

A pilot study of parent education intervention improves early childhood development among toddlers with sickle cell disease

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Abstract

Background: Young children with sickle cell disease (SCD) are at risk for cognitive delay. In addition to biologic risk factors associated with SCD, environmental factors contribute to cognitive dysfunction within this cohort.

Methods: We completed a single-arm, prospective cohort study. Children with SCD between the ages of 3 and 36 months and their caregivers were followed between October 2010 and December 2013. The aim was to describe the role of a home visitation model, the home environment, and socioeconomic status in the development of young children with SCD. Primary outcome measures were the Bayley Scales of Infant and Toddler Development, Third Edition (BSID-III) and the Home Observation for Measurement of the Environment (HOME). We hypothesized that the home visitation model, Parents as Teachers[®] (PAT), would encourage positive parent-child interactions and improve cognitive outcomes.

Results: Thirty-five participants had at least two PAT visits and BSID-III assessments. Mean scores within all five subtests of the BSID-III improved between enrollment and exit, with significant changes within cognitive ($P = 0.016$) and expressive language (EL) domains ($P = 0.002$). Multivariate modeling found the HOME score associated with the exit results of the cognitive domain.

Conclusion: We report longitudinal results of the first home visitation program within the early childhood SCD population and show significant improvement in cognitive and EL development. Additionally, home environment was a significant predictor of cognitive development. Randomized controlled trials to test the impact of interventions targeting the home environment are warranted for this vulnerable population.

KEYWORDS

cognition, development, intervention, parenting, sickle cell disease

ABBREVIATIONS: BSID-III, Bayley Scales of Infant and Toddler Development, Third Edition; EL, expressive language; HOME, Home Observation for Measurement of the Environment; IQR, interquartile range; OT, occupational therapist; PAT, Parents as Teachers; RBC, red blood cell; SCA, sickle cell anemia; SCD, sickle cell disease; SCI, silent cerebral infarct; SD, standard deviation; SES, socioeconomic status; SLCH, St. Louis Children's Hospital; WIC, Women, Infants, and Children

1 | INTRODUCTION

Sickle cell disease (SCD) affects one in 500 African-American infants annually and approximately 100,000 people in the United States.^{1,2}

SCD is caused by a point mutation in the beta globin gene that results in formation of hemoglobin S, which pathologically polymerizes into chains in its deoxygenated state, distorts red blood cell (RBC) shape, and ultimately leads to hemolysis, obstruction of micro-

circulation, intravascular clotting, endothelial activation, and inflammation in all organ systems.³ Common phenotypes of SCD include homozygosity for the sickle mutation (HbSS), compound heterozygous Hb S and Hb C disease (HbSC), β^0 thalassemia (HbS β^0 thal), and β^+ thalassemia (HbS β^+ thal). HbSS and HbS β^0 thal are more severe clinical phenotypes, labeled sickle cell anemia (SCA) in clinical trials.

The neurologic burden of SCD is extensive, with pathophysiology of SCD often resulting in stroke and cognitive deficits. By 20 years of age, 10% of individuals with SCA have overt strokes⁴ and 39% have silent cerebral infarcts (SCIs).^{5,6} Cognitive deficits associated with both silent and overt stroke in SCD are well established.⁷⁻⁹ However, more recent findings indicate cognitive deficits commonly occur even in the absence of stroke or SCI.¹⁰⁻¹² The majority of research investigating development and cognition within SCD has focused on school-aged children, but limited data available for infants and toddlers suggest that cognitive deficits appear well before the age of 5 years.¹³ In fact, infants with SCD have shown developmental delays during the first year of life¹⁴ and decreases in mental abilities between 12 and 24 months.¹⁵ Furthermore, behavioral adaptation decreases between ages of 7 and 18 months.¹⁶ Among school-aged children with SCD, measures of intelligence appear to decline over time,^{10,17,18} with decreases in full-scale IQ by approximately one point per year.¹⁸ Based on our work¹⁹ and on that of others,^{20,21} we conclude that cognitive deficits exist in children with SCD well before they reach school age, and these deficits intensify with age.

