Reducing Barriers to Care in the Office-Based Health Care Setting for Children With Autism

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ABSTRACT

The purpose of this survey-design research study was to evaluate the usefulness of a researcher-developed tool designed to improve office-based health care services and to assess the barriers and resources affecting office-based health care services for children with autism spectrum disorder. Fifty-four health care providers (HCPs) and 59 parents participated in the study. HCPs reported child behaviors, communication, and fears as barriers to providing care, whereas parents reported child behavior, sensory issues, and feelings of a disconnect with the HCP as barriers. HCPs identified the parent as a key resource. Parent-identified resources included provider adaptations to the patient, including slowing down the delivery of care and environmental adaptations to the office. In addition, both HCPs and parents indicated that the researcher-developed tool would be useful in reducing barriers during the HCE. Reducing barriers and improving health care interactions during delivery of care for children with autism spectrum disorder has the potential to improve health outcomes. J Pediatr Health Care. (2016) *30*, 5-14.

KEY WORDS

Autism spectrum disorder, barriers, resources, primary care, health care delivery

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Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by marked impairments in reciprocal social communication, as well as restricted interests and repetitive behaviors (American Psychiatric Association, 2013). Recent data from the Centers for Disease Control and Prevention indicate that 1 in 68 children in the United States have an ASD (Wingate et al., 2014). Data show that such children have more health care encounters (HCEs) that are longer in duration than their neurotypical peers (Liptak, Stuart, & Auinger, 2006). It is not uncommon for children with ASD to present to their health care provider (HCP) with complex developmental and behavioral symptom profiles requiring the use of an individualized and innovative approach to managing the child's behaviors within the office setting (Lombroso, Ogren, Jones, & Klin, 2009).

Given the complex behavioral profile that children with ASD present with, HCPs have reported a lack of confidence and training in appropriate communication skills and strategies needed to interact effectively with families of children with ASD (Minnes & Steiner, 2009; Weil & Inglehart, 2010). Additionally, parents of children with ASD have reported dissatisfaction with

their child's HCEs, citing the HCP's lack of confidence, knowledge, and skills in handling the challenging child behavior that often presents with ASD (Minnes & Steiner, 2009; Rhoades, Scarpa, & Salley, 2007). To date, few empirical data are available regarding the types of office-based supports that HCPs and parents need to enhance the delivery of health care services for children with ASD who present with challenging behaviors. Office-based care presents different challenges than acute care settings for many reasons, including a limited amount of time for appointments, tight appointment schedules, limited office personnel, and limited resources. The purpose of this study was twofold: (a) to evaluate the acceptability and usefulness, from the perspectives of both parents and HCPs, of a researcher-developed tool designed to facilitate communication and improve health care delivery outcomes during HCEs, and (b) to conduct a needs assessment of the barriers and resources that parents of children with ASD encounter during office-based health care delivery.

LITERATURE REVIEW

Research has shown that children with ASD experience a greater number of HCEs per year than do their neurotypical peers (Gurney, McPheeters, & Davis, 2006; Liptak et al., 2006). Furthermore, it has been shown that the length of time the HCP spends during an HCE with a child with ASD is almost two times longer than for other children, including those with chronic illness (Liptak et al., 2006). This increase in visit length is, in part, related to the frequency and duration of challenging behaviors displayed by the child during the encounter. Unfortunately, this increased number of HCEs and increased length of time of the visits do not necessarily translate into a higher quality of health care for this population of children with ASD. Zuckerman, Lindly, Bethell, & Kuhlthau (2014) found that children with autism experience a poorer quality of health care than do children with special health care needs who do not have autism.

CHALLENGING BEHAVIORS EXHIBITED DURING HCES

Researchers have shown that typical behaviors of autism—including screaming or verbalizations, tantrums, aggression toward self or others, inappropriate activities, anxiety, fears, and irritability—complicate the delivery of health care for children with autism because these behaviors are often exacerbated in the health care environment (Bultas, 2012; Hellings et al., 2005; Matson, 2009). Increased anxiety, although not always externalized, may be exhibited by children with ASD when they visit the HCP because of their unfamiliarity with the office routine and their inability to fully communicate their fears and frustrations (Johnson, Bekhet, Robinson, & Rodriguez, 2014). The social and communication impairments that are central to autism often cause these difficulties for the child. Environmental triggers such as bright lights, noises, and the fast-paced health care setting have also been linked to increased anxiety and fear for children with ASD in the acute care setting, which can then lead to poor compliance with the HCE (Johnson et al., 2014; Scarpinato et al., 2010). Children with autism also have difficulty with emotional regulation, which may also cause anxiety and externalizing behaviors such as aggression and acting out in the HCE (Davignon, Friedlaender, Cronholm, Paciotti, & Levy, 2014).

