

Palliative Care - A Beginning

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The WHO has defined palliative care as "the active total care of patients whose disease is not responsive to curative treatment"¹ where the focus will be on care and comfort. The goal is to reduce suffering and achieve the best possible quality of life for such patients.

Features of palliative care are the affirmation of life while regarding dying as a natural process, it neither hastens nor prolongs death, provides relief from pain and other physical symptoms, integrates the psychological and spiritual aspects of patient care while helping patients to live as actively as possible until death. Additionally it helps the family cope both during the illness and bereavement².

Many of the above aspects of palliative care such as good symptom control and emotional support are in fact essential from the time of diagnosis and during anticancer treatment. Palliative radiotherapy, chemotherapy and surgery do have a role provided the benefits of treatment exceed the burden. In management clinical acumen is the key rather than investigations.

As the provision of palliative care is a recent development in Malaysia we have to be clear about what it means. Two terms are used to describe this care - hospice and palliative care and often they are used as synonymous.

Hospice care has evolved over many centuries with the setting up of shelters for travellers about

the 4th century AD in Europe. The Greeks called them xenodochia or refuge for the stranger. In Roman times they were called hospitium from the Latin hospes or host. Hospices proliferated during the Middle Ages and in addition to the travellers took in the destitute, the sick and the dying but ceased to exist in the 16th century. It resurfaced towards the end of the 19th century when religious orders set up hospices in Dublin, Lyons and Sydney to care specifically for the dying.

The modern hospice movement can be attributed to the pioneering work of Dame Cicely Saunders^{3,4} who in the late forties worked in St Luke's Hospice as a nurse and social worker and later as a doctor in St Joseph's Hospice, both in London. In 1967 she set up an inpatient service - St Christopher's Hospice - to demonstrate that by combining the medieval tradition of compassion with modern medicine it was possible to relieve the suffering of terminally ill patients and their families. Since then hospices have developed all over the world with care being provided either in the home, as dedicated units in a hospital or in an institution. In 1987 Palliative Medicine was recognised as a speciality in the United Kingdom and its education is part of the curriculum of medical and nursing students along with post graduate training.

The term hospice can be used in two ways - one as a concept of holistic care and the other as an institution providing this kind of care. Palliative care has its origin from the Latin pallium meaning

to cloak or mask a disease through the relief of symptoms. In some countries palliative care is the preferred term.

In Malaysia hospice care began in the community as home programmes for incurable cancer patients in Kuala Lumpur and Penang in 1992. Similar programmes are now available in other towns and to date there are a total of sixteen all run by NGO's. A total of 2577 patients were provided hospice care in their homes in 2001⁵. This provision of care in the homes of patients is a unique development for health care in Malaysia in that in our formal health care system a patient has got to go to an institution or clinic for treatment.

Two other related developments in the community were the setting up of an umbrella body for hospices namely Majlis Hospis Malaysia in 1998 and the opening of two inpatient hospice services each with eight beds both in Penang in 2001.

Other models of hospice care - Palliative Care Units and Palliative Care Teams - were introduced as part of the service provisions of the Ministry of Health in 1998. Apart from lobbying by the NGO's what led the Ministry to this important decision was the experience arising out of a local initiative - the Palliative Care Unit set up in 1995 at the Queen Elizabeth Hospital, Kota Kinabalu. With this recognition hospice or palliative care has become of age with the provision of beds and no longer seen just as a function of some NGO's outside the formal health care system.

This decision of the Ministry of Health has led by the end of 2001 to the setting up of 48 Palliative Care Teams with from 2 to 4 beds for palliative care and 11 Palliative Care Units with 6 to 12 beds in public hospitals. The former is in hospitals where space and staffing considerations have not allowed the creation of a dedicated unit for

palliative care. Staff who have an interest in palliative care make up the team providing services to patients wherever they may be in the hospital.

The article in this issue by Khoo⁶ on her experience in providing palliative care in a General Hospital is not only timely but also unique for a number of reasons. This is the first local report on a developing discipline, it covers experience both of a PCT as well as a PCU and finally though the doctor concerned was no longer a staff member during the latter part of the period under study she continued as a volunteer. Her dedication to patients in need of palliative care is indeed highly commendable.

This study describes care given to 156 patients referred for palliative care over a period of almost two and a half years. The author makes the point that this number does not represent the palliative care population or the prevalence of the types of cancer seen at the hospital as some disciplines in the hospital did not refer.

As up to seventy percent of cancer patients are at stage three or four at diagnosis it is likely that the need for palliative care is enormous in any acute general hospital.

