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AUTISM SCREENING KNOWLEDGE AND PRACTICE IN SOUTHEAST KANSAS

A Project Submitted to the Graduate School
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AUTISM SCREENING KNOWLEDGE AND PRACTICE IN SOUTHEAST KANSAS

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AUTISM SCREENING KNOWLEDGE AND PRACTICE IN SOUTHEAST KANSAS

An Abstract of the Scholarly Project by
Briana M LaForge

Autism spectrum disorder (ASD) is classified as a neurodevelopmental disorder characterized by delays in social communication and interaction as well as restricted repetitive behaviors, interest, and activities. According to the most recent reports from the CDC (2018), it is estimated that 1 in 68 children are diagnosed with some form of ASD in the United States. Research has shown that early identification and intervention can significantly improve outcomes in those individuals diagnosed. As a result of this research, the American Academy of Pediatrics (AAP) has recommended routine screening on all children for ASD at the age of 18 months and again at 24 months using a standardized autism-specific tool.

This descriptive research design examined the autism screening and referral practices of providers in the southeast Kansas counties of Montgomery, Allen, Labette, Cherokee and Crawford using a paper survey. Results of the study show that providers in Southeast Kansas are aware of the AAP guidelines regarding screening and feel that screening every childhood for autism is important. However, these providers are not screening children for autism using an autism specific screening tool nor do they feel confident in screening for autism. Providers in this area had a strong desire to learn more about autism screening guidelines and specific autism screening tools.

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INTRODUCTION

Description of the Clinical Problem

Autism spectrum disorder (ASD) is classified as a neurodevelopmental disorder characterized by delays in social communication and interaction as well as restricted repetitive behaviors, interest, and activities (Devescovi et al., 2016). The cause of autism is still unknown, but risk factors have been identified through research. According to the most recent reports from the CDC, it is estimated that 1 in 59 children are diagnosed with some form of ASD in the United States (Data & Statistics, 2018). The prevalence is quickly on the rise as this statistic was reported 1 in 110 in 2009 by the CDC (Fenikile, Ellerbeck, Filippi, & Daley, 2015). This rise in incidence could be attributed to the increase over the past decade in the awareness of the disorder, or it could be that more children are developing the disorder. Research has shown that early identification and intervention can significantly improve outcomes in those individuals diagnosed. As a result of this research, the American Academy of Pediatrics (AAP) has recommended routine screening on all children for ASD at the age of 18 months and again at 24 months using a standardized autism-specific tool (Allen, 2014; Crais et al., 2014; Dawson et al., 2012; Fenikile, Ellerbeck, Filippi, & Daley, 2015; Kleinman et al., 2008)

The average age of diagnosis for autism is between 3-5 years of age (Allen, 2014; Kleinman et al., 2008; Nadal & Poss, 2007). There is a significant amount of literature that shows children exhibit symptoms long before the age of three but are not diagnosed at the time of those symptoms (Allen, 2014; Kleinman et al., 2008; Nadal & Poss, 2007). Kleinman et al. (2008) reports that the average age of reported symptoms is between 17-18 months of age with a significant amount of parents reporting symptoms as young as 11 months. Fifty percent of parents whose children are diagnosed with autism, suspect that their children have problems at 12 months of age (Allen, 2014; Nadal & Poss, 2007). Nadel and Poss (2007) report that between 12-76% percent of parents report they believe their child has autistic symptoms in the first year and are later diagnosed with ASD. Even with evidence that children exhibit signs and symptoms far before diagnosis, the age of diagnosis is not changing.

As noted above, with the increase in incidence of autism the AAP has made recommendations on early screening at the ages of 18 and 24 months to increase early diagnosis. Despite this recommendation, the number of providers who actually screen for autism is drastically low. Literature indicates that only 8%-28% of providers perform routine screenings for ASD (Crais et al., 2014; Nadal & Poss, 2007; Fenikile, Ellerbeck, Filippi, & Daley, 2015). Even more startling is that some providers that are screening are not using an autistic specific screening and are not aware of the recommendations from the AAP (Fenikile, Ellerbeck, Filippi, & Daley, 2015). There have been several factors in the literature that contribute to this low incidence in screening including time restraints,

lack of funding, lack of resources and lack of knowledge/inadequate training (Crais et al., 2014; Fenikile, Ellerbeck, Filippi, & Daley, 2015).

Significance

The prevalence of autism has increased by 123% since 2002 (Carbone, Norline, & Young, 2016). According to the CDC autism has a significant economic impact in the United States with the average total cost per year for autism between 11.5 billion and 60.9 billion dollars. Children with ASD have a 4.1-6.2 increase in their medical expenditures when compared to children without ASD. The average medical cost for Medicaid-enrolled children with ASD in 2005 was six times higher than those Medicaid enrolled children without ASD. In addition, to the medical cost the interventions for children with autism also increase the cost. It is estimates that these interventions cost $40,000-$60,000 per child per year (Data & Statistics, 2018).

Due to the increasing rise in autism prevalence and it's raising medical costs, several federal actions have taken place over the last several years. The Children's Act of 2000 established the National Center on Birth Defects and Developmental Disabilities which promote autism research and monitoring of research related to the autism causes, diagnosis, early detection, prevention, and treatment. The Autism Collaboration, Accountability, Research, Education and Support (CARES) Act of 2014 which remains in effect in September 2019, releases annual strategic plans for autism research. Some federal acts like the Combating Autism Act provide funding for autism research, screening, treatment and education (NCLS, 2016).

Despite this drastic increase in autism and its economic burdens, there continues to be a very low rate of providers screening for autism. The failure to diagnose children

who exhibit signs and symptoms early is detrimental to the child and their future. There is mounting research noting the benefits of initiating intensive early intervention as soon as possible. Early intervention has shown significant improvement in speech, developmental growth, and intellect in children who started interventions at a young age compared to those who begin the same interventions at an older age (Nadal & Poss, 2007). Research in early intervention in young children 18 months to 36 months of age has shown improvement in autistic symptoms, communication, and cognition (Dawson et al., 2012; Devescovi et al., 2016; Wong & Kwan, 2010). This data adds to the significance of early screening and diagnosis by primary care providers.

Families of a child with autism typically come to their primary care provider's first with concerns about their child's development. Providers are really the "first line of defense" for identifying a child with autism. It is crucial that primary care providers take a leadership role in routine screening of autism and guarantee those children identified at risk for autism get a timely referral to proper services (Self, Parham, & Rajagopalan, 2015).

Purpose of the DNP Research Study

This research study aimed to identify routine autism screening practices and early referral, thereby improving the quality of life of individuals affected by autism and their families. The purpose of the research study was to assess provider knowledge on autism screening and on the referral processes. The specific goals of this research study were as follows:

- assess the current autism screening and referral practices of providers in Southeast Kansas

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- assess provider's attitudes towards routine autism screening

- assess provider awareness of the AAP recommendations for screening and assess their knowledge on the M-CHAT, an autism- specific screening tool

- assess provider knowledge on referral processes for children who screen positive as well as assessing if and where referrals are being made

As a result of this research, interventions to increase provider knowledge or assist providers in screening/referral can be determined for future implementation. Research has shown that screening rates for autism and referral practices for positive screenings are inadequate and unacceptable (Crais et al., 2014; Nadal & Poss, 2007; Fenikile, Ellerbeck, Filippi, & Daley, 2015). Increasing provider knowledge on this topic can help to elicit a much needed change in practice resulting in more comprehensive healthcare to children with autism.

Theoretical Framework

The theoretical framework chosen for this research study was the Health Promotion Model by Nola J Pender. This theory defines health as more than just the absence of disease but rather a positive state of well-being. Health promotion is aimed at increasing a person's overall state of well-being. Pender's theory comprises behaviors that improve health and that apply across the life span. Pender believes that health promotion is to improve the well-being of an individual to their actual human potential (Alligood, 2014).

The Health Promotion Model makes four assumptions:

1. Individuals seek to actively regulate their own behavior.

2. Individuals, in all their biopsychosocial complexity, interact with the environment, progressively transforming the environment as well as being transformed over time.

3. Health professionals, such as nurses, constitute a part of the interpersonal environment, which exerts influence on people through their life span.

4. Self-initiated reconfiguration of the person-environment interactive patterns is essential to changing behavior (Alligood, 2014, p. 402).

There are 13 assertions in Pender's Model that show the multifactorial nature of individuals interrelating with the environment as they pursue health. The statements are as follows:

1. Prior behavior and inherited and acquired characteristics influence beliefs about, effects of, and enactment of health-promoting behavior.

2. Persons commit to engaging in behaviors from which they anticipate deriving personally valued benefits.

3. Perceived barriers can constrain commitment to action, a mediator of behavior, and actual behavior.

4. Perceived competence or self-efficacy to execute a given behavior increases the likelihood of commitment to action and actual performance of the behavior.

5. Greater perceived self-efficacy results in fewer perceived barriers to a specific health behavior.

6. Positive affect toward a behavior results in greater perceived self-efficacy, which can in turn, result in increased positive affect.

7. When positive emotions or affect are associated with a behavior, the probability of commitment and action is increased.

8. Persons are more likely to commit to and engage in health-promoting behaviors when significant others model the behavior, expect the behavior to occur, and provide assistance and support to enable the behavior.

9. Families, peers, and health care providers are important sources of interpersonal influence that can increase or decrease commitment to and engagement in health-promoting behavior.

10. Situational influences in the external environment can increase or decrease commitment to or participation in health-promoting behavior.

11. The greater the commitments to a specific plan of action, the more likely health-promoting behaviors are to be maintained over time.

12. Commitment to a plan of action is less likely to result in the desired behavior when competing demands over which persons have little control require immediate attention.

13. Persons can modify cognitions, affect, and the interpersonal and physical environment to create incentives for health actions (Alligood, 2014, p. 403)

The emphasis of this research study is in regard to assertion numbers five and eight. This research study identified areas where providers needed an increase in knowledge on certain topics regarding autism, autism screening, and referral. Findings from this study can be used to develop educational opportunities for providers. Increasing provider knowledge on autism screening and referral practices will increase the provider's self-efficacy leading to fewer perceived barriers, and thus increasing screening

and referral rates. Educating providers on the AAP recommendations regarding screening practices will help them to understand what is expected of them. Future education on specific screening tools as well as references and algorithms for screening and referrals will act as assistance and support. According to the model, these actions should help provider commit to health promoting behaviors. This should act as a domino effect as well. Providers will model health promotion behaviors including screening and referral to other providers who will then model these behaviors to other providers.

Research Study Questions

1. What is the knowledge level regarding early screening and referral for autism of healthcare providers in Southeast Kansas?

2. What are the attitudes of healthcare providers in Southeast Kansas on early screening and referral for autism?

3. Are provider's in Southeast Kansas routinely screening for autism using an autism-specific screening tool at 18 and 24 months of age?

