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OUR GUEST OF HONOUR

Sr. Helen Kenny
Pioneer in Hospice Movement in Hong Kong
Awardee of Hong Kong Humanity Award 2009

Sr. Helen began her speech by referring to Dr. Kin-sang Chan’s introduction and her Hong Kong Award of Humanity for her contribution in the local hospice movement, “Nothing could have done without the people of Hong Kong, all the healthcare professionals, the lay people, and everyone else contributed to the growth of hospice care, palliative care and now the end-of-life care. You are the future. You have been part of it (the movement), and are still the part of it. You are the future of hospice. It’s my privilege and honor to have done my very little bit.”

She then talked briefly about how it all began with people believing in the new concept of hospice. She commented, “In the 20 years since we took off. We are at level with the West if not ahead of them… Hospice started in England by Dame Cicely Saunders. Her dream was that some day we would not need hospices because every doctor, nurse, whoever in contact with the dying, would know how to care for them…”

“As I look at the program today- bereavement care, end of life care at nursing homes etc, which means we have a vision for all of the dying, no matter what their diseases or their chronic ailments are, this is a glimpse of heaven, I feel very strongly that we are ahead of the West because we have progressed so far. Keep it up! Keep it going and be happy in doing it. It’s tough (work). It’s really tough for you. You are at the bedside watching people come and go, and you are giving them the great gift, in this world of trouble- you give them peace. That’s all anyone asks for. …I thank God everyday for you, and I pray for you everyday- May you carry this gift (of peace) to the family, the patient, to everyone whose life you touch and enrich. Thank you very much.”
DEAR FRIENDS,

The 6th Hong Kong Palliative Care Symposium was held at Hui Pun Hing Lecture Hall, University of Hong Kong on 7 July 2009. The hall was filled with more than 350 healthcare workers. As previous years, we have received many positive comments about the Symposium.

We are honored to have Sister Helen Kenny to be our Guest of Honour who delivered a heartwarming and enlightening speech. In the first plenary, we were pleased to have Dr Geoffrey Chan, Queen Mary Hospital to share “Management of Terminal Symptoms in Children with Cancer”, Dr Raymond Lo, Shatin Hospital to lecture on “End-of-Life Care in Old Age Homes”, and Dr Lam Po Tin, United Christian Hospital to talk on “Crisis in Palliative Care”. In the second plenary, Dr Amy Chow, University of Hong Kong shared “Bereavement Care for Sudden Death, and Dr Esther Mok, Hong Kong Polytechnic University talked on “Communication and End-of-Life Care in the Intensive Care Unit”. There were three concurrent workshops in the afternoon. “Family Therapy for Traumatic Death” was conducted by Prof Joyce Ma, Chinese University of Hong Kong and Dr Flora Mo, Alice Nethersole Tai Po Hospital. “When Helping Professionals Become Helpless: Development of ‘Self Competence’ in Working with Death, Dying and Bereavement” was facilitated by Dr Wallace Chan and Ms Agnes Tin, Centre on Behavioral Health. “Play-based Intervention for Bereaved Children” was conducted by Ms Brenda Koo, JTTC-Society for the Promotion of Hospice Care.

DR. CHAN KIN SANG, 
CO-CHAIR, ORGANIZING COMMITTEE
Bereavement Care for Sudden Death

Dr. Amy Y. M. Chow,  
Department of Social Work & Social Administration,  
The University of Hong Kong.

There were around 40,000 deaths in Hong Kong every year, with over 9,000 as unnatural deaths that mandated reporting to the Coroner’s Court. Unnatural deaths include occupational and vehicular accidents or accidents of any types, suicides, homicides, and acute medical conditions. These deaths are usually sudden for both the deceased and the family, and pose a different trajectory for grieving. Based on literature review and frontline experiences, the unique features of bereavement by sudden death - the unpreparedness, the possibility of traumatic witness, the secondary traumatisation of the necessary procedures, the possible ambiguous loss, as well as the intertwine of trauma and bereavement are discussed. With a mapping of the possible trajectory, bereavement care at different stages, addressing these unique features, is suggested and elaborated with illustrative case examples. Practical insights in provisions of bereavement care for such group are also highlighted.

Communication and end-of-life care in the intensive care unit

Dr. Esther Mok,  
Hong Kong Polytechnic University.

In the recent decade, there are increasing recognition of importance and needs of end-of-life care in the intensive care setting. Communication has been reported as the unique skills for promoting high quality end-of-life care in all settings. However, there are limited guidelines guiding nurses to promote effective communication in ICU end-of-life care while family members identified it is the most important skill of clinicians in the intensive care unit. It is important to explore barriers of communication in ICU end-of-life care after discussion of comfort care or do not resuscitate order (DNR) with families. A qualitative study of doctors’ and nurses’ perception showed that interpersonal communication confusion took place among the health care professionals. Nurses’ descriptions of their role were reflective of a framework incorporating advocacy, negotiation, mediation, and sensitivity to patients’ and families’ needs.

Critical care doctors and nurses play an active role in assisting patients and families with end-of-life decisions. A communication framework and strategies on communication with families related to end-of-life care in ICU is proposed.
Family Therapy for Traumatic Death

Prof. Joyce Ma, Chinese University of Hong Kong.
Dr. Flora Mo, Alice Nethersole Tai Po Hospital.

A family has witnessed the death of their only son in a traffic accident. They experienced tremendous grief which brought the family on the verge of breaking down. After the tragedy her daughter experienced frequent nightmares which led her to the child and adolescent psychiatric service. The mother was very depressed and irritable. The family relationship was very much jeopardized by domestic violence. Because of the severity of the family situation the medical social worker referred them for family therapy in Chinese University of Hong Kong.

Through handling the marital crisis and the complex family dynamics, we came to understand how the tragedy has deeply traumatized each and every member of the family. Through their effort in the therapy their wound started to heal up bit by bit, the family started to reconcile with each other and were ready to move on with their lives. In this section how the family dealt with the grief through family therapy from both medical and social work perspectives will be discussed in this section.

Using Play Based Intervention with Bereaved Children

Ms. Brenda Koo Wing Sze,
Jessie and Thomas Tam Centre,
Society for the Promotion of Hospice Care.

"Toys are used like words by children, and play is their language."
Garry L. Landreth, 2005

All children play. They play at all times and all places. Children do not need to be taught how to play, nor must they be made to play. Play is a spontaneous, enjoyable, voluntary and aimless activity, in which, the child can flexibly choose how to play and how toys and materials to be used. According to Piaget (1962), in play, the child is dealing in a sensory-motor way with concrete objects that are symbols for something else the child has experienced directly or indirectly. Play is the child's attempt to organize his experience. He may feel more in control and thus more secure, through the process of play.

Children have to deal with a number of novel experiences once a family member died. Play does not only provide a natural medium for bereaved children to express themselves, but also a way to organize the unchangeable reality to manageable situations.

In this workshop, the author will share her experience in applying child-centered play based intervention with local bereaved children. After the accomplishment of the workshop, the participants are expected to acquire:

1) a basic understanding on child-centered play therapy; and
2) a caring, sensitive and empathic ear to listen to children’s stories.
End of Life Care for Old Age Homes
Dr Raymond Lo,
Consultant, Geriatrics and Palliative Medicine, Shatin Hospital; Chief of Service, Bradbury Hospice.

Care for the dying is a litmus test for our health and social services, and is a measure of society in looking after our sick and vulnerable citizens. There should be no ageism in this regard. Significant proportion of our older population spent their end of life in old age homes, and should receive appropriate support regardless of their diseases conditions and trajectories. Ageing and dying is a priority issue.

The residential care setting is different from country to country, and our local set up has its unique features to consider when applying palliative care principles in day to day care. Currently there are over 500 private old age homes and over 140 subvented and contract homes. The number of elderly residing in these long term care facilities has more than doubled during the last decade to more than 70,000 in 2007. Appropriate palliative support for old age home residents is a pressing issue.

Older people have palliative needs which can be similar yet different from the younger age groups. Pain is always a top concern by patients of all ages. Yet symptom profiles may be different especially in elderly with non-cancer conditions. Use of medications need to be with caution, especially with alternative opioids. Psychological well-being does not necessarily have to be poor for the elders in residential homes, but the social and family support is not guaranteed. Quality of life issues are equally relevant in older age groups, and existential issues such as dignity, meaning of life, self-perceived burden are pertinent issues in long term care setting. Our local data revealed that QOL scores of vulnerable elderly in old age homes could be poorer than dying cancer patients in hospitals.

Yet application of palliative care to old age homes needs to be well thought out and planned. Skills, knowledge and attitude of local old age home staff must be explored. Perception and concerns of all ranks of workers, including personal care assistants, have to be carefully considered. Support programmes need to be evaluated, with the outcome of interventions properly assessed. Shatin Hospital and Bradbury Hospice had implemented a palliative care at old age home project with promising results. The programme provided training as per the needs of old age home staff; and interventions were offered to clients requiring intensive support. Anticipatory grief workshops were held for elderly with psychosocial needs, and a randomised controlled trial was used to evaluate an initiative in early and better preparation for residents facing end of life. Experience and results of the programme were further discussed in the presentation.
Crisis in Palliative Care

(Presented in 6th Hong Kong Palliative Care Symposium)

Definition of Crisis in Palliative Care

Crisis means a time of great danger, difficulty or uncertainty when problems must be solved or important decisions must be made. To individuals, it is the subjective reaction to a stressful life experience that compromises the individual’s stability and ability to cope or function.

