

Living with Advanced Colorectal Cancer: How Prepared are Informal Caregivers to Care for their Loved ones?

Kassam S, Simon J, Biondo P, Beaumont C, Watanabe S, Earp MA, Sinnarajah A

Interim Results

30th Annual Palliative Education & Research Day
October 21, 2019

**PaCES**

PALLIATIVE CARE EARLY AND SYSTEMATIC

Presenter Disclosure

Faculty: Shireen Kassam

Relationships with financial interests:

Grants/Research Support: CIHR and Alberta Health

Speakers Bureau/Honoraria: None

Consulting Fees: None

Patents: None

Other: Employee of University of Calgary

Disclosure of Financial Support

This program has received financial support from the following in the form CIHR PHSI and Alberta Health.

This program has received in-kind support from Alberta Health Services in the form of Data Analytics and Operational Support.

Potential for conflict(s) of interest: None



PaCES

PALLIATIVE CARE EARLY AND SYSTEMATIC

Mitigating Potential Bias

Not Applicable

PaCES

PALLIATIVE CARE EARLY AND SYSTEMATIC



Living with Colorectal Cancer:
Patient and Caregiver Experience



Caregiver Data



Caregiver
Preparedness

Study Overview

Objective:

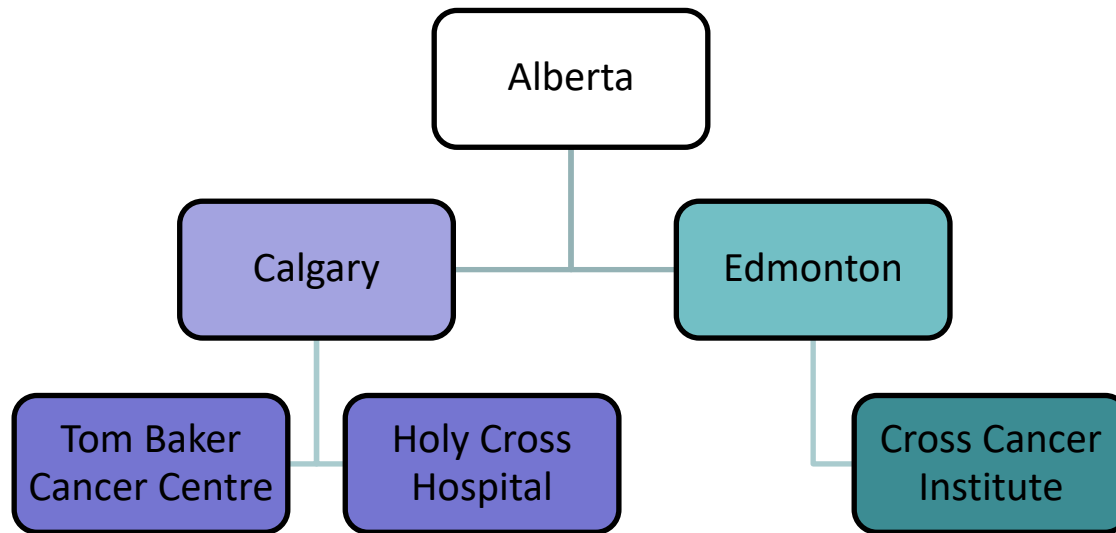
- Measure how quality of life in this population changes over time
- Before and after the Palliative Care Early and Systematic (PaCES) pathway is implemented

Study Overview

What:

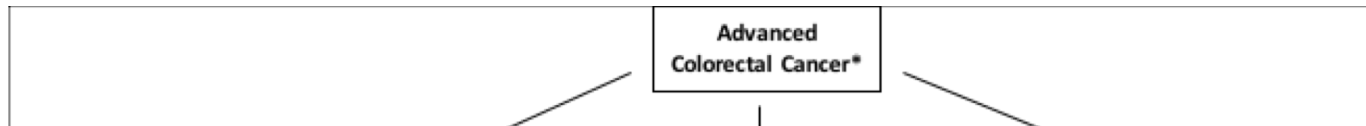
- Observational study
- Gather experience of patients with advanced colorectal cancer and their **caregivers**

