

A balancing act: An interpretive description of healthcare providers' and families' perspective on the surgical experiences of children with autism spectrum disorder

Autism
2022, Vol. 26(4) 839–848
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DOI: 10.1177/13623613211034057
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Abstract

Children with an autism spectrum disorder (autism) are vulnerable to negative experiences within the surgical setting. This qualitative study used Interpretive Description. Individual interviews were conducted with 8 parents of children with autism who had recently undergone surgery, and 15 healthcare providers (HCPs) with experience caring for children with autism. Participants were asked open-ended questions on the approaches used to support children with autism around the time of surgery and their effectiveness, how the surgical experience could be improved, and the barriers and facilitators to potential improvements. Results yielded three main themes within an overarching metaphor of a balancing act. The first theme, *finding your footing through an uncertain journey*, described individual factors (e.g. anticipatory anxiety) that set the foundation for surgery-related experiences. The second theme, *relationships can help to keep everyone steady*, highlighted how interpersonal dynamics (e.g. collaboration and empathy) influence the experience. Finally, the *systems shape the experience* theme captured the impact of systemic factors (e.g. the hospital environment) on the balancing act. These findings enriched our understanding of how individual, interpersonal, and systemic factors influence the surgical experiences of children with autism, families, and HCPs. Insights gained from this study can be used to inform future interventions.

Lay abstract

Children with an autism spectrum disorder (autism) often have negative experiences within the surgical setting. We conducted individual interviews with 8 parents of children with autism who had recently undergone surgery, and 15 healthcare providers (HCPs) with experience caring for children with autism. We asked open-ended questions on the approaches used to support children with autism around the time of surgery, how effective they were, suggestions for improvement, and the barriers and facilitators to improvement. Three main themes emerged within an overarching metaphor of a *balancing act*. The first theme, *finding your footing through an uncertain journey*, described individual factors (e.g. anticipatory anxiety) that set the foundation for experiences. The second theme, *relationships can help to keep everyone steady*, highlighted how personal interactions (e.g. collaboration and empathy) influence the experience. Finally, the *systems shape the experience* theme captured how systemic factors (e.g. the hospital environment) affected the *balancing act*. These findings enriched our understanding of the surgical experiences of children with autism, families, and HCPs by demonstrating the importance of individual characteristics, relationships, and systemic factors. Future interventions should consider this complexity and intervene not just with children, but also their parents, healthcare providers, and in policy to improve experiences.

Keywords

autism spectrum disorders, family functioning and support, health services, pre-school children, qualitative research, school-age children

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Introduction

Children with autism spectrum disorder (hereafter, autism) are susceptible to the full range of childhood medical conditions that may necessitate surgical intervention, such as tonsillitis, ear infections, and appendicitis. Children with autism may also require general anesthesia to complete routine medical and dental procedures, such as blood work, imaging, and dental cleaning (van der Walt & Moran, 2001). As a result, the proportion of children with autism accessing surgical services may be greater than expected based on autism prevalence rates (approximately 1.5% of children; Baio, 2014; Public Health Agency of Canada, 2018). For example, one study reported that children with autism were 10% of consecutive pediatric perioperative cases who were administered general anesthesia for dental rehabilitation between 2006 and 2011 (Arnold et al., 2015). Although specific rates at which children with autism access surgical services will fluctuate based on institutional mandates and resources, healthcare providers (HCPs) involved in delivering pediatric surgical services will inevitably encounter children with autism.

Children with autism may be an especially vulnerable group around the time of surgery (Koski et al., 2016; Taghizadeh et al., 2015). The surgical process, which entails fast-paced interactions, varied personnel, an unpredictable setting, bright lights, and novel sounds, may be especially challenging given the core symptomatology (e.g. social-communicative difficulties, preferences for routines, sensory sensitivities) and increased rates of trait anxiety in children with autism. Distress and potential corresponding behaviors (e.g. non-compliance, aggression or self-injury) in children with autism can be difficult to prevent or reduce, and may lead to the use of medical and/or physical restraints or costly last-minute decisions to forego surgery (Lewis et al., 2007; Nelson & Amplo, 2009). Witnessing and managing these children's behavioral expressions of distress can also be upsetting for families and HCPs and may compromise safety for all involved.