4. What screening tool are providers using to screen for autism in Southeast Kansas?

5. Are children who screen positive for autism being promptly referred to early intervention services?

6. If a child in Southeast Kansas screens positive for autism and is referred to early intervention (EI) services, where are they being referred to?

Definition of Key Terms

The following defined terms are for the basis of this research study.

Autism - a neurodevelopmental disorder characterized by delays in social communication and interaction as well as restricted repetitive behaviors, interest, and activities (Devescovi, et al., 2016).

Primary Care Provider (PCP) - A primary care provider is a health care practitioner who sees people that have common medical problems. This person is usually a doctor, but may be a physician assistant or a nurse practitioner (Medline Plus, 2015).

Provider - A term used by managed care organizations, referring to anyone rendering medical care, including physicians, nurse practitioners, physician assistants, and others (Farlex, 2012).

American Academy of Pediatrics (AAP) - an advocacy organization or pediatrician and other healthcare professionals dedicated to providing the optimal physical, mental, and social health and well-being for all infants, children, adolescents, and young adults.

Screening Tool - measures the differentiation between children who are at risk for atypical development from those who are not. This ranges from questionnaires to in office observations (First Signs, n.d).

Modified Checklist for Autism in Toddlers (M-CHAT)- scientifically validated twenty-three item screening tool devised to detect autism that can be used at 18 to 24 months of age (Guevara, et al., 2013; Kleinman, et al., 2008)

Early Intervention Services (EI) - support provided to children ages birth to three with a disability or developmental delay. A range of targets services are provided including special education, therapy, counselling, service planning and coordination, assistance and support.

Southeast Kansas - the geographical region in Kansas involving the most southern and eastern counties of the state. For this research study Southeast Kansas will be defined as the following counties: Allen, Cherokee, Crawford, Labette and Montgomery.

Logic Model of the DNP Research Study

The largest inputs to this research study were the DNP students and the area clinics in Southeast Kansas who participated in the research study. Time was also a significant input in this research study. This includes the time it took to develop the research study (creating surveys, distributing the surveys etc.) to the actual process of analyzing the data. Assumptions for the research study were that clinics in Southeast Kansas allowed this research study to take place in their facility and the assumption that providers would complete the surveys. These were also external factors that could affect the research study throughout its course.

The activities for this research study included a three step approach. The first step involved developing a survey to assess the current screening practices, referral practices and provider's views/attitudes on routine autism screening. The second step was distributing and collecting the survey to clinics in five different counties in Southeast Kansas. The final activity included analyzing the data from the surveys and making recommendations for further interventions and research based on these findings.

The outcomes were separated into three different goals including short-term, medium-term, and long-term. The short term-goals focus on assessing provider knowledge on screening and referrals. The medium-term goals focus first on acknowledging the barriers associated with routine early autism screening in rural areas of Kansas. A second medium-term goal is the hope that this research study will increase

research in the area of early autism screening and diagnosis based on the results of this study. A third goal includes eliciting practice change and increasing the rates of early autism screening and early referral. The long-term goals are aimed at improving healthcare practices and providing more comprehensive healthcare to patients. A visual of this logic model can be seen in Figure 1.

Project: Routine Autism Screening in Southeast Kansas Logic Model

Goal: To assess current autism screening and referral practices in Southeast Kansas and increase screening by raising provider awareness and knowledge on this topic

Inputs	Output		Outcomes		
	Activities	Participation	Short	Medium	Long
Time DNP Student Irene Bradley School of Nursing Area clinics in Southeast Kansas	Develop a Survey to assess current Distribute survey to clinics in 5 different clinics in Southeast Kansas Gather surveys from clinics and analyze the data	Providers in Southeast Kansas Clinics in Southeast Kansas	Assess provider knowledge on autism screening Assess provider knowledge on autism screening tools Assess provider knowledge on referrals for a positive screening for autism	Acknowledge barriers to routine autism screening in rural areas of Kansas Increase research on early autism screening and interventions to increase this screening Illicit practice change in clinics for autism screening in accordance to the AAP recommendations	Improve the outcomes of children with autism as a result of early diagnosis Provide more comprehensive healthcare to patients

Assumptions

Clinics will allow survey to be dispensed

Providers will complete the survey

External Factors

Providers attitudes on routine screening

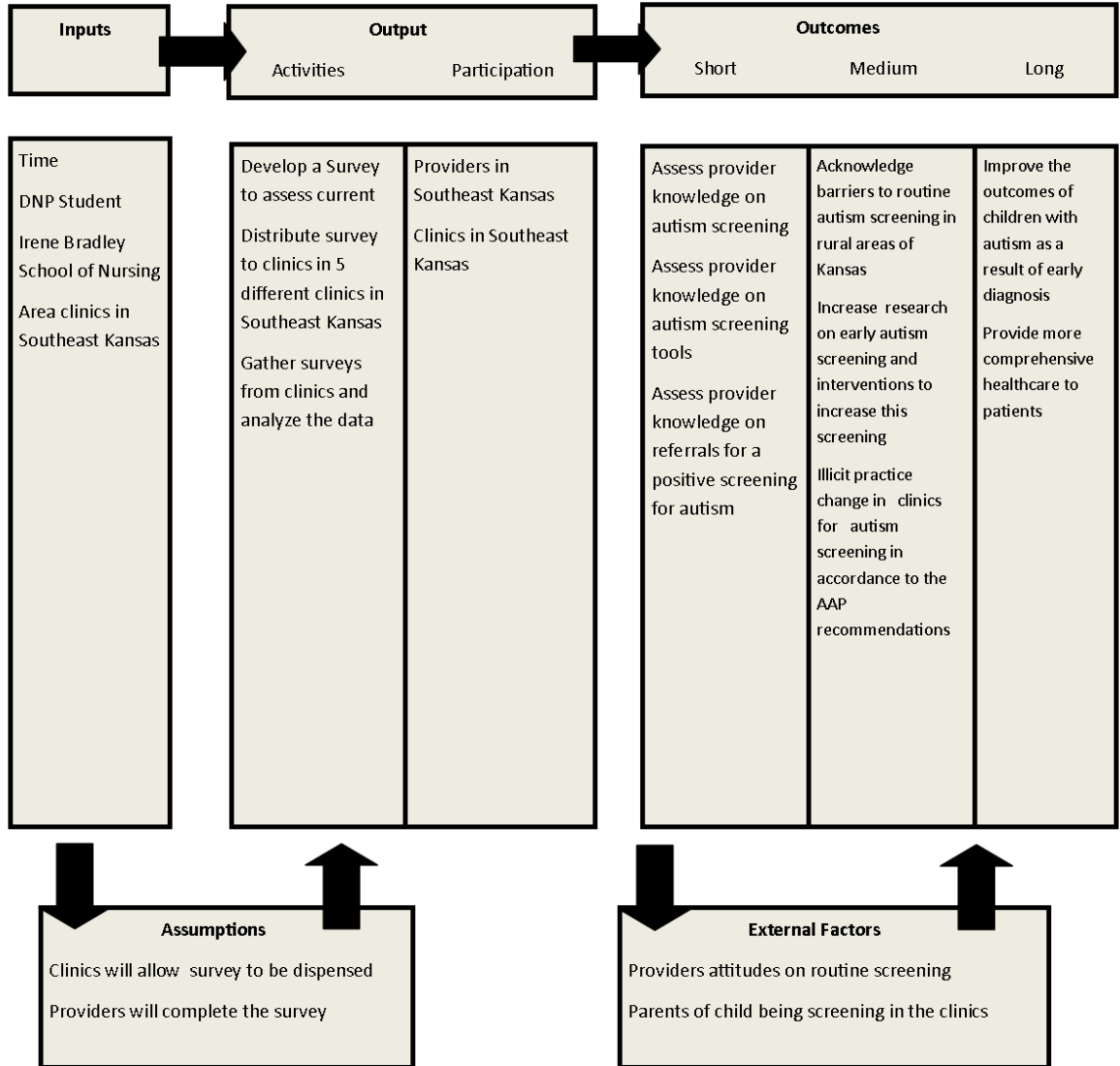Parents of child being screening in the clinics

Figure-1. Logic Model-Routine Autism Screening in Southeast Kansas

Summary

The incidence of autism is on the rise, and although we are not certain the cause of the disorder, there is growing evidence that proves early diagnosis and intervention can significantly improve the symptoms and effects of autism. The American Academy of Pediatrics developed recommendations based on these facts, yet only a minute group of primary care providers are observing them. Understanding the barriers to early diagnosis and interventions and addressing the need for change in the screening process are paramount in changing the age of average diagnosis in ASD. If we can implement change in age of diagnosis and age of intervention initiation, then we can improve the quality of life of those individuals affected by this disorder.

Studies have shown providers who routinely screen for autism are confident in their knowledge on the topic (Self, Parham, & Rajagopalan, 2015). One major barrier of routine screening that has been identified is provider knowledge (Elder, Brasher, & Alexander, 2016). Therefore, inadequate pre-professional training on this topic likely correlates with low screening rates for autism. The purpose of this research study was directed at assessing the knowledge of primary care providers on the AAP recommendations for routine autism screening, tools for autism screening, and the current referral process. The intent is for the information obtained from this research study to be used in future research studies and health education mediums to increase provider knowledge on autism as well as increase early screening and referral for autism.

Chapter II

REVIEW OF THE LITERTURE

Many research articles have been published on a wide variety of topics surrounding autism. A systematic search of the literature was performed using the electronic databases of CINAHL Plus with Full Text, Pubmed, and Proquest Nursing and Allied Health Source that were provided by Pittsburg State University's Axe Library. Addiotnal articles that were relevant to the main purpose of this literature review were identified for supplementary references. Multiple key terms and phrases were utilized during the search of the literature:

- Autism

- Autism Screening

- M-CHAT

- Barriers to Autism Screening

- Early Intervention Services

- Autism Screening Tools

Secondary resources were utilized as well including the American Academy of Pediatrics and the Center of Disease Control where data statistics were obtained. Early screening for autism was the primary concept reviewed in this literature review. Concepts covered include barriers to early screening and diagnosis, eliminating barriers

to autism screening, autism screening tools, and early interventions in children less than 36 months of age. A brief review of systematic screening of ASD was included in the review to further knowledge on time constraints being a barrier to screening.

Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is a complicated neurobiological and neurodevelopmental disorder. The disorder is characterized by deficits or delays in social interaction, communication, and cognitive skills. (Burns, Dunn, Brady, Starr, Blosser, Garzon, 2017). Currently, the CDC reports 1 in 59 children are diagnosed with ASD a year in the United States. Autism is four times more common in boys than in girls. There is no reported difference in the incidence among race, socioeconomic status or ethnicity (Data and Statistics, 2018). The exact cause of autism is unknown, but research has shown that there is both a genetic and environmental component to its cause. The CDC is currently conducting studies to identify risk factors and possible genetic, biological and environmental causes of this disorder (Burns et. al, 2017; Data and Statistics, 2018).

