

# Nurture – Empower – Support

## A Human-Centered Approach to Understand and Support ICU Families

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# Watching a loved one fight a critical illness can be terrifying!

- Family members often struggle with making decisions.
- The complex ICU environment can be very overwhelming.
- They often experience anxiety, depression and PTSD.



*W. G. Anderson, R. M. Arnold, D. C. Angus, and C. L. Bryce. Posttraumatic stress and complicated grief in family members of patients in the intensive care unit. J. Gen. Intern. Med., 23(11):1871–1876, 2008.*

# Family members can profoundly affect patient outcomes

- They provide emotional support.
- They are responsible for making medical decisions.
- They are a vital source of information for the care team.



*C. M. Williams. The identification of family members' contribution to patients' care in the intensive care unit: a naturalistic inquiry. Nursing in critical care, 10(1):6-14, 2005.*

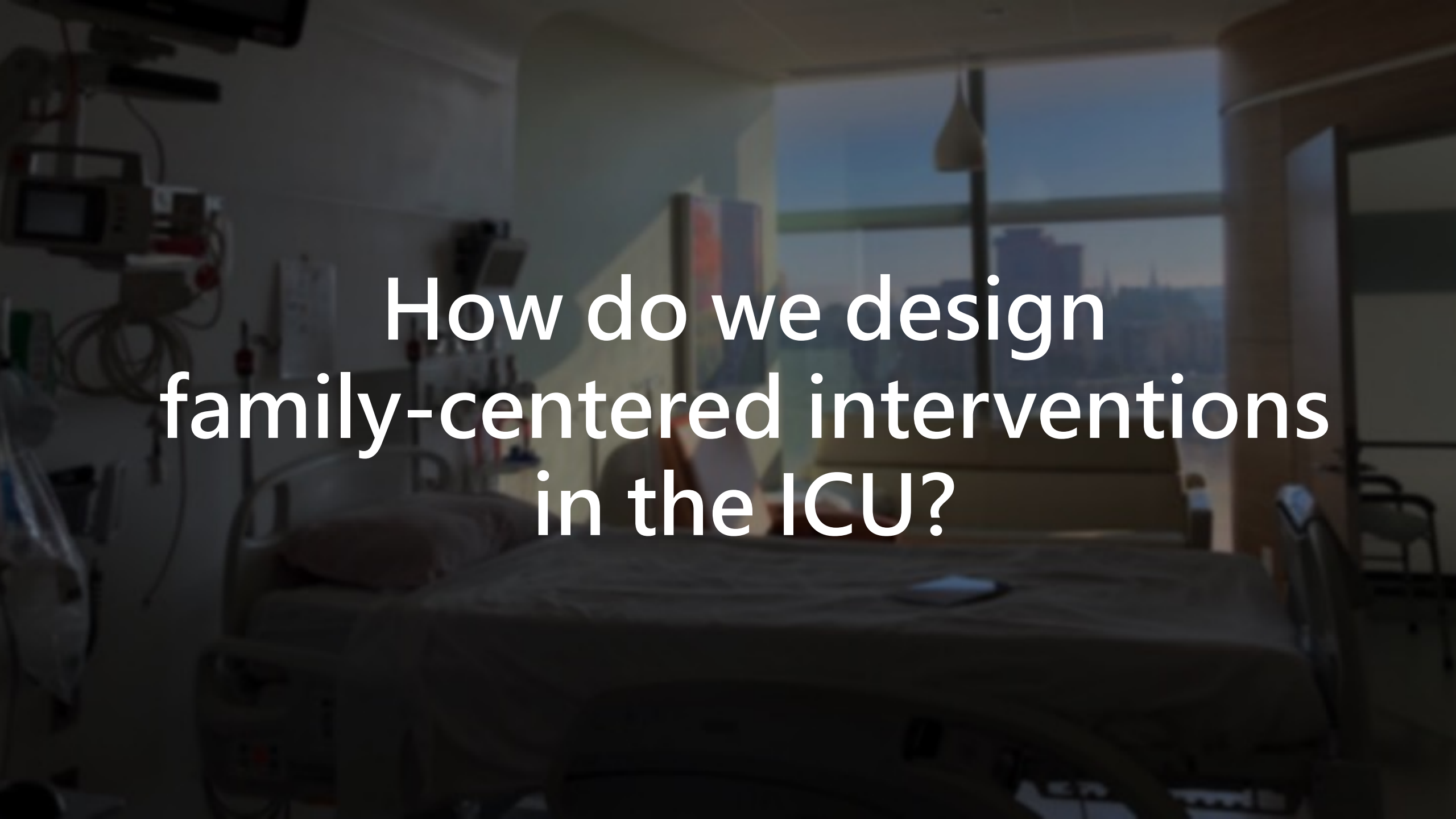


# It's important to recognize and support needs, but responding to them can be challenging.

- Despite clinical guidelines to enhance family-centered care, families do not receive enough support - often comes down to personal interaction styles.
- Heavy workload and lack of time make it harder for the care team to support family members.



*I.-M. Söderström, E. Benzein, and B.-I. Saveman. Nurses' experiences of interactions with family members in intensive care units. Scand J Caring Sci, 17(2):185–192, 2003*

A dimly lit Intensive Care Unit (ICU) room. In the foreground, a hospital bed is visible with a patient lying in it. To the left, there is a stand with various medical monitors and equipment. In the background, a large window offers a view of a city skyline at dusk or dawn. The overall atmosphere is somber and clinical.

How do we design  
family-centered interventions  
in the ICU?

