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Caregiver Insights and Improvement Strategies for Youth with Autism Undergoing Gastrointestinal Endoscopy

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Abstract

Limited guidance is available for families of youth with ASD (YASD) to prepare for invasive medical procedures. This study examined caregiver perspectives regarding YASD's gastrointestinal endoscopy (GE) experience to improve the endoscopy experience for YASD. Thirty-four caregivers of YASD, ($M=9.85$ years, $SD=4.6$) who underwent GE at Rady Children's Hospital, San Diego between May 2018 and July 2019 (identified via electronic health record) participated in a structured phone interview. Caregivers reported a positive experience due to the procedural team's responsiveness to the needs of YASD and appropriately answering/addressing questions/concerns. Caregivers reported a need for ASD-specific information on how to prepare for GE. Specific recommendations are discussed. Study findings offer strategies to improve the care experience of YASD undergoing GE.

Keywords Autism spectrum disorder · Procedural care · Healthcare service · Patient experience · Qualitative research

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by challenges with social communication and interaction, as well as repetitive behaviors and interests (Escolano-Pérez et al., 2019; Gurney et al., 2006). Youth with ASD (YASD) also have a high prevalence of co-occurring health conditions (medical and psychiatric) that result in interaction with a number of treatment providers and clinical settings (Gurney et al., 2006). Interactions with treatment providers in a variety of clinical settings can be

particularly stressful for YASD. There is a small but growing body of literature on best practices for supporting YASD to prepare for medical interactions (e.g., Social Stories, visual schedules) but this is more limited in acute care settings (Turcios et al., 2017). The focus of this study was to qualitatively examine the experiences of YASD undergoing gastrointestinal endoscopy to inform specific recommendations for improving the medical care experience for YASD and their families.

Some reports have estimated that the prevalence of gastrointestinal symptoms is greater in YASD than those without ASD (Coury et al., 2012; McElhanon et al., 2014) and can be nonetheless difficult to identify and manage among YASD (Parmeggiani, 2014). Diagnostic evaluation of these complaints can be complex (Holingue et al., 2018) and may involve endoscopy (Wasilewska & Klukowski, 2015). However, due to the behavioral rigidity and sensory sensitivities (American Psychiatric Pub., 2013) of ASD, undergoing an invasive procedure can cause significant distress to YASD and their families. There is growing attention to this issue by the medical community, as evidenced by targeted efforts to improve care for individuals with ASD during hospitalization and when seen in the emergency department (Broder-Fingert et al., 2016; Kopecky et al., 2013; Venkat et al., 2016).

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Quality indicators of endoscopy and colonoscopy focus primarily upon procedural protocols (e.g., consent procedures, pre-procedural medical risk identification, documentation of findings, medications dosed, adverse event identification) with relative minimal consideration of patient experiences (Rex et al., 2015). However, patient experiences are of significant concern to families of YASD, as we demonstrate in the current report. Similarly, expert guidelines from relevant European pediatric societies on endoscopy performance do not specifically address patient pre-procedural preparation, anxiety, or concerns (Tringali et al., 2017). The literature addressing procedural management with YASD in other fields is relatively scant. Nevertheless, recommendations can be found for dental procedures that begin to address YASD patient experiences including a pre-procedural visit to assess capabilities and parental presence during the procedure for patient comfort (Cote & Wilson, 2016; Friedlander et al., 2006). Similarly, a recent review of perioperative management of YASD in the field of anesthesia provides communication and comfort strategies to prepare youth for the upcoming procedure with parent support (Vlassakova & Emmanouil, 2016).

Nevertheless, limited clinical guidance exists for health-care providers to families of YASD who require an invasive procedural intervention (Koski et al., 2016; Povey, 2016; Whippey et al., 2019). Similarly, there is limited data on what is needed to support YASD through pre-procedural protocols (i.e., fasting for endoscopy and anesthesia with or without a bowel cleanout for colonoscopy). Previous qualitative research that has examined caregiver perspectives on ASD services has been a valuable and critical source of information to shape tailoring of interventions and service delivery (Brookman-Frazer et al., 2012; Stadnick et al., 2013). Engaging important stakeholders like caregivers offers the opportunity to gather in-depth experiences that are essential for implementing evidence-based care and ultimately improving the patient experience and outcomes (Palinkas, 2014). To address the gaps in the literature regarding procedural care experiences for YASD, the current study used an exploratory qualitative approach to gather caregiver perspectives regarding YASD's experiences undergoing a gastrointestinal endoscopic procedure.

