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COMPARING ACCESS TO MEDICAL HOMES FOR CHILDREN AGED 6-17 YEARS WITH ADD/ADHD AND AUTISM IN ARKANSAS

A thesis presented
by
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of Bachelor of Science in Nursing

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ABSTRACT

BACKGROUND: A growing number of children are being diagnosed with attention deficit disorder and hyperactivity (ADD/ADHD) and autism in Arkansas. These developmental disorders necessitate comprehensive, holistic, effective and well-coordinated care, and require a complex treatment regimen. Lack of access to coordinated care creates a real impediment for these children as they are in constant need for medical services. Pediatric care provided within a medical home has been suggested to improve health outcomes of children with special health care needs.

OBJECTIVE: The purpose of this study was to determine access to a medical home among children aged 6-17 years with ADD/ADHD, autism, and with both disorders in Arkansas.

METHODS: We used the National Survey of Children with Special Health Care Needs (2009-2010) to describe medical home among children with ADD/ADHD, with autism, and with both disorders as reported by their families. We conducted bivariate analyses to study access to a medical home based on race/ethnicity, education, insurance type, family structure and poverty status. Multivariate logistic regressions were used to ascertain the odds for these children of having a medical home.

RESULTS: 43,249 children had ADD/ADHD, 3,338 had autism, and 5,205 had both ADD/ADHD and autism in Arkansas. As compared to parents of children with ADD/ADHD, parents of children with ADD/ADHD and autism were less likely to report having a medical home. These parents were less likely to state that their child had received a family-centered care; they were less likely to report that their child had received effective care coordination; they were less likely to mention that they had received help to coordinate their child’s health care when needed, and they were less likely to report being very satisfied with communication among their child’s doctors. No statistical differences were found in access to a medical home between children with ADD/ADHD vs. autism.
CONCLUSION: Children with developmental disorders such as ADD/ADHD and autism have multiple and complex health care needs. They need accessible, coordinated and family-centered care. The coexistence of these two conditions renders access to a medical home even more challenging for these children who need it the most. More efforts should be made by health care providers and policy-makers to expand access to medical home to children with ADD/ADHD, autism, and to those with both of these conditions.
BACKGROUND AND SIGNIFICANCE

According to the National Survey of Children with Special Health Care Needs (NS-CSHCN; 2009-2010), an estimated 139,580 children 0-17 years of age have special health care needs (CSHCN) in Arkansas (Data Resource Center for Child and Adolescent Health, 2010). These children with complex health conditions represent 20% of all children in the state; a proportion higher than that of the nation (15% of children) (NS-CSHCN, 2009-2010). Thirteen years ago, the prevalence of CSHCN was estimated at 14%; this indicates a rampant and troublesome trend within the state (NS-CSHCN, 2001). CSHCN either have functional limitations (i.e. are limited or prevented in their ability to do the things most children the same age do) or a developmental, behavioral, or emotional problem that requires ongoing medical treatment or counseling. Indeed, in 2010, one-third of parents living in Arkansas reported that the daily activities and school attendance of their CSHCN were consistently affected by their condition (NS-CSHCN, 2009-2010). CSHCN need health services beyond those required by their healthier counterparts; they usually experience higher health care utilization and expenditures than the average pediatric population (McPherson et al., 1998). These children often use more hospital days, emergency room visits, surgical or medical procedures, medical specialist visits, and home health days than non-CSHCN children (Boulet et al., 2009). Thus, caring for CSHCN requires an ongoing commitment in time and financial resources from families. Indeed, more than two out of ten parents in Arkansas have reported having financial problems due to caring for their CSHCN. Over a quarter of parents caring for CSHCN had to cut back hours or stopped working completely in order to care for their children, and 17% of parents of CSHCN declared to pay out-of-pocket medical expenses of more than $1,000 yearly (NS-NSCH, 2009-2010).

Much of the increase in developmental disability in the nation is
being driven by Attention Deficit Disorder or Attention Deficit Hyperactivity Disorder (ADD/ADHD) and autism diagnoses (Goodwin, 2011). Among the CSHCN population in Arkansas, almost four out ten (38.6%) have ADD or ADHD as compared to three out of ten nationwide. According the National Survey of Children with Special Health Care Needs (2009-2010), eight out of ten children with ADD/ADHD had used medication in the past week. Furthermore, 7.6% of CSHCN have autism spectrum disorders; a developmental disability that can cause significant social, communication and behavioral challenges. These two conditions alone affect almost half of the CHSCN population in Arkansas. ADD/ADHD and autism are complex disorders that necessitate comprehensive, holistic, effective and well-coordinated care. A lack of access to care creates a real impediment for these children as they are in constant need for medical services.

Pediatric care provided within a "medical home" has been suggested to improve satisfaction and health outcomes of children with special health care needs (Sia et al., 2004). According to the American Academy of Pediatrics (AAP), high-quality medical homes for CSHCN offer care that is accessible, continuous, coordinated, family-centered, comprehensive, compassionate, and culturally competent (Sia et al., 2002). The medical home model is seen as a way to substantially improve the quality of care, reduce fragmentation of services, and potentially alleviate the financial burden associated with caring for CSHCN. Access to a medical home for all children is also identified as a critical indicator of progress towards meeting the aims of Healthy People 2020 (objective MICH-30.1) (US Department of Health and Human Services).

