

Original Articles

Meeting the Needs of Children With Autism Spectrum Disorder and Their Families in Hospital Settings: The Perspectives of Certified Child Life Specialists and Nurses

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Objective:

Children who have Autism Spectrum Disorder (ASD) have complex psychosocial, behavioral, and physiological profiles and are hospitalized at higher rates than their typically developing peers. This study examined the perspectives of two key members of the health care team, certified child life specialists and nurses, on how to meet the needs of children who have ASD and their families in hospital settings.

Method:

Participants included seven health care professionals from two urban hospitals in the Northeast. One-on-one interviews were held with four child life specialists and three nurses.

Results:

Qualitative analyses yielded six themes that addressed ways to serve children who have ASD: partner with the family, individualize care, advocate for more education, understand ASD is a spectrum of differences, think psychosocially not just medically, and emphasize consistency in care.

Conclusion:

Findings illustrate the complexity of the ASD diagnosis in light of the limited training and education health care professionals receive and are discussed with regard to their implications for the ways that institutional policies, including those within the child life profession, can facilitate the delivery of optimal care for this population in hospital environments.

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According to the Centers for Disease Control and Prevention, one in 54 children are diagnosed with Autism Spectrum Disorder (ASD; Center for Disease Control and Prevention, 2016). ASD is a neurological and developmental disorder that begins at a young age and lasts throughout the lifespan (Benson, 2016; Taghizadeh et al., 2015). This disorder is characterized by deficits in social communication and social interaction and the presence of restricted, repetitive behaviors, the symptoms and severity of which vary widely (Benson, 2016; Hudson, 2006; Straus et al., 2019). Individuals who have ASD benefit greatly from individualized and targeted supports to help build skills and manage symptoms (Hudson, 2006). Health care profession-

als who work in hospital settings hold essential roles in supporting the ASD community.

According to the American Psychiatric Association, the ASD diagnosis is conceptualized as a spectrum because children and individuals can have a wide range of skills and levels of disability. However, there are common characteristics that are frequently observed among people who have ASD (National Institute of Mental Health, 2016). One common and very prominent characteristic that is required for the ASD diagnosis is impaired or disrupted communication. Individuals who have ASD can have spoken language; however, all do not. Specifically, children who have ASD may have difficulties initiating or maintaining a conversation,

be unable to use the language of their peers, or have stilted or limited speech (Hudson, 2006; Taghizadeh et al., 2015). Such challenges can dramatically impact the child's ability to interact socially with others. Many children who have ASD share similar difficulties in social situations, such as failure to respond to their name, poor eye contact, preference for playing alone, failure to develop peer relationships, lack of empathy, or resistance to holding and touch (Jolly, 2015).

Sensory challenges are also prominent in the ASD diagnosis. Children who have ASD may have difficulties with sensory integration and sensory processing, such as when the child does not interpret and react to sensations in an organized manner and has a lack of awareness of themselves within the environment (Hudson, 2006). Sensory processing difficulties can also include over or under-reactions to sensory input, including tactile, auditory, visual, gustatory, and vestibular stimuli (Taghizadeh et al., 2015). Such disruptions in sensory processing can contribute to an inability to regulate behavior in both commonly enjoyable and novel activities.

Behavioral challenges are another prominent component of the required criteria of ASD. Specifically, children who have ASD often display ritualistic and repetitive behaviors that can range from the need for inflexible routines, to hyper-focusing on special interests at the expense of other expected activities (e.g., schoolwork). In some children who have ASD, ritualistic behaviors can lead to self-injury and aggression, such as head banging or biting the wrist, especially in times of higher stress or novel experiences (Taghizadeh et al., 2015).

It is often not widely understood that mental health problems are often comorbid with the factors noted above in children who have ASD. Research suggests that 70% of children who have ASD have at least one concurrent psychiatric disorder, while 40% have two or more mental disorders, most commonly attention-deficit/hyperactivity disorder (ADHD), oppositional, or anxiety disorders (Taghizadeh et al., 2015). A large percentage of children who have ASD have medical comorbidities such as allergies, asthma, gastrointestinal issues, respiratory infections, seizures, and migraines.

Due to the range of sensory, behavioral, mental health challenges, and medical concerns noted above, children who have ASD often require ongoing medical appointments or frequent hospitalization. In fact, the percentage of inpatient hospitalizations for children with ASD is 55.9 percent, while those without ASD only have a 22.9 percent rate of hospitalization (Straus et al., 2019). In addition, higher injury rates have been noted in some cases. While DiGuseppi et al. (2018) found no association between ASD and injuries, there are two large and nationally represented samples of children aged three to five years that found significantly higher injury risks among children with ASD compared to unaffected controls. As such, it is critical that they receive medical care that is responsive to their unique developmental profiles.

