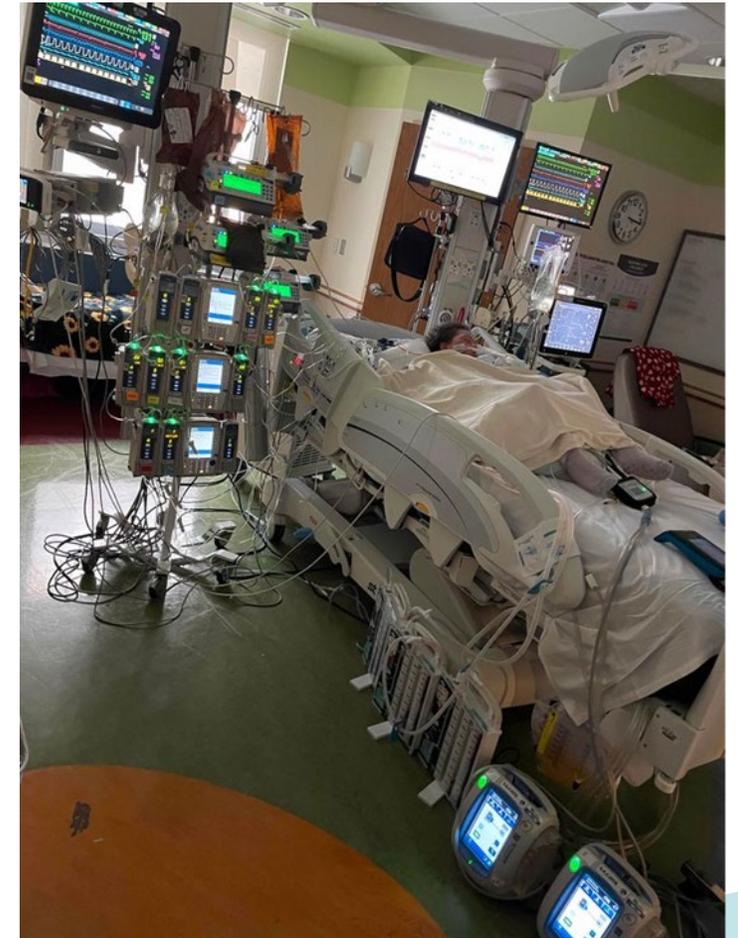




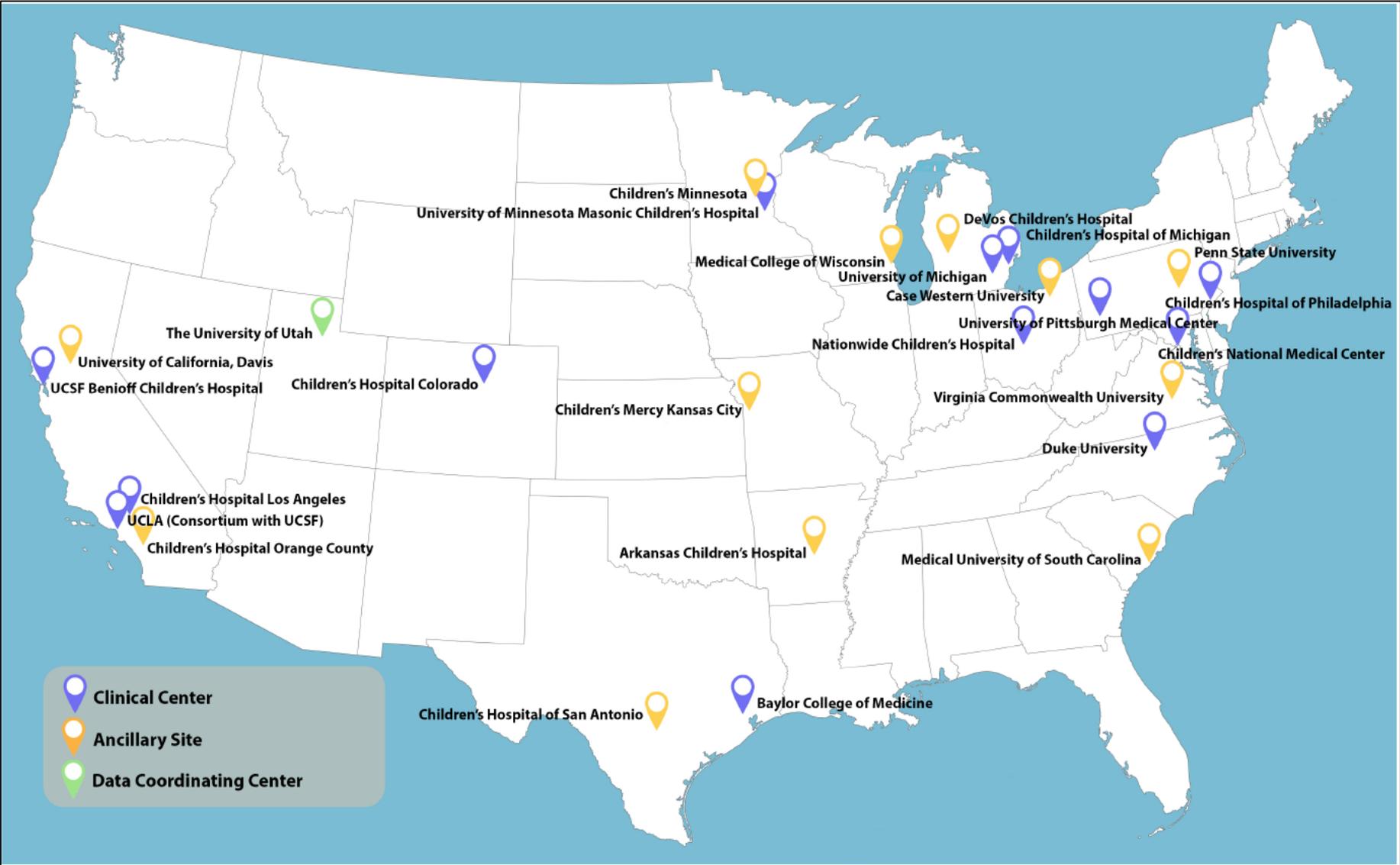
Therapeutic Alliance in the Pediatric  
Intensive Care Unit: A Study of Bereaved  
Parent's Mental Health

