CAREGIVERS’ PERSPECTIVES OF THEIR EXPERIENCES WITH THEIR CHILDREN WITH AUTISM SPECTRUM DISORDER IN HEALTHCARE SETTINGS

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by
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Director of Studies

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Abstract

Though there is an extensive body of literature focused on the cognitive, linguistic, and social challenges of children with ASD, relatively less is known about the experiences of children with ASD and their families in real-world environments including healthcare settings. Specifically, little is known about how caregivers prepare and support their children with ASD in these settings and whether differences exist across healthcare settings. There is a gap in the literature describing the preparation and supports that caregivers use to improve their experiences in healthcare settings. The purpose of the current study is to examine caregivers’ perceptions of their children’s behaviors and the strategies they use to prepare and support their children with ASD in two healthcare settings: visits to the doctor’s office and the speech-language therapy clinic. Knowledge of which strategies and supports are most effective will benefit caregivers of children by providing them with different supports to use with their children in healthcare appointments to better their overall experience.
Chapter 1: Introduction

Autism Spectrum Disorder Overview

According to the U.S. Centers for Disease Control and Prevention (2016), 1 in 68 American children is diagnosed with autism spectrum disorder (ASD). Over 3 million individuals in the United States are affected by ASD and tens of millions are affected worldwide (Autism Speaks Inc., 2016) whether they are the person being diagnosed or his or her family members. According to the definition of ASD in the Diagnostic and Statistical Manual of Mental Disorders-Fifth Edition (DSM-V; American Psychiatric Association, 2013), individuals with ASD display varying degrees of difficulty in the areas of social interaction across contexts and restrictive and repetitive behaviors.

Caregiver Information

Living with and taking care of children with ASD affects not only the child, but the whole family—especially the child’s caregivers. Raising a child with ASD can be a very stressful and challenging experience (Kuhlthau, Payakachat, Delahaye, Hurson, Pyne, Kovacs, & Tilford, 2014; Derguy, Michel, M’bailara, Roux, & Bouvard, 2015; Strunk, Pickler, McCain, Ameringer, and Myers, 2014; Reinke & Solheim, 2015). The number of parents affected by their child’s disorder is increasing (Kuhlthau et al., 2014). These parents often experience high levels of stress and social anxiety related to the behavioral challenges associated with their child’s disorder (Derguy et al., 2015; Kuhlthau et al., 2014; Strunk et al., 2014). In addition, parents of children with ASD experience and report increased difficulties with finances, feelings of judgment by society, limited access to adequate facilities as well as insufficient awareness of appropriate resources and identifying the right healthcare professionals (e.g., speech-
language pathologists, occupational therapists) to work with their children (Derguy et al., 2015). Quality of life is affected for the parents of children with ASD and interventions and resources can be used to not only improve the child’s condition, but also to better the overall well-being of the parents (Derguy et al., 2015; Kuhlthau et al., 2014).

Parents of children with ASD often do not feel confident in decisions about their child with just the basic knowledge related to ASD; they also need supports regarding daily management, emotional support, relational support, and material resources (Derguy et al., 2015). This lack of confidence may lead to an elevated level of stress and social anxiety in parents stemming from feelings of isolation and a lack of social supports; for example, it is suggested that care providers should have a knowledge of community services to provide families to get additional help and resources (Kuhlthau et al., 2014). Parents of children with ASD, who have high levels of stress, tend to rely on these supports (Reinke & Solheim, 2015). One study which supports this is that by Derguy et al (2015). Derguy et al. (2015) interviewed parents of children with ASD. The researchers of this study found that the objective of support is to provide a pleasant family dynamic, reduce isolation, and allow the parent to play an active role in the child’s life. In this study, Derguy et al. (2015) define support as assistance in the following areas related to parenting: material resources, information, parental guidance, daily management, relational support, and emotional support. They found daily management to be difficult for parents of children with ASD, and they need additional material resources, information, and educational guidance (Derguy et al., 2015).
Caregivers’ Perspectives in Public Settings

Such supports are valuable across all settings, whether it is at home or in public. Caregiver stress may be enhanced in public settings because of the behaviors exhibited by their child with ASD. Children who are diagnosed with ASD often have behavioral problems stemming from the social, intellectual, and sensory difficulties they encounter everyday (Ryan, 2010). Ryan (2010) state that society has socially prescribed expectations for how to behave in public, and children with ASD often go against these expectations due to their unpredictability. Children with ASD have a tendency to not act their age, get bored easily, participate in inappropriate play, have obsessive behaviors, fail to adapt to rules and the environment, and lack independence; these characteristics all add to their unpredictable behavior in public settings (Tayyare, Akin, Fakultesi, Bolumu, & Kampusu, 2013). These behaviors have been observed in healthcare facilities as well (Vohra, Madhavan, Sambamoorthi, & St. Peter, 2014).

Additionally, since there is no physical or outward sign of ASD, parents of children with ASD may experience particular tension in public places (Ryan, 2010). Community members who are unfamiliar with the disorder may affect the comfort level of the parents of children. Parents may have to use strategies to provide necessary support with their children with ASD; for example, they may have to hold their child’s hand or help them walk independently, tasks that might not be done for a child their age without ASD. These behaviors may lead others to stare and react with confusion, which may result in discomfort for the parents (Tayyare et al., 2013). This is not to blame people who are uninformed about ASD for their unpredictable reactions; they simply lack an understanding of ASD and everything it encompasses (Ryan, 2010). This is a problem for
parents of children with ASD because some stop going into public to avoid these encounters because of the fear of being “judged” (Ryan, 2010). However, attending the doctor and other healthcare appointments is unavoidable. According to DePape and Lindsay (2014), it is imperative to study parent experiences to provide insight to the parent-child dynamic by illustrating a glimpse into the everyday realities of raising a child with ASD.

**Healthcare Settings**

Healthcare settings pose particular challenges for both a child with ASD and his or her caregivers. There are several anxiety-provoking factors in healthcare settings, including: the unpredictable waiting time, sensory overload, and loud, crowded waiting rooms. This overwhelming anxiety can influence the child with ASD to become withdrawn or have behavioral outbursts (Ryan, 2010; Vaz, 2010). For example, children with ASD have a strong preference for routines; activities that interrupt the predictable daily flow of life, such as a doctor’s visit, may be difficult (Vaz, 2010). These changes in routines can trigger behavioral issues for the child with ASD (DePape & Lindsay, 2015). Further, sensory issues, the unpredictability of visits, and variability in the overall experience may lead to behaviors not typically expressed in the child’s daily life. Parents know their child best and play a key role in supporting their child in healthcare settings (Liptak et al., 2006; Vaz, 2010).

Vohra et al. (2014) discuss numerous challenges and obstacles that caregivers of children with ASD have to overcome in healthcare settings. Some are due to the complexity of ASD which requires interdisciplinary cooperation between several healthcare providers, the extensive physical and developmental comorbidities that need
significant medical attention, and the lack of evidence-based behavioral therapies for caregivers of these children. The caregivers of children with ASD have greater unmet needs pertaining to their child compared to caregivers of children with other disorders in healthcare settings; it is known that the negative experiences of caregivers and their child’s special needs conditions are associated. The researchers of this study suggested that this is in part due to the difficulties accessing services, lack of source care, limited specialty care providers for children with ASD. Moreover, caregivers of children with ASD express negative experiences from difficulties with eligibility and availability of services, delays in appointments, and difficulties obtaining information about the services.

Strunk et al. (2014) interviewed parents (i.e. caregivers) of children with ASD regarding their experiences with their children in healthcare settings. The essence of these experiences was that parents need assistance. Parents expressed feelings of hopelessness and frustration about how to manage their child’s healthcare needs along with a lack of understanding about the disorder. Strunk et al. (2014) further described that these parents have a little to no resources and limited services for their children with ASD.

One of the most important aspects of quality of care is parent satisfaction. Families are often the primary coordinators for their child’s healthcare. In order to ensure the highest quality of care for their children, caregivers must be respected, listened to, and provided with ample information (Liptak, Orlando, Yingling, Theurer-Kaufman, Malay, Tompkins, & Flynn, 2006). Vohra et al. (2014) measured quality of care by the following parameters: lack of shared decision-making, lack of coordination, and lack of routine screening or well-child visits. Participants of this study revealed that there is a
greater lack of shared decision-making and care coordination for parents of children with ASD as compared to parents of children with other disabilities. This is alarming because caregiver satisfaction within a healthcare setting is essential in having a successful experience taking the child with ASD to his or her appointment.

Visual Supports

One strategy caregivers can use to support their child and, in turn, better the overall experience in a public healthcare setting is the use of visual supports including visual schedules, calendars, Social Stories™, and 5-point scales. Armstrong, DeLoatche, Preece, and Agazzi (2015) noted that these supports are helpful for those who have communication impairments, social interaction deficits, and behavioral problems. The researchers of this study suggest that one particular aim of visual supports is to help improve social interactions; this is relevant to the present study because visual supports can be used to both prepare the child and help facilitate interactions at the child’s healthcare appointment. They specifically note that visual supports such as visual schedules are useful tools within parent-child interaction therapy and would benefit from further research. Armstrong et al. (2015) also revealed through a particular case study and parent standardized assessments that a child with ASD benefitted from the visual supports; the parents of this case study reported that they were able to take their child into public settings that they had not been able to go to before. This illustrates the effectiveness of the use of visual supports from the perspective of the caregiver.