Palliative care aims to improve quality of life by early identification, impeccable assessment and treatment of symptoms while meeting the needs of patients with advanced and progressive diseases. It comprises diseasespecific and symptom-guided interventions, with emphasis on preparing patients and their families for foreseeable, distressing clinical problems. Hence, any unexpected change near the end-of-life may be considered as crisis to the palliative care patient, family and even staff until more information about the change can be obtained.

Crisis in palliative care is not exactly equivalent to medical or oncological emergencies which are defined by diseasespecific processes, such as spinal cord compression, pathological bone fractures, superior vena caval obstruction, septic neutropenia, hypercalcemia, hyponatraemia. In these situations, we focus on “what can be done to save life?” with diagnostic or therapeutic algorithms, and aggressive treatment can sometimes enhance overall survival. However, towards the end-of-life when death is an expected and accepted outcome; we question the emergency nature of these situations, we question the mechanisms and algorithms used in standard emergency treatment to be used for crisis in palliative care. The priorities of palliative care gradually shift towards the end-of-life. Insteadad, we focus on “what is the appropriate treatment for this patient in this particular situation?”

Precipitating events and Assessment

When a crisis occurs near the end-of-life, the clinician should carry out an impeccable assessment including (1) identification of the precipitating events; (2) prompt understanding of the underlying disease-specific or pathophysiological processes; (3) determination on whether active/life sustaining treatment could prolong life or maintain quality of life; (4) prognostication – both tumour and co-morbidity related; (5) patient’s wish; (6) extent of clinical decline or course of expected illness; (7) attitude of family; and finally (8) overall care. All these might have a more decisive role than disease-specific features and the complexity of a therapeutic decision during crisis near the end of life usually requires the expertise of a multi-professional palliative care team. The precipitating events can be (i) physical-related, e.g. acute dyspnoea, acute delirium, acute pain or massive haemorrhage; (ii) psychological-related e.g. suicidal attempt; (iii) social-related e.g. acute decompensating family or caregiver such as caregiver fatigue / caregiver illness; and (iv) spiritual-related, e.g. existential distress. Clinician and the palliative care team should be familiar with the clinical approach in managing these precipitating events.

Decision making and its factors

At the time of crisis in palliative care, either category of decisions should be made, namely the decision to use potentially life-sustaining treatments or decisionsto use treatment modalities that emphasize quality of life & comfort care. However, such discussions on medical decisions can be facilitated prior to the occurrence of crisis. The optimal timing for this discussion is during a routine outpatient visit, during which the patient should have an opportunity to learn from the physician the anticipated disease course, the potential treatment options, and together with the physician, define the goals of care in case acute crisis arises. Needless to say, the physician has to balance the anxiety of alerting and preparing the patient and the family for such an event.

Dr Lam Po Tin,
Department of Medicine & Geriatrics,
United Christian Hospital.
Correspondence: lampt@ha.org.hk
against the likelihood of occurrence. Although not every crisis or possible intervention can be anticipated and discussed beforehand, beginning the conversation can enhance the physician’s understanding of the patient’s preferences, reassure the patient that the physician is open to discussing end-of-life care, and begin what may be a slow process toward acceptance of a terminal diagnosis.

There are many factors that can influence the decision making at the time of crisis, which are grouped into disease factors, patient factors and physician factors. For example, for disease factors, the pattern of rapid functional decline in advanced cancer patients in the last few months is generally recognised by patients and families as the beginning of the dying process. Thus, discussions regarding the appropriateness of various treatment options during this time are held with the recognition that death is approaching. In contrast, there is often no clear dividing line for non-cancer diseases. Patients, families and even physicians are more likely to have difficulty recognising dying in non-cancer, and by implication, when further disease modifying therapies should be withheld. For physician factors, those who tend to adopt a curative approach as far as possible may feel perplexed in withholding or withdrawing life sustaining treatment near the end-of-life.

Sometimes, dying patients can accept the impending death but not the family or caregiver or those individuals whose live intersect with the patient through strong personal connections. In this situation, physician and his team can help by including them as active participants in discussing end-of-life care with patient. In this venue, patient is encouraged to express his/her feelings, desires, concerns and goals of end-of-life care. Patient and family members need reassurance that no matter what treatment option is chosen, ensuring comfort of patient is always of paramount importance.

The impact of crisis

The outcome of crisis is also dependent on the help available from palliative care team during the critical period. A “traumatic death” or “sudden death” may be perceived by the family in such crisis. Unsuccessful crisis intervention may lead to complicated grief or post traumatic stress disorder of the family members or caregivers. The common reactions arising include panic or fear, being upset or depressed, feeling overwhelmed or exhausted, being angry or frustrated; which may require psychiatric intervention. On the other hand, successful crisis intervention can contribute to good death of patient and personal growth of caregivers and staff.

Conclusion

Crisis does occur near the end of life. Its management begins with the team’s ability to anticipate and communicate crisis; assist patients in deciding the appropriate treatments by detailed exploration of the life-sustaining and palliative treatment options; honest and timely prognostic telling; affirm patient choices; be familiar with clinical approach to precipitating events (symptom-guided therapy); facilitate patient-family discussion and deal with conflicts and emotions; mobilise resources/supports that will institute relief; aim at good death and be supportive to family and staff.

References


Figure 1 – Factors that affect decision making during crisis

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<th>Patient factor</th>
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<td>Cancer vs non-cancer disease</td>
<td>Goals of end-of-life care</td>
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<tr>
<td>Prognosis of disease</td>
<td>Personality and psychological variables e.g. hope, denial, grief, depression</td>
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<td>Risk vs benefit of treatments</td>
<td>Age &amp; life stage</td>
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<td>Symptom burden</td>
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<td>Less obvious:</td>
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<tr>
<td>Past response to treatment</td>
<td>Treatment burden imposed on family</td>
</tr>
<tr>
<td>Co-morbid conditions</td>
<td>Treatment financial cost</td>
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<td></td>
<td>Physician’s feelings e.g. guilt, inadequacy, peer pressure, Personal value / beliefs</td>
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Physician factor

- Attitude in adopting the curative approach
- Accuracy in prognostication

Crisis in Palliative Care

HKSPM Newsletter 2009 Sep Issue 2 P14
Editors’ Column

Humanity • Humility

When I attended the Ceremony of the Hong Kong Humanity Award in May as a member of the humble audience, I was delighted to see Sr Helen Kenny as one of the awardees. The Hong Kong Humanity Award is a tribute to her selfless contribution to the Hospice movement in Hong Kong. I also noticed many more familiar faces among the supporters, the audience, and even among those who received the award. Among them, some were disabled, but that did not at the least a barrier to altruism. It was a moving occasion which exemplified the greatness and yet the humility in their deeds of compassion, and the gracefulness of the weak helping the weak. Humanity and humility often go hand in hand.

An act of compassion requires an awareness of the sufferings of others, a sensation of their emotional distress, and the urge to relieve them. The need to be aware of others’ sufferings explains why those who help with compassion are often those who were once wounded and those who have gone through difficult times of their own. At times of seemingly unbearable distress, some escape by committing suicide, some look for a quick fix by asking for a hastened death, but there are always more who can transcend their suffering and find meaning as many of our palliative care patients do. Compassion does not extinguish suffering as such, but compassion can lift one up to the horizon to see beyond the limits of human.

In this issue, we share with you photos and abstracts from the 6th Hong Kong Palliative Care Symposium, and other articles contributed by our local palliative care professionals. Although we are making considerable progress professionally, there are still many challenges ahead - developing palliative care for non-cancer, educating the public on death and dying, and advocating for quality care of the dying.

Dr. Tse Man Wah, Doris,
Editor-in-Chief.
Editors’ Column

A Response to the South China Morning Post on Dignified Death

To the Editor,
South China Morning Post.
21 August 2009.

We refer to the article by Mr. Victor Fung Keung of 18 August entitled “A person has a right to a dignified death”. We agree totally that every person should have a right to a dignified death. However, a dignified death does not mean euthanasia. A dignified, peaceful and natural death could be achieved with appropriate care to relieve pain and suffering, without resorting to kill the patient. We do not support the practice of euthanasia in Hong Kong. Here, euthanasia means “the direct intentional killing of the patient as part of the medical care being offered”. The gravity of euthanasia far exceeds that of an individual choice. The far-reaching societal consequences of legalizing euthanasia, including the impact on societal values, the negative implication on the chronically ill and the vulnerable groups, and the possibility of going down the slippery slope should be taken seriously.

Not supporting euthanasia does not mean that death is a taboo subject in Hong Kong. We organize workshops in the community on death and dying and participants are very open in the discussion. From our extensive experience in caring chronically ill and the terminally ill, we understand that a request for euthanasia is more often a request for attention to and relief of pain and suffering. This unfortunate patient, Mr. Choi, mentioned in Mr. Fung’s article, should be no exception. We have visited the patient yesterday and will assist the patient to request appropriate care from the relevant health care providers. If appropriate care could be provided to help this patient, we believe that the patient would change his mind.

In Hong Kong, we would like to see the public and the Government put emphasis on strengthening the existing services to help these needy patients, instead of promoting euthanasia.