In addition to biologic risk factors associated with SCD, environmental factors also contribute to family function and child development.²² Children with SCD are more likely to live in racially and economically segregated neighborhoods.^{23,24} In a longitudinal cohort of 24 toddlers with SCD, a combination of biomedical and parenting risks accounted for 42% of the variability in cognitive function.¹⁵ Reports of daily maternal stress or feelings of helplessness to support their children indicated low self-efficacy and increased parenting risk. While biologic factors have been associated with neuropsychological measures among children with SCD in higher socioeconomic status (SES) families,²⁰ factors such as lower income and parent education may have a more profound negative impact on cognitive development than disease-related factors. Previous work has identified the relationship between family income and developmental progress in young children.¹⁶ Compelling evidence indicates that a broader approach to health and well-being may be required to address the bio-psycho-social needs of young children with SCD, enabling them to live full, meaningful lives.

Children with chronic medical conditions require comprehensive care that addresses both medical and psychosocial needs to better control their disease and ultimately maximize function at home, in school, and the community.^{25,26} Considering the complexity of care and frequent hospital visits required for young children with SCD, a home visitation program may support comprehensive patient care. Home visitation is recognized as an effective method for providing education and addressing the psychosocial needs of families. Intervening at this level has been shown to positively influence child development.²⁷ Home

visitation programs supporting high-risk populations have resulted in improved language, problem-solving skills, social development, and academic achievement, in addition to decreases in abuse and neglect.²⁸⁻³⁰ Home visitation programs are also effective in improving the quality of the home environment (e.g., increasing safety, parent-child interactions), as assessed by the Home Observation for Measurement of the Environment (HOME).³⁰ One such program, Parents as Teachers[®] (PAT), focuses on the parent-child relationship, knowledge of development, and language acquisition. We have previously shown that a home visitation program with parents of infants and toddlers with SCD is feasible³¹ and that this population demonstrates cognitive deficits.¹⁹ Given the identified association between a child's environment and developmental progress and the high risk for delay in SCD, a home visitation model that targets the environment through constructs including parent-child interaction and parental understanding of child development may help minimize the negative impact of SCD and poor environmental factors on cognitive and language development.

The specific aims of this study were to describe the impact of PAT in ameliorating the cognitive deficits of young children with SCD enrolled in an open trial in our longitudinal cohort³¹ and to examine the relationship of home environment and SES to cognitive development. We hypothesized that implementing a home-based parent education model using PAT would improve developmental outcomes.

2 | METHODS

2.1 | Participants

Approval for this study was obtained from the Institutional Review Board of Washington University School of Medicine. Caregivers of children with SCD were approached from the hematology clinic at St. Louis Children's Hospital (SLCH) following regularly scheduled visits. Children with all SCD genotypes between the ages of 3 and 36 months living within 30 miles of the hospital and whose caregivers spoke fluent English were eligible for participation.

2.2 | Measures

2.2.1 | Bayley Scales of Infant/Toddler Development, Third Edition

Bayley Scales of Infant/Toddler Development, Third Edition (BSID-III) is a standardized, therapist-administered evaluation that is normed for children between the ages of 1 and 42 months to identify delays in development. Five subtests of the BSID-III were administered: cognitive (91 items), receptive language (48 items), expressive language (EL) (49 items), fine motor (66 items), and gross motor (72 items). The number of items administered varied depending on the child's age at the time of assessment. Raw scores were converted to scaled scores.³² A scaled score of 8-12 is average, with a score of 10 corresponding with the 50th percentile. A scaled score of 7 or less is at least 2 standard deviations (SDs) below the mean and considered below average.

