

# Parental mHealth Adherence: Results of the DOMAIN Study

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## DOMAIN

- A Descriptive Correlational Study Of Rate and Determinants of Parental mHealth Adherence to Symptom Home Monitoring for Infants with Congenital Heart Disease during the Single Ventricle Interstage Period



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## Objectives

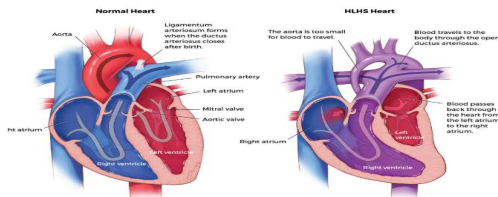
- Analyze the DOMAIN study which examines the rate and determinants of parental mHealth symptom home monitoring adherence for infants with congenital heart disease during the single ventricle interstage period
- Propose future investigations based on the determinants found during DOMAIN study on parental mHealth adherence



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## Background

- 1% of infants born with heart disease have single ventricle congenital heart disease.<sup>1</sup>



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Figure: Chidsey, B. Regents of the University of Colorado; 2017

1. Hoffman, J. L., & Kaplan, S. *Journal for American College of Cardiology*, 39(12), 10; 2002.



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### Background

1 → 2 → 3

Interstage

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### Background

- Interstage home monitoring<sup>1</sup>
  - Daily symptom monitoring with weekly reporting.
  - Oxygen saturation- pulse oximetry.
  - Infant weight- scales.
- Symptom Home Monitoring for Red Flags<sup>2</sup>
  - Changes in oxygen saturation.
  - Changes in heart rates.
  - Changes in weights.
  - Parent concerns.

1. Ghanayem, N. S., Hoffman, G. M., Mussatto, K. A., Cava, J. R., Frommelt, P. C., Rudd, N. A., . . . Tweddell, J. S. *The Journal of Thoracic and Cardiovascular Surgery*, 129(5), 1367-1376; 2003.
2. Shirali, G., Erickson, L., Apperson, J., Goggin, K., Williams, D., Reid, K., . . . Stroup, R. *Circulation: Cardiovascular Quality and Outcomes*, 9(3), 303-311; 2016.

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### Background

- Parental mHealth technology<sup>1</sup>
  - Improved pediatric disease management.
  - Better communication.
  - Improved decision-making with home monitoring.
- MHealth adherence
  - Pediatrics: Parental behavior.<sup>2</sup>

1. Slaper, M. R., & Conkol, K. *Pediatric Annals*, 43(2), e39-43; 2014.
2. Modi, A. C., Pai, A. L., Hommel, K. A., Hood, K. K., Cortina, S., Hilliard, M. E., . . . Drotar, D. *Pediatrics*, 129(2); 2012.

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### Concept Parental mHealth Adherence

Antecedents → Attributes → Consequences

Parent training by nurses

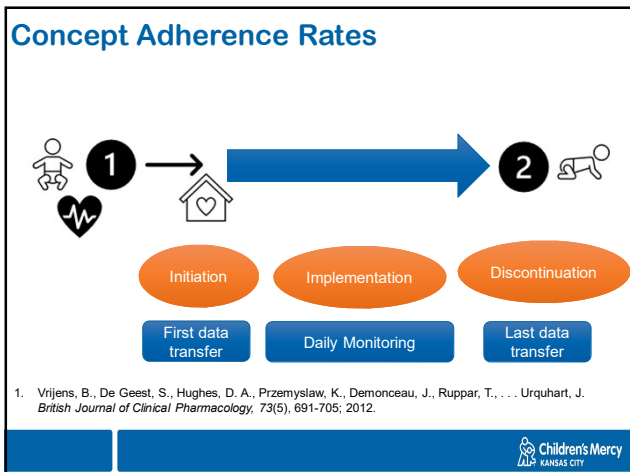
Development of mHealth Application, Efficiency, End user Satisfaction, Effectiveness

mHealth Use, Usability, Engagement, Social Determinants, Communication

Parental mHealth adherence, Non-adherence

1. Modi, A. C., Pai, A. L., Hommel, K. A., Hood, K. K., Cortina, S., Hilliard, M. E., . . . Drotar, D. *Pediatrics*, 129(2), e473-485; 2012.
2. Erickson, L., Emerson, A., & Russell, C. *JSPN*, . (2020).

