

# **Examining Health Literacy among Caregivers of Children Diagnosed with a Critical Congenital Heart Defect Participating in a Simulation Program**



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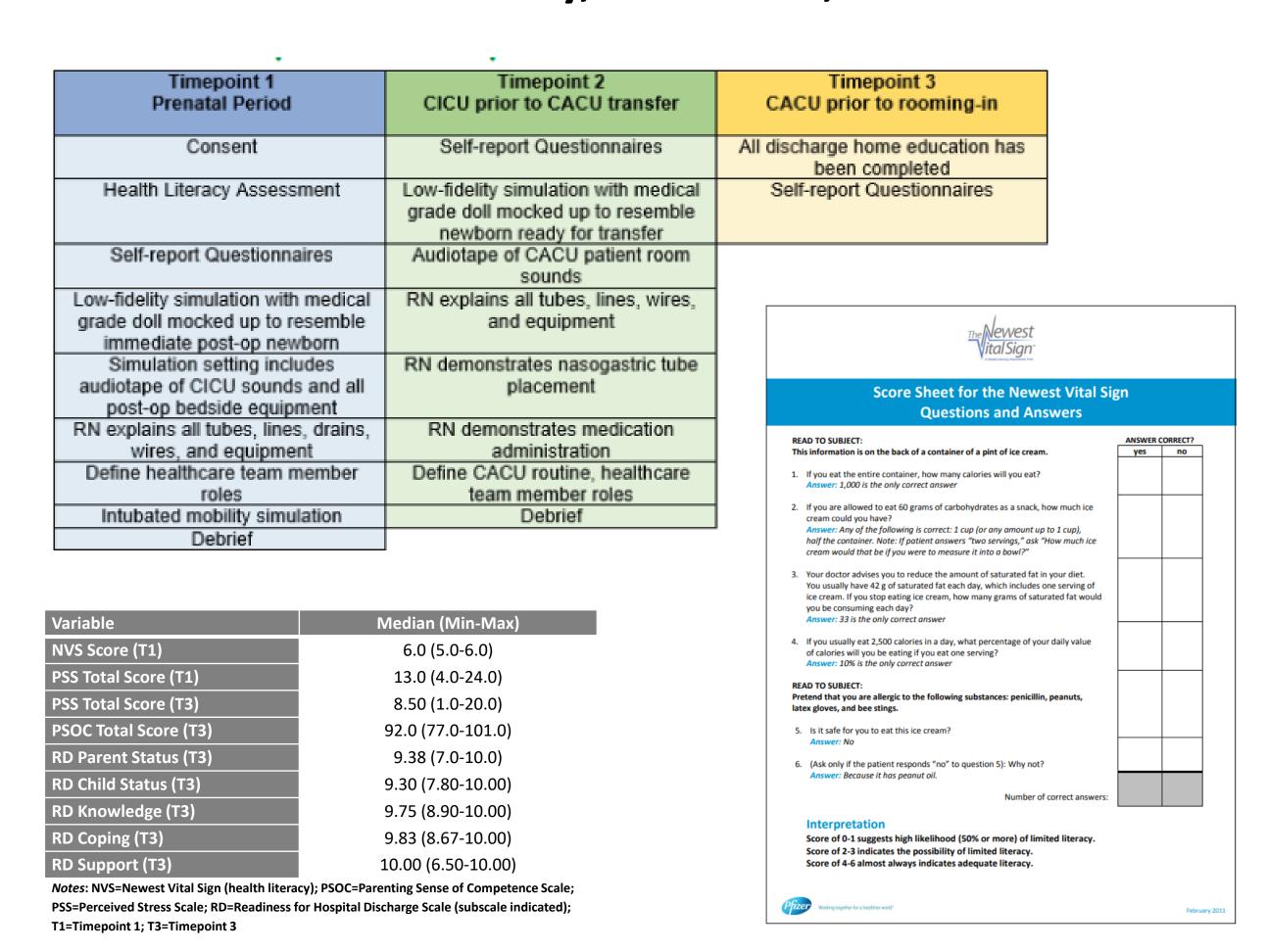
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#### Introduction

- Caregivers of infants with critical congenital heart disease (CCHD)
   require complex education that must be met prior to discharge home.<sup>4</sup>
- Caregivers of critically ill neonates are at an increased risk for stress, which may impact the ability to learn complex skills.<sup>3</sup>
- Low health literacy in combination with stressful situations, such as a CCHD diagnosis and surgery, may interfere with their ability to competently provide home care.<sup>2</sup>
- The purpose of this study is to assess health literacy among caregivers of infants with CCHD who require cardiac surgery after birth participating in a low-fidelity simulation program and the relationship to caregivers' competence, stress, and readiness for discharge.
- This study is part of a larger research project utilizing low-fidelity simulations and a rooming-in program to examine health literacy, competence, stress, and readiness for hospital discharge in caregivers of infants with CCHD prenatally and post surgery.<sup>1</sup>