ASD-Specific Techniques in Health Care Settings: Brief Review of Best Practices

The applied literature is replete with many different techniques and strategies that are helpful in assisting children who have ASD. Although such techniques are often not specifically designed for hospitalized children, they can serve as guidelines for practice and be readily adapted to hospital settings. Although it is the case that the range of ASD-specific techniques utilized within and across hospitals (if they are utilized at all) is wide, the review by Straus et al. (2019) found that most clinicians lacked ASD-specific training.

One of the most important first steps in assisting children who have ASD is to have a screening or therapeutic assessment completed (Jolly, 2015). This is extremely important for the hospital team to do initially, as it may eliminate further problems during their care, such as hospital personnel not being on the same page or lack of collaboration (Jolly, 2015). In many instances, the hospital team is unfamiliar with the child and their family and do not know the details of the child's diagnosis, their home environment, or their routines. The health care team might also initiate a developmental and environmental assessment as part of this initial screening (Hudson, 2006). Using these practices, the health care team can learn more about the individual needs of the child, as well as particular triggers that might produce behavioral escalation or emotional disturbances in the child. In short, the health care team can utilize the screening to determine the best methods to help the child cope and feel comfortable (Jolly, 2015). As well, the initial screening assists the health care team in working with the family to establish both short- and long-term care plans, including the selection of interventions and supports that will be necessary throughout the child's hospital stay (Hudson, 2006). Hudson (2006) provides these screening tools throughout the book for readers to reference.

Once this screening is completed, the hospital team can work together to create an Autism-Specific Care Plan (ACP; Broder-Fingert et al., 2016; Liddle et al., 2018). These plans are designed to help improve the hospital experience for patients who have ASD by including the child's past experiences to promote safety, comfort, and understanding. In the health care setting, a patient who has ASD will undoubtedly have to interface with many different people. Using an ACP, consistency in care can be maintained and it would prevent families from having to constantly re-advocate for their child's needs. Discussing a care plan prior to the patient's visit is ideal as it allows for better care coordination and planning to support the individualized needs of the patient more successfully during their visit. As highlighted in one study, an ACP requires considerable resources to implement and sustain, but results in a better experience for both families and staff (Liddle et al., 2018). Unfortunately, ACPs are a newer initiative that is not widely used within hospitals (Broder-Fingert et al., 2016).

Beyond initial screening and assessment, a particular intervention strategy for children who have ASD that can be readily utilized in hospital settings is movement and dance

therapy. Movement and dance therapy provide a sense of calmness to a stressful situation. It also integrates the body and mind in a non-verbal way, which can be very helpful for children who do not have language (See, 2012). In a similar frame, play therapy can also be beneficial to a child who has ASD. As play is a natural mode of communication, it becomes an effective way for children to grapple with their anxieties and questions, instead of having to use language. Play therapy is also a great aid to sensory challenges that are common in children who have ASD (Parker & O'Brien, 2011). For example, professionals in health care settings can initiate a connection with a patient through simple play materials that light up, spin, and/or are squishy, which can help facilitate the down regulation of the patient's sensory systems.

There are also informal strategies that the health care team can initiate during the child's hospital stay. For example, using different modes of communication is one way the health care team can better assist the child and family as they are integrated into the hospital setting (Brown & Elder, 2014). As previously noted, children who have ASD have a wide range of communication abilities, and the health care team must accommodate the child's particular competency in this area. Hence, they must be knowledgeable in many different forms of communication, such as sign language, assistive technology, facial affect, and other modes of nonverbal communication (Brown & Elder, 2014). In fact, Jolly (2015) notes that it is critical for the health care team to establish a clear method of communication with patients who have ASD when they first arrive, since an improper communication method can lead to increased frustration, as well as aggressive tendencies that are detrimental to both the staff and child's safety.

Another strategy the health care team can use when working alongside the ASD population is to find effective ways to assist with change and transitions (Jolly, 2015). Children who have ASD are challenged by change, and they prefer to have a routine that can act as a comfort mechanism. Although this is challenging during a hospital stay, the medical team might work to keep a similar meal and play time, to limit anxiety and frustration from both the patient and family (Jolly, 2015). Family should also be encouraged to bring comfort items from home to support transitions during the hospital stay (Jolly, 2015). The team can also advocate for the least number of interruptions in the child's room as possible and to have consistent providers (Jolly, 2015). In addition, the medical team can reduce stimulation in the immediate environment as much as possible or provide a quiet play space with activities in place (Jolly, 2015).

