

Southern California CSU DNP Consortium

California State University, Fullerton  
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PARENT PRESENT INDUCTION OF ANESTHESIA IN CHILDREN WITH  
AUTISM: PARENTAL PREPARATION

A DOCTORAL PROJECT

Submitted in Partial Fulfillment of the Requirements

For the degree of

DOCTOR OF NURSING PRACTICE

By

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## ABSTRACT

This exploratory study investigated perceptions of parents-caregivers of children with Autism Spectrum Disorder (ASD) who were present during induction of anesthesia for their child's dental procedure. An education handout about the induction experience was developed for the study. Participants completed an 11-item survey assessing parent-caregiver and child anxiety level and usefulness of the handout.

A convenience sample of nine parents-caregivers of children with ASD who had dental procedures under general anesthesia and self-identified as able to understand and read English completed a survey about their perceptions of the induction experience. The parents received an educational handout explaining their role and what to expect during their child's anesthesia induction.

Wilcoxon signed-rank test and an upper tailed  $t$  test were used to analyze survey responses. Parents-caregivers perceived that their presence during induction of anesthesia helped to reduce the child's anxiety :  $\mu = 3, p = .005; t = 6.38, p = .000$ ) Findings supported effectiveness of the educational handout that described what parents-caregivers could experience in the operating room during induction of anesthesia : median = 4.67,  $p = .004; t = 5.74, p = .0002$ .

This study supports parental presence during induction of anesthesia for the child with ASD undergoing dental procedures. It confirms the need to provide parents-caregivers information about anesthesia induction and how their child may react during this process, as well as familiarize parents about what to expect in the operating room.

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## INTRODUCTION

Family-centered care has become the cornerstone of pediatric medical centers. The momentum of this transition has resulted in greater involvement by families in the health care delivery model for children in both hospital and ambulatory care settings. Pediatric medical centers and facilities have recently intensely introduced and incorporated a greater involvement of families in the care of their child. Evidence has shown that this implementation of the family-centered care partnership during the hospitalization of the pediatric patient has decreased the stress related to hospitalization for both parents and child (Chorney & Kain, 2010).

Children who are scheduled for surgical and diagnostic procedures under general anesthesia require preparation. Child preparation is imperative; however, parental anxiety on the day of surgery can exacerbate the child's anxiety level. According to Chorney and Kain (2010),

similar to children, parents desire information about their child's procedure. In fact, more than 50% of parents do not just want to know, but believe that they have a right to know about all possible complications, details on pain or pain relief and details on sedative premedication. Indeed, when provided detailed information, parents were not more anxious when compared with parents who received minimal information. (p. 752)

A critical literature review by Franck and Spencer (2005) found that parents desired information about their child's anesthesia and that this information increased their knowledge and reduced anxiety. Parents who wish to be present during the induction of anesthesia for their child must be prepared for this procedure because it can be frightening for a parent to see the child become limp, agitated, or assisted with breathing through the use of supplemental oxygen delivered via a mask and Ambu bag.

The pre-anesthesia experience deserves attention because of its emotional impact on the pediatric patient. Children who are at particular risk for negative outcomes related to their anesthesia experience are those at specific developmental ages (the very young child) and those with special needs due to developmental delays, behavioral issues, and/or cognitive deficiencies. They are often the most vulnerable pediatric population with respect to anesthesia and the entire perioperative experience. Separating certain pediatric patients from their parents for the induction of general anesthesia may be traumatic, even with adequate pre-operative sedation. This traumatic event has the potential to be extremely anxiety producing for the child with a behavioral diagnosis such as Autism Spectrum Disorder (ASD).

Hospitalization, especially surgery, can be a particularly anxiety-producing event for the patient. Attempting to explain the pre-anesthesia process to children, especially those with cognitive delay or impairments such as ASD, is often difficult. It can be taxing and filled with tension for parents and health care providers as they try to prepare and convey information in words and images that the child can understand.

Children with the neurodevelopmental disorder ASD may have disconnection with social interaction or communication (Abraham, Shah, & Parray, 2010). Due to their neurocognitive disorder, these children are at heightened risk for increased anxiety and agitation that may be manifested in self-destructive behaviors and heightened aggressiveness during the pre-operative event and during the induction of anesthesia. Some common concerns found in clinical studies of children with ASD are anxiety and deficient stress management (White, Oswald, Ollendick, & Scahill, 2009). White et al. (2009) concluded that, in children and adolescents with ASD, anxiety can be influenced

by age, level of cognitive development, ASD-specific complications (e.g., overstimulation), and level of social impairment. The perioperative process may be exacerbated by separating the child from the parents and bringing the child to a cold, sterile operating room (OR) where the staff are wearing masks and hats. For the nonverbal communicative child with ASD, this highly charged environment may initiate a cascade of combative behavior.

### **Need for This Study and Problem Statement**

The emotional fragility and potential behavioral issues of the child with ASD are unique and require specialized interventions. These children are considered a special needs group. Having parents present during induction of anesthesia may facilitate the child's experience because the parents are communicators for this group. The perioperative experience may be extremely anxiety producing, and parents of these children may be able to help comfort the child and assess the staff's understanding of the child's communication patterns.

ASD is a neurodevelopmental disorder that presents with a range of manifestation or on a continuum of severity. Some children with ASD exhibit repetitive movements or even self-abusive behaviors, including rocking, twirling or biting, or head banging (National Institutes of Health, 2006). Some children with ASD tend to show delayed language development, speak in a third-person identification, and experience difficulty in interacting with people. The struggle with communication is likely to impair social interaction for the child with autism (Fernandez & Challands, 2009). The perioperative process can be stressful for any child but for these children with ASD, it can be especially challenging. 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; it can lead to panic attacks, aggression, tantrums, confusion, and-or combative behaviors (Fernandez & Challands, 2009).

