Gaps and Factors Related to Receipt of Care within a Medical Home for Toddlers Born Preterm

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Objective To characterize gaps and factors related to receipt of care within a medical home for toddlers born preterm.

Study design Participants were 202 caregivers of children born at <35 weeks of gestation. At 10-16 months of corrected age, caregivers completed the National Survey of Children's Health (2011/2012) medical home module and a sociodemographic profile. Care within a medical home comprised having a personal doctor/nurse, a usual place for care, effective care coordination, family-centered care, and getting referrals when needed. Gestational age and neonatal follow-up clinic attendance were abstracted from the medical record. The Bayley Scales of Infant and Toddler Development, Third Edition assessed developmental status. Log-binomial regression examined factors related to receiving care within a medical home.

Results Fifty-three percent (n = 107) of the children received care within a medical home. Low socioeconomic status (young caregiver: risk ratio [RR] = 0.73; 95% CI 0.55, 0.97; low education: RR= 0.69; 95% CI 0.49, 0.98) and delayed language (RR = 0.63; 95% CI 0.42, 0.95) were associated with a lower likelihood of receiving care within a medical home. Degree of prematurity and neonatal clinic follow-up participation were unrelated to receipt of care within a medical home.

Conclusions Receipt of care within a medical home was lacking for nearly one-half of preterm toddlers, especially those with lower socioeconomic status and poorer developmental status. Discharge from a neonatal intensive care unit may be an optimal time to facilitate access to a primary care medical home and establish continuity of care. *(J Pediatr 2019;207:161-8).*

Trial registration ClinicalTrials.gov: NCT01576783.

Children born preterm are at increased risk for physical, neurologic, behavioral and social-emotional delays and chronic medical conditions that may persist into adulthood.[1-5] As such, they require high levels of health service use and coordination from birth. Therefore, children born preterm are an important group of children with special healthcare needs (CSHCN) and are optimally cared for in a medical home.

Although CSHCN are a major focus of medical home research, those born preterm have not been a specific focus. Some children born preterm need little specialty care, but others require substantial services. Many children's hospitals have neonatal follow-up programs dedicated to monitoring the unique needs of children born preterm at regular intervals for the first few years after birth. Such specialized services may influence access to and engagement with a medical home.[6] The objective of this study was to assess gaps and factors associated with receiving care within a medical home for a broad group of children born preterm during toddlerhood. We explored associations among socioeconomic characteristics, gestational age, neonatal follow-up clinic attendance, developmental status, and receiving care within a medical home.

Methods

This is a secondary analysis of data from the Omega Tots trial (ClinicalTrials.gov: NCT01576783), a randomized, double-blind placebo-controlled trial which tested the effect of long chain polyunsaturated fatty acid supplementation on the development of toddlers born preterm.[7] Data presented here were collected before the intervention began, at the baseline visit.

Bayley-III	Bayley Scales of Infant and Toddler Development, Third Edition
CSHCN	Children with special healthcare needs
NICU	Neonatal intensive care unit
NSCH	National Survey of Children's Health
SES	Socioeconomic status

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A census was compiled of all children 10-16 months of age (adjusted for prematurity) who were born at <35 weeks of gestation and admitted to a Columbus-area neonatal intensive care unit (NICU) or referred to the Nationwide Children's Hospital Neonatology Clinic for clinical follow-up. Initial trial eligibility was assessed through retrospective medical record review and confirmed via recruitment and eligibility phone calls with families when the children were age-eligible to participate. Inclusion criteria included weight between the 5th and 95th percentiles for corrected age and sex,[8] discontinued human milk and formula, and English as the primary language. Children were excluded for consuming fatty acid supplements, fatty fish, or nutritional support beverages with docosahexaenoic acid (DHA) more than twice weekly; having a fish, corn, or soy allergy; planning to relocate; or having a major malformation or feeding, metabolic, or digestive disorder precluding participation or nutrient absorption. Although the Omega Tots trial enrolled 377 children (**Figure**; available at www.jpeds.com) during the period from April 2012 to September 2016, the present analysis only included children enrolled from April 2015 to September 2016 (n = 202; 54%), as the study collected medical home data during that time. The study was reviewed and approved by the Institutional Review Board at the single study site, Nationwide Children's Hospital, Columbus, Ohio.

At the baseline study visit, caregivers completed a sociodemographic profile comprised of their age, relationship to the child, insurance status, highest level of education, marital relationship status, and the child's race and ethnicity. They also responded to 17 items from National Survey of Children's Health (NSCH) Medical Home Module (2011/2012). The questions were used in both the NSCH and the National Survey of Children with Special Healthcare Needs since 2001 and were used most recently in the 2016 NSCH. The items underwent extensive testing during the development of these national surveys to ensure readability and understanding by diverse participants and to ensure they captured relevant content.[9-11] Care consistent with that received within a medical home was defined as having a personal doctor/nurse, having a usual place for care, receiving effective care coordination, receiving family-centered care, and getting referrals when needed.[12] This does not presume that the child was receiving care in a National Committee for Quality Assurance recognized medical home.

