

ASSESSING CHILD LIFE SPECIALISTS' KNOWLEDGE, COMPETENCY,
AND COMFORT LEVELS MANAGING CHALLENGING
BEHAVIORS IN PEDIATRIC PATIENTS WITH
AUTISM SPECTRUM DISORDER

by

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DEDICATION

In the hopes that this work may in some way positively impact the healthcare experiences of children with Autism Spectrum Disorder, this work is dedicated to children and families affected by Autism Spectrum Disorder and the Certified Child Life Specialists who support them. This work is also dedicated to Willis D. Stebbins and Katherine J. Stebbins, whose love and support has made this research possible.

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LIST OF ABBREVIATIONS

Abbreviation	Description
ASD	Autism Spectrum Disorder
HCP	Health Care Provider
CCLS	Certified Child Life Specialist
ED	Emergency Department
CARD	Center for Autism Related Disorders
ACLP	Association for Child Life Professionals
KCAHW	Knowledge About Childhood Autism Among Health Workers
ASKSG	Autism Spectrum Knowledge Scale, General Population Version
ASD-BPC	Autism Spectrum Disorder-Behavior Problems for Children

ABSTRACT

The present study assessed perceived competency and comfort levels among Certified Child Life Specialists (CCLSs) regarding the management of common challenging behaviors exhibited by pediatric patients with autism spectrum disorder (ASD) in healthcare settings. Utilizing a mixed-methods design, 131 CCLSs completed an online survey that assessed perspectives on managing challenging behavior, current knowledge of childhood ASD, as well as any training or education participants had received on childhood ASD and challenging behavior. The majority of participants reported having experience providing care to children on the spectrum who exhibited challenging behavior while working as a CCLS in a healthcare setting. Findings indicated that very few participants reported high levels on both their perceived competency and comfort regarding managing a variety of challenging behaviors. Results showed that knowledge and the amount of training CCLSs had received on childhood autism and challenging behaviors positively and significantly correlated with their perceived competency and comfort levels managing such behaviors in the hospital.

I. INTRODUCTION

Characteristics of Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition that ranges in both symptomology and severity. The cause of ASD is believed to be a combination of both environmental factors and genetic predispositions (Hallmayer et al., 2011).

According to the Center for Disease Control (2019), the prevalence of ASD has increased from one in every 150 children in 2002, to one in every 59 children in 2014. ASD can cause difficulties in information and sensory processing, increased anxiety levels, and special obsessions or interests (Aylott, 2004). Additionally, those with ASD often exhibit difficulties in adaptive, communication, and social skills, as well as increased stereotyped and ritualistic behaviors (MacDonald et al., 2007). Examples of stereotyped behaviors, otherwise known as stereotypy, include but are not limited to, hand-flapping, swaying, rocking back and forth, pacing, or engaging in self-stimulating actions. According to McLaughlin and Fleury (2018), although these stereotypic behaviors are usually not harmful, depending on how individuals respond to the stereotypy, these behaviors can progress and become destructive, usually indicating the child is anxious or stressed and is likely to have a behavioral outburst.

Challenging behavior. Challenging behaviors, or behavioral outbursts, can be defined as behaviors that are not deemed socially acceptable, can be physically dangerous, and can impede learning (Matson et al., 2010). Challenging behaviors commonly exhibited by this population often include, but are not limited to, aggression, screaming, flopping on the floor, leaving the supervision of a caregiver without permission, disrobing, self-injury, property destruction, tantrums, biting, scratching, noncompliance, and pica, which can be defined as an inappropriate behavior where one

engages in eating or chewing non-food items without any nutritional value, such as stone, chalk, soap, paper, etc. (Advani et al., 2014). These challenging behaviors increase the risk of harm to both the child and those around them and can be highly stigmatizing (Machalicek et al., 2007). Although the expression of challenging behavior varies depending on the child and the severity of their ASD, up to 94.3% of children with an autism diagnosis exhibit at least one challenging behavior (Matson et al., 2008). These behaviors often vary in both frequency and intensity, ranging from mild to severe. For example, Murphy et al., (2009) found that severity of disability, presence and amount of behavioral intervention services being received, and frequency of stereotyped or ritualistic behaviors can all effect the presence and severity of challenging behaviors.

Medical comorbidities in children with ASD. Many children on the spectrum have at least one co-occurring condition alongside ASD that requires medical attention. For example, research conducted by Kohane et al., (2012) shows that children on the spectrum had higher rates of medical conditions such as eczema, asthma, inflammatory bowel disease, diabetes mellitus Type I, muscular dystrophy, respiratory infections, migraines, gastrointestinal disorders, allergies, and seizures compared to children without an autism diagnosis. Additionally, Scarpinato et al., (2010) found that children on the spectrum are at higher risk for being diagnosed with a mood disorder such as depression. Furthermore, Leyfer et al., (2006) have shown that 37% of children diagnosed with ASD have also been diagnosed with co-occurring obsessive-compulsive disorder.

Because of this widespread comorbidity, children with autism often accesses health related services more frequently than neurotypically developing children. The high frequency of accessing health related services in children with ASD occurs in various medical settings, as this population experiences greater numbers of physician visits, non-

emergency care visits, and hospitalizations per year (Muskat et al., 2015). When comparing neurotypically developing children to those diagnosed with ASD, 64.9% of children on the spectrum were hospitalized within the first five years of life, compared to only 48.2% of typically developing children (Williams et al., 2005). Studies have also shown that children with ASD visit the Emergency Department (ED) more frequently than children without ASD (Wu et al., 2014). According to Iannuzzi et al., (2014), the most frequent reasons for ED visits amongst children with ASD were epilepsy convulsions, self-injury, mood disorder episodes, open wounds, and gastrointestinal disorders. In addition, children on the spectrum are at a higher risk for having an accident or injury compared to children who are typically developing and are more likely to take long-term medications (Muskat et al., 2015). These underlying health problems and medical conditions can generate or exacerbate challenging behaviors in addition to negatively impacting a child's ability to participate and engage in health-related treatments and interventions (Richdale et al., 2014).

Hospital stressors. Although a child's temperament and individual characteristics are certainly a factor in the manifestation of challenging behaviors, setting events and environmental factors play an important role in the expression and intensity of such behaviors (Matson, 2009). Many children with ASD struggle to moderate their emotions, reactivity, and behavior at baseline. Therefore, added stressful stimuli such as loud noises, changes in routine, demands, intense sensory experiences, and abrupt transitions can all serve as a precursor to, or worsen, maladaptive and challenging behaviors. Hospital settings often involve these factors (e.g., loud noises, intense sensory experiences) that can be potential antecedents to challenging behaviors. Understanding how hospitalization influences children with ASD is of importance as the number of

children with ASD accessing healthcare services rises along with the growing prevalence of diagnoses, as children on the spectrum are being exposed to hospital stimuli and sensations that can be especially distressing to them at higher rates as a result.

In a hospital setting, children might experience multiple unfamiliar Health Care Professionals (HCPs) coming in and out of their room at unpredictable times. The unpredictability and changes in routine that often occur in healthcare settings can be overwhelming for any child experiencing hospitalization. However, unpredictability and disruption in regular routine can be especially stressful for a child with ASD. This is because children on the spectrum typically find unanticipated change and inconsistency in their environment highly aversive and stressful and often prefer a regular and predictable routine (Fuld, 2018). Therefore, being exposed to many new HCPs coming in and out of the room at inconsistent times can be particularly difficult for this population.

