ORIGINAL ARTICLE

Palliative Care: Experience with 156 Cases in a General Hospital

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Summary

The concept of Palliative Care is still quite new in Malaysia and there is a need to promote the awareness of its importance for patients with incurable and advanced illnesses, not only to the public but also to the nursing and medical professionals. These patients especially the poor ones very often have no one to turn to; they cannot afford to seek treatment from the private hospitals, they are turned away from acute General Hospitals and are told that there is nothing more to be done because their illnesses are no longer curable, they cannot pay for GPs to come to their homes, and there is difficulty in purchasing opiate drugs for pain relief. This is a retrospective observational study of the palliative care services we try to provide to those few patients referred to us. This study showed that out of the total of 156 patients, majority were Chinese, peak age between 50 - 59 years, referrals were mainly from the community and the Obstetrics + Gynaecology department, patients were referred rather late, 60% of patients died at home, most common malignancies being those of the breast, colorectal and cervix, common sites of metastases being the lungs, liver, bones, peritoneum and local infiltration, 87% of patients experienced pain, about 40% of patients were not fully aware of both diagnosis and prognosis, common drugs used being opiate analgesics followed by dexamethasone, H2 antagonist, antiemetics and NSAID.

Key Words: Palliative care, Malignancy, Metastases, Pain, Spinal cord compression, Morphine, Dexamethasone

Introduction

Palliative care is an important part of the work of most health care professionals, whatever his particular setting. All should feel confident in the core skills and knowledge of basic physical and non- physical symptom control. Moreover, it is necessary to have a grasp of the communication skills surrounding issues in incurable and advanced illness, and to be able to identify the need for referral to the specialists and other services [1].

Palliative care is not an alternative to other care but is a complementary and vital part of total patient management [1].

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The aim of this study is to provide an overview of the demographic and clinical characteristics of patients referred to Palliative Care Unit in Penang General Hospital. This is a retrospective study of cases seen by me from January 1999 to May 2001 whereby patients have since passed away. This overview helps us to identify areas of patient care that needs improvement and enables us to plan further prospective studies in the specific field.

Materials and Methods

The Palliative Care Team of Penang General Hospital was set up in January 1999 comprising of several volunteer doctors, nurses and paramedical staff who were allocated patients referred from other departments, to clerk and follow up. The aim of the team was to provide psychosocial support and relief of physical symptoms for advanced cancer patients within the hospital and in the community. We worked closely with the staff of Hospice Home Program of National Cancer Society, Penang branch, to whom we referred patients on discharge from the hospital and from whom patients from the community were referred to us for consultation, medication and for admission. Since the end of 2001 our patients are referred to the Mount Miriam Palliative Care Home Programme that also provides free home care service.

It was converted into a Palliative Care Unit (PCU) in April 2000 after being given 4 beds in the male and female acute medical wards. For the past year PCU has been managed by four main staff members: a volunteer administrative head who is an anaesthesist, a volunteer family physician who conducts two clinical sessions a week and two full time staff nurses.

This study did not include cases seen by the other volunteer doctors from the period of January 1999 to April 2000 and did not represent the population of palliative care patients in Penang General Hospital as only the staff of 2-3 departments referred their patients to us.

The medical records of all the patients seen and followed up by me from January 1999 to May 2001 and who have since passed away were reviewed. Additional information was obtained from the nurse coordinators of Hospice Home Programme, nurses of PCU and relatives of patients especially for those patients who had passed away at home. Data collected were charted and analyzed.

Results

Age, sex and race distribution

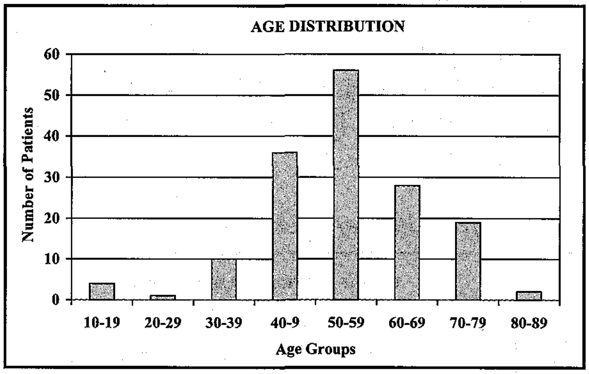

Fig. 1: Age distribution of 156 cancer patients seen in Palliative Care unit

Two thirds of patients were female mainly because of more gynaecological cases seen. Nearly three quarters, 72% of them were Chinese, 20% were Malays and 7% were Indians. Age of patients ranged from 14 years to 85 years the peak group being 50-59 years.

