

Understanding the Impact of Medical Procedures on Individuals with Asperger Syndrome

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Abstract

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Understanding the Impact of Medical Procedures on Individuals with Asperger Syndrome

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Research on the impact of hospitalization on individuals with Asperger Syndrome and Autism Spectrum Disorder is beginning to grow. Asperger Syndrome is starting to get recognition but limited research has examined the effects and the impact of medical procedures. This research project utilized a questionnaire for individuals with Asperger Syndrome who had previous medical experiences to evaluate effective and noneffective ways certified Child Life Specialists were helpful or not helpful during the experiences. Common themes and considerations for effective practice and support for individuals with Asperger Syndrome are discussed.

Dedication

To my husband, mom, dad, family, friends, and professionals who have supported and guided me through my academic journey.

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Chapter 1: Introduction

Background Information

Certified Child Life Specialists (CCLSs) are trained professionals with a strong background in child development and family systems who assist children and families during some of the most challenging events during hospitalization (Child Life Council, 2015). CCLSs promote effective coping skills through self-expression, play, preparation, and education when working with children and families (Child Life Council, 2015). CCLSs are focused on the optimal development and well-being of infants, children, adolescents, and young adults by endorsing coping skills while minimizing the adverse effects of hospitalization and other stressful experiences (American Academy of Pediatrics, 2014).

CCLSs use primary tools such as therapeutic play, expressive modalities, and psychological preparation with the health care team and family. Child life interventions help children cope and adjust in overwhelming situations (American Academy of Pediatrics, 2014). CCLSs can help reduce hospital stressors for children and families by effective distraction, medical play, and other developmentally appropriate activities (American Academy of Pediatrics, 2014). CCLSs also provide guidance and support to parents/caregivers, siblings, and other family members during a child's hospitalization (Bell, Johnson, Desai, & McLeod, 2009).

Child Life Interventions for Asperger Syndrome

CCLSs and other medical professionals encounter children with disabilities daily in the healthcare setting. Asperger Syndrome (AS) was recently removed from the

Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2013). The DSM is “the standard classification of mental disorders used by mental health professionals in the United States” (American Psychiatric Association, 2016, para. 1). Individuals who have a well-established DSM-IV diagnosis of AS are given the diagnosis of autism spectrum disorder (ASD). According to the Centers for Disease Control and Prevention (CDC), a diagnosis of ASD includes multiple conditions that used to be diagnosed individually: autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and AS. ASD is a group of developmental disabilities that include social, communication, and behavioral challenges (CDC, 2012).

Healthcare professionals such as doctors, nurses, psychosocial teams and CCLSs still encounter patients with an AS diagnosis. CCLSs are ethically responsible for providing services to everyone based on their needs; therefore, it is important that CCLSs understand AS in order to provide the best quality care to children and families.

The Child Life Council (2015) has thirteen ethical principles. Principle three states that “Individuals shall have an obligation to serve children and families, regardless of race, gender, religion, sexual orientation, economic status, values, national origin or disability” (para. 6). As professionals and experts on child development, it is important that CCLSs help advocate for the individual needs of infants, children, and youth with disabilities.

Research has shown that individuals with a developmental disability have more frequent hospital visits than typically developing individuals without a developmental delay (Drake, Johnson, Stoneck, Martinez, & Massy, 2012). However, there is little

research explaining which forms of distraction tools and coping skills work best for patients with developmental delays during a healthcare experience (Drake et al., 2012). Hospitalization can cause all children to experience anxiety and stress during interactions with health care professionals. It can be difficult to gain cooperation from a typical developing child and can be more difficult with a child diagnosed with developmental issues (Drake et al., 2012).

CCLSs need basic knowledge of ASD and AS to better assist patients with AS. It is important in the profession of child life to have basic information on this population. If CCLSs are educated, they will be able to identify techniques that will be effective when working with the AS population. The CCLS would understand different strategies to use and not use. Every adolescent copes differently and the needs of the individual with AS will change how CCLSs approach the scope of practice.

The purpose of this study was to learn from adolescents who have AS and discover the best ways for CCLSs to help patients through their hospitalization experiences, including routine medical exams, scheduled or spontaneous medical procedures, short or long term hospitalization. The author's goal was to identify professional practices that work best for this population.

The most difficult time for an adolescent to be hospitalized is between the ages of 14 to 18, because peer groups, independence, and self-image are very important to these young patients. According to Erikson's psychosocial developmental stage of adolescence, these patients are dependent on peers and social groups (Rollins, 2005). Being reliant on peers and social groups might already be a challenge for an adolescent with AS. Short or

long-term hospitalization can be stressful, as it increases anxiety levels about appearance, diminishes an adolescent's normal group activities, and interferes with future plans.

Symbolic Interactionism

Symbolic interactionism is a concept that is a unique contribution to family studies. La Rossa and Reitzes (1993) stated:

Symbolic interactionism focuses on the connection between symbols (i.e., shared meanings) and interactions (i.e., verbal and nonverbal actions and communications). (p. 135)

Individuals develop both a concept of self and their identities through social interaction, permitting them to construct and assign value to their family activity (La Rossa & Reitzes, 1993). Individuals learn to interpret and give meaning to everything they encounter through interactions, and it is important for individuals to be able to give meaning to their world. They are able to give meaning through interactions with verbal and nonverbal communication, and through shared meanings or symbols (LaRossa & Reitzes, 1993).

LaRossa and Reitzes (1993) emphasized that families are social groups, and that individuals and families have interacting personalities. Individuals develop both a concept of self and their identities through social interaction (LaRossa & Reitzes, 1993), so they can learn to live independently and to assess and assign different values to the meaning of their activities.

According to Erikson's psychosocial stages of development, adolescence is the identity vs. role confusion stage of development. Symbolic interactionism helps explain

the concept of self and identity that the individual is trying to achieve. Adolescents are connected to their parents during this stage but more likely to rely on their peers for guidance. Adolescents tend to have strong peer relationships during adolescence and learn who they are by interacting and communicating their feelings with peers.

Adolescents are learning the meaning of friendships and the value that they have.

Individuals with AS might have difficulty with symbolic interaction due to their resistance to the interaction needed to create meaning. As mentioned earlier in this chapter, individuals with AS have social deficits, communication difficulties, and repetitive behaviors and interests that may be off-putting to peers (Woods, Mahdavi, & Ryan, 2013). An adolescent with AS might only have a handful of peers that they feel comfortable speaking with, therefore there might not be enough interaction and communication to create the meaning of value of the friendship.

Three themes of symbolic interactionism have been identified by Blumer (1969):

1. Human beings act towards things on the basis of the meanings the things have for them;
2. The meaning of things is derived from, or arises out of social interaction that one has with others; and
3. These meanings are handled in and modified through an interpretative process used by the person in dealing with the things he or she encounters.
(p. 2)

“Meaning” is an important component in human development because it is the central idea in symbolic interactionism (Burbank & Martins, 2010). Individuals are thinking beings who cope with events and situations by giving them meaning and then determining how to react. Burbank and Martins (2010) wrote that “a person’s actions are

then based on the meanings the situations have from him or her rather than the direct response to the event or situation” (p. 27). For example, if an adolescent who is terminally ill relapses and goes back to the hospital, he or she might worry that this hospitalization could signify the end of life. This affects the person emotionally and physically, which creates more challenges for recovery. Many stressors accompany the challenges adolescents face during hospitalization.

An adolescent with AS who is also diagnosed with a chronic illness might have trouble understanding the concept of a relapse and could become frustrated with the idea of returning to the hospital. Individuals with AS think in concrete terms and they might feel confused about returning to the hospital because they were told they were not sick anymore. When interacting with this patient population it is important to remind them along the way that chronic means long term, and there is a chance of getting sick again. Although they might not fully understand, breaking down big words and simplifying could be beneficial. It is important to explain to the patient both the positive and negative effects of the diagnosis.

Blumer’s second principle is that the meaning of things is derived from, or arises out of social interaction. Meaning “emerges out of the ways in which other people act towards the person in relation to the thing for which meaning is being developed. These actions of other people serve to define the things for the person” (Burbank & Martins, 2010, p. 28).

Since individuals with AS might have difficulty communicating with others, they might misinterpret what certain objects are used for in the exam room. For example, a

healthcare provider might say that the reason for an injection (commonly referred to as a “shot”) is that it will make the patient better. But in the eyes of children and adolescents, the most important thing is that shots hurt. Having the provider connect “getting better” with a procedure that causes pain may be very confusing to an AS patient who thinks in very literal terms.

It is important when working with children and adolescents with AS not to define objects concretely for them, which leads to Blumer’s third principle. The third principle deals with handling and modifying the meaning through an interpretive process. Individuals with AS will have to use coping skills and what works best for them to deal with the meanings of healthcare experiences (Burbank & Martins, 2010).