**METHODS/NEEDFINDING**

# Where?

## The ICU Environment

- UC San Diego Health's Jacobs Medical Center
- Separate room for each patient
- The patient nurse ratio in the ICU unit is 1:1 or 1:2





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graph LR; A[Design Ethnography] --> B[Experience Journals]; B --> C[Semi-structured Interviews];
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Design Ethnography

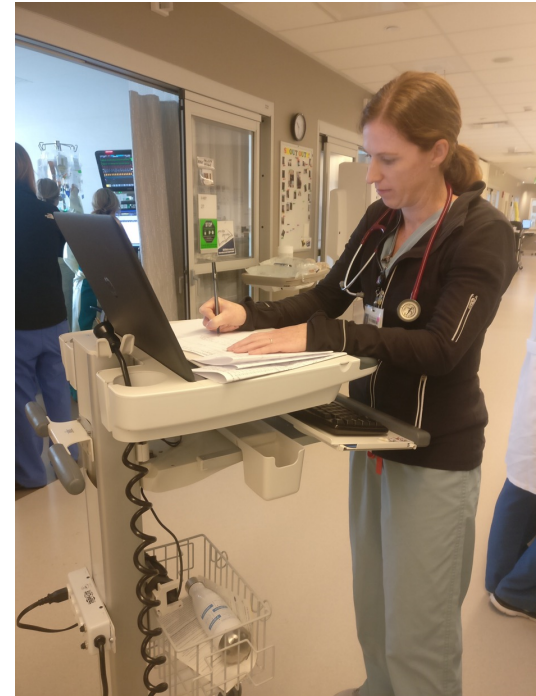
Experience Journals

Semi-structured Interviews



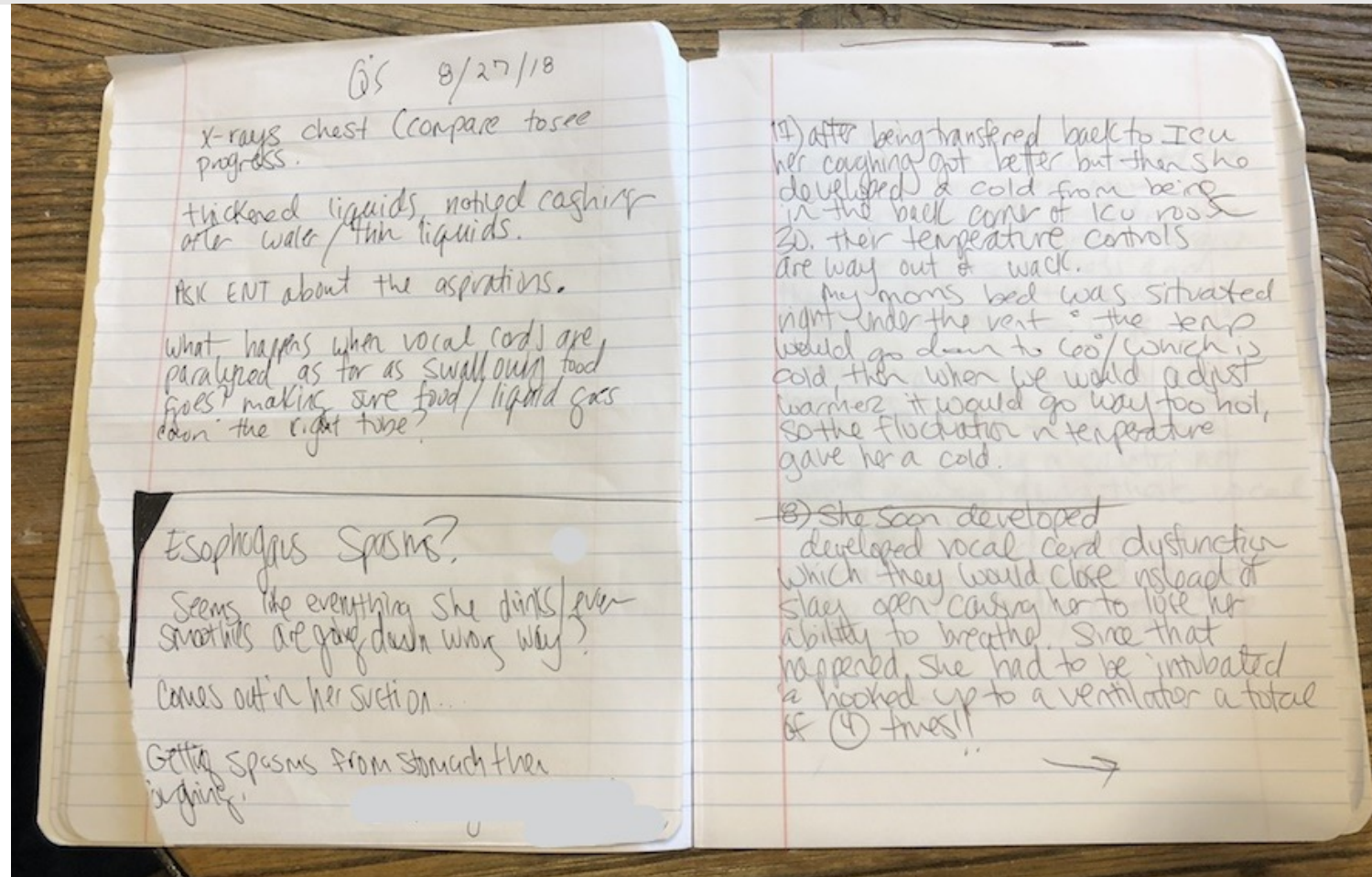
# Design Ethnography

- 2 researchers , 80 hours, 3 months.
- Observed Care-team workflow and interactions with patients and families
- How?
  - Shadowed physicians during daily rounds
  - Shadowed charge nurse
  - Shadowed patient nurse
  - Observations from nurse stations



# Experience Journals

- We gave family members journals to capture their experience in any way they felt appropriate.
- They also had the option to text or send pictures to a number.
- Journals were given to 11 family members, we got 5 back.



