

EOL Champions: Caring for Palliative Patients from Pediatrics to Geriatrics

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BC Nephrology and Renal Transplant
Days 2011

Pediatric Palliative Care in the Setting of Complex Chronic Disease or



"Care of the Well, the Ill, and the Dying"

How Did We Get Here?

1800 Medicine

QuickTime™ and a
decompressor
are needed to see this picture.

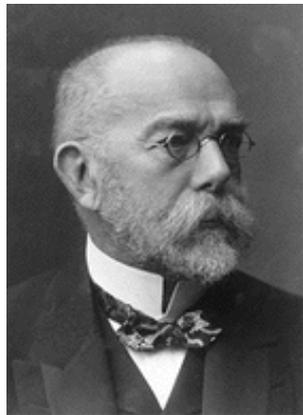
QuickTime™ and a
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are needed to see this picture.

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Louis Pasteur



Rudolf Virchow



Robert Koch



William Osler

Nephrology History





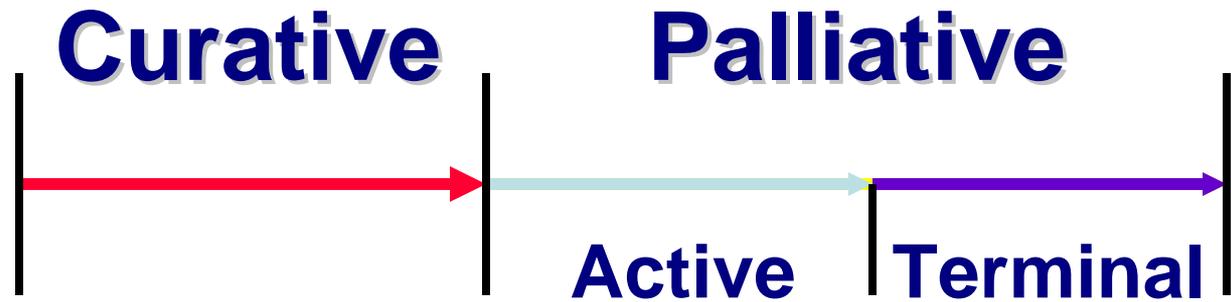
Groote Schuur Hospital Cape Town

Dame Cicely Saunders, (MB, ChB)