Individuals with AS tend to focus on a topic that interests them and focus only on that topic. These individuals will often learn as much as they can about their topic of interest, until it no longer interests them. Humans typically act toward things on the basis of meaning that these things have for them. Individuals with AS are intelligent individuals and would be able to figure out the meaning of something that interests them. They struggle to understand the meanings of relationships, communication, and emotions which can lead to awkward behaviors (LaRossa & Reitzes, 1993). These individuals have difficulty understanding relations and emotions. For example, an adolescent with AS who is starting to experience puberty might not understand why his or her body is changing. Adolescents with ASD and AS oftentimes have a difficult time adjusting to bodily changes. It causes them to be fearful, nervous, and confused that something is wrong with them. If a patient with AS has a typical routine/habit of removing their shirt

or other articles of clothing it is important that parents explain why these behaviors and habits need to change as the body is going through changes. They are not going to understand why taking off their clothes in front of others violates relationship boundaries and why others would be upset by this behavior.

Self-Concept

LaRossa and Reitzes (1993) explain how individuals are not born with a self-concept; instead individuals begin to develop a self-concept through social interactions. Jackson, Skirrow, and Hare (2006) compared individuals with AS with non-AS individuals, and found that people with AS are relatively underdeveloped when it comes to their self-concept. It was shown that individuals who were diagnosed with AS developed fewer social and psychological descriptions of themselves. They were not able to understand why their bodies were changing and understand the aging process. They were able to understand themselves in simple characteristics compared to those who did not have AS.

Individuals with AS might have a hard time developing a self-concept and a social understanding of interactions (Jackson et al., 2006). They usually describe themselves to others in simple terms. In one study, a participant was asked, “If you change from year-to-year how do you know you are still you?” (Jackson et al., 2006, p. 704) Jackson et al. (2006) found that participants felt as if they did not even know themselves and did not understand they would be the same person in the present and future. The study also found that participants felt very anxious and lost when routines were disrupted (Jackson et al., 2006). The distress taking place is a behavioral

manifestation of a lack of internal self-continuity in people with AS because of relying on routines and repetitive behaviors to keep anxiety low.

Difficulty in Projecting Outcomes

Individuals with AS have difficulty understanding the meaning of the future and how they can change. When talking to others, they focus on themselves in regards to the past or current personal characteristics. This is another effect on the development of self-concept in individuals with AS. They have trouble connecting what they might look like after medical treatment (Jackson et al., 2006) and that bruising and hair loss may go away if treatment is stopped in the future.

People with AS focus more on what is happening right in front of them, and focus less on the broader context of their lives and actions (Jackson et al., 2006). When it comes to self-continuity, people with AS tend to think in terms of permanence. They feel that they cannot change their self-characteristics and cognitive capabilities (Jackson et al., 2006). The inability to imagine how one will be after treatment may be an additional source of anxiety for adolescent AS patients.

Symbolic interactionism states that once self-concepts are developed, they provide an important motive for behavior (LaRossa & Reitzes, 1993). Self-values, self-beliefs, self-feelings, and positive self-assessment all affect behavior (LaRossa & Reitzes, 1993). To better understand how a person deals with AS every day, knowledge must be gained directly from those individuals. The principal researcher hoped to find ways a CCLS can help ease stressors of individuals with AS in the hospital setting. It is

important for individuals to build positive relationships with doctors, nurses, and Child Life Specialists.

Rationale for Present Study

The findings from this research study may help CCLSs understand what tools and coping skills will work best for children with AS. This research may also assist in improving professional practices on how to handle individuals with AS. It is important to find the best practices to help individuals create a more positive environment and approach to treatment. It is important that CCLSs have tools that help reduce stress and help adolescents and families cope.

Limitations of Study

This study is not intended to be generalized to the larger population. Due to the restricted sample size included in this research, readers need to keep in mind that the results from this research are limited to the specific population studied. The researcher used a small geographic area, which also contributed to the limitations of this study. Gender was a limitation to this study because more males are diagnosed with AS than females.

Delimitations of Study

The delimitations for this research project required the participants to have a previous hospital experience, defined as routine medical exams in the hospital setting, or short-term or long-term hospitalization. Participants needed to be between 15 to 25 years of age and have retrospective memories of their hospital experience. This age range was selected because individuals with AS typically do not know of their diagnosis until they

are older and are beginning to understand what AS is. Subjects were required to read written English. Individuals were recruited for this research through parent letters in surrounding local high schools and classroom announcements in a university located in the Midwest region of the United States.

Through data collection and analysis the researcher hoped to answer the following questions:

- What do individuals with previous hospital experience and an AS diagnosis find helpful during routine medical exams and short-term or long-term medical visits?
- What do individuals with previous hospital experience and an AS diagnosis find unhelpful during medical exams and short-term or long-term medical visits?
- How can child life specialists use this information to help improve coping and distraction skills when working with individuals with AS?

Definition of Terms

Autism. Autism spectrum disorder (ASD) and autism are broader general terms for a group of complex disorders of brain development. These disorders are characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors (Autism Speaks, 2014).

ASD. Autism Spectrum Disorder is a group of developmental disabilities that include social, communication, and behavioral challenges (CDC, 2012).

AS. Asperger syndrome is an autism spectrum disorder (ASD) considered to be on the “high functioning” end of the spectrum. Affected children and adults have difficulty with social interaction and exhibit a restricted range of interests and/or repetitive behaviors (Autism Speaks, 2014).

DSM-5. The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) is the standard classification of mental disorders used by mental health professionals in the United States (American Psychiatric Association, 2013).

Chapter 2: Literature Review

Foundations of Child Life

As defined by the Child Life Council, the national governing bodies of the profession, Certified Child Life Specialists (CCLSs) are professionals that are present in pediatric health care settings to reduce the negative impact of stressful or traumatic life events that can affect the health, development, and well-being of infants, children, youth and families. CCLSs are available to help minimize stress and trauma that children and families experience in the hospital (Bell et al., 2009). CCLSs ensure that children have calm and nurturing experiences in the hospital setting.

According to the American Academy of Pediatrics (2014),
Child life specialists facilitate coping and the adjustment of children and families by providing play experiences, presenting information about events and procedures, and establishing supportive relationships with children and parents to encourage family involvement in each child's medical care. (p. 671)

Children communicate their needs through play, words, and behaviors. CCLSs are devoted to facilitating all forms of communication when working with children and families and value the use of play as a foundational conceptual framework. Play is essential to child development and is a normative part of childhood. Play assists children in self-expression, creativity, healing, coping, mastery and achievement, and learning (Bell et al., 2009).

Therapeutic play is an important tool for child life and is defined as play that is used to prevent psychological injury (Boling, 2005). Therapeutic play helps facilitate self-

expression, helps children cope with unfamiliar surroundings, increases the child's knowledge of their hospitalization and treatment, and meets developmental needs (Bolig, 2005).

According to Jessee and Gaynard (2009), Child Life Specialists have three main objectives when engaging in therapeutic play:

- Establish contact,
- Facilitate observation,
- Collect useful data to interpret behaviors.

Play allows children to communicate their feelings in a more effective and natural way. Adult understanding becomes clearer when observing children's play. It is important for children to play because it helps them relax, which therefore reduces defensiveness and anxiety (Jessee & Gaynard, 2009). Patients who have AS benefit from play to help calm them if they are responding in an aggressive manner. Play also allows children to express and release feelings that might be hard to express with words and allows children to develop social skills. Research has shown that individuals with AS lack social skills (Schnur, 2005). Therefore, play can be very beneficial to this population of children during hospitalization.

Family-Centered Care and the Role of Child Life

Family-centered care recognizes that families understand their child best. Family members take care of their children's developmental, social, and emotional needs throughout many years of life (Rollins, 2005). Family-centered care plays an important role in the hospital, as the main goal of family-centered care is to provide optimal care for

children (Rollins, 2005). The parents love and value their child and can be a positive source of support during medical procedures.

There are nine elements of Family-Centered Care. The Family-Centered Care elements are designed to help professionals meet the needs of the patients and families during hospitalization. The elements are a guide to benefit patient and family involvement while in the hospital.

Out of the nine elements, there are three elements that are important to keep in mind when working with individuals with AS and their families. Element one recognizes that the family is the constant in the child's life, while healthcare professionals and services systems often change (Bell et al., 2009). When working with AS patients and their families, it is important to ask the family how much they want to be involved and to encourage the parent and child to speak up if there are concerns. This is particularly important because individuals with AS rely on familiarity and routine, which the family is in the best position to provide.

Element six recognizes individual family strengths and respects various methods of coping (Bell et al., 2009). When working with the AS and ASD population, it is important to avoid making assumptions about the patient. Not all coping strategies work with all children, so it is important to respect how families/patients cope with the hospital experience.

Element seven recognizes understanding and incorporating the developmental needs of infants, children, and adolescents and their families into healthcare systems (Bell et al., 2009). It is important to help families adapt when the mental or developmental state

of the patient changes. This would be a good time to develop goals and priorities for those patients with AS and develop which ways work best when having a medical procedure.