Another factor complicating behavior for the child with ASD are psychiatric comorbidities (Hofvander et al., 2009; Pondé, Novaes, & Losapio, 2010). These comorbidities include attention deficit hyperactivity disorder, as well as externalizing behaviors that often hinder and interfere with a child's ability to have appropriate interactions (Mayes et al., 2012), especially in the health care setting. Complicating matters, HCPs may have limited experience managing the challenging behaviors children that with ASD often display in the novel health care environment (Johnson, Lashley, Stonek, & Bonjour, 2012). The fast pace of the office-based setting further complicates the situation because of limited appointment lengths, appointment schedules, and lack of resources, including additional staff (Bultas, 2012).

PARENT PERCEPTIONS OF THE HCE

Parents have also expressed dissatisfaction with the HCE, citing the HCP's lack of confidence, knowledge, and skills needed to effectively manage, communicate, and tailor the HCE in order to maximize outcomes (Minnes & Steiner, 2009; Rhoades et al., 2007; Weil & Inglehart, 2010). A disconnect between the HCP and the parent's interpretations of the child's behaviors may confound the delivery and outcomes of the HCE in this population (Davignon et al., 2014). Johnson et al. (2014) found that mothers of children with ASD viewed challenging child behavior occurring in the health care setting as being indicative of their child's frustration and hyperactivity, whereas HCPs interpreted these behaviors as aggression and self-stimulation. Additionally, HCPs and mothers used different strategies to reduce these behaviors. Mothers tended to focus on preparing the child for the encounter, as well as helping the HCP develop strategies to address the child's behavioral needs, whereas HCPs tend to use less child-focused strategies to reduce behaviors (Johnson et al., 2014). Understanding more about the barriers that exist during the HCE for children with ASD, as well as improving collaboration between the HCP and parents, have the potential to reduce and promote effective management of challenging behaviors in the health care setting (Bultas, 2012; Johnson et al., 2014).

CURRENT RECOMMENDATIONS FOR ACUTE CARE SETTINGS

The literature includes some recommendations regarding strategies to support HCPs in facilitating care of children with ASD in the acute care setting. Scarpinato et al. (2010) recommend resources formulated with the family and tailored to the child. Johnson et al. (2014) also recommend that HCPs work with the parent in developing plans to address challenging behaviors in the acute care setting, and Johnson and Rodriguez (2013) identify family collaboration as essential in reducing behaviors that complicate the delivery of health services in the hospital setting. Proactive planning, modifications to delivery flow and environment, and individualizing care have also been found to be effective and recommended in minimizing stressors for children with ASD in hospital settings (Balakas, Gallaher, & Tilley, 2015; Davignon et al., 2014). Tablet computers such as iPads have been used successfully to help communicate with and inform children who have ASD to prepare them for medical procedures. In one small study, an iPad application was found to reduce the child's state anxiety during a radiology procedure, leading to fewer externalized child behaviors (Johnson et al., 2014).

The aforementioned literature review supports the idea that proactive preparation of children in the health care setting can reduce challenging behaviors that complicate health care delivery, lengthen the HCE, and reduce the quality of the health care services for children with ASD in acute care settings (Balakas et al., 2015; Drake, Johnson, Stoneck, Martinez, & Massey, 2011). Additionally, steps taken to individualize approaches and increase attention to child preferences and temperaments, because of the diverse needs profile of this population, have also been found to optimize acute care health care experiences and outcomes (Koller & Goldman, 2012; Kopecky, Broder-Fingert, Iannuzzi, & Connors, 2013). However, few recommendations for supporting children with ASD in the primary care or office setting exist. Parents have suggested a need for a mechanism to be available to HCPs to communicate real-time nuances and information about the child as a way to improve care delivery, prevent challenging behaviors, and increase collaboration between the parent and HCP (Bultas, 2012).

CURRENT STUDY

The purpose of this study was to obtain feedback from parents and HCPs on the usefulness and acceptability of a researcher-developed tool designed to facilitate office-based interactions and improve delivery of health services to children with ASD and to assess the barriers and resources that parents and HCPs encounter during office-based health care services. Specific aims included (a) assessment of parent and HCP perspectives of the feasibility and potential usefulness of a researcher-developed tool designed to empower parents, facilitate communication, and improve office-based health care interactions for children with ASD, and (b) identification of parent and HCP perceptions of barriers and resources affecting office-based HCEs for children with ASD. It is important to understand more about the actual barriers that parents and HCPs experience and to identify potential resources to improve HCEs for this growing population of children as a step toward improving quality outcomes during office-based HCEs.