Where:



Study Overview

Who:



Caregiver Eligibility:

must be a caregiver for a patient who is eligible for and enrolled in the ‘Living with Colorectal Cancer- Patient study’

*Advanced Colorectal Cancer (aCRC) is defined as primary or metastatic cancer that is unlikely to be cured, controlled, or put into remission with treatment

Study Overview

Duration :



Study Overview

Methods:

- Initial and periodic surveys
 - 1 month after enrollment then every 3 months until the end of study

Methods of participation

MAIL



PHONE



IN PERSON



E-MAIL



THE PREPAREDNESS FOR CAREGIVING SCALE

Subject ID	Date form completed
<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/>
	Y Y Y Y M M D D

YOUR PREPARATION FOR CAREGIVING

We know that people may feel well prepared for some aspects of giving care to another person, and not as well prepared for other aspects. We would like to know how well prepared you think you are to do each of the following, even if you are not doing that type of care now.

	Not at all prepared	Not too well prepared	Somewhat well prepared	Pretty well prepared	Very well prepared
1. How well prepared are you to care for someone's physical needs?					4
2. How well prepared are you to take care of someone's emotional needs?					4
3. How well prepared are you to set up services and equipment?					4
4. How well prepared are you to deal with the stress of caregiving?					4
5. How well prepared are you to make caregiving activities pleasant?					4
6. How well prepared are you to respond to emergencies?					4
7. How well prepared are you to get help and information?					4
8. Overall, how well prepared do you think you are to care for your family member?	0	1	2	3	4
9. Is there anything specific you would like to be better prepared for?					
Free-text question					
MEAN SCORE of the number of items answered: _____					