Furthermore, sensory sensitivities often pose challenges to physical examinations and procedures in hospitals due to aversion to touch or certain tactile stimuli commonly exhibited by those on the spectrum. According to Marco et al., (2011) children with autism often display hypersensitive or hyposensitive responses to sensory stimuli. These sensory differences, like many other characteristics of pediatric autism, can range from mild to severe and, although not unique to ASD, are “more prevalent in this population than in other developmental disabilities” (Marco et al., 2011). Riquelme et al., (2018) reported that those diagnosed with ASD can exhibit hypersensitivity to painful sensory experiences, including lower pressure and thermal pain thresholds, potentially resulting in slower recovery rates after painful experiences have occurred. These sensory sensitivities are possibly due to alterations in somatosensory processing in children with ASD. Moreover, children on the spectrum may feel pain or discomfort when coming into

contact with sensory stimuli that a child who is typically developing would not find painful or uncomfortable (Nunez, 2018). Examples of routine procedures or items found in a hospital that may aggravate the sensory sensitivities experienced by children with ASD are the texture of bed sheets or hospital gowns, the smell of certain medicines or cleaning products, masks, having a stethoscope placed on the chest, bandages being placed on the skin, and bright lights, many of which cannot be avoided. Sensitivities such as these can make it difficult for children with autism to tolerate simple treatments, interventions, and medical procedures that a typically developing child would, in most cases, have little problem tolerating.

Moreover, communication challenges are common in children with ASD, such as difficulties with receptive and expressive language skills. Communication challenges can make hospital environments particularly stressful. This is because it may be more difficult for these patients to verbalize their distress, pain, fears, preferences, or any of the unique challenges they may experience during hospitalization (Nunez, 2018). Difficulties in communication can become a large problem for children with ASD accessing healthcare related services, as it can leave the child afraid and with no way to communicate their feelings to a provider.

Hospital stressors as an antecedent to challenging behavior. These unique sensitivities, differences in sensory processing, and social and communication difficulties can all cause high levels of tension and may serve as a precursor to challenging behavior for pediatric patients with ASD. For example, Marco et al., (2011) found that self-injury and aggression are common behavioral responses in pediatric patients with ASD, especially in those who are unable to communicate their duress due to difficulties in language and communication skills. Additionally, noncompliant behavior may occur

upon sensory distress or discomfort, often preceding emotional outbursts and tantrums related to a child's hospital experience, further complicating a provider's ability to care for pediatric patients with autism (Browne, 2006).

Hospital environments are often very fast paced, which can be an additional antecedent to challenging behavior, as many children on the spectrum often prefer quiet, low stimulation environments. Children with ASD often require time to familiarize themselves with a new environment before a provider can expect to receive their compliance. If a child is not given the proper amount of time, preparation, or detailed information in a developmentally appropriate way before entering a new environment, or a care provider begins to place demands on the child before they have adjusted, challenging behavior is likely to occur. Due to the need for increased time and preparation for children with ASD to become comfortable with their surroundings, "accessible and processable information becomes imperative for environmental participation" and to lower the risk of challenging behaviors (Krieger et al., 2018).

Stereotypy, occasionally referred to as stimming, is typically harmless and occurs in response to sensory dysfunctions in children with autism and can include, but is not limited to, "hand flapping, head banging, and rocking back and forth" (Lawson et al., 2014). Stimming behaviors often occur in a child with ASD as a result of either hyperresponsiveness or hyporesponsiveness to stimuli within their environment.

For example, a child who is hypersensitive to sensory stimuli may experience an inability to habituate to certain sensory experiences or "contextualize sensory information," resulting in a "constant state of sensory attentiveness" and alertness that is much higher than that of a neurotypically developing child (Lawson et al., 2014).

Hypersensitivity to sensory experiences can cause an overwhelming response in a child

with ASD, which may cause the child to begin engaging in stimming behaviors as a method of self-soothing in an attempt to cope with the overwhelming amount of sensory information in their environment. Contrastingly, children on the spectrum who exhibit hyporesponsive, or lowered, reactions to sensory experiences might show “absent, diminished, or delayed behavioral responses to sensory stimuli” (Simon et al., 2017). Hyporesponsive reactions to sensory experiences can also have serious implications for the hospitalized child diagnosed with ASD, as the hospital environment may lack stimulating sensory experiences a child in this situation would most likely be seeking. A child who exhibits hyporesponsive reactions to stimuli may engage in stimming behaviors to compensate for lowered reactions or the limited presence of sensory sensations in their current environment, whereas a child who exhibits a constant state of alertness due to sensory sensitivities, or hyperresponsiveness, may engage in stimming behaviors as an attempt to create a sense of predictability and control through “repetition of self-generated actions” (Lawson et al., 2014).

Regardless of whether a child with autism engages in these self-stimulating behaviors due to hyperresponsive or hyporesponsive reactions to sensory sensations, stimming is often a coping mechanism for many individuals on the spectrum and is typically harmless. However, if a provider is unaware that children with ASD often exhibit these stimming behaviors as a means of self-soothing or stimulation and attempts to block or interrupt them, as they can appear intimidating or unnecessary to those unfamiliar with these behaviors and can impede procedures, providers can unknowingly escalate the situation and cause a behavioral outburst to occur. This means that the way adults react to stimming behaviors in the hospital directly impacts the progression and intensity of challenging behaviors, as incorrect responding “has been shown to increase

aggression” and can further negatively impact the healthcare experience of individuals on the spectrum and their ability to cope (McLaughlin & Fleury 2018). The importance of correct responding to stimming behaviors emphasizes the need for HCPs to have an understanding of ASD and typical behaviors exhibited by this population to foster positive healthcare experiences and avoid unnecessarily causing or escalating challenging behaviors.

With all of these unique support needs, stressors, and distinctive triggers for challenging behaviors seen in clinical environments, it is understandable that children on the spectrum struggle to adjust to hospitalization with greater difficulty compared to neurotypically developing children. It is important to note that the individual needs of children with developmental disabilities can be very similar to children who are neurotypically developing, however, meeting their needs and accommodating their unique considerations may be more difficult in an environment that, in many ways, cannot be controlled or predicted (Nunez, 2018). For example, smells, bright lights, feelings of pain or discomfort, and noises can sometimes not be adjusted for children on the spectrum who might be more sensitive to these sensations than a child who is neurotypically developing. All of these factors can increase the amount of stress and anxiety experienced by pediatric patients diagnosed with ASD in a hospital environment, potentially acting as an antecedent to challenging behavior. Consequently, because hospitalization and treatment can increase the risk for challenging behavior in children with ASD, caring for this population can cause increased resultant stress and anxiety for HCPs as well.

Health Care Professional's Knowledge and Comfort Levels in Serving Pediatric Patients with ASD Exhibiting Challenging Behavior

The disproportionate exposure of children with ASD to hospital settings and the potential for healthcare environments to evoke or exacerbate challenging behaviors emphasizes the need for HCPs to be knowledgeable on ASD and its common symptoms and feel comfortable and competent managing challenging behaviors. Having HCPs who are knowledgeable on ASD, trained in behavioral antecedent manipulation and de-escalation strategies, and are comfortable and competent in managing challenging behavior when it does occur, can help improve the quality of care patients with ASD receive. Studies have shown that there are a number of benefits associated with professional knowledge and skill related to autism, including greater trust in healthcare systems and promotion of strength and resiliency in children and families receiving care (Kogan et al., 2008).

However, there is a concerning disparity between the growing prevalence of children with ASD accessing healthcare and the lack of preparation and education provided to HCPs on how to properly serve patients on the spectrum and manage their behaviors. Professionals who interact with and care for children with ASD commonly report a lack of education and training on childhood ASD and challenging behavior. Many HCPs report that this makes their ability to deliver services and care for this population ineffective and challenging (Brookman-Frazer et al., 2012). If HCPs have limited experience or knowledge with this population, they may be unaware of common antecedents to challenging behaviors or effective strategies to communicate and relate to children with ASD. This is problematic, as having this knowledge could improve the healthcare experiences of children with ASD and their families. Although there are many tools available to aid in communication for children with ASD that can help manage or

prevent challenging behaviors, if HCPs have limited knowledge of childhood ASD or training focused on working with this population and common behaviors they exhibit, they may be unaware of the existence of such tools or how to find and utilize them.

Families with children diagnosed with ASD, specifically those who exhibit behavioral problems, have more trouble accessing services, receiving referrals, coordinating care, obtaining support, and report having more problems receiving family-centered care (Kogan et al., 2008). These challenges lower the quality of care received by pediatric patients with ASD. Parent and caregiver reports indicate negative experiences where the specific needs of their child with ASD were not being met or acknowledged during hospitalization, often resulting in the escalation of disruptive behavior and negative interactions (Muskat et al., 2015).

