

Living Well Until You Die

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Wonderful Wednesdays

St. George's Anglican Church, Cadboro Bay

October 31, 2018

Catherine and Sarah's Story





Care givers say 'hearts are broken' after death

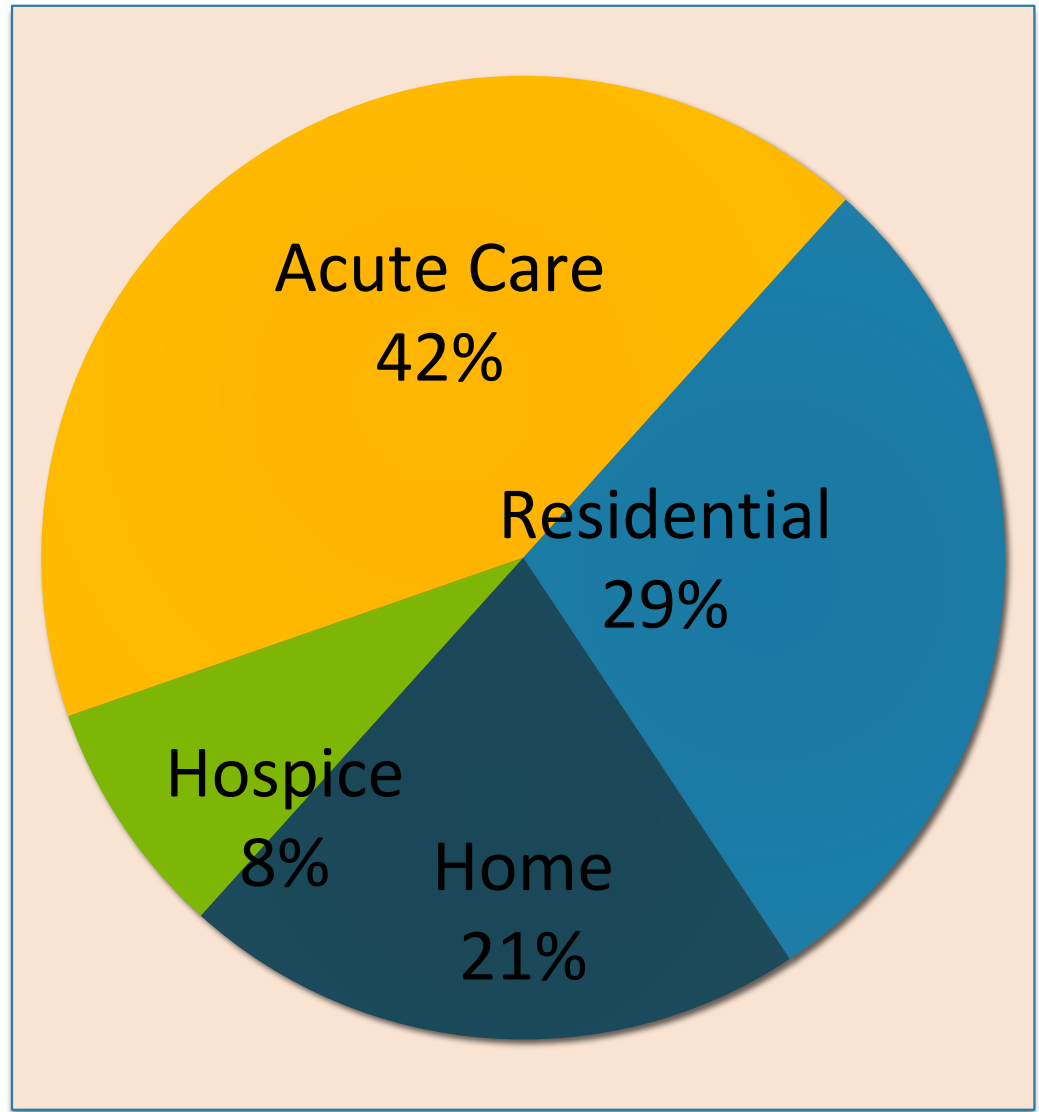
Staff members of the Parksville care home where George Cook lived out the final years of his life were in tears after learning their elderly friend died on a stretcher in the emergency room at Nanaimo Regional General Hospital.

BY THE DAILY NEWS (NANAIMO) APRIL 29, 2006



Images of Illness: The Art of Robert Pope (2007). Robert Pope Foundation

Where Do People Die?



Data from Vital Statistics for Island Health, 2014

Bereaved Family Members' Perceptions of the Quality of End of Life Care Provided in Inpatient Health Care Settings

*Stajduhar, Allan, Bidgood, Norgrove,
Cook, Heyland, Williams & Cohen*

Funded by the Michael Smith Foundation for Health Research



Differences Across Care Settings of Caregivers Completely Satisfied with CANHELP Individual Items

Domain	ICU	PCU	ECU	MCU
Doctor and Nurse Care Health care workers compassionate and supportive	70%	60%	46%	44%
Illness Management Relative/Friend received good care when they could not be there	62%	41%	35%	19%
Health Services End of Life care was coordinated	57%	40%	38%	26%
Communication and Decision Making Understanding of what to expect in the final days	63%	46%	36%	35%

Differences In Health Care Domains Across Settings

- In general, family members whose relative or friend died in a MCU or ECU were not as satisfied with particular aspects of care as those whose relative or friend died in an ICU or PCU
- Qualitatively, family members were overall, not overly satisfied with the care on medical care units and extended care (n=26)

Stajduhar, K.I., Funk, L., Cohen, R., Williams, A., Bidgood, D., Allan, D., Norgrove, L., & Heyland, D. (2011). Bereaved family members' assessments of the quality of end of life care: What is important? *Journal of Palliative Care*, 27(4), 261-269.

Funk, L., Stajduhar, K.I., Cohen, R., Heyland, D., & Williams, A. (2012). Legitimising and rationalizing talk about satisfaction with formal health care among bereaved family members. *Sociology of Health and Illness*. Sept. 34(7):1010-24.



