



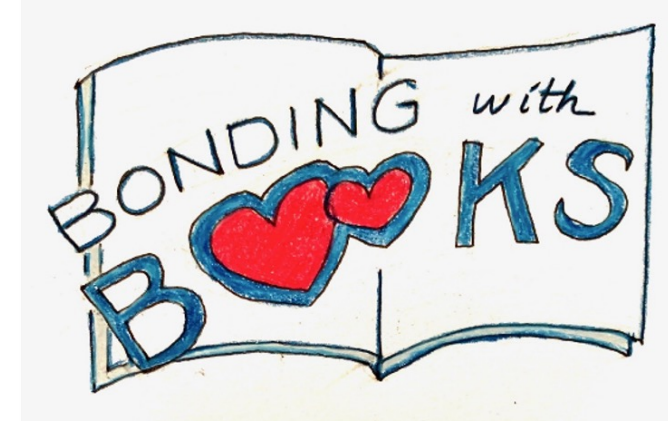
Early Literacy Intervention for Infants with Congenital Heart Disease: A Pilot Study

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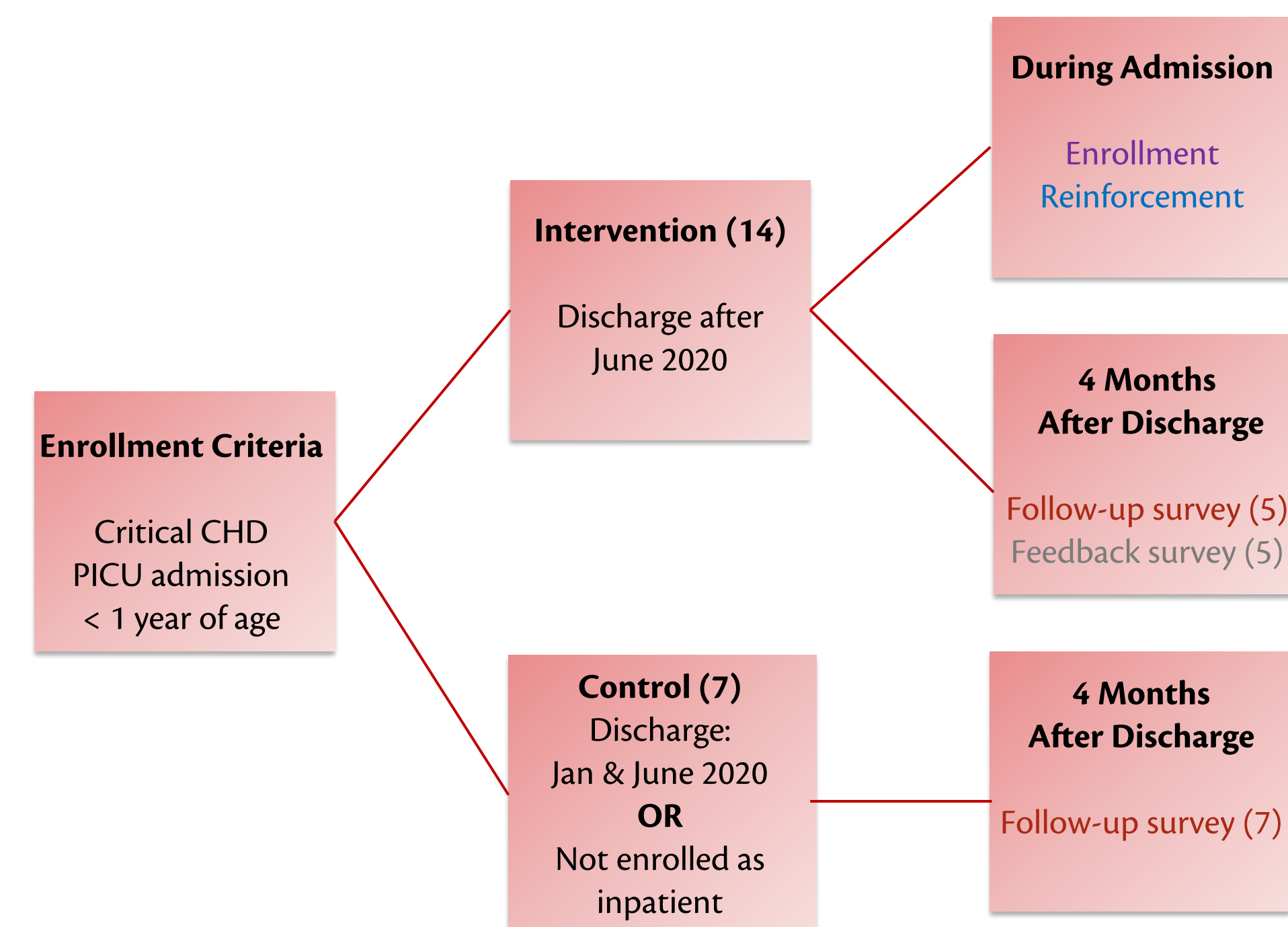
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BACKGROUND