Methods

Our qualitative study was part of a quality improvement project to improve the procedural care experience for families of YASD at a large children's hospital in Southern California. A qualitative design was selected to gather in-depth perspectives from caregivers about YASD's procedural experience (Marshall & Rossman, 2014). The joint Rady Children's Hospital, San Diego and UC San Diego IRB determined

that this project was quality improvement and exempt from IRB review as human subjects research.

Participants and Procedures

Primary caregivers of YASD (defined as age < 18y) with ASD who underwent a gastrointestinal endoscopic procedure between May 2018 and July 2019 and who spoke English or Spanish were contacted and invited to participate in a 20-min structured phone interview during the summer of 2019. Diagnosis of ASD was verified through patient records. Caregivers were contacted after their child's endoscopic procedure. No verbal or written informed consent was required per the IRB's determination that this project was exempt. However, the trained research team members who conducted the outreach and phone interviews provided an overview of the project, purpose of the interview, and asked the caregiver for their permission to participate in the interview. Caregivers were also reminded that they could refuse to answer any question and end the interview at any time. Each caregiver was contacted a total of three times with a voicemail message inviting callback to participate. When interviews were performed, interviews were audio recorded with consent of the caregiver for further analysis.

Caregivers were recruited via telephone outreach using a script led by members of the research team. First, a sample of youth with a recorded ASD diagnosis and who had completed a gastrointestinal endoscopic procedure between May 2018 and July 2019 were identified via electronic health record review ($n = 105$). The contact information of the sample's caregivers was abstracted from the child's electronic health record. Of the 105 families, 104 were contacted and 34 caregivers (33% of eligible families) were successfully reached and agreed to participate. One family was excluded from participation because the interview could not be conducted in the family's preferred language.

Three trained staff conducted the phone interviews. Training included the following: a one-hour in-person training in qualitative interviewing and review of the interview guide with a clinical researcher (NAS) with qualitative and mixed methods expertise, self-study of qualitative training materials and research articles about the clinical population, and a mock interview practice with feedback. Interviewers completed a post-interview templated summary of each performed interview.

Measures

Patient demographics, gastrointestinal symptoms, diagnoses and clinical problem lists, and procedural information were extracted from the electronic health record. A structured interview guide was developed to elicit caregiver perspectives regarding YASD's endoscopy experiences.

A total of 11 questions inquired about the following: what information was presented to families about what to expect and how to prepare for the procedure, how the families prepared YASD for the procedure, length of the procedure, the child and family's reaction to the procedural care experience, most and least helpful strategies employed by the care team, and suggestions for improving care. There was also one close-ended question that asked families to rate the care experienced on the day of the procedure on a scale from 0 being very poor to 5 being excellent. The final question invited caregivers to share anything additional about the care that their child received on the day of the procedure.

Data Analyses

Quantitative Analysis

Descriptive statistical analyses were performed to characterize patient demographics and procedural information. Between group analyses were performed using t-tests for continuous variables and chi-square analyses for categorical variables to compare demographics and procedural information between participants and non-participants. JMP Professional software version 14 (Cary, NC) was utilized for these analyses. Statistical significance of performed analyses was assigned at a $p < 0.05$.

Qualitative Analysis

We employed a rapid qualitative analytic approach to qualitative data analysis to facilitate timely delivery of results and quicken the pace of clinical decision-making to inform care procedures (Hamilton, 2013). Rapid qualitative approaches are particularly well-suited for quality improvement projects when stakeholders are in need of rapid results to shape policy and clinical care implementation (Taylor et al., 2018). There is accumulating support that rapid qualitative approaches deliver comparable findings to more traditional, time-intensive approaches (Gale et al., 2019). For this study, qualitative data analysis proceeded in three steps. This included first creating a domain name that corresponded with each interview question, then creating a matrix (respondent by domain) to track summaries (Hamilton, 2013). A doctoral student from the research team summarized each transcript using the matrix template and identified preliminary themes. The final step included two group consensus/discussion meetings to finalize themes.

