Guided Participation to Support Parental Caregiving

Models, Processes, and Outcomes
Guided Participation to Support Parental Caregiving

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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 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

Motivation

ISSUES
Nurturing
Protecting
Relating
Guiding
Maintaining life quality
Guided Participation Model – Processes

- Issues
  - PROCESSES
    - Getting and staying connected
    - Joining attention; sharing understanding
    - Building bridges, making connections
    - Structuring the task and the learning
    - Transferring responsibility
  - COMPETENCIES
Guided Participation Model – Competencies

COMPETENCIES
- Being with the child
- Relating to the child as a person
- Giving care to the child
- Communicating and engaging
- Problem solving/decision making
- Regulating emotion

 ISSUES

PROCESSES
Complete Guided Participation Model

COMPETENCIES
- Being with the child
- Relating to the child as a person
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- Nurturing
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PROCESSSES
- Joining attention; sharing understanding
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- Transferring responsibility

Motivation
Applying Guided Participation to the Clinical Setting: Perinatal Bereavement

Rana Limbo
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: 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?

**Internal Environment**
- Brain injury/immaturity
- Altered ANS function
- Genetic syndromes

**Physical environment**
- Bright lighting
- Unpredictable noise
- Painful procedures
- Chemical odors

**Social environment**
- Aversive touch
- Multiple caregivers
- Limited holding
- Maternal separation

**Neurodevelopment**
- Cognitive
- Motor
- Social emotional
- Stress response (ANS)

**Physiologic Regulation**
Alterations in:
- ANS function
- HPA axis
- Sympathetic-adrenal-medullary axis
- Sleep organization

Adapted from: Weber, Harrison, & Steward, 2012
What impacts physiologic regulation in high-risk infants?

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Adapted from: Weber, Harrison, & Steward, 2012
Physiologic Regulation: Heart Rate Variability
Model for Studying ANS Function: Autonomic Regulation of Challenge

- State of homeostasis (HF HRV)
- Start challenge
- Stress response (HF HRV)
- End challenge

- CCHD or healthy
- Time since surgery

Maternal behavior
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

Healthy

TGA

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

Harrison, 2009; Harrison & Brown, 2012; Harrison, 2013
# Infant Social Engagement & Physiologic Regulation

## Parameter Estimates and Standard Error Infant Affect and Behavior

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Harrison & Ferree, 2014
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

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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
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- The American Heart Association

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- Gundersen Medical Foundation/www.gundersenhealth.org
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- www.respectingchoices.org
- 1900 South Avenue, La Crosse, WI 54601/Mailstop AVS-003
Dr. Harrison’s Credits/Funding

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- Research Institute, Nationwide Children’s Hospital

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  – Karen Pridham, PhD, RN, FAAN, University of Wisconsin-Madison

• **Co-Investigator**
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