Children with ASD respond well to visually presented information and modeling as opposed to verbal instruction (Vaz, 2010). They have strengths in their ability to easily process visual information rather than other modes of communication (Meadan,
Ostrosky, Triplett, Michna, & Fettig, 2011). Temple Grandin (1995), a well-known adult advocate with ASD, describes her mind as one that “thinks in pictures.” She says, “When somebody speaks to me, his words are instantly translated into pictures” (p. 3). This relative strength in visual thinking is enhanced by the use of visual supports for children with ASD.

For children with ASD, healthcare appointments represent a break from their typical routine and consequently, may lead to managing difficult behaviors (Mills, 2012). Mills (2012) focuses on the ways in which caregivers prepare and support their child in healthcare settings in order to have a better overall experience. Specifically, caregivers are asked about their use of visual supports. Visual supports, according to Meadan et al. (2011) “are a fairly nonintrusive intervention strategy that can be individualized easily to provide assistance in the areas of social and behavioral learning” (p. 33). Caregivers can use a variety of visual supports to aid their child in both preparation and attendance of a visit in healthcare settings. For example, the use of simple language and pictures to show what will happen is an important strategy to keep in mind when preparing a child with ASD for a visit to a healthcare setting (Vaz, 2010).

Healthcare appointments often entail waiting. Waiting is a problematic task for individuals with ASD, as it can be anxiety provoking and may be an undercurrent of disruptive behavior (Vaz, 2010). Visual supports can be used to help prepare the child for this situation, particularly healthcare appointments, as well as aid them during it (Mills, 2012). Caregivers can simultaneously converse with their child prior to attending these situations to help them prepare and be aware of what is going to happen (Vaz, 2010) as well as utilize these supports during the visit.
The visual supports examined in the current investigation include visual schedules, calendars, Social Stories™, and 5-point scales. According to Meadan et al. (2011), visual schedules help to increase autonomy by visually providing the order of daily events and activities to a child with disabilities through the use of pictures. These schedules with picture illustrations of daily tasks can help the child with ASD anticipate what will happen during a given activity, what will happen next, and identify any irregular changes in the day (Meadan et al., 2011), such as attending a healthcare appointment. Meadan et al. (2011) provides the example of lining up pictures of “table,” “snack,” “play dough,” “centers,” and “pick up/home.” This schedule provides a visual representation of the daily activities that the child will be completing.

Similar to visual schedules, calendars are another type of visual support used to help children with ASD. According to Cohen and Gerhardt (2016), calendars can be used to indicate important events. This gives the child with ASD a sense of how much time will elapse before an event will occur. For example, the child can see they are going to the doctor’s office several days before the actual appointment day. These calendars can also be formatted to provide a space for the time of day the event will be occurring (Cohen & Gerhardt, 2016). In regards to this project, caregivers can prepare their child before an appointment with the use of a calendar.

Another type of visual support that can help children with ASD in these settings is a Social Story™. Created by Carol Gray, Social Stories™ use the child’s preexisting knowledge of a social situation and incorporate it into a story that helps to anticipate and understand certain social situations that they have trouble with (Mills, 2012). Gray (2015) explains that Social Stories™ aim to convey accurate information about a specific
concept, skill, or situation in a meaningful and safe manner. These stories outline the framework of a particular situation and describe what to anticipate and how to react to these certain situations, events, or activities (Vaz, 2010). For example, Gray (2015, p. 145) created a Social Story™ about how to greet a person, the different ways to greet someone, and what the other person will do. This could be used in a public healthcare setting to prepare the child with ASD before going to the appointment by visually presenting them with information about what is going to be expected of them.

In addition, 5-point scales are another type of visual support that children with ASD may use. According to Buron and Curtis (2012), the purpose of the 5-point scale is to systematically teach children with ASD social and emotional information in a concrete and visual way that is easy to understand. These children often exhibit challenging behaviors secondary to deficits in emotional regulation and social thinking. This means they do not have the required skills necessary to effectively navigate social situations. Caregivers and their children with ASD can communicate effectively by using the same language as the 5-point scale. An example of a 5-point scale used by Buron and Curtis (2012, p. 50) to help a child with ASD regulate his or her emotions involves visual images corresponding to values from 1 to 5: (1) “I can handle this”, (2) “I am a little nervous”, (3) “Please don’t talk”, (4) “I need some space”, and (5) “I need to leave.” Accompanying these emotions could be visual representations and suggestions for activities to subdue these feelings of anxiety. The goal is to reduce the challenging behaviors that are typically expressed by giving the child with ASD a way to communicate how they are feeling and replace the troublesome behaviors with an activity. An example of a compensatory activity could be “when I am at the 4, I need to
think about relaxing by closing my eyes” (Buron & Curtis, 2012, p. 22). The 5-point scale is an example of a visual support that a caregiver and child with ASD could use in a public healthcare setting. For example, if the child experiences high levels of anxiety in the healthcare setting the 5-point scale can provide the child with coping strategies to manage the anxiety. These visual supports can help the caregivers assist their children with regulating their children’s emotions and breaking the challenging behaviors.

**Gap in Theory and Research**

Past research examining caregivers of children with ASD and their public experiences is not always situated within a theoretical framework. However, this research on caregivers’ experiences with their child with ASD fits well within the ecological human development theory (Bronfenbrenner, 1994). To illustrate, Bronfenbrenner (1994) states that one must take into account the entire ecological system in order to understand true human development. He further describes that the individual person is surrounded by five organized subsystems: microsystem, mesosystem, exosystem, macrosystem, and chronosystem. With respect to the current study, observing caregiver perspectives of their children with ASD in healthcare settings focuses on both relations in the microsystem, mesosystem, and exosystem. The microsystem involves a pattern of face-to-face activities in the person’s (child with ASD) immediate environment. This refers to the child’s interactions during the healthcare appointment. Additionally, Bronfenbrenner (1994) discusses the mesosystem level. Human activity at this level involves a system of microsystems; these are processes taking place between the child with ASD at home and at the appointment. For example, children with ASD may prepare for the appointments at home and transfer these skills to the doctor’s office and speech-language therapy clinic.
Third, the exosystem is comprised of two settings including an environment that does not involve the child directly. For example, the caregivers’ work environment can affect the child even though the child is not explicitly engaged in this setting as it is the caregivers’ workplace. In regards to this study, the caregiver’s work environment directly affects the child depending on how much time they allot to prepare their child for the appointment or how much time they have to take their child to these appointments. The questions in this study are motivated by these three primary ecological systems with a particular focus on the mesosystem level.

Theoretically grounded research is needed to examine whether the use of supports and resources alleviates some of the burden for caregivers of children with ASD (Kuhlthau et al., 2014) and whether this varies across healthcare settings (e.g. doctor’s office and speech-language therapy clinic). There is a gap in the research regarding caregivers’ experiences in healthcare settings, especially since children with ASD are significantly more likely to use these services compared to children without ASD (Vohra et al., 2014). There needs to be a focus on examining ways to lower the stress for caregivers taking their children with ASD to healthcare settings, specifically attending to caregivers’ needs and their overall quality of care. This is necessary in order to enhance the overall experience of attending appointments for both the child with ASD as well as their caregiver. In doing so, caregivers in the future will be able to use the effective visual supports to help prepare and facilitate their child in these appointments. These challenges in healthcare settings need to be discovered and further studied to help caregivers of children with ASD have better experiences.
Research Questions

The specific research questions of this study were motivated by a need to bridge the gaps in the research and theory. They are as follows: (1) What are the caregivers’ perspectives of their children’s behaviors in healthcare settings? (2) What strategies and visual supports do caregivers use to prepare their children before the visit? (3) What strategies and visual supports do caregivers use to support their children during the visit? (4) What are the similarities and differences between visits to the doctor versus the speech-language pathologist?
Chapter 2: Method

Participants

Fifty-six caregivers of children with diagnosed ASD attempted to complete the survey. Ten were excluded because: they were not the primary caregiver (n=1), duplicate surveys (n=1), child over the age of 22 (n=1), and incomplete data (n=7). Complete surveys were defined as completion of full demographic information as well as full completion of information on healthcare experiences at the doctor’s office. Less than half of the sample of children were currently receiving speech-language therapy services (n=22). Therefore, receiving speech-language therapy services was not a criterion for inclusion in this study. In total 46 participants’ data comprised the sample and were included in analyses. There were no limitations on the race, age, health status, or education of caregiver participants. Participants were all caregivers of children with ASD including but not limited to mothers, fathers, grandparents, or other relationships such as legal guardian or adopted parent. All participants were residents of the state of Ohio and the majority were female, Caucasian, English speakers, with a college-level or beyond education. See Table 1 for full demographic information on caregiver participants.

