

# Journals: A Promising Family- Centered Intervention in the PICU

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# Objectives

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## **Goal 1**

Understand what post-intensive care syndrome is, and why it is important.

## **Goal 2**

Understand possible stressors families experience due to admission to the PICU.

## **Goal 3**

Recognize the need for stress-reducing interventions to mitigate negative long-term outcomes of children and families admitted to the PICU.

# Background

## *Literature Review*



Admission to the PICU has long been recognized as a stressful experience for the patient and family.

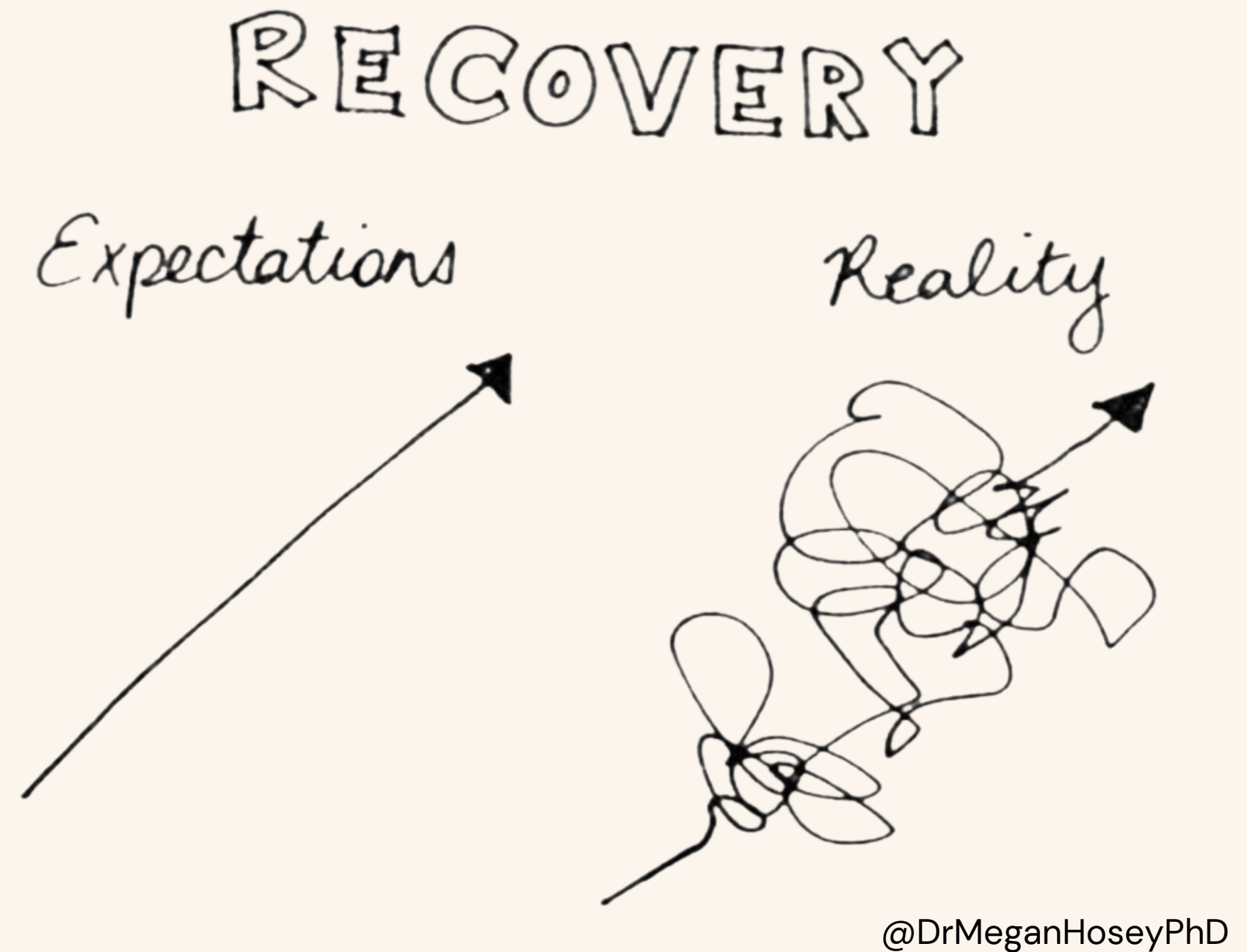


Mortality rates have decreased, and the focus has shifted to emotional and behavioral morbidities post-PICU.

