Pediatric Palliative Care

Introduction, cases, challenges

Ken Pituch, MD
Medical Director, Palliative Care Team
CS Mott Children’s Hospital
University of Michigan Medical Center
Ann Arbor, MI

University of Michigan
C.S. Mott Children’s Hospital

Carla’s story

- Severe birth asphyxia, 1985. Apgars 0, 0, 1
- 9 week NICU stay. Grade 3 IVH. Hydrocephalus
- No advance in milestones
- 19 VP shunt revisions by age 7 years
- Feeding gastrostomy tube, age 3 months
- Spastic CP, severe developmental delay
- Reflux, constipation, feeding intolerance.
- 4 GI surgeries age 3 months to 6 years.
- 2 months of broviac nutritional support 1990
- 6 surgeries for tendon releases, scoliosis
- 26 pneumonia admissions 1987 – 2004
- Tracheostomy at age 10 years
- Night time vent support age 15 years
- Full-time ventilator support age 17

Carla

- Developmental age in 2004: Age 2 months
- Parents divorced 1991
- Family history denotes "Maternal depression"
- No record of discussions of . . .
  - **Advanced care plan**
  - **Surgical options**
  - **Palliative care options**

What is palliative care?

Palliative care is specialized medical care for people with serious illnesses. It is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis. The goal is to improve quality of life for both the patient and the family.

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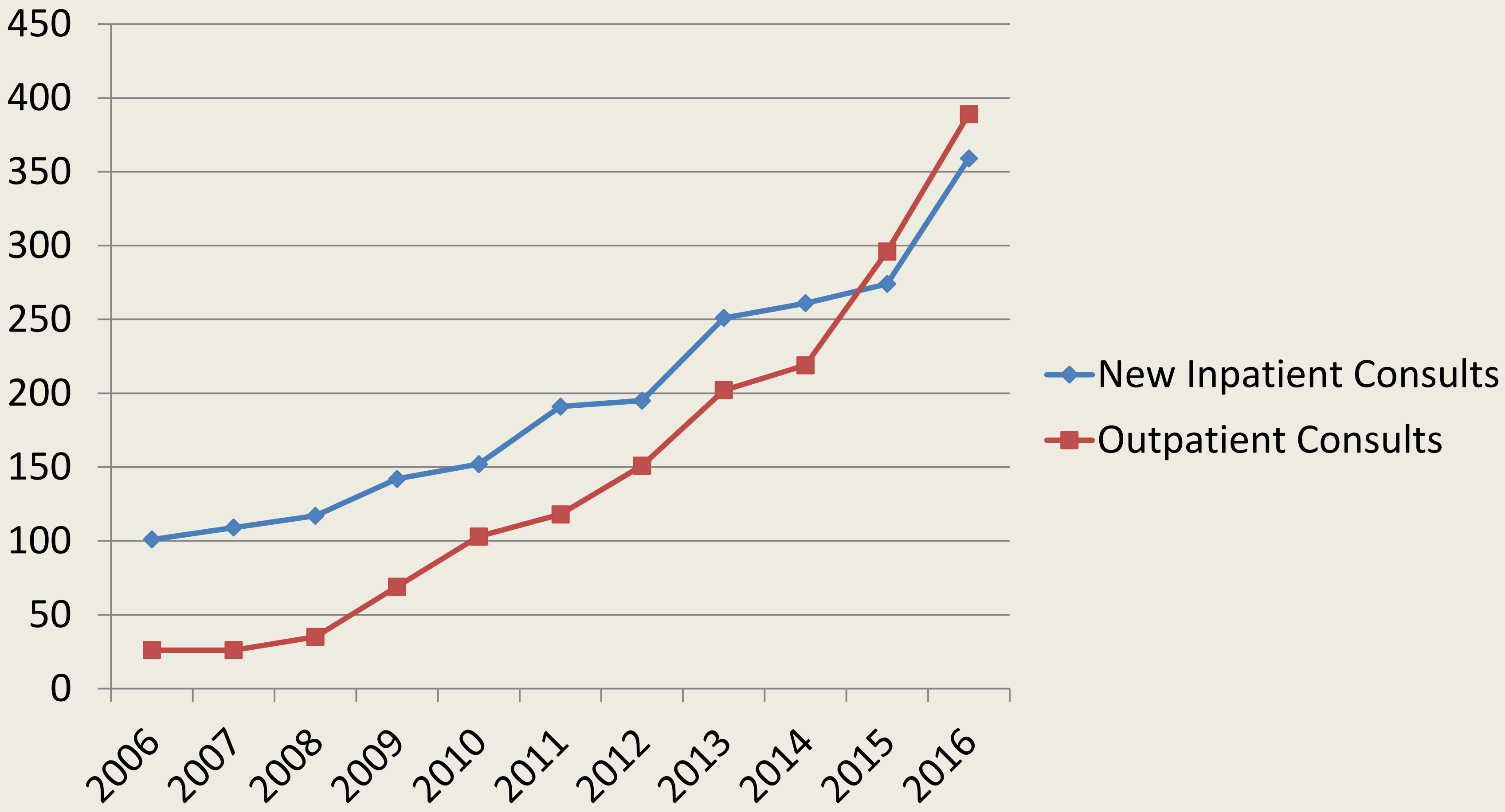
Palliative care is provided by a team of doctors, nurses, and other specialists who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.

Pediatric Palliative Care Consults by Year



New Consults: Pediatric Palliative Care, 2006 - 2016

- Reasons for consulting palliative care:
  - Help with symptoms (pain, vomiting, sleep, irritability, constipation): 30%
  - Help with difficult decisions: (goals of care, limits to aggressive care): 55%
  - Transitions/ out of hospital support: 15%

