



School of Nursing
UNIVERSITY OF WISCONSIN-MADISON

Guided Participation to Support Parental Caregiving

Models, Processes, and Outcomes

Guided Participation to Support Parental Caregiving

Karen Pridham, PhD, RN, FAAN

University of Wisconsin-Madison School of Nursing

Rana Limbo, PhD, RN, FAAN

Gundersen Medical Foundation

Tondi Harrison, PhD, RN

The Ohio State University School of Nursing

Aims

- Introduce Guided Participation (GP)
- Illustrate with clinical situations
- Describe outcomes
- Describe interventions
- Identify policy and organizational issues
- Look toward the future

Situations for Guided Participation

- A baby with a cardiac defect is slow to nipple feed
- Parents have a stillborn baby
- A prematurely born baby is dysregulated during feeding

A Situation for Guided Participation

A baby with a complex congenital heart defect takes little oral feeding and is mostly gastrostomy-tube fed

Distinguishing Features of Guided Participation as a Paradigm for Teaching and Learning

- Socially and culturally situated
- Learning a practice
- By novices with experts
- In the context of a relationship
- To develop competencies
- That must evolve with time (development), life circumstances, and transitions

Origins of Guided Participation

- Where did Guided Participation come from as an approach to teaching/learning?

Barbara Rogoff, social-cultural education

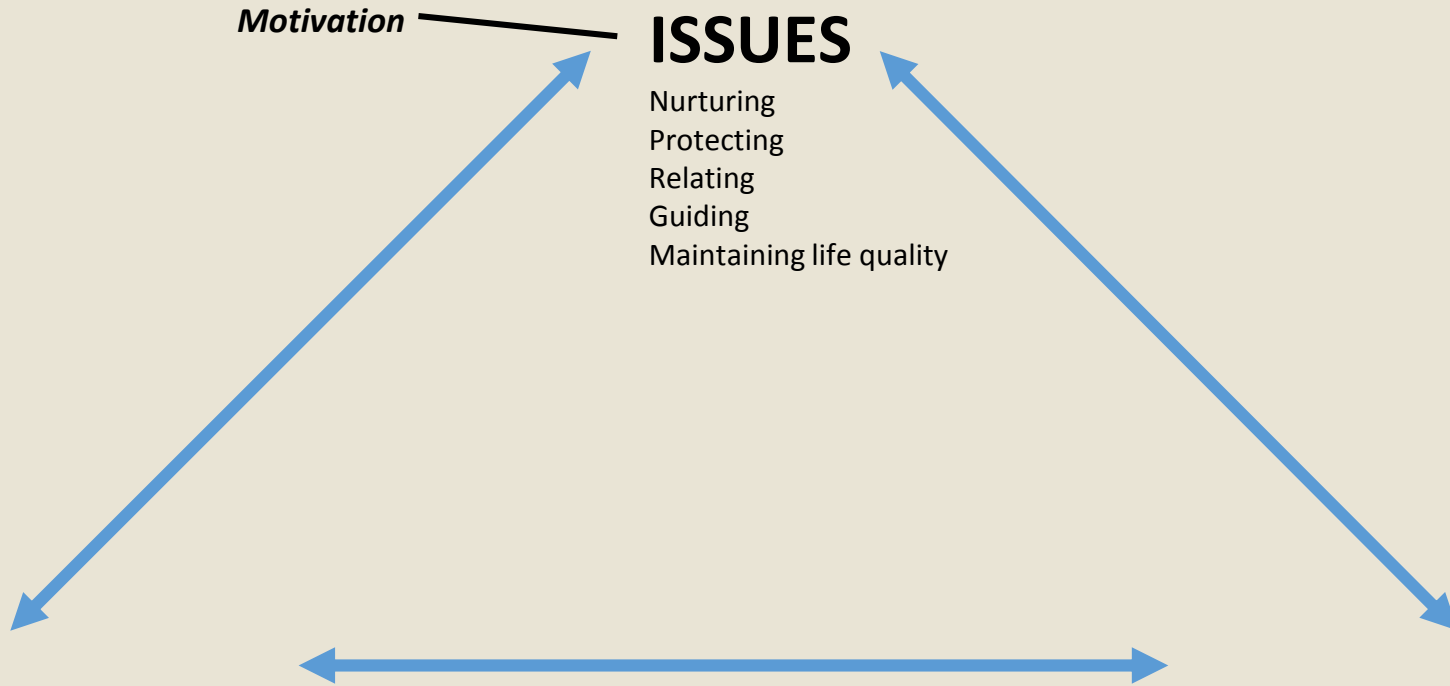
Learning through doing – guided by a more experienced person