IMPROVING END OF LIFE CARE IN ACUTE CARE AND RESIDENTIAL CARE SETTINGS

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Funded by the Canadian Institutes of Health Research

BARRIERS TO THE PROVISION OF HIGH QUALITY EOL CARE IN INSTITUTIONAL SETTINGS

- Time pressures, multiple and competing demands
- Overburdened with “paperwork” – no time to “be with” patients and families
- Communication breakdowns among team members – “not on the same page”
- Delay in receiving physician’s orders
- Orders and treatments that are not appropriate
- Physical environment
- Staff inexperience
- Demoralization of the health care workforce
 - Feeling unappreciated
 - Interpersonal stress
 - Lack of autonomy or agency
 - Resignation
 - Cynicism



HOSPICE AND PALLIATIVE CARE AS THE “GOLD STANDARD”

- Because of these barriers, health care providers often turn to the specialized services offered by palliative care to obtain help for their patients – “if they can’t get to hospice, we want hospice to come to them”
- Hospice image of a ‘good death’ has permeated understandings and expectations of these health care providers
- This image is the measuring stick from which all deaths seem to be evaluated
- In this sense, providers were left feeling distressed that they could not uphold the ideal in their minds of what a “good death” should look like



CONCEPTUALIZATIONS OF HOSPICE/PALLIATIVE CARE

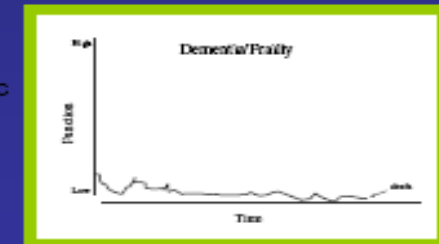
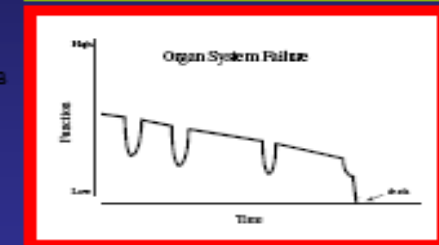
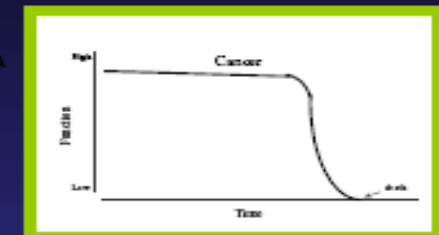
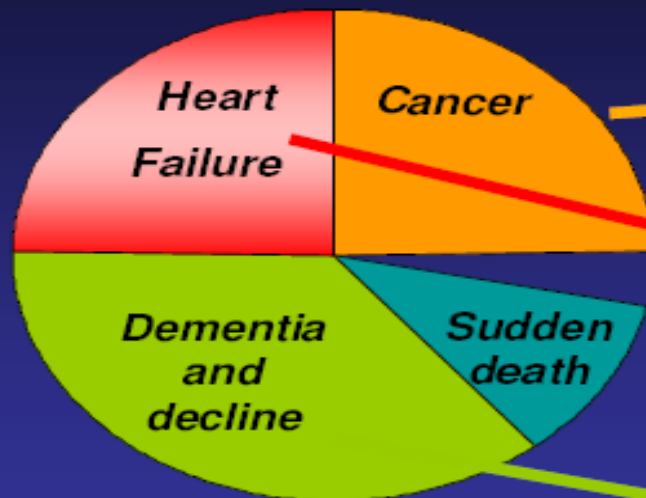
- Conceptualizations of hospice palliative care as a *place* – an inpatient unit where people go to die and where they are cared for by nurses who *specialize* in care of the dying
- Little consideration of hospice palliative care as a philosophy and approach to care
- Little recognition that people die in all locations in the health care system and that everyone has a responsibility for providing a palliative approach to care
- These conceptualizations resulted in a general belief, particularly in acute care, that these patients “don’t belong”



AMBIGUITY OF DYING

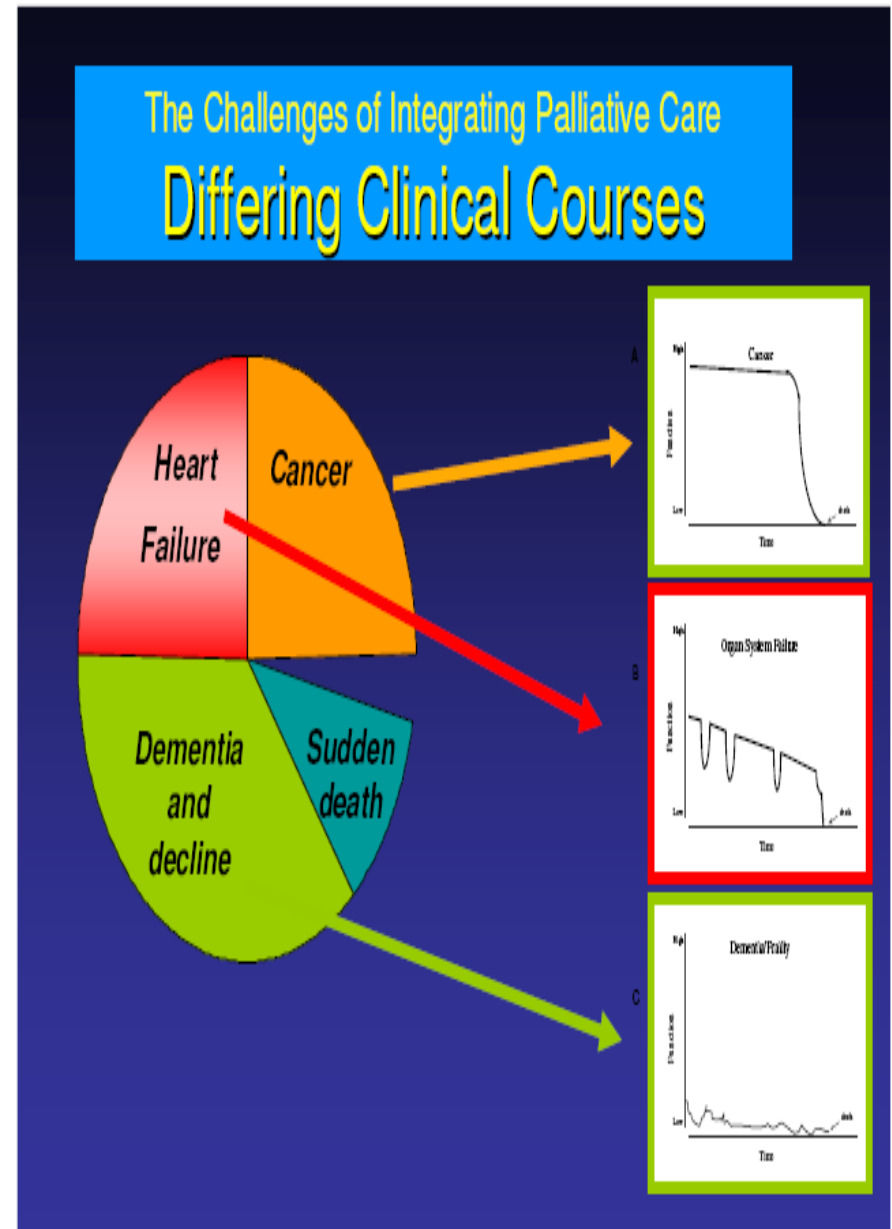
Patient populations experience ambiguous illness

