Pediatric Project ECHO-Palliative Care

Core Competency Session:

What is Pediatric Palliative Care?

Dr. Christina Vadeboncoeur MD FRCPC
Medical Director, Pediatric Palliative Care Program
CHEO and Roger Neilson House

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Land Acknowledgement

- I live in Ottawa, which is built on unceded Algonquin Anishinabe territory
- The peoples of the Algonquin Anishinabe Nation have lived on that territory for millennia and I honour them and the land
- Their culture and presence have nurtured and continue to nurture our land
- I also honour all First Nations, Inuit and Métis peoples and their valuable past and present contributions to our land
- I invite you to consider the peoples who have lived on your territory in order to honour them as well.

Speaker Disclosure

- I have no conflicts of interest to declare

Objectives

At the end of the session, attendees will be able to:

- Define pediatric palliative care (PPC)
- Identify predictable opportunities for palliative care intervention
- Describe when and how to utilize a subspecialty palliative care team
- Evaluate myths and assumptions about PPC

What is Pediatric Palliative Care?

Palliative care aims to prevent and relieve health related suffering of adults, children and their families facing problems associated with life-threatening illness

(World Health Organization)

Other Definitions of PPC

- An active, holistic approach to care which focuses on relieving the physical, social, psychological and spiritual suffering experienced by children and families who face a progressive, [life threatening condition, and helping them fulfil their physical, psychological, social and spiritual goals

  Canadian Hospice Palliative Care Association

Other Definitions

- Hospice palliative care is holistic care – comfort, meaning and support for people facing the end of life, and their families

  Hospice Palliative Care Ontario

Hospice

- Historically was care, services and resources centered on end-of-life issues
- In the US, it is an insurance benefit associated with a terminal prognosis
- In Canada it is a building, a place where palliative care is provided

Aspects Particular to Pediatric Palliative Care

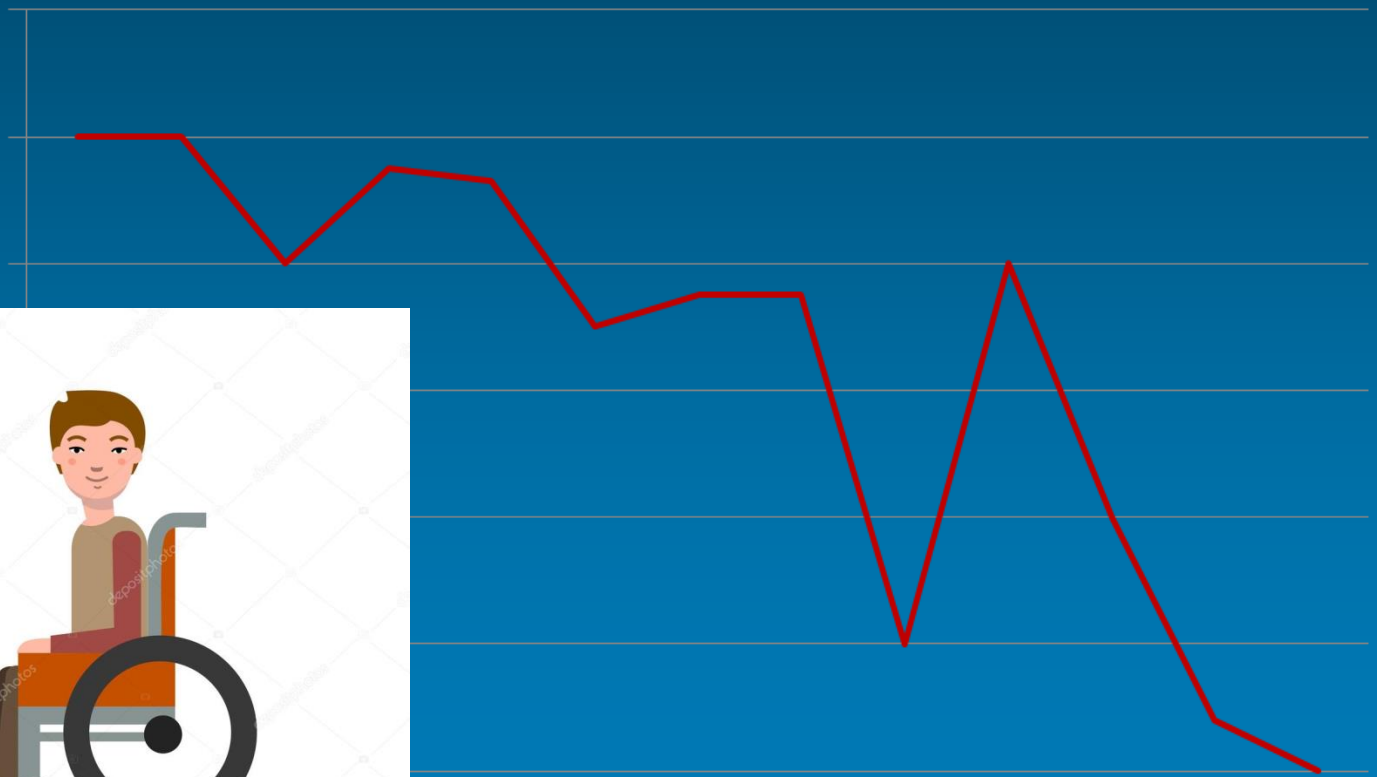
- Trajectory of illness
- Different diagnosis
- Focus on developmental stage
- Resilience
- Family responsibility and involvement

Questions?