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### Significance

- Symptom home monitoring: Reactive model<sup>1</sup>
- MHealth symptom home monitoring: Proactive
- Reduced mortality<sup>1</sup> and morbidity<sup>2</sup>

1. Shirali, G., Erickson, L., Apperson, J., Goggin, K., Williams, D., Reid, K., ... Stroup, R. *Circulation: Cardiovascular Quality and Outcomes*, 9(3), 303-311; 2016.  
 2. Bingler, M., Erickson, L. A., Reid, K. J., Lee, B., O'Brien, J., Apperson, J., ... Shirali, G. *World Journal for Pediatric and Congenital Heart Surgery*, 9(3), 305-314; 2018.

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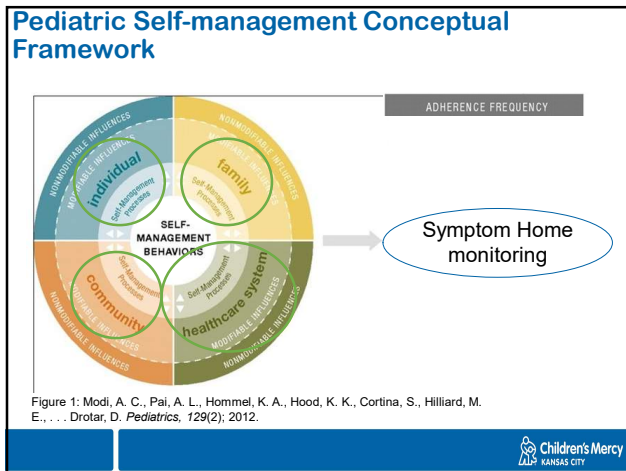
### Significance

- Few studies reporting outcomes of parental mHealth adherence<sup>1-2</sup>.
- Initiation- 3 days<sup>3</sup>
- Adherence to daily data- 50.3-80%<sup>2</sup>
- Non-adherence<sup>3</sup>

1. Shirali, G., Erickson, L., Apperson, J., Goggin, K., Williams, D., Reid, K., ... Stroup, R. *Circulation: Cardiovascular Quality and Outcomes*, 9(3), 303-311; 2016.  
 2. Bingler, M., Erickson, L. A., Reid, K. J., Lee, B., O'Brien, J., Apperson, J., ... Shirali, G. *World Journal for Pediatric and Congenital Heart Surgery*, 9(3), 305-314; 2018.  
 3. Black, A. K., Sadanala, U. K., Mascio, C. E., Hornung, C. A., & Keller, B. B. Challenges in implementing a pediatric cardiovascular home telehealth project. *Telemedicine and e-Health*, 20(9), 858-867; 2014.

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### Research Design

- Descriptive, cross-sectional, correlational retrospective design using structural equation modeling.
- Structural equation modeling can test theories with variable relationships.

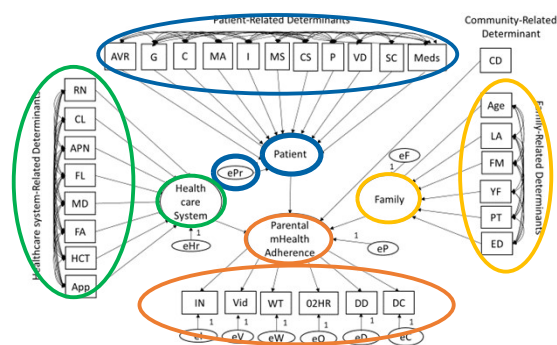
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### Research Questions

1. What is the rate of parental mHealth symptom home monitoring initiation, implementation, and discontinuation adherence of infants with single ventricle heart disease during the interstage period?
2. What is the relationship between patient-related, family-related, community-related, and healthcare system-related determinants and parental mHealth symptom home monitoring adherence of infants with single ventricle congenital heart disease during the interstage period?

