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NEW ZEALAND

# **Comparison of the end of life experience for those with cancer, dementia and chronic illness in residential aged care in New Zealand:**

## **A retrospective, cross-sectional study**

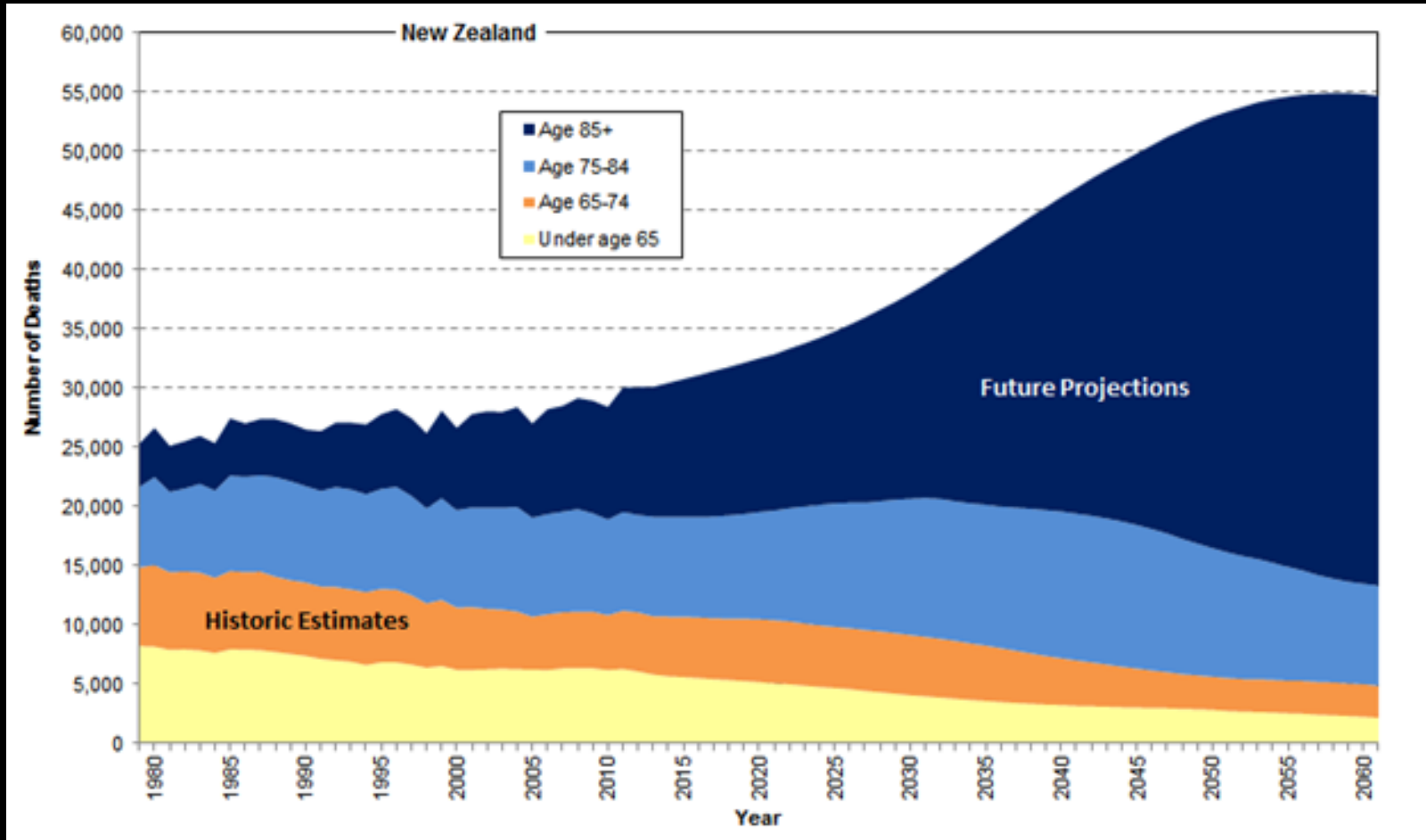
Dr Michal Boyd, RN, NP, ND, FCNA(NZ), FAANP  
Assoc Prof. and Gerontology Nurse Practitioner

