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Original Research

The Patient-Centered Medical Home: Mental Health and Parenting Stress in Mothers of Children With Autism

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Abstract

Objective: This study examined the correlations between receiving care in patient-centered medical home and maternal reports of their mental health and parenting stress in a national sample of mothers of children with autism spectrum disorder (ASD). **Method:** Participants were 1108 mothers of children with ASD (average age = 10.6 years; 81% male) from the 2011-2012 National Survey of Children's Health. Multiple linear regression analysis and polynomial logistic regression analysis were used to evaluate if having a child with ASD cared for in a patient-centered medical home was significantly associated with maternal reports of their parenting stress and mental health. We also assessed whether 5 indicators of the American Academy of Pediatrics medical home definition were differentially associated with maternal outcomes. **Results:** Receiving care in a patient-centered medical home was associated with maternal reports of less parenting stress (standardized $\beta = -0.201$; $P < .001$) and better mental health (odds ratios range from 0.204 to 0.360; $P < .001$) after controlling for sociodemographic variables. Of the 5 indicators of the medical home definition, only effective care coordination was significantly associated with maternal perceptions of their parenting stress and mental health. **Conclusion:** Future longitudinal studies are needed to assess the temporal associations between patient-centered medical home status and maternal perceptions of their mental health and parenting stress in mothers of children with ASD.

Keywords

autism, patient-centered medical home, maternal outcomes

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Introduction

Autism spectrum disorder (ASD) is a developmental condition associated with chronic deficits in social communication and interactions across multiple settings and restricted, repetitive patterns of behavior, interests, or activities.[1] As rates of ASD have increased in the United States,[2] more children with ASD are in need of health care services.[3] Researchers who study health care utilization in children with ASD have identified a number of unmet health care needs in this population,[4] particularly in the areas of behavioral health, specialty health care services, family support services, and the receipt of referrals.[5,6] Receiving care in a patient-centered medical home, which is a model of primary care delivery that involves centralized, accessible, team-based, and coordinated care (ie, care that connects children who have special health care needs and their caregivers with resources and services in an integrated manner),[7] increases the quality of care children with ASD receive and reduces the financial burden experienced by parents of children with ASD.[4-6]

There has been an absence of research examining whether there are differences in parental perceptions of their mental health and parenting stress between parents whose children with ASD are managed in a patient-centered medical home or not. This is noteworthy since parents of children with ASD, particularly mothers, report elevated levels of parenting stress[8,9] and often experience feelings of isolation, anger, frustration, and fatigue in managing their child's condition.[10] Golnik and colleagues[11] evaluated an autism-specific primary care medical home intervention, which involved an implementation team that was comprised of 5 parents of children with ASD, a general pediatrician, a nurse care coordinator, and a scheduling care coordinator, as well as ASD-specific supports, including an ASD care

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plan, an ASD provider and resource list, and tools aimed at improving appointments (eg, longer clinic visits, ASD-specific toys). The authors found that compared to children with ASD receiving standard care, children with ASD treated in the autism-specific primary care medical home manifested greater satisfaction, less unmet healthcare needs, and more shared decision making.[11] There were no reported differences in family stress between children with ASD receiving standard care and children with ASD who were treated in the autism-specific primary care medical home.[11] Potential methodological explanations for the absence of a significant family stress finding include the small sample size (n = 34 for the autism-specific primary care medical home intervention group) and the lack of a national sample. Furthermore, the study by Golnik and colleagues[11] evaluated an autism-specific primary care medical home intervention and did not assess the patient-centered medical home as it is implemented in real world settings.

The objective of this study was to evaluate the associations between receiving care in a patient-centered medical home and maternal reports of their mental health and parenting stress in a national sample of mothers of children with ASD. The study also sought to assess if 5 indicators of the medical home definition were differentially associated with maternal perceptions of their mental health and parenting stress. We hypothesized that children with ASD receiving care in patient-centered medical home would be significantly correlated with maternal reports of their mental health and parenting stress and the 5 indicators of the medical home would be differentially correlated with these maternal outcomes.