In the hospital specializing in the care of children, there is currently an impetus to be acutely aware of the child's needs during 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 (Short & Caulder, 2013). 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 (Short & Owen, 2012). A parent's visible anxiety and being upset can affect the child through a phenomenon called emotional contagion (Brown, 1997). 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.

Parents need to understand what the process of accompanying the child into the OR entails so they can be present during the induction of anesthesia. They need education to prepare them for this experience and their supportive role with their child. Education can help in decreasing anxiety and, with knowledge of what to expect, help parents be more effective in their supportive parental role. This 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 OR staff to communicate effectively with the special needs child. Based on their research findings related to PPI, Chan and Molassiotis (2002) concluded that education for parents that prepares them for their child's induction of anesthesia can reduce anxiety and increase parents' satisfaction with the care that their child receives.

Although in the study's participating medical center, PPI is mentioned to parents by nurse practitioners during their child's presurgery approval assessment, this nurse practitioner researchers noted that few parents actually took advantage of this opportunity to be with the child as a source of support. This lack of parental participation became the impetus for this research study, which was designed after discussion and consultation with nurse practitioner colleagues and anesthesiologists at the medical center.

## REVIEW OF LITERATURE

This review of literature includes information about ASD, stress related to the surgical experience of children and their families, and key research findings about parental presence during induction of anesthesia. This information and evidence noted in these research studies guided this project director in identifying the key educational elements to be addressed in the PPI handout and the factors related to parental perceptions of their involvement in PPI that were explored in the PPI survey.

Hospital policy changes, such as permitting a parent-caregiver to be present during induction of anesthesia or allowing a parent or spouse to be present during cardiopulmonary resuscitation, have been momentous steps to promote family involvement in the care of loved ones. In caring for pediatric patients, the PPI program is a vehicle to involve parents in comforting their child and possibly lessening the trauma of the surgical experience for the child.

Separation, leaving the parents' side and going into surgery, can cause distress in a child (LaRosa-Nash & Murphy, 1996). Worry and concern can be compounded in the autistic child. As described by Lindberg, Von Post, and Eriksson (2012), autism is a neurocognitive disorder that lies on a spectrum of expression for children who are affected. A child with autism can present with many ranges of behaviors and symptoms that can be plotted along the spectrum. The autistic child may have any of the various neurocognitive behavioral disorders that range from 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 a child can be high functioning but exhibit nonsocial behaviors and fixation on a particular interest or object.

Thus, children with ASD are at significant risk for increased communication difficulties and behavioral issues when hospitalized. In addition, if a surgical intervention or general anesthesia is needed, the OR setting and its sterile environment can overwhelm a child with ASD, especially if that child is separated from a parent or caregiver who is familiar with the child's style of communication and the meaning of the child's behaviors.

On a positive note, PPI has the possibility of helping the autistic child to cope with an upsetting and possibly terrifying experience. An extremely unfamiliar arena such as the OR and unknown people such as the OR staff can send the child with ASD into a panic due to an inability to handle change. Lindberg et al. (2012) conducted a qualitative study that investigated the experiences of parents of children with severe autism in connection with their children's anaesthetics in the presence and absence of the perioperative dialogue. Parents reported that discussions with the anesthesiologist were helpful in alleviating their fears. This research study supports the need for parental education for this special needs group undergoing anesthesia. The study education tool used in this study was designed to provide information to parents about the induction procedure.

Hallahan and Kauffman (2005) identified ASD as five states : Autism, Asperger's Syndrome, Rett Syndrome, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder. ASD encompasses a range of behaviors that include problems with communication, social interactions, and the action of repeating a behavior many times. Each child with ASD has a different reaction or response to a tactile, verbal, or sensory event. An important characteristic of children with ASD is that they are unable to use cognitive thoughts to calm themselves in a situation that is not a rigid routine

(Hallahan & Kauffman, 2005). Depending on developmental levels, some age groups of children have difficulty with being flexible; in the child with ASD, this is extremely problematic. Taking a child to the OR engenders a particular concern and may pose a problem in attempting to deliver anesthesia to a combative, aggressive child with limited behavioral, cognitive, and communicative abilities.

Several responses to stress and anxiety prior to surgery have been identified as the child's perception of the threat of bodily mutilation, the process of being separated from parent or caregiver, and overstimulation from being in a strange environment. The child may feel a loss of control and a violation of familiar routines. Rosenbaum, Kain, Larsson, and Lonnqvist (2009) estimated that about 70% of all children in the pre-operative setting may display some type of stress and anxiety before surgery.

Family-centered care has developed as an essential component of quality health care delivered at children's hospitals throughout the United States and internationally, as it benefits both staff and families. The family-centered care methodology uses the approach of incorporating teamwork. The ideal is for the team to respect each individual family member's strengths; identify the family's strengths, culture, mores, and traditions; and assess their proficiency for caring for the child (Chorney & Kain, 2010).

### **Theoretical Framework**

The theoretical framework for this project was Lewin's change theory, one that is consistently studied in nursing. Lewin studied the change processes of humans and the driving forces that develop and implement change. The first stage of the change process is "unfreezing," which means that people let go of old behaviors; the next step is the changing movement; and the last stage is "refreezing" the new idea or process. The most

significant procedure is to consider potential driving and restraining forces; this must be done before implementing a change process (Kritsonis, 2005). Lewin's theory demonstrates effects of forces that can implement or impede change.

In the current project, change was implemented by developing a PPI handout (input) to educate parents. Collecting data from parents via the PPI survey was another component of input that can be used to develop a protocol (output) to assist staff in their family-centered care of children and parents when a child must be given general anesthesia and the parent is allowed to be present during the induction phase.

This project involved PPI for children with ASD because these children represented a special needs group whose communication skills were limited. The parent may be the only one who can read the child's nonverbal behaviors and who can keep the child relaxed in new and potentially frightening hospital experiences. Thus, the need for this project is great in the pediatric hospital setting under investigation.

