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ORIGINAL PAPER

Working with Children with Autism Spectrum Disorder in a Medical Setting: Insights from Certified Child Life Specialists

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Abstract

This study aimed to gain an understanding of Certified Child Life Specialists' (CCLS) experiences with and suggestions for working with children with autism spectrum disorder (ASD) in a medical setting. Using a mixed-method design, 118 CCLS completed an online survey and 16 participated in follow-up interviews. Participants believed many medical professionals, including CCLS, are not adequately prepared to work with children with ASD, negatively impacting quality of care. Participants emphasized that outcomes are best for children with ASD when parents and medical staff collaborate to meet the unique needs of each child. CCLS reported working with children with ASD can provide insights for enhancing the quality of care for all children. Participants' suggestions for training and resource development are discussed.

Keywords Autism spectrum disorder · Child life specialists · Pediatric medical care · Mixed-methods

Introduction

Autism spectrum disorder (ASD) is a developmental disorder that can significantly impact communication and behavior (National Institute of Mental Health [NIMH] 2019). The type and severity of symptoms present differently in each individual. Key characteristics of ASD include: difficulty with social communication and interaction (e.g., little or inconsistent eye contact) and restricted, repetitive behaviors (e.g., more or less reactive to sensory input; NIMH 2019). The estimated prevalence of ASD in the United States has increased sharply from 1 in 150 in 2000 to 1 in 59 in 2018 (Baio et al. 2018). An important implication of this increase is that professionals across disciplines will more frequently encounter children with ASD.

The increased prevalence of ASD is particularly relevant for professionals in medical settings because children with ASD have been found to utilize many categories of health care services more than children without ASD (Cummings et al. 2016). Greater likelihood of medical comorbidities (e.g., psychiatric disorders, seizure disorders, and gastrointestinal issues) contributes to more physician and emergency room visits for children with ASD (Liu et al. 2017; Wu et al. 2015). Additionally, more outpatient medical services (e.g., psychiatric, speech and language therapy, and occupational therapy) are utilized by children with ASD (Al-Sharif et al. 2016). Children with ASD also are more likely to be hospitalized, and hospitalization rates for children with autism have substantially increased in recent historical time (Nayfack et al. 2014).

The hospital environment can be stressful for children with ASD, due to sensitivities to sensory stimuli, problems with communication, transitioning between areas, unfamiliar people and places, and pain or painful procedures (Kopecky et al. 2013; MacKenzie et al. 2013). Children with ASD also have more anxiety, which can lead to emotional meltdowns and non-compliance (Johnson and Rodriguez 2013). These factors can make hospital stays difficult for the child, family, and staff. The increased prevalence of ASD, in combination with the unique challenges of medical settings, underscore the importance of adequate preparation for medical staff working with children with ASD.

Preliminary findings of this research were reported in a poster presentation at the Society for Research in Child Development Biennial Meeting, March 2019, in Baltimore, Maryland.

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Parents of children with ASD can be an important resource in helping medical professionals work more effectively with their children due to their high level of knowledge about their children's needs (Edwards et al. 2018). Although parents of children with ASD acknowledge ways that health care providers promote positive medical experiences, parents also describe ways their medical experiences have been hindered (Wilson and Peterson 2018). Issues raised by parents include: feeling like doctors dismissed their concerns; limited attention given to the child's psychosocial and emotional needs; feeling like hospital staff were inflexible at times; and suggested accommodations viewed as unnecessary (Bultas 2012; Muskat et al. 2015).

Previous research has surveyed medical professionals about their knowledge and experiences with ASD. Both physicians and nurses have expressed needing and desiring more training about how to work effectively with children with ASD (Rooth and Olinder 2016; Zwaigenbaum et al. 2016). In their comprehensive review, Straus et al. (2019) emphasized that lack of medical staff training is a risk factor for poorer care for youth with ASD. Professional development trainings focused on working with children with ASD have increased healthcare providers' knowledge, decreased fear, and increased comfort in dealing with challenges (Johnson et al. 2012).