RESEARCHER-DEVELOPED TOOL: QUICK TIPS CARD

The development of the Quick Tips Card (QTC) stemmed from the results of an initial study focused on gaining an understanding of the health care needs of preschool-aged children (3 to 6 years) with ASDs during HCEs (Bultas, 2012).Data from the study added to the body of literature indicating that mothers had concerns that their child's HCP did not always understand the complexity of ASD or how ASD affected their child's HCEs. Mothers also expressed concerns that HCPs did not always tailor care and make adaptations for the child, which often led to increased anxieties and fears for the child during the HCE. Based on these data, the researcher developed the QTC. Revisions were made to the initial QTC after completion of a content validity study in which the QTC was reviewed by expert clinicians who care for children with autism.

The QTC is a parent-driven information tool designed to empower parents to quickly and easily communicate unique and specific characteristics about their child that may not be contained in the medical record.

The QTC is a parent-driven information tool designed to empower parents to quickly and easily communicate unique and specific characteristics about their child that may not be contained in the medical record. This information includes how the child communicates, the child's challenging behaviors, the child's current mood, the child's fears related to the HCE, and more specifically, real-time concerns or child nuances that may be different or changed for that day. The QTC is simple and quick for the parent to complete and is printed on a small "sticky" note pad of paper so it can be kept in a purse or pocket. The parent is then able

to present the completed tool upon arrival to the appointment to provide the HCP and other office personnel with information that is unique to the child before the HCE begins. The QTC is intended to reduce communication barriers that could have a negative impact on health care experiences for children with ASDs. It is hypothesized that the use of the QTC during the HCE has the potential to improve the flow, efficiency, interactions, and thus the outcome of the HCE while decreasing time (which may translate to reduced cost) associated with the visit. See the Figure for an example of a completed QTC.

METHODS

Design

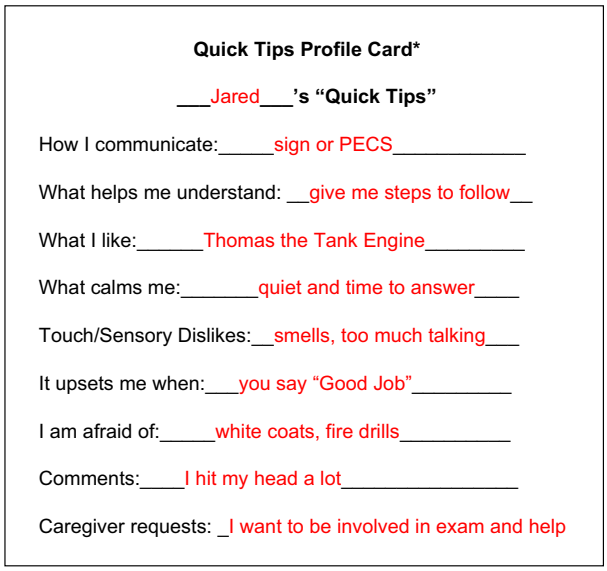
A cross-sectional survey design was used to obtain information from both HCPs and parents of children with ASD regarding perceptions of barriers and resources affecting office-based HCEs, as well as to assess the acceptability of the QTC card. The primary author developed two online surveys, one for parents and one for HCPs; surveys were at approximately an eighth-grade reading level. Institutional Review Board approval for an exempt study was obtained prior to recruitment and posting of both survey links. Each survey link included a participant recruitment statement that appeared at the beginning of the survey; this statement identified the purpose of the study and provided the participant with the opportunity to continue or decline to participate. All parent and HCP participants were offered a chance to enter a gift card drawing at the end of the survey.

Participants and Procedure

A convenience sample of two groups of pediatric HCPs was recruited via e-mail. The first group included 150 unique e-mail addresses of pediatric physicians providing office-based services; the e-mail addresses were provided by a local pediatric hospital in the Midwestern United States. The second group of HCPs included 158 unique e-mail addresses of pediatric nurse practitioners (PNPs) who were members of the local, Midwestern U.S. chapter of their professional organization. These two groups were chosen because of the high likelihood that they regularly provide care to children with ASD. Inclusion criteria posted on the participant recruitment statement for pediatric HCPs included: (a) a physician or nurse practitioner and (b) provided direct medical care to a child with ASD within the past year.

A convenience sample of parents was also used. Ten autism parent group electronic e-mail list managers (seven national and three local) were contacted by the researcher and asked to post the survey link for the parent survey. The seven national LISTSERV e-mail list managers did not respond to the request; therefore, it was only known that the parent survey link was posted on three local parent LISTSERV e-mail lists. The following inclusion criteria were posted on the participant recruitment statement for the parent survey: (a) is 18 years of age or older; (b) has been informed that his/her child is diagnosed with ASD by a physician; (c) is the primary decision maker and caregiver for his/her child; (d) is the biological parent, stepparent, or legal guardian of a child; (e) has a child with ASD between the ages of 3 and 15 years of age; (f) has access to the Internet to complete study-related surveys online; (g) resides in the continental United States; and (h) reads, speaks, and understands English to complete planned data collection methods. The selected age range was chosen because many children are not diagnosed before age 3 years and transition services may be starting for children with ASD by age 16 years.