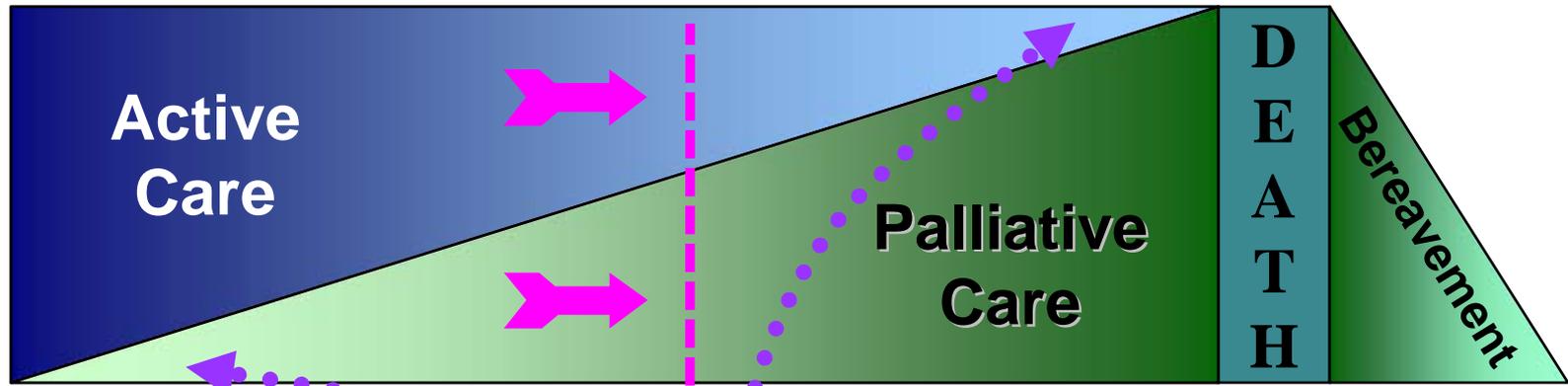


St. Christopher's Hospice

Traditional Cancer Model



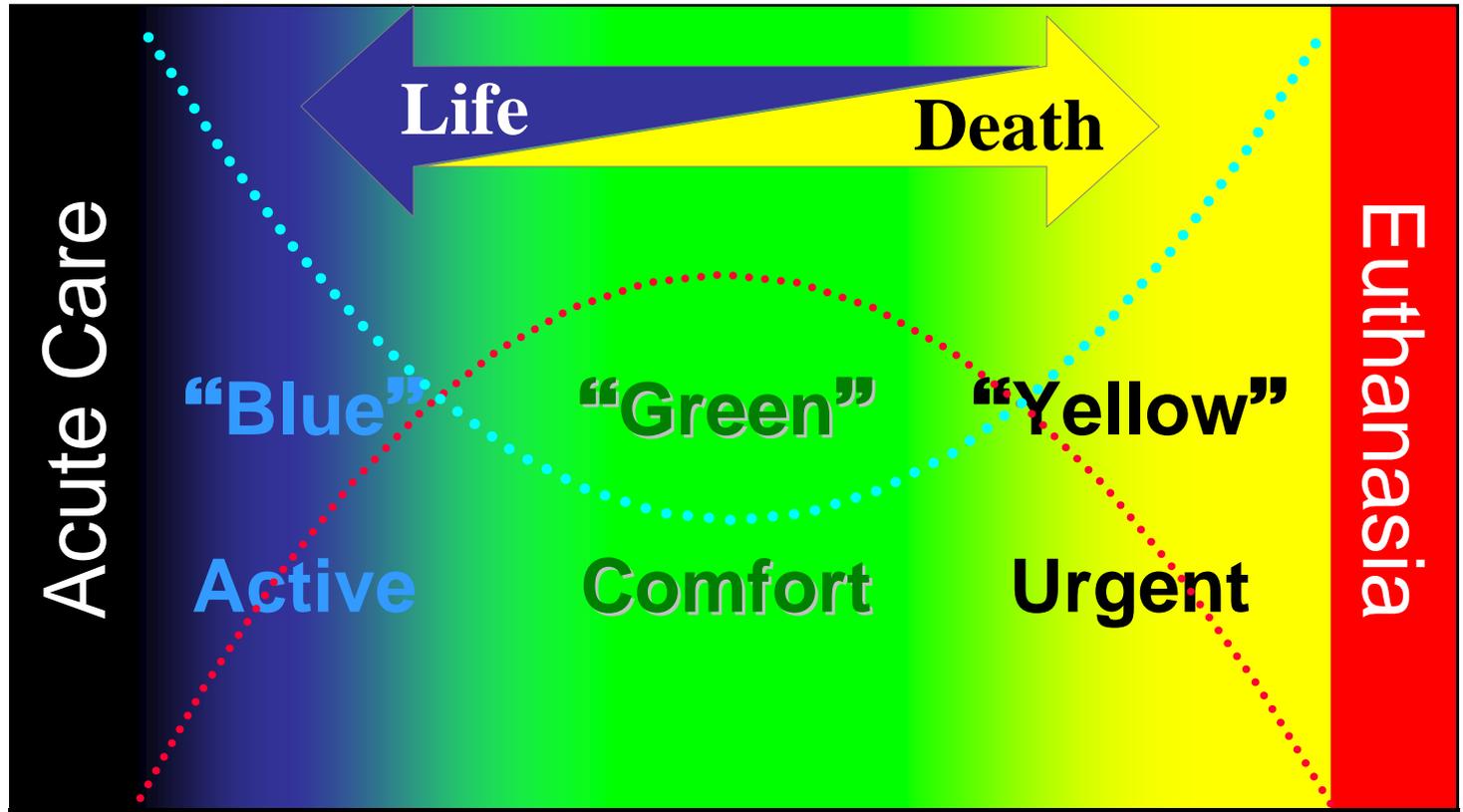
Newer AIDS Model 1988



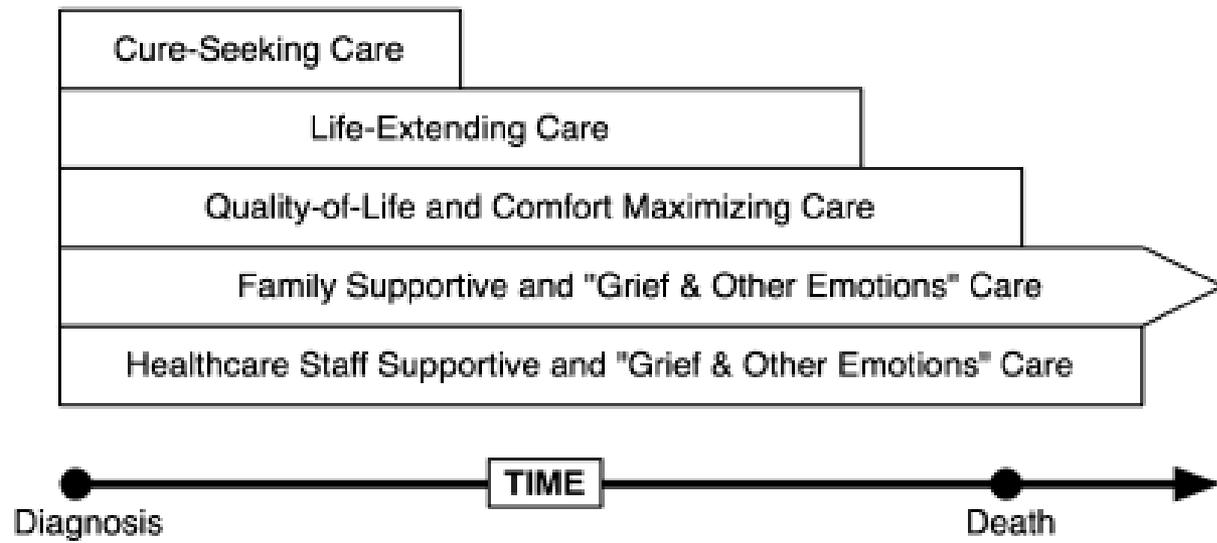
**With many early deaths,
palliative care was
needed early on**

**Active care was
often demanded