# Introduction

- ▶ The *Collaborative Pediatric Critical Care Research Network (CPCCRN)* is a multicenter program devoted to the investigation of the safety and efficacy of treatment management strategies used for the care of critically ill and injured children.
- ▶ Network Goals
  - Develop an infrastructure to pursue well-designed collaborative clinical trials and meaningful descriptive studies in pediatric critical care medicine
  - Provide a framework for the development of the scientific basis of pediatric critical care practice
  - Reduce morbidity and mortality in pediatric critical care illness and injury



# CPCCRN Sites: CPCCRN IV

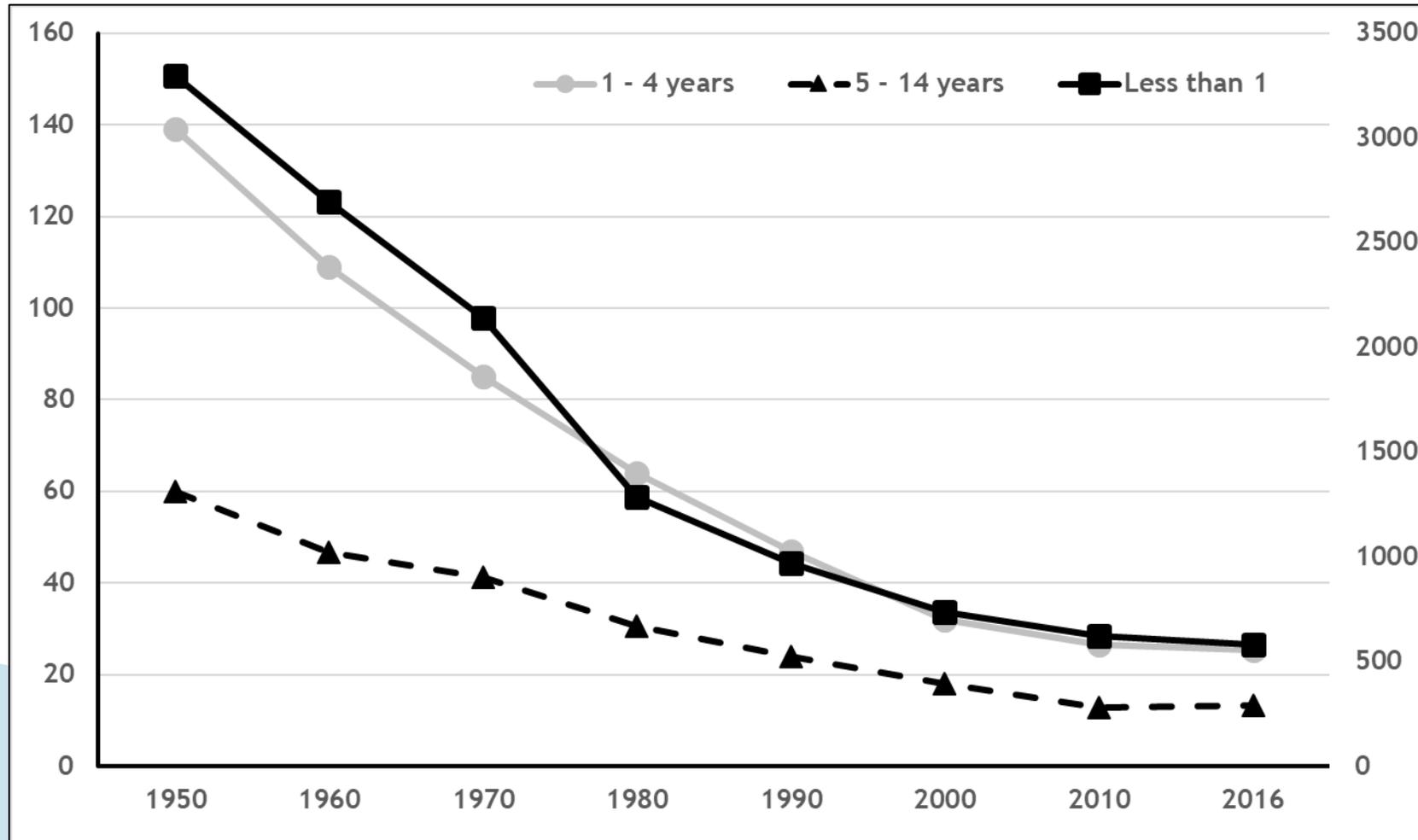


# Mentorship

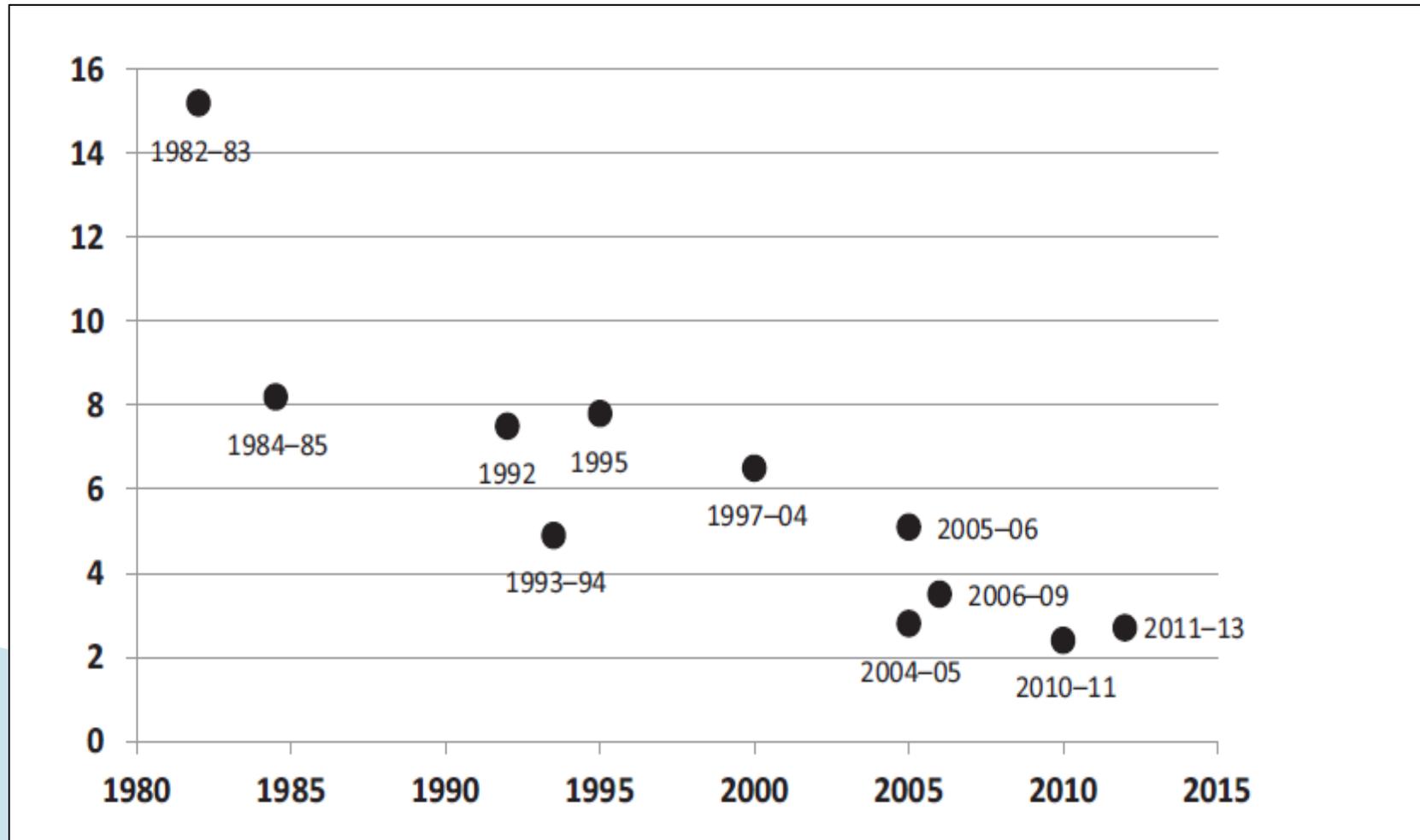
- ▶ Fellowship work in end-of-life (EOL) care in the pediatric intensive care unit (PICU).
- ▶ CPCCRN's history of EOL work
  - Parental needs and coping
  - Physician communication
  - Complicated grief
  - A framework for follow-up with families
- ▶ Project on the impact of *therapeutic alliance* on bereavement
- ▶ CPCCRN opted to support our project utilizing network infrastructure
  - Commitment to the development of future scientists
  - Promotion of diversity in the research workforce



# Epidemiology of Pediatric Death in the U.S.



# Mortality Rates for PICU Admissions Over Time



# Parental Bereavement

- ▶ Devastating for parents
  - Disruption of the natural order of life
  - Feelings of failure
  - Losses: personal identity, parental role, family structure
- ▶ Grief after the loss of a child is intense and prolonged
  - Child loss >> Spouse, parent, or other loss
- ▶ Many parents whose children die in PICUs exhibit signs and symptoms of prolonged (complicated) grief
  - At least 60% of parents at 6 months after a child's death
  - Persists in 40% of parents at 18 months after a child's death



