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

April 29, 2013
HPCO Conference
Deanna Bryant, MPA
Dr. Hsien Seow
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

• 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
- Outcomes Based Pathways/Reimbursement: All CCACs and SPOs
- Nurse Practitioners
- LHIN Wide Palliative Care Planning
- ICCP-PC: Select CCACs and SPOs
Balancing the Triple Aim helps to develop balanced measures

*Adapted from: The Institute for Healthcare Improvement
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.

<table>
<thead>
<tr>
<th>Cost</th>
<th>Process</th>
<th>Client/Family Experience</th>
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</thead>
<tbody>
<tr>
<td>Use ICES admin data up to March 31, 2013</td>
<td>Provider Experience Tool</td>
<td>Online surveys using validated tools</td>
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<tr>
<td>• Compares enhanced care vs. usual care</td>
<td>• Compares enhanced care vs. usual care</td>
<td>• Compares enhanced care vs. usual care</td>
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<tr>
<td>• Use propensity score matching to simulate a Randomized Control Trial (RCT)</td>
<td>• <strong>Tools to be determined</strong></td>
<td>Key dimensions of care important to client/family. Examples include:</td>
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<tr>
<td></td>
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<td>• Communication</td>
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<td>• Shared decision-making</td>
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<td>• Symptom management</td>
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<td>• Spiritual support</td>
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<td>• Skill of care team</td>
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<td>• Access to care team 24/7</td>
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<td></td>
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<td>• Etc.</td>
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<td></td>
<td>Qualitative Analysis of Sites</td>
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<td></td>
<td>• Compares enhanced care vs. usual care</td>
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<tr>
<td></td>
<td>• <strong>What did the team do?</strong></td>
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<td></td>
<td>• <strong>What is the intervention?</strong></td>
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<td></td>
<td>Outcomes Based Pathways/Reimbursement (OBP/R)</td>
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In collaboration with Sites & OA

Adapted from: The Institute for Healthcare Improvement
### “Real World” Applicability

#### The Three Faces of Performance Measurement

<table>
<thead>
<tr>
<th>Aspect</th>
<th>Improvement</th>
<th>Accountability</th>
<th>Research</th>
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</thead>
<tbody>
<tr>
<td><strong>Aim</strong></td>
<td>Improvement of care</td>
<td>Comparison, choice, reassurance, spur for change</td>
<td>New knowledge</td>
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<tr>
<td><strong>Methods:</strong></td>
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<tr>
<td>• Test Observability</td>
<td>Test observable</td>
<td>No test, evaluate current performance</td>
<td>Test blinded or controlled</td>
</tr>
<tr>
<td>• Bias</td>
<td>Accept consistent bias</td>
<td>Measure and adjust to reduce bias</td>
<td>Design to eliminate bias</td>
</tr>
<tr>
<td>• Sample Size</td>
<td>“Just enough” data, small sequential samples</td>
<td>Obtain 100% of available, relevant data</td>
<td>“Just in case” data</td>
</tr>
<tr>
<td>• Flexibility of Hypothesis</td>
<td>Hypothesis flexible, changes as learning takes place</td>
<td>No hypothesis</td>
<td>Fixed hypothesis</td>
</tr>
<tr>
<td>• Testing Strategy</td>
<td>Sequential tests</td>
<td>No tests</td>
<td>One large test</td>
</tr>
<tr>
<td>• Determining if a change is an improvement</td>
<td>Run charts or Shewhart control charts</td>
<td>No change focus</td>
<td>Hypothesis, statistical tests (t-test, F-test, chi square), p-values</td>
</tr>
<tr>
<td>• Confidentiality of the data</td>
<td>Data used only by those involved with improvement</td>
<td>Data available for public consumption and review</td>
<td>Research subjects’ identities protected</td>
</tr>
</tbody>
</table>
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:
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?  
   - 18-19  
   - 20-29  
   - 30-39  
   - 40-49  
   - 50-59  
   - 60-69  
   - 70-79  
   - 80-89  
   - 90+  
   - 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?  
   - Bolton, Brampton, Caledon, Dufferin County, Malton, Orangeville, Rexdale, Shelburne, Woodbridge  
   - South Etobicoke, Mississauga, Halton Hills, Oakville, Milton  
   - Brant, Burlington, Haldimand, Hamilton, Niagara, Norfolk  
   - Waterloo Wellington  
   - Central Toronto  
   - United Counties of Leeds & Grenville, Lanark County  
   - Other (specify) ____________________________