In an effort to curb health care spending in the United States, the Centers for Medicare and Medicaid Services (CMS) is currently testing new models of care delivery and payment. Recently, six states have received payments from CMS to test this Model Innovation Initiative. As part of the Triple Aim objectives of improving population health outcomes, patients’ experience of care, and cost effectiveness of care (Berwick,
Arkansas has received $42 million to develop a model that focuses on developing a medical home for people with chronic and complex conditions (Services, 2013). The vitality of researching medical homes for children with autism and ADD/ADHD has become apparent as the prevalence of these two conditions is increasingly pervading the health care system. Toomey et al. (2010) used the National Survey of Children with Special Health Care Needs (2005-2006) to compare access to medical among children with attention-deficit/hyperactivity disorder (ADHD) and with asthma in the United States. They found that parents of children with ADHD report worse performance across key dimensions of primary care compared with parents of children with asthma. The study by Toomey et al. (2010) did not investigate differences in access to medical home in children ADHD as compared to those with autism. Furthermore, their study did not look at the association between a coexistence of both ADHD and autism in children and access to a medical home.

**PURPOSE OF THE STUDY AND RESEARCH QUESTIONS**

The overarching aim of this study is to examine the extent to which children aged 6-17 years with ADD/ADHD and autism have access to a medical home in Arkansas. More specifically, our goal is to investigate the following research questions:

1. Are there differences in access to a medical home between children aged 6-17 years with ADD/ADHD as compared with children with autism and with children who have both disorders in Arkansas?
2. What are the socio-demographic characteristics associated with having a medical home for children with either of these two disorders?
3. Does the likelihood of having a medical home differ between children with ADD/ADHD, with autism, and with both ADD/ADHD and autism in Arkansas?
4. What are the specific components of a medical home that are lacking for these children?

In this study, we built-upon the work of Toomey et al. (2010) research to study differences in access to a medical home among children with ADD/ADHD and autism, and among children with both conditions in Arkansas.

HYPOTHESES

Based on the review of the literature, we posit the following hypotheses:

1. There are statistically significant differences in access to a medical home between children aged 6-17 years with ADD/ADHD and children with autism, and children with both conditions in Arkansas;

2. These children will differ in terms of their socio-demographic characteristics; and

3. The likelihood of having a medical home will differ depending on the child’s condition (i.e. ADD/ADHD vs. autism vs. ADD/ADHD and autism).

Our fourth research question is more exploratory; therefore, we do not make any a priori assumption for this question.

LITERATURE REVIEW

Prevalence of Developmental Disabilities in Children

In the United States, developmental disabilities are reported in 1 out of 6 children (Boyle et al., 2011). The CDC defines developmental disabilities as conditions stemming from impairment in physical, learning, language and behavior areas. These conditions take root early in the child development and will typically last throughout her/his lifetime. A close monitoring of the milestones can assist in predicting future developmental disabilities. Since these developmental disabilities can impact a child’s
daily life activities, milestones should be monitored carefully through a partnership between parents and health care providers. Once a developmental disability is suspected, parents should seek appropriate health care as soon as possible (Houtrow, Larson, Olson, Newacheck, & Halfon 2014).

According to the NS-C SHCN, a growing number of children are being diagnosed with a developmental disability in the United States. A study comparing multiple surveys such as the National Survey of Children with Special Health Care Needs, the National Survey on Children Health and the Medical Expenditures Panel Surveys of developmental disorders revealed similar prevalence of developmental disabilities among children, as well as similarities in their demographic characteristics and health care needs (Bethel, Read, Blumberg, & Newacheck, 2013).

The National Health Interview Surveys – a parent-reported survey on children’s health- revealed that among children aged 3-17, developmental disorders are more prevalent in boys than in girls. Moreover, Hispanic children have the lowest prevalence when compared to white and black children. Developmental disability is more concentrated among children with public health insurance, and among those living in low income households.

According to the National Health Interview Surveys, attention deficit hyperactivity disorder and autism are developmental disorders that are increasingly being reported among children ages 3-17.

**Prevalence of ADHD in Children**

According to the American Psychiatric Association, 5% of children in the United States have been diagnosed with ADHD (Akinbami et al., 2011). The Centers for Disease Control state that children affected by ADHD might exhibit symptoms such as fidgeting, daydreaming, difficulty getting along with others, losing objects frequently, have a hard time resisting temptation and take unnecessary risks. The diagnosis of ADHD
is a multi-step process that comprises a full medical history, hearing and vision tests. There is no single test to diagnose ADHD; ruling out other similar learning disabilities aids in the diagnosis.

The prevalence of children with ADHD has changed over time with an increase in the number of parents reporting their children being afflicted by the disorder throughout the years (CDC, 2015). Since the CDC conducted its first survey in 1997, there has been a clear upward trend in the prevalence of childhood ADHD. Concomitantly, diagnostic standards and techniques have improved over time. Therefore, it remains unclear whether the number of children with the disorder has increased due to better detection, or whether the prevalence of ADHD has actually increased in and of itself (Akinbami et al., 2011).

When compared to the United States, the South has a higher prevalence of childhood ADHD (Akinbami et al., 2011). In Arkansas more specifically, more than 11% of children have been diagnosed with ADHD, a proportion higher than that of the nation, according to the CDC.

Furthermore, studies have found that children living in households below 100% or between 100-199% of the poverty line are more likely to develop ADHD, as compared to those living in households above 200% of the poverty line (Akinbami et al., 2011). Studies have also revealed gender differences in ADHD, with a higher prevalence of ADHD among boys (Akinbami et al., 2011). More girls being under-diagnosed has been suggested as a possibility for the gender disparity observed among children with ADHD (Akinbami et al., 2011). Studies have also unveiled disparities in symptomatology among different age groups: Symptoms of ADHD seem to be more frequent in adolescents than in any other age groups. Thus, consideration of age is essential when diagnosing and treating ADHD (Ramtekkar, 2010).
Prevalence of Autism in Children

Autism spectrum disorder is “a disability that can cause significant social, communication and behavioral challenges” (Kim 2013, p. 904). This disorder involves multiple conditions including autistic disorder, pervasive developmental disorder and Asperger syndrome, which now all fall under the umbrella of autism spectrum disorder, with autism being the most debilitating. Children with ASD might “not point at objects to show interest, not look at objects, have trouble relating to others, avoid eye contact, have trouble understanding other people’s feelings or talking about their own feelings, prefer not to be held or cuddled, and repeat actions over and over” (Kim 2013, p.689). Autism is a lifelong disorder with initial symptoms surfacing in early childhood development (Baio 2010).

