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Behavioral Coping Plans: One Inter-Professional Team's Approach to Patient-Centered Care

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ABSTRACT

Background: Surgical encounters for children with Autism Spectrum Disorder (ASD) are stressful to patients, families and health care providers. It is recognized that parents best anticipate needs of children with ASD. Including a family in the plan of care for the child is imperative. In response to the need for targeted, tailored care, an inter-professional surgical services team convened to determine best practices for addressing a behavioral and developmental plan for children with ASD in the surgical services arena.
Purpose: This evidence based practice project was conducted to optimize best practices for perioperative staff in caring for children with ASD through a targeted, individualized plan of care for the autistic child and his or her family.
Methods: Psychosocial and medical care strategies were utilized to create a coping plan with standardized questions. The coping plan allowed for tailored interventions specific to each child's needs.
Conclusion: Actively reducing the anxiety a child experiences in a current encounter is paramount to the success of future visits. The coping plan is a formalized summary aimed at helping healthcare providers give individualized care, thereby decreasing the anxiety of both the parent and child. The individualized plan outlines the needs of the patient and allows for the medical team to make adaptations to lessen the stressors a health care visit can present. Plans are shared with the medical team, documented, and updated in the electronic medical record for future encounters. Information captured includes: previous healthcare experiences, sensory sensitivities, communication methods, stressors and coping suggestions. Utilizing best practice, patients are able to receive individualized care to foster positive coping experiences within healthcare.

Surgical encounters for children with Autism Spectrum Disorder (ASD) are stressful to patients, families and health care providers. In 2014, a large pediatric facility noticed an increase in the number of ASD patients restrained during their surgical encounter. In response to these encounters and the need for targeted, tailored care, an inter-professional team convened to determine best practices for addressing a behavioral and developmental plan for children with ASD. The result of this meeting was the development of an individualized plan of care or coping plan for the child with autism and his or her family. The coping plan was developed to optimize best practices for perioperative staff in caring for children with ASD, and was first utilized in the surgical services area followed by the implementation in the entire institution.

The Center for Disease Control (CDC) describes developmental disabilities as a "group of conditions due to impairment in physical, learning, language or behavior areas, that begin during the developmental period but last throughout a lifetime" (Center for Disease Control, 2017). These disabilities occur along all racial, ethnic and socioeconomic lines and may affect as many as 1 in 68 children. Developmental disabilities may include conditions such as Autism Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD), Cerebral Palsy (CP), hearing loss, intellectual disability, vision impairment and other delays (Center for Disease Control, 2017). The child with ASD may present with multiple characteristics of their diagnosis, such as impaired social skills, communication challenges, restrictive interests, repetitive behaviors, sensory issues, poor problem-solving skills, and a high level of stress and anxiety (DSM-5, 2013). These behaviors separately, or in concert, may influence a child's ability to cope with a surgical procedure and lead to challenges such as hitting, kicking, aggression, biting and scratching (Panella, 2016). In response to the new environment or social situation, children with ASD may behave negatively in the hospital setting and experience what is sometimes referred to as an "emotional meltdown" as a maladaptive coping mechanism (Thompson & Tielsch-Goddard, 2014).

Because of this, surgical preparation for children with ASD can be a challenge to perioperative staff because of their unique individual

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needs and behaviors (Broderfingert et al., 2016). Most children with autism function best in comfortable, predictable, routine environments. Hospitals and other healthcare settings can create a stressful situation due to uncertainty of the new setting. Parents understand this as they seek to constantly establish a safe and predictable routine for their child. This may include offering the same object or process to promote security when confronted with new stressors (Panella, 2016). For the surgical services team, establishing a sense of trust and security in the surgery environment can be challenging (Espinel, Shah, McCormick, Krakovitz, & Boss, 2014). Hospitals and healthcare facilities involve people moving quickly, disruptive noises, and can be overwhelming for even the typically developing child. Asking a child with ASD to operate outside of his or her normal habits can produce adverse responses.