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### Hypothesized Model



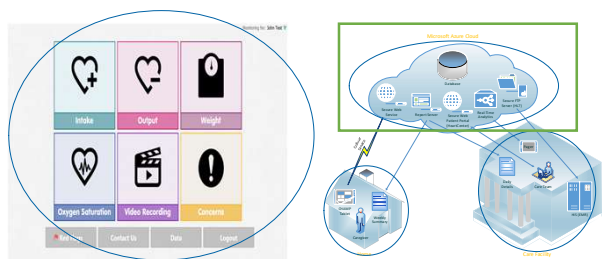
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### Setting

- Cardiac High Acuity Monitoring Program: CHAMP®.
- Clinical interstage application with retrospective registry and existing data set.
- Multi-site registry from 9 pediatric hospitals
  - Children's Mercy, Seattle Children's, Primary Children's, Cincinnati Children's, Nationwide Children's, Arkansas Children's, West Virginia University, Cook Children's, & Children's National

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## CHAMP Application



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## Sample

- 312 infants with single ventricle congenital heart disease.
- March 2014- October 2019.
- Power analysis 300 infants,  $dF$  492 at alpha .05, RMSEA .08. Variables to participant ratio 1:8.82.

1. MacCallum, R. C., Browne, M. W., & Sugawara, H. M. *Psychological Methods*, 1(2), 19; 1995.

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## Procedures

- Each multi-site center was trained for data entry by primary investigator.
- Children's Mercy Kansas City Institutional Review Board (IRB) with interagency agreement at UMKC for non-human subjects.
- After IRB approval, de-identified data from registry received by primary investigator.
- Data stored in REDCap® from UMKC.

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## Measures


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### Parental mHealth Adherence

- Initiation (IN)<sup>1</sup>: First day of data transfer.
- Implementation- Data days (DD)<sup>2</sup>: Number of non-hospitalized days data is transferred.
- Implementation- Weight (WT): Number of weights received per recommended rate.
- Implementation- Oxygen saturation/heart rate (O2HR): Number of O2HR received per recommended rate.
- Implementation- Video (Vid): Number of videos received for recommended rate.
- Discontinuation (DC): Last day of data transfer.

1. Vrijens, B., De Geest, S., Hughes, D. A., Przemyslaw, K., Demonceau, J., Ruppard, T., . . . Urquhart, J. *British Journal of Clinical Pharmacology*, 73(5), 691-705; 2012.


2. Bingler, M., Erickson, L. A., Reid, K. J., Lee, B., O'Brien, J., Apperson, J., . . . Shirali, G. *World Journal for Pediatric and Congenital Heart Surgery*, 9(3), 305-31; 2018.



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### Determinants

- **Patient-related**: Gender, cardiac diagnosis, secondary cardiac diagnosis, cardiac surgery type, prenatal detection rate, single ventricle dysfunction, av valve regurgitation, age at discharge, # of interstage days, major syndromes, major anomalies of other systems, # of medications
- **Family-related**: Age of primary caregiver, education level, primary language at home, # of family members in home, # kids in home, insurance type
- **Healthcare system-related**: Clinic visits, interstage communications
- **Community-related**: Distance from tertiary center



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# Results




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### Infant Demographic Results

n=312

Demographic Variable	Description	Frequency % or Mean ± SD
Race	White	81.7%
	Black/African American	9.6%
	Native American	1.3%
	Asian	2.2%
Ethnicity	Hispanic	13.5%
Birthweight	Kilograms	3.14 ± 0.53
Gestational Age	Weeks	38.2 ± 1.67
Interstage Hospital Readmission	Days	12.44 ± 21.57
End of study status	Stage 2 surgery	97.1%
	Death	2.9%



