

## **Palliative Care in Kerala**

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### Elective Objectives:

- To compare and contrast the model of UK palliative care and Keralan palliative care
- To compare and contrast the patient population and disease prevalence in UK and Kerala
- To observe the teaching of palliative care to students and volunteers
- To observe the model of community-based palliative care and to assess whether this could be incorporated into UK palliative care models and to identify any possible barriers

### **UK and Keralan models of palliative care**

The WHO define palliative care as 'an approach that improves the quality of life of individuals and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'. (1)

In the UK, palliative care originated from the hospice movement founded by Dame Cicely Saunders in 1967. The underlying philosophy of the hospice movement included holistic care, emphasising emotional, social and spiritual needs, alongside a medical approach to managing end-of-life symptoms. (2). Palliative care services were traditionally provided for patients with terminal diagnoses such as cancer, and progressive end stage disorders. More recently, the model has widened to provide services for patients with chronic diseases such as heart failure and COPD.

Palliative services in the UK are provided largely by medical professionals, including palliative care teams in hospitals and hospices and community-based teams consisting of GPs, hospice at home teams, Macmillan nurses, Marie Curie nurses, and allied workers including therapists, social workers, dietitians, voluntary organizations and religious or spiritual workers. These teams exist primarily to support the carers and provide care for the patient in the community. Funding for the services is from the National Health Service, with some hospices also receiving funds from charitable donations. National government policy provides standards for palliative care provision and end of life care.

In Kerala, the palliative care movement is younger but very well established. The pain and palliative care society (PPCS) formed in Kozhikode in 1993 and started a palliative care clinic at Calicut Medical College within the anaesthesiology department. Subsequently the home care teams were formed and palliative care was delivered to patients in their homes. In 2003, the Institute of Palliative Medicine (IPM) was established in its own building with facilities for training courses and inpatient care. They have a 30 bed

unit providing hospice care for patients, providing admissions for symptom control, respite care, and terminal care. The IPM Care Pathway, based on the Liverpool Care Pathway provides a checklist of needs for patients receiving end of life care. Home care teams visit patients 6 days a week but emergency cover is in place 24/7. Nurses or doctors (+/- community palliative care workers) visit patients with nurses performing procedures such as catheter changes, enemas and ascitic taps. Family members are also trained to provide care and administer medications.

Today the IPM also provides a base for other likeminded organizations including KIP (Kozhikode Initiative of Palliative care), NRHM (National Rural Health mission palliative care project), MHAT (Mental Health Action Trust, an initiative providing counselling and treatment for mentally challenged patients at their homes), IAPC (Indian Association of Palliative Care, and Footprints, a social rehabilitation project for bed-ridden and incurable patients (3). The pain and palliative outpatient clinic also still resides in the campus of Calicut Medical College but now within its own building.

IPM is an NGO and the funding is gathered by microfunding, with thousands of contributors donating 1-3 rupees per day. Patients' financial status is assessed on their initial clerking and their financial contribution towards their own care varies. Very poor patients have all of their care and medications provided free of charge and may receive financial assistance with travel costs if necessary.

In 2008 the Kerala government introduced a policy on pain and palliative care. Local self government institutions (LSGIs) facilitate rural home care palliative care services in each of the panchayats (local areas/ villages). There are currently more than 1,000 home care teams in Kerala, covering more than 80,000 patients with secondary and tertiary centres in 74 government hospitals (4).

Within the rest of India, palliative care services are not so advanced. 3% of the Indian population lives in Kerala yet the state provides two thirds of the country's palliative care (3). A spokesperson for the WHO has stated that the Kerala model is a true reflection of community based public health oriented palliative care (4).

### **Patient population and disease prevalence**

The patients and diagnoses are not dissimilar to patients in the UK but the stage of disease at presentation is very different. Many patients present with malignancy that would be curable in the UK but present at such a late stage in Kerala that their condition is incurable. It is likely that this late presentation is multifactorial but it may partly be due to poor attendance or lack of awareness about screening programs (for instance cervical screening), differences in primary care provision, and complex cultural and psychosocial differences in receiving and accessing healthcare.

The referral procedure is different to the UK insofar as patients or patient proxies can refer themselves to the pain and palliative care team if they feel they require assistance.

## **Teaching of palliative care to students and volunteers**

During our time at IPM, a 6 week Basic Certificate Course in Palliative Medicine (BCCPM) was running and we were able to attend some of the teaching sessions. These included seminars and lectures on a range of palliative care topics aimed at qualified doctors and nurses training in palliative medicine. During this time we were able to discuss differences in education and services with local doctors and nurses as well as those from different parts of India and Malaysia.

In the UK, during our 5 year MBBS we receive 2 days compulsory training on palliative care. In India, during MBBS, a local doctor reports they have one week internship in palliative medicine upon completion of MBBS.

During these sessions and in communicating with the IPM doctors, we learnt about the concept of 'total pain', which is the idea that pain has physical, emotional, social and spiritual components. This idea is from the original hospice movement and I found it to be integral in the work of the IPM practitioners (5).

## **Community based palliative care and barriers to implementation in the UK**

Community care forms the backbone of palliative care services in Kerala. The essential ingredients for the palliative care programme in the community are medical, nursing, trained volunteer and sensitized volunteers (4). Student volunteers and family members are heavily involved in the provision of palliative services in a way that does not happen in the UK. In India, there appears to be a stronger sense of community and of family. Families are larger and live together for longer. In the UK we have a small number of children who mostly leave home when they reach adulthood. We migrate between different areas and are more reliant on social care and care homes.

In India, patients also seem to have more responsibility for their healthcare in that they hold some of their own records, investigations and drug charts and carry them between doctors. In the UK, records and results are held on the hospital or GP computer systems, patients may never see them or even know what has been tested for. It is not uncommon in the UK for patients to not know the names of their medications or their indication. Perhaps if patients were made responsible for their own records they would have a greater interest in their health care, although this would be difficult for patients with no family or friends to assist them.

The cultural differences in family and healthcare mean that implementing a community-based healthcare system in the UK that is not reliant on medical professionals would be more complicated and may depend on friends and neighbours having a stronger bond and sense of community. However, if more students could be encouraged to volunteer with care services as part of their education we might instill a stronger sense of community and social responsibility from an earlier age.

## References

- (1) WHO <http://www.who.int/cancer/palliative/definition/en/>
- (2) Palliative care <http://www.patient.co.uk/doctor/palliative-care>
- (3) <http://www.instituteofpalliativemedicine.org/palliativecare.php#pcarefaq>
- (4) <http://www.ehospice.com/india/ArticleView/tabid/10675/ArticleId/3163/language/en-GB/Default.aspx>
- (5) <http://www.stchristophers.org.uk/about/history/pioneeringdays>