Non referrals is not surprising as even the PCU at Queen Elizabeth Hospital still has this experience with referrals. A question that arises is what was the function of the PCT? ⁷ Was it a consultancy with ultimate responsibility for the patient carried by the referring physician or did the PCT take on this responsibility? This should be clearly spelt out in order to mitigate any disagreement that may arise in perceptions of patient management. In either case it would appear that many departments did not see the need for referral. A related issue is can in patient palliative care be provided in an acute ward or only in a dedicated unit set up for that purpose?

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Another feature of the referrals was the links with the community, especially the Hospice at Home service provided by an NGO. The PCU offered consultancy and at times arranged for admissions while continuity of care was provided by the home service. This is already becoming the norm in many other towns in Malaysia where there are PCU's and hospice home programmes provided by NGO's.

However, what of towns where there are no home programmes run by NGO's? A case can be made for the hospital with a PCU to take on this service through a Hospital Support Team so that there is continuity of care. In Kedah some hospitals with palliative care services have begun an urban programme for those living not far from the hospital. For patients living in rural areas a similar programme is possible through Health Support Teams from the wide network of rural health centres. Again this is beginning in Kedah.

When should patients be referred for palliative care? Ideally it should be when the disease is no longer responsive to curative treatment. Thus for cancers it can vary from months to even some years as in some forms of breast cancer. Though the patient and the family often will need time to come to acceptance (and some may go on not accepting till the end) the patient will usually have physical, emotional, social and spiritual problems that need to be addressed thus reducing needless suffering. In this study only one third survived more than ninety days. Some died on the day of referral. This is indeed a sad commentary of perceptions of doctors of what can be done in a disease which takes many months or sometimes years to reach end stage.

That late referrals are the norm is the experience of the many hospice at home programmes in the country. For instance in the hospice home programme in Penang last year 77 out of 340 new patients entering the programme died within ten days⁸. Awareness that something can be done

to alleviate suffering is obviously lacking both amongst health professionals and the public. The term "terminal illness" has not been helpful either and should not be used locally especially where talking of dying and death is taboo.

One of the fears expressed by health professionals and administrators when dedicated beds for palliative care was being considered was that public hospitals would become a dumping ground. This has not been borne out in this study for only 41 (26%) died at the hospital (but not in PCU beds) while 94 (60%) died at home. As we do not have any particulars about the patients who were admitted and died in other wards we can only speculate on the reasons for place of death. In the case of the first inpatient hospice (Rumah Hospis Pulau Pinang) which opened last year only 14 out of 65 (21%) patients died in the hospital⁹.

It is likely that this fear is unfounded. In many surveys conducted in connection with various programmes of the National Cancer Society of Malaysia, Penang Branch well people almost all preferred to die at home¹⁰. Ten years experience of hospice home programmes in Penang (2091 patients enrolled) show that about 80% died at home.

Another factor is cultural where amongst all ethnic groups death at home is desired. If this is not achieved it is often social factors such as living in high rise flats and including the willingness or otherwise of families to cope with the final days come into play. In Singapore there is a growing tendency for deaths to take place in hospice institutions in recent years and it would appear that social factors and perhaps changing traditional values are leading to this trend¹¹.

As mentioned earlier clinical acumen is important in palliative care so that investigations are kept to a minimum which the author emphasises. An old adage for doctors is that investigations should

only be considered if it is going to materially alter the management. Besides the patient must agree and here we do have a problem with some families wanting to decide for the patient.

The physical symptoms at presentation are those usually encountered though it is difficult to compare with other studies as referrals were selective but not by design of the study. However, that 59 (38%) had spinal cord compression is noteworthy. The author has divided this symptom into two phases, prodromal and compressive and draws attention to the seriousness of this complication and how there was delays in diagnosis in some patients. Any backpain (about 90% have pain) or strange feelings about the legs such as heaviness should be regarded with suspicion in a patient with cancer. It should be stressed that pain usually predates cord compression by some weeks or months. Sensory loss and sphincter disturbances are less common and develop later than pain. A plain x-ray of the spine will reveal involvement in about 80% and this should be borne in mind where there is no MRI or even if available there may be delays because of a waiting list. Spinal cord compression is indeed an emergency but it need not be with clinical acumen.

That patients with progressive cancer have pain is well known yet doctors do not give due recognition of pain to this universally feared symptom. Simply put pain is what the patient says. Health professionals should recognise that it is not only subjective but also unique to that person. Another clinical fact is that a person can have from one to three or more types of pain¹². Failure to recognise this can result in poor pain control. This should not happen as pain itself is often more easily controlled than some other physical symptoms such as nausea or vomiting. The drugs needed for pain control have been available for years be they analgesics, opiates, NSAID's and adjuvants such as dexamethasone, anti depressants and anti convulsants. While a

number of medications may be necessary for good symptom control the risk of polypharmacy does arise^{13,14}. The patient may also be on herbal medications by choice as well as "health foods" - truly a plethora of stuff to take.

