	Very Satisfied	Satisfied	Neither	Dissatisfied	Very Dissatisfied	Don't know
a) His/her comfort	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) The way in which his/her condition and likely progress were explained by the homecare providers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Information given about the side effects of treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) The way in which the homecare providers respected his/her dignity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Meetings with the homecare providers to discuss his/her condition and plan of care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Speed with which symptoms were treated	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) Homecare providers' attention to his/her description of symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) The way in which his/her physical needs for comfort were met	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) Availability of the homecare providers to the family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) Emotional support provided to family members by the homecare providers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k) The practical assistance provided by the homecare providers (e.g. bathing, respite)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l) The Doctor's attention to his/her symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m) The way the family was included in treatment and homecare decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n) Information given about how to manage his/her symptoms (e.g. pain, constipation)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

PART B: General Satisfaction *continued*

	Very Satisfied	Satisfied	Neither	Dissatisfied	Very Dissatisfied	Don't know
o) How effectively the homecare providers managed his/her symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p) The homecare providers' response to changes in his/her care needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
q) Emotional support provided to him/her by the homecare providers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
r) Homecare providers knowing about the problems that had bothered him/her at previous visits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
s) Homecare provided in a manner respectful of his/her culture, customs, and faith	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

PART C: Care in Different Settings

The questions in the next sections are about care your family member/friend may have received in different settings, as specified.

1. Did he/she spend any time at home during the last three months of life?

- Yes
- He/she was in a long term care home for the whole 3 months – **go to Q24 (page 9)**
- No – **go to Q28 (page 10)**

Care at Home

2. When he/she was at home in the last three months of life, did he/she get any help at home from any of the services listed below? *Tick all that apply*

- | | |
|--|--|
| <input type="checkbox"/> Homecare nurse | <input type="checkbox"/> Physiotherapist (PT) |
| <input type="checkbox"/> Any other nurse at home | <input type="checkbox"/> Occupational therapist (OT) |
| <input type="checkbox"/> Personal support worker | <input type="checkbox"/> He/she did not receive any care |
| <input type="checkbox"/> Social worker | <input type="checkbox"/> Don't know |
| <input type="checkbox"/> Religious leader | <input type="checkbox"/> Other (specify): _____ |
| <input type="checkbox"/> Meals-on-wheels or other home delivered meals | <input type="checkbox"/> Other (specify): _____ |
| <input type="checkbox"/> Hospice volunteers | <input type="checkbox"/> Other (specify): _____ |

3. When he/she was at home in the last three months of life, did all these services work well together?

- Yes, definitely
- Yes, to some extent
- No, they did not work well together
- He/she did not receive any care
- Don't know

4. Overall, do you feel that you and your family got as much help and support from health and supportive services as you needed when caring for him/her?

- Yes, we got as much support as we wanted
- Yes, we got some support but not as much as we wanted
- No, although we tried to get more help
- No, but we did not ask for more help
- We did not need help

5. During the last three months of his/her life, while he/she was at home, how well was his/her pain relieved?

- Does not apply – he/she did not have any pain
- Completely, all of the time
- Completely, some of the time
- Partially
- Not at all
- Don't know

Urgent Care Provided Out of Normal Business Hours

6. Other than calling “911”, did he/she or you know how to contact the homecare providers any time assistance was needed with an urgent problem? This includes during evenings or weekends.

- Yes
- No
- Not sure

7. In the last three months of life, while he/she was at home, did he/she ever need to contact a health professional for something urgent in the evening or during the weekend?

- Not at all in the last 3 months – **go to Q12 (page 7)**
- Once or twice – **go to Q8**
- Three or four times – **go to Q8**
- Five times or more – **go to Q8**
- Don't know – **go to Q12 (page 7)**

8. The last time this happened, who did he/she contact, or who was contacted on his/her behalf?

His/her family doctor or the doctor's after-hours number

Homecare

Hospice

He/she used his/her lifeline pendant

911

Something else – please write in the space below:

9. What happened as a result? (e.g., visited by nurse, advised to go to ED) *Tick one only*

Visited by his/her family doctor at home

Visited by a palliative care doctor or another doctor at home

Visited by a homecare provider at home

Visited by a hospice volunteer at home

Given medical advice over the telephone

Given another number to call to get medical advice

Advised to go to an Emergency Department at a hospital

Advised to call 911

Something else – please write in the space below:

10. In your opinion, was this the right thing for them to do, or not?

Yes

No

Not sure

11. Overall, do you feel that the care he/she got when he/she needed care urgently in the evenings or weekends in the last three months of life was:

Excellent

Good

Fair

Poor

Don't know

Homecare

12. Did he/she have care from homecare providers (nurses, personal support workers, social workers, etc.) in the last 3 months of life?