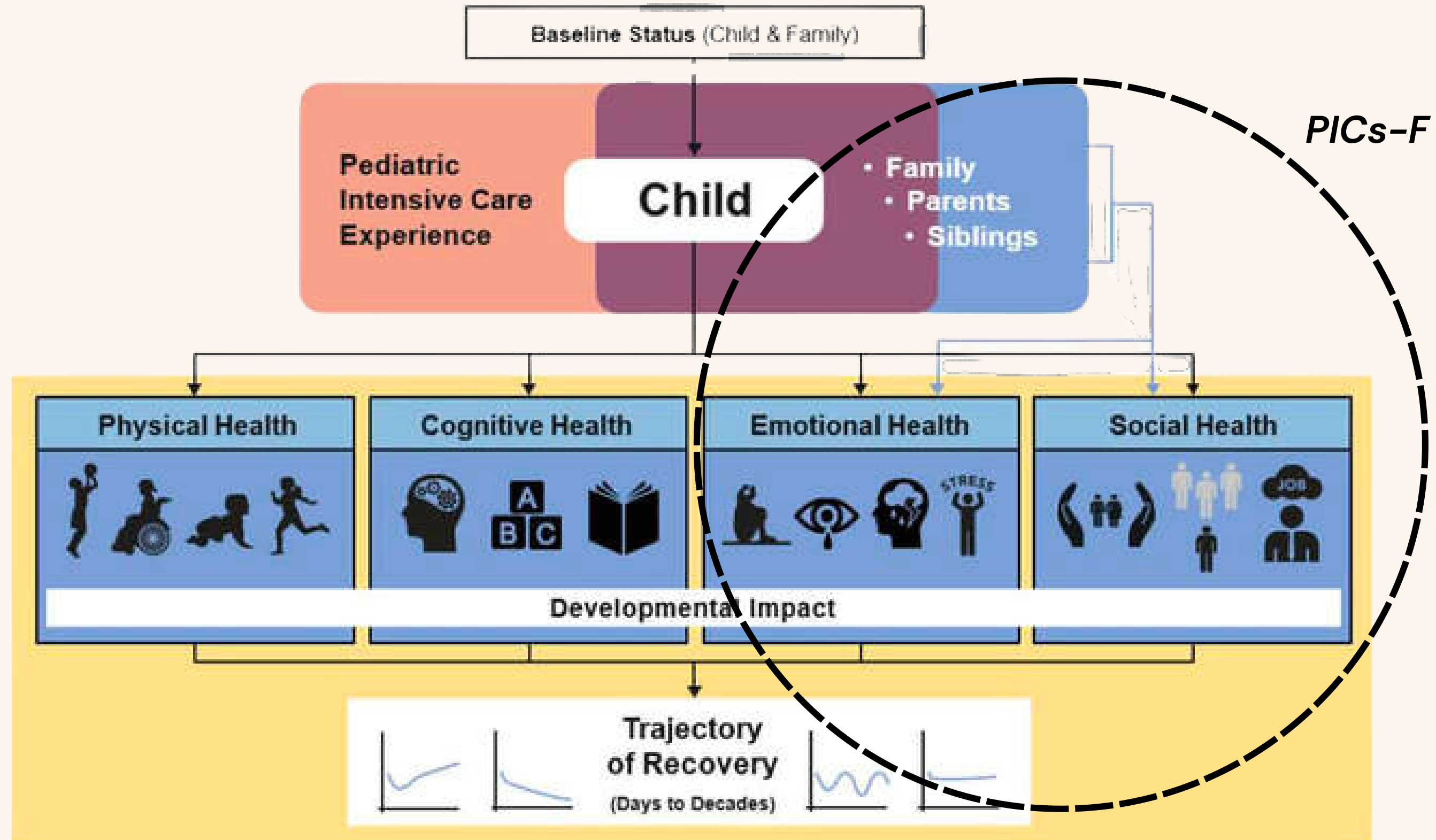
# Post-Intensive Care Syndrome (PICs)