Consequently, HCPs often report hesitation to care and provide for this specific population as a result of previous negative interactions that they have experienced due to maladaptive and challenging behaviors (Muskat et al., 2015). Zwaigenbaum (2016), found that HCPs reported many challenges working with children on the spectrum, specifically when these children were physically larger in size and showed increased levels of aggression. Moreover, HCPs identified symptom severity and limited or absent verbal communication skills as additional challenges, specifically in children who exhibited destructive behavior, as inability to communicate pain and anxiety can serve as a precursor to a behavioral outburst (Zwaigenbaum et al., 2016).

Difficulties working with children with ASD becomes a critical problem given that the majority of children on the spectrum exhibit at least one type of challenging behavior. These findings underscore the high probability of HCPs experiencing

challenging behavior in pediatric patients diagnosed with ASD during hospitalization and the current lack of preparation and comfort in caring for this population amongst HCPs.

For example, Unigwe et al., (2015) found that almost two-thirds (63.5%, $n=193$) of Primary Care Providers reported not having any training on autism during their primary medical degree or their specialist training. In addition, 39.5% reported never having any training on autism, either during their degree or after qualifying (Unigwe et al., 2015). Attesting to the importance of training, after training providers reported feeling better prepared to care for patients with autism, as evidenced by a pilot study conducted by Johnson et al., (2012), in which 604 HCPs took part in an instructor-led training on challenging behavior in pediatric patients with ASD. This training aimed to improve participant's comfort and ability to serve patients who were on the spectrum. As a result, staff showed increased knowledge of ASD and decreased fear in working with children with developmental disabilities. After training, over half of participants reported that they now knew how to help parents prepare for their child with ASD to go to the hospital and how to identify the stages and precursors of escalating behavior. These findings provide support for the efficacy in training professionals to better serve children on the spectrum who exhibit challenging behaviors and how this type of training can increase knowledge, comfort, and competency levels in working with this unique population.

Although proven to be effective, specialized training and education on childhood autism and challenging behavior are still being given to HCPs at low rates. For example, many HCPs report never having any specialized training on ASD. HCPs often report that, without this training, they have struggled to communicate with children who have ASD, not only adversely impacting their interactions and hospital experiences, but also serving as a precursor to behavioral outbursts. Moreover, Houghton et al., (2017) found that

HCPs reported the lowest amount of skill and information regarding managing challenging behaviors compared to any other domain when working with patients with disabilities.

Contributing to the lower quality care experienced by children on the spectrum, HCPs also report frequent “challenges to providing necessary accommodations, often due to limited time availability, staffing constraints, and resources” (Zwaigenbaum et al., 2016). These challenges experienced by HCPs imply that, for a variety of reasons, pediatric patients with ASD are not being given the time to adjust to novel stimuli and clinical environments that they often require. Additionally, it shows that many HCPs are failing to acknowledge and accommodate for the unique support needs seen in children with ASD that could improve healthcare experiences and decrease challenging behaviors and healthcare related trauma. Due to lack of resources, provider knowledge, and lowered perceived competency and comfort levels in properly managing challenging behaviors, children with autism are more likely to be physically and chemically restrained, which can lead to longer hospital stays and higher medical expenses compared to any other pediatric population (Davignon et al., 2014). In addition to longer hospital stays and higher medical expenses, this methodology to control patients with ASD who exhibit challenging behavior can be traumatic and make hospitalization even more aversive and frightening for this population, increasing the likelihood that future healthcare experiences will evoke stress, anxiety, and challenging behavior.

The Role of Certified Child Life Specialists

Certified Child Life Specialists (CCLSs) are professionals who have obtained a minimum of a bachelor’s degree, fulfilled the required coursework in child development and related fields, completed a 600-hour minimum clinical internship under the direct

supervision of a current CCLS, and passed a certification exam. CCLSs work to promote the well-being of hospitalized children, reduce healthcare related fears, and foster positive coping skills. Additionally, CCLSs work to increase healthcare satisfaction and advocate for patient and family needs and best interests. According to the Association for Child Life Professionals, CCLSs enhance children's medical experiences through providing evidence-based and developmentally appropriate individualized interventions supported by developmental research. These interventions strive to promote development and mastery and increase self-confidence in children during hospitalization. In sum, as described by the American Academy of Pediatrics (2014), child life services are a critical element in caring for pediatric populations.

The field of child life has rapidly grown since its beginning during the 1960s as a foundation to family-centered care practices. Alongside this growth, the roles and responsibilities of a CCLS are constantly evolving as we learn more about how early experiences and potential trauma from hospitalization can affect children as they grow (Thompson et al., 2018). This rapid growth and recognition emphasize the need to understand the full potential for child life services (LeBlanc et al., 2014). Although a variety of HCPs will interact with patients diagnosed with ASD, CCLSs can serve a unique role in supporting and guiding children with ASD through their hospital experience. This is because CCLSs specifically work to alleviate stress and anxiety and foster emotional and psychosocial health in children, which can be defined as the culturally sensitive provision of psychological and social care through therapeutic communication (Chen et al., 2017).

One of the primary roles of a CCLS is to prepare children on what to expect while they are in the hospital and educate them on new diagnoses and upcoming treatments or

procedures. According to the American Academy of Pediatrics (2014), this has been shown to result in less emotional stress, enhanced positive coping skills, a clearer understanding of healthcare experiences, and more positive physical recoveries for hospitalized children. Thompson et al., (2018) suggests that when children are prepared for procedures, they often report less anxiety, as they know what to expect, which reduces fear and clears up misconceptions the child might have related to their healthcare experience. Therefore, it is clear that many children greatly benefit from receiving child life services while undergoing hospitalization.

However, the limited existing research that has focused on CCLSs working with children with ASD has found that, while CCLSs seem like the ideal interdisciplinary team member to support children with ASD, many still feel underprepared to work with this unique population. Discomfort or perceived lack of competence may stem from lack of important knowledge regarding common triggers for challenging behavior or effective de-escalation strategies, making caring for this population intimidating. The perspectives of CCLSs working with children on the spectrum who exhibit challenging behaviors are vital to consider when assessing how we provide care and prepare patients within this population for upcoming treatments, procedures, and healthcare experiences in the way that they deserve.

Without specialized training or education on ASD, CCLSs might be unfamiliar with specific evidence-based strategies for educating and preparing children on the spectrum. This is because, according to Sparapani et al., (2016) ASD can often present itself with unique learning differences and adjustment challenges. This has the potential to make CCLSs feel uncomfortable or incompetent when preparing or educating this

population if they have not received specialized training or education on how to effectively do so.

Presently, a variety of evidence-based intervention strategies currently practiced by CCLSs might not be as effective for a child with ASD compared to a neurotypically developing child and may actually be more harmful and aversive rather than beneficial for many in this population. For example, CCLSs often use play as a common modality to achieve various psychosocial goals. These goals can include building therapeutic relationships, assessing hospital adjustment, promoting development and positive coping, and performing interventions designed to educate children on hospital equipment and desensitize them to novel stimuli they may observe while in the hospital. Play is proven to be a highly effective tool in both reducing a hospitalized child's stress and anxiety and has even been shown to reduce pain and discomfort during and after painful procedures (Moore et al., 2015). However, this can be difficult for children with autism, as many of these children do not develop certain play skills in the way that many typically developing children do. According to Jung and Sainato (2012), play is often an area of weakness for children with autism, defined by lack of pretend and imaginative play. This common evidence-based strategy for preparing and educating children during hospitalization commonly employed by CCLSs could be ineffective for a child with autism for these reasons and could result in challenging behaviors if the child becomes stressed or aggravated during this time, or at the time of treatment if not prepared in a way that is appropriate for a child with ASD. Straus et al., (2019) emphasize that it is not uncommon for behavioral problems to intensify if staff attempt to communicate with children on the spectrum through play. For example, problem behaviors may occur if staff members try to prepare a child with ASD for an upcoming procedure using medical

play, such as pretending to administer medication to a doll, as many of these patients do not often have the sophisticated play skills to engage in this type of pretend play.