# Prolonged (Complicated) Grief

## Separation distress

yearning and longing for the deceased

## Cognitive, emotional, and behavioral symptoms

diminished sense of self

sense of disbelief

avoiding reminders of the deceased

bitterness or anger

difficulty moving on

numbness

feeling that life is meaningless

intense loneliness

## Impairment in social, occupational, other functioning

>12 months elapsed since the death

# Health Outcomes for Bereaved Parents

- ▶ General decrease in physical health
  - Decline in self-reported health
  - Increase in physician visits, sick days, sleep problems
- ▶ Risks for specific illnesses inconsistent
  - Cardiovascular disease
  - Cancer
  - Immunologic disorders



# Health Outcomes for Bereaved Parents

- ▶ General decrease in mental health
  - Increased physician visits for mental health complaints
  - Higher rate of psychiatric hospitalizations
- ▶ Specific symptoms and conditions
  - Anxiety
  - Depression
  - PTSD



# Health Outcomes for Bereaved Parents

- ▶ Increased mortality risk among bereaved parents
  - Mothers > Fathers
  - Minor child > Adult child
  - Unnatural cause of child death > Natural cause
- ▶ Mortality risk changes with time since death
- ▶ Could PICU physicians play a role in bereaved parents' adjustment to the loss of their child?



# Therapeutic Alliance

- ▶ A multifaceted construct reflecting the strength and quality of the relationship between a patient/family and their physician.
- ▶ Positive effects on health outcomes for adults and children.
- ▶ *The Human Connection Scale (HCS)*
  - 16-item measure
  - Adapted from adult oncology
  - Domains:
    - Physician understanding of parent concerns
    - Mutual caring and respect
    - Parent understanding of information
    - Parent trust in physician(s)
    - Collaboration

## Measuring Therapeutic Alliance Between Oncologists and Patients With Advanced Cancer

The Human Connection Scale

Jennifer W. Mack, MD, MPH<sup>1,2,3</sup>; Susan D. Block, MD<sup>4</sup>; Matthew Nilsson, BS<sup>4</sup>; Alexi Wright, MD<sup>4,5</sup>;  
Elizabeth Trice, MD, PhD<sup>4,5</sup>; Robert Friedlander, MD<sup>6</sup>; Elizabeth Paulk, MD<sup>7</sup>; and  
Holly G. Prigerson, PhD<sup>4</sup>



# Parent-Provider Alliance Study

- ▶ Describe the therapeutic alliance that exists between bereaved parents and pediatric intensivists, and the extent to which this alliance is associated with parental health outcomes.
- ▶ Describe the frequency and intensity of adverse mental health symptoms among parents at 6 and 13 months after their child's death in a PICU.
- ▶ Identify additional factors associated with parents' mental health symptoms at 6 and 13 months after a child's death in the PICU.



# Parent-Provider Alliance Study

- ▶ Design and setting
  - Longitudinal multicenter survey conducted across 8 sites
- ▶ Participants
  - Biological parent or legal guardian
  - Child died in PICU
  - English or Spanish speaking
  - Age  $\geq 18$  years
- ▶ Data Collection
  - Surveys mailed at 6 and 13 months after child's death
  - Option of completing surveys by telephone



# Outcome Measures

- ▶ Inventory of Complicated Grief (ICG)
  - 19-item measure, frequency of grief symptoms
- ▶ Patient Health Questionnaire Version 8 (PHQ-8)
  - 8 item measure, frequency of depression symptoms
- ▶ Short Post-traumatic Stress Disorder Rating Interview (SPRINT)
  - 8 item measure, frequency of post-traumatic stress symptoms

# Independent variables (Parents)

## ▶ Sociodemographics

- Gender
- Age
- Race/ethnicity
- Marital status
- Education
- Relationship to deceased child
- Number of surviving children