Diagnosing ASD can be difficult since there is no single test. Health care providers examine the behavior and gather developmental history in order to establish a diagnosis. Currently, there is no fully effective way to treat the disorder, thus diagnosing it early is key in order to optimize care. According to the National Institute of Mental Health, over the past few years continued efforts have been deployed to expand research on Autism. A “services roadmap” aimed at improving care coordination is in place so that existing programs in the treatment of autism are enhanced.

Just like ADHD, a growing number of children have been diagnosed with autism. Indeed, according to the CDC, the prevalence of childhood autism has tripled since studies on autism began in the 1960’s (CDC, 2015). In Arkansas, autism is currently diagnosed in 15-16 out of every 1,000 children (Baio, 2010). Increases in autism diagnosis have been specifically noted in children with one or more concomitant intellectual disabilities (Kim, 2013).

Autism is more commonly found in boys than in girls, with 1 in 42 boys and 1 in 189 girls diagnosed with the disorder, respectively (Kim 2013). Although autism has been recorded in all ethnic groups, prevalence
of autism is higher in white children versus black or Hispanic children. One possibility for this discrepancy is that white children are more likely to be identified as having an autistic disorder than any other races or ethnicities (Baio 2010).

Studies have found that the first clinical evaluation for autism starts, on average, as early as 44 months, with the diagnosis being confirmed, on average, at 48 months (Baio, 2010). With the growing prevalence of autism, needs for early diagnosis and specialty care services have been on the rise (Baio, 2010).

**Health Care Services to Children with Developmental Disabilities**

In the United States, children diagnosed with autism and ADD/ADHD face a panoply of challenges regarding their medical care. The many barriers that these children face result in poor health outcomes (Glasper & Evans 2014). Among these barriers are unmet needs, especially in specialty care. Indeed, according to Boudreau et al. (2014) CSHCN have more unmet needs, particularly for specialty care, than the general pediatric population (Boudreau et al. 2014). With up to 9% of the CSHCN population having unmet needs, these children are not receiving appropriate care.

Among CSHCN, care coordination has been suggested as a way to decrease unmet needs (Boudreau et al. 2014). The American Academy of Pediatrics defines care coordination as “a process that links children and youth with special health care needs and their families with appropriate services and resources in a coordinated effort to achieve good health” (Boudreau et al. 2014, p. 1047). It is thought that care coordination leads to reduced health care costs and enhanced health (Boudreau et al. 2014). Moreover, care coordination has been associated with higher patient satisfaction (Boudreau et al. 2014). When health care services are well coordinated, relationships between providers and families are
strengthened, and fewer problems obtaining referrals are reported (Boudreaux et al. 2014)

Uninsured children, and those living in low-income households or with parents with less than a high school education, as well as children in the minority group are less likely to use specialty care (Boudreaux et al. 2014). While specialty services are available, not all are able to have access to them.

A study conducted by Boudreaux et al. (2014) and published by the American Academy of Pediatrics, examined care coordination in CSHCN within a medical home versus without. Multiple variables were taken into account such as race, poverty level, insurance, education level, age, and gender. Results of the study showed that when care is coordinated within the context of a medical home it is optimized (Boudreaux et al. 2014). However, this study also found that CSHCN living in lower-income homes have the highest number of unmet specialty care needs (Boudreaux et al. 2014). Although higher income families have more access to care, and are more apt at navigating the health care system, the benefit of care coordination is the same for both high income and low-income families (Boudreaux et al. 2014).

In a study that examines experiences of parents of CSHCN in relation to their needs when caring for their child indicated that the most reported unmet need was respite care (Whiting 2014). Furthermore, for parents of CSHCN reaching adulthood, transition of care was also a significant unmet need. In the United States, 750,000 children will make the transition from childhood to adulthood and will need care annually, yet fewer than half will receive transition of care (Davis, Brown, Taylor, Epstein, & McPheeters, 2014).

A recent survey from parents of children with autism spectrum disorders also supports this preponderance of unmet needs among CSHCN, and reports low satisfaction rates among parents caring for these children (Kopecky et al. 2013).
According to Kopecky et al. (2013), a series of challenges need to be addressed in order to maximize care benefits when diagnosing childhood autism. Indeed, these CSHCN are at an increased risk of having one or multiple comorbidities; and since they have manifold needs, an individualized approach is primordial in planning for their care (Kopecky et al. 2013).

In order to meet the pressing needs of these CSHCN, interventions must be tailored to treat developmental disabilities such as ADHD/ADD or autism as well as other possible co-existent disorders (Yoshimasu 2012). The medical home has been presented as a more efficacious and effective approach of care coordination that better suits the needs of CSHCN, and with a greater potential to improve their health (Boudreau et al. 2014).

The Medical Home: A Panacea for Children with Developmental Disorders?