### **Purpose of the Project**

This was an exploratory and quality improvement pilot project for designated parents-caregivers of special needs children with ASD who underwent dental restoration and-or dental extractions. This project investigated the perceptions of parents-caregivers who were given approval by the Department of Anesthesia (specifically by the child's anesthesiologist) to be present in the OR during the induction of anesthesia. At the time of this study, there were no specific educational materials available to prepare parents for this procedure or their role and expected events during the anesthesia induction, nor was there a written protocol in place to guide staff about PPI for children with ASD. Therefore, an educational handout was developed for parents of children with autism to

educate and prepare them for the perioperative experience that culminates in induction of anesthesia.

The purpose of this project was twofold. First, the author sought to develop a clinical project-protocol related to promoting family-centered care for children with ASD. This particular group of patients was assessed as needing general anesthesia for the procedure of dental restorations and-or possible dental extractions. The project protocol was to present to the parent of the child with ASD the option to be present with the child during the induction of anesthesia to evaluate whether their presence reduced the anxiety of their special needs child. The second goal was to explore the effectiveness of the educational handout in preparing the parent of the child with autism for the PPI process.

### **Program Goals and Objectives**

This project has three goals. The first goal was production of a simple educational handout to inform parents-caregivers about what to expect and their role with their autistic child in the OR while the child receives anesthesia. Examples include wearing surgical attire, following OR protocols for where to stand, how anesthesia affects the child in relaxing the body, and how the parents will exit the OR immediately once the child is anesthetized or at the discretion of the anesthesiologist.

The second goal of the project was to identify the parents' perception of and significance, if any, of anxiety reduction and cooperation of the child with autism as the child receive anesthesia by having the parents-caregivers present in the OR. This was achieved by data collection using a short questionnaire completed by the parent-caregiver upon leaving the OR.

The third goal of the project was development of a PPI protocol-procedure to be presented to a selected perioperative committee for possible implementation of the protocol for children with autism. This included screening for suitability of the parent-caregiver to be present and communication among presurgical admitting staff, the attending dental surgeon, the perioperative nurse practitioners, nursing staff, and anesthesiology staff.

## **METHODS**

### **Design**

This quality improvement project involved a two-phase development plan. The first phase focused on development of a quality improvement effort by the perioperative division of a children's hospital related to supporting parental presence during induction of anesthesia (PPI). A PPI handout was developed to prepare parents of autistic children who wish to be present during the induction of their child's anesthesia. The second phase of the project involved a pilot study using a survey tool to explore parent-caregiver perceptions of the benefit of the PPI handout and parent experiences and perceptions while present with the child during induction of anesthesia. The second phase employed an exploratory research design to evaluate PPI in the project setting.

### **Tool Development**

Three tools were developed for this project. The first tool was the PPI survey, which was used to elicit data about three areas related to PPI that were under investigation in this project : (a) the child's anxiety level as perceived by the parent or caregiver, (b) the parent or caregiver's anxiety level, and (c) the effectiveness of an educational handout.

The PPI survey (Appendix A) contained questions asking parents to rate the usefulness of the PPI guide as an educational handout and to provide information about their perceptions of the experience. Questions 1 through 6 were child focused and questions 7 and 8 were parent focused, related to their level of anxiety in the OR. The content of these eight questions was based on the researcher's review of the literature that identified parental and child anxiety during the induction of anesthesia as factors and-or

issues of concern most often reported by OR staff and anesthesiologists. The survey assessed the parents' perception of their child's anxiety level and their own anxiety level during this procedure. It also assessed the benefits of the educational handout (Question 9 through 11) to prepare parents for what they could expect and their role during the induction of the child's anesthesia.

The tool was developed with simply worded questions to elicit parents' self-perceptions of the anxiety level of their child with autism during the induction of anesthesia and to evaluate whether the parents perceived that their presence helped to lower the child's anxiety during the induction of anesthesia. The survey contained questions that were similar but reworded in an alternating technique to measure reliability for dichotomy and consistency of parental responses to survey questions.

Other questions in the survey tool asked about age and any "prn" or as-necessary medications administered by the parent or caregiver prior to arrival at the hospital or any medications given in the pre-op area. Reporting of any sedation medications given in the pre-op area was included in the survey because it was addressed in the review of literature; it was also included at the request of the perioperative anesthesia staff, who thought that pharmacotherapy could be a possible confounding variable that could influence study results.

The survey tool was developed by the researcher and approved by select physicians in the Department of Anesthesia. The survey was then reviewed by a statistician to evaluate for appropriate wording of the questions. The tool was also evaluated to ensure that it was written at a basic literacy level. A Likert-type scale was determined to be the best format for levels of agreement or disagreement related to the

parents' perceptions. An open-ended question was added to the survey to solicit comments that parents wished to share about their experience (Appendix B).

The second instrument (Appendix C) was an educational resource handout for parents, developed by this researcher. The educational handout outlined the protocol required for parents-caregivers who wished to be present during the induction procedure and what to expect in the OR. This set of instructions included a statement indicating that final approval for PPI had to be given by the anesthesia physician. The handout also delineated the OR procedure for parents, for example, appropriate OR jumpsuit attire to ensure a sterile environment, where to stand in the OR for maximum benefit for the child, and when to exit the OR suite—all basic instructions.

The third tool was a Nurse Practitioner Information Script (Appendix D) developed by the researcher to ensure consistency of information when inviting parents to become participants in the study and to provide participants with consistent, reliable information about the study, its requirements, and procedure. Eligible parents of children according to the sample criteria were identified and then asked whether they were interested in participating in the study.

### **Ethical Considerations**

This project was presented to the Department of Anesthesia at the target hospital for review and approval of the PPI handout and survey. A minor change in the PPI handout was made and approval was obtained to submit the project to the hospital's Institutional Review Board (IRB). This change involved substituting the words, "Once your child is asleep" to "during the induction of anesthesia, you may notice the anesthesiologist" in the educational handout. The hospital IRB required an Information

Sheet to serve as informed consent for this quality improvement project, according to medical center policy and procedures for IRB approval. A specific Information Sheet template was given to the researcher to adapt for this study. The template is designed to give information about the project and purpose, informed consent issues, consent requirements, and information on how to contact the researcher and the hospital IRB. A copy of the PPI Information Sheet as adapted from the hospital's template and used in this project is found in Appendix E.