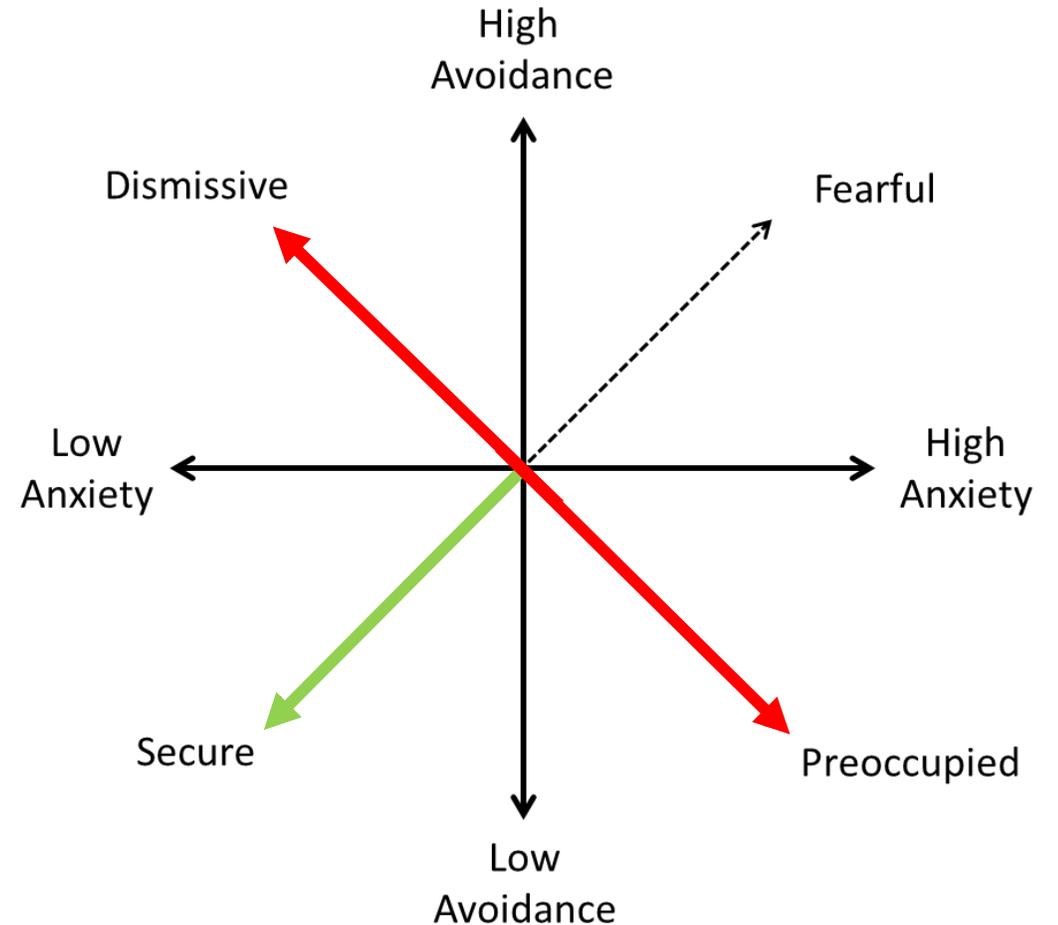
## ▶ Therapeutic alliance

## ▶ Attachment style (Revised Adult Attachment Scale)



# Attachment

- ▶ How one thinks, feels, and behaves in close relationships
- ▶ High attachment anxiety
  - negative self image
  - worries about others' availability
- ▶ High attachment avoidance
  - views others negatively
  - no reliance on others
- ▶ Insecure attachment styles are a known risk factor for complicated grief in bereaved parents.

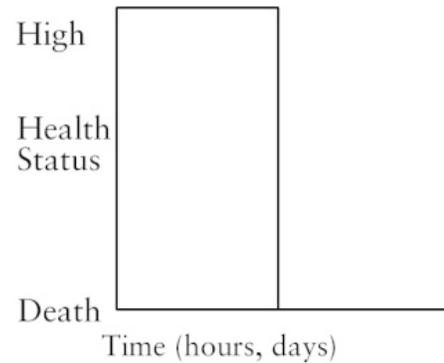


# Independent variables (Child)

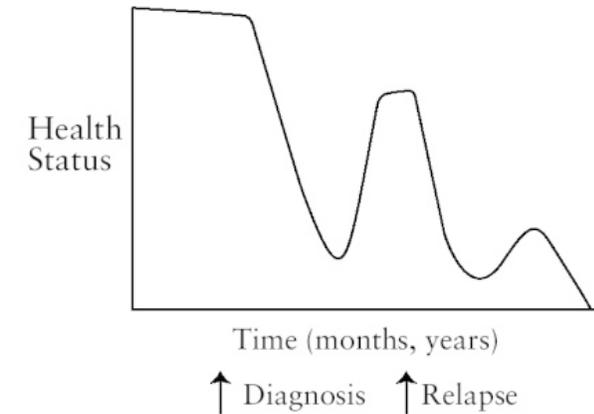
## ► Child characteristics

- Age, gender
- Cause of death
- Mode of death
  - Limitation/withdrawal
  - Brain death
  - Failed CPR
- PICU length of stay
- Trajectory of death

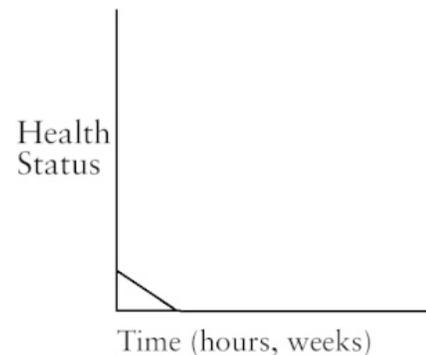
a. Sudden, unexpected death



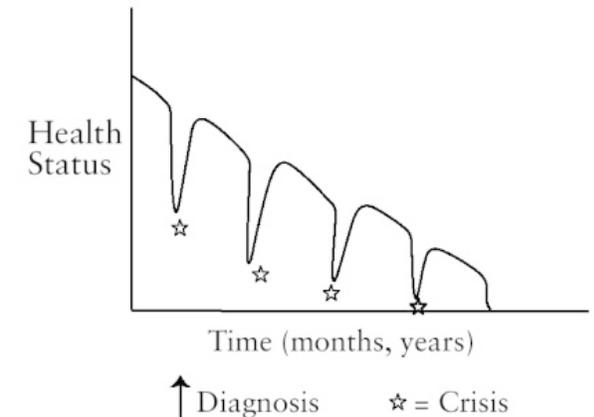
b. Death from potentially curable disease (e.g., brain cancer)