#### Methods

- A descriptive, pilot study was used to assess caregiver's health literacy, competence, stress, and readiness for hospital discharge in a convenience sample of caregivers of infants with CCHD enrolled in a simulation program at three timepoints (prenatal, after surgery for CCHD, and rooming-in).
- Data collection included completion of self-report surveys (The Newest Vital Sign, The Perceived Stress Scale, The Parenting Sense of Competence Scale, and The Readiness for Hospital Discharge Scale) in an inpatient pediatric cardiac unit at three timepoints.
- The Multidisciplinary Research Team included CICU and CACU registered nurses, fetal nurse coordinators, a cardiac respiratory therapist, a cardiac psychologist and psychology student, nurse researchers, and a clinical nurse specialist.
- The setting included a large heart center in a pediatric healthcare system in the southeastern United States.
- Hospital and University IRB obtained, and participants provided written informed consent.
- Data analysis included:
  - Descriptive statistics for demographics and study variables
  - Spearman's rho was calculated to assess relationships between study variables, given the small sample size and non-normal distribution of the data
  - Correlations were examined between health literacy and parenting competence, stress, and readiness for discharge.



	NVS(T1)	PSOC(T3)	PSS(T1)	PSS(T3)	Parent RD(T3)	Child RD(T3)	Knowledge RD(T3)	Coping RD(T3)	Support RD(T3)
NVS(T1)	1.00	-0.26	0.13	0.64*	-0.74*	-0.75*	-0.32	-0.44	-0.07
PSOC(T3)	-0.26	1.00	-0.36	-0.71*	0.04	0.35	0.86*	0.76*	0.44
PSS(T1)	0.13	-0.36	1.00	0.32	-0.54	-0.36	-0.42	-0.55	0.18
PSS(T3)	0.64*	-0.71*	0.32	1.00	-0.79*	-0.52*	-0.64*	-0.73*	-0.24
Parent RD(T3)	-0.74*	0.04	-0.54	-0.79*	1.00	0.71*	0.78*	0.84*	0.23
Child RD(T3)	-0.75*	0.35	-0.36	-0.52*	0.71*	1.00	0.48	0.70*	0.35
Knowledge RD(T3)	-0.32	0.86*	-0.42	-0.64*	0.78*	0.48	1.00	0.91*	0.47
Coping RD(T3)	-0.44	0.76*	-0.55	-0.73*	0.84*	0.70*	0.91*	1.00	0.41
Support	-0.07	0.44	0.18	-0.24	0.23	0.35	0.47	0.41	1.00

#### Results

- Fourteen caregivers were enrolled in the study, and twelve caregivers completed the study at all three timepoints (*n*=12 in the analytic sample).
- Demographic Information:
  - All women
  - Over half white, non-Hispanic (58.3%)
  - Mean age of 31.0 years (SD=4.47)
- Results
  - Participants' NVS scores indicated an adequate level of health literacy, with two-thirds (*n*=8) selecting all correct responses on the NVS measure. The remaining participants (*n*=4) selected five out of six correct responses.
  - Correlation analyses showed moderate to strong and statistically significant relationships between health literacy and stress  $(r_s=.64)$ , parent readiness for discharge status  $(r_s=-.74)$ , and child readiness for discharge status  $(r_s=-.75)$ .

## Discussion and Implications

- Prior research suggests health literacy difficulties among caregivers contribute to poor outcomes.
- In addition to assessing health literacy among caregivers, a simulation program has the potential to improve competence and readiness for discharge and to decrease stress for caregivers of infants with CCHD.
- Higher literacy correlated to higher stress and lower readiness for discharge.
- The unexpected relationships could be due to the high level of health literacy in this sample; therefore, limitations suggest future studies with larger, diverse samples.
- Given the complexity of CCHD and few studies examining health literacy among caregivers of infants with CCHD, findings have the potential to identify health literacy gaps, and utilizing a simulation program may decrease stress levels and improve competence and readiness for discharge.
- Identifying caregivers with limited health literacy has important implications for how clinicians deliver information, educate, and support families during their admission and beyond.
- Strategies such as simplifying language, limiting information, using written and/or pictographic aids, and teach-back methods can be increased in clinician practice to promote patient understanding

#### References

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### Acknowledgments

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