Method

Data Collection From the National Survey of Children's Health

The current study included 1108 mothers of children with ASD from the 2011-2012 National Survey of Children's Health, which was a cross-sectional phone survey carried out in the United States to evaluate factors associated with the psychological and physical well-being of children up to 17 years old. Data collection took place between February 2011 and June 2011. Parents or guardians who had a minimum of 1 child residing in the house with them and had knowledge to report on the health and health care of the child were eligible to participate. For parents/guardians who had greater than 1 child living in the house with them, 1 child was randomly selected for them to answer the survey questions about. Approximately 850 000 homes were screened for the study, of which 187 422 reported having a child reside in the home between the ages of 0 and 17 years. Interviews were completed via cell phones and landlines with 95 677 respondents who resided in each state in the United States and the District of Columbia (numbers ranged from 1811 respondents in South Dakota to 2200 respondents in Texas). The majority of respondents (68.6%) were mothers and because the current study focused on maternal perceptions of parenting stress and mental health in children with ASD, only maternal responses were utilized. As noted previously, children with ASD whose mothers reported that the child was uninsured were excluded from the study to guarantee that findings were due to patient-centered medical home status access and not differences in health care as usual (ie, children without health insurance are less likely than children with insurance to receive health care services). Informed consent was obtained from each study participant and the research was performed in accordance with the tenets of the Helsinki Declaration. The Centers for Disease Control and Prevention's website (https://www.cdc.gov/nchs/slaits/nsch.htm) contains more detailed information about study procedures.

Measures

ASD Status. Maternal responses to the question, "Does [child] currently have autism?" were used to determine whether the child had ASD. Children whose mothers responded yes to this question were eligible for the current study.

Patient-Centered Medical Home Status. Patient-centered medical status for the child with ASD was deemed to be present if mothers endorsed all 5 indicators of the American Academy of Pediatrics medical home definition. These included endorsing the child had a personal doctor or nurse, usual source for sick and well care, family-centered care, no problems getting needed referrals, and the availability of effective care coordination. This dichotomous patient-centered medical home variable, developed by the Child and Adolescent Health Measurement Initiative (CAHMI) using interviews with a national expert panel and a substantial body of previous research, has been utilized in a number of previous peer-reviewed studies.[12-16] Specifically, for the personal doctor or nurse component mothers were asked, "Has your child had one or more person(s) that they consider to be a personal doctor or nurse?" Mothers who responded, "Yes, the child has at least one personal doctor or nurse," met the personal doctor or nurse component of the patient-centered medical home. For the usual source of sick care component mothers were asked, "Does your child have a usual place for sick care or advice?" and if they responded yes a follow-up question was asked, "What type of place does your child go to most often for medical care?" Mothers who responded that their child had a usual place of care and indicated this place to be a, "doctor's office, hospital outpatient department, clinic or health center, school, friend or relative, some other place, or a telephone advice

line," met the usual source of sick care component of the patient-centered medical home. For the family-centered care component mothers who indicated their child received medical care in the past 12 months were asked how often the child's doctors or other health care providers, "spent enough time with the child, listened carefully to you, showed sensitivity to family values/customs, provided specific information needed for the child, and helped you feel like a partner in the child's care?" Mothers who responded, "Usually," or, "Always," to all 5 of these questions met the family-centered care component of the patient-centered medical home. For the receiving referrals component, mothers were asked, "During the past 12 months, did your child need a referral to see any doctors or receive any services?"; if mothers responded yes to this question, a follow-up question was asked, "Was getting referrals a big problem, small problem, or not a problem?" Mothers who responded that their child needed a referral in the past 12 months and that receiving the referral was not a problem met the receiving referrals component of the patient-centered medical home. Mothers who responded their child did not need a referral in the past 12 months were coded as not needing a referral and the overall patient-centered medical home variable was designated as not relevant to them. Finally, for the effective care coordination component mothers who reported their child received 2 or more medical services (ie, general medical, mental health, dentistry, medical specialty) in the past 12 months and/or counseling or treatment from a mental health professional in past 12 months and/or care from a nonmental health medical specialist during past 12 months were asked, "Does anyone help you arrange or coordinate your child's care among the different doctors or services that (he/she) uses?"; "During the past 12 months, have you felt that you could have used extra help arranging or coordinating your child's care among the different health care providers or services?; if mothers responded yes to this question a follow-up question was asked, "During the past 12 months, how often did you get as much help as you wanted with arranging or coordinating your child's care?"; "Overall, are you very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied with the communication among your child's doctors and other health care providers?"; and "Does your child's doctor or other health care providers need to communicate with (his/her) child care providers, school, or other programs?"; if mothers responded yes to this question a follow-up question was asked, "Overall, are you very satisfied, somewhat satisfied, or very dissatisfied with that communication?" Mothers who reported they had someone to help them arrange or coordinate their child's care among the different doctors or services used, usually or always received sufficient help in coordinating these services when needed, and were very satisfied with the communication among their child's doctors and other care providers/school/programs met the coordinated care component of the patient-centered medical home. Mothers who responded their child did not receive two or more medical services (i.e., general medical, mental health, dentistry, medical specialty) in the past 12 months and/or counseling or treatment from a mental health professional in past 12 months and/or care from a non-mental health medical specialist during past 12 months were coded as not needing coordinated care and the overall patient-centered medical home variable was designated as not relevant to them.