Moreover, variability in behavior during interventions is common amongst children with autism, requiring an individualized interpretation of responses (Bulkeley et al., 2016). However, this can be difficult to interpret without a baseline understanding of ASD, distinctive behaviors, and the common functions of such behaviors. Due to the high variability of ASD, without an understanding of common triggers, especially those that are common within a hospital environment, it can be especially difficult to effectively minimize antecedents for challenging behaviors, which negatively impact a child's ability to adjust and cope with hospitalization and learn about their treatment or procedure. It is not uncommon for children on the spectrum to display socially unacceptable or challenging behaviors in addition to having amplified anxiety or uncommon coping styles compared to neurotypically developing children, particularly in a clinical setting. This type of responding can provide further complexity to a CCLS's ability to conduct assessments, preparations, and intervention planning for patients that fall within this population. Conducting assessments or planning individualized interventions can be especially difficult if the CCLS has little experience or training, as well as diminished comfort and perceived competency levels, in managing or recognizing these unique behavioral responses or ASD symptoms.

Potential challenges working with children with ASD in a hospital setting underscores the importance of CCLSs having a comprehensive understanding of ASD, as developing intervention strategies that will benefit the individual child with autism will decrease the likelihood of challenging behaviors and promote a more positive healthcare experience. Additionally, it is likely that having a more complete understanding of ASD

and common behaviors will increase CCLS's comfort and perceived competency in working with patients on the spectrum and managing challenging behaviors when they do arise. Learning the unique considerations of children with ASD and better understanding how to prevent and manage challenging behaviors will provide a more positive experience not only for staff and pediatric patients with autism, but for their families as well.

Family-centered care. CCLSs often work very closely with parents, siblings, caregivers, and other family members during a patient's hospital stay. This is especially important when working with patients with ASD, as important information regarding behavioral triggers, preferences, and coping methods can be learned from those who best know the child. However, without their own knowledge of challenging behaviors expressed in pediatric patients with ASD, as well as common problem behavior antecedents and behavioral management strategies, CCLSs might not know relevant or important questions to ask caregivers and may miss vital information necessary when conducting assessments that could prevent later outbursts. By having a foundational knowledge of ASD and challenging behaviors exhibited in this population, CCLSs would be better suited to work with families and provide the best possible healthcare experience for children with autism.

Additionally, as advocates of family-centered care, CCLSs can be a vital resource to help families cope with their child's challenging behavior in the hospital. During hospitalization, challenging behaviors, distress, and behavioral outbursts can be difficult for a family to cope with, often causing resultant stress for the family (Morris et al., 2018). In addition to resultant stress, parents often describe embarrassment or feeling stigmatized by their child's challenging behavior (Gray, 2002). This can be problematic,

as the stress of dealing with challenging behaviors puts mothers in particular at a higher risk for poor mental health outcomes (Herring et al., 2006). Parental mental health is extremely important in the hospital setting, not only because parents are already in a vulnerable state where they are at a higher risk for negative outcomes, but because HCPs often rely on family members who know their child best to be active members in developing an individualized plan of care for their child as well (Inglese, 2009). Therefore, if parents are struggling with their own stress and mental health due to their child's behavior, they may be less able to be fully involved in their child's plan of care due to high levels of anxiety, embarrassment, and exhaustion. Given that families can experience resultant stress and poor mental health as a result of their child's challenging behavior in the hospital, it is important for CCLSs to understand ASD and challenging behavior and know how to develop appropriate antecedent manipulation strategies and coping plans not only for the patients, but families as well. In doing so, CCLSs can better promote family-centered care, support family needs effectively, and reduce the risk for negative mental health outcomes.

Family-centered care strategies have been proven to aid in the prevention of challenging behaviors in the hospital setting. By implementing family-centered care principles, providers recognize the uniqueness of each family and acknowledge that the family is the expert on the child's abilities and needs. Bulkeley and colleagues (2016), found that family-centered interventions were effective in changing sensory-related problem behaviors in young children with autism. Although the literature supports the benefits of family-centered care when serving pediatric patients with ASD, mothers of children on the spectrum often report that HCPs do not understand children with ASD and fail to acknowledge the expertise of the mother on their particular child (Butlas,

2012). Mothers of children with ASD have also reported that HCPs fail to recognize the emotional toll when caring for a child with ASD, as well feeling ostracized while their child with ASD was in the hospital (Butlas, 2012).

CCLSs are often the ones who talk to families about their needs and relay those needs to the interdisciplinary healthcare team, serving as a point of contact for all those involved in a child's healthcare experience (Jensen et al., 2019). If challenging behavior does occur, it is critical for CCLSs to be familiar with calming and supportive de-escalation strategies that are effective for children with ASD to manage such behaviors. This is because, not only can this promote parental mental health and positive outcomes for that child, but because CCLSs are often the point of contact when anxiety or distress levels increase in patients and are frequently the ones other HCPs rely on for help in such situations as well. As advocates of family-centered care, CCLSs can further support families and caregivers and improve healthcare experiences for patients with ASD by educating medical staff on information learned from parents and caregivers, advocating for their emotional and psychosocial support needs, and supporting them during behavioral outbursts to foster parental mental health.

Given that children with ASD have an increased risk of experiencing high levels of stress, maladjustment, and coping challenges during hospitalization, CCLSs are the most suitable interdisciplinary healthcare team members to enhance positive medical experiences for children on the spectrum. It is no doubt that CCLS's current assessment skills, ability to implement individualized interventions to facilitate coping, and extensive developmental knowledge can be used to increase comfort and predictability and aid in preventing and managing challenging behaviors. However, it is vital that we evaluate the perspectives of CCLSs specifically regarding childhood ASD and challenging behavior.

Information on CCLS perspectives on working with children on the spectrum who exhibit challenging behavior can be used to help minimize the risk for negative outcomes, further meet the unique needs of children on the spectrum experiencing hospitalization, and inform future training and educational practices for CCLSs and those seeking certification.

Child Life Specialists' Perspectives Working with Pediatric Patients with ASD Exhibiting Challenging Behavior

Although there is a substantial amount of research supporting the idea that HCPs feel underprepared and less competent working with children on the spectrum and navigating behaviors and unique support needs exhibited by this population (Morris et al., 2019), there is limited literature specifically examining the individual perspectives of CCLSs. Given their specialized expertise in child development and psychosocial care, it might be expected that CCLSs are better prepared to care for pediatric patients on the spectrum compared to other healthcare team members. However, the limited research that has focused on CCLSs suggests that many of them still feel hesitant to work with children with ASD (Jensen et al., 2019). One of the few studies specifically addressing this issue was conducted by Jensen and colleagues (2019), who found that CCLSs often felt underprepared to work with patients who were nonverbal or exhibited aggression and many were uncomfortable around children with ASD. This is an important finding as discomfort experienced when serving children on the spectrum can decrease the quality of care children and families within this population receive. The researchers also found that many CCLSs reported a strong desire for training in working with pediatric patients on the spectrum. With the dramatic increase in children being diagnosed with ASD and the rate at which they are accessing healthcare services, it is important that a specialized healthcare team member designated to promote positive coping, hospital adjustment, and

psychosocial well-being, such as a CCLS, feel comfortable working with this at-risk population and advocating for their needs to effectively serve them and provide high quality care. Moreover, CCLSs are often training other members of the healthcare team on best practices to facilitate coping and promote positive hospital experiences.

Therefore, if confident in their abilities to work with children on the spectrum, CCLSs would be better prepared to confidently instruct team members on how to manage behaviors and increase positive outcomes for children with autism through meaningful, engaging, and ethical strategies as well.

