



Hong Kong Society of Palliative Medicine

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Report from Scientific Committee Hong Kong Society of Palliative Medicine

Time flies and since the last report, our Society has further co-organised joint seminars with various collaborators. On Oct 30th, an evening seminar was held jointly with Centre on Behavioural Health University of Hong Kong, Society of Life and Death Education, Society for the Promotion of Hospice Care, and Hong Kong Hospice Nurses' Association.

Two speakers were invited to speak and update us on the development of hospice services outside Hong Kong. Dr Cynthia Goh, Head of Dept of Palliative Medicine, National Cancer Centre, Singapore gave a talk on teaching palliative care in Asia Pacific Region. She briefed us on the work of Asia Pacific Hospice Network, especially on the training and mentorship provided to fellow workers in Vietnam. Dr Chan Yu, Project Manager of Li Ka Shing Foundation, together with her colleague, updated us on the needs and development of palliative care in the Mainland China. We are especially encouraged to see the setting up of more home care teams serving our fellow citizens in different provinces of our Mainland.

Hong Kong Society of Palliative Medicine
2008 Annual Scientific Meeting

Co-organizers:
CC on Palliative Care Hospital Authority
Hong Kong Hospice Nurses' Association

Dignity in dying, using integrated care pathways to improve care at the end of life

Speakers: Dr. Andrew Fowell (Macmillan Consultant, North West Wales NHS Trust, UK)
Ms Rosalynde Johnstone (Project Manager, North West Wales NHS Trust, UK)

Date: 5 December 2008

Time: 6:00pm to 6:30pm Annual General Meeting
6:30pm to 8:00pm Lecture
8:00pm to 9:30pm Dinner

Argyle Theatre, M/F, Hospital Authority Building,
Argyle Street, Kowloon

All are welcome!

Registration and dinner are free of charge.
Registration for lecture is not required.
Phone number and email address.
Name, Cordelia Chan (Fax No: (852) 2881 5644) your name,
Name, ASM of Hong Kong Society of Palliative Medicine
Name, Cheung at (852) 2958 6261

Our Society also co-organized and supported the Enable International Symposium 2008 and the 5th Hong Kong Palliative Care Symposium. You will find a report from Dr. K S Chan, Co-Chairman of the Organizing Committee, in the centerfold of this newsletter. Enjoy the photos that have captured the memorable moments of the symposium.

Our Annual Scientific Meeting on 5th December would be of the theme: 'Dignity in dying, using integrated care pathways to improve care at the end of life'. We have two UK experts with us- Dr Andrew Fowell, Macmillan Consultant, and Ms Rosalynde Johnstone, Project Manager, North West Wales NHS Trust. This is a precious opportunity to learn from them on this very important topic!

Family focused grief therapy – A Randomized Controlled Trial in Palliative Care and Bereavement

Professor David Kissane,
Alfred P. Sloan Chair and Chairman, Department of Psychiatry & Behavioral Sciences,
Memorial Sloan-Kettering Cancer Center and
Professor of Psychiatry and Vice-Chair, Department of Psychiatry, Weill Medical College,
Cornell University.

A patient's acceptance of their dying is achieved through courage and gratitude for the life they have lived. Saying farewell to the family generates sadness, yet open communication about these themes enriches the process of caring for the dying. Families may on the other hand want to protect their relative from distress or hopelessness, avoiding any open communication about death and dying.



Palliative care strives to care for both the patient and their family. Accomplishment of the latter goal is a significant challenge at times. How do we recognize families in greater need? How can we target services preventively to those at risk?

Assessment of the patient's and family's relationships through attention to communication styles, level of family cohesiveness and ability to tolerate differences without conflict helps the clinician to understand the functioning of the family. The development of a service model of supportive care for all families and focused preventive care for those families deemed to be at greater risk will help palliative care to move beyond the rhetoric of family-centered care to achieve an integrated program that is responsive to a range of different family needs. The Family Focused Grief Therapy Trial confirmed its efficacy is a systemic model of effective preventive intervention.

Demoralization Syndrome in Palliative Medicine: Its Recognition and Treatment

"I do not see the point anymore. There is no reason to go on living."

One of the more common ways for existential distress to manifest itself in palliative care is through the mental state of meaninglessness and hopelessness.

Demoralization syndrome is a useful diagnostic category in palliative care because

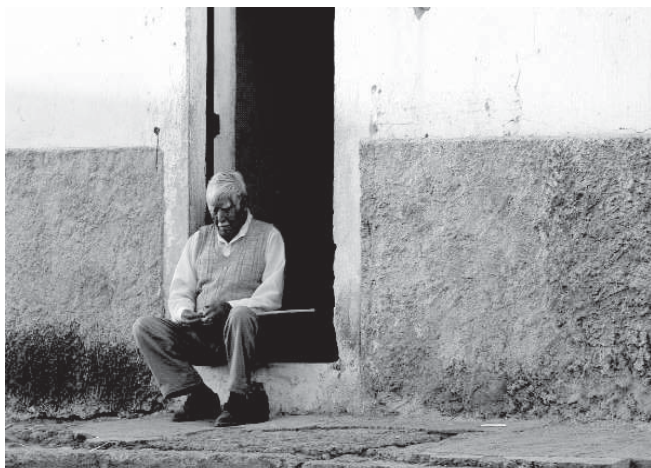
not all of these patients go on to become depressed, yet they may desire death, and the distress inherent in this state warrants intervention. The core feature of anhedonic depression is loss of interest and pleasure in the present moment, while the core feature of demoralization is the loss of anticipatory pleasure in the future.

Key diagnostic criteria for Demoralization Syndrome include:

- 1) meaninglessness, pointlessness and hopelessness;
- 2) a sense of stuckness or helplessness in which the circumstances seem unalterable;
- 3) rising distress;
- 4) prominent social isolation or alienation;
- 5) persistence of this mental state over two weeks (such that it is not a transient state of mind).

A desire to die can develop without progression of the mental state into definite clinical depression, although in many patients, demoralization syndrome and clinical depression will eventually co-exist.

In this workshop, background research on hopelessness across the past 25 years will be drawn together to delineate the evidence for validity of Demoralization Syndrome.



Recent research suggests prevalence rates of between 8.5% and 31.7% in populations of medically ill patients. One pertinent issue for palliative medicine is the capacity of a demoralized patient to give informed consent. Having a disordered relationship to their future, the demoralized's appreciation of the significance of key clinical facts is coloured by their altered assumptive world.

A number of clinical approaches to the treatment of demoralization will be explored, including meaning-based therapies that explore the role, sense of purpose, beliefs, the value of relationships and the worth of the self. Folkman's research on the contribution of meaning-based coping to the development of resilience and positive affect states informs these therapies. All members of the multidisciplinary palliative care team need some skill in restoring or sustaining morale and fostering hope.

Grief Therapy: Current Status and Future Directions

Prof. Robert A. Neimeyer, University of Memphis

Recent controversies about the effectiveness of grief therapy arise in part from previous reviews of small samples of studies, which make inferences about the evidence base for bereavement interventions precarious at best. Drawing on a new and comprehensive analysis of over 60 controlled studies, we offer a more definitive view of the efficacy of psychosocial treatments for those who have lost loved ones, and discuss moderators associated with more effective interventions. Finally, we conclude by considering one theory-based approach that holds promise for the further refinement of evidence-based therapies for bereavement complications, one premised on the idea that grieving entails reaffirming or reconstructing a world of meaning that has been challenged by loss.



How non-cancer patients die in Hong Kong?

Dr KS LAU, Ruttonjee and TSK Hospitals
Dr Doris MW TSE, Dr Tracy WT CHEN,
Caritas Medical Centre
Dr PT LAM, United Christian Hospital
Dr WM LAM, Dr KS CHAN, Haven of Hope Hospital



Non-cancer deaths account for two-thirds of the mortality in Hong Kong. Unlike cancer which usually projects a progressive decline during the last few months of life, chronic diseases may run a more protracted course that is interrupted by acute or even life threatening exacerbations before death. The study was conducted in four hospitals with specialised palliative care service. The records of patients who died from congestive heart failure, chronic obstructive pulmonary disease and chronic renal failure. in the year 2006 were reviewed. A random sampling of 1 in 8 of cancer deaths during the same period were reviewed for comparison.

