Measuring End-of-life Care Experience: Perceptions From Bereaved Caregivers

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McMaster University HEALTH SCIENCES

PALLIATIVE CARE INNOVATION

Escarpment Cancer Research Institute

Background

- End-of-life (EOL) when patients/families vulnerable
  - Also high costs utilizers
- Much HSR admin data on utilization and costs at EOL
  - Admin data limited in measuring quality of care
- To measure quality:
  - Satisfaction tools exist
    - Covers many difficult to measure domains of care
    - but are limited in ceiling effect
  - Few experience tools exists
    - Often long surveys administered by telephone
    - The new gold standard?

Study Concept

- Embed a EOL quality pilot project into an existing provincial homecare QI evaluation (ICCP-PC)
- ICCP-PC:
  - 6 sites in Ontario (i.e. 6 CCACs)
  - Improve EOL homecare coordination and services (collaborate with provider agencies)
  - Over 2 year period
- Goal: Test feasibility / willingness to elicit caregivers' experience on EOL quality using online survey

Survey Development

- Selection of the final survey was informed by:
  - ⇨ our review of palliative care performance measures,
  - ⇨ the literature on the quality of the palliative care experience
  - ⇨ a literature review of existing, relevant instruments

- Survey based on two validated instruments:

  FAMCARE to measure satisfaction (19 items)

  VOICES to measure the care experience

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FAMCARE v2

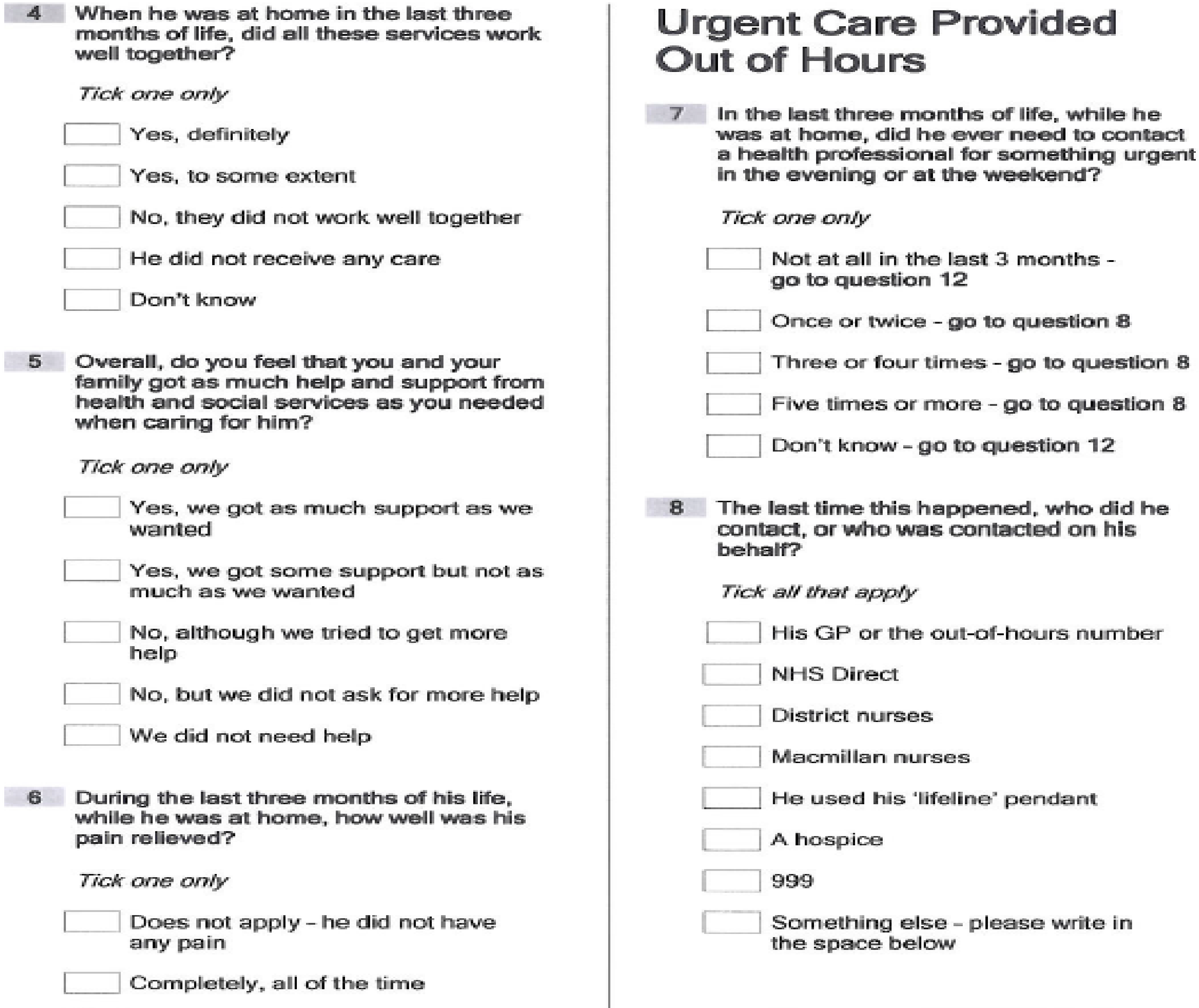
- Validated scale to measure family satisfaction
  - Originally tested in cancer and noncancer
  - Tested in multiple settings (inpatient unit, homecare, hospice, outpatient cancer)
  - Used around the world (US, Europe, Australia)
  - Used by Accreditation Canada for palliative care
- Degree of satisfaction of health care providers behaviors directed toward the patient and family
- 20 questions, 5 point Likert scale (very satisfied to very dissatisfied)