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- A broader focus on survivor **outcomes**
- First examined in adult ICU survivors
- Today, evidence suggests that children and families may experience new impairments across **physical, cognitive, emotional, and social** domains after discharge



# PICs-P Framework



# Why Should We Care About PICs-F?

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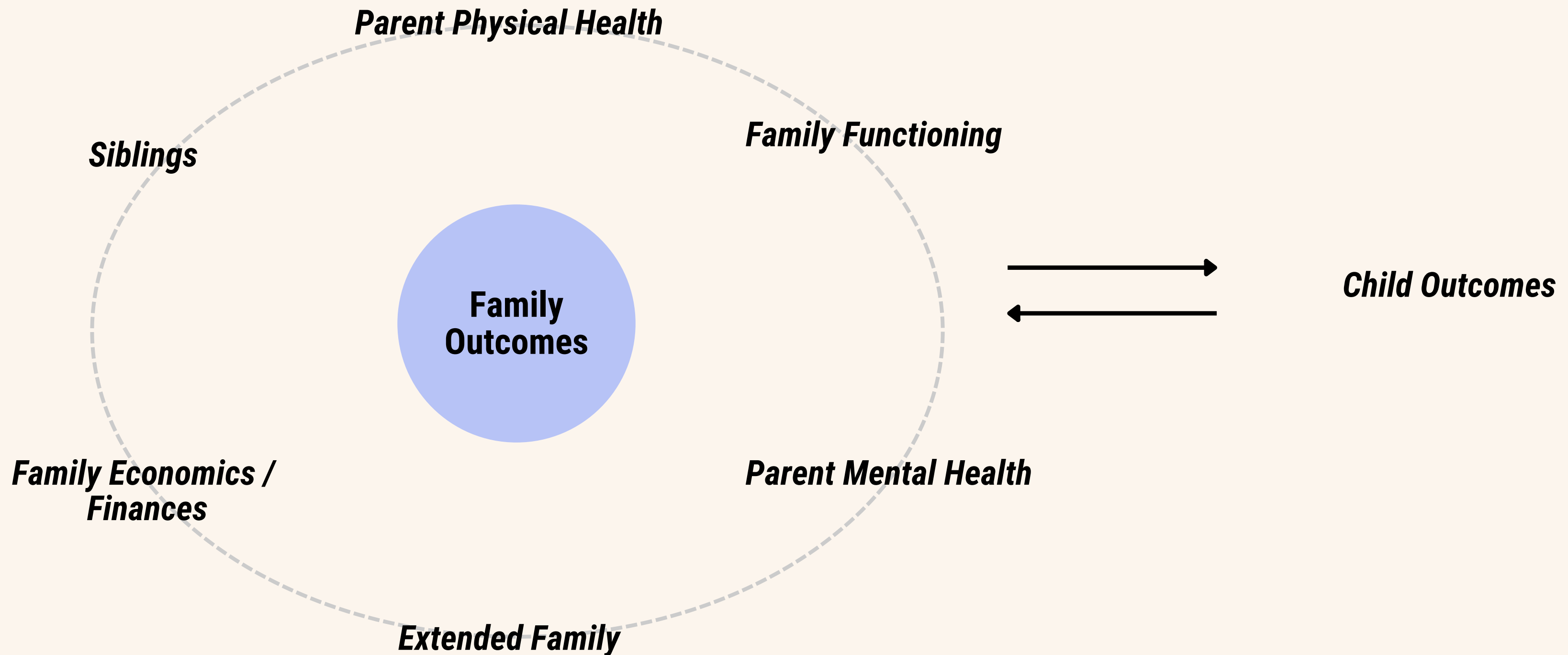
- Begins with a perceived or actual threat to the life of a family's loved one who is hospitalized in a critical care unit.
- Symptoms include
  - Anxiety
  - Acute Stress Disorder (ASD)
  - Post-traumatic stress disorder (PTSD)
  - Depression
  - Complicated Grief



