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Attributed Meanings and Strategies to Prevent Challenging Behaviors of Hospitalized Children with Autism: Two Perspectives

Norah L. Johnson PhD, RN, CPNP
Marquette University, norah.johnson@marquette.edu

Abir K. Bekhet
Marquette University, abir.bekhet@marquette.edu

Karen Marie Robinson
Marquette University

Dana Rodriguez
Marquette University, dana.rodriguez@marquette.edu

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Norah L. Johnson
Marquette University College of Nursing, Milwaukee, WI
Abir Bekhet
Marquette University College of Nursing, Milwaukee, WI
Karen Robinson
Marquette University College of Nursing, Milwaukee, WI
Dana Rodriguez
Marquette University College of Nursing, Milwaukee, WI

Abstract

Introduction

Understanding is limited of the meaning attributed to behaviors of children with autism spectrum disorder and strategies used to prevent challenging behaviors in the context of hospitalization.

Methods

This qualitative study consisted of two focus groups (*n* = 10; five mothers and five health care providers [HCPs]). Transcripts were analyzed using the qualitative method of narrative inquiry.

Results

The meaning attributed to behaviors by the mothers and the HCPs differed. The mothers attributed behaviors to the child's communication of frustration, hyperactivity, and self-calming. The HCPs attributed challenging behaviors to self-stimulation and child aggression. Strategies to prevent behaviors also differed. Mothers focused on preparation prior to hospitalization and attempts to partner with HCPs. HCPs identified fewer strategies and consulted mothers for strategies to manage challenging behaviors.

Discussion

HCP and parent collaboration could lead to strategies to increase supports for children with autism spectrum disorder in the hospital to decrease their frustration and challenging behaviors.

Key Words

Autism, challenging behaviors, focus groups

Autism spectrum disorders (ASDs) are neurodevelopmental impairments of communication, socialization, and repetitive behaviors with severity ranging from mild to severe (American Psychiatric Association, 2013). The prevalence of ASD is approximately 1 per 88 children in the United States (around 1% of the population; Centers for Disease Control and Prevention, 2012). Approximately 82% of children with ASD have co-existing developmental disorders (e.g., language disorders, attention deficit–hyperactivity disorder [ADHD], and intellectual and/or sensory integration disorders), and approximately 10% have a diagnosed co-existing psychiatric disorder (e.g., anxiety, obsessive-compulsive disorder, and/or oppositional defiant disorder; Levy et al., 2010) that affects their behavior.

A literature review demonstrated no research study on the meaning attributed to behaviors of children with ASD in the hospital setting from the parent's perspective. One qualitative study reported on the experience of parents of preschool children with health care in general, discerning two themes for mothers about the health care providers (HCPs): (1) “They just don't get it” and (2) “marginalized by those who should care the most” (Bultas, 2012). Few studies reported on the HCPs' perspectives of child behaviors (Lowe et al., 2007, Lubisch et al., 2009, Searcy, 2001, Souders et al., 2002). Only one study combined the perspectives of the parents and HCPs, but that study described children with ASD in the community and was related to setting up a medical home for the child with ASD (Carbone, Behl, Azor, & Murphy, 2010). The purpose of this study was to describe the meaning attributed to

challenging behaviors of hospitalized children with ASD and the prevention strategies used by parents and HCPs.

Methods

Participants

The study included two small focus groups (parents and HCPs). The parent group was composed of English-speaking biological parents or guardians of a child with diagnosed ASD who was hospitalized in the past 12 months. The HCP group included a registered nurse, advanced practice nurse, occupational therapist, child life specialist, and computed tomography scan technologist who cared for a hospitalized child with ASD in the past 12 months. The group size was intentionally small to facilitate in-depth discussion of the meanings attributed to child behaviors.