Typical Adolescent Development

Adolescence is a period of time when a child is transitioning into an adult and going through the stages of puberty. During adolescence, children develop a variety of abilities. Adolescents begin to establish and maintain relationships, which lead to learning to share intimacy without feeling inhibited or worried (Adolescent development, n.d). Adolescents begin to mature and become more of themselves and their purpose in life. Adolescents also start to become more abstract thinkers and understand abstract ideas (Adolescent development, n.d). Physical characteristics start to change in adolescents and when sudden changes occur, adolescents can become very self-conscious and sensitive about their body changes. They often start comparing themselves to their peers.

When adolescents begin to find their own identity, they pull away from parents and peers become more important. Peer interaction is a crucial aspect to becoming a teenager. In early adolescence, peer groups are normally made up of non-romantic friendships, which include “cliques.” In these peer groups teenagers tend to dress alike, engage in the same activities, and act alike. In mid-adolescence and beyond, romantic friendships are formed. This is when young people begin to feel comfortable with their sexuality and their bodies. There are also times when transitioning into an adult can cause

stressors. Admission to the hospital for an acute or chronic illness can disrupt adolescents' routines and peer interactions.

Hospital Stressors for Typically Developing Adolescents

Identifying and understanding the stressors of hospitalization is a core purpose of child life practice. Hospital stressors impact adolescents and families and are essential for CCLSs to understand and recognize. With optimal knowledge of child development, CCLSs understand common hospital stressors of adolescents. The potential for additional stressors that are unique to individuals diagnosed with AS is unlimited. Understanding how these stressors can manifest will assist health care professionals in understanding the health care experiences of those individuals.

The common age for adolescents is between 13 and 18 years. There are a variety of stressors that could occur during a hospitalization of adolescents. They often feel a loss of independence and control during hospitalization. Offering choices allows some independence and control for the adolescent. During this stage of development, adolescents rely on their peer groups and peer involvement. They naturally pull away from their parents during this time and depend on friends. Adolescents are worried about restrictions on their physical activities because they are not able to participate in their extra-curricular activities, such as sports (Rollins, 2005). They are also starting to be concerned about the future and what is actually going to be the outcome of their diagnosis. They also may have a loss of peer acceptance and a fear of rejection (Rollins, 2005). When patients are in the hospital for a long period of time, they lose time with their friends and may feel a loss of acceptance (Rollins, 2005). Adolescents are going

through bodily changes and have fears about their body image. They worry about their appearance and privacy during their hospitalization (Rollins, 2005). It is important to respect the autonomy of these adolescent patients and remember to offer them preparation and distraction. They need support just as much as younger patients.

Additional Hospital Stressors for Patients with Special Needs

Learning from parents can be beneficial when working with the special needs population. Parents can often explain an unusual behavior type the child exhibits and what coping skills work best for that child. For example, when working with children with developmental disabilities, it is especially important to allow time for them to become familiar with their environment, because they may have highly individual ways of investigating a new physical location. Communication needs to be simple to allow the patient to feel comfortable and safe in the new environment (Drake et al., 2012).

Even after the patient becomes comfortable in the health care environment, changes in routine, the addition of painful procedures (such as starting an IV or inserting nasogastric tubes), and new faces can cause additional anxiety for children with special needs (Drake et al., 2012). Simple procedures such as obtaining vital signs and having a routine physical examination can be very difficult for a child with developmental disabilities.

McGonigle et al. (2014) found that aggressive pharmacologic sedation and physical restraints were used on patients with ASD due to the misunderstanding of their behavior and communication impairments. Since AS is an autism spectrum disorder is important that CCLSs and other medical professionals have knowledge and training

about this disorder. Families and patients in this study reported that health care providers had very little knowledge of the characteristics of ASD and, as a result, the care that was provided was ineffective in the situation (McGonigle et al., 2014).

Background on Asperger Syndrome

Individuals with AS operate near the “high functioning” end of the spectrum. Individuals with AS have social deficits, communication difficulties, and repetitive behaviors and interests (Woods et al., 2013).

According to Autism Speaks (2016):

There can be a considerable overlap in the diagnostic symptoms of AS and that of other forms of Autism Spectrum Disorder (ASD) among children and adults who have normal intelligence and no significant language delay, so-called “high-functioning autism” and Asperger syndrome share similar challenges and benefit from similar treatment approaches. (n.p.)

Hans Asperger was an Austrian pediatrician that observed a group of boys who appeared to have the same social difficulties. The boys appeared to be typical, but they lacked nonverbal communication skills and were not able to show empathy (Shankar, Smith, & Jalihal, 2013). For example, when individuals with AS have conversations they focus on a topic of interest and only talk about what they want to talk about (Autism Speaks, 2016).

The difference between AS and autism is there is no delay in speech in autism (Schnur, 2005). The lack of delays in speech in this disorder is the major factor that differentiates AS from autism. The cause of AS is unknown. Genetics could be a factor in

this disorder as well as combined environmental factors. Some genes have been linked to AS but no specific gene has been identified (Schnur, 2005).

According to research “a recent estimate indicates that 1 in 88 US children are diagnosed with ASD. It occurs more frequently in boys than girls; one in 54 boys and one in 252 girls are affected and this gender bias is also true for AS” (Woods et al., 2013, p. 1).

Characteristics Associated with Asperger Syndrome

Individuals with AS usually appear to be fine physically, and their cognitive state of mind is about average or above. Individuals with AS tend to have inappropriate and limited social interactions. They have a hard time understanding nonverbal communication such as facial expressions and gestures (Lobar, Fritts, Aribide, & Russell, 2008). Individuals with AS normally talk about themselves rather than others. They have a hard time with reciprocal conversations and lack eye contact. They have an inability to understand social and emotional issues (Autism Speaks, 2014). A person with AS is unable to process the emotions of others. They tend to obsess about certain topics of interest (Lobar et al., 2008). It is hard for them to understand sarcasm and humor, so they may misinterpret conversations (Roud, 2013).

Adolescents who are not persistent in developing social skills have a hard time making friends and forming relationships with other individuals (Tse, Strulovitch, Tagalakis, Meng, & Fombonne, 2007). Forming relationships is hard for individuals with AS because social connections can be difficult for them.

Sensory Processing Related to Asperger Syndrome

Sensory processing disorders are common in individuals with AS (Shanker et al., 2013). It is important for health care professionals to be aware of daily challenges for adolescents with AS. Sensory processing disorder (SPD) is a condition that occurs when sensory signals do not get ordered into appropriate responses (SPD Foundation, 2014). Individuals with SPD have difficulty processing and acting upon information that is received through their senses, which makes it difficult to perform numerous everyday tasks (SPD Foundation, 2014).

Individuals with SPD can become stimulated by a certain sensation and respond dramatically to the sensation. For example, these individuals could respond negatively to sounds from beeping machines, if the lights are too bright, if the room is too quiet, if the room is too loud, or if the texture of food is different than usual. These sensory reactions can be unbearable (SPD Foundation, 2014). Some individuals with SPD can illustrate the opposite behavior and not have any reaction to stimulation, even hot, cold, or pain.

Shankar et al. (2013) explained difficulties and signs of sensory processing in people with AS. Major signs of sensory dysfunction in people with AS include: hypersensitivity to outside stimuli, problems with motor skills, problems processing sensory information, and hyposensitivity to outside stimuli.

When individuals with AS are hypersensitive, they might not want to touch or be touched by other people or objects. They can become very sensitive to sounds and smells. Individuals with AS are easily distressed by certain types of noises (Shankar et al., 2013).

When moving, individuals with AS might be clumsy and uncoordinated. During hospitalization, patients with AS might have a difficult time moving around in a small and crowded area. Individuals with AS typically take more time to process information and respond accordingly (Shankar et al., 2013). Instructions are better understood if explained one step at a time. Order is important when describing steps to an individual with AS or ASD. Verbal and visual tactics work well depending on the needs of the individual. When individuals with AS are frustrated, they might show signs of aggressive behavior, because it is a coping mechanism they use when routines are disrupted (Johnson & Rodriguez, 2013).

Effective Interventions

When teaching social skills, researchers have found that participation in groups can be beneficial and can help reduce behavioral disruptions for children with ASD (Drake et al., 2012). Social skills group therapy prepares the individual to cope with social and interpersonal expectations (Countryman, 2008). Social skills groups can help verbal adolescents with ASD develop a level of comfort and confidence with social interactions (Tse et al., 2007). In social skills group therapy, individuals are learning from each other. Some starting points that make group therapy effective are making eye contact, altering tone of voice, using facial and hand gestures, and using body language (Tse et al., 2007). During social skill group sessions, new skills are taught to individuals through role-play, eye contact, and simple tasks to help them understand how to use the skill (Tse et al., 2007).