FIGURE. Example of a completed Quick Tips Card to be used by parents to communicate their child's unique needs to providers.



This figure appears in color online at www.jpedhc.org.

Survey Tools

The HCP survey included 14 questions, and estimated completion time was 5 to 10 minutes. The survey primarily used Likert-style and multiple-choice question formats and included only one free response question to minimize the survey burden. The questions were developed and reviewed by members of the research team, who have extensive experience working with children and families with ASD. The questions asked the HCP to (a) evaluate the usefulness of the QTC, (b) assess the likelihood of using the QTC in his or her practice, and (c) identify barriers to providing care to children with ASD. Survey questions related to barriers of care were developed using the available literature.

The parent survey contained 10 questions that asked parents to evaluate the QTC card and to identify barriers

and resources they encountered during HCEs with their child with ASD. The survey questions were developed by the researchers using the available literature; question formats were primarily free response but also included a few multiple-choice and Likert-rating questions. It is estimated that the parent survey took 10 to 15 minutes to complete.

Data Analysis

Quantitative data obtained from Likert-style and multiple-choice questions were analyzed using descriptive statistics. Qualitative data obtained from free response and open-ended questions were analyzed for common themes using qualitative description (Sandelowski, 2000, 2010). The three members of the research team read the participant responses individually and identified themes. The research team then met and discussed the responses and themes to achieve consensus. The data analysis process was aimed at summarizing the information obtained from both the parents and the HCP, as well as identifying the most frequently occurring themes.

RESULTS

Demographics of Participants

HCPs

The HCP survey link was sent by e-mail to 150 unique pediatric physician addresses and 158 unique PNP addresses; 52 surveys (17%) were completed either partially or completely (not all respondents answered all questions). Twenty-seven physicians (52%) and 25 PNPs (48%) submitted survey responses. Thirty-one providers (60%) provide care to children with ASD one to two times per month, and 18 (35%) provide care to children with ASD one or more times per week. Fifty-five percent of respondents (27 of 42 responses) identified themselves as feeling uncomfortable or only slightly comfortable providing care for children on the autism spectrum.

Parents

The parent survey link was successfully posted on three local autism LISTSERV e-mail lists for parents, and 58 parents completed the survey either partially or completely. Because of the use of local LISTSERV e-mail lists and to reduce the time burden of the survey, very little demographic information was collected. Forty-two parents (72%) indicated that their child received care from the HCP between one and four times per year; 14 children (24%) received care either monthly or bimonthly, and two children (3%) received care one or less times per year. All respondents were female caregivers. Not all respondents answered all the questions on the survey.

Barriers During HCEs

Health care providers

HCPs were asked to identify the top challenges or barriers in providing care to children with ASD (see Table 1). Providers were given a list of child behaviors, compiled from the available literature, to choose from and were able to choose more than one challenge. Forty-nine participants responded and identified the top five challenges and barriers as child behavior(s) (78%), uncooperative and unable to completely examine (71%), child fears about the examination (67%), difficulty communicating with the child (55%), and parent overwhelmed during the visit (53%).

TABLE 1. Perceived barriers during the health care encounter for children with autism

Health care providers (49 responses)			Parents (45 responses)		
Challenge	No. of respondents*	%	Challenge (theme)	No. of comments†	%
Child behavior during encounter	38	78	Provider/staff doesn't understand impact of ASD	19	42
Uncooperative, unable to completely examine	35	71	Child behavior during encounter	11	24
Child fears about the examination	33	67	Environmental issues (e.g., waiting, lights, noise)	11	24
Difficulty communicating with child	27	55	Face pace of office	8	18
Parent overwhelmed during encounter	26	53	Child communication deficits	5	11
Child fears about the provider	23	47	Need case management for child	4	9
Parent distracted by child	22	45	Parent distracted during encounter	3	7
Family dynamics	17	35			
Parent beliefs about health care	13	27			
Office environment	11	22			

Note. *ASD, autism spectrum disorder.*
**Respondents were able to choose more than one.*
†Respondents may have provided more than one comment.