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	☐	☐	☐	☐	☐	☐
b) The way in which his/her condition and likely progress were explained by the homecare providers	☐	☐	☐	☐	☐	☐
c) Information given about the side effects of treatment	☐	☐	☐	☐	☐	☐
d) The way in which the homecare providers respected his/her dignity	☐	☐	☐	☐	☐	☐
e) Meetings with the homecare providers to discuss his/her condition and plan of care	☐	☐	☐	☐	☐	☐
f) Speed with which symptoms were treated	☐	☐	☐	☐	☐	☐
g) Homecare providers' attention to his/her description of symptoms	☐	☐	☐	☐	☐	☐
h) The way in which his/her physical needs for comfort were met	☐	☐	☐	☐	☐	☐
i) Availability of the homecare providers to the family	☐	☐	☐	☐	☐	☐
j) Emotional support provided to family members by the homecare providers	☐	☐	☐	☐	☐	☐
k) The practical assistance provided by the homecare providers (e.g. bathing, respite)	☐	☐	☐	☐	☐	☐
l) The Doctor's attention to his/her symptoms	☐	☐	☐	☐	☐	☐
m) The way the family was included in treatment and homecare decisions	☐	☐	☐	☐	☐	☐
n) Information given about how to manage his/her symptoms (e.g. pain, constipation)	☐	☐	☐	☐	☐	☐

VOICES Survey

- VOICES (Views Of Informal Caregivers EOL Survey)
- Developed and used in the UK
  - Experiences in last 3 months of life
    - Care at home / Urgent Care Out of Hours
    - Care from Community Nurses / Care from Family Doctor
    - LTC homes
    - Last Hospital Admission / Last Hospice Admission
  - Experiences in last 2 days of life
    - Circumstances surrounding his death
    - Open ended questions about good and bad experiences



4 **When he was at home in the last three months of life, did all these services work well together?**

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No, they did not work well together

☐ He did not receive any care

☐ Don't know

5 **Overall, do you feel that you and your family got as much help and support from health and social services as you needed when caring for him?**

Tick one only

☐ 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

6 **During the last three months of his life, while he was at home, how well was his pain relieved?**

Tick one only

☐ Does not apply – he did not have any pain

☐ Completely, all of the time

Urgent Care Provided Out of Hours

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

Tick one only

☐ Not at all in the last 3 months - go to question 12

☐ Once or twice – go to question 8

☐ Three or four times – go to question 8

☐ Five times or more – go to question 8

☐ Don't know – go to question 12

8 **The last time this happened, who did he contact, or who was contacted on his behalf?**

Tick all that apply

☐ His GP or the out-of-hours number

☐ NHS Direct

☐ District nurses

☐ Macmillan nurses

☐ He used his 'lifeline' pendant

☐ A hospice

☐ 999

☐ Something else – please write in the space below

Final Survey

- Both FAMCAREv2 and VOICES
- 87 questions featuring scaled, multiple choice, and opened-ended items covering multiple domains of care, settings, and provider types
- Framed in the *last three months of life**
- Online (paper form also available) (www.caregivervoice.com)
- Anonymous
- Willing to be contacted for follow-up