Certified Child Life Specialists (CCLS) are healthcare professionals who work to facilitate coping, decrease stressors, and encourage positive development for children in medical settings using developmentally appropriate, evidence-based interventions (Association of Child Life Professionals [ACLP] 2018b). CCLS complete a minimum of a bachelor's degree, ACLP required coursework, a child life internship, and pass a certification exam. Common majors among CCLS include child life, human development/family studies, and psychology (Lookabaugh and Ballard 2018).

CCLS focus on the psychosocial care of children and are therefore in an ideal position to help children with ASD cope with their health care experiences. The American Academy of Pediatrics (AAP 2014) recognizes the provision of child life services as an important component of quality pediatric care and CCLS as valued members of the interdisciplinary healthcare team due to their developmental and psychosocial expertise, and patient- and family-centered focus. Moreover, Nicholas et al. (2016) reported that some health care providers in their investigation underscored the important role child life specialists play in teaching staff techniques for working with children with ASD. While other medical professionals have been the focus of previous studies, in the review conducted for this investigation, no studies were found that exclusively focused on CCLS. Insights from CCLS have the potential to further improve the quality of care for children with ASD in the medical setting. Therefore, this study aims to gain a broader understanding of CCLS' experiences and needs regarding working with children with ASD. Specifically, this study explores the following questions:

1. How do CCLS describe their preparation for and experiences working with children with ASD in medical settings?
2. What strategies are identified by CCLS as most effective in working with children with ASD?

Methods

Design and Procedure

Using a convergent mixed-methods design (Creswell and Plano Clark 2018), both quantitative and qualitative survey data and qualitative interview data were collected. Triangulation of data collection and analysis, including statistical analysis of survey data, content analysis of open-ended survey questions, and thematic analysis of interview data, allowed for comparisons of results across methods increasing both depth of understanding and credibility of findings (Creswell and Plano Clark 2018; Patton 2002). Multiple researchers were involved in data collection and analysis, and peer debriefings were conducted throughout the analysis further enhancing credibility of results (Patton 2002).

Certified Child Life Specialists were invited through a social media site for a regional child life group in the United States and an online forum of an international child life organization to complete an anonymous online survey about their experiences working with children with ASD. At the end of the survey, participants were invited to be contacted for a follow-up phone interview. Those that agreed were taken to a separate page where they could provide contact information. Contact information could not be traced back to a participant's completed survey.

Measures

Survey

The online survey was developed for this study based on existing research and the guiding research questions. The survey began with a series of questions regarding education and experience in the field. Participants then responded to a series of questions about their education, training, preparedness, comfort level, and perceived effectiveness of strategies commonly used when working with children with ASD. In addition, they answered two open-ended questions examining biggest challenges and greatest joys of working with this population.

Semi-Structured Interview

Phone interviews consisted of a series of open-ended questions asking participants about their background, education/training, and experiences working with children with ASD in the medical setting. Participants were asked about their preparedness for working with a child with ASD, approaches and strategies they commonly used, challenges and joys of working with children with ASD, and additional resources or trainings they believed would be valuable.

Results

Quantitative Results

The online survey was completed by 118 CCLS. Time employed as a CCLS ranged from 3 months to 44 years, $M = 9.15$ years. Time in current position ranged from 2 months to 33 years, $M = 5.05$ years. The majority worked in a children's hospital ($n = 83$), followed by a general hospital ($n = 14$), or other settings (e.g., hospice, outpatient facility, schools; $n = 18$). Participants worked in a variety of departments, with the most common being multiple units/floating ($n = 21$), surgery ($n = 15$), and emergency department ($n = 14$). Although no additional demographic data were collected to better ensure participant anonymity, a membership survey of the larger organization from which this sample was drawn indicated that 99% of the participants identified as female, and 91% were Caucasian (ACLP 2018a).