2.2.2 | Infant/Toddler HOME Inventory (HOME)

The child's living environment and interactions with their primary caregiver were assessed via semistructured interview and observation. The HOME includes six subscales: responsivity (11 items), acceptance (eight items), organization (six items), learning materials (nine items), involvement (six items), and variety (five items). Raw scores for each subscale are summed to determine the total score, which is categorized as representing the lower fourth, the middle half, or the upper fourth of scores as compared to normative data.³³

2.2.3 | Socioeconomic status

SES was approximated using methods outlined by Diez-Roux et al.,³⁴ utilizing the participant's address and the American Community Survey data obtained by the U.S. Census Bureau. The Diez-Roux score was derived using a formula incorporating median household income, median housing values, and the following percentages: households receiving dividend or rental income, adults who completed high school, adults who completed college, and households with employed persons 16 years or older in executive, managerial, or professional occupations. Diez-Roux z-scores above zero indicate a higher SES compared with the average for the local area; those below zero indicate a lower SES.

As a proxy for social needs, a record of referrals to local resource and support agencies provided during home visits was maintained. Examples of referrals made to outside agencies include, but are not limited to, early intervention services; SLCH Safety Stop; United Way; Missouri LIHEAP (energy assistance); Women, Infants, and Children (WIC) Nutrition Assistance; and Nurses for Newborns. The decision to provide referrals was at the discretion of the provider depending on the family's stated concerns.

2.2.4 | Biologic measures

To account for disease severity in our analysis of developmental outcomes, we abstracted hematocrit and oxygen saturation from within 30 days of the initial BSID-III assessment from the participants' medical records.

3 | PROCEDURE

Hoyt-Drazen and colleagues¹⁹ report results from Phase I of this study in which caregivers consented to child developmental and home environment assessments. The initial BSID-III was completed in a private room with minimal distractions at SLCH prior to initiation of the home visitation program. The cohort for Phase II was formed from this initial cross-sectional cohort and included child-caregiver dyads who consented to participate in an accredited PAT Born to Learn[®] curriculum with ongoing assessment using the BSID-III and HOME. Participants were eligible for Phase II until 36 months of age due to the age constraints of the PAT curriculum. A small subgroup of eight participants from Phase I did not consent for Phase II of the study with PAT, but they did consent to longitudinal developmental evaluations with the BSID-III.

An occupational therapist (OT) certified in the PAT curriculum provided all instruction and completed the BSID-III and HOME assessments. Home visits were scheduled monthly but could be rescheduled or canceled at the family's discretion. The PAT curriculum has a standardized format for each 60-min visit that includes open discussion between the provider and caregiver; a child-based, developmentally appropriate activity that is standardized for each month of age; and handouts related to developmental skills and safety awareness for that month of age. To ensure standardization of the intervention, each visit was planned according to the PAT curriculum model according to the child's age.³¹ Developmental assessments were completed every 3 months for children less than 1 year of age and every 6 months for children between the ages of 12 and 36 months. Parents were given an evaluation summary following each BSID-III with suggested activities to promote development with the opportunity to discuss results. The HOME was completed during the first home visit and upon exit at participant age of 36 months or after approximately 12 months of participation.

The provider addressed family concerns with discussion and handouts. If deemed appropriate by the provider, families were provided with additional handouts or readings and referred to community agencies for added support. The provider verbally determined whether the community referral was accessed at the subsequent home visit.

4 | ANALYSIS

Statistical analyses were performed using IBM SPSS Statistics (Version 22, Chicago, IL). Data were described as mean (\pm SD) or median (interquartile range [IQR]) depending on data distribution. Parametric comparisons were performed with a Student t-test; nonparametric comparisons were performed with the Wilcoxon signed ranks test or Mann-Whitney U-test, and Pearson r described bivariate correlations. Significance was achieved with a *P* value of 0.05. Multivariate linear regression models of the final cognitive and EL domains of the BSID-III were performed with a block entry approach. Covariates included within the multivariate models were chosen a priori: the number of participants limited a baseline model to the total number of visits from the PAT provider, total HOME score on enrollment, and BSID-III subtest score upon enrollment. Additional covariates were then added, individually, to the baseline model to assess whether they improved the model, including parent and child age at enrollment, Diez-Roux z-scores, hematocrit, peripheral oxygen saturation, number of additional handouts provided at the home visit and referrals to community agencies.