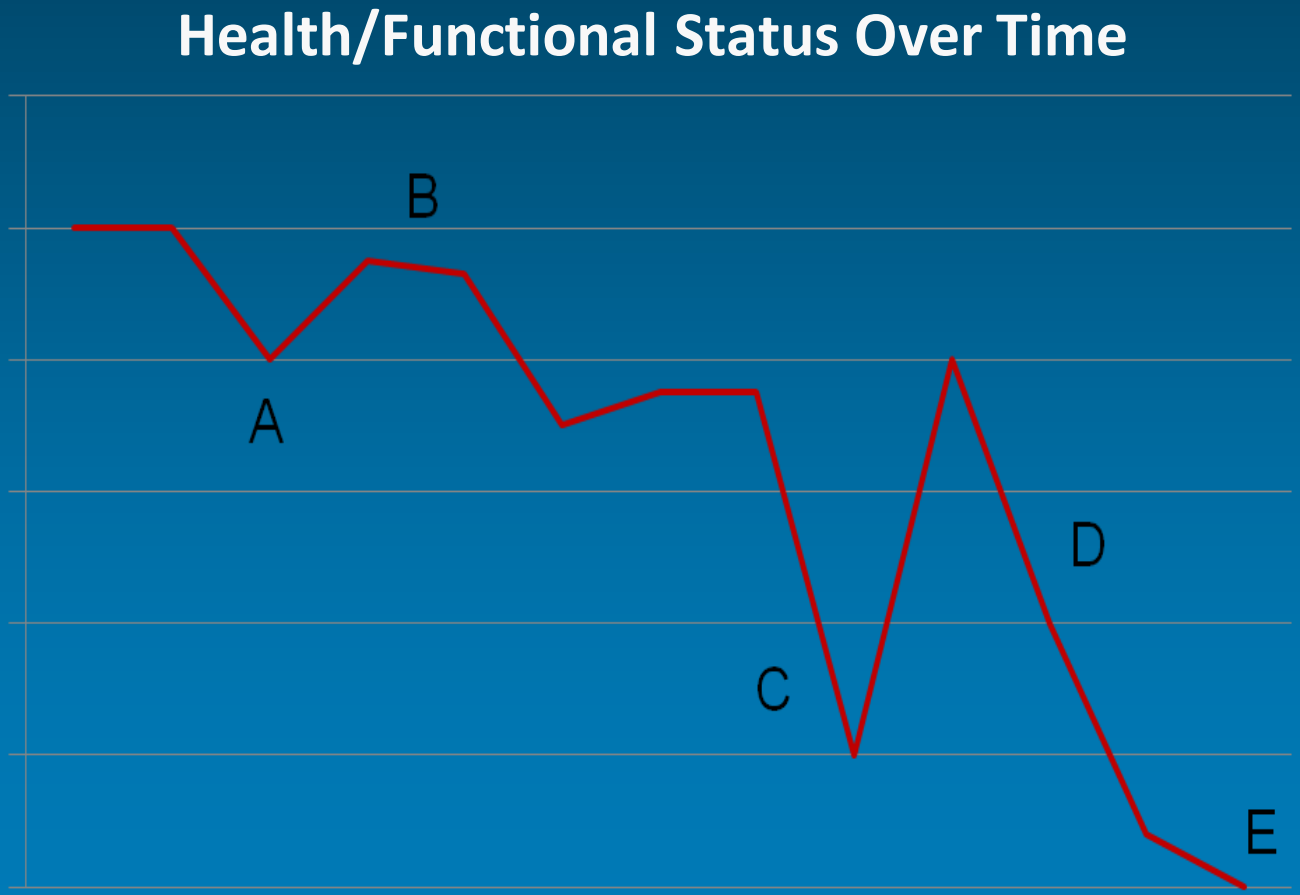
Tasks of Palliative Care: Mitigating Suffering

- Communication
- Care Coordination
- Intervention

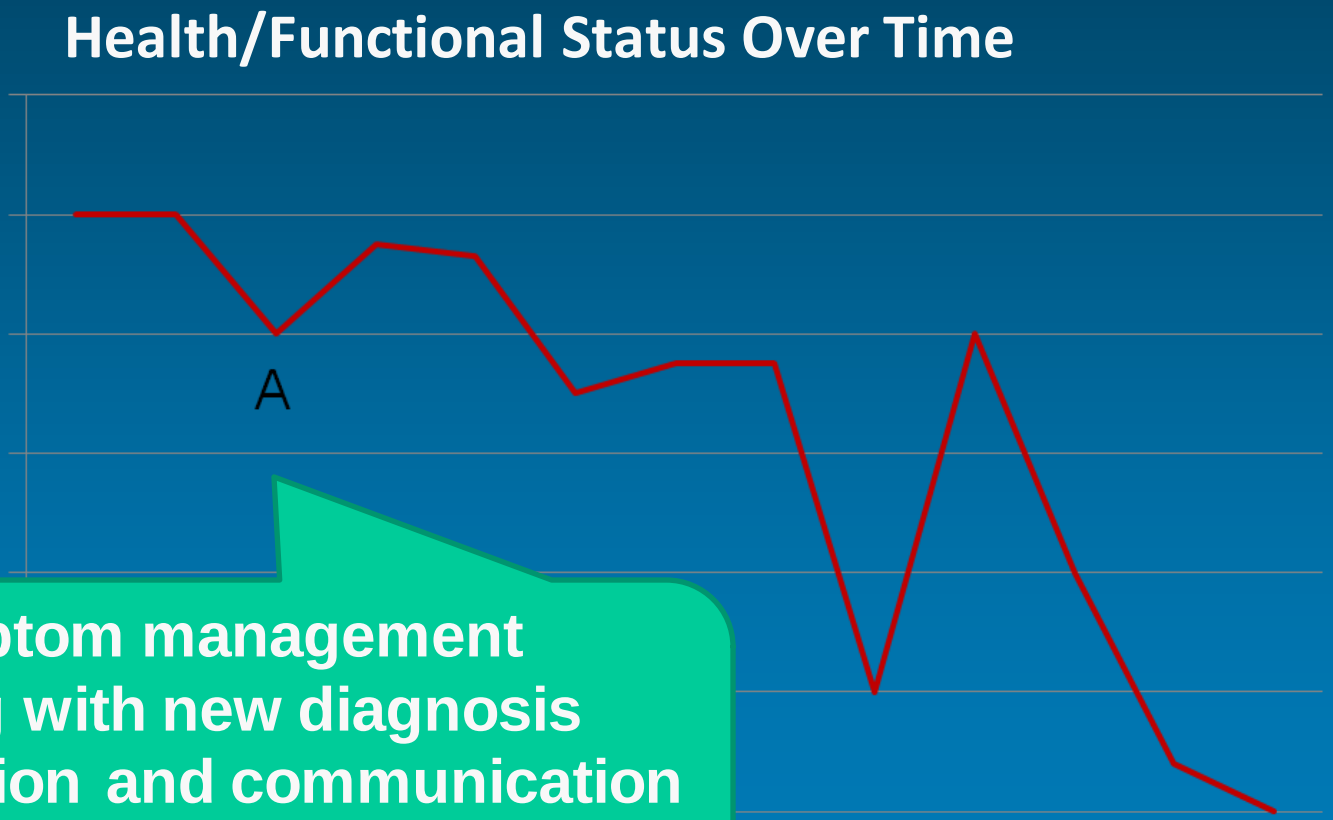
Sam's Suffering



Predictable Opportunities to Initiate PPC Tasks



Acute Decompensation and Hearing Bad News (Point A)



symptom management
Coping with new diagnosis
Collaboration and communication with new team members
Distress re siblings

