The Star Online > Health

Sunday July 2, 2006

Healing beyond cure

BY DR MICHAEL YOONG

Good hospice care can make a huge difference to a patient's life.

The organisation of modern hospices and their role in the overall healthcare system varies from country to country.

WHEN curative treatment is no longer an option, patients with advanced cancer and other conditions may feel as if they are facing a void. After the surgeon and the oncologist have done all they can, the patient and their family still require care and treatment, albeit of a different sort. It may seem as if there is medically nowhere to turn. These patients, their loved ones and surprisingly often, their doctors, are left asking “Where can I seek help?”

Patients who receive a referral for hospice care are sometimes deterred by the misconception that hospice care is merely “better than nothing”. Well-run hospice care, however, can be invaluable for patients at this stage.

The modern hospice movement has its roots in the work of British physician Dame Cicely Saunders. It was her belief that “we do not have to cure to heal.” She pioneered work with the dying and founded the first modern hospice, St Christopher’s Hospice, in London in 1967. The success in treating terminally ill patients that followed established St Christopher’s as a centre of learning in this new field of medical care. The ideas developed at St Christopher’s now form the philosophy and principles of hospice care.

The philosophy of hospice care is to treat the patient and his/her family together as the unit of care, affirming and supporting the role of the family in preparing for and managing life while facing terminal illness.

Accordingly, hospice services address key aspects of holistic care. Firstly, the patient receives specific medical treatment aimed at pain and symptom management. Support and education for the primary caregiver(s) are also provided. The family is enabled and encouraged to participate in the patient’s care.

Finally, the hospice promotes understanding and acceptance of the difficult process ahead. By alleviating the physical and psychological burden of care, hospice services allow the patient and the family to focus together on the quality of life.

The organisation of modern hospices and their role in the overall healthcare system varies from country to country. In affluent countries like the UK, hospices are well-integrated with the formal healthcare system, employing qualified physicians and nursing staff specially trained in hospice/palliative care. Funding for the hospices comes mainly from the government or non-governmental organisations (NGOs). Although hospice care is for all forms of terminal illness, typically 90% of patients are cancer patients. Services offered by most hospice centres include the following -

- Home visits – by specialist home care nurses
- Outpatient clinics
- Day care

- Inpatient care – hospice hospitals
- Bereavement support
- Education

A major focus of these services is the management of chronic pain, which is experienced by more than 70% of cancer patients. In spite of its common nature, pain-management for cancer patients is still largely poorly understood both by laymen and the medically-trained.

Like many other symptoms suffered by patients of advanced cancer, pain can be alleviated but may be neglected due to the mistaken belief that nothing can be done. It is in fact now possible to relieve almost all types of pain, whether it be somatic pain (pain upon movement), visceral pain (deep abdominal pain), bone pain or neuropathic pain (nerve pain), but popular myths and misinformation continue to create barriers to effective pain-management.

Two key concepts are fundamental to pain-management in palliative care – the “pain relief ladder” regime and the dictum of “by the clock and by mouth”.

The first addresses what medication should be given. The idea behind the pain relief “ladder” is that pain medication should follow three progressive steps. At each step, the decision to progress to the next is based on whether pain persists or increases at that particular step. By adhering to this regime, pain can be appropriately and effectively controlled.

The second concept provides guidance on how to administer medication. Most relevant drugs can be taken orally most of the time, i.e. “by mouth”.

In addition, most patients have chronic, 24/7 pain and therefore medication must be given “by the clock” – regularly, to last throughout the day. A common mistake is to order pain medicine to be taken “when necessary”, which is only correct for breakthrough, intermittent or incidental pain.

In Malaysia, the local hospice movement has been in existence for more than 10 years. These hospices are largely run by NGOs set up by medical and non-medical volunteers. There are about 20 such non-profit, non-governmental organisations, “loosely” associated with each other. Each organisation is independently responsible for its own activities and has to raise its own funds for its work.

In Malaysia, the local hospice movement has been in existence for more than 10 years. These hospices are largely run by NGOs set up by medical and non-medical volunteers.

The better-established hospices are in major cities such as Penang, Kota Kinabalu and Kuala Lumpur, where it has been easier to create awareness and support in wealthier and better-educated populations. These organisations have full-time paid staff (doctors, nurses and office support) and centres for outpatient care. Except for having inpatient hospice hospitals, these hospices provide services similar to those available in more affluent countries.

Most NGOs that operate in the smaller towns, such as Klang, do not have the same resources, and services are usually provided by volunteer doctors and nurses. Hospice care is also now provided for in some state hospitals, as the Health Ministry has recognised its importance and given priority to developing this area of medical care.

There are plans to establish more palliative care units in state hospitals throughout the country.

In spite of this, it should be emphasised that the overall extent and quality of local hospice services still lag far behind the more affluent countries. Less than 10% of patients with advanced cancer receive proper palliative care in Malaysia. Urgent steps should be taken to improve this situation. Among these include the following:

- More awareness and understanding of hospice care amongst the general public.

- Better understanding and recognition of the value of hospice care in the medical community.

- Teaching of palliative care in our medical colleges and encouragement of young doctors to specialise in this area of medical care.

- Integration of all existing hospice NGOs. There is a need for better sharing of resources – knowledge, manpower, equipment and funds, potentially through an umbrella body overseeing or providing hospice care to the whole country.

- Higher government priority for developing this new and important area of medical care through the establishment of hospice hospitals and assistance to NGOs

“If not days to their life, add life to their days.” Healing is more than just cure. When extending life is no more an option, care must continue to preserve quality of life till the end.

- *This article is contributed by the Federation of Private Medical Practitioners Associations Malaysia. For further information, e-mail starhealth@thestar.com.my. The information provided is for educational and communication purposes only and it should not be construed as personal medical advice. Information published in this article is not intended to replace, supplant or augment a consultation with a health professional regarding the reader’s own medical care. The Star does not give any warranty on accuracy, completeness, functionality, usefulness or other assurances as to the content appearing in this column. The Star disclaims all responsibility for any losses, damage to property or personal injury suffered directly or indirectly from reliance on such information.*