Published literature about caring for children with autism around the time of surgery includes clinical commentaries (e.g. Nelson & Amplo, 2009; Taghizadeh et al., 2015) and consensus-based guidelines (Gimpler Berglund et al., 2016, 2017). Common recommendations include consulting with parents to individualize care, adapting the environment (e.g. limiting exposure to stimulation, such as lights, noises, and smells), using simple concrete language, minimizing the number of interactions in which children with autism are expected to engage, designating a familiar person to accompany the child throughout the surgery, and preparing the child for surgery (e.g. through familiarization by rehearsal with pictures of or experiences with the locations and/or steps involved, and using sedative medication as appropriate). This literature offers an important starting point, but recommendations rely on HCPs' perspectives and miss important contributions

from families receiving care. Moreover, the literature currently lacks a comprehensive description of the experiential context within which proposed recommendations are to be implemented. Although commentaries hint that the perioperative experience is difficult for everyone involved, recommendations have focused largely on procedural strategies to mitigate children's distress without consideration of the importance of addressing the subjective experiences of HCPs and families.

The purpose of this study was to address these gaps in the literature by exploring the perspectives of parents and HCPs in relation to surgery for children with autism. Our research questions were: What do HCPs and families experience when supporting children with autism through the surgical course, and what are their perspectives on factors that shape these experiences? Understanding the experiences of HCPs and families may help to identify barriers to care within the surgical setting and facilitators that may ease the surgical process, advance the literature by identifying intervention targets important to HCPs and families, and, ultimately, improve care for children with autism.

Method

Participants

Participants included both parents/guardians (hereafter, parents) and HCPs.

Parent participants. Parent participants had a 3- to 18-year-old with autism who had undergone ambulatory surgery at a Canadian pediatric tertiary care hospital (serving a population of almost 2 million) between 2012 and 2014. Parents were ineligible if their children had a co-morbid genetic syndrome (e.g. CHARGE, Fragile X). Parent ratings on the Autism Spectrum Rating Scale (ASRS; Goldstein & Naglieri, 2009) corroborated their children's ASD diagnoses. Adaptive Behavior Assessment System—Second edition (ABAS-II; Harrison & Oakland, 2003) ratings indicated that 7 children had overall skills in the *extremely low* range, whereas one child's adaptive skills were *below average*.

Parent participants were 8 mothers (aged 28 to 67 years ($M=42$, $SD=13$)) of children with autism (3 females, 5 males, aged 4–16 years). All families had two parents (7 were biological parents); 6 of the households included between 1 and 3 children in addition to the focus child with autism. Household incomes ranged from \$41,000 to more than \$100,000 (CAD). Children's most recent surgical procedures were dental ($n=5$), orthopedic ($n=1$), urological ($n=1$), or otorhinolaryngological ($n=1$). Several had multiple procedures completed while under anesthesia (e.g. blood work, dental care). Four children had undergone anesthesia at least once before their most recent experience. Rating how well their children handled previous medical visits, 4 parents endorsed *average*, 3 *poorly*, and 1 *very poorly*.

HCP participants. Dentists, physicians, surgeons, registered nurses, or licensed practical nurses were eligible to participate if they were working within the surgical service, had been in their current role for at least 1 year, and had cared for at least two children with autism. Fifteen HCPs were interviewed (7 nurses, 5 pediatric physician specialists, and 3 pediatric dentists; 10 females, 5 males, age range 33 to 60 years ($M=45$ years, $SD=9$ years)). HCPs had worked in their professions for a median of 19 years (range=2–37 years) and estimated having cared for 15 to more than 500 ($Mdn=75$) children with autism. HCPs reported having learned about autism through personal experiences (e.g. on the job, knowing children with autism, self-directed reading) and formal learning opportunities (e.g. lectures, presentations, workshops).

Procedure

This study was approved by the (IWK Health) Research Ethics Board (Project #1016492) Recruitment of staff was by study posters, word of mouth, and presentation at staff meetings. Eligible families were identified by a member of the direct care team with approved access to lists of children with autism who recently had surgery. Approximately 40 invitation letters were sent in the summer of 2014 to the families of children with autism who had most recently undergone day surgery. Sampling methods precluded an accurate count of how many potential HCP participants were approached. All parents and HCPs who began the informed consent process participated.