Health Insurance Coverage. To assess for health insurance coverage, mothers were asked, "What type of health insurance coverage, if any, did your child have at the time of the survey?" Response options were public insurance such as Medicaid or SCHIP, private health insurance, or currently uninsured. Children whose mothers responded, "currently uninsured," were excluded from the study (n = 21) to guarantee that findings were due to patient-centered medical home status access and not differences in health care as usual (ie, children without health insurance are less likely than children with insurance to receive health care services).

Maternal Parenting Stress. To measure maternal parenting stress, mothers responded to 3 questions related to the stress experienced by the mother over the past month as a result of child demands. These questions were: "How often have you felt [child] is much harder to care for than most children [his/her] age?"; "How often have you felt [he/she] does things that really bother you a lot?"; "How often have you felt angry with [him/her]?". The answers were scored as: never (=1), rarely (=2), sometimes (=3), usually (=4), or always (=5). Responses to these 3 questions together ranged from 0 to 15, with higher total scores indicative of more maternal parenting stress. These 3 items and response scales were taken from the Parenting Stress Index, one the most widely used and validated measures of parenting stress in the empirical literature, and have been utilized in other peer-reviewed studies as an indicator of parenting stress.[17,18]

Maternal Mental Health. To assess maternal subjective mental health, mothers were asked one item, "Would you say that, in general, your mental and emotional health is excellent (1), very good (2), good (3), fair (4), or poor (5)?" This self-report item has been used widely in previous research as an indicator of subjective maternal mental health, with a higher score reflective of worse maternal perceptions of their mental health.[12,19,20]

Comorbid Conditions. The 2011-2012 NSCH asked mothers to rate if their child currently had any of the following conditions: attention deficit disorder/attention deficit hyperactivity disorder (ADD/ADHD), depression, anxiety, oppositional

defiant disorder/conduct disorder (ODD/CD), developmental delay, intellectual disability/mental retardation, learning disability, cerebral palsy, speech and language difficulties, Tourette's syndrome, asthma, diabetes, epilepsy/seizure disorder, hearing difficulties, vision difficulties (beyond glasses), bone/joint/muscle disorders, brain injury. More detailed information about the measures and scoring procedures can be found at the Centers for Disease Control and Prevention's website at https://www.cdc.gov/nchs/slaits/nsch.htm.

Statistical Analysis

Statistical Package for the Social Sciences (SPSS), Version 25 was used for all statistical analyses. We ran a hierarchical multiple regression analysis in order to assess the associations between the child with ASD receiving care in a patient-centered medical home and maternal parenting stress. Multiple linear regression analysis is the most appropriate analysis because maternal parenting stress is a summed index and a continuous variable. Sociodemographic variables (ie, child age, sex, race, and household poverty level) were included in the first step as control variables. Patient-centered medical home status was added in the second step. One-hundred-ten participants were not included in this analysis due to maternal parenting stress missing data.

An additional hierarchical multiple regression analysis was run to evaluate if the 5 indicators of patient-centered medical home status were differentially associated with maternal perceptions of parenting stress. Similar to the first regression model, the sociodemographic variables were included as control variables in the first step. The 5 indicators of patient-centered medical home status were entered separately in the second step. A total of 707 participants were not included in this analysis due to maternal parenting stress missing data or the medical home subcomponents were not relevant to their child because they did not meet the overall criteria for patient-centered medical home care.

Polynomial logistic regression analysis was used to examine the associations between the child with ASD receiving care in a patient-centered medical home and subjective maternal mental health. Polynomial logistic regression is the most appropriate analysis since maternal mental health is a single-item indicator with 5 response choices (excellent = 1, very good = 2, good =3, fair = 4, poor = 5). For the purposes of the polynomial logistic regression analysis, the response choices were collapsed into 4 categories (excellent = 1, very good = 2, good = 3, fair and poor = 4) because there were not enough participants in each cell to run the analysis with the original 5 response choices. Sociodemographic variables (ie, child age, sex, race, and household poverty level) were included in the first step as control variables. The dichotomous variable that indicated whether patient-centered medical home status was met was added in the second step. A total of 107 participants were not included in this analysis due to maternal mental health missing data.

