



# Medication Compliance Protocol for Pediatric Patients With Severe Intellectual and Behavioral Disabilities

Christina Epitropakis BSN, RN<sup>a</sup>, Elizabeth A. DiPietro MSN, CRRN<sup>b,\*</sup>

<sup>a</sup>*Pediatric registered nurse on the Neurobehavioral Unit at Kennedy Krieger Institute, Baltimore, MD*

<sup>b</sup>*Clinical nurse specialist at Kennedy Krieger Institute, Baltimore, MD*

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Pediatric nurses are well aware of patient medication refusal. For a variety of reasons, many pediatric patients are noncompliant with their medication regimen. Medication administration is even more difficult when the population has severe intellectual and behavioral disabilities. An inpatient unit composed of children with these diagnoses presented a unique challenge. To address this issue, the unit RNs devised a medication compliance protocol. Initial implementation resulted in a success rate of 83.3% for six patients, after 4 weeks. Despite the small sample size, the RNs experienced a positive outcome with medication administration through consistent application of a medication compliance protocol.

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AN INTERNATIONALLY KNOWN children's hospital in Baltimore, Maryland, addresses the needs of outpatient and inpatient children who have brain, spinal cord injuries and neurobehavioral issues. The medical and behavioral needs of the patients are met through a comprehensive multidisciplinary approach in an inpatient or outpatient setting, dependent on the complexity of the patient's healthcare needs. The inpatient setting consists of three separate units, a Pediatric Comprehensive Neurorehabilitation Unit for children with disorders of the brain and/or spinal cord, a Pediatric Feeding Disorders Unit, and a Neurobehavioral Unit for children with neurobehavioral issues.

The Neurobehavioral Unit (NBU), a 16-bed inpatient unit, admits children with intellectual disabilities and significant behavioral issues including autism spectrum disorders (ASD), such as Asperger's syndrome and pervasive developmental delay. The most common concomitant

diagnoses associated with ASD are disruptive behavioral disorder (DBD), stereotypic movement disorder (SMD) with self injurious behaviors (SIB), bipolar disorder (BPD), mood disorder (MD), anxiety disorder (AD), conduct disorder (CD) and attention deficit hyperactivity disorder (ADHD). Children from all over the world are admitted and treated on the NBU. Interdisciplinary team members, consisting of clinical behavioral psychologists, clinical specialists, psychiatrists, psychologists/case managers, nurses, social workers, physical therapists and speech therapists, create and implement treatment plans for all patients. Uniquely created patient treatment plans target specific problem behaviors related to individual diagnoses. An admission to the NBU spans approximately 3 to 9 months with the overall goal of a reduction in problem behaviors by 80%.

Most of the individualized treatment plans include decreasing or eliminating medication refusal, an issue well known to pediatric nurses. Medication compliance is imperative, as many of these patients require multiple medications to treat their complex medical needs. Typically developing pediatric patients often refuse medication

\* Corresponding author: Elizabeth A. DiPietro, MSN, CRRN.  
E-mail address: [dipietroe@kennedykrieger.org](mailto:dipietroe@kennedykrieger.org).

administration due to a variety of reasons. These factors may include an unknown environment, fear, fatigue, illness, and/or prior negative experiences with medication administration. It is often up to the pediatric nurse to develop creative strategies to encourage medication administration compliance, while simultaneously maintaining patient dignity and adhering to the facilities' policies to reduce the incidence of medication errors. The pediatric nurse must provide safe and effective medication administration while maintaining an "understanding of child development from a bio-physiological and psychological perspective" (Murphy & While, 2005, p. 930).