Medical homes are paving the way for more individualized and consistent care for children with developmental disabilities. Both autism and ADD/ADHD are complex conditions for which the medical home model can provide a more comprehensive and holistic care. The concept of the medical home was instigated to overcome the many barriers that children with complex health conditions regularly face. (Sia et al., 2004). According to the American Academy of pediatrics, medical home is defined as “accessible, family centered, coordinated, comprehensive, continuous, compassionate, and culturally effective” (Sia et al., 2004, p.184), and constitutes an enhanced partnership between families and health care providers (Sia et al., 2004, 1473). The medical home has become a gold-standard so much that the American Academy of Pediatrics has prescribed that "every child should have access to a medical home" (Sia et al., 2004, 1477).
It has been shown that care provided within the context of the medical home is superior to the traditional way of providing care (Starfield & Shi, 2004). The medical home offers a more comprehensive and integrated approach to providing care, instead of the obsolete fragmented services that currently prevail in the health care system. Furthermore, medical home enables more effective care and has the potential to reduce health care disparities among populations (Starfield & Shi, 2004). The idea of collaborative relationships among different organizations to deliver patient care has been on the rise, and the medical home provides the mean to facilitate this coordination (Perrin et al., 2007).

A study examining the medical home for children without special health care needs demonstrated that children with a medical home have better and easier access to care, resulting in a higher quality of life, as well as decreased emergency room visits (Hadland & Long, 2014). Care coordination within the context of medical home has been shown to reduce unmet meets in children with special health care needs as well as lowering the rate of functional disability in children with special health care needs (Litt &McCormick 2014).

In 2007, as many as 56.9% of children in the US had access to a medical home, there were however significant racial/ethnic as well as socioeconomic related disparities among these children (Strickland et al. 2011). Parents have reported that their autistic children are less likely to have medical home care (Golnik, Ireland, Borowsky 2009). A study examining barriers to provide effective care to autistic patients identified specific hurdles such as access to a usual source of primary and specialty services, financial resources and social support, as well providers’ competency (Golnik, Ireland, Borowsky 2009). In part because of these barriers, the medical home seems a much better alternative that could address the many unmet needs of children with developmental disabilities.
METHODOLOGY

Data Source
This study is based on a secondary analysis of data of the 2009-2010 National Survey of Children with Special Health Care Needs. The NS-CSHCN is a random sampled telephone survey conducted by the National Center of Health Statistics at the Centers for Disease Control under the direction and sponsorship of the Federal Maternal and Child Health Bureau. Survey results are weighted to represent the population of non-institutionalized children ages 0-17 years who are classified as having one or more special health care needs (CSHCN) nationally and in each state. The NS-CSHCN is an independent random sample administered in all 50 states and the District of Columbia. Telephone numbers are randomly generated and called to find households with one or more children under the ages of 18. The NS-CSHCN is parent-reported, that is trained interviewers ask parents a series of questions for all children in the household to identify those with special health care needs. According to the National Survey of Children with Special Health Care Needs, in 2009-2010, a total of 371,617 children less than 18 years old were identified as having special health care needs in the US. A total of 40,242 interviews were collected during 2009-2010; 750 interviews were conducted in the state of Arkansas. The 2009-2010 NS-CSHCN was administered in English, Spanish, Mandarin, Cantonese, Vietnamese and Korean.

Weighting Method and Sample
We applied the weight so that the sample is representative of the population of children with special health care needs in Arkansas. The weight was obtained based on complex multistage probability sampling. We restricted the sample to children ages CSHCN 6-17 years. Thus, 51,792 children composed our study sample. Among these CSHCN, 43,249 (40%) had ADD or ADHD, 3,338 had autism (3%), and 5,205 (5%)
had both ADD or ADHD and autism in Arkansas. Children were classified as having ADD/ADHD if their parents answered “yes” to the following question: “Has a doctor or other health care provider ever told you that your child has ADD or ADHD”?. Children will be classified as having autism if their parents answered “yes” to the following question: Has a doctor or other health care provider ever told you that your child has Autism, Asperger’s disorder, pervasive developmental disorder, or other autism spectrum disorder?”. We specifically address ages 6-17 as at a younger age, it is more difficult to differentiate normal toddler behavior from ADD/ADHD or autism (Marks, 2013).

**Operational Definition of Variables**
- **Medical Home** is the primary outcome of interest. It is a dichotomous derived variable that indicates whether the child has received care within a medical home or not. To meet this criterion, parents must report the presence of the following: 1) a personal doctor or nurse, 2) family-centered care, 3) problem-free referrals, 4) a usual source of care, and 5) coordinated care. Secondary outcomes of interest are the elements that composed the medical home.
- The main predictor is a categorical variable that indicates whether the child has ADD/ADHD, autism or both.
- Other independent variables included: age (6-10; 11-17), gender, race (White only, Black only, other), ethnicity (Hispanic vs. non-Hispanic), type of insurance status (public, private, dual insurance, uninsured), insurance adequacy defined as whether the child’s current insurance coverage is usually/always adequate to meet child name’s needs, household poverty level, household highest level of education, and family structure (two parent biological or adoptive family; two parent family, at least one step-parent, mother only-no father present, other family structures).
Statistical Analysis

All calculated statistics are among the population of CSHCN, not the overall Arkansas or U.S. population. Statistical analyses were conducted considering stratification, clustering, and appropriate sample weight to account for the complex multistage sampling design of the survey data. We conducted univariate analysis (e.g. graphs) to describe the socio-demographic characteristics of children with ADD/ADHD, autism, or with both conditions in Arkansas and the U.S.

Bivariate analyses were then performed to examine unadjusted differences between selected categorical variables and ADD/ADHD and autism on the basis of Rao -Scott Chi-square test of association.

Weighted multivariate logistic regressions were used to examine whether the odds of having a medical home – and its components- differ by the child’ condition (ADD/ADHD, autism or both). Statistical significance was determined at a priori level of alpha=0.05. The study received IRB approval from the University of Arkansas, Fayetteville.