The Challenges of Integrating Palliative Care Differing Clinical Courses

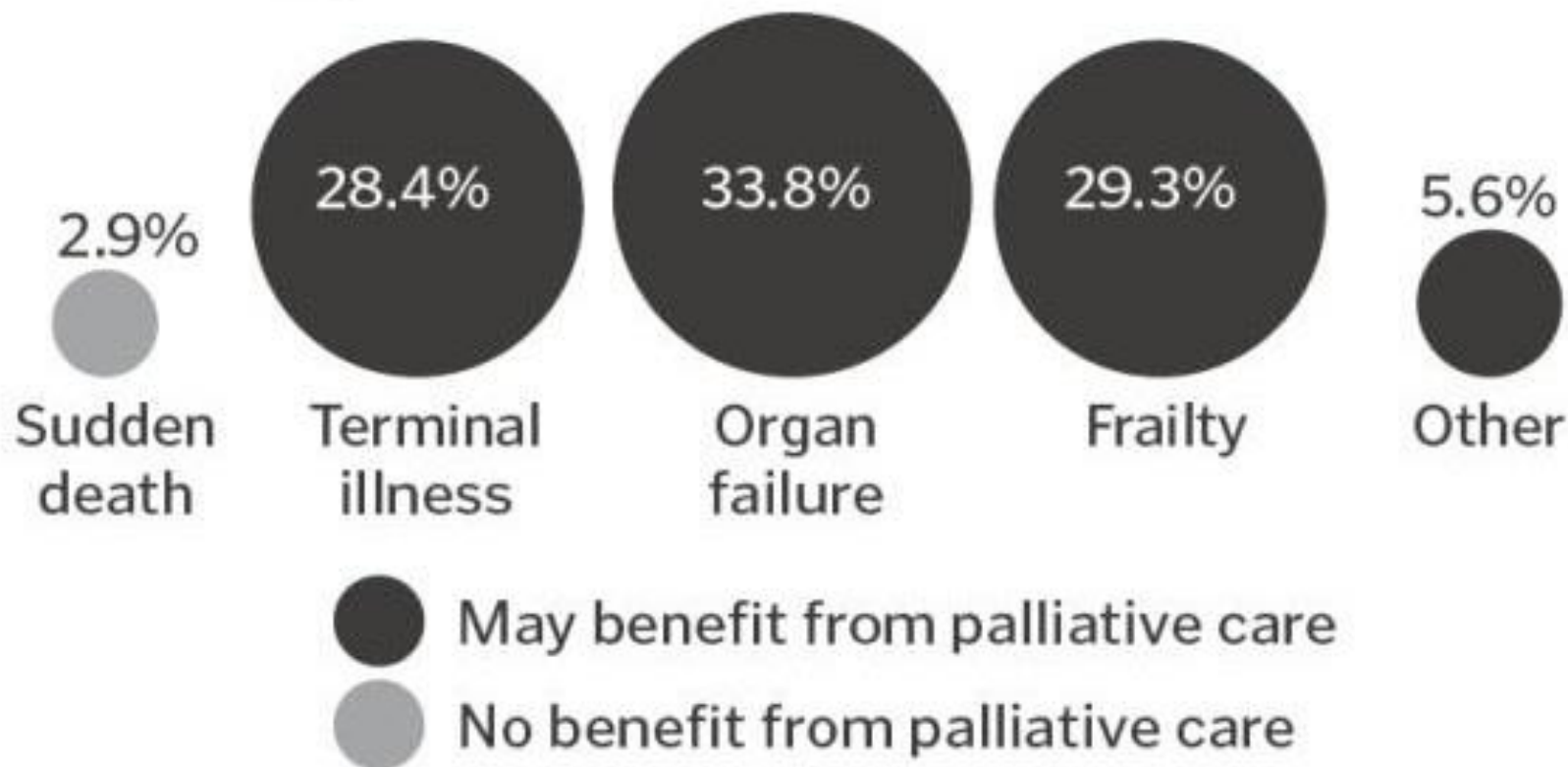


AMBIGUITY OF DYING

- Blurring of distinctions between palliative care and treatment plans
- Where palliative care begins is not clear
- Everyone sees the importance of a coordinated care plan but the complexity and uncertainty of the illness makes things challenging