An additional polynomial logistic regression analysis was used to examine if the 5 indicators of patient-centered medical home status were differentially associated with subjective maternal mental health. Similar to the first polynomial logistic regression analysis, the response choices were collapsed into 4 categories (excellent = 1, very good = 2, good =3, fair and poor = 4) and sociodemographic variables were included as control variables in the first step. The 5 indicators of patient-centered medical home status were entered separately in the second step. In all, 705 participants were excluded from these analyses due to maternal mental health missing data or the medical home subcomponents were not relevant to their child because the child did not meet the overall criteria for patient-centered medical home care.

Results

Participant Characteristics

A total of 1108 mothers reported having a child with ASD that had health care coverage when the survey was administered. Table 1 presents the sociodemographic characteristics of the sample. The mean age of mothers in the sample was 41.7 years (SD = 8.2). Approximately 29% of mothers reported being single. The mean age of children in the sample was 10.6 years (SD = 4.0). The majority of children in the sample were male (81.0%) and white (77.1%), which is consistent with national data from the Centers for Disease Control and Prevention that indicate higher rates of ASD among White males (https://www.cdc.gov/mmwr/volumes/67/ss/ss6706a1.htm?s_cid=ss6706a1_w#T3_down).

Most of the children were from homes in which the income was over 200% of the federal poverty level (57.2%). All but 5.6% of our sample of children with ASD had at least 1 comorbid condition. Nearly half of the children in our sample (49.2%) had more than 3 comorbid conditions.

Descriptive Statistics

The majority of mothers self-reported mental health that was very good (37.3%) or good (29.0%). Approximately 30% of mothers reported that over the past month they sometimes felt their child was more difficult to care for than other children of similar age. Approximately 40% of mothers indicated that over the last month sometimes their child did things that were bothersome to them, but that they rarely felt mad with their child.

Approximately one-third of children with ASD (32.2%) received patient-centered medical home care. Among all

Table 1. Sample Characteristics.

Variable	Mean (SD) or n (%)
Maternal age (years), mean (SD)	41.7 (8.2)
Maternal highest level of education, n (%)	
More than high school	839 (75.7)
High school	194 (17.5)
Less than high school	63 (5.7)
Missing	12 (1.1)
Family structure, n (%)	
Two parents married	661 (59.7)
Two parents cohabitating	31 (2.7)
Parent married or cohabiting with stepparent	87 (7.8)
Single mother	317 (28.6)
Other/missing	13 (1.2)
Child age (years), mean (SD)	10.6 (4.0)
Child sex, n (%)	
Female	210 (19.0)
Male	897 (81.0)
Missing	1 (0.1)
Comorbid conditions, n (%)	
1 comorbid condition	126 (11.4)
2 comorbid conditions	161 (14.5)
3 comorbid conditions	214 (19.3)
>3 comorbid conditions	545 (49.2)
Child race. n (%)	
Caucasian	854 (77.1)
African American	91 (8.2)
Other	149 (13.4)
Missing	14 (1.3)
Household poverty level, n (%)	
0%-99%	188 (17.0)
100%-199%	210 (18.9)
200%-399%	331 (29.9)
≥400%	302 (27.3)
Missing	77 (6.9)
Patient-centered medical home (PCMH) status, n (%)	
Care meets medical home criteria	357 (32.2)
Care does not meet medical home criteria	723 (65.3)
Missing	28 (2.5)
PCMH subcomponents	
Personal doctor or nurse	
Does not have a personal doctor or nurse	60 (5.4)
Has at least one personal doctor or nurse	1046 (94.4)
Missing	2 (0.2)
Usual source for sick and well care	
Child does not have usual source	64 (5.8)
Child has usual source	1044 (94.2)
Family-centered care	
Does not have family-centered care	445 (40.2)
Has family-centered care	643 (58.0)
Did not have medical, dental, or mental health care in past 12 months	7 (0.6)
Missing	13 (1.2)

(continued)

Table 1. (continued)