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### Patient-related Descriptive Statistics

n=312		
Variable	Description	Frequency
Cardiac Diagnosis	Hypoplastic left heart syndrome	36.6%
	Double inlet left ventricle	18.6%
	Unbalanced canal	11.2%
	Tricuspid atresia	10.6%
	Double outlet right ventricle	16.7%
Cardiac Surgery Type	Norwood and variants	53.1%
	Shunt for pulmonary blood flow	21.8%
	Pulmonary Artery Band/Other	12.9%
	No Stage 1 at Neonatal Discharge	12.2%
Prenatal Detection	Yes	82.7%

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### Patient-related Descriptive Statistics

n=312		
Variable	Description	Frequency or Mean $\pm$ SD
Secondary Cardiac Diagnosis	None	75.0%
	Pulmonary venous abnormality	3.5%
	Restrictive atrial septum	6.1%
	Combinations of secondary diagnoses	6.1%
Interstage Length	Days	126 $\pm$ 71.7
Medications at Discharge	0-11 Range	3.45 $\pm$ 2.2

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### Patient-related Descriptive Statistics

n=312		
Variable	Description	Frequency or mean $\pm$ SD
Major Genetic Syndrome	None	82.1%
Major Non-Cardiac Anomalies	None	87.8%
Ventricular Dysfunction	None	92.3%
Atrioventricular Valve Regurgitation	None	49.4%
	Mild	28.8%
	Moderate	15.7%
	Severe	0.6%
Age at Initial Discharge	Days	45 $\pm$ 39
Gender	Female	37.5%

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### Family-related Descriptive Statistics

n=312		
Variable	Description	Frequency or Mean $\pm$ SD
Primary Caregiver	Mother	96.2%
Age of Primary Caregiver	Years	28.2 $\pm$ 6.1
Education Level of Primary Caregiver	Years	13.4 $\pm$ 2.4
Language at Home	English	94.2%
Total Family Members	0-11 range	3.5 $\pm$ 1.5
Children in the Home	0-9 range	1.32 $\pm$ 1.4
Insurance Payer Type	Medicaid/State insurance	53.8%

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### Family-related Descriptive Statistics

n=312		
Variable	Description	Frequency
Distance from Tertiary Center	0-10 Miles	11.5%
	11-20 Miles	12.8%
	21-50 Miles	12.8%
	51-100 miles	20.8%
	Greater than 100 miles	41.7%



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### Healthcare System-related Descriptive Statistics

n=312 Descriptive statistics - Healthcare team-related		
Variable	Description	Mean ± SD
Clinic visits		5.6 ± 3
Red Flag Communications	CHAMP App	2.2 ± 6.6
	Parent Initiated Call	2.5 ± 3.5
	Team Initiated Call	1.1 ± 1.6
Initial Contact	Nurse	2.1 ± 3.4
	Advanced Practice Nurse	3.3 ± 5.7
	Fellow	0.5 ± 3.8
	Attending	0.1 ± 4.4



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### Transformations

- Missing data
  - Expectation-maximization algorithm.
- Distribution
  - Two Step Approach for normalization.
- Categorical
  - Rank transformation.



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What is the rate of parental mHealth symptom home monitoring initiation, implementation, and discontinuation adherence of infants with single ventricle heart disease during the interstage period?