until close to death.**

Victoria BGY Palliative Model



1. Broad Spectrum
2. Lateral Tension
3. Vertical Tension
4. Palliative Approaches
5. Profile - Balance or Skew



Helen House, Oxford



1982

Canuck Place Children's Hospice

Vancouver, British Columbia

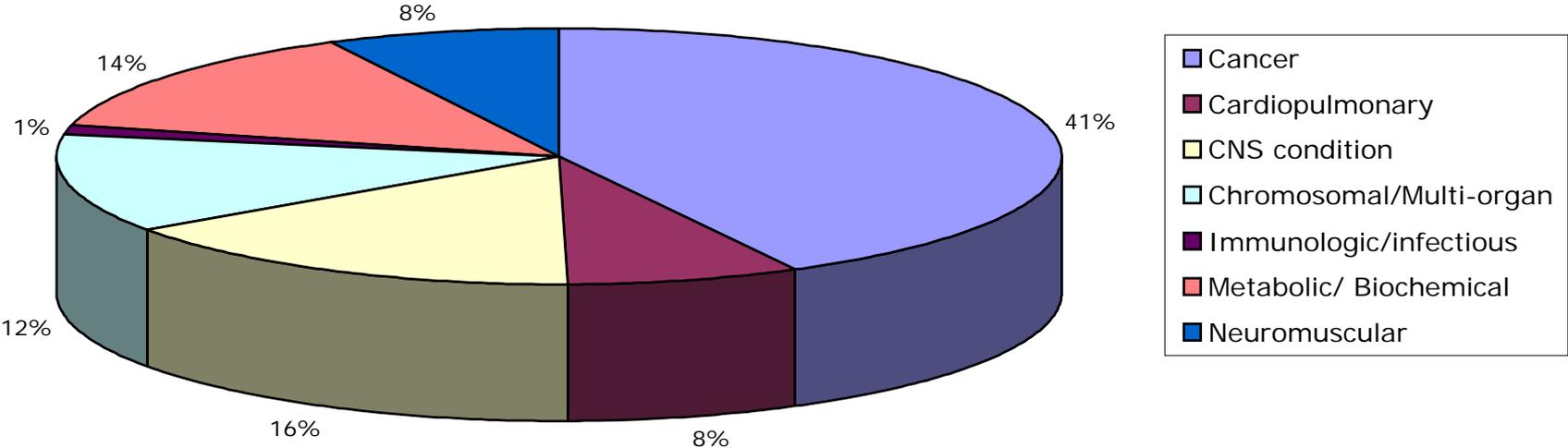


So Who Is It?

