



Improving the Perioperative Experience for Children with Autism

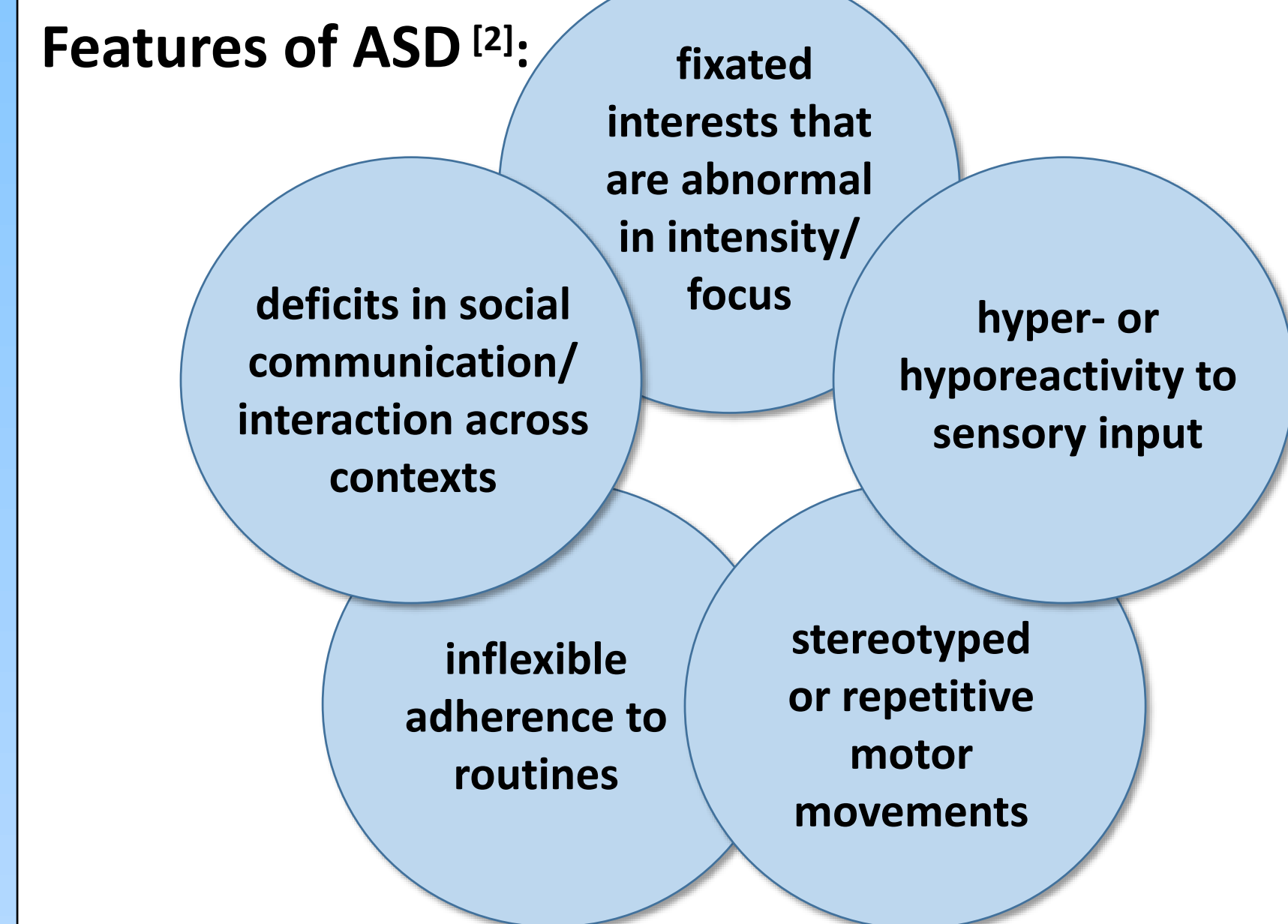
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Background and Introduction

Recent data suggests that **1 in 68** children meet the criteria to be diagnosed with Autism Spectrum Disorder (ASD) [1]



Children with ASD...

- have higher rates of health care utilization, yet paradoxically are more likely to have unmet health needs [3]
 - are more likely to have chronic illnesses, and are nine times as likely as their counterparts to have an ear, nose, and throat conditions [4]
 - are also more likely to suffer from anxiety [5]
 - are therefore prone to experiencing additional discomfort when their normal routine is disrupted during hospitalization
- This study is a qualitative analysis that features parental phone interviews about their experiences with their child's otolaryngological surgery. The emphasis in conducting this research is in determining ways that perioperative ENT experiences can be made better for both children with ASD and their guardians.