One study described a group of boys with AS placed in a social skills group. The study was designed to determine how much progress could be made. The group met for 14 weeks, once a week, for 2 hours. The boys started with simple tasks and moved on to more complex tasks. Some of the simple tasks included making eye contact and greeting new people. The group was moved to four different sites, and staff members rotated to help the boys from becoming comfortable with just one person (Marriage, Gordon, & Brand, 1995). The study showed that after 14 weeks, the boys had fewer problems with eye contact and felt more comfortable speaking with others (Marriage et al., 1995). Tse et al. (2007) studied high-functioning autism and AS. They found social skills groups to be effective and found that significant improvements in problem behavior were made by those with AS and high-functioning autism.

Social stories were created to help individuals who have ASD. Social stories can be short explanations of a specific situation, occasion, or activity that include detailed information about what to expect in that situation and why (Thomas et al., 1998). Social stories were originally created for individuals on the higher-end of the ASD, which includes those diagnosed with AS. These stories are helpful because the information presented is literal and concrete (Thomas et al., 1998). This can improve individuals' understanding of the situation and make it less difficult. Social stories have been found to reduce anxiety and help with behavior difficulties in certain situations.

Social stories benefit individuals with ASD and AS, because they break down procedures or tasks into steps and improves social understanding that may lead to

improvements in behavior (Johnson & Rodriguez, 2013). Providing simple illustrations of tasks for these individuals has been successful.

There are many ways parents can create social stories. Parents can use technology. For example, they can use communication software or an iPad to record themselves, giving step-by-step instructions of a procedure so the children are able to hear and see their parents throughout their procedure (Johnson & Rodriguez, 2013). Figure 1 illustrates an example of a social story.



Figure 1. Going to the doctor social story. Reprinted from “Going to the Doctor,” by D. Vescolani, 2011. Available from <https://www.etsy.com/shop/MyAutismStore> Copyright 2011 by DVAssist Autism Services. Reprinted with permission.

Intervention Strategies for Asperger Syndrome in the Academic Setting

Children with AS frequently need help with coping within the learning setting (Griffin, Griffen, Fitch, Albera, & Gingras, 2006). Frustration arises within the learning setting and children with AS often experience depression, anxiety, aggression, and hyperactivity (Griffin et al., 2006). Research has suggested that intervention can help adolescents adjust to behavioral and emotional feelings toward school. Intervention tools include cards that show different behaviors on them; this helps children with AS identify how they are feeling. It is important to be consistent throughout the school day, be patient during interactions with the child, and use social stories to help students know the expectations and transitions of social interactions (Griffin et al., 2006).

Griffin (2006) stated:

Limited range of interests also can be manifested in interactive play skills. Play skills can be broadened through the use of activities that include assembling and dismantling objects, as well as participating in concrete and predictable events. (p. 153)

Teachers often modify assignments for children with AS so the assignments are understandable. Teachers also allow more time for students with AS to complete assignments, limit the number of questions asked, create alternatives to traditional assignments, and provide more detailed study guides so the guides are easier to follow (Griffin et al., 2006).

Myles and Simpson (2003) stated that many different structural strategies can also help students learn, including visual supports, graphic organizers, outlines, assignment

notebooks, time lines, and travel cards. All of these structural strategies help students visually organize their school work. Students with AS are able to have control over what needs to be done and they have a choice of how they want to organize their life at school. Some techniques might work better than others. These structural strategies could be helpful in the hospital setting as well; for example, an individual with AS could create travel cards for every time they are going on a visit. No research has examined the effectiveness of these strategies in the hospital setting for children with AS.

Stressors on the Family System

Research has shown that families of patients with ASD find emergency departments and general health care challenging, burdensome, and dissatisfying, both emotionally and financially (McGonigle et al., 2014; Kogan et al., 2008). These negative experiences can cause family stress and stress on the individual who has AS.

There is additional stress on parents if they have to bring siblings along during hospital visits with the child with AS. It can be difficult for siblings to understand how difficult a medical experience can be for their brother or sister. Stress can sometimes come from a sibling bullying or rejecting an individual who has AS (Lobar et al., 2008).

There is not much research that focuses solely on AS and the health care setting, although there is research on ASD as a whole that deals with hospitalization and hospital visits. Scaroinato et al. (2010) described that ASD prevalence rates are on the rise and ASD is becoming more frequent in the hospital. Most of the articles pertaining to the health care setting focused on ASD. The articles discussed how important it is for nurses to understand the challenges associated with ASD (Scaroinato et al., 2010).

CCLSs are likely to come in contact with an individual with AS at any time because children are frequently admitted to the hospital. Therefore, it is important that CCLSs are informed and educated about individuals with ASD and AS so they have proper knowledge about these diagnoses.

Chapter 3: Methodology

Research Design

This research study was an IRB-approved qualitative study that used an online questionnaire to gain more knowledge about beneficial techniques to help individuals with AS through a medical experience. Participants were asked general questions about experiences within the hospital setting. Subjects were also asked to determine if a Certified Child Life Specialist was present during the time of the hospital visit and which interventions were effective. The questionnaire asked participants to recall their own experiences in the hospital setting in order to identify the pros and cons of best practices. The participants were asked which tools CCLS used during their hospital visit were beneficial. There is limited data on positive techniques and tools for Child Life Specialists when working with AS patients and other patients with developmental disabilities.

After a few months of recruitment and no participants, the researcher submitted an amendment to the Ohio University Institutional Review Board to add an additional recruitment tool to allow the principal researcher to utilize social media sites in hopes of expanding the possible participant pool. After adding a recruitment tool using social media, the researcher began to recruit participants.

Online questionnaires were completed by subjects who participated. The data were analyzed by the principal researcher for emerging and common themes. Common themes that were found were considered significant and then expanded upon within the analysis.

Participants and Participant Recruitment

To be eligible for inclusion in this study, subjects needed to meet the following guidelines; (a) presently between the ages of 15-25 (the researcher chose this age range because individuals with AS do not typically understand the disorder until they are older); (b) a known diagnosis of AS and have experience with basic medical procedures (routine medical examination, short-term or long-term hospitalization); and, (c) the ability to understand and read English.

The desired sample size for this study was between 15-20 participants. There were 10 participants in this study, but only 1 out of the 10 participants completed the questionnaire in its entirety. In regards to the nature of AS, participants might have lost interest in the questionnaire, which could have led to not completing it. Two other participants filled out the questionnaire half way. Out of 10 participants, 2 were female between 22-25 years of age (see Figure 4); 1 male was at the age of 20 (see Figure 4), and the others did not complete the questions regarding age and gender. The female participants identified as having a routine checkup and a short-term hospital stay. The male participant identified having a routine checkup.

Participant recruitment. For recruitment of subjects ages 18-25 there was a variety of outlets, including announcements made by the researcher in seven collegiate-level academic classes, flyers handed out, and media posts on various media sites (one that was child life specific), and student forums (see Appendix B). The researcher made announcements explaining the research study and passed out a handout (see Appendix B) with the researcher's contact information and link to the questionnaire. If students wanted

to participate in the study, the link was provided on the handout. The link guided them to an online consent form to either agree or disagree. The principal researcher made a parental consent form available for those participants who were under the age of 18. Parents would have to read the consent form to allow their child to participate in the study. Once parents selected “agree,” they were routed to the questionnaire. If parents selected “disagree,” the questionnaire ended and they were not able to participate in the study. The principal researcher had a consent form available for participants who were over the age of 18 and did not need parental consent to participate in the questionnaire. Once subjects selected “agree,” they were routed to the questionnaire. If the subject selected “disagree,” the questionnaire ended and they could not continue. The questionnaire showed participants a series of questions, through Qualtrics (see Appendix C).

For recruitment of subjects ages 15-17, the principal researcher contacted a local high school principal. The researcher set up a meeting with the principal to discuss options to recruit participants from the high school. The principal suggested speaking with the local high school special education coordinator for support. The researcher then set up a meeting with the high school special education coordinator and a school psychologist to discuss possible options. The special education coordinator and school psychologist work closely with diagnoses of AS and autism. They agreed to contact the families about the research study. The school psychologist then referred the researcher to another special education coordinator that oversees the whole school district. This special education coordinator is in charge of four counties, which include 12 independent school

districts. The school psychologist and the special education coordinator provided letters of support (see Appendix D).

The researcher created a letter for the coordinators to send out to the parents explaining the research study (see Appendix B). The coordinators contacted parents and explained a letter was being mailed and/or emailed, announcing the study.

The researcher asked participants a series of questions (see Appendix C), through Qualtrics, so participants could have easy access to the questionnaire. Participants completed the questionnaire on a home computer or public computer.

