Challenges in parenting of children with single ventricle

Gwen Rempel PhD, RN

54th Annual Meeting of Association for European Paediatric and Congenital Cardiology
Gothenburg, Sweden - VIRTUAL
May 25, 2021
Presenter Disclosure Information

Financial Disclosure: None

Unlabeled/Unapproved uses Disclosure: None

Permission to use Photos: Yes
OBJECTIVES

RECOUNT
- Rempeľ’s parenting research
- Lisanti and Kasprian research

EXPLORE
- Intervention studies, Stollery Children’s Hospital, Canada

RESOLVE
- To progress with interventions.
BACKGROUND

SAFEGUARDING SURVIVAL
Precarious survival of child, self and couple relationship
(Rempel & Harrison, 2007)

“TREAT YOUR CHILD NORMALLY”
Is this helpful advice?
(Rempel et al., 2009)

PARENTING UNDER PRESSURE
Iterative process
(Rempel et al., 2013)

PARENTAL VIGILENCE
Vigilant parental actions
(Meakins et al., 2015)

FACETS OF PARENTING
Theoretical model → interventions
(Rempel et al., 2013)
SAFEGUARDING SURVIVAL

Precarious survival of child, self and couple relationship
(Rempel & Harrison, 2007)

“TREAT YOUR CHILD NORMALLY”

Is this helpful advice?
(Rempel et al., 2009)

PARENTING UNDER PRESSURE

Iterative process
(Rempel et al., 2013)

PARENTAL VIGILENCE

(Meakins et al. Vigilant parental actions, 2015)

FACETS OF PARENTING

Theoretical model → interventions
(Rempel et al., 2013)
SAFEGUARDING SURVIVAL
Precarious survival of child, self and couple relationship
(Rempel & Harrison, 2007)

“TREAT YOUR CHILD NORMALLY”
Is this helpful advice?
(Rempel et al., 2009)

PARENTING UNDER PRESSURE
Iterative process
(Rempel et al., 2013)

PARENTAL VIGILENCE
(Meakins et al. Vigilant parental actions, 2015)

FACETS OF PARENTING
Theoretical model → interventions
(Rempel et al., 2013)
SAFEGUARDING SURVIVAL
Precarious survival of child, self and couple relationship
(Rempel & Harrison, 2007)

“TREAT YOUR CHILD NORMALLY”
Is this helpful advice?
(Rempel et al., 2009)

PARENTING UNDER PRESSURE
Iterative process
(Rempel et al., 2013)

PARENTAL VIGILENCE
(Meakins et al. Vigilant parental actions, 2015)

FACETS OF PARENTING
Theoretical model → interventions
(Rempel et al., 2013)
PARENTING UNDER PRESSURE
(Rempel et al., 2013)

- Realizing and adjusting to the inconceivable
- Making critical decisions
- Recognizing potential problems
- Growing increasingly attached
- Imagining the future for their child
- Watching for and accommodating the unexpected
- Transitioning between hospital and home
- Encountering new challenges
- Developmental transitions
- Realizing the precariousness of survival
- Adjusting expectations
- Seeing the baby as their child
SAFEGUARDING SURVIVAL
Precarious survival of child, self and couple relationship
(Rempel & Harrison, 2007)

“TREAT YOUR CHILD NORMALLY”
Is this helpful advice?
(Rempel et al., 2009)

PARENTING UNDER PRESSURE
Iterative process
(Rempel et al., 2013)

PARENTAL VIGILENCE
(Meakins et al. Vigilant parental actions, 2015)

FACETS OF PARENTING
Theoretical model → interventions
(Rempel et al., 2013)
PARENTAL VIGILANCE
Vigilant parental actions
(Meakins et al., 2015)
SAFEGUARDING SURVIVAL
Precarious survival of child, self and couple relationship
(Rempel & Harrison, 2007)

“TREAT YOUR CHILD NORMALLY”
Is this helpful advice?
(Rempel et al., 2009)