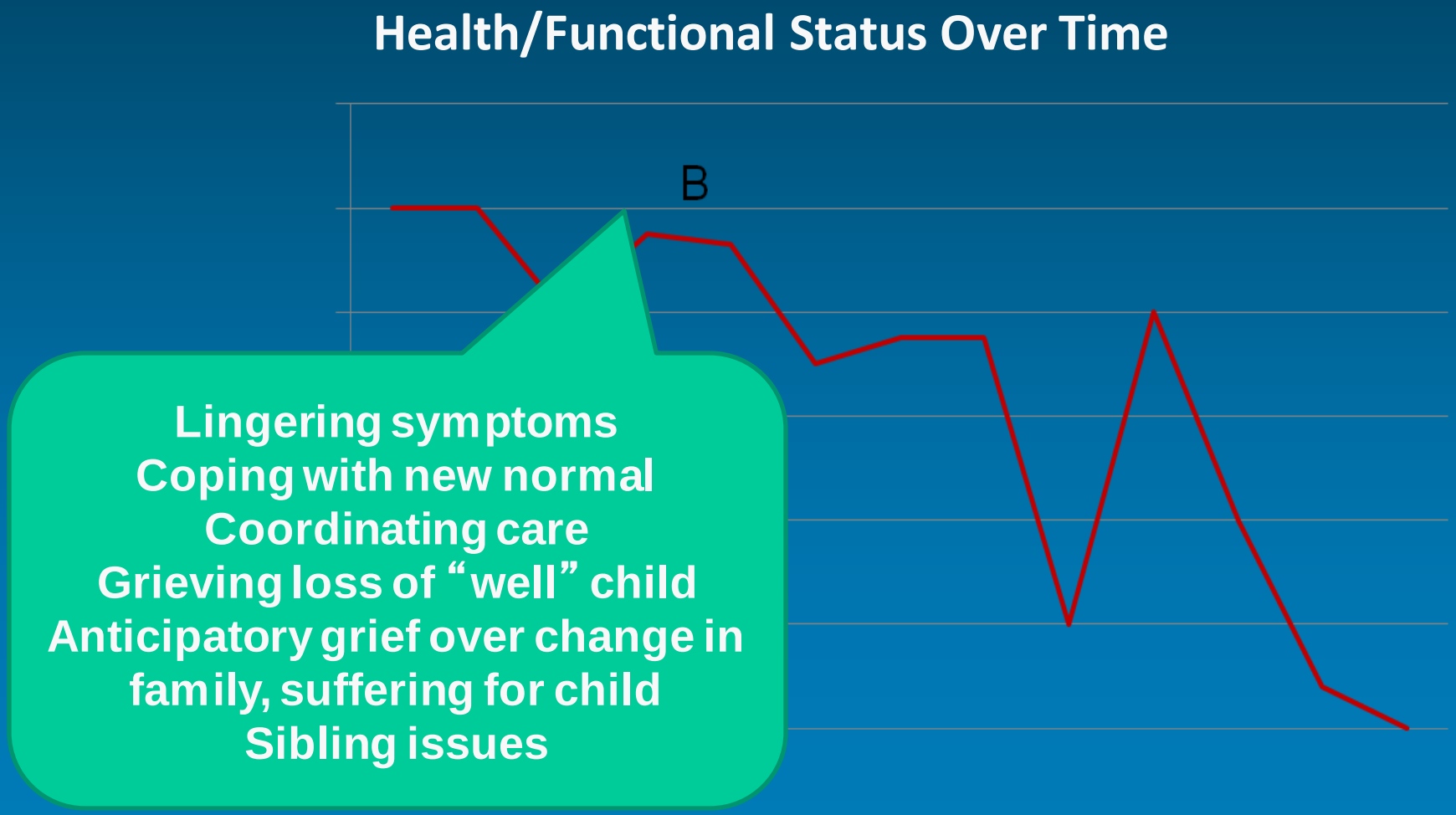
Opportunities to Treat Suffering

- Identify problems & challenges
- Facilitate understanding
- Explore hopes & worries/ set goals
- Aid in making decisions

Opportunities to Treat Suffering

- Physical Suffering
- Spiritual Suffering
- Family, sibling support
- Facilitate collaboration with specialists

Recovery and Accommodating to a New Life (Point B)