### Research Question 1



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### Rate of Parental mHealth Symptom Home Monitoring Adherence

n= 312

	Min	Max	Mean	SD	Median
Initiation (IN) (days)	0	104	5.28	15.03	0
Implementation- WT %	.36	533.33	64.81	42.0	62.5
Implementation- O2 %	1.68	1313.9	103.01	114.4	86.22
Implementation- HR %	1.68	1313.9	103.01	114.4	86.22
Implementation- Vid %	0	500	52.86	47.29	43.5
Implementation- DD%	1.68	100	75.54	30.22	92.7
Discontinuation (DC) (days)	0	167	15.56	27.42	4

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### Outcome Correlations

	Initiation	Data days	Weight	Video	O2/HR
Data Days	-.222				
Weight	-.289	.736			
Video	-.255	.533	604		
O2/HR	-.163	.607	617	.422	
Discontinuation	.054	-.563	-.364	-.272	-.178

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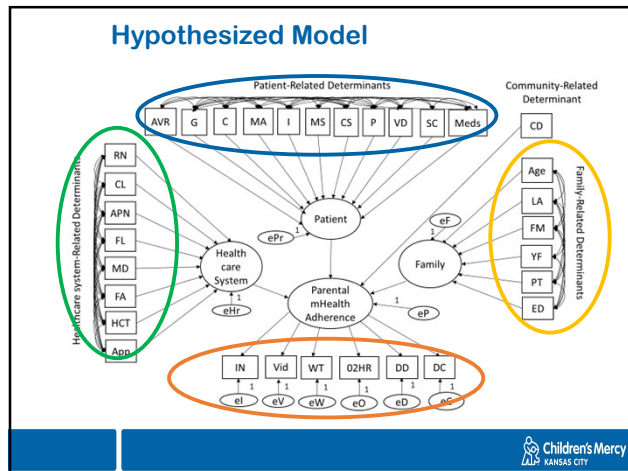
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What is the relationship between patient-related, family-related, community-related, and healthcare system-related determinants and parental mHealth symptom home monitoring adherence of infants with single ventricle congenital heart disease during the interstage period?

## Research Question 2

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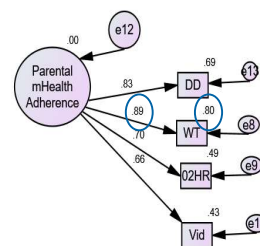
### Determinants Factor Loading

- **Patient-related:** Secondary cardiac diagnosis, cardiac surgery type, prenatal detection rate, single ventricle dysfunction, major syndromes, # of medications
- **Family-related:** Age of primary caregiver, education level, primary language at home, # of family members in home, # kids in home, Insurance type, Distance from tertiary center
- **Healthcare system-related:** Clinic visits, interstage communications

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### Measurement Model

- Exploratory Model
  - Factor Loading.
  - Removed- Initiation (IN) and Discontinuation (DC).



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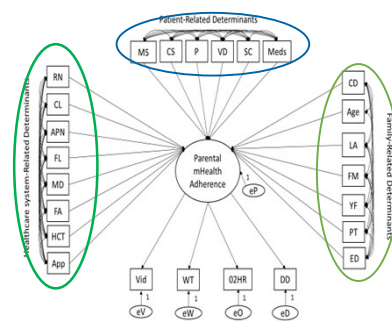
### Determinants of Parental mHealth Symptom Home Monitoring Adherence

- Final Model explained through:
  - Structural Model
  - Modification Indices
  - Model Analysis
  - Outcome Variable Variances
  - Direct Regression Weights

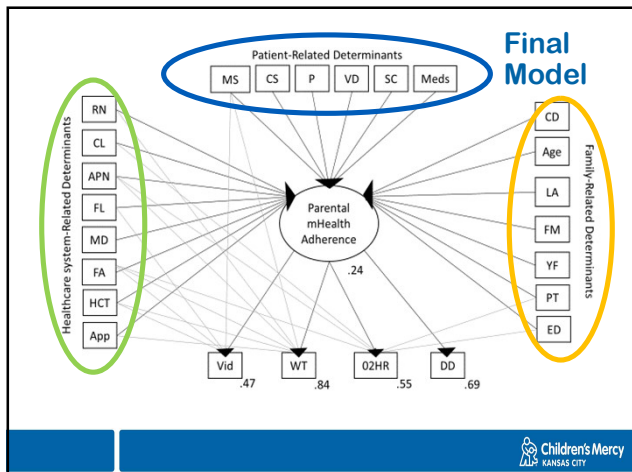
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### Structural Model

- Multiple Indicators Multiple Cause (MIMIC) Model
  - Reflective indicator variable.
- Model Trimming and Building.



