Expectation Versus Reality: An Examination of the Training and Awareness Primary Care Physicians Have About Communication Differences and Sensory Sensitivities Adults with Autism Spectrum Disorder (ASD) Present and Accommodations Provided During Office Appointments

Rachel H. Topper
The College of Wooster, rtopper19@wooster.edu

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EXPECTATION VERSUS REALITY: AN EXAMINATION OF THE TRAINING AND AWARENESS PRIMARY CARE PHYSICIANS HAVE ABOUT COMMUNICATION DIFFERENCES AND SENSORY SENSITIVITIES ADULTS WITH AUTISM SPECTRUM DISORDER (ASD) PRESENT AND ACCOMMODATIONS PROVIDED DURING OFFICE APPOINTMENTS

By Rachel H. Topper

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Advisor: Joan E. Furey, Ph.D.
ABSTRACT

The purpose of this study was two-fold. First, this study investigated the awareness and training primary care physicians have about the communication differences and sensory sensitivities adults with Autism Spectrum Disorder (ASD) may present. Second, this study examined how primary care physicians accommodate for the communication differences and sensory sensitivities adults with ASD may present, as well as how they integrate caregivers during office appointments. Most of the prior research regarding these topics only focuses on pediatric populations. To expand this literature, data were collected through an online survey that was distributed to primary care physicians. The results revealed that primary care physicians have a strong awareness of the communication differences and sensory sensitivities adults with ASD may present during office appointments. Primary care physicians accommodate for those differences and sensitivities less than half of the time during office appointments, and present varying perspectives about the necessity of caregivers to accommodate for the needs of adults with ASD.

Keywords: Primary Care Physician, Autism Spectrum Disorder, Communication Differences, Sensory Sensitivities, Accommodations, Caregivers
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CHAPTER I: INTRODUCTION

Like most parents, I did not know how to deal with my autistic child’s transition to adulthood. A disabled child’s adulthood carries within it the ultimate fears about finding others to support his life; What will his life look like? Where will he live? And, of course, the one that haunts us the most- what will happen when I die? (Senator, 2016, p. XXIV)

As Senator (2016) poignantly articulates, parenting a child with Autism Spectrum Disorder (ASD) through the transition into adulthood can be daunting. Adulthood brings more independence, and with that, many adults with ASD handle their healthcare needs on their own instead of with a caregiver. This would typically include the person with ASD communicating their medical needs on their own, which can result in varied communication differences during appointments with primary care physicians.

This chapter will present multiple components necessary to understanding this study and research. These include a purpose statement, a series of rationales, two definitions pertaining to the content carrying out this investigation, background information about Autism Spectrum Disorder, and a description of the method that will be used in this study.

Purpose Statement

The purpose of this study is two-fold. First, this study will investigate the awareness and training primary care physicians have about the communication differences and sensory sensitivities adults with ASD may present. Second, this study will examine how primary care accommodate for the communication differences and sensory sensitivities adults with ASD may present, as well as how they integrate caregivers during office appointments.
Rationales

There are both scholarly and practical reasons to pursue this investigation. First, this study will contribute to the literature by expanding our understanding concerning how primary care physicians provide accommodations for adults with ASD. This study will also contribute to the limited research about physicians’ comfort level to facilitate communication with adults with ASD. Most of the prior research, regarding physicians’ comfort level and prior training for working with patients with Autism Spectrum Disorder (ASD), has primarily focused on pediatrics and not on the needs of adults in primary care medical settings (Zerbo, Massolo, Qian, & Croen, 2015, p. 4002). Therefore, the first scholarly rationale is that this investigation will contribute to the limited research about physicians’ comfort level to facilitate communication with adults with ASD.

Second, this research will increase our knowledge of what physicians know about the communication needs of adults with ASD. The prevalence of Autism Spectrum Disorder (ASD) has increased steadily, including for the adult population; however, there is limited research on the adult population and what physicians understand to be their communication needs (Havercamp et al., 2016, p. 203). Adults with ASD may experience comorbid conditions that may require them to seek more medical care than their peers without Autism Spectrum Disorder (ASD) (Jones, Cottle, Bakian, Farley, Bilder, Coon, & McMahon, 2016, p. 559). Given that adults with ASD tend to have a greater need to utilize their primary care physicians for these conditions, it is important to investigate how physicians understand and are trained to best communicate with these patients during office visits. Therefore, the second scholarly rationale for this study is to address the preparedness physicians have to provide care to this increasing population.
Finally, from a clinical perspective, the results of this study will benefit primary care physicians because it will provide understanding of the preparedness of individuals to communicate with and provide care for adults with ASD. Additionally, this study will indirectly benefit adults with ASD, because we will better understand how physicians are trained to provide communication accommodations during office appointments to promote a better patient-physician relationship. This research will also provide insight to caregivers of adolescents with ASD about how caregivers can prepare their adolescent child to transition into adult healthcare. Finally, this study will also benefit Speech-Language Pathologists, as they may be able provide intervention for young adults with ASD transitioning into adulthood. Therefore, this is the practical and clinical rationale for this study.

Definitions

Two terms need to be defined to better understand the content of this study. The primary developmental disorder discussed in this study is Autism Spectrum Disorder (ASD). Autism Spectrum Disorder is defined in the Diagnostic and Statistical Manual of Mental Disorders (5th edition), as including deficits in social interaction and communication, and restricted and repetitive behaviors across a wide range of contexts (American Psychiatric Association, 2016, p. 50). More information about Autism Spectrum Disorder will be provided in the background section of the study, as well as in Chapter II. To improve the readability of this study, Autism Spectrum Disorder or ASD will be the terms used to refer to this disorder.

Primary care physicians are being investigated in this study. Primary care is defined by the World Health Organization as “The first point of contact that people have with the healthcare system. Primary care provides comprehensive, accessible, community-based care that meets the health needs of individuals throughout their life.” (World Health Organization, 2018, para. 3-5).
This study uses the term “communication difference” to refer to the communication characteristics of adults with a diagnosis of ASD. Other terms often used in the literature include “communication difficulty” or “communication impairment.” Communication difference is being used in this study, because this topic is being presented through the lens of the Neurodiversity approach to ASD. Tomlinson and Newman (2017) define the Neurodiversity approach as “focusing on Autism as a part of human experience and values adaptive techniques, as opposed to dwelling on a cure of ASD.” (p. 91). As this study examines the accommodations made by physicians during office appointments for the communication characteristics of ASD, the term “communication difference” is the most suitable term to refer to the communication characteristics presented by adults with ASD.

Background

Autism Spectrum Disorder (ASD) is a developmental disorder, in which diagnosed individuals typically present differences in verbal and non-verbal communication, sensory stimulation, motor skills, and the affective process (Kalyva, 2011, p. ix). There is not a known cause of ASD, however there are risk factors that may lead to a greater likelihood of diagnosis. Males are diagnosed with ASD significantly more often than females (National Institute of Mental Health, 2017, p. 1). Also, the ages of the individual’s parents at the time of conception (notably parents above the age of 40 years) can be factor, as does having a sibling with ASD, and other genetic factors (National Institute of Mental Health, 2017, p. 1).

Autism Spectrum Disorder is often diagnosed in infancy or by the age of two years. It is possible, however, to have a later diagnosis, in adolescence or adulthood, especially when teachers and caregivers have begun to develop concerns about a student’s social skills (Centers for Disease Control, 2018, para. 2). One difficulty with later diagnosis for older individuals with
ASD is that the disorder is often misdiagnosed as schizophrenia, or Attention Deficit Hyperactivity Disorder (ADHD) (National Institute of Mental Health, 2017, p. 1). The DSM-5 *Diagnostic and Statistical Manual of Mental Disorders* (5th edition) categorizes the severity of the diagnosis of ASD into three levels of support required for individuals with ASD. Those three levels include, “Requiring Very Substantial Support,” “Requiring Substantial Support,” and “Requiring Support,” in the areas of social communication and restrictive, repetitive behaviors (APA, 2013, p. 52). Individuals who require “very substantial support” present with severe deficits in verbal and nonverbal social communication skills, and great difficulty coping with change. Individuals who require “substantial support” present with “marked deficits of verbal and nonverbal communication social communication skills, and difficulty coping with change” (APA, 2013, p. 52). Individuals “requiring support” present with noticeable social communication impairments in settings where they do not have support and difficulty initiating social interaction (APA, 2013, p. 52).

The general characteristics of ASD, used to identify the disorder as needed, include repetition of specific behaviors or obsession over a specific topic or object. Individuals with ASD may exhibit difficulty with change in routines, expressing emotions (especially anger and sadness), and may demonstrate heightened sensitivity to different environmental stimuli, such as light, fabric, or noise (National Institute of Mental Health, 2017, p. 1). Individuals with ASD may exhibit a varying number of social communication and interaction behaviors, which will be discussed in the next chapter. It is important to note that the characteristics discussed in this chapter and future chapters are not present in every individual with ASD, as the disorder is truly a “spectrum,” whereby individuals present with different types or degrees of repetitive behaviors, social communication impairments, and sensory sensitivities.
Once an individual is diagnosed with ASD by a healthcare professional, (e.g., a psychologist or physician specifically trained to work with individuals with ASD), there are multiple resources available. There are some medications available to reduce irritability, aggression, and attention difficulties (National Institute of Mental Health, 2017, p. 1). Aside from medication, there are different types of behavioral, cognitive and peer-mediated interventions, often implemented by speech-language pathologists (SLPs), including some which make use of “typically developing peers.” Examples include the following: Applied Behavioral Analysis (ABA), Positive Behavioral Support, LEAP, and Circle of Friends, among others (ASHA, 2017, p. 1). Other types of intervention often implemented by SLPs include, story and narrative approaches and social stories (Selfe, 2013, p. 60). Narrative practice involves using language, pictures, and multi-sensory props for a greater understanding of the social dimensions in personal situations and events. Social stories describe a specific social situation that is relevant to the individual, in terms of the appropriate social cues and responses. Descriptive sentences are used to provide guidance on social behavior and responses to the situation presented in the social story (Selfe, 2013, p. 60). This background information is helpful in understanding ASD, which is the disorder being investigated in this study; a description of the method used to conduct this study will be described in the next section.

**Description of Method**

This study was a quantitative study that utilized survey research and data was collected with one online survey, formatted using Qualtrics Survey Software. The survey was designed for practicing primary care physicians (Pediatricians, Internal Medicine, and Family Medicine) who work with adults (age 18 and over). The survey included questions focused around training received in medical school to effectively communicate with their adult patients with ASD, their
knowledge of the social communication difficulties and sensory sensitivities adults with ASD may present, the integration of caregivers during office appointments, as well as how physicians accommodate for the communication differences and sensory sensitivities their adult patients with ASD present.

**Conclusion**

This chapter provided information about the purpose of this study, rationales, background information about Autism Spectrum Disorder (ASD), and definitions necessary to better understand this study. A large number of children with ASD will be transitioning into adulthood and gaining more independence from their caregivers. Part of that independence may include working with healthcare physicians, potentially without the presence of their caregivers, and having to communicate their medical needs to those healthcare professionals. Like Susan Senator, caregivers of these individuals may be justified in fearing that their children will not receive optimal care in their adult years. Given that adult individuals with ASD commonly present verbal and non-verbal communication difficulties, primary care physicians must be trained to effectively communicate and treat their adult patients with ASD. With more research in this domain, we will ideally be able to understand just how much physicians are trained (or are not) to work with this population. To better understand the prior research and basic principles behind this study, a literature review will be presented in the next chapter.
Within the last few years, there has been a steady increase of diagnosis of Autism Spectrum Disorder (ASD), especially for younger children (Centers for Disease Control and Prevention, 2016, p. 6). With the increase of the diagnosis of ASD, there will be a subsequent increase of children transitioning from pediatric healthcare to adult healthcare (Gerber, McCormick, Levine, Morrow, Anders, & Sheinkopf, 2017, p. 1896). Adults with ASD also experience multiple comorbid medical conditions that may require them to utilize their primary care physicians more than their peers without a diagnosis of ASD. Those conditions include obesity, anxiety, gastro-intestinal (GI) difficulties, and sleep disorders, among others (Saqr et al., 2017, p. 2). Therefore, it is essential to understand, how primary care physicians are trained to meet the healthcare needs of this sample population, and to learn how effectively they communicate with their patients.

This chapter will address the prior research about adults with Autism Spectrum Disorder (ASD) and the healthcare services they have received from primary care physicians, particularly the communication accommodations made by physicians during office appointments. This chapter will also synthesize the results of prior studies to better understand what training, if any, is being provided for physicians who work with adults with ASD, and the perceived ability that those physicians have about how to provide care to adults with ASD. The chapter will also summarize the training implemented for primary care physicians and the benefits that come from that training. Finally, the chapter will close with the transition services provided for adolescents with ASD transitioning into adult healthcare, specifically from the perspectives of adolescents and their caregivers.
**Communication Differences of Adults with Autism Spectrum Disorder**

The background section of this study presented a discussion of many of the various signs and symptoms associated with Autism Spectrum Disorder (ASD). In this section, the form, content and use differences adults with ASD demonstrate will be the primary focus of discussions, as well as how those differences impact patients’ ability to receive care from their primary care physicians.

**Verbal Communication**

Adults with ASD present various speech and language differences. A practical way to describe and organize these differences is to refer to the specific components of Bloom and Lahey’s (1978) model of language, which includes form, content, and use. These three components of language are fundamental to understanding speech and language differences (Bloom & Lahey, 1978, p.11). The following paragraphs will provide a description of each of these three components within speech and language.

Form is described in multiple ways, “in terms of the sounds in words, or phonology; the units of meaning that are words or inflections, or morphology, and the ways in which units of meaning are combined with one another, or syntax” (Bloom & Lahey, 1978, p. 15). Some individuals with a diagnosis of ASD may present with an additional language impairment that includes difficulty with aspects of form. Individuals who present with language impairments involving form are considered to be part of ASD phenotype Autism with Language Impairment (ALI) (Tager-Flusberg, 2006, p. 221). Most language differences experienced by these individuals stem from content and especially use.