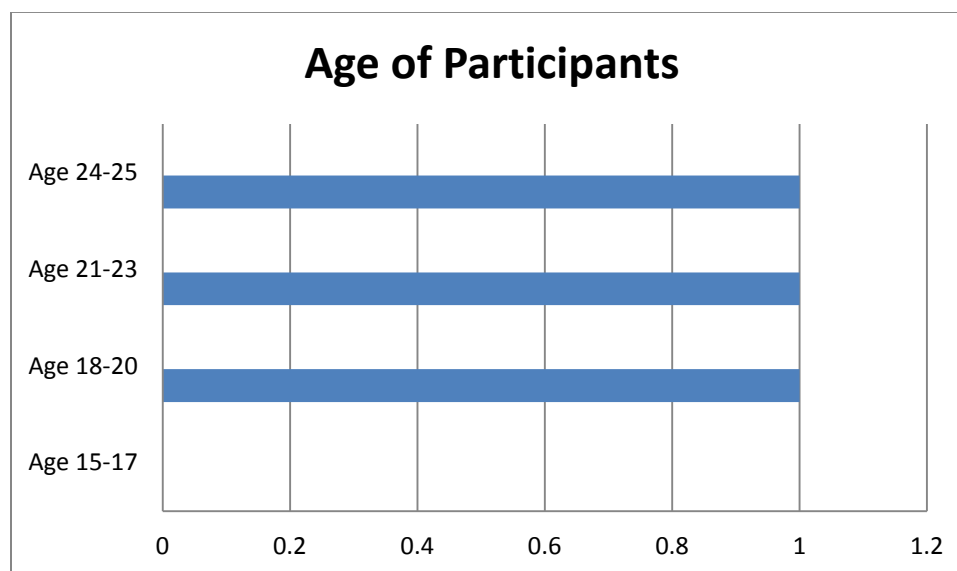


Figure 2. Age of participants.

Approach to Analysis

From the limited data collected through the questionnaire using Qualtrics, an online survey method, themes were created from the results. Once the 10 participants

filled out the questionnaire, the researcher analyzed the questionnaires. The following procedure was done:

1. The principle researcher read all responses to questions to mark themes.
2. The principle researcher looked for common and reoccurring themes of what participants felt that was helpful and not helpful during hospital visits.
3. Once themes were identified, the researcher reread the responses to ensure all relevant instances were coded.

The themes were expanded upon to help Child Life Specialists create new coping skills and techniques for this unique population of patients. The themes were assessed by relating the information provided to current research on AS tendencies and the characteristics of these individuals. The themes will help certified Child Life Specialists to be more comfortable and prepared when working with patients with AS and autism.

Chapter 4: Results

Questionnaire/Participant Results

Ten individuals began filling out the questionnaire and 6 out of 10 dropped out of the study. There was no indication from the participants responding as to why they dropped out. Individuals with AS lack social communication skills and take more time to process information (Shankar et al., 2013; Woods et al., 2013). With the significant drop-out rate of this study, the researcher concluded that subjects had difficulty processing the information that was asked or they were not interested. Subjects might have had a hard time following and reading the directions. Johnson and Rodriguez (2013) explain that instructions are better understood if explained one step at a time. Order is important when describing steps to an individual with AS or ASD. Participants could have had difficulty with instructions and the order of the questions. The characteristics of AS may have led to a low participation rate.

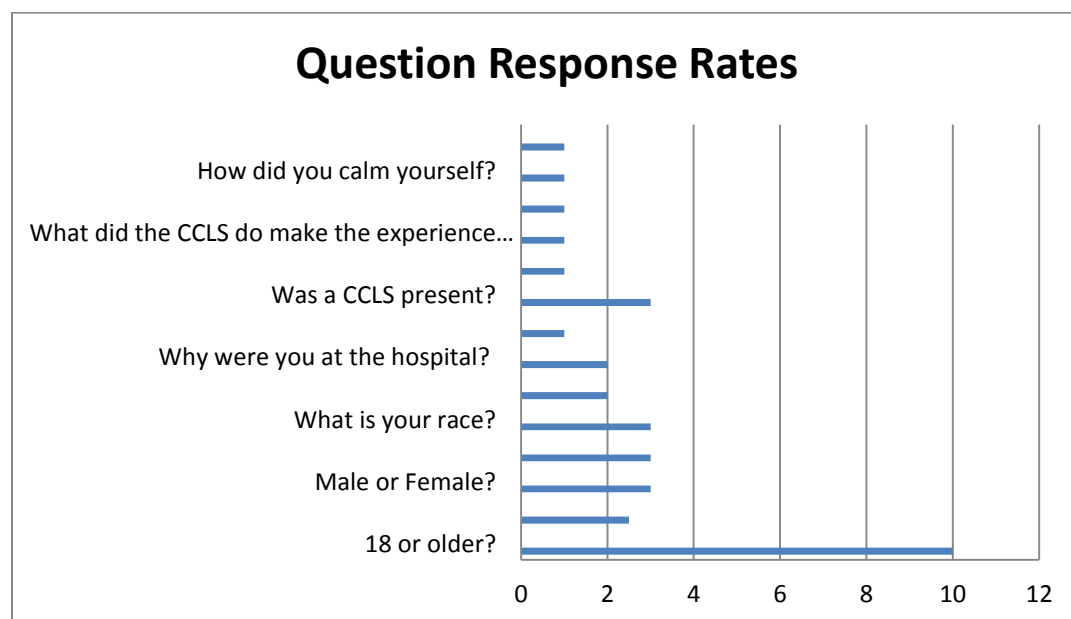


Figure 3. Question response rates.

One subject completed the questionnaire in its entirety and two participants answered the questions half way through. The 2 participants who answered questions half way through were both female between 22-25 years of age. Both female participants identified themselves as being White/Caucasian. The female participants selected that a routine checkup was completed and a short-term hospitalization. One female participant did not have a Child Life Specialist present and the other participant left the question blank.

The subject who completed the questionnaire completely was a 20-year-old male who identified himself as White/Caucasian. The subject had a known diagnosis of AS and reflected on a routine checkup from when he was 8-years-old. The subject identified having a Child Life Specialist present during his routine checkup. The question was

asked “What did the Child Life Specialist do to make the experience better?” The subject responded with “They let my mom stay in the room with me.”

The researcher was able to identify four themes from the data that were collected during this research study. Theme one, the dropout rate was very high. Theme two, participants engage in behaviors that help them to cope with medical experiences. Theme three, CCLS helped to make the medical experience better. Theme four, participants offered brief rather than elaborate responses.

Theme One

The dropout rate was very high. Seventy percent of the participants who agreed to consent dropped out. Three of them dropped out after question 1. Given the nature of AS, the participants could have intended to complete the questionnaire but once they began, they stopped. The data show that a majority of the participants dropped out of the study after the first question.

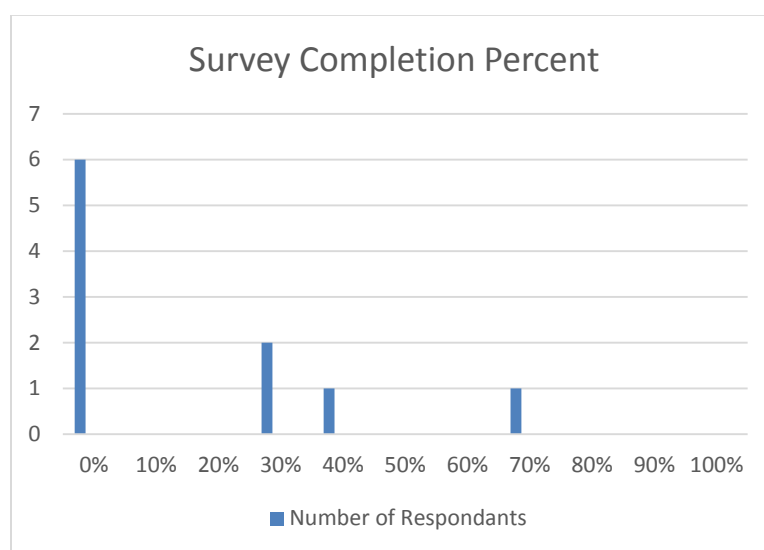


Figure 4. Survey completion percent.

Theme Two

Participants engage in behaviors that help them to cope with medical experiences. On the questionnaire the researcher asked participants how they calm themselves during healthcare visits. a) Repetitive Motions: One respondent stated that he found that rocking back and forth was helpful to calming himself down during his experience in a routine medical checkup. The same respondent also mentioned how pacing back and forth in the room helps calm him down during stressful moments during a medical checkup. b) Positive impact of being able to cope with challenge: At the end of the questionnaire the same respondent stated that “While it was challenging and I had self-doubt, I grew comfortable with who I was and came out better for it.” This statement shows that although the healthcare experience is difficult and challenging for this population, some do grow and learn from their experiences. It is possible to become comfortable with the diagnosis of AS.

Theme Three

CCLS helped to make the medical experience better. The questionnaire also asked participants what the CCLS did to make their experience better during their healthcare experience. A respondent stated that their experience was better because the CCLS let the mother stay in the room with them. This response mirrors the importance of Family-Centered Care. Family-Centered Care advocates for parental presence during anything related to the hospitalization of the child. It is important that CCLSs and other health care professionals be aware of Family-Centered Care and the effectiveness of parental presence during routine checkup and hospitalization stays.