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**Model Analysis**

- Theoretically identified, recursive structural equation model (SEM).
- Degrees of Freedom (df)= 182.
- Parameters= 143.
- Sample moments= 325.

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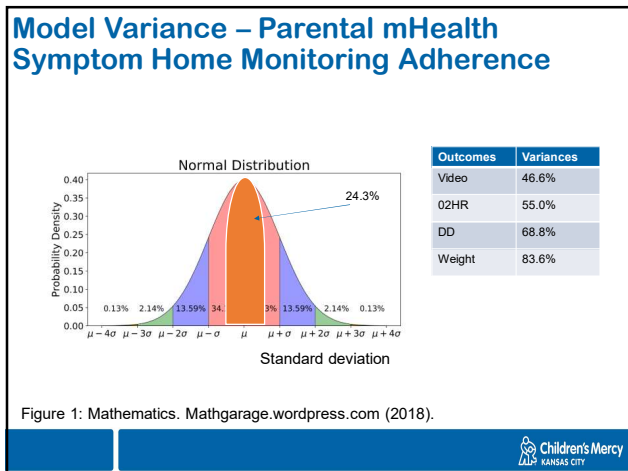
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**Final Model Evaluation**

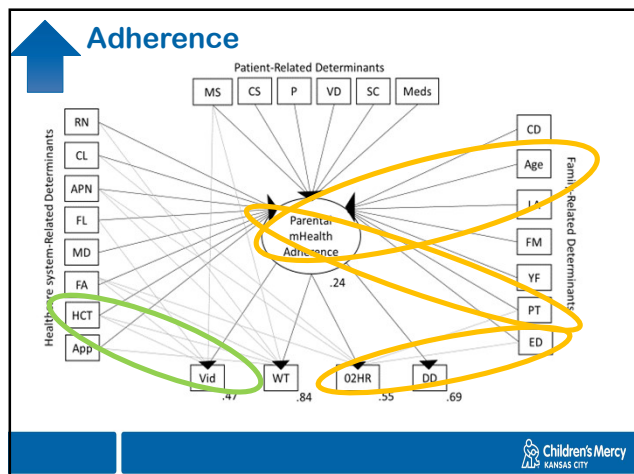
Variable	Finding	Goal
Chi-Square	200.25	≠ Above 0
p-value	.168	↑ Above 0.05
Standard root mean square (SRMR)	.0430	↓ Close to 0
Root mean square error of approximation (RMSEA)	.018 [0.0, .032]	↓ Close to 0
Comparative Fit index (CFI)	.995	↑ Close to 1
Bootstrapping Variance	.243 [0.0, .279]	= Close to .243

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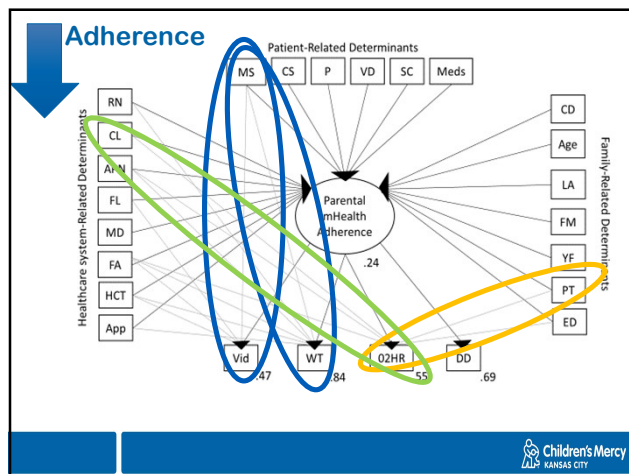
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### Discussion- Rate

- Initiation- Lower median than previous publications.<sup>1</sup>
- Implementation
  - Data days- 75%<sup>2,3</sup>
  - Video- 50%
  - Weight- 60%
  - O2/Heart rate- 103%
- Discontinuation- 4-day median.