Referrals

Total number of patients who were referred from the community through Hospice Home Programme accounted for 26% (40 cases) of overall referrals, another 23% (36 cases) each from Surgical and

Obstetrics and Gynaecology departments. Of 36 cases referred from Surgical Unit, 26 of them were referred before April 2000. After the set up of PCU, there were only 9 patients in the year 2000, none in year 2001. The remaining 28% (44 cases) were referred from OPD, private GP, Medical, Oncology, Orthopaedic and Urology Units.

State and District Distribution

Of 156 patients, 104 (67%) patients were from Penang island; 9-11 (6%) each from the mainland of Bukit Mertajam and Butterworth; 11 (7%) and 21 (13%) from the states of Kedah and Perak respectively. From Penang island, the three main districts with most number of patients were Air Itam, Georgetown and Jelutong. These areas corresponded to the areas put in charge by a particular HHP nurse coordinator who had been working closely with PCU. Referrals from her also accounted for the large number of cases from Penang island.

Interval from time of referral to time of death

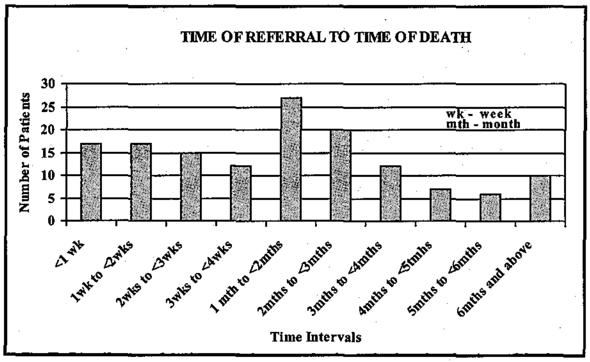

Fig. 2: Distribution of the intervals between the time of referral to the time of death

From the chart, the median interval from the time of referral to the time of death was between 1-2 months. The mean interval was calculated to be 2.03 months (wide range of interval of less than one day to a maximum of 2 years, SD of 2.8 months, SE of 1.38). Only about a third of patients survived for 3 months or more after referral; 2 patients died on the same day and 2 others died the next day after referral; overall about one third of patients died in less than one month after referral.

Place of Death

Feedbacks from the nurse coordinator of home programme and phone calls to patients' caregivers enabled us to find out where, when and how patients died. Ninety-four (60%) patients died at home, about 41 (26%) died in the General Hospital, the others in the private hospitals, nursing homes and Mt Miriam hospital. We were not able to contact 8 patients; they were mainly those from other states who could not come back for follow up and where there was no Hospice Home Programme to cater to their needs. All the patients who died in GH were in their own wards after being referred or readmitted through casualty into their specific wards. So far no one had died on our palliative beds, the reasons being that direct admission from casualty to PCU is not permitted and those from PCU outpatient clinic are usually of short duration mainly for blood transfusion, surgical procedures or providing accommodation and transport for those patients who come from outstation to receive radiotherapy. Two patients particularly had their last wish to die in the hospital - one of them found it difficult to accept that he would be dependent on his family on going home, after all these years of being the head and master of the home, while the other patient was psychologically dependent on oxygen and IV drip. One patient was admitted to die in the hospital on humanitarian ground as he was staying in an isolated place without any caregiver and feeling fearful that he would die without anyone knowing. On admission the change of his facial expression from that of fear to peace was indescribable - he died two days later in the comfort of having people around.