Demographics of Children

Child demographics were reported based on caregivers’ responses about their children. To be included in this study, children had to have a diagnosis of ASD per caregiver report and be between the ages of 2 and 22 years old. Though children reported on ranged from 2-22 years old, the majority of sample was older than 12, male, and diagnosed prior to age 5. Most children attended public schools, used spoken language as their primary mode of communication, and the majority had comorbid conditions
including language delays and emotional/behavioral problems. The most frequently occurring comorbid condition as indicated by caregivers was anxiety. See Table 2 for full child demographic information.

Table 1

Demographics of Caregivers of Children with ASD

<table>
<thead>
<tr>
<th>Age, mean ± SD (range)</th>
<th>44.74 ± 8.56 (28 - 67)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>2.2%</td>
</tr>
<tr>
<td>Female</td>
<td>97.8%</td>
</tr>
<tr>
<td>Relation to child (n=45)</td>
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</tr>
<tr>
<td>Mother</td>
<td>84.4%</td>
</tr>
<tr>
<td>Father</td>
<td>2.2%</td>
</tr>
<tr>
<td>Grandmother</td>
<td>24.4%</td>
</tr>
<tr>
<td>Other</td>
<td>8.9%</td>
</tr>
<tr>
<td>Race/ethnicity</td>
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</tr>
<tr>
<td>African American</td>
<td>4.3%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>8.7%</td>
</tr>
<tr>
<td>Native American</td>
<td>2.2%</td>
</tr>
<tr>
<td>White/Caucasian</td>
<td>84.8%</td>
</tr>
<tr>
<td>Education</td>
<td></td>
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<tr>
<td>High school</td>
<td>4.3%</td>
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<tr>
<td>Some college</td>
<td>26.1%</td>
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<tr>
<td>2-year college degree</td>
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<td>4-year college degree</td>
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<td>Master’s degree</td>
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<td>Doctoral degree</td>
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<tr>
<td>Geographic location of residence</td>
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<td>Central (Columbus)</td>
<td>19.6%</td>
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<tr>
<td>Northeast (Cleveland)</td>
<td>28.3%</td>
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<td>Northwest (Toledo)</td>
<td>34.8%</td>
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<tr>
<td>Southeast (Marietta)</td>
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<tr>
<td>Southwest (Cincinnati)</td>
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</tr>
<tr>
<td>Primary Language</td>
<td></td>
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<tr>
<td>English</td>
<td>97.8%</td>
</tr>
<tr>
<td>Other</td>
<td>2.2%</td>
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</tbody>
</table>

Note. n=46
Table 2

**Demographics of Children with ASD**

<table>
<thead>
<tr>
<th></th>
<th>Child with ASD (n=46)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean ± SD (range)</td>
<td>12.30 ± 5.55 (2 - 22)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>76.1%</td>
</tr>
<tr>
<td>Female</td>
<td>23.9%</td>
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<tr>
<td>ASD diagnosis</td>
<td>100%</td>
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<tr>
<td>Diagnosis age</td>
<td></td>
</tr>
<tr>
<td>&lt; 2</td>
<td>8.7%</td>
</tr>
<tr>
<td>2 – 5</td>
<td>63%</td>
</tr>
<tr>
<td>&gt; 6</td>
<td>28.3%</td>
</tr>
<tr>
<td>Education Setting</td>
<td></td>
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<tr>
<td>Homeschool</td>
<td>15.2%</td>
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<tr>
<td>Private school</td>
<td>4.3%</td>
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<tr>
<td>Public school</td>
<td>73.9%</td>
</tr>
<tr>
<td>Does not attend</td>
<td>6.5%</td>
</tr>
<tr>
<td>Comorbid diagnoses</td>
<td></td>
</tr>
<tr>
<td>ADD(^a)</td>
<td>19.6%</td>
</tr>
<tr>
<td>ADHD(^b)</td>
<td>34.8%</td>
</tr>
<tr>
<td>Emotional/behavioral problems</td>
<td>45.7%</td>
</tr>
<tr>
<td>Hearing impairment</td>
<td>2.2%</td>
</tr>
<tr>
<td>Language delay</td>
<td>54.3%</td>
</tr>
<tr>
<td>Language impairment</td>
<td>26.1%</td>
</tr>
<tr>
<td>Neurological problems</td>
<td>17.4%</td>
</tr>
<tr>
<td>Other</td>
<td>54.3%</td>
</tr>
<tr>
<td>Communication method</td>
<td></td>
</tr>
<tr>
<td>AAC(^c)</td>
<td>10.9%</td>
</tr>
<tr>
<td>Gestures</td>
<td>26.1%</td>
</tr>
<tr>
<td>Sign language</td>
<td>15.2%</td>
</tr>
<tr>
<td>Spoken language</td>
<td>87.0%</td>
</tr>
<tr>
<td>Symbol systems</td>
<td>6.5%</td>
</tr>
<tr>
<td>Other</td>
<td>4.3%</td>
</tr>
</tbody>
</table>

*Note.* SD: Standard deviation; \(^a\) Attention Deficit Disorder; \(^b\) Attention Deficit Hyperactivity Disorder; \(^c\) Augmentative and Alternative Communication

**The Survey**

To determine the perceptions of caregivers’ experiences as they prepare and facilitate a healthcare appointment, a 46-item survey was created using Qualtrics (2005) survey software. The survey consisted of four sections encompassing a variety of
closed- and open-ended questions. For the purpose of this study, Parts I, II, and III were analyzed. Part I, Demographics, included questions about participants’ age, sex, health status, education, geographic location, and primary language. This section also included questions regarding their child with ASD’s sex, age, education level, age of diagnosis, primary mode of communication, and sibling(s) age, sex, and any comorbid diagnosis.

Parts II and III, Doctor’s Office and Speech-Language Therapy Clinic, respectively, consisted of questions designed to gain insight into participants’ experiences preparing for and engaging with these settings (see Appendix A). These two healthcare settings were chosen because the relative frequency of appointments throughout a year is expected to be different, thus potentially distinguishing the results. General questions included topics such as frequency of appointment, time duration of appointment, and behaviors exhibited by the child. Survey questions also inquired about the supports and techniques caregivers use to prepare their children before taking them to the appointment as well as the supports and techniques they use at the appointment.

“At the appointment” was defined as when the child and caregiver enter the building of the doctor’s office. Rating scales similar to those used in other survey investigations (e.g., Schwartz and Drager, 2008) were utilized to assess the effectiveness of the supports and techniques. Participants were presented with statements such as “A visual schedule is effective in preparing my child before visits.” Participants then stated whether or not they agreed with this statement by indicating a numeral between 1 “Strongly disagree” and 5 “Strongly agree.” They also had the option to indicate “Not applicable” if they had never used the support with their child. Open-ended questions inquired about what could make the participants’ experiences better as well as their
experiences with their other children if applicable and any additional comments they may have. Part IV included questions about any additional children that the caregiver may have. These questions were entirely open-ended and took into account any other developmental disorders the children may have as well.

**Participant Recruitment**

Participants were recruited by an email describing the intent of this study to regional autism societies and caregiver groups across the state of Ohio (About Autism Society Ohio, 2017; Ohio Support Groups by County, 2017). The following Autism Societies were contacted for participation in this study: Central Ohio, Greater Akron, Cincinnati, Greater Cleveland, Northwest Ohio, Mahoning Valley, Dayton, and Southeast Ohio. An initial email was sent to the individual Autism Societies and caregiver groups requesting permission to use their society as a means of recruitment. Once approval from these Autism Societies and caregiver groups was granted, an email was sent to each individual society with a link to the online survey for distribution. Each society distributed the survey via email communications and social media sites (e.g., Facebook) to their members who were all caregivers of children with diagnosed ASD.

**Procedure**

The potential participants had the option to accept or decline participation in the current study. If members of the contacted Autism Societies and caregiver groups agreed to participate, they proceeded to the online survey through the attached link which included an online consent form (See Appendix B for a copy of the online consent form). Once the consent form was complete, participants followed the link to complete the Qualtrics survey provided in the email. They survey took approximately 37 minutes to
complete ($M=36.8, SD=70.46$). Demographic information such as region of Ohio, age of caregiver, education level of parent, age of child, and age of diagnosis was completed first. Then, they were presented with a variety of closed- and open-ended questions regarding their perspectives of their experiences taking their children to healthcare settings including the doctor’s office and speech therapy clinic as well as a final section about any additional children they may have.

**Quantitative Data Analysis**

Quantitative data were manually entered into SPSS software for data analysis. A trained research assistant verified the data to ensure all data was entered correctly. Frequencies and descriptive statistics (means, standard deviations, and ranges) were analyzed in IBM SPSS-23.0 Premium.