RESULTS

I. Are there differences in access to a medical home between children aged 6-17 years with ADD/ADHD as compared with children with autism and with children who have both disorders in Arkansas?

In 2010, 8,775,693 and 106,707 children aged 6-17 years had special health care needs (CSHCN) in the United States and in Arkansas, respectively. Among these CSHCN, an estimated 43,249 (40%) had ADD or ADHD, 3,338 had autism (3%), and 5,205 (5%) had both ADD or ADHD and autism in Arkansas.
Whereas the vast majority of parents reported that their child with either ADD/ADHD or autism has one or more personal doctors or nurses (94% and 100%, respectively), only eight out of ten parents with both conditions did so. In stark contrast with the high proportion of children with both ADD/ADHD and autism who have a personal health care provider in the U.S (Chart 1).

Chart 1. ADD/ADHD and Autistic Children ages 6-17 years with a Personal Doctor or a Nurse: Arkansas vs. United States

Although a very high proportion of parents claimed having a personal doctor or a nurse for their child, a lesser proportion stated having a usual source of care when their child was sick. However, the disparities found between children with either ADD/ADHD or autism as compared to children with both conditions with respect to having a personal physician or a nurse is less salient with regard to the usual source of care. Nonetheless, overall, fewer parents reported having a usual source of care in Arkansas than nationwide (Chart 2).
Chart 2. ADD/ADHD and Autistic Children ages 6-17 years with a Usual Source of Care in case of Sickness: Arkansas vs. United States

Close to six out of ten CSHCN (58%) did not meet all the criteria (i.e. having a personal doctor or nurse, family-centered care, problem-free referrals, a usual source of care, and coordinated care) for having a medical home in the State. This problem is even more exacerbated among children with ADD/ADHD, autism, or both. Indeed, as Chart 3 depicts, in Arkansas six out of ten children aged 6 to 17 years with either ADD/ADHD or autism did not meet all the criteria for having a medical home (59% and 63%, respectively). Children with both conditions are the least likely to have a medical home in Arkansas (83%), a proportion higher in the State than nationwide (Chart 3).
According to their parents, almost six out of ten children (58%) with ADD/ADHD and seven out of ten (72%) children with autism had a family-centered home in Arkansas. However, 65% of parents of children with both conditions reported that their children did not have a family-centered care in Arkansas. This proportion is much greater in the State than it is nationwide 65% vs. 50% (Chart 4).
Care coordination is one of five subparts that make up the Medical Home measure. Effective care coordination part of Medical Home summary measure was derived from three separate components: 1) CSHCN's families receive some type of help with care coordination; 2) CSHCN's families are VERY SATISFIED with communication among child's doctors and other health care providers if the child visited a specialist doctor, used mental health services, received OT/PT/Speech therapy, got substance abuse treatment, or used home health care services during the past year; 3) When such interactions are needed, families are VERY SATISFIED with how child's doctors communicate with school, day care or other programs. Four out of ten parents (41%) stated that their children with ADD/ADHD did not meet 1 or more elements of care coordination in Arkansas whereas half parents (53%) with autism reported so in Arkansas. More than half parents of children with the two conditions (68%) reported that their child did not meet 1 or more elements of care coordination, a proportion higher in the State than in the nation (Chart 5).
Chart 5. Coordination of Care of ADD/ADHD and Autistic Children ages 6-17 years: Arkansas vs. United States

Six out of ten parents of children with ADD/ADHD (61%), and of children with autism (59%) reported not needing any help for care coordination in the past 12 months. Nevertheless, 19% and 24% of parents with children with ADD/ADHD, and of children with autism stated having not received any help to coordinate their child's health care when needed. Close to half of parents of children with both disorders claimed having not been helped to coordinate their child's health when needed (Chart 6).
Chart 6. ADD/ADHD and Autistic Children ages 6-17 years needing help for Coordination of Care: Arkansas vs. United States

In Arkansas, the proportion of parents who mentioned having problems getting a referrals was 14% for children with ADHD, 12% for children with autism, and 17% for children with both conditions. Although these proportions were not very high, they were still greater than the proportion of parents reporting referrals issues in the nation (Chart 7).
Chart 7. Differences between ADD/ADHD and Autistic Children ages 6-17 years in having problems getting needed referrals: Arkansas vs. United States

A similar proportion of parents of children with ADD/ADHD or autism reported that they needed a specialist care for their child (69% and 67%, respectively). A much higher proportion of parents of children with both conditions reported being in need of specialty care for their child (84%). However, the need for specialty care, although high in the State, is even greater in the country (Chart 8).
In Arkansas, none of the parents of children with either ADD/ADHD or autism reported that their child’s doctor had always spent enough time with them. Close to three out of ten parents of children with ADD/ADHD and two out of ten parents of children with autism reported that doctors have sometimes or even never spent sufficient time with them. However, when it comes to parents of children with both conditions, more than half of them reported this problem of lack of time, a proportion almost twice as much than what is found in the nation (Chart 9).
Chart 9. Child’s doctors spend enough time with him or her: Differences between ADD/ADHD and Autistic Children ages 6-17 years: Arkansas vs. United States

In Arkansas, the vast majority of parents (92%) of children with autism mentioned that their child’s physician listened to them carefully, whereas 84% of parents of children with ADD/ADHD said so. However, a much lesser proportion of parents of children with both conditions (74%) reported that their child’s health care provider had carefully listened to them (Chart 10).

