

## Background

- Many populations are aging and people are living longer with advanced chronic disease
- Where and how care is provided during the end of life has become increasingly important
- With the dispersion of many family circles, care is often provided within long-term care (LTC) facilities where primary care is the key health service provider
- In Nova Scotia, Canada, a mortality follow-back survey was conducted to gather information about care experiences and health services provided during the last month of life across all potential care locations.

## Objective

To examine the perception of unmet need among family members of decedents who spent the majority of their last 30 days of life in LTC.

## Method

### Design

- Population based mortality follow-back survey, administered by telephone

### Setting

- Nova Scotia, Canada (population ~950,000)



### Participants

- 1316 knowledgeable informants (next-of-kin) identified from death certificates of adult (18+ yrs.) Nova Scotians who died from advanced disease between June 2009 to May 2011

### Survey Instrument

- 'The 'After-death bereaved family member interview' (Teno J et al. 2004)
  - Plus additional questions of interest (e.g. service provision, preferences)
- Six patient-focused, family-centered domains of care
  - Provision of desired physical comfort (pain, dyspnea, emotional support)
  - Promotion of shared decision making
  - Treatment of decedent with respect
  - Co-ordination of care
  - Attending to family needs for information, what to expect
  - Family emotional & spiritual support
- Overall satisfaction.

### Acknowledgements

This study is financially supported by the Canadian Institutes of Health Research & the Network for End of Life Studies

## Measures

### Outcomes

- The six domains of care plus overall satisfaction
- Dichotomized as 'all needs met vs some unmet need / concerns'

### Primary variable of interest

- Location of majority of care during the last 30 days of life
  - LTC, home, hospital palliative care unit, hospital acute care

### Covariates

- Decedent and informant demographics
- Awareness of approaching death

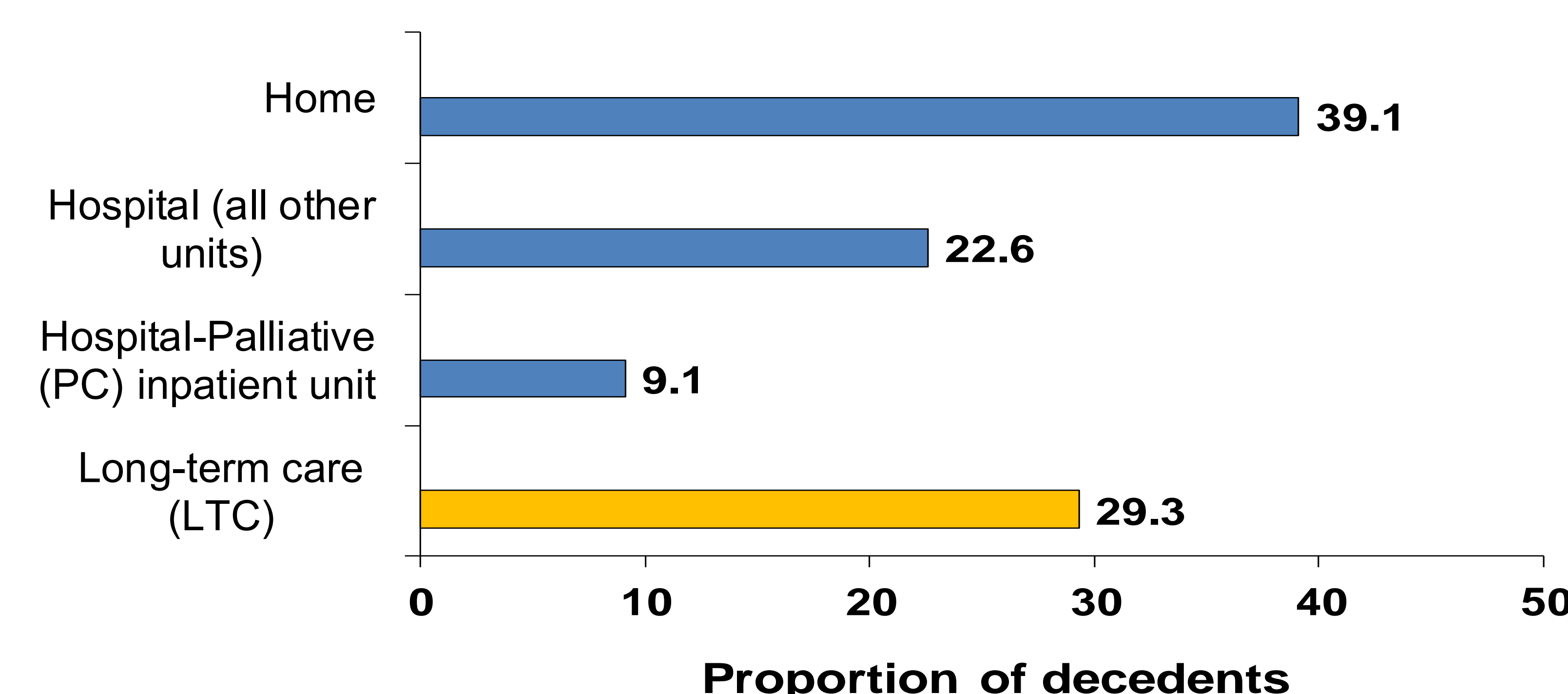
## Analysis

- Descriptive statistics, cross-tabulations
- Unadjusted and adjusted logistic regression to examine association between location of care and the perception of unmet need.