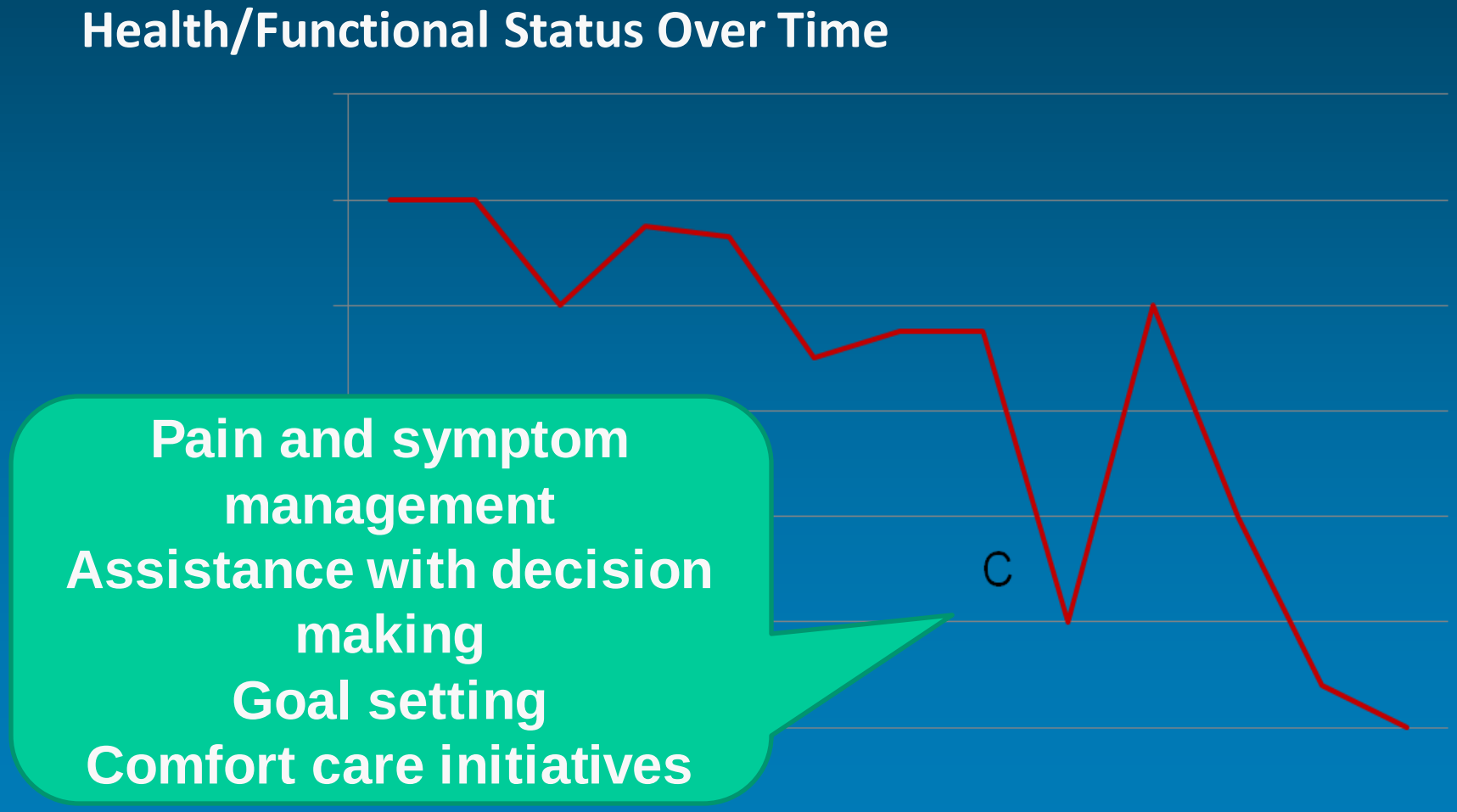
Opportunities to Treat Suffering

- Facilitate understanding of disease
- Explore hopes and worries/ set goals for physical and psychosocial suffering
- Support family

Opportunities to Treat Suffering

- Facilitate collaboration with specialists
- Opportunity to build therapeutic relationships that will be essential later

Acute Decompensations and Unexpected Recoveries (Point C)



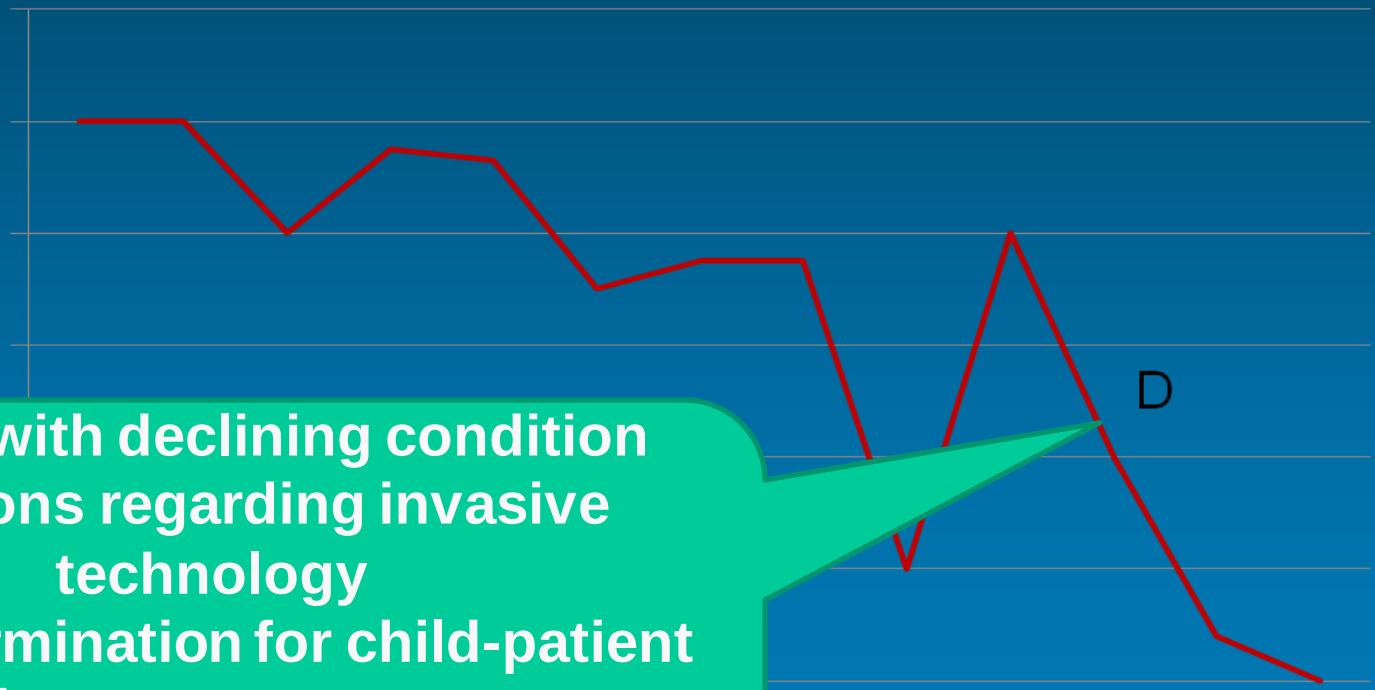
Opportunities to Treat Suffering

- Identify problems and challenges
- Facilitate understanding
- Explore hopes, worries/ set goals
- Advanced care planning
- Aid in decision making
- Physical suffering

Opportunities to Treat Suffering

- Spiritual suffering
- Anticipatory grief and bereavement
- Family, sibling support
- Team support
- Facilitate Collaboration with specialists, primary care providers

Slow or Precipitous Decline Preceding End-of-Life (Point D)