Parents

Forty-five parent respondents provided comments related to barriers during HCEs; parents were not limited on the number of comments and may have identified more than one challenge (see Table 1). Nineteen comments (42%) related to the theme that the provider or office staff doesn't understand the impact ASD has on all aspects of life and care. One parent stated, "Providers' services are so compartmentalized—my son's primary care doctor doesn't really understand autism to the degree I would like, but he is great handling his overall medical health. I feel a severe disconnect between the different aspects and professionals involved in my son's care that I find extremely frustrating." Eleven comments (24%) referred to child behaviors as a barrier, with one parent stating, "I feel most [barriers] come from behaviors from my child that make it difficult to focus with the Dr." Another 11 comments (24%) identified environmental issues, including waiting times and sensory issues such as bright lights, loud televisions, and crowded waiting areas as problematic. Eight comments (18%) identified the fast pace of the office as a barrier, with one parent commenting, "He's always in a hurry and doesn't take the time to try to understand how to make an office visit less uncomfortable for our daughter." The remaining comments included five (11%) identifying child communication deficits, four (9%) identifying need for case management, and three (7%) identifying parent distraction during the visit as a barriers.

Resources During HCEs

Health care providers

Forty-nine participants responded to a list of resources, again developed from the available literature (see Table 2). Respondents were allowed to choose more than one resource. The top five resources/supports in providing care to children with autism were identified as parent partnering with the provider (94%), provider familiarity with ASD (63%), parent advocating and making suggestions to help the provider during the examination (61%), child familiar with office routine (57%), and parent helping to plan the encounter (45%).

Parents

Thirty-three respondents provided comments pertaining to resources during HCEs with their children (see Table 2). Fifteen comments related to adapting to the child, including using a patient and calm approach, slowing down to give time for the child to process what is happening, and taking the effort to relate to the child. One parent's response stated, "Patience, compassion, consideration, listening, positive regard, and praise. And we love the nurses who don't make a huge deal about the kids' shoes and orthotics." Ten comments related to the environmental or physical office adaptations as being a positive resource during the office visit. Environmental and physical office recommended adaptations included quiet waiting areas, shorter wait times, less bright lights, presence of fish tanks, increased number of sensory-based toys, and the availability of some type of communication board for the child to use. Examples of sensory-based toys include small, portable fidget and squeeze toys, toys and books with a variety of tactile surfaces, and fine-motor manipulative items. Three respondents recommended that HCPs partner with the parents, and another three comments related to the increased need for case management from the HCP. Lastly, two respondents remarked that having office personnel who could

TABLE 2. Perceived resources, during the health care encounter, for children with autism

Health care providers (49 responses)			Parents (33 comments)	
Resource	No. of respondents*	%	Resource (theme)	No. of comments†
Parent partnering with provider	46	94	Adapt to child: patience and slowing down	15
Provider familiar with ASD	31	63	Adaptations to office environment, including toys	10
Parent advocating/making suggestions during encounter	30	61	HCP takes cues from the parent during the encounter	3
Child familiar with office and routine	28	57	Case management	3
Parent helping plan the encounter	22	45	Office personnel watch child so parent can talk to HCP	2
Reward for child when done	20	41		
HCP using behavior management strategies	19	39		
Special toys for child during encounter	17	35		
Modifying the office environment	12	24		

Note. *ASD, autism spectrum disorder; HCP, health care provider.*
**Respondents were able to choose more than one.*
†Respondents may have provided more than one comment.

watch the child while the parent talked with the HCP after the visit would be beneficial.

Acceptability of the QTC Tool

Health care providers

Results evaluating the QTC were favorable among HCPs. Overall, 46 of 49 respondents (94%) thought the QTC card would be helpful for a child with ASD. Thirty-nine of 48 respondents (81%) identified the QTC as being helpful or extremely helpful during an HCE with a child with ASD, with 41 of 48 respondents responding favorably or extremely favorably to the card if it was presented to them by a parent at an HCE. All of the items contained on the QTC, except the comment line, were identified as helpful by more than half of the respondents (see Table 3). Fifteen respondents provided general comments about the QTC, with six of the comments identifying the card as useful and liking it, five comments identifying the card as helpful in situations in which the provider is not familiar with the child (such as in the emergency department or in an office with multiple providers), and five comments identified the card as having useful information on it. One provider remarked, "I can see so many values for this card…do not limit card to primary care, think broader. These pieces of info help all of us to give better care."

Parents

Parents were also asked to evaluate the QTC. Seventy-seven percent (37 of 48 responses) indicated they thought the QTC would be helpful or extremely helpful for the general HCP caring for a child with ASD if it was presented to the provider prior to seeing the child, with 73% (36 of 49 responses) indicating they would be likely or extremely likely to use the card. Parents were also asked to identify which sections of the card were most helpful; 47 comments (with some comments indicating more than one section) were recorded (see Table 3). Parents indicated that the most helpful information on the card was information related to the child's sensory needs (14 comments), what calms the child (12 comments), communication needs of child (11 comments), what upsets the child (8 comments), what the child likes (8 comments), and how the child understands (7 comments). Six parents commented that all sections of the card were helpful. More than half of the respondents did not have anything further to add to the card; one parent commented, "I think it provides the essentials." Last, parents were asked if they had any general comments about the QTC. Of 32 comments, 26 (81%) were positive about the card; negative comments included concerns that the HCP would not read it, the card would be hard to have ready, and the parent would prefer to have a discussion about these issues directly with the provider.