Yours sincerely,
Dr. TSE Chun Yan
Honorary Advisor
Hong Kong Society of Palliative Medicine

Ms Faye Man-yu CHAN
Program Development Director
Society for the Promotion of Hospice Care

In early August, a television series on euthanasia was launched in Hong Kong, with the first of the series featured by Dr. Philip Nitschke of Exit International. Dr. Nitschke is a doctor of controversy as he is promoting more than “euthanasia” or “physician assisted suicide” for the terminally ill patients. In other parts of the world, Dr. Nitschke has been teaching and promoting to the public various ways to commit suicide, including how to use a bag to suffocate oneself, and how to buy lethal drugs from Mexico. The Hong Kong Society of Palliative Medicine considered it unethical to publicize suicide, and therefore objected to dialogue...
Editors’ Column

with Dr. Nitschke. Our stand is shared by the Society for the Promotion of Hospice Care and ten other organizations, and in one voice, we jointly declare against the promotion of suicide and euthanasia in Hong Kong.

In the television program, a quadriplegic patient, Mr. Choi, was featured. Mr. Choi openly requested euthanasia because of pain and meaninglessness in life. We are against euthanasia. However, we should not just deny euthanasia on moral high ground but leave individual patients to suffer. Patients who requested euthanasia should be attended to, listened to and with their distress acknowledged. Dr. C.Y. Tse, the Honorary Advisor of the Hong Kong Society of Palliative Medicine, visited Mr. Choi together with Ms. Faye Chan of the Society for the Promotion of Hospice Care, and a worker of the Direction Association for the Handicapped, all as volunteers. The underlying reason why Mr. Choi requested euthanasia was ascertained and he was referred to the relevant health care team of the Hospital Authority. We believe that, if appropriate care could be provided to Mr. Choi, he would change his mind.

An article by a political commentator was published in the South China Morning Post, arguing for legalization of euthanasia; the story of Mr. Choi was quoted to support his arguments. The Hong Kong Society of Palliative Medicine and the Society for the Promotion of Hospice Care responded to the article by sending a letter to South China Morning Post. We believe that a dignified, peaceful and natural death could be achieved with appropriate care to relieve pain and suffering, without resorting to killing the patient.

For meaningful discussions to happen in our society, the public should be educated on the relevant terms within the context of medical care. The health care professionals, while respecting patient’s autonomy, are also paying due respect to other prima facie ethical principles simultaneously, namely do good, do no harm and justice. These principles interplay with each other and no single ethical principle will constantly over-ride the others to protect patients from extreme medical decisions.

A direct link from the ‘right to be killed’ to ‘respect of autonomy’ is like creating a short circuit in the moral and legal arena; bypassing the rest of the circuit by connecting through a path of seemingly low resistance that is actually not operable morally and legally. Euthanasia in its Chinese translation is synonymous to joyful and peaceful death; but to one who knows the definition of euthanasia, the term is merely a euphemistic way of saying ‘to kill the patient directly and intentionally’.

As a physician, it would be most appalling to see what should be a healing profession is franchised to kill patients who are suffering. As a vulnerable patient in future, it would be most intimidating to realise that doctors by then may yield to my moaning and distress by killing, instead of preserving with compassion and skills to palliate at all times.

It would be difficult to imagine a life without an end, a life without any suffering. It is beyond the capacity of physicians, or even any human being, to bring life any nearer to these impossible goals. What is requested inappropriately from the medical profession nowadays by a few has profound effect on numerous others in future; which the few would never be able to see. I shall end here with a quotation that might cast light on what should be expected of the medical profession.

Dr. TSE Man Wah, Doris
Editor-in-Chief

Albert Schweitzer (1875 - 1965),
a physician who won the Nobel Peace Prize in 1953 for his philosophy of “Reverence for Life”.

“What does Reverence for Life say about the relations between humanity and the animal world? Whenever I injury any kind of life I must be quite certain that it is necessary. I must never go beyond the unavoidable, not even in apparently insignificant things.”
Background

Palliative care (PC) for patients suffering from non-cancer terminal illnesses provides important support to these patients and their caregivers. Palliative care should be considered as an integral part of modern medical care as stipulated in the recent UK National document. Six months before the patient’s death is often considered as the suitable starting point for PC. For cancer patients, PC is well organised in Hong Kong but this important service for patients facing life-limiting non-cancer diseases is only at its early development. An estimation of the case load of this service demand is valuable in the service and resource planning. However, the estimation is difficult as there is a lack of complete registries of the various chronic medical illnesses in Hong Kong. The terminal stage of these illnesses is sometimes difficult to define and only inconsistently documented in the medical records. This study was an attempt to estimate the case load of non-cancer PC service in the departments of medicine and geriatrics (M&G) in the New Territories West Cluster (NTWC) of Hospital Authority (HA), using the UK NHS Gold Standards Framework (GSF) for case identification.

Introduction

NTWC is one of the seven HA clusters which serves a population of 1.06 million in Tuen Mun and Yuen Long areas. There are two hospitals, Tuen Mun Hospital (TMH) and Pok Oi Hospital (POH), with acute admissions to M&G departments.

Method

This was a case review cohort study. All patients who died in the M&G departments of TMH and POH in the year 2008 were identified. This consisted of 2,376 deaths from TMH and 416 deaths from POH, making a total of 2,792 deaths. Ten percent of the total deaths (n=278) were randomly selected for record review of hospitalisation episodes, outpatient and A&E attendances. The clinical prognostic indicators of GSF were used as the guide to identify and classify patients requiring PC retrospectively. The simplified descriptions of the criteria were listed in table 1. Readers are suggested to refer to the original paper for details. The investigator would assess whether each patient at a time six months before his/her death could be classified as suitable for PC in the categories of (1) organ failures: heart disease, chronic obstructive pulmonary disease, renal disease, neurological disease, (2) frailty and dementia or (3) cancers.

Results

Among the 278 deaths being studied, 116 patients (41.7%) were identified as candidates for PC service according to the criteria, including 67 male and 49 female patients. The mean age of these patients was 78.7 +/- 12.6 years. The PC indication of organ failure was identified in 36.2 % of patients; frailty or dementia in 31.2%; cancer in 31.2% of patients. Among the group of patients with organ failures, chronic obstructive airway disease was most prevalent (17.3%), followed by renal disease (9.5%), heart (6.8%) and neurological diseases (2.6%) (Table 2).

A total of 79 non-cancer medical patients were identified in the study who fulfilled the PC indication criteria. As the sampling was 10% of the total deaths, it was estimated that the total case load of terminally ill non-cancer patients requiring PC service would be around 800 patients per year in our cluster.

Discussion

This retrospective review included all those who fulfilled the GSF and died within 6 months. In real practice, one would recruit patients who fulfilled the PC indication criteria but may have life span longer than six months. Thus, the case load estimation above is likely an underestimate and probably represents the lowest limit of the estimation. The cases that did not fulfill the GSF criteria were mortalities from acute diseases.
such as sepsis, acute stroke, acute myocardial infarction. The cases that would be missed by such criteria were those who attended other medical services (e.g. private sectors), and those who were admitted to our wards but died during the same admission. Our results served as a crude estimation of a case load of 800 per year for the NTWC cluster, which had a population of 1.06 M.

Limitations
As this was a retrospective study, important data might be missing. Also, as only 10 percent of the total deaths were reviewed, extrapolation of the results to the whole cluster could subject to variations. All the case records were reviewed by one investigator in this study, and could give rise to bias in judgment on the suitability of patients for palliative care service. Assessment by another reviewer and comparison for inter-reviewer differences might improve the validity of the data.

Conclusion
Among the medical deaths per year, the present study gave an estimation of around 800 non-cancer patients who might benefit from PC service in our cluster. Appropriate service planning and resource allocation should be in place to serve these patients and their families.

References

An estimation of the case load of non-cancer palliative care service

HKSPM Newsletter 2009 Sep Issue 2 P19

Table 1: Simplified PC indication criteria adopted from the Gold Standards Framework

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<th>Indication for PC</th>
<th>Criteria (simplified description)</th>
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<tbody>
<tr>
<td>1. Organ Failure</td>
<td>At least 2 of the following:</td>
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<tr>
<td>a. Heart disease</td>
<td>1. CHF NYHA stage III or IV</td>
</tr>
<tr>
<td></td>
<td>2. Recurrent hospital admissions* with heart failure</td>
</tr>
<tr>
<td></td>
<td>3. Severe symptoms despite optimal therapy</td>
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<tr>
<td>b. COPD</td>
<td>1. Clinically severe disease e.g. FEV1 &lt;30% predicted</td>
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<tr>
<td></td>
<td>2. Recurrent hospital admissions* with COPD exacerbation</td>
</tr>
<tr>
<td>c. Renal Disease</td>
<td>1. Stage 5 kidney disease and not for dialysis</td>
</tr>
<tr>
<td></td>
<td>2. Stage 4 kidney disease with rapid deterioration</td>
</tr>
<tr>
<td></td>
<td>3. Symptomatic renal failure</td>
</tr>
<tr>
<td>d. Neurological disease</td>
<td>4. Recurrent hospital admissions* related to renal disease</td>
</tr>
<tr>
<td></td>
<td>1. Motor Neuron Disease with rapid deterioration</td>
</tr>
<tr>
<td></td>
<td>2. Parkinson’s Disease with treatment failures and severe disabilities</td>
</tr>
<tr>
<td></td>
<td>3. Multiple sclerosis with severe disabilities</td>
</tr>
<tr>
<td></td>
<td>4. Recurrent hospital admissions* related to above</td>
</tr>
<tr>
<td>2. Frailty &amp; Dementia</td>
<td>1. Multiple co-morbidities with poor functioning and severe disabilities</td>
</tr>
<tr>
<td></td>
<td>2. Dementia with poor functioning and severe disabilities</td>
</tr>
<tr>
<td></td>
<td>3. Recurrent hospital admissions* related to above</td>
</tr>
<tr>
<td>3. All Cancers</td>
<td>Cancers with metastasis or not amenable to treatment</td>
</tr>
</tbody>
</table>