Theoretical Framework

This study is grounded in the patient- and family-centered care perspective, as outlined by Thompson (2018) and Rollins et al. (2018). This framework promotes the idea that the health and well-being of children and families is maintained through a respectful family-professional partnership. It honors all members of the relationship and is truly the standard of practice that reflects high-quality

care. According to the Institute for Patient- and Family-Centered Care, there are four core concepts of this model (Thompson, 2018). The first is respect and dignity, which places absolute value on the health care team listening to and honoring patient and family perspectives and choices. An integral component of this is incorporating their values and beliefs into the delivery of care. The second core concept is information sharing, which is the idea that health care providers communicate and share complete and unbiased information in ways that are helpful for the entire family. The third core concept is participation, whereby patients and families are empowered to participate in care and decision-making. Finally, the concept of collaboration asserts that patients, families, health care members, and leaders all collaborate in policy and program development, implementation and evaluation, health care facility design, and professional education. Together, all four concepts recognize that the family is the constant in the patient's life and has a dramatic influence on their health and well-being. The focus on exploring the nature of collaborations between Certified Child Life Specialists (CCLSs), nurses, and families in optimizing the care and support of children who have ASD in this study is consistent with this theoretical perspective and served as a framework and guided the analytic process.

The present study examined the ways that two key members of the health care team (CCLSs and nurses) provide care and support of children who have ASD in hospital settings. CCLSs and nurses are critical members of the health care team because they have direct, frequent, and often sustained contact with children and families as they interact with the health care system. CCLSs receive specialized education in child development, family systems, and play in relation to the health care environment. Therefore, their knowledge and direct clinical experience holds great implications for better understanding how to best support this population.

Study Purpose and Research Question

As shown in this review, the challenges that children who have ASD may face in their daily interactions are likely to be heightened in the health care environment. This can make hospitalization experiences exceptionally difficult for children who have ASD and their families. Although a variety of formal and informal techniques to assist children who have ASD in these settings is present in the research literature, studies that document the perspectives of health care professionals regarding the delivery of care for children who have ASD are largely absent, especially among those who may be on the front lines of administering or managing children's care. This is a significant gap in the literature, because understanding the unique experiences of such professionals can inform best practices for serving this population of patients with the goal of forging stronger partnerships with families.

The present study focused on the experiences and perspectives of CCLSs and nurses regarding the delivery of care for children who have ASD. Individual, face-to-face interviews with these key members of the health care team in

two urban pediatric hospitals were conducted, guided by the following qualitative research question: What are the perspectives of CCLSs and nurses regarding meeting the needs of children who have autism and their families in the health care setting? It is important to note that since our study participants worked with a majority of pediatric patients, our inquiry regards young children who have autism, rather than a broader age spectrum within this population.

Method

Participants

Registered nurses and CCLSs working in two different hospitals in a major metropolitan city in the Northeast served as study participants. One hospital was a level one trauma center that features 404 beds and provides comprehensive outpatient care and includes its own autism clinic. The second hospital site was a 128 bed, level one trauma center that additionally offers outpatient services in every medical and surgical specialty.

A snowball sampling method was used to recruit participants. Specifically, the first author had a prior connection with a CCLS at both sites. These two CCLSs disseminated an invitation to participate in the study to all CCLSs and nurses across their respective units. Individuals who wished to participate were put in contact with the researchers and were provided with a study overview. The final participant sample was seven health care professionals, each of whom provided written consent to be interviewed. This final number represents the total number of individuals who consented to participation. Four participants were CCLSs, and three were nurses. Six of the participants were female and one was male (a nurse). The ages of the participants ranged from 26 to 36 years, with 29 years the average. All participants held at least a bachelor's degree, and three of the CCLSs held a master's degree. More specifically, the nursing professionals held Bachelor of Science degrees in nursing, and all CCLSs held bachelor's degrees in some form of child and family studies.

The premise of this research study was to select participants who have an active role in supporting patients with ASD in the health care environment. Participants were not selected based on their prior experience and expertise in working with this population. In fact, only one of the seven participants held specific education and experience that is centered on the ASD population. Broadening the participant sample beyond those who hold expertise in ASD allows insight into the reality of the care provided to patients with ASD in the health care environment.