Semi-structured interview guides were developed based on literature reviews, clinical researchers' observations, and consultations with experienced clinicians and qualitative researchers. Questions aimed to elicit perspectives related to surgical experiences, including (1) the presentation and nature of children's surgery-related distress, (2) what approaches were used to support children around the time of surgery, and how they were perceived, (3) how these experiences could be improved, and (4) barriers and facilitators to potential improvements. Questions were open-ended, ranging from broad (e.g. "Can you share with me your experience of having your child go through day surgery?") to specific (e.g. "What strategies for caring for children with autism and their families have you found helpful?").

Interviews were conducted in person by author S.S. over a 5-month period. Twenty-two interviews took place in private rooms in a pediatric hospital; one parent was interviewed at home. Following written consent, participants completed brief demographic questionnaires. Interviews were audio-recorded and ranged from 17 to 76 min ($M=38$ min, $SD=16$ min). Field notes captured non-verbal, tonal, and/or emotionally laden aspects of the interview. Following each interview, the interviewer shared a summary of key points and provided participants

with an opportunity to elaborate and/or clarify. Interviews were transcribed verbatim by a professional transcriptionist, and data were managed using NVivo 10 software (QSR International Pty Ltd, 2012).

Qualitative analysis

This study employed Interpretive Description (Thorne, 2008), an approach to qualitative inquiry with the explicit goal of developing knowledge that informs and advances clinical care. To develop this knowledge, analyses go beyond a simple description of data, to a level of interpretation that requires inductive reasoning, pattern recognition, and concept linking. As recommended by Thorne (2008), an interpretive description should pull together knowledge into a mental heuristic that allows a clinician to better understand, remember, and ideally act with this knowledge in mind. Interpretive description is pragmatic. It has an applied goal of advancing clinical care and draws on techniques from various methodologies (e.g. ethnography, grounded theory; Giacomini, 2010).

Data collection and analysis were concurrent and iterative. Insights from early participants informed new ideas to explore in later interviews. Broad non-categorical labels (e.g. stressed emotions, communication challenges, positive outcomes) were applied to potentially relevant pieces of data. Labels were not mutually exclusive or exhaustive; they were intended to gather related pieces of data for comparison. Exceptional or outlying cases could be identified and carefully considered, and patterns within and between data groupings could be explored. Through discussions within and beyond the research team (e.g. with clinicians and other researchers), and disciplined critical reflection (challenging emerging patterns and themes; e.g. "What else might there be to see and how would I know that?"), the insights gained through the data analysis process were iteratively refined into the thematic summary presented here. Consideration was then given to relations among themes and how to convey these in a coherent interpretation.

Multiple verification and rigorous techniques were integrated to enhance trustworthiness. Techniques included: source triangulation (i.e. sampling to provide multiple perspectives on the experience), analyst triangulation (i.e. researchers included authors S.S., then a clinical psychology PhD student, two PhD-level clinical psychologists with respective expertise in autism (I.M.S.) and perioperative care (J.C.) and a PhD-level nurse with expertise in qualitative research and procedural care, M.L.), peer debriefings (i.e. sharing, discussing, refining preliminary insights with colleagues), second readers (i.e. two readers not associated with the study audited the logic trail), prolonged engagement with context (i.e. author S.S. maintained relationships with stakeholders and discussed reasoning and implications of interpretation throughout

the project), and thick description (i.e. results were grounded in verbatim accounts). A meaningful part of prolonged engagement included sharing the metaphor and preliminary results with both participating and non-participating parents and HCPs. All 23 participants were emailed a written summary of the metaphor and results, and convenience samples of non-participants were presented with the same information in stakeholder meetings. Fourteen participants (61% of interviewees; four parents and 10 HCPs) and 23 non-participants (child life specialists, pediatric specialist physicians, pediatric dentists, and parents) chose to provide feedback. All who responded indicated that the preliminary results conveyed by the metaphor reflected important aspects of their experiences.

Sample size justification

The adequacy of sample size for this study was based on recommendations consistent with Interpretive Description methodology (Thorne, 2008) and the concept of Information Power (Malterud et al., 2016). We deemed our sample size as sufficient based on these criteria: our study examined a relatively narrow phenomenon with a pragmatic aim of advancing clinical care (study aims), individuals in our sample had characteristics that were specific for the study aim with variability in their experiences (sample specificity), our study applied specific theory in line with Interpretive Description (degree of theory use), a strong and in-depth dialogue took place between our interviewer and participants (quality of dialogue), and our sample provided enough data for cross-case analysis (analysis strategy).