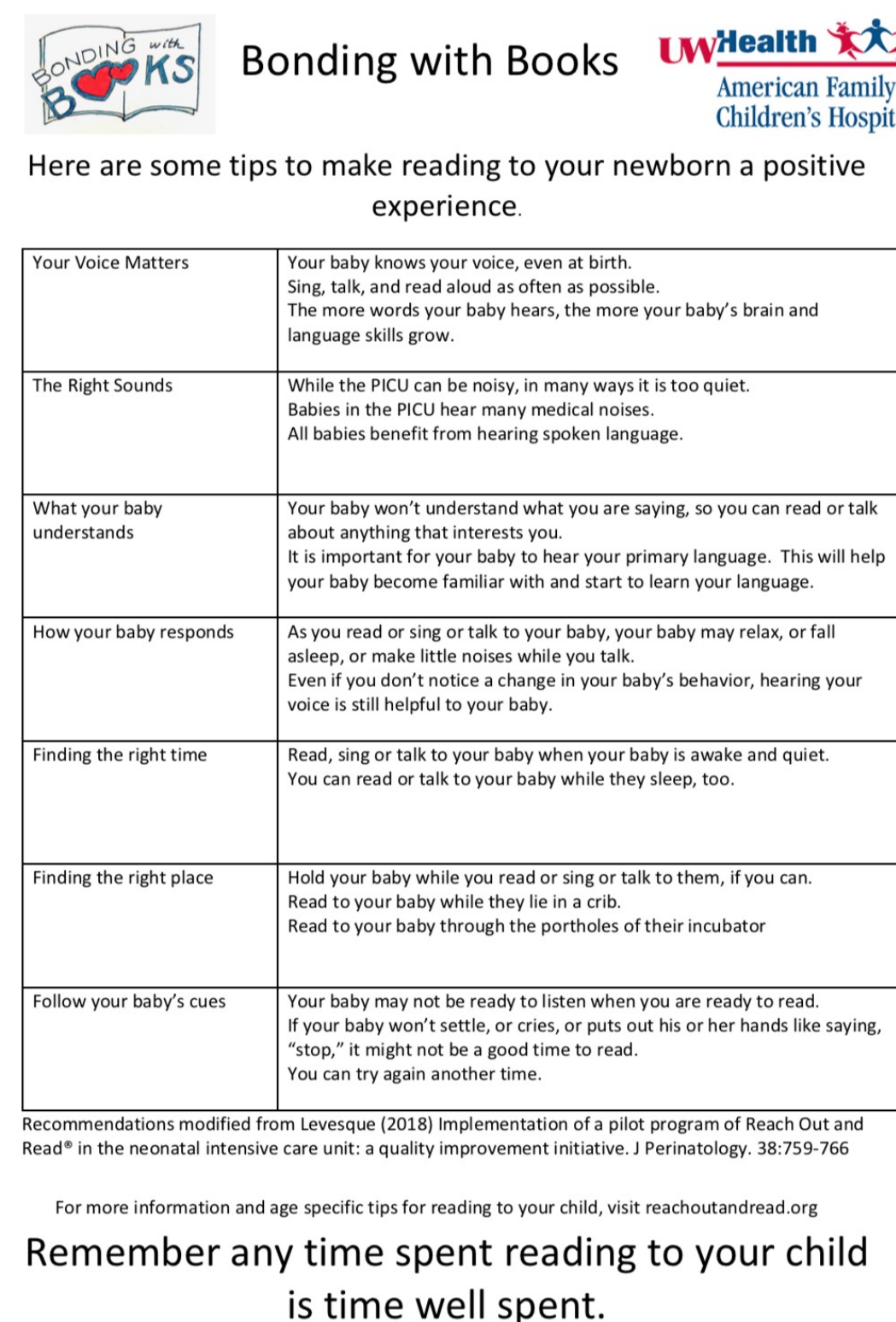
- Children with critical congenital heart disease (CHD) are at greater risk of adverse neurodevelopmental outcomes compared to children without CHD.
- We implemented an early literacy program, Bonding with Books (BWB), in the pediatric intensive care unit (PICU) for infants undergoing heart surgery.
- Objectives:**
 - Facilitate parent-child interaction in the PICU & at home
 - Encourage early language input
 - Encourage neurodevelopmental focus