A total of 656 non-cancer patients and 183 cancer patients were analyzed. The gender distribution in both groups was similar (M:F = 3:2). In the non-cancer group, the patients were older (79.12 vs 71.05, $p < 0.001$), had more co-morbidities (2.34 vs 1.61, $p < 0.001$) and more co-existing acute events at death (0.98 vs 0.69, $p < 0.001$). Cancer patients were functionally better than non-cancer patients at 6 months and 3 months before death but rapidly decline to become more dependent than non-cancer patients at 2 weeks before death.

Health care utilization in last 6 months of life

Non-cancer patients had more admissions to acute wards with longer length of stay and more ICU admissions than cancer patients. Near 80% of cancer patients received palliative care as compared with that of 1.5% in non-cancer patients.

Last 2 weeks of life

More symptoms were documented in cancer patients than non-cancer in the last 2 weeks of life. Pain, dyspnoea, edema and fatigue were among the commonest documented symptoms in both groups. Analgesics were more prescribed in cancer patients (91.3% vs 41.0%, $p < 0.001$) and morphine was more utilized in cancer patients (65.5% vs 8.3%, $p < 0.001$).

Despite the use of morphine, most cancer patients (80.6%) remained mentally alert at 72 hours before death.

Within the last 2 weeks of life, more life-sustaining interventions were initiated (3.75 vs 2.57, $p < 0.01$) and less life sustaining interventions withdrawn (0.15 vs 0.23, $p = 0.03$) in non-cancer patients. Overall, withdrawal of intervention was uncommon in both groups.

Documentation of advance care planning (ACP) was reviewed. Items discussed were similar in both groups (cardiopulmonary resuscitation, ventilation, nasogastric tube / PEG and other diagnostic investigations) except for disease specific items such as surgery / chemotherapy / radiotherapy in cancer patients and dialysis in chronic renal failure patients. Family members were often involved (92.6% non-cancer group; 85.8% cancer group) in ACP discussion; whereas 11.5% of non-cancer patients and 40.8% of cancer patients were involved. The low rate of mental competency (21.7%) may account for the low rate of involvement in non-cancer patients in the last ACP discussion before death.

DNR order was in place in 84.5% of non-cancer patients and 95.6% of cancer patients ($p = 0.25$). More non-cancer patients received CPR at death ($p < 0.01$). More patients in the cancer group received pastoral care service as compared with non-cancer (40.8% vs 6.0%, $p < 0.01$). Documentation of the events after death was found in 70.3% of cancer deaths as compared with 32.8% of non-cancer deaths ($p < 0.01$).

Psychological Empowerment Programme for Advanced Cancer Patients and Their Families

Dr. Kitty Wu,
Clinical Psychologist,
Caritas Medical Centre.



Introduction

Diagnosis of advanced cancer threatens patients' basic assumption about resilience of self, the world and fundamental perceptions of meaning. Patients and caregivers who were distressed by patient's terminal illness may link the events of their lives according to themes of loss, failure, incompetence, or hopelessness. According to narrative approach, re-authoring and meaning making conversations could facilitate the development of alternative themes and form a foundation for new initiatives in addressing the problems of lives. These formed the background for the development of the Psychological Empowerment Programme (PEP) for patients and caregivers in the Palliative Care Unit of Caritas Medical Centre.

Aims of PEP

Based on patients' and caregivers' needs, PEP was tailor-made for individuals aiming at: i) thickening patients' and caregivers' identities and to enlarge their sense of the possibilities of life in the midst of life adversity; ii) assisting relationship building between patients and caregivers; iii) increasing caregiver's psychological strength in caring for the patient.

Elements within the programme included the use of narrative approach which consists of conversations about life stories for enriching meaning and identity of life; other treatment approaches like cognitive behavioural therapy would also be adopted based on needs identified.

Psychological Well-being Scale & Impact of Psychological Treatment

To document the psychological needs and the impact of psychological intervention for advanced cancer patients and caregivers in the programme, a standardized questionnaire: Psychological Well-being Scale (PWS) was developed. PWS consists of 5 subscales, namely: Life Meaning, Social Support, Emotional Distress, Strength for Caregiving, and Hospital Support. Factor analysis was conducted to examine the factor structure of PWS. The validity of PWS was examined by utilising Hospital Anxiety and Depression Scale and Chinese Geriatric Depression Scale – Short Form.

A preliminary study on the impact of psychological intervention for caregivers by examining the change in scores in various scales before and after psychological intervention using repeated measures design indicated that caregivers could benefit from psychological intervention with increased psychological well-being and decreased psychological distress.

Conclusions

Present findings review both encouraging outcomes and challenges for the PEP which adopts an evidence-based approach for studying the psychological needs and impact of psychological intervention for patients and caregivers in palliative care.

My Wonderful Life: A Game Based Intervention for Patients with Terminal Illness

Alicia K.L. PON, Centre on Behavioral Health.

My Wonderful Life[®] board game was developed for use in counseling session for patients with terminal illness. This game is designed to provide a lighted hearted and non threatening platform for Chinese patients to engage in meaningful reflection, sharing life stories, acknowledgment of achievements and contributions, and disclosure of final concerns and wishes. By engaging in light hearted activities such as playing a board game, it also aims to provide momentary distractions from the



stress of dealing with their illness. This presentation describes the conceptual framework behind the development of this board game and the use of this board game with specific target groups. The game proved to be an effective tool in facilitating legacy creation and a sense of closure.

Care for Family Members at Patient's Last Days of Life

Ms CHAN Lai Ngor,
Palliative Care Nurse Specialist, Haven of Hope Hospital.

Ms YEUNG Wai Fong, Ellen,
Palliative Care Nurse Specialist, Ruttonjee & Tang Shiu Kin Hospitals.

Family members who have experienced the final days of their loved ones life will remember their death for life. Health care professionals have a vital role to facilitate a dignified and peaceful death and support family members in that distressing time. Care of dying must be interdisciplinary. The objective of the workshop is equipping participants with essential attitude, knowledge and skill in caring for family members at patient's last days of life.



Upon completion of the workshop, participants will be able to describe the physical signs and symptoms as death occurs; identify patient's physical, psychological, social and spiritual needs, together with the needs of family members. Intervention for imminently dying patients and their families, ethical issues such as nutrition and hydration and debunking myths will be also discussed.

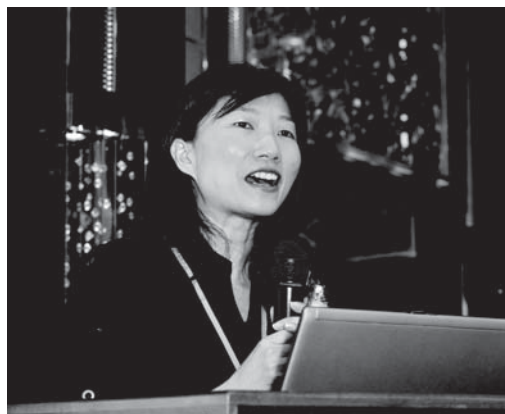
Facilitating Patients to Tell Life Stories

Cecilia Kwan, Bradbury Hospice.

The use of life stories is gaining more attention by palliative care professionals as a way to help the terminally ill patients to come to terms with their illness and death. It bears a technical term 'life review' when adopted clinically.

Life review refers to the process of organizing and evaluating the overall picture of an individual's life (Trueman & Parker, 2006). The concept of life review was formally introduced by Butler in 1963. He advocated that life review is a universal phenomenon which occurs spontaneously and naturally in people's later stage of life.