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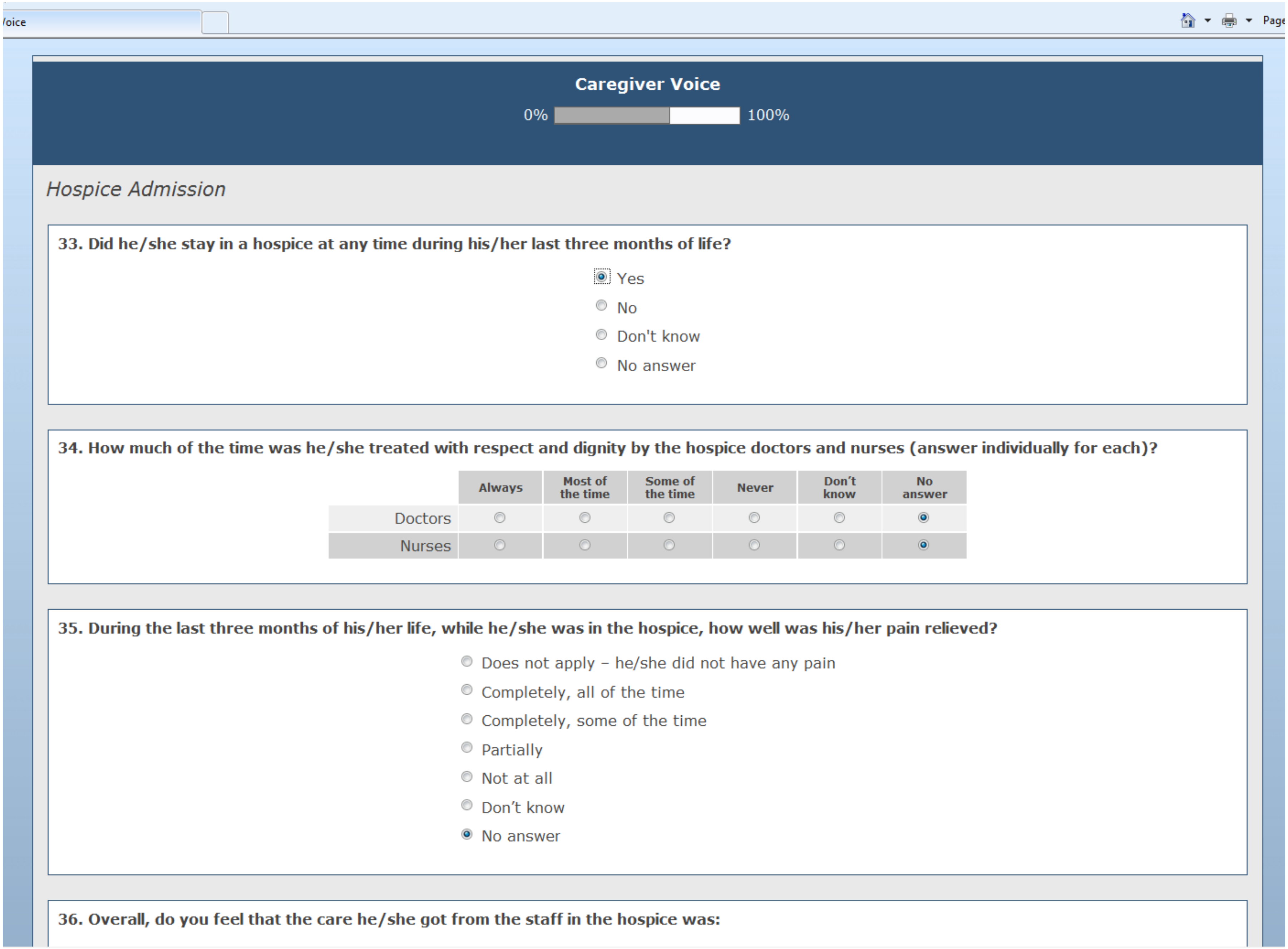


Caregiver Voice

Hospice Admission

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

● Yes
○ No
○ Don't know
○ No answer

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

	Always	Most of the time	Some of the time	Never	Don't know	No answer
Doctors	○	○	○	○	○	●
Nurses	○	○	○	○	○	●

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
● No answer

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

Survey Administration

- 6 sites in Ontario
- September 2012 (to mid January 2014)
- Bereaved family caregivers of homecare patients (~4 to 6 weeks after death)
- Administered by the CCAC and/or service provider organizations (SPOs)
- Methods of survey distribution varied by site

Results (n=330)