In sum, current research highlighting the increased prevalence of ASD in children and the unique support needs and challenges this population faces in hospital settings underscores the importance of preparing healthcare team members to work with children on the spectrum who exhibit challenging behaviors, as these challenging behaviors can increase stress in patients, families, and healthcare providers (Carbone et al., 2010). The current research shows that, while effective behavioral management strategies are crucial due to fundamental risks to patients and providers, these strategies are also needed to manage the broader range of needs for patients diagnosed with ASD (Zwaigenbaum et al., 2016). Therefore, until healthcare team members are comfortable and confident in their ability to prevent and manage challenging behavior in children with autism, these patients and families are receiving less quality care where various important needs are being ignored or left unmet.

As important members of the interdisciplinary healthcare team with extensive knowledge in development and psychosocial care, CCLSs are the ideal healthcare team member to help improve hospital experiences for children with autism. With knowledge and increased comfort and perceived competency in managing challenging behaviors in

children with ASD, CCLSs will most likely be better prepared to manipulate behavioral antecedents, de-escalate children engaging in maladaptive behaviors, and support children and families within this population. Additionally, CCLSs would be better prepared to utilize their existing strengths as a psychosocial professional to develop effective intervention strategies to improve the healthcare experiences for children with ASD, support interdisciplinary team members, and reduce the risk for negative outcomes or healthcare related trauma for this population.

II. PRESENT STUDY

Currently, there is limited literature assessing CCLS's experiences and perceptions specifically working with children on the spectrum. Although the limited research currently supports the fact that many CCLSs currently feel underprepared and uncomfortable working with children with ASD, this study seeks to expand upon current literature, such as the research conducted by Jensen and colleagues (2019), by focusing on the perceptions of CCLSs specifically working with children diagnosed with ASD who exhibit challenging behavior and assess comfort and perceived competency levels managing an array of specific challenging behaviors exhibited by this population. Additionally, this study seeks to identify factors related to increased levels of perceived competency and comfort levels managing such behaviors and knowledge of ASD. Finally, this study will compare current levels of knowledge on childhood ASD amongst CCLSs to other HCPs represented in previous literature, which, to our knowledge, no other existing research has thoroughly explored.

This study sought to identify what CCLSs already know about childhood ASD, what training or education CCLSs have received on childhood ASD and challenging behavior, what experience CCLSs have had with challenging behavior in pediatric patients with ASD, and their perceived comfort and competency levels managing this type of behavior in a healthcare setting. This study also explored factors related to increased knowledge of ASD and increased perceived competency and comfort levels managing challenging behaviors amongst CCLSs. Motivated by the existing research discussing the ability for child life services to improve healthcare experiences, the growing prevalence of childhood ASD and the rise in utilization of healthcare services by this population, and existing research examining knowledge of ASD as well as common

challenges when working with children on the spectrum amongst HCPs, four hypotheses were proposed:

Hypothesis 1: It was expected that the majority of CCLS participants would report having experienced providing care to pediatric patients with ASD who have exhibited challenging behavior during hospitalization.

Hypothesis 2: It was expected that CCLS participants would exhibit similar or higher levels of knowledge about childhood ASD compared to other HCPs and members of the general public, as measured in previous studies (McClain et al., 2019; Bakare et al., 2008).

Hypothesis 3: It was expected that participants would report having received some training or education on childhood ASD and challenging behavior; the present study sought to describe this amount.

Hypothesis 4: Lastly, it was expected that CCLS participants could readily report about their levels of both perceived competency and comfort in managing a variety of challenging behaviors exhibited by children with ASD; the present study sought to describe these levels and explore factors related to increased perceived competency and comfort levels.

III. METHODOLOGY

Participants

CCLSs were recruited to participate in a voluntary survey through social media pages comprised of nationwide child life professionals, as well as through the Association For Child Life Professionals (ACLP) forum and directory. All participants were 18 years of age or older and included those who currently work as a CCLS or have worked as a CCLS within the past 10 years.

The online Qualtrics survey was completed by a total of 131 participants (100% female, 94% White). Most participants held a graduate degree (68.4% Graduate, 30.1% Bachelor's). The majority of participants were between the ages of 24-29 ($n=53$), followed by 30-35 ($n=28$), 36-41 ($n=19$), 42-47 ($n=14$), 48-53 ($n=8$), 18-23 ($n=4$), 54-59 ($n=3$), with the remaining participants falling between 60-65 ($n=2$). Moreover, 69.17% ($n=92$) of participants reported working as a CCLS full time, averaging 40 hours or more per week, whereas 29.32% ($n=39$) of participants reported working part time, averaging below 39 hours per week.

Design and Procedure

Utilizing a mixed-methods design, qualitative and quantitative survey data was collected from CCLSs who were either currently practicing, or who had been employed as a CCLS within the past 10 years. The online survey for this study was developed based on the following guiding research questions, 1) how knowledgeable are CCLSs on childhood ASD, 2) what, if any, training or education have CCLSs received on childhood ASD and challenging behavior, 3) what experience have CCLSs had with pediatric patients with ASD, and 4) how competent and comfortable do CCLSs currently feel

managing various types of challenging or maladaptive behaviors commonly exhibited by this population?

Prior to beginning the survey, all participants provided informed consent. The survey was completely anonymous and began with items pertaining to basic demographic information followed by a question prompting participants to select any training or education they have received on childhood ASD and challenging behavior, with a free response option for participants to list any additional training they have received not already listed in the survey. The survey then consisted of a knowledge of autism assessment that was comprised of the Knowledge about Childhood Autism Among Health Workers Scale (KCAHW) and items from the Autism Spectrum Knowledge Scale, General Population Version (ASKSG). The knowledge assessment for this study consisted of the full 19-items from the KCAHW and 3 items from the ASKSG addressing ASD symptomology and common behaviors for a total of 22 items assessing participant's knowledge of childhood ASD. The survey concluded with items measuring experience, comfort, and perceived competency managing various challenging behaviors amongst participants utilizing a modified version of the Autism Spectrum Disorder-Behavior Problems for Children (ASD-BPC) index. All behaviors from the ASD-BPC were used in the survey, however the measure was modified to allow participants to rate their comfort and perceived competency levels managing these behaviors as a CCLS using a seven item Likert-scale. At the end of the survey, participants were given a link to participate in a post-survey online training developed by the Center for Autism Related Disorders (CARD) on preventing and managing challenging behavior in children with autism.

Measures

Demographics. Basic demographic information was collected based on the APA publishing guidelines and standards. Participants provided information regarding their educational background, gender, age, ethnicity, as well as their current employment status and typical number of hours working in a child life setting per week. Participants also listed whether or not they had received any prior training or education regarding childhood autism and challenging behavior, such as professional development obtained outside of work, training brought in by their employer, or education, such as specific coursework obtained through an academic program throughout their undergraduate or graduate degrees.

Knowledge about childhood autism among health workers (KCAHW). The KCAHW is a 19-item questionnaire that assesses baseline knowledge about childhood ASD amongst healthcare workers. The scale is divided into four domains that address impairments in social interaction, communication and language development, obsessive and compulsive behaviors, and other comorbid conditions as well as the typical onset of childhood ASD (Bakare et al., 2008). A maximum and minimum total score of nineteen (19) and zero (0) respectively are possible when all four domain scores are summed. The KCAHW has been shown to be a reliable tool to measure healthcare workers' knowledge of ASD and identify knowledge of childhood autism among a particular sample population or community. This scale has been used in several studies globally and has been proven to have good test-retest reliability, internal consistency ($\alpha = 0.97$), and cultural validity (Bakare et al., 2008). Additionally, in a study conducted by Harrison et al., (2016) that assessed 44 various tools designed to measure knowledge of ASD, the KCAHW was one of only seven measures that qualified as meeting a best practice

assessment standard set forth by participating researchers. A maximum score of 19 indicates adequate knowledge of childhood symptoms and signs of ASD. Igwe et al., (2011) stated that the knowledge of early symptoms and signs of ASD assessed using this instrument may aid in early recognition, appropriate referrals, and interventions for children with autism and was therefore determined to be an appropriate tool to measure knowledge of autism amongst CCLSs for this study.

