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ARTICLE

Preterm infants are less likely to have a family-centered medical home than term-born peers

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Abstract

Objective The family-centered medical home (FCMH) is the recommended healthcare delivery model for children. It is unknown how frequently preterm (PT) children receive care in a FCMH and how this affects health services use.

Study design We studied 18,397 children aged 0–3 years in the 2010/2011 National Survey of Children's Health. We compared PT (<37 weeks) and full-term (FT) children on rates of FCMH and receiving prescribed health services. Regression models included sex, race, income, insurance status, and having a special health care need (SHCN).

Results PT children were significantly less likely to have a FCMH (57% vs. 66%) compared to FT peers despite higher rates of SHCN (16% vs. 5%). PT children were less likely to receive prescribed services (aOR 0.34, 95% CI 0.34, 0.34); lacking a FCMH explained 69% of this effect.

Conclusions Ensuring PT children have access to medical homes may decrease unmet service needs post-hospital discharge.

Introduction

The family-centered medical home (FCMH) is the recommended model for delivering pediatric care in the US. The key components of the FCMH include having a personal doctor or nurse, a usual source for sick and well care, access to needed referrals, effective care coordination, and family-centeredness as reflected by shared decision-making, cultural competence, and satisfaction with communication among providers [1]. Sharing some aspects of care delivery with the adult-oriented patient-centered medical home, the FCMH has a special emphasis on the unique epidemiology and developmental needs of the pediatric population [2]. Receiving care within a medical home has been associated with improved access to services, greater family satisfaction with care, and lower healthcare costs [3–5].

The benefits of family-centered care are especially apparent for children with special health care needs (SHCN) [6–8]. Data from the National Survey of Children with Special Health Care Needs reveal that children without a FCMH are twice as likely to have unmet healthcare needs and three times more likely to have unmet needs for family support services compared to those with a medical home [9]. A recent publication from our group reported that receiving care coordination services within the context of a medical home was associated with 29% lower odds of having a functional disability in a nationally representative sample of children with SHCN [10]. And a randomized controlled trial of a family-centered, comprehensive follow-up care intervention led to a halving of risk for life-threatening illness among high-risk, preterm (PT) infants [11].

Infants born PT are particularly vulnerable to adverse health and developmental outcomes over time [12–15] and have higher rates of SHCN compared to term-born peers [16–18]. Infants discharged from the Neonatal Intensive Care Unit (NICU) are at high risk for rehospitalization, especially within the first year of life [19–21]. With this understanding, the American Academy of Pediatrics Committee on the Fetus and Newborn has issued recommendations for comprehensive discharge planning, the stated goal of which is to "ensure the successful transition to home care" that includes network primary and subspecialty

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providers and community-based support services and the potential scope of these services has been described [22]. Wang et al. used a consensus process to establish recommended follow-up services for high-risk, PT infants [23]. Despite this, there is little information about the post-discharge care environment of PT infants, and scant data to indicate whether this group of high-risk infants receives ongoing, coordinated, family-centered care after leaving the NICU. Moreover, the effect of having FCMH on health services use among PT infants is also unknown. We compared rates of having a FCMH between PT children and full-term (FT) peers and to what extent having medical homes impacts the receipt of all recommended preventive and all prescribed, non-preventive health services.

Methods

We used data from the 2011/12 National Survey of Children's Health (NSCH). The NSCH is a large, multi-wave, nationally representative telephone survey of the physical and mental health of non-institutionalized children aged 0–17 years living in the US. It is conducted by the National Center for Health Statistics at the Centers for Disease Control and Prevention and funded by the Maternal and Child Health Bureau. The sample consisted of all children aged 0–3 years with complete information on predictor and outcomes variables. Fewer than 10% of participants had missing predictor or outcomes data making their removal from the analytic sample unlikely to alter the study results.