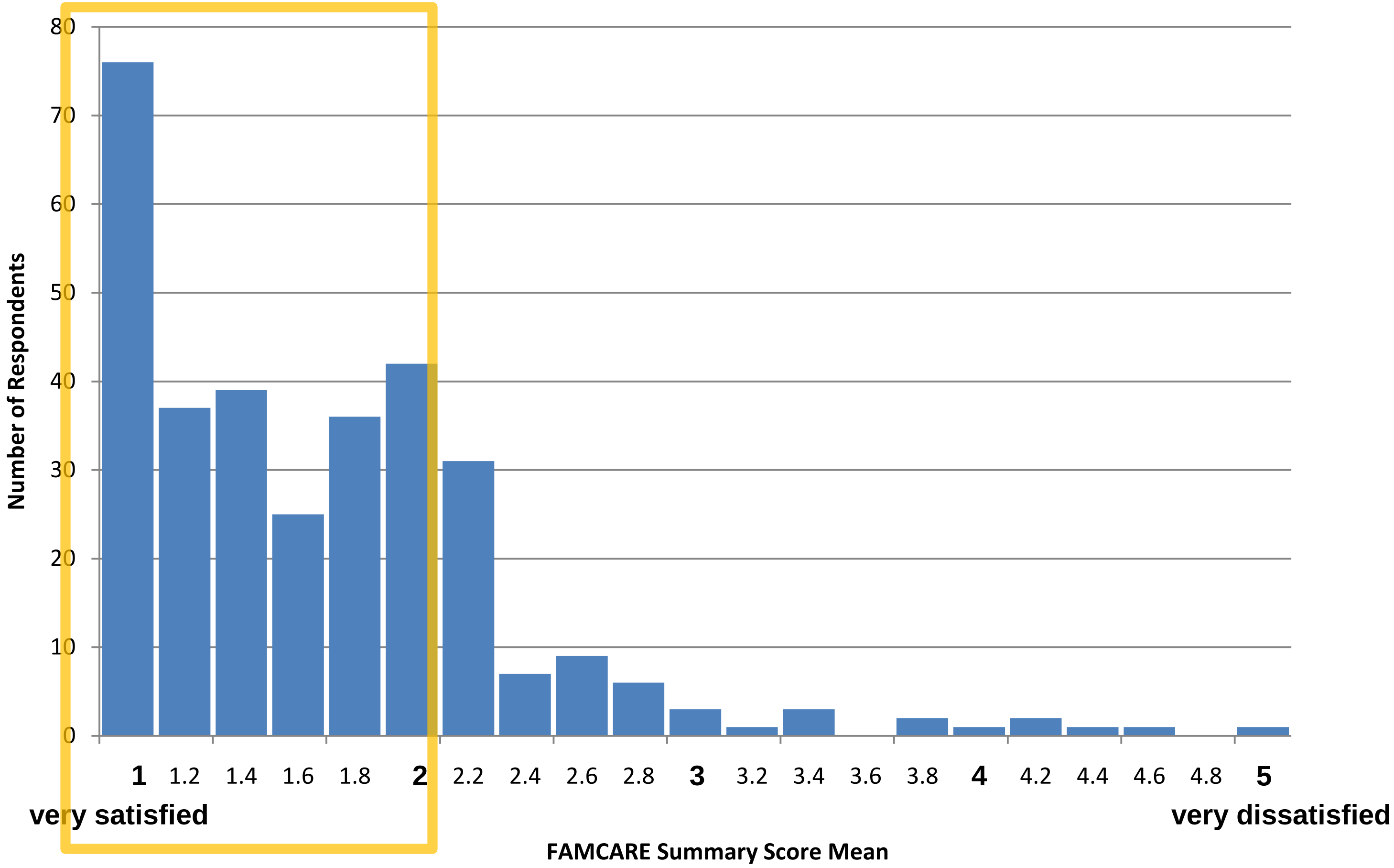
A total of 330 surveys were completed with a site response rate up to 83%

Over half of caregivers (53%) completed the survey online rather than on paper form

Patient Characteristic	**Total** *n (%)*
Patient Gender: Female	173 (52.4)
Cancer Diagnosis	271 (82.1)
Ethnic Group: European/Canadian *n (%)*	263 (79.7)
Religion: Christian *n (%)*	236 (71.5)

Caregiver Characteristic	**Total** *n (%)*
Gender: Female *n (%)*	210 (63.6)
Relationship to Patient: *n (%)*	
Husband/wife	180 (54.5)
Son/daughter	105 (31.8)
Brother/sister	10 (3.0)
Son/daughter-in-law	5 (1.5)
Parent/parent-in-law	8 (2.4)
Niece/nephew	6 (1.8)
Friend	5 (1.5)

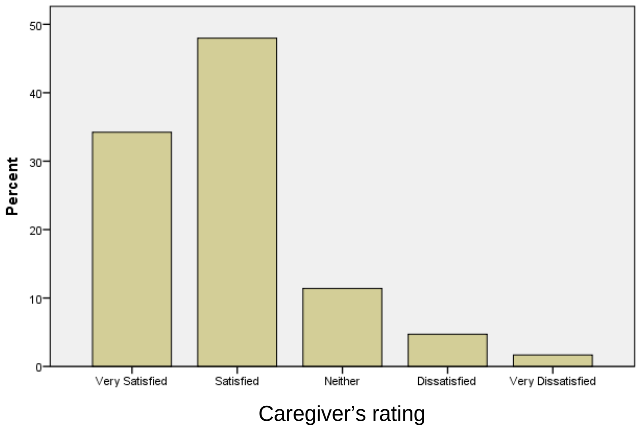
FAMCARE Overall Score (N=323)



⇨ Responses to the FAMCARE items represent the caregivers' cumulative perceptions of all providers that were involved in homecare