DISCUSSION

Barriers and Resources

Results from this survey revealed that concerns about barriers and resources to improve the delivery of health care services in the office-based setting were similar to those found in the literature on acute care settings (Davignon et al., 2014; Johnson et al., 2014; Johnson et al., 2012). Top challenges identified by HCPs include challenging behaviors, uncooperativeness, fearfulness, and communication difficulties; parents confirm these concerns. Environmental stimulation, unfamiliarity with novel situations, and difficulty in communication skills are present and complicate care delivered in the office-based setting, as well as the acute care hospital setting. Additionally, HCP familiarity in working with children with ASD is identified and serves as a resource in improving the delivery and quality of the HCE in both acute and office-based settings.

Similar to the findings of Johnson and colleagues (2014), parents and providers do perceive some barriers differently in the office-based setting. Parents identify HCPs' lack of understanding of the

TABLE 3. Items identified as most useful items on the Quick Tips Card

Health care providers (48 responses)			Parent (47 responses)	
Item	No. of respondents*	%	Item mentioned as most useful	No. of comments†
What calms the child	42	88	The child's sensory needs	14
What upsets the child	41	85	What calms the child	12
The child's sensory dislikes	35	73	How the child communicates	11
How the child communicates	33	69	What upsets the child	8
What helps the child understand	30	63	What the child likes	8
What the child likes	28	58	How the child understands	7
What the child is afraid of	28	58	All sections are important	6
Caregiver requests	24	50		
Comments	4	8		

Respondents were able to choose more than one.
†Respondents may have provided more than one comment.*

impact of caring for a child with ASD as the biggest barrier during the HCE, whereas HCPs view child behavior and child uncooperativeness as most concerning. This mismatch of viewpoints is echoed in other differences in perceived barriers where parents identify more global concerns such as environmental issues, the fast-paced atmosphere, and the need for more case management and coordination of services. However, parents are acutely aware of the child's challenging behaviors and agree with HCPs that these behaviors are difficult and complicating aspects of the HCE.

About half of the HCPs surveyed admit they still have concerns related to their level of comfort in providing care for the child with ASD, similar to other findings in the literature (Minnes & Steiner, 2009; Weil & Inglehart, 2010). This decreased comfort level felt by HCPs may be felt by parents as they describe a lack of empathy in understanding the impact of autism globally for the family as their top barrier. The complexity and heterogeneity of the presentation and needs of children with ASD is likely the reason HCPs have lower comfort levels in providing care to this population. Consequently, both parents and providers have clearly identified parent-provider collaboration as a key resource during the HCE.

> …the use of patience in the approach to the child and slowing down the pace in delivering care are key strategies because they provide processing time for children with ASD.

Overall, important resources identified by both providers and parents primarily centered on the need to adapt or tailor care specifically to the child's needs; this finding is consistent with the literature for acute care settings (Davignon et al., 2014; Johnson & Rodriguez, 2013). However, adapting and tailoring care can be difficult because of the spectrum nature of autism. Each child not only presents very uniquely, each child's behaviors and reactions can differ from day to day, which further complicates delivery of health care services. Parents have been found to be the best resource in knowing how to approach their child given the situation. Additionally, the use of patience in the approach to the child and slowing down the pace in delivering care are key strategies because they provide processing time for children with ASD. Environmental adaptations (including reducing noise, bright lights, and wait times), the availability of communication tools, and the presence of sensory toys/fine-motor manipulative items also assist in providing care in the office-based setting.

Acceptability of the Tool

Overall, there were high rates of acceptability from both HCPs and parents with regard to the QTC. HCPs stated that they would respond favorably if a parent provided them with the card prior to an HCE, and parents expressed a high likelihood of using the card if it was available. Items on the card were also identified as useful and helpful by both groups. Parents provided comments on the card related to the card's ability to provide important and timely information about the child's mood and behaviors, while providers' comments identified the card as having useful information in tailoring their approach for the individual child.