The content of language, broadly, refers to the “topics” that an individual expresses and how those topics relate to each other in a statement (Bloom & Lahey, 1978, p. 11). These
“topics” include references to an object, action, or a relationship between two objects (Bloom & Lahey, 1978, p.11). Individuals with ASD may have limited receptive and expressive vocabulary (or lexicon), especially with regards to more sophisticated terminology. Due to their potentially limited lexicon this population may experience difficulty understanding certain vocabulary during conversation, and thus have reduced comprehension of conversational discourse (APA, 2013, p. 50; Vicker, 2009, p. 1).

The final component of Bloom and Lahey’s model includes the use of language, or pragmatics. Bloom and Lahey (1978) divided the use of language into two areas, the “goals,” or what an individual wants to achieve with language, and how the context of a situation impacts the language an individual uses (p. 19). This component is where adults with all ASD present the most differences. Adults with ASD may experience difficulty with interpreting non-verbal cues and/or using non-verbal aspects of conversation accurately. As individuals with ASD present difficulty with aspects of verbal communication, they also express difficulty with aspects of non-verbal communication. Those differences will be described in the next section.

Non-Verbal Communication

Non-verbal cues that adults with ASD may have difficulty interpreting include eye rolling, shoulder shrugging or grimaces (APA, 2013, p. 50). With limited interpretation of these cues, adults with ASD may respond to others in an “atypical” manner or may not know how to respond to that individual at all. Individuals with ASD may have limited facial expressions, or, likewise, may not correctly interpret facial expressions provided by others (ASHA, 2017, p. 1). Socially unconventional usage of gestures, such as excessive pointing, grabbing, and nodding also may be present while interacting with an adult with ASD.
Additionally, atypical body proximity, such as being too close to an individual is common. During conversations, and adult with ASD may not use eye contact (ASHA, 2017, p. 1). Both verbal and non-verbal communication can be impacted by an individual with ASD’s perception of sensory stimuli, and their perception of environmental stimuli will be further explored in the following section.

**Sensory Stimuli Perception**

Within language content and use, adults with ASD present symptoms of unusual sensory perception. Crane, Goddard, and Pring (2009) examined the types of sensory perception adults with ASD exhibit. Using the Adult/Adolescent Sensory Profile (AASP), Crane and colleagues (2009) examined four sensory modalities, including, low registration, sensation seeking, sensory sensitivity, and sensation avoiding (p. 219). Low registration refers to when an individual responds slowly to a stimuli, such as not smelling a scent that every other person in the room does, and sensation seeking is when an individual seeks a location with a particular sensory stimuli, such as going to a colorful room if the individual finds bright colors visually pleasing (Crane et al., 2009, p. 219). Sensory sensitivity is when an individual responds negatively to an environmental stimuli (e.g., bright lights, loud sounds), and sensation avoiding is when an individual avoids environments where an unpleasant stimuli is present (Crane et al., 2009, p. 219).

A total of 18 participants complete the AASP. The results revealed that 95% of the participants experienced unusual sensory perception in one of those four modalities, and there was variability within each modality, which suggests that ASD manifests differently in each individual with ASD (Crane et al., 2009, p. 223). These sensory, verbal and non-verbal differences are present while adults with ASD interact with their primary care physicians. The
specific instances where these differences may be present while working with primary care physicians will be discussed next.

**Communication Modifications Needed**

The prior section described the atypical verbal and non-verbal communication characteristics exhibited by adults with ASD, as well as the impact of environmental stimuli on those characteristics. The types of accommodations needed for those characteristics exhibited by adults with ASD will be described in this section, through the synthesis of prior research.

**Verbal Communication Modifications**

Barber (2017) provided insight on the types of accommodations needed for verbally and non-verbally communicating with patients during appointments. These adults with ASD conveyed, broadly, that they needed information communicated to them, that clearly states the meaning, cause, diagnosis, and management of different medical conditions. Often, this communication can be presented in easy to read medical pamphlets. The specific medical conditions these individuals with ASD wanted more information about included the topics of smoking, drug use and alcohol, weight management, exercise, and sexual health (Barber, 2017, p. 424). Aside from lifestyle choices, other areas of interest needing clarification for adults with ASD included mental health (specifically comorbid conditions associated with ASD), along with questions regarding gynecology, heart conditions, aging, and cancer. Information about what to expect during visits with physicians who specialize in these conditions was also considered to be helpful for patients, so that adults with ASD can make preparations (e.g., knowing what examinations will be done, what questions would be asked) before the actual visits (Barber, 2017, p. 424).
Barber (2017) noted that while pamphlets would be helpful, it is important to note that adults with ASD found this type of intervention to feel like they are being “preached at” by their primary care physicians and were uncomfortable with this feeling (p. 424). Easy to read formats are helpful for conveying difficult to understand information, but there needs to be sensitivity so that those documents do not come across condescending or patronizing (Barber, 2017, p. 424). Also, while pamphlets might work for many individuals with ASD, they do not accommodate everyone. Physicians should consider the use of visual simulations through photos and videos, as well as the use of verbal one-on-one or small group conversations incorporating the caregiver (Barber, 2017, p. 424).

Nicolaidis et al. (2015) examined the healthcare satisfaction of adults with ASD. They distributed an online survey to 39 adults with ASD and 16 caregivers. Nicolaidis and colleagues (2015) also conducted follow-up interviews with individuals that included topics such as healthcare, and how being diagnosed with ASD impacted the types of care and communication accommodations received from their healthcare providers. Many of the participants demonstrated concerns similar to the results obtained by Barber in that physicians should not present information to an adult patient with ASD in a condescending manner. One participant stated,

I have used my Alphasmart [portable communication device] when my speech is too slow or difficult to understand for medical appointments. Some of the doctors have been really great, but others have acted really condescending when I have used it, almost immediately assuming I couldn’t be alone, had to have my parents here too…So I try to go without, even when my speech is in poorer shape. (Nicolaidis et al., 2015, p. 828)
The results obtained by Nicolaidis and colleagues (2015) supported that healthcare providers often fail to provide communication modifications for individuals with ASD during office appointments. The participants shared that the physicians with whom they interacted did not provide the option to provide written communication to explain symptoms. Or, if written communication was provided, the physicians would refuse to read it (Nicolaidis et al., 2015, p. 828). One patient explained,

I prefer and find it easier to communicate in text…But with every doctor I speak to, they wave away the note-card and look at me to ask the same question I have just answered and interpret my confusion as my being non-compliant with the medicine. I wish healthcare providers would read the notes I make for them. (Nicolaidis et al., 2015, p. 828)

Nicolaidis, Kripke, and Raymaker (2014) compiled a literature review that provided recommendations on how physicians can modify their verbal discourse to better accommodate their adult patients with ASD. The way adults with ASD communicate varies, and it is important for physicians to understand the aspects of their patients’ spoken and receptive language, reading, writing, usage of Augmentative and Alternative Communication (AAC) devices, and how environmental stimuli can impact their patient’s ability to communicate (Nicolaidis et al., 2014, p. 11).

For example, telephone communication may be difficult for patients, so there may need to be a different mode of communication established for use in between office appointments. When considering the language used while interacting with these individuals, vague and broad statements may cause confusion for individuals who take statements literally. Both Barber and Nicolaidis and colleagues recommended that physicians should be concise with their language,
as well as frame their questions to be answered in a multiple-choice fashion (Barber, 2017, p. 424; Nicolaidis et al., 2014, p. 11). Open ended questions may be difficult for an adult with ASD who may not have the vocabulary to describe how or what they are feeling. Aside from differences with verbal communication, adults with ASD present unusual perceptions of environmental stimuli, which may be present during office appointments, and will be examined in the following section.

**Sensory Stimuli Sensitivity**

Aylott (2010) presented the information collected by Jones and colleagues (2009) about sensory stimulation, more specifically, the sensory profiles of individuals with ASD. The results revealed that one in five individuals with ASD experience a hyper-frequency discrimination ability that individuals without a diagnosis of ASD will not experience (Jones et al., 2009, p. 2855; Williamson, Contreras, Rodriguez, Smith, & Perkins, 2017, p. 231). Hyper-frequency discrimination ability causes an individual to experience environmental sounds at a heightened frequency, therefore potentially causing adults with ASD distress (Aylott, 2010, p. 52; Nicolaidis et al., 2015, p. 827). Any equipment that emits noise may be perceived at a higher frequency for individuals with ASD. Therefore, adjustment of equipment or general environmental noise may be required to ensure the patient is not facing unnecessary distress (Aylott, 2010, p. 52; Nicolaidis et al., 2015, p. 827). In a Nicolaidis and colleagues (2015) study, a patient commented,

> The lights in the office are very bright, and that is exacerbated by the white walls.

> Sometimes the waiting rooms are crowded, and I cannot filter out the background of people talking or shuffling magazines…I am not able to bring up my concerns because it
is all I can manage to figure out what the doctor is saying so I can respond to his questions. (Nicolaidis et al., 2015, p. 827)

Aside from environmental stimuli, Aylott (2010) also presented that individuals with ASD may experience sensitivity to touch from healthcare providers. Touch is often used during examinations, and while counseling patients. For an adult with ASD, touching may not be perceived in the way it was intended. Further, a physicians’ touch may cause the patient to feel as if their senses are “flooded,” and therefore may inhibit the patient’s ability to process verbal discourse (Aylott, 2010, p. 52; Barber, 2017, p. 422). Aside from not engaging in verbal discourse when a patient’s senses are “flooded,” individuals with ASD may present idiosyncratic behaviors, which is their way of reacting to the present stimuli (Goldschmidt, 2016, p. 1141).

Primary care physicians should be aware of the impact of specific clinical environment sounds, and attempt to minimize them, whenever possible. If the sounds cannot be minimized, physicians should relocate the adult with ASD to a place where those environmental sounds are not present, if possible (Barber, 2017, p. 422). Also, some adults with ASD may be sensitive to certain scents, including, aftershave, perfume, and/or deodorants. If a physician is aware of that sensitivity in a patient, the physician should limit the usage of those products (Barber, 2017, p. 422; Carter, Broder-Fingert, Neumyer, Giauque, Kao & Iyasere, 2017, p. 1512).

Additionally, once the physician becomes aware of the sensory modifications needed, it is recommended that if possible, the physician schedules the patient for a quieter time of day in the office. Also, physicians who have the availability should schedule a double appointment, which would provide the patient more time to process information during the appointment in the presence of environmental stimuli. It is important to note that some adult patients with ASD present with hyposensitivity in the specific areas of touch, smell, and sound, and may not be
responsive to those stimuli (Barber, 2017, p. 422; Carter et al., 2017, p. 1512). Aside from modifying environmental stimuli during appointments, a patient’s caregiver can provide further insight for physicians on how to modify their interactions with adult patients with ASD. Effective ways to integrate caregivers for adults with ASD will be described in the following section.

**Integrating Caregivers**

Aylott (2010) provided insight on the possible advantages of consistently integrating a caregiver during office appointments. Adults with ASD are most comfortable in their home environment and most anxious when entering new and unfamiliar environments (Aylott, 2010, p. 48). Presenting the option to bring in a caregiver from a home environment may limit the stress a patient has when entering an office appointment (Aylott, 2010, p. 48; Nicolaidis et al., 2014, p. 15). Also, adults with ASD may communicate with an idiosyncratic vocabulary and use words or phrases that, without context, may not be understandable to the physician. A caregiver who is consistently with the patient can explain what the patient is attempting to communicate (Aylott, 2010, p. 48).

Aylott (2010) also explained how important a strong relationship with the caregiver of an adult patient with ASD is for learning how the patient communicates. Families or caregivers provide support for a patient who is feeling overwhelmed because of a new environment (Aylott, 2010, p. 48; Nicolaidis et al., 2014, p. 15). For example, a caregiver may be able to explain how a patient is experiencing a certain symptom while the patient is in distress and thus unable to communicate themselves. The caregiver can provide the physician with an explanation about how to effectively communicate with that patient during difficult situations (Aylott, 2010, p.48; Nicolaidis et al., 2014, p. 15).
While these accommodations are being considered, it is important to not overgeneralize that the same needs apply to every adult patient with ASD, or to present the information in a condescending manner. Not all adult patients with ASD are the same or seek the same communication accommodations just described in these three sections. In the next section, the training primary care physicians have received to provide these accommodations will be examined.

**Primary Care Physician Training**

Adults with ASD experience with a variety of medical conditions that cause them to utilize their primary care physicians more than their peers without ASD (Saqr et al., 2017, p. 2). It is therefore critically important that primary care physicians are trained to provide the necessary communication accommodations during appointments, to ensure adults with ASD are receiving comprehensive and appropriate care. Within this section, the training primary care physicians have received will be discussed, as well as recommended training for clinicians who may not have received prior training.

**Prior Training Received for Intellectual Disabilities**

When analyzing the quality of care individuals with ASD receive from their primary care physicians, it is important to note that Intellectual Disabilities can co-occur with ASD (Srivastata & Schwartz, 2014, p. 1). Approximately 75% of individuals with ASD also present with an intellectual disability of some kind, that requires additional social and educational support (Mefford, Bathshaw, & Hoffman, 2012, p. 1; Srivistata & Schwartz, 2014, p.1). It is necessary to not only analyze the care individuals with ASD receive, but the care individuals with Intellectual Disabilities receive from their primary care physicians, and the training physicians receive to work with adults with Intellectual Disability. Trollor et al. (2016) examined the specific medical
school curriculum in 12 medical schools in Australia. The dean of each school completed both a questionnaire about the general medical school course structure, and an online questionnaire about how students are informed about individuals with intellectual disabilities (Trollor et al., 2016, p. 1).