Community involvement

HCPs working in the day surgery unit had identified that children with autism may be more vulnerable during the surgical experience. Informal conversations with three HCPs catalyzed the decision to apply for grant funding to support this needs assessment. Although parents of children with autism were included as participants in the present study, they were not involved in the design. Parents and youth with autism were involved as partners in the creation of the intervention that was the basis of the research program that followed, which was informed by this needs assessment.

Results

Interpretation: the experience is a balancing act

The metaphor of a *balancing act* was the overarching heuristic designed to capture participants' experiences supporting children with autism through the perioperative course. Parents and HCPs shared that their goal was to

support children to move from admission to discharge as smoothly as possible. That said, the process is a precarious one that can leave everyone involved feeling on "edge" (P 1 & HCP 7), with the looming possibility of the child experiencing distress. Participants sensed that a single misstep could result in distress for the child with autism and conveyed that supporting children from admission to discharge was, therefore, a delicate *balancing act*. In presenting this metaphor to introduce our results, we aim to provide readers with an overall context. Three themes and seven subthemes describe individual, interpersonal, and systemic factors that participants identified as influencing this *balancing act*. Our intention is not to suggest a one-to-one relationship between the metaphor and themes, but rather to build a mental heuristic that offers an organizing conceptual framework for the qualitative knowledge developed in this study (Thorne, 2008).

Theme 1: finding your footing through an uncertain journey—individual factors

Participants conveyed that children, families, and HCPs have varying levels of comfort stepping into this balancing act, and discussed child, family, and HCP factors that affected the ability to find stable footing.

Subtheme: individualized care helps children find their balance. Most participants identified strategies to help children with autism find their footing on the day of surgery, including preparation, active distraction, parental presence, sedation, and reducing sensory stimuli, non-essential interactions, and wait times. Participants acknowledged that not every strategy would help all children with autism. For example, in discussing approaches to care for children with autism, HCP 10 said, "It really depends on the kid. I find you have to tailor the stuff that you do for each child because not everything's going to work." Overall, participants acknowledged the importance of recognizing each child as unique. A few participants suggested that the primary challenge is not knowledge of strategies, but rather responding to individual needs within a complex and fast-paced environment; as HCP 10 put it, "you have to find out what works for [each child]."

Participants also conveyed that it can be helpful to consider triggers that might cause *any* child to lose their footing and become distressed (e.g. introduction of medication or anesthetic mask, separation from parents), in addition to potential specific triggers for some children with autism, such as sensory (i.e. sights, sounds, smells, taste, and touch) or social stimuli (e.g. interactions with multiple unfamiliar people). For example, HCP 13 said:

When I know somebody has autism, I may ask the family directly, are there certain things we need to know about your child? Are they okay if I approach them? Do loud noises bother them?

In addition to finding out whether “particular things . . . are upsetting” (HCP 13), participants talked about how it is important to think about what kinds of things might be “particularly calming or useful” (HCP 13). For example, HCP 15 commented that they try to find out, “what interests [a child has], what [they can] talk to [the child] about that will put them at ease.”

Participants explained that considering children’s communication styles and preferences can inform how to tailor care. At times, communication differences were easy to identify—some children had few words or used pictures to communicate—whereas subtle differences were more easily overlooked. One mother (P6) described her child’s needs: “although he speaks . . . it’s not always for communication.” Elaborating, she stated she would want HCPs to know that “[if her son says] ‘yeah, okay,’ it doesn’t always mean that. Sometimes he’s just saying that because he doesn’t want to answer your question.”

To identify “what works for each child” (HCP 4), it is also critical to understand and monitor children’s responses. Participants reported that children reacted to the surgical experience differently; some find their footing easily and remain calm; others lose their balance and experience distress. Participants noted that distress could manifest in autism-specific behavior (e.g. repetitive behavior), but could also look the same as in children without autism (e.g. crying, screaming). Children’s outward expressions of “calm” and “anxious” were characterized in some cases as nuanced and idiosyncratic. For example, when describing her child’s anxiety, one mother (P3) said, “it’s hard to explain . . . it’s more a change in his expression, a change in his movement. It’s just something that you’ve learned over time to notice.”