# Semi-structured Interviews

We interviewed 18 family members - 40min to 2hrs

## Topics (not strict)

- (1) Prior experience in an ICU
- (2) Medical background, if any
- (3) Involvement in decision making + daily care plan
- (4) Information Sources
- (5) Interactions with the care team
- (6) Emotional state + family dynamics outside the ICU
- (7) Preferences/What matters most
- (8) Challenges faced

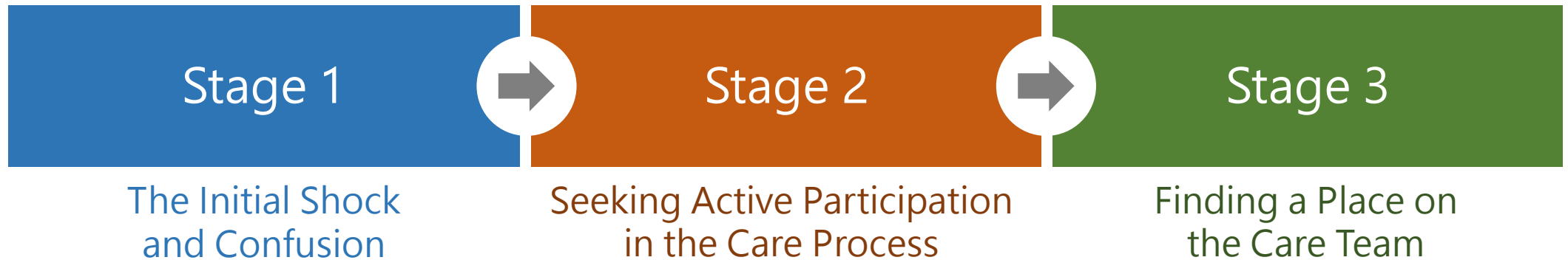




# FINDINGS

- A look at family member experiences
- 6 classes of needs
- 2 main characteristics of these needs
- A stage-based approach to introducing interventions

# THE FAMILY MEMBER EXPERIENCE





# Stage 1

## The Initial Shock and Confusion

Why are we here?

"very overwhelming"

Foreign Environment

"hostile"

Flood of Information

"not knowing what's going on is scary"

Feeling Out of Place

"needed someone to help [them] understand  
What was happening"

Maintaining Vigil

"helpless"

"I've been here pretty much 24/7"

## Stage 2

The importance and difficulty  
of asking questions

Missing and Conflicting  
Information

Taking part in daily rounds

Interpreting medical jargon

Caring for the patient

## Seeking Active Participation in the Care Process

"after you're there for longer than a week, you learn"

"[rounds] empowered us...I could have all of our  
questions answered"

"their own language..."

"ability to ask questions and receive answers is  
critical..."

"understanding what the trends were, what concerns  
the doctors had"

## Stage 3

Families gain confidence

Learn to cope with stress

Can navigate their way  
around the ICU

Understands how they can  
be of value to the care team

## Finding a Place in the Care Team

"It took me a while [but] I felt like I was just  
as much a valued member of the care team  
when I got more confidence"