Theme Four

Participants offered brief rather than elaborate responses. (a) Open Ended

Responses: Subjects were asked five open ended questions on the questionnaire.

Participants who answered the open ended questions offered a brief response rather than a long explanation of their experience. For the question asked “what did he or she do for you?” in relation to the CCLS, the respondent answered “testing”. This answer was very short and offered no explanation or further details about the testing. (b) Straight forward answers: The answers given by participants were straight forward and to the point. There was no extra adding on explanation to responses. For the question “What things did you do to calm yourself during or to handle your experience?” the respondent answered “I would rock back and forth and pace.” In this response they just stated what needed to be stated and moved on to the next question.

Chapter 5: Discussion

The author was limited in gaining effective findings on AS and the healthcare setting due to the lack of participants. As stated previously due to the population being studied, participants are hard to come by. Individuals with AS have a difficult time focusing and might not have had enough patience to complete a questionnaire. Professionals in the hospital setting who have access to patients with ASD could conduct further research on this topic. The researcher was unable to find adequate participants due to the regulations of the Health Insurance Portability and Accountability Act (HIPAA).

From the data collected in this study, the researcher was able to pull four themes that can help future CCLSs when working with patients who have AS. Although there was a low participation rate, the researcher was still able to identify useful information from the responses given.

Discussion of Themes

Theme one: The dropout rate was very high. The high dropout rate could be related to their focused topics of interest. Individuals with AS are typically drawn to things that they find interesting. After reading the consent form and learning what the study was about, they could have felt intimidated or uninterested in the topic. If the subject had a traumatic medical experience, they could have felt intimidated by knowing the questionnaire was going to ask questions about a previous medical experience.

Theme two: Participants engage in behaviors that help them to cope with medical experiences. Participants used two types of behaviors to engage in a way to cope with their medical experiences. The use of repetitive motion was of importance with

this study. Strategies such as rocking back and forth and pacing back and forth were helpful to participants. These techniques could be useful to others who are having a stressful time during a medical procedure. As research suggests individuals with AS do have repetitive behaviors, so this theme was not surprising to the researcher. Another behavior was the positive impact of being able to cope with challenge. A participant acknowledged that her experience was challenging but she grew to feel comfortable with who she was and came out better from it. Although the healthcare experience is difficult and challenging for this population, some do grow and learn from their experiences.

Theme three: CCLS helped to make the medical experience better. Allowing parental presence during medical exams was helpful to the patient. FCC allows families to advocate for their child and it is shown that FCC is great value in the field of child life. The coping strategies listed in this research suggest that they could be helpful to others but everyone copes in different ways. Every family is diverse and it is important to respect their differences and attempt to meet the needs of the child when it is possible

With such a wide range of diagnose in the ASD population it is hard to justify how effective procedural preparation would be in this population of patients. The CCLS would have to assess the situation carefully and figure out what tools would be effective for that specific child.

If the CCLS is unable to prepare the patient for the procedure or medical checkup he or she can educate and prepare the parent or family member who is with the patient. Parents know their child best and often know how their child copes in situations. The CCLS can inform the parents about the outcomes and what to expect to happen next.

CCLSs are able to help families understand reasons for treatments and help validate parents' thoughts and feelings about their child's hospitalization. It is important to let the families know that they are not alone and they are supported. CCLSs involve families in decision making and let them know that their opinions and needs are heard.

Theme four: Participants offered brief rather than elaborate responses.

Open Ended Responses and Straight Forward Answers: Participants were asked open ended questions on the questionnaire. The open ended questions that were answered offered a brief response rather than a long explanation of their experience. Individuals with AS have a hard time defining the meanings behind things they do not understand. These responses were brief and concrete, which is typical of individuals with AS. Individuals with AS have tendencies to stay focused on what they are doing and the participant could have been focused on getting the questionnaire completed, which caused him to give brief details about the questions asked. This population does not usually offer a wide range of details when describing or explaining something.

Intervention Suggestions

Distraction techniques. Although the participants did not mention distraction techniques, it is another way for CCLSs to help patients through medical experiences. Distraction can be utilized to focus the patient's attention on something of interest to them rather than paying attention to what the medical professional is doing. Research has shown that individuals with a developmental disability have more frequent hospital visits than a typically developing individual without a developmental delay (Drake et al., 2012). However, there is little research explaining which forms of distraction tools and

coping skills work best for patients with developmental delays during a healthcare experience (Drake et al., 2012). This would be effective with a patient with AS because they typically have something they are interested in. The family would be a good resource to help CCLSs figure out what interests the patient. The parents can offer suggestions on techniques that work at home and they could be translated to the medical setting. It is important to educate the whole family about what a hospital room and/or medical room looks like so they can help explain to the patient with AS what they will experience. If an overnight hospital stay is needed, CCLSs can explain to the parent the sights, sounds, and smells of the hospital. It could be alarming and overwhelming to a patient with AS.

Implications for Future Research

There is not much research that focuses solely on Asperger syndrome and the health care setting, although there is a little research on ASD as a whole that deals with hospitalization and hospital visits. Scaroinato et al. (2010) described that ASD prevalence rates are on the rise and ASD is becoming more frequent in the hospital.

Most of the articles found on the health care setting had to do with ASD. The articles discussed how important it is for nurses to understand the challenges that will arise from working with these individuals (Scaroinato et al., 2010). There are children in and out of the hospital constantly and a CCLS could come in contact with an individual with AS at any time. Therefore it is important that CCLSs are informed and educated on individuals with ASD and AS so they have proper knowledge about these diagnoses

Research could be done on the effects of parent stressors when dealing with their child who has ASD or AS and the challenges the family faces as a whole during hospitalization. Parents who deal with hospitalization already have high stress rates, just relating to the hospitalization. Parents with children who have AS or ASD could have higher stress points. They are used to taking care of their child every day and understand them the best. More research would be productive in this area because professionals could learn how to help the families cope as well as the patient. Questionnaires could be provided for the parents to have them reflect on their experience and compile a list of suggestions the CCLS could do to provide them with more support or coping techniques. Research could also be done in current programs that have an autism center. CCLSs could work in conjunction with other professionals who are more educated on ASD.

Further research is essential for future child life specialists and those working in the medical profession. ASD is on the rise and it is important to take research seriously when trying to develop new ways to help these patient populations. Using this research project as a model, a study should be launched in a child life department on the effects of hospitalization for individuals with ASD and what child life specialists are currently implementing and what can improve.

Implications of Practice

The principal researcher has brainstormed suggested ideas on how to recognize and advocate for patients who suffer from special needs, such as ASD and AS. For professionals it is crucial to have basic education and knowledge about children with special needs and how to assist and adapt needs during hospitalization.

The principal researcher is advocating for a new child life competency to be created that focuses on the special needs population of patients. The principal researcher is also proposing an in-service training for all child life interns and new hires to learn more about ASD and AS. A specialist that is educated on working with populations of individuals with special needs. It would be beneficial if the in-service training was offered by the hospital, that way other medical professionals could attend. Nurses and doctors often times are not aware of the stressors of these patients as well. Being able to offer the training to anyone who is interested would be a great asset to the Child Life program and the special needs patient and family.

In addition, a special needs competency should be considered in order to elevate the professional understanding of ASD and other special needs practices.

Proposal for Implementing an In-Service Training

CCLSs and other medical professionals are not required to have trainings on AS and ASD. It is imperative that CCLSs are aware of the basic needs of patients with these two developmental disabilities. A presentation has been created to educate others about why it is important that CCLSs and other medical professionals understand the characteristics of this population. A specialist that is educated on the special needs population and works with individuals with ASD and AS would do the training. A child life specialist who has had experience working with patients with ASD and AS would also be beneficial to be at the training to allow others to ask questions about the specialist's experience.

The presentation that has been created (see Appendix E) could be used for child life student interns, new hires, or seasoned professionals in the hospital setting. The presentation breaks down in simple terms what ASD is and its history. Medical professionals would gain a great deal of information about ASD from this presentation. The presentation explains the history and characteristics of AS and how it would be found less common in adolescents today because of its recent disappearance from the DSM-5; it is no longer being diagnosed. The presentation can suggest activities that help professionals apply this knowledge to the hospital setting. In a recent study done on coping kits for children with challenging behavior in a pediatric hospital, nurses had items in a coping kit to help them with children with ASD (Drake et al., 2012). The coping kits included social stories, sensory input activities (such as chewing on items, holding something in their hands and manipulating a toy, or watching something spin, with a colorful spinner toy). These items listed above can help children relax.

