

PaCES

PALLIATIVE CARE EARLY AND SYSTEMATIC

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

Presenter Disclosure

Relationships with financial interests:

Grants/Research Support: CIHR, Alberta Health and Student Work-Integrated Learning Program (SWPP)

Speakers Bureau/Honoraria: None

Consulting Fees: None

Patents: None

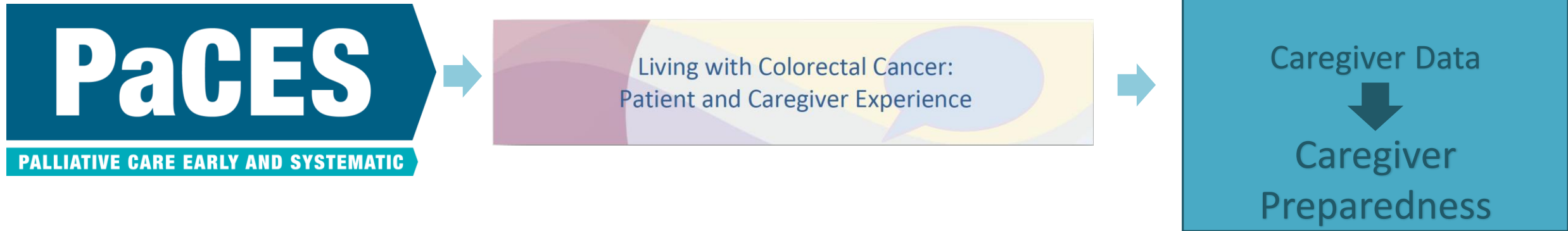
Other: Employee of University of Calgary

Financial Disclosure

This project has received financial support from the CIHR and Alberta Health.