Results

Patient Demographics

The mean age of participating YASD at the time of the procedure was 9.85 years ($SD=4.63$ years; Range=2–17); 79% were male; 41% were Caucasian; 12% Asian-American, <1% African-American and 47% "other". The average age of YASD at the time of ASD diagnosis was 5.71 years ($SD=4.28$; Range=1–16). Sixty-five percent ($n=22$) of the families were on government insurance at the time of the procedure, 9% ($n=3$) were on military insurance, and 24% (8/34) were on private insurance. Half of participating families ($n=17$) were Latinx. Sixty-five percent ($n=22$) of the participating families reported English as their primary language and 35% ($n=12$) reported Spanish as their primary language. Eighty-two percent ($n=28$) of caregiver participants were mothers. There were no significant demographic differences (age, sex, race, and ethnicity) between participating and non-participating youth (all statistical analyses $p > 0.05$).

Procedural Information

Among study participants, 73% ($n=25$) underwent an upper gastrointestinal procedure; 6% ($n=2$) underwent a lower gastrointestinal procedure; 18% ($n=6$) underwent both upper and lower procedures; 3% ($n=1$) underwent both upper and lower procedure and an additional procedure such as anorectal manometry or exploratory laparotomy. Sixty-six percent ($n=22$) of children from participating families underwent a repeat endoscopy procedure. Of the participating families, 12% ($n=4$) of the children underwent an emergency endoscopic procedure. The mean duration of upper endoscopic procedures for participants was 14 min ($SD=16$), 22 min ($SD=16$) for lower endoscopic procedures, and 46 min ($SD=16$) for combined upper and lower procedures. The overall mean procedural visit duration was 213 min ($SD=61$). Based on a review of the child's electronic health record (EHR), documented pre-operative communications were performed to discuss preparation and overview of the procedure for 82% ($n=28$) of the interviewed families. During these pre-operative calls, less than half [44% ($n=15$)] of telephone communication notes were found to acknowledge the child's ASD diagnosis in their discussion with the caregiver.

Qualitative Results

Helpful Care Team Strategies

Prior to the procedure day, caregivers described the following care team strategies as particularly helpful in preparation for and on the day of the procedure. First, the care team

went through what to expect with families in terms of the procedure, such as discussing the risks and benefits of the procedure, options available for anesthesia, and giving clear instructions about what to do on the day of the procedure (e.g., where to park, where to check in). Second, the care team gave caregivers the time and space to express any concerns about the procedure. In some instances, the care team met with families before the procedure, or completed a pre-operative phone call with caregivers. One caregiver explained that, “[They were helpful in] understanding the risks and how to calm down and letting us know that there are other options [for anesthesia].” Thirdly, caregivers also appreciated that the care team asked for parent input regarding how to make the child as comfortable as possible on the day of the procedure and that the care team gave the family a reminder/check in call the day before the procedure.

On the day of the procedure, caregivers were pleased with the duration of the procedure itself but feedback about the duration of the waiting period before the surgery were mixed (i.e., the intake process). For example, one caregiver commented that the “...sensitivity to the autism diagnosis...the ability to shorten the time prior to check in is very useful.” Another caregiver explained that “[The waiting time] was a little difficult...anything that goes past 40 min...is like all we are trying to do is stop him from getting into another kids or adult’s privacy...” Caregivers appreciated the care team’s sensitivity and compassion to the child’s needs on the day of the procedure. This was demonstrated by the care team providing the child with snacks following the procedure and toys, speaking to the child about their preferred interests to distract the child, and being sensitive to the child’s specific needs although care providers had not received specialized training for working with children with ASD. For example, one caregiver stated: “The level of attention...and the nurses provided [the child] a juice...the nurses approach to the child]...that they know how to approach kids with [ASD].. they have a positive behavior...I was impressed because that’s not their area, but they really have the right attitude.” Finally, caregivers found it helpful that the care team provided frequent updates to caregivers and were responsive to caregivers’ questions, comments, and concerns throughout the procedure.