Tools used

Preparedness
availability

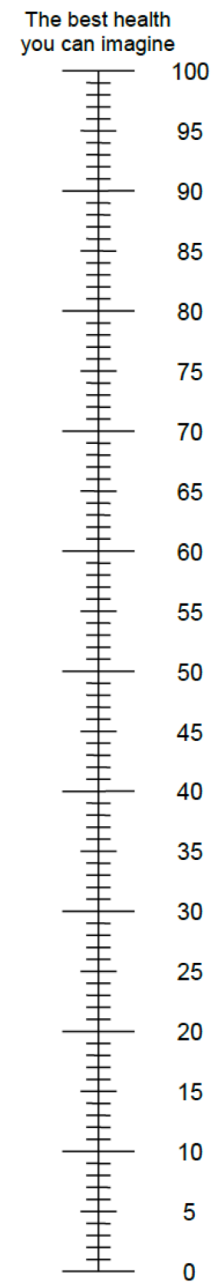
is and

Tools used

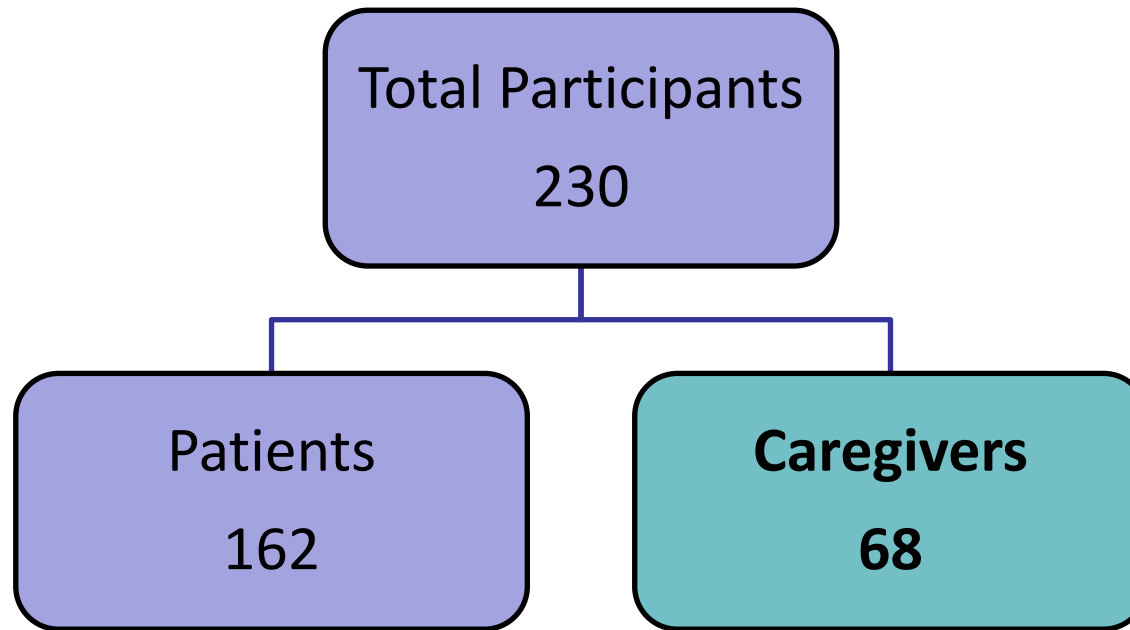
EQ-5D-5L-

- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the best health you can imagine.
0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY =



