Parent Discharge Education & Readiness for the Transition to Home after Congenital Heart Surgery

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Background

- Optimal inpatient care & discharge readiness is associated with favorable outcomes including reduction in hospital readmissions & increased medication adherence in the adult medical-surgical population (1,2)
- Discharge readiness research within the complex medical pediatric population has been limited to needs assessments & directed towards streamlining the discharge education process
- Congenital heart disease (CHD) populations, especially interstage/single ventricle, are at high risk for significant morbidity & mortality (3)
- We sought to describe our institutions current discharge processes & parent's discharge readiness within the postsurgical population
- We hypothesize that families who report "lower scores of discharge readiness" would include younger patients of more vulnerable surgical categories (high STAT, interstage) & lower socioeconomic status (SES)

Methods

- Prospective study at a large pediatric tertiary referral center including patient families whose children underwent CHD surgery from April to December 2021
- Parents & caregivers were approached within 24 hours prior to discharge; consenting families participated in filling out the modified Readiness for Hospital Discharge Scale (mRHDS), a validated instrument to measure discharge readiness (4)
- Surveys were administered at 3 time-points: 1) day of discharge, 2) one week post-discharge, 3) one month post-discharge
- Surveys were completed verbally with a research team member or occasionally used a tablet only at time of discharge
- Primary outcome was parent/caregiver discharge readiness via mRHDS score
- mRHDS score is broken down into 5 domains: 1) Parent Personal Status, 2) Child Personal Status, 3) Knowledge, 4) Coping Ability, 5) Expected Support
- Scores were calculated with the median value & broken into 4 categories: 1) Very High (9-10), High (8-8.9), Moderate (7-7.9), Low (<7)
- An additional domain was created for this study: 6) Cardiac Care Knowledge (of note, this was not included in the mRHDS score)
- A total of 199 eligible families were identified; 54 families were missed for consent
 - 128 families consented to the study & completed mRHDS survey 1; 17 families refused
 - 115 families completed survey 2
 - 86 families completed survey 3
- Survey data from time-points 2 and 3 will be presented in a future study

Results and Analysis										
Table 1. Parent and patient characteristics Table 3. Linear regression models examining for six predictors with										
	Parent Characteristics	Participants (n=128)	Patient Characteristics	Participants (n=128)	mRHDS survey 1 scor freedom.	es. Note: CI, confidence	e interval; df, degree of			
kelation to Patient, n (%)	Mother	116 (91%)	Age at surgery (days), median (IOR)	168 (16.5, 1352 8)		Model 1	Model 2			
	Father	11 (8.6%)	Cardiac Lesion, n (%)			Coefficient (95% Cl, p- value)	Coefficient (95% CI, p- value)			
~		21 (0.0%)	ASD or VSD	11 (8.9%) 14 (11%)	Parent age	-0.03 (-0.06 to 0.00,	-0.03 (-0.06 to 0.01,			
, n (%)	Age, median (iQit)	2 (1.6%)	Transposition of the	9 (7.3%)	Patient age	p=0.097)	p=0.107) 0.16 (-0.42 to 0.75, p=0.580)			
	Black	11 (8 6%)	Great Arteries (IGA)	16 (13%)		0.22 (-0.30 to 0.75, p=0.405)				
	Hispanic or Latino	4 (3.1%)	Hypoplastic Left Heart	20 (16%)	(>=1 yr old vs. < 1 yr old)	$0.04 (0.46 \pm 0.027)$	$0.02(0.42 \pm 0.20)$			
Sace	White	106 (83%)	Syndrome (HLHS)	20(1070)	SES (4-5 vs. 1-3)	p=0.834	p=0.916)			
	Other	7 (5.5%)	Pulmonary Atresia (PA)	1 (0.8%)	First surgery (yes vs. no) -0.26 (-0.72 to 0.20,		0.24 (-0.22 to 0.69,			
Ethnicity, n (%)	Hispanic, Latino or Spanish origin	5 (3.9%)	Total anomalous pulmonary venous return (TAP\/R)	1 (0.8%)	STAT category (3-5 vs. 1- 2)	0.14 (-0.26 to 0.55, p=0.486)	0.12 (-0.27 to 0.52, p=0.540)			
	Not Hispanic, Latino, or Spanish origin	121 (95%)	Coarctation of the aorta	16 (13%)	Interstage (yes vs. no)	-0.20 (-0.89 to 0.48, p=0.555)				
	Unknown	2 (1.6%)	Double Outlet Right	(1.370)	Tube feeds (yes vs. no)		-0.10 (-0.55 to 0.35,			
(%)	Male	11 (8.6%)	Ventricle (DORV)	6 (4.8%)		0.883 (df - 6, 121, p-	p=0.660			
D Gel	Female	117 (91%)	disease	26 (20.3%)	F-statisics (df, p-value)	0.510)	0.529)			
cial us,	Single	32 (25%)	Comorbidities**, n (%)	80 (62%)	R square	0.042	0.04			
Mart Stati n (%	Married	73 (57%)	First cardiac surgery, n (%)	83 (65%)	Adjusted R square	-0.006	-0.00			
	Other	23 (18%)	STAT category, n (%)							
	Living with another adult at home, n (%)	113 (88%)	1	27 (21%) 36 (28%)			and the second se			
(%)	Public	62 (48%)	3	24 (19%)						
er, n	Private	65 (51%)	4	29 (23%)	and the state of the second					
Рау	Self	1 (0.8%)	5	12 (9.4%)	and the second second	the second second				
	Less than high school	3 (2.3%)	Tube feeds at home, n (%)	66 (52%)		212				
(%) L	Completed high	33 (26%)	Home oxygen, n (%)	24 (19%)			- All			
tion, r	Trade school or	29 (23%)	IV medications at home, n (%)	2 (1.6%)	XI	~ /) =	33 N			
Educa	Undergraduate degree	37 (29%)	Arrhythmia medications for home, n (%)	5 (3.9%)						
	Graduate degree	26 (20%)	medications, median	4 (2, 6)		A state said for the state	Image 1. Digital			
ead	Professional	58 (45%)	(IQR)	ome of the			representation of			
omio ngshe (%)	Minor professional	23 (18%)	following: Trisomy 21, 22q	11 deletion			post-op CHD			
econ Iollir x), n	Skilled worker	19 (15%)	syndrome, heterotaxy syne tethered cord syndrome.	drome,	1 all all and		patient for future parent VR-based			
ocio us (F Inde	Semi-skilled worker	17 (13%)	sleep apnea (OSA), CHARG	SE syndrome,			simulation			
S stat	Menial worker	11(8.6%)	atrial tachycardia), premat	turity						