Participants responded to questions about education, training, comfort levels, and perceived effectiveness of strategies using slider scales from 0 (*not at all*) to 10 (*extremely*). When asked about how well they felt their education prepared them to work with children with ASD, participants' responses had a $M = 5.87$ ($SD = 1.93$). Mean level of comfort working with children with ASD was rated $M = 7.41$ ($SD = 1.68$). Table 1 shows participants' ratings of comfort by age range of child. Rating of preparedness to work with these patients had a $M = 7.07$ ($SD = 1.68$). Participants reported there was great need for additional training ($M = 9.42$; $SD = 1.1$) and they were interested in receiving additional training for themselves ($M = 8.52$; $SD = 1.99$).

Table 1 Participants reported comfort working with children with ASD by age of child

Age of child	*M*	*SD*	*n*
Under 5 years	7.41	1.92	116
5–12 years	7.29	1.84	116
13–17 years	6.82	1.97	116
18 years and above	5.91	2.31	116

Finally, participants identified and rated the effectiveness of strategies they used when working with children with ASD. Preplanning for a child with ASD, input from the parents, weighted blankets, and minimizing transitions were rated as most effective strategies while distraction techniques, sensory stimulation devices, minimizing transitions, PECS or similar visual system, and music therapy were the strategies reported to be used by the most participants (See Table 2).

Content analysis

Content analysis was used to analyze responses to the open-ended survey questions that asked participants to describe their "biggest challenge" and "greatest joy" in working with patients with ASD. The third author used a constant comparative method (Lincoln and Guba 1985; Strauss and Corbin 1990) to generate initial coding categories for "biggest challenge" and "greatest joy." All three authors then met to further revise and refine categories. The first and third authors then independently coded the responses. A follow-up meeting with the second author was used to resolve any coding discrepancies. Only the most dominant category for each participant was used in the final analysis and some initial categories were collapsed in the final coding. The inter-rater agreement for the two independent coders was 85% overall for "biggest challenge" (range 72–100% for each category). For "greatest joy," overall inter-rater agreement was 91% (range 86–100% for each category).

Seven categories of "biggest challenge" emerged from the content analysis with *getting staff on board* and *uniqueness of each situation* occurring most frequently (see

Table 2 Reported use and rated effectiveness of different strategies for helping children with ASD cope with medical procedures

Strategy	# of participants using	*M*	*SD*
Distraction tools	100	7.30	2.01
Sensory stimulation devices (e.g., rover, sensory bags)	82	6.96	2.31
Ability to minimize transitions	78	7.49	2.18
PECS or similar visual system	65	5.88	2.66
Music therapy	65	7.18	2.29
Art therapy	41	5.24	2.72
Massage therapy	24	2.88	2.59
Strategies written in as "other"			
Parental support/input	11	8.82	0.94
Preplanning with staff	3	10.0	0.0
Weighted blankets	3	8.66	1.53
Minimizing environmental stressors	3	6.0	1.0

Table 3 Biggest challenge and greatest joy: content analysis categories, frequency and percent of occurrence

Biggest challenge (n = 89)	Frequency (%)
Getting staff on board	19 (21.4)
• Lack of willingness/flexibility of staff to modify practices or procedures to ease stress for patients with ASD	
“Getting staff on board with coping plans”	
Uniqueness of each situation	18 (20.2)
• Challenges stemming from the diverse presentation of symptoms and severity of disability in ASD	
“Every child with autism is completely different and there is no one way to work with this population”	
Constraints of the hospital environment	16 (18.0)
• Constraints of the hospital that conflict with challenges of ASD (e.g., lack of time in the emergency room)	
“Minimizing stimulation in the hospital environment.”	
Limited training and lack of resources	14 (15.7)
• Lack of training/resources for self and medical staff make working with patients with ASD difficult	
“Not being able to provide the best intervention due to lack of training or resources available.”	
Challenges stemming from dimensions of the disability	10 (11.2)
• Challenges related to ASD, including behavior, communication, self-harm, and size (older patients)	
“Children who self-harm or are very tough to connect with–I feel helpless in knowing what to do to help them.”	
Lack of advanced knowledge about child	8 (9.0)
• Difficulty of making adaptions (e.g., in procedures) on the spot; advanced knowledge would help	
“Not knowing helpful information prior to meeting family.”	
Lack of help or insight from parents	4 (4.5)
• Parents’ lack of insight about how to help child cope creates challenges	
“Not all parents are extremely forthcoming or helpful.”	