Theory Sources: John Dewey, Lev Vygotsky, Jean Lave

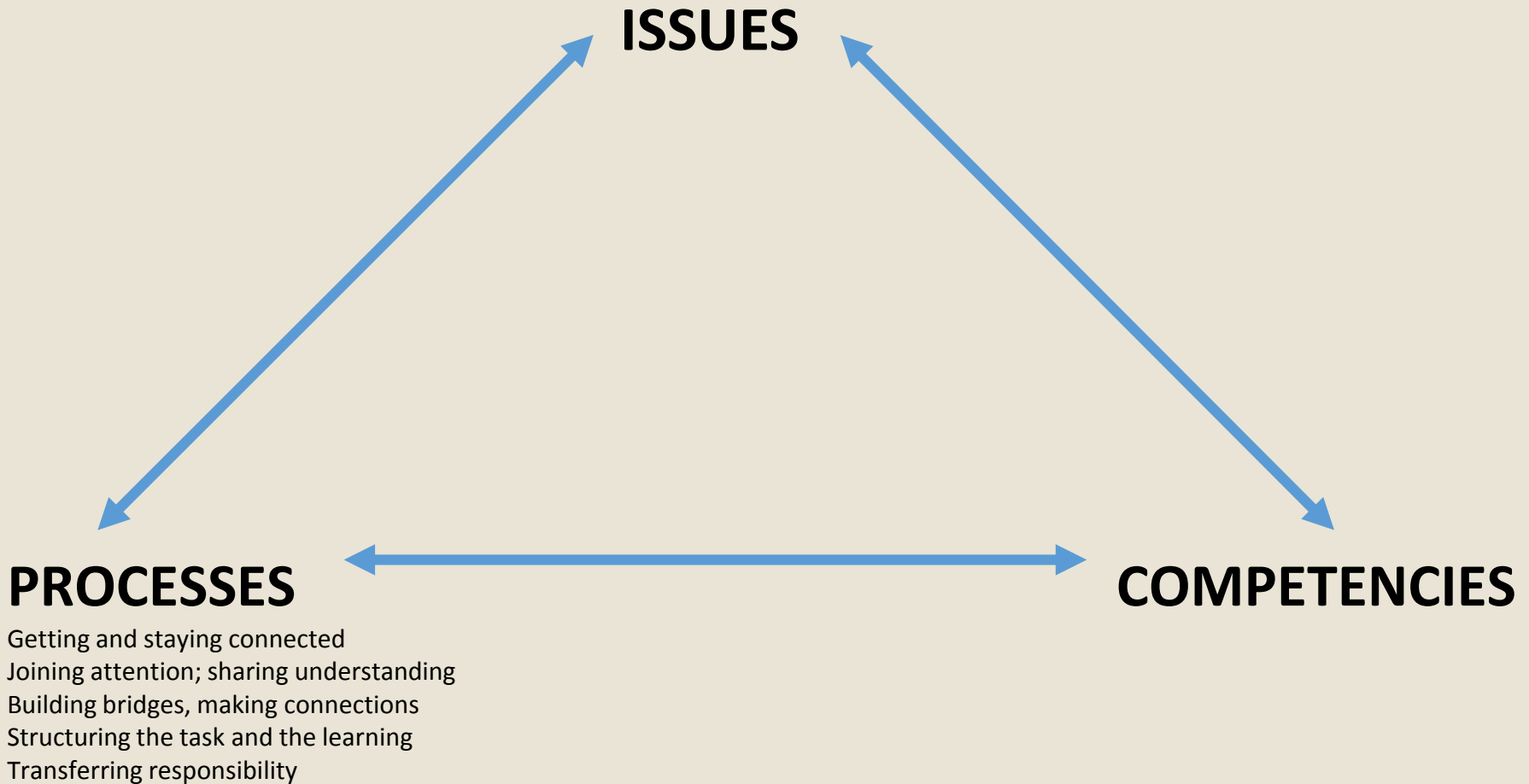
Components of Guided Participation

- Issues (The What)
- Processes (The Methods)
- Competencies (The Outcomes)