**Coding of Qualitative Data**

Qualitative comments were entered into a spreadsheet. Two trained research assistants organized the data by a thematic analysis (Derguy et al., 2015). Transcriptions were coded highlighting main themes and subthemes of participants’ responses. Disagreements were resolved via discussion.
Chapter 3: Results

Overview

Quantitative data are presented first. Quantitative results include both doctor’s office as well as speech-language therapy clinic information. Tables are provided to include additional information about the use and effectiveness by the types of supports. Qualitative data are presented in the following sections, with a particular focus on the themes that emerged from caregivers’ responses to the open-ended questions at their children’s doctor’s and speech-language therapy clinic appointments. In the final section, an unanticipated theme of retrospective accounts is presented.

Quantitative Findings

**Doctor’s Office General.** Quantitative data for the doctor’s office is represented from the full data set including all 46 participants. The highest percentage (50.0%) of caregivers indicated taking their children with ASD to the doctor’s office between 2 to 4 times per year and 43.5% of caregivers spent 1 day preparing their child for the appointment. Only 17.4% of participants indicated no preparation time before attending the appointment with their child. Caregivers (73.9%) indicated taking their children to their appointments with no other adult in attendance; only 19.6% of participants indicated taking an additional child to the appointment. At the office, 45.7% of participants revealed spending between 15 to 30 minutes in the waiting room with the majority noting their child exhibited some type of hyperactivity. See Table 3 for all quantitative data associated with visits to the doctor’s office.

**Quantitative Speech-Language Therapy Clinic General.** Less than half of caregivers (47.8%) responded that their children attended speech-language therapy. Not
all 22 caregivers completed the entire Part III of the survey. Therefore, the number of quantitative responses for the speech-language therapy clinic is provided per item on each individual table. All caregivers indicated their children attended speech-language therapy either biweekly or weekly with the majority (77.8%) waiting less than 15 minutes before their appointment. The largest proportion (38.9%) of caregivers prepared their children with ASD a few hours before going to the speech-language therapy clinic. Hyperactivity was the most frequently occurring behavior exhibited by the children as reported by the caregivers. Of the caregivers, 76.5% reported taking their children to the speech-language therapy clinic with no additional children. Over 82% of caregivers indicated no other adult attending the appointment with themselves and their child. See Table 3 for all quantitative data associated with visits to the doctor’s office.

**Better Experiences.** In regards to better experiences at the doctor’s office with their children, 37.8% of caregivers stated that “less time in the waiting room” would make their experiences better whereas only 2.2% of caregivers said “more time in the waiting room” would make their experiences better. Similar to the doctor’s office, the highest percentage (35.3%) of caregivers noted that “less time in the waiting room” would better their experiences at the speech-language therapy clinic. None of the caregivers indicated that more supports, more knowledge about how to use supports, better preparation before the visit, or more time in the waiting room would better their experiences at their child’s speech-language therapy appointment. See Table 4 for further information about factors that could potentially better caregivers’ experiences in healthcare settings.
Table 3

*General Appointment Overview*

<table>
<thead>
<tr>
<th>Frequency of appointment&lt;sup&gt;b&lt;/sup&gt;</th>
<th>Doctor’s Office (n=46)</th>
<th>Speech-Language Therapy Clinic</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 1 year</td>
<td>2.2%</td>
<td>-</td>
</tr>
<tr>
<td>Once a year</td>
<td>15.2%</td>
<td>-</td>
</tr>
<tr>
<td>2 – 4 times a year</td>
<td>50.0%</td>
<td>-</td>
</tr>
<tr>
<td>4 – 6 times a year</td>
<td>17.4%</td>
<td>-</td>
</tr>
<tr>
<td>Once a month</td>
<td>15.2%</td>
<td>-</td>
</tr>
<tr>
<td>Biweekly</td>
<td>-</td>
<td>21.1%</td>
</tr>
<tr>
<td>Weekly</td>
<td>-</td>
<td>78.9%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Time spent in waiting room&lt;sup&gt;c&lt;/sup&gt;</th>
<th>Doctor’s Office (n=46)</th>
<th>Speech-Language Therapy Clinic</th>
</tr>
</thead>
<tbody>
<tr>
<td>&gt; 1 hour</td>
<td>2.2%</td>
<td>-</td>
</tr>
<tr>
<td>30 – 60 minutes</td>
<td>8.7%</td>
<td>5.6%</td>
</tr>
<tr>
<td>15 – 30 minutes</td>
<td>45.7%</td>
<td>16.7%</td>
</tr>
<tr>
<td>&lt; 15 minutes</td>
<td>43.5%</td>
<td>77.8%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Preparation time before appointment&lt;sup&gt;c&lt;/sup&gt;</th>
<th>Doctor’s Office (n=46)</th>
<th>Speech-Language Therapy Clinic</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 weeks</td>
<td>2.2%</td>
<td>-</td>
</tr>
<tr>
<td>1 week</td>
<td>15.2%</td>
<td>-</td>
</tr>
<tr>
<td>1 day</td>
<td>43.5%</td>
<td>33.3%</td>
</tr>
<tr>
<td>A few hours</td>
<td>21.7%</td>
<td>38.9%</td>
</tr>
<tr>
<td>Never</td>
<td>17.4%</td>
<td>27.8%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Abnormal behaviors exhibited at appointment&lt;sup&gt;a, d&lt;/sup&gt;</th>
<th>Doctor’s Office (n=46)</th>
<th>Speech-Language Therapy Clinic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hyperactivity</td>
<td>42.2%</td>
<td>43.8%</td>
</tr>
<tr>
<td>Restricted, repetitive patterns</td>
<td>37.0%</td>
<td>31.3%</td>
</tr>
<tr>
<td>Outbursts</td>
<td>37.8%</td>
<td>31.3%</td>
</tr>
<tr>
<td>Other</td>
<td>48.9%</td>
<td>31.3%</td>
</tr>
</tbody>
</table>

*Note.* <sup>a</sup>n=45 for doctor’s office. <sup>b</sup>n=19 for speech-language therapy clinic; <sup>c</sup>n=18 for speech-language therapy clinic; <sup>d</sup>n=16 for speech-language therapy clinic
Table 4

<table>
<thead>
<tr>
<th>Better Experiences</th>
<th>Doctor’s Office</th>
<th>Speech-Language Therapy Clinic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Better communication with my child</td>
<td>15.6%</td>
<td>17.6%</td>
</tr>
<tr>
<td>Better communication with others</td>
<td>33.3%</td>
<td>23.5%</td>
</tr>
<tr>
<td>Better communication with the doctor/SLP</td>
<td>26.7%</td>
<td>17.6%</td>
</tr>
<tr>
<td>Better preparation before the visit</td>
<td>11.1%</td>
<td>-</td>
</tr>
<tr>
<td>Less frequent visits</td>
<td>4.4%</td>
<td>5.9%</td>
</tr>
<tr>
<td>Less time in waiting room</td>
<td>37.8%</td>
<td>35.3%</td>
</tr>
<tr>
<td>More frequent visits</td>
<td>6.7%</td>
<td>29.4%</td>
</tr>
<tr>
<td>More knowledge about how to use supports</td>
<td>22.2%</td>
<td>-</td>
</tr>
<tr>
<td>More supports</td>
<td>22.2%</td>
<td>-</td>
</tr>
<tr>
<td>More time in waiting room</td>
<td>2.2%</td>
<td>-</td>
</tr>
<tr>
<td>Other</td>
<td>17.8%</td>
<td>23.5%</td>
</tr>
</tbody>
</table>

\(^a\) n=45 for doctor’s office; \(^b\) n=17 for speech-language therapy clinic

**Doctor’s Office Supports.** Quantitative results for the doctor’s office are based on all 46 participants. The majority (80.4%) stated that their main preparation method was conversation. Conversation was also rated as the highest effective tool in preparing their child for appointments with a mean score of 4.36. Effectiveness is based on a 5-point Likert scale (1=strongly disagree and 5=strongly agree.) The second most frequently used support (28.3%) to prepare children before appointments is calendar with a mean effectiveness of 3.63. None of the caregivers indicated using a 5-point scale to prepare their child before the appointment. Similarly to preparation, 80.4% of caregivers indicated using conversation during the appointment for facilitation as well. Again, this was also the most effective support used during appointments with a mean score of 4.36. “Other” supports were the second most frequently used support during the appointment as indicated by 13.0% of the sample with a mean effectiveness score of 3.53. “Other” supports will be further discussed in the following qualitative section. See Table 5 for full comparison data between preparation (before) and facilitation of (during) appointment.
Speech-Language Therapy Clinic Supports. A total of 17 caregivers responded to survey questions inquiring about supports used at and before appointments to the speech-language therapy clinic. To prepare for appointments with the speech-language pathologist, the majority, 76.5%, of the total caregiver responses used conversation with their children. This support method also had the highest rated effectiveness with a mean score of 4.42. None of the caregivers indicated using 5-point scales or other supports prior to attending the appointment in preparation. To facilitate the appointment, caregivers again rated conversation as the most frequently used support (76.5%) with an overall mean effectiveness score of 4.29. See Table 5 for full comparison data between preparation (before) and facilitation of (during) appointment.
Table 5