Greatest joy (n = 92)	Frequency (%)
Helping children succeed and positively cope	47 (51.1)
• Satisfaction from helping children succeed in the medical environment (e.g., complete a procedure)	
“Success! Kids being able to cope with a positive outcome.”	
Helping children and families have successful, less stressful medical experiences	31 (33.7)
• Satisfaction derived from aiding family coping, empowering families, and experiencing their gratitude	
“Creating a less stressful environment for them AND their parents.”	
Uniqueness of each child	
• Joys inherent in each child being unique and working with children as unique individuals	7 (7.6)
“Their unique personalities and interests, and their ability to cope!”	
Building rapport and connection	7 (7.6)
• Overcoming communication barriers and connecting with children with ASD is satisfying	
“Making them laugh and interact with me”	

Table 3 for category descriptions, frequencies, percentages, and sample quotes). Four “biggest joy” categories emerged, with the most frequent being *helping children succeed and positively cope* (see Table 3). The second most frequent category, *helping children and families have successful, less stressful medical experiences* differed from the first in its additional focus on the family beyond the child. Some of the CCLS described satisfaction from empowering parents and families whereas others expressed the joys of experiencing families’ gratitude and appreciation.

Qualitative Analysis

Sixteen phone interviews were completed by one or both of the first and second authors. Participants were all CCLS with seven working in a children’s hospital, four in a general hospital, three in a children’s hospital within a hospital, and two in outpatient clinics. Interviews lasted between 12 and 36 min ($M = 21$). All interviews were audio recorded and transcribed verbatim by the first author. Interviewers took field notes during each interview, and debriefed following each joint interview, making note of key points made by the participant. Interviews were completed until additional participants were not adding new information to the developing codes and themes (Creswell 2015).

A thematic analysis approach was used to identify patterns in the data (Braun and Clarke 2006). Both the first and second author immersed themselves in the data by reading and re-reading each transcript. Both researchers independently coded all transcripts using in vivo coding to summarize key points made by interviewees in their own words (Saldaña 2016). All three authors collaborated to identify themes from the coded data. Five major themes were identified and are discussed below.

Collaboration and Communication

Collaboration and communication between parents and medical professionals, as well as among medical professionals, was noted in every interview as key to successfully meeting the needs of children with ASD in the medical environment.

Parents

Participants noted that parents are experts on their child and can provide important information about the child's triggers and sensitivities, favorite items and activities, and previous medical experiences. This information can help medical staff effectively connect with that child. One participant summed up what all participants noted, "One best tip? Ask their parents… they really know their child best." Another participant provided more detail,

> I feel like I'm a much stronger advocate by listening to the family. I think when you've just graduated, you tend to be like, and "I know everything about children!" And no, the parents know everything about their children. And we're like their escorts through this and we're their advocates and their spokespeople, but they get it and they know their kids. I guess the number one lesson for me has been just listen and try to follow along to what they recommend because they know their kids. They've had them for 12 years, 20 years whatever. They know them and they know what's going to get them through the day in our weird environment.

Interviewees noted that occasionally parents, particularly those whose child was more recently diagnosed, were unsure how the medical team might support their child. In these cases, CCLS can help parents by providing tips and coping tools they can use at home. For example, one participant discussed the reaction of parents,

> Wow, those tools were great. I can use those and maybe eventually take him to the grocery store with me. Or I can use those tools and go through the comic book and maybe have a better interaction with this child.

Another participant discussed the value to parents of seeing their child succeed,

> I think it's nice for parents to see their kids on the spectrum facing a challenging situation and succeeding. I think it helps parents see what their child is capable of doing and seeing a little more insight on how their child is processing what is going on. It's always cool when the parents are like, "Wow, he's really listening!"