University of Auckland

School of Nursing and Freemasons' Dept. of Geriatric Medicine



# New Zealand Historic Deaths and Future Projections by Age Band

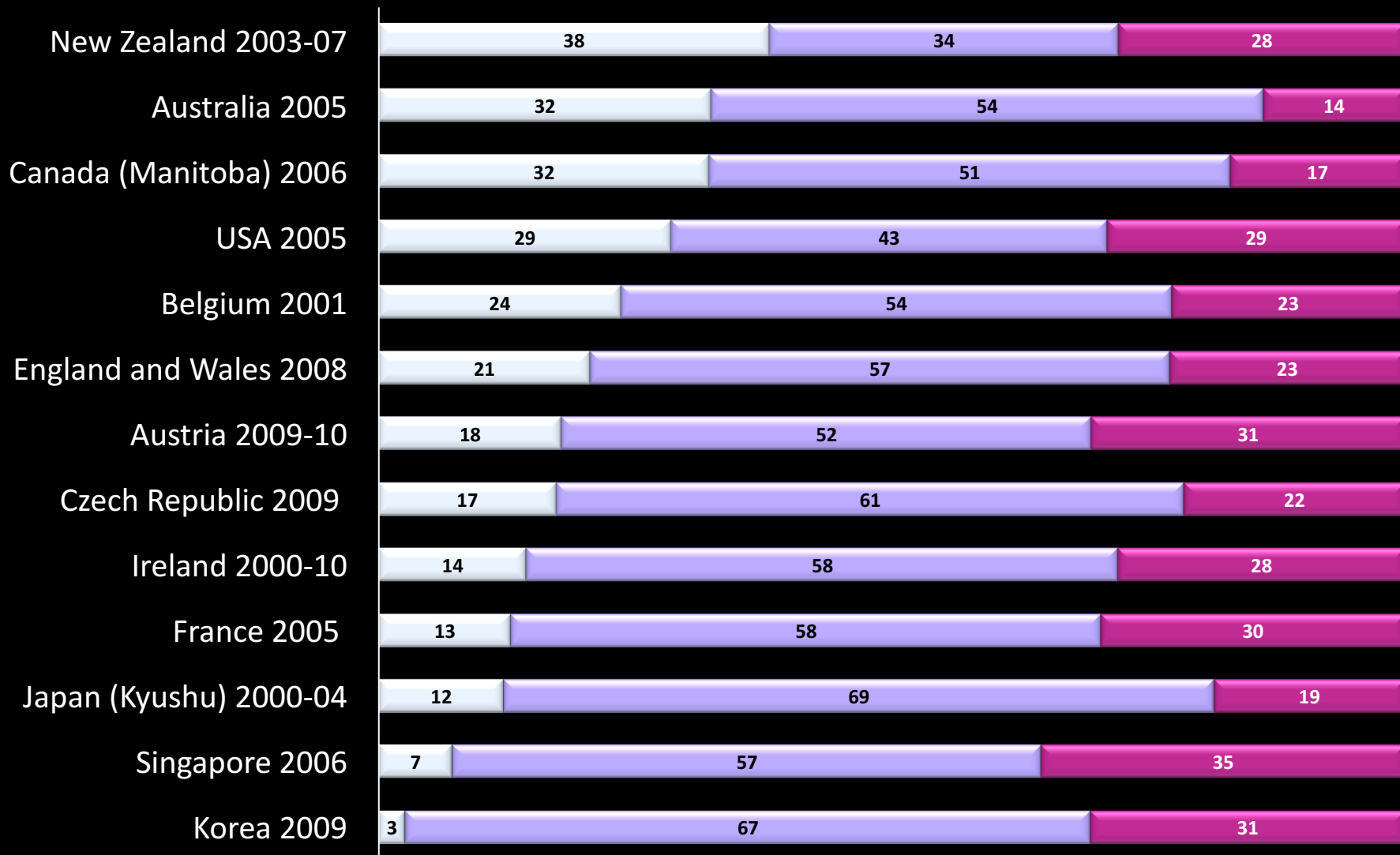


Heather McLeod, Palliative Care Council, July 2013. Drawn using data from Statistics New Zealand; personal communication Joanna Broad.

## International Comparison of Place of Death for those >65

JB Broad, et al. 2012

■ Residential aged care %    ■ Hospital %    ■ Other# incl. own home %





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**ELDER**

END OF LIFE WITH  
DEMENTIA RESEARCH

Research Team:

Michal Boyd (lead), Deborah  
Balmer, Susan Foster, and  
Rosemary Frey

*This project is co-funded by the MBIE  
National Science Challenge: Ageing Well*

&

*Perpetual Guardian Trust  
Ted and Mollie Carr Trust*



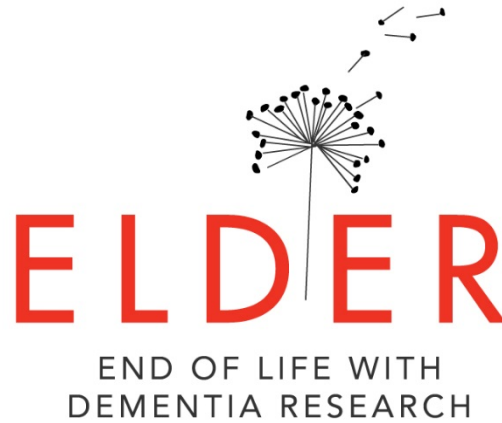
# ELDER Objectives

- Explore quality of death in residential aged care from staff and family perspectives

- Based on methods from:

Vandervoort A, Van den Block L, van der Steen J T, Volicer L, Stichele R V, Houttekier D and Deliens L. Nursing Home Residents Dying With Dementia in Flanders, Belgium: A Nationwide Postmortem Study on Clinical Characteristics and Quality of Dying. JAMDA. 2013;14:485-92.

- ELDER included assessment of all deaths over a three month period



## Methods:

- Mixed methods approach
- Representative random sample of facilities across New Zealand
  - Stratified by size, ownership (profit/non-profit), and area
- Monitor deaths for 3 months in each facility
- Follow up each death with an standardised staff questionnaires:
  - Diagnoses at the time of death and dementia diagnosis and stage
  - Diagnoses at time of death, symptoms before death
  - Standardised quality of death questionnaires – QUALID, CAD-EOLD, SM-EOLD
  - Manager, GP/NP, RN, Healthcare Assistants (HCA)
- Qualitative Interviews with convenience sample of staff and families

# Sample

Auckland  
January – March 2016  
64 deaths

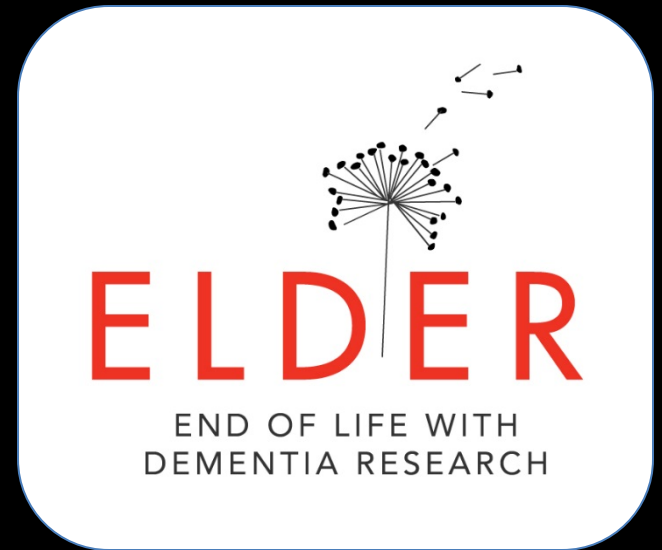
Wellington  
April – July 2016  
73 deaths

