

Elective at Great Ormond Street Children's Hospital (GOSH)

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What are the prevalent endocrine conditions seen at GOSH, compared to a paediatrics department in a secondary care hospital?

The most common condition I noticed, with regards to the general endocrine clinics, was to do with disorders of growth. I was surprised to see how concerned parents were that their children were shorter than their peers, more so than the patients themselves. There were also a number of children with a diagnosis of congenital hypothyroidism, which I had previously believed to be an extremely uncommon condition, but there were a surprisingly large number of patients presenting in the clinic. When I did my previous paediatrics placement at Southend Hospital, a secondary care setting, the majority of the clinics were taken up by asthma and diabetes as the two prevalent conditions. The services at the local hospital level were smaller and less specialised. A consultant would see a variety of conditions in one morning, whereas at GOSH patients presented to clinics with a variety of problems, but only those relating to endocrine disorders were investigated in the clinics I sat in on, and other problems e.g. respiratory, or GI, were subsequently referred on to other departments. Likewise many of the patients on the ward at GOSH were there because of problems relating to hypoglycaemia, and hyperinsulinism, whereas in a secondary care hospital, a lot of inpatients were suffering from more straightforward cases of dehydration or gastroenteritis. Because these problems are readily managed in the community, they are unlikely to be seen at GOSH, which deals with more complex cases. Some other conditions I was fortunate enough to witness included Turners, Prader-Willi, Beckwith-Wiedemann syndrome, disorders relating to genital ambiguity and congenital adrenal hyperplasia. Although these cases do present in secondary care, the frequency and prevalence of such cases is far lower compared to at GOSH and this creates the impression of a skewed pattern. By far the most common endocrine conditions presenting in the secondary care hospital were Type One diabetes, and problems of childhood obesity.

How are paediatric health services delivered and managed in the UK, compared to the less-developed world?

In both the developed world and less-developed world, resources are finite and there is a need to allocate according to urgency and prioritise accordingly. In the UK, prescriptions are free for school aged children and babies, and pregnant women, so access to medicines for children is far simpler in this country than abroad. In the UK there are community paediatricians to help promote health and wellbeing amongst children, enabling them to reach their full potential. Emphasis is placed in the UK on social and educational wellbeing, alongside physical health, whereas in less-developed countries the focus of treatment is on infection, such as malaria, and ensuring adequate nutrition, e.g. preventing malnourishment and Kwashiorkor's, and the treatment of cholera from infected water supplies. In the UK funding is available to treat disorders of growth, for example, which is largely a cosmetic problem, as well as providing support for children with learning disorders whereas in less developed countries these children are often neglected in favour of treating more pressing problems such as malnourishment and HIV. In the UK there are child development

centres and specialist paediatric clinics, which tailor services to the individual requirements of the child; other countries are not so fortunate, and children are often treated as 'miniature adults' or simply not treated at all.

Assessment of my elective project on Turners Syndrome

As part of my time spent at GOSH I was offered the opportunity to undertake a patient experience questionnaire, to see what improvements could be made within the outpatient department to improve patient satisfaction with the services provided. The focus of this survey was Turners syndrome. There are approximately 60 patients with Turners syndrome on the clinic list at GOSH, which seemed a large enough sample size. The decision was made to target adolescents over the age of 10, along with their parents or guardians, and so the language and tone of the survey was adjusted to be suitable for both of the target audiences. It was felt that patients 10 years or older would have sufficient insight into their condition and the affect it would have on the rest of their lives, as well as a level of literacy competency to be able to answer the necessary questions, and provide a satisfactory, interpretable response. Likewise, as this is a paediatric service, it was important to gauge the opinions of the parents/guardians accompanying the child, as they play a vital role in ensuring the child is able to access healthcare, and are often more influenced by behaviours and attitudes of staff. The survey was divided into four components. The first part of the questionnaire involved finding out more about the patient themselves, looking at their emotional wellbeing, as well as highlighting any need for additional psychological input in terms of social and educational needs. Although for ethical reasons the surveys are anonymous, if a large proportion of patients are responding that they are unhappy with living with a diagnosis of Turners, then greater emphasis can be placed on ensuring a psychiatrist is available for all future Turners clinics and that each patient is able to access psychiatric services as and when needed. The second part of the survey looked at all of the complications of Turners syndrome and how well aware the children and their primary carers were of these. This will help guide future discussions in the clinic, if certain complications are under recognised compared to others. One particular question asked about healthy living and eating, which is useful to serve as a reminder to parents the importance of ensuring their children are a good weight, as childhood obesity is a common problem in today's society. The third component of the questionnaire looked at the outpatient experience and questions ranged from how quickly patients are seen, were the patients given sufficient time with each member of staff, and how the patients felt about their care and management. The aims of these questions are to help staff improve their communication skills and to improve timekeeping. One question asked whether patients would prefer to be seen by every member of the team at the same sitting, and this could well be brought into practice if the majority answer in agreement. This will certainly improve efficiency of the service provided, as there would be less waiting around between seeing each individual. It is also often felt that clinicians dominate the consultation, and so a question was posed asking who did the most talking during an appointment. The hope is that after carrying out many repeated surveys, that a shift will be seen from doctor to patient in this regard. The final part of the survey looked at the multidisciplinary team and how patients felt they were treated throughout the whole hospital visit by each member of staff. This will emphasise where improvements need to be made, e.g. providing information about where to go and waiting times, and whether staff are too patronising or overuse medical jargon. I am pleased with how the survey has turned out and we are starting to get responses. I

think the survey needs to be repeated initially monthly until all, or nearly all, of patients have responded, and then perhaps it can be carried out annually to ensure that improvements are being made where possible. Initially we had hoped to work alongside the IT department at GOSH to make the survey more user friendly and paperless, which would make analysing the responses a lot less time consuming, however in reality this did not happen as well as we had expected. There were difficulties with putting the survey online, and it was felt that we would be more likely to get responses if patients were asked to complete the survey whilst they attended for clinics, as this is less time consuming for them. Despite the fact that email and online communications are more prevalent today than ever before, we still had to resort to traditional surveying methods to achieve results. It was also difficult to access email addresses for parents as this information is not yet asked for at initial booking. This is an area for improvement in future.

Reflective component of my overall elective experience

Overall I was pleased with my elective experience, which followed on from a worthwhile and interesting time spent at GOSH earlier on in the year. It is very satisfying to have completed a questionnaire, which may benefit patient experience in time to come, and I hope my contribution will be appreciated. With regards to clinical experience, I am always intrigued to see unusual and rare conditions in the outpatient setting, because of my underlying interest in both endocrinology and paediatrics. Whilst what I have experienced may not have immediate clinical benefit for me, I feel privileged to have seen rare cases at such an early stage of my career and enjoyed meeting the patients and their families alike. I was able to sit in on a variety of consultations and be involved with all members of the multidisciplinary team. My time spent at GOSH was an extremely rewarding experience and I am grateful to Dr Amin, and the rest of the clinical staff, for allowing me this opportunity.