

# Effect of Parent Present Induction of Anesthesia on Anxiety of Children with Autism Spectrum Disorder

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## RESEARCH

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## ABSTRACT

This exploratory research study investigated the perception of parents about the level of anxiety their child with Autism Spectrum Disorder (ASD) experienced during induction of anesthesia for dental procedures with the parent present in the operating room. An educational pamphlet about the induction experience was developed to educate parents about the Parent Present Induction (PPI) of anesthesia and what to expect during induction of anesthesia and their role in alleviating their child's level of anxiety. Participants completed an 11-item survey assessing parent-caregiver and child anxiety level and the usefulness of the PPI handout.

A convenience sample of nine English speaking parent-children with ASD dyads was recruited. The children with ASD were scheduled to undergo dental procedures under general anesthesia. After the child was safely under general anesthesia, and the parent left the operating room, the parent/caregivers was asked to complete an 11-item questionnaire that assessed parental perceptions of the child's anxiety level and their own anxiety level. Parents

received a written educational pamphlet explaining their role and what to expect during their child's anesthesia induction.

Wilcoxon signed-rank test and a paired t- test were used to analyze survey responses. Results showed that parents perceived that their presence during induction of anesthesia helped to reduce the child's anxiety:  $\mu = 3$ ,  $p = .005$ ;  $t = 6.38$ ,  $p = .000$ ), as well as their anxiety. Findings also supported effectiveness of the educational handout in reducing parental anxiety.

This study supports parental presence during induction of anesthesia for the child with ASD and it confirms the need to provide parents information about anesthesia induction and what to expect during the procedure.

**Key Words:** Stress, autism, child anxiety, surgery, parental teaching.

## BACKGROUND INFORMATION

The emotional fragility and potential behavioral issues of the child with Autism Spectrum Disorder (ASD) are unique and require specialized interventions. ASD is a neurodevelopmental disorder that presents with a range of manifestation or on a continuum of severity. Children with ASD are considered a special needs group and some exhibit repetitive movements or even self-abusive behaviors, including rocking, twirling or biting, or head banging [1]. Children with ASD tend to show characteristics of various delays in social interactions and communication. They may speak in third-person identification, experience difficulty in interacting with people, and in conjunction with repetitive and restricted behavior exhibition. These challenges for the child with ASD can become a struggle with communication



for them and has the potential to impair social interaction for this population with special needs [2].

The perioperative process is stressful for any child but for children with ASD, it can be especially challenging. Reducing the negative effect of any traumatic experience when a child undergoes surgery is of paramount importance for parents as well as for the healthcare professionals such as nurses, doctors and anesthesiologists. This study is significant as no other studies have been conducted that focus on parental presence with autistic children undergoing surgery. Furthermore, it adds to the literature about strategies that can be used to reduce the anxiety levels of autistic children undergoing traumatic experience, as well as reducing the parent's level of anxiety.

Change in routine or rituals, such as the perioperative process and induction of anesthesia, can be upsetting and stressful, especially for the child with autism. For the child with ASD, characteristics include compulsions, repetitive motor gestures, sensory seeking concerns, repetitive use of toys and objects, necessary rituals, and significant resistance to change. These criteria of behaviors have the serious potential to lead to panic attacks, aggression, tantrums, confusion, frustration, and-or combative behaviors [3]. Children with ASD typically experience abnormal sensory processing. The preoperative restrictions of fasting, in conjunction with major sensory overload such as bright lights, crying patients, unusual clothing, and cold rooms, are likely contributing factors to a traumatic operative experience that also includes induction of anesthesia and postoperative frustration, and agitation for the child with ASD [4].

Having parents/caregivers present during induction of anesthesia may facilitate a more positive experience for this group of children because parents/caregivers are often the best communicators for their special needs child and their presence may have a calming influence for them. They may be able to help comfort their child and assist the staff in understanding the child's communication patterns and sensory processing issues. However, parents need to be prepared for their role for this experience because the unfamiliar operative environment and their concern for

their child undergoing an operative procedure can be an anxiety producing experience. Therefore, the purpose of this pilot study was to determine the effect of parent present induction of anesthesia on the level of anxiety of children with autism spectrum disorder and the level of anxiety in parents present during their child's anesthesia induction. Two factors related to promoting quality patient and family centered care were investigated in this study: how to reduce anxiety to this special needs population undergoing anesthesia and how to best prepare the parent/caregiver.

In hospitals specializing in the care of children, there is currently an impetus to be acutely aware of the child's needs during the induction of anesthesia and the surgical process. The pediatric patient with autism may not be able to communicate fears in a manner that is understood by the hospital staff. The child may be seen as uncooperative and show troublesome and disruptive actions [5]. Some of the children with ASD may possess a level of cognition that is impaired, and they may not comprehend what is going on even though their chronological age may be older. A standard operative procedure for children is administration of oral medication such as midazolam in the pre-operative holding area. However, the child with ASD may have difficulty taking this medication or completely refuse the sedation due to an oral aversion, or severe inability to tolerate the bitter taste [6].