Life review was later developed into a therapy which helps clients discover their meaning of life, confront with unresolved conflicts and achieve reconciliation through the process of reintegration. It is usually performed individually, covers the entire life span and address both positive and negative experiences. There is a variety of methods for undertaking life review. They include structured life span questionnaire, oral history, autobiography, photographs, tape recording and video.



Life review has also been applied by palliative care nurses as a therapeutic tool for the terminally ill patients. A qualitative study using focus group interviews was performed earlier this year to explore experienced palliative care nurses' insights in facilitating life review with their patients. The objectives of this study are:

1. To explore the ways the palliative care nurses employed in conducting life review with terminally ill patients,
2. To identify the difficulties they encountered during the process and the elements that they considered essential or important during the process, and
3. To formulate a practical guide for conducting life review activities based on the palliative care nurses' experiences

It was found that the majority of palliative care nurses prefers a more spontaneous intervention approach to a structured life span approach in facilitating patient to tell his/her life story. They encountered difficulties in the process. Yet, from their experience valuable skills and elements are identified that guide novels in facilitating the life review with patients



FREE PAPER PRESENTATION

Let Me Talk – An Advance Care Planning Programme for Frail Nursing Home Residents

Helen YL CHAN, Samantha MC PANG,
School of Nursing,
The Hong Kong Polytechnic University.

Objective

Advance care planning (ACP) helps patients and family to better prepare for the end-of-life care. Yet, such practice seldom takes place due to its sensitive nature and thus left their concerns unattended. This study aimed to test the plausibility of engaging frail elderly in care planning.

Methods

This was a 1-year quasi-experimental study to test the Let Me Talk ACP programme in nursing home setting. It uses the storytelling approach to encourage the participants to share their views, voice their concerns and care preferences. Three assessments were conducted at six-month interval to monitor the programme impacts.

Results

Findings showed that the stability in care preference over six months was significantly higher in the intervention group ($\kappa = 0.529$, $p \leq 0.001$). There were also significantly more participants in this group communicated their end-of-life care preferences with the loved ones (35.7% vs. 11.1%, $p = 0.012$), with odd ratio at 4.52 (95% CI, 1.24 – 16.41). Throughout the programme, five approaches towards treatment-limiting decision making were identified: holding on life, weighing benefits, planning ahead, avoiding and procrastinating. In addition, the findings showed that the programme had positive effect on relieving the participants' existential distress.

Conclusion

This study demonstrated that the Let Me Talk programme was feasible in clarifying the older people's care preferences and encouraging the communication in this regard between them and family or healthcare providers. This study has also shed light on how to integrate ACP into nursing home care practice and devise appropriate strategies for individuals.

Anticipatory Grief Therapy for Elderly Facing the End of Life

Joanna O.Y. CHENG ¹, Raymond S.K. LO ²,
Faye CHAN ³, Jean WOO ¹

¹Department of Medicine and Therapeutics,
Chinese University of Hong Kong,

²Palliative Care Unit, Shatin Hospital,

³Society for the Promotion of Hospice Care.

Objective

This study aims to develop qualitative descriptions of the experience of elderly old age home (TWGH OAH) residents facing the end of life, and to evaluate the benefits of Anticipatory Grief Therapy (AGT) for this client group.

Methods

A total of 26 elderly residents who participated in AGT were recruited for this study. A range of experiential and expressive activities adapted for the elderly were used to facilitate discussions on living and dying during AGT. Focus groups were held after each session for the elderly to further elaborate their views. Qualitative comments were analyzed using Interpretative Phenomenological Analysis. The McGill Quality of Life Scale-HK version and the Geriatrics Depression Scale-14 were used to quantify AGT benefits before, after and 4 weeks following the AGT.

Results

Immediate post-AGT improvements were found in all QOL domains as well as depression; whereas physical, existential and total QOL improved further in follow-up. Preparedness towards death; quality of life determinants (independence and autonomy, social support and economic sufficiency); psychological and existential suffering; insights and coping strategies were identified during focus groups as major qualitative themes of concern to OAH elderly facing the end of life. Reflections and experiences during AGT helped identify the issues which were successfully dealt with during the sessions.

Conclusion

The present study shows that AGT is beneficial for OAH elderly on all domains of QOL and helps to alleviate depression. To the elderly, not only was AGT an enjoyable activity,

but it deepened their insight and helped them achieve closure before death, both psychologically and spiritually. AGT delivered in the OAH setting is confirmed to be acceptable, feasible and useful for elderly facing the end of life.

A Pilot study on the Quality of Life of Informal Caregivers of Advanced Cancer Patients

Margaret HP SUEN¹, Annie OL KWOK², Tracy WT CHEN¹, Louisa CHAN², Doris MW TSE¹.

¹Caritas Medical Centre

²Our Lady of Maryknoll Hospital

Aim

To assess the quality of life (QOL) of informal caregivers of advanced cancer patients

Methods

Dyads of advanced cancer patient and the caregiver were recruited from the Palliative Care Clinic of two HA hospitals from September 2007 to March 2008. Data collected from the dyads included demographics, socioeconomic variables, and perceived social support. Patients' symptoms were rated by ESAS and functional status by PPS. QOL of caregivers were assessed by MOS SF-36 with 8 domains: general health (GH), physical functioning (PF), role limitation by physical (RP), role limitation by emotion (RE), social functioning (SF), vitality (VT), bodily pain (BP) and mental health (MH).

Results

A total of 52 dyads completed the study. The median duration from cancer diagnosis to palliative care service and then to time of study was 6.5 months and 2.5 months respectively. Caregivers were younger than patients (52.2±14.0 vs 74.5±10.4yrs, p=0.018) and with more females (78.8% vs 21.2%, p<0.001). Patients had a mean PPS score of 65 (±14). Among the caregivers, 52% received primary or little education, and 60% were financially dependent. Caregivers scored significantly lower than local population in the following domains of QOL: PF, RP, RE, SF, BP, MH (all p<0.005). The QOL scores were negatively correlated with (a) PPS of patient in PF, RP, RE, VT, MH; (b) caregivers' perceived social support in GH, RP, RE, SF, BP, MH; (c) caregivers' medical needs in GH, PF, RP, RE, VT, BP, MH.

(all p<0.05). QOL scores had no correlation with duration of diagnosis or palliative care service. Patients perceived spouse as significantly more supportive than children in offering practical help (p=0.02). Handling patient's emotion was among the top three most difficult caregiving tasks in 69% of caregivers.

Conclusion

The QOL scores of our caregivers were significantly compromised than the general population. Further study is warranted to identify factors affecting the QOL of caregivers.

Continuing Bonds as a Means to Alleviate Survival Guilt in Bereaved Chinese Organ Recipients

Ivan M. H. WOO¹, Cecilia L. W. CHAN^{2,3}

¹Lien Centre for Palliative Care, Duke-NUS Graduate Medical School Singapore

²Centre on Behavioral Health, The University of Hong Kong

³Department of Social Work and Social Administration, The University of Hong Kong

Worldwide, there is an acute shortage of organs for individuals on an organ transplant waiting list. Individuals are observed to be more inclined to donate their organs if the organ recipients are their immediate family members. This paper describes the experience of a Chinese organ recipient who was stricken with survival guilt when his wife, the organ donor, died from postsurgical complications after the organ donation. It argues that utilitarianistic familism plays a key role in shaping Chinese individuals' decision to donate an organ to immediate family members. Organ donors who died after donating their organs to immediate family members often leave the organ recipients struggling with survival guilt. Continuing bonds were observed to be effective in helping Chinese individuals alleviate survival guilt. This paper also suggests that the concept of self among Chinese may account for recent studies that have found Chinese benefiting from continuing bonds more than their counterparts in the United States. However, it is believed that not all Chinese individuals would benefit from continuing bonds. Strategies for identifying bereaved Chinese organ recipients who would benefit from continuing bonds with the deceased organ donors would end this paper.