The results revealed that medical schools only provided a minimal amount of mandatory training for their students regarding individuals with intellectual disabilities (Trollor et al., 2016, p. 6). The participating programs seldom trained their students on topics that are important for the wellbeing of individuals with intellectual disabilities, including, areas in specialist medicine (cardiovascular, neuroscience, genetics) and sexual health. Furthermore, a majority of participating programs offered fewer than six hours of training of the more frequently emphasized areas of pediatrics, general practice, legal issues, preventative health, along with others (Trollor et al., 2016, p. 6). The results demonstrated that medical schools need to provide consistent training for future physicians to effectively interact with their adult patients with intellectual disabilities. By doing so, future physicians will be better suited to provide higher quality care to improve the health status of individuals with intellectual disabilities (Trollor et al., 2016, p.7; Zerbo, Massolo, Qian, & Cohen, 2015, p. 4008).

Researchers have assessed the implementation and success of training future physicians through various standardized measures that involve the direct observation of future physicians’ skills while interacting with a standardized patient (SP). Brown, Graham, Richeson, Wu, and McDermott (2009) further investigated evaluations students received in medical school while working with a neurotypical standardized patient, as opposed to a patient with an intellectual disability. The medical students also were evaluated on their interactions with SPs who had spinal cord injuries.
Family medicine students at the University of South Carolina were scored while conducting an Objective Structured Clinical Exam (OSCE) on a SP exhibiting symptoms of a common disease, that was not a comorbid symptom of an intellectual disability (Brown et al., 2009, p. 1767). The two scenarios presented to the participants were diabetes and hypertension. Out of the 126 participants, 53 participants interacted with the SP who presented an intellectual disability, and 73 interacted with a neurotypical SP. The results revealed that the participants who interacted with the SPs that presented with an intellectual disability scored a significantly lower score during obtaining the patient’s history, physical examination, and while suggesting ordering laboratory tests (Brown et al., 2009, p. 1769).

Brown and colleagues (2009) found that medical students do indeed score lower while conducting an OSCE on a SP without an intellectual disability in comparison to one without. They suggested that the participants may have felt they would not have much influence on the lifestyle of a patient with an intellectual disability, or they did not have enough time to fully administer the exams due to the communication and physical exam modifications that needed to be made (Brown et al., 2009, p. 1771; Trollor et al., 2016, p.7; Zerbo et al., 2015, p. 4008). The specific training current physicians receive and knowledge they have about ASD will be addressed in the next section.

**Prior Training Received -Adults with Autism Spectrum Disorder (ASD)**

Bruder, Kerins, Mazzarella, Sims, and Stein (2012) examined 1,580 primary care physicians’ knowledge about the care and communication modifications adults with Autism Spectrum Disorder (ASD) requested during appointments. A small number of the physicians who responded to the survey had prior experience working with adults with ASD, though, most respondents worked very little or not at all with that population. Moreover, most respondents,
whether working with the population or not, reported having little to no prior training in the care of adults with ASD (Bruder et al., 2012, p. 2502; Zerbo et al., 2015, p. 4006).

Across the three areas of training evaluated (Professional Education, Residency, and Post Residency), the participants who reported receiving training in one of those areas did not exceed more than 23%. The results also presented that 55% of physicians who consistently worked with adults with ASD did not receive any prior training to do so, and 72% of primary care physicians who seldom work with adults with ASD never received training to work with that population (Bruder et al., 2012, p. 2501). Thus, this demonstrates that there is a need for more training in medical school, particularly in residency, which happens before these professionals begin practicing on their own. A promising result from this study was that 64% of physicians working with adults with ASD indicated that they would be willing to partake in training to improve the care they provide for these individuals (Bruder et al., 2012, p. 2501).

Zerbo and colleagues (2015) not only analyzed the accommodations physicians working with adults with ASD made, but the prior training these clinicians received to implement that training effectively. Physicians completed an online survey that asked about various aspects of their level of comfort while working with adults with ASD. When acknowledging and assessing the various communication differences, over 90% of the respondents reported that they would have further evaluated a patient for the possibility of ASD if they showed limited eye contact (Zerbo et al., 2015, p. 4006).

Physicians, specifically 84.15% of the sample, would have also referred adult patients to be evaluated for ASD if they showed an atypical communication style. Practically significant results were also noted for referring patients who had a monologue style of communication, or who were unusually direct (Zerbo et al., 2015, p. 4006). Thus, physicians have the understanding
of the various characteristics adults with ASD exhibit, however, the modifications for those characteristics are not being made during office appointments (Zerbo et al., 2015, p. 4006). The communication modifications and accommodations that primary care physicians provide for these patients may be impacted by physicians’ perceptions of their (the physicians’) abilities, which will be described in the section that follows.

**Physicians’ Perceptions of Ability**

Zerbo and colleagues’ (2015) assessed other areas of treatment, including the need for training and resources, and they gathered this information through interviews with various physicians. Out of the entire sample, only one physician in family and internal medicine reported having prior training to work with adults with ASD. One participant noted that they have been practicing family medicine for over 25 years, and stated, “I think that…we need education. I mean, autism was like *Rain Man* [reference to the 1988 film] when I was in medical school. There wasn’t anything besides that: it was *Rain Man* or nothing” (Zerbo et al., 2015, p. 4008).

Another physician, who had prior knowledge about the diagnosis of ASD commented

> Boy…I don’t really recall…I mean certainly we knew about autism, and we may have learned about it in some of our classes, but from a training standpoint in managing patients or understanding it, I think very, very little. I don’t recall any directed training in autism: you know, outside of my pathophysiology. (Zerbo et al., 2015, p. 4008)

Multiple physicians commented on their difficulties communicating with adults with ASD, especially those who have limited verbal abilities (p. 4008). A family practitioner who was currently working with two individuals with ASD stated that:

> I feel very uncomfortable, very…One of them, recently, fell and broke his hand and he could tell me that it hurt, but he must have had a very high pain threshold because I was
looking at his hand and it was just god awful…and he was just sitting there. It is more like doing medicine for an infant, because he can’t tell me the severity of his feelings. (Zerbo et al., 2015, p. 4008)

Other physicians who responded to the survey noted that the communication differences of adults with ASD make it challenging to build rapport with their patients, and that rapport is crucial to make adults with ASD feel more at ease during appointments. The physicians felt that they do not have the ability to bond with the patient due to their patients limited verbal communication skills, and the physicians’ lack of training to best address these communication barriers presented (Zerbo et al., 2015, p. 4008). With many primary care physicians expressing frustration while working with their adult patients with ASD, further training would appear to be beneficial to increase their level of comfort while working with these patients. In the next section, the training physicians do receive in medical school will be addressed.

**Benefits of Training for Current and Future Primary Care Physicians**

Training is starting to be implemented in medical schools today, as not many experienced primary care physicians have had training in medical school to effectively accommodate for the communication differences adults with ASD present. Havercamp and colleagues (2016) supported pairing training, along with the medical doctors’ present skills as being beneficial. Third-year, medical-school students at Ohio State University attended training that covered the diagnostic aspects of ASD and attended a panel of professionals who work with individuals with ASD, current adults with ASD and their family members.

After the training, Havercamp and colleagues obtained quantitative and qualitative data about how beneficial the training was for these medical students. Overall, students reported that they were able to make positive changes in their interactions with adults with ASD during their
interactions in residency (Havercamp et al., 2016, p. 208). Havercamp and colleagues’ (2016) also assessed factors that allowed these participants to make positive changes to their interactions with adults with ASD. Those factors included level of understanding of the difficulties adults with ASD face, their communication and their ability to provide better care. Significant results ($p = .008$) were also reported in more overall competency when communicating with adults with ASD (Havercamp et al., 2016, p. 210). Perhaps more practicing physicians or physicians in training would experience similar levels of comfort if the same training to effectively treat adults with ASD was provided more often. Aside from preparing future physicians to effectively modify their practice to fit the needs of adults with ASD, future physicians also need training to provide appropriate transition resources for their adolescent patients with ASD who are transitioning into adult healthcare. Those transition services will be examined in the next section.

**Transition Services for Adolescents into Adulthood**

An important component of ensuring that adult individuals with ASD receive appropriate care in adulthood is to examine the health care transition process, which is the time period that prepares adolescents to transition from their pediatric physicians to their adult physicians (Reiss, Gibson & Walker, 2005, p. 112). Ensuring that adolescents have the skills to independently navigate appointments with their future adult physicians is crucial, as the comorbid conditions associated with ASD may require receiving care from their physicians (Cheak-Zamora & Teti, 2015, p. 993; Saqr et al., 2017, p. 2). Within this section, the concerns caregivers have for their adolescent children obtaining care will be described, through the synthesis of prior studies. Recommendations for physicians to provide the appropriate resources and support for their adolescent patients making the transition will also be addressed in this section.
Caregiver Concerns

A majority of the literature about the transition services provided comes from the insight of the caregivers of adolescents with ASD. A common theme within the literature regarding the concerns caregivers have is low confidence for their adolescent’s independence. Caregivers want their child to be independent, but they are not certain of what that independence looks like (Cheak-Zamora & Teti, 2015, p. 995; Cheak-Zamora et al., 2017, p. 1034). Caregivers understand the need of their children to be independent, especially since many have stated that they will not be around forever to ensure their child is receiving appropriate medical support (Check-Zamora et al., 2017, p. 1034). Furthermore, according to the Health Insurance Portability and Accountability Act (HIPAA), caregivers lose their right to communicate with their child’s healthcare provider once their child reaches the age of 18, which can limit the caregiver’s ability to guide their child to being more independent (Cheak-Zamora & Teti, 2015, p. 996). In particular, the areas of independence of concern for caregivers include identifying medical needs, making appointments, attending the appointment, and both the understanding and following through with medical instructions (Cheak-Zamora et al., 2015, p. 1032).

Caregivers often struggle to determine their child’s ability to communicate their needs in those four areas, as they feel their child’s answers to questions in those areas are “out there,” and their (caregiver) role is to interpret their child’s answers (Cheak-Zamora et al., 2015, p. 1034). Also, caregivers fear their child will not be able to understand what medical treatment the physician is asking them to complete or agree to a treatment that is not what they, the patient, intended (Cheak-Zamora & Teti, 2015, p. 996). Aside from their child’s ability to communicate their medical needs to their primary care physician, caregivers also expressed concerns with primary care physicians’ knowledge of ASD in general, especially how the disorder manifests
differently in individuals. Furthermore, physicians’ perceived lack of knowledge about ASD leaves caregivers feeling unsupported and with the responsibility of educating their child’s current and future physicians about the medical conditions and communication differences their child demonstrates (Cheak-Zamora & Teti, 2015, p. 996). The concerns adolescents have about transitioning to adult healthcare will be described in the following section.

Adolescent Concerns

Like caregivers, adolescents also have their own concerns about transitioning into adult healthcare. For many adolescents with ASD, their caregivers have handled most of their interactions with their current physicians, whether that be setting up the appointment or explaining medical symptoms to the physician (Cheak-Zamora & Teti, 2015, p. 997). However, just like caregivers, adolescents understand the importance of gaining independence as they transition into becoming an adult. Generally, adolescents with ASD believe that becoming independent from their caregiver will provide them with better healthcare (Cheak-Zamroa et al., 2017, p. 1034; Cheak-Zamora & Teti, 2015, p. 997).

However, receiving that independence can be difficult for adolescents with ASD. Some adolescents are not sure of their physicians’ role in their overall care. Many are unaware of the differences among the various healthcare professions, such as what specific physicians’ specialties are and the differences among the various medical providers (physicians vs. nurses etc.) (Cheak-Zamora & Teti, 2015, p. 996). When adolescents are asked by researchers about what their physicians discuss with them or what treatments they are provided by their physicians, many respond with that they are unsure of or confused by the information they receive (Cheak-Zamora & Teti, 2015, p. 996). They also comment that that their physicians are “too busy” to provide them with the resources they need to transition into adult care, and when providing
support, the discussions only are focused on medication management (Cheak-Zamora & Teti, 2015, p. 997).

Another barrier for adolescents with ASD transitioning from pediatric to adult care is how their current physicians interact with them during appointments. For many, their current physicians only communicate with their caregiver during appointments. That indirectly presents concerns that physicians feel that their adolescent patients are unable to take responsibility for their own care (Cheak-Zamora & Teti, 2015, p. 997; Cheak-Zamora et al., 2017, p. 1033). Some adolescents are not bothered by their caregiver communicating on their behalf, however, others feel discouraged. In a Cheak-Zamora and colleagues (2017) study, one participant commented,

They probably think, oh, he’s just autistic. He can’t answer these questions because he’ll get confused. Like, yeah, kind of, if you ask the wrong question. If you don’t ask it in a simple way…I put my headphones in, like, you know, I’m done with this cr*p. (Cheak-Zamora et al., 2017, p. 1034)

The participants who indicated that they are not offended when their caregiver communicates on their behalf during appointments also indicated that they “would feel more like an adult” if their physicians interacted with them more, and they would feel more comfortable transition into handling their own care if they had the opportunity to communicate with their physicians (Cheak-Zamora et al., 2017, p. 1034). Recommendations for how primary care physicians can prepare their adolescent patients and their caregivers for the transition into adult healthcare will be described in the next section.

**Recommendations for Physicians**

In the eyes of caregivers and adolescents, adult and pediatric healthcare are different in terms of how family centered the care provided is, the pace and duration of visits, the knowledge
physicians have about conditions, and the communication differences across those two sectors of care (Reiss et al., 2005, p. 119). However, there are strategies physicians can integrate into appointments to reduce the discrepancies between pediatric and adult care to better prepare their adolescent patients with ASD to obtain necessary care (Devine, Monaghan, & Schwartz, 2017, p. 907; p. 268; Vogan, Lake, Tint, Weiss, & Lunksy, 2017, p. 268; Williamson et al., 2017, p. 231)

The transfer of medical records is an important part of the process of switching from one physician to the next. Given that the caregivers of adolescents manage the correspondence between their child and the physician, having electronic versions of medical records with detailed descriptions about each appointment aides in the transition process. Specifically, having electronic records of the patient’s medical history and progress with treatments and medications takes the pressure off the adolescent communicating that information to their new physician (Kuhlthau, Warfield, Hurson, Delahaye, & Crossman, 2015, p. 265).