Procedures and Measures

Individual, face-to-face interviews were conducted with all study participants regarding their experiences in working with children and families who have ASD. Interviews were held in a private setting in each of the hospitals. All interviews were audio-recorded with permission, and transcribed verbatim for analysis. The average interview time with the CCLSs was 39 minutes, with an average transcript

length of 19 pages. Interviews with nurses averaged 20 minutes, with an average transcript length of 10 pages.

An interview protocol was developed for the purposes of this study and utilized a semi-structured format. The interview questions addressed participants' experiences in working with children who have ASD and their families across three areas: specific ASD-related protocols within their hospital, specific techniques used with the ASD population, and their perspectives on the ASD-specific education and training they received. Interview questions are provided in the Appendix.

Qualitative Analyses and Coding

Analysis of interview data followed qualitative content analytic coding procedures. Qualitative content analysis strives to examine meanings, themes, and patterns that may be manifest or latent in a particular text, and codes are generated inductively (Sandelowski, 2000; Zhang & Wildemuth, 2009). In this regard, analysis of all transcripts began with open coding and memoing by the first author to expose the thoughts, meanings, and ideas that were contained in the texts (Charmaz, 2014). Next, a set of seven lower-level concepts (Corbin & Strauss, 2007) was generated through multiple readings of three transcripts to create an initial codebook. Subsequently, both authors independently coded all remaining transcripts, and segments of text were sorted, color-coded, and compared through constant comparative analysis (Corbin & Strauss, 2007). During this process, the content and boundaries of lower-level concepts were refined through discussion with disagreements resolved through consensus. Axial coding was then conducted where lower-level concepts were examined and merged (Corbin & Strauss, 2007). This resulted in the construction of six thematic categories, vividly phrased as actions, that provided explanatory insights into our research question.

Researcher Reflexivity

Reflexivity is the process of reflecting critically on the self in research; it demands that the researcher analyze interpretations of truth and issues of power in the research process and on the meaning they make and present from the experience (Charmaz, 2014). During the data collection process, detailed notes were written after each respective interview to serve as a mechanism for examining potential biases and assumptions. Reflexivity was further enhanced during the collaborative coding process as one author did not participate in the data collection. As such, the author was able to read the transcripts with a fresh perspective, yet also contribute important sensitizing concepts (Charmaz, 2014) regarding possible interpretations of the data that were explored during the analyses.

Results

Qualitative analyses provided important insights into health care professionals' perspectives on caring for patients who have ASD and their families. Each thematic cat-

egory was present in the narratives of at least six of the seven participants. Themes are presented below according to their frequency across transcripts. The first three (partner with the family, individualize care, and advocate for more education) were prevalent in all seven interviews. The remaining three (understand ASD is a spectrum of differences, think psychosocially not just medically, and emphasize consistency in care) were discussed in six of the seven interviews. To address validity of the themes, supportive quotations from participants are included in the presentation of the results.

Partner with the family. The most prevalent theme that was frequently expressed in all participants' narratives was the importance of including the entire family in the patient's care plan. It was readily acknowledged that it was the family that knew the child best, and therefore, should be the first resource health care professionals seek out for support. One CCLS shared her thoughts on partnering with the family:

The most important part is always talking to the family or the caregivers. First, partnering with them. They're going to know their child best or some kids have their school staff with them, they're going to be able to tell you what works, what doesn't work, what's challenging, and what's not challenging. Really starting with them and using that as your basis to kind of figure out where to start.

Participants stressed that these partnerships should occur at all stages of the admission process. As several noted, health care professionals should partner with the family prior to admission, if possible, as well as during the admission to provide optimal individualized support. One participant noted that the medical team might learn information such as the patient's triggers, behaviors, coping strategies, and past medical experiences that would likely impact the delivery of care. Also, participants clarified that maintaining a strong connection with the family after the admission and upon discharge allowed for the opportunity to assess whether the family's needs were met, as well as to ensure that future visits for the patient would go smoothly.

Another dimension of this theme that was highlighted by participants was the idea that the family should be included in the administration of procedures when it can be done safely. For example, as one participant noted, working with the parent to administer medication, complete procedures, and daily tasks can positively alter the entire health care experience. Several participants mused that like any patient, children who have ASD find safety in their caregivers. Therefore, it may be easier for a patient when someone safe and trusting is working with the medical team, not just watching from the outside. One nurse participant shared the importance of incorporating parents during the delivery of care:

If the parents are there they usually can step in, and especially with giving medications, sometimes I just hand it off to the parents to do. I step into the room, do what I have to do quickly, and then get out to let the parents handle the situation.