The Management of Venous Thromboembolism in Advanced Cancer Patients under Palliative Care Units in Hong Kong

HC FAN¹, KS LAU¹, PT LAM², WM LAM³, WT CHEN⁴

¹Ruttonjee Hospital, ²United Christian Hospital, ³Haven of Hope Hospital, ⁴Caritas Medical Centre.

Objective

Advanced cancer patients with venous thromboembolism (VTE) have an increased risk of bleeding and recurrent thrombosis compared to non cancer population. Risks of both thrombotic and bleeding events also increase as cancer progresses. The objective of this study is to explore how VTE was managed in advanced cancer patients in term of benefits, risks and burden of anticoagulation.

Methods

This retrospective and descriptive study was performed in four local palliative care units. Among a total of 5241 patients admitted over a period of four years from 1 July 2003 to 30 June 2007, 146 cases with diagnosis of VTE were identified and recruited.

Results

A total of 146 patients were recruited and analyzed, with 38 patients (26%) without anticoagulation and 108 patients (74%) with anticoagulation. The major factor affecting the decision of anticoagulation was the presence of contraindication to anticoagulation. Among 108 patients on anticoagulants, 27 patients (25%) received low molecular weight heparin (LMWH) and 81 patients (75%) received warfarin. Eight patients (30%) on LMWH and 39 patients (48%) on warfarin had major bleeding. Only 27% of international normalized ratios (INR) were within therapeutic range. Major bleeding was associated with prolonged INR (INR > 3.0) in 22 patients receiving warfarin.

Conclusion

Anticoagulated cancer patients had higher risk of bleeding. With warfarin, maintaining INR within therapeutic range was difficult and resulted in more unnecessary interventions. LMWH may be the preferred drug in treatment of VTE in advanced cancer patients.

Association between Quality of Life and Patients' Characteristics and Symptoms in a Palliative Care Unit

Dr Jeffrey SC NG,
Haven of Hope Hospital.

Objective

To study the association between quality of life (QOL) and socio-demographic / clinical status and symptoms in advanced cancer patients receiving palliative care.

Methods

Patients receiving specialist palliative care service in Haven of Hope Hospital were approached between October 2007 and March 2008. Individual QOL was assessed using a terminal-illness specific, locally derived and validated instrument, covering physical, psychological, social and spiritual dimensions. Symptoms were assessed with Edmonton Symptom Assessment System (ESAS).

Results

Totally 125 patients were recruited. Female patients gave poorer scores in total QOL, food-related concerns, negative emotions and sense of alienation ($p=0.001$). Younger age and having dependent children were both associated with worse negative emotions and sense of alienation ($p<0.05$). Patients without religious belief and those with history of chemotherapy or surgery were also associated with poorer QOL. No association between QOL and marital status, employment state, educational level and primary/metastatic tumour sites was found. Total QOL scores were strongly correlated with fatigue, poor appetite and depression ($r_s > 0.5$, $p < 0.001$) and moderately with pain, drowsiness and anxiety scores ($r_s > 0.3$, $p < 0.001$). Moderate correlation was found between symptom scores in fatigue and depression and QOL scores in sense of alienation and existential distress ($r_s > 0.3$, $p < 0.001$).

Conclusion

Younger age, female gender, having dependent children, no religion, and history of surgery or chemotherapy were associated with poorer subjective well-being. Various physical and psychological symptoms warrant early intervention in order to ameliorate their negative impacts in quality of life.

Grantham Hospital Specialist Outreach Palliative Care Service to TWGHs Jockey Club Rehabilitation Complex in Hong Kong - Reasons of Referral in the First 7 Months

Dr K K LAM, Dr. Michael SHAM,
Palliative Medical Unit, Grantham Hospital.

Objective

This paper reports and discusses the reasons of referral to the Grantham Hospital visiting palliative care service provided to TWGHs Jockey Club Rehabilitation Complex within a 7-month period from 1st December 2007 to 31st June 2008.

Methods

The reasons for referral to the visiting palliative care service were noted. The staff of the Rehabilitation Complex was interviewed for further clarification of the details of the reasons for referral. Demographic data of the referred residents was collected. The reasons of referral were recorded, analyzed and discussed.

Results

A total of 34 referrals were made during the period. There were 12 male (35%) and 22 female (65%). 6 subjects aged 60 years and under (18%) and 28 subjects aged over 60 (82%). Eleven subjects had a diagnosis of malignancy (32%). The reasons for referral were classified into 2 categories. Residents were referred either for a poor prognosis, as indicated by significant weight loss and/or functional decline; and/or for common palliative care needs. Each subject might have one or more palliative care needs. The most common palliative care needs were pain/symptom control (33 subjects) and emotional distress of residents and/or their families (23 subjects).

Conclusion

Though there is no consensus on when and why patients should be referred to a palliative care service, especially for those with non-malignant disease, there is concordance in the reasons of referral to our visiting specialist palliative care service from the rehabilitation complex with the recommendations from the Prognostic Indicator Guidance (Gold Standards Framework, 2006) and other relevant literatures.

Clinical Audit on Management of Venous Thromboembolism (VTE) and Use of Anticoagulants in Cancer Patients

Dr. NY YEUNG, Dr. KC LEUNG, Dr. Alex LEUNG, Dr. KH WONG,
Department of Clinical Oncology,
Queen Elizabeth Hospital.

Objective

To audit on diagnosis, immediate treatment and prolonged treatment of venous thromboembolism (VTE) of cancer patients in our department.

Methods

The cancer patients who were admitted to the oncology wards of our unit during the period from September 2007 to January 2008 and who received anticoagulation for treatment of VTE were recruited.

Results

Fourteen patients were treated for VTE. Their median age was 55 years. Concerning the immediate treatment of VTE, low molecular weight heparin (LMWH) was used in all patients and the median time of starting anticoagulants was 1 day after diagnosis of VTE. As for the prolonged treatment of VTE, 78.6% of patients used LMWH while 21.4% of patients used warfarin. The most common consideration for using LMWH as prolonged treatment was concomitant chemotherapy (45.5% of all considerations). When oral warfarin was given for definite prolonged treatment, two patients had discontinuation of enoxaparin when INR was <1.0 instead of ≥ 2.0 . Among all patients, 67% of patients had regular monitoring of INR while on warfarin. Concerning the outcome at the time of audit, 76.4% of patients died and 23.5% of patients were alive. None of these patients had recurrence of VTE. Major bleeding occurred in 14.3% of patients.

Conclusion

The overall compliance rate on the management of VTE was satisfactory. Recurrence rate of VTE using warfarin and LMWH was lower than the literature but the rate of major bleeding using LMWH was higher.

Study of humour therapy and its effectiveness as an anxiety relieve intervention in patient with gynecological cancer

CHAN Sau Man¹, CHIU Siu Ying¹, CHEUNG King Yee¹, CHAN Mun Yee Lina¹, CHAN Terry²

¹Queen Mary Hospital

²Regeneration Society

Objective

1. To make a comparison in anxiety level before and after humorthrapy in local chinese patients with gynecological cancer
2. To explore the preception of Hong Kong Chinese gynecological cancer patients on humorthrapy

Methods

A convenient sample of local Chinese female adult patients receiving care in QMH gynecological ward participated in this pilot study. Patients were recruited if they had been

diagnosed with gynecological cancer (any stage and tumor type) and were receiving some type of treatment (chemotherapy, radiation therapy, or operation) or medical consultation. Patients with psychiatric illness were excluded.

All recruited patients were invited to watch a comedy video which lasted for 30 minutes. A simplified Chinese version of the Spielberger State Trait anxiety inventory (STAI) was used to measure anxiety level before and after the video. Another questionnaire was used to ask about patient's perception of the video as well as humor therapy.

Results

A total of 27 patients completed the study. Patients had a significantly lower level of state anxiety than before viewed comedy 30 minutes video, the effective size of our study was large ($t=2.134$, $N=27$, $Eta\ squared=0.149$).