Pediatric Palliative Diagnosis Mix

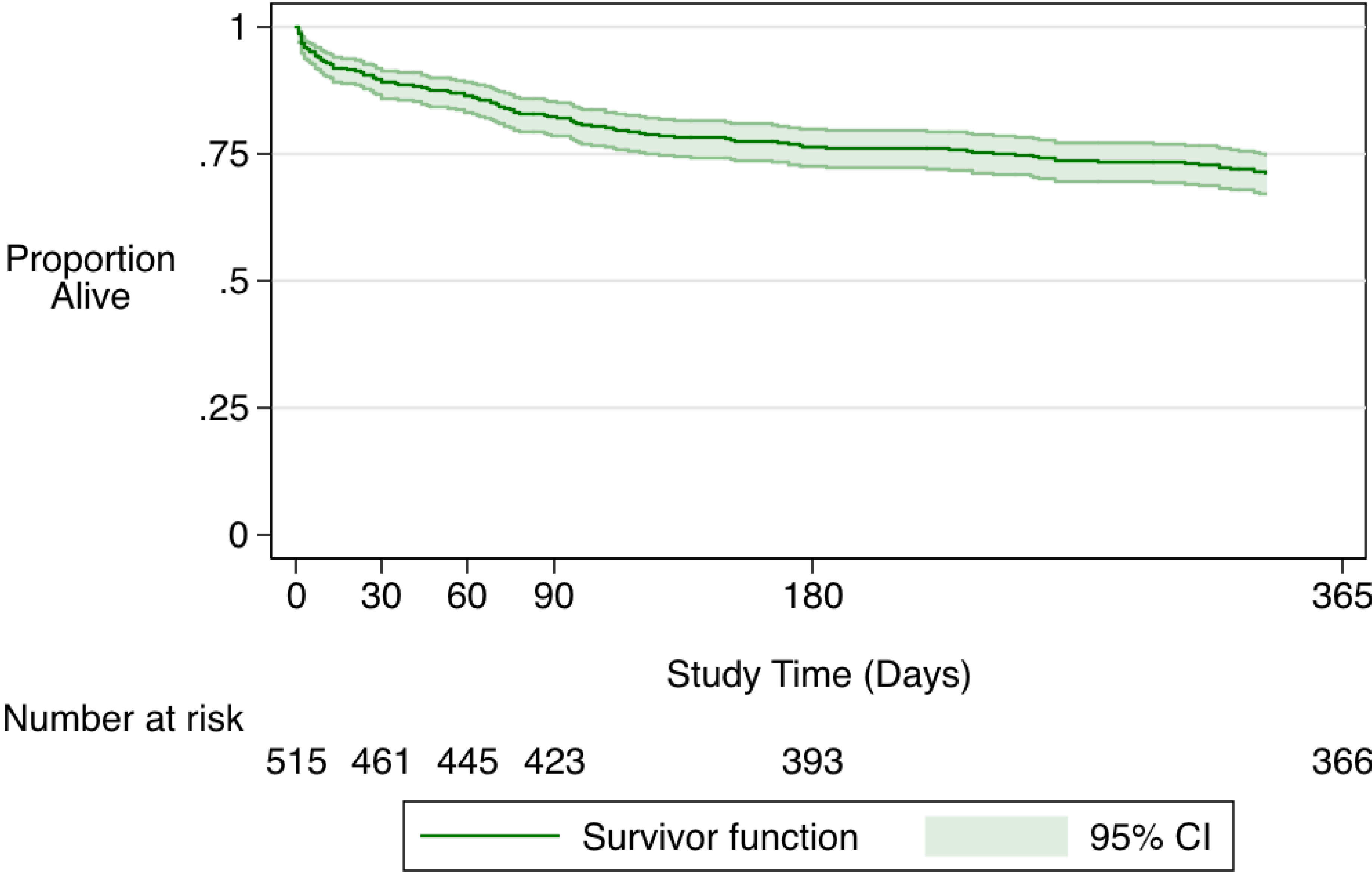
Research Network Cohort Study, 2008

Diagnoses	Percentage of 515 total consults
Genetic/ congenital	40.8
Neuromuscular	39.2
Static	61.3
Progressive	38.7
All Cancers	19.8
Hematologic	36.3
Solid tumor	36.3
Brain Tumor	14.4
Respiratory	12.8
Other	10.7
GI	9.9
Cardiovascular	3.3 **(16% of Mott Consults in 2008)**
Metabolic	7.2
Renal	2.7
Immunologic	2.6

C. Feudtner et al and the Pediatric Palliative Care Research Network, Pediatrics Sep 2010

Survival Function in the Cohort

for 515 patients receiving Pediatric Palliative Care



C. Feudtner et al and the Pediatric Palliative Care Research Network, Pediattrics Sept, 2010

Kiara

- Born 1993, poor weight gain, slow development. “Unusual Cry”
- Diagnosed in 1995 “Cri-du-chat” a genetic syndrome.
- 1995 – 2003: severe GI dysmotility: 20 surgeries: g-tubes, g-j, broviacs.
- 2003 – 2004: 15 admissions for obstructions, line infections

Kiara

- December 2004, team and family meeting

- Concensus:
  - No more indwelling lines
  - Feed to tolerance
  - Accept a shorter life

- Outcome
  - No admissions in next 8 months

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"There's no easy way I can tell you this, so I'm sending you to someone who can."

Hospital Gunman Kills Mother, Himself After Shooting Doctor

(Sept. 16) -- A man upset over his mother's medical condition wounded a doctor inside Baltimore's Johns Hopkins Hospital today, then fatally shot his mother and himself, police said.

The gunman shot the doctor after receiving some upsetting news about his mother's condition, Baltimore Police Commissioner Frederick Bealefeld told reporters.

http://www.aolnews.com/

Learned from colleagues:

- The Big Questions:

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  - What is your understanding of your son’s / daughter’s condition?

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- The Big Questions:
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  - What are you most afraid of?
  - What do you think might help?

Learned from colleagues:

- The Big Questions:
  - What is your understanding of your son’s / daughter’s condition?
  - What are you hoping for?
  - If that doesn’t happen, what else is important?
  - What are you most afraid of?
  - What do you think might help?
  - How are you able to be the best parent you can be?

Learned from colleagues:

Quality of life survey:

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- What does it take to get him to smile?

Learned from colleagues:

Quality of life survey:

– What does it take to get him to smile?

– How has that changed?

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- How has that changed?
- What makes for a good day?

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Quality of life survey:

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- How many good days does he have?
- How has that changed in the last few months/years?

.

Learned from colleagues:

Quality of life survey:

- What does it take to get him to smile?
- How has that changed?
- What makes for a good day?
- How many good days does he have?
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- .

Conclusions / Bottom line

- Palliative Care is good medical care and can be provided by any health professional.
- All it takes is asking 4 questions:
  - "What is your understanding of your child's disease?"
  - "What are you hoping for?"
  - "What are you afraid of?"
  - "How can I help?"

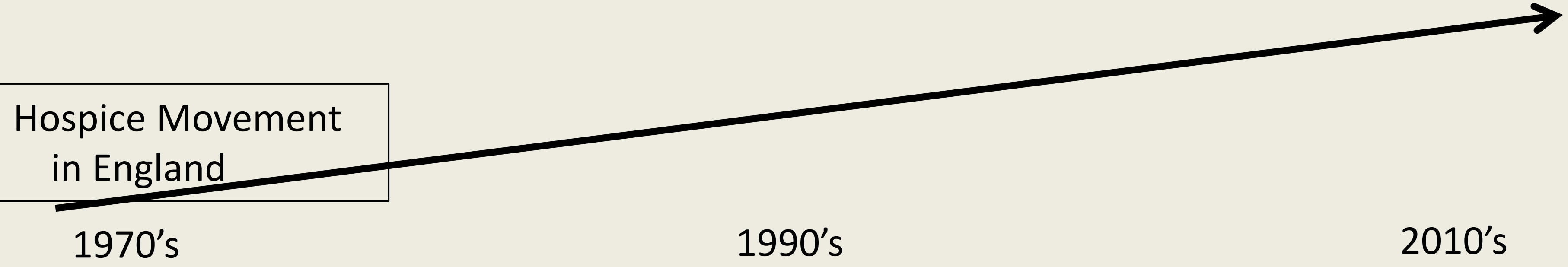
Two timelines: support

1970’s

1990’s

2010’s

Two timelines: support



Hospice Movement in England

1970’s

1990’s

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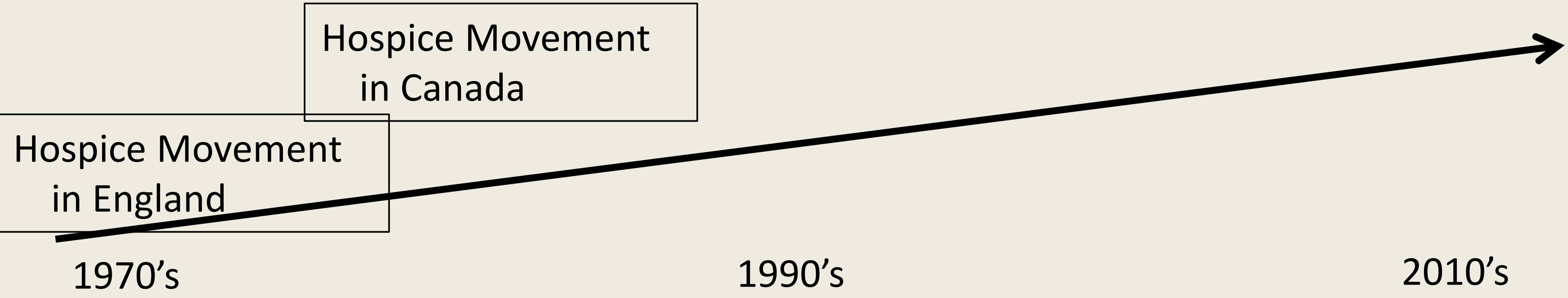
Two timelines: support



Hospice Movement in Canada

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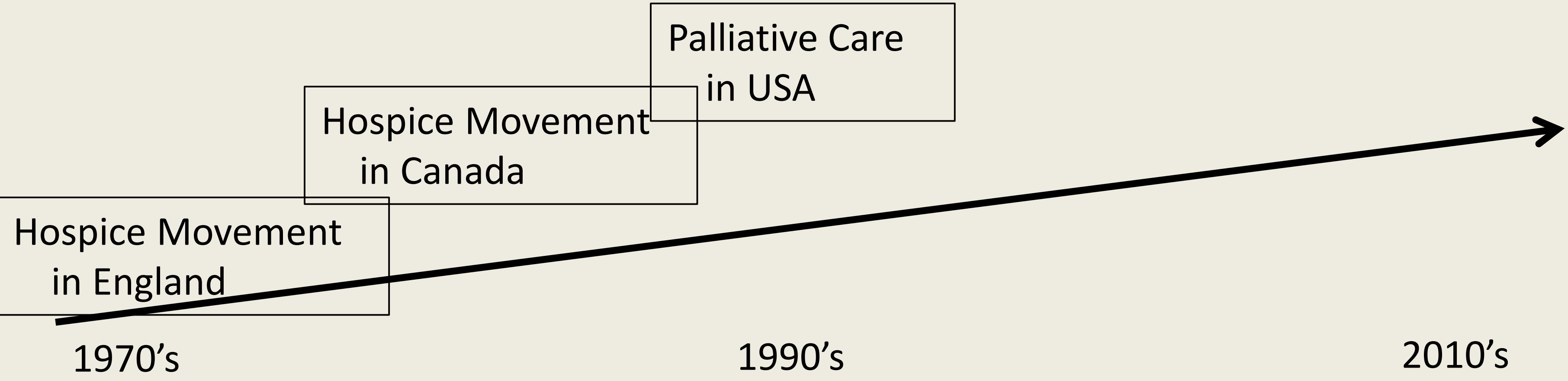