Also, is it recommended that physicians of adolescents with ASD compile a list of resource links, including information about physicians who will accept patients with ASD, support groups or locations for transition centers where support groups typically meet (Kuhlthau et al., 2015, p. 265; Williamson et al., 2017, p. 229). Providing written materials for adolescent patients and their caregivers, such as a transition checklist, is also helpful. These checklists provide an opportunity for implementing collaborative strategies between the adolescent and their caregiver, rather than all the responsibilities of communicating with the physician being placed on the caregiver (Kuhlthau et al., 2015, p. 265).

Training adult physicians and medical school students may also helpful in ensuring a smooth transition from pediatric to adult care. Educating providers and future providers on strategies for working with individuals with ASD and other intellectual disabilities and their
needs in general provides physicians a better understanding of what transition services need to take place (Cheak-Zamora, Farmer, Mayfield & Clark, 2014, p. 347; Kuhlthau et al., 2015, p. 266). Kuhlthau and colleagues (2015) presented that a participant commented on the importance of training medical school students early in their career,

I think even presenting that [the difficulties individuals with ASD present] to people and giving them that exposure, more so that it’s not just developmental pediatricians that are coming through and doing practicums and rounds, you know, on a longer basis, but it’s more general to everyone’s training that this is what you would do and exposing them to what adult care means for autism. (Kuhlthau et al., 2015, p. 266)

Specifically, providing training on identifying differences between pediatric and adult care, the barriers those differences may present, and finding ways to promote interest in caring for patients with ASD is helpful in providing appropriate HCT services (Kuhlthau et al., 2015, p. 266). Providing workshops for patients and their caregivers is another strategy that can be used to promote a smoother transition into adult care (Cheak-Zamora et al., 2014, p. 347; Kuhlthau et al., 2015, p. 266; Vogan et al., 2017, p. 268). That training includes information sessions to help families understand the resources available to them, as well as information about how to utilize their physician as a resource to have a successful transition into adult care (Kuhlthau et al., 2015, p. 267).

**Conclusion**

This chapter presented an extensive review of the literature about the communication differences and sensory sensitivities individuals with Autism Spectrum Disorder (ASD) demonstrate and how those characteristics and sensitivities may impact office appointments. Specific topics presented in this chapter included, information about communication
accommodations those individuals need, and the level of training primary care physicians have in order address these communication differences. Adults with ASD may demonstrate significant communication barriers while working with primary care physicians which can make it challenging for an untrained primary care physician to provide appropriate care. Results of various studied showed that primary care physicians, generally, have limited training when it comes to working with adults with ASD, especially those individuals who present with significant communication differences.

Therefore, physicians’ perceived ability to effectively work with that population was reported to be low. However, there is reportedly training being implemented in isolated medical schools, which has been noted to improve students in residency’s ability to modify and accommodate for the communication differences for adults with ASD. Finally, literature regarding the transition services for preparing adolescents for adult healthcare was consulted, as well as how physicians can best prepare adolescents with ASD to receive necessary care and communication accommodations in adulthood. In the next chapter, the methods of this study will be presented and discussed in the next chapter.
CHAPTER III: METHOD

The purpose of this study was two-fold. First, this study investigated the awareness and training primary care physicians have about the communication differences and sensory sensitivities adults with ASD may present. Second, this study examined how primary care physicians accommodate for the communication differences and sensory sensitivities adults with ASD may present, as well as how they integrate caregivers during office appointments. This chapter will present the methods used to conduct this study and will describe the justification of method, participants, instrument distributed in this study, as well as the research procedures used in this study.

Justification of Method

Survey research was the most appropriate method of data collection for this study. Survey research is defined as a “social scientific method for gathering quantifiable information about a specific group of people by asking the group members questions about those individuals’ attitudes, beliefs, behaviors, knowledge, and perceptions” (Wrench, Thomas-Maddox, Richmond, & McCroskey, 2015, p. 217). Survey research provides us with the opportunity to inquire about a populations’ beliefs and/or understanding about a subject or concept and yields data that can be analyzed in a quantitative manner. The participants of this study used “self-administration” to complete the survey instrument. Wrench and colleagues (2015) define self-administration as when “an individual receives the survey and then fills out the survey without the help of an interviewer” (p. 229).

Self-administering a survey was beneficial, because it was an inexpensive method that allowed the researcher to reach a large sample of participants in a short period of time (Wrench et al., 2015, p. 230). Specifically, the survey link was distributed via email. There are multiple
benefits from distributing a survey over the internet. One specific benefit identified by Wrench and colleagues (2015) is that the internet allows researchers to access a population who may be difficult to access due to location or other limiting factors (p. 229).

At the conclusion of the survey, participants had an option to indicate if they would like to participate in a follow-up phone interview. Telephone interviews provide the researcher with an opportunity to ask to follow-up questions about the survey topic. Similarly, telephone interviews provide participants with the opportunity to provide further insight about survey questions (Wrench et al., 2015, p. 228).

Two methods of non-probability sampling were used to recruit the participants for this study. Non-probability sampling is “selecting members of the accessible population in a nonrandom manner” (Wrench et al., 2015, p. 311). The first method of non-probability sampling used was purposive sampling. Purposive sampling involves selecting participants who fulfill or meet a specific purpose or requirement. Those requirements are usually based on certain characteristics the researcher seeks to investigate (Wrench et al., 2015, p. 318). The second type of non-probability sampling used in this study was snowball sampling. Snowball sampling is asking participants to first participate in your study, then forward the request to participate in your study to others who are a part of the same or a similar population (Wrench et al., 2015, p. 322). Snowball sampling provides researchers with access to a population who they may not be able to easily reach (Wrench et al., 2015, p. 322).

Participants

A total of 19 primary care physicians completed the survey. Two participants indicated interest in participating in a follow-up interview but did not respond to the researcher when asked to review the consent form and set up a time to complete the phone interview. Primary
care is divided into three specializations, including: Family Medicine, Internal Medicine, and Pediatrics and the various specializations reported by participants are graphed in Figure 1. Demographic information also included the year that participants completed residency, which ranged from 1990-2017, with seven (36%) participants choosing to not respond to the question. These data are presented in Figure 2. Participants also reported the geographical area in which they completed residency, all regions (Western, Southern, Midwest, and Eastern) besides “Other” (AK, HI) were represented in the sample. These data are graphed in Figure 3.

![Diagram](https://via.placeholder.com/150)

**Figure 1.** Participants’ responses regarding their specialization within Primary Care (n = 18).

![Diagram](https://via.placeholder.com/150)

**Figure 2.** Physicians’ responses regarding what decade they completed residency (n = 12). Seven (36%) of participants chose not to respond to this question.
Figure 3. Distribution of regions where participants completed residency (n = 19). The regions were defined as the following: Western (WA, OR, CA, NV, ID, UT, AZ, CO, NM, WY, MT), Midwest (NE, SD, ND, MN, IA, MO, WI, IL, IN, MI, OH), Southern (TX, OK, AR, LA), Eastern (ME, NH, VT, MA, RI, CT, NY, PA, NJ, DE, MD, VA, DC), and Other (AK, HI). A total of one (9%) of participants chose not to respond to this question.
**Instrument**

The survey instrument was created using an online survey generator, Qualtrics Software. The survey included 61 questions, including multiple choice, Likert-scale, choose all that apply, and open-ended items. Survey items pertaining to physicians’ awareness of the communication differences (e.g., *Adults with ASD may present with atypical social skills*) and sensory sensitivities (e.g., *Adults with ASD may be sensitive to scents present in my office*) included answer options “Yes,” “No,” or “Unsure”. Items pertaining to the communication accommodations (e.g., *I provide my patients alternative ways to contact my office besides the telephone*) and sensory accommodations (e.g., *I limit the use of scented products*) provided to adults with ASD during office appointments were asked using a five-point Likert-scale, with 0= “Never” and 100= “Always.” The statements regarding integration of caregivers (e.g., *Caregivers are necessary to communicate with a patient with ASD*) and training received to work with adults with ASD (e.g., *I have enough training to work with adult patients with ASD*) during office appointments were presented using a five-point Likert-scale, with -1= “Strongly Disagree” and = +2 =“Always.” The full survey instrument is included in Appendix A. The materials created to conduct the follow-up interviews are included in Appendix B.

**Procedures**

This research protocol received Human Subjects Research Committee approval on November 29th, 2018. The researcher distributed a recruitment message by email to a list of College of Wooster alumni who are currently employed as primary care physicians. All recruitment materials can be found in Appendix C and Appendix D. Due to limited response, the researcher requested Human Subjects Research Committee approval to expand recruitment procedures to primary care physicians outside the Wooster alumni database, social media sites,
and personal contacts. On December 5th, 2018, the researcher received approval to expand recruitment procedures. The researcher continued to distribute the recruitment message by email to primary care offices, personal contacts, hospitals, and on social media sites geared towards primary care physicians. The researcher closed the survey on January 28th, 2019. The results from the 19 participants’ responses to this survey instrument will be presented and discussed in the next chapter.
CHAPTER IV: RESULTS AND DISCUSSION

The previous chapter presented the purpose of this study, which was two-fold. First, this study investigated the awareness and training primary care physicians have about the communication differences and sensory sensitivities adults with ASD may present. Second, this study examined how primary care physicians accommodate for the communication differences and sensory sensitivities adults with ASD may present, as well as how they integrate caregivers during office appointments. A total of 19 participants completed a 61-question survey with items pertaining to these various topics outlined in this purpose statement. This chapter will present the results of these survey items. Specifically, this chapter will present the results and discussion of the experiences physicians have providing support to adults with Autism Spectrum Disorder (ASD), and a discussion of these results and how they connect to the current literature will follow.

Results

This section will present the results of this study. A total of 19 participants began the survey. However, if they responded “None” to “Within the past 12 months, approximately how many adult patients with ASD have you had experience with?” the participant was not able to answer any more survey items and was directed to the end of the survey instrument. Two physicians indicated that they have had no prior experience with adults with ASD, so unless otherwise indicated, the total number of participants for these results is 17.

Primary Care Physician Training

Physicians learn about adults with ASD as they have experience working with this population, therefore, participants were asked to report how many adult patients with ASD they currently provide care for, or, have provided care for in the past. Participants had the option to
select “None,” (as indicated earlier, this answer choice took respondents to the end of the survey), “1-10,” “11-20,” and “More than 20.” The responses to this question are graphed in Figure 4.

![Figure 4](image)

**Figure 4.** Number of Adult Patients with ASD Physicians Have/Are Currently Providing Care for during Office Appointments (*n* = 17)

Primary care physicians responded to six questions regarding their training and level of experience working with adults with ASD. First, physicians indicated if they had the option to subspecialize in intellectual disabilities and/or Autism Spectrum Disorder. Out of the 18 participants who responded to this question, a total of three (15.8%) of participants reported that they had the option to subspecialize in intellectual disabilities and/or ASD in medical school, and 15 (84.2%) of participants responded that they did not have that option. None of the participants who indicated that they had the option to subspecialize in intellectual disabilities and/or ASD chose to do so.
Next, physicians reported how they learned about working with adults with ASD while in medical school. Participants could choose from among the following options, including “Embedded in curriculum,” “Attended a supplemental lecture,” “Read journal article(s),” “Clinical rotation(s),” “Experience with patients,” “Conducted research,” “None of these,” and “Other (please specify).” The option physicians selected the most was “Experience with Patients”, as 13 respondents selected this response. The number of physicians who selected each option are graphed in Figure 5.

![Bar chart showing the number of participants who selected each type of training. The most common was "Experience with Patients" with 13 respondents, followed by "Embedded in Curriculum" with 8, "Clinical Rotation(s)" with 7, "Read Journal Article(s)" with 3, and "Attended a Supplemental Lecture" with 1.]

*Figure 5. Participants’ responses regarding how they learned about working with adult patients with ASD in medical school and/or residency (n=19). Participants had the option to choose all options that applied to them and all 19 participants chose at least one option. No participants chose “None of These” or “Other.”*

Physicians reported whether or not they engaged in any training beyond medical school and/or residency regarding providing care to adults with ASD. The four (21.1%) participants who chose “Yes” were directed to another question, which prompted them to select training experiences that applied to them. Those experiences included “Attended training session(s),”
“Experience with patient(s),” “Conducted research,” “Read journal article(s),” and “Other (please specify).” All four participants reported that they had both experience with patients and read journal articles. These data are graphed in Figure 6.

![Bar chart showing training experiences](chart.png)

**Figure 6.** Physicians’ Training Experiences Beyond Medical School and/or Residency ($n = 4$).

**Perceptions of Training**

Four survey items addressed physicians’ perceptions of their training to provide care to adults with ASD. Participants indicated how much they agreed with the four statements presented using a five-point Likert scale, where 2 represented “Strongly Agree,” 1 represented “Somewhat Agree,” 0 represented “Neither Agree or Disagree,” -1 represented “Somewhat Disagree,” and -2 represented “Strongly Disagree.” Overall, physicians indicated that they Somewhat agree to Strongly Agree that training is important in medical school and beyond. Physicians also responded that they Somewhat Disagree that they have enough training to effectively work with patients with a diagnosis of ASD. Table 1 presents descriptive statistics regarding participants’ perceived preparedness to work with adults with ASD.
Table 1

*Descriptive Statistics of Physicians’ Perceptions of Training*

<table>
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<tr>
<th>Survey Item</th>
<th>M</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Training and coursework regarding working with patients with ASD is</td>
<td>1.53</td>
<td>0.51</td>
<td>1 to 2</td>
</tr>
<tr>
<td>important for primary care physicians</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Training and coursework regarding working with patients with ASD is</td>
<td>1.18</td>
<td>1.13</td>
<td>-2 to 2</td>
</tr>
<tr>
<td>necessary for primary care physicians.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have enough training for working with adults with ASD.</td>
<td>-0.35</td>
<td>1.53</td>
<td>-2 to 2</td>
</tr>
<tr>
<td>My current practice provides training opportunities to work with</td>
<td>-0.18</td>
<td>1.43</td>
<td>-2 to 2</td>
</tr>
<tr>
<td>individuals with ASD.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note.* Items were coded that *Strongly Agree* corresponded with 2, *Somewhat Agree* corresponded with 1, *Neither agree or Disagree* corresponded with 0, *Somewhat Disagree* corresponded with -1, and *Strongly Disagree* corresponded with -2.