# THE FAMILY MEMBER EXPERIENCE



# THE SIX CLASSES OF NEEDS

Need for Emotional Support

Need for Enhanced Awareness

Need to Build Relationships

Need to Support Sensemaking

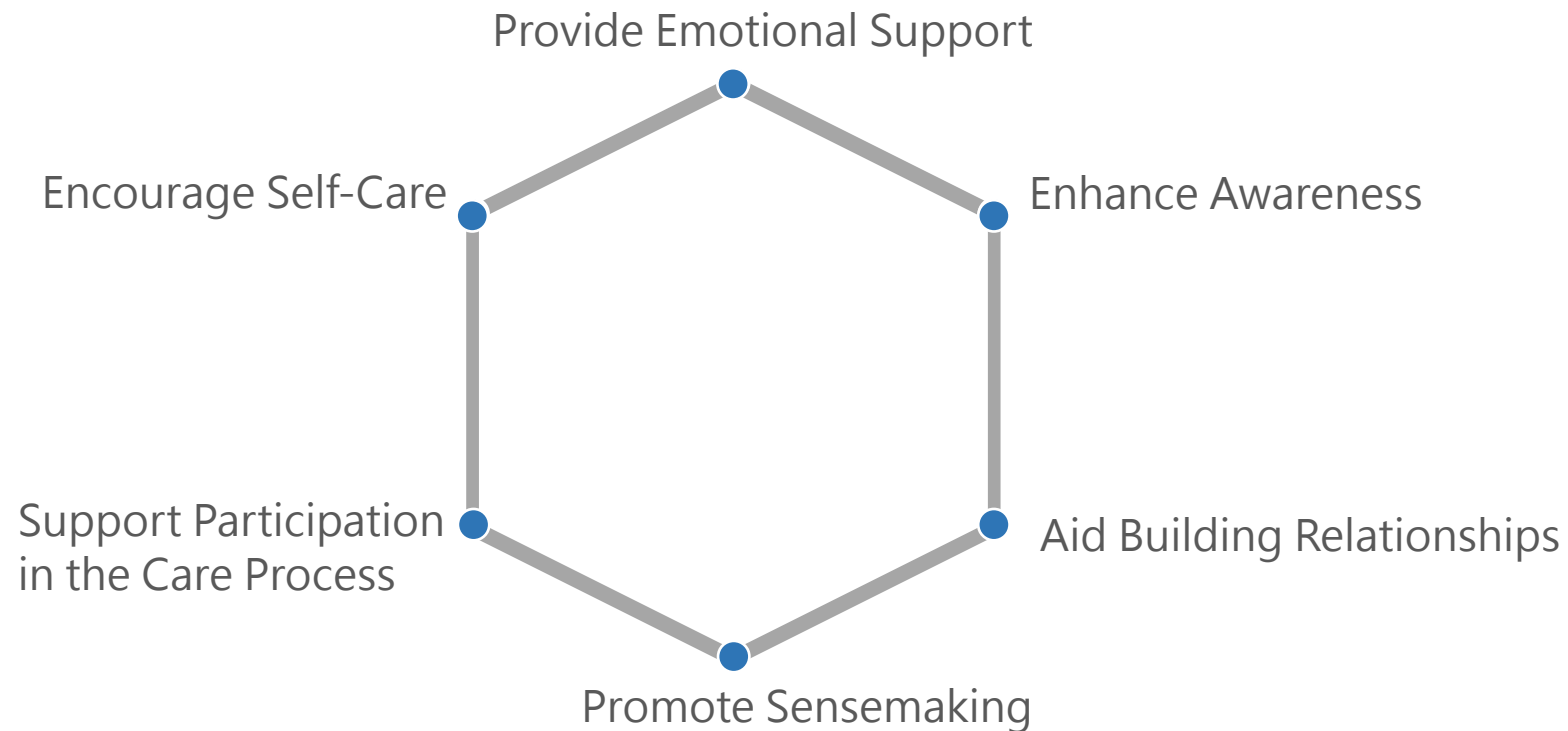
Need to be Part of the Care Process

Need to Care for Themselves



# CONCURRENCY OF NEEDS

All family members require direct or indirect support for all six classes of needs **simultaneously**.



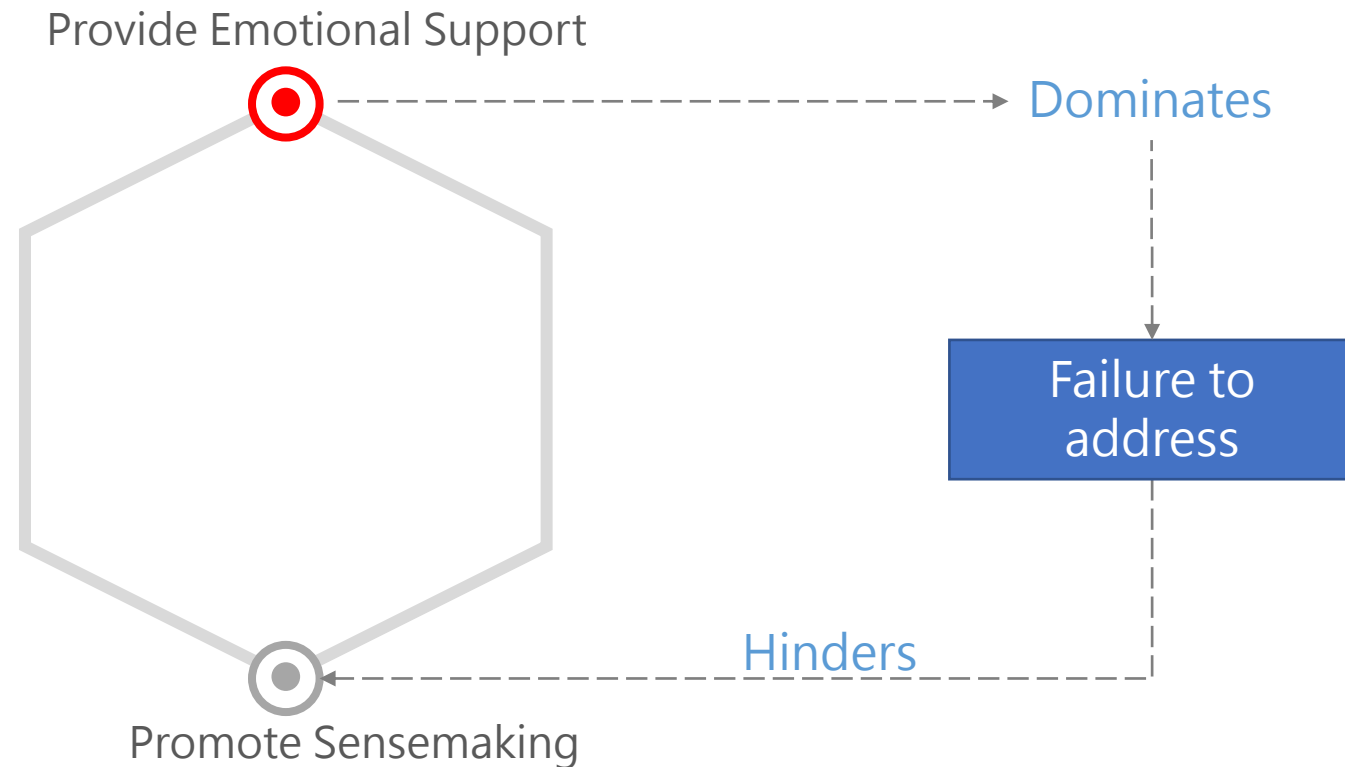
# PREPOTENCY OF NEEDS

Needs are inherently **interdependent** – they support or hinder each other.

Failure to address **dominant** needs reduces receptiveness to aids for other needs.