Supports Used with Child Before or During Appointments

<table>
<thead>
<tr>
<th>Supports</th>
<th>Doctor’s Office (n=46)</th>
<th>Speech-Language Therapy Clinic (n=17)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Preparation (before)</td>
<td>Facilitation (during)</td>
</tr>
<tr>
<td>Visual schedule</td>
<td>15.2%</td>
<td>2.2%</td>
</tr>
<tr>
<td>Social story</td>
<td>17.4%</td>
<td>8.7%</td>
</tr>
<tr>
<td>5-Point scale</td>
<td>-</td>
<td>2.2%</td>
</tr>
<tr>
<td>Conversation</td>
<td>80.4%</td>
<td>80.4%</td>
</tr>
<tr>
<td>Calendar</td>
<td>28.3%</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>8.7%</td>
<td>13.0%</td>
</tr>
<tr>
<td>None</td>
<td>8.7%</td>
<td>6.5%</td>
</tr>
</tbody>
</table>

Effectiveness of support, mean (SD)

<table>
<thead>
<tr>
<th>Supports</th>
<th>Doctor’s Office</th>
<th>Speech-Language Therapy Clinic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visual schedule</td>
<td>3.12 (1.34)</td>
<td>2.97 (1.38)</td>
</tr>
<tr>
<td>Social story</td>
<td>3.08 (1.42)</td>
<td>2.73 (2.05)</td>
</tr>
<tr>
<td>5-Point scale</td>
<td>2.30 (1.00)</td>
<td>2.59 (0.37)</td>
</tr>
<tr>
<td>Conversation</td>
<td>4.36 (1.00)</td>
<td>4.42 (0.80)</td>
</tr>
<tr>
<td>Calendar</td>
<td>3.63 (1.44)</td>
<td>4.26 (0.60)</td>
</tr>
<tr>
<td>Other</td>
<td>3.21 (1.56)</td>
<td>3.83 (0.11)</td>
</tr>
</tbody>
</table>

Note. Other supports and techniques will be further discussed in the Qualitative Data section.
Qualitative Findings

Doctor’s Office Thematic Analysis. Doctor’s office qualitative responses are based on the following number of participant responses as it was not required to complete all open-ended questions on the survey: before the appointment (n=17), during the appointment (n=20), better experiences (n=8), and additional comments (n=19). The analysis was divided into three categories. Categories 1 and 2, before and during the appointment, elicited three themes each: verbal supports, visual supports, and other. First, verbal supports included the verbal techniques the caregivers used with their child both before and after the appointment. Second, visual supports encompass the visual stimuli to prepare for and facilitate the appointment. Finally, extraneous comments were thematically analyzed into an “other” theme. The third category combines open-ended survey questions inquiring about caregivers’ opinions as to what could make appointments better and any additional comments the caregiver may have about attending the doctor’s office. Each theme within each category yields a variety of subthemes. The order in which themes are presented does not reflect importance.

Category 1: Before the Appointment.

Theme 1: Verbal supports. When asked what types of supports and techniques caregivers use to prepare their child before the appointment, 47.1% of the overall sample size responded with statements of using verbal supports in various ways to prepare their children with ASD. Caregivers indicated using conversations and explanations to prepare their child. For example, one caregiver noted, “We discuss what will happen, and what we will do afterwards.” In addition to explanations, the event sequence described in the previous quote was another subtheme emerging from verbal supports. Caregivers also
indicated using reminders to prepare their child. “Constant reminders where we are going, how to behave, and then where we go after” was said by a caregiver. Explanations, reminders, and event sequence all are found within the theme of verbal supports.

*Theme 2: Visual supports.* Caregivers not only expressed use of verbal supports, they (n=7) but also expressed using visual supports to prepare their child for doctor’s appointments. One caregiver noted:

> I talk to him verbally and let him know we are going to the doctor. He sees the visual calendar. I give him lots of warnings when we are ready to leave. He usually brings his DS system or tablet for the drive there and the wait time.

This quotation explores using a combination of both verbal and visual supports with children with ASD, a common theme within the open-ended responses as indicated by caregivers. Another example of using visual supports to prepare children with ASD before appointments is as follows:

> Before each appointment I will visit a new doctor’s office location. I will take actual pictures of the inside and outside of the building, waiting room, reception area, and exam room. If available, I will take a picture of the doctor or find the pictures on the internet. I print them and make a Social Story™ for my son. I also include information that is relevant to the appointment, dental, eye etc. it would be wonderful and very simple if each doctor had these available on the internet for patients and families to take advantage of.

The use of event sequence, technology, and distractions were all subthemes emerging within using visual supports to prepare children with ASD before their appointment.
Theme 3: Other supports. The final theme in Category 1, Before the Appointment, is the use of other supports. Other supports as indicated by caregivers were rewards, music, and motivators. These subthemes did not specifically fall under verbal supports nor visual supports, hence the need for their own category. An example of using other supports to prepare for visits to the doctor’s office is, “We might use his favorite motivation: food. For example, if you are good at the doctor appointment then you can have a burger.” A portion of the caregivers (17.3%) used these other techniques in addition to verbal and visual supports.

Category 2: During the Appointment.

Theme 1: Verbal supports. A total of 20 caregivers responded when asked what types of supports and techniques they use at their child’s appointment. The first theme to emerge was again, verbal supports. Subthemes emerging based on caregiver report of facilitation of the appointment with verbal supports are as follows: reminders, repetition, event sequence, and explanations. One caregiver said, “We talk a lot about what’s next at the appointment and after we leave.” This is an example of utilizing event sequences with the child with ASD during doctor’s appointments.

Theme 2: Visual Supports. The second emerging theme within Category 2 was visual supports. Similar to before the visit, subthemes found are event sequence, technology, and entertainment. Caregivers also noted a shift in utilizing various supports based on their children’s developmental age. One caregiver said:

When my son was younger, we used various strategies to help decrease anxiety and help him understand the procedures he would encounter. These included
visual schedules and Social Stories™ until he was of middle school age. After middle school, open, clear communication has been the primary support provided. The use of visual supports was reported from 7 caregivers.

*Theme 3: Other Supports.* Extraneous responses not specifically falling under the themes of verbal or visual supports were put in the other support category. Subthemes of other supports are doctor communication, distractions, and sensory input. Some types of distractions are music, snacks, and toys. For example, one caregiver said, “We always have special, favorite toy/activity for visits. Also, he enjoys having his back scratched so we sometimes do that too.” A total of 8 caregivers responded with other supports being an effective way to facilitate the appointment with their child.

*Category 3: Additional Comments.* The final category involves a combination of 2 questions from the survey. The first question inquired about what could make the experiences for not only the child better but also the caregiver when taking their child to doctor’s appointments. A total of 8 responses were recorded for this question. The second and final open-ended question asked for caregivers to state any additional comments or thoughts about their perception of taking their child with ASD to these appointments. A total of 19 responses were recorded. Three caregivers indicated challenges occurring with waiting. Some indicated spending too much time waiting in the actual examination room itself. One caregiver indicated more activities in the waiting room would better his or her experiences for his or her child with ASD.

A few caregivers (n=3) responded by expressing their positive experiences at the doctor’s office. These caregivers praised their child’s physicians for being understanding and “wonderful.” One caregiver expressed:
We are very fortunate to have great primary care physicians for our children. They have been helpful and supportive. We do try to see the same physician in the group every time we go. This is extremely helpful for our son who likes consistency. The office is very good about accommodating this.

Another caregiver positively commented on her child’s doctor’s explanations to her son. She said:

Many doctors will take their time with our son and explain and let our children explore their instruments before using them. This is very beneficial. Also, a sticker or some type of reward is helpful. Our biggest concern as a parent with a child with autism, often times his symptoms are blamed on his diagnosis of autism. It would be extremely beneficial for our children for the doctor to treat individual symptoms rather than the typical doctor’s response of “Unfortunately, children with autism are notoriously known to have sleep issues, digestive problems, anxiety, etc.”

In addition to all of the positive experiences caregivers have at the doctor’s office, a proportion of the sample also expressed some challenges that they face taking their child to appointments. These challenges experienced are not intended to undermine the positive role a physician has on a child’s development and health. Caregivers simply expressed medical staff training about ASD could benefit the child, the caregiver, and ultimately the doctor as well. Over half (51.9%) of the responses recorded indicated that medical staff training would improve their experiences at the doctor’s office. Several caregivers indicated the environment could be altered to improve the experiences of children with ASD. For example, one caregiver noted, “Doctor’s office needs to be more
autism friendly.” An additional caregiver expressed concerns about the environment of the office:

In the past, when my son was younger, there were no apparent supports offered by my son’s pediatrician or their staff. We often waited a long time in a waiting room with far too many distractions—other children, messy environment, loud interactions, etc. Once inside the “examination room” the environment was cold and sterile with mostly hard/cold surfaces and little comfort. These circumstances added to the anxiety my son experiences as a younger child. My memories of these visits include tears from him, my trying to soothe him as we sat together waiting for the doctor to see him.