Recruitment

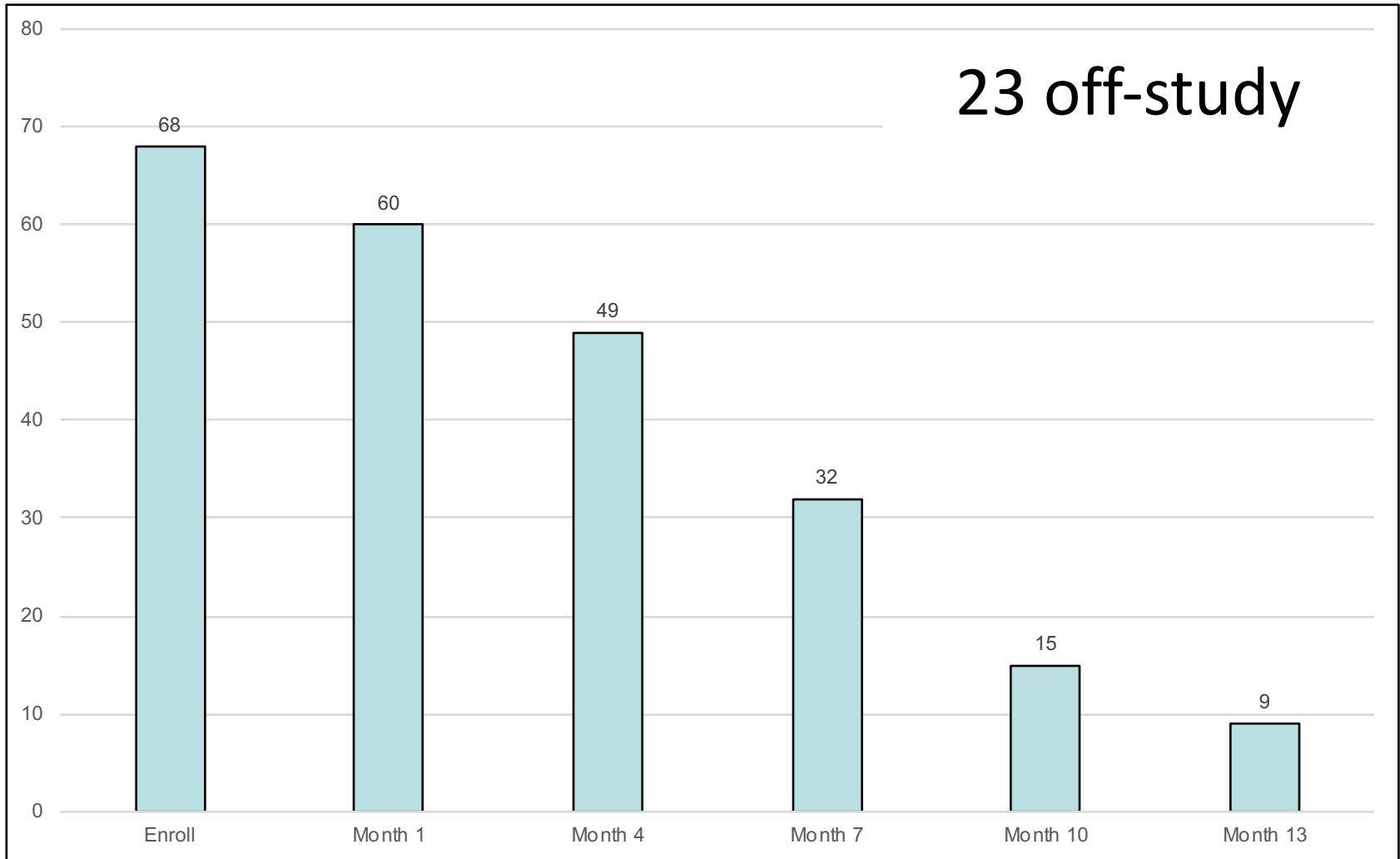


as of August 2019

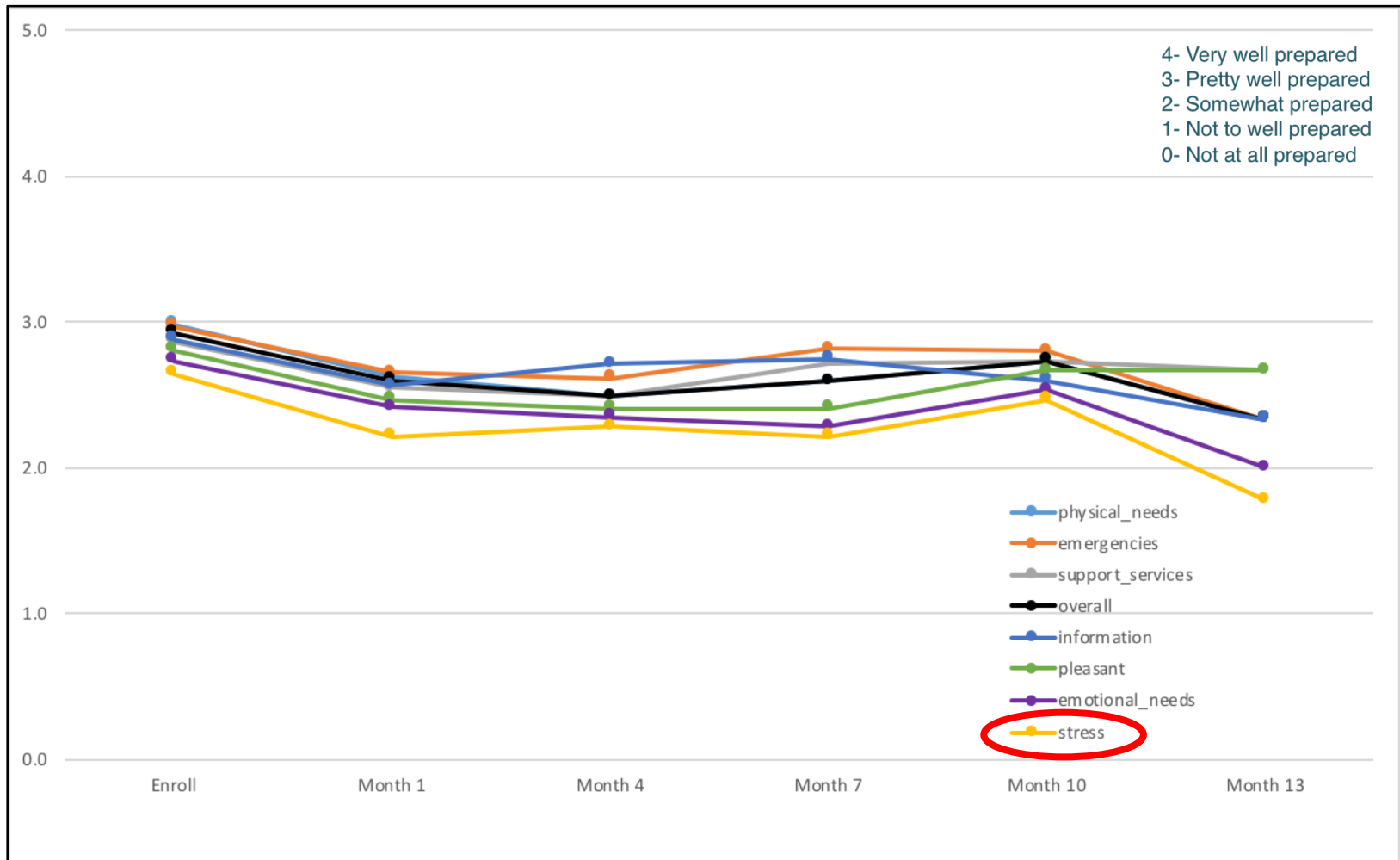
Demographics

Caregivers	Median age (Range)	Female	Male	Live with the patient	Spouse/ partner of the patient
68	59 (25-90)	48 (71%)	20 (29%)	56 (82%)	49 (72%)