Although participants rightly acknowledged that parents cannot take over care in many instances, it is important for the medical team to take advantage of these opportunities when possible. As noted in the comment above, the medical team should cluster their care and only enter the room for necessary reasons, as too many unnecessary interactions can hinder the patient and family's experience.

Individualize care. Another highly prevalent theme was the need for health care providers to individualize care for the patient. Like the idea of adjusting plan of care based on the patient's age, participants felt that health care providers must consider the patient's needs and abilities when implementing care. As described by one CCLS participant, "their [child's] care has to be unique, it has to be curtailed to their needs, and individualized, and sometimes it's unconventional." She went on to make the point that in her experience, when a health care professional works with a patient who has ASD, there is not a set of accommodations automatically made. Instead, health care professionals need to take the necessary time to complete a more extensive and elaborate observation and assessment before making any accommodations and adjustments to care. This willingness to take time was an important dimension of individualizing care that was noted by several participants as an effective practice—one that required caregivers to look beyond the traditional protocols that might be provided by the hospital. As one CCLS articulated:

The policies and procedures of a hospital were not created with an individual with autism in mind. We are very much 'this is the policy, we have to stick with it,' but that policy probably doesn't work for a kid with autism. So we have to think outside of that box.

In the quote above, the importance of being willing to go against what might be hospital "norms" is critical. However, as this participant mused, many health care professionals often lack the resources to change and evolve their thoughts and practices.

Advocate for more education. All participants, regardless of hospital or role, confidently expressed the need for more education and ASD-specific training. They considered this education as having two fundamental components. The first component was formal training where people would receive a general presentation explaining what ASD is as a diagnosis. The second component was described as the practical application of ASD knowledge in hospital settings, such as the use of actual simulations, case studies, or specific examples that would offer the opportunity for professionals to brainstorm practical ways they might handle different situations. However, according to participants, this kind of education and training was lacking in both hospital sites, despite the frequency with which children who have ASD were served. Furthermore, neither hospital held mandatory ASD training for staff. As one CCLS participant shared, training would be extremely helpful, and more comprehensive forms of support for professionals with varied levels of experience should be offered, "Speaking from my experience, when nurses are new, oftentimes that's where we see that lack of education. I think that if the

training was mandatory, we would all be better supported in caring for patients with autism.”

Even though all participants felt that the ASD-specific training they were provided with was lacking, the level of education and support that was provided to staff did vary across both hospital sites. One participant in the larger site expressed her view that some areas of the hospital excelled at supporting children who have autism, while other areas needed more support. Those that succeeded were often led by members of the health care team that were comfortable with the ASD population and wanted their team to be as well. As this CCLS participant clearly stated, education is what it “again comes down to”:

Certain areas in the hospital are doing a fantastic job of providing that education and figuring out ways to best work with these kids. There are other areas that have a little more way to go. So, I think everybody’s trying to provide the best care and again it comes down to education and how can we best get that education to everybody.

In the smaller hospital site, it appeared that participants agreed with the larger site, in that education and training on ASD is lacking. In fact, both participants at the smaller site shared that there are no specific modules during the hospital-wide yearly learning on the topic of working with patients who have ASD. It is important to note that both were aware of this lack of education but had hope that the hospital would be initiating this education and training on ASD soon, however likely not mandatory. Both participants shared similar visions regarding the layout of this training. Specifically, one participant felt the health care team are taught medical components of ASD but could greatly benefit from education and training that focuses on how to interact and support this population.

Understand ASD is a spectrum of differences. Nurses and CCLSs who were interviewed also stressed the importance for health care professionals to understand that ASD is indeed a spectrum. Because of this, they acknowledged that the severity of behaviors and characteristics and level of abilities would range, depending on the individual child. Based on their experiences, they held the belief that no two children with this diagnosis are the same. As one CCLS vividly shared, “If you have met one person with autism you’ve met one person with autism. They don’t fall into one neat box with a cookie cutter approach for every single one of them.”

As illustrated here, participants felt that what worked for one patient who has ASD would not necessarily work for another patient who has ASD. Similarly, one CCLS viewed this issue as one of taking each child at “face value,” as shared in the following quote:

I think as practitioners we have the responsibility to understand that it is a spectrum and to then take the child at face value...We really need to understand that because it’s a spectrum, children can be at different developmental levels when looking at them as a whole in terms of their social abilities, language abilities, and cognitive abilities. With children with autism, it’s not a one size fits all.