Autism spectrum knowledge scale, general population version (ASKSG). The Autism Spectrum Knowledge Scale, General Population Version (ASKSG) is a 31-item measure that assesses current knowledge and understanding of ASD within the general population. Available findings suggest that the ASKSG is a measure that is both valid and reliable and adequately measures ASD knowledge in the general population. McClain et al., (2019) found that Cronbach's Alpha on the ASKSG indicated acceptable internal consistency ($\alpha = .73$ raw, $\alpha = .75$ standardized). Moreover, Guttman's λ_6 indicated good internal consistency ($\lambda_6 = .80$). Similar to the KCAHW, items from the ASKSG are coded as binary responses (correct, incorrect), where "not sure" responses were recoded to reflect an incorrect response. Previous literature has calculated and reported the percentage of participants in various studies who scored correct on each item included in the measure after being administered. The current study utilizes a modified version of the ASKSG, as a select few items were chosen to assess knowledge of ASD in addition to the full aforementioned KCAHW scale. Percentages for each correct response for the three items chosen to use in the present study were compared to percentages of correct responses reported in previous studies conducted on members of the general population that utilized the same measure.

Autism spectrum disorder-behavior problems for children (ASD-BPC). This scale assesses the presence of problem behaviors in children with ASD. This scale is used as part of a comprehensive battery to assess ASD symptoms, psychopathology, and behavioral problems. Traditionally, this scale requires informants to rate items comprising of various common problem behaviors from zero to two, where a score of zero (0) signifies there is no difference or impairment, one (1) signifies somewhat of a difference or mild impairment, and two (2) signifies a large difference or severe impairment in behavior exhibited by a child with ASD compared to a neurotypically developing child. All items in this scale were created after a comprehensive literature review of childhood ASD, diagnostic criteria, and clinical experience. Matson et al., (2008) found this scale to have good to excellent clinical significance and excellent internal consistency. All behaviors from the scale were used in the present study, however the scale was modified to assess whether or not participants had prior experience with pediatric patients with ASD who exhibit each behavior and their perceived competency and comfort levels managing such behaviors, rather than assessing whether or not a particular child with ASD exhibits differences or impairments in a specific challenging behavior. Participants rated their perceived competency and comfort levels in managing each type of challenging behavior using a seven item Likert-scale ranging from extremely incompetent to extremely competent, and extremely uncomfortable to extremely comfortable.

The present study also explored severity of challenging behavior as a factor related to increased perceived competency and comfort levels. Severity of each challenging behavior listed in the ASD-BPC was determined based on informal discussions with practitioners and the author's clinical experience.

IV. ANALYTIC APPROACH

Pearson's correlations are reported for listed correlational analyses. Additionally, following guidance by Winer et al., (1991), for cases in which the Mauchly's tests indicated a violation of the assumption of sphericity, Greenhouse-Geisser corrected *F* values are reported for any significance. Skewness and Kurtosis values were calculated to ensure the data were normally distributed.

To assess knowledge of ASD amongst participants, scores were summed across both knowledge of autism scales, the KCAHW and the ASKSG. Additionally, descriptive statistics were calculated to identify participant levels and sources of training and education regarding childhood ASD and challenging behavior and the percentage of participants who had experience working with children diagnosed with ASD who had exhibited challenging behavior in the hospital. Pearson's correlations were conducted to establish whether or not there was a relationship between knowledge of ASD, training, and perceived comfort and competency in managing challenging behaviors exhibited by pediatric patients with ASD. A repeated measure analysis of variance and subsequent pairwise comparisons were conducted to assess severity of challenging behavior as a factor relating to participant's perceived competency and comfort managing challenging behavior in children with ASD experiencing hospitalization. Moreover, regression analyses were performed to identify whether there were any significant unique and independent predictors of knowledge of ASD as well as perceived competency and comfort managing challenging behaviors.

V. RESULTS

Table 1.

Intercorrelations and descriptive statistics for participant's knowledge, perceived competence, and comfort levels managing challenging behavior

	Knowledge	Competence	Comfort
Knowledge	-	.20*	.23**
Competence		-	.91**
Comfort			-
Mean	15.72		5.4
SD	3.18	5.27	0.55
Range	5-22	1-7	1-7
<i>n</i>	131	130	128

* Correlation is significant at the 0.05 level (2-tailed).

** Correlation is significant at the 0.01 level (2-tailed).

Table 1 reports the range, means, and standard deviations for knowledge of ASD amongst participants, as well as perceived competence and comfort levels managing challenging behaviors amongst participants. Skewness and Kurtosis values were calculated for all three domains, establishing the data were normally distributed, as skewness values for knowledge, competence, and comfort respectively were -1.023, .318, and .096. Kurtosis values for knowledge, competence, and comfort were 1.665, -.061, -.152 respectively.

To test Hypothesis 1 (if the majority of CCLS participants would have experience with pediatric patients with ASD who have exhibited challenging behavior during hospitalization) descriptive analyses were run that revealed that 100% of participants ($n=131$) had experience working with patients who have been diagnosed with ASD while working as a CCLS. Additionally, the majority of participants (96.99%, $n=129$) had experienced one or more challenging behaviors when working with a child with ASD during hospitalization.

To examine Hypothesis 2 (CCLS participants would exhibit similar or higher levels of knowledge about childhood ASD compared to other HCPs and members of the general public, reported in previous studies) (McClain et al., 2019; Bakare et al., 2008.), sum scores were created for both the KCAHW and ASKSG items, as well as a total knowledge of autism score combining the two assessment tools. When combined, there was a possibility for a maximum score of 22 and a minimum score of 0, with 19 points coming from items obtained from the KCAHW and three items obtained from the ASKSG. The mean score when combining items from both the KCAHW and the ASKSG was 15.72 (SD = 3.18). With a mean score of 15.72 out of a possible 22 points, participants scored an average of 71.45% correct on the present study's measure designed to assess knowledge of autism.

Scores exclusively from the KCAHW measure were assessed separately to accurately compare results from the present study to previous studies that also utilized the KCAHW to measure knowledge of autism amongst HCPs. When assessing the mean score of the KCAHW items alone, where a maximum score of nineteen (19) and minimum score of zero (0) is possible, participants in the present study scored an average of 13.90 (SD=2.99). This finding supports Hypothesis 2, as participant's scores on the KCAHW reflected similar or higher levels of knowledge about childhood ASD compared to other interdisciplinary health care team members around the world. For example, a study conducted by Esegbe et al., (2015) revealed a KCAHW mean of 13.50 (SD=3.70) amongst 167 physicians, ages 26-60, who were attending an annual Nigerian Medical Association conference. The study included HCPs who worked in a tertiary health facility as well as those who were either specialists or specialists in training. Moreover, in a study of 300 HCPs in Pakistan conducted by Akhter et al., (2020), KCAHW means across

Medical Practitioners (Medical Specialists, Medical Officers, Psychiatrists, General Practitioners, and Pediatricians) and Allied-Medical Practitioners (Occupational Therapists, Speech-Language Pathologists, Physiotherapists, and Psychologists) were 8.84 (SD=6.31) and 15.20 (SD=5.17) respectively. Furthermore, in a study conducted by Salama (2017), involving 70 family physicians earning a master's degree at the School of Medicine, Suez Canal University in Egypt, a total KCAHW mean score of 11.20 (SD=3.5) was observed. Salama (2017) found that those with prior experience working with individuals with ASD ($M=12.9$ $SD=2.70$), were more knowledgeable on childhood autism than those without any prior experience ($M=10.70$, $SD=3.5$).

To further understand current knowledge amongst CCLSs on childhood ASD, patterns of missed items were explored. One of the most commonly missed items on the KCAHW in the present study assessed whether or not participants knew if children with autism “exhibit lack of spontaneous will to share enjoyment, interest, or activities with other people,” as 36.09% ($n=48$) selected either “no” or “not sure.” Additionally, 36.84% ($n=49$) of participants responded incorrectly when asked whether or not children with ASD “exhibit loss of interest in the environment and surroundings.” Other items that participants responded to that were most frequently missed by selecting either “no” or “not sure” asked whether or not the following behaviors were present in children with ASD, “social smile is usually absent” (21.8%, $n=29$), “Delay of total lack of spoken language” (20.30%, $n=27$), “abnormal eating habits,” (23.31%, $n=31$).