Guidelines for pain control were first published by WHO¹⁵ emphasising the oral route, by the clock (regularly and not prn), by the ladder (titrating the analgesic) and individualised. When opiates are used laxatives must be prescribed as well. Simple pain scores are useful in pain assessment and management.

One of the contributions of palliative care has been the use of syringe drivers to deliver medications when the oral route is not possible¹⁶. It is not only acceptable to patients but also can be used both in hospitals and in homes thus assuring pain control till the end.

As shown in this study 20 (13%) had no pain till the end. Other studies¹⁷, have given figures as high as 25% without pain. This should help to dispel somewhat the universal fear of cancer as synonymous with pain and even a painful death.

It is well known that the diagnosis of any life threatening illness is frightening and never more so then with cancer as it is an uncertain entity as compared with a heart condition. It is noteworthy that in this study 121 (78%) knew that they had cancer and a further 14(9%) had been told but denied knowing what it meant. Thus almost 87% knew or had been told that they had cancer. This can be regarded as a positive finding as in the past doctors felt that bad news is best withheld from a patient. In this age of right to know that would be not only untenable but also prevents trust between patient and doctor as well as joint decision making in management. However, conveying bad news is not easy¹⁸. A pertinent question is are doctors trained in communication?

However the diagnosis was withheld from the patient in about 20% of patients with two patients managing to even hide it from their families. How and why they did so will be a fascinating insight on how people perceive and cope with a life threatening illness. Though the study does not state the reasons why the families took the "do not tell path" anecdotal evidence from hospice home programmes reveal the reasons as - cannot take it, will give up hope, will not fight, will get depressed, will die more quickly or may commit suicide. All are legitimate concerns but obviously it is not patient centered. This must also been seen in the context of local cultures where decisions are often familial and not solely that of an individual. While it will be generally accepted that a patient has the right to know the converse should also hold - the right not to know which is often a form of coping.

However, over time most patients, including children, become aware of the diagnosis and when information is explicitly withheld another scenario is seen - that of mutual pretence. Often both the patient and the family quietly prepare for the worst. Again carers should regard this as a form of coping and not be judgemental.

How should doctors address the contrary perceptions? In the inpatient situation when the patient wants to know he should tell as his primary responsibility is to the patient, even though the family may not agree they can be usually persuaded otherwise. In a home hospice situation the doctor has to get the family to agree first before telling the patient.

Another aspect of knowing is that it is not synonymous with acceptance of the illness however advanced it may be. The patient and or the family will often continue to seek treatment - orthodox or alternative- and some even up till the last breath hoping for a cure. That doctors may also be prone to continuing treatment is suggested by a recent study on the use of

chemotherapy at the end of life ¹⁹. Where treatment is likely to be futile the doctor does have a duty not to accede to such requests albeit taking time to explain to the patient and family why he has come to this conclusion.

One of the issues that arises when alternative treatments are sought is that often the patient goes of orthodox medications, even analgesics. Another is that the patient has a often advised to avoid certain foods because they are thought to contain "tok" (toxins). Thus nutritional intake may be compromised.

Why is acceptance of incurability important? It may lead to a sense of liberation despite the limitations of the illness, of control (my coming death), purpose of life transformed, the discovery of new possibilities in oneself, restore self esteem and relationships with family, reduce feelings of isolation and may even ease physical pain. With acceptance providing care becomes easier for both the family and carers.

Psychosocial assessment suggested that 44 (28%) were depressed which is almost double the usual findings ²⁰. Though the diagnosis of depression in a person with any debilitating and advancing illness is difficult ²¹ it is important to identify as conventional treatment is often effective. Besides untreated depression aggravates other symptoms.

A large number of issues have been raised in this study - no referrals or late referrals, inadequate symptom control and psychosocial support, poor communication - all suggesting that palliative care is indeed a new concept. Are these incidents isolated or are they germane to other PCT's and PCU's in the public sector? Anecdotal evidence would suggest the latter and if found to be true the Ministry of Health does have a huge problem. The issue is how to translate a policy into practice at the point of delivery? Specifically answers have to be found as to why there are no referrals, late referrals, inadequate pain control and poor communication.

A decade of hospice has eased the suffering of some. However, if palliative care is to be for all who need it then the task is enormous indeed. A priority would be increasing awareness of palliative care amongst the public and health professionals. For health professionals appropriate attitudes, knowledge and skills for palliative care has to be instituted - as continuing medical and nursing education and incorporated into undergraduate curricula while resources must

be available to provide palliative care in more dedicated units in the public sector.

When a disease is not responsive to cure then the focus must be on palliation - to mitigate symptoms, enable life to be tolerable and ease especially the emotional burden of dying. The author concludes by hoping that every doctor is capable of providing palliative care. I would like to echo that call as palliative care and good medical practice are synonymous.

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