Cause of Deaths in Canada



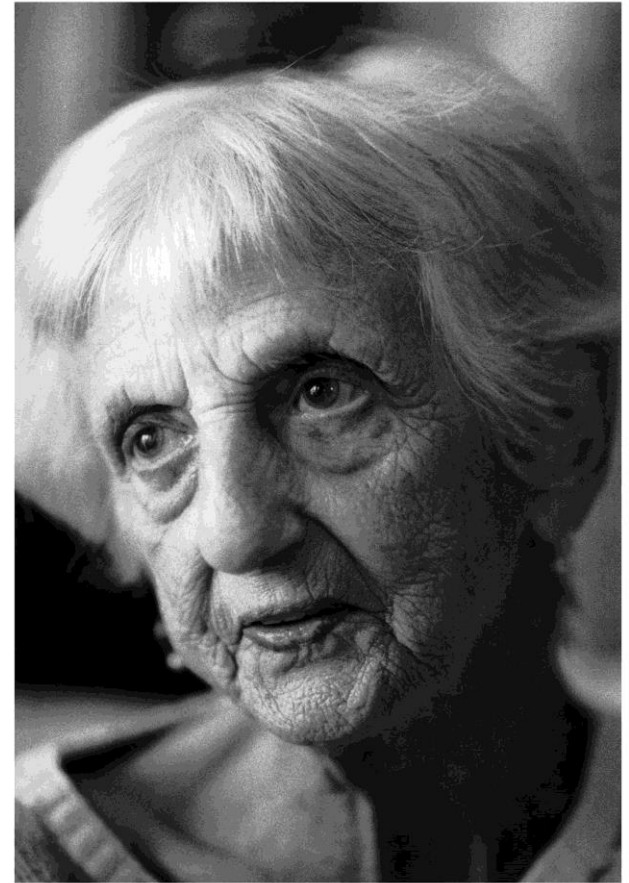
— Source: Raising the Bar: A Roadmap for the Future of Palliative Care in Canada

Changing the Face of Dying

We are living longer.

By 2025:

- **30%** of the population >65.
- **33%** increase in deaths over 2004.
- **2/3** will die with 2 or more chronic diseases after months or years in state of “vulnerable frailty”.
- Only **20%** of us will die in a recognizable terminal (“palliative”) phase.





We need to educate others about palliative approaches to care





**We need to remove, not
increase the stigma**



Public and care provider perception of palliative care:

Participants' initial perceptions of palliative care were of death, hopelessness, dependency and end-of-life comfort care for inpatients.

These perceptions **provoked fear and avoidance**, and often originated from interactions with health care professionals."

Zimmerman et al, Perceptions of palliative care among patients with advanced cancer and their caregivers, CMAJ, July 12, 2016, 188(10)

What is Palliative Care?



Palliative care is a philosophy of care that aims to help individuals and families to:

- Address physical, psychological, social, spiritual and practical issues
- Prepare for and manage end of life choices and the dying process
- Cope with loss and grief
- Treat active issues and manage symptoms
- Prevent new issues from occurring
- Promote opportunities for meaningful and valuable experiences



We need to dispel myths and allay fear about palliative approaches to care



MYTH 1: Palliative care hastens death.

FACT: Palliative care does not hasten death. It provides comfort and the best quality of life from diagnosis of an advanced illness until end of life.



MYTH 6: Pain is a part of dying.

FACT: Pain is not always a part of dying. If pain is experienced near end of life, there are many ways it can be alleviated.



MYTH 2: Palliative care is only for people dying of cancer.

FACT: Palliative care can benefit patients and their families from the time of diagnosis of any illness that may shorten life.



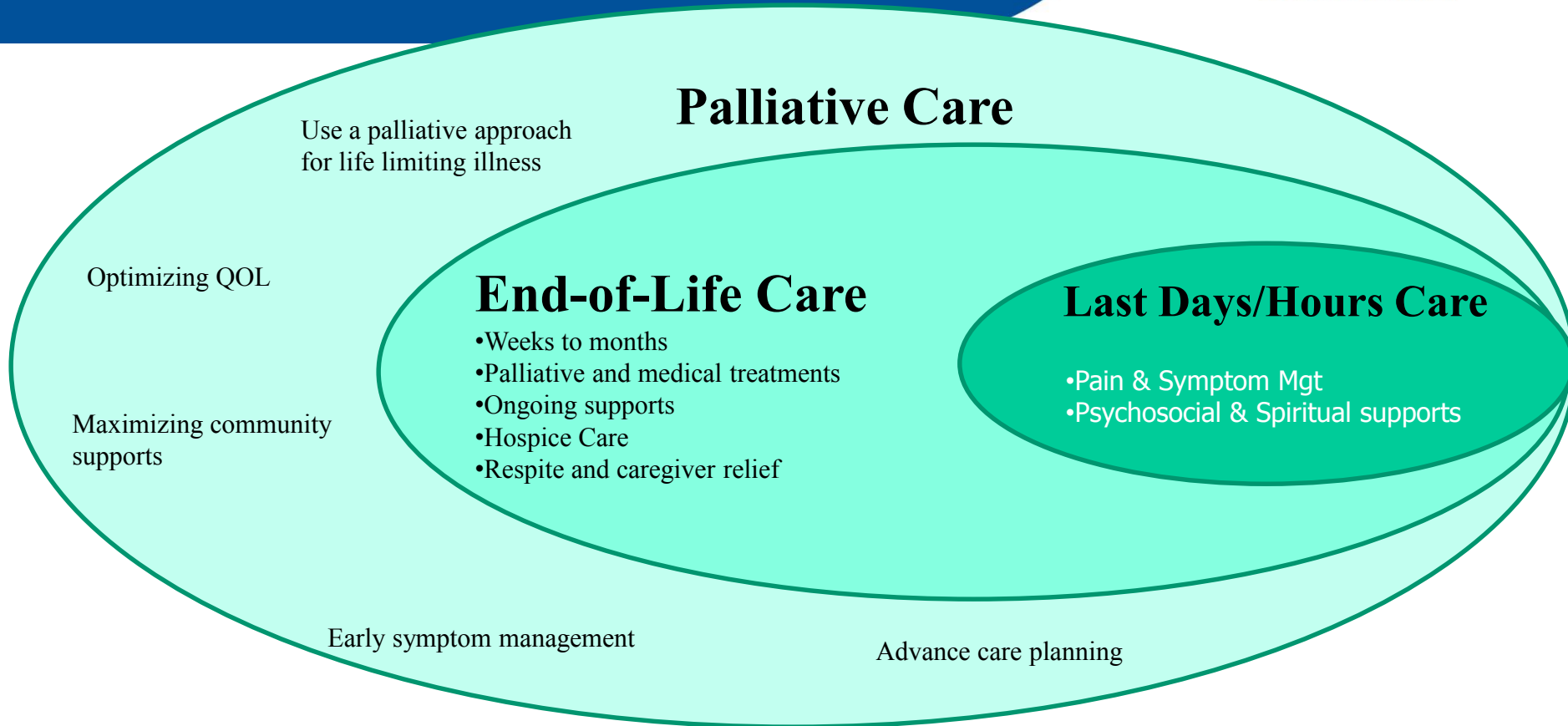
MYTH 8: Morphine is administered to hasten death.