**Physicians’ Awareness of Communication Differences and Sensory Sensitivities**

The survey included 13 communication differences and eight sensory sensitivities adults with ASD may demonstrate during office appointments. If physicians chose “Yes” as a response, they received credit for that response. If physicians chose “No” or “Unsure” as a response, they received no credit for that response. Given that all of these items, except one, were possible communication differences or sensory sensitivities, an accuracy score was calculated. The researcher then computed an overall percentage of accuracy using the scores from all 17 participants. The lowest score received for communication differences was 6/13 (46%) and the highest was 13/13 (100%). The lowest score received for sensory sensitivities was 5/8 (63%) and the highest score was 8/8 (100%). A side by side comparison of the participants’ overall accuracy can be viewed in Figure 7.
Figure 7. Physicians’ percentage of correct responses for awareness questions about communication differences and sensory sensitivities (n=17).

Physicians’ Awareness of Pragmatic and Content Differences

Participants responded to 15 questions to indicate their awareness of the communication differences adults with ASD may present during office appointments. Within communication differences, participants answered two types of questions: content difference questions and pragmatic difference questions.

Participants responded to statements about communication differences an adult patient with ASD may present during an office appointment using “Yes,” “No,” and “Unsure.” Given that all of the statements reflected actual communication differences, physicians with awareness of these differences would have responded “Yes” to all of the statements. Respondents with a lower level of awareness of the communication differences adults with ASD may present would have generally responded “No” or “Unsure” to these statements. Generally, physicians demonstrated a strong awareness of the content and pragmatic differences adults with ASD may
demonstrate during office appointments. The responses to statements about Content Differences and Pragmatic Differences are graphed in Figures 8 and 9, respectively.

**Figure 8.** Physicians’ Awareness of Content Differences. \((n=17)\)

**Figure 9.** Physicians’ Awareness of Pragmatic Differences. \((n=17)\)

**Accommodating for Communication Differences**

A total of eight items on the survey addressed how physicians accommodate for the various communication differences that adults with ASD may present. Physicians answered
using a five-point Likert scale, where 100 represented “Always,” 75 represented “Most of the Time,” 50 represented “About Half of the Time,” 25 represented “Sometimes,” and 0 represented “Never.” The maximum value fell between Most of the Time and About Half of the Time. Table 2 presents the data for all of these survey items.

Table 2

<table>
<thead>
<tr>
<th>Survey Item</th>
<th>M</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>I write down instructions or provide written documents with important medical instructions.</td>
<td>69.12</td>
<td>22.58</td>
<td>25-100</td>
</tr>
<tr>
<td>I attempt to use the most effective communication mode for my adult patients with ASD, even if it requires me to alter my usual interview style.</td>
<td>67.65</td>
<td>26.17</td>
<td>25-100</td>
</tr>
<tr>
<td>When first interacting with a patient with ASD, I obtain information about their preferred mode of communication.</td>
<td>54.41</td>
<td>34.50</td>
<td>0-100</td>
</tr>
<tr>
<td>I provide alternate ways for patients to contact the office besides by telephone.</td>
<td>51.47</td>
<td>39.99</td>
<td>0-100</td>
</tr>
<tr>
<td>I encourage my adult patients with ASD to prepare notes in advance about what they want to discuss with me.</td>
<td>36.76</td>
<td>26.69</td>
<td>0-100</td>
</tr>
<tr>
<td>I direct my adult patients with ASD to detailed information or resources about health conditions for review outside of the appointment.</td>
<td>33.82</td>
<td>23.29</td>
<td>0-75</td>
</tr>
<tr>
<td>I provide lists of symptoms for my adult patients with ASD to choose from during office appointments.</td>
<td>27.94</td>
<td>26.34</td>
<td>0-75</td>
</tr>
<tr>
<td>I provide adult patients with ASD worksheets or diaries to help them keep track of their symptoms.</td>
<td>13.24</td>
<td>15.61</td>
<td>0-50</td>
</tr>
</tbody>
</table>

*Note.* Items were coded that Always corresponded with 100, Most of the Time corresponded with 75, About Half of the Time corresponded with 50, Sometimes corresponded with 25, and Never corresponded with 0.
Ability to Provide Communication Accommodations

One survey item addressed how physicians accommodate for the various communication differences that adults with ASD may present, specifically, physicians’ ability to spend more time with a patient who may require more communication accommodations. Physicians answered this question using a five-point Likert scale, where 100 represented “Always,” 75 represented “Most of the Time,” 50 represented “About Half of the Time,” 25 represented “Sometimes,” and 0 represented “Never.” On average, physicians reported that they can spend more time with a patient sometimes to about half of the time during office appointments ($M=35.29$, $SD=26.60$, Range= 0-100).

Sensory Sensitivity Awareness

Physicians also indicated their awareness of the sensory sensitivities adults with ASD may present during office appointments. Given that all but one of the statements reflected actual sensory sensitivities an adult patient with ASD may present during an office appointment, physicians with awareness of these differences would have responded “Yes” to all of the statements. Physicians with a lower level of awareness of the sensory sensitivities adults with ASD may present would have generally responded “No” or “Unsure” to these statements. The exception was the statement “All adults with ASD respond the same to environmental stimuli,” for which the correct answer is “No.” Generally, physicians demonstrated a strong awareness of the sensory sensitivities adults with ASD may demonstrate during office appointments. The specific responses physicians provided are graphed in Figure 10.
Figure 10. Physicians’ awareness of sensory sensitivities adults with ASD may present during office appointments (n= 17). The target response to adults with ASD “Are impacted the same by environmental stimuli” was “No.” The target response to all other statements was “Yes.”

Accommodating for Sensory Sensitivities

A total of seven items on the survey addressed how physicians accommodate for the various sensory sensitivities that adults with ASD may present. Physicians responded to all seven survey items using a five-point Likert scale, where 100 represented “Always,” 75 represented “Most of the Time,” 50 represented “About Half of the Time,” 25 represented “Sometimes,” and 0 represented “Never.” The maximum value fell between Most of the Time and Always. Responses to these statements are presented in Table 3.
Table 3

*Descriptive Statistics for Physicians Accommodating for Sensory Sensitivities During Office Appointments*

<table>
<thead>
<tr>
<th>Survey Item</th>
<th>M</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>I avoid unnecessarily touching an adult patient with ASD if need be (e.g., during counseling or general conversation).</td>
<td>85.29</td>
<td>29.39</td>
<td>0-100</td>
</tr>
<tr>
<td>If an adult patient with ASD is bothered by florescent lights, I limit the use of them.</td>
<td>66.18</td>
<td>36.38</td>
<td>0-100</td>
</tr>
<tr>
<td>I ask my adult patients with ASD about the sensory accommodations they require.</td>
<td>41.18</td>
<td>33.00</td>
<td>0-100</td>
</tr>
<tr>
<td>If I am aware that I will be working with an adult patient with ASD on a certain day, I limit the use of scented products.</td>
<td>38.24</td>
<td>47.69</td>
<td>0-100</td>
</tr>
<tr>
<td>My current practice provides an alternative place for adult patients with ASD to wait if waiting room noise upsets them.</td>
<td>32.35</td>
<td>41.24</td>
<td>0-100</td>
</tr>
<tr>
<td>I encourage my adult patients with ASD to bring ear plugs or headphones to appointments if the noise bothers them.</td>
<td>30.88</td>
<td>32.51</td>
<td>0-100</td>
</tr>
<tr>
<td>My adult patients with ASD tell me of the sensory accommodations they require.</td>
<td>29.41</td>
<td>5.37</td>
<td>0-100</td>
</tr>
</tbody>
</table>

*Note.* Items were coded that *Always* corresponded with 100, *Most of the Time* corresponded with 75, *About Half of the Time* corresponded with 50, *Sometimes* corresponded with 25, and *Never* corresponded with 0.

**Ability to Provide Sensory Accommodations**

Physicians reported their ability to provide accommodations for sensory sensitivities to their adult patients with ASD. Physicians responded to these three survey items pertaining to their ability to provide sensory sensitivities using a five-point Likert scale, where 100 represented “*Always,*” 75 represented “*Most of the Time,*” 50 represented “*About Half of the Time,*” 25 represented “*Sometimes,*” and 0 represented “*Never.*” Generally, physicians reported
they provide sensory accommodations between About Half of the Time to Most of the Time. The data in response to these statements are presented in Table 4.

Table 4

*Physicians’ Ability to Provide Sensory Accommodations for Adults with ASD*

<table>
<thead>
<tr>
<th>Survey Item</th>
<th>M</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>If an adult patient with ASD is bothered by florescent lights, I am able to limit the use of the lights.</td>
<td>61.76</td>
<td>39.65</td>
<td>0-100</td>
</tr>
<tr>
<td>If an adult patient with ASD is sensitive to sound present in the waiting room, I am able to move them to another location.</td>
<td>60.29</td>
<td>38.59</td>
<td>0-100</td>
</tr>
<tr>
<td>If I am aware that I will be working with an adult patient with ASD on a certain day, I can limit the use of scented products.</td>
<td>35.29</td>
<td>46.82</td>
<td>0-100</td>
</tr>
</tbody>
</table>

*Note.* Items were coded that Always corresponded with 100, Most of the Time corresponded with 75, About Half of the Time corresponded with 50, Sometimes corresponded with 25, and Never corresponded with 0.

**Caregiver Integration**

A total of four questions in the survey addressed how caregivers for adults with ASD are integrated into office appointments. Two questions focused on the need to have caregivers present at office appointments to communicate with their adult patients with ASD. Those statements included Caregivers of an adult patient with ASD should oversee all communication during office appointments and Caregivers are necessary to effectively communicate with any adult patient with ASD. Participants responded using a five-point Likert scale, where 2 represented “Strongly Agree,” 1 represented “Somewhat agree,” 0 represented “Neither agree or disagree,” -1 represented “Somewhat disagree,” and -2 represented “Strongly Disagree.” Overall, physicians reported that they Somewhat disagree to Neither Agree or Disagree that caregivers are necessary to communication with an adult patient with ASD. Table 5 presents
physicians’ responses to both questions pertaining to how caregivers are integrated while
communicating with an adult patient with ASD.

Table 5

*Physicians’ Perceptions of the Necessity of Caregivers to Communicate with Adult Patients with ASD During Office Appointments*

<table>
<thead>
<tr>
<th>Survey Item</th>
<th>M</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregivers of an adult with ASD should oversee all communication during office appointments.</td>
<td>-</td>
<td>1.18</td>
<td>-2 to 1</td>
</tr>
<tr>
<td>Caregivers are necessary to effectively communicate with any adult patient with ASD.</td>
<td>-</td>
<td>1.25</td>
<td>-2 to 2</td>
</tr>
</tbody>
</table>

*Note.* Items were coded that *Strongly Agree* corresponded with 2, *Somewhat Agree* corresponded with 1, *Neither agree or Disagree* corresponded with 0, *Somewhat Disagree* corresponded with -1, and *Strongly Disagree* corresponded with -2.

Two survey items focused on the need for caregivers to be present during office appointments for physicians to understand how to accommodate for the communication differences and sensory sensitivities adults with ASD may present during office appointments. Physicians reported their responses using a five-point Likert scale, where 2 represented “*Strongly Agree*,” 1 represented “*Somewhat Agree*,” 0 represented “*Neither Agree or Disagree*,” -1 represented “*Somewhat Disagree*,” and -2 represented “*Strongly Disagree*.” Physicians reported that they *Neither Agree or Disagree to Somewhat Agree* caregivers are necessary to accommodate for the communication differences adults with ASD present during office appointments. Table 6 presents how physicians responded to these two survey items.
Table 6

Descriptive Statistics of Physicians’ Perceptions of the Necessity of Caregivers to Accommodate for the Needs of Adult Patients with ASD During Office Appointments

<table>
<thead>
<tr>
<th>Survey Item</th>
<th>M</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregivers are necessary to accommodate for the communication differences adults with ASD present.</td>
<td>0.29</td>
<td>1.31</td>
<td>-2 to 2</td>
</tr>
<tr>
<td>Caregivers are necessary to accommodate for the sensory sensitivities adults with ASD present.</td>
<td>0.06</td>
<td>1.14</td>
<td>-2 to 1</td>
</tr>
</tbody>
</table>

*Note.* Items were coded that Strongly Agree corresponded with 2, Somewhat Agree corresponded with 1, Neither agree or Disagree corresponded with 0, Somewhat Disagree corresponded with -1, and Strongly Disagree corresponded with -2.

**Discussion**

In this section, I will discuss the results that I presented in the prior section in the context of the existing literature. Additionally, the responses to the one open ended survey question will be integrated into this discussion to provide context for the quantitative data.