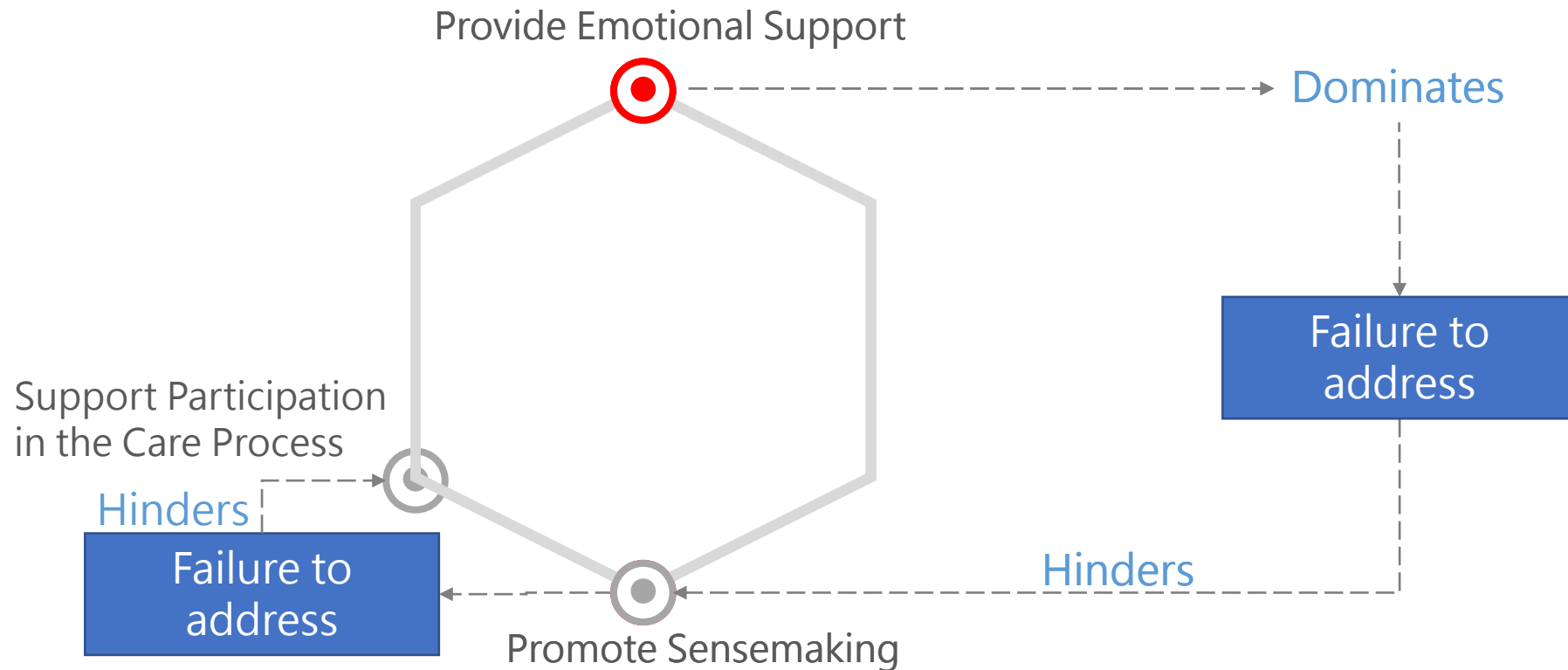
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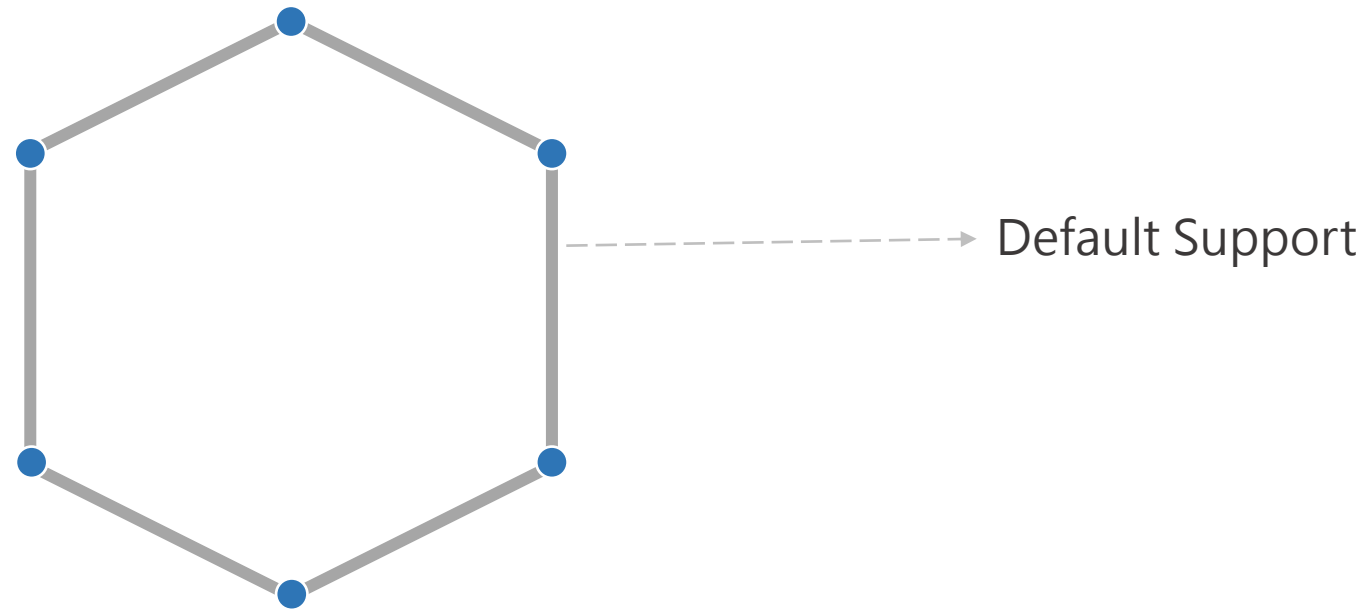


A dimly lit hospital room with a patient bed in the foreground, medical equipment on the left, and a large window in the background showing a city skyline. The text "How do we support families across these needs?" is overlaid in white.