Coping with declining condition
Decisions regarding invasive technology
Self-determination for child-patient
Pain and symptom management
Increasing sibling distress
Bereavement

Opportunity to Treat Suffering

- Identify problems and challenges
- Facilitate understanding of disease
- Explore hopes/worries, Set goals
- Advanced care planning
- Aid in making decisions

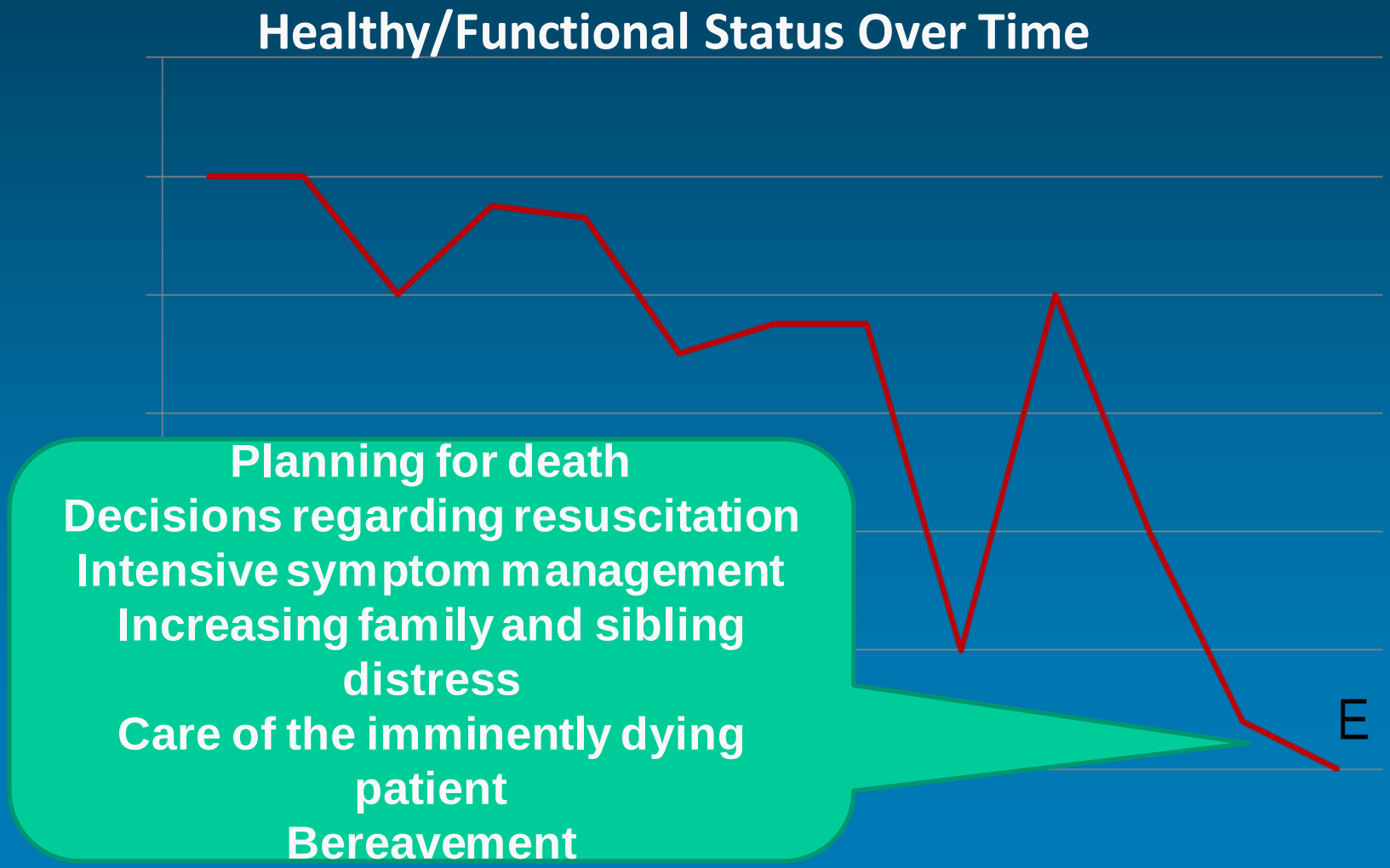
Suffering Requiring Interventions

- Physical Suffering
- Psychosocial suffering
- Spiritual suffering
- Bereavement
- Family and Sibling support
- Team support
- Community Support

Suffering Requiring Care Coordination

- Facilitate collaboration with specialists
- Partner with community programs to transition
- Identify community resources to support additional care and requirements

End-of-Life (Point E)



Opportunity to Treat Suffering

- Tasks more specific to EOL care
  - Establishing goals of treatment decisions
  - Discussing dying process: anticipatory guidance
  - Identifying barriers to care in all settings
  - Proactive planning to manage symptoms
  - Establishing partnerships with PC resource

Opportunity to Treat Suffering

- Tasks more specific to EOL care
  - Collaboration with PC to work on symptom management and likely specific cause of death
  - Partner with community programs to prepare for EOL
  - Planning for rituals, memorial assisted by PPC team

The Family Experience as Context

- From moment of diagnosis, coping with fear and hope for the best
  - Stress and anxiety
  - Multiple demands
  - High degrees of uncertainty

The Family Experience as Context

- From moment of diagnosis, coping with fear and hope for the best
  - Balancing hopes for a good outcome with fears of a bad one: death
  - Pressures last months to years and can erode resilience

Bereavement Support

- Offered as early as dx of a life-limiting illness
- Offered to those who have lost a child
- Depends on needs

Bereavement Support

- May include individual, couple's and group counselling
  - Anticipatory Bereavement - siblings, parents
    - decrease the sense of isolation
    - reduce fear of unknown
  - Grandparent group
  - Perinatal Palliative Care group

Impact of Pediatric Palliative Care

- Children with serious illnesses and their families benefit from PPC
- Earlier initiation improves symptom management & quality of life
- May lead to prolonged life, less distress and less ineffective treatments

Questions?