PaCES Project Background



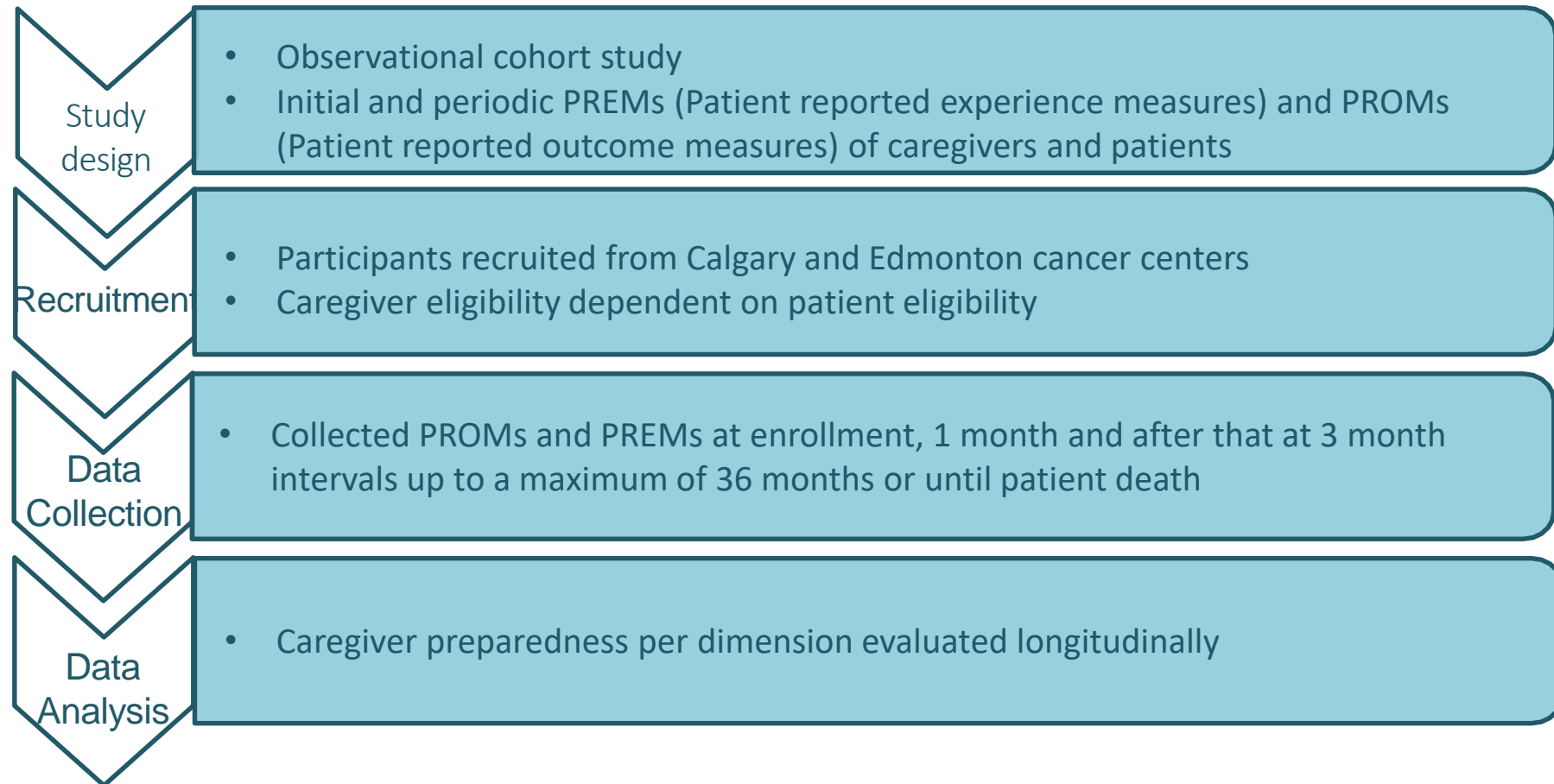
Aim of Study

Evaluate preparedness and health state of informal caregivers such as family members in relation to patients with advanced colorectal cancer longitudinally

Background – Why caregiver preparedness?

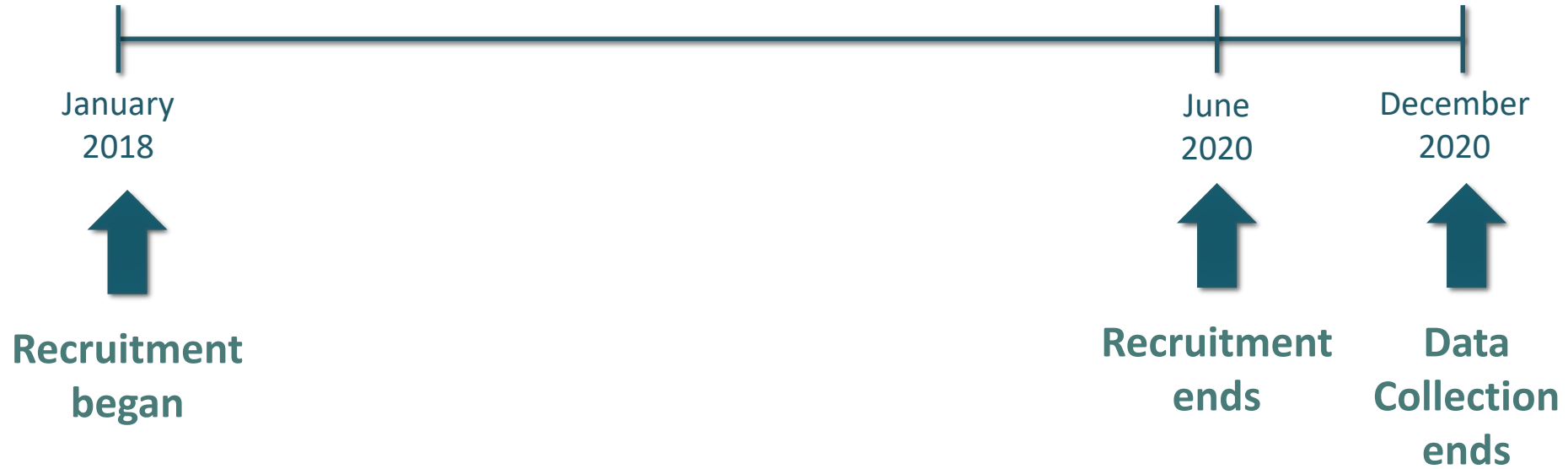
- Cross-sectional designs have been implemented in evaluating mean preparedness comparing non-intervention and intervention that consists of enhanced caregiver training program comparing baseline vs post training (Hendrix et al. 2020)
- Caregiver preparedness was evaluated longitudinally up to 6 months as a singular mean (Grant et al. 2013)
- Caregiver preparedness was significant when comparing caregivers who were well informed about patient care (Kayabulutlu et al. 2020)

Methods



Study Timeline

Duration :