Child Life Council Competencies

Introduction. The Child Life Council has a document that states the child life competencies. These competencies are in place to guide professionals about knowledge and skills they need to have while caring for children and families. In order to be a successful professional it is imperative to have a minimal level of acceptable practice as defined by the Child Life Council. The child life competencies serve as a guide for organizations and individuals who may want to further outline the competencies to their program (Child Life Council, 2010). The child life competencies document includes three sections of competencies. The first section lists competencies based on the care of

infants, children, youth and families. Each competency has a list of skills and knowledge base to better understand the importance of the child life practice. The second section lists competencies based on education and supervision. The third section is about administration in child life and important competencies for the practice.

Advocating for patients with special needs competency. There currently is not a competency that focuses on patients with special needs and their families as whole. Competency 1, D is the “ability to provide teaching, specific to the population served, including psychological preparation for potentially stressful experiences, with infants, children, youth and families” (Child Life Council, 2010). This could be relevant to AS and other special needs children. However, it does not specify “special needs” population. The researcher believes that the special needs competency would be placed after the competency 1, D mentioned above. The new competency would be more detailed on special needs, such as Autism Spectrum Disorder. If the principle researcher were to propose a new competency to be created it would be stated as: The ability to provide teaching, effective supervision, and mentoring specific to special needs patients, including ways to assist with preparing for stressful and overwhelming experiences, with infants, children, youth and families.

Knowledge:

- Attend annual education sessions on the practice of Autism Spectrum Disorders, as the research is widely growing.
- Learn the needs of individuals with ASD and how they develop differently and be able to articulate learning styles.

- Identify common stressors and fears experienced by this population and be able to address and calm these fears and stressors.

Skills:

- Assess previous experiences and misconceptions of medical experiences to understand best practices for the patient and family.
- Describe medical procedures and preparations in concrete terms while using developmentally supportive language during medical procedures and preparations.
- Be able to adapt accordingly when working with a non-verbal or verbal patient.

Conclusion

This study suggests validation that CCLSs are effective and an important component to providing patient and FCC. Child life professionals are critical members of the multidisciplinary and psychosocial team and can offer resources and support to patients and families who are dealing with stressors of hospitalization. There is a need for support of patients with AS and their families. Professionals need to be aware of the signs and signals of AS and ASD or the child may become more traumatized than before.

While this research project intended to add to child life coping strategies and distraction techniques for individuals with AS during a healthcare encounter, this study is not without limitations. Due to the limited services, and a restricted geographical area, the sample size for this research project was restricted to only a handful of participants. In addition, 6 out of 10 participants dropped out of the study. This study was intended to

gain information on hospital experiences for individuals with AS and to compile a list of strategies and techniques to better assist these patients.

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Appendix A:

Ohio University Consent Form

Title of Research: Understanding the impact of medical procedures on individuals with Asperger syndrome

Researchers: Courtney Sulfridge
Faculty Advisor: Dr. Jenny Chabot

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 provide consent from the survey link provided. This will allow your participation in this study.

Explanation of Study

This study is being done in order to evaluate effective tools and coping skills for adolescents in hospital settings that have been diagnosed with Asperger syndrome. If you agree to participate in this study you will be asked about your own hospital experiences which could include routine medical exams, short term hospitalization, or long term hospitalization. The survey will be conducted online. You must be 18-25 to participate, must have a diagnosis of Asperger syndrome, and have medical experiences. Your participation in this study is on your own time and will take approximately 15-20 minutes.

Risks and Discomforts

The survey will ask about your experiences with doctors and hospitals. If recalling or writing about these experiences might upset you, you might not want to participate. You can also discontinue or skip any items that might cause distress.

Benefits

This study is important to society because this research project will provide new information to medical professionals and the findings of this research may help others

with Asperger syndrome have more positive experiences in the hospital. This study is not expected to provide a benefit to you personally.

Confidentiality and Records

No personal information will be collected from this research study. If you are completing this survey on a public computer, the researcher suggests clearing the browser history and closing the browser before leaving.

Contact Information

If you have any questions regarding this study, please contact the principle researcher, Courtney Sulfridge by email at courtneysulfridge@gmail.com or by phone at (740) 516-4347. You may also contact the researcher advisor Dr. Jenny Chabot by email at Chabot@ohio.edu or by phone at (740) 593-2871.

If you have any questions regarding your rights as a research participant, please contact 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.

Version Date: *12/1/2014*

Appendix B:

Ohio University Parental Consent Form

Title of Research: Understanding the impact of medical procedures on individuals with Asperger syndrome

Researchers: Courtney Sulfridge

You are being asked permission for your child to participate in research. For you to be able to decide whether or not you want your child 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 child's 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 provide consent from the survey link provided. This will allow your child's participation in this study.

Explanation of Study

This study is being done in order to evaluate effective tools and coping skills for adolescents in hospital settings that have been diagnosed with Asperger syndrome. If you agree to allow your child to participate in this study they will be asked about their own hospital experiences, which could include routine medical check-ups, short term hospitalization, or long term hospitalization. The survey will be conducted online. Your child must be 15-17 to participate, must have a diagnosis of Asperger syndrome, and have medical experiences. Their participation in this study will take approximately 15-20 minutes.

Risks and Discomforts

The survey will ask about your child about experiences with doctors and hospitals. If recalling or writing about these experiences upset your child, your child might not want to participate. Your child can also discontinue or skip any items that might cause distress.

Benefits

This study is important to society because this research project will provide new information to medical professionals and the findings of this research may help others with Asperger syndrome have more positive experiences in the hospital. This study is not expected to provide a benefit to your child personally.

Confidentiality and Records

No personal information will be obtained about your child. If your child is completing this survey on a public computer, the researcher suggests clearing the browser history and closing the browser before leaving.

Contact Information

If you have any questions regarding this study, please contact the principle researcher, Courtney Sulfridge by email at courtneysulfridge@gmail.com or by phone at (740) 516-4347. You may also contact the researcher advisor Dr. Jenny Chabot by email at Chabot@ohio.edu or by phone at (740) 593-2871.

If you have any questions regarding your rights as a research participant, please contact 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 to your child and they have been explained to your satisfaction;
- you understand Ohio University has no funds set aside for any injuries your child might receive as a result of participating in this study;
- you are 18 years of age or older;
- your child's participation in this research is completely voluntary;
- Your child may leave the study at any time; if your child decides to stop participating in the study, there will be no penalty to your child and he/she will not lose any benefits to which he/she is otherwise entitled.

Version Date: *12/1/2014*

Appendix C:

Assent Form

Title of Research: Understanding the impact of medical procedures on individuals with Asperger syndrome

Researchers: Courtney Sulfridge

My name is Courtney Sulfridge. I am trying to learn about effective tools and coping skills for adolescents in hospital settings that have been diagnosed with Asperger syndrome. If you would like, you can be in my study.

If you decide you want to be in my study, you will be asked about your own hospital experiences, which could include routine medical check-ups, short term hospitalization, or long term hospitalization.

This study is important to society because this research project will provide new information for medical professionals and the findings of this research may help others with Asperger syndrome during their routine check-ups, short term hospitalization, or long term hospitalization. This study is not expected to provide a benefit to your child personally.

Other people will not know if you are in my study. I will put things I learn about you together with things I learn about other teens, so no one can tell what things came from you. When I tell other people about my research, I will not use your name, so no one can tell who I am talking about.

Your parents or guardian have to say it's OK for you to be in the study. After they decide, you get to choose if you want to do it too. If you don't want to be in the study, that is fine. If you want to be in the study now and change your mind later, that's OK. You can stop at any time.

My telephone number is 740-516-4347. You can call me if you have any questions about the study.

If you agree to be in this study, please select 'agree'; otherwise select 'disagree'.

Version Date: *12/1/2014*

Appendix D:

Recruitment Tools

Parent Letter

Dear Washington County Parents/Families,

My name is Courtney Sulfridge and I am graduate student at Ohio University. I am pursuing my Master's Degree in Child and Family Studies with a concentration in Child Life. A Certified Child Life Specialist (CCLS) is a professional who promotes effective coping through play, preparation, education, and self-expression activities. A CCLS also provides support and guidance for parents, siblings, and other family members (Child Life Council).

As a graduate student, I am working on a research project that focuses on Asperger syndrome (AS) and the healthcare setting. Since CCLS help adolescents and children understand and prepare for what will take place during a medical experience, it is important for us to understand the best ways we can help adolescents diagnosed with AS during medical procedures. My intention is to really learn from adolescents who have AS and identify the best ways for CCLS to help them through their hospital experiences. My hope is to identify professional practices that work best.