The project proposal was submitted to and approved by the California State University, Long Beach (CSULB) Human Rights Subject IRB. The CSULB IRB requested that a script be developed for the nurse practitioners to use when describing the project to parents. The script (Appendix D) was developed and approved by the CSULB IRB. The study hospital also approved the use of the Nurse Practitioner Script.

### **Sample**

The subject pool was composed of parents-caregivers of children with ASD who underwent dental procedures with general anesthesia from December 10, 2013, to March 7, 2014. It was restricted to parents who self-identified as being able to understand and read English. All eligible parents-caregivers of children with autism who were scheduled for dental restorations and-or extractions under general anesthesia and were coming for their presurgical appointment were asked whether they wished to be present during induction of anesthesia. This is a normal standard of care. Only parents who received approval for PPI the anesthesiologist caring for the child for that surgical day were asked to complete the PPI survey questionnaire.

### **Setting**

This quality improvement project was conducted in a large metropolitan medical center hospital dedicated to the care of children. The hospital provides dental services for children who require general anesthesia for treatment of various diagnoses. General anesthesia for complex dental surgery is significant for children with autism and is provided at this children's hospital.

### **Protocol Procedure**

The following procedure was put in place for this project:

1. Prior to the start of data collection with parents, staff were familiarized with the pilot procedures approved by the necessary perioperative administration related to the role of staff who interact with parents wishing to be present during their child's induction of anesthesia.
2. A description of the project and its requirements was presented to the NPs working in the Surgical Admitting Department, the nurses in the OR Department, and the Pre-Operative Department staff. An information sheet describing the study was emailed to the anesthesiologists in the Department of Anesthesia by the chief anesthesiologist physician.
3. During the pre-operative appointment visit required for a child's clearance to have dental surgery under general anesthesia, eligible parents of children with ASD were identified and asked by the NP about their willingness to participate in the study. The NP used the approved script to ask parents whether they wished to be present during their child's anesthesia induction. The NP script was used to ensure consistency in study information given to

parents. Those who affirmed their desire to be present were given the PPI Educational Handout (Appendix C) and the Information Sheet (Appendix E).

4. When the child and parent returned on the day of surgery, the surgical admitting staff gave the parents the approved designated PPI Educational Handout (Appendix C) and Information Sheet (Appendix E) to read again and the survey (Appendix A) in an envelope marked “Parents Survey.”
5. Parents of children with autism who met the criteria but did not attend a pre-operative appointment and instead arrived on the day of surgery were given the Information Sheet, the PPI Education Handout, and the survey. This was done on the day of dental surgery because the parent and child had not made a pre-operative appointment.
6. The surgical admitting staff provided instructions to the parents about completing the survey after leaving the OR and they were told where to deposit the sealed envelope containing the survey.
7. The anesthesiologist met with the parents to discuss the procedure, as is the standard of care.
8. Parents who were approved for PPI by the anesthesiologist completed the PPI questionnaire after leaving the OR and put the survey in a sealed envelope marked “Parents Survey” before placing it in a designated secure box in the Surgical Waiting Room.
9. The project director was the only person to collect the envelopes with surveys.

10. Survey data from parents were uploaded into SPSS<sup>®</sup> and analyzed by the project director at the conclusion of data collection. Collection of survey data ended on March 7, 2014.

### **Data Collection**

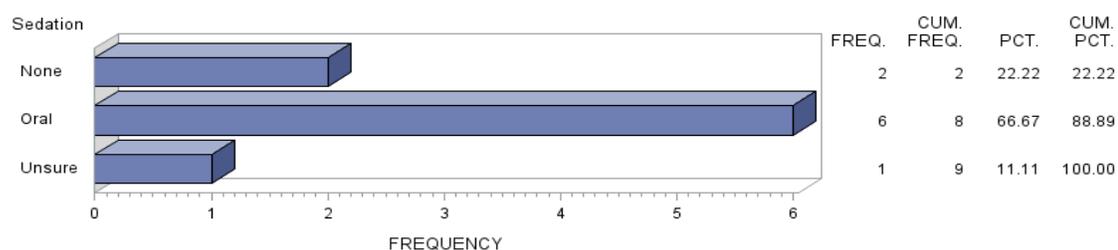
All survey data were coded and entered into a database using SPSS version 21. Descriptive statistics were collected, including percentages, means, standard deviations, and chi-square test results. Assistance by an expert statistician was used for the data analysis. Preparation for data for analysis involved grouping responses into three categories : (a) parents' perceptions of their anxiety level, (b) parents' comfort level related to their operative experiences regarding anxiety, and (c) whether their child with autism was anxious or relaxed. Further questions asked whether the parents felt that their presence had made the child more relaxed and calm. Questions were also asked about usefulness of the educational handout. Dichotomous responses related to questions 3, 6, and 8 were properly coded to be consistent with a positive experience, as the other eight questions were framed in a positive manner.

Comments from parents about their experience were solicited as a final question at the end of the PPI Survey Tool and can be found in Appendix B. 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

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.

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.



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

Questions 1 through 8 on the survey asked parents about their perceptions of the PPI experience, focusing on parental level of anxiety in being present in the OR and the child's level of anxiety during the procedure. The scores for responses to these questions

were summed and descriptive statistics (mean, *SD*, median, and range) were calculated to measure the perceptions of parents after staying in the room with the child while anesthesia was administered. In Table 1 these scores are labeled AvgParView to represent the variable of parental perceptions about anxiety in response to Questions 1 through 8. The overall mean score for these items was 4.26 (*SD* = 0.59), with a median of 4.50 and a range of 3.38 to 5.00.