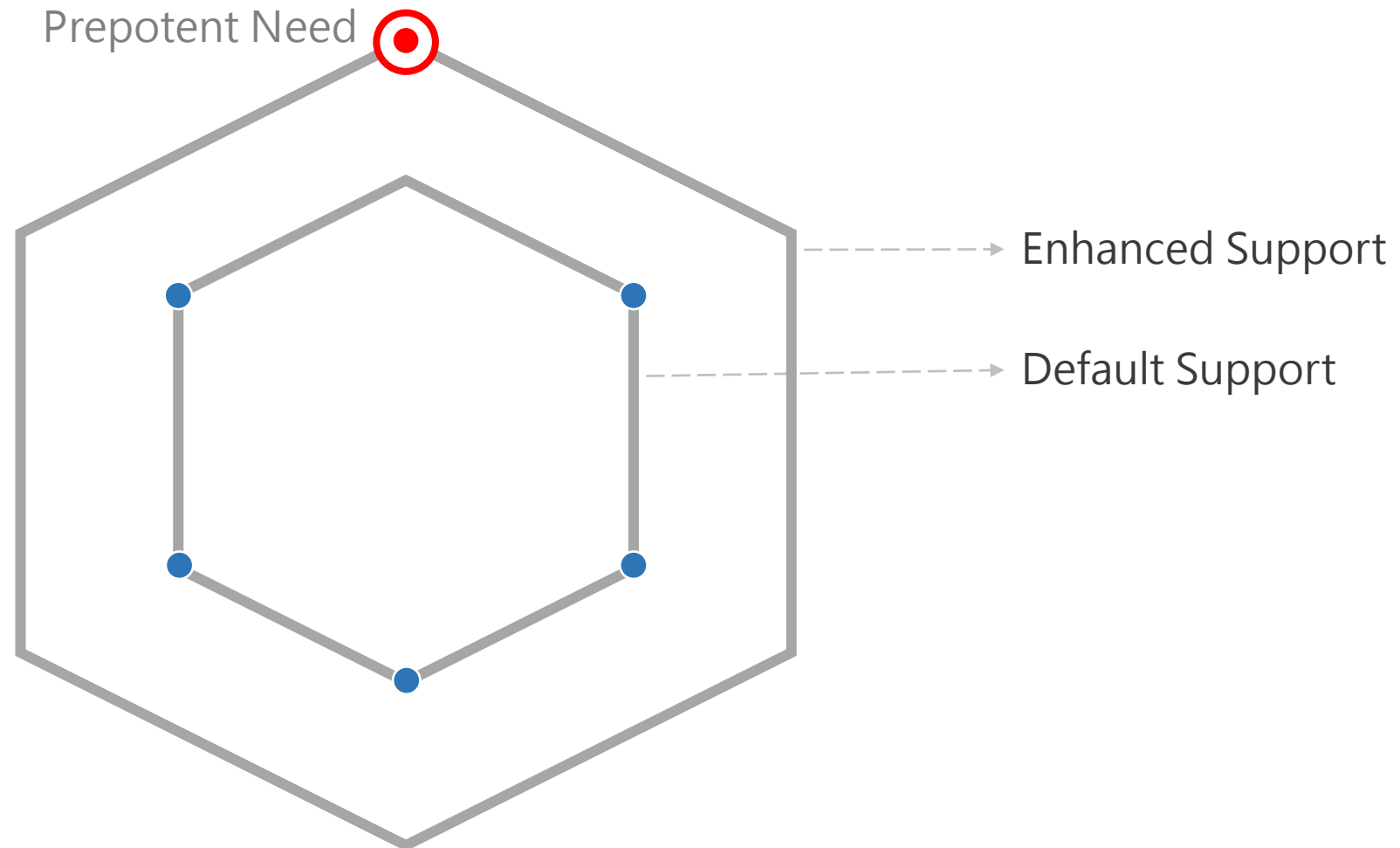
How do we support families  
across these needs?