Palliative Care in USA

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Hospice Movement in England

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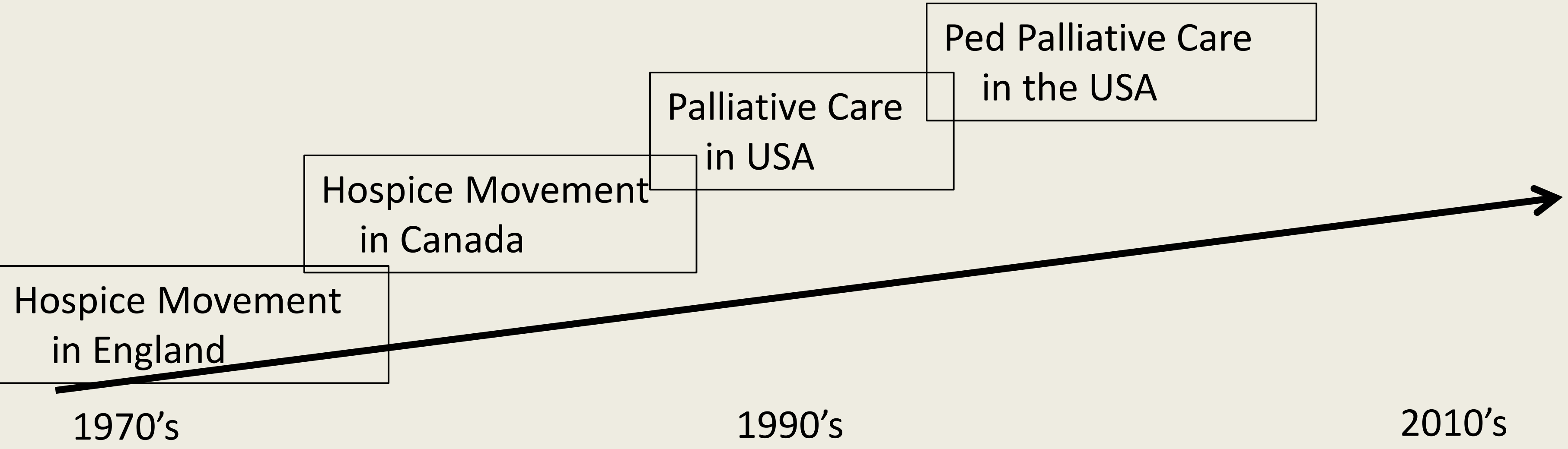

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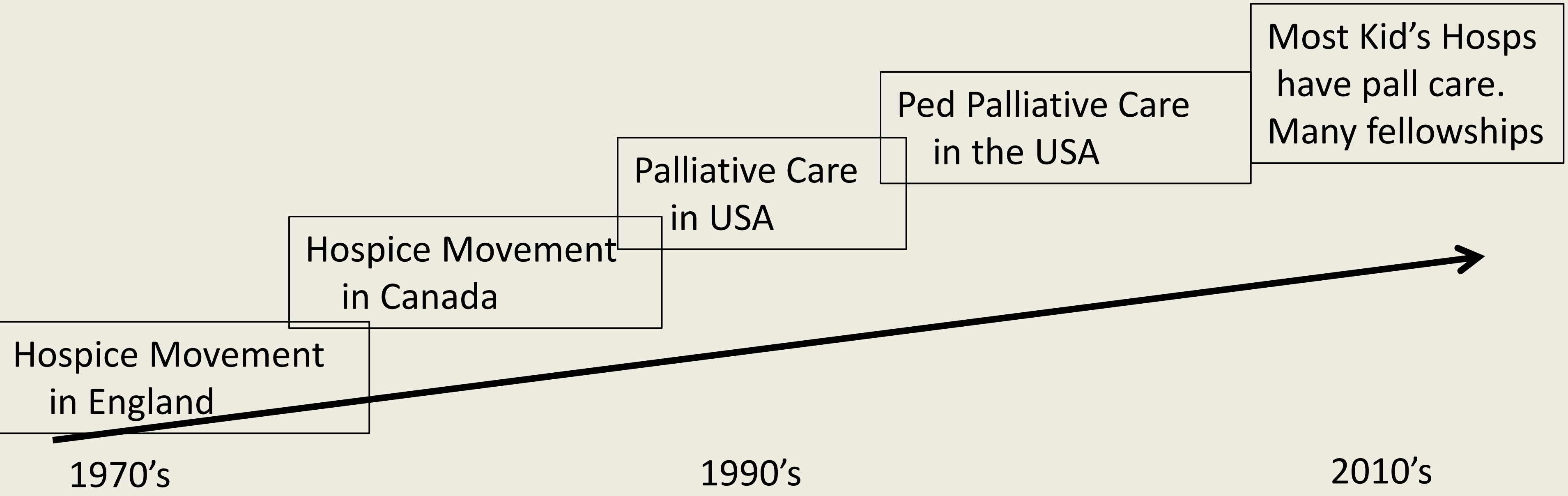

Hospice Movement
in England

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Palliative Care
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Ped Palliative Care
in the USA

Most Kid's Hosps
have pall care.
Many fellowships

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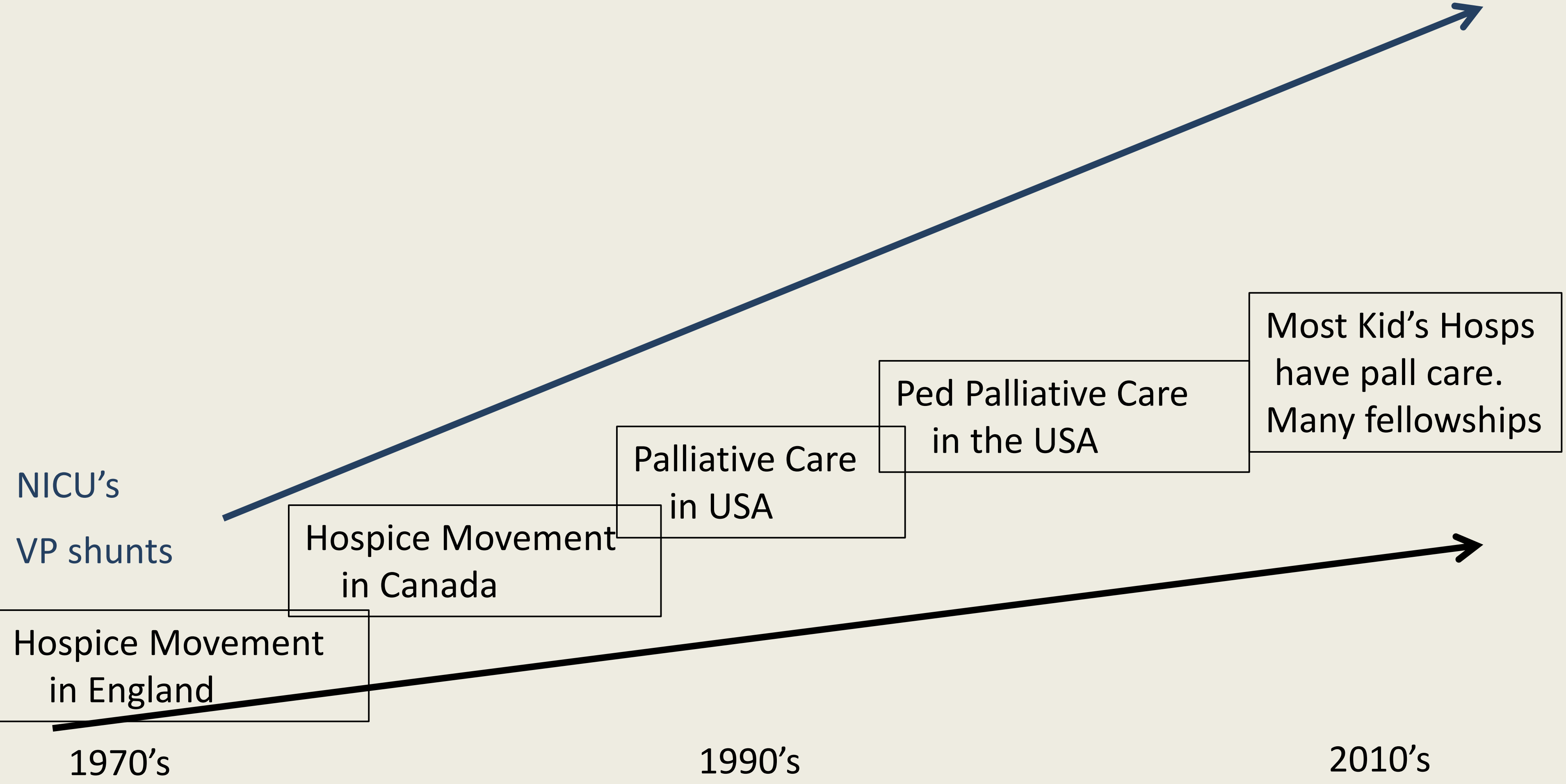
Two timelines: support / survival



