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Short Commentery

A Potential Gap in Access to Anesthetic Care for Patients with Special Considerations

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In 2020, the Centers for Disease Control and Prevention (CDC) reported [1] that approximately 17% of children in the United States (US) aged 3-17 have some form of developmental disability. Specifically, about 1.8% of children in the US have a diagnosis of autism. Autism and many disorders of the brain, spinal cord, and musculoskeletal system have important health implications that require multidisciplinary care. Unfortunately, some of these patients with special considerations are unable to tolerate routine care, possibly due to factors such as inability to understand and communicate [2] care preferences, insufficient patient-specific training [3] for providers, and difficulty coordinating multidisciplinary care [4]. It is unclear how many patients with autism are diagnosed with severe, or level three, autism, categorized [5] by the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) as having significant difficulties with verbal and nonverbal communication, struggling with unexpected events, and requiring substantial support. Upon review of the literature, it appears these patients are at risk for health care disparities as it relates to their access to developmentally appropriate anesthesia services, which are often required in this population to obtain routine medical care. We have observed that this gap in care only grows as patients age into adulthood, possibly due to limited training for adult providers in caring for patients in this population [6].

One example is Jane*, a 33-year-old female with severe autism (defined as above), who has received continued care from a combined internal medicine and pediatric physician at a quaternary care center. Because of her severe autism, Jane cannot tolerate basic medical procedures such as dental exams, gynecologic exams, blood draws, or radiologic imaging. One solution that has been considered is completing all her required medical services at one visit under general anesthesia. While providers at her healthcare facility have tentatively agreed to this plan, there are still barriers, such as coordinating Operating Room (OR) time in which all the required personnel can be present, familiarizing the involved providers with Jane's medical history and special considerations, and training the providers to provide developmentally appropriate care. Even with these challenges, Jane is comparatively lucky to receive primary care from a provider trained in both adult and pediatric medicine, who can appropriately advocate for her specific healthcare needs. More investigation is needed to better quantify this problem for other patients with special considerations, who may not receive adequate care as they transition from childhood to adulthood. In the meantime, institutions should consider conducting their own Quality Improvement (QI) studies to determine the need for transitional care planning and anesthesia services for these individuals.

In addition to the logistical challenges described above, we believe another barrier to adequate anesthesia services is that their utility in this population is often underrecognized or misunderstood. A cursory review of the literature revealed only a handful of dedicated sedation centers in the US. Among these, the majority are limited to anesthesia for dental procedures in outpatient settings and are not specific to the needs of patients with special considerations. One sedation center [7] in Florida has begun to address this gap in care by expanding their services to provide anesthesia for pediatric and adult patients with special considerations. They routinely provide IV sedation and oral anxiolytic therapy before procedures like MRI, CT, biopsy, drainage, Peripherally Inserted Central Catheter (PICC) insertion, wound dressing, and labs. Another [8] accommodates such patients seen for dental services by scheduling longer appointment times (often required to overcome communication challenges and increase patient comfort) and by attempting to obtain all radiographs and complete all required dental care in one appointment while under sedation.

The role of anesthesia services in an outpatient setting for patients with special considerations is similarly not well understood. Clinical trials [9] relating to the subject are often limited by small sample sizes. There is also some conflicting data on the use of specific medications in this group, which can be a barrier as safety and efficacy become concerns. For example, many patients with autism can become paradoxically dysphoric [10] rather than sedated when treated with common anesthetic medications such as midazolam, making it even more difficult to provide them with basic health services. Providers must also consider that these patients are often on many home medications such as stimulants, antipsychotics, and drugs for medical conditions related to their developmental disability, which may interact with routine anesthetic drugs. Because of these concerns, many providers are simply not comfortable prescribing oral anxiolytics for patients with special considerations, especially for routine procedures such as blood draws and imaging.

From discussions at our institution, this is often a barrier to care as these patients are often dependent on the availability of the few providers who are comfortable providing such services. Pediatric anesthesiologists are specially equipped to meet this perceived gap in care, as they are trained in both adult and pediatric populations, have advanced knowledge of sedation and anxiolytic services, and

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are familiar with treating patients with developmental and intellectual disability, which typically presents in childhood. Child life specialists are also vital to the process of care coordination for these patients, as they often are the most familiar with the patient's history and individual requirements. Many child life specialists at our institution have independently emphasized the need for formal education for all healthcare providers in treating patients with intellectual and developmental disabilities. They have also agreed that institutional guidelines on providing anesthetic services to this population, especially anxiolytics and/or sedatives prior to routinely uncomfortable procedures, would increase the quality of healthcare they receive.

More work needs to be done to better understand these gaps in care on a national level. At the institutional level, there are many options for healthcare improvement that should be considered. Adaptive care planning [11], in which a permanent record of a patient's specific needs is made and shared with all their providers, can inform providers of the best approach to each patient and allows some degree of consistency between different types of medical visits, which may help patients with autism cope better with care. These records may indicate the usefulness of anesthesia services for each patient, based on their history of requiring and tolerating such services. As the need for such services is elucidated, institutions should work toward creating safe and effective guidelines for anesthesia administration and for coordinating multidisciplinary care for these patients.

**Name has been changed to preserve patient confidentiality*

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