As Chart 11 displays, in Arkansas 90% parents of children with autism or with both autism and ADD/ADHD felt that usually their child’s doctors provided information specific to their child health; a much higher proportion than in the country. In Arkansas, only eight out of ten parents (79%) of children with ADD/ADHD reported that usually their child’s doctors provided pertinent information relative to their child’s health.
Chart 10. Child's doctors listen carefully to his/her parent(s):
Differences between ADD/ADHD and Autistic Children ages 6-17 years: Arkansas vs. United States

![Chart 10 Diagram]

Chart 11. Child's doctors provided information specific to child's health: Differences between ADD/ADHD and Autistic Children ages 6-17 years: Arkansas vs. United States

![Chart 11 Diagram]
In Arkansas, the vast majority of parents of children with autism (97%) reported that their child’s doctors made them feel like a partner in the child’s care, where 79% of parents of children with ADD/ADHD stated the same. An even smaller proportion of parents of children with both conditions (64%) mentioned that they felt like a partner in their child's care (Chart 12).

At 87%, parents of children with autism were more likely to report that their child’s doctors were sensitive to their family customs and values in Arkansas than parents of children with ADD/ADHD (78%). Again, parents of children with both disorders were the least likely to report that their child’s doctors were sensitive to their customs and values (Chart 13).

**Chart 12. Child’s doctors help family feel like partners in care:**
*Differences between ADD/ADHD and Autistic Children ages 6-17 years: Arkansas vs. United States*
Chart 13. Child's doctors are sensitive to family customs and values: Differences between ADD/ADHD and Autistic Children ages 6-17 years, Arkansas vs. United States

As Chart 14 shows, the level of satisfaction of parents of children with ADD/ADHD or with autism is quite similar: 30% of parents of children with ADD/ADHD reported being less than satisfied with communication among doctors as compared to 32% of parents of children with autism. However, over half parents of children with both conditions (56%) reported being less satisfied with the communication among doctors. Still, parents of children with autism were more likely to be less satisfied with communication between the doctors and the schools (48%) as compared to parents of children with ADD/ADHD (21%), or to parents of children with both conditions (34%) (Chart15).
Chart 14. Satisfied with communication among child's doctors: Differences between ADD/ADHD and Autistic Children ages 6-17 years: Arkansas vs. United States

Chart 15. Satisfied with communication between child’s doctors and schools or Programs: Differences between ADD/ADHD and Autistic Children ages 6-17 years: Arkansas vs. United States
II- What are the socio-demographic characteristics associated with having a medical home for children with either of these two disorders?

Although boys are more likely to have either ADD/ADHD, autism or both conditions, there was no significant bivariate association between the sex of the child and having a medical home (Table 1). Among children with ADD/ADHD, a slightly higher proportion of children aged 6-10 years-old have a medical home as compared to their peers aged 11-17 years. However, among children with both conditions, a higher proportion of younger children have a medical home than older ones (77% vs. 23%). Nonetheless, there was no association with between the age of a child and the presence of a medical home.

Although no statistically significant relationship was found between race and medical home, there was nonetheless one found between being Hispanic and having a medical home in the ADD/ADHD children population. Furthermore, statistically significant differences were found between household poverty and having a medical home in the autistic children population. Although no bivariate association was found between the type of health insurance and having a medical home, there was however, a statistically significant association between insurance adequacy and having medical home among children with ADD/ADHD or autism. Close to four out of ten parents of children with autism reported that their child’s health insurance was not adequate to meet their child’s needs.
Table 1. Socio-Demographic Characteristics associated with having a Medical Home in Arkansas

<table>
<thead>
<tr>
<th>CHARACTERISTICS</th>
<th>ADD/ADHD Medical Home</th>
<th>AUTISM Medical Home</th>
<th>ADD/ADHD-AUTISM Medical Home</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No (%)</td>
<td>Yes (%)</td>
<td>P-values</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Girls</td>
<td>38</td>
<td>36</td>
<td>0.84</td>
</tr>
<tr>
<td>Boys</td>
<td>62</td>
<td>64</td>
<td>0.57</td>
</tr>
<tr>
<td>Age categories</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6-10 years-old</td>
<td>45</td>
<td>51</td>
<td></td>
</tr>
<tr>
<td>11-17 years-old</td>
<td>55</td>
<td>49</td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White only</td>
<td>67</td>
<td>69</td>
<td>0.62</td>
</tr>
<tr>
<td>Black only</td>
<td>24</td>
<td>26</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>9</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>6</td>
<td>1</td>
<td>0.01</td>
</tr>
<tr>
<td>Non-Hispanic</td>
<td>94</td>
<td>99</td>
<td></td>
</tr>
<tr>
<td>Poverty Level</td>
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<td></td>
</tr>
<tr>
<td>0% - 99%</td>
<td>47</td>
<td>32</td>
<td>0.12</td>
</tr>
<tr>
<td>100% - 199%</td>
<td>28</td>
<td>23</td>
<td></td>
</tr>
<tr>
<td>200% - 399%</td>
<td>16</td>
<td>33</td>
<td></td>
</tr>
<tr>
<td>400% or more</td>
<td>9</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>Household Education Level</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>8</td>
<td>8</td>
<td>0.77</td>
</tr>
<tr>
<td>High school</td>
<td>40</td>
<td>33</td>
<td></td>
</tr>
<tr>
<td>More than high school</td>
<td>52</td>
<td>59</td>
<td></td>
</tr>
<tr>
<td>Type of Health Insurance</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private</td>
<td>21</td>
<td>37</td>
<td>0.07</td>
</tr>
<tr>
<td>Public</td>
<td>71</td>
<td>48</td>
<td></td>
</tr>
<tr>
<td>Dual insurance</td>
<td>6</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>uninsured</td>
<td>2</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Insurance Adequacy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>never</td>
<td>0</td>
<td>0</td>
<td>0.00</td>
</tr>
<tr>
<td>sometime</td>
<td>19</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>usually</td>
<td>21</td>
<td>13</td>
<td></td>
</tr>
<tr>
<td>always</td>
<td>60</td>
<td>85</td>
<td></td>
</tr>
</tbody>
</table>
Family Structure | 0.36 | 0.29 | 0.38
---|---|---|---
Two parent biological or adoptive family | 30 | 44 | 48 | 94 | 24 | 59
Two parent family, at least one step-parent | 20 | 11 | 4 | 6 | 24 | 8
Mother only (no father present) | 40 | 35 | 27 | 0 | 24 | 33
Other family structures | 11 | 10 | 21 | 0 | 28 | 0