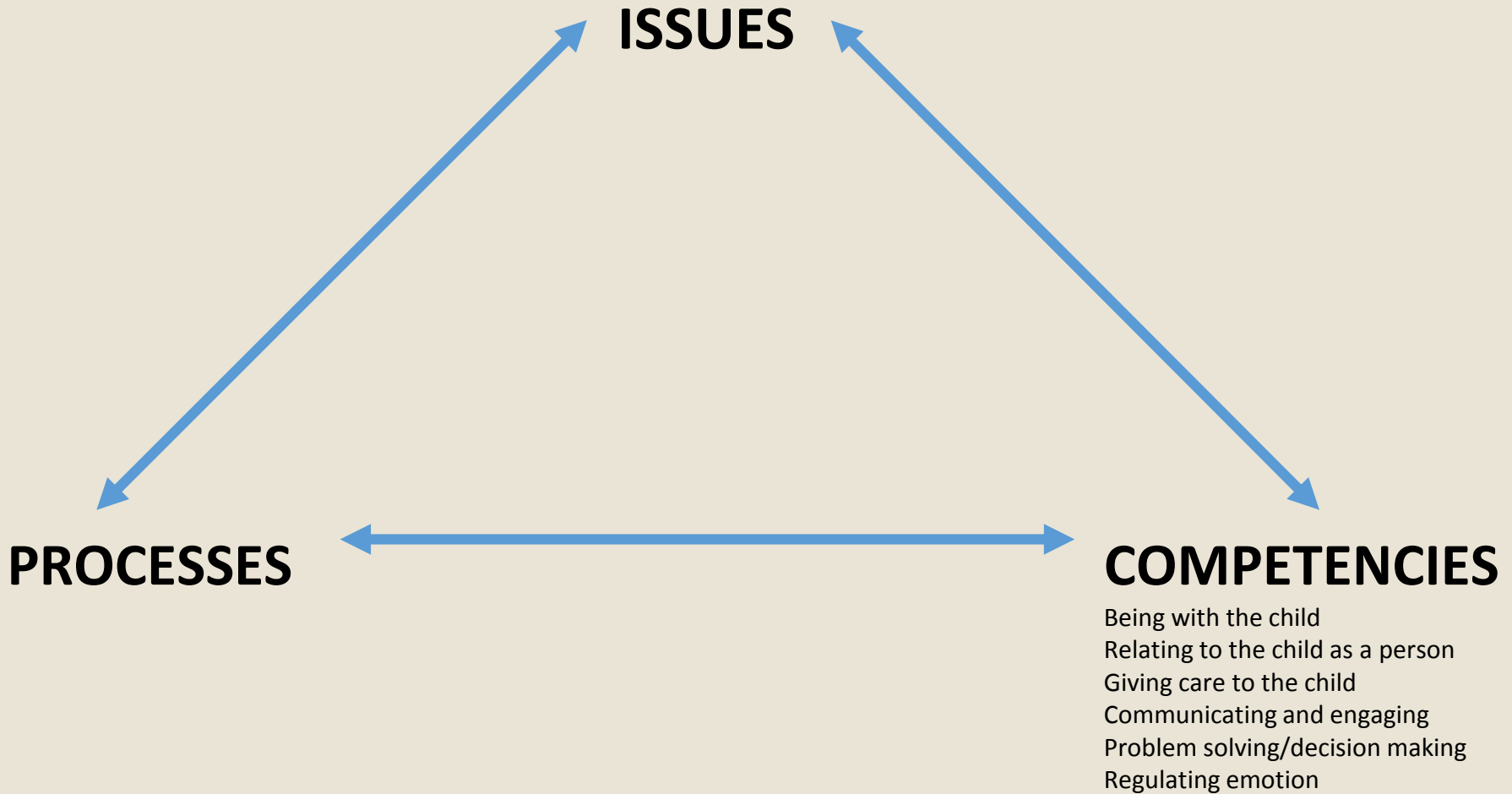
Guided Participation Model – Issues



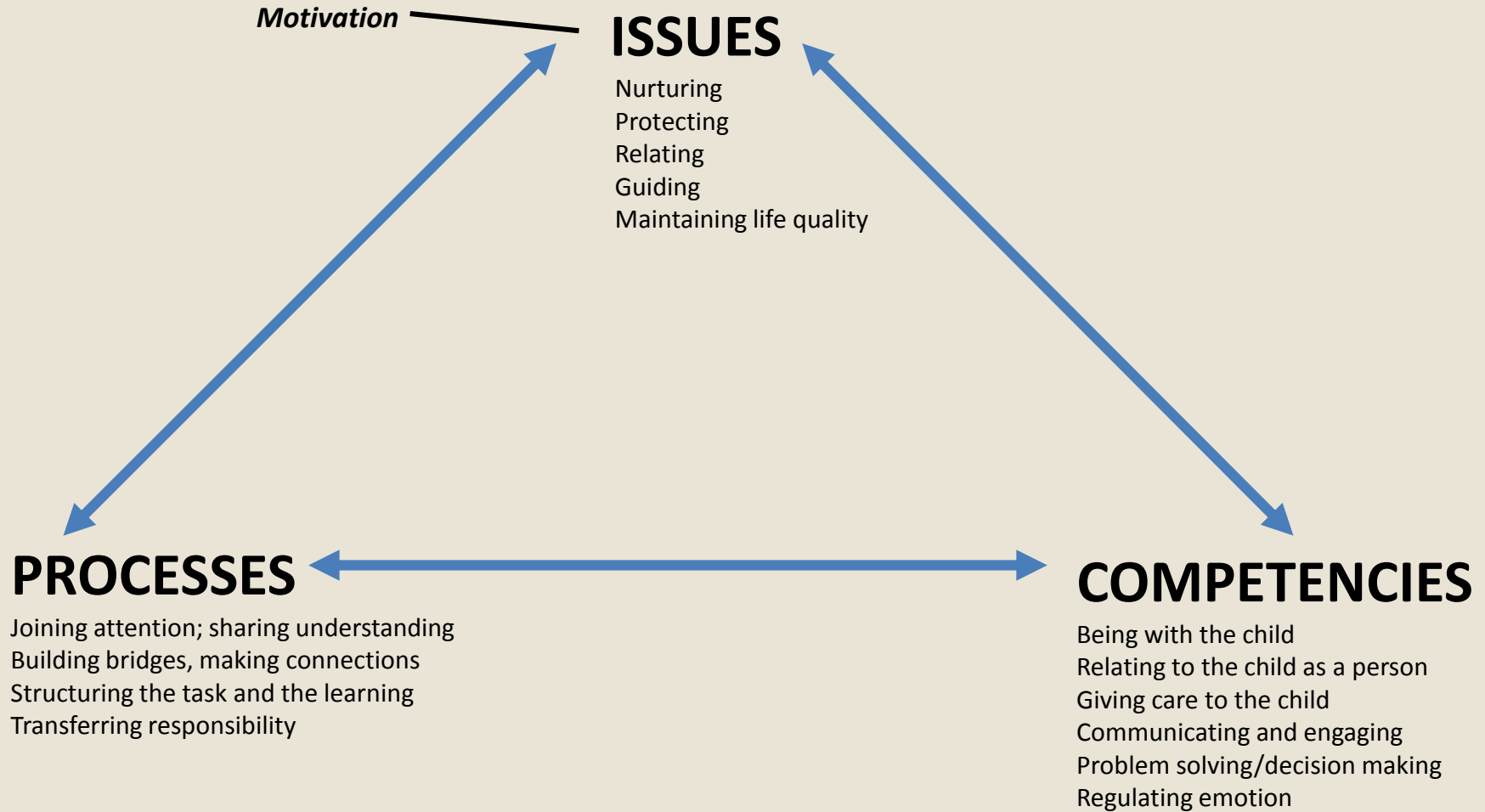
Guided Participation Model – Processes



Guided Participation Model – Competencies



Complete Guided Participation Model



Applying Guided Participation to the Clinical Setting: Perinatal Bereavement

Rana Limbo





Process:
Getting and staying connected



Process:
Getting and staying connected



Process:
Joining and maintaining attention



Competencies:
Communicating and Regulating emotions



Process:
Transferring responsibility



Competency:
Giving care (to oneself)



Process:
Joining and maintaining attention



Competency:
Communicating



Competency:
Knowing and relating

The Critical Importance of Maternal Caregiving on Infant Physiologic Regulation

Tondi M. Harrison

Outline

- Physiologic regulation
 - Definition
 - Effects on neurodevelopment
 - Relationships with caregiving
- Measurement
 - Physiologic regulation
 - Caregiving
 - Neurodevelopment
- Research examples

Healthy infants have flexibility in their ability to grow in a range of environments and with a variety of caregiving styles.

Infants who begin their lives in a stressful environment, separated from their mother, may be less flexible in the type of care they require in order to overcome their early adversity.

(Gribble, 2007)

Physiologic Regulation

Dynamic regulation of physiological processes to maintain a state of functioning optimal for:

- growth and development
- effective response to challenges (stressors)

Effects of Physiologic Regulation

- Optimizes growth
- Supports effective response to stressors
- Serves as the structural framework for all aspects of neurodevelopment: physical, social, emotional, behavioral, cognitive

(Porges, 2011)

Theory: Physiologic Regulation & Caregiving

- Bowlby (Attachment Theory)
 - Infants with secure attachment have better developmental outcomes (Gander & Buchheim, 2015)
- Porges (Polyvagal Theory)
 - Physiologic regulation is the foundation for all neurodevelopment. Adverse early experience, including stressful environments (e.g. ICU), impairs maturation of this regulatory system (Porges, 1995; 1996)
- Schore (Regulation Theory)
 - Sensitivity of caregiving, is a critical factor in modulating infant regulatory response (Lewis & Ramsay, 1999, Nachmias et al., 1996)
 - Infants and children of more supportive mothers exhibit better physiologic regulation at rest as well as in response to challenge. (Schore, 2001, Calkins et al., 2008)

Physiologic Regulation & Maternal Caregiving

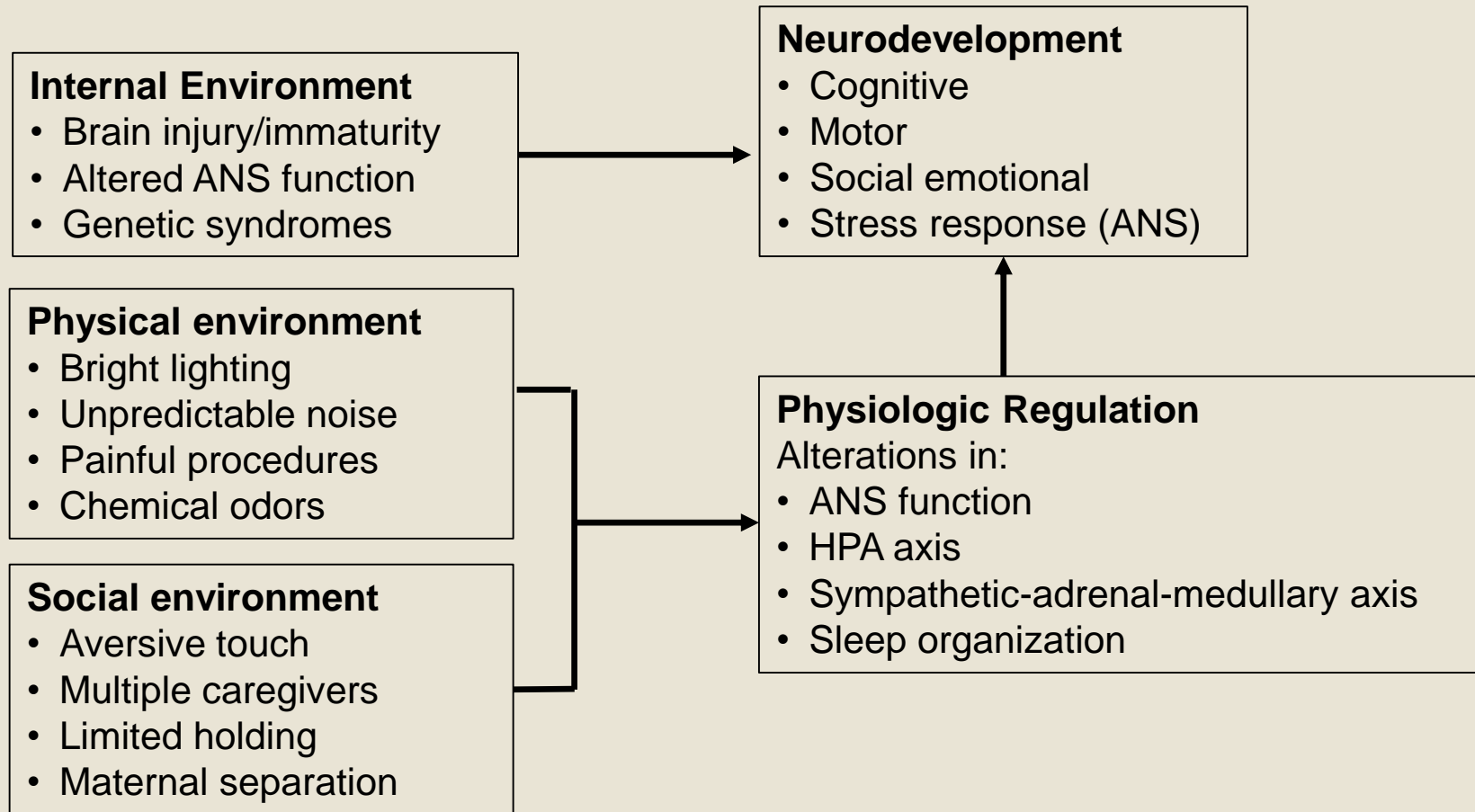
1. Effective physiologic regulation is critical for optimal neurodevelopment.
2. The infant's early experience with the mother is **central** to the development of foundational regulatory physiology.