Although having the parent present at the time of induction of anesthesia can be comforting for the child, there are issues that should be addressed and acknowledged with parent-present induction (PPI). If the parent is outwardly anxious, this can be picked up by the child and can increase the child's level of anxiety. For this reason, parents should be properly prepared regarding their role during PPI [7]. A parent who is visibly anxious and upset can affect the child through a phenomenon called emotional contagion [8]. Having a child's parent present during the induction of general anesthesia has been debated in the literature. A parent who is fearful about anesthesia, the operative recovery process, and the possibility of an associated surgical death would not be a

candidate for PPI. If a parent is extremely anxious in the operating area, then PPI would not be beneficial for either the parent or the child [9]. If the parent becomes physically ill or nauseated or faints, the parent will require attention that will distract the OR staff from the child patient. The parent may not be prepared to see the child become “limp” when the anesthesia is administered, and this may increase parental anxiety.

An avenue to assist in lowering the parental anxiety may be by providing an educational handout to the parent regarding the process of anesthesia induction, and the temporary physiology changes seen in their child as they fall asleep. The process of accompanying the child into the operating room (OR) entails special instructions to prepare parents/caregivers for this experience so they can be in a supportive role for their child. Education can help in decreasing anxiety by providing knowledge of what to expect. Presurgical preparation can provide information to parents about how their child may react during the induction process and thus reduce the potential for emotional contagion. Parents would then be better able to calm the child, reduce the child’s anxiety, and help the operating room staff to communicate effectively with the special needs child. A study conducted by Chan and Molassiotis [10] demonstrated that parental education regarding their child’s induction of anesthesia had the potential of reducing parental anxiety and increasing their level of satisfaction with the care that their child has received. Therefore, a protocol was developed that included a teaching tool for parents of children with ASD to educate them with the goal of reducing parental stress during their child’s anesthesia induction period. The protocol also included a procedural component that outlined the necessary processes to conduct the study. The research questions tested were:

1. Will the presence of the parent with child with ASD in the Anesthesia induction room reduce the child’s level of anxiety as perceived by the parent?
2. Will the educational pamphlet and instruction given to the parent as to what to expect in the anesthesia induction room reduce the parent’s level of anxiety?

3. Will the parents find the educational pamphlet and instruction useful as their child is being prepared for anesthesia and surgery?

## METHODOLOGY

This pilot study used an exploratory research design to determine if (1) the presence of the parent of an ASD during anesthesia induction (independent variable) would reduce the anxiety of the ASD child as perceived by the parent (dependent variable); (2) if instruction to the parent regarding the process of pre-anesthesia induction process (independent variable) would decrease their level of anxiety (dependent variable).

The subjects or the participants were nine pairs of parent/primary caregiver-child dyads. The inclusion criteria were that they had to be English speaking and be the parent/or primary caregiver of a child with ASD. Only one parent/caregiver was allowed to accompany the child into the operating room during the anesthesia induction procedure. The child had to have a confirmed diagnosis of ASD and be scheduled for dental surgery under general anesthesia.

Data Collection Instruments: One questionnaire was developed by this researcher based on the review of the literature. The questionnaire had the following four parts: (1) Demographic Data; (2) Parent’s Perception of Child’s Anxiety Level; (3) Parent’s Anxiety Levels; (4) Effectiveness of the Parents’ Instructional/Educational Program.

**Part I: Demographic Data: It included three question items:** child’s age, whether or not the child had taken any anti-anxiety medications prior to coming to the hospital the day of the surgery, and whether or not any sedation was given while in the pre-operative area on the day of surgery.

**Part II: Parent’s Perception of Child’s Level Anxiety:** There were three pairs of question items that assessed parent’s perceptions of their ASD child’s anxiety level. Each pair assessed the same area of anxiety, only the questions were worded differently in an alternate form. Consistency in parental answers to the questions, whether

stated in a positive, negative or alternative format, were analyzed. The reliability of responses was at a 98% level. The questions were adaptive with approval from Mind Garden, Inc for the author to use the State Trait Anxiety Inventory for Children (STAIC). Once written approval was completed, the author selected inventory items to adapt to the study. Pediatric experts reviewed and confirmed the questions chosen were key items to assess the child's anxiety. Each question was developed using the 5-point Likert-type rating scale ranging from "Strongly agree" as receiving 5 points, "Agree: -4 points," "Neither Agree Nor Disagree" -3 points, "Disagree" -2 points, "Strongly Disagree"- 1 point., Scoring was done by three methods: (1) Since there were 6 question items, each ranging from 1 to 5, the total could range from 6 as very high anxiety and to 30 as very low anxiety. (2) Each of the questions were also scored and analyzed individually. Each question item ranged from "1" as having high anxiety on that one item to "5" as having no anxiety. (3) The third scoring method was achieved by assigning the answers into two categories--if the parent assessed Strongly Agree and /or Agree, it was categorized as "no anxiety" and coded and given a score of (1). If the parent circled the Neither agree or disagree, Disagree or Strongly Disagree, that question item was categorized as child experiencing "anxiety" and it was coded and given a score of "0".