Child date of birth (used to calculate corrected age at the baseline study visit), gestational age, birthweight, sex, and neonatal follow-up clinic attendance were abstracted from the medical record. The Bayley Scales of Infant and Toddler Development, Third Edition (Bayley-III), was administered by a trained research assistant to evaluate cognitive, motor, and language development.[13]

Binary exposure variables included caregiver age at survey completion (<30 vs ≥30 years), insurance status (public or none [see footnote on **Table I** for grouping rationale] vs private), highest level of education achieved by the caregiver (less than associate's degree vs associate's degree or higher), neonatal follow-up clinic attendance (never attended vs attended at least once), and delayed cognitive, motor, or language development (Bayley-III composite score ≤85 vs >85). These exposure variables were dichotomized a priori to combine similar, small categories together, or to divide the sample into similar sized groups to avoid sparse cell sizes. Gestational age at birth was a continuous exposure variable. Each exposure was examined in relation to binary medical home outcomes.

Statistical Analyses

Bivariate statistics (*t*, Fisher exact, χ^2) evaluated associations between socioeconomic factors, child characteristics, and receiving care within a medical home. In line with the recommended analytical approach for commonly occurring (>10%) outcomes, log binomial regression estimated risk ratios of experiencing the outcome for children exposed to the variable of interest, relative to those unexposed.[14] In these models, associations between socioeconomic characteristics, gestational age, neonatal follow-up clinic attendance, developmental status, and receiving care within a medical home were examined. Socioeconomic covariates that were associated with receiving care within a medical home were retained in adjusted models where the socioeconomic covariate was not the exposure variable of interest. In cases where the adjusted log-binomial regression model did not converge, a modified Poisson approach was used.[15] There were minimal missing data in the analytical dataset; no variable had more than 1 missing observation. Analyses were based on complete cases and used SAS v 9.4 (SAS Institute, Cary, North Carolina).[16]

Results

Between April 2015 and September 2016, 202 caregivers (96% mothers) and their children (**Table I**) were enrolled. Caregivers were 30 years of age (SD = 7.4 years). Other sociodemographic and clinical characteristics of the caregivers and children are shown in **Table I**. Caregiver age ($t = 2.37$, $P = .02$), insurance status ($X^2 = 8.58$, $P = .0003$), and education ($X^2 = 13.95$, $P = .0002$), but not caregiver relationship to the child or marital relationship status were associated with receiving care within a medical home; 53% of the children (n = 107) received care within a medical home. Specific areas in which the definition of a medical home was not met were 8% did not have a personal doctor or nurse, 8% did not have a usual place for care, 15% experienced problems getting referrals when needed, 23% lacked family-centered care, and 34% lacked effective care coordination (**Table II**; available at www.jpeds.com).

Factors Associated with Receipt of Care within a Medical Home

Table III presents associations between receiving care within a medical home and exposure variables. Younger caregivers, caregivers with lower levels of education, and caregivers of children with delayed language were much less likely to report that their child received care within a medical home than caregivers who were 30 years of age or older, those with an associate's degree or higher level of education, or caregivers of children who obtained Bayley-III language scores above 85.

Table I. Sociodemographic characteristics of the study sample, Omega Tots trial, 2015-2016 (n = 202)