NICU's

VP shunts

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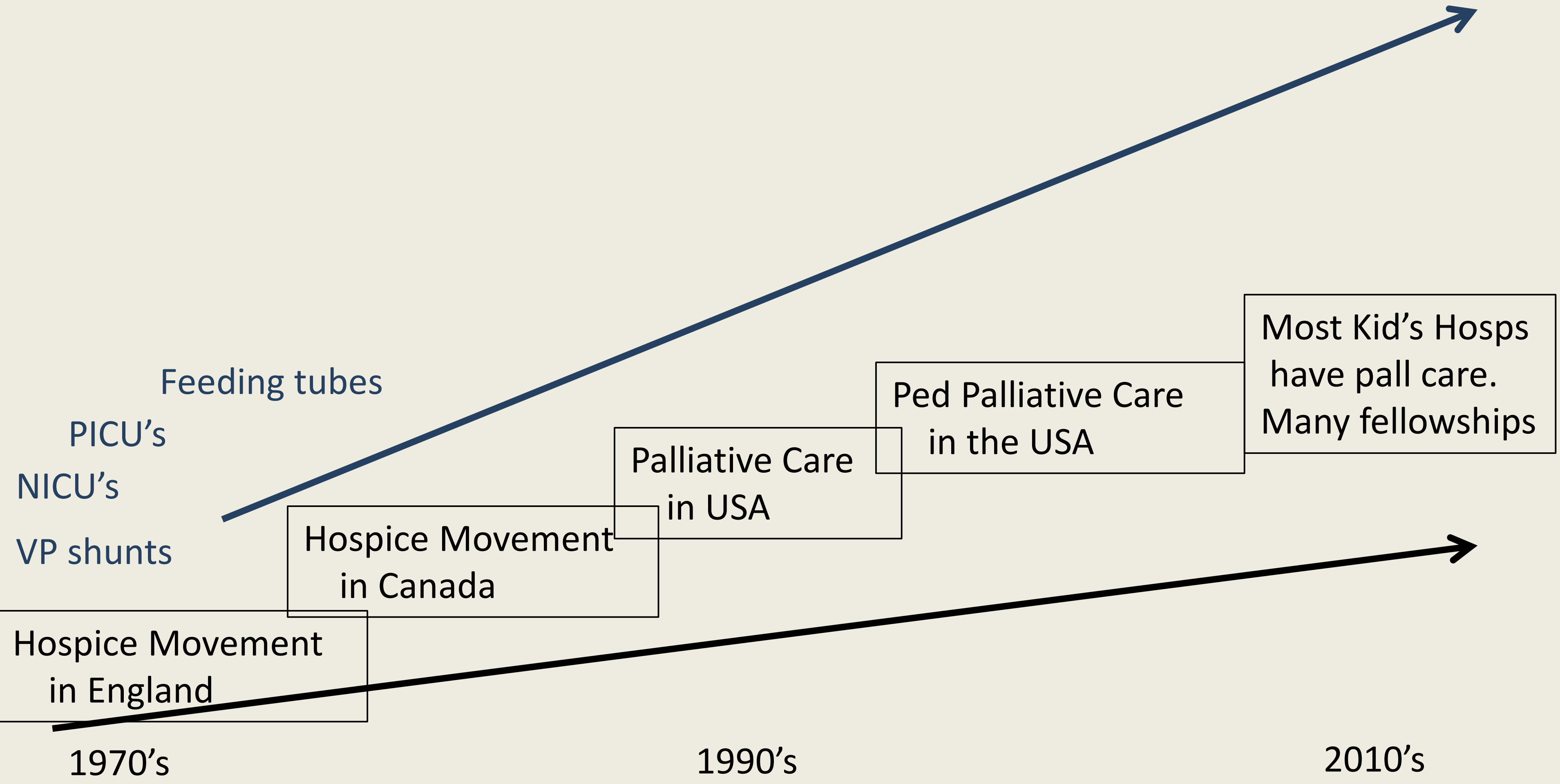

Feeding tubes

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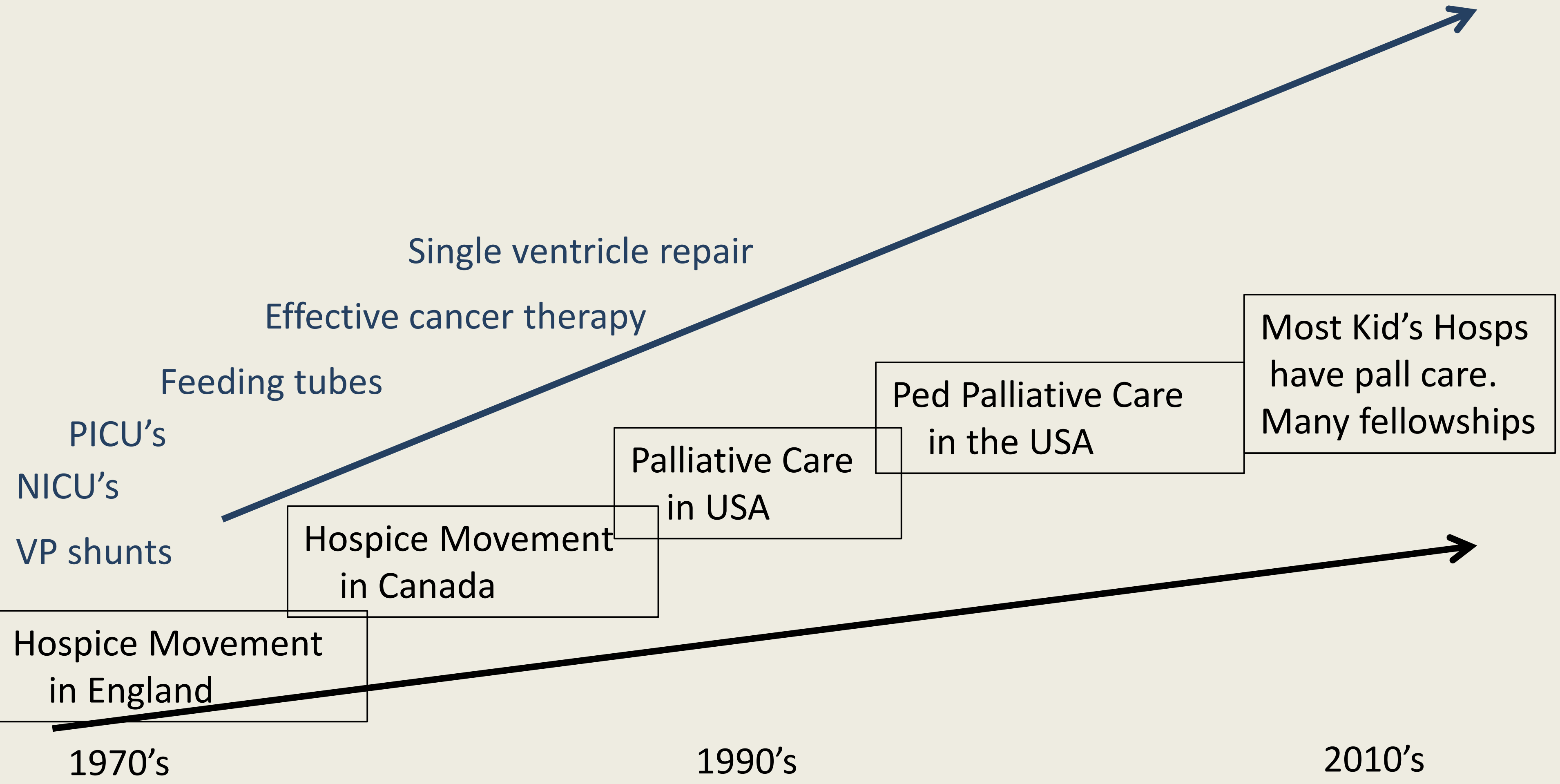