PARENTING UNDER PRESSURE
Iterative process
(Rempel et al., 2013)

PARENTAL VIGILENCE
(Meakins et al. Vigilant parental actions, 2015)

FACETS OF PARENTING
Theoretical model → interventions
(Rempel et al., 2013)
FACETS OF PARENTING
(Rempel et al., 2013)

Survival Parenting
Accommodating to complex and uncertain circumstances
It will test you to the utmost
Psychosocial intervention:
Addressing stress and vigilance

Hands-Off Parenting
Relinquishing care of child to service providers
There’s nothing we could do
Attachment intervention:
Promoting parent-child attachment

Figure 1: Theoretical model: Facets of parenting a child with hypoplastic left heart syndrome.
GUIDING CONCEPTS

TRAUMA
Pediatric medical trauma - child and parents

ATTACHMENT
Relationship-based parenting intervention
Individualized Family-Centered Developmental Care (IFCD) Model

A.J. LISANTI
PhD, RN, CCNS, CCRN-K
Nurse Scientist & Clinical Nurse Specialist

IFDC interventions to reduce the impact of environmental and early life stress on child neurodevelopmental outcomes in congenital heart disease. (Lisanti et al., 2019. J of Card Nurs)
... discuss the evidence for an integrated, life course approach, highlighting the areas where evidence is lacking and calling for national standards of mental health care in congenital heart disease (CHD). They explore the mental health of expectant parents, early life experiences of children with CHD, and the transition of adolescence. (Kasparian et al., 2016 Med J Aust)
1. FONTAN EDUCATION STUDY

RCT of three videos for parents; qualitative interviews as well (Rehman et al., 2020)

2. HEART HEROES CAMP EVALUATION

Medically complex children with CHD go to camp; parent and child interview data (Senych et al., 2020)

3. MedBIKE STUDY

Home-base HiIT bike program protocol and pilot (Khoury et al., 2021)

4. CIRCLE OF SECURITY

Protocol for intervention research (Rempel, 2020)
FONTAN EDUCATION
STUDY
PRE-OPERATIVE EDUCATION VIDEOS

1. Psychological distress
2. Prolonged pleural drainage
3. Postoperative anticoagulation
FONTAN EDUCATION STUDY

**DESIGN**
- Single-center mixed-methods cluster randomized controlled trial

**DATA**
- State Trait Anxiety Inventory
- Post Hospital Behaviour Questionnaire
- Telephone interviews

**SAMPLE**
- 26 children (13 females; 16 intervention group)
- and one parent/child

FINDINGS

STATE TRAIT ANXIETY INVENTORY
Mean State Trait Anxiety Inventory scores did not differ significantly between intervention vs. control at 1 week or 1 month postoperatively.

POST-HOSPITAL BEHAVIOUR QUESTIONNAIRE
Post-Hospital Behaviour Questionnaire scores were in the maladaptive range (>81) but did not differ between study groups.
“You grow so much more attached to your kid ... so it’s hard to think of any sort of negative outcome.”

“So, the videos, it’s not that they weren’t helpful, but I basically kind of had heard everything in them already.”

“I was hoping for more information on exactly what they were going to do.”

“I would love to watch a live Fontan procedure.”

“It’s almost like nothing ever, she’s just herself.”

“Other families were going through this ... you know they made it through... comfort knowing that ... and their children have been fine.”
HEART HEROES
CAMP STUDY
HEART HEROES CAMP STUDY
RESEARCH DESIGN

**DESIGN**
Single-center interview study; qualitative description

**DATA SOURCE & ANALYSIS**
Telephone interviews; content and thematic analysis

**SAMPLE**
10 campers (6 girls), and their mothers (n = 12); one year following camp

FINDINGS

**PARENT ANTICIPATORY CONCERNS**

C. limitations, safety, reaction to separation

“you never know what can happen”

**POSITIVE EXPECTATIONS**

“meet kids with ... similar scars, similar stories.”