1. Black, A. K., Sadanala, U. K., Mascio, C. E., Hornung, C. A., & Keller, B. *Telemedicine and e-Health* (2014).
2. Cross, R., Steury, R., Randall, A., Fuska, M., & Sable, C. *Future Cardiology*, (2012).
3. Binglel et al. *World Journal of Pediatric and Congenital Heart surgery*, (2018).

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### Discussion- Increased adherence

<p><b>Family-related</b></p> <ul style="list-style-type: none"> <li>• Primary Caregiver Age<sup>1</sup></li> <li>• Payer Type<sup>2</sup></li> <li>• Education Level increased O2/HR<sup>2</sup></li> </ul>	<p><b>Healthcare system</b></p> <ul style="list-style-type: none"> <li>• Healthcare team video review</li> </ul>
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1. Black, A. K., Sadanala, U. K., Mascio, C. E., Hornung, C. A., & Keller, B. *Telemedicine and e-Health* (2014).
2. Demianczyk et al. *Journal of Pediatrics* (2019).

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### Discussion- Decreased adherence

<p><b>Patient-related</b></p> <ul style="list-style-type: none"> <li>• No Major Syndromes- less Video and Weight<sup>1-3</sup></li> </ul> <p><b>Family-related</b></p> <ul style="list-style-type: none"> <li>• Payer type- Medicaid Less Q2HR</li> </ul>	<p><b>Healthcare system</b></p> <ul style="list-style-type: none"> <li>• Increased clinic visits with less oxygen saturation/heart rate<sup>1</sup></li> </ul>
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1. Bingler et al. *World Journal of Pediatric and Congenital Heart surgery*, (2018).  
 2. Harasheh et al., *Pediatric Cardiology*, 37(5), 899-912, (2016).  
 3. Nkoy et al., *International Journal of Medical Informatics* (2019).



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### Limitations


- Outliers and missing data requiring imputation.
- Retrospective data set.
- Multiple Indicators Multiple Cause (MIMIC) Model.
- Exploratory model.



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### Implications


- Clinical Practice
  - Healthcare team communication and video.
  - Rate of clinic visits.
  - Family centered care for infants without major syndromes.
  - Equity of care with mobile version.



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### Implications

- Theory
  - Pediatric Self-management Conceptual framework and clinical outcomes.
- Policy
  - Advocates at state and federal level for improved access and coverage with association of Medicaid payer type with increased adherence.
  - Telemedicine reimbursement.



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## Implications

- Research
  - Initiation and discontinuation time to event analysis.
  - Clinic Visits and non-adherence.
  - Patterns of decreased implementation with events like readmissions and clinic visits.
  - mHealth Video Review.
  - Parental health belief and implementation adherence.
  - Parental mHealth adherence and clinical outcomes.

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## Conclusions

- Parental symptom home monitoring mHealth adherence
  - Mean rate of data days of 75%.
  - Explained through initiation, implementation of weight, O2HR, video, and data days, and discontinuation.
  - Explained through SEM with multi-factorial patient, family, and healthcare system-related determinants.

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- Bingler, M., Erickson, L. A., Reid, K. J., Lee, B., O'Brien, J., Apperson, J., . . . Shirali, G. (2018). Interstage outcomes in infants with single ventricle heart disease comparing home monitoring technology to three-ring binder documentation: a randomized crossover study. *World Journal for Pediatric and Congenital Heart Surgery*, 9(3), 305-314. doi:10.1177/2150135118762401
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