Procedure

Institutional Research Board approval was obtained from both the University and a Midwestern pediatric hospital. Institutional Research Board–approved flyers were distributed in the hospital clinics and via the hospital intranet, autism society newsletter, e-mail, and ASD-focused listservs. The participants contacted the principal investigator (PI) directly by e-mail or telephone (contact information was provided in the flyer) to register for a focus group, and a mutually agreeable time for the focus group was selected. Each focus group was held in a private hospital conference room. At the focus group session, the participants read and signed the study consent and filled out a demographic questionnaire. The PI led the focus groups, using a question guide (Box). Participants were asked open-ended prompts and follow-up questions for clarification or elaboration throughout the process. A co-investigator attended the focus groups, which were audio recorded. The tapes were professionally transcribed into a Microsoft Word document. Each of the five mothers who participated in the focus groups received a $25 gift card to thank them for their time. HCPs did not receive incentives.

Box
Focus group question guide

A. Parents
    1. What was the behavior pattern of your child before you went to the hospital?
    2. What was the behavior pattern of your child in the hospital?
    3. What was the behavior pattern of your child once you returned home?
    4. What strategies did you use before the child came to the hospital?
    5. What strategies did you use when the child was in the hospital?
    6. What strategies did you use once the child returned home?
B. Health care providers
    1. What was the behavior pattern of the child in the hospital?
    2. What strategies did you use before the child came to the health care setting?
    3. What strategies did you use when the child was in the health care setting?

Data Analysis

Focus group tapes were transcribed verbatim and analyzed with narrative methodology. Narratives capture human motivation or why people behave as they do (Holloway & Freshwater, 2007). The PI and the co-investigators used thematic analysis to study the themes across cases (Kohler-Riessman, 2008). Thematic analysis involves a process of reading the transcripts and discerning themes in each

case, then re-reading the transcripts to identify similar themes across cases (Holloway & Freshwater, 2007). The researchers read for themes representing the meanings the participants attributed to the behaviors of the children. The process of sharing stories in the small groups facilitated the participants' ability to give meaning to the experiences.

The PI and three co-investigators individually performed data analysis of the transcribed narratives, highlighting text in the typed transcript, labeling common words and phrases, and discerning the themes and subthemes. Next, the four researchers met in person and compared the interpretations of the transcriptions. They discussed the initial differences, the rationale, and the supporting quotations from the transcriptions until they reached consensus on the themes and subthemes from the narratives as an iterative process.

Results

Demographics

The study demographics are presented in the Table. Each focus group had five participants. The children with ASD ranged from 5 to 12 years of age. All the HCPs in the focus group had hospital-provided training on working with children with developmental disabilities within the past 2 years. No fathers or physicians volunteered to be a part of the study.

Table. Demographics

	Parent *N* (%)	**Health Care Provider *N* (%)**
Gender		
Female	5 (100)	5 (100)
Age (years)		
21-30	0	2 (40)
31-40	3 (60)	2 (40)
41-50	2 (40)	0
>50	0	1 (20)
Race		
White	4 (80)	5 (100)
African American	1 (20)	0
Age of child (years)		
All ages (3-18)	0	3 (60)
3-5	3 (60)	1 (20)
6-11	0	1 (20)
11-12	2 (40)	0
Diagnosis of child		
Autism	3 (60)	
PDD-NOS	2 (40)	
Highest degree		
High school	1 (20)	0
Associate's	2 (40)	1 (20)
Bachelor's	2 (40)	2 (40)
Master's	0	2 (40)
Unit work on		
Neuroscience	N/A	1 RN (20)

Medical floor		1 RN, 1 CLS (40)
Clinics—OT		1 (20)
CT scan Technologist		1 (20)
Years experience		
5-10	N/A	3 (60)
>10		2 (40)

Note. CLS = Child life specialist; CT = computed tomography; N/A = not applicable; OT = occupational therapy; PDD-NOS = pervasive developmental disorder not otherwise specified; RN = registered nurse.

Themes of Meaning Attributed to Behaviors as Described by Mothers

The following three themes regarding the meaning attributed to the child's behaviors emerged from the mothers' narratives: communication of frustration, hyperactivity, and self-calming.