Table 1

*Descriptive Statistics for Responses to Survey Questions (N = 9)*

Variable	Mean	Median	<i>SD</i>	Minimum	Maximum
Age of child	12.72	14.00	4.487	6.00	18.00
AvgParView	4.26	4.50	0.59	3.38	5.00
AvgEffTool	4.37	4.67	0.72	3.33	5.00

Scores for responses to Questions 9 through 11 were summed and descriptive statistics were calculated to reflect the overall perceptions of parents about 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.

Table 1 reports descriptive statistics for the variables of age, AvgParView, and AvgEffTool. A more extensive analysis of the PPI survey is located in Appendix F, which reports the response percentages for each question on the survey.

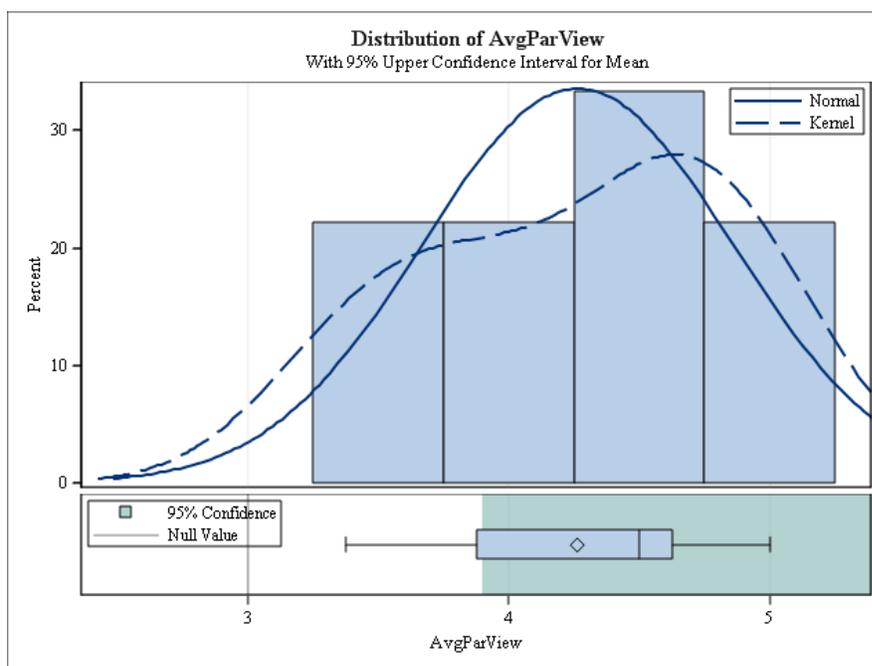
At the end of the PPI survey was section for parents to provide comments about their experience if they wished to do so. Handwritten comments revealed a strong positive response to the PPI experience and being present with the child with ASD during the induction procedure. Individual remarks by parents are reported in Appendix B.

### **Effect of Parental Presence During Induction on Anxiety Levels**

Data related to the effect of parent-caregiver presence in the OR during induction of anesthesia in reducing anxiety in the child with autism were calculated to obtain a mean survey score. 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.

As a parametric alternative, a Wilcoxon signed-rank test with continuity correction was conducted to test the null hypothesis that parents-caregivers of children with autism believed that being present while the children was being sedated did not affect the child's anxiety. The results showed that the parents-caregivers perceived that accompanying the child to the OR for anesthesia induction reduced the child's anxiety, statistically significant (median = 4.5000,  $p = .005$ ) at a 1% significance level. The Wilcoxon signed-rank test is a nonparametric statistical hypothesis test that is the equivalent of the paired-samples  $t$  test. It was used to calculate parental responses related to their perceptions of anxiety, with statistically significant results,  $\mu = 3$  (the median of *neither agree nor disagree*),  $p = .004545$ . Therefore, the null hypothesis was rejected. There was support for accepting the hypothesis that the parents perceived that their child with autism had a lowered anxiety level when the parents were present in the OR during induction of anesthesia.

As a parametric test, an upper tail  $t$  test was performed to see whether the AvgParView was significantly greater than 3 (*neither agree nor disagree*). The statistically significant  $t$ -test result ( $t = 6.38, p = .0001$ ) was consistent with results of the Wilcoxon signed-rank test. 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 that the parents-caregivers perceived it to be helpful to be present during the induction of anesthesia of their child with autism. The dotted line kernel is a nonparametric smoothing density to demonstrate the predicted results from a larger sample of participants.



*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.

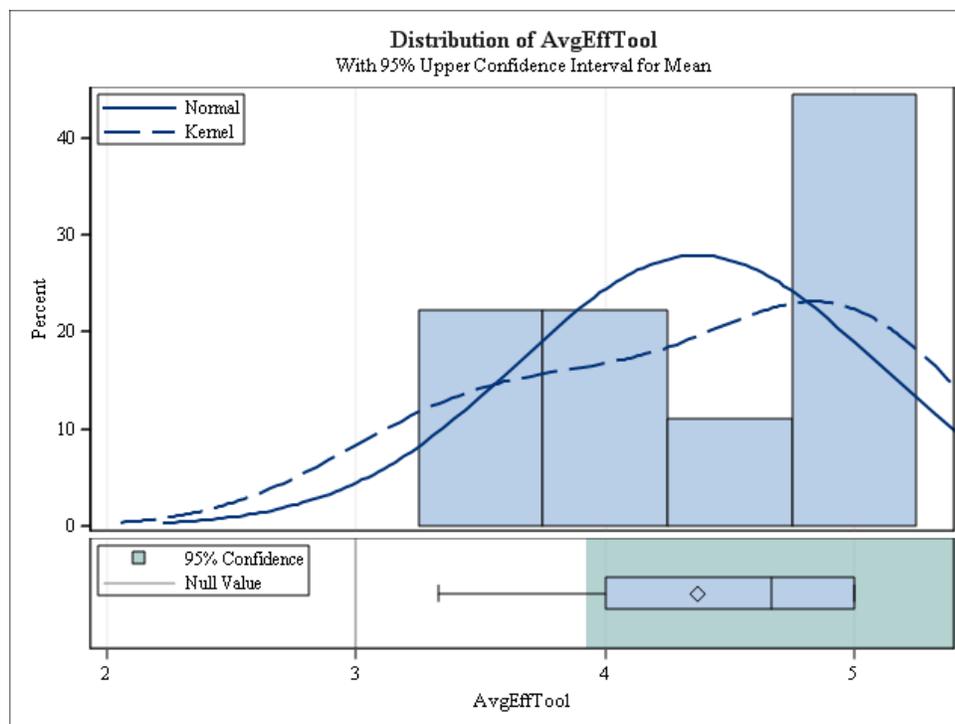
It is important to note that the ninth child took an antidepressant medication, Paxil, which presented the potential for the child to be different from the other children. Therefore, the sample mean was analyzed without the ninth score. After deletion of the ninth score, the  $p$  value was still less 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.