As for the perception of humour therapy, 20 patients (74%) with high scores (15 or above) in their perception questionnaire had significant correlation with change in post anxiety feelings ($r=-0.570$, $P=0.002$).

Congratulations to Winners of the Young Investigator Award !



Ms. Helen YL CHAN from the Hong Kong Polytechnic University who presented her paper titled 'Let Me Talk – An Advance Care Planning Programme for Frail Nursing Home Residents'

Dr. Hon Cheung FAN from Ruttonjee Hospital who presented his paper titled 'The Management of Venous Thrombo- embolism in Advanced Cancer Patients under Palliative Care Units in Hong Kong



Insomnia in Palliative care

Dr. M H Khemlani,
Palliative Care Unit, Caritas Medical Centre.
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Introduction

Sleep is a basic human need. Over the last few decades, there has been a significant growth in our knowledge and understanding about sleep. Sleep problems are common in patients with chronic illnesses such as cancer. Clinicians and patients tend to consider poor sleep as inevitable in the context of a chronic or advanced illness. Furthermore, many patients fail to alert their physicians of their problem because their concerns may have never been addressed or previously dismissed as being an inevitable part of a terminal illness. Not surprisingly the sleep problems of these patients go unrecognized or untreated.

The following covers a brief review on normal sleep and sleep regulation, discusses factors that lead to insomnia, presents the approach to a palliative care patient with insomnia, and concludes with a discussion on some of the interventions to promote sleep. The aim is to help the reader gain a broader understanding of this common palliative care problem.

Case Presentation

The following case histories reflect commonly encountered patients in a palliative care setting.

Case 1

Mr. Chan, a 64 year old gentleman, suffering from cancer of the sigmoid colon with liver metastases, was receiving palliative care as an in-patient. He suffered from persistent right upper quadrant pain, which was suboptimally controlled despite regular doses of morphine. He also complained of poor sleep during the course of his hospitalization. He had no difficulties initiating sleep but suffered from fragmented sleep, which left him feeling unrefreshed in the mornings. As an in-patient, he remained relatively inactive and frequently napped during the day. The usual hospital environment and routines were also contributing

to his poor sleep at night. His regular dose of morphine was escalated to improve pain control, and the hospital routines were reduced to a minimum. He was encouraged to remain active during the day. From the case history, it becomes clear that several mediating factors contributed to his sleep disturbance, correction of which, helped improve his sleep.

Case 2

Mrs. Lam, a 53 year old lady, suffering from cancer of the lung with intrapulmonary and lymph node metastases was referred to our Palliative care unit as an out-patient. She remained relatively well except feeling unrefreshed in the mornings despite having spent hours in bed at night. A detailed history showed that the culprit was Dexamethasone 4mg BD. Her previous history, as to why she was on steroids, was unclear. The steroids were gradually tailed down and then stopped, which helped improve her sleep.

Sleep and its mechanisms: an introduction

Sleep is no luxury, but an essential human need. Sleep is important for immune, endocrine and metabolic functions. Qualitatively or quantitatively deficient sleep affects health and well-being¹.

Sleep follows a circadian rhythm, regulated by environmental and biohumoral factors². Melatonin, produced from pineal gland, is produced in the night and involved in the sleep-wake cycle. Sleep consists of rapid-eye-movement (REM) and non-rapid-eye-movement (NREM) states. The REM state has been depicted as a "highly activated brain in a paralyzed body", consisting of dreams, EEG activity, muscle atonia and autonomic variabilities. The NREM state has been depicted as a "relatively inactive brain in a movable body", where EEG activity slows, and voluntary muscle control and tone remain intact. Each cycle, including both REM and NREM stages, lasts about 90 minutes and there are about 4 to 6 such cycles for 7 to 8 hours of sleep¹.

Insomnia - definition

Insomnia represents a subjective complaint of poor sleep³. It encompasses both quantitative and qualitative sleep problems including those of insufficient sleep hours, fragmented sleep, prolonged sleep latency, non-restorative sleep and sleep during the wrong time of the circadian rhythm.

Insomnia is a symptom and not a diagnosis, and warrants a detailed history. Insomnia means different things to different patients. As there is no gold standard definition of normal sleep, insomnia becomes difficult to define and measure. In clinical practice, it is the patients' subjective complaint of impaired sleep quality and/or quantity which is the most important.

Prevalence of insomnia in cancer

Sleep disturbances are common in cancer patients. Estimated prevalence of sleep disturbances in cancer patients vary widely ranging from 24% to 95%.⁴ Prevalence estimates vary significantly because of differences in the adopted definition, the measurement tool used and the specified time frame in which it was measured.

According to a cross-sectional study by Davidson et al⁵ involving a heterogenous group of 982 cancer patients, the estimated prevalence of insomnia in the previous 4 weeks was 31%. The estimated prevalence of insomnia in another cross-sectional study by Hugel et al⁶ conducted on 74 patients receiving palliative care was 70%.

Factors contributing to disturbed sleep

Disturbed sleep is usually the result of multiple factors, some reversible and others not. Some physical, psychological and lifestyle factors precipitate sleep disturbances.

1. Physical factors

Uncontrolled physical symptoms such as pain, nausea/vomiting, dyspnea, urinary frequency are amongst the many physical symptoms that can contribute to disturbed sleep. Helping patients alleviate their physical symptoms can improve sleep quality. In a cross-sectional study by Hugel et al including 74 in-patient palliative care patients, 60% of patients with insomnia attributed uncontrolled physical symptoms to their sleep disturbance⁶.

2. Psychological factors

Symptoms such as anxiety and depression can affect sleep quality, but can also be the result of poor sleep. It is important to obtain a detailed history to assess for such psychological symptoms. In a descriptive study involving 123 advanced cancer in-patients at a Palliative care unit, using a questionnaire and nonstructured interview, Mercadante et al concluded that patients who reportedly felt anxious and depressed had less restoring sleep and more nightmares⁴.

3. Behavioral factors¹

Many hospitalized patients tend to remain relatively inactive during the day or take frequent day-time naps which disturbs the sleep-wake cycle.

4. Cognitive factors

In the cross-sectional study by Davidson et al⁵ on a heterogenous group of cancer out-patients, the authors reported that 52% patients felt that their thoughts contributed to poor sleep. Concerns about their personal health, and concerns about their families or friends also contributed to sleep disturbances.

5. Drugs

Many concomitant drugs that patients are taking have arousing properties that interfere with sleep and those used commonly in palliative care include steroids and psychostimulants¹. Davidson et al reported that cancer treatment in the previous 6 months including surgery, chemotherapy or radiation therapy contributed to sleep disturbances⁵.

6. Emotional factors⁷

Going to bed with negative emotions such as fear and anger can impair sleep. Psychiatric problems e.g. anxiety and depression can present as sleep problems.

7. Environmental factors

A typical acute hospital environment creates further disturbances to patients' sleep-wake cycle. The noise from beeping machines and lights, some drug treatment schedules such as 4-hourly medications, and hospital routines such as blood pressure taking, also contribute in affecting the patients' quality and quantity of sleep.

Onset of the problem

In the paper by Hugel et al⁶, 75% of patients suffering from insomnia developed the problem after their diagnosis of cancer. In a separate study⁵ involving cancer patients, 48% of those patients reported to be suffering from insomnia reported that their symptom onset occurred around the time of their cancer diagnosis (6 months pre-diagnosis to 18 months post-diagnosis). Some cases of insomnia have existed way before the cancer diagnosis; further emphasizing the importance of a detailed history.

Impact of insomnia

Insomnia can impact patients significantly in the physical, psychological, cognitive and social realms. In the cross-sectional study by Davidson et al⁵ involving 982 cancer patients, 31% had insomnia. Among patients with insomnia, 89% of them felt that their sleep disturbance affected how they felt physically; 76.3% indicated that the sleep trouble affected their ability to cope with stress; 72.3% indicated that it affected their emotions; 65% felt it affected their ability to carry out usual activities; and 64.7% felt that it affected their ability to concentrate.