**Primary Care Physician Training**

Overall, the primary care physicians who participated in this current study indicated that they agree training is important in medical school and/or residency to effectively provide care to adults with ASD. In fact, a majority of the primary care physicians who participated in this study selected either somewhat agree or strongly agree about the importance of training in medical school and/residency. In response to an open-ended question, one participant wrote “I would recommend training be integrated into medical school and residency.” All other responses to this open-ended question can be found in Appendix E. Although participants agreed about the importance of training, a majority of participants also reported that the training they have is not adequate to provide communication and sensory accommodations for adults with ASD. Specifically, most respondents indicated that they somewhat disagree to strongly disagree that
the training they have to provide care to adults with ASD is sufficient to make them feel comfortable supporting this population. These results I obtained are consistent with those documented in the literature. For example, Warfield and colleagues’ (2015) had multiple participants who commented that they had little to no training to provide care to their adult patients with ASD (p. 2214). A participant mentioned that “There was virtually no education or supervised experience for me during residency; and although that is a little bit better today, it is still far from being where it needs to be today” (Warfield et al., 2015, p. 2214). Bruder and colleagues (2015) similarly reported that physicians feel there is a deficit in their training when it comes to adults with ASD (p. 2500). In addition, half of Bruder and colleagues (2015) participants stated that they would like to receive more training in medical school and residency and beyond (p. 2500).

There are several possible reasons why physicians may not be receiving training in medical school and beyond. The results from the current study demonstrate that physicians do not provide care to that many patients with ASD. Specifically, of the 17 physicians who reported having experience with adults with ASD, 12 physicians in the sample only provide care to 10 or fewer adult patients with ASD in their practice. Only three physicians reported providing care to 11 to 20 patients in their practice, and two participants reported providing care to more than 20 patients. Bruder and colleagues (2012) reported a similar finding when they examined physicians’ perceptions of their training to provide care for adults with ASD, as their findings suggested that a small number of physicians provide care at all to adults with ASD, and those who do only provide care to few patients with a diagnosis of ASD (p. 2500). Also, given that primary care is a broad field, medical schools and training providers may find training about ASD to be too specific for the diverse patients these physicians provide care to during office
appointments. A participant in Bruder and colleagues (2015) suggested that training be made broader and more applicable to multiple types of developmental or intellectual disabilities that may impact a client’s ability to communicate (p. 2502). This way, training regarding the communication characteristics and necessary accommodations for individuals with developmental or intellectual disabilities is still being provided, however, the training can be applicable to a wider variety of patients, as the training would not just focus on ASD (Bruder, et al., 2012, p. 2502).

In the current study, physicians reported the training they received pertaining to adults with ASD, specifically how they received training within their medical school and residency and beyond medical school and residency. Physicians reported whether or not they received training in medical school and/or residency, and 13 of the 19 respondents responded that they received training through “Experience with patients.” Additionally, eight participants responded that they had their training embedded in their curriculum. A few physicians reported that they had read journal articles or conducted their own research in medical school and/or residency to increase their knowledge about ASD, and how it may impact the care they provide for their adult patients with ASD.

While it is encouraging to learn that physicians are receiving training about ASD and the various components of the disorder, the training may not be extensive enough that physicians feel adequately prepared, as physicians in this current study reported that their perceptions of training are low. Zerbo and colleagues (2015) reported a similar finding, as the physicians who responded to their survey reported their training just focused on the characteristics of ASD, with very limited information beyond identifying those characteristics and the criteria for making referrals to psychiatrists (p. 4010).
The four physicians in the current study who received training beyond medical school and/or residency indicated that they had “Experience with patients” and “Read journal articles” about adults with ASD. Three of those participants also had conducted their own research or attended supplemental lectures. Aside from experience with patients, the physicians who had training beyond medical school and residency had to take their own initiative to obtain it. That is, their practice location or hospital did not provide or require physicians to complete training, and if they wanted to receive it, they had to seek out those opportunities on their own. This finding is consistent with Warfield and colleagues (2015) who reported a similar finding. Warfield and colleagues (2015) had several participants report that they learned about adults with ASD through “personal experience,” or “self-directed internships” or “conferences” (p. 2214). This suggests a need for more direct training opportunities within medical school and/or residency and beyond medical school and/or residency. There are medical schools that are incorporating ASD training in their curriculum. For example, Havercamp and colleagues (2016) reported that third year medical students at The Ohio State University viewed an online lecture on ASD and also attended a panel that included individuals with ASD, caregivers, and related professionals (p. 204). After the training, the medical students reported having more confidence when interacting with individuals with ASD and accommodating for their communication needs (Havercamp et al., 2016, p. 208). Explicit training can be beneficial for current and future physicians, as it expands their perspectives about ASD and provides insight about potential accommodations patients with ASD may require.

**Communication Differences Awareness**

As adults with ASD may present communication differences that may create barriers when receiving medical care, it is imperative that we understand how aware physicians are of the
potential communication differences their adult patients with ASD may demonstrate. The survey instrument included a number of items regarding how physicians can identify the communication differences adults with ASD may present during office appointments. With the except for a few questions referring to the use of gestures (e.g., pointing), a majority of the physicians who participated in the survey were aware of the communication differences adults with ASD may demonstrate during office appointments, despite their perceived lack of training and experience working with adults with ASD. Physicians were able to correctly identify the communication differences included in the survey instrument with 83 percent accuracy, which means primary care physicians were able identify the communication differences of adults with ASD. Warfield and colleagues (2015) reported a similar pattern, and they also included that physicians lack knowledge about how to accommodate for the needs of adult patients with ASD (p. 2214).

However, Nicolaidis and colleagues present a different perspective, from the view of individuals who have a diagnosis of ASD. Nicolaidis and colleagues (2012) found that adults with ASD reported lower satisfaction rates with their physicians understanding of how to accommodate for their communication needs during office appointments, in comparison to the satisfaction rates of their peers without a diagnosis of ASD (p. 761). Nicolaidis and colleagues (2015) also explored the patient-provider relationship, to investigate the barriers that may be present during office appointments. The primary difficulty reported by adult patients with ASD was lack of understanding of the different ways adults with ASD may communicate with their primary care physicians. One patient wrote,

“People attribute behaviors to the autism rather than looking for an illness first. Oh that's her autism, she's banging her head against the wall because that's her autism. Nobody
thinks, ‘Oh gosh! Maybe she has a migraine!’ … They forget to realize that she can’t verbally express it so she uses behavior instead.” (Nicolaidis et al., 2015, p. 5).

Patients perceived that the reason why their physicians may not understand their communication needs is due to primary care physicians making false assumptions about their needs (Nicolaidis et al., 2015, p. 5). Others reported that they believe that physicians understand communication differences, yet they do not accommodate for them during appointments, which gives the impression that physicians are not aware of these communication differences (Nicolaidis et al., 2015, p. 5). Thus, these inconsistencies seem to be caused by a disconnect between adults with ASD and primary care physicians, specifically, between physicians’ knowledge of their adult patients with ASD’s communication differences in comparison to how they demonstrate that understanding to their patients during office appointments.

**Communication Differences Accommodations**

Physicians reported they provide communication accommodations for their adult patients with ASD during office appointments either “Sometimes” or “About half of the time,” meaning accommodations for the communication differences adults with ASD may present are not being consistently provided during office appointments. There has been limited research from physicians’ perspectives about providing accommodations for communication differences. However, there is literature that focuses on the perceptions of adults with ASD about the accommodations that primary care physicians may provide.

For example, Nicolaidis and colleagues (2015) interviewed adults with ASD about their perspectives of the communication accommodations they are provided by their primary care physicians. Participants reported that their physicians are not accommodating for their varying modes of communication, because they are not given the ability to communicate using other
modes of communication besides verbal discourse, such as through writing (Nicolaidis et al., 2015, p. 828). The results of the current study demonstrate that physicians alter their mode of communication somewhere between *About half of the time* and *Most of the time*. That accommodation is also one of the most provided accommodations by the physicians in this sample. In comparison to the Nicolaidis and colleagues (2015) findings, this finding is somewhat encouraging.

Nicolaidis and colleagues (2015) also reported that some patients did have positive experiences with accommodations being provided, such as receiving emails ahead of time with explanations of medical procedures and the length of the appointment. These accommodations led patients to feel more positive about interactions with their primary care physicians (Nicolaidis et al., 2015, p. 828). The findings from these two studies, along with what physicians reported regarding how often they provide communication accommodations during appointments in the current study, demonstrate a more consistent need for accommodations to be provided to adults with ASD. However, there may be factors that prevent primary care physicians from providing communication accommodations. In the current study, one participant wrote at the end of the survey,

“ASD is too wide of a spectrum to have one way of caring for these pts, just like all pts. we must adapt to every pts needs and they in turn must adapt to our personal and office abilities and inabilities. there is no perfect office in primary care. a specialty center may be most equipped, but then you are outside the realms of primary care and there a very few of these most places.”

As such, while patients may require accommodations, some of them may fall outside the bounds of primary care. Also, there may need to be compromise between physicians and their adult
patients with ASD on what accommodations can and cannot be provided during office appointments due to the limitations within primary care and the clinical setting.

**Sensory Sensitivities Awareness**

Generally, most of the respondents in this current study indicated that they have a strong understanding of the sensory sensitivities adults with ASD may demonstrate; physicians in this sample correctly identified 87% of sensory sensitivities. This result is encouraging, because Nicolaidis, Kripke, and Raymaker (2015) stated that physicians need to have a strong understanding of the sensory sensitivities adults with ASD may demonstrate during office appointments (p. 10). Sensory stimuli such as bright lights, loud sounds or touch can overstimulate a patient with ASD, which can impact their ability to communicate with their physician or tolerate an office appointment (Nicolaidis et al., 2015, p. 10).

Although physicians accurately identified sensory sensitivities at a high level, they were less consistent in their knowledge of how adults may respond to pain. Physicians may have responded that they were unsure about those characteristics due to their lack of extensive training regarding the characteristics of ASD. Havercamp and colleagues (2016) found that prior to their sample of medical students receiving training regarding the characteristics of ASD, many based their knowledge of ASD off media representations of individuals with ASD, such as *Rain Man*. The sample of medical students often made their assumptions of the characteristics of ASD based of these media representations, which may not include or represent all the characteristics of ASD (Havercamp et al., 2016, p. 208). However, after receiving training about the characteristics of ASD and interacting with patients who have ASD, their understanding of these characteristics was expanded beyond those presented in the media (Havercamp et al., 2016, p. 208). Zerbo and colleagues (2015) described that practicing physicians who have limited training
regarding ASD also often base their knowledge of ASD off media representations as well, as some of their participants also referred to *Rain Main* as how they initially learned about the disorder (p. 4008). Thus, over or under responding to pain may not be a common characteristic associated with ASD due to the limited depictions of this characteristic in media representations of ASD.

**Sensory Sensitivity Accommodations**

The physicians who participated in this study reported that they accommodate for sensory sensitivities either “Sometimes” or “About half of the time,” meaning these accommodations are not being consistently provided for adult patients with ASD. This result is consistent with Carter and colleagues (2017), who reported that sensory accommodations typically do not occur, unless a patient asks for them, or, demonstrates agitation and discomfort with the current environment (pp. 1513-1514). For example, Carter and colleagues (2017), provided an example of a patient who was demonstrating that they were agitated by the sounds present in the medical setting they were in. Up until that point, the physician and others in the medical staff had not asked about what the patients’ needs are, or, how they could make the patient more comfortable. The patient’s caregivers requested that the patient be moved (p. 1513). However, once asked, the physician was unable to relocate the client due to a lack of private, noise-free spaces that were available at the time (Carter et al., 2017, p. 1514). Physicians can be more mindful and aware of the sensory accommodations that patients may need during office appointments, however, even if they are aware or are made aware, there are still limitations that may occur that prevent physicians from providing these accommodations. As Carter and colleagues (2017) reported, physicians may not be able to provide accommodations due to space or other facility related limitations (p. 1514).
Caregiver Integration

Overall, most physicians in the current investigation reported that they *neither agreed or disagreed* to incorporate caregivers when accommodating for sensory sensitivities. Likewise, when accommodating for communication differences, a majority of physicians reported that they *neither agreed or disagreed* that caregivers are necessary to provide accommodations. Physicians also indicated that they *somewhat disagreed to neither agreed or disagreed* that caregivers are necessary for communicating effectively with adult patients with ASD, demonstrating some uncertainty among the physicians in the sample about how often caregivers should be included while communicating with an adult patient with ASD. Interestingly, physicians also *somewhat disagreed to neither agreed or disagreed* that caregivers should oversee all communication during office appointments. The ambiguity of these responses is similar to the patterns documented in previous investigations, as how physicians integrate caregivers has been a source of some debate in the literature. Some researchers believe that caregivers should be utilized to improve communication between the patient and the physician (Aylott, 2010, p. 49). Aylott (2010) presented this perspective, as speaking to a patient’s caregiver before an appointment can help the physician find ways to accommodate for the patient’s communication and sensory needs and make the patient more comfortable overall (p. 49). However, other researchers have presented different perspectives, including Cheak-Zamora and Teti (2015).

Cheak-Zamora and Teti (2015) asked their participants a number of questions regarding how they (as the caregiver) should be included and how the adolescent participants would like their caregiver included in adulthood. The caregivers reported that they would find it difficult to not be included in their child’s care in adulthood, as they do not believe physicians have
adequate training to work with adolescents and adults with ASD (Cheak-Zamora & Teti, 2015, p. 999). However, the adolescents with ASD had mixed feelings; some reported that they would prefer if they handled their healthcare matters independently throughout the transition into adulthood and as adults, and others felt more comfortable with their caregiver still being involved in the process (Cheak-Zamora & Teti, 2015, p. 999). These varying viewpoints about caregiver integration may due to the complexity of ASD and how the different severities of the diagnosis of ASD impact the necessity of caregivers. In the current study, one physician commented that their training comfort levels vary depending on the level of their patient’s ASD diagnosis. This participant wrote that, “I am not equipped whatsoever to care for patients with moderately severe or severe autism symptoms - basically, symptoms severe enough to prevent a patient from having a fairly clear one on one conversation with me/patients who would need to have a caregiver present during the appointment.” Thus, given that ASD is indeed a spectrum and includes three levels of diagnosis, caregivers may be more necessary for those who require more support and have a level two or three diagnosis, and less necessary for those patients with a level one diagnosis of ASD.
CHAPTER V: CONCLUSION

The purpose of this study was two-fold. First, this study investigated the awareness and training primary care physicians have about the communication differences and sensory sensitivities adults with Autism Spectrum Disorder (ASD) may present. Second, this study examined how primary care physicians accommodate for the communication differences and sensory sensitivities adults with ASD may present, as well as how they integrate caregivers during office appointments. This chapter will present the major conclusions of this study, implications of those conclusions, limitations of this study, recommendations for further research, and final thoughts.