Christchurch  
August – November 2016  
92 deaths

Dunedin  
September – November 2016  
34 deaths

Whangarei  
November 2016 – February 2017  
23 deaths

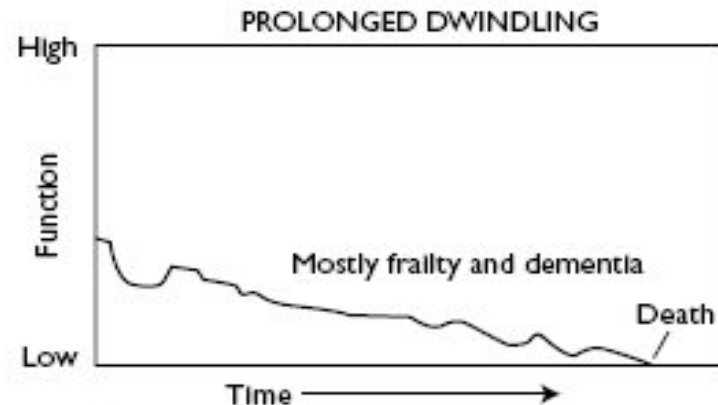
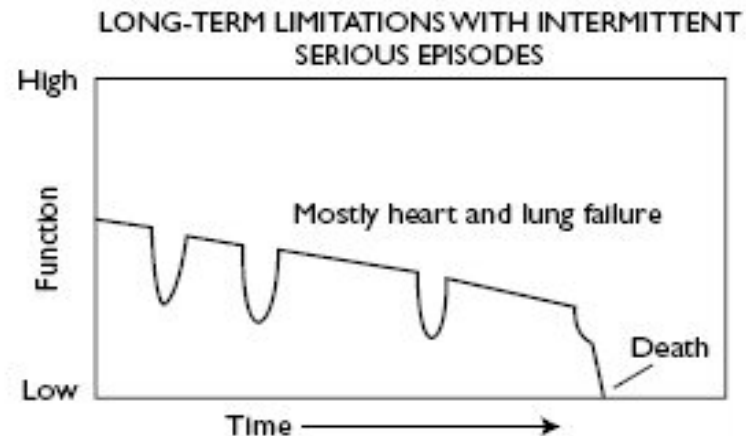
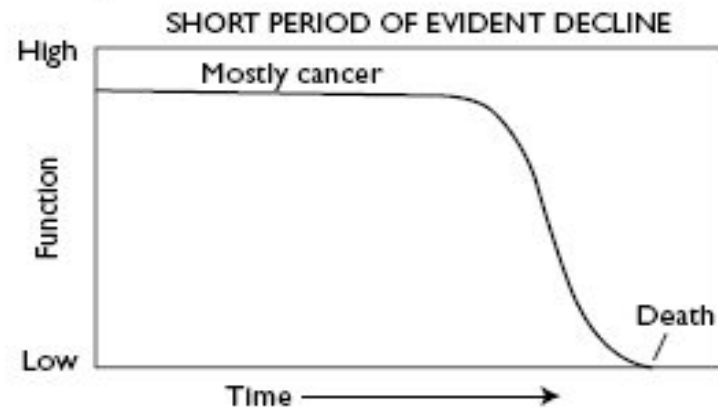
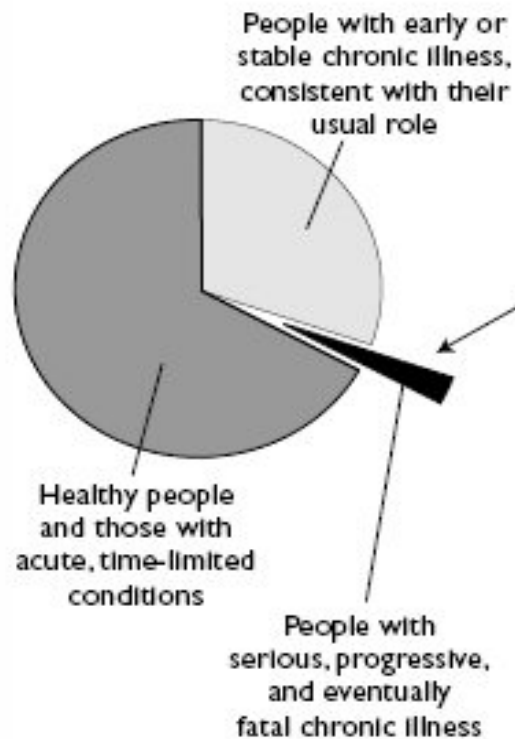
61 Facilities  
(60% of those  
approached)  
3702 beds  
286 Deaths