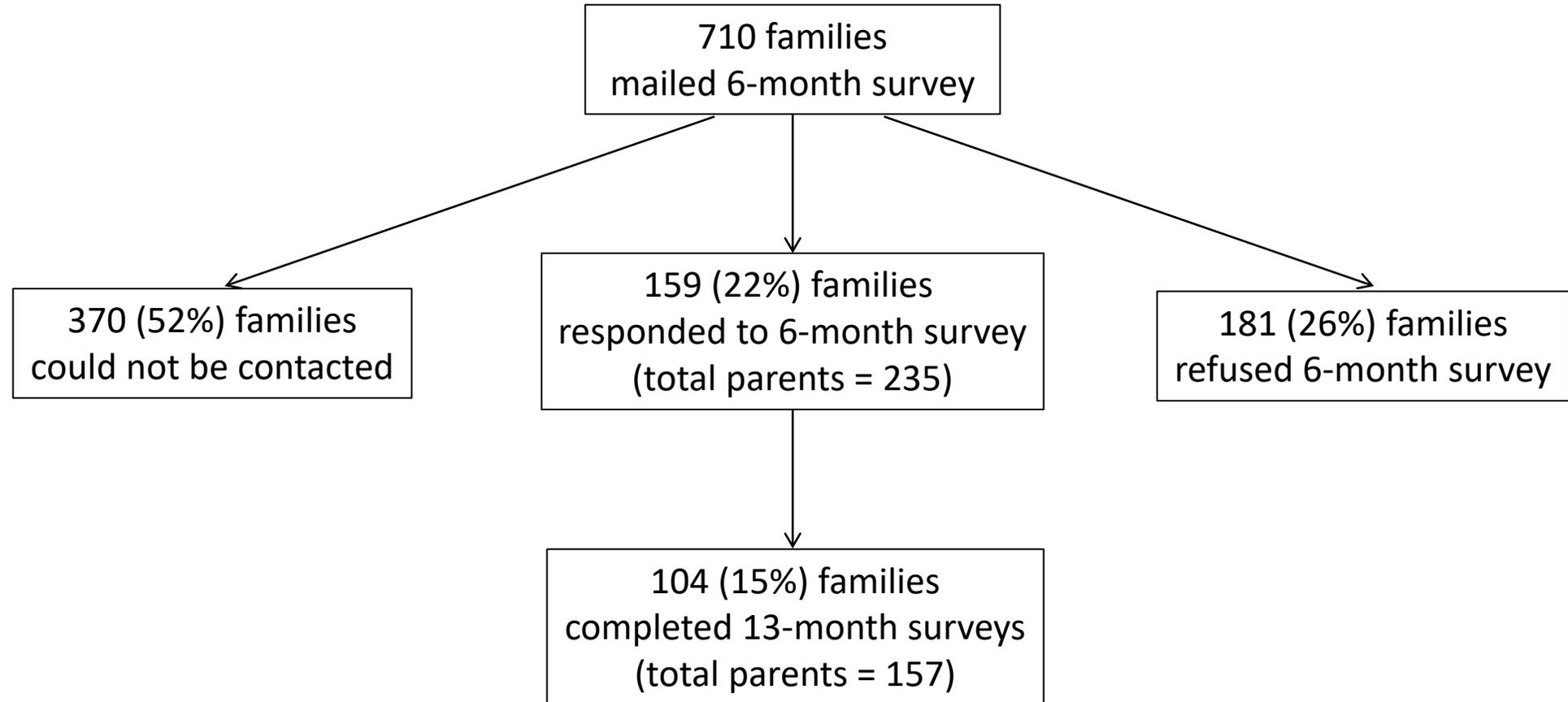
c. Death from lethal congenital anomaly



d. Death from progressive condition with intermittent crises (e.g., muscular dystrophy)



# Recruitment



# Parent Characteristics

		Responded to 13-month survey		
	Overall (n=235)	Yes (n=157)	No (n=78)	P=value
Female parent	147 (62.6%)	98 (62.4%)	49 (62.8%)	1.00
Race				0.098
Black	46 (19.6%)	25 (15.9%)	21 (26.9%)	
White	157 (66.8%)	111 (70.7%)	46 (59.0%)	
Other	27 (11.5%)	19 (12.1%)	8 (10.3%)	
Ethnicity				0.079
Hispanic	36 (15.3%)	21 (13.4%)	15 (19.2%)	
Non-Hispanic	193 (82.1 %)	134 (85.4%)	59 (75.6%)	
Parent Education				0.066
Less than high school grad	22 (9.4%)	17 (10.8%)	5 (6.4%)	
High school or GED	62 (26.4%)	34 (21.7%)	28 (35.9%)	
Vocational school of some college	64 (27.2%)	42 (26.8%)	22 (28.2%)	
College degree of higher	85 (36.2%)	64 (40.8%)	21 (26.9%)	
Married	177 (75.3%)	129 (82.2%)	48 (61.5%)	<0.001
Has additional children	192 (82%)	131 (83%)	16 (20.5%)	0.178