“make friends”

“anxiety maybe lessening”

“confidence”

**OVERWHELMINGLY POSITIVE**

Zip lining, rock climbing, obstacle course, paddle boarding

“it felt like I fit right in”

**ORGANIZED**

“drop off process was smooth, welcoming and calm”

“nurse would call me”

“sent me a clip from the news of my child zip lining”

MEDBIKE™ STUDY
MEDBIKE™ STUDY RESEARCH DESIGN

PILOT
Safety and feasibility of high-intensity interval training (HIIT) via a novel telemedicine ergometer (MedBIKE™) in children with Fontan physiology

PHASE 1
N=10 (11.5 ± 1.8 years old, range 10-16 years, 30% male)
Completed a MedBIKE™ HIIT session with no adverse events

PHASE 2
N=2 (1 male); 8-week in-home-protocol was tolerated well with completion of 23/24 (96%) and 24/24 (100%) of sessions; no adverse events; improvements in VO2peak (50% for P1 and 8% for P2).

FINDINGS

PHYSICAL ACTIVITY CONCERNS

“Deep down I think I am pretty protective of her.”

“Outwardly we’ve made a conscious decision...to not hold her back in any way...more mindful.”

Getting tired too quickly; not keeping up; being made fun of; get hit in the chest; poor confidence

“It was safe the whole time.”

“They kept a really close eye on her.”

“It was excellent. ...well designed ...doable ...a great success.”

“Seeing her challenge herself ... they would say ‘You want us to back it off?’ She’d say ‘No I’m good. I want to turn it up a little bit I’m OK’.”

“Mom, I think I might throw up’. She never did, but she was pushing herself...the doctors were trying to encourage her but ...I’m thinking to ‘Did we sign up for more than we could handle?’”

MedBIKE™

GUIDING CONCEPTS

TRAUMA
Pediatric medical trauma - child and parents

ATTACHMENT
Relationship-based parenting intervention
CIRCLE OF SECURITY®
PARENTING™ PROGRAM

- Eight-session intervention rooted in attachment theory
- Aims to increase parent:
  - Relational capacity
  - Reflective functioning - to learn how to recognize, honour and give a name to their child’s emotions
  - Empathy towards their child

Cooper, Hoffman, & Powell, 2009
Powell et al., 2014
Early Intervention Programs for Parents & Children

An accessible step-by-step process driven by decades of attachment research

https://www.circleofsecurityinternational.com/
CIRCLE OF SECURITY PARENTING PROGRAM

RESEARCH PROTOCOL

- Before and After
  - Questionnaires
  - Semi-structured interviews
  - Observed play and clean-up sessions
PARCHISY CODING SYSTEM

- Parent-Child Interaction System
- Video taped play and clean-up – parent/child
- Parent-child mutuality

OBSERVATION MEASURE

Deater-Deckard et al., 1997
Deater-Deckard & O’Connor, 2000
Challenges in parenting of children with single ventricle

RESOLVE
To progress with interventions.

Theory and evidence based; Implemented and evaluated.
ACKNOWLEDGEMENTS

FONTAN EDUCATION STUDY
- Julie Rehman
- Elina Williams
- Andrew Mackie

HEART HEROES CAMP
- Devin Chetan
- Jacqueline Senych
- Telford Yeung
- Andrew Mackie

MEDBIKE™
- Michael Khoury
- Nee Khoo
- Jennifer Conway
- Andrew Mackie

CIRCLE OF SECURITY
- Tasha-Lynn Gregory
- Lorraine Thirsk
- Shawna Fraser
- Gina Wong

Presentation Design & Layout: Andrea Shippey-Heilman
REFERENCES


Rempel, G. R. et al. “There is so much more to a child than their heart”: Supports and services for children with complex congenital heart disease and their parents. Final report-Alberta Centre for Child, Family, & Community Research. DOI: 10.13140/2.1.2443.9366


Thank you

Dr. Gwen R. Rempel
grempel@athabascau.ca
@gwendolynrempel
https://gwenrempel.com/