Variable	Mean (SD) or n (%)
Problems getting needed referrals	
Big or small problem with getting referral when needed	118 (10.6)
No problems getting referral when needed	342 (30.9)
Referrals not needed during past 12 months	646 (58.3)
Missing	2 (0.2)
Effective care coordination	
Care does not meet one or more necessary components	579 (52.3)
Care meets all necessary components	388 (35.0)
Care coordination not needed during past 12 months	127 (11.5)
Missing	14 (1.3)
Maternal mental and emotional health status	
Excellent	212 (19.1)
Very good	413 (37.3)
Good	321 (29.0)
Fair	131 (11.8)
Poor	29 (2.6)
Missing	2 (0.2)
Maternal parenting stress subcomponents, n (%)	
Child was much harder to care for than other children during past month	
Never	147 (13.3)
Rarely	140 (12.6)
Sometimes	340 (30.7)
Usually	253 (22.8)
Always	226 (20.4)
Missing	2 (0.2)
Child did things that really bother me a lot during past month	
Never	148 (13.4)
Rarely	286 (25.8)
Sometimes	448 (40.4)
Usually	144 (13.0)
Always	80 (7.2)
Missing	2 (0.2)
I felt angry with child during past month	
Never	195 (17.6)
Rarely	430 (38.8)
Sometimes	419 (37.8)
Usually	51 (4.6)
Always	12 (1.1)
Missing	1 (0.1)
Maternal parenting stress composite (child was much harder to care for than other children, child did things that really bother me a lot, I felt angry with child), mean (SD)	8.3 (2.6)

mothers, the majority indicated that their child had a usual source for sick and well care (94.2%), received family-centered care (58.0%), had a minimum of one personal nurse or doctor (94.4%), and did not need referrals or did not have any issues receiving referrals when necessary (89.2%). However, only 35.0% of mothers of children with ASD in the sample indicated that their child received effective care coordination from providers.

In the hierarchical multiple linear regression analysis for which maternal parenting stress was the outcome (Table 2), demographic variables as a whole were not significantly correlated with maternal perceptions of their parenting stress ($P = .372$). Entered in step 2 as a dichotomous variable, receiving care in a patient-centered medical home accounted for an extra 3.9% of the variance above and beyond the control variables and was significantly

Table 2. Multiple Linear Regression Analysis for Maternal Parenting Stress: Medical Home as Dichotomous Variable.[a]

Variables	Maternal parenting stress (n = 998), standardized β (95% CI)
Block 1	
R^2	0.004
Child sex	0.006 (–0.372, 0.454)
Child age	–0.023 (–0.056, 0.026)
Race	–0.049 (–0.412, 0.050)
Poverty level	–0.045 (–0.106, 0.018)
Block 2	
R^2 change	0.039
Medical home status	–0.201*** (–1.457, –.773)
Cumulative R^2	0.044

[a]Betas presented are standardized betas (βs) for the full model.
*$P < .05$, **$P < .01$, ***$P < .001$.

Table 3. Multiple Linear Regression Analysis for Maternal Parenting Stress: Medical Home 5 Indicators as Separate Predictors.[a]

Variables	Maternal parenting stress (n = 401), standardized β (95% CI)
Block 1	
R^2	0.010
Child sex	–0.058 (−1.021, 0.267)
Child age	–0.460 (−0.092, 0.033)
Race	–0.059 (−0.542, 0.139)
Poverty level	0.025 (−0.069, 0.115)
Block 2	
R^2 change	0.050
Personal doctor or nurse	0.027 (−0.911, 1.583)
Usual source for sick and well care	0.082 (−0.174, 2.039)
Family-centered care	–0.047 (−0.784, 0.309)
Problems getting referrals	–0.043 (−0.347, 0.843)
Effective care coordination	–0.194*** (−1.629, −0.465)
Cumulative R^2	0.060

[a]Betas presented are standardized betas (βs) for the full model.
*$P < .05$, **$P < .01$, ***$P < .001$.

associated with maternal reports of their parenting stress ($P < .001$).

When the 5 indicators of patient-centered medical home status were entered separately in the second steps of the regression analyses (Table 3), above and beyond the control variables, effective care coordination was the only indicator that was significantly associated with maternal parenting stress ($P < .001$).