This caregiver has a child with ASD who now has better experiences at his appointments, but was recalling the challenges experienced when her child was younger. Caregivers also reported training the medical staff about various community supports for the whole family. Doctor knowledge of resources could greatly improve experiences as found in parent report open-ended questions. For example, another caregiver said, “Doctors need training on how to support families. They need to know about the struggles we face and community resources available.” In sum, medical staff training was a frequent theme found within Category 3.

**Speech-Language Therapy Clinic Thematic Analysis.** Due to a smaller number of children with ASD attending speech-language therapy all together (n=22), there were too few qualitative responses to complete a thematic analysis. Only 10 caregivers total provided responses to all of the open-ended questions on the survey. Caregivers indicated using reminders and event sequence both before and during their child’s appointments
with the speech-language pathologist. One caregiver said he or she uses “discussion about rewards and expected behavior for a successful appointment” to prepare for these appointments. Another said, “reminders about what is going on” is their primary support to facilitate the appointment with their child. A variety of positive comments about caregivers’ experiences at the clinic with their children also were apparent. For example, one caregiver said, “She usually doesn’t want to leave.” Another stated, “There are lots of kid friendly activities in their waiting room and my granddaughter loves going. She hardly ever has behaviors during her visit.” One other caregiver noted, “Because we are in the speech therapy clinic more often, these visits have become more ‘routine’ and cause less disruptions to our day.” The frequency of appointments plays a role in positive experiences with the speech-language pathologist.

The challenges experienced with attending the speech-language therapy clinic with a child with ASD were centered on inconsistencies and environmental factors. For example, one caregiver said “Consistent staff. We tend to get used to a therapist and then they get moved or they leave” when asked what could improve experiences at the clinic with their child. Another challenge faced in the clinic was recorded as follows:

The waiting area is very noisy with many children arriving and departing along with family members. The waiting area is where the speech-language pathologist informs the parent how the session went and what to work on at home. It would be more beneficial if the parent and speech-language pathologist bet in the therapy room at the end of the session or if there was a transitional area between leaving the therapy room and entering the waiting area.
These challenges expressed by caregivers of children with ASD are again not to undermine the speech-language therapy clinic. They represent responses as reported by the caregivers.

**Retrospective Overview**

One general, a consistent theme within the qualitative data was the comparison between experiences when the child was younger to current experiences. Since the mean age of children studied was 12.30, caregivers had the ability to retrospectively reflect on their time spent preparing for and going to doctor’s appointments. Caregivers often expressed having a more challenging outlook on experiences when their children were younger relative to children in adolescence. One caregiver noted, “When he was younger, he would have meltdowns, now that he’s older he plays on his phone and doesn’t mind going.” They also expressed using more visual supports in the early years of taking their child to the appointment rather than verbal communication and conversations used currently. For example, “When my child was younger, we use a visual reminder for him. Now that he’s older, we tell him the day before and the day of we remind him,” and “As a younger child, I used more supports in preparing my son for appointments…” Some indicated the use of conversation and modified visual supports benefiting their child: Used Social Stories™ and visual schedules when our son was younger and nonverbal. Excellent tools. Now he is older and has better communication skills, we augmented to a verbal communication, calendar, and a list of activities of the week broke up by days. The list is our modification of a traditional calendar. He seems to be able to process the lists better than the graphic organizer of a calendar.
Transition to Adulthood

Contrasting with the previous finding with caregivers reporting less challenging experiences with their older children, another overall theme apparent was difficulties with transition to adulthood. Caregivers expressed concerns with having their children becoming completely independent when they turn 18, “This has to change for all those coming into adulthood.” Another caregiver stated:

It was harder when he was younger. Now that he’s older he understands more about what they’re doing and can ask questions himself. I’m trying to get him to advocate more for himself and since he’s over 18, he is the one who signs things and has to be more knowledgeable now. So, I guess you would say there’s a trade-off in that some things are easier, but, some things are harder now. I have to make sure I ask the doctor(s) all the right questions after the visit(s). He doesn’t remember and has a hard time telling me what they said.

Some children with ASD need less visual supports as they get older, but they need more assistance in gaining independence. Caregivers made note that their children need better programs and assistance regarding the transition into adulthood period of their children’s lives.
Chapter 4: Discussion

The goal of this study was to examine the perceptions of caregivers of children with ASD and their experiences taking their child to healthcare appointments. Caregivers prepare and support their child before and during appointments based on their child’s individual needs and preferences. Caregivers of children with ASD know their child best; they know their child’s preferred mode of communication, favored type of reward, and their specific sensitivities (Vaz, 2010). Therefore, the most knowledgeable people to prepare and facilitate appointments with children with ASD is their caregivers. It is imperative to individually look at each child to determine what is best. Caregivers noted a variety of positive and challenging experiences during healthcare appointments. The findings of this study offer some insight into the experiences of raising a child with ASD, specifically when taking him or her to healthcare appointments. Caregivers used a combination of both verbal and visual supports with their child. As needed, caregivers should be encouraged to utilize these supports with their children before and during appointments. Discussion of the results focus on the use of both verbal and visual supports with the child.

The majority of caregivers surveyed in this study had children who used spoken language as their primary mode of communication. This aligns with the qualitative major and most frequently occurring theme of verbal supports to both prepare and facilitate appointments. Verbal supports were also rated as the most effective support used with a child with ASD. For example, to prepare the child, conversation had a mean effectiveness of 4.36 as compared to the highest rated visual support, a calendar, with a mean effectiveness of 3.63. Past studies have reported that brief conversations can make for a
successful clinical encounter (Vaz, 2010). Caregivers used verbal supports to explain what is going on to their children, remind their children of certain aspects of the appointment, and discuss event sequences such as what they will do after the appointment. This was possible with the sample of children from this study because the majority used verbal language as their primary mode of communication.

Similar to past research (Vaz, 2010; Meaden et al., 2011), caregivers also reported using visual supports with their children with ASD. This was a second theme that emerged in the thematic analysis. Caregivers in this study reported using visual supports specifically for event sequence, reminders, and repetition. Children with ASD often have challenges transitioning to different environments and activities (Knight, Sartini, & Spriggs, 2014). Attending appointments to the doctor’s office not only involve multiple transitions and sequences of events, but they also represent a change in their typical daily routine. Changes in routine may lead to anxiety and thus behavioral outbursts such as hand flapping, rocking, or other repetitive body movements in children with ASD (Vaz, 2010).

Caregivers in this study indicated primarily using visual schedules and calendars as strategies to prepare their child before appointments to prepare their children for the change in routine. These tools are known to be effective and practical in reducing challenging behaviors (Knight et al., 2014, Meadan et al., 2011) and should be encouraged as a practical tool for children with ASD when transitioning to new settings. Social Stories™, another visual support used with children with ASD as reported by caregivers are also an effective tool to help with social behavior in situations that people with ASD may not fully understand (Meadan et al., 2011).
The most frequently reported comorbid diagnosis for children with ASD was anxiety. Children with ASD find medical appointments to be extremely anxiety-provoking, thus potentially causing challenging behaviors (Vaz, 2010). This anxiety can be heightened in the waiting room of the appointment. Caregivers in this study indicated difficulties with waiting in both the waiting room and the exam room itself. The majority reported that less time waiting would better their overall experiences at their child’s appointments. This is also in line with past research in that waiting is one of the most difficult tasks for children with ASD (Vaz, 2010).

Results of this study also revealed a common theme of medical staff training programs. Medical staff training programs could provide medical professionals with information and resources that they could in turn provide to caregivers. This training could also specifically focus on transitioning the child with ASD into adulthood. Based on caregiver report, doctor’s offices are often not as autism friendly or informative as they could be. Minnes and Steiner (2008) called for a large-scale survey in order to identify the different healthcare needs from varying disabilities across the lifespan. The survey in this study revealed caregivers of children with ASD in particular feel that medical staff training would be beneficial. This is in line with past research revealing the need for syndrome-specific education for medical students (Minnes & Steiner, 2008). Caregivers in this study expressed concerns that their overall quality of care would be significantly increased if medical staff could provide them with additional community resources. Previous studies have found similar results regarding caregivers’ dissatisfaction with their experiences in healthcare settings because medical staff do not
have access to information about additional resources and supports to provide caregivers (Liptak et al., 2006; Strunk et al., 2014).

To the author’s knowledge, this is the first study to examine specifics of doctor’s appointments and visits to the speech-language therapy clinic. This is the first study of its kind to compare and contrast supports used before medical appointments and during the appointment as well. Past studies examining children with disabilities in healthcare settings have looked at access to services, understanding/satisfaction of healthcare systems, and quality of care (Vohra et al., 2014; Strunk et al., 2014; Liptak et al., 2006). This study is novel in that it examines not only the caregivers’ perspectives of their experiences with their children in healthcare settings, but it also specifically examines what the caregivers do with their child before and during the appointment in order to enhance the overall experience and lower the stress for themselves and their child at healthcare appointments.