Medical Staff

Communication between medical professionals about each child's specific needs is necessary to ensure the highest quality of care. CCLS reported the best outcomes for patients occurred when all medical staff were working together. As one participant stated, "we need to partner with our colleagues [medical staff]. That's when we've had the most success is working together as a team." She provided examples of the medical team listening to parents and making accommodations to improve the medical experience for patients such as,

> Okay this is Joe, and Joe hates loud noises, so everyone shh. Or we had this one kid that really hated the color blue and we're all wearing blue scrubs so I called ahead and got everyone in a yellow precaution gown so everyone put on the yellow precaution gown on top of the blue so he didn't have to see any blue.

While collaboration as a team is ideal, participants noted that sometimes the structure and fast-pace of the medical environment can make this collaboration difficult. In the words of one CCLS, "The kids themselves and the family are never an issue. It's us and our system that's the issue."

When the medical team communicates well and is willing to be flexible, creative strategies for meeting a child's needs can be developed. One CCLS noted,

> We need to be able to break the rules when they're stupid rules. Turns out, you don't have to wear pajamas in the OR, you can wear whatever you want. So, guess what? If the kids really have to wear pajamas, like if it's going to be a colonoscopy, we'll just put them in pajama bottoms but they can keep everything else. If they hate our pajamas then they can go in their clothes."

Occasionally participants felt frustrated when they believed their input was ignored or the staff seemed inflexible. As one interviewee discussed, "One of my biggest challenges is the staff,… It's hard to always get people on board with things that are best for the patient but may be inconvenient for the staff."

Child Life

Certified Child Life Specialists identified a part of their role as a liaison between families and medical staff. CCLS often are the ones who talk to families about their needs and then convey those needs to the health care team. Needs might include minimizing environmental stressors for the child (e.g., lights or sounds), or minimizing the number of people in the room at one time. Once again, the importance of good communication was emphasized. As one participant discussed,

> Parents are going to advocate for their child but we also need to advocate within the system… How do we as child life specialists advocate for those kids within the institution and with our colleagues. So, we can't do this by ourselves and we're not going to provide a good experience if something we did was very specifically supportive for a child on the spectrum and another staff member comes in and does something completely opposite."

Training

Participants repeatedly noted a lack of training to prepare child life specialists and medical staff to work with children with ASD. Several participants found it difficult to successfully work with children when medical staff, including CCLS, were uncomfortable around children with ASD. In the words of one participant, "The other hard part is working with staff who are unfamiliar or scared of kids with autism." Another interviewee noted,

> I just want child life to feel more comfortable in working with these patients and not be scared of them… You can't pick and choose who you're going to be working with as a child life specialist, so let's help you be prepared because no matter where you work, you will encounter a patient with autism.

In addition, discomfort working with this population can decrease the quality of care for the patient. As exemplified by one participant's discussion of some staff,

> They kind of tense up a little bit and they're so afraid of doing the wrong thing that I think they don't look at them. They're still a child. We shouldn't treat them any different, it's just that our approach might be changed.

The CCLS interviewed noted that most of their training came through experience. For example, one participant said, "I just learned on the job. Here's the patient, they are under the table. We don't know what to do. And you figure it out." Many discussed seeking out information at conferences and online. Several noted their facility offering some professional development focused on working with children with autism for medical staff including CCLS.

Participants reported that they had not taken any required courses about working with children with special needs during their undergraduate or graduate studies, nor did they learn much about working with children with ASD. Several suggested that working with children with ASD should be an emphasized component of child life education.

Participants reported being particularly underprepared to work with patients with more severe levels of ASD, especially those who were nonverbal or aggressive. One interviewee said, "I don't know the appropriate safe holds or if I'm strong enough to hold this child. Sometimes I feel unprepared or like it's past my professional abilities." Their concern often was focused on safety for adolescents who are larger and stronger. As one CCLS stated, "The bigger kids that will fight and then it becomes a safety concern because if they are too strong, the kid could end up getting poked in the wrong spot or a staff member gets poked which has happened."