Major Conclusions

This study has three major conclusions. The first major conclusion is that despite the limited training during and beyond medical school primary care physicians have regarding adults with ASD in general, physicians demonstrate a strong understanding of the communication differences and sensory sensitivities adults with ASD may present during office appointments. Figures 8 and 9 demonstrate that the physicians who participated in this study were able to identify the various communication differences and sensory sensitivities adults with ASD may demonstrate during office appointments. With few exceptions, most of the physicians answered “Yes” to the statements that were true and “No” to the statements that were false. In prior studies, many adults with ASD have reported that they do not feel their physicians understand their communication and sensory needs (Nicolaidis et al., 2012, p. 761; Nicolaidis et al., 2015, p.5). By contrast, participants in the current investigation demonstrated a solid understanding of the sensory sensitivities and communication differences adults with ASD may present during office appointments.
The second major conclusion is that despite physicians’ awareness of the communication differences and sensory sensitivities adults with ASD may demonstrate during appointments, they only provide accommodations for those differences and sensitivities less than half of the time during office appointments. Tables 2 and 3 present how physicians provide accommodations for adults with ASD during office appointments and most of their responses to those statements were either “About half of the time” or “Sometimes.” Physicians also reported that they are slightly more likely to provide sensory accommodations in comparison to communication accommodations during office appointments.

The third and final major conclusion of this study is that physicians present varying perspectives about the necessity of caregivers during office appointments to communicate and accommodate for adults with ASD. Physicians’ responses primarily ranged from that they “Somewhat Disagree” to “Somewhat Agree”, with many responses near “Neither Agree or Disagree” for all items regarding the integration and necessity of caregivers. One physician commented that the necessity of a caregiver varies depending on the individuals’ level of diagnosis, however more research would need to be conducted to determine if an individual with ASD’s required level of support influenced all of the physicians’ responses regarding the necessity of caregivers in this study.

**Research Implications**

Several implications can be drawn from the major conclusions of this study. Multiple physicians indicated that there is a need for more training in medical school and/or residency through their responses to the survey items pertaining to their perceptions of the training they have received in the past. The physicians who participated in this study demonstrated that they understand the communication differences and sensory sensitivities adults with ASD may
present during office appointments, but they do not provide accommodations for those
differences and sensitivities consistently. This suggests that perhaps there needs to be a shift in
the training physicians receive during medical school and/or residency. Given what appears to be
a solid understanding of the communication differences and sensory sensitivities adults with
ASD present, medical schools could additionally include instruction about ASD to teach their
students’ how to apply their knowledge during office appointments. That training could
specifically include how to apply their knowledge of the communication differences and sensory
sensitivities adults with ASD may present to provide more consistent accommodations for these
differences and sensitivities.

Similarly, physicians also indicated that they have had limited training beyond medical
school and residency. Perhaps training could also be provided, either through their own practice,
or through various organizations that support and advocate for adults with ASD. Physicians
could also be required to have an observational rotation with other professionals, such as speech-
language pathologists or psychiatrists who also provide care to individuals with ASD or to those
with other developmental disabilities.

**Limitations**

This study has three limitations. The first limitation is that there was a small sample size
in this study. The final number of participants came to 19, with 17 complete responses. In
addition, many of the participants who participated in this study completed their medical school
residency in the Midwest. The researcher made multiple attempts to contact various College of
Wooster alumni, physician offices, hospitals, social media sites, and personal contacts of the
researcher. Unfortunately, these attempts either received no response or the site responded that
an individual must have an affiliation with the organization to have research inquiries sent to
their physicians. A low and geographically limited sample size weakens the generalizability of the results of this study to all primary care physicians across the various regions of the United States.

The second limitation was that there was very limited qualitative data in this study. The survey instrument only provided participants one question to further expand on their responses to the Likert-scale and multiple-choice questions. The original research protocol included the use of follow-up interviews to obtain more in-depth information about how physicians interact with and provide accommodations for adults with ASD during office appointments. Qualitative data would have provided more context as to why physicians do not provide accommodations for adults with ASD very frequently during office appointments.

The third limitation is that while the survey broadly addressed the communication differences and sensory sensitivities adults with ASD may demonstrate during appointments, the survey did not address those differences and sensitivities in relation to how they may be different among the various levels of diagnosis for ASD. The survey instrument also did not address how the accommodations for adults with ASD may have be altered depending on the patients’ severity of diagnosis. The survey instrument would have had to be much more extensive to include how the characteristics of ASD manifest differently within the varying diagnostic levels of ASD. However, without the survey instrument addressing these different diagnostic levels, it is not clear if the physicians were responding to the questions based on their experiences working with patients of a specific diagnostic criteria.

**Recommendations for Further Research**

There are several ways this research can be further expanded in the future. First, since most participants in this study indicated they have very limited training to work with adults with
ASD, further quantitative and qualitative research could be conducted to determine what the specific limitations exist for training primary care physicians in medical school and/or residency about how to accommodate for adults with ASD. Further research could also explore the limitations beyond medical school and/or residency for physicians to receive training about adults with ASD.

Second, this topic can be expanded to include different types of medical professionals and physicians besides those who work in primary care, such as nurses, nurse practitioners, gynecologists, neurologists, dentists, and gastroenterologists. Due to the noted comorbid conditions adults with ASD may or may not present, adults with ASD may visit different types of medical professionals besides those in primary care. Expanding the types of medical professionals and types of physicians included in the sample also would allow for different perspectives on this topic.

Third, this research could be investigated from the viewpoint of a speech-language pathologist. The literature review addressed the transition adolescents make into adult healthcare systems, and how physicians can make that transition easier. Speech-language pathologists work with adolescents with ASD on social-pragmatic skills and life skills, which may or may not include how to navigate through office appointments with medical professionals. Further research could include surveying speech-language pathologists to determine if they play any role in the transition into adult healthcare and if so, what that role may look like.

This research could also be expanded to include comparisons between when physicians completed residency and their awareness of ASD. Those comparisons were not made in this study due to the limited sample size and limited variability of when physicians reported completing residency. As the diagnostic criteria for ASD has changed multiple times over the
years, it would be interesting to see if physicians have continued their education to remain knowledgeable about these changes in diagnostic criteria.

**Final Thoughts**

I am very grateful I was able to conduct this study. Unlike many of my peers, I do not have any personal connection to this research topic, besides an interest in ASD and other social-pragmatic impairments. However, I am a firm believer that all individuals who present with exceptionalities deserve to feel comfortable and supported in any environment they are in, especially when receiving a necessary service such as healthcare. My study allowed me to explore how aware physicians are of the characteristic of ASD and how they accommodate for the needs of adults with ASD during office appointments, which is a positive direction for research to head towards. While I struggled to get participants and follow up interviews, I was still able to obtain some insight as to how these physicians accommodate for adults with ASD, in which I was able to make some suggestions to how they could improve the accommodations they provide this population, and training they receive in medical school and residency.

You may be wondering, “How does this research relate to Communication Sciences and Disorders?” This question is one I have received throughout this whole process, and here is my response to it. As speech-language pathologists (and audiologists), we collaborate with many other professionals, including those in the medical field. Individuals with ASD often have a “care team” or a group of professionals who collaborate to ensure that they are receiving consistent support and care. As such, we need to ensure all those professionals are on the same page regarding the communication and sensory needs of their adult patients with ASD, especially if they do not have as much knowledge or experience with this population in comparison those experiences of a speech-language pathologist. This way, we ensure that adults with ASD can feel
as comfortable and supported while interacting with all professionals; not just those who specialize or provide therapy for ASD. Also, conducting studies such as this one provides speech-language pathologists with insight as to how they can prepare their adolescent clients with ASD to communicate with their primary care physicians as they enter adulthood.

REFERENCES


Devine, K. A., Monaghan, M., & Schwartz, L. (2017). Introduction to the special issue on adolescent and young adult health: Why we care, how far we have come, and where we are going. *Journal of Pediatric Psychology, 42*(9), 903-909.


APPENDIX A
SURVEY INSTRUMENT

Q1 CONSENT TO PARTICIPATE IN A RESEARCH STUDY THE COLLEGE OF WOOSTER  Principal Investigator: Rachel Topper, Communication Sciences and Disorders
Purpose: You are being asked to participate in a research study. We are investigating the perspectives of primary care physicians on various aspects of healthcare communication during office appointments while working with adults with Autism Spectrum Disorder (ASD).

Procedures: If you decide to volunteer, you will be asked to complete an online survey. The survey contains questions about training regarding Autism Spectrum Disorder (ASD), level of comfort while working with adult patients with ASD, awareness of communication differences and sensory sensitivities of these patients, the types of accommodations provided for these differences and sensitivities, and the use of caregivers during appointments with adults with ASD. At the end of the survey, you will have the opportunity to indicate if you would like to be contacted for a follow-up interview.

Risks: There are no risks for completing this study.

Benefits: There are no direct benefits to you for your participation. An indirect benefit is that we learn more about how primary care physicians interact with adults with Autism Spectrum Disorder (ASD) during office appointments.

Compensation: There is no compensation for participating in this study.

Confidentiality: Any information you provide will be kept anonymous.

Costs: There is no cost to you beyond the time and effort required to complete the procedure described above.

Right to Refuse or Withdraw: You may refuse to participate in the study. If you decide to participate, you may skip questions while taking the survey.

Questions: You can contact me by email at rtopper19@wooster.edu You may also contact my advisor, Dr. Joan Furey, at jfurey@wooster.edu.

Consent: By clicking the “I agree” button below, this will indicate that you have decided to volunteer as a research subject, that you have read and understand the information provided above, and that you are at least 18 years of age.

☐ I agree. (1)

☐ No, thank you. (2)
Q28 In what area do you hold certification?

- Pediatrician (please answer the questions based on your knowledge/experiences while working with adults (over the age 18+ years) with Autism Spectrum Disorder (ASD). (1)

- Internal Medicine (please answer the questions based on your knowledge/experiences while working with adults (over the age 18+ years) with Autism Spectrum Disorder (ASD). (2)

- Family Medicine (please answer the questions based on your knowledge/experiences while working with adults (over the age 18+ years) with Autism Spectrum Disorder (ASD) (3)

Q3 In what year did you complete residency training?

________________________________________________________________

Q4 In what geographical region in the United States do you currently practice?

- Western (WA, OR, CA, NV, UT, AZ, NM, CO, WY, MT, ID) (1)

- Southern (NC, KY, TN, SC, GA, FL, AL, MS, LA, OK, TX, AR) (2)

- Eastern (ME, NH, NY, PA, WV, VA, VT, NH, NJ, CT, DE, MD, MA, DC) (3)

- Midwest (OH, IN, MI, WI, IL, MN, IA, KS, ND, SD, NE, MO) (4)

- Other (AK, HI) (5)
Q5 While in medical school, did you have the option to subspecialize in intellectual disabilities and/or Autism Spectrum Disorder?

- Yes (1)
- No (2)

Skip To: Q6 If While in medical school, did you have the option to subspecialize in intellectual disabilities and/or Autism Spectrum Disorder? = No

Page Break

Q25 Did you choose to subspecialize in intellectual disabilities and/or Autism Spectrum Disorder?

- Yes (1)
- No (2)

Page Break
Q6 While in medical school, how did you receive information about working with adults with Autism Spectrum Disorder? Select ALL that apply.

- Embedded in curriculum (1)
- Attended a supplemental lecture (2)
- Read journal article(s) (3)
- Clinical rotation(s) (4)
- Experience with patient(s) (5)
- Conducted research (6)
- None of these (7)
- Other (Please specify) (8)

Q8 Following your residency training, have you completed any additional coursework and/or training to work with individuals with Autism Spectrum Disorder?

- Yes (1)
- No (2)

Skip To: Q11 If Following your residency training, have you completed any additional coursework and/or training to work... = No
Q26 Which of the following experiences have you had? Select ALL that apply.

☐ Attended training session(s) (1)

☐ Experience with patient(s) (2)

☐ Conducted research (3)

☐ Read journal article(s) (4)

☐ Other (Please specify) (5)

Q11 Within the last 12 months, approximately how many adult patients did you provide care to who are diagnosed with Autism Spectrum Disorder?

☐ None (1)

☐ 1-10 (2)

☐ 11-20 (3)

☐ More than 20 (4)

Skip To: End of Survey If Within the last 12 months, approximately how many adult patients did you provide care to who are... = None
Q12
The following questions are about the **communication differences** which may or may not be routinely present in adults with Autism Spectrum Disorder (ASD). Please choose the answer that best represents your knowledge of ASD. (Adapted from: Centers for Disease Control and Prevention, 2015)

<table>
<thead>
<tr>
<th>Adults with Autism Spectrum Disorder....</th>
<th>Yes (1)</th>
<th>No (2)</th>
<th>Unsure (3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>May repeat words over and over. (1)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>May give unrelated answers to questions. (2)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>May avoid eye contact. (3)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>May have difficulty expressing feelings. (4)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>May have difficulty describing pain. (5)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>May have a monotone voice. (6)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>May have difficulty understanding jokes, sarcasm, or teasing. (7)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>May present atypical social skills. (8)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The following questions continue to ask about the communication differences which may or may not be routinely present in adults with Autism Spectrum Disorder (ASD). Please choose the answer that best represents your knowledge of ASD. (Adapted from: Centers for Disease Control and Prevention, 2015)

Adults with Autism Spectrum Disorder....