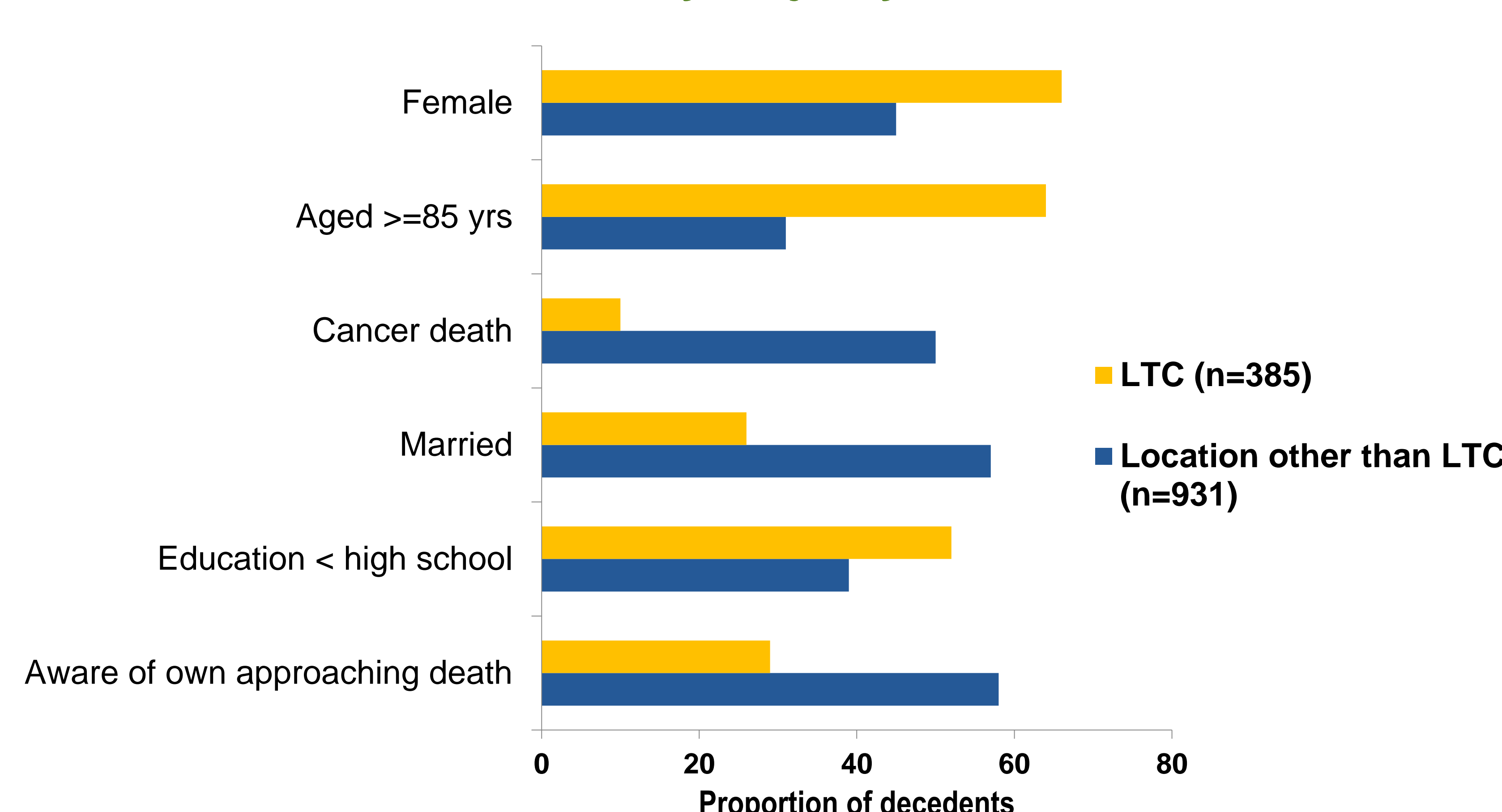
## Results

### Location of the majority of care

- 385 of 1316 decedents spent the majority of last 30 days in LTC

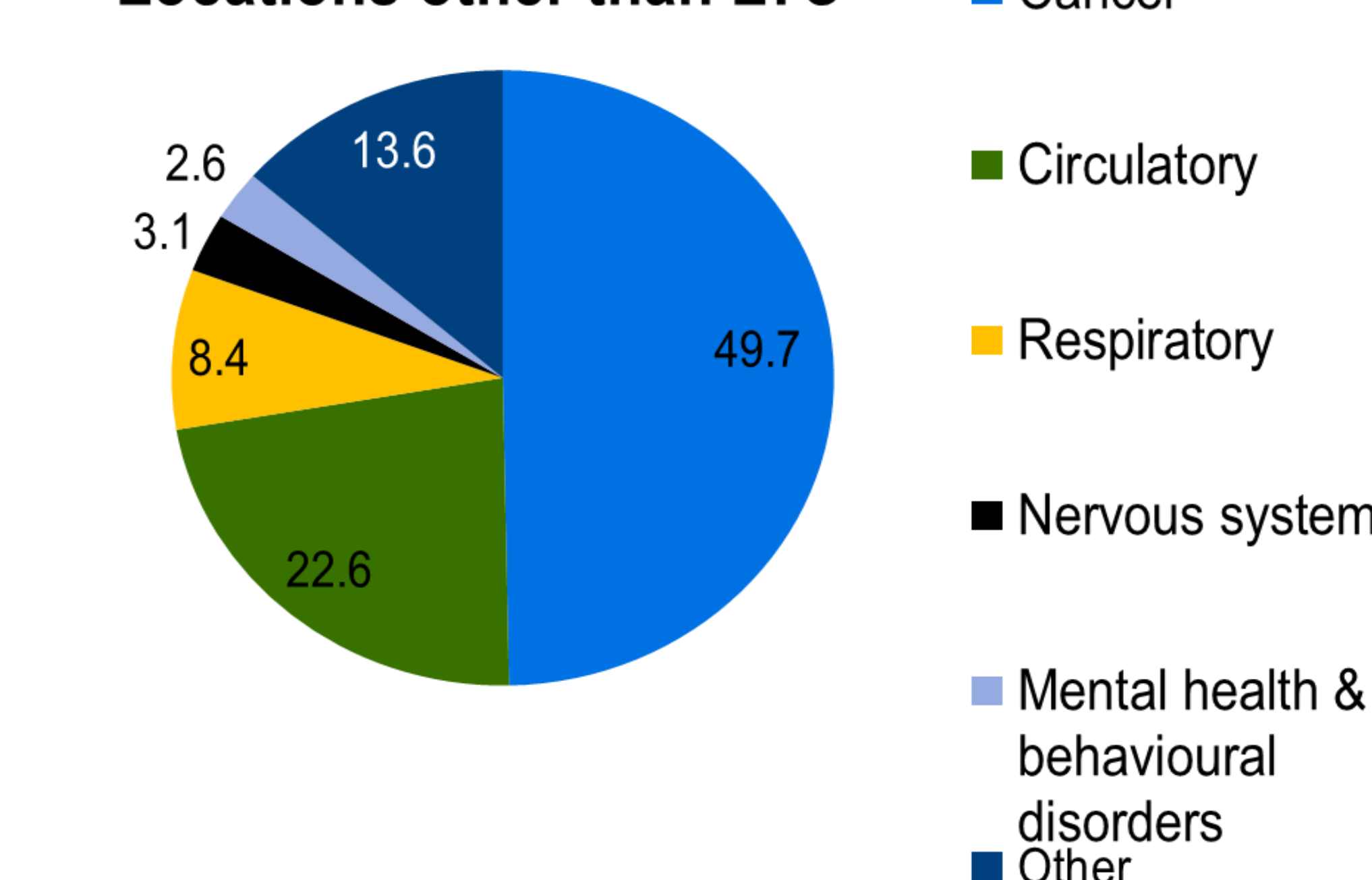


### Decedent characteristics by majority of care

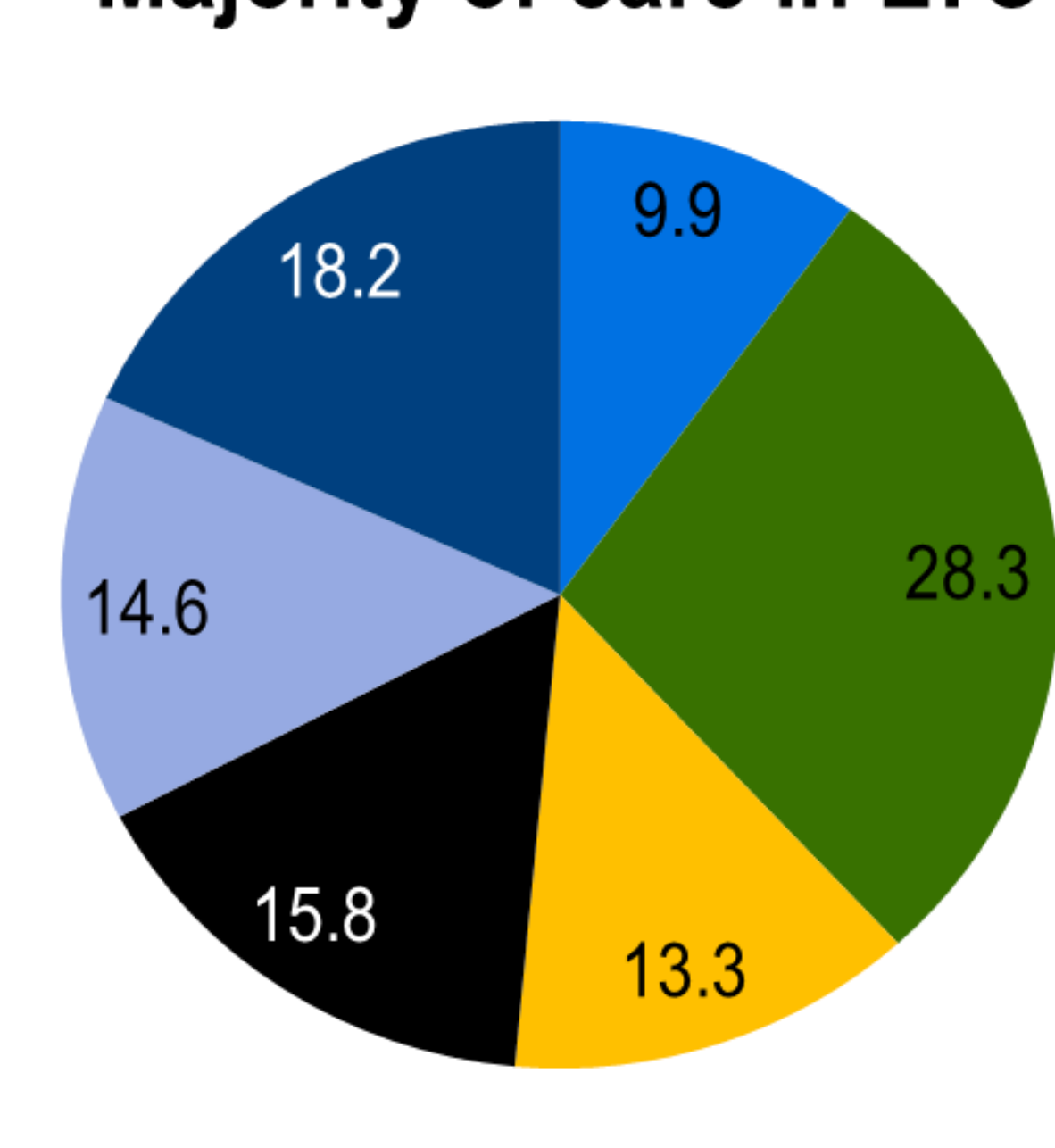


## Decedent cause of death

### Locations other than LTC



### Majority of care in LTC



## Adjusted odds of experiencing unmet need or concerns with care among decedents who spent the majority of their last 30 days in LTC versus those at 'home'

Patient-focused family-centered domain of care	Odds Ratio (95% Confidence Intervals)	