ACT Quadrant Model

<p><u>Quadrant 1</u></p> <p>Life-threatening conditions for which curative treatment may be feasible but can fail.</p> <p><i>(e.g., cancer, irreversible organ failure)</i></p>	<p><u>Quadrant 2</u></p> <p>Conditions where premature death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities.</p> <p><i>(e.g., cystic fibrosis, HIV/AIDS)</i></p>
<p><u>Quadrant 3</u></p> <p>Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years.</p> <p><i>(e.g., neurodegenerative, metabolic diseases)</i></p>	<p><u>Quadrant 4</u></p> <p>Irreversible but non-progressive conditions with severe disability susceptible to health complications and premature death.</p> <p><i>(e.g., anoxic brain injury)</i></p>

Deaths on Program 2000-09



Children on Canuck Place program March 2011

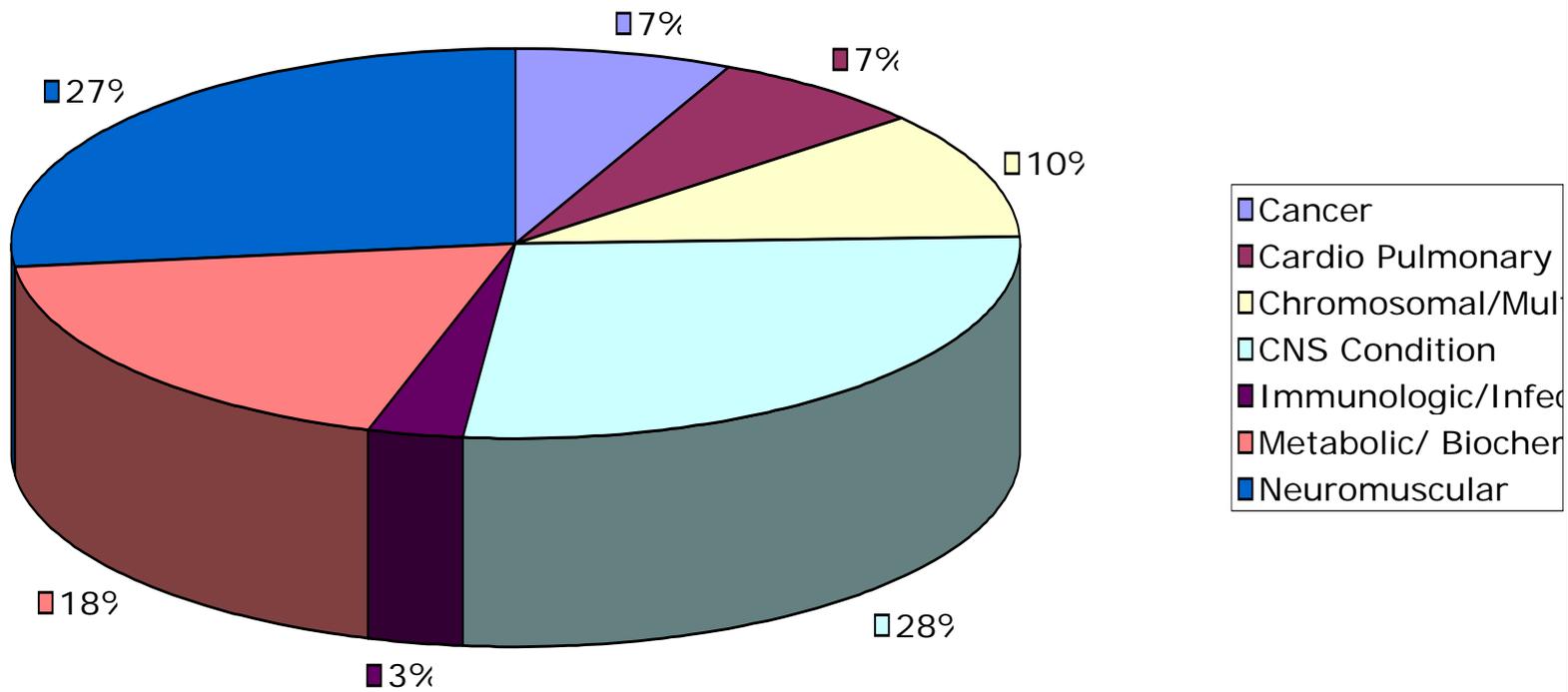
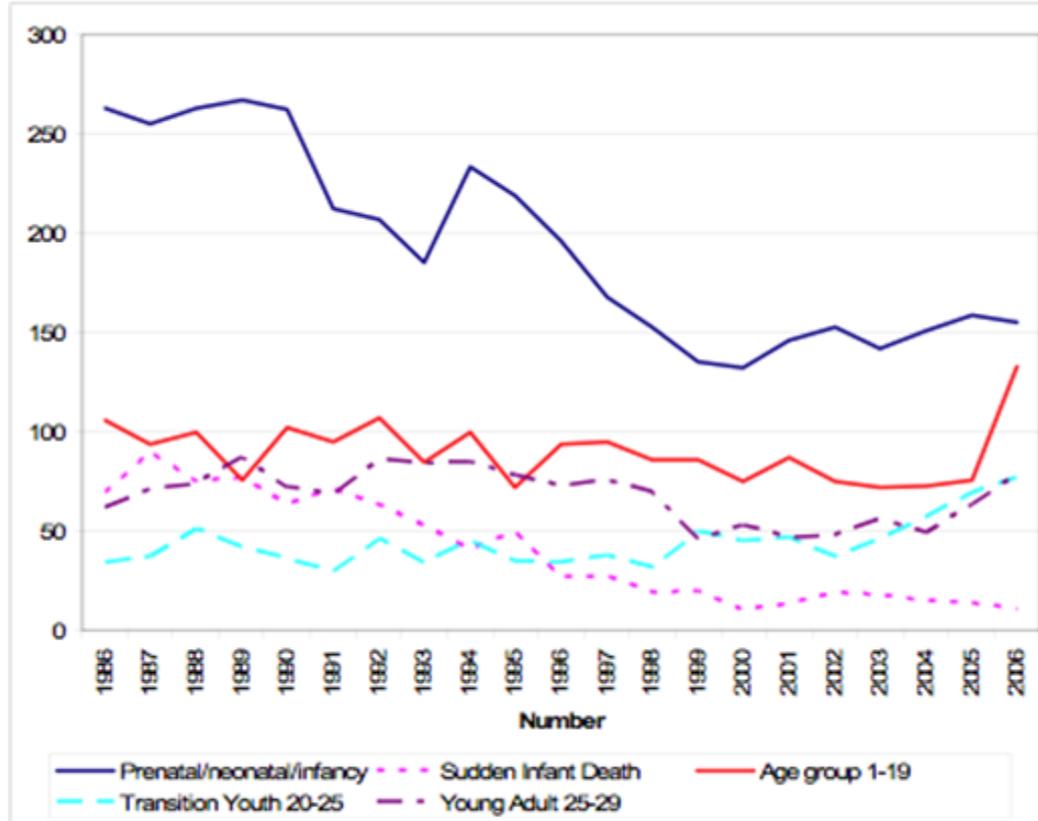