Data collection

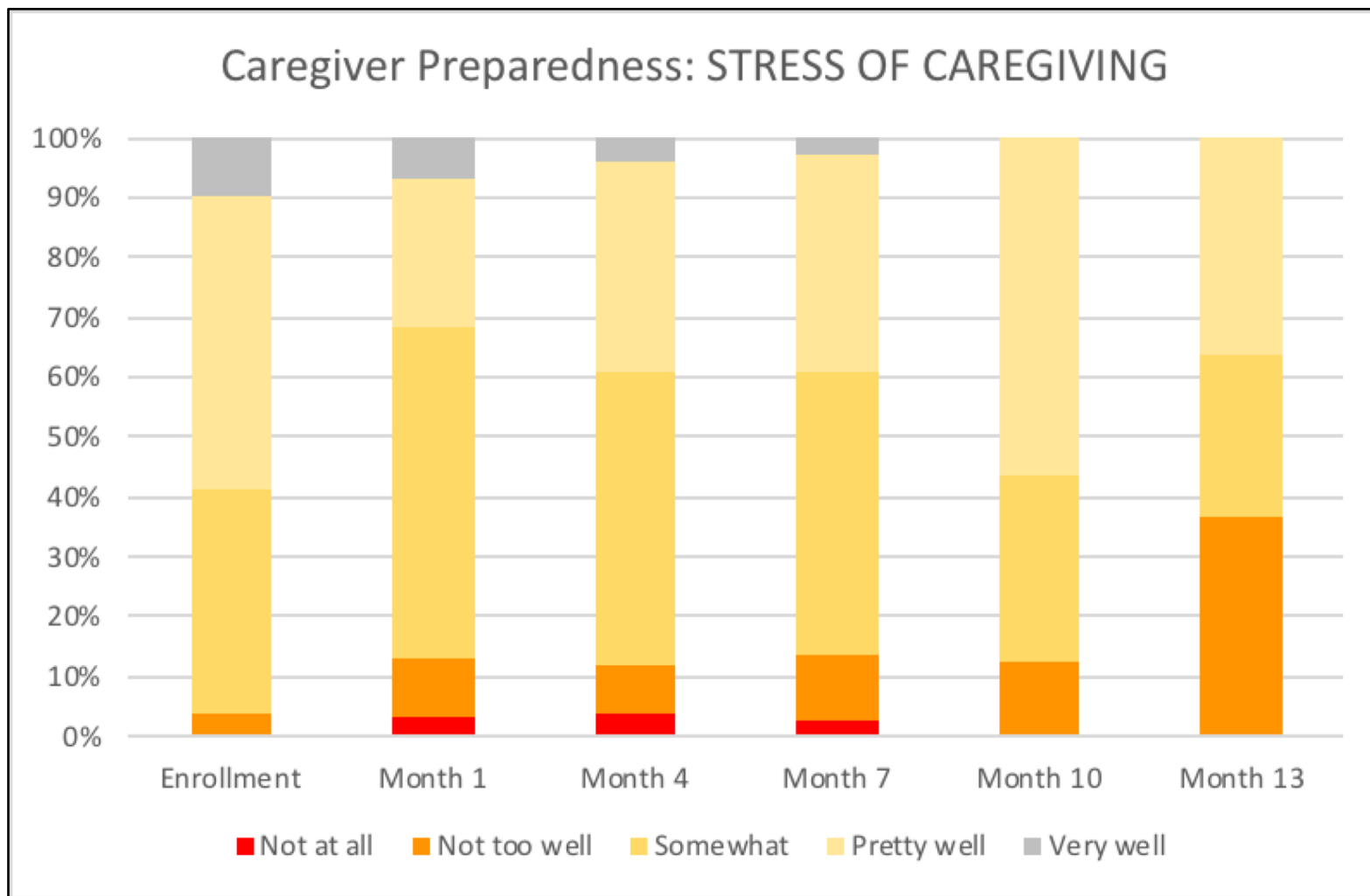


Preparedness Trend*



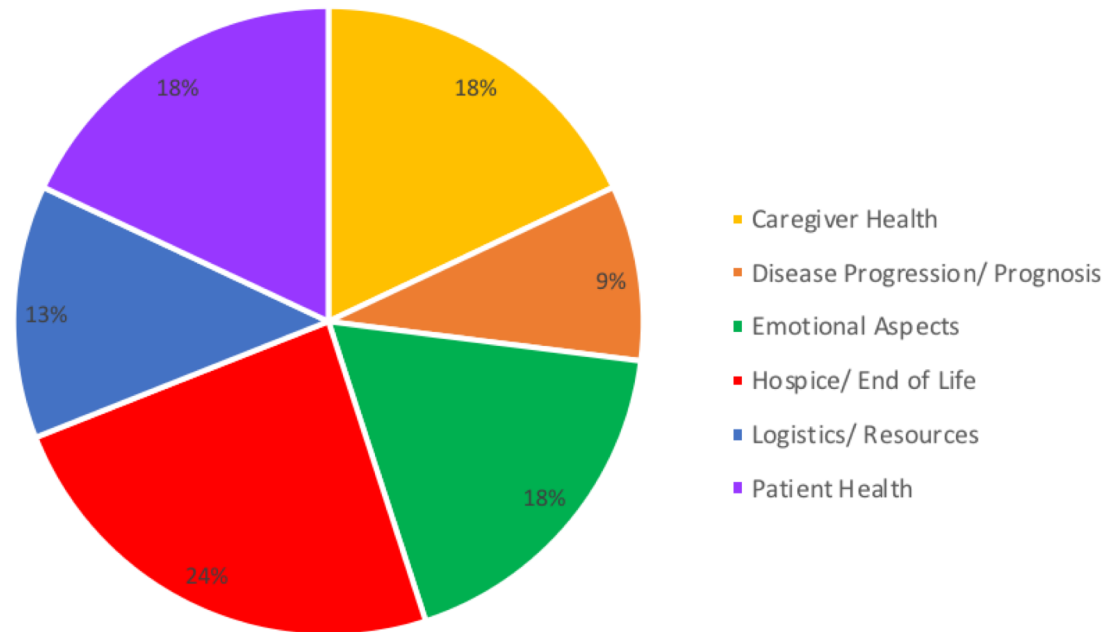