Primary site of malignancy

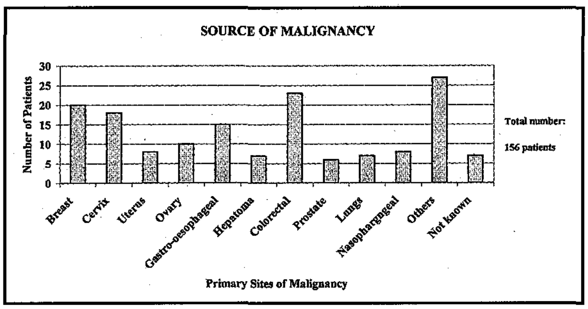

Fig. 3: Distribution of the various primary sites of malignancy

Colorectal carcinoma accounted for 23 (15%) cases seen, followed by 20 (13%) patients with breast carcinoma, 18 (12%) with carcinoma of the cervix and 15 (10%) with gastro-oesophageal malignancy. Again this did not reflect the prevalence of diseases in the general hospital due to the uneven distribution of referrals from the different departments. Other 27 (17%) cases included renal and bladder carcinoma, multiple myeloma, lymphoma, osteosarcoma, teratoma, and the less common ones like gall bladder, appendicular and submandibular gland carcinoma. There were five patients with double malignancy - one with carcinoma of the sigmoid colon and ovary, two with carcinoma of the uterus and breast and two with bilateral breast carcinoma.

Sites of metastases and correlation to primary malignancy

The more common sites for metastases seen here were the lungs, 45 (29%) cases, followed by the liver, 40 (26%), spine, 32 (21%) and other bones, 36 (23%), local infiltration 34 (22%) and peritoneum, 24 (15%) All tumors will gradually increase in size and infiltrate the surrounding structures. The figure for local infiltration was based on symptoms caused by the infiltration. Sites of metastases recorded were based on the clinical findings and investigation results noted down at the first visit. Extensive routine screening tests to look for all sites of metastases were not justified.

The number of cases of each type of malignancy was not standardized so we cannot draw conclusion that certain carcinoma has predilection for certain sites. Just a general observation here, breast carcinoma commonly spread to the lungs, liver, spine and other parts of the skeletal system. Cervical carcinoma was well known for local infiltration causing recto - vaginal and vesico-vaginal fistulae, obstructive uropathy with hydronephrosis and renal impairment. There was a high rate of peritoneum metastases associated with intestinal obstruction from ovarian carcinoma. Gastrointestinal carcinoma had predilection for liver, peritoneum and local infiltration causing intestinal obstruction too. There was a tendency for prostate carcinoma to metastasize to the liver, spine and bones, while nasopharyngeal carcinoma, to the lungs and bones. There was a tendency for brain metastases to come from lung carcinoma and two cases of which the primary source was not known.

Physical symptoms

Clinical assessment of patients was followed by a list of problem oriented medical records (POMR) whereby all physical, psychosocial, environmental (such as noisy crowded home near to the main road, living in flats without lifts etc), cultural and spiritual problems which were serious enough to be treated would be included. From these lists the frequency of the various physical symptoms was analyzed. Spinal cord compression included those patients with only bone pain and neuropathic pain (prodromal phase) and others with inclusion of loss of power and sensation of both limbs and sphincteric dysfunction (compressive phase) [2,3]. About 136 (87%) patients experienced at least one type of pain, 37 (24%) patients with vomiting, 32 (21%) patients with ascites and 23 (15%) patients with dyspnoea. There were 59 (38%) patients with spinal cord compression, 8 (5%) patients with intestinal obstruction and 2 patients with superior vena cava obstruction.