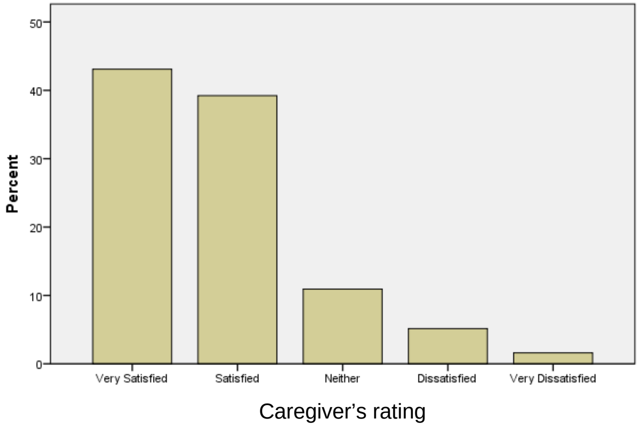
FAMCARE – Select Item Distributions

Information given about the side effects of treatment (n=298)



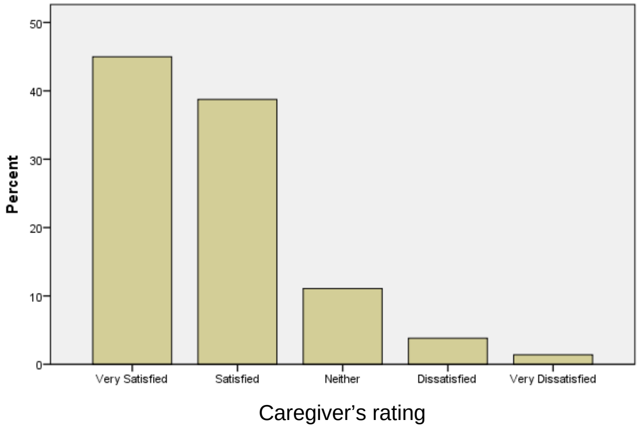
82% either Very Satisfied or Satisfied

Emotional support provided to family members (n=311)



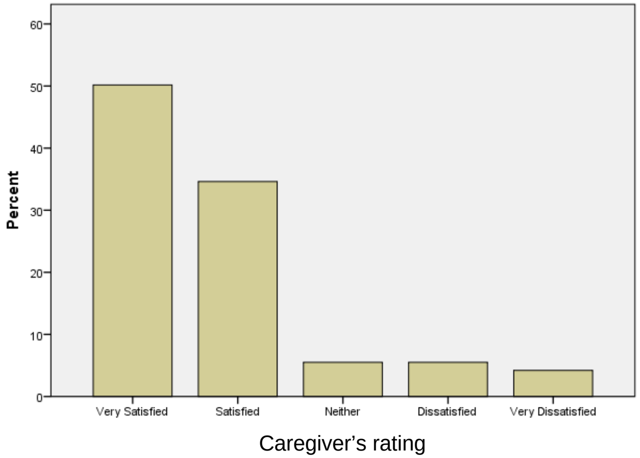
82% either Very Satisfied or Satisfied

The practical assistance provided (e.g. bathing, respite) (n=289)



84% either Very Satisfied or Satisfied

The Doctor's attention to his/her symptoms (n=309)