Communication of frustration

Four mothers described their children as being frustrated by their lack of ability to communicate their feelings in association with the demands of others: (1) “She does get really frustrated because she is nonverbal. She will exhibit behaviors like hitting her head, or throwing something if she's mad, or, to show her frustration…She gets very frustrated with people in general if they put demands on her.” (2) “When he expresses frustration, it would be the typical, you know, yelling or throwing himself down, crying, those types of things.” (3) “When he does not understand what's going on…he’ll communicate it through things like screaming, or other sorts of loud vocalizations, throwing things, throwing a pencil on the ground, kicking people and objects.” (4) “There's been much more sort of expressive burnout, frustration, you know, that he's shared with us.” She further explained how her child expressed frustration as follows: “He’ll sort of try and button his pants and he can't do it, and all of a sudden he’ll drop to the ground and start, you know, crying and screaming and whatnot.”

Hyperactivity

Three mothers described their children as hyperactive: (1) “She's a fast mover, so her pace can be very high”; (2) “Very active, bouncy, all over the place”; and (3) “ Very active, swinging, riding, hiking, running. He's a very, very busy guy.” One mother reported that although her child was not diagnosed with ADHD because he had not been screened for it, she believed he might meet the clinical definition for ADHD: “I am sure that if we had him evaluated, he would meet the clinical definition of ADHD or at least hyperactivity.” The mother attributes the hyperactivity to an undiagnosed condition rather than willful defiance. One mother perceived that her child's hyperactivity was intensified in the hospital environment when compared with their home environment:

“The behaviors that we see with our son are mostly the same behaviors that we see at home but they’re just increased here because the intensity has increased and usually the supports go down…so if he's hyperactive at home, he's really mobile and hyperactive and distracted here. If he has a hard time waiting at home, his ability to wait is significantly less here.”

The meaning of the hyperactivity for this mother was that it is the child's natural response to the increased activity in the environment. After hospitalization, one mother reported: “We do see behavioral sort of carryover sometimes for days after…and he was especially hyperactive, and he had a really hard time focusing when he went back to school.”

Self-calming behaviors that help children deal with their stress were identified in the transcripts as stereotypical behaviors and attention seeking.

Self-calming

Self-calming behaviors that help children deal with their stress were identified in the transcripts as stereotypical behaviors and attention seeking. One mother described her son's stereotypic behavior as follows: “He has lots of anxiety as well, almost compulsive behaviors of, you know, tidying things up, closing drawers, you know, things like that. He's into the typical Thomas the Train puzzles, watching videos, rewinding videos, (and) replaying a stage or an activity scene.”

Another mother described her child's compulsive behavior as: “He kind of lines up things still, not as bad as he used to, but all his ‘Thomas the Trains,’ you know, we have the whole big line in the living room.” A third mother commented on the child's compulsive behavior by sharing the following example: “He lines up little cars, big cars. And then he has a shopping cart that he likes to (use to) collect things.” When the child is in the hospital, these self-calming activities are not available or are less available.

One mother explained that her children calmed themselves by seeking another person's attention as follows: “When he wants your attention, you know, he’ll get in your face and he’ll squeak, or he’ll like grab your face, and then he's smiling the whole time, and then he starts laughing, giggling, and it gets really over the top.” Another example provided by a mother was: “A lot of his problem behaviors are motivated by sort of attention seeking.” Thus one would expect that as frustration and anxiety increase, these behaviors increase.

Themes of Strategies as Described by Mothers

Five themes of strategies emerged from the mothers' narratives. The themes include advanced preparation, structured activities, rewards and reinforcement, distraction, and parent engagement.

Advanced preparation

Advanced preparation involves explaining to the child what the experience will entail. One mother stated, “If there's not advanced preparation or if we have to, on the spot, break it to him that, no, there's somebody else you have to see, every point is a trigger point for a massive meltdown and just like protest, I am not doing this any more.”

One mother described a common strategy:

“So one of the strategies that we use, which I think is probably very common around the table, is a lot of social stories and working very intentionally with our son in advance of the doctors' visits to prepare him for what's going to happen so that he knows, there's going to be five doctors and there may be waits, and so on and so forth.”