Subtheme: parents anticipate losing balance and feel on edge. Although families commonly experience some concern when children have medical procedures, families of children with autism often feel especially on edge. Speaking to this, HCP 7 said, “my sense is that people just sort of cope. . . and then something like [day surgery] tips them a bit over the edge.” Parents’ reports corroborated this observation. Only two of eight parents reported that their children became explicitly distressed, yet most parents had trouble finding their footing—even when things went well. They conveyed a sense of foreboding, or anticipatory anxiety, in some cases long before the child’s surgery. One parent commented, “any time [the upcoming surgery] would come to my mind that year, I would panic about it” (P1). Previous challenging healthcare experiences and difficulty tolerating the uncertainty of future experiences can result in heightened parental anxiety. One mother (P3) explained,

The anxiety is . . . because . . . you never really know how they’re going to respond to something that’s not on a regular basis familiar to them. He could always throw me a curveball . . . it’s that stress and that anxiety of how he’s going to react, and whether I am going to be able to get him through the procedure or not.

Some HCPs were attuned to parents’ heightened anxiety. Several HCPs commented that parents will “be really worried about their child misbehaving, and that we, the healthcare providers, have to deal with it” (HCP 2). When things went smoothly, several parents were “bewildered to think how things could have gone” (P1) and discussed specific moments or alternative approaches “that could have made things go completely wrong” (P2). Parents who were more comfortable believed in their own and the HCP team’s abilities to navigate this uncertain journey. Instead of worrying about what might go wrong, they moved steadily through the surgical experience, confident that they and the team possessed the necessary skills and resources to mitigate potential distress.

Subtheme: HCPs’ comfort maintaining balance. HCPs themselves have varying levels of comfort in caring for children with autism. Some shared experiences supporting children with autism that were mostly “positive” (HCP 2), stating that “it’s usually quite smooth for most of these kids” (HCP 7). Others discussed how some HCPs are “really scared to look after [children with autism]” (HCP 11) and are “just more comfortable. . . seeing somebody else [without autism]” (HCP 14). Some fear appeared to come from previous experiences. Most HCPs vividly recalled instances when a child with autism had become so distressed that they (i.e. HCP) felt overwhelmed, afraid, and helpless. One HCP (12) recalled: HCP 7 shared, “I remember in one case [an HCP] was visibly sort of distressed and flustered and just said, I’m not doing it.”

There was an interesting disconnect between HCPs’ knowledge about autism and their comfort and self-efficacy in providing care for children with autism. With rare exceptions, HCPs’ reports suggested that they possessed enough knowledge and skills to provide high-quality care for children with autism. Specifically, all HCPs were able to comment on how symptoms associated with autism may influence the surgical course, discuss ways that distress might manifest in children with autism, and describe strategies that they use to support children with autism and their families around the time of surgery. However, knowledge, skills, and experience did not always ensure that HCPs felt *comfortable* caring for children with autism. Despite knowing enough to provide high-quality care to children with autism, most HCPs seemed reluctant to take ownership of their knowledge, emphasizing that they “don’t know as much as they would like to know” (HCP 14) and need more training and education.

Theme 2: relationships can help keep everyone steady—interpersonal factors

Participants conveyed that the experiences of children with autism, their parents, and HCPs are inextricably

linked—empathy, collaboration, and coordination may keep everyone steady throughout children’s surgical experiences.

Subtheme: unsteadiness affects everyone, but empathy can be a safety net. Difficult feelings, particularly children’s distress, amplified discomfort experienced by families and HCPs. Regarding an experience in which a child with autism became very upset, HCP 6 said, “you could see, it made everybody so much more nervous and frustrated because his behaviour was escalating.” Participants expressed that seeing a child in distress can be “disheartening.” Despite some participants feeling stuck or paralyzed in the face of children’s distress, others conveyed that empathy could turn challenging moments into opportunities to strengthen relationships between children with autism, their families, and other HCPs. As P1 put it, “I can’t tell you how immediately reassuring . . . [it was to] know that [the HCP] knew that [my child] was really anxious; it just lifted all of the weight off my shoulders.”

