Delayed diagnosis of a unicornuate uterus with a non-communicating horn in a patient with intellectual disability

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Background

We are reporting a case in which the diagnosis of unicornuate uterus with a non-communicating horn was delayed in a patient with intellectual disability. This report was written to highlight the diagnostic pitfalls and reasons for significant delay from presentation to diagnosis and management. The lessons learnt from this case include the importance of, continuity of care, acknowledging health disparity in patients with disability, and considering rare conditions in the possible differentials.

Profile

A 16-year-old was seen at Gynaecology Clinic for right iliac fossa pain associated with menstruation. Our patient had multiple congenital anomalies including a TOF and double aortic arch with vascular ring (repaired at 5 months old), hydrocephalus and macrosomia. Our patient was non-verbal, legally blind secondary to microphthalmia, and had an intellectual disability. She communicated through sign language. Her mother was very supportive.

Case Presentation

- After an original referral for dysmenorrhoea at age 16, our patient was lost to follow-up until representing at the age of 25. A Mirena was inserted. A pelvic USS showed a large right sided adnexal mass and a working diagnosis of a dermoid cyst was made. Further treatment was deemed inappropriate in the setting of her co-morbidities.
- Presented 18 months later to our clinic with ongoing dysmenorrhea. A MRI diagnosed our patient with a rudimentary, non-communicating right uterine horn. Imaging displayed internal blood products suggesting a functioning endometrium.
- Patient's mother consented for laparoscopic removal of the uterine horn.
- Findings at surgery were:
  - An enlarged dilated right sided noncommunicating horn.
  - A right sided haematosalpinx with a paratubal cyst.
  - Evidence of haemosiderin staining of peritoneum but no endometriosis.
  - A hematometra was confirmed after removal.

Discussion

A unicornuate uterus with a rudimentary horn is a rare condition that is often delayed in diagnosis. This delay can be due to many causes including, a lack of experience and incorrect interpretation of imaging. Our patient was only formally diagnosed at 26 years old, after being seen in other areas of our Gynaecology service, by multiple doctors, over 12 years.

In our case, we also acknowledge gaps in communication between her health professionals, that combined with the other causes, demonstrates the "Swiss Cheese model" of causation.

Perhaps we need to consider what underlying cognitive biases we have as clinicians when treating patients with intellectual disabilities, and whether this drives us to have a paternalistic approach in our care, which is not necessarily in the best interests of our patients.

There is a significant health disparity between people with intellectual disabilities and the general population1on. This has been attributed to a lack of training and education for managing patients with intellectual disability. We need to consider how we can grow as clinicians to service the the entire community in an inclusive manor, including women with disabilities, and how we can pave a way for our future clinicians, so that they do not repeat the same mistakes.