The main exposure variable was birth <37 weeks gestation and <2500 g birth weight (PT). There were three main outcomes, all of which were measured as dichotomous variables. The first outcome variable, FCMH, was defined as current receipt of pediatric care meeting all five criteria described by the AAP. This was ascertained by the NSCH in a series of survey questions. Having a usual source of care was measured by an affirmative answer to: Do you have a personal doctor/nurse and do you have a usual source for both well and sick care? Family-centeredness was measured by a response of "often" or "all of the time" to each of the following: How often does your doctor spend enough time with you, listen carefully to your concerns, is sensitive to your family values and customs, provides needed information, and makes you feel like a partner in your child's care? Comprehensiveness of care was defined as having no problems receiving needed referrals. Effective care coordination was defined as having someone to help coordinate care when needed and being "satisfied" or "very satisfied" with doctor-to-doctor or doctor-to-school communication, if needed. The subcomponents were combined to create a dichotomous composite FCMH variable.

The second outcome was receipt of all recommended preventive medical and dental preventive services in the last 12 months. The third was receipt of all prescribed, non-preventive health services in the last 12 months.

We included the presence of a SHCN due to a chronic condition as an effect modifier of the relationship between PT birth and unmet service needs. In the NSCH, a SHCN was defined as a condition lasting or expected to last at least 1 year associated with: use of prescription medication other than vitamins, use of more services than typical child, limitations in ability of typical children, need of special therapy, emotional or behavioral problems requiring treatment. Chronic conditions included parent report of the child currently, or ever, having, one or more of following diagnoses: learning disability, attention deficit hyperactivity disorder, depression, anxiety, behavioral or conduct problems, autism or other autism spectrum disorder, developmental delay, intellectual disability, cerebral palsy, speech problems, asthma, diabetes, seizure disorder, hearing problems, vision problems, or brain injury.

We considered an additional set of covariates to assess for potential confounding. These included sex (male vs. female), race/ethnicity (white vs. non-white), family composition (2-parent vs. 1-parent household), and income (<100% vs. ≥400% federal poverty level). We also included three measures of health insurance status: public vs. private coverage, coverage that is continuous vs. interrupted during the preceding 12 months, and coverage that meets perceived needs adequately vs. inadequately.

We compared baseline characteristics between PT and term-born children using Chi-square tests. We also compared the groups on rates of preventive and non-preventive service receipt, SHCN, and FCMH. We then fit logistic regression models for the two outcomes adjusting for covariates that were significant at $p < 0.1$ in bivariate analyses.

To test for effect measure modification by the presence of SHCN, we added an interaction term, PT*SHCN, to the logistic regression model.

Finally, we then fit full and reduced logistic regression models with FCMH as a mediating variable. We used a mediation strategy for binary outcomes described by Schluchter [24] using generalized estimating equations (GEE). We began by creating a duplicate data set, one that includes the mediator and another that does not. The next step was to create a dummy variable with a value of "1" if the mediator is present and "0" if the mediator is absent. The resulting GEE model—with predictor, the mediator, and an interaction between the exposure and the indicator variable—yields estimates similar to those from separate full and reduced mediation models. The advantage is that this model also produces standard errors and confidence intervals. We included the same covariates as in the logistic regression models to correct for potential confounding.

To make effect estimates comparable between full and reduced models, and to quantify the degree of mediation present, we standardized each estimate by multiplying by the standard deviation of the predictor variable and dividing by the standard deviation of the outcome variable. We then calculated the percent of the effect due to mediation by dividing the indirect effect of FCMH by the total effect of PT birth on service receipt [25].

All analyses and statistical models used the final survey weights published by the NSCH. Each weight was comprised of a base weight accounting for the probability of selection, an adjustment for non-response and sub-sampling by age, and a final adjustment to match each state's weighted survey responses to the state's population of non-institutionalized children age ≥17 years [26].

Results

There were 18,397 children in the sample who were 0–3 years of age representing 14,704,308 children in the US population (Table 1). Six percent (931,790) were born PT and 50% (475,654) were male. Those in the PT group were more likely to be non-white (44% vs. 36%) and living in single-parent (21% vs. 15%) and/or impoverished (25% vs. 19%) households, and to have public insurance coverage (48% vs. 35%) compared to term-born peers.