Single ventricle repair

Effective cancer therapy

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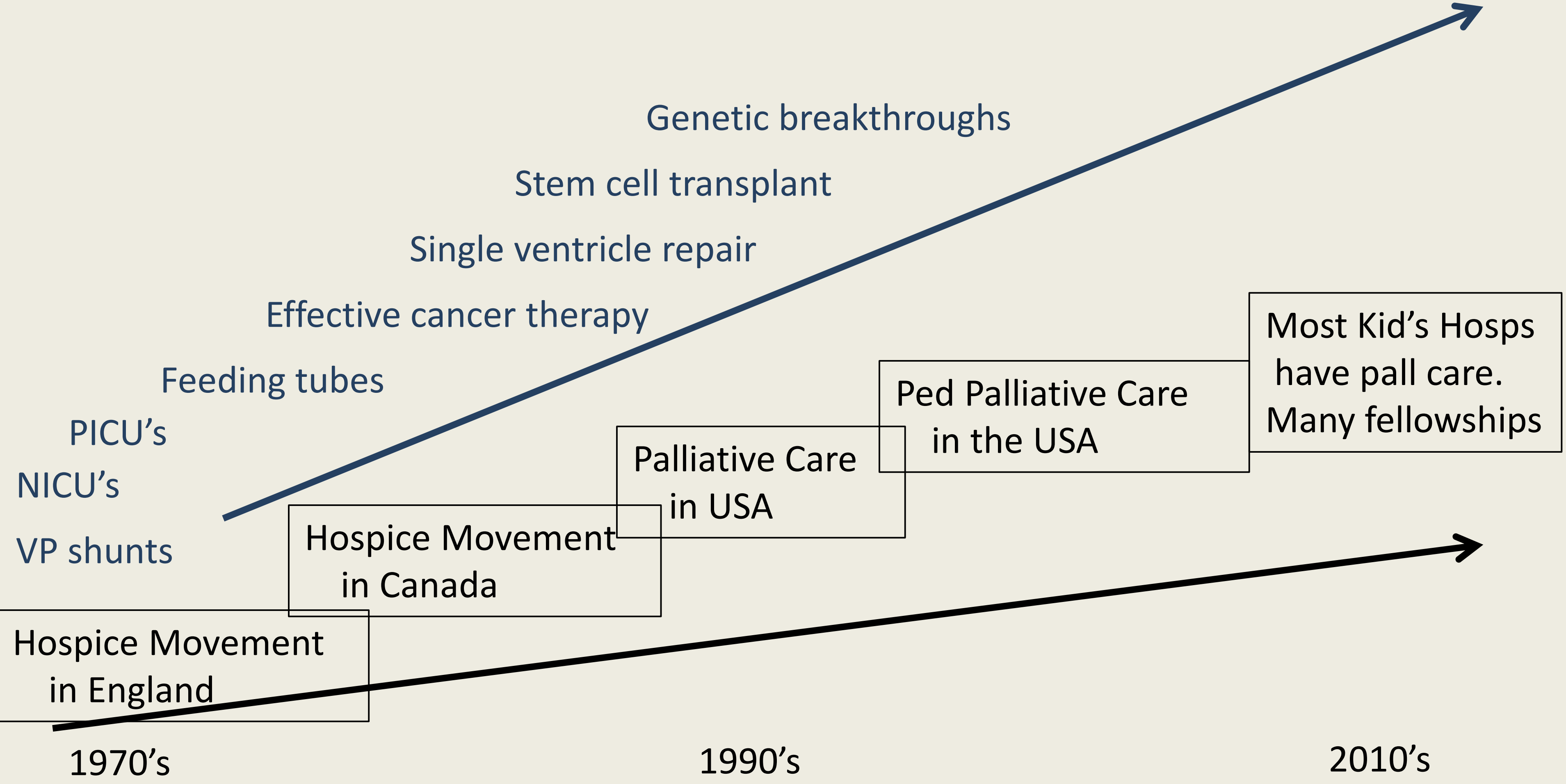

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Single ventricle repair

Stem cell transplant

Genetic breakthroughs

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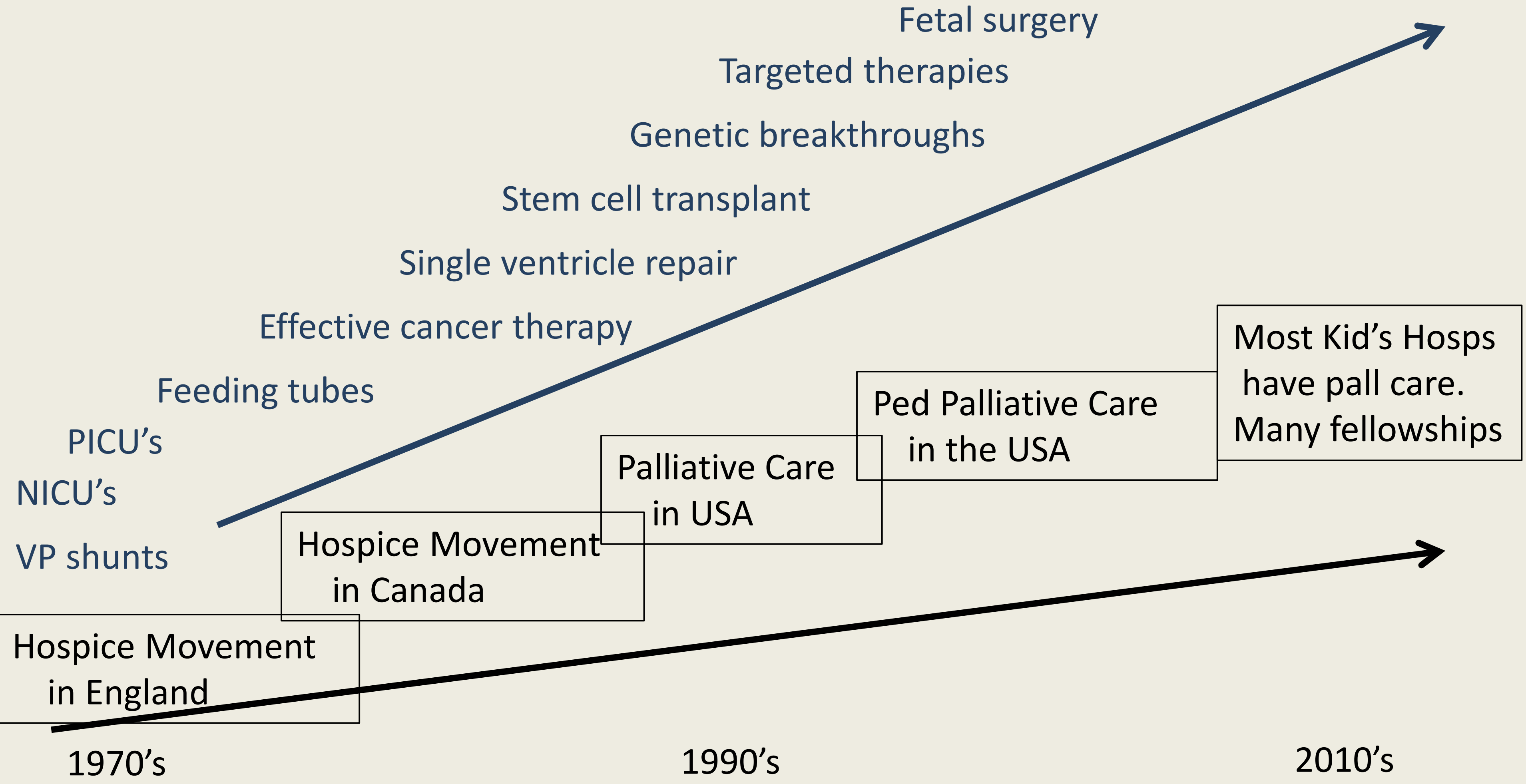