5 | RESULTS

Caregivers consented to participate in assessments of child development and home environment during Phase I.¹⁹ From this initial cross-sectional cohort, 81% (*N* = 43) of the families chose to participate in

Phase II, which included the home visitation program. Of the 43 participants consented for Phase II, 35 participants had at least two PAT visits including BSID-III assessments over a mean of 17.2 (± 8.6) months. Table 1 provides a description of the cohort.

Of the 35 participants with multiple BSID-III assessments receiving PAT, each family received a median rate of 0.92 (IQR 0.45–1.25) visits per month of enrollment. The mean age of the primary caregiver was 25.2 (± 5.0) years, and the households had a median Diez-Roux z-score of -2.5 (IQR -5.8 to 0.3). A negative Diez-Roux score indicates that participating families were below average compared with households in the St. Louis metropolitan area. The OT provided an average of 6.4 (± 3.4) referrals to outside agencies per participant depending on family needs. Participants followed up referral to outside agencies a median of 1 (IQR 1–3) time. An increased number of referrals to outside agencies correlated strongly with a lower Diez-Roux z-score ($r = -0.408$, $P = 0.017$), and there was a significant increase in the number of outside agency referrals made to families in the lower 50th percentile of the Diez-Roux z-score when compared with the upper 50th percentile ($P = 0.025$). Additionally, the therapist provided participants with an average of 8.5 (± 5.2) handouts or readings in addition to those associated directly with the PAT program.

Increased mean scores were found in all five subscales between enrollment and exit testing in participants receiving PAT. The greatest effects were observed in cognition ($P = 0.016$) and EL ($P = 0.002$). Conversely, there was a decrease in mean score between enrollment and exit in the gross motor, fine motor, and cognitive subscales in the participants not receiving home visitation with PAT (Table 2). Participants receiving PAT completed a median of 4 (IQR 2–4) BSID-III assessments, while those not receiving PAT completed a median of 2 (IQR 2–3) assessments.

Controlling for the total number of PAT visits and total HOME and BSID-III subtest scores on enrollment, multivariate linear regression models of the final cognitive and EL domains of the BSID-III were performed within the cohort receiving PAT. The multivariate model accounted for 24% of the variability in exit cognitive subscale scores (see Tables 3 and 4). The total HOME score upon enrollment was a significant predictor of the exit cognitive score ($P = 0.036$), with an increase in cognitive scores by 0.15 points for every 1-point increase in the total HOME score (Table 3). When the other prespecified variables were added, separately, to this model, none were significant predictors of the exit cognitive score, including parent age ($P = 0.760$), child age ($P = 0.274$), Diez-roux score ($P = 0.839$), hematocrit ($P = 0.240$), peripheral oxygen saturation ($P = 0.439$), additional handouts or readings ($P = 0.350$), and referrals to community agencies ($P = 0.608$). The multivariate model accounted for 21% of the variability in exit EL scores. The enrollment EL score was significant ($P = 0.040$) in the multivariate model, with an increase in the exit EL by 0.35 points for every 1-point increase in the initial score (Table 4). When the other prespecified variables were added, separately, to this model, none were significant predictors of the exit EL subscale score, including parent age ($P = 0.322$), child age ($P = 0.380$), Diez-roux score ($P = 0.696$), hematocrit ($P = 0.162$), SpO₂ ($P = 0.156$), additional handouts ($P = 0.211$), and referrals to community agencies ($P = 0.739$).