Figure One: 20 Year Mortality Trends for Population Segments



End-Stage Renal Disease Patients 2009

Age Group 0–19 Years

Incident Canada

(Number, Rate per Million Population, Percentage of Total)

N	RPMP	%
78	9.9	1.5

Prevalent Canada

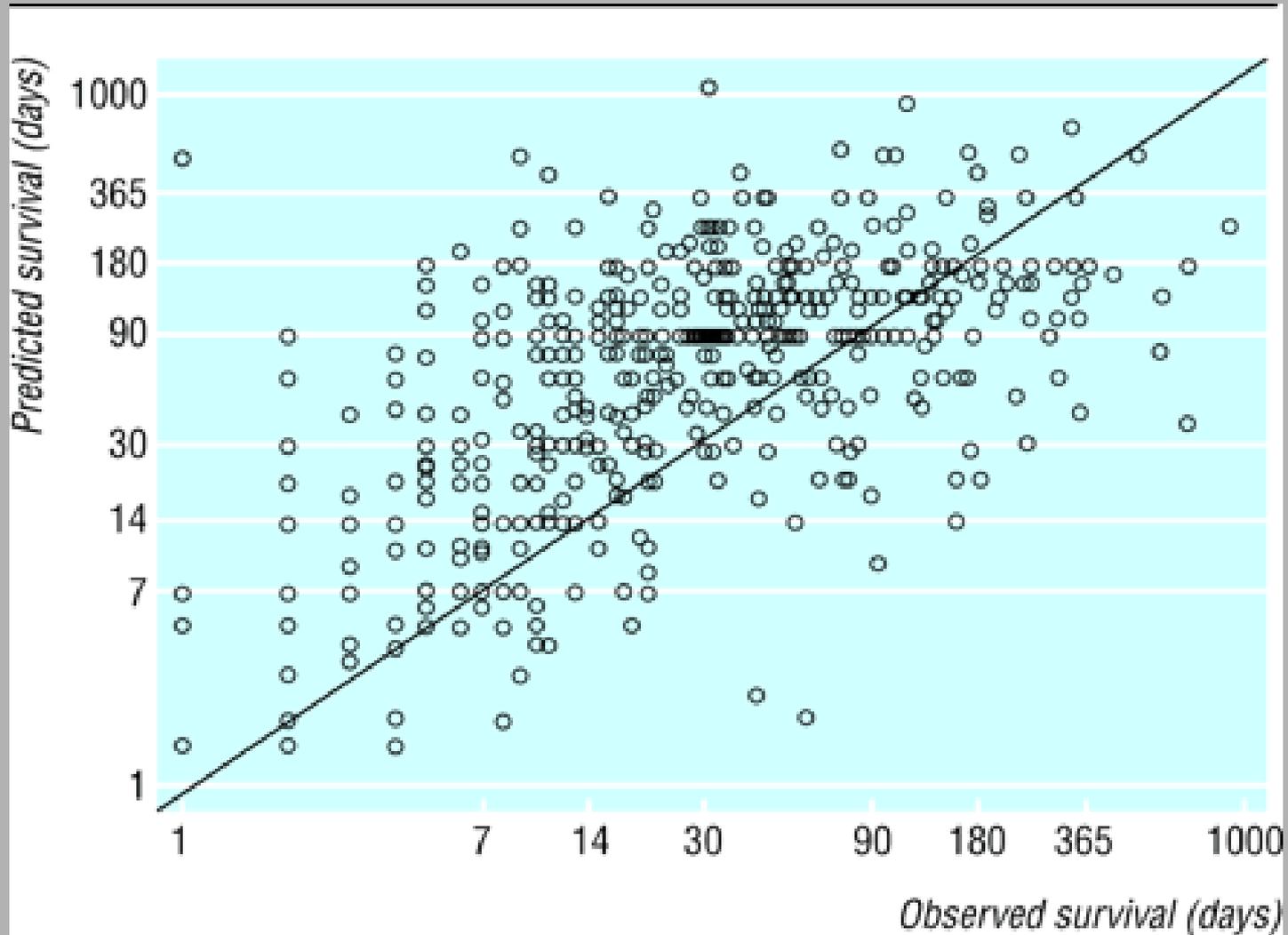
N	RPMP
548	69.7

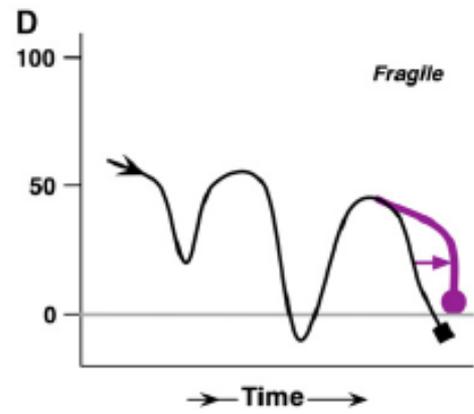
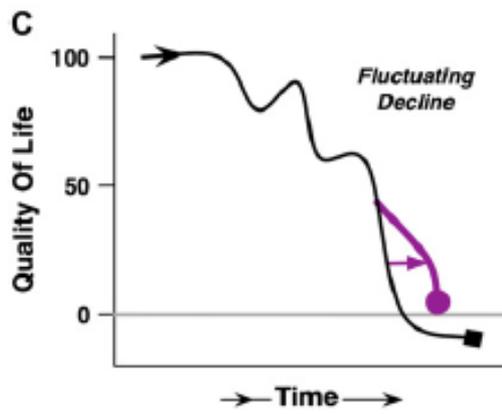
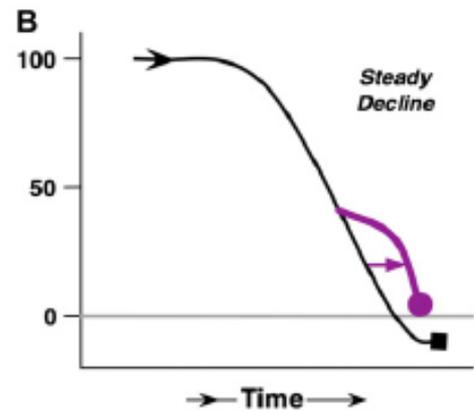
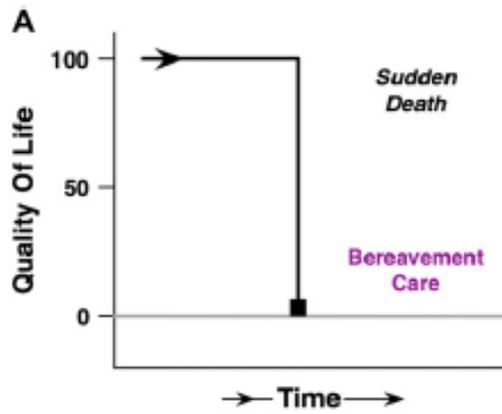
Prevalent Province, BC/YT (Number, Percentage)	
N	%
73	1.5

Mortality Province, BC /YT
Prenatal, Neonatal, Infancy: 4
Ages 1-19: 9
Transition Youth 20-25: 13

What don't we know?

Challenge of Prognosis





How is it done?

Canuck Place / Paediatric Palliative Care Consultation Framework

PHYSICAL	SOCIAL (Family, school, friends, community)
EMOTIONAL (Not “Psychological”)	SPIRITUAL
TRAJECTORY (DNAR/PND, CSR, Community Planning, Transition to Adult Care)	

“A certain death at an uncertain time”



The Most Challenging Kind of Care



- Clinical Uncertainty
- Lack of Evidence
- Ethical Dilemmas
- Family Journey
- Team Dynamics

Thinking Ahead



“He Who Must Not Be Named”



Nephrology Consults by the Pediatric Palliative Care Team at CS Mott Children's Hospital, University of Michigan

- Consults /year: 148 (2010)
- Consults to Nephrology: 12 / 16 months
- All dialysis patients
 - Symptom management (nausea, fatigue, pain, fear/anxiety)
 - Identifying critical issues and decisions
 - Supportive communication
 - Community linkages
 - Preparing for unknown outcomes