<table>
<thead>
<tr>
<th></th>
<th>Yes (1)</th>
<th>No (2)</th>
<th>Unsure (3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>May not point to objects or will not respond to pointing when asked. (1)</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>May not understand non-verbal communication, such as the use of gestures, tone of voice, or facial expressions. (2)</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>May use few to no gestures (such as waving goodbye). (3)</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>May present with difficulty answering broad and open-ended questions. (4)</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>May present difficulty understanding the use of non-verbal communication. (5)</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>May use different modes of communication. (6)</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>May use facial expressions that do not match the content of what they are saying. (7)</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
Q14
This next set of questions refers to the types of **sensory sensitivities** adults with Autism Spectrum Disorder (ASD) may or may not routinely present. Please choose the best answer that represents your knowledge of the characteristics of ASD. (Adapted from: Centers for Disease Control and Prevention, 2015)

<table>
<thead>
<tr>
<th>Adults with Autism Spectrum Disorder...</th>
<th>Yes (1)</th>
<th>No (2)</th>
<th>Unsure (3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>May be bothered by scents present in my office. (1)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Are all impacted the same way by environmental stimuli. (2)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>May not respond in an atypical manner to environmental stimuli. (3)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>May be bothered by certain textures. (4)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>May overreact to pain. (5)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>May underrespond to pain. (6)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>May be bothered by touch. (7)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>May present discomfort with bright lights. (8)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
Q15
This next section of questions refers to how the **caregivers** of Adults with Autism Spectrum Disorder are or are not included during office appointments. Please choose the answer that best represents your current practice or opinion. (Adapted from: Nicolaidis, C., Kripke, C., & Raymaker, D., 2014)

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree (1)</th>
<th>Somewhat disagree (2)</th>
<th>Neither agree nor disagree (3)</th>
<th>Somewhat agree (4)</th>
<th>Strongly agree (5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregivers of an adult with ASD should oversee all communication during office appointments. (1)</td>
<td></td>
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<tr>
<td>Caregivers are necessary to accommodate for the <strong>communication differences</strong> adults with ASD present. (2)</td>
<td></td>
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<tr>
<td>Caregivers are necessary to effectively communicate with any adult patient with ASD. (3)</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Caregivers are necessary to accommodate for the <strong>sensory sensitivities</strong> adults with ASD present (4)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Q17 The following questions refer to the accommodations that may be provided for adults with ASD who may routinely present with **communication differences**. Please indicate how frequently you provide these accommodations for your adult patients with ASD. (Adapted from: Nicolaidis, C., Kripke, C., & Raymaker, D., 2014)
<table>
<thead>
<tr>
<th></th>
<th>Never (1)</th>
<th>Sometimes (2)</th>
<th>About half the time (3)</th>
<th>Most of the time (4)</th>
<th>Always (5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I encourage my adult patients with ASD to prepare notes in advance about what they want to discuss with me. (1)</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>I write down instructions or provide written documents with important medical instructions for my adult patients with ASD. (2)</td>
<td></td>
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<tr>
<td>I direct my adult patients with ASD to detailed information or resources about health conditions for review outside of the appointment. (3)</td>
<td></td>
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<tr>
<td>I provide lists of symptoms for my adult patients with ASD to choose from during office appointments.</td>
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</tbody>
</table>
Q18
The following questions continue to refer to the accommodations that may be provided for adults with ASD who may routinely present with **communication differences**. Please indicate how frequently you provide these accommodations for your adult patients with ASD. (Adapted from: Nicolaidis, C., Kripke, C., & Raymaker, D., 2014)

<table>
<thead>
<tr>
<th></th>
<th>Never (1)</th>
<th>Sometimes (2)</th>
<th>About half the time (3)</th>
<th>Most of the time (4)</th>
<th>Always (5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I provide alternate ways for patients to contact the office besides by telephone. (1)</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>When first interacting with a patient with ASD, I obtain information about their preferred mode of communication. (2)</td>
<td>o</td>
<td>o</td>
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<td>o</td>
<td>o</td>
</tr>
<tr>
<td>I have the ability to spend more time with my adult patients with ASD. (3)</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>I provide adult patients with ASD worksheets or diaries to help them keep track of their symptoms. (4)</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>I attempt to use the most effective communication</td>
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<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
</tbody>
</table>
mode for my adult patients with ASD, even if it requires me to alter my usual interview style. (5)
Q19
This set of questions refers to the **sensory sensitivity accommodations** that may be provided during appointments for adults with Autism Spectrum Disorder (ASD). Please indicate how frequently you provide or are able to provide these accommodations for your adult patients with ASD. (Adapted from: Nicolaidis, C., Kripke, C., & Raymaker, D., 2014)
<table>
<thead>
<tr>
<th>If an adult patient with ASD is bothered by florescent lights, I limit the use of them. (1)</th>
<th>Never (1)</th>
<th>Sometimes (2)</th>
<th>About half the time (3)</th>
<th>Most of the time (4)</th>
<th>Always (5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I encourage my adult patients with ASD to bring ear plugs or headphones to appointments if noise bothers them. (2)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>If an adult patient with ASD is bothered by florescent lights, I am able to limit the use of the lights. (3)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>If an adult patient with ASD is sensitive to sound present in the waiting room, I am able to move them to another location. (4)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>If I am aware that I will be</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
working with an adult patient with ASD on a certain day, I limit the use of scented products. (5)
Q20
This set of questions continue to refer to the **sensory sensitivity accommodations** that may be provided during appointments for adults with Autism Spectrum Disorder (ASD). Please indicate how frequently you provide or are able to provide these accommodations for your adult patients with ASD. (Adapted from: Nicolaidis, C., Kripke, C., & Raymaker, D., 2014)

<table>
<thead>
<tr>
<th>My current practice provides an alternative place for adult patients with ASD to wait if waiting room noise upsets them. (1)</th>
<th>Never (1)</th>
<th>Sometimes (2)</th>
<th>About half the time (3)</th>
<th>Most of the time (4)</th>
<th>Always (5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>If I am aware that I will be working with an adult patient with ASD on a certain day, I limit the use of scented products. (2)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I avoid unnecessarily touching an adult patient with ASD if need be (e.g., during counseling or general conversation). (3)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My adult patients with ASD tell me what sensory accommodations they require. (4)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

91
I ask my adult patients with ASD about the sensory accommodations they require. (5)
Q21 This last set of questions refers to the amount and *types of training* you have received to provide care to adult patients with Autism Spectrum Disorder (ASD). Please choose the answer that best represents your experiences or opinions. (Adapted from: Nicolaidis, C., Kripke, C., & Raymaker, D., 2014)

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree (1)</th>
<th>Somewhat disagree (2)</th>
<th>Neither agree nor disagree (3)</th>
<th>Somewhat agree (4)</th>
<th>Strongly agree (5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have enough training for working with adults with ASD. (1)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My current practice provides training opportunities to work with individuals with ASD. (2)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Training and coursework regarding working with patients with ASD is <strong>important</strong> for primary care physicians. (3)</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Training and coursework regarding working with patients with ASD is <strong>necessary</strong> for primary care physicians. (4)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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Q27 Is there anything else not asked on this survey that you would like to share to help this researcher better understand primary care physicians’ perspectives on providing care to adults with ASD?

________________________________________________________________
________________________________________________________________
________________________________________________________________
________________________________________________________________

Q22 Would you be interested in completing a follow-up phone interview?

☐ Yes (1)

☐ No (2)

Skip To: End of Survey If Would you be interested in completing a follow-up phone interview? = No

Q24
If you are interested in completing a follow-up phone interview, please email the primary investigator, Rachel Topper, at rtopper19@wooster.edu
CONSENT TO PARTICIPATE IN A RESEARCH STUDY THE COLLEGE OF WOOSTER
Principal Investigator: Rachel Topper, Communication Sciences and Disorders

Purpose: You are being asked to participate in a research study. We are investigating the perspectives of primary care physicians on various aspects of healthcare communication during office appointments while working with adults with Autism Spectrum Disorder (ASD).

Procedures: If you decide to volunteer, you will be asked to complete a phone interview. You will be asked questions about your experiences while working with adults with Autism Spectrum Disorder (ASD) during office appointments and will have the opportunity to provide any commentary regarding topics addressed by the online survey. With your permission, the phone interview will be audio recorded for transcription purposes.

Risks: There are no risks associated with participating in this study.

Benefits: There are no direct benefits to you for your participation. An indirect benefit is that we learn more about how adults with Autism Spectrum Disorder (ASD) are supported by primary care physicians during office appointments.

Compensation: There is no compensation for participating in this study.

Confidentiality: Any information you give will be held confidential. The audio recordings will be stored securely on a password-protected computer and destroyed after they have been transcribed. The interview findings will be reported without using any identifying information. Thus, all data will become anonymous at the conclusion of the study.

Costs: There is no cost to you beyond the time and effort required to complete the procedure described above.

Right to Refuse or Withdraw: You may refuse to participate in the study. If you decide to participate, you may change your mind about being in the study and withdraw at any point during the phone interview.

Questions: If you have any questions, please ask me. If you have additional questions later, you can contact me by email at rtopper19@wooster.edu You may also contact my advisor, Dr. Joan Furey, at jfurey@wooster.edu

Consent: Your email response will indicate that you have decided to volunteer as a research subject, that you have read and understand the information provided above, and that you are at least 18 years of age.
Follow-Up Interview Questions:

1. What types of experiences have you had while accommodating for the communication needs of adults with Autism Spectrum Disorder?
2. Do you have any success stories from working with adults with Autism Spectrum Disorder regarding their communication needs?
   a. If so, what strategies and techniques helped you be successful?
   b. Do you have any recommendations for other physicians?
3. What are some challenges you face while providing communication modifications for adults with Autism Spectrum Disorder?
4. How do you feel primary care physicians can overcome those challenges?
5. Do you have anything else you would like to share?

6. What types of experiences have you had while accommodating for the sensory needs of adults with Autism Spectrum Disorder?
7. Do you have any success stories from working with adults with Autism Spectrum Disorder regarding their sensory needs?
   a. If so, what strategies and techniques helped you be successful?
   b. Do you have any recommendations for other physicians?
8. What are some challenges you face while providing sensory modifications for adults with Autism Spectrum Disorder?
9. How do you feel primary care physicians can overcome those challenges?
10. Do you have anything else you would like to share?
APPENDIX C
HUMAN SUBJECTS RESEARCH COMMITTEE (HSRC) APPROVAL

College of Wooster IRB

To: Rachel Topper
From: John Neuhoff, HSRC Chair
Subject: Protocol #2018/11/16
Date: 11/29/2018

The protocol #2018/11/16, Not just Rain Man: Investigating the Perspectives of Primary Care Physicians on Healthcare Communication During Office Appointments has been approved by the Human Subjects Research Committee Chair on 11/29/2018.

The approval of your study is valid through 11/28/2019, by which time you must submit an annual report either closing the protocol or requesting permission to continue the protocol for another year. Please submit your report by 10/31/2019 so that the IRB has time to review and approve your report if you wish to continue it for another year.

If you have any questions, feel free to contact me.

John Neuhoff,
HSRC Chair
jrneuhoff@wooster.edu
To: Rachel Topper
From: John Neuhoff, HSRC Chair
Subject: Protocol #2018/11/16
Date: 12/05/2018

The amendment to protocol Not just Rain Man: Investigating the Perspectives of Primary Care Physicians on Healthcare Communication During Office Appointments has been approved by the HSRC on 12/05/2018.

If you have any questions, feel free to contact me.

John Neuhoff,
HSRC Chair
jneuhoff@wooster.edu
APPENDIX D
RECRUITMENT MESSAGE

My name is Rachel Topper, and I am conducting research for my senior thesis at The College of Wooster. My study investigates primary care physicians’ experiences while working with adults with Autism Spectrum Disorder (ASD) during office appointments. This research protocol has been approved by the Human Subjects Research Committee at The College of Wooster.

If you are a currently practicing primary care physician (Pediatrician, Internal Medicine, or Family Medicine practitioner) who has had experience with working with adults with a diagnosis of Autism Spectrum Disorder (ASD), I would appreciate your participation in my research.

The following is a link to my survey. All survey data are anonymous, and participants may choose to skip questions or opt out at any time. At the end of the survey, you will have the opportunity to indicate your interest in participating in a follow-up phone interview. In total, the survey will take approximately 15 minutes to complete. If you know of any primary care physicians who would be interested in participating in my study, please forward them the link to my survey.

If you have any questions, feel free to contact me at rtopper19@wooster.edu. You can also contact my advisor, Dr. Joan Furey at jfurey@wooster.edu

Thank you for your consideration.
APPENDIX E:
SURVEY ITEM 27 RESPONSES

Survey Question: Is there anything else not asked on this survey that you would like to share to help this researcher better understand primary care physicians’ perspectives on providing care to adults with ASD? (n=6)

- “some of these questions were hard to answer as there is such a wide variety of adult autistic patients - some are very high functioning, and some are nearly nonverbal”

- “I am very comfortable providing care for patients with mild autism/Aspergers. If autism symptoms are severe enough to create disability, then generally I will have them also see a specialist for this or make sure they have good community disability resources. I am not equipped whatsoever to care for patients with moderately severe or severe autism symptoms - basically, symptoms severe enough to prevent a patient from having a fairly clear one on one conversation with me/patients who would need to have a caregiver present during the appointment.”

- “I didn’t realize how many fully functional adults I had in my practice that we discovered autistic tendencies, and once identified, it helped us to understand why they had such difficulties in every day life. And, it helps that my son with Down Syndrome (age 27) has autistic tendencies. His 4 siblings helped us a lot raising him.”

- “I would recommend training be implemented in medical school and residency.”

- “ASD is too wide of a spectrum to have one way of caring for these pts, just like all pts. we must adapt to every pts needs and they in turn must adapt to our personal and office abilities and inabilities. there is no perfect office in primary care. a specialty center may be most equipped, but then you are outside the realms of primary care and there a very few of these most places.”

- “I run a primary-care based program focused on improving care for adults with autism. we care for over 700 patients with autism currently, so my answers on this survey may not reflect those of the average primary care physician.”