Subtheme: collaboration stabilizes, but dependency can upset the balance. Parents and HCPs emphasized the importance of collaborative relationships. HCPs told us that it is especially important to draw on parents’ expertise when caring for children with autism. HCP 6 said, “if anything I’ve ever learned, these parents know their kids. They know exactly what their kids need and what their kids don’t need.” In addition to facilitating effective tailoring of care, participants expressed that collaboration comforts parents, providing them an opportunity to share their expertise on their children. When family knowledge is harnessed to inform the child’s care it may also increase families’ trust in the healthcare team. One mother (P2) commented, “[the healthcare team] respected the parents’ point of view, and that was the first time I think I really kind of felt like we belonged, and they understood.” Other examples illustrated how effective parent-provider collaborations help to buffer the negative impact of challenging experiences. Regarding her daughter’s significant distress, P7 said, “I felt so helpless for her . . . and I think the nurses were [stressed] too . . . but they were excellent . . . Because when we [gave a suggestion] they were like . . . let’s do it.”

The relationship between HCPs and parents is nuanced. An important distinction was made between collaborative relationships, which are essential and valued, and dependent relationships, which can leave families and HCPs “floundering” (HCP 9). Several HCPs talked about depending on families more than they would for a child without autism. For example, HCP 14 commented, “I rely more on the family than I would—like if I went in and [saw] a child that wasn’t autistic then I would be more the one in charge.” Although many parents valued the opportunity to be actively involved in their children’s care, participants commented that some families may be too

stressed, or simply may not have had enough opportunities to learn how to care for their child in a healthcare context. The ideal relationship was articulated in HCP 9’s desire that “as much as we lean on [families], for them to lean on us, and that they feel comfortable that we’re okay.” Even simple things such as acknowledging their child had autism and asking a few questions about how to adjust care seemed to indicate “autism awareness,” reassuring parents that they could trust the HCPs involved in their child’s care and that true collaboration was feasible.

Theme 3: systems shape the experience—systemic factors

Surgery-related interactions among children with autism, their families, and HCPs occur within an established hospital system. Participants conveyed that open and adaptable organizational cultures, and “autism friendly” spaces and resources facilitate this uncertain journey.

Subtheme: an open and adaptable culture is key. Statements by HCPs suggested that an organizational culture that values the importance of individualized care, openness, adaptability, and trust makes it easier to see straight ahead. Touching on this, HCP 9 emphasized the importance of the team “being able to adapt. . . going with an open approach, and just doing things that you have to do versus doing the things that have always been done.” Further, HCP 7 commented, “there aren’t too many variables that can be modified, but you try to tip whatever ones you can in your favor to try to tip the whole thing towards success.” In contrast, “old school” (HCP 9) ideas about how to approach care, preconceived notions about how care will unfold, resistance to change, and distrust or shame can create obstacles. As HCP 10 stated, “the inability to evolve would be, I think, the biggest barrier.” Participating HCPs explained how preconceived ideas and expectations can interfere with team members’ abilities to see each child with autism as unique. For example, HCP 8 shared a story about an older adolescent boy with autism who was scheduled to undergo dental surgery. Before any information about him had been shared, another team member called the hospital security service to be on standby. Reflecting on this experience, HCP 8 commented, “trying to change some perceptions would be another thing I would like to achieve. Because I think a lot of time people apply labels, and there’s less time in thinking and trying to understand.” A culture of trust, in which HCPs are not “worried or ashamed [to] ask for help” (HCP 10) would provide opportunities for staff to be vulnerable, ask questions, address preconceptions, or try new things.

Subtheme: value of autism-friendly spaces and resources. Participants commented on the benefits of a physical environment that promotes children’s coping, including

appropriate distractors and spaces that afford families and healthcare control over sensory stimulation (e.g. lights and sounds). Participants stated that “darkened rooms” (HCP 1), games or “videos on iPads” (P2), “headphones” (HCP 6), and “sensory items” (P7) can promote coping while children wait to go into the operating room or as a distraction during induction of anesthesia. Patient rooms with doors, which are preferred by many HCPs, were not always available. Many HCPs discussed the value of being cued to a child’s autism diagnosis before meeting the child and highlighted the potential utility of information and communication systems that would allow this. HCP 6 suggested that a “checklist” that was “short and sweet and to the point” would allow the whole healthcare team to gather “the critical information that may impact that day’s treatment.”