Fetal surgery

Targeted therapies

Genetic breakthroughs

Stem cell transplant

Single ventricle repair

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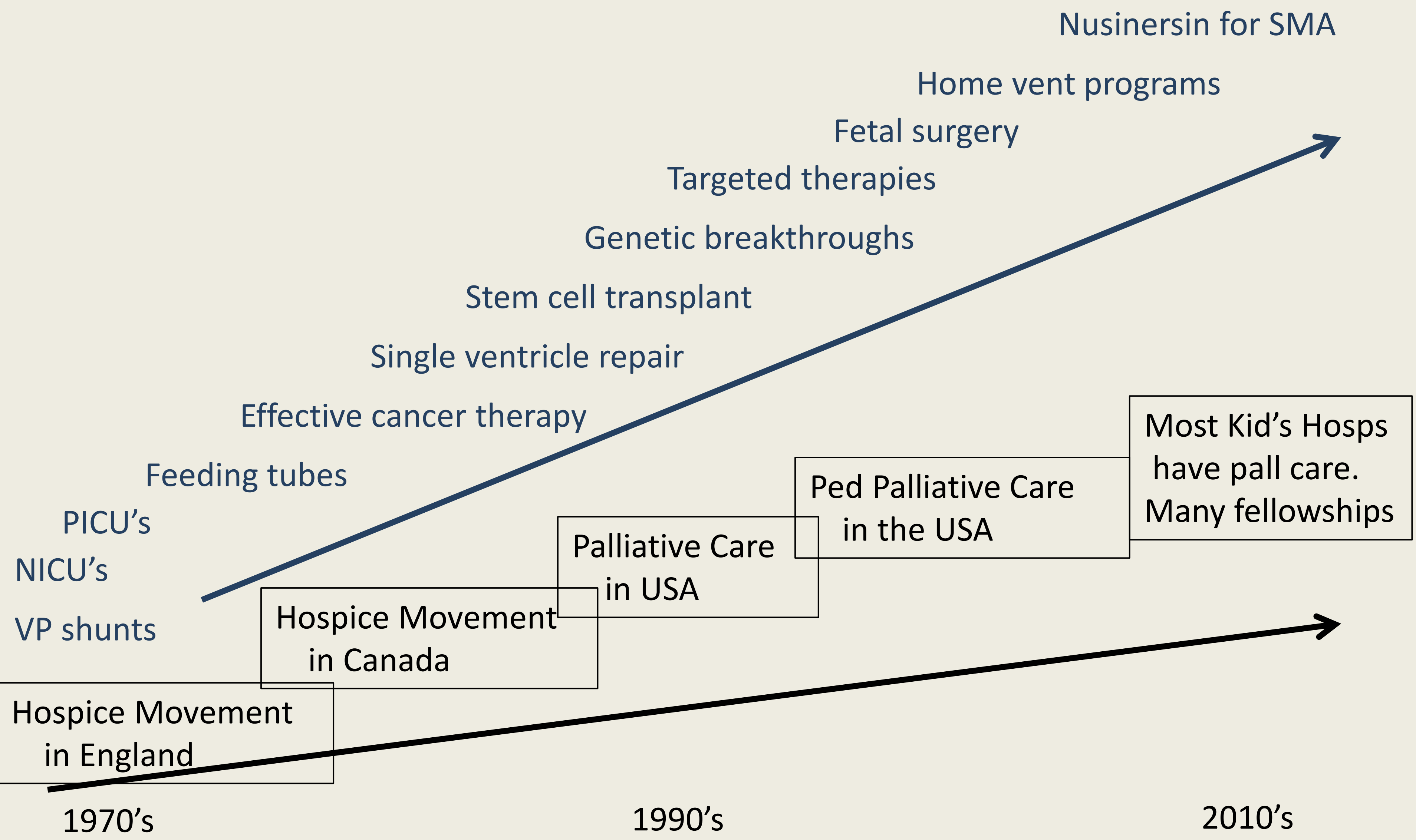

Nusinersin for SMA

Home vent programs

Fetal surgery

Targeted therapies

Genetic breakthroughs

Stem cell transplant

Single ventricle repair

Effective cancer therapy

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Paul: USA

- Cerebral palsy, seizures, scoliosis, neurogenic bladder, constipation, asthma
- Wheelchair, g-tube, baclofen pump
- 13 medications
- 15 specialist visits in 2015 with 5 specialists
- Loved school

Paul: age 14

- Late 2015 got sicker
- Seizures, resistant UTI’s, feeding intolerance
- 3 admissions, 6 ED visits
- March, 2016: Mom asked for hospice help

Paul’s mom’s issues

- “Pediatrician sends me to the ER when I call her”
- “Urology calls me back in 8 hours, and then says, “Call Infectious diseases”
- “When I ask, ‘could he die from this?’ they think I’m crazy!”

- Died in May, 2016 at home with hospice support

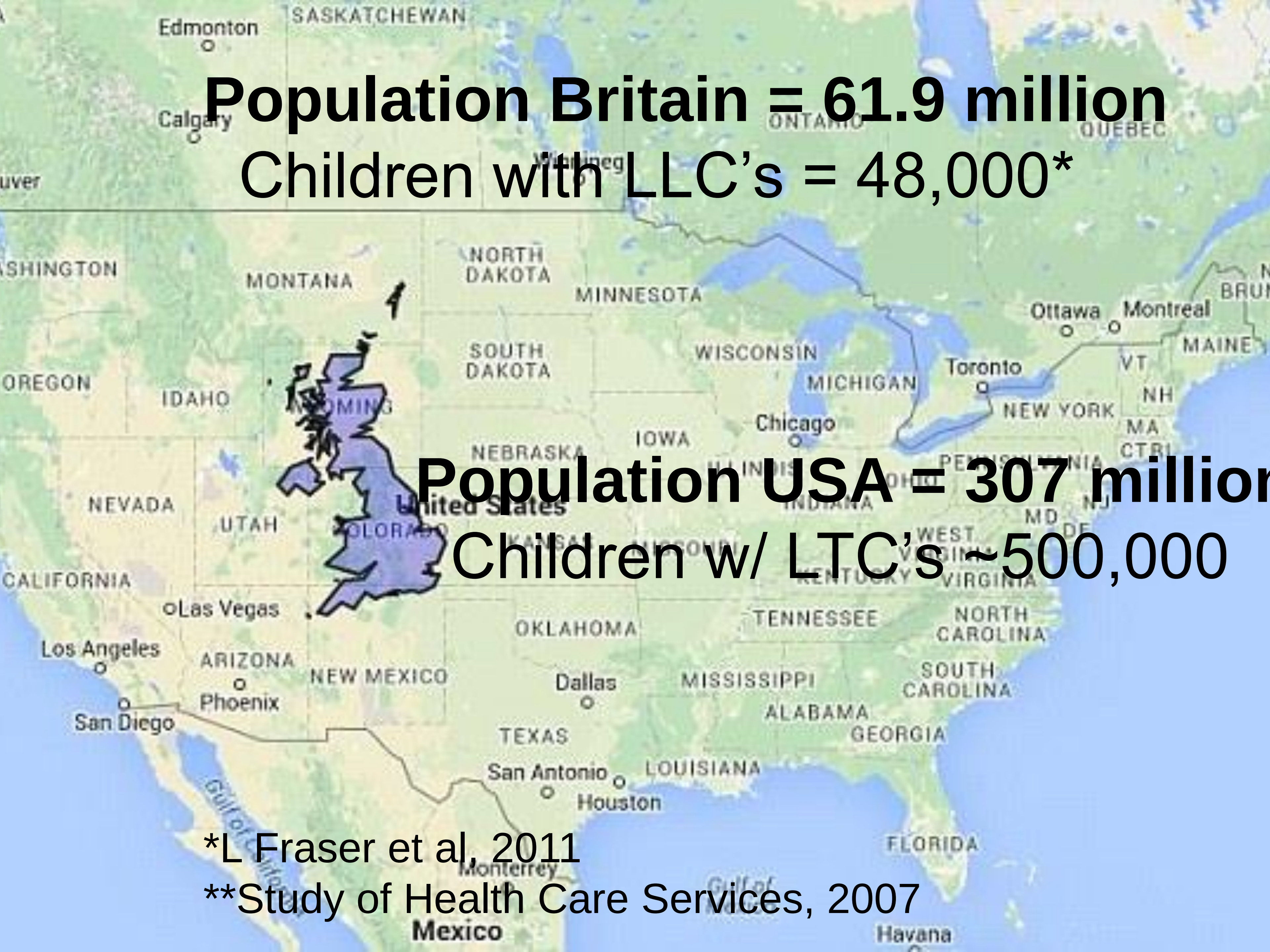
Derrick, Oxfordshire, UK

- Derrick:
- 16 y.o. with Duchenne Muscular Dystrophy
- Since diagnosis has a dedicated home nurse
- Care coordinated and managed by a district pediatrician
- Douglas House: Short Breaks 16 days per year
- Advanced Care Plan since age 11—available to school, EMS, local hospital