Diagnosis for ASD is obtained by meeting the criteria set forth by the DSM-5. These criteria are as follows:

1) Persistent deficits in both social communication and interaction demonstrated in all three of the following:

- Social-emotional reciprocity
- Nonverbal communication barriers used for social interaction
- Developing, maintain, and understanding relationships

2) Restricted, repetitive behaviors, interests, and activities demonstrated by 2 or

more of the following:

- Stereotyped or repetitive movements, use of objects, or speech

  stereotypes

- Insistence on sameness, unwavering adherence to routines, or

  ritualized patterns of behavior (verbal or nonverbal)

- Highly restricted, fixated interests that are abnormal in strength or

  focus

- Increased or decreased response to sensory input or unusual interest in

  sensory aspects of the environment

3) These symptoms must be present in early development (before age 3) and impair

function (social, academic).

4) Disturbances cannot be better explained by intellectual disability or other

developmental delays. (Autism Spectrum Disorder, 2016).

There are no diagnostic tests for ASD, so diagnosis is based on screening for behavioral

indicators and developmental delays (ASD, 2018). Based on recommendations laid out

by the American Academy of Pediatrics, all children should be screened for autism at 18

and 24 months and additionally if there is any regression in development. Screening

should be done with an autism-specific tool like the M-Chat (Burn et al., 2017). If the

child screens positive, they should then be referred for a comprehensive diagnostic

evaluation to confirm diagnosis. This comprehensive evaluation is performed by a

specialist such as a developmental pediatrician, pediatric neurologist, or pediatric

psychologist (ASD, 2018). Diagnosis can be made at 18 months of age (ASD, 2018), but

the average age of diagnosis is between 3-5 years of age (Allen, 2014; Kleinman, et al., 2008; Nadal & Poss, 2007).

Treatment for autism is targeted at the symptoms of the disorder and based on improving the functioning of the child (ASD, 2018). Research has shown that getting children into early intervention services shows drastic improvements in the child's symptoms. These interventions are typically started prior to age three and target social skills, language, communication, and cognition (Devescovi, et al., 2016). There are many other treatments currenlty offered for children with ASD and are inititated based on the specific symptoms the child exibits. These treatments include behavoir therapy, dietary alterations, medications to help with behaoviral symptoms, occupational therapy, physical therapy, and complementary medicine (Burn et. al, 2017) . Many of these treatment options like dietary alterations and complementary medicine are not scientifically supported at this point but are still widely used (ASD, 2018).

Barriers to Early Screening and Diagnosis

The prevalence of routine screening for autism is identified as very low. Self, Parham, & Rajagopalan (2015) reported a mere 17% of providers in their study (located in Kansas, Oklahoma and Iowa) routinely screened for autism following the AAP recommendations. Crais et al. (2014), and Fenikile et. al (2015) identified several barriers to routine screening. Both studies performed focused groups with providers who regularly provided well-child visits. Elder, Brasher, & Alexander (2016) also identified several barriers to early diagnosis of autism, but their study was unique. They performed a qualitative study which included focus groups of not just providers but also people with ASD, family members of persons with ASD, and early intervention service providers.

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This study allowed for a more comprehensive qualitative analysis on the perceived barriers surrounding early autism diagnosis.

One major barrier that was identified was lack of time to perform the screening (Crais et al., 2014 ; Fenikile, Ellerbeck, Filippi, & Daley, 2015). Providers feel that well child visits are already time consuming with many recommendations. Adding a screening tool that is specific to one condition only adds to the time constraints placed on these visits (Crais et al., 2014; Fenikile, Ellerbeck, Filippi, & Daley, 2015). Some parents feel that even the screening tools that are being used are only utilized due to time constraints and don't actually screen in-depth enough to raise concern. The screening tools that are being used are meant to recognize more severe cases, and the subtler signs are under-represented (Elder, Brasher, & Alexander, 2016).

The general lack of knowledge was another barrier identified. This lack of knowledge was identified not just with providers but also with parents or caregivers (Elder, Brasher, & Alexander, 2016). Providers don't feel confident in their knowledge to identify early signs of autism or when is the appropriate age to screen. There was also lack of knowledge in the screening tools used for autism. Providers wanted the knowledge on how to use the tool but also evidenced based research regarding the validity of the tool. (Crais et al., 2014 ; Fenikile, Ellerbeck, Filippi, & Daley, 2015). It should be noted that this lack of knowledge is not just about autism signs/symptoms and autism screening, but about the resources available as well. Many providers, especially in rural areas, are unaware of the services and resources available for children who screen positive or have been diagnosed with autism (Elder, Brasher, & Alexander, 2016).

Provider attitudes and opinions on autism-specific screening play a role in the delayed diagnosis of autism. Some providers feel the general developmental assessment tools and direct observation of the child in their office is sufficient to screen. Providers believe that screening children for autism is not a priority (Fenikile, Ellerbeck, Filippi, & Daley, 2015). Many providers have a "wait and see" approach when they do have a concern about a child or even when they do screen positive for autism. This leads to a delay in the referral process, and children are not getting further evaluation and treatment needed in an acceptable time (Carbone, Norlin & Young, 2016). Since the AAP's recommendation are founded from a pediatrician based group, many family practice providers are not following the recommendations (Self, Parham & Rajagopalan (2015). Self, Parham, & Rajagopalan (2015) report that only 3% of the family practice providers they surveyed screened for autism using the AAP recommendations. While these guidelines may be published from the AAP, it is reported from this foundation that both pediatricians and family practice providers play an equally vital role in the identification and referral of these children (Self, Parham, & Rajagopalan, 2015).

Studies have shown that early age diagnosis of autism is correlated to providers who performed screening and referrals based on parental concerns (Adeleman & Kubiszyn, 2017). Despite this evidence, Elder, Brasher, & Alexander (2016) identified parental credibility and parental fear of stigma as barriers to early autism screening diagnosis. Providers and parents alike in this study felt that even though autism is becoming more prevalent there is still this stigma attached to its diagnosis. This stigma makes it hard for providers to talk to parents and vice versa when it comes to conversation about autism screening and diagnosis (Elder, Brasher, & Alexander, 2016).

Many parents voice concerns for autism to their primary care providers by age 12 months (Allen, 2014; Nadal & Poss, 2007), yet providers continue to ignore these concerns leading to a later age of diagnosis. Elder, Brasher, & Alexander (2016) reported "countless" instances where parents felt ignored when voicing concerns about possible ASD to their providers.

There was high concern placed on the lack of funding for doing an autism specific screen. In healthcare, reimbursement is huge, and if you can't bill for it, then many providers felt doing the screening was wasting time and money (Fenikile, Ellerbeck, Filippi, & Daley, 2015; Crais et al., 2014). Unfortunately, today in healthcare insurance companies get to dictate the care provided; therefore, inadequate insurance coverage acts as a barrier (Elder, Brasher, & Alexander, 2016).

Finally, lack of resources was another identified barrier to screening. Many providers felt that the referral process for children identified as having autism was inadequate. Providers feel screening isn't important if there is limited services in place to care for them (Crais et al., 2014; Fenikile, Ellerbeck, Filippi, & Daley, 2015). The providers who can give a definite diagnosis for autism after a positive screening are inadequate. This lack of resources is even more of a concern in rural areas where services are very limited, and many resources require the person with autism to travel distances to obtain the help they need (Elder, Brasher, & Alexander, 2016). Yingling, Hock, and Bell (2018) found a significant time lag of three years between diagnosis and initiation of interventional services. This substantial time lag can have significant effects on patient's outcomes. As stated previously, while there may be a lack of resources, there is also a lack in knowledge among providers about what resources are available. These barriers to

early screening are so important to identify and understand so steps can be made to alleviate them allowing for improved practice.

Elimination of Screening Barriers

There have been many research articles about barriers to autism screening, and more recent articles are being published about how to eliminate these barriers. One of the major barriers reported by physician is low self-efficacy regarding autism screening, diagnosis, and treatment (Carbone, Norlin, & Young, 2016; Crais et al., 2014; Elder, Brasher, & Alexander, 2016; Fenikile, Ellerbeck, Filippi, & Daley, 2015). Correlations have been made between both education on this topic and confidence in knowledge leading to an increased rate of routine screening. When providers have been questioned on ways to improve autism screening and referral rates, a resounding theme identified was increasing education on the topic through conferences, workshops and webinars (Self, Parham, & Rajagopalan, 2015). Several studies have implemented educational initiatives as a way to increase provider knowledge and self-efficacy on the topic (Carbone, Norlin, & Young, 2016; Keil et al, 2014;). Carbone, Norlin and Young (2016) performed a learning collaborative in Utah with twenty-six participating primary care practices. This collaboration involved workshops (webinars and in class) where providers learned about current evidenced based recommendations on ASD surveillance and screening as well as training on the M-CHAT. Pre and post surveys were completed at these workshops to evaluate learning objectives. Chart audits were completed after the workshops to measure if there was an increase in screening practices based on this education. Monthly chart audits concluded that there was a 95% increase in M-CHAT documentation for urban areas and an 84% increase in M-CHAT documentation in rural

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areas. Providers reported a significant increase in knowledge on the post survey (p=<0.001) and a decrease in perceived barriers to screening and referral (p=<0.001). Another astounding result from this study is that four years after the intervention 70% of practices were still routinely screening for autism (Carbone, Norlin &Young, 2016).

Keli et al. (2014) performed a similar study in Wisconsin. An outreach designed to increase the use of validated autism specific screening tools began in 2006 for many primary care providers throughout Wisconsin. In 2007, a survey was sent to many primary care providers to evaluate the current rate of routine screening using an autism specific screening tool as well as the rate of routine developmental screening. Results from this survey concluded that only 25% of the providers who returned the survey were routinely screening. Over the course of the next six years, providers partook in voluntary trainings designed to educate and promote the routine use of validated autism specific screening tools. After these six years, a follow up survey was administered which indicated an increase from 25% -55% of providers routinely screening for autism using a validated autism specific tool as well as screening for other developmental delays.

A more current study performed by Mazurek, Brown, Curran & Sohl (2017), piloted a twelve biweekly clinics over a six month period that educated providers on screening and identification of ASD symptoms and management of medical and psychiatric comorbidities. Providers were given a pre-test and post-test within each clinic. The pilot study results in statistically significant improvements (p=<0.001) in self-efficacy, adherence to ASD screening guidelines, and use of ASD-specific resources. High satisfactory scores with the program were also reported (Mazurek et al., 2017).

These studies show that providing education and increasing provider knowledge can have a large and positive impact on guideline based screening rates and self-efficacy of providers for autism. While more studies like these need to be completed to further validate these findings, they act as a reference for future studies with their impressive results.