### **Parental Perceptions of the Usefulness of the Educational Handout**

Statistical analysis of the data was conducted to examine perceptions of the parents of children with autism to determine whether the handout covering the OR experience during the induction phase of the child's anesthesia was an effective educational tool. A mean of 3 or more on the AvgEffTool would suggest that the handout was an effective tool in preparing parents for what to expect while present in the room for the procedure.

As a nonparametric alternative, the Wilcoxon signed-rank test with continuity correction was conducted to test the null hypothesis that the parents of autistic children did not believe that the handout was an effective tool in preparing them for what to expect. With 1% statistical significance, the handout was shown to be an effective tool in preparing parents for what to expect as they accompany the autistic child to the OR for anesthesia induction (Median = 4.67,  $p = .004$ ). As a parametric test, an upper tail  $t$  test was performed to investigate whether the AvgEffTool was significantly greater than 3. The result,  $t = 5.74$ ,  $p = .0002$ ) was consistent with the result of the Wilcoxon signed-rank test.

There was 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.



*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.

### Correlation Between Age and (Lowered) Anxiety

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 2 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.

Table 2

*Pearson Correlation of Child's Age and Parent's Perception of Lowered Anxiety (N = 9)*

Variable	Measure	Age	AvgParView
Age	Pearson correlation	1	-.134
	Significance (2-tailed)		.732
AvgParView	Pearson correlation	-.134	1
	Significance (2-tailed)	.732	

*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.

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. As discussed in the review of literature, the neurocognitive behavior disorders of children with ASD have a varying range of expression. That spectrum extends to children with autism 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 needs group, chronological age is not necessarily relevant in

predicting children's behavioral responses to anxiety-producing situations (Lindberg et al., 2012).

## **DISCUSSION AND RECOMMENDATIONS**

The review of literature noted the paucity of research in children with autism and the PPI experience. There is substantial evidence of problems associated with PPI, including issues related to parents' fainting in the OR, refusal to leave the OR once the child is sufficiently under anesthesia, and insufficient education about what to expect in the OR and proper procedures to follow while in the OR. 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.

The researcher acknowledges several limitations of the study: 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. Furthermore, using a tool to assess anxiety reduction during PPI was not possible because the study was designed as a pilot project that would be simple to implement and would not require additional work for the OR staff. Because this study was to be a quality improvement project that had restrictions on the type of data and how data were to be collected, only parental self-report questions could be used

to collect data. Quality improvement efforts often have to be done in small steps. Thus, this study represents the first step to initiate a comprehensive policy that will govern procedures for the hospital's surgical admitting staff and anesthesiologists to follow for PPI. With the completion of this study and data demonstrating that PPI is well received by parents, the next step will be to identify champions in the Surgical Admitting staff, such as registered nurses, medical assistants, child life specialists, and anesthesiologists, to encourage greater family-centered care by promoting PPI.

Another parental resource that should emerge from this study is a simple video for parents to view regarding preparation for PPI. Many people are visual learners, and this modality has become an effective tool as most people typically find time to watch a simple video on one of their many technological devices. It may also be helpful in the next phase of this quality improvement project to ask parents who have undergone PPI with their child with autism what information about PPI that they believe would be most helpful for other parents of children with autism to know.

PPI is a highly debated issue for anesthesiologists and Certified Nurse Anesthetists because of the possibility of experiencing unforeseen difficulties with parents in the OR during the sensitive time associated with induction of anesthesia. These complications can be placed in several categories: parents-caregivers who refuse to leave once the child is adequately anesthetized, parents who faint in the OR, the possibility of contaminating a sterile field in the OR, and the parent's lack of preparation to see the child limp once the child is sufficiently anesthetized. Therefore, this study was designed to be a pilot project to gain baseline assessment data to begin conversations about how best to implement PPI at the hospital.

Recommendations for future study include collection of data from a larger pool of subjects and translating the material into Spanish so that the Hispanic population can be included in data collection related to the study topic. There were difficulties in recruiting participants because of the winter time frame in which data were collected. The researcher noted a high rate of rescheduling of dental procedures-surgeries during the winter months, which are typically marked by severe respiratory illnesses in children. Summer months would be a better time to collect data as there is typically an increase in surgery scheduling dates during the summer months due to a decrease in respiratory illness and increase in children on vacation from school. The researcher plans to meet with the anesthesiologists, Surgical Admitting Staff, and OR staff to identify any negative experiences that they may have encountered and to receive their recommendations for further study of PPI with children with ASD. It should be noted that no untoward events related to parent or children in this PPI study were reported to the researcher.

One final discussion 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 additional time expenditure. However, PPI could result in a delayed procedure if a parent is not properly prepared to accompany the child into the OR and stay for the induction procedure. 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 (Macario, 2010). In 2005, basic OR fees ranged from \$22 to \$133 per minute, with an average of \$62 per minute (Shippert, 2005). These two cost estimates did 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. Therefore, future studies should weigh the importance of family-centered care in the pediatric hospital with the realities of cost effectiveness in the 21st century. PPI of anesthesia should be handled in a way that provides parents with education tools before the procedure so they can be adequately prepared for their supportive role. This is especially relevant for parents with a special needs child. Thus, the perioperative experience for parent and child should be well organized with staff (nursing and physician) roles and duties outlined in a PPI protocol.