FACT: Appropriate doses of morphine keep patients comfortable but do not hasten death.





Palliative Care is more than just end-of-life care





We need to improve access to palliative care



- 16-30% of Canadians had access to palliative care services

BC Palliative Population Needs Assessment
March, 2015



Who are we missing?



3403 patients who die each year are missed!

92 % are non-cancer patients

42 % die in hospital, 42 % die in residential care

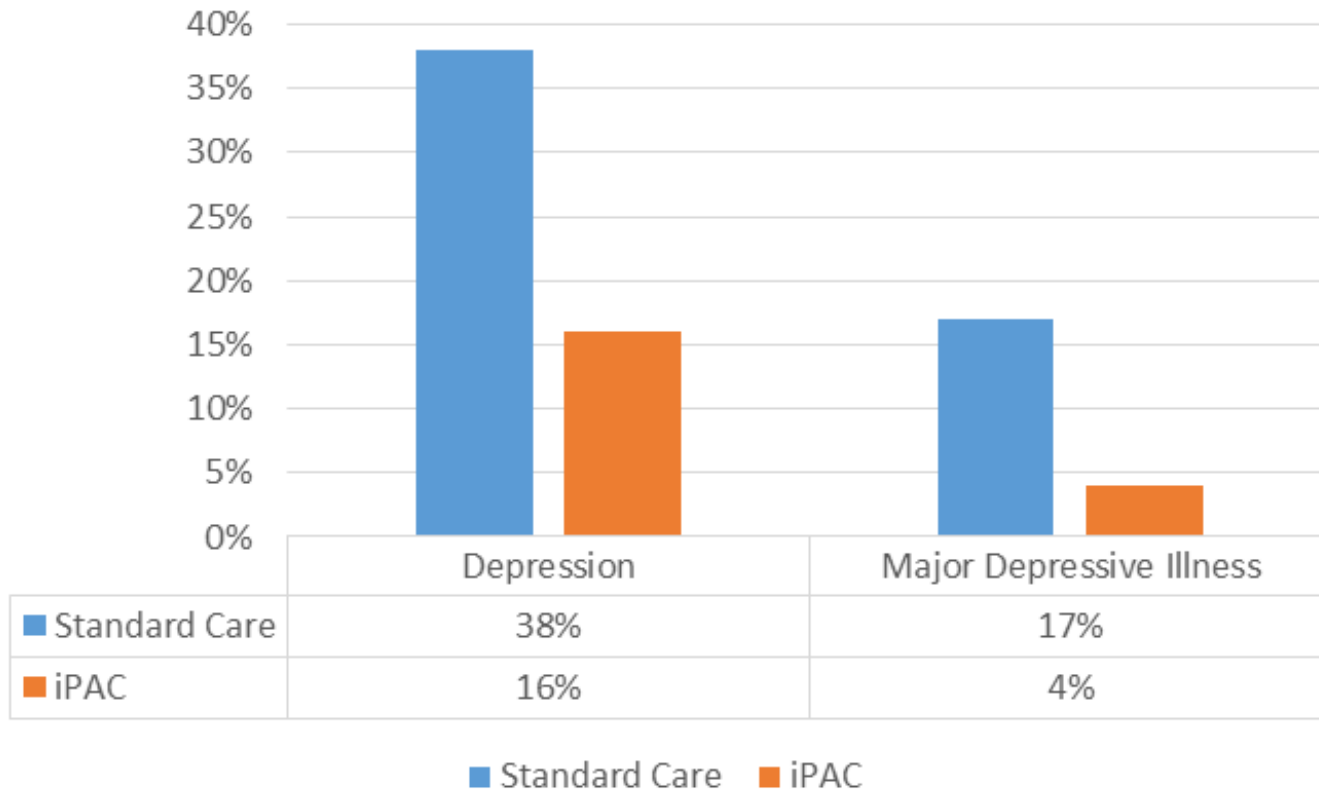
BC Palliative Population Needs Assessment
March, 2015