Characteristics	Total N (column %)	
No. Caregiver Patient Dyads	79	
Demographics	Caregiver	Patient
Age, median (IQR)	59 (21)	64 (15)
Sex		
Male	23 (29)	29 (38)
Female	56 (71)	50 (63)
Relationship		
Spouse/partner	58 (73)	
Child of the patient	15 (19)	
Parent to the patient	1 (1)	
Sibling of the patient	0 (0)	
Other (eg. Other family, friend, colleague etc.)	5 (6)	
Race		
White	65 (82)	62 (78)
Non-White	14 (18)	17 (22)
Household Income		
<25,000	3 (4)	6 (8)
\$25,000 - \$49,999	9 (11)	9 (11)
\$50,000 - \$74,999	12 (15)	11 (14)
\$75,000 - \$99,000	8 (10)	11 (14)
>\$100,000	22 (28)	18 (23)
Prefer not to answer	25 (31)	24 (30)

ECOG Performance Status of Full Patients (n=55 patients)	Patient Count (%)
Fully active (grade 0)	25%
Difficulty with physically strenuous activity (grade 1)	45%
Not able to carry out work activities (grade 2)	22%
Limited self-care (grade 3)	4%

← 71%

Caregiver Study Time

- 62/79 (78%) caregivers had patients with a death date
- Caregivers were on study for an average of 288 days, completing on average 4-5 surveys
- On average, the last caregiver's survey was administered 72 days before the death date of the patient they were caring for

Preparedness for Caregiving Scale (PCS)

- Measurement construct that evaluates family caregiver preparedness with 8 dimensions
- Instrument was chosen due to ease of use
- Quantitative Aspect (Likert Scale)
 - 0 – Not at all prepared
 - 1 – Not too well prepared
 - 2 – Somewhat well prepared
 - 3 – Pretty well prepared
 - 4 – Well prepared
- Qualitative Aspect
 - Caregiver free text regarding preparedness

1. How well prepared do you think you are to take care of your family member's physical needs?

➡ Physical Needs

2. How well prepared do you think you are to take care of his or her emotional needs?

➡ Emotional Needs

3. How well prepared do you think you are to find out about and set up services for him or her?

➡ Support Services

4. How well prepared do you think you are for the stress of caregiving?

➡ Stress

5. How well prepared do you think you are to make caregiving activities pleasant for both you and your family member?

➡ Pleasant

6. How well prepared do you think you are to respond to and handle emergencies that involve him or her?

➡ Emergencies

7. How well prepared do you think you are to get the help and information you need from the health care system?

➡ Information

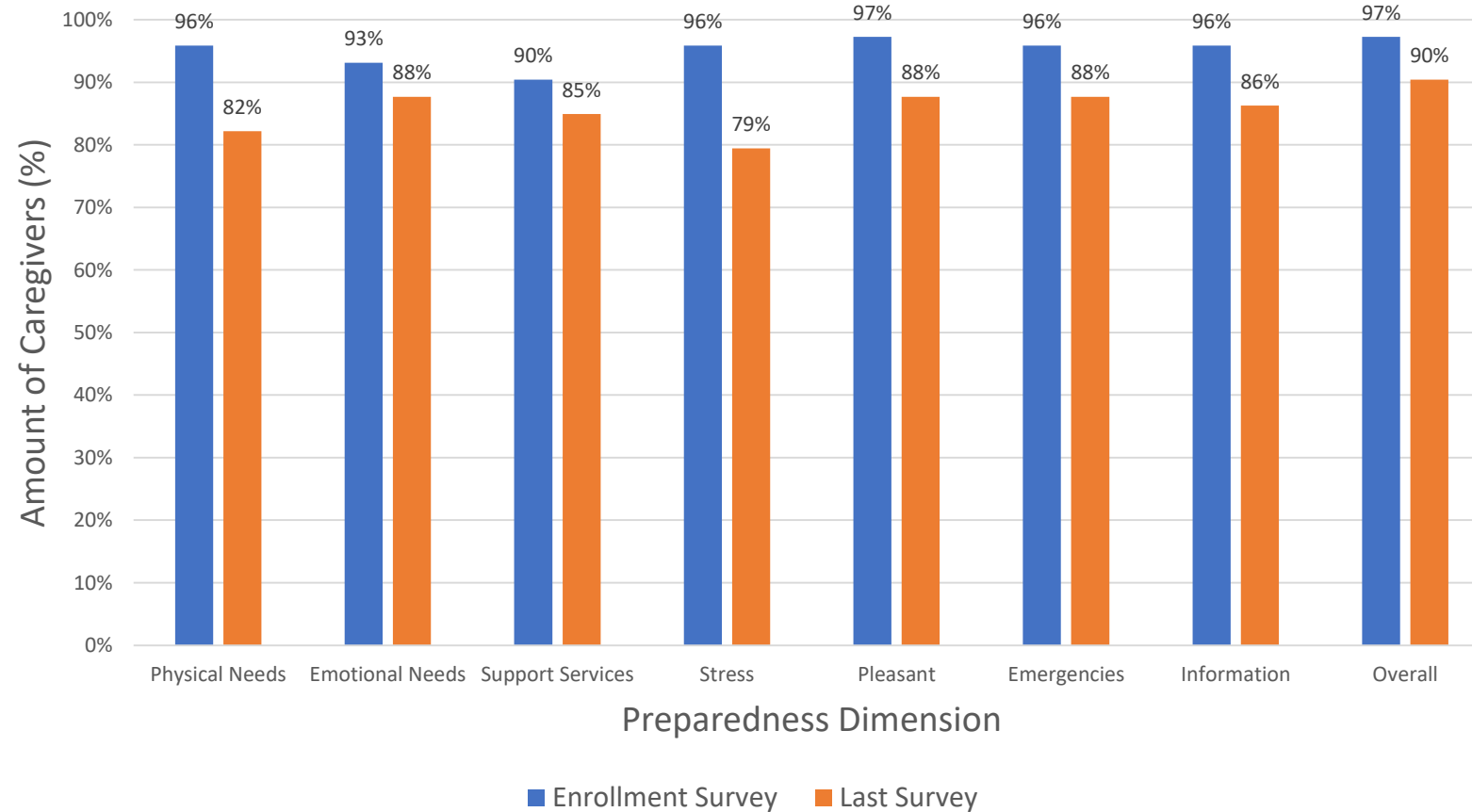
8. Overall, how well prepared do you think you are to care for your family member?