Table 2: Case no. and % of the various PC indication categories

<table>
<thead>
<tr>
<th>Indication for PC</th>
<th>Case no.</th>
<th>% of total (n=116)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Organ Failure</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a. Heart disease</td>
<td>8</td>
<td>6.9%</td>
</tr>
<tr>
<td>b. COPD</td>
<td>20</td>
<td>17.2%</td>
</tr>
<tr>
<td>c. Renal Disease</td>
<td>11</td>
<td>9.5%</td>
</tr>
<tr>
<td>d. Neurological disease</td>
<td>3</td>
<td>2.6%</td>
</tr>
<tr>
<td>Subtotal</td>
<td>42</td>
<td>36.2%</td>
</tr>
<tr>
<td>2. Frailty &amp; Dementia</td>
<td>37</td>
<td>31.9%</td>
</tr>
<tr>
<td>Subtotal of 1. &amp; 2.</td>
<td>79</td>
<td>68.1%</td>
</tr>
<tr>
<td>3. All Cancers</td>
<td>37</td>
<td>31.9%</td>
</tr>
<tr>
<td>Total</td>
<td>116</td>
<td>100.0%</td>
</tr>
</tbody>
</table>
Introduction

Bisphosphonates are a class of drugs capable to work against the osteoclast-mediated bone loss. In link with treatments for malignancy, it has several potential roles like treating hypercalcaemia, as adjunctive therapy to anti-neoplastic treatments such as in multiple myeloma, breast cancers and prostate cancers. Its anti-osteoclastic effects make it an attractive agent against bone mineral density loss in osteoporosis which may occur as a result of treatment against malignancies.

Pharmacology of Bisphosphonates

Bisphosphonates are chemically stable derivatives of inorganic pyrophosphate (PPI), which is a naturally occurring by-product of many body’s synthetic reactions (Fig. 1). PPI can inhibit calcification by binding to hydroxyapatite crystals. In addition to the property as like PPI, bisphosphonates is also capable of suppressing bone resorption through the inhibition of hydroxyapatite breakdown.

The potency of bisphosphonates is mainly governed by the structural moiety (in the R2 position) attaching to the central carbon. The presence of nitrogen or amino group (Fig.1C) can increase the antiresorptive potency of bisphosphonate by a factor of 10 to 10,000 relative to the early non–nitrogen-containing bisphosphonate (Fig. 1B)\(^1\).

Treatment for hypercalcaemia of malignancies

Hypercalcaemia is always thought to be an oncological emergency. It happens in around 10-20% of cancer patients along their course of diseases. Hypercalcaemia most commonly occurs in malignant diseases like lung cancer, breast cancer, renal cell carcinoma, head-and-neck cancer, and multiple myeloma, which is thought to be mediated by cellular release of cytokines, parathyroid hormone-related protein, and prostaglandins. The typical symptoms include nausea, cramps, bone pain and even mental changes. If untreated, hypercalcaemia can lead to dehydration and is potentially life threatening. Except in situation of extreme hypercalcaemia requiring calcitonin, patients with hypercalcaemia are usually manageable by hydration and intravenous bisphosphonates. The usual time to reach normalized calcium level is around 4-7 days after bisphosphonate administration.

Bisphosphonates are effective against hypercalcaemia because of its potent inhibition of osteoclast activity.

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![Bisphosphonate structures and relative potencies in osteoclast inhibition](adapted from Matthew T. Drake, Bart L. Clarke, Sundeep Khosla Mayo Clin Proc.2008;83(9):1032-1045)
The information needs and satisfaction with communication of cancer patients receiving palliative chemotherapy

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Introduction

Chemotherapy is used widely in the management of patients with advanced cancer. However, the decision to use chemotherapy is often complex and difficult.(1) Palliative chemotherapy aims at the alleviation of symptoms or postponing future symptoms of disease and thus maintaining or enhancing quality of life. However survival gains are modest. Furthermore, the chemotherapy itself may be associated with adverse effects such as nausea, hair loss and fatigue.

The available evidence indicates that almost all patients want to be fully informed by their physician about the various aspects of their disease and their treatment.(2) Although the expressed desire for information is uniformly high, patients vary widely in the type and amount of information-seeking behavior they actually exhibit during medical visits. Clinicians commonly underestimate patients’ desire for information and discussion.(3) Doctors do not always communicate well with their patients and patients may have difficulties in expressing their needs. Patients and doctors must depend on each other if they want to achieve their common goals; effective communication is the necessary foundation of this alliance.

In the decision-making process, giving information as well as patients’ values and preferences become important issues. An insight into the patient’s decision making process can support clinicians having to inform their patients.(4) Ensuring that patients receive appropriate information about the prognosis of their cancer and the likely outcomes of treatment and involving them in the clinical decision making process related to the management of their cancer may facilitate the process of informed decision making regarding their care. Two issues are important when discussing treatment options with patients. Firstly, the information given should match the patients’ preferences for the amount and type they need and want. Secondly, the extent to which patients are involved in the decision-making process should be congruent with their actual desire for participation. (5)

Although these findings have led to an ever-growing interest in identifying the specific needs and preferences for information and communication of cancer patients in western countries, these issues have not been examined in our locality. Therefore, we have designed this study to examine the information needs, satisfaction with communication and perceptions on the decision making process of our patients.

Patients and Methods

The study was performed at the Department of Clinical Oncology, Queen Elizabeth Hospital from 1st May to 30th June 2009. Patients who are due to start a course of palliative chemotherapy will be approached by our research assistant and invited to participate in a questionnaire. These patients would have discussed their disease and management with a clinical oncologist from our department. Patients were explained about the aim of the study and informed consent to participate in the study was obtained. The questionnaire was developed from a literature review and through discussion with relevant experts including clinical oncologists and palliative care experts. The questionnaire was designed in Chinese and includes questions regarding 4 areas: patient’s demographic detail, information needs, perceptions on information disclosure and perceptions on the clinical decision making process. The investigator also reviewed the records of patients who participated in the study and collected relevant clinical data.

Results

A total of 97 patients were recruited in the study with median age of 62 years. Male to female ratio was 2:1 and the most common primary was lung cancer. (Table 1)
Patients were asked about their information needs including items shown in Table 2. Almost all of these information were considered to be very important by more than 90% of the patients.

The average score for information needs was calculated for each patient. There was a significant association between gender ($p=0.013$) and occupation ($p=0.045$) with information needs using the one-way ANOVA test. Females patients were found to have more information needs than males. Housewives and retired patients have greater information needs than blue and white collar workers. Analysis revealed no significant effects for age, education, marital status, performance status, primary site, stage of cancer or line of treatment.

Patients were then asked whether their doctors had explained to them the information listed in the previous question and whether they understood the information provided. It was found that around one-third of patients were not given explanation or information about the prognosis and stage of the cancer. (Table 3)
Sixty percent of patients reported that they would like to have further information and thirty percent of them needed no more information. The categories of extra information most frequently required included the disease condition, follow up after completion of chemotherapy, efficacy and side effects of chemotherapy.

The next section included questions regarding patients’ perceptions on the process of information disclosure. Seventy-seven percent of patients reported that the doctors appeared concerned during the consultation whereas only one percent reported their doctors appeared unconcerned. Ninety-three percent of patients reported that the pace of information provision was optimal for them. Regarding the amount of information provided, 83 percent of patients considered it to be appropriate. Fifteen percent of patients considered the information to be a bit inadequate and only two percent considered the information too excessive. On analysis, the more educated patients were found to be more likely to consider the amount of information insufficient (p=0.034).

Ninety-two percent of patients reported that they were given adequate time to ask questions and 93 percent of patients had asked their doctors questions. Seventy-eight percent of patients perceived that they understood what the doctors told them. For those who failed to understand, a lack of medical knowledge was the most common reason given for the inability to comprehend. Eighty percent of patients were satisfied with the consultation in general and only one percent of patients were dissatisfied. The reason for dissatisfaction was that the consultation was too brief.

Those who are retired and housewives were more likely to be satisfied than blue collar and white collar workers. Less educated patients and those married and living with their families were more likely to be satisfied.

The last section of the questionnaire sought the patients’ perceptions regarding the decision making process. They were asked about much they depended on their doctors during the process of deciding whether to receive chemotherapy. Fifty-eight percent reported that the doctors’ influence was big and they depended on them for making the decision. Twelve percent of patients reported that doctors’ influence was little and they decided mostly for themselves. We found that older patients, those more than 75 years of age, were less likely to be influenced by doctors. Patients of poorer performance status and receiving more lines of chemotherapy were also less likely to be influenced by doctors.

