

ELECTIVE (SSC5b) REPORT (1200 words)

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

The Oak Centre for child and teenagers with cancer is based at the Royal Marsden. It comprises of an outpatient department, a 22 bed day care centre, a 13 bed inpatient teenage cancer trust unit and 18 bed children's cancer ward. Also based at the centre is the CYPOONS team (child and young people's oncology outreach and service, with whom I spent the majority of my placement. This consists of a team including a palliative care consultant and clinical nurse specialists. This team provide advice, practical support for patients with a cancer or life limiting illness diagnosis, both on the ward, in outpatients and in the community. This team works alongside an out of hours' specialist telephone advice service, PATCH (paediatric patient advice by telephone for care at home) for those with a non oncology diagnosis.

The main two groups of patients cared for by the CYPOONS team are those with symptoms caused by cancer or it's treatment, and those with life limiting conditions. When looking at the global picture, the highest causes of infant deaths are due to infections and malnutrition, due to the lack of money available, palliative care is often non existent.

Having had more experience of adult palliative care than in paediatrics, I quickly realised there are many differences. They both aim to treat symptoms, improve the patient's quality of life, and use many of the same drugs (although obviously in different doses). However, I noticed several differences:

The relationship between families and the palliative care team, felt very different in paediatrics to adults. Often I've observed that the families of adults entering the end of life, can be relieved to get help from the palliative care team, grateful for the holistic and gentle approach a palliative care team offer.

It's not to say that all parents aren't grateful of the palliative care team, but I was surprised when I heard of several families not accepting help from CYPOONS and that it was a relatively common occurrence. I cannot imagine how hard it must be to face losing a child, but I would guess that the palliative care team to some families represent that doctors are saying that there is no hope of recovery and that they will lose their child. It seemed to me that many families held on to the hope of a miracle, whether supernatural or through the latest treatment at Harley street, and accepting the idea of palliative care to them could potentially be saying goodbye to that hope.

Another difference is the way treatment is offered to children. In adults, treatment is either aggressive and aims to cure or less invasive with palliation in mind. At the point where active recession headed treatment stops, the palliative care team are involved. However, children diagnosed with a cancer known to have a poor prognosis would be introduced to palliative care from the start of treatment and may continue treatment up until the day of death. I think it's beneficial for the families and patients to meet the palliative care team from the beginning to allow the relationship to build, trust to form and with the team knowing the child well, the best care to be given.

I really enjoyed visiting Christopher's children's hospice. As the hospices', oncology and CYPOON teams work so closely, it was great to see this element in action. Like most hospices I have visited it was beautiful, with great facilities. I noticed that unlike adult hospices, children's hospices have a large number of admissions for respite. Respite admissions are offered to families with a child with a long term or palliative diagnosis, requiring care. It allows the family to have a break from being a full time carer, the child a holiday with access to fun/ specialist equipment and opportunities, and the doctors to review the patient's current medications/situation.

The children's hospice is also often used by parents after the death of the child, wherever they died. It offers cold rooms for up to a week so that the family have time to create keepsakes and memories. Although I know that adult hospices generally have a cold room for the patient's family after a death, the length of time families seem to spend with the body in pediatrics seems a lot longer. I suppose this may be due to a sense of death before their child's time, whereas perhaps adult deaths can be easier to accept.

It seemed very common for parents to be very educated on their child's condition due to internet. Lots of families hear about new/experimental treatments and cling on to the hope they offer. This can mean families can be set on getting the latest treatment. I was surprised by the number of children receiving care from Harley street. I understand the need for parents to try everything possible, but I suppose I was also surprised at how although they are under one of the most well renowned hospitals for cancer in the UK they still seek treatment elsewhere that is not clinically proven.

I met many children throughout my placement but there were a few that stuck in my mind.

A four year old boy with a DIPG who was severely neurologically compromised. In this condition I learned that he was only going to get worse, and likely progress to locked-in syndrome before death. I found this a distressing thought, that a 4 year old would be totally unable to communicate or move, so how many times tougher must this have been for his Mum?

While at the hospice I witnessed the removal of ventilation from a 16 year old adolescent after transfer from a prolonged hospital and PICU admission. His family appeared so comfortable in the hospice, with plenty of space for them to stay and facilities for the whole family, so much more suitable than an intensive care unit. I was quite shocked by how awake the patient was on arrival, considering it was possible he would die in the next few hours. It was tense and emotional when the ventilator was disconnected and seeing his family holding him and being so brave for him, was heart breaking. He continued to breath for himself until I left at the end of the day, by which point the team had to begin to think about restarting his medications and feed. This case really highlighted to me some of the many difficult situations and decisions in paediatric palliative care.

I became very aware that the CYPOONS team are incredibly professional around the awareness of their emotions. What they do for patients and their families isn't about getting gratitude and thanks, but about helping and enabling them as a family unit to support the child and cope as much as possible. At points I found it difficult to hold in my emotions and I wonder whether I could ever be controlled enough to give the families the professionalism they so need and deserve to help them through. This placement has definitely given me a good insight in to the positives and challenges in paediatric palliative care, and whether it is something I could pursue later down the line as a career.