ELECTIVE (SSC5c) REPORT (1200 words)

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

My elective was spent with the respiratory team at Great Ormond Street Hospital (GOSH) in London. In particular, I focused upon children with Cystic Fibrosis (CF) who were severely affected and warranted listing on the lung transplantation list and subsequent transplant.

The respiratory unit at GOSH cares for children with a vast array of complex respiratory pathologies who are referred from hospitals around the globe. The CF unit coordinates care for around 180 children, who form the largest homogenous group of respiratory patients at GOSH. These patients account for approximately half of the inpatients on one respiratory ward since they frequently require admission for administration of intravenous antibiotics or screening for the multi-organ complications of CF, often annually.

CF is an inherited condition caused by a defective CFTR transporter protein. Concentrated mucus accumulates in the airways leaving patients susceptible to viral and bacterial infections. Acute infections can become chronic, such as Pseudomonas Aeruginosa, unless prevented by frequent surveillance and aggressive therapy. Chronic infections lead to lung scarring as a result of an inflammatory process and lead to poorer long term outcomes. CF affects multiple organs in the body causing a range of pathologies for example, pancreatic insufficiency, CF related diabetes mellitus, CF related liver disease, gastrointestinal disease and osteoporosis.

The incidence of CF varies around the globe. In the UK, the incidence is calculated to be 1 in 2500 live births. In 2013, there were 10,338 patients registered on the UK CF Registry . In the United States of America, the incidence is 1 in 3500 live births and in Asia, the incidence of CF is believed to be rare, although part of this may be due to reduced reporting.

Lung transplantation is a palliative procedure and reserved for patients who are expected to live no longer than 2 years and have a poor quality of life . As part of my elective I became involved with data collection for a CF audit. The audit seeks to evaluate lung transplantation as a therapy for end-stage lung disease in patients with CF. My role primarily involved data collection. At first we collated a list of all patients who were assessed for listing to have a bilateral lung or heart-lung transplantation procedure since 1998. This list was narrowed to only include patients with CF. I then spent time reading electronic notes to establish the clinical status of these patients at the time of their transplant listing in order to assess their severity. Examples of factors recorded included the presence of comorbidities such as CF related diabetes. To establish whether patients who unfortunately had passed away because of lung transplant rejection, I read the most recent notes. Having accumulated this data, I spent time in the lung function laboratory to acquire lung function data from their system which included lung function measurements from the time of transplant listing and lung function measurements recorded shortly after transplantation. For patients who had been listed for transplant but not received a transplant, I took several lung function data recordings to evaluate their inevitable decline in lung function over time in the absence of a lung transplant.

I believe as a result of this elective I have learnt several skills and gained valuable experience, which will impact upon my future clinical practice. From the outset, I was advised that my paediatric experience at GOSH would be different to most other hospitals. The nature of a paediatric unit in a

District General Hospital is to deal with acutely unwell children, the majority of who make full recoveries. At GOSH, as a tertiary centre, patients tend to have chronic conditions which often must be managed but cannot be cured. My previous experience of paediatrics related to a placement at District General Hospital, therefore the time I spent on this elective, both on the ward rounds and also in clinics was fascinating and informative.

I frequently noted how complex were each of the cases. Each ward round began with a multi-disciplinary meeting involving an extensive discussion regarding the progress of each patient. The complexity and chronicity of the patient cases were further made apparent when I observed clinics and meetings such as x-ray meetings.

Of all my experiences a GOSH, the CF audit had the most profound effect upon me. Discussing the process and logic behind the audit were undoubtedly valuable learning experiences and I am grateful to have been given the opportunity to be a part of the audit. Prior to my elective, I was aware that lung transplants occurred at GOSH. In my naivety, I relied purely on my medical knowledge gained thus far as a student and assumed that lung transplantation was a curative procedure similar to transplantation of other organs in the majority of cases. It was therefore a surprise to learn that the lung transplants being offered were for palliative benefit. My work on the audit involved reading the most recent patient clinical documents to gain a picture of their current clinical status. Frequently, when patients had passed away, the most recent clinical document was a bereavement letter from the respiratory team to the grieving parents. This alone had a profound effect on me and emphasised for me the harshness of CF as a life-limiting condition. A trawl through the notes would often reveal a snapshot of the emotional turmoil involved with deliberating whether to process with a transplant. The risk of the procedure and the chances of rejection made the decision complex. Documents that detailed a psychiatric analysis of patients revealed children being forced to make decisions requiring maturity far beyond their years. Each day I worked on this audit I reflected further upon the sadness of the condition and enormity of the decision demanded from people. This new appreciation of transplantation in a palliative setting as an emotional challenge will surely remain with me throughout my clinical career and I am grateful to all those who allowed me to benefit from this experience.