Some of the items participants most frequently answered correctly by responding “yes” to asked whether or not the following behaviors were present in children with ASD, “marked impairment in use of multiple non-verbal behaviors such as eye contact, facial expression, body postures, and gestures during social interactions” (90.98%,

n=121), “failure to develop peer relationships for developmental age” (90.98, *n*=121), “lack of social or emotional reciprocity” (90.98, *n*=121), and “stereotyped and repetitive movement (e.g., Hand flapping, finger flapping, twisting, etc.)” (90.98%, *n*=121).

Hypothesis 2 is further supported when results exclusively from the ASKSG items were compared to existing ASKSG data from previous studies. When asked whether or not “children with ASD may not play with toys the way they are intended,” 91.60% (*n*=120) of participants in the present study responded with the correct answer, “yes,” compared to 81.13% (*n*=318) of participants in a 2019 study conducted on members of the general public with no prior specialized training on ASD (McClain et al., 2019). Additionally, when asked whether or not “symptoms of ASD do not appear before the age of two years,” 64.12% (*n*=84) of participants in the present study correctly answered “false,” compared to 56.29% of participants in the 2019 study (McClain et al., 2019). Finally, 25.95% (*n*=34) of participants in the present correctly selected “false,” when asked whether or not diagnosis of ASD can only be made by a medical doctor, compared to 20.44% of participants in the study conducted by McClain et al. (2019).

To examine Hypothesis 3 (if participants would report having received some training or education on childhood ASD and challenging behavior), descriptive statistics for participant levels and sources of training and education were analyzed. Hypothesis 3 was supported due to many participants reporting that they had received at least one source of training. To further address hypothesis 3 and describe the training reported by participants, the percentage of participants who received each type of training was calculated. The most common source of training was professional development obtained outside of work, (27.6%, *n*=24), followed by education or coursework on childhood ASD (26.4%, *n*=23), and training provided or brought in by employers (19.5%, *n*=17).

Additionally, 5.7% of participants received training or education through other sources and over 20% (20.7%, $n=18$) of participants had received no training or education at all prior to becoming a CCLS or after becoming certified. Sources of training or education for participants who responded “other,” included personal research, being the parent or a relative of a child with ASD, and/or working in applied behavior analysis or early intervention programs.

Table 2.

Participant mean perceived competency levels across behaviors from the Autism Spectrum Disorder-Behavior Problems for Children index (ASD-BPC)

Challenging Behavior	<i>N</i>	<i>M</i>	<i>SD</i>	Minimum	Maximum
Repeated or unusual body movements	124	5.69	.83	4.00	7.00
Repeated or unusual vocalizations	125	5.79	.83	4.00	7.00
Property Destruction	113	5.15	.84	4.00	7.00
Leaving the supervision of caregiver(s) without permission	118	5.17	.88	4.00	7.00
Smearing and/or playing with feces	90	4.64	.84	4.00	7.00
Banging on objects with hand	127	5.87	.81	4.00	7.00
Aggression towards others	112	5.54	.78	4.00	7.00
Inappropriate sexual behavior	100	4.68	.75	4.00	7.00
Unusual play with objects	127	5.91	.97	4.00	7.00
Removal of clothing at inappropriate times	110	5.16	1.01	4.00	7.00
Mouthing or swallowing objects causing bodily harm	108	4.92	1.03	4.00	7.00
Harming self through one or more self-injurious behaviors (hitting, pinching, scratching, etc.)	109	5.43	.91	4.00	7.00
Poking him/her self in the eye	106	4.69	.91	4.00	7.00

Table 3.

Participant mean comfort levels across behaviors from the Autism Spectrum Disorder-Behavior Problems for Children index (ASD-BPC)

Challenging Behavior	<i>N</i>	<i>M</i>	<i>SD</i>	Minimum	Maximum
Repeated or unusual body movements	119	5.86	.77	4.00	7.00
Repeated or unusual vocalizations	125	5.95	.80	4.00	7.00
Property Destruction	99	5.31	.83	4.00	7.00
Leaving the supervision of caregiver(s) without permission	102	5.25	.91	4.00	7.00
Smearing and/or playing with feces	67	4.70	.85	4.00	7.00
Banging on objects with hand	126	5.87	.80	4.00	7.00
Aggression towards others	103	5.56	.76	4.00	7.00
Inappropriate sexual behavior	75	4.69	.79	4.00	7.00
Unusual play with objects	122	5.98	1.01	4.00	7.00
Removal of clothing at inappropriate times	100	5.28	1.00	4.00	7.00
Mouthing or swallowing objects causing bodily harm	94	5.00	1.01	4.00	7.00
Harming self through one or more self-injurious behaviors (hitting, pinching, scratching, etc.)	98	5.52	.86	4.00	7.00
Poking him/her self in the eye	98	4.85	.90	4.00	7.00

To address Hypothesis 4 (that CCLS participants could readily report about their levels of both perceived competency and comfort in managing a variety of challenging behaviors exhibited by children with ASD), means and standard deviations for both variables were assessed. Hypothesis 4 was supported as participants were able to report their perceived competency and comfort levels managing challenging behaviors across a variety of behaviors from the ASD-BPC. As shown in Table 1, the average scores were slightly above the midpoint for both competence ($M = 5.27$, $SD = .56$) and comfort ($M = 5.40$, $SD = .55$), on 7-point Likert scales assessing self-reported competence and comfort levels in working with such behaviors. Additionally, 37.8% of participants ($n=49$) had competency averages that fell between “neither competent nor incompetent” and “slightly competent,” managing challenging behaviors. Similarly, 27.1% of participants ($n=35$)

had comfort averages that fell between “neither comfortable nor uncomfortable” and “slightly comfortable.” Moreover, very few CCLSs reported high levels on both scales (i.e., fewer than 15% with average scores above 6).

To further address hypothesis 4, factors related to increased perceived competency and comfort levels managing challenging behaviors when working with pediatric patients diagnosed with ASD as a CCLS were explored. Results revealed that knowledge about childhood autism positively correlated with perceived competency $r(130) = .20, p < .05$ and comfort $r(128) = .23, p < .01$ in managing challenging behaviors. The perceived competency of CCLSs in managing challenging behavior was significantly higher if the participant had gained their knowledge through academic education ($M = 5.38, SD = .49$) compared to other domains such as professional development or training outside of work ($M = 5.12, SD = .56; t = 2.09, p < .05$). Moreover, the amount of training by source an individual received positively and significantly correlated with perceived competency $r(130) = .34, p < .01$, and comfort $r(128) = .32, p < .01$, managing challenging behavior.

Further exploring factors related to increased perceived competency and comfort levels regarding managing challenging behavior and increased knowledge, a series of regression analyses were conducted. The first regression examined training by source on childhood ASD and challenging behavior as a predictor of knowledge of ASD to examine whether knowledge of ASD improved with various trainings. Results revealed that training brought in by an employer ($\beta = .06, t = 2.44, p < .05$) and training that fell under the “other” category ($\beta = .10, t = 2.46, p < .05$) were unique and independent predictors of ASD knowledge.

A second and third regression analysis examined training by source on childhood ASD and challenging behavior as a predictor of perceived competency and comfort levels managing such behaviors. In both cases, education or coursework on childhood ASD was a significant predictor of perceived competence ($\beta = .38, t = 4.12, p < .05$) and comfort ($\beta = .30, t = 3.30, p < .05$). Additionally, training reported by participants that was not already listed in the survey that fell under the “other” category, such as personal research, being the parent or relative of a child with ASD, and/or working in applied behavior analysis or early intervention programs, was also a significant and independent predictor of both perceived competence ($\beta = .55, t = 3.68, p < .05$) and comfort ($\beta = .58, t = 4.06, p < .05$).