I am looking for participants ranging from age 15-25. If your son/or daughter has been diagnosed with AS and has had any healthcare experience (routine medical exam, short term hospitalization, or long term hospitalization), please give thought to having him or her participate in my study. The survey will last approximately 10-15 minutes. I have attached a list of the questions that will be asked on the survey. I have also provided a link to the survey.

https://qtrial2014az1.az1.qualtrics.com/SE/?SID=SV_bwwjnNOI7niaohn

The link will take you to an online consent form for you to read. After reading the consent form, you may indicate your agreement or not to letting your child participate in the study. If you click the agree button, the next screen that appears will be an assent form. This is a form for your child to read which provides much the same information as the consent form. Your child then has the choice to agree or disagree to be in the study. If your child agrees, the next screen will be the survey questions. If you have any questions about having your adolescent participating in my study, and/or any questions about I am asking, please feel free to contact me with any questions. I can be reached by email at courtneysulfridge@gmail.com

Thank you and sincerely,

Courtney Sulfridge

Classroom Announcements

I will introduce myself, the title of my thesis topic, and what criteria are needed to be eligible for the study. I will then ask the class to consider being a participant in my research project, or if they know anyone that would be interested in being a part of the project. I will then pass out an information sheet with my information on it for students to contact me if they are interested. I will then thank the classroom and the instructor for their time.

Classroom Announcements- Handout

Hello Everyone,

My name is Courtney Sulfridge. I am graduate student and I am in the process of working on my thesis. I need your help! I am focusing on Asperger syndrome and the hospital setting. I am trying to find participants that have a known diagnosis of Asperger syndrome, that are between the ages of 18-25, and have some medical experience (routine check-up, short or long term hospitalization). If you are interested in participating in this research study please go to the link provided. The link will provide you with more details about the study and will direct you to the research questions.

[Link to survey]

If you have any questions please feel free to email me at courtneysulfridge@gmail.com or call me at 740-516-4347. Thank you for your time.

Social Media Information

Thesis Participants Needed:

I am a graduate student and I am in the process of working on my thesis. I need your help! I am focusing on Asperger syndrome and the hospital setting. I am trying to find participants that have a known diagnosis of Asperger syndrome, that are between the ages of 18-25, and have some medical experience (routine check-up, short or long term hospitalization). If you are interested in participating in this research study please go to the link provided. The link will provide you will more details about the study and will direct you to the research questions.

https://qtrial2014az1.az1.qualtrics.com/SE/?SID=SV_bwwjnNOI7niaohn

If you have any questions please feel free to contact me (Courtney Sulfridge) at courtneysulfridge@gmail.com, or call me at 740-516-4347. Thank you for your time.

Appendix E:
Survey Questions

What is your current age?

Do you classify yourself as male or female?

What race do you classify yourself as?

____ White/Caucasian

____ Black/African American

____ Asian

____ Middle Eastern

____ Bi-Racial

____ Other

What ethnicity are you?

____ Hispanic

____ Non-Hispanic

Why were you visiting the doctor/hospital?

____ Routine check-up

____ Short term hospitalization (1-2 days)

____ Long term hospitalization (more than 1 week)

How old were you at the time of your last routine check-up?

How old were you at the time of your last short term hospitalization?

How old were you at the time of your last long term hospitalization?

Do you have a known diagnosis of Asperger syndrome?

YES NO

Was a Certified Child Life Specialist present during this experience?

YES NO

If you answered yes, what did he or she do?

What did the staff do to make the experience better?

What did the staff do to make the experience more challenging?

What things did you do to help calm and handle yourself during your experience?

Any other thoughts you would like to share about your hospital experience?

Appendix F:**Letters of Support**

Warren Local Schools

220 Sweetapple Road
Vincent, Ohio 45784

740-678-2366
www.warrenlocal.org



September 29, 2014

Dear Ms. Sulfridge,

It was a pleasure to meet with you earlier this month to discuss your potential research project. We support systems that better the lives of all children and are interested in your work with individuals with Autism Spectrum Disorders. These individuals have special needs when it comes to communicating with others and regulating their systems, especially in high stress situations such as medical appointments and procedures.

Warren Local Schools will be happy to support your search for survey participants by sharing your project with our parents. In addition, I will share your research needs with other school districts in Washington County in order to increase the potential for respondents.

Good luck as you plan your project and I look forward to meeting with you in the near future.

A handwritten signature in blue ink, appearing to read 'Tricia Hawkins', is written over a faint, larger version of the Warren Local Schools logo.

Tricia Hawkins
School Psychologist, Warren Local Schools

I AM A WARRIOR



Chris Keylor, Superintendent
Megan Atkinson, Treasurer

September 29, 2014

Dear Ms. Sulfridge,

This letter is to summarize and confirm my commitment to assisting you in your research project that focuses on Asperger's Syndrome and the healthcare setting. As stated in our meeting, I am the Director of Special Education for the Ohio Valley Educational Service Center, an agency supporting school districts in four counties with twelve (12) independent school districts. Through my association with these districts, I will share information and surveys with the Special Education Coordinators/Directors to garner the information you are requesting for your research project. While I cannot confirm anyone will take the information any further, I know my counterparts try to assist graduate students in their learning projects when they can.

I look forward to hearing more from you and seeing how we can work together. If there is anything else I can do to assist you, please do not hesitate to contact me.

Respectfully,

Andrew W. Brooks
Director of Special Education
Ohio Valley Educational Service Center
1338A Colegate Drive
Marietta, Ohio 45750
(740)373-6669, Ext. 5204
andy.brooks@omeres.net

Appendix G:
In-Service Training Presentation

The Basics of Asperger Syndrome and Autism Spectrum Disorder

A TRAINING FOR NEW INTERNS, NEW
HIRES, AND SEASONED CHILD LIFE
PROFESSIONALS AND OTHER MEDICAL
PROFESSIONALS

BY: COURTNEY A. SULFRIDGE



What is Autism Spectrum Disorder (ASD)?

- A diagnosis of ASD includes several conditions that used to be diagnosed separately: autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger syndrome. These are now all called autism spectrum disorder.
- Individuals with ASD are affected in their language, social skills, and behaviors.

What is Asperger Syndrome (AS)?

- Asperger syndrome is an autism spectrum disorder (ASD) that is near the “high functioning” end of the spectrum. Individuals with AS have social deficits, communication difficulties, and repetitive behaviors and interests (Woods, Mahdavi & Ryan, 2013).
- No longer diagnosed in the DSM-5 but it is still important to be educated on the diagnosis because many individuals have AS.
 - 1 in 88 individuals have AS

Basic Characteristics of AS

- Hard time understanding nonverbal communication such as facial expressions and gestures (Lobar, Fritts, Arbide, & Russell, 2008).
- Hard time with reciprocal conversations and lack eye contact
- Inability to understand social and emotional issues (Autism Speaks, 2014)
- Unable to process the emotions of others
- Obsessive behaviors over a certain topic of interest

Hospital Stressors

- **Common stressors of hospitalization that could relate to Asperger syndrome would include:**
 - Change in routine
 - Unfamiliar environments
 - Heightened fears of pain, strangers, medical equipment, misconceptions from the lack of understanding, loss of bodily control, lack of trust, fear of rejection

Child Life Specialists

- **Trained professionals with a strong background in child development and family systems, which assist children and families during some of the most challenging events during hospitalization**
 - Members of the interdisciplinary team, psychosocial team
 - Sibling and family support
 - Child life specialists also promote effective coping through play, preparation, education, and self-expressive activities

Importance of Child Life Specialists

- Child life specialists facilitate coping and the adjustment of children and families by providing play experiences, presenting information about events and procedures, and establishing supportive relationships with children and parents to encourage family involvement in each child's medical care (American Academy of Pediatrics, 2014, p.671)
- Family-centered care recognizes that families understand their child best. Family members take care of their children's developmental, social, and emotional needs throughout many years of life (Rollins, 2005).



The Need for Child Life Specialists



- Changes in routine, painful procedures (such as starting an IV or inserting nasogastric tubes), and new faces cause anxiety in the healthcare setting for special needs children (Drake, Johnson, Stoneck, Martinez, & Massy, 2012).
- Families and patients in a study reported that health care providers had very little knowledge of the characteristics of ASD and, as a result, the care that was provided was ineffective to the situation (McGonigle et al., 2013).

Suggested Tools

• Social Stories

- Helps individuals see in picture form what is going to happen next.
- They know the order in which things are going to happen, which gives them some control of the situation.



Suggested Tools Continued

• Sensory Items

- Stress balls: allows the patient to manipulate and squeeze something during a procedure.
- Items to chew on: allows the patient to keep busy chewing on a "chew toy"
- If a patient is really anxious the use of weighed items could be helpful. Such as weighted lap blankets, or weighted bracelets. These items help the child calm down.



Websites for More Information and Helpful Products

- Autism Speaks: <https://www.autismspeaks.org/>
- Got-Autism: <http://got-autismproducts.com/>
- National Autism Resources: <http://www.nationalautismresources.com/calming-products.html>
- Asperger Syndrome: http://www.ninds.nih.gov/disorders/asperger/detail_asperger.htm

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- Woods, A., Mahdavi, E., & Ryan, J. (2013). Treating clients with asperger's syndrome and autism. *Child and Adolescent Psychiatry and Mental Health*, 2013, 7(32). doi: 10.1186/1753-2000-7-32

Questions, Comments, Concerns?



- Thank you for your time!



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