# Why Should We Care About PICs-F?

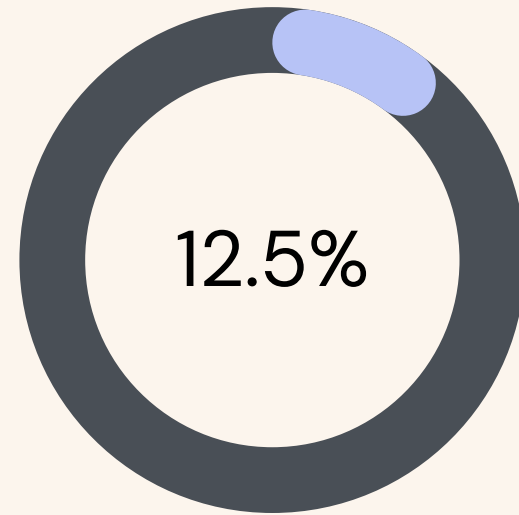
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Integrated Family Functioning Framework After a Child's PICU Admission

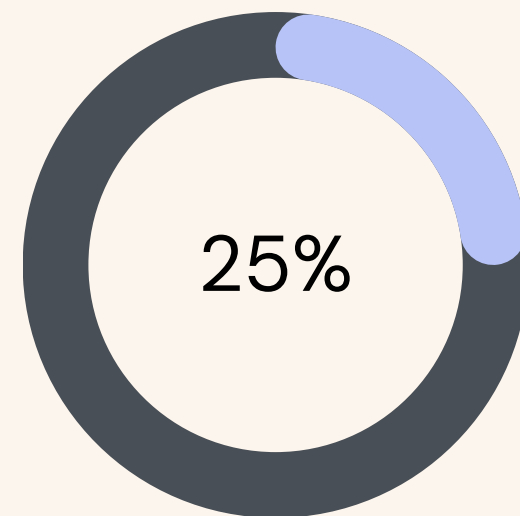


# PICs-F Outcomes

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12.5% of parents meet criteria for PTSD  
at **18 – 30 months post-discharge**