- Yes
- No – **go to Q16**

13. How often did the homecare providers visit (at the most frequent time)?

- More than once a day
- 2-3 times a month
- Everyday
- Less often
- 2-6 times a week
- Don't know
- Once a week

14. How much of the time was he/she treated with respect and dignity by the homecare providers?

- Always
- Most of the time
- Some of the time
- Never
- Don't know

15. Overall, do you feel that the care he/she got from the homecare providers in the last three months of life was:

- Excellent
- Good
- Fair
- Poor
- Don't know

Visiting Hospice Volunteers

16. Did he/she get help from visiting hospice volunteer(s) in the home in the last 3 months of life?

- Yes
- No – **go to Q19 (next page)**
- Don't know – **go to Q19 (next page)**

17. How often did the visiting hospice volunteer(s) visit (at the most frequent time)?

- More than once a day
- Everyday
- 2-6 times a week
- Once a week
- 2-3 times a month
- Less often
- Don't know

18. Indicate your opinion about the help he/she got from the visiting hospice volunteer(s) in the last three months of life as to the following:

	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree	Does not Apply	Don't Know
a) Helped to improve his/her quality of life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Helped him/her to avoid unnecessary emergency department visits or hospitalizations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Care from the Family Doctor or Palliative Care Doctor

19. In the last 3 months, which type of doctor provided the most of his/her care? *Tick one only*

- His/her family doctor
- Palliative care doctor
- Other doctor
- He/she did not need to see a doctor – **go to Q24 (next page)**
- He/she needed to see a doctor but did not see one – **go to Q24 (next page)**
- Don't know – **go to Q24 (next page)**

20. How much of the time was he/she treated with respect and dignity by this doctor?

- Always
- Most of the time
- Some of the time
- Never
- Don't know

21. Were you able to discuss any worries and fears you may have had about his/her condition, treatment or tests with this doctor? *Tick one only*

- I had no worries or fears to discuss
- Yes, I discussed them as much as I wanted
- Yes, I discussed them, but not as much as I wanted
- No, although I tried to discuss them
- No, but I did not try to discuss them

22. Overall, how easy or difficult was it to get this doctor to visit him/her at home in the last three months? *Tick one only*

- Very easy
- Very difficult
- Fairly easy
- He/she wanted the doctor to visit but they would not
- Fairly difficult
- Don't know

23. Overall, do you feel that the care he/she got from this doctor in the last three months of life was:

- Excellent
- Good
- Fair
- Poor
- Don't know

Long Term Care Homes

24. Did he/she live or stay in a long term care home at any time during his/her last three months of life?

- Yes
- No – **go to Q28 (next page)**
- Don't know – **go to Q28 (next page)**

25. How much of the time was he/she treated with respect and dignity by the staff at the long term care home?

- Always
- Most of the time
- Some of the time
- Never
- Don't know

26. During the last three months of his/her life, while he/she was in the long term care home, how well was his/her pain relieved?

- Does not apply – he/she did not have any pain
- Partially
- Completely, all of the time
- Not at all
- Completely, some of the time
- Don't know

27. Overall, do you feel that the care he/she got from the long term care home in the last three months of life was:

- Excellent
- Good
- Fair
- Poor
- Don't know

Last Hospital Admission

28. Did he/she stay in hospital at any time during his/her last three months of life?

- No – **go to Q33 (next page)**
- Don't know – **go to Q33 (next page)**
- Yes – what was the reason? _____

29. During his/her last hospital admission, how much of the time was he/she treated with respect and dignity by the hospital doctors and nurses (*answer individually for each*)?