Another mother shared that new technology assists with the preparation: “With all the technology now, it's becoming really easy, like with the iPhone, we take a picture of the doctor, oh, we’re going to see doctor so and so.” Two mothers reported they contacted the hospital in advance of hospitalization: (1) “I’ve called into the clinic or to the doctor and said, listen, I just want to tell you, I'm coming with a

special needs kid and I'd like to do some advanced preparation." (2) "Being able to talk to the doctors about how you want this to go prior to (a procedure)."

Structured activities

Structuring activities involves breaking an activity into parts: "We also work real hard to break down tasks for him, and really give him a sense of, okay, you have to do this, but then we break it down to five small steps. We're just going to go see the doctor, we're going to do this, we're going to do that." Another mother stated:

"He tends to do best with well-practiced activities and activities that he does within the context of a structure and with people and an environment that he's familiar with. When he doesn't have that, when it's not a practiced skill or he's not given that structure, and/or he doesn't understand what's going on, then we will see a spike in sort of negative behavioral issues."

Three mothers echoed her sentiments. The first stated, "And so we try and provide that structure using strategies like other people mentioned, visual schedules and whatnot." The second mother shared her experience with advanced preparation:

"Being able to talk your child through the steps, like you said, through a white board or, for my child who's nonverbal, being able to write it out for him so he can see exactly what's going to happen, we're going to have to drink something before we can leave, we need to do this."

The third mother paired verbal choices with visuals: "We give her choices either by written paper or we use the picture exchange that's down with the little pictures on it so she can actually have a visual too and the auditory. And that's been really helpful in having her understand what we're doing." The mother also advocates for the first appointment of the day to decrease child anxiety of having to wait, and potentially challenging behaviors: " Being the first appointment…we found that that's really, really helpful in decreasing a lot of anxiety."

Rewards and reinforcement

One mother finds it helpful to reward her child along the way to the completion of a task: "Break it down to five small steps and provide frequent rewards or reinforcement as he completes each of those steps" and provide reassurance; for example, "It's going to be fine." Another example of reinforcement was provided by the mother of a nonverbal girl with ASD, who uses positive language: "As we spoke to her, and tried to teach…that whole sense of pride and her feeling of accomplishment, and who she was, flourished." This mother also encourages other mothers to use reinforcement: "Don't be embarrassed. Don't talk down to child. Be respectful."

Distraction

Mothers reported that it was important to keep the child busy with distracting activities and items: "Electronic devices that can occupy our kids" and "the iPad and the coloring books, and now they have child life specialists that can give our kids a lot of things." One mother stated, "Working with her hands, we found that that's really, really helpful in decreasing a lot of anxiety." Another mother also commented about the usefulness of distraction with "manipulatives." These are small toys made of stretchy plastic. The mother stated:

“They could have a bag of little tricks, like a coloring book or puzzles and little manipulatives to keep your child occupied, number one. Which is what we’ve used for the horrendous amount of visits we’ve done at the hospital.”

Along with distracting items, mothers reported about distracting techniques: “Ah huh. Counting is really calming, especially if you have a really calm voice ” and “We don't wait in that room because being confined for too long makes both me and my son batty. So we usually walk around, do laps. And so that's one strategy.”

Parent engagement

Individual assessment of a child's behavior triggers can be obtained from one-to-one engagement between the HCP and the parent: “I could talk about strategies, but I think more to the point is one should be cautious of one-size-fits-all strategies.” One mother was able to go back into the operating room and assist with the induction of the anesthesia, which is not the normal protocol.

“She essentially allowed me to hold the mask and put the mask on. I sat on the bed with him and supported him. So direct engagement of the primary caregiver and involvement, and having the medical staff stay back was a really great strategy for my son, and we had a great experience when I was allowed to do that versus when I wasn't.”

One example out of the mothers' transcripts related to a child with ASD who perseverates on items and that may make it difficult to complete the physical examination.

“So there's often a real struggle for us around having my son stay in one place and be still enough for the doctor to examine him. And often the doctor's response has been to say oh, sure, you can play with this button and you can press that one, not understanding that pressing one, you can't stop it at one.”