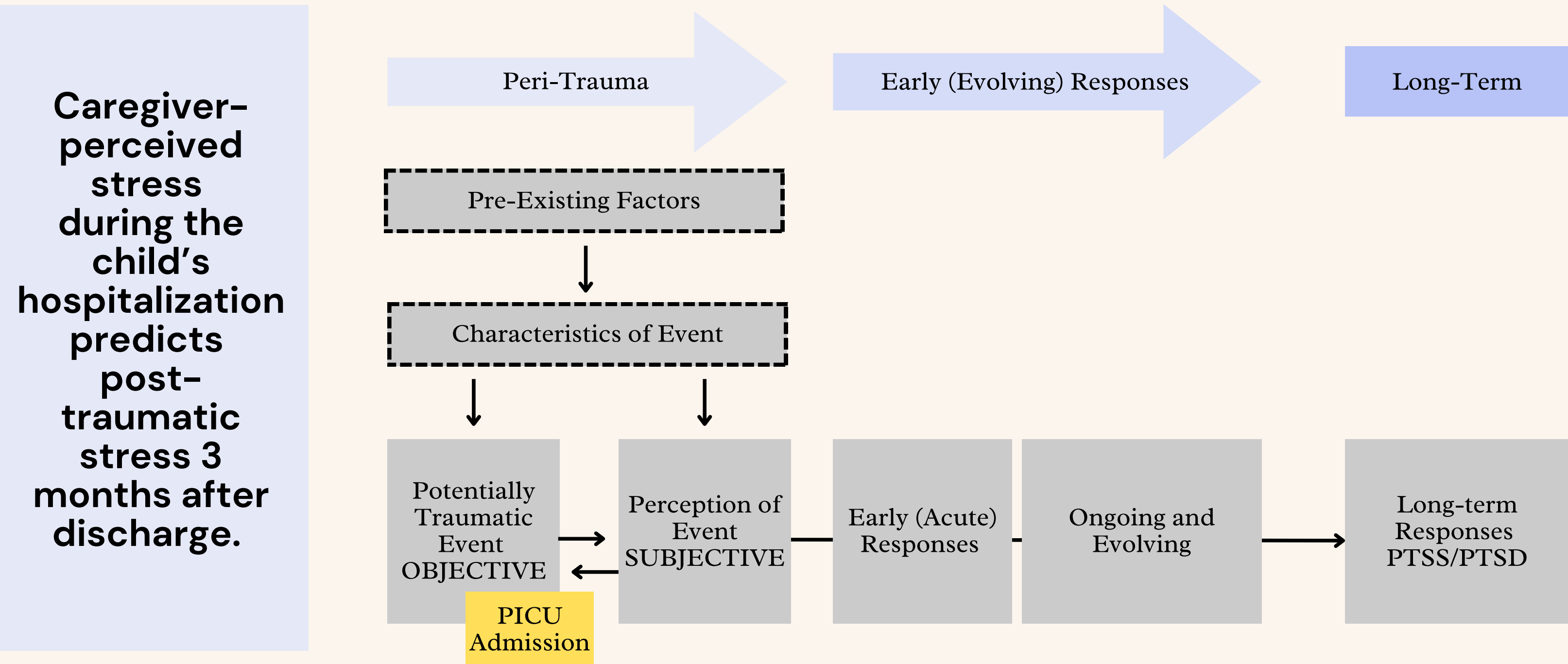


25% of parents experience persistent traumatic stress  
reactions that **impair daily functioning, affect treatment  
adherence, and can impede optimal recovery**



# PICS-F Outcomes

Model of Pediatric Medical Traumatic Stress



# Parent Quotes

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"I didn't expect to have to be a full-time parent and responsible for my child's care. I was used to having somebody constantly by my side and suddenly I was alone" (Dahav & Sjöström-Strand, 2017)

# Parent Quotes

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"Sometimes at night... I start crying and screaming [at my husband] for nothing. I said "What happened? Why just me? I saw everything" ...Sometimes I feel I'm still there. Whenever I'm not happy, I go back... I'm suffering again and I start to scream"" (Rennick et al., 2021).

# Parent Quotes

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“Every time I hear her cough, I'm like, ‘What is that? Why are you coughing?’ She's like ‘It's just a cough.’ No, [for me] there's no such thing” (Rennick et al., 2021).

# Thus...

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As we learn more about PICS and the long-term impacts of hospitalization in the PICU **identifying and implementing** stress-reducing interventions is increasingly important.

# Parent Reported Stressors

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## Initial Stressors

- Survivorship / fear of death
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- PICU environment
    - Sights, sounds, witnessing procedures
  - Feeling of inadequacy / helpless
  - Unclear communication

## Ongoing Stressors

- Thinking about the child's future
- Inability to engage in self-care
- Struggles with changing identify
- Strain on existing relationships (partners, other children, family, friends)

## Post-Discharge Stressors

- Managing the child's new physical and emotional health needs
- Managing relationships
- Establishing a new normal
- Increasing anxiety and worry
- Suppressing triggering flashbacks, thoughts, and places

# Parent - Reported Protective Factors

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- Being involved in the child's care
- Understanding procedures and the child's behavior/appearance
- Trust and respect from the care team
- Open and honest conversation
- Making meaning of the experience
- Hospital environment that provides physical and social support to maintain humanity in healthcare
- Being prepared for transitions

# Exploring the Benefits of Journaling

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## ICU Research

- Since the 1980s, the act of personally writing about a traumatic event has been used effectively to decrease traumatic stress symptoms and improve numerous health outcomes in participants
- Helps reinforce real memories
- Research shows significantly less PICS among ICU patients who keep journals

## PICU Specific Research

- A thematic analysis revealed that caregivers wrote about 1) social and spiritual support, 2) emotions, feelings, and distress, and 3) PICU life
- Families identified 3 main themes, 1) value to the entire family, 2), creating memories, 3) importance of pictures
- Importance of PICU staff comments, room for photos and mementos, and recording activities that happened in the PICU.



