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Elective Report

Report objectives

- Investigate the provision of palliative care in Kerala
- To discover the different reasons patients need palliative care in Kerala
- To learn about the management of end of life conditions
- Reflection on how I feel towards the dying and the what I have learnt about end of life care

Provision of Palliative Care in Kerala

The Kerala Pain and Palliative Care Clinic was set up in 1993 at Medical College, Kozhikode by two anesthetists who saw that there was a need to provide end of life care in Kerala. Patients are able to attend this clinic in person by self-referral, by referral from another part of the hospital, or by referral from the family, another part of the hospital or from the home care team. The clinic is open 6 days a week and on public holidays. At the clinic patients can see a doctor about their concerns, receive medication, and receive therapeutic interventions such as ascitic drainage. All of this is provided free of charge.

Over time it became clear a community palliative care team was needed as many of the patients were not physically able to attend clinics. Teams of nurses or doctors visit patients' homes to provide them with medications and other general nursing needs such as dressing changes, catheter insertion/change and drainage of peritoneal ascites. The patients are discussed with doctors before the home care team sets out so that any concerns can be addressed. In 2000 the Institute of Palliative Medicine was built which allowed for an inpatient facility for patients. There are 19 beds; 4 single rooms and 5 wards with 3 beds in each. The patients are categorized in to three groups depending on the reason for admission; symptom relief, respite and terminal care. Patients can only be admitted if they have attended an outpatient appointment. If outpatients is closed then the patient may attend casualty to be reviewed y a palliative care doctor in the morning. At the institute the patient is provided with palliation in much the same way as a hospice would operate in the UK. They are provided with medications and symptom relief and have input from a doctor every day. Their families are able to stay with them all day which is important in India as many members of family come to visit the patient.

In 2008 the government of Kerala realized the impact that community palliative care was having and incorporated its provision into government policy. As a result every 'panchai' or parish should have a community palliative care team that centers on the GP in the area. The people who are involved are usually local people who are trained to manage simple palliative care needs. There are also 40 link centers that provide outpatient appointments to make it easier for patients to access care.

The palliative care provision in funded almost entirely by 'microdonations' where individuals pledge 1 rupee a day (1 pence) or 3 rupees (3 pence) a day for 3 years. There are also those who donate large sums of money. This money pays for all the community palliative care provision, the doctors and nurses at the institute and inpatient palliative care. The Medical College provides some of the medication and equipment required for the clinics to operate. The provision of all these services is free to the patient.

Through this system Kerala provides two thirds of all the palliative care in India despite having only 3% of the population.

Reasons for accessing Palliative Care

Before I set out for India it was my belief that many of the patients would be palliative as the result of conditions that we do not see as commonly in the UK such as TB or leptospirosis. Whilst there are some patients who are palliative in this way the patient population is in fact very similar to the UK in as much as most of the patients have cancer. What I have learnt however is that the patients who present to outpatients are usually at a much later stage of the disease than they would in the UK. On speaking with staff at the institute this is thought to be due patients' disinclination to trouble their doctor with what seem to them like trivial symptoms, such as a persistent cough, lack of patient education and an absence of any screening programmes. For example in just two days I saw a lady with stage 3 cervical cancer, a lung cancer case who presented with dysphagia and SVC obstruction and a lady who had a fungating ulcerative breast lesion on first presentation. These are all things that may be seen in the UK but they would be very rare as all three of these conditions would have been picked up through screening either formally or at the GP. Patients also access palliative care for conditions that would not be considered palliative in the UK, for example paraplegia. These patients basic nursing needs, such as catheterization and medication support is provided through the home care teams. They also receive support through 'footprints' which is a palliative care programme that seeks to integrate them into the community by providing work that can be completed in the home for example, making umbrellas or jewelry, which can be sold and provide an income for these patients. Palliative care is also provided for those who have had a stroke or those who have other long term chronic conditions such as COPD whose care would be provided by the GP in the UK.

Management of Palliative Care Conditions

Whilst we were here the institute was running its 'Certificate n Palliative Care Course' which is a WHO recognized course in palliative care. We were lucky enough to be able to sit in with the lecture and learn about the management of palliative care conditions. We were also able to join in with philosophical discussions such as 'what constitutes a good death?' and learn the communication skills required for dealing with palliative patients and their families. The management is very comparable to that in the UK; the treatment is often symptom relief and many invasive interventions are not necessary. We also learned that the Institute had instituted a Palliative Care Pathway which was very similar to the Liverpool Care Pathway that is used in the UK. The palliative care course also covered basic nursing care such as managing lymphoedema.

Reflection on my time in Palliative Care

Since being at the institute I have learnt a lot about the provision of Palliative Care. Previous to this I had only spent a couple of days at St Joseph's Hospice in Hackney and so my experience is limited. I am amazed at the difference the provision of community palliative care makes to the lives of its patients. Some live in such difficult locations that they would never be able to access care otherwise and the smallest interventions such as a catheter insertion can make all the difference. Importantly it does not only make a difference to the lives of the patients but to their families, who can be provided with respite from care and support, but also the community providers who without this job would have been able to do very little. Being a palliative care provider gives them an income and status which is very important in India. My feelings towards the dying have not changed since I have been here; I am not uncomfortable with the situation when dealing with the patient directly. However, I have found the intense family involvement very hard as watching people grieve so openly as they do here is saddening. Due to late presentation some of the patients are very young and they leave behind a young family who are obviously devastated and it is very difficult to imagine what life has in store for them especially if it the breadwinner who has passed. However, I have also found the family and community involvement in palliative care to be incredibly supportive to paients at the end of their life. This cantrasts with what I have seen in the UK where in many places a sense of community is lacking and often the elderly or sick can live a very isolated life.