Finally, participants commented on the benefits of resources and supports that facilitate families’ abilities to prepare for surgery. For example, P6, who felt that she did not have enough information to prepare her child said, “one thing I thought would have been great to have would be almost like a flip book that kind of shows the process.” Other parents commented on the benefits of having “a social story with pictures” (P7), or “a little video, maybe with a cartoon or something of a kid going into surgery” (P4). Many participants also commented on the value of drawing on pediatric health psychologists or child life specialists to teach families and children what to expect and how to prepare. Reflecting on the value of these services, P1 said, “I just don’t know what I would have done had we not had [that support]. I just don’t even know where I would have started or how I would have ever managed.” Families are not always aware of whether such supports are available to them. For example, P2 commented, “I think the thing that is frustrating across the board is that the information is not there freely. There should be some forum for people to know that they can go to certain things [preparation resources/services].” Participants felt that there should be an effort to build awareness and understanding about existing resources and supports, so that families “know what the service is going to give them” (P1).

Discussion

This study aimed to build an in-depth understanding of surgery-related experiences surrounding children with autism. The perspectives of parents and HCPs provided a nuanced understanding of individual, interpersonal, and systemic factors that influence the surgical experience. We have likened the experience to a balancing act; caring for children with autism around the time of surgery can leave everyone feeling on edge. Consistent with existing recommendations and guidelines (Gimbley Berglund et al., 2016, 2017; Koski et al., 2016; Thompson &

Tielsch-Goddard, 2014) participants emphasized the need for HCPs to collaborate with families to identify how to individualize care for a given child with autism. Participants also highlighted the importance of ensuring that everyone involved in this “balancing act” feels comfortable and confident enough to find their footing, works collaboratively, conveys empathy, and ensures consistent care around the time of surgery.

This study advances the literature on caring for children with autism around the time of surgery by contributing a thorough understanding of the experiential context in which healthcare must be delivered. As previously described, the limited existing literature has largely focused on clinical care recommendations that may help to mitigate the surgical experience for children with autism (Taghizadeh et al., 2015). Perspectives from parents and HCPs in this study pertaining to helpful child-directed strategies corroborated existing recommendations (e.g. minimize the time children spend waiting, use distractions). However, our findings also suggest that it may be helpful to shift the focus away from children’s distress as the *sole* problem to a broader perspective that more fully considers the experiences of parents and those providing care.

The precariousness of caring for children with autism around the time of surgery may bring up difficult feelings for HCPs and families (Lewis et al., 2007; Lindberg et al., 2012; Vlassakova & Emmanouil, 2016). In this study, HCPs and families described experiencing anxiety, fear, disappointment, and frustration before, during, and after the surgical experience. This finding is not unique; other studies have noted that some HCPs and families feel anxiety and stress in anticipation of and during healthcare interactions involving children with autism (e.g. Aston et al., 2014; Lindberg et al., 2012; Solomon et al., 2016). For example, in one of the few perioperative studies to have included families’ perspectives, Lindberg et al. (2012) highlighted that families may experience feelings of hopelessness and suffering in association with the healthcare delivered when their children with autism underwent procedures that required anesthesia. In Aston et al.’s (2014) qualitative exploration of the hospital-based experiences of children with cognitive differences (including children with autism), HCPs reported fear associated with caring for children with various cognitive differences that stemmed from uncertainty regarding how the interaction would unfold. Difficult feelings may influence HCPs’ or families’ behavior, including how they communicate and support the child (Aston et al., 2014; Solomon et al., 2016). Consistent with the present findings, the broader healthcare literature has identified that collaboration, empathy, and understanding help to prevent and resolve challenging emotions that HCPs and families might experience during healthcare interactions (Aston et al., 2014; Davignon et al., 2014; Lindberg et al., 2012; Muskat et al., 2015; Solomon et al., 2016). Rather than evaluating the

outcomes of a perioperative experience based only on whether the child is distressed or non-compliant, a broader conceptualization of success that focuses on the interpersonal dynamics (e.g. the interaction between HCP and parent comfort, empathy, and collaboration) is needed.