- : no observations.
* : statistical test could not be performed because of no observations in both "no medical home" and "medical home"

**III- Does the likelihood of having a medical home differ between children with ADD/ADHD, with autism, and with both ADD/ADHD and autism in Arkansas?**

In table 2 below, the Odds-Ratios adjusted for gender, age, race, ethnicity, family structure, poverty level, education level, and type of insurance are shown. Only the coefficients that are statistical significant are reported.

- Parents of children with ADD/ADHD and autism were 74% less likely to report having a medical home than parents of children with ADD/ADHD, holding all other variables in the model constant. No statistical significances were found in the likelihood for children with autism to have a medical home as compared to children with ADD/ADHD.

**IV- What are the specific components of a medical home that are lacking for these children?**

- Parents of children with ADD/ADHD and autism were also 63% less likely to state that their child had received a family-centered care as compared to parents of children with ADD/ADHD, although this relationship is marginally significant (p=0.06).
- Parents of children with ADD/ADHD and autism were 60% less likely to report that their child have received effective care coordination than parents of children with ADD/ADHD, holding all other variables in the model constant.
- Parents of children with ADD/ADHD and autism were 89% less likely to mention that they had received help to coordinate their child's health care when needed.
- Parents of children with ADD/ADHD and autism were 80% less likely to report being very satisfied with communication among their child's doctors.

Table 2. Adjusted Odds-Ratios*

<table>
<thead>
<tr>
<th></th>
<th>Adjusted Odds-Ratios</th>
<th>P-Values</th>
<th>[95% Confidence Interval]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical Home</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Autism</td>
<td>0.40</td>
<td>0.202</td>
<td>[0.10-1.66]</td>
</tr>
<tr>
<td>ADD/ADHD-Autism</td>
<td>0.26</td>
<td>0.031</td>
<td>[0.08-0.88]</td>
</tr>
<tr>
<td>Family-Centered Care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Autism</td>
<td>0.90</td>
<td>0.849</td>
<td>[0.32-2.55]</td>
</tr>
<tr>
<td>ADD/ADHD-Autism</td>
<td>0.37</td>
<td>0.061</td>
<td>[0.13-1.05]</td>
</tr>
<tr>
<td>Care Coordination</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Autism</td>
<td>0.30</td>
<td>0.076</td>
<td>[0.08-1.13]</td>
</tr>
<tr>
<td>ADD/ADHD-Autism</td>
<td>0.40</td>
<td>0.007</td>
<td>[0.08-0.66]</td>
</tr>
<tr>
<td>Received help to coordinate child's health care, when needed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Autism</td>
<td>0.63</td>
<td>0.537</td>
<td>[0.15-2.76]</td>
</tr>
<tr>
<td>ADD/ADHD-Autism</td>
<td>0.11</td>
<td>0.000</td>
<td>[0.03-0.33]</td>
</tr>
<tr>
<td>Satisfied with communication among child's doctors</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Autism</td>
<td>0.31</td>
<td>0.071</td>
<td>[0.08-1.11]</td>
</tr>
<tr>
<td>ADD/ADHD-Autism</td>
<td>0.20</td>
<td>0.009</td>
<td>[0.06-0.67]</td>
</tr>
</tbody>
</table>

*ADD/ADHD is the reference category. AORs adjusted for gender, age, race, ethnicity, family structure, poverty level, education level, and type of insurance
DISCUSSION

The medical home is at the forefront for improving health care as Arkansas has received $42 million to begin developing these homes (U.S. Department of Health and Human Services, 2013). Children with complex health conditions, such as ADD/ADHD and autism, represent 20% of those in the state of Arkansas (NS-CSHCN, 2009-2010). These conditions require ongoing, professional care, making apparent the necessity for these children to have a medical home. To examine the extent to which current children aged 6-17 years with ADD/ADHD and autism have access to a Medical Home in Arkansas we examined the following: (1) Are there differences in access to a medical home between children aged 6-17 years with ADD/ADHD as compared with children with autism and with children who have both disorders in Arkansas?; (2) What are the socio-demographic characteristics associated with having a medical home for children with either of these two disorders? (3) Does the likelihood of having a medical home differ between children with ADD/ADHD, with autism, and with both ADD/ADHD and autism in Arkansas? (4) What are the specific components of a medical home that are lacking for these children?

Are there differences in access to a medical home between children aged 6-17 years with ADD/ADHD as compared with children with autism and with children who have both disorders in Arkansas?

In Arkansas six out of ten children aged 6 to 17 years with either ADD/ADHD or autism did not meet all the criteria for having a medical home. However, a higher proportion of children with both disorders did not have a medical home. Furthermore, children with both ADD/ADHD and autism faced more hurdles with regard to access to care in Arkansas as compared to children who suffer from ADD/ADHD or autism alone. Indeed, a higher proportion of them did not have one or more personal
doctors or nurses, and more than half did not have a family-centered care or did not meet 1 or more elements of care coordination. They faced problems related to coordination of care, access to specialty care, problem of insufficient time during doctor’s visits. A higher proportion of parents of children with both disorders reported having issues with their child’s health care provider carefully listening to them, and considering them like a partner. A higher proportion of parents also reported that their child’s doctors were insensitive to their customs and values, and were less satisfied with the communication among doctors.