*Median values

Preparedness Trend

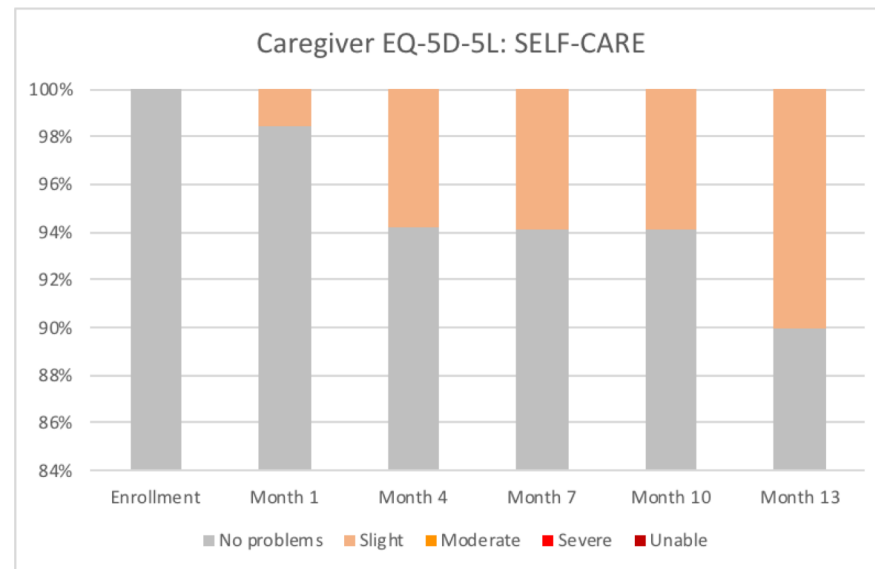
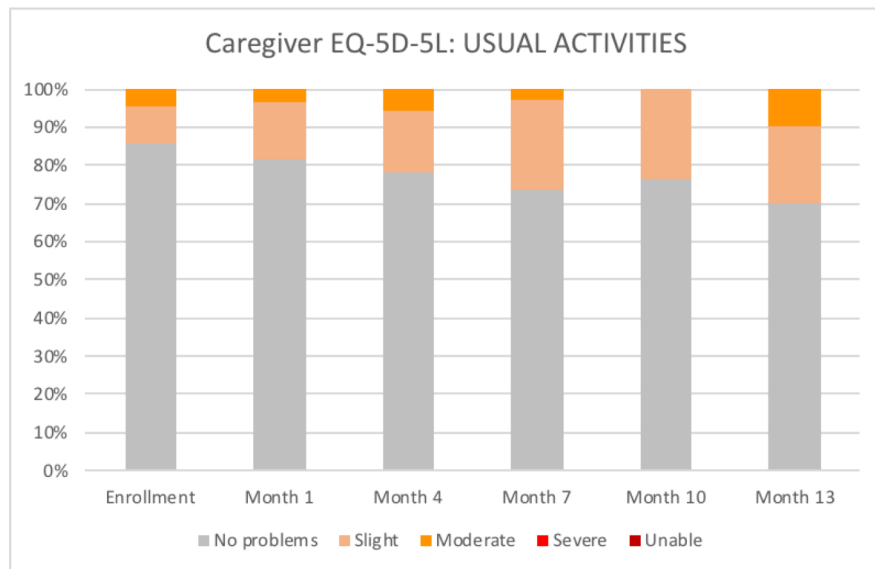