(Hofer, 1994; Porges & Furman, 2011; Schore, 2001)

Role of Caregiving

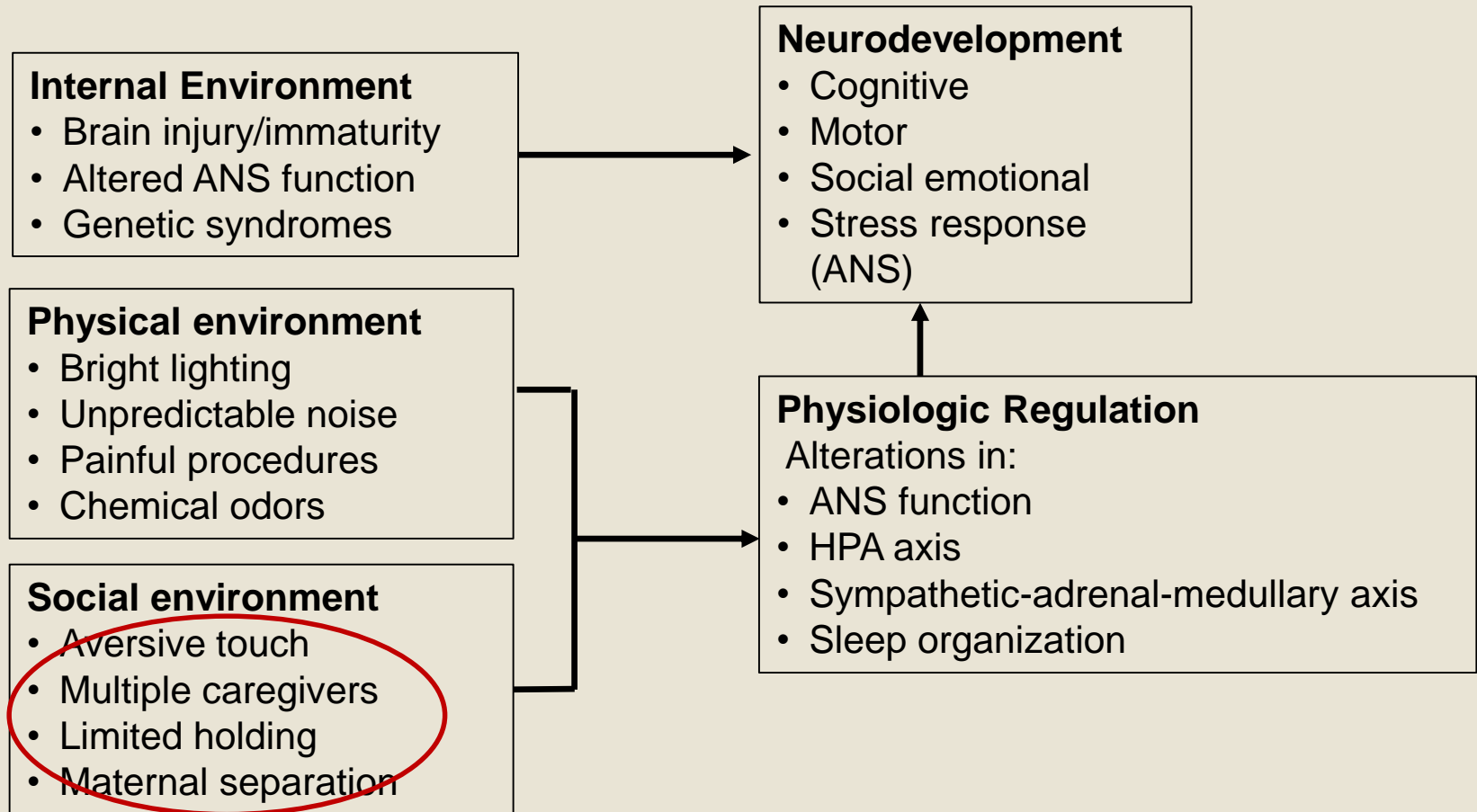
- This biobehavioral process is co-created within the moment-to-moment mother-infant interaction in which gaze, affect, and vocalizations are synchronized (Feldman et al., 2011).
- This mother-infant synchrony
 - predicts long-term infant development (Kaye & Fogel, 1980; Cohn & Tronick, 1988; Jaffe et al., 2001)
 - is associated with biologic synchrony in heart rhythms between mother and infant (Feldman et al., 2011)
- The mother and the infant each contributes to this co-regulatory process (Feldman et al., 2011). However, the mother is the leader (Cirulli et al., 2003; Stern, 1995).
- ***We theorize that GP provides the support needed by mothers of high-risk infants to achieve this neurobiological synchrony.***

What impacts physiologic regulation in high-risk infants?



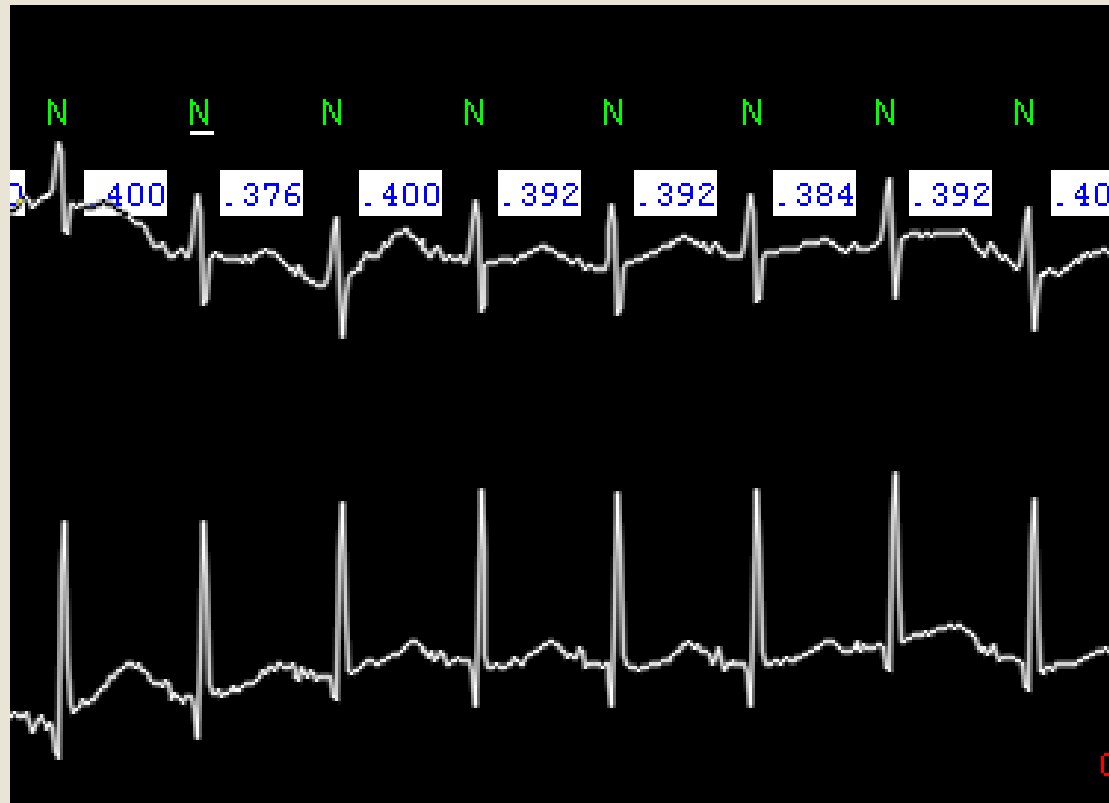
Adapted from: Weber, Harrison, & Steward, 2012