Autism Screening Tools

While the AAP recommends using an autism specific screening tool at 18 and 24 months, it does not identify which tool to use. There are several tools identified that are autism specific, but not one has been proven to be the most supported or validated. The literature review will focus on the M-CHAT and the M-CHAT-R/F. The M-CHAT is a twenty-three item parents report checklist devised to detect autism that can be used at 18 months of age (Guevara, et al., 2013; Kleinman, et al., 2008). There are six critical and seventeen non-critical items on the tool. Positive screenings are identified as failure of two critical items or three items in total. This questionnaire can be filled out by the parents prior to the appointment or with the parents during the appointment.

Gurvara et al. (2013) tested the M-CHAT and found that implementing it improved identification of autism in a primary care setting compared to those who just received developmental surveillance. There was as high as 68% shorter time of identification and 70% shorter time to early intervention related to using the M-CHAT to identity autism. Kleinman et al. (2008) also looked the the M-CHAT. In this study, the M-CHAT included a follow up interview on the children who tested positive on the screening tool, and also for those who the passed the M-CHAT but the physician flagged

the results as concerning. The follow up interview was performed approximately two years after the initial screening, and all failed items were reviewed with the parent to determine any change. This follow up call proved to be very important in eliminating false negatives and false positives. The positive predictive value drastically increased (.36 to .74) when adding the follow up phone call.

Since this study more research has occurred, and this method of using M-CHAT tool with follow up (M-CHAT/F) has shown adequate sensitivity and specificity (Robins, et al., 2014). The M-CHAT is at a sixth grade reading level (Kleinman, et al., 2008). However, it has been questioned if this is a valid tool because the average reading level in America is first to second grade (Crais, et al., 2014). Robins et al. (2014) researched the validation of a revised version of the M-CHAT. One aspect of this revision included simplifying the language of the survey to enhance understanding. This revised screening tool had a considerably higher detection rate (67 per 10,000 cases) then the original M-CHAT (45 per 10,000 cases). Another positive outcome from this study showed the average age of diagnosis was two years earlier than the median age of diagnosis. This allows for an increase in the time the children can get early interventions (Robins, et al., 2014). While more research is required to make a clinical decision on which assessment tool is the more sensitive and specific, these studies prove there are steps being made in the right direction.

Early Interventions

Research has shown that implementation of early intervention will improve long term outcomes in individuals diagnosed with autism. These interventions are considered

early because they are initiated by 36 months of age which is almost two years earlier than the average age of diagnosis. These interventions have shown improvements in social skills, language, communication, and cognition (Dawson et al., 2012; Devescovi et al., 2016; Wong & Kwan, 2010). More recent research reports intensive therapy started as early as 18 months leads to improvement in ASD symptoms as well as improvement in cognition, language and adaptive skills (Carbone, Norlin, & Young, 2016). In a study by Clark et al. (2018), children diagnosed prior to three years of age have significantly better outcomes. These children accessed more intervention, revealed better verbal and overall cognition at school age then those children diagnosed after three years of age. They were also more likely to attend conventional school and required less continuing support than children diagnosed after the age of three. There are many different models being researched to determine the most effective intervention model, but for this literature review the Autism 1-2-3 (Wong & Kwan, 2010) and the Early Start Denver Model (ESDM) (Dawson, et al., 2012; Devescovi, et al., 2016) are discussed.

The Autism 1-2-3 project is daily interventions for 30 minutes a day 5 days a week and requires parent involvement. The trainer works with the children on eye contact, gestures, and vocalization but also trains the parents so these techniques can be reinforced at home. The children enrolled in the intervention group had significantly improved vocalization, social interactions, and symbolic play after just two weeks when compared to the control group (Wong & Kwan, 2010).

Dawson et al. (2012) and Devescovi et al. (2016) both looked at the ESDM efficacy. ESDM is a comprehensive developmental behavioral intervention that focuses

on communication, joint attention, social interaction, imaginative play and cognition (Devescovi et al., 2016). The parents are trained so these interventions can be utilized at home for more reinforcement (Dawson, et al., 2012). Both studies showed significant improvement in all focuses areas of the intervention and showed improvement in the severity of the autism. Dawson et al. (2012) also looked at brain activity with an EEG. These EEG measurements showed the children with ASD who had received ESDM exhibited increased brain activity compared to those children with ASD who did not receive the treatment. Furthermore, the children who received ESDM displayed brain activity that was comparable to typically developing children of the same age (Dawson, et al., 2012). It should be noted that children who started interventions before 27 months had the most drastic increase in symptom improvement (Devescovi, et al., 2016). These studies prove that early interventions of some kind can drastically change the effects autism can have on an individual.

Systematic Screening

There was a theme that erupted through the literature review about systematic screening in the primary care setting. Time constraints were noted as a barrier to systematic screening (Crais, et al., 2014; Fenikile, Ellerbeck, Filippi, & Daley, 2015). Due to this finding, researchers looked into interventions that would make screening more time efficient. Having the screening as part of the EMR would help remind providers to perform the exam and lessen the chance the paper version would get misplaced or not scanned into the patient's chart. This would also help incorporate the screening into the flow of the visit (Fenikile, Ellerbeck, Filippi, & Daley, 2015). Guevara

et al. (2011) actually did incorporate the M-CHAT into the electronic system during their study to help clinicians complete the screening. A study was developed to look at the feasibility of incorporating a systematic screening for autism in a pediatric office (Miller, et al., 2011). All toddlers who came to the clinic between the ages of 14 months and 30 months were screened for autism whether they were there for a well child, sick visit, or vaccination appointment. Those who screened positive were given a follow up phone interview to rule out false positives. Thirty-two percent of children who screened positive were at the doctor for something other than a well-child visit. As a result of this finding, the researcher went back and found that during the time of the study 78% of children who were uninsured never accessed the clinic for a well child (Miller, et al., 2011). This study proves the importance of systematic screening on children not just in a well child visit but at any visit. More research need to be done on this area and how best to incorporate this kind of a system into the health care provider's routine.

Summary

Autism prevalence is on the rise, and so is the research for how to best screen for and treat this disorder. There has been significant research proving that early diagnosis and early intervention are key to improving the life of an individual with autism. Recommendations have been made on early diagnosis, but it appears through the literature review that these recommendations have yet to take hold in practice. Barriers have been identified as to what is holding back this early diagnosis, but little research has been done on ways to ease these obstacles. Further research needs to be done on ways to

increase routine provider screening for autism on all children. The majority of the research on early screening/diagnosis and early intervention is performed in urban locations leaving a major gap in the literature on rural areas. Adelman & Kubiszyn (2017) reported that age of diagnosis (3 years, 3 months) in the Midwest, which consists of mostly rural areas, was significantly higher than more urban areas like the Northeast and Southern regions (2 years 9 months). Studies must be performed in these areas as they are often the ones lacking the most resources. Research that helps educate providers on the early signs of autism, the recommendations for clinical practice on screening for autism, and how to use and facilitate the screening tools could lead to increased routine screening. If routine screening for early autism increases, then so does the prevalence of early intervention. Providers are the first line and gateway to early intervention for these children, but it must start first at identifying this condition as early as possible through routine screening and early referral.

Chapter III

METHODOLOGY

Research has shown that early screening for autism leads to earlier diagnosis and earlier interventions for autism. These early interventions then lead to improved outcomes for children diagnosed with autism. Providers play a vital role in starting this process by initiating early screening practices. Unfortunately, literature is proving that many providers are not screening, and the majority of this research is from urban areas. Understanding the current screening and referral practice, as well as, the knowledge on autism in rural areas is extremely important for future research.

A descriptive research design was used to gain knowledge on current autism screening, referral practices, and knowledge on autism from providers in Southeast Kansas. The design of this study, a description of the sample population, the instrument used and an outline for the statistical analysis of the data will all be discussed in this chapter.

Research questions addressed with this study include:

1. What is the knowledge level regarding early screening and referral for autism of health providers in Southeast Kansas?

2. What are the attitudes of healthcare providers in Southeast Kansas on early screening and referral for autism?

3. Are provider's in Southeast Kansas routinely screening for autism using an autism specific screening tool at 18 and 24 months of age?

4. What screening tool are provider's using to screen for autism in Southeast Kansas?

5. Are children who screen positive for autism being promptly referred to early intervention services?

6. If a child in Southeast Kansas screens positive for autism and is referred to early intervention (EI) services, where are they being referred?

Study Design

According to Gray, Grove, and Sutherland (2017), descriptive research helps the nurse to better understand individuals, events or situations so that they can design effective nursing interventions. This study utilized a descriptive research design to assess current knowledge of autism screening as well as current autism screening practices. A paper survey (see Appendix B) was developed and distributed to primary care providers in Southeast Kansas to gather information to answer the research questions. The participating clinics were located in the Southeast Kansas counties of Allen, Cherokee, Crawford, Labette, and Montgomery. Two types of clinics were utilized from each county, one private and one federally qualified health clinic. Permission for participation was obtained from the clinic coordinators prior to the delivery of the surveys. The researcher was unable to obtain permission from a private clinic in Allen County therefore, only a federally funded clinic participated in this county. The surveys were hand delivered along with a cover letter to each clinic with an envelope to mail the completed survey back to the researcher. The cover letter (see Appendix A) described the

purpose of the survey as well as detailing participation was voluntary and all participation would be anonymous. Two weeks after delivery, a reminder email was sent to providers reminding them to complete and return the survey if they have not already done so. The following week, the researcher sent one last reminder email for providers to complete and return their survey if they had not already done so. Data from the survey was evaluated and statistical analysis was completed on information gathered from each of the surveys.

Sample

The sample population for this study was a convenient, purposive sample. Due to sampling limitations of the study only primary care providers in Southeast Kansas were utilized. The counties included in this study are some of the most eastern and southern counties in Kansas. These counties were selected due to the proximity to the researcher, the rural status of the clinics, and due to each of the counties containing federally qualified health clinics as well as private clinics. The purpose of surveying both public and private clinics is to make the sample population more generalizable and to assess if there is a difference in screening and referral practices between the federally funded clinics and private clinics. A total of 41 providers were surveyed for this study. In Montgomery County five surveys were delivered to a private clinic, and eight surveys were delivered to a federally funded clinic. In Labette County seven surveys were delivered to a private clinic, and two were delivered to a federally funded clinic. In Allen County four surveys were delivered to a federally funded clinic. In Crawford County seven surveys were delivered to a private clinic, and six were delivered to a federally funded clinic. Finally, in Cherokee County two surveys were delivered to a private clinic,

and four were delivered to a federally funded clinic. The sample size consisted of twenty-nine completed surveys.

Inclusion criteria included the following: 1) providers must be practicing and licensed in the state of Kansas (Doctor of Medicine, Doctor of Osteopathic Medicine, Advanced Practice Registered Nurse, Physician Assistant); 2) providers must be practicing in Southeast Kansas in one of the five counties utilized for the study; 3) providers must routinely see pediatric patients for well-child and sick visits. Providers who did not routinely see pediatric patients for well-child and sick visits were excluded from the study.