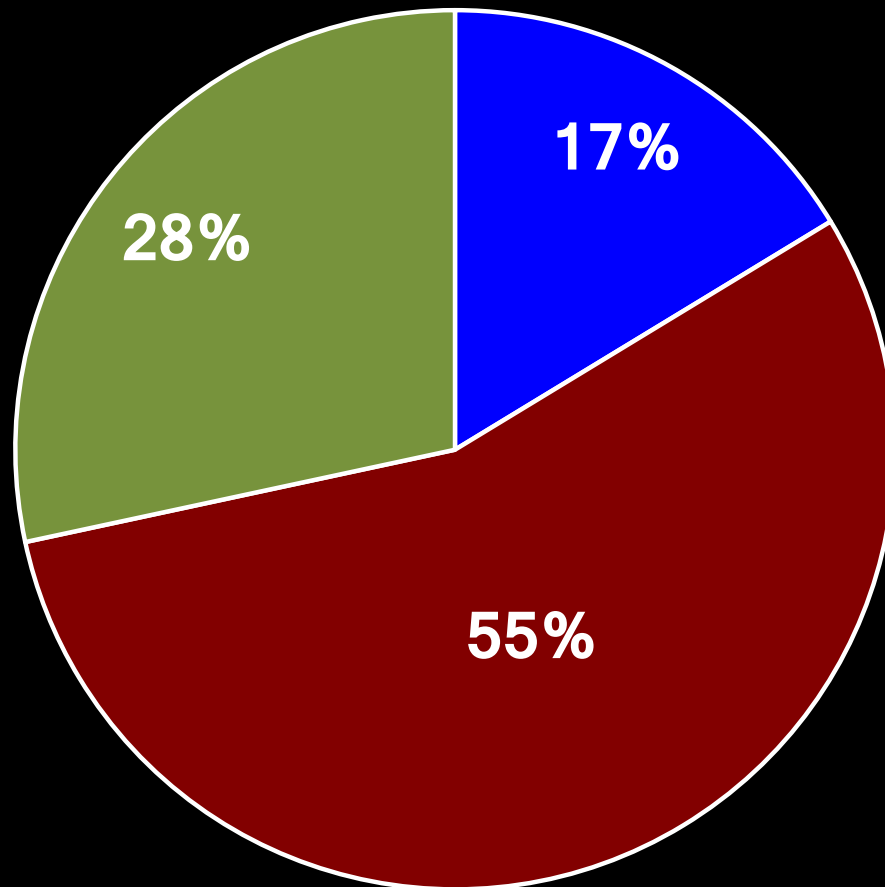
# Trajectories of Illness Over Time

Lynn and Adamson, 2003



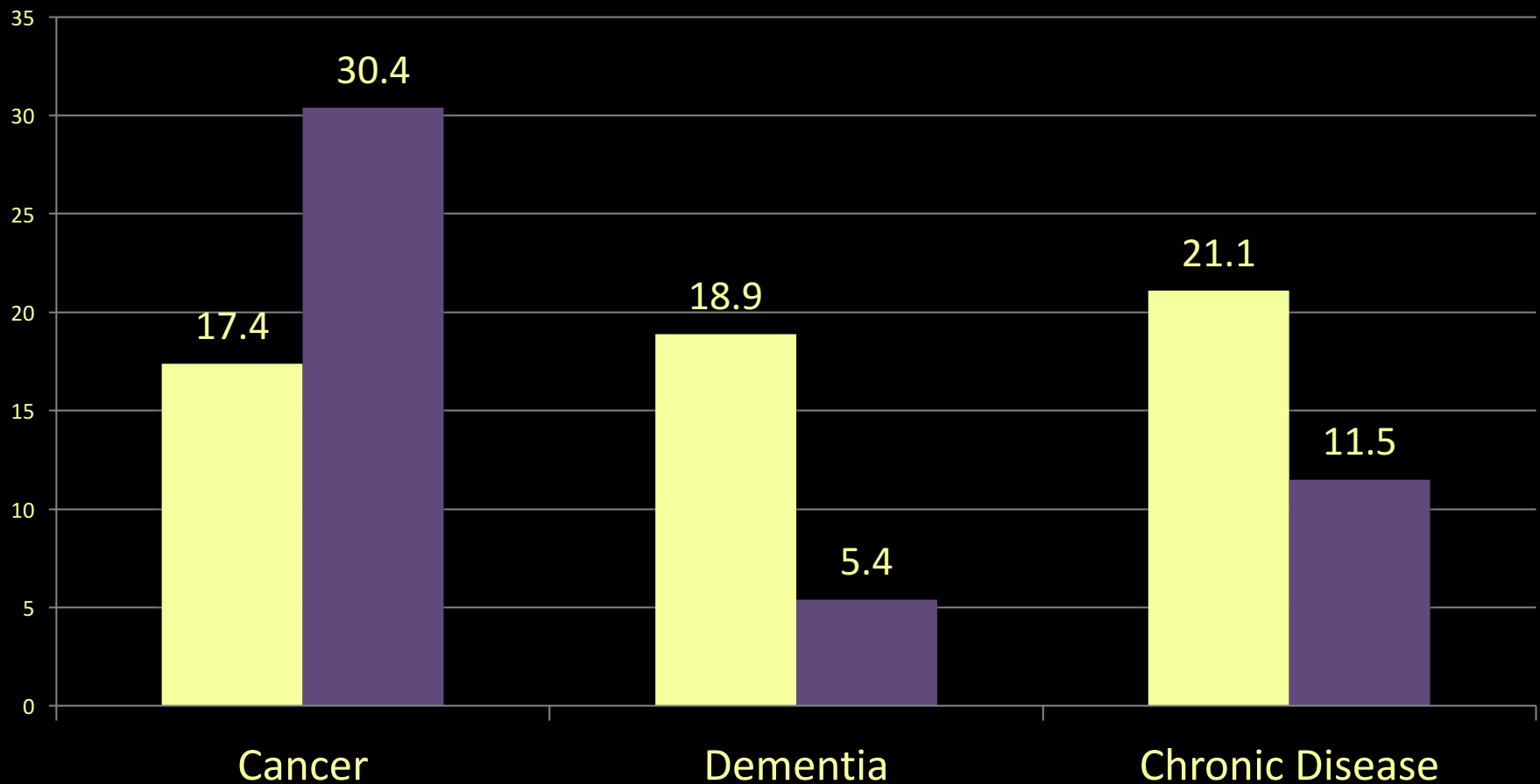
# Primary Diagnosis at Death

■ Primary Dx Cancer ■ Primary Dx Dementia ■ Primary Dx chronic disease

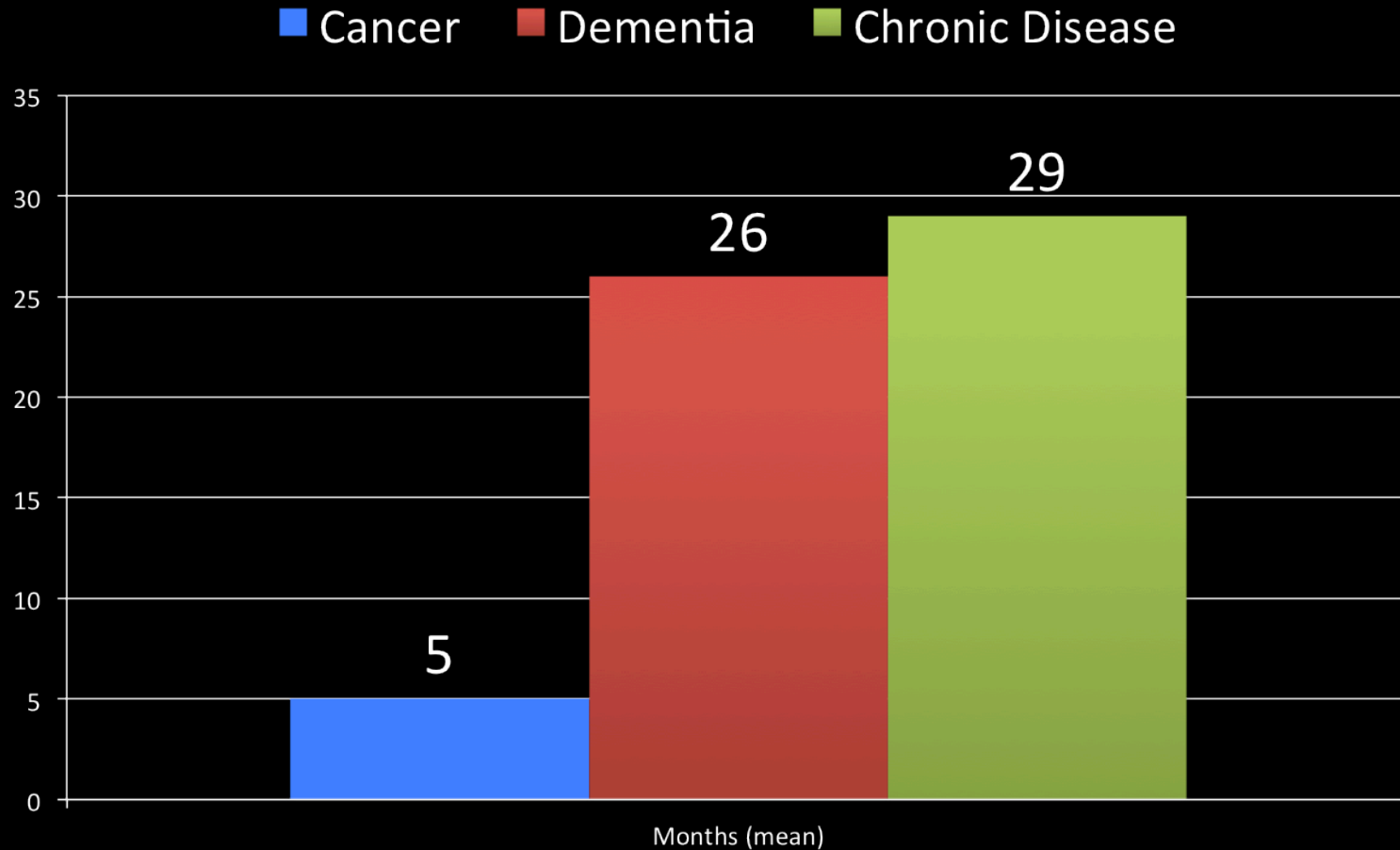


# End of Life Care Support: % by primary diagnosis

■ End of life pathway used ■ Local hospice involvement?