# Blending It Together

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## Important Considerations

- Context
- Identified Stressors
- PICS-P & PICS-F
- PMTS
- Family feedback
- Feasibility

## Keys

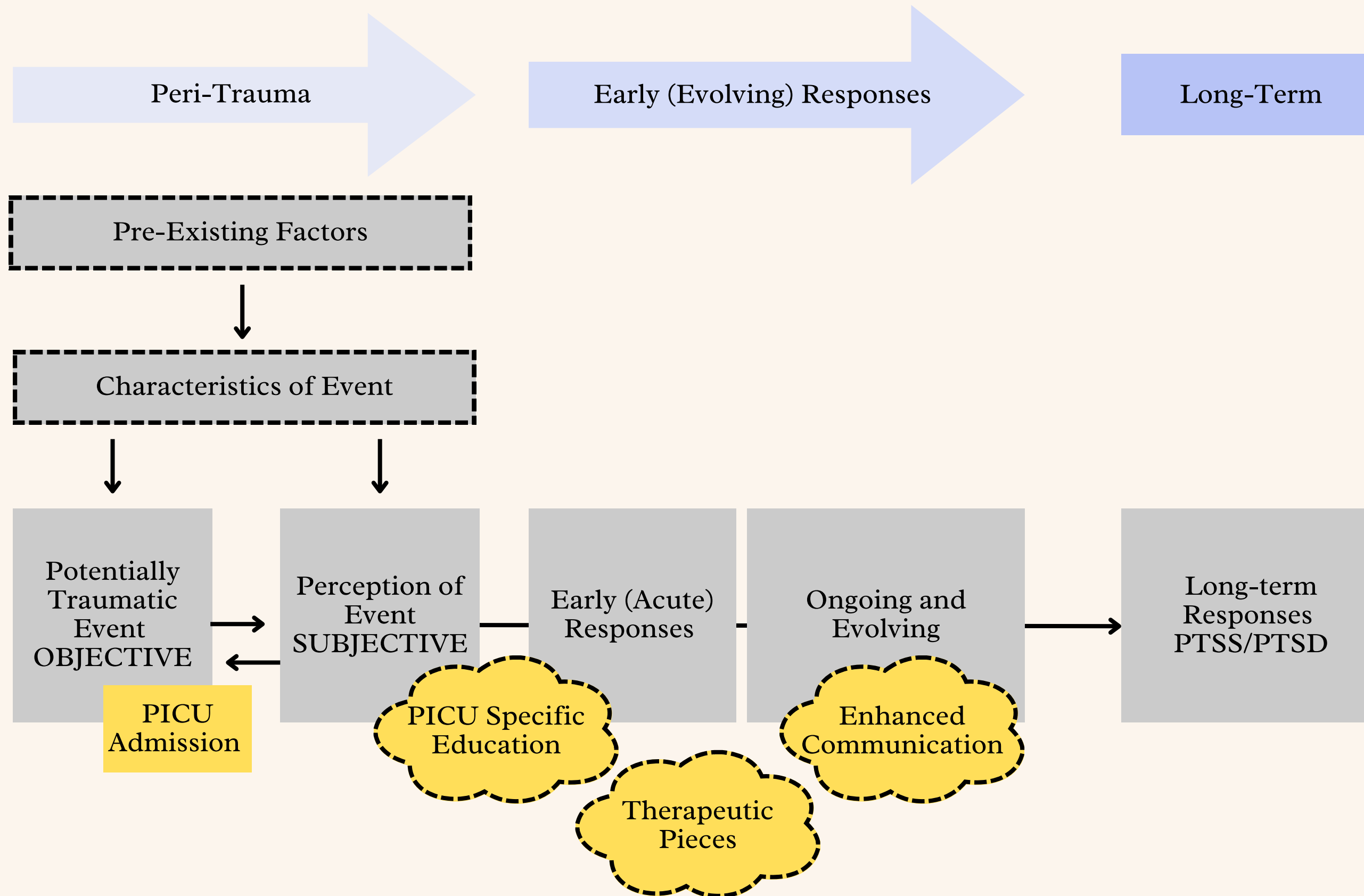
- Individualized
- Balanced
- Family-Driven
- Transferrable
- Legacy Building