Number and different types of pain

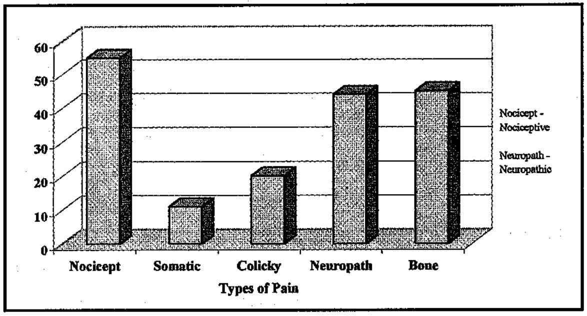

Fig. 4: Precentage of patients with different types of pain

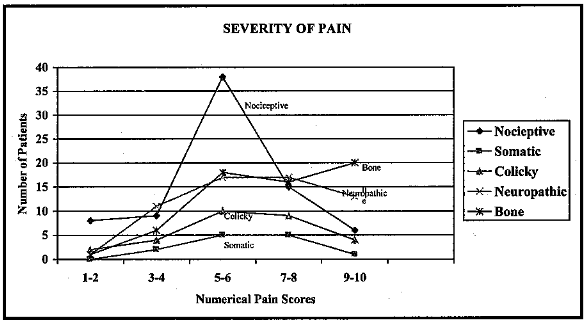

Fig. 5: Distribution of severity of pain in the various pain catagories

Pain was classified into nociceptive visceral, somatic, colicky, neuropathic and bone pain. Nociceptive pain is caused by stimulation of the nerve endings (nociceptors) causing impulses to be carried along the usual pain transmission pathway. Nociceptors may be free nerve endings in the skin and connective tissues (somatic nociceptors) or those from the viscera (visceral nociceptors) that also includes colicky pain and bone pain. Neuropathic pain is caused by peripheral or central nervous system injury [4].

Assessment of pain was based on that of the first and follow up visits as far as possible but for others who could not come for follow up, feedbacks given by caregivers were taken into account. Pain severity was assessed using numerical pain score with a scale from 1 to 10 [1,2].

There were 20 (13%) patients with no complaint of pain right till the end, 43 (28%) with one type of pain, 57 (37%) with two types of pain, 30 (19%) with three types and 6 (4%) with four or greater numbers of pain [1].

The most common pain here was nociceptive visceral pain which was described by 86 (55%) patients followed by bone pain in 70 (45%) patients and neuropathic pain in 69 (44%) patients. The peak pain score for all types of pain was at score 5-6 while bone pain had another peak at score 9-10. The mean score for all were: nociceptive visceral pain (5.6), somatic pain (6.3), colicky pain (6.1), neuropathic pain (6.5) and bone pain (7.0).

Patient's perception of illness and psychological impact

Ninety two (59%) patients knew their diagnosis and prognosis at the first visit while 29 (19%) patients knew only diagnosis but not prognosis, 14 (9%) patients had been told they had cancer but denied knowing what "cancer" meant, and the rest, 17 (11%) patients did not know both diagnosis and prognosis. The perception of 4 (2%) patients could not be assessed properly because of communication barrier - deafness and language problem.

Psychosocial assessment of patients was based on observation of verbal and body language, behavior, vegetative symptoms, mood and emotions [5]. About equal number of patients experienced acceptance 41 (26%) and depression 44 (28%) while 22 (14%) showed denial as a protective mental mechanism. A small number (9 patients) expressed anger towards the medical professionals and carers. Reasons for anger being:

- Against the medical professionals:
  Delay in diagnosis / Poor breaking of bad news / Forced to be discharged from hospital / Patient being told that cancer pain was inevitable and that he had to bear with it / Being told that there was nothing else to be done, to go home and count the days / Nothing was done for 6 months for multiple skin nodules that finally fungated and metastasized to the lungs and bones.
- Against their mother:
  The two youngest teenage patients who overheard doctors telling their mothers about the diagnosis and prognosis while they appeared to be sleeping, accused their mothers of telling them lies and one of them threatened to starve to death.
- Against the family members:
  A 39 - year old man recently registered to be married was with severe anger right till the last day, isolating himself in the room, refused to talk to family members and with pain that was uncontrolled with all sorts of medication.

There were 35 (22%) cases with conspiracy of silence; majority with the family conspiring against the patient, hiding the truth from him, only 2 cases with patient conspiring against the family and 3 with both way conspiracy.

Pharmacological treatment

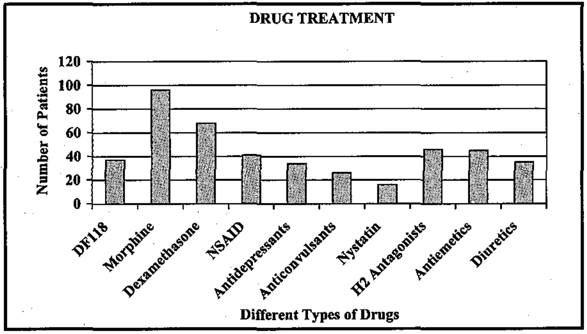

Fig. 6: Frequency of the various common drugs used for symptom control

Management plans adopt a holistic approach which includes non pharmacological strategies such as providing patients with education and advice, psychological support, referrals to the paramedical units and social welfare officer and physical therapy for pain control. Many of these patients would also be taking alternative medicine at the same time. Although we do not encourage this, we also do not condemn it for it is the patients' rights to try what they want at this stage of their illness.