Discussion

Results of this study support previous research that most patients want as much information as possible about treatment and illness.6 Traditionally, it was assumed that younger patients and patients who were professionals would have higher information needs.

However, our study however showed no significant differences in the age and education of the patients with their requirements for information. Housewives and retired patients were actually found to have higher information needs.

We found that the stage and prognosis of cancer were not explained to patients by their doctors in around one-third of cases. Anecdotal reasons of the doctors for not disclosing diagnosis and prognosis to their patients especially in an Asian country like Hong Kong include the following: (1) patient does not wish to know, preferring doctors to decide management, (2) family is influential, and family will be given information first and they shall decide whether to disclose to patient, (3) patients (especially elders) may be less well educated or less able to understand medicine7 (4) ‘never destroy hope’.

However from this study we found that more than 95% of patients actually wish to know about the diagnosis, stage and prognosis of their cancer including elderly patients. Withholding the truth may lead to a lack of co-operation with the doctor, prohibit patients from sorting out practical issues and result in state of confusion in long run.8 It is more important to assess how to give what individual patients needs and what he or she can take instead of holding false assumptions.

In our study, 16% of patients considered the amount of information provided to be too little compared with 2% considering information to be excessive. Research has suggested that not being told enough is a more usual complaint than being told too much.8 No patients in the study consider the pace of information provision to be too slow, whereas 7% of patients
considered the pace too fast. This emphasised the importance of providing as much information as possible at a pace comfortable for patients. It could be difficult for doctors to strike a balance in practice where time is always limited in these busy clinics.

More educated patients were more likely to consider the amount of information provided insufficient and they had lower levels of satisfaction with the consultation. This may be accounted for by their higher ability to comprehend information and more access to other information sources. On the other hand, twenty-two percent of patients do not understand the information given due to a lack of medical knowledge, poor comprehension and poor memory. This highlighted the importance of using simple appropriate language when communicating with patients and avoiding medical jargons. We need to tailor to the individuals needs of patients, providing the right types of information given in ways optimal to their own level of understanding. Other resources may be invaluable for consolidating and supplementing information, including information booklets, DVD and websites which could be distributed to patients after the clinic.

Patients’ desire to participate in decision making varies. The role of doctors in the decision making process remain important despite the shift to a more egalitarian doctor-patient relationship nowadays. In the study, 58% of patients reported a big influence by doctors in their decision making process. The ability of doctors to predict the preference of patients in adopting an active, shared or passive role in decision making is very poor in palliative care. Studies showed that desire for information is not the same as desire to participate in decision making. In this study, older patients, those of poorer performance status and receiving more lines of chemotherapy were associated with lesser influence by doctors during decision making which is in contrary to what we commonly believe in.

Conclusion

Instead of questioning the need for giving more information, we need to develop ways to provide adequate information in a flexible and sensitive manner. Doctors should detect specific needs of the individual patient, and know how best to structure and present the information so that it is understood and remembered. Patients cannot participate in decision making to their desired extent unless they have the right types of information, given in ways optimal for their own levels of understanding. Desire for level of participation in decision making should be gauged for individual patients in the process of deciding treatment.

References

Palliative Medicine Doctors’ Meeting

Coping Strategies in the Face of Death

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Introduction: Theoretical background to stress, coping and death

Coping can be defined as ‘a process by which a person deals with stress, solves problems or makes decisions.’ ¹ Stress has been defined as ‘a particular relationship between a person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being.’ ² According to the stress-coping paradigm as developed by Lazarus, an individual will engage in two processes of appraisal when confronted by a stimulus that is potentially stressful – primary and secondary appraisal. ³

Primary appraisal determines whether a stimulus is perceived to represent a harm, loss or threat (i.e. whether it is perceived to be a stressor) while secondary appraisal determines how the individual responds to and deals with the stressor (i.e. a process of coping). The stress-coping paradigm is represented in Figure 1.⁴ Different individual appraises a stimulus and his/her own resources to cope with the stressor differently. Therefore, the same stimulus will lead to different coping responses in different individuals.

Patients with advanced cancer and their families are often facing enormous stress and use many different and varied approaches to reduce emotional distress. However, each individual travels a unique life journey. Each person responds differently to difficulties and copes in his or her individual way.

For patients diagnosed with cancer, four primary psychological responses have been identified that can be grouped into four themes:
1. denial
2. fighting spirit
3. acceptance
4. hopelessness.⁵ (Figure 2)

As shown in Figure 2 ⁶, coping is seen as a dynamic and fluctuating process and people use a range of coping strategies, depending on the situation. It is important not to permanently place an individual into any one coping strategy as each individual’s coping may change over time.

The dynamic nature of an individual’s coping with one’s own impending death from cancer is also demonstrated in a qualitative study in 20 Swedish patients on how they reflected and acted when they tried to create
helpful strategies in the presence of their own impending deaths and how the strategies had served their purposes. Their coping efforts could be visualized as a cognitive and emotional pendulum, swinging between the extremes of life and death. (Figure 3) During the swings of the pendulum, the individuals used every means available: their own resources, other people, animals, nature, a transcendent power, hope, imagination and magical thinking. They strove to find factors that fitted their conceptual system and supported their inner balance and structure, all to keep death at a discreet distance and preserve their links to life. These links were togetherness, involvement, hope and continuance, and they served as a shield against hurtful feelings connected to their impending death.

Patient 1

Miss Chu, a 39-year-old office lady, single but lived with a constant boyfriend for years, and a newly converted Christian, had been diagnosed to have ovarian cancer with intraperitoneal metastases. Palliative surgery was done and chemotherapy was suggested. However she declined chemotherapy and sought help from a herbalist. One year later, she presented again with large pelvic recurrence. One course of chemotherapy was given but she developed complete small bowel obstruction which did not resolve with medical treatment. She was then referred to our palliative care unit.

On arrival to the palliative care ward, she looked dehydrated and cachexic and was very weak physically. Palliative Performance Score was only 30%. She was aware of the diagnosis and prognosis but she avoided to touch on death and dying issues. ‘I do not think about life and death issues at this moment,’ she said, ‘and I do not know how to face the future or even today.’ She could not make decisions regarding Cardiopulmonary Resuscitation (CPR) and delegated treatment decision making to her boyfriend.

A family meeting was held involving her boyfriend, mother and two brothers. All were shocked to hear about the poor prognosis and they thought that the patient was transferred to our unit for rehabilitation. They found it hard to accept her impending death and asked for active treatment. After an explanation on the poor condition and the palliative approach that our team would offer, the patient’s boyfriend cried intensely while her brother agreed to our approach for comfort care. ‘Do-Not-Resuscitate’ (DNR) was reluctantly accepted.

Sepsis due to urinary tract infection developed and she became semiconscious. Her boyfriend asked for various types of active interventions such as albumin infusion, parenteral nutrition, blood transfusion, and herbal medicine. He did not want to miss any possibility of making her survive longer. Intravenous antibiotics were given and her conscious state improved. Hoping to know the patient’s view, the doctor had a talk with her about her physical condition, poor prognosis, her goals and the risks and benefits of various life-sustaining interventions. She expressed a wish to prolong life as long as she remained alert, but preferred comfort care if she became

The Stories

The following three real patient stories illustrated how different individuals were coping with their terminal illnesses. By reflecting on these encounters, we might gain a deeper understanding on the needs of patients and their families, and how we as palliative care workers could fulfill our mandate of improving their quality of life during this highly stressful period in their lives. The patients’ names were changed to ensure anonymity.

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**Figure 3: Coping strategies in the presence of one’s own impending death from cancer**
unconscious. She preferred not to make decisions on life-sustaining treatment then.

The clinical psychologist and the chaplain were involved in psycho-spiritual support of Miss Chu and her boyfriend. She was baptized according to her request. From their observation and assessment, her mood remained stable and good, and she expressed no worry or other negative emotions. However, her boyfriend was observed to have intense emotions and stress, and he was physically and emotionally exhausted.

Miss Chu’s condition deteriorated fast and died after two weeks. Cardiopulmonary resuscitation (CPR) was not performed. Her boyfriend was still ambivalent about the DNR decision and even requested our team to do CPR after Miss Chu’s deceased body had been transferred to the mortuary.

Reflections on Patient 1

Miss Chu was aware of the prognosis and accepted comfort care in case she became terminally ill and unconscious. However, apparently she avoided to think and talk about death and dying with the medical team and with her family. She found discussion about life-sustaining treatment difficult and delegated such decision making to her boyfriend. It seemed that such coping strategy served her in maintaining a calm and positive mood while she was still lucid, but at the expense of the high stress level in her boyfriend and family. She was shielded from the hurtful feelings of impending death by a protective family.

The rapid deterioration of Miss Chu’s condition and the transfer to a palliative care setting rendered the family, especially the boyfriend, unprepared in facing her death. They coped by fighting – seeking information about and asking for various life-sustaining interventions and alternative therapies. They cherished any means that might offer them a glimpse of hope, no matter how small it was. With Miss Chu’s rapid downhill course, there was not enough time for them to change from fighting for prolongation of life to acknowledging the reality of death and grieving. As the boyfriend still could not accept the patient’s death after death had been certified, a higher risk for complicated grief was anticipated.