Overall, participants stressed that the medical team cannot judge patients who have ASD based solely on their diagnosis, but rather must use their observational skills to keep an open mind. Of course, as one CCLS noted, this can often be challenging for many who hold preconceived notions regarding this population.

Think psychosocially not just medically. Study participants also expressed how important it was for health care professionals to think psychosocially and not exclusively medically; that is, while it is important for staff to focus on the medical needs of the patient, this should not be their only concern. From the perspective of participants, high quality medical care consisted of many things, and in their view, this stemmed from looking at the individual holistically. This was described as an attention to the patient and family’s mental, emotional, and spiritual well-being. As the following CCLS described, such a focus does not always take priority:

The medical team is looking at all patients through a medical lens and they’re looking for a diagnosis. They’re looking for what’s wrong, why are they here, what are the things medically wrong with them. That you know the psychosocial stuff kind of gets I don’t want to say forgotten, but it doesn’t always take priority.

Several participants noted that the fields of child life and social work, for example, train individuals to think psychosocially and that other professionals in the medical field have less of a focus on this. For example, although the primacy of the physician’s role was noted by several participants to be essential, it was also acknowledged by many participants that the differences in their respective orientations and expertise held the potential for conflict. This is illustrated in the segment below which focuses on the priorities and goals of different health care professionals, according to one CCLS participant:

Oftentimes we have a butting of heads between the data-driven minds and the minds coming from the side of understanding what the patient and family really feel is a quality level of care at this point. Sometimes it feels like the goals are different.

Emphasize consistency in care. A final theme that emerged from most of the interviews was the importance of emphasizing consistency in care practices and procedures. For children who have ASD, routine is a huge component of their daily living. This, they noted, is extraordinarily difficult to maintain in a hospital setting where things are unpredictable and constantly changing. However, several participants suggested that health care professionals might better support children who have autism by creating specific protocols or plans that would emphasize the need for consistency among all team members throughout the patient’s entire length of stay. In their view, this could keep everyone on the same page regarding what does and does not work and would also limit the number of times parents would have to explain themselves to different team members. For example, one CCLS participant noted that “we might have these conversations with families, but if noth-

ing's kind of written down, how are we ensuring the consistency in care?" A second CCLS participant elaborated further, commenting on the way that information can often get lost, or important strategies or decisions around care can get left out when communication falters:

I think communication of information can be challenging in the hospital setting but also is highly important given that one person may have one interaction or may gain information in a certain manner and then it can be passed on to another professional and a detail may be left out. So communication, enhancing our communication as a medical and interdisciplinary team I think is the primary way to improve the care that we provide.

Discussion

This study examined the perspectives of child life specialists and nurses meeting the needs of children who have ASD and their families in the health care setting. Although many of the techniques suggested by Straus et al. (2019) and Jolly (2015) were reflected in the narratives of our participants, this study is the first to document what is considered to be an "insider" perspective on how such strategies play out on the ground, in two large urban hospitals. In particular, the ways that CCLSs conceptualize their role in providing care to children and families, while drawing upon their unique expertise and training, has not been previously addressed and is a unique contribution of this study. As well, this investigation builds upon previous studies (Kouo & Kouo, 2020; Straus et al., 2019) that highlight the importance of education and training for professionals in their efforts to enhance the medical encounters of children who have ASD. Specifically, clinical recommendations on how such training should be implemented in hospital settings is provided with a particular focus on the ways that the CCLSs can play a lead role in such efforts.

Overall, the findings here provide evidence that a strong desire to provide the best patient- and family-centered care to this population is foremost among their concerns. Specifically, analyses generated six themes regarding practices that participants felt were essential to provide the best care to patients who have ASD and their family in the health care setting. These are: partner with the family, individualize care, advocate for more education, understand ASD is a spectrum of differences, think psychosocially not just medically, and emphasize consistency in care. As the patient- and family-centered care framework is the forefront of many institutions, the perspectives of child life specialists and nurses in this study were consistent and fit within this view of practice. Like Muskat et al.'s (2015) findings that documented the importance of listening to parents to provide optimal care for children who have ASD, the most robust and frequently noted theme generated from these data were the need to partner with the family, which is arguably a thread woven throughout the patient- and family-centered care framework. The fact that participants reflected an authentic commitment to this is an encouraging finding upon which future research and education efforts might build.