For example, to understand whether presence of the parent/caregiver during anesthesia induction helped reduce the child's anxiety, questions 1-8 were coded as:

Levels	Meaning	Coded As
Strongly Agree, Agree	Presence of parent help child anxiety	1
Neither Agree nor Disagree, Disagree, Strongly Disagree	Presence of parent did not help child anxiety	0

**Part III: Parental Anxiety Level:** It consisted of two question items that measured parental anxiety level. The first question was "I had a positive experience in the operating room when I was present with my child during anesthesia". The second question was, "I experienced

tremendous anxiety while in the operating room when my child received anesthesia". The scoring on these two questions could range from 2 indicating high parental anxiety to 10 No parental anxiety. These two questions that tapped the same area of parental anxiety provided the reliability of this part of the tool, which was 100%.

**Part IV: Effectiveness of the Parents' Instructional/Educational Program:** It consisted of three question items that assessed parent's evaluation of the written handout/instruction as to what to expect in the operating room (OR) when they accompany their child to the OR on the day of surgery. The topics covered were, the expectations of the parent present in the OR, where they will be standing, the disposable attire they will be wearing, and the physical changes they will be observing in their child as they fall asleep once the anesthesia takes effect, and when they will be asked to leave the OR., and if they had any questions or comments that they wanted to share with the researcher.

The validity of this entire questionnaire was established via content validity by backing with the following literature: Short & Caulder, (2013); Short & Owen (2012), Brown, (1997), Lindberg et al, (2012).

**Procedure:** After permissions were obtained from the Institutional Review Board of the university, the children's hospital and a verbal consent from the parent, data collection started as each child was scheduled for their dental surgery. On the day of the surgery, the researcher or her designee who was trained in the protocol met the parent and the child in the pre-anesthesia room. After introducing and explaining the purpose of the study to those who volunteered to participate in the study, their verbal consent was obtained. Both, verbal and written instructions were given that explained the proceedings of the anesthesia administration protocol and expectations of the parent when they opt to be present in the operating room when their child is being prepared for anesthesia administration. Once the anesthesia induction had begun, and the child was properly under general anesthesia, then the parent was escorted out of the OR. Parents are also instructed to answer the questionnaire and place the data

sheet in the envelope, seal it, and place it in a locked receptacle on the pediatric waiting room area.

**Data Analysis:** Descriptive analysis was done using the means, median, standard deviations, and percentages. Additionally, paired t-test and Wilcoxon signed-rank test were used as appropriate, to answer the three research questions. More specifically, to compare parental perceptions of their child's anxiety levels between those answers below the "Neither agree nor disagree" and those above. Similarly, the same statistical test was conducted in analyzing parental evaluation of the usefulness of the educational information in reducing their level of anxiety.

An overall score for Questions 1 through 8 (AvgParView) in the survey was calculated to measure the perception that parents had regarding staying in the room with the child while the child was administered anesthesia. Likewise, an overall score for the PPI survey Questions 9 through 11 (AvgEffTool) was calculated to measure the effectiveness of the handout given to parents to help them understand what to expect while present in the operating room during the anesthesia induction procedure.

## RESULTS

Results are presented in the order of demographics followed by findings on each of the research questions. Eleven parents agreed to participate in the study, and 9 parents completed the PPI survey. Although two other parents agreed to participate, their child's sedation in the pre-operative area adequately caused sedation and calmness in the child and the anesthesiologist in charge of the case determined that parental presence would not be necessary. The age range of the nine participant children was 6 to 18 years, with a mean age of 12.7 years ( $SD = 4.5$  years) and a median age of 14 years (See results in Table 1).

All children were offered sedation in the pre-operative area but not every child received the medication. Whether the child was given or willingly took the sedation medication was a question of interest as to its potential effect on the PPI experience. Figure 1 illustrates the percentage of children (66.7%) who received oral sedation before being taken to the OR, based on parental recall. One

of the 9 parents (11.11%) was unsure whether the child had received pre-operative sedation and 2 (22.22%) indicated that the child either did not receive or refused to take the sedation medication.