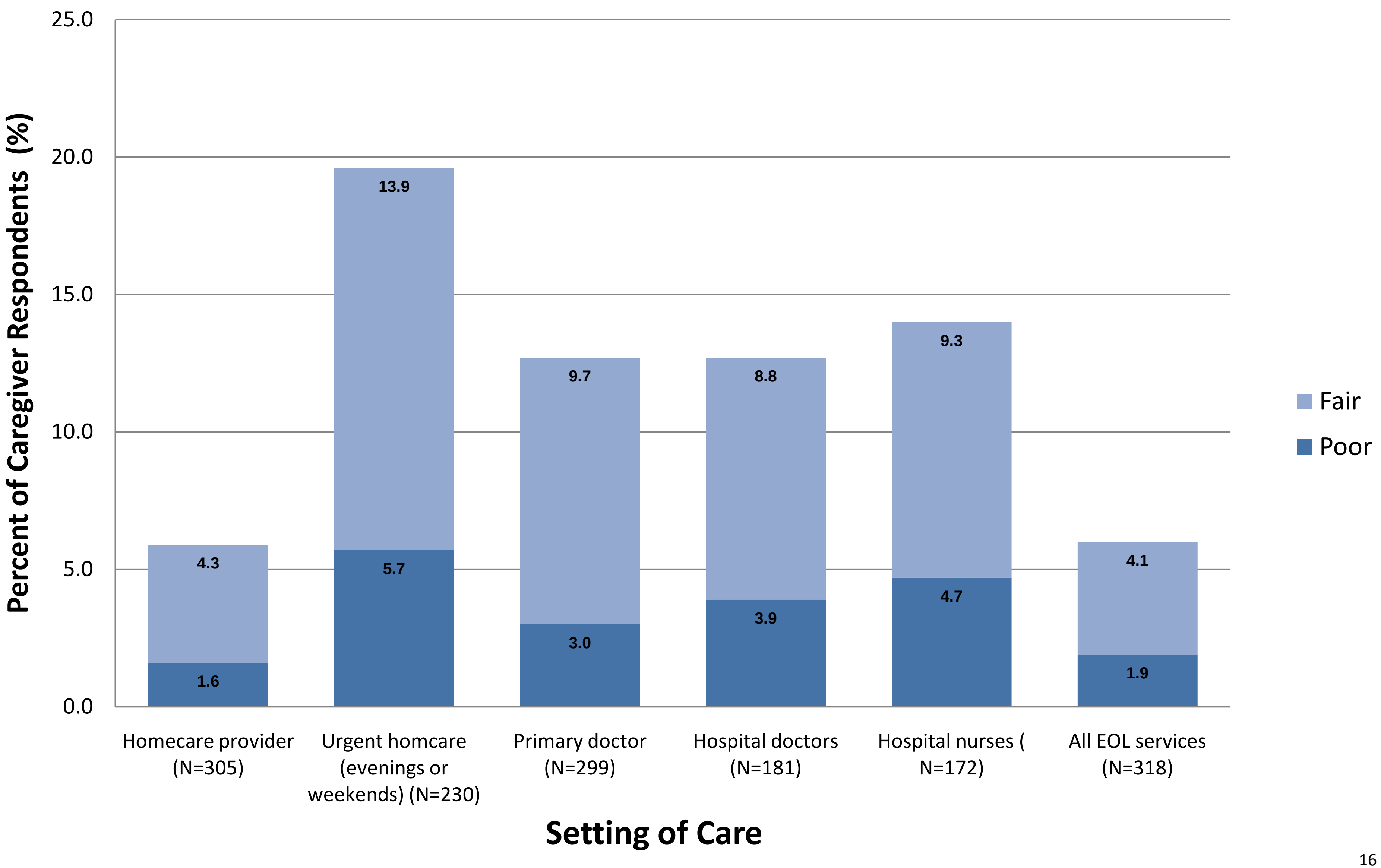


85% either Very Satisfied or Satisfied

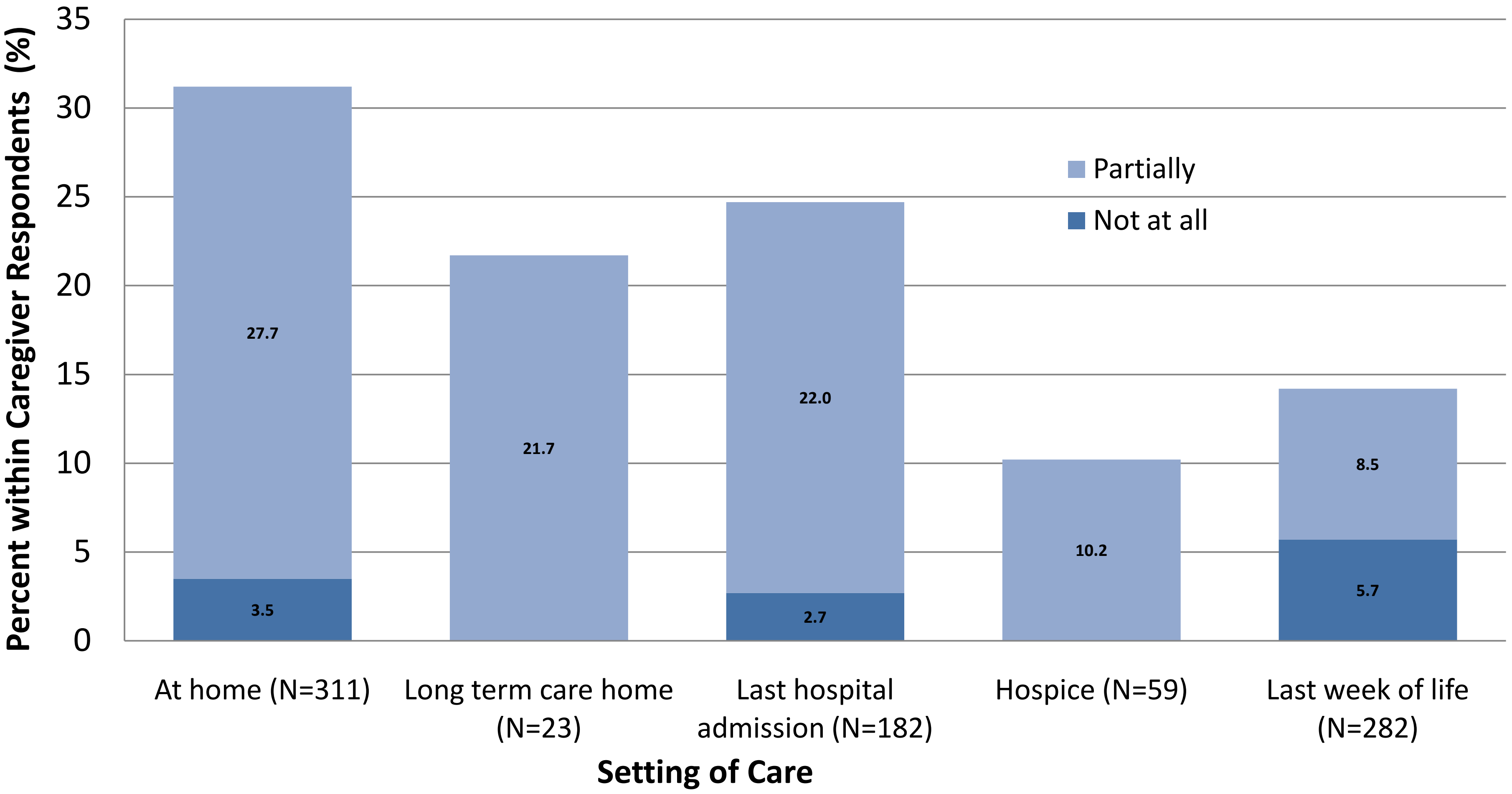
Settings of Care

in last 3 months of life	**Total (n=330)** **N (%)**
Got help from homecare services	330 (100%)
Got help from **visiting hospice volunteer(s)** in the home	61 (20%)
Had a **palliative care doctor**	167 (55%)
Lived or stayed in a **long term care home**	24 (8%)
Stayed in **hospital** at any time	188 (59%)
Stayed in a **hospice** at any time	60 (20%)

Fair or Poor Ratings Across Settings