Table 4. Polynomial Logistic Regression Analysis Mothers of Children With Autism Spectrum Disorder (ASD) who Reported Excellent Maternal Mental Health Compared to Mothers of Children With ASD Who Reported Poor or Fair Maternal Mental Health: Medical Home as Dichotomous Variable.[a]

Predictors	Odds ratio	95% CI
Child sex	0.814	0.475-1.394
Child age	0.943	0.891-0.999
Race	1.150	0.850-1.557
Poverty level	1.155**	1.062-1.256
Medical home status	0.204***	0.115-0.360

[a]In this table, mothers of children with ASD who reported excellent maternal mental health are being compared with the referent group of mothers of children with ASD who reported poor or fair maternal mental health.
*Significant at $P < .05$ level. **Significant at $P < .01$ level. ***Significant at $P < .001$ level.

Table 5. Polynomial Logistic Regression Analysis Mothers of Children With Autism Spectrum Disorder (ASD) Who Reported Very Good Maternal Mental Health Compared to Mothers of Children With ASD Who Reported Poor or Fair Maternal Mental Health: Medical Home as Dichotomous Variable.[a]

Predictors	Odds ratio	95% CI
Child sex	1.130	0.690-1.852
Child age	0.938*	0.892-0.987
Race	0.821	0.616-1.093
Poverty level	1.206***	1.119-1.300
Medical home status	0.258***	0.151-0.439

[a]In this table, mothers of children with ASD who reported very good maternal mental health are being compared with the referent group of mothers of children with ASD who reported poor or fair maternal mental health.
*Significant at $P < .05$ level. **Significant at $P < .01$ level. ***Significant at $P < .001$ level.

Tables 4, 5, and 6 present the odds ratios and 95% confidence intervals for the polynomial logistic regression analysis for which the primary outcome variable was subjective maternal mental health. Entered in step 2 as a dichotomous variable, receiving care in a patient-centered medical home was significantly associated with maternal reports of their mental health (odds ratios range from 0.204 to 0.360; $P < .001$) after controlling for sociodemographic variables.

When the 5 indicators of patient-centered medical home status were entered separately in the second steps of the polynomial logistic regression analysis (Tables 7, 8, and 9), above and beyond the control variables, effective care coordination was the only indicator that was significantly associated with maternal mental health (odds ratios range from 0.187 to 0.228; $P < .01$).

Table 6. Polynomial Logistic Regression Analysis Mothers of Children With Autism Spectrum Disorder (ASD) Who Reported Good Maternal Mental Health Compared to Mothers of Children With ASD Who Reported Poor or Fair Maternal Mental Health: Medical Home as Dichotomous Variable.[a]

Predictors	Odds ratio	95% CI
Child sex	1.276	0.766-2.125
Child age	0.967	0.918-1.018
Race	1.125	0.855-1.480
Poverty level	1.068	0.991-1.152
Medical home status	0.360***	0.208-0.625

[a]In this table, mothers of children with ASD who reported good maternal mental health are being compared to the referent group of mothers of children with ASD who reported poor or fair maternal mental health.
*Significant at $P < .05$ level. **Significant at $P < .01$ level. ***Significant at $P < .001$ level.

Table 7. Polynomial Logistic Regression Analysis for Maternal Mental Health Mothers of Children with Autism Spectrum Disorder (ASD) Who Reported Excellent Maternal Mental Health Compared to Mothers of Children With ASD Who Reported Poor or Fair Maternal Mental Health: Medical Home 5 Indicators as Separate Predictors.[a]

Predictors	Odds Ratio	95% CI
Child sex	1.215	0.526-2.806
Child age	0.924	0.846-1.010
Race	0.917	0.589-1.426
Poverty level	1.103	0.970-1.255
Personal doctor or nurse	2.253	0.387-13.135
Usual source for sick and well care	0.864	0.205-3.646
Family-centered care	0.477	0.216-1.050
Problems getting referrals	1.021	0.441-2.365
Effective care coordination	0.187***	0.074-.474

[a]In this table, mothers of children with ASD who reported excellent maternal mental health are being compared to the referent group of mothers of children with ASD who reported poor or fair maternal mental health.
*Significant at $P < .05$ level. **Significant at $P < .01$ level. ***Significant at $P < .001$ level.