	Unadjusted	Adjusted
Did not receive desired help for:		
Pain	0.9 (0.5-1.9)	1.2 (0.7-2.2)
Dyspnea	<b>0.3 (0.2-0.6)</b>	<b>0.2 (0.1-0.5)</b>
Emotional support	0.7 (0.4-1.1)	0.7 (0.4-1.1)
Shared decision making (communication)	0.8 (0.5-1.1)	1.2 (0.8-1.8)
Treated with respect	2.2 (1.5-3.4)	<b>2.3 (1.4-3.8)</b>
Coordination of care	0.8 (0.5-1.1)	1.0 (0.6-1.6)
Family needs:		
Obtaining information	<b>0.7 (0.5-0.9)</b>	<b>0.7 (0.5-1.0)</b>
Knowing what to expect	<b>0.6 (0.5-0.9)</b>	<b>0.7 (0.5-0.9)</b>
Family emotional & spiritual support	1.0 (0.8-1.4)	<b>0.7 (0.5-1.0)</b>
Not completely satisfied with overall care	<b>1.3 (1.0-1.8)</b>	1.2 (0.8-1.6)

Adjusted for: decedent sex, age, cause of death, marital status, education, income, living alone, informant relationship, informant's awareness of decedent's approaching death

## Conclusions

- LTC resident characteristics differed significantly from all others
- Although some LTC experiences were perceived as better than those at home, family needs and communication are lacking across all locations and require attention
- In particular, issues of treating the decedent with respect should be addressed by all primary care providers.