This mother described that she is not always asked about her strategies for her child:

“But when we’re not listened to and think some of these ideas, well that's ridiculous, you know, and they might even, not even say that but it's their demeanor or the way that they speak to you or not speak to you, however, or not accommodate to you, makes you feel like really, are you just saying that I'm part of the team or am I really part of the team.”

The mothers also commented on the importance of remaining calm:

> Mother 1: “Well, our kids really pick up on our demeanor and our anxiety.”
> Mother 2: “Sure.”
> Mother 3: “Ah huh.”
> Mother 1: “And our calmness and whatever you have. So, yeah, that happens in my household quite often. I'm trying to get everyone to level ground. Like, hey, dad, cool it. [Laughter] Because everyone else is going to start escalating, you know. I guess is another way to describe it.”

Themes of Meaning Attributed to Behaviors as Described by HCPs

Two themes emerged from the HCP perspective regarding the meaning of the behaviors of children with ASD in the hospital setting: self-stimulatory behaviors and behaviors of aggression.

Self-stimulatory behavior

Self-stimulatory behaviors are stereotyped, repetitive movements that serve a particular purpose for children with ASD in terms of helping the children deal with their stress and anxiety. An HCP shared her experience of the meaning attributed to dealing with a child with ASD as follows: “Anxious-type behaviors…self-stimulatory behaviors…and any sort of stereotypic behaviors they may rely upon.” She elaborated on those behaviors as follows: “So some kids do hand flapping, some tend to clench their fists, or rock, or constantly be in motion, and kind of appear to be agitated.” Another description of a self-stimulatory behavior was “a lot of rocking.”

HCPs pointed out that the self-stimulatory behaviors were exacerbated when children were asked to comply with instructions to complete procedures. An example from the HCP transcript was: “A lot of repeating words like no picture, no picture, no picture, you know, just saying it, repeating it over and over. Go home.”

Aggression

HCPs described behaviors of acting out as being aggressive. Three subthemes have been identified: attention seeking, self-injury, and injury to others.

In terms of the subtheme of attention seeking, one HCP attributed the aggressive behavior to the child's desire to get attention. “If the child becomes aggressive…pinching of parents, really strong grasps on a parent's hand that is, you know, intended to be, to get a reaction. Not necessarily intended to be painful but intended to get more of a reaction.”

Regarding the self-injury and injury to others subthemes, another HCP described her interaction with a child with ASD as follows: “He was acting out very violently, kicking, spitting.” Others attributed the severity of the behaviors as being related to the child's level of functioning. Another elaboration of the HCP experience of caring for children with self-injurious behaviors was: “I see a lot of kids who have calluses on their fingers and hands from biting, they do a lot of hand biting sort of behaviors” and “head banging, hitting their own head against a hard object or the back of the bed; or picking, a lot of picking at scabs or lines in some cases.”

HCPs noted that the severity of the child's aggressive behaviors might be related to the severity of the child's ASD. The HCPs noted a variety of behavior presentation among children depending on their level of functioning. With a wide variety in functioning, one HCP described her inability to predict a child's triggers for their challenging behaviors.

“Sometimes you hear a child has autism and it's really hard to know what to expect when he or she walks in the room. Some kids are going to come in and be nonverbal, doing lots of self-stiming, self-interest behaviors, you know, with a high risk of behavioral outbursts; and then some, you probably would never have even guessed that they had autism when they come in.”

These behaviors might affect the child's ability to cooperate in terms of holding still and completing procedures such as medical imaging. One HCP stated, “The more autistic the child is, the more their behavior, the more agitated they are at what's going on in their room.”

Themes of Strategies as Described by HCPs

The following five themes of strategies as described by HCPs emerged from analysis of the transcripts: child preparation, rewards and reinforcement, distraction, partner with parents, and decreasing environment stimulation.

