Pediatric Intensive Care Unit Management and Discharge of a Severely Autistic Patient

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Citation

Abstract
Management of patients with autism and other behavior disorders can be difficult, especially in a hospital setting. A 17 y.o. patient with severe autism developed respiratory failure from status epilepticus and pulmonary aspiration. Following extubation, sedation with propofol was required to control behavior in the ICU. Successful discharge home was achieved via unique cooperation between the ICU and Emergency Department (ED). After transport to the ED, the propofol was discontinued and, following sufficient arousal, the patient left in the care of his family. This case emphasizes the need for active family involvement in the care of behaviorally difficult patients and a willingness to consider novel management strategies for such patients.

INTRODUCTION
While severity varies, aggressive behaviors, decreased impulse control, and decreased ability to adapt to environmental changes or altered sensory inputs are common features of autism and related developmental disorders (1) and frequently require the use of behavior-modulating medications (2). The presence of these behaviors may make the medical care of these children difficult as the unfamiliar, often chaotic nature of the clinic environment can trigger significant distress. These issues may become magnified when medical procedures and/or inpatient care, particularly in the ICU, are required, due to the pervasiveness of background noise and sensory stimulation.

Unfortunately, data describing strategies for patient management in these care environments is limited. Small series describe effective use of various sedative regimens to facilitate diagnostic tests or minor dental/surgical procedures (3,4,5,6,7,8) but only a single case report exists describing burn care and a prolonged hospital course in an adolescent patient with autism (9). Authors agree that active involvement of the patient's main at home caregivers is of paramount importance.

We describe the management strategy used to facilitate care of a severely autistic child in the Pediatric ICU for status epilepticus and aspiration pneumonitis. Specifically, transition of this child from the ICU to his home was accomplished with a family-centered care plan that included a medium-term propofol infusion, active parental input, and unique interdepartmental cooperation.

CASE REPORT
Presentation of this report was approved by the Institutional review Board of the University of Louisville. A 17 year old, 130 kg, caucasian male with a history of autism, seizure disorder, and severe aggressive behaviors presented to our emergency department (ED) in status epilepticus. Pre-hospital care by EMS personnel included bag mask ventilation and the administration of 2 mg of lorazepam. He vomited en route to the ED. Upon arrival he was still seizing and required endotracheal intubation and mechanical ventilation for hypoxemia secondary to presumed aspiration. Seizure control was achieved roughly 90 minutes later following administration of additional lorazepam and fosphenytoin. He was transferred to the PICU for ongoing management.

The patient's past medical history was significant for profound developmental delay and behavior disorders secondary to his autism. He was nonverbal and frequently exhibited severe aggressive and combative behaviors. These were ameliorated with risperidone and paroxetine but became particularly pronounced in unfamiliar environments including medical caregiver clinics. In fact, while his seizure disorder had been well-controlled with lamotrigine, follow up with his neurologist could only be performed in the office parking lot in the family car due to violent rages upon entry.
to the clinic itself.

On arrival to the PICU, the patient was intubated and mechanically ventilated. Chest radiograph demonstrated bilateral infiltrates consistent with aspiration and it was anticipated that mechanical ventilation would be required for several days. Based on the family's description of the patient's behavior patterns and their firmly stated belief that awareness during his ICU stay would trigger violent outbursts, it was decided to keep him deeply sedated until his lung disease had resolved. This was achieved with fentanyl (up to 100 µg/hr) and midazolam (up to 5 mg/hr) infusions and subsequently supplemented with a sodium pentobarbital (40 mg/hr).

Moderate renal insufficiency secondary to rhabdomyolysis (maximum creatine phosphokinase was 28,460) from prolonged seizure activity developed but resolved by hospital day 8. By hospital day 3 the patient had been weaned to minimal ventilatory support. Discussions with the family and medical caregivers focussed on strategies to maintain behavior control during the peri- and post-extubation periods. Due to rapid titratability, it was felt that a propofol infusion would most effectively achieve this. An infusion was started at 0.3 mg/kg/hr, rising to a maximum of 1.8 mg/kg/hr following discontinuation of the fentanyl, midazolam and pentobarbital infusions. Twenty-four hours later, the patient was successfully extubated to oxygen by facemask with the propofol infusion still running. In preparation for transfer to a general medical ward, the infusion was weaned but was accompanied by the development of severe agitation, necessitating its reinstitution.