Although there is a trend to provide palliative care to cancer patients earlier in the course of their illness, the transition from an acute setting to a hospice setting is still sometimes difficult as the shield from dying and death is often perceived by patients and families to have been taken away. The differences in practice in provision of life-sustaining treatment including CPR and policy about DNR between acute setting and palliative care units sometimes act as triggers to the distress in patients and families. There is no easy solution. On the referring end, integration of palliative care principles with focus on alleviation of suffering and enhancing quality of life into the service, timely referral to specialist palliative care service, as well as a truthful and sensitive preparation of patients and families before their transfer to a palliative care unit are important in smoothing out the transition. On the receiving end, sensitive exploration of patients’ and families’ needs, goals and expectations on admission, flexibility in clinical management based on sound ethical principles especially during the transition period, and ongoing communication with the patients and families and within the team are essential. On a more global level, raising public awareness on death education and palliative care, increased collaboration between palliative care and other clinical units, and integration of palliative care principles into medical and nursing school curriculum will reap their fruits in the long run.

Patient 2

Mr Lee was a 45-year old shop-owner with four children. The family relationship was good and close. He was suffering from recurrent colon cancer with peritoneal metastases not responding to two different courses of chemotherapy. He developed persistent intestinal obstruction and was then transferred to our palliative care ward.

On admission, his main goals were to be comfortable and mobile. He was fully aware of the poor prognosis, claimed that there was no unfinished business and could accept death naturally. His wife grieved that she could not share with her husband the fruits of their years of efforts in setting up their own business.

On admission, his main goals were to be comfortable and mobile. He was fully aware of the poor prognosis, claimed that there was no unfinished business and could accept death naturally. His wife grieved that she could not share with her husband the fruits of their years of efforts in setting up their own business.

The intestinal obstruction progressively deteriorated and the couple coped differently. Mr Lee tried to seek active treatment. He asked for surgery despite a clear surgical opinion that surgical treatment was not feasible and for continuation of dexamethasone despite knowing...
that it was not effective. He bought alternative medicine from Japan and was reading a book about some case studies of its effectiveness. He wanted to ‘maintain some hope and live for a few more months’. He remained quiet and seldom talked about his emotions and grief anymore. Mrs Lee started to handle her own grief by reading books about death and bereavement, made a photo album sharing family stories of their dating and marriage, the birth and growth of each child, and their successful business. The family wanted to cheer up the patient by arranging family gathering, taking family photo and sharing the album. However, Mr Lee remained quiet and Mrs Lee was upset.

He deteriorated gradually and died. Mrs Lee and their children were able to cry and express grief at the deathbed.

Reflections on Patient 2

Mr Lee used different coping strategies at different time. On initial assessment, he apparently understood and accepted the poor prognosis well. As his condition deteriorated, he tried to fight by asking for treatment for his intestinal obstruction and seeking information about complementary medicine. He sought to maintain linkage with life and hope instead of focusing on dying and grief.

In a qualitative study on how US-Resident Chinese immigrants with advanced cancer searched for meaning at the end of their lives, hope and faith was one of the 6 major themes revealed. Participants built hope and faith by continuing to live, believing in a possible cure, having religious beliefs, and receiving encouragement from family and others. Participants described how they had mentally prepared themselves for the possibility of dying at any time after they were diagnosed with metastatic cancer, yet they found hope and faith when they believed that a cure for their cancer was possible. They acted on this belief by continuing to receive treatment. In Mr Lee’s case, the team adopted a supportive and non-judgmental stance in dealing with the issues of using herbal medicine and seeking treatment for intestinal obstruction by exploring with him the potential benefits and harms of the treatment while keeping the communication accurate, realistic and honest. ‘Being with and meeting the patient and the family at the point where they are’ helps in fostering an open and holding environment where they can explore and develop what they really want in the remaining time.

Mrs Lee coped in a different way. She had more readily accepted her husband’s impending death and prepared herself by reading, reflecting and life review through album making. The couple’s different coping strategies were not in tune with each other as reflected by the distress experienced by Mrs Lee when she could not cheer her husband up by various means. Our team members including a nurse and a social worker once attempted to facilitate communication between the couple but such attempts apparently did not lead to much change.

Coping is unique to each individual. Even a couple with longstanding and close relationship may cope in very different ways. Whether, when and how palliative care workers should intervene when such a discrepancy is observed is more of an art than a science. The principles of respect, openness, support, honesty, and being with should be observed in handling such discrepancies.

Patient

Mr Luk was a 51-year old surveyor with Buddhist faith. He was married and had no children. He suffered from small cell carcinoma of lung with mediastinal lymph node metastases and radiotherapy and chemotherapy were completed. He developed adrenal metastases and one dose of second line chemotherapy was given but it was later stopped due to deranged liver function. Subsequently an enlarging lymph node in the retroperitoneal region developed leading to biliary obstruction and a biliary stent was inserted. He and his wife actively asked for palliative care and he was hospitalized for symptom control and psychological support.

The couple acknowledged the diagnosis and poor prognosis. Mr Luk had a naturalistic view on death and his main goal was comfort. He still wanted some anti-cancer treatment and herbal medicine with the aim to prolong his life, but requested comfort care if such treatment failed. He was also concerned about his wife’s grief.

Multiple complications developed during his hospital stay including left sided pneumothorax requiring chest drainage, herpes zoster, upper gastrointestinal bleeding, urinary tract infection, urinary retention, and upper
Intestinal obstruction. Further chemotherapy and surgical treatment were not feasible.

Experiencing these complications, Mr Luk accepted that no further life-prolonging treatment was possible. His main goal changed from life prolongation to comfort and symptom control. He adopted a ‘let nature take its course’ and ‘here and now’ attitude. From then on, the staff observed that he stayed in the room all of the time without much activities although he was physically able to do so. He was assessed not to be depressed. Symptoms were satisfactorily controlled by subcutaneous medications. Psychological support was given to Mrs Luk. On exploring his goals, he said he was ready and waiting to die.

On one occasion, one of our staff invited him to our garden with different types of flowers. He responded positively to this invitation. According to our staff’s report, he smiled brightly, picked some flowers to his wife, sang a love song and took photos with his wife and the team. After this, he gradually deteriorated and succumbed a few days later.

Reflections on Patient 3

We witnessed a change in coping during Mr Luk’s hospital stay, from fighting and hope to accepting, yielding and readiness to die. There are questions on why our staff should invite him out to the garden. Apparently, his goals of symptom control, dying naturally and psychological support to his wife had been achieved. So why should we not stop at that point while continuing to provide the physical and psychological care he needed?

Our staff invited him to the garden out of a sincere hope that he might experience some connections with Nature, with its inherent life and beauty. It was a spontaneous, intuitive, and human act rather than a result of careful considerations of evidence-based practice and ethical principles. Learning to diagnose suffering is never a purely scientific endeavor. ‘Knowing patients as individuals well enough to understand the origin of their suffering and ultimately its best treatment requires methods of empathetic attentiveness and non-discursive thinking that can be learned and taught’. Such non-discursive thinking sometimes involves intuitive thinking that takes place below awareness.

The spontaneous joy in the patient while he was in the garden illustrated that change in coping was still possible near the very end of life. Palliative care workers’ presence, empathic attentiveness and intuition might sometimes act as resources from which patients obtain strength in coping with this stressful time of their lives.

Conclusion

In the face of death, each individual copes in his or her unique way. People in the same family may cope with the same stressor in very different ways. Coping is a fluid and dynamic process and individuals will change from one coping strategy to another. Moreover, it is also an interactive process – there are interactions among patients, their families and health care professionals. As palliative care workers, we should try to understand these processes in order to serve the needs of our patients and their families with respect, honesty, flexibility and empathy.

References

Case report

Ms Pui was a 32 year-old lady who was admitted to the Palliative Care Unit of Caritas Medical Centre in April 2008 for pain management. She suffered from left sided renal tumor with metastasis to the left sided supraclavicular lymph node in June 2006. Biopsy of lymph node revealed metastatic adenocarcinoma. She declined chemotherapy suggested by oncologist. She subsequently developed bilateral leg weakness in February 2008 due to extensive left paraspinal tumor invasion from the twelfth thoracic spine to the third lumbar spine. After radiotherapy, Ms Pui was transferred to palliative care unit for pain control.

Ms Pui’s pain originated from abdominal tumor, spinal metastasis and sacral score. Tramadol and gabapentin were ineffective in pain relief. Morphine was not considered due to renal impairment. The switch to methadone provided short term control of back pain. Ms Pui’s physical condition declined gradually and she could not take drugs orally. Therefore she was commenced on fentanyl infusion at a daily dose of 200mcg administered subcutaneously through a syringe driver. Fentanyl was stepped up to 400mcg next day to achieve a better pain relief. Upon scheduled nursing observation, it was discovered that the syringe barrel was emptied at four hours after the commencement of fentanyl infusion. Re-checking of the Graseby MS16A syringe driver confirmed an incorrect infusion rate setting at 48mm per hour instead of at 2mm per hour, i.e. the presumed daily dose of 400mcg of fentanyl was administrated within one hour. Ms Pui’s vital signs were closely monitored and she remained stable. She preferred to continue the fentanyl infusion through the syringe driver for pain control. She died peacefully after 19 days. The medication incident was reported to Hospital Authority via the Advanced Incidents Reporting System.