HOSPITAL

PPC in Canada V.2002

- 8 Pediatric Palliative Care Programs
  - 7 based in tertiary care hospitals
  - 1 based in a free-standing Hospice
- Estimated 5% of all children who might benefit from PPC were receiving it

Widger et al., 2007

Hospices and Dedicated PPC- Canada V.2012

- 3247 children ≤ 19 died in Canada
- 2317 children may have benefitted from PPC
- 1401 children (60%) received specialized PPC services
  - 517 in 3 free-standing hospices
  - 884 cared for by 10 programs based in hospitals

Widger et al 2012

PPC Canada 2012

- Estimates - 9.8/10,000 children might benefit from PPC services
- # children who received specialized PPC services quadrupled in 10 years but
  - more children died in critical care
  - more had delayed referrals to PPC

Other

- 60% with access to pediatric hospice in 2012 had access for over a year
  - Availability of respite likely a factor
- 41.9% of children with access died in hospice
  - alternative to hospital or home
- Increasing #s of children <1 yr of age at time of referral received care
  - > % of children die in first year of life
  - reflected in increased referrals in perinatal period.

Primary Dx of Children Receiving PPC -Canada 2012

	n	%
Cong malfns, deform, chromosomal abn	402	(28.7)
Disease of Nervous system	375	(26.8)
Neoplasms	221	(15.8)
Endo., nutritional, metabolic disease	148	(10.6)
Conditions originating in prenatal period	102	(7.3)

Primary Dx of Children Receiving PPC - Canada 2012

- Mental & behavioural disorders 26(1.9)
- Infectious and parasitic diseases 25(1.8)
- External causes of morbidity/mortality 25(1.8)
- Other 76(5.4)
- Unknown 1(0.1)

Location of Death

	n (431)
Critical Care/emergency dept.	105 (24.4)
Home	92
General Hospital unit	85
Hospice/palliative care bed	66
Labour and delivery	41
Community hospital	26
Other/unknown	16

- 158 (36.7%) died in non-acute care settings

Age at Referral to PPC

Age	n
<1	508
1-4	284
5-9	247
10-14	221
15-25	134
Unknown	7

- 50 +% < 4

Time from Referral to Death

# days	
≤ 1	49
2-7	61
8-3	111
31-90	68
91-180	42

# days	
181-365	32
>365	64
Unknown	4

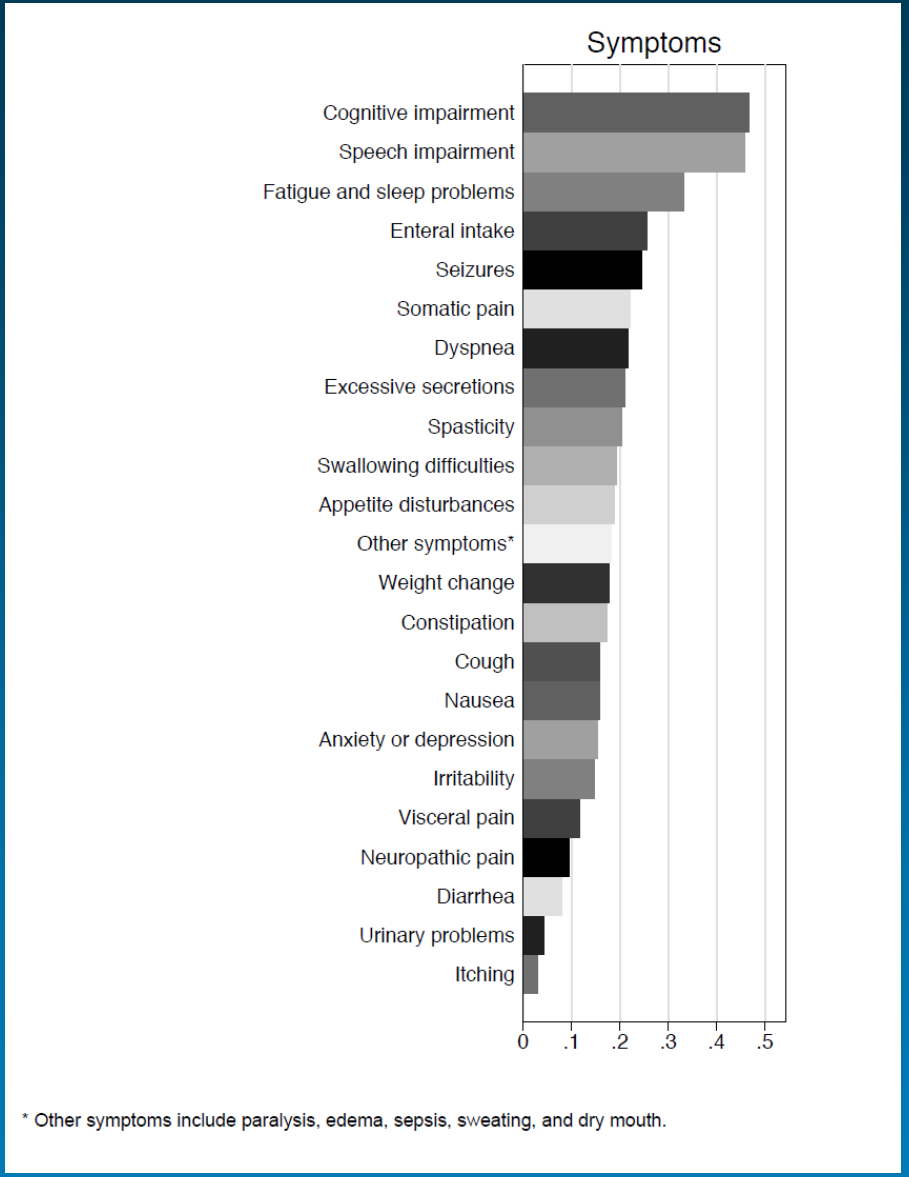
- 14.6 % > 6 mos

Time from DNR order to Death

Day	n
≤ 1	68
2-7	79
8-30	95
31-90	33
91-180	19
181-365	9
> 365	32
No DNR order	48
DNR status unknown	48