### **Impact of the Project**

There were two desired outcomes. It was anticipated that the study findings would provide knowledge of whether parents perceived the handout to be beneficial in preparing them for PPI with their autistic child and whether parents perceived their presence during induction of anesthesia to be helpful in reducing the child's anxiety. With initial data now reported and favorable, a decision has been made to continue data collection to reach a sample size of 30 parents. When a larger sample has been secured, the data will be re-analyzed. If the findings continue to be favorable, the next step for this researcher will be refinement, if needed, and then formalization of a PPI protocol for staff to support family-centered care for parents involved in PPI of children with ASD

and to provide a procedure to assist staff in implementing an effective strategy to guide this experience for these special needs children.

### **Dissemination of Findings**

The results of the parental survey will be presented in summer 2014 to the perioperative staff as part of a focused group discussion related to practice improvement in the area of PPI. The main point of the discussion will be the study data that indicated a strong positive experience reported by participating parents, who perceived that their presence during the induction of anesthesia decreased their child's anxiety and apprehension. It is anticipated that recommendations will come from the focus group discussion that will lead to development of a formalized PPI protocol designed in conjunction with the Department of Anesthesia. The purpose of the protocol will be to guide staff and parents when PPI is an option for parents of children with ASD.

Findings of the study will be disseminated to other groups in the hospital setting, including the perioperative nursing staff, nurse practitioners, the Advance Practice Nurse group, and the Department of Anesthesia. This researcher will also recommend that the protocol be designed to include other groups of children with special needs.

It is the intent of the researcher to continue this study and to collect survey data from study participants. When a sufficient number of surveys has been collected to provide robust data, an article will be prepared for submission to a scholarly journal. The study and its results will also be featured in an article published in the participating hospital's newsletter.

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## APPENDIX A

**QUESTIONNAIRE FOR PARENTS WHO ARE PRESENT WITH THEIR  
CHILD WITH AUTISM DURING THE INDUCTION OF ANESTHESIA**

**Please fill out this form. Place in the secure box in the Surgery Waiting Room on  
the 1<sup>st</sup> floor**

1. Child's Age \_\_\_\_\_
2. Please list any "as needed" or "prn" anti-anxiety medications your child took prior to coming to the hospital today

- 
3. Was your child given any sedation while in the pre-op area (2<sup>nd</sup> floor)?

Oral sedation

Injectable sedation

None

Unsure

**Please indicate your level of agreement with the following statements by checking the appropriate box.**

	<b>Strongly Agree</b>	<b>Agree</b>	<b>Neither Agree nor Disagree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>
<b>1. My presence in the operating room helped to lower my child's level of anxiety while he-she was given anesthesia</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>2. My presence in the operating room helped keep my child calm while he-she was given anesthesia.</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>3. My presence in the operating room didn't seem to calm my child or make them less nervous.</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<p><b>4. My presence in the operating room helped my child relax while he-she was given anesthesia.</b></p>	<input type="checkbox"/>				
<p><b>5. My presence in the operating room made my child more cooperative while he-she was given anesthesia.</b></p>	<input type="checkbox"/>				
<p><b>6. My presence in the operating room didn't seem to make my child less confused.</b></p>	<input type="checkbox"/>				
<p><b>7. I had a positive experience in the operating room when I was present with my child during anesthesia.</b></p>	<input type="checkbox"/>				
<p><b>8. I experienced tremendous anxiety while in the operating room when my child received anesthesia.</b></p>	<input type="checkbox"/>				
<p><b>9. The handout I received was helpful in preparing me for the experience of being in the operating room while my child received anesthesia.</b></p>	<input type="checkbox"/>				
<p><b>10. After reviewing the handout I feel it answered my questions about being in the operating room with my child.</b></p>	<input type="checkbox"/>				

<b>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.</b>	<input type="checkbox"/>				
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**12. Do you have any comments you would like to share with us?**

**Thank you for participating in this survey. Please place this in the black locked box in the Parent's Waiting Room on the first floor.**

**APPENDIX B****COMMENTS**

Comments
“I was unaware or prepared to see my child go under the last stag [sic] of conciouness [sic] he was very resistant and it was hard to watch, I feel more instructions on what to expect from the child and the stages of it should be addressed by the dr. before parents go into the O.R.”
“Overall it was very positive experience and I truly believe it helped my child having me there.”
“He was very calm. He go to hold my hand. I think it help him a lot.”
“I would like to be present during procedures.”
“All the staff helping a lot with my son.”

## APPENDIX C

### INFORMATION FOR PARENTS OF CHILDREN WITH AUTISM WHO WILL BE PRESENT DURING ANESTHESIA

Here is some important information for the parent-caregiver of the child with autism who will be present during anesthesia administration:

1. Only one parent-caregiver may participate in being with your autistic child while they receive anesthesia.
2. Once you are escorted up to the operating room (OR) area, your child's anesthesiologist will meet with you and decide about your presence in the OR. The decision depends on many reasons that the anesthesiologists takes into consideration.  
If the anesthesiologist decides you may accompany your autistic child into the OR then:
3. In the pre-op area you will need to put on a disposable jumpsuit and a hair cover that will be given to you by the OR staff that you will need to put on prior to going into the OR with your child.
4. The anesthesiologist and OR staff will give you directions about where to stand to be close to your child in the OR. If you have questions about any instructions you are given, let the staff know right away.
5. All children react differently to anesthesia: As they become sleepy they may become limp (like a rag-doll) or sometimes they become excited and move their arms or legs. All of this is a normal reaction.
6. During the induction of anesthesia, you may notice the anesthesiologist may use a mask to assist your child's breathing. Again this is a common procedure that is used while your child receives anesthesia.
7. Once your child falls asleep the anesthesiologist will notify you that it is time to leave the OR.
8. It is important that you leave the OR and follow the directions of the OR staff.
9. You may remove your hair cover and jumpsuit once you leave OR area and please dispose of them into the proper trash receptacle.
10. After you leave the OR, please complete the survey-questionnaire located in the Parent's Waiting Room about the OR experience. You may place it in the secure box in the Parent's Waiting Room on the 1<sup>st</sup> floor near surgical admitting.