➡ Overall

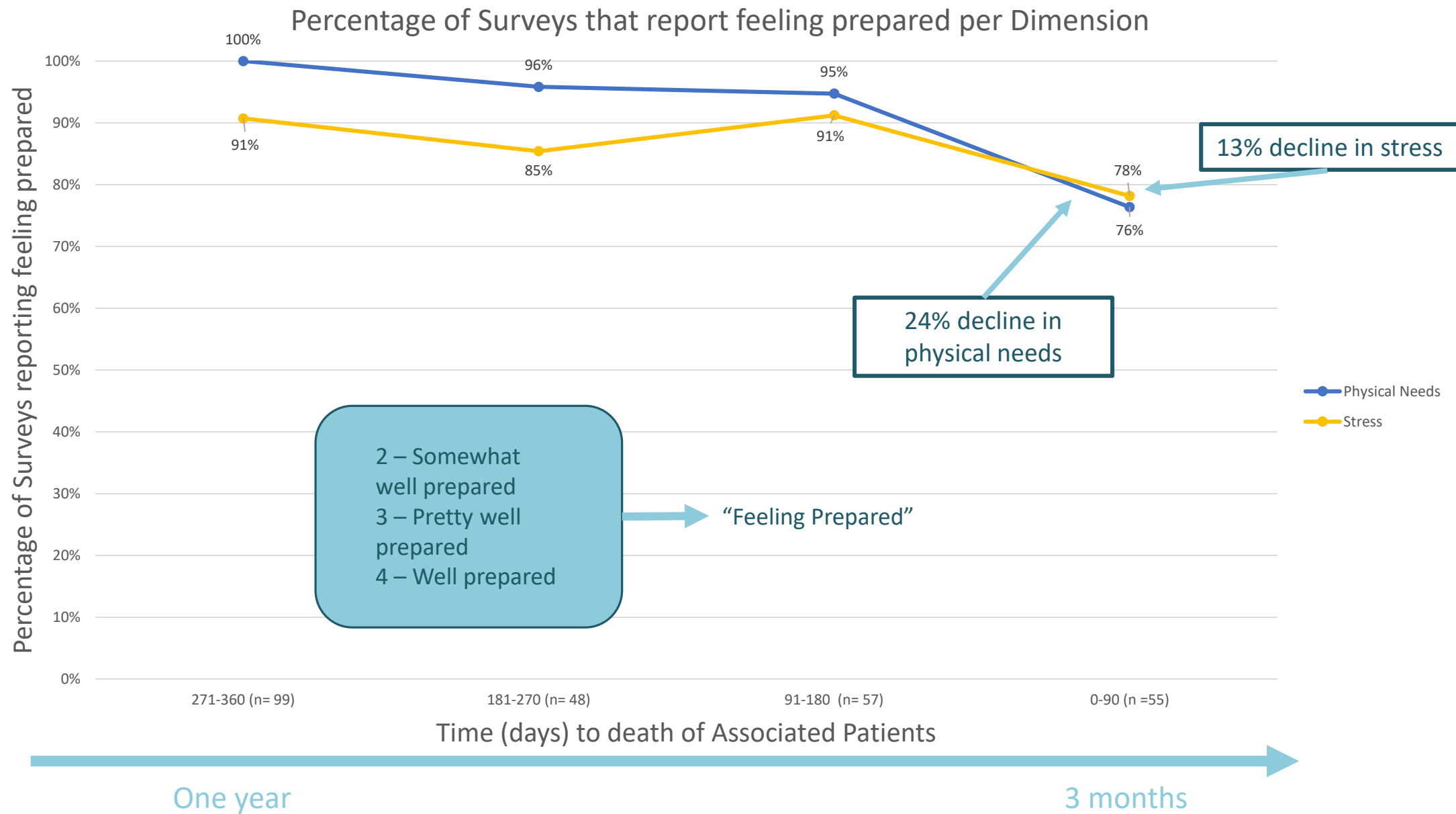
2 – Somewhat
well prepared
3 – Pretty well
prepared
4 – Well prepared