Discussion

This study evaluated the associations between receiving patient-centered medical home care and maternal perceptions of their mental health and parenting stress in mothers of children with ASD. The study also assessed if the 5 indicators of the American Academy of Pediatrics medical home definition were differentially associated with maternal reports of their mental health and parenting stress in this population. We found that children with ASD receiving patient-centered medical home care was associated with maternal perceptions of better mental health and less parenting stress in a national sample. This is consistent with past research with children with diabetes[12] and chronic health conditions as a whole.[21] Taken together, the data demonstrate the need for future longitudinal research to assess the potential benefits of receiving patient-centered medical home care on maternal mental health and parenting stress in families of children with ASD.

Table 8. Polynomial Logistic Regression Analysis for Maternal Mental Health Mothers of Children With Autism Spectrum Disorder (ASD) Who Reported Very Good Maternal Mental Health Compared to Mothers of Children With ASD Who Reported Poor or Fair Maternal Mental Health: Medical Home 5 Indicators as Separate Predictors.[a]

Predictors	Odds ratio	95% CI
Child sex	2.080	0.980-4.415
Child age	0.927	0.859-1.000
Race	0.596*	0.395-0.900
Poverty level	1.099	0.984-1.228
Personal doctor or nurse	2.294	0.484-10.886
Usual source for sick and well care	0.871	0.251-3.016
Family-centered care	0.596	0.307-1.156
Problems getting referrals	0.828	0.411-1.671
Effective care coordination	0.228**	0.098-0.531

[a]In this table, mothers of children with ASD who reported very good maternal mental health are being compared to the referent group of mothers of children with ASD who reported poor or fair maternal mental health.
*Significant at $P < .05$ level. **Significant at $P < .01$ level. ***Significant at $P < .001$ level.

Table 9. Polynomial Logistic Regression Analysis for Maternal Mental Health Mothers of Children With Autism Spectrum Disorder (ASD) Who Reported Good Maternal Mental Health Compared to Mothers of Children With ASD Who Reported Poor or Fair Maternal Mental Health: Medical Home 5 Indicators as Separate Predictors.[a]

Predictors	Odds ratio	95% CI
Child sex	2.337*	1.080-5.060
Child age	0.935	0.867-1.009
Race	0.811	0.556-1.183
Poverty level	1.046	0.938-1.167
Personal doctor or nurse	1.867	0.388-8.981
Usual source for sick and well care	0.459	0.113-1.859
Family-centered care	0.627	0.326-1.209
Problems getting referrals	1.175	0.602-2.294
Effective care coordination	0.462	0.192-1.12

[a]In this table, mothers of children with ASD who reported good maternal mental health are being compared to the referent group of mothers of children with ASD who reported poor or fair maternal mental health.
*Significant at $P < .05$ level. **Significant at $P < .01$ level. ***Significant at $P < .001$ level.

Effective care coordination was the least likely component of the patient-centered medical home to be endorsed by mothers of children with ASD in our sample. One explanation for this finding is that mothers of children with ASD with more severe symptoms may tend to have maternal perceptions of less effective care coordination because care coordination is more complex and challenging due to the increased number of agencies and/or providers involved. Consistent with this explanation, we found that effective care coordination was significantly correlated with maternal reports of their mental health and parenting stress. Given the complexity of the health care needs of children with ASD,[22] this population requires careful coordination between providers and clear communication with caregivers and families.[10] Our findings underscore the importance of effective care coordination in children with ASD. It will be critical for future research to evaluate which strategies are most effective in facilitating efficient care coordination in patient-centered medical homes, including brief, solution-focused therapies that have been identified as one approach to address family concerns that relate to ASD coordination of care.[23] These therapies can be delivered by nurses and physicians, are short in duration (ie, 30 minutes or less) facilitating integration into the fast-paced medical setting, and target a specific problem experienced by the family (ie, my child with ASD is scared of the sound of his electric toothbrush and will not brush his teeth). A behavioral health consultative service has been shown to improve the coordination of care and reduce depressive symptoms in adult patients with mood disorders.[24] In this model, coordination of medical and behavioral health services was accomplished by colocating the behavioral health consultant within a primary care office. It is possible that colocating services especially relevant to children with ASD (eg, speech therapy services, occupational therapy services) within primary care settings could improve coordination of care among families of children with ASD. This co-location of relevant services within the primary care setting is consistent with the Systematic Network of Autism Primary Care Services (SYNAPSE) model proposed by Kong and colleagues[25], which incorporates elements of the medical home and healthcare coproduction, including obtaining input from caretakers of children with ASD when developing and implementing care protocols. Care coordinators embedded within a practice is another potential method to improve care coordination.[26,27] Future research is needed to assess the impact of implementing care coordinators embedded within a practice and models like SYNAPSE on care coordination in families of children with ASD.