Participants

Inclusion Criteria

Participants were parents or guardians of children (ages 0-18) who were diagnosed with an ASD and had undergone an otolaryngological surgery within the previous 6 months at our tertiary care pediatric hospital. The participant was at least 18 years of age, and was fluent in English.

Context

These children had gone through surgery in a children's hospital that included pediatric specialists in nursing, anesthesia, otolaryngology and an active child life program. The pre-op section had private walled cubicles with glass sliding doors for each patient, with a television for each room. Most rooms had a large window. The décor was child-centered, and the unit was well-controlled and fairly quiet.

Materials and Methods

Interview Process

Interviews were semi-structured and transcribed by the interviewer.

Participants were asked about:

- patients' ages, autism diagnoses, and which procedure the patients underwent in the OR at Penn State Hershey Medical Center
- patients' regular behavior, communication issues, home objects used for comfort, triggers, and specific actions the parents used regularly to keep the patients calm
- patients' preferences of sounds, clothing, bedding and furniture
- smoothness of their child's most recent visit to the operating room
- advice based on their experiences with the goal of improving the process for patients with autism

Data Analysis

- QSR NVIVO 11 Starter software was used to analyze transcripts with a directed content analysis approach. Coding was close to the data (e.g., largely predetermined by the questions) and not highly interpretive or conceptual, but rather a taxonomic representative of responses.
- The following nodes based upon interview questions were assigned to each transcript: Behavioral Triggers, Response to Sounds, Expression of Anxiety, Expression of Pain, Tools for Comfort, Communication Issues, Important People, Advice.
- All responses were placed into the appropriate nodes for further examination. Accessory words such as "something" and "that" were removed, and each of the most frequently used words was further analyzed for relevance in context (i.e. for the node "Advice" a commonly used word was "waiting." A further analysis of "waiting" in context yielded phrases such as "pre-op wait time,"). A Memo was created that listed all the nodes. The most commonly used words with similar ideas in context were noted in the Memo under their respective node (i.e. the themes related to "waiting" were placed beneath the various nodes under which they were mentioned, such as "Advice," The nodes were reexamined and details were added to each of the most common ideas listed in the Memo.
- Categories that repeatedly appeared in all the nodes were identified and added to a separate list called "Major Topics" (i.e. for "waiting," an idea expressed across multiple nodes, the predominant idea was that "the pre-operative wait time should be shortened.").

Aspects Adding to Trustworthiness of Findings

- Training of interviewers
- Team weekly meetings
- Oversight by experienced qualitative collaborator
- Improved transferability by inclusion of multiple degrees of affected children and different types of guardians
- Clear recruitment protocols
- Audit trail kept using a detailed code book, not changing course to pursue novel ideas
- Comparison to previously published information on this topic

Conclusions

The perioperative setting can pose unique challenges for children with ASD, especially with regard to sensitivity to stimuli and communication difficulties. Children with ASD are likely to have other co-morbidities which often warrant evaluation and potentially surgical intervention by otolaryngologists.

This qualitative analysis of a semi-structured interview of twelve guardians of children with ASD provides insight into the common challenges faced by children and family members in the surgical setting. This information was operationalized by constructing a pre-op questionnaire to streamline the care of our patients. This includes specific triggers, tools for comfort, and communication. It is important to consider the individual needs of children with ASD undergoing surgery. By collecting this information prior to the child's arrival, we aim to increase the comfort and outcomes of such patients in the future.

Literature Cited

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Results

From node 1: Behavior

PR 4: "He has a high pain tolerance, for some reason, sometimes pain is delayed. He can't tell you what's hurting, because he doesn't sign, you have to guess pretty much, or check everything in the hospital to see what's going on."