Table 2. Comparisons of mRHDS survey 1 scores with patient age (including interstage group), SES, STAT category, and first surgery. ¹Wilcoxon rank-sum test; ²Kruskal-Wallis test

	Overall, n=128	First surgery	Not first surgery	p-value ¹	SES 1-3	SES 4-5	p-value ¹	Interstage	Infants (non- interstage)	Children	p-value ²
mRHDS score, median (IQR)	8.6 (7.5 <i>,</i> 9.2)	8.7 (8.2, 9.2)	8.4 (7.8, 9.0)	0.04	8.8 (8.2 <i>,</i> 9.2)	8.5 (7.8, 9.0)	0.2	9.0 (8.3 <i>,</i> 9.4)	8.6 (8.1 <i>,</i> 9.1)	8.5 (7.8, 9.0)	0.2
Parent personal status	8.4	8.5	8.1	0.3	8.8	8.4	0.3	8.8	8.4	8.2	0.02
Child personal status	7.2	7.4	6.6	0.03	7.8	6.8	0.01	7.5	7.4	6.4	0.7
Knowledge	9	9	9.2	0.5	9	9.1	0.6	9.3	9	9.2	0.3
Coping ability	9.7	9.7	10	0.8	10	9.7	0.04	10	9.7	10	0.6
Expected support	9.8	10	9	0.02	9.8	9.5	0.8	10	9.8	9.5	0.6
Cardiac care knowledge	9.3	9	9.3	0.2	9	9.3	0.04	8.8	9	9.3	0.2



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Results and Analysis

Table 4. Comparison of clinical engagement with SES clusters & age
 groups. Note: **number of clinic visits within 30 days post-discharge; +one patient family was noted to have no documented clinic followup after discharge; ¹Chi-square test

		Overall, n=128	SES 1-3	SES 4-5	p-value ¹	Interstag e	Infants (non- interstag e)	Children	p-value ¹
calls	0 to 1 calls	85 (66%)	29 (62%)	56 (69%)		5 (42%)	44 (66%)	36 (73%)	
Phone	2 or more calls	43 (34%)	18 (38%)	25 (31%)	0.5	7 (58%)	23 (34%)	13 (27%)	0.1
sits	1 visit	71 (56%)	26 (57%)	45 (56%)		1 (8.3%)	42 (64%)	28 (57%)	
Clinic vi	2 or more visits	56 (44%)	20 (43%)	36 (44%)	>0.9	11 (92%)	24 (36%)	21 (43%)	0.002
visits	0	100 (78%)	31 (66%)	69 (85%)		7 (58%)	49 (73%)	44 (90%)	
ED v	1 or more	28 (22%)	16 (34%)	12 (15%)	0.02	5 (42%)	18 (27%)	5 (10%)	0.02
oital issions	0	101 (79%)	32 (68%)	69 (85%)		4 (33%)	53 (79%)	44 (90%)	
Hosl readmi	1 or more	27 (21%)	15 (32%)	12 (15%)	0.04	8 (67%)	14 (21%)	5 (10%)	<0.001

Conclusions

- The mRHDS scores were overall 'High' to 'Very High' across group categories
- families
- Highest risk populations with respect to clinical engagement remain those of the interstage population, younger patients, and lower SES
- There is a considerable gap when equating mRHDS discharge readiness scores & clinical engagement; this may be due to parents not knowing what to expect even with current discharge models creating a sense of confidence (based on high mRHDS scores)
- Future studies should look to expand studies to multiple centers & a wider range of diversity including non-English speaking families
- Future interventions can include novel educational modalities to help parents further conceptualize medical emergencies in patients, such as VR simulation (Image 1)

References

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- The mRHDS was not predictive in clinical engagement for

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