TABLE 1 Description of cohort

	Receiving PAT (N = 35) N = 20 (57%)	No PAT (N = 8) N = 3 (37.5%)
Participant gender, male		
Primary caregiver		
Age upon enrollment (years)	25.2 (± 5.0)	23.5 (± 4.8)
Definition of primary caregiver		
Mother	18 (51.4%)	8 (100%)
Father	1 (2.9%)	0
Both mother and father	13 (37.1%)	0
Grandparent	2 (5.7%)	0
Other	1 (2.9%)	0
Education level attained by primary caregiver		
Less than high school/GED	9 (25.7%)	1 (12.5%)
High school graduate or equivalent	13 (37.1%)	3 (37.5%)
Some college	9 (25.7%)	1 (12.5%)
College graduate	4 (11.4%)	0
Unknown	–	3 (37.5%)
Participant age upon enrollment (months)	5.0 [4.0–11.0]	17.0 [6.0–25.3]
Participant age upon exit (months)	26.0 [14.0–35.0]	29.0 [13.0–33.0]
Hematocrit (%)	28.0 (± 3.5)	27.4 (± 4.3)
Peripheral oxygen saturation (%)	100.0 [98.0–100.0]	98.0 [97.0–100.0]
Phenotype		
HbSS	16 (45.7%)	5 (62.5%)
HbSC	15 (42.9%)	2 (25.0%)
HbS β^{thal0}	1 (2.9%)	1 (12.5%)
HbS $\beta^{\text{thal+}}$	1 (2.9%)	0
HbSS with PFHb	2 (5.7%)	0
Participant insurance status		
State or Federal assistance	27 (77.1%)	8 (100%)
Private	7 (20%)	0
Self-pay	1 (2.9%)	0
Enrollment HOME scores		
Responsivity	7 [6–9]	–
Acceptance	6 [5–6]	–
Organization	5 [4–5]	–
Learning materials	5 [3–7]	–
Involvement	3 ^{2–5}	–
Variety	3 [2–4]	–
Total	28 [23–35]	–

TABLE 2 BSID-III assessment scores

		Receiving PAT				No PAT				
		Mean (\pm SD)	Mean change (\pm SD) in score	P value			Mean (\pm SD)	Mean change (\pm SD) in score	P value	
Gross motor	N = 35	Enrollment	8.7 (\pm 2.7)	0.7 (\pm 3.0)	0.114	N = 7	Enrollment	7.3 (\pm 3.0)	-0.1 (\pm 3.2)	0.524
		Exit	9.5 (\pm 2.1)				Exit	7.1 (\pm 3.1)		
Fine motor	N = 33	Enrollment	7.7 (\pm 2.7)	1.0 (\pm 3.9)	0.152	N = 7	Enrollment	7.9 (\pm 3.3)	-0.3 (\pm 2.9)	0.666
		Exit	8.8 (\pm 2.6)				Exit	7.6 (\pm 3.7)		
Cognitive	N = 34	Enrollment	7.4 (\pm 3.0)	1.4 (\pm 3.4)	0.016*	N = 8	Enrollment	8.0 (\pm 3.0)	-1.0 (\pm 4.1)	0.397
		Exit	8.8 (\pm 3.2)				Exit	7.0 (\pm 3.7)		
Receptive language	N = 34	Enrollment	7.7 (\pm 3.1)	0.9 (\pm 3.9)	0.159	N = 7	Enrollment	6.4 (\pm 3.6)	1.1 (\pm 2.8)	0.336
		Exit	8.6 (\pm 3.1)				Exit	7.6 (\pm 3.3)		
Expressive language	N = 34	Enrollment	6.7 (\pm 2.7)	1.9 (\pm 3.0)	0.002*	N = 7	Enrollment	7.6 (\pm 2.4)	0.1 (\pm 3.3)	0.932
		Exit	8.7 (\pm 2.8)				Exit	7.7 (\pm 4.5)		

*Statistically significant.