Palliative patients are often given a large number of drugs to relieve their symptoms. The most common drugs used were morphine, followed by dexamethasone, H2 antagonist, antiemetics and NSAID. H2 antagonist was mainly used together with high dose of dexamethasone and NSAID to prevent gastric side effects. So far the only complaint from the patients regarding the latter combination was dyspepsia; we have not seen any patient suffering from gastrointestinal bleeding because of it.

Dexamethasone was mainly used for spinal cord compression followed by reduction of hepatomegaly to reduce pain due to the stretching of liver capsule, and subacute intestinal obstruction [2,6,7,8,9]. So far it has not been used solely for stimulating appetite. There were five patients suffering from subacute intestinal obstruction - two of whom had obviously benefited from subcutaneous infusion of morphine, buscopan, dexamethasone and haloperidol, for two other patients, our treatment was called off by the ward doctor and the fifth patient was discharged home to Perak, against his wish after 2-3 days.

Discussion

There is a wide range of age groups of patients from the teens to the elderly elders, the peak group of 50-59 years reflecting the middle-aged patients who usually find it difficult to accept their illness. They have just taken early retirement with plans to "enjoy life" and this unexpected interruption to future plans can be met with severe depression or anger. Younger patients have very young families and are devastated emotionally at the prospect of that loss and its implications for their children. Patients of advanced age are generally less surprised by a terminal diagnosis although no less grieved. They may have experienced the death of several friends or siblings and may see disease and death more in terms of "when" rather than "if". They may see their approaching death in the context of a full life with a sense of accomplishment and even completion relative to their personal history [10].

Palliative care unit of Penang GH reaches out more to the community needs than to patients within the hospital mainly because the departmental heads may not recognize the need to refer their patients to us. Often palliative treatments suggested in the ward are not carried out but we have great satisfaction of looking after the same patients while they are out in the community. The Obstetrics + Gynaecology department has provided us the greatest support; surgical referrals were mainly from the volunteer doctors, a number of whom were from the Surgical Unit. After the set up of PCU when these doctors were no longer helping to see cases there was a drastic drop in the number of surgical referrals.

Quite a large percentage of referrals were from the mainland because Penang GH is a referral center for Oncology patients from the northern states of Perlis, Kedah and Perak to receive radiotherapy and chemotherapy.

We would encourage referrals to be made at least 3-6 months before time of death so that we can have a better rapport with patients and caregivers, enough time to assess their psychosocial, physical and spiritual problems and be able to help them to cope with the prospect of dying. From the results obtained which indicated only one third of patients survived for 3 months or more after referral, this was not achieved. Patients and doctors have to change their ideas that receiving palliative care is the last resort, that nothing more can be done, that it is a complete takeover from the other specialties.

Death at home is generally encouraged in Palliative Care. Home is where they are surrounded by their loved ones; familiarity of the environment and their belongings give them a sense of control and authority, home is also where they can have a peaceful natural death without needles, tubes and catheters stuck into them [11]. Majority of patients also prefer to die at home. Certain culture and religion may dictate that patients who die outside the home may not be contented and at peace in the "other" world. With the increasing trend of people living in flats nowadays and funerals being conducted in funeral parlors, this belief is gradually taken over by the practical needs of the community.

About 40% of patients died in the hospital, the main reasons being majority of caregivers had no confidence in handling the needs of the patients at the dying stage, some were still hoping for active treatments, a minority on social grounds. If a good home care service with proper explanation is given to patients and caregivers regarding the concept of palliative care, what to expect at the end stage and mutual discussion of management plan, deaths in the hospital can be avoided.

Initially when we were given beds of our own, there was the fear from the ward staff that palliative patients might be left abandoned in the hospital by the caregivers. With the above findings we need to modify our thoughts. With good communication skills and tactful explanation, so as not to make them feel rejected, nearly all of them would prefer to take the patients home at the dying stage.