Results related to the first research question of "Will the presence of the parent with their ASD child in the anesthesia induction room reduce the child's level of anxiety as perceived by the parent?" (AvgParView) are presented in Table 1. The overall mean score for the parental perception of child's anxiety level was 4.26 ( $SD = 0.59$ ), with a median of 4.50 and a range of 3.38 to 5.00. The Wilcoxon signed-rank test with continuity correction was conducted to answer the first research question. Results showed the value to be  $\mu = 3$ ,  $p > .004$  indicating that the parents perceived accompanying their child to the OR for anesthesia induction reduced the child's anxiety significantly. A paired t-test was also conducted to see whether the AvgParView was significantly greater than 3 (*neither agree nor disagree*). A mean of 3 or more on the AvgParView suggested that the parents felt that their presence in the OR with their child diagnosed with autism was helpful in keeping the child calm and less anxious. The overall mean score on this variable was 4.26 ( $SD = 0.59$ ). A t-value of 6.38,  $p > .0001$  was obtained indicating that presence of the parent was perceived as lowering the child's anxiety level.

It is important to note that the ninth child took an antidepressant medication, Paxil, which presented the potential for the child to be different from the other children. Therefore, the sample mean was analyzed without the ninth score. After deletion of the ninth score, the  $p$  value was still less than .0004 for the parametric  $t$  test and .004 for the nonparametric Wilcoxon signed-rank test. Based on this result, it was concluded that the parents perceived that being with the child made the child calmer or less anxious.

Figure 2 illustrates the distribution of the average parent view or perception of how their presence affected the child's anxiety level. The majority distribution of parental-caregiver responses shows a left skew, illustrating the preferred response of the parents-caregivers of children with ASD perceived their presence to be helpful during the

induction of anesthesia of their child with autism. The dotted line kernel is a nonparametric smoothing density to demonstrate the predicted results if the sample size was larger.

When each question was in terms of the percent of parents responding positively (relieved their child's anxiety) or negatively (it did not relieve their child's anxiety), findings presented in Table 2 supports the results of both Wilcoxon and paired t-test results.

Results presented in Table 2 showed the following findings presented in the order of the questions presented to the parents:

1. *My presence in the operating room helped to lower my child's level of anxiety while he/she was given anesthesia.* For this question 100% of the participants believed that their presence in the operating room helped to reduce their child their child's level of anxiety.

2. *My presence in the operating room helped keep my child calm while he/she was given anesthesia.* For this question 100% of the participants believed that their presence helped keep their child calm in the operating room while the child was given anesthesia.

3. *My presence in the operating room didn't seem to calm my child or make them less nervous.*

Seven of the 9 (78%) of the participants stated that their presence helped their child to calm down or be less nervous

4. *My presence in the operating room helped my child relax while he/she was given anesthesia.*

Eight of the 9 (89%) of the participants believed that their presence in the OR helped their child relax while he/she was given anesthesia.

5. *My presence in the operating room made my child more cooperative while he/she was given anesthesia.* Eight of 9 (89%) of the participants believed that their presence in the OR made their child more cooperative while being given anesthesia.

6. *My presence in the operating room didn't seem to make my child less confused.* Five of the 9 (56%) participants stated that their presence in the operating room help their child be less confused.

7. *I had a positive experience in the operating room when I was present with my child during anesthesia.* Eight of the 9 (89%) of the participants stated that they had a positive experience in the OR.

8. *I experienced tremendous anxiety while in the operating room when my child received anesthesia.* Five of the 9 (56%) experiencing anxiety while in the OR when their child received anesthesia.

Collectively, between the 9 pairs of parent child dyad, there were 72 responses. Of the 72 responses 59 (82%) of those suggested that the presence of the parent/caregiver helped reduce the anxiety of the child with autism and the parent (Items # 7 and #8). Therefore, having the parent/caregiver present in the operating room during the induction of anesthesia helps reduce the child's anxiety as well as the parents' anxiety.

In analyzing the findings related to research question two, there were 24 responses and 18 (75%) of those responses suggested that the educational handout was an effective tool in preparing the parent/caregiver for what to expect in the operating room.

9. *The handout I received was helpful in preparing me for the experience of being in the operating room while my child received anesthesia.* Eight of the 9 (89%) found the handout helpful in preparing them for the experience of being in the operating room while their child received anesthesia.

10. *After reviewing the handout I feel it answered my questions about being in the operating room with my child.* Six of the 9 (67%) of the participants reported the handout answered their questions about being in the OR with their child.

11. *I feel that I knew what to do in the operating room: like putting on the cover-up, hat and where to stand after reading the handout.* Seven of the 9 (78%) felt like they knew what to expect in the OR after reading the handout. Therefore, 21 (78%) of the 27 responses to the questions found the handout helpful.