Helpful Caregiver Strategies

Caregivers also shared several strategies that they themselves employed that eased the preparation and day of the procedure for YASD. Before the procedure, caregivers independently researched the procedure by watching videos about the procedure and reached out to the care team to gather more information. Caregivers shared that they also employed strategies to emotionally prepare YASD including: explaining the procedure to YASD in age-appropriate

language, role playing the situation at home, and preparing a social story for YASD to review before and on the day-of the procedure. Additionally, caregivers identified and packed items that would provide comfort to YASD on the day of the procedure (e.g., a favorite blanket). One caregiver said: “We usually bring stuff to entertain her while we are waiting...she’s not really into toys...so she was happy watching TV in the waiting area.” Finally, for YASD who were undergoing colonoscopy, caregivers made sure that YASD took their bowel cleanout as instructed, while being creative about alternative modes of laxative administration that would ease the experience for YASD (e.g., making popsicles with the medication).

Caregiver Recommendations

Finally, while most care experiences were positive, caregivers also provided several recommendations to improve the pre-procedural care experience. Although caregivers were overall satisfied with how the care team helped them prepare for and on the day of the procedure, caregivers reported that the care team did not provide information specific to YASD about how best to prepare for the surgical procedure. In terms of preparation for the surgical procedure, caregivers expressed a desire for more subspecialty coordination (e.g., “looking at the overall picture and condition of the child”). Similarly, caregivers would have liked to have had a mental health professional available to provide emotional support to the family and child before and after the procedure. One caregiver shared, “I think [it would be helpful if they provided] more psychological help...they don’t have a lot of psychological support. So, if took a few days to get somebody to call me and talk to me...but that was through the hospital, not specifically tied to the procedure.” Additionally, caregivers suggested the use of text-based reminders in their preferred language as a strategy to improve communication and coordination before the procedure.

In terms of recommendations for improving the care experience on the day of the surgical procedure, caregivers shared suggestions for minimizing the wait time and improving the waiting room experience during the intake process on the day of the procedure. First, caregivers suggested that forms that need to be filled out before the procedure be sent home with the family in advance (e.g., “If there’s a way to do some paperwork ahead of time...that would be good.”) Second, caregivers suggested that they be allowed to minimize time that their child spend in the procedural unit and/or hospital setting in general (e.g., “...if I can call and we can get him out of the van when we know that the doctor is getting close to finishing with the other person.”) Third, caregivers would have liked for the care team to directly ask whether the child has an ASD diagnosis in order to make special preparations for the procedure, rather than caregivers

having to bring it up themselves. Similarly, caregivers would have liked if the care team were more familiar with how to communicate with *non-verbal* YASD, specifically so that the care team could explain the procedure directly to the child, rather than just to the caregivers. Finally, caregivers expressed the desire for an ASD-friendly waiting room to support YASD's emotional and behavioral regulation. For example, one caregiver explained, "I kind of wonder if having like a little one-off room...that is a little more quiet would be more helpful...it would be a little easier to manage and not disrupt the other people in the hospital."

Caregiver Satisfaction

The structured interview closed with a one item quantitative rating of satisfaction with their child's care experience. Overall, caregivers of YASD reported that their procedural experiences were generally positive. The average rating of experiences was 4.6 (SD=0.7) on a scale of 0, very poor, to 5, excellent. Of interviewed caregivers, 91% (n=31) rated the experiences as 4 or 5, indicating a very good or excellent care experience with their child.

Discussion

This qualitative study examined caregiver perspectives regarding the endoscopic procedure of YASD. Overall, caregivers reported a positive procedural experience attributed to a combination of helpful strategies employed by the clinical care team and caregivers. In addition, caregivers highlighted several clinical recommendations that could be implemented to improve the procedural experience of YASD undergoing endoscopy. Identified areas for improvement included: desire for ASD-specific information, improved coordination of care, and special considerations for ASD needs both in regard to the waiting room environment and available resources. Our findings and pragmatic recommendations offered by caregivers of YASD contribute to the scant but growing literature and clinical guidelines for addressing the needs of YASD undergoing endoscopy and similar surgical procedures (e.g. Tringali et al., 2017, Cote & Wilson, 2016; Friedlander et al., 2006). Most significantly, our current report addresses a significant gap in these existing scientific and clinical resources by explicitly considering the unique care needs of YASD and their families (e.g., communication preferences, sensory sensitivities, co-occurring mental health needs) to promote a more optimal procedural care experience for a vulnerable population who frequently interact with multiple service providers.