Characteristic	Full sample	Received care within a medical home	Did not receive care within a medical home	Number missing n (%)	Test of group differences
Caregiver characteristics					
Age					
<30 y*	106 (52.5)	44 (41.1)	62 (65.3)	0 (0)	$X^2 = 11.8$
≥30 y	96 (47.5)	63 (58.9)	33 (34.7)		$P = .0006$
mean (SD)†	30.4 (7.3)	31.5 (7.3)	29.1 (7.1)		$t = 2.37$
Relationship to child, no. (%)‡				0 (0)	$P = .02$
Mother	194 (96.0)	103 (96.3)	91 (95.8)		$P = 1.00$
Other	8 (4.0)	4 (3.7)	4 (4.2)		
Insurance status, no. (%)*				0 (0)	
Public or none§	112 (55.5)	49 (42.3)	63 (52.7)		$X^2 = 8.58$
Private	90 (44.5)	58 (59.3)	32 (47.7)		$P = .003$
Highest level of education, no. (%)*				0 (0)	
Less than associate's degree	119 (58.9)	50 (46.7)	69 (72.6)		$X^2 = 13.95$
Associate's degree or higher	83 (41.1)	57 (53.3)	26 (27.4)		$P = .0002$
Marital relationship status, no. (%)*				1 (0.5)	
Single/not living with spouse/partner	71 (35.3)	34 (31.8)	37 (39.4)		$X^2 = 1.26$
Living with spouse/partner	130 (64.7)	73 (68.2)	57 (60.6)		$P = .26$
Child characteristics					
Race/ethnicity, no. (%)‡				0 (0)	
White, non-Hispanic	116 (57.4)	67 (62.6)	49 (51.6)		$P = .22$
Black/African, non-Hispanic	58 (28.7)	24 (22.4)	34 (35.8)		
Other, multiracial, non-Hispanic	19 (9.4)	11 (10.3)	8 (8.4)		
Hispanic	9 (4.5)	5 (4.7)	4 (4.2)		
Age, mo, adjusted for prematurity, mean (SD)†	14.4 (1.9)	14.2 (1.9)	14.6 (1.8)	0 (0)	$t = -1.55$
					$P = .12$
Gestational age, completed wk, mean (SD)†	30.7 (3.0)	31.0 (2.8)	30.4 (3.2)	0 (0)	$t = -1.34$
					$P = .18$
Birthweight, g, mean (SD)†	1619.1 (575.0)	1672.1 (557.4)	1560.0 (591.2)	1 (0.5)	$t = 1.39$
					$P = .17$
Child sex, no. (%)*				0 (0)	
Male	92 (45.5)	51 (47.7)	41 (43.2)		$X^2 = 0.41$
Female	110 (54.5)	56 (57.3)	54 (56.8)		$P = .52$
Ever attended neonatal follow-up clinic, no. (%)*				0 (0)	
No	73 (36.1)	44 (41.1)	29 (30.5)		$X^2 = 2.45$
Yes	129 (63.9)	63 (58.9)	66 (69.5)		$P = .12$
Bayley-III cognitive composite score, no. (%)				0 (0)	
≤85*	36 (17.8)	13 (12.1)	23 (24.2)		$X^2 = 5.00$
>85	166 (82.2)	94 (87.9)	72 (75.8)		$P = .03$
mean (SD)†	99.9 (12.7)	101.0 (12.2)	98.6 (13.3)		$t = 1.31$
					$P = .19$
Bayley-III motor composite score, no. (%)				0 (0)	
≤85*	42 (20.8)	19 (17.8)	23 (24.2)		$X^2 = 1.27$
>85	160 (79.2)	88 (82.2)	72 (75.8)		$P = .26$
mean (SD)†	95.6 (14.0)	96.2 (14.3)	95.0 (13.8)		$t = 0.61$
					$P = .54$
Bayley-III language composite score, no. (%)				0 (0)	
≤85*	45 (22.3)	16 (15.0)	29 (69.5)		$X^2 = 7.05$
>85	157 (77.7)	91 (85.0)	66 (30.5)		$P = .008$
mean (SD)†	92.0 (11.5)	94.3 (16.7)	89.5 (10.7)		$t = 3.02$
					$P = .003$

*χ^2 test examined group differences.
†Independent samples t test examined group differences.
‡Fisher exact test examined group differences.
§Because a small number of caregivers (n = 6; 3%) reported not having insurance and analyses excluding these families from the creation of the insurance status variable are consistent with the findings reported here, children whose caregivers reported not having insurance were grouped with children whose caregivers reported having public insurance.

Gestational age and neonatal follow-up clinic attendance were unrelated to receiving care within a medical home.

Factors Associated with Medical Home Components

Table III illustrates associations among each medical home component and exposure variables. Caregivers who were younger than 30 years of age were less likely than caregivers who were 30 years of age or older to report that their child received family-centered care. Caregivers who reported having public or no insurance were less likely to report that their child had a personal doctor or nurse and were less likely to report difficulty getting referrals for their child when needed than caregivers who reported having private insurance. Caregivers with lower levels of education were less likely to report that their child had a usual place for care and less likely to report their child received effective care coordination relative to caregivers with an associate's degree or higher. Gestational age,

Table III. Factors associated with receipt of care within a medical home and medical home components, Omega Tots trial, 2015-2016 (n = 202)