In this national sample of mothers of children with ASD, approximately one-third of children with ASD who had health care coverage had health care delivery that fell under the domain of patient-centered medical home care. This percentage is higher than the 18.9% of children with ASD whose care met patient-centered medical home criteria in the study by Farmer and colleagues.[6] Although both samples were national samples, the Farmer sample was substantially smaller than the present sample (n = 371) and did not only include children with ASD who had health care coverage. Both studies suggest that a large percentage of children with ASD in the United States are not receiving services in a patient-centered medical home and further initiatives are necessary to ensure the health care of children with ASD meets patient-centered medical home criteria. In their qualitative study with 25 primary care physicians,[28] found a number of areas of barriers to children with ASD receiving patient-centered medical home care, including provider education, communication, office factors, cost and coverage, and access. Our findings in conjunction with previous research[5,6] suggest that when children with ASD receive patient-centered medical home care, there are potentially a myriad of benefits for both children with ASD and their caregivers.

The current study has a number of limitations. Given that we used a database that was already existing, we were restricted by the variables we could use. For example, we used one item to assess subjective maternal mental health and a 3-item indicator of parenting stress. Given the items that made up the parenting stress indicator (eg, hard to care for, maternal feelings of anger and bother), it is likely that this index was also tapping into severity of child ASD symptoms. While the measures we used have been utilized in the peer-reviewed literature and validated in the past, it will be valuable for subsequent research to duplicate our findings using more thorough assessments of maternal parenting stress and mental health. It is also possible that there were other factors not accounted for in our analysis (eg, maternal factors, ASD types and severity) that confounded our results. Another limitation of our study was that it relied on maternal diagnosis of ASD rather than ASD in the index child. Consequently, we were not able to confirm the child's ASD diagnosis in medical or psychiatric records and it is possible that some children were included in the analysis who had not received a formal ASD diagnosis from a healthcare provider. Another limitation of our study was utilization of data from 2011-2012. While there are newer data sets from the National Survey of Children's Health (2016, 2017, 2018), we purposely selected the 2011-2012 data set because the method for determining the medical home care coordination component. Specifically, in the 2011-2012 NSCH determination of the care coordination component was based on whether or not a child had seen a mental health professional or other specialist in addition to their primary care provider in the last 12 months. In the 2016, 2017, and 2018 NSCH, determination of the care coordination component was based on a direct question of whether or not a child saw more than one health care provider in the past 12 months. We believe that the manner in which the

question was posed in the 2011-2012 NSCH is more consistent with the language used to describe care coordination in the American Academy of Pediatrics definition of care coordination (ie, pediatric medical subspecialists, surgical specialists, and mental health/developmental professionals). It will be important for future studies to replicate our findings with more current national data sets. It is likely that in the present study maternal self- reports of their mental health and parenting stress were influenced by social desirability. As such, mothers may have minimized their reports of mental health difficulties and elevated parenting stress, resulting in measurement error and misclassification bias which has the potential to compromise the validity of the study findings. The cross-sectional nature of our study precludes us from inferring causation. It is possible that rather than patient-centered medical status predicting subjective maternal mental health and parenting stress, mothers of children with ASD who experience better mental health and less parenting stress are more likely to seek out care for their child in a patient-centered medical home. Future longitudinal studies are necessary to disentangle the associations between patient-centered medical status and mental health/parenting stress in mothers of children with ASD. Our sample was composed of participants who all had health coverage and they were predominantly White and from relatively high socioeconomic status backgrounds, which may limit the generalizability of our findings. Future research should examine whether our findings generalize to mothers of children with ASD from lower socioeconomic status backgrounds and those who identify as racial minorities. The way the data were coded we were not able to examine how subcomponents of each of the 5 indicators of patient-centered medical home differentially contributed to maternal outcomes. Finally, we excluded a large number of participants for the analysis for which we examined the associations between the 5 indicators of the patient-centered medical home and maternal outcomes because they did not meet the overall criteria for patient-centered medical home care; this likely reduced the power to detect statistically significant associations and may have further limited the generalizability of our findings.

In summary, we found receiving care in a patient-centered medical home was significantly correlated with reports of better maternal mental health and less parenting stress. Effective care coordination emerged as the only indicator of the American Academy of Pediatrics medical home definition that was significantly associated with maternal reports of their mental health and parenting stress.

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