Over the next 48 hours, numerous conferences occurred between ICU medical and nursing staff and the patient's family. The family maintained that cooperation within the hospital would be impossible unless moderate to deep sedation was maintained but were confident that he would be compliant if in a familiar environment. Subsequently, a plan was agreed upon whereby the patient would be maintained on propofol until his oxygen requirement had resolved at which time he would be transferred to the ED where the propofol would be discontinued and the patient, once awake, would be discharged directly home.

On hospital day 9 the patient was transferred from the PICU to a quiet room near the exit of the ED under the care of both ICU and ED staff. The family vehicle was moved to the ambulance entrance of the ED to minimize the distance between this room and the vehicle. The propofol infusion was discontinued with the patient's mother remaining at the bedside to facilitate patient comfort. Within 10 minutes, the patient was sitting up in bed breathing comfortably and a short time later he walked (self-initiated) to the car with his mother. Both parents felt that he was acting and breathing at his baseline and were comfortable with leaving the ED, after agreeing to call the PICU attending medical staff when they arrived home. Thirty minutes later, the mother called to report that the ride home had been uneventful and that the patient was doing well, comfortable in his home environment.

**DISCUSSION**

The current case highlights several important points regarding the care of behaviorally difficult patients in the ICU. First and foremost is the importance of family-centered care. In this instance, parental knowledge of their child's behaviors and triggers was invaluable in successfully facilitating his safe care in the ICU and, ultimately, his discharge home. Of course, extremes such as were deemed necessary in this instance (discharge home immediately following discontinuation of a prolonged sedation infusion) must be case-specific. As we had been interacting closely with the parents over several days, all caregivers were able to assess and voiced comfort with their abilities and reliability following ED discharge. Had both parents not demonstrated understanding of these issues, assured us that they would divert to the nearest hospital if problems arose, and promised to contact us upon arrival home we would likely have been forced to investigate other avenues.

The flexibility of our ED colleagues in facilitating the discharge plan was vital and highlights the importance of openness to unique arrangements under unique circumstances. While children are often discharged from our ED following sedation for various procedures, the fact that sedation had been present for days, as opposed to minutes, could have made the ED staff uncomfortable with our proposal. Co-management in the ED by both ED staff and ICU staff, who knew the patient well was important in making this discharge possible.

Finally, it is unlikely that this discharge could have occurred as smoothly as it did had we not had access to a sedative with the rapid clearance profile of propofol. While the risks were not negligible, propofol's very short half-life allowed us to feel much more comfortable about a rapid discharge following wakefulness. Despite the potential risk of propofol...
infusion syndrome (10,11), we had extended the duration of the propofol infusion (5 days) beyond our usual practice (<24 hrs). However, all parties agreed that this risk was outweighed by the benefits of behavior control and throughout the infusion time the propofol dose remained low at <2 mg/kg/hr.

The current case adds to the limited literature regarding management of children with autism in the hospital setting. With a rising prevalence and increased public awareness about autism and related disorders, discussions about the disease are becoming increasingly prevalent. However, the major focus of these discussions is epidemiology, diagnostic criteria and speculations on etiology. Reports or advice regarding management in the hospital setting remain limited, with most focusing on strategies for brief, outpatient procedures (3,4,5,6,7,8). A single case report describes ICU management for a burn injury utilizing prolonged intubation and mechanical ventilation with deep sedation until graft healing had occurred (9).

Both this case and the above (9) highlight the need for further descriptions of inpatient treatment strategies for such severely behavior-disordered patients, particularly methods for decreasing the distress associated with being in a non-familiar environment. While strategies such as bringing familiar items from home, maintaining as quiet a room as possible, and minimizing intrusions by alarms and interventions are helpful (6), they do not always suffice. While the high prevalence of co-morbidities, especially seizure disorders (1,12), puts the autistic population at risk, it is rare for these children to require inpatient management. This also suggests, however, that descriptions of others experiences and more formalized recommendations from caregivers of autistic children would be beneficial.

In summary, we describe a novel strategy for management of a severely autistic adolescent with respiratory failure. While the use of moderate to deep sedation until the point of discharge is rarely desirable, we believe that in this instance, the course described facilitated discharge in as safe and minimally traumatic a manner as possible. The assistance of the family via their knowledge of their son's behaviors and willingness to collaborate with us also proved invaluable.

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References
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