Whereas some interventions focus on the unique characteristics of children with autism and highlight differences in care approaches, it may be helpful to consider how focusing on such differences may contribute to HCPs' discomfort. Many of our participants' suggestions are arguably relevant for all children. Individualizing care, partnering with families, providing empathy, and coordinating care could be considered best practices for perioperative care regardless of whether a child has autism (e.g. Chorney & Kain, 2009; Kain et al., 2007; Shields, 2007). As pediatric healthcare delivery entails HCPs working within systems, interpersonal and systemic factors necessarily influence all experiences. Despite these parallels, HCPs conveyed less comfort caring for children with autism, which has important implications for interventions. A strengths-based approach (Richer et al., 2010; Trajkovski et al., 2013) that supports and empowers HCPs may be more effective by conveying how to apply their existing knowledge in providing care for children with autism. Use of a strengths-based approach does not preclude specifying prerequisite knowledge and skills for individualizing care effectively for this population. For example, it is important that HCPs know to ask how best to communicate with the child or how to identify potential triggers or indicators of distress. That said, knowledge alone may not suffice to shift care (McGonigle et al., 2014; Michie et al., 2014). HCPs in our study knew enough about autism to care for this group, yet still conveyed relative discomfort providing care. This finding is consistent with previous research that has highlighted discrepancies between knowledge about autism and comfort caring for children with autism across HCPs in varied roles and contexts (e.g. general practitioners, emergency personnel; Unigwe et al., 2017; Wachob & Pesci, 2017; Zerbo et al., 2015). HCPs need the psychological capability, motivation, and resources to engage in appropriate care behavior (Michie et al., 2014). They must manage their own emotions, have access to resources, and learn to build empathic, supportive relationships with families.

Limitations, strengths, and future directions

We described participant demographics, care contexts, and study procedures to facilitate readers' assessment of the transferability of findings to their own contexts. That said, given the qualitative nature of this study, we cannot conclude that the experiences of these HCPs and families represent the experiences of those who were not interviewed, nor others who care for children with autism elsewhere. Parents in this study care for a wide age range of children

with autism (3 to 18 years), and we acknowledge that findings may have been different had there been a more limited age range. Although we judiciously applied criteria recommended by Thorne (2008) and Malterud et al. (2016) to judge our sample size as sufficient, we recognize the limitation of our small number of participants. In addition, although we feel that our decision to interview HCPs and families on the same issues using qualitative methods was a key strength of this study, we acknowledge that the perspectives of children with autism were not gathered directly. Consistent with priorities that have been identified in the broader field of autism research (Fayette & Bond, 2018; Harrington et al., 2014), additional studies addressing this notable limitation are warranted. Moreover, recent advances in methods for eliciting the views of children across the autism spectrum have improved the representativeness of such efforts (Tesfaye et al., 2019).

The metaphor we developed resonated with our participants and other stakeholders, lending credibility to the notion that drawing results together in a heuristic can assist understanding of research findings. In turn, this understanding may help HCPs to recall and act in accordance with the expanded awareness that this heuristic brings. These assertions are supported by a broader literature on the function and power of metaphors within and beyond the field of healthcare (Hodgkin, 1985; Lakeoff & Johnson, 2008; Ortony, 1975; Reisfield & Wilson, 2004). Metaphors bring coherence to complex experiences, assist in building shared understanding, help to reframe existing ideas, and promote memory (Lakeoff & Johnson, 2008; Ortony, 1975). Further research is needed to examine relationships among individual, interpersonal, and systemic factors proposed to influence this balancing act, and to begin exploring questions of generalizability.

Findings from this study could be used to inform the development and implementation of interventions to improve clinical practice (Alderfer & Sood, 2016), as our team has done (<https://balanceforautism.com/>). Care processes influenced by complex factors offer many potential avenues for intervention—the experiential knowledge gained in this study could be used to guide the development of interventions directed to children, families, HCPs or care systems.

Conclusion

This interpretive descriptive study highlights the lived experiences of families and HCPs who care for and support children with autism throughout the surgical course. In-depth interviews with parents of children with autism and HCPs highlighted a number of factors at the individual (e.g. parent and HCP anxiety), interpersonal (e.g. the importance of collaborative, empathic relationships between HCPs and families), and systems (e.g. a need for flexible policies and autism-friendly resources and

environments) levels that create challenges and have the potential to improve the surgical experience for children with autism. Despite calls for improvements in care, and clinical recommendations for the surgical care of children with autism (see Koski et al., 2016, for review), little attention has been given to understanding the experiences of children, families, and HCPs comprehensively. This study addresses this gap and sheds new light on the experiential context within which existing care recommendations or interventions aimed at improving care experiences must be implemented. Findings may help to inform future interventions and policy aimed at improving the surgical experience for families of children with autism and their surgical care providers.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship and/or publication of this article: Funding for this research was provided by a Translating Research into Care grant from the IWK Health Centre. Stephanie Snow was supported by a Canadian Institutes of Health Research Vanier Canada Scholarship and the Autism Research Training Program.

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