We need to provide a palliative approach to care early, not late

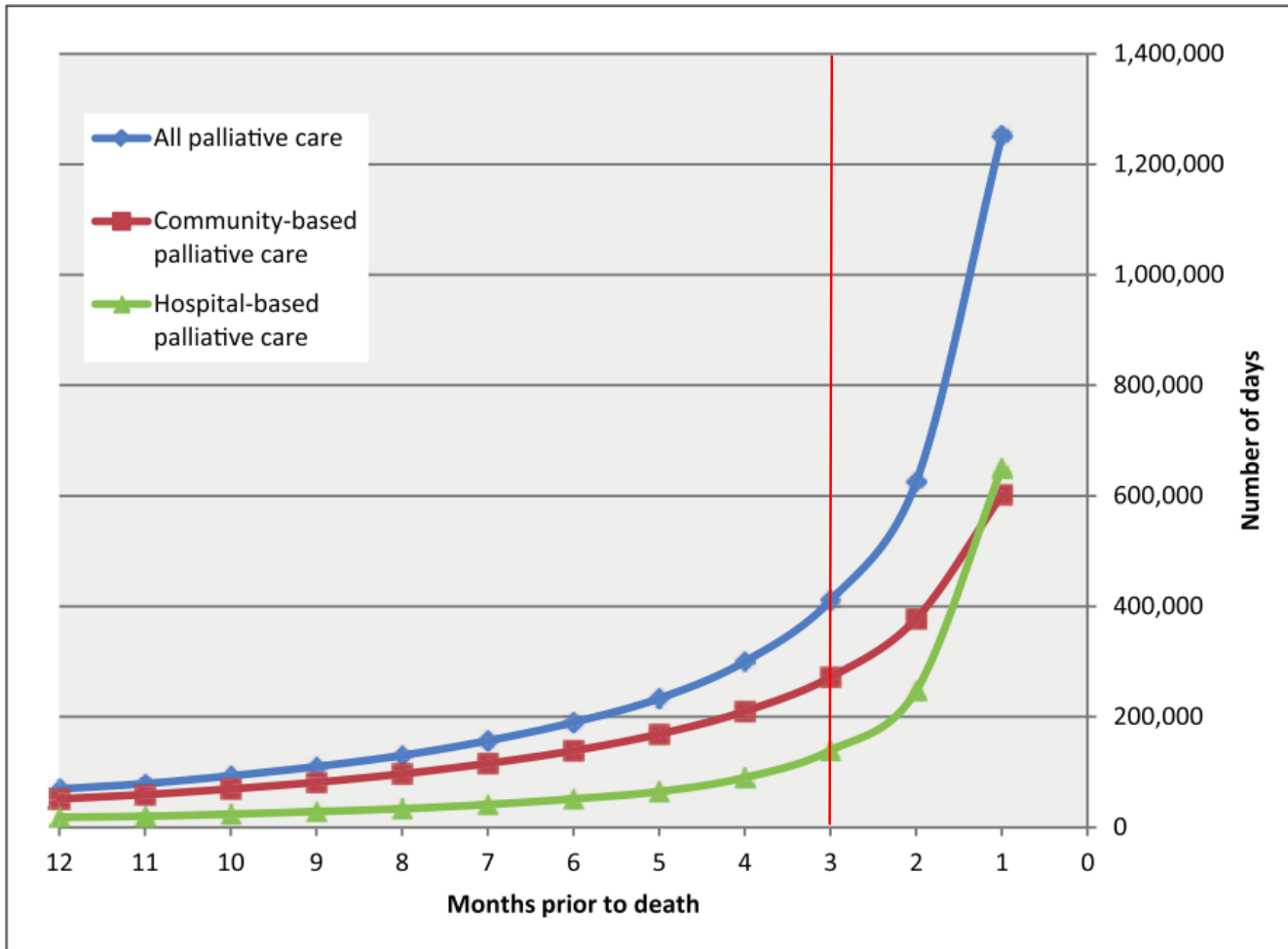


Effect of iPAC on 12 week depression





To be effective, we need to provide palliative approaches to care earlier



Number of days of palliative care delivered by month prior to death, All decedents in Ontario, Canada, from 1 April 2010 to 31 March 2012 (n = 177,817)

Half (49.1%) of all palliative care days were delivered in the last 2 months prior to death

(50.1%) had palliative care initiated in these last 2 months.



Our health system needs to provide **early** access to quality palliative approaches to care



Early access = ALOS Palliative Care Program > 90 days

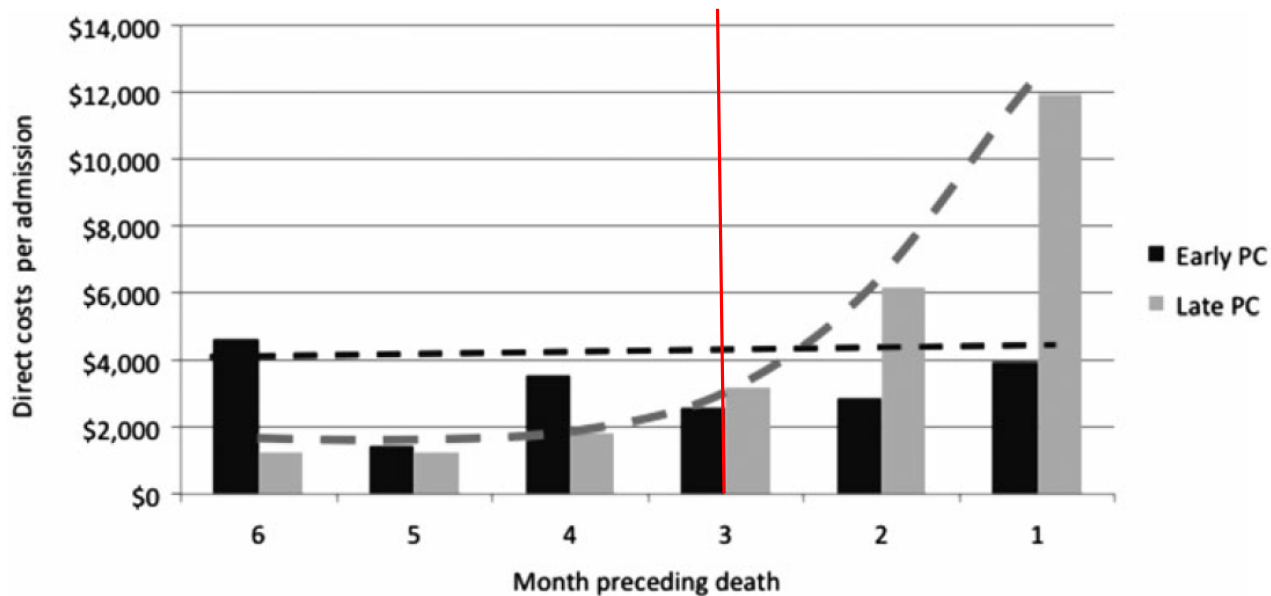
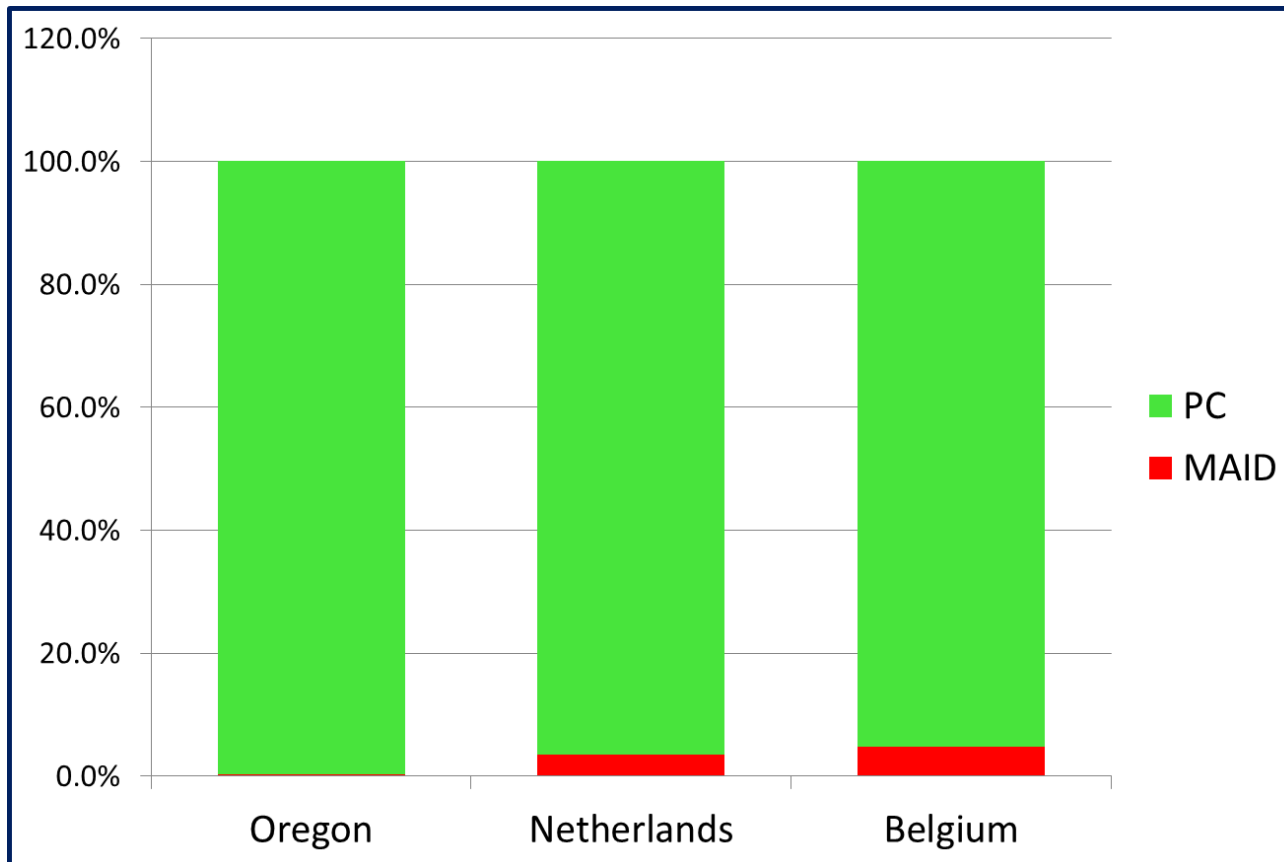