Factor	Care within medical home		Personal doctor/nurse		Usual place for care	
	Unadjusted RR (95% CI)	Adjusted RR (95% CI)	Unadjusted RR (95% CI)	Adjusted RR (95% CI)	Unadjusted RR (95% CI)	Adjusted RR (95% CI)
Socioeconomic characteristics						
Caregiver <30 y (vs ≥30)	0.63 (0.48, 0.83)	0.73 (0.55, 0.97)	0.97 (0.89, 1.05)	1.00 (0.93, 1.08)	0.94 (0.86, 1.02)	0.97 (0.90, 1.05)
Public or no insurance (vs private)	0.68 (0.52, 0.88)	0.90 (0.65, 1.25)	0.91 (0.85, 0.99)	0.94 (0.89, 0.99)	0.91 (0.84, 0.98)	0.94 (0.88, 1.01)
Less than associate's degree (vs associate's degree or higher)	0.61 (0.47, 0.79)	0.69 (0.49, 0.98)	0.92 (0.86, 0.99)	0.96 (0.92, 1.01)	0.90 (0.83, 0.97)	0.93 (0.87, 0.99)
Prematurity characteristics						
Gestational age (per 1 wk)	1.03 (0.98, 1.08)	1.02 (0.98, 1.06)	1.00 (0.99, 1.02)	1.00 (0.99, 1.02)	1.01 (0.99, 1.03)	1.01 (0.99, 1.02)
Never attended neonatal follow-up (vs attended)	1.23 (0.95, 1.60)	1.16 (0.90, 1.49)	1.04 (0.96, 1.13)	1.02 (0.95, 1.11)	1.03 (0.95, 1.12)	1.01 (0.93, 1.09)
Developmental status						
Cognitive ≤85 (vs >85)	0.64 (0.40, 1.00)	0.71 (0.45, 1.11)	0.92 (0.80, 1.06)	0.82 (0.94, 1.08)	0.89 (0.77, 1.04)	0.91 (0.78, 1.06)
Motor ≤85 (vs >85)	0.82 (0.57, 1.18)	0.87 (0.62, 1.22)	1.01 (0.92, 1.11)	1.02 (0.92, 1.12)	0.98 (0.88, 1.10)	0.99 (0.89, 1.10)
Language ≤85 (vs >85)	0.67 (0.41, 0.93)	0.63 (0.42, 0.95)	0.99 (0.89, 1.09)	0.99 (0.90, 1.10)	0.96 (0.86, 1.08)	0.96 (0.86, 1.08)
	Effective coordination*		**Family-centered care**		**Difficulty getting referrals when needed**	
	Unadjusted RR (95% CI)	Adjusted RR (95% CI)	Unadjusted RR (95% CI)	Adjusted RR (95% CI)	Unadjusted RR (95% CI)	Adjusted RR (95% CI)
Socioeconomic characteristics						
Caregiver <30 y (vs ≥30)	0.79 (0.63, 0.98)	0.94 (0.74, 1.20)	0.82 (0.70, 0.95)	0.86 (0.74, 0.99)	1.67 (0.67, 4.17)	1.59 (0.63, 4.06)
Public or no insurance (vs private)	0.77 (0.62, 0.96)	0.94 (0.77, 1.22)	0.87 (0.75, 1.01)	0.96 (0.81, 1.14)	0.57 (0.24, 1.37)	0.38 (0.15, 0.95)
Less than associate's degree (vs associate's degree or higher)	0.69 (0.55, 0.86)	0.72 (0.55, 0.97)	0.81 (0.71, 0.94)	0.87 (0.73, 1.03)	1.51 (0.61, 3.77)	2.20 (0.81, 5.98)
Prematurity characteristics						
Gestational age (per 1 wk)	1.00 (0.97, 1.04)	1.01 (0.98, 1.04)	1.01 (0.98, 1.04)	1.01 (0.98, 1.04)	1.02 (0.89, 1.18)	1.01 (0.87, 1.17)
Never attended neonatal follow-up (vs attended)	1.08 (0.86, 1.37)	1.05 (0.85, 1.30)	1.13 (0.98, 1.31)	1.12 (0.97, 1.29)	0.81 (0.29, 2.29)	0.78 (0.27, 2.24)
Developmental status						
Cognitive ≤85 (vs >85)	1.02 (0.78, 1.35)	1.02 (0.79, 1.31)	1.05 (0.88, 1.26)	1.08 (0.90, 1.29)	1.12 (0.40, 3.11)	1.56 (0.53, 4.61)
Motor ≤85 (vs >85)	1.16 (0.91, 1.47)	1.11 (0.90, 1.36)	1.10 (0.94, 1.29)	1.10 (0.94, 1.29)	0.81 (0.29, 2.29)	0.86 (0.31, 2.35)
Language ≤85 (vs >85)	0.93 (0.70, 1.24)	0.92 (0.70, 1.20)	0.90 (0.74, 1.10)	0.89 (0.73, 1.09)	1.81 (0.77, 4.23)	2.17 (0.96, 4.91)

RR, risk ratio.

Adjusted models included the following covariates: caregiver age (continuous), insurance status (public or none vs private), caregiver education (less than associate's degree vs associate's degree or higher). Covariates were not included in adjusted models where the socioeconomic covariate was the exposure of interest.

