The Development of a Family-Centered Intervention Program for Patients with Autism Spectrum Disorder in the Outpatient Surgery Unit

Purpose

The purpose of this qualitative study was to develop a family-centered intervention program for patients with autism spectrum disorder who underwent an outpatient procedure with general anesthesia at a pediatric hospital.

Research Questions

RQ 1: What psychosocial interventions or other accommodations do parents report as helpful for their child with autism spectrum disorder in the outpatient surgery setting?

RQ 2: What psychosocial interventions do multidisciplinary staff already do to help patients with autism spectrum disorder and their families in the outpatient surgery setting?

Relevant background information

According to the United States Centers for Disease Control and Prevention (CDC, 2012), one in 88 children is currently diagnosed with an autism spectrum disorder (ASD). Autism spectrum disorder is a neurodevelopmental disorder characterized by impairments in social interaction and communication, and by restrictive and repetitive behaviors (American Psychiatric Association [APA], 2000; APA, 2013). Children with ASD often have difficulty with new environments, transitions, and experiences out of their usual routine (APA, 2013; CDC, 2012; Seid, Sherman, & Seid, 1997) and may also exhibit unusual reactions or behaviors to what they see, hear, taste, touch, and smell (CDC, 2012; Ben-Sasson et al., 2009; Lang et al., 2012; Danesh
& Kaf, 2012). In the healthcare setting, these behaviors can harm the patient, their family, medical staff, and other patients and families who come into contact with the patient.

With the increase in prevalence of ASD in the population (CDC, 2012), there is an increase in children with ASD who are in contact with inpatient and outpatient hospital facilities (Venkat et al., 2012; Atladóttir et al., 2012; Scarpinato et al., 2010). There are few studies published about treating the psychosocial needs of children with ASD in the hospital or the outpatient surgery setting (Davit et al., 2011; Bagshaw, 2011). Existing literature consists of single case studies that make recommendations for best practice (Venkat et al., 2012; Souders, Freeman, DePaul, & Levy, 2002; Davit et al., 2011; Scarpinato et al., 2010; Nelson & Amplo, 2009; Shah et al., 2009; Christiansen & Chambers, 2005; van der Walt & Moran, 2001; Seid, Sherman, & Seid, 1997; Rainey & van der Walt, 1998); however, an Australian facility reported keeping a database of interventions used for patients with ASD (Rainey & van der Walt, 1998; van der Walt & Moran, 2001). These studies provided minimal information about the level of collaboration or partnership with the parent or family when providing recommendations for best practice. Given the anxiety and behaviors that children with ASD are known to exhibit in new environments (CDC, 2012; White et al., 2009), and particularly in healthcare environments (Bagshaw, 2011; Scarpinato et al., 2010; Davit et al., 2011; Christiansen & Chambers, 2005), it is important to collaborate with parents and family to develop an intervention procedure to decrease the anxiety these children experience and the incidence of challenging behaviors that can be exhibited by this population in the healthcare environment (Nelson & Amplo, 2009).

Methods and Analysis

This study took place in the outpatient surgery department at Dell Children’s Medical Center of Central Texas in Austin, Texas. The sample consisted of patients with autism spectrum
disorder ($N = 50$), their parent or legal guardian ($N = 50$), and the perioperative nurses who directly cared for patients enrolled in the study ($N = 60$). Inclusion criteria for patients consisted of the (1) diagnosis of autism spectrum disorder and (2) completion of an outpatient procedure under general anesthesia. Data took five months to collect, with only one patient—parent dyad declining to participate in the study. This study was approved by the healthcare organization’s IRB.

The parent completed the *Patient and Caregiver Stress Survey*, which is a written survey that includes self- and parent-reported stress perception ratings, areas for medical staff improvement, and the challenging behaviors exhibited by the patient in the surgery unit. Part of this survey was adapted from the Behavior Problems Inventory-Short (BPI-S) survey (Rojahn et al., 2012). Clinical notes from the day of each participant’s procedure were collected through the each participant’s electronic medical record. In addition, nurses completed the *Staff Stress Survey* after directly caring for the patient. The *Staff Stress Survey* is a written survey that includes a checklist of the accommodations made for the patient. Four nurses (pre-operative, operative, post-anesthesia phase one, and post-anesthesia phase two) completed this survey for each patient enrolled in the study. Both of these measures were specifically developed for this study.

Currently, content analyses are being conducted from parents’ responses to the *Patient and Caregiver Stress Survey*, and the frequency of accommodations reported by nurses in the *Staff Stress Survey* are being consolidated.

**Results**

Preliminary results to RQ 1 included parents wanting staff members (1) to know their child’s triggers and stressors (e.g., wearing a hospital gown or seeing a stretcher), (2) to work with the parent to keep the child’s behavior from escalating, and (3) to collaborate with the
parent and develop an individualized coping plan for the child prior to entering the hospital on the day of the procedure.

Preliminary results to RQ 2 included nurses (1) talking with the parent and patient on the morning of the procedure to assess the child’s triggers, likes/dislikes, and previous experiences in the surgery unit; (2) allowing the child to remain in clothing from home and not change into a hospital gown; and (3) keeping the door closed to the patients’ preoperative room to minimize the noise level for the patient. Because analyses are not complete, a more extensive and thorough report will be provided at the symposium.

**Discussion of findings**

The results indicate that parents would generally like to be included in how their child experiences the healthcare environment. Most parents feel like they can help their child have a less stressful experience if they are included as an equal member of the healthcare team and their child’s needs are heard. One of the provisions of family-centered care is that the medical team views the “parent as the expert” on his or her child. Although this is not an outcome of this study, it may be critical that medical teams collaborate with parents of children with ASD more so than with parents of children who are neurotypical because children with ASD present different challenges to the medical environment than typically-developing children. Thus, the medical team may need more guidance from parents to help the child experience low levels of stress in the healthcare environment.
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