Participants provided a variety of ideas for trainings that could be helpful for CCLS and medical staff working with children with ASD, including webinars, staff in-services, and conference presentations. Several suggested partnering with schools and special education professionals, and some participants stated it would be valuable to attend presentations from individuals with ASD and parents of children with ASD as exemplified in this statement,

> I think hearing parents' feedback at a time that they kind of have their thoughts collected and they have a space to kind of really share their needs. I would love to hear what parents need from us and the healthcare system and ways we can adapt.

Strategies and Resources

Interviewees discussed a range of valuable strategies for working with children with ASD. They noted whenever possible, it is useful to know a child's diagnosis beforehand. However, there is considerable variation in how often CCLS find out the diagnosis prior to meeting with the child. Several participants noted some hospitals are piloting intake sheets to identify a child's diagnosis prior to a visit or admission. These sheets ask parents questions about the child's stress triggers, communication systems, and interests. This information can be useful in reducing stress and helping the child successfully cope in the medical setting.

Participants discussed additional strategies to inform medical staff of a child's specific needs. One interviewee shared, "Some hospitals in the ER, they will have little hang tags that will go on the door to the rooms and every kid is green for like autism and developmental delays so you know from the beginning." Another participant discussed leaving notes on a child's door with strategies for helping a child feel comfortable such as "Before you enter the room, please stop at the doorway and say hi to me. Speak softly and go to where my mom is first before you go to my bed."

Participants emphasized that ASD presents differently in every child; therefore, it is essential to recognize strategies that work for one child with autism may not work with another. As one interviewee explained, "It's so individualized. And even with the same patient, what works today may not work tomorrow for that same child with autism." That said, a wide range of strategies and resources can be useful for helping children with ASD cope in the medical environment. Commonly discussed were a variety of distraction techniques, sensory stimulation, iPads, and calming music.

The need for additional resources was also noted. One idea several interviewees suggested was to develop accessible internet resources for parents and professionals that could be personalized for a child's individual situation and needs; for example, one CCLS explained,

> I think resources for parents to pick up, more social stories and having them readily available so parents don't have to create their own… I made one specific to my hospital, but if there was one that was generic, I wouldn't have had to do that. And I could have one on blood tests, on IV starting, on having surgery, going to the hospital, having a NG tube. You know, all these different things would be great to have social stories and resources for parents and professionals to access that are free.

Joys and Benefits

Participants emphasized that working with children with autism and their families was very rewarding. As one interviewee stated, "I tell you what, I love these kids. The honesty and the candidness of the things they say crack me up." Participants particularly found joy in helping children make it successfully through a challenging environment and procedure, as exemplified in the following quote,

> Having kids leave, giving us all high fives and smiling after surgery, that's the best thing ever. Having people wipe away tears of happiness as they walk in the elevator and looking us in the eye and saying, "you guys have just changed our lives."

The joy associated with helping reduce parents' stress and helping them feel valued was also discussed. In the words of one interviewee,

> It's so rewarding, which I think is true for any child life specialist. I think autism specifically because the parents are so used to not getting the care that every other patient gets because they're just kind of brushed aside and they're just rushed through but when you take the time and work with them and you sit there and ask the questions and the parents are like, "Wow you really want to know, you really want to help my child." And when they see that, their eyes change and their body language changes.

The CCLS interviewed noted an additional benefit of working with children with ASD was that it provided them insights about to reduce challenges in the medical environment for all children. As one participant explained,

> I totally think kids on the spectrum are like canaries in a coal mine. They show us what all kids are worried about. So, the environmental overwhelming piece: sounds, lights, everything. It has made a difference in my care delivery by trying to reduce that sensory stimulus for all kids. Paying attention to lighting, simple things like that can make a big difference for kids. And I think kids on the spectrum are more present in how they respond to it. But all kids are bothered by those things as well.

Discussion

Certified Child Life Specialists are trained in developmentally appropriate strategies to assist children and their families in successfully coping in medical environments (Lookabaugh and Ballard 2018), and their insights can help improve care for children with ASD. The CCLS in this study described the rewards of working with this population and found great joy in building connections and helping children with ASD and their families have successful medical experiences. They also noted that children with ASD provide insight into aspects of the medical setting that can be stressful for all children, helping medical professionals better meet the needs of all patients.