Compared to term-born children, the PT group was equally likely to have received recommended preventive medical and dental services but significantly less likely to receive prescribed, non-preventive services (RR 0.42, 95% CI 0.41, 0.42) (Table 2). Despite being more likely to have

Table 1 Sample characteristics

	Weighted *N* (%)	
	Preterm	Term
Total	931,790 (5.9)	13,772,518 (94.1)
Sociodemographic		
Sex, male	475,654 (50.6)	6,998,231 (50.4)
Race, nonwhite*	513,736 (43.6)	6,487,114 (36.1)
Primary language, English	789,273 (90.1)	11,289,760 (90.5)
Single parent household*	213,796 (21.0)	2,349,021 (15.3)
Household income*		
<100% FPL	317,555 (25.0)	3,544,869 (19.3)
100–199% FPL	184,121 (18.9)	2,972,079 (18.6)
200–399% FPL	237,030 (26.9)	3,584,957 (28.5)
≥400% FPL	193,084 (29.2)	3,670,612 (33.6)
Insurance		
Public*	523,570 (47.6)	5,742,044 (34.6)
Coverage gap	89,885 (8.7)	1,427,845 (8.5)
Inadequate coverage	162,358 (18.0)	2,413,872 (16.8)
Health		
Chronic health problem*	172,098 (18.8)	1,022,393 (7.0)
Special health care need*	168,897 (13.7)	1,138,885 (5.2)
Special health care need due to a chronic health problem*	105,572 (15.7)	604,242 (5.4)
Received all preventive medical and dental care	433,188 (49.9)	6,812,031 (50.1)
Received all prescribed services*	837,823 (92.9)	13,199,439 (96.0)
Family-centered medical home*	465,020 (57.3)	8,372,207 (66.2)
Medical home subcomponents		
Personal doctor/nurse	846,032 (93.5)	12,652,405 (93.4)
Family-centered	605,243 (70.4)	9,221,016 (72.5)
Getting needed referrals*	207,340 (24.2)	1,807,922 (14.6)
Usual source of care	814,167 (92.8)	12,739,693 (94.4)
Effective care coordination*	250,701 (31.4)	2,644,123 (20.7)

FPL federal poverty level

*$p < 0.01$ Chi-square test

Table 2 Predictors of medical home, receipt of preventive services, and receipt of prescribed services

	Medical home	Preventive service receipt	Prescribed service receipt
	RR (95% CI)	RR (95% CI)	RR (95% CI)
Medical home		0.99 (0.99, 0.99)	3.91 (3.89, 3.93)
Preterm birth	0.78 (0.78, 0.78)	0.94 (0.94, 0.95)	0.42 (0.41, 0.42)
Sex, male	0.96 (0.95, 0.96)	1.03 (1.02, 1.03)	0.81 (0.80, 0.81)
Race, nonwhite	0.54 (0.54, 0.54)	1.09 (1.08, 1.09)	0.61 (0.61, 0.61)
Primary language, English	2.02 (2.02, 2.03)	0.99 (0.99, 0.99)	0.66 (0.65, 0.66)
Single parent household	0.73 (0.73, 0.73)	0.98 (0.98, 0.98)	0.50 (0.50, 0.50)
Household income:			
<100% vs. ≥400% FPL	0.60 (0.60, 0.60)	0.95 (0.95, 0.95)	0.72 (0.71, 0.72)
Insurance			
Public vs. Private	0.66 (0.66, 0.66)	1.05 (1.05, 1.06)	0.65 (0.65, 0.66)
Gap in coverage	0.73 (0.73, 0.73)	0.79 (0.79, 0.80)	0.17 (0.17, 0.17)
Inadequate coverage	0.64 (0.64, 0.65)	0.96 (0.96, 0.96)	0.35 (0.35, 0.35)
Special health care need due to a chronic condition	0.73 (0.73, 0.73)	1.00 (0.99, 1.00)	0.39 (0.39, 0.40)

FPL federal poverty level

Table 3 Prescribed service receipt

	Prescribed service receipt	
	aOR[a]	95% CI
Preterm	0.34	0.34, 0.34
Race, nonwhite	0.98	0.98, 0.99
Single parent household	0.67	0.66, 0.67
Household income		
<100% vs. ≥400% FPL	1.08	1.08, 1.09
Insurance		
Public vs. Private	0.56	0.56, 0.57
Gap in coverage	0.19	0.19, 0.19
Inadequate coverage	0.34	0.33, 0.34

FPL federal poverty level

[a]Odds ratio adjusted for race, single parent household composition, household income, insurance type, and consistency and adequacy of insurance coverage

SHCN (RR 1.08, 95% CI 1.08, 1.08), the PT group was less likely to have a FCMH (RR 0.78, 95% CI 0.78, 0.78).