There were two items that measured parental anxiety level and addressed the second research question- Will the educational pamphlet and instruction given to the



parent regarding expectations in the anesthesia induction reduce parental level of anxiety? The first question was: "I had a positive experience in the operating room when I was present with my child during anesthesia". Eight of the 9 (89%) parents reported that they had a positive experience in the operating room. The second question item was, "I experienced tremendous anxiety while in the operating room when my child received anesthesia". Results showed that five of the 9 (56%) parents reported as experiencing anxiety when their child was receiving the anesthesia. When the two questions are put together 66.6% of the parents reported reduction in their anxiety level.

Findings related to the third research question of "Will the parents find the educational pamphlet and instruction useful as their child is being prepared for anesthesia and surgery?" are presented in Table 1. Scores for responses to questions 9 through 11 were summed and descriptive statistics were calculated to reflect the overall perceptions of parents about the usefulness of the educational handout. In Table 1 these scores are labeled as AvgEffTool to represent the variable of parental perceptions about the effectiveness of the educational tool. The overall mean parental score for these three items was 4.37 (SD = 0.72), with a median of 4.67 and a range of 3.33 to 5.00. The Wilcoxon signed -rank test with continuity correction was conducted to answer the third research question. Results showed the value to be  $\mu = 3$ ,  $p > .01$ , indicating that the parents found the written instruction helpful in keeping the child calm and less anxious. A paired t-test was also conducted to determine whether the AvgEffTool was significantly greater than 3 (*neither agree nor disagree*). A mean of 3 or more on the AvgEffTool suggested that the parents felt that their presence in the OR with their child diagnosed with ASD was helpful in keeping the child calm and less anxious. The overall mean score on this variable was 4.37 (SD = 0.72). A t-value of 5.74,  $p > .0002$  was obtained indicating a significant number of parents found the instructional pamphlet useful. This finding was consistent with the Wilcoxon signed-rank test.

There was additional support that the educational handout discussing what the parent-caregiver should expect

while present in the OR during induction of anesthesia for their child with autism was an effective tool. Figure 3 illustrates the distribution of the average effectiveness scores for the educational handout-tool as reported by the sample.

### ADDITIONAL FINDINGS

A Pearson correlation test was conducted to test the relationship between age of the child with autism and the parent-caregiver's perception of lowered anxiety during PPI of anesthesia. Table 3 reports the findings of the Pearson correlation testing that compared the variables of age and perception of lowered anxiety. Results,  $r = -.134$ ,  $p = .732$ , demonstrated no significant correlation between the age of the child and the level of the child's anxiety while parents stayed in the OR during induction of anesthesia.

Although the correlation of anxiety and age was not significant, it is important to understand that, in children with ASD, chronological age does not necessarily relate to behavioral or cognitive age. The neurocognitive behavior disorders of children with ASD have a varying range of expression, extending to children who may be noncommunicative, with no expression of language, severe anxiety and combative or aggressive behaviors, repetitive behaviors or tics, to the opposite end of the spectrum in which the child may be high functioning but exhibit nonsocial behaviors and fixation on a particular interest or object. Therefore, in this special need group, chronological age is not necessarily relevant in predicting children's behavioral responses to anxiety-producing situations [11].

A more extensive analysis of the PPI survey was done on the parental perception of child's anxiety level. Table 3 presents the results in terms of the response percentages for each question on the questionnaire (items 1-8).

### DISCUSSION

The major finding of this study is that parental presence during anxiety producing events in the life of their child has a soothing effect on the child and reduction in

their stress level [5, 8]. Findings related to the first research question, *“Will the presence of the parent with their child with ASD in the anesthesia induction room reduce the child’s level of anxiety as perceived by the parent?”* demonstrated having the parent present in the anesthesia induction room reduced the anxiety of the child. This finding can be explained from the perspective that perioperative process is stressful for any child; however, for these children with ASD, it can be especially challenging. Children with ASD typically experience abnormal sensory processing, therefore a change in routine or rituals, can be upsetting, anxiety producing, and stressful. It can lead to panic attacks, aggression, tantrums, confusion, and-or combative behaviors [3]. This finding is also consistent with the study of Short and Caulder, (2013) and Short and Owen, (2012) who found similar results.

The first and second research questions are related to one another. Will giving instructions to the parents of children with ASD, who are accompanying their child to the anesthesia induction room, assist them in what to expect when they go to the OR (eg., the hospital attire they will be given to wear, a safe place where they will be designated to stand, physical changes that they will be observing in their child as the child falls asleep under the influence of the anesthesia)? Will the instructions provided be perceived by the parent as helpful in decreasing their anxiety? Results presented in Tables 1 and 2, and Figures 2 and 3 demonstrate giving instruction had a mixed result with respect to lowering the anxiety level of the parent. Approximately 66.6% of the parents felt that their anxiety was reduced. One of the possible explanations of this lack of strong support may be due to the misinterpretation of the second question, where it asks the parent to rate from strongly agree to strongly disagree the following question: *“I experienced tremendous anxiety while in the operating room when my child received anesthesia”*. Whereas the first question asks, *“I had a positive experience in the operating room when I was present with my child during anesthesia”*, where the same parents score 89% in agreement that the instructions given made them have a positive experience. These two sentences were designed to tap the same area

only worded one in terms of positive (reduction of anxiety) and the other in the opposite direction (increase in anxiety). The incongruence between the responses to these two questions may have been due to either the misinterpretation of the questions or that the questions are not tapping the same construct.