Yet consistent with reports by other medical professionals (Straus et al. 2019; Zwaigenbaum et al. 2016), this study found that many CCLS felt inadequately prepared and perceived that many other medical professionals also felt inadequately prepared and uncomfortable working with children with ASD. Responses to survey questions, content analysis, and interview results all indicated CCLS do not believe they received adequate training for working with children with ASD. Both content analysis and interview data emphasized that the nature of the medical environment was the problem—not the child or the family. When medical professionals, including CCLS, are more informed about ASD, they are more likely to make reasonable accommodations that can improve the experience for children with ASD.

CCLS reported they learned most of what they knew about working with children with ASD on the job or by seeking out professional development opportunities. The participants highlighted the need for improved education and expressed that undergraduate and graduate child life curriculum should include instruction on working with children with ASD. Participants suggested a variety of formats for teaching all medical professionals effective strategies for working with children with ASD including webinars, staff in-services, and conference presentations. They recommended including presentations by patients with ASD, parents of children with ASD, and educators or other professionals with knowledge about best practices for working with children with ASD could be particularly valuable.

Autism spectrum disorder varies significantly across individuals. Different cognitive abilities and behaviors bring unique challenges. Participants were consistently less comfortable working with more severe levels of ASD, and especially noted the challenges of working with non-verbal, physically stronger, and aggressive older children and adolescents. These characteristics potentially raise safety concerns for both patients and staff, and participants expressed a strong desire for training and clearer procedures for dealing with these challenges.

Also consistent with findings from previous research, CCLS reported collaboration with parents (Bultas et al. 2016; Muskat et al. 2015; Straus et al. 2019; Strunk et al. 2014) and between medical professionals (Muskat et al. 2015; Todorow et al. 2018; Zwaigenbaum et al. 2016) is key to successfully meeting the needs of children with autism in the medical setting. Both survey and interview participants noted that individual differences of children with ASD means there is no one strategy that is most effective for all children. Participants emphasized the importance of recognizing parents as experts on how to best meet their child's needs. They also highlighted the benefits of advanced preparation for the child and medical professionals including the use of social stories, good communication among the medical team, and having a range of materials and interventions ready to use. Finally, participants identified a wide range of items or approaches that can be useful for facilitating coping such as distraction and sensory stimulation tools, music therapy, and massage therapy.

CCLS recommended the sharing of resources across facilities and with parents. Most frequently mentioned was the development of a website that housed resources such as social stories. Participants envisioned social stories explaining a wide variety of medical procedures that could be personalized to a child's specific situation and developmental level. Through collaboration with experts on ASD, valuable, evidence-based resources could be created and shared.

Strengths and Limitations

The mixed-methods design and convergence of results across methods are strengths of this study. Quantitative survey results provided insights into the experiences and perceptions of CCLS working with children with ASD while content analysis and interview data supported and provided a deeper understanding of the survey results. Although the interview sample was small, the consistency in findings across the surveys and interviews suggest that the interviews were representative of the larger sample. However, those who volunteered to participate in this investigation may have a strong passion for and investment in working with children with ASD.

Conclusion

The input provided by participants in this study is valuable for all pediatric medical professionals. The consistent message from participants was training, communication, and collaboration are key to effectively meeting the needs of children with ASD and their families. Piloting and evaluating training and resources suggested by the participants are logical next steps. Understanding best practices for working with children with ASD improves the experience for children, families, and medical personnel. When professionals become comfortable working with children with ASD, they report working with this population is very rewarding. Moreover, as underscored by participants in this study, understanding the needs of children with ASD enhances the ability of professionals to meet the needs of *all* children in the medical environment.

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Author Contributions EJ and CG designed and collected data for the study. PS provided input on study design and participant recruitment. EJ, CG, and PS were all involved in data analysis, writing of the manuscript and final edits for publication preparation.

Compliance with Ethical Standards

Conflict of interest The authors declare they have no conflict of interest.

Ethical Approval This study was approved by the University Institutional Review Board [1190330-2].

Informed Consent Informed consent was obtained from all individual participants included in the study.

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