FIG. 1. Average direct cost per admission by month, final 6 months of life: Cancer patients who received early palliative care versus those who received late palliative care.

Scibetta et al, *The Costs of Waiting: Implications of the Timing of Palliative Care Consultation among a Cohort of Decedents at a Comprehensive Cancer Center*, Journal of Palliative Medicine, (19)1, 2016.



By far the majority will benefit from palliative approaches to care





**For “effective access” to
palliative care, we need to
remove, not increase the stigma**



“Stigma associated with the term palliative care may be a barrier to timely referral and deprives patients and care givers of the full benefits of palliative care.”

Caprio, A. Palliative care: renaming as supportive care and integration into comprehensive cancer care, CMAJ, July 12, 2016, 188(10)

Bernie's Story



Why Is Talking About Dying Crucial to Your Quality of Life?

- ~ 50% of persons will not be able to make their own decisions near death & 92% wanted limited care when asked (Silviera NEJM 2011)
- Loved ones have a significant chance of not knowing a person's views without discussion
- Health professionals typically treat when uncertain



In your opinion, how important is it to discuss one's end-of-life care with...?

	% Total (Ex/V. important)	% Had Discussion
Family member	83%	34%
Health care provider	51%	5%
Friend	40%	11%
Lawyer	36%	7%
Financial advisor	29%	5%

CHPCA-Harris Decima Poll (n=2,976) 2013

What about older patients?

Advance care planning evaluation in sick, elderly patients (ACCEPT Study)

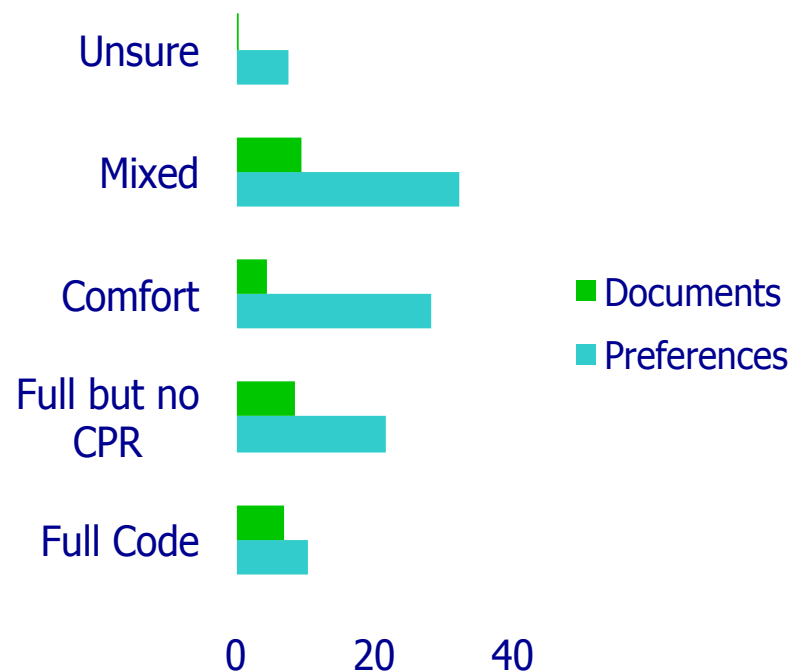
- 75% participants have thought about care they want
- 90% discussed with family
- 55% discussed with a health care provider
- 30% discussed with lawyer
- 20% recall being informed of their prognosis