# Child Characteristics

		Responded to 13-month survey		
	Overall (n=158)	Yes (n=104)	No (n=54)	P=
Male	87 (55.1%)	58 (55.8%)	29 (53.7%)	0.867
Age (years)	7.9 (7.77)	8.3 (8.19)	7.1 (6.91)	0.347
Cause of Death				0.310
Cardiac	40 (25.3%)	26 (25.0%)	14 (25.9%)	
Respiratory	25 (15.8%)	16 (15.4%)	9 (16.7%)	
Malignancy	13 (8.2%)	9 (8.7%)	4 (7.4%)	
Sepsis	30 (19.0%)	24 (23.1%)	6 (11.1%)	
Neurologic	25 (15.8%)	16 (15.4%)	9 (16.7%)	
Trauma	20 (12.7%)	9 (8.7%)	11 (20.4%)	
Other	5 (3.2%)	4 (3.8%)	1 (1.9%)	
Trajectory of death				0.061
Sudden, unexpected	49 (31.0%)	26 (25.0%)	23 (42.6%)	
Lethal congenital anomaly	29 (18.4%)	24 (23.1%)	5 (9.3%)	
Potentially curable disease	36 (22.8%)	25 (24.0%)	11 (20.4%)	
Progressive, intermittent crisis	44 (27.8%)	29 (27.9%)	15 (27.8%)	
Mode of death				0.061
Limitation/withdrawal	114 (72.2%)	81 (77.9%)	33 (61.1%)	
Brain death	25 (15.8%)	12 (11.5%)	13 (24.1%)	
Failed CPR	19 (12.0%)	11 (10.6%)	8 (14.8%)	
PICU length of stay (days)	22.2 (38.9)	23.1 (38.37)	20.5 (40.30)	0.702

# Results

- ▶ The extent of therapeutic alliance reported by bereaved parents ( $51.4 \pm 11.1$ ) was moderately high.
- ▶ The mean HCS score for Black parents was  $47.0 \pm 13.7$  and  $52.6 \pm 9.0$  for White parents.
- ▶ In multivariable modeling predicting HCS scores, race was the only parent or child characteristic in the final model.

Therapeutic Alliance Final Model			
Characteristic	Estimate (95% CI)	P-value	Model P-value
Parent race			0.0617
White/Caucasian	Reference		
Black/African American	-4.56 (-8.53, -0.60)	<b>0.025</b>	
Other	0.25 (-3.73, 4.22)	0.90	

# HCS Comparison by Parent Race

The Human Connection Scale Item		
	Black (N = 38)	White (N = 150)
How much did you trust your child's doctor(s) in the ICU?	2.9 (1.13)	3.5 (0.74)
How much did you feel your child's doctor(s) cared about your child in the ICU?	3.0 (0.97)	3.6 (0.72)
How much of the time would you say your doctor(s) was honest with you in the ICU?	2.9 (1.02)	3.5 (0.75)
<i>1=Not at all, 2=Somewhat, 3=Quite a bit, 4=A great deal</i>		

- ▶ Medical mistrust and poor communication are known factors in racial differences in parental decision-making at EOL.
- ▶ Black patients and parents report medical mistrust, poor communication, and perceived discrimination as barriers to care.
- ▶ Partnership building communication styles, patient-centered and empathetic approaches, and multicultural competence → stronger alliances.

## Mental Health Outcomes at 6 and 13 Months

	6 Month n (%)	13 Month n (%)	P-value
Complicated Grief (ICG score $\geq 30$ )	86 (57.7%)	<b>78 (52.3%)</b>	0.269
Depression (PHQ-8 score $\geq 10$ )	66 (44.0%)	<b>49 (32.7%)</b>	0.025
Post-traumatic Stress (SPRINT score $\geq 14$ )	77 (52.0%)	<b>65 (43.9%)</b>	0.110

# Predictors of 6-month Mental Health Outcomes

Complicated Grief Symptoms		Depression Symptoms		PTSD Symptoms	
Attachment-related anxiety	↑	Attachment-related anxiety	↑	Attachment-related anxiety	↑
Attachment-related avoidance	↑	Attachment-related avoidance	↑	Attachment-related avoidance	↑
Therapeutic alliance	↓	Therapeutic alliance			
		Parent gender (female)	↑	Parent gender (female)	↑
Parent age					
		Parent Ethnicity (non-Hispanic)			
		Child age (older)	↑		
PICU length of stay (longer)	↓				
				Sudden unexpected death	↑