- | <i>Doctors</i> | <i>Nurses</i> |
|---|---|
| <input type="checkbox"/> Always | <input type="checkbox"/> Always |
| <input type="checkbox"/> Most of the time | <input type="checkbox"/> Most of the time |
| <input type="checkbox"/> Some of the time | <input type="checkbox"/> Some of the time |
| <input type="checkbox"/> Never | <input type="checkbox"/> Never |
| <input type="checkbox"/> Don't know | <input type="checkbox"/> Don't know |

30. During his/her last hospital admission, how well was his/her pain relieved?

- | | |
|--|-------------------------------------|
| <input type="checkbox"/> Does not apply – he/she did not have any pain | <input type="checkbox"/> Partially |
| <input type="checkbox"/> Completely, all of the time | <input type="checkbox"/> Not at all |
| <input type="checkbox"/> Completely, some of the time | <input type="checkbox"/> Don't know |

31. Did the hospital services work well together with his/her family doctor and other services outside of the hospital?

- Yes, definitely
- Yes, to some extent
- No, they did not work well together
- Don't know

32. Overall, do you feel that the care he/she got from the staff in the hospital on that admission was (answer individually for each):

Doctors

Excellent

Good

Fair

Poor

Don't know

Nurses

Excellent

Good

Fair

Poor

Don't know

Hospice Admission

33. Did he/she stay in a hospice at any time during his/her last three months of life?

Yes

No – **go to PART D Q37 (next page)**

Don't know – **go to PART D Q37 (next page)**

34. How much of the time was he/she treated with respect and dignity by the hospice doctors and nurses (answer individually for each)?

Doctors

Always

Most of the time

Some of the time

Never

Don't know

Nurses

Always

Most of the time

Some of the time

Never

Don't know

35. During the last three months of his/her life, while he/she was in the hospice, how well was his/her pain relieved?

Does not apply – he/she did not have any pain

Completely, all of the time

Completely, some of the time

Partially

Not at all

Don't know

36. Overall, do you feel that the care he/she got from the staff in the hospice was:

Excellent

Good

Fair

Poor

Don't know

PART D: Experiences in the Last Week of Life

37. During his/her last week of life was he/she:

- At home all the time
- In a long term care home all the time
- In a hospital all the time
- In a hospice all the time
- Other – please write in the space below:

38. How much of the time was he/she treated with respect and dignity in the last week of life by the doctors, nurses, and personal support workers (*answer individually for each*)?

	<i>Doctors</i>	<i>Nurses</i>	<i>Personal Support Workers</i>
	<input type="checkbox"/> Always	<input type="checkbox"/> Always	<input type="checkbox"/> Always
	<input type="checkbox"/> Most of the time	<input type="checkbox"/> Most of the time	<input type="checkbox"/> Most of the time
	<input type="checkbox"/> Some of the time	<input type="checkbox"/> Some of the time	<input type="checkbox"/> Some of the time
	<input type="checkbox"/> Never	<input type="checkbox"/> Never	<input type="checkbox"/> Never
	<input type="checkbox"/> Does not Apply	<input type="checkbox"/> Does not Apply	<input type="checkbox"/> Does not Apply
	<input type="checkbox"/> Don't know	<input type="checkbox"/> Don't know	<input type="checkbox"/> Don't know

39. Indicate your opinion about the help he/she received in the last week of life to the following:

	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree	Does not Apply	Don't Know
a) There was enough help available to meet his/her personal care needs (such as toileting needs)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) There was enough help with nursing care, such as giving medicine and helping him/her find a comfortable position in bed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) The bed area and surrounding environment had adequate privacy for him/her	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

40. During the last week, how do you assess the overall level of support given in the following areas from those caring for him/her?

	Excellent	Good	Fair	Poor	Does not Apply	Don't Know
a) Relief of pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Relief of other symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Spiritual support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Emotional support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Support to stay where he/she wanted to be	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

PART E: Circumstances Surrounding His/Her Death

41. Did he/she know he/she was likely to die?

- Yes, certainly
- Yes, probably
- Probably not
- No, definitely
- Not sure

42. In your opinion, did the person who told him/her that he/she was likely to die break the news to him/her in a sensitive and caring way? *Tick one only*

- Yes, definitely
- Yes, to some extent
- No, not at all
- Don't know
- Does not apply – they did not know he/she was dying
- Does not apply – they did not tell him/her that he/she was dying

43. Were you contacted soon enough to give you time to be with him/her before he/she died?

Tick one only

- Yes
- No
- I was there already
- It was not clear that he/she was going to die soon
- I couldn't have got there anyway