Two repeated measures analysis of variance (ANOVA) with follow-up pairwise comparisons were conducted to examine whether severity of the challenging behavior influenced 1) perceived competency and 2) participants’ comfort levels. Both ANOVA models were significant: perceived competency $F(12,54)=14.90, p < .001, \eta_p^2 = .77$; and comfort level, $F(12,28) = 6.54, p < .001, \eta_p^2 = .74$. Post hoc analyses revealed that for many challenging behaviors that were considered more severe, based on informal discussions with practitioners and clinical experience, perceived competency and comfort levels were significantly lower.

For example, Table 2 shows that participants perceived themselves as significantly less competent in managing property destruction ($M=5.15$) compared to repeated or unusual vocalizations ($M=5.79$), repeated or unusual body movements ($M=5.69$), banging on objects with his/her hand ($M=5.87$), and unusual play with objects ($M=5.91$). Participants perceived themselves as significantly less competent managing mouthing or swallowing objects to cause bodily harm ($M=4.92$) compared to all other

behaviors except smearing and/or playing with feces ($M=4.64$), inappropriate sexual behavior ($M=4.68$) and poking him/her self in the eye ($M=4.69$). Similar trends were assessed when comparing comfort levels across individual challenging behaviors that ranged from mild to severe. For example, Table 3 illustrates that participants were significantly less comfortable managing more severe behaviors such as property destruction ($M=5.31$) and mouthing or swallowing objects causing bodily harm ($M=5.00$), compared to repeated or unusual body movements ($M=5.86$), repeated or unusual vocalizations ($M=5.95$), and unusual play with objects ($M=5.98$). Moreover, participants were significantly less comfortable managing smearing and/or playing with feces ($M=4.70$) compared to all other challenging behaviors except inappropriate sexual behavior ($M=4.69$) and mouthing or swallowing objects causing bodily harm ($M=5.00$).

VI. DISCUSSION

Although CCLSs are trained in child development and psychosocial and emotional care, consistent with existing research on other HCPs (Morris, et al., 2019), findings in the present study reveal that many CCLSs might benefit from training or education to increase their perceived competency and comfort managing challenging behaviors. Specifically, results indicate that many CCLSs feel varying degrees of incompetence and discomfort when managing challenging behaviors exhibited by this population, as fewer than 15% of participants had mean scores of both perceived competency and comfort managing challenging behaviors above “moderately competent” or “moderately comfortable”.

Findings also revealed that the majority of participants had experienced at least one or more challenging behaviors when working with a child on the spectrum. These results were expected due to the frequency at which children with ASD are hospitalized due to co-occurring conditions, as well as the stressful nature of the healthcare environment for this population. Given the high frequency at which CCLSs interact with children with ASD who exhibit challenging behavior, there are several implications of these findings that might be used to better prepare and support CCLSs when working with children on the spectrum and managing challenging behavior.

For example, it is important to consider that, although CCLSs scored in line with other HCPs and slightly above members of the general public on measures designed to assess knowledge of childhood autism, the mean score across both measures was only 71.45%, indicating that there is still room for improvement regarding CCLS’s knowledge of autism and challenging behaviors. This is important, as findings indicate that knowledge of childhood ASD and challenging behaviors positively correlated with both

perceived competency and comfort managing challenging behaviors, however only 26.4% ($n=23$) of participants reported receiving any education, such as coursework or specific classes that pertained to childhood ASD, during their undergraduate or graduate degrees. These findings reveal that there is a relationship between knowledge of ASD and challenging behaviors and increased perceived competency and comfort levels managing such behaviors in a healthcare setting, while highlighting the low frequency at which CCLSs are receiving this type of relevant education. Thus, the findings have significant implications for curriculum and instruction in child life programs. Child life, and similar programs preparing professionals for practice, should aim to incorporate further opportunities for students to gain knowledge and experience providing care to children with ASD and challenging behaviors.

Additionally, consistent with the limited previous research assessing CCLS perspectives on working with children with ASD (Jensen et al., 2019), this study found that many participants could benefit from increasing their comfort level working with children on the spectrum and managing challenging behaviors. The present study also expanded on this literature to discover that many participants could also benefit from increasing their perceived competency level working with children on the spectrum and managing challenging behaviors. Findings suggest that there is still room for improvement in perceived competency and comfort levels managing challenging behaviors across CCLS participants. A substantial number of participants still had mean scores ranging from neither competent nor incompetent to slightly competent and neither comfortable nor uncomfortable to slightly comfortable managing challenging behaviors listed in the ASD-BPC. Additionally, with fewer than 15% of participants feeling more than moderately competent and comfortable managing challenging behaviors listed in the

ASD-BPC, findings suggest that many CCLSs could still benefit from ways to increase both their perceived competency and comfort levels managing challenging behavior.

There were several other important implications regarding the findings related to sources of training reported by participants in the present study as well. First, out of all possible sources of training on childhood ASD and challenging behavior reported by participants, the most common source of training was professional development received outside of work. Moreover, more participants reported never receiving any training at all, both as a student and after becoming certified, than did those who reported receiving training brought in by their hospital or employer. The number of participants who reported never receiving any education on childhood ASD and challenging behavior is problematic, as the present study found that the amount of training an individual received positively and significantly correlated with increased perceived competency and comfort levels managing challenging behavior. Additionally, with training being brought in by an employer as one of the less common sources of training and participants most frequently reporting that they had obtained training outside of their work setting, it could be beneficial for more hospitals to bring in this type of training for CCLSs, as results also showed that training brought in by an employer on childhood ASD and challenging behavior was a unique and independent predictor of knowledge on ASD, which has the potential to improve healthcare experiences of children and families affected by autism.

Findings also suggested that severity of challenging behavior was often a significant factor related to perceived competency and comfort managing challenging behaviors, as participants generally perceived themselves as more competent and felt more comfortable managing less severe challenging behaviors compared to those that were more severe. Given that CCLSs report lower levels in both domains amongst more

sever behaviors, it may be useful to provide training to both future and current CCLSs that focuses on more severe behaviors in a hospital setting to improve perceived competency and comfort levels amongst CCLSs in managing challenging behaviors.

Limitations

Several limitations were identified in the present study. For example, the present study utilized a relatively small sample size. Additionally, many participants within the present study were Caucasian, therefore it is possible that this lack of diversity could potentially limit generalization across various racial demographics. Similarly, the entirety of the present sample comprised of female CCLSs, which could further limit generalization across gender demographics. Another limitation of the present study was that participants were asked to rate their perceived competency rather than utilizing an object measure to quantify how competent the participant is in managing challenging behaviors. Likewise, there is also the possibility that participants rated themselves as more competent and comfortable due to social desirability, as CCLSs might feel pressure to exhibit a certain level of competency and comfort in managing challenging behaviors due to the nature of the field and what might be expected of them. Moreover, although the KCAHW questionnaire is recognized as a valid and reliable tool to assess knowledge of autism amongst health care workers, the present study, to our knowledge, was the first to utilize this measure within the United States. Future directions should focus on utilizing this measure within the United States across more CCLSs as well as other HCPs. Additionally, subsequent studies should attempt to broaden both the gender and racial demographics across participants to promote generalization and further understand perspectives from a more diverse participant population.

Conclusion

The findings from the present study provide valuable information on current levels of CCLSs knowledge of ASD, training provided to CCLSs, and perceived competency and comfort levels managing challenging behaviors common across children on the spectrum experiencing hospitalization. Additionally, this study highlights various factors related to increased levels of perceived competency and comfort managing challenging behaviors that could help to positively impact the hospital experience of a child with ASD and their family. These findings can be useful when considering various ways to reduce the likelihood or severity of challenging behaviors by identifying ways to support and prepare CCLSs who work with children on the spectrum who exhibit such behaviors in a health care setting. This information can be used to help inform future training and educational practices for aspiring or practicing CCLSs which can lessen the risk for challenging behaviors and healthcare related trauma for children with ASD and their families.

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