Pain Management across Settings



⇨ Generally, across the sites of care, about 70% of caregivers reported that the patient's pain was relieved completely, either all or some of the time or that there was no pain to begin with

⇨⇨ 6% reported that pain management was poor in the last week of life

Urgent Care After Hours

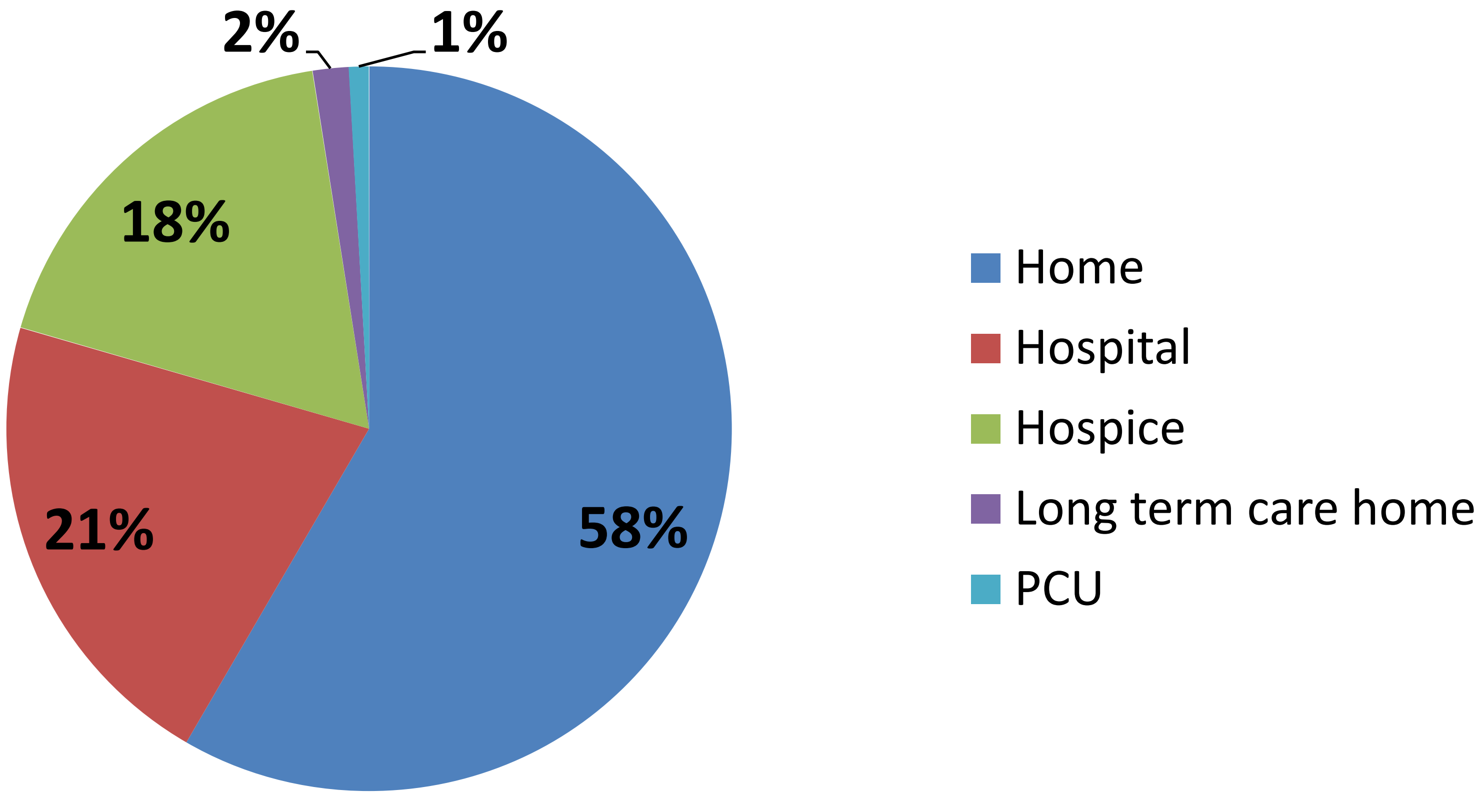
In the last three months of life, while he/she was at home, did he/she ever need to contact a health professional for something urgent in the evening or during the weekend? (n=302)