Detailed literature on medication administration challenges involving pediatric patients diagnosed with severe intellectual and behavioral disabilities is limited; however a fair amount of research addresses the chronically ill pediatric population's non-adherence to prescribed healthcare regimens. Many components contribute to noncompliance and "factors that have been associated with non-adherence include psychiatric illness, psychological factors, family issues, and health problems" (Smith & Shuchman, 2005, p. 615). Low-level cognitive function and poor comprehension influence the pediatric patient's ability to fully comply with the prescribed treatment plan. According to Hommel, Denson, Crandall, and Machner (2008), "studies across pediatric populations have demonstrated poorer adherence to long-term medical regimens in children and adolescents who exhibit behavioral and emotional dysfunctions" (p. 787). Pediatric patients with these behavioral and emotional dysfunctions include children with severe developmental disabilities who either may not intellectually understand the rationale for medication compliance or may have an alteration in sensory perception. This variant can be either an increased or decreased sensitivity to external stimuli or diminished mental processing. There may be a heightened or reduced sense of taste, touch, texture and smell; altered proprioception; distorted comprehension; and/or oral-motor aversion. Sensations that would be acceptable to a typically developing child may be perceived as unpleasant, irritating or even painful for the child diagnosed with developmental and cognitive delays.

The pediatric nurse should be prepared to address these differences during medication administration. A heightened response to anything placed in or around the oral cavity could result in a negative reaction such as medication refusal. Maladaptive behaviors, such as aggression, self-injurious behavior, and resistance to medication administration, are often the only mechanisms of communication and control, and may develop due to hyposensitivity/hypersensitivity to external stimuli, and/or lack of understanding. Pediatric nurses caring for this type of special needs population must understand the pediatric patients' intellectual disability and sensory processing differences, while ensuring medication administration compliance (Hagopian & Hardesty, 2014; Kern et al., 2006).

The NBU pediatric nurses have devised several resourceful approaches to decrease medication refusal in this particular

pediatric patient population. The patients on the NBU often have difficulty with consuming their medications, exhibiting such behaviors as mouth closure, head turning, refusal to swallow, and spitting. To address this problem, the nursing staff works directly with the behavioral psychology team to perform a preference assessment with each patient to determine which edible or tangible reinforcement such as candy, cookies, crackers, ice cream, toys, music or cartoons, the patient prefers. Suggestions from family members are also obtained during the preference assessment period, which occurs within the first week of admission, in order ensure their involvement in the medication compliance protocol development. The behavioral team members observe which reinforces the patient prefers the most using data analysis. After several sessions, the nursing staff and the behavioral psychology team outline the patient's preference; incorporate the specific item (s) as a positive reinforcer(s) for the medication procedure; and develop an individualized medication compliance protocol.

Applied behavior analysis (ABA) is the framework utilized to decrease or eliminate problem behaviors that frequently develop in children with intellectual and developmental disabilities regarding medication compliance. ABA is a discipline concerned with the application of behavioral science in real-world settings such as clinics and schools to improve socially important issues such as behavior problems and learning (Baer, Wolf, & Risley, 1968; Rapoff, 2010). ABA procedures are separated into two categories: comprehensive and focused. Many children with intellectual disabilities and autism require both procedures be used in order to improve behavioral difficulties. Comprehensive ABA interventions target global measures of functioning including IQ, adaptive skills, and social skills in children with autism. This treatment is often provided for several years and is used in the home, at school and within the community. The following skills are targeted: attention, discrimination, language/communication, socialization and more advanced educational skills such as reading. Focused ABA interventions are time limited since they address certain problems such as: self-injury, disruptive behavior, pica and other behaviors. Focused ABA involves identifying the variables controlling the problem behaviors (Hagopian & Hardesty, 2014). Once the variables are identified, an individualized treatment plan is created. Individualized treatment plans may include medication protocols if medication compliance has been a problem. Environment and consistency are both significant variables that impact medication compliance and must be regulated to minimize problem behaviors while encouraging adaptive behaviors (Hagopian & Hardesty, 2014). Furthermore, reinforcement for undesired action associated with medication compliance must be withheld (Hagopian & Hardesty, 2014).

Education and coaching are necessary to assist the patient with his or her understanding of the expectations, therefore patients who require the implementation of medication protocols are provided the opportunity to practice. Practice sessions are conducted using placebo medications before

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