

Past, Present of Hospice in Malaysia

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Although the formal birth of Palliative Care in Malaysia may be marked by the formation of Hospice Organisations in Penang and Kuala Lumpur in 1991, there were already individuals who had recognised such a need prior to this date. However to fully appreciate the growth of hospices in Malaysia, one has to appreciate the intricacies of the Malaysian Community.

Malaysian Community and Healthcare

Malaysia is a developing nation with a rich and diverse multi racial, cultural and religious community of about 22 million. The main ethnic groups are the Malays, Chinese and Indians whilst the main religious beliefs are Islam, Christianity, Hinduism and Buddhism. There is also a social diversity with several large cities and rural communities. There is both a government and private healthcare service.

With regards to hospice work, the incidence and prevalence of serious illnesses such as cancer and AIDS continue to increase. It is estimated that the current incidence of cancer is about 36,000 cases/year. Most cancers present at Stage 3 and 4 but Oncology services are available only in large cities.

The Past

Those that pioneered Hospices and Palliative Care in Malaysia were drawn from all walks of life. Doctors, nurses, social workers, civil servants, lawyers, businessmen and others who recognised the plight of the dying were united in their endeavour to create service based Palliative Care organisations.

The creation of many of the current 15 hospices in Malaysia follow a similar path. All operate as charities and depend on a huge input from volunteers drawn from within the community. All started as homecare services although as they continue to develop, further services are then developed.

In 1995, the first Palliative Care Unit was formed in Kota Kinabalu, Sabah. This local initiative has now been recognised by the Ministry of Health and all major hospitals has been instructed to set up similar units by 2000. This was further strengthened with a directive that smaller hospitals should form small Palliative Care teams.

The Present

Most major towns in Malaysia now has some access to Palliative Care either through the hos-

pices or the Palliative Care Units and Teams. The characteristics of the current state of Palliative Care in Malaysia is as follows.

Hospices

In 1999, about 1800 patients were cared for the 15 hospices. The vast majority were cancer patients.

- All offer homecare services with 1 Day Care service.
- The first residential hospice is due to open in Penang in Feb 2001.
- Staffing and financial constraints are among the main problems facing hospices yearly. All the hospices operate as charities.
- There are few full time doctors and perhaps just over a dozen nurses working full time in hospices. A great of work depends on volunteer support.
- Although operating independently in their own areas, some measure of cooperation exists within the framework of the Malaysian Hospice Council, which was formed in 1998. The secretariat of the MHC is in Penang.

Professional

Palliative Care is not recognised as a medical speciality but there is good cooperation with the majority of healthcare professionals.

- The is now a small amount of Palliative Care education in the training of medical, nursing and other allied healthcare professionals.
- Most healthcare professionals believe that hospice care only concerns counselling skills and appropriate only for extreme end-of-life

care. Many are not aware that palliative care involves a great deal of symptom control as well.

- General awareness of knowledge of symptom control among professionals is somewhat lacking. However the increase availability of drugs useful in patient care allow increase options for the palliative care physician
- Many professional medical bodies representing specialities such as oncology and anaesthetics now recognise that palliative medicine is important in patient care and related topics are often presented at their respective scientific meetings. There is now increasing interest in Palliative Care meetings.

Patient

- The majority of patients are referred at a late stage. (less than 1 week prognosis)
- Many may not be aware of their diagnosis and prognosis.
- Some associate hospice care with failure and hopelessness.
- Most believe in traditional and alternative treatment

Community

- Awareness of hospices and palliative care is still poor.
- Some associate hospices with religious orders.
- There is a strong misconceptions of the use of opioids especially with regards to the risk of addiction

The Future

Hospices and Palliative Care have made great strides over the past decade. Excellent programmes now exist in many parts of the country and many more services are being planned. The hope is that attitudes and awareness to Palliative Care is

broadened and services planned and implemented efficiency. More doctors and nurses are required to join the palliative care fraternity and consequently career pathways need to be mapped out. If financial and training resources added to this equation, the future for Palliative Care in Malaysia is indeed bright.