What impacts physiologic regulation in high-risk infants?

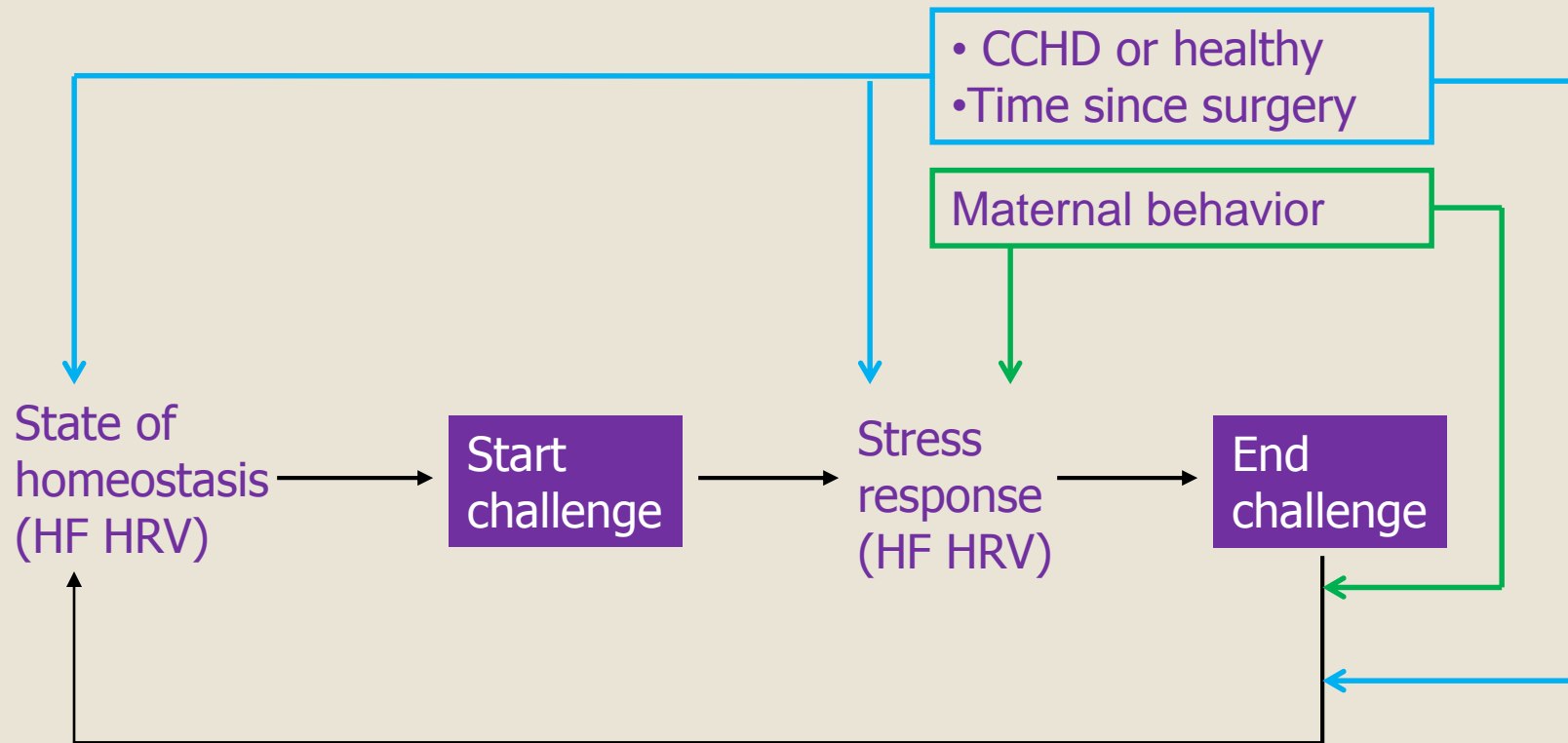


Adapted from: Weber, Harrison, & Steward, 2012

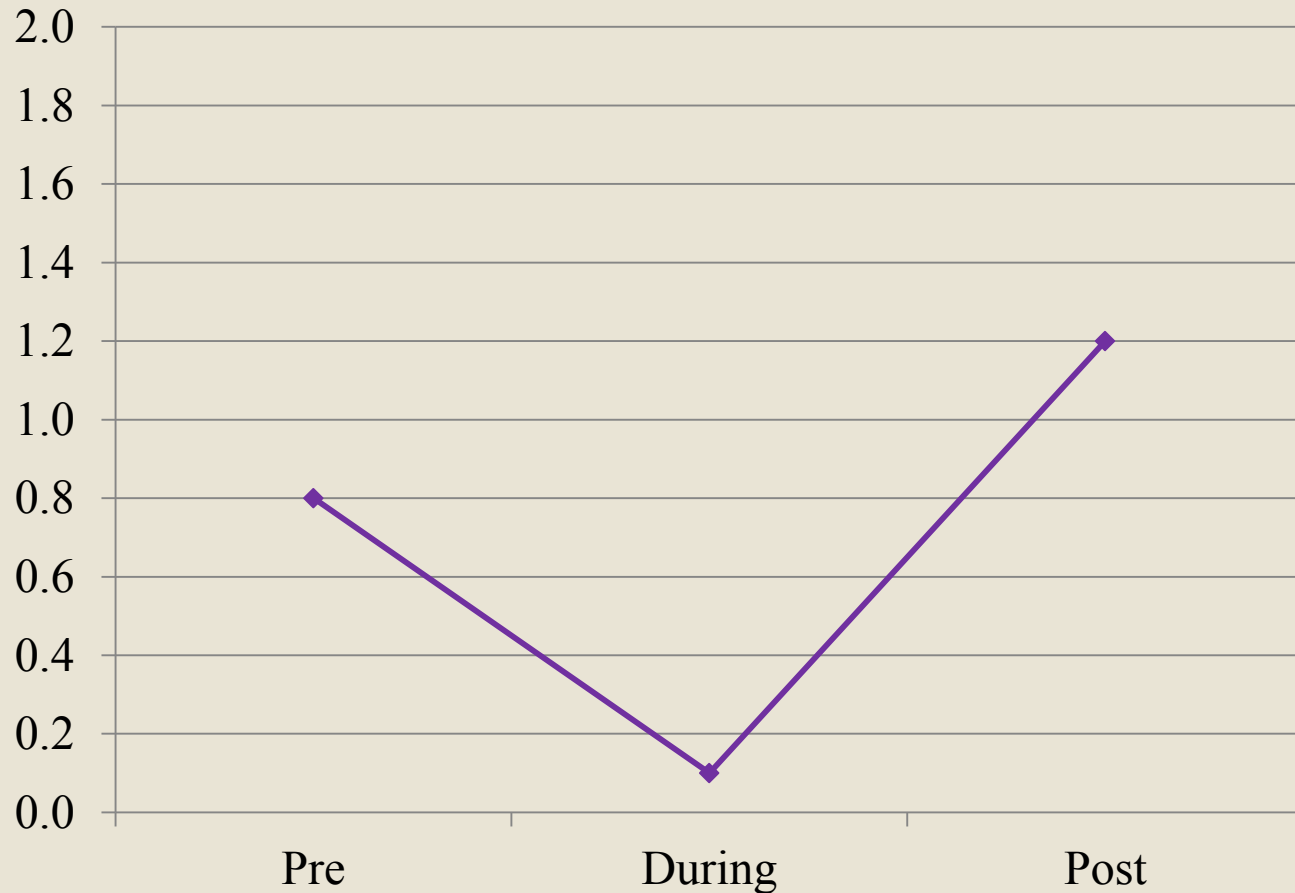
Physiologic Regulation: Heart Rate Variability