## Main Buckets Identified

- Incorporating PICU-specific education
- Enhancing communication and advocacy
- Incorporating therapeutic/coping pieces, while fostering a connection with child/staff

# Mapping on to PMTS

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# Semi - Structured Journal

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## Process

- Literature Reviews
- Prototype  
Development
- Gathering Feedback &  
Editing
- IRB Submission
- Grant Submission

## Design

- Binder Style
  - Chronological order
  - Customizable
- 25 "Core Pages"
  - Families can add/remove pages that make sense for them

# Journal Content

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## **PICU Specific Resources**

- What to Expect in PICU
- Members of the Care Team
- Places in the Hospital

## **Enhanced Communication**

- Helpful Questions to Ask
- People on My Team
- Life After the PICU

## **Therapeutic Pieces**

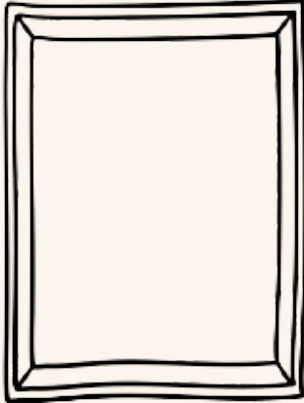
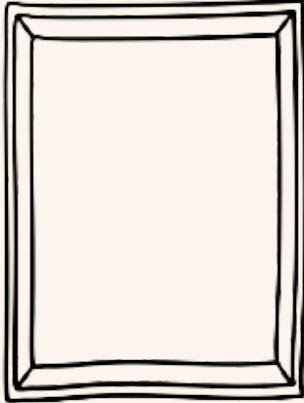
- Caring For Yourself
- Ways to Care for Your Child
- Daily entries

# Overall Goals of the Journal Intervention

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- Reinforce the authenticity of parental presence and their role during hospitalization
- Enhance communication between caregivers and the care team and foster a space where caregivers feel equipped to advocate for themselves and their child