In adjusted, multivariable logistic models (Table 3), PT children were almost half as likely to receive prescribed, non-preventive services (aOR 0.34, 95% CI 0.34, 0.34) compared to FT children. The major influence on the receipt of services was the type of insurance coverage, with a lower likelihood of receiving prescribed, non-preventive services with public insurance (aOR 0.56, 95% CI 0.56, 0.57); a gap in coverage (aOR 0.19, 95% CI 0.19, 0.19); and inadequate coverage (aOR 0.34, 95% CI 0.33, 0.34).

Having a SHCN due to a chronic health condition was also independently associated with lower odds of receiving prescribed, non-preventive services in the multivariable model (aOR 0.40, 95% CI 0.40, 0.40). The adjusted odds ratio for the interaction between PT birth and having a SHCN was 1.63 (95% CI 1.59, 1.67), evidence of effect measure modification of the relationship between PT birth and service receipt by having a SHCN. This means that children born PT are more likely to receive prescribed services if they also have a SHCN than if they do not.

The mediation analysis results are presented in Tables 4a and 4b. After accounting for covariates and the indirect effect of having a FCMH, the direct effect of PT birth on service receipt was lessened (aOR 0.94, 95% CI 0.91, 0.98). The indirect effect of having a FCMH was small but significant (aOR 1.04, 95% CI 1.03, 1.06). Comparing the standardized effect estimates, the indirect effect of lacking a FCMH explained 69% of the total effect of PT birth on service receipt.

Table 4a Mediation by medical home

	Prescribed service receipt		
	Model #1: predictor without mediator	Model #2: mediator without predictor	Model #3: both predictor and mediator
	aOR[a] (95% CI)	aOR (95% CI)	aOR (95% CI)
Preterm	0.34 (0.34, 0.34)		0.94 (0.91, 0.98)
Medical home		4.08 (4.05, 4.10)	1.04 (1.03, 1.06)

[a]Odds ratio adjusted for race, single parent household composition, household income, insurance type, and consistency and adequacy of insurance coverage

Table 4b Proportion of the mediation effect of medical home

	Prescribed service receipt Standardized[a] aOR[b]
Total effect of preterm	0.80
Direct effect of preterm	0.25
Indirect effect of preterm mediated by medical home	0.55
Proportion of total effect that is mediated	69%

[a]To make effect estimates comparable between full and reduced models, each was standardized by multiplying by the standard deviation of the predictor variable and dividing by the standard deviation of the outcome variable. Estimates represent the standardized odds of having unmet service needs given preterm birth with and without having a medical home

[b]Odds ratio adjusted for race, single parent household composition, household income, insurance type, and consistency and adequacy of insurance coverage

Discussion

Our study is the first of to our knowledge to describe rates of FCMH among PT children and to explore the role of the FCMH in the receipt of both recommended preventive and prescribed, non-preventive services during early childhood in this population. We found that, while children born PT receive recommended preventive services with the same frequency as their term-born peers, they are significantly less likely to receive prescribed health services and to have a FCMH. Children with SHCN also have significantly higher odds of having unmet service needs in both PT and FT groups. Receiving care in the setting of a FCMH appears to attenuate the increased risk for unmet service needs conferred by being PT.

The medical home has been promoted as the gold-standard delivery model for children, especially those with medical complexity or SHCN [1]. Yet, there are known barriers to implanting medical homes in community settings including limitations in time and personnel [27]. Among the components of a medical home, nearly all respondents report having a personal doctor or nurse and a usual source of care, and this may be sufficient for healthy children with routine care needs. However, only two-thirds of children and adolescents receive care in a medical home setting meeting all the indicators. For those with SHCN, a comprehensive medical home model that includes effective care coordination services and shared decision-making has demonstrable benefits for those with SHCN. Thus, access to medical homes becomes increasingly important as rates of SHCN and chronic health conditions in the pediatric population rise [28].