5. Which ethnic group did he/she belong to?  Tick one only  
   - South Asian  
   - Chinese  
   - Black  
   - Filipino  
   - Latin American  
   - European  
   - Middle Eastern  
   - Aboriginal  
   - Don’t know  
   - Other group (specify): ____________________________

6. What was his/her religion?  Tick one only  
   - No religion  
   - Christian (all denominations)  
   - Buddhist  
   - Hindu  
   - Jewish  
   - Muslim  
   - Sikh  
   - Don’t know  
   - Other religion (specify): ____________________________
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:

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

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

☐ Homecare nurse  
☐ Any other nurse at home  
☐ Personal support worker  
☐ Social worker  
☐ Religious leader  
☐ Meals-on-wheels or other home delivered meals  
☐ Hospice volunteers  
☐ Physiotherapist (PT)  
☐ Occupational therapist (OT)  
☐ He/she did not receive any care  
☐ Don’t know  
☐ Other (specify): _____________________  
☐ Other (specify): _____________________  
☐ 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)
- [ ] Five times or more – go to Q8
- [ ] Once or twice – go to Q8
- [ ] Three or four times – 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
   - Everyday
   - 2-6 times a week
   - Once a week
   - 2-3 times a month
   - Less often
   - Don’t know

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:

<table>
<thead>
<tr>
<th></th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neither</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
<th>Does not Apply</th>
<th>Don’t Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Helped to improve his/her quality of life</td>
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<tr>
<td>b) Helped him/her to avoid unnecessary emergency department visits or hospitalizations</td>
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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)

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
- Fairly easy
- Fairly difficult
- Very difficult
- He/she wanted the doctor to visit but they would not
- 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
- Completely, all of the time
- Completely, some of the time
- Partially
- Not at all
- 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)*?

**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

30. During his/her last hospital admission, 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

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)?

<table>
<thead>
<tr>
<th>Doctors</th>
<th>Nurses</th>
<th>Personal Support Workers</th>
</tr>
</thead>
<tbody>
<tr>
<td>[ ] Always</td>
<td>[ ] Always</td>
<td>[ ] Always</td>
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<tr>
<td>[ ] Most of the time</td>
<td>[ ] Most of the time</td>
<td>[ ] Most of the time</td>
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<td>[ ] Some of the time</td>
<td>[ ] Some of the time</td>
<td>[ ] Some of the time</td>
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<tr>
<td>[ ] Never</td>
<td>[ ] Never</td>
<td>[ ] Never</td>
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<tr>
<td>[ ] Does not Apply</td>
<td>[ ] Does not Apply</td>
<td>[ ] Does not Apply</td>
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<tr>
<td>[ ] Don’t know</td>
<td>[ ] Don’t know</td>
<td>[ ] Don’t know</td>
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</tbody>
</table>

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

<table>
<thead>
<tr>
<th></th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neither</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
<th>Does not Apply</th>
<th>Don’t Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) There was enough help</td>
<td>[ ]</td>
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<td>available to meet his/her</td>
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<td>personal care needs (such as</td>
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<td>toileting needs)</td>
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<td>b) There was enough help with</td>
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<td>nursing care, such as giving</td>
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<td>medicine and helping him/her</td>
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<td>find a comfortable position in</td>
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<td>bed</td>
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<tr>
<td>c) The bed area and surrounding</td>
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<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
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<td>environment had adequate</td>
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<td>privacy for him/her</td>
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</tbody>
</table>
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?

<table>
<thead>
<tr>
<th></th>
<th>Excellent</th>
<th>Good</th>
<th>Fair</th>
<th>Poor</th>
<th>Does not Apply</th>
<th>Don’t Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Relief of pain</td>
<td></td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>b) Relief of other symptoms</td>
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<tr>
<td>c) Spiritual support</td>
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<tr>
<td>d) Emotional support</td>
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<tr>
<td>e) Support to stay where he/she wanted to be</td>
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</tbody>
</table>

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 would have liked to be more involved
   - He/she would have liked to be less involved
   - He/she wasn’t able to be involved due to incapacity
   - Don’t know

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

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