

Diagnostic Overshadowing in Patients with Autism and Learning Disabilities: The Serious Ongoing Concern

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In the complex landscape of healthcare, the phenomenon of diagnostic overshadowing has far-reaching implications for the accurate diagnosis and treatment of patients with autism and learning disabilities, particularly in the context of sepsis.

It is well known that individuals with learning disabilities, autism, or a combination of both face an elevated risk of sepsis compared to the general population. Moreover, their susceptibility to infections is heightened, and the progression of the illness tends to be more rapid.

Communication difficulties may also make it challenging for them to convey their symptoms effectively. Additionally, healthcare providers may sometimes misconstrue symptoms of sepsis as a normal part of the patient's pre-existing illness, known as diagnostic overshadowing, which represents a further significant challenge that impedes access to proper healthcare and support.

The Learning Disability Mortality Review Report (LeDeR) published in May 2018, based on findings from over 1,000 reviews into the deaths of people with a learning disability, highlighted sepsis as a key contributor to premature mortality, with 11% of deaths reviewed being recorded as sepsis related (likely an underestimate). The Report recommended a national focus on sepsis for people with a learning disability, to raise awareness of prevention, early identification, and treatment.

Shockingly, the 2021 LeDeR states that 49% of deaths reported were rated as "avoidable" for people with learning disabilities, compared to 22% for the general population.

At least some of the 'avoidable' deaths will be due to diagnostic overshadowing. The phenomenon presents several challenges:

Delayed or Missed Diagnosis: Perhaps the most concerning consequence is the delayed or missed diagnosis of sepsis. Healthcare providers may concentrate on the pre-existing illness, inadvertently overlooking other medical issues, including sepsis.

Attribution of Symptoms: Symptoms that might be indicative of both a pre-existing illness and sepsis can be attributed solely to the pre-existing illness, preventing the accurate identification of sepsis.

Lack of Targeted Treatment: When overshadowing occurs, the patient may not receive the specific interventions and treatments needed for co-existing medical conditions, particularly sepsis.

These precise issues arose in a recent inquest in which I supported the family of a young man with autism and learning disabilities, with the Coroner concluding, amongst a number of other failings, that there was a failure to diagnose sepsis contributed to by neglect.

The Coroner, following a thorough and robust investigation, made the following narrative conclusion:

AB presented with physiological markers indicative of sepsis at the point of his admission to Colchester General Hospital on the 12th September 2021. His Physiological markers repeatedly evidenced sepsis and were consistent with peritonitis throughout his admission, up to, at the point of, and post discharge on the 16th September 2021. By the time of AB's discharge the sepsis had become systemic. The evidence shows that during AB's hospital admission from the 12th to the 16th September that the following matters more than minimally contributed to his death:

- a. A failure to undertake further imaging or other objective diagnostic technique prior to discharge;
- b. A failure to undertake a digital rectal examination proximate to discharge;
- c. There was a failure to recognise the deterioration of the physiological infection markers contained within AB's blood work resulting in a failure to diagnose sepsis, contributed to by neglect;
- d. Insufficient consideration of the impact of AB's autism on his presentation and communication combined with a concomitant failure to make reasonable adjustments

to account for AB's autism, including a failure to engage with the hospital's Learning Disability service;

e. A failure to undertake a multi disciplinary assessment of the requirement for a surgical procedure to manually remove faecal matter from AB's colon; and

f. The absence of an appropriate antibiotic course from the 15th September 2021, or acute observation and monitoring, combined with a premature discharge on the 16th September 2021.

It was clear during the inquest that despite the national focus from NHS England on raising awareness of sepsis for people with a learning disability, much still needs to be done to ensure that clinicians are always mindful of a potential diagnosis of sepsis and the dangers of diagnostic overshadowing.

Recognising the significance that autism and learning disabilities often occur alongside other health conditions is imperative to counteract the adverse effects of diagnostic overshadowing. Clinicians must adopt a proactive stance when dealing with patients who have autism and/or learning disabilities.

This should involve; conducting thorough assessments, fostering collaboration among various specialists, and embracing a holistic approach to patient care, delivering individualised care plans, continued awareness and education, and regular re-evaluation to ensure that individuals with learning disabilities receive an accurate, timely diagnosis, targeted treatment, and the necessary support for their well-being.