DESIGN/METHODS



- Enrollment**
 - Teach about language input for infants
 - Emphasize parent's role in child's development
 - Give families 3 age-appropriate books
- Reinforcement**
 - Weekly visits to encourage reading
 - Collect reading log(s)
 - Give additional book(s)
- Follow-up Survey**
 - Importance of reading
 - Language input frequency
 - Parental feelings of efficacy
- Feedback Survey**
 - Program evaluation



Incorporation of an early literacy intervention into the inpatient workflow is **feasible**.

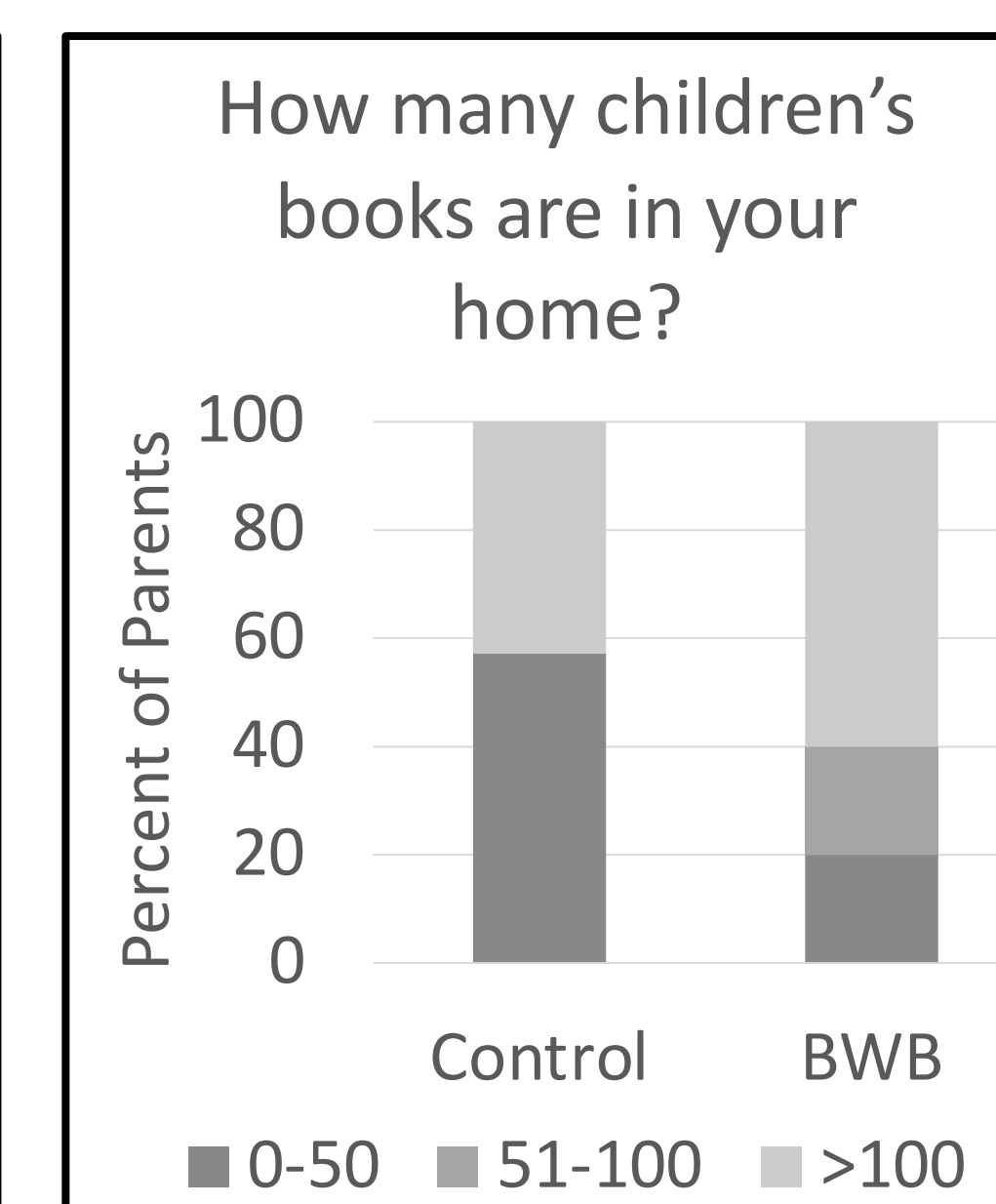
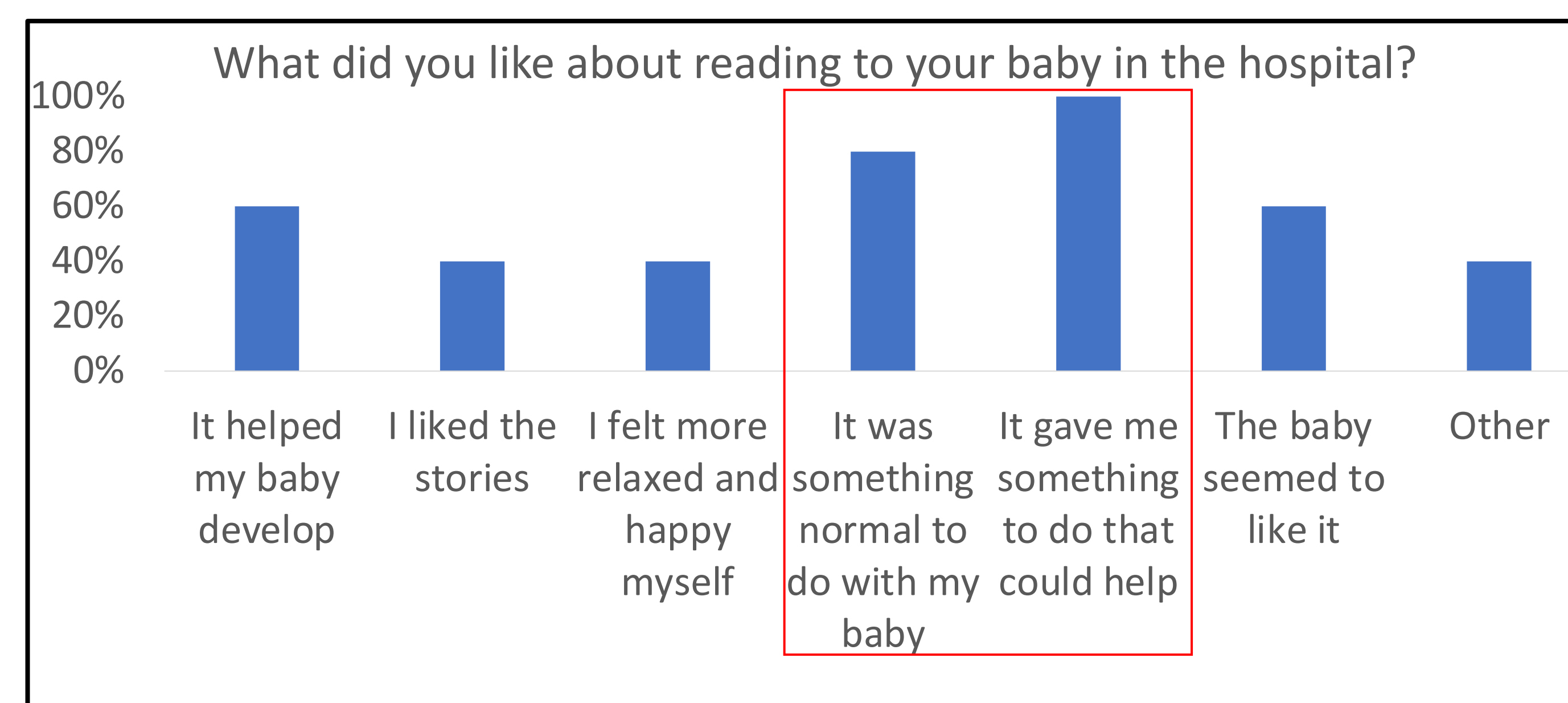
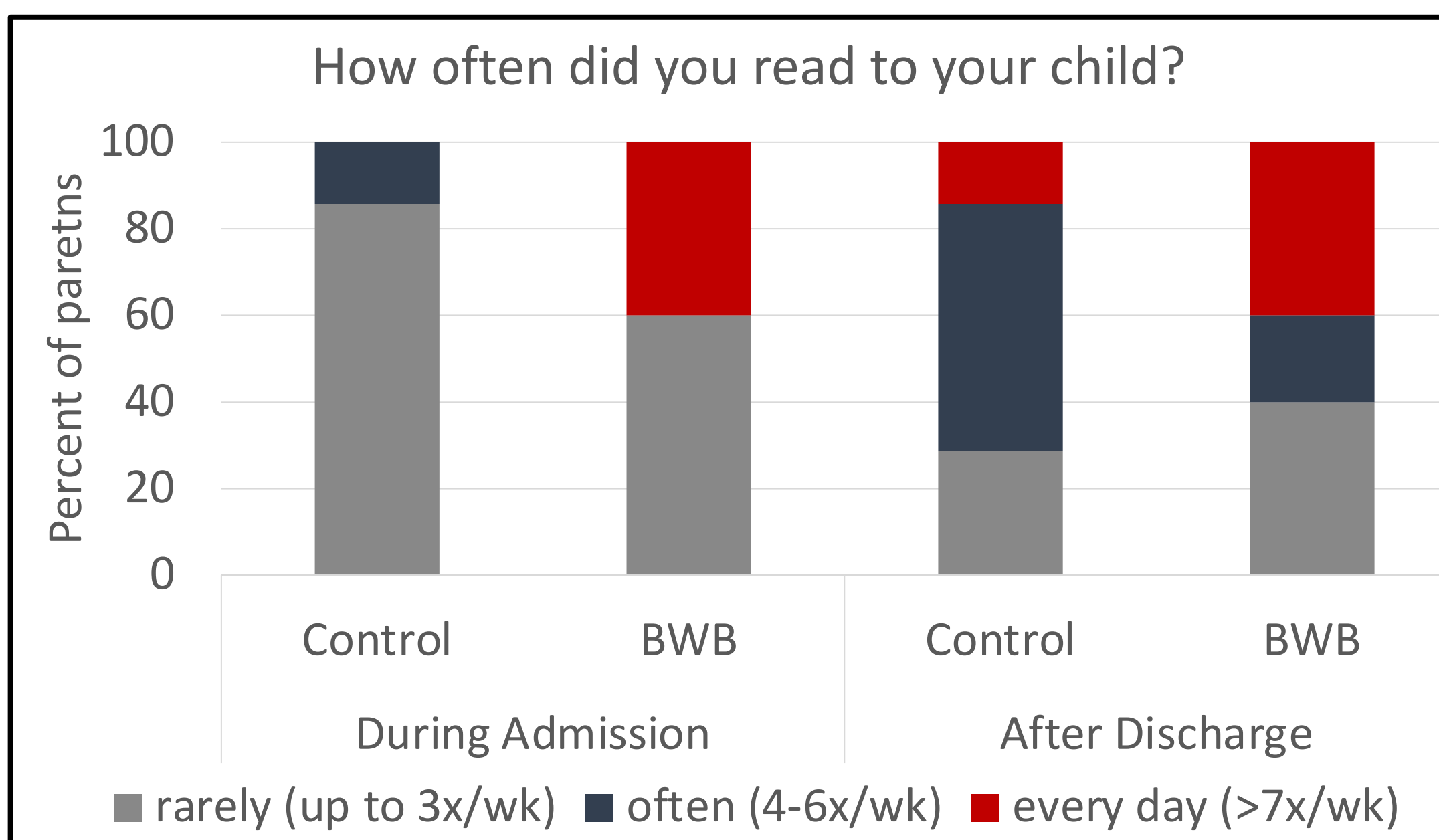
Such programs may promote parental neurodevelopmental focus.