Some Interesting Cases

or,

Care of the Well, the Ill, and the Dying

Jaxson

- Spinal Muscular Atrophy
- s/p scoliosis stabilization surgery



- Respite
- Psychosocial support
- Transition planning at 19

Jordyn

- Neurological impairment and physical deformities
- Outbursts, crying, insomnia: “pain” behavior, escalating in severity



- Symptom Management
- Respite
- Family Support
- Advanced Care Planning



Symptoms in Children with SNI

- | | | | |
|------------------------|-----|---------------------|-----|
| • Aphasia | 71% | • Pain | 36% |
| • Constipation | 44% | • Respiratory Sx | 38% |
| • Feeding difficulties | 69% | • Seizures | 60% |
| • Incontinence | 71% | • Sleep disturbance | 31% |
| • Immobility | 64% | • Secretions | 31% |
| • Movement Disorders | 38% | • Visual loss | 20% |
| • Muscle spasms | 27% | | |

Symptom Control

- Continuous infusion sufentanil
- Ketamine infusion
- Topical morphine
- Epidural fentanyl and bupivacaine
- 15,000 mcg/kg/hr PME

Conclusion

- Care of the Well, the Ill and the Dying is a seamless continuum
- Physical Emotional Social Spiritual Trajectory
- Build a Safety Net
- Think Ahead
- Speak the unspeakable and accompany families where no one really wants to go
- Walk the tight-rope of contradictory ideas
- Nil Admirari: Try not to be surprised

Please Complete the Evaluation Form



Credits

Piggy Bank: www.wellheeledblog.com

Gi belts: www.commonswikimedia.org

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Marx Brothers, Horsefeathers: Paramount Pictures