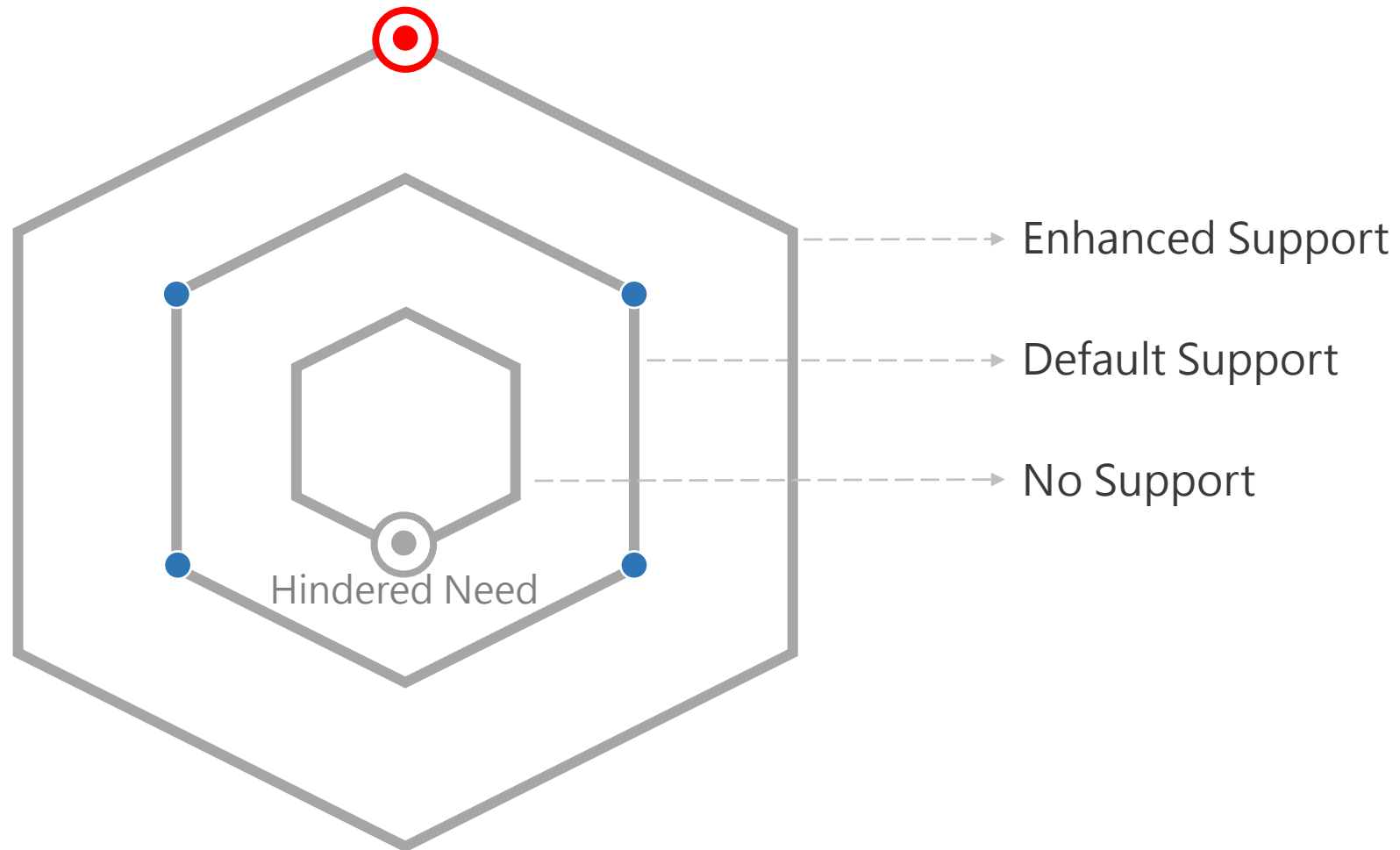
# THREE LEVELS OF SUPPORT



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# A STAGE BASED APPROACH

**NURTURE**



**EMPOWER**



**SUPPORT**



Stage 1



Stage 2



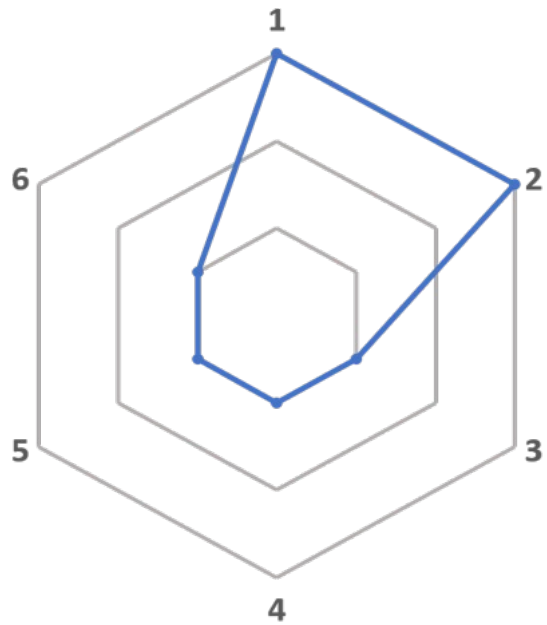
Stage 3

The Initial Shock  
and Confusion

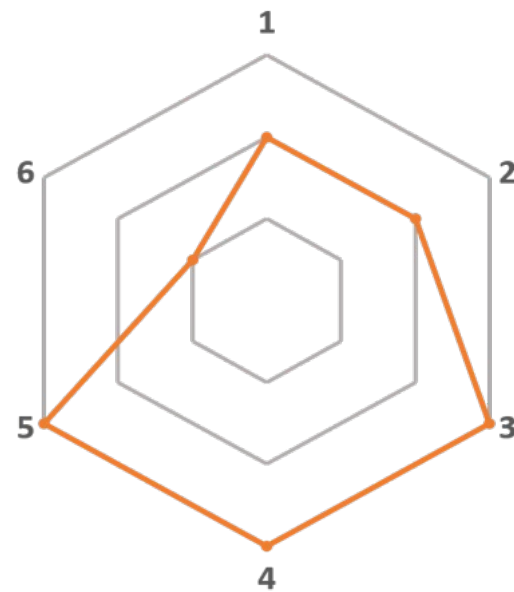
Seeking Active Participation  
in the Care Process

Finding a Place on  
the Care Team

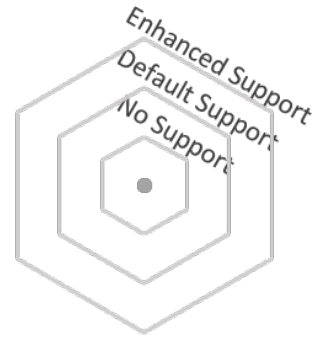
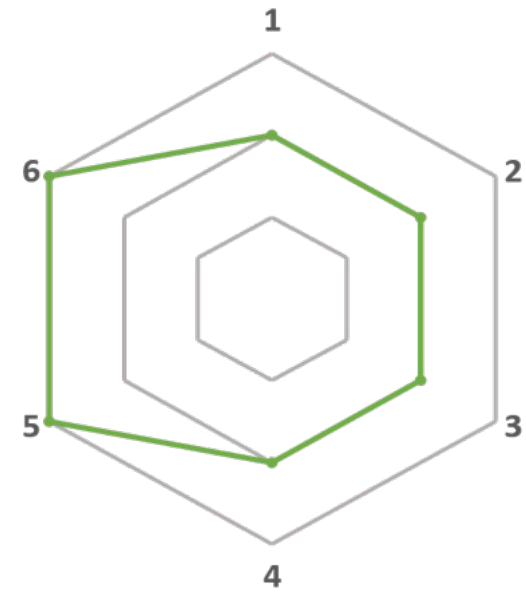
# NURTURE



