

CARDIOLOGY
2023

Parents Post-traumatic Stress Before And After Their Infant's Second Palliative Heart Surgery: The PaTHS Descriptive Correlational Longitudinal Study

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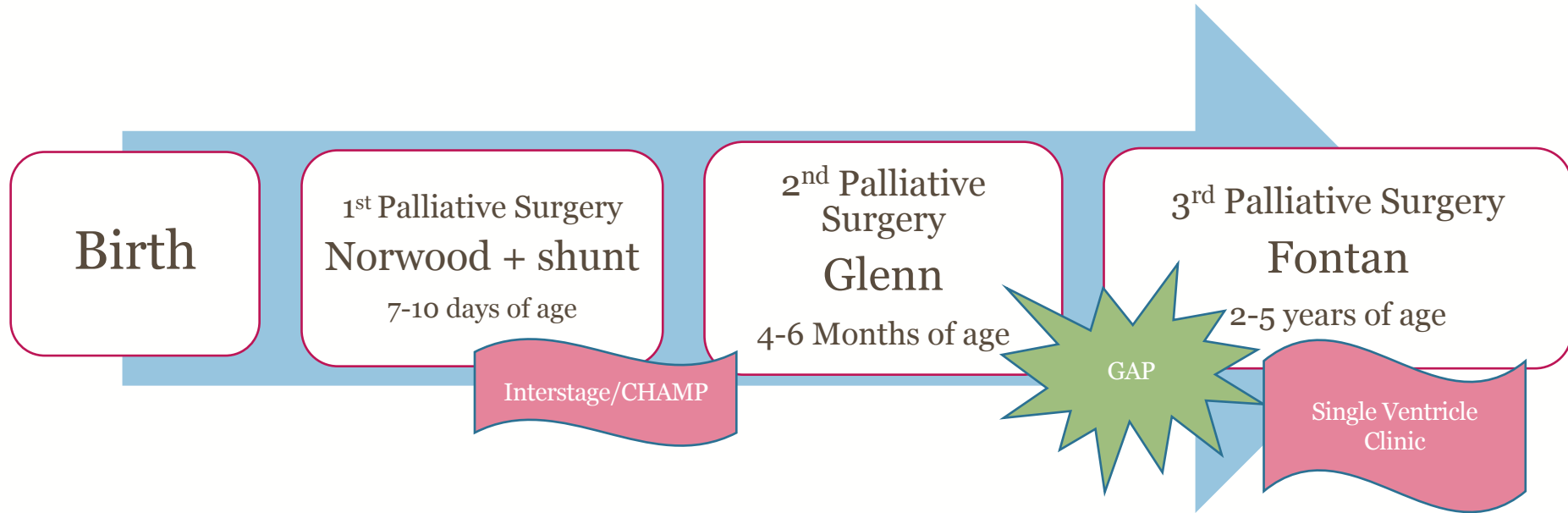
Children's Mercy
KANSAS CITY

DISCLOSURES

- I have no conflicts of interest to share.



INTRODUCTION



¹ Roger VL, Go AS, Lloyd-Jones DM, et al. *Circulation*. 2012;125(1):e2.

² Anderson JB, Beekman RH, Kugler JD, et al. *Circ Cardiovasc Qual Outcomes*. 2015;8(4):428-436.

³ Ghanayem NS, Allen KR, Tabbutt S, et al. *J Thorac Cardiovasc Surg*. 2012;144(4):896-906.

⁴ Goldberg DJ, Dodds K, Rychik J. *Cardiol Young*. 2011;21(S2):77-79. ⁵ Oster ME, Ehrlich A, King E, et al. *Circulation*. 2015;132(6):502-508.

RATIONALE



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- The purpose of this study is to describe and correlate the levels of parent posttraumatic stress before and after their infant's second palliative heart surgery.
- Research lacking on the parent experience after second surgery and on parent posttraumatic stress outside of the acute care setting.

SIGNIFICANCE

- Parenting infants with single ventricle congenital heart disease (SVCHD) is an extraordinary task¹
- Parents psychosocial wellbeing is associated with long term child outcomes ¹
- 83% of parents demonstrate posttraumatic stress symptoms in acute care setting²
- Child's medical fragility is lifelong³



¹ Kasparian et al. (2019). *Early Human Development*, 139, 104837. ² Cantwell-Bartl & Tibballs (2013). *Pediatric Critical Care Medicine*, 14(9), 869–875. ³ Elliott, M. et al. (2021). *Journal of Advanced Nursing*, jan.14785. <https://doi.org/10.1111/jan.14785>