Discussion

Syringe drivers are commonly used in the palliative care setting to treat pain and other distressing symptoms. In United Kingdom (UK), it was first described in 1979 by Dr. Patrick Russell who reported the use of the Graseby syringe driver to deliver continuous subcutaneous infusion in hospice context. This technology offers an effective method of drug administration that is particularly suited to and has been firmly established in palliative care. Since their introduction in the UK, syringe drivers have played a role in enhancing ambulatory and home based care outside of hospital environment, thereby increasing the options of place of care for palliative patients. The most widely used models of syringe driver in the UK are Graseby MS26 and MS16A (Fig. 1). The length of fluid in syringe barrel determined the rate of infusion. The MS16A is calibrated in millimeter (mm) per hour and the MS26 is designed in mm per 24 hour.

Figure 1. The Graseby MS16A syringe driver
The Graseby syringe drivers have the advantages in terms of simplicity in use, being light weight, ambulatory and low cost to run (one 9 voltage PP3 battery lasts for up to 50 infusions). However, there has been a number of operator related problems associated with syringe drivers. In UK, monitoring of standards for electronic syringe drivers comes under the auspices of the Medical Devices Agency, which issues alerts and hazard warnings relating to these problems since 1994. In particular, there is continuing reporting of incidents in which confusion between MS16A and MS26 syringe driver has led to incorrect infusion rates being set. The two models are visually similar and users have mistakenly set rates on an MS16A (calibrated in mm/hour) thinking it was an MS26 calibrated in mm per 24 hour. This has resulted in serious over-infusion and fatality. The manufacturer Graseby Medical have introduced enhanced labeling for the front panel of new syringe drivers. Old style devices should also be fitted with the appropriate new label. The term “Graseby syringe driver” is commonly used for both models and is not recommended as it fails to differentiate between the two. Furthermore, to minimize mixing up of the two drivers, it is advised to avoid keeping two similar devices in the same ward or palliative care unit.

Inadequate user training has also been identified as one of the factors that contribute towards adverse incidents related to the use of syringe driver. A survey done in a syringe driver study day discovered that none of the 180 staff knew how to test the syringe drivers before use. It is essential that users should be provided with adequate training and updating knowledge, particularly those who only come in contact with the syringe driver infrequently. Apart from face-to-face training session, online learning is an alternative and innovative strategy to meet this education and training need. In UK, an online learning programme on the use of Graseby syringe drivers in palliative care organized by “Nurse Learning” had been established in 2003. Report of three years experience showed that this flexible form of learning environment is acceptable to learners and can lead to improvements in both knowledge and understanding of the palliative care issues. However, the course is not intended to replace the face-to-face training where this is available.

Despite the availability of education programmes on the use of syringe drivers, there are intrinsic problems of Graseby MS16A and MS26. The two devices failed to comply with the appropriate standard such as International Electrotechnical Commission IEC 60601-2-24 which is particular requirement for safety of infusion pumps. They also failed to fulfill any safety features that the Medicines and Healthcare products Regulatory Agency of the UK considered to be important for infusion devices. Regulators in several countries, including Australia and the UK have previously issued safety alert in relation to these devices. Unfortunately, some of the adverse events could not be fully analyzed as the syringe driver does not have a memory of events and alarms that may have proven useful in the full investigation. From October 2007, these devices are no longer compliant with the best practice standards for contemporary devices as set by the Therapeutic Goods Administration of Australia and have been voluntarily withdrawn from the market.

<table>
<thead>
<tr>
<th>Table 1: Intrinsic problems of Grasby MS16A and MS26 syringe drivers</th>
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<tr>
<td>• The visually similar MS16A and MS26 models have a 24-fold difference in infusion rate. Confusing the two has resulted in multiple serious adverse events</td>
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<tr>
<td>• The device does not use standard measuring units requiring a calculation to set the flow rate, thus introducing the risk of error.</td>
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<td>• The pump lacks a stop button.</td>
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<td>• The rate can be changed while the pump is in operation.</td>
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<tr>
<td>• There is no protection against misleading of the syringe, air entrainment, tampering or siphoning.</td>
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<tr>
<td>• The occlusion response characteristics of this pump are very poor.</td>
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<tr>
<td>• The pump does not retain a record of operation.</td>
</tr>
<tr>
<td>• A “prime” button provides maximum infusion rate when depressed. There is no limitation on the number of times this may be activated nor a record of activation. Serious adverse outcomes have resulted from inappropriate use.</td>
</tr>
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While they can no longer be purchased, the manufacturer Smiths Medical has a formal agreement to continue to provide maintenance and service support for a further five years. Discontinuation of supply occurred at the same time in New Zealand.

Palliative care Australia had launched the search for alternative devices and another newer syringe driver Niki T34 or McKinley T34 became adopted widely in Australia. (Fig 2) A number of hospices in the UK are currently piloting the T34 which was launched in the UK in May 2005. The T34 is similar in size to the Graseby MS26 and MS16A. It is designed to deliver the contents of a 2 to 50ml syringe over a specific duration or at a given rate in millilitre per hour (ml/hr). It is equally suitable for both adult and paediatric use. Some of the advantages are summarized in table 2. More importantly, T34 complies with the safety consideration mentioned in the Hospital Authority Operation Guidelines on Safe Use of Infusion Pump Guidance which became effective from February 2009. T34 had recently been available in our palliative care unit to replace all the Graseby MS16A syringe driver. Further clinical experience and evaluation are required to confirm its effectiveness and safety in palliative care setting.

![Figure 2. The Niki/McKinley T34 syringe pump](image)

### Table 2: Some advantages of McKinley T34 syringe driver
- Its size makes it suitable for ambulant patients
- Its ability to detect syringe size automatically and calculate the rate of delivery using the volume of the fluid in the syringe.
- It can be programmed to infusion in ml/hr rather than mm/24 hour, reducing the potential for user error, and also serious under-/overdose of drugs.
- Its design ensures it addresses all the safety features as that the MHRA recommends and IEC 60601-24 proposes as essential.
- Infusion rate cannot be altered once the device is infusing
- No bolus facility.

### References
Dealing with Anger in Palliative Care Setting

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Correspondence: Lcw167@hotmail.com

Case History

Mdm W was a 57-year-old woman who suffered from metastatic cancer of cervix. She was found to have pelvic recurrence at six months after commencement of chemotherapy and radiotherapy. She was referred to our palliative care consultative service because of difficult pelvic pain control, and later transferred to our palliative care ward after stabilization for massive per vaginal bleeding.

Mdm W was widowed, and she lived with her elder son. She was a traditional Chinese herbal medicine dispenser, but retired with onset of her disease.

Her elder son, Mr T, was single and left home in his teens when he had serious behavioral problems. He moved back to live with his mother after she was diagnosed to have cancer. He was the main caregiver of the patient and he was unemployed. The second son was married and worked in a pharmacy as dispenser.

Mdm W had poor compliance to medical treatment and complained of intolerance to multiple analgesics, making pain control difficult. She had always been skeptical about western medicine. Instead, she preferred to take the over the counter herbal medication brought to her by Mr T daily.

She developed acute renal failure with anuria, and ultrasound revealed bilateral obstructive uropathy resulting from the pelvic tumor mass. An urgent transfer to acute hospital was arranged and percutaneous nephrostomy was performed subsequently. Her sons were interviewed on several occasions before the transfer, and grave prognosis was communicated. During the interviews, they appeared upset, while hoping the herbal medication might help, they realized she was deteriorating and agreed with do-not-resuscitate decision.

Despite a partial recovery of her renal function post operatively, she was febrile with severe metabolic acidosis and post obstructive diuresis. Her general condition was further compromised, and she was bedbound, lethargic, anorexic, and had acidotic breathing. Intravenous fluid replacement, bicarbonate infusion and antibiotics were given.

As Mr T was confronted with patient’s deterioration, our nurses started to report problems with his behaviour in ward. He became overwhelmed, and was very emotional and agitated. He would demand the nurses to give immediate attention to his mother with the slightest signal of any change in his mother’s physical state. Despite the irreversible organ failures, the patient appeared calm and sleepy most of the time. However, any frowning or noise from breathing would trigger a huge emotional response in Mr T.

On one occasion, in the middle of the night, Mr T yelled and shouted in the ward, requesting immediate transfer of patient to a private hospital. He thought her mother should be under better care. However, the patient was too ill for transfer and he did not have any specific ideas in his mind. Eventually he settled down and he was interviewed again with an attempt to align the goals of care. On another occasion, the focal muscle twitching of patient was interpreted as a major seizure by Mr T. He yelled and appeared furious; he scolded the nurse who attended the patient immediately. The nurse felt threatened and intimidated by his emotions and behaviour. The doctor immediately came to assist to explain that the muscle twitching was related to uraemia and calmed Mr T down.
All these episodes of emotional outbursts and verbal violence created great tension in the ward. Our palliative care team members were scared of Mr T, felt threatened by him and work stress was building up. Many staff felt exhausted and had poor morale at work. Some felt burnt out and a few cried because of the unjustified hostility directed towards them from Mr T.