TABLE 3 Multivariate linear regression model for exit cognitive score of the BSID-III

Covariates	Unstandardized β	Standard error	95% Confidence interval	P value
Enrollment total HOME score	0.147	0.067	0.011–0.283	0.036*
Visit number	0.039	0.058	-0.079–0.157	0.500
Enrollment cognitive score	0.266	0.179	-0.101–0.632	0.149
Model R ² = 0.240				

*Statistically significant.

TABLE 4 Multivariate linear regression model for exit expressive language score of the BSID-III

Covariates	Unstandardized β	Standard error	95% Confidence interval	P value
Enrollment total HOME score	0.110	0.055	-0.002–0.221	0.054
Visit number	0.024	0.050	-0.078–0.127	0.633
Enrollment EL score	0.345	0.160	0.017–0.672	0.040*
Model R ² = 0.213				

*Statistically significant.

A complete HOME assessment was obtained upon enrollment for all 35 participants receiving PAT, and 14 had a second assessment allowing for longitudinal evaluation of the living environment and caregiver-child interaction. The median HOME score upon enrollment was 28.0 (IQR 23.0–35.0), with 31.4% falling within the lower fourth compared with normative data. In comparison with those with only one HOME assessment, participants with multiple HOME assessments had significantly more home visits (median + 17 [12.75–22.75] vs. 9 [4.50–17.00], $P = 0.004$) and received an increased number of handouts or readings (11 [7.00–13.25] vs. 7 [2.00–10.00], $P = 0.024$). There was no difference in the Diez-Roux

z-score ($P = 0.669$), age of the primary caregiver ($P = 0.736$), age of participant upon enrollment ($P = 0.396$), or number of referrals made to outside agencies ($P = 0.409$) between those with one or two HOME assessments. For those 40% with multiple assessments, the total HOME score trended toward improvement over time but was not significantly different, most likely due to being underpowered with a sample size of 14. Scores on the acceptance subscale decreased as the child aged ($P = 0.028$), but all other subscales improved longitudinally, with the organization ($P = 0.029$) and learning materials ($P = 0.010$) subscales having the greatest improvement (Table 5).

TABLE 5 HOME assessment scores (N = 14)

		Median [IQR]	P value
Responsivity	Enrollment	6.5 [5.50–10.00]	0.151
	Exit	8.0 [6.25–10.00]	
Acceptance	Enrollment	6.0 [4.00–6.00]	0.028*
	Exit	5.0 [3.00–6.00]	
Organization	Enrollment	5.0 [4.00–5.00]	0.029*
	Exit	6.0 [4.00–6.00]	
Learning materials	Enrollment	5.0 [4.00–7.00]	0.010*
	Exit	7.0 [5.75–8.00]	
Involvement	Enrollment	3.0 [1.75–5.25]	0.711
	Exit	3.5 [2.00–6.00]	
Variety	Enrollment	4.0 [3.00–5.00]	0.335
	Exit	4.0 [3.00–5.00]	
Total	Enrollment	27.0 [23.0–36.0]	0.161
	Exit	32.0 [26.75–38.25]	

*Statistically significant.

6 | DISCUSSION

We found significant improvement in cognitive and EL domains of the BSID-III in infants and toddlers with SCD who participated in a home visitation program with a certified PAT provider. We report the first longitudinal cognitive assessments in conjunction with an evidence-based home visitation intervention within the SCD population. Cognitive deficits associated with SCD appear within the first 2 years of life^{14–16} and progressively worsen with age.^{35,36} Unfortunately, medical interventions to date have not improved cognitive outcomes.³⁷ Our current findings are highly encouraging when compared with previous reports of decline in mental abilities of infants and toddlers with SCD between the ages of 12 and 24 months.¹⁵

The association between the total HOME score and exit cognitive BSID-III score is consistent with prior reports highlighting the association of environmental factors with cognitive dysfunction in children with SCD.^{16,20,38} The home visitation model is now being applied to high-risk medical populations and to those who are high-risk secondary to SES.³⁹ However, this is the first study to identify home visiting as a possible method for addressing cognitive decline in young children with SCD. Specifically, PAT had a direct effect on school readiness and subsequent academic achievement through the third grade in a cohort of over 4,000 children in Missouri public schools,⁴⁰ which is directly applicable to our cohort based in St. Louis, Missouri. While shown to be an effective approach, application of a home visitation intervention to the SCD population is novel.