Main concerns reported by caregivers

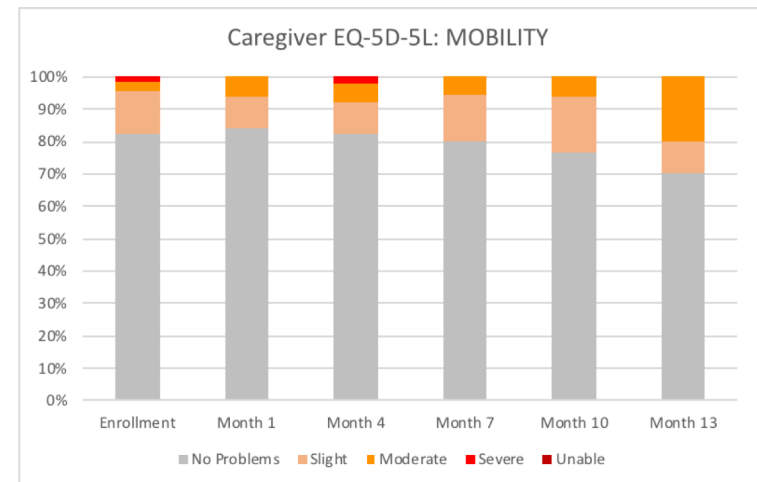
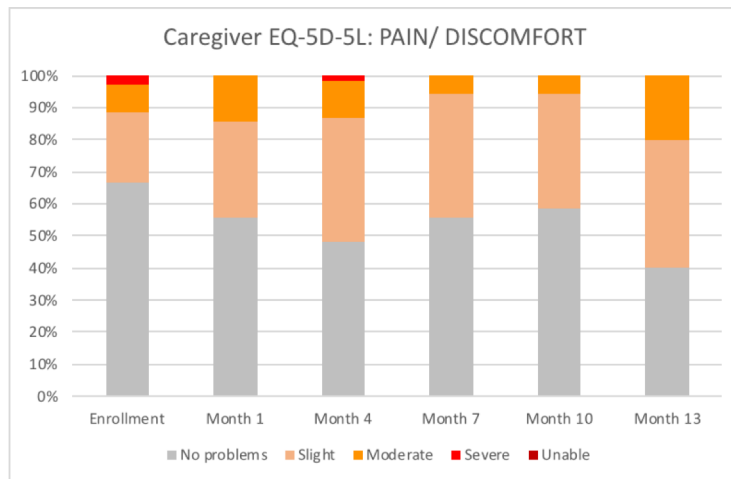
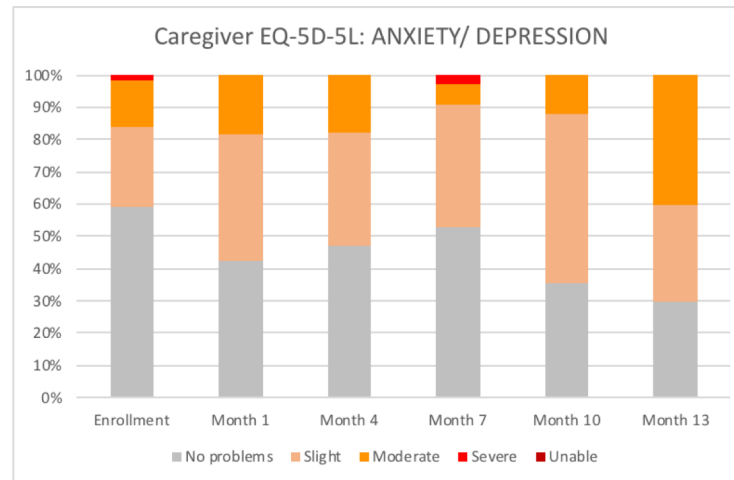
TOP CONCERNS REPORTED BY CAREGIVERS
FROM FREE-TEXT QUESTION



EQ-5D-5L Trends



EQ-5D-5L Trends



So how prepared are Informal Caregivers
to care for their loved ones?

Caregiver perceived preparedness and overall health decline, with increasing stress and emotional distress over time.

Caregiver experience, including sense of preparedness, is often under evaluated and more attention is needed.

Next Steps

Explore the relationship between caregiver preparedness and quality of life and time of patient death

Determine the effect of palliative interventions

“My husband has been on palliative care now for almost 2 years & it has been going very well. However I don't feel well prepared for hospice care when that time comes & will need to do some research to find out what is available for him.”

-Caregiver A at Month 1

“I feel anxious about my husbands end of life & when that will be. I do have a good resource with Palliative Care & I'm quite sure I will be asking our nurse for advice with this when the time comes.”

-Caregiver A at Month 13

Thank You

Questions / Comments?