*One observation (0.5%) missing for this variable.

neonatal follow-up clinic attendance, and developmental status were unrelated to medical home components.

Factors Associated with Family-centered Care Components

Table IV includes associations among family-centered care components and exposure variables. Caregivers who were younger than 30 years were less likely to report that their child's healthcare provider listens carefully to them than caregivers who were 30 years or older. Caregivers who reported having public or no insurance were less likely to report that their child's doctor or healthcare provider spends enough time with their child or that their child's doctor or healthcare provider is sensitive to their family's values or customs compared with caregivers who reported having private insurance. Gestational age, neonatal follow-up clinic attendance, and developmental status were unrelated to family-centered care components.

Factors Associated with Effective Care Coordination

Table V demonstrates associations among effective care coordination and exposure variables. Caregivers who were younger than 30 years were less likely to report satisfaction with communication among healthcare providers compared with caregivers who were 30 years or older. Gestational age, neonatal follow-up clinic attendance, and developmental status were unrelated to effective care coordination.

Discussion

A medical home was lacking for 47% of this preterm sample of toddlers. This study identified that socioeconomic characteristics and language development were strongly associated with receipt of care within a medical home for toddlers born preterm. Specifically, children from lower socioeconomic status (SES) households and those who experienced delayed language demonstrated greater risk of not receiving care within a medical home. A contribution of this work was the examination of prematurity characteristics and developmental status in their association with receiving care within a medical home and its components. Although delayed language development was associated with reduced likelihood of receiving care within a medical home, cognitive and motor development were not. In addition, gestational age and neonatal follow-up clinic attendance within this preterm sample were not associated with receiving care within a medical home or any of its components.

Previous research shows children of caregivers with greater income and higher levels of education demonstrate greater odds of having a medical home than children who live in lower SES households, however, receipt of care within a medical home has not improved despite initiatives aimed at improving access for low-SES families living in the US.[17,18] In addition, having private medical insurance and lower gestational age is associated with having a usual care provider, an important component of the medical home; and although the presence of a medical home is associated with improved child developmental outcomes, only 31% of children with a developmental disability receive care within a medical home.[19-21]

Table IV. Factors associated with family-centered care, Omega Tots trial, 2015-2016 (n = 202)

Factor	Enough time		Listens carefully		Provides needed information		Sensitive to values		Feel like a partner in care	
	Unadjusted RR (95% CI)	Adjusted RR (95% CI)	Unadjusted RR (95% CI)	Adjusted RR (95% CI)	Unadjusted RR (95% CI)	Adjusted RR (95% CI)	Unadjusted RR (95% CI)	Adjusted RR (95% CI)	Unadjusted RR (95% CI)	Adjusted RR (95% CI)
Socioeconomic characteristics										
Caregiver <30 y (vs ≥30)	0.91 (0.82, 1.01)	0.95 (0.85, 1.07)	0.90 (0.83, 0.97)	0.92 (0.85, 0.99)	0.94 (0.88, 1.01)	0.96 (0.90, 1.03)	0.91 (0.83, 0.99)	0.96 (0.88, 1.04)	0.95 (0.86, 1.04)	0.96 (0.87, 1.05)
Public or no insurance (vs private)	0.86 (0.78, 0.95)	0.87 (0.77, 0.99)	0.93 (0.85, 1.00)	0.99 (0.89, 1.11)	0.95 (0.89, 1.02)	1.00 (0.92, 1.09)	0.84 (0.77, 0.92)	0.89 (0.82, 0.96)	0.96 (0.88, 1.05)	1.03 (0.91, 1.17)
Less than associate's degree (vs associate's degree or higher)	0.88 (0.79, 0.97)	0.96 (0.85, 1.09)	0.92 (0.85, 0.99)	0.95 (0.86, 1.04)	0.94 (0.88, 1.00)	0.97 (0.90, 1.04)	0.87 (0.80, 0.95)	0.95 (0.89, 1.01)	0.93 (0.85, 1.01)	0.92 (0.82, 1.04)
Prematurity characteristics										
Gestational age (per 1 wk)	0.99 (0.98, 1.01)	0.99 (0.97, 1.01)	1.01 (0.99, 1.03)	1.01 (0.99, 1.03)	1.00 (0.99, 1.02)	1.00 (0.99, 1.01)	1.01 (0.99, 1.03)	1.01 (0.99, 1.03)	1.01 (0.99, 1.03)	1.01 (0.99, 1.03)
Never attended neonatal follow-up (vs attended)	1.01 (0.91, 1.13)	0.98 (0.88, 1.09)	1.08 (0.99, 1.16)	1.06 (0.98, 1.15)	1.01 (0.94, 1.08)	1.00 (0.93, 1.07)	1.10 (1.02, 1.20)	1.08 (0.99, 1.16)	1.05 (0.97, 1.15)	1.05 (0.96, 1.14)
Developmental status										
Cognitive ≤85 (vs >85)	1.10 (0.99, 1.22)	1.12 (0.98, 1.27)	1.00 (0.90, 1.12)	1.07 (0.95, 1.20)	1.01 (0.92, 1.10)	1.04 (0.97, 1.11)	0.98 (0.87, 1.12)	1.02 (0.89, 1.16)	1.02 (0.91, 1.14)	1.10 (0.98, 1.23)
Motor ≤85 (vs >85)	1.08 (0.98, 1.20)	1.08 (0.96, 1.22)	1.05 (0.97, 1.14)	1.11 (1.02, 1.20)	0.98 (0.90, 1.08)	0.99 (0.91, 1.08)	0.97 (0.86, 1.10)	1.02 (0.90, 1.15)	0.97 (0.86, 1.10)	0.98 (0.86, 1.12)
Language ≤85 (vs >85)	1.06 (0.95, 1.18)	1.04 (0.92, 1.18)	0.90 (0.79, 1.03)	0.90 (0.78, 1.04)	0.96 (0.87, 1.06)	0.98 (0.91, 1.06)	0.95 (0.84, 1.08)	0.95 (0.84, 1.08)	0.89 (0.77, 1.03)	0.88 (0.76, 1.02)