While it is stated in the textbook that bone pain from metastases is the most common cause of pain in advanced cancer [10], our study showed that the most common pain encountered among our patients was nociceptive visceral pain. As nociceptive visceral pain here included those due to raised intracranial pressure, stretching of liver capsules, soft tissue infiltration etc. Perhaps bone pain would still be the most common if the former was subdivided further.

One striking feature here was the high rate of spinal cord compression. In the textbook the figure given is about 5-10% [1,3]. Probably we saw more cases because these patients experienced neuropathic pain that was difficult to be controlled by the conventional analgesics of opiates and non steroidal anti-inflammatory drugs (NSAID). Spinal cord compression is a palliative emergency - the neurological deficit is still reversible if it is treated with high dose of steroids and radiotherapy within 2 days [7, 12, 13]. Sad to say in my experience majority of patients were referred to us very late and as a result suffered from permanent paraplegia. Once this happened, the quality of life for patients sharply declined - the greatest fear they had was not of death itself but dependency on others that led to loss of self-esteem and self-control. A number of patients developed spinal cord compression while under the supervision of doctors in the ward or clinic but somehow nothing was done about it. A prospective study with proper questionnaire needs to be carried out to assess this condition further.

Conspiracy of silence is very common in our culture; it creates a barrier to communication between the patient and caregivers and may cause anxiety, depression and isolation with loneliness for the patient. Patient's autonomy to know the truth should be respected so that he can make valid decisions and plans for himself before leaving this world. We cannot underestimate the intellectual and emotional capacity of teenagers to receive the truth; anger can be destructive once they discover that they have been deceived by their doctors or their parents.

Daily dosage of 60 - 90 mg of morphine was used for maximum number of patients. Although there is no ceiling dose for morphine, experience showed that for majority of patients, combination of this low dose of morphine with other non-opiate and adjuvant analgesics was good enough to control their pain. Among all the symptoms, pain was the most easily controlled [2]. So far none of the 156 patients required surgical intervention. Nowadays no patient should die in severe pain and yet we still saw two patients who were driven to committing suicide because of pain not being controlled by the doctors.

It is a common practice in GH for using injection pethidine and tramal for control of acute post surgical pain. However, in advanced cancer, pain is of a chronic progressive form with no prospect of improvement, so it is not appropriate to use this "hit and run" technique. The ideal strong opioid to use is morphine that can usually be given orally, the dose required is that which controls the individual patient's pain which may range from 30mg to several hundreds and thousands of mg per day. Besides pethidine is metabolized into norpethidine which is pharmacologically active and has a substantially longer half- life (8-12 hours) than pethidine. It is a potent CNS stimulant - its accumulation leads to irritability and nervousness, tremors, myoclonic jerks, twitches and eventually convulsions [1].

Another common practice in the hospital is drip and suck for patients presenting with subacute intestinal obstruction. Very often in palliative care patients obstruction has occurred at multiple sites and their general conditions do not permit further surgical intervention. Subcutaneous infusion of multiple drugs is able to reduce the intestinal secretions, vomiting, abdominal colic and shrink the tumor mass to provide comfort [1]. Hydration with intravenous infusion is likely to cause more gastrointestinal secretions, generalized oedema, acute pulmonary oedema, ascites and further obstruction (by increasing the tumor size) because patients tend to have low serum albumin [4]. We have often seen patients suffering more at the dying stage because of our inappropriate medical intervention.

Conclusion

This study has provided us insight into the needs of advanced cancer patients for palliative care and our clinical experience has proven to us that palliative care does work to help them face death peacefully and with dignity. Experience shows that these patients have simple needs; they do not ask us to save them from death but if they can be comfortable from day to day they are most grateful. There are three aspects that we need to pursue further with appropriate questionnaires for future prospective studies, namely:

- Spinal cord compression with paraplegia
- More objective assessment of the achievement for pain control
- Psychosocial issues

It is essential to have a palliative care ward and a home programme of our own in order to improve in our clinical skills and to ensure good palliative care services. We need the support of all the other doctors in the hospital to reach out to this group of patients. In time to come palliative care should be considered as a basic need for all advanced cancer patients who should have the autonomy to request for such care and not to be deprived of it just because their doctors refuse to refer. Better still every doctor should be capable of providing palliative care to his/her patients in whatever specialty he/she is working in.

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