QUALITATIVE WORK






- Qualitative Descriptive study with thematic analysis
- 8 previous Cardiac High Acuity Monitoring Program (CHAMP®) families
- Parents are ***defining a new normal*** cyclically
- Themes of medical, social, emotional, and growth
- Parents felt pressure to perform at a higher level than other parents
- “It changes you as a person”

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ORIGINAL RESEARCH: EMPIRICAL
RESEARCH - QUALITATIVE

JAN
Journal of Advanced Nursing Research WILEY

Defining a new normal: A qualitative exploration of the parent experience during the single ventricle congenital heart disease interstage period

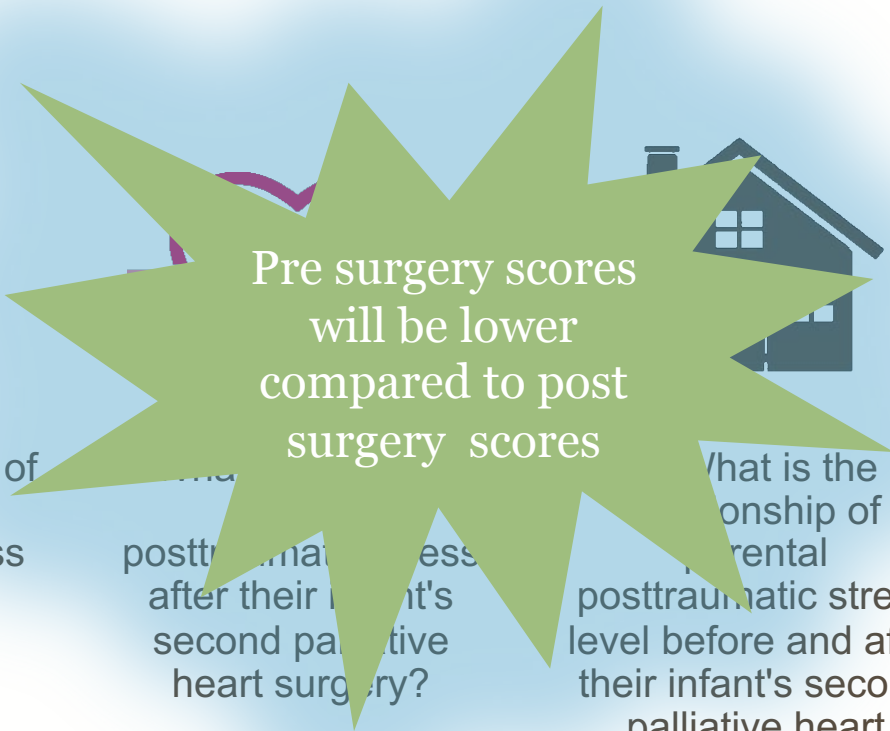
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¹ Elliott, M. et al. (2021). *Journal of Advanced Nursing*, jan.14785. <https://doi.org/10.1111/jan.14785>

RESEARCH QUESTIONS



1. What is the level of parental posttraumatic stress before infant's second palliative heart surgery?



2. What is the level of parental posttraumatic stress after their infant's second palliative heart surgery?



3. What is the relationship of parental posttraumatic stress level before and after their infant's second palliative heart surgery?



4. What demographic variables are the mediators and moderators of the findings?

METHODS

- Descriptive correlative design
- Setting- Children's Mercy Hospital
- Recruitment and data collection March 2021 - June 2022
- Convenience sample
- Inclusion Criteria
 - CHAMP
 - Parent \geq 18 years of age
 - Responsible for infant care at home
- Exclusion
 - Non-English or Spanish speaking
 - Child undergoing end of life care



METHODS

- Measured trauma using the Posttraumatic Stress Disorder Checklist for The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) (PCL-5)
 - Likert Scale
- Obtained the measurement 2-4 weeks prior to Surgery 2 and 2-4 weeks after surgery 2

PCL-5

Instructions: Below is a list of problems that people sometimes have in response to a very stressful experience. Please read each problem carefully and then circle one of the numbers to the right to indicate how much you have been bothered by that problem in the past month.