44. Where did he/she die? *Tick one only*

- At home
- In a hospital
- In a hospice
- In a long term care home
- Other – please write in the space below:

45. How long had he/she been ill before he/she died?

- He/she was not ill – he/she died suddenly
- Less than 24 hours
- One day or more, but less than one week
- One week or more, but less than one month
- One month or more, but less than six months
- Six months or more, but less than one year
- One year or more

46. Did he/she ever say where he/she would like to die?

- Yes
- No – **go to Q49**
- Not sure – **go to Q49**

47. Where did he/she say that he/she would like to die? *Tick one only*

- At home
- In a hospice
- In a hospital
- In a long term care home
- He/she said that he/she did not mind where he/she died
- He/she changed his/her mind about where he/she wanted to die
- Other – please write in the space below:

48. Did the health care providers have a record of this?

- Yes
- No
- Not sure

49. Do you think that he/she had enough choice about where he/she died?

- Yes
- No
- Not sure
- He/she died suddenly

50. Do you think that he/she died in the right place?

Yes

No – why not? _____

Not sure

51. Were you or his/her family given enough help and support by the health care providers at the actual time of his/her death?

Yes, definitely

Yes, to some extent

No, not at all

Don't know

52. After he/she died, did the health care providers deal with you or his/her family in a sensitive manner?

Yes

No

Not sure

Does not apply, I didn't have any contact with the care providers

53. Looking back over the last three months of his/her life, was he/she involved in decisions about his/her care as much as he/she would have wanted?

He/she was involved as much as he/she wanted to be

He/she wasn't able to be involved due to incapacity

He/she would have liked to be more involved

Don't know

He/she would have liked to be less involved

54. Looking back over the last three months of his/her life, were you involved in decisions about his/her care as much as you would have wanted?

I was involved as much as I wanted to be

I would have liked to be more involved

I would have liked to be less involved

Don't know

55. Were any decisions made about his/her care that he/she would not have wanted?

- Yes
- No
- Don't know

56. Overall, and taking all services into account, how would you rate his/her care in the last three months of life?

- Outstanding
- Excellent
- Good
- Fair
- Poor
- Don't know

57. Since he/she died, have you talked to anyone from health and social services, or from a bereavement service, about your feelings about his/her illness and death?

- Yes
- No, but I would have liked to
- No, but I did not want to anyway
- Not sure

PART F: Information about You

58. What was your relationship to him/her? *Tick one only*

- Husband/wife
- Son/daughter
- Brother/sister
- Son/daughter-in-law
- Brother-in-law/sister-in-law
- Parent/parent-in-law
- Other (specify): _____

59. What is your gender? Male Female

60. How old are you?

- 18-19
- 20-29
- 30-39
- 40-49
- 50-59
- 60-69
- 70-79
- 80-89
- 90+

PART G: Final Thoughts You Wish to Share

Lastly, please share any other thoughts you have about what was **good** and what was **bad** about the care services that were provided to your family member or friend within the **last 3 months of life**.

What, if anything, was **good** about the care?

- Not sure Nothing was good Specified below ↓

What, if anything, was **bad** about the care?

- Not sure Nothing was bad Specified below ↓

Would you be willing to be contacted by a researcher to tell us more about your care experience? *Please note that a "yes" response doesn't necessarily mean that you will be contacted.*

- Yes No

If **Yes**, please provide us with your name and either your phone number or email address:

Name: _____ Tel: _____ Email: _____

Writing your name this survey will mean that it is no longer anonymous; however, this contact information will be kept strictly confidential and not be shared with the healthcare providers or anyone else

Thank you!

The time you spent completing this survey is greatly appreciated

Please return completed survey in the stamped, self-addressed envelope provided As Soon As Possible.

**Caregiver Experience Survey
c/o Juravinski Cancer Centre
699 Concession Street
Level 4, Room 204
Hamilton, Ontario
L8V 5C2**

Should you have any questions or concerns please contact:

Adrienne Van Dam at PH: (905) 387-9711 ex. 64507 EMAIL: adrienne.vandam@jcc.hhsc.ca

**Or the study principal investigator, Dr. Hsien Seow
PH: (905) 387-9711 ex. 64509 EMAIL: seowh@mcmaster.ca**