Protection of Human Subjects

Prior to the obtaining permission from the clinics and dissemination of the surveys approval was obtained from the Pittsburg State University and the Irene Bradley School of Nursing Institutional Review Committee (IRBC). The surveys were distributed by the researcher after permission was obtained from each individual facility participating in the study. Confidentiality was maintained regarding all information obtained from the surveys. Although demographic information was obtained from the survey, careful attention was placed on keeping the surveys anonymous. The completed surveys were placed back in an unlabeled envelope which allowed the identity of the provider completing the survey to be unidentified. Participants were informed that the data obtained from the survey would only be used for the purposes of the research study. The surveys were kept in a locked and secure location during the study and were shredded at the conclusion of the study.

Ethical Considerations

Participation in this survey was voluntary and anonymous. While the basis of this research study was centered on screening of pediatric patients there are no ethical concerns as the surveys were administered to adult providers regarding their autism screening and referral processes of pediatric patients. A second ethical concern was the validity of the information provided by the providers regarding their screening and referral practices. Another ethical concern for this study was anonymity. As previously stated, special attention was paid to keeping the surveys free of any identifiers and the surveys were stored in a secure location to keep the information anonymous.

Instrumentation

This study utilized a paper survey that was delivered to the clinics. The survey included questions regarding demographics, questions to gain knowledge about current autism screening and referral practices and provider's attitudes and education on routine autism screening. The survey contained sixteen questions. Likert-type questions, dichotomous and multiple choice questions were utilized on the survey. Content validity was established by having two health care providers and one statistician review the survey and assess it for accuracy and reliability. Assessing the current knowledge and confidence of providers on autism screening and referral is instrumental in order to increase routine autism and screening. The survey used for the research study can be found in Appendix B.

Procedure

Surveys were hand delivered to each participating clinic. The research spoke to some of the participating providers. Due to time constraints of providers, the researcher left the surveys with the attached cover letter for some of the other providers. Each

survey was accompanied by a pre-addressed, pre-stamped envelope and cover letter

which detailed the purpose of the survey, how the information provided in the study

would be used and the process for completing and returning the survey. The cover letter

guaranteed to the providers that the information they provided in the survey would

remain anonymous. Two weeks after the initial delivery of the surveys an email reminder

was sent to providers to remind them of the survey. One week later a final email was sent

to each of the clinics to remind providers to mail back the survey or the survey would be

collected by the researcher if the health care provider indicated they were willing to give

the survey to the researcher at that time.

Once the final surveys were obtained, data from the surveys will be recorded and

analyzed. Analysis of the data was performed using Excel. Descriptive statistics were

obtained from the data.

Assumptions

There are several assumptions made for this study. Consent to participate was not

formally obtained from each participant but instead was voluntary and assumed through

completion of the survey. It is assumed that all participants were honest when completing

the survey. In addition, it is assumed that the sample of participants would be

generalizable and represent the majority of providers in Southeast Kansas.

Limitations

The sample population of this study could be considered a limitation. The

population was purposively chosen for this study as the researcher wanted to evaluate the

providers in rural areas. The results of this study may not be generalizable to urban areas

of the country or even other rural areas of the country as a result of the sample

population. Providers in five different rural, Southeast Kansas counties were used in this study. By using five different counties the researcher hopes to increase generalizability of the findings.

Another potential limitation is the small sample size. A convenient, purposive sampling procedure was used. The population was purposively chosen for this study as the researcher wanted to use providers in rural Southeast Kansas. Unfortunately, this resulted in a rather small sample size.

The descriptive design of the study is also a potential limitation of the study. The purpose of this study is to understand the current screening and referral practices for autism as well as provider's views on autism screening. It was determined a descriptive study was the best design to use for this type of research. However, there are limitations to this type of design. These include 1) the possibility that the participants not being truthful when answering the questions of the survey; 2) the fact that no variables are manipulated and; 3) no cause and effect can be determined from this type of study.

Summary

Autism rates are on the rise and research has shown that early diagnosis and early intervention can improve outcomes in those diagnosed with autism (Allen, 2014; Kleinman, et al., 2008; Crais, et al., 2014; Fenikile, Ellerbeck, Filippi, & Daley, 2015; Dawson, et al., 2012).

The rate of providers who routinely screen for autism are very low and most of the research done on this topic is from urban areas (Crais, et al., 2014; Nadal & Poss, 2007; Fenikile, Ellerbeck, Filippi, & Daley, 2015).). There is very little research on the screening and referral practices as well as knowledge on screening for autism in the rural

communities. The purpose of this study was to gain more knowledge on this data so future research can be performed based on the results.

Chapter IV

FINDINGS

This research study utilized a descriptive research design. The data from this study was collected to determine the current autism screening and referral practices, as well as provider knowledge and attitudes of routine autism screening in Southeast Kansas. Data for this research study was collected from a survey distributed to five of the most southern and eastern counties in Kansas:, Allen, Crawford, Cherokee, Labette, and Montgomery.

The survey was distributed to providers (MD, DO, APRN, PA) in this area who routinely perform well child visits. Private clinics and federally funded clinics were utilized in all counties except for Allen County. In Montgomery County, five surveys were delivered to a private clinic, and eight surveys were delivered to a federally funded clinic. In Labette County, seven surveys were delivered to a private clinic, and two were delivered to a federally funded clinic. In Allen County, four surveys were delivered to a federally funded clinic. The researcher was unable to obtain permission to utilize a private clinic in Allen County. In Crawford County, seven surveys were delivered to a private clinic, and six were delivered to a federally funded clinic. Finally, in Cherokee County, two surveys were delivered to a private clinic, and four were delivered to a federally funded clinic. A total of 41 questionnaires were distributed between the five

counties and 29 were completed and returned. Results from the surveys were analyzed and are examined in detail in the following sections.

Demographics

This study used convenient purposive sampling technique of providers who routinely perform well child visits in five Southeast Kansas counties. Demographic information was obtained to describe the characteristics of the providers who completed the survey. Demographic information obtained included age, gender, county of practice and funding of clinic in which they practice (private or federally funded).

Gender, Age, County of Practice and Clinic Type

Participants (N=29) of the study were overwhelming female (76%), while 24% of participants were male. The age range of participants was between 25 and 75 years of age with 38% of participants being in the 35-44 age range. Twenty-one percent of participants were between the ages of 25 and 34. Twenty-four percent of participants were between the ages of 45 and 54. Seventeen percent of participants were between the ages of 55 and 75 (Figure 4.1).
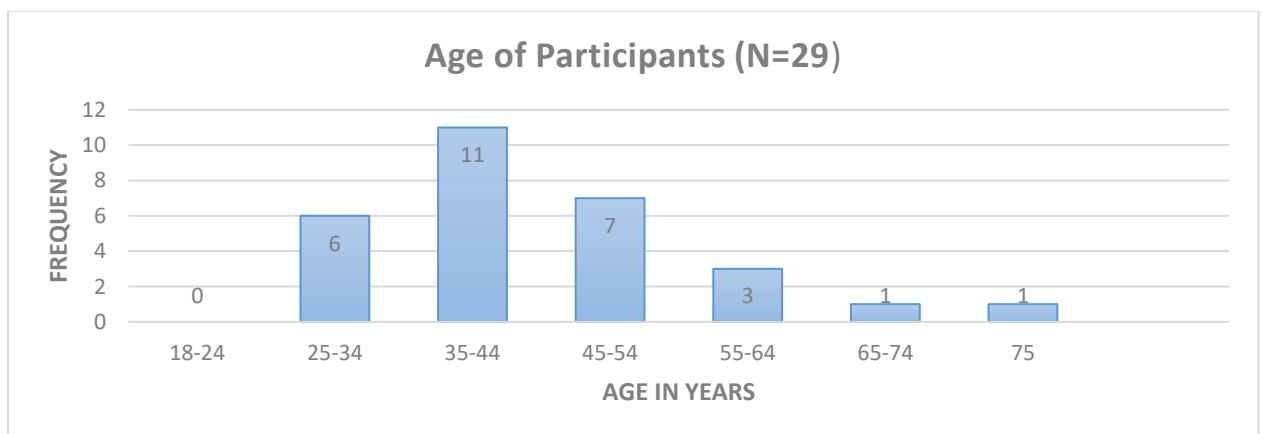

Figure 4.1 **Age of Participants**

The Southeast Kansas counties surveyed were Montgomery, Allen, Labette, Crawford and Cherokee. Completed surveys were received from all five counties, with Montgomery County having the largest return rate at 38%. Crawford County had the second highest return at 24%, Labette had a 17% return rate. While Allen and Cherokee counties were both 10% respectively (Figure 4.2).
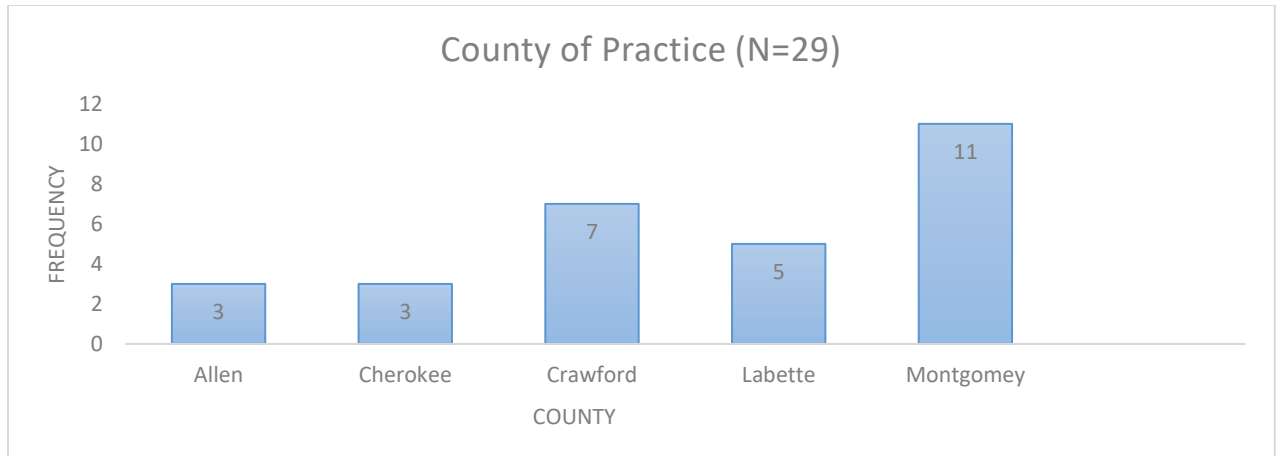

County of Practice (N=29)

Figure 4.2 **County of Practice**

Federally funded clinics and private clinics from each county were asked to participate in this study. Date from both types of clinics were obtained from 4 of the 5 counties. No private clinics in Allen county participated in the study, as researcher was unable to obtain consent from any private clinic in this county. The percentage of participants from each type of clinic is similar with fifty-five percent being from federally funded clinics and forty-five percent being from private clinics.