In the past month, how much were you bothered by:	Not at all	A little bit	Moderately	Quite a bit	Extremely
1. Repeated, disturbing, and unwanted memories of the stressful experience?	0	1	2	3	4
2. Repeated, disturbing dreams of the stressful experience?	0	1	2	3	4
3. Suddenly feeling or acting as if the stressful experience were actually happening again (as if you were actually back there reliving it)?	0	1	2	3	4
4. Feeling very upset when something reminded you of the stressful experience?	0	1	2	3	4
5. Having strong physical reactions when something reminded you of the stressful experience (for example, heart pounding, trouble breathing, sweating)?	0	1	2	3	4
6. Avoiding memories, thoughts, or feelings related to the stressful experience?	0	1	2	3	4
7. Avoiding external reminders of the stressful experience (for example, people, places, conversations, activities, objects, or situations)?	0	1	2	3	4
8. Trouble remembering important parts of the stressful experience?	0	1	2	3	4
9. Having strong negative beliefs about yourself, other people, or the world (for example, having thoughts such as: I am bad, there is something seriously wrong with me, no one can be trusted, the world is completely dangerous)?	0	1	2	3	4
10. Blaming yourself or someone else for the stressful experience or what happened after it?	0	1	2	3	4
11. Having strong negative feelings such as fear, horror, anger, guilt, or shame?	0	1	2	3	4
12. Loss of interest in activities that you used to enjoy?	0	1	2	3	4
13. Feeling distant or cut off from other people?	0	1	2	3	4
14. Trouble experiencing positive feelings (for example, being unable to feel happiness or have loving feelings for people close to you)?	0	1	2	3	4
15. Irritable behavior, angry outbursts, or acting aggressively?	0	1	2	3	4
16. Taking too many risks or doing things that could cause you harm?	0	1	2	3	4
17. Being "superalert" or watchful or on guard?	0	1	2	3	4
18. Feeling jumpy or easily startled?	0	1	2	3	4
19. Having difficulty concentrating?	0	1	2	3	4
20. Trouble falling or staying asleep?	0	1	2	3	4

SAMPLE DEMOGRAPHICS

	Frequency (%)
Gender parent (n=22)	
Male	2 (9.1)
Female	20 (90.9)
Other	
Income	
< \$20,000	2 (9.1)
\$20,000- \$40,000	5 (22.7)
\$40,000- \$60,000	4 (18.2)
\$60,000- \$80,000	5 (22.7)
>\$80,000	6 (27.3)
Education Level (years of education)	
1-12 years	8 (36.4)
13 years	1 (4.5)
14 years	2 (9.1)
16 + years	11 (50)
Family Structure	
Single parent	2 (9.1)
Two parents	19 (86.4)
Single parent plus extended family	1 (4.5)
Two parents plus extended family	1 (4.5)

SAMPLE DEMOGRAPHICS

	Min	Max	Mean	Median	Interquartile Range	
					25th	75th
Age of parent in years	20	42	30	29.50	25.5	32.50
Days in the intensive care unit before first discharge	7	75	29.64	27.50	18.50	37.50
Cardiac Bypass time (in minutes)						
Surgery 1	0	196	98.14	119.50	39.00	144.50
Surgery 2	55	219	118	106.00	71.50	164.50
Number of Medications						
Surgery 1	1	14	6.36	6.00	5.00	8.00
Surgery 2	5	14	8.5	9.00	7.00	9.50

INFANT DEMOGRAPHICS

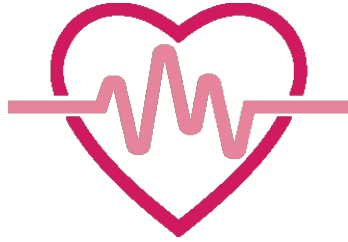
	Yes	No
Experienced cardiac resuscitation	2	20
Experienced extracorporeal membrane oxygenation	0	22
	Frequency (%)	
Diagnosed		
Prenatal	17 (77)	
Postnatal	5 (23)	
Route of Feeding Surgery 1		
By mouth (PO)	16 (73)	
By surgically placed feeding tube (GT)	2 (9)	
Combination of both (PO+GT)	4 (18)	
Route of Feeding Surgery 2		
By mouth (PO)	16 (73)	
By surgically placed feeding tube (GT)	1 (5)	
Combination of both (PO+GT)	5 (22)	

DATA ANALYSIS



RQ1 Trauma level
before surgery

Descriptive
statistics

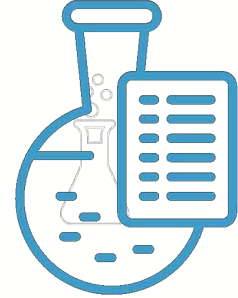


RQ2 Trauma level
after surgery

Descriptive
statistics



RQ3 comparing scores
before and after surgery
Wilcoxon signed rank test¹



RQ4 Mediators and
moderators of
scores Descriptive
Statistics

RESULTS

	n	Min	Max	Mean	Median	Interquartile Range	
						25th	75th
PCL- 5 pre surgery	22	0	61	26.45	23.00	11	44.25
PCL- 5 post surgery	22	0	52	18.68	16.00	4.75	32.75
Difference	22	-38	16	-6.77	-2.00	-15	1.25

**Positive score ≥ 31

FINDINGS RQ1

RQ1: What is the rate of clinically measurable post-traumatic stress on the PCL-5 2-4 weeks prior to surgery 2?