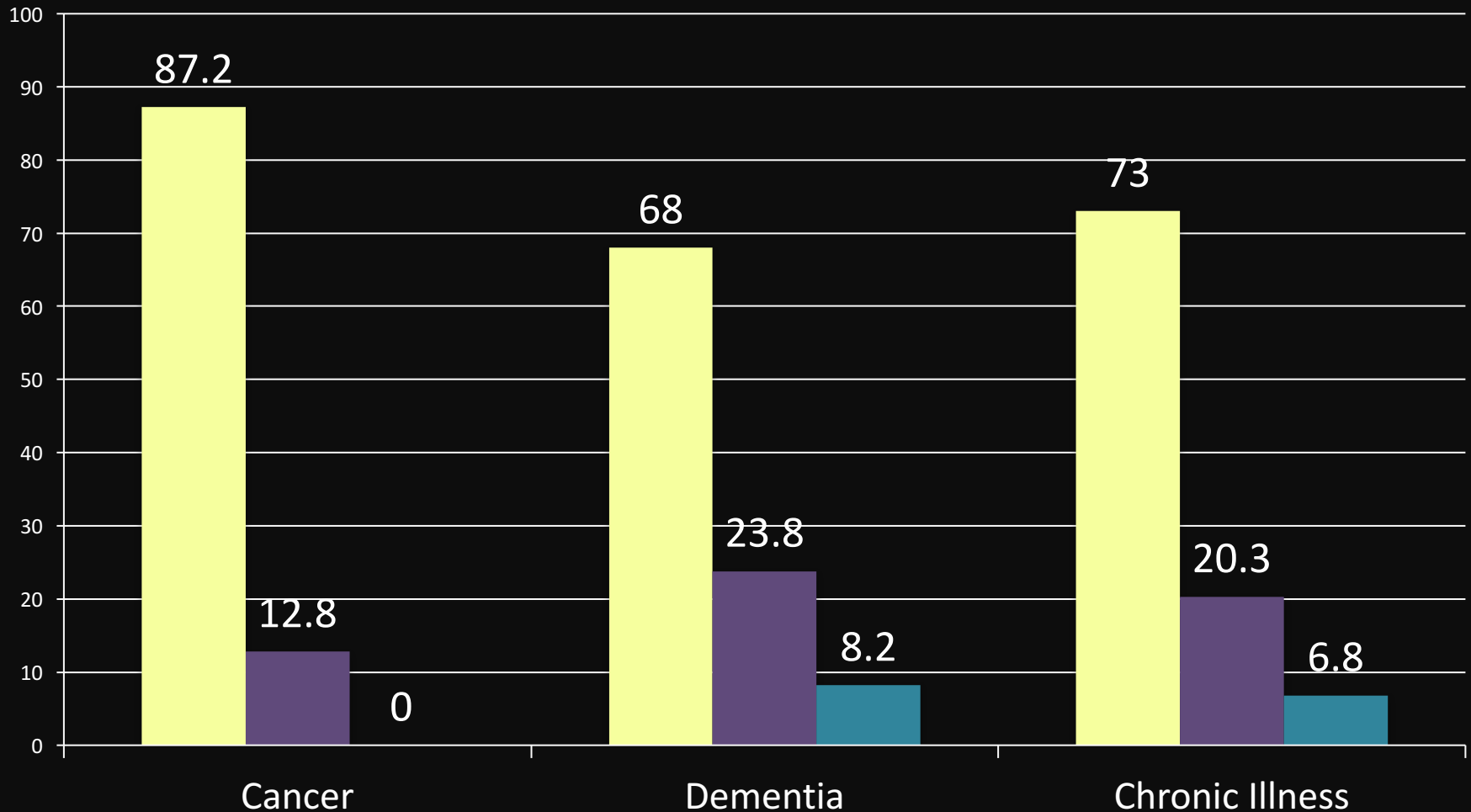


# Residential Aged Care Length of Stay



# Expected/Unexpected Deaths: % by primary diagnosis

■ expected but faster   ■ neither expected or not   ■ unexpected



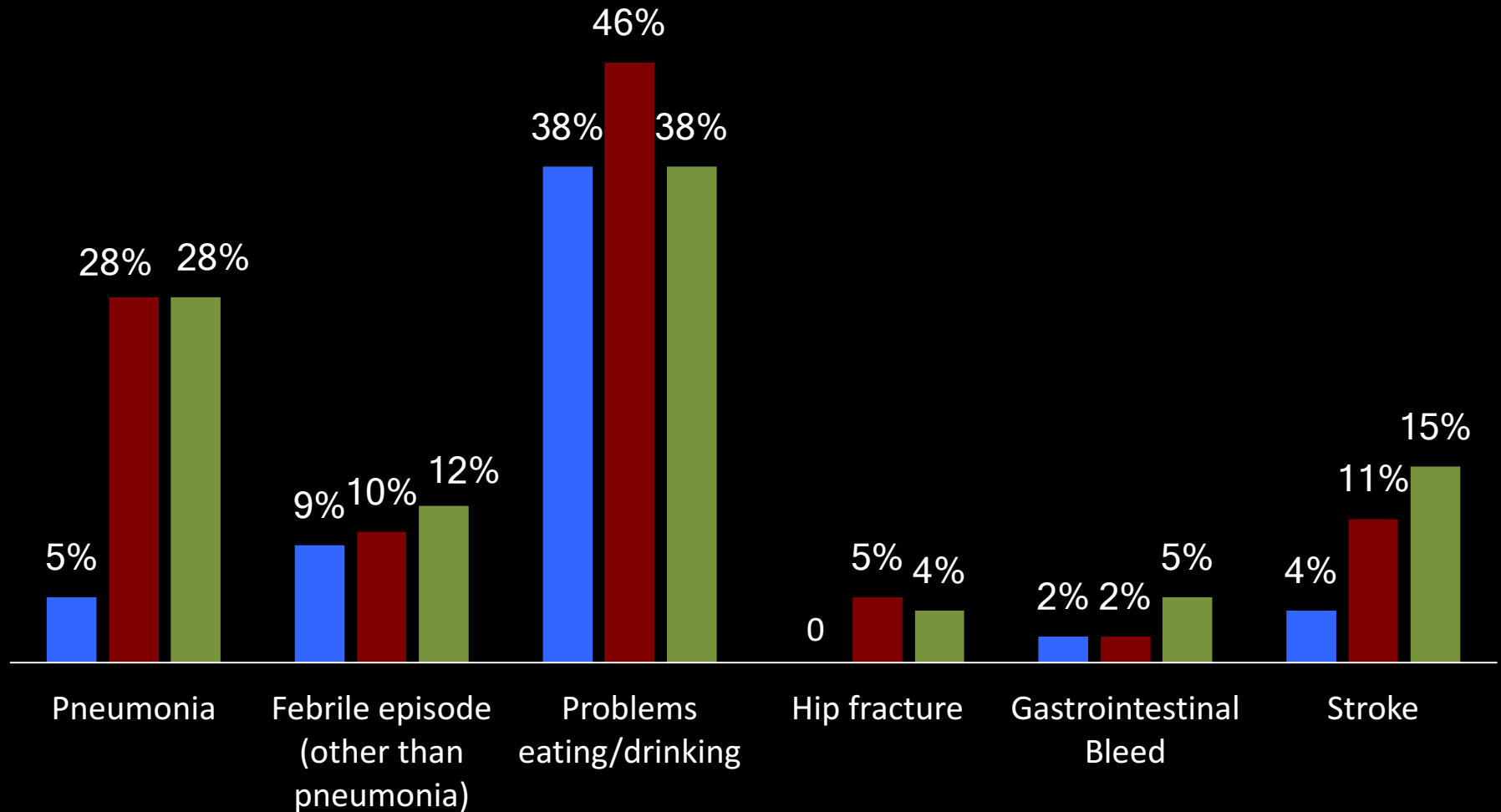
# Aged differences by primary diagnosis

**Table 2** *Sample demographics* (n = 286)

	total sample n (%)	Cancer n (%)	Diagnosis Category		P Value*
			Dementia n (%)	chronic disease n (%)	