Educational Background and Work Experience

Over half of the participants (55%) in this study were APRNs. Twenty-one percent reported they were PAs, 17% were MD's and 7% were DOs. The years of work experience for participants ranged from less than five years to greater than twenty years of experience. Twenty-seven percent of participants reported less than five years of

experience. This work experience category had the largest response rate. Twenty-one

percent of providers reported 5-10 years of experience. Providers with 10-15 years of

experience also had a 21% response rate. Only 10% of providers reported having 15-20

years of experience. Whereas another 21% reported greater than twenty years of
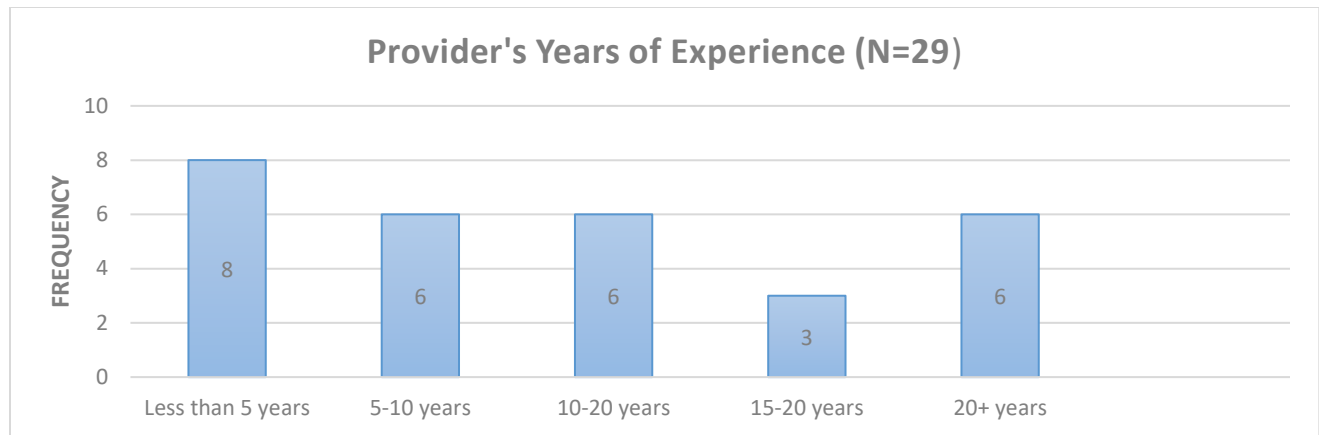
experience (Figure 4.3).

Provider's Years of Experience (N=29)

Figure 4.3 **Provider's Years of Experience**

Findings Related to Research Purpose and Questions

Participants of this study largely reported that they do not evaluate and treat

children for autism. Sixty-two percent of providers surveyed answered no when asked if

they evaluated and treated children for autism. Thirty-eight percent of providers reported

they do evaluate and treat children for autism.

Most of the participants (52%) reported seeing between 1and 5 children with

autism a year in their practice. Thirty-one percent of participants reported seeing 6 to 10

children. Seventeen percent of providers reported seeing 11 to 20 children a year in their

practice with autism (10% see 11-15 children; 7% see 16-20). It can be concluded from

the data that vast majority of providers in Southeast Kansas see between one and ten

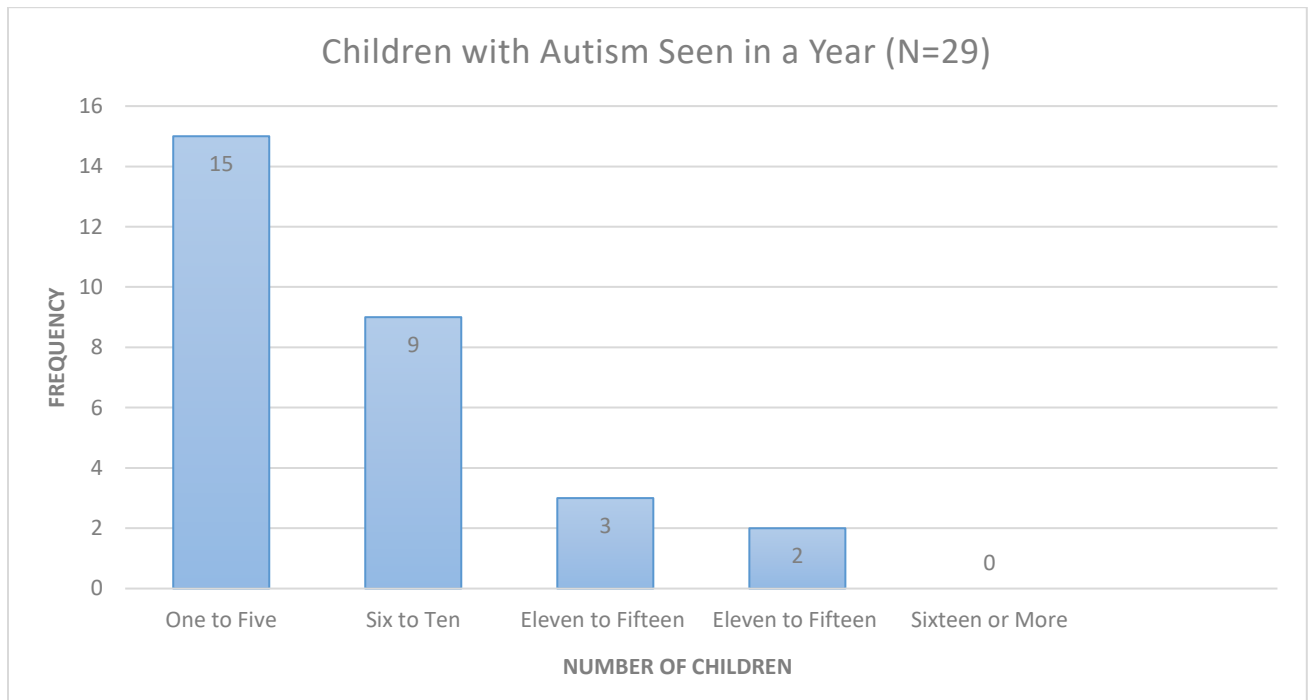children a year in their clinics with autism (Figure 4.4).

Figure 4.4 **Children with Autism Seen in a Year**

One of the purposed and research questions of this study was to assess the current screening and referral practices of providers in southeast Kansas as well as their current knowledge and attitudes towards autism screening. The data collected from the survey indicated provider's knowledge of this screening was almost equally divided. Fifty-two percent of providers stated, they did know about the AAP guidelines while forty-eight percent of providers reported not being aware of these guidelines (Figure 4.5).
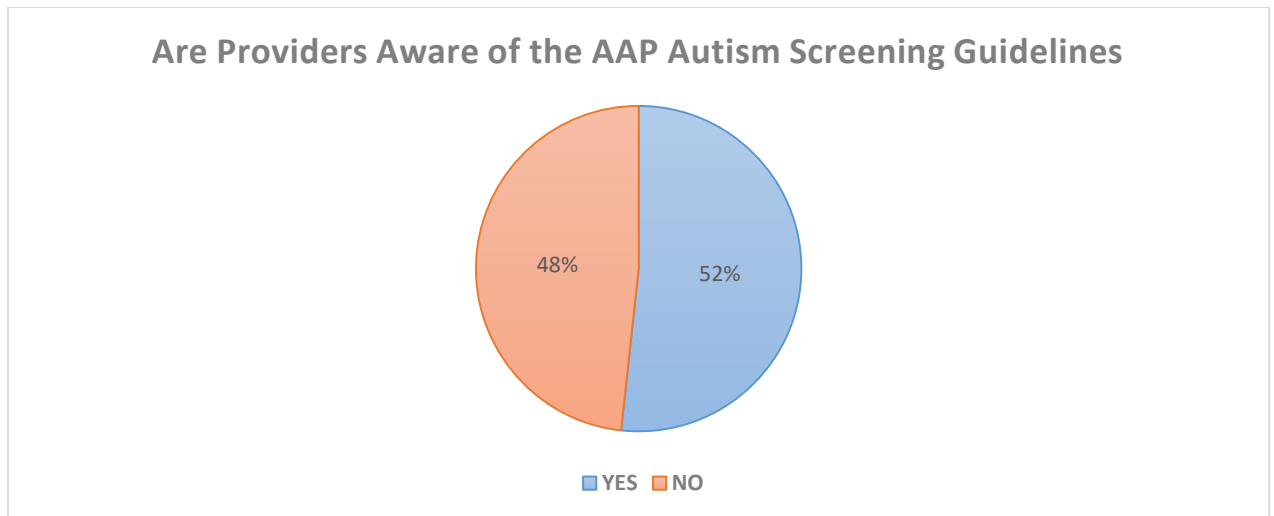
Figure 4.5 **Provider Awareness of AAP Guidelines**

The research study sought to determine providers in Southeast Kansas's attitudes on routine autism screening. Providers in the area surveyed felt that screening was important and should be performed on every pediatric patient with 65% of providers either agreeing (48%) or strongly agreeing (17%). Twenty-eight percent of providers had no opinion related to the importance of screening, answering "neither agree nor disagree". Only 3% of providers believe that screening every patient was not important while another three percent strongly disagreed with this idea.

The main research question of this study was to determine current screening practices of providers in the five Southeast Kansas counties surveyed. A large majority of providers reported not feeling confident in their ability to routinely screen for autism. Forty-eight percent neither agreed nor disagreed to feeling confident. While 34% disagreed to feeling confident and 4% strongly disagreed to feeling confident. Only 14% of providers reported feeling confident in their ability to screen for autism (Figure 4.6). The analysis of the data concluded that the majority of the providers surveyed know the

AAP guidelines and feel it is important to screen every patient for autism. Yet, the large

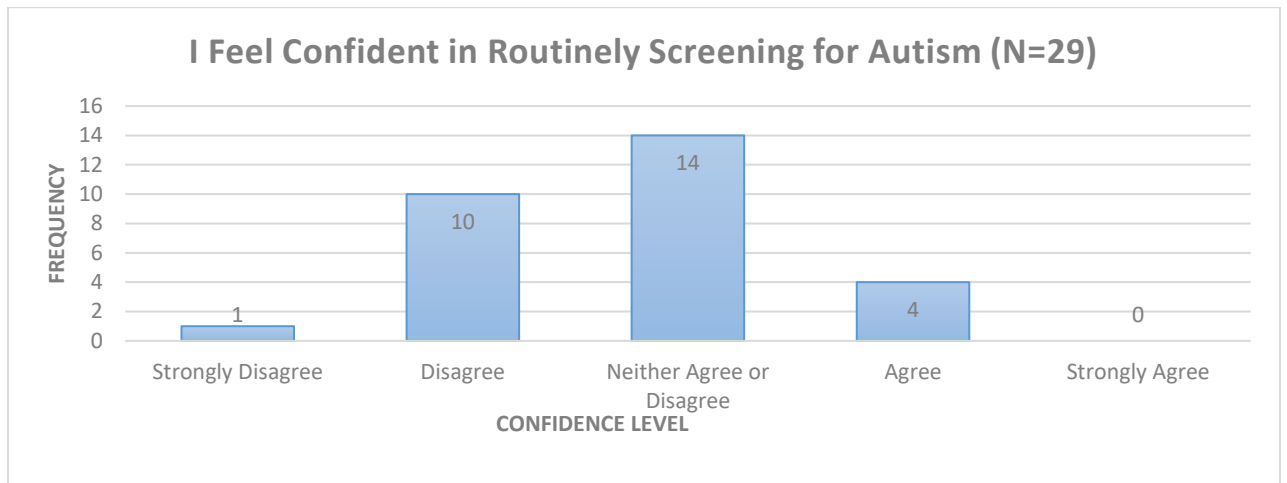majority do not feel confident in their ability to screen for autism.