- Presurgery 9/22 (41%) of scores were positive
- *Anticipatory stress*
- *Intrinsic Trauma*
- *Surgical Delays*

FINDINGS RQ2

RQ2: What is the rate of clinically measurable post-traumatic stress on the PCL-5 2-4 weeks after surgery 2?

- Post surgery 6/22 (27%) of participants' scores were positive
- Significant endpoint to return to “normal”₁

FINDINGS RQ3

RQ3: What is the relationship between the two scores?

- Most of the scores 13/22 (59%) decreased between the two timepoints
- Statistically significant ($p=.027$)
- *Analysis revealed decreasing means instead of increasing ones*

FINDINGS RQ4

RQ4: What demographic variables are the mediators and moderators of the findings?

- Unable to draw any definitive conclusions without making possibly erroneous correlations

INTERPRETATION



- First study examining PCL-5 scores in the outpatient setting
- There are clinically measurable amounts of PTSD symptoms at both timepoints
- Rejected hypothesis that PTSD symptoms would increase after the second surgery, may be due to the timing
- Seven participants did follow the hypothesized findings
- Demographic data differs from our sites CHAMP data₁

CONCLUSIONS

- Results somewhat contradictory to previous findings
- Retrospective versus prospective study
- Significant symptoms found at both timepoints
- Follow up of scores provided an opportunity to counsel families



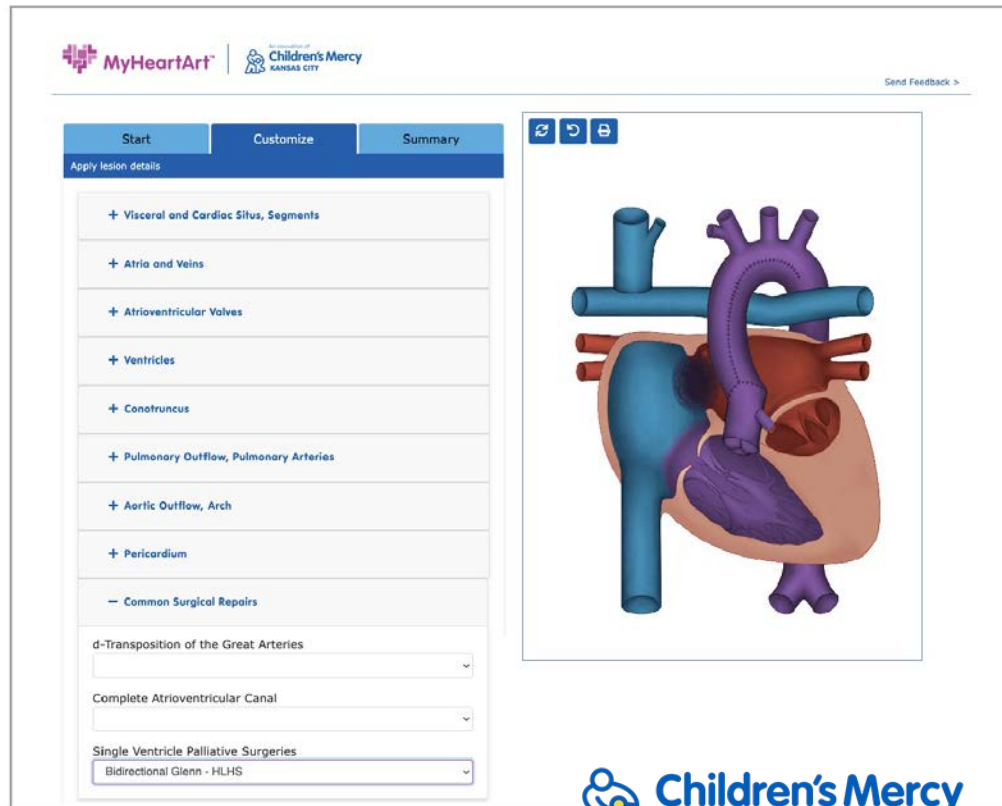
FUTURE RESEARCH

- Identify more definitive timeline of parent trauma
- Increase generalizability
- Avoid surgically timebound testing or intervention if possible
- Test new timepoints
- Consider including patients who stay in the hospital during the interstage



THANK YOU!

- Poster presentation on Sunday
- MyHeartArt



RESULTS

Survey timing in days

	PCL-5 #1 Pre-surgery	PCL-5 #2 Post- surgery
Mean	31	19
Median	23	17
Mode	21	14
Range	117	18
Minimum	1	14
Maximum	118	32