Provision of the information contained in the QTC has the potential to reduce or prevent challenging and disruptive child behaviors that could complicate the HCE. Parents in this study identified the need for the HCP to adapt to the child and for adaptations of the office environment as the top two resources related to a positive HCE. The QTC provides the HCP with a tool and avenue to provide those adaptations. A tailored approach can improve the efficiency of the visit, improve the quality of the interaction, and improve parent, child, and provider satisfaction with the visit (Davignon et al., 2014). Access to this information prior to the health care visit may also increase the level of confidence of HCPs because it provides them with the information to have a successful and positive HCE with the child rather than one that is plagued with challenging and disruptive reactions. Parents may also develop increased comfort and confidence in their HCP as the provider uses the parent's input from the QTC. Providing an opportunity for parents to use this parent-driven tool empowers them to advocate for their child's psychosocial needs related to their health care. Additionally, the tool provides an avenue for family collaboration, which has been found to be beneficial in reducing challenging child behaviors in the health care setting (Johnson & Rodriguez, 2013).

An additional benefit of the QTC may be related to the length of the HCE. Reducing the barrier of challenging child behavior may result in increased quality of the HCE or attainment of the goal of addressing the child's health care concern. Both of these outcomes have the potential to reduce the number of health care visits, reduce overall health care costs, and improve satisfaction for the parent, which in turn translates into a better health outcome for the child. Lengthy HCEs result in increased health care costs or increased numbers of health care visits necessary to meet the child's needs (Liptak et al., 2006).

LIMITATIONS

This study has several limitations. First, the use of volunteer convenience samples from both HCPs and parents may not have provided a representative sample. Second, the use of local LISTSERV e-mails also may have

yielded a nonrepresentative sample, and the use of local samples limited the demographic information that could be obtained because of concerns about anonymity. Third, parent report of ASD diagnosis was used to determine eligibility. Finally, survey completion rates were slightly lower than what the literature revealed; the usual survey response rate for HCPs is between 20% and 60% (McLeod, Klabunde, Willis, & Stark, 2013).

Future research should include pilot programs or randomized controlled trials using the QTC to evaluate the effect of the QTC on health care outcomes. Evaluation should focus on both office implementation of using the QTC, as well as outcomes of QTC use on the quality of HCEs in the pediatric office-based setting. Implementation evaluation should examine whether HCPs actually read the card when it was used, because some parents in this sample who endorsed the QTC still expressed skepticism that providers would use the QTC even if it was available. The outcomes of QTC use on the quality of HCEs should be examined from the perspective of both patient/parent satisfaction and on practice efficiency. Efficiency analysis should track whether HCEs, when the QTC was used, were the length of time planned and whether HCEs still needed to be unexpectedly rescheduled.

CONCLUSION

Results of the surveys show that office-based barriers to care delivery for the children with ASD are similar to concerns cited in the literature for acute-care settings. These barriers include child behavior related to uncooperativeness and fears, child communication difficulties, environmental issues, and providers not fully understanding the impact of ASD on the child and family life. HCP and parent perceptions of resources that are important in positive health care experiences include collaboration/partnering with the parent, provider familiarity with ASD, making child-specific adaptations, and adapting the office environment. The acceptability of the QTC appears to be positive from the perspective of both the parent and the HCP. HCPs see the card as helpful, and even more helpful in situations in which the provider is less familiar with the child, and parents also see the card as helpful. Overall, both parents and providers find the information on the QTC to be usable and helpful and are amenable to using it.

HCP and parent perceptions of resources that are important in positive health care experiences include collaboration/partnering with the parent, provider familiarity with ASD, making child-specific adaptations, and adapting the office environment.

REFERENCES

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: American Psychiatric Association. revised.

Balakas, K., Gallaher, C. S., & Tilley, C. (2015). Optimizing perioperative care for children and adolescents with challenging behaviors. *MCN. The American Journal of Maternal Child Nursing, 40*(3), 153-159.

Bultas, M. W. (2012). The health care experiences of the preschool child with autism. *Journal of Pediatric Nursing, 27*(5), 460-470.

Davignon, M. N., Friedlaender, E., Cronholm, P. F., Paciotti, B., & Levy, S. E. (2014). Parent and provider perspectives on procedural care for children with autism spectrum disorders. *Journal of Developmental & Behavioral Pediatrics, 35*(3), 207-215.

Drake, J., Johnson, N., Stoneck, A. V., Martinez, D. M., & Massey, M. (2011). Evaluation of a coping kit for children with challenging behaviors in a pediatric hospital. *Pediatric Nursing, 38*(4), 215-221.

Gurney, J. G., McPheeters, M. L., & Davis, M. M. (2006). Parental report of health conditions and health care use among children with and without autism: National Survey of Children's Health. *Archives of Pediatrics & Adolescent Medicine, 160*(8), 825-830.

Hellings, J. A., Nickel, E. J., Weckbaugh, M., McCarter, K., Mosier, M., & Schroeder, S. R. (2005). The overt aggression scale for rating aggression in outpatient youth with autistic disorder: Preliminary findings. *The Journal of Neuropsychiatry and Clinical Neurosciences, 17*(1), 29-35.