	285 (100%)	n=47 (16.4%)	n=158 (55.2%)	n=80 (28.0%)	
Age					
<65 years	14 (5.0)	9 (19.6)	3 (1.9)	2 (2.5)	
66-75 years	23 (8.2)	8 (17.4)	13 (8.3)	2 (2.5)	
76-85 years	63 (22.3)	11 (23.9)	35 (22.4)	17 (21.3)	
86-95 years	141 (50.0)	13 (28.3)	89 (57.1)	39 (48.8)	
>96 years	41 (15.5)	5 (10.9)	16 (10.3)	20 (25.0)	
Mean Age (Mean ± SD)	86.32 (10.23)	79.32 (13.77)	86.85 (8.59)	89.33(9.05)	0.001

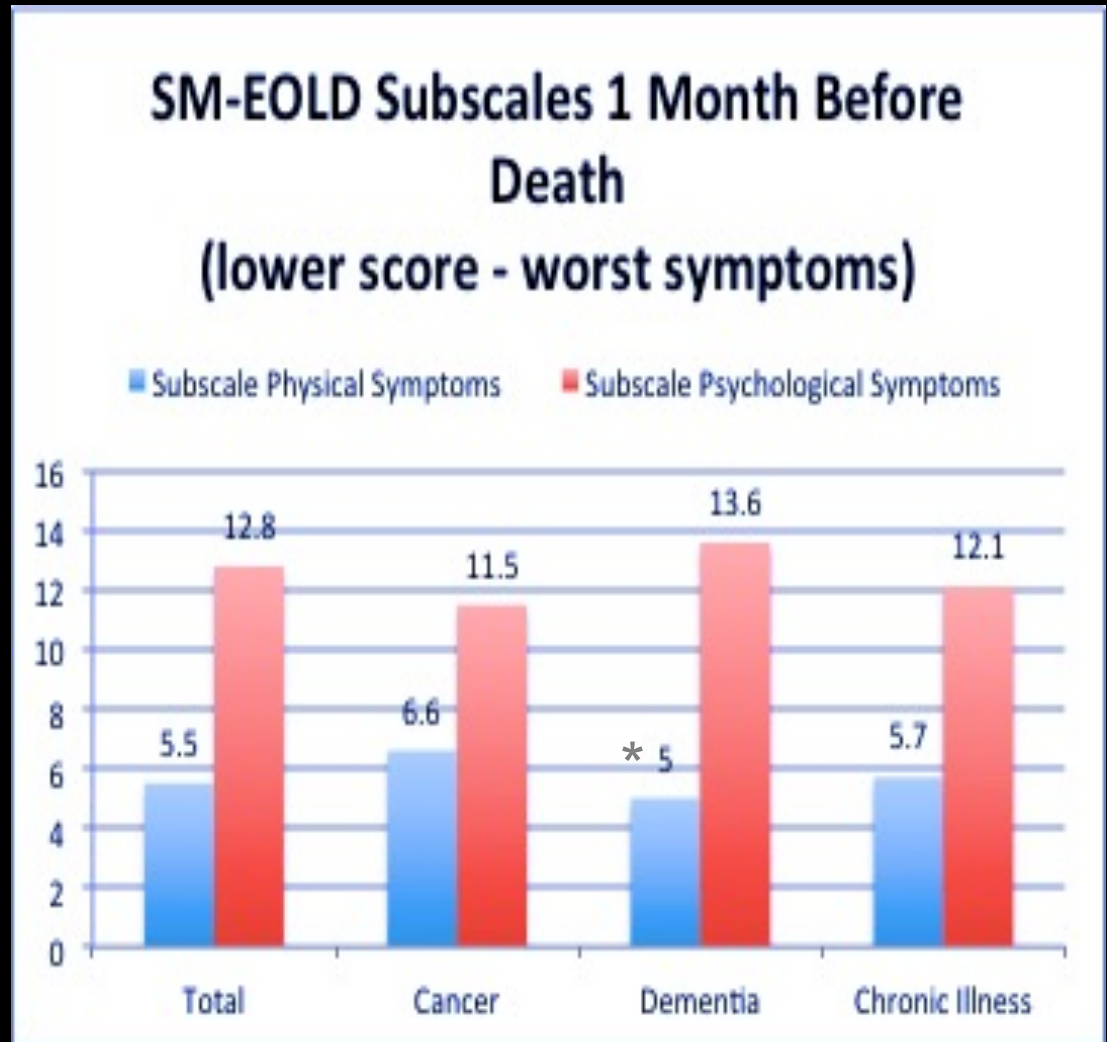
# Sentinel events in the month before death