	Total (n=302)
Not at all in the last 3 months	22% (67)
Once or twice	53% (159)
Three or four times	19% (57)
Five times or more	5% (15)
Don't know	1% (4)

The last time there was an urgent situation, who did he/she contact, or who was contacted on his/her behalf? (n=229)

	TOTAL (n=229)
Homecare	43% (98)
His/her family doctor or the doctor's after-hours number	23% (53)
911	15% (33)
Hospice	3% (7)
Palliative Care Physician	9% (20)
Both doctor's after-hours number AND Homecare	5% (11)
Added: Other	3% (7)

Reported Place of Death (N=322)



- ⇨ **Almost all caregivers (94%) said that this was the right place for the patient to die**, 4% said it was the wrong place, and the remaining were unsure
- ⇨ 81% of patients had said that they wanted to die at home, 10% wanted to die in hospice

What was Good about Care (n=253)

- 77% (253) commented on what was good
- 55% (138) of the comments directed towards homecare in general, 31% (47) to the homecare nurses

What was GOOD **(Some respondents indicated multiple accolades)**	Indicated theme	
	N	%
HSPs provided great care overall	110	43.5
HSPs were sensitive and empathic to patients needs	86	34.0
Responsive	55	21.7
HSPs were easy to speak to	42	16.6
Services and equipment initiated/received when needed	24	9.5
Pre-emptive care and planning and caregiver education	22	8.7
Pain, symptom, and medical management	19	7.5
Trust and Rapport built	19	7.5
Efficient and/or dedicated	16	6.3
Provided what the patient wanted	10	4.0
Gave peace of mind	8	3.2
Home visits by HSPs	8	3.2
Compensated for system issues	3	1.2
Other	2	0.8

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What was Bad about Care (n=150)

- 45% (150) commented on what was bad. 17% (26) of these respondents focused their comments on one or two people.
- 31% (47) of the comments referred to homecare in general, 11% (17) to the homecare nurses, and 10% (15) to the PSWs

Nature of Complaint **(Some respondents indicated multiple issues)**	Indicated theme	
	N	%
Caregiver needed more help and/or services to support patient	36	24.0
HSP was insensitive, lacked empathy, was condescending, or unpleasant	22	14.7
Organization of medicines/pain control lacking or no symptom management kit	22	14.7
HSP had no palliative training/experience or had questionable practice	21	14.0
HSP rushed through care, should had done more during visit, or cut short visit without addressing patient's needs	19	12.7
HSP did not come when scheduled or caregiver didn’t know who was coming or when	16	10.7
No consistency in particular HSPs seen and/or timing of visits	15	10.0
Delay in initiation of or rough transition to EOL care	14	9.3
HSP dismissed patient issues and/or symptoms or didn't follow up to ensure issues resolved	12	8.0
Issues with hospital care in general	12	8.0
HSP had inappropriate or unwanted discussions with patient (e.g., too blunt about death, mention of religion)	9	6.0
Poor sharing of information of patient's condition (inc that death was imminent) with caregiver	9	6.0
Coordination of services lacking in general	8	5.3
Impossible/difficult to contact HSP in time of need or response at crisis too slow (resulting in 911 use)	7	4.7
Other	59	39.3

Pain Points & Possible Actions

1. Replace Coordinators, Nurses, or PSWs upon request
2. Provider consistency – particularly with PSWs
3. Providers with palliative experience – but no last minute switches
4. Knowing what to expect as the patient declines
5. Bypass the Emergency Dept
6. More homecare support!
7. Caregiver inclusion in the communication loop between the provider and the patient
8. Better communication between agencies

Take Homes / Conclusions

- Pilot successful! Eliciting caregiver responses is feasible
  - Over half left their contact info to be interviewed
- 80/20 rule: 80% comments positive; 20% negative
  - No aspect or setting was overwhelmingly negative
  - 70% (excellent); 20% (good); 10% (major problems)
- Survey asks about difficult domains
- Surveys provide info that is actionable; can lead to QI
- Can be useful for measuring changes over time, or regional differences, or intervention effects

Next Steps

- Need a generalizable sample
- Vision is for an EOL experience tool:
  - "Standardized", common tool
  - Across all settings (e.g. hospice, hospital, cancer centre, LTC, CCACs, etc.)
- Customized / buy-in at the provincial level
- Customization at the local level
- Need partners and funders