Adjusted models included the following covariates: caregiver age (continuous), insurance status (public or none vs private), caregiver education (less than associate's degree vs associate's degree or higher). Covariates were not included in adjusted models where the socioeconomic covariate was the exposure of interest.

Table V. Factors associated with effective care coordination, Omega Tots trial, 2015-2016 (n = 202)

Factor	Help with care coordination		Communication among healthcare providers		Communication among healthcare providers and other services*	
	Unadjusted RR (95% CI)	Adjusted RR (95% CI)	Unadjusted RR (95% CI)	Adjusted RR (95% CI)	Unadjusted RR (95% CI)	Adjusted RR (95% CI)
Socioeconomic characteristics						
Caregiver <30 y (vs ≥30)	1.16 (0.81, 1.65)	1.29 (0.90, 1.84)	0.74 (0.61, 0.90)	0.79 (0.64, 0.97)	0.93 (0.75, 1.15)	0.96 (0.74, 1.25)
Public or no insurance (vs private)	0.79 (0.59, 1.06)	0.74 (0.51, 1.05)	0.92 (0.77, 1.11)	1.18 (0.96, 1.48)	0.93 (0.76, 1.14)	0.97 (0.76, 1.25)
Less than associate's degree (vs associate's degree or higher)	0.83 (0.61, 1.12)	0.75 (0.52, 1.10)	0.78 (0.65, 0.94)	0.86 (0.70, 1.05)	0.92 (0.75, 1.13)	0.99 (0.78, 1.25)
Prematurity characteristics						
Gestational age (per 1 wk)	0.99 (0.95, 1.04)	0.99 (0.95, 1.04)	1.00 (0.97, 1.03)	1.01 (0.97, 1.04)	1.01 (0.98, 1.04)	1.02 (0.94, 1.10)
Never attended neonatal follow-up (vs attended)	1.08 (0.78, 1.49)	1.03 (0.75, 1.41)	1.16 (0.97, 1.38)	1.19 (0.99, 1.44)	0.88 (0.68, 1.14)	0.89 (0.69, 1.16)
Developmental status						
Cognitive ≤85 (vs >85)	1.08 (0.76, 1.54)	1.48 (0.97, 2.26)	0.99 (0.79, 1.25)	1.00 (0.83, 1.21)	0.99 (0.76, 1.28)	0.96 (0.71, 1.29)
Motor ≤85 (vs >85)	1.18 (0.86, 1.61)	1.21 (0.81, 1.81)	1.15 (0.96, 1.38)	1.20 (0.97, 1.49)	1.12 (0.92, 1.37)	1.18 (0.94, 1.48)
Language ≤85 (vs >85)	0.81 (0.53, 1.25)	0.84 (0.51, 1.40)	1.05 (0.86, 1.29)	1.07 (0.89, 1.29)	1.11 (0.90, 1.37)	1.05 (0.83, 1.34)

Adjusted models included the following covariates: caregiver age (continuous), insurance status (public or none vs private), caregiver education (less than associate's degree vs associate's degree or higher). Covariates were not included in adjusted models where the socioeconomic covariate was the exposure of interest.
*One observation (0.5%) missing for this variable.