The premise of PAT is that parents are in the best position to influence a child's ability to learn. Our results support the concept that readiness to learn is enhanced by increasing a parent's connectedness to their young child. The greatest functional improvements were in cognition and EL. To an extent, children may acquire motor and language skills independently through play, but more complex tasks, such as conceptual learning (i.e., numbers, letters, pretend play, problem solving) and language, require caregiver interaction and

responsiveness.^{41,42} Lack of interaction and conversation between caregivers and young children results in delay in both cognitive and EL development.⁴³ The home visitation program implemented within the present cohort focused on providing education and guidance to caregivers regarding child development and encouraging frequent, positive caregiver–child interactions. We hypothesize that the developmental progress within our cohort was due in part to positive changes in parenting and home environment facilitated by the PAT curriculum. While the improvements in the cognitive and EL domains are promising, receptive language and motor development domains did not show significant improvement. Children in less-nurturing environments may be required to be more self-sufficient in certain tasks, such as holding bottles, self-feeding, or retrieving toys and other desired objects, allowing for a more rapid development of gross motor skills. Hence, changes to the home environment may have a greater impact on cognitive and EL domains than motor domains.

The current study was a single-arm intervention funded as a pilot demonstration project and was not without limitations. Thus, there was no control group, which prevents determination of causality for the developmental findings we report. The Infant/Toddler HOME Inventory depends on direct observation or responses through a semistructured interview. Item scoring is likely to be affected by child's age. For example, items such as "Parent does not shout at child" or "Parent does not scold or criticize child during visit" are more likely to be endorsed at very young ages. Changes in parenting style by the child's age may contribute to the significant decline in the acceptance subscale in the present study. Future studies might include more detailed or in-depth observational methods to quantify the environment. Finally, the OT performing the home visits also obtained all BSID-III and HOME assessments. Minimizing the number of providers was done to limit attrition and maintain trust and consistency. Standard procedures outlined in the BSID-III manual were followed.

The present study provides the initial framework for understanding the complexity contributing to and possibly buffering cognitive decline in young children with SCD. We report the longitudinal results of the first home visitation program within the SCD population and show significant improvement in the cognitive and EL domains of the BSID-III. Although improvement in the remaining domains was not significant, children in this cohort did not show declines observed in previous studies. The preliminary evidence garnered through this pilot study supports the implementation of a randomized, controlled trial evaluating the role of a home visitation model to improve cognitive outcomes among children with SCD. Further investigation is warranted to test the effect of early home visitation in a larger cohort of this vulnerable population.

ACKNOWLEDGMENTS

Thank you for the efforts of Ashley Hosten, Kelley Chadwick-Mansker, Tinishia Greene, Terianne Lindsey, and Kim Ferguson for their efforts that contributed to the success of this project. Thank you to

the families who trusted us to enter their homes and be a part of their young child's life.

Research reported in this publication was supported by the Washington University Institute of Clinical and Translational Sciences grant UL1TR000448 from the National Center for Advancing Translational Sciences (NCATS) of the National Institutes of Health (NIH); the Clinical Hematology Research Career Development Program grant 5K12 HL087107 from the National Heart, Lung and Blood Institute; and by the Human Resources and Services Administration (HRSA) and the Genetic Services Branch of the Maternal and Child Health Bureau grant number H46MC09231. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

CONFLICT OF INTEREST

Allison A. King, MD, MPH, PhD, had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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