“Feeling Prepared”

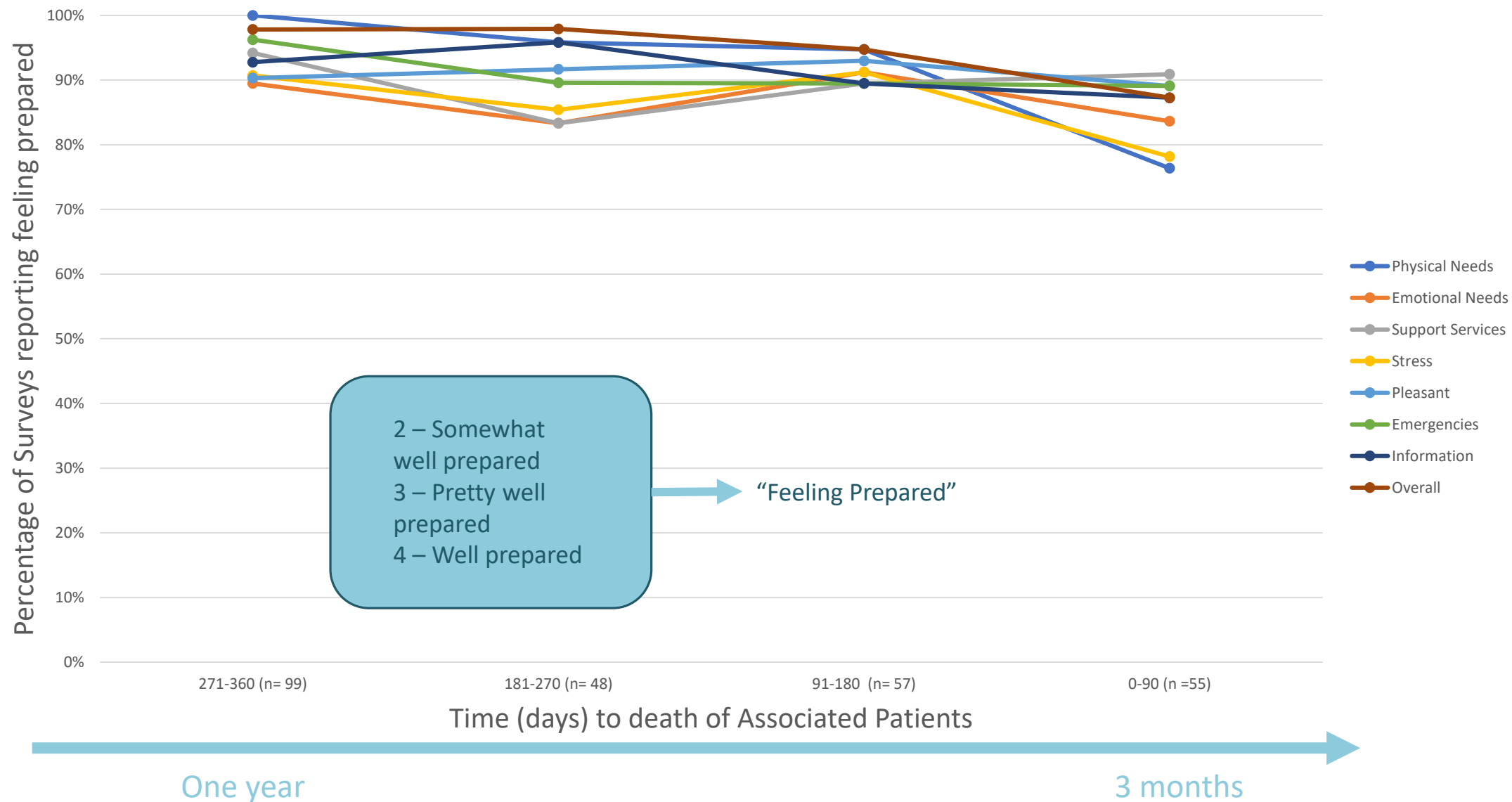
Amount of Caregivers reporting Preparedness per Dimension
(n=73 caregivers)