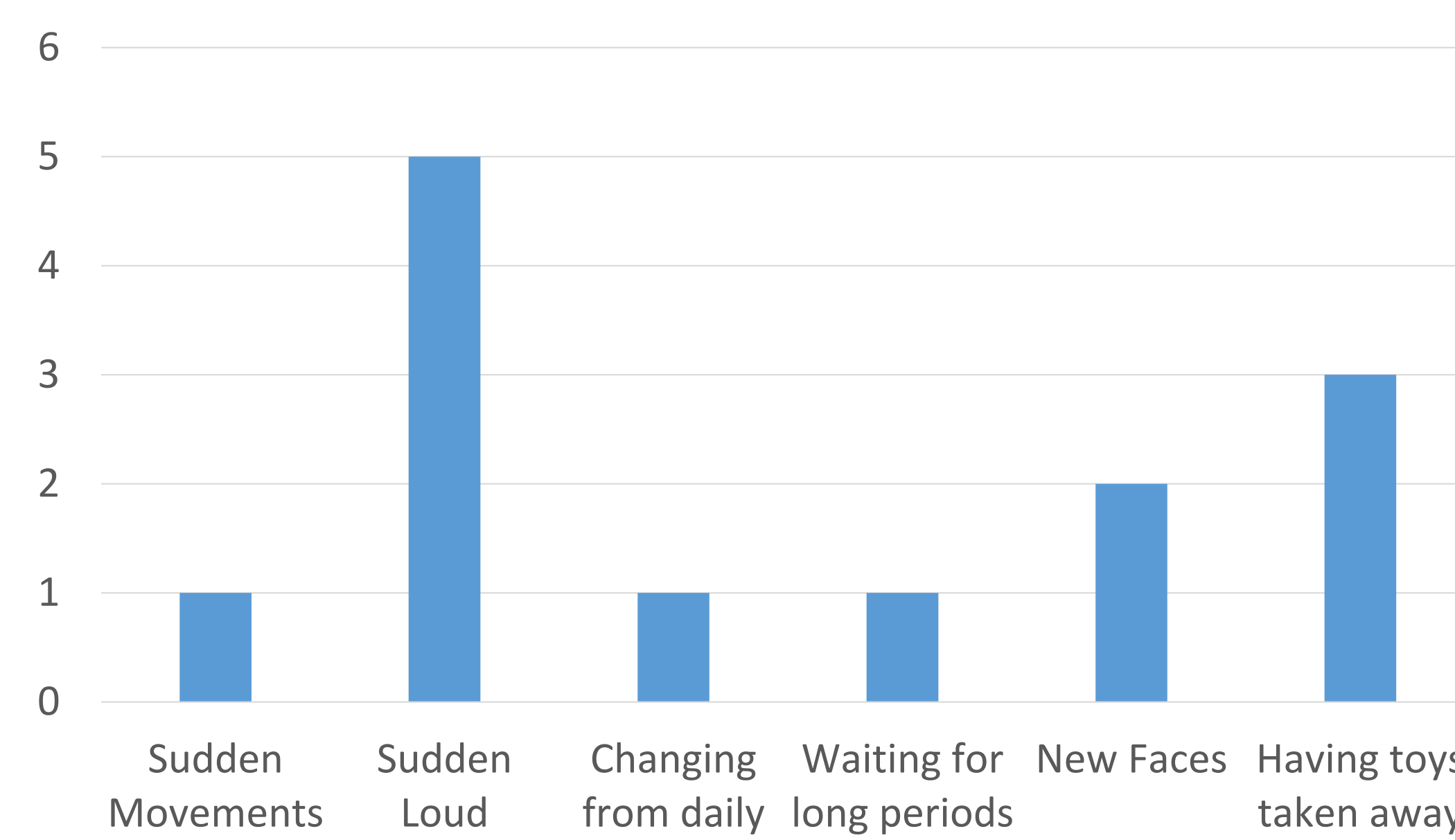
From node 3: Communication Issues

PR 6: "... When he is upset, he can't express what he's feeling, he can't express what he needs and he can't express what he wants or what he doesn't like. He ends up speaking his own language, and we have a hard time figuring out what it is that's going on."

From node 4: Important People

PR 3: "Important things are minimizing wait time and minimizing the amount of interactions with the baby, unless they are very needed, vitals we need to have. But if we can minimize interactions, he doesn't get upset before surgery"

Triggers for Behavioral Outbursts



- Mothers were the most common participant responders (10 out of 12), with one custodial grandmother and one father included.
- 9 of the 12 children were male, with age range 3-16 years, (median 6.5 and mean 7.33 years).

Out of 11 participants who spoke of specific behavior outburst triggers, the above were the most commonly mentioned triggers.

Major Suggestions Identified from Caregivers of Children with ASD:

- Waiting time should be minimized
- Parents need to be informed on what to expect post-operatively specific to ASD
- Patients must be talked to in calm, soothing voices
- Extraneous noise should be minimized
- Patients should be reminded to bring comforting toys from home
- Patients should have specific bedding from home if possible
- Interactions with patients should be minimized so they don't see many unfamiliar faces
- Staff should ask about any egregious triggers
- How to prepare the child for procedures should be discussed with caregivers; using the mask as a plaything may be helpful
- Staff should ask how to calm the patient pre or post operatively
- Staff should ask how the patient expresses pain
- Tools for communicating that the child uses regularly should be present
- Caregiver should be present in the recovery room before the child awakens
- The Vecta machine should be described and offered