In doing so, this study is situated within the theoretical framework of Bronfenbrenner (1994) as it does not only specifically look at the child with ASD. It observes the child with their caregivers and in environments such as healthcare appointments. Observing a child at the doctor’s office or speech-language therapy clinic involves examining the child’s microsystem, mesosystem, and exosystem. Studying what the child does to prepare at home and what they do at the healthcare setting is beneficial because the child is interacting with both their caregivers and the doctor or speech-language pathologist.
Limitations

This study is limited to a small sample of caregivers currently living in Ohio. Larger sample sizes including caregivers from other states could increase the generalizability of these findings and allow for additional analyses exploring the effects of age and communication modality on the types of supports used by caregivers. The majority of children in this study used verbal communication as their primary mode of communication, consequently limiting the need for visual supports. An additional limitation involves recruitment. Researchers in this study recruited participants via autism societies and support groups. Some caregivers of children with ASD, especially younger children, may not be involved in or aware about these groups. Another limitation of the current study is the lack of a control group. It would be beneficial to compare the results of this study to children without ASD. Finally, the caregivers with children with ASD may not have time to complete the full survey. A number (n=10) of submitted surveys did not have fully complete data and therefore the survey response had to be excluded.

Future Directions

Future investigations should explore the types of supports used as a function of developmental status, severity level of ASD, and communication modality. Also, an unanticipated theme that emerged in this study involved caregivers’ discussion of retrospective accounts of experiences in healthcare. In future studies, researchers could systematically explore experiences during childhood vs. adolescence/early adulthood and compare experiences in healthcare between different developmental time frames.

Additional future directions include evaluating the use and effectiveness of both verbal and visual supports with children with ASD whose primary mode of
communication is not spoken language. Technology was indicated to both prepare and facilitate the healthcare appointment; future studies should explore the use of technology in healthcare settings. Finally, results of this study suggest the need for medical staff training. Possibilities include developing outreach programs and focused continuing education efforts to enhance medical professionals’ interactions with children with ASD in healthcare settings.

**Conclusions**

Results of this study provide some insight into the lives of caregivers of children with ASD while taking their child to the doctor’s office and speech-language therapy clinic. Caregivers indicated using a variety of both verbal and visual supports to better their experiences with their child before and during healthcare appointments. Caregivers of children with ASD are encouraged to use supports with their child to help them attend and to support them during healthcare appointments as it is a break in their daily routine. By using verbal and visual supports for children with ASD, caregivers and healthcare providers can work together to ensure that experiences in healthcare settings are beneficial to all stakeholders involved. Finally, it is imperative to study caregivers of children with ASD to gain a better understanding of the unique strengths and challenges of the child across settings.
References


DePape, A.-M., & Lindsay, S. (2015). Parents’ experiences of caring for a child with


Appendix A: Demographic and Healthcare Settings Questions from the Survey

DEMOGRAPHICS

Please complete the following questions about yourself and one of your children with autism spectrum disorder. Note that "doctor" in this survey represents your child's primary care physician.

Please answer the following questions about YOUR CHILD.

1. Is your child diagnosed with autism spectrum disorder?
   ( ) Yes  ( ) Once a year

2. What is the biological sex of your child?
   ( ) Male  ( ) Female

3. What was your child's age on his or her last birthday? ________________

4. At what age was your child diagnosed with autism spectrum disorder?
   ( ) Younger than 2  ( ) 2  ( ) 3
   ( ) 4  ( ) 5  ( ) Older than 6

5. What is your child's primary education setting?
   ( ) Homeschool  ( ) Private school  ( ) Public school
   ( ) Does not attend school

6. What grade of school is your child currently in?
   ( ) Not applicable  ( ) Preschool  ( ) Kindergarten
   ( ) 1st grade  ( ) 2nd grade  ( ) 3rd grade
   ( ) 4th grade  ( ) 5th grade  ( ) 6th grade
   ( ) 7th grade  ( ) 8th grade  ( ) 9th grade
   ( ) 10th grade  ( ) 11th grade  ( ) 12th grade
   ( ) Other (Please specify) ____________________

7. How many siblings does your child have?
   ( ) No siblings  ( ) 1  ( ) 2
   ( ) 3  ( ) 4  ( ) More than 4
   (please specify) ____________________
8. Please provide additional information about each sibling.
   Date of birth
   Sex
   Does this child have an autism spectrum disorder diagnosis?
   Does this child have other developmental disability or language disorder?

9. Indicate any other diagnoses your child has. Please select all that apply.
   ( ) Attention Deficit Disorder   ( ) Attention Deficit Hyperactivity Disorder
   ( ) Emotional/behavioral problems   ( ) Hearing impairment
   ( ) Language delay   ( ) Language impairment
   ( ) Neurological problems   ( ) Other (please specify) ____________________

10. Does your child have an individualized education program (IEP)?
    ( ) Yes   ( ) No

11. Does your child have a 504 plan?
    ( ) Yes   ( ) No

12. In what ways does your child communicate? Please select all that apply.
    ( ) Augmentative & alternative communication system (iPad, Tobii Dynavox, LAMP)
    ( ) Gestures
    ( ) Sign language
    ( ) Spoken language
    ( ) Symbol systems
    ( ) Other (please specify) ____________________

Please answer the following questions about YOURSELF.

13. What is your biological sex?
    ( ) Male   ( ) Female

14. What was your age on your last birthday? ____________________

15. Are you the primary caregiver or legal guardian of your child?
    ( ) Yes   ( ) No

16. What is your relation to your child?
    ( ) Mother   ( ) Father   ( ) Grandmother
    ( ) Grandfather   ( ) Aunt   ( ) Uncle
    ( ) Foster parent   ( ) Other (please specify) ____________________
17. What is your race or ethnicity?
   ( ) African American   ( ) Asian   ( ) Hispanic
   ( ) Native American   ( ) Pacific Islander   ( ) White/Caucasian
   ( ) Other ____________________

18. What is the highest level of education you have completed?
   ( ) Less than High School   ( ) High School / GED   ( ) Some College
   ( ) 2-year College Degree   ( ) 4-year College Degree   ( ) Masters Degree
   ( ) Doctoral Degree   ( ) Professional Degree (JD, MD)

19. How would you describe the geographic location where you live in Ohio?
   ( ) Northeast (Cleveland)   ( ) Northwest (Toledo)
   ( ) Southeast (Marietta)   ( ) Southwest (Cincinnati)
   ( ) Central (Columbus)

20. What is the primary language spoken in your household?
   ( ) English   ( ) Chinese   ( ) French
   ( ) Spanish   ( ) Other (please specify) ____________________

DOCTOR'S OFFICE

*Please complete the following questions about your experience with your child at the doctor's office. Doctor’s office is defined as your child’s primary care physician during scheduled, routine appointments.*

1. How frequently do you take your child to the doctor's office?
   ( ) Less than once a year   ( ) Once a year   ( ) 2-4 times a year
   ( ) 4-6 times a year   ( ) Once a month   ( ) Biweekly
   ( ) Weekly   ( ) More than once a week

2. How long do you spend in the waiting room on an average visit?
   ( ) More than 1 hour   ( ) 30-60 minutes   ( ) 15-30 minutes
   ( ) Less than 15 minutes

*Before the Appointment*

3. How long in advance do you prepare your child for appointments at the doctor's office?
   ( ) More than 1 month   ( ) 1 month   ( ) 2 weeks
   ( ) 1 week   ( ) 1 day   ( ) A few hours
   ( ) Never
4. What supports and techniques do you use to prepare your child for appointments at the doctor's office? Please select all that apply.

( ) Visual schedule  ( ) Social story  ( ) 5-Point scale
( ) Conversation  ( ) Calendar  ( ) Other
( ) None

*Please use the following scale to complete the following questions about the doctor's office.*

5- Strongly agree
4- Agree
3- Neutral
2- Disagree
1- Strongly disagree

5. A visual schedule is effective in preparing my child before visits. [___]
6. A social story is effective in preparing my child before visits. [___]
7. A 5-point scale is effective in preparing my child before visits. [___]
8. A conversation is effective in preparing my child before visits. [___]
9. A calendar is effective in preparing my child before visits. [___]
10. Other supports are effective in preparing my child before visits. [___]

*Please answer the following open-ended question.*

11. If you use any other types of supports or techniques to prepare your child before the appointment, please explain. Indicate the strategies you use with your child to make your experience preparing for the doctor's office easier. ________________________________

*At the Appointment*

12. What supports and techniques do you use at the appointment? At the appointment begins when you enter the building of the doctor's office. Please select all that apply.

( ) Visual schedule  ( ) Social story  ( ) 5-Point scale
( ) Conversation  ( ) Other  ( ) None

*Please use the following scale to complete the following questions about the doctor's office.*

5- Strongly agree
4- Agree
3- Neutral
2- Disagree
1- Strongly disagree

13. A visual schedule is effective in helping my child during visits. [___]
14. A social story is effective in helping my child during visits. [___]
15. A 5-point scale is effective in helping my child during visits. ______
16. A conversation is effective in helping my child during visits. ______
17. A calendar is effective in helping my child during visits. ______
18. Other supports are effective in helping my child during visits. ______

Please answer the following open-ended question.