Only 24% of children cared for by PPC teams had DNRs

Signs and symptoms of patients receiving PPC services



Feudtner et al, Pediatrics 2011

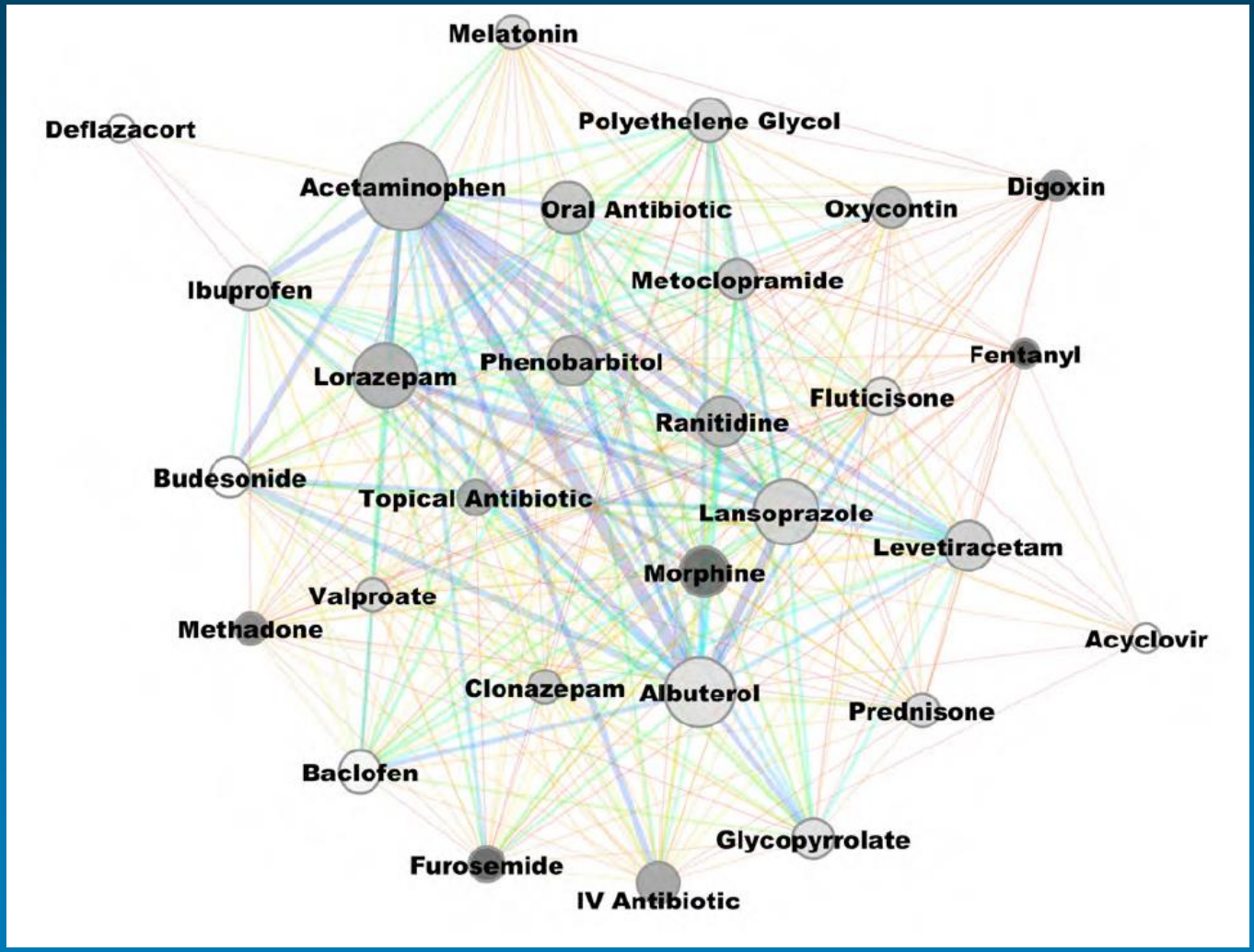
Common Baseline Signs and Symptoms

- Cognitive impairment
- Speech impairment
- Fatigue and sleep problems
- Enteral intake
- Seizures

Common Baseline Signs and Symptoms

- Somatic pain
- Dyspnea
- Excessive secretions
- Spasticity
- Swallowing difficulties

Meds Received by Children Receiving PPC



Feudtner et al, Pediatrics 2011

The Interdisciplinary Palliative Care Team

The Interdisciplinary Team

- Majority of Canadian PPC teams consist of a physician, a nurse, a bereavement coordinator, social worker or psychologist.
- Key additions: spiritual support, recreation or child life therapists
- Collaborative services: oncology or neurology, hospice teams and community care providers.

Tasks of a Subspecialty PPC Service

Symptom management (58%)