Model for Studying ANS Function: Autonomic Regulation of Challenge



HF HRV response to feeding in healthy infant



(Adapted from Lappi et al., 2007)

Parent-Infant Interaction/Caregiving

Parent-Child Early Relational Assessment

- Parent
 - Positive affective involvement, sensitivity, & responsiveness
 - Negative affect and behavior
- Infant
 - Positive affect, communicative, and social skills
 - Dysregulation and irritability
- Dyadic
 - Mutuality and reciprocity
 - Dyadic tension

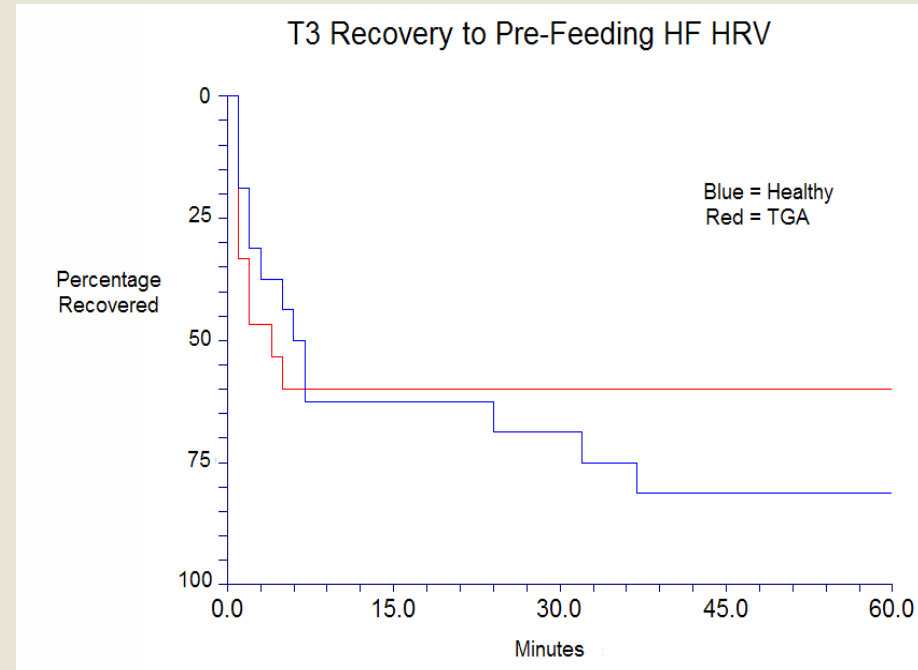
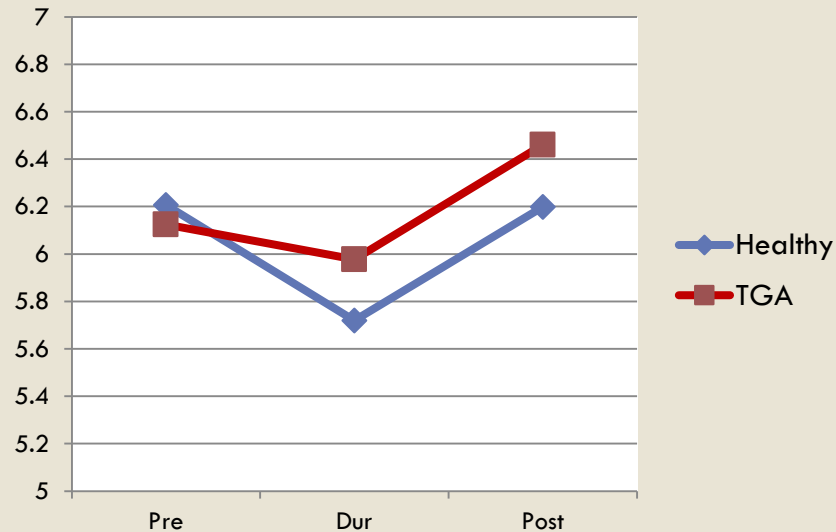
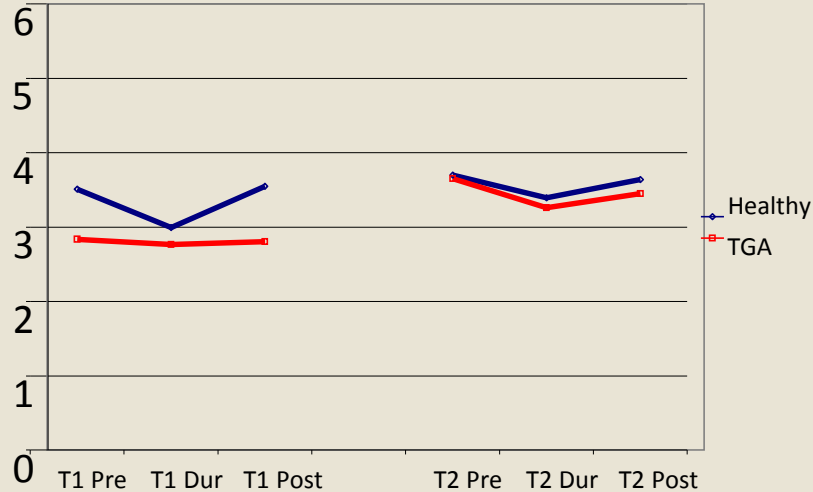
(Clark, 1985)

Measures: Neurodevelopment

- Bayley Scales of Infant Development
 - Cognitive, language, and motor skills
- Test of Infant Motor Performance
 - Fine and gross motor skills
- Mobile paradigm
 - Learning and memory
- High density EEG
 - Brain function and maturity