Consistent with previous reports, lower SES was associated with an increased risk of not receiving care within a medical home within this preterm sample. The components of a medical home that were frequently lacking for children of young caregivers, caregivers who had less than an associate's degree level of education, or those who were in receipt of public or no insurance were effective care coordination (lacking for 38%, 34% in full sample) and family-centered care (lacking for 28%, 23% in full sample). This is of particular importance for children born preterm who often require integration of many health services such as speech, physical, and occupational therapy by age one.[22] Within the family-centered care component of the medical home, caregivers of children living in low-SES environments were significantly less likely to report that their child's doctor or nurse spent enough time with them or listened carefully to them, compared with children living in higher-SES environments. Environments in which low-SES children receive their medical care may drive this disparity. Specifically, these children may receive their medical care in large facilities, with many practitioners who see large numbers of patients. These constraints on time, coupled with limited resources may pose additional barriers to establishing a medical home characterized by an "accessible, family-centered, coordinated, comprehensive, continuous, compassionate, and culturally effective" partnership between families and the medical community.[23,24]

This study found that 22.3% of children scored 1 SD or more below the mean on the language scale of the Bayley-III.[25,26] Children born preterm with delayed language were 37% less likely to receive care within a medical home compared with those with Bayley-III language scores above 85 after accounting for confounding variables. This suggests that some children with a clearly defined need for a medical home do not report having one. Receiving care within a medical home was not associated with delayed cognitive or motor development, areas of development that may be more visible to caregivers. It is plausible that families may not identify the need for language interventions for their child at such a young age, especially given the host of physical, neurologic, behavioral and social-emotional delays, and chronic medical conditions that children born preterm may face. Given the noted delays in language development of children born preterm and the specialty services used to remediate such delays, access to and engagement with a family-centered medical home may be crucial to improved health, functional, and developmental outcomes of children born preterm.

Care for children born preterm after NICU discharge is complex, requiring more than 20 pediatrician and specialist visits, on average, and many pharmaceutical prescriptions in the first year alone.[27] Children born preterm continue to experience more hospital admissions than their term peers throughout childhood.[28] In addition, care for the preterm infant is costly.[29] Therefore, establishing a medical home for these children is essential. The American Academy of Pediatrics asserts that the primary care practice should provide a child's medical home, however, 37% of primary care physicians do not agree that primary care should be the medical home for CSHCN.[6,23] Therefore, there is a need for clarity and education for families,

physicians, and hospital systems concerning the most advantageous medical home for CSHCN. Because 90% of infants born at less than 34 weeks of gestation interact with the NICU, it is reasonable that NICU discharge is an optimal time to establish a collaborative plan for continuous care, inclusive of a primary care medical home.[30]

Compared with a national sample of CSHCN, caregivers of children born preterm in the Omega Tots trial reported higher rates of receiving care within a medical home (53% vs 43%).[31] Children born preterm are a unique group of CSHCN because they present risk for developmental delays and chronic medical conditions at birth. Therefore, it is reasonable to strive for higher rates of care within a medical home for children born preterm, even above the 53% found in this study. Because their CSHCN status is known at birth, this is an optimal time to establish a comprehensive plan for care inclusive of a medical home for children born preterm. Doing so is essential to improve short- and long-term outcomes for children born preterm, reduce cost of care associated with care of the preterm infant, and to provide effective and comprehensive care of the child, which will ultimately improve outcomes for both the child and family. Integrated care, inclusive of establishing a primary care medical home and continuity of care at NICU discharge may provide enhanced access to and engagement with a medical home for children born preterm, compared with all CSHCN.

There were limitations to this work. First, the sample was limited to families in 1 geographic region who took part in a randomized clinical trial. Eligible children were born at <35 completed weeks of gestation, had discontinued regular human milk and infant formula feeding, and their families were English-speaking, which may limit the generalizability of our findings to all children born preterm, especially those born at 35 or 36 weeks of gestation. Next, this study was cross-sectional and, therefore, we did not collect information on long-term outcomes related to receiving care within a medical home to enable examination of temporal relationships. We also could not characterize the settings within which children received care, such as the emergency department. Therefore, we are unable to characterize the types of medical care received by children whose caregivers did not report receiving care within a medical home. The study did not confirm whether each child was referred to neonatal follow-up clinic at NICU discharge, and some children would not have been referred because they were born at later gestational ages. The study outcome was based on caregiver report and did not have an objective measure of medical home availability and access. Finally, the study was unable to ascertain who families believed was their medical home, which may identify which primary or subspecialty provider settings would be the focus of interventions.

