

Elective Report

Alfie Abbott, 2014 Palliative Care. Institute of Palliative Care

- 1) Investigate the provision of palliative care in Kerala.
- 2) Understand the different reasons patients need palliative care in Kerala.
- 3) To learn about the management of end of life care.
- 4) Reflection on how I feel about 'Dying' and what I have learnt about end of life care during this attachment.

- 1) The Palliative Care service in Kerala began in 1993 with the formation of the 'Pain and Palliative Care Society' in the anaesthetics department at Medical College Kozikhode. In same year the first Community volunteers joined the teams operation, a group that would swell to an enormous number over the next 20 years becoming a central part of the operation of the Kerala model for delivering palliative care. After beginning with a small but busy OP clinic the doctors became increasingly aware of the number of patients who for various reasons (illness, poverty, distance for example) were unable to attend. It was in response to this need that the first Homecare services began in 1995, allowing doctors and nurses to visit patients and deliver care, medications and therapeutic treatments to ease the suffering and improve quality of life of these patients who otherwise would have been isolated.

Over the following years an increasing number of satellite Community Centers and Rural Clinics were created to the point that now Kerala boasts around 250 Palliative centers (where the total in all of India is only 350 total!). The third main arm of the service in the Medical College Area was the development of the IP facility at the newly constructed Institute of Palliative Medicine which admitted the first patient in 2004. With this, the main structure of OP clinic for referrals, Homecare Service for patients unable to attend OP, and an IP facility allowing for symptomatic, respite and terminal care in up to 30 patients was complete. And all of this set across the backdrop of a rapidly expanding rural clinic network means that Kerala is now one of the most well covered regions in terms of palliative care access anywhere in the world.

While the care, love and dedication of the doctors can never be overlooked, what strikes me as one of the larger differences between the provision of care here and in the U.K. is the vast army of volunteers who form a key part of the organization in the Kerala model, who I believe now number around 15000 strong. This is in keeping with the message I have heard while observing in the institute about the mission of the Palliative Service and IPM in engaging the population

and engendering the spirit of compassion among the wider community. Something that I have seen in person when talking to a number of the many young, intelligent caring volunteers who attend the IPM to help or observe or attend classes variously.

- 2) Patients in Kerala require the services of the Palliative Care team for broadly 4 reasons; symptom relief, respite care, terminal care and pain management/relief. I refer pain separately from symptom relief here as the physicians on the palliative care team are experts in pain management and are often given referrals from other specialties for their input in managing patients with chronic pain.

Symptom relief is a hugely significant part of palliative medicine, it is often of vital importance to maximizing the patients comfort and quality of life whatever their underlying condition may be, from peripheral arterial disease, to metastatic cancer, to paraplegia. A wide variety of patients and conditions come under the care of the palliative team and each case must be understood and taken individually with regard to deciding what treatment – if any – will benefit the patient most. Many procedures such as catheterization, **lymphoedema** bandaging and ascetic taps can be carried out for the patient's relief and comfort at the OP, IP and in the homecare setting and I have been fortunate to see these taking place on my visit here. Some of these techniques are also able to be learned by the close care givers and family members of the patients so that they can be carried out at home as required, so empowering the patient's carers.

Respite care offered by the IP facility allows a patient to be admitted for a period of time to allow a chance for their carers to relax safe in the knowledge that their loved ones are receiving the best care. This is of vital importance to the well being of the care givers and is something that I recognize from the health care settings I have seen while studying in the U.K..

I would say that in India, there seems to be a larger proportion of patients who present significantly later with masses, tumours and long term symptoms like cough for example. It is my feeling after discussing this briefly with a couple of doctors, this is most likely a combination of a difference in culture and difference in provision between the U.K. and the state of Kerala. In India there may be more of an attitude that it is not worth bothering a doctor for simple issues which might be recognized as red flag symptoms by these same doctors. Something that was very much similar in the U.K. at one time but now seems to have changed. In this way patients with worrying symptoms like the chronic cough previously mentioned that may be the only early sign of a lung cancer go unnoticed until more troubling dyspnoea and haemoptysis (and more

progressive disease) bring the patient to the doctor's surgery – with little to be done for them sadly more likely. Conversely in the U.K., provision is such that a large amount of money is spent each year advertising to the population informing patients of which symptoms need urgent assessment like frank haematuria and unexplained weightloss so as to increase the number of earlier detections in such conditions like cancer where this helps prognosis. Certainly too issues like access and poverty in some patients play their role delaying consultation in India as they do in the U.K.

3 reasons not yet mentioned but increasingly important are the concept of total pain, which takes into consideration all the patients' physical, social, spiritual and financial needs. The counseling and psychological support the service offers the patients and the patients families. And the financial independence the Footprints Service gives some patients since its inception in 2009.

- 3) Since coming I have learned a lot about the subtleties of management in end of life care including how to prescribe pain medications, and how to manage the symptoms common to end of life care such as nausea, vomiting, thickened secretions, incontinence and immobility. Many of the medications were familiar to me from my previous studies, and some things like the 3 step pain management approach was essentially analogous to the WHO pain ladder I was already familiar with. One of the more interesting points for me was observing how procedures were carried out safely and effectively using what, in comparison to the hospitals I am used to, was very limited equipment. One thing for me in particular stands out as a very good idea and elegant solution - the use of autoclaved newspaper to make sterile fields for catheter insertion/ replacement

- 4) (I will keep this section brief because I am approaching the word limit and also because a second report for my school that I will submit later will focus entirely on reflection about these topics). What I would like to say is that my time at the IPM has most definitely made an impression upon the way I think about death. Adding life to the days as opposed to adding days to the life is an example of a concept I believe more deeply now. More significantly than this in my opinion it has allowed me to re-evaluate what 'Care' should be or mean for patients who fall under the arms of palliative medicine. I believe this came about through a deepened understanding of patients changing hopes, needs and dreams that I was able to gain through witnessing

the practice of the doctor's nurses and volunteers at the institute and in the Homecare setting. This was also heavily influenced by being able to share some of each doctor's experiences, thoughts and philosophies about death and the nature of palliative care. It is my intention to carry forward as many of these lessons as I can as I begin my career in medicine in the U.K. in whichever field of medicine I end up.