An expected finding to emphasize is that parents in Arkansas had less reports of a usual source of care as compared to the United States. In accordance with the literature, when compared to the United States, the South, specifically Arkansas, has a higher prevalence of childhood ADHD, therefore making it more difficult to gain access to care (Akinbami et al. 2011). The literature emphasizes coordinated care as a way to reduce health costs and enhance overall health (Boudreau et al. 2014).

**What are the socio-demographic characteristics associated with having a medical home for children with either of these two disorders?**

With the southern region of the United States having a higher population of children with developmental disorders, according to the CDC, it makes it more challenging for parents of these children to gain access to care for their child. This can be due to a variety of socio-demographic reasons. Although research shows that males are more likely to be diagnosed with developmental disorders over females (Boyle et al., 2011), gender does not come into play when determining access to medical homes in Arkansas.

Age was a slight factor with regard to having a medical home or not, with parents of children aged 6-10 years reporting more access. Furthermore, although parents of Hispanic children with ADD/ADHD
reported having less access to a medical home than white children, race was not found to be a significant factor in having access to medical home. Poverty was found to be associated with having a medical home. Indeed, parents of autistic children living in households with income levels at 100%-199% of the poverty level (e.g. between $20,090 and $40,180 for a family of three) have less access to medical homes. This parallels with the literature in the sense that lower income level populations have been found to have more difficulty accessing medical care (Akinbami et al. 2011).

**Does the likelihood of having a medical home differ between children with ADD/ADHD and autism in Arkansas?**

As compared to parents of children with ADD/ADHD, parents of children with ADD/ADHD and autism were less likely to report having a medical home. Toomey et al. (2010)'s research did underline that ADD/ADHD are less likely to have a medical home. However, to our knowledge, no studies have previously investigated access to medical home with respect to these two conditions.

**What are the specific components of a medical home that are lacking for children with these two disorders?**

Parents of children with both ADD/ADHD and autism were less likely to state that their child had received a family-centered care; they were less likely to report that their child had received effective care coordination; they were less likely to mention that they had received help to coordinate their child’s health care when needed, and they were less likely to report being very satisfied with communication among their child’s doctors. No statistical differences were found in access to a medical home between children with ADD/ADHD vs. autism. This supports the findings of Toomey et al. (2010) who found that parents of children with ADHD report worse performance across key dimensions of primary care compared with
parents of children with asthma. Again, to our knowledge the lacking of these specific components of a medical home in children with both conditions have not been previously investigated.

**Nursing Implications**

Nurses play a vital role in the care of patients with ADD/ADHD and Autism. These children often times have special needs at school and the nurse has an important part in setting a care plan including medications, interdisciplinary appointments, and goal setting. Nurses are a key member to the medical home interdisciplinary team and are facilitators of communication among families, children, and physicians. This research is significant to nursing in that it can further the development and improvement of the medical home for these children.

**Limitations of the Study**

Because this study was based on secondary data, we were limited to the variables available in the dataset. Other variables that have been found to have a potential effect on access to medical home in the literature were not included in our analysis. Moreover, in the NS-CSHCN survey, answers on children are parent-reported, and may not reflect an accurate reflection of the variables measured. This may introduce some bias in the study. Finally, the NS-CSHCN (2009-2010) is a cross-sectional data; it only provides a snapshot of the factors at one point in time. Therefore, only associations can be incurred, not causality. Despite these limitations, the findings from this study have the potential to inform both health care professionals and policy-makers on the importance of providing a medical home to children with chronic health conditions in Arkansas.
CONCLUSION AND RECOMMENDATIONS

More research needs to be undertaken in order to determine why children with autism and ADD/ADHD have limited access to medical home in Arkansas. Because of the complexities of these conditions, and the multiple needs of these children incorporating a behavioral component into patient centered-care and the medical home is vital (Kathol, deGruy, Rollman 2014). It has been shown that incorporating behavioral services into primary care is exceptional practice rather than usual (Kathol, deGruy, Rollman 2014). According to Kathol, deGruy, and Rollman, there are seven necessary components to provide integrated behavioral health care into a medical home. These components include combining medical and behavior health benefits, targeting behavioral health history, using behavioral teams, matching behavioral expertise to treatment need, using evidenced based behavioral treatments, and cross-disciplinary care (Kathol, deGruy, Rollman 2014). With 40% of patients seen in primary health having behavioral health conditions, behavioral comorbidities are common (Kathol, deGruy, Rollman 2014). Billions of dollars are being spent each year on unnecessary services because behavioral conditions are not properly treated and coordinated among health care providers (Kathol, deGruy, Rollman 2014). A major problem with behavioral health is that almost 70% of conditions are neither assessed nor treated (Kathol, deGruy, Rollman 2014). This can no longer be overlooked. Integrated behavioral health services have the potential to add an important component to patient care and the medical home.

Children with autism and ADD/ADHD in Arkansas are in greater need of medical homes. With the growing prevalence of these disabilities, it is vital that these homes become more accessible. Arkansas has been granted $42 million dollars as part of The Triple Aim Objective in order to begin developing this medical model. With reported satisfaction rates and
gaps in care, improvements must be made in order to provide the best level of care to these children.
REFERENCES


sustainable behavioral health components in patient-centered medical homes. *Annals Of Family Medicine, 12*(2), 172-175


Strickland, B.B., et al., *The Medical Home: Health Care Access and