The sleep of family members, especially those who are caregivers for the chronically and terminally ill, is also at risk for being disrupted or inadequate due to either the patients' sleep problems or the burdens of care-giving^{8,9}.

Tools to aid assessment

There are various tools, some which offer an objective assessment, and others subjective¹.

In objective assessment, the polysomnography is the gold standard tool for sleep assessment as recommended by the American Sleep Disorders Association (ASDA)¹. It is inclusive of an electroencephalography, electrocardiography, and electromyography assessment. It can be conducted either in the hospital or in a home-setting. However, polysomnographic testing can prove burdensome on patients receiving palliative care.

Subjective assessment tools include sleep quality questionnaires (e.g. Pittsburg Sleep Quality Index PSQI), use of sleep diaries (e.g. National Sleep Foundation Sleep Diary NSFSD;

Pittsburg Sleep Diary PSD) and daytime sleepiness inventories (e.g. Epworth Sleepiness Scale ESS)¹.

Approach to insomnia in palliative care

There is a growing body of evidence showing the impact of sleep disturbances on patients. It is important that we as members of the palliative care team regularly assess for disturbances in quality or quantity of sleep. Although various objective and subjective measures of sleep are available, an initial assessment relies on subjective information, first-hand, from our patients.

Some important points that need to be covered in a thorough history include:

1. What does the patient specifically mean by poor sleep?
2. Evaluate 24 hour sleep-wake cycle
3. Look for reversible causes/mediating factors that contribute to sleep disturbances
4. Detailed drug history
5. Consumption of caffeine/alcohol
6. Previous treatment tried for insomnia, including those which have been used with success, and those failed therapies
7. Impact of insomnia on patient/caregiver

Management of insomnia

1. Explore the impact of the problem and patients' expectations

The first step in management of insomnia is to explore its effects on the patient. As with the management of any other symptom in palliative care, it is important to explore the patients' expectation and realign them closer to reality if necessary. The ultimate aim is to allow for enough restorative sleep. What is enough for one patient may not be for another. So it is important to individualize management as per patients' requirements.

2. Reverse the reversible factors contributing to disturbed sleep where possible

The causes of sleep disturbances are often multifactorial. A detailed history helps evaluate the contributing factors. It is important to reverse these as far as possible before considering other interventions to improve sleep.

3. Interventions to improve sleep

Because sleep disturbances often result from a combination of factors, no single intervention is likely to be effective universally. Often a combination of pharmacological and non-pharmacological interventions is warranted. Non-pharmacological options include emphasis on sleep hygiene and behavioral interventions. Various pharmacological options are available - some as prescription drugs; whereas others can be purchased over the counter.

Sleep Hygiene

Sleep promoting behaviors can be reinforced in all patients. Though simple and easily followed, these day-to-day measures have not been tested for efficacy in managing insomnia. The following 10 tips have been recommended by the American Sleep Association (ASA)¹⁰:

1. Maintain a regular sleep routine
2. Avoid naps if possible
3. Do not stay in bed awake for more than 5-10 minutes
4. Do not drink caffeine inappropriately
5. Do not watch TV or read in bed
6. Avoid substance that interferes with sleep
7. Exercise regularly
8. Have a quiet, comfortable bedroom
9. If you are a "clock watcher" at night, hide the clock
10. Have a comfortable pre-bedtime routine

Behavioral interventions

Different interventions have different levels of evidence. Common types studied in cancer patients include hypnosis, imagery training, muscle relaxation, stimulus control and multimodal interventions¹¹. These various interventions have resulted in subjective and/or objective improvement in sleep.

Pharmacological interventions^{1,12,13}

When non-pharmacological interventions alone do not resolve sleep problems, the addition of medications are usually warranted. Drugs commonly used in the management of sleep disturbances include the benzodiazepine group of drugs (BDZ), benzodiazepine-like drugs, sedating antidepressants, sedating antihistamines and melatonin. In our local setting, herbal mixtures with hypnotic properties are also available over the counter e.g. Suanzaorentang 酸棗仁湯¹⁵.

1. Benzodiazepine and Benzodiazepine-like group

The BDZs produce exert their effect by binding to the gamma-aminobutyric acid (GABA)-benzodiazepine receptor complex without displacing GABA. The drug binds to its specific attachment site and improves GABA's attraction to its own receptor site on the GABA-benzodiazepine receptor complex. Other than for their sedative effects, this group of drugs is commonly used in palliative care for their anti-convulsant properties. They improve sleep by decreasing sleep latency, reducing awakenings, increasing total sleep and imparting a sense of refreshing sleep.

Because longer term studies assessing the adverse effects of prolonged use of such drugs are lacking, the BDZs are recommended only for short term use, ideally for a period of less than 4 weeks.

The UK Committee on the Safety of Medicines (UK-CSM) has put forth recommendations for the use of BDZ group of drugs in insomnia¹⁵. These include the use of these drugs only when insomnia is causing considerable distress. The lowest dose being recommended for the shortest duration possible (i.e. less than 4 weeks), after which the dose must be tapered gradually and stopped. There is a risk of tolerances, physical dependence and psychological dependence developing with prolonged use. Patients also need to be monitored for side effects. However, limiting the use of these drugs to a period of less than 4 weeks in a palliative care setting has raised some concerns. Because the life expectancy of palliative care patients is usually short, the time restriction (i.e. use of BDZ for less than 4 weeks) is sometimes ignored and BDZs are used for longer durations. However, this practice is controversial.

Intermediate acting BDZs are preferred. Longer acting drugs with active metabolites especially in the elderly or those with altered liver function can pose significant problems, where the sedative effects are especially prolonged causing excessive drowsiness or dizziness the following day. Short acting drugs with inactive metabolites can also pose problems because the sedative effects are time limited, resulting in insufficient rest or sleep.

Adverse effects include nausea and vomiting, cognitive changes (including decreased attention span, impaired concentration and memory retrieval) and impaired psychomotor functioning such as impaired coordination and balance.

BDZs need to be used cautiously especially when combined with opioids in palliative care, with a risk of increased drowsiness and confusion. One needs to be cautious when using such drugs in the elderly because of paradoxical agitation, risk of falls and cognitive impairment.

The BDZ-like group of drugs includes Zopiclone, Zolpidem and Zaleplon. These selectively bind to type 1 benzodiazepine receptors in the CNS. Unlike the BDZ group of drugs, BDZ-like drugs do not have anxiolytic nor anticonvulsant properties. They are better tolerated and safer for use in the elderly. They improve insomnia by diminishing sleep latency (Zolpidem, Zopiclone and Zaleplon) and reducing nocturnal awakenings (Zopiclone).

A meta-analysis conducted by Nowell et al¹⁶ including 22 randomized placebo-controlled trials with a total of 1894 patients with chronic primary insomnia concluded that the use of Benzodiazepine group of medications or Zolpidem was significantly more effective than placebo in reducing sleep latency, reducing the number of awakenings, increasing total sleep time and improving sleep quality. On the contrary, research on the use of these drugs in cancer or palliative care patients, is lacking. As such, a review by the Cochrane¹⁷ collaboration concluded that there was no evidence from randomized controlled trials to help draw any conclusions regarding the use of benzodiazepines in palliative care.

2. Sedating Antidepressants

Some examples of sedating antidepressants include Amitriptyline, Mianserin and Doxepin. This group of medications is a useful option for depressed patients with insomnia. The hypnotic dose used is lower than the recommended dose to manage depression. The Selective Serotonin Receptor Inhibitor (SSRI) group of antidepressants (e.g. Fluoxetine, Sertraline) is more stimulating and is likely to cause insomnia if taken close to bedtime. Because there is little evidence to establish the efficacy and safety of

these drugs in nondepressed insomniacs, this group of medications is not recommended as the first line treatment for insomnia.