Figure 4.6 **Provider Confidence in Screening for Autism**

Despite over half of the providers reporting being aware of the AAP guidelines, a

very large percent of providers are not screening for autism using an autism-specific

screening tool. When asked which screening tool they are using to detect autism, 59%

reported using no autism-specific screening tool. Twenty-four percent of providers

reported using the M-CHAT autism screening tool which is the recommended tool per

the AAP. Seven percent reported using the ASQ, a developmental screening tool to

screen for autism. Another 7% reported using a combination of screening tools (M-

CHAT, ASQ, PEDS) to detect autism (Figure 4.7). While it can be concluded that more

than half of providers in Southeast Kansas are aware of the AAP guidelines, feel autism

screening is important and feel confident in their ability to screen for autism they are

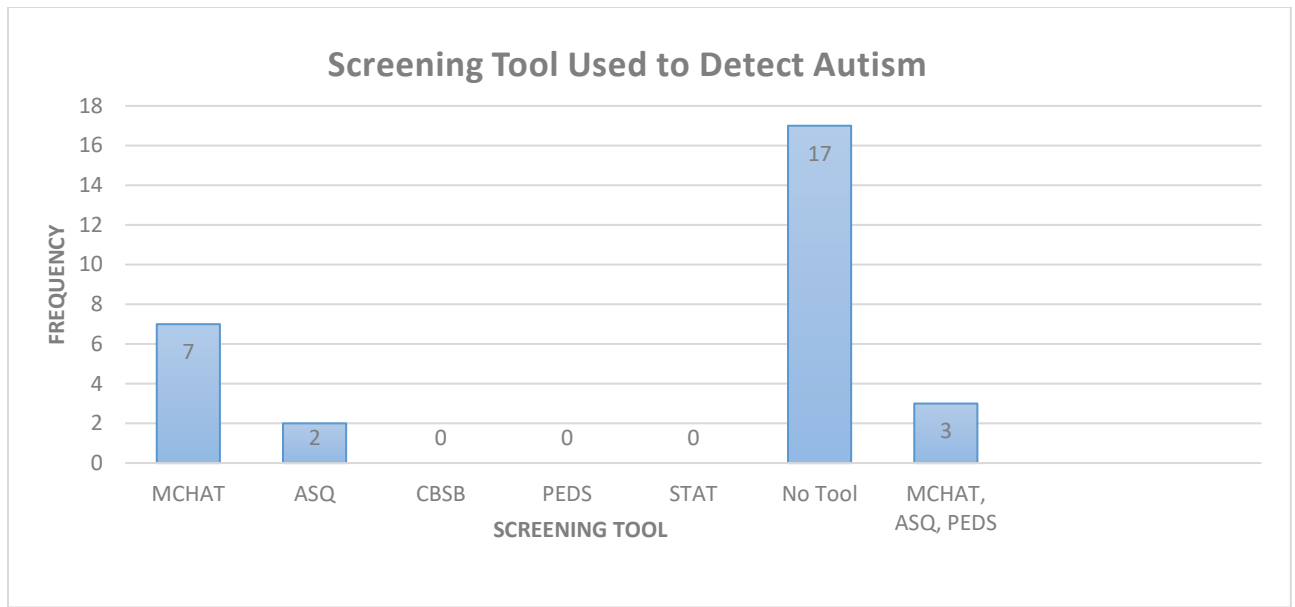overwhelmingly not using an autism specific screening tool.

Figure 4.7 **Screening Tool Used to Detect Autism**

Another research question this study addressed was the current referral practices of providers who they suspect has autism. One provider reported, "Rural medicine creates increased challenges for autism referral and treatment." Another provider discussed a program referred to as SEK Interlocal that helped children who screened positive for autism to get in-depth testing, evaluation and diagnosis locally. However, this provider reported this organization no longer provides these services; therefore, children are required to travel hours away to be able to get that same in-depth testing, evaluation and diagnosis. Thirty-eight percent of providers reported the referral time is two weeks to one month. Seventeen percent reported an even shorter time of referral as less than two weeks. Ten percent of providers report referral time was one to three months and a final ten percent reported a referral time of greater than three months. This survey question asked about the time to referral but the survey did not address how long it takes for the child to actually get in for testing and diagnosis. One provider reported that while the referral process takes less than two weeks the actual time to get an evaluation is more

than three months. This provider stressed the importance of getting these children who screen positive for autism into local therapies, e.g., speech or OT, while waiting for a formal diagnosis to be made.

The facility of referral for children suspected of autism from providers in Southeast Kansas was overwhelmingly Children's Mercy in Kansas City, Missouri. Sixty-nine percent of providers reported referring to Children's Mercy alone or referring to there as well as to other locations. Other locations where children were referred was KU Medical Center, Greenbush, and Birth to Three. Forty-five percent of providers reported referring to more than one of the locations listed on the survey when a child demonstrates symptoms of autism.

Finally, this research study evaluated the current knowledge of providers on autism screening. Fifty-nine percent of providers are not using an autism-specific screening tool to screen for autism. Interestingly, 38% of these same providers do not feel confident in their ability to detect symptoms of autism in a child, answering either "disagree" (10%) or "neither agree nor disagree" (28%) when asked if they felt confident in their ability to detect symptoms of autism. Fifty-nine percent of providers did in fact feel confident in their ability to detect symptoms of autism (Figure 4.8). While the majority of providers did feel confident in their abilities to detect autism, 38% of providers did not feel confident in their ability.
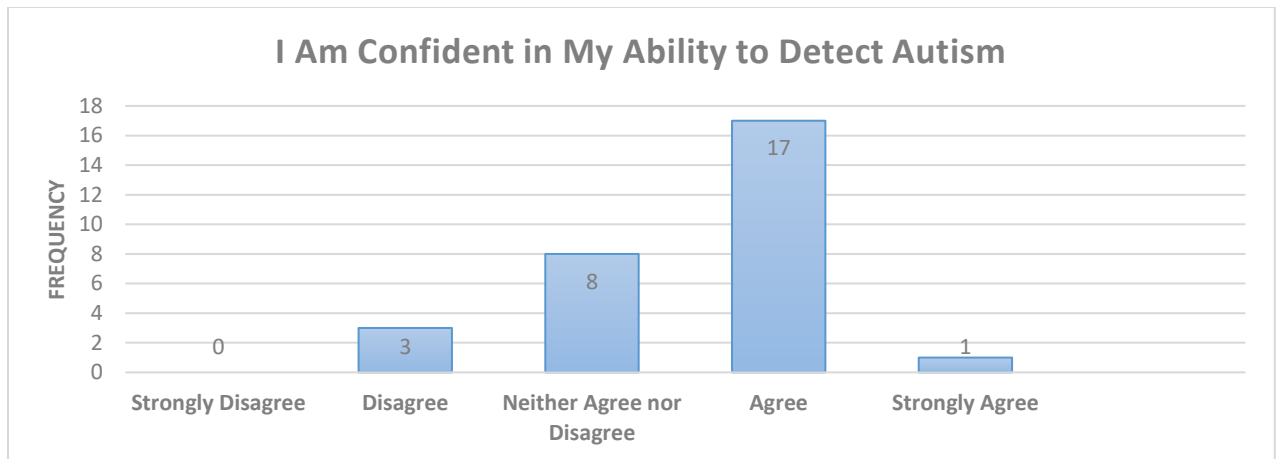
Figure 4.8 **Provider Confidence in Ability to Detect Autism**

Providers in Southeast Kansas definitely want to learn more about autism screening guidelines as well as autism screening tools. Eighty-six percent of providers reported wanting to learn more about these topics. The majority (76%) agreed they wanted to learn more about autism screening guidelines and screening tools and 10% strongly agreed. A smaller portion of providers, 14%, strongly disagreed in wanting to learn more about these topics.

Several statistical correlations were run by the researcher. These analyses looked at correlations between provider age, experience, credentials, and type of clinic (federally funded and private) with knowledge of AAP guidelines. Correlations were completed on provider age, experience, credentials, and type of clinic with the type of screening tool used to detect symptoms of autism. Finally, statistical analysis was run to determine is any correlation existed between provider confidence in screening and confidence symptom detection with provider age, experience, credentials, and type of clinic. There were no statistically significant correlations observed during analysis of the above data.

Summary

The purpose of this research study was to assess the current autism screening and referral practices by providers in the Southeast Kansas counties of Montgomery, Labette, Allen, Cherokee, and Crawford. The study also sought to examine providers' knowledge of autism screening as well as providers' attitudes on routine autism screening. Analysis of the data indicated the majority of providers in the research area are aware of the AAP guidelines and, feel confident in their ability to detect autism symptoms. However, these same providers are not following the AAP guidelines and are not using an autism-specific screening tool to screen for autism. In addition, a large number do not feel confident in their ability to screen for autism. This data indicates a need for education on screening and screening tools to detect autism in this area of Kansas. Most importantly, the vast majority of providers are interested in increasing their knowledge. Providers are also initiating referral for children who are suspected to have autism fairly quickly with most providers referring to Children's Mercy or other specialized agencies.

Chapter V

SIGNIFICANCE AND CONCLUSION

The purpose of this research was to determine the current autism screening and referral practices of providers in Southeast Kansas as well as their knowledge and attitude toward routine autism screening. The research study provided demographic data of providers in Southeast Kansas and illustrated the current autism screening and referral practices, autism screening knowledge and attitudes towards routine autism screening of these providers.

Comparison of Literature

According to the CDC (2018) the incidence of autism in children in the United States is fairly prevalent with 1 in 59 children being diagnosed with some form of autism. The literature review indicates only 8%-28% of providers routinely screen for autism (Crais et al., 2014; Fenikile, Ellerbeck, Filippi, & Daley, 2015; Nadal & Poss, 2007) and those that do screen do not use an autism specific screening tool (Fenikileet al., 2015). In a study performed in Kansas, Oklahoma and Iowa, only 17% of providers screening for autism following the AAP guidelines (Rajagopalan, 2015). This research study found that 59% of the providers surveyed in Southeast Kansas do not screen for autism using an autism-specific screening tool, and about half of the providers surveyed are aware of the AAP guidelines regarding screening.