Child preparation

The first theme out of the HCP's transcripts about the strategies they use for preventing challenging behaviors for a hospitalized child with ASD was child preparation. One HCP explained that she talks to the child ahead of time to tell him or her what she will be doing: “First we’re going to, then we’re going to, to prepare the child.” The HCP also prepares a child for transitions from one task to another, which can be difficult for children with ASD: “And then I also make sure to use cues for transitions. So, in 2 minutes we’re going to, in 1 minute we’re going to, in 30 seconds, and count it down that way.” One HCP referred to preparation as “foreshadowing”: “ But I see it as very successful and I guess I overemphasize it a little bit with children with autism, is the foreshadowing.” Furthermore, the HCP explained that the foreshadowing was a strategy to prevent challenging behaviors in the children. “So prevention of the behaviors, again I really try and do as much foreshadowing so that I can do the things I need to get done, but then also staying cued into the patient and watching his or her behaviors.”

Rewards and reinforcement

The second theme from the HCP's perspective on preventing challenging behaviors was using “rewards and reinforcement.” One HCP reported their process, criteria, and time frame for offering rewards to the child: “We (HCPs) had certain identifiable behaviors that we documented per shift, so at the end of each shift a nurse would evaluate how well he did that shift and rewarded him.” Another HCP stated in a more general way that she provides reinforcement, in the form of praise: “I'm giving a lot of praise to the child. I find that it helps them sort of process the situation and transition.” The verbal praise is thought to help the child be able to calmly transition from one activity to another, which is a time when some children with ASD are more prone to being frustrated and act out.

Distraction

The third theme from the perspective of the HCP for preventing a child's challenging behaviors was using “distraction” to help calm the child: “The children that I’ve worked with have been able to engage in distraction play prior to the procedure, so they’ve stayed calm, they’ve stayed engaged in play.” The HCP commented that the child was able to complete the procedure: “Afterwards we’re able to re-engage in play almost immediately after.”

Sensory toys (sturdy plastic items that can be chewed) may be used to distract children for medical procedures to gain their compliance, because these items are typically appealing and commonly used with children with ASD during applied behavior analysis therapy.

“I utilized some specific sensory toys from a coping kit that we have at the hospital that I knew the children were familiar with. The parents had stated, oh, this is a toy they use in therapy; they’re really

familiar with it. So it gave them kind of what I perceived as a sense of safety with items that they're used to manipulating and playing with."

Partner with parents

The fourth theme discerned from the HCP transcripts was to partner with parents. HCPs voiced that they would like to talk to parents before caring for the child but are not always able to. One HCP stated, "Working through the parents, if they're available." A parent may be asked to bring in familiar items from home that help the child cope with being in the health care setting: "Bring their favorite movie, do they have a toy that they like to hang on to." Children tend to feel more comfortable with their familiar toys and also when their parent is close by: "Sometimes they (child) want mom to sit down on the scanner table with them. Anything that's familiar we'll let them try." Another HCP shared that she looks to the parent first to talk to the child: " I tend to allow the parents to lead any sort of interaction that I need to do with the child." Another HCP partnered with a parent of a child with ASD: "I often begin with a parent interview and then ask that the parents primarily interact with the child, especially if the child has low social functioning." Yet another HCP shared the specific questions she asks that parent:

"I always defer to the parents, who are the experts, what works well, does the child like to be prepared prior to the procedure, what helps with distraction, what's overstimulating."

Reduce environment stimulation

The fifth theme for preventing the child's challenging behaviors from the HCP transcripts is to "reduce environment stimulation." Strategies include, "We try to keep the number of people in the room less as well. Like, we usually, we have two techs in the room to try and help and with this we'll just try to keep one tech in the room" and "We try to keep the lights dim, or we'll ask the parents." One HCP noted that when child behavior escalates, she reduces stimulation as a strategy to prevent further escalation of behavior.

"Watching their (child) behaviors, you know, the self-stiming is fine, but if it goes from hand flapping to self-injurious behaviors and that's a change, well then that's when you realize, well, the patient may be escalating. So those are some of the cues I try to look for so that when they happen I can sort of back off in my activity and hopefully prevent the behavior outburst. "

Another HCP agreed that she steps away from a child with escalating behavior:

"I'm thinking of in a procedure if a child is starting to be overstimulated or lashing out, behavioral outburst, I step back. I'm there for distraction and if that's not being successful, and I'm just another person overstimulating. When an outburst does happen, I mean I think the major goal is to keep everyone as safe as possible, including the patient, including the family, including the staff members."