3. Sedating Antihistamines

Examples of antihistamines producing drowsiness include Chlorpheniramine and Diphenhydramine. Similar to the previous group, efficacy and safety of antihistamines for use as hypnotics has not been well established. Because of the absence of well-established evidence supporting their use in insomnia and the possible adverse effects such as psychomotor and cognitive impairment, antihistamines are not recommended for management of insomnia.

4. Melatonin

A naturally occurring hormone produced by the pineal gland at night, melatonin is widely available in over the counter preparations. A local study¹⁴ on over the counter sleeping pills reported that melatonin was found in 5 out of 17 preparations. There is conflicting evidence supporting its use as a hypnotic. However, there are concerns on possible contaminants in the melatonin manufacturing process causing hypersensitivity reactions. Up to date, there are no large scale controlled trials that provide data on long term safety and efficacy to support the use of Melatonin for the symptomatic management of insomnia in palliative care patients.

5. Herbal mixtures

One of the most commonly available over-the-counter sleeping pills in a local survey¹⁴ was the Chinese herbal mixture Suanzaorentang 酸棗仁湯. A study by Chen et al¹⁸ reported that this herbal mixture helped improve sleep quality in comparison to patients receiving placebo.

Summary

Insomnia is a symptom, and not a diagnosis per-se. Poor sleep means different things to different people. Numerous mediating factors contribute to disturbed sleep, which need to be reversed where feasible. If these fail, pharmacological and non-pharmacological measures should be initiated early to reduce the impact of poor sleep on both patients and their caregivers.

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Two Patients with Hypoglycaemia

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Recurrent hypoglycemia is not uncommon in palliative care patients. Ideally, treatment should be targeted at the underlying causes. In palliative care setting, some of the underlying causes may not be reversible and thus hypoglycaemia is treated symptomatically. Treatment can be given via intravenous or oral route. As long term dextrose infusion has the disadvantages of being more invasive and inconvenient for patient, per oral treatment may be a better option. The following cases illustrate two causes of recurrent hypoglycaemia in advanced cancer and their treatment.

Case history 1

Madam X was a 90-year-old, old age home (OAH) resident and was partially dependent in her daily activities. She had history of recurrent hypoglycaemia and suspected to have insulinoma around 15 years ago. She was advised to have more frequent carbohydrate intake at that time. Investigations performed in April 2006 showed an insulin level of 28 H and C-peptide of 1.86 H.

She was admitted to Queen Mary Hospital (QMH) in Dec 2006 for increased frequency of hypoglycemic attacks in OAH, manifested as agitation and irrelevant speech. Her random blood glucose on admission was 1.4mmol/l.

Despite dextrose infusion, she continued to have frequent hypoglycemia, ranging from 1.8-2.8mmol/l. Diazoxide was given orally and titrated against clinical response. The dosage was stepped up to 100mg tid and her condition improved. Her agitation and confusion subsided and blood sugar was maintained in the range of 9-15mmol/l.

Case history 2

A 79-year-old woman was diagnosed to have metastatic carcinoma of rectum in May 2007. There was multiple lung and liver metastasis with gross hepatomegaly. She was admitted to QMH for drowsiness and bleeding per rectal. The patient declined chemotherapy and radiotherapy. She developed recurrent hypoglycaemia requiring constant dextrose infusion. She was later transferred to our unit for pain control. As her hypoglycaemia persisted (lowest blood sugar at 1.2mmol/l), finding intravenous (IV) access became difficult with prolonged dextrose infusion. As non-islet cell tumour hypoglycaemia (NICTH) was suspected clinically, dexamethasone 4mg was given orally. Subsequently, there was no recurrence of hypoglycaemia and no further intravenous dextrose solution was needed. She died peacefully eventually.

Insulinoma

Existence of hyperinsulinism was first suggested by the occurrence of episodes of severe hypoglycaemia in a patient with malignant pancreatic islet-cell tumour in 1927. The first cure of hyperinsulinism by removal of insulinoma was reported in 1929. The hypoglycaemia caused by insulinoma is primarily due to reduced hepatic glucose output rather than increased glucose utilization.

The mechanism by which insulinoma maintain high levels of insulin secretion in the presence of hypoglycaemia is unknown. However, one study reported that a variant of insulin mRNA with increased translation efficiency is present in high amounts in insulinoma when compared to normal islets. The incidence was 0.4 per 100,000 person-years (or 4 cases per million per year) in one series.¹

The neuroglycopenic symptoms of insulinoma included confusion, visual change, and unusual behaviour. The sympathoadrenal symptoms included palpitations, diaphoresis, and tremulousness. Amnesia was common. The median duration of symptoms before diagnosis was less than 1.5 years in the Mayo Clinic series. However, a few patients had probably been symptomatic for decades.

Insulinoma can be single or multiple, and benign or malignant. Insulinomas have been reported in pregnant women, in patients with type II diabetes mellitus and those with renal failure. The diagnosis of insulinoma in a patient with fasting hypoglycaemia is established by demonstrating inappropriately high serum insulin concentrations during a spontaneous or induced episode of hypoglycaemia, e.g. 72-hour fast or in the case of the patient with solely postprandial symptoms, the mixed meal test. Imaging techniques are then used to localize the tumour.

Surgical treatment

Surgical removal of the insulinoma is the treatment of choice. Recurrences were found to be more common in the patients with MEN 1; the cumulative 10- and 20-year recurrence rates were 21 percent at both times compared to 5 and 7 percent in those without MEN 1 ($p < 0.001$). Survival was significantly worse in the patients with malignant insulinomas and in older patients.¹

Medical therapy

In controlling symptomatic hypoglycaemia, medical therapy should be considered when surgery is not feasible or not contemplated. The therapeutic choices to prevent symptomatic hypoglycaemia include:

1. *Diazoxide* diminishes insulin secretion and is given in divided doses of up to 1200 mg/day for controlling hypoglycemia.² However, it can cause marked oedema (which may require high doses of loop diuretics) and hirsutism.
2. *Octreotide*, an analogue of somatostatin (growth hormone-inhibitory hormone), inhibits GH secretion, but in large doses, it also inhibits the secretion of TSH, insulin, and glucagons.³ While octreotide is highly effective in controlling the symptoms associated with glucagonomas, VIPomas, and carcinoid tumours, efficacy is less predictable for symptomatic patients with insulinoma. Nevertheless, it is a reasonable choice for patients with persistent hypoglycaemia that is refractory to diazoxide.
3. *Lanreotide*⁴ is another somatostatin analogue which appears to have similar clinical efficacy as octreotide.
4. Others: Verapamil and phenytoin have also been used with some success.

Non-islet cell tumour hypoglycaemia (NICTH)

Non-islet-cell tumour-induced hypoglycemia (NICTH) is a syndrome which is attributable to the production of insulin-like growth factor II (IGF-II) by the tumour⁵ although in these patients the levels of circulating IGF-II are usually in the normal range. This syndrome has attracted more attention in recent years, with better elucidation of the underlying pathophysiology and increasing identification by application of appropriate tests⁶.