**I didn't know what he (doctor) was saying when asking me when I was in the ER. “Do I want CPR?” He asked with no explanation. I said “sure if it works.’ He put down YES on the form, but then told me it probably wouldn't work and I would have brain function problems. Good God! I don't want that!
(Patient)**

Lack of Concordance with Patient Preference & Orders

- only ~ **30%** agreement
- Greatest discordance: 28% preferred comfort measures, but only 4.5% documented as such



Advance Care Planning Definition

- A **process** of reflection and communication about values, beliefs and goals of care
- A **process** of planning for a time when a person cannot make their own medical decisions
- A **process** that involves discussions with healthcare professionals and significant others
- A **process** that may result in an advance directive

What is the Evidence for ACP?

- Are much more likely to have their end-of-life wishes known and followed
- Have family members who had significantly less stress and depression
- Are more satisfied, as were their families and substitute decision makers
- Have fewer life-sustaining procedures and lower rates of ICU admission
- Have a better quality of life and death
- Have less costly care in last weeks of life

What Do You Know about ACP?

- CHPCA- National IPSOS Reid Poll (2012)
 - **How many Canadians out of 10 have heard of Advance Care Planning?**





8 out of 10 Canadians have never heard of Advance Care Planning

What Do You Know about ACP?

- CHPCA- National IPSOS Reid Poll (2012)
 - **What % of the general public have done some Advance Care Planning?**



Not Many!!

19%



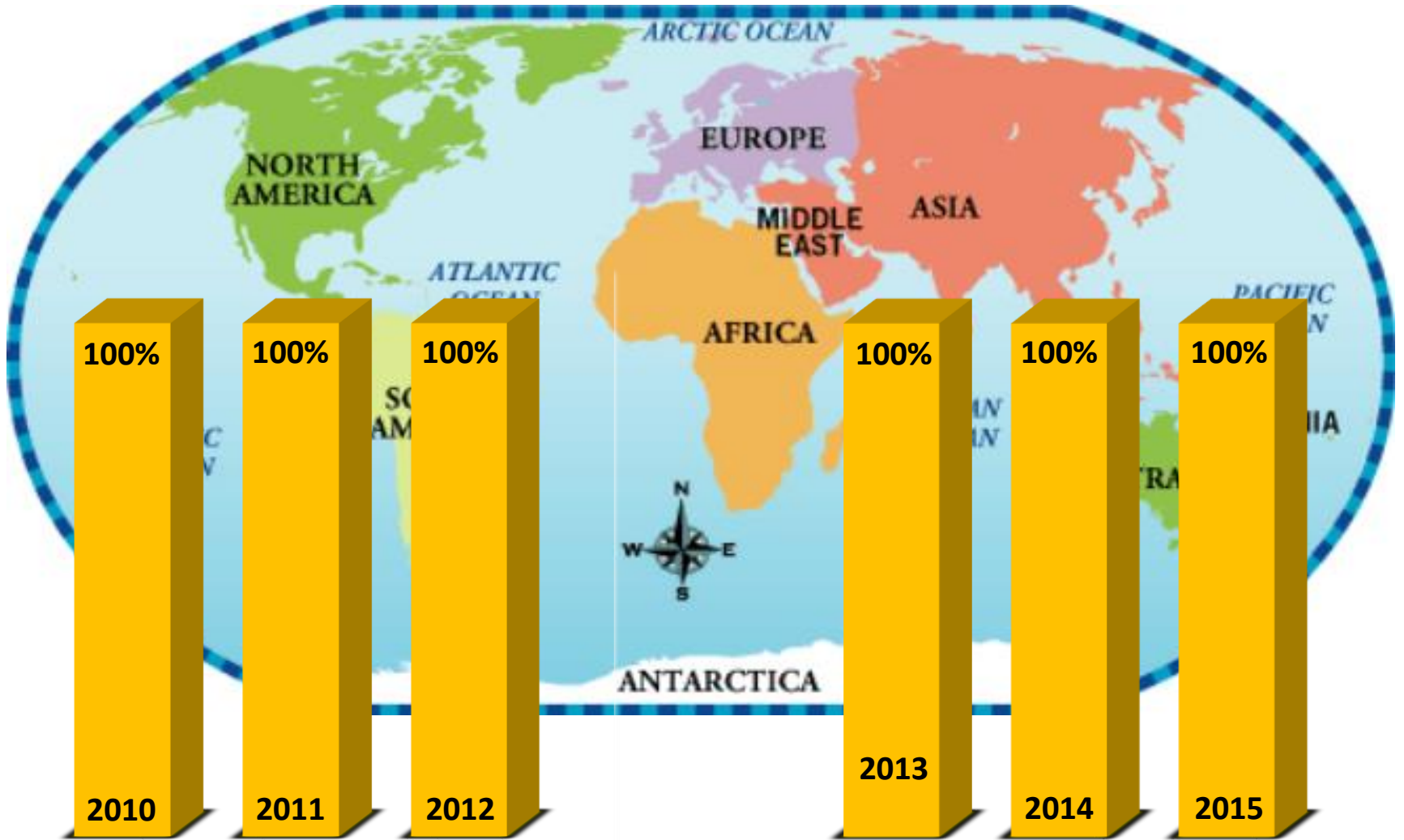
WHO SHOULD HAVE AN ACP CONVERSATION?

All! But with an emphasis on:

- ▶ Those without a family member to speak for them or
- ▶ Those with a clear intent to refuse certain types of treatment or
- ▶ Living with a chronic life-limiting disease (with a diagnosis of dementia consider early in disease trajectory) or
- ▶ Based on the Surprise question (Would you be surprised if this person died within the next six months?) or
- ▶ Capable adults with life expectancy of less than 6-12 months



"I'm right there in the room, and no one even acknowledges me."



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