The one practice that grounds all others, as reflected in the findings, is a commitment to education and training by hospital administrators and staff. Regardless of their site or role, all participants felt strongly about the need to advocate for more education and ASD-specific training. As neither site held mandatory trainings, it was often up to the health care professionals themselves to seek out education regarding ASD. Considering the implications of this issue more broadly, this could result in the unanticipated consequence of leaving support services like child life to be among the only professionals relied upon to support this population. Unlike many other medical providers, CCLSs do hold an educational background on child development and family centered care. While this may serve as a foundation, it does not focus nearly enough on atypical development, which is needed to support this population in an effective and appropriate manner. Not only are many CCLSs lacking the ASD-specific education, but hospital budgets nationwide often do not allow for nearly enough child life professionals to be hired, in relation to the needs of the hospital. Not offering broad-based support for the range of individuals in hospital settings who serve this population is a critical gap in the delivery of care for children who have ASD. Mandatory education and training may be costly for hospitals to implement, however; it is a critical and strategic investment considering the growing population of children who have ASD (Straus et al., 2019). This level of commitment to education and training is the best way to build the most comprehensive knowledge base on ASD and ASD-specific care practices that is shared by many, not just a few, health care professionals in hospital settings. This responsibility should be held by both hospital administration and the academic institutions which provide requisite training for providers.

The ways that the findings clarify dimensions of practices in the service of children who have ASD provides a blueprint for the content of the kinds of mandatory ASD-specific training and education in hospitals that our participants called for. Taken together, the themes found in this study suggest that the care for children who have ASD and their families is multi-dimensional. For example, the need to understand that ASD is a spectrum of differences should undoubtedly be central and reinforced throughout formal training sessions. At the very least, health care professionals must leave any training session with more than just a basic definition of ASD. They must have knowledge about prominent characteristics of individuals with this diagnosis and the importance of individualizing their care. Education and training would also go a long way in addressing what might be the most unwieldy of the recommendations that were noted by participants: the need for consistency of care for individuals who have ASD and the difficulty in providing this in a hospital setting where maintaining a child's home routine can be challenging. It is reasonable to assume that health care professionals such as CCLSs and nurses may feel overwhelmed with this idea because they may feel they have limited power to enact change in this area. Through training, health care professionals can learn

effective strategies to make this possible and improve their agency in this area.

Limitations

A limitation of this study is the small number of participants, all of whom self-selected to participate. As such, our findings cannot represent the perspectives of the larger population of nurses and CCLSs in the country. Although it is argued here that child life specialists and nurses offer key insights into effective practices in serving children who have ASD, future studies should include larger samples that include the perspectives of other professionals that make up the health care team. As noted by several participants, different health care professionals hold different kinds of expertise, experiences, and definitions of what constitutes the delivery of quality care for this population. Examining varied perspectives on this issue would not only increase the research knowledge base on caring for children who have ASD in health care settings, but provide insights into the kinds of ASD-specific education and training that might be further tailored for each crucial member of the team.

This study also focused on two relatively well-funded and well-resourced urban hospitals. Future studies would do well to compare health care settings in different locations (i.e., suburban and rural), as well as the kind of population served (i.e., community-based, national, or international), in terms of the different ways they support children who have ASD and their families. For example, are ASD-specific units or clinics more typical in large urban hospitals or small suburban ones? Are there different priorities for care in different settings? For example, do cultural interpretations of partnering with the family hold relevance in hospitals that serve families from outside the U.S.? What can different institutions learn from each other regarding effective practices and strategies?

Finally, it is important to acknowledge that most textual quotations used in our presentation of the findings here were from CCLSs and not nurses. Our choice to do this is both a function of interview breadth and depth, and interviews from CCLS were notably longer than those from nurses, yielding more text, more specifics, and more richness in terms of content. Although this certainly biases the findings toward the perspectives of CCLSs, we wonder if this might suggest a greater sense of comfort and agency in serving this population within the profession of child life as opposed to others in the nursing field and within health care more broadly. In the final section below, we discuss the implications of this possibility.

The Role of Child Life in the Care of Children who have ASD

Among the many forms of support, we argue the CCLS has potential to play a fundamental role in the support of patients who have ASD in the hospital setting. As highlighted earlier, the education and training that child life specialists receive focuses mainly on child developmental knowledge and the psychosocial effects of hospitalization on the entire family (Committee on Hospital Care and Child

Life Council, 2014). While CCLSs still lack the thorough education on atypical development, their specificity of working with children and families still distinguishes child life from other health care professions. Child life specialists are educated to be versatile in their clinical skill set and expertise and often carefully hone the ability to serve children across a wide age range who present with a variety of needs, diagnoses, and backgrounds. Because of this, the role of the CCLS is important when working with patients who have ASD and is likely one that both children and families might be grateful for when faced with the need to navigate the complexity of the hospital environment.