# EMPOWER



# SUPPORT



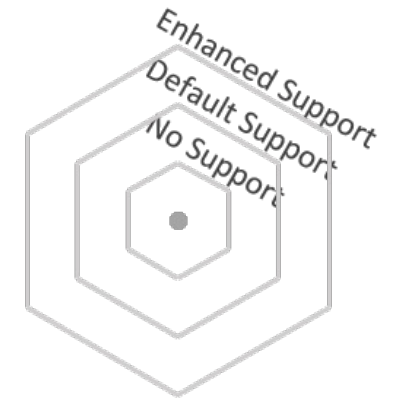
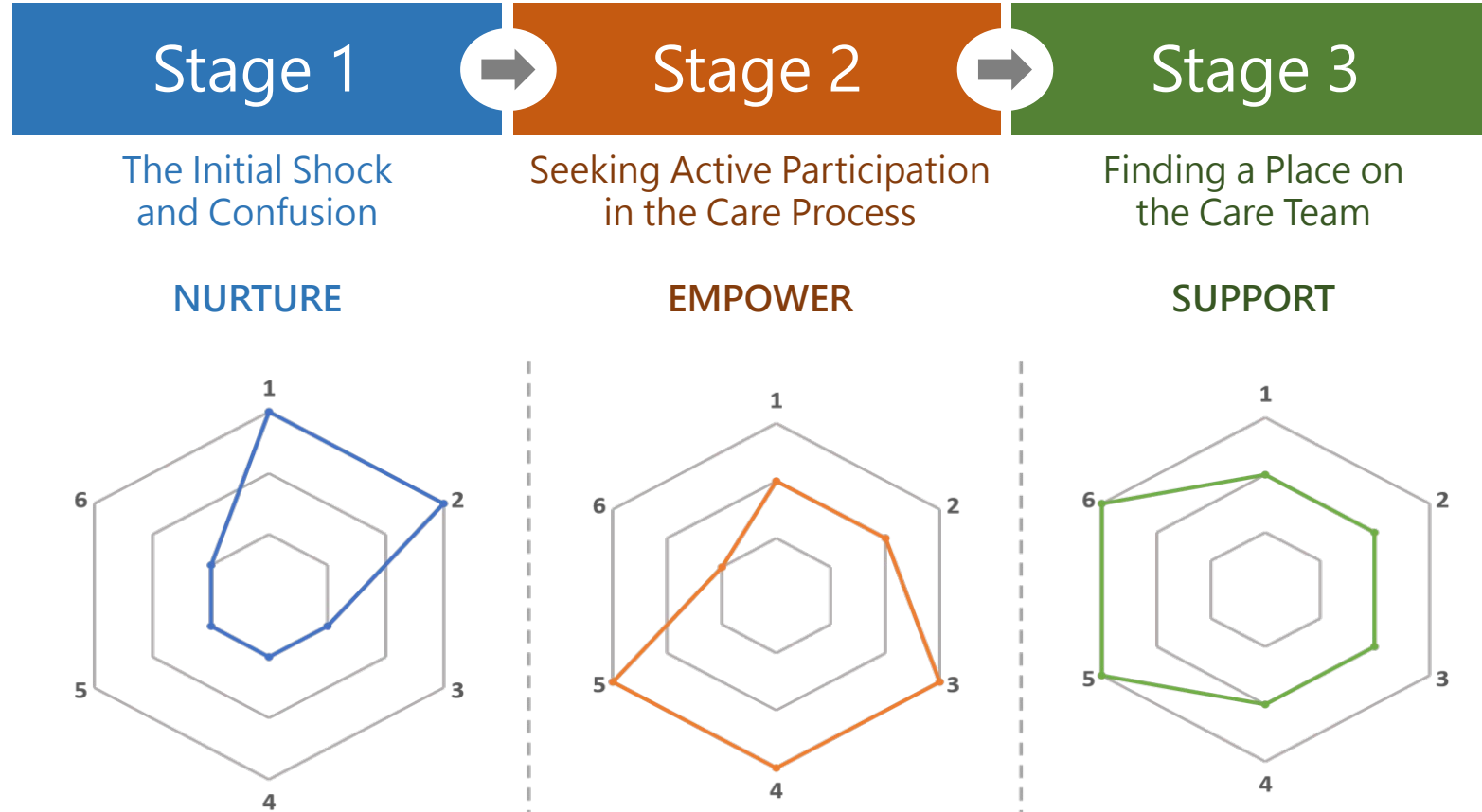
1. Provide Emotional Support
2. Enhance Awareness
3. Aid Building Relationships
4. Promote Sensemaking
5. Support Participation in the Care Process
6. Encourage Self-Care



# How do we apply this model?

- It encourages designers **to take a holistic approach in creating aids** by calling attention to evolution of needs through the family member journey in the ICU.
- It can be adapted to **any number and combination of aids** and does not dictate the specifics of an intervention.
- It helps **identify gaps in existing systems** and guides the creation of additional design goals create an effective support system for family members.
- It helps **prioritize these design goals and informs designers of when aids can be introduced** to ensure family member receptiveness.
- **It strives for sufficiency** – a need is provided with enhanced support up until the point it is no longer prepotent (versus attempting to completely satisfy the need before moving forward).

# Questions?



1. Provide Emotional Support
2. Enhance Awareness
3. Aid Building Relationships
4. Promote Sensemaking
5. Support Participation in the Care Process
6. Encourage Self-Care

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# What is next?

- Understanding dynamic events and the best way to incorporate ad-hoc/targeted aids to create a more robust framework.
- Expanding the model by understanding the family member behaviors that could trigger the transitions between stages.
- Designing and evaluating interventions that address one or more needs.
- Evaluating [and refining] the model by studying these interventions in use at the ICU.