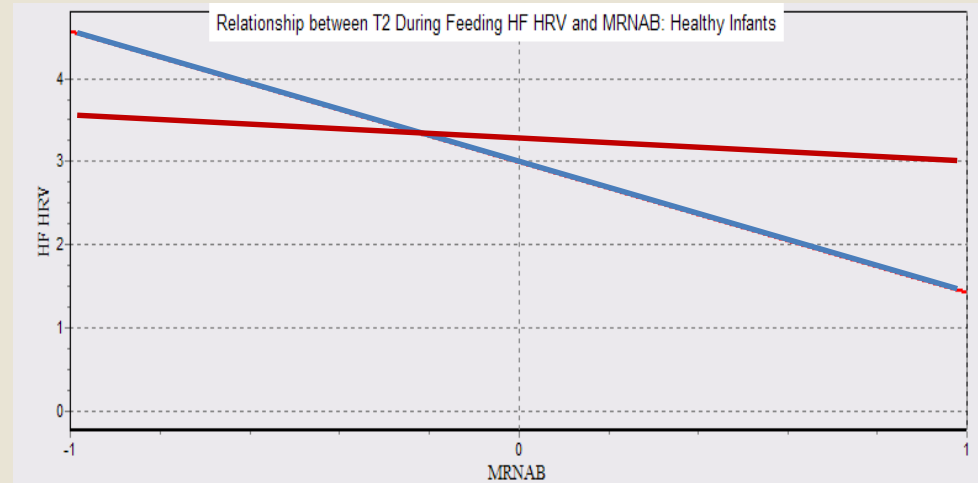
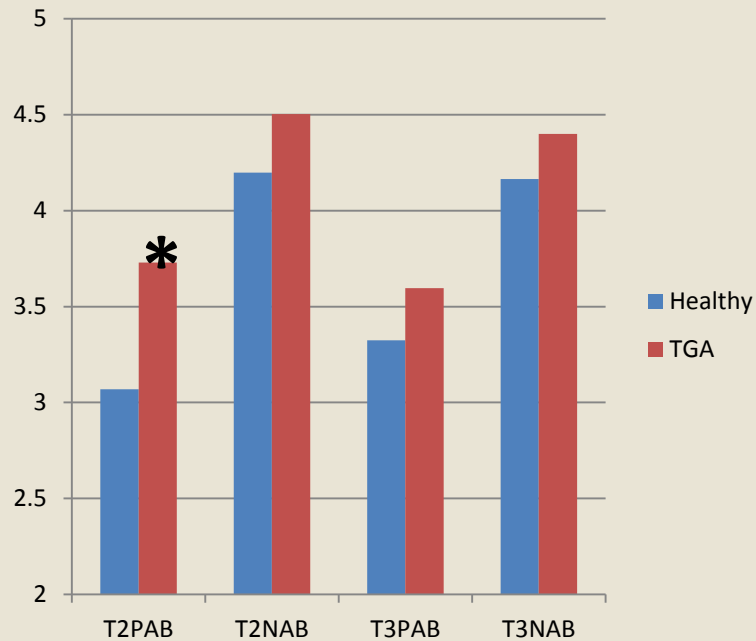
Physiologic Regulation

HF HRV at Each Feeding Phase by Group

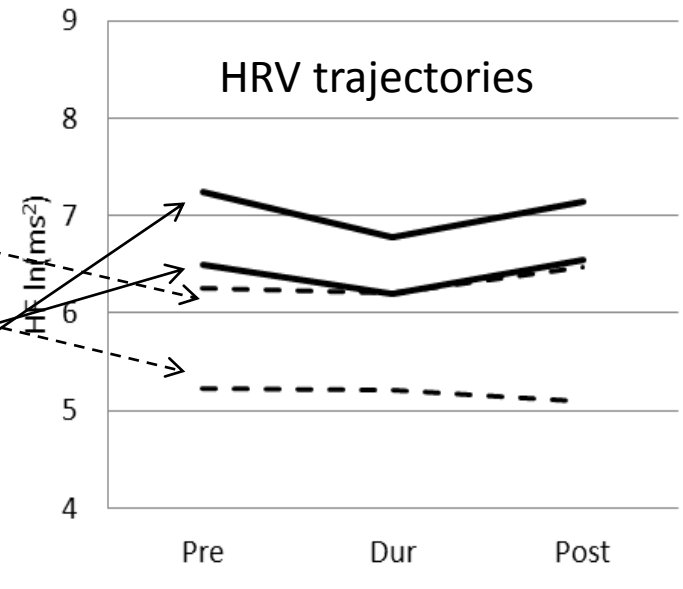
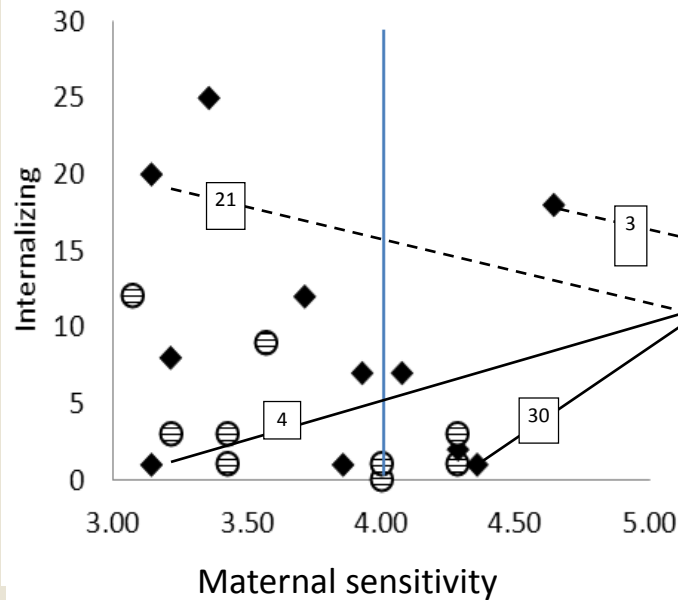


Harrison, 2009; Harrison & Brown, 2012; Harrison, 2013

Maternal Caregiving



Behavior



Infant Social Engagement & Physiologic Regulation

Parameter Estimates and Standard Error Infant Affect and Behavior				
	B	SE	t	p
IPACS				
Constant	2.877	.553	5.198	.000
Group	.020	.191	.107	.915
Time	.357	.199	1.799	.078
Baseline	-.087	.125	-.696	.490
Reactivity	.282	.139	2.019	.049
IDI				
Constant	4.557	.306	14.867	.000
Group	-.037	.106	-.355	.724
Time	.121	.110	1.103	.275
Baseline	-.130	.069	-1.881	.066
Reactivity	.191	.077	2.473	.017

Conclusions

- Impaired physiologic regulation
 - HRV
 - Behavior
- Associations between physiologic regulation and maternal sensitivity as well as infant social engagement
- Intervention: enhance physiologic regulation

Effects of skin-to-skin contact

Premature infants

- Enhanced ANS function (Feldman & Eidelman, 2003; 2007)
- Enhanced regulation of sleep (brain maturation)
(Scher et al., 2009; Feldman et al., 2002)
- Organization of responses to visual and auditory stimuli
(Feldman & Eidelman, 2007; Ludington-Hoe, et al., 2004; 2006)
- Accelerated neurobehavioral maturation (arousal modulation, behavioral reactivity, sustained exploration) (Feldman et al., 2002; 2003; Tessier et al., 2003)

Infants with CCHD

- Improved cardiorespiratory status (Gazzolo et al., 2000)

Mothers

- More sensitive caregiving (Feldman et al., 2003)

