

Deterioration of a developmentally delayed child with an acute abdomen

A 16 year old male with cerebral palsy, and global developmental delay presented to the Emergency Department for assessment of increased losses from his gastrostomy. The patient was admitted under the surgical team for blood work, and replacement of fluid loss. An abdominal x-ray revealed substantial faecal loading.

Overnight his gastrostomy continued to drain green fluid while his observations remained between the flags. An enema was ordered, however, his mother questioned the diagnosis of constipation as he had regular laxatives. The enema was given and a focus on constipation continued.

The following evening his heart rate was in the Yellow Zone and the surgical team was requested to review the patient. On assessment, he was slightly agitated with mild abdominal distension; however, there were no signs of sepsis and his other observations remained between the flags. The plan included analgesia, a strict fluid balance, and follow up by the surgical team.

The patient continued to deteriorate over the next four hours with increasing tachycardia (Red Zone criteria), and later, fever and hypotension (Red Zone criteria).

A blood gas revealed a lactate of 6mmol/L (Red Zone criteria). Nursing staff escalated their concerns to junior medical staff, however, despite these Red Zone observations, his condition was not escalated to a rapid response.

The patient's electronic record was reviewed by a paediatric registrar as the patient was handed over as "someone to watch". The registrar identified the concerning lactate and persistent tachycardia, and a decision was made to transfer him to a Paediatric Intensive Care Unit with a diagnosis of sepsis.

A paediatric surgical consultant reviewed the patient and ordered an abdominal CT which identified a volvulus. A decision was made to transfer the patient to theatre. In theatre it was found that the patient's gut was non-viable due to malrotation with volvulus. Following discussions with the family a decision was made to withdraw active care and the patient was extubated. The patient passed away soon after.

Investigation

A review of RCAs conducted in 2016 and 2017 demonstrated five unexpected deaths of children with developmental disabilities as a result of an acute abdomen.

In all five cases there were issues pertaining to diagnostic error or delay as a result of diagnostic anchoring. There was also a component of delay, or failure to recognise and escalate management of the deteriorating patient.

Lessons Learnt

Children with developmental disabilities often manifest pain differently. They may be unable to self-report pain, which can make them vulnerable to inaccurate assessment of pain, and subsequent inadequate management of pain.

It is crucial to engage and partner with the parents and carers of these patients to better recognise and understand those behavioral cues they may demonstrate while in the hospital setting. This includes how their child expresses pain, what is normal behavior for them; as well as identifying and responding to atypical behavior or sudden clinical deterioration. This is critical, as these children can often deteriorate suddenly and expectantly.

A patient with atypical behavior and observations outside of the flags should be a 'red flag', and clinicians need to have a low threshold for early escalation and senior review.

The patient had a blood pressure and heart rate (4 hours) in the Red Zone which was not escalated as a Rapid Response. In patients that are difficult to assess because of age or developmental delay, the physiological signs become even more important in identifying signs of serious illness or deterioration.

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