Care of Patients With Autism Spectrum Disorder Undergoing Surgery for Cancer

Deena Damsky Dell, MSN, RN, BC, AOCN®, Mary Feleccia, RN, Lisa Hicks, ADN, RN, OCN®, Erin Longstreth-Papsun, BSN, RN, OCN®, Sue Politsky, MSN, RN, CNA-BC, and Courtney Trommer, BSN, RN

M.J., a 28-year-old nonverbal autistic male, was referred to a comprehensive cancer center for a second opinion regarding recurrent metastatic mixed nonseminomatous germ cell testicular cancer in the left testis. M.J.’s medical history included an untreated cryptorchidism (an undescended right testicle) but his left testicle was normal. M.J. was diagnosed with autism at age 2 and lives at home with his mother and father. He had been attending a day program prior to diagnosis and treatment of testicular cancer. His younger sister is a special education teacher and is very involved in his care. M.J. was diagnosed with cancer 18 months prior to his visit to the cancer center when his mother discovered a lump in his left testicle while bathing him. He underwent an inguinal orchietomy at a local hospital. Pathology revealed an 80% bridle cell and 20% immature teratoma. No complications from the surgery were reported; however, a computed tomography scan after surgery revealed metastatic disease in his lungs and retroperitoneal areas. He was treated with four cycles of cisplatin and etoposide. M.J. was intubated and sedated during the first two cycles of chemotherapy because of behavior issues. Aspiration pneumonia resulted from being ventilated and complicated his recovery. M.J.’s mother stayed with him in the hospital for the last two cycles and reported that they walked almost continuously for the duration of each hospital stay. A computed tomography scan done at the completion of chemotherapy revealed a residual 8 cm cystic retroperitoneal mass consistent with nodal metastasis. The left kidney was displaced by the retroperitoneal tumor. The lung metastases had resolved.

The urologic surgeon at the comprehensive cancer center believed that M.J. was a candidate for a retroperitoneal lymph node dissection despite an increased risk of complications after surgery from M.J.’s autism. M.J.’s behavior in the outpatient clinic had been difficult. He was unable to sit still for a physical examination and spent most of the visit running up and down the halls. Realizing that certain arrangements would be needed during M.J.’s hospital stay, the surgeon notified the intensive care unit’s clinical manager. The clinical manager and the clinical nurse specialist coordinated a literature search on autism and general needs of patients with autism. The clinical manager also visited M.J.’s home to meet him and his family and identify his needs prior to admission.

The retroperitoneal bilateral lymph node dissection was completed but was complicated by a right renal artery injury that was repaired by vascular surgery. Bilateral ureteral stents were put in place. M.J. remained ventilated and sedated in the intensive care unit so he would not injure himself or dislodge any tubes. He was extubated the day after the surgery, but progressive dyspnea with desaturation required reintubation the following day. M.J.’s chest x-ray also showed evidence of bilateral aspiration pneumonia. He was extubated 12 days after surgery; however, he had developed bilateral pleural effusions that were drained and a right pigtail catheter was placed. M.J. was breathing normally when he was discharged. M.J.’s creatinine also was elevated after surgery. A renal vascular ultrasound revealed that no blood was flowing to the right kidney. The right stent was left in place until six days after surgery, and his creatinine level slowly returned to normal. The urinary catheter was removed 18 days after surgery.

M.J. was NPO for the first two weeks following surgery. He had minimal oral intake after extubation. An abdominal computed tomography scan revealed a large amount of ascites. A pigtail catheter was placed after several abdominal paracenteses because a chylous leak was the suspected cause of the ascites. Liver function tests and amylase and lipase levels also revealed pancreatitis. A peripherally inserted central catheter line was placed so total parenteral nutrition could be started. M.J. was NPO again.

M.J. experienced numerous complications from the surgery and his emotional and cognitive impairments, but he finally was discharged—on total parenteral nutrition and with an abdominal pigtail catheter in place—37 days after his surgery.

What is autism and how does it affect cognitive and emotional functioning? Autism spectrum disorders (ASDs) or pervasive developmental disorders (PDDs) are...