Effects of skin-to-skin contact

Premature infants

- Enhanced ANS function (Feldman & Eidelman, 2003; 2007)
- Enhanced regulation of sleep (brain maturation)
(Scher et al., 2009; Feldman et al., 2002)
- Organization of responses to visual and auditory stimuli
(Feldman & Eidelman, 2007; Ludington-Hoe, et al., 2004; 2006)
- Accelerated neurobehavioral maturation (arousal modulation, behavioral reactivity, sustained exploration) (Feldman et al., 2002; 2003; Tessier et al., 2003)

Infants with CCHD

- Improved cardiorespiratory status (Gazzolo et al., 2000)

Mothers

- More sensitive caregiving (Feldman et al., 2003)

Pilot Studies

Pilot 1

- 10 full-term infants: 8 SV; 2 TGA
- SSC 60 minutes daily for 14 consecutive days

Pilot 2

- 10 infants: 4 TGA, 3 HLHS, 1 ToF, 1 IAA, 1 Coarctation
- Pre-operative SSC
- SSC 60-90 minutes

Guided Participation & Physiologic Regulation

- GP intervention will support infant physiologic regulation and, ultimately, neurodevelopment through:
 - enhancing parenting competencies
 - strengthening caregiver-infant relationship
 - increasing caregiver-infant synchrony

Interventions Using Guided Participation

Rana Limbo

Tondi Harrison

Karen Pridham

Case Studies

- Relationship
- Parenting role
- Trusting self and infant

Potential Pathways of Guided Participation Effect: Maternal Caregiving to Infant Physiologic Regulation

Tondi Harrison

Intervention Studies with Parents of Prematurely Born, Very Low Birth-weight Infants

**Karen Pridham, Sue Thoyre, Rana Limbo,
Michele Schroeder, Lisa Brown**

A Randomized Clinical Trial of Guided Participation for Feeding Support of Very Low Birth-Weight Infants





Intervention to Support Co-Parenting

Karen Pridham, Tondi Harrison, Kathy Mussatto, Janice Melby, and Roger Brown

- Feasibility Study— Hand Book to guide co-parenting through the baby's first year (binder and tablet formats)
- Pilot Study—Randomized clinical trial, intervention and control groups, longitudinal: prenatal diagnosis or birth dx through 6 months
 - Primary outcome: Parents' communication competencies, including sharing information, goal setting, problem solving, negotiating differences
 - Secondary outcomes: Feeding interaction, physiologic regulation (HRV)
 - More information available from Karen Pridham

Policies and Organizational Arrangements

Rana Limbo

Implementing Guided Participation Within an Organization

- Designate nursing as the lead or principal discipline for implementation
- Use for mentoring and supervision
- Involve an inter-professional (or cross-discipline) team
- Provide GP education: workshops, online, reflective supervision sessions
- Use GP approach to all follow-up
- Keep track of barriers and facilitators for ongoing organization and implementation discussions

Future Directions

Randomized clinical trial to examine the effectiveness of Guided Participation in contrast to usual care in parent, family, and infant context

Guided Participation and Development of Joint or Collaborative Problem Solving

For family caregivers

For caregivers and clinicians

Dr. Pridham's Credits/Funding

- US Public Health Service, Maternal & Child Health Bureau
- March of Dimes
- McBeath Foundation
- Herma Heart Center, the Children's Hospital of Wisconsin
- The Children's Hospital of Wisconsin Foundation
- The University of Wisconsin-Madison School of Nursing Florence Blake Fund; Helen Denne Schulte Fund
- Clinical and Translational Science Award (CTSA) program, through the NIH National Center for Advancing Translational Sciences (NCATS), grant UL1TR000427
- The National Institutes of Nursing Research, grant 5R03NR9272-2 to the University of Wisconsin-Madison School of Nursing
- The American Heart Association

Contact information: [kpridham @wisc.edu](mailto:kpridham@wisc.edu); Signe Skott Cooper Hall, Room No. 5134, 701 Highland Ave., Madison WI 53705, USA

Dr. Limbo's Credits/Funding

- Senior consultant and associate director, Resolve Through Sharing®
- Bereavement & Advance Care Planning Services
- Direct: 608-775-5278 / 800-362-9567, ext. 55278
- rklimbo@gundersenhealth.org
- Gundersen Medical Foundation/www.gundersenhealth.org
- www.bereavementservices.org/
- www.respectingchoices.org
- 1900 South Avenue, La Crosse, WI 54601/Mailstop AVS-003

Dr. Harrison's Credits/Funding

- NINR Grant No. 1F31NR010172-01
- NINR Grant No. T32NR7102 University of Wisconsin-Madison
- NINR Grant No. P20 NR008992 Center for Health Trajectory Research, University of Minnesota School of Nursing
- American Nurses Foundation Sanofi-Pasteur Scholar program
- The Ohio State University College of Medicine Medical Student Research Scholarship awarded to A Ferree.
- Research Institute, Nationwide Children's Hospital

Harrison.473@osu.edu

The Ohio State University College of Nursing

Dr. Harrison's Research Team

- **Research Coordinator**

- Sarah Landry

- **Research Assistants**

- Jacki Daniels
- Valerie Pickett
- Ebonee Walker
- Ashley Weber

- **Consultants**

- Roger Brown, PhD, University of Wisconsin-Madison
- Mark Laudenslager, PhD, University of Colorado
- Lenora Lehwald, Nationwide Children's Hospital
- Karen Pridham, PhD, RN, FAAN, University of Wisconsin-Madison

- **Co-Investigator**

- Jill Heathcock, PhD, PT, OSU School of Health & Rehabilitation Services

Dr. Pridham's Research Team

Project Implementation at the Herma Heart Center, Children's Hospital of Wisconsin (CHW), Milwaukee:

Pediatric Translational Research Unit—Beth Gissibl, RN, BSN, Nurse Manager, and Nursing Staff, Natalie Bettin, BSN, RN, Ann Miller, BSN, RN, and Tina Murray, BSN, RN; Jeffrey Crawford, Research Coordinator

Mary Krolikowski, MSN, RN, Research Nurse

Amy Delaney, PhD, Speech & Language Pathologist

Katherine frontier, MS, Speech & Language Pathologist

Julie Slicker, MS, RD, Nutritionist

Ray Fedderly, MD, Pediatric Cardiologist

Michelle Frommelt, MD, Pediatric Cardiologist

Unit-based nurses:

Maura Flynn-Galganski, BSN, RN, and Paula Welch, BSN, RN, Coordinators of the Cardiology Fetal Diagnosis Clinic

Nicole Gereau, BSN, RN, and Alexis Sullivan, BSN, RN—Research Ambassadors on the Pediatric Cardiovascular Critical Care Unit

Co-Investigators:

Tondi Harrison, PhD, RN, The Ohio State College of Nursing, Columbus, Ohio

Janet Melby, PhD, Iowa State University, Ames, Iowa

Kathleen Mussatto, PhD, RN, Nurse Scientist at the Herma Heart Center, CHW

Roger Brown, PhD, University of Wisconsin-Madison School of Nursing

Consultant:

Suzanne Thoyre, PhD, RN, FAAN, University of North Carolina at Chapel Hill School of Nursing



School of Nursing
UNIVERSITY OF WISCONSIN-MADISON