Hofvander, B., Delorme, R., Chaste, P., Nydén, A., Wentz, E., Ståhlberg, O., … Gillberg, C. (2009). Psychiatric and psychosocial problems in adults with normal-intelligence autism spectrum disorders. *BMC Psychiatry, 9*(1), 35.

Johnson, N., Bekhet, A., Robinson, K., & Rodriguez, D. (2014). Attributed meanings and strategies to prevent challenging behaviors of hospitalized children with autism: Two perspectives. *Journal of Pediatric Health Care, 28*(5), 386-393.

Johnson, N., Bree, O., Lalley, E., Rettler, K., Grande, P., Gani, M., & Ahamed, S. (2014). Effect of an iPad application for medical imaging procedure preparation for children with autism spectrum disorder. *Journal of Pediatric Nursing, 29*(6), 651-659.

Johnson, N., & Rodriguez, D. (2013). Children with autism spectrum disorder at a pediatric hospital: A systematic review of the literature. *Pediatric Nursing, 39*(3), 131-141.

Johnson, N. L., Lashley, J., Stonek, A. V., & Bonjour, A. (2012). Children with developmental disabilities at a pediatric hospital: Staff education to prevent and manage challenging behaviors. *Journal of Pediatric Nursing, 27*(6), 742-749.

Koller, D., & Goldman, R. (2012). Distraction techniques for children undergoing procedures: A critical review of pediatric research. *Journal of Pediatric Nursing, 27*(6), 652-681.

Kopecky, K., Broder-Fingert, S., Iannuzzi, D., & Connors, S. (2013). The needs of hospitalized patients with autism spectrum disorders: A parent survey. *Clinical Pediatrics (Philadelphia), 52*(7), 652-660.

Liptak, G. S., Stuart, T., & Auinger, P. (2006). Health care utilization and expenditures for children with autism: Data from U.S. national samples. *Journal of Autism and Developmental Disorders, 36*(7), 871-879.

Lombroso, P. J., Ogren, M. P., Jones, W., & Klin, A. (2009). Heterogeneity and homogeneity across the autism spectrum: The role of development. *Journal of the American Academy of Child & Adolescent Psychiatry, 48*(5), 471-473.

Matson, J. (2009). Aggression and tantrums in children with autism: A review of behavioral treatments and maintaining variables.

Journal of Mental Health Research in Intellectual Disabilities, 2(3), 169-187.
Mayes, S. D., Calhoun, S. L., Aggarwal, R., Baker, C., Mathapati, S., Anderson, R., & Petersen, C. (2012). Explosive, oppositional, and aggressive behavior in children with autism compared to other clinical disorders and typical children. *Research in Autism Spectrum Disorders, 6*(1), 1-10.
McLeod, C. C., Klabunde, C. N., Willis, G. B., & Stark, D. (2013). Health care provider surveys in the United States, 2000–2010: A review. *Evaluation & the Health Professions, 36*(1), 106-126.
Minnes, P., & Steiner, K. (2009). Parent views on enhancing the quality of health care for their children with fragile X syndrome, autism or Down syndrome. *Child: Care, Health and Development, 35*(2), 250-256.
Pondé, M. P., Novaes, C. M., & Losapio, M. F. (2010). Frequency of symptoms of attention deficit and hyperactivity disorder in autistic children. *Arquivos de Neuro-Psiquiatria, 68*(1), 103-106.
Rhoades, R. A., Scarpa, A., & Salley, B. (2007). The importance of physician knowledge of autism spectrum disorder: Results of a parent survey. *BMC Pediatrics, 7*, 37.
Sandelowski, M. (2000). Focus on research methods: Whatever happened to qualitative description? *Research in Nursing and Health, 23*(4), 334-340.
Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research in Nursing and Health, 33*(1), 77-84.
Scarpinato, N., Bradley, J., Kurbjun, K., Bateman, X., Holtzer, B., & Ely, B. (2010). Caring for the child with an autism spectrum disorder in the acute care setting. *Journal for Specialists in Pediatric Nursing, 15*(3), 244-254.
Weil, T. N., & Inglehart, M. R. (2010). Dental education and dentists' attitudes and behavior concerning patients with autism. *Journal of Dental Education, 74*(12), 1294-1307.
Wingate, M., Kirby, R. S., Pettygrove, S., Cunniff, C., Schulz, E., Ghosh, T., … Constantino, J. (2014). Prevalence of autism spectrum disorder among children aged 8 years-autism and developmental disabilities monitoring network, 11 sites, United States, 2010. *MMWR Surveillance Summaries, 63*(2), 1-21.
Zuckerman, K. E., Lindly, O. J., Bethell, C. D., & Kuhlthau, K. (2014). Family impacts among children with autism spectrum disorder: The role of health care quality. *Academic Pediatrics, 14*(4), 398-407.

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