RESULTS: LANGUAGE INPUT AND PARENTAL FEEDBACK

Demographics

	Control	BWB
Number	7	5
Older siblings (%)	20%	100%
Age of parent (years)	28.4 ± 3.6	34 ± 5.8
Age of infant (months)	9.4 ± 3.6	7.2 ± 4.5
Parents completed college (%)	60%	100%

On average, parents in the BWB intervention were older, more highly educated, and had more children at home than did control parents.



RESULTS: THEMATIC ANALYSIS

When asked to talk about their babies, all parents in both groups focused on their child's medical status and heart disease

- "He's almost 5 months old and he has hypoplastic left heart syndrome."
- "...he is very medically complex between the heart, cleft palate and GI issues..."

When asked why they read to their child:

BWB parents cited development (3/5)

- "Just encouraging development, because there are studies linking reading and speaking with language development and brain activity or processing."
- "You cannot move her after a major surgery with the tubes, so reading could help a little bit in a way when she is hearing. Or the parent can find something to do."
- "General baby wellness, they want babies to – it's a lot different now because everyone is on a device, so they don't get spoken to a lot, but it also helps with developmental delays in language"

No control parents mentioned development

CONCLUSIONS

- Early literacy interventions can be incorporated into the inpatient workflow of children with critical CHD
- Early literacy interventions:
 - Encourage parents to read to sick infants in the PICU, not just at home
 - Make parents more aware of the neurodevelopmental needs of children with complex cardiac conditions
 - Are appreciated by parents
 - Provide avenues for typical infant – parent interaction



LIMITATIONS AND FUTURE DIRECTIONS

Limitations

- Small numbers
- Differences in control vs. interventional group
- Less than 100% enrollment
- Covid restrictions
- Staffing issues

Future Directions

- Extend program to all PICU patients with child life
- Further investigate impact on parental self efficacy and engagement in the PICU