Discussion

The study reported here is the first to describe both the meaning attributed to the behaviors of children with ASD in the context of hospitalization by mothers and HCPs along with prevention strategies. Mothers described more intense child behaviors in the hospital setting as a result of environmental triggers, underlying co-morbid hyperactivity (Levy et al., 2010), and the usual supports

(e.g., toys and routines) not being in place. This finding matches literature that reports that triggers in the hospital environment frustrate children with ASD (Scarpinato et al., 2010).

Likewise, all the HCPs in the study noted challenging behaviors of children with ASD in the hospital environment, but the HCPs attributed different meaning to the behaviors, with no HCPs using the term “communication of frustration” for the meaning of the child's behavior. HCPs attribute the intensity of behaviors to the severity of the ASD, that is, the level of the child's social and communicative functioning, with the children functioning at a higher level (i.e., those who can communicate) doing better in the stimulating hospital environment than children who cannot communicate.

Strategies to prevent challenging child behaviors differed between mothers and HCPs. The meaning that the mothers and the HCPs attributed to the behaviors informed their strategies. Understanding the meanings leads to a better chance of finding a way to intervene effectively to prevent challenging behaviors of children with ASD in the health care setting. An effective intervention involves the process of arriving at a shared definition of the situation and of shared roles of the mother and the HCP.

Comparing the strategy themes reveals that the mothers did more advanced preparation individualized to the child and ongoing structured activities with their child than did the HCPs. This finding matches research by Souders et al. (2002), who also described individualized strategies used by nurses to prepare children with ASD for procedure preparation. HCPs talked about decreasing stimulation in the health care setting environment, but mothers did not talk about the environment as a problem. Instead, mothers used a strategy of staying calm, which they understood was helpful for decreasing their child's anxiety (noted in the parent engagement theme).

Mothers reported other strategies for preventing challenging behaviors by structuring activities and using technology to prepare their child for health care visits. For example, mothers showed their child photos of the HCP who the child would be seeing and used social scripts to model the steps of a health care procedure. These strategies prepare the child for the environmental stimulation, such as loud sounds and unfamiliar people. Structured preparation books may include affirmation and scripting for the child to respond with words or counting instead of challenging behaviors when overstimulated (Gray, 2010, Scarpinato et al., 2010).

> Whereas both mothers and HCPs report that they use rewards and reinforcement to prevent the child's challenging behaviors, there were differences in the timing of the rewards.

Whereas both mothers and HCPs report that they use rewards and reinforcement to prevent the child's challenging behaviors, there were differences in the timing of the rewards. Mothers were more successful with rewarding the child for steps of the structured activity along the way, whereas one HCP was less successful at preventing behaviors when rewarding the child at the end of a shift.

Mother-HCP partnering strategies also differed. HCPs in this focus group gave permission for the mothers to participate in the tasks of health care. For example, one mother talked about being “allowed” to hold her son's mask during induction of anesthesia, and another mother spoke of an HCP that “let” her child touch a button. From the HCP narratives, one HCP mentioned “letting” the mother try sitting with her son on the scanner and another “allowed” the parents to lead interaction with the child. Thus an opportunity exists for better perception of partnership.

Only HCPs talked about a strategy for managing behavior outbursts after overstimulation. HCPs step away and defer to the parents when these behaviors happen; however, mothers' narratives point to mothers looking to be partners in care earlier in the health care encounter time frame, before the challenging behavior happens.

The different perspectives in the present study can inform nursing interventions to prevent challenging behaviors of children with ASD in the hospital. Study limitations include the small sample size, ASD diagnosis by maternal report rather than being verified for the study, and the lack of fathers or physicians in the study. Future research should include fathers and physicians to represent the parental and HCP perspective and test interventions to decrease challenging behaviors for children with ASD.

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