The third research question asked, *“Will the parents find the educational pamphlet and instruction useful as their child is being prepared for anesthesia and surgery?”* A significant number of parents found the written instruction given to them prior to their child’s undergoing anesthesia induction were very useful in calming the parent down and that assisted them in helping calm their child. This finding is consistent with very well-known classic theoretical framework of stress, causes and interventions for relieving them by Hans Selye) and Janis [12, 13]. Both researchers postulate that one of the causes of stress is fear of the unknown. One way to remove the anxiety and fear of the unknown is through education. This study provided the education piece through the handout and the proper instruction to the parent/caregiver to lessen or relieve the parental stress that would be due to lack of knowledge. The findings of this study are consistent with the studies of Aranha et al., who found that parents have the potential to be disturbed and anxious while they are in the preoperative area waiting for their child to surgery. They concluded that a preoperative education program of parents viewing a preoperative video and given an educational handout had a significant change ( $P=0.001$ ) in their experimental study group. The program allowed the parent to gain knowledge and empowered the parent to feel more prepare for the anesthesia and surgery [14].

## IMPLICATIONS OF THE STUDY

Although the sample size was small, cautious generalizations and implications can be made based upon the findings of this study. Whenever possible parents should be allowed to accompany their hospitalized child when they are undergoing traumatic or stressful procedure such as anesthesia induction. Parental or caregiver presence can



reduce their child's anxiety when undergoing stressful procedures. This is especially important for "special needs" children who are diagnosed with ASD.

Another key implication is based upon the finding that parents found the written instruction about what to expect in the anesthesia induction room as very helpful. The preparation for the induction experience reduced their own level of stress about the experience, which, in turn, helped them to be present for their child and to reduce their child's anxiety. As mentioned previously, one of the causes of anxiety is the fear of the unknown. The antidote for lack of knowledge is provide knowledge through instruction.

Finally, the study adds to the body of knowledge on the care of autistic children undergoing traumatic experiences and in the reduction of parental stress level. Having a parent whom the child knows, and trusts accompany the child to the operating room has a stress/anxiety reduction buffering effect on the child with special needs. Also, providing instructional information to the parent about their role in comforting the child and what to expect during the operative induction experience can better prepare the parent and thus reduce parental stress associated with not knowing what to expect. Less anxious parents translate to less anxious children.

A word of caution is also in place regarding taking parents to the operating room or the anesthesia room. Proper assessment of the parent needs to take place for possible adverse effects prior to allowing a parent to accompany their child to the anesthesia induction room is important. There is substantial evidence of problems associated with parental presence during anesthesia induction of their child, including issues related to parents' fainting in the OR, refusal to leave the OR once the child was sufficiently under anesthesia, and insufficient education about what to expect in the OR and proper procedures to follow while in the OR. These points to the need for preparatory education and the establishment of published guidelines. This project involving parents of children with ASD revealed positive responses as noted by parental self-reports. Parents who received approval from their child's anesthesiologist reported no untoward anxiety-related

experiences for either themselves or their child; however, one parent asked for additional information about what to expect during the induction of anesthesia as her child "appeared very resistant" during the induction process.

Interdisciplinary research is needed that involves professional and ancillary staff whose role is to prepare the child and parent for the anesthesia induction and the OR environment and experience. Research efforts should focus on strategies emphasizing a holistic approach to the PPI experience with support of the child and parent from the healthcare team. In-services and education for the perioperative staff in collaboration with anesthesia providers and dentists performing dental procedures under anesthesia is a best practice that supports quality of care for children with ASD and their families. Therefore, an area of study that needs to be addressed is how to best prepare parent/caregiver and child for anesthesia induction knowing the common behaviors and sensory issues of the child with ASD. Moving this concept forward also requires providing parents with education tools before the procedure so they can be adequately prepared for their supportive role. Dialoguing with the ASD community and experts to seek recommendations on how best to prepare children and their parents for the surgery experience can be of value. Accordingly, the perioperative experience for parent and the child with ASD should be well organized with both ancillary and professional staff roles and duties outlined in a PPI protocol. Clinical practice guidelines outlining best practice PPI interventions for this vulnerable population of pediatric patients are also needed.