## APPENDIX D

### NURSE PRACTITIONER SCRIPT FOR PARENT PRESENCE DURING INDUCTION OF ANESTHESIA

When the participants (parents of autistic children) attend their pre-operative appointment they will be asked by the attending nurse practitioner whether they wish to be present with their child during the induction of anesthesia. This is routine care at Children's Hospital of Los Angeles.

**Nurse Practitioner :** It is our standard practice here at Children's Hospital Los Angeles to offer parents the opportunity to be present in the operating room while their child initially undergoes the anesthesia process. We call this experience "Parent Present during the Induction of Anesthesia". Would you like to be present with your child during anesthesia induction and receive an information sheet, *Educational Handout for Parents*, about what to expect?

**Parent:** Yes \_\_\_\_ (Continue to next section) No \_\_\_\_ (If no, END Script)

**Nurse Practitioner:** We are seeking information from parents of autistic children about their perceptions and experiences while present during the initial anesthesia process necessary for their child's dental procedure. Would you be willing to complete a short 10 minute survey, titled *Parent Present Induction Survey*, about your experience and also evaluate the *Educational Handout for Parents* we will give you regarding this procedure?

**Parent or caregiver:** Yes \_\_\_\_ (Continue to next section) No \_\_\_\_

**Nurse Practitioner:** Here is the *Information Sheet* approved by Children's Hospital Los Angeles along with the *Educational Handout for Parents*. Your agreement with the explanation of this project as explained in the CHLA "Information Sheet" signifies your consent to complete the survey.

When you return the day of surgery, you will have the opportunity to fill out the survey and will be given an envelope in which to put your completed survey. There is a secure box where you may deposit the envelope containing your survey once you have filled it out. The secured box is located in the Parent's Waiting Room which is on the first floor of the Surgical Area.

The information you provide is kept confidential. There are no names, medical record numbers or birthdates on the form that may identify you or your child.

Thank you for agreeing to participate.

## APPENDIX E

### INFORMATION FOR PARENTS OF CHILDREN WITH AUTISM WHO WILL BE PRESENT DURING ANESTHESIA INDUCTION

Here is some important information for the parent-caregiver of the child with autism who will be present during anesthesia administration:

1. Only one parent-caregiver may participate in being with your autistic child while they receive anesthesia.
2. Once you are escorted up to the operating room (OR) area, your child's anesthesiologist will meet with you and decide about your presence in the OR. The decision depends on many reasons that the anesthesiologists takes into consideration.

If the anesthesiologist decides you may accompany your autistic child into the OR then:

3. In the pre-op area you will need to put on a disposable jumpsuit and a hair cover that will be given to you by the OR staff. You will need to put on this surgical attire prior to going into the OR with your child.
4. The anesthesiologist and OR staff will give you directions about where to stand to be close to your child in the OR. If you have questions about any instructions you are given, let the staff know right away.
5. All children react differently to anesthesia: as they become sleepy they may become limp (like a rag-doll) or sometimes they become excited and move their arms or legs. All of this is a normal reaction.
6. During the induction of anesthesia, the anesthesiologist may use a mask to assist your child's breathing. Again this is a common procedure that is used while your child receives anesthesia.
7. Once your child falls asleep the anesthesiologist will notify you that it is time to leave the OR.
8. It is important that you leave the OR and follow the directions of the OR staff.
9. You may remove your hair cover and jumpsuit once you leave OR area and please dispose of them into the proper trash receptacle.
10. After you leave the OR, please complete the survey-questionnaire you were given about the OR experience. You may place it in the secure box in the Parent's Waiting Room on the 1<sup>st</sup> floor near surgical admitting

## APPENDIX F

### ADDITIONAL DESCRIPTIVE ANALYSIS

To understand if the presence of the parent/caregiver helped the child in the reduction of 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

Therefore we obtained the following results:

**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 their child reduced 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.

For this question 7 out of 9 or 78% of the participants stated that their presence helped their child to calm down or make less nervous.

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

For this question 8 out of 9 or 89% of the participants believed that their presence in the operating room 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.

For this question 8 out of 9 or 89% of the participants believed that their presence in the operating room made their child more cooperative while he/she was given anesthesia.

**6.** My presence in the operating room didn't seem to make my child less confused.

For this question 5 out of 9 or 56% of the 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.

For this question 8 out of 9 or 89% of the participants stated that they had a positive experience in the operating room.

**8.** I experienced tremendous anxiety while in the operating room when my child received anesthesia.

For this question 5 out of 9 or 56% experience anxiety while in the operating room when their child received anesthesia.

There were 72 questions asked and 59 (82%) of those questions suggested that the presence of the parent/caregiver helped reduce the anxiety of the child with autism. Therefore, having the parent/caregiver present in the operating room during the induction of anesthesia helps reduce the child's anxiety.

<b>Helped</b>	<b>Did NOT Help</b>
59	13

In Research Question 2, There were 24 questions asked and 18 (75%) of those questions 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.

For this question 8 out of 9 or 89% of the participants found the handout helpful in preparing 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

For this question 6 out of 9 or 67% of the participants felt that the handout answered their questions about being in the operating room 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

For this question 7 out of 9 or 78% of the participants felt like they knew the procedures in the operating room after reading the handout.

Therefore, 21 out of 27 or 78% responses to the questions found the handout helpful.

<b>Handout Helpful</b>	<b>NOT Helpful</b>
21	6