We presented several strengths in this work. Nationwide Children's Hospital serves a very large preterm population that made this work possible. Our study drew from a large sample of children born preterm. Specifically, children were recruited from a complete census of all former patients, narrowed by the trial eligibility criteria (eg, less than 35 completed weeks of gestation). By starting with a comprehensive list of the regional preterm population, we reduced a major source of selection bias by not recruiting solely among those who attended follow-up clinic. In addition, the characteristics of our sample mirror that of the US population of children born at <35 weeks of completed gestation. Therefore, this study was not subject to the biases often seen in studies that rely purely on volunteers or patients with high attendance at neonatal follow-up clinics (36% of the present sample did not attend). Thus, our findings may be more generalizable to the larger population of children born at <35 weeks of gestation. Next, our sample was diverse: more than 42% of caregivers indicated they were a racial or ethnic minority. Therefore, our results may apply to families of varying sociodemographic characteristics.

Children born preterm represent a unique group of CSHCN. They require more time, services, and coordination among multiple healthcare providers and services, yet 47% of caregivers reported that their child did not receive care within a medical home. Improved engagement with a medical home may improve outcomes for all CSHCN, especially those born preterm and their families. Both primary care providers and specialists are vital contributors to establishing a medical home for children and families. An important way to facilitate access to and care within a medical home and establish continuity of care is at NICU discharge. Future research should address the long-term implications of not receiving care within a medical home in the preterm population. ■

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Table II. Receipt of care within a medical home, Omega Tots trial 2015-2016 (n = 202)

Medical home component	% endorsed
Receipt of care within a medical home	53.0
Personal doctor or nurse	92.1
Usual place for care	91.6
Effective care coordination	66.5
Family centered care	77.2
Healthcare provider spends enough time	87.1
Healthcare provider listens carefully	92.6
Healthcare provider provides needed information	94.1
Healthcare provider is sensitive to family values and customs	90.1
Healthcare provider makes you feel like a partner in care	90.1
Received referrals when needed	85.4
Healthcare communication satisfaction	
Help coordinating care when needed	69.0
Communication among healthcare providers	79.8
Communication among healthcare providers and other services	82.1

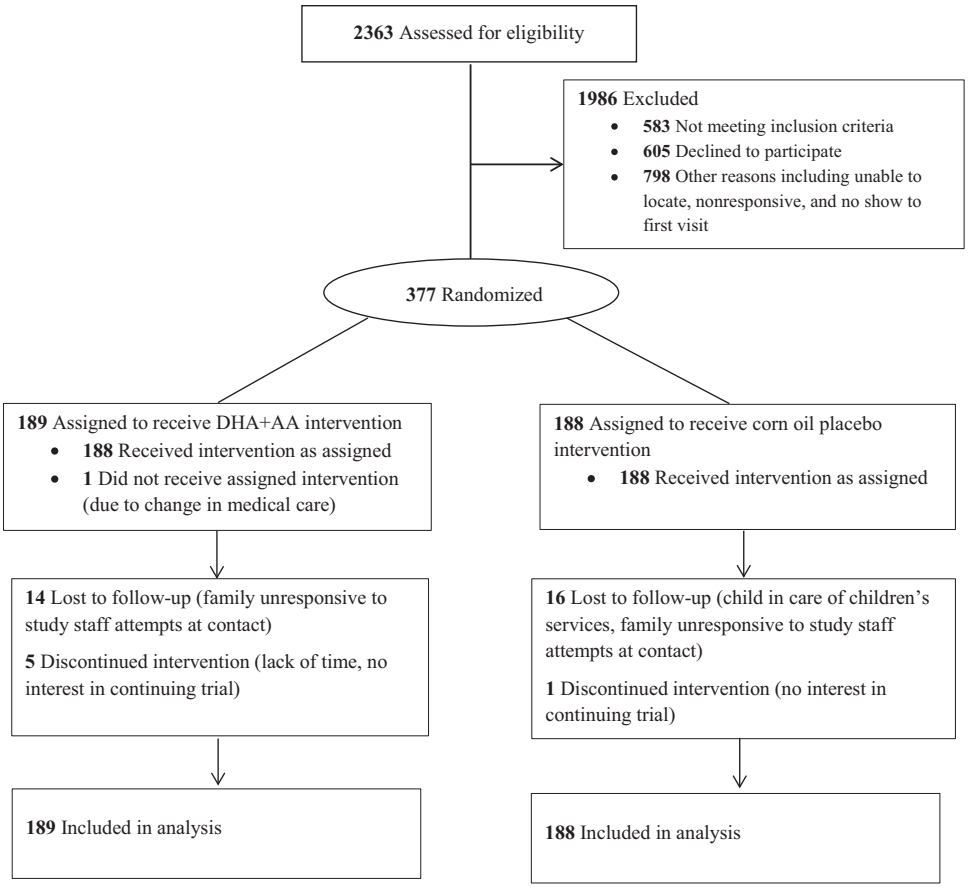

Figure. Participant CONSORT flow diagram, Omega Tots trial (n = 377), 2012-2017. *AA*, Arachidonic Acid; *DHA*, Docosahexaenoic Acid.