Out of Hospital Support for Children with Life Limiting Conditions—UK

- Community nurses
- “POONS”
- Diana nurses

- LONG relationships
-



Population Britain = 61.9 million

Children with LLC’s = 48,000*

Population USA = 307 million

Children w/ LTC’s ~500,000

*L Fraser et al, 2011

**Study of Health Care Services, 2007

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Childrens Hospices = 53

Population USA = 307 millio

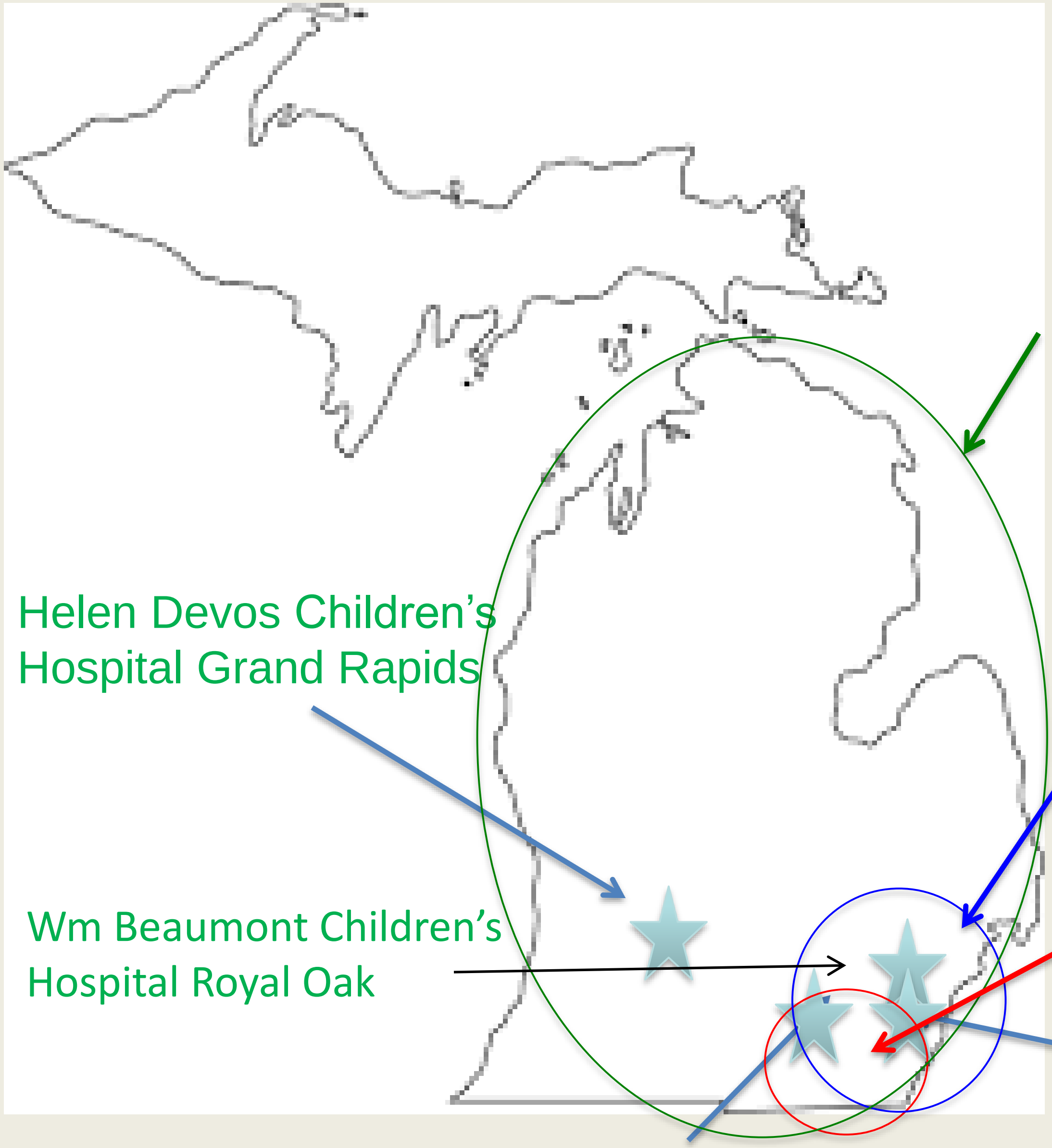
Children w/ LTC’s >300,000

Children’s Hospices < 5

*L Fraser et al, 2011

**Study of Health Care Services, 2007

Children's Hospices and Palliative Care



Anchors Program, HOM/Arbor
20 to 30 Hospice patients,
80% of the Lower Peninsula
250 'Compass Patients' SW support

Helen Devos Children's
Hospital Grand Rapids

PATCH Hospice
30 to 40 patients
Metro Detroit

Angela Hospice
2 to 6 patients
West Detroit Suburbs

Wm Beaumont Children's
Hospital Royal Oak

Children's Hospital of Michigan
Detroit

CS Mott Children's
Hospital Ann Arbor

Hospice of Michigan

ANCHORS

Jo Elyn Nyman &
The Samuel and Jean Frankel Foundation
Programs for Children

University of Michigan
S. Mott Children's Hospi

Michigan's
Partners for Children

An Anchors / Michigan Medicine Pilot

Marcie Hillary, Barbara Anderson, Patrick Miller, Ken Pituch
Anchors Programs for Children, Hospice of Michigan

Mike Klett, Jason Battaglia, Ken Pituch
Michigan Medicine/CS Mott Children's Hospital

;

California Partners for Children

UCLA CENTER FOR
HEALTH POLICY RESEARCH

Health Policy Brief

August 2012

Better Outcomes, Lower Costs: Palliative Care Program Reduces Stress, Costs of Care for Children With Life-Threatening Conditions

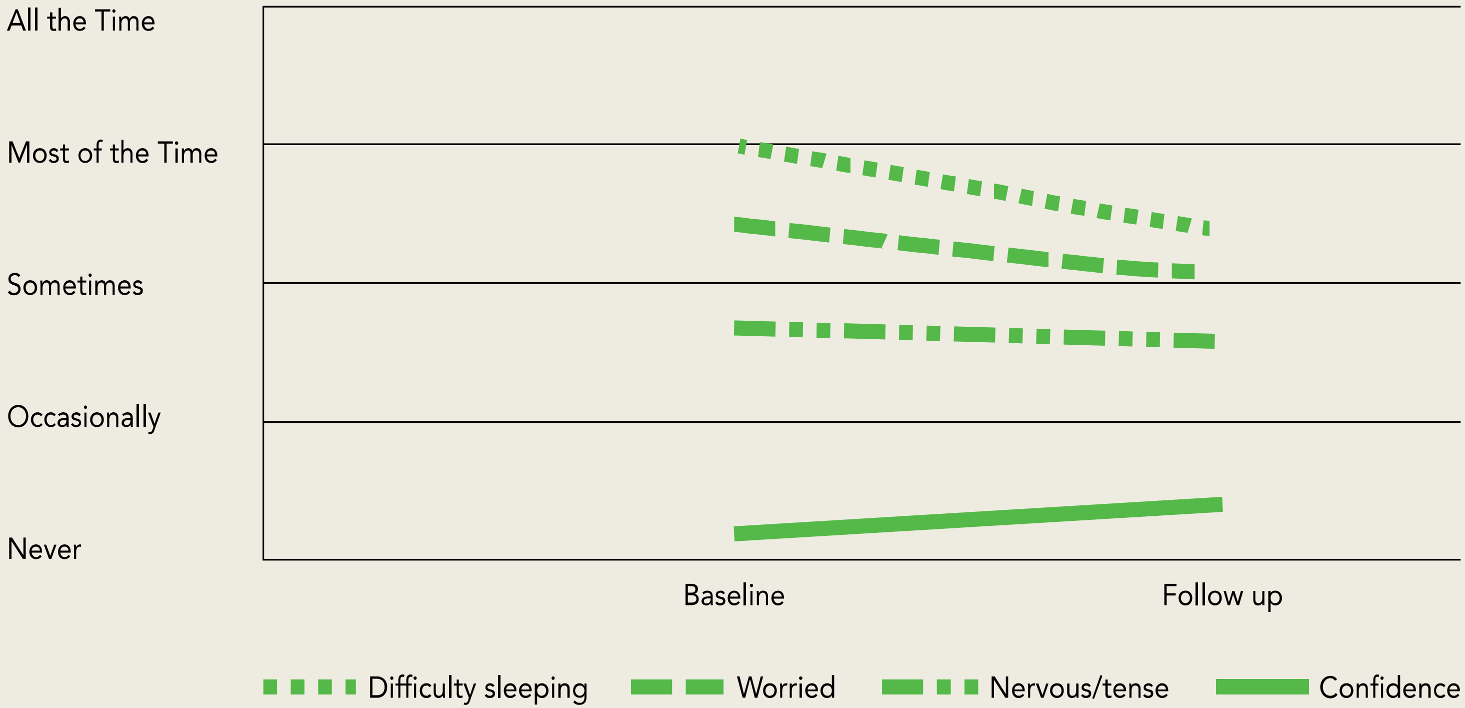
Daphna Gans, Gerald F. Kominski, Dylan H. Roby, Allison L. Diamant, Xiao Chen, Wenjiao Lin and Nina Hohe