Various team members, including nursing specialist, clinical psychologist and doctors, further explored the background. Mr T had a poor relationship with his family as he left home since teenage. Being the eldest son of the family, he felt obliged to move back home and looked after his mother. As he was unemployed, he spent all his time in caregiving and developed strong emotional attachment yet ambivalent relationship with his mother. Besides, Mr T perceived the doctors had abandoned her mother. As curative oncological treatment was no longer feasible, he thought that the western medicine had failed her mother. Therefore, he relied on the traditional Chinese herbal medicine that he gave to her mother because he had heard of successful stories.

In dealing with his anger, we tried to mobilize other family members to engage in caring for patient. The other family members, including patient's younger son, patient's brothers and sisters from China came to accompany Mr T so that he felt more secured, and the team was able to calm him down more easily. We, as doctors, proactively conveyed timely, consistent and clear patient's progress daily and Mr T had a chance to express his concerns. The senior nursing staff held debriefing sessions with the affected staff to allow ventilation and sharing. The verbal violence was reported to the hospital management through the Advanced Incident Reporting System.

With the relatives from China around, Mr. T remained calm and was more receptive to information from staff as the others would try to reassure him by acknowledging the facts. When at end-of-life, patient was given low dose subcutaneous morphine for pelvic pain and shortness of breath. Patient finally died in peace and this was very much appreciated by Mr T.

Discussion

Being aware of the emotional responses of ourselves as well as others allowed us, as health care workers, to cope with challenging situations involving difficult communication. In dealing with highly expressed emotions, this is especially important. In the Satir Model of personal iceberg, a congruent coping stance that takes care of one’s self, others, and the context facilitates good communication and anger resolution.

Mr T’s coping stance of blaming others and expressing anger rooted from incongruence within the personal iceberg - unmet expectation and unfulfilled yearning with low self esteem.

![Figure 2: Mr. T's iceberg - Blaming](image-url)
Staff, when challenged with a difficult relative, had their own coping stances which could be different from Mr. T. Feelings of being unhappy, being hurt and scared might be rooted from unmet expectation of respect from others and out of touch with one's inner self. This was again originated from incongruence in the iceberg and such coping might not be sustainable. (Figure 3) Some of the staff might adopt the coping stance of being super-reasonable and ended up in arguing with the angry son, which would not be helpful in dealing with difficult emotional scenes.

Dealing with anger is common in palliative care. Anger was recognized as one of the essential stages in grieving as described by Kubler-Ross. Prevalence of anger emotions ranged from 9% to 18% in cancer patients and their families in various descriptive studies. Verbal abuse in palliative care is also not uncommon. In Australia, a survey in 2005 showed 62% of doctors had been verbally abused in the previous 12 months.

In a descriptive qualitative study on a focus group in an acute hospital palliative care team, various aspects of anger were analyzed. Source of anger was often shared between patient and the family. Source of anger from patient might arise from perceived neglect or abandonment from doctors, delay in diagnosis and accusation of doctors giving too much or too little information, or even in the wrong style. Family members' guilt towards patient might also be expressed as anger. Negative impact of anger on medical staff could be significant. Staff confidence and self efficacy might be undermined. Staff may feel exhausted with repeated efforts to engage patient or the relatives, rendering staff difficult to show empathy and establish rapport further. Staff often feel threatened, and may become defensive or even angry themselves, with a spiral down effect as anger escalates. The long term effects on nursing staff included absenteeism, sub-standard care and reduced job satisfaction. Dealing with anger might distract time of staff from other aspects of patient care. Last but not least, anger emotion often blocks effective communication.

Practical tips in dealing with anger

Practical tips for communication in the challenging scenario of dealing with anger are suggested. (Figure 4) It is important to acknowledge the anger and demonstrate that you have grasped what the client is angry about. It is also important not to 'dismiss' the anger as part of an adjustment process. Always take the source of the anger seriously (e.g. waiting room delays, or other expectations not being met), even if the response seems out of
proportion. If anger persists, one can try to get the patient to see that, no matter how justified the anger is, it is beginning to affect him adversely. If he needs help, then simple anger management techniques can be taught (relaxation training, distraction activities, limiting rumination).5

In conclusion, anger emotion is not uncommon in palliative care. In the busy acute wards, staff often tends to avoid interactions that may lead to expression of anger. However, in providing holistic palliative care, anger emotion should be treated as something that requires exploration, expression and understanding. It can lead to blockade in communication and adversely affect patient care and staff morale and team spirit. Anger may induce violence, be it physical or verbal. Understanding patient as well as our own emotional response, with high self awareness, laid the foundation for dealing with such difficult situations. Mutual support within the team is of utmost importance. There would be tremendous satisfaction when anger is transformed into more constructive emotional response following intervention by the team.

References

Figure 4: Some practical tips in handling anger emotion

Consider limits
- Frequent and unreasonable demands for physician time by family may be limited to regular updates at agreed occasion
- Family meeting, involve more family members

Support of team
- Debriefing and regular meetings

Independent broker
- An alternative independent voice maybe provided by a family representative or advocates

Preparation
- Private room, indicating uninterrupted attention
- Seated, sense of time
- Power inequality conferred by height difference is reduced

Listen
- Allow to tell the story, uninterrupted, avoid defensiveness or give explanation
- Repeat and rename emotion (anger --> upset)
- Common position, goals of care negotiated

Involve others
- Single staff handling anger, limited by tiredness and burnout
- If anger persists, shift of focus from attempting to resolve the anger to support of the team
Hong Kong Society of Palliative Medicine
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1. PERSONAL PARTICULARS
Surname ______________ First name _______________________(BLOCK LETTER)
Contact tel number______________________ (Office)__________________(Mobile)

2. OTHER INFORMATION (Renewal members do not need to fill unless information has changed)
Corresponding Address (BLOCK LETTER)__________________________________
______________________________________________________________E mail______________________________

Current Practice □ HA □ DH □ Private □ HKU □ CUHK □ Others
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Title (Dr. Mr. Ms. Mrs. etc) _________Profession____________________________

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I, the undersigned, is hereby applying for / renewing full membership / associate membership (delete if inappropriate) of Hong Kong Society of Palliative Medicine.
Applicant Signature:_____________________________ Date:_________________

Proposer:________________________(BLOCK LETTER) Signature________________________
(for new application)

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Membership fee paid for yr__________Cheque No__________Amount__________

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Please send by mail the completed application form, together with a crossed cheque (payable to "Hong Kong Society of Palliative Medicine Limited") to:

Hong Kong Society of Palliative Medicine Ltd,
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Dept of Clinical Oncology, Tuen Mun Hospital,
Tsing Chung Koon Road, Tuen Mun, Hong Kong.
**Palliative Medicine Doctors’ Meeting (PMDM)**
Every 2 months, Tuesday

Organisers: Hong Kong Society of Palliative Medicine, Training Subcommittee CC in Palliative Care, HA; Hong Kong Hospice Nurses’ Association
Time: 5:30 PM Refreshment, 6:00 to 7:30 PM Lecture
Venue: Queen Elizabeth Hospital, Lecture Theatre, G/F, M Block
Enquiry: Dr. Raymond Lo, Chairma, Scientific Subcommittee, HKSPM, c/o Dept of Medicine & Geriatrics, Shatin Hospital,
Tel 2363 7500 Fax: 2647 7850

**Multidisciplinary Meeting (MDM)**
Every 3 months, Tuesday

**Date & Presenting Units**

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<th>Presenting Units</th>
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<tr>
<td>29/9/09</td>
<td>Princess Margaret Hospital, Bradbury Hospice</td>
</tr>
<tr>
<td>11/12/09</td>
<td>ANNUAL SCIENTIFIC MEETING</td>
</tr>
<tr>
<td>26/1/10</td>
<td>Prince of Wales Hospital, Ruttonjee Hospital</td>
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<td>30/3/10</td>
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<td>25/5/10</td>
<td>Tuen Mun Hospital, Caritas Medical Centre</td>
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<td>27/7/10</td>
<td>Queen Mary Hospital, United Christian Hospital</td>
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**Palliative Medicine Grand Round (PMGR)**

Monthly
Tuesday 6:00 - 8:00 PM

**Date**
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<td>Dr Cora WS Yau, Dr Eric KY Lam</td>
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**Date**
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<tr>
<th>Presenters:</th>
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<td>Dr WY Cheung, Dr Jeff Ng</td>
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**Date**
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<th>Presenters:</th>
<th>1/12/2009</th>
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<tr>
<td>Dr Benjamin Cheung, Dr. CM Ma</td>
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**Note:**
The meeting schedule is based on the information at time of printing. Please refer to the latest announcement for confirmation.
ANNUAL SCIENTIFIC MEETING
OF
HONG KONG SOCIETY OF PALLIATIVE MEDICINE

Central Committee in Palliative Care
Hospital Authority

Co-organized by

Hong Kong Hospice Nurses’ Association

GUEST SPEAKER

DR. DAVID JEFFREY
Palliative Care Consultant, Ninewells Hospital Dundee,
Honorary Senior Lecturer in Palliative Medicine, University of Edinburgh

Topic

ETHICS IN PALLIATIVE CARE
A discussion of the Concept of Dignity and
the Ethical Virtue of Kindness in Medical care

11 December 2009
6:30pm - 7:30pm
LECTURE HALL , M/F, HOSPITAL AUTHORITY BUILDING

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