19. If you use any other types of supports or techniques at your child's appointment, please explain. Indicate the strategies you use with your child to make your experience at the doctor's office easier. ____________________________

Please answer the following questions about taking your child to the doctor's office.

20. Indicate any abnormal behaviors your child exhibits at the doctor's office. Please select all that apply.
   ( ) Hyperactivity (e.g. running around, crawling, any constant motion, etc.)
   ( ) Outbursts (e.g. crying, yelling, tantrums, etc.)
   ( ) Restricted, repetitive patterns (e.g. repeat phrases, rocking, etc.)
   ( ) Other (please specify) ____________________________

21. Do you typically take your child to the doctor's office alone or with your other children?
   ( ) Not applicable ( ) Alone ( ) With other children

22. Do you typically take your child to the doctor's office alone or with your other children?
   ( ) Not applicable ( ) Alone ( ) With another adult

23. Indicate what could make your experiences at or before the doctor's office better. Please select all that apply.
   ( ) Better communication with my child
   ( ) Better communication with others at the doctor’s office
   ( ) Better communication with the doctor
   ( ) Better preparation before the visit
   ( ) Less frequent visits
   ( ) Less time in waiting room
   ( ) More frequent visits
   ( ) More knowledge about how to use supports
   ( ) More supports
   ( ) More time in waiting room
   ( ) Other (please specify) ____________________________
Please answer the following open-ended question.

24. Please state any additional comments about your perspective of your experience taking your child to the doctor's office.

**SPEECH-LANGUAGE THERAPY CLINIC**

Please complete the following questions about your experience with your child at the speech-language therapy clinic.

1. Does your child attend speech-language therapy clinic?
   (Yes) (No)

2. How frequently do you take your child to the speech-language therapy clinic?
   ( ) Less than once a year ( ) Once a year ( ) 2-4 times a year
   ( ) 4-6 times a year ( ) Once a month ( ) Biweekly
   ( ) Weekly ( ) More than once a week

3. How long do you spend in the waiting room on an average visit?
   ( ) More than 1 hour ( ) 30-60 minutes ( ) 15-30 minutes
   ( ) Less than 15 minutes

**Before the Appointment**

4. How long in advance do you prepare your child for appointments at the speech-language therapy clinic?
   ( ) More than 1 month ( ) 1 month ( ) 2 weeks
   ( ) 1 week ( ) 1 day ( ) A few hours
   ( ) Never

5. What supports and techniques do you use to prepare your child for appointments at the speech-language therapy clinic? Please select all that apply.
   ( ) Visual schedule ( ) Social story ( ) 5-Point scale
   ( ) Conversation ( ) Calendar ( ) Other
   ( ) None

Please use the following scale to complete the following questions about the speech-language therapy clinic.

5- Strongly agree
4- Agree
3- Neutral
2- Disagree
1- Strongly disagree

6. A visual schedule is effective in preparing my child before visits. _____
7. A social story is effective in preparing my child before visits.  
8. A 5-point scale is effective in preparing my child before visits.  
9. A conversation is effective in preparing my child before visits.  
10. A calendar is effective in preparing my child before visits.  
11. Other supports are effective in preparing my child before visits.

Please answer the following open-ended question.

12. If you use any other types of supports or techniques to prepare your child before the appointment, please explain. Indicate the strategies you use with your child to make your experience preparing for the speech-language therapy clinic easier. ______________________

At the Appointment

13. What supports and techniques do you use at the appointment? At the appointment begins when you enter the building of the speech-language therapy clinic. Please select all that apply.

( ) Visual schedule    ( ) Social story    ( ) 5-Point scale
( ) Conversation      ( ) Other         ( ) None

Please use the following scale to complete the following questions about the speech-language therapy clinic.

5- Strongly agree
4- Agree
3- Neutral
2- Disagree
1- Strongly disagree

14. A visual schedule is effective in helping my child during visits.  
15. A social story is effective in helping my child during visits.  
16. A 5-point scale is effective in helping my child during visits.  
17. A conversation is effective in helping my child during visits.  
18. A calendar is effective in helping my child during visits.  
19. Other supports are effective in helping my child during visits.

Please answer the following open-ended question.

20. If you use any other types of supports or techniques at your child's appointment, please explain. Indicate the strategies you use with your child to make your experience at the speech-language therapy clinic easier. ______________________
Please answer the following questions about taking your child to the speech-language therapy clinic.

21. Indicate any abnormal behaviors your child exhibits at the speech-language therapy clinic. Please select all that apply.
   ( ) Hyperactivity (e.g. running around, crawling, any constant motion, etc.)
   ( ) Outbursts (e.g. crying, yelling, tantrums, etc.)
   ( ) Restricted, repetitive patterns (e.g. repeat phrases, rocking, etc.)
   ( ) Other (please specify) ____________________

22. Do you typically take your child to the speech-language therapy clinic alone or with your other children?
   ( ) Not applicable      ( ) Alone      ( ) With other children

23. Do you typically take your child to the speech-language therapy clinic alone or with your other children?
   ( ) Not applicable      ( ) Alone      ( ) With another adult

24. Indicate what could make your experiences at or before the speech-language therapy clinic better. Please select all that apply.
   ( ) Better communication with my child
   ( ) Better communication with others at the speech-language therapy clinic
   ( ) Better communication with the speech-language pathologist
   ( ) Better preparation before the visit
   ( ) Less frequent visits
   ( ) Less time in waiting room
   ( ) More frequent visits
   ( ) More knowledge about how to use supports
   ( ) More supports
   ( ) More time in waiting room
   ( ) Other (please specify) ____________________

Please answer the following open-ended question.

25. Please state any additional comments about your perspective of your experience taking your child to the speech-language therapy clinic.
Appendix B: Consent Form

Ohio University Online Consent Form

Title of Research: Caregiver’s Experiences with their Child with Autism Spectrum Disorder in Healthcare Settings
Researchers: Dr. Joann P. Benigno, Bridget K. Coologhan, Bridget M. Gornicheck, Courtney Barker, and Heather Hamm

You are being asked to participate in research. For you to be able to decide whether you want to participate in this project, you should understand what the project is about, as well as the possible risks and benefits in order to make an informed decision. This process is known as informed consent. This form describes the purpose, procedures, possible benefits, and risks. It also explains how your personal information will be used and protected. Once you have read this form and your questions about the study are answered, you will be asked to participate in this study. You may print a copy of this document to take with you.

Explanation of Study
This study is being done because we are interested in investigating more about the experiences of caregivers taking their children with autism spectrum disorder (ASD) to healthcare settings including the doctor’s office and speech-language therapy clinic. We would like to gain an understanding of the techniques, supports, and strategies that are used to help prepare and navigate through these experiences. We hope that the information gathered can be used to create clinical techniques to support children’s behavior in healthcare settings to provide caregivers with a satisfying experience. If you agree to participate, you will be asked to complete an online survey comprised of closed- and open-ended questions. Questions will include a brief section about basic demographics, individual sections with questions relating to your experiences at the doctor’s office and speech-language therapy clinic with your child, and an additional children section.

You should not participate in this study if you are not the caregiver of a child with or without ASD or if your child is not between the ages of 2 and 22 years old.

Your participation in the study will last for the amount of time it takes you to complete our survey.

Risks and Discomforts
No risks or discomforts are anticipated.

Benefits
This study is important to science/society because society will learn more about other parent experiences of children with and without ASD in healthcare settings. They will also gain an understanding of techniques, supports, and strategies to help prepare and navigate through these healthcare experiences. It is necessary to gain an understanding of
caregivers’ perspectives to help facilitate these experiences for not only the caregiver but also the child. The information gathered from this study can be used to create different clinical techniques to support children’s behavior in healthcare settings to provide the caregivers with a satisfying experience.

Confidentiality and Records
Your study information will be kept confidential because it is an anonymous survey; therefore, no personal information will be shared.

For maximum confidentiality, please clear your browser history and close the browser before leaving the computer.

Additionally, while every effort will be made to keep your study-related information confidential, there may be circumstances where this information must be shared with:

* Federal agencies, for example the Office of Human Research Protections, whose responsibility is to protect human subjects in research;
* Representatives of Ohio University (OU), including the Institutional Review Board, a committee that oversees the research at OU;

Contact Information
If you have any questions regarding this study, please contact the investigator, Bridget Coologhan or the advisor, Dr. Joann Benigno, at 740-597-2993

If you have any questions regarding your rights as a research participant, please contact Dr. Chris Hayhow, Director of Research Compliance, Ohio University, (740)593-0664 or hayhow@ohio.edu.

By agreeing to participate in this study, you are agreeing that:

- you have read this consent form (or it has been read to you) and have been given the opportunity to ask questions and have them answered;
- you have been informed of potential risks and they have been explained to your satisfaction;
- you understand Ohio University has no funds set aside for any injuries you might receive as a result of participating in this study;
- you are 18 years of age or older;
- your participation in this research is completely voluntary;
- you may leave the study at any time; if you decide to stop participating in the study, there will be no penalty to you and you will not lose any benefits to which you are otherwise entitled.