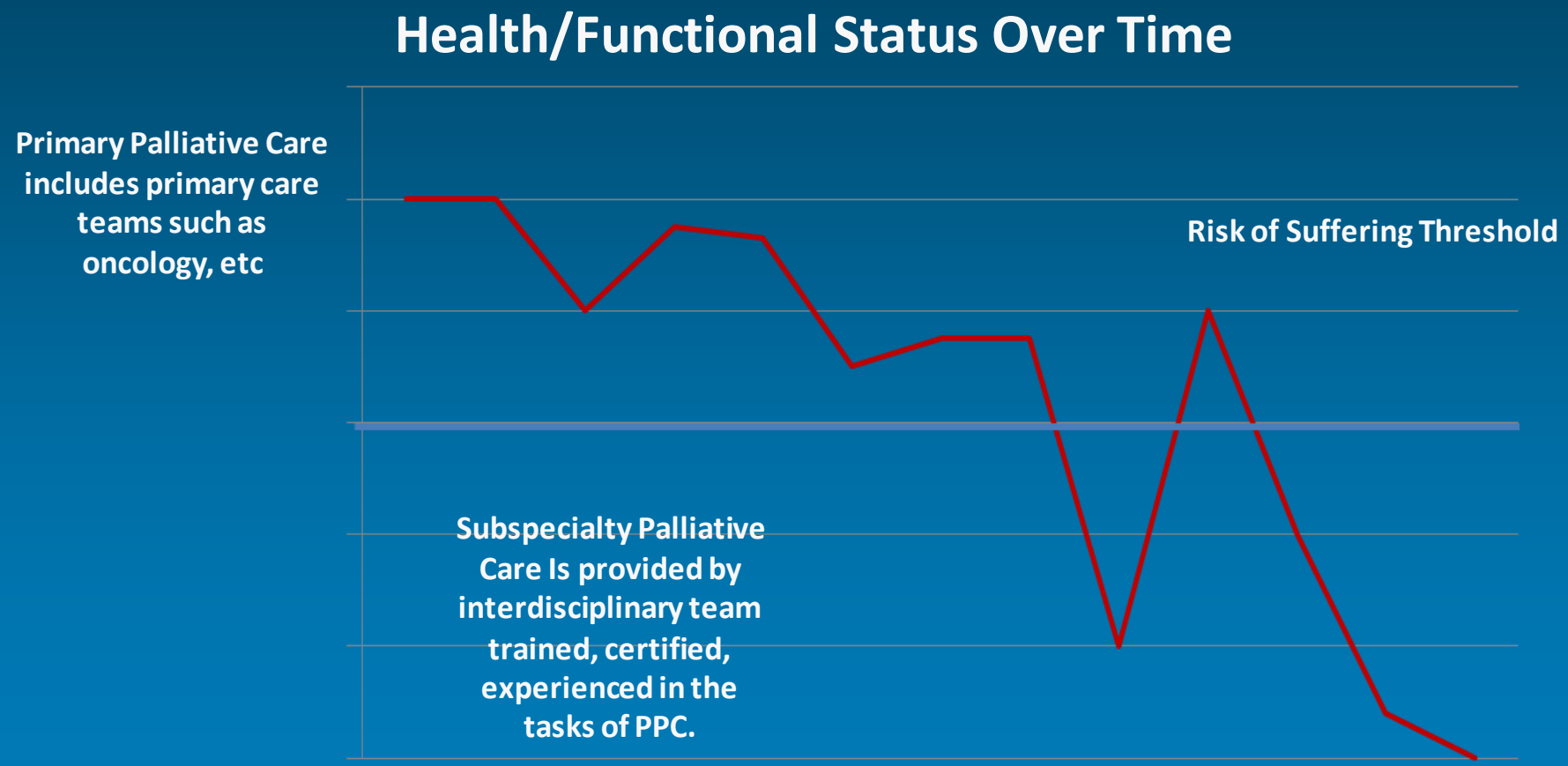
- **Cognitive impairment (47%)**
- **Seizures (25%)**
- **Dyspnea (22%)**
- **Pain (31%)**
  - **Somatic (22%)**
  - **Visceral (12%)**
  - **Neuropathic (10%)**

Tasks of a Subspecialty PPC Service

Other tasks (42%)

- **Communication (48%)**
- **Decision making (42%)**
- **Care coordination (35%)**
- **Transition to home (14%)**
- **Limiting interventions – DNR/DNAR (12%)**
- **Bereavement (11%)**
- **Recommendations at end-of-life (9%)**

Primary vs. Subspecialty Palliative Care



Myths in Palliative Care, Hospice

- Palliative care = hospice = giving up hope
- Child must be terminally ill or at the end of life
- Child must have a DNR to have hospice care

Myths in Palliative Care, Hospice

- Only for children with cancer
- Must abandon all disease-directed treatment
- Must abandon primary treatment team
- Child must move to a different unit/location

Myths in Palliative Care, Hospice

- Child will die sooner/lose hope if PC introduced
- All families want end-of-life to be at home
- Administering opioids causes respiratory depression and quickens death

Early Integration

- Care integrated at diagnosis
  - Provides focus of disease and suffering in all stages
  - Provides necessary supports to help families cope
  - Prevents perception of transition in care or abandonment

Early Integration

- Subspecialty care integrated with primary team
  - Keep PMD or primary specialist in control

Early Integration

- Synergism of disease modifying and palliative care strategies
  - Better symptom and psychosocial management may improve tolerance of treatments and outcomes
  - Palliation and restorative strategies both aim to improve function

Introducing Palliative Care to Families

- As close to diagnosis as possible
- "The part of care for kids with serious illness that focuses on:"
  - Help manage symptoms, stress of serious illness
  - Provide extra layer of psychosocial support
  - Spend time with patients, families to help them understand disease and treatment

Integrating Subspecialists Early

- Prevents disruptive transition to new care team at worst possible time
  - Decreases feelings of abandonment
- Minimizes fragmentation of care
- Umbrella of support through process
  - Support for primary team too (time, resources, self-care, prevention of compassion fatigue)

Integrating Subspecialists Early

- Allows patient, family self-determination about treatment options
- Empowers parents to be capable of maintaining dual goals of care concurrently
- Health care justice: access to emerging best practice

Integration Strategies

- Automatic consultation
- Prioritize symptom management & find a symptom to invite the PPC team to treat
- Consider PC as adjunct medical specialty, part of package, not an optional service

Integration Strategies

- Forget prognosis entirely:
  - Resource management for complex needs of family and community
  - Preventive and anticipatory guidance for children with life-threatening conditions

Integration Strategies

- Honest appraisal of “doing to” vs. “doing for”
- Think about list of applicable diagnoses
  - Acknowledge likelihood of cure
  - Acknowledge burdensome treatment course

Integration Strategies

- Think about appropriate time points
  - Bad news/overwhelmed at diagnosis
  - Phase I enrollment
  - Relapse/recurrence
  - Serious complications
  - ICU admissions/transfers
  - Change in technology (new trach)
  - Listing for transplant

The Language of PPC

- Interdisciplinary
- Life-threatening, not just life-limiting, progressive
- Children range in age from prenatal to young adult
- Family (biological, adoptive, foster, etc) core to decisions

The Language of PPC

- Surrogate decision making
- Benefits/Burdens
- Goals of care
- AVOID: Withdrawal of support/care/treatment
- Transition to focus on quality and comfort

Summary

Pearls

- Refer to PPC early
- Focus on the relief of suffering
- Consider careful use of language

Pearls

- Additional referral points
  - Complex, higher risks situations
  - Conflicts
  - Communication challenges
- PPC works with the primary care team to enhance care
- Define goals for care

Pitfalls

- Confusing PPC with hospice or end of life care
- Asking families to choose PPC when they may not understand what it is or when it is considered standard of care
- Using language that suggests “giving up” or loss of hope

Pitfalls

- Waiting so long to refer that suffering increases
- Using terms like “withdrawing” or “withholding” care

Comments or Questions???

EPEC - Pediatrics

The Education in Palliative and End of Life Care: EPEC-Pediatrics

2010 –2016

Stefan J. Friedrichsdorf, Stacy Remke, Joshua Hauser, Joanne Wolfe

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EPEC.Pediatrics@childrensMN.org

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