■ Cancer ■ Dementia ■ Chronic Illness



# Mean EM-EOLD Sub-Scores

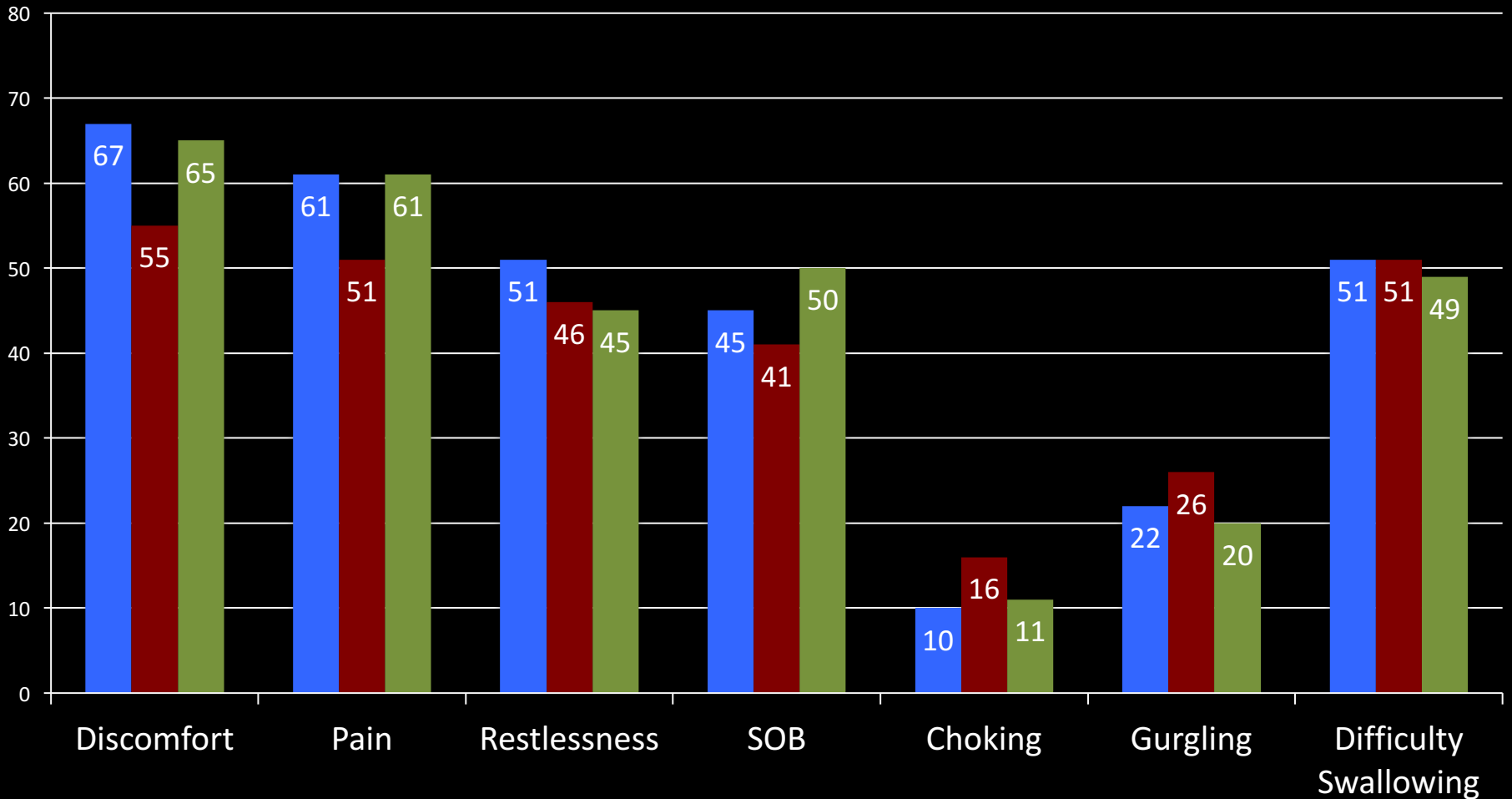
- Physical Sx Subscale
  - Pain
  - Breathlessness
  - Skin Breakdown
- Psychological Sx Subscale:
  - Calm
  - Depression
  - Fear
  - Anxiety
  - Agitation
  - Resistive to care