One final point that requires consideration is the cost of possible delay of OR start times when a child with ASD is uncooperative and behavioral issues delay the induction process. The goal of PPI is to reduce the child's anxiety level so that there is a smooth transition without addition time expenditure. Although this project was not focused on cost-cutting containment in medical centers, it is prudent to address this issue and include it in this discussion because cost factors associated with delayed surgical start times are discussed in medical centers today. Cost per minute of OR time has many variables that are influenced

by geographical location of the hospital, type of procedure or surgery being performed, complexity of the case, staff, and surgical devices needed. OR charges can range from \$29 per minute for low-complexity cases to \$80 per minute for high-complexity cases [15]. These cost estimates do not include anesthesiologist and surgeon provider fees. The impact of the average of these costs delayed start in the OR is \$435 to \$1,200 for a postponement of only 15 minutes. PPI could also result in delayed procedure if a parent is not properly prepared to accompany the child into the OR and stay for the induction procedure. Therefore, the importance of parental education and preparation is paramount to ensure that parental participation does not increase delays in OR time. Future studies should weigh the importance of family-centered care in the pediatric hospital with the realities of cost effectiveness in the 21st century.

### LIMITATIONS OF THE STUDY

One of the limitations of the study is the smallness of the sample size. It is recommended that the study be repeated with a larger sample to increase its generalizability. Other limitations of the study that limits the generalizability of the study included the fact that parents had to be English speaking, there was a self-selection bias, participation was limited to parents of children with ASD, and the anesthesiologist had the right to exclude any parent whose child had a comorbidity or problems that the anesthesiologist believed would make it inappropriate for the parent to be present during the induction of anesthesia. The severity of the behavioral component of the child's ASD was not measured because of the lack of a reliable tool and the negative impact that adding a behavioral assessment would have had in recruiting study participants. One other limitation was that 8 of the 9 children received medication sedation prior to the induction of anesthesia, which may have confounded the determination of what proportion of anxiety reduction was due to the sedative and what proportion for the presence of the parent. Future studies need to control for this factor.

### SUMMARY AND CONCLUSION

The perioperative process is stressful for any child but for children with ASD, it can be especially challenging. Parental presence as the child is about to undergo a traumatic event such as anesthesia induction prior to undergoing surgery helps relieve the child's anxiety. Providing instruction to parents of children scheduled for surgery helps parents to be more instrumental in relieving both their child's anxiety as well as their own.

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#### **PEER REVIEW**

Not commissioned. Externally peer reviewed.



## TABLES

**Table 1:** Descriptive Statistics for Responses to Survey Questions.

Variable	Mean	Median	SD
Age of child	12.72	14.00	4.487
AvgParView	4.26	4.50	0.59
AvgEffTool	4.37	4.67	0.72

**Table 2:** Additional Descriptive analysis of all the questions dealing with child's and parent's anxiety levels.

Question # and Item	Meaning	Score	Percentage (%)
1. My presence in the OR helped to lower my child's level of anxiety while he/she was given anesthesia	Participants believed that their presence in the operating room (OR) helped reduce their child's anxiety	9:9	100%
2. My presence in the OR helped keep my child calm while he/she was given anesthesia	Participants believed that their presence helped keep their child calm in the OR while the child was given anesthesia	9:9	100%
3. My presence in the OR didn't seem to calm my child or make them less nervous	7:9 Participants stated that their presence helped their child to calm down or make less nervous. (scoring in reverse)	7:9	78%
4. My presence in the OR helped my child relax while he/she was given anesthesia	Participants believed that their presence in the OR helped their child relax while he/she was given anesthesia	8:9	89%
5. My presence in the OR made my child more cooperative while he/she was given anesthesia	Participants believed that their presence in the OR made their child more cooperative while he/she was given anesthesia	8:9	89%
6. My presence in the OR didn't seem to make my child less confused	Participants stated that their presence in the OR helped their child be less confused. (scored in reverse)	5:9	56%
7. I had a positive experience in the OR when I was present with my child during anesthesia	Participants stated that they had a positive experience in the OR	8:9	89%
8. I experienced tremendous anxiety while in the OR when my child received anesthesia	Participants experienced anxiety while their child received anesthesia	5:9	56%

