ELECTIVE (SSC5b) REPORT (1200 words)

A report that addresses the above four objectives should be written below. Your Elective supervisor will assess this.

1. Describe the pattern of gastroschisis in the population served by Southampton Children's Hospital and its prognosis in the context of patient-centred care and general impact on the NHS.

I undertook my elective placement in paediatric surgery at Southampton Children's Hospital. In contrast to London, where specialist paediatric surgical services are spread across 5 main tertiary centres, the hospital serves the south of England including the Channel Islands and the Isle of Wight, and is the closest tertiary centre for children living across the region.

Although the paediatric population served by London's hospitals is estimated be to be around 8 to 17 million, the spread of services means that any one condition can present to hospitals with varying incidence 1. This is particularly true for congenital abnormalities such as gastroschisis; for example, over a five-year period (2010-2015), annual numbers of patients presenting with gastroschisis to The Children's Hospital at the Royal London averaged at 2.8, whereas over the past year (2016- 2017), Southampton admitted 13 patients with the same condition [data collected from Badgernet database]. To the best of my knowledge, incidence across the UK is homogenous, and these numbers reflect the varying distribution of patients within London, and the high volume and variety of conditions seen at Southampton as a result of the large catchment area.

Gastroschisis is a congenital abdominal wall defect with herniation of the abdominal contents in utero, exposing the organs to amniotic fluid 2,3. It exists across a spectrum defects which include umbilical hernias and exomphalos. It is classified according to the presence of associated anomalies as simple or complex. Simple gastroschisis presents only with evisceration of organs which can be reduced with no subsequent complications 4–6. Complex gastroschisis occurs in 11- 20% of cases, in the presence of intestinal atresias, perforations or necrosis and is associated with significant long term complications.

In the UK, incidence has been reported as varying between 1 in 3000 to 1 in 8000 live births, with a well reported rise of almost 60% in the past 20 years 2,6. It is more common in urban areas, particularly to young mothers. In the UK, there have been reported associations showing increased incidence in women from Caucasian backgrounds, whereas in the US, it has been shown to be associated with those from an African American backgrounds 4,6. These discrepancies may point towards stronger links with environment and toxin exposure during pregnancy, as opposed to stark genetics.

With its increased incidence however, have also come improvements in mortality attributed to advances in surgical and neonatal care 4. Survival rates currently stand at 90- 95% 2,4,5. This has led to attention being drawn to the long-term morbidities affecting these children throughout both the neonatal and childhood period, and the impact this has on local healthcare providers.

Many of the long-term complications seen in these patient groups are common with children suffering from gastro-intestinal pathologies, with varying degrees of intestinal disturbances. These include, but are not limited to, long term use of PN, chronic abdominal pain, chronic constipation/ diarrhoea, bowel obstructions, umbilical hernias and failure to thrive 3,7. Many children have also reported being affected by what can be a significantly large scar where primary closure was not possible, and

recurrent hospital admissions affecting their home and school life. As children progress, growth does appear to improve and there is a reduction in the number of complications. Additionally, neurodevelopmental outcomes are normal.

The above illustrates the far-reaching impact of the condition beyond its management in the neonatal period, and highlights the importance of multi-disciplinary care.

2. Describe the role of the multi-disciplinary team both within the hospital and in the community in caring for this patient population throughout childhood. Compare this with the systems in place in London.

As described above, the long-term implications of gastroschisis are extensive. This results in the need for input beyond the surgical team, to involve general and gastroenterology paediatricians, dieticians, community nurses and clinical nurse specialists (CNS). At Southampton, the surgical CNS is ever-present with patients and their families, where they take on an active role in supporting families holistically. Their work involves liaising with health visitors and community nurses, and once discharge has been planned, reviewing the patients one week later. They are then available for advice via phone, and ensure a follow up appointment with the consultant paediatric surgeon is organised for 3 months later.

Whereas this is similar to the support offered by teams in London, including the surgical CNS, I believe it varies in two regards. The first is location. As aforementioned, Southampton hospital covers a very large area, including islands, and as such, organising continuity of care can be challenging. For example, follow up appointments can be difficult for patients to attend. To remedy this, consultants carry out clinics at local district generals. However, I imagine that ongoing support which could be provided by a local CNS for example within London, may be difficult to access in the South. Secondly, one of the largest barriers to care in London is language. This does not seem to be a significant concern within the population served by Southampton, which in theory should allow for development of good relationships between the surgical team and the families, and hence good quality long term care. However, this is in theory and could merit investigations into whether this leads to improved long term outcomes.

3. Describe the global disease burden of gastroschisis and discuss contrast in management between countries.

As a result of the Lancet commission for Global Surgery, much attention has been focussed on establishing partnerships between high and low income countries in a bid to encourage research and improve delivery of surgical services globally. Within the UK, this led to the development of Gastroschisis International (GIT), a collaboration across six countries (UK, Malawi, Cote D'Ivoire, South Africa, Uganda and Nigeria), to identify variations in outcomes and ways to overcome barriers 8. As was predicted, neonates in low and middle income countries have higher mortality in comparison to the UK. This has been attributed to multiple factors, including: lack of antenatal care; late presentation post-delivery; poor paramedic/ transportation services from satellite hospitals to specialised units; lack of neonatal intensive care facilities; lack of equipment including pre-formed silos and parenteral nutrition, and poor experience leading to early closure and subsequent complications. Death was most commonly attributed to septicaemia or hypothermia, which could be

argued are preventable if the exposed bowel (prone to inflammation and dehydration) was managed appropriately.

Gastroschisis is an obvious diagnosis at birth, and where available, make-shift or surgical silos were successful when applied promptly. Of those factors stated within this initial GIT report, lack of health-seeking behaviour was highlighted, with late presentation to appropriate services. However, even if adequate immediate management was obtained, neonates would still require supportive management in specialised units, which is not currently available to the majority of those living in low to middle income countries.

Whereas reports highlight vast discrepancies between countries for a condition that is largely survivable- where experience and specialised services exist- it fails to suggest sustainable solutions for its improvement, other than the use of gastroschisis as an indicator of good surgical neonatal outcome.

4. Develop clinical and surgical skills in the context of paediatric surgery

Throughout my elective period, I had fantastic opportunities to observe surgeries ranging from complex congenital malformations and general paediatric presentations, to tumour resections and laparoscopic procedures. Due to the nature of the patients on the lists- often very young and very little- practice of my own surgical skills was limited, but hugely enjoyable when the opportunity presented itself. Clinics and on calls were where I gained the most insight into overall approaches to paediatric patients, including histories, examinations and awareness of the patient not as a single entity, but as a family to be addressed.

The program of training for the specialist registrars also meant I was able to attend teaching sessions and learn through a variety of means including practicing surgical skills, journal clubs and case presentations. This environment established by the consultants, predominated by active teaching and discussion around research, was highly motivating and I feel that whilst I still have a lot to learn regarding this vast speciality, I certainly fulfilled my objective of advancing my knowledge in this field.

References

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