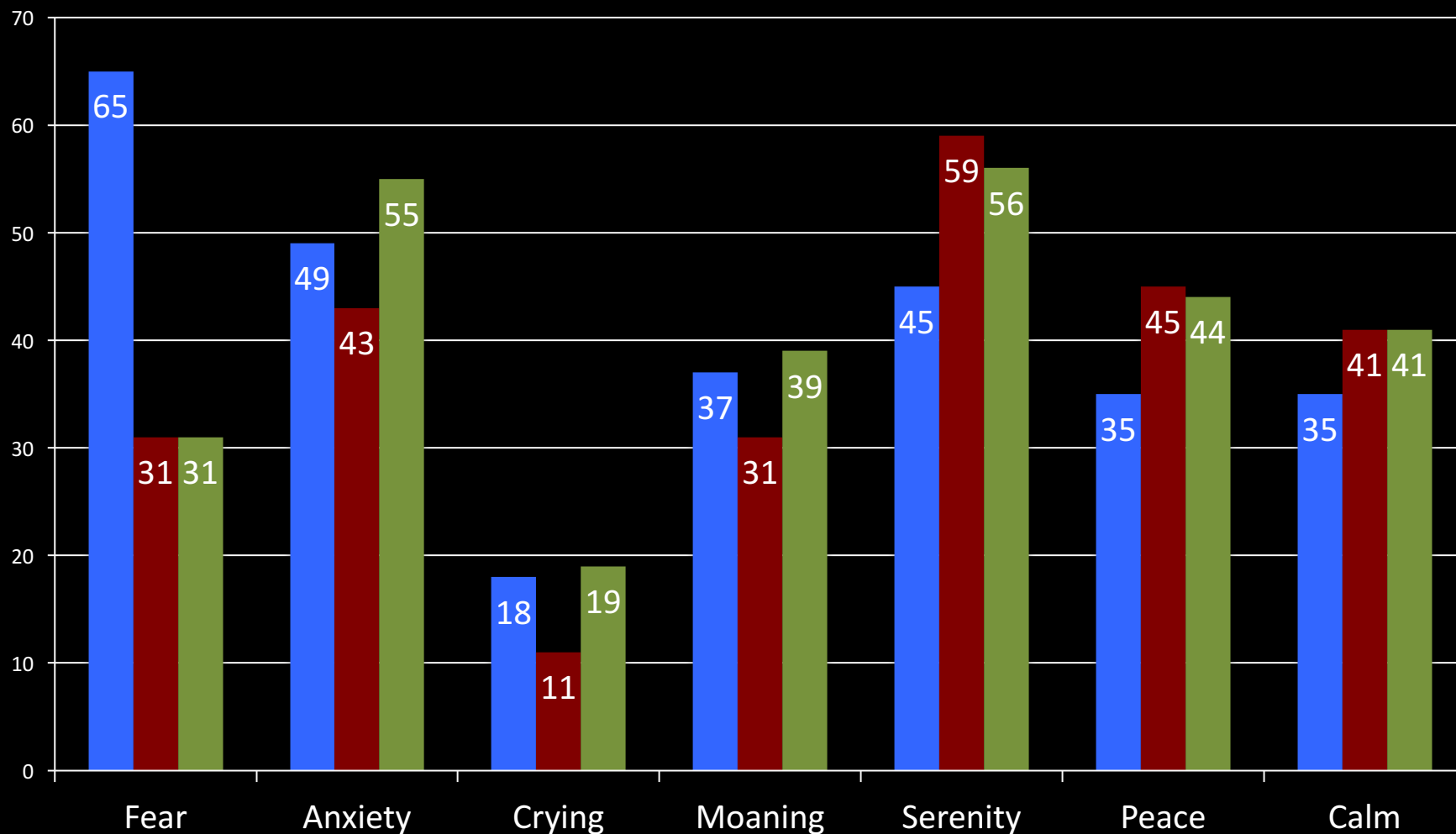
# CAD-EOLD Symptoms Last Week of Life: % with symptoms

■ Cancer ■ Dementia ■ Chronic Disease



# CAD-EOLDE Symptoms Last Week of Life: % with Symptoms

■ Cancer ■ Dementia ■ Chronic Disease



## Two Paradigms: Advanced Frailty and Palliative Approach

### **Advanced Frailty Care**

- Death is difficult to predict
- Long term interventions for multiple gerontology issues
  - Weight
  - Skin integrity
  - Falls
  - BPSD
  - Cardiorespiratory issues
- “Palliative” is understood to be end of life care
- The focus is on adaptation to functional deficits
- Curing and comfort interventions occur together

### **Palliative Approach**

- Identification of palliative need
- Advanced Care Planning
- Diagnosing dying
- Last days of life guidelines
- Bereavement support
- Staff debriefing after death

# Palliative Care Understanding

**...did you hear the word palliative care? What does it mean to you?**

*I wouldn't say that I had an acute understanding, I just had a general idea that it referred to looking after people as they are dying, and trying to make the dying process as comfortable as possible.*

*...in my heart of hearts, I didn't really think it was relevant to us...it was up fairly late in the piece, and fairly late in the whole scheme of things, before I really accepted that, she wasn't going to get better. So, I had a general idea of what it meant, as far as any lay person can, I guess.*

## Residential Aged Care

Resident to RN ratio:  
>20 to 1

GP availability variable  
55% without 24 hour  
'On call' GP

High Staff Turnover  
Few Multi-Disciplinary Team  
Members available

## In-patient unit Hospice

RN to Patient Ratio:  
2-3 to 1

Palliative Care Consultant or GP  
usually available

Social Worker, Chaplain, Volunteers  
Complimentary Therapy,  
Counselling



**GINGER ROGERS  
DID EVERYTHING  
FRED ASTAIRE DID  
BUT BACKWARDS  
AND IN HIGH HEELS**

# Where to From Here?

Specialist or Generalist?



**Gerontology**

**Palliative Care**

# Conclusion

- Primary diagnosis makes no differences in the symptoms the last week of life
- People with dementia, and chronic disease have more gerontology symptoms of concern for a longer period of time
  - Traditional palliative care models don't fit the needs of advanced frailty
- Integration of palliative and gerontology providers: both need to learn from each other
- Other ELDER papers in process:
  - for profit/non profit and facility size palliative care comparison
  - cost and healthcare utilization by diagnosis at end of life
  - Qualitative analysis 113 interviews, e.g.. facility death rituals description
  - staff palliative care confidence and compassion fatigue , e.g. in relation to spirituality beliefs
- SHARE intervention study – integration of specialist palliative and gerontology in residential aged care



# Thank You.



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[Michal.boyd@auckland.ac.nz](mailto:Michal.boyd@auckland.ac.nz)