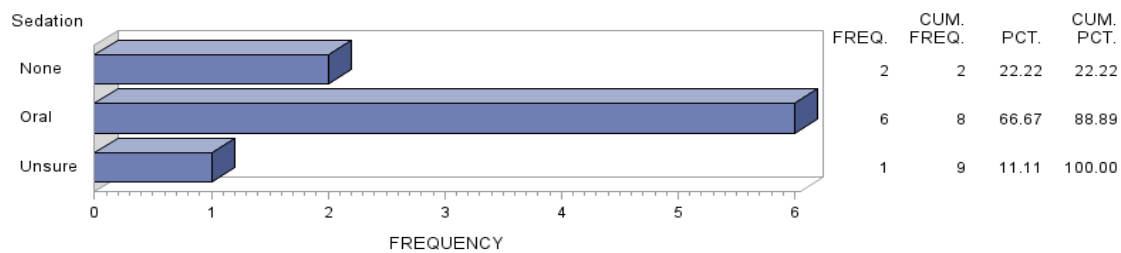
**Table 3:** Pearson Product Moment Correlation (r) of Child's Age and Parent's Perception of Lowered Anxiety

Variable	Age	AvgParView
Age	1	-.134 (p=.732)
AvgParView	-.134(p -.732)	1

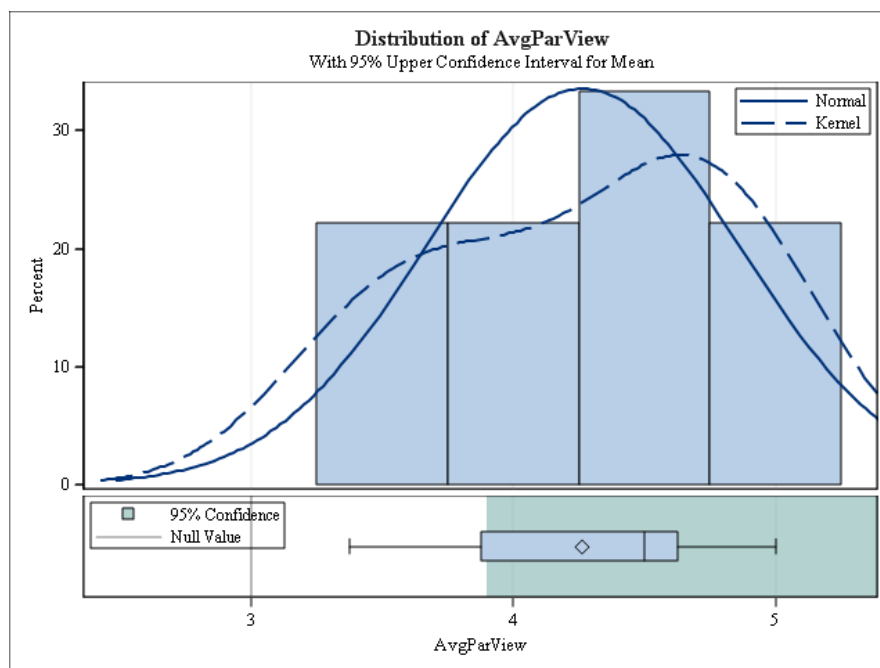
Note. A  $p$  value of  $>.05$  shows that the result was not statistically significant. The negative Pearson correlation illustrates a negative correlation and therefore age was not significant in the parent's perception of lowered anxiety level during induction of anesthesia.



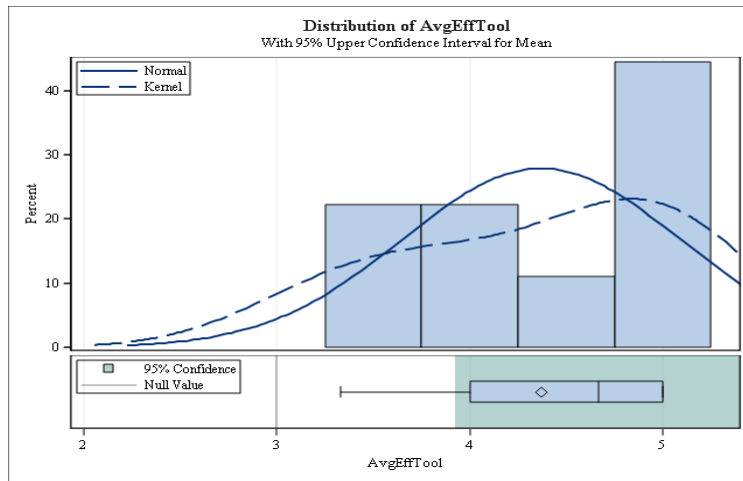
## FIGURES



**Figure 1.** Sedation received in the pre-operative area before the induction of anesthesia.



**Figure 2.** Distribution of the average parent view or perception of the autistic child's anxiety level. A score of 3 is the median response neither agree nor disagree. Below the histogram, the diamond represents the mean and the solid line following that represents the median of the parental responses. Having the parent-caregiver present in the operating room during induction of anesthesia helped to reduce the anxiety of the child with autism.



**Figure 3.** Distribution of the average effectiveness scores for the educational handout. The handout, which described what the parent-caregiver should expect while present in the operating room during induction of anesthesia for the child with autism, was perceived by the parents-caregivers to be an effective tool.