# Predictors of 13-month Mental Health Outcomes

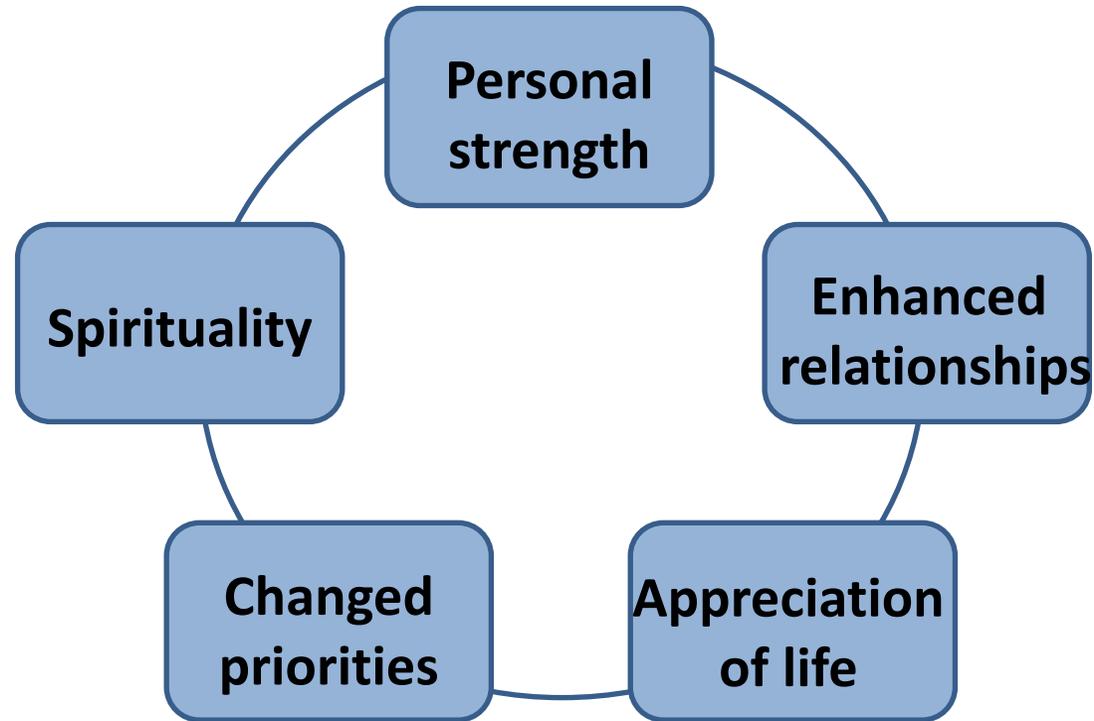
Complicated Grief Symptoms		Depression Symptoms		PTSD Symptoms	
6-month ICG score	↑	6-month PHQ-8 score	↑	6-month SPRINT score	↑
Sudden unexpected death	↑	Sudden unexpected death	↑		
		Black race	↑		
		Attachment-related anxiety	↑		
				Parent education (<HS)	↓

# Conclusions about Mental Health Symptoms

- ▶ Parents whose children die in PICUs experience high levels of adverse mental health symptoms.
- ▶ Symptoms improve during the first 13 months, but high symptom levels persist for many parents.
- ▶ Greater therapeutic alliance with PICU physicians is a potential opportunity to improve parents' mental health, at least early in bereavement.
- ▶ Risk factors for poor mental health include insecure attachment, being a mother, Black parental race, having an older child die, short PICU stays, and sudden unexpected child death.

# Post-traumatic Growth (PTG)

- ▶ Positive change that occurs as a result of one's struggle with highly challenging life crises.



## PTG after a Child's Death in the PICU

- ▶ Describe the extent of post-traumatic growth among bereaved parents at 6 and 13 months after their child's death in a PICU.
- ▶ Identify factors associated with post-traumatic growth at 13 months.



## Post-traumatic Growth at 6 and 13 months

	6-month	13-month	Change	P-value
<b>PTG total score</b>				
Mean (SD)	27.5 (12.52)	28.6 (11.52)	0.1 (0.99)	0.1810
<b>PTG domain scores</b>				
Relating to others	5.7 (3.03)	5.7 (2.92)	-0.1 (2.68)	0.8110
New possibilities	4.4 (3.13)	4.9 (3.00)	0.4 (3.16)	0.1161
Personal strength	6.2 (3.23)	6.4 (3.14)	0.1 (2.72)	0.5490
Spiritual change	4.6 (3.87)	5.0 (3.83)	0.3 (2.73)	0.1737
Appreciation for life	6.4 (2.73)	6.7 (2.33)	0.3 (2.60)	0.1872

## Relationship between Mental Health Scores and PTG in Bereaved Parents

	Effect (95% CI)	P-value
6-month ICG (Complicated Grief)	-0.16 (-0.28, -0.03)	0.017
6-month PHQ-8 (Depression)	-0.48 (-0.77, -0.2)	0.001
6-month SPRINT (PTSD)	-0.26 (-0.49, -0.04)	0.023

## Predictors of PTG at 13-months

	Effect (95% CI)	P-Value
<b>Parent education</b>		0.005
Some high school or less	Reference	
High school graduate	-4.31 (-11.1, 2.48)	
Vocational school or some college	-9.36(-15.99, -2.73)	
College degree or higher	-9.95 (-16.21, -3.69)	
6-month ICG score	-0.14 (-0.27, -0.01)	0.033
PICU length of stay	0.05 (0, 0.09)	0.057

# Conclusions about Post-traumatic Growth

- ▶ Parents perceive a moderate degree of PTG in the first 13 months after their child's death in a PICU.
- ▶ Adverse mental health symptoms may hinder PTG, especially complicated grief.
- ▶ For reasons that remain unclear, parents with higher levels of education may have difficulty achieving PTG.

# What are the next steps?

- ▶ Deeper exploration into the racial differences in physician alliances with families, as well as risks for mental health outcomes.
- ▶ Multicenter studies aimed at bereavement interventions
  - enhanced mental health screening
  - follow-up meetings
  - hospital based/organized support groups
  - psychology led crisis teams



# THANK YOU



Artist: Celeste Roberge  
*A Parent's Grief*