At our institution (Rady Children's Hospital, San Diego), there were some interventions already in place to improve the procedural experience for YASD at the time of

evaluation. In particular, the pre-procedural check-in time was substantially shortened by 30–60 min to reduce the waiting period for ASD patients. Since typical socialization cues and inferences cannot be used with ASD patients, clinical staff can find interactions with these patients difficult (Solomon et al., 2016). This disrupted communication can lead to suboptimal interactions. One useful intervention to ameliorate this situation has been to provide patient-specific information to clinical staff regarding known stressors (i.e. bright lights, loud noises, etc.), behaviors indicating anxiety/stress (e.g., wringing hands, hitting head) and known mechanisms for relaxation (e.g. use of technology (iPads, darkened rooms, reduced noise, etc.). As shared by caregivers in this study, a number of families prepare for the stressful environment of the procedural center by spending time outside of waiting rooms and bring favorite toys, iPads, etc. to help YASD manage the experience. Another ongoing ASD-friendly initiative that is hospital-wide includes implementation of the Autism Support Checklist, adapted from Boston Medical Center (Boston Medical Center. (n.d.)) to facilitate clinical staff awareness of the individualized needs and preferences of YASD.

In addition to these ongoing initiatives, caregivers in our study also recommended several strategies that vary in their complexity and feasibility to employ. For example, caregivers recommended modifications to the waiting room environment including a designated space for quiet activities and a communication system that would allow families to wait in a more preferred area (e.g., in their car, outside) with call-back closer to their needed check-in time. A few caregivers also suggested that a mental health or developmental specialist familiar with ASD be added to the care team to improve their procedural experience. This recommendation may be difficult to implement given the significant changes in personnel and workflow that would be needed. However, a workaround that could be considered is offering brief clinical staff training in best practices for caring for YASD along with organizational support (or recognition) for clinical staff who review the modified Autism Support Checklist with families prior to procedural visits.

The findings from this study support and extend the growing number of institutions creating an "ASD-friendly" clinical environment to improve the care experience for YASD. For example, Boston Medical Center has implemented an Autism Friendly Initiative that provides training for clinicians and staff addressing communication and sensory needs of patients during visits (Benson, 2019). This initiative also involves an Autism Support Checklist project that focuses on giving caregivers the opportunity to provide specific communication, sensory, and safety needs to clinicians through the patient's electronic medical record. Orlando Children's Hospital has also started a new program structured to improve overstimulating

waiting areas by providing headphones, eliminating loud equipment, and shortening waiting periods (Miller, 2016).

Although this study contributes new insights by reporting the experiences of YASD and their families undergoing gastrointestinal endoscopy, it is not without limitations. The study was conducted in a single gastroenterological unit with a relatively small sample size. However, through these efforts, we are moving towards developing tools for system-wide use in collaboration with hospital leadership. Additionally, our sample size is aligned with our scope as a qualitative study, focused on the experiences of a narrowly defined patient population. Methodological research indicates that data saturation in qualitative data collection can occur after 12 interviews with themes emerging in a smaller number of interviews (Guest et al., 2006). We observed data saturation within our eligible sample ($n = 34$) and determined that additional recruitment was not needed. Additionally, we had limited access to parent demographic information, such as parent education, because our primary data source for sample characteristics was the child's electronic health record.

In conclusion, we report the care experiences of YASD and their families who underwent a gastrointestinal endoscopy procedure at a large children's hospital in Southern California. While most experiences were viewed as positive, areas for improvement were identified. Families: desired ASD-specific information regarding how to emotionally prepare their child for the procedure; suggested minimizing the wait time and improving the waiting room experience during the intake process on the day of the procedure; and recommended ASD-specific training for care staff. Our next steps will be to prioritize and implement responsive interventions feasible in the endoscopy suite with ongoing collaboration with caregivers and providers.

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Author Contributions Drs. NS and JH contributed to the study conception and design. Material preparation, data collection and analysis were performed by TK, KM, and BLC. The first draft of the manuscript was written by TK and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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Declarations

Conflict of interest The authors have no relevant financial or non-financial interests to disclose.

Ethical Approval The joint Rady Children's Hospital, San Diego and UC San Diego IRB determined that this project was quality improvement and exempt from IRB review as human subjects research.

Consent to Participate No verbal or written informed consent was required per the IRB's determination that this project was exempt. However, the trained research team members who conducted the outreach and phone interviews provided an overview of the project, purpose of the interview, and asked the caregiver for their permission to participate in the interview. Caregivers were also reminded that they could refuse to answer any question and end the interview at any time.

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