Enrollment Survey = First month caregiver was on study
Last Survey = Last Month Caregiver was on study

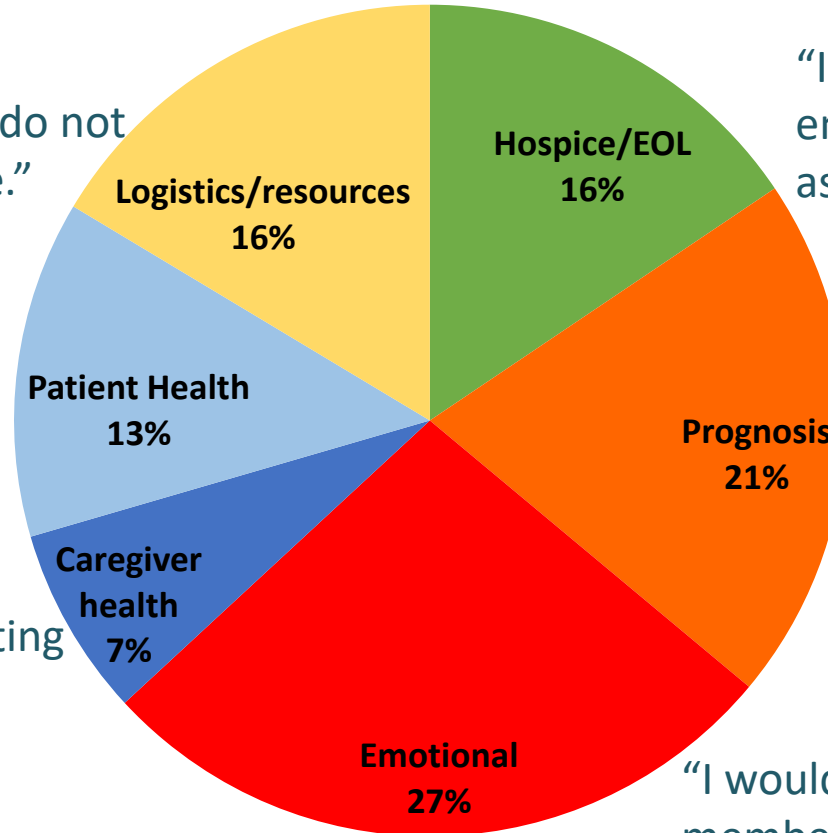


Percentage of Surveys that report feeling prepared per Dimension (n=259 surveys)



Qualitative Comments

Frequency of Caregiver Concerns



“I am hearing impaired and it's difficult to communicate unless it's via email or text. I do not know what palliative home care is available.”

“My husband has just had a change in chemo protocol, just dealing with the different side effects and knowing what is 'okay' is very stressful”.

“My own personal physical abilities. I am waiting for surgery on my arm in the near future.”

“I would like to have more hospice & end of life information available to me as I do not know how to find this out.”

“How bad is this going to get?”

“I would like to be more prepared for my family member's loss of hope”

Conclusion and Next Steps

Conclusion:

1. As death approaches (last 90 days) caregivers feel less prepared for their role.
2. Other qualitative studies and quantitative studies, using a range of tools, have similarly found decreases in self-assessed preparedness, quality of life and increased emotional distress overtime.

Next Steps:

1. Evaluate early palliative care intervention with early specialist palliative care referrals to determine if this had an effect on preparedness
2. To evaluate caregiver health status and quality of life outcomes through the EQ5D instrument

Questions?