Diagnosis is characterized by the clinical picture of constant or frequent hypoglycaemia; findings of suppressed serum insulin, C peptide and growth hormone (GH); low serum insulin-like growth factor-I (IGF-I); but apparently normal, or even elevated, serum levels of immunoreactive IGF-II.⁷

Various tumours have been associated with this syndrome⁸. (Table 1)

Table 1: Non-islet cell neoplasms associated with hypoglycaemia

Mesenchymal
□ Mesothelioma
□ Fibrosarcoma
□ Rhabdomyosarcoma
□ Leiomyosarcoma
□ Haemangiopericytoma
Carcinoma
□ Hepatic: hepatoma, biliary carcinoma
□ Adrenocortical carcinoma
□ Hypernephroma, Wilms' tumour, prostate
□ Reproductive: cervical or breast carcinoma
Neurologic / Neuroendocrine
□ Pheochromocytoma
□ Carcinoid
□ Neurofibroma
Haematological

In one series of 68 consecutive tumours investigated, histological classification showed 31 carcinomas and 23 sarcomas of tissues mainly in the thorax or retroperitoneal space. Another 14 tumours included hepatomas, carcinoid tumours and 10 tumours were of unknown type. In cases subjected to detailed examination, over-expression of the IGF-II gene has been reported. The serum contained an abnormal (big) form of IGF-II which was incompletely sequestered in high molecular weight IGF binding protein (IGFBP) complexes and therefore capable of exerting potent insulin-like activity resulting in severe hypoglycaemia.⁹

Identification of NICTH in palliative care patients should not be difficult. When a patient with known tumour burden develops hypoglycaemia, a search for other causes of hypoglycaemia is generally unwarranted and fruitless, especially if the tumour type is known to be associated with hypoglycaemia.

Treatment

1. *Glucocorticoid* is the most effective group of drugs in symptomatic relief of NICTH when surgery is not an option. The glucocorticoid can be given as prednisolone 20-60mg/day or as dexamethasone 4mg/day.¹⁰ There is variable efficacy, which is also dose dependent and reversible. Moderate to high doses of steroids may cause shrinkage of the tumour and suppression of IGF-mediated tissue growth

2. *Glucagon* has been shown to be effective for the treatment of patients with hypoglycaemia due to tumor overproduction of IGF-II.¹¹
3. *Growth hormone, intrahepatic adriamycin and percutaneous ethanol injection* were shown to have beneficial effects in hepatoma with hypoglycaemia and overproduction of IGF-II (E-21).^{12,13}

Summary

Recurrent hypoglycemia is not uncommon in palliative care. Treatment should be directed to underlying cause whenever possible. Long term dextrose infusion may not be appropriate or feasible.

Medical treatment for insulinoma includes diazoxide and octreotide. Palliative treatment of NICTH include use of counter-regulatory hormones such as glucocorticoid and glucagon. For hepatoma, growth hormone, intrahepatic adriamycin and percutaneous ethanol injection may be treatment options.

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Challenges in Palliative Care of Neurodegenerative Patients

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Introduction

Although palliative care needs of non-cancer patients are recognized, palliative care provision to these patients is still limited in Hong Kong. In this article, we shall focus our discussion on two patients with neurodegenerative diseases whom we cared for in Bradbury Hospice. These two cases demonstrate the challenges in the care process from the perspectives of health care workers and family caregivers.

Case history one

Mr X was a 52-year-old gentleman suffering from Machado-Joseph Disease since the age of 33 (1987). He presented with unsteady gait and the diagnosis was confirmed by genetic study. Mr X was married and had one teenage daughter. Mr. X's father and younger sister also suffered from Machado-Joseph Disease.

Machado-Joseph disease (MJD) is a rare type of hereditary ataxia characterized by clumsiness and weakness of limbs, spasticity, a staggering lurching gait, difficulty in speech and swallowing, involuntary eye movement, double vision and frequent urination. The life expectancy of affected patient ranges from mid-thirties in severe forms of MJD to a normal life expectancy in mild forms. Aspiration pneumonia is often the cause of premature death in MJD.-

Mr X had progressive deterioration and became chair bound since 2003. In 2004, he developed coughing and choking with meals. He also had progressive weight loss, double vision, urinary retention and terminal dribbling. In 2005, he was referred to Bradbury Hospice for palliative care.

Mr. X was admitted to Bradbury Hospice in August 2007 for dysphagia, choking on feeding and persistent fever. Physical examination showed cerebellar signs and decreased air entry over right chest. Chest X-ray showed a large shadow over right lung with well-defined border and a suspected fluid level within the shadow. Mr. X was treated as aspiration pneumonia.

However, he did not respond to antibiotic treatment initially and he underwent a protracted clinical course requiring chest drain insertion for draining of loculated pleural effusion. Mr. X was referred to speech therapist and tube feeding was suggested. The feeding tube had caused him much discomfort and he was further agitated by his inability to express his views and emotions effectively. The occupational therapist assisted Mr X in using pictures for better communication.

Eventually Mr X recovered from the acute infection. He requested oral feeding but was advised against by the team. He became emotionally labile and eventually he was resumed on oral feeding after long discussions with him and his family. Mr. X tolerated oral food well and continued to improve. The feeding tube was removed before he went home.

Challenges facing the palliative care team

In caring for Mr X, our palliative care team had to overcome barriers in communication and to work with the uncertainty of the clinical course and prognosis. The clinical course of Mr. X lasted for more than 15 years, and disease progression could be less predictable than that of cancer. Defining the end of life stage could be difficult. As in Mr X, his acute infection was initially thought to be a terminal event, but he recovered with some functional improvement. Without effective communication with Mr X, it would not be possible to elicit his concerns and arrived at the decision of resuming oral feeding.

In a questionnaire survey of 220 specialist palliative care units in the UK and Ireland¹, it was found that many hospices were involved only in the terminal stage of neurodegenerative diseases. It has been recommended that early stages involvement can be advantageous in easier communication with patient and for a clearer understanding of the patient's views on their care². Moreover, involvement of the wider multidisciplinary team varied from hospice to hospice. For example, lack of access to speech and language therapist could impair service to patients with speech and swallowing problems.

For symptom palliation in neurodegenerative diseases, one should be aware of the possible differences in symptom profile as compared with cancer. In a systematic review of symptom prevalence among patients suffering from neurodegenerative diseases³, it was found that these patients suffered from more neurological symptoms than cancer. Problems with communication, symptoms of weakness, spasms, bowel and bladder dysfunction and swallowing problems were more prevalent. Palliative care providers have to acquire knowledge and skills in neurological symptom control. It is suggested that there is greater need for the involvement and integration of neurological and rehabilitation in the development of palliative care service.

Case history 2

Ms C was a 29 year-old lady diagnosed to suffer from sporadic Type II neurofibromatosis in 2000. MRI of her brain and spine showed bilateral acoustic neuroma and spinal tumors at multiple cervical levels with spinal cord compression. She had multiple operations done in her spine from 2000 to 2006. However, Ms C continued to develop multiple neurofibromata. She was on long term foley and her right lower limb was paralysed since 2006. She became deaf and then tetraplegic in 2008, and was then referred to Bradbury Hospice.

Ms C was admitted to Bradbury Hospice in April 2008 for symptom control and respite care. She had increased left upper limb weakness and became totally dependent. She had pain over multiple sites and frequent re-positioning only gave modest relief. Her sleep was disturbed and her elderly parents were exhausted.

After admission, pain was controlled with methadone and NSAID. Frequent turning was performed by nurses. Physiotherapist performed limb stretching exercise and occupational therapist modified a wheelchair to suit her needs. Medical social worker attended to the needs of her parents. Finally Ms C was discharged with home care support.

Challenges facing the family caregivers

Patient's mother expressed worries about looking after her daughter in the future. She did not know what to expect and worried about what

would happen to her. She did not know how long her daughter would live. She reflected on the many surgeries she had had and in the end it was useless. Her own health had suffered; she had aches and pains and difficulty sleeping. Now they had financial difficulties.

In a qualitative study on the responses of family carers of patients with muscular dystrophy and motor neuron diseases⁴, three key themes had emerged: including reactions and responses, health care system crossing points and reaching forward. Reactions and responses of family members included grieving everyday, fearing each crisis may mean the end and watching life in reverse. As for health care crossing points, family caregivers felt getting lost in the system and had to live with limits. Lastly, theme of reaching forward included sub-themes of holding on the big picture, needing help to plan the future and just getting on with it.

Results from another qualitative study also echoed with these findings⁵. In addition, family caregivers did not always seek help in particular with regard to their emotional needs.

Challenges facing the family caregivers are no less than the patients. Palliative care professionals have yet much to learn in caring for these patients with non-cancer diseases.

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