- 400 patients in 11 California counties
- Hospice-like services **without limit of a 6 month prognosis**
- 24/7 nurse access, pain and symptom management
- Respite services
- Expressive therapies
- Family counseling and support

California Partners for Children

> *"Nearly all PFC families would recommend the program to a friend or family member."*

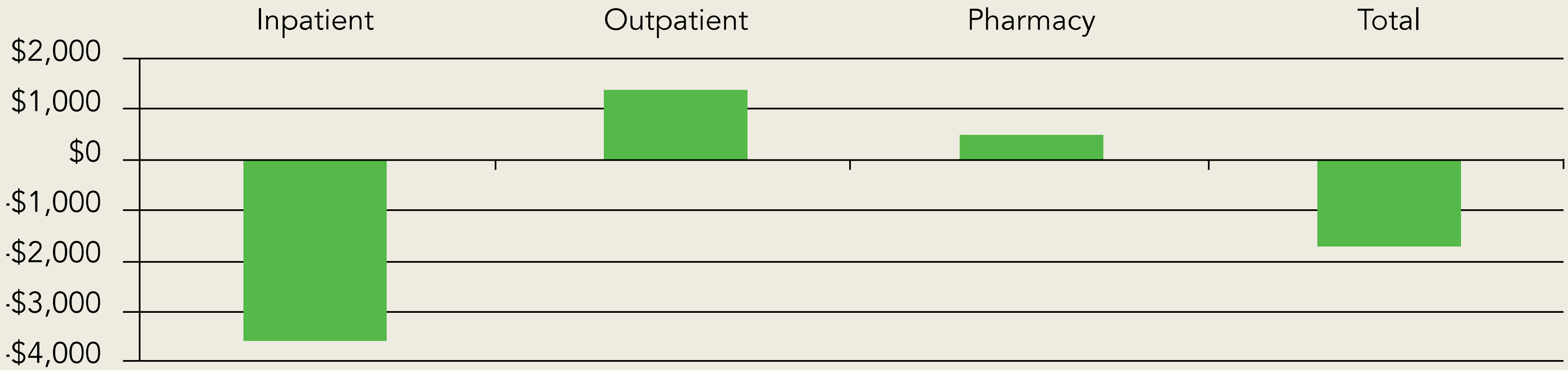
Change in Stress, Worry and Confidence Levels Before and After PFC Services



Source: A survey developed by the UCLA Center for Health Policy Research and administered to families by California Children's Services Nurse Liaisons at baseline (enrollment) and follow up (six months after enrollment). Based on 33 surveyed families.

California Partners for Children

Change in Per Enrollee Per Month Cost in U.S. Dollars From Pre- to Post-Enrollment in the PFC Program by Type of Service



Source: UCLA Center for Health Policy Research preliminary analysis based on MIS/DSS claims, MEDS and CMS Net data from 2009 until September 2011.

Year One Funding

University of Michigan
S. Mott Children's Hospi

$255,000

HEALTH
FUND

$500,000

Hospice of
Michigan

$100,000

Michigan's Partners for Children

MPC: Teams

Community team (Anchors):

Nurse Practitioners (2 FTE)
Social Worker (1.5 FTE)
24/7 phone triage
Therapists (music, massage, etc)
Parent(s) of CMC
Liaison with Medicaid Managed-Care Coordinators

↔

Hospital Team:

Pediatricians (0.4 FTE)
Nurse Practitioners
Clerical Support
Assessment Support

Affiliate Team: 2-4 hr/wk

PM&R physician
Dietitian
PharmD
PT/OT/Speech
Education liason

Target Patient Population/Qualification Criteria
The U of M sample

- Age =≤17 years
- **Complexity:**
  - Multiple specialists
  - More than 15 clinic visits in a year. OR
- **Fragility:**
  - At least **3** unscheduled hospital admissions** within the past 12 months OR
  - At least **15** hospital days*** within the past 12 months AND
  - Not better served by another single clinic (i.e. hematology/oncology, CF, transplant, etc.)

Michigan’s Partners for Children
Program Launch

- Enrolling 30 patients in June. All 100 patients by Sept 30

- NP’s will do home visits, see patients when admitted and at some clinic appointments

- Social work / ancillary support as needed
-

- Families will have 24/7 phone access to a team member.

Program Assessment

Parent survey data	Clinical Data	Payer Data
Stress / coping	Clinic visits	Total costs
Phone responsiveness	Miles travelled for clinic visits	Comparison Group
Clinic responsiveness	Number of meds	
School / work missed	ED visits	
	Hospital days	
	ED visits	
	Clinical interventions	

Data analysis in first 9 months to be provided by the CHEAR unit, U of Michigan

Sustainability

- Medicaid Match funding – starts 2019
- Michigan Medicine commitment
- Medicaid / Children’s Special Health commitment
- Second, third hospital partners

My Hope: in 5 years Michigan will have

- A state-wide complex- chronic care program
- Respite services for families/children with life-limiting conditions
- Integrated palliative care services in all hospitals caring for these children
- Improved decision-support for families with seriously ill children
- Improved grief support

Discussion

CASES

I have permission from the patients and parents to tell their stories and use their photos

Melanie and Luke

Complex care is not cheap

	Hospital Charges	Professional Charges	Total
Melanie **13 months in PICU**			
Luke **15 months in PICU**	$4,030,697	$515,474	$4,546,171

Complex care is not cheap

	Hospital Charges	Professional Charges	Total
Melanie **13 months in PICU**	$3,862,596	$432,922	$4,295,518
Luke **15 months in PICU**	$4,030,697	$515,474	$4,546,171

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Luke 15 months in PICU	$4,030,697	$515,474	$4,546,171

A FAMILY STORY

AND YOU ASKED ME THE QUESTION, “WHAT DO YOU WANT FOR HER?”

YOU DIDN’T SAY, “WHAT DO YOU WANT US TO DO FOR HER?” YOU SAID, “WHAT DO YOU WANT FOR YOUR DAUGHTER?”

AND I REMEMBER I TOLD YOU, “YOU ARE ASKING ME VERY VERY HARD QUESTON” BECAUSE HONESTLY, THIS IS THE TRUTH . . .

I WANT MY BABY TO BE COMFORTABLE, IN THE MEANTIME I DON’T WANT MY BABY TO GO.

- A FAMILY STORY Cont.

I WANT HER TO
BE WITH ME.

BUT FOR HER
TO BE WITH ME,
I KNOW THAT
SHE WILL HAVE
TO GO
THROUGH
VENTILATOR
EVERY TIME.

BECAUSE IT WAS SUGGESTED TO DO TRACHE IF WE HAVE TO , IF WE DECIDE TO PUT HER ON VENTILATOR, THEN THEY SAY WE ARE GOING TO OPEN HER THROAT AND PUT A TRACHE.

AND I SAY ‘NO TRACHE’. SO I . . . THEN I WAS THINKING, WHAT MEANS . . . FOR HER TO BE COMFORTABLE . . .

. . . IS ONLY TO
LET HER GO.


YOU
DECIDE

Children's Palliative Care Coalition of Michigan

Annual Meeting. Friday. November 2, 2018

"Extending the Reach"

People's Church, East Lansing

www.childpalliative.org