Children born PT are a particularly vulnerable population due to high rates of chronic conditions and risk for poor functional outcomes [12]. There have been substantial investments in reducing the incidence and severity of neonatal morbidities associated with prematurity such as chronic lung disease, necrotizing enterocolitis, and intraventricular hemorrhage [29, 30]. Much less attention has been paid to the health services environment after NICU discharge despite explicit descriptions of what is potentially needed [23, 31]. While our results reveal higher rates of referral receipt and effective care coordination for PT children compared to those born at term, the majority of PT children lacked access to these services. With well-established risks to both short- and long-term health and development, ensuring access to care that meets complex patient and family needs is paramount.

Strikingly, only half of the children in the sample reported receiving all recommended medical and dental services regardless of medical home status. This may be explained by the inclusion of dental care, and the results are consistent with national data [32]. Low rates of dental care reflect the lack of the shortage of pediatric dentists [33] and dental insurance [34, 35]. In addition, children with SHCN may be at greater risk of poor dental care. Also, despite AAP recommendations, parents and physicians of very young children are unlikely to recommend dental visits until teeth have come in [32]. Those with public insurance were actually more likely to receive recommended preventive services than those with private insurance, possibly due to the benefits and services guaranteed by Medicaid's Early and Periodic Screening, Diagnostic, and Treatment program [36]. However, a recent report of expenditures for pediatric dental visits using data from the Medical Expenditure Panel Survey Household Component 2010–2012 found that children with public insurance were had lower rates of preventive dental visits compared to those with private insurance [32]. More detailed information on the factors influencing access to different types of services will allow for specific interventions and policy correctives.

The significant role of insurance coverage in facilitating access to pediatric health services has been well described previously [37, 38]. Consistent [39] and comprehensive [40] coverage has been shown to reduce rates of unmet care needs; our results support these earlier findings. A study of publically insured children demonstrated that even children with a personal health care provider may lack coverage for all needed services [40]. Increasing coverage for high-quality FCMH for children with or at risk for SHCN can further reduce the likelihood of unmet care needs.

We had hypothesized that having a SHCN would be associated with even greater likelihood of unmet needs among children born PT. PT birth and SHCN are independently and significantly related to higher risk for unmet service needs. However, children born PT with SHCN in actuality have lower risk of unmet service needs compared to PT children without SHCN. We note the differences in very low household income and non-white race between PT and FT children, which have been correlated to reduced access to services and poor health outcomes in America [41–43]. Our finding suggests that PT children with increased medical or developmental need due to SHCN are somewhat protected from having unfulfilled service prescriptions.

Having a FCMH is associated with lower risk for having unmet service needs in our sample. Despite lower rates of medical homes among PT children, having a FCMH appears to significantly reduce the odds of unmet needs. Improved access to comprehensive medical homes may help close the gap in unmet services between PT and term children, as having a FCMH reflects 69% of the total effect of PT birth on unmet service needs in our analysis but other measures may be needed as. Insurance status, socio-economic factors, race, and likely other factors not measured help account for the remainder of unmet service need in this population.

Our study has several strengths. We used data from a large, nationally representative survey of American children. This ensured sufficient power required to detect meaningful statistical differences. The results are also generalizable and apply to the average American child. The NSCH uses standardized definitions of the FCMH and SHCN, reducing the risk for misclassifying participants.

Despite these strengths, our study has several limitations. The exact gestational age at which each child was born is not available in this dataset. By restricting our PT group to those born less than 37 weeks' gestation and 2500 g we may have included many late PT infants whose risk for SHCN and unmet service needs are, while not zero, close to that of the term-born group. Thus, we may be underestimating the potential effects for more premature infants. The NSCH queries families about their children's health and health services needs and utilization. Physicians and care practices are not surveyed and there is no way to discern whether families reporting lack of services such as care coordination are simply unaware of their availability. This distinction is of importance when planning interventions or policy changes aimed at reducing unmet care needs.

Children born PT face significant risks to their health and development in early childhood. Though they have higher rates of SHCN due to chronic conditions compared to term-born peers, they are less likely to receive care in a FCMH. The medical home model is specifically designed to address the needs of children with chronic or complex problems. Determining why PT children are underserved by medical homes is a critical next step in the health services research agenda. It is possible that the FCMH model does not meet the needs of this population and that other strategies may be required. Meeting the care needs of PT infants and children in the first years after hospital discharge is an essential component of neonatal follow-through.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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