Communication with both children with ASD and their parents prior to surgery is paramount to successful outcomes for the child (Van Der Walt & Moran, 2001). Many children with ASD require inpatient or outpatient surgery and benefit from a perioperative plan that will decrease anxiety for the child, the parent and the members of the perioperative inter-professional team. Typically, children who require surgery experience high levels of anxiety. Elliott, Holley, Ross, Soleta, and Koh (2018) found when observing children with ASD, overall anxiety has been known to be amplified as seen by levels of increased stress during the holding room and induction phase of anesthesia. During the surgical process in times of increased stress children with ASD may be uncooperative for exams, refuse medications, exhibit combative behaviors, or need restraints. There is poor clarity around preoperative anxiety and postoperative pain in this specific population. Given that there is a direct preoperative anxiety to postoperative pain correlation for typically developing children, we must also consider the potential that heightened anxiety and maladaptive behaviors could produce a more challenging and painful post-operative experience for children with ASD (Chieng, Chan, Klainin-Yobas, & He, 2013). It is the healthcare professional's responsibility to consider all issues when developing a plan of care for this patient population. In turn, escalating behavior of the child with ASD due to anxiety can create stress for the inter-professional surgical team as they attempt to decipher the needs of the child, at times with little success. For parents, this leads to fragmented medical care and unmet healthcare needs for their child, particularly in specialty care disciplines, due to concerns of how their child may act out (Mzaurek, Brown, Curran, & Sohl, 2017).

Literature Review

The team felt intuitively that individualized care should be the norm for patients. It was evident the scientific literature would validate which of their actions were best practice. Through consultation with the organization's nursing research department, a searchable and answerable question was developed. Thus the question became: To decrease maladaptive behaviors perioperatively in pediatric surgical patients with ASD, what interventions are considered best practice? The team and research department agreed to proceed as an Evidence Based Practice (EBP) Change and sought a Non-Human Subject Determination from their institution's review board. Key terms for literature search utilizing CINAHL and PubMed included: coping, perioperative surgery, preparing autistic/developmentally delayed children for surgery. The MeSh terms included: perioperative or postoperative anxiety/prevention limited to children, perioperative stress, psychological/prevention limited to children, perioperative or postoperative adaption, psychological limited to children. The team appraised the findings, graded the evidence and constructed a summary table. Recommendations fell broadly into the following categories: (a) Medical Interventions (b) Play therapy/distraction interventions (c) Management Plan Interventions. In response to this literature search, a targeted, individualized plan of care for the child and his/her family was developed to optimize best practices for perioperative staff in caring for children with ASD known as a coping plan.

Methods

An inter-professional team at one pediatric institution convened with the goal of enhancing the perioperative experience for patients with ASD and their parents. The members of the team included nursing leadership, child life specialist (CLS), preoperative clinic, day surgery, operating room (OR), post anesthesia care unit (PACU), anesthesiology and registration. Also included were members of the Marcus Autism Center, the institution's nationally renowned center for autism. Experts from the center joined the team to provide current, relevant research to support changing practice in surgical services. The initial goals were 1). Provide a positive hospital experience for the child and family and 2). Prevent the cycle of negative emotional effects (Sahiner & Bal, 2016).

Developing the Coping Plans

It was acknowledged by the team that involving the family in the preparation and care of the child prior to surgery will result in superior outcomes and overall positive medical experiences (Terry & Crego, 2016). It was vital for the staff to understand and identify individual patient stressors before the hospital encounter. Each phase of care was evaluated with the goal of promoting positive coping and improving patient and family satisfaction during the surgical encounter. The coping plan helped to develop a tool to better prepare staff for the needs of the patient.

The CLS collaborated with the autism experts and developed a list of questions to ask by phone with parents prior to the patient's arrival. Questions included: (1) In your child's past healthcare experiences, are there any fears or things he/she may have difficulty cooperating with that you have identified? (2) How does your child prefer to take medication? (3) What are some things that may be stressful to your child in our setting (i.e., wait time, putting on a gown or ID band, NPO status, etc.)? (4) What have you found to be calming for your child (i.e., favorite toy, weighted blanket, music, etc.)? (5) What are motivators for your child? This initial phone call provided a rapport building conversation where parents felt free to elaborate on their child's special needs without feeling judged. It was the first step in the parent feeling comfortable in trusting the staff (Sharkey et al., 2014).

An informatics technologist partnered with the team to develop a key template within EPIC® software. This template was created to be user friendly and easily accessible by all providers. The template provided an area to detail a formalized plan within the patient chart. Detailed diagnosis, comfort measures, past experiences, methods of communication, preferred methods of medication administration and parental presence were detailed in the coping plan template. All surgical service staff received education on how to access the coping plans in EPIC®. On subsequent visits to surgical services or other units within the hospital system, all clinicians were prompted to review the coping plan by the best practice advisory alert.

Educating Staff

Staff members were hesitant to care for this population due to prior negative experiences with maladaptive behaviors. The team identified this as an area of opportunity for education about ASD. The goals of the staff education were to improve the overall comfort level, time management and confidence of the providers caring for this population. Included in the education was a presentation of current guidelines on specific strategies to interact and care for the patient and family. The inter-professional team presented the information collaboratively at staff meetings within surgical services. In addition, system-wide education was presented in multiple nursing forums including nursing educator meetings and grand rounds.

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