The literature review identified that general lack of knowledge was a barrier to routine autism screening. According to the literture, providers don't feel confident in their knowledge to identify early signs of autism as well as knowledge on screening tools and when to screen (Crais et al., 2014 ; Fenikile, Ellerbeck, Filippi, & Daley, 2015). Similarly, this study found 86% of providers surveyed in the Southeast Kansas area do not feel confident in their ability to screen for autism. Ironicly, this set of information brings up a significant issue. Providers report they do not feel confident in screening for autism yet the majority of these providers do not use an autism-specific screening tool. This lack of guideline-based screening could be due to multiple factors including lack of knowledge on the guidelines or lack of knowledge on the screening tools. In any case, this is a significant finding. This finding leads the researcher to question how the providers appropriately screen for autism when they do not feel confident in their ability to screen and do not use a tool specifically for autism to help them identify children who may have autism. The research study showed a signficant need for education on the AAP autism screening guidelines and education on autism-specific screening tools for those providing care of pediatric patients in Southeast Kansas. Based on the participant's responses they want education on autism symptoms, autism screening guidelines and autism screening tools. Other research studies (Crais et al., 2014 ; Fenikile, Ellerbeck, Filippi, & Daley, 2015), found similar results. Studies have shown that increasing provider education will increase autism screening rates (Carbone, Norlin & Young, 2016 ; Keli et al, 2014). Review of literaure indicates that that provider attitudes and opinions on autism-specific screening also play a role in delayed screening for autism. According to Fenikile, Ellerbeck, Filippi, & Daley (2015), many providers felt that screening for

autism specifically wasn't a priority. However, findings from this research study suggests that providers in Southeast Kansas did feel autism screen is a priority, with a large portion of participants (65%) feeling routine autism screening was important and should be performed on all pediatric patients.

Health care providers who participated in the study largely referred to Children's Mercy which is located in Kansas City, Missouri, about a two and half hour drive from the area surveyed. Several of the other locations where providers surveyed referred children were also more than one hour away. Elder, Brasher, and Alexander (2016) reported that lack of resources in rural areas required individuals to travel long distances to obtain specialized care. One research participant in the study discussed a program in Southeast Kansas that helped decrease travel to resources and providers for an actual diagnosis, but unfortunately this program no longer exists. Based on the literature reviewed and information received from this study it appears more focus needs to be given on providing autism diagnostics services in rural, underserved areas.

Theoretical Framework

Nolan J. Pender's Health Promotion Model was the theoretical framework chosen for this research study. The study was guided by two major assumptions of the theory: greater perceived self-efficacy results in fewer perceived barriers to a specific health behavior, and persons are more likely to commit to and engage in a behavior when others model the behavior, expect it to occur, and provide assistance and support (Alligood, 2014).

According to this research study, providers are not confident in their ability to screen for autism. In addition, it was discovered that close to half of providers are not

aware of the AAP guidelines regarding routine autism screening and the large majority of the providers are not screening using an autism-specific screening tool. These are all areas where providers need an increase in knowledge and confidence. The findings from this research study can be used to support the development of educational opportunities to increase provider knowledge in autism screening guidelines and autism-specific screening tools, thus increasing self-efficacy. Alligood (2014), indicates that an increase in self-efficacy will lead to fewer perceived barriers and therefore an increase in guideline based autism screening.

Educating providers on the AAP guidelines will help providers know what is expected of them. Future education on specific screening tools and, referral practices, and providing algorithms for screening and referral can serve as assistance and support to these providers. Providers will in turn model guideline-based autism screening and referral to other providers who will then model this health promoting behavior to other providers. The theory states the providers will be more likely to commit to and engage in screening if these areas are all met (Alligood, 2014).

Implications for Health Care

Primary care providers are the "first line of defense" for screening and identifying children with autism (Self, Parham, & Rajagopalan, 2015). Research has shown that initiating early intervention during younger ages in children with autism results in significant improvement in speech, developmental growth and intellect (Nadal & Poss, 2007). Providers are the gateway to these early intervention services. It is crucial that every provider is 1) routinely screening early for autism to identify children; 2) making timely referrals; and 3) initiating early interventions as soon as possible.

This research study found that the majority of providers feel routine autism screening is important and should be performed on every child. However, a large number of providers who participated in the study are not screening for autism nor using an autism-specific screening tool despite being aware of the AAP guidelines to do so. The majority of the participants reported they do not feel confident in their ability to screen for autism, which could play a large role in why they are not screening using an appropriate tool. Education for providers on routine autism screening and autism screening tools is very important. Providers must understand the guidelines on routine autism screening and how to appropriately screen to be able to detect children early thus initiating early diagnosis and early intervention services. Education can lead to increased early screening rates thus improving the outcomes of children diagnosed with autism. Additional education will lead to providers delivering more competent and comprehensive healthcare.

Recommendations for Future Research

The research study provided insight into current autism screening and referral practices of providers in Southeast Kansas, their knowledge on autism screening as well as their views on routine autism screening. The research revealed that the majority of providers in this area feel autism screening is important and should be performed on every child. However, the majority of providers are not following AAP guidelines and screening with an autism-specific screening tool. The vast majority of providers did not feel confident in their ability to screen for autism. Almost all providers were interested in receiving education regarding autism screening tools and current guidelines. Future

projects are recommended to provide education and retention of knowledge, as well as practice changes in screening as a result of receiving more education

Replication of this research study with a larger population sample is recommended as this study looked at a very small sample of health care providers in rural areas of Southeast Kansas.   This research study could also act as a stepping stone for more wide-scaled research on the same topic. The majority of research has been completed in urban areas. More research needs to be completed in rural areas regarding autism screening and referral practices and providers' knowledge on autism and autism screening.

The fact that the majority of providers reported using no autism screening tool is something that should be investigated further. The research study also identified approximate referral times by providers, but future research needs to identify the time it takes for the children to get an actual diagnosis and into the appropriate services they need. Additional research investigating what factors are affecting providers screening practices and longer referral times and interventions to aid in increasing screening practices and timely referrals are definitely warranted based on the findings of this study.

Limitations

Limitations identified with this study included the inability to know if the participants were being truthful when answering the questions. Another limitation, is the fact that no variables were manipulated and no cause and effect can be determined from this type of study.

The sample size of this study is a limitation. The sample size of this study was very small with only twenty-nine participants. A convenient, purposive, sampling

procedure was used as the researcher was investigating only providers in Southeast Kansas. Unfortunately, this type of sampling procedure resulted in a small sample size.

The study is not generalizable to urban areas or to other rural areas. The researcher used five different rural counties in the Southeast Kansas area in hopes to increase generalizability. Unfortunately, some counties had limited number of providers and some providers were not willing to participate in the study.

Conclusion

The prevalence of autism is on the rise and whether this is because there is an actual increase in autism or there is an increase in autism awareness, research has proven that early identification and early intervention is crucial in improving patient outcomes. Recommendations on early routine autism screening have been made but research shows these recommendations have yet to become standard of practice.

The purpose of this research study was to identify autism screening and referral practices of providers in Southeast Kansas, as well as, providers' attitudes on routine autism screening and their knowledge on autism screening. Valuable information was gained about provider's practices and knowledge on autism screening from this study. The majority of providers in Southeast Kansas are aware of the AAP guidelines on routine autism screening but are not screening children using an autism-specific screening tool. While providers feel confident in identifying symptoms of autism they do not feel confident in their ability to routinely screen for autism. Providers in Southeast Kansas want to learn more about autism, autism screening and screening tools for autism. This education could increase provider knowledge and self-efficacy which in turn could increase autism screening based on guidelines. Referral for children in this rural area

requires them to travel long distances for car; therefore, funding needs to be focused on increasing resources to children in these rural areas.

The majority of research on early screening and early intervention for autism has been completed in urban areas. More research must be performed in these rural, underserved areas to improve screening and referral rates. This research study and its findings can be used as a platform for future research and education on autism screening, referral, and early intervention in rural areas.

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APPENDIX

APPENDIX A

Dear Participant,

I invite you to participate in a research study related to autism screening in Southeast Kansas. I am currently enrolled in the Doctor of Nursing Practice program at Pittsburg State University in Pittsburg Kansas and completing my scholarly project. The purpose of this research is to assess current autism screening and possible referral practices of providers in Southeast Kansas.

Your participation in this research project is completely voluntary. You may decline altogether, or leave blank any questions you don't wish to answer. Your answers will remain confidential and anonymous. Data from this research will be kept in a secure location and reported as aggregated data as it pertains to this research project.

Please answer the questions on the survey to the best of your ability. The survey should take approximately five minutes to complete. Please return the completed survey in the enclosed envelope.

Thank you for your time and support.

Sincerely,

Breezy LaForge BSN, RN, DNP Student

APPENDIX B

Autism Survey

Circle the best response to each of the items listed below.

1. What is your age?

18 to 24
25 to 34
35 to 44
45 to 54
55 to 64
65 to 74
75 or older

2. What is your gender?

Female
Male

3. How many years have you been practicing as a primary care provider?

Less than 5 years
5-10 years
10-15 years
15-20 years
Greater than 20 years

4. What are your credentials?

MD
DO
APRN
PA

5. What county do you currently practice?

Montgomery
Labette
Allen
Crawford
Cherokee

6. What kind of clinic do you practice in?

Private
Federally Funded

7. I feel confident in my ability to detect symptoms of autism.

Strongly Disagree
Disagree
Neither agree nor disagree
Agree
Strongly Agree

8. Approximately, how many children do you see with autism in a year?

1-5
6-10
11-15
16-20
More than 20

9. Are you aware of the American Academy of Pediatrics guidelines on screening for autism?

Yes
No

10. What screening tool do you use to detect autism?

M-CHAT
ASQ
CBSB
PEDS
STAT
I don't use an autism specific screening tool

11. Do you evaluate and treat children for autism?

Yes
No

12. If a child is suspected of having autism and referred, how long does it take to refer the child for further evaluation?

Less than 2 weeks
2 weeks to 1 month
1 to 3 months
Greater than 3 months

13. If a child is suspected to have autism where are they referred? (Choose all that apply)

Greenbush
Children's Mercy
Birth to Three
Treated at your facility
Other_____

14. Screening for autism is important and should be performed on every pediatric patient by the primary care provider.

Strongly Disagree
Disagree
Neither agree nor disagree
Agree
Strongly Agree

15. I would like to learn more about autism symptoms and autism screening guidelines and tools.

Strongly Disagree
Disagree
Agree
Strongly Agree

16. I feel confident in routinely screening for autism in my practice.

Strongly Disagree
Disagree
Agree
Strongly agree

17. Please include any additional comments related to care of children with autism at your facility.

_____

_____

_____

_____

_____