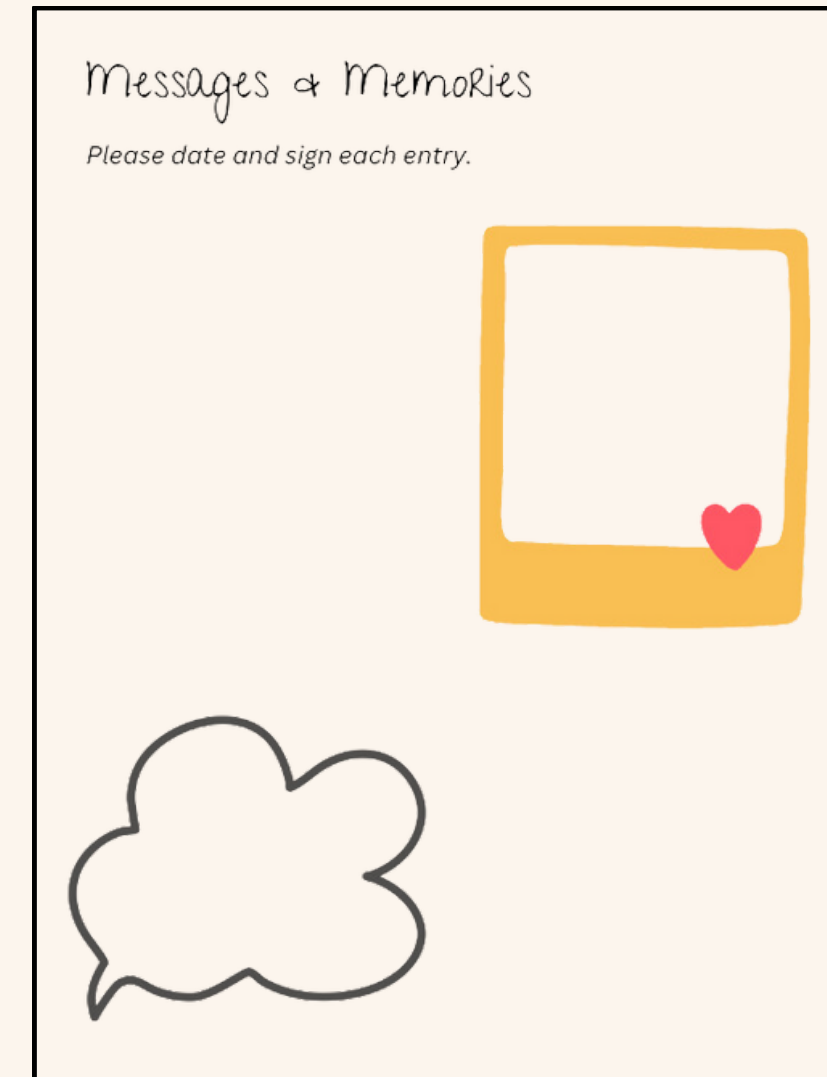
People ON my Team  
*Ask those on your care team to fill this out.*

	My name is: I help by...
	My name is: I help by...

# Overall Goals of the Journal Intervention

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- Provide a platform for parent and child to develop a shared narrative of the experience post-discharge
- Mitigate impacts of traumatic experiences and symptoms of PICS-F to support parents and children for whom future contact with the healthcare system is likely



# What We Hope to Learn: Pilot Study

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- How does participation in a semi-structured journaling intervention relate to perceived stress, satisfaction, connectedness, and the development of PICS in parents/caregivers of children hospitalized in the PICU?
- How do pediatric patients, their parents/caregivers, and PICU staff perceive the feasibility, utility, and impact of the journaling intervention?

# What We Hope to Learn: Pilot Study

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T1: 24h - 72hr	T2: Peri-Discharge	T3: 3- months post discharge	T4: At completion
Demographics Parent & Child	Parent Use / Satisfaction Survey	At Home Parent Use / Satisfaction Survey	Provider Satisfaction Survey
A: PSS:PICU	A: PSS: PICU	CRIES-8 / IES- R	-
CHE-s	CHE's	-	-
-	HADS	HADS	-
-	-	Semi-Structured Interviews*	-



# Translating it into Practice

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Create a journaling supply station

Create an activity collage for the family

Help parents identify / create a meaningful project

Prepare for transitions to acute units & home

Educate about and normalize PICS

# Key Takeaways

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Hospitalization in the PICU can lead to new impairments across physical, cognitive, emotional, and social domains (PICS) in children and families

Prior research demonstrates that medical trauma is more closely related to an individual's subjective experience than the objective medical severity of the illness

There are actionable ways staff can work to reduce perceived stress. The use of PICU journals has been shown to be feasible and well-received by families in the PICU

# Resources

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## Websites

- [Post Intensive Care Syndrome \(PICS\) in Pediatric Patients](#)
- [After PICU](#)
- [Society of Critical Care Medicine](#)

## Videos

- [THRIVE: Pediatric Post-Intensive Care Syndrome and the Family](#)
- [THRIVE: Redefining Recovery](#)

## Podcast (Adult ICU): Walking Home From the ICU

- The Power of ICU Diaries to Treat Post-ICU PTSD (Episode 132)
- Post-ICU PTSD: Fact vs. Fallacy (Episode 51)
- The Reality of Post-ICU PTSD (Episode 50)

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# Thank you!

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