CCLSs are positioned to lead the charge in implementing the recommendations highlighted in this study through specific clinical interventions that can be woven into the format and content of training and education. As noted in the *individualize care* theme, supporting this population requires adjustments to conventional care provided. To aid professionals in this endeavor, health care institutions can hold training sessions that model how to support patients who have ASD using live actors. Actors can simulate different health care experiences with children on all ends of the spectrum, allowing health care professionals to practice curtailing their care based on the needs of the patient and situation. Through live practice in a simulation environment, health care professionals can work together to create a standard of care for working with this population.

As this study identified, *partnering with the family* is crucial. A CCLS might create opportunities and spaces for enhanced family involvement. Allowing families to share their stories regarding the joys and challenges of caring for a child who has ASD can help provide insight into ways their care can be modified. Perhaps families might be included in the mandatory education sessions described above, which a CCLS can help facilitate. This would allow families to help educate staff based on their expertise as a parent.

Think psychosocially not just medically reminds professionals that individuals in the hospital are more than just their medical needs. One useful resource that CCLSs can educate others on is the use of ASD-specific sensory bins (Gupta et al., 2019). These bins include a variety of materials that aid in sensory management, such as headphones, pop tubes, weighted blankets, stress balls, and visual communication tools. While these materials are helpful when working with the ASD population, some health care professionals may be unfamiliar with the tools and will require an overview of the box to properly utilize it with patients and families.

When working with this population, professionals need to maintain familiarity as much as possible, an issue that was captured in the theme of *consistency in care*. CCLSs can educate staff on how to do this through autism support checklists (ASC). The ASC is administered by phone and the information is summarized and entered into the electronic medical record. ASCs allow pertinent information about the patient and family, such as communication style, triggers, safety concerns, and de-escalation strategies to be available to all staff members (O'Hagan et al., 2019). Templates

of these sheets could be distributed during the mandatory ASD education and training that staff attend.

For the entire health care community to serve children who have ASD, mandatory education and training for all health care professionals that focuses on the kinds of multidimensional support that was identified by participants in this study is needed. Indeed, ASD-specific training for CCLSs can maximize their impact and potential in serving this diverse population with competence, skill, and in-

formed care. By offering such training, children who have ASD and their families can receive the most optimal, affirming, and supportive hospital experience that supports their unique developmental abilities and strengths.

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Appendix

I. Demographics

- a. What is your highest level of education?
- b. What are your degrees in?
- c. What is your age, if you are comfortable sharing with me?
- d. What gender do you identify as?

II. Hospital Protocols on Type and Extent of Care Provided

- a. On a weekly basis, how many children with ASD do you come into contact with while at work?
- b. How is it determined whether the child has an ASD diagnosis?
- c. Do the parents provide this information ahead of time?
- d. Is there an initial assessment conducted regarding the child's specific profile?
- e. If it is determined that the child has an ASD diagnosis, is there a protocol that professionals are supposed to follow?
 - i. If so, what is the protocol and who is involved?
- f. Have families ever commented either positively or negatively regarding the care provided to their child with Autism?
 - i. If so, please explain the scenario for each?
- g. What changes do you have to make when caring for a child with Autism versus a typically developing child?
- h. What differences do you see between the two?

III. Education and Training

- a. Does the hospital you are employed at hold any education or trainings specific to Autism?
 - i. If not, do you think these should be mandatory?
 - ii. If yes, who holds these trainings?
 - iii. If yes, were these trainings effective?
- b. If yes, do trainings include caregivers or other individuals with direct experience with ASD?
 - i. How so?
- c. Do you feel that your place of work has prepared you and your coworkers to properly care for children and families with Autism?
 - i. If yes, why?
 - ii. If no, what could they do?

IV. Participants perspectives on best practices

- a. How much do you know about the ASD diagnosis?
- b. What personal experiences or other connections do you have with this diagnosis?
- c. What are your views on how children with autism are cared for in this hospital?
- d. When first coming into contact with a child and family with autism, what steps do you personally take to ensure a smooth transition beyond traditional policy?
- e. Specific to the care you provide, what techniques do you feel are most effective when working alongside children with autism?
- f. Do you feel as if these techniques are implemented thoroughly throughout the hospital by all professionals?
- g. How can you and the professionals you work with improve the care and support provided to